europeanpatients'forum

STOP PRESS *On Friday, President Barroso unveiled his new team, announcing the portfolios of the Commissioner Designates. Commissioner Designate, John Dalli from Malta will head health and consumer policy.*
The new Commission must gain approval from the European Parliament before it takes office for a term of office running until 31 October 2014. Commissioners-designate will appear in individual hearings before Parliamentary committees from 11-19 January. The vote of consent on the new Commission as a whole is foreseen to take place on 26 January. On the basis of the vote of consent, the Commission shall be appointed by the European Council.

www.eu-patient.eu
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COUNCIL BLOCK DIRECTIVE ON CROSS-BORDER HEALTH CARE
EPF is very disappointed at the surprising outcome of the Health Council on the Patients' Rights in Cross-Border Health Care Directive. On December 1 2009, Member States were not able to find an agreement on the Swedish EU presidency compromise. Five Member States voted against the directive, which was enough to form a blocking minority! In regards to the compromise text, it was in itself unsatisfactory for the patients as it was a step backwards particularly on quality and safety commitments. However, progress was made on several issues and EPF regrets the inability of Member States to find a political agreement and to move forward the Directive for a second reading in the European Parliament.
Read more in section 9.

Dear EPF Members and Allies,

It is our pleasure to share with you the latest health policy and programme developments from EPF.

Since our last issue, EPF board staff and members have attended a whole range of health related events and EU level expert meetings on health. We give a brief report on each of these and sign post you to more material. Meetings that took place after 20 November will be reported in the next EPF Mailing.

Much emphasis has been placed in the last few weeks on work in the European Parliament regarding the Pharmaceutical Package – read about our work in this area in section 8. We are also setting the scene for another round of intensive work in the European Parliament regarding the proposed Directive on cross border healthcare, in the context of the second reading next year. In general, we are disappointed with the Council compromise text to be presented today and its step backwards on quality and safety commitments. Read more in section 7.

Our Value+ Conference on Meaningful Patient Involvement is just around the corner, and EPF together with our Value+ partners are finalising the tools that have been developed through the project. We are very much looking forward to this landmark event, under the patronage of the Swedish Presidency, to be attended, it is hoped by EU Health Commissioner Androulla Vassiliou, two health ministers and high level officials from the Member States and the Commission. If you cannot join us personally we hope you will be able to contribute online through the real time video streaming. More details on the EPF will soon be available on our website www.eu-patient.eu.

As we move towards the end of 2009, our thoughts turn to planning for 2010 and beyond. A very substantial work plan is being prepared by the board that looks at unfinished business from 2009 and new opportunities and challenges in 2010, set against the backdrop of the new Commission and Parliament. The wider EPF membership will be consulted on this plan during late November and December to be ready for action at the beginning of next year.

Looking forward to seeing many of you in Gothenburg!!

Warmest greetings,
Anders Olauson, President
Nicola Bedlington, Director

Contents

Special Conference issue will be distributed late December 2009. Next issue of the EPF Mailing -deadline for articles 5thFebruary, distribution 12th February.

Where are previous issues of the mailing? Click on the image!

Recommended for our Readers:

EPF Value+ Regional Seminar Report is available online.

1. EPF LETTER TO THE PRESIDENT OF THE EUROPEAN COMMISSION

In early November, EPF President Anders Olauson sent correspondence to the new President of the Commission President Barroso. The letter:

- Highlights EPF's role in representing the voice of patients' across the European Union, and our desire to work closely with the European Commission
- Indicates again our support for the EU strategy "Together for Health" and in particular Health in All Policies and DG SANCO's leading role in driving this.
- Stresses the importance of using the legal base on protection of public health and patient safety in relevant health dossiers
- Welcomes the debate to move the public health dimension of pharmaceuticals to SANCO, whilst the competitive dimension should remain with DG ENTERPRISE, whilst highlighting that this should not digress from SANCO's core business

Anders Olauson also held a meeting with Health Commissioner Vassilou in late October, on the above points and several other issues linked to our work on 'A Europe for Patients'.

Please see attached a copy of this letter. For further information please contact Nicola Bedlington.

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2. EUROPEAN COMMISSION COMMUNICATION ON HEALTH INEQUALITIES

The European Commission adopted its Communication of Health Inequalities in late October. EPF welcomes the Communication but expresses some disappointment at the absence of a reference to the fundamental role of Health Literacy in relation to tackling health inequalities.

EPF will organise a high level roundtable on Health Inequalities and Health Literacy under the auspices of the Spanish EU Presidency, in order to ensure this important perspective is made more explicit in future work. This is likely to take place in Spain in late February. More details will be available in the next issue of the EPF Mailing.

3. EMEA TRANSPARENCY INITIATIVE

EPF President Anders Olauson and Director Nicola Bedlington wrote recently to the EMEA summarising EPF's perspective on the EMEA Transparency Initiative and highlighting the work undertaken by EPF to support this.

Please see attached the correspondence. To follow further developments on the EMEA Transparency Initiative, please contact Dr Valentina Stamouli.

4. THE EU EXPLORATORY PROCESS IN RELATION TO MEDICAL DEVICES

EPF Vice President Susanna Palkonen represented EPF a launch meeting in relation to the EU Exploratory Process on medical devices on the 1st of October, and technical meetings took place on the 9th and 10th of November in which Maria Navarro, EPF board member from Spain and Nicola Bedlington participated. The overall objective of the exercise is to identify fundamental issues of importance to the development of medical devices sector from both a public health and competitiveness perspective.
Maria made two presentations on the patients' viewpoint in the work stream 'Future Challenges for Public Health and Medical Technologies Developments '. This work stream is exploring the future challenges of public health systems and how the medical device industry could respond to them, with a particular focus on emerging needs (e.g. developing a shared understanding of future healthcare goals), increasing expectations (e.g. overcoming health inequalities), societal changes (e.g. ageing society), and the emergence of new medical technologies (e.g. potential of the e-Health technologies).

Nicola attended the work stream "Balance Between the Patients' Needs and Financial Sustainability", which sets out to explore all the challenges of access to medical devices for the European citizen. These include issues such as how to measure appropriately the value of medical devices, how to enhance better access of patients to medical devices looking at different factors including pricing and reimbursement policies.

In this context, an exchange of views will take place on possible new financing models and how to ensure effective deployment of resources. In preparation for the next meeting, Nicola will prepare, in collaboration with BEUC an overview of EU developments in relation to information to patients.

The next meetings of these work streams will take place on 21st and 22nd of January. EPF will consult its membership on the specific issues emerging out of the preliminary debates in these areas.

5. CLINICAL TRIAL DIRECTIVE IMPACT ASSESSMENT MEETING WITH PATIENT GROUPS

On November 13, Nicola Bedlington represented EPF at a meeting of patients groups organised by the European Commission in the context of the Clinical Trials Directive Impact Assessment and the Public Consultation on the Clinical Trials Directive that will end on January 8.

There are approximately 5000 EU clinical trials per annum, involving half a million EU patients, and about 25% of trials involve 'third countries'. The Clinical Trial Directive set out to improve the safety and rights of participants and the reliability of the data collected through clinical trials, but has been met with considerable criticism from the research community, industry, and patients. The Consultation is seeking concrete solutions to overcome the shortcomings of the legislation and addresses issues such as management of clinical trials in multi-national settings, risk management, paediatric clinical trials, clinical trials in an emergency situation and clinical trials in 3rd countries.

EPF will coordinate a response to the consultation on behalf of its members, using the expertise of the Policy Advisory Group to prepare a draft that will be circulated to the membership and patient group allies for input. We will also draw on evidence from the Value+ project, the Patient Partner project and the Respect project and the work we are undertaking with EMEA in relation to Third Country Trials.

Key concerns from a patients' perspective will explore:

- Delays due to bureaucracy impacting ultimately on access to medicine
- Access to quality information regarding the processes around Clinical Trials
- Transparency regarding Clinical Trials across Europe, including learning from those that have failed
- Meaningful patient involvement in Clinical Trials processes, not only as a research "subject"

Should any EPF member or patient group ally be particularly interested in working closely with the Secretariat on this issue, offering examples and case studies from your disease area or country, please contact Nicola Bedlington.

6. HTA STAKEHOLDERS MEETING

Health Technology Assessment (HTA) has become a priority area at the EU level, primarily as part of a strategy to ensure the sustainability of healthcare systems. Significant work is underway to enhance EU cooperation and good practice in the area of HTA.

The European Commission is funding a Joint Action on HTA, EUnetHTA, that will commence formally in January 2010. This grew in part out of the EUnetHTA project outcomes and the conclusions and recommendations from the Pharmaceutical Forum on Relative Effectiveness. See www.eunethta.net for further details.

An EUnetHTA meeting chaired by the European Commission on how to work effectively with stakeholders took place on November 6, 2010 to which EPF attended. The meeting's main purpose was to discuss and develop a draft policy document on how to involve stakeholders in both governance and the implementation of the joint action.

EPF promotes the notion that patients, as individual experts, and patient organisations should be involved meaningfully in HTA processes. In general terms, this is happening only in an ad hoc, piecemeal fashion

across the Member States, with some reservations in a number of countries on the added value of involving patients.

On the other hand, with some exceptions, there is generally limited knowledge and knowhow across the broad EU patient community on the science and the policy rationale behind HTA and mechanisms to get involved effectively.

EPF Spring Seminar on HTA

To help to respond to this gap, EPF will organise a seminar in Brussels in May 2010 targeted towards EPF membership, patient group allies and other stakeholders etc.

The purpose of the event is to enable around 60 - 80 patient leaders across different parts of Europe to learn more about the science, methodologies, processes and policies behind HTA, and how they can get involved in a constructive, meaningful way as patient representatives. This will draw on important work which to date include the HTA Guide by Health Equality Europe and the HTA MasterClass, at the London School of Economics (LSE) in Autumn, led by the European Federation of Neurological Associations.

EPF President, Anders Olauson will also be speaking at the HTA Methodology Conference in Stockholm on the 3rd of December.

More information on the seminar will be available in the next issue of the EPF mailing.

7. PATIENT SAFETY AND QUALITY OF CARE

With its Working Group on Patient Safety and Quality of Care (PSQCWG), the Commission has moved forward in engaging representatives of Member States and stakeholders on quality of healthcare and possible policy actions at the European Union level. Different aspects of healthcare quality have been already addressed by the European Commission in a number of initiatives such as quality and safety of blood, tissues and organs, guidelines for high quality cancer, screening and quality indicators. However, an overarching approach that addresses various aspects of healthcare quality in a comprehensive manner is still lacking.

For the PSQCWG discussion, the Commission proposed a series of specific objectives and policy options that could contribute to improving the quality of healthcare in the EU. For example to: achieve a common understanding of quality in EU Member States and collection of comparable data, promote continuous healthcare quality improvements in all Member States and establish a culture of mutual learning among Member States.
EPF provided some preliminary comments to the Commission draft reflection paper based on its values and baseline positions already agreed by members. The comments outline the need for a patient-centred approach in all healthcare systems, for patients' meaningful involvement in policies around the issue of quality and the importance of patients' health literacy. These were included in a joint stakeholders' response, which put forward the views of other organisations like the European Society for Quality of Care (ESQH), European Health Management Association (EHMA,) and the Standing Committee of European Doctors (CPME).

The next PSQCWG meeting will be held in Brussels on the 2nd of December. For further information, please contact Roxana Radulescu.

8. PHARMACEUTICAL PACKAGE

During the months of October and November, the Secretariat had been working hard with Members of the European Parliament, rapporteurs and shadow rapporteurs from the Environment, Public Health and Food Safety Committee (ENVI), Internal Market and Consumer Protection Committee (IMCO) and Industry, Research and Energy Committee (ITRE), with public officials in charge of the dossiers in the European Parliament and the political groupings coordinators. The objective was to present EPF's arguments and positions on three proposals of the so-called "pharmaceutical package": information on prescription-only medicines, counterfeiting and illegal distribution of medicines, and pharmacovigilance.

Concerning the proposals on information on prescription medicines, EPF highlighted their too limited scope and urged for a comprehensive information to patients strategy, incorporating the important recommendations put forward by health NGOs and the wealth of recommendations endorsed during the Pharmaceutical Forum process.

With regard to the legislative proposals on pharmacovigilance, EPF welcomed the warnings for products under intensive monitoring and particularly supported the possibility for the patients and their families to report on suspected adverse effects of medicines. We advocated for the provision of accessible information to patients about the procedures to report and for a real cooperation between regional and national pharmacovigilance centres and patients' organisations in order to enable a meaningful patients' reporting.
In relation to the proposal on combating counterfeit medicines, EPF highlighted the need for consistent information and communications strategies to tackle sales of counterfeit medicines, including the Internet-based sales, and called for patients' organisations' involvement in this process.

EPF is currently in the process of conducting a consultation with our members in order to consolidate the baseline positions agreed before the summer. The deadline for tabling amendments is the 3rd and 4th of February 2010. Reports are expected to be voted by the ENVI Committee on the 16th of March (pharmacovigilance and anti-counterfeiting) and on the 6th of April 2010 (information on prescription medicines).

For further information, please contact the Secretariat.

9. PATIENTS' RIGHTS IN CROSS BORDER HEALTHCARE

The blocking of the Directive on Patients' Rights in Cross-Border Health Care came as a very surprising and unfortunate outcome of the Health Council held on 1 of December in Brussels! Although the Ministers present at the meeting moved forward constructively with Council Conclusions on effective antibiotics, e-Health, alcohol and a Council Recommendation on smoke free environment, they were regrettably unable to reach a political agreement on the draft Directive. This reflected once again Member States' strong concerns about the Directive limiting their competence for financing and organising healthcare.

Expectations towards a political consensus were high as the Swedish EU Presidency made considerable efforts to come to a compromise. During recent meetings of the permanent representatives committee (COREPER) in October and November, various issues of concern for Member States were solved. One single issue remained however particularly tricky: the issue of private healthcare providers who do not have a contract with the healthcare in the host country. This was the one which triggered the blocking. Finally, five Member States (Spain, Portugal, Poland, Romania and Greece) could not accept this, with Greece shifting at the last moment

in the “NO camp”. The absence of the Minister of France from such important negotiation was also concerning.

In regards to the Swedish compromise text, it was in itself quite unsatisfactory for the patients’ community, as some very important elements were taken away, such as the establishment of European-wide standards on safety and quality regarding e-Health and telemedicine use. Otherwise, although patients’ organisations and their role in providing information to patients were excluded, the draft compromise text outlined however various provisions to make the information publicly available to citizens - about patients’ rights in cross-border health care, procedures, costs of cross-border healthcare that are to reimbursed to patients.
Present at the Health Council deliberations, Commissioner Vassiliou said : “This is a sad moment for patients(...). A golden opportunity has been missed to reinforce their rights to seek treatment in another Member State and be reimbursed”. “Today we missed a chance to progress towards a Europe which matters to EU citizens and towards a Europe for patients”, she added.

EPF regrets very much the inability of Member States to reinforce the rights of the patients through this Directive and to move it forward for a second reading in the European Parliament. Since October, EPF has sent letters addressed to Health Ministers of the 27 EU Member States and health attachés urging for their support on the Directive. The letters called for further cooperation on cross-border health issues and on quality and safety among EU Member States. EPF will continue to engage with the Spanish EU Presidency on this issue and will advocate for ALL patients’ fundamental rights to quality healthcare, in their country and abroad. We will work with the forthcoming EU Presidencies, new Health Commissioner and the European Parliament, and will urge for reaching an agreement on cross-border healthcare and putting patients at the centre. Our conference in Gothenburg coming up will also be a key opportunity to discuss with the members and allies on how to move forward on this issue.

For further information, please contact the Secretariat.

10. SPANISH EU PRESIDENCY 2010

At the end of 2009, the Swedish EU Presidency will end their term and Spain will hold the next EU Presidency beginning January 1st and ending on June 30th 2010.

The country holding the Presidency leads the meetings of the European Council (the summits where the heads of states of governments meet). It also acts as the driving force behind the EU's legislative and political work, mainly functioning as an adviser between Member States to reach compromises. The Presidency rotates every six months between Member States of the EU.

The President of the Spanish Government, Rodríguez Zapatero, announced that the three priorities of the Spanish EU Presidency are going to be the promotion of a new economic model; the reaffirmation and strengthening of a social, supportive European Union; and the adaptation of Europe to speak in 'one voice' in a multipolar world.
The year 2010 will be the European Year for Combating Poverty and Social Exclusion. In general terms this means that Spain will focus its attention on shared responsibility in fighting against poverty. Finally, Spain will promote social cohesion and share best experiences on social inclusion.

In line with the Spanish Presidency will try to stimulate innovation both economically and politically in order to create more jobs. Furthermore, the Spanish President stated that they will tackle issues related to gender inequalities.

With regard to the specifics on health, the Spanish Presidency will focus on e-Health, health inequalities, organ donations and the implications of the ageing population.

More information on the official programme of the Spanish EU Presidency and details regarding the main events are expected soon.

11. COMPLIANCE DRUG PACKAGING – THE PRESCRIPTION FOR SUCCESS

On November 8 2009, the Healthcare Compliance Packaging Council Europe (HCPC Europe) organised a conference on concordance-promoting medical packaging. The conference brought together representatives from the pharmaceutical and packaging industry, pharmacists and representatives from patient organisations in order to discuss how medical packages can be designed to add value for patients and enhance treatment outcomes. EPF presented findings from their survey on "Patients' Views on Medical Packaging" that was carried out by participants of the Regional Advocacy Seminar in Sofia, Bulgaria.

Medical packaging can play a key role with regard to concordance. The goal is to design medical packages in a way that they can help patients to take their medication in the right dosage, at the right time, and for the right period of time.

Experts in the field of medical packaging agree that standardisation of packages is a pre-requisite for smarter solutions; so far however standardisation does not exist. Important attributes of packages include convenience of use, accessibility, and attractiveness.

For a copy of EPF's survey report on concordance and packaging please contact Valentina Strammiello.

12. EMEA WORKING GROUP ON THIRD COUNTRY CLINICAL TRIALS MEETING

The European Medicine Agency (EMEA) Working Group on Third Country Clinical Trials met for the third time this year, in London, on 12 November. Roxana Radulescu, Senior Policy Advisor participated in the meeting, on behalf of EPF. Representatives of the International Alliance of patients Organisations (IAPO) were also present.

The number of clinical trials conducted in countries outside of the European Union (EU) research areas has been growing for a number of years. At the same time, the review of the EU pharmaceutical legislation placed emphasis on the ethical standards required for clinical trials conducted outside the EU. The EMEA Working Group has been asked to develop some practical proposals for tasks, procedures and guidance in four specific action areas:

- Clarify the practical application of ethical standards for clinical trials, in the context of EMEA activities
- Determine the practical steps undertaken during the provision of guidance and advice in the drug development phase
- Determine the practical steps to be undertaken during the Marketing Authorisation phase
- International cooperation in the regulation of clinical trials their review and inspection and capacity building in this area.

At the meeting on the 12th November, the group discussed on a draft consolidated document which included contributions on the four above-mentioned topics. It highlighted that the safety and wellbeing of participants in clinical trials are the most important considerations and should prevail over the interests of science and society. For the purpose of research, three ethical principles should be adhered to : respect for persons,

beneficence (the ethical obligation to do good and avoid harm) and justice (a fair distribution of burden and benefits of research).
The paper will be adopted and circulate for public consultation by the end of March 2010. The consultation period should last about three months. During the consultation period, a workshop involving interested parties and Regulatory agencies will be organised by EMEA on the 1st and 2nd of June 2010. The next meeting of the Working Group has been set for the 26th of January. EMEA invited members of the Working Group to suggest external experts with knowledge and expertise in the areas discussed.

For further information, please contact Roxana Radulescu.

13. ANIMAL DIRECTIVE REVIEW

EPF recently co-signed a letter with other patient groups led by EGAN addressed to the AGRI Committee members in the European Parliament regarding the impact that the review of Directive 86/609/EEC on Animal Research will have on patient communities.
This letter reiterates the key points in the EPF statement of animal research developed two years ago at the beginning of the political process linked to the review.
The letter (see attached) highlighted three key points:

- Patients are the direct beneficiaries of biomedical research
- Animal research needs to remain in the EU
- Decisions on non-human primate use need to be made by ethical review

In the lead up to the second reading in the European Parliament, a strong and active patient voice on this issue is crucial - for more details of how you can add your organisation's voice, please contact Nick Meade nick@gig.org.uk who is coordinating this campaign.

14. PRESENTATION OF THE EURO HIV INDEX

On the 13th of October the Health Consumer Powerhouse organisation presented their first Euro HIV Index at the European Parliament. Dr. Beatriz Cebolla presented the outline and results of the Index which indicated that the issues concerning HIV across Europe are still far from over.

The Index examined all European countries on topics such as involvement and patient rights, access to treatments, prevention, and overall outcomes concerning HIV. The list acknowledged Luxembourg as the country to provide the best HIV care. It especially performed well on the topics concerned with the involvement of patients and access to treatments. Second and third on the list were Malta and Switzerland that scored high on prevention (Switzerland) and overall outcomes (Malta).

The Index served a dual purpose. It also raised awareness that HIV is still a major public health issue. This was supported by the fact that the number of people becoming infected with HIV is increasing at a significant rate. Another area of concern is the fact that the incidence of new infections is far higher than the number of people that have access to proper treatment. On the positive side, the number of people dying from AIDS has decreased due to the antiretroviral treatment.
The main areas where HIV care can still be improved is the coordination of the following at a European level: stigma and discrimination, universal access to care and treatment, and prevention.
More information on the Euro HIV Index can be found on the Health Consumer Powerhouse website: www.healthpowerhouse.com. The European Aids Treatment Group also participated in the presentation – for more information about their work please go to: www.eatg.org/about-us.

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15. ALLIANCE FOR MRI EUROPEAN PARLIAMENT LAUNCH

MRI (Magnetic Resonance Imaging) is essential in fighting against life-threatening diseases such as brain tumours, cancers and heart conditions.

The Alliance for MRI, with two leading Members of Parliament (MEP), Dr. Liese and Stephen Hughes, launched a campaign in the European Parliament to highlight the "serious risk" posed to patient safety of the draft EU Directive regarding the use of MRIs.

The current EU Directive restricts and limits the use of MRI in interventional applications and in imaging vulnerable patients and children where closer patient contact is required. Furthermore, new research and developments in MRI will be severely restricted as will routine cleaning and maintenance of MRI equipment.

MRI has been used for over 25 years without evidence of harm to workers due to electromagnetic field exposure. It is also well known that MRI is free from most health risks compared to alternative techniques (such as the use of x-rays).

There is a lack of understanding regarding the implications of the EU legislation on the use of MRI to treat and diagnose diseases today and in the future.

The Alliance for MRI aims to ensure that the threat posed by the Directive to the future use of MRIs is averted and that patients in Europe will not be precluded from healthcare services.

More information on this subject can be found at: www.alliance-for-mri.org.

16. EUROPE FOR PATIENTS MEDIA SEMINAR

Director Nicola Bedlington presented EPF and our relationship with the media at a seminar on the 29th of October for journalist nominees of the Europe for Patients Media Prize 2009.

The Prize rewarded journalists who have contributed in a significant way to help citizens understand health issues under the campaign, and through their work reflecting patients' and health workers' expectations and thoughts.

The Prize was awarded in the spirit of respect for media freedom and pluralism and in the context of the Commission's desire to improve communication between the European Institutions and European citizens.
The Jury awarded the outstanding articles (press or on-line) published between July 2, 2008 and June 15, 2009 in one of the official languages of the European Union.

By the June 15, 2009 deadline, 468 articles were submitted by 304 journalists from the 27 countries of the European Union.

The selection of the winner was a two-step procedure:

1. National juries, one for each Member State, selected one national nominee, see "national level"
2. An EU jury selected the winner and two runners-up of the EU-wide award

The Prize was awarded on October 29th, 2009 in the presence of EU Health Commissioner Androulla Vassiliou.

17. EUROPEAN HEALTH FORUM GASTEIN

The 12th European Health Forum Gastein (EHFG) “Creating a Better Future for Health in Europe” took place between on the 30th of September to the 3rd of October in Bad Hofgagastein, Austria. The conference focussed on the impact of the financial crisis and subsequent economic recession on health and healthcare. Senior decision-makers from policy and administration, industry, research and civil society NGOs discussed the impacts of the crisis but also its opportunities for health. "Resilience" was the key word used to reflect an appropriate way to handle the challenges of the crisis.

Nicola Bedlington and Roxana Radulescu represented EPF at this major conference, which brought together about 600 participants from 45 countries. The following topics were proposed for debate and reflection, in plenary and parallel sessions: sustainability of health systems, health technology assessment, health inequalities (policy and research), health care decision-making, medical technology, cancer drug development, biopharmaceuticals, medical progress, hospitals of the future, addressing antibiotic resistance, rare diseases, knowledge, transfer and action, health professionals mobility and others.

Nicola Bedlington gave a presentation in a session dedicated to analysing the impact of the crisis, challenges faced by society, and potential solutions for the sustainability of health systems. The presentation drew from examples from Romania, Latvia and Finland regarding patients’ experiences and expectations in addressing the economic crisis and how and where patients and their representative organisations can play a role. She highlighted that patients do buy into the need for policies where investment in health services feed into sustained benefit, not only for health but also economic growth, but this cannot compromise equity. Patients, through their representative patient organisations want to be part of the solution, not the problem. This requires investment in harnessing their expertise and experience at institutional, advisory level and also at programme level. And an unequivocal commitment to health literacy as THE most significant factor in health inequalities.

During the discussions on solutions to overcome the crisis, several key points were highlighted: the need for everyone to be a partner for health, continuous monitoring and analysis of health systems, assessment of the impact of the financial crisis on health, strengthening social safety nets and involvement of service users, making better use of health professionals' capacities, intelligence investment to have both clinical and managerial leadership, education in order to build resilience to health systems, adoption of fiscal stimulus packages, etc.

For the conference agenda, session reports, presentations and conclusions, please visit the EHFG website. A video with highlights of the conference is available at: www.youtube.com/watch?v=mym_NogE8Qk

18. MEDTECH FORUM – HEALTH POLICY SUMMIT

On the 8th of October EPF Director Nicola Bedlington gave a presentation at the Health Policy Summit of the MedTech Forum. This session was moderated by John Bowis, former Member of Parliament (MEP) and chair of Health First Europe, and Robert Madelin gave a key note address.

For a copy of the presentations please go to www.medtechforum.eu

19. EUROPEAN UNION HEALTH POLICY FORUM (EUHPF)

EPF Director Nicola Bedlington and Roxana Radulescu, EPF Senior Policy Advisor participated in the European Union Health Policy Forum meeting on the 16th of October. The key issues discussed were the EUHPF Work Plan 2009/2010, specifically Follow-up to the Open Letter on the economic crisis and health and implementation of the EU health strategy. A discussion on global health and the Commission consultation for gender equality also took place.

Ms. Pastorek, representative of the Swedish Presidency, presented the priorities of the Council Working Party at Senior Level in the area of public health during the Swedish Presidency. She informed the Forum about the current activities of the group including the activities and draft agenda for the next meeting which will take place on the 16th of December 2009. The group will concentrate on two main themes: the follow up of the implementation of the Health Strategy and the quality and sustainability of health systems with a focus on Health Systems Performance Assessments. She stressed the openness of the Swedish presidency to co-operation with stakeholders and encouraged the Forum to be involved in the work of the Council Working Party at Senior Level through a written contribution on the above issues. Please see attached contribution.

Of particular relevance to EPF during the meeting was the Commission's initiative on capturing patient feedback through the electronic toolkit that will be discussed at the E-health conference under the Spanish Presidency in March 2010 to which EPF has been invited. The Secretariat will be contacting the EPF membership regarding this in the coming weeks.

For a copy of the papers presented at this meeting and the notes of the meeting please go to: http://ec.europa.eu/health/ph_overview/health_forum/ev_20091016_en.htm.

20. INTERNATIONAL SOCIETY OF PHARMACOECONOMICS AND OUTCOMES RESEARCH EUROPEAN (ISPOR)

EPF Director Nicola Bedlington gave a presentation to the one of the Plenary Sessions of the International Society of Pharmacoeconomics and Outcomes Research European Conference in Paris on 27 October.
This session focused on patient and citizens' involvement in healthcare decisions. During the meeting, informal discussions took place on opportunities for ISPOR and EPF to cooperate, particularly in relation to issue like Health Technology Assessment.

For more information on the meeting and a copy of presentations please go to :

www.ispor.org/congresses/Paris1009/ReleasedPresentations.asp.

21. CUTTING EDGE HEALTHCARE QUALITY FOR A COMPETITIVE EUROPE

EPF President Anders Olauson attended a conference on ' Cutting Edge Healthcare Quality for a Competitive Europe on the 29th of October organised by the Västra Götaland Region in Sweden.

The aim of the conference was to explore the importance of continuously developing quality, including patient safety, within the European healthcare systems.

The organisers highlighted, ''The European regions, like the Region Västra Götaland in Sweden, have important roles to play and knowledge to contribute in this context. Especially where healthcare financing, purchasing and delivery is made a regional responsibility within a nation's healthcare system. And

collaboration will pay off, since after all we all face about the same challenges (aging populations, growing demands, raising costs etc.)."

For more information and for a copy of all presentations , please go to: www.vgregion.se/healthqbrussels

22. EUROPEAN SOCIETY OF INTENSIVE CARE MEDICINE (ESICM) 22ND ANNUAL CONGRESS

EPF President Anders Olauson represented EPF at the ESICM 22nd Annual Congress that took place in Vienna 6-8 October where the ESICM Vienna Declaration on Patient Safety was also adopted.

For more information on the event and a copy of Anders' presentation, please go to: www.esicm.com.

23. SUSTENTO CONFERENCE

Efstathia Megas presented EPF at a conference organised by EPF member, Sustento and the International Association of Innovative Pharmaceutical Firms in Riga, Latvia on the 30th of October. Participants included patient organisation representatives as well as representatives from social departments of local municipalities.

The one day conference opened with a speech from Latvian Health Minister, Baiba Rozentale. Key discussions revolved around the debate of compensated medicine for chronic disease patients in Latvia, particularly those with low income. The key takeaway message was that solidarity is still very important and that patients should continue to be at the centre.

The conference ended with break out groups where participants discussed patient organisations' concerns and challenges. They then regrouped to disseminate discussions and develop best practices.

24. NANOMED ROUND TABLE

On November 16th and 17th 2009, EPF participated in the final meeting of the NanoMed Round Table. The NanoMed Round Table is a "Coordination and Support Action" project in the European Commission's Seventh Framework Programme (FP7) Nanosciences.

The use of nanotechnologies in medicine is very promising but raises new ethical, social and economic issues. Many patients expect new cures and treatments from advances in nanomedicine but the safety of these advances and a responsible approach to nanomedicine have to be ensured. One of the issues raised is that there is no generally accepted definition of nanomedicine. It is, however, of crucial importance to understand possible impacts and consequences of nanomedicine in advance and to create guidelines for all stakeholders.

The one year project was divided into five working groups composed of nanotechnology experts, healthcare professionals, industry (technology and pharma) as well as representatives of patient organisations. The working groups were divided to address the issues involved in: "Patient Needs", "Ethics and Societal Impact", "Economic Impact", "Regulation", and "Communication". The groups were intended to bring experts in their respective fields in order to shed light on the possible issues caused by nanomedicine. At the beginning of 2010 a list of recommendations will be submitted to the European Commission to guide its further action in this field.

25. EUROPEAN LARGE SCALE ACTION ON EHEALTH (ELSA) - DG INFSO CONSULTATION MEETING

On September 29th of 2009, a consultation meeting concerning e-Health was organised by the Directorate General Information Society and Media of the European Commission. Participants included representatives of national authorities, patient associations, research institutions, health providers, and industry.

The meeting's objective was to discuss European healthcare system's priorities and needs, and to translate them into a set of goals and specific targets for a potential initiative on e-Health called ELSA.

The goal of ELSA would be to transfer Research & Development results into innovative products and services which would help solve a specific challenge of the healthcare systems. The overarching goal of the initiative is to support the efforts leading to sustainability of European healthcare systems.

Meeting Outcomes

Participants expressed the need for a pan-European Health Infostructure (*European Health Information Area*) both for facilitating patient care as well as research and public health.

Another need is to enable the provision of an interoperable Electronic Health Record (EHR) for every European citizen, fed from his/her diverse Electronic Patient and Personal Health Records. This will provide the basis for more personalised, integrated and seamless health services across the Union.

Support in combating age-related diseases, including chronic diseases and conditions can be done as well. This is possible due to the fact that EHR longitudinal data (anonymous) would allow studies to focus on the

progression of diseases over a longer period of time, and later predicting their probable progression and how to combat it.

A key success factor is the full engagement of all relevant stakeholders to reach consensus on the overall goal and concrete objectives of such an endeavour. This can only be realised in a pan-European context, building on the expertise, experience and lessons learned in all Member States and supported by common, European resources.

Next Steps

The next steps will be to develop a clear roadmap to prepare ELSA. This would include identifying the main objectives and specific barriers; developing policies, strategies and implementation measures; and outlining a timeline and milestones.

Next Steps and Timeline:

- Consultation meetings May 2009 - March 2010
- Meeting with policy makers 10-11 November in Visby, Sweden
- Concrete plan by spring 2010
- Commission decision in 2011
- MS agreements and governance by 2013

26. EUROPEAN TECHNOLOGY PLATFORMS CONFERENCE

The European Technology Platforms (ETPs) provides a framework for stakeholders to define research and development priorities, timeframes and action plans on a number of strategically important issues (including health). Achieving Europe's future growth, competitiveness and sustainability objectives is dependent upon major research and technological advances in the medium to long term.

On October 13 2009 the European Technology Platforms organised their annual conference hosted by DG Research. The European Patients' Forum (EPF) participated in the Public Health workshop panel and gave a presentation highlighting priorities in research and technology development from a patients' perspective.
The conference report and presentations are available at cordis.europa.eu/technology-platforms/seminar11_en.html

27. BOARD MEETING

The EPF board met on the 24th and 25th of November to review the year's activities and to prepare our work plan and budget for 2010. Also on the agenda will be the outcomes of our first Policy Advisory Group Meeting on the 20th of November and final preparations for the Value+ Conference.

The draft workplan 2010 will be circulated to EPF members for comments and input during December 2009.

28. GOODBYE SABINE

At the end of November, Sabine Lobnig's internship as Communications Assistant will come to an end. During her seven month internship, Sabine worked on the membership guide, conference reports, communication with members and regularly wrote articles for EPF's Mailing.

She also participated in events and conferences on behalf of EPF which allowed her to get to know and better understand the European dimension of EPF's work. Sabine will take her experience with her as she embarks on a new career as Communications Officer in a communication and consulting agency focusing on the promotion of environmentally friendly technologies.

She wishes the staff of EPF as well as our membership all the best for the future! We thank Sabine so much for her contribution to EPF and wish her continued success in Brussels.

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29. DIARY

Thu, Nov 19	EFPIA Patients Think Tank Attendance: Nicola Bedlington and Roxanna Radulescu Place: Brussels
Fri, Nov 20	EPF Policy Advisory Group Attendance: Nicola Bedlington, Yves Brand, Liuska Sanna Place: Brussels
Mon, Nov 23	e-Health User Group Attendance: Liuska Sanna Place: Brussels
Tue, Nov 24	Commission High Level Advisory Board on Research Attendance: Anders Olauson Place: Brussels
Tue, Nov 24 -- Wed, Nov 25	EPF Board Meeting Attendance: EPF Board Members
Wed, Dec 2	European Commission's Working Group on Patient Safety and Quality of Care Attendance: Roxana Radulescu Place: Brussels
Thu, Dec 3	HTA Methodology Conference Attendance: Anders Olauson (speaker) Place: Brussels

Thu, Dec 3	Friends of Europe event Attendance: Christoph Thalheim Place: Brussels
Thu, Dec 3	European Parliament meeting on Information to Patients Attendance: Nicola Bedlington Place: Brussels
Tue, Dec 8	Life Sciences Meeting EP Attendance: Nicola Bedlington (speaker) Place: Brussels
Wed, Dec 9 -- Thu, Dec 10	Value+ Swedish Presidency Conference Place: Gothenburg