



Dear EPF Members and Allies,

Welcome to the 6th issue of the EPF Mailing for 2008. A number of key activities have taken place since our last issue. Anders Olauson represented EPF at the final meeting of the High Level Pharmaceutical Forum on 2nd October 2008. Our [special feature](#) outlines some of the key outcomes of the Forum, from the perspective of EPF and how we perceive next steps.

“A Europe for Patients” campaign was launched by Commissioner Vassiliou on 30 September. EPF was invited to make a presentation at the launch event and welcomed warmly the initiative: for more information go to [section 3](#). Anders Olauson gave a presentation outlining the synergies between a Europe for Patients and EPF’s own manifesto “150 million reasons to act”. More on progress linked to our Manifesto campaign in [section 16](#).

EPF was represented in the European Health Forum Gastein by Mike O’Donovan, EPF treasurer and Roxana Radulescu, who played an active role in several sessions. Read about their impressions of Gastein in [section 7](#).

EPF was also very active the Conference under the French Presidency on a Europe for Patients on 13 and 14 October where EPF was officially represented by Vice President Susanna Palkonen. Several of our members were represented and participated in the programme. For a detailed report go to [section 8](#).

EPF has also focused a great deal this month on developing our response to the Cross Border Health Care Directive, in close cooperation with our members, several of whom participated in an EPF policy meeting on the issue on 25 September. Nicola Bedlington took place in a Panel Discussion organised by COCIR on 22 October and we have exchanged views with a number of other key stakeholders. [Section 12](#) gives more background on our position.

Many of you will be aware that the much awaited Pharmaceutical Package with legislative proposals on information to patients, counterfeiting and pharmacovigilance has been delayed to the end of November. Key proposals on patients’ safety will also be adopted before the end of November. Our next issue, due in mid December will give a preliminary analysis of these proposals, the degree to which EPF’s input has been taken on board and the likely next steps in the legislative procedure. The next issue will also report on important developments in relation to the European Union Health Policy Forum and the outcomes of the Open Health Forum taking place on 10th and 11th December.

Finally, we are very pleased to announce that Rainald Von Gizycki from Retina Europe has been co-opted to join the EPF board. We are delighted to welcome Rainald who has vast experience in patients’ involvement and e-health and will be a strong asset to our team!

Warmest greetings,
Anders Olauson, President
Nicola Bedlington, Director

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The next issue of the EPF Mailing will take place in the middle of December 2008. The deadline for contributions is 2nd of December.

1. THE OUTCOMES OF THE HIGH LEVEL PHARMACEUTICAL FORUM

Readers will be aware that the final meeting of the High Level Pharmaceutical Forum took place on 2 October in Brussels. EPF was represented by our President Anders Olauson.

The primary focus of the meeting after three years' work, was the adoption of the final conclusions and recommendations for future. Participants were also invited to comment on the process and reflect on how to take the results forward.

All of the documents pertaining to the Pharmaceutical Forum are on the following website <http://ec.europa.eu/pharmaforum>.

EPF and its representatives have been very committed to the entire Pharmaceutical Forum process and have contributed constructively and actively to all of the work areas: information to patients, pricing and reimbursement and relative effectiveness, from a patient's perspective. This contribution is largely reflected in the Conclusions and the Recommendations of the Forum, and the

final report, which we were able to support wholeheartedly.

The Conclusions and Recommendations were adopted formally during this last meeting and all Member States were positive about both the process and the outcomes, in spite of some of the clear challenges. They committed to taking forward the results at national level and engaging in follow up activities.

In his statement to the Forum on behalf of EPF, Anders Olauson said:

"EPF would like to express once again our congratulations to the Commissioners, their officials, Member States and all of the stakeholders for their tremendous efforts and cooperation - and the achievements. No-one can say this was an easy process – so many different players with very different perspectives – but a crucially important one because of that. We have gained a greater

insight and understanding and I believe the recognition of the importance and value of working in partnership – Member States and stakeholders together. We can all be proud of this legacy.

With regard to the specific outcomes, we believe that the wide range of tools and reference documents produced in each of the working groups will be of lasting value on a number of levels. A pertinent example is the inclusion of “quality principles on information to patients” in the forthcoming Commission proposal on Information to Patients, providing clarity and authority on what constitutes high quality information.

We know from talking to patient group allies at national level that these tools could be widely used in patient communities across Europe.

We are very pleased that the Pharmaceutical Forum recognises the need to enhance Health literacy as a policy at both European and national levels. From a patient’s perspective, health literacy is critical to enable patients to genuinely manage their health and condition. We cannot circumvent this.

We also welcome the clear sign posting towards a comprehensive and coherent information to patients strategy at EU level and a how this could be taken forward in practice– this is one of the key ‘by-products’ of the Pharmaceutical Forum in our view and one that will help to ensure that all patients throughout the EU access the information they need, when they need it”.

For a complete version of Anders’ intervention, please go to the EPF website www.eu-patient.eu

The importance of a patient-centred approach and the added value of the informed patient and health literacy was also highlighted by several delegations. CPME mentioned our partnership and our future cooperation on health literacy, the new patient doctor relationship and the important role of the health professional re. ITP and the Pharma Forum Conclusions were reiterated by a number of countries.

During the course of the discussion, the “Information to patients” legislative proposal came up frequently. There is clearly a diversity of views across the Member States regarding the role of industry in the provision of information.

Several Member States talked about the importance of equity of access to medicines in relation to orphan drugs and also small markets. On 11 and 12 December, under French EU Presidency there will be a meeting on pricing and reimbursement that will also address orphan drugs. One Member State highlighted that as part of the future work of the Forum, authorisation for orphan medicines should be made at EU level and all EU patients should have access.

The importance of linking the Council Conclusions on Common values and principles in the European Union Health Systems <http://eurlex.europa.eu/> with the outcomes of the Forum was stressed.

The competence of Member States vis a vis EU was also highlighted – particularly regarding pricing and reimbursement decisions but the real need for EU cooperation was also mentioned on several occasions. [Click here to read more.](#)

2. WRITTEN DECLARATION ON HEALTH LITERACY IN THE EUROPEAN PARLIAMENT

Following the launch of EPF's Patients' Manifesto in the European Parliament, [MEP Nicodim BULZESC](#) (EPP-ED) from Romania committed to fight for more action on health literacy. He has initiated a Written Declaration on Health Literacy, calling on the Commission and Council to acknowledge EPF 2008 Conference Recommendations and to encourage their implementation through political commitment and resources.

These recommendations are:

- Setting up an EU Health Literacy Network that involves all Member States and stakeholders
- Wider distribution of quality health information to patients
- Further training for health professionals to improve communication with patients
- Further research on Health Literacy and its role in healthcare and health outcomes
- Patients' meaningful involvement in health literacy policies and programmes

The Declaration will be officially launched on **17 November 2008** in Strasbourg and will stand in the European Parliament's register until **12 March 2009**. It will be translated in the 23 official EU languages. EPF is launching now a campaign among MEPs to sign the Declaration and we are calling upon all our members and allies to promote the Declaration among all MEPs, so that the necessary number of signatures (a minimum of 363) is collected. We are pleased that the European Associations representing doctors (CPME), nurses (EFN) and pharmacists (PGEU) have supported the Declaration and agreed to support EPF in this campaign.

If the Declaration is signed by the majority of Parliament's component Members, it will be forwarded to the institutions named therein, which will be formally asked to take action in this area.

For further information about this, please contact [Roxana Radulescu](#).

3. A EUROPE FOR PATIENTS CAMPAIGN



[A Europe for Patients campaign](#) was launched by Commissioner Androula Vassiliou on 30 September. The campaign highlights the different health policy initiatives the Commission intends to adopt, which are bound by a common goal: better healthcare for all in Europe. These initiatives address: cross-border healthcare, patient safety, rare diseases, organ donation and transplantation, cancer screening, health workforce, flu and childhood vaccination and antibiotic use. The campaign will continue until the 10 healthcare initiatives are adopted. EPF has been invited by the Commission to collaborate on the campaign and support its roll-out in the Member States.

The event was well attended by various stakeholders involved in the EU policy arena. The EU French Presidency representative stressed that the campaign was in line with some of the French EU Presidency priorities. EPF was also present at the launch event and welcomed warmly the initiative. Anders Olauson gave a speech highlighting that the campaign echoes very much the spirit and vision behind EPF's Patients Manifesto "150 million reasons to act". While reminding that our current health systems can be unfair and divisive, he stressed EPF's belief that ALL patients within the European Union have the right to equal access to quality medical treatment, regardless of where they live, their status or their income.

With regard to the "Cross Border Healthcare" and "Information to patients" initiatives, he called for efforts to ensure that these legislative proposals genuinely meet the needs of all patients.

Finally, he expressed confidence in working together closely with the Commission in advancing patient-centred health policy-making to improve standards of healthcare across the European Union. "If we work together this is achievable, makes economic sense and will make a significant difference to the health outcomes and quality of life of vast numbers of patients in every Member State".

For further information: http://ec.europa.eu/health-eu/europe_for_patients/media/index_en.htm

4. DIRECTIVE ON PATIENTS RIGHTS IN CROSS BORDER HEALTHCARE

As highlighted in our [previous Mailings](#), EPF has welcomed the adoption of the draft [Directive on Patients' Rights in Cross-Border HealthCare](#). On 25th September we have discussed with policy experts from our membership key points of the Directive that are important for patients.

More specifically, EPF welcomes that:

- The Directive recognises a **new right for EU patients**: the right of insured persons to seek healthcare abroad and to be reimbursed by the Member State of affiliation. However, access to healthcare - be it in the country of origin or in another Member State – should be provided for ALL patients, included undocumented persons. Although this Directive doesn't look at this aspect, this issue should be further reflected upon and taken on board by Member States and Community legislation.
- The Directive provides for the establishment of the **national contact points** in each Member State to inform patients of their rights. EPF calls for these contact points to be established in an efficient and transparent way and that information about their existence to be appropriately disseminated across the country and regions. Patients organisations, if appropriately resourced, can undertake important outreach work in supporting the national contact points.
- The Directive facilitates the development of **European reference networks**, where patients with rare conditions can have access to highly specialised care. However, appropriate mechanisms should be created to ensure a continuity of care for patients when they are back home. eHealth and ICT technologies have significant potential in this regard.

We have also identified some key elements of concern, that in our view undermine the fundamental vision behind a Directive focusing on patients' rights in cross-border healthcare:

- **Up-front payment:** From the patients' perspective, it is not acceptable for patients to be asked to pay up-front for treatment (in their country of affiliation or abroad). This will widen the social inequalities. Member States and the Commission should work together to put in place some mechanisms to pay healthcare providers directly.

- **Higher quality of healthcare at home:** Although Member States are responsible for the organisation and provision of healthcare services and it is up to them to decide on the standards for healthcare in their country, there is space for further support and cooperation among Member States to achieve a better quality and safety of healthcare in all EU countries. EU can support this.

- **Stakeholders' involvement** in health technology assessment: The Directive provides that Member States shall facilitate development and functioning of a network connecting national authorities or bodies responsible for health technology assessment. Stakeholders, including patients, should be involved in this network.

For further information, please contact [Roxana Radulescu](#).

5. TELEMEDICINE COMMUNICATION

A European [Communication on Telemedicine for the benefit of patients, healthcare systems and society](#) was adopted on the 4th of November as a result of the joint work of DG Information Society and DG SANCO. In an ageing Europe, where more and more citizens live with chronic health diseases, telemedicine is an important tool. Despite the potential benefits that telemedicine can provide, its use is still limited in most parts of the EU.

The actions proposed by the Commission are:

1. To increase confidence and **acceptance of telemedicine services** among users. In particular, by encouraging provision and dissemination of scientific evidence of its effectiveness and cost effectiveness.
2. To **bring legal clarity on existing EU legislation** regarding telemedicine services and encourage Member States to improve provision of telemedicine services.
3. To **solve technical problems** such as the lack of adequate community-wide broadband infrastructure and interoperability of telemedicine devices.

EPF Secretariat is pleased with the degree to which the views expressed in earlier consultation with patients have been taken on board. We will further analyse the Communication from a patients' perspective and will share our views on it in our next issue.

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

6. Commission's Patient Safety Working Group – to Patient Safety and Quality of Care Working Group

EPF has been actively involved in recent years in the Commission's Patient Safety Working Group (including Member States representatives and stakeholders) which has advised the High Level Group on Health Care Services. With the forthcoming adoption of the Commission's patient safety legislative proposals, this Working Group (WG) will have finished its mandate and will no longer meet in its current form.

In 2009, the Working Group will become a Patient Safety and Quality of Care Working Group. There will be a relationship between the re-formed WG and the new Council Working Party on Public Health at Senior Level. More information about the exact mandate of the new WG will be provided to you in the next Mailing.

EPF welcomes this move forward towards an extended European cooperation between Member States on improving the quality of healthcare, as well as Commission's approach to involve and consult stakeholders. This reflects our own vision of high quality patient-centered health-care and meaningful patients' involvement and our concerns about equal access of all patients to quality healthcare as close to home as possible.

EPF Secretariat will continue to play an active role and to represent a patients' perspective in the new WG. For further information, please contact [Roxana Radulescu](#).

7. EUROPEAN HEALTH FORUM GASTEIN, 1-4 OCTOBER



The [11th European Health Forum Gastein](#) was held until Bad Hof Gastein, Austria during 1-4 October. Under the title “Values in health – from visions to reality”, the event brought together numerous key decision makers in health policy, leading experts from science and academia, business and industry, patient organisations and NGOs to discuss about common values and their influence on health policy and health. The [programme](#) was particularly rich and intensive with 29 parallel workshops and plenary sessions on a variety of topics.

An interesting and positive dimension of EHFG has been Young Forum Gastein Scholarship – an initiative launched in 2007 at EHFG 10th anniversary, and continued this year, to bring together about 50 young researchers and officials from EU Member States working in the field of health to network and learn about current health policy developments in Europe.

On the same line, the Health Forum Award –which aims to promote health policy initiatives that have contributed in a significant way to meet European health challenges – has been awarded this year (not surprising, given the new Directive on cross-border care and the patient safety initiatives) to a project on Cross-border Collaboration for Quality Improvement in Delivery of Renal Care across the Irish Border Region.

EPF was represented by Mike O’Donovan, its Treasurer and by Roxana Radulescu, Policy Officer. Speaking in the session on challenges to prevention “*Promoting health –preventing disease: strengthening the role of health professionals in Europe*” - organised by CPME and DG SANCO - Mike O’Donovan brought forward the

importance of health literacy as a means of solving the problems. Patients, not only informed, but also health literate, can consistently contribute to better outcomes in treatment and prevention. EPF's Patients Manifesto – 150 million reasons to act – calls for action in this direction.

In the session dedicated to the **Pharmaceutical Forum**, he welcomed the inclusion of quality principles on information to patients in the forthcoming Commission proposal on Information to Patients. With regard to Pricing and Reimbursement, he strongly called for including equity as part of the equation. He also stressed EPF's key message to involve patients in a meaningful way in relative effectiveness processes.

While chairing a session on **Health and Ethics**, Mike highlighted EPF's advocacy work to align health policies on health values and on the views and needs of patients and illustrated how EPF continuously strives to reflect an ethical dimension in its policy work on our key priority areas: health literacy, patient safety, eHealth and interoperability, information to patients, patients' access to health care and patients' cross-border mobility.

In the EHFG conclusions, leadership and political consensus between governments and stakeholders, between EU Member States was seen as a clear issue to develop further. It was highlighted that although the values in health are generally broadly known, there is a deficit implementing them in all settings, at all levels. There is a clear role to play by politicians, by professionals and civil society. One of the concluding statements of Commissioner Vassiliou alluded to the need for Europe's leadership needed to come up with health education and literacy.

While having had the merit of bringing together so numerous prominent experts, high level policy makers, young people and a variety of stakeholders representatives to exchange views on a wealth, topics, the EHFG would have further benefit if it had brought along politicians and decision makers from policy areas others than health.

For further information, please contact [Roxana Radulescu](#).

8. EU FRENCH PRESIDENCY CONFERENCE ON “EUROPE FOR PATIENTS”, 13-14 OCTOBER, PARIS

The French Presidency of the Council of the EU held a Conference in Paris on [Europe for Patients](#) (Europe de la santé au service des patients) which aimed at presenting the added value of EU-led action in the field of health, regarding safety, quality of care and the promotion of patients' rights. It focused on six major themes, with specific examples of good practices from various Member States and from the European Commission:

- Mapping the state of health and chronic illnesses of European;
- Moving forward on patient safety and information on the quality of care;
- Improving access to diagnosis and quality healthcare – the rare diseases patients' cases;
- Ensuring healthcare provision for patients in cross-border areas and guaranteeing their rights to health care abroad, while preserving the regulations and equilibrium of national systems;
- Ensuring respect for patients' rights with the aim of fostering active European Citizenship;
- Identifying paths for progress through multiannual European health research, innovation and development programmes.

Susanna Palkonen, EPF's vice-president, sat on a panel together with health professionals' representatives and highlighted patients' fundamental right to have access to information about their treatment, diagnosis and any health-related intervention. She reminded that informed and empowered patients can play an important role in preventing adverse events in the process of healthcare delivery. The need for a productive partnership at country level, following the model of a EUNetPas Network, between the patient safety responsible authorities and stakeholders, including patients and health professionals' representatives - in a culture based on trust - was also highlighted.

The conference brought together a wide range of stakeholders: health professionals, academic experts, European Commission and Member States representatives, health insurers as well as very large number of representatives of patients' organisations. While actions towards a patient-centered healthcare at regional and national level are crucial, the conference clearly outlined that there is still a need for a reinforced collaboration at EU level to ensure the respect of patients' rights an improved access to quality health care.

For further information, please contact [Roxana Radulescu](#).

9. 16TH COCHRANE COLLOQUIUM EVIDENCE IN THE ERA OF GLOBALISATION, FREIBURG, GERMANY 3-7 OCTOBER

EPF President Anders Olauson was invited to make a presentation in a plenary session on patients and research at this 16th Cochrane Colloquium that brings together world renowned health researchers on an annual basis. This session and Anders' intervention is another welcome illustration that researchers are serious about meaningful patient involvement in their work, that in turn leads to more patient-centred, sustainable outcomes.

For more information on the Colloquium and for recordings of all of the presentations and debates please go to

www.colloquium.info/urlhost/cochrane/events/5319/Welcome.jsp

10. MSD SYMPOSIUM ON ACCESS, INNOVATION AND AFFORDABILITY OF MEDICINES PHARMACEUTICAL POLICY IN EMERGING MARKETS, 14 OCTOBER, ISTANBUL

Nicola Bedlington participated in this MSD Symposium in Istanbul on 14th October. The event was a continuation of the first symposium on Access, Innovation and Affordability of Medicines held in Munich in 2007, and addressed various aspects of pharmaceutical policy in the Central & Eastern European and Middle-East & Africa Regions.

Through these AIA symposia, MSD intends to create a platform for high-level discussions on the most challenging topics in healthcare. The audience of the symposium was a mix of policy makers, academics, patient organizations, health authorities, and experts from across Central & Eastern Europe and the Middle-East & Africa regions.

The key topics addressed were:

- Competitiveness Strategies for Emerging Economies – The Link with Health Care
- Innovation, Healthcare & Cluster Policy
- Patient Empowerment
- Health Sector & Knowledge Economy
- Health policies in emerging economies
- Future of Medicine: A New Golden Era in Vaccines?

Nicola participated in a panel session that explored the increasing role of patient organisations in emerging economies and the new EU Member States and pre-requisites for them to be as effective as possible in advocating for patient-centred healthcare. The panel also examined the added value of European and international cooperation in this regard.

For more information on the programme or to get a copy of presentations, please contact [EPF Secretariat](#).

11. WORKSHOP ON ACCESS TO HIGH QUALITY PHARMACY SERVICES, 15 OCTOBER, BRUSSELS

The European Commission, DG Internal Market and Services organised a Workshop on Access on High Quality Pharmacy Services in Brussels, on 15 October. This was organised primarily for Member States representatives. However, in the morning session several associations (PGEU, EPF, GIRP, European Union of the Social Pharmacies, Health Consumer Powerhouse) were invited to give their perspectives on three key issues that were at the heart of the debate:

- what are the least restrictive means to ensure that an appropriate level of independence of pharmacist's decisions is attained
- what are the least restrictive means to ensure that accessibility (in terms of geographic coverage, opening hours, home delivering possibilities) at the desired level is attained
- what regulatory system is most favourable to the performance of a pharmacy system.

Roxana Radulescu represented EPF at the workshop and presented EPF's views on this topic. She first referred to the common values and principles that underpin Europe's health systems - universality, equity and solidarity – and highlighted the importance of safeguarding these values and the European Social model when taking any measures about market or competition rules related to healthcare.

For patients, community pharmacists are among the most accessible and most trusted health professionals. EPF firmly believes that it is important to have a solid investment in pharmacists' competence, knowledge, continuous medical development, so that they can provide patients quality advice and quality information.

Another key message was that patients need to have pharmacies close and accessible. The pharmacy should not be an ordinary shop because the patient is not an ordinary consumer. The necessary framework and conditions should be in place in pharmacies so that the patients receive the advice and information they need with respect for privacy and confidentiality.

The last point highlighted was about affordability of medicines. EPF firmly believes that pricing and reimbursement policies need to balance first and foremost, timely and equitable access to pharmaceuticals for all patients, control of pharmaceutical expenditure for Member States and reward for innovation within a competitive market.

For further information, please contact [Roxana Radulescu](#).

12. ROUNDTABLE ON CROSS BORDER HEALTHCARE ORGANISED BY HOPE (EUROPEAN HOSPITAL AND HEALTHCARE FEDERATION) AND COCIR (EUROPEAN ASSOCIATION REPRESENTING THE RADIOLOGICAL, ELECTRO-MEDICAL AND HEALTHCARE IT INDUSTRY), 22 OCTOBER BRUSSELS

Nicola Bedlington represented EPF in this Roundtable discussion on cross border healthcare that explored some of strengths and weaknesses of the proposed Directive on Patients Rights in Cross Border Healthcare. Whilst welcoming the over-arching objectives of the Directive, in terms of providing legal clarity, quality assurance and protection for patients across the EU and the boost for cooperation across the member states in terms of quality of care, safety and equity, a number of concerns were shared by the panellists. These focused on the view that practical implementation of such a Directive that would take “years and years” according to one representative.

For more information about EPF’s position on the Directive – [please go to section 4](#).

For more information about COCIR and HOPE, please go to their respective websites:

www.cocir.org and www.hope.be

13. DELIVERING FOR TOMORROW'S CONSUMERS, 29-30 OCTOBER, BRUSSELS

Nicola Bedlington represented EPF at the Conference “Delivering for Tomorrow’s Consumers” held in Brussels 29 and 30 October. The purpose of the conference was to review the main drivers of change for the EU and in particular for DG Health and Consumers (SANCO). The outcome of the conference will be used to finalise a strategic paper identifying action areas for the new Commission. Although the primary broad target group focused on “consumers”, it was a highly relevant conference for EPF, as patients with chronic illness and their families clearly form a specific “constituency” of consumers with particular interest in delivery in the spheres of healthcare, a person, or patient-centred approach, quality and equity. The conference was co-organised by the European Youth Forum and the perspectives of young consumers resonated throughout the conference.

The event provided a very interesting opportunity for “blue sky thinking” and also realistic approaches to both immediate challenges in the current economic climate, and the opportunities and threats this presents, and also longer term reflections on how to build values- driven solidarity and real commitment to sustainability that embraces fully the economic, environmental, cultural and social tenets of this concept. The Conference explored the kind of global leadership the EU is able to offer in terms of good governance and regulation in key areas of importance to consumers, and also know-how in relation to identifying and replicating local actions for positive change; it also examined the potential of a new philosophy and culture both within and across the Commission in the context of health and consumer policy, to be more entrepreneurial and bold. Another key dimension of the conference was a debate on the role of science, to provide an evidence base for new policy, albeit not the only one, and the importance of listening to citizens – and their “evidence –base” through personal experience and know-how. The challenges of a new digital age, and how this has precipitated fundamental change in consumer behaviour and consumer “capital” was also debated.

In relation to health policy per se, the critical importance in “health impact assessments” across all policy areas was stressed, and also the notion of citizens and consumers, and inter alia, patients, not being seen as targets, but rather empowered actors and implementers. The strategic and political role of the European Union Health Policy Forum was also acknowledged and welcomed.

The conference concluded with the recognition of a “duty to act”, not only on the part of the Commission but all stakeholders; the Commission, over the next 6 months, intends to continue the dialogue to prepare a strategic paper for the new Commission – all stakeholders have been invited to engage in this process.

From EPF’s perspective, we have been and will continue to be active in this endeavour and will be feeding in, on the basis on the conclusions and recommendations of this conference. If any member organisation is interested in being part of a small reflections group within EPF to support this process, please contact [Nicola Bedlington](#).

For a comprehensive overview of the conclusions and outcomes of the conference, and the presentations please visit www.sanco-tomorrow.eu

14. PLANS FOR THE CZECH EU PRESIDENCY

The Czech Republic will take over the EU presidency from the beginning of 2009. The priority areas of interest of the Presidency are determined by the anticipated global political and economic context in which it takes place, the long-term direction pursued by the EU as a whole, the EC's plans and also the policy preferences of France and Sweden.

The Czech Republic's main motto for its Presidency is "Europe without Barriers".

The main priorities are:

- A Competitive and Open Europe: Innovation, Research, Education, Free movement of persons, goods and capital, internal market
- Sustainable and Secure Energy: Electricity, gas, climate change, external energy policy
- A Budget for Europe's future: Common Agricultural Policy (CAP)
- Europe as a Global Partner: transatlantic cooperation, NATO, Western Balkans, Russia
- A secure and Free Europe: Hague Programme, EU policy on asylum and migration, Schengen cooperation, cooperation in criminal matters, civil justice cooperation

The Czech Republic will focus on several topics on public health sector.

- **Financial sustainability of healthcare systems:** the aim is to highlight that the sustainability of systems relates not only to population ageing, but also to medical progress, new technologies as well as innovation.
- **Ehealth** for citizens, society and economy
- **Antimicrobial Resistance** (identified as a common theme during 2009): the main intention of the Czech Republic in the field of AMR is to find suitable antibiotic stewardship and infection control programmes, to define standards and quality indicators and to identify potential models of support and financing of national antibiotics programmes.

15. EPF AUTUMN REGIONAL ADVOCACY SEMINAR, 27-28 NOVEMBER, VILNIUS

EPF Autumn Regional Advocacy Seminar for Patient Leaders – The politics of health policy making at EU level and meaningful patient involvement through VALUE +.

On 27-28 of November EPF and the VALUE+ Consortium organise a seminar for patients' leaders representing patients' organizations from Lithuania, Estonia, Poland, the Czech Republic and Latvia. The seminar will take place in Vilnius, Lithuania and is hosted by the Health Policy Center of Lithuania (SPC). To date four highly successful European seminars have taken place. These seminars have reached out through patients' leaders to the patient community throughout Europe, and particularly the new member states to enhance knowledge on health issues at European Union (EU) level and to build capacity on how to engage.

One of the outcomes of the evaluations was the need to hold such seminars on a regional basis to enable a broader section of the patients' community to benefit. The purpose, location and audience of the seminar in Vilnius address this need: it brings together leading players of national patient organisations who do not have many opportunities to attend a European seminar in Brussels, to enhance their capacity to contribute effectively to the policy and strategic work EPF is undertaking at EU level and to explore and review progress within the EPF VALUE+ project.

The purpose of the seminar is to

- Build knowledge and know-how on working at EU level through and with EPF and influencing effectively the EU health policy debate through initiatives at national and regional level.

- Explore initial findings from the VALUE + project, compare this with examples of patient involvement in national and regional health projects, and glean feedback from grassroots organisations.

The seminar will have contributions from representatives from the European Parliament, the European Council, the European Commissions, the Czech Presidency, the Directorate General for Health and Consumers and its Executive Agency, and patients' leaders.

A detailed programme is available at the [following link](#).

Registrations are almost closed; but we are flexible to still accept a few more participants who can bring important contributions through their expertise and experience.

For more information on the seminar please contact [Liuska Sanna](#).

16. UPDATE ON EPF MANIFESTO CAMPAIGN

As readers will know, EPF launched its Manifesto Campaign “150 Million Reasons to Act” in September with the support of committed Member of the European Parliament.

The Manifesto, developed by the EPF membership representing over 150 million patients, citizens and voters across the European Union “**calls upon all the political groups within the European Parliament, MEPs, prospective MEPs, national representatives in EU Member States, and the Commission, to commit to the legitimate rights and needs of patients and to make our proposals their priority**”. Three fundamental areas have been prioritized to improve the quality of healthcare delivered across the EU, from a patients' perspective:

- Equal and timely access to safe, effective diagnosis, treatments and support;
- Better information and resources for patients to be partners in determining their care;
- A patients' voice to be heard in Brussels and throughout the European Union

The wide array of legislative and non legislative instruments on the EU health agenda will be vital tools in driving this change.

The Manifesto has been widely distributed among EPF Member organisations, the European institutions, and other relevant stakeholders at both national and European level. Member organisations have also received a Campaign Guide to encourage their active and ongoing participation over the next year.

The Conference on “Europe for Patients” held by the EU French Presidency on the 13-14 October 2008 was a great opportunity to raise the awareness of the participants on the on-going campaign. The Manifesto has been translated into French and is now available on our website: www.eu-patient.eu/manifesto/attached_documents/Manifeste_Patients_FR.pdf

It was also discussed and distributed at the launch of the Europe for Patients Campaign and at the European Health Policy Forum Gastein.

There has been significant interest in the EPF Manifesto at national level. In Poland, Lithuania and Romania activities are taking place in cooperation with the national parliaments. The secretariat has also received enquiries from patients organisations in Serbia and Turkey who wish to use the Manifesto as a basis for their own advocacy work at national level.

EPF met recently with Active Citizenship Network, regarding how to work more closely on one vital aspect of the Manifesto – the institutionalisation of a Patients' Rights Day, which emerged thanks to ACN's on – going work over the last few years on the European Patients Rights Charter. Further information on this will be made available in the next issue.

Many individuals and organisations from throughout Europe and beyond have affirmed their support for the Manifesto through the EPF website. We would like to invite you to support EPF Campaign by signing up on our website (www.eu-patient.eu/manifesto/signup.php). Please do not hesitate to contact EPF Secretariat if you would like to receive copies of the Manifesto for information or dissemination or further support materials.

A Campaign Briefing will be distributed to the EPF membership will be distributed in the next few days regarding next steps in the Campaign and a “model letter” to adapt to their specific context.

17. VALUE + PROJECT - UPDATE - OUTCOMES OF THE STEERING GROUP MEETING

The third meeting of the VALUE+ partners took place in Brussels on 22-23 October.

The key topics on the agenda focused around the state of play regarding the assessment of patient involvement in EC supported health-related projects and the methodological approach to be used for analysing the findings.

Since the last meeting at the end of June we have progressed in many areas. [More...](#)

18. RESPECT PROJECT

At the end of October Liuska Sanna participated in the second meeting of the project RESPECT where EPF is an associated partner. For the first time all partners were present and that was extremely important to better know our respective expertise and the contribution we would bring to the project.

The purpose of RESPECT is to empower children and adolescents participating to clinical trials with the ultimate aim of increasing paediatric trials and provide treatments and drugs more appropriate and effective than those actually provided.

As an opening for discussions, the Paediatric Clinical Trials Group of the University of Göteborg presented a literature review aimed at identifying existing studies concerning children's needs in clinical trials in Europe (in both formal and 'grey' literature). Approximately 100 publications were reviewed and we could conclude that the focus is mainly on the health outcome of clinical trials rather than children's needs and motivations for participating in research.

After getting this general perspective the group brainstormed on what we wanted to know exactly and whom we would address to find it out and some of the ethical considerations around this. The stakeholders we decided to consult are children and their parents; clinicians; patients' organizations; ethics committees, pharmaceutical industries and lawyers. We formulated more in details the questions we will ask to each type of stakeholder having in mind the project objectives.

Once agreed on the "content" we discussed the methodology. A diversity of approaches will be used depending on the stakeholders, but we will make use mainly of one-to-one interview; focus groups; questionnaires and case studies.

The next steps will be reviewing and finalizing the questions agreed and setting up the consultations. The aim is to complete this process in six months. After this period a third meeting will take place to share the information collected and identify issues for further consideration.

To know more about the project RESPECT please contact [Liuska Sanna](#).

19. CALLIOPE PROJECT – OUTCOME OF SECOND MEETING

The second meeting of the CALLIOPE Consortium was held in Crete, Greece on 8 October.

The meeting kicked off with updates and progress reporting. General progress over the summer was satisfactory with most of the activities planned in the previous meeting completed on time. The projects leaflet is in phase of completion and the website has been updated with more information.

However not all of the six working groups (WGs) had started their work yet and the priority now is to finish establishing the capacities to enable the groups to advance. WGs' chairs provided a brief overview of current status of work in WGs. The main topics discussed were.

Governance principles and policies: a proposal was reviewed in plenary and by a specific working group. It was decided that the CALLIOPE Network should be appropriately open, meaning that organizations and individuals are invited to join according to their activities and their potential contribution to CALLIOPE. Therefore the objective is not to achieve quantity of members but rather selectively establish an appropriate membership. The network should furthermore focus on producing value for the decision makers.

Knowledge Tools: the discussion focused on issues related to the membership of the CALLIOPE Network. Some tools for registration of experts and new members were presented.

Communication policies and public presence: a comprehensive proposal for communication was presented. The discussion focused on the editorial processes and the multinationality aspects of the communication. An Editorial Committee will be set up to decide on public content based on proposals from all members of the Executive Committee.

The EC Recommendation on Interoperability: The work of the WG in charge of this topic was launched at the meeting. The discussion focused on defining target groups and interest groups that need to be formed to deal with specific aspects. EPF will be involved in this working group as well as on the one related to a Road map for interoperability.

The next plenary meeting is planned for the spring 2009.

The contact person at the Secretariat for more information on CALLIOPE is [Liuska Sanna](#).

20. SWEDISH VISITING GROUP

On October 22nd the European Patients' Forum hosted a Swedish visiting group representing several national organizations. The meeting was chaired by Nicola Bedlington, EPF's Director, and was the occasion for introducing EPF' activities in liaising with the European Institutions, its mission and main objectives.

21. DIARY

Thu, Nov 6	<p>Dutch health Charities event Place: Netherlands Attendance: Liuska Sanna</p>
Wed, Nov 12	<p>Health First Europe - New Horizons Conference Place: Brussels Attendance: Elisabeth Kasilingam</p>
Fri, Nov 14	<p>Medtronic Foundation - Patient Link Workshop Place: Brussels Attendance: Roxana Radulescu</p>
Mon, Nov 17	<p>European Health Management Association Round Table debate on Managing cross-border healthcare Place: Brussels Attendance: Roxana Radulescu (speaker)</p>
Thu, Nov 20	<p>European Network for Health Technology Assessment Conference Place: Paris Attendance: Roxana Radulescu</p>
Thu, Nov 20	<p>Information to Patients Roundtable Place: London Attendance: Nicola Bedlington (speaker)</p>
Fri, Nov 21	<p>EFPIA Patients Think Tank Place: Brussels Attendance: Nicola Bedlington</p>

Thu, Nov 27 -- Fri, Nov 28	<p>EPF Autumn Regional Advocacy Seminar for Patients' Leaders Place: Vilnius, Lithuania Attendance: EPF Staff (Nicola Bedlington, Liuska Sanna, Roxana Radulescu, Zilvinas Gavėnas)</p>
Wed, Dec 3	<p>Seminar in the European Parliament concerning the Telemedicine Communication as well as wider Telemedicine issues Place: European Parliament, Brussels Attendance: Nicola Bedlington (speaker)</p>
Mon, Dec 8	<p>Friends of Europe Conference 'Long live Europe! Shaping our healthcare revolution' Place: Brussels Attendance: Anders Olauson (speaker)</p>
Tue, Dec 9	<p>Board Meeting Place: Brussels Attendance: EPF Board</p>
Wed, Dec 10	<p>Health Policy Forum Place: Brussels Attendance: Anders Olauson, Nicola Bedlington</p>
Wed, Dec 10 -- Thu, Dec 11	<p>EU Open Health Forum Place: Brussels Attendance: Anders Olauson (chair), Rainald von Gizycki (speaker), Nicola Bedlington, Roxana Radulescu</p>
Thu, Dec 18	<p>French National Authority for Health (HAS) Round Tables on Patient Safety Place: Brussels Attendance: Roxana Radulescu (speaker)</p>