

## Issue 4 (31): 14 July, 2010

### Dear EPF Members and Allies,

Welcome to the summer issue of the EPF Mailing. This issue focuses on recent policy developments and also preparations for autumn and 2011.



We also give you an overview of our intensive work within DG Research and the Innovative Medicines Initiative (IMI), focussing on patient involvement on the eve of the next Calls for Proposals, and our contribution to the Open Health Forum through the organisation of a parallel session focussed on "Putting Health at the Centre of Cohesion Policy". [See section 10.](#)

Significant work has taken place on Health Technology Assessment, in particular participation in the EUnetHTA Stakeholder Group ([see section 13](#)), our Consultation on eHealth ([see section 8](#)) and developments on patient safety with the closing conference of the EUnetPaS project, and planning for a Joint Action underway ([see section 7](#)).

It is our pleasure to welcome warmly a new member of the Secretariat team, Kaisa Immonen, who replaces Roxana Radulescu as Policy Officer ([see section 29](#)).

Our first board since the AGM met on 22 June and Timo Nerko from CEAPIR was affirmed as EPF Treasurer, replacing Mike O' Donovan. [See section 28](#) for an overview of the key decisions of the board.

You will see from our Diary ([see section 30](#)) that much planning is underway for autumn 2010, and EPF will also hold a special event on "Patients Rights on Cross-border Healthcare" with the support of the Belgian Presidency, on the eve of the Second Reading in the European Parliament. More details on that in our September issue of the EPF mailing.

Our warmest wishes to you all for a relaxing summer break – we look forward to our continued close collaboration. For your information the EPF Secretariat remains staffed during the summer so please do not hesitate to contact us.

Warmest greetings,  
Anders Olauson, President  
Nicola Bedlington, Director

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Next issue of the EPF Mailing -deadline for articles 30 August 2010, distribution September 2010.

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## 1. PHARMACEUTICAL PACKAGE: LEGISLATIVE PROPOSAL ON PHARMACOVIGILANCE NEARS FINALISATION, EPF INPUT IS WELL REFLECTED IN THE DRAFT

In previous EPF Mailings, we have written about EPF's successful work on the Pharmaceutical Package, which was to a large extent reflected in the European Parliament (EP) reports on these dossiers. EPF participated in innumerable internal and external debates on the issues, conducted several consultations with members, held a policy workshop with a cross-section of our members and patient group allies, and worked closely and intensively with the European Parliament in Brussels and in Strasbourg to make sure the patients' views were taken into account.

The two reports prepared by MEP Linda McAvan on **pharmacovigilance** and MEP Marisa Matias on **anti-counterfeiting** at the end of December reflected this input.

We also did some robust work with the Council, in particular on the **Information to patients on prescription medicines proposal** and urged for continuing the work on this proposal, and, to place it in the broader context of a comprehensive information to patients strategy. Our close work with the rapporteur, MEP Christofer Fjellner, was evident in his [report](#), which shifted the focus firmly from the right of industry to provide information to the right of patients to have access to information.

### **Pharmacovigilance proposal close to finalisation**

With regard to the pharmacovigilance proposal, EPF welcomed the warnings for products under intensive monitoring and particularly supported the opportunity for patients and their families to report on suspected

adverse effects of medicines. We advocated for the provision of accessible information to patients about the procedures to report, and the cooperation between regional and national pharmacovigilance centres and patients' organisations in order to enable meaningful patients' reporting. This is included in the text which is now to be voted by the plenary session of the European Parliament (EP).

Once adopted by the EP, the proposal will be sent to the Council of the European Union. The Belgian Presidency has prioritised these dossiers in its programme. Depending on the Council decision, the draft may be adopted as it is, or be returned to the Parliament for a second hearing.

Key provisions of the proposal include:

### **1. Reporting and the Eudravigilance database**

Doctors, pharmacists and other healthcare professionals are encouraged to report suspected adverse reactions to their National Competent Authority (NCA). To avoid extra bureaucracy, marketing authorisation holders and Member States will report reactions only to the Eudravigilance database, which will immediately notify all Member States electronically of the reports submitted. Healthcare professionals may also request individual adverse reaction reports from the European Medicines Agency or NCA, which must be provided within 90 days. Marketing authorisation holders may not refuse reports of suspected adverse reactions provided in any format by health professionals.

Patients will have better access to the Eudravigilance database, although the level of that is yet to be defined in collaboration by all stakeholders, including patients' organisations.

### **2. Direct patient reporting**

The draft Directive emphasises the active role of healthcare professionals in pharmacovigilance reporting; unfortunately, at the last moment the patient reporting aspect was weakened by the fact that – although it is encouraged – Member States are allowed to decide whether patients can report directly

to the NCA, or only through healthcare professionals. On the positive side, the Directive asks Member States to undertake measures to support patient reporting, including training for health professionals and public information campaigns developed in cooperation with patients' organisations.

**3. Extra warnings for products under intensive monitoring**

A specific symbol has been conceived to let the user know that a given medicinal product is under intensive monitoring, including information on the different options to report a suspected adverse reaction with the relevant contact details.

**4. Support for national and regional pharmacovigilance centres**

Member States are encouraged to support national and regional centres to ensure high-quality information. NCAs are encouraged to collect the reports from those centres and transfer the data to the Eudravigilance database.

**5. Proposal to review the Package Leaflet and Summary of Product Characteristics**

MEPs support a comprehensive review of the statutory information – the Package Leaflet and Summary of Product Characteristics – which are widely considered not to be user-friendly. EPF welcomes this proposal, having argued for better information to patients and the involvement of patients' organisations in developing such information. The details of the review are yet to be worked out, as the issue concerns all three Pharmaceutical Package dossiers, in particular Information to Patients.

EPF is following all three dossiers very closely, particularly the Information to Patients proposal, and we will report on developments in the next EPF mailing.

For further information, please contact the [EPF Secretariat](#).

## 2. COUNCIL REACHES POLITICAL AGREEMENT ON CROSS-BORDER HEALTHCARE – THE PROPOSAL PROCEEDS TO SECOND READING IN THE EUROPEAN PARLIAMENT

At the Employment, Social Policy, Health and Consumers (EPSCO) Council of 8 June 2010, the Council arrived at a political agreement regarding the draft Directive on the applications of patients' rights in cross-border healthcare. The Directive has been controversial since it was first proposed by the Commission in 2008, with some Member States concerned that it would undermine the principle of subsidiarity in the field of healthcare.

The Spanish compromise text resolved the key concerns of opposing Member States (Greece, Lithuania, Portugal, Romania and Spain) concerning the responsibilities of the "Member State of residence" (in the case of pensioners residing abroad), private health providers not contracted to the healthcare system, and prior authorisation. The draft Directive will now go back to the European Parliament for a second reading. The Belgian Presidency has committed itself to trying to finalise the legislation before the end of its six month term.

From the patients' point of view, the Spanish compromise text – like the Swedish text before it – is not ideal. EPF worked extensively with the rapporteurs on this proposal in 2008 and 2009, and a patients' perspective was well reflected in the text adopted by the European Parliament in the first reading in April 2009. Unfortunately, many important elements were subsequently removed by the Council.

### **More work is still needed to make the Directive work for patients**

The Directive on cross-border healthcare is extremely important for European patients. It will form the basis of much future legislation and research. It recognises a new right for European patients: the right to seek healthcare abroad without prior authorisation and to be reimbursed; it introduces national contact points for

information to patients about their rights regarding cross-border care; it provides for European Reference Networks for conditions requiring particular concentration of expertise or resources (such as rare diseases). As such, we welcomed the proposal.

However, EPF has several concerns about the current legislative text:

1. Up-front payments. We strongly advocated for alternative mechanisms of payment to be put in place to avoid patients having to shoulder the costs of cross-border care, and we are concerned that the Council removed these provisions. Maintaining up-front payment is clearly not acceptable from an equity perspective, being in conflict with the overarching values of “universality, access to good quality care, equity, and solidarity” as expressed in the Council Conclusions of 2006, and undermining the fundamental vision of the original proposal.
2. Quality and safety standards. While we welcome the obligation on Member States and health providers to provide clear and accessible information on their safety and quality standards, the same standards should be explicitly applied to eHealth and telemedicine services. Further, EPF strongly advocates for enhanced cooperation at European level in collecting and making available information and good practices, including key quality indicators, for the continued improvement of quality and safety throughout the European Union.
3. Involvement of patients’ organisations. We were pleased to see the endorsement by the European Parliament of the involvement of all stakeholders, including patients’ organisations, in cooperation with the national contact points for information, in the development of the European health technology assessment network, as well as in the eventual transposition, evaluation and review of the Directive. Unfortunately these references were removed by the Council.

EPF will be extremely active together with our members in the coming months on this dossier, in the context of the second reading of the proposal in the European Parliament as well on-going work in the Council. We will present a strong case for improvements that would make the Directive more patient-centred and give real added value for European patients. And we have the opportunity to get our message across at numerous events during the autumn ([see diary](#)), including our own event in early December, focussing on quality of care and patient safety.

[Proposal adopted by the EP, April 2009](#)

[Proposal adopted by Council, June 2010](#)

### 3. EU ADOPTS LEGISLATION ON ORGAN TRANSPLANTATION

On 19 May 2010 the European Parliament adopted two specific documents regarding quality and safety standards for organ transplantation: the draft Directive on standards of quality and safety of human organs Intended for transplantation (COM(2008)819 final), and an Action Plan on organ donation and transplantation for 2009-2015. EPF welcomes the new legislation. We hope it will help boost the supply of organs for the benefit of those patients whose lives depend on them, and secure a high level of patient safety in transplantations across Europe.

#### **Background**

The shortage of organs is a major factor affecting transplantation programmes in Europe: according to a Council of Europe report in 2007, nearly 56,000 patients are on a waiting list. Donation rates systems, and consequently the availability of organs, vary considerably across the EU. For example, in Spain in 2009 there were 34.4 donations recorded per 1 million inhabitants, while in Romania only 0.5 per million. Related to the



problem of shortages is also the worrying rise in illegal organ trafficking. The aim of the new Directive is to help increase the supply of donated organs from deceased and living donors, while enhancing the accessibility and efficiency of transplantation systems, and ensuring a high quality and safety level of the procedures.

### **Legal base**

Although the competence for the organisation and delivery of national health systems lies with the EU Member States, in certain areas of public health a shared competence applies. Such areas include the standards of quality and safety for organs and substances of human origin, blood and blood derivatives, as defined under Article 168(4)(a) of the Treaty. Standards for blood and blood derivatives have already been regulated since 2003 (Directive 2002/98/EC) and for tissues and cells since 2004 (Directive 2004/23/EC). The new Directive covers organs that are used for transplantation, including transplantations done in the context of clinical trials.

### **Main provisions**

Under the new rules, Member States will be required to set up national competent authorities responsible for implementing national quality programmes in order to ensure quality and safety throughout the process. The quality programmes include systems for the traceability of all organs, reporting serious adverse events and reactions, collection of data on the outcomes of transplants, standard operating procedures and qualifications for all personnel involved in transplantations. The authorities will also be in charge of accrediting and overseeing transplant centres and procurement organisations. All organ donations must be voluntary and non-remunerated, and several measures are included for the protection of living donors. Exchange with third countries will be subject to the same standards. The Directive also provides for the creation of an EU-wide database of organs and donors, and close networking between the national competent authorities.

## Next steps

Once the Directive is adopted by the Council and published in the Official Journal of the European Union\*, it will become law and Member States will have two years to transpose the Directive into their national legislations. This means the focus is now on the national level. The EU legislation does not make explicit reference to the role of patients' organisations, so groups with an interest in organ donation and transplantation issues are encouraged to proactively engage with their national ministries of health to ensure that they are involved in the process of transposing the Directive.

*\* This is expected to take place in June but has not yet happened at the time of writing*

## More information

Draft Directive: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2008:0818:FIN:EN:PDF>

Action Plan: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2008:0819:FIN:EN:PDF>

## 4. BELGIAN PRESIDENCY

On 1 June 2010, Belgium took over the rotating EU Presidency from Spain for the next six months.

The Presidency takes place in a delicate domestic political context, after elections in June failed to produce an outright winner. While the negotiations on forming a new government are ongoing, and not expected to conclude until September or October, the country is being led by a caretaker government. Many commentators predict that this will provide an opportunity for the first full-time President of the European Council, Herman van Rompuy, to take a strong political lead during the Presidency; he is himself Belgian and the country's former Prime Minister.

The Belgian Presidency will be focusing around the goals of the [Europe 2020 strategy](#), with five main components:

**1. Socio-economic component**

- Objective: to restore sustainable growth and competitiveness
- Priority areas: employment; fostering innovation; internal market, financial regulation and economic governance

**2. Social component**

- Objective: to promote social cohesion and encourage convergence towards higher standards
- Priority areas: setting out objectives and indicators; addressing poverty and social exclusion; social protection; ageing Europe and pensions; discrimination and equality

**3. Environmental component**

- Objective: achieving a green economy
- Priority areas: energy; transport; climate change; goals for the 10th COP (Conference of the Parties of the Convention of Biodiversity)

**4. Freedom, security and justice component**

- Objective: Implement Stockholm Programme? Consolidate and complete the European area of freedom, security and justice
- Priority areas: procedures on immigration and asylum; fighting terrorism and organised crime; human trafficking; mutual recognition of court rulings

**5. External action component**

- Objective: EU as a force for peace and security
- Priority areas: setting up the European External Action Service; enlargement negotiations; bilateral and regional trade agreements; promotion of human rights; chairing ASEM and Africa summits.

## Health priorities

In the area of health, the Belgian Presidency will focus on the motto “health safety”, with particular attention paid to the areas of disease prevention (especially the Belgian Cancer Plan); the health workforce; and chronic diseases. Ageing Europe is another priority linked to health. The Presidency wishes to highlight the European added value in improving public health.

**Upcoming conferences** under the Belgian Presidency include a Ministerial Conference on the Health Workforce – 9-10 September 2010, La Hulpe, Belgium, and a conference on Chronic Diseases in October. EPF will speak at two major events under the Presidency, looking at Corporate Responsibility, Solidarity and Innovation – more details in the next issue of the EPF Mailing

**EPF** is establishing a tradition of holding high-level events under the patronage of the EU Presidency, as exemplified by the Value+ conference in 2009. We will organise a stakeholder Roundtable in December 2010 around the highly topical theme of Cross-Border Healthcare, focusing on inequalities in health, safety and quality aspects.

### More information:

The programme of the Belgian Presidency can be found [here](#).

The official website of the Belgian Presidency can be found at [www.eutrio.be](http://www.eutrio.be)

## 5. RENEWING HEALTH PROJECT: USER ADVISORY BOARD KICK-OFF MEETING

In previous Mailing issues we introduced you to RENEWING HEALTH (REgions of Europe WorkINg toGether for HEALTH), a project implementing large-scale real-life test beds in nine European regions for the validation and subsequent evaluation of innovative telemedicine services for patients suffering from diabetes, cardiovascular diseases, and chronic obstructive pulmonary disease using a patient-centred approach and a common rigorous assessment methodology.

EPF is involved together with EHTEL (European Health Telematics Association) in the management of the User Advisory Board (UAB). The role of the UAB is to ensure that the interest and needs of the users of the piloted telemedicine services, i.e. healthcare receivers, (patients), providers (health professionals, formal and informal carers) and payers are properly taken into account throughout the stages of deployment. The role of the UAB is also to ensure that the implemented solutions support the empowerment of the patients, improve the satisfaction of healthcare professionals and informal carers and benefit the wider medical scientific community.

The UAB kick-off meeting was held on 23 June in Brussels on the EHTEL premises. To ensure the equal representation of all user groups within the UAB, EPF and EHTEL have extended the invitation to participate in the UAB kick-off meeting to some 15 relevant European organisations representing the abovementioned user groups. During this meeting the “prospective” members of the UAB were introduced to the project and to the Catalan pilots in particular. The main features of the multi-disciplinary assessment methodology (MAST) were also presented. MAST is the main reference framework for the assessment and evaluation of the piloted

services and applications and as such it is of primary concern to the UAB. The prospective members were also invited to discuss and provide feedback on the Terms of Reference (ToR) which is now in the process of being finalised.

The membership of the UAB will be consolidated before the next meeting of the RENEWING HEALTH partners which will take place on 9 and 10 September in Trikala (Greece). The next meeting of the UAB will be held in Brussels on 2 November.

In the next couple of months EPF will be also working towards the development of the first deliverable of the UAB, the User Requirements, a comprehensive analysis of needs, requirements and expectations of end-users of telemedicine services. Further details on this document will be provided in the next Mailing issue.

For more information about RENEWING HEALTH and the User Advisory Board contact [Liuska Sanna](#).

## 6. RESPECT HARMONISATION WORKSHOP



On the 14-17 June the partners of the [RESPECT project](#) gathered in Ljubljana, Slovenia for a harmonisation workshop.

The aim of the meeting was to bring together all the input and information gathered through the various investigations of the issues related to empowerment of children and families in the context of pediatric clinical trials and agree on recommendations.

Each partner was in charge of a specific topic and presented the findings from surveys, case studies, interviews, and focus groups. The themes addressed were as follows:

- The role of ethic committees
- Transparency of clinical trials
- Patients and patient organisations as research partners
- Clinical trial networks
- Recruitment and self-recruitment
- Decision tools
- Patient education
- The role of industry

Invited experts attended the meeting and provided their own insights. Further consultation work on the recommendations is likely to be conducted.

The body of evidence and knowledge thus built will converge into a model of empowerment that is inspired by the [Value+ Model of Meaningful Patient Involvement](#). Additionally, a set of resources or references to resources to support the model will be provided.

The next project phase is dissemination. A series of events will be organised to share the recommendations on increasing participation in pediatric clinical trials and empowering the children and families.

For more information on the projects and the planned events please contact [Liuska Sanna](#).

## 7. THE EUNETPAS PROJECT CONCLUDES - AND OPENS DOOR TO A JOINT ACTION ON SAFETY AND QUALITY

Patient safety is a strategic priority for EPF and goes to the heart of our work for equitable patient-centred healthcare across the EU. The EUNetPas project, launched in 2008, involved a network between all EU Member States with the aim of encouraging and enhancing collaboration in the field of patient safety. EPF was an associate partner in this project.

For EPF the EUNetPaS project was an opportunity to learn about policies and activities in patient safety in a variety of Member States, and to identify good practice examples. We worked closely with our partners in Work Package 2 (WP2), including the European Federation of Nurses Associations (EFN) and the Standing Committee of European Doctors (CPME), and contributed to the preparation of a [Guidelines document](#) on Education and Training in Patient Safety. The document aims to support healthcare providers on national and local levels to design, establish and evaluate training interventions in patient safety in order to ultimately promote transferability of methods from one Member State to another.

The EUNetPaS project was brought to an official conclusion at a final conference held on **1-2 July** in Brussels. The first day focused on patient safety developments in the EU and included presentations of the EUNetPaS deliverables, as well as presentations from the World Health Organization (WHO), the Organisation for Economic Cooperation and Development (OECD) and various national Patient Safety Platforms. **Nicola Bedlington**, EPF's Director, participated in a panel discussion on the views and contributions of civil society organisations on patient safety in the EU. ([Read EPF's contribution](#)). The second day was devoted to working meetings in order to finalise the deliverables of the work packages, with an afternoon discussion of a future Joint Action on Patient Safety for 2011.



## Next step: Joint Action in Patient Safety and Quality of Healthcare

We were pleased to see that good progress was achieved by EUNetPaS in establishing National Patient Safety Platforms in several Member States. However, the level of patient engagement in the National Platforms varies enormously, with little involvement and little knowledge about ways to be involved in many Member States.

Building on the achievements of the EUNetPas project, a plan has been put forward for a Joint Action in Patient Safety and Quality of Healthcare. This Joint Action is based on the Commission's Communication and the Council Recommendation on patient safety, including the prevention and control of healthcare associated infections. It also incorporates the closely linked topic of Quality of Healthcare, where a lot of work has been done by the Patient Safety and Quality Working Group (PSQWG) of which EPF is a member.

The experience of the EUNetPaS project has demonstrated clearly the importance of including primary care in the future joint action, as well as the importance of involving all stakeholders in a meaningful way. EPF believes the involvement of patients' organisations is particularly crucial in order to ensure a two-way dialogue reaching down to the grass-root patient communities. The importance of patient engagement and empowerment was also demonstrated by the presentations made by the representatives from OECD and WHO at the final conference, and it has been recognised by the Council's Working Group in Public Health at senior level.

EPF is pleased to be one of the stakeholder organisations set to participate in the future Join Action. We will attend a preparatory meeting on **8 July**, where the objectives and tasks of the Joint Action will be discussed in more detail.

For further information, please visit [www.eunetpas.eu](http://www.eunetpas.eu) or contact the [EPF Secretariat](#).

## 8. EXPLORING PATIENTS' NEEDS AND EXPECTATIONS RELATED TO EHEALTH - AN INITIATIVE FROM EPF

EPF has recently developed a concept paper to develop a consultation with its Members to start-up discussions on possible future actions and activities to explore patients' needs and expectations related to eHealth.

The premise of this initiative is that at the moment there is no enormous evidence of how patients view and what they expect from eHealth. There is too often a poorly-grounded assumption that patients trust, accept and are keen on using eHealth services and, although there is indeed some proof of the potential benefits for patients, there is not a comprehensive overview of patients' perception of and perspective on such services. Due to this gap, EPF is often in a challenging situation when it comes to providing clear positions on various eHealth-related issues. It has now become urgent to build that evidence and those positions if patients want to influence decisions that will impact on how healthcare will be delivered in the future.

At EPF's Annual General Meeting 2010, members gave a strong mandate to the EPF Secretariat to carry out a consultation with a view to building the evidence needed to establish EPF's position in the wide area of eHealth.

Our aim is to extend this consultation beyond our membership to reach out to the following stakeholders:

- Patient organisations that are members of EPF members
- Patient organisations that are not EPF members
- Patients with chronic diseases both users and non-users of eHealth services

Potential consultation methods envisaged in the concept paper include face-to-face or phone interviews, focus groups, electronic or online questionnaires as well as online forums, blogs, etc.

The final goal of this exercise is to gather increased evidence of patients' perspective on eHealth reflecting the diversity of our membership to feed into EPF's policy and programme work on eHealth.

If you are interested in participating in this consultation or would like to get more information and/or contribute to this initiative through your ideas, please contact [Liuska Sanna](#).

## Events and Conferences

### 9. OPEN HEALTH FORUM 2010

This year's fourth Open Health Forum was held on 29-30 June in Brussels under the theme "Together for Health - A Strategy for Europe 2020". This two-day event aimed at strengthening the involvement of all stakeholders in contributing to the development and implementation of actions and activities to protect and improve the health of European citizens.

The conference represented also an opportunity to increase the profile of Health in all policies through discussion between EU policy-makers and stakeholders on pressing public health issues and their impacts on the community. The importance of having Health in all policies was stressed by Commissioner John Dalli in his opening speech. Commissioner Dalli emphasised that without bridging health inequalities and ensuring access to health for all we will not be able to deliver against the EU 2020 objectives." Investment in Health",

continued the Commissioner, “means investment for sustainable growth, and this is how Health fits in the new EU 2020 Strategy.”

You can access the full speech of Commissioner Dalli [here](#).

To be fully effective the “Health in all Policies” approach needs to be applied to all relevant policies at all governance levels. This idea was clearly reflected in this year’s Open Health Forum, specifically in the six parallel sessions dealing with different policy areas such as Environment, Innovation, Cohesion Policy and Common Agriculture Policy (CAP) as well as with cross-cutting issues such as stakeholder involvement and impact assessment, each organised by a different stakeholder involved in the Open Health Policy Forum.

EPF was responsible for organising the parallel session on Cohesion Policy and Health, whose outcomes are briefly reported in a separate article below.

EPF was also present in the exhibition area to showcase our recent activities to more than 500 participants which included a spectrum of healthcare stakeholders, national and regional authorities, SME associations, research and scientific institutions, regional organisations and media.

At the end of the conference members of the Open Health Policy Forum formally agreed on a stakeholder resolution which was also handed over to DG SANCO’s Director General Ms. Paola Testori Coggi.

For more information visit the [conference website](#) or contact the [EPF Secretariat](#).

## 10. OPEN HEALTH FORUM WORKSHOP "POSITIONING HEALTH AT THE CENTRE OF THE POST-2013 COHESION POLICY"



EPF organised a workshop on “Positioning Health at the Centre of the Post-2013 Cohesion Policy” in the framework of the 2010 Open Health Forum (see above). The workshop looked at reconsidering the role of “Health” as a key element for supporting economic, social and territorial cohesion across Europe and exploring ways to integrate Health into sustainable regional development frameworks through the Structural Funds in the 2014-2020 programming period.

The workshop, which was held on 29 June, was moderated by Ms. Debbi Stanistreet from the University of Liverpool. Speakers included Mr. Jonathan Watson ([HealthClusterNet](#)), Mr. Steve Wrights ([ECHAA](#)), Mr. Edmund Škorvaga (Slovak Ministry of Health), Ms. Agneta Granström (Norrbotten County, Sweden) Mr. Octavian Purcarea ([COCIR](#)), Mr. Luigi Bertinato (EUREGHA) and Ms. Rostislava Dimitrova (DG SANCO). A panel discussion reflecting on the future of Health in the post 2013 Cohesion Policy benefited from the contributions of Ms. Gabriella Fesus (DG REGIO), Ms Karin Kadenbach (MEP), Ms. Ourania Georgutsakou ([AER](#)) and Mr. Dave Wilcox (Committee of the Regions).

All presentations will be uploaded soon onto the conference website that you can access [here](#).

EPF President, Mr. Anders Olauson was Rapporteur. In his report to the plenary, Mr. Olauson remarked that if we really aim to put into



practice the “Health in all Policies” approach all actors involved must work together to advocate for Health to continue to remain a priority for Cohesion Policy in the future. As one of the most tangible EU policies, Cohesion Policy, and particularly its key financial mechanisms, the Structural Funds, represents the appropriate tool to put into practice, implement and test the Health in all Policies approach.

A recent [report](#) from Mr. Jonathan Watson conveys that there are different ways in which Health gains can be generated from Structural Funds. During the workshop we heard of some successful examples of applying all approaches, but we also identified a number of weaknesses and challenges associated with using Structural Funds for Health in ways which meet needs and expectations of citizens and patients. These factors gave us much food for thought in preparation for the next programming period.

One of the main lessons we have learnt is that using Structural Funds to invest in Health does not necessarily lead to health gains. Health investments have the most impact when they are effectively integrated into a regional master plan and strategically geared towards the need of local citizens and patients.

It is no doubt that future Structural Funds spending priorities will be fully aligned to the EU2020 Strategy. The key challenge for all those involved in this area will be to ensure that Health, although not singled out as a priority for the EU2020 Strategy, is effectively recognised as a key determinant to sustain inclusive growth in the future. Adopting the “Health in all Policies” approach is how we can make sure that Health is actually incorporated in the delivery of this strategy.

When it comes to Structural Funds, it will be crucial that the health sector learns how to make and present an economic case that shifts health spending from the cost line in budgets to the investment line. The workshop also recalled the importance for national authorities to consider setting up a specific operational programme for Health, but also to take action to effectively integrate health considerations in all other sectoral operational programmes (health mainstreaming) through health assessment of all programmes.

In concluding his speech Mr. Olauson emphasised that to be successful and meet citizens' expectations Cohesion Policy needs to be developed in full partnership with all stakeholders. Health strategies and priorities should be driven by the people who are actually using healthcare services.

You can access the full report of the workshop presented by Anders Olauson [here](#).

EPF committed itself to producing a more detailed report. This document, which is now in the process of being developed, is meant to serve as a basis to follow-up to the workshop and as a contribution to the upcoming debate on the future of Cohesion Policy at EU, national and regional levels.

## 11. FP7 HEALTH RESEARCH INFORMATION DAY AND UPCOMING CALL

More than 400 participants attended the Open Information Day – FP7 (Seventh Framework Programme) Health Research earlier last month which highlighted the priorities and features of the 2011 Work Programme and provided guidance to participants interested in becoming involved in EU health-related research projects in the new Call that is due to be launched before the end of July 2010.

Those who were unable to attend the Open Information Day can now view the plenary sessions through the European Commission's website portal clicking [here](#).

In this short article we present the major outcomes of the event, but should you need more information do not hesitate to [contact us](#).

### **EPF spoke at the FP7 Information day**

Director Nicola Bedlington of EPF gave a presentation during the morning plenary session on the importance of patient involvement in EU-funded projects, specifically in research intensive projects and Diane

Whitehouse showcased the Value+ project as an example of good practice for meaningful patient involvement during one of the parallel workshops, which focused on clinical trials.

You can access both presentations [here](#).

### **Showcasing our activities**

During the small exhibition, in which we participated, we had an opportunity to showcase our work and reiterate the importance of patient involvement in EU health related projects to various participants which included patient representatives, SME associations, research institutions and small-medium sized enterprises (SMEs).

Through its active participation in the Information Day, EPF sought to promote a more patient-centred approach in upcoming FP7 health-related projects and increase the profile of patients' organisations as valuable and reliable project partners.

### **Towards a more patient-centred approach in future health research projects**

One of the most important features of the 2011 Work Programme is the explicit recognition of patient involvement as an important element of future FP7-supported health projects, particularly in the area of clinical trials. The early involvement of patients and their advocacy groups in the planning, implementation, and monitoring of a clinical trial is considered important so that patient needs are appropriately considered right from the project's onset.

Readers may be pleased to know that the Commission's Orientation Paper highlighting the proposed priorities for Health Research explicitly refers to the Value+ model as an example of good practice for the early involvement of patients in Health related-projects. You can access the draft Orientation Paper [here](#).

For this reason we would like to encourage all patients' organisations to consider invitations they may receive from project leaders wishing to involve them in their projects.



The final version of the 2011 Work Programme is scheduled to be published on July 20, 2010 together with the first Call for Proposals.

### The way forward

While the inclusion of the principle of patient involvement in the 2011 FP7 Health Research Work Plan represents a big step forward and a major achievement for the patient movement, we believe that more effort has to be made if our aim is to ensure that this principle is effectively integrated in future research projects.

One of the major hindrances to patient organisations' involvement in FP7 projects is the well known difficulty project leaders face when it comes to integrating in their consortia partners which do not perform *stricto-sensu* research activities. EPF believes that in order to facilitate the participation of patient organisations in future project consortia there is a need for more flexible rules.

EPF will closely monitor the implementation of the 2011 Work Programme and the upcoming Call to ensure that principle of patient involvement is reflected in future research projects also through the meaningful participation of patient organisations in future consortia.

## 12. IMI - SCIENTIFIC COMMITTEE AND IMI STAKEHOLDER FORUM

Using the deliverables from Value+ and anecdotal evidence from our members on their involvement to date in the Innovative Medicines Initiative (IMI), **Nicola Bedlington** gave a presentation to the IMI Scientific Committee, on 1 and 2 June, and to the IMI Stakeholder Forum on 14 and 15 June.

Ms. Bedlington's key message was the importance of patient involvement in IMI projects, some of the bottlenecks to date, and strategies to facilitate this in future calls. At the first meeting Kim Wever,

coordinator of the Patient Partner project also made a presentation based on the experience of this project exploring meaningful patient involvement in clinical trials.

EPF is working very closely with the IMI Executive Office to advance this in practical terms in relation to the forthcoming 3<sup>rd</sup> Round of Calls for Proposals. Please go to [http://imi.europa.eu/calls-03\\_en.html](http://imi.europa.eu/calls-03_en.html) for more information on the topics and procedures.

For a copy of Nicola Bedlington's presentation please [go here](#).

## 13. EPF REPRESENTED AT EUNETHTA 1st STAKEHOLDER FORUM MEETING

Readers may recall that EPF was recently appointed as one of the members of the Stakeholder Forum established under the framework of the EUnetHTA Joint Action (JA) 2010-2012. This Joint Action was established to be a formal collaboration between EU Member States and the European Commission aiming at putting into practice an effective and sustainable collaboration on [Health Technology Assessment \(HTA\)](#) in Europe that brings added-value at the European, national and regional level. The EUnetHTA JA builds on the momentum and achievements of a number of the previous European initiatives, notably amongst others the [EUnetHTA Project \(2006-2008\)](#) and the [Pharmaceutical Forum on Relative Effectiveness](#).

The Stakeholder Forum was created with a view to having a permanent structure for involvement of stakeholders as part of the governance structure of the EUnetHTA JA. More precisely, the aim of this Forum is to provide stakeholders the opportunity to comment and give advice on the work and governance of the JA.

The first Stakeholder Forum meeting was held on 9 June in Dublin. This meeting represented the first opportunity for the stakeholders to provide feedbacks on the two core documents that will guide the work of

the Forum, namely the Policy and Operating procedures. These two documents convey an advisory role to the stakeholders in the form of participation in the EUnetHTA Stakeholders Forum, public consultations on deliverables, and facilitation of the provision of information to be used in work on specific technologies emerging from the work packages.

EPF values the opportunity to participate in this very important action. During the meeting we asked jointly with other stakeholders for a more direct involvement in the specific work package activities and more generally, for a continuous and more effective participation in the JA three-year work plan. This is very much in line with EPF's engagement for meaningful patient involvement.

The HTA seminar EPF organised in May 2010 and the involvement in EUnetHTA and other initiatives converge towards our aim of bringing patients' voice in HTA. We will provide you with updates and outcomes of future EUnetHTA meetings and developments through our following Mailing issues.

For more information, please visit the EUnetHTA website: [www.eunetha.net](http://www.eunetha.net) or contact [Liuska Sanna](#).

## 14. EPF REPRESENTED PATIENTS AT THE INTERNATIONAL CONFERENCE ON PATIENT SAFETY

On 3 - 4 June, Spain hosted an International Conference under the auspices of the EU Spanish Presidency. The objective of the conference is to present international and national experiences in the prevention of healthcare-associated infections (HCAI) and antimicrobial resistance (AMR). EPF was represented by Nicola Bedlington, who shared with the audience EPF's work on patient safety through the European Commission

Working Group on Patient Safety and Quality of Care, the EUnetPaS project promoting an EU Network on Patient Safety and our work on legislative proposals such as pharmacovigilance and anti-counterfeiting.

For a copy of Nicola's presentation please contact [EPF Secretariat](#).

## 15. EFPIA AGM

On 21 June, Nicola Bedlington participated in a workshop organised in the framework of the European Federation of Pharmaceutical Industries and Associations (EFPIA) Annual General Meeting, focusing on "Partnerships". The European Commission, EFPIA and EPF all presented their perspectives and strategies around partnership in the current EU Health Environment.

For more information please visit [www.efpia.org/content/default.asp?PageID=317](http://www.efpia.org/content/default.asp?PageID=317).

For a copy of Nicola's presentation please [go here](#).

## 16. PATIENT SAFETY VS. SUSTAINABLE HEALTHCARE



On behalf of EPF, Magdalena Machalska attended a meeting with Portuguese patients organisations held on 1 June in Lisbon. Its purpose was to identify the main challenges that patient communities face in Portugal. More than 10 disease-specific patients' organisations attended the meeting, which provided a unique opportunity for participants to exchange experiences and information on different patient-related issues.

The 2 June a conference, also held in Lisbon on Patient Safety and Quality Healthcare was organised by the Portuguese Nursing Council, in collaboration with Councils of Doctors, Pharmacists and Dentists. The conference was organized to celebrate the World Health Day and the panel gathered distinguished representatives from the European Federation of Nurses Associations, Portuguese Doctors Councils as well as from the Portuguese Pharmacists Society.

At this occasion, Magdalena Machalska gave a presentation on EPF's commitment and work within the EU quality and safety sector to ensure patient-centered healthcare across Europe.

For more information, please contact [Magdalena Machalska](#).

## 17. EPF PARTICIPATION AT THE LAUNCH OF THE COMMITTEE OF THE REGIONS TECHNICAL PLATFORM FOR COOPERATION ON HEALTH

Although health policies in the EU are set at national level, it is regional and local authorities that are usually responsible for managing health resources and configuring services to meet local needs. Despite this, the engagement of sub-national authorities in shaping and implementing EU strategies in this field has been so far rather limited.

With a view to bridging this gap and strengthening the active participation of regional and local authorities the [Committee of the Regions](#) (CoR) and [HealthClusterNet](#) with the collaboration of the three relevant Directorate Generals of the European Commission, specifically DG SANCO, DG REGIO and DG EMPL, organised a joint conference on 11 June at the CoR premises to launch a new platform for cooperation between the

regions and the European Commission on health issues. The topic of the first conference of the Technical Platform was “Structural Funds and Health: Learning lessons and next steps”.

In presenting the view of regional and local health authorities, Dr. Luigi Bertinato (Veneto Region, vice-chair of [EUREGHA](#)) attached high expectations to this new mechanism and highlighted how this platform should ensure the effective and regular engagement of the regions in areas where they can really make a difference in terms of better health for the citizens, notably health promotion, patient-centred disease management, sustainable health workforce, health inequalities and health investments from the Structural Funds.

The reasons for EPF's interest in this Platform are multifold:

- Ensuring that patients needs are recognised and effectively integrated in the delivery of healthcare at regional and local level
- Promoting the dissemination of the Value+ model of patient involvement at national, regional and local level
- Raising the profile of patients' organisations as equal and strategic partners in the healthcare policy arena at all levels, particularly in the planning and implementation of Structural Funds-supported health projects and investments
- Ensuring that a genuine dialogue with relevant healthcare stakeholders, notably patients' groups, is featured as one of the main elements of this platform

The next meeting of the Technical Platform is scheduled for late September and will target two different topics, i.e. the role of regions in delivering the EU Health Strategy and health prevention.

For more information on the CoR Technical Platform on Health contact [Walter Atzori](#).

## 18. CONFERENCE ON SHAPING THE FUTURE OF THE EUROPEAN SOCIAL FUND

### What was this Conference about?

On 23-24 June the Directorate General for Employment and Social Affairs and Inclusions (DG EMPL) of the European Commission held a conference around the theme “Shaping the Future of the European Social Fund (ESF)”. The aim of this event was to acknowledge past achievements of the ESF in supporting EU objectives and to explore how this Fund can contribute effectively to the [Europe 2020](#) Strategy.

Established as far back as in 1957 by the [Treaty of Rome](#), under the current seven year period (2007-2013) the ESF will be investing some EUR 76.2 billion to support employment and social cohesion across the EU. Managed at national and/or regional level, the ESF is one of the two EU [Structural Funds](#).

### What is the ESF doing in the area of Health?

Although in the current [ESF Regulation](#) “Health” is only featured in relation to its contribution to a “healthier work-force”, evidence from the various ESF [operational programmes](#) shows that opportunities for health gains from this Fund are potentially manifold ranging from initial and continuous education and training in the healthcare sector to partnership and capacity-building for all healthcare stakeholders as well as actions to target health inequalities and access to healthcare. However, a clear link with the labour market is often a fundamental requirement for determining the scope of ESF-supported intervention in the area of health. This largely explains the limited use, but also the difficulties some Member States are facing to use the ESF for Health.

Despite existing opportunities for health-related activities from the ESF, background research undertaken under EPF's flagship Value+ project has shown that for a number of reasons patients' and patient organisations' participation in ESF-related activities and processes (including drafting, monitoring and evaluating programmes and projects) has been so far very limited.

## What will be the future of the ESF?

It is certain that the future ESF Regulation for the years 2014-2020 (proposal expected in mid-2011) will make this Fund one of the key financial levers in delivering the Europe 2020 Strategy. In his opening speech Commissioner László Andor has himself strongly called for a full-alignment of the ESF to the objectives of the new EU strategy for growth.

In the Europe 2020 Strategy the Health component is rather marginal. The risk is that the future regulation will no longer feature Health as an area eligible for ESF support.

## Where does EPF stand on the issue?

EPF believes that although it is important to ensure that EU funding instruments are used to serve common policy objectives set at EU level, the ESF, as the major EU funding instrument to promote social cohesion should not only continue to play a role to support health, but its contribution to this area should be strengthened through effective health mainstreaming.

To this end EPF believes that the ESF should:

- integrate the “Health in all Policies” approach to lead to effective health gains for all citizens and the patients
- include patients with physical and mental chronic conditions as people deserving special support in terms of access to labour market, education and training and public services
- promote activities in the area of health literacy to build mutual trust among users and providers of healthcare services, particularly in the area of eHealth.

For more information please contact [Walter Atzori](#).



## 19. LUNCH DEBATE: HEALTH LITERACY

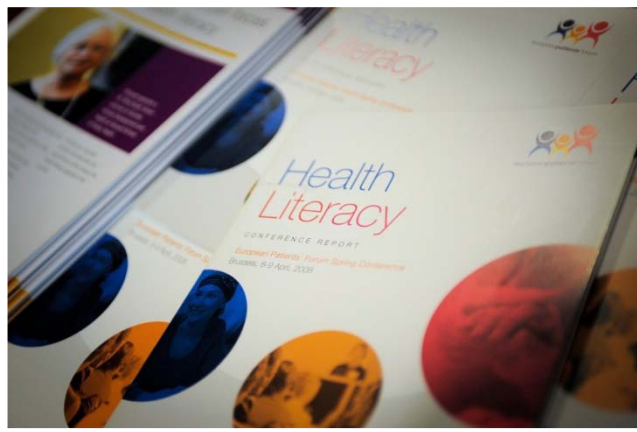


EPF was represented by our President Anders Olauson at a debate on Health Literacy in the European Parliament last month which was organised by the Faculty of Health, Medicines and Life Sciences, University of Maastricht.

The debate focused on recent achievements regarding Health Literacy and has been set as one of the key actions to reduce health inequalities within the EU. This was established under the framework of the White Paper “Together for Health” adopted by the European Commission in 2007.

The conference provided participants the opportunity to discuss the importance of Health Literacy as it relates to healthcare system access. It was noted that there is still a lack of understanding of organisational and functional structures of the healthcare system, which stops citizens from fully exercising their rights. EPF President, Anders Olauson, explained that Health Literacy is a key element to ensure citizens benefit their right to health, being a key pillar of comprehensive information to patients. He explained that Health Literacy has a positive impact on a sustainable healthcare system and thus is essential for equity, quality and efficiency of patient-centred healthcare systems.

Patients universities were discussed as a possible means to provide patients with necessary skills to benefit from healthcare. This was made clear in a recent study conducted on Irish citizens which concluded that only 33% were aware of the maximum amount of aspirin that should be taken on daily basis. Therefore, it was advocated that teaching life skills would become part of making knowledge accessible, and thus, a healthcare system more participatory.



However, more information is needed to assess Health Literacy achievements, since it has been put on the EU agenda as a key element to reduce health inequalities. As there are only few national studies in this regard, Maastricht University had taken an initiative and conducted the first European Health Literacy Study, a project co-funded by the European Union. The survey collected data from nine countries, and the first results of the study will be presented at a workshop at the Health Policy Forum Gastein in October 2010, in which EPF will also speak.

For more information please contact the [EPF Secretariat](#).

## 20. PATIENTS RIGHTS AND INSURANCE

On 28 June, Nicola Bedlington attended a conference organised by Swiss Re, that explored some of the challenges and opportunities regarding the provision of insurance to specific groups such as disabled people, patients, and older people, and potential discrimination in this area. This meeting built on the outcomes of a meeting in February also organised by Swiss Re entitled “Getting the balance right: Risk selection in private insurance”. [Please see attached for report.](#)

The meeting was attended by representatives of the AGE, the European organisation representing older people, the European Disability Forum, the European Patients’ Forum (EPF), the European Multiple Sclerosis Platform and the European Cancer League.

It was also attended by a representative of the European Commission DG Employment and Social Affairs who highlighted that a report was currently being completed that will look at discrimination outside the employment arena, where EU legislation has already been adopted with a view to a potential legislative proposal. EPF will analyse this report, to explore its relevance to patients with chronic diseases.

For presentations, please see attached:

- [Risk assesment in private insurance](#)
- [Getting the balance right](#)

## 21. HEALTH SECURITY COMMUNICATORS' NETWORK

How to communicate with citizens on the pandemic Influenza? This was the starting point of a roundtable discussion which gathered European and national stakeholders from various EU Member States. The roundtable was organised under the auspices of the European Commission's Directorate – General for Health and Consumers, on 18 June, in which Magdalena Machalska participated on behalf of the European Patients' Forum. It was an opportunity for participants to exchange views and experiences on the H1N1 management process.

The meeting's agenda was to discuss the possibility of conceiving and developing a communication network on Influenza pandemic to help citizens better manage information they receive on Influenza-related issues.

Attendees were invited to contribute to a public consultation on pandemic Influenza, launched by the European Commission in May 2010.

Further discussion on how to communicate with citizens on Pandemic Influenza related issues will be tackled during the Belgian Presidency conference which will take place on 2 July this year.

## 22. ASEF SUMMER UNIVERSITY ON PUBLIC HEALTH AND VULNERABLE GROUPS: ACCESS TO QUALITY HEALTH CARE SERVICES

The ASEF University, is a two-week intensive programme which offers undergraduates the opportunity to broaden their horizon and knowledge on international issues. Organised by the Asia-Europe Foundation in collaboration with the Medical University of Lodz, the ASEF University is a flagship project of ASEF which is committed to building bridges between Asia and Europe through educational and youth cooperation, strategic thinking and policy dialogue.

This year, the ASEF Summer University which began on 29 June focused on Access to Quality Healthcare Services from a perspective of vulnerable groups. General discussions took place in the areas of the patients' voice in EU health policy debates, challenges to healthcare policy, commercialisation of medical science, and public health promotion.

On behalf of EPF, Magdalena Machalska gave a presentation on EPF to a culturally diverse and dynamic young audience. It was followed by a presentation from EPF board member, Tomasz Szelaḡowski, who explained how the Polish Patients' Federation works together with EPF to ensure patient-centred healthcare across Europe. Both presentations led to a very challenging and interesting discussion on issues such as patient empowerment, patient involvement as well as a patient-centred healthcare.

At the end of the Summer University, participants will be asked to draft policy recommendations on issues discussed during the programme.

For more information on the two-week programme and discussions, please contact the [EPF Secretariat](#).

## 23. EPF TO PARTICIPATE IN THIS YEAR'S CAREUM CONGRESS

President Anders Olauson will be representing EPF at this year's Careum Congress under the theme "The power of patients – patients' role in shaping the healthcare system of the future". Mr. Olauson will open a discussion on the challenges of patient involvement from a European perspective during a panel discussion on patient revolution and the challenges and opportunities of autonomy in the health society.

The congress which takes place on 11-12 of November in Zurich will highlight activities and programmes which support people affected by disease to play a decisive role in shaping the healthcare system of the future. Key note speeches, workshops and panel discussions will address how patients can play a more active role in developing innovations in the healthcare community.

For more information and to register for the congress please visit their website at: [www.careum-congress.ch](http://www.careum-congress.ch)

## 24. EUROPEAN CANCER PATIENT COALITION LAUNCHED FACE AT THE PARLIAMENT LAST MONTH

The European Cancer Patient Coalition (ECPC) launched the initiative "Forum Against Cancer Europe (FACE)" at the European Parliament on 23 June. The initiative was set up by ECPC with an aim to continue the successful dialogue between patient communities around Europe and the European Parliament, Commission and key stakeholders. The aim of FACE is to continue to learn, debate and form policies that are geared towards cancer patients across regions and political parties and promoting action against cancer as an EU priority. Every family in Europe is somehow affected by cancer. It is estimated that there will be two million

new cases of cancer in the coming year. Therefore it is extremely important to keep the dialogue going between cancer patient groups and EU institutions and ensure the dialogue is a two-way communication process.

The [FACE website](#) supports activities of the initiative and will provide workshops of the Forum. The interactive website will initiate two-way dialogues and provide information about supporters and focus topics.

For more information on the European Cancer Patient Coalition and the work they do, please see [here](#) or view the [press release](#).

## 25. HEALTH AND ENVIRONMENT: TIME TO ACT

On behalf of the European Patients' Forum (EPF), Magdalena Machalska attended a conference on "Health and Environment- Time to Act" held on 4 June which was organised by the Association Internationale de la Mutualité. The purpose of the conference was to enhance political commitment on the Parma Declaration, promoting better health through a better environment. The declaration was adopted during the 5<sup>th</sup> Ministerial Conference on Environment and Health that took place earlier this year.

Brussels-based stakeholders, as well as governmental representatives from the EU Member States brought together their expertise to discuss and advocate on environmental policies. The discussions focused on environmental effects on health and on possible incorporation of the education and prevention on environmental health aspect into all awareness-raising and information activities.

The idea of the debate was to encourage stakeholders from different sectors to work together in order to conceive and develop information to citizens on the consequences that the environment has on our health.

For further information, please consult AIM's website: [www.aim-mutual.org](http://www.aim-mutual.org)

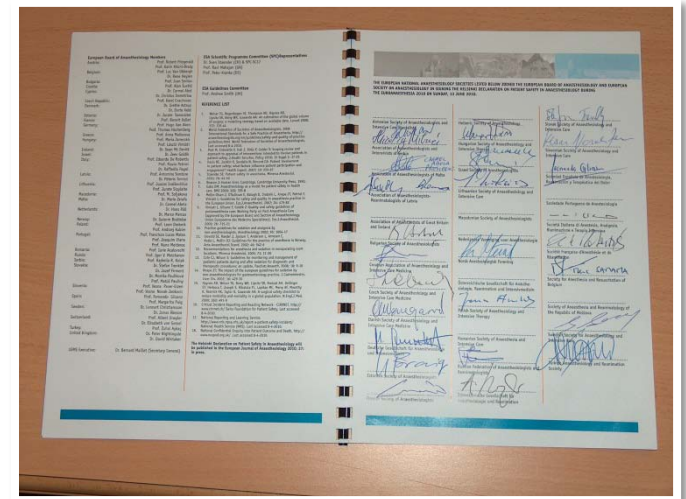
## 26. EPF WELCOMES THE EUROPEAN DECLARATION ON PATIENT SAFETY ON ANESTHESIOLOGY



EPF was invited to comment from the patient's perspective on the Helsinki Declaration on Patient Safety in Anesthesiology that was presented at a roundtable at the Euroanesthesia conference in Helsinki 13 June. The roundtable was organised by the European Board of Anesthesiology and European Society of Anesthesiology.

200.000 people in Europe die as consequence of severe complications related to surgery. The anesthesiologists want to take their responsibilities as a specialty

and nurture patient safety across the profession. EPF welcomed the rights' based approach to patient safety in the Declaration, the recognition of the role, responsibility and empowerment of patients themselves in supporting patient safety and the commitment to education – including that of patients - and awareness raising. The Declaration also reflected the importance of a new culture of patient





safety developed at EU level that moves away from blame and shame and towards a more constructive approach to patient safety. EPF Vice President Susanna Palkonen signed the Declaration on behalf of EPF alongside with representatives from the European Union of Medical Specialities, the World Health Organization (WHO) and the societies of anesthesiology across Europe and the world.

The Declaration is available at:

[www.euroanesthesia.org/sitecore/content/Publications/~media/Images/Publications/Heslinki%20Declaration%20signed.ashx](http://www.euroanesthesia.org/sitecore/content/Publications/~media/Images/Publications/Heslinki%20Declaration%20signed.ashx)

## 27. EPF AT THE EUROPEAN CONFERENCE ON RHEUMATOLOGY

EPF was invited by the European League of Rheumatism to speak on patient safety and information at their annual conference in Rome 18 June in a session devoted to informed decision making, and co-organised by PARE, the 'patient section' of EULAR composed of 35 national organisations of people with arthritis/rheumatism. EPF Vice President Susanna Palkonen spoke about the role that patient organisations at European and at national level can, and do play in patient safety through examples on EPF involvement in the European Commission Patient Safety Working Group, the EUNetPas project and EPF member projects, such as the Patient safety campaign by the Polish Federation Patient Organizations, and the importance of learning from the individual patient's experience on their healthcare journey. EPF would like thank colleagues at EULAR and looks forward to closer collaboration with PARE.

For more information, please visit here: [www.eular.org](http://www.eular.org)

## 28. EPF BOARD MEETING OUTCOMES

The new [EPF board](#) met on 22 June and agreed on roles and responsibilities of respective board members, agreed on the follow up issues from the Annual General Meeting and the Health Technology Seminar, including the resources that the Secretariat will develop in the coming months, discussed the funding scenario in the framework of the EU Public Health Programme and continued planning work in relation to the last semester of 2010 and the Belgian and Polish Presidency.

It was agreed that an EPF high level select event should take place focused around the draft Directive on Patients' Rights in Cross Border Health Care with particular emphasis on quality and safety. This will be organised in collaboration with the Belgian Presidency, the European Parliament and the European Commission on the eve of the Second Vote in the European Parliament.

The next board meeting will take place on 14 September and will be followed by the annual EPF briefing for sponsors.

## 29. WELCOME TO NEW POLICY OFFICER

EPF would like to welcome Kaisa Immonen-Charalambous who joined the Secretariat in June 2009 as our new Policy Officer. Kaisa, a Finnish native has worked in both the public and private sectors in the area of health and culture. In her previous role, Kaisa was responsible for the coordination of European policy work and liaised with EU-level partner organisations and the Commission. She holds a Masters of Art in International Relations and Conflict Resolution from the University of Kent at Canterbury in the UK and a Bachelors in International Relations from the University Tampere in Finland.

Kaisa oversees EPF's policy dossiers and contributes to developing the portfolio. She monitors EU developments and actions in relation to health and patients' rights and works to provide this information to our members. She will be coordinating EPF's political approach and relations with external bodies. We would once again like to welcome Kaisa to the team.

If you would like to contact Kaisa, you can reach her at:

[kaisa.immonen.charalambous @ eu-patient.eu](mailto:kaisa.immonen.charalambous@eu-patient.eu) or +32 (0) 02 280 23 36.

## 30. DIARY

1 September	Policy Advisory Group Place: Brussels Attendance: Kaisa Immonen
1 – 2 September	Belgian Presidency Meeting "Future of Independent Academic Clinical Research in Europe Attendance: Anders Olauson
14 September	EPF Board Meeting Place: Brussels

14 September	EPF Sponsors Meeting Place: Brussels EPF Board Staff
15 September	“Direct Patient Reporting” Lunch Debate in European Parliament co-organised by EPF and PGEU Place: Brussels Attendance: Anders Olauson, Nicola Bedlington and Magdalena Machalska
18 September	EFAPH (European Federation of Association of Patients with Haemochromatosis) AGM Place: Brussels Attendance: Kaisa Immonen
22 September	Think Tank EFPIA Place: Brussels Attendance: Nicola Bedlington and Kaisa Immonen
23 September	Belgian Presidency Event on Innovation  Speaker: Nicola Bedlington
6 – 9 October	13 <sup>th</sup> European Health Forum Place: Gastein, Austria Speakers: Anders Olauson, Nicola Bedlington and Kaisa Immonen
12 – 14 October	Eucomed MedTech Forum 2010 Place: Brussels  Speaker: Nicola Bedlington
22 – 23 October	EU Presidency Meeting on Chronic Diseases Place: Brussels Attendance : Kaisa Immonen
23 – 26 October	EPF Regional Seminar Place: Budapest  Attendance: Anders Olauson, Nicola Bedlington, Liuska Sanna, Kaisa Immonen