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Dear EPF Members and Allies,

Welcome to the last EPF Mailing of 2008 at the end of a very exciting year for EPF. One of the highlights of this year was certainly our very first regional autumn advocacy seminar (26-28 November, Vilnius, Lithuania) that welcomed 50 patient leaders from the Baltic countries, the Czech Republic and Poland. Go to our [special feature](#) for a report on this memorable meeting.

We are working very hard this month to obtain support for the European Parliament Written Declaration on Health Literacy, launched by Nicodim Bulzesc, MEP. Please see [section 5](#) on the EPF Manifesto to read how you could contribute to this.

Much energy has gone into attempts, together with sister NGOs in the health field to reverse the negative Council discussions on the draft Directive on Patients Rights in Cross Border Healthcare, that attempt to water down considerably the Directive, particularly in relation to fundamental principles around quality of care and patient safety. Please go to [section 2](#) for more details. This will be a long and difficult battle over the next few months.

Since our last issue the Communication on Rare Diseases has been adopted by the European Commission, that aims towards an integrated approach towards rare diseases at EU level. We congratulate EURORDIS on their enormous efforts in this regard. A detailed article on the Communication and EURORDIS's views on the way forward will feature in our next issue in the New Year.

We are also very pleased to be able to report on the European Commission Open Health Forum where Anders Olauson chaired a parallel session on a Europe for Patients, new EPF Board member Rainald von Gizycki gave a presentation on E-health, and Sofia Jönsson gave a presentation on behalf of EPF on the young patients' perspective on EU healthcare. For a report of this meeting, please go to [section 17](#).

It is our great pleasure to include an article from IAPO announcing their new toolkit on patient safety. ([See section 14](#)). This has been sent directly to the EPF membership across the EU, and we would like to congratulate and thank IAPO for this excellent initiative.

As 2009 approaches, the EPF board met on 9th December to discuss the work plan and budget for next year, a revised framework for working with funders and EPF's Code of conduct.

Because of delays in adoption, we are unable to provide you with detailed information at this stage on the Pharmaceutical Package that was launched on 10th December. We have however done a brief commentary in [section 4](#). A detailed analysis will be included in our next issue.

We take this opportunity to thank all readers for their interest in and support for EPF over the last year. We are very much looking forward to continuing our common work to move forward together on patient – centred equitable health care in the European Union.

Our warmest greetings for a very happy holiday season and a peaceful and successful new year!!

Warmest greetings,
Anders Olauson, President
Nicola Bedlington, Director

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The next issue of the EPF Mailing will take place on 15 February 2009. The deadline for submission is 3rd February 2009.

1. VALUE+ EPF AUTUMN REGIONAL ADVOCACY SEMINAR FOR PATIENT LEADERS

On 27-28 November EPF held its annual autumn seminar for patients' leaders. This year the seminar was linked to the project VALUE+ and was therefore prepared in cooperation with the partners of the project, in particular the Health Policy Center of Lithuania and the Council of Patient Organisations in Lithuania.



The purpose of the seminar was to build knowledge and know-how on working at EU level through and with EPF and explore initial findings from the VALUE+ project.

The delegates represented patients' organizations mainly from Lithuania, Estonia, Poland, the Czech Republic and Latvia.

The first part was dedicated to an introduction to EU policy-making and decision-making processes. The perspectives were quite diverse since the speakers came from the European Parliament, different bodies of the European Community, the patient community and the Czech Republic Government. The audience appreciated the practical and concrete insights the speakers brought from their experience and expertise.

The other main focus was VALUE+, which was introduced to the delegates. VALUE+ is conducting an assessment of patient involvement in health-related projects supported by the European Commission. The findings to date were shared.

Delegates had the opportunity to address more in depth some of the issues touched upon during the plenary sessions in a series of workshops.

While the full programme can be seen [here](#) and a report will be soon available, we want to give you here an anticipation of the main conclusions mainly coming from discussions in the workshops.

How to get involved in a consultation process at EU level

- Patients' organisations need training in different areas: leadership, management, lobbying, working with media, negotiation skills, etc.
- It is important to set up partnerships with the Ministries.
- Being a member in a European organization is good for continuity of work.
- Building relationships with members of the National Parliaments can help influence Ministries.
- Cooperation with health professionals is beneficial to integrate a patient perspective.

Patients' Organisations as Partners in Policy-making

- Lack of understanding or recognition by governments of the value and importance of patient involvement;
- Lack of resources for patients' organisations – human, financial;

- Need for an independent and professional representation of patients at national level.

Information to patients – how to apply at national level the deliverables of the European Pharmaceutical Forum

- Information is a central instrument/tool
- Information is the right communication at the right time.
- The concept of health literacy is crucial.
- Importance of the quality, reliability, accessibility of information.
- Importance of resources and of the cooperation between all health care actors and patients' representatives.

Patient involvement in projects: how project outcomes feed into policy development and advocacy

- Strategize advocacy and lobbying activities around the evidence collected through projects;
- Organise conferences and information days on the project outcomes;
- Seek for partnerships with other patients' organisations to have a stronger voice.

The role of Patients' Organisations in European Campaigns – the EPF Manifesto

- The Manifesto should be translated.
- Effective use of Banner on websites and website links with decision-makers and other health stakeholders – encouragement to sign up to the Manifesto.
- Using the Manifesto on all possible occasions –a tool to get the message across –integrate the Manifesto in other campaigns.
- Take the opportunity offered by the European Patients' Rights Day.



Assessing the needs for patient involvement and best practices

- Patients' organisations want to be involved in all aspects of projects they participate in.
- There is a strong need for training to support patients' organizations' involvement.
- Financial and human resources are crucial to get involved in projects and policy work.
- Networking and cooperation between patients' organisations can optimize the few resources available.

A full report will be available in EPF's website by the beginning of January. Meanwhile you can download the presentations from the [EPF website](#).

2. DIRECTIVE ON PATIENTS RIGHTS IN CROSS BORDER HEALTHCARE

On 1 December, the Committee on the Environment, Public Health and Food Safety (ENVI) in the European Parliament discussed MEP John Bowis' s report on the proposal for a Directive on the application of patients' rights in cross-border healthcare.

The report makes it clear that the Directive it is an opportunity for patients, based on need and not means, on informed choice and not compulsion. With regard to the concerns raised by EPF and its members on up-front payment, the report proposes to put in place system of reimbursement direct from home funder to receiving hospital. One option is a Central Clearing House to manage the cross-border, cross-currency, cross-system (Beveridge/Bismark) complications. However, as a Clearing House could take time to establish, an additional and swifter mechanism is suggested: a patient who chooses to use the prior authorisation process established by his or her home country of affiliation, should receive a voucher to take to the treating hospital, guaranteeing payment up to a given amount. Another aspect strongly highlighted in the report is that Member State of can and should ensure that healthcare quality and safety standards are described publicly.

EPF together and several major NGOs in the health field have worked on a [Statement](#) to reverse the negative discussions in the Council on the draft Directive that attempt to water it down considerably, particularly in relation to fundamental principles around quality of care and patient safety. Key messages in the statement are:

- The Directive should explicitly uphold the Council's commitment to the values of universality, access to good quality care, equity, and solidarity.
- The Directive should recognise the Commission's role in taking the lead in ensuring the collection and availability of accurate information on key quality indicators across the EU.
- Where prior authorisation for hospital care is adopted, authorisation processes should be swift, transparent and underpinned by clear information for patients.

- A group of experts should work with Member States and the Commission to develop a common-sense framework for defining hospital care that neither restricts nor extends the intended scope of prior authorisation.

The Statement has been sent to deputy permanent representatives and health attachés in all Member States.

On 16 and 17 December the Employment, Social Policy, Health and Consumer Affairs Council will meet to discuss the draft Directive. Key questions that will be explored:

- Is it desirable for the Directive on patients' rights to aim to codify all Court of Justice case law on the application of the principle of free movement of goods and services in the field of health?
- What must be the objectives of organising a link between the Directive on patients' rights and the Regulation on the coordination of social security systems?
- What are the guiding instruments that you consider essential in order for patients' mobility not to compromise equal access by all to healthcare?
- What guarantees must be given to patients as regards information on healthcare provided in another Member State, including in terms of quality and safety?

The European Data Protection Supervisor (EDSP) transmitted also his opinion on the draft Directive to the Council, in the view of the forthcoming discussions. While expressing his support for the initiative, EDPS called for better coordination of the EC healthcare initiatives with regard to data protection (ex. the forthcoming Directive on human organs donation and transplantation, the Recommendation on the interoperability of electronic health records, the Communication on Telemedicines). He suggested the Directive should feature a clear definition of "health data" which should include medical data, as well as administrative and financial data related to health. Lastly, he strongly recommended the introduction of a specific article on data protection, which should describe the responsibilities of the Member States of affiliation and treatment and identify main areas for future development.

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

3. CONFERENCE ON THE OUTCOMES OF THE PHARMACEUTICAL FORUM – DELIVERING FOR PATIENTS

EPF will be co-organising a Conference on the Outcomes of the Pharmaceutical Forum and their dissemination among patient groups and the Health Community at large. The Conference will take place on 25 March 2009 and will be followed by the EPF Annual General Meeting on 26 March 2009.

As readers are aware, the Pharmaceutical Forum was set up for a 3 year period in 2005 with the objective of improving the performance of the pharmaceutical industry in terms of competitiveness and contribution to social and public health objectives. The final conclusions and recommendations of the Forum as well all the information relating to the process is available at <http://ec.europa.eu/pharmaforum/>.

The conference should provide patients' leaders and health stakeholders throughout the European Union an opportunity to share the knowledge gathered by the members of the Forum on **information to patients, pricing & reimbursement and relative effectiveness**, to explore the solutions proposed and to put forward proposals for actions for implementation and follow up with their respective organisations.

Given that direct involvement in the process was mostly focused on experts of Member States and key stakeholders at European Union level, it is important to ensure that the Conclusions and Recommendations and specific deliverables from each of the working groups are shared with the Health Community at large.

The primary focus of the conference will be the **dissemination of the results** of the Forum.

In addition, concrete experiences will be presented to illustrate how the Conclusions and Recommendations could be translated into reality by the whole range of health stakeholders and to ensure the momentum and energy underpinning the Pharmaceutical Forum can be maintained at all levels.

The conference is primarily dedicated to patients groups either specialised in specific disease areas and/or representing patients at the local, national or European levels.

Representatives from the broader health community with a stake in the three key areas addressed by the Pharmaceutical Forum are also very welcome.

A preliminary programme is available at <http://ec.europa.eu/pharmaforum/>. Further information on the conference will be available online as from January 2009.

4. THE EUROPEAN COMMISSION ADOPTS THE PHARMACEUTICAL PACKAGE

On the 10 December the European Commission adopted the Pharmaceutical Package consisting of:

- a communication on the future of the pharmaceutical sector,
- a proposal on counterfeiting and illegal distribution of medicines,
- proposals to enable citizens to have access to high-quality information on prescription-only medicines and
- a proposal to improve patient protection by strengthening the EU system for the safety monitoring ("pharmacovigilance") of medicines.

For more information and to access the texts of the proposals, please click on the following link:

http://ec.europa.eu/enterprise/pharmaceuticals/pharmacos/pharmpack_en.htm

EPF has been extremely active in relation to all of these developments, having prepared substantive responses to the Commission earlier consultations – please see the EPF website www.eu-patient.eu.

EPF President Anders Olauson said: “We clearly need to look at the details and implications of each of the proposals, however our overall preliminary reading is positive – we welcome the Package. Collectively these proposals should provide for a better, safer deal for patients across the European Union. On information to patients, we are especially pleased to see that the work of the Pharmaceutical Forum on quality principles on information to patients is reflected in the text.”

We will be developing a formal response to the Package in consultation with our Members in the New Year.

A detailed report, including our members’ feedback will be included in the next issue of the Mailing. EPF will be running a Patients Evidence Workshop on the Pharmaceutical Package in the second week of January (date to be finalised).

An invitation will be sent to all EPF member organisations, who will be encouraged to send a representative.

5. CAMPAIGN UPDATE ON EPF PATIENTS' MANIFESTO CAMPAIGN AND HEALTH LITERACY

EPF is continuing our campaign on the EPF Patients' Manifesto "150 Million Reasons to Act". As reported from the Value+ Seminar in Vilnius, there is great enthusiasm to mobilise patients organisations at national level. The Manifesto has already been translated into French and Romanian and will be translated into Lithuanian, Latvian, Estonian, Polish and Czech by the early New Year. Standard templates for the Manifesto brochure, press releases and letters are being provided by the secretariat.

The secretariat would welcome greatly feedback from other members with regard to how you are working with the Manifesto in a national and European context.

An integral part of the Manifesto is our call for increased commitment to prioritise Health Literacy as a political and programmatic priority at member state level. To that effect, a **Written Declaration on Health Literacy** has been launched in the European Parliament and we are working closely with all Groupings to ensure sufficient signatures by the deadline of **12 March 2009**.

If members and allies can support EPF in this work by encouraging their MEP champions also to sign up to the Declaration, this would be welcomed warmly.

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

6. THE EUROPEAN TRANSPARENCY INITIATIVE

Launched in 2005 by the European Commission, the transparency initiative was conceived to:

1. strengthen public trust in the EU institutions through increased openness and accessibility;
2. raise awareness of EU budget spending and
3. increase EU's accountability.

The European Transparency Initiative (ETI) is a package with four main components:

1. increasing the transparency of interest representatives seeking to influence EU decision making and upholding minimum standards of consultation;
2. increasing transparency about the use of EU funds;
3. ethical rules and standards for public officials;
4. public access to documents.

In 2008 the European Commission has further fostered the ETI by adopting a Code of Conduct for lobbyists and launching a voluntary online-register of interest representatives.

The Code of Conduct contains "clear and precise rules" for lobbyists to follow in their relations with staff at the EU executive, setting out general principles to be adhered to like "openness, transparency, honesty and integrity".

Lobbyists wishing to be included in the Commission's register are required to accept its terms or abide by their own equivalent code of conduct with identical or more stringent requirements.

The register is organisation-based and features three main categories of lobbyists:

1. Professional consultancies and law firms,
2. Corporate lobbyists and trade associations and
3. NGOs and think tanks.

Lobbyists wishing to be included in the register are required to disclose factual and financial information with some variations according to the type of organisation.

Consultancies and law firms are asked to provide a detailed breakdown of lobbying revenue in brackets of €50,000 or percentage brackets of 10%, while NGOs and think tanks must publish their overall budgets and indicate their main sources of funding (e.g. public European, national or sub national funding, donations, membership fees).

In October 2008, the “Financial Transparency System” website and search engine were launched. The aim of the FTS is to offer free access to the details of those receiving the EU funds directly managed by the European Commission and its executive agencies.

Further information and latest news on ETI can be found on:

http://ec.europa.eu/commission_barroso/kallas/transparency_en.htm

EPF is in the process of applying to the on-line register. It would be very useful if your organisation, as an umbrella European or national advocacy NGO working on behalf of patients, also registered in your own capacity.

Should you need any additional information or support on this, please contact [Valentina Strammiello](#).

7. LAUNCH OF PATIENT SAFETY ADVOCACY TOOLKIT - IAPO



The International Alliance of Patients' Organizations (IAPO) has recently launched an advocacy toolkit for patient groups. The toolkit, "Addressing Global Patient Safety Issues: An Advocacy Toolkit for Patients' Organizations", is the first multi-issue resource for patient groups, providing the means for patients and patients' organizations to engage in the provision of healthcare and contribute to a quality and safe healthcare system, and a reduction in harm to patients.

IAPO has a core value of providing capacity building resources for patients' organizations and involving patients and patients' organizations in debate and policy-making at the international, regional, national and local levels.

It is a key part of IAPO's mission to empower and enable patients' organizations around the world to be well-informed and effective advocates at every level where healthcare decisions are made. To this end, IAPO undertakes a role in providing accurate, balanced information to patients' organizations on relevant issues and resources and tools to enable them to become informed, and active on the issue.

The Patient Safety Advocacy Toolkit was developed following a request from our member patients' organizations for a resource that clearly explained some of the key patient safety issues and would allow them to practically advocate around them.

In consultation with our 200 member patients' organizations, we put together a list of issues and asked them to prioritize these. Following our discussions, the toolkit focused on: Medical Error, Taking Medicines

Correctly, Hospital Acquired Infections, The Quality and Safety of Medicines, Injection Safety, The Re-Use of Single-Use Medical Devices, Maternal and Child Health and Safety and Patient Participation in Clinical Trials. Key patient safety issues have been brought together in the main booklet, with crucial advocacy messages, background information, facts and figures, a case study and links to further information. Included inside the toolkit are inserts on the first four issues that can be photocopied and used as posters. The inserts have FAQs on one side and a checklist on the other.

The main booklet also contains a section on advocacy and partnerships as well as communications. These sections provide tips and models for working with key stakeholders and communicating key patient safety messages.

The toolkit also comes with a CD-ROM, that contains a PDF of the main booklet, press release templates and letters to healthcare stakeholders, key IAPO documents and links to other tools. The information found in the toolkit can be used to produce your own press releases, letters to government officials, presentations, leaflets, posters, website content and other materials.

Hussain Jafri, IAPO Chair Elect and Chair, Alzheimer's Pakistan, in highlighting the importance of the toolkit, stressed that "...everyone has a role to play in protecting patient safety. However, it is imperative that all healthcare providers, in particular governments, support measures that can protect patients from adverse events. The IAPO Toolkit will provide patients and their representatives with the information and confidence to hold all healthcare stakeholders to account and ensure that they receive the highest achievable level of quality and safe healthcare. "

We are pleased to be able to share the Patient Safety Advocacy Toolkit with EPF members and a copy is available to all patients' organizations at no charge. If you have not yet received a copy and would like to receive one or have any questions, please contact Jeremiah Mwangi, IAPO Senior Policy Officer, by email on [info \(at\) patientsorganizations.org](mailto:info@patientsorganizations.org) or by telephone on +44 20 79537613.

8. HEALTH FIRST EUROPE, NEW HORIZONS CONGRESS, 12 NOVEMBER 2008, BRUSSELS

The New Horizons Congress “Tackling the healthcare challenges of today for a healthier tomorrow” was organized by Health First Europe on the 12 November 2008.

A wide range of stakeholders – patients’ representatives, EU institutions and Members States representatives as well as healthcare professional – attended this Congress.

The first session devoted to the patient perspective on the future healthcare was warmly welcomed by patients’ representative as it allowed them to give the tone to the rest of the conference. During this session patients’ views and expectations regarding patient safety, access to healthcare and patients’ involvement issues were presented through patients organizations representatives (IAPO and Pelvic pain Support Network) and through the presentation of the EUnetPAS project and its main achievements.

The European Commission representatives recalled that Patient Safety is a priority in the EU Agenda and acknowledged the need for action. They also confirmed that an EC Communication on Patient Safety as well as the Pharmaceutical Package (which will address also information to patients concern) will be issued before the end of the year.

The keynote speech was given by the European Commissioner for Health, Ms Androulla Vassiliou who presented the EU Key initiative “Europe for Patients”. The aim of this initiative is to provide patients with clear information on EU work through a campaign made up of 10 policy initiatives for better healthcare and the launch of a web portal.

A specific session on healthcare professional issues was held giving the opportunity to discuss the EC upcoming Green Paper on the EU Workforce for health. One of the issues that were raised is the need for cross-border collaboration in this field to tackle a problem linked to social and economical issues. The publication of the Green Paper will launch a public consultation process – which will run until the end of March 2009 - to obtain everyone's views on a wide range of issues connected with the healthcare workforce and preparing for the care of an ageing population.

Conference report, presentations and videos are available at:

www.healthfirsteurope.org/index.php?pid=173.

9. MEETING ON INFORMATION TO PATIENTS 20 NOVEMBER, LONDON

Nicola Bedlington represented EPF at a meeting organised by the Association of the British Pharmaceutical Industry ABPI, on 20th November in London, that brought together key patient and industry representatives to discuss the then pending EU proposal on Information to Patients. Nicola gave the perspective of the European Patients' Forum on the legislative proposal and outlined the importance of the quality principles adopted by the Pharmaceutical Forum, that should be a key dimension of the proposal. Other speakers included Jeremy Mean, Group Manager - Information for Public Health Vigilance and Risk Management of Medicines, MHRA, Claire Lilley Principle Policy Advisor, Which, Paul Woods, Co-Chair of the Information to Patient Taskforce, EFPIA (The European Federation of Pharmaceutical Industries and Association). The meeting was chaired by Joanne Shaw, Chair of NHS Direct and Chair of Datapharm, all of whom gave their viewpoints on the implications of the proposed legislation for patients in the UK.

For a report on the key discussion points emerging from this meeting please contact the [EPF secretariat](#).

10. EUNETHTA CONFERENCE, 20 NOVEMBER, PARIS

More than 400 people participated in the EUnetHTA Conference in Paris on 20 November where current developments in European health technology assessment (HTA) along with the planned activities of the European Network for Health Technology Assessment – EUnetHTA- were presented and discussed. Roxana Radulescu represented EPF at this meeting.

Background

In 2004 EU Member States in the High Level Group on health services and medical care requested the establishment of a sustainable network for HTA in Europe. This was endorsed by the Council of Health Ministers and the European Commission. Following a call for proposal, the EUnetHTA project was set up in 2006 and co-funded for 3 years by the European Commission. Its aim was to connect public national/regional HTA agencies, research institutions and health ministries and enable an effective exchange of information and support to policy decisions by the Member States. A total of 63 HTA institutions and organizations joined the EUnetHTA network, organized as an open network with extensive communication facilities.

“Health technologies” cover a broad range of issues comprising diagnosis and treatment methods, medical equipment, pharmaceuticals, rehabilitation and prevention methods, as well as the organizational and supportive systems within which healthcare is provided. From this perspective, health technology assessment (HTA) is a multidisciplinary process that summarizes information about the medical, social, economic and ethical issues related to the use of health technologies. Its aim is to inform policy-makers to formulate safe and effective health policies that are patient-centered and seek to achieve the best value. Despite its policy goals, HTA must be always be firmly rooted in research and scientific method.

At the Paris Conference, the results of the EUnetHTA project collaboration were presented. A key achievement was the development of the HTA adaptation Toolkit which currently includes five domains: technology use and development, safety, effectiveness (including efficacy), cost-effectiveness, organisational aspects. A Glossary has also been produced identifying terms that cause confusion, gathering explanations and definitions from all partners and developing EUnetHTA definitions. The Toolkit and the Glossary will go through further testing, review and improvement within EUnetHTA and beyond and will extend their scope to include diagnostic, testing and screening.

In the context of the draft Directive on the application of patients' rights in cross-border healthcare, HTA is clearly defined as a field in which collaboration between Member States can yield relevant added value. Currently there are wide variations and frequent duplications in such assessments between and within Member States in terms of methodologies used and the consequent uptake of innovations, which act as a barrier to the free movement of the technologies concerned and undermine the confidence in standards of safety and quality across EU. EPF strongly supports patients' organisations' involvement in these processes and clear and transparent rules that ensure that balanced stakeholders' views are obtained.

Another key message was EUnetHTA's interest in communicating with stakeholders (national and regional policy makers, patients' organizations, health professionals organizations, industry and health related media) about general HTA processes and in engaging in partnerships with umbrella organizations working at European level. EPF expressed a strong interest in getting involved in EUnetHTA collaboration and in the possibility of taking part in the Advisory Council in the coming years.

For further information: www.eunethta.net

11. EFPIA PATIENT THINK TANK, 21 NOVEMBER, BRUSSELS

Nicola Bedlington represented EPF at the EFPIA Patients Think Tank on 21 November 2008.

Key items on the agenda were the Commission Communication on Telemedicine for the benefit of patients, healthcare systems and society, by Christoph Steffen (European Commission, DG INFSO), patients' access to new medicines, an update on the new Commission proposal for a Directive on the protection of animals used for scientific purposes.

Christoph Thalheim also shared information on the newly launched Multiple Sclerosis Barometer, developed in the framework of the Multiple Sclerosis Information Dividend project. The “MS barometer” charts the situation faced by people with MS across Europe in 7 key areas: access to treatment and therapies, research, employment, empowerment of people with MS, reimbursement of costs related to MS, data collection and medication on the market. It was released in November in the European Parliament where high level representatives from the Commission and national governments, leading neurologists and people with multiple sclerosis met for the second annual Multiple Sclerosis Information Dividend (MS-ID) Conference.

Flaminia Macchia gave an overview of the Commission Communication on Rare Diseases. A detailed article on this Communication, and EURORDIS perspective on the next steps will feature in the next issue of the Mailing.

For more information or copies of presentations made at the meeting please contact the [EPF secretariat](#).

12. HAS REFLECTION GROUP ON PATIENT SAFETY, 2 DECEMBER, PARIS

The French National Authority for Health ([Haute Autorité de Santé - HAS](#)) organized a brainstorm meeting with representatives of patients' organizations, research institutions, healthcare and health education professionals on patient's role in improving the quality and safety of healthcare across EU. This has been a first from a series of workshops with the aim of stimulating the debate on this topic. The ultimate objective of these workshops will be to produce a White Paper on the new role and responsibilities of patients in improving the quality and safety of healthcare. EPF was invited to join the group and contribute to the discussions from a European policy perspective. Roxana Radulescu represented EPF at this meeting.

It was highlighted that France is in a rather good position in terms of quality of care and patient safety, but it faces major challenges in terms of coordination and continuity of healthcare. HAS key role in prospective thinking on health care systems' sustainability and in advising the decision-makers was stressed.

The group discussed about the dates and structures of next meetings and identified a series of key topics to be debated in the coming months:

- Patients vs citizens;
- Challenges of shared-decision making, for health professionals and patients;
- Patient's place in elaborating policy recommendations;
- What language to use when engaging with the public?
- Patients' self-management – what are the limits?
- Patient's place: inside the system or outside the system? Involvement or engagement?

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

13. EUROPEAN PARLIAMENT SEMINAR ON TELEMEDICINES, 3 DECEMBER BRUSSELS

Nicola Bedlington represented EPF at a seminar organized by the [CONTINUA](#) Health Alliance in the European Parliament to discuss the new Communication on Telemedicines. In the introductions it was highlighted: “As the European population is ageing and the share of the population with chronic diseases is increasing, the demands on healthcare services grow. The ageing of the population will result in a dramatic increase in chronic diseases which are the diseases that put the biggest strain on healthcare systems. At the same time, it will become increasingly difficult to provide adequate care to this growing population as the provider pool shrinks and funding is stretched tighter and tighter. Telemedicine can be part of the solution to provide high quality care to a large share of the population, whilst ensuring autonomy for patients”.

Chaired by Petra Wilson of CONTINUA, a presentation was first given by Gerard Comyn from the European Commission, followed by a commentary by Ms Mian De Vits MEP. Brian McKinstry, University of Edinburgh, Scotland and Atul Kumar, National Health Service, England gave very interesting presentations on how they are integrating telemedicines in their work as doctors and observations with regard to how their patients are responding positively. Discussion also took place on the economics of telemedicines, and the need for further research in the arena. Nicola Bedlington gave some insights on EPF 's perspective on the new Communication and our specific role in terms of creating acceptance and trust, contributing the ethical Guidelines linked to the application of telemedicines, and our role of the new Platform to be set up in 2009 on Telemedicines.

For more information about this event please contact the [EPF secretariat](#).

14. EPOSSI WORKSHOP ON CHRONIC CONDITIONS, 3 DECEMBER, BRUSSELS

The European Platform for Patients' Organisations, Science and Industry (EPPOSI) - a EU patient-led partnership between patients, industry and academic science - held a workshop on Chronic Conditions on 3 December, in Brussels.

Roxana Radulescu and Nicola Bedlington represented EPF at this event. The meeting was attended by around 50 representatives of patients organizations working at European level or at national level, industry, as well as European Commission.

Having as a starting point the concerns raised by the burden of chronic diseases and the pressures on the health authorities and health services providers, the workshop offered an opportunity to debate on what should a **European Strategy for Chronic Conditions** be like.

In the morning session, several interesting presentations were given reflecting the perspective of patients with hemophilia and patients with arthritis and rheumatism. One of the key messages was that patients' organizations can play a key role in educating medical and paramedical staff.

The perspectives of carers and their importance as a huge resource at statutory level, at local and family level was also highlighted. A representative of the European Commission gave an overview of the EU approach to disability and work. In the following discussions it was recommended that the Disability Directive should create links with the situation of patients with chronic conditions.

Participants split in break-out sessions in the afternoon and discussed specific topics such as: medical and integrated care, social life and employment, access to intervention.

Finally, some key aspects towards a European strategy on chronic conditions were pointed out: continue raising awareness about the burden of chronic conditions, support Member States to develop national actions plan on chronic diseases, develop work rehabilitation programmes, involve patients organizations in research. A common and strong patient voice among patients groups in working at EU level – via EPF for example - was strongly encouraged.

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

15. LONG LIVE EUROPE – SHAPING OUR HEALTHCARE REVOLUTION, 8 DECEMBER, BRUSSELS

Anders Olauson participated in a panel session on behalf of EPF at this one-day summit co-organised by Friends of Europe and Novartis. The key question for the panel was “Is an EU – wide healthcare market unthinkable?” Free and fair competition is widely held in the EU as the best way to boost innovation and improve efficiency. Yet in the healthcare sector patients have little choice on health insurance and treatment. Even in the field of e health, restricted competition and investment are preventing productivity increases that information and communications technologies could yield. Is freer intra-EU competition in healthcare really incompatible with the European social model? What are the political obstacles to healthcare reform, and how might they be overcome? How far could the Commission’s plans for a “common EU e-health area” take us towards a common market in medical services and treatment?

Anders’ key messages in the debate focused on the kind of sustainable society we all want for the future and the place of patients in that society. He highlighted the need for a balancing act between a healthy rights-based society, and a “market driven” society. He also described the importance of an empowered, and also responsible patient and the role that e-health can play in achieving this. Interoperability across different health systems will be crucial for the principles behind cross border healthcare to really work in practice and provide the informed choice, quality and safety to which we believe all patients across the EU have the right.

For a full report of the event – please go to www.friendsofeurope.org.

16. CONFERENCE ON HUMAN RIGHTS AND BIOMEDICINE, 10-12 DECEMBER 2008, ROTTERDAM

On the 60th Anniversary of the Universal Declaration of the Human rights, Erasmus University held a three days conference focusing on Human rights and Biomedicine issues in Rotterdam. Elisabeth Kasilingam represented EPF at this event.

The European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine, 1997, stipulates the legal principles which are binding on the field of medicine and biology. Together with the European Convention of the Human Rights, it is one of the leading treaty documents passed by the Council of Europe. The Biomedicine Convention is the first international document formulating guiding principles on equitable access to healthcare, informed consent, organ transplanting and the use of substances of human origin, medical research on human beings, the protection of the human embryo and fetus, and the use of medical information.

This conference brought together a wide range of stakeholders from various national, European and international institutions from all over the world to discuss the meaning of the Convention's principles and fundamental rights in healthcare.

The latest improvements in the field of biomedicine, biomedical research and innovation have raised several concerns about their accordance with human rights and human dignity. The different sessions held on specific topics such as patients' rights, equitable access to healthcare as a human right issue, clinical trials, organ transplant, etc. opened interesting debates on the role of the existing legislations in this field.

The Erasmus University has launched a new website: The Erasmus Observatory on Health Law (www.erasmusobservatoryonhealthlaw.nl). The Erasmus Observatory's mission is to improve and promote the understanding on health law through a variety of programmatic activities, including research, education, training, collaboration and dissemination of information. To respond to the increasing need of legal advisors in the health

sector, the university has also created a new Master in healthcare law and summer courses on Health law and ethics.

Some of the points raised and conference outcomes:

An EU common approach has to be built on ethical issues and principles. Although it is difficult to come to an agreement, this is not a reason to abandon. Global standards are needed to increase public awareness and to promote public debate.

Equity in healthcare is a core issue, especially for patients from vulnerable groups (older population, women, asylum seekers, migrants, etc.) The following-up of the framework regulations, especially of the European institutions (European Commission, Council of Europe, etc.), and their implementation need a better monitoring.

Legal regulation of biomedical research has to take into account two principles: the freedom of research and the respect for human dignity and human rights. This can be ensured with the establishment of a legal framework. The EU has played a significant role in this field. It appears that those two principles often do not serve the same purpose. Therefore, EU should clarify its decisions and give a clear explanation of its motivation.

Regarding Patients' rights issue, only few countries have adopted specific laws on Patients' rights. The European Convention on Human rights and biomedicine proclaims general rights linked to health. Several fundamental rights can be affected when patients are affected. Public authorities should undertake this issue and ensure the respect of each individual's rights.

Health and healthcare are not an individual issue - being a patient has a consequence on family, social, professional life. This becomes a collective issue and has to be seen such as.

A full conference report will be available later on. Meanwhile, please contact [EPF secretariat](#) should you require further information.

17. EU OPEN HEALTH FORUM, 11-12 DECEMBER, BRUSSELS

The EU Open Health Forum is a mechanism for the European Commission to get feedback from stakeholders on the implementation of the EU health policy and to identify the need for new policy initiatives at EU level. It also facilitates networking and exchange of good practice in the implementation of public health policies at EU, national, regional and local level.

This year the EU Open Health Forum gathered more than 500 participants from across EU. Under the overall theme of "Developing and Implementing Health in the European Union" the Forum was an opportunity to stimulate discussion on the challenges of implementing the EU Health Strategy and strengthening the involvement of all stakeholders in contributing to its implementation.

EPF was represented by its president, Anders Olauson, who chaired a parallel session on a Europe for Patients, by Nicola Bedlington and Roxana Radulescu from the Secretariat, as well as by Rainald von Gizycki, new EPF board member, and Sofia Jönsson, a young patient, who gave two powerful presentations in the parallel workshops.

In his presentation on the patients' perspective on maximizing health benefits through health technologies, Rainald strongly highlighted the great potential of information and communication (ICT) technologies for patients' empowerment, information to patients and patients' health literacy, patient-centred disease management, patient safety, patient cross-border mobility and the quality and continuity of health care. Taking the example of telemedicine, he explained the risks and benefits of ICT: isolation vs increased quality of life (home environment), "big brother" effect vs telemonitoring, losing autonomy vs access to expert advice, technology driven healthcare vs patient empowerment. He further pointed out why electronic health records should be in patients' hands: less than 5% doctors receive patients' records

from colleagues in time, less than 2% family doctors inform specialists about changes in patients' health (source VSD), more than 90% of patients believe that their medical info should be available to all professionals involved (source: EURORDIS) and more than 70% of patients believe in shared-decision making with doctors (source: HKV study). He concluded that EHR in the hand of patients are a powerful tool to strengthen doctor – patient relationship and improve quality of medical care, as well as enhancing life planning.

Sofia Jönsson gave a presentation in the session healthy lifestyles for young people on the young patients' perspective on EU healthcare. Sofia is involved with Ågrenska Foundation in Sweden in a project on a young patient's perspective which aims to try to find what young chronic patients think about their situation and opportunities to live and take care of themselves. She highlighted that for chronic young chronic patient systems, organizations and people that are supposed to help them are often regarded as enemies. In order to get help, they always have to struggle, beg, be "system smart". Although spontaneous change is difficult for young patients who are permanently sick, their perspective is important and needs to be taken seriously. The limitations in their own mind and in others' expectations them us actually narrow what they can and what will really achieve in life. Another issue discussed by the young people participating in this project was that organisations like EPF can be a platform for greater influence and understanding, but on the other hand, EPF can be seen also as another barrier. It depends on how organizations like EPF manage to integrate the youth perspective in they work.

Some key messages coming out from the discussions in the three working group:

- Member States organize health systems, but patients' rights are trans-national and need European debate.
- There is a need to look beyond EU and national budgets and redefine overarching global budgets to include health.
- Safety and quality of care for patients are crucial drivers for the EU and MS should state out their standards for quality and safety.

A specific session also took place on Reducing Inequalities in Health – the Way Forward. This session explored the potential of key actions by the EU in a number of areas:

- Raise awareness about the extent and consequences of health inequalities and to promote the tackling of health inequalities as a policy priority both at Community level and in all Member States;
- Improve mechanisms to monitor inequalities in health across the EU (between and within the Member States) by improving data collection via more systematic and comparable information, that complements existing data.
- Support Member States, by encouraging greater policy coordination and best practice exchange, and through financial support via the Structural Funds and other EU funding instruments;
- Mobilise all relevant policies to contribute to reducing inequalities in health by bringing together under a coherent framework the work of different Commission services in line with the 2008 Renewed Social Agenda and the 2007 Health Strategy.

The Commission will launch a Communication on Tackling Health Inequalities as part of its work plan for 2009. EPF will be, during the early part of 2009 consulting its members regarding the key elements to be included from a Patient's perspective.

For more information on the outcomes of the Open Health Forum, please go to http://ec.europa.eu/health/ph_overview/health_forum/open_2008/index_en.htm.

18. REPORT AVAILABLE: CONFERENCE “EUROPE FOR PATIENTS”, PARIS, 13-14 OCTOBER

The report on the conference “European Health at the service of patients” held in Paris on 13 and 14 October 2008 is [now available in French](#). Organized in the framework of the French Presidency of the Council of the European Union as a first step of a wider programme involving the presidential troika France-Czech Republic –Sweden, the conference had a twofold objective:

- to present the added value of EU action on health issues, such as safety, quality of care and the promotion of patients' rights, and
- to compare the progress achieved with patients' expectations and forthcoming challenges.

The conference, organized in six different sessions, hosted around 400 participants from across EU bringing experiences from the point of view of experts, health professionals, patients' associations, European Commission, Member State representatives and MEPs.

19. SECRETARIAT NEWS

Roxana Radulescu promoted to senior policy advisor

The board and secretariat would like to congratulate Roxana Radulescu who has been promoted to EPF senior policy advisor. Roxana has been with EPF almost since the beginning of the secretariat and has made a major contribution to our policy input in close collaboration with the members. We wish her continued success in her work and dedication to the aims of EPF.

Goodbye to Elisabeth Kasilingam

Elisabeth Kasilingam will leave EPF at the end of December, having worked with us as assistant policy officer for just over a year. Elisabeth has made a very positive contribution to EPF during the extremely active year, both on the policy support side and office management. A big vote of thanks from the board and the secretariat to Elisabeth, and our warmest wishes in her future professional challenges.

New Intern joins EPF

EPF's new assistant policy officer Sophie Letorey joins the secretariat on 2nd December. Sophie -of French origins- has already had an internship with the French sector of Caritas, an international non-profit organization. She worked for the department of the international defence and developed a study on the South Kivu and particularly on the subject of "rape as a weapon".

Sophie holds a BA in Political Science and Public Management and studies at present to obtain her diploma of master in Political and Public Strategy and Decision from the Higher Institute of Public and Political Management (ISMAPP). She will focus on the public and political institutional watch and will participate in internal and external communications strategy of EPF.

20. DIARY

	Wed, Dec 3	Seminar in the European Parliament concerning the Telemedicine Communication as well as wider Telemedicine issues Place: European Parliament, Brussels Attendance: Nicola Bedlington (speaker)
	Mon, Dec 8	Friends of Europe Conference 'Long live Europe! Shaping our healthcare revolution' Place: Brussels Attendance: Anders Olauson (speaker)
	Tue, Dec 9	Board Meeting Place: Brussels Attendance: EPF Board
	Wed, Dec 10 -- Thu, Dec 11	EU Open Health Forum Place: Brussels Attendance: Anders Olauson (chair), Rainald von Gizycki (speaker), Nicola Bedlington, Roxana Radulescu
	Wed, Dec 10	Health Policy Forum Place: Brussels Attendance: Anders Olauson, Nicola Bedlington
	Thu, Dec 18	French National Authority for Health (HAS) Round Table on Patient Safety Place: Paris Attendance: Roxana Radulescu (speaker)
	Fri, Jan 16	eHealth Stakeholders group meeting Place: Brussels Attendance: Roxana Radulescu
	Mon, Jan 19	Royal College of Physicians EU Policy Roundtable on Quality of Care Place: London Attendance: Mike O'Donovan, Roxana Radulescu
	Wed, Jan 21	Health Policy Forum Place: Brussels Attendance: Nicola Bedlington
	Thu, Jan 22	EHMA Roundtable on Patient Safety Place: Brussels Attendance: Nicola Bedlington (speaker)
	Thu, Jan 29	Meeting of Editorial Board of the Health EU Portal Place: Luxembourg Attendance: Nicola Bedlington

	Tue, Feb 3 -- Thu, Feb 5	Meetings with Patients Groups in Poland Place: Poland Attendance: Anders Olauson
	Mon, Feb 9	EFPIA Think-Tank Place: Brussels Attendance: Nicola Bedlington
	Mon, Feb 9	Meeting with co-chair and CEO of National Voices UK Place: London
	Tue, Feb 10	EPF Board Meeting Place: London Attendance: EPF Board
	Thu, Feb 19 -- Fri, Feb 20	eHealth Conference 2009 Place: Prague Attendance: Anders Olauson, Roxana Radulescu
	Wed, Mar 25	Conference of the Pharmaceutical Forum Delivering for Patients Place: Brussels
	Thu, Mar 26	EPF Annual General Meeting Place: Brussels

