



SIP

Societal Impact of Pain

Abstract & Background Booklet

TIME FOR ACTION!

#SIP2016action

The Societal Impact of Pain (SIP) symposium takes place under the high patronage of the Italian Ministry of Health.

The scientific framework of the Societal Impact of Pain (SIP) platform is under the responsibility of the European Pain Federation EFIC®. Cooperation partners for SIP 2016 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP symposia have been endorsed by a large number of international and national pain advocacy groups, scientific organisations and authorities.

www.sip-platform.eu





European Pain Federation EFIC®

Grensstraat 7
1831 Diegem
Belgium
Phone: +32 2 251 55 10
www.efic.org
secretary@efic.org



Pain Alliance Europe (PAE)

Grensstraat 7
1831 Diegem
Belgium
Phone: +32 2 725 01 51
www.pae-eu.eu
info@pae-eu.eu
Twitter: @pain_europe
Facebook: /PainAllianceEurope



Active Citizenship Network (ACN)

HEADQUARTERS
via Cereate, 6
00183 Rome - Italy
Phone: (+39) 06.36.71.81
www.cittadinanzattiva.it mail@activecitizenship.net

REPRESENTATIVE OFFICE TO THE EU
Rue Philippe Le Bon, 46
1000 Brussels - Belgium
Phone: (+39) 3408465097
www.activecitizenship.net brussels@activecitizenship.net

Twitter: @activecitnet
Facebook: www.facebook.com/activecitizenshipnetwork



Grünenthal GmbH

Zieglerst. 6
52078 Aachen
www.grunenthal.com
sip-platform@grunenthal.com

Project management:

Elena Bertozzi
<https://fr.linkedin.com/in/elenabertozzi>

Graphic design:

Frank Maurer, Silvia Pfeifer
www.artletico.de

About the 6th “Societal Impact of Pain” (SIP) symposium 2016: **TIME FOR ACTION!**

The 6th European symposium on the “Societal Impact of Pain” (SIP 2016) brings together international experts in the field of pain care, along with patient representatives, policy makers and other stakeholders in the field of pain policy.

Taking place under the high patronage of the Italian Ministry of Health, SIP 2016 focuses on areas of EU policy that affect pain care and aims to have a lasting political impact, with conclusions expected to be enshrined in the EU policy-making process through their inclusion in a European Parliament Resolution.

SIP 2016 is co-hosted by the following Members of the European Parliament (MEPs): Clara Eugenia Aguilera García, Heinz K. Becker, Soledad Cabezón Ruiz, Nicola Caputo, Theresa Griffin, José Inácio Faria, Takis Hadjigeorgiou, Marian Harkin, Merja Kyllönen, Giovanni La Via, Jeroen Lenaers, Roberta Metsola, Piernicola Pedicini, Sirpa Pietikainen and Sabine Verheyen. It is also supported by MEPs Francoise Grossetête, Therese Comodini Cachia, Miriam Dalli and Agnes Jongerius.

The scientific framework of the SIP symposium and platform is under the responsibility of the European Pain Federation EFIC®. This year's edition sees for the first time the formal cooperation of the patient community, represented by Pain Alliance Europe (PAE), and the civil society, represented by Active Citizenship Network (ACN), partners for SIP 2016, further providing added value in addressing the topic of the societal impact of pain. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support).

The objectives of this years' SIP 2016 symposium have been endorsed by 160 pain advocacy and scientific organisations.

About this booklet

This booklet contains background readings to SIP 2016, providing contextual information on the working groups' discussions and speakers and faculties' abstracts. The booklet also includes the full list of 160 endorsing organisations supporting the scientific objectives of the symposium.

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Due to printing deadlines this booklet, however, does not guarantee inclusiveness of each speaker or organisation. The final complete version will be made available electronically after SIP 2016 at www.sip-platform.eu.

About the “Societal Impact of Pain” and the SIP platform

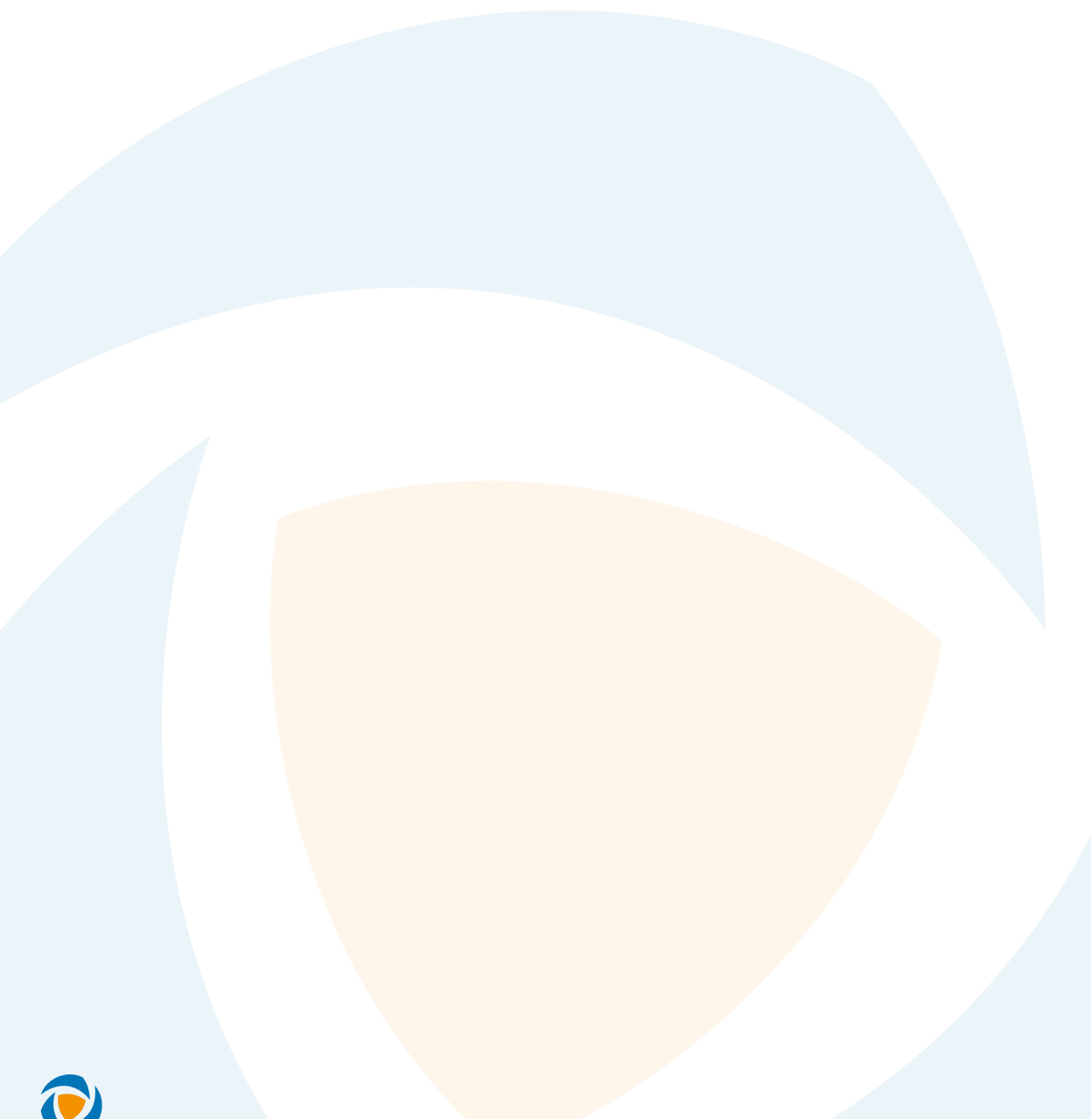
The burden that pain imposes on individuals and the enormous costs that society has to bear, not only by healthcare systems but also related social, economic and employment costs, illustrates the urgency for European governments and the EU Institutions to act and to put the societal impact of pain on their policy agenda. At the same time, basic and clinical science has demonstrated the feasibility of care pathways out of pain for many types of acute and chronic pain, but health care systems frequently do not guarantee general access for patients to these.

In order to address the societal impact of pain, a number of different stakeholder groups joined forces in 2009. Today the SIP is an international multi-stakeholder platform aiming to:

- Raise awareness of the relevance of the impact that pain has on our societies, health and economic systems
- Exchange information and share best-practices across all member states of the European Union
- Develop and foster European-wide policy strategies & activities for an improved pain care in Europe (Pain Policy)

The scientific aims of the SIP symposia have been endorsed by more than 300 international and national pain advocacy groups, scientific organisations and authorities.


More information on events and publications by the SIP platform can be found at: www.sip-platform.eu.



The Societal Impact of Pain (SIP) symposium takes place under the high patronage of the Italian Ministry of Health.

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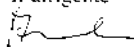
Dott. Chris Wells
Dott. Bart Morlion
Presidenti
christel.geevens@efic.org

e p.c.
Presidenza Consiglio Ministri
Ufficio del Cerimoniale
Roma
cerimonialedistato@pec.governo.it

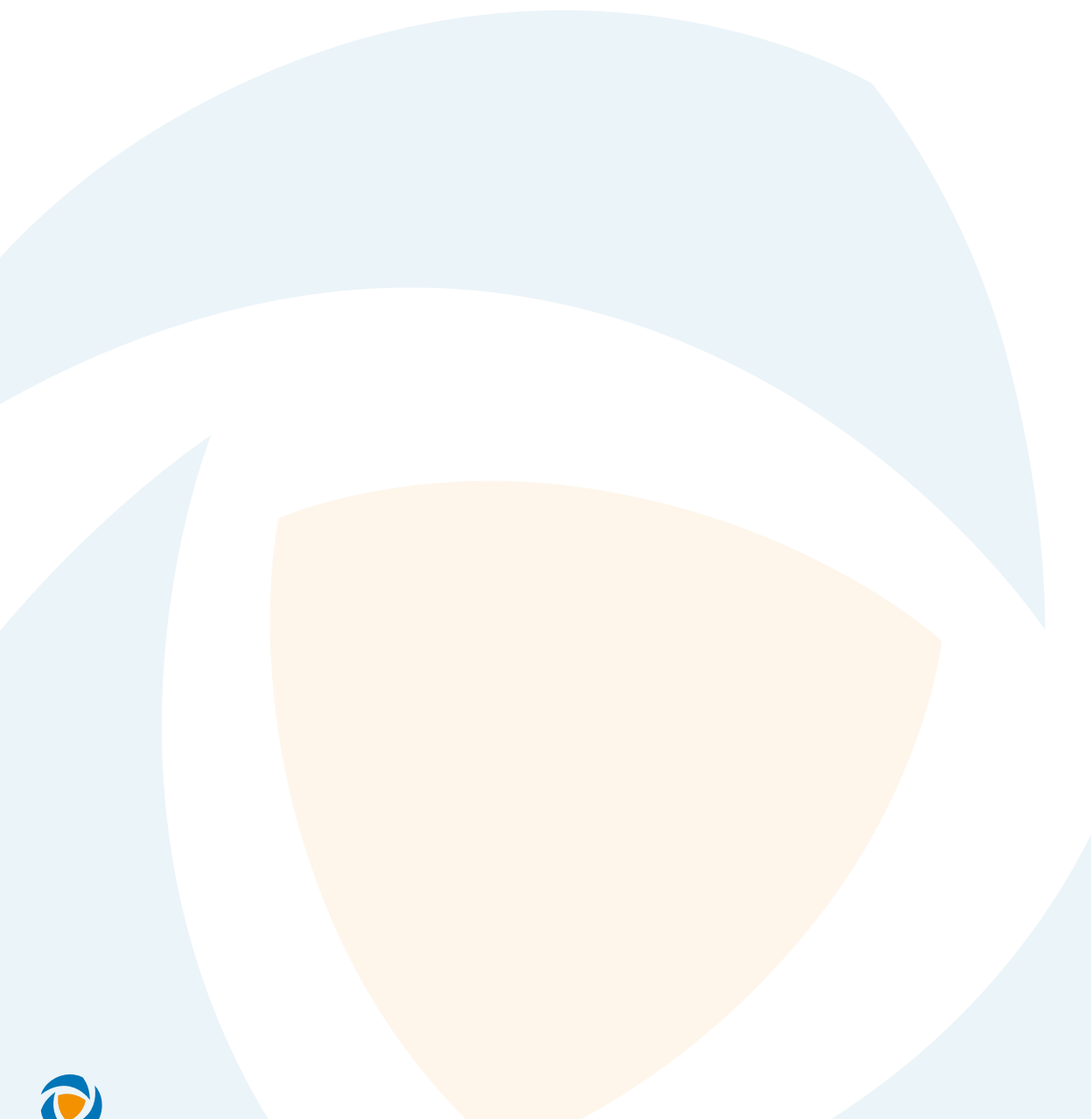
Con riferimento alla richiesta, pervenuta allo scrivente Ufficio, si comunica la concessione del patrocinio del Ministero della Salute al Simposio "Impatto sociale del dolore" in programma a Bruxelles dal 23 al 24 maggio p.v..

Al riguardo, si chiede di attenersi a quanto assicurato con Vostra nota del 22 marzo u.s..

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

Il dirigente


TARCO



Dear Reader,

Welcome to the 6th European Symposium on the “Societal Impact of Pain (SIP 2016): Time for Action”. 2016 represents a milestone in the policy change process towards a European framework that addresses the societal impact of pain. The European Pain Federation EFIC®, the scientific society of healthcare professionals for the study of pain in Europe, is delighted to work with such a vibrant and committed community.



Chris Wells
President
European Pain Federation EFIC®



Bart Morlion
EU-Liaison Officer and
President Elect
European Pain Federation EFIC®

The numbers are astonishing. Chronic pain affects almost 1 in 5 European citizens. This means over 100 million individuals and 50% of the older population. It is one of the major reasons why people exit the labour market prematurely and causes 500 million days of illness per year, costing the European economy more than €34 billion. This year's Symposium aims to identify policy solutions to address this societal and economic burden, striving for better pain management to facilitate cost savings and a reduction in sick leave and disability.

Thanks to the great advocacy work undertaken in the last few years, specific policy opportunities have arisen at EU level. At European Pain Federation EFIC®, we feel an obligation to pursue our actions to improve pain management at all levels and decided to concentrate our efforts around four policy opportunities. We, as EFIC® and the SIP platform, are committed to providing our expert contribution to these debates.

1. Pain as a quality indicator for health care

The EU law foresees the need to identify common European pain indicators to guarantee access to cross-border healthcare in Europe.

2. Chronic Pain: a disease or symptom?

This includes the issue of better pain management in the European discussion of chronic disease. This would result in delivering better chronic disease management.

3. The relevance of pain in cancer care and rehabilitation

The European Guide on Quality Improvement in Comprehensive Cancer Control, under development as part of the Cancer Control Joint Action, would benefit from including pain management recommendations.

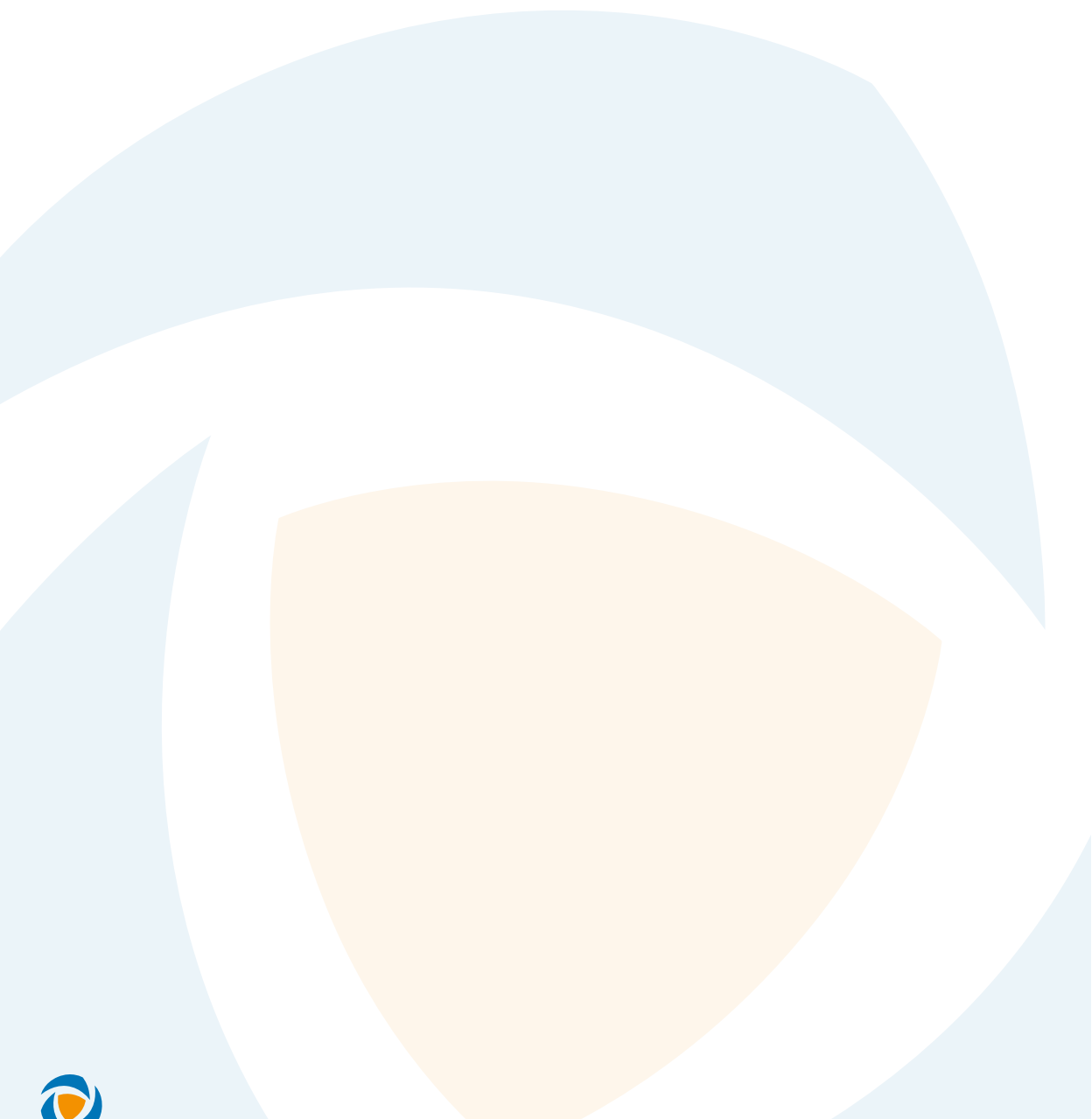
4. Pain, rehabilitation and reintegration of workers in the workforce

The European Council has launched reflections on the integration of long-term unemployed into the labour market. Moreover, the system of economic and fiscal policy guidance by the Commission would benefit from recommendations on better pain care to improve social and employment policies.

We are confident that the policy solutions identified during this Symposium will be enshrined in the EU policy-making process and generate a lasting political impact, and we look forward to a productive SIP 2016 in Brussels!

Chris Wells
President
European Pain Federation EFIC®

Bart Morlion
EU-Liaison Officer and President Elect
European Pain Federation EFIC®



Dear Reader,


Pain Alliance Europe (PAE) considers chronic pain to be much more than just a medical condition, which should be addressed. The impact that chronic pain has on each individual, his loved ones, his direct family, his caregiver, his employer, his co-workers and society at large is enormous. As the Breivik report says: 1 person in 5, on average, has chronic pain. When we take into account how many people are in direct contact with them, we should be aware that everyone knows, works with, or cares for a chronic pain patient.

Be part of this Symposium, discuss with us what to do and how to do this. If you won't do it on behalf of someone with chronic pain that you know, take care of, or work with, then do it for yourself as the chance you will become a chronic pain patient increases year by year as you get older. In this way you can ensure a better future for yourself.

PAE is very happy with the topics in this year's symposium. They come to the heart of the matter, addressing those issues, which can help to improve the quality of life for people with chronic pain. Not only for those who have the classical chronic pain conditions, but also for those who have survived what once was a terminal disease. All of these topics are subjects, which help to improve the situation of the chronic pain patient. Not only for the people themselves but also for their care givers, employers and co-workers.

As we discuss these subjects, we have to respect everyone's position and feelings. That's the only way we can reach an agreement on what we, the participants of this Symposium and those which we represent, find necessary to address and how. We also need to discuss this with everyone who has to play a role in this. It doesn't work if we are trying to tell others what they have to do. It only works if it is "we" who are doing it. By we, I mean the stakeholders like the healthcare professionals, the scientists, the patients, the industry, the policy makers, the politicians and everyone who works or has an interest in chronic pain. Let's work together so we can say in a couple of years from now that this was the starting point when we really began to improve the quality of life of people living with chronic pain; when we started to create the possibility for each individual patient to choose the best possible solution according to the patients wishes and possibilities.

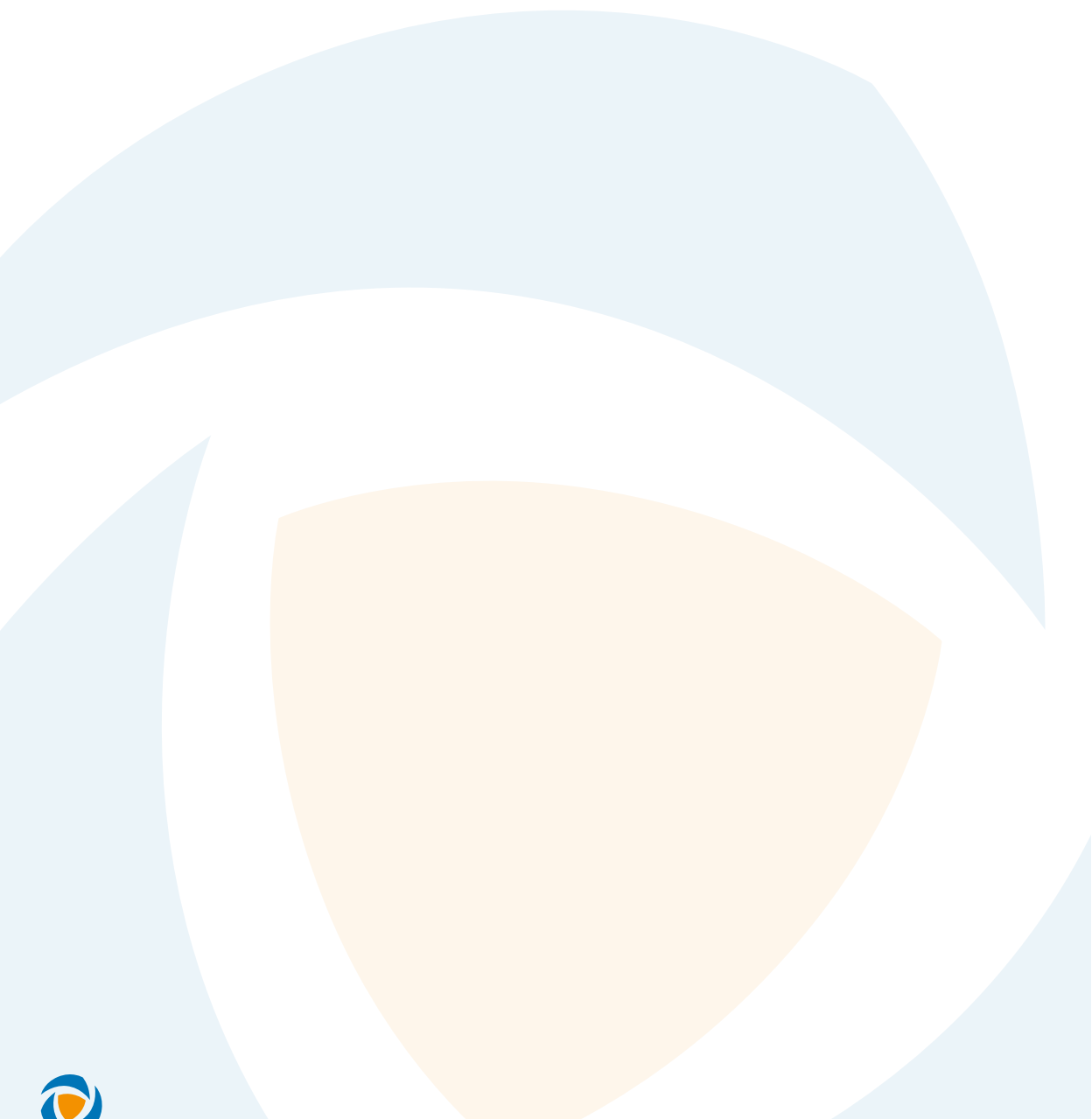
If we really want to achieve this, it is now more than ever **"time for action"**.



Joop van Griensven
President
Pain Alliance Europe (PAE)



Joop van Griensven
President
Pain Alliance Europe (PAE)



“Chronic pain, from the European political agenda to the EU culture”

In compliance with art. 13 of Law no. 234/2012 on “general regulation on Italian participation in the development and fulfillment of the EU legislation and policies”, the Italian Government, on January 10th, 2014, sent to the Italian Parliament the annual programmatic report for 2014 concerning “the Italian participation to the EU”. For what concerns health protection, the Government indicated pain therapy and palliative care as areas of focus during the Italian Presidency of the Council of the European Union, and as aspects “that medicine progress makes news of current interest and on which our Country wants to share its own experience with other Member States”.

In other words, during the Italian Presidency of the Council of the European Union (July-December 2014), for the first time chronic pain was included in the European agenda. As all of us well remember, during the Informal Meeting of European Health Ministries, held on 22-23 September 2014 in Milan, Ministers from the 28 EU member states reached a common position on the need of building a European network ensuring training of health professionals and of exchanging information on the effectiveness of therapies for the weakest population groups.

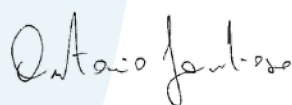
In general, the inclusion of the issue of chronic pain in the European political agenda was certainly gratifying for those who have worked to achieve this important result, but what about the next steps? Our commitment could be to transfer this achievement from the European agenda into the European culture: to raise awareness, fight stigma, improve quality of life for people suffering from acute and severe chronic pain, reduce the socio-economic impact of chronic pain in Europe by ensuring that the right to avoid unnecessary suffering is guaranteed everywhere and to everyone.

At present, unfortunately, the situation is still not positive, as the Survey carried out in 18 countries by Active Citizenship Network and Pain Alliance Europe in 2013 and 2014 has highlighted. Therefore, it is time to join forces and work as a team. Speaking of which, however, we can see encouraging signals at national and EU level in the past few years.

In Italy there is still much work to do on pain treatment, considering that 16% of patients who complain about pain are not believed or have to see their problem diminished. For this reason, there is a section of the Technical Committee on Health of the Ministry of Health devoted to this matter, that is an organization bringing together 204 experts for advice and support in policies covering different areas of health and science. And in 2015, our organization was officially appointed to represent the civic associations interested in the topic in the working group of this Committee focused on palliative care and pain management.

At European level, on September 2015, the European Pain Federation (EFIC) invited for the first time civic and patient organizations dealing with chronic pain and the respect of patients’ rights against unnecessary and useless pain in its permanent Patient Liaison Committee. The same strategic decision was also taken last December 2015 by the “Societal Impact of Pain” (SIP), which has officially included in its Steering Committee the citizens and patients’ point of views.

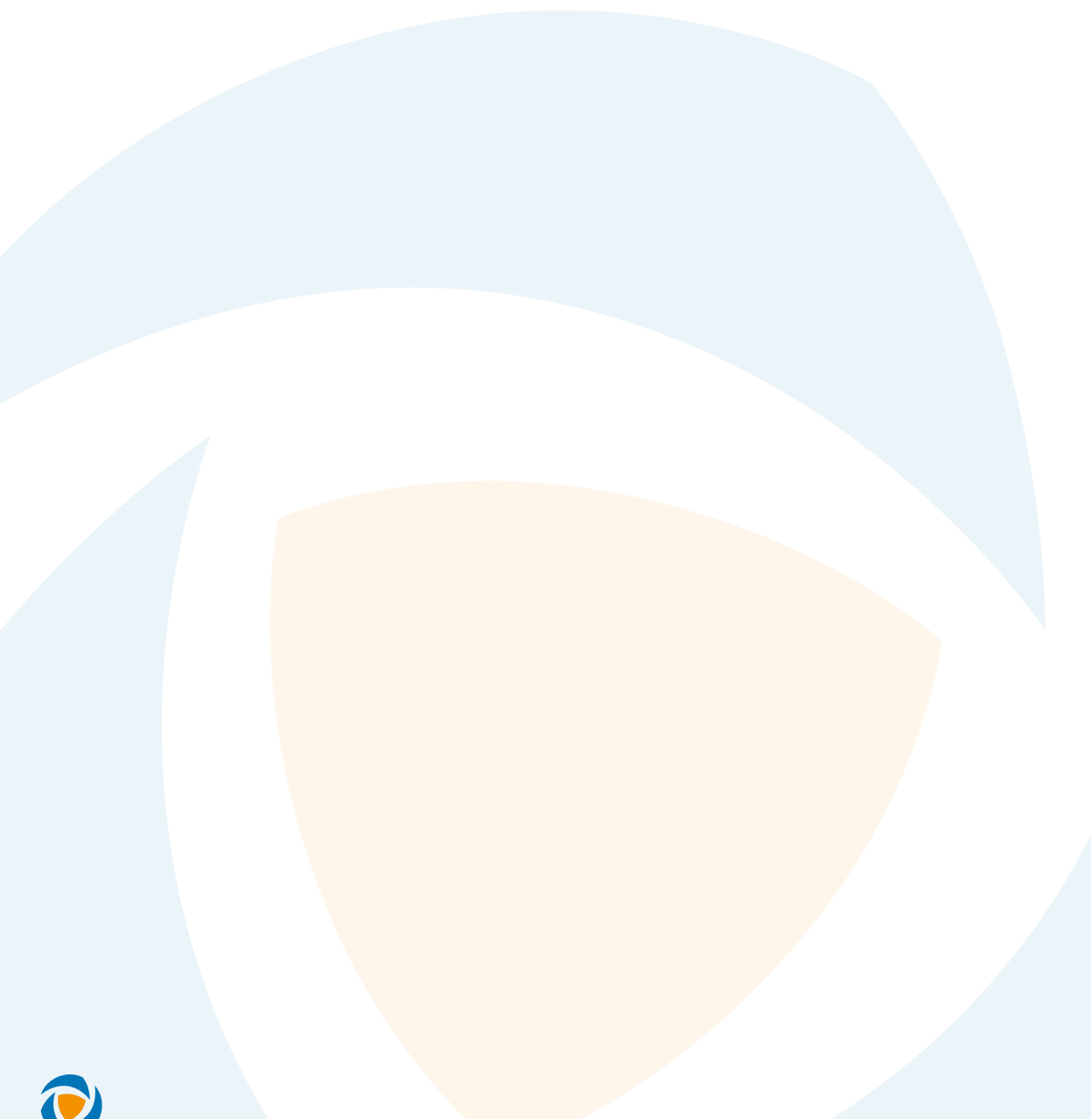
Cittadinanzattiva Onlus and its European branch Active Citizenship Network (ACN), being deeply involved in the European and national debate on patients’ rights against unnecessary and useless pain, welcomed these decisions and accepted to take part to the abovementioned committees, as well to be officially involved as cooperation partners for SIP 2016.



Antonio Gaudioso
Secretary General
Cittadinanzattiva Onlus



Antonio Gaudioso
Secretary General
Cittadinanzattiva Onlus



“Working together to improve pain policy”

Dear Madam,
Dear Sir,

The “Societal Impact of Pain” (SIP) is an international platform which has been created in 2010 as a joint initiative of the European Pain Federation EFIC® and the Grünenthal Group. The SIP platform pursues the following principles:

- to raise awareness of the relevance of the impact of pain,
- to exchange information and to share best-practices across all EU member states
- to develop and foster European-wide policy strategies & activities for an improved pain care in Europe.

During the SIP event 2016 multiple stakeholders come together to evaluate and discuss the societal consequences of pain. Our common target is to illustrate to the social, economic and employment sectors the urgency for European governments and the EU Institutions to act and to put, as a priority, the societal impact of pain on their political agenda. Pain is an important factor limiting the quality of life and should be a top priority of all national healthcare systems in Europe.

Like in all SIP events also this year healthcare professionals, politicians, representatives of pain advocacy groups, insurances, health authorities, regulators and budget holders are amongst the participants. The number of delegates from the majority of the different European member states and the huge number of endorsing organisations who join this event underline the high societal relevance of the Societal Impact of Pain.

What is different compared to previous SIP meetings? For this year’s symposium at the European Parliament in Brussels, the organizations Pain Alliance Europe (PAE) and Active Citizenship Network (ACN) are cooperation partners. As both partners have been involved right from the beginning they have proven to be true allies in addressing the Societal Impact of Pain.

In respect to pain policy the topics of this year’s symposium are even more relevant than ever before:

- Pain as a quality indicator for health care
- Chronic Pain: a disease or an underlying symptom?
- The relevance of pain in cancer care and rehabilitation
- Pain, rehabilitation and reintegration of workers in the working force

Under the auspices of European Pain Federation EFIC® these topics have been carefully identified by the SIP Steering Committee regarding their relevance in current EU policy processes. I would like to thank the members of the Steering Committee, the faculty of the symposium and all involved for their contribution to this project. The excellent cooperation of all partners demonstrates how relevant a joined European approach is for a consistent pain policy, a consistent pain policy which potentially can improve the quality of life for patients on a transnational scale.

“Time for action” has been chosen as the title of SIP 2016 demonstrating our ambition for a clear definition and commitment for actions to be taken immediately after the event. Now is the time to address the societal impact of pain by all involved in pain policy measures.

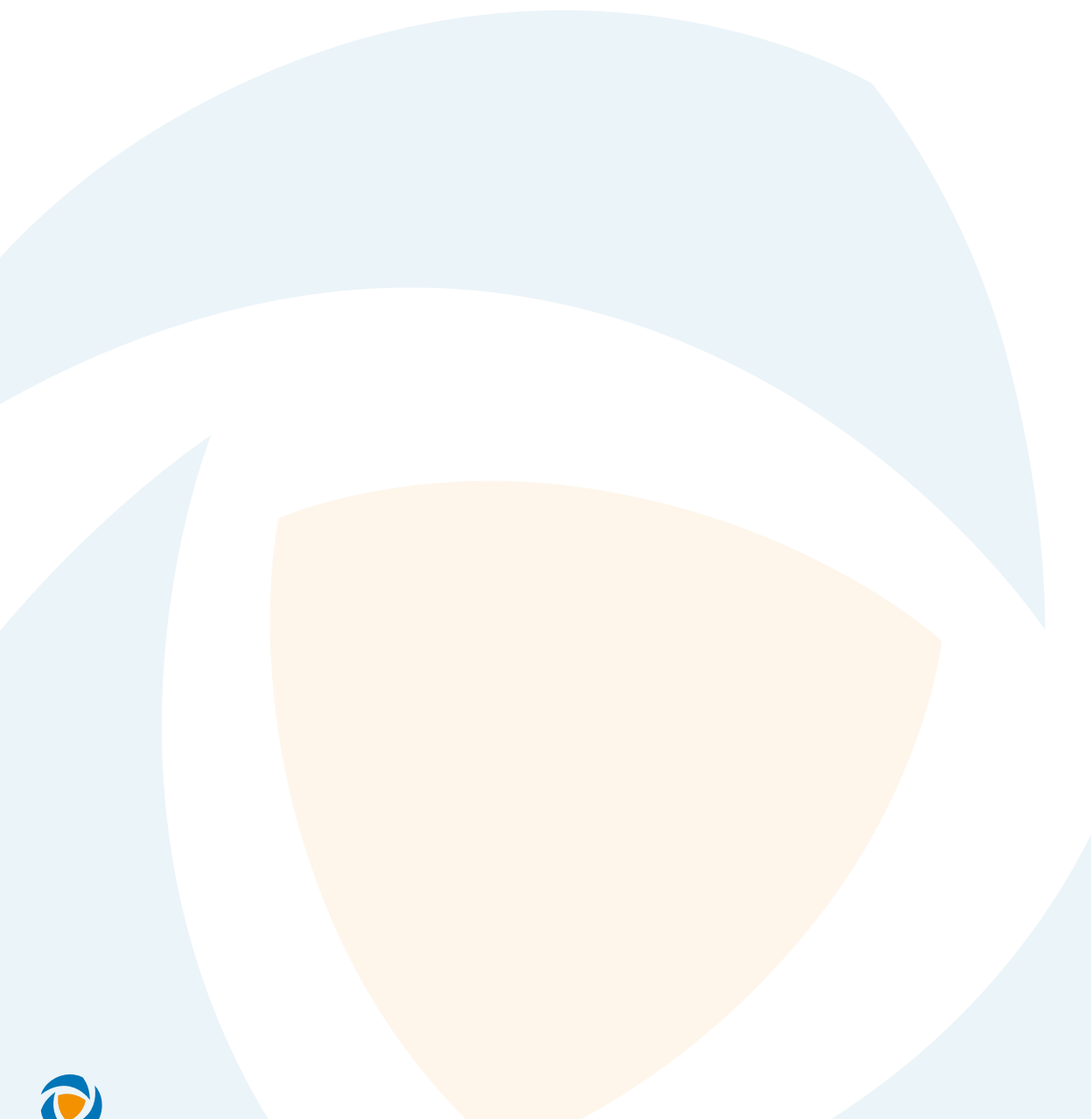
On behalf of Grünenthal I am very proud to welcome you to this unique event. I wish you fruitful discussions and a very successful SIP 2016!



Dott Alberto Grua
Member of the Corporate Executive Board
Grünenthal Group



Dott Alberto Grua
Member of the Corporate
Executive Board
Grünenthal Group





“The Societal Impact of Pain A Road Map for Action”

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”, almost one third of respondents experience musculo-skeletal 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 a top priority 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.

This “Road Map for Action” to address the societal impact of pain in the EU has been endorsed by many organisations and was signed at the Symposium “Societal Impact of Pain 2011”, 3-4 May 2011, Brussels.

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



4th European Action Plan
Societal Impact of Pain (SIP) Policy Group 2016-2020
European Economic and Social Committee & European Parliament
14 - 15 May 2013



SIP
Societal Impact of Pain



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 (EAPIC) 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 EAPIC 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 a recent survey on "Health in the European Union", almost 10% of the population suffer from chronic pain which affects their day-to-day life. This has a significant impact on the social, economic and employment situation of individuals and the enormous costs that society incurs. The survey also found that governments and the EU Institutions to act on pain on their policy agenda.

EU Institutions to:

- Factor limiting the quality of life and should be a priority in the national health care system.
- Address the issue through the availability of resources.
- Implement a pain and management strategy in the healthcare system.
- Ensure the medical, health and social care systems are able to manage the pain.
- Implement a pain management strategy through the medical, health and social care systems.
- Ensure the medical, health and social care systems are able to manage the pain.

PROGRAMME OVERVIEW

Monday, 23 May

- 11:00 Registration and networking**
Thon Hotel EU, Rue de la Loi 75, 1040 Brussels
- 14:00 - 18:30 Working Group meetings**
European Parliament, Rue Wiertz, 1047 Brussels
- Check with your SIP liaison contact on exact timing!**
- 20:00 - 22:00 Dinner**
Thon Hotel EU

Tuesday, 24 May

- 08:30 Registration and networking**
Concert Noble, Rue d'Arlon 82-84, 1000 Brussels
- SIP Marketplace** - exhibition of stakeholder materials
Foyer, Concert Noble
- 09:00 - 12:30 Plenary session 1**
- 12:30 - 13:00 Lunch**
- 13:00 - 16:00 Plenary session 2**
- 16:00 - 17:00 Press briefing**

About SIP 2016 working groups

Discussions during the 2016 Societal Impact of Pain (SIP) Symposium will be stimulated through task-oriented working groups, looking at particular areas of EU policy that affect pain care. The working groups will be in charge of making concrete policy suggestions drafted by each working group on 23 May. These conclusions will be presented at the symposium plenary on 24 May 2016.

Topics to be discussed are:

1. Pain as a quality indicator for health care
2. Chronic pain: a disease or symptom?
3. The relevance of pain in cancer care and rehabilitation
4. Pain, rehabilitation and reintegration of workers in the workforce

The format of the working groups will be interactive with different key note speakers representing various areas. In order to create an optimal environment for discussion, we have asked several persons to help in the following roles:

- The **chair and co-chair** are expected to provide leadership for the working groups. The chair should in each case be a representative of the European Parliament, who will play an honorary role and give an opening statement
- The **secretary** ensures the briefing of the speakers and oversees the reporting process
- The **moderator** is expected to monitor the length of the presentations and stimulate the discussion during the working groups
- The **speakers** are requested to be as clear and concise as possible, while trying to leave some curiosity in the audience, and give as much input on the topic as possible, especially during the working groups. Speakers using a digital presentation are requested to deliver their presentation at least 30 minutes prior to the session start to the SIP secretariat on a USB/flash drive.
- The **reporter and co-reporter** will handle the practical part of the Secretary's role, taking notes and compiling comments to adjust the draft conclusions throughout the session

Meeting language

The meeting language for presentations, workshops and discussions is English.

Documentation

For documentation, press and publication purposes video, photo and audio recordings will be made. In case you do not want to appear in this documentation please contact the event staff on site.

Networking Dinner

On May 23rd a networking dinner for the participants of the SIP 2016 has been made possible by a grant from Grünenthal GmbH. As the number of places is limited, participants are asked to register as soon as possible using the "on line" registration form available at: <http://www.regonline.co.uk/sip-2016>

Monday 23 May 2016 – Working group 1

Pain as a quality indicator for health care

Background

Pain, besides causing untold suffering for millions of patients worldwide, tears at the very economic and social fabric of our culture. To date there are no comprehensive pan-European figures outlining the impact of pain to society. However, investigators in various countries have begun to compile information of this nature, which illustrates the magnitude of burden pain, both acute and chronic, has on society.

The burden that chronic pain imposes on individuals and the enormous costs that society has to bear, not only by healthcare systems but also related social, economic and employment costs, illustrates 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.

Pain is a central element of the patients' experience in many healthcare settings (chronic primary pain, postoperative pain, cancer pain, neuropathic pain, headache and visceral pain), the quality of pain care can be considered an indicator of the general quality of a healthcare system.

Evaluating organizational improvement in pain management performance depends on measurement. Although several studies exist on pain levels in some EU member states, a quality benchmark (like the European Core Health Indicators - ECHI) is not available for consumers and patients.

Therefore cross border and cross institutional comparison of health care services in pain care requires outcome criteria on patient-, consumer-, medical- and policy level and the establishment of benchmarks.

Policy opportunity

Article 8 paragraph 5 of the **Cross-border Healthcare Directive** foresees that an objective assessment of 'the degree of the patient's pain' must be used to assess the right to cross-border healthcare. Indicators are therefore needed in member states to set criteria for granting access to cross-border healthcare and to compare the quality of health care services available to citizens, consumers and patients. The implementation of the Directive is now under review by the European Commission, thus opening up the debate on the implementation of Article 8(5).

So far, the transposition of the article has not been discussed in the successive reports on the implementation of the Directive. This opens a window of opportunity to provoke debate within the EU institutions and expert organisations on the need to develop indicators for pain measurement as part of the implementation of the Directive.

- **Using national experiences of the (lack of) implementation of Article 8(5) of the Directive will be essential for informing the working group's debate.**
- **An understanding of, and possible consensus on, the applicability of certain indicators for the measurement of pain is required if member states are to adequately implement Article 8(5) of the Directive**
- **The next step would be to identify how the Commission can best support member states in addressing potential gaps in implementation.**
- **Participants are invited to draw attention to other European Union policy initiatives of relevance in this area.**

Institutional timeline

- **European Parliament's own-initiative report on the implementation of the Cross-Border Healthcare Directive – Date TBC** - Opportunity to address gaps in the implementation of the Cross-Border Healthcare Directive
- **Issuance of the Commission infringement package in the implementation of the Cross-Border Healthcare Directive – Date TBC** – Opportunity for the Commission to review the state of implementation of the Article 8(5) of the Cross-Border Healthcare Directive
- **Maltese Presidency of the European Union: January – June 2017** – The implementation of the Cross-Border Healthcare Directive is expected to be among the Presidency priorities

Monday 23 May 2016 – Working group 2

Chronic pain: a disease or symptom?

Background

Pain is a common element of numerous chronic health conditions, such as cancer and musculoskeletal diseases, and often persists past normal healing time. Although acute pain may reasonably be considered a symptom of disease or injury, chronic and recurrent pain is a specific healthcare problem, leading to typical co-morbidity, such as sleep disturbances, anxiety, depression and low self-esteem among many others. Thus, chronic pain develops into a typical syndrome and even a disease in its own right. While acute pain by definition is a brief and self-limiting process, chronic pain comes to dominate the life of the people concerned and often also family, friends and caregivers.

The most widespread chronic pain conditions, low back pain, arthritis and recurrent headache (including migraine) are so common that they are often seen as a normal and unavoidable part of life. In addition to the erosion in quality of life and financial burdens caused, chronic pain often sets the stage for the emergence of a complex set of physical and psychosocial changes that are an integral part of the chronic pain problem, greatly adding to the individual burden.

Therefore the question as to whether pain - and in particular chronic pain – for policy purposes is to be understood as a mere symptom of an underlying disease or should be acknowledged as a disease in its own right is central in the mission of the European Pain Federation EFIC® with regard to policymakers in the EU and in member states.

Policy opportunity

In 2011 the European Parliament adopted a resolution on the European Union position and commitment in advance to the UN high-level meeting on the prevention and control of non-communicable diseases (NCDs). The Resolution includes a reference to chronic pain as a common symptom to the majority of NCDs:

L. whereas the majority of NCDs have common symptoms, such as chronic pain and mental health problems, which directly affect sufferers and their quality of life and should be addressed by means of a common, horizontal approach, so that healthcare systems can tackle these diseases more cost-effectively;

At the end of 2013, the Commission launched the Joint Action on Chronic Diseases (JA CHRODIS). CHRODIS sees EU member states' experts put together recommendations on health promotion and primary prevention as well as the management of diabetes and multi-morbid chronic conditions. CHRODIS' work does not currently mention the relevance of pain treatment in the management of chronic diseases.

During the EU Health Ministers meeting in Milan, 2014, Ministers from 28 EU member states concluded in their summary of the conclusions regarding pain to have reached a common position on the need to create a European network ensuring training of professionals in the sector and exchange of information on the effectiveness of therapies for the weakest population groups.

An initiative on better treatment of chronic diseases is expected to be announced by the European Commission in 2016. It will be crucial for stakeholders to express that better pain care will in turn deliver better management of chronic diseases. In autumn 2016, the European Commission is expected to conduct the mid-term review of the 3rd Health Programme 2014-2020 and to launch a consultation on the topic. Stakeholders will have the opportunity to assess whether the priorities above have been adequately addressed, and will be able to indicate to the Commission which disease areas the Health Programme should prioritize in the future.

In their trio programme the Dutch, Slovakian and Maltese Presidencies of the Council of the EU (January 2016 – June 2017) announced that they will take forward discussions on ways to improve the health status of the EU population, by fighting non-communicable diseases.

- Working group 2 participants will be asked to address a fundamental policy issue: to what extent, and in which circumstances, should chronic pain be considered a disease in its own right, or a 'symptom'?
- Insights on how to overcome the reluctance of the Commission to address pain in its recent initiatives on chronic diseases will be a second very important element of the debate. The aim will be to offer policy makers guidance on how the EU should address the problem.
- Participants are invited to draw attention to other European Union policy initiatives of relevance in this area.

Institutional timeline

- **Commission initiative on the prevention and management of chronic diseases – April 2016 onwards** – Opportunity to call for better management of pain as part of better chronic disease management
- **Mid-term review of the 3rd Health Programme 2014-2020 – Autumn 2016** - Opportunity to indicate to the Commission which disease areas the Health Programme should prioritise in the future
- **Dutch, Slovakian and Maltese Trio Presidency – January 2016 – July 2017**
 - Potential Council Conclusions on fighting non-communicable diseases



GLOBAL DAY AGAINST PAIN

**The following declaration put to the European Parliament in 2001,
is now recommended by EFIC & IASP to be globally adopted.**

EFIC's declaration on chronic pain as a major healthcare problem, a disease in its own right

"Pain is a major healthcare problem in Europe. Although 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."

Commentary:

Acute pain, such as that following trauma or surgery, constitutes a signal to a conscious brain about the presence of noxious stimuli and/or ongoing tissue damage. This acute pain signal is useful and adaptive, warning the individual of danger and the need to escape or seek help. Acute pain is a direct outcome of the noxious event, and is reasonably classified as a symptom of underlying tissue damage or disease. However, in many patients pain persists long after its usefulness as an alarm signal has passed, and indeed, often long after the tissue damage has healed. Chronic pain in these patients is probably not directly related to their initial injury or disease condition, but rather to secondary changes including ones that occur in the pain detection system itself.

In addition to being due to different physiological mechanisms than acute pain, chronic pain often sets the stage for the emergence of a complex set of physical and psychosocial changes that are an integral part of the chronic pain problem and that add greatly to the burden of the pain patient. These include:

1. Immobility and consequent wasting of muscle, joints etc.
2. Depression of the immune system and increased susceptibility to disease
3. Disturbed sleep
4. Poor appetite and nutrition
5. Dependence on medication
6. Over-dependence on family and other carers
7. Overuse and inappropriate use of professional healthcare systems
8. Poor performance on the job or inability to work, disability
9. Isolation from society and family, turning inwards
10. Anxiety, fear
11. Bitterness, frustration, depression, suicide

Prevalence of chronic pain:

Although comprehensive epidemiological data for the European Union are not available, chronic pain is clearly a very widespread condition. Several recent community-based surveys for example, found that nearly 50% of adults sampled suffered from one or more types of pain or discomfort at any given point in time.

In a substantial proportion of those surveyed the pain was both chronic and severe, the numbers increasing considerably in older age groups. The most widespread chronic pain conditions, low back pain, arthritis and recurrent headache (including migraine) are so common that they are often seen as a normal and unavoidable part of life. Although few people die of pain, many die in pain, and even more live in pain.

Social costs of chronic pain:

While acute pain is by definition a brief and self-limiting process, chronic pain comes to dominate the life and concerns of the patient, and often also of family, friends and other carers. 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. These include:

1. Costs of healthcare services and medication
2. Job absenteeism and disruption in the workplace
3. Loss of income
4. Non-productivity in the economy and in the home
5. Financial burden on family, friends and employers
6. Worker compensation costs and welfare payments

Authoritative sources place the overall financial costs of chronic pain to society in the same range as cancer and as cardiovascular disease.

Utility of widespread governmental endorsement of the declaration on chronic pain as a major healthcare problem, a disease in its own right:

The magnitude of the chronic pain epidemic in terms of human suffering and costs to society is well known in the field of Pain Medicine. However, it is not widely appreciated within the larger biomedical community, among makers of social policy and in the public at large. In calling attention to this problem, national governments will benefit the large population of chronic pain sufferers in Europe by:

1. Increasing the attention devoted to the problem by healthcare professions, including increased awareness and use of existing pain relief modalities, increased training in the management of chronic pain, and increased research efforts towards the discovery of novel treatments
2. Facilitating efforts by pain professionals at the national level to recruit more human and financial resources in the battle against chronic pain.

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Drafted by Professors D. Niv and M. Devor, May 2001

Presented by EFIC at the European Parliament
Brussels, Belgium 9 October 2001

Monday 23 May 2016 – Working group 3

The relevance of pain in cancer care and rehabilitation

Background

There is a clear relationship between pain and cancer and as well as between pain and palliative care.

1. **Pain treatment plays a role during cancer treatment.** Most cancer pain is caused by the tumour pressing on bones, nerves or other organs in your body. Sometimes pain is related to cancer treatment. For example, chemotherapy can cause numbness and tingling in hands and feet or a burning sensation at the place of injection. Cancer related pain can be acute or chronic.
2. **Pain is a common problem in cancer survivors.** Pain is a common problem in cancer survivors, especially in the first few years after treatment. In the longer term, approximately 5 to 10% of survivors have chronic severe pain that interferes with functioning. Although more comprehensive information about the prevalence of persistent pain in the cancer survivor population is currently lacking, it is known to depend on the type of cancer, comorbid conditions, and the initial pain management.
3. **Pain treatment in palliative care.** Pain occurs in up to 70% of patients with advanced cancer and in about 65% of patients dying from non-malignant disease. In about 10% of these patients the pain is difficult to control. Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support to from diagnosis to the end of life and bereavement.

Based on this there is an increasing need for improvement in cancer related pain care policy in Europe. Improving the treatment of pain will result in a better quality of life and wellbeing for the patients concerned. This can be achieved through consistent, integrated healthcare and social policies addressing pain treatment as a key component, policies shaped with the involvement of all relevant stakeholders, including the broader healthcare community and patients.

Policy opportunity

The European Commission launched the Joint Action on Cancer Control (CanCon JA) which is a project co-financed by the EU and participating organisations, institutes, universities and healthcare units. The final deliverable of CanCon JA is a European Guide on Quality Improvement in Comprehensive Cancer Control targeted at governments, parliamentarians, healthcare providers and cancer care professionals. Work Package 8 of CanCon JA deals specifically with the issue of cancer survivorship and rehabilitation and will develop a European framework on the topic that could be promoted at EU level. It will also develop tools, a European “distress barometer”, and personalised rehabilitation and survivorship care plan.

The European Commission has identified the Cancon JA is one of the appropriate platforms to take forward the September 2014 call by EU Health Ministers for the establishment of a European network for palliative care and pain therapy. This call followed a working lunch held during the Italian Presidency’s informal meeting of health ministers. Work on the call by EU Health Ministers is also being taken forward by the Commission’s Expert Group on Cancer Control which, in late 2015, requested voluntary contributions from its members on new initiatives at EU level in the field of palliative care.

- **A clear understanding of the potential outcomes of ongoing EU initiatives in the area of cancer pain treatment will help inform discussion.**
- **A clear understanding of how cancer and cancer treatment relates to pain will help inform discussion.**
- **Knowledge of recent innovations in pain care in the context of palliative care will be essential in providing recommendations to policy makers on which care pathways to support.**
- **Participants are invited to draw attention to other European Union policy initiatives of relevance in this area.**

Institutional timeline

- **End of CanCon JA – First half 2017**
 - Opportunity to improve the guidance on cancer pain as part of the final European Guide on Quality Improvement in Comprehensive Cancer Control
 - Opportunity to organise an event on pain treatment on the side-lines of the presentation of the European Guide on Quality Improvement in Comprehensive Cancer Control
- **Reflection on the Commission Expert Group on Cancer Control's EU initiatives on palliative care – Ongoing**
 - opportunity to address the topic of pain treatment



Monday 23 May 2016 – Working group 4

Pain, rehabilitation and reintegration of workers in the workforce

Background

In a report published on 27 January on 'Health-related constraints to raising Retirement Ages in the EU' the European Commission found that decreasing the incidence of diseases and disabilities results in increases in the total number of years active in the labor force and decreases in public payer expenditures.

The Commission findings confirm that health status is a major predictor of labor supply. Deteriorating health associated with chronic disease and comorbidities, together with symptoms such as severe and frequent pain, negatively affects labor supply. Studies point out that chronic pain results in more than 500 million sick days per year in Europe, costing the European economy more than €34 billion. If the productivity gap caused by pain is considerable, chronic pain also leads to substantial expenditure in workers compensation and disability benefits. Add to this that the proportion of people 65 and over will soar from 20% of the EU population to 28% of the EU population between 2020 and 2060 while the population aged 15 to 64 will decrease from 64% to 57% of the total population over the same period. Total labor supply in the EU (and in the euro area) is projected to stabilize between 2013 and 2023 (age group 20-64), while it is projected to decline by 8.2% between 2023 and 2060, representing roughly minus 19 million people. The European Union and its Member States are therefore facing a tremendous challenge and new strategies will be needed to extend workers' active lives.

Policy opportunity

In their trio programme the Dutch, Slovakian and Maltese Presidencies of the Council of the EU (January 2016 – June 2017) announced that they will take forward discussions on ways to improve the health status of the EU population, by fighting non-communicable diseases. Additionally the European Council have recently agreed Conclusions on the integration of the long-term unemployed into the labour market. The disability burden plays a great role in long-term unemployment and chronic pain is a key contributor to this burden. There are opportunities to show how better pain treatment can help EU economies address this key challenge. The European Semester, the system of economic and fiscal policy guidance by the Commission to member states, presents another opportunity to show that better pain care has a role to play in improving social and employment policies and can support member states' fiscal sustainability. Any guidance coming from the Commission should be based on the best evidence available on the financial impact of pain care policies.

- **Any evidence linking health status improvement with better social and economic performance will be useful.**
- **The segmentation between health, social and economic policies should be addressed as a potential barrier.**
- **An understanding of EU social and employment policies and competences will aid discussion, as will a working knowledge of the European Semester process.**
- **Participants are invited to draw attention to other European Union policy initiatives of relevance in this area.**

Institutional timeline

- **Dutch, Slovakian and Maltese Trio Presidency – January 2016 – July 2017**
 - Potential Council Conclusions on fighting non-communicable diseases
- **European Semester process – Annual – Opportunity to provide evidence to DG ECFIN, DG EMPL and national contact points on the financial impact of pain care policies.**



SUPPORTING INITIATIVES

Let's make chronic pain visible... joining the RED BALLOON PROJECT!

Pain Alliance Europe's mission is to improve the quality of life of people living with chronic pain. One of our main objectives is to raise awareness with politicians and policymakers, healthcare providers, employers and the general public. There are over 100 million people suffering with chronic pain in Europe.

Chronic pain has a huge societal and economic impact and can affect any one of us in our lifetime.

The Red Balloon Campaign aims to raise awareness of the critical impact of chronic pain on the individuals, their loved ones and us as a society. We want to make a change and improve pain management across Europe for today and for future generations.

In order to do so we need your help to spread the word and 'Release the Pain' ...because together we can achieve so much more!

Support the Red Balloon campaign. Show yourself and make chronic pain visible. Be part of the project by posting your pictures and videos of the red balloon on Facebook, Instagram or Twitter using the hashtag **#RELEASETHEPAIN**.

Thank you for your support.

Joop Van Griensven

PAE President



The cooperation partners of the SIP Platform 2016 are happy to endorse the objectives of the Red Balloon project.

The Red Balloon Project is sponsored by Boston Scientific

“MY PAIN FEELS LIKE...” Initiative

The “My pain feels like...” initiative has been developed by Grünenthal in collaboration with the Departments of Clinical Neurophysiology & Pain Rehabilitation Unit, of Montescano and Habilita, Bergamo, Italy.

On the occasion of the SIP event in Brussels 2016, policy makers and other stakeholders will get the opportunity to experience a realistic simulation of localized neuropathic pain symptoms. Visitors of the “My pain feels like...” information booth are invited to take part in the **“My pain feels like...” ‘pain box’ experience**. This psychophysical testing has been developed by Professor Roberto Casale from the Bergamo Pain School of Italy. “The ‘pain box’ experience truly is an eye-opener for many people, because it makes them really understand what neuropathic pain feels like and why there are so many individual descriptions for it”, says Professor Casale.

Another centerpiece of the initiative is the educational website **www.mypainfeelslike.com**, where patients can find out more about the pain they are suffering from, read about other patient experiences and complete the accompanying **pain questionnaire**. This tool can help patients to describe the pain they feel as accurate as possible in order to prepare well for their next doctors consultation.

We look very much forward to welcome you at the My pain feels like... information booth.







SIP

Societal Impact of Pain

**Background information on speakers
and workshop chairpersons, moderators,
secretaries, and reporters, including
supporting Members of the European
Parliament, in alphabetical order of
their last name**

The scientific framework of the Societal Impact of Pain (SIP) platform is under the responsibility of the European Pain Federation EFIC®. Cooperation partners for SIP 2016 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP symposia have been endorsed by a large number of international and national pain advocacy groups, scientific organisations and authorities.

www.sip-platform.eu





MENNO AARNOUT

Executive Director

Association Internationale de la Mutualité (AIM)

How Payers Perceive Pain...

Association Internationale de la Mutualité (AIM)
Rue d'Arlon 50
Brussels, 1000
Belgium
Phone: +32 2 2345703
menno.aarnout@aim-mutual.org
www.aim-mutual.org

Health budget cuts, increasing costs of treatment and ageing populations make it more and more important to make wise decisions about how to organise our healthcare systems and which treatments to reimburse.

Pain has without a doubt a tremendous impact on societies. Treatment options that deal with pain are therefore of utmost importance. The healthcare system needs to facilitate the development and use of such treatment options. Healthcare payers play there an important role, together with health professionals, patients, the industry and policy makers, to ensure sustainable access to quality treatment options. In his presentation Mr Aarnout will highlight what AIM considers important elements in the discussion about sustainable access to health, healthcare and health technologies and to pain treatment in particular.

Menno Aarnout is since 2014 executive director of AIM, the international association of non-profit healthcare payers, bringing 61 members from 30 countries together, which provide healthcare coverage to some 200 million people in Europe, but also in Africa and Latin America. AIM provides a network platform to its members and advocates for sustainable access to good quality care for all. Before joining AIM, Menno Aarnout worked at different positions in the European Commission on strengthening of healthcare systems. He also held different positions in the Dutch Ministry of Health. He is an economist by training.

CLARA EUGENIA AGUILERA GARCÍA

Member of the European Parliament

Group of the Progressive Alliance of Socialists and Democrats in the European Parliament (S&D), Spain

What the EU can do to improve pain care

Clara Eugenia Aguilera García has been Member of the European Parliament for the Progressive Alliance of Socialists and Democrats in the European Parliament since 2014.

In the European Parliament, she is a member of the Committee on Fisheries, and a Substitute of the Committee on the Environment, Public Health and Food Safety (ENVI). She began her political career after having obtained her degree in Law from the University of Granada in 1983, when she started militating in the Partido Socialista Obrero Español de Andalucía (PSOE-A) (Spanish Socialist Workers' Party of Andalusia).

In 2000, she was elected as member of the Andalusian Parliament, where she served as spokeswoman for agriculture. Between 2004 and 2008, she covered the role of Secretary of Agriculture and Rural Development on the Executive Committee of the PSOE-A.

Between 2009 and 2012, she was appointed Minister of Agriculture, Fisheries and Rural Development of the Junta de Andalucía.

Ms Aguilera has extensive knowledge of the agricultural sector, having worked for more than twelve years in agricultural cooperatives, as Manager of the Federation of Agricultural and Livestock Cooperatives (FECOAGA) in the province of Granada, and in the Andalusian Federation of Agrarian Co-operatives (FAECA).



European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45783
claraeugenia.aguilera@europarl.europa.eu

Pain and its impact in society should be addressed by the European Union. I fully support the Societal Impact of Pain platform and consider the symposium the greatest forum to unite healthcare professionals, patients, policy makers and politicians to discuss how to move forward to address the quality of life of pain patients at the European level.



PROF TIT ALBREHT

Head of Centre

National Institute of Public Health

National Institute of Public Health
Trubarjeva 2
Ljubljana, 1000
Slovenia
Phone: +38612441420
tit.albreht@nijz.si
www.nijz.si/en

Treatment and comprehensive management of pain in cancer care is one of key issues and an inseparable part of comprehensive cancer care at all levels.

Joint Action CanCon and Pain

Joint Action Cancer Control (CanCon) is a project dedicated to advise policymakers on some of the key aspects of cancer care, which need improvement, more attention or more structuring across Europe.

One of the topics raised in the framework of this project is also treatment and overall comprehensive management of pain. Given the nature and chronicity of their disease, nature of their different treatments and potential recurrences and palliation, cancer patients have clear needs with respect to pain management. There is an explicit need to include this topic in all documents aiming at addressing policy-relevant issues, advice, recommendations, guidance and guidelines concerning cancer care. The identification of needs for treatment of pain needs to include: acute (on presentation of the disease, immediate to interventions, whether diagnostic or therapeutic, on recurrence, etc.), chronic as a symptom of the disease or its recurrence, or as a symptom accompanying patients in need of palliative and end-of-life care. This means that pain treatment needs to be made available to patients at all stages of the disease, at all different phases of treatment. It should be an inseparable part of comprehensive cancer care.

In CanCon there is a special focus on palliative care within the topic of survivorship, where the issue of pain comes to the front as a highly relevant one. However, treatment and management of pain has also the implications, such as patient rights, where it has to be a part of all services and all patient pathways, it should not depend on the patient's ability to pay but it should be reimbursed as other cancer services instead. Adequate treatment of pain in acutely managed cancer patients and in those with life prolonging therapies can reduce the need for sickness absence and disability and can provide better quality of life to all cancer patients, regardless of their age, gender or employment status.

Dr Tit Albreht is a senior researcher of health services at the National Institute of Public Health of Slovenia (NIPH). He was promoted as a PhD at the University of Amsterdam in the field of health services research and has dedicated an important share of his career to health system research and policy development in different topics, such as health workforce planning, hospital reporting and reimbursement system and cancer policies. He is actively involved in cancer policy since 2007 when Slovenia and the NIPH were preparing for the Slovenian Presidency to the Council of the European Union. He is currently the co-ordinator of the Joint Action CanCon. Institution National Institute of Public Health of Slovenia is the key national public health institution, providing professional and expertise work in all subfields of public health with professional support to the policymakers, educational and training programmes in public health and research in many different disciplines of public health.

MASSIMO ALLEGRI MD, FIPP

Assistant Professor University of Parma

**Pain Therapy Service Azienda Ospedaliera Universitaria Parma,
Scientific Responsible of SIMPAR, Editor in Chief „Fighting Pain”,
Section Editor „Minerva Anestesiologica”**

Reporter Working group 2 Chronic Pain: a disease or multi-morbidity?

Born in Milan in 1973. Graduated in Medicine at University of Pavia in 1999. In 2003 Residence in Anesthesia, Intensive Care and Pain Medicine.

He worked as anesthesiologist and researcher in Pavia's Hospital University where he was the head of research about acute and chronic pain. He had clinical and research stage in Massachusetts General Hospital (Boston USA), Hospital del Mar (Barcelona, Spain), Pain Clinic AZ Maria Middelaers Sint-Niklaas (Belgium), Methodist Research Institute (Houston, USA), Pain Clinic Bern Hospital (Switzerland).

In 2008 he has funded SIMPAR (Study in Multidisciplinary Pain Research) group (<http://www.simpar.eu>) and SIMPAR meeting.

He won, as Principal Investigator, two grants:

1. Italian Health Ministry grant (350.000 euros) about "Nanotechnology and Acute Postoperative Pain" with Methodist Research Institute and two Italian Institutes
2. European Community FP7 Project (6 millions of euro) about "PainOmics: genomics and low-back pain" with 9 other European Institutes, 1 from USA and 1 from Australia.

Currently he is Assistant Professor at Department of Surgical Science of University of Parma. He is working as Pain Specialist in the Pain Clinic (center of excellence in Italy) of Parma Hospital. He is the responsible of omic research in Pain for University of Parma and Hospital of Parma. He is in the scientific board of the CoreLab where all biomolecular studies about Acute and Chronic Pain are conducted. He is also in the Scientific Committee of a spin off between University of Parma and Italian Center on National Research (CNR): BioGeNaP (Bioelectronic, Genetics, Nanotechnology in Pain).

He is F1000 Faculty member. Since 2012 he has been Chief Editor of "Fighting Pain Journal" and Section Editor of "Minerva Anestesiologica". Since 2016 he has been section editor of "Journal of Scoliosis and and Spinal Disorders".

He has been involved in several research clinical trials. Principal research interests: genetics, low-back pain, localized neuropathic pain and opioids. He has published more than 80 articles in peer reviewed journals (<https://orcid.org/0000-0002-8201-980X>).

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University of Parma
Parma

Italy

Phone: + 39 349 3540151
massimo.allegri@unipr.it
www.simpar.eu

Chronic pain is a complex disease that affect not only quality of life but also that could affect the long. term outcome of the patients. It is important to diagnose it correctly identifying the specific pathophysiological mechanism underline the chronic pain disease. Finally, chronic pain patient is a frail patient. Hence his treatment has be driven by the careful evaluation of all other mobility related to chronic pain disease.

A



PROF LUIS AZEVEDO

Professor and Researcher - Clinical and Health Services Research

**Dep. Health Info. & Decision Sciences (CIDES) - Faculty of Medicine
University of Porto**

Faculdade de Medicina
Universidade Porto
Rua Dr. Plácido da Costa, s/n
Porto, Porto 4200-319
Portugal
Phone: +351225513622
lazevedo@med.up.pt

Chronic pain is associated with high societal costs. In Portugal we estimate annual costs of €4,612 millions, with 57% of indirect costs. Given the high rate of indirect costs, restricting healthcare should not be the response; and improving the quality of chronic pain prevention and management is recommended.

The economic impact of chronic pain in Portugal

In addition to its high frequency and its relevant individual and social impact, chronic pain (CP) has been shown to be a major contributor to increased healthcare utilization, reduced labour productivity, and consequently large direct and indirect costs.

In the context of a larger nationwide study, we aimed to assess the total annual direct and indirect costs associated with CP in Portugal. A population-based study was conducted in a representative sample of the Portuguese adult population. The 5094 participants were selected using random digit dialling and contacted by computer-assisted telephone interviews. Questionnaires included the brief pain inventory and pain disability index. Estimates were adequately weighted for the population. From all CP subjects identified, a subsample (n=562) accepted to participate in this economic study. Mean total annualized costs per CP subject of €1883.30 were observed, amounting to €4611.69 millions nationally, with 42.7% direct and 57.3% indirect costs, and corresponding to 2.71% of the Portuguese annual GDP in 2010. Only socio-demographic variables were significantly and independently associated with CP costs, and not CP severity; raising the possibility of existing inequalities in the distribution of healthcare in Portugal.

The high economic impact of CP in Portugal was comprehensively demonstrated. Given the high indirect costs observed, restricting healthcare services is not a rational response to these high societal costs; and instead improving the quality of CP prevention and management is recommended.

Luís Filipe Ribeiro de Azevedo, MD, PhD is a professor and researcher at the Faculty of Medicine - University of Porto (FMUP) - Portugal, working in the Department of Health Information and Decision Sciences (CIDES), the Centre for Health Technologies and Services Research (CINTESIS) and the Portuguese National Observatory on Pain (NOPain). He is the Director of the Advanced Studies Program in Clinical and Health Services Research at FMUP. He is also currently a member of the National Committee on Health Technology Assessment. His academic and research areas of expertise include Pain Epidemiology and Impact Assessment, Health Technology Assessment, Biostatistics, Clinical Epidemiology, Evidence Based Medicine, Evidence Synthesis and Meta-analysis, Pharmacoepidemiology, Pharmacovigilance and Economic Evaluation.

DR MARY BAKER

MBE, BA, Hon DSc

Dr Mary Baker, MBE, is Immediate Past President of the European Brain Council and Past President of the European Federation of Neurological Associations, Consultant to the World Health Organisation (WHO), Chair of the Working Group on Parkinson's Disease and a member of the Strategic Advisory Board of the Human Brain Project. Academic appointments include Associate Membership of the Health Services Research Unit, University of Oxford and Visiting Fellow within the London School of Economics (LSE) Health Centre.

An Honorary Doctorate from the University of Surrey was conferred upon Mary in 2003 and an Honorary Doctor of Science degree was awarded by Aston University in July 2013. In 2009 she received the prestigious British Neuroscience Association Award for Outstanding Contribution to British Neuroscience and for Public Service. In 2014, Mary received the Dana/EDAB Lifetime.

Achievement Award for Outreach on Behalf of Brain Research and in 2015, she received the ECNP Media Award and in recognition of her contribution to and support of pharmaceutical medicine, she also received an Honorary Fellowship of the Faculty of Pharmaceutical Medicine.

Mary graduated from the University of Leeds with a BA Hons in Sociology and Political Theory.



B

Pain must not be ignored for the patients' sake. We should take care of those who have little voice.



HEINZ K. BECKER

Member of the European Parliament

Group of the European People's Party (EPP), Austria

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45288
heinzk.becker@europarl.europa.eu

**Together with SIP I
want to raise aware-
ness of the impact of
pain and identify poli-
cies at European level
to improve pain care.**

What the EU can do to improve pain care

I fully support the Societal Impact of Pain platform. Our strategy on active ageing in Europe has to take into account the impact that untreated pain can have on the quality of life of elders as well as their age of retirement and inactivity. Together with SIP I want to raise awareness of the impact of pain and identify policies at European level to improve pain care.

Heinz K. Becker is Member of the European Parliament for the European Peoples Party since 2011 and Vice President of the European Seniors Union since 2013. In the European Parliament he is a member of the committee on civil liberties, justice and home affairs and substitute member and vice coordinator of the committee on employment and social affairs. He is active in politics since 2001, when he became general secretary of the Austrian Seniors Association, which is the biggest and most powerful seniors association in Europe with over 300,000 members. Before he became a full-time politician he was self-employed with his own advertising company, based in Vienna.

NICOLA BEDLINGTON

Secretary General

European Patients' Forum (EPF)

Moderator Working group 2

Chronic Pain: a disease or multi-morbidity?

Nicola Bedlington (British, born in Scotland) studied business and HR management in the UK and France. Nicola Bedlington is EPF's Secretary General since September 2014 and was previously the Executive Director since the setting up of the EPF Secretariat in June 2006. From 2004 to 2006, she worked for the Swiss Government, leading the Environment and Schools Initiatives Secretariat, an international government-based network set up by OECD focussing on innovation, action research and policy development in the field of Education for Sustainable Development. She worked as an external expert for the European Commission on disability policy and NGO cooperation and during the 90s was the first Director of the European Disability Forum, an umbrella organisation uniting over 70 European NGOs and National Councils of Disabled People to advocate for the human rights and inclusion of disabled citizens in Europe.



B

European Patients' Forum (EPF)

Rue du Commerce 31

1000 Brussels

Belgium

Phone: + 32 2 280 23 34

nicola.bedlington@eu-patient.eu

www.eu-patient.eu

Patients with chronic conditions are often referred to as the most under-used resource in the health system. Too many patients are still struggling to get the support they need to become equal partners in care. To make real progress, patient empowerment needs to become a priority.



DR PAMELA F. BELL

MB BCh FFARCSI FRCA FFPMCAI FFPMRCA
Consultant in Pain Medicine (retired)

Chair, The Pain Alliance of Northern Ireland (PANI)

Northern Ireland (UK)

Phone: +44 (0) 78 03 29 37 93

pamela.bell@notebook.myzen.co.uk

The Painful Truth data show the importance of getting a timely diagnosis, the need for better information, treatment and support, and lack of education of healthcare professionals in chronic pain management. Only 40% of patients were referred to hospital services, and of these only 18% were sent to a Pain Clinic.

Pain Policy in Northern Ireland

February 2014 saw the publication of "The Painful Truth". This document reported the experience of over 2,500 people living with chronic pain; the impact of the burden of pain on their lives and of the care provided by Health and Social Care organisations and General Practices in Northern Ireland. The report made 10 recommendations to The Minister for Health, Social Services and Public Safety; 7 of these were accepted wholly or in part. The full report is available on the Patient and Client Council's website: www.patientclientcouncil.hscni.net.

Following the publication of "The Painful Truth":

- The Health and Social Care Board and the Public Health Agency undertook a scoping exercise which identified significant gaps in service provision in both primary and secondary care, with no region providing a comprehensive service;
- The Chronic Pain Forum was established, led jointly by the Public Health Agency and the Health and Social Care Board. The forum brings together patients and carers, multidisciplinary pain teams, general practitioners, high street pharmacists, voluntary sector organisations, and mental health services to redesign care;
- To improve the education of healthcare professionals in the management of chronic pain, the Medical Faculty of the Queen's University of Belfast has reinstated a lecture on the management of chronic pain and is encouraging students to undertake extra training at Pain Clinics as part of their student electives;
- The Regulation and Quality Improvement Authority have added pain assessment and management is a Quality Indicator for all hospital and care home inspections.

Dr Pamela Bell graduated in Medicine from Queens University Belfast in 1980. She trained in anaesthesia and held Consultant Posts in the Ulster, North Down and Ards Hospitals where she set up the first Pain Clinic at Bangor Hospital. In 1995 she was appointed to Musgrave Park Hospital where she established a Pain Clinic and developed a specialist interest in the management of children and adolescents with long term pain, the first in Northern Ireland. Strongly interested in supporting training and professional development of others in the field of pain management, she was instrumental in setting up a Masters Degree in the Science and Practice of Pain at the Queens University of Belfast.

Since retirement she has been actively involved in raising awareness of the burden of long term pain to the individual, their families and carers, and society through the work of the Pain Alliance of Northern Ireland of which she is the Chair. She remains committed to lobbying for access to effective pain management for all who suffer long term pain regardless of cause. She is a Trustee of Pain Concern, a charity that supports those who live with long term pain in the UK, where she oversees their research programme. She also supports doctoral and post-doctoral research at the University of Ulster Health Sciences Faculty

NEIL BETTERIDGE

Director

Neil Betteridge Associates

Secretary working group 2 Chronic Pain: a disease or multi-morbidity?

SIP working group 2 seeks to address whether chronic pain should be considered a disease in itself or an issue of multi-morbidity, and to offer policy makers guidance on how the EU should address it.

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.

After standing down as CEO of Arthritis Care in the UK 4 years ago, Neil now runs his own company, Neil Betteridge Associates, acting as an independent patient representative, working with the NHS, not-for-profit organisations, clinician organisations and industry to promote patient focus. Roles in this period have included Strategy Adviser to the British Society for Rheumatology and Patient Involvement Lead to the Royal College of Physicians.

Additionally he is currently:

- Co-Chair of the Chronic Pain Policy Coalition
- International Liaison Officer, Public Affairs, EULAR
- Patient and Public Voice, Clinical Reference Group, Specialised Pain Services
- Patient and Carer Adviser, Professional Record Standards Body



Neil Betteridge Associates
8 Lochaline Street
W6 9SH London
United Kingdom
Phone: +44 (0)7880 501166
neil@neilbetteridge.me.uk

Chronic pain should be a far greater priority in policy terms, both as a dimension of other diseases where appropriate and in its own right where patients are otherwise insufficiently supported by health and care systems oblivious to its personal and social impact.

B



PROF STEPHEN BEVAN

Head of HR Research Development

The Institute for Employment Studies

Chronic Musculoskeletal Pain and Work Productivity in Europe

City Gate
185 Dyke Road
Brighton BN3 1TL
United Kingdom
Phone: +44 (0) 1273 763424
Stephen.bevan@employment-
studies.co.uk
www.employment-studies.co.uk

**Early intervention helps
working age people with
chronic musculoskeletal
pain to remain in, or
return to work.**

As the European workforce ages and has to retire later, young people starting work today can look forward to working lives of 50 years or more. But with longer life expectancy comes an elevated risk of developing work-limiting chronic illness and chronic pain meaning that the quality of life and productivity of working age people with health conditions can be severely limited. In this presentation data on the burden and impact of chronic musculoskeletal pain in the European workforce will be presented. It will examine the prevalence of musculoskeletal disorders among the working age population, the balance of work-related and non work-related causes, the economic impact, the impact of co-morbid mental health problems and the potential for cumulative life-course impairment. The presentation will make the case for early intervention which helps working age people with chronic musculoskeletal pain to remain in, or return to work, and what clinicians, employers and policymakers need to do to ensure that chronic pain does not become an insurmountable barrier to living a healthy, fulfilling and productive working life.

Professor Stephen Bevan is Head of HR Research Development at the Institute for Employment Studies (IES). Stephen was, until March 2016, Director of Research at The Work Foundation, Lancaster University. Stephen has a special interest in workforce health and wellbeing, having led a number of national and international projects focusing on workforce health and the impact of chronic illness on productivity and social inclusion.

Stephen is an advisor to a number of UK government departments and has advised employers and policymakers in Europe, Asia-Pacific, Australasia and North America. He has received a special award from GAMIAN-Europe for his contribution to the field of mental health and is a reviewer for several academic journals, including The Lancet; a regular columnist for HR Magazine; a judge at the Global Healthy Workplace Awards; and is a member of Public Health England's Health & Work Advisory Board. Stephen has also been Chair of the Fit for Work Europe Coalition.

PROF CAROL BLACK

Expert Adviser on Health and Work

Department of Health England & Public Health England



B

Pain and the Workplace

Professor Dame Carol Black DBE, FRCP, FMedSci is Principal of Newnham College Cambridge, Expert Adviser on Health and Work to the Department of Health England and to Public Health England, and Chairman of the Nuffield Trust for health policy. She is also a member of the Welsh Government’s Bevan Commission on health in Wales, Chair of the RSSB’s Health and Wellbeing Policy Group, and a member of PwC’s Health Industries Oversight Board. In November 2011 when National Director for Health and Work she completed as Co-Chair an independent review for the UK Government of sickness absence in Britain. The recommendations of this report are now being put in place, with for example a national Fit for Work Service. Professor Black is a past-President of the Royal College of Physicians, of the Academy of Medical Royal Colleges, and of the British Lung Foundation. The Centre she established at the Royal Free Hospital in London is internationally renowned for research and treatment of connective tissue diseases such as scleroderma. She is a Trustee of the National Portrait Gallery, of the Work Foundation and of Uppingham School. In November 2013 she was named one of the 100 most powerful women in the UK in the BBC Woman’s Hour list.

Department of Health England &
Public Health England
28 Cornwall Terrace Mews
London, NW1 5LL
United Kingdom
Phone: + 44 (0)79 89 38 47 39
profblack@btinternet.com

Ensuring all stakeholders including governments work together to address the very painful problems that keep people out of work.



SOLEDAD CABEZÓN RUIZ

Member of the European Parliament

Group of the Progressive Alliance of Socialists and Democrats (S&D), Spain

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45596
soledad.cabezonruiz@europarl.
europa.eu

Pain and chronic pain are issues that impact European society. Pain patients should be granted access to healthcare services and treated in all countries with the highest standards. From the European Parliament we should push for the proper implementation of the Cross-Border Healthcare Directive which already states that pain should be a quality indicator to grant this overdue European access.

Soledad Cabezón Ruiz has been a Member of the European Parliament for the Spanish Socialist Workers' Party since 2014. She is a Coordinator for the Group of the Progressive Alliance of Socialists & Democrats in the European Parliament's committee on petitions (PETI), a member of the committee on the environment, public health and food safety (ENVI), and a substitute member in the industry, research and energy (ITRE) committee. She focuses in particular on health systems strengthening issues, health and energy policies. She sits on the board of IDEAS Foundation for progress, a Spanish think tank that works on political ideas and proposals for the Spanish Socialist Workers' Party (PSOE).

A cardiologist by profession, Cabezón worked for several years at the Hospital Universitario Virgen del Rocío. She has been active in national politics since 2003. She served as mayor of Albaida del Aljarafe between 2003 and 2011, and was elected to the Congress of Deputies, the lower house of Cortes Generales in 2008, representing Seville Province.

In the 2008–2012 period, she served as secretary of equality in the executive committee of the PSOE.





NICOLA CAPUTO

Member of the European Parliament

Group of the Progressive Alliance of Socialists and Democrats in the European Parliament (S&D), Italy

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45763
nicola.caputo@europarl.europa.eu

I am supporting the SIP symposium as I would like to work with pain experts to ensure that the Cross-Border Healthcare Directive functions in the way it was intended, namely protecting patients' right to seek treatment outside their home country when they are experiencing a high degree of pain.

What the EU can do to improve pain care

As a MEP I have a strong interest in defending the rights of European citizens. One of those rights should be the ability to access medicines and treatments in other Member states, when required. I am supporting the Societal Impact of Pain symposium as I would like to work with pain experts to ensure that the Cross-Border Healthcare Directive functions in the way it was intended, namely protecting patients' right to seek treatment outside their home country when they are experiencing a high degree of pain. This implies that Member States have properly transposed the Directive into their national legislation and, consequently, put in place mechanisms to assess the patient's level of pain.

Nicola Caputo started his mandate as a Member of the Group of the Progressive Alliance of Socialists and Democrats in the European Parliament on 1 July 2014. He is currently a member of the agriculture and rural development (AGRI), the environment, public health and food safety (ENVI) and the fisheries (PECH) committees.

Since his election Mr. Caputo has shown increased interest in public health issues and in particular the one related to access to medicines and treatments. He is an active member of the S&D Group Task Force on "Access to medicines" and he has been working hard to fight against unfair and unequal access to healthcare in the EU via a series of initiatives (motions, written questions, etc.). As member of the ENVI committee, Mr Caputo has been monitoring the enforcement of the directive on "the application of patients' rights in cross-border healthcare" which represents a major breakthrough for EU patients as it means empowerment in particular through greater choice of healthcare and easier recognition of prescriptions across-borders.

Nicola Caputo is a professional business adviser, specialized in commercial law, finance and administration of local authorities. He holds a degree in Economics from the Federico II University and has extensive experience in the agriculture, wine and automotive industries. Before joining the European Parliament, Nicola Caputo served 2 mandates (2005-2014) as Councillor for the Campania Region in Italy. As Regional Councillor and member of the Regional Health committee, Mr Caputo launched a series of initiatives in order to improve fair and equal access to medicines and treatments in his constituency.

PROF AUGUSTO CARACENI

Director Palliative Care, Pain Therapy and Rehabilitation Department

Fondazione IRCCS Istituto Nazionale dei Tumori di Milano – National Cancer Institute of Milan

The incidence and impact of cancer pain: clinical guidelines and research

Chronic pain in cancer patients may be caused by the cancer disease itself or by the anticancer treatment. Estimated pain prevalence in patients with advanced cancer varies between 30 to 70% depending on disease stage. Pain due to advanced cancer is often not satisfactorily controlled, the estimated amount of under-treatment of cancer pain reaches 30%. Given the predicted number of deaths for cancer in Europe in 2016 equals 1.360.000, more than 100.000.000 will have pain and about 300.000 poorly controlled pain. The consequences of suboptimal pain management on quality of life, physical functioning, and psychological distress can be devastating. Two-thirds of patients report that pain interferes with their activities of daily living, and half believe that their care providers do not prioritize quality of life in their overall plan of care. Since 1986 the WHO program to control cancer endorsed pain relief as a priority and disseminated guidelines to improve the use of opioid analgesics for this patients population, more recently the European Association of Palliative care promoted updated guidelines (Caraceni 2012, www.eapcnet.org ; www.ntnu.no/prc) to make state of the art treatment available to all patients but also highlighted the lack of research, the lack of new drugs development of and of strategies for addressing the needs of cancer patients with poor analgesic outcomes. This combines with the need of more academic recognition to focus research resources and education on palliative cancer care and in particular on cancer pain management. The low priority given at all levels of our society to the palliation of symptoms, in particular of pain due to all disease conditions and to pain in incurable cancer, has to be compared to the consideration given to any other area of health care and testifies a societal lack of responsibility in respect to the most vulnerable populations of citizens, such as the terminally ill, who depend on the available care networks and on dedicated groups of professionals for receiving appropriate pain relief and care until death.

Augusto Caraceni was born in Milan on August, the 8th 1960. He participated in the WHO program to test and disseminate the WHO ladder for cancer pain relief. He is presently director Palliative Care, Pain Therapy and Rehabilitation at the Fondazione IRCCS National Cancer Institute, Milano Italy vice president of the European Association for Palliative Care Research Network (EAPC - RN) and associate professor of palliative medicine at the Norwegian University of Science and Technology, Trondheim. Main previous office was the vicepresidency of the European Association of Palliative Care 2006-2010. He is responsible of the Cancer pain guidelines development of the European Association for Palliative Care and the author of 175 articles in indexed journals, on palliative cancer care, cancer pain and of more than 80 other publications, book chapters and books.



Fondazione IRCCS Istituto
Nazionale dei Tumori di Milano
Via Venezian 1
Milan
Italy
Phone: 39-02-23902792
[augusto.caraceni@istitutotumori.
mi.it](mailto:augusto.caraceni@istitutotumori.mi.it)

Improving advanced cancer pain control requires better knowledge and research on opioids and other analgesics. Quality of life, as a goal of care, when cure is not achievable should be part of the wider public discourse on cancer control and of a combined strategy between oncology and palliative care.

C



ANA SOFIA CARVALHO

Professor

Institute of Bioethics - Catholic University of Portugal

Catholic University of Portugal
Rua Diogo Botelho 1327
4169-005 Porto
Portugal
Phone: +351226196216
acarvalho@porto.ucp.pt

**Treatment of pain
is one of the most
prominent tasks of any
doctor.**

Bio-ethical implications of pain management

Although there is a consensual opinion that adequate management of pain is a medical must, with roots in classical Greek practice, there are numerous alarm signals that often the patients suffer from uncontrolled, unnecessary and personality-disrupting pain, even in hospitals. This surprising contrast accepted doctrine and its practical application merits a bioethical analysis.

Some factors have been identified as causes of this situation, which deprives patients from treatment to which they have the right to access. Mainly (and with some differences due to regional, economic and cultural differences) there are: insufficient knowledge of clinical situation and adequate therapy restriction of prescription of opioid analgesics; false notion of drug-induced risks of tolerance and addiction; irrational fears irrational concerning "last-ditch" treatment of severe pain.

All these aspects should be subject to an ethical based analysis and practical conclusion drawn. Our opinion, as non-medical specialist in Bioethics, is the following:

1. Treatment of pain is one of the most prominent tasks of any doctor;
2. Health sciences schools, especially medical ones, have the duty to cover in a comprehensive way teaching of pain management;
3. Regulatory measures which prevent patients from access to opioid treatment as indicated in their case are unethical and should be annulled. Some countries, like Portugal, have taken important steps in this direction;
4. Unsubstantiated notions of opioid-induced risks (tolerance, addition, adverse drug reactions) are irreconcilable with medical knowledge and good practice.

Two thousand years ago, Galen taught that "it is a divine to eliminate pain". It is time to ask all health professionals know and practice this axiom.

PALOMA CASADO

Deputy Director of Quality and Cohesion

Spanish Ministry of Health Social Services and Equality

Implementation of the Spanish National Strategy for addressing chronicity. Time for action

On 2012, a National Strategy for Addressing Chronicity was set in Spain, and contains a set of goals and recommendations, including management of pain under the scope of chronicity. The Strategic lines of this Strategy are the following: Health promotion, Prevention of Health Conditions and Chronical Limitations of Activity, Continuity of Care, Reorientation of Health Care (stratifying the population and promoting individualized care plans as a result of the comprehensive assessment of medical needs, and functional and social care), Health Equity and Equal Treatment and Research and Innovation.

As part of this Strategy, various projects and areas of work are being developed in order to carry out the implementation of the Strategy. For instance, we can highlight a Project of Stratification of the Population, A Network of Health Schools for Citizens, The Chronic diseases management project (an IT tool for the clinical decision support which includes managing of pain as principal task) and a Framework document for the Improvement of chronic pain in the NHS. So, a framework document for addressing pain was set on 2014. Having this framework in our NHS is essential in a decentralized system as our healthcare system is, and it must ensure: healthcare quality in managing pain, equity on accessibility and procedure's efficiency. Improving quality of care of patients with pain in the NHS, contributes to improve people's quality of life. The pain management document's wide scope includes: Acute pain, Non-oncological chronic pain, Oncological chronic pain, surgical pain, Pain related to diagnostic and therapeutic procedures, in adults and so in children.

This is a framework document that contains such strategic lines, objectives and recommendations in order to promote correct assessment of pain, to improve early detection and prevention of pain, and to encourage integrated care of people with pain, in order to provide a biopsychosocial approach.

The Spanish framework document to address pain is structured into four strategic lines:

1. Mainstreaming

- a. Pain as a priority in the frame of strategies and health policies
- b. Integrated approach
- c. Patient's Empowerment
- d. Reducing inequalities
- e. Training and research

2. Prevention

- a. Prevention of pain and its chronification
- b. Promotion of healthy lifestyles
- c. Chronic pain risk identification
- d. Pain prevention on diagnostic and treatment procedures
- e. Systematized assessment of pain: 5th sign
- f. Patient centered healthcare

3. Treatment: Patient safety and Therapeutic appropriateness

4. Coordination and Continuity of care

Paloma Casado Durández, MD specialist on Clinical Chemistry and Laboratory Medicine, is a Health Quality Management expert with 20 years of experience, and she has managed as Medical Director different Hospitals in Madrid. Since 2014 she is working for the Spanish Government as Deputy Director of Quality and Cohesion in the Ministry of Health, Social Services and Equality. She also participates in different Masters and professional events as Quality instructor and speaker.



Ministry of Health Social Services and Equality

Paseo del Prado 18-20

28071 Madrid

Spain

Phone: +34915964438 /58/59

pcasado@msssi.es

Pain is a priority health problem because of its frequency, its impact in person life's quality, its high societal and economic impact, so that a whole biopsychosocial approach is required. It also requires an integrated and coordinated health care system. Managing pain is essential to ensure a correct healthcare quality on chronic diseases.

C



DR MARILYN CASHA

**MD, MSc(Wales), MMCFD, DESA,
Consultant in Anaesthesia and Pain Management**

Mater Dei Hospital, Malta

Reporter Working group 3 The relevance of pain in cancer care and rehabilitation

Mater Dei Hospital
Dept. of Anaesthesia, Level -1
MSD 2090 Msida
Malta
Phone: +356 2545 0000
ext 4436
cashamarilyn@gmail.com

Providing information, support and capacity building of individual patients with chronic diseases and chronic pain, as well as their carers, is key to a good recovery, rehabilitation and ultimately reintegration in the workforce.

Dr Marilyn Casha is currently the only full-time Pain Management Consultant in Malta and works at Mater Dei Hospital and in private practice. She was instrumental in starting a dedicated Oncology related Pain Clinic in 2009 and was responsible for introducing spinal column stimulation to Malta. Dr Casha is heavily involved with NGOs like ARAM and No Pain Foundation with the aim of increasing awareness on the availability of pain management techniques in Malta. She also works as a lecturer at the University of Malta.

PROF JOSÉ M. CASTRO-LOPES

Faculty of Medicine of the University of Porto

Co-chair working group 4 Pain, rehabilitation and reintegration of workers in the working force

José M. Castro-Lopes is president of the National Observatory for Pain – NOPain of Portugal, and full professor at the Faculty of Medicine of the University of Porto, where he is the head of the Department of Experimental Biology, chair of Pain Medicine and director of the Post-Graduate Course on Pain Medicine. His research interests include the neurobiology of pain, particularly the changes induced in the central nervous system by chronic pain, and he also coordinates a recently established research group focusing on the epidemiology of pain in Portugal.



University of Porto
Portugal
jclopes@med.up.pt

C

Productivity losses and costs associated with presenteeism are hard to estimate but should be kept in mind when designing any strategy devoted to minimize the problem of the impact of chronic pain in the workplace.



FERNANDO CERVERO

MD, PhD (Madrid), DSc (Edinburgh)

Director, The Alan Edwards Centre for Research on Pain, Professor of Anesthesiology, Faculties of Medicine and Dentistry

Co-Chair of the plenary session

The treatment of pain must take into account its biomedical aspects and the psychological and social factors that influence its perception. As the Past President of the International Association for the Study of Pain, a professional organization dedicated to the study and relief of pain, I welcome initiatives aimed at increasing awareness of the societal impact of pain with the goal of reducing pain and suffering.

Dr. Cervero trained in medicine and neuroscience and throughout his professional life has studied basic mechanisms of pain with a special interest in clinically relevant aspects of visceral pain and the central mechanisms of hyperalgesia. He is currently the director of the McGill University pain research center, a long-established center of excellence in pain research and management. While on IASP Council, he introduced programs such as the Research Symposia and Collaborative Grants. Dr. Cervero has been International Association for the Study of Pain (IASP) Member since 1975 as Treasurer; Councilor; Chair of Finance, Committee on Committees, Research, and Financial Aid Committees; Member of numerous committees

Previous Appointments:

2009-2015 Director, the Alan Edwards Centre for Research on Pain (McGill University, Montreal, Canada)

2002-2015 Professor of Anesthesiology and Dentistry, Adjunct Professor of Physiology and Neurology (McGill University, Montreal, Canada)

1994-2002 Professor and Chair of Physiology (University of Alcalá, Madrid, Spain)

1983-1994 Reader in Physiology (University of Bristol, UK)

1990-1991 Visiting Scientist (Johns Hopkins Medical School, Baltimore, USA)

1975-1983 Lecturer in Physiology and Research Fellow (University of Edinburgh, UK)

Awards and Honors (selected):

- Member of the Academia Europaea
- Co-founder and Editor-in-Chief of the European Journal of Pain
- Canadian Institutes of Health Research (CIHR), Research Chair
- J.J. Bonica Award of the American Society of Regional Anesthesia and Pain Medicine
- Honorary Doctorates (Honoris Causa) from Universities of Cadiz and Rey Juan Carlos (Spain)
- President of the International Association for the Study of Pain
- Distinguished Career Award of the Canadian Pain Society

Selected Publications:

Author of over 200 articles in journals and books. Editor of several books on pain mechanisms.

1. Cervero, F. (1994) Sensory innervation of the viscera: peripheral basis of visceral pain. *Physiol. Rev.* 74, 95-138.
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McGill University
McIntyre Medical Bldg. Room 1207
3655 Promenade Sir William
Osler
H3G 1Y6 Montreal
Quebec
Canada
Phone: +1 (514) 398-5764
fernando.cervero@mcgill.ca
<https://www.mcgill.ca/dentistry/research/our-researchers/cervero>

Pain is a complex experience that can only be measured by the verbal reports of patients.

THERESE COMODINI CACHIA

Member of the European Parliament

Group of the European People's Party (EPP), Malta

What the EU can do to improve pain care

Therese Comodini Cachia is a lawyer by profession working in the field of human rights. She has been representing victims of human rights violations since 1997 through court proceedings both before the Maltese courts as well as before the European Court of Human Rights.

She has also been heavily involved in non-governmental organisations having acted as their legal advisor. Her work with non-governmental organisations has kept her abreast with the perceptions held by and the social needs of different groups in society. She believes in respect for the dignity of each individual.

She is a lecturer at the Faculty of Laws of the University of Malta and coordinates the Masters degree in Human Rights and Democratisation. She also lectured at the University of Utrecht, in Holland and presently lectures at the Europa-Viadrina University in Germany.

In May 2014 Comodini Cachia was elected Member of the European Parliament. She is a member of the Culture, Education, Youth Policy, Media and Sport Committee (CULT), the Legal Affairs Committee (JURI) and also serves on the Subcommittee on Human Rights (DROI). She is also a member of the delegation for relations with the Palestinian Legislative Council, that to the Parliamentary Assembly of the Union for the Mediterranean and the Delegation for relations with the People's Republic of China.

Comodini Cachia has actively participated in the Partit Nazzjonalista and was a member of the Commission for the revision of the Statute and Party Structures. She is also seen as a point of reference for the Parliamentary Group having contributed to a number of positions including amendments to the Constitution of Malta. Currently she coordinates the Policy Fora of the Nationalist Party. In January 2015 she was appointed shadow Minister for Education and Employment.

Comodini Cachia graduated in law in 1997 and holds a Ph.D. in human rights law. She is married to Vladimiro and mother of a daughter, Laura.



European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)22845835
therese.comodinicachia@
europarl.europa.eu

Everyone must be relieved from unnecessary pain. Relevant solutions must be used to address the negative impact that pain has on people, in order to address the burden on people's quality of life, healthcare and employment. Please join me supporting the societal impact of pain platform.

C



VIORICA CURSARU

Myeloma Euronet Romania

Availability versus affordability of medical treatment for pain

Myeloma Euronet Romania
Calea Victoriei 194
Bucharest 100097
Romania
Phone: +40723543333
viorica@myeloma.ro

There is a need for minimum standards of health for all EU patients

Presently, there is an enormous gap between the medical health systems in the most developed EU member states and the EE EU countries. Over the years, the quality of medical services rendered in the EE EU countries has failed to meet the generally accepted standards of health due to several factors such as a severe shortage of Medical Doctors, who have massively emigrated to the most developed EU countries, lack of access to proper treatment and medication, and economic conditions. The impact is devastating in terms of increased mortality, increased rate of incidence in diseases which have been eradicated a long time ago and in general in the daily struggle of patients who are forced into trying to cope with availability and affordability of medical services.

Over 200 million people suffer from chronic pain in Europe and, by matter of consequence, the scale of the social impact both at the national and European levels represents the real challenge, especially in the field of health, economics and social security.

Ms Cursaru is the president of Myeloma Euronet Romania, an organization founded in 2006 when her late husband Mihai Cursaru was diagnosed with multiple myeloma. She has a bachelor's degree in English Literature and worked for the United Nations for 20 years prior to retirement. For the last 10 years, she was actively involved in patients' advocacy, mainly focusing on health system inequalities within Europe, the need for minimum standards of medical treatment, access to medication and a more patient-oriented policy at EU level. Presently, Ms Cursaru is a board member of Pain Alliance Europe (PAE), an European organization comprising 33 members in 16 European countries. The mission of PAE is to have chronic pain recognized as a disease on its own and, in this respect, it is actively advocating at the European Parliament, EU Health Commission and other European organization.

MIRIAM DALLI

Member of the European Parliament

Group of the Progressive Alliance of Socialists and Democrats in the European Parliament (S&D), Malta



European Parliament

60, rue Wiertz

B-1047 Bruxelles

Belgium

Phone: +32(0)2 28 45635

miriam.dalli@europarl.europa.eu

D

What the EU can do to improve pain care

Miriam Dalli was elected to the European Parliament in May 2014. She currently sits as a full member on the committee on the environment, public health and food safety (ENVI) and on the Delegation for relations with the Maghreb countries and the Arab Maghreb Union. She is a substitute member on the committee on industry, research and energy (ITRE), the committee on civil liberties, justice and home affairs (LIBE) and delegation to the EU-Armenia, EU-Azerbaijan and EU-Georgia Parliamentary Cooperation.

Recently she has been appointed on the Committee of Inquiry into Emission Measurements in the Automotive Sector. She also represented the European Parliament as part of the official delegation to the Climate Change Conference, COP21 that was held in Paris in December 2015.

Miriam Dalli successfully completed her Doctorate of Law at the University of Malta and she obtained a first class degree in her LL.B. course which leads to the conferment of Bachelor of Laws. She is a Communications graduate (1998) and she obtained an MA in European Studies (2003) and an MBA (2001).

With over 15 years of experience in the Communications sector Miriam Dalli established herself as one of the main television journalists in Malta. She was also News Editor of ONE TV and ONE Radio.

Prior to her election as MEP, Dr. Dalli held the post of Advisor with the Ministry of Energy and Conservation of Water focusing on Communications, Corporate Social Responsibility and Stakeholder Management.

Even though we registered significant advances in medical treatments and also treatment options, unfortunately until this very day, pain continues to be poorly managed and under treated. I strongly believe that the issue of pain must be addressed effectively. The European Union must provide guidelines to all the Member States to consider pain in its own right. Member States need to be provided with the necessary information and support, in order for them to be able to introduce the proper policies which can really make a difference. Better pain treatment at an early stage is fundamental for our patients' wellbeing. Awareness, education and further budget allocations are tools that are required to address pain as a condition in its own right. Ultimately our citizens' health should always be our main priority.



GÜNTER DANNER

Department Director, DSV-AE

Special Advisor, Techniker Krankenkasse

Pain-care and rehabilitation are threatened by failing systems of care

DSV-AE

50 rue d'Arlon

1000 Brussel

Belgium

Techniker Krankenkasse

Bramfelder St. 140,

22305 Hamburg

Germany

Phone: +491716400178

g.danner@gmx.net

In times of shrinking public funds systems of health-care are falling apart. More should be done to help them and their patients.

SIP events of the past have always marked stepping-stones toward progress in the interest of pain-patients. Yet, as we speak, many EU systems and others are threatened by financial erosion. This brings about many calamities, e.g. a renewed competition among “publicly palatable illnesses for better funding” or, even worse, competition among those suffering. Where basic hospital equipment and therapies are no longer assured, rehabilitation won’t make much headway on the agenda. Years of financial strains have left marks on the discussion and reality of care-provision.

What can we do? There is no one-EU-Europe answer feasible, since our Member States are rather moving apart, as the refugee-drama underlines. Thus at patient and scientific level, we may still make ourselves be heard. Weekend systems should be supported by know-how and political help. Thus more exchange as closely linked to the patients as possible is of considerable social and moral momentum.

JOSE DE ANDRES

President European Society of Regional Anesthesia and Pain Therapy
Professor of Anesthesia.Valencia School of Medicine
Chairman Anesthesia Critical Care and Pain Management Department

General University Hospital

European Charter of the Rights of Citizens over 65 with Chronic Pain

Chronic pain is not an inevitable part of aging, but it is, unfortunately, a fairly common occurrence among those aged 65 or older. The European Union recognizes the rights of the elderly in art. 25 of the Charter of Fundamental Rights of the EU (Charter of Nice, Official Journal 2000 / C 364/01 of 18/12/2000 p. 0001-0022), and the right to protection of health in art. 35. It is stressed that these rights are fully binding on the EU institutions and the Member States with the entry into force of the Lisbon Treaty and the Charter of Nice takes the same value as the Treaties.

In addition, an important milestone as the "European Charter of Patients' Rights" (published by Active Citizenship Network, 2002) clearly sets out the rights: to preventive measures, access, information, consent, freedom of choice, privacy and confidentiality, respect of patients' time, respect of quality standards, security, innovation, avoid unnecessary suffering and pain, a personalized treatment, complain, and refund.

Chronic pain as a disease it is virtually unknown to health professionals and the public in general. Nevertheless chronic pain is one of the most significant causes of suffering and disability in the world. One European in five suffers from chronic pain, and one in four Europeans suffers of severe chronic pain, 100 million only in the 27 EU countries, half of whom were not receiving any treatment or even not taken seriously. On average, people with chronic pain lives 7 years. 19% of adults suffer from chronic pain from moderate to severe, impacting severely on the quality of their work and social life. Of these people, few are treated by pain specialists and about half receive inadequate treatment for pain, in addition, each country has its own peculiarity.

Chronic pain produces enormous costs to society, both direct costs in terms of health and social care, that indirect costs in terms of inability to perform work for patients and care-giver. 21% of European patients suffering from chronic pain is unable to work, and among these, 61% said that the disease has greatly affected their status in the workplace. According to the Pain Proposal European Consensus Report, chronic pain would cost Europe **300 billion Euros** a year.

Pain relief is therefore a fundamental right, recognized as such by the World Health Organization (WHO) and the Observatory on the respect of Human Rights (Human Rights Watch), which means that the Member States of the EU should consider the treatment of chronic pain and access to health a public health priority. It is essential to contextualize the epidemiological reality, taking into account that older people are the segment of the population that is growing rapidly around the world, and with specific needs in diagnosis and management.

In conclusion we need to implement adequate structure for providing information suitable for elderly people. **Diagnosis, appropriate treatment** and to take charge for people suffering from chronic pain also aimed at the physical and psychosocial rehabilitation. The elderly patient with chronic pain has a right of access to innovation if: contribute to the prevention, improved health status, quality of care and management of people with chronic pain by the physician / health care provider / caregiver.



General University Hospital
Valencia, Spain
deandres_jos@gva.es

D

The European citizens have a long life expectancy and 17% of them are the elderly. In this demographic background it is necessary to guarantee a good quality of life also in the advanced age. To safeguard and improve the life of the elderly people and to successfully fight against the most common risks connected to this phase of their life, an action from the public health system and curative interventions are necessary, aimed at upholding their quality of life by reducing the problems linked to inadequate pain relief treatment.



DR SASKIA DECUMAN

Expert Research and Development

**National Institute of Health and Disability Insurance (NIHDI),
Department of Benefits**

Centre of knowledge in work incapacity focuses on reintegration with disabling pain

National Institute of Health and
Disability Insurance (NIHDI)
Tervurenlaan 249
1150, Brussels
Belgium
Phone: +32 2 739 76 33
saskia.decuman@riziv.fgov.be
www.riziv.fgov.be

**Studies show that
pain is without any
doubt one of the most
significant contributing
factors for sickness
absence due to MSD.
Participation and
coping with pain are
also key aspects for pa-
tients facing diseases
like cancer.**

Belgium has one of the highest prevalence of chronic pain. Moreover the problem is significant in people within the labour active age. Consequently we have high absenteeism (21% does not work due to a pain-related problem) and presenteeism (more than 1/3 is limited in functioning while at work) (Breikvik, 2006; WIV, 2008). Nevertheless research shows that this people want to work (VPP, 2014). In the figures about work incapacity we find MSD as one of the major causes of sickness absence, with pain without any doubt as one of the most significant contributing factors. But also in other diseases like cancer we see that, as survival augments focus is also on participation and coping with factors such as pain.

The center of knowledge in work incapacity, installed in the Department of Benefits of the National Institute of Health and Disability Insurance (NIHDI), focuses since some years on this topic in the study program they launch. This program is executed in collaboration with experts and serves policy development. Some months ago a research was finalised in which the current situation on the social-professional reintegration of chronic pain patients was mapped. The results of this project will be used in several follow-up studies the centre plans to launch in 2016. In this studies focus will be on development of the trajectory to work for people with pain followed-up in Belgian pain centres. Besides that we plan to support several research projects on cancer and return to work (RTW). In all projects attention will be on early intervention, transmurality, communication between stakeholders.

Besides research, the NIHDI foresees formal systems which stimulate RTW. One of the tools is the possibility to RTW in an adapted way (level of time, task, ...), while remaining on work incapacity. This gives important benefits for employer and employee (eg. earlier RTW). The NIHDI has also conventions with regional employment services and the social insurance companies to support updates of competences, and education to another job, in order to make sure the insured worker can, nevertheless his disability RTW. Reintegration to the former job within the same employer as first objective, but if not possible other options are elaborated.

Dr Decuman is OT and MSc in medical-social sciences (health education and promotion). In 2014 she achieved a Phd degree for the work she performed on "work participation in people with systemic sclerosis" at the department of Rheumatology of the Ghent University. Currently, she is expert research and development at the Department of Benefits (NIHDI). She is scientific coordinator of the centre of knowledge in work incapacity which has as main aims (inter)national networking and supporting research in order to be able to guide policy. Beside that she's project leader for the implementation of the disability management curriculum as developed by the National Institute of Disability Management and Research (Canada). With this educational framework the NIHDI wants to support their stakeholders to develop the necessary competences in job retention and reintegration.

JOSÉ INÁCIO FARIA

Member of the European Parliament

Group of the Alliance of Liberals and Democrats for Europe (ALDE),
Portugal

What the EU can do to improve pain care

Bachelor in Law by the Universidade de Lisboa. Completed a post-degree in Environmental Law by the same University and is currently working on his PhD thesis in International Public Law at the Universidad de Cáceres.

As a lawyer, José Inácio Faria provided legal support to the Lisbon City Hall from 1992 to 2012. His responsibilities included running the City Hall International Relations Office, assisting several Environment aldermen, and providing legal advice directly to the Mayor's Office and to the Institutional and Social Departments of the City Hall. From 2012 to 2014 he provided legal and political support to the Partido da Terra Political Group at the Lisbon Municipal Assembly.

José Inácio Faria joined Partido da Terra - MPT in 2005. He performed various roles in the party up to 2014, when he was elected its President. In July of that same year, he became Member of the European Parliament, where he takes part in the environment, public health and food safety and transport committees.

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45454
joseinacio.faria@europarl.europa.eu

F

The effect pain has on patients and societies is something which policy makers in Europe should take very seriously. I have asked the European Commission to fully implement legislation affecting pain such as the Patients' Rights Directive, and will continue to fight for patients in need of adequate pain treatment.



PROF BARONESS ILORA FINLAY OF LLANDAFF

National Mental Capacity Forum chair

House of Lords

Pain's impact on mental capacity, fear and decision making

House of Lords
SW1A 0PW
Westminster, London
United Kingdom
Phone: +44 207 219 6693
finlayi@parliament.uk

Pain is multifactorial: physical pain is magnified by fear, emotional turmoil, and social and spiritual concerns. Good communication skills underpin pain assessment - distress is a medical emergency. Poor opioid access globally means 80% of patients die without any pain relief, 6% are children.

The multiple domains of pain result in it being the most feared of symptoms. As a pointer to underlying disease, whether physical or mental, it poses a medical emergency. Those with pain often have some impairment of mental capacity, whether through the underlying disease, through the effect of pain itself, through concomitant depression and drug side effects. Without good pain relief rapidly, the distress is reinforced and patients can rapidly become hopeless, driving a desire for death.

Where children experience or witness people in pain, the trauma can deeply affect their life course. When that experience is part of bereavement, such children are often invisible in health and social care systems.

The world-wide effects of unrelieved pain in severe disease have a profound effect on both the patient and family. Provision of adequate access to analgesia needs to become a key concern of all governments worldwide.

Prof Baroness Finlay has been a consultant in palliative medicine since 1987, and palliative care lead for Wales since 2008. She is now a politically independent crossbench member of House of Lords. She introduced the Access to Palliative Care Bill, and is Vice Chair of All Party Parliamentary groups on Hospice and Palliative Care, Cancer, Suicide Prevention. She is Chair of the National Council for Palliative Care, the National Mental Capacity Forum, and the Living and Dying Well think tank. She has an established internationally renowned Diploma/MSc in Palliative Medicine / Care and has written publications with a focus on ethics in end of life care.

ROSA MARIA FRAGOSO

Senior Consultant in Medical Oncology

Portuguese Institute of Oncology (IPO)

Cancer survivors: Between bureaucracy and clinical duty

Cancer survivor (CS) refers to people at any point on the cancer trajectory from diagnosis to end of life. It can include those who live with cancer and those who have had cancer in the past. We will focus on patients surviving for more than 5 Years, as, in most countries, they will be discharged from their “cancer-treating” hospitals.

Worldwide, 24.6 million people were diagnosed with cancer in the last five years and it is expected that 50% of these will live at least five years (CR UK, 2008). The number of cancer survivors continues to grow, and 50% of survivors are likely to be over age 65. Although survival rates are increasing, we do not know at what cost to the health and well-being of the survivors.

The impact of cancer does not end after treatment; survivors are often left with the physical reminders of cancer and its treatment such as a wide range of physical and psychological symptoms (fatigue, pain, neuropathies, depression and anxiety), physical complications (such as cardiopulmonary compromise), recurrence of cancer, second malignancy and functional declines. However, the late effects of cancer may be dismissed as signs of ageing in older survivors.

Most chronic pain in CS is a consequence of cancer and cancer treatment. As survival is the main goal in cancer treatment, chronic pain, adverse treatment related effects, disfigurement may be either unappreciated or considered a subordinate risk in a quest for survival.

Treating cancer survivors with chronic disease (cancer pain) and prolonged lifespan may be unaffordable due to the changing challenges of contemporary hospital care (changing consumer expectations and demands, fiscal constraints, increasing demands for access to care, a mandate to improve patient centered care, and issues concerned with levels of quality and safety of health care) and primary health care. However, CS are innocent bystanders of the therapeutic trends in the improvement of cancer treatment, and clinical adverse effects may still be reported more than 20 years after treatment.

CS are part of an evolving story; although biologically “cured from cancer” they may remain with lifelong sequelae of cancer and cancer treatment and the added-on comorbidities as they get older. We do need to keep on following these symptomatic CS under the bio-psycho-social model promoting multidisciplinary team care; we will need to define who is going to take charge and promote undergraduate and graduate health professionals’ education.

Health politics needs to make a clear care shift towards personalized assessment, care planning and self-management, supported with information on the consequences of cancer and its treatment. This will necessitate a shift from viewing cancer as an acute illness to a greater focus on cancer as a chronic illness, with the objective of maximizing health and well-being after treatment.

IPO Porto
Av Montevideu 500 – 1º
4150-516, Oporto
Portugal
Phone: +351 225084000
carocha321@hotmail.com

Health systems still focus on the acute phase of cancer treatment aiming cure. The increased number of cancer survivors with chronic cancer pain and prolonged lifespan may be unaffordable. Who should take charge of these individuals in the future? Should we remain distracted spectators leaving them lost in the transition?

F



University College Dublin
Belfield Campus UCD
Dublin, 8
Ireland
Phone: 01-7166516
brona.fullen@ucd.ie

The burden and cost of pain to society needs to be addressed by all stakeholders.

DR BRONA FULLEN

Physiotherapist

Health Science Centre, University College Dublin

Co-chair working group 4 **Pain, rehabilitation and reintegration of workers in the working force**

Dr Brona Fullen is a lecturer in the UCD School of Public Health, Physiotherapy and Sports Science, Dublin, Ireland. She holds a BSc Physiotherapy (UUJ), MSc Healthcare (Acupuncture, UCD), and PhD (UCD) degrees. Clinically Brona specialized in the topic of pain working in Pain services at Massachusetts General Hospital, Boston, St Vincent's University Hospital and Tallaght Hospital Dublin.

In UCD she teaches in the area of pain science to both undergraduate and postgraduate students. She is Director of the MSc programmes in Advanced Physiotherapy Studies and Healthcare (Acupuncture). Her research areas of interest include the assessment and rehabilitation of people with chronic pain in a range of conditions including musculoskeletal dysfunction, obesity, and spinal cord injury. She has supervised MSc and PhD students to completion, and has presented her research at national and international meetings.

Brona is a past President of the Irish Pain Society (Chapter of the International Association for the Study of Pain), and the first Chartered Physiotherapist to be elected to the European Pain Federation EFIC® Executive Board.

THERESA GRIFFIN

Member of the European Parliament

Group of the Progressive Alliance of Socialists and Democrats (S&D),
United Kingdom



European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45271
theresa.griffin@europarl.europa.eu

G

What the EU can do to improve pain care

In May 2014, Theresa was elected to the European Parliament, as the top Labour Party candidate in her region, to represent the North West of England. Theresa is a member of two committees in the European Parliament. She is a full member and Labour Party Spokesperson for industry, research and energy and a substitute member on the transport and tourism committee. Theresa also follows the Disability Rights, the Digital Agenda for Europe, Children's Rights and Well-being, LGBTI, SMEs, Tourism, Trade Union and Urban Intergroups.

Theresa has been a Labour Party member for 26 years; an active campaigner at local, constituency, national and European levels. She was a member of Unite's North West Political Committee and represented the North West Constituency Labour Party on the National Policy Forum. As a Liverpool City Councillor in the 1990s, she was lead member for Economic Development and Europe and was instrumental in bringing Objective One status and billions of pounds of investment to the Liverpool city region.

In the European Parliament, Theresa has been working on issues concerning fuel poverty, regional funding, equalities and disability rights, the promotion of a digital single economy, and climate change. Theresa is a committed trade union activist and has campaigned closely with all unions on employment rights, rights for young people and against the far-right.

Throughout my political career I have held the strong belief that everyone should have access to quality employment - regardless of their circumstances. One difficult and under-debated barrier into work is poorly managed pain. Chronic pain and lack of proper holistic pain management often pushes individuals into early retirement, or keeps them out of work, when they would otherwise chose to keep working.



FRANCOISE GROSSETÊTE

Member of the European Parliament

Group of the European People's Party (EPP), France

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45952
francoise.grossetete@europarl.
europa.eu

I whole hardly support the objectives of the symposium on the Societal Impact of Pain where all stakeholders seek to improve pain policy under the motto "Time for Action!".

What the EU can do to improve pain care

On 11 October 2001, I hosted the launch, in the European Parliament, of the inaugural EFIC European Week Against Pain. The purpose of the Week was to raise awareness of chronic pain as a disease in its own right amongst decision-makers, doctors and the general public, with a view to improving access by patients to the treatments available for it.

10 core objectives of the Week were identified. Three of them are as follows:

- To inform decision-makers of the significant impact that chronic pain has on patient morbidity and quality of life, avenues for improvement, and anticipated social and economic benefits for Europe.
- To inform decision-makers of the cost-effectiveness of available pain relief modalities and encourage their incorporation into health fund coverage and management modalities.
- To seek ways of reducing governmental obstacles to analgesic availability and use.

15 years and many "European Weeks Against Pain" later, there is little evidence that these objectives have been heard by European governments, let alone met. Most critical of all, however, is that the fundamental message of the "European Week Against Pain", that chronic pain is a disease in its own right and should be treated as such, continues to be ignored. Whilst strategies are developed to combat other diseases across Europe, there is no such strategy for chronic pain, only an irregular hotchpotch of policies that provide little by way of a framework for improvement.

I therefore whole hardly support the objectives of the symposium on the Societal Impact of Pain where all stakeholders seek to improve pain policy under the motto "Time for Action!"

Françoise Grossetête is a Member of the European Parliament and 1st Vice-Chair Group of the European People's Party (EPP - Christian Democrats). She has been a French Member of the European Parliament since 1994 and was previously a municipal councillor then deputy mayor of Saint-Etienne (France, Rhône-Alpes). She is a member of the committee on environment, public health and food safety (ENVI) and substitute member of the committee on industry, research and energy (ITRE).

Françoise Grossetête is Chairwoman of The European Alliance Against Alzheimer's and of the European Cervical Cancer Association which are multinational and cross-party groups that unite Members of the European Parliament.

DOTT ALBERTO GRUA

Member of the Corporate Executive Board

Grünenthal Group

Working together to improve pain policy

Pain has many faces. It can be pulsing, aching, sharp, dull, or even drilling. The differentiation of these different forms of manifestation is crucial for the treatment since it provides clues about the cause of the pain and the place where it originates from. Even if you know about chronic pain and different therapy opportunities, it is often difficult to accept the pain. In most health care systems pain is considered merely a symptom while for patients dealing with pain it is a disease in its own right.

Pain is a major healthcare problem in Europe as it imposes a huge burden on the individual as well as the surrounding society. However, the influence that pain has 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 policy 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 – and improving pain care in Europe is our ambition.

About Alberto Grua

In July 2013 Alberto Grua took over the position as Chief Commercial Officer EU, North-America and since then he is member of the Corporate Executive Board. In June 2014 he additionally took over the responsibility of the area Global Product Supply and in March 2016 of the area Global Supply Chain.

Before, since July 2010 he was Executive Vice President Grünenthal Europe & Australia. From 2008 to 2010 he assumed responsibility for the Palexia® Global Business Unit. Alberto Grua joined Grünenthal in 2005 as General Manager of Grünenthal Italy.

Until this, he worked for 17 years with Bayer AG in different sectors, such as consumer care, diagnostics and pharmaceuticals in Marketing and Sales positions in Italy with additional responsibility as Worldwide Vice President Marketing Point of Care in the USA. He studied Business Administration at the Bocconi University in Milan/Italy. Alberto Grua was born in Turin/Italy in 1961.

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



Grünenthal GmbH
52099 Aachen
Germany
Phone: +49 241 569-1526
alberto.grua@grunenthal.com
www.grunenthal.com

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At SIP 2016 we have the unique opportunity to bring the discussion of the societal impact of pain one step further in favour of those who count most: patients, relatives, friends, all people we know and people we love.



TAKIS HADJIGEORGIOU

Member of the European Parliament

Confederal Group of the European United Left - Nordic Green Left (GUE-NGL),
Cyprus

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
takis.hadjigeorgiou@europarl.
europa.eu

Chronic pain affects a large proportion of the adult population in Europe. It is our duty as elected representatives of this people to do our utmost to ensure that European policies in the health sector have at their core this population group. As Vice-Chair of the inter-group for rheumatic and musculoskeletal diseases, I closely track the developments in the health sector and I must say that Europe is still far away of achieving that “basic need” of universal access to health care and to provide to people affected the essentials for their living.

What the EU can do to improve pain care

Takis Hadjigeorgiou is a Cypriot politician, who has been serving a Member of the European Parliament since 2009. Coming from the Progressive Party of Working People (AKEL) in Cyprus. He has also served as Member of the Cyprus House of Representatives for two tenures. He is currently Vice Chairman of the EU-TURKEY Joint Parliamentary Committee as well as Member of the committees on foreign affairs (AFET) and petitions (PETI) respectively. Takis Hadjigeorgiou is also Vice Chair of the European Parliament Interest Group on rheumatic and musculoskeletal diseases (RMDs).

Since his completion of his academic studies in Law and Journalism, his political and social activities have had an active and lasting impact in Cyprus society.

PROF GUY HANS

Antwerp University Hospital (UZA)

The role of pain as indicator in hospital accreditation

Pain is the most common complaint of hospitalized patients. A comprehensive care pathway for the assessment and reassessment of pain in all hospitalized patients is therefore of crucial importance. Creating such pathway is a difficult task for hospital administrators and clinical leaders, requiring education, sensibilisation and continuous monitoring. Accreditation is nowadays considered as an important tool in the quality evaluation of hospital institutions throughout the world. In this presentation the importance of pain as an indicator in hospital accreditation will be evaluated. Moreover, the creation of a hospital-wide comprehensive care pathway for pain will be discussed as well as the measures that need to be taken to ensure the maintained quality of such a care program.

Guy Hans is an anaesthesiologist from training. During his training he developed an interest in the pathophysiology and treatment of acute and chronic pain. At the end of his training in anesthesia he held the Philip A. Lief Fellowship in pain at the Harvard Medical School (Boston, USA). In 2000 he started his career as a pain physician at the Multidisciplinary Pain Center of the Antwerp University Hospital (UZA). In 2004 he became medical coordinator of this pain center. As such he participated in many trials that led to a nationwide reform of pain treatment in Belgium in the period 2002-2012. In 2011 he was appointed professor in Algology (pain treatment) at the University of Antwerp. In June 2015 he was elected as president of the Belgian Pain Society. In October 2015 he was appointed to become the Chief Medical Officer (CMO) of the Antwerp University Hospital.



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Belgium
guy.hans@uza.be

Pain should be considered as the fifth vital sign. The assessment of pain is as such a valuable indicator for the accreditation of hospitals.

H



MARIAN HARKIN

Member of the European Parliament

Group of the Alliance of Liberals and Democrats for Europe (ALDE), Ireland

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45797
marian.harkin@europarl.europa.eu

The Societal Impact of Pain is a campaign I have supported for a number of years. Chronic pain can have a significant impact on patients individually as well as on our health systems and societies. This year I want other Members of the European Parliament to join me to push for improved policies affecting pain care.

What the EU can do to improve pain care

Marian Harkin is an Independent MEP representing the 15 counties of the Midlands-North-West constituency of Ireland in the European Parliament. She is now in her third European term following the 2014 European Election in May and previously represented Sligo/Leitrim as a TD in Dáil Éireann.

Marian is a full member and ALDE Coordinator of the employment and social affairs committee, a substitute member on the economic and monetary affairs committee and the petitions committee. Marian has also recently been appointed to the newly established tax committee in the European Parliament.

In her work on the Petitions Committee, Marian has facilitated many petitioners in having their voices heard and their cases examined at European level. Part of her work involves connecting ordinary citizens to the EU Institutions to try to resolve issues where there is non-compliance with EU legislation and she has achieved a number of successes in this area. As well as her legislative work Marian has a deep interest in Social and Public Health issues. She is Chair and founding member of both the Carers Interest Group and the Volunteering Interest Group and is also Vice Chair of the Credit Union Interest Group, Mental Health Group, Epilepsy Support Group, the Brain, Mind and Pain Group and Complementary and Alternative Medicine Group. She is a member of the MEP Heart Group, LGBTI Intergroup, and MEPs against Cancer Group, the Intergroup on Ageing and Solidarity between Generations, and the Social Economy Intergroup.

As Vice President of the Disability Intergroup Marian is spearheading an initiative to have an EU Commissioner for Disability and has actively worked on accessible public websites, the European Disability Card and using the Parliament as a vehicle to pressurise Member States to ratify the UN Convention on the Rights of Persons with Disability.

Other areas where Marian remains active include her support for Credit Unions, her support of independent living for persons with disabilities and for adequate services for children with special needs, as well as work in the area of political transparency. Marian visits schools on a very regular basis to debate and explain her work and makes every effort to link in with and support community endeavours.

In 2011 in the MEP of the Year Awards Marian won the "Outstanding Achievement Award" in recognition of her work in promoting the interests of volunteers and volunteering in the European Union. In 2012, she won the MEP of the Year award for her work in the area of Employment & Social Affairs.

DAVID HARLEY

Senior Advisor

Burston-Marsteller

Moderator of the plenary session

David joined Burson-Marsteller Brussels as a Senior Advisor in April 2010. Before that, he was Deputy Secretary-General of the European Parliament.

David started his career in the European Parliament in 1975 as an advisor in the office of the Secretary-General and then held a succession of increasingly senior roles, including as an aide to Parliament President Lord Plumb (a British Conservative), as Spokesman for Parliament President Pat Cox (an Irish Liberal) and as Secretary-General of the Socialist Group, the Parliament's second largest political family.

In 2007, he took up his final post as Deputy Secretary-General and Director-General of the Presidency.

David is a modern languages graduate of Cambridge University and speaks English, French, Spanish, Italian and German.



Burston-Marsteller
37, Square de Meeûs
B-1000 Brussels
Belgium
Phone: +32 2 743 66 11
<http://burson-marsteller.be>

I am delighted to be part of this initiative. As someone who has worked at the heart of the European Parliament, I know the importance of getting support across many political groups in order to make a campaign successful. SIP aims to achieve real policy change in the field of pain care, and with the support shown at SIP 2016 by MEPs from across the Parliament, as well as by other EU institutions, this time it could really happen.

H



THOMAS ISENBERG

Executive Director

German Pain Society (Deutsche Schmerzgesellschaft e.V)

Deutsche Schmerzgesellschaft e.V
Alt-Moabit 101 b
10559 Berlin
Germany
Phone: +49 30 390409689 1
isenberg@dgss.org
www.dgss.org

Strong National Pain Societies are an important factor to achieve success in terms of a comprehensive multi-level agenda setting for "Pain Issues" internationally

Moderator Working group 4 **Pain, rehabilitation and reintegration of workers in the working force**

Summing up to nearly 3,500 individual members, the German Pain Society (Deutsche Schmerzgesellschaft e.V) is the largest scientific and medical specialty society in the field of pain in Europe. The membership of the German Pain Society e. V. is interdisciplinary and inter-professional and consists of pain experts from hospitals, clinics, psychologists, nursing, physiotherapy plus experts from research, academia and teaching.

Furthermore, the German Pain Society is the interdisciplinary umbrella organization of currently 18 large medical and scientific societies in the area of pain representing approximately 100,000 members.

The German Pain Society is a member of IASP (International Association for the Study of Pain) and the AWMF (Association of the Scientific Medical Societies in Germany).

Approximately 23 million German (28%) report chronic pain, 95% of them over chronic pain that is not caused by cancer. Taking the "yardstick" of impairment from the pain as a basis, 6 million German meet the criteria of a chronic, non-tumor-related, debilitating pain. The number of chronic, non-cancer-related pain with severe impairment and associated mental impairments (pain disease) is 2.2 million Germans.

Since 2012 Thomas Isenberg (48) has been working with the German Pain Society (Deutsche Schmerzgesellschaft, Berlin) as its Executive Director.

Previously, from 2008 to 2012, Mr Isenberg headed the Marketing & Public-Affairs department of spectrumK GmbH, the joint venture of 80 individual statutory health insurance funds. Starting in 2001, Mr Isenberg managed six years the department of health at the Federation of German Consumer Organizations (vzbv, Berlin), being responsible for the units of "Health-Care", "Nursing-Care/Elderly People", "Food/Nutrition" and "Agricultural policy". After this, Thomas Isenberg served as Health Programme Manager at Bertelsmann Foundation (Gütersloh/Berlin), being member of its extended management team.

Thomas Isenberg is a member of the Berlin House of Representative (Abgeordnetenhaus/Landtag) and health spokesman of the SPD fraction since 2008.

Thomas Isenberg started in 1998 with consumer organizations in Bonn as a consultant for health care services and consumer health protection. Previously, he graduated an international management / trainee program of Bayer AG Leverkusen and studied medicine in Düsseldorf for several years. He graduated Senior-High-School (Abitur) in 1987. Before, in 1984-1985, he was an exchange student in Pittsburgh, USA.

DR WOLFGANG JAKSCH

President

Austrian Pain Society (ÖSG)

The way to pain policy: From bottom up to top down (The Austrian way?)

Most of the structures for specialized pain care in Austria have been established over the last years bottom-up by dedicated persons and groups of pain specialists. Austerity measures and massive financial pressure on the entire health system over the last years have led to restructuring processes and personnel bottlenecks at Austrian hospitals. As a consequence, many outpatient pain departments have reduced their hours of service or closed altogether while acute pain services likewise fell victims to cutbacks.

In the light of the fact that the patients' right to the "best pain treatment possible" has been adopted more than 10 years ago in the "Patients' Charter", an agreement with the force of law, health policy now is called to act: the traditional bottom-up system has to be transformed into a top-down planning process in order to secure nationwide pain treatment for all patients in the future.

In order to promote this idea, the Austrian Pain Society has initiated a number of activities:

- We discussed the situation with stakeholders in health policy, social insurances and the Austrian Physicians' Chamber. The main focus of these contacts was to raise awareness for the suffering of more than 1.5 million pain patients and the societal impact of insufficient treatment of those affected.
- Under the umbrella of the Austrian Pain Society different medical associations involved in pain treatment, together with patients' associations, have defined quality criteria for pain institutions. The aim is to support policy makers in carrying out structured planning for a multi-stage concept in pain care. Such a concept has already been developed in 2008, but unfortunately at that time health politicians failed to utilize this expertise.
- In 2005 a diploma of the Austrian Physicians' Chamber was established to certify continued training in pain therapy. Although this was a success of the Austrian Pain Society it is now time to strive for a postgraduate specialization in this area. Together with medical associations involved in pain therapy a curriculum and the necessary application process for this specialization are currently being prepared.
- The Austrian Pain Society is putting much effort in continuously informing the broad public about the critical situation of pain care. These information activities lead to regular reports in the media.

Consequently, we are now quite optimistic to reach our aim: standards and statutory regulations for the care of millions of pain patients in Austria following the Belgian example.

Dr. Wolfgang Jaksch is DEAA President of the Austrian Pain Society Head of Pain Medicine - Acute Pain Service, Department of Anaesthesiology, Wilhelminenspital, Vienna.



Austrian Pain Society (ÖSG)
Liechtensteinstr. 46a
1090 Vienna
Austria
Phone: +431319437843
wolfgang.jaksch@chello.at
www.oesg.at

In times of austerity measures and massive financial pressures on the health system it is now time for health policy to turn the bottom-up approach into a structured top-down planning to secure the best possible pain treatment for all patients in the future.

J



DR MARTIN JOHNSON

**Royal College of General Practitioners (RCGP),
UK Clinical Champion for Chronic Pain, Chronic Pain Policy Coalition (CPPC)**

Welcome to my Passion; the conquest of chronic pain!

49 St Clements Avenue
Harold Wood
Romford, West Yorkshire RM3
0FH
United Kingdom
Phone: +44 (0)17 08 34 57 31
martin.johnson58@me.com

**Pain can be defeated,
but we have to un-
derstand both it and
ourselves first. All too
often it wins the battle
because it divides our
opinion and the most
important person, the
patient, gets mixed
confusing messages.**

If SIP can bring consensus across Europe regarding the management of pain, then it will have achieved one of the most important objects of our Society.

Dr Martin E Johnson was a General Practitioner from 1985 until 2014. For many years, after devoting much of his time to Primary Care Research, he developed a specific interest in the management of chronic pain. He also has an interest in virus research and at present he works as Senior Medical Director to hVivo Ltd.

Dr Johnson has written several articles regarding pain management, particularly focusing on neuropathic pain, the use of opioids and the organisation of pain services in the community. Recently he was one of the lead authors of the commissioning support document for chronic pain services.

Dr Johnson is Vice Chair of the Primary & Community Pain Management Special Interest Group of the British Pain Society. He is the Honorary Secretary to the British Pain Society. On 1st April 2011 he was appointed as RCGP Clinical Champion for Pain and after three years as Clinical Champion, he continues as RCGP Lead for Chronic Pain. In this role he is trying to raise awareness of chronic pain and develop initiatives that will enhance its management. He is also the Co-Chair of the Chronic Pain Policy Coalition helping to drive national issues in the UK surrounding pain management. Previously he served 6 years as a Trustee of The Patient's Association.

His particular interests in pain management are the effective management of pain within Primary Care and having adequate systems in place to deliver this service, neuropathic pain and early intervention of pain.

AGNES JONGERIUS

Member of the European Parliament

Progressive Alliance of Socialists and Democrats in Europe (S&D),
the Netherlands

What the EU can do to improve pain care

Agnes Jongerius (1960) is a member of the European Parliament for the Dutch delegation of the Socialists and Democrats group since 1 July 2014. Jongerius is vice-chair of the Committee on Employment and Social Affairs. Born in Vleuten, a small village in the Netherlands, she started her career at the Dutch trade union of the transport sector. From 2005-2012 she was chair of the Dutch federation of Trade Unions (FNV). Thereafter she was an associated researcher at the expert centre for institutions of the Open Society at Utrecht University, where she studied the question how citizens can be better involved in the European Union.

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45699
agnes.jongerius@europarl.
europa.eu

It is my sincere believe that we should take pain and especially chronic pain seriously. Pain can have a devastating effect on people's physical and mental wellbeing. Although our knowledge of pain and how to prevent it has increased in the past years, I believe that there is still a long way to go. More research on pain therapy is needed and successful therapy should be promoted more, as well as training to cope with pain. It is time for real action.

J



STEIN KAASA, MD PHD

Head of Department of Oncology, professor
Oslo University Hospital and University of Oslo, Norway
Director of the European Palliative Care Research Centre (PRC),
Norwegian University of Science and Technology and the Cancer Clinic,
Trondheim University Hospital

Oslo
Norway
Phone: + 47 918 97001
stein.kaasa@ntnu.no

Pain is the most feared and prevalent symptom in cancer care and it is undertreated.

Pain treatment- Pain diagnosis

Pain is the most feared and prevalent symptom in cancer care and it is undertreated.

Three main barriers have been identified:

1. systematic assessment of pain and other symptoms evaluated by the patients i.e. Patients Reported Outcomes Measures (PROMs).
2. The use of PROMs as a part of the cancer pain classification process.
3. The lack of use of common pain treatment guidelines.

As a part of the Cancer Control Joint Action (CanCon), an EU project, recommendations on the use of care pathways will be given. "The patients' voice" thru a systematic use of PROMs should be an integrated part of the care pathways.

EIR is an innovative ICT system developed for symptom assessment with pain as one of the key symptoms. The evaluation is performed by the patients, in hospitals, in nursing homes, at home or at any other place where the patients are. EIR is a HTML-based, patients enter data system. Patients are entering the data by using a tablet or any other devices connected to web browsers. The EIR doctor module is for physicians or any other health care provider where PROMs is presented effectively and can interactively be a part of the clinical decision making process.

EIR can be considered as a demonstration methodology on how to take advantage of modern ICT system in symptom management in general and cancer pain specifically.

PER KJÆRSGAARD-ANDERSEN

Head at Section for Hip & Knee Replacement, Department of Orthopaedics, Vejle Hospital, South Danish University, Denmark

Secretary General, European Federation of National Associations of Orthopaedics and Traumatology (EFORT)

Impact of pain versus clinical reality

Clinical experience

- 2007: Associate professor in Orthopaedic Surgery at University of Southern Denmark
- 2002: Head of Sector for Hip and Knee Replacement, Department of Orthopaedics, Vejle Hospital, Denmark

Earlier Employments within Orthopaedic Surgery at Odder Hospital, Kolding Hospital, Aalborg University Hospital, Vejle Hospital at South Danish University, Aarhus University Hospitals and The Orthopaedic Hospital, Aarhus in various positions a.o. Administrative Consultant

Administrative experience

- 2012: Secretary General, European Federation of National Associations of Orthopaedics and Traumatology (EFORT)
- 2011: President for 12th EFORT Congress in Copenhagen, Denmark
- 2010: Consultant Chairman for the Norwegian Government regarding Health Task Organisation within Orthopaedic Surgery in Norway, Region South-East
- 2010: Board Member in Danish Medical Association for advising the Danish Government / Danish Health Institute in organisation of the medical specialities
- 2008: Editor-in-Chief for the Orthopaedic Newsletter "Orthopaedics Today Europe"
- 2008: Chairman of the Danish National Board of Health task group concerning specialist planning in orthopaedic surgery
- 2008-2010: Chairman / president of the Danish Orthopaedic Society
- 2007-2011: Co-opted member EFORT Executive committee
- 2001-2006: Chairman / president of the Danish Society for Hip and Knee Surgery
- 1998-2011: Expert Advisor in the Danish Health Authorities Patient Complaints Board

Teaching

- Clinical Lecturer at University of Southern Denmark since 2004;
- Clinical Lecturer at Aarhus University Hospital 1994-1998;
- Annually since 2002: Lecturer at "A seminar" in hip joint arthrosis for orthopaedic residents.

Department of Orthopedic Surgery, Vejle Hospital
Kabbeltøft 25, 7100 Vejle, Denmark
Phone: +45 7940 5716
Per.Kjaersgaard-Andersen@rsyd.dk, pka@dadlnet.dk

Basically 99% of all patients coming to our practice is due to pain. Therefore we really need to be focused on the societal impact of pain and stay close to the patient's needs.

K



NEVENKA KRČEVSKI ŠKVARČ ASS PROF, PHD

EFIC Honorary Secretary, physician

University Clinical Center Maribor

University Clinical Center Maribor
Ljubljanska 5
Dogoska 88
Maribor 2000
Slovenia
Phone: +386 321 1568
nevenka.krcevski.skvarc@amis.net

**Significant impact
of pain management
should be more visible
in cancer care and re-
habilitation programs**

The site of pain management in cancer care and rehabilitation programs

One of the most important challenges in cancer control is to coordinate national plans and services to cover all aspects of the management of cancer. While healthcare policy-makers and funders are taking efforts to establish optimal cancer control it is also essential to immediately improve the quality of life of patients in all stages of cancer. The effective management of symptoms, dominantly pain during treatment and rehabilitation represents the main goal to improve the quality of life. The outcomes for management of cancer pain are often poor. The management of pain differs in various stages of disease and in survivors. Current perception and management of cancer lead to greater need for chronic pain management in patients living with cancer and those who are cured. Projections of further cancer incidence indicate the urgent need to take better care for pain management and rehabilitation.

Pain is one of the most prevalent and troubling symptoms and patients and families fear it during cancer treatment and especially near the end of life. In palliative care pain control is well appreciated and there is need for better integration of palliative care during cancer care, not only at the end of life. Many patients cannot use specific and palliative care treatment due to unrelieved pain. The problem of pain is presented beyond the cancer treatment being presented in cancer survivors, especially in the first few years after treatment and influences on their rehabilitation and their quality of life. Chronic pain in the longer term interferes with their function and ruins the quality of life especially in the population with much higher prevalence. The management of chronic pain in these patients needs integrative multidisciplinary and multimodal programs.

Pain management is indispensable part of integrated cancer care. It could be effective in the majority of patients by conventional treatment but small population needs highly specialized approaches. This should be more emphasized in European and national cancer control programs, pain management should be more visible and respected in whole cancer care. In the guide for cancer care programs psychosocial oncology care is well recognised and distress is proposed to be 6th vital sign while pain as 5th vital sign is not mentioned.

Pain management in cancer care should be ethical priority based on equity and availability of resources and treatment services. From this reason structural and processing indicators should be established in all European countries. This includes education, training, monitoring and evaluation as well as the investments in cancer pain research.

MERJA KYLLÖNEN

Member of the European Parliament

Confederal Group of the European United Left - Nordic Green Left (GUE-NGL), Finland

What the EU can do to improve pain care

Merja Kyllönen (born 1977) is a Finnish Member of the European Parliament in the GUE/ NGL Group, representing the Left Alliance. Ms Kyllönen is a member of the committee on transport and tourism and a substitute member in the committee on environment, public health and food safety. She is also a member in the recently established committee of inquiry on emission measurement in the automotive sector.

Ms Kyllönen is a former Minister for Transport in Finland (2011-2014). She started her political career at 19, and served as a councillor in her home town Suomussalmi from 2000. She was a member of the Finnish parliament 2007-2014. Before concentrating on full-time political work, she had a career as a professional in healthcare, working e.g. in hospital and pharmacy.



European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45543
merja.kyllonen@europarl.europa.eu

Pain can be a huge burden for patients, their families and society. Adequate pain treatment is essential for healthcare systems and I call upon national governments to address this. I would like to offer my support to the Societal Impact of Pain in 2016, the year of action.

K



GIOVANNI LA VIA

Member of the European Parliament

Group of the European People's Party (EPP), Italy

What the EU can do to improve pain care

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 66739
giovanni.lavia@europarl.europa.eu

Mr. Giovanni La Via is a Member of the European Parliament since 2009. He has been Rapporteur for the new Common Agricultural Policy 2014-2020 and General Rapporteur for the EU budget 2013. Since July 2014, he serves as Chairman of the committee on environment, public health and food safety (ENVI) of the European Parliament. He has served as Regional Minister for Agriculture and Forest in Sicily (2006-2009). He is full Professor at the University of Catania. As a delegate of the Rector of the University of Catania, he started and co-ordinated the "European Office" working on European projects planning and management between 1994 and 2000. He has been responsible for several research projects (Sprint, Rittz, Fair). He has been named as expert evaluator of the 5th RTD Framework Programme. He is the author of many scientific papers and articles published in referred national and international journals.

JEROEN LENAERS

Member of the European Parliament

Group of the European People's Party (EPP), The Netherlands

What the EU can do to improve pain care

Jeroen Lenaers graduated from the Master program in European Studies in 2008 and started working in the European Parliament as a policy assistant to the Dutch Christian Democrat delegation in the EPP Group. His main focal points during the past 5 years were foreign affairs and social affairs & employment. Last year, after a successful campaign, he was himself elected Member of the European Parliament for the same delegation. Jeroen Lenaers is a member of the committee on social affairs & employment and a substitute member in the committee on civil liberties, justice and home affairs. Next to that he is a member of the DASE delegation (South-East Asia) and substitute member of the DCAS delegation (Central Asia).



European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45560
jeroen.lenaers@europarl.europa.eu

We have to focus on retention and integration of people affected by chronic diseases as well as to support reasonable adaptation of workplaces, which will ensure a timely return to work; we call on the European Commission to promote integration and rehabilitation measures for people with disabilities and to support Member States' efforts by raising awareness and identifying and sharing good practices on accommodations and adjustments in the workplace

L



DR LEONIE MALLMANN

Referee of the management

Bundesverband privater Anbieter sozialer Dienste e.V.

Bundesverband privater Anbieter
sozialer Dienste e.V.
Friedrichstrasse 148
10117 Berlin
Germany
Phone: +49 30 30 87 88 60
mallmann@bpa.de
www.bpa.de

Pain management and care

The Federal Association of Private Social Service Providers (bpa) is active with more than 9,000 member institutions and therefore stands for the largest lobby of private social services in the care marketplace in Germany. The bpa-members are responsible for 275,000 jobs and about 21,000 training places. The invested capital amounts to 21,8 billion euros. More than 495,000 patients are taken care of by bpa-member facilities such as nursing homes for part-time, inpatient and disabled care, child and youth services. bpa stands for at least every third nursing home nationwide. For the most part bpa-members are medium-sized enterprises including many family businesses. bpa as an approved institution of the voluntary social year offers social education and orientation to interested people. bpa founded in 1964 has its national office in Berlin. Since 1989 bpa is a founder member of the European Confederation of Care Home Organizations (E.C.H.O.) with its registered seat in Brussels, Belgium. From 2006 to 2010 bpa-president Mr. Bernd Meurer was president of E.C.H.O. and since 2010 is vice-president.

Chronic pain is a substantial public health problem. Most of the older patients have several chronic problems but physical and cognitive impairments make it difficult for them to report their pain to the staff. Therefore, it is important to manage pain and to provide individually tailored care.

MAURO MARIO

Secretary General

No Pain Foundation

Improving pain treatment through education, research and care

The social impact of chronic pain on a national and community level should be considered as an urgent matter not to be underestimated anymore. I am here representing the No Pain Foundation as Secretary General, and myself being a chronic pain patient I think it is important to explain what Pain actually means, especially from a patient's point of view.

Pain also means Dignity in the form of ability of the sufferer to fight pain, especially when it seems to take over and when the person's vested rights seem to be trampled over and irreversibly taken away. Dignity represented by the strength to fight even when letting go seems the simplest and, ironically, a painless solution.

Chronic pain not only represents a serious concern related to health ethics and social equality, but also places a huge burden on national economies. I would like to refer to an article published in 2012 in Journal of Pain, in which it is noted that the Pain disease is linked to an estimated socio-sanitary cost of 600 billion dollars a year. Chronic pain has a very significant negative impact on the quality of life of patients, affecting daily activities and in particular the ability to work. In fact, persons affected by chronic pain are more frequently absent from work and are also forced to stop working earlier than others. In Europe, the number of leave days taken because of pain is estimated to be about 500 million, which represents an economic burden equivalent to approximately 35 billion euro annually. The total cost for European systems for chronic pain is equivalent to approximately 300 billion euro/year.

However, in order to calculate the real socio-economic impact of pain, it is also necessary to calculate the intangible costs which negatively impact the quality of life of patients suffering from chronic pain. In fact, these patients may suffer from psycho-social distress, poor nutrition, sleep disorders, social isolation, marital problems, anxiety, fear and depression. Pain is a subjective symptom and as such difficult to fit into one clear-cut definition. Chronic pain has always been considered a symptom of an illness which needs to be diagnosed and treated accordingly. In reality, however, pain should be considered as an illness in itself, given that its chronic nature does not correspond to temporal but to physio-pathological criteria.

In spite of positive premises, the wider availability of evidence-based guidelines and the availability of pain-treating medication, a significant proportion of the European population still suffer from pain. Chronic pain remains a challenge for medics and paramedics and remains a main health issue on a global level, both because of population ageing and because of the increase of chronic-degenerative diseases.

The chronic pain aspect, its socioeconomic effect and most evident shortcomings in terms of support are priority areas for action within European and national health policies. The effective treatment of pain not only significantly improves quality of life but also prevents secondary disabilities.



No Pain Foundation
95 Old College Street
SLM1379 Sliema
Malta
Phone: +35699399602
mauro.mario@nopainfoundation.org
www.nopainfoundation.org

The key to optimal management of chronic pain is a comprehensive assessment of the patient with persistent pain, rather than pain, per se. This assessment needs to take into account not only the site, duration, intensity and quality, and impact of pain, but also a wide range of possible contributors to the person's experience of pain, disability, and emotional distress. Furthermore, the importance of viewing pain through a multifaceted lens allows one to understand pain as an interdisciplinary problem.

M



PROF DR WINFRIED MEISSNER

Head of Pain Unit and Palliative Care Department

Dept. of Anesthesiology and Intensive Care Medicine, Jena University Hospital

Phone: +49 3641 9323353
Winfried.meissner@med.uni-jena.de
www.uniklinikum-jena.de
www.pain-out.eu

Quality indicators (QI) help assessing quality of care, but so far rarely cover pain management. To improve quality assurance programs, benefits and risks of using pain-related QIs need to be discussed.

How can we use pain as a quality indicator for health care?

Quality indicators (QI) are widely used in health systems to give an indication of quality of care. So far, most QIs are linked to parameters as mortality, complications, and resource use. Quality of life, pain or other "subjective" dimensions are rarely covered by QI. QI may measure quality directly (outcome) or indirectly (structures and processes). Indirect (surrogate) parameters should only be used if they are strongly linked to outcome quality. As a prerequisite, it is necessary to define "good outcome" for determining the appropriateness of QI. Most QI are based on quantifiable routine data. Patient-reported outcomes – essential in the area of pain – are rarely used as QI. On the one hand, they are often considered as less "objective" than other data, on the other hand, assessment is resource-demanding because it needs direct interaction with the patient.

An indicator should fulfill several conditions: it should be medically relevant and usable in (more or less) daily routine. In the area of pain, several QI have been proposed and/or used:

- Structure: Availability of dedicated personnel (e.g., Acute Pain Services), devices (e.g., PCA pumps)
- Processes: Regular pain assessments, use of protocols and treatments, prevention of complications, patient involvement, avoidance of i.m. injections
- Outcome: Pain intensity, pain reduction, functional impairment, side effects, perception of care, duration of stay, costs, long term consequences

So far, few of these QI have been used in the context of generic quality assurance programs, and results are conflicting. Some process-related QI might even decrease overall quality by triggering over-treatment ("pain assessment as fifth vital sign"). On the other hand, other parameters have clearly been shown to be linked to increased quality of care (e.g., procedure and patient-specific pain management). In the talk, the potential benefits and risks of using pain-related QIs are discussed.

After his residency as an anesthesiologist at University Hospital Berlin-Steglitz, Prof. Meissner was appointed head of Jena University Hospital's Pain Unit in 1994, and head of the Palliative Care department in 2009. Since 2013, he is also head of the interdisciplinary Day Pain Unit. His clinical expertise covers all aspects of pain management with a focus on acute pain and palliative pain treatment. He coordinates the two well-known acute pain registries QUIPS and PAIN OUT (Improvement in postoperative PAIN OUTcome), was coordinator of the NeuroPAIN project and has broad teaching experience.

ROSAPAOLA METASTASIO

Agenzia di Valutazione Civica (Civic Evaluation Agency), Cittadinanzattiva

Hospitals and the right to avoid unnecessary pain and suffering

Cittadinanzattiva is historically committed to pain care and to pain avoidance with projects and informative campaigns in Italy and Europe.

The Project “In-dolore 2014”, unconditionally supported by Grunenthal, is a pilot audit promoted by the Tribunal for Patients’ rights (which is the health network of Cittadinanzattiva) and realized in collaboration with the Civic Evaluation Agency to monitor citizens’ perspectives about treatment and attention to pain as well as the presence of fundamental services, features and best practices in the Italian hospitals. Goals of the project are: build a network and promote centres of excellence, draw attention on the topic and encourage a healthy competition among healthcare providers to improve pain treatment on the basis of citizens’ needs. Indeed, the project has informed citizens about attention to pain provided by 46 Hospitals that have voluntarily submitted to: detailed data are available online. 214 wards have been monitored and 711 patients have been interviewed, thanks to the help of our volunteers. Data have been collected through two main tools: a checklist containing 50 items and a questionnaire addressed to patients of 5 key wards.

Some results: there’s still a lot to do with pain treatment for children and elderly, as well as in ERs. Regardless of the disposition of the law 38/10, patients’ information on the topic is very poor, and the same applies to patients’ awareness about their rights. Healthcare providers often do not offer proper training to their staff. Pain is reported almost always on medical records and promptly treated with drug therapies, but intensity of pain is not detected with appropriate equipment in 1 out of 2 cases.

Rosapaola Metastasio has a Master degree in Sociology, postgraduate course in “Social needs and living areas planning”. She has been working for Cittadinanzattiva since 2008 as Project Manager in the field of civic audits. She deals with methodology, data analysis, training and empowerment, improvement of quality in healthcare and humanization of care. She is member of the Civic Evaluation Agency of Cittadinanzattiva since 2010.

The Civic Evaluation Agency is a branch of Cittadinanzattiva which promotes and develops civic audits of public services from citizens’ perspectives and by directly involving citizens as well. Indeed, initiatives are performed with the support of trained volunteers who collaborate with providers of public services.



r.metastasio@cittadinanzattiva.it
www.cittadinanzattiva.it

Reliable information on protection of patients’ rights with regard to attention to pain is essential nowadays. Institutions should monitor proper application of laws, strengthen information flows and awareness, draw attention to elderly and children and take care of patients’ transitions from hospitals to their home, being the latter one of the biggest weaknesses of the (our) health system.

M



ROBERTA METSOLA

Member of the European Parliament

Group of the European People's Party (EPP), Malta

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45686
roberta.metsola@europarl.europa.eu

People in pain should not have to suffer in silence. Too often their plight is overlooked or underestimated and together we can do something about that. We need to raise awareness as to the impact that chronic pain can have on people, those who care for them and on their ability to work and enjoy life. Dealing with chronic pain must be put on EU Member States' health care agenda. It cannot be ignored.

Roberta Metsola was elected to the European Parliament in 2013, becoming one of Malta's first female Members of the European Parliament. Professionally she is a lawyer who has specialised in European law and politics. She has previously worked at the Permanent Representation of Malta to the European Union and as legal advisor to the High Representative of the European Union for Foreign Affairs and Security Policy. MEP Roberta Metsola is the EPP Vice-Coordinator of the Committee on Civil Liberties, Justice and Home Affairs (LIBE), where she is the lead MEP on migration issues. MEP Roberta Metsola is also the co-rapporteur on the situation in the Mediterranean and the need for a holistic EU approach to migration. MEP Roberta Metsola is also the Vice-Chair of the European Parliament Committee on Petitions (PETI) and a member of the Delegation for relations with the United States (D-US). She is also a substitute member of the Committee on the Internal Market and Consumer Protection (IMCO) and the Delegation for relations with Australia and New Zealand (DANZ).

MIHAELA MILITARU

Director

European Cancer Patient Coalition (ECPC)

ECPC position on pain and cancer

Mihaela Militaru joined ECPC in August 2013 as Director. Prior to this she had worked in EU affairs for 12 years, first as a liaison officer of the Senate of Romania with the European Parliament and subsequently as a policy adviser within the European Parliament (8 years). Her activity in the European Parliament focused in the last years on healthcare policy and the measures needed at EU-level for fighting diseases such as cancer, multiple sclerosis, autism and fibromyalgia. Mihaela holds a Masters' Degree in International Relations and European Affairs from the National School for Political and Administrative Studies in Bucharest as well as a Masters' Degree in Conference Interpreting from the University of Bucharest, Faculty of Foreign Languages. Mihaela speaks Romanian, English, French and Bulgarian and has basic knowledge of Spanish and Italian.

As a cancer patient organisation, the ECPC has focused its advocacy efforts in the past years predominantly in asking better health outcomes for cancer patients. Palliative care is one of the areas in medicine that poses most philosophical and ethical questions. We all die, and although this reality is much a part of life, thinking about it is not easy and in general terms, this is a discussion society avoids.

Some experts sometimes refer to palliative care as failure in medicine. Society prefers innovating and discovering new medicines to cure than accepting that life, inexorably, comes to an end.

However, palliative care is about the suffering, the dignity and the quality of life of people at the end of their lives but also of their families and friends.

In line with the ageing of the population, the pattern of diseases that people suffer and die from is also changing and as result, people in need of palliative care at the end of their lives will increase. Aging could be considered as the single biggest risk factor for developing cancer. Although malignant tumors occur at all ages, cancer disproportionately strikes individuals in the age group 65 years and older.

ECPC considers that addressing the shortcomings of palliative care policy across Europe is a question of human dignity but also a public health issue of great importance.

ECPC focuses its advocacy efforts around palliative care in improving the regulatory framework; the impact of austerity measures on palliative care and more importantly patients' needs including care and treatment.



Rue Montoyer, 40
Brussels 1000
Belgium
Phone: +32 473 49 18 43
Mihaela.militaru@ecpc.org
www.ecpc.org

ECPC advocates for advancing EU and national legislation to have a comprehensive and integrated palliative care in all European countries. Policy and legislation should have adequate and sustainable funding.

M



HARALD MÖHLMANN

Advisor to the CEO

AOK Nordost

AOK Nordost
Galenstraße 6
13597 Berlin
Germany
Phone: + 49 800 265080 - 22835
Diana.Geburzi@nordost.aok.de
Harald.Moehlmann@nordost.aok.de
www.aok.de/nordost

There are programs that help to rehabilitate and reintegrate workers into the workforce by avoiding sick certificates and operations. They may improve the quality of healthcare and everyday life.

Back pain and second opinion or Headache and cooperation

Chronic pain causes high costs and trammels the everyday life of patients - and the collective sector of the statutory health insurance in Germany does not always supply appropriate care. Selective bargaining may improve this situation. Therefore two examples will be shown and explained:

1. Chronical headache: a cooperation with the Charité hospital allows well structured clinical diagnostics and individual medical therapy.
2. Chronical backpain: a cooperation with medical specialists to avoid operations on the spine by a second opinion. Special manual therapies enlarge the quality of life, reduce times of sickness.

Both programs help to rehabilitate and to reintegrate workers into workforce by avoiding sick certificates and operations. They may improve the quality of healthcare and everyday life.

Harald Möhlmann works as advisor to the CEO of the statutory health insurer AOK Nordost, which provides comprehensive health care for over 1.75 million insured. The AOK is Germany's largest statutory health insurer. Its 12 regional chapters together cover close to 24 million insured, almost one third of Germany's population. The AOK's regional chapters have different profiles. But all are legal entities under public law, have their own self-governing bodies composed of employee and employer representatives, and report to their respective state health ministries.

Before becoming an advisor, Möhlmann's area of responsibility as a managing director has comprised all ambulatory care that is provided by physicians and dentists including the pharmaceuticals as well as quality-monitored programs such as chronic disease services for patients with diabetes I and II, asthma, coronary disease or breast cancer. Möhlmann studied economics. He joined AOK Berlin in 1990 and has held a series of leadership positions (planning and organization; policy issues; management, restructuring) before assuming his present position in April 2016.

Möhlmann worked as scientific assistant at the Freie Universität Berlin; he also served as a consultant on behalf of Germany's Federal government and the EU and provided advice to health ministries in Czechoslovakia, Romania and Bulgaria in the early 90s.

PROF BART JAN MORLION

EU-Liaison Officer and President Elect, European Pain Federation EFIC®

Director of the Leuven Center for Algology & Pain Management
University Hospitals Leuven

Co-chair of the plenary session of the Societal Impact of Pain Symposium 2016

Bart Morlion is director of the multidisciplinary pain centre at Leuven University in Belgium. He has been appointed president-elect of the European Pain Federation EFIC® to take office late 2017 and also acts as EFIC® EU-Liaison Officer, representing the Federation towards European policy makers and the European pain community.

Between 2006 and 2012, 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 represented Belgium as councillor in EFIC®. 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, including the International Association for the Study of Pain (IASP).

Bart Morlion teaches pain management and pharmacology at the Leuven University and several higher institutions. He has given more than 400 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 deputy editor of the European Journal of Pain and a regular reviewer for several international journals. His professional interests include all aspects of multimodal chronic pain management, analgesics, and quality management.



Belgium

Phone: + 32 16 33 84 51

bart.morlion@efic.org

Identifying policies that address the societal and economic impact of pain needs to remain a priority on the agenda of the EU institutions and Member States. Policy makers should realise the positive impact of pain policies in the health care systems and in terms of reintegration of workers in the workforce.

M



MARIAN NICHOLSON

Herpes Viruses Association and Shingles Support Society

Reporter Working Group 4 Pain, rehabilitation and reintegration of workers in the working force.

Herpes Viruses Association
41 North Road
London, N7, 9DP
United Kingdom
Phone: +44 020 7607 9661
marian@hva.org.uk
[https://herpes.org.uk/
shingles-support-society](https://herpes.org.uk/shingles-support-society)

At Shingles Support Society we supply information/advice on medical treatment and self-help for post-herpetic neuralgia (PHN) which - particularly in older patients - may follow shingles (herpes zoster). Early treatment gives a greater chance of eliminating PHN. We encourage people to get the new vaccine to prevent shingles.

Marian Nicholson has had many different careers, including a two year contract with UNICEF in Paris. She acquired her interest in herpes simplex in 1981. From 1985 onwards she has been a helpline volunteer for the Herpes Viruses Association and its authorized sub-group the Shingles Support Society. From 1993 she has been working full-time for the charity and is now the director. She has published in the British Journal of Sexual Medicine, SHINE, Dermatological Nursing, Practice Nursing (guest editorial), Nursing in Practice and many less prestigious publications. She had three posters accepted for display at meetings of the British Association for Sexual Health and HIV/American STD Assoc. in 2003 and 2004.

She is a trustee for the umbrella organization Pain UK and a board member of Pain Alliance Europe.

PROF GRAZIANO ONDER

Assistant Professor

Università Cattolica del Sacro Cuore

Recommendations for multimorbidity by the Joint Action CHRODIS: what is the role of pain?

Graziano Onder, MD, PhD is a Geriatrician working as an Assistant Professor at the Department of Geriatrics of the Università Cattolica del Sacro Cuore, Rome, Italy. Dr. Onder has previously worked as Research Associate at the J. Paul Sticht Center on Aging, Wake Forest University, Winston Salem, NC, USA (2001-2002). He is Fellow of the European Academy for Medicine of Ageing. The main focuses of his research are multimorbidity, pharmacoepidemiology in the elderly, frailty and its impact on clinical outcomes, and organizational characteristics of health care systems. He led several project funded by public and private institutions including the Italian Ministry of Health and the European Commission through the Seventh Framework Programme (FP7). He is member of the Geriatric Working Group of the Italian Medicines Agency (AIFA), the national authority responsible for drugs regulation in Italy . He is leading the workpackage on multimorbidity in the Joint Action on Chronic Diseases (CHRODIS) a project funded by the 2014-2020 Health programme of the EU. He is author of more than 250 publications in peer-reviewed journals.



Università Cattolica del Sacro
Cuore
Largo Francesco Vito 1
00168, Rome
Italy
Phone: +39 06 30154341
graziano.onder@unicatt.it
www.unicatt.it

The prevalence of chronic diseases is progressively increasing and older adults experience the co-occurrence of multiple diseases, a condition known as multimorbidity. Given its high prevalence and its frequent association with other diseases, pain has a relevant role in the multimorbidity phenomenon. The Joint Action CHRODIS, has recently proposed a multimorbidity care model in order to provide a framework for the care of multimorbidity.

O



PROF DR CHRISTOPH OSTGATHE

Vice-President

European Association of Palliative Care (EAPC)

Universitätsklinikum Erlangen
Krankenhausstrasse 12
91054 Erlangen
Phone: 09131 85 34064
christoph.ostgathe@uk-erlangen.de

The management of pain is an essential component of palliative care, and the availability of medication to manage pain effectively is key to the improvement of quality of life for all in need.

Pain in palliative care, do we care?

According to the WHO definition (2002) palliative care aims “to improve quality of life for patients and their families who are living with a life-threatening condition. Palliative care aims to prevent or relieve suffering through early identification and impeccable assessment and treatment of pain and other symptoms (physical, psychosocial and spiritual)¹”. Although traditionally associated with cancer, the WHO definition takes a broader view and encompasses care of those with conditions other than cancer and the associated pain and symptoms. Nevertheless, pain remains one of the major concerns for patients and their families; epidemiological data confirms that 56% of cancer and 49% of non-cancer patients admitted to a palliative care unit suffer from moderate to severe pain². Pain has a significant impact on quality of life and therefore pain management is an essential component of palliative and end of life care.

As an anesthesiologist and pain specialist, working in palliative care for the last twenty years, pain diagnosis and management has always been a focus of my work. It is important to recognise the unique experience of each patient, which requires a multifactorial approach to assessment of pain. In order to successfully treat pain there is a need to identify the type and multiple causes of pain. Treating pain effectively requires a systematic approach; administration of appropriate analgesics at the appropriate dose and by the appropriate route is a first step however, other non-pharmacological interventions to pain management should also be considered including multi-professional approaches (e.g. physiotherapy, psychology or art therapy). Many fears remain regarding the prescribing of for example strong opioids however national³ and international guidelines⁴ for palliative care and pain management provide an evidence-based approach to managing pain. Drug availability for the treatment of pain, remains an issue in many regions of the world especially in developing countries. Recent evidence suggests that accessing opioids in some parts of Europe is also a problem^{5,6,7}.

To overcome these obstacles will be one of the foci of the EAPC and for me personally. The management of pain is an essential component of palliative care, and the availability of medication to manage pain effectively is key to the improvement of quality of life for all in need. Hence: Yes, we care!

1. World Health Organisation <http://www.who.int/cancer/palliative/definition/en/>
2. Ostgathe C et al. (2011) Noncancer patients in specialised palliative care in Germany: What are the problems? *Palliative Medicine*; 25(2):148-52.
3. <http://leitlinienprogramm-onkologie.de/Palliativmedizin.80.0.html>
4. Caraceni et al. (2012) Use of opioid analgesics in the treatment of cancer pain: evidence-based recommendations from the EAPC. *Lancet Oncol*, 13, e58-68.
5. Human Rights Watch report on National Drug Control Strategies and Access to Controlled medication
6. WHO report in January 2016 – in section 16 reported the need for “ensuring the adequate availability of controlled substances for medical and scientific purposes”
7. The EAPC Project Access to Opioid Medication in Europe (ATOME) identified regulatory and legislative barriers to opioid accessibility across Europe: Linge-Dahl et al. (2015) Identification of Challenges to the Availability and Accessibility of Opioids in Twelve European Countries: Conclusions from Two ATOME Six-Country Workshops. *J Palliative Medicine* 18: 1033-1039.

ANNE-SOPHIE PARENT

Secretary General

AGE Platform Europe

Achieving longer working lives through more age-friendly work places

Anne-Sophie Parent is Secretary General of AGE Platform Europe, an EU network representing directly 40 million people aged 50+ across the EU-28 which she has been leading since 2002. AGE aims to voice and promote the interests of the 190 million inhabitants aged 50+ in the European Union.

Ms. Parent sits on various advisory committees set up by the European Commission: European Health Policy Forum, European Pensions Forum, Financial Services Users' Group, Steering Group of the European Innovation Partnership on Active and Healthy Ageing. She is also a member of the Advisory Board of Assisted Ambient Living Joint Programme, of the More Years Better Lives Joint programme, member of the Euro Retail Payment Board set up by the European Central Bank, of the Advisory Group of the UN-ECE Generations and Gender Programme and Expert Group of the EU UN-ECE Active Ageing Index.

In January 2016, Ms. Parent was elected Secretary General of the newly established European Covenant on Demographic Change.



AGE Platform Europe
111, rue Froissart
1040, Brussels
Belgium
Phone: +32.2.280.14.70
annesophie.parent@age-platform.eu
www.age-platform.eu
www.agefriendlyeurope.org

To cope with its demographic challenge the EU needs to support longer working lives. Political action to promote age-friendly workplaces is needed at EU, national and local level to prevent work-induced chronic pain, reduce pain-related functional limitations and help workers age in good health.

P



PIERNICOLA PEDICINI

Member of the European Parliament

Europe of Freedom and Direct Democracy Group (EFDD), Italy

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45382
piernicola.pedicini@europarl.europa.eu

Through my previous experience as an expert in radiation and oncology, I am familiar with the links between cancer and pain. The SIP symposium is an important opportunity to address the issues of pain and cancer care, in terms of pain caused by tumours, pain experienced through radiotherapy, chemotherapy and surgery, as well as post-operative chronic pain.

Piernicola Pedicini was born on 22 May, 1969 in Benevento in the south of Italy. He has a wife and two sons. Piernicola took a Degree in Physics in 1998 and a Medical Physics Specialisation in 2006 at the University Federico II of Naples, Italy. He worked as a Medical Physicist at the Department of Radiation Oncology in Rionero in Vulture, Potenza, Italy, since 2008 as health Director, until his recent election as a Member of the European Parliament. He has been involved in political activities with the Five Star Movement since its foundation, with a specific eye on healthcare and environmental issues, always defending patients' rights. He is a member of the environment, public health and food safety (ENVI) committee and coordinator for the EFDD political group. At present, he is Head of the Five Star Movement delegation in the European Parliament.

DR. GIULIANO PICCOLIORI

Director

Academia Altoatesina di Medicina Generale (AcAMG)

P in GP stands for Pain

Dr Piccoliori is Responsible of the theoretical activity and of the educational curricula for the Vocational Training in General Practice since 2004.

Research activity in care epidemiology as author and/or coordinator of several projects u.o.: IPSE – Italian Pain reSEarch of SIMG (Italian Society of General Practice), Studiochef– Integrated management and care of chronic heart failure by hospital and general practice, GA – Multidimensional assessment of elderly people in General Practice, Low Back Pain in General Practice, IQuaB- Improving Quality by Benchmarking, PRIMaEDS – Polypharmacy in chronic diseases: Reduction of Inappropriate Medication and Adverse drug events in elderly populations by electronic Decision Support, PRIMA – Polypharmacy Reduction of Inappropriate Medication and Adverse Drug Events in Older Patients Randomized Controlled Trial.

He is Director of the Southtyrolean Academy of General Practice, organisational responsible of the vocational training in General Practice, Member of the Provincial Committee for Bioethics, and Hygienist of the District.

He is Member of the Area Palliative care and Pain Therapy of the SIMG. He has been general Secretary of the South tyrolean Academy for General Practice until 20016.

His interests and scientific competences are in the area of specific and continuing education in General Practice, research in GP, EBM, Guidelines in GP, Pain Therapy, Palliative care, Bioethics, chronic diseases.



Academia Altoatesina di
Medicina Generale (AcAMG)
Wangergasse 18 -
Via dei Vanga 18
39100 Bozen-Bolzano
Italy
Phone: +39 (0)471 982 788
info@sakam.it
www.sakam.it

Chronic pain with time badly damages the life of who suffers of it. It is therefore a real devastating and destroying pathology. Being “a person’s illness” it is of pertinence of the general practitioners, who are used to a holistic approach to the patient and to his problems.

P



SIRPA PIETIKÄINEN

Member of the European Parliament

Group of the European People's Party (EPP), Finland

European Parliament
60, rue Wiertz
B-1047 Bruxelles
Belgium
Phone: +32(0)2 28 45264
sirpa.pietikainen@europarl.europa.eu

Untreated pain is a problem for those who experience it, but also for society as a whole. We tend to think of pain as a normal manageable part of life, but for many people chronic pain can mean early retirement and negative psychosocial consequences. I believe that SIP can offer us policy solutions to tackle the societal impact of pain

Ms. Sirpa Pietikäinen is a Finnish member of the European People's Party (EPP) in the European Parliament since 2008. Ms. Pietikäinen is former Finnish Minister of Environment (1991-1995). Her career at the Finnish parliament is extensive, ranging from the year 1983 to 2003.

At the European Parliament, Ms. Pietikäinen is member of the economic and monetary affairs committee and substitute member of the environment, public health and food safety committee, special committee on tax rulings as well as of the women's right and gender equality committee.

TAPANI PIHA

Head of Unit, Cross-Border Healthcare & eHealth Unit

Directorate General for Health and Food Safety (DG SANTE)
European Commission

What the EU can do to improve pain care

Tapani Piha is the Head of the Cross-Border Healthcare & eHealth Unit in the European Commission. In addition to the implementation of the Directive on Patients' rights in cross-border health care, the Unit deals also with data management and protection in healthcare, health workforce and patient safety. Since 2001 in the Commission, he has been responsible for Health Technology Assessment (HTA) policy, health strategy, health information, expert advice for health systems, health law, health research coordination, and - human resources.

Before joining the Commission, he carried out epidemiological and intervention research on health behaviours and cardiovascular disease. He held positions at the Finnish Ministry of Health, and coordinated Finland's EU policies in health in 1995-2001. At the WHO Regional Office for Europe in 1989-94 he was responsible for the Action Plan for a Tobacco-free Europe.



European Commission
4 Rue Breydel
1000, Bruxelles
Belgium
Phone: +32 (0)2 29 51194
Tapani.piha@ec.europa.eu

**Pain is a health problem
that is often under-
rated while it hampers
many lives and causes
large economic losses.
A true public health
challenge**



PROF LUKAS RADBRUCH

University Hospital Bonn

University Hospital Bonn
Sigmund Freud Str. 25
53359 Bonn
Germany
Phone: +49 228 28713495
lukas.radbruch@malteser.org

Patients with life-limiting diseases such as cancer or HIV/AIDS suffer from a variety of physical symptoms. However, pain often is predominant because of the intensity and the impact on quality of life. In consequence access to opioids is an acknowledged indicator of palliative care quality.

Does universal access to high-quality palliative care include pain care?

National governments have an obligation to prevent unnecessary suffering, and pain in cancer or other life-limiting diseases can be alleviated easily with opioids and other analgesic medicines.

However, even in a highly developed region such as Europe, there are still a number of countries with inadequate access to opioids and inadequate provision of palliative care. This is due to legal and regulatory barriers, but even more to lack of training and attitudinal barriers in health care professionals.

The EU should define standards of palliative care and provide information on good models, for example for national strategies on palliative care.

Lukas Radbruch holds the Chair of Palliative Medicine at the University of Bonn since 2010. He is the director of the Department of Palliative Medicine, University Hospital Bonn in Germany, and Director of the Palliative Care Centre, Malteser Hospital Bonn/Rhein-Sieg. Before this he was the founding Director of the Department of Palliative Medicine at University Hospital, in Aachen. He has published extensively, his main research interests being symptom assessment, opioid treatment, fatigue, cachexia and ethical issues in palliative care.

Professor Radbruch is president of the German Association for Palliative Medicine since 2014. He joined the International Association for Hospice and Palliative Care (IAHPC) Board of Directors in 2011, was Incoming Chair from 2012 to 2013 and has been Chair of the Board since 2014. He is a member of the WHO Technical Advisory Group on Long-term and Palliative Care initiated in November 2014.

PROF DR MICHIEL RENEMAN

Center for Rehabilitation & Rehabilitation Medicine , University Medical Center Groningen

Rehabilitation and reintegration of workers with pain

Demographic trends tell us that in an ageing workforce and a higher retirement age the incidence of chronic conditions will be increasing. Natural aging processes and (multiple) chronic diseases will have a negative impact on work capacity.

Evidence tells us that early and appropriate clinical interventions aimed at and organized to support staying at work or return to work, can be both cost-effective and have a significant impact on workforce productivity and quality of life. At the moment, however, there are some substantial challenges that are barriers to a broad implementation of evidence based and cost-effective services for many EU citizens. Among those are:

1. Evidence based and cost-effective services are at present not available for all EU citizens.
2. Modified work is not available for all EU citizens.
3. 'Healthcare' and 'work' systems function independently, yet they are mutually dependent.
4. Work is not considered a desirable or attainable clinical outcome by many healthcare professionals. Because good work and good health are related, this narrow perspective may actually harm patients.
5. Beliefs of 'the public' about pain and work are often not based on evidence.

During this short presentation, these challenges will be introduced, and some solutions will be presented.

Michiel Reneman is Professor in Rehabilitation Medicine. His main focus areas are pain rehabilitation, vocational rehabilitation, and work participation. He is Board member of the Dutch Pain Society, member of the SIP Platform, and member of the Fit for Work Netherlands.



University Medical Center
Groningen
P.O. Box 30.002
9750 RA Haren
The Netherlands
Phone: 31.50.5338550
m.f.reneman@umcg.nl

**Because good work
is good for health and
well-being, 'work' con-
tributes to good patient
care.**



PROF DR MED ROMAN ROLKE

Chair and Director

Department of Palliative Medicine, Medical Faculty RWTH Aachen University

Aachen University
Pauwelsstr. 30
52074 Aachen
Germany
Phone: +49 (0)241-8080880
rrolke@ukaachen.de
www.palliativmedizin.ukaachen.de

Pain is among the most burdening symptoms in patients supported by palliative care – still with an insufficient prescription of opioids for cancer pain. Despite recent developments - such as the hospice and palliative care law in Germany - the availability of palliative care is sparse in the Europe.

When PAIN meets PALLIATIVE CARE

International political actions include the aim to establish “palliative care” as a human right. This approach includes initiatives to increase the availability of palliative care and hospice services and sufficient opioid prescriptions for patients suffering from cancer pain. The societal burden of pain needs to have a political impact to create the frame conditions to further increase the number of trained physicians specialized for palliative care (PC), the numbers of PC and hospice services per inhabitants across Europe. The “Atlas of Palliative Care in Europe” (Centeno et al., EAPC press 2013) presents detailed data on this topic describing the distributions of these services per country. Political decision-makers need to bring more action into the framework in order to facilitate qualification and reimbursement of professionals and service structures across Europe.

Prof. Rolke is the current holder of the first Chair of Palliative Medicine in Germany located in the University of Aachen. As a trained neurologist and palliative care specialist his interests include pain in neurological disorders, cancer neuropathic pain and transitional pain research. He is member of the research committees of the German Palliative Care Association (DGP) and German Pain Association (German IASP chapter), the second largest pain association worldwide.

DR JOSÉ ROMÃO

Steering Committee Coordinator "National Strategic Plan for Prevention and Pain Control"

Directorate-General for Health

National Plans for Pain Control – Portuguese examples

In Portugal, since 1999, the Directorate-General for Health, APED (Portuguese IASP Chapter) and several experts in the pain field, have been working together for the definition of a national strategy for a better management of pain. From this team work resulted in 2009 the creation of a "National day Against Pain". Since then PAIN has arised attention of professionals, health authorities, media and general society.

In 2011 the 1st National Plan Against Pain" was published. It was a 6 years program whose main aims were the development of chronic and acute pain clinics in at least 75% of Portuguese hospitals. It also provided general principles for both organization and management of pain. The objectives were only partially achieved but this new reality triggered several other achievements. In June/2003 the Directorate-General for Health published a regulation, which declared pain to be the Fifth Vital Sign. As such, it has since become considered good clinical practice and mandatory to evaluate and record the intensity of pain regularly, in all health care services. In 2004 the Portuguese Medical Association created a Competence in Pain Medicine, as a way of promoting and recognizing the specialization of physicians dedicated to this field of medicine.

In 2008 strong opioid reimbursement was increased from 37 to 95%.

The Directorate-General for Health published guidelines regarding: the use of opioids for the treatment of noncancer pain, management of procedural pain in childhood, as well as other settings. Guidelines on the organization of acute pain units have also been published. At this time the 3rd national plan -National Plan for Prevention and Pain Control- is being implemented.

It has been a long and sometimes a very hard journey. There is still a long way to run.

Dr José Romão is Consultant in Anesthesiology with Competence in Pain Medicine and Coordinator of the Pain Unit – Centro Hospitalar do Porto (Portugal); Invited Associate Professor in Instituto de Ciências Biomédicas Abel Salazar (Porto-Portugal); Steering Committee Coordinator of the "National Strategic Plan for Prevention and Pain Control".



Portugal

Phone: +351 917939966

jmromao2@gmail.com

I strongly believe that the creation and implementation of a strategy for pain control at a national level – brings together all stakeholders - is essential to change the state of the art of pain control.

R



PROF BOAZ SAMOLSKY DEKEL

Scientific Director

No Pain Foundation

Italy

Phone: +39 3342465204

boaz.samolskydekel@

nopainfoundation.org

<http://www.nopainfoundation.com>

Free access to pain facilities, medications and treatments, sharing best-practices across the EU and the awareness of the relevance of pain's impact on our societies, social, health and economic systems are lacking. Individual's comprehensive needs should be the centre of each curative approach.

Filling the gaps in the forgotten issue of Chronic pain

Chronic pain occurs in 19% of European adults, negatively affecting their daily, social, and working lives; most patients do not receive pain treatment and 40% receive an inadequate one. Chronic pain is less a symptom of a disease than a disease in itself. It is a complex mix of physical, psychological and social components which produce both physical psychological and social suffering. Ideally it should be managed by a biopsychosocial multidisciplinary approach where the focus is not only on the treatment of the underlying 'disease', but also on the secondary impacts of pain on the patient's life particularly in fragile individuals like children, women and the elderly. Thus, it represents a challenge for patients, health care providers and policy makers given its multiple nature, and because the underlying complex pathophysiological mechanisms require individualized management and holistic treatment.

The lack of free access to pain facilities, medications and treatments, sharing best-practices across all member states of the EU and the awareness of the relevance of the impact that pain has on our societies, health and economic systems lead to under- or inappropriate treatments, patient frustration and suffering, useless analgesic dose escalations, and the failure of multiple therapies; these may result in ineffective pain control, harmful adverse effects, low patient compliance, therapy discontinuation, and increased healthcare and social costs. Thus, a key issue to limit these caveats is developing and fostering European-wide policy strategies & activities for an improved pain care in Europe involving all stakeholders at the national and community levels. This may include the sharing of best-practices and free access to pain medications and treatments (eg. opioids and cannabis), trans-border cooperation in pain care among European nations, increasing the awareness of chronic pain issues and their impact on both social and economic domains at all levels from the citizen to healthcare providers and to policy makers; increasing formal education of pain medicine (not only in medicine school) and clinical research of all aspects of chronic pain having the individual's comprehensive needs at the centre of each curative approach.

Dr. Boaz Gedaliahu Samolsky Dekel, MD, PhD is the Scientific Director of NoPain Foundation, Malta. He is an Aggregate Professor and Investigator of Anaesthesia, Intensive care and Pain Medicine at the department of Medical and Surgical Sciences of the University of Bologna, Italy. Senior Anaesthesia, Intensive care and Pain Medicine Consultant at the University of Bologna Teaching Hospital Policlinic S. Orsola Malpighi, Italy. Responsible of the Hospital's inpatients Acute Pain Service and the Centre of Pain Therapy for outpatients with chronic pain. Fields of interest and research: postoperative pain, chronic pain evaluation and treatment, opioids for chronic pain, cancer and breakthrough pain, pain in high risk persons.

PROF ANDREAS SANDNER-KIESLING

UNIV PROF DR MED UNIV

Dept. of Anaesthesiology and Intensive Care Medicine, Medical University of Graz

Co-Chair Working Group 1

Pain as a quality indicator for health care

One of the greatest difficulties we are challenged with in Pain Management is that we have no useful or reliably defined, unique ICD (International Code of Diagnosis) or similar codes for pain or pain syndromes. Thus, analyzing our databases creates diffuse and unreliable data about the prevalence or incidence of pain syndromes. The same critic applies to pain treatment codes. This makes it very difficult to evaluate the outcome of individuals, physicians or institutions, even worse when comparing for outcome. These weak data lead to rejection of our argument when we talk to stakeholders or key opinion leaders, like from governments or health insurances: "rubbish in – rubbish out!" is the killing argument to initiate any steps forward, any progress.

To solve this it is highly necessary to create useful and precise codes on one hand, and to define good quality indicators on the other hand. For codes, only ICF (International Code of Function) seems to be appropriate for future use. Regarding quality indicators, luckily the Austrian National Anaesthesia Society (ÖGARI) has defined a good set of indicators for acute and chronic pain. As a next step, these indicators will be tested in daily practice to confirm their usefulness. On European level, the European Society of Anaesthesiologists (ESA) Committee on Patient Safety and Quality Management also became active on quality indicators, based on the Austrian definitions.

Last, but not least, pain is a major topic in all clinically active medical specialties. That means that pain belongs to all specialties, not to one only. This implies fruitful and constructive cooperation as a guarantee for progress and success. However, the competition between the specialties is still too big and inhibits success and progress in improving visibility or political activities. Thus, the future shall be lively interdisciplinary on political or societal levels, not only bed-side from some individuals.

About Prof Sandner-Kiesling

- Borne in Graz, Austria, in Jun27, 1964; married, 3 boys.
- Trained both as General Physician and Specialist in Anaesthesiology and Intensive Care Medicine at the Medical University of Graz, Austria
- Scientific Scholarship 1999-2001: Pain Mechanism Lab, Wake Forest Medical University, NC, US (Prof. James P. Eisenach)
- Field of Interest: General and Regional Anaesthesia, Pain Medicine, Palliative Care Medicine, Quality Management
- Field of Research: Acute Pain Management, Chronic Pain Treatment, Quality Management, Regional Anaesthesia, Psychosomatic Medicine
- Member of the ESA Board of Directors, Vice-President of the Austrian National Anaesthesia Society (ÖGARI)
- Chair of the ESA Education & Training Committee, Chair of the ESA e-learning Subcommittee



Austria
andreas.sandner@medunigraz.at

It is highly necessary to create useful and precise codes and to define good quality indicators.



PROF MICHAEL SCHÄFER

President

German Pain Society

Pain as health care quality indicator in Germany

Alt-Moabit 101 b
10559 Berlin
Phone: +49 30 390409689 0
info@dgss.org
www.dgss.org

The Permanent Conference of Health Ministries of the German Federal States passed a resolution demanding the introduction of a "Pain-Indicator" in Hospitals.

The German Pain Society set up a "National Pain Forum", involving the relevant societal, medical and political organizations of the German health care system. Annually the National Pain Forum discusses major "Pain-issues" in context of the of the political and technical framework of the German Health Care System. As a result, a broad agenda was identified, leading to several political approaches. For example, the Permanent Conference of Health Ministries of the German Federal States passed a resolution demanding the introduction of a "Pain-Indicator" in Hospitals. This could go along with further activities in the scientific as well as political agenda the German Pain Society is involved in.

Education Medical School:

- Westf.-Wilhelms-University Münster, Germany, 1979-83, 1984-85, Medicine
- Welsh Medical School of Medicine, Cardiff, UK, 1983-84, Medicine
- Ludwig-Maximilians-University, München, Germany, 1984-85, Medicine

Licence:

Approbation als Arzt: 11/86

Academic career:

- Doctoral Thesis, Westfälische-Wilhelms-University Münster, 11/86
- Board Certification, Licence, Landesärztekammer Berlin, Arzt für Anästhesie, 6/98
- Habilitation, Freie Universität Berlin, 01/2001
- Call, C3-Professor for „Pain Research and Pain Therapy“, 10/2002
- Tenure C3-Professor für „Pain Research and Pain Therapy“, 10/2007
- Call for Harold Griffith Chair, full professor tenure position, McGill University, Canada (declined), 12/2008
- 10/2012, Nomination, President-elect of the German Pain Society
- 10/2014, Nomination, President of the German Pain Society

University positions:

- 6/88 - 8/92 Residency, Ludwig-Maximilians-Universität München, Dep. of Anaesthesiology
- 8/92 -12/96 Postdoc Fellow of the Dep. of Anesthesiology and Critical Care Medicine, The Johns Hopkins University, Baltimore, USA
- 8/92 -12/96 Guest Scientist, National Institutes of Health, National Institute on Drug Abuse, Division of Intramural Research, Baltimore
- 3/97 -12/97 Instructor, Ludwig-Maximilians-Universität München, Dep. of Anaesthesiology
- 12/97- 6/98 Staff Anesthesiologist, Freie Universität Berlin, Dep. of Anaesthesiology and Intensive Care Medicine
- 6/98 – 1/02 Senior Staff Anesthesiologist, Freie Universität Berlin, Dep. of Anaesthesiology and Intensive Care Medicine
- 1/98 - 1/02 Consultant in Anaesthesiology and Head of Research, Freie Universität Berlin, Dep. of Anaesthesiology and Intensive Care Medicine
- 1/02 – present Professor in Anesthesiology and Head of Clinical Research Group KFO 100, Charité University Berlin
- 12/2008 Call for Harold Griffith Chair, full professor tenure position, McGill University, Canada (declined)

MICHAEL SCHENK

Head Center of Integrative Pain Medicine Berlin, Consultant in Pain Medicine

Palliative Care Medicine and Anesthesiology

Multimodal pain therapy is effective and economic to restore working capability.

17 % of the European population suffers from chronic pain, of which 30% have strong pain and 10% of these need a hospitalization (Breivik 2006). The economic consequences are enormous: The indirect expenses (unfitness for work, early retirement) for chronic pain were assessed at more than 29 billion Euros in Germany (Dietl 2011). In the German health system 6-8% of the costs are caused by treatment of chronic pain (Neumann 2002). Unfortunately there is a mistreatment with a „too much“ of invasive procedures and operations and a lack of problem-adequate appropriate measures like multimodal pain therapy (MMPT).

For the treatment of chronic pain MMPT is considered as the gold standard (Guzmán 2002). Besides a good quality of treatment the intensity and length of treatment (e.g. between 14 and 21 days) must be adequate (Bendix, Härkäpää). Persistent effects regarding an improvement of quality of life, restoration of working capability are only proven for interdisciplinary multimodal pain treatments (Chou 2007, Guzmán 2002, Van Geen 2007, Van Tulder 2006, Williams 1996). Multimodal approaches also have a clear advantage compared to unimodal approaches regarding return to work 81% vs 29% und 54% vs 20% (Hazard 1989, Flor 1992).

Fortunately in the German health care system there exists a system for an adequate reimbursement of treatment expenses of intensive programs of MMPT in hospitals. There are „pain-DRG's“ (B47, I42, U42), which are induced by a pain-diagnosis and a complex pain procedure (OPS 8-918).

The costs for MMPT are completely covered by the health care providers, no matter if the patients have „private“ or „public“ health insurances.

But there exist still some unsolved issues: Specialized pain clinics are still not part of the German hospital plans. This resulted in an arbitrary historically caused non-symmetric distribution of pain clinics with many facilities in the south (e.g. Bavaria) and a big lack (e.g. Berlin).

It must also be mentioned, that ambulant multimodal structures are not economically supported by the health care providers. Exceptions are some smaller „lighthouse-projects“, which do not reach the broader patients' population.



Gemeinschaftskrankenhaus
Havelhoehe
Kladower Damm 221
14089 Berlin
Germany
Phone: + 49 30 36501 160
michael.schenk@havelhoehe.de
<http://www.havelhoehe.de/pain-centre.html>

Chronic pain is known as one of the highest risk factors for social well-functioning and working capability (Langley 2010). Multimodal pain therapy addresses bio-psycho-social aspects and is an evidence-based effective instrument to support social well-being as well as working function.

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DR MED HUBERT SCHINDLER

Head of Unit in the Health Division

Verband der Ersatzkassen e.V. (vdek)

Verband der Ersatzkassen e. V.
(vdek)
Abteilung Gesundheit
Askanischer Platz 1
10963 Berlin
Germany
Phone: +49 (0) 30 / 26931 - 1961
hubert.schindler@vdek.com
www.vdek.com

The outpatient pain management was a priority date in the design of supply for the statutory health insurance in Germany. Structural deficits in hospital care are obvious. Therefore the vdek actively supports the work of the National Pain Forum.

Pain as management indicator for health insurances

The statutory health insurance system in Germany can look back at 25 years of dealing with pain care. To date, the outpatient treatment of pain has been the focus of contractual medical care in Germany. Contractual partner has been either regional or national Associations of Statutory Health Insurance Physicians.

Around 1990, the reimbursement of pain management services provided by the substitute funds and their associations based on the "Pain agreement" was improved. In 1993, the establishment and implementation of pain management quality circles was promoted in the German federal state of Hessen and subjected to scientific accompaniment. Meantime, the number of practices specialised in pain therapy grew and the specific remuneration of pain therapy services have been adopted by all health insurance companies.

In 2005, the financial incentive for outpatient pain management was reduced. This happened, among other reasons, based on the argument that deficiencies in the treatment of pain resulting from the early stages of health care provisions cannot be solved by ambulatory outpatient centres as a "repair shop" so to speak. Almost simultaneously complaints about the disproportionate increase, compared to international standards, on surgical interventions in hospitals due to persistent back pain were reported. In this area, the special agreement "integrated care" enabled the remuneration of new medical interventions and focussed diagnosis for outpatients.

Beside other problem areas deficits in hospital care have been addressed by the German Pain Society with the launch of its "National Pain Forum". The initiative touches upon fundamental questions, such as how to manage a crosscutting area like pain treatment in an ongoing hospital operation in an effective and efficient manner and respecting the patient needs.

The vdek actively supports the work of the National Pain Forum to identify ways of problem solving. The results will be reported in September in Berlin.

From today's perspective the insurant benefits more from the development of adequate care structures rather than from the attempt of another construction to further expand a diversified individual case management.

Bibliography

Dr. med. Hubert Schindler has worked as a pharmacy assistant before he studied human medicine and mathematics at the University in Heidelberg. He practiced several years as a physician for the German Federal Armed Forces. From 1991 until 2009 he was managing the vdek representation in the German federal state of Hessen for all state related tasks in the statutory health and long term care insurance. Since October 2009 he is leading the health unit in the vdek headquarters in Berlin and is responsible for all medical questions related to national cancer plan, palliative medicine and provision of familial breast and ovary cancer. Further, he is collaborating with the National Pain Forum and is involved in specific topics from the G-BA sub-commissions for outpatient provision, quality assurance and disease management programs.

CHRISTOPH SCHWIERZ

Policy analyst

Directorate General for Economic and Financial Affairs (DG ECFIN)

Monitoring the efficiency of health systems: What does the European Commission need for pain policy?

The health systems of European Union Member States are a crucial part of Europe's high levels of social protection and cohesion; they play a central role in modern societies in helping people maintain and improve their health.

Health systems in EU Member States are varied, reflecting different societal choices. However, despite organisational and financial differences, they are built on common values, as recognised by the Council of Health Ministers in 2006[1] universality, access to good quality care, equity and solidarity. The need to make health systems financially sustainable in a way which safeguards these values into the future is also widely recognised.

Over the last decade, European health systems have faced growing common challenges: increasing cost of healthcare, population ageing associated with a rise of chronic diseases and multi-morbidity leading to growing demand for healthcare, shortages and uneven distribution of health professionals, health inequalities and inequities in access to healthcare.

Pain is negatively associated with health status, labour force participation and has an impact on the costs of care. Despite this impact, knowledge on the societal and economic impact of pain is not widely discussed, but it seems to deserve a wider recognition as one important factor related to population ageing and the associated debate on costs of care.

In recent years, the economic crisis has limited the financial resources available and thus aggravated Member States' difficulties in ensuring their health systems' sustainability. In turn, this jeopardises Member States' ability to provide universal access to good quality healthcare. Discussing the impact of pain in this regard seems important for identifying the right solutions to deal with these challenges.

Christoph Schwierz, Dr. rer. pol. (PhD Economics), is a policy analyst at the Directorate General for Economic and Financial Affairs in the European Commission. He studied economics in Berlin, Lausanne and Oslo and earned a Ph.D. in health economics at University of Bochum. Schwierz is specializing in the financial sustainability of public finances and health systems. He has published in Health Economics and other peer-reviewed journals.

[1] Council Conclusions on Common values and principles in European Union Health Systems (2006/C 146/01): <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF>

European Commission
Brussels
Christoph.SCHWIERZ@ec.europa.eu

Pain is negatively associated with health status, labour force participation and has an impact on the costs of care. Despite this impact, knowledge on the societal and economic impact of pain is not widely discussed, but it seems to deserve a wider recognition as one important factor related to population ageing and the associated debate on costs of care.

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PROF BLAIR H SMITH MD MED FRCGP FHEA FRCP EDIN

Professor and Clinical Director, Division of Population Health Sciences, University of Dundee; Consultant in Pain Medicine, NHS Tayside; and National Lead Clinician for Chronic Pain, Scottish Government

University of Dundee

University of Dundee
Mackenzie Building,
Ninewells Hospital & Medical
School Kirsty Semple Way
DD2 4DB, Dundee
Scotland, UK
Phone: +44 (0)1382 383728
b.h.smith@dundee.ac.uk
[http://medicine.dundee.ac.uk/
staff-member/professor-blair-smith](http://medicine.dundee.ac.uk/staff-member/professor-blair-smith)

Chronic pain is a major health and social problem, needing multi-disciplinary management. This requires leadership and investment, locally, nationally and internationally. Leaders must first understand the nature and extent of the problem, and thus opportunities for improved cost-effective care.

Pain facts and figures to inform policy

Chronic pain is very common throughout society, causing poor general (physical and psychological) health and disability, and has a major impact on individuals, families, health services and society. As well as the devastating effects on health, the economic impact includes the costs of treatment and investigation, reduced productivity and absence from work, and the provision of benefits to sufferers. Furthermore, chronic pain is one of the commonest co-morbidities linked with other serious conditions (including cancer, heart disease and depression), and results in increased hospital use and higher mortality. Chronic pain particularly affects older age groups, and will therefore have a growing prevalence and impact with current and projected changes in European demography. Health inequalities are also important, chronic pain prevalence and severity being associated with deprivation.

It is clear, therefore, that significant investment and leadership is required to address this major health and social problem. This presentation will summarise and quantify the extent of the chronic pain, focusing on statistics that are most likely to engage the policymakers who can influence the development of the necessary services and education.

Blair is Professor and Head of Clinical Director, Division of Population Health Sciences, University of Dundee (Scotland), where he also leads the Chronic Pain Research Group. Clinically, he is a General Practitioner, currently also practising as a Consultant in Pain Medicine, Ninewells Hospital, Dundee. He was appointed by the Scottish Government as Lead Clinician for Chronic Pain, April 2014.

Graduating at the Universities of Glasgow (MBChB, 1987) and Aberdeen (MEd Distinction 1998; MD 2000), he held an NHS Primary Care Career Scientist Award (2000 to 2005) and was Professor Primary Care Medicine at the University of Aberdeen until 2011. His research on chronic pain and neuropathic pain has been published widely, specifically studying the epidemiology, genetics, primary care management and self-management. He is a Chief Investigator on Generation Scotland, a major programme for studying genetics and health, with over 30,000 volunteer participants. He is Vice Chair of the International Association for the Study of Pain Neuropathic Pain Special Interest Group (NeuPSIG), and also established the Scottish Pain Research Community (SPaRC). He has authored over 160 peer reviewed research papers and various books and chapters, and has been a (co-)investigator on research grants totalling over £17M.

MARCO SPIZZICHINO

Director

Italian Ministry of Health

Best practice in pain policy: law 38/2010

With the adoption of Law no. 38/2010 on "Measures to ensure access to palliative care and pain therapy", Italy is at the top among EU countries with regard to the commitment to the fight against unnecessary pain. This is a highly innovative law, which protects and guarantees the patients access to palliative care and pain management as part of the essential levels of assistance, in order to ensure the respect of the dignity and autonomy of the persons, equity in access, quality of care and appropriateness.

After six years since the law's adoption, an assessment is needed. The first aspect to consider is the definition of the support network for pain management, which ensures the homogeneity of care pathways and quality of the services provided. Criteria have been provided throughout the national territory on the characteristics and requirements of a hub and spoke structure, and their role in general practice. The second aspect is the activation of a specific information system that allows verifying the work done by regional centres of reference, and makes it possible to monitor the consumption of analgesic drugs with a focus on opiate drugs. This system also allows the monitoring of the implementation of the law. Master programmes for pain therapists and nurses have been foreseen and defined. Meaningfully, the name of the graduate school in anaesthesia and resuscitation has been recently changed to "School of Anaesthesia, reanimation, intensive care and pain". Moreover, the Ministry of Health and the regions have implemented various communication projects for Italian citizens the result turns out to be not yet satisfactory. The theme of the fight against pain should not only involve the professionals but should be shared with citizens who, only through correct information, may become aware of structures and professionals dedicated to pain relief.

Born in Rome in 1961, Marco Spizzichino graduated in population statistics at the university of Rome "La Sapienza". He worked as a systems engineer with IBM in Italy, then worked at the Central Statistical Office of the Ministry of Health as an official dealing with statistical control of quality of statistical data on the dissemination and relations with National Statistical System (SISTANI) in collaboration with ISTAT. He was statistic executive responsible for Special Projects of healthcare facilities; in particular, has addressed to the implementation of Law 39/99 on the national territory on the National Programme for the construction of residential facilities for palliative care (hospice). He developed more and more expertise in the field of palliative care and pain therapy, becoming Director of the Ministry of Health's department on palliative care and pain therapy between 2011 and 2014. Since 2015 he is coordinator of the department on the estate and technological planning of the National Health Service structures.



Ministero della Salute
Via Giorgio Ribotta 5
00144 Rome
Italy
Phone: +39659942432
m.spizzichino@sanita.it

It is imperative to ensure access to pain therapy to reduce existing health inequalities between regions and safeguard the right to health.

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PROF THOMAS R. TÖLLE

UNIV-PROF DR MED DR RER NAT

Center for Interdisciplinary Pain Medicine „am Klinikum rechts der Isar“
Technische Universität München

Technische Universität München
Ismaninger Str. 22
81675 München
Germany
toelle@lrz.tu-muenchen.de

**Chronic pain should be
regarded as a disease
in its own right.**

Pain: a disease in its own right

Pain is an elementary and universal symptom of almost all diseases that can affect mankind. In 2001, the European Pain Federation (EFIC) declared: "Acute pain, such as that following surgery, constitutes a signal to a conscious brain about the presence of noxious stimuli and/or ongoing tissue damage..., and (this) is reasonably classified as a symptom of underlying tissue damage or disease. However, in many patients pain persists long after its usefulness as an alarm signal has passed, and indeed, often long after the tissue damage has healed. Chronic pain in these patients is probably not directly related to their initial injury or disease condition, but rather to the secondary changes including ones that occur in the pain detection system".

Regardless of the medical views on the bio-psycho-social backgrounds of chronic pain in the current literature, and having in mind that pain is a horizontal problem affecting all medical disciplines, for the purpose of policy-, budget- and resource allocation chronic pain should be regarded as a disease in its own right. While acute pain by definition is a brief and self-limiting process, chronic pain comes to dominate the life of the patients concerned with it and often also family, friends and caregivers. Chronic and recurrent pain is a specific healthcare problem, leading to typical co-morbidity, such as sleep disturbances, anxiety, depression and low self-esteem and often sets the stage for the emergence of a set of physical and psychosocial changes adding to the individual and societal impact of pain.

In order to meet the challenges caused by the societal impact of pain we will need to implement individualized health care delivery systems. This can be very simple support for some patients, while for other patients it might need an intensive multimodal approach. Although in recent years the topic of pain and pain management has moved into the consciousness of the media and drew more attention from politics, we must forcefully strive for an overall European strategy. Now, with the growing knowledge about the societal impact of pain, the health policy needs to act and address pain prevention and management as a key health policy focus of the EU.

Thomas Tölle is a Professor of Neurology at the Technische Universität München, Germany. He is a neurologist and psychologist by training. He was formerly also appointed as Professor of Medical Psychology and Neurobiology at the Ludwig-Maximilians-University in Munich. He set up an interdisciplinary research group for clinical and experimental research into pain, focusing primarily on the neurobiological mechanisms of neuronal plasticity, pharmacological treatment and central imaging with fMRI and PET. His research and clinical interests also include the prevention and treatment of chronic neuropathic pain and he is spokesman and runs the headoffice of the German Research Network for Neuropathic Pain (DFNS). Prof. Tölle has authored many peer reviewed publications and lectures on many aspects of pain medicine all over the world, served as the president of the German IASP chapter and will chair the scientific program committee for the EFIC European Pain Congress in 2017 in Copenhagen.

PROF DR MED ROLF-DETLEF TREEDE

Full professor, Chair of Neurophysiology, Vice Dean for Research, Managing Director of the Center for Biomedicine and Medical Technology Mannheim

Medical Faculty Mannheim, Heidelberg University

Can we use pain as a quality indicator for health care?

Education

1974 - 1980 Medical school at the University of Hamburg, Germany

1977 - 1980 Studies of computer sciences at the University of Hamburg, Germany

Academic positions

1981 Dr. med., University of Hamburg

1980 - 1988 Postdoc and assistant professor (C1) at the University Hospital Eppendorf, Hamburg

1988 - 1990 Visiting Scientist, Department of Neurosurgery, Johns Hopkins Medical Institutions, Baltimore, USA

1988 Habilitation (venia legend) in Physiology, University of Hamburg, Germany

1990 - 1992 Assistant professor (C1), Institute of Physiology, University Hospital Eppendorf, University of Hamburg

1992 - 2007 C3-Professor for Neurophysiology, Institute of Physiology and Pathophysiology, Johannes Gutenberg-University, Mainz

1996 Facharzt für Physiologie (as a medical specialty)

since 2008 W3-Professor, Chair of Neurophysiology, Medical Faculty Mannheim, Heidelberg University

2011 - 2019 Managing Director of the Center for Biomedicine and Medical Technology Mannheim (CBTM), Medical Faculty Mannheim, Heidelberg University

2013 - 2019 Vice-Dean for Research, Medical Faculty Mannheim, Heidelberg University

Research interests

Peripheral sensory transduction mechanisms in nociception; Efferent functions of nociceptive afferents on microcirculation and neurogenic inflammation; Mechanisms and assessment of nociceptive and neuropathic pain; Hyperalgesia and pain memory; Cortical representation of pain; Pain processing in patients with psychiatric disorders.



Medical Faculty Mannheim,
Heidelberg University
Germany
Phone: (+49) 621 – 383-9926
rolf-detlef.treede@medma.uni-
heidelberg.de

Pain is a major health-care problem world-wide. Although acute pain may reasonably be considered a symptom of disease or injury, chronic and recurrent pain is a specific healthcare problem, with its own diagnostic and therapeutic requirements.

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JOOP VAN GRIENSVEN

President

Pain Alliance Europe (PAE)

Pain Alliance Europe (PAE)
Phone: +31650222735
president@pae-eu.eu
www.pae-eu.eu

The patients right to be believed on his word that he has pain. The need to recognize that being a chronic pain patient has an influence / limitation on the person's ability to participate in society. Realise that the chance of becoming a chronic pain patient increases with ageing.

The need to improve the attitude towards chronic pain patients

Chronic pain patients are still often not seen as people with a condition which doesn't have to be combined with any underlying condition. People are seen and treated as just as bones, nerves, blood vessels, heart, lungs and so on. Patients are almost never looked at as a complete human being as they are. Recognizing that everything has a relation with each other. Mind, body, social structure, economical situation they all interact with each other. People working as a professional in the healthcare systems, in the most broadest way, do need to understand that. Even more when you speak about chronic conditions. And chronic pain is a chronic condition. However you may think on the causes why it exists it is a chronic condition with all its typical items.

We can never say that enough times, it all starts with believing the patients. I realize this is difficult as we are living in a society where superstition, double agenda's, egocentric and egoistic behaviour is more or less encouraged by the economical "need" to make more profit. However just because of the same reason it is difficult it is also the best reason to do something about this.

More and more information is becoming public, demonstrating that denying the chronic pain patients' right to proper treatment increases the cost for society. Proving early access to and realising adequate pain therapy in an early stage will give profit and in that way help national economies. This works for people when they are 16, 26, 36, 46, 56, 66, 76, or 86 and older. Giving the younger people the possibilities to have a good education, letting people in their working years participate in the labour process, whether it is a paid job or a voluntary job, letting the elderly participate in society so they can play their role. We all benefit from that. The healthy, the sick, the disabled, the elderly and the society at large.

As from the start of Pain Alliance Europe (PAE), Joop van Griensven, is the president of the European umbrella organisation for national associations involved with chronic pain. He is also the treasurer of the European Network of Fibromyalgia Patients (ENFA). He is a member of the patient advisory board of the Dutch Medical Evaluation Board (CBG/MEB) and chair of the local patient advisory board of a large Dutch home care organisation. Before starting his European adventure he was active on a national level as board member of the Dutch Fibromyalgia Association (F.E.S.). With his technical background he has a refreshing look at the issues belonging with chronic pain.

SABINE VERHEYEN

Member of the European Parliament

Group of the European People's Party (EPP), Germany



European Parliament

60, rue Wiertz

B-1047 Bruxelles

Belgium

Phone: +32(0)2 28 45299

sabine.verheyen@europarl.

europa.eu

What the EU can do to improve pain care

Sabine Verheyen has been a Member of the European Parliament for the German Christian Democrats (CDU) since 2009. She is Coordinator for the European People's Party (EPP) in the European Parliament's culture and education committee and a substitute member in the internal market and consumer protection committee. She focuses in particular on media policy, intellectual property, copyright and digital agenda issues.

She took part in the Conciliation Committee on the Telecom package and has been a Member of the European Parliament's annual delegation to the Internet Governance Forum since 2009. As former mayor of Aachen (1999 to 2009) she focuses additionally on issues that are of relevance to the local authorities.

She has been a member of the Euregio Council since 1999 and a member of the council of WDR, the West German public broadcaster, since 2003 and is a substitute member since 2009. She is furthermore a member and part of the Steering Committee of the European Internet Foundation.

Sabine Verheyen studied architecture at FH Aachen University of Applied Sciences.

Pain treatment is something which I consider to be very important because untreated pain can cause great distress to patients. It is therefore crucial to raise awareness of these problems, offer guidance and especially to encourage targeted training for doctors and nursing staff.



PROF DAVID VODUŠEK

Chair, EAN Liaison Committee

European Academy of Neurology (EAN)

Education and research on pain in European Neurology

Dept. of Neurology-Univ Medical
Center Ljubljana
Zaloska 2
Ljubljana, 1525
Slovenia
Phone: +38615222293
david.vodusek@kclj.si
www.eaneurology.org

Pain needs research, resources and dedicated stakeholders of several professions making sure that those living with chronic pain are adequately helped. EAN alerts European neurologists on the societal impact of pain and provides up-to-date information on pain and neuropathic pain in particular.

As a neurologist I am aware of the societal impact of chronic pain which accompanies many neurological conditions, and is even a disease in itself - chronic neuropathic pain. The particular burden on patients, doctors and society is the lack of dependably effective treatment for the latter.

The European Academy of Neurology (EAN) is the pan-European scientific neurological society, uniting 47 European national neurological societies with their members as well as 800 individual members. The EAN consists of an Assembly of Delegates of institutional and individual delegates; the Board of elected officers; 4 committees (+ 2 sub-committees), and 31 subspeciality Scientific Panels. The Aim of EAN is Excellence in Neurology in Europe. EAN is a non-profit organisation and identifies itself with the following five values:

- Professionalism. The EAN will strive to reach the highest scientific standards and to deliver unbiased information in its research and educational activities;
- High ethical standards. The EAN will apply high ethical standards in all its activities within science, education, liaison, and administration, complying with applicable regulations and codes of ethics;
- Involvement. The EAN will strive to involve its members and collaborators in the organisation of research, education and liaison activities;
- Independence. The EAN will operate as a professional and scientific organisation, independent from the political or commercial interests of external companies or organisations;
- Transparency. The EAN will provide transparency in the organisation of all its scientific and administrative activities.

EAN has among its Scientific panels, dedicated to particular fields in neurology, the panel for Neuropathic Pain. About Professor David B. Vodusek Dr. Vodusek is the Medical Director of the Division of Neurology in the University Medical Centre Ljubljana, and full professor of neurology at the Medical Faculty, University of Ljubljana, Slovenia. He is a practising neurologist and lists neuropathic pain among his interests. He is at present Chair of the Liaison Committee, European Academy of Neurology and thus in charge to build bridges to partner societies wishing to cooperate with EAN.

MICHAEL VON FISENNE

Manager Live-Communication

Grünenthal

Moderator of the plenary session of the Societal Impact of Pain Symposium 2016

Treatment of pain especially chronic pain is challenging. Sometimes it takes a long time before it is correctly diagnosed. The awareness is still low and it is not regarded as a disease in its own right. Pain is a burden not only for the individual who is suffering from reduced quality of life, low physical capacity, as well as restrictions in activities of daily living but also for the patients' families as well as for the society which has to deal with the consequences of pain. Every year we lose billions of euros due to chronic pain.

Over the last few years I have moderated many meetings and events in the area of health and I realized that there is still a long way to go. SIP is an excellent platform to exchange different perspectives and positions on pain with different stakeholders. SIP is a unique opportunity to advance this topic further. It is time to move from awareness and attention to action.

Michael von Fisenne holds a Master of Science in biology from the University RWTH Aachen. He has been working at Grünenthal for almost three decades. After starting in development followed by marketing he is now responsible for live-communication in the department of Corporate Communications.



Grünenthal
Germany
Michael.von.fisenne@
grunenthal.com

**It is time to move from
awareness raising and
attention to action on
pain treatment.**



MARIANO VOTTA

Director

Active Citizenship Network (ACN)

Tel: +39 06 36718351
m.votta@cittadinanzattiva.it
www.cittadinanzattiva.it

Do you have a way of working with chronic pain that is innovative and prize-winning? ACN is launching in 2016 the project "EU Civic Prize on Chronic Pain - Collecting good practices" to contribute to make the invisible visible on chronic pain.

Making the invisible visible on chronic pain

In the last few years, many initiatives – both Institutional and grass-root ones – have been focusing on the patients' right to avoid unnecessary suffering and chronic pain. At EU level, the EU Parliamentary Interest Group "Brain, Mind, Pain" is working hard to strengthen awareness and spread knowledge of this phenomenon at institutional level. The MEP Interest Group "European Patients' Rights & Cross-Border Healthcare" also devoted its most recent meeting to the topic of the degree of patient's pain, which was related to the implementation of the EU Directive on cross-border healthcare.

At non-institutional level, there are increasing activities to raise awareness on the topic, research and projects all conducted at national and EU level. This is a new way of operating that the statement "Making the invisible visible" explains well, and which was not by chance also the headline of an event promoted by Active Citizenship Network (ACN) at the European Economic and Social Committee on 2 October 2014 in Brussels, during the Italian EU Semester of Presidency. The event was the final act of a research-project carried out at European level with the aim to give evidence of existing good practices in several European countries in terms of struggle against pain.

To give continuity to this initiative and to contribute to make the invisible visible on chronic pain, ACN is launching in 2016 the project "EU Civic Prize on Chronic Pain - Collecting good practices", realized with the financial and non-financial support of Grünenthal and Pfizer. This is the only European Prizes of this kind led by citizens. The "European Civic Prize on Chronic Pain" will demonstrate what different healthcare stakeholders (patients' associations, health professionals, private and public hospitals, universities, Institutions, etc.) can offer in terms of good practices and experiences, useful in raising awareness about the phenomenon, enhancing the body of knowledge of positive cases and success, and strengthening commitment to this topic. A Jury composed of international experts on chronic pain will choose the winners. The celebration of the Prize, which will take place every two years, will represent the recognition of ongoing excellences. The promoters will be invited to create a network for the benefit of operators of good practices on chronic pain, provide mutual information, advice and practical help. Tell us about your way of working with chronic pain and win!

Mr Votta graduated in Political Science at University of Rome, Italy. He attended a postgraduate course in European Public Relations and another in Corporate Social Responsibility. He has more than 10-years experience working in the field of protection of citizens' rights, stakeholder engagement, communication and civic information. In 2011 – 2012, he worked as consultant for the United Nations Development Programme in Colombia to assert a new governance in the management of Public Services and Health. Since June 2013, he has been working as Director of Active Citizenship Network, the European interface of the Italian civic organization Cittadinanzattiva, and is also responsible for European Policy and international relations.

DONNA WALSH

Executive Director

European Federation of Neurological Associations (EFNA)

Moderator working group 1 Pain as a quality indicator for health care

Donna Walsh is the Executive Director of the European Federation of Neurological Associations (EFNA).

Donna's background is in journalism but she began her career working in patient advocacy on a national platform as Information and Communications Officer at the Migraine Association of Ireland. This led to her first involvement at the European level via the European Headache Alliance, before she took up her current position within EFNA in 2012. Since then she has been actively involved as EFNA stepped up its advocacy activities at the Brussels Institutions which culminated in February 2015 with the launch of the MEP Interest Group on Brain, Mind and Pain.



EFNA
Gurteen, Johnstownbridge
Enfield
Co Meath
Ireland
Phone: +353 87 983 0816
executivedirector@efna.net
www.efna.net

EFNA endorses the SIP initiative as it is very much in line with the policy outcomes we aim to achieve through the MEP Interest Group on Brain, Mind and Pain and beyond.





DR CHRIS WELLS

President

European Pain Federation EFIC®

Pain Matters
25 Rodney Street
Liverpool, L1 9EH
United Kingdom
chris.wells@efic.org

Since 2011, the European Pain Federation EFIC® has worked, together with European and national policy makers, on the “Road Map for Action” outlining how to effectively address the societal impact of pain at policy level. Five years later, we are seeing some concrete results!

The EU roadmap to action

Dr Chris Wells is President of the European Pain Federation EFIC®. This is the largest multidisciplinary professional organisation in the field of pain science and medicine in the world. It comprises the 37 European Chapters of the National Pain Societies of IASP® (International Association for the Study of Pain). Established in 1993, EFIC's constituent Chapters represent Pain Societies from 36 countries and more than 20,000 healthcare professionals across Europe, who study pain and treat patients suffering from pain.

Dr Wells has just retired from clinical practice in the management and treatment of pain in Liverpool and the North West of England.

Born in Durban, South Africa on 5th October 1947 of one Welsh and one English parent, Chris Wells trained in Liverpool, graduated in 1970 and then worked in Canada for 4 years. He did further training in anaesthesia and then pain medicine; specialising solely in pain medicine from 1982. He was Director of the Pain Research Institute in Liverpool from 1983 to 1994.

Dr Wells pioneered drug delivery systems in the UK and also Pain Management Programmes in Europe, setting up the first continuously running programme in Liverpool in 1983. His clinical interests include assessment and management of back pain and neuropathic pain.

Dr Wells has been an active Council member of the British Pain Society, Chair of the Scientific Committee from 1995 to 1999 and Secretary from 1999 to 2002. He has organised 4 Pain Society meetings and was made an Honorary Member of the British Pain Society in 2008.

He gave the Pain Society's Annual Lecture in 2008 on “Back to the Future: A Review of Pain

Management Past and Present”.

He has given the British Pain Society lecture, and also the EFIC lecture in memory of David Niv. He has been an invited lecturer at plenary sessions and workshops throughout the world.

He has been a Board member and Treasurer of the World Society of Pain Clinicians and a Board member of the World Institute of Pain. He is a Founder Examiner for the WIP Fellowship of Interventional Pain Practice.

Dr Wells was a Founder Member of NeuPSIG, setting up the group with Ed Charlton in 1999. He was Treasurer of NeuPSIG from 2001 to 2010, and was made the second Honorary Member of this group. He co-organised their 3 successful meetings in Madrid (2004), Berlin (2007) and Athens (2010), Chairing this last meeting.

Dr Wells has been active in the European Pain Federation EFIC® for 13 years. He was Secretary of EFIC® from 2002 to 2005, and Chair of the Bye-laws Committee from 2005 to 2008; he became President Elect of EFIC® in June 2011 and President in June 2014. He lectures throughout Europe and the rest of the world on pain and its management, and is actively involved at these meetings to reshape the face of pain management through research, evidence based medicine, education and innovation. He has initiated a multidisciplinary core curriculum in Europe, leading to a Diploma in Pain Medicine for all medical doctors.

He is a member of the current NICE Guideline Development Group on low back pain and sciatica. He has just been selected as a Citizen of Honour by the Liverpool City Council.

He is the author of 3 books and over 150 articles.

HILDA WIEBERNEIT-TOLMAN

Pijn Platform Nederland

Reporter Working Group 1 Pain as a quality indicator for health care

Hilda Wieberneit-Tolman worked for several years for the Dutch Pain Society, as part of the International Association for the Study of Pain (EFIC / European Pain Federation). She has cooperated in the initiation of the Platform for Pain and Pain Treatment and was director of the Dutch Pain Fund (development of information material and organization of meetings for patients and health care workers).

Together with several partners she realized for several years the Journal Pijnperiodiek and other materials for illustration and information about pain (DVD about experiences from patients with different diagnoses and DVD about pain-treatment).

Further on Ms Wieberneit-Tolman has been involved in the organization of the Pain Alliance Europe (PAE), the European patient organization for pain, pain-problems and pain management, for several years. Two years ago she became a board member of the PAE, being involved with European activities that brings the attention to chronic pain on a higher level. In the last years she was project-manager on behalf of Foundation Pijn Platform Nederland on a project "Vision on Pain" together with the Dutch Institute for Primary Care Research and Dutch Centre for Consumer Experience in Health Care.

Lately Ms Wieberneit-Tolman was asked to be a member of the Dutch Brain Council. She is also involved in organising events in the Week van de Pijn 2016 in the Netherlands. In the past she received the reward of the NVBP (today the DPS) and the Royal Honour for my activities for pain.

Ms Wieberneit-Tolman is married, has two daughters and three grandchildren. Her present job is coordinator for research on the Health Department for General Practitioners and Geriatric Specialists of the University Hospital in Leiden.



Pijn Platform Nederland
Postbus 2254
2301 CG Leiden
The Netherlands
Phone: +31 6 20611387
Info.pijnplatform.nl

Since a long time I am involved in stakeholders organizations for pain with the aim to stimulate multidisciplinary collaboration for patients with pain.



DR STEFAN WIRZ PHD, MD

GFO

CURA-Hospital

CURA-Hospital
Schuelgenstr. 15
53604 Bad Honnef
Germany
Phone: +49 2224 772-1194
Extension: +49 2224 772-1269
Stefan.wirz@cura.org
anaesthesia@cura.org

Rising cancer survival rates result in increasing numbers of cancer survivors. However, a large subgroup of patients suffer from chronic cancer pain after curative cancer treatment due to an insufficient management. Compulsory early integration of pain specialists is needed.

The Burden of Chronic Pain in Long-Term Cancer Patients

Due to advances in oncologic therapies, 5-year survival rates increased to nearly 70%. However, chronic pain arises in his population frequently as an undesirable effect after oncologic surgery, chemotherapy or radiotherapy. Tumours are capable to initiate an escalation of pain via tissue processes. Also genetic variables may lead to elevated pain levels in several types of tumours. Significant predictors for chronic pain are nerve damage ('neuropathic pain'), higher pain levels at the beginning of the disease, and demographic variables. Further on, also psychosocial factors are associated with chronic cancer pain. Whereas the impact of these variables is well known in chronic non-cancer pain, the association of psychodynamic mechanisms with chronic cancer often is neglected.

The rate of chronic cancer pain amounts to 20% of cancer survivors and approximately 40% of cancer patients suffer from pain during the course of their oncologic treatment. Overall, the numbers of cancer patients with an insufficient pain therapy in western countries reaches 50%. Multifarious reasons for this undertreatment are: problems related to the health care system, such as deficiencies in education resp. training in pain medicine, problems related health care professionals, problems related to patients, such as concerns about opioids, and communicative barriers of both physicians and patients. Many physicians reveal deficiencies in pain assessment, e.g. problems in diagnosing nerve pain in cancer patients. Otherwise, many patients with chronic cancer pain feel reserved to attend palliative specialists, because in contrast to the palliative population, cancer survivors show no need for palliative medicine. The relevance of an adequate pain control is underlined by the fact that an adequate pain therapy at an early stage of a cancer disease shows a positive of cancer on both quality of life and survival rates. Therefore, an early integration of pain specialists in the curative cancer treatment is compulsory. However, a differentiation of cancer pain according to different stages should be made, because patients' needs differ in the 'palliative' and 'non-palliative' situation.

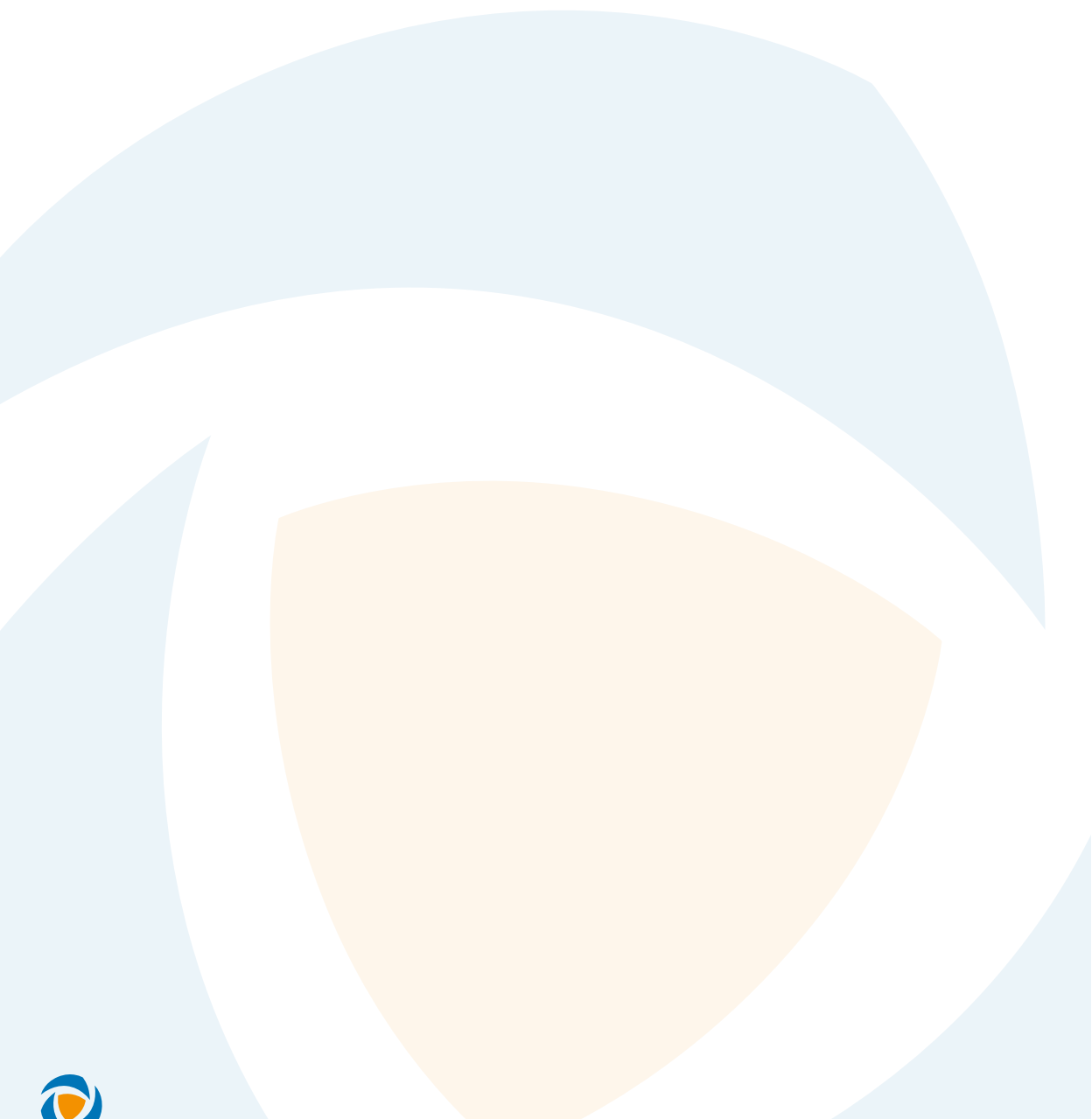
In summary

- early integration of pain specialists at an early stage of a cancer resp. its oncologic treatment
- educational programmes on pain medicine in academic institutions and medical capacities
- investigation on epidemiology, diagnosis, and treatment of chronic cancer pain
- are warranted.

Stefan Wirz, PhD, MD, is speaker of the Working Group of the German Pain Society, member of the Special Interest Group Cancer Pain of the IASP (International Association for the Study of Pain), and has been involved in the German Guideline Program in Oncology. He completed his PhD thesis on pain and symptom control in cancer pain, published many publications on this topic, and is speaker at national and international congress.



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SIP

Endorsing Organisations

**The scientific objectives of the
SIP 2016 symposium have been
endorsed by 160 pain advocacy and
scientific organisations,
listed in alphabetical order**



Grensstraat 7
1831 Diegem
Belgium
Phone: +32 2 251 55 10
www.efic.org
secretary@efic.org

1. European Pain Federation EFIC®

The European Pain Federation EFIC® is a multidisciplinary professional organization in the field of pain medicine and research, consisting of 37 European national pain societies, so-called chapters of the International Association for the Study of Pain (IASP). Established in 1993, EFIC represents 37 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. EFIC is established as a non-profit foundation in Belgium.

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.

2. Pain Alliance Europe (PAE)

Pain Alliance Europe (PAE) was founded in November 2011 by 18 national associations involved with chronic pain, from 11 EU countries. Currently (2016), PAE has 33 members from 16 EU countries. Together all these associations represent over 350,000 individual chronic pain patients.

In the past PAE was involved with the Pain Patients Pathway Recommendations project. It has organised European parliament events on its own such as the launch of PAE in 2011; the launch of the website in 2012; and the exhibition and cocktail event in 2014. PAE was actively involved as partners and/or speakers by other European Parliament events such as the "Out of Office" meeting.

Together with EFNA, PAE started the European parliament interest group on Brain, Mind and Pain, which had its first meeting in February 2015 and since then has already three more with more to come.

PAE was also involved with the making of and the presentation from the European Charter of the Rights of Citizens over 65 with Chronic Pain. For the work PAE has done for citizens over 65 with chronic pain, we have received an award presented by the Italian Minister of Health, Beatrice Lorenzin.

PAE also endorsed the Italian awareness campaigns of Hundred Cities Against Pain and will do so again this year.

PAE is involved as member of the jury in the European Civic Prize on Chronic Pain.

PAE will start its own awareness campaign called "The Red Balloon" which can be endorsed and seen just before the start of SIP.

PAE is more and more frequently asked to participate in projects aiming to improve the quality of life of people living with chronic pain in Europe. We will also try to start with our own project which will be to identify the additional costs for the individual chronic pain patient.

And, of course, PAE is also actively involved within SIP as a Cooperation partner.



Grensstraat 7
1831 Diegem
Belgium
Phone: +32 2 725 01 51
www.pae-eu.eu
info@pae-eu.eu
Twitter: @pain_europe
Facebook: /PainAllianceEurope



HEADQUARTERS

via Cereate, 6
00183 Rome - Italy
Phone: (+39) 06.36.71.81
www.cittadinanzattiva.it
mail@activecitizenship.net

REPRESENTATIVE OFFICE TO THE EU

Rue Philippe Le Bon, 46
1000 Brussels - Belgium
Phone: (+39) 3408465097
www.activecitizenship.net
brussels@activecitizenship.net

Twitter: @activecitnet

Facebook: www.facebook.com/
activecitizenshipnetwork

3. Active Citizenship Network (ACN)

Active Citizenship Network (ACN) is one of the most widespread and flexible European network, composed by more than 100 civic, patients and users organizations. Established in 2001, it is coordinated by Cittadinanzattiva, the Italian non-profit organization founded in 1978, independent from any political affiliation, trade unions, private companies and public institutions.

The main objectives of ACN are the promotion of civic activism & participation in the political arena, and the protection of citizens' rights, which are both the strength and the uniqueness of ACN.

As an international interface of Cittadinanzattiva, ACN focuses on the following two objectives:

- encourage the active participation of citizens in the EU policy-making in order to promote the construction of an "European active citizenship", through the citizens' powers and responsibilities in public policies.
- promote abroad all the successful experiences achieved by Cittadinanzattiva in Italy.

ACN is also active in Colombia since 2009 with a Citizen Advisory Centre on Public Services and Health.

Field of actions

Over the years, ACN has promoted political activities and carried out more than 30 EU projects together with partners from and extra EU countries, working in the following areas:

- Assessing, monitoring and promoting the respect of patients' rights
- Patients' empowerment and involvement
- Cross-border Healthcare
- Fight against unnecessary suffering and chronic pain
- Collecting best practices
- Volunteering
- Corporate social responsibility
- Civic evaluation in the Public Services
- Healthy ageing and elderly care
- Sustainable issues in different areas: healthcare system, mobility, energy, etc.

Milestones

- 2002:** drafting the **European Charter of Patients' Rights** which has become a reference for EU citizens' healthcare rights.
- 2005-2006:** drafting the **EU Charter of Active Citizenship**, to bridge the gap existing in the EU about the rights, duties, powers and responsibilities of civic organizations acting in the public policies.
- 2007:** launching of the **European Patients' Rights Day**, celebrated every year on the 18th April with local, national and EU events.
- 2007:** awarded the **Civil Society Prize** of the EU Economic and Social Committee for its work on citizens' rights.
- 2011:** drafting the First **Charter of Patients' Rights in Colombia**.
- 2015:** Promotion of the **Member of EU Parliament Interest Group "European Patients' Rights & Cross-Border Healthcare"** with the support of associations from all over Europe.

ACN is an official member of ...

- "Health Policy Forum", the EU platform dealing with health led by the EU Commission-DG Santé
- "Active Citizenship Structured Dialogue Group", led by the EU Commission-DG Migration and Home Affairs, the EU platform dealing with civic participation

4. The Grünenthal Group

Pain is the most single common reason why an individual consults a medical professional. The European Pain Federation (EFIC®) states that in contrast to acute pain, 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.

The Grünenthal Group is an independent, family-owned, international research-based pharmaceutical company headquartered in Aachen, Germany. We are an entrepreneurial specialist delivering true benefits to patients. By sustainably investing in research and development above the industrial average, we are committing to innovation in order to treat unmet medical needs and bring value-adding products to markets. Grünenthal is a fully integrated research & development company with a long track record of providing patients with innovative pain treatments and state-of-the-art technologies.

Research and Development

Grünenthal is one of five remaining research-oriented pharmaceutical companies with headquarters in Germany which sustainably invests in research and development. Research and development costs amounted to about 20 percent of revenues in 2014. Grünenthal's research and development strategy concentrates on selected fields of therapy and state-of-the-art technologies. We are intensely focused on discovering new ways to treat pain better and more effectively, with fewer side-effects than current therapies.

We consider it highly important to co-operate closely with external opinion leaders and development partners. Grünenthal is already involved in a number of successful long-term co-operations. Given the rapid transformation in research and technology, successful R&D strategies can nowadays only be implemented in close co-operation with other highly specialized partners in industry and education.

Being committed to innovations in pain management Grünenthal fully supports the discussion on the Societal Impact of Pain and is delighted to collaborate with EFIC, PAE and ACN on this exciting platform. The significant high number of endorsing organizations reflects the high need and relevance the topic of the societal impact of pain has for entire Europe.



Steffen Fritzsche
Senior Director
Corporate Communications
Grünenthal Pharma GmbH &
Co. KG
52099 Aachen
Phone: +49 241 569-1335
Fax: +49 241 569-51335
www.grunenthal.com
steffen.fritzsche@grunenthal.com



5. ACTHealthy lab, Clinical Psychology and Behavioral medicine laboratory, and ALGEA Research group, University of Cyprus

75str Kallipoleos,
Department of Psychology,
University of Cyprus
20537, 2108 Nicosia,
Cyprus
Phone: +357.22892024
www.algea.com.cy
algea@ucy.ac.cy

The "ALGEA" project is a new multilevel research approach for chronic pain in Greece and Cyprus. Primary aim of the study is to investigate multiple factors (e.g. psychological, biological etc.) involved in pain adjustment and create innovative psychological interventions for chronic pain patients and their families.



6. AGE Platform Europe

111, rue Froissart
B – 1040 Brussels
Belgium
Phone: +32 2 280 14 70
www.age-platform.eu
info@age-platform.eu

AGE Platform Europe is a non-profit European network. It brings together about 150 non-profit organisations of or for people aged 50+ which represent over 40 million older people in the European Union.

AGE Platform Europe strives to achieve an age-friendly Europe.

algos:

7. ALGOS. Recerca en dolor (Research on Pain)

Edifici N0
Universitat Rovira i Virgili
Carretera de Valls, s/n
43007 Tarragona
Spain
www.algos-dpsico.urv.cat
jordi.miro@urv.cat

Pediatric chronic pain is a highly prevalent problem, largely unrecognized and undertreated. Youth with chronic pain and their families deserve a better care; they have the right to receive the best treatment possible.

8. Allianz Chronischer Schmerz Österreich (Alliance Chronic Pain Austria)

The Alliance Chronic Pain Austria was founded two years ago to raise public awareness for the situation of pain patients who as a rule are grossly under diagnosed and poorly treated. Now up to 47 self-help groups representing all sorts of chronic pain such as migraine, rheumatic pain, Fibromyalgia etc. have joined the platform. They want to make their cause visible by raising awareness, both in Health politicians and the General Public, for an imminent need to acknowledge chronic pain as a disease in its own right which should be diagnosed as early as possible, provide more efficient therapies for pain patients, and install specialised pain centres, where chronic pain patients will receive interdisciplinary evaluation and multimodal treatment.



Curlandgasse 22
A-1170 Vienna
Austria
www.schmerz-allianz.at
info@schmerz-allianz.at

A

9. Alvleeskliervereniging (AVKV)

AVKV is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



The Netherlands
www.alvleeskliervereniging.nl/ik-ben-patient.aspx
info@patientennaar1stem.nl

10. Arthritis and Rheumatism Association of Malta (ARAM)

ARAM is a non profit organisation in Malta composed of patients with arthritis whose aim is to help and support patients with arthritis.



PO Box 55
B'Kara
Malta
Phone: +356 99259532
www.aramalta.com
aramalta@gmail.com



11. Asociația Română Pentru Studiul Durerii (ARSD, Romanian Association for the Study of Pain)

Spitalul Universitar de Urgență București
Clinica Anestezie-Terapie Intensivă - Dr. Virgil Dinca,
Splaiul Independenței nr. 169,
Sector 5, București,
Cod 050098, Romania
Phone: +40 (0)21 318 05 22
int.150
www.arsd.ro
arsd_rasp@yahoo.com

ARSD was established in 1991 by 12 founding members from University Emergency Hospital- its motto is „Sedare dolorem opus divinum estE”. Its aim is to develop a network pain treatment in the hospitals of Romania and to promote and encourage studies and publications in the field of acute and chronic pain. The Society organises annual conferences with national and international participation, sends representatives to national and international interdisciplinary events and sustains promotion of Pain Therapy Centres and interdisciplinary activities in university centres and county hospitals.

Although the ARSD brought up the subject of the Societal Impact of Pain and pain management in the last 5 years, these issues are still not a priority for the current government.



12. Associação de doentes de dor crónica dos açores (Chronic Pain Patients Association)

Rua Dr. Aristides Moreira da
Mota, 69
9500-054 Ponta Delgada,
Açores
Portugal
Phone: + 351 296654454
+ 351 910696806
addcacores@iol.pt,
addcadirecao@iol.pt

This Chronic Pain Patients Association in Açores, Portuguese Islands, is the only patient association devoted to specific chronic pain as a disease.

The idea started in 2004 when, in Ponta Delgada, we had a Pain Unit in the Hospital, the public information about pain was a reality, the professionals were thinking about a regional pain control Program and all national and international events were celebrated. In October 2015 four patients made the official record of the name. It is a Non-profit Institution of Social Solidarity.

We know that the pain cannot be cured, but it must be relieved and treatment is to relieve pain and improve the quality of life.



13. Association française de la cystite interstitielle (AFCl, Interstitial cystitis French patients support group)

7 avenue du Rocher
Saint-Maur
94100
France
www.asso-afci.org
ci_france@hotmail.com

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

AFCl 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.

14. Association Francophone pour Vaincre les Douleurs (AFVD, French association to win the pain)

AFVD is a non-profit patient organization founded in 2006 by Martine Chauvin and represents chronic pain patients and their carers. The association has about 150 members, among patients, relatives and friends, all over France. AFVD was recognized of general interest in the June 2008, and authorized to issue tax receipts.

Martine is a founding member of the Pain Alliance Europe network (PAE) and adheres to the CISS (Collectif Inter-associatif Sur la Santé) in her region. She received the National Accreditation to represent users in the hospital authorities or public health (Official Gazette of 18 July 2012), and also received the IDEAS label in October 2014. She practices risk management.



La Tillerolle
79200 Pompaire
France
Phone: +33 (0)6 15 57 83 83
www.association-afvd.com
association-afvd@neuf.fr

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15. Association luxembourgeoise des patients à douleurs chroniques (ALPADOC, Luxembourgish association of chronic pain patients)

People with chronic pain also have the right to work, to be a part of social activities and to be accepted as precious human beings.



16, Rue de Champs
3314 Bergem
Luxembourg
www.alpadoc.lu
contact@alpadoc.lu

16. Associazione Italiana per lo Studio del Dolore (AISD, Italian Association for the Study of Pain)

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.

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.



Rome
Italy
www.aisd.it
info@aisd.it



Via Ornera, 14
47895 Domagnano
Repubblica di San Marino
www.assdolore.org
assdolore@gmail.com
Twitter : @assdolore
Facebook : www.facebook.com/assdolore
LinkedIn : www.linkedin.com/assdolore

17. Associazione Sammarinese per lo Studio del Dolore

Pain spreads throughout population and does not discriminate colour, 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.

The Association for the Study of Pain of San Marino was founded in 2008 to offer to the population and healthcare professionals a scientific reference on the treatment of pain.



Calle Azorin 32-34
28935 Móstoles
Madrid
www.afinsyfacro.es

18. Asociación de Fibromialgia y Síndrome de Fatiga Crónica de la Comunidad de Madrid (AFINSYFACRO, Association of Patients with fibromyalgia and chronic fatigue syndrome of the Community of Madrid)

Operating within the Autonomous Community of Madrid, Afinsyfacro was founded in 2004 with the aim of providing an answer the legal and socio-healthcare vacuum affecting persons suffering from both pathologies and their relatives. Its goal is to reach the reestablishment of patients' life quality, with the vision: "one can't just be focused on the problems, but on the search for solutions instead".

Afinsyfacro is running a multidisciplinary care project for patients suffering from Fibromyalgia and Chronic Fatigue Syndrome, aiming at the patient's functional recovery, at a physical, psychological and cognitive level. It is also working in the promotion of research, awareness raising of the disease, training, defence of the patients' rights towards the public organisms.

We know that the pain cannot be cured, but it must be relieved and treatment is to relieve pain and improve the quality of life.



BILBOKO
MEDIKU ZIENTZIEN
AKADEMIA
ACADEMIA DE
CIENCIAS MÉDICAS
DE BILBAO

c/ Lersundi 9-5º
48009 Bilbao
Spain
www.acmbilbao.org
academia@acmbilbao.org

19. Academia de Ciencias Médicas de Bilbao

The goals of the Academy are established in the Statutes, article 2: "The study of medical sciences, as well as the involvement of its members in scientific, cultural and human aspects, being these items means to express their collective activities. Furthermore, the Academy will be the link to Societies and Associations aiming at similar goals."

In order to reach such goals, the Academy publishes activities performed by its members, persons, entities or working groups who may provide their knowledge and experience; it creates awards, incentive allocations or endowments for the performance of works in their field of interest; it develops economic activities, directed at the performance of its objectives or at gathering resources with that goal, etc.



SIP

Societal Impact of Pain



Monkey Puzzle House, 69-71
Windmill Road
Sunbury-on-Thames
Middlesex TW16 7DT
United Kingdom
Phone: +44 20 8977 5474
www.backcare.org.uk
info@backcare.org.uk

20. BackCare

BackCare is the charity for helping people with back pain and promoting back health. We provide support, advice and information through our website and publications on the diagnosis and treatment to minimize the risk of pain becoming chronic and disabling. Lifestyle conditions, a reliance on modern transport, day to day stress, obesity and a lack of exercise are all reasons for the continuing prevalence of back pain.



Weligerveld 1
3212 Pellenberg
Belgium
www.belgianpainsociety.org
info@belgianpainsociety.org

21. Belgian Pain Society (BPS)

The Belgian Pain Society, Belgian chapter of the International Association for the Study of Pain, is a multidisciplinary scientific association which assembles the medical profession and non-medical professionals involved in chronic and acute pain. The goals of our association is to support the education for the treatment of pain, stimulate the pain research, encourage the treatment of a patient by creating a network that is adapted for the correct treatment and participate in the application of the public health care.



10559 Berlin
Germany
Phone: + 49 30 28867260
www.bv-schmerz.de
bgst@bv-schmerz.de

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

The Professional Association of Physicians and psychological psychotherapist in pain and palliative care in Germany e.V. (BVSD) is the largest federal and nationally organized professional policy advocacy in pain and palliative care. The BVSD is committed to the interests of its members and represents their interests with success towards politics, institutions, government agencies, insurance companies and all bodies of the common self-government in public health insurance in Germany. The BVSD is committed to the further qualitative and structural development of general and special pain management and palliative care. Focus the association's work are in the contract development and in cooperation management, and quality assurance and management.

23. Berufsverband Deutscher Anästhesisten e.V. (BDA)



The Professional Association of German Anesthesiologists (BDA) represents since over 50 years the professional group of anesthesiologists in all occupational policy matters and beyond.

Roritzerstraße 27
90419 Nürnberg
Germany
www.bda.de

B

24. Bijnierverseniging NVACP



Bijnierverseniging NVACP is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.

The Netherlands
www.nvacp.nl
info@patientennaar1stem.nl

25. British Pain Society



The British Pain Society is an alliance of professionals advancing the understanding and management of pain for the benefit of patients. We achieve this by promoting excellence and awareness for the benefit of people living with pain; promoting partnership in pain research, education and management; influencing policies relevant to pain; nurturing the next generation of pain researchers and healthcare professionals; encouraging dialogues about pain; contributing to national and international dialogue of pain.

The British Pain Society is the largest multidisciplinary professional organisation in the field of pain within the UK, and is the British Chapter of IASP and EFIC.

Third Floor, Churchill House,
35 Red Lion Square
London WC1R 4SG
UK
Phone: +44 (0)20 7269 7840
www.britishpainsociety.org
info@britishpainsociety.org



Residenz am Deutschen Theater
Reinhardtstr. 29
10117 Berlin
Germany
Phone: +49 (0)30 2800 81 981
www.buerger-initiative-gesundheit.de
Info@buerger-initiative-gesundheit.de

26. Bürger Initiative Gesundheit e.V.

The current pain therapy in Germany is characterized by inadequate time for attention of the doctor/therapist for diagnosis and therapy of the individual patient. Therefore we demand statutory configuration of pain therapy in direction of optimal individual care of patients and performance-based payment for doctors/therapists.



Universitat Rovira i Virgili –
Fundación Grünenthal
Carretera de Valls, s/n
43007 Tarragona
Catalonia
Spain
jordi.miro@urv.cat

27. Càtedra de Dolor Infantil (Chair in Pediatric Pain)

Pediatric chronic pain is a highly prevalent problem, largely unrecognized and undertreated. Youth with chronic pain and their families deserve a better care; they have the right to receive the best treatment possible.



Carmichael Centre
North Brunswick Street
Dublin 7
Ireland
www.chronicpain.ie
info@chronicpain.ie

28. Chronic Pain Ireland

Chronic Pain Ireland is a National organization offering support and information for people living with Chronic Pain. We run courses on the Self Management of Chronic Pain Nationwide.

29. Chronic Pain Policy Coalition (CPPC)

CPPC promotes policy solutions that contribute towards the improvement of the quality of life of those affected by chronic pain. The CPPC works to achieve this by linking representatives of people living with pain, policy-makers and parliamentarians, creating an expert forum to increase awareness and understanding of the issues surrounding pain and to influence and facilitate positive action that will reduce the impact of pain in individuals and society. The CPPC's work is steered by an Executive Committee made up of leading figures in chronic pain and led by Co-Chairs, Neil Betteridge and Dr Martin Johnson. The CPPC focuses its work in England but also communicates more widely, working collaboratively across the UK, the EU and more widely to further its aim of improving the lives of people affected by pain.



Policy Connect
CAN Mezzanine
32.36 Loman Street
Southwark
London
SE1 0EH
Phone: + 44 0207 202 8577
Katherine.Perry@
healthinparliament.org.uk
www.policyconnect.org.uk/
cppc/home@paincoalition

C

30. Coordinadora Española de Asociaciones de Espondiloartritis (CEADE, Spanish Federation of Spondyloarthritis Associations)

CEADE represents people affected by Spondyloarthritis diseases, defending their rights, to achieve full integration into society. It aims to integrate various Spanish associations, representing the joint work of interest groups. It struggles to guarantee the full social, health and labour integration of affected people by any of these diseases under equal conditions.



Calle Pinto Nº10 - 28944
Fuenlabrada (Madrid)
Spain
info.espondilitis@gmail.com
www.espondilitis.es
www.espondiloartritisaxial.org

31. Coordinadora Nacional de Artritis (ConArtritis, Arthritis' National Coordinator)

The assignment of ConArtritis is to integrate and represent those associations of persons suffering from Arthritis before the Public Administration and Health Care Managers, with the aim of promoting public and legislative initiatives. These actions shall result in a full social and labor integration of people suffering from Arthritis and in the improvement of their quality of life.

ConArtritis provides to those comprehended associations of persons suffering from Arthritis its experience, advice and relevant information on Arthritis, as well as the last medical and scientific progresses related to their treatment.

ConArtritis promotes on an ongoing basis the knowledge of this disease and the consequences it has among society in general lines.



C/ Ferrocarril, 18, 1º, oficina 2
28045 Madrid
Spain
Phone: +34 91 535 21 41 /
644 00 77 18
www.conartritis.org
conartritis@conartritis.org
Facebook: /ConArtritis
Twitter: @ConArtritis



University Hospital Osijek
J.Huttlera 4
31000 Osijek
Croatia
Phone: +38531511531
www.hdlb.org
mira.fongler@gmail.com

32. Croatian Pain Society – Croatian Medical Association

The Croatian Pain Society currently promotes multidisciplinary pain management program (PMP) as the standard of care for patients with chronic pain. PMP based on cognitive behavioural principles and promises significant improving impact of pain on physical, psychological and social function. The first such program was established in the University Hospital Osijek under the sponsorship of the Croatian Pain Society. First experiences showed stronger participation in daily activities and improved quality of life for those with persistent pain and physical disability, reducing emotional distress, increasing mobility, improving the individual's ability to self-manage pain-associated disability, and reducing reliance on medication or healthcare use. Return to work can be achieved as an essential component. PMS is cost-effective and reduce significant health care consumption.



Kings Court
17 School Road
Hall Green
Birmingham B28 8JG
UK
Phone: +44 (0)121 702 0820
www.cobfoundation.org
suzanne@cobfoundation.org

33. Cystitis & Overactive Bladder (COB) Foundation

COB is a patient-based information and support charity. We are a registered charity, founded in 1994 and are dedicated to helping people with all forms of cystitis, overactive bladder and urinary continence issues. We aim to help people understand their bladder condition and the treatments/help available to them. Also we help sufferers with the isolation and frustration of living with an often painful, chronic bladder illness and reassure people that they are not alone. In addition we attempt to advance education amongst the general public and the medical profession into the causes and treatment of cystitis, overactive bladder and continence by offering the patient experience.



Roritzerstraße 27
90419 Nürnberg
Germany
www.dgai.de
dgai@dgai-ev.de

34. Deutsche Gesellschaft für Anästhesiologie und Intensivmedizin (DGAI)

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 strives to improve the way pain is perceived and managed to better support people in pain and drive healthcare efficiencies.

35. Deutsche PalliativStiftung (German Foundation for Palliative Care)

Death and dying are pushed aside by most people. Only a few think about what kind of care they would prefer in case of severe diseases. The German Donation for Palliative Care promotes a new culture for end-of-life care.

Everywhere predominates a spirit of "higher, faster, further". But we are in need of a spirit of "not too high, not too fast, not too far". We are in need of a measured medical care.



...leben bis zuletzt!

Deutsche PalliativStiftung
Am Bahnhof 2
D - 36037 Fulda
Germany
Phone: +49 (0)661 48049 797
www.palliativstiftung.de
buero@palliativstiftung.de

D

36. Deutsche Schmerzgesellschaft e.V. (German Pain Society)

The German Pain Society, with nearly 3,500 individual members, is the largest scientific and medical specialty society in the field of pain in Europe. It is a member of IASP (International Association for the Study of Pain) and the AWMF (Association of the Scientific Medical Societies in Germany).



Deutsche Schmerzgesellschaft e.V.
Section der International Association for the Study of Pain (IASP)

Federal Office
Alt-Moabit 101 b
10559 Berlin
Germany
www.dgss.org
info@dgss.org

37. Direção Regional da Saúde - Plano Regional de Saúde 2014-2016 (Regional Health Directorate – Health Regional Plan 2014-2016)

From 2009 to 2013 the Department of Health of the Azorean Autonomic Government organized a Regional Program for Pain Control, considered a Good Practice to treat better pain of Azorean people, 260.000 inhabitants in nine islands in the Atlantic. The major objectives were: organization, education and information, supported by the 5 principles of pain control: (1) pain as a subjective symptom, (2) pain registered as the 5TH vital sign, (3) need of multidisciplinary team to treat complex chronic pain patients, (4) to treat pain is an human right, (5) the health Institutions have the obligation to support pain control.

In the 2014-2016 Regional Health Plan, the continuity of the strategies defined is directed to better education of General Practitioners and information of all health professionals and public about the strategies to prevent, to treat chronic pain and to reduce the social impact of pain.



Solar dos Remédios
9701-855 Angra do Heroísmo
Azores
Portugal
Phone: (+351) 295 204 200
www.azores.gov.pt
sres-drs@azores.gov.pt



Hôpital Lariboisière
2 Rue Ambroise Paré
75475 Paris Cedex 10
France
www.douleurs.org
dsf.france@douleurs.org

38. Douleurs Sans Frontières (Pains without Borders)

Douleurs sans Frontières is the only French NGO specialized in the treatment of pain, suffering and palliative care of vulnerable populations in several developing countries. DSF fights for better quality and access of care for all in the world. Today, DSF develops humanitarian projects in Madagascar, Mozambique, Haiti, Cambodia, and Armenia in collaboration with local stakeholders.



Dutch Pain Society

Gustav Mahlerlaan 3004
1081 LA Amsterdam
The Netherlands
Phone: +31 (0)20 5980393
www.dutchpainsociety.nl
info@dutchpainsociety.nl

39. Dutch Pain Society

The Dutch Pain Society values, supports and facilitates multidimensional pain treatment. Our mission is to achieve less pain, less burden and less functional limitation as a result of pain, in society.



The Netherlands
www.dwarslaesie.nl
info@patientennaar1stem.nl

40. Dwarslaesieorganisatie Nederland

Dwarslaesieorganisatie Nederland is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.

41. Endometriosis Association of Ireland

The Endometriosis Association of Ireland is a small voluntary organisation, set up to support people effected by endometriosis and related conditions, to raise awareness and aid research. Endometriosis is a common condition (1 in 10 women) but because of the lack of awareness and the stigma attached to pelvic pain, diagnosis is typically delayed by 7-10 years. The pain suffered is often dismissed and women are left to deal with both the excruciating pain caused by the endometriosis and the chronic pain caused by the delay in treatment given.



Carmichael Centre for
Voluntary Groups
Carmichael House
4 North Brunswick Street
Dublin 7
Ireland
www.endometriosis.ie
info@endo.ie

E

42. Estonian Pain Society

The Estonian Pain Society is an association of professionals, who are dealing in their daily practice with issues related to the study of pain and pain management. Established in 1990, its primary goal is the creation of the best possible conditions for vocational education, science and practice in the field of pain management in the Estonian Republic. In addition, the aim of our work is to introduce the problems of people suffering from pain and in need of pain treatment, regardless of its causes, to doctors, nurses, physiotherapists, psychologists, other health professionals, and society as a whole. All that is necessary for the implementation of every person's right for life and treatment without pain.

The Estonian Pain Society is a member of IASP® (International Association for the Study of Pain) as member of the European Pain Federation EFIC®.

KESTI VALU SELTS



Ravi 18
Tallinn
Estonia
www.valu.ee
kaire.pakkonen@ph.ee

43. EURAG Österreich

EURAG Austria is a non-political non-profit organisation campaigning for the needs of the older generation. Realising that there is a majority among older people who do not speak up for themselves but suffer their pain in silence - often consulting five doctors or more without hope for a better life quality - action was needed. EURAG Austria is member of the Alliance Chronic Pain Austria (www.schmerz-allianz.at), founded two years ago.



Curlandgasse 22
A-1170 Vienna
Austria
www.eurag.at
eurag@eurag.at



Breite Gasse 4/7
1070 Vienna
Austria
Phone: +43 1 889 05 03
www.eaneurology.org
headoffice@eaneurology.org

44. European Academy of Neurology (EAN)

The European Academy of Neurology (EAN) alerts European neurologists on the societal impact of pain and advocates that pain needs research, resources and dedicated stakeholders of several professions making sure that those living with chronic pain are adequately helped.



Phone: +32 2 213 13 12
laure.sonnier@interelgroup.com

45. European ADPKD Forum (EAF)

The European ADPKD Forum (EAF), comprising experts and patients, is dedicated to improving the health and quality of life of people with autosomal dominant polycystic kidney disease (ADPKD) by contributing to health policy. Its 2015 report, "Translating science into policy to improve ADPKD care" and "Brussels Declaration on ADPKD" (supported by 31 organisations) are online: www.pkdinternational.org/eaf_adpkd_forum_policy_report_2015/.



Instituto Nazionale dei Tumori
Via Venezian 1
20133, Milano
Italia
www.eapcnet.eu
julie.ling@eapcnet.eu

46. European Association of Palliative Care (EAPC)

The European Association for Palliative Care (EAPC), established in 1988, is a membership organisation that aims to advance, influence, promote and develop palliative care in Europe. The EAPC is the leading palliative care organisation in Europe providing a forum for all of those working, or with an interest in, palliative care throughout Europe and beyond. Currently the EAPC has 55 member associations from 31 European countries and individual members from 48 countries globally. The EAPC is respectful of the cultural and political diversities of members across Europe and yet aims to speak with 'one voice-one vision' on matters important for the practice and development of palliative care.

47. European Brain Council

165 million Europeans are living with a brain disorder, causing a global cost (direct and indirect) exceeding 800 billion euros for the National Health budgets. EBC is a non-profit organisation gathering patient associations, major brain-related societies and industries. Established in March 2002, its mission is to promote brain research in order to improve the quality of life of those living with brain disorders in Europe. This is made through increased cooperation with EBC members organisations; promotion of dialogue between scientists, industry and society; interactions with the European Commission, the European Parliament and other relevant international institutions; raise in awareness and promotion of education on the brain; dissemination of information about brain research and brain diseases in Europe.



Rue d'Egmont 11
BE-1000 Brussels
Belgium
Phone: + 32 (0)2 513 27 57
www.braincouncil.eu
info@braincouncil.eu

E

48. European Cancer Patient Coalition (ECPC)

Established in 2003, ECPC is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups from the most common to the rare forms of cancer. ECPC is an independent, non-profit umbrella organisation bringing together 395 cancer patient organizations. ECPC interacts fruitfully with EU institutions and Member States, advocating the patients' perspective.



40, rue de Montoyer/
Montoyerstraat
B-1000 - Brussels
Belgium
Phone: + 32 (0) 2 342 01 04
www.ecpc.org
Twitter: @cancereu
Facebook Page: <https://www.facebook.com/ECPCfb/>

49. European College of Neuropsychopharmacology (ECNP)

ECNP is Europe's leading scientific association for applied and translational neuroscience, with a 30-year history of fostering research and education into the science of central nervous system disorders – from behaviour, cognition and emotion to memory, sleep and pain – and the development of improved treatments. ECNP endorses the scientific aims of the Societal Impact of Pain (SIP) 2016 Symposium to raise awareness of the relevance of the impact that pain has on our societies, health and economic systems; to exchange information and sharing best-practices (in pain policy making) across all member states of the European Union; and to develop and foster European-wide policy strategies and activities for improved pain care in Europe (Pain Policy).



PO Box 85410
3508 AK Utrecht
The Netherlands
Phone: +31 88 7569555
www.ecnp.eu
secretariat@ecnp.eu



30, Avenue Marnix
B – 1000 Bruxelles
Belgium
Phone: +39 (0)6 97840505
www.echo-eu.com
alberto.desantis@acho-eu.com

50. European Confederation of Care Home Organisations (E.C.H.O.)

The European Confederation of Care Home Organisations (E.C.H.O.) pursues mainly the following objectives:

- fair and reasonable terms among care providers in long term care sector
- high quality standards throughout Europe and a simultaneous reduction in bureaucracy
- recognition of elderly care sector as a productive economy factor.

E.C.H.O. has the pleasure and honour to endorse the scientific aims of the SIP symposium that will be in Brussels on May 23-24 2016.



Rue Antoine Dansaert 18
1000 Bruxelles
Belgium
Phone: + 41 79 946 38 43
Facebook: /EUDIPPA/

51. European Digital Peer Patient Alliance (EuDiPPA)

We are the next step; a well informed Digital consumer patient that knows all about the rules on IP , ICT, Genomics, Robotics, Informatics, Biometrics



ZA La Pièce 2
1180 Rolle
Switzerland
Phone: +41 21 343 4400
www.efort.org

52. European Federation of National Associations of Orthopaedics and Traumatology (EFORT)

EFORT works on behalf of the European orthopaedic and traumatology community to restore and secure mobility, musculoskeletal health and quality of life. It is the platform organisation linking Europe's national orthopaedic associations. Its aims reflect the will of all the participating associations to promote the exchange of scientific knowledge and experience in the field of prevention and both the conservative and surgical treatment of diseases and injuries concerning the musculo-skeletal system. To this end, particular emphasis is placed upon activities focusing on education and research.

53. European Federation of Neurological Associations (EFNA)



EFNA is an umbrella group representing pan-European neurology patient groups. Its slogan 'Empowering Patient Neurology Groups' encapsulates its goals as an Association. EFNA strives to add capacity to its Members – allowing them to be the most effective advocates possible in their own disease specific areas. EFNA embraces the concept of Partnership for Progress – working at a high level with relevant stakeholders from the fields of policy, medical, scientific/research, industry, patient partners and other key opinion leaders.

Gurteen
Johnstownbridge
Enfield, Co Meath
Ireland
Phone: +353 87 983 0816
www.efna.net
executivedirector@efna.net

E

54. European Headache Alliance (EHA)



EHA promotes awareness of migraine and other primary headache disorders to improve access to appropriate diagnosis and treatment. EHA co-ordinates efforts of national advocacy groups to voice views and concerns of headache patients and inform and influence policy makers.

Belgium
Phone: +35 38 78 29 99 26
www.europeanheadachealliance.org
generalmanager@europeanheadachealliance.org

55. European League Against Pain (EULAP®)



The European League Against Pain (EULAP®) is an international, multi-stakeholder platform in the field of pain advocacy. Members of EULAP® are organizations whose focus is improving pain management, like European and National organizations representing patients, European and National scientific societies, health care professional organizations, and other organizations with an interest in the field of pain management and advocacy.

Switzerland
www.eulap.org
eulap@eulap.org

Close ranks against pain!



www.enfa-europe.eu
contact@enfa-europe.eu

56. European Network of Fibromyalgia Associations (ENFA)

Promote Fibromyalgia awareness to politicians, physicians, scientists and the general public on a European level.



Rue du Commerce 31
1000 Bruxelles
Belgium
Phone: +32 2 280 23 34
www.eu-patient.eu
Twitter @eupatientsforum
Facebook: /
EuropeanPatientsForum

57. European Patients' Forum (EPF)

EPF is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe. Our members represent specific chronic disease groups at EU level or are national coalitions of patients.

Our vision is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

Our mission is to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

We coordinate best practice exchanges between patient organisations at European and national levels.



38-40 Square de Meëus
B-1000 Brussels
Belgium
Phone: +32 (0) 2 401 68 18
www.epposi.org
secretariat@epposi.org

58. European Platform for Patients' Organisations, Science and Industry (EPPOSI)

Founded in 1994, the European Platform for Patients' Organisations, Science and Industry (Epposi) is an independent, not-for-profit, partnership-based multi-stakeholder organisation based in Brussels, Belgium. Epposi's mission is to provide a consensus-driven multi-stakeholder perspective from European patient organizations, science and industry to improve European public health outcomes.

59. European Society of Regional Anaesthesia and Pain Therapy (ESRA)



ESRA was founded in 1980 to further regional anaesthesia in Europe. The first congress was held in Edinburgh in 1982 and since then the society strengthened, with a current membership of over 3,500 throughout Europe, a track record of over 30 Annual Congresses, and the upcoming 35th one taking place in 2016 in Maastricht, The Netherlands. The scientific standard of the annual congress is recognised as one of the best in Europe with a high rating in the Accreditation Council for Continuing Medical Education, which assigns credit hours to all ESRA congresses. The society also holds eight to ten zonal meetings each year, and provides grants and educational material through the ESRA Academy online platform. The European Diploma in Regional Anaesthesia & Pain Therapy, created in 2005, aims to establish standards in regional anaesthesia in Europe. The European Diploma in Pain Medicine Management was created to harmonize and improve quality standards for safe, independent practice of pain medicine in Europe and elsewhere. The Diploma Program assesses the minimal competencies of anesthesiologist, as specialist part of multidisciplinary team, necessary to practice as a pain medicine specialist.

Avenue Florimont 4
1006 Lausanne
Switzerland
Phone: +41 22 510 56 10
office@esraeurope.org
esraeurope.org

F

60. Fibromyalgia Association of Sweden



The Fibromyalgia Association of Sweden is a national patient organization dedicated to improving the situation for people suffering from fibromyalgia. An important part of our work is to try to influence politicians and policy makers, and also to raise awareness of fibromyalgia among the general population, as well as within the medical community.

Fibromyalgiförbundet
Jordhyttegatan 11
S- 414 73 Göteborg,
Sweden
Phone: +4631414408
www.fibromyalgi.se
johanna.spetz@fibromyalgi.se

61. Fit for work Global Alliance



Chronic musculoskeletal pain affects at least 100 million people in Europe and is yet undiagnosed in over 40% of cases. Musculoskeletal disorders (MSDs) account for half of all absences from work and for 60% of permanent work incapacity. Fit for Work Global Alliance is a multi-stakeholder Coalition, driving policy and practice change across the work and health agendas. We aim to deliver more investment in sustainable healthcare by promoting and implementing early intervention practices. Research shows this approach is the most effective way of ensuring people with MSDs can enter and remain in work across the EU and globally.

21 Palmer Street
London SW1H 0AD
United Kingdom
Phone: +44 (0)207 976 3500
www.fitforworkeurope.eu
info@theworkfoundation.com

Fibromyalgie



Rue Frérot, 30
7020 Mons
Belgium
Phone : +32 474 821 104
Hotmail line: +32 60 37 88 58
www.focusfibromyalgie.be
gestionsecretariat@focusfibromyalgie.be

62. FOCUS Fibromyalgie Belgique asbl

Created in 1998, Focus Fibromyalgie Belgique ASBL (formerly LBFPF) is based on the wish to support the many people living with fibromyalgia, their families and caregivers and the aim of developing a legal framework for the benefit of patients.



Via Venezian 1,
20133 Milano
Italy
Phone: +39 02 2390 1
www.istitutotumori.mi.it

63. Fondazione IRCCS - Istituto Nazionale dei Tumori di Milano (National Cancer Institute of Milan)

The National Cancer Institute of Milan Scientific direction endorses the SIP initiative supporting the inclusion of cancer pain control in the global actions against cancer, the facilitation of scientific research on cancer pain relief and advocating European policies focusing on a common strategy to identify quality of life as one goal of cancer control programs within the collaboration between different specialties in oncology and palliative care.

Giovanni Apolone Scientific Director
Augusto Caraceni Director Palliative Care Pain and Rehabilitation



Via San Salvador, 204
47922 Torre Pedrera di Rimini,
RN
Italy
Phone: +39 0541 725166
www.fondazioneisal.it/en/
isal@fondazioneisal.it

64. Fondazione ISAL

ISAL was established in Italy in 1993 as the first European Institute providing training in algological science. ISAL promotes knowledge, scientific research and training in the field of pain therapy. Today, ISAL is a leading pain association in Italy, thanks to its widespread support network.

65. Fondazione ISTUD



The ISTUD Foundation is happy to endorse SIP 2016.

Strada Nazionale del Sempione
Oltrefiume, 25
28831 Baveno (VB)
Italy
Phone: +30 323 933 801
www.fondazioneistud.it
info@istud.it

F

66. Fondazione Paolo Procacci



Understanding and curing pain to help improve the quality of life of patients affected by chronic pain. To defend the right of pain relief as a fundamental Human Right. The patient with chronic pain has the right to be understood, to receive professional support and optimal pain management.

The Paolo Procacci Foundation (FPP) is a non profit organization created in 2008 to promote and support all sort of initiatives that advance prevention, early diagnosis, cure and related social services for illness called "pain" and connected symptoms.

Via Tacito 7
00193 Roma
Italy
Phone: +39 339 6195974
www.fondazioneprocacci.org
info@fondazioneprocacci.org

67. Foreningen Af Kroniske Smertepatienter (FAKS, Danish Association for Chronic Pain Patients)



Chronic pain is often complex and individual involving bio-psycho-social elements. The current health system poses both structural and training issues we need to improve in order to facilitate a more successful interdisciplinary approach and treatment.

Filosofvænget 7, 3.
København NV, 2400
Denmark
Phone: +45 61 27 40 47
www.faks.dk
faks@faks.dk



Velázquez, 59 – 3º dcha.
28001 Madrid
Spain
www.fuinsa.org
secretaria@fuinsa.org

68. Fundación para la Investigación en Salud (FUINSA, 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. 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.



ul. Ksawerów 3
02-656 Warsaw
Poland
Phone: +48 734 437 680
www.fundacjachustka.pl
biuro@fundacjachustka.pl

69. Fundacja Chustka

Chustka Foundation has been established to support people living in pain. Our primary goal is to establish and maintain contacts with patients and their families and educate them about their pain control options.

The second area of our operations is focused at educating and informing the public that the pain treatment concept is both possible and necessary. We accomplish it through media campaigns, direct contacts, and provision of support to the organizations involved in pain management.



Calle Sant Antoni Maria
Claret, 171 4ª planta
08041 Barcelona
Spain
www.universidadpacientes.org
www.fsie.cat universitat.pacients@uab.cat
[@Upacientes](https://twitter.com/Upacientes)

70. Fundació Salut i Envel·liment de la UAB – Universidad de los Pacientes (Health and Ageing Foundation of the Autonomous University of Barcelona)

The Fundació Salut i Envel·liment UAB is a non-profit organization fostered by the Universitat Autònoma de Barcelona, with the mission of promoting knowledge improving population's health and aging process, as well as contributing to professional and health organizations development. It carries out Research, Citizens and Professionals Training, Knowledge Management and also provides Consulting and Technical Support to Public Policies and Services.

The Fundació aims to become a national and international reference center in the field of Health and Ageing Process for Research, Knowledge Management and Citizens and Professionals Training. Therefore its vision is to promote knowledge to improve health and aging process.

71. Geriatric Medicine Society e.V.

Pharmaceutical products have to meet the needs of any patient. They need to be designed for the targeted patient population to ensure appropriate usability, drug safety and effectiveness. This is even more important for treatment of pain and the disabilities caused by pain.

Geriatric
Medicine
Society

Franz-Wallraff-Str. 128
52078 Aachen
Germany
www.geriatric-medicine.org
sven.stegemann@capsugel.com

G

72. German-Maltese Medical Society (GMMS)

The German-Maltese Medical Society (GMMS) was founded in 1999 under the patronage of the German-Maltese Circle. 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 and educational programmes for postgraduate medical training
- Teaching courses in public speaking, moderation and especially presentation of medical data in English for international congresses
- Exchange programmes for training, tutorials, hands-on live surgical demonstration
- Exchange programmes for students and for children of GMMS members
- Support of clinical studies (Clinical Traineeship / Internship Scheme for Maltese Medical Students)



Messina Palace, 141
Triq San Kristofru
Valletta
Malta
K.-H. Oedekoven.
Turmblick 7,
D-52222 Stolberg, Germany
www.germanmaltesecircle.org
gmms@germanmaltesecircle.org





73. Hellenic Society of Algology

4-6 Makrinitas
11522 Athens
Greece
Phone: +30 210 642 1700
or +30 210 644 4174
www.algologia.org
info@algologia.gr

The Hellenic Society of Algology endorses with great pleasure the “Societal Impact of Pain”.



74. Hereditaire Multiple Exostosen – Multiple Osteochondromen (HME-MO)

The Netherlands
<http://www.hme-mo.nl>
info@patientennaar1stem.nl

HME-MO is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



75. International Association for Hospice and Palliative Care (IAHPC)

5535 Memorial Dr. Suite F -
PMB 509
Houston TX 77007
USA
Phone: +1 (936) 321-9846
Toll Free: +1 (866) 374 2472
www.hospicecare.com
Lukas.Radbruch@malteser.org

The International Association for Hospice and Palliative Care (IAHPC) is a non for-profit organization. Its mission is to collaborate and work to improve the quality of life of patients with advanced life-threatening conditions and their families, by advancing hospice and palliative care programs, education, research, and favourable policies around the world. It has worldwide approach, with members from all regions of the World. Its programs and projects have the capability of making an impact at all levels. It collaborates with existing organizations at the global, regional and local levels.

76. International Headache Society (IHS)



The International Headache Society (IHS) is a multidisciplinary scientific society which was founded to improve research and clinical management of headache disorders worldwide. IHS publishes the scientific journal *Cephalalgia* 14 times per year and the International Classification of Headache Disorders, and organises the bi-ennial International Headache Congress. In Europe, IHS is represented in nearly all countries; it co-operates closely with the European Headache Federation and the European national headache societies.

52-53 Russell Square
London, WC1B 4HP
UK
Phone: +44 1629 733406
www.ihs-headache.org
carol.taylor@i-h-s.org

77. International Painful Bladder Foundation (IPBF)



The International Painful Bladder Foundation (IPBF) is a voluntary non-profit organisation that raises awareness of Interstitial Cystitis/Bladder Pain Syndrome, Hypersensitive Bladder, Chronic Pelvic Pain and comorbidities worldwide by means of its website, e-newsletter, publications and presentations, with the aim of ensuring that patients worldwide get the right diagnosis and have access to the right treatment and care. The IPBF helps support groups get started and provides them and existing groups with the latest information on developments. The IPBF plays an advisory role, stimulates and participates in research and international discussions and encourages international cooperation.

Mahlerlaan 4
1411 HW Naarden
The Netherlands
Phone: 31(0)35 8879516
www.painful-bladder.org
info@painful-bladder.org

78. Irish Pain Society



The Irish Pain Society believes that every individual suffering from a chronic pain condition has the right to access appropriate information for the better understanding of his/her condition. It believes all patients should have access to the highest possible standard of care, from appropriately trained clinicians, in facilities adequately equipped to meet their needs.

The society endeavours to promote public awareness of persistent pain as a chronic illness, which seriously impacts quality of life for patients and their families. The society believes that greater recognition and understanding is required at government level so that greater resources are made available to meet the needs of patients suffering from this condition.

22 Merrion Square, North
Dublin 2
Ireland
www.irishpainsociety.com
odoran@coa.ie



Pain Clinic
Tel Aviv Medical Center
Weizman 6
84516 Tel Aviv
Israel
www.ipa.org.il
silviub@tasmc.health.gov.il

79. Israel Pain Association

The IPA Israel Pain Association is a multidisciplinary professional organization in the field of pain science and medicine. IPA is the Israeli chapter of IASP.

IPA is happy to endorse SIP 2016.



40 Maskavas street
Riga
LV - 1050
Latvia
dr.mihailsarons@gmail.com

80. Latvian Association for Study of Pain (LASP)

The Latvian Association for Study of Pain is happy to endorse SIP 2016.



R. Quinta do Loureiro, 13,
Loja-2
Lisbon, 1350-410
Portugal
Phone: +351 21 36 48 776
www.lpcdr.org.pt
lpcdr@lpcdr.org.pt

81. Liga Portuguesa contra as Doenças Reumáticas (LPCDR, Portuguese League against Rheumatic Diseases)

When 30% of Portuguese suffers from chronic pain we have to take control.

In Patient Group of Chronic Pain, (LPCDR, 2014), we want to preserve the dignity and well-being; manage its impact and take control, cooperate/disseminate action-driven good practices, disclose, inform, raise public awareness and call to action; and identify scientific & therapeutic approaches.

82. Liga Reumatológica Española (LIRE, Spanish Rheumatological League)

Since its incorporation as a non-profit association in 1973, LIRE is conducting a major task for raising awareness about rheumatic and musculoskeletal diseases (RMDs). Its particular purpose is to promote and develop the fight against RMDs and their consequences both at individual and social level. LIRE develops and promotes educational activities aimed at prevention and prophylaxis of RMDs, treatment and rehabilitation as well as assistance and relief for those affected by these diseases, in accordance with statutory and regulatory provisions relating to the subject.



Calle Hilarión Eslava, 2
28015 Madrid
Spain
Phone: +34 911 25 01 50
www.lire.es
lire@lire.es

83. Liga Reumatológica Galega (LRG, Galician Rheumatological League)

LRG is a non-profit organization formed by people with rheumatological disease, their relatives and professionals who work with the aim of providing support and advice to the persons affected by a rheumatic disease and their families.

Since its formation in 1996, its activity is directed at improving the quality of life of people affected by any type of rheumatic disease. LRG represents the group of people affected by these diseases against the government and in society, in order to sensitize the public authorities and institutions, of the importance of research on new treatments to combat these illnesses. It is called League instead of Association, because it encompasses the more than 200 existing rheumatic diseases.



C/Venela s/n . Centro social
"A Silva"
15010 A Coruña
Spain
Phone: +34 981236586
www.liga-reumatologica-galega.webnode.es
info@ligagalega.org
Facebook: LigaReumaGalega
Twitter: @ligareumagalega

84. Lithuanian Pain Society (LDS, Lietuvos Skausmo Draugija)

Lithuanian Pain Society (LPS) is non-governmental association of healthcare professionals and others dealing with clinical and theoretical pain problems. The first LPS Congress was held in 1998, the Society has 64 members.

Each year LPS organizes annual meeting, and the conference related to the topic of Global year against pain. In 2001-2010 the society was an organizer of "October week against pain" campaign initiated by European Pain Federation (EFIC). LPS has received two grants - from IASP and from EFIC. LPS publishes the magazine "Skausmo medicina".



Mickevičius 9
Kaunas 44307
Lithuania
Phone: +370 (37) 333514
www.skausmomedicina.lt
skausmo@medicina.lt



c/Llibertat, 48, baixos.
08012 Barcelona
Spain

www.lligareumatologica.org
lalliga@lligareumatologica.org
Facebook: [lligareumatologica](https://www.facebook.com/lligareumatologica)
Twitter: @llicat

85. Lliga Reumatològica Catalana

The Lliga Reumatològica Catalana, is a non-profit association, declared of Public Utility, formed of people affected by one or more rheumatic diseases, their family and friends.

Our goals are to raise awareness about these diseases, inform and educate people living with them, provide activities and services that help the self-empowerment and responsibility for the managing of the day-to-day disease, as well as represent the people of this collective to improve their quality of life and social inclusion, transferring their concerns and defending their rights before the various administrations and competent authorities. Ultimately, be the VOICE of all the people with any of the different rheumatic diseases.



Malta Association of
Physiotherapists

The Professional Center
Sliema Road
Gzira, GZR1633
Malta
Phone: (+356) 21312417
www.physiomalta.com
secretariat@physiomalta.com

86. Malta Association of Physiotherapists (MAP)

Founded in 1974, the Malta Association of Physiotherapists (MAP) is the sole voluntary organisation representing the physiotherapy profession in Malta and Gozo. We aim to advance and expand the scope of physiotherapy, ultimately optimising the level of care experienced by the Maltese citizen.

The MAP is in support of a more holistic and multi-disciplinary approach towards the treatment of the person in pain.



PO Box 2,
Qormi Rd
MARSA, MRS 1000
Malta
Phone: +356 99 87 32 13
www.maltahealthnetwork.org
info@maltahealthnetwork.org

87. Malta Health Network (MHN)

MHN was set up in 2007 with the aim of representing in the interests of patients and the health of the community. Since 2013 MHN has been collaborating with various entities on the topic of chronic pain and has promoted in Malta the International Day Against Pain.

88. ME/CVS-Stichting Nederland



ME/CVS-Stichting Nederland is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.

The Netherlands
www.mecvs.nl
info@patientennaar1stem.nl

89. Moldovan Society for the Study and Management of Pain



The pain is not a fatality. Let's manage it. Together we'll win!

The aim of Moldovan Society for the Study and Management of Pain is the contribution to the public health quality improvement through promotion of education, theoretical and practical knowledge and research in pain field for medical and extra medical areas.

41-29/2, Roses street
Chisinau, MD 2038
Moldova, Republic of
Phone: +373 22212111
www.neverpain.org
adrian_belii@hotmail.com

M

90. Myeloma Euronet Romania (MAR)



Myeloma Euronet Romania (MER) is actively involved in advocating for the rights of the patients both at the national and European level. MER is one of the founding members of Pain Alliance Europe and a full member of several European patients organizations such as ECPC, MPE and EURORDIS.

Calea Victoriei 194
010097 Bucharest
Romania
www.myeloma.ro
viorica@myeloma.ro



Untere Burg 21
53881 Euskirchen
Germany
Phone: +49 163-908 44 93
www.mica-online.org
info@ica-ev.de

91. Multinational Interstitial Cystitis Association (MICA)

MICA was created in 2006 to encourage and support international cooperation between patients support groups in the field of painful uro-gynecological diseases such as Interstitial Cystitis, Overactive bladder (OAB), vulvodynia, chronic pelvic pain (CPP), Chronic prostatitis and diseases associated with these. First intended to be a worldwide umbrella association, it decided in 2009 to focus on cooperation between European countries and to set up regular meetings and concrete actions.

MICA's objectives are to advocate for better treatment throughout Europe for interstitial cystitis, better knowledge of the condition, and to encourage research and cooperation.



4th Floor, Hospice House
34-44 Britannia Street
London
WC1X 9JG
Phone: +44 20 7697 1520
www.ncpc.org.uk
p.casbon@ncpc.org.uk

92. National Council for Palliative Care (NCPC)

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.

Since 2009 NCPC has led the Dying Matters coalition. Dying Matters is a coalition of 32,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. Its membership includes hospices, care homes, NHS organisations and staff, GPs, funeral directors, the legal sector, charities, faith groups and many more.



Noordse Bosje 16, 1211 BG
Hilversum, The Netherlands
Phone: +31 356220612
fes@fesinfo.nl
www.fesinfo.nl
Twitter: @fesalgemeen
Facebook: /Fibromyalgie-
Patienten-Vereniging
Google: /+FibromyalgiePatienten
Vereniging
LinkedIn: /company/
fibromyalgie-en-samenleving

93. Nationale vereniging voor Fibromyalgie-patienten, "Fibromyalgie en Samenleving" (F.E.S.)

The mission of the F.E.S. is: Stand for the interest of anyone who is direct or indirect involved with Fibromyalgia. In order to live to that mission we made up 6 main objectives in order to improve the quality of life of people living with Fibromyalgia: encourage fellow sufferers contact, provide information for patients, provide information for healthcare professionals, raising national awareness, encourage research on Fibromyalgia and keep informed on medical and legal developments.

94. National Institute of Health and Disability Insurance (NIHDI)

Our department focuses on development of tools to stimulate RTW (eg. system of progressive reintegration and a collaboration with partners to offer education to update/acquire competences) and on supporting research to guide policy (specific for pain we have several research projects with focus on the trajectory to work, communication, early intervention, transmurality, etc.).



Tervurenlaan 249
1150 Brussels
Belgium
Phone: +32 2 739 76 44
www.riziv.fgov.be
Francois.perl@inami.fgov.be

95. Nederlandse Vereniging van Hoofdpijnpatiënten

Nederlandse Vereniging van Hoofdpijnpatiënten is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



The Netherlands
www.hoofdpijnpatiënten.nl
info@patientennaar1stem.nl

N

96. Nederlandse Vereniging van Patiënten met Sternocostoclaviculaire Hyperostose (SCCH)

SCCH is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



The Netherlands
www.scch.nl
info@patientennaar1stem.nl



95, Old College Street Level 1
SLM 1379
Sliema
Malta
www.nopainfoundation.org
info@nopainfoundation.org

97. No Pain Foundation

No Pain Foundation (NPF) has been established in Malta at the end of 2014 by Silvana Fanalista and Mauro Mario to create an international non-profit organisation for the purpose of carrying out social, educational as well as research and development activities in the field of pain management and pain therapies. No Pain Foundation aims to influence health related policies and practices for the welfare of the patients suffering from chronic pain. All of the foundation's activities and events are aimed at improving quality of life of patients suffering from pain. Indeed NPF is always prompted to support European activities, which aims to improve quality of life of citizens.



Av Montevideu 500 – 1º
4150-516, Oporto
Portugal
Phone: +351 225084000
www.ipoport.pt

98. Oporto Portuguese Institute of Oncology (IPO Porto)

Quality – to assure high quality of clinical care.
Integrity – patients and professionals should be treated with dignity and respect.
People – people and professionals are the hospital's most valuable resources.
Excellence – planning based on community needs, continuous improvement and audit
Community – Decision making is to be made in partnership with the community to effectively reduce its environmental impact.



The Netherlands
www.osteoporosevereniging.nl
info@patientennaar1stem.nl

99. Osteoporose Vereniging

Osteoporose Vereniging is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.

100. Österreichische Gesellschaft für Geriatrie und Gerontologie (ÖGGG, Austrian Society for Geriatrics and Gerontology)



The Austrian Society for Geriatrics and Gerontology was established in 1955. It is a non-profit organization, a scientific association with the aims of promoting research of aging and of geriatric and gerontologic knowledge.

The Society is happy to endorse SIP 2016.

Präsidentin:
Prim. Dr. Katharina Pils
SMZ-Sophienspital
Apollogasse 19
1070 Vienna
Austria
www.geriatrie-online.at
ilse.howanietz@extern.wienkav.at

101. Österreichische Schmerzgesellschaft (ÖSG, Austrian Pain Society)



It is among the main objectives of the Austrian Pain Society (Österreichische Schmerzgesellschaft, ÖSG) to unite all pain researchers in Austria and to improve the conditions for scientific activities in this field. However, the promotion of comprehensive and structured pain care throughout the country, as well as training and education in the field of pain medicine are among our priorities. We need to join forces in order to advance the process of optimizing pain care and pain management for all patients in need.

Liechtensteinstr. 46a
A-1090 Wien
Austria
Phone: +43 1 319437843
www.oesg.at
office@oesg.at





The Stables
2A Maryville Park
Belfast
County Antrim, BT9 6LN
Northern Ireland
pamela.bell@notebook.myzen.
co.uk
Twitter: @PainAllianceNI

102. Pain Alliance of Northern Ireland (PANI)

The Pain Alliance of Northern Ireland was established in 2008 by a group of clinicians who were concerned that the current Health and Social Care services for those who lived with long term pain were not fit for purpose and had a very low priority for investment and development. The organisation's aims are to raise awareness of the burden of long term pain on people, our society and on our healthcare and wider economy.



Suite D, Moncrieffe Business
Centre
Friarton Road
Perth, PH2 8DG
United Kingdom
Phone: + 44 (0)1738 629503
www.chronicpaininfo.org
scottom@painassociation.com

103. Pain Association Scotland

Self-Management training and learning for people with Chronic Pain.

Our main focus is to help the significant numbers of people who suffer from the debilitating effects of chronic pain irrespective of diagnosis; by introducing them to and quickly enabling them to apply self-management strategies and coping skills.



Post Office Box 770
Waverley NSW 2024
Australia
www.painaustralia.org.au
lesley.brydon@painaustralia.
org.au

104. Painaustralia

Painaustralia's strategic plan has six principles that guide our work to improve healthcare for people living with pain:

1. Recognition of chronic pain as a complex multi-dimensional chronic condition in its own right
2. Assessment and treatment of chronic pain must address the physical, psychological and environmental/social factors that play a key role in chronic pain
3. Person centred care for chronic pain at all levels of the health system
4. Rights and validation of the person in pain and recognition of their families and carers
5. Whole of community awareness and responsibility to support people with chronic pain
6. Intervention at an early stage of transition from acute (e.g. postoperative) pain to chronic pain

105. Pain Concern

Pain Concern is a charity working to support and inform people with pain and those who care for them, whether family, friends or healthcare professionals.



painconcern.org.uk

United Kingdom

www.painconcern.org.uk

info@painconcern.org.uk

106. Pain Nursing Magazine – Italian Online Journal

Pain Nursing Magazine, Italian online Journal is published by the Paolo Procacci Foundation and it's the first publication for nurses completely dedicated to Pain Patients and to those taking care of them, Nurses as well as Physicians. 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.



Italy

www.painnursing.it

redazione@fondazioneprocacci.org

org

107. 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 7th Framework Program, PAINOUT started with 17 clinical and research partners in 9 European countries. By end of 2015, more than 200 hospitals have joined PAIN OUT or its German counterpart QUIPS, having collected more than 450,000 datasets. PAIN OUT created an Acute Pain Registry and developed tools for data collection, feedback and benchmarking. It provides the medical community with a unique, web-based, user-friendly system to improve treatment of patients experiencing postoperative pain. Furthermore, it provides a large platform for observational and prospective research.

PAIN OUT is endorsed by the International Association for the Study of Pain and is an official research group of the European Society of Anaesthesiology. Its coordination and project management is done by Prof. Winfried Meissner and his team at Jena University Hospital.



Jena University Hospital

Dept. of Anesthesiology and

Intensive Care Medicine

Erlanger Allee 101

07747 Jena

Germany

www.pain-out.eu

[winfried.meissner@med.uni-](mailto:winfried.meissner@med.uni-jena.de)

[jena.de](http://www.pain-out.eu)



Harvard NeuroDiscovery Center
Goldenson Building, Room 524
Harvard Medical School
220 Longwood Ave.
Boston, MA 02115
USA
Phone: +1 617-462-5202
www.painresearchforum.org
editor@painresearchforum.org

108. Pain Research Forum

The Pain Research Forum (PRF) is an interactive web community dedicated to finding treatments for untreatable pain conditions. PRF serves as a virtual meeting place for investigators in academia, industry, medicine and other fields who are working to translate basic neurobiology into new treatments for chronic pain. The ultimate goal of the site is to help researchers to speed the rendering of new knowledge into novel therapies by improving information sharing between labs and the clinic, by fostering new collaborations among researchers, and by raising interest in pain research among a wider community of scientists and clinicians.



South Africa
www.painsa.org.za
painsa@global.co.za

109. Pain South Africa (PainSA)

PainSA is the national chapter of the International Association for the Study of Pain (IASP) in South Africa. The society's mission is to improve pain management in all its aspects in Southern Africa by promoting education and inter-disciplinary co-operation amongst healthcare professionals managing pain, developing management guidelines that are locally relevant, and promoting local pain research.



United Kingdom
Phone: +44 (0)7811 222 044
www.paintoolkit.org
pete.moore@paintoolkit.org
Twitter: @paintoolkit2

110. Pain Toolkit

"The Pain Toolkit is an educational and training organisation working mainly in primary, acute and social care promoting active self-management to help and support the reduction of persistent pain via workshop and on the Internet."

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.

111. Pain UK

Pain UK aims to improve the quality of life for people living with pain in the UK. Its objectives are:

- To ensure that the voice of people living in pain is heard and to raise awareness of the burden of pain on individuals and society.
- To provide signposting to a comprehensive information resource for those living in pain as Pain UK and in partnership with our member charities.
- To work together with our member charities to improve their efficiency and effectiveness and to develop a strong united voice to identify the barriers in order to improve the quality of life for people in pain.



c/o SSS, 41 North Road
London, N7 9DP
United Kingdom
<https://painuk.org>
info@painuk.org
Twitter: @pain_uk

112. Palliatives Netzwerk für die Städteregion Aachen (Network Palliative Care in the Region of Aachen)

The Network Palliative Care in the Region of Aachen is a non-profit organization, which founded in 2008. The association has about 60 members, all institutions of public health Care. Together they see their common task to improve the care of the end of life in the region in the west of Germany.



Adalbertsteinweg 257
52066 Aachen
Germany
Phone: +49 (0)2415153490
www.servicestellehospizarbeit.de
info@servicestellehospizarbeit.de

P

113. Patiëntenvereniging CRPS

Patiëntenvereniging CRPS is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



The Netherlands
www.posttraumatischedystrofie.nl
info@patientennaar1stem.nl



The Netherlands
www.pvvn.nl
info@patientennaar1stem.nl

114. Patiënten Vereniging Voor Neurostimulatie (PVVN)

PVVN is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



PO BOX 6559, Poole
Dorset, BH12 9DP
United Kingdom
Phone: +44 1202 603447
www.pelvicpain.org.uk
info@pelvicpain.org.uk

115. Pelvic Pain Support Network

A significant proportion of those with chronic pain suffer from long term pelvic/abdominal pain. Those with pelvic/abdominal pain have been neglected either because they are undiagnosed or their condition is considered 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 and deserves to be given far more attention.



Postbus 2254
2301 CG Leiden
The Netherlands
www.pijnplatform.nl
info@pijnplatform.nl

116. Pijn Platform Nederland (PPN, Dutch Pain Cooperation)

The PPN is a non-profit, volunteer organisation. One of the goals is to accomplish cooperation 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.

117. Plataforma SinDOLOR

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.

**PLATAFORMA
SinDOLOR**

C/ Velazquez, 59 – 3o drcha.
28001 Madrid
Spain
www.plataformasindolor.com
comunicacion@plataformasindolor.com

118. Polish Myeloma Patient Help Association

Our goal is to provide Multiple Myeloma patients and their families with information, treatment possibilities and hope. We do not stop in our efforts to make new drugs and therapies available to patients in Poland and now, also in Europe. We are united, Our voice is heard worldwide.

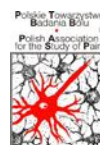


Elbląska 5
Olsztyn, 10-049
Poland
Phone: +48 791660922
www.szpiczak.org.pl
rafal.zebrowski.pl@gmail.com

119. Polskie Towarzystwo Badania Bolu (PTBB, Polish Association for the Study of Pain)

The Polish Association for the Study of Pain, Polish Chapter of IASP, was founded in 1991 as a professional organization to promote research, education and pain treatment. At the end of 2015 there were 580 members of various medical and non-medical specialties.

The main objectives of the organization are initiating and supporting research on the mechanisms, symptomatology and treatment of pain; integrating basic scientists, medical doctors of various specialties and other health care professionals interested in pain medicine; promoting the current advances in diagnosis and treatment of pain.



Śniadeckich str. 10
31-531 Krakow
Poland
www.ptbb.pl
andrzej.basinski@wp.pl



The Netherlands
www.pdsb.nl
info@patientennaar1stem.nl

120. Prikkelbare Darm Syndroom Belangenvereniging

Prikkelbare Darm Syndroom Belangenvereniging is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



Bazhdarhana 2, kulla 4/602
20000, Prizren
Kosovo
www.pha-ks.com/en
info@pha-ks.com

121. Professional Health Association (PHA)

PHA is one of the largest professional associations multidisciplinary for treatment of pain in Kosovo. It includes health professionals actively involved in the diagnosis and treatment of pain.

For future development of pain services there are some challenges and opportunities: the allocation of sub-specialization or specialization for pain specialist by the specializations committee in the MOH, the establishment of counselling for patients with pain, the opening of public centres for the diagnosis and treatment of chronic pain. A good opportunity to improve this situation is to insert the subject of "Pain and its Management" in secondary middle schools of medicine, as well as in the University of Prishtina, Faculty of Medicine.



Avda Buenos Aires, 5-6 – 1º B-C
15004 A Coruña
Spain
Phone: +34 981 916 082
redespdlorssc@gmail.com
Facebook: Red Española de FM,
SFC, SQM

122. Red Española para Defensa de los Enfermos (RED FM-SFC-SQM)

The Spanish Network for the defence of Sufferers of Fibromyalgia, Chronic Fatigue Syndrome, & Multiple Chemical Sensitivity, was created to reach the people affected by the mentioned illnesses living beyond the borders of the regional autonomy of Galicia.

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.

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.

123. RSI-vereniging

RSI-vereniging is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



The Netherlands
www.rsi-vereniging.nl
info@patientennaar1stem.nl

124. Russian Association for the Study of Pain (RASP)

The RASP founded in 1990 is the voluntary self-directed non-for-profit public organization combining all specialists, involved in Pain Medicine in Russia. Its objectives are 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.



11, Rossolimo St.
Moscow, 119021
Russian Federation
Work Phone: +79 03 68 61 815
www.painrussia.ru
mchurukanov@gmail.com



R



Weezenhof 2972
Nijmegen, 6536HP
Netherlands
Phone: +31 (0)24 34422374
www.pijnpatientennaar1stem.nl
ilonathomassen@
pijnpatientennaar1stem.nl

125. Samenwerkingsverband Pijnpatiënten naar een stem (Pain Patients with One Voice)

With the collective action group Pain Patients With One Voice, people suffering from chronic pain are able to speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government. There are 17 patient organizations member of this collective action group.



Passeig Sant Joan de Déu n° 2
Barcelona
Spain
Phone: +34 677595929
www.hsjdbcn.org
egomeez@hsjdbcn.org

126. Sant Joan de Deu Hospital

Sant Joan de Déu Children's Hospital has opened an innovative line to incorporate the program "Hospital without pain in minor procedures" as cures, punctions or the withdrawal of catheter. The objective is to prevent and minimize the pain and discomfort in children when they are subjected to potentially painful clinical procedures.

Methodology:

The program includes a wide range of pharmacological and non-pharmacological methods adapted to each child.

1. The administration of analgesics such as ointments, syrups, drops...
2. The effectiveness of distraction as a powerful tool to combat the fear and pain, by "Kit distraction": and so to direct attention away from the pain and focus on pleasing elements. Everything is useful: talk to the kid, singing pampered.
3. The presence of parents: Family are actively involved and present during the procedures. Health professionals encourage parents to hold their children with comfort positions, to facilitate the development of the procedure and combat anxiety of the patient, family and professionals.
4. The positive reinforcement: Reinforcing positive behaviour of the child is essential to streamline procedures and achieve the objectives of reducing pain and anxiety during procedures

Results:

- The children's game and other strategies provide relaxation and adaptation in the children for minor procedures
- Increase good relation with patients and families
- The patients feel real stars
- Minor procedures are more successful when use holistic treatments

Conclusions:

- Hospital works transversely through a network of professionals who help to meet the needs of patients and work initiatives proposed
- Professionals use a language adapted to age and procedures of children
- Professionals have training programs to increase knowledge
- The Professionals systematically apply all the resources available to assess whether patients are suffering pain
- Pain can occur in any process not only in the more complex interventions



127. Servicestelle Hospizarbeit für die Städte Region Aachen (Palliative Network for the Region 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 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 centre of all actions. This requires 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.

Adalbertsteinweg 257
52066 Aachen
Germany
Phone: +49 (0) 241-5153490
www.servicestelle-hospizarbeit.de
info@servicestellhospizarbeit.de

128. Shingles Support Society



Shingles is a recurrence of chickenpox. The Shingles Support Society empowers the patient with the information needed to get the correct treatment from their doctors. Referral to Pain Clinics (tertiary services) is slow and sometimes not available (cost) therefore giving the patient information to show the GP can make a major difference to the outcome of their disease. During the last three years, a vaccine to prevent shingles has been available to more and more people between 70-79 years. The Shingles Support Society has been working to increase awareness of this vaccine so as to improve take-up. Preventing herpes zoster could remove an important source of pain in the older patient.

41 North Road
London, N7 9DP
United Kingdom
Phone: +44 020 7607 9661
www.herpess.org.uk/shingles-support-society
marian@hva.org.uk

129. Slovak Society for Study and Treatment of Pain (SSSTP)



S

Chronic pain is a specific healthcare problem, a disease in its own right.

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 European against pain campaigns. The SSSTP officially endorses and completely supports enclosed SIP 2016 document.

Department of Chronic Pain
Management, Martin University
Hospital Kollarova 2,
03659 Martin
Slovakia
Phone: +421434203850
www.pain.sk
kulichova@mfnsk



130. Slovensko združenje za zdravljenje bolečine (SZZB, Slovenian Association for Pain Management)

Ljubljanska 5
2000 Maribor
Slovenia
Phone: + 386 (0)2 321 15 36
or + 386 (0)2 321 15 68
www.szzb.si
nevenka.krcevski.skvarc@amis.net

The Slovenian IASP chapter (SZZB) would like to endorse the objectives of the 2016 symposium on the "Societal Impact of Pain" SIP 2016, which will take place on May 23-24 2016 in Brussels. SZZB promotes management and general knowledge of pain. Pain is a significant factor in our society influencing the well being and quality of life.



131. Sociedad Andaluza de Geriatria y Gerontología (SAGG)

Ilustre Colegio Oficial de
Médicos de Málaga
Calle Curtidores, 1
29006 Málaga
www.sagg.org
secretaria@sagg.org

The goals of this Society are:

1. To promote the current knowledge of the human ageing process, by means of clinic observation and research which may be performed upon living organisms, as well as socioeconomic researches.
2. To gather researchers and clinicians studying aging problems in order to connect them to the International Society of Gerontology.
3. To direct and assess problems related to medical and social welfare services concerning aging.
4. To conduct campaigns on protection and prevention of aging and aimed at improving the quality of life of elderly people.
5. To design and promote trainings and continuing education on aging sciences.
6. To use possibilities granted by new information and communication technologies.



132. Sociedad Asturiana de Medicina Física y Rehabilitación (SAMEFYR, Asturian Society of Physical Medicine and Rehabilitation)

Spain
Ricardollavona@ibermutuamur.es
Twitter: @samefyr
[LinkedIn:/company/sociedad-asturiana-de-medicina-fisica-y-rehabilitacion-samefyr](https://www.linkedin.com/company/sociedad-asturiana-de-medicina-fisica-y-rehabilitacion-samefyr)

SAMEFYR is a scientific, non-profit entity within the framework of the health sciences applied to people with a deficit, disability and / or handicap. Attached as regional society to the Spanish Society for Rehabilitation (SERMEF), currently has 80 members. Its objectives include bring together graduates in Medicine with an interest in Physical Medicine and Rehabilitation; improve scientific partnerships and exchange experience among members of society and other professionals; represent the Rehabilitation at the Civil Society, Public Institutions and Private Companies Administration of Physical Medicine and Rehabilitation; foster collaboration with other national or international organisations.

133. Sociedade Galega da Dor e Cuidados Paliativos (Galician Society of 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 is composed of health professionals with different specialties and backgrounds, especially physicians, but also psychologist and graduates in nursing (210 members). Its objectives are: (1) promote scientific research about mechanisms and treatment of pain, (2) raise public awareness on this problem, (3) encourage the continuous improvement in assessment and therapy of patients suffering pain.

The society 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.

Ronda República Argentina
nº 39-4º B
27002 Lugo
Spain
Phone: +34 646 486 903
www.sgador.com
secretariasgd@hotmail.com

134. Sociedad Extremeña de Geriátría y Gerontología (SOGGEX, Extremaduran Society of Geriatrics and Gerontology)



Extremaduran Society of Geriatrics and Gerontology (SOGGEX) is a medical, scientific and nonprofit society, which groups geriatricians and other health professionals. Its principal aiming is improving health care of elderly and promotion and developing of Geriatric Medicine in the region of Extremadura (Spain).

Colegio de Médicos de Cáceres
Av/ Virgen de Guadalupe, 20
10001 Cáceres
Spain
www.mayorex.es
secretaria@soggex.es

135. Sociedad Española del Dolor (SED, Spanish Society of Pain)



The Spanish Society of Pain (SED) is a professional, multidisciplinary, non-profit association, founded in June 1990 with the intention of promoting scientific research on the mechanisms and treatment of pain, raise awareness on this issue and encourage the constant improvement in the assessment and therapy of patients suffering pain.

The Spanish Society of Pain is a chapter of the International Association for the Study of Pain (IASP) as well as a chapter of the European Pain Federation (EPF-EFIC), which in turn are referred to pain issues in the World Health Organization.

The Spanish Society of Pain integrates professionals of different specialties and degrees, including medicine, pharmacists, psychologists, physiotherapists and nursing.

Paseo de la Castellana
241 – 4º A
28046 Madrid
Spain
Phone: 34 911 729 144
www.sedolor.es
secretaria@sedolor.es



Via del Pignoncino, 9-11
50142 Firenze
Italy
Phone: +39 (0)55 700027
055 7399199
info@simg.it
segreteria@simg.it
www.simg.it

136. Società Italiana di Medicina Generale e delle Cure Primarie (SIMG, Italian Society of General Medicine)

SIMG is an autonomous and independent association founded to promote, enhance and support the professional role of general practitioners, both within the Italian healthcare system and in European and extra-European healthcare organizations. The association was founded in 1982, and counts 100 provincial and sub-provincial sections in Italy. The association pay close attention to training, research and continuing professional development. SIMG also works on clinical research and epidemiology in general practice, as well as in the field of quality assessment. The association, which aims to promote collaboration with public and private institutions, has relationships with major national and international associations. It is a member of Scientific Societies Federation (F.I.S.M.).



CHU - Hôpital de Cimiez
Pavillon Mossa -
Département Douleur
4, avenue Reine Victoria
06000 Nice
France
Phone: +33 4 92 03 79 46
www.sfetd-douleur.org
sofradol@club-internet.fr

137. Société Française d'Etude et de Traitement de la Douleur (SFETD, French Society of the Study and Treatment of Pain)

The SFETD is the French chapter of IASP. Since 2000 it became the main multidisciplinary organization that includes both scientists and clinicians interested in pain in France. SFETD has more than 1200 health professionals involved in the study and treatment of pain.

The main objectives of SFETD are to bring together scientists, health care professionals to stimulate, improve and support the study of pain throughout France. SFETD strongly interacts with policy makers with the aim to translate knowledge into improved pain relief.



C/ San Ramón Nonato, 1 – Piso
12
28046 Madrid
Spain
www.pacientesatm.com
info@pacientesatm.com /
aepa@pacientesatm.com

138. Spanish Association of Patients with Neuropathic Pain, Trigeminal Neuralgia and Temporomandibular Pathology (AEPA ATM)

The Spanish Association of Patients with Neuropathic Pain, Trigeminal Neuralgia and Temporomandibular Pathology (AEPA ATM) is a nonprofit patient advocacy organization whose mission is to improve the quality of health care of everyone affected by Neuropathic Pain, Trigeminal Neuralgia and Temporomandibular Disorders. AEPA ATM is inscribed on the Register of Associations maintained by the Ministry of Interior of Spain. AEPA ATM has helped hundreds of patients since it was first established in 2006.

As more than 20% of the population in Spain suffer different types of pain, our main goal is to raise awareness on the importance of leading to the right diagnosis and treatment of pain.

139. Stichting Pijn-Hoop

Stichting Pijn-Hoop is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



The Netherlands
www.pijn-hoop.nl
info@patientennaar1stem.nl

140. Study In Multidisciplinary PAin Research (SIMPAR)

SIMPAR has been founded by Dr Massimo Allegri in 2008. It is a research group whose purpose is to link basic and clinical science obtaining a multidisciplinary approach for a translational and personalized pain medicine. In the Scientific Committee there are some of the most recognized scientists and physicians about acute and chronic pain: Prof Giorgio Cruccu (La Sapienza Rome University, Italy), Prof Jose De Andrés (Universidad de Valencia, Spain), Prof Troels Jensen (Aarhus University, Denmark), Prof Patricia Lavand'homme (Université Catholique Bruxelles, Belgium), Prof Luda Diatchenko, Prof Juan Asenjo, Dott Pablo Ingelmo and Prof Inna Belfer (all these scientists from McGill University, Canada), Prof Ed Mariano (Stanford University, USA), Dr Vijaya Gottumukkala and Juan Cata (MD Anderson University, USA), Dr Christopher Gharibo (New York Langone Medical Center, USA). SIMPAR group purposes are favouring international translational studies. Currently the group has published more than 20 articles in peer reviewed Journals and organises international meetings since 2008.



www.simpar.eu
malleagri@parmanesthesia.com

141. Suomen Kipu ry (Finnish Pain Association)

The Finnish Pain Association was founded in 1991 when a group of pain related people recognised the need for an own association to support interest of 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 Finnish Pain Association is a member of the Pain Alliance in Europe (PAE).



Kauppamiehentie 6
01200 Espoo
Finland
Phone: +358 40 551 6867
www.suomenkipu.fi
liisa.mikkonen@suomenkipu.fi

S



Sweden
www.swedishpainsociety.com
Email address: malin.ernberg@ki.se

142. Swedish Pain Society

The Swedish Pain Society aims to promote collaboration, development and education regarding the diagnostics, treatment and rehabilitation of pain in Sweden. The Society is multidisciplinary and multiprofessional joining physicians, nurses, physiotherapists, psychologists, social workers, occupational therapists and specialists in paediatric and orofacial pain.



Secretary's Office
Aargauerstrasse 250
CH-8048 Zürich
Switzerland
Phone: +41 (0) 44 496 10 16
www.pain.ch
info@pain.ch

143. Swiss Association for the Study of Pain

To raise quality standards in pain treatment the Swiss Association for the Study of Pain has put up a title "pain specialist SASP®". Already 70 physicians, psychologists and health professionals have been qualified for the title, the number is growing.



The Netherlands
www.syringo-chiari.info
info@patientennaar1stem.nl

144. Syringomyelie Patiënten Vereniging

Syringomyelie Patiënten Vereniging is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.

145. The Work Foundation

The Work Foundation transforms people's experience of work and the labour market through high quality applied research that influences public policies, organisational practices while empowering individuals.

The Work Foundation seeks to ensure that Good Work can benefit all: individuals; organisations; communities. It's mission is to improve knowledge and understanding of what constitutes Good Work, today and for tomorrow.



21 Palmer Street
London, SW1H 0AD
United Kingdom
Phone: + 44 020 7976 3575
www.theworkfoundation.com
info@theworkfoundation.com

146. Trigeminal Neuralgia Association UK

TN is an extremely severe facial pain that tends to come and go unpredictably in sudden shock-like attacks. It is normally triggered, e.g. by light touch, and is described as stabbing, shooting or burning. It usually lasts for a few seconds but there can be many bursts of pain in quick succession.



United Kingdom
Phone +44 1883 370214
www.tna.org.uk
adrian47@virginmedia.com





Đorđa Nikšića Johana, 30
21000 Novi Sad
Serbia
uitbs@sbb.rs
www.uitbs.org.rs

147. Udruženje za Istraživanje i Tretman Bola Srbije (UITBS), Serbian Association for Pain Research and Treatment (SAPRT)

Staying active in painful reality is essential.

SAPRT is a professional, multidisciplinary and non profit Association focused on pain, founded in 2006. The SAPRT is a chapter of the IASP and the EFIC.

The problem of chronic pain is still not well enough recognized in the Serbian Health Care System, although pain specialists are recognized in the SHCS. Additional efforts are done towards introducing Pain Medicine and Palliative Medicine as teaching subjects into curricula of Medicine and Nursing studies.

SAPRT recognizes the SIP as EU initiative and platform, endorses and completely supports the SIP 2016. The SIP is an ideal forum for presenting facts, exchanging ideas and bringing the issue of chronic pain to general public awareness.



A. Santica 1
71000 Sarajevo
Bosnia and Herzegovina
www.apb-bh.ba
apt_bh@yahoo.de

148. Udrueenje za terapiju bola u BiH (UTBBiH), Association for Pain Therapy in Bosnia and Herzegovina (APTBH)

Multidisciplinary team of doctors who are involved in treating pain. Its mission is to promote pain science, to educate and training through lectures; to support PM development in an efficient and standardized way; to coordinate between public Health institutions, Ministry, Government to engage in dialogue; to provide the Bosnian Pain society with international contacts; to improve the quality of life of pain patients.

APTBH appeals and help the Government and Ministry regarding modulation of law to accessibility of drugs in pain treatment (Opiates, CSs) and pain policy.



PO box 3
Kiev, 01004
Ukraine
Phone: +380955179929
www.pain.in.ua
vladimir.romanenko@pain.in.ua

149. Ukrainian Association for the Study of Pain

Pain should be a key priority of healthcare systems all over the Europe.

We declare that pain and chronic pain should be recognized as a key priority in national healthcare systems of all European countries. Pain education, availability of pain management approaches and reimbursement policies to pain patients should be extended on all levels.

150. University of Parma, Faculty of Medicine



Via Università, 12 - I
43121 Parma
Italy
Phone: +39 0521 90 21 11
www.unipr.it
protocollo@pec.unipr.it

The Faculty of Medicine of University of Parma is one of the most important and recognized Faculties in Italy. Anesthesia, Intensive Care and Pain Therapy Unit, headed by Prof Guido Fanelli is in the Department of Surgical Sciences. Prof Guido Fanelli has been part of the Italian Health Ministry Commission for the law 38/2010, first law (approved in 2010) in the world to recognize the right of each citizen to have access to Pain Therapy and Palliative Care, as also stated by WHO in 2012.

In Parma University it has been organized in 2014 the first Italian Master Course in Pain Therapy and the first in Palliative Care, officially recognized by Italian University Ministry. In 2016 more than 80 physicians from all Italy are attending to these two masters.

In 2015 two other important projects have been founded in order to improve the Education and the Research in the field of Pain Therapy:

1. University without Pain, a project defined by the Dean, Prof Borghi, and Prof Fanelli. This project is unique in Italy. The Project is willing to improve the knowledge about acute and chronic pain in all students of the University of Parma (not only in Medical Courses). Several courses have been organized and will be organized in different Faculties in order to face the different aspects (philosophic, economic, social, basic science, and so on) of Pain Therapy. The idea that drives this project is to approach in a real multidisciplinary way the pain therapy in order to succeed in considering all different problems that Pain Disease can create.

The project will also focus its attention in improving the knowledge in Pain Therapy of all physicians. For this reason through this project all residents will have a stage in Pain Clinic in order to learn the basics of Pain Therapy. Furthermore, in 2016 the project will deepen also the concerns, through the involvement of Veterinary Faculty about pain in animals.

2. Bioelectronic Genomics Nanotechnology in Pain (BioGeNaP), a spin off between University of Parma and Italian Center of National Research (CNR) aiming to research and validate in laboratory and clinical practice (translational medicine) new technologies for acute and chronic pain. In Parma there is an Institute of CNR (IMEM), headed by Dr Salvatore Iannotta, especially dedicated to nanotechnology and bioelectronics. The University of Parma was collaborating with Methodist Research Institute for a project, funded by Italian Health Ministry, about the use of nanotechnology in acute postoperative pain. In 2015 these two experiences were united in the spin off BIOGENAP that is currently collaborating with some of important Companies involved in chronic pain .

The current projects are especially dedicated to three topics:

- Development of nanotechnology based devices for postoperative pain
- New technologies for mini-interventional techniques integrating new nanotechnology and bioelectronic technology
- Personalized medicine through omics analysis

BioGeNaP is a University research project willing to create new international collaborations with Private and Public Companies involved in acute and chronic pain.



Taborska ulica 8
SI-2000 Maribor
Slovenia

Phone: +38622345821
www.mf.uni-mb.si/index.php/en
Assist. Prof. Nevenka Krčevski
Škvarč, MD, PhD: nevenka.krcevski.skvarc@amis.net
Assist. Prof. Uroš Maver,
MPharm, PhD: uros.maver@um.si

151. University of Maribor, Faculty of Medicine, Institute for Palliative Medicine and Care

Our institution is aware of significant and profound influence of pain on personal and societal level. We find important to start with pain medicine and palliative care education on undergraduate level.



The Netherlands
www.ehlers-danlos.nl
info@patientennaar1stem.nl

152. Vereniging van Ehlers-Danlos Patienten

Vereniging van Ehlers-Danlos Patienten is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



Impulsstraat 6 C
B- 2220 Heist-op-den-Berg
Belgium
www.fibromyalgie.be
info@vlfp.be

153. Vlaamse Liga voor Fibromyalgie-Patiënten vzw

Spreading information around Fibromyalgia and promote it at patients and their environment, healthcare professionals, aid workers, assisting agencies, politicians, etc. Anyone who's directly or indirectly involved with fibromyalgia, patients and non-patients, bringing together and find ways to their best interests. The provision of practical, emotional, psychosocial or other assistance to patients and to their families.

154. Vlaamse Pijnliga vzw (Flemish Pain League)

The Flemish Pain League is an umbrella organisation that brings together organisations that are concerned about pain in Flanders. 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, (2) Information, (3) Lobby work, (4) The best possible treatment for pain patients, (5) Attention for pain Pain is often invisible.



Haachtsesteenweg 579 PB40
Brussel, 1031
Belgium
Work Phone: +32 2 246 57 14
www.vlaamsepijnliga.be
vlaamsepijnliga@cm.be

155. Whiplash Stichting Nederland (WSN)

WSN is a member of the Dutch collective action group Pain Patients With One Voice, aiming to make people suffering from chronic pain speak with one voice to care providers, the pharmaceutical industry, insurers, politicians and government.



WHIPLASH STICHTING NEDERLAND

The Netherlands
www.whiplashstichting.nl
info@patientennaar1stem.nl

156. World Federation for Incontinent Patients (WFIP)

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.



38-40 Square de Meüs
1000 Bruxelles
Belgium
Phone: +41799463843
www.wfip.org
secretariat@wfip.org

W



21 Portland Place,
London W1B 1PY
United Kingdom
Phone: +44 20 7631 8880
www.anaesthesiologists.org
admin@wfsahq.org

157. World Federation of Societies of Anaesthesiologist (WFSA)

The World Federation of Societies of Anaesthesiologists (WFSA) unites anaesthesiologists to improve patient care and access to safe anaesthesia, around the world.

With a network of hundreds of thousands of anaesthesiologists in over 140 countries the WFSA facilitates learning and promotes the highest standards of patient care. It delivers this change through programmes in Advocacy, Education and Training, Safety and Quality and Innovation and Research all of which are made possible by working together as a Federation and with other partners that share our goals.

Each programme is supported by qualified anaesthesiologists who volunteer their time and expertise, be that as members of governance, through serving on committees, as trainers, fundraisers or as project leaders.



145 Kimel Park Drive
Suite 208
Winston-Salem, NC, 27103
United States
Phone: + 1 336 760 2933 (208)
www.worldinstituteofpain.org
wip@worldinstituteofpain.org

158. World Institute of Pain (WIP)

The World Institute of Pain® promotes worldwide advancement of pain education, training, and certification of physicians; facilitating global accessibility of the best practices of interventional pain medicine by individuals throughout the world who suffer from chronic pain syndromes.

WIP is committed to promoting the best practice of pain medicine and worldwide access to pain relief, and is honoured to join forces with EFIC® and all stakeholders of the Societal Impact of Pain to raise awareness, exchange information, develop and foster best strategies and activities for the continuum of pain care throughout Europe and beyond.



United Kingdom
[www2.kenes.com/wspc-soc/
pages/home.aspx](http://www2.kenes.com/wspc-soc/pages/home.aspx)
akbhaskar@btinternet.com

159. World Society of Pain Clinicians

The World Society of Pain Clinicians (WSPC) was formed over three decades ago for purely educational, scientific and charitable purposes. The society aims to unite clinicians with a common interest in treating pain; to publicize the WSPC's objectives amongst relevant governmental and health authorities; and to encourage scientific research on the treatment and clinical aspects of pain. The WSPC Biennial Congresses draw prestigious experts in Pain Medicine; stimulate education and learning; increase awareness of pain as a disease in its own right; and introduce new drugs, technologies and therapeutical opportunities available to clinicians.

The World Society of Pain Society is delighted and honoured to support and endorse the SIP 2016 Symposium under the auspices of the European Pain Federation.

160. Young Against Pain (YAP)



Young Against Pain (YAP) project has been founded in 2013, through an unconditioned grant of Grunenthal Italy.

www.simpar.eu/simpar/progettoyap/
yap@simpar.eu

The idea of the project is to favour the research in Italy of young clinicians (younger than 40 yo) and scientists helping to link different groups coming from different specialties and interests. The project is a call for the best 30 research projects looking especially for multidisciplinary and innovative projects. In order to not select only people from the more known and skilled centers, the evaluation is based on the evaluation of the research idea more than on their CV. Usually the grants select people according to their CV and publications. In this project we gave less value to publications and CV in order to select also Young researcher that are not well structured in well know centers but who are really promising

The award for the selected researcher is to create occasion to stay al together in 2 meeting each year in order to present each research interest and find the way to create a link together. The researcher selected has also the possibility to interact with the scientists of the advisory board in order to be supervised for their project. All the selected people has also the possibility to participate free of charge to all SIMPAR meeting and activities. In addition, the three best researcher (1 from basic science and 2 from clinics) are awarded with the opportunity to participate to annual IASP or EFIC meeting (this year the 3 best researchers will attend to IASP meeting in Japan).

The project has permitted to select 90 young scientists and clinicians (younger than 40 yo). This network has already obtained several publications, some new research project and two proposals to Italian Health and University Ministry. Furthermore, the success of the project has been certified by the huge number of the project received each year (in the 3 years we received more than 130 projects).

Adresses:

- 1

European Parliament
Rue Wiertz
1047 Brussels
- 2

Concert Noble
Rue d'Arlon 82
1000 Brussels
- 3

Thon Hotel EU
Rue de la Loi 75
1040 Brussels

Find more information on how to get to the Thon Hotel EU by public transport, car or taxi at: <http://www.thonhotels.com/hotels/countrys/belgium/brussels/thon-hotel-eu/>
- 4

Parking Loi
Rue de la Loi 85
1040 Brussels





The scientific framework of the Societal Impact of Pain (SIP) platform is under the responsibility of the European Pain Federation EFIC®. Cooperation partners for SIP 2016 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support). The scientific aims of the SIP symposia have been endorsed by a large number of international and national pain advocacy groups, scientific organisations and authorities.

www.sip-platform.eu

