

# EFIC® 2011: Societal Impact of Pain in Europe



Hans G. Kress, President EFIC®

“Many years ago EFIC® realised the need to increase the awareness of chronic pain and the societal impact of chronic pain”, said Professor Hans Georg Kress, President of EFIC® and chair of the ‘Societal Impact of Pain in Europe’ symposium. Not only did the awareness of healthcare professionals of the importance of this issue need raising, but also that of the general public and decision-makers in national healthcare systems and the European Parliament. “The SIP initiative is an important step towards public recognition of chronic pain as a burden and challenge for patients, physicians and healthcare systems”, added Kress.

The ‘Societal Impact of Pain’ (SIP) is an international multi-stakeholder platform in Europe. The aims are to raise awareness of the relevance of the impact that pain has on our societies, health and economic systems, to exchange information and to share best practices across all member states of the European Union, as well as to develop and foster European-wide policy strategies and activities for improved pain management in Europe. The ‘Road Map for Action’ – the major outcome of the 2<sup>nd</sup> SIP Symposium held in May 2011 at the European Parliament in Brussels – targets European and member state governments to put the SIP, especially chronic pain, on the agenda. The first insights and outcomes of the strategic international and national implementation of this road map were presented and discussed at the symposium ‘Societal Impact of Pain in Europe’ on 23<sup>rd</sup> September 2011 in Hamburg, Germany, on the occasion of the 7th Congress of the European Federation of IASP Chapters (EFIC®).

Responsibility for the scientific framework of the SIP platform and SIP symposium rests with the European Federation of IASP® Chapters (EFIC®). The pharmaceutical company Grünenthal GmbH is responsible for logistics, support and organisation. The “Societal



Impact of Pain - A Road Map for Action” is endorsed by more than 55 organisations.



**SIP**  
Societal Impact of Pain

## Fighting Chronic Pain – the first 10 years



**Kris Vissers**  
University Medical Centre Nijmegen, The Netherlands

**Professor Kris Vissers from the University of Nijmegen, The Netherlands, gave an overview over the last ten years, during which several important steps finally led to the establishment of the SIP initiative. In 2001, the EFIC® published its 'Declaration on Pain', which declared chronic pain to be a major healthcare problem, and a disease in its own right<sup>1</sup>. Before this declaration, most professionals never took into account that pain is more than just a symptom, in Vissers' words. For the**

**first time, this declaration called on national governments and EU Institutions to increase the level of awareness of the societal impact of pain.**

In 2007, a European survey demonstrated that almost one third of respondents experience musculoskeletal pain that affects their day-to-day life<sup>2</sup>. The survey showed that pain imposes a huge burden of suffering on individuals, and also generates enormous costs which not only healthcare systems but also the social, economic and employment sectors have to bear. This illustrates the urgency for European governments and to act and to put, as a priority, the societal impact of pain on their policy agenda.

The next step was an emphatic statement issued by Human Rights Watch in 2009 which stated that the 'pain treatment gap' is an international human rights crisis that needs to be addressed urgently, both on an international and national pain and palliative care level. Human Rights Watch recommended working groups on palliative care, if not yet established, an effective supply system, and proper training for healthcare workers in the consequences of pain and its effective management<sup>3</sup>.

In 2010, the International Association of the Study of Pain (IASP) published the 'Declaration of Montreal 2010' which confirmed that access to pain management is a fundamental human right<sup>4</sup>.

### 2010: Development of SIP

Although basic and clinical scientific research had demonstrated the feasibility of pathways for many types of acute and chronic pain – and despite the above-mentioned declarations and survey

– national and European policy actions had been very limited, Vissers commented. As a consequence, the SIP was founded in 2010. This international, multi-stakeholder platform aims to raise awareness of the relevance of the impact that pain has on society, health and economic systems. To achieve this, information must be exchanged and best practices shared across all member states of the European Union, so that we can develop and foster European-wide policy strategies and activities for improved pain care in Europe, according to Vissers. The platform provides opportunities for discussion for healthcare professionals, pain advocacy groups, politicians, representatives of health authorities and insurances, regulators and budget holders. "But most important – it gives us a platform to create together with the patients a programme which will improve their life, not only their day-to-day life, but also the recognition of pain as a disease entity", added Vissers. The responsibility for the scientific framework of SIP rests with the European Federation of IASP® Chapters (EFIC®). The pharmaceutical company Grünenthal GmbH is responsible for logistics, support, and organisation.

### 2<sup>nd</sup> SIP symposium in Brussels

Since its launch, the SIP has held two symposia. The last was on 3 and 4 May 2011 at the European Parliament in Brussels, Belgium. More than 300 participants from more than 30 countries took part and discussed the societal impact of pain in 12 sessions and 4 fringe meetings. In total, 88 scientific and patient organisations took part: for example, the European Federation of Neurological Associations (EFNA), the WHO Atlas of Headache Disorders & Resources 2011, the European Network of Fibromyalgia Associations (ENFA), European Headache Alliance (EHA), Chronic Pain Ireland (CPI), and the German Foundation for Palliative Care (DPS). Vissers mentioned that all three institutions of the European Union had been persuaded to put pain management on their agenda. A major supporter of the SIP is John Dalli, EU Commissioner for Health and Consumer Policy, as well as further delegates of the EU Commission. Support was also given by members of the European Parliament, of whom two co-hosted at the symposium, and by the Hungarian Presidency (January-July 2011).

### "Pain Milestones" during the last decade

- **EFIC®: Declaration on Pain 2001**
- **Human Rights Watch 2009**
- **IASP: Declaration of Montreal 2010**
- **The Societal Impact of Pain 2011**
  - **A Multi-Stakeholder platform in Europe**
  - **The Symposium**
  - **A Road Map for Action**
  - **The European Road Map Monitor**
- **EU Parliament: EU Resolution on Non-Communicable Diseases (NCDs) 2011**

### The Societal Impact of Pain – a Road Map for Action

The main outcome of the symposium in Brussels was the 'Road Map for Action', a policy document outlining the key issues on how to put pain on the agenda of the EU institutions and member states so that they can effectively address the societal impact of pain on an EU level. For Vissers, this Road Map is a major step forward in the long process which will finally lead to recognition of pain as a disease entity, and ensuring that patients with chronic pain will have the right to pain and palliative therapy all over Europe. He hopes that all national ministries of health will put pain on their agenda in the near future, as this would really be a huge progress on the still long way to go.

## European Parliament officially recognises chronic pain



**Eli Alon**  
Chair EFIC® EU Liaison Committee, Switzerland

**Professor Eli Alon, University of Zurich, Switzerland, reported about a very recent European Parliament resolution that was adopted on 15 September 2011. This resolution represents the European Parliament position and commitment in advance of the United Nations Summit on non-communicable diseases on 19 and 20 September 2011 in New York, USA. A non-communicable disease, or NCD, is a medical condition or disease which is non-**

**infectious. NCDs are chronic diseases of long duration and generally of slow progression, for example heart disease, cancer, asthma, other lung diseases, and diabetes, but not HIV. The resolution stated that the majority of NCDs have common symptoms, such as chronic pain and mental health problems, which directly affect sufferers and their quality of life. This should be addressed using a common, horizontal approach, so that healthcare systems can tackle these diseases more cost-effectively.**

This resolution indicates to national governments that there is an urgent need to better tackle NCDs, Alon confirmed. And it testifies that the European Parliament acknowledges that chronic pain is a common symptom of the majority of NCDs. The resolution also calls for establishing a European strategy on NCDs to be followed by Council recommendations with individual sections on NCDs, and it also calls for national NCD plans.

### The Societal Impact of Pain A Road Map for Action

**We call on European governments and the EU Institutions to:**

- 1. Acknowledgement of pain as an important factor limiting the quality of life;**
- 2. Availability of information and access to pain diagnosis and management;**
- 3. Increased awareness of the medical, financial and social impact that pain and its management have;**
- 4. Increased awareness of the importance of prevention, diagnosis and management of pain;**
- 5. Enforcement of pain research;**
- 6. Establishment an EU platform for the exchange, comparison and benchmarking of best practices;**
- 7. Trend monitoring in pain management by using the EU platform.**

## The European Road Map Monitor 2011

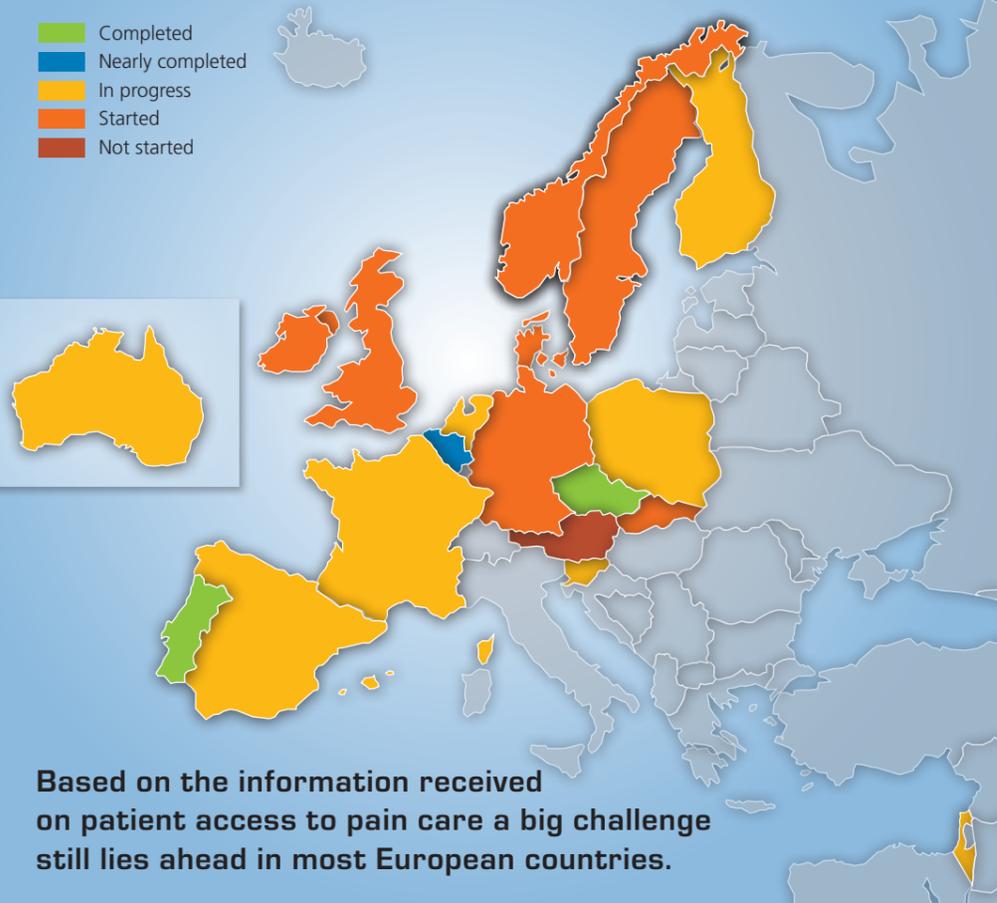
**To monitor the implementation of the road map on a national level, the EFIC® EU Liaison Committee designed a survey based on a twopage checklist. This questionnaire is divided into 9 blocks with tick boxes that address the dimensions of the road map, and two free-text questions that cover achievements and problems in each country. The first results using the survey were presented by Professor Rolf-Detlef Treede, University of Heidelberg, Germany. The analysis was based on data from the questionnaire, sent out this summer to EFIC® councillors and Grünenthal affiliates in 34 European countries, Israel and Australia. In total, 27 completed questionnaires were returned in time to be included in the analysis for the presentation at the Hamburg Symposium. Treede stated that the results are an early snapshot of the current situation, but that they do give a good preliminary overview of the development of the SIP platform across Europe.**



**Rolf-Detlef Treede**  
Medical Faculty Mannheim, Heidelberg University, Germany

Is patient access to pain care - diagnosis, treatment, medication - sufficiently ensured?  
(EU Road Map Monitor, September 2011: Question No 3)

- Completed
- Nearly completed
- In progress
- Started
- Not started



Based on the information received on patient access to pain care a big challenge still lies ahead in most European countries.

Belgium and Australia already have national action plans. In other countries, the process is still in progress, has started – or has not yet started. Portugal and the Czech Republic have reported that patients have access to properly organised pain care and management programmes. And only in Portugal, France and Italy, pain care is a top priority for the national statutory healthcare authorities.

With regard to the introduction of pain management training as mandatory subject for all healthcare professionals, including physicians, there is still much catching up to do. At present, it is only mandatory in France and Slovakia, and legislation is in process in Germany. In Spain and Germany, an educational programme on pain pathophysiology for the general public (“Pain is real”) has been launched. Up until now, the authorities in none of the countries have implemented plans to declare pain research a priority. Even countries with national

action plans against pain do not have national pain research programmes in the areas of basic, clinical or social research.

Treede’s résumé: “We are off to a good start as communication is going on, but there are still gaps to fill. For future exercises we need a consensus-finding process on a local level that integrates all stakeholders represented on the SIP platform at an EU level, i.e. the IASP chapter, professional organisations, and patient advocacy groups”. Some questions need to be phrased more precisely (e.g. has a policy been requested by advocacy groups or implemented by authorities). The current responses reflect the knowledge of the local EFIC® councillor, IASP chapter president, or Grünenthal manager, so the job of the next survey will be to validate the findings. Treede called on all stakeholders to communicate on all national and European levels that the road map must be implemented as rapidly as possible.

## Portugal: National Programme for Pain Control



Beatriz Craveiro Lopes  
EFIC® Councillor, Portugal

Portugal is one of the few European countries that has already implemented pain management in its national healthcare system. It started in the mid-1990s, when the Portuguese Association for the Study of Pain (Portuguese Chapter) convened a meeting at which the societies of anesthesiology, neurology, neurosurgery, physiatry, orthopedics, oncology and rheumatology considered pain as a disease, **Doctor Beatriz Craveiro Lopes, EFIC® Councillor, Portugal, reported. The outcome of this multidisciplinary meeting was a task force responsible for establishing the competence in Pain Medicine granted by the National Medical Association and for exchange of information with the National Medical Association and the health ministry.**

“Within 12 years, we achieved 6 milestones in pain management in Portugal”, Lopes commented. In 1999, a ‘Day Against Pain’ was introduced. The National Plan Against Pain was implemented in 2001. And in 2003, pain was recognised as the ‘5th vital sign’. One year later in 2004, pain management was recognised as a medical competence by the National Medical Association. In 2008, the National Plan Against Pain initially established in 2001 has evolved to the actual National Programme for Pain Control, followed by a national survey to draw attention to the prevalence of chronic pain in Portugal in 2010 conducted by OBSERVADOR, a coalition between the Faculty of Medicine of the Oporto University and the Portuguese Association for the Study of Pain.

The National Programme for Pain Control now has established pain clinics, healthcare financing groups, electronic prescription of opioids, educational programmes, guidelines for pain management in the elderly, and guidelines for prescription of opioids for non-malignant pain. Other general objectives are ongoing, such as organising the annual National Day Against Pain, educational programmes, guidelines for pain management in children, evaluation of the chronic pain clinics, and establishment of a pain clinics network. Still missing in the National Programme are priority financing for basic scientific research, the involvement of patient interest groups in care programmes, and the adoption of approaches that support self-care. “How the severe Portuguese economic crisis will impact the progress we have already made, we have no idea, but we are still continuing with optimism, of course”, Lopes concluded.

## Galicia in Spain Strategy SERGAS 2014



Dolores Martín Rodríguez  
General Department of Quality Programs and Healthcare Safety, Galician Ministry of Health, Spain

According to Doctor Dolores Martín Rodríguez from the Galician Ministry of Health, Santiago de Compostela, Spain, there were many different approaches to pain care in the region in 2010. Despite pain care strategies in 13 of the 15 major Galician hospitals, delivery of care, structural elements, medical records, and follow-up indicators had not been standardized. In 2010, the Galician health service implemented a strategy called ‘StrategySERGAS 2014’ to improve public healthcare and patient service in general. The strategy includes an integral pain care programme. The aim is to improve care for inpatients by implementing a global strategy directed towards optimum pain management – standardized and affordable – for all patients, and, in this way, achieving ‘pain-free’ hospitals’.

“Our first priority was to systematize and implement an acute pain evaluation procedure in our 15 hospitals”, Martín explained. To achieve this, a multidisciplinary working group was implemented at each hospital. A pain record, using a visual analogue scale (VAS) and the ‘faces’ pain scale was set up in GACELA, the region’s nursing care computer register system in hospitals. A follow-up indicator system which would demonstrate adherence to the procedure by healthcare workers and its impact on patients was also implemented.

The aim was to have pain records for at least 50% of the hospital patients in 2011. “At the beginning of 2011, we had records from 18.4% of patients and we managed to increase this to 26.8% in the first 6 months”, Martín reported. The pain intensity of patients with a pain record between May and July 2011 was mild in 57%, moderate in 34%, and severe in 10% of the patients.

Some important areas need improvement: training of nurses, the use of standardized scales, lack of time is a problem, and data entry into GACELA in intensive care units, according to Martín. To address these needs, the Galician Assessment Committee on Pain

will be constituted, and a training programme for professionals and patients and caregivers will be designed and implemented from September 2011 onwards.

In 2012, the priority will be to implement standard procedures for different types of pain. In 2013, it is planned to implement indicators on scorecards that monitor and evaluate the effectiveness of the strategy and the processes involved, also incorporating a procedure for information and feedback to professionals and patients.

## Innovative Medicine Initiative (IMI) - The EuroPain Project



**Elisabetta Vaudano**  
Principal Scientific Manager, Innovative Medicine Initiative (IMI), Belgium

**Chronic pain truly is a nervous system disease, and there really is a need to develop new analgesics, Elisabetta Vaudano from the Innovative Medicine Initiative (IMI), Brussels, Belgium, emphasized, and stressed what a burden chronic pain is. But the development of new analgesics is a great challenge because pain experiences and pain-related problems are not always predictably related to the underlying cause. And the different forms of chronic pain have different underlying mechanisms. Above all, the gap**

**between animal behavioural models and humans has not yet been bridged. The identification of novel targets and genes important in chronic pain has only recently become fairly easy thanks to new technologies.**

The EuroPain Project was initiated to improve the pharmacological treatment of chronic pain and to reduce the burden of illness for very large groups of the European population. This project is part of the European 'Innovative Medicines Initiative' (IMI), the largest private-public partnership in the healthcare sector. IMI has a total budget of €2 billion: €1 billion from the Health FP7 budget and matching €1 billion in kind resources provided by the pharmaceutical industries members of the European Federation of Pharmaceutical Industries and Associations (EFPIA). The aim of the

IMI is to support collaborative projects in the public and private sector. "In order to succeed in providing better medicines to patients we need to collaborate closely between academic partners and biotechnical and pharmaceutical companies", Vaudano explained. The EuroPain Project comprises the London Pain Consortium, the German Neuropathic Pain Network, the Danish Pain Research Centres, and major players in the pharmaceutical industry working on pain. The total budget is € 18.3 million, the project started on 1 October 2009, and will last until 30 September 2014.

The EuroPain Project has already passed some milestones. For example, a novel imaging technique based on magnetic resonance imaging (MRI) has visualised changes in the normal brain resting state network (RSN) in patients with low-back pain compared with healthy controls; this can be used to predict the intensity of pain experienced by the patients. And a new model for cold hypersensitivity has been developed in healthy human volunteers, similar to the sensory profile for chemotherapy-induced pain. This model can be used for faster and more efficient testing of novel treatments. Additionally, the EuroPain Project could bridge the gap between animal models and humans: A novel translational study from scientists on the EuroPain team has shown that the chemokine CXCL5 is an important mediator of the inflammatory pain that occurs after sunburn<sup>5</sup>.

Vaudano concluded that better pain management will reduce not only the socio-economic burden of pain on patients and society, but that improved success rates in drug development will give EFPIA members and biotechnical companies better possibilities of contributing to economic growth in Europe.

### Burden of chronic pain in Europe

(Breivik H et al. European Journal of pain 2006:287-333)

- On average, one out of five Europeans suffers from chronic pain.
- Chronic pain can affect anyone, independent of gender and age.
- In 21% of cases, chronic pain lasts more than 20 years.
- In 31% of cases, the chronic pain is defined as unbearable.
- Chronic pain influences job perspectives and may lead to depression.
- Existing drug therapies are insufficient and most patients withdraw from treatment due to lack of efficacy or subjective side effects.

## Interview with Gina Plunkett, Representative of the Pain Alliance Europe, Chair Chronic Pain Ireland (CPI), Dublin/Ireland

### You yourself suffer chronic pain. How did this happen?

**Gina Plunkett:** It was a car accident which I thought was a simple one as I had no apparent injuries. Now, 16 years later, I still have some very bad days, but at least nowadays I have realised that I can manage it and I know the pain will abate. In the early years, I was in a very dark place where I really did think I would not be able to take much of it. And many people do feel like that when the pain is that severe.

### How did you get involved in the patient organisation?

**Gina Plunkett:** It started with my own involvement on a national level in the patient support group Chronic Pain Ireland. I became a member because I wanted to know more about the pain that I was experiencing. Further on, I realised that a lot of people need support, and not the sort of negative image I had of support. But support in a really constructive way. I realised that there was a huge gap in the health system: there were no services for people with chronic pain. That was quite a shock for me as I assumed in a modern Western health system that there would be a well-trodden route for people with pain and its treatment. But there was not. And I knew from my own experience that not just medical intervention is needed, but also support from physiotherapists and psychologists, i.e. a more multidisciplinary approach. I suppose my former career as a barrister gave me the mental energy and the desire to actually do something about what I think is a huge injustice.

### Which is?

**Gina Plunkett:** I just thought it is not right that people are suffering so much and that their pain is not being recognised as being real. And I struggled with that myself – not being believed. That was actually a huge burden for me personally; it hindered my own personal development and ability to deal with the pain. And it was not until I really came to the fact that it was real and that I was not imagining it, that the door opened to self-management and progress.

### You gave presentations at both SIP Symposia in Brussels and you were one of the Chairs of the present SIP symposium during the EFIC® congress in Hamburg in September. What was your impression?

**Gina Plunkett:** I became the Vice Chair of Chronic Pain Ireland and therefore had the opportunity to be involved with the first SIP Symposium in Brussels in 2010. It was interesting to see this broad spectrum of different people. They were not only representing the healthcare professions, but also the health economics and politics sectors, and other patient organisations. This kind of meeting is really required as a forum for discussing unmet needs and progress. And now this symposium here during the EFIC® covered a broad array of speakers talking about the EFIC® declaration covering progress made since 11 years ago to what is actually happening on the ground in Galicia today.

### What do you wish for the future?

**Gina Plunkett:** I would be happy if chronic pain is recognised as a disease. And that there will be a change in the attitudes towards people with chronic pain, so that people with chronic pain would be able to say "I've got chronic pain" and the response would be "That's tough, that must be really hard". I want a transformation of the attitudes and misperceptions across the board, and symposia about SIP touching on the societal perception of pain are taking us one step further.



**Gina Plunkett**  
Representative of the Pain Alliance Europe, Chair Chronic Pain Ireland

## Interview with Eli Alon, Professor of Anaesthesiology and Pain Management at the University of Zurich/Switzerland, Chair EFIC® EU Liaison Committee, and EFIC® Honorary Treasurer

**Pain management and access to adequate pain care vary tremendously across Europe. Do you think this can be changed in the near future?**

**Eli Alon:** Yes, I am very optimistic for the future, although there are not only differences between European countries, but also within countries themselves. But with the 'Societal Impact of Pain' (SIP) we have established an international, multi-stakeholder platform to emphasise not only the burden of suffering that pain imposes on individuals, but also the enormous costs for healthcare systems. Starting with this platform and implementing the 'Road Map for Action' across the EU member states, I truly believe we can improve pain care in Europe.

**You presented one of the first successes of SIP, which include the Road Map for Action and the recent EU resolution on non-communicable diseases. How long has it taken to reach this point?**

**Eli Alon:** It is not possible to give an exact duration because it was and is an ongoing development which includes national and international processes. SIP is a relatively young platform. It started two years ago when the EFIC® and Gruenthal had the idea to organise a European congress in Brussels focussing on the impact of pain in Europe. We invited not only pain specialists, but also non-medical representatives from the economy, the government, healthcare financers, and patient organisations to explain and discuss how important pain is in Europe and what we should and could do in the future. At the second congress in May this year, we managed to win over many European politicians to our cause, above all John Dalli, European Commissioner for Health and Consumer Policy, one of the most significant players in ensuring that our policy on pain management for all will become a reality. And now the European Parliament has endorsed a resolution on chronic pain in non-communicable disease.

**Why is this European resolution on non-communicable diseases so important?**

**Eli Alon:** This is the first official recognition by the European Parliament of the relevance of chronic pain. The resolution refers to very important common chronic diseases that are difficult to treat, such as heart disease, lung disease, diabetes, asthma, and cancer. Chronic pain can be a typical symptom of all these diseases. The resolution could and should be used to encourage national policy makers to exert pressure on a European level for the development of a council recommendation on non-communicable diseases, which would include specific indications and how to better manage associated chronic pain.

**But pain is referred to in the resolution as a symptom and not as a disease. Is this therefore really a breakthrough?**

**Eli Alon:** Yes, it is. At least the European Parliament has recognised chronic pain in an official resolution – this is a major step forward. The recognition that such common diseases are often associated with inextorable pain has spurred us on to continue with other activities. Based on the EFIC® declaration from 2001 stating that chronic pain is not only a symptom but a real disease, we will continue to work until it is recognised as a disease entity in its own right on a European level.



**Eli Alon**  
Chair EFIC® EU Liaison Committee,  
Switzerland

I See: <http://www.efic.org/index.asp?sub=724B97A2EJBU1C>  
II Eurobarometer survey on "Health in the European Union", Special Eurobarometer 272e, September 2007; [http://ec.europa.eu/health/ph\\_publication/eb\\_health\\_en.pdf](http://ec.europa.eu/health/ph_publication/eb_health_en.pdf)  
III <http://www.hrv.org/en/node/81080/>  
IV <http://www.iasp-pain.org/Content/NavigationMenu/Advocacy/DeclarationofMontr233al/default.htm>  
V (Dawes JM et al. Sci Transl Med 2011;3(9):90a60).

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Programmes, presentations, and proceedings from both SIP symposia in 2010 and 2011 held in Brussels, Belgium, and the programme and presentations of the symposium held at the EFIC® 2011 held in Hamburg, Germany, are available on the webpage <http://www.sip-meeting.org/grt-sip/154700556.jsp> or please contact: [sip-meeting@grunenthal.com](mailto:sip-meeting@grunenthal.com)

