SIP

Societal Impact of Pain

Abstract & Background Booklet

The SIP 2012 symposium takes place under the high patronage of the Italian Presidency of the Council of Ministers and the Italian Ministry of Health.

The SIP 2012 symposium is hosted by the Danish Association for Chronic Pain Patients (FAKS). The scientific framework of SIP 2012 is under the responsibility of the European Federation of IASP® Chapters (EFIC®). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP 2012 symposium have been endorsed by a large number of pain advocacy and scientific organisations.

www.sip-platform.eu

FAKS EFIC EUROPE AGAINST PAIN GRÜNENTHAL

The Ethical Committee for the Pharmaceutical Industry in Denmark (ENLI) has been notified of the Symposium. The SIP 2012 Symposium has been pre-approved by ENLI with the current format and content.

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http://www.efic.org
EU Transparency Register ID: 35010244568-04

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Palazzo Chigi - Piazza Colonna,
370 - 00187 Roma, Italy
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Presidenza Consiglio Ministri
Ufficio del Cerimoniale
Roma, Itlay

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This booklet comprises SIP 2012 speakers' abstracts from workshops and plenary sessions, as well as background texts on endorsing organisations which support the scientific aims of the symposium. Due to printing deadlines this booklet does, however, not guarantee inclusiveness of each speaker or organisation. The final complete version will be made available electronically on 29 May 2012 at www.sip-platform.eu.

Societal Impact of Pain (SIP) 2012
Copenhagen, Denmark
29 - 31 May, 2012

The Societal Impact of Pain (SIP) 2012 symposium takes place under the high patronage of the Italian Presidency of the Council of Ministers.

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PROF. HANS G. KRESS PRESIDENT EUROPEAN
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TELEGRAAF
24 APR. 2012
BRUSSEL

UCE F 333/2012 (.) IN RIFERIMENTO ALLA SUA RICHIESTA LE COMUNICO LA CONCESSIONE DEL PATROCINIO DELLA PRESIDENZA DEL CONSIGLIO DEI MINISTRI AL SIMPOSIO "SIP 2012-SOCIETAL IMPACT OF PAIN-L'IMPATTO SOCIALE DEL DOLORE" IN PROGRAMMA A COPENAGHEN DAL 29 AL 31 MAGGIO 2012 (.) CORDIALI SALUTI(.)
SEGRETARIO GENERALE PRESIDENZA CONSIGLIO MINISTRI
MITTENTE
PRESIDENZA DEL CONSIGLIO DEI MINISTRI
CENTRO MESSAGGI
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00187 ROMA

NNNN

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Con riferimento alla richiesta, pervenuta allo scrivente Ufficio, si comunica la concessione del patrocinio del Ministero della Salute al Simposio " SIP 2012 societal Impact of Pain – L'impatto sociale del dolore", in programma a Copenaghen dal 29 al 31 maggio 2012.

Si formulano i migliori auguri per la riuscita dell'iniziativa.

Il vice capo di Gabinetto
(dott.ssa Anna Camera)

Prof. Hans G. Kress, MD, PhD
President
European Federation of IASP®
Chapters (EFIC®)
www.efic.org

Dear Reader,

Chronic pain poses a severe burden on the individual, but also on the society, including an enormous economic burden for health care systems. So far, a structured program of the institutions of the EU targeting these challenges and long-term consequences of chronic pain is missing:

- Chronic pain is one of the major reasons for discontinuation of work and early retirement and undermines the Europe 2020 Strategy for smart, sustainable and inclusive growth.
- Chronic pain, which is pre-dominant mainly in elderly people, also undermines the European goal of healthy ageing, as expressed in the European innovation partnership on active and healthy ageing.
- Chronic pain directly affects sufferers and their quality of life and should be addressed by a common, horizontal approach according to a resolution on non-communicable diseases adopted by the European Parliament recently.

The European Federation of IASP® Chapters (EFIC®), as one of the most relevant scientific societies of healthcare professionals for the study of pain in Europe, calls for policymakers and decision-makers alike to adopt a much wider, strategic perspective in their deliberations regarding service provision and resource allocation.

Therefore, in May 2011 the symposium "Societal Impact of Pain" took place in the European parliament. An important outcome of SIP 2011 was the "Road Map for Action", which outlines the key issues on how the EU institutions and member states could effectively address the societal impact of pain at both EU and national levels. Based on the tremendous response of the previous SIP symposia, FAKS, EFIC® and Grünenthal have decided to organise a 3rd European symposium SIP 2012. The national and European implementation of the Road Map for Action will be a central theme for discussion.

In the first half of 2012, Denmark holds the Presidency of the Council of the European Union. Supported by a large group of Danish and European stakeholders EFIC® aims to raise awareness with the Presidency of the Council of the European Union for the societal impact of pain by organising SIP 2012 in Denmark.

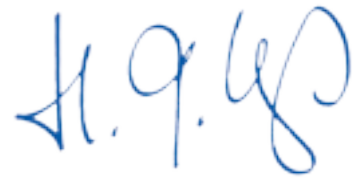
This year there will be discussed a variety of topics with utmost relevance for future policy-making: During the first day, in workshop 1 one will discuss along EFIC's position on pain as a disease in its own right, which will be live-web streamed and thus be available for a worldwide audience. Workshop 2 will elaborate on the influence of pain for an active and healthy ageing, as the EU Commission has launched its programme on the European Innovation Partnership on Active & Healthy Ageing. Workshop 3 will deal with pain commissioning and delivering results in best-practice cooperation model, workshop 4 will focus on the development and implementation of education & research programmes, workshop 5 will offer a platform to exchange experiences from establishing national multi-stakeholder pain platforms and finally future pain management scenarios the European Union and Member States will be the topic for workshop 6. High-level key note speakers will pick up these topics in the plenary sessions on the second day.

SIP 2012 will thus provide an optimal platform to create awareness, share best practices and create alliances for future collaborations and policy-making for an improved pain care in Europe.

EFIC® looks forward to an inspiring meeting in springtime Copenhagen.

Welcome to the 3rd SIP Symposium!

Prof. Hans G. Kress, MD, PhD
President
European Federation of IASP®
Chapters (EFIC®)



Pia Frederiksen
President FAKS
The Danish Association of Pain Patients
Foreningen Af Kroniske Smertepatienter
www.faks.dk

Dear Madam, dear Sir,

In 1990 a group of Danish pain patients, brought together in an interdisciplinary pain unit, came up with the idea of founding FAKS, the Danish Association of Chronic Pain Patients. The vision was to bring pain patients together in order to inspire and activate each other in various positive ways. Thus, one of the main objectives was to deal with common problems such as physical, mental, and social inactivity.

FAKS sets itself aside from other patient groups by being a non-specific- diagnosis-dependent-association. The fact that in many cases pain becomes a disease in its own right - no matter the initial cause - calls for a different approach. Even though chronic pain patients have universal problems, people and their pain issues are in many ways as different and unique as themselves.

Among our vision for pain patients in Denmark we look for achieving recognition of chronic pain as a serious and debilitating condition and to disseminate knowledge on pain management and hence support individual patients and their families to cope better with their situation.

As president of FAKS, I truly hope that the discussions during SIP 2012 will substantially contribute to raise awareness on chronic pain not only in Denmark, but also in other EU Member States. Together with other international patient advocacy groups, FAKS will continue to challenge politicians and budget holders to revise their perception of chronic pain and to acknowledge it as a separate health state amongst other chronic diseases, which tremendously impacts patients' quality of life as well as budgets of health care systems.

I wish you a successful and interesting symposium here in Denmark und look forward to fruitful outcomes for the improvement of pain care for all pain patients in Europe!

Pia Frederiksen
President FAKS
The Danish Association of Pain Patients
Foreningen Af Kroniske Smertepatienter

Alberto Grua
Executive Vice President
Grünenthal Europe & Australia

Dear Madam, dear Sir,

In the discussion on pain – chronic pain in particular – as a separate entity or even a disease in its own right one of the key questions which is eventually being asked by different stakeholders is whether we are talking about "Science" or "Politics": Can chronic pain in fact be considered a separate entity, prevalent in many chronic disease health states with a significant impact on patient's quality of life? Or is it "but" a symptom of the underlying disease, a complex, multifactorial experience for the patient?

Various large studies have demonstrated that the prevalence of pain amongst the European population is very high. In fact, pain is the most common reason why patients seek medical attention. Pain presents a serious problem for a large proportion of the population.

The economic and social burden of chronic severe pain is derived from inherent direct costs and indirect costs; a burden which our health care systems have to tackle in spite of demographic change and increasing costs for technological advancements.

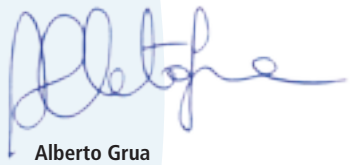
Following the two preceding symposia in Brussels in 2010 and 2011, this year's 3rd European symposium on the "Societal Impact of Pain" (SIP 2012) is taking place in Copenhagen on the occasion of the Danish Presidency of the Council or the European Union, which has defined chronic diseases as one of the agenda priorities for the first half of 2012.

Collaborating with the Danish Association of Pain Patients (FAKS) and with the European Federation of IASP Chapters (EFIC®) we are therefore proud to facilitate the discussion around chronic pain amongst chronic diseases in Europe.

Grünenthal is highly committed to support the improvement of access to pain management for patients in the European Union. In doing so Grünenthal closely follows the seven dimensions of the "Road Map for Action", the key result from SIP 2011 and action plan for European and national health care policy on pain management.

More than 155 organisations have confirmed their endorsement of the scientific aims of SIP 2012: Their outstanding support and contribution strongly demonstrates the societal impact of pain and illustrates the broad relevance the topic of chronic pain has for such a variety of stakeholders and organisations.

On behalf of Grünenthal GmbH, I would like to thank all presenters for their efforts in preparing this year's presentations and look forward to lively debates on the "Politics" and "Science" around chronic pain. I wish you all a successful symposium, with fruitful and constructive discussions and clear outcomes for improving the lives of pain patients in the whole of Europe.



Alberto Grua
Executive Vice President
Grünenthal Europe & Australia
www.grunenthal.com

Societal Impact of Pain (SIP) 2012
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The Societal Impact of Pain
"A Road Map for Action"

One of the key results from the 2nd European symposium on the "Societal Impact of Pain" (SIP 2011) in the European Parliament in Brussels/Belgium, published on 4 May 2011 (www.sip-platform.eu).

In 2001, the European Federation of the International Association for the Study of Pain Chapters (EFIC) published its Declaration on Pain which called on national governments and the EU Institutions to increase the level of awareness of the societal impact of pain. Ten years on from the EFIC Declaration on Pain, national and EU policy action has been very limited. At the same time, basic and clinical science have demonstrated the feasibility of pathways out of pain for many types of acute and chronic pain, but health care systems currently do not guarantee general access to these.

According to the 2007 Eurobarometer survey on "Health in the European Union"[1] , almost one third of respondents experience musculoskeletal pain which affects their day-to-day life. The burden of suffering that pain imposes on individuals and the enormous costs that society has to bear not only by healthcare systems but also the social, economic and employment sectors only illustrate the urgency for European governments and the EU Institutions to act and to put, as a priority, the societal impact of pain on their policy agenda.

We call on European governments and the EU Institutions to:

1. Acknowledge that pain is an important factor limiting the quality of life and should be put on the top of the priority list of the national health care system.
2. Activate patients, their family, relatives and care-givers through the availability of information and access to pain diagnosis and management.
3. Raise awareness of the medical, financial and social impact that pain and its management has on the patients, their family, care-givers, employers, and the healthcare system.
4. Raise awareness of the importance of prevention, diagnosis and management of pain amongst all healthcare professionals, notably through further education.
5. Strengthen pain research (basic science, clinical, epidemiological) as a priority in EU framework programme and in equivalent research road maps at national and EU level, addressing the societal impact of pain and the burden of chronic pain on the health, social, and employment sectors.
6. Establish an EU platform for the exchange, comparison and benchmarking of best practices between member states on pain management and its impact on society.
7. Use the EU platform to monitor trends in pain management, services, and outcomes and provide guidelines to harmonize effective levels of pain management to improve the quality of life of European Citizens.

[1] Eurobarometer survey on "Health in the European Union", Special Eurobarometer 272e, September 2007 http://ec.europa.eu/health/ph_publication/eb_health_en.pdf

SIP

Endorsing Organisations

The scientific aims of the SIP 2012 symposium under the responsibility of the European Federation of IASP® chapters have been endorsed by the following large number of pain advocacy and scientific organisations:

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1. **Academia de Ciencias Médicas de Bilbao**
www.acmbilbao.org

2. **Action on Pain**
www.action-on-pain.co.uk

3. **Andalusian Society of Palliative Care**
www.paliativosandalucia.com

4. **Arthritis and Musculoskeletal Alliance (ARMA)**
www.arma.uk.net

5. **Asociación Andaluza del Dolor**
www.asociacionandaluzadeldolor.es

6. **Asociación española de enfermería de anestesia-reanimación y terapia del dolor (aseedar-td)**
www.aseedar-td.org

7. **Asociación Extremeña de Fibromialgia**
http://afibroex.com/

8. **Association of Patients with fibromyalgia and chronic fatigue syndrome of the Community of Madrid (AFINSYFACRO)**
http://www.afinsyfacro.es/

9. **Association française de la cystite interstitielle (AFCI)**
http://asso.orpha.net/AFCI/cgi-bin/

10. **Association Francophone pour Vaincre les Douleurs (AFVD)**
www.association-afvd.com

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11. **Azorian Association of Chronic Pain Patients (ADDCA)**

12. **Associação Portuguesa de Cuidados Paliativos – Núcleo Regional dos Açores (Portuguese Association of Palliative Care – Azorian Regional Nucleus)**
www.apcp.com.pt

13. **Associazione Sammarinese per lo Studio del Dolore**
www.assd-rsm.org

14. **Association for Pain Therapy Bosnia and Herzegovina**
www.apt-bh.ba

15. **BackCare, the charity for healthier backs**
www.backcare.org.uk

16. **Belgian Back Society (BBS)**
www.belgianbacksociety.be

17. **Belgian Pain Society (BPS)**
www.belgianpainsociety.org

18. **Berufsverband der Ärzte und Psychologischen Psychotherapeuten in der Schmerz- und Palliativmedizin in Deutschland e.V. (BVSD)**
www.bv-schmerz.de

19. **Bildungswerk Aachen: Servicestelle Hospizarbeit für die Städte Region Aachen**
www.servicestelle-hospizarbeit.de

20. **British Pain Society**
www.britishpainsociety.org

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21. **Chronic Pain Ireland**
www.chronicpain.ie

22. **Cittadinanzattiva**
www.cittadinanzattiva.it

23. **Collectif DOLOPLUS**
(Pain Assessment in non communicating elderly patients)
http://www.doloplus.com/

24. **Consellería de Sanidade de Galicia**
www.sergas.es

25. **Croatian Society for Pain Treatment**
www.hdlb.org

26. **Czech Pain Society**
(Spolecnost pro studium a lécbu bolesti - SSLB)
www.pain.cz

27. **Danish Association for Chronic Pain Patients**
(FAKS) Foreningen Af Kroniske Smertepatienter
http://www.faks.dk

28. **Deutsche Schmerzgesellschaft e.V. (German Pain Society)**
www.dgss.org

29. **Deutsche Schmerzliga e.V.**
www.schmerzliga.de

30. **Deutsche Gesellschaft für Anästhesiologie und Intensivmedizin (DGAI)**
www.dgai.de

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31. **Deutsche Gesellschaft für Schmerztherapie e.V. (DGS)**
German pain association - Société Allemande de la Douleur
www.dgschmerztherapie.de

32. **Deutsche PalliativStiftung**
www.PalliativStiftung.de

33. **Deutsche Seniorenliga e.V.**
www.deutsche-seniorenliga.de

34. **Deutscher Orthopäden-Verband e.V. (DOV)**
www.dov-online.de, www.ihrarzt.de

35. **Deutsche Wachkoma Gesellschaft**
www.schaedel-hirnpatienten.de

36. **Douleurs Sans Frontières (Pains without Borders)**
www.douleur.org

37. **Dutch Pain Society**
www.dutchpainsociety.nl

38. **Endometriosis Association of Ireland**
www.endo.ie

39. **EURAG Österreich**
www.eurag.at

40. **EUMUSC.net**
www.eumusc.net

The scientific aims of the SIP 2012 symposium under the responsibility of the European Federation of IASP® chapters have been endorsed by the following large number of pain advocacy and scientific organisations:

41. **Europacolon Portugal (Association for the Fight Against the Colorectal Cancer)**
www.europacolon.pt

42. **European Cancer Patient Coalition (ECPC)**
www.ecpc-online.org

43. **European Federation IASP Chapters (EFIC)**
www.efic.org

44. **European Federation of National Associations of Orthopaedics and Traumatology (EFORT)**
www.efort.org

45. **European Federation of Neurological Associations (EFNA)**
www.efna.net

46. **European Headache Alliance**
www.e-h-a.eu

47. **European Network of Fibromyalgia Associations (ENFA)**
www.enfa-europe.eu

48. **European Platform for Patients' Organisations, Science and Industry (EPPOSI)**
www.epposi.org

49. **European Society for Regional Anaesthesia & Pain Therapy (ESRA)**
www.esraeurope.org

50. **European Society of Anaesthesiology (ESA)**
www.euroanaesthesia.org

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51. **Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP)**
www.faecap.com

52. **Federdolore-Società Italiana dei Clinici del Dolore**
www.federdolore.it

53. **Fibromyalgie en Samenleving (F.E.S.)**
De nationale Vereniging voor Fibromyalgiepatienten
www.fesinfo.nl

54. **Finnish Association for the Study of Pain**
www.suomenkivuntutkimusyhdistys.fi

55. **Finnish Pain Association**
www.suomenkipu.fi

56. **Focus Fibromyalgia Belgium ASBL**
www.focusfibromyalgie.be

57. **Fondazione ISAL**
www.fondazioneisal.it

58. **Fondazione ISTUD**
www.fondazioneistud.it

59. **Fondazione Paolo Procacci**
www.fondazioneprocacci.org

60. **Foro Español de Pacientes**
www.webpacientes.org/fep

The scientific aims of the SIP 2012 symposium under the responsibility of the European Federation of IASP® chapters have been endorsed by the following large number of pain advocacy and scientific organisations:

61. **Foundation Pijn-Hoop**
www.pijn-hoop.nl

62. **Fundació Acadèmia de Ciències Mèdiques I de la salut de catalunya I de Balears**
www.academia.cat

63. **Fundación Afectados y Afectadas Fibromialgia y Síndrome Fatiga Crónica**
www.laff.es

64. **Fundación para la Investigación en Salud (Fuinsa)**
www.fuinsa.org

65. **Fundación Signo**
www.fundacionsigno.com

66. **Fundesalud, Consejeria de Sanidad de Extremadura**
www.fundesalud.es

67. **Fundolor**
www.fundolor.org

68. **Galician Society of Pain and Palliative Care**
www.sociedadgallegadeldolor.sedolor.es

69. **Geriatric Medicine Society e.V.**
www.geriatric-medicine.org

70. **Grünenthal GmbH**
www.grunenthal.com

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71. **German Maltese Medical Society**
http://www.germanmaltesecircle.org/gmms.htm

72. **Hellenic Society of Algology**
vww.algologia.gr

73. **herescon gmbh**
www.herescon.com

74. **HRVATSKO DRUŠTVO ZA PALIJATIVNU MEDICINU, HLZ**
Croatian Society for Palliative Medicine,
Croatian Medical Association
www.palijativa.com

75. **Institute for Research in Operative Medicine (IFOM)**
http://www.uni-wh.de/ifom

76. **Instituto Aragonès de Ciencias de la Salud**
www.iacs.aragon.es

77. **Instituto de Estudios de Ciencias de la Salud de Castilla y León**
www.iecscyl.com

78. **International Alliance of Patients' Organizations**
www.patientsorganizations.org

79. **International Headache Society**
www.ihs-headache.org

80. **International Painful Bladder Foundation (IPBF)**
www.painful-bladder.org

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81. **Irish Pain Society**
www.irishpainsociety.com

82. **Israel Pain Association (IPA)**
www.ipa.org.il

83. **Italian Association for the Study of Pain**
(Associazione Italiana per lo Studio del Dolore, AISD)
www.aisd.it

84. **Italian Society of Neurological Rehabilitation**
(Società Italiana di Riabilitazione Neurologica, SIRN)
www.sirn.net

85. **Junta de Andalucía Consejería de Salud**
www.juntadeandalucia.es/organismos/saludybienestarsocial.html

86. **Leon-Castelian Society of Pain**
(Sociedad Castellano Léonesa de Dolor)
www.sociedaddocyl.wordpress.com

87. **Liga Reumatológica Gallega**
www.ligagalega.org

88. **Medicinski fakultet sveučlišta u Zagrebu**
centar za palijativnu medicinu, medicinsku etiku i
komunikacijske vještine
www.mef.hr

89. **Myeloma Euronet Romania**
www.myeloma.ro

90. **National Association of Patients with Rheumatoid**
Arthritis (ANDAR)
www.andar-reuma.pt

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91. **National Council for Palliative Care**
www.ncpc.org.uk

92. **Nederlandse Vereniging van Rugpatiënten**
"deWervelkolom"
www.nvvr.nl

93. **Neil Betteridge Associates**

94. **Netherlands Interstitial Cystitis Patients Organization (ICP)**
www.icpatienten.nl

95. **Neurologiskt Handikappades Riksförbund**
(The Swedish Association of Person with Neurological Disabilites)
www.nhr.se

96. **Osservatorio Italiano Cure Palliative (OICP)**
www.oicp.org

97. **Österreichische Gesellschaft für Geriatrie und Gerontologie**
(ÖGGG, Austrian Society for Geratrics and Gerontology)
www.geriatrie-online.at

98. **Österreichisches Rotes Kreuz (Austrian Red Cross)**
www.roteskreuz.at

99. **Österreichische Schmerzgesellschaft**
www.oesg.at

100. **Painaustralia**
www.painaustralia.org.au

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101. **Pain Alliance Europe**
www.pae-eu.eu

102. **Pain Concern**
www.painconcern.org.uk

103. **PAIN OUT**
www.pain-out.eu

104. **Pain Nursing Magazine – Italian Online Journal**
www.painnursing.it

105. **PAIN South Africa (PAINSA)**
www.painca.co.za

106. **Palliactief**
www.palliactief.nl

107. **Palliatives Netzwerk für die Region Aachen e.V.**
www.servicestelle-hospizarbeit.de

108. **Pain Toolkit**
www.paintoolkit.org

109. **Patientenschutzorganisation Deutsche Hospiz Stiftung**
www.patientenschützer.de

110. **Pelvic Pain Support Network**
www.pelvicpain.org.uk

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111. **Plataforma SinDOLOR**
www.plataformasindolor.com

112. **Polskie Towarzystwo Badania Bolu (Polish Pain Society)**
www.ptbb.pl

113. **Portuguese Association for the Study of Pain (APED)**
www.aped-dor.org

114. **Portuguese Association of Palliative Care**
www.apcp.com.pt

115. **Portuguese League Against Rheumatic Diseases (LPCDR)**
www.lpcdr.org.pt

116. **Presidenza della Regione Abruzzo**
www.regione.abruzzo.it

117. **Regional Health Directorate – Azorean Regional Plan for Pain Control**
www.azores.gov.pt/Portal/pt/entidades/srs-drs/

118. **REDE Fm, SFC y SQM**
Red Española para la Defensa de los enfermos de fibromialgia, síndrome de fatiga crónica y sensibilidad química múltiple
www.acofifa.org

119. **Russian Association for the Study of Pain (RASP)**
www.painrussia.ru

120. **Russian Headache Research Society (RHRS)**
www.headache-society.ru

The scientific aims of the SIP 2012 symposium under the responsibility of the European Federation of IASP® chapters have been endorsed by the following large number of pain advocacy and scientific organisations:

121. **SchmerzNetzNRW eG**
www.schmerznetznrw.org

122. **Slovak Society for Study and Treatment of Pain**
www.pain.sk

123. **Slovensko združenje za zdravljenje bolecine (SZZB)**
Slovenian Association for Pain Management
www.szzb.si

124. **Sociedad Andaluza de Geriatría y Gerontolgía**
www.sagg.org

125. **Sociedad Canaria del Dolor (SCD)**
www.socadolor.org/es/

126. **Societat Catalana de Medicina Física i Rehabilitació**
www.academia.cat

127. **Societat Catalano-Balear de Cures Palliatives (SCBCP)**
http://webs.academia.cat/societats/curespal

128. **Societat Catalano-Balear d´Oncologia**
www.webs.academia.cat/societats/oncologia/

129. **Sociedad Española Del Dolor**
www.sedolor.es

130. **Sociedad Española de Directivos de Atención Primaria (SEDAP)**
www.sedap.es

The scientific aims of the SIP 2012 symposium under the responsibility of the European Federation of IASP® chapters have been endorsed by the following large number of pain advocacy and scientific organisations:

Societal Impact of Pain (SIP) 2012
Copenhagen, Denmark
29 - 31 May, 2012

131. **Sociedad Española de Directivos de la Salud (SEDISA)**
www.sedisa.net

132. **Sociedad Madrileña del Dolor**
www.sociedadmadrilenadeldolor.sedolor.es

133. **Sociedad Madrileña de Gereatría y Gerontología**
www.seqq.es

134. **Sociedad Murciana de Dolor**
http://murciadolor.com/

135. **Sociedad Valenciana Terapèutica del Dolor**

136. **Sociedade Portuguesa de Medicina Física e Reabilitação (SPMFR)**
(Portuguese Society of Physical Medicine and Rehabilitation)
www.spmfr.org

137. **Société Française d'Etude et de Traitement de la Doleur (SFETD)**
www.sfetd-douleur.org

138. **Society of Pain of Castilla la Mancha**
http://sociedadcastellanomanchegadeldolor.sedolor.es/

139. **Spanish Association of Patients with Neuropathic pain,**
Trigeminal neuralgia and mporomandibular pathology
www.pacientesatm.com

140. **Swedish Association for Survivors of Accident and Injury (RTP)**
www.rtp.se

The scientific aims of the SIP 2012 symposium under the responsibility of the European Federation of IASP® chapters have been endorsed by the following large number of pain advocacy and scientific organisations:

141. **Swiss Headache Society**
www.headache.ch

142. **Swiss Association for the Study of Pain (SGSS/SSED)**
www.pain.ch

143. **Stichting PijnPlatform Nederland (PPN)**
www.pijnplatform.nl

144. **The Work Foundation**
www.theworkfoundation.com

145. **Trigeminal Neuralgia Association UK**
www.tna.org.uk

146. **Udruženje za Istraživanje i Tretman Bola Srbije (UITBS) Serbian Association for Pain Research and Treatment (SAPRT)**
www.uitbs.org.rs

147. **Ukrainian Association for the Study of Pain**
www.pain.in.ua

148. **Universidad Carlos III of Madrid**
www.uc3m.es

149. **Universidad Rey Juan Carlos (URJC)**
http://www.urjc.es

150. **Universidad de los Pacientes**
www.universidadpacientes.org

The scientific aims of the SIP 2012 symposium under the responsibility of the European Federation of IASP® chapters have been endorsed by the following large number of pain advocacy and scientific organisations:

Societal Impact of Pain (SIP) 2012
Copenhagen, Denmark
29 - 31 May, 2012

151. **University of Cádiz**
www.uca.es

152. **ULSS7 del Veneto**
www.ulss7.it

153. **Vlaamse Liga voor Fibromyalgie-Patiënten vzw**
http://fibromyalgie.be

154. **Vlaamse Pijnliga**
www.vlaamsepijnliga.be

155. **Whiplash Stichting Nederland**
www.whiplashstichting.nl

156. **WIP Foundation**
www.wipfoundation.org

157. **World Federation for Incontinent Patients (WFIP)**
www.wfip.org

158. **World Federation of Societies of Anaesthesiologist (WFSA)**
www.anaesthesiologists.org

159. **World Institute of Pain**
www.worldinstituteofpain.org

How to find your speaker or your endorsing organisation?

One the following pages you will find abstracts and background text from all speakers and persons with an active function during the SIP symposium as listed on the final programme, as well as from organisations which confirmed their endorsement of the scientific aims of SIP 2012.

The texts are listed in alphabetical order: For speakers and persons with active function, please look for the **first letter of his or her last name**; for endorsing organisations, please search for the **first letter of the organisation's name.**

In addition, in the middle of the right page you can find a letter index for facilitation of your search.

The electronic version of this booklet you can find online at www.sip-platform.eu

Basic Programme

Tuesday, 29 May

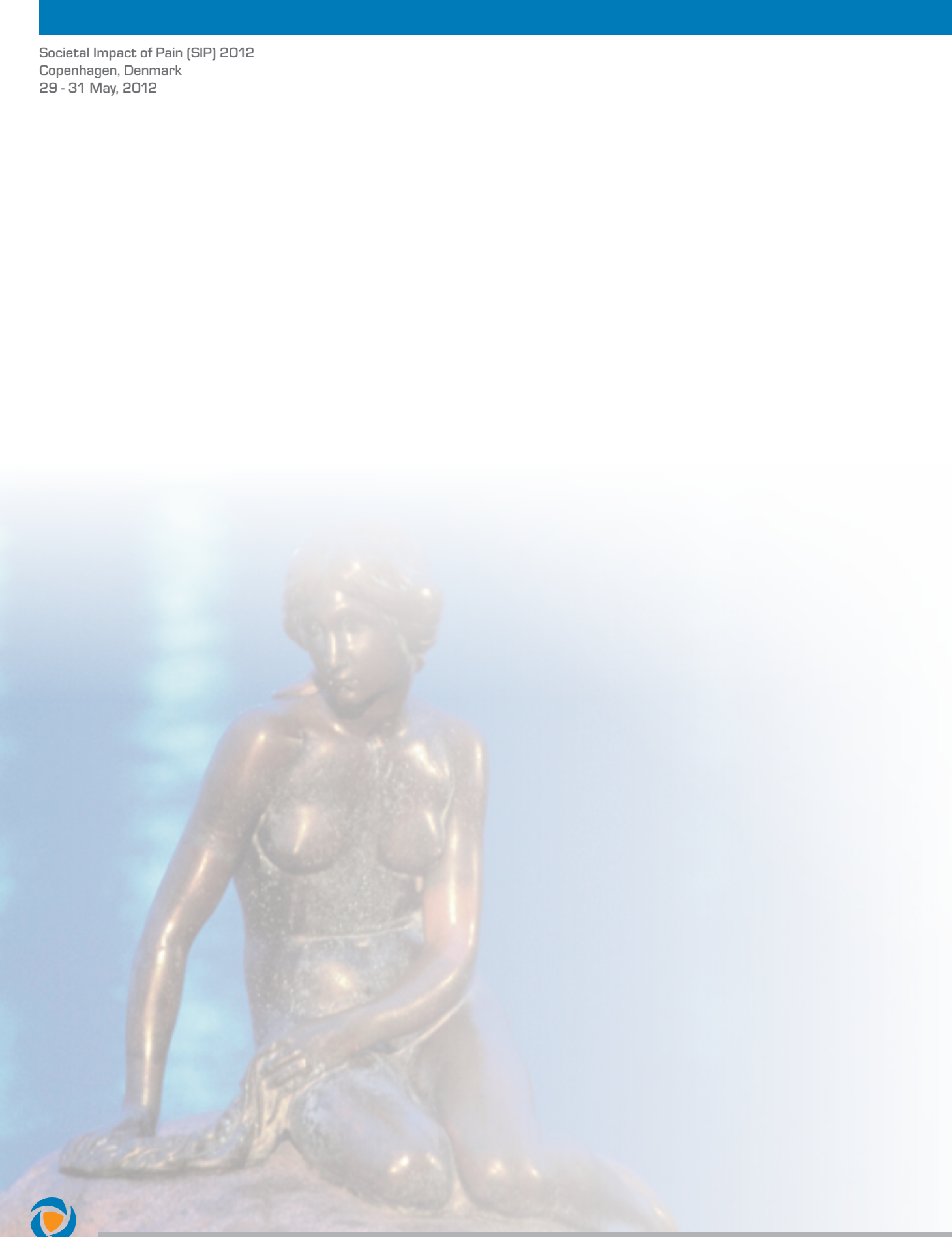
13:00	**Special group meetings**
	Danish SIP platform (Danish language symposium)
13.00	**Theme 1:** Chronic pain care in Denmark. Description of the current situation
14:00	**Theme 2:** How should it be
15:00	**Theme 3:** Future outlook
16:00	**Theme 4:** Round panel discussion: where do we go from here
	EFIC® council meeting (participation for EFIC councillors and board members only)
	Pain Alliance Europe (PAE) general assembly

Wednesday, 30 May

09:00	**Special group meetings**
	Swedish stakeholder meeting (Swedish language meeting)
11:00	**Market place**
	Exhibition of stakeholder materials - Congress foyer
12:00	**Registration & Get together** - Congress foyer & Congress Hall A3
13:00	**Opening** - Auditorium
14:00 - 18:00	**Six parallel workshops**
	WS 1: Chronic Diseases: Chronic Pain as a disease in its own right
	WS 2: Active & Healthy Ageing: Pain management for an improved quality of life
	WS 3: Improving pain management: Delivering results in best practice cooperation models
	WS 4: Benchmarking, education and research programmes on pain management in the European Union
	WS 5: Establishing multi-stakeholder pain platforms in Europe
	WS 6: Outlook on future pain management
20:00	**Symposium Dinner** - Congress Hall A 3

Thursday, 31 May

09:00	**Presentation and discussion** of the findings from the special interest groups and parallel workshops from 29-30 May 2012
12:00	**Lunch** - Room "Bella Vista"
13:00	**Plenary sessions** - Auditorium
15:30	**Discussion & Closing remarks**
16:00	**Closing**



SIP
Societal Impact of Pain

Background information on speakers and workshop chairpersons, moderators, secretaries, and workshop reporters in alphabetical order of their last name

The SIP 2012 symposium takes place under the high patronage of the Italian Presidency of the Council of Ministers and the Italian Ministry of Health.

The SIP 2012 symposium is hosted by the Danish Association for Chronic Pain Patients (FAKS). The scientific framework of SIP 2012 is under the responsibility of the European Federation of IASP® Chapters (EFIC®). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP 2012 symposium have been endorsed by a large number of pain advocacy and scientific organisations.

www.sip-platform.eu

FAKS EFIC EUROPE AGAINST PAIN GRÜNENTHAL

The Ethical Committee for the Pharmaceutical Industry in Denmark (ENLI) has been notified of the Symposium. The SIP 2012 Symposium has been pre-approved by ENLI with the current format and content.

Main workplace/Organisation
Academia de Ciencias Médicas de Bilbao

Profession/Function
President

Academia de Ciencias Médicas de Bilbao

The Academy of Medical Sciences of Bilbao is an institution that is over a hundred years old, founded on 9th January 1895 at the First-aid Post in the Ensanche area of Bilbao. Over its long history, it has enjoyed the participation and collaboration of the most distinguished doctors, chemists, veterinary surgeons, odontologists and biologists from Bizkaia, as well as distinguished members of the university.

Since that time, the Academy has carried out uninterrupted work in the field of continuous training of professionals from the health sector by organizing courses, workshops, symposiums, conferences and all types of scientific meetings in which medical advances are studied in depth and debated, also incorporating other medical and health-related disciplines such as pharmacy, biology, veterinary medicine and odontology. The Academy in turn promotes and strengthens the humanistic side attached to medical practice and has entered into partnership agreements with different social and health institutions.

The passing of time and the effective work carried out by the institution over this time has made it a leading socio-health reference point. The Academy constitutes the bridge that links two worlds that are not really so far away from each other – health and society.

ENDORSING ORGANISATION SIP2012

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http://www.cost-td1005.net/

"Pain is grossly undertreated in dementia, and regular and dementia specific assessment is not implemented. Researchers and clinicians in the EU are dedicated to improve this situation."

Main workplace/Organisation
Leids Universitair Medisch Centrum (LUMC)

Profession/Function
Professor of institutional care and elderly care medicine

Pain in impaired cognition

When dementia and pain concur, their impact on the European society multiplies and asks for transnational solutions. It already seems evident now that pain is grossly undertreated in dementia. Unanswered questions regard the underlying brain pathology, optimal pain assessment, treatment and care. So far the lack of validated pain assessment tools has prevented major progress.

The aim of the EU-COST action "Pain Assessment in Patients with Impaired Cognition, especially Dementia" is to reduce the fragmentation in European research and to strive for worldwide cooperation. At this moment it consists of 13 European nations and Australia and brings together leading researchers from a wide range of scientific disciplines. The major aim is the development of a comprehensive and internationally agreed-on assessment toolkit for older adults, targeting the various subtypes of dementia and various aspects of pain, including pain diagnostics, cognitive examination and guidelines for proper assessment. Validation of this toolkit requires joint action of both basic and clinical sciences. Only hereby, the urgently needed improvement of pain management in dementia can start.

Since it started in May 2011 the COST Action has arranged three meetings, the latest of which was held in Leiden January 2012, which was a joint meeting with PAIC, the original scientific initiative in that field.

Objectives COST pain in impaired cognition

The main objective of the Action is the development of a comprehensive and internationally agreed-on toolkit for assessing pain in adults with cognitive impairment, especially with dementia.

Secondary objectives: preparing appropriate dissemination strategies for both toolkit and Guidelines analyzing and, if possible, correcting scientific, social and political barriers against dissemination encouraging cross-national learning and consideration of cross-national differences in this process increasing the overall awareness for the deleterious situation of pain sufferers with cognitive impairment in the public and in bodies of experts.

Pain in impaired cognition EU-COST working groups

COST working groups

Working Group 1 – Psychometrics and Algesimetry is responsible for evaluating the formal qualities of the existing scales and propose alternatives where necessary.
Working Group 2 – Nursing and Care will assess the clinical/practical usability and usefulness of the tools for preparing and monitoring pain management.
Working Group 3 – Clinical Evaluation and Epidemiology will initiate and run the necessary clinical multi-center and international population-based studies.
Working Group 4 – Experimental Evaluation: will provide experimental tests for the validity of the tools and for physiological markers of pain, which do not solely rely on self-report.
Working Group 5 – Palliative Care: will focus on the particular challenge of assessing pain at the end of life when dementia is only one of many complicating factors for the quality of life.

ENDORSING ORGANISATION SIP2012

Action on pain!

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Action on Pain!
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"Action on Pain! – Providing support and advice for people affacted by chronic pain."

Main workplace/Organisation
Action on Pain!

Profession/Function
Chairmant

Unnecessary pain – why live with it?

Action on Pain is a national charity established in 1998 by Ian Semmons, our Chairman, as a result of his own frustration that it took so long to get treatment for his pain. That frustration was heightened by the fact that when he eventually discovered Pain Clinics some three years after his injuries the treatment he received was superb. During that journey he met many others in a similar position. Knowing that complaining to the NHS was a pointless exercise he was determined to do something positive to help others who were faced with a similar challenge.

Over the past ten years Action on Pain has grown to a national organization developing a good reputation for the quality of the support and advice that it provides. Currently run entirely by volunteers AOP is run from a small office in Norfolk from where we reach out to not only the UK but to other parts of the world. AOP is involved in a number of key projects which have the potential to help people affected by chronic pain wherever they live.

Always looking for new opportunities to help people with pain, 2007 saw the introduction of our Mobile Information Unit which now plays a pivotal role in enabling us to reach out to far more people whilst also raising the overall profile of pain. We are told that this unit is the only one of its type across the world that specializes entirely on pain related matters.

About Ian Semmons
After being critically injured whilst trying to prevent a robbery Ian has lived with chronic pain for over twenty years. As a result of his own experiences he formed "Action on Pain" in 1998 which has now developed into a charity reaching out to people across the world.

He also serves on the Fitness to Practice Committees at the General Medical Council as well as being involved in many health related projects over the past fifteen years. He is married to a Chartered Physiotherapist who has a MSc in Pain Management.

ENDORSING ORGANISATION SIP2012

Main workplace/Organisation
Active Citizenship Network

Profession/Function
Director

The right not to suffer unnecessarily, a right of individuals and collectivity

Active Citizenship Network
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t.petrangolini@activecitizenship.net
www.activecitizenship.net

"The necessity to adopt the Charter of rights on unnecessary pain. The main rights: access to therapy, continued assistance, rights of children, the elderly and those "without a voice"."

Every individual has the right to know that pain does not necessarily have to be put up with and that much suffering can be alleviated by adopting the right treatment. This is especially requested by people with chronic pain and by elder citizens. Avoiding pain can change your life deeply! For this reason it is necessary to strengthen the active role of patients as empowered citizens and actors of Health policies.

The Charter of rights on unnecessary pain (promoted by Active Citizenship) is an example of civic activism in pain avoiding policies. Pain should be eliminated or at least reduced in all those cases where it is possible to do so, given its significant influence on the quality of life. The right not to suffer unnecessarily must be recognized and respected, always and everywhere in hospital wards and in long term care facilities, in the A&E and in the patient's home.

This "Charter of rights on unnecessary pain" sets out to inform citizens about pain and promote its prevention, control and treatment; the operatively of the Charter is entrusted to citizen's organisations involved in safeguarding health rights, as well as healthcare professionals and the various institutional bodies exerting governing responsibilities at different levels.

1. Right not to suffer unnecessarily: Every individual has the right to have their pain alleviated as efficiently and rapidly as possible.
2. Right to acknowledgement of pain: Every individual has the right to be listened to and believed when reporting personal pain.
3. Right to access pain therapy: Every individual has the right to access the treatment needed to alleviate their pain.
4. Right to qualified assistance: Every individual has the right to receive pain assistance, in observance of the latest, approved quality standards.
5. Right to continued assistance: Every person has the right to have their pain alleviated continuously and assiduously throughout all phases of illness.
6. Right to a free, informed choice: Every person has the right to actively participate in the decisions made regarding their pain management.
7. Rights of children, the elderly and those "without a voice": Children, the elderly and "sensitive" subjects have the same right not to suffer unnecessary pain; special consideration should be given to their particular status.
8. Right not to suffer pain during invasive and non-invasive diagnostic tests: Anyone having to undergo diagnostic tests, especially those which are invasive, must be treated in such a manner as to prevent episodes of pain.

Main workplace/Organisation
AFINSYFACRO

Profession/Function
Non-profit organization

AFINSYFACRO (Association of Patients with fibromyalgia and chronic fatigue symdrome of the Community of Madrid)

From our Association we work every day to provide the individual information and counseling about their disease, and to help to alleviate pain and symptoms associated with various socio-educational activities. We also offer counseling and legal advice to assist the patients at their specific problems, a consequence of suffering from these diseases.

At the community level AFINSYFACRO also aims to promote social awareness through outreach, promote early diagnosis and appropriate medical treatment, and encourage new avenues of research in this area.

According to the main objectives of our association we are willing to endorse the "Societal Impact of Pain" meeting since it is a very relevant initiative and very good opportunity for us to share our concerns and improve the health status of all the patients who make this Society.

ENDORSING ORGANISATION SIP2012

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AFINSYFACRO
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28935 Móstoles (Madrid)
Spain
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http://www.afinsyfacro.es/

"The Association of Patients with fibromyalgia and chronic fatigue of the Community of Madrid (AFINSYFACRO) is a non-profit organization whose primary objective is to improve the quality of life of every person with Fibromyalgia and / or Chronic Fatigue Syndrome."

ENDORSING ORGANISATION SIP2012

Association Francophone pour Vaincre les Douleurs (AFVD)
Mrs. Martine Chauvin
La Tillerole, 1 route de la petite roche
79200 Pompaire
France
Phone: +33 615578383
association-afvd@neuf.fr
www.association-afvd.com

"AFVD is a non-profit chronic pain patient organization aiming to improve the way chronic pain is considered and managed, and to help and support patients suffering from chronic pain."

Main workplace/Organisation
Association Francophone pour Vaincre les Douleurs

Profession/Function
Pain patient's Association

AFVD

AFVD is a non-profit patient organization founded in 2006 by Martine Chauvin and represents chronic pain patients and their carers. AFVD works closely together with health professionals, health authorities and scientific societies to improve chronic pain prevention, diagnosis, management, and recognition as a chronic disease.

Through Struggle, Support and Information, AFVD goals are to change the status of chronic pain consideration: chronic pain and its psychological consequences should no longer be a fatality, chronic pain should be recognized as a disease, and chronic pain management and prevention should be improved.

Prof. Eli Alon
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Switzerland
Phone: + 41 43 344 9900
Eli.alon@efic.org
www.efic.org

"Pain is a major healthcare problem in Europe. Although acute pain may reasonably be considered a symptom of disease or injury, chronic and persistent pain is a specific healthcare problem, a disease of its own right."

Main workplace/Organisation
EFIC

Profession/Function
Board Member

Chronic pain as a disease of its own right

Pain has often been regarded merely as a symptom that serves as a passive warning signal of an underlying disease process. Using this model, the goal of treatment has been to identify and address the pathology causing pain in the expectation that this would lead to its resolution. However, there is accumulating evidence to indicate that persistent pain cannot be regarded as a passive symptom. Indeed, in many patients pain persists long after its usefulness as an alarm signal has passed, and often long after the tissue damage has healed. Continuing nociceptive inputs result in a multitude of consequences that impact on the individual, ranging from changes in receptor function to mood dysfunction, inappropriate cognitions, and social disruption.

Chronic pain often sets the stage for the emergence of a specific complex set of physical and psychosocial changes that are an integral part of the chronic pain problem. These include a long list of associated features: immobility and consequence, wasting of muscle, joints etc. poor appetite and nutrition, disturbed sleep, dependence on medication, over-dependence on family, overuse and inappropriate use of professional healthcare systems and other carers, poor performance on the job or inability to work, disability, isolation from society and family, anxiety, fear, bitterness, frustration, depression, suicide. In addition to the severe erosion in quality of life of the pain-sufferer and those around him/her, chronic pain imposes severe financial burdens on many levels: costs of healthcare services, costs of services and medication, job absenteeism and disruption in the workplace, loss of income, non-productivity in the economy and in the home, financial burden on family, friends and employers, worker compensation costs and welfare payments. Thus, all these changes that occur as a consequence of continuing nociceptive inputs argue for the consideration of persistent pain as a disease entity in its own right.

As with any disease, the extent of these changes is largely determined by the internal and external environments in which they occur. Thus genetic, psychological and social factors may all contribute to the perception and expression of persistent pain. Optimal outcomes in the management of persistent pain may be achieved not simply by attempting to remove the cause of the pain, but by addressing both the consequences and contributors that together comprise the disease of persistent pain.

Main workplace/Organisation
Andalusian Association of Pain and Continuing Care
(Asociación Andaluza del Tratamiento del Dolor y Asistencia Continuada)
Profession/Function
President of the Andalusian of Pain and Continuing Care

Dealing with pain in Andalusia

Andalusian Association of Pain and Continuing Care is a scientific, non-profit organization staffed by professionals. Our main goal is the correct treatment of pain so we organize scientific activities and collaborate with other companies and institutions.
The general purposes of the Foundation are:

- Encourage and promote researching on the mechanisms and pain syndromes, as well as help improving treatment of patients with pain gathering both the scientific and health care areas.
- Promote researching, education and teaching on pain treatment.
- Advertising our objectives to main Institutions and General Administrations.
- Promote the development of the Pain Treatment Unit in Andalusia.

Andalusian Association of Pain and Continuing Care
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www.asociacionandaluzadeldolor.es

"Encouraging the right treatment of pain in Andalusia".

Main workplace/Organisation
The Andalusian Society of Geriatrics and Gerontology (ASGG)

Profession/Function
President

The Andalusian Society of Geriatrics and Gerontology (ASGG)

It is a scientific association with a non-profit-making personality and with a histroy of more than 30 years. In its path we gather professionals of different disciplines (medicine, infirmary, physical therapy, psychology, social workers, etc.) compromised with the improvement of the quality of life of the majority of Andalusians.

We develop three different lines of action:

- Promotion and collaboration with all those activities directed to the improvement of the knowledge of the process of aging and its physical, psychological, social and welfare implications.
- Advice and collaboration with both Public and Private Institutions.
- Design and promotion of programs and activities of gerontology and geriatric teaching directed to those different professionals who deal with these disciplines. Organizing campaigns of public health promotion and prevention to the active aging and general population.

The Andalusian Society of Geriatrics and Gerontology (ASGG)
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41005 Seville
Spain
Phone: +34 902.108.542
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www.sagg.org

"Improvement of the knowledge of the process of aging and its physical, psychological, social and welfare implications in Andalusian population."

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ENDORSING ORGANISATION SIP2012

Andalusian Society of Palliative Care (SACPA)
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Phone: +34 648790845
jujoluca@telefonica.net
www.paliativosandalucia.com

"Encouraging actions in Andalusia related to the attention for patients in terminal situation, their families and their caregivers."

Main workplace/Organisation
Andalusian Society of Palliative Care (SACPA)

Profession/Function
Secretary

Andalusian Society of Palliative Care

Our objectives are:

- to bring together those people who in their work or studies are related to attention to patients in terminal situation, their families and their caregivers:

- Doctors, nurses, auxiliaries.
- Psychologists, social workers.
- Physiotherapists, occupational therapists.
- Experts in ethics

- the development of palliative care in our field of action
- Educating the population about the problems of these people and educating the population to improve the quality of life of these patients
- cooperate with the regional organizations, State, international, as well as the World Health Organization (O.M.S), so that they can meet their objectives in our autonomous community in this area
- Advise the autonomous official institutions as well as any institution requesting our collaboration within the autonomous territory
- properly trained staff must integrate the equipment in all basic sciences of this type of care through a specific programme of training
- promote the study of ethical issues and moral associated to palliative patients care.
- informative public acts about palliative care
- promote and encourage the study of the issues and problems specific to palliative care from the point of view scientist
- get resources, both in the Administration and other agencies in order to ensure adequate in the terminally assistance

Main workplace/Organisation
AALBORG UNIVERSITY, Center for Sensory-Motor Interaction

Profession/Function
Professor, Dr. Med. Sci, Ph. D

Active and Healthy Ageing: Pain management for an improved quality of life

How to assess health care and develop tools to document the quality of pain management and its societal impact in relation to Active & Healthy Ageing will be most important in the future due to the demographic changes in societies. Age related painful conditions such as osteoarthritis will be much more prominent and new procedures and management regimes will be highly needed and evaluating the impact of such initiatives have to be documented.

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ENDORSING ORGANISATION SIP2012

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"Musculoskeletal disorders affect one in four of the UK adult population or more than 10 million people. Despite their importance, musculoskeletal services have failed to get the attention and priority they deserve. The economic and social costs are huge and set to grow without improvements in the delivery of services and outcomes."

Main workplace/Organisation
Arthritis and Musculoskeletal Alliance (ARMA)

Profession/Function
Project Coordinator

Arthritis and Musculoskeletal Alliance (ARMA)

The Arthritis and Musculoskeletal Alliance (ARMA) is the umbrella association body providing a collective voice for the arthritis and musculoskeletal community in the UK. Today we have 37 member organisations, ranging from specialised support groups to major research charities and national professional bodies.

ARMA's vision is of an effective, unified musculoskeletal community working together to improve the lives of over 10 million people in the UK with musculoskeletal disorders. This is achieved through partnership with its member organisations, by shaping policy and best practice.

Main workplace/Organisation
Kleijnen Systematic Reviews Ltd

Profession/Function
Health Economics Manager

Reflection process on chronic diseases in the EU – the role of chronic pain

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http://www.systematic-reviews.com/

"There is evidence that chronic pain has a large impact in terms of both prevalence and cost, which appears not to be sufficiently recognized in terms of specifically targeted policy."

Background
In December 2010, the Council of the European Union adopted "Innovative approaches for chronic diseases in public health and healthcare systems", which invited the European Commission and member states to initiate a reflection process on chronic diseases/non-communicable diseases (NCDs). NCDs are non-infectious medical diseases or conditions which are of long duration and generally slow progression. Chronic pain is often associated with chronic conditions. The European Commissioner for Health and Consumer Policy, John Dalli, stated on 5 May 2011: "The Commission is well aware of the societal impact of chronic pain, which is often associated with underlying, chronic, diseases. This puts a burden on healthcare systems and on the economy."

In addition, as well as being part of many other chronic diseases, pain specialists argue that it can be useful to consider chronic pain as a chronic disease in its own right. We also know that chronic pain is very common but good data about prevalence and utilisation of healthcare are scarce, perhaps partly because chronic pain has been seen not as a separate entity, but as merely a symptom.

Approach
In order to establish the contribution of chronic pain to the burden of chronic diseases and to evaluate the available evidence of the impact of chronic pain as a chronic disease by itself, we reviewed the most recent epidemiological and cost data on chronic pain. We also examined which policies and budgets in the EU, as a whole and in member states, currently include reference to chronic pain.

Key Findings
1. The overall impact of pain measured in terms of prevalence and cost is high.
2. Chronic pain is most prevalent in those patients with other chronic diseases.
3. Chronic pain can be considered as a very common and costly chronic disease in its own right.
4. There is a strong link between increasing age and prevalence of chronic pain.
5. Chronic pain deserves higher prioritisation within the health care policies and budgets of EU member states as well as at the level of the EU itself.

Conclusions
The study highlights the impact of chronic pain. It reflects that chronic pain, as a chronic disease or NCD, is common. It also shows that the cost of chronic pain is high, perhaps per individual not as high as some other NCDs such as stroke. However, total population cost is perhaps at least as high if not higher when accounting for the high prevalence. Furthermore, despite its high impact, chronic pain as a condition seems to have had little specific policy response. However, there does appear to be sufficient evidence to at least make addressing chronic pain a high priority alongside other chronic diseases as well as to conduct more research, particularly regarding cost.

Main workplace/Organisation
Association of Nurses in Anestesiology - Reanimation and Pain Therapy (ASSEDAR-TD)

ASEEDAR-TD is the Association of Nurses in Anestesiology- Reanimation and Pain Therapy (Asociación de Enfermería en Anestesia-Reanimación y Terapia del Dolor

ASEEDAR-TD is the Association of Nurses in Anestesiology- Reanimation and Pain Therapy (Asociación de Enfermería en Anestesia- Reanimación y Terapia del Dolor) and was built in order to gain academic and professional recognition of nursing professionals involved in the areas of anesthesiology, reanimation and pain therapy.

The aim of our association is to support the improvement of pain care in the form of an increase of efficiency of the professionals, always acting with quality and security to have the lowest risks for patients.

ASEEDAR-TD endorses initiatives like SIP which support the principles of the association as it helps to gain insights on best practices in pain and pain education with different stakeholders and reach excellence in pain care within the framework of a sustainable health care model. Thus, such initiatives might help the further development of health professionals at different levels and also in the improvement of pain care, always with a focus on a better treatment for the patient within the Health System.

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"ASEEDAR-TD is an Association of Nurses built to achieve academic and professional recognition of nursing professionals in the areas of anesthesiology, reanimation and pain therapy, and with the aim of supporting the improvement of pain care."

Main workplace/Organisation
Association for Pain Therapy Bosnia and Herzegovina (APTBH) Eurofarm Clinic

Profession/Function
President of APTBH

Recommendations of APTBH on the Action Plan on PM. to BiH responsible ministries - "Road Map" and the EU policy

What are the major achievements in BiH?
Law on Health Protection of the Federation BiH, 08/25/2010
Article 33 – Human rights and values in Health Care and patients rights on the care at the primary level include:
- Access to palliative care
- Accessibility of opioids

Federal Ministry of Health (Commission of experts) are currently working on legislation on the accessibility of opioids for cancer pain.
2011 - Federal Health Minister: "We Will Revoke waiting lists for anti-cancer drugs and the revision of the list of drugs that are funded by the Solidarity Fund.
Important Events:
I. Conference, "Experience and challenges in the new public health";
II. Conference- Consider Further extension plans of strategic directions.
- Pain medicine is mandatory teaching in 2000 at the Medical University for nurses. In 2011, it started for doctors. APTBH realized the Continuing education (2006-2010) of doctors and professionals of CBRs for mine victims
- Awareness – APTBH doing on campaign about Global Year Against Pain – Seminars, media, translated doc.-recommendation of EFIC, books, brochures, written guidelines and general recommendations
- Epidemiological and health economic data

APTBH realized a project a project: "Pain prevalence and SIP in BiH"

What are the major problems ?
- Still struggling with government commitment for effective pain management
- Lack of legislation on the availability of drugs for pain
- Number of pain specialists is insufficient
- Missing epidemiological data
- Insufficient financing
- Lack of coordination of all stakeholders
- The lack of an action for national program

Action for development of National Programme on pain control in BiH
To reach Agreement and schedule of activities between those responsible in the Council of Ministers, Ministry of Health in the Federation, RS and Brcko District, Health Insurance, Agency for Medicines, professionals and Bosnian Pain Association.
1. A platform in place representing all stakeholders in BiH
2. Establish a Commission with representatives of all those concerned in action for a national program on pain control
3. Re-activate and support an established system of "Network PM. in BiH" (implemented in 2008/ 2010 and organization of 7 Departments/ Centers for treatment of pain. Through these projects 2,500 members of medical staff have been trained.
   - Apply the treatment of pain in clinical pathways
   - Be supported and confirmed by the hospital administration, government bodies
4. Interactive education
5. Provide Funding
6. Provide access to pain drugs
7. Remove barriers

Assignments of the Commission representatives of all concerned
- Establish an action plan
- Establish monitoring and feedback systems on action plans
- Establish a coordination for all concerned

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"Action for development of National Programme on pain control in BiH."

Main workplace/Organisation
Association française de la cystite interstitielle (AFCI)

Profession/Function
Chairperson

Association française de la cystite interstitielle: interstitial cystitis French patients support group

Interstitial cystitis (IC), also known as painful bladder syndrome, bladder pain syndrome, hypersensitive bladder syndrome and chronic pelvic pain, is a distressing, chronic bladder disorder of unknown cause, with symptoms of pain, pressure or discomfort related to the bladder and usually accompanied by a frequent and urgent need to urinate day and night.

AFCI was founded in 2004 by a small group of patients to promote awareness of interstitial cystitis, to provide information on interstitial cystitis to patients and their families and to health professionals, to promote research and be the voice of patients for better healthcare and social care. Its newsletter reaches several hundred patients and health professionals every two months with news on research and many original articles.

AFCI works closely with scientific bodies such as INSERM (National institute for Medical Research), SFETD (Society for the Study of Pain), Convergences-PP...

AFCI is a member of Alliance Maladies Rares (Alliance for Rare Diseases), the French federation of rare diseases patients groups. It is a founding member of RDCP (Chronic Pelvic Pain Network) which unites 3 associations representing painful pelvic diseases.

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"Interstitial cystitis is a very painful, invalidating, depressing condition. AFCI's objective is to help patients to live with this condition and to promote knowledge and awareness of interstitial cystitis."

Main workplace/Organisation
Associazione Sammarinese per lo Studio del Dolore

Associazione Sammarinese per lo Studio del Dolore

Pain spreads throughout population and does not discriminate color, age, sex or social condition.

It's a real societal plague, and any effort to combat suffering must be endorsed both by politicians and healthcare professionals.

At his third edition, the SIP Symposium is a milestone in letting policy-makers understand how big the problem is, and how an integrated effort is mandatory to give any people a chance to stop suffering.

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"Give Society Knowledge to Combat Pain."

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ENDORSING ORGANISATION SIP2012

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"The objectives of the BBS are to promote research on low back pain, to implement guidelines in the daily practice of belgian health care providers, to help politicians to make evidence-based decisions in health care management and to organize media campaigns."

Main workplace/Organisation
The Belgian Back Society (BBS)

The Belgian Back Society (BBS): a scientific association with a societal impact

The Belgian Back Society is the unique belgium organization for scientists and health care professionals focused on the prevention and treatment of low back pain (LBP) through the promotion and presentation of research, education and the national dissemination of new knowledge. BBS involves belgian psychologists, physical therapists, rheumatologists, occupational therapists and orthopaedic surgeons.

The objectives of the BBS are to promote research on low back pain, to implement guidelines in the daily practice of belgian health care providers, to help politicians to make evidence-based decisions in health care management and to organize media campaigns. By this way, BBS has significantly modified health care providers practice, most particularly, the prescription of rest and imaging in acute low back pain. Media campaigns have largely contributed to positively change the beliefs of patients with chronic LBP about exercises and physical activities.

BBS has also promoted the implementation of pluridisciplinary centres based on a biopsychosocial approach of LBP in Belgium. Furthermore, every two years the BBS organizes an international congress gathering of over 400 attendees.

Main workplace/Organisation
Center of Medicine Based Evidence (CEMBE) Faculty of Medicine - University of Lisbon
Profession/Function
Consultant

Indirect Costs of Chronic pain in Portugal

In this study we estimate the indirect costs of chronic pain in the lower back and joints, following the human capital methodology. The analysis is conducted from the society's point of view and it is based on the prevalence of chronic pain using a bottom-up approach. We take demographic and social data from the 4th National Health Survey 2005/2006, whilst the database "Quadros do Pessoal" was used to calculate average wages by gender and age group, to estimate productivity.

Knowledge of the indirect costs of chronic pain is important for the development and consolidation of efficient prevention and treatment strategies and to mitigate the consequences of chronic pain in the health and wellbeing of the Portuguese population. The indirect costs of chronic pain in the lower back and joints, estimated using the wage costs of 2010, were € 739,85 million in mainland Portugal, where € 280,95 million is attributable to the absenteeism generated by short term disability and € 458,90 million is the result of the reduction of individuals in the work force, owing to early retirement and other forms of non-participation in the labor market.

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"The knowledge of the indirect costs of chronic pain is a relevant step for the development and consolidation of efficient prevention and treatment strategies to mitigate the consequences of this disease in the health and wellbeing of the Portuguese."

ENDORSING ORGANISATION SIP2012

Associação de Doentes de Dor Crónica dos Açores

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"The Association of Chronic Pain Patients in the Azores (ADDCA) is a nonprofit organization. It is under the umbrella of the Institute for Social Development of the Azores (IDSA) and was founded in October 2005 by a group of people with chronic pain."

Main workplace/Organisation
Azorian Association of Chronic Pain Patients (ADDCA)

Azorian Association of Chronic Pain Patients (ADDCA)

The Association of Chronic Pain Patients in the Azores (ADDCA) is a nonprofit organization. It is under the umbrella of the Institute for Social Development of the Azores (IDSA) and was founded in October 2005 by a group of people with chronic pain.

Its overall mission is to help, monitor, advise and sensitize patients suffering from chronic pain, helping to improve their quality of life is supported by the following specific objectives:

1. Disseminate information on Chronic Pain in different diseases and promote health education;
2. Cooperate in the treatment of Chronic Pain at all stages of the disease;
3. Cooperate in the humanization of social support and care to patients and their families;
4. Cooperate with institutions that develop activities in the area of Chronic Pain, including Pain Units;
5. Establishing links with similar national and foreign institutions;
6. Develop, alone or in collaboration with other entities, actions of solidarity and social structures for the treatment and rehabilitation of patients;
7. Promote scientific research;
8. Coordinate with local and government entities.

The actions already developed are:

1. A support group for Chronic Pain Patients;
2. Seminars and debates;
3. Raising awareness events in special dates;
4. Sharing experiences among people with chronic pain and / or their families;
5. A documentation center on Chronic Pain and related areas;
6. Multiple meetings, exchanges with other associations, exhibitions and conferences on pain.

The Association has an administrative officer and is an exciting social and cultural forum that works twice a week with several activities such as: paintings, embroidery, crochet, restoration of objects and building objects with various materials. In addition, stroke is the pain with music, dance and singing traditional Portuguese music. In our Association it is usual to celebrate notable dates such as: European Week and National Day Against Pain, the most representative religious parties or other important days as the ADDCA's birthday.

It should be noted that through new action implemented by the recently elected Managing Bodies, the ADDCA is being driven and designed as an association that aims to broaden its horizons through more and different initiatives to meet those who, because they suffer from pain, need to improve their quality of life and those around them.

The Association of Chronic Pain Patients in the Azores has great growth prospects. The number of people who come to us is growing every week. Please join us and build a better future for those suffering from pain!

ENDORSING ORGANISATION SIP2012

Associação Portuguesa de Cuidados Paliativos

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"We believe the best way to obtain good results is to support the governmental health departments, the University, patients associations and families."

Main workplace/Organisation
Associação Portuguesa de Cuidados Paliativos – Núcleo Regional dos Açores (Portuguese Association of Paliative Care – Azorian Regional Nucleus)

Portuguese Association of Palliative Care – Azorian Regional Nucleus

The Azorean Nucleus of the Portuguese Association of Palliative Care (NRA-APCP)* is a professional association for all members who live in the islands called Azores. We are organized with a Board Direction** who depends on the APCP. We intend to encourage the organization of Multidisciplinary Palliative Care Teams and education, research and information about palliative care in the Azorean islands according to their geographic characteristics and particularities.

Our special aim is to:

a) stimulate the organization of palliative care, grouping multidisciplinary health care professionals, such as, doctors, nurses, social workers, psychologists, physiotherapists and volunteers;
b) encourage teaching, research and information in the field of palliative care;
c) help the discussion of ethical issues in palliative care;
d) organize education courses for health professionals interested in working in this area;
e) be present in events related to palliative care, organized in Azores, in Portugal or abroad;
f) disseminate studies, documents and other information by different means;
g) strengthen collaboration with the Portuguese Association of Palliative Care and other national and international societies, organizations or institutions dedicated to palliative care;
h) increase people awareness about the concerns of modern palliative care;
We believe the best way to obtain good results is to support the governmental health departments, the University, patients associations and families. Since we are professionals with specific education in pain management, ethics, psychology, geriatrics and palliative medicine, the missing issue is organization. And if all of our members are aware of the concern of pain and suffering, we will benefit from joining the objectives of SIP organization to develop more and more in the field of pain treatment and palliative care.

** Maria Teresa Flor de Lima

ENDORSING ORGANISATION SIP2012

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"Over four million working days in the UK are lost each year due to back pain. While the cost to the economy is enormous, the real pain is felt by the individual. Unable to sit or stand without pain, they are more likely to slip into depression, to be divorced, and to die early."

Main workplace/Organisation
BackCare, the charity for healthier backs
Profession/Function
BackCare is a medical charity campaigning to improve awareness of the problems caused by back pain.

BackCare, the charity for healthier backs

Founded in 1968, BackCare is the only charity in the UK that is solely dedicated to providing support for, and campaigning on behalf of people affected by back pain. Our goal is to provide back health information to the whole community, both the lay person and health care professionals, and to significantly reduce the number of people affected by back pain.

We do this by providing a helpline service, a forum and publications, including the renowned Handling of Patients manual for healthcare professionals. BackCare's website (www.backcare.org.uk) receives over a million hits a year, and our iPhone App was recently selected by the Sunday Times as one of the top 10 health Apps in the world.

As well as engaging in promotional and campaigning work, including an annual awareness week, BackCare supports a UK wide network of branches providing hydrotherapy classes and other forms of support to people with back pain. Its reputation for research into back pain related issues saw the charity selected as a contributor to the NICE guidelines on back pain.

Back pain is very common and it is estimated that as many as four out of every five adults will experience it at some stage in their life. Back pain is also the highest physical reason for long term sickness in much of the UK, causing the loss of 4.1 million working days in 2008-09. It is the second most common reason for visiting a doctor, after the common cold.

Main workplace/Organisation
Swedish Association of Local Authorities and Regions (SALAR)

Profession/Function
Senior Advisor

The national agreement between the Swedish government and SALAR of advancing quality registries in Sweden

A system of national quality registries has been established in the Swedish health and medical services in the last decades. In 2011 the Government and Swedish government and the Swedish Association of Local Authorities and Regions (SALAR/SKL) reached an agreement to jointly fund further development of national registries for the following five years.

In 2012 200 million SEK are to be invested in registries. Lars Backlund, PhD and Senior advisor, SALAR, will provide an overview of the agreement but also enter a bit more deeply into the integration of primary care into national quality registries.

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"Quality registries are a useful tool to increase quality of health care. A large increase in funding with primary health care as one focus is now carried out in Sweden."

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"Guidelines for best patient care should be based upon robust evidence where it exists and involve explicit common sense when it does not. Appropriate expectations and recurrent assessment are key to implementation of best practice guidelines. Those actively involved in guideline production are best to produce informed commissioning."

Main workplace/Organisation
UCLH

Profession/Function
Consultant and Honorary Senior Lecturer in Pain Medicine

Clinical engagement in guidelines and commissioning

Dr Baranowski is a full time consultant in pain medicine and works within the framework of a multi disciplinary pain management centre. His unit within the National Health Service serves as a national centre for referral of patients with complex pains. He regularly performs a range of interventions within the framework of a multidisciplinary team.

Dr Baranowski was the main instigator of Pain Medicine meetings at The Royal Society for Medicine for over 14 years and set up the Pain Subsection before he remitted in 2011. He was a Royal College of Anaesthetists Regional Advisor for 7 years and helped to set up the London Pain Training Advisory Group. He has written multiple papers, chapters and guideline documents and is editor of two books.

He is a past president of PUGO (the International Association for the Study of Pain's (IASP) Special Interest Group for Urogenital Pain) and currently chairs their taxonomy committee – the latest classification will be published by IASP in 2012.

Dr Baranowski sits on several international guidelines committees including the European Association for Urology Chronic Pelvic Pain Guidelines Committee since 2003; their guidelines are accepted by the National Clearing House and the latest version will also be published in 2012. He has advised several agencies including the NIH and has been involved in the guidelines of the European Society for the Study of Interstitial Cystitis.

Dr Baranowski currently is an elected member to the British Pain Society (BPS) and is their Honorary Treasurer Elect. He also chairs the BPS Patient Pain Pathway Mapping (PPPM) Committee.

The PPPM committee has produced 5 guidelines (Primary Assessment and Management, Spinal, Musculoskeletal non-inflammatory, Neuropathic and Pelvic) which are evidence-based and will be published 2012. These are designed to foster education at all levels of management as well as best practice and as a consequence commissioning.

Dr Baranowski was recently appointed as Chair for the Department of Health Clinical Reference Group for Specialized Services – Pain and is currently drawing up guidelines around what specialized pain services should look like in England.

Main workplace/Organisation
Araba Universitary Hospital. Osakidetza

Profession/Function
Medical Director

A story about how patients and practitioners improve their quality of life using an Electronic Unified Clinical Record called Osabide Global.

Technology is regularly employed in the daily activity of doctors. The utilization of IT tools for the communication between patients and professionals is a reality nowadays. Osabide Global (OG), the Electronic Unified Clinical Record developed in Osakidetza, allows professionals from the hospital and from the rest of the area to share the necessary information for the attention of their patients. Pain Unit is actively participating in the development of what represents a new way of medical assistance. Because in practice, Osabide Global took us to an absolute reorganization of the activity. As the Electronic Record allows us to share information immediately, we have reduced wasted time to nearly zero, creating non-face to face consultations. These have the aim to avoid the unnecessary displacement of patients up to the hospital and improve the time used for attending them. These consultations can be realized in an indirect way, in which the Pain Unit attends to the request for help from the Primary Assistance for the patient treatment after a certain time (1 or 2 days). And it can be realized directly, by using the telephone, web cams and systems for video-conferences.

To develop all these consultations, we first had to redefine the daily agendas, to elaborate new protocols for patients follow-up, and only then we could estimate the potential of the change. Today, up to 45 % of the activity in the Pain Unit is performed without physical patient presence. In satisfaction questionnaires, 100 % of the patients and professionals consider that the Electronic Unified Clinical Record contributes to improve clinical attention and allows to increase the frequency of controls in patients. Professionals also think there is clearly a type of patient in whom the use of non-face to face attention is more practical. The type of patient for whom ensues from special interest, might be divided into three groups: the first one are patients with serious difficulties for the displacement (those who need a wheelchair, for example). The second are patients who live far from the hospital (peripheral patients). The last one is young active patients, new technology users. Certainly in all cases we must not need to physically explore for a diagnostic or a therapeutic approach. 93 % of the patients affirms that they feel comfortable with distantly attention, increasing their information on management decisions. 100 % of the patients think that his quality of life increases considerably avoiding unnecessary trips to health centers, clinics and hospitals, while minimizing interference with work and private life of patients and their families

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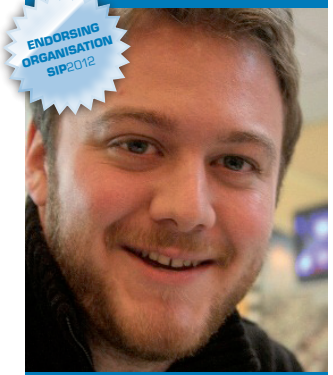
"The Electronic Unified Clinical Record and Non-face to face attention as a future option for patients, families and professionals."

B



Dr. Daniele Battelli
San Marino

"Chronic pain is a challenge, and a wrong prescription could be a false start: running for his life, every patient hopes to start with no handicap."

Profession/Function
MD

San Marino Analgesic Observatory: results and perspectives.

A nationwide analgesic consumption analysis in our country, linked with incidence of gastroenteric NSAID's related complications and NSAIDs overuse in ipercreatininemic population showed a general misuse of this analgesic class despite the presence of a wide choice of non-NSAID pain medications and approaches, that carries with lower side effects for the patients and less complication-related costs for the National Healtcare System.

Pain education and opioid prescription simplification, along with a stronger HTA-based approach should be given to healtcare professionals when giving pain medications for chronic pain patients.

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"The burden of chronic pain cannot be addressed by specialist healthcare professionals alone. Multi-stakeholder working is required to achieve meaningful change."

Main workplace/Organisation
Ulster Independent Clinic

Profession/Function
Consultant in Anaesthesia and Pain Medicine

Establishing multi-stakeholder pain platforms in Europe; a Northern Ireland Perspective

The burden of chronic pain is well known to sufferers, their family and carers and healthcare professionals with a special interest in the field. Its impact on society, employment and on direct and indirect healthcare costs is not always so well recognized. Improving the quality of life of sufferers and reducing these burdens requires not only investment in specialist services but also enhancement of the understanding of what can be achieved by patients, carers, employers and society to reduce this burden. In Northern Ireland we have brought together patient groups, healthcare commissioners and providers, educators and politicians to work towards a Pain Summit meeting with a view to setting an agenda for the changes needed to achieve these improvements.

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"We need much more awareness of pain in our society!"

Main workplace/Organisation
Austrian Pain Society (Österreichische Schmerzgesellschaft)

Profession/Function
Assoc. Prof.; President of the Austrian Pain Society

Pain awareness in the society

Pain is one of the biggest burdens in destroying the quality of life. Patients are not only suffering from pain but also have big problems in their daily lives like productivity (job) loss etc. In order to increase the level of awareness of the societal impact of pain last year our society has started a great media initiative for patients. For example we organized the so called pain week which was focused on lower back pain.

More than 250 articles about activities we organized were printed in different newspapers. We got feedback from many patients that they want to have more information about pain therapy and also about the precaution of pain. Overall more information about nonmedical therapy is wanted. With another initiative we started several discussions with the so called "Hauptverband der Österr. Sozialversicherungsträger" in order to get medical doctors more motivated for a better pain therapy.

I am convinced that our health care system has to accept the insufficient reality of treating suffering from people in pain much more. Pain is a major burden for society and it is a great challenge for public health. National policy makers need to recognize pain management as a top priority and introduce better pain therapies and pain prevention programs. More education of medical doctors in pain therapy is needed: In the meantime more than 600 medical doctors of Austria received the so called pain diploma from the Austrian Ärzteakademie.

Of course, costs for the healthcare system would increase at the moment, but in the long run all costs could likely decrease. The Austrian Pain Society is convinced that we need much more data about the occurrence of different forms of pain. We are also convinced that people in the lowest socio-economic classes and people living out in the country in a longer distance to pain centers have big deficits in pain therapy which should also be changed. The good news is that the bio-psycho-social model of pain is more accepted. Because of this most patients with all their complaints and diseases are mostly understood as whole persons. The Austrian Pain Society has about 650 members.

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"People who live with chronic pain deserve access to the safest and most effective treatments and support, including self-management support, no matter where they live."

Main workplace/Organisation
Neil Betteridge Associates

Profession/Function
Director

Putting people with chronic pain first

Neil Betteridge Associates is a UK based company which offers high level consultancy and advice on issues affecting people living with chronic pain, musculoskeletal and other long-term conditions.

Its founder, Neil Betteridge, has first-hand experience of living with chronic pain, having grown up with severe juvenile arthritis.

Professionally, he has over 25 years' experience working in strategic leadership, public affairs and high level communications in this area, acting as a representative and ambassador of the rights of people with long-term conditions.

As well as being the company director he is currently also:

- Patient and Public Adviser, Enhanced Recovery, Department of Health / NHS Improvement
- Vice President, European League Against Rheumatism (EULAR), representing the European network of patient groups called People with arthritis and rheumatism in Europe (PARE)
- Vice Chair, Chronic Pain Policy Coalition, UK
- Patient and Public Engagement member, Department of Health Clinical Reference Group, Specialised Pain

For the last 6 years he was CEO of Arthritis Care, the largest organisation in the UK representing people with any form of MSK condition. During that time the UK government appointed him to provide advice to ministers in two Departments (Transport and Health) to represent the needs of disabled people and patients.

Other recent positions of responsibility include:

2006-'09: Chair, Arthritis and Musculoskeletal Alliance (ARMA), the umbrella body for MSK organisations in the UK – previously Vice-Chair for four years
2003-'09: Chair, Disabled Persons Transport Advisory Committee (DPTAC), Department for Transport
2001-'05: (and 2009 ongoing): Vice President, representing People with Arthritis and Rheumatism in Europe, European League Against Rheumatism (EULAR)

Neil Betteridge Associates is proud to endorse the SIP meeting 2012.

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"This session will look at the importance of addressing the growing burden of musculoskeletal pain in the working age population of the EU."

Main workplace/Organisation
The Work Foundation, Lancaster University

Profession/Function
Director

Fit for Work - MSDs and Work in the EU

A healthy workforce means a healthy economy. Yet conventional measures to improve productivity, from investment in skills, technology and innovation to labour market deregulation, fail to take account of one of the most serious barriers to growing prosperity: poor workforce health. Over 44 million (one in six) members of the European Union (EU) workforce have a long-standing health problem or disability that affects their ability to work, and musculoskeletal disorders (MSDs) account for a higher proportion of sickness absence from work than any other health condition. Appropriate interventions and workplace adjustments for individuals with these conditions are needed to allow them to continue to lead productive and active working lives.

Fit for Work Europe studied the social and economic impact of MSDs across 25 countries. The research was conducted by reviewing recent academic and practitioner literature on the relationship between four particular types of MSDs and labour market participation and by conducting interviews with over 100 experts. The project investigated the impact of low back pain and work-related upper limb disorders (WRULDs) – two groups of conditions which are usually characterised by short but intense episodes of pain and incapacity – and rheumatoid arthritis (RA) and spondyloarthropathy (SpA), two inflammatory conditions that are often progressive, painful and increasingly incapacitating.

The Fit for Work Europe report examines the causes, effects and costs of MSDs in the European workforce and assesses what more can be done by policymakers, health care systems, social welfare regimes, health care professionals, employers and by workers themselves to help alleviate the often damaging economic and social consequences of this widespread, but frequently hidden, problem.

The quality and quantity of data on the definition, prevalence, impact and costs of MSDs vary considerably between countries. Even at the most basic level, great differences exist across European countries in the variety of MSDs included on occupational disease lists. Nonetheless, chronic musculoskeletal pain affects 100 million people in Europe, and that its widespread in Europe's working age population – although undiagnosed in over 40% of cases. They represent an estimated cost to European society of up to 2% of gross domestic product.

Main workplace/Organisation
Pelvic Pain Support Network

Pelvic Pain Support Network

The Pelvic Pain Support Network is a registered charity and was established in 2006. It is a patient led organisation with a board of trustees who are all patients or carers. Our medical advisory panel is multi-disciplinary and includes experts from many countries and areas of expertise.

The charity provides support, information and advocacy for those with pelvic pain, their families and carers. We also facilitate education of the public and the medical profession by raising awareness in all matters relating to pelvic pain and its treatments and encourage the advancement of research to increase knowledge and understanding of pelvic pain. The charity actively participates in relevant health technology appraisals and at many local, national and international meetings and conferences for clinicians and policy makers.

An important area of our work is highlighting the societal impact of pelvic pain conditions in an effort to raise awareness about the huge cost of these conditions, in terms of the impact on the quality of life of those who suffer and to the health service and the employment sector.

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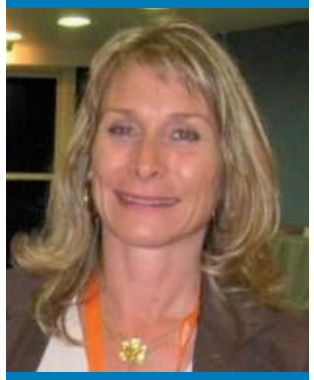
"A significant proportion of those with chronic pain suffer from pelvic pain. They have been neglected either because they are undiagnosed or their condition is not life-threatening. The impact on quality of life and the cost to society as a whole in economic and social terms is huge. This is not ethically acceptable; they need to be given more attention."



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"Developement and validation of pain behavioral tools in elderly patients.
Educational programs to improve pain assessment in different geriatric cares."

Main workplace/Organisation
Société Française de Gériatrie et Gérontologie, Aix Marseille Université
Profession/Function
Professeur de Gériatrie, Conseiller Scientifique la Société Française de Gériatrie et Gérontologie

Pain management for elderly patients in various geriatric cares

Since 1995, a panel of pain physicians and geriatricians experts has been working on pain assessment and management in elderly patients (the Doloplus collectif). This panel developed and validated two behavioral pain assessment scales in elderly patients with inability to communicate verbally: Doloplus® and Algoplus®. Pluridisciplinary workshops also elaborated specific guidelines in pain management in frail elderly patients.

Furthermore, in the early 2000, French Health authorities delegate to the French Geriatric National Society educational actions about pain assessment in different geriatric cares. Thus, the Mobiqual program was developed with the aim of improving quality of care in Nursing Homes.

Main workplace/Organisation
European Network for Health Technology Assessment (EUnetHTA)

Profession/Function
Director, EUnetHTA Secretariat

European collaboration in Health Technology Assessment

The mission of the EUnetHTA Collaboration is to support effective Health Technology Assessment (HTA) collaboration in Europe that brings added value at the European, national and regional level. The EUnetHTA Collaboration recognises and facilitates solutions to overcome barriers caused by language, variations in perceptions of terminology and facilitates national solutions to deliver context specific HTA reporting in the most appropriate manner.

The EUnetHTA Joint Action (JA) (2010-12) is a response to the request by the EU Commission and EU Member States to continue fostering the development of HTA in Europe. Focusing on scientific cooperation in HTA in Europe, thirty four governments appointed organisations from the EU Member States, Accession Countries and EEA work together to help developing reliable, timely, transparent and transferable information to contribute to HTAs in European countries.

The EUnetHTA JA will continue into EUnetHTA JA2 for the years 2012-15. The EUnetHTA JA activities are facilitated by the EUnetHTA Collaboration organisational and governance structure, which includes a Stakeholder Forum, and has received funding from the European Union, in the framework of the Health Programme.

B

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"HTA is fostering a focus on the value of health interventions - and cross-border collaboration in HTA can facilitate a broad scope when assessing their value."

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"Pain management without good education of health professionals, students and public leads to unsuccessful outcome. Our approach is to put education at the highest academic level but to develop different educational programs for undergraduate and postgraduate students, continuing medical education, volunteers and patients. Education is always one step before intervention!"

Main workplace/Organisation
Marijana Braš, Veljko Djordjevic, School of Medicine, University of Zagreb
Profession/Function
Centre for Palliative medicine, Medical Ethics and Communication Skills – Deputy Head

The Founding of the Centre for Palliative Medicine, Medical Ethics and Communication Skills at the School of Medicine, University of Zagreb

School of Medicine, University of Zagreb has recently completed activities that lasted several years, aimed at further development and creation of undergraduate and postgraduate education in the areas of communication skills in medicine, medical ethics and palliative medicine (with special emphasis on education on pain). In this context, one of the very important events was the establishment of the Center for Palliative Medicine, Medical Ethics and Communication Skills in Medicine, University of Zagreb (CEPAMET), which was established by the Faculty Council meeting, held on 21 September 2010.

CEPAMET is a research-oriented, educational and professional organizational unit of the School of Medicine, which will be organized in several departments and sections, dealing with the development of academic programs on palliative medicine, pain, medical ethics and communication skills, and encouragement for the establishment of the first health care institution for palliative care in Croatia. The team involved in CEPAMET creation and work is interdisciplinary and consists of professionals who are experts in psychiatry, neurology, oncology, anestesiology, psychology and family medicine.

Professor Veljko Djordjevic, MD, PhD was elected for the Head of the unit, while Marijana Bras, MD, PhD was elected as deputy. Promotion of CPEK was held on October 6 2010 at the School of Medicine, University of Zagreb, and the celebration of World Day of hospice and palliative care in Croatia. A large number of academic institutions and non-governmental organizations support this initiative, as well as Prime Minister and President of the Republic of Croatia. We stressed out the need for further development of education on communication skills, medical ethics, palliative medicine and pain on all levels and for all employees in health care system and in accordance with the recommendations of competent international institutions and modeled on examples of excellent practice in the world.

Therefore, we established cooperation with a dozen international experts from Germany, Italy, Great Britain, Austria, Germany, Canada and the United States who agreed to be members of the Advisory Board and actively assist in developing training programs in Croatia. CEPAMET immediately began working, and especially emphasized the organization of many different national and international meetings (courses, conferences etc.) as well as different educational programs for students and health professionals related to communication skills, pain management and palliative medicine.

Main workplace/Organisation
British Pain Society

Profession/Function
President

Pain and other symptoms in palliative cancer care

The British Pain Society is the largest multidisciplinary professional organization in the field of pain within the UK. Our membership comprises doctors, nurses, physiotherapists, scientists, psychologists, occupational therapists and other healthcare professionals actively engaged in the diagnosis and treatment of pain in pain research for the benefit of patients. We have a steady increasing number of members annually.

The Society was first registered as a charity on 29 November 1979 as the Intractable Pain Society of Great Britain and Ireland with a membership limited primarily to anaesthetists working in pain clinics. Over time, the membership of the Society became increasingly multidisciplinary and in 1988, the Society changed its name to the Pain Society and subsequently to The British Pain Society. The Society is involved in all aspects of pain and its management through the work of the Council, Standing Committees, Working Parties, twelve Special Interest Groups and via its publication including regular newsletters and continuing professional development publications, the Annual Scientific Meeting and educational Study Days.

Today, the British Pain Society has a membership of over 1,450 and is a uniquely relevant representative body on all matters relating to pain. The Society aims to promote education, training, research and development in all fields of pain and has recently increasingly engaged with policymakers, politicians and the media to increase both professional and public awareness of the prevalence of pain and the facilities that are required for its management. The Society fully endorses the aims and objectives of this SIP meeting.

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"The British Pain Society (BPS) is the leading organisation for healthcare professionals, educators and researchers in the field of pain medicine. The Society has been striving to secure a higher profile and resourcing for pain medicine in the UK, and has recently had confirmation from the National Health Service of Pain Management being listed for a Quality Standard, and of funding allocated for a major 'e-learning in pain' project (the latter in collaboration with the Faculty of Pain Medicine). In 2012, the BPS will be publishing national guidelines in the form of chronic pain patient pathways. These are important components in the Society's strategy to improve pain medicine in the UK for the benefit of patients."

ENDORSING ORGANISATION SIP2012

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"BVSD's objective is the qualitative and structural development of the general and specialised pain therapy and pallitive medicine."

Main workplace/Organisation
Berufsverband der Ärzte und Psychologischen Psychotherapeuten in der Schmerz- und Palliativmedizin in Deutschland e.V. (BVSD)
Profession/Function
Geschäftsführer / General Manager

Berufsverband der Ärzte und Psychologischen Psychotherapeuten in der Schmerz- und Palliativmedizin in Deutschland e.V. (BVSD)

BVSD is organised throughout Germany via its regional associations and represents the professional and political interests of physicians and psychological psychotherapists who are active in pain therapy and palliative medicine.

It aims for the qualitative and structural development of the general and specialised pain therapy and palliative medicine.

Focus of the regional associations is on the development of contracts, management of cooperations and quality assurance and management.

Main workplace/Organisation
San Raffaele Hospital of Milano,
University Vita e Salute of Milano
Profession/Function
Head of Department of Obstetrics and Gynecology

Chronic Pelvic Pain: Quality of Life and Economic Correlates

Chronic pelvic pain (CPP) is defined as pain originating in the lower abdomen or pelvis with a duration of at least six months, severe enough to cause disability or require treatment. It is a common condition among women, with an estimated prevalence of 38/1000 women between 15 and 75 years (similar to asthma or chronic back pain), accounting for approximately 10% of all referrals to a gynaecologist, 20% of all hysterectomies performed for benign disease and over 40% of gynecologic diagnostic laparoscopies.

The range of gynaecological causes of CPP is wide and in many cases a variety of contributing factors may coexist: Dysmennorrhoea related to endometriosis is the most common and debilitating CPP related disease, characterized by the greatest health distress and interference with daily activities, followed by pelvic adhesions, cysts, adenomyosis and fibrosis. Frequently the identification of the underlying disorder remains difficult and challenging, leading to a significant delay in diagnosis. Despite the high prevalence of CPP, the awareness of its impact on quality of life and estimated direct and indirect costs[including diagnostic delay, healthcare resources utilization, autonomy and productivity loss, treatment for depression and associated disorders, often experienced by these patients] is still too low.

We suggest that a timely assessment will contribute to a better understanding of the economic and societal burden of CPP, therefore promoting increased attention to these conditions,, the impact and prevalence of which highlights its importance in women's healthcare.

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"It is not acceptable that chronic pelvic pain is still so poorly recognized, coordinated and treated."

C

ENDORSING ORGANISATION SIP2012

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Main workplace/Organisation
Castilla y Leon Society of Pain (DOCyL)

The Leon-Castelian Society of Pain

Leon-Castilian Health professionals focused on pain. Leon-Castilian Pain Society is a professional society, multidisciplinary and non-profit organization that focuses on pain management. It has been working since 2.000. It is composed by health professionals with different specialties and backgrounds, especially physicians, but also other professionals such as psychologist and graduates in nursing.

At this moment the Leon-Castilian Society of Pain and Palliative Care counts with 54 members.

The Society has different objectives:

1) Promoting scientific works about mechanisms and treatment of pain.
2) Raise public awareness about this problem.
3) Encourage the continuous improvement in assessment and therapy in patients suffering pain.

According to the main objectives of our society we are willing to endorse the "Societal Impact of Pain" meeting since it is a very relevant initiative and very good opportunity for key stakeholders to exchange their best practices in pain, and create consensus for future collaborations on improving pain care.

Main workplace/Organisation
Director of Policy & Parliamentary Affairs

Profession/Function
The Fitzpatrick Building

Influencing public policy to drive change in end of life care

C

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The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430. Visit www.npcp.org.uk for more information.

We lead the national Dying Matters coalition, which currently has over 15,000 members, to change knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make 'living and dying well' the norm.

Visit www.dyingmatters.org for more information.

"The direction of national policy in the UK countries is to support more people at the end of life to be cared for and die in the community setting of their choice. Ensuring access to essential services and support, including medication and pain relief, at any time of day and night, is essential to achieve that. This session will examine the influences and drivers in public policy that can bring about improvements in the care and experience of people at the end of life care. Delegates will learn about the impact of the national End of Life Care Strategy in England, together with the NICE Quality Standard on End of Life Care, the Dying Matters coalition to raise awareness and change attitudes and behaviours towards death and dying, patient reported outcome measures (PROMs), and other levers for change."

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"The numerous and impactful consequences of chronic pain on patients' lives can quickly result in bio-psycho-social, familial, and professional desinsertion. Pain patients precariousness is underestimated and worsened by the absence of recognition of chronic pain as a disease."

Main workplace/Organisation
AFVD

Profession/Function
Consultant & Professor, DMSc

Precariousness and pain. The added value of expert patients.

Chronic pain has multiple and multidimensional consequences for patients: familial disturbances (separation, divorce), physicial disability (reduced mobility), psychological and motivational difficulties, social isolation, and professional misunderstanding and desinsertion.

Complexity, poor access, and poor reimbursement of management solutions for these various consequences of chronic pain regularly lead to patient precariousness.

Expert patients are experienced chronic pain patients "in peace" with their pain. They complement and actively participate to the patient management process coordinated by health professionals. After dedicated training (listening skills, educational skills), expert patients bring a strong added value to medical management by providing information, advices and mediation between the medical knowledge and patient experience. The synergy between medical team and expert patients helps to accelerate patient reinsertion.

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Main workplace/Organisation
Regione Abbruzzo

Profession/Function
Governor

Abruzzo: from the avoided default to the improvement of the public healthcare system

After years of debts and a constant inefficient management, Abruzzo's healthcare system has been put under legal tutoring by the Italian central Government, trying to avoid major consequences to a regional system on the verge of default. At that time, Abruzzo ranked some unflattering records: the highest indebted region, first region put under legal tutoring, the region with the highest grade of taxation. After Mr CHiodi was nominated "Commissario ad acta" (a special legal function with decisional powers of intervention), a restless activity has been initiated, with the aim to achieve a sharp financial and economical upturn. The Region Government established a set of structural reforms and proceeded with strict choices to level the healthcare parameters back to the national standards. On the last 4th of April, after Abruzzo had already achieved its first profit ever at the end of 2010, the financial statements for the year 2011 showed a budget surplus of 60,986,000 and a net income of 5 millions. This is certainly an historical result, giving that Abruzzo has never been able to score a budget surplus before this date and, at the same time, being so close to the good level in terms of quality of assistance set by the Government's standards.

It is clear that the improvement is still in progress and that there is much more to do, especially on the reduction of the waiting lists for diagnostics. The renovation path will be claimed completed only when the last Abruzzo's citizen will be counting on a Healthcare System with high quality services at sustainable costs.

In this framework, our commitment for the implementation of the Law 38/2010 for Palliative Cares and Pain Therapy is among the primary ones. Following the national directives of the National Healthcare Plan, Regione Abruzzo activated the "Pain Therapy Regional Net" with the intention of accomplishing the following objectives:

- Continuous improvement of the quality of life of adult patients with pain, independently of its etiopathogenesis and causes;
- Reduction of the rank of disability among the population suffering from pain
- Simplified reintegration of the pain patient in a social and working context

A "Special Regional Coordination Committee" has been constituted with the aim of carefully planning the clinical and organizational activities for the management of avoidable chronic pain along with the continuous search of areas of improvement of the quality of cares. This Group also carries out functions of coordination and monitoring of the "Pain Management Regional Net", with the purpose of interconnecting all the professionals operating within the "Net" itself, and caring for pain and terminal patients. The next step will be the realization of a regional program for the activation of the "Net", for the definition of the interventional guidelines, effective on the brief, medium and long terms and to be able to meet the requirements of building and constantly upgrading a system of pain management, ensuring the total implementation of laws and regulations on the matter.

Management of suffering patients certainly is one of the priorities, in the Abruzzo Region.

Main workplace/Organisation
Chronic Pain Ireland (CPI)

Profession/Function
Chairperson Chronic Pain Ireland, BA econ., Barrister at Law (BL)

Chronic Pain Ireland – greater awareness for chronic pain

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"Chronic Pain Ireland's mission it to create a greater awareness of Chronic Pain and to provide relevant information and support for those living with the condition, for their families and friends."

CPI (formerly Irish Chronic Pain Association) was founded in 1992. The aim of the organisation is to provide information and support to those living with chronic pain, their families and friends. In addition CPI campaigns for greater education and understanding within the medical profession of the condition. Historically chronic pain was misunderstood, under-diagnosed and neglected. Over the years CPI has demonstrated professional leadership in Ireland and throughout Europe by drawing attention to Chronic Pain and promoting new and better methods of dealing with the disease. Recent years has seen a substantial development of global research, both physiological and psychological, into the mechanisms and effects of chronic pain. In more recent years there is increasing evidence to consider, study and treat chronic pain as a separate disease entity.

CPI continues to provide support and information to those suffering with chronic pain while working with all the major stakeholders. CPI lobbies for multi-disciplinary treatment centres, improved health services and changes to the educational curriculum so that Healthcare Professionals are more aware of the condition, the challenges of diagnosing, treating and managing the condition.

CPI provides a range of services including, information meetings, guest speaker events, awareness campaigns and self-management workshops which are held nationwide. In addition the organisation produces a quality newsletter and provides telephone and website support. The website will be the main communications tool enabling our members, healthcare professionals and members of the public access a range of material, information and support relevant to the condition of Chronic Pain. It will be the first port of call for many suffering from chronic pain and will provide information and support as well as papers on the most up to date research worldwide.

CPI is run by a Committee of volunteers, most of whom suffer from chronic pain. The organisation employs an office administrator who manages the day to day workings of the organisation and also provides telephone support for its members.

Main workplace/Organisation
Perugia University, District of Terni - Italy

Profession/Function
Associate Professor of Internal Medicine

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www.painnursing.it

"Pain: from a symptom to a disease; from the disease-of-silence to a disease with its own rights. The scientific and academic community is call out to stimulate and support the political authorities in order to increase the level of attention, as well as to improve the interventions about one of the most relevant issue concerning the human being."

Degree in Medicine

Post-graduated courses: Internal Medicine, Rheumatology

- Head and Chief, Dept. of Internal Medicine, Rheumatology, and Medical Pain Therapy
- Associate Professor of Internal Medicine, and Teacher in Postgraduated Schools: Rheumatology; Cardiology; Forensic Medicine; Urology; Internal Medicine; Oncology.

Papers on: rheumatic diseases, osteoporosis, chronic degenerative and cancer pain. References on: Pain Practice, European Journal of Pain, Journal of Pharmacology and Experimental Therapy, Journal of Immunology, International Journal of Functional Syndromes, Clinical Medicine: Therapeutics, Rheumatology.

- Proposal of a questionnaire to evaluate the foot in the rheumatic diseases. Clin Ter 2006; 157(3):199-205
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- Narrative Medicine: the modern communication between doctor and patients. Clin Ter 2011; in press
- Chronic Degenerative Pain: an update on abdominal pain in comparison to rheumatic diseases. J CLin Gastroenterol 2011
- An Ethics Code for Pain. Eur J Pain 2012 (submitted)

- Member of the Centre for the Study of Pain in Animals, Perugia University
- President, Paolo Procacci Foundation for the Study of Pain
- Councillor for Italy, European Federation of IASP Chapters
- Advisor, Change_Pain, and Societal Impact of Pain Study Groups
- Member, EFIC Task Force: European Reimbursement Policies
- National Secretary: Italian Association for the Study of Pain (AISD)
- Ordinary Member: International Association for the Study of Pain; European Federation of IASP Chapters
- Editor-in-Chief: Pain Nursing Magazine, P.Procacci Foundation – Italy
- Member of the Editorial Board: ISRN Rheumatology, Hindawi Publishing; La Clinica Terapeutica, SEU, Rome.
- Referee for: Pain Practice, European Journal of Pain, Pain Research and Treatment.
- Member of Scientific Committee: National Congresses of AISD (editions: 2009-2012).

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"The impact of chronic pain on health is hugely detrimental, both at individual and population level and yet there is so much for potential for change. Better health and quality of life can happen where the core focus of care is on a person or population centered multidimensional model. This guides a more holistic, compassionate and integrated approach based on health needs using existing health and social care services and community resources differently, so better health outcomes."

Main workplace/Organisation
Bradford Teaching Hospitals

Profession/Function
Pain Rehabilitation Specialist

Enabling better health and well being for people with chronic pain and their health related needs through commissioning services and resources, both at local and nation levels.

Frances Cole is a part time GP and pain rehabilitation specialist working in West Yorkshire. She trained in cognitive behavioural therapy at Newcastle CT Centre in 1993-4.

In 1996, she started the first UK multidisciplinary primary care pain rehabilitation service in Bradford based on cognitive behavioural therapy principles. She continues to run this service and works in clinical health psychology at Bradford Teaching Hospitals using CBT in a wide range of mental and physical health problems. She has developed a pain health needs assessment tool that won a regional NHS Modernisation award in 2005.

She runs a range of workshops and training courses for primary care trusts in Yorkshire and UK for primary care practitioners in CBT techniques for both mental health, chronic pain and long term health condition self management.

She is a co-author of a CBT self help guide "Overcoming Chronic Pain", part of the CBT based self help guides published by Constable Robinson. She has recently commissioned and implemented in three pain management programme sites, a new CBT workbook "The Pain Management Plan" with Professor R Lewin, York University, designed for partnership working with patients both home and community settings.

She is a clinical lead for commissioning care pathways and services for people with long term pain at NHS Kirklees and NHS Bradford & Airedale, West Yorkshire and currently involved in the British Pain Society Map of Medicines pain pathways work. She was a finalist in the 2011 National Clinical Leaders Network leadership award for leading and implementing changes in provision of services for patients with pain.

She is currently the chair of the British Pain Society Pain Management Programme Special Interest Group whose current focus is on measuring patient outcomes and Pain Management Programme guidelines review. She is on a working group for guidelines opioid drug management for primary care with the British Pain Society.

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C

Main workplace/Organisation
Chronic Pain Policy Coalition (CPPC)

Profession/Function
Chair CPPC, of the Pain Summit Steering Group

Pain Summit 2011

On Tuesday 22 November the Pain Summit 2011 took place at Central Hall, Westminster. The Summit was a joint initiative of the Faculty of Pain Medicine, the Royal College of General Practitioners, the Chronic Pain Policy Coalition (CPPC) and the British Pain Society. The Summit was attended by over 150 people and attracted a wide variety of delegates including healthcare professionals, commissioners and patient groups.

The Pain Summit was opened by Earl Howe, Parliamentary Under-Secretary of State for Quality at the Department of Health, who confirmed that the Government recognizes the enormous collective burden of pain and the impact that it has on society. He noted that 'the successful management of chronic pain requires seamless integration between primary, secondary and tertiary care'. He commented that consideration is being given to the inclusion of pain management in the NHS quality standards.

Professor Sir Bruce Keogh, Medical Director of the NHS referred to the National Pain Audit and the marked variation in access to pain services across the country. He invited delegates to define what is needed to make the NHS 'good' in terms of treating acute and chronic pain and what is needed deliver the services that delegates want for people living with pain. The plenary sessions were completed by Professor Dame Carol Black, National Clinical Director for Health and Work, who highlighted that more should be done to enable those with pain to remain at work and feel of value in the workplace.

People living in pain gave their personal account of their life, focusing on the impact of chronic pain. This was supplemented by talks from patient organizations and professionals concentrating on the delivery of services for people living with pain.

The day was concluded with remarks from former Chief Medical Officer Professor Sir Liam Donaldson who suggested a 5 point plan:

1. Undertake a burden of disease analysis to be able to describe the scale of the problem
2. Ensure that chronic pain is seen as a 'high street disease' in the eyes of the public and the media
3. Embed chronic pain within an NHS performance framework and ideally more than one
4. Showcase centres of excellence
5. Achieve universal use of pain as a clinical metric in the same way as blood pressure is regularly recorded

It was a privilege to be part of this day that brought so many organizations and individuals together working to produce a unified plan for the better management of pain throughout primary, secondary and tertiary care. November 22nd was just the beginning of the Pain Summit's work; a report detailing the activities of the day was published in December, a copy can be downloaded from the Pain Summit website. The ideas and feedback received from the workshops will provide the basis for a fuller report to be launched at a reception in the Houses of Parliament in July 2012.

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Main workplace/Organisation
Consellería de Sanidade de Galicia

Profession/Function
Galician Health Service

Consellería de Sanidade de Galicia

Galicia is an autonomous region located in the Northwest of Spain. It has an extension of twenty nine thousand five hundred seventy four square kilometers, divided in four provinces. It has a population of 2.778.913, of which 22% are over age 65. This region is fully competent in health issues.

The health system is made up of 15 hospital complexes with a total of 8.020 beds and 391 primary care centers. In 2011 there were 239.000 hospital admissions, 181.000 surgical interventions and 14.800.000 primary care consultations. One of our goals is to improve the care provided to patients, by means of implementing a global strategy directed towards optimal pain management, both standardized and equitable, for all patients and, in this way, obtaining "pain free hospitals."

ENDORSING ORGANISATION SIP2012

XUNTA DE GALICIA
CONSELLERÍA DE SANIDADE

C

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"One of our goals is to improve the care provided to patients, by means of implementing a global strategy directed towards optimal pain management, both standardized and equitable, for all patients and, in this way, obtaining "pain free hospitals."

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"Portugal is one of the few European countries that has already implemented pain management in its National Healthcare System."

Main workplace/Organisation
Hospital Garcia de Orta, EPE

Profession/Function
EFIC Councilor

Defined outcomes from the implementation of pain management in a National Healthcare System

Portugal is one of the few European countries that has already implemented pain management in its National Healthcare System. It started in the mid-1990s, when the Portuguese Association for the Study of Pain (Portuguese Chapter) convened a meeting at which the societies of anesthesiology, neurology, neurosurgery, physiatry, orthopedics, oncology and rheumatology considered pain as a disease. The outcome of this multidisciplinary meeting was a task force responsible for establishing the competence in Pain Medicine granted by the National Medical Association and for exchange of information with the National Medical Association and the Health Ministry.

Within the last 12 years, the Portuguese Health System achieved 7 important milestones in pain management.

1999	implementation of the 'National Day Against Pain'
2001	approval of the "National Plan Against Pain"
2003	pain recognized as the '5th vital sign'
2004	pain management was recognized as a medical competence by the National Medical Association.
2008	the "National Program for Pain Control" substituted the "National Plan Against Pain"
2010	creation of the National Observatory of Pain (NOPain), a coalition between the Faculty of Medicine of the Oporto University and the Portuguese Association for the Study of Pain.
2011	establishing of the electronic prescription of opioids

Other general objectives have been achieved or are ongoing, such as educational programmes, guidelines for pain management in the elderly, guidelines for prescription of opioids for non-malignant pain, organizing the annual National Day Against Pain, guidelines for pain management in children, evaluation of the chronic pain clinics, and establishment of a pain clinics network.

Still missing in the National Programme are priority financing for basic scientific research, involvement of patient interest groups in care programmes, and the adoption of approaches that support self-care.

Main workplace/Organisation
Croatian Association for the Treatment of Pain (HDLB)

Profession/Function
President Croatian Association for the Treatment of Pain

The Osijek Declaration on the Rights of Patients with Chronic Pain

In our opinion, every patient is entitled to the right to life without pain. Thus, in approach to the chronic pain as an important health problem and a separate illness, the following rights of patients must be respected: Patient has a right to an adequate prevention and control of the pain.

1. Patient has a right to be informed about the nature of his/her pain and its anticipated duration;
2. Patient has a right to be informed about all the options of medical treatment of the pain, as well as all the risks and advantages of various ways of its medical treatment;
3. Patient is entitled to a free choice of the way of medical treatment of his/her pain, including the right to change the type of the treatment, respectively, to stop the course of the current treatment;
4. Patient has a right to ask for a second opinion about the status of his/her pain and the possibilities of its treatment;
5. Patient is entitled to the right of the participation of his/her family in the decision making concerning the way of his/her medical treatment;
6. Patient is entitled to the protection of his/her privacy and the confidentiality of all the data from his/her medical files, which should also contain the data about the kind and the type of the pain the patient has been or is still exposed to, as well as the data about all forms of medical treatment that have been applied;
7. Patient is entitled to the right of insight into his/her medical document.

In Osijek, the 10th of May 2003.

ENDORSING ORGANISATION SIP2012

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"Pain management is a fundamental human right. 'People in pain' needs to become a national health priority."

C

ENDORSING ORGANISATION SIP2012

Croatian Society for Palliative Medicine – Croatian Medical Assocation
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"Croatia still doesn't have palliative medicine in the health system and the role of professional society is to help to develop it!"

Main workplace/Organisation
Croatian Society for Pallliative Medicine, Croatian Medical Association

Profession/Function
Professional Society

Croatian Society for Pallliative Medicine, Croatian Medical Association

Croatian Society for Palliative Medicine is one of the professional societies of the Croatian Medical Association, which gathers specialists from various areas with special interest in palliative medicine and pain management. This society was founded in 1994. CROATIAN MEDICAL ASSOCIATION (CMA) is the oldest non-governmental, autonomous and independent professional association of doctors and dentists established in February, 26th in 1874, act independently 135 years in this area by gathering all Croatian doctors and dentists. CMA was founded at a time when Europe seemed only 7 of the same national medical association, which is especially important data and facts valued by other European and national associations of physicians worldwide. The CMA operates through 26 branches and 121 Professional Societies. Branches organize professional and scientific work and social life of physicians and dentists of various specialties and subspecialties, by county centers. Professional societies gather the same specialist physicians or subspecialties areas who come together precisely in order to progress and for development specialization and subspecialization.

Direct beneficiaries of the association are its regular members – medical doctors, doctors - dentists, or specialists with higher education who are not medical doctors from the country or abroad, who are working in the health services and researchers in the field of medicine so they can be associate members. Undoubtedly, the direct benefit of the work CMA has the entire population of Croatia because all the professional and scientific work taking place right through the Croatian Medical Association. The activity of the Association and its subsidiaries takes place primarily in organizing numerous meetings, symposiums, congresses or similar meetings with the aim of continuing medical education and improving health care.

The CMA works closely with the Ministry of Health, Ministry of Science and Technology, the Croatian Medical Chamber, Croatian Medical Syndicate and all government authorities and the Croatian Government, the judiciary, the Croatian Health Insurance Institute, and numerous other institutions or related organizations, scientific and educational health and related databases, and with the Croatian Academy of Arts and Sciences, and the Croatian Academy of Medical Sciences. Croatian Medical Association has been publishing the oldest professional journal of medicine for 132 years. Medical Journal is one of the oldest medical journal in Europe. Croatian Medical Association has published its own Medical Journal Gazette since 1972. The dentists within the Croatian Dental Society have published their own professional journal – Acta Stomatologica. CMA is a member of numerous professional associations throughout Europe and the world:

1. World Medical Association (WMA) - World Association of physicians
2. European Forum of Medical Associations and WHO (EFMA / WHO) - European Forum of medical associations and the World Health Organization
3. European Union of Medical Specialists (UEMS), and many others.

Main workplace/Organisation
Myeloma Euronet Romania

Profession/Function
President

Hope for the Future

My name is Viorica Cursaru.

I am the President of ME Romania and a Board member of Pain Alliance Europe. I am also a retiree of the United Nations, an organization I worked for almost 20 years prior to my retirement.

My husband, Mihai Cursaru, died at the age of 64, because of multiple myeloma, a cancer of the bone marrow.

The right to live is one of the most meaningful principle ever formulated by the mankind and transposed into important documents such as UN Charta of Human Rights and EU Charta of Fundamental Rights. Furthermore, Treaty of Lisbon stipulates that the life must be protected by all means, while WHO defines health as a matter of safety and security.

Last, but not least, starting from the same principles, on 15 October 2010, Health Commissionr Dalli stated that the ultimate objective of the EU is to have EU nationals treated well in their own countries.

Yet, in spite of all these principles, the right to live in respect and dignity has different dimensions at the EU level.

Whereas in the most developed parts of Europe, the respective national governments take the most appropriate actions for the implementation of better health systems, by increasing the level of quality of life, reducing morbidity and, in general, by creating healthy environment s for their citizens, in the less developed countries, and here I am making reference to the Central European Countries, for various reasons, ranging from lack of funds, budgetary constraints, economic crisis and not in the least, corruption, the health of the population does not seem to represent a priority issue. In such regions, concepts such as HTA, QOL, Pain Management are simply not on the agenda of the officials.

What needs to be done:
First an foremost, a different political approach by the European Parliament who should be issuing law binding directives instead of reccomendations when it comes to health. The old concept whereby the national governments should be responsible for the implementation of the health systems is detrimental to the rights of the European citizen, as it is otherwise stipulated in the European Charta of Human Rights. The precedent has already been created by the latest Cross Border Health Directive .

Only a harmonized health system within the European member states, with clearly defined standards below no governments should be allowed to remain, will ensure safety and security for the EU citizens, a principle which is so clearly stipulated by WHO.

ENDORSING ORGANISATION SIP2012

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C

Main workplace/Organisation
Czech Pain Society (SSLB)

Profession/Function
Professor of Primary Care Medicine

Czech Pain Society (SSLB)

The Czech Pain Society is a member of Czech medical societies of Jan Evangelista Purkyn. It has 337 regulary members. Mostly they are the algesiologist, anaesthetists, surgeons and many other medical disciplines. The organisational bacground is the Board with 13 members and revisory board with 3 members.

Each year we organis the come congresses with Slovak Pain Society (one year in Czech Republic, one year in Slovak Republic). Every two years we are organising the Symposia about the treatment of pain in Brno togedher with Czech Neurological Society (section for headache). We are publishing the Journal Bolest (Pain) - editor in chief prof. Richard Rokyta. We have 8 complex center of pain with several specialists, 9 teaching centers with acrediations for effectuated postgraduate study and more than 100 algeziological out patient clinics, with 1 algesiologiest, 4 years ago we published the monography Pain (Bolest), 700 pages, main editor in chief prof. Richard Rokyta.

In 2003 Czech Pain Society organised IV.th EFIC Meeting in Prague (organisers J. Kozák, R. Rokyta) with 3000 participants. Besides of the large meetings we organise also many conferencies, education meetings, colloqueias and other types of conferencies. Czech Pain Society very active society among other medical societies in the Czech Republic.

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Main workplace/Organisation
Surgery Department. Valencia School of Medicine General University Hospital

Profession/Function
Professor and Chairman

Roadmap for Synergy between Pain Management and Palliative Care in Valencian Autonomous Region-Spain

General Objective: To promote the management of pain in both cancer and noncancer patients with pharmacology analgesia as well as with minimally invasive interventional techniques for pain control, of an individualized manner, by facilitating access to the Pain Management Department (PMD), especially in cases of patients with complex or refractory pain.

Actions

1. Raise awareness among health professionals and administrators, patient / family and the general public that pain is a condition that limits the quality of life
2. Provide information and access to diagnostic and therapeutic approach of pain
3. To make visible the impact that pain has on the medical, economic, and social, and benefit specialized treatment of pain has on patients, families, careers and social work environment and the health system

3.1. Publicity campaigns of studies of particular relevance

3.2. Publicity of PC dispositions among professionals and general population

4. Promote education awareness of the importance of prevention, diagnosis and treatment of pain among health professionals.

4.1. Educational activities given by experts in PC and PM.

4.2. Encourage the development of clinical sessions and case studies among professionals in PC amd PM

5. Develop Clinical research on pain and especially those related to clinical problems addressed jointly caring network within the Health Care department
6. Establishing In Valencian Autonomous Region and through the Health Care portal of PC "With You" enhanced dissemination of good practice and coordination of PM and PC resources, promoting medium term benchmarking studies on the treatment of pain and its impact on society.
7. Monitor trends in pain management, services and results and periodic evaluation of the results of the synergy between PC and PM, exposed in a bi-annual joint conference and provide guidelines to harmonize efficiency levels of pain to improve quality of life of citizens

Conclusions

1. Pain is a prevalent symptom that has a large impact on quality of life of people and economic social systems
2. The approach of pain should be comprehensive and multidisciplinary by committed professionals, and the patient and his/her environment (family and social) the focus of this approach
3. All Healthcare professionals should have a basic training in pain management
4. The specific resource professionals in PM and PC, should establish scientific and organizational synergies to address the PM as standardized and multidisciplinary, through the establishment of protocols, guidelines and clinical pathways and promotion update meetings day or case discussion
5. The Health Department of the Valencian Autonomous Region acquires the commitment to promote a way of collaborative work between professionals of the two areas of care
6. The Health Department will encourage research on pain, especially under multi-interdisciplinary approach
7. The Health Department will promote the dissemination of PM best practices and its implementation in whole Valencian Autonomous Region

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"Pain management (PM) and palliative care (PC), are essential to improve or maintain quality of life for many patients suffering from incurable processes, chronic, or terminal."

ENDORSING ORGANISATION SIP2012

Deutsche Gesellschaft für Anästhesiologie und Intensivmedizin

Deutsche Gesellschaft für Anästhesiologie und Intensivmedizin (German Society of Anaesthesiology and Intensive Care Medicine, DGAI)
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"Improving the way pain is perceived and managed to better support people in pain and drive healthcare efficiencies."

Main workplace/Organisation
Deutsche Gesellschaft für Anästhesiologie und Intensivmedizin (German Society of Anaesthesiology and Intensive Care Medicine, DGAI)
Profession/Function
Executive Director

German Society of Anaesthesiology and Intensive Care Medicine (DGAI)

The German Society of Anaesthesiology and Intensive Care Medicine (Deutsche Gesellschaft für Anästhesiologie und Intensivmedizin, DGAI) was founded in 1953, with the role "of uniting the efforts of German physicians in creating and developing the fields of anaesthesiology, intensive care, emergency medicine and pain therapy, and to provide the highest possible standard of care for the population in these fields".

The DGAI is the scientific society of anaesthesiology in Germany and therefore responsible for research and training in anaesthesia, critical care medicine, pain- and emergency medicine. The DGAI is member of the World Federation of Societies of Anaesthesiology (WFSA), which includes the international societies of anaesthesiology worldwide, and of the European Society of Anaesthesiology (ESA). The official journal of the DGAI is "Anästhesiologie & Intensivmedizin"; other journals are "Der Anaesthesist" and "Anästhesiologie - Intensivmedizin - Notfallmedizin - Schmerztherapie".

The DGAI annually organizes the German Congress of Anaesthesia (DAC), the "Capital City Conference of the DGAI - Congress of Anaesthesiology and Intensive Care Medicine" (HAI) and five regional meetings. According to the federal structure of Germany, the DGAI is divided into 17 regional sections, gathering more than 13,000 members.

Since pain is a leading symptom in all fields of anaesthesiology, the therapy of pain with its societal impact is of major clinical relevance for the members of the DGAI. Numerous studies show that fewer than half of postoperative patients receive adequate pain relief. Acute pain often evolves into chronic pain: persistent pain follows acute postoperative pain in 10–50% of patients who undergo common surgical procedures; severe chronic pain develops in 2–20% of these patients. Emerging evidence suggests that poorly controlled acute postoperative pain is a cause of chronic postoperative pain. Furthermore, pain is the most frequent reason why patients visit an emergency department, accounting for over 70% of department visits. Thus, the DGAI is highly interested in improving the way pain is perceived and managed to better support people in pain and drive healthcare efficiencies.

ENDORSING ORGANISATION SIP2012

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"It is essential to make the current knowledge of pain research and its implementation available to all pain care professionals."

D

Main workplace/Organisation
Deutsche Gesellschaft für Schmerztherapie e.V. (The German Pain Association, DGS)

Profession/Function
President

The German Pain Association (DGS)

Pain management in Germany is still a fringe area of medicine. Although a quarter of the German population suffers from chronic pain, the problems of care provision for patients suffering from chronic pain are not recognized adequately in university education, specialists' training and among the statutory and private health insurance.

Therefore it is essential to make current knowledge of pain research and its implementation available to all pain care professionals. The platform "Societal Impact of Pain" provides a good opportunity for the international exchange of information and experiences.

- The German Pain Association's aims are the following:
- Promoting Algesiology of pain as a science
- Quality assurance in pain management
- Development of clinical standards
- Qualitative and quantitative improvement of patient care
- Promotion of palliative care for people living in the final phase
- Training in the fields of pain diagnosis and pain management
- Recognition of the additional designation
- Algesiology for appropriately trained doctors in all areas
- Establishment of interdisciplinary pain management centers pain (pain conference, Pain Forum)
- Modification of the Law on Regulation of narcotics

ENDORSING ORGANISATION SIP2012

Deutsche Schmerzgesellschaft e.V.

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"The German Pain Society (former German Society for the Study of Pain - DGSS) connects scientists, instructors and therapists to ensure high quality pain medicine in Germany."

Main workplace/Organisation
Deutsche Schmerzgesellschaft e.V. (German Pain Society)

Profession/Function
President

The German Network on Pain

With approximately 3.000 members the German Pain Society is the largest scientific pain society in Europe. It was founded on 8 September 1975 during the 2nd World Congress on Pain in Florence as the German Chapter of the International Association for the Study of Pain (IASP).

The German Pain Society is acknowledged as charitable organisation and as member of the working group of scientific medical associations ("Wissenschaftlichen Medizinischen Fachgesellschaften", AWMF).

Main workplace/Organisation
Deutsche Schmerzliga e. V. - German Pain League

Profession/Function
Vice-President

Deutsche Schmerzliga e.V. – German Pain League

Which are the social effects of chronic pain in Germany?
In Germany, 12 Million people suffer from chronic pain, because of a lack of knowledge among medical doctors and because of insufficient structures within the health system. This leads to very high healthcare costs and follow-up costs for the national economy and of course it means terrible suffering for every chronic pain patient and his or her family. In general, pain patients see 10 medical physicians of different specialisations before they find their way to a pain specialist, also because there is a lack of specialized pain units in Germany. They have to fight against prejudices: they are often regarded as malingerers and drug addicts. They often have to fight for their rights to get support from their health insurance and when they are unable to work because of their pain, they have to fight for their disability pension. When people become a chronic patient at an early age, they often fall through the social net of benefits.

Why does the German Pain League take part in the SIP Symposium?
We take part in the SIP Symposium as we find it very important and remarkable that in this symposium both patients and medical doctors work together to improve pain therapy and heath care structures. We could like to discuss the situation in Germany with the situation in other European countries, so that all organisations can learn from each other and find good solutions to improve the quality of life of pain patients and to prevent pain from turning into chronic pain. Surely we all have to fight for the rights of patients at a national level, but today and in the future it gets more and more important to cooperate at a European platform and to bring our concerns to the European Parliament.

The "Deutsche Schmerzliga", founded in 1990, is a non-profit and non-governmental organization with more than 5,500 members; most of them are chronic pain patients themselves. It is the largest chronic pain patient organization in Germany and runs almost 110 regional self-help groups.

The Deutsche Schmerzliga is calling for:
- Recognition of pain as a symptom in itself
- Exemption of chronic pain patients from prescription fees
- Off label channel of prescription
- No "aut idem" application to chronic pain patients
- Satisfaction of the legally founded claim to pain therapy
- Lifting of restrictions for the treatment of chronic pain patients
- Qualified training of pain therapists, quality assurance

ENDORSING ORGANISATION SIP2012

Deutsche Schmerzliga e.V.

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"Our mission is to improve the situation and life of pain patients. Above all, this means improving the general framework of health care policies and opening up therapeutic channels for patients with chronic pain."

D

ENDORSING ORGANISATION SIP2012

Main workplace/Organisation
Deutsche Wachkoma Gesellschaft (German Society for Patients in Vegetative State), Bundesverband "Schädel-Hirnpatienten in Not" e.V.

Bundesverband "Schädel-Hirnpatienten in Not" e.V.

The German society for patients in a vegetative state (Deutsche Wachkoma Gesellschaft) represents in all phases (A to G) the interests of humans concerned. These include cranial brain patients, patients with cranio-cerebral injury, re-vitalised patients; patients with serious apoplectic strokes, cerebral haemorrhaging etc. and patients in coma and/or persistent vegetative states.

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Main workplace/Organisation
Deutscher Orthopäden-Verband e.V. (DOV)

Profession/Function
Consultant & Professor, DMSc

Deutscher Orthopäden-Verband e.V. (DOV)

Back pain, osteoarthritis and osteoporosis received the status of so-called "common diseases", based on the frequency of their occurrence in society. They are focusing on issues of everyday orthopedic practice. The numerically intensive examination of the diseases mentioned above has the effect that dealing with the issue of pain – often the first and most important reason for a patient to look for a different diagnosis or orthopedic advice – is increasing to be more to the forefront of orthopedic efforts and advices.

The significance of pain in orthopedic practice will therefore be continuous. The DOV has recognized this and responded accordingly, and deals extensively with this subject, not only but especially in the osteologically oriented practices.

On the Internet portal supported by DOV, www.ihrarzt.de, patients and other interested people can be informed about wide-ranging topics for many different aspects of common diseases like back pain, arthritis and osteoporosis. But even there, the education on the topic of pain, from the experience of the therapy to dealing with pain on a daily basis already has a prominent role. The authors do not only place particular emphasis on the portal being easy to understand, but also on the representation of the individual experience, as well as on the topic of the personal experience of dealing with pain.

The DOV sees itself as an active participant in this process.

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"The DOV supports efforts to inform patients on aspects of pain management."

D

Main workplace/Organisation
Deutsche PalliativStiftung (German Donation for Palliative Care)

Profession/Function
Vorstandsvorsitzender Deutsche PalliativStiftung

End of life pain relief in homecare? A medical chance but problems by law!

Severe pain can be treated easily, fast, non-invasive and safe not only in hospital but even for out-patients in hospice, nursing homes or at home. Especially in home care there is a need for excellent symptom control. Otherwise severe pain or dyspnoea are the main reasons for undesirable hospitalisation in end of life. Not uncommon patients at home wait too long until they call for help, sometimes they had not been treated following the common state-of-the-art with the result that palliative care teams have to take care for the first time for a new patient with overwhelming pain or life threatening dyspnoea in the late evening, at weekends and holidays. Symptom control usually is easily done at the first visit.

Outside the buisiness hours of the pharmacies opioids are not available within an acceptable time. In spite of this lack in Germany a palliative care team must not hand out opioids to bridge the gap until a pharmacy can deliver the appropriate drugs. This started an interest discussion about the delivery of opioid drugs in end of life homecare. By law it is stricly prohibited that palliative care teams or physicians not only use opioids directly for the patients but also hand out some doses to the patients or their care givers. We need to do this in home care sometimes to fill the gap between drug prescriptions and delivery of the drug through the pharmacists.

Similiar problems in the EU are shown and possible solutions which we initiated this year in Germany. It must not be that appropriate sedation of pain and other severe symptoms in end-of-life homecare might be a crime in Europe!

About Thomas Sitte
Sitte is a Pain Specialist with a special interest in Palliative Care and is widely published in organisation and problems of ambulatory palliative care, including the use of opioids for breathlessness, where he is regarded as an expert. He also trains GPs in Palliative Care and pain therapy as one of his special teaching and research interests is Palliative Care at home. In 2010 he became a co-settlor of the Deutsche Palliative Stiftung (German Donation for Palliaitive Care) and is now CEO. In 2011 the Deutsche Schmerzpreis (German prize for therapy of pain) was awarded to Sitte.

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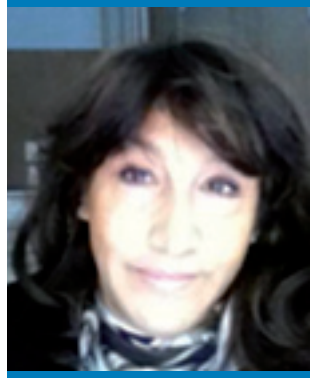
"Adequat access to a state of the art opioid therapy should be handled as a human right!"

Main workplace/Organisation
Agenzia Regionale Sanitaria Regione Marche

Profession/Function
Dirigente Servizio Salute

Pain Relief Acute-Primary Care Net

The project aims to developing a care model which is able to guarantee, within the hospitals of the Marche Region, both a systematic and uniform detection of pain by the health professional involved (ability to methodically detect pain, ability to understand the level of pain) and consequently, when necessary, the administration of the appropriate and efficacious analgesic treatment. The health professionals observe and document the level of pain of the patient, as the V vital parameter, using a standardised tool, validated to evaluate the intensity of pain.



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D

Hospital-Territory without pain

ENDORSING ORGANISATION SIP2012

DPS Dutch Pain Society

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"In the Netherlands the awareness for the 'epidemic' of chronic pain is growing. It seems that also politicians address chronic pain as a significant public health problem."

Main workplace/Organisation
Dutch Pain Society / Ziekenhuis Bernhoven

Profession/Function
Anesthesiologist and Pain Specialist

Dutch Pain Society, working together for pain relief

In the Netherlands, a committee of pain care professionals and various other specialists involved, has explored the current status of barriers and needs with respect to chronic pain in 2010-2011 (on behalf of the Regieraad). The committee has examined the most squeezing 'pain points' associated with chronic pain in the Netherlands, such as epidemiology, first line facilities, diagnosis, (under)treatment and education. They drafted 11 statement and opportunities for further action and recommendations for improvement of care for the patient with chronic pain. This report is comparable with the SIP Road Map for Action with this distinction that it is tapered to the state of care for chronic pain in the Netherlands.

In November 2011, this report was presented to health care politicians during a combined hearing & press conference. Result is that the Dutch healthcare politicians indeed address chronic pain as a significant public health problem and that there is a need for coordinated, cross-country efforts to improvement of care for chronic pain.

The Dutch Pain Society emphasizes on interdisciplinary coordination at various levels (policy, research, establishment of a guideline on diagnosis & treatment of chronic pain, etc) and will provide a platform for all professionals and organizations involved in chronic pain. It will be a long way to go to relieve this health problem, but the first step forward in addressing the nation's leading health problem – untreated and undertreated chronic pain – has been made!

Main workplace/Organisation
European Cancer Patient Coalition (ECPC)

Chronic pain – an unnamed disease of the society

Chronic pain is one of the most important reasons of human discomfort and suffering all around the world. According to the statistical information, up to 70% of cancer patients suffer from chronic pain. Yet, they rarely report it to their physician out of fear that either he will treat the pain and not the disease or that they will get addicted to the strong drug pills and, additionally, suffer from their side effects. These reasons lead to under-recognition and under-treatment of pain which remains the major unsolved healthcare problem of the contemporary world.

Pain means much more that just "hurting". Pain has a profound impact on the quality of life and reduces one's the emotional, psychosomatic, motor and spiritual skills and well being. Loss of normal sexual relations with one's spouse and fear of carrying one's children invariably leaves a mark on the sufferer's emotions. Marital conflicts develop and escalate which can lead to patient's depression. The combination of immobility and depression leads to irritability, nervousness and an unhealthy desire for isolation. Chronic pain patients tend to become more angry, easily frustrated, often moody, and plagued with feelings of hopelessness. Moreover, sufferers from chronic pain often experience sleep disturbances and anxiety (1).

These emotional, psychosomatic, motor and spiritual factors sum up to the deterioration of the social life of chronic pain patients. A large scale computer-assisted telephone survey conducted in 2004 in fifteen European countries and Israel found out that 19% of adult Europeans suffer from moderate to severe pain which seriously affects the quality of their social and working lives. 59% of surveyed had suffered from pain for a long time (from two to 15 years), 21% had been diagnosed with depression because of their pain, 61% were less able or unable to work outside the home, 19% had lost their job and 13% had changed jobs because of their pain. 60% visited their doctor about their pain 2–9 times in the last six months, which affected their working hours. Nevertheless, only 2% were currently treated by a pain management specialist (2). Nowadays, most countries do not have palliative care and pain treatment policies. Chronic pain management should not be just an add-on, but a service offered to patients as part of standard care. It can bring about tangible improvement for patients and their families as well as for the whole healthcare system.

1. Gureje O, Von Korff M, Simon GE, Gater R: Persistent pain and well-being: a World Health Organisation study in primary care. JAMA 1988, 80: 1947-1951 2. Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. Eur J Pain. 2006; May. 10(4): 287-333. Epub 2005 Aug 10.

ENDORSING ORGANISATION SIP2012

EUROPEAN CANCER PATIENT COALITION

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"Chronic pain management should not be just an add-on, but a service offered to patients as part of standard care. It can bring about tangible improvement for patients and their families as well as for the whole healthcare system."

ENDORSING ORGANISATION SIP2012

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"EFIC's aims are to advance research, education, clinical management and professional practice related to pain and to serve as an authoritative, scientifically based resource concerning policy issues related to pain and its management."

Main workplace/Organisation
European Federation of IASP® Chapters (EFIC®)

EFIC

What is EFIC? (European Federation of IASP® Chapters)
The European Federation of IASP® Chapters (EFIC®) is a multidisciplinary professional organization in the field of pain medicine and research, consisting of 35 European national pain societies, so-called chapters of the International Association for the Study of Pain (IASP). Established in 1993, EFIC represents 35 countries and close to 20,000 scientists, physicians, nurses, physiotherapists, psychologists and other healthcare professionals across Europe, who study pain and treat patients suffering from pain.

The affairs of EFIC are conducted by its Council, which consists of the President or Councilor of each European IASP Chapter, and five elected officers, including the EFIC President, who form the Executive Board of EFIC. The Council meets once a year, while the Executive Board manages affairs between meetings. EFIC is established as a non-profit foundation in Belgium.

EFIC's Aim
EFIC's aims are to advance research, education, clinical management and professional practice related to pain and to serve as an authoritative, scientifically based resource concerning policy issues related to pain and its management.

The specific aim is to create a forum for European collaboration on pain issues and to encourage communication at a European level between IASP Chapters and also with other bodies interested or involved in the fields of pain research and therapy, such as the European societies or federations of medical specialities (anaesthesiology, neurology, headache, palliative care etc.), institutions of the European Community, EuroPain and national educators and legislators.

Examples of pain issues that may be dealt with by EFIC:

- The epidemiology of acute and chronic pain in Europe.
- The availability of pain treatment facilities.
- The interface between patient needs and treatment facilities.
- The recognition of differences in therapeutic strategies and pain education within Europe.
- The harmonisation of such differences.
- Review of existing curricula and plans for training of pain specialists (it might be desirable to develop a European academy to accredit pain specialists, possibly by examination).
- Setting standards for diagnosis and treatment of chronic pains of different types and mechanisms.
- Organization of the biennial "Pain in Europe" congress and other scientific meetings.

Main workplace/Organisation
European Federation of Neurological Associations (EFNA)

Profession/Function
Executive Director

The European Federation of Neurological Associations

About EFNA
The European Federation of Neurological Associations (EFNA) brings together European umbrella organisations of neurological patient advocacy groups, to work with other associations in the field of neurology, in what has been termed a 'Partnership for Progress'. EFNA engages in activities, which contribute to the advancement of neurology and related areas with a view to improving the quality of life of people living with neurological conditions, their families and carers.

ENDORSING ORGANISATION SIP2012

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"EFNA looks forward to the time when chronic pain is understood and accepted as a condition by the policy makers, the general public and employers. EFNA understands that there needs to be access to healthcare professionals who have been adequately trained and fully understand chronic pain (specifically how to diagnose and appropriately manage the condition to limit it worsening) and who can identify the best possible pain management and support for each patient at the earliest possible stage."

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"Pharmaco-epidemiology of pain treatment in Austria compared with survey data shows 3,1 million persons receiving treatment in 2006+2007 and 2,7 million reporting pain."

Main workplace/Organisation
Hauptverband der Österreichischen Sozialversicherungsträger

Profession/Function
General practitioner

Pain and chronic pain represented in reimbursement data

Dr. Gottfried Endel; Hauptverband der Österreichischen Sozialversicherungsträger. A pharmaco epidemiologic approach to measure the burden of pain by using reimbursement data show interesting results compared with the official health survey. We used data from 2006 and 2007 to detect persons who got pharmacological treatment associated with pain. The list of pharmaceutical specialities was created by to medical doctors expert opinion. This resulting data were compared with the results of the health survey of 2006.

Province	SA-ges GB-do HV-do
Burgenland	(240.582 1,009 0,98)
Kärnten	(474.770 1,759 2,01)
Niederösterreich	(1.335.701 4,445 5,63)
Oberösterreich	(1.169.717 4,770 4,99)
Salzburg	(439.054 1,570 1,93)
Steiermark	(1.025.281 4,207 4,45)
Tirol	(580.073 2,621 2,49)
Vorarlberg	(298.341 0,967 1,17)
Wien	(1.419.566 5,625 6,42)
missing	(- - 0,06)
sum	(6.983.085 26,975 30,133).

This table shows rates per 100000 with their regional distribution. Detailed results will be presented. The working group consited of: Gottfried Endel; Gabriele Grögl- Aringer; Wolfgang Dorda; Milan Hronsky; Walter Gall; Wilfried Grossmann; Karl Anton Fröschl; Georg Duftschmid.

Main workplace/Organisation
Endometriosis Association of Ireland

Profession/Function
Charity (CHY8693)

Endometriosis Association of Ireland

The Endometriosis Association of Ireland is a registered charity, established in 1987. It is a patient led organisation with a voluntary board of directors. We offer support and advice to women with endometrosis as well as their partners and family. We work to raise awareness about endometriosis and pelvic pain amongst the public and the medical profession in Ireland. Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction. It is associated with dysmenorrhoea, pain at ovulation, dyspareunia, abnormal bleeding, chronic pelvic pain, fatigue and infertility, yet is often under-diagnosed. Medical or surgical treatments aim to manage symptoms.

The later the diagnosis, the more severe the disease is likely to be, and the lower the quality of life. The decrease in quality of life is reflected in not just higher health care costs but also the cost of lost productivity. The costs are greater with increasing severity of the disease, presence of pelvic pain, presence of infertility and a higher number of years since diagnosis. Recent research has put the average annual cost per women with endometriosis at € 9,579. It is a huge challenge to take this silent, invisible disease out in the open, but it needs to be done so that women and their families no longer suffer in isolation and that society does not lose out on the energy, creativity and vitality of women and girls in the most productive years of their lives.

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"Endometriosis is a disease which effects 1 in 10 women during their reproductive years, often causing great pain and internal damage, but remains consistently under recognised and under diagnosed. This leads to delayed treatment and a hugely negative impact on quality of life."

European Network of Fibromyalgia Associations (ENFA)
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"Due to lack of understanding, knowledge about fibromyalgia, patients have to suffer more pain than necessary."

Main workplace/Organisation
European Network of Fibromyalgia Associations (ENFA)

Profession/Function
Treasurer

Pain by Fibromyalgia not fully understand

As pain is the most important symptom within fibromyalgia it also includes it is not the only one. So if we patients, scientist, physicians are looking for a way to reduce the problems of fibromyalgia one has to look to the complete story and not just one symptom.

That would mean that if one is to "judge" if a therapy is successful one has to take all things in account. This would mean that quality of live should be the starting point. For measuring the starting point the voice of the patients is crucial.

SIP is such a starting point where the patients' voice is taking in account. We, ENFA, are waiting for policy makers to follow this road and start talking to patient representatives and start listening to that voice. Only in that way we can come to a solution to improve the quality of life of people living with (fibromyalgia) pain.

Main workplace/Organisation
Radboud University Nijmegen MC

Quality Indicators for improving pain management in cancer patients

Yvonne Engels, PhD assistant professor and head EBP research in pain and palliative medicine Radboud University Nijmegen MC (RUNMC); born 1958.

From 1980 till 1998 I worked as a midwife in primary and secondary care. After studying Health Promotion (University Maastricht, 1995-1998), I became researcher at did my PhD on assessing and improving the organisation of general practice in the Netherlands and in Europe.

I supervise 8 PhD-students and per year about 10 medical students. My main research topics are systematic pain assessment and neuropathic pain in cancer patients. We have collected all European clinical practice guidelines (CPGs) about this topic, and assessed whether these guidelines have been developed in a scientifically sound way (AGREE II), what kind of diagnosis is adviced and how this symptom should be treated optimally.

We assess cost-effectiveness from a societal perspective of amitriptyline or pregabalin to treat neuropathic pain in cancer patients. We recently started a study to implement the Dutch guideline 'pain in patients with cancer'. More than half of cancer patients have pain. Physicians (medical oncologists, GPs, other specialists) don't systematically assess pain of their cancer patients. Patients hesitate for all kind of reasons to speak about pain. In a retrospective study we found that medical oncologists hardly ever assess pain with a VAS or NRS. In an RCT in six hospitals we will study the effect of training GPs, medical oncologists, nurses, and the use of SMS-voice responding for regular pain assessment of outpatients. This will improve personalized care.

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"More than half of cancer patients have pain. Physicians (medical oncologists, GPs, other specialists) don't systematically assess pain of their cancer patients. Patients hesitate for all kind of reasons to speak about pain."

ENDORSING ORGANISATION SIP2012

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Partnering for Healthcare policy

Main workplace/Organisation
European Platform for Patients' Organisations, Science and Industry (Epposi)

Profession/Function
Programme Manager

Epposi

Founded in 1994, Epposi is an independent, not-for-profit, partnership-based and multi-stakeholder think tank based in Brussels, Belgium.

Our goal is to work at the "cutting edge" of European health policy-making, providing members and the wider public with high quality independent research, capacity-building, knowledge exchange and dissemination with the aim of bridging the gap between innovation and improved public health outcomes.

In order to fulfill our mission and build on our established, unique, citizen-centric and multi-constituency approach, Epposi enables consensus-driven, equally-weighted outcomes between the different stakeholder groups of its membership: patients' organisations, science and industry.

Epposi is open to members from EU-facing umbrella patients' organisations, commercial enterprises and their related trade bodies, research institutes, professional and business federations. Associate membership is open on nomination to NGOs representing a broad range of civil society interests, foundations and international organisations which support the Epposi ethos and are active in human healthcare.

Main workplace/Organisation
DAK-Gesundheit

Profession/Function
Member of the extended Board - Head of Product Management

We need a multitude of innovative care concepts for patients suffering from chronic pain!

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Dr. Cornelius Erbe is currently holding a position as senior vice president and member of the extended Board of DAK-Gesundheit; Hamburg/Germany.

DAK is the third largest German statutory health insurance organization with 5.0 million members and 6.5 million insurants. Dr. Erbe is head of Product Management and is responsible for developing and contracting all medical and paramedical services for DAK's members.

Previously, Dr. Erbe was holding positions as a partner at Roland Berger Strategy Consultants, and as a product manager for diabetes pharmaceuticals at Boehringer Mannheim, Mannheim/Germany. Dr. Erbe studied medicine at Albert-Ludwigs-University, Freiburg/Germany.

"Our experience with the development of new care management concepts for patients suffering from chronic pain shows that there is no ideal solution to the problem. We need to implement and evaluate a multitude of different managed care approaches to find out which concept fits best for which target group under which specific circumstances. We have to adopt a long-term perspective as we are dealing with a long-term condition. It is better to respond to region-specific framework conditions rather than to wait for general solutions to structural problems. All concepts can only be successful if we take care to offer the right concepts to the right patients at the right time."

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"Recently EFIC, WIP, WSPC and WIP Foundation has signed a declaration in Miami on the 5th of February 2012,for joining the forces for the promotion of pain medicine and worldwide access to pain relief.

Main workplace/Organisation
World Institute of Pain

Profession/Function
Immediate Past President of World Institute of Pain

Chronic Pain; a disease without a name

Chronic unrelieved pain is a major unsolved healthcare problem world-wide. It is universal, has enormous financial costs and is a tremendous burden in terms of quality of life for sufferers and their families and immediate society. Unfortunately due to recent developments and improvements in Pain Medicine, there is a difference between what can be done, and what is done for pain. Pain relief as a human right may be misinterpreted by the public and by health professionals. Pain management is not a priority with governments and health providers, thus the resources are inadequate for treatments including analgesics and dedicated pain management teams. Pharmaceutical companies have limited interest in producing low cost medication for the treatment of pain.

In September 2008, the World Health Organization (WHO) estimated that approximately 80 percent of the world population has no, or insufficient, access to treatment for moderate to severe pain and that every year tens of millions of people around the world, including around four million cancer patients and 0.8 million HIV/AIDS patients at the end of their lives suffer from such pain without treatment. "Please, do not make us suffer any more…" (http://www.hrw.org./)

A large scale of survey conducted in 46,394 respondents over 18 years of age showed that chronic pain of moderate to severe intensity occurs in 19% of adult Europeans, seriously affecting the quality of their social and working lives. 19% had lost their job and 13% had changed jobs because of their pain. 60% visited their doctor about their pain 2-9 times in the last six months and only 2% were currently treated by a pain management specialist. One third of the chronic pain sufferers were currently not being treated. Forty percent had inadequate management of their pain (3), In another study in Europe (4).

Thus we can easily say that chronic pain is a disease still without a name.

1. Erdine S. Chronic pain a disease without a name. Med Pregl. 2007; Sep-Oct. 60(9-10): 417-9.
2. Access to Pain Treatment as a Human Right; Humar Rights Watch, March 2008. http://www.hrw.org./en/ reports/2009/03/02/ please - do – not - make - us - suffer - any – more
3. Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. Eur J Pain. 2006; May. 10(4): 287-333. Epub 2005 Aug 10.
4. Survey of Pain in Europe, Quantitative research among patients by age, gender and weak vs. strong opioid users, Mundipharma. 2005; March 9.

Main workplace/Organisation
Andalusian School of Public Health – Escuela Andaluza de Salud Pública

Innovative Agreements for Financing medicines: a new way of involving stakeholders in paying for real health outcomes

Innovative agreements (also known as "risk sharing agreements", "access with evidence development schemes", "innovative pricing schemes", "patient access schemes", "coverage with evidence", "managed entry agreements", etc) refer to the pharmaceutical policies for pricing and financing medicines that have emerged as a consequence of uncertainties (effectiveness, budget impact, etc.) associated with launching new, high-cost drugs. The main goal of these agreements is to link the manufacturer's final payment to a new pharmaceutical's clinical or health outcomes, rather than basing payment exclusively on the number of units sold.

Although this is a relatively recent instrument, several types of these agreements have been implemented around the world, mainly in Europe, the United States, Australia and New Zealand. They range from simple instruments (price volume agreement) to complex mechanisms (clinical or outcomes guarantee), and while evidence is currently insufficient for making any specific recommendations regarding the use of such instruments, some les-sons can be drawn from the first experiences and usefully contribute to policy reflections. These agreements have not been exempt from criticism and detractors raise doubts about their functionality, as well as the benefits for a pharmaceutical industry accustomed to receiving revenues independently from the clinical or health outcomes provided by the pharmaceutical.

But one of key issues to discuss in SIP 2012 is that these instruments can generally help improve collaborative agreements and relations between the industry and the different stakeholders

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"Innovate agreements for pricing and reimbursement medicines can improve the stakeholders' relationships and future collaborations for pain therapies."

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ENDORSING ORGANISATION SIP2012

Main workplace/Organisation
European Headache Alliance (EHA)

Profession/Function
President

European Headache Alliance calls for migraine/headache to be pushed up the political agenda

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The European Headache Alliance is a non-profit, patient umbrella group which was launched in 2006. Since then, the Alliance has grown to represent patient groups from across the continent. The development of European umbrella organisations is a natural progression with more relevance for European nations.

EHA is an active member of the European Federation of Neurological Alliances [EFNA] and also works closely with organisations such as the European Headache Federation, European Brain Council and World Headache Alliance.

EHA's Madrid Manifesto calls on governments to:

- Recognise migraine as a chronic, debilitating and disabling condition
- Provide the resources and support services needed to achieve optimal headache care
- Prioritise headache education/awareness programmes for both the general public and health professionals
- Promote research into the causes of headache/migraine and new medicines
- Work to improve the quality of life of those affected, especially in the working environment as it will reduce absenteeism and increase safety and productivity

Main workplace/Organisation
European Society of Anaesthesiology (ESA)

ENDORSING ORGANISATION SIP2012

European Society of Anaesthesiology (ESA)

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The aims of the Society are:

- To promote exchange of information between European anaesthesiologists,
- To disseminate information in regard to anaesthesiology,
- To raise the standards of the speciality by fostering and encouraging education, research, scientific progress and exchange of information,
- To promote and protect the interest of its members,
- To promote improvements in safety and quality of care of patients who are under the care of anaesthesiologists inside and outside the operating room by facilitating and harmonising the activities of national and international societies of anaesthesiologists in Europe.

The ESA is organizing the European Diploma in Anaesthesiology and Intensive Care in 12 languages and more than 20 centers all over Europe and abroad.

The ESA organises the European Anaesthesiology Congresses throughout Europe under the banner EUROANAESTHESIA. These meetings are attended by members and non-members representing more than 80 countries from around the world. The European Anaesthesiology Congresses offer a comprehensive scientific programme of refresher course lectures, symposia and workshops, together with presentation and discussion of the latest research undertaken in Europe in particular.

The ESA is has a lot of educational and research programmes throughout the year, including trainee exchange programmes. A Clinical Trial Network has been set up and different clinical trial research project are running simultaneously.

For more information on ESA's activities please consult the website www.euroanaestehsia.org

"To aim for the highest standards of practice and safety in anaesthesia, intensive care, emergency medecine and pain treatment through education, research and professional development throughout Europe."

ENDORSING ORGANISATION SIP2012

Main workplace/Organisation
The European Society for Regional Anaesthesia & Pain Therapy (ESRA)

Profession/Function
General Secretary

The European Society of Regional Anaesthesia and Pain Therapy

The European Society of Regional Anaesthesia and Pain Therapy was founded in 1980 to further regional anaesthesia in Europe. The first congress was held in Edinburgh in 1982 and since that year the society has gone from strength to strength, with a current membership of over 2,600 throughout Europe. The society is still growing, and has now established a strong track record with 30 Annual Congresses and of course our forthcoming 31st in Bordeaux.

The scientific standard at the annual ESRA congress is now recognized as one of the best in Europe, and as a result carries a high ratingwith the Accreditation Council for Continuing Medical Education, who now assigns credit hours to all ESRA congresses. The annual congress has taken place in a different European city each year, with Prague hosting the first year in a Central European city, in 1995. The Board of ESRA plan to expand membership in Eastern Europe in line with its aim of improving and standardizing the level of regional anaesthesia throughout Europe.

Apart from the annual ESRA Congress, the society holds eight to ten zonal meetings each year as well as grants and educational material through its brand new ESRA Academy online platform. Finally, the European Diploma in Regional Anaesthesia & Pain Therapy (EDRA) was created in 2005 with the goal of establishing standards in regional anaesthesia in Europe. The Diploma is intended to widen the activity spectrum of those specialists in anaesthesia, who are already in clinical practice and are interested in acquiring additional knowledge in the entire field of regional anaesthesia.

Enhance your knowledge in the various aspects of anaesthesia, and assist the aims of ESRA in furthering knowledge and standards in regional anaesthesia and pain therapy.

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"The European Society of Regional Anaesthesia and Pain Therapy was founded in 1980 to further regional anaesthesia in Europe."

Main workplace/Organisation
Eumusc.net

Profession/Function
Communicationsofficer

Driving Musculoskeletal Health for Europe

Musculoskeletal conditions are the biggest cause of physical disability in Europe, incurring major social care costs and loss of productivity (Major and Chronic Diseases Report 2007). Their prevalence and associated disability increases with aging, obesity and lack of physical activity. All these determinants are increasing across EU Member States and without action the burden of MSC will grow. Recommendations for the prevention and treatment of musculoskeletal conditions have been developed (European Action Towards Better Musculoskeletal Health Report 2004) but these are not being implemented equitably across the EU.

eumusc.net is a facilitating information and surveillance network promoting a comprehensive European strategy to optimise musculoskeletal health. The network provides updated and harmonised information on the health, social, employment and economic impact of musculoskeletal conditions across all EU member states. It also establishes what standards of care patients can expect, the quality of healthcare provided, what barriers and facilitators affect local implementation, examples of European good practice and makes recommendations to improve healthcare across the EU.

This website aims to provide a gold standard of information regarding musculoskeletal health. Whether you are a patient, career, healthcare provider or member of the press we have a level of information to suit your needs.

ENDORSING ORGANISATION SIP2012

eumusc.net Driving musculoskeletal health for Europe

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"eumusc.net is a facilitating information and surveillance network promoting a comprehensive European strategy to optimise musculoskeletal health. The project will lead to improved musculoskeletal health through evidence based policy recommendations for the implementation of a community strategy and by highlighting good practice so that it can be copied across the EU."

Main workplace/Organisation
EURAG Austria

Profession/Function
Managing Director

EURAG Austria

EURAG is a non-political, non-confessional and non-profit European organization which has been representing the interests of older persons in 34 countries for more than 40 years and holds an advisory status with the UN, the WHO and the European Commission.

EURAG Austria, the Austrian platform, supports the main objectives of EURAG on a national level which are:

- Preserving life quality and self –determination of older persons
- Maintaining a bridge between the generations

In order to get a wider audience acquainted with the benefits of healthy ageing EURAG Austria has been organizing lectures on health prevention for laymen for the past 13 years in the Vienna Town Hall. In doing so the organization relies on the advice of its Medical and Scientific Board, headed by Katharina Pils, Head of department of Physical Medicine and Rehabilitation at the SMZ Ost Sophienspital in Vienna, who strongly believes that "Pain should not be accepted as part of the ageing process".

EURAG Austria is a founding member of Pain Alliance Europe (PAE).

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"The local platform for preserving life quality in old age."

Main workplace/Organisation
Europacolon Portugal –
Association for the Fight Against the Colorectal Cancer

Europacolon Portugal – Association for the Fight Against the Colorectal Cancer

The Europacolon Portugal, association for the fight against the colorectal cancer is a non-governmental organization with the following main activities:

- Education for the Prevention
- Support of Patients/Relatives

In the Education area for the prevention we promote the diffusion of knowledge about the disease and its symptoms, advantages of the population screening, as well as the preventive attitudes that can contribute to lower the incidence of the disease. Through public actions with volunteers we tried to sensitize patients and relatives about their rights and duties as well as the population about risk factors for the disease.

For the support of patients and relatives we have free psychology and nutrition consultations, a direct telephonic line for support and a webpage with discussion forums. In addition it has been establish a Program for Homecare Support for patients with advance colorectal cancer in palliative care, through a sequential visit of a multidisciplinary team (psychologist, nursing, social agent, nutritionist). Detail information and tools are given for the patients and caregivers regarding this evaluative phase of the disease. The work in the sense/significance of the disease is one of the priorities in this project.

In short notice we predict that Europacolon may support a project in the Discharge Management of a specialized oncology hospital. The main purpose is to support the patient with digestive pathology and caregiver in the return at home after the hospital discharge, being the interface between the specialized care and the proximity care.

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Saving Lives is urgent! Political decision is needed to put into action Colon Rectal Cancer full screening program.

E

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"Pain is the most common symptom of any illness and long term pain can have a devastating effect on the quality of life of sufferers and families. An estimated 20% of adults in the UK live with chronic pain, with evidence that the incidence of post-herpetic neuralgia and painful diabetic neuropathy increases with age. The management of pain and enabling EU citizens to lead active, healthy lives whilst ageing requires the multi-disciplinary approach outlined in this workshop."

Main workplace/Organisation
Imperial College, London

Profession/Function
WHO Collaborating Centre for Public Health Education and Training

Norman Evans

About Norman Evans

Norman Evans is currently a Consultant Pharmacist and Clinical Senior Lecturer in the Department of Primary Care and Public Health, Imperial College, London. He was previously Chief Pharmacist to a large Primary Care Trust in London. He also serves on the Editorial Board of the British journal: Managing Pain in Practice.

Main workplace/Organisation
Azienda Ospedaliero Universitaria di Parma
Profession/Function
President of the National Committee of Palliative Care and Pain Therapy – Ministry of Health

Law 38, activities and 2011 account. Incidence and impact of cancer pain and in particularof BTcP

To treat pain properly is a must for any doctor; not to suffer is a right for each patient: the Law 38 of March 2010 protects Italian citizens by ensuring a reasonable access to proper care and treatment. Now, two years after the issue of the law, the outcome is encouraging. It is still needed a strong commitment by all involved actors so that every citizen, wherever resident in Italy, could benefit from a qualified assistance. Initiatives like Project BEHTA, in particular, exploring an important and delicate topic as the BTcP, creates profitable opportunities for discussions and reflections among experts.

Law 38/2010 actually "forces" the physician to deal with the pain a patient feels, whatever the cause. A so innovative law takes time to move from theory to the daily clinical practice: many obstacles must be overcome and a proper training and a wide working group team is requested: in short a cultural "revolution" is needed in order to change habits and long time established behaviors.

Let's go to see in details what has been accomplished so far. First of all the guidelines prepared by the Ministerial Commettee for the promotion, development and coordination of the network of palliative care and pain had the imprimatur of the State-Regions Conference too. This is a key step to ensure full application of the Act.

In these months minimum requirements and structural criteria for the accreditation of the Hub and Spoke in the area were established and it has been defined the equal distribution of economic funds to the regions. Many regions have already adopted specific resolutions and are working to implement the local networks of palliative care and pain management in line with the standards of the new regulation.

We have established a joint table between the Ministry of Education, University and Research and Ministry of Health, to define the criteria to set the Master degrees in pain management and palliative care for health caregivers.

We have not failed to look into the most important field of volunteering, where it was necessary to fix the professional and educational requirements that volunteers should have in their curricula. On this very matter a technical table with all organizations operating in this field has been organized, even for pediatric field.

I can now say that, on the whole, 85% of what expected and required by new legislation was achieved. On 24 June 2011 a widespread monitoring on the consumption of opioids and prescriptive appropriateness has been carried out in order to determine a turnaround of NSAIDs use. A tool called "Dashboard" is a specific software to detect, through the data of Health Information System and those provided by the regions, the type of hospital services and prescribed drugs.

The treatment of pain will become one of the objectives set by the General Managers of Hospitals and Healthcare Organizations. It is a real revolution in medicine field which can be realized in our country if we will all work together.

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"To treat pain properly is a must for any doctor; not to suffer is a right for each patient: the Law 38 of March 2010 protects Italian citizens by ensuring a reasonable access to proper care and treatment. Now, two years after the issue of the law, the outcome is encouraging. It is still needed a strong commitment by all involved actors so that every citizen, wherever resident in Italy, could benefit from a qualified assistance. Initiatives like Project BEHTA, in particular, exploring an important and delicate topic as the BTcP, creates profitable opportunities for discussions and reflections among experts. On the whole 85% of what expected and required by new legislation was achieved. It is a real revolution in medicine field which can be realized in our country if we will all work together."

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Main workplace/Organisation
Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP)
Profession/Function
Federation

Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP)

FAECAP is a Federation of Nursery Associations with scientific profile created in 1998 with the aim of grouping in its environment the different associations and societies related to Community and Primary Care Nursery, actually having more than 3.000 members who represent a group of nurses who develop their work in Primary Care in the different Autonomous Communities.

FAECAP endorses initiatives like SIP with the aim of promoting the exchange of best practices in pain with stakeholders and reach excellence in pain care within the framework of a sustainable health care model. It is also important to increase awareness on pain treatment from the Primary Care perspective in Spain, especially the importance of an overall treatment, not only for the patient but also for his family and regarding the sociosanitary resources of his nearest environment.

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Main workplace/Organisation
Federdolore-Società Italiana dei Clinici del Dolore

Federdolore - Società Italiana dei Clinici del Dolore

Federdolore was born from the need of many physicians who work in the centers of Pain Therapy and Palliative Care to have first, a cultural confrontation and second, to face together the many challenges that inevitably occur in the development of this new discipline. The will of the Society Federdolore is to make real the" "Pain Medicine and Palliative Care" by training experts and validating the structures by defining structural and organizational standards, diagnostic and therapeutic pathways and connections between the various procedures and systems of finance.

F

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"Establishing an educational activity of patients to update knowledge on chronic pain and promote the acquisition of knowledge, skills and attitudes in order to understand and accept the disease between them."

Main workplace/Organisation
Fibromyalgia Association of Extremadura (Asociación de Fibromialgia de Extremadura, AFIBRO)
Profession/Function
Secretary

Fibromyalgia Association of Extremadura (Asociación de Fibromialgia de Extremadura, AFIBRO)

Founded in October 2000

Purposes and objectives:

- detect and guide those affected FM.
- encourage group therapies.
- promote training and dissemination
- activities collaborate with official institutions (regional, national, local, public and private)
- disclose the existence of the FM and its important social
- improve the quality of life of those affected by this disease and provide them with all the means at our disposal for their social and labor integration.

Since the Association was drawn up a comprehensive Regional Health Plan works as a partner in our patients, preparing for them and together with all the professionals a health education programme.

Main workplace/Organisation
Fibromyalgie en Samenleving (FES) -
De Nationale Vereniging voor Fibromyalgie-patiënten

Bring the right information on the right place

Fibromyalgia is a prevalent disorder. Pain, fatigue and other symptoms of fibromyalgia have major consequences for the wellbeing and functioning of people with fibromyalgia. An extra burden is the invisibility and medically unexplained character of the symptoms. There is no uniformly accepted pharmacological treatment for fibromyalgia.

Research should be aimed at the physiological mechanisms that explain and maintain the disorder and at behavioral processes that impact the physiological underpinnings and the consequences of fibromyalgia. Health care professionals should be educated to recognize the disorder and to help patients by learning them to cope with fibromyalgia. Society should acknowledge fibromyalgia as being a disorder with adverse consequences for wellbeing and functioning.

Prof.dr. Rinie Geenen, psychologist
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"Fibromyalgia is a rheumatic disorder. The Dutch association of fibromyalgia will improve the position of patients. Therefore, they will give more information to the patients and their families, just as to the medical professionals and the politicians."

ENDORSING ORGANISATION SIP2012

Suomen Kivuntutkimusyhdistys ry
Föreningen för Smärtforskning i Finland rf
Finnish Association for the Study of Pain

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"Increasing awareness of improved pain management is one of the key challenges of FASP."

Main workplace/Organisation
The Finnish Association for the Study of Pain (FASP)

Profession/Function
Vice President

The Finnish Association for the Study of Pain (FASP)

Ethical, medical, economical and legal reasons provide the basis for the treatment of pain. Scientific knowledge on the mechanisms of pain and pain management is increasing. Access to adequate treatment of pain is a basic right of all citizens. While the expertise for biopsychosocial assessment, treatment and rehabilitation of individuals with pain is available on a national level in Finland, resources still vary locally.

The Finnish Association for the Study of Pain (FASP) was founded in 1996 as a multi-professional organization to promote multidisciplinary research and treatment of pain in Finland. Other objectives of the organization are to increase awareness of pain within the general public, health care professionals and policymakers, to legitimate diseases associated with pain, and to improve the education and working conditions of professionals working with pain patients.

There were 1117 regular members in FASP at the end of the year 2010. These were physicians of various disciplines, dentists, psychologists, nurses, physical therapists, social workers and other professionals. FASP organizes a two-day symposium on a pain-related topic each spring with the annual meeting. The framework of this educational event is multi-professional. Other annual educational events include a two-day symposium on Acute pain and Cancer pain. FASP also collaborates with several other medical and health care organizations and associations to provide pain education.

On the original initiative of FASP, a qualified certification for pain management has become available for pursuit for medical and dental specialist physicians in Finland. Likewise, specializing training programs in pain management for psychologists and nurses are ongoing. Similar programs for physical therapists and practical nurses are in preparation.

FASP and its individual members have been active in several national projects to promote the management of patients with pain in the society. These include the preparation and implementation of the National criteria for the non-urgent treatment of pain which were launched by the Finnish government (2007) and the preparation of reform of legislation for the assessment of degree of disability (2010). Currently, we are getting prepared to meet the government-mandated guidelines for wait times for the treatment of pain.

FASP became a national chapter of IASP in August 2010 and thereafter joined EFIC. Collaboration with SASP is also close. FASP has endorsed the scientific framework of SIP and we see increasing the awareness of improved pain management as one of the key challenges of FASP in the future.

ENDORSING ORGANISATION SIP2012

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F

Main workplace/Organisation
The Finnish Pain Association (Suomen Kipu ry)

Suomen Kipu ry (The Finnish Pain Association)

Suomen Kipu ry (The Finnish Pain Association) was founded in 1991 when a group of pain related people recognised the need for an own association for people living with chronic pain.

The aim of the association is to improve the conditions of people living with chronic pain by increasing the knowledge of pain and of its impact on everyday life. The Finnish Pain Association aspires to develop cooperation between home, work, environment, politicians and especially with healthcare organizations. Important elements are information, skills and the willingness to help.

The principles of the Finnish Pain Association are to act as an advocate for the people who suffer from chronic pain, promote pain research, treatment and rehabilitation. We also aim to increase awareness about pain related issues, and to develop support group activities together with public healthcare.

The Finnish Pain Association offers a possibility for the people living with chronic pain and their proxies to participate in a meaningful life by organizing lectures and training events as well as supplying literature and other materials related to pain. Our aim is to respond to our members' lack of social contacts and missed opportunities for living an active life by having peer groups all over the country through various regional happenings, as well as having phone and e-mail support.

The Finnish Pain Association is determined to abolish all the barriers of people living with chronic pain to be able to live as normally as possible. We can do this together with healthcare professionals, authorities, politicians, associations, and foundations by improving social security, treatment, rehabilitation and other services for pain patients.

The Finnish Pain Association is a member of the Pain Alliance in Europe (PAE), www.pae-eu.eu

Main workplace/Organisation
Focus Fibromyalgie Belgique

Profession/Function
Consultant-delegate

Activities

Created since 1998 by patients themselves, Focus Fibromyalgie Belgique is the leading society in French speaking Belgium. Broadcasting information and organization of conferences for medical and paramedical practitioners. Educative and informative sessions for socio-professional groups. Editing periodical publication where patients can express what they feel. Creation of a phone call center, which is called "fibrophone". Edition of vulgarization booklets about fibromyalgia in French.

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"Participation of patients and information of medical and paramedical practitioners."

Main workplace/Organisation
Fondazione ISTUD

Profession/Function
Responsabile Area Sanità e Salute

Narrative medicine for a deep understanding of patients' and providers' needs; a particular application in pain therapy

Silence is broken, broken the taboo of the privacy of the illness, now people sign consent and release their own testimony, write-off of the way they live the disease, from sketchy few lines to more complete diaries.

Desire to be there? To finally be heard? Hope of change, leaving a sign and changing the course of their journey and also to other patients in care? But why so much attention to the narrative? The theoretical answer is easy to the researcher: only through the narrative (verbalization / or absence of verbalization, the script reference speaker and the listener) it is possible to give a meaning to what is happening and to select the actions to be taken or not taken.

It remains to be seen how all patients' and providers' collected stories should be analyzed in depth to better understand the social needs of patients and carers and organize for them less entropic cure trips and less entropic centers of care.

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"Only through the narrative (verbalization or absence of verbalization, the script reference speaker and the listener) it is possible to give a meaning to what is happening and to select the actions to be taken or not taken."

F

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Main workplace/Organisation
Foro Español de Pacientes

Profession/Function
Presidente

Foro Español de Pacientes

The Spanish Forum of Patients is an organization for the representation of Spanish patients collectively, in front of different forums - both national and international - health professionals, the administration and the private sector.

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F

Main workplace/Organisation
Foundation Pain-Hope (Stichting Pijn Hoop)

Profession/Function
Voorzitter / President, Elly Roetering

The Foundation Pain-Hope (Stichting Pijn Hoop)

The Foundation Pain-Hope is an organization for people with chronic pain, by people with chronic pain, which was founded in 1988 by 5 people with chronic pain. In the meantime the Foundation Pain-Hope has developed into an important support and information point for people with chronic pain, but also for many workers in healthcare.

Our objectives are:
- Acknowledgement of chronic pain as a separate disorder and handicap
- More attention and support for people with chronic pain
- Better knowledge of general practitioners and specialists concerning the phenomenon chronic pain
- More attention to the subject chronic pain at educations in the health care
- The appointment of specialized pain nurses and practical assistants
- Establishing a coordinating organization where everyone works in the field of pain suppression
- Pain policy and pain research can participate
- Make an inventory of who does - where - what in the Netherlands in the field of pain suppression
- Formulating of quality requirements for pain practitioners - (poli)clinics - hospitals or other institutions which are operative in the field of pain treatment

All our employees are people who themselves are suffering from some sort of pain that for some reason does not cease. Nowadays the Foundation Pain-Hope operates with more than 30 volunteers for a better quality of life for people with chronic pain. They are achieving this by:

- Organizing meetings for fellow-sufferers and others who are interested in the matter, whether on a professional basis or not
- Organizing readings and training hours at health care organizations or other patients' associations
- Providing information on pain and pain treatment
- Organizing workshops to learn to handle chronic pain.

The Foundation Pain-Hope releases the brochure "About life with chronic pain" concerning tools to handle pain and publishes the trimester booklet "Newsletter" 4 times per year with information, book discussions and other interesting pieces of information regarding pain. The newsletter also communicates locations and dates regarding the fellow-sufferer meetings and the phone numbers where you can get further information or a consultation with someone who knows what it means to have to live with pain on a daily basis.

> "Chronic pain is not a mistake in thought! It is a real handicap that needs serious attention and treatment."

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"Time is of great importance when dealing with pain. The sooner the better is paramount. It is imperative, that the pain patient is met by the relevant specialists as soon as possible. This enables the pain patient to behave in keeping with his or her disease."

Main workplace/Organisation
Foreningen Af Kroniske Smertepatienter
(Danish Association for Chronic Pain Patients, FAKS)
Profession/Function
Chairman

Pia Frederiksen, chronic pain patient and chairman of FAKS - The Danish Association of Chronic Pain Patients.

8 years ago, age 31, I was put through a surgical procedure that went wrong. I had a problem with my right wrist that today, in the light of everything, seems quite trivial. At that time, however, it seemed obvious to me to go through surgery in order to remove the pain. Especially, when considering the fact that the operation was supposed to be a piece of cake. By god, I was wrong! Something went terribly wrong, and I was left in agony after the operation.

The following time, I was put through a lot of different specialists, but no somatic cause could be found. Finally, after 2 years without any pain medication, I ended up at a pain clinic, where they could conclude that it was a matter of nerve damage. At this point, however, the pain had spread to other segments of the body. It took 2 years, in addition, to find the pain medication that suited my needs. By then it was too late, and I got a retirement.

By myself and by means of others, I slowly gained the tools and coping strategies to lead an active life.

I wanted to put my own experience into use and help other pain patients doing voluntary work. Thus, joining FAKS -The Danish Association Of Chronic Pain Patients, I became a board member and shortly after that the chairman. Today, 3,5 years into this position, I have fought for the rights of those often too weak to fight for themselves. The numbers of the Danish pain patients do not lie. According to recent numbers 70% are divorced, 36% experience depression and 21% have lost the will to live. We need to do better; we need to ensure proper individual, quality treatment of pain patients. In order for this to happen we need to screen the patients early on and provide them with interdisciplinary specialists to suit their individual needs.

We aim to lower the waiting time at the interdisciplinary pain units in order to avoid acute pain turning chronic. Last but not least, we call upon all personal health staff and decision-makers, advocating pain as a disease on its own. People acknowledging this is of utmost importance when trying to change the fundamental view on pain treatment today. Finally, realizing the fact that a lot of decisions are made on a European level, FAKS aspire to unify across borders. We really need to work together on this one, thus joining and putting our effort into the SIP only feels natural.

Main workplace/Organisation
Fundació Acadèmia de Ciències Mèdiques de Catalunya i Balears

Profession/Function
President

Acadèmia de Ciències Mèdiques i de la Salut de Catalunya i de Balears

The Academy is an organisation founded in 1872, officially recognised legally, which constitutes a forum and meeting point for healthcare professionals from Catalonia, the Balearic Islands, Valencia, and Andorra. It is an independent institution at the service of the country, and is not linked to any official body.

The main aim of the Academy is to foment continuing education and study and the cultivating of health science in every aspect: human, technical, social, and civic, in terms of healthcare, teaching, and research.

We form a part of a living scientific community, the fruit of a group effort, adapting to the needs and scientific and social circumstances of the times; we work in collaboration with other medical, biological, and pharmaceutical societies, both national and foreign, in a constant search for progress.

We are the most important medical corporation in our country, due to the number of members, societies, and associations that form a part of it, and due to the volume of scientific activities that we carry out annually.

We are present all over Catalonia, in the Balearic Islands, Valencia, and Andorra, through the branch offices of the Academy.

Because of all of these special characteristics promoted by civil society, we may be considered the only institution of our kind in the world.

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F

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Main workplace/Organisation
Fundación de afectados de fibromialgia y síndrome de fatiga crónica (FF)

Profession/Function
Presidenta

Fundación de afectados de fibromialgia y síndrome de fatiga crónica

The fundamental objective of the Foundation of Fibromyalgia and Chronic Fatigue Syndrome Affected Patients is to collaborate in the process of improving the life quality of the people affected by Fibromyalgia and Chronic Fatigue Syndrome. Its activities are directed towards information, training, awareness increasing, and investigation promotion.

The activities of the program Foundation FF and Science include the DNA Bank, international conferences for professional training, research awards, etc. The most important activity within the program Foundation FF and Society is an annual Congress Codo con Codo with sharing information, doing trainings, establishing relationships, and encouraging discussions between more than 130 Spanish associations that have an agreement of collaboration with the Foundation FF.

Main workplace/Organisation
Fundación SIGNO

Funcación SIGNO

The "SIGNO" Foundation is a reference in the promotion and funding of proposals aimed at improving the management and evaluation of healthcare costs.

To improve quality, equity, efficiency and productivity of the National Heath System, the Foundation proposes the following vectors of change of the NHS: 1) The patient should come first. 2) A flexible and integrated health care model that suits the needs of patients. 3) An equitable system that ensures the highest quality of care regardless of place of residence, sex, age or social status. 4) A Government for the NHS in line with the regional model. 5) A new professional leadership. 6) Efficiency and ethical commitment. 7) Costs, Efficiency, productivity and quality: a virtuous synergy. 8) The challenge for the solvency of the health system. 9) The NHS as an engine of innovation, development and competitiveness. 10) Investing in information & communication technologies. 11) A new approach to public-private partnership, based on a corporate concept.

From "SIGNO" Foundation we endorse initiatives like SIP with the aim of promoting the exchange of best practices in pain with stakeholders and reach excellence in pain care within the framework of a sustainable health care model.

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"The "SIGNO" Foundation is a reference in the promotion and funding of proposals aimed at improving the management and evaluation of healthcare costs."

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ENDORSING ORGANISATION SIP2012

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"Managing R&D, innovation and promotion of health in Extremadura."

Main workplace/Organisation
Fundesalud, Consejeria de Sanidad de Extremadura

Profession/Function
Chief Director

The perfect intermediary for the Extremadura health professionals

Goals:
Managing not only R&D and innovation but also the promotion of health in the field of health through the transfer of knowledge and expecting results

Vision:
Being the perfect intermediary for the Extremadura health professionals, promoting research and training performances, promoting an improvement in health care processes and trying to consolidate our groups of excellence at national and international levels

Main workplace/Organisation
FUNDOLOR

Profession/Function
Secretaria

FUNDOLOR

The Foundation for the Study and Treatment of Pain of Comunidad Valenciana (FUNDOLOR) was created on march 1998 by a group of health professionals (physicians, psychologists, pharmacists and nurses), who were aware of the importance of the treatment of the chronic pain to relieve the personal suffering that it generates. Their main ends are:

1. The promotion of the investigation of the mechanisms of the pain and the painful syndromes, helping to improve the control and treatment of the patients with agony and chronic pain.
2. To educate in the treatment of the pain any professional group of the health, patients and keepers.
3. To obtain and to spread information on painful mechanisms and syndromes and to realize activities to sensitize on the need to improve the boarding of the pain.
4. To promote and to support the creation of patients associations with a common link of disease that partner takes the pain, for the improvement of his boarding.
5. To advise to entities and institutions which have been interested in the improvement of the boarding of pain.

ENDORSING ORGANISATION SIP2012

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"The Foundation for the Study and Treatment of Pain of Comunidad Valenciana works to improve the treatment of the chronic pain in this region of Spain."

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"It is necessary to develop specific strategies addressing RA from the experiential knowledge of its individual representation and trough the particular impact of pain in the patient, relative and professional behaviour."

Main workplace/Organisation
Josep Laporte Foundation - Autonomous University of Barcelona - Patients' University
Profession/Function
Researcher

Rheumatoid Arthritis: A vision of the present and look into the future. Results of a multidisciplinary qualitative study

The centralization of health and social care in the patient is a major issue in the perception of quality, health, welfare and satisfaction. However, there still remains a significant deficit of qualitative studies that are focused on levels of appropriateness of health and social care systems to individuals' needs with rheumatoid arthritis (RA).

The purpose of this research has been, on the one hand, to assess the degree of centralization and adequacy of Spanish NHS to rheumatoid arthritis (RA) from the perspective of patients, families and professionals. On the other hand to identify the key health and social care of inadequate approach to RA with regard to the best national and international standards and recommendations. Finally, to analyze to what extent patients' perspectives on quality of care in RA are associated with patient characteristics (genre, age, social position, health literacy, disease duration, year of diagnosis and treatment and social support). We conducted an exploratory, descriptive and contextual qualitative study based on a phenomenological approach. Three focus group were set up: (a) rheumatoid arthritis patients (N = 11), (b) their relatives (couples) (N = 7), and (c) trained professionals in primary care, rheumatology, nursing, pain, physiotherapy, occupational therapy, preventive health and management (N = 10). At the same time we conducted a total of 16 semi-structured face to face key informants agents of RA in Spain according to the following profiles: rheumatology, primary care, psychology and psychiatry, rural medicine, occupational therapy, nursing, social work, patient associations and working groups in Reumatology.

Several aspects of inadequate approach of RA were identified, namely in the field of knowledge, diagnosis and treatment of this disease and particularly in the matter of pain. In the light of the results of this research it was possible to highlight that the maladjustment of RA health and social system from the experiences of patients and their relatives causes a serious and sometimes irreversible "biographical disruption" that alters the global life at labour, economic, social, psychological and physical dimensions but also the own self-perception of the person. Inadequate pain diagnosis and treatment was found to be a more serious quality problem than an inadequate performance on other aspects that were less important to patients and their relatives.

The main consequences of the inadequate diagnosis and treatment of pain had negative impact on the following factors: poor subjective health perception; loss of quality of life at private sphere (a biographical level, personal and family) public sphere (social and professional level) and health and social sphere (in terms of the navigation and route followed in the disease process within and outside the formal system).

Main workplace/Organisation
Galician Society of Pain and Palliative Care

Profession/Function
President

The Galician Society of Pain and Palliative care

Galician Health professionals focused on pain and Palliative Care. Galician Pain Society is a professional society, multidisciplinary and non-profit organization that focuses on pain management and palliative care. It has been working since 1995. It is composed by health professionals with different specialties and backgrounds, especially physicians, but also other professionals such as psychologist and graduates in nursing. At this moment the Galician Society of Pain and Palliative Care counts with 167 members.

The Society has different objectives:
1) Promoting scientific works about mechanisms and treatment of pain.
2) Raise public awareness about this problem.
3) Encourage the continuous improvement in assessment and therapy in patients suffering pain.

According to the main objectives of our society we are willing to endorse the "Societal Impact of Pain" meeting since it is a very relevant initiative and very good opportunity for key stakeholders to exchange their best practices in pain, and create consensus for future collaborations on improving pain care.

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"Galician Health professionals focused on pain and Palliative Care."

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Main workplace/Organisation
Faculty of health Sciences, Linköping University, Linköping
Pain and rehabilitation Centre, University Hospital, Linköping

Profession/Function
Professor and Head of Centre

Advancing pain management in Swedish primary care through quality registry – a regional collaboration project in Sweden

At the moment multimodal rehabilitation is foremost provided in specialist health care, however, within the framework of the Swedish national rehabilitation guarantee multimodal rehabilitation programmes are now implemented in primary health care in all/nearly all county councils in Sweden.
However, there is a lack of clear and uniform strategies to identify patients with more complex pain problems in need of rehabilitation at specialist level and patients with less complexity that could participate in primary care rehabilitation. There is also a lack of simple and systematic routines to follow up and evaluate patients in multimodal rehabilitation in primary care.

Professor Bjorn Gerdle will present a a collaboration project between the county councils in Västerbotten and Östergötland with the aim to develop a tool for assessment, selection to and evaluation of multimodal rehabilitation in primary care.

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There is a need of a tool for assessment, selection to and evaluation of multimodal rehabilitation in primary care.

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"Pain is the fifth vital sign but it is often overlooked among older individuals. In these patients, pain comes in cluster with other distressing symptoms and impact the quality of life in a substantial fashion."

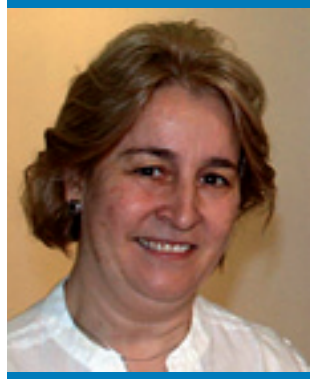
Main workplace/Organisation
Policlinico Universitario Agostino Gemelli, Università Cattolica del Sacro Cuore

Profession/Function
Professore di Medicina Interna-Geriatria c/o Centro Medicina Invecchiamento

Pain in geriatrics: an oxymoron or a syllogism?

Trouble with pain has been reported by 25 to 50% of elders living in the community and in as many as 80% of nursing home residents. Pain is chronic by definition in most instances and as such is maintained by an altered modulation of the nervous system. Pain comes in cluster with other common symptoms like fatigue, anorexia and anxiety. Pain can also lead to an increased sense of helplessness, depression, lessened activity, and disrupted sleep.

In addition to pain, the elderly patient experiences physical and cognitive changes that are part of the aging process. While cognitive impairment and agitation are often blamed on analgesic intake, they are actually more likely to be related to pain. Cognitive impairment does not alter an elder's ability to state that they have pain and indicate its location. Management of pain thus extends beyond analgesia to include other interventions and treatments focusing on the person's quality of life and ability to function.



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"Pain Management in Palliative Care needs an Assertive Approach."

Main workplace/Organisation
Servicio Madrileño de Salud

Profession/Function
Coordinator

Madrid New Palliative Care Pain Program

Palliative care focuses on the needs of patients of all ages and all diagnosis that may reduce life expectancy, no matter what the stage of the disorder. Its main goals being to prevent and relieve suffering and to enable the best quality of life possible.

Madrid Palliative Care Program endeavors to approach pain at the end of life rigorously, irrespective of patient´s other needs, treatments or setting. Care and pain management are delivered by multidisciplinary teams via approaches incorporating pharmacologic, nonpharmacologic, and/or complementary therapies. In addition to physical aspects of pain, palliative care takes into account the psychosocial, psychiatric, spiritual, and other aspects of a comprehensive pain management program.

As an essential component of palliative care, effective pain control must be given due consideration by regional and local administrations, ensuring funding and resources are available. At the time of referral, adequate evaluation is of paramount importance as is documentation of facts and findings in commonly accessible clinical notes. As a disease progresses, continuity of care becomes increasingly important – coordination between services is required, and information must be transferred promptly and efficiently between professionals in the community, in hospitals, and in hospices. Rehabilitation, with the aim of maximising independence, is also essential to good care.

Madrid Regional Government has promoted development in this field over the last decade: its first Strategic Plan resulting in a multiplication of its resources and the current one looking for ways of integrating them and giving continuity of care priority over new resource creation. Thus, the new Palliative Care Central Unit in Santa Cristina Hospital offers the space and structure to facilitate a seamless pain program integrating professionals, resources and levels of care and expertise. Not only will it offer ample facilities for patients, families and other users in its bedded unit, first Spanish public Day Unit, and outpatient facility but it is envisaged to become a PC training and research hub for the capital of Spain in the near future.

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"Patient empowerment in pain".

Main workplace/Organisation
Galician Health Service

Profession/Function
Citizen Care Manager

Galician School in Public Health for Citizens: Education in Pain

The Galician Health Service, in its Strategy SERGAS 2014, includes a line of patient and citizen participation and in accordance with this line, in 2009 the Galician School in Public Health for Citizens is created. It starts off as a network based on knowledge management, which offers training and education to patients, caretakers and citizens in order to improve their empowerment, provide tools so they may manage their illness and improve their co-responsibility in decision making as to health issues which affect them. It also provides activities focused on health promotion in order to improve chronic disease care and to increment health literacy levels.

The School creates a Patient Advisory Council in Clinical Safety which acts as an advisory organ in terms of citizen education and participation. It is made up of health authorities belonging to the Galician Health Service and 80 patient organizations dealing with chronic diseases. The Council has the following duties: propose educational needs; review and advise on pedagogical material, guidebooks and documents in order to divulge information and knowledge to patients; participate in new staff admittance programs in order to inform them as to their needs and expectations; and inform their members as to whatever new information comes out of the Galician Health Service.

Recently, the Galician Commission on the Strategy Against Pain has been constituted as a collegiate organ of a permanent and consultative nature, made up of health care professionals and patient organizations where pain is of great concern. Its objective is to improve integral pain care procedures in our region.

Results: As a result of this joint task, since 2010, the following activities have taken place: four workshops on pain management for patients and 112 workshops on other pathologies, the main line here being pain care and teaching how to measure pain by means of the Visual Analogue Pain Scale, in order that the patient is able to control and record his own results. 15 online forums have taken place, available to all citizens where physicians and patients, experts on chronic diseases, have participated and where specific recommendation guidelines have been elaborated.

3820 patients and 1187 health care professionals have participated and the results evaluation, by means of surveys, reflects a high degree of satisfaction (87.6%) as well as knowledge applicability (82.2%).

Patients, who are members of the Patient Advisory Council as well as the Pain Commission, participate as speakers in conferences and educational activities both for patients as well as health care professionals in the numerous forums which take place during the year.

Two conferences on pain care for health care professionals have taken place where patients, experts on this subject, have conveyed their views and needs to health care professionals. These conferences had great participation and knowledge sharing.

Main workplace/Organisation
Geriatric Medicine Society e.V.

Profession/Function
President

Geriatric Medicines Society e.V.

The Geriatric Medicines Society e.V. aims to raise the awareness of the urgent need to stimulate and facilitate the development and provision of age appropriate medicines that older patients can easily and safely take.

The Geriatric Medicines Society e.V. ambition is to be an interdisciplinary platform and network for all disciplines involved in the research and development, manufacturing, distributing, prescribing, utilizing and financing of medications with the objective, taking into account healthcare needs of older patients, to enhance compliance and safety, independence and health.

The Geriatric Medicines Society e.V. promotes scientific research in geriatric medication from drug discovery to medication management by the patient taking into account specificities and needs of the population and addressing as well education, training and professional development in all disciplines involved.

The Geriatric Medicines Society e.V. aims for an interdisciplinary harmonization in geriatric medicines to the benefit of the patient, the health care systems as well as the society as such.

ENDORSING ORGANISATION SIP2012

Geriatric Medicine Society

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"Maintain and improve older patients' health by making better medicines available with the objective, along with better medication practices, to treat and prevent diseases effectively while increasing their health, compliance and consequently independence leading to efficient use of the economical resources of the health care systems."

ENDORSING ORGANISATION SIP2012

German Maltese Medical Society
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"The German-Maltese Medical Society (GMMS) was founded in 1999 under the patronage of the German-Maltese Circle."

Main workplace/Organisation
German Maltese Medical Society (GMMS)

Profession/Function
President MD

German-Maltese-Medical-Society

The institution aims at promoting:
The exchange of knowledge about generally accepted scientific standards and the present and future state of the art in medicine.

The organisation of high-level scientific medical symposia.

The Council is made up of:

President:	Dr. med. Herbert M. Lenicker, Balzan, Malta
Vice-President:	Dr Helmut Heddaeus, Würselen, Germany
Treasurer:	Mr. Emmanuel Cassar, Msida, Malta
Secretary:	Mr. Karl-Heinz Oedekoven, Aachen, Germany

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Main workplace/Organisation
Healthcare Improvement Scotland

Profession/Function
National Lead Clinician for Chronic Pain in Scotland

Measurement of Pain as the 5th Vital Sign

I am the National Lead Clinician for Chronic Pain in Scotland. This job is divided between Healthcare Improvement Scotland & the Scottish Government & my brief is to implement the recommendations of the GRIPS report[1]. I have been working with Pain Services, non-specialist health care providers, voluntary organizations, politicians & managers to try to improve awareness & understanding of Chronic Pain. I also work as a Consultant in Anesthesia & Pain Management for half the week.

I believe that the SIP conference can help to raise awareness among the public & health care professionals about the advances in knowledge & understanding of effective pain management.

The introduction of the measurement of pain as the fifth vital sign was intended to improve awareness & quality of pain management. The concept was introduced by the American Pain Society in 1996[2] & has spread to be adopted by the International Association for the Study of Pain in its declaration of Montreal in 2010[3].

There have been objections to the idea of pain as a vital sign, as there is no objective measurement. Two people with identical pathology may report different pain measurements[4]. Indeed there may be no pathology detectable & the same patient may report different scores[5]. There is some evidence that the focus on a numerical pain rating has not improved pain management[6] & there is concern at rising levels of opiate use[7].

I will argue that, while the 5th vital sign campaign has successfully raised awareness of the importance of the assessment of pain & its management, we need to move beyond simple numerical scoring of pain & use of the analgesic ladder.

We should aim to increase understanding of the complexity of pain & suffering, the limitations of analgesic medication & the importance of non pharmacological treatment. To achieve this we need to listen to & understand our patients – not ask them for a number[8].

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"The International Association for the Study of Pain has designated pain as the 5th Vital Sign. This has been controversial as pain cannot be measured in the same way as Heart rate or Blood Pressure. I will argue that in Chronic Pain, the most important thing is not the measurement but understanding & awareness of the problem."

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"A clear definition of health care indicators measuring pain in the population will be supportive in the implementation of a best practice approach to improve pain care in Europe."

Main workplace/Organisation
Grünenthal GmbH

Profession/Function
Executive Vice President, Grünenthal Europe & Australia

Pain as quality indicator for health care systems – improving pain care in Europe

Pain is present in many disease states: In most medical disciplines pain is more than merely a symptom, but should be considered a disease in its own right, able to influence the outcome of medical and surgical treatment.

In addition, the prevalence of pain is very high: about 25 % of the European population is affected. In fact, pain is the most common reason why patients seek medical attention and presents a serious problem for a large proportion of the population.

The economic and social burden of chronic severe pain is derived from inherent direct costs and indirect costs. However, the influence that pain as on societies in the European Union is probably largely underestimated. With respect to the management of pain we are confronted with a very heterogeneous situation across Europe. Unfortunately, best practices in prevention and in the management of pain are sparsely shared.

Due to the high prevalence pain and its significant impact on patients and society, 'pain' should be recognised as a significant health care quality indicator. More in-depth knowledge on the societal impact of pain may lead to a definition of measures to improve the clinical and economic burden of pain. A clear definition of health care indicators measuring pain in the population will be supportive in the implementation of a best practice approach to improve pain care in Europe.

About Alberto Grua

From 1981-1986 Alberto Grua studied Economics and Marketing at the Università Commerciale 'Luigi Bocconi'. He became Vice President at the Global Marketing Point of Care at Bayer Diagnostics, based in Elkhart - Indiana – USA from 1997 to 2000. Starting in 2001, he filled in the role of Commercial Director and Commercial Director Sales at Bayer, Pharmaceutical Division.

In February 2005, he started as Managing Director at Grünenthal Italy, followed by the position as Senior Vice President Palexia in the Global Business Unit at Grünenthal GmbH (Germany). In his current function starting in 2010 Alberto Grua works as Executive Vice President, Head of Grünenthal Europe & Australia.

From the very beginning Alberto Grua has been supporting and promoting the international platform of the "Societal Impact of Pain" (SIP).

Main workplace/Organisation
National Health Service. Andalusian Health Service

Profession/Function
Director of The Andalusian Plan for the Attention of people with pain

Improving chronic pain Management through integrated care processes, training program in primary care and quality sign: "Centres Against Pain"

In Andalusia, in response to national laws and the actual Andalusian autonomic law, which includes the right of patients to receive adequate pain treatment and within the Andalusian Quality Plan, integrated care processes (ICP) were developed, like Non- Cancer Chronic Pain ICP, Fibromyalgia ICP and Palliative Care ICP, all of them published in 2005.

These processes are directly related to addressing pain, and in late 2007 a working group was formed to develop a comprehensive strategic plan aimed at pain prevention, care and rehabilitation of patients with pain, which was published in May 2010 with the title "Andalusian Caring Plan for People in Pain" (ACPPP).

The ACPPP was developed by a multidisciplinary group composed of 24 professionals (anesthesiologists, surgeons, nurses, sport experts, pharmacists, A&E physicians, pediatricians, psychologists, psychiatrists, rehabilitation physicians, interventional radiologists, orthopedic surgeons, epidemiologists, technical and administrative personnel led by Reyes Sanz, phD,MD and Juan Antonio Guerra phD,MD.

Once established, the group proceeded to define the scope of the plan and to analyze the situation from a quantitative and qualitative perspective. The state of the existing care situation and needs in our community were established, the objectives were formulated and improvement and implementation actions were designed in relation to training, resources, evaluation and communication; these actions are grouped into 6 major lines consistent with the strategic objectives.

The draft was subsequently sent to external review to both scientific societies and professional experts, the necessary changes were incorporated and the final ACPPP document was published.

The ACPPP was launched in June 2010 and until 2011 it has developed the foundations for the subsequent implementation of other elements, the most important ones developed to date are:

1. The review and update of ICPs: non-cancer chronic pain, fibromyalgia, Palliative Care, and ICP "surgical block" (deals with care to postoperative pain from any mayor surgery procedure) and the development of an evidence based clinical practice guideline about the safe use of opioids for terminal care.
2. The training program, which covers general training on chronic pain and specific training on psycho-education, exercise prescription and physical activity and the safe use of opioid prescriptions.
3. The development of general competencies for all health service professionals, shared skills for groups of professionals in areas related to the scope of the plan and specific skills in relation to the ICPs developed.
4. The development of a sign of quality called: "Centres Against Pain " aimed at GP Centers, hospitals and pain management units.
5. The development of a safety program for the Pain Management Units of hospitals.

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"A comprehensive strategic plan should be designed and implemented at regional or national level to address pain. The Andalusian plan includes a quality sign for centres, integrated care processes for care organization, a training program and clinical practice guidelines for professionals and other projects under design or implementation."

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Main workplace/Organisation
Dr. Roman Haas Medical Quality GmbH

Profession/Function
General Manager

Chronic pain - is it a disease in its own right?

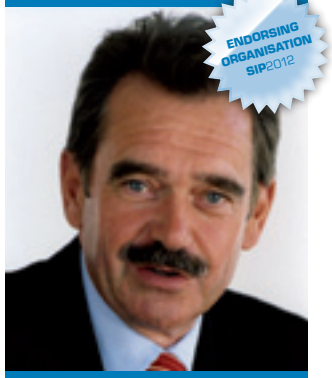
No doubt, there are weaknesses even in the best existing health care systems. Depending upon the approach towards chronic pain, all concerned groups and individuals can add a variety of valid and important suggestions for improvements of our systems. It will then be politics to analyze, evaluate and handle these suggestions: the influence and importance of underlying political and socio-economic systems and therefore the attitude of decision-makers towards pain and pain-patients cannot be over-estimated: it is crucial to provide them with facts, it is crucial to make them understand the dimension of this problem, and it is crucial to make them affected if not hit by the affliction and harm these patients experience.

The result of the discussion whether pain is categorized and classified as a disease of its own or not should therefore NOT be the basis for decision-makers: pain, no matter how categorized, needs research, resources, and dedicated stakeholders of all professions. It will only be then that we can help those who suffer.

The symposium "Societal Impact of Pain" will offer a unique opportunity for all involved in pain management to discuss the different and often conflicting viewpoints, and to provide politics with both data and suggestions for improvements.

I look forward to give my contribution by moderating this exciting discussion.

"The discussion whether pain is to be understood as a disease or not is one of the most exciting hot debates in our modern health care system, with good arguments from both sides. Working as general practitioner I see pain patients daily. Many if not all these patients could not care less about this question - they suffer pain, for very different reasons. It should be the upmost priority of all health care professionals, stakeholders in health care systems and politicians to help these patients - no matter where these patients live and why these patients suffer. On the other hand - as my second interest is quality management including guidelines, I consider the answer on the question whether pain is to be understood as a disease or not of key relevance for high quality pain management. Pain being present in almost all health conditions is a factor influencing the quality of life for many. As such the occurrence or absence of pain is one of the best benchmarks to see whether we (as a health care system and as health care professionals) are meeting the needs of society as well as those of the individual patients."



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Main workplace/Organisation
German Senior Citizens League (German Seniorenliga e.V. - DSL)

Profession/Function
Executive Member (Geschäftsführender Vorstand)

German Senior Citizen League: In support of more public awareness of pain conditions amongst the elderly

Founded in 1993 the DSL is the leading organization addressing the 50plus generation in Germany. The DSL is centrally organized and based in Bonn.

Originally DSL was focused on age related diseases, such as Alzheimer's and Parkinson's and rapidly became the leading non-profit-organization in this area in Germany. In recent years the DSL widened their scope substantially, encompassing complex health, wellness, financial services, sports, travel and education topics. This broad competence range enables DSL to represent today's 50plus generation in Germany as a whole.

Prof. Dr. Ingo Fusgen, former President of the German Geriatric Association, heads the scientific board. The board represents scientists and experts in healthcare, politics and communication, also leading entrepreneurs. A major current concern for the DSL are chronic pain conditions amongst the elderly: In the elder generation, pain, next to malnutrition, is one of the most ignored and publically unknown health and societal issues in Germany.

Especially elder people who are not able to express themselves properly, mainly due to cognitive loss from senile dementia or the level of education, are not treated against pain disorders appropriately. Other decisive factors resulting in substandard treatment and diagnostics are a lack of public awareness for the problem and governmental restrictions that do not support (or make difficult) prevention strategies and free choice of the best possible treatment.

The DSL is currently preparing a nationwide campaign addressing patients and relatives, politics and the general public. This campaign will aim at raising public awareness of the pain issue, informing patients and caring relatives about accepted and ideal standards in pain diagnostics and treatment, and influencing political decision makers to set the stage for the best possible pain treatment for the elder generation in Germany.

"In Germany, chronic pain disorders amongst the elderly aren't an issue in public discussion, diagnostics and treatment are often substandard. Only more public awareness for pain conditions amongst the elderly can substantially change the societal involvement with the problem."

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"Danish pain patients need a national plan for action Denmark need a plan for organizing pain treatment."

Main workplace/Organisation
Multidisciplinary pain centre

Profession/Function
Senior consultant, Leader of pain centre

National consensus for the treatment of chronic pain in Denmark – could it be?

In this speak the attempt to bring decision makers to focus on organising chronic pain treatment in Denmark is presented. Up to the SIP-meeting we arranged a national meeting with Danish politicians and employees placed in central positions in the national health and social security departments to point out which problems the patients are meeting in a system that does not realise the dimensions of the problems they are facing.

With speaks from a GP, a vice director from the consultant from The National Labour Market Authority, a scientist from Aarhus University and the leader of a multidisciplinary pain centre we had a broad spectre on the issue to make the invited politicians and decision makers interested enough to support the foundation of a working group with the agenda of making a national program.

The social impact on the patients, on the local health and social sectors and on national level was highlighted. At the end of the meeting there was a panel discussion with, among others, a politician from one of the big opposition parties and a decision maker from the Local Government Denmark.

The results of all the work will be presented and hopefully discussed at the workshop.

Main workplace/Organisation
Hellenic Society of Algology, "Thriassio" General hospital of Elefsina

Profession/Function
Director of Anaesthesia Department & Pain Clinic

Hellenic Society of Algology Pain Management in Greece: The reality today.

The population of Greece is about 11 million. The National Health System was established in 1985. Nowadays the public sector is only 50% of the total Health Sector. 138 General Hospitals all over Greece covers this NHS. Today's dire economic situation has dramatically reduced the funding of the NHS and Social Welfare collapses daily. In this challenging environment the doctors involved in the relief of pain patients have difficulties in offering significant help.

The Hellenic Society of Algology (HSA) is the unique scientific society with the responsibility to defend the human right of all people to have access to pain management without discrimination. The Hellenic Pain Society (HPS) was established in 1994 by 27 Greek Anaesthesiologists. In the end of 1994 the HPS became official member (chapter) of IASP and some months later member of EFIC (1995). In 2005 became the renaming as Hellenic Society of Algology. In 1994 when the HPS was established, only 8 Pain Clinics were active all over Greece.

Nowadays (2012) the Pain Clinics are 56: Attica (26), Thessaloniki (3), Province (27). The HSA has 823 members (doctors from all specializations and other health professionals). The SA organizes Scientific Meetings for its members, Clinical Workshops, Seminars in Hospitals, Discussions in Interesting Case Report studies etc. and participates in Congresses held by other Scientific Societies.

Every two years the National Panhellenic Congress on Pain is held outside of Athens. During the last years the HSA organizes by the approval of EFIC an annual seminar (4 courses per year) in Continuing Medical Education (in the field of pain management). The relationship with the Ministry of Health is characterized as poor and in-effective!!! There is not any support of HSA by the State. The National Statistical Service (2006) estimates that there are >30.000 new cancer patients every year. Cancer is the second cause of death in Greece (24.4%) after cardiovascular diseases (29.4%). It is easy for cancer patients suffering from pain to approach pain clinics, but in some areas of Greece it is very difficult because there is an unequal distribution of pain clinics. The pain clinics in Greece have developed only in Public Hospitals and there is no possibility to follow up the pain clinic patients in an outpatient basis.

The Palliative Care in Greece is at very low levels. There are neither Public Hospices nor Care. There is a legislated framework but has not been applied yet. Only 3 or 4 Hospitals with Pain Clinics have the ability to follow up the patients at home and to offer a basic home care. There is some difficulty in the prescription of opioids and a great bureaucracy, which is very annoying for the patients and their relatives.

Despite the difficulties and obstacles that exist under these conditions, and the current severe socioeconomic crisis, the efforts of the Greek Doctors involved in the treatment of chronic pain is highly emotional and full of self-denial.

ENDORSING ORGANISATION SIP2012

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"Dr. E. Anastassiou Councillor of Greece to the EFIC Director of Anaesthesia Department & Pain Clinic "Thriassio" General Hospital of Elefsina."

ENDORSING ORGANISATION SIP2012

herescon gmbh
health economic research and consulting

herescon gmbh
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"The fight against pain will play a major role in different approaches to assess the cost-benefit outcome of innovations."

Main workplace/Organisation
herescon gmbh - health economic research & consulting

Profession/Function
Managing Director

Assessment and evaluation of innovation in the health care sector

The assessment and evaluation of innovation in the health care sector gets more and more complex as regulators and payers all over the world focus on not only on benefits but also on cost-benefit relations. The challenge in this field is to be able to find common comparators for all kinds of different diseases as the budget must be allocated to different areas. Of all clinical outcomes in different indications pain is one of the central problems why patients seek for help from health care professionals. Being such a dominant symptom with all its different facets and manifestations it will stay one of the central outcomes that clinicians and researchers want to have an impact on. Hence, the fight against pain will play a major role also in different approaches to assess the cost-benefit outcome of innovations.

About Herescon gmbh
Herescon gmbh provides professional consulting and research services to the pharmaceutical industry, to health insurers as well as other organizations in the health care market. Major areas of expertise are all aspects of empirical research in health care services as well as the broad spectrum of health economic research in general. Founders are Prof. Dr. J.-Matthias Graf von der Schulenburg (Leibniz University Hannover), Prof. Dr. Wolfgang Greiner (University of Bielefeld) and Dr. Thomas Mittendorf, who is the CEO of the company. Herescon was founded in 2008, re-naming Graf Schulenburg Greiner & Partner, a research-based consulting company in health care that has been on the German market for many years.

The spirit of herescon is driven by combining theoretical and methodological research in health economics as well as health policy issues with a wide application of these methods to the specific needs of pharmaceutical companies, regulatory bodies or other stakeholders in the system. The research team of herescon looks back on more than 25 years of experience in health care management and health economics research. Almost every German pharmaceutical company as well as international companies or their German affiliates can be found among the list of previous clients. In addition, we also conducted projects for sickness funds, private health insurers, ministries and governmental agencies, physician associations, patient advocacy groups, the European Union, varies local governments around the world and the World Bank.

To suit specific needs of clients herescon also regularly collaborates with a wide network of additional researchers on a project driven basis. To further intensify these efforts, herescon became a founding member of The Minerva Network (www.minerva-network.com) in 2008, an international CRO aiming at offering the capabilities needed for large international health economic and health policy related projects.

ENDORSING ORGANISATION SIP2012

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"FUINSA is a reference meeting between all the stakeholders who are involved in research and in health and social care."

H

Main workplace/Organisation
FUINSA Fundación para la Investigación en Salud

Profession/Function
Director

Foundation for Health Research

The Foundation for Health Research, FUINSA, was born in 2001 when a group of professionals from different backgrounds realized the need to develop an independent initiative that would promote and encourage research in health.

If research in any field has a real value to society, that one focused on improving health and extending life spam of individuals, is no less than strategic. Therefore, health research is the key to society, a path that must be supported and developed.

There are some aspects in the health research field that deserve to be highlighted, like the importance of making sure that the new biological knowledge transforms quickly into an improved diagnosis, treatment, or prevention of diseases; and how vital it is to disseminate research findings to Society, so that such society commits and involves in that process, promoting a cutting-edge type of research.

The main goals of FUINSA are: development of health sciences; support and training of professionals in knowing and studying scientific and technical advances; development, dissemination, disclosure and support of health studies; development and promotion of research in health and science; and improvement of quality in social and health care delivery.

FUINSA has shown over the years that research in health is a guarantee of innovation and a need for society's future.

FUINSA commits to involve health authorities in empowering health research, industries in developing it, health professionals in being trained and able to apply it, and patients and citizens in acknowledging it.

The Foundation is aware of the current conflicts taking place in the field of health and, by being a meeting point for dialogue and analysis, it tries to get together the various agents involved, raising an awareness on some persistent and not satisfactorily resolved situations within the Health Care System.

Since its beginning FUINSA has promoted several seminars to discuss different issues related to the improvement of clinical research quality. It has also organized forums for discussion and debate about research incentives; it has established working groups with Scientific Societies, independent research teams, and Ethics and Clinical Research Committees; it has organized training in Pharmacoeconomics and Good Clinical Practice; and for the first time in Spain, it has promoted meetings on Corporate Social Responsibility in Clinical Research.

FUINSA addresses a major challenge: becoming a meeting point between the Health System and Society. As a result society can be aware of how the Health Systems works in a daily basis researching and training professionals towards a better care, and in turn, the Health System does not forget that behind all it activities there is only one goal, a better service to citizens.

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"Multidisciplinary Pain Therapy relieves individual Pain und reduces costs for the society and health systems."

Main workplace/Organisation
Schmerzzentrum am Hebronberg

Profession/Function
Facharzt für Anästhesie, Spezielle Schmerztherapie

Multidisciplinary Pain Management is State of the Art

We have 33 specialized Pain Centers which overlook more than 5500 Back-Pain Patients with various diagnoses from neck to back. After a maximum of 60 multidisciplinary therapeutic Units, including medical, psychological and physio-therapy including body workout within 4-8 weeks, we saw about 90% of them going back to work with a dramatically reduced pain score, saving about 1800 per person for the health insurance involved and an unspecified sum for the social system.

Main workplace/Organisation
NHS Kirklees

Profession/Function
Director of Public Health

Moderator of WS6 Outlook for future of pain management

Dr Judith Hooper
Executive Director of Public Health for both NHS Kirklees and Kirklees Council, West Yorkshire, England.

She worked as an academic GP in the deprived part of inner city Newcastle upon Tyne with a training role in primary care in both undergraduate and postgraduate levels. She then converted to public health in 1989. She joined Kirklees, West Yorkshire in 1993. Her passion has always been tackling all factors that affect health and striving to reduce health inequalities. This has included implementing behavioural change programmes, joining up services and helping them to be user focused. She has extensive experience in health intelligence and health assessments using different techniques, as well as inter-agency working.

In her role as Director of Public Health across a richly diverse, population of 500,000 her focus is:

a. Providing intelligence about levels of ill health and the factors that affect health such as educational attainment, income, housing etc.
b. Ensuring threats to human health by communicable disease are minimised e.g. immunisation, outbreaks and swine flu. This includes providing expertise to the emergency planning response.
c. Ensuring action to support people in having healthy behaviours, especially those most at risk. Key areas are tobacco, food, physical activity, emotional wellbeing, alcohol, sexual health etc. This involves working with target groups and involving them in creating and delivering solutions.
d. Provide evidence both on need and what actions work for programmes of care across health and wider factors affecting health. For example what works to clinically manage long term conditions such as chronic pain as well as helping people cope with the consequences in managing their condition, job, relationships etc.

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"Health needs assessment across a population is crucial to shape services and care within it. It widens possibilities through greater understanding and has lead to innovative management of long term pain within a population in Kirklees."

H

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"2012 is the year when the Dutch Council for the quality of health care has put chronic pain on the agenda."

Main workplace/Organisation
Erasmus MC

Profession/Function
Professor in Anesthesiology

Dutch Council for Quality of Healthcare and chronic pain

About 19% of the European adults suffers of chronic pain. Women are affected slightly more often than men (56% versus 44%). The highest prevalence is seen in the age group 41-60 years. Chronic pain is often of long duration, the natural course is unfavorable. The intensity of chronic pain is reported high. Chronic pain is frequently so severe, that it cannot be tolerated any more. Arthriritis, Osteoarthritis and Rheumatoid arthritis are the most common etiologies, directly followed by herniated, deteriorating discs. This is remarkable, due to the fact that with a known etiology it should be clear which medical discipline is responsible for these patients. We can conclude that these specialties do not succeed to treat the pain in an adequate way. Chronic pain is not only an unpleasant feeling, it has a large impact on daily functioning and quality of life. Chronic pain is associated with high direct and indirect costs.

The burden of chronic pain is high. Chronic diseases like diabetes, chronic obstructive lung disease and chronic heart failure rightly receive much attention from the policymakers. Until now chronic pain is not always recognized as in this way.

In the Netherlands "The Dutch Council for the Quality of Health Care" was established in 2009 by the Minister of Health, Welfare and Sport in order to promote high-quality care in the Netherlands. The working area of the Council covers prevention, cure and long-term care. The Council sets tasks for advisory and research activities and gives recommendations, whether solicited or not, to the Ministry and to the field. The Council's activities are mainly aimed at increasing safety, enhancing the patient/client perspective and stimulating the efficacy of care. The Council consists of independent experts in health care quality, who have been appointed in a personal capacity. The council assesses the wants and needs of the field in continuous consultation with all parties involved in cure, long-term care and prevention. The information acquired is processed into recommendations and plays a role in defining the Council's activities. The Council directs the development and implementation of guidelines.

In 2011, the Council initiated a "workgroup Chronic Pain". In September 2011 they delivered a rapport, which was presented to the chairman of the standing parliamentary committee on health care. Important recommendations in the rapport are:

- install a multidisciplinary national committee on chronic pain with the mission to improve pain care
- develop a general guideline on chronic pain
- develop a definition and classification system
- develop a framework for education in chronic pain
- promote special interest group on pain within the different scientific associations of medical specialties.
- promote new research programs on pain

2012 is the year when the Dutch Council for the quality of health care has put chronic pain on the agenda.

Main workplace/Organisation
Institute for Research in Operative Medicine (IFOM)
Faculty of Health - School of Medicine Witten/Herdecke University
Profession/Function
Director, Chair of Surgical Research and Dean for Research

Institute for Research in Operative Medicine (IFOM)

Since 2005 the IFOM is part of the Witten/Herdecke University. It is directed by Prof. Dr. Edmund Neugebauer, chair for surgical research and plays an important part in the scientific output and development of the Faculty for Health. With more than 40 staff members the IFOM is one of the biggest and scientifically most successful research institutes of Witten/Herdecke University. The IFOM shows a high percentage of third-party fundraising by DFG, BMBF as well as foundations and industry. In 2011 3.5 Mio Euro have been acquired. The impact factor of scientific publication ranges about 85.

As an interdisciplinary institute, IFOM implements its own research projects and supports the operative disciplines including anesthesia on Campus Köln-Merheim in their scientific activities. According to its activities, the organizational structure is divided into four sections: (1) Experimental research, (2) Evidence-based medicine / health technology assessment, (3) Clinical research with the associated study centre for clinical reasearch (ZKSI) and (4)Health services research. At IFOM the traditional separation between basic sciences and application-oriented research is abolished. Clinicians and scientists work closely together and cooperate interdisciplinary in the fields of basic science, translational research (from the Bench to the Bedside), clinical research and health services research.

We regard the orientation towards the Clinical Topics of the operative disciplines; the institutePLA is considered a model structure for the surgical research in Germany. At IFOM scientists work in different fields and disciplines. In the field of basic research, Experimental Surgery, Biochemistry, Immunology and Cell- and Molecular Biology. In the field of clinical research, Epidemiology, Medicine, Biology, Biostatistics and in the fields of health services research and evidence based medicine/HTA, Psychology, Medical Sociology and Health Economics. By involving clinicians, basic researchers obtain clinical knowledge and are therefore able to understand clinical problems and vice versa. Above all, it is in addition to both partners, the patient who finally should benefit from this cooperation.

Beside outcomes research (quality of life, pain etc.) the two most important fields of research are trauma/multiple Injury and wound healing. Trauma research is focused on new therapeutic approaches for neurological dysfunction after traumatic brain injury. Here e.g. the therapeutic potential of neuronal precursor cells, generated by differentiation of induced pluripotent stem cells, is evaluated by using clinical relevant Traumatic Brain Injury (TBI) models. In wound healing the pathophysiology of chronic wounds is examined on cellular and molecular level. By comparison with the physiology of acute wounds, new therapeutic approaches for chronic wounds can be developed.

ENDORSING ORGANISATION SIP2012

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"From the Bench to the Bedside - Translational research for the patient's benefit."

I

Main workplace/Organisation
Instituto Aragonés de Ciencias de la Salud (IACS)

Profession/Function
Director

Instituto Aragonés de Ciencias de la Salud

IACS is a public institution dependent on the Government of Aragon devoted to Health Sciences development. Its objective is to generate knowledge in order to fulfill the main needs in health, producing scientific results capable of raising resources and promoting research amongst the public hospitals and health services in the Region of Aragon.

According to the framework agreement signed between the Regional Health System of Aragón and the IACS, all the research groups and infrastructures from public hospitals and health centers are managed by IACS, besides their structural dependence.

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Main workplace/Organisation
Fundacion Instituto de Estudios de Ciencias de la Salud de Castilla y León

Profession/Function
Formacion sanitaria / investigación clinica

Fundacion Instituto de Estudios de Ciencias de la Salud de Castilla y León

The "FUNDACION DEL INSTITUTO DE CIENCIAS DE LA SALUD" is a non-profit organization that aims to promote: Training, Research, and dissemination on matters of Public health, Welfare, Health Planning and Management, and Health Law.

The Foundation carry out all type of activities that, in a broad concept of health, contribute to the achievement of the foundational purpose.

The Foundation was created in 2001 and, although originally the geographical areas in which it operates is the Autonomous Community of Castilla and León, currently it is expanding its activities to different Regions and even countries.
It is located in the city of Soria.

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Training in Pain Treatments is one of its strategic lines

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Main workplace/Organisation
International Headache Society

Profession/Function
Charity

Advancing headache science, education and management and promoting headache awareness worldwide

IHS is the world's leading membership organisation for all whose professional commitment, whatever their discipline, is to helping people whose lives are affected by headache. The official journal of IHS is Cephalalgia, a scientific journal published by SAGE Publications providing an international forum for original research papers, review articles and short communications on topics such as: diagnosis and management of primary and secondary headaches and related syndromes, pathophysiology , pharmacology, epidemiology, imaging, genetics, medico-legal aspects, migraine and pharmacoeconomics.

IHS also develops guidelines on the management of headache; recent guidelines include 'Guidelines for controlled trials of drugs in migraine', and 'Guidelines for controlled trials of drugs in tension-type headache'.

A major activity is the International Classification of Headache Disorders (ICHD). The ICHD-II, published in 2004, is used by physicians worldwide to assist in the diagnosis of different headache types, and is translated into many different languages. Work on ICHD-3 is ongoing, with publication expected in 2014.

IHS organises the International Headache Congress (IHC) on a bi-ennial basis, the next congress to be held in Boston, USA, in June 2013, in collaboration with the American Headache Society.

Other IHS activities include online education materials and offering grants/fellowships to young physicians worldwide.

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"IHS is an international professional organisation working with others for the benefit of people affected by headache disorders. The purpose of IHS is to advance headache science, education, and management, and promote headache awareness worldwide."

ENDORSING ORGANISATION SIP2012

IPBF

International Painful Bladder Foundation (IPBF)
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"The International Painful Bladder Foundation is a voluntary, non-profit organization, based in the Netherlands but active worldwide. Its focus is interstitial cystitis (painful bladder syndrome, bladder pain syndrome) and related disorders."

Main workplace/Organisation
International Painful Bladder Foundation (IPBF)

Profession/Function
Chairman

International Painful Bladder Foundation (IPBF)

The IPBF raises awareness and provides up-to-date information for patients and professionals worldwide through its website, e-newsletter, publications, presentations and congress booths, with the aim of ensuring that patients around the world get the right diagnosis and treatment.

The IPBF promotes the interests of IC patients globally, helps new support groups get started, supports individual patients with information and advice, stimulates research and promotes international cooperation at all levels.

Main workplace/Organisation
Irish Pain Society

Profession/Function
President

The Irish Pain Society is dedicated to the cause of alleviating Pain and Suffering

The Irish Pain Society is a multidisciplinary organisation, which has 197 members and is dedicated to the advancement and promotion of Pain Medicine in Ireland, through education, research and cooperation between all of the disciplines involved in the care of patients who suffer from pain.

Our offices are based at the College of Anaesthetists in Ireland at 22 Merrion Square North, Dublin 2. In 2010 our Annual Scientific Meeting was held in October in the Royal College of Physicians in Ireland. The theme of the meeting was Musculoskeletal Pain and our list of Guest Speakers included Prof. Sean Mackey from Stanford University and Prof. Stephen Schugg from Perth, Australia, together with many excellent local experts on this subject. In 2011 our Annual meeting will be held on the 22nd October, again in the Royal College of Physicians.

Our officers are Dr. Liam Conroy (President), Dr. Laserina O'Connor (Hon Secretary), Dr. Raymond Victory (Vice President). Other committee members include Miss Joanne O'Brien (Nursing), Dr. David Finn (Research), Dr. Roisin Mac Sullivan (EFIC representative), Dr. Brona Fullen (Past President, Physioptherapy) and Dr. Brian Maguire (Clinical Psychology).

Our organisation was involved in collaborating together with Chronic Pain Ireland and Arthritis Ireland in the Pan European Pain Proposal Project. The Irish Pain Society is actively involved in supporting Pain Research and Education through a number of Scholarships and Bursaries. Last year we welcomed 17 new members and we can guarantee a warm welcome to any prospective members.

ENDORSING ORGANISATION SIP2012

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"The Irish Pain Society through education, research and interdisciplinary support, is dedicated to further the Cause of Pain Medicine and Pain Management. Our goal is the alleviation of the burden of Pain that so many of our patients carry on a daily basis. We will use the impact of the SIP to increase the awareness of the media, politicians, governmental agencies and the public at large to effects and consequences of Pain in our society."

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Main workplace/Organisation
Israel Pain Association (IPA)

Israel Pain Association (IPA)

The IPA Israel Pain Association is a multidisciplinary professional organization in the field of pain science and medicine.

In 2011 we have witnessed beginnings in Israel of the emergence of "Pain Medicine" as a distinct academic discipline with clear borders and aims. The emerging trend has been towards the development of Pain Centers within which pain, per se, is the central focus.

Pain Centers specialize in the management of pain associated with a variety of medical conditions, typically using a multidisciplinary approach.

The burden of suffering that pain imposes on individuals, and the enormous costs that society has to bear as a result, calls for policymakers and decision makers alike to adopt a much wider, strategic perspective in their deliberations regarding service provision and resource allocation.

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"One of the key factors in effective pain management certainly is communication between medical team and patients, as it is the only way to assess the level of pain that the individual patient is experiencing. By establishing this dialogue with patients we can set individual treatment objectives, inform them about therapy and manage their expectations; therefore, raising awareness among physicians and patients for this crucial topic is a key objective that I hope we can achieve with our campaign."

Main workplace/Organisation
Italian Association for the Study of Pain (AISD)

The Italian Association for the Study of Pain

The Italian Association for the Study of Pain is the largest and oldest multidisciplinary professional organisation in the field of pain within Italy. Founded in Florence, on March 10th 1976, it has always been engaged in education, in the field of pain, open to all professionals involved in research, diagnosis or treatment of pain.

Members are doctors, nurses, physiotherapists, scientists, psychologists, occupational therapists and other healthcare professionals actively engaged in the diagnosis and treatment of pain and in pain research for the benefit of patients.

The Italian Association for the Study of Pain aims at promoting education, training, research and development in all fields of pain. It endeavors to increase both professional and public awareness of the prevalence of pain and available facilities for its management. The Association is involved in all aspects of pain and its management through the work of the Council, various Committees, Special Interest Groups and Working Parties and via its publications, Annual Congress, Scientific Meeting and Educational Seminars.

The fight against pain is also a cultural problem; therefore all initiatives aimed at sensitizing politicians and institutions are welcomed and supported by the Association.

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"All initiatives aimed at sensitizing politicians and institutions are welcomed and supported by the Italian Association for the Study of Pain, because the fight against pain is not only a scientific challenge but also a cultural problem."

ENDORSING ORGANISATION SIP2012

S.I.R.N.

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"Pain is a common problem in neurological rehabilitation, but to date there are no guidelines on this topic. Holding a consensus conference on pain in neurological rehabilitation will help reduce the burden of pain in this setting."

Main workplace/Organisation
Italian Society of Neurological Rehabilitation (Società Italiana di Riabilitazione Neurologica, SIRN)

Towards a consensus conference on pain in neurological rehabilitation.

The Italian Society of Neurological Rehabilitation (SIRN) was founded on june 2000.

SIRN Members are medical doctors, nurses, physiotherapists, occupational therapists, psychologists, and other healthcare professionals, who are actively engaged in the field of neurological rehabilitation.

Pain is a common target of rehabilitation procedures, but it may also represent a problem in patients undergoing neurorehabilitation, in terms of reduced compliance to the treatment. To date there are no guidelines on pain in neurological rehabilitation.

To cover this gap, SIRN will set a task force and hold a consensus conference on pain in neurorehabilitation. The task force and the consensus conference will involve other national scientific societies, which are interested in pain, and will use methods derived from evidence based medicine. The consensus conference is aimed to help medical and paramedical professionals, who are involved in the field of pain in neurorehabilitation. We will expect that the consensus conference will reduce the burden of pain in the setting of neurological rehabilitation and improve the quality of life of patients affected by neurological disease and reporting pain.

Main workplace/Organisation
World Health Organization (WHO)

Profession/Function
Medical Officer

The International Classification of Diseases (ICD) 11 in development

The International Classification of Diseases (ICD) is a key instrument of the World Health Organization. Initially developed for coding causes of death, continuous evolution now renders ICD useful for coding morbidity, as well as recording specific diseases, injuries, signs, symptoms, complaints, social circumstances, reasons for presentation and external causes of both injury and disease. ICD informs public health bodies, clinicians and researchers alike in the evolving environment of increasingly complex health systems, ensuring the provision of language and system-independent definitions that are applied for:

- National and international health statistics (mortality and morbidity);
- Epidemiology, surveillance, and monitoring:
- Individual patient records and electronic health records;
- Reimbursement and health system financing;
- Reference for treatment guidelines, scientific literature and research;
- Quality assessment at the level of individual cases up to assessment of health system outcomes and monitoring.

Developing countries bear a large burden of disease with many of their health systems lacking resources in the face of an overwhelming tide of urgent and life threatening demands. Effective deployment of ICD-derived tools would facilitate the use and collection of health information under such challenging circumstances and therefore facilitate quantitatively informed decisions. Historically, ICD is revised approximately every 10 years, with the exception of the 20-year period between the last two revisions, ICD 9 and the most recent version, ICD 10. The WHO Secretariat provides support for the transition from ICD 10 to ICD 11.

Goals for the ICD revision: ICD 10 to ICD 11

1. Update ICD to accommodate new scientific, clinical and public health knowledge
2. Accommodate the usecases mortality, morbidity, primary care, casemix, quality and patient safety
3. Define diseases and categories with a pattern of symptomatology and manifestations, etiology, course and outcome, treatment response, and genetic factors and environmental factors
4. Integration and cross-referencing with health-related terminology systems, making ICD fit for use in electronic health information systems
5. Harmonize with ICD-related and derived classifications as well as other members of the WHO Family of International Classifications
6. Work in multiple languages
7. Use of internet-based technologies for information gathering, integration and sharing, and digital curation, allowing for broad, participation and consultations
8. Planned field tests
9. Electronic and print copies
10. Accelerate global implementation plans with particular focus on developing countries

Some 160 experts in over 15 groups are reviewing and proposing edits to the classification. The results of this work can be seen in real time (4 to 48 hours delay) in the ICD-11 Alpha browser online on the WHO website. Experts are invited to review relevant sections of the classification. Volunteers can register online to contribute to the reviews (http://www.who.int).

ICD Revision Timelines

May 2011: Open ICD-11 Alpha Browser to the public for viewing
July 2011: Open ICD-11 Alpha Browser to the public for commenting
May 2012: Open ICD-11 Beta to the public
WHO will engage with interested stakeholders to participate in the ICD revision process

Individuals will be able to:

- Make comments
- Make proposals to change ICD categories
- Participate in field trials
- Assist in translating

May 2015: Present the ICD-11 to the World Health Assembly

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"The ICD is the international standard diagnostic classification for all general epidemiological, many health management purposes and clinical use The new design makes ICD-11 fit for electronic health records, includes scientific updates, and acknowledges the needs of its de facto uses (mortality, morbidity, casemix, primary care, quality and patient safety). Pain is a relevant aspect in health. The needs and ways of reflecting pain in the international classification of diseases need to be laid out and addressed in discussion with the specialty tags and the reviews."

J

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"Pain must not rule our lives. Effective management of pain is a fundamental right for all."

Main workplace/Organisation
International Alliance of Patients' Organizations (IAPO)

Profession/Function
IAPO Governing Board Member

The Patient Speaks

The International Alliance of Patients' Organizations (IAPO) works to achieve patient centred Health care throughout the world. IAPO is the global group representing patients from all disease areas and all regions of the world. IAPO's membership comprises of over 200 patients' and non-profit health-related organizations. IAPO focuses on issues that are of importance to patients' organizations regardless of their disease area or geographical location including access to healthcare, patient safety and patient information.

Robert Johnstone was appointed to the Governing Board of IAPO in August 2010. He is the IAPO representative of National Voices, a coalition representing health and social care organizations in the UK. Robert is well qualified to speak about the impact of pain on a person's life having lived with chronic rheumatoid arthritis for over fifty-five years since the age of three years old. His vision is that all patients will receive appropriate treatment for their conditions and the pain and disabilities associated with them.

This is a new era of patient engagement with healthcare - where growing numbers of patients' access information about illnesses and treatments, have questions for their doctors and expect to work in partnership with them, sharing decision-making and making informed choices about treatments. Attitudes are changing and moving away from the old expectation of paternalism in doctor-patient relationships epitomised by 'doctor knows best' to a new expectation of doctor and patient in partnership. And yet, there are millions people with chronic pain from whom life means long-term suffering – not only because of physical pain but because of the effect this has on:

- their personal relationships
- their capacity to earn a living
- their lifestyle and
- their dignity and independence

Life for them is a struggle against pain that constrains their activities and gradually erodes their energy, leading to depression and bouts of utter hopelessness. Quality of life diminishes to the hope for a pain free day or even hour. The financial cost of pain can be quantified in terms of the impact on people's ability to work, in disability and in absenteeism. But, imagine the human cost when, for many individuals, pain permeates their life for each minute, each day and each year ad infinitum. Pain management is a fundamental human right in the same way as access to treatment for the disease itself. Pain is an effect of a disease but can cause more suffering and disruption to a person's life than the disease itself and must therefore receive significant attention in disease management.

It is a tragedy, particularly, in this era of patient empowerment, consumerism and innovation in healthcare that people are suffering unnecessarily because they believe that nothing can be done. How can this happen? Unfortunately, because many health professionals are unaware that anything can be done or because it is not the responsibility of anyone in particular so there is a lack of awareness approaches to the management of pain. It is often left to the patient.

But, there are things that we can and must do to progress with patient-centred pain management. We can raise awareness across the health sector and contribute our experience to the formation of health policies on pain. And, we can utilise the knowledge of patients and patients' organizations. As expert patients we can help in the development and implementation of policies and the training of patients and health professionals in the management of pain.

Main workplace/Organisation
Junta de Andalucía Consejería de Salud

Junta de Andalucía Consejería de Salud

Andalusia was constituted in June 1979 and decides, with the support of the majority of Andalusian Councils , eligible for the fast-track to obtain autonomy. It was a planned route for the historical nationalities and allowing a greater transfer of skills. On 28th February of1980 held the autonomy referendum which triumphs in seven of the eight Andalusian provinces, not reaching the legal ceiling in Almería. After intensive discussions, the amendment of the organic law of referendum modalities allows unlock Andalusian autonomy, complete with the adoption of the Statute of autonomy in referendum

The Andalusian Ministry of health is the body of the administration of the Junta de Andalucía responsible for the policy guidelines of health and the higher direction of the agencies directly responsible for the provision and management of health services of our autonomous region, configured under the name of Andalusian public health system.

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"The burden of symptom load is more important to the patient's functional capacity and quality of life than the underlying diagnosis. Pain is the most important symptom."

Main workplace/Organisation
International Association for the Study of Pain (IASP®)

Profession/Function
IASP® Executive Officer (Finland)

Adequate treatment of pain

Dr. Eija Anneli Kalso is Professor of Pain Medicine, University of Helsinki, Finland, and Director of the Multidisciplinary Pain Clinic, Department of Anaesthesia and Intensive Care Medicine, Helsinki University Central Hospital. Her interests in the pain field include: opioid pharmacology; spinal mechansims of neuropathic and inflammatory pain; clinical trials in chronic pain; acute and chronic postoperative pain; and pain, opioids, and cognition.

In 1983, Dr. Kalso received the Royal Society European Exchange Fellowship (Nuffield Department of Anaesthetics, University of Oxford). In 1990, she was awarded the European Academy of Anaesthesiology Traveling Fellowship (Nuffield Department of Anaesthetics, University of Oxford; and Department of Pharmacology, University College London). In 1999 she worked at the Karolinska University Hospital and Karolinska Institute, Stockholm, Sweden. Her most recent IASP activities include serving as a Councilor and a member of the Scientific Program Committee. She also served on the Committee on Publications, the Committee on Opioids, the Research Committee, and the Publications Committee. Previously, she was a Section Editor for the journal PAIN®.

Dr. Kalso is interested in the mechanisms that make acute postoperative/traumatic pain persistent, including genetics and psychosocial factors, and how this process could be prevented. Pharmacology of opioids, from basic mechanisms to clinical efficacy, has been one of her long-term interests with ramifications to the alpha-2-adrenergic system and COMT. A major challenge is the development of pharmacological functional brain imaging to study drug effects in patients with chronic pain. Recently, she has become increasingly involved in studies assessing the role of genetics and life style factors in persistent pain.

Additionally, Dr. Kalso seeks to better understand why cancer pain is not adequately managed.

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"During evidence based medical and surgical treatments to treat or prevent pain in musculoskeletal diseases, thereby securing mobility for patients at all ages and keeping their quality at life at a high level."

Main workplace/Organisation
EFORT

Profession/Function
Secretary General

Securing mobility, musculoskeletal diseases and quality of life

Mission Statement:
EFORT (European Federation of National Associations of Orthopedics and Traumatology) works on behalf of the European Orthopaedic & Traumatology Community to secure mobility, musculoskeletal health and quality of life. This is the EFORT Mission Statement and it refers to EFORT as the umbrella organisation of the European national orthopaedic scientific societies.

EFORT was established by the national associations for orthopaedics and traumatology from twenty European countries. The federation was founded in Marentino, Italy, in 1991 and now has 42 national member societies from 40 member countries and 6 associate scientific members. As regards its legal structure, EFORT was established as a non-profit organisation, all funds are used exclusively in the pursuit of the federation's aim.

What we want and what we offer: EFORT is in the process of establishing itself as a pan-European partner for international organisations, authorities, universities, the orthopaedic industry, scientific bodies and professional and patient organisations. As a non-profit professional association, EFORT provides important services and benefits in terms of economics, healthcare policy and social issues.

The major mission of EFORT is:
- Representation of state-of the-art orthopaedic surgery in Europe
- Promotion of research, science and training in orthopaedics and traumatology in Europe
- Exchange of scientific experience and knowledge and improvement of education through training
- Work out EFORT standards and guidelines for the various areas of activity pursued by our members

In pursuit of its aims, EFORT today organises yearly European conferences and instructional courses. It also initiates and supports basic and clinical research. Since many years now, EFORT arranges Travelling and Visiting Fellowships where the different national associations alternate to host a group or young orthopaedic surgeons.

EFORT is recognised as representing an out-standing level of orthopaedics, traumatology and rheumatology in Europe. It promotes the exchange of experience, knowledge, education and research European-wide. Related to those efforts, work is also ongoing to make a new version of the EFORT Textbook and a European Journal of Orthopaedics and Traumatology has just been started as well as the publication of investigational reports in special book series.

As a majority of patients consulting orthopaedic surgeons, show up due pain from their disease and /or inabilities, the orthopaedics surgeon is constantly involved in pain evaluation, pain education and pain treatment. Therefore, EFORT has decided that pain is a main topic in all aspects of our educational programmes from sessions and lectures during the Congress through chapter in our Textbook. Moreover, EFORT encourage all or educational sessions to involve pain evaluation and treatment as a standard item.

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"Policy makers are advised to consider pain care in future policies aiming at improving the quality of life for European citizens as part of the goals set within the Healthy Ageing framework."

Main workplace/Organisation
Kleijnen Systematic Reviews Ltd

Profession/Function
Director

Systematic review on healthy ageing in relation to chronic pain in the EU

The EU has decided to focus on Active and Healthy Ageing, which has a goal of increasing the average healthy lifespan by two years by 2020. Chronic pain is a common health state and results in lost working days and reduced quality of life.

The question is what can be done to improve quality of life, particularly of older people by addressing chronic pain? The aim of this study was therefore to review the evidence on the relationship between chronic pain and quality of life and the effect of interventions in terms of pain reduction and quality of life improvement.

Results showed that there is limited (only a few studies) evidence in that interventions, such as treatments e.g. pregabalin or gabapentin or hydrotherapy, can improve quality of life as well as reduce pain, although it is less clear the extent to which improved quality of life is mediated by pain reduction is less clear.

Results also showed that is stronger evidence of a correlation between pain severity and quality of life, which does not prove that reducing pain will improve quality of life, but is nevertheless consistent with this possibility. Moreover, the average age of study participants was no younger than in the 40s. Therefore, if reduced pain improves quality of life in middle-age then we have an opportunity for interventions that reduce pain to improve quality of life as people age. This might especially be the case in the over 50s, who have the highest prevalence of chronic pain.

In terms of the research questions, there appear to be sufficient grounds for further research and we could recommend that all intervention studies are appropriately designed to investigate differences in both pain and quality of life.

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"Community pharmacists are one of the most accessible healthcare professionals for the public. Pharmacists, working in collaboration with doctors and other healthcare professionals, have an important and expanding role in optimising the use of medicines and in supporting better health."

Main workplace/Organisation
University of Nottingham

Profession/Function
Associate Professor in Clinical Pharmacy Practice

The role for the pharmacist in supporting patients with persistent pain

Roger has a longstanding interest in pain management which began when studying for a doctorate in opioid pharmacology. For nearly ten years, his main role was to provide a clinical pharmacy service to the Anaesthetics directorate and the Pain Management Service and also has Trust-wide responsibility for handling and administration of Controlled Drugs, including opioids. In collaboration with medical colleagues in Nottingham he is an integral member of multidisciplinary team and has a clinic to support appropriate medication use. In September 2011, he was appointed to a new academic position that provides teaching and research opportunities whilst maintaining regular clinical practice.

Medicines have the potential to transform people's lives, add enormously to life expectancy, and may transform health service outcomes and delivery. Analgesics are prescribed frequently for the management of chronic pain but sub-optimal, and sometimes inappropriate, use of analgesics is documented among chronic pain patients. Pharmacist-led interventions may promote the safe and effective use of medicines, both those bought over the counter by consumers and those prescribed analgesics. Given limited healthcare resources and the changing population demographic it is imperative that better value in the use of medicines is obtained through better informed and more involved patients.

In a collaboration between the UCL School of Pharmacy and the United Kingdom Clinical Pharmacy Association Pain Management Group published a report "Persistent Pain: Improving Health Outcomes" in January 2012 (see http://www.ucl.ac.uk/pharmacy/documents/news_docs/Relieving_Persistent_Pain). The report highlights a potential opportunity for pharmacists to improve patient care for patients with persistent pain, whether in primary or secondary care.

More widespread use of pain assessment instruments in primary care may assist in identifying the transition from acute to persistent pain and where early treatment and intervention may improve outcomes. Published together with the report are ''Eight 'LESS PAIN' questions to discuss with your pharmacist when you are troubled by pain", the opportunity for pharmacists to have a structured discussion with patients who either have chronic pain or are at risk of developing chronic pain about their condition and the impact on their lives.

Community pharmacy based services could play a key role in extending access to effective pain relief via supporting the appropriate use of all types of medicines by undertaking regular reviews of analgesic medicines and patient education, and facilitating access to other non-pharmacological therapies for pain management, including physiotherapy and cognitive behavioural therapy, that may complement use of analgesic medicines.

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"Pain continues to be a leading health problem and several recent epidemiological surveys have consistently shown that the overall prevalence of chronic pain in the general populations is around 20%. The research of my team focuses on clinical and experimental aspects of peripheral nerve disease and mechanisms of pain. Our goal is to translate the knowledge obtained from experiments of animals and healthy human volunteers to clinical practice in patients with neuromuscular disorders."

Main workplace/Organisation
UCL

Profession/Function
Professor of Clinical Neurophysiology

Martin Koltzenburg, FRCP

Martin Koltzenburg is Professor of Clinical Neurophysiology at UCL, head of the Department of Clinical Neurophysiology at the National Hospital for Neurology and Neurosurgery at Queen Square and Deputy Director of the MRC Centre for Neuromuscular Diseases. After medical school in Kiel, Germany and UCL he was postdoctoral fellow in the Department of Physiology, University of Erlangen, Germany and visiting fellow in the Department of Clinical Neurophysiology, Uppsala, Sweden. He received his specialist training in Clinical Neurology in the Departments of Neurology and Psychiatry, University of Würzburg, Germany where he sub-specialised in Clinical Neurophysiology.

The focus of his clinical work is the diagnosis and treatment of neuropathic pain. These investigations involve clinical neurophysiology, quantitative sensory testing and magnetic resonance imaging of peripheral nerves and skeletal muscle. His basic science research investigates the properties of sensory neurons that signal pain. This includes the analysis of how specific subpopulations of pain signalling neurons emerge during early embryonic development, how they function in normal life and how changes of their properties lead to chronic pain.

He has published over 100 articles in journals and textbooks and is editor of several books on pain including Wall and Melzack's Textbook of Pain, the standard text in the field.

Main workplace/Organisation
Charité - University Medicine Berlin

Profession/Function
Department of Anaesthesiology and Intensive Care

Pain Management in the Medical School

A number of diseases have pain as a leading symptom. Pain is one of the most prevalent symptoms, why patients consult a physician. Therefore all physicians (and nurses, psychologists, physiotherapists) should have basic knowledge about pain management. This is especially true since pain management of cancer and acute pain is rather simple to achieve for the majority of patients with well validated treatment algorithms.

Although in the last decades a multitude of educational initiatives have been undertaken to raise awareness regarding pain and to promote pain management algorithms, studies still show a considerable shortage of adequate pain management. Therefore the strategy should be to foster the implementation of pain management in medical schools to ensure that all medical students graduating have basic knowledge regarding the diagnosis and treatment of frequent pain syndromes.

It is also of importance to realize, that outside Western Europe, Northern America and few other regions of the world, pain management is not a priority. That is a sad truth, since the relieve of symptoms matters even more in underdeveloped health care systems where causative treatment is unavailable or rudimentary. The key to success in these health care systems would be also medical school teaching of pain management essentials as well as opioid availability.

The IASP and EFIC, as well as several chapters of the IASP and EFIC have started to address these needs and have developed a student core curriculum for pain management as well as educational material and initiatives for high and low resource settings. The presentation will focus on teaching contents and tools suitable for pain management in medical schools.

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"Pain Management should not be restricted to specialists, but general knowledge should be available to all practitioners. Integrating pain management into the medical school curriculum is seen as a prerequisite for this."

K

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"Chronic pain may sometimes be considered a predominant symptom of another ongoing chronic disease, such as osteoarthritis or cancer, but chronic pain can also be a disease in its own right!"

Main workplace/Organisation
Dept. of Special Anaesthesia and Pain Therapy

Profession/Function
President EFIC® (European Federation of IASP® Chapters)

Chronic Diseases: Chronic Pain as a disease in its own right

While acute pain, such as that following an injury or surgery, is a direct outcome of the noxious event and thus a useful biological signal to the individual of the imminent danger, chronic pain usually persists for a longer period of time, when the usefulness of the alarming symptom has long passed.

Chronic pain is therefore not always only a result of an ongoing chronic condition, e.g. diabetes, cancer or osteoarthritis, but can become a disease in its own right that must be treated independently like any other disease of the nervous system. As a consequence, chronic pain should also be represented as a disease in the new ICD 11, and the various types of chronic pain should be reflected by respective subcategories.

Chronic pain induces a complex set of physical, psychological and also social changes to the individual patients and their social environment, respectively. Chronic pain thus imposes a huge substantial burden, both on the individual and on society at large including enormous economic costs for health care systems. It is not only that the indirect consequences and costs of inadequately treated chronic pain have been underestimated or even neglected in the past, the national governments spend only a small portion of their health budget on understanding chronic pain or how to effectively prevent and treat it.

Chronic pain is a disease that affects more people than heart disease, diabetes and cancer combined, but interestingly enough, chronic pain is still not adequately recognized by politicians and the public as a real challenge to social security and health care systems of industrial societies. One reason for this might be that the whole variety of chronic pain syndromes is hidden behind more 'traditional' diagnostic and patho-morphological categories of organ-related diseases.

This 3rd European symposium on "Societal Impact of Pain" offers a platform for all stakeholders involved and aims at these issues. It provides a forum for presenting facts, defining the unmet needs, developing and exchanging new ideas and bringing the issue of chronic pain to a more general public awareness.

About Professor Hans G. Kress
Hans G. Kress is Professor of Anaesthesiology, Intensive Care and Pain Medicine at the Medical University/AKH Vienna, Austria. He is certified by the Austrian and the German Board of Physicians, with added qualifications in pain management, critical care medicine, and emergency medicine.

Professor Kress is President of the European Federation of IASP Chapters (EFIC). He was founder of the Task Force on Pain Management for the Austrian Society of Anaesthesiology, Resuscitation and Intensive Care Medicine, co-founder and board member of the Austrian Society for Palliative Care, and Past-President of the Austrian Pain Society, where he is now a board member.

Professor Kress is Editor of the Change Pain News & Reviews Journal, Deputy Editor of the high-ranked European Journal of Pain and former co-editor of Acute Pain. He has authored numerous scientific articles, books and book chapters. His multiple clinical and experimental research interests include pharmacological treatment of acute and chronic pain, invasive pain therapy and neuromodulation in cancer and noncancer patients.

Main workplace/Organisation
Société Française d'Etude et de Traitement de la Douleur (SFETD)

Profession/Function
SFETD President

The four French national Program of actions for the management of Pain

Since 1998, French Authorities supported pain topic with three governmental pain programs (1st 1998-2001 / 2nd 2002-2005 / 3rd 2006-2010). Following an evaluation of the last governmental pain program performed by an independent committee involved in Public Health (Haute Comité de Santé Publique), French Authorities decided to set up a further national pain program. The French Health Ministry is the pilot of this project in partnership with French Pain Society (Société Française d'Etude et Traitement de la Douleur), French Anaesthesiology Society (Société Française d'Anesthésie-Reanimation) and the associated professors in pain management recently nominated by French University. This 4th national pain program will be declined considering procedural pain, acute pain and chronic pain.

Its objectives will be :

I) quality of pain prevention and pain management in primary care with a best cooperation between primary care actors and pain centres;
II) development of pain management in mental health domain;
III) promotion of pain education for health professionals and population;
IV) support of clinical and translational research in pain. Finalisation of this new national pain program is currently in a multi-professional and multi-disciplinary process by auditions of several representative French health professional organisations with the aim to define best actions that will be include in the four program axis. Final draft of this national pain program will be officially presented between July and September 2012 after validation by the new French Health Ministry.

Upcoming meeting: November 21-24, 2012, Lille, The 12th Congress of the SFETD

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"Set-up of a new national pain program confirms involvement of French Authorities in the pain topic."

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Main workplace/Organisation
CEDR (Cercle d'Etude de la Douleur en Rhumatologie)

Profession/Function
Doctor

Chronic pain and therapeutic patient education; does it work?

Therapeutic patient education (TPE) has never been evaluated among chronic low back pain patients. However, many publications have shown that multidisciplinary approaches are efficacious. There is no specific international guideline. However, NICE has suggested to take into account patients' expectations and preferences. TPE establishes an exhaustive evaluation during an educational diagnosis. Therefore, an appropriate treatment program, including pain coping strategies, may be proposed to each patient. Indeed, patients need to be active and should be involved as much as possible in a share medical decision. This may be a major condition of success. Many efficient tools are available, such as information, re-learning, reformulation, activity-exposure, problem solving…

Indeed, educational objectives are to make the patient more active and autonomous. Different modalities are available; individual or collective education, training workshops focused on one specific objective, relaxation, medication self-management.

Main workplace/Organisation
Liga Reumatológica Gallega (LRG)

Profession/Function
President

Liga Reumatológica Gallega (LRG)

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The Galician Rheumatologic League (Liga Reumatolóxica Galega – GRL) was set up in 1996 to become the collective rheumatologic patients' voice at Galician and Spanish level. The ultimate objective is helping improving the quality of life of the people with rheumatic illnesses. For these reasons, GRL, is an entity created with the aim of providing support, information and counselling to people suffering from rheumatic illnesses and their families. Also it aims to support research into these types of conditions and raise the awareness of society.

The GRL adopts in its services a global interpretation of healthcare, to include the individual, social and economic burden of rheumatologic diseases.

Currently, we have three local offices in Galicia: Pontevedra, A Coruña and Lugo.

Since the foundation in 1996, our activities have been aimed at improving the quality of life of those afflicted with any type of rheumatic illness. RGL is seen as a patient association that really cares for the patient and offers considerable value-add patients services. RGL is member of the committee on pain and chronic disease in Galicia. It also participates in national advisory committees, being a reference partner with Public Sector.

The Rheumatologic League represents an important role in order to increase the awatreness about the burden of rheumatic diseases and to encourage research into the causes of such illnesses and the new treatments developed to combat them.

The Association currently has 550 people in Galicia.

General Objectives
To improve the quality of life of both those suffering from rheumatic illnesses, and their families.

Specific Objectives
- To help people with rheumatic illnesses and their families in what refers to the confusion, fears and doubts caused by the illness, by providing them with the means to solve the difficulties their illness brings about.
- To offer clear and intelligible information about rheumatic illnesses and the areas affected by them (social, psychological, labor, legal and economic)
- To provide psychological and social support.
- To learn from being in contact with others who live in similar situations and find other ways to face the illness.
- To raise the awareness of society and the public opinion in relation to rheumatism.

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"I have been supporting the SIP platform since the first symposium in 2010 ensuring continued support for the development of well-written, succinct and informative reporting of the symposiums, workshops and projects. I am looking forward to this year's outcomes at SIP 2012 and the international collaboration for optimal and timely reporting of these."

Main workplace/Organisation
Freelance journalists

Profession/Function
SIP 2012 Proceedings Reporter & Editor

Ensuring well-written, succinct and informative reporting on the "Societal Impact of Pain" for Europe

Andrew is a freelance broadcast journalist with many years of experience working for the BBC, swissinfo.ch and Austria's national broadcaster, ORF. His background is in 'live' audio production, presenting and feature-making. Andrew attended SIP 2010 & 2011 and edited both Societal Impact of Pain publications from these conferences in Brussels. Most recently, he helped compile the booklet for Europe's first Road Map Monitor. This year Andrew will again write-up and edit presentations from particpating speakers at each plenary session. He will also support and advise all proceedings reporters during and after SIP 2012 to ensure well-written, succinct and informative reporting from the various workshops attended by delegates.

Additional information
Andrew is editor of the Swiss Review, an English magazine for the Swiss community living abroad. He is also a media consultant, training business managers how to spot newsworthy stories within their organisations and, most importantly, how to get their message across with aplomb in media interviews. During his time at the BBC, he produced many of the network's flagship programmes and worked extensively on its daily and weekly output. Andrew contributes audio and print reports on a regular basis to swissinfo.ch, an entity of the Swiss Public Broadcasting Corporation.

Training and development have always played a central role throughout Andrew's career. He has spent time in Kathmandu training journalists to conduct live phone-in talk shows focusing on Nepal's peace and political reform process. He also teamed up with more than fifty journalists from developing nations to report from the UN Climate Change Conference in Poznan, Poland. Working for the NGO Panos London, which promotes media projects for marginalized communities, he has worked closely with reporters in Africa and South-east Asia to help raise their level of feature-making skills.

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Main workplace/Organisation
The Patients Association

Ms Ann Lloyd CBE

Ann Lloyd was appointed as Head of Health and Social Services for Wales in 2001. She was the chief advisor to the Welsh Government on all health and social care policy. Her role was extended in 2003 to include the position of the Chief Executive of NHS Wales, becoming accountable for a budget of £5.8 billion per annum and a staff of 96,000. She retired from this position in 2009, taking up the position of the Health and social care appointments Commissioner for London.

Prior to her appointment in Wales, from 1988 she was the Chief Executive of Frenchay health care NHS Trust and its successor organization, North Bristol NHS Trust.

During this time she was the CEO representative on the CMOs advisory committee on medical education training and development and chaired the overseas doctors' subgroup. She was also the Chair of the Avon, Gloucestershire and Wiltshire education consortium and the chair of the SW executive development consortium.

She was educated at St. Asaph Grammar School, University of Wales, Aberystwyth and University of Wales Cardiff. She is a Companion of the Institute of Healthcare Management and a Fellow of the Royal Society of Medicine. She was awarded the honor of Commander of the British Empire for her work in Wales in 2008.

She is currently a Trustee of Shaw Trust and the patients Association and a member of the Policy Board of the Good Governance Institute.

Her particular professional interests are in organizational development, management standards, the management of change and the governance of public institutions. She is a qualified mentor.

Main workplace/Organisation
Liga Portugesa Contra as Doenças Reumáticas
(Portuguese League Against Rheumatic Diseases, LPCDR)

Portuguese League Against Rheumatic Diseases

The Portuguese League against Rheumatic Diseases (LPCDR) was founded in 1982. The aims of the organisation are:

- to raise awareness about rheumatic diseases
- to campaign for equal rights and treatment
- to improve the quality of life for people with arthritis
- to promote contacts with fellow patients, and
- to promote contact with fellow organisations.

The types of rheumatic diseases that are represented by the organisation are the following: rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, juvenile arthritis, fibromyalgia, lupus (SLE), scleroderma, vasculitis, sjögren, Behçet disease, osteoporosis and lumbago. The organisation has no local branches and it is run by one member of paid staff, volunteers who are people with rheumatic diseases and rheumatologists. Total number of members is approximately 500 individual members.

The most important topics for the organisation in the coming years are:

- Fundraising
- Extending the network of volunteers
- Acquiring expertise in certain areas

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"The LPCDR is a non-profitable social entity that associates rheumatic patients, their relatives and friends, health professionals and other singular and collective persons."

Main workplace/Organisation
ULSS 7 - Pieve di Soligo

Quantitative and qualitative analysis of the use of the opiates and satisfaction of recruitment standards of Palliative Care. Measurement of efficacy of the network of Palliative Care and Pain Control in the Local Health Authority No. 7 in Veneto

In Italy the percentage of access to palliative care and pain management are not in line with expectations. Compared to European average of 25%, only 16% of cancer patients has received an effective treatment of pain. The latest national law in 2010 stated standard measures to ensure access to palliative care and pain therapy. The Local Health Unit n° 7 of Veneto (Italy), according to this legal issue, started in 2005 a Palliative Care Team for home cares. The team recorded pain intensity (numeric scale) and therapeutic strategies applied to single patients from 2005 to 2011.

In 2011 the Palliative Care Unit recruited 63% of patients, who can spend at home 90% of the treatment time. From 2005 to 2011 the use of the main opiates in the Local Health Unit territory has increased from 1,16 DDD/inhabitants/day in 2005 to 3,25 DDD/inhabitants/day in 2010. The data of the first half of the 2011 marked the value of 3.52 DDD/inhabitants/day, confirming an increase of about three times of the starting value. The Palliative Care Unit increased the intake of the terminally ill patients from 50 in 2006 to 353 in 2011.

Referring to the distribution of the molecules used, the qualitative analysis was consistent with the EACP recommendations.

The implementation by the Local Health Unit No.7 of the statutory model expected by the Law 38/2010 has led to an increase in the recruitment of patients in the palliative care network and a correct use of opioids. This can be considered a proxy measure of care quality and equity.

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"In Italy the Law 38/2010 recently established a network model for palliative care and pain management. This has led to an increase in the recruitment of patients and in an improvement in correct use of opioids."

L

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"Getting a high quality treatment is an important right for every patient."

Main workplace/Organisation
Praxis Doktor-Ludwig

Profession/Function
Oncologist (specialist in gynaecology)

Outlook on future pain management

Particularly with regard to the demographic transition the health care system has to face a huge challenge: cost saving vs. the best available treatment. Unfortunately we can observe that cost saving is much more in focus of sick funds and policy than high quality treatment of patients.

Against this background it is very important, that the different professional groups of physicians collaborate with each other to avoid any mistreatment or double investigations. Particularly oncologists which I belong to should accept pain as a separate disease which needs a professional and high quality treatment.

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"In 2010, the Galician Health Service (SERGAS) set forth the "Integral Pain Care Strategy" within the Strategy "SERGAS 2014. In 2011 pain evaluation as a fifth vital sign is implemented in all 15 hospitals belonging to the Galician Health Service."

Main workplace/Organisation
Galician Society of Pain and Palliative Care (SERGAS)

Profession/Function
Quality Programs Manager

Pain as the fifth vital sign in Galicia: overcome challenge

In 2010, the Galician Health Service (SERGAS) set forth the "Integral Pain Care Strategy" within the Strategy "SERGAS 2014: public healthcare at the patient's service".

In 2011 pain evaluation as a fifth vital sign is implemented in all 15 hospitals belonging to the Galician Health Service, including the Visual Analogue Pain Scale in the vital signs chart within the Management of Care Application (GACELA) data record. The following standard is then decided and included as an objective in the management contract which is signed by all hospital directors: that 50% of all in-patients have a pain evaluation register in their vital signs chart.

On February 7, 2012, the Galician Ministry of Health published in its Official Journal of Galicia, the creation of the Galician Commission on the Strategy Against Pain (Decree 60/2012, dated 26 January). The Commission is a collegiate organ of a permanent and consultative nature, attached to the office of the Director General of Health Care. The purpose of this Commission is to improve integral care policies on pain in the Galician Health Service. Patients participate in this multidisciplinary Commission as full members.

Results: In 2011 there were 220 706 in-patients. Pain was registered as a fifth vital sign in 71 235 patients (32.3%): 18.4% in the first quarter, 26.8% in the second quarter; 30.2% in the third quarter and 44.9% in the last quarter. 22 075 patients had a complete qualitative pain follow-up in the GACELA Management of Care Application.

Of all in-patients who had a pain register, 21 477 suffered pain with VAS value > 0 (30.2%). Of these, 58% were female (43.4% age > 60) and 42% were male (57.3% age > 60). 12 390 (59.7%) patients had mild pain (58.2% female, 43% age > 60 and 41.9% were male, 58.6% age > 60); 7 680 (35.8%) patients had moderate pain (58.9% female, (43.6% age > 60 and 41.3% male 55% age > 60); 1 407 (6.6%) patients had acute pain (53% female, 45.7% age > 60) and 47% male, 57.5% age > age 60).

In 34.4% of patients, pain was due to a health illness, 24% due to surgery and 14.4% due to traumatisms. 79.8% of patients had localized pain where the abdomen was the main localization 36.1%, extremities 26.7%, head/neck 12%, back 8% and thorax 7.2%.

The most frequent associated symptoms were nauseas/vomiting 5.7%, weakness/paresthesia 3.5%, infection signs 3%, sweating 2.6%, fever/sweating 2.5%, hematoma/hemorrhage 1.7%. Intermittent intravenous analgesia was administered in 52.7% of cases and oral analgesia in 23.8%; 10% were not prescribed analgesia and 6.4% did not require analgesia. Pain ceased with analgesia in 45.6% of patients and diminished in 32.2%. 3% required rescue analgesia.

Conclusions: Near one third of all in-patients suffer from pain, more so in females over 60 years old. The implantation of the pain evaluation procedure has allowed us to become aware of the real situation and thus put forth actions in order to improve health care procedures.

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"Sean will be acting as a co-rapporteur for Workshop 1, asking whether or not pain is a disease in its own right."

Main workplace/Organisation
Pain UK

Profession/Function
Chair

Chair, Pain UK

Sean McDougall is Chair of Pain UK, an alliance of charities supporting people living with pain.

The aims of Pain UK include:

- Improving the efficiency and effectiveness of member charities
- Working with others to provide a strong voice for people living with pain and to improve understanding of pain as an issue in its own right
- Providing support to individual people living with pain

Founding members include BackCare, the Fybromyalgia Association, Migraine Action, the Migraine Trust, the Pain Association Scotland, Pain Concern, the Pelvic Pain Support Network and the Trigeminal Neuralgia Association.

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"PAIN OUT is a research project that aims at providing the medical community with a unique, web-based, user-friendly system to improve post-operative pain treatment. This includes a registry, tools for data collection, feedback and decision support."

Main workplace/Organisation
University Hospital Jena

Profession/Function
Head of Pain Unit and Palliative Care

About PAIN OUT

PAIN OUT is a research project designed to develop effective, evidence-based approaches to improve care of pain in patients after surgery (www.pain-out.eu). Launched in January 2009, with four-year funding from the European Commission's (EC) 7th Framework Program, PAIN-OUT involves 17 clinical and research partners in 9 European countries. PAIN OUT is creating an Acute Pain Registry and is developing tools for data collection, feedback and decision support. It will provide the medical community with a unique, web-based, user-friendly system to improve treatment of patients experiencing postoperative pain. Furthermore, it will provide a large platform for observational and prospective research.

PAIN OUT will feature three principal functions for participating hospitals:

- The feedback and benchmarking module will provide participating sites with continuously updating patient-reported outcomes and analyses about the quality of care they currently provide compared to their performance in the past and that of other participating institutions wards treating similar patients. This allows identification of 'best clinical practice'.
- A Clinical Decision Support System for Post-Operative Pain which responds to queries made by physicians for advice regarding treatment of individual patients
- A Knowledge Library which provides clinicians with easily accessible and updated, summaries of evidence-based recommendations tailored to specific post-operative situations.

PAIN OUT relies on experience gained from the German Post-operative Pain Registry (QUIPS), which tracks postoperative outcomes and related data, operating for the last 6 years, in over 140 hospitals, with over 200,000 records.

PAIN OUT is endorsed by the International Association for the Study of Pain. In 2013, PAIN-OUT and QUIPS will be merged and participation will be possible for hospitals from all over the world.

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Main workplace/Organisation
Haute AutoritéSanté (HAS)
Profession/Function
Director and advisor to the President, International Affairs
(Conseiller du Président, affaires internationales)

Dr François Meyer – Haute Autorité Santé (HAS)

In 1984, Dr. Francois Meyer received his MD from the University of Montpellier Medical School in France. He became a specialist in Endocrinology and Metabolic Disorders.

Till 1992 François Meyer worked in Montpellier teaching hospitals. From 1989 to 1992 he also had a part-time private practice.

For five years, from 1992 to 1997, he worked in the R&D department of a pharmaceutical company, initially as a medical sponsor and, from 1994 on, as Group Leader of Oncology.

In 1997, he became Deputy Director in charge of Medical Affairs in the Medicines Evaluation Department at the French Medicines Agency. As the French representative, he was member of the EMA's Committee for Orphan Medicinal Products (COMP) between 2000 and 2002.

In 2005 he then joined a new public independent body, the French National Authority for Health (Haute Autorité de santé, HAS), with the mission to set up the Health Technology Division of this institution. He was Director of this HTA Division till 2011, and was then given the responsibility of heading the international activities of HAS, that are numerous in the field of Health Technology Assessment, Quality of Care and Patient safety.

HAS' missions
HAS' missions are defined by government decree (see Legal texts). Currently, its main missions are:

1. To provide health authorities with the information needed to make decisions on the reimbursement of medical products and services.
2. To encourage good practices and the proper use of health services by professionals and users.
3. To improve quality of care in health care organisations and in general medical practice.
4. To provide information for the public and generally improve the quality of medical information.

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Main workplace/Organisation
Suomen Kipu ry – Finnish Pain Association

Profession/Function
President

Chronic pain is a disease from a patient's point of view

Pain came into my life in 1998 just when I was graduating from the University of Plymouth to start my dream work as a M.Sc. international logistic. My life and plans collapsed at the same time with slipped disc. Having pain and at the same time locking up to the rat race of having the right treatment, rehabilitation and not forgetting financial issues were a hard course in the University of Life.

It was sadder than funny to realize that my body has its own life as pain didn't care about what I tried to do. Operations, medical and mental rehabilitation helped a little bit, but the pain stayed and became chronic. At some time pain becomes the core problem. Chronic pain became the one thing which doctors treated and the one thing which tries to control my everyday life. Pain wasn't a symptom anymore. It became a disease of its own.

The Finnish Pain Association (Suomen Kipu ry) was the answer to my question what I could do with my life now. Chronic pain affects you all the time and disables normal life and working. Important elements of the Finnish Pain Association are information, skills and a willingness to help so the aims and principals were easy adapted.

The association strives:

- to improve the conditions of people living with chronic pain by decreasing stigma and increasing the knowledge of pain
- to develop cooperation with home, work, environment, politicians and especially with healthcare organizations
- to act as an advocate for the people with chronic pain
- promote pain research, treatment and rehabilitation
- to inform about various issues related to pain
- to develop support group activity together with public healthcare

I became an active member of the association in 2002 and acting President from 2005 till present day. I also started as a board member of the Pain Alliance in Europe (PAE).

"We seem to agree that pain has a negative impact on the patient's and his/her close ones in life, but nothing happens. Chronic pain is just a word, even not so nice one, to them whose life it does not effect. When chronic pain affects you all the time and disables normal life and working it is a disease from a patient's point of view."

M

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"The fact that pain in many cases becomes a disease of its own, no matter the initial cause, calls for a different perspective and approach. We have to stop the predominant way of solely focusing on finding a physical cause, thus postponing the treatment. We need action plans and put an end to the dualistic mindset and structure of the health system. We need to stop wasting money and life quality."

Main workplace/Organisation
The Danish Association of Chronic Pain Patients (FAKS)

Profession/Function
Boardmember, Managing director of youth department

Lars Bye Møller. Pain patient. Board member. Managing director of the youth department. Writer and photographer.

It never stops to amaze me, the ability of the human mind to put behind things that hurt too much to remember. When I think about it my whole situation and the course of events it seems so absurd and out of this world that it is almost comical. Anyway, laughing is sometimes a natural way to cope with tragedy.

The pain started back in 1998 when I was 19 and in high school. I always loved sports, and I was doing all kinds - windsurfing, skating, hockey, swimming etc. One day when bicycling, I suddenly felt a strong burning, cutting pain in my shoulder. The doctor just told me to go home and relax, however, the symptoms soon spread to the other shoulder as well.

Two years after, returning from windsurfing in Australia, I was out windsurfing when pain struck again. Landing a high loop, I felt a first tingling then burning and cutting pain only this time in my forearm and much worse.

Not getting any help, I tried to cope as good as I could, living a normal life despite the never ending pain. In retrospect, had a really bad GP that did not take me seriously or take the time to understand my situation. Finally, when I was send to different specialists, they too did not take me seriously.

3 years without any pain medication really started to take a tool on me. I did not sleep, and had a hard time doing basic everyday things. Losing my faith in the system and slipping into a depression, I turned to alternative medicines. I was desperate and an easy target. I spend a small fortune, and, finally, had a massive anxiety attack when I was given some capsules with herbs. I was committed to a psychiatric unit, was pumped full of anti-depressants, and I was given electroshock therapy. The whole time, I was begging for something to stop the pain. I was desperately trying to make the psychiatrist see the big picture, but in vain.

In 2004, for the first time in 6 years after the pain had started, I finally got some pain medication; Simply by mere coincidence, I ended up at a doctor who gave me pain killers. A year after, I was diagnosed with fibromyalgia and in 2006 I got a pension. It has taken me a long time to get back on my feet again and lead a somewhat normal life.

Working in FAKS - The Danish Association of Chronic Pain Patients - has given me hopes for the future. I am not alone anymore and that gives me comfort. It is so easy to get lost in the health system if you do not have someone to fight for your rights when pain throws you off your feet. Treatment of pain is too random, and the outcome very much depends on share luck and your ability to navigate through the system. We need to improve today's standards of pain treatment with action plans, specific education of professionals, and general enlightenment of the public.

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"Increasing the training of nurses in pain, improving care and facilitating the well-being."

Main workplace/Organisation
Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP)

Developing Pain Education for nurses by nurses

Increased life expectancy leads to a greater number of life years gained, and simultaneously leads to an improvement of chronic problems that may be presented with pain.

Disabling pain, retracts, paralyzes... isolates people from their world of relationships, their careers, their reason for being and living. This is something that is well known by nurses, particularly those working in Family and Community Care, in Spain over 80% of these patients are seen in primary care. Their proximity to patients and their global and integral vision of the person outlines nurses as important professionals in the approach and management of pain, in the context of a multidisciplinary team.

In order to improve the quality of life of individuals, nursing interventions must respond to the needs of patient care in regards to pain. This requires the constant improvement of nurse training especially in this specific and extensive field.

Although we found no significant studies on specific training in the field of pain for nurses, if we look at the work of Dr. Lynda Ayken it demonstrates that increasing specialization of nurse training, does not only influence the quality of care that the patients receive and decreases morbidity, but it also directly affects the mortality of patients. This supports the recommendations of the American Association of Colleges of Nursing to increase the level of training of nurses with the aim of improving patient safety and provide better quality care.

In the current economic crisis we want to emphasize the study of S. Donnas Havens, who speaks of the importance of the reorganization of nursing services to provide "better service" whilst saving costs without sacrificing quality. The study states that besides training, the best results are obtained when nurses are autonomous to apply their knowledge when they have available resources and when relationships with fellow doctors are good. The U.S. has credited and identified these services for nursing excellence.

Looking to continue the improvement of nursing interventions in Spain, the study ENEAS on Adverse Events (AE) related to incidents of care that caused harm to the patient, showed that 20.6% of AE occurred in pre-hospitalization, of which 34.8% are due to medication errors. In both situations, the nurse may be the key professional in patient education and in self-care support (management beliefs, dosage, side effects, interactions, capacity...).

Therefore, we need increased training and skills in pain management for nurses and by nurses, continuously, which is accredited and accessible.

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"The Pain Toolkit organization is an educational and training organization working mainly in primary, acute and social care promoting active self-management to help and support the reduction of persistent pain."

Main workplace/Organisation
Pain Toolkit
Profession/Function
Author of the Pain Toolkit & Senior Pain Toolkit Trainer;
Supporting doctors and patients in pain self-management

Pain Toolkit

Modern day thinking is not just around what the doctor can do for the patient, but also how the patient can be part of the decision making process as to what treatment is available and also what part the patient has in also managing their pain. It simply is a team-work approach. The doctor and the patient work together as a team in the management of the pain.

Main workplace/Organisation
Northgate Surgery
Profession/Function
Drogheda based G.P. with a special interest in Orthopaedic Medicine and the management of pain within a Primary Care setting

When Listening Helps

By nature I am a mechanic. I love understanding how machines work, and especially cars. My first interest in medicine was orthopaedics. I find remarkable similarities with the body and mechanics. In general practice I developed an interest in orthopaedic medicine, but as this did not provide all the answers I and my patients needed I became involved in pain medicine. And as I observed patients with pain, I observed their depression, their mood and the ways they communicated not only with me, but with themselves.

So why is communication with yourselves important?

Think of a time when someone is late…Do you assume they are enjoying themselves and forgot the time, or do you think there has been an accident. Were you right or were you wrong? And how often does this happen.

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"Are we there yet? Some of us may be closer than we think."

M

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"Adequate pain management is a prerequisite for healthy ageing. Therefore, general awareness, broad education and the establishment of professional structures are needed."

Main workplace/Organisation
EFIC / Belgian Pain Society

Profession/Function
EFIC Counciller / President Belgian Pain Society

Ageing with pain is not very healthy!

Over the last decennia life expectancy has increased significantly in our European society. However, for many elderly a longer life is not accompanied by a longer life in quality. Many elderly are more afraid of pain than of impending death. So awareness for pain and assessment of pain in the elderly should be promoted. Education of caregivers at large is needed. In addition, a professionalized setting and network of specialists in pain can catalyze and promote actions towards effective management. The European Union promotes healthy aging. Pain is an important obstacle and associated with many comorbidities. Ignoring pain in elderly is not healthy. The SIP initiative is an ideal forum to bring together all the stakeholders and advice the EU.

Background: Bart Morlion is director of the multidisciplinary pain center at Leuven University. Since 2006 Bart Morlion has been the President of the Belgian Pain Society – the Belgian Chapter of the International Association for the Study of Pain (IASP) and represents Belgium as counciller in EFIC – the European Federation of IASP Chapters. He steers the Organizing Committee of the Belgian Interuniversity Course of Algology and is also an active member of several committees in international scientific societies: chairman of the EFIC website committee, editor-in-chief of EFIC newsletter, member of the editorial board of the European Journal of Pain Supplements and member of the IASP membership committee.

Bart Morlion teaches pain management at the Leuven University and several higher institutions. He has given more than 350 international and national invited lectures and seminars on pain management, and has authored a number of primary manuscripts, reviews, books and book sections. He is a regular reviewer for several international journals. His professional interests include all aspects of multimodal chronic pain management, analgesics, and quality management.

Main workplace/Organisation
The University of South Australia – Sansom Institute for Health Research

Profession/Function
Body in Mind Research Group

Politics or science? Is chronic pain really a disease?

Pain emerges into consciousness when the body seems to be under threat and action is required. Almost anything that provides credible evidence that body tissue is in danger can modulate or evoke pain. Nociception is neither sufficient nor necessary for pain, although many hang on to the erroneous theory that nociceptors are pain fibres. Patrick Wall lamented the massive problems with this theory in 1986 - 'the mislabeling of nociceptors as pain fibres was not an elegant simplification but a most unfortunate trivialization'. Now, I see the misconception that pain is an isomorph of tissue damage to be the most significant conceptual barrier to recovery from chronic pain.

There are similarities between the position lamented by Prof Wall, and the position we are now promoting, similarities that should warn us to tread carefully. Chronic pain is clearly associated with changes in the central nervous system, but by redefining chronic pain in terms of these changes, are we simply moving up the system, from peripheral tissue and nociceptors to central nociceptive pathways? On what grounds would we ask patients to delve into the many and various factors that might lead their brain to conclude that their body is in danger if we can 'locate' their pain anatomically after all? I contend that calling chronic pain a disease contradicts the IASP definition of pain; the idea that pain emerges into consciousness when the body is perceived to be under threat - that pain is the output, not the input. I unreservedly endorse the prioritisation of chronic pain as a major health and productivity problem, but the whispering in my heart is: 'If we 'rebrand' chronic pain as a disease, will the concessions we must make in our understanding and treatment of pain as a complex emergent human experience, be worth the political/funding gains it provides?'

Lorimer Moseley is Professor of Clinical Neurosciences and Chair in Physiotherapy at the University of South Australia & Neuroscience Research Australia. He has 20 years of clinical experience with patients with chronic pain. After appointments at Sydney and Oxford University, he now leads a team of 25 clinical scientists undertaking human systems research into the role of the brain and mind in chronic pain. He authored Explain Pain, which has been published in several languages and has sold over 50,000 copies. He was judged in 2007 by the IASP to be the outstanding mid-career clinical scientist working in a pain-related field. He has written 100 papers, three books and numerous book chapters on chronic pain and rehabilitation. He is convinced that people with chronic pain are outcast and disadvantaged by the dominant clinical paradigms and he wholly endorses the pursuit of better policies to decrease the massive burden of chronic pain to society and to individuals in pain.

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"To define chronic pain as a disease represents a fundamental redefining, and 'rebranding' of pain, which has clear political advantages, but I contend it is scientifically inaccurate and we should not be naïve about what the implications might be."

ENDORSING ORGANISATION SIP2012

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Recognition of pain as a disease in its own right not as a side effect and/or symptom. Empowerment of patients. Fair access to decent treatment. Establishment of a European frame of minimum standards of health assistance.

Main workplace/Organisation
Myeloma Euronet Romania (MER)

Profession/Function
President

Pain care in Romania

Health system in Romania is confronted with an unprecedented situation whereby, over the last 12 months, due to various reasons, the number of hospitals and medical doctors has decreased dramatically. Whereas the hospitals have been closed down due to bad management of the health system and obedient implementation of the IMF impositions, the medical doctors have chosen to work elsewhere in Europe for better salaries. Therefore, it makes medical assistance almost impossible for a great number of Romanians who find themselves in the awkward situation whereby they cannot benefit from services they paid for through medical insurance.

Main workplace/Organisation
Klinik für Anästhesiologie, Universität Bonn

Profession/Function
Head of Pain Centre, University of Bonn

The influence of health care services on the chronification of pain

The cost of health care in Germany is increasing year by year. The question however is whether more money yields to a better medical treatment. Especially patients with chronic pain often undergo a lot of invasive treatments before being treated by a specialist in pain medicine.

In Germany the number of X-ray investigations in patients with back pain increased about 70% in the last five years. The number of surgical interventions like lumbar nucleotomy or spinal fusion has risen two to three times in the last six years. So far there is no conclusive explanation for this tremendous increase.

One possible reason might be the payment for these procedures. The average proceeds of a simple spinal fusion are about 6000 Euros, for double or multisegmental spinal fusion the proceeds are more than 11000 Euros. Apparently the invasive pain treatment seems to be more profitable than noninvasive, multimodal pain therapy. Thus financial incentives might promote pain chronification.

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"The cost of health care in Germany is increasing year by year, however, the question is whether more money yields to a better medical treatment. Apparently, invasive pain treatment seems to be more profitable than noninvasive, multimodal pain therapy. Thus financial incentives might promote pain chronification."

N

ENDORSING ORGANISATION SIP2012

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"ANDAR is a non-profit, social and private institution; it's main objective is to widen and to ensure the rights of patients with rheumatoid arthritis to better treatment."

Main workplace/Organisation
National Association of Patients with Rheumatoid Arthritis (ANDAR)

National Association of Patients with Rheumatoid Arthritis (ANDAR)

ANDAR is a non-profitable organization, founded in 1995, with the special status of private institution of social solidarity.

ANDAR has as its main objective the defense of the interests of patients with rheumatoid arthritis, focusing on improving their quality of life and their social, family and labour integration, by spreading the knowledge and the means of prevention in the battle against this disease.

ANDAR promotes and conducts programs and actions deemed necessary to attain this objective, namely in the areas of prevention, information, education, social advice and scientific investigation. In order to support its activities, ANDAR promotes and markets products, equipments and technical help, as well as publishing magazines, books and other didactic materials.

Main workplace/Organisation
International University of Catalonia (UIC) and Spanish Patients Forum (SPF)

Profession/Function
Professor (UIC) and vicepresident (SPF)

Pain from the Spanish Patients' Forum perspective

Patients should be the main priority of health systems but, in order to accomplish that, health systems need to change in some aspects: patients' participation is the key element.

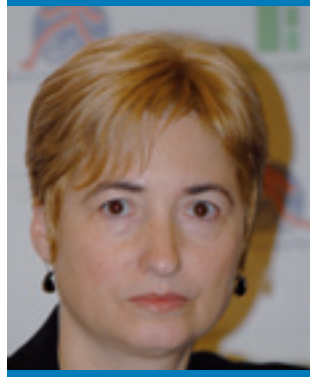
Currently, the population is gnerally better educated than it was decades ago, seeking for information about topics that are important for them and like to participate in the society. In turn, different groups of people come together and, through information technology and communication, share, contribute and participate in decisions about aspects that are important for them, including health.

The same happens with patients and their families. Being also part of the community, patients seek for information about their health condition. In this sense, the relationship between patient and health professionals has changed in recent decades, establishing a more deliberative kind of relationship in which the quality and easy to understand information plays an essential role.

In this context, the Spanish Patients Forum (SPF) was created with the aim to establish a permanent forum for patients organizations. Currently, it represents more than 1,100 Spanish patient associations and around 850,000 persons. Some of these organizations have first hand experience in pain issues and how pain is afecting quality of life.

People suffering from conditions like reumatological diseases, cancer, fibromialgia, or neurological pain, among others, face the need of being among the priorities of health systems. For that reason, it is important that patients participate in the decision making process. In order to do that, patients and relatives need to be informed and also trained about health and quality of life issues.

In this context, the SPF develops different kind of activities for patients, relatives, voluntary workers and people who are interested in health and health care related topics. Some of these activities focus on the improvement in the quality of health care, carrying out information kits, education on managing illness, and research activities, in order to ensure that patients and users of health care services have equal opportunities in health education and access to high quality medical care.



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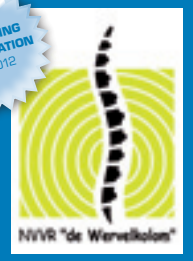
"Good and clear information is a key issue for patients in order to better manage the impact of pain in their lives. Patients are ready to participate in the decision making process along with their health professionals in order to reduce the societal impact of pain and improve quality of life."

N

ENDORSING ORGANISATION SIP2012



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"Méér dan een steuntje in de rug!" ("More than just a push in the right direction!")

Main workplace/Organisation
Nederlandse Vereniging van Rugpatiënten "de Wervelkolom"

Profession/Function
Voorzitter

Nederlandse Vereniging van Rugpatiënten "de Wervelkolom"

Goal
The association strives to look after the individual and collective interests of patients who suffer from back problems and to offer them support by:

- Providing advice, information and education;
- Preventing and/or breaking down social isolation and helping the members improve functioning in their daily lives;
- Creating more awareness about the research methods used on people which have complaints, which can lead to pointing out an ailment in the spine;
- Improving multidisciplinary collaboration between different relevant scientific, medical, paramedical and social sectors;
- Improve being able to recognize an ailment in an early stage in order to secure the independent functioning of a person in society as well as securing the quality of life as good as possible;
- Improving scientific research and improving the diagnostics and diagnostic instruments.

The association works together with other organizations and is part of an umbrella organization for, amongst others, lobbying. The association is affiliated with the Chronically Ill and Disabled Counsil ("Chronisch Zieken en Gehandicaptenraad" (CG-Raad)) and the Dutch Patients Consumers Federation ("Nederlandse Patiënten Consumenten Federatie" (NPCF) also participates in PijnPlatform Nederland (PPN)).

Main workplace/Organisation
Netherlands Interstitial Cystitis Patients Organization (ICP)

Profession/Function
Chairperson

Netherlands Interstitial Cystitis Patients Organization

The Netherlands Interstitial Cystitis Patients Organization (ICP) looks after the interests of IC/PBS patients. It is a non-profit organization that acts as a knowledge-base on IC and Chronic Pelvic Pain issues and helps raise awareness at national and international levels. IC and CPPS sufferers are brought together in different ways in order to exchange experiences.

The organization´s most important activities are:
- Stimulating contact between its members
- Providing patients, family members, health professionals and all interested stakeholders with up-to-date information about the disease
- Stimulating scientific research on the causes and treatment of the disease
- ICP is a member of CG-Raad, MICA, Eurordis, EAU, ICS, IAPO, EPF amongst others and is prominent in lobbying for IC-related issues at EU level in particular.

ENDORSING ORGANISATION SIP2012

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"ICP is currently lobbying both in the Netherlands and at international level for earlier diagnosis of IC/CPPS and for greater awareness of pain-related issues, especially in relation to chronic conditions management. We are keen advocates of clustering with like-minded organizations and advocating a multidisciplinary and multi-stakeholder approach to pain in general."

N

ENDORSING ORGANISATION SIP2012

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"We aim to improve the lives of people with severe illnesses through research and development, activities, advice and lobbying. Our members are people with neurological disabilities, their families and others who wish to support our work and have solidarity for our mission."

Main workplace/Organisation
Neurologiskt Handikappades Riksförbund

Neurologiskt Handikappades Riksförbund

About us
The Swedish Association of Persons with Neurological Disabilities is the association for persons with neurological diseases or injuries and their relatives and friends. In Sweden, over half a million people live with neurological diseases such as Multiple Sclerosis, Parkinson's disease, Stroke or ALS. We offer information, support and advice. NHR currently has around 14 000 members and 90 local branches.

NHR - The Swedish Association of Persons with Neurological Disabilities was founded in 1957. We were then the Swedish Associaiton of Multiple Sclerosis. Today we represent a wide range of neurological diseases and injuries.

Our mission
The Swedish Association of Persons with Neurological Disabilities adress our member's interests by influencing public agencies at various levels. One of our major goals is to improve the quality of Swedish neuroscience care.

As a service organization, we provide services when community resources are not sufficient. We organize workshops, courses, recreational trips within and outside the country, camping and family groups. We provide information, advice and help with practical problems. In everything we do we strive towards greater personal development and personal responsibility. Our local branches offer peer support and help, the possibility of exchanging experiences and social activities. Our goal is to break the isolation that otherwise threatens many of our members.

The Swedish Association of Persons with Neurological Disabilities:
- The key to a better life for half a million Swedish citizens
- The association for people with neurological disease or injury
- For the love of life and hope for the future

Main workplace/Organisation
90TEN Healthcare

Profession/Function
Healthcare communications consultancy

James Osborn & 90TEN Healthcare

90TEN is an award-winning healthcare communications consultancy that offers public relations, medical education and government and public affairs.

Established in 2001, 90TEN is owned and run by its founders, Paul Tanner and Carole North. An active member of the Healthcare Communications Association, 90TEN offers solid client/agency partnerships, a responsive and supported team and targeted campaigns that deliver work of the highest standard. In short, smart healthcare communications with a creative edge.

In 2011, 90TEN was named by PR Week as their Healthcare Agency to Watch, due to impressive client success, and won the coveted Judges Special Award for Innovation at the 2011 Communiqué Awards.

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"James Osborn began his career at LEO Pharma before making the move into consultancy in 2008.
James is an established writer, having developed reports, articles and other materials for audiences across a broad range of specialisms and therapy areas, including pain. His work for 90TEN has included a number of award-winning programmes."

Main workplace/Organisation
Osservatorio Italiano Cure Palliative (O.I.C.P.)

Profession/Function
Consultant & Professor, DMSc

Osservatorio Italiano Cure Palliative (O.I.C.P.)

Italian Observatory of Palliative care (OICP) has been launched in 2001 as a consequence of the ascending development of the Italian network of palliative care centers. The first aim consisted in creating a directory of all organizations operating in Italy: palliative care units, hospices and no-profit organizations.

The mailing list, permanently updated, has increased from 250 to more the 600 addresses over the last 10 years. All people needing information about the centers operating in every Italian geographic area can freely consult the OICP website and obtain indications. The OICP data have been used for the preparation of EAPC (European Association of Palliative Care) atlas, containing the directory of palliative care sites in Europe.

From 2002 up to now, all the clinical centers recorded in the website have been yearly invited to participate in epidemiological studies or surveys mainly, but not solely, focused on cancer pain. Due to this second activity, OICP has published eight monothematic books that can be found and downloaded from the website. These books are part of a wider scientific and educational program supported by OICP.

OICP is one of the most visited and consulted Italian websites on palliative care.

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"Directory of Italian palliative care units and NPOs Palliative Care Research Center"

Main workplace/Organisation
Swedish Association of Local Authorities and Regions (SALAR) / Sveriges Kommuner och Landsting (SKL)
Profession/Function
Head of section Health & Equality

The Swedish national rehabilitation guarantee – an overview

In 2008 an agreement was made between the Swedish government and the Swedish Association of Local Authorities and Regions (SALAR/SKL) on a national guarantee of evidence based and medical rehabilitation. The purpose of the guarantee is to support people with anxiety, depression, stress or chronic pain in shoulder, neck and back to return to work or to prevent sick leave.

The agreement for 2012 means that the regions get access to funding up to 900 million SEK from the state to the implementation of the guarantee. Anna Östbom, officer, SALAR, will present a background and an outlook of the future of this unique collaboration mode.

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"The rehab guarantee has led to increased access to multimodal treatment throughout the country."

ENDORSING ORGANISATION SIP2012

ÖGGG
Altern Mitten im Leben

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"Old age is often associated with different chronic diseases, cognitive impairment und loss of autonomy. Pain is associated with aging. Pain has an impact on quality of life in every stage and functional status. Pain awareness, diagnosis and treatment are three of the important issues in geriatrics."

Main workplace/Organisation
Österreichische Gesellschaft für Geriatrie und Gerontologie (Austrian Society for Geriatrics and Gerontology, ÖGGG)
Profession/Function
President

Austrian Society for Geriatrics and Gerontology

The "European Charta of rights and responsibilities of elderly people in need of long-term care and assistance" focuses on different needs of elderly people. Their physical, psychological and emotional well-being is one of the main topics. Pain awareness and adequate treatment are a prerequisite for well-being. Even in patients with cognitive or emotional decline pain is detectable and measurable.

It is a fact that patients sometimes refuse treatment with painkillers because of their expected side effects. Physicians and nurses should be trained in a sensitive way to find an adequate approach. Non pharmacological pain management should be offered complementarily.

To increase the efficiency of pain management, the communication between patients, formal and informal carers, general practitioners and other health care professionals must be improved. Systematic communication and feedback should be part of the routine.

Main workplace/Organisation
Österreichisches Rotes Kreuz / Austrian Red Cross
Profession/Function
Chief Medical Advisor

Red Cross advocates for improved pain management

The "European Charta of rights and responsibilities of elderly people in need of long-term care and assistance" focuses on different needs of elderly people. Their physical, psychological and emotional well-being is one of the main topics. Pain awareness and adequate treatment are a prerequisite for well-being. Even in patients with cognitive or emotional decline pain is detectable and measurable.

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To increase the efficiency of pain management, the communication between patients, formal and informal carers, general practitioners and other health care professionals must be improved. Systematic communication and feedback should be part of the routine.

ENDORSING ORGANISATION SIP2012

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"Pain is still one of the most limiting factors for the well-being and the quality of life of elderly people. The awareness for pain should be raised in all sections of our social and health system, especially in the field of home care and home help."

ENDORSING ORGANISATION SIP2012

painaustralia
working to prevent and manage pain

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"Three Australian states – Queensland, NSW and Western Australia – are implementing state-wide pain plans and Sydney University launches new pain education initiative."

Main workplace/Organisation
Painaustralia

Profession/Function
CEO

Painaustralia: Implementing the National Pain Strategy

Implementing the Australian National Pain Strategy

Painaustralia was formed in February 2011 as a national body to facilitate implementation of the National Pain Strategy. Key goals are:

- People in pain as a national health priority;
- Knowledgeable, empowered and supported consumers;
- Skilled professionals and best-practice evidence-based care;
- Access to interdisciplinary care at all levels;
- Quality improvement and evaluation; and
- Research.

Considerable progress has been made working with state governments and educational institutions:
The **Queensland** Government committed $39.1 million to a State-wide Persistent Pain Plan. This included staffing with multi-disciplinary teams of four new Persistent Pain Management Services at public hospitals in North Queensland, Sunshine Coast, South Brisbane and Gold Coast, to complement services at Royal Brisbane Hospital.
Western Australia has aligned its Models of Care for chronic health conditions such as Spinal Pain and Inflammatory Arthritis with the recommendations of the National Pain Strategy.
In **New South Wales** a Ministerial Taskforce made recommendations for a State-wide Pain Plan. Funding for this, including for improved pain services and pain research, is expected in the May Budget.

Painaustralia is also engaging in regional areas, with Medicare Locals, to expand pain services into the community. This work includes an educational video called "Understanding Pain: What to do about it in less than five minutes." www.youtube.com

Professional Education:
Sydney University has established a new Discipline of Pain Medicine, which is now enrolling students from medical and other health faculties. Professor Michael Cousins is head of the Discipline.
The Discipline held the Inaugural Multi-disciplinary Pain Symposium for undergraduates in March, attended by 280 students from medical, dental, and other health faculties.
An online education program for GPs is being developed by the Faculty of Pain Medicine and the Royal Australian College of General Practitioners, funded by Bupa Australia Foundation.

A report: **The $6 million Woman and the $600 Million Girl**, which investigates the problem of pelvic pain in Australia and provides recommendations for integration into women's health services, was released in 2011.

Veterans Organisations are responding to the strategy with The Department of Veterans Affairs devoted the March Issue of **Men's Health Peer Education Magazine** to giving advice to Veterans and serving military personnel on management of chronic pain.

These documents are available at painaustralia.org.au

ENDORSING ORGANISATION SIP2012

PAIN CONCERN

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"The traditional view of pain as a symptom means that its treatment is fragmented across numerous disciplines which mask the huge scale of the problem - only a small number of pain specialists have a full view of pain. Treating pain as a condition in its own right; according it the same importance that is accorded to other debilitating long-term conditions is essential to ensure early access to pain management, and to lessen individual suffering and the societal impact of pain."

Main workplace/Organisation
Pain Concern

Profession/Function
Charity

Putting You in Control

Pain Concern is a UK charity for those living with pain and those who care for and about them.

Pain Concern produces Airing Pain, an internet radio show for everyone who lives with chronic pain. It looks at a wide range of topics with the aim of easing every aspect of life for people in pain. Once a fortnight Airing Pain brings people living with pain and healthcare professionals together to talk about the resources that can help.

Programmes are broadcast on the internet, then made available as podcasts and CDs. They are easily accessible and can be downloaded onto iTunes.

Pain Concern publishes a quarterly magazine "Pain Matters". The magazine features interviews, discussions, questions and answers and ties in with the topics discussed on the radio show.

In addition Pain Concern maintains a website and uses social media. We publish a monthly e-magazine which tells you what we are broadcasting and publishing and features current debates and our book of the month.

Pain Concern runs a helpline and an information service, listening to what matters to people in pain and, in turn, informing and encouraging.

Pain Concern works with policy makers, parliamentarians, the voluntary sector, health professionals and the media to improve pain services and access to pain management.

P

ENDORSING ORGANISATION SIP2012

Pain Nursing Magazine
Italian Online Journal

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"It would be necessary to include Chronic Pain among the Disease Related Groups in order to give nosological dignity to such a highly prevalent and affecting morbid condition."

Main workplace/Organisation
Pain Nursing Magazine - Italian Online Journal

Taking care of the patient affected by pain

Pain Nursing Magazine, Italian Online Journal is the first publication for nurses completely dedicated to Pain Patients and to those taking care of them, Nurses as well as Physicians, through the perspective of answering to a health question, but answering more and more urgent cultural, social and economic needs, wishing to offer a helpful tool of updating news and communication for those who suffer from chronic pain.

It is generally recognized nowadays that pain is the first cause people request medical assistance for, and the Pain in Europe Survey demonstrates that the prevalence of chronic non-cancer pain ranges 19% within Europe and 26% within Italy. On March 2010, a new Italian law has been enacted (ref. L.38 – 15.3.2010) according to which, chronic pain has to be compulsorily detected in each patient.

For the effect of the same law, cancer pain therapy, as a palliative care, necessarily has to be separated and distinguished from degenerative non-cancer pain, treated with opioids, thus giving a simpler definition on the possibilities of prescription and administration of medicines for type of clinical case. It is with these premises that it would be necessary to include Chronic Pain among the Disease Related Groups in order to give nosological dignity to a so highly prevalent and affecting morbid condition.

Stefano Coaccioli, MD, PhD
Editor in Chief

Main workplace/Organisation
PAIN South Africa (PAINSA) – South African Chapter of the International Association for the Study of Pain (IASP)

Imroving pain patient's life in South Africa

Objectives

To promote an understanding amongst the health care community that the management of pain needs a team approach.

To promote co-operation between itself and hospitals, public and private institutes, government authorities, medical schemes, the health care professionals and the public generally.

To co-ordinate issues surrounding pain between itself and international groups with similar objectives.

To promote research into the diagnosis and treatment of pain.

To promote education at all levels in pain management.

To organise national, regional and local meetings and annual congresses.

The collecting and administering of funds for the furtherance of the above objectives.

To provide central co-ordination for the various groups involved in the management of pain in Southern Africa.

ENDORSING ORGANISATION SIP2012

painsa

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"PAINSA's mission is to improve the management of pain in all its aspects in Southern Africa."

ENDORSING ORGANISATION SIP2012

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"Understanding and curing pain to help improve the quality of life of patients affected by chronic pain. The patient with chronic pain has the right to be understood, to receive professional support and optimal pain management."

Main workplace/Organisation
Paolo Procacci Foundation

Understanding and curing pain

The Paolo Procacci Foundation (FPP) is a non-profit organization created in 2008 to promote and support all sorts of initiatives that advance prevention, early diagnosis, cure and related social services for illness called "pain" and connected symptoms. The Foundation is endorsed by internationally renowned scientists and researchers who have been active for years in some of most important scientific societies and associations dedicated to the study of chronic pain and its effects, including the Italian Association for the Study of Pain (AISD), the European Federation of IASP Chapters (EFIC), the International Association for the Study of Pain (IASP) and the World Institute of Pain (WIP).

Professor Paolo Procacci, a Florentine doctor of enormous and respected medical and humanistic culture was a pioneer in research into pain: one of the founders of the International Association for the Study of Pain, of which he was vice president from 1975 to 1978. He also served as the first president of the Italian Association for the Study of Pain. The FPP, named after him, intends to build on his heritage and that of the many other researchers who have been working on and teaching extensively about pain for years in order to make concrete contributions and further progress to the treatment and cure of patients suffering from chronic pain.

This is the reason why the FPP has fully and enthusiastically endorsed the initiative of EFIC on the social impact of pain and is actively sensitizing the Italian community of politicians, patients' association and healthcare-givers to consider pain not only as a significant health problem that affects millions of people in Europe, but also in terms of the wider societal costs on welfare systems and the negative impact on the economy.

Main workplace/Organisation
D A K - Gesundheit, Unternehmen Leben

Profession/Function
Head of the Department Care Management

D A K - Gesundheit

Since 2010 Dr. Detlev Parow has been Head of the Department Care Management at DAK–Gesundheit in Hamburg. From 2002 to 2009, he worked for Hamburg Münchener, initially as Head of the Medical Competence Center, then as Head of Care Management. From 1999 to 2002, he headed the medical advisory service of ProCOMED/4sigma GmbH in Hamburg and Oberhaching near Munich. After completing his medical studies in Hamburg in 1981, he worked as an anesthesiologistin various hospitals in Hamburg. Dr. Parow is a freelance lecturer at the University of Hamburg.Hamburg, March 2012

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P

© www.wonderfulcopenhagen.dk

Main workplace/Organisation
Patientenschutzorganisation, Deutsche Hospiz Stiftung

Patient Organisation German Hospice Foundation

We are a non-profit and charitable organisation and are financed only by membership fees and donations.

We give detailed suggestions for a reform of the public health system in Germany concerning professional end-of life-care.

We realize our mission to inform by public relation (PR).

Our organisation is against immunity from prosecution for euthanasia and against commercial suicide service and physician-assisted suicide.

We offer individual help free of charge at the nationwide hotline for patient shelter and patient rights and offer competent advice for all people needing help. Furthermore we offer help for writing living will documents in a correct way. We have a German national registration for living will documents.

ENDORSING ORGANISATION SIP2012

Patientenschutzorganisation Deutsche Hospiz Stiftung

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"The German Hospice Foundation is an independent patient organisation for shelter of the terminally ill and dying people. We represent the interests of terminally ill and dying people and their family members against policy, health insurance companies and care providers."

P

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"It's good to feel better but it's better to feel good and even better to feel good as soon as possible for as long as possible."

Main workplace/Organisation
Cercle d'étude de la douleur en Rhumatologie (CEDR)

Patient-Reported Outcome in analgesic treatments: switching assessment towards the patient for more realistic goals

Prof Serge Perrot , Cercle d'étude de la douleur en Rhumatologie (CEDR), Internal Medicine and Rheumatological Pain Center, Paris Descartes University, Hôtel Dieu Hospital, Paris, France

Patient-reported outcome (PRO) provide a means of gaining an insight into the way patients perceive their health and the impact that treatments or adjustments to lifestyle have on their quality of life.

Several years ago, important steps were gained with generalized use of VAS and NRS for pain assessment. However, these monodimensional measurements have demonstrated their limits, especially for the assessment of pain management efficacy. With the development of Patient-Reported Outcome (PRO), more relevant therapeutic assessment have been provided, and these PRO are now promoted as a mandatory outcomes for clinical studies (see IMMPACT recommendations) but also for clinical practice (see NICE recommendations for clinical practice).

In this session, we will discuss several recent PRO, specifically adapted to pain management, in 2 directions:

1. Several questionnaires, to assess pain quality and painful conditions, developed from patients reports may help to a better assessment of pain symptoms.

   In fibromyalgia, FiRST questionnaire represents a screening tool, easy-to-fill-in with good psychometric properties. In neuropathic pain, NPSI represents a very precise tool to analyze pain descriptors.

2. Recent concepts, adapted to a more realistic approach of chronic pain patients, may help to establish patient-centered aims of pain management:

   In chronic pain, especially in osteoarthritis (OA), it seems more relevant to detect the PASS: Patient Acceptable Symptomatic State, compared to absolute VAS values. Studies have demonstrated that PASS in OA pain is estimated around 4 at rest and 5 on movement, both for knee and hip OA.

   In chronic pain management, relevant changes should be detected by the concept of MCII: minimal Clinically Important Improvement. This value is estimated around 1 in chronic pain, especially in OA. Number of patients reaching MCII and PASS represent more relevant and patient-centered analyses of pain management.

   In conclusion, PRO represent new concepts of pain assessment and pain management assessment, that should be developed and accepted by pain clinicians in the next future.

Main workplace/Organisation
College of Human and Health Sciences, Swansea University

Profession/Function
Professor of Health Economics

Pain in society: need for action

Chronic and persistent pain poses a substantial burden on societies in general and it is recognised that its impact is greater than most other health conditions, due to its effects on rates of absenteeism, reduced levels of productivity and increased risk of leaving the labour market, as well as the costs to the healthcare system and other government agencies.

Indicators of the cost and burden of chronic pain fail to do justice to the magnitude of suffering and reduced quality of life experienced by patients, which for some is a permanent feature of their lives with wide reaching effects, leading to depression, sleep disturbance and fatigue, decrements in physical and cognitive functioning, and changes in the mood, personality, and social relationships of sufferers.

The burden of suffering that pain imposes on individuals and the enormous costs which society has to bear as a result, clearly demonstrate that policy makers at governmental level and commissioners, and health care decision-makers alike should adopt a broad, strategic and coherent perspective in determining issues relating to service provision and resource allocation.

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"The burden of suffering that pain imposes on individuals and the enormous costs which society has to bear as a result, clearly demonstrate that policy makers at governmental level and commissioners, and health care decision-makers alike should adopt a broad, strategic and coherent perspective in determining issues relating to service provision and resource allocation."

ENDORSING ORGANISATION SIP2012

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"Pain is still a greatly underestimated problem in the Netherlands."

Main workplace/Organisation
Pijn Platform Nederland (Dutch Pain Cooperation)

Profession/Function
Director

Pijn Platform Nederland (Dutch Pain Cooperation)

The PPN is a non-profit, volunteer organisation. One of the goals is to accomplish coöperation between patients-organisations on the subject of pain. The cooperation is important because pain is still a greatly underestimated problem in the Netherlands. A great number of diseases is related with pain. Together with the different organisations we want to improve the circumstances and treatment (possibilities) for pain-patients. Hilda Wieberneit-Tolman represents the PPN.

Living/coping with pain in connection to the following quotes:

- have the right to be believed
- have the right to be treated with dignity and respect
- have the right to have the pain treated and managed at the earliest possible stage
- have the right of access to the best possible technologies and therapy in pain treatment and management
- have the right to be informed about all the pain management options available so that the best decisions and choices for wellbeing
- have the right to live with the least amount of pain possible
- have the right to be treated on at least an equal footing with all others who have been diagnosed as having a chronic illness

Fight together for these rights and don't suffer in silence!

ENDORSING ORGANISATION SIP2012

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"Increasing the training of nurses in pain, improving care and facilitating the well-being."

Main workplace/Organisation
Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP)

Developing Pain Education for nurses by nurses

Increased life expectancy leads to a greater number of life years gained, and simultaneously leads to an improvement of chronic problems that may be presented with pain.

Disabling pain, retracts, paralyzes ... isolates people from their world of relationships, their careers, their reason for being and living. This is something that is well known by nurses, particularly those working in Family and Community Care, in Spain over 80% of these patients are seen in primary care.

Their proximity to patients and their global and integral vision of the person outlines nurses as important professionals in the approach and management of pain, in the context of a multidisciplinary team.

In order to improve the quality of life of individuals, nursing interventions must respond to the needs of patient care in regards to pain. This requires the constant improvement of nurse training especially in this specific and extensive field.

Although we found no significant studies on specific training in the field of pain for nurses, if we look at the work of Dr. Lynda Ayken it demonstrates that increasing specialization of nurse training, does not only influences the quality of care that the patients receive and decreases morbidity, but it directly affects the mortality of patients. This supports the recommendations of the American Association of Colleges of Nursing to increase the level of training of nurses with the aim of improving patient safety and provide better quality care.

In the current economic crisis we want to emphasize the study of S. Donnas Havens, who speaks of the importance of the reorganization of nursing services to provide "better service" whilst saving costs without sacrificing quality. The study states that besides training, the best results are obtained when nurses are autonomous to apply their knowledge when they have available resources and when relationships with fellow doctors are good. The U.S. has credited and identified these services for nursing excellence.

Looking to continue the improvement of nursing interventions in Spain, the study ENEAS on Adverse Events (AE) related to incidents of care that caused harm to the patient, showed that 20.6% of AE occurred in pre-hospitalization, of which 34.8% are due to medication errors. In both situations, the nurse may be the key professional in patient education and in self-care support (management beliefs, dosage, side effects, interactions, capacity ...)

Therefore, we need increased training and skills in pain management for nurses and by nurses, continuously, which is accredited and accessible.

ENDORSING ORGANISATION SIP2012

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"The purpose of the NoPain PLATFORM is to define, develop and establish measures to address issues related to different aspects involved in pain management such as research, training and care of pain, bringing together all the agents involved in those processes."

Main workplace/Organisation
Plataforma SinDOLOR (NoPAIN PLATFORM)

Its objective is to improve pain-related patient care in Spain

NoPAIN PLATFORM is a project born in 2008 from a collaboration agreement between the Foundation for Health Research (FUINSA) and the Grünenthal Foundation. Both foundations had the common objective of improving pain-related patient care in Spain. The purpose of the NoPain PLATFORM is to define, develop and establish measures to address issues related to different aspects involved in pain management such as research, training and care of pain, bringing together all the agents involved in those processes.

In its implementation, the Platform defined a "Decalogue" as the core pillar with its main messages to support the initiative. During these almost three years of work, a lot of initiatives aligned with these principles have been developed, and the Platform is continuously studying possible actions to meet the goals proposed. The NoPain Platform "Decalogue" was developed and signed by a relevant group of different agents involved in health as health decision markers, senior representatives of regional governments, presidents of scientific societies, researchers, experts in clinical practice, experts in pain...

Some of the activities that have been carried out by the Platform need to be highlighted, like several workshops and seminars, both national and regional, that have been meeting points to share the pain-related measures put into practice both in the public and the private field. They have been useful to share experiences as well, possible alternatives and solutions in the pain field, providing a dialogue amongst over a thousand different health care professionals.

The Platform launched the First Awareness Campaign on the Importance of Pain under the message "Every pain has a history, assess it." This campaign, supported by the Ministry of Health (maximum national health agency), several Autonomous Communities, and Scientific Societies, claims to consider pain as the "fifth vital sign" and in that way, to be reflected in the patient´s record together with body temperature, pulse, blood pressure and respiratory rate. This initiative has been awarded by national media with recognized expertise in health:

- "Diario Médico" Award: Award for the best Idea of the Year in the health field. It is a recognition of the NoPain Platform as a pioneering initiative with a general interest to improve the approach and management of pain.
- "Medical Economics" Award: Best Health Campaign of the year in the patient Information section, due to its key role in showing people how to communicate pain to their doctors.
- "Correo Farmacéutico" Award: Best Pharmacy Initiatives of the year within the Pharmaceutical Care and Health Education
- Section.

In order to recognize the work done by the media and journalists to make society more aware of the issue of pain in Spain, the Platform created in 2009 the "Pain and Journalism Awards" coinciding with the World Day of Pain. This award is addressed to all journalistic works published in print, digital or audiovisual media, focusing on pain as its main topic, from a healthcare, social, socioeconomic, or disclosure perspective.

Main workplace/Organisation
Polish Pain Society (Polish Chapter of IASP)

Profession/Function
Secretary

The Polish Pain Society, Polish Chapter of IASP

The Polish Pain Society, Polish Chapter of IASP, was founded in 1991 as a professional organization to promote research, education and pain treatment. At the end of 2011 there were 414 members of various medical and non-medical specialities.

The main objectives of the organization are initiating and supporting research on the mechanisms, symptomatology and treatment of pain; integrating scientists, doctors of various specialities and other health care professionals interested in pain management; promoting the current advances in diagnosis and treatment of pain.

The objectives are realized by organization of national congresses, symposiums and local meetings on pain and its treatment; supporting educational and editorial projects, elaboration and publication of national recommendations on acute and chronic pain treatment, cooperation with other medical societies to promote appropriate pain management.

The exceptional initiative of the Polish Pain Society is organization of the two-year postgraduate study "Pain Medicine" in cooperation with Postgraduate Medical Centre of Jagiellonian University in Krakow. So far more than 300 medical doctors of various specialities have been graduated from the studies. The studies are the first and exceptional project in Europe and are based on "Core Curriculum for Professional Education in Pain" edited by J.E. Charlton.

Since 2009 the Polish Pain Society in cooperation with other professional organizations has implemented the project "Pain-Free Hospital" to improve acute pain management by increasing awareness of its impact on patients and health care system, and by continuous education of health care professionals. So far more than 100 hospitals and hospital departments have obtained the certificate.

The Polish Pain Society became a chapter of IASP and joined EFIC, and nowadays has an opportunity to endorse the scientific framework of SIP emphasizing the necessity of continuous education of health care providers to improve the quality of pain management.

ENDORSING ORGANISATION SIP2012

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"The continuous education of health care professionals is the key issue to improve the quality of pain management."

P

ENDORSING ORGANISATION SIP2012

APED
Associação Portuguesa para o Estudo da Dor

Portuguese Association for the Study of Pain (APED)
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"APED's main goals are promoting the study, teaching and divulgation of the physiopathological mechanisms, means of prevention, diagnostic and therapy of pain."

Main workplace/Organisation
Portuguese Association for the Study of Pain (APED)

Profession/Function
President

Portuguese Association for the Study of Pain (APED)

The Portuguese Association for the Study of Pain (APED) is the Portuguese Chapter of the International Association for the Study of Pain (IASP).

APED main goals are promoting the study, teaching and divulgation of the physiopathological mechanisms, means of prevention, diagnostic and therapy of pain, according to the parameters established IASP and by the WHO.

To accomplish its goals APED uses the following procedures, as necessary:

- Promoting the organization of scientific meetings and the education of professionals in pain management (congresses, conferences, courses and related activities);
- Supporting the conduction of scientific studies in the scope of pain;
- Establishing and promoting the contact with similar national and international scientific societies;
- Cooperating with Pain Units;
- Promoting contacts with national and international Health Organisms;
- Promoting and informing the general public about its activities;
- Assuring the publication of a scientific magazine, freely distributed to its members

Main workplace/Organisation
Portuguese Association of Palliative Care (APCP)

Portuguese Association of Palliative Care (APCP)

The actual Portuguese Association of Palliative Care is a professional association that gathers professionals of multiple areas that have the common interest of developing and practicing palliative care, although it does not have a direct responsibility to take care of patients and their relatives.

The APCP objectives are as follows:

- To be a promoter of the palliative care in Portugal and a preferred partner of authorities responsible for the development of those services.
- Work in synergy with organizations that aim for the development of palliative care and related areas in Portugal and abroad.
- Contribute to the credibility and to the quality control of the structures that practice care in this area.
- Support the health professionals that wish to dedicate themselves to this area and strengthen the specific investigation to be developed.

To do so the APCP counts with theirs members that with their pro-active and dynamic attitude to participate in the activities that aimed the mentions objectives.

Only with a strong association we will be able to improve the national picture related to the palliative care in Portugal and, as a result, improve the quality of life of patients with a prolonged disease, incurable and/or progressive, as well as theirs relatives.

ENDORSING ORGANISATION SIP2012

Associação Portuguesa de Cuidados Paliativos

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Portuguese Society of Physical Medicine and Rehabilitation (SPMFR)
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"The SPMFR was created in 1953 and is the National Society that represents more than 500 physician's experts in physical medicine and rehabilitation."

Main workplace/Organisation
Portuguese Society of Physical Medicine and Rehabilitation (SPMFR)

Portuguese Society of Physical Medicine and Rehabilitation (SPMFR)

The SPMFR was created in 1953 and is the National Society that represents more than 500 physician's experts in physical medicine and rehabilitation.

The SPMFR is a non-profitable scientific association that has as main objective the study and divulgation of the science and technical development of areas related to the physical medicine and rehabilitation.

The SPMFR has also as objective to improve the knowledge and attitude of physicians towards the comprehension of the physiopathology and care of the deficiencies and disabilities and to collaborate to the improvement of the quality of life of the individuals with deficiencies and disabilities.

To accomplish those goals the Society promotes the realization of conferences and other medical meetings, the divulgation of scientific information between its members and the publication of magazines, leaflets and scientific works regarding physical medicine and rehabilitation.

It's also under the responsibility of SPMFR the promotion of the expert title of physical medical and rehabilitation in collaboration with the Medical College and the Health Authorities and the contribution for strength the scientific, cultural and professional relations between them.

Main workplace/Organisation
Fondazione ISAL, Institute for Research on Pain

Profession/Function
Research on Pain

Good practices for the treatment of pain

The most important action to be developed is to create a knowledge-base on the procedures to which all the national centers of pain therapy confer.

For this reson, the following registries were activated in in Italy:
1. Register of ziconotide use in intrathecal therapy.
2. Register of spinal cord stimulation (SCS).
3. Register of analgesics: opioid category.

We will discuss, in particular, the data on the use of opioid drugs and patterns of monitoring and preventing the risk of abuse, in order to guarantee a safe care.

It will be presented the start up of a new monitoring system for innovative drug, characterized by MOR / NOR (opioid, nociceptine receptors); in order to classify the quality process and prevent inappropriate use.

The research is sponsored by the scientific society: Federdolore-SICD and is implemented through the coordination of its research institute: Foundation ISAL.

Doctors involved are afferent to a network of 210 specialist centers nationwide.

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"The scientific society Fededolore-SICD is committed to the study of good practices for the treatment of pain."

Dr. Patrice Rat
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How to improve the quality of pain assessment (i.e. patients with inability to communicate verbally).
How to improve the quality of pain treatment: efficacy and safety (i.e.frailty old patients).

Main workplace/Organisation
Doloplus Collective team. Collectif Doloplus,
Centre de Soins Palliatifs, CHR Metz-Thionville, Thionville, France
Profession/Function
Praticien attaché hospitalier
Président of CLUD (Hospital comity of fight against pain)

Pain management guidelines for elderly persons

The elderly often experience Pain at rates of 60 to 80%. Furthermore, old patients with Inability to Communicate Verbally receive fewer analgesics than communicative patients. Indeed, assessing AP of old ICV patients remains a fundamental clinical problem because healthcare workers often underestimate patient pain intensity and also because pain behavioral tools in routine practice are underused.

Moreover, frailty increases the risk of inappropriate analgesia, especially opioid administration. Therefore, proposing pain management guidelines should be useful for the decision-making process.

Dr. Patrice Rat:

- Pain and geriatric Medical Doctor
- Member of the Doloplus collective team since 1994 (date of creation, Doloplus collective team developed, valdates and publicated Doloplus® behavioral tool).
- Responsible inside of Doloplus collective team for leading development and validation of Algoplus®, acute pain-behavior scale for older persons with inability to communicate verbally
- Member of the French pain society (SFETD) and of SFETD SIG for elderly people
- Member of IASP and IASP SIG on Pain in Older Persons

Main workplace/Organisation
Red Española para Defensa de los Enfer Rede Fm Sfc y Sqm

Profession/Function
President

"Better without Pain"

"Red Española para la Defensa de los Enfermos de Fibromialgia, Síndrome de Fatiga Crónica y Sensibilidad Química Múltiple" ("Spanish Network for the Defense of People Suffering Fibromyalgia, Chronic Fatigue Syndrome and Multiple Chemical Sensitivity") was established in A Coruña on June 9th, 2010, an associative and non-profit organization, which will take the legal form of association, under the provisions of article 22 of the Spanish Constitution, the Organic Law 1/2002, of March 22nd, on the Right of Association and other provisions issued in developing and implementing it, as well as consistent compliance with regulatory requirements.

The Association's territorial scope of action is National.

Objectives:

1. The Association's Mission is to represent and defend the rights and global interests of people suffering from Fibromyalgia, Chronic Fatigue Syndrome and Multiple Chemical Sensitivity, as well as those of their families, both nationally and internationally.

2. The fundamental aim of the Association is to obtain solutions to needs faced by people affected by these three diseases, as well as their families.

3. In order to achieve these aims, the entity will carry out the following activities:

a) Dissemination among health workers of all issues related to the three conditions, promoting sensitization and training.
b) Maximize the evidence of the need for multidisciplinary teams open to all kinds of therapies and providing health educational programs.
c) Promote, develop and organize those services required for research, planning and providing information, as well as activities and courses on different aspects of all three diseases.
d) Encourage public and private agencies to take the appropriate measures in order to achieve full social, work and health integration of those affected.

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"Our mission is to represent and defend the rights and global interests of people suffering from Fibromyalgia, Chronic Fatigue Syndrome and Multiple Chemical Sensitivity, as well as those of their families, both nationally and internationally."

R

ENDORSING ORGANISATION SIP2012

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"We, as Coordinator of this program and Health Authorities, found in the SIP and EU platform the best place to exchange knowledge and monitor services and outcomes in order to improve better pain treatment. So, we endorse SIP 2012."

Main workplace/Organisation
Regional Health Directorate – Azorean Regional Plan for Pain Control

Regional Health Directorate – Regional Plan for Pain Control

The Department of Health of the Autonomic Government of Azores organized a Regional Program for Pain* from 2009 to 2012 through the definition of three strategies: organization, education and information. The main objective is to improve pain management in Azores, which are about 260.000 people that live in nine Portuguese islands in the Atlantic.

This Regional Program of Pain has a Coordinator** who defined the actions together with the authorities, focused on:

1. Multidisciplinary Pain Units located in the three Hospitals and a regular work together with a representative member of which Primary Care Facility in relating area;
2. The education of all healthcare professionals, nurses, doctors and others, oriented to the evaluation of pain as the fifth vital sign, the rational use of opioids and to the undergraduate education of nurses and postgraduate education in Pain Medicine for doctors;
3. Information to public about the burden of chronic pain in local media.
4. Next step is to start with the study of real prevalence of pain and his impact and stimulate research in connection with the University.

We, as Coordinator of this program and Health Authorities found in the SIP and EU platform the best place to exchange knowledge and monitor services and outcomes in order to improve better pain treatment. So, we endorse SIP 2012.

*http://www.azores.gov.pt/NR/rdonlyres/58E1085F-3CBD-45C7-9A79-061B97D27317/417978/ProgramaRegionaldeControlodaDor.pdf

**Maria Teresa Flor de Lima

Main workplace/Organisation
Center for Rehabilitation University Medical Center Groningen

The impact of pain on work articipation; Healthy Aging @ Work?

Workshop 2 focuses on Active and Healthy Aging. This contribution will focus on the impact of pain on work for the largest and financially most costly subgroup of people with pain: patients with chronic non-specific musculoskeletal pain (CMP). Most of these costs are related to (temporary) work productivity loss.

In line with the anticipated outcome of this workshop, the following topics will be covered:

- A brief overview of challenges when measuring 'work capacity, ability and participation'
- Results of a study among a large and underreported group of people with CMP: workers who stay at work despite CMP. What went right? Are they just 'not absent', or can they still be productive? How are these people or their work different from those with CMP who seek tertiary care? What lessens can we learn from these workers?

Prof. Michiel Reneman
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"In general, work is good for health and well-being, and may contribute to healthy aging."

R

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"ICD-11 proposals could be further optimized to better reflect the treatment needs of pain patients."

Main workplace/Organisation
University of Marburg

Profession/Function
Head of the Division of Clinical Psychology and Psychotherapy

Are pain diagnoses adequately reflected in ICD-11?

An adequate representation of pain diagnoses in classification systems like ICD-11 is a necessary precondition to offer evidence-based clinical management programs, to integrate pain management in health care and compensation regulations, and to stimulate focused research programs for pain conditions. Moreover, there is an urgent need to harmonize classification of pain syndromes of special expert groups (e.g., ICHD) and general classification systems (e.g., ICD-11, DSM-V).

A qualitative review of the literature concerning new proposals for classification of pain syndromes that are based on consensus groups was conducted. Selected proposals of pain societies are presented, and it will be discussed whether and how they are integrated into the current ICD-11 proposal. It will be highlighted that there is further need to optimize the integration of results of pain research into the classification systems.

Because an adequate consideration of pain diagnoses in ICD-11 is needed, suggestions for improvement of the ICD-11 draft will be provided, and general remarks about future perspectives of the classification of pain will be presented. There is a need to classify pain as a diagnosis of its own, especially chronic pain, but also as an important comorbid condition of medical diseases that requires special attention.

Main workplace/Organisation
Department of Rehabilitation Medicine, Skånes University Hospital

Profession/Function
Head of Department

Marcelo Rivano Fischer

Born in 1956. PhD in Psychology, 1988 on nonverbal communication. Clinical Psychologist with focus on chronic pain since 1991 at the Department of Rehabilitation, Lund University Hospital.

Program director and Chief of staff at the Pain unit of the Department of Rehabilitation, Lund University Hospital, Lund, from 1998 to 2003. Head of Department, Department of Rehabilitation Medicine, Skånes (Lund) University Hospital, Sweden since 2002. Since 2004 Surveyor (Medical Rehabilitation) for the CARF Commission for the Accreditation of Rehabilitation Facilities (CARF international), USA.

Since 2008, President of the Swedish Pain Society (IASP), member of The International Association for the Study of Pain (IASP), Sweden, and since 2011, Chairman of the Swedish Quality Registry for Pain Rehabilitation (SQRP).

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"Focus on enhancing education on pain, building up an organization capable of meeting the challenges of pain and its impact on society and development of new methods for treating pain and its consequences."

Dr. José Romão
Hospital de S. António
Largo Prof. Abel Salazar
4099-001 Porto
Portugal

"Pain must be identified as an important issue in Europe. If health-care professionals, policy-makers, people suffering from pain and all those involved in pain management work together, then real change is a possibility."

Main workplace/Organisation
National Program for Pain Control

Profession/Function
Coordinator

Dr. José Romão – short biography

Graduated in medicine in 1984 by the Faculty of Medicine of the Oporto University.

Consultant in Anesthesiology with the Competence in Pain Medicine granted by the National Medical Association

Head of the Chronic Pain Unit of Hospital de Santo António, Oporto.

Member of the executive board of the portuguese IASP chapter – APED (2001- 2007) and past President (2007-2010).

He is currently the Coordinator of the National Program for Pain Control.

Main workplace/Organisation
European Conservatives and Reformists (ECR)

Profession/Function
Member of the European Parliament (Denmark)

A strong European voice on Chronic pain

Today we are bringing together stakeholders from all over Europe to discuss issues of pain. This will provide an opportunity to share knowledge and to understand the wide scope of interests involved.

The 3rd symposium on the Societal Impact of Pain is an opportunity to share what is already found; what kind of experience have we got so far with regard to the topic of pain management in Europe?

As Member of the European Parliament I am struggling to improve the living conditions for people with chronic pain. A very important first step is to get chronic pain acknowledged as a disease in all member countries.

Because people with chronic pain do not receive the attention of society they often isolate themselves. This is unfortunate. We need a strong voice in order to change things. We need to hear the voices of the patients. That is why I support Pain Alliance Europe. Patients need to be organized on a European level in order to create a strong voice.

I hope that today's conference will contribute to closer working relations amongst different organizations working with issues of pain. We all have great ideas and different perspectives. Sharing knowledge is a very important first step towards improving conditions for the millions of people in Europe suffering from different kinds of pain.

About Anna Rosbach
Anna Rosbach is the ECR group coordinator in the Committee on Environment, Public Health and food Safety. She is also a substitute member of the Fisheries Committee and the Committee on Transport and tourism and Vice-chair of the Delegation for relations with the Korean peninsula.

In addition to her parliamentary positions Anna is engaged in numerous activities involving fisheries, biodiversity and animal welfare. She is a member of the interparliamentary group Fish for The Future, and chairman of the organisation Waste Free Oceans.

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"Chronic pain is a burden to millions of people in Europe. Because the pain is chronic it is often not considered a disease by society and health care systems. This must be changed. Chronic pain should no longer be given less attention and care than temporary pain."

R

ENDORSING ORGANISATION SIP2012

Russian Association for the Study of Pain (RASP)
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The Russian Association for the Study of Pain (RASP) founded in 1990 is the voluntary self-directed non-for-profit public organization combining all specialists, involved in Pain Medicine (neurologists, general practitioners, anesthesiologists, rheumatologists, physiologists, pharmacologists and others).

Main workplace/Organisation
Russian Association for the Study of Pain (RASP)

Profession/Function
President

The Russian Association for the Study of Pain (RASP) confirms to endorse the scientific aims of SIP 2012

The objectives of the The Russian Association for the Study of Pain (RASP) is to promote and support scientific and clinical research in the field of physiology, pathophysiology, epidemiology, diagnosis, treatment and prophylaxis of pain syndromes, to facilitate the organization and development of medical centers, special offices and laboratories for the treatment of pain syndromes; assistance in training of specialists in Pain Medicine.

From 2004, the RASP publish scientific journal, which now named "Russian Journal of Pain." The journal is published four times a year. The Presidium of RASP has decided to make free e-newsletter version of the magazine.

From 1990, RASP organized 18 national conferences on different aspects of pain research and treatment. Currently, the RASP has 364 regular members.

In 1990, the RASP has become a collective member of the International Association for the Study of Pain (IASP), and in 1993 a collective member of the European Federation of IASP Chapters (EFIC).

In accordance with charter and goals, RASP endorse the scientific and social aims of SIP 2012 and ready to continue discussions with Health Care officials, based on Road Map of Action, for development of Pain Medicine in Russian Federation.

Main workplace/Organisation
Russian Headache Research Society (RHRS)

Profession/Function
President

The Russian Headache Research Society (RHRS) confirms to endorse the scientific aims of SIP 2012

The RHRS has an official relations with the European Headache Federation and The Global Campaign against Headache "Lifting the Burden" and functions in accordance with the up-to-date European principles of headache diagnosis and management. The official site of the RHRS: www.headache-society.ru

The objective of the RHRS - is to improve the quality of health care for headache disorders in the Russian Federation. The objective of the future is also to raise awareness with the government for need for improvement and to obtain its support

The main tasks of the RHRS include:

- Education of physicians in classification, diagnostic principles, clinical manifestations, pathophysiology and treatment of most common headache disorders – migraine, tension-type headache, medication-overuse headache, cluster headache; principles of diagnosis and management of primary and secondary headaches;
- Elaboration and distribution of educational materials (handbooks, guidelines, electronic materials, leaflets) for neurologists and GPs;
- Organization of Headache Schools, seminars and biannual National Headache Congresses;
- Support and encouraging of research activity in headache field;
- Assistance in organization (including information support) of headache consulting rooms and Headache Centers in the Russian regions in accordance with European principles;
- Public education focused on headache sufferers (through the media).

ENDORSING ORGANISATION SIP2012

Russian Headache Research Society (RHRS)
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The Russian Headache Research Society (RHRS) founded in 2008 is the voluntary self-directed non-for-profit public organization combining Russian neurologists and General Practitioners interested in the diagnostics and treatment of headache disorders.

R

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"A set of indicators on the quality of pain management have been built and pilot-tested. They refer to all types of pain and are grouped into indicators for the management of acute, chronic malignant, and chronic non-malignant pain."

Main workplace/Organisation
Universidad de Murcia

Profession/Function
Professor of Public Health

Good Practices indicators for Pain Management

Adequate pain management is becoming a priority for the quality of health services, due to the high incidence, prevalence and subsequent societal and monetary costs of this health problem. Yet, the field of pain management is just beginning to define quality, measurable attributes have not been clearly defined, and the implementation of quality improvement activities in pain management in the health system as a whole remains a challenge.

The objectives of the project presented here are the building, pilot testing and measuring of a comprehensive set of evidence-based indicators which may be used for quality management in the assessment, treatment and control of pain.

Methods:
A multidisciplinary team was formed to deal with the following sequential phases of the project:

1. Agreement on a classification of pain conditions which may be used for quality management. The ones proposed by IASP, ICSI and WHO were considered, and the latter adopted, classifying conditions in three groups: acute pain, chronic malignant pain, and chronic non-malignant pain.
2. Review and systematization of evidence-based recommendations for pain management. We searched systematic reviews in Cochrane, Medline and OVID, and Clinical practice Guidelines in BMJ Evidence, Topics, SIGN, OVID, NZGG, Medline and Guíasalud, for all the three groups of conditions.
3. Review and systematization of existing indicators and quality measures in relation to pain management, matching them with the evidence-based recommendations, and further classifying them by health care setting (PHC, hospital, long-term care) where they may be applicable. We searched in The AHRQ's National Quality Measures Clearinghouse, articles published since 2000 and indexed in the Scopus, PubMed, Psycinfo, and Academic Premium databases, as well as grey literature using Google.
4. Building new indicators and measures, when appropriate, for a comprehensive and yet parsimonious monitoring of pain management quality.
5. Pilot testing of the final set of proposed indicators and measuring methods and tools.

Results:
The final proposed set of indicators includes 54 for acute pain, 22 for chronic malignant pain, and 46 for chronic non-malignant pain. All of them have been tested for reliability, feasibility of measurement and capacity for identifying quality problems, and ranked by general to more specific applicability. General applicability indicators include 4 for acute pain, 7 for chronic malignant pain and 9 for chronic non-malignant pain. Detailed results of the pilot testing and estimates of compliance will be presented at the Symposium.

Main workplace/Organisation
SchmerzNetzNRW eG

Profession/Function
Vorstandsvorsitzender

SchmerzNetzNRW eG – association of 43 pain centers

SchmerzNetzNRW eG is the association of 43 specialized medical pain practices in Nordrhein-Westphalia. The key target of this association is to ensure pain therapy and to use synergistic effects in organizational questions.

SchmerzNetzNRW is a potent collaboration partner for institutions in public health, pharmaceutical research and health insurance funds. The data system PainPool® offers an unique platform to develop patient centred care.

ENDORSING ORGANISATION SIP2012

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S

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Main workplace/Organisation
World Health Organization

Profession/Function
Team Leader, Access to Controlled Medicines

Live report from the ATOME Symposium in Nicosia, Cyprus Subject to the availability of a video connection Nicosia-Copenhague

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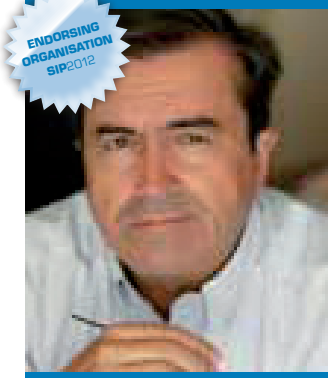
"ATOME engages in working to help twelve eastern European governments identify and remove barriers that prevent people from accessing medicines that could improve end of life care, alleviate debilitating pain and treat heroin dependence."

The World Health Organization (WHO) developed the Access to Controlled Medicines Programme (ACMP) and formed the ATOME-consortium (Access to Opioid Medicines in Europe; www.atome-project.eu) that is composed of 10 partners from the fields of palliative care and pain management, treatment of opioid dependence, public health and legal affairs. Together, this group consists of national, European-wide and international organisations with long-standing experience in opioid medicine issues in Europe. The consortium engages in working to help the governments of Bulgaria, Cyprus, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Serbia, Slovenia, Slovakia and Turkey identify and remove barriers that prevent people from accessing medicines that could improve end of life care, alleviate debilitating pain and treat heroin dependence. The ATOME Project is funded by European Commission's 7th Framework Programme

Part of the project was the development of the policy guidelines entitled Ensuring Balance in National Policies on Controlled Substances: guidance for availability and accessibility of controlled medicines by WHO (2011). The University of Utrecht conducts legislative reviews (2011-2013). Similarly, twelve country teams conducted policy reviews to identify policies needed to improve access to these medicines in two workshops in Bucharest, Romania (2011). From 2012 until 2014, the consortium conducts twelve national symposia to make a number of stakeholders aware of the importance of the issue and to create a critical mass for change. The outcome of these activities will lead to recommendations that will facilitate access for all patients requiring treatment with medicines controlled under international drug conventions. ATOME will report these recommendations and other findings to the national governments at the end of the Project in 2014.

So far, national symposia were conducted in Brdo, Slovenia and Ankara, Turkey. Simultaneous with SIP 2012, the third symposium will be conducted in Cyprus. Stakeholders from government agencies, health-care institutions and patients are invited to attend. In the morning, several international experts will present on issues like the current state of access to pain management, palliative care and access to treatment of opioid dependence in the world. The relevant WHO policy and treatment guidelines will be presented and patients will tell about their experiences. Then, the participants will discuss in groups how to improve access in Cyprus and report back to the plenary.

A report from the symposium will be transmitted live from Nicosia immediately after the symposium.



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"Management of Pain, suffering and symptoms of end of life, and training."

Main workplace/Organisation
Douleurs sans Frontières

Profession/Function
Association humanitaire

Douleurs sans Frontières

We are a humanitarian association for international solidarity with the name Douleurs Sans Frontières (pains without borders). We work in the field of management of pain, suffering and symptoms of end of life.

Main workplace/Organisation
Servicestelle Hospizarbeit für die StädteRegion Aachen (Service Pain Hospice); Palliative Network for the Region of Aachen – Palliatives Netzwerk für die Region Aachen e.V.
Profession/Function
Coordinator

The Palliative Network for the Region of Aachen

Established in 2008, it is the aim of the Palliative Network for the Region Aachen to provide support to seriously ill people and their families during their last days and hours before passing away and during the time in bereavement, both at home as well as in inpatient settings, thereby putting human dignity in the center of all actions. This required many helping institutions and services in the outpatient and inpatient area, which will work closely together, in order to pool their resources, experiences and skills.

The members of the Palliative network come from all areas, which play a central role in the hospice and palliative care: nursing homes, outpatient hospice services, pharmacies, undertakers, "Bunter Kreis in der Region Aachen e.V., specialists, family doctors, "Home Care Aachen e.v.", municipalities, hospitals, health insurances, palliative care, care services, physical therapists, emergency physicians, the inpatient hospice, medical suppliers, counseling services, service centers for hospice, bereavement care, etc.

More than 300 institutions from the region of Aachen will receive invitations for the "Servicestelle Hospizarbeit Aachen" – workshops.

Servicestelle Hospizarbeit für die StädteRegion Aachen (Service Pain Hospice)
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"It is our central aim to develop and improve palliative care by focusing on a highly valuable medical, psychosocial and spiritual care-giving."

Slovensko združenje za zdravljenje bolecine (SZZB)
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"Chronic pain should be recognized as a health care priority, and the recognition will only have its proper validity if supported by the relevant law directives and the national plan for pain management."

Main workplace/Organisation
Slovensko združenje za zdravljenje bolecine (SZZB)

Profession/Function
Slovenian Association for Pain Management

SIP in Slovenia

Despite the achieved general priority of health and health care, the chronic pain in Slovenia is still not well enough recognized as an important indicator of health, health-related quality of life as well as the personal and national welfare. Slovenian Association for Pain Management is implementing the EFIC policy and actions with the aim to gain and enhance the awareness of the Slovenian society of the impact of pain and the need for the improvement of pain patients' healthcare.

In the same manner as EFIC has been performing its activities to convince the European Parliament about the importance of societal impact of pain and has delivered the roadmap for action, the Slovenian Association for Pain Management and National Council organized a similar meeting in the Slovenian Parliament in the October 2011. The facts and issues relating to the societal importance of chronic pain were discussed among physicians who are active in chronic pain treatment and rehabilitation, chronic pain patients and representatives of patients' rights, the representative of the Medical Faculty, representatives of the Health Insurance Institute, National Institute of Public Health, Ministry for Health and an EFIC representative for Roadmap for action.

The Slovenian Association for Pain Management manifested the Slovenian Declaration of the National plan for pain management. The conclusions of the said meeting were documented and were discussed at the National Council's Commission for Social Protection, Labor, Healthcare and Disability in March. The representatives of the Slovenian Association for Pain Management were invited to provide additional information. The conclusions of the meeting were the positive mark, further harmonization with the Ministry for Health and presentation of the initiative at the National Council's session. The action is going on.

Slovenia is in some ways the prototype of a country in transition in which the Parliament is willing to hear about the chronic pain impact to the society and the need to improve its management yet could greatly benefit from the EU directives. This is the reason why it is very important that the SIP actions prove to be successful in the European Union, alongside the endeavors in the individual countries.

Main workplace/Organisation
Slovak Society for Study and Treatment of Pain (SSSTP)
Profession/Function
President of SSSTP, Councilor of Slovakia

Slovak Society for Study and Treatment of Pain (SSSTP)

The Slovak Society for Study and Treatment of Pain (SSSTP) is member of EFIC and IASP.

The SSSTP has been established in 1993, it has got 200 members, doctors, mainly pain specialists and anaesthesiologists with special interest in the treatment and assessment of acute, chronic and cancer pain.

The SSSTP participated on all Europe against pain campaigns. The SSSTP officially endorses and completely supports enclosed SIP 2012 document.

Slovak Society for Study and Treatment of Pain (SSSTP)
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"Chronic pain is a specific healthcare problem, a disease in its own right."

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Main workplace/Organisation
Sociedad Canaria del Dolor (SCD)

Profession/Function
President

The Canary Islands Pain Society

The Canary Islands Pain Society is a scientific society associated with the Spanish Society of Pain (SED), founded on May 2000 by a group of medical experts in pain management, with the aim of encouraging and promoting the research on mechanisms of pain and pain syndromes, stimulating education and learnings in the field of pain; to promote and encourage the dissemination of information on pain, organizing scientific meetings, to publish the objectives of the Society to the relevant government institutions; to promote and create pain units according to internationally recognized standards and promote any other activity that follows the purposes mentioned above.

We are proud to be able to contribute from our modest company with the promotion of activities around the study, research and treatment of pain, as well as to reinforce health authorities to have a higher involvement in this area According to the main objectives of our Society we are willing to endorse the "Societal Impact of Pain" meeting since it is a very interesting initiative and an unique opportunity to create consensus and share good practices in the pain management.

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Main workplace/Organisation
Sociedad Castellano Manchega del Dolor (SCMD)

Pain and other symptoms in palliative cancer care

The Castilla la Mancha Pain Society (SCMD) was founded in 2011 with the hopeful project of uniting the interests and concerns of all those people involved in the diagnosis, treatment and study of Pain.

Our main objectives are:

a) Encourage and promote research on the mechanisms of pain syndromes.
b) Help in improving treatments for patients with acute or chronic pain by bringing together the health professionals who share an interest in pain research and pain treatment.
c) Encourage research, education and training in the field of pain.
d) Promote and encourage pain information through scientific meetings and briefings, and by other means available to do it.
e) Organize scientific meetings to show new aspects of pain diagnosis and pain treatment, in addition to any other meeting that could be useful for advancement of the purposes of the Society.
f) Promote the development of regional databases related to the mechanisms, symptoms and treatments of pain.
g) Promote any other activity that may favor the above purposes.

According to the referred aims of our Society, we are willing to endorse the "Societal Impact of Pain" meeting since it is an excellent occasion to promote and exchange the best practices in pain research, diagnosis and treatment

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Main workplace/Organisation
Sociedad Española de Directivos de Atención Primaria (SEDAP)

Profession/Function
Presidenta

Sociedad Española de Directivos de Atención Primaria (SEDAP)

The Spanish Society of Primary Care Managers is a scientific society whose objectives are the promotion of knowledge and professional development of managerial sciences in the field of Primary Healthcare. We implement training and research initiatives, and collaborate with other societies with the broader aim of enhancing Primary Healthcare.

Among the activities developed by the Society it provides annual reports on current affairs which reflect the opinion of health professionals, scientific societies, managers, patients and experts in the matter and, after analyzing, proposals are made for the reflection and discussion by the sectors involved.

This line of activity began in 2009 with proposals for improving the Primary Care Model, it continued in 2010 with the integrated care management and in 2011 with proposals for hospital organization, all of it in order to analyze the fundamental cycle of the health structure.

According to the main objectives of our Society we are willing to endorse the "Societal Impact of Pain" meeting since it is a major initiative and brings the opportunity for key stakeholders to exchange their best practices in pain, and create consensus for future collaborations on improving pain care.

Sociedad Madrileña del Dolor (SMD)
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Main workplace/Organisation
Sociedad Madrileña del Dolor (SMD)

Profession/Function
Presidente de la Sociedad Madrileña del Dolor

Sociedad Madrileña del Dolor (SMD)

The journey of Sociedad Madrileña del Dolor (SMD) started after the elections of the 4th Board of the Sociedad Madrilena del Dolor in May 2010, intending to continue the work undertaken by our partners in previous projects. At the individual level, our goals are the development of outreach programs, training and scientific activities related to the treatment of pain and to create recognition in the specific training area on the treatment of pain, which we have been working on for years already.

Collectively, our idea is to work on the development of pain clinics, as well as the implementation of quality standards in community schools which we consider necessary for the proper functioning of these structures. Finally, we will strengthen the representativeness of the SMD in our environment, both scientifically and socially.

To meet these objectives it is necessary to feel as a united group of professionals with a common policy objectives, and work together to achieve them. We have no hesitation in resorting to the cliché that gives unity among all the strength.

Junta Directiva
Presidente: José Luis De la Calle Reviriego
Vicepresidente: José Cid Calzada
Secretario: Esther López Pérez
Tesorero: Cristina del Pozo Martín
Vocales: Carlos Goicoechea García
Alfredo Perucho González

"Sociedad Madrileña del Dolor aims at the development of outreach programs, training and scientific activities related to the treatment of pain and to create awareness of the importance of specific pain education."

ENDORSING ORGANISATION SIP2012

Sociedad Madrileña de Geriatría y Gerontología
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"Helping the ageing population to improve pain care and quality of pain is always a great initiative."

Main workplace/Organisation
Sociedad Madrileña de Geriatría y Gerontología

Sociedad Madrileña de Geriatría y Gerontología

The "Society of Geriatrics and Gerontology" of Madrid is a regional society, whose main objectives are

- To promote and improve the knowledge of human aging process.
- To group researchers and professionals related to aging and elderly people.
- To promote actions addressed to improve quality of life of elderly people.
- To advice and give support to Health and Social bodies and institutions responsible for health and social problems associated to old age.
- To design and promote training systems in Geriatrics and Gerontology.

Being aware of the importance of pain for elderly people, we are willing to endorse the "Societal Impact of Pain" event since we consider it is a very good initiative to exchange best practices in pain, helping the aging population to improve pain care and quality of life.

Main workplace/Organisation
Sociedad Murciana del Dolor (SMD)

Profession/Function
Secretario

The Society of Pain of Murcia (MurciaDolor)

MurciaDolor was founded in June 2011 with the intention of promoting scientific research on the mechanisms and treatment of pain, sensitizing the society about this problem and encourage continuous improvement in assessment and therapy of patients suffering pain. This organization is integrated mainly by doctors and also by other non-medical professionals such as pharmacists, psychologists and nurses.

ENDORSING ORGANISATION SIP2012

Sociedad Murciana del Dolor (SMD)
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"The Society of Pain of Murcia (MurciaDolor) is a professional, multidisciplinary and nonprofit organization, to promote the study of pain."

ENDORSING ORGANISATION SIP2012

Sociedad Valenciana de Terapéutica del Dolor y Cuidados Paliativos (SOVTED)
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"The Society of Pain and Palliative Care of Valencia is a professional association whose main objective is to promote the continuous improvement of treatment of patients with pain."

Main workplace/Organisation
Sociedad Valenciana de Terapéutica del Dolor y Cuidados Paliativos (SOVTED)

Profession/Function
Presidente

The Society of Pain and Palliative Care of Valencia

This society was created in 1993, is integrated into the Spanish Society of Pain and is composed mainly by doctors specializing in pain management.

Main workplace/Organisation
Societat Catalana de Medicina Física i Rehabilitació

Profession/Function
Presidenta

Societat Catalana de Medicina Física i Rehabilitació

Catalan's association of physical medicine and rehabilitation mission is to:

a. Group all specialists in medicine and surgery with an interest or linked to the speciality of Rehabilitation and Physical Medicine, along with all the graduates in other health sciences who apply and are accepted to be a part of it.
b. Contribute in the scientific improvement of all members.
c. Promote the development of the specialty.
d. Assess public organizations and private societies in all matters related to rehabilitation and physical medicine when requested.
e. Define the resources to expand the studies of the specialty.
f. Cooperate with universities for a scientific and technical development
g. Promote potential partnerships with other national and international associations.
h. Promote potential partnerships with other national and international scientific associations

ENDORSING ORGANISATION SIP2012

Societat Catalana de Medicina Física i Rehabilitació
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Societat Catalano-Balear de Cures Pal.liatives
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Main workplace/Organisation
Societat Catalano-Balear de Cures Pal.liatives

Profession/Function
Presidente

Societat Catalano-Balear de Cures Pal.liatives

The main aims of the Society, which has no lucrative purposes, are:

- To assemble all the doctors specialized or interested in palliative care, and university graduates in other health sciences who request it.
- To promote the awareness and diffusion of palliative care at a scientific, clinical and social level and to contribute to the improvement of the scientific members of the Society.
- To promote the application of existing knowledge on palliative care, forming those who intervene at any of the levels involved in the care of terminally ill patients and who promote research.
- To treat ethical problems associated with palliative care and to advise public bodies and private companies on Palliative Care.
- To establish the means for further studies on Palliative Care. To promote or sponsor events, publications, etc. on Palliative Care.
- To collaborate with universities in the scientific and technical development of Palliative Care.
- To encourage collaboration with other national and international companies.
- To promote the development of resources for adequate care.
- To recognize and promote the rights of patients and their families.
- To fulfill these objectives, the Societat Catalano-Balear de Cures Pal.liatives is a member of the Sociedad Española de Cuidados Paliativos and the European Association for Palliative Care.

Main workplace/Organisation
Societat Catalano-Balear d´Oncologia

Profession/Function
Presidente

Societat Catalano-Balear d'Oncologia

The Societat Catalano-Balear d' Oncologia (SCBO) was founded in 1964 by several doctors who treated cancer patients with the will to share their experiences, develop protocols, generate and share knowledge. The SCBO is integrated in the Acadèmia de Ciències Mèdicas de Catalunya i Balears.

Since the beginning has been a society in which coexist multidisciplinary professionals from different specialties with the common aim of improving care for cancer patients.

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ENDORSING ORGANISATION SIP2012

Spanish Association of Patients with Neuropathic Pain, Trigeminal Neuralgia and Temporomandibular Pathology (AEPA ATM)
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"Our Association supports every action aimed to raise awareness and foster research concerning the central nervous system and all the initiatives that can improve the quality of life of patients."

Main workplace/Organisation
Spanish Association of Patients with Neuropathic Pain, Trigeminal Neuralgia and Temporomandibular Pathology (AEPA ATM)

The Official Spanish Association of Patients with Neuropathic Pain, Trigeminal Neuralgia and Temporomandibular Pathology (AEPA ATM)

The Official Spanish Association of Patients with Neuropathic Pain, Trigeminal Neuralgia and Temporomandibular Pathology (AEPA ATM), is a non-profit association for patients that suffer any kind of Craniomandibular disorder, Temporomandibular Joint Disorder (TMD), Neuropathic pain, or Trigeminal Neuralgia (TN). The association is legally inscribed in the Register of Associations of the Spanish Ministry of Interior with the National Number (Número Nacional) 587586, Group 1, Section 1.

Our Association supports every action aimed to raise awareness and foster research concerning the central nervous system and all the initiatives that can improve the quality of life of the patients, such as the 3rd Societal Impact of Pain Symposium.

Our entity serves people who suffer from neuropathic pain. In our opinion, undergoing every available treatment is NOT ALWAYS moving forward. For our Scientific Committee and our volunteers, the priorities are finding the causes of the pain that each of our patients endure and trying to mitigate their suffering with all the means at our disposal. For that purpose, we have a multidisciplinary international medical team with more than 20 doctors specializing in investigating Neuropathic Pain.

Project carried out in Memoriam of Mother Teresa of Calcutta.

Main workplace/Organisation
Spanish Society of Health Directors (SEDISA)

Profession/Function
Manager

Spanish Society of Health Directors (SEDISA)

SEDISA (the Spanish Society of Health Directors) is a society founded in last October 2004 and currently composed by more than 700 health professionals working in health sector, with high responsibilities in hospitals and health centers management. Members of SEDISA are mostly in charge of optimizing resources within their influence area, in order to keep the health system in working order; this will have clear benefits for the patients access to a quality health system.

In terms of pain, SEDISA is endorsing the "Societal Impact of Pain" event since we are committed to the need of placing the patients in the center of the health care system. We have to create awareness within our membership and start developing projects for improving the quality of life of patients with pain.

ENDORSING ORGANISATION SIP2012

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"SEDISA is willing to endorse SIP since we are committed to create awareness within our membership and start projects to improve quality of life of patients with pain."

S

ENDORSING ORGANISATION SIP2012

Main workplace/Organisation
Spanish Society of Pain (SED)

Spanish Society of Pain (SED)

The Spanish Society of Pain (SED) is a professional, multidisciplinary and non-profit making Society focused on pain, founded in June 1990. It is composed by health professionals with different specialties and backgrounds, especially physicians, but also other professionals such as pharmacologists, psychologists and graduates in nursing. At this moment, the Spanish Society of Pain counts1.392 members.

The Society has different objectives:
1) promoting scientific works about mechanisms and treatment of pain,
2) create awareness about this problem and
3) encourage the continuous improvement in assessment and therapy of patients suffering pain.

The Spanish Society of Pain is a chapter of the International Associations for the Study of Pain, IASP, which is a reference for pain related issues at the World Health Organization (WHO). According to the main objectives of our Society we are willing to endorse the "Societal Impact of Pain" meeting since it is a very relevant initiative and very good opportunity for key stakeholders to exchange their best practices in pain, and create consensus for future collaborations on improving pain care.

Spanish Society of Pain (SED)
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"The Spanish Society of Pain is willing to endorse the 'Societal Impact of Pain' meeting since it is a very relevant initiative and very good opportunity for key stakeholders to exchange their best practices in pain, and create consensus for future collaborations on improving pain care."

Main workplace/Organisation
Italian Ministry of Health

Profession/Function
Head of Office Palliative Care and Pain Therapy Uff. XI

Pain relief acute-primary care net

The project aims to developing a care model which is able to guarantee, within the hospitals of the Marche Region, both a systematic and uniform detection of pain by the health professional involved (ability to methodically detect pain, ability to understand the level of pain) and consequently, when necessary, the administration of the appropriate and efficacious analgesic treatment. The health professionals observe and document the level of pain of the patient, as the V vital parameter, using a standardized tool, validated to evaluate the intensity of pain.

ENDORSING ORGANISATION SIP2012

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ENDORSING ORGANISATION SIP2012

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"Pain is the most single common reason why an individual consults a medical professional. Grünenthal is committed to support the pain relief of these patients."

Main workplace/Organisation
Grünenthal Group

Profession/Function
Chief Executive Officer

Fostering pain research and education for improving pain patients' lives

Being a global pharmaceutical company with long-time experience in the development of innovative analgesics, Grünenthal is passionate about being the preferred partner worldwide in pain management for patients, healthcare professionals and payors. Grünenthal's main efforts lie in pain research and providing high-potential and reliable medications to the patient. Our portfolio covers a broad range of highly effective products indicated for both chronic pain conditions and acute pain conditions. This includes products being effective for the relief of nociceptive pain and neuropathic pain causes.

Pain is the most single common reason why an individual consults a medical professional. The European Federation of the International Association for the Study of Pain chapters (EFIC®) states that, whereas acute pain may reasonably be considered a symptom of disease or injury, chronic and recurrent pain is a specific healthcare problem, a disease in its own right. Pain and especially chronic pain can have a significant negative impact on the quality of life for patients and their loved ones.

Grünenthal is actively involved in EUROPAIN, a public-private partnership funded by the Innovative Medicines Initiative (IMI) and the pharmaceutical companies under the umbrella of the European Federation of Pharmaceutical Industries and Associations (EFPIA) to implement a five-year research project to understand and improve treatment of chronic pain. The project has now run for 2 year and has already achieved significant results, which will improve the possibility to predict the clinical efficacy of new analgesic compounds.

The Grünenthal Group is an independent, family-owned international research based pharmaceutical company headquartered in Aachen, Germany. Building on its unique position in pain, its objective is to become the most patient-centric company to be a leader in therapy innovation. Altogether, the Grünenthal Group has affiliates in 26 countries worldwide. Grünenthal products are sold in more than 155 countries and approx. 4,200 employees are working for the Grünenthal Group globally.

We consider it very important to cooperate closely with external opinion leaders and development partners. Grünenthal is already involved in lots of successful long-term cooperations. Given the rapid transformation in research and technology, successful research and development strategies can today only be implemented in close cooperation with other highly specialized partners in industry and education.

Being committed to innovations in pain management Grünenthal supports the discussion on the Societal Impact of Pain and is happy to collaborate with EFIC and FAKS on this exciting platform.

ENDORSING ORGANISATION SIP2012

PERSONSKADE FÖRBUNDET RTP

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"We don't demand more care for people living with pain – we demand right care!"

Main workplace/Organisation
Swedish Association for Survivors of Accident and Injury (RTP)

Profession/Function
Chief of Staff

Improve care and rehabilitation for people living with pain

RTP works to promote participation and accessibility in society for the survivors of road traffic accidents, other accidents and polio. We mainly work with empowering our members in such a way that they can take charge of their own life situations. Members can support and guide each other in their new life situations, for example with contacting authorities. Activities include self-help groups and constructive initiatives. RTP provides support and guidance in matters relating to traffic insurance, social insurance and care and rehabilitation issues.

RTP influences society on a broad front in terms of care and rehabilitation, social insurance issues, training and employment. RTP seeks fair treatment and a more accessible society. The experiences of our members always form the basis for influencing decision-makers at local and central levels. RTP has built up a network of members of the parliament, and is continuously serving them with facts and views on matters of special concern to the RTP members. RTP also initiates research of benefit to our members.

The purpose of RTP is to promote a society characterized by diversity and respect for people with disabilities resulting from traffic injuries, accidents or polio. We work towards goals based on the UN Convention on the Rights of People with Disabilities:

- To ensure opportunities for people with disabilities to participate in society on equal terms as the rest of the population.
- To promote health care and rehabilitation to secure a positive life situation for people with disabilities.
- To keep up-to-date with scientific research and development within RTP's areas of interest.

The work of RTP is founded on our belief in an egalitarian society where all people are of equal value and where all citizens have the same rights and responsibilities.

ENDORSING ORGANISATION SIP2012

Swiss Association for the Study of Pain (SASP)
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www.pain.ch

The aims of the SASP mainly include

- **the promotion of scientific research,**
- **knowledge as well as practical know-how transfer and exchange,**
- **endorsement of teaching and continuous education in the field of pain**

Main workplace/Organisation
Swiss Association for the Study of Pain (SASP)

Profession/Function
President

Swiss Association for the Study of Pain (SASP)

The Swiss Association for the Study of Pain (SASP) is the Swiss Chapter of the International Association for the Study of Pain (IASP) and of the European Federation of IASP Chapters (EFIC).

Founded in the 1980s, the SASP convenes over 250 health professionals involved in the treatment and study of pain problems. These professionals have different backgrounds: medicine (e.g. anesthesiology, neurology, pharmacology, internal or general medicine, rheumatology, psychiatry, rehabilitation), psychology, physical or occupational therapy, nursing, chiropractics,… thus making the SASP a truly multidisciplinary society.

The aims of the SASP mainly include

- the promotion of scientific research,
- knowledge as well as practical know-how transfer and exchange,
- endorsement of teaching and continuous education in the field of pain.

In order to encourage research in the field of pain, the SASP grants Poster Prizes at the time of the annual meeting of the society, awarded competitively on the basis of scientific merit in clinical studies and studies in basic science areas. The SASP also supports continuous education by attributing grants covering part of the fees of multidisciplinary courses on pain mechanisms and treatment.

Furthermore, the society's website (www.pain.ch) offers health professionals and patients information regarding topics related to the treatment of pain as well as links with various institutions or organizations involved in the management of pain, from a therapeutic and/or scientific standpoint.

Main workplace/Organisation
Swiss Headache Society

Profession/Function
President

Swiss Headache Society

Founded in 1995, the Swiss Headache Society consists of specialists, general practitioners and scientists who are involved in the medical field of headache.

Furthermore the administrative office often assists patients suffering from headache and offers these patients a variety of brochures, flyers and texts on the society's website (www.headache.ch) with helpful information.

The Swiss Headache Society is a member of the European Headache Federation and since 1996 a member of the International Headache Society.

With its 120 members, mainly neurologist but also internal specialists and psychiatrist, the society pursues the following goals:

- support of medical research on the topic of headache
- advancement of the cooperation between doctors and people who are involved in the treatment of patients suffering from headache and/or do research on headache related topics
- to inform and advise patients on new methods of treatment

ENDORSING ORGANISATION SIP2012

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"The society supports the improvement of research, diagnostics and therapy of headache and shares new knowledge with doctors, patients and scientists."

S

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Pain has a price, whether it is mental, physical or both. Can authorities offer remedies, without necessarily striving for a perfect world?

Main workplace/Organisation
Senate

Profession/Function
Member Commission Social Affairs

Pain and Social Affairs

Rik Torfs is a member of the Belgian Parliament; senator for the Christian Democrats.

He is a member of the Commission Healthcare and Social Affairs of the Senate. As a politician, an academic and a writer he has a keen interest in the quality of life, of which pain management can be an important part.

He studied law and canon law at Katholieke Universiteit Leuven in Belgium. He is professor at the Faculty of Canon Law in Leuven since 1988 and visiting professor in Strasbourgh (France), Paris (France) and Stellenbosch (South Africa).

Rik Torfs is also an active member of several international boards and commissions including the editorial board of the Revue de Droit Canonique (RDC), the Board of Directors of the European Consortium for State-Church Research.

He has authored a number of books and has written nearly 350 articles on Canon Law, Law, Church and State relationships. He is columnist for the Belgian newspaper De Standaard and even hosted his own TV-show Nooitgedacht (Canvas, 2006-2010).

Main workplace/Organisation
Lehrstuhl für Neurophysiologie

Profession/Function
Professor

The Road Map for Action and the Road Map Monitor

An important outcome of last year's symposium SIP 2011 was the Road Map for Action, which outlines the key issues on how the EU institutions and member states could effectively address the societal impact of pain at both EU and national levels.

The 'Road Map for Action' outlines seven key policy dimensions, including identification of acute and chronic pain as specific health care problems, initiation of national action plans against pain, education of the public on pain mechanisms and the interference of pain with quality of life, funding for pain research, education of health care professionals on diagnosis and treatment of acute and chronic pain, funding for pain treatment plans, benchmarking and monitoring of best practices in pain care at national and EU levels. The Road Map for Action aims to provide politicians and health care decision-makers with a benchmark on national policy in pain care throughout Europe. Recognising the need for an improved pain care agenda, the European Road Map Monitor 2011, which is based on the 'Road Map for Action', has been developed to document progress.

Preliminary results from this first European Road Map Monitor into pain care were presented in Hamburg (21-24 September 2011) at the 7th Congress of the European Federation of the IASP® Chapters (EFIC®). These early findings offer a snapshot of how countries have addressed and implemented, nationally and internationally, the "Road Map for Action" for improved pain care in Europe.

The preliminary findings from the European Road Map Monitor 2011 have reinforced many of the ongoing issues relating to the societal impact of pain. Although the majority of countries in Europe reported to be in the process of establishing some form of pain platform, ten years on from the EFIC® Declaration of Pain, national and EU policy action had been very limited and was not adequately prioritised with governments and health providers in many parts of Europe.

In the future, a consensus finding process will be required on a local level to integrate all stakeholders represented in the SIP platform at EU level (e.g. IASP® chapters, professional organisations, patient advocacy groups and all other stakeholder representatives involved in pain care). An important role for EFIC® will be to serve as broker for information exchange between countries on best practice examples and to communicate with the EU institutions to improve pain care throughout Europe.

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"Everybody seems to agree that pain has a tremendous negative impact on the individual life and on the human community at large, but this common sense does not lead to action. It seems that each decision makers assumes all the other decision makers are already taking action to solve this important issue in the health care system. To end this paradoxical state of inaction, we need the initiative 'Societal Impact of Pain' by all European Pain Societies."

T

ENDORSING ORGANISATION SIP2012

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"The impact of the excruciating and debilitating facial pain of Trigeminal Neuralgia on the lives of sufferers and their families is immense and, unfortunately, little understood by employers, work colleagues or even those closest to them."

Main workplace/Organisation
Trigeminal Neuralgia Association UK (TNA UK)

Profession/Function
Patient Support Group

Trigeminal Neuralgia, TNA UK and the Societal Impact of Pain

The Trigeminal Neuralgia Association UK (TNA UK) is a support group for people suffering from an agonizingly painful neurological condition. Trigeminal Neuralgia (TN) affects one or more of the three branches of the trigeminal nerve in the head and has been called "the worst pain known to man". It is characterised by sudden, excruciating spasms of electric shock-like pain, usually just on one side of the face. Thankfully, it is a relatively rare condition, with an incidence rate of 12.6 per 100,000 people per annum. It is more common in women than in men and it generally affects people aged 50 or over.

The exact cause of the condition is unknown but it is thought to be as a result of damage to the root of the trigeminal nerve at the base of the skull where it emerges from the brain stem, often because the nerve is being compressed by a vein or an artery. This damage causes the nerve to malfunction and send messages of intense pain to the brain in response to just a light touch on a 'trigger' area of the face. The pain can last from a few seconds to a few minutes and there can be several bursts of pain in quick succession. Any facial movement such as eating, talking, smiling or kissing, washing the face or brushing the teeth can provoke an attack and this can completely destroy any quality of life. Unable to live normally, patients become isolated and depressed, sometimes to the point of suicide.

The broader impact of the pain from TN arises mainly from a lack of awareness and knowledge of TN from primary healthcare professionals; leading to misdiagnosis, subsequently leading to the cost and consequences of inappropriate interventions; and failure to recognize and provide for the disabling effects on sufferers and carers. Regrettably, TN is often misdiagnosed due to lack of knowledge amongst some medical professionals. Many patients suffer for months or years without correct treatment and, because the nerve goes to each of the teeth, some even undergo extensive, unnecessary and even harmful dental work before getting a diagnosis.

Normal painkillers bring no relief and TN is usually treated with ever increasing doses of anticonvulsants (used to treat epilepsy) which have very unpleasant and often intolerable side-effects, and lose their efficacy with time. Even though various surgical procedures are available, there is no known cure for TN and recurrences of pain are common.

As time goes by, there can be periods of complete pain remission but these gradually become shorter and shorter, and patients therefore live in constant fear of a severe attack of debilitating pain. This not only affects their ability to work and their earning capacity, but also destroys their quality of life, and ultimately their relationships with family and friends. The impact of this condition on the lives of sufferers and their close contacts is immense, as is the cost in financial terms due to the inability to work and lead a normal life.

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Udruženje za Istraživanje i Tretman Bola Srbije (UITBS), Serbian Association for Pain Research and Treatment (SAPRT)
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"Don't take one step - jump forward! Patients can't wait anymore. Pain management is a fundamental human right."

Main workplace/Organisation
Udruženje za Istraživanje i Tretman Bola Srbije (UITBS), Serbian Association for Pain Research and Treatment (SAPRT)
Profession/Function
EFIC Councelor

Steps towards an Adequate Pain Management in Serbia

The Serbian Association of Pain Research and Treatment (SAPRT) was founded in 2006. In spite of the SAPRT's activities and strive to find ways to adapt pain treatment systems to the national realities, the problem of pain is still poorly recognized in the Serbian Health Care System. Many reasons have been addressed:

The Health Care System (HCS)
Pain treatment facilities in Serbian HCS are insufficient. After the National Palliative Care (PC) Strategy was adopted in 2009, PC became integrated into the HCS and significant progress towards overcoming barriers and improving the availability and accessibility of opioids had started. The NSAIDs are not the first therapeutic choice anymore. The majority of coanalgesics is expensive, and in spite of the availability of medicines, equal access to pain management is not provided for all patients who suffer neuropathic pain, which is due to reimbursement strategy.

The patients
There is no national epidemiological study on chronic pain and no accurate diagnosis of the problem, but the chronic non-cancer pain is the major health problem after cancer and cardiovascular diseases. It was estimated that almost 17% of the Serbian population is older than 65 years. National PC Strategy resulted in obvious positive changes, and particularly, cancer pain management in Serbia has been improving.

The Health Care Professionals (HCPs)
A lack of core knowledge among physicians how to assess and treat pain, inadequate communication between physicians and patients, as well as opiophobia are the consequences and the main barriers related to HCPs. Anesthesiologists are the most skilled doctors involved in pain treatment. Pain specialists are not recognized in the HCS.

Education
CME courses, symposia and workshops on chronic pain have been launched by the SAPRT. Educational resources: National PC Guidelines, National Cancer Pain Guidelines, Pharmacotherapy of Cancer Pain (2007), Opiophobia brochures (2009), Treatment of Chronic Pain in Adults (e-learning publication-Interactive CD-R, 2011), Recognize Your Pain brochure (2012) are additional efforts for making improvements in pain management. Introducing the teaching subject Pain Medicine into the curricula of Medicine and Nursing Studies at the Faculty of Medicine of the University of Novi Sad and Palliative Medicine in curricula of Medicine Studies are a great educational step forward.

Conclusions
The research on the prevalence of chronic pain in Serbia is a highly important task. SAPRT is on the way to adapt pain management systems to the national realities and to overcome pain undertreatment and suffering from pain. SAPRT's task is more than ever oriented towards increasing awareness and interest in pain in the Serbian HCS. Besides the Palliative Care, Pain Management also needs to be incorporated into the national HCS. Without the MoH awareness and willingness, a launch of the National Action Plan against Pain would not be achievable.

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"Ukrainian Association for the Study of Pain (UASP) is a multidisciplinary organization that brings together healthcare practitioners, researchers, policy-makers and politicians to improve medical assistance to people suffering from pain."

Main workplace/Organisation
Ukrainian Association for the Study of Pain (UASP)

Profession/Function
Professor of Primary Care Medicine

Ukrainian Association for the Study of Pain

Key areas of work of Ukrainian Association for the Study of Pain include:

- support of clinical research in the area of epidemiology pathophysiology, pharmacology, diagnostics, treatment and prevention of pain;
- support of establishment and development of specialized medical centers, clinics, laboratories, working in the field of diagnostics, treatment and prevention of pain;
- consolidation of efforts of healthcare practitioners of various specialties in the field of diagnostics, treatment and prevention of pain;
- support of establishment and conduction of training and refresher courses for medical doctors in the field of pain;
- promotion of information on chronic pain syndromes among the population and healthcare practitioners.

UASP recognizes the Societal Impact of Pain (SIP) as an EU initiative and has endorsed SIP 2011 "Road Map for Action". During 2011-2012 UASP members hasve been working hard to implement it on national level under the direction of President Professor Igor Romanenko. UASP has also endorsed such important International documents as the Declaration of Montreal and the Declaration of Miami.

Each year UASP performs numerous activities during European Week Against Pain (EWAP), which are highlighting the Societal Impact of Pain and are aimed to raise peoples' awareness of chronic pain and its societal burden. In 2011 following activities were performed:

- the premiere of new piece of famous Austrian composer and director Kurt Schmid (Vienna) in Lugansk State Philharmonic. The Maestro supported European Week Against Pain and devoted his new composition called "Ode to life" to eternal struggle of human beings with pain;
- conference and press-conference on Societal Impact of Pain;
- publications on societal aspects of chronic pain in Ukrainian newspapers;
- Radio interview of President of UASP, professor Igor Romanenko about the burden of chronic pain and its high societal impact. The interview was followed by a big amount of live calls and questions from listeners.

Main workplace/Organisation
Universidad Carlos III de Madrid

Universidad Carlos III de Madrid

Since the nineteenth century one began to use the first successful anesthetic in surgical operations which changed the relationship between men and the pain. It laid the groundwork for an approach in which the pain is not considered an inescapable curse but a set of problems to solve and solvable by science. Pain management has advanced dramatically in every aspect, from its experimental characterization and measurement to the pharmacological or psychological approaches. In studies the quality of life of a patient is a fundamental parameter.

The social implications are of great importance. We think of the direct costs of their treatment and that pain is a determining cause of work disability. Initiatives to promote the study of pain in all its dimensions, deserves the most support of all institutions and indeed the entire research community.

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ENDORSING ORGANISATION SIP2012

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Main workplace/Organisation
Universidad de los Pacientes

Profession/Function
Director General

Universidad de los Pacientes

The Patients' University main goal is to promote modernization and improvement in the quality of health care. It focuses on carrying out information kits, education, and research activities, in order to ensure that patients and users of health care services have equal opportunities in health education and access to high quality medical care.

Main workplace/Organisation
University of Cádiz

Profession/Function
Professor of Department of Neuroscience, Pharmacology and Psychiatry

University of Cádiz

With the establishment of its first cloister, on 30th of October 1979, the University of Cádiz (UCA) was founded, culminating a long process of vindication of a university institution that recovers to Cádiz and its province, the fruitful tradition of higher education initiated and developed under the protection of maritime and commercial activities in modern and contemporary ages. The historical background of the superior studies in Cádiz dates back to the 15th century.

At the University of Cádiz we know and recognize the value of people. Nothing would be possible without the team that works to create and live the University. And if anything characterizes the human being it is its ability for communication. Thanks to the communication we know people. It is more a socio-cultural fact than a mechanical process. The University of Cádiz is a living, active, modern, tireless University which organizes daily activities for a main purpose: integrating and giving back to society what society itself gives to the University.

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"A University that has a lot to tell on Sciences and other fields."

U

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"An institution with a future vision."

Main workplace/Organisation
Universidad Rey Juan Carlos

Universidad Rey Juan Carlos

Even with just 15 years of life – it was created by law in 1996 –, this period of time has been enough for the Universidad Rey Juan Carlos (URJC), the youngest one in the Comunidad de Madrid, to become a regional and national referee, and to be a clear example on how work should be done in order to achieve international excellence.

The URJC is a University model that spreads its arms via four campuses, in various areas of the region: Madrid, Alcorcón, Fuenlabrada and Móstoles.

In its 15 years of existence, the growth of its number of students has been vertiginous, as currently there are nearly 33.000 students registered who take a Grade or Post-grade (Master and Doctorate) as well as other programs that are particular of the Institution. These students are attended by 1.800 professors.

Within the new horizons opened after the Bologna process, the Universidad Rey Juan Carlos walks on the European Space of Higher Education with more than a hundred Post-grade studies, adapted to the requirements of this common space.

The investigation and the entrepreneurship through the association with businesses are two of the main aspects contributing to the growth experienced by the University.

The awarding with the stamp of the International Excellence Campus "Intelligent Energy" is the ideal instrument to walk towards the world elite.

The international dimension of the URJC becomes visible in the fact that 11% of its students come from other countries, and in the increasing participation of our students in the exchange programs like Erasmus and Erasmus Munde.

Main workplace/Organisation
European Commission DG sanco

Profession/Function
Policy analyst

European Innovation Partnership on Active and Healthy Ageing

In its Europe 2020 flagship initiative Innovation Union, the European Commission put forward the concept of European Innovation Partnerships (EIP) to promote breakthroughs to address societal challenges and gain competitive advantages. It proposed to test the concept by launching a pilot EIP on Active and Healthy Ageing. In its conclusions of 26th November 2010 the Competitiveness Council welcomed the objectives of the proposed EIP and supported the development of a pilot EIP on Active and Healthy Ageing.

The pilot EIP on Active and Healthy Ageing is a new stakeholder-driven approach to research and innovation. The overarching target is to raise the average number of healthy life years by 2 by the year 2020 in the European Union. The pilot EIP on Active and Healthy Ageing is expected to bring added value by: joining up efforts, bridging the gaps between public and private actions and instruments, facilitating scaling up of results and improving the framework conditions. It seeks to improve older people's quality of life, lead to more efficient care solutions and to stimulate growth in the EU.

The Steering Group has put forward a Strategic Implementation Plan on the 7th November, which focuses on actions developed around 3 pillars: prevention, screening and early diagnosis; care and cure; and active ageing and independent living. Within each pillar, the Plan sets out the following limited number of specific actions to be implemented from 2012: Prescription and adherence action at regional level; Personalised health management, starting with a Falls Prevention Initiative; Actions for prevention of functional decline and frailty; Replicating and tutoring integrated care for chronic diseases, including remote monitoring at regional level; Development of interoperable independent living solutions, including guidelines for business models; Innovation for age friendly buildings, cities and environments.

At the end of February, the Commission adopted a Communication endorsing the content of the Strategic Implementation Plan and setting out its commitment to support the move from plan to action. The Commission will build a monitoring and assessment framework for the EIP actions. That should deliver the evidence to convince others to move along with us. Furthermore, the Commission will work on the regulatory framework: legislative issues; Standardisation; a robust evidence base; the exchange of good practices; and the alignment of its funding instruments.

About Marianne van den Berg
Mrs Marianne van den Berg is a policy analyst at the European Commission, at the Directorate General for Health and Consumers (SANCO) since February 2011. She is involved in the European Innovation Partnership on Active and Healthy Ageing, launched as part of the European Commission's "Innovation Union" initiative.

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"The ageing of society is not only one of the greatest achievements of the 21st century, but also a social and economic challenge for European society.
We have to commit ourselves to providing care to those in need, whilst giving ample opportunities to those that are active and healthy to continue to contribute to society."

V

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"A professional coaching system has to be established for the patient with chronic pain."

Main workplace/Organisation
MLOZ

Profession/Function
Director Innovation

Coaching for chronic patient

For patients with chronic diseases and conditions, as chronic pain, a holistic approach, including screening and early diagnosis, but also patient empowerment, should be developed with the outcome of rational programs for risk management, disease management and case management.

Coaching plays an essential role is these programs. The contributors want to discuss the content of coaching: which targets can be fixed? Which indicators used? Which monitoring?

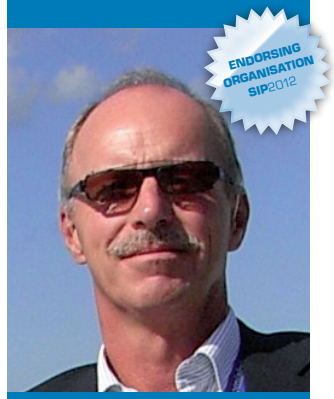
Main workplace/Organisation
Pain Alliance Europe

Profession/Function
President

To improve the quality of life of people living with pain in Europe

PAE is a European umbrella alliance of national organizations involved in chronic pain. Since pain is the most common issue of the PAE members, the PAE's biggest interest is to work on a European approach on chronic pain management. This should start with recognizing chronic pain as a disease in its own rights.

As a result of that, a European strategy for education of caregivers as well for patients should be developed. A European strategy to inform the general public should also be developed such as a prevention program for chronic pain. Prevention is always better than cure.



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"Awareness for chronic pain across Europe has to rise to a higher level in order to create a surrounding in which chronic pain can be diagnosed and treated in a better way."

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"The challenge that EFIC is recently facing, goes to direction of calling, through the Road Map for Action, for policymakers and scientific societies to adopt a much wider perspective to plan a common strategy."

Main workplace/Organisation
ASL Teramo

Profession/Function
General Manager

Pain Management and the importance of walking on the same pathway

In 1999 EFIC declared that "chronic […] pain is a specific healthcare problem, a disease in its own right", a position later endorsed by the WHO, which stated "pain is a problem in its own right […]". As for this first important step, it is has been recently acknowledged that severe chronic pain should be treated as more than just a symptom.

The EFIC's and SIP Platform's work in the past years, has lead to recognize, to a certain degree, that chronic pain does not only present a special therapeutic challenge, but it also holds a formidable challenge for social and political operators, for its prevalence and impact on social and economical costs. Approximately 20% of the European population experiences chronic pain, but prevalence estimates vary widely. Typically, chronic pain persists for a considerable period and its incidence tends to increase with age; one recent study found that the average time from the onset of pain to consultation with a primary care physician was 3 years, and to referral for specialist help was 12 years. This has enormous consequences on costs and deeply affects assessments on the budget planning activity of the national and local healthcare providers.

Current guidelines and approach

Numerous national and international guidelines for treating chronic pain are available, whereas treatment decisions are based mainly on pain intensity. However, chronic pain is often multifactorial and while optimal pharmacological treatment is still the mainstay of successful pain therapy, a multimodal approach is required for chronic cases, incorporating such modalities as physiotherapy, psychological therapy, patient education and peripheral stimulation. It is important to try and achieve an optimal balance between analgesic efficacy and adverse events, because inadequate pain relief and/or intolerable side effects may lead to the establishment of a Vicious Circle that significantly impairs the patient's quality of life. This suggests that a common and widely accepted therapeutic strategy would lead to a better management of resources, with medical and economical implications.

Importance of training for health care professionals

A consistent approach to the treatment of chronic pain is currently lacking across Europe. Adequate training for health care authorities and pain care professionals is not standard practice throughout Europe, as most medical specialists lack specialized training on chronic pain. The overall picture is that chronic pain in Europe is inadequately treated and there is a general feeling of a need to improve healthcare professionals' knowledge on the physiology and pharmacology of pain.

The challenge that EFIC is recently facing goes to direction of calling, through the Road Map for Action, for policymakers and scientific societies to adopt a much wider perspective to plan a common strategy to provide adequate services, share guidelines and allocate resources. This should lead to a greater appreciation of the prevalence of chronic pain and a better understanding of the needs of these patients. It might also raise the awareness of pain on the political agenda, with a beneficial effect on regulations.

Main workplace/Organisation
Innovative Medicines Initiative

Profession/Function
Principal Scientific Manager

EUROPAIN – Understanding Chronic pain and improving its treatment

EUROPAIN is a public-private partnership funded by the Innovative Medicines Initiative (IMI) and the pharmaceutical companies under the umbrella of the European Federation of Pharmaceutical Industries and Associations (EFPIA) to implement a five-year research project to understand and improve treatment of chronic pain. The project receives 6M of public funding from IMI as well as 12.5M in kind contribution from the involved pharmaceutical companies.

Under the leadership of Astra Zeneca and King's College London EUROPAIN brings together laboratories drawn from the London Pain Consortium (www.lpc.ac.uk), the German Neuropathic Pain Network (www.neuro.med.tumuenchen.de/dfns), the Danish Pain Research Centre (www.dprc.dk) and Spanish based research intensive small/medium enterprise (Neurosciences Technologies (www.nsc.anacronico.com)) as well as the pharmaceutical companies Boehringer-Ingelheim, Pfizer, Eli Lilly, Esteve, UCB Pharma, Sanofi-Aventis, Astellas, Abbott and Grünenthal.

The scientific programme of EUROPAIN covers in vitro and in vivo research in laboratory animals, healthy human volunteers and pain patients. The project has now run for 2 year and has already achieved significant results. Progress will be presented on the work done to understand changes in the nervous system contributing to pain, on translational studies to identify new pain mediators, and on the validation of mechanism-based pain models in healthy volunteers. Clinical research results will be shown on the finding of objective measures of spontaneous pain, on the detailed characterisation of clinical findings in chronic pain patients, on determining risk factors for the development of chronic pain, and on analyzing placebo responses in clinical trials.

The improved knowledge that will come out of this collaborative cross-functional project will increase our knowledge of clinical phenotypes, disease mechanisms and the correlation between different outcome measures. These assessments and measurements are also performed in animal studies, thereby validating relevant translational mechanisms and pharmacodynamic outcome measures. The results will improve the possibility to predict the clinical efficacy of new analgesic compounds, which until now has not been very successful.

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"Presently, the socio-economic burden of chronic pain is great, both on the individual and on society. Direct costs are large, and indirect costs are several-fold. Existing drug therapies are insufficient and a majority of patients withdraw from treatment due to lack of efficacy or subjective side effects. Innovative collaborative research approaches involving all relevant stakeholders to boost R&D for chronic pain are keys to solve such impasse."

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"The burden of pain and other symptoms in advanced cancer is still unacceptably high."

Main workplace/Organisation
Centre de Psychiatrie et Neurosciences, INSERM U.894

Profession/Function
Director of Research

Luis Villanueva

Date and Place of Birth
February, 10, 1957 at Viña del Mar (Chile)

Education and Training
DDS; Faculty of Dentistry, University of Chile, Santiago; 1978.
PhD; University of Paris-6, 1984.
DDS; University of Paris-5, 1985.
DSc; Docteur d'Etat, University of Paris-6, 1986.

Leadership Roles in Pain Associations
Member, Research Committee, IASP, 1996-2000
Coordinator, IASP Core Curriculum for Professional Education in Pain, Chapter Anatomy and Physiology of Pain, JE Charlton Editor, IASP Press, 2005.
Member, Membership Committee, IASP, 2002 – 2006.
Councilor, French Chapter of IASP (SFETD), 2010-2013.
Vice-Chair, Committee on Research, European Federation of IASP Chapters (EFIC), 2011-2014.
Chair, Committee on Research, EFIC, 2014-2017.
SFETD Councilor at EFIC, 2011-2014.

Areas of interest
My research interests have centered on basic, animal studies of central nervous system (CNS) networks that are involved in pain processing. My doctoral dissertations were devoted to the study of the role of descending bulbospinal systems in the modulation of nociception, with special emphasis in Diffuse Noxious Inhibitory Controls. My post-doctoral work was devoted to the anatomo-functional identification of a distinct region within the medullary reticular formation that plays a key role in both the transmission and modulation of pain signals. My group is currently studying the functional architecture of endogenous CNS mechanisms of pain modulation by employing combined anatomical, electrophysiological and behavioral in vivo approaches, with special emphasis on top-down, corticofugal and hypothalamic controls.

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"Pain is the most forgotten disease, but once you get it, you will never forget it!"

Main workplace/Organisation
Radboud University Nijmegen Medical Centre / Expertise Centre on Pain and Palliative Medicine, Palliactief – Nederlandse vereniging voor professionele palliatieve zorg, Board member of the Dutch Pain Society, Executive Board of World Institute of Pain
Profession/Function
Professor in Pain and Palliative Medicine

Pain Policy: Ensuring Access to Pain Treatment: a Roadmap to Action!

Pain is the most frequent cause of suffering and disability in society. Pain is a serious health issue that takes epidemic proportions. The financial burden of chronic pain problems for society is more expensive than cardiac and cancer disease taken together!

From a public health perspective, the challenges are to enhance the prevention of chronic pain, to improve the diagnosis and to improve the treatment and care for pain sufferers. Therefore improving care for those people suffering from chronic pain will restore the quality of their life and improve the feeling of dignity of the individual and his family.

According to Article 2 of the Lisbon Treaty living with chronic pain is a serious challenge for the feelings of dignity for the patient and his family. Time has come, 12 years after the EFIC declaration on "Chronic Pain as a Major Healthcare Problem, a Disease in its Own Right" which was also launched in the European Parliament, to examine the efficiency of policy measures and regulations aimed at the elimination or reduction of health inequalities and barriers surrounding pain care. A specific program should be started within the European Parliament and in the member states to improve the treatment and quality of life of people now still suffering in silence.

In the White paper "Together for Health" of the commission of the European Communities pain is not named, but important actions were launched. There should come a coherent framework – a EC Health Strategy – to give directions to Community activities in Health. Each citizen should have access to preventive healthcare and to medical treatment. The commission should start a system of European Community Health Indicators with common mechanisms for collection of comparable health data at all levels, including a Communication on an exchange of health-related information.

A special program should be developed to perform analytical studies of the economic relationships between health status, health investment and economic growth and development. Impact Assessment and evaluation tools should be integrated at all Member States and regional levels. The Commission should strengthen mechanisms for surveillance and response to health threats such as chronic pain.

Therefore, SIP & EFIC launched the "Roadmap to Action" in 2011 during the second symposium on the societal impact of pain. Pain should be acknowledged as an important health threat for each European Citizen impacting the quality of life of millions of people every day. Awareness should be raised on the prevention, diagnosis and high standard management of pain amongst all healthcare professionals, by starting a long-term European Framework for pain education & research, and for exchange, comparison, benchmarking of best practices between member states on pain management. Since last year several new initiatives were launched at the national levels in member states.

A good collaborative program of scientific societies, innovative industrial partners, policymakers and decision-makers can improve the care for those patients and families who suffer now in silence. Make pain more visible at all levels of the Society and in the European Parliament.

ENDORSING ORGANISATION SIP2012

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"VLFP is a patient organization for people who suffer from fibromyalgia."

Main workplace/Organisation
Vlaamse Liga voor Fibromyalgiepatiënten vzw

Profession/Function
Treasurer

Vlaamse Liga voor Fibromyalgie-patiënten vzw

VLFP is a patient organization for people who suffer from fibromyalgia. The universal symptom of fibromyalgia is pain. The pain in fibromyalgia is not caused by tissue inflammation. Instead, patients seem to have an increased sensitivity to many different sensory stimuli and an unusually low pain threshold. Minor sensory stimuli that ordinarily would not cause pain in individuals can cause disabling, sometimes severe pain in patients with fibromyalgia. The body pain of fibromyalgia can be aggravated by noise, weather change, and emotional stress.

The pain of fibromyalgia is generally widespread, involving both sides of the body. "Tender points" are localized tender areas of the body that can bring on widespread pain and muscle spasm when touched. Fibromyalgia tender points, or pressure points, are commonly found around the elbows, shoulders, knees, hips, back of the head, and the sides of the breastbone.

Chronic pain can have a devastating impact on all aspects of an individual's life. It can limit the ability to participate in work and social activity, shattering confidence and further impairing quality of life. The subjective nature of pain can lead others to doubt its severity and public views of people with chronic pain are not always sympathetic. The current picture of fibromyalgia management is characterized by significant waiting time to diagnosis and treatment, multiple healthcare professional visits and suboptimal pain management. This needs to change.

The objectives of VLFP are:

- Put everyone who has to do with fibromyalgie directly or indirectly, both patients and non-patients, in contact with each other.
- Supplying practical, emotional or other assistance, both to patients and to their family.
- Giving information and guidance by editing a magazine and brochures, by giving lectures and on our website and forum.
- The promotion of awareness by - participation in umbrella organizations such as Reumanet.be, Vlaamse Pijnliga, Vlaams Patiëntenplatform, - attending national and international conferences, - making contact with medics, politicians, … .

Main workplace/Organisation
Vlaamse Pijnliga (Flemish Pain League)

Vlaamse Pijnliga

The 'Vlaamse Pijnliga' (Flemish Pain League) is an umbrella organisation that brings together organisations that are concerned about pain in Flanders. It is made up of a growing number of concerned patients' organisations (such as MCP, Ruggensteun vzw, 't Lichtpuntje, VMCP, Whiplash vzw, Belgische hoofdpijnliga, CVS Contactgroep, CMP, Pijnprikkels, de Maretak) in close co-operation with Ziekenzorg CM. In 2012 the league celebrates its 10th birthday.

The common goal of the Vlaamse Pijnliga and its members is to improve the quality of life of people who suffer from chronic pain and their relatives. To achieve this, the Vlaamse Pijnliga concentrates on 5 key issues.

1. Contact between chronic pain patients
Living with chronic pain is a difficult and challenging task. Talking about it can help. The Vlaamse Pijnliga aims to contribute in two ways. Within the member organisations, group meetings organised for people with chronic pain are a central activity. The Vlaamse Pijnliga offers support and inspiration to continue these contacts and organises exchange between the different organisations.

2. Information
Good and accessible information is very important for people with chronic pain. It is a first step towards managing it. During meetings, the patients' organisations inform their members about different aspects of living with chronic pain. The Vlaamse Pijnliga publishes an information newsletter in order to support that process of informing by the member organisations. Furthermore, the monthly magazine 'Prikkel' contains specific information for and life stories of people with chronic pain.

3. Lobby work
Living with chronic pain means living with limitations of many sorts. Often these include financial limitations due to a cutback in income and high medical costs. The league tries to monitor this situation closely and aims to lobby for an increased substitute income linked to the national level of prosperity. The Vlaamse Pijnliga also wishes to defend the interests of people with chronic pain on other issues, such as modified employment possibilities, 'availability of tools', … and wants to act as the voice of all pain patients in Flanders.

4. The best possible treatment for pain patients
Recent research shows that many pain patients don't always benefit from the received pain treatment. The Vlaamse Pijnliga aims –in dialogue with doctors and paramedics- for treatments that are more satisfactory for the patients. Multidisciplinary treatment has to be encouraged. The role of the general practitioner is central. Trust and confidence are key conditions.

5. Attention for pain
Pain is often invisible. Because of the social ignorance, people are not able to assess the consequences of living with pain. As a result, persons with chronic pain often get isolated. The Vlaamse Pijnliga has the important task to inform society about pain and its consequences. The league supports initiatives that aim to inform the broad public in Flanders or prevent chronic pain.

ENDORSING ORGANISATION SIP2012

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"The common goal of the Vlaamse Pijnliga and its members is to improve the quality of life of people who suffer from chronic pain and their relatives."

© www.wonderfulcopenhagen.dk

Main workplace/Organisation
Pain Matters Ltd

Profession/Function
Consultant Anaesthetist, Specialist in Pain Management

National Health & Wellness Survey 2010 – 65+ Analysis

Dr Wells trained at, and then became Director of, the Walton Centre for Pain Relief, organising services there from 1983 to 1994. He started the first continuously running Pain Management Programme in the UK. He sees, assesses and treats all types of pain problems from acute back pain with sciatica, through to chronic neurological pain. After assessment, treatments recommended might include medication, appropriate nerve blocks and rehabilitation programmes.

Dr Wells is currently president-elect of EFIC, a group of some 19,000 doctors and paramedical personnel, responsible for treatment, research and guidelines on pain across Europe. He founded the NEUPSIG with Ed Charlton, and successfully organized 3 major international meetings for the group. Outside of work he is a keen curler, skier and enjoys anything to do with boats.

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"We all need to work together to reduce the adverse societal impact of pain."

W

ENDORSING ORGANISATION SIP2012

WHIPLASH STICHTING NEDERLAND

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"The Whiplash Stichting Nederland or WSN was established in 1989 for the recognition and acknowledgment of the whiplash syndrome and to enhance the position of whiplash patients. The organization is active in a wide range of activities in the field of advocacy, information, assistance and guidance. At the end of 2011 WSN had approximately 2250 whiplash patients supporting the organization."

Main workplace/Organisation
Whiplash Stichting Nederland (WSN)

Profession/Function
Chair

The Whiplash Stichting Nederland (WSN)

Advocacy
As a proactive advocate of whiplash patients the WSN establishes a well-founded dialogue with professionals about employment, absenteeism and disability. Our personal knowledge about whiplash, the signals of patients through our hotline and help desks and taking joint action with other interest groups contribute to this.

In the project "Knowledge and Power" the WSN and the ME Support Group and Disability work together to improve the inspection practice. An important pillar of the project is the consultancy and hotline for absenteeism and disability. The WSN and its project partners organized an informative meeting for patients on medical reviews in ME / CFS and whiplash and a meeting for professionals called "Occupational, insurance, sick worker: 3 Perspectives, 1 goal?"

The WSN also works towards creating a larger focus on whiplash in the medical world. Our own practical research concerning primary whiplash complaints is an important start. WSN participates in projects and has gained more insight into the problem of pain patients (national pain measurement), the incomprehension that whiplash patients experience (study by the University of Utrecht), and the dreams people with brain injury have. The participation in these projects will continue to occur in the society (conference 'NAH and participate').

Information and Information
The informative activities focus on supporting empowerment of patients, encouraging interactive communication about whiplash and creating awareness and understanding of whiplash injuries to the general public and semi-pros. Means like the website, our own Whiplash Magazine, brochures, the organization of lectures and the representation at informative fairs are used to improve the awareness of both the organization and the condition, and to gain understanding.

Assistance and Guidance
Internally trained competent staff offer whiplash patients help and support so that they can handle their lives as good as possible and to improve their positions in society. This contact with peers often offers a lot of support to whiplash patients by recognizing and understanding them and by giving them valuable information and tips.

Creating Conditions
The group members of this voluntary organization have a major focus on collaboration, as well as on customer needs. To support the volunteers a digital community was set up to provide and exchange information.

Organization and Governance
Within the foundation, there are more than 30 active contacts and 10 supporting volunteers. They are supported by a secretariat of 4 p.t. employees, coordinated by a full time director. The policy of the foundation is established by the board, assisted by the Medical Advisory Council (MAR). The board, led by Mr. L. Both, Chairman, critically follows the implementations and gives his support where this is needed.

Main workplace/Organisation
Swedish Social Insurance Agency

Profession/Function
Program Manager

How can society help people back working

In 2008 an agreement was made between the Swedish government and the Swedish Association of Local Authorities and Regions on a national guarantee of evidence based and medical rehabilitation. The purpose of the guarantee is to support people with anxiety, depression, stress or chronic pain in shoulder, neck and back to return to work or to prevent sick leave.

Simultaneously, a national research program was initiated, REHSAM, with overall aim to identify the best methods for retaining and rehabilitating the ability to work among people suffering from mental illness and/or pain. REHSAM grants is administered by the Swedish Social Insurance Agency and currently 24 research projects are being run in Sweden.

Funding for up to 80 MSEK have so far been allocated to the regions to cover costs of these research projects. Med Dr. Clairy Wiholm, research program leader (Swedish Social Insurance Agency and Uppsala University, Department of Public Health and Caring Science) will provide an overview of REHSAM, some of the findings and what lies ahead in the future of this unique collaboration model.

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"A national research program with the goal to increase the evidence based rehabilitation for people suffering from unspecified pain and mental ill-health."

W

Prof. Anthony Derek Woolf
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www.boneandjointdecade.org

"Musculoskeletal conditions are the most common cause of severe long term pain and physical disability but there is little priority or concerted action for the prevention and management."

Main workplace/Organisation
EUMUSC.NET; Bone and Joint Decade

Profession/Function
Consultant & Professor, DMSc

Musculoskeletal pain: incidence, prevalence and impact on healthy ageing

Musculoskeletal conditions (MSC) are the commonest cause of long term pain and physical disability, affecting hundreds of millions of people around the world. MSC encompass joint diseases (osteoarthritis, rheumatoid arthritis), osteoporosis, low back pain and regional pain problems. Their prevalence increases with age, and many are affected by lifestyle factors, such as obesity and lack of physical activity. Their prevalence and impact is increasing with Europe's ageing population and the changes in lifestyle.

Pain is the most prominent symptom in most people with MSC and is the most important determinant of disability in patients with osteoarthritis. A UK survey of people with arthritis indicated that people have to endure significant limitations on everyday life due to unmanaged pain.

This large and growing burden needs measuring and monitoring across Europe to look for inequities and trends but there are major gaps in our knowledge because available data are often inconsistent and not comparable. The Indicators and Monitoring Programme developed a question on musculoskeletal pain for use in surveys which was used in the 2007 Health in Europe Eurobarometer survey establishing that 22% of adults currently had, or had experienced long-term muscle, bone and joint problems; 32% had such symptoms limiting their daily activities in the previous week.

In 2010 the EUMUSC.net project, bringing together experts from across EU Member States (MS), has provided where possible harmonised information on health, social, employment and economic impact of MSC across MS; and developed a set of core indicators and an assessment tool to harmonise the measurement of the impact of MSC across MS. Efforts to measure the impact of musculoskeletal pain on healthy ageing in a comparable way across MS must be increased to and facilitate public health initiatives to tackle this important problem.

Main workplace/Organisation
World Federation of Incontinent Patients (WFIP)

Profession/Function
President

World Federation of Incontinent Patients

Our Mission
The Federation is dedicated to promoting worldwide the interests of sufferers of incontinence and related pelvic floor disorders. The WFIP provides its individual member associations with the most comprehensive and up-to-date information, guidelines, and educational resources. It seeks global cooperation and consensus via advocacy, public health education, and contact with official and scientific bodies and other patient advocacy groups.

Call To Action
- Developing international guidelines for patients in preventive, lifestyle measures to reduce risks of incontinence and when to seek help for symptoms;
- Elevating the visibility of WFIP; and
- Mentoring to give life to new patient advocacy groups in countries without a patient voice.

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"The WFIP is a global non-profit association for people suffering from incontinence and related pelvic floor disorders and their respective national associations."

W

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Main workplace/Organisation
World Federation of Societies of Anaesthesiologists® (WFSA)

Profession/Function
WFSA Scientific Affairs Committee Chairman

World Federation of Societies of Anaesthesiologists® (WFSA)

Executive Committee Members
The EXCO carries out the resolutions of the General Assembly and takes all measures within the limits of these resolutions designed to further the aims of the Federation. It comprises President, Secretary, Treasurer and 12 elected members representing the following geographical groupings. Africa and the Middle East; Asia; Australia, New Zealand and the Pacific Islands; Central and South America, Mexico and the Caribbean Islands; Europe and Israel; The United States of America and Canada.

President
Dr David Wilkinson / United Kingdom
Treasurer
Dr Mark Lema / United States
Chairman, Executive Committee
Prof Yehia Khater / Egypt
Past President
Dr Angela Enright / Canada

Permanent Committees
Education Committee
The Education Committee is the busiest committee and deals with the main activities that further the goals of the Federation, namely education and dissemination of scientific information. As such it is responsible for the majority of the Federation Expenditure.

Finance Committee
The Finance Committee comprises five delegates from five member societies, two of whom are on the Executive Committee. It establishes the formula for and administration of payment of the annual subscription for the Member Societies. It prepares and administers a budget of anticipated expenditure for the succeeding fiscal years until the next General Assembly.

Publication Committee
The function of this Committee is to promote the highest standards of safety and quality in anaesthesia internationally; to this end it is involved in several projects and is establishing liaison with other groups around the world (notably IAPSF).

Safety & Quality of Practice Committee
The function of this Committee is to promote the highest standards of safety and quality in anaesthesia internationally; to this end it is involved in several projects and is establishing liaison with other groups around the world (notably IAPSF).

Constitution Committee
The Constitution Committee comprises a Chairman and five other delegates from each of the geographical regions of the WFSA. It recommends to the Executive Committee amendments to the Constitution which it considers will facilitate the work of the Federation.

Scientific Affairs Committee
This newly created committee has a function to facilitate the cooperation between centres from advanced and developing countries, in link with national societies, not to develop scientific and research programmes specific to the WFSA.

Professional well-being committee
This newly created committee intends to create awareness of the impact of occupational stress in our profession and to implement strategies for its prevention and management

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Main workplace/Organisation
World Institute of Pain Foundation

Profession/Function
Director of Development

World Institute of Pain Foundation

Founded in 2010 the WIP Foundation has been created to give back to the pain community and to the pain patients, the advances we have made in education and training of pain physicians. The Foundation's mission is to promote education and training of pain physicians who lack the funds and resources (poor and developing countries) to provide them a scholarship for travel and learning in approved centers of excellence. Scholarships will be provided on an on-going basis to the physicians in need, who wish to attend our cadaver workshops, symposia and world congresses.

The Foundation is currently looking for funding to facilitate global research to promote new innovations for chronic complex pain, including cancer pain. In addition, our goal is to expand our resources to the pain patient in order to educate them on available treatments and forums for the betterment of their individual lives, locally, by partnering with Pain Pathways, the Official Magazine of the World Institute of Pain, a consumer based pain publication. The WIPF also bestows the distinguished Hassenbusch Award to the individuals who embody the highest principles of excellence embraced by WIP & WIPF annually, to promote recognition of advancements in pain medicine.

As we continue to be challenged by the realities of pain medicine worldwide, financial help is now even more important to resolve the issues before us. This help can come in the form of small or large projects such as, scholarships to physicians and trainees to attend WIP approved educational meetings, congresses and workshops, allowing the far away pain physician to certify by taking the FIPP examination, or by joining the cause as we work towards recognition of pain as a unique specialty by WHO and other governmental organizations.

Recently, WIPF joined together with WIP, EFIC & WSPC to declare and promote the Declaration of Miami. Leaders in pain management, press and WHO representatives were in attendance as we joined forces for the promotion of pain medicine and worldwide access to pain relief. We are urging anyone who is involved in pain, knows someone in pain, or is a caregiver for someone in pain, to make a difference and sign the on-line declaration at www.wipfoundation.org.

WIP Foundation, Board of Trustees:
Chairman: P. Prithvi Raj, MD, DABPM, DABIPP, FIPP (USA); Chief Executive Officer: Serdar Erdine, MD, FIPP (Turkey); Secretary: Craig T. Hartrick, MD, DABPM, FIPP (USA); Treasurer: Philip M. Finch, MBBS, DRCOG, FFPMANZCA, FIPP (Australia); Liaison to WIP: Ricardo Ruiz-López, MD, FIPP (Spain); Trustees: Gabor B. Racz, MD, DABIPP, FIPP (USA); Richard L. Rauck, MD, FIPP (USA); Giustino Varrassi, MD, PhD, FIPP (Italy); Alex Sow Nam Yeo, MD, PhD, FIPP (Singapore); Charles A. Gauci, KHS, MD, FRCA, FIPP, FFPMRCA (United Kingdom); José R. Rodriguez Hernández (Puerto Rico); Enrique Chico, PhD, (Spain).

"The World Institute of Pain Foundation aims to have a large and permanent impact in pain management in every part of the world."

W

Main workplace/Organisation
World Institute of Pain (WIP)

World Institute of Pain

WIP provides a global forum for open communication through its international membership of physicians to foster the exchange of information in the field of interventional pain management. Through world congresses, symposia, and workshops, physicians learn and train in the most advanced procedures in interventional pain management. Through its journal, Pain Practice, physicians contribute to the scholarly exchange of best practices in pain medicine. Through the Fellow of Interventional Pain Practice (FIPP) physician certification program, WIP is helping to define global standards of best pain practice. Through the Excellence in Pain Practice Award program for pain centers, WIP is engaging a broader network of physicians who dedicate themselves to the worldwide phenomenon of acute and chronic pain syndromes.

- WIP World Congresses have attracted thousands of pain physicians to some of the most vibrant cities: Eilat, Egypt; Istanbul, Turkey; Barcelona, Spain; New York, USA; and Miami Beach, FL, USA. WIP's 7th World Congress will be in Maastricht, Netherlands in 2014.
- Pain conferences and workshops are offered in conjunction with FIPP exams, and organized by leaders of WIP's 22 Sections of: Africa, Australia, Benelux, Canada, Cent-East Europe, Colombia, Hungary, Iberian, India, Iran, Israel, Italy, Latin America, Mediterranean, Middle East, NE Asia, Puerto Rico, SE Asia, Switzerland, Turkey, UK-Eire, and USA.
- Pain Practice publishes multidisciplinary articles on pain and analgesia with emphasis on current research, evaluation methods, and evidence-based techniques for pain management.
- WIP's Board of Examination has certified 702 physicians as FIPP from 38 countries.
- The EPP Award has been issued to 14 pain centers in countries of: Argentina, Australia, Belgium, Brazil, India, Italy, Korea, Netherlands, Switzerland, Turkey, and USA.

In February 2012 at its World Congress in Miami Beach, WIP was joined by EFIC®, World Society of Pain Clinicians, and WIP Foundation and jointly affirmed through the Declaration of Miami that this consortium of pain societies will actively promote the best practice of pain medicine and worldwide access to pain relief. Pain physicians globally are encouraged to sign the online petition at www.wipfoundation.org.

Executive Board - President/Founder, Ricardo Ruiz-López, MD FIPP (Spain); President-Elect, Richard Rauck, MD FIPP (USA); Immediate Past President/Founder, Serdar Erdine, MD FIPP (Turkey); Past President/Founder, Gabor Racz, MD FIPP (USA); Past President/Founder, Prithvi Raj, MD FIPP (USA); Honorary Secretary, Charles Gauci, MD FIPP (United Kingdom); Honorary Treasurer, Kris Vissers, MD PhD FIPP (The Netherlands); Editor-in-Chief, Pain Practice, Craig Hartrick, MD FIPP (USA); Chair, Advisory Board, Ira Fox, MD FIPP (USA); Chair, Board of Examination, Miles Day, MD FIPP (USA); Chair, Board of Sections, José Rodríguez-Hernandez, MD FIPP (Puerto Rico); Secretariat - Dianne Willard (USA), Executive Officer.

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"It is the right of every individual to have access to adequate pain management, generally available information about pain relief options, and systems to provide financial, personnel, and structural resources for proper pain management."

Main workplace/Organisation
University Hospital Jena

Registries as a base for pan - European health services research in the field of pain

Surveys from different countries show that the quality of pain management is far from satisfactory despite the availability of evidence-based guidelines and advanced pain management techniques. What are the reasons for these deficits? Randomized Controlled Trails (RCTs) tend to include highly selected patient groups under "ideal" conditions, and thus, RCT-based recommendations do not always mirror daily practice. Furthermore, clinicians often find it difficult to get evidence-based information at the point of care from the available resources.

"Real life" data, collected by registries, may overcome some of these gaps. A 'registry', or database comprises a large and continuously growing number of cases, it includes patient groups often not studied in RCTs (e.g., very old patients, patients with comorbidities), it reflects the most recent therapies, and thus is an evolving system. If they meet certain requirements on data quality and analysis, registries mirror reality of medical care, allow for comparison and benchmarking, and for in-depth analysis of health care provided under different conditions. Combined with improved availability of evidence derived from clinically relevant trials, registry-based tools might support clinical decision making in daily routine. Furthermore, registries allow for epidemiological and observational research. The network of participating partners may even serve as a platform for conducting of prospective studies.

PAIN-OUT may serve as an example of an advanced pain registry project offering both individual feedback as well as possibilities for research (www.pain-out.eu). PAIN-OUT is funded by the EC's 7th Framework Program and involves 17 clinical and research partners in 9 European countries. PAIN-OUT is creating an Acute Pain Registry and developing tools for data collection, feedback and decision support. It will provide the medical community with a web-based, user-friendly system to improve treatment of patients with postoperative pain. Furthermore, it serves as a large platform for observational and prospective research.

PAIN-OUT relies on experience gained from the German Post-operative Pain Registry (QUIPS), which tracks postoperative outcomes and related data, operating for the last 6 years, in over 140 German hospitals, with over 200,000 records.

PAIN-OUT is endorsed by the International Association for the Study of Pain. In 2013, PAIN-OUT and QUIPS will be merged and participation will be possible for hospitals all over the world.

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"Surveys show that the quality of pain management is not optimal. Registries that show 'real life data' may help to solve this problem. PAIN OUT is an example for an advanced registry offering individual feedback as well as possibilities for research."

Z

Societal Impact of Pain (SIP) 2012
Copenhagen, Denmark
29 - 31 May, 2012

The SIP 2012 symposium takes place under the high patronage of the Italian Presidency of the Council of Ministers and the Italian Ministry of Health.

The SIP 2012 symposium is hosted by the Danish Association for Chronic Pain Patients (FAKS). The scientific framework of SIP 2012 is under the responsibility of the European Federation of IASP® Chapters (EFIC®). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP 2012 symposium have been endorsed by a large number of pain advocacy and scientific organisations.

www.sip-platform.eu

FAKS EFIC EUROPE AGAINST PAIN GRÜNENTHAL

The Ethical Committee for the Pharmaceutical Industry in Denmark (ENLI) has been notified of the Symposium. The SIP 2012 Symposium has been pre-approved by ENLI with the current format and content.

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