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Issue 1 (21): 16 February, 2009

Dear EPF Members and Allies,

"There is a temptation in times of economic hardship to spend less. However in the field of health this would amount to a false economy. Investment in health pays future dividends".

This statement, by Commissioner Vassiliou on 9 December reflects much of the current debate in the field of health both in Brussels and the Member States.

Members of the European Union Health Policy Forum, which includes EPF, have called on governments to ensure that our health does not bear the highest cost in the current economic crisis. In an open letter we have highlighted that short-term solutions of cutting health and social expenditure are short-sighted and damage the economic recovery prospects for not just individual countries but Europe as a whole. This is precisely the challenge being faced by patients in Latvia and EPF has been active in the last few weeks in working with our member organisation there to highlight the importance of sustaining healthcare budgets in the framework of the IMF/ EU rescue package to Latvia.

Access to high quality, equitable and timely health services has never been more crucial, not just because stress and lifestyle choices are affected in times of crisis, but also because delays in treatment mean the number and duration of hospital admissions increases – and this is the single highest cost to health sectors.

This will of course be the canvas for lively discussion at our forthcoming Annual General Meeting, taking place in Brussels on 26 March 2009. We are very much looking forward to seeing many of our members and patient group allies there. The recently adopted Pharmaceutical Package will also feature high on the agenda of our AGM. In our special feature, read about the Package and some preliminary thoughts from the patients' community.

We are also delighted to include in this EPF mailing some insights from EURORDIS on developments at EU level regarding rare diseases (see section 4), and an update from EGAN on the current state of play regarding animal testing (see section 5).

Other key areas of policy work are also reported in this issue: patient safety, e-health, and cross border healthcare. Much pro-active was has taken place in the European Parliament and at national level in relation to the Health Literacy Declaration and of course the EPF Manifesto "150 million reasons to act" (see section 6).

We thank you once again for your active support, as a member of EPF or as a patients ally from the broader health community in advancing this work, which we hope will help to set a different, more patient centred agenda in the EU Institutions, in the spirit of Commission's own campaign "A Europe for Patients".

Warmest greetings,
Anders Olauson, President
Nicola Bedlington, Director

Contents

The next issue of the EPF Mailing will be distributed 6 April 2009. The deadline for submission is 20 March 2009

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1. EU PHARMACEUTICAL PACKAGE

On 10 December 2008, the Commission adopted the so-called "pharmaceutical package", with four key elements all of which have significance for Europe's patients.

The package covers three sets of legislative proposals and a general policy communication. The legislative proposals cover three areas:

(i) Information to patients:

- A Directive amending Directive 2001/83 on Human Medicines;
- A Regulation amending Regulation 726/2004 on the centralized procedure;

(ii) Counterfeit medicines:

- A Directive amending Directive 2001/83 on Human Medicines;

(iii) Pharmacovigilance:

- A Directive amending Directive 2001/83 on Human Medicines;
- A Regulation amending Regulation 726/2004 on the centralized procedure.

A Communication entitled "Safe, innovative and accessible medicines: a renewed vision for the pharmaceutical sector" addresses various broader policy issues, which will be reviewed by the new Commission in the coming years.

The adoption of the Pharmaceutical Package was delayed twice because of extensive discussion within the Commission on key points, including the conditions for allowing information to patients on prescription-only products and the repackaging of medicines.

In general terms, EPF can welcome the rationale behind legislative package. It aims to introduce a harmonized set of quality standards and rules for provision of non-promotional information on prescription-only medicinal products, new and clearer responsibilities to improve pharmacovigilance and tackles the issue of fake drugs. There are however some concerns regarding the detail that we will be discussing with our membership in the coming months and at our forthcoming Annual General Meeting with a view to arriving at a consensus position. More...

2. DIRECTIVE ON PATIENTS RIGHTS IN CROSS BORDER HEALTHCARE

The Secretariat has been working on a series of amendments to the Directive on the application of patients' rights in cross-border health care that were sent to relevant MEPs. These reflect the EPF Statement on the Directive that was agreed in November by EPF members. We have proposed several amendments calling for further cooperation among Member States and asking for more action from the Commission to encourage and support cooperation among Member States to share experiences and information about good practices in health policy, available treatments, research outcomes and thus contribute to an improved quality and safety of healthcare throughout the EU. In line with our equity and inclusion principles, we have also proposed to define the patient as "any natural person, with our without documents, who receives or wishes to receive healthcare". We have strongly supported the need for the Commission, in cooperation with Member States, to develop guidelines that will support Member States in defining clear quality and safety standards for healthcare provided on their territory. On the issue of upfront payment for hospital treatment, the amendment we put forward called for " the Member States of affiliation to put in place appropriate and coherent mechanisms to pay healthcare providers directly for costs that would have been paid by its statutory social security system, had the same or similar healthcare been provided in its territory". In case of an introduction of a prior authorization system the criteria need absolutely to be fair, clear and transparent.

An amendment was proposed regarding the specific circumstances of patients with rare diseases and their families: in a context of scarcity of knowledge and expertise at national level, patients affected by rare diseases, both diagnosed and undiagnosed, should have the right to choose where to purchase healthcare, without prior authorisation. They also should have the right for their care, often expensive, to be fully paid directly by the country of affiliation to the country of provision of care (without having to pay up-front), even

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and especially when the care they need does not exist in their country of affiliation, as this is often the reason for which they need to go abroad.

With regard to the role of patients' organizations, they should be involved in cooperating with competent national authorities in the process of providing and disseminating information to patients. These national contact points should be established in an efficient and transparent way and information about their existence should be appropriately disseminated across Member States, so that patients have an easy access to the information, in various formats.

A total of 556 amendments have been already tabled. Some of the EPF amendments were included. Other patient-focused amendments, suggested by other organizations, looked at, for example, patients' access to a written or electronic records, setting up an independent adjudicator or Ombudsman or the obligation for Member States to define clearly patients' rights in relation to healthcare in accordance with the Charter of Fundamental Rights of the European Union.

The report is scheduled for adoption in Committee for a first reading on 12 March and for adoption in plenary sitting on 23 April.

Active Citizenship Network will be organising an event in the European Parliament on the eve on this vote. See section 7.

EPF will continue to work with key MEPs to attempt to ensure that the outcome of the proposals reflect the points outlined above. EPF Secretariat will keep you informed with further developments.

3. PATIENT SAFETY RECOMMENDATION

On 15 December 2008, the European Commission adopted a Communication and a proposal for a Council Recommendation on patient safety, including the prevention and control of healthcare associated infections. Although the problem of patient safety is primarily the responsibility of Member States, the European Union can encourage cooperation between Member States and support their actions in areas where EU intervention can have an added value. This initiative intends to foster political commitment by Member States to make patient safety a priority in national public health objectives. The EU can also play a role in collecting comparable data at Community level and in disseminating best practices among the Member States. A common "language" or "taxonomy" for patient safety and common indicators need to be developed.

EPF very much welcomes the Communication and Proposal for a Council Recommendation as a significant step forward – even though the recommendation is a not a legally binding instrument In particular, we welcome that:

- Member States are recommended to embed patient safety as a priority issue in health policy and programmes and designate a competent authority responsible for patient safety on their territory.
- Member States are encouraged to consider the development of core competences in patient safety (core knowledge, attitudes and skills) for patients - (very important move forward in the context of health literacy).
- Patients organisations' role in contributing to developing policies and programmes on patients' safety is clearly acknowledged: (II. (2) (b) "Member States should empower and inform citizens and patients by involving patients' organisations and disseminating information to patients (…)".
- Education and training of healthcare workers in patient safety is strongly promoted.

The Recommendation will not go through a co-decision procedure, but the European Parliament, the Committee of the Regions and the Economic and Social Committee will present an opinion. A meeting in the Committee on Environment, Public Health and Food Safety (ENVI) is scheduled for 17 February. Two meetings of the Working group on public health in the Council have already taken place. The intention is for the Recommendation to be adopted in June 2009 Czech EU Presidency meeting of the Employment, Social policy, Health and Consumer Affairs Council.

For further information, please see the article on EHMA Patient Safety Roundtable (section 13) or contact EPF Secretariat.

4. COMMUNICATION ON RARE DISEASES

By Flaminia Macchia, EURORDIS

Recently, three major documents have been elaborated at European level in the field of rare diseases representing important steps in the fight of rare disease patients. These documents are interrelated, mutually reinforcing and converge towards the political recognition of rare diseases as a public health priority, as advocated by EURORDIS in the last 10 years. They create the conditions for a proper implementation of solutions for people living with rare diseases throughout the European Union.

In October 2008, the Pricing and Reimbursement Working Group of the High Level Pharmaceutical Forum adopted a series of conclusions and recommendations, amongst which recommendations focusing on specific access problems related to orphan drugs. This document, known as the **Pharma Forum conclusions on "Improving access to orphan medicines for all affected EU citizens"**, aims at promoting the sustainable development of orphan drugs and at improving sustainable access to these medicines.

In November 2008, the Commission adopted a proposal for a Council Recommendation on a European action in the field of Rare Diseases. This document will hopefully be adopted at the next Health Council (June 2009 under Czech Presidency) and will lead to the elaboration of national plans for rare diseases. At the same time, the Commission adopted its Communication on Rare Diseases: Europe's challenges. The Commission public consultation was officially launched at the European Conference on Rare Diseases in Lisbon (November 2007). The consultation was very successful with about 600 contributions from different stakeholders, including industries, patient organisations and national authorities.

The Communication is very much welcomed by EURORDIS and its members in particular because the document, for the first time ever, proposes an integrated approach for rare diseases in Europe based on patients' needs. The objective of the Communication is to establish an *"overall Community strategy for support to Member States in ensuring effective and efficient recognition, prevention, diagnosis, treatment, care, and research for rare diseases in Europe"*. The Commission will orient the operational actions in three main fields: to improve recognition and visibility on rare diseases, to support policies on rare diseases in the Member States through the adoption of national plans on rare diseases and to develop European cooperation on rare diseases. In this context, specific positive aspects from the patients' perspective are the following ones:

- Recognition of rare diseases as a "unique domain of very high European added value";
- Common definition of rare diseases;
- Recognition of specific issues for rare diseases: lack of knowledge and expertise, scarcity of scattered research, delayed diagnosis, unequal access to expert services, care and authorised orphan drugs;
- Development of European Reference Networks of Centres of Expertise;
- Developing and facilitating patients' access to specialised social services (Help Lines, respite care centres and therapeutic recreation programmes);
- Increased collaboration at EU level for the assessment of the clinical added value of orphan drugs as a way to address bottlenecks in accessing orphan drugs and creation of a specific working party;

- Long term sustainability of data collection systems (registries, databases);
- Cooperation in the area of screening practices and networks of expert diagnostic laboratories.

While receiving the Communication very positively, EURORDIS and its members would wish some elements to be reinforced through the Council recommendation. Concerning research on rare diseases, public/private partnerships could help ensuring the sustainability of research efforts at national and European levels. It is fundamental to involve patients into the management and evaluation of the Centres of Expertise and the European Reference Networks. This also links to the empowerment of patients living with rare diseases at individual and collective levels: networking activities, exchange of experience, dissemination of information, identification of best practices, training, capacity-building are activities which require long-term sustainable funding.

The rare disease community will maintain its efforts to contribute to and facilitate the implementation of these fundamental documents in order to ensure that they don't remain a dead letter. The outcomes should articulate efficaciously and consistently with the plans or strategies on rare diseases at national level.

For further information, please contact Flaminia Macchia, EURORDIS.

5. ANIMAL TESTING DIRECTIVE

By Nick Meade, EGAN

The revision of the EU Animal Welfare Directive 86/609/EEC has been looming for six years, and publication of the draft revision was beset by delays for most of last year. Suddenly, in the past months, the process has moved into a very high gear.

The idea behind this review is to strengthen and modernise EU law on the treatment of laboratory animals, bringing it into line with the best standards currently required in the EU, and to standardise the law across Europe. These are laudable aims, and theses motives should be supported. If these revisions are carried out correctly, scientists will be able to continue pursuing avenues of scientific inquiry which could greatly increase our understanding of serious medical conditions affecting millions of people, while also ensuring that the welfare of animals used in such research is of the highest possible standard in line with the "3Rs" - reduction, refinement and replacement. However, if the revisions are carried out without proper consideration of their impact, the continuing progress of the high quality biomedical research performed in the EU could be under threat.

After a long delay the Commission adopted the proposal to revise Directive 86/609 on 5th November last year. This proposal contained some areas of great concern to patients, the pharmaceutical industry, and the research community for their potential to limit or end drug development. Of most concern is the proposal to limit research using Non-Human Primates (NHPs) to debilitating and life-threatening diseases. This could rule out research on serious chronic conditions such as diabetes. More...

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

EPF is continuing our campaign on the EPF Patients' Manifesto "150 Million Reasons to Act".
In preparation for our Annual General Meeting on 26 March, we have started writing to the leaders of the political groupings in the European Parliament asking them how far the key demands in the EPF Patients' Manifesto are reflected in their Grouping's own Manifesto for the European Parliament elections.

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

An integral part of the Manifesto is our call for political commitment to Health Literacy. To that effect, the Secretariat has intensively worked with Members of the European Parliament to raise awareness about the Written Declaration on Health Literacy 95/2008 and to collect signatures. We have requested members and allies to support these efforts and write in national languages to those MEPs they have established contacts with and the call them to sign the Declaration. Thank you very much for your support and we count on you to continue the advocacy work until 12 March, the deadline to collect signatures.

7. PATIENTS RIGHTS – GET INVOLVED - THE THIRD EUROPEAN PATIENTS' RIGHTS DAY

Active Citizenship Network (ACN) is the driving force behind the third European Patients' Rights Day on 18th April. EPF is also supporting strongly ACN's actions to institutionalise the Day, making it an annual, EU supported official event.

All health related organisations with a commitment to patients' rights are encouraged to join in and organise activities on 18th April at local, regional, or national level that promote the rights of patients and at the same time add their weight to making the Day official.

EPF is working closely with ACN in promoting the Day across our membership. For more details on how to get involved – please go to www.activecitizenship.net/content/view/52/78

ACN is also organising a Patients Rights Event in the European Parliament on 21 April, to which EPF has been invited. Importantly, this will take place on the eve of the EP vote on Patients Rights in Cross Border Healthcare.

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

Readers will recall that the European Commission is co-organising with the European Patient's Forum a conference in order to facilitate the dissemination of the outcomes of the Pharmaceutical Forum initiative among European and national patients groups and the Health Community at large.

Registration for this conference is now closed, however those readers who are not attending and would be interested in seeing it live via webcam should go to http://ec.europa.eu/pharmaforum

The conference will commence at 9.00h. A video of the event will also be made available on the website.

9. eHEALTH USERS STAKEHOLDERS GROUP MEETING, 16 JANUARY 2009, BRUSSELS

Roxana Radulescu attended the meeting of the eHealth user stakeholders group on 16 January. The e-Health Users' Stakeholders Group is an advisory group of the i2010 Subgroup on e-Health, working under the coordination of the Information Society and Media Directorate-General. The meeting provided an opportunity for the members of the group to exchange information about their latest activities on eHealth. Following the publication of the Telemedicine Communication, an update was given on the Commission's work on setting up a platform with stakeholders that will be supported financially by INFSO and coordinated by DG SANCO. Moreover, ongoing work is carried out on a staff working paper that is due by the beginning of 2010. The Commission also plans to set up a platform for Member States to discuss Telemedicines.

An update was also given on the epSOS project which is a cooperation platform among 12 Member States aiming to achieve interoperability among systems and services across national and regional border. The objective is to go from strategy to practical services and deliver a pilot on patient summaries, ehealth prescriptions.

Further discussion was dedicated to the eHealth Conference 2009 in Prague and to the content of the pre-session on "Users Perspectives on eHealth and Ethics". The Group decided that EPF represented by its President, Anders Olauson will give a key speech from a patient perspective. This will be followed by contributions from different healthcare professionals' organisations that will raise the key issues of the ethical use of eHealth towards building trust on eHealth solutions.

The group also decided to take forward the work on EHTEL Patients' Charter in the forthcoming meetings with the aim to collectively endorse the Charter.

10. NANOMED ROUND TABLE, 20 JANUARY, BRUSSELS

On 20 January 2009 Liuska Sanna represented EPF at the Nanomed Round Table.

The Nanomed Round Table is a "Coordination and support action" in the European Commission's Seventh Framework Programme (FP7) under the theme Nanosciences, Nanotechnologies, Materials and New Production Technologies (NMP). The project is currently under contract negotiation with an agreed starting date of 1 January 2009.

Although very promising, nanomedicine may add new dimensions to many ethical, social and economic issues. It is therefore of primary importance to understand its possible impacts and consequences in advance and to provide for all stakeholders a well-organised forum to express their needs and requirements, in particular for patients and society.

The Nanomed Round Table's main purpose is to provide to European stakeholders a set of recommendations to support decision making regarding nanomedical innovations. These recommendations will be based on a thorough analysis of existing documents, multi-stakeholder debate, and construction of scenarios on the possible consequences and impacts of nanomedicine. A further aim will be to raise awareness and understanding of the field and associated issues among policy makers and the wider public and to propose longer term structures to consider nanomedical issues in the future.

The Round Table will bring together stakeholders in five Working Groups: Regulation, Economic Impact, Communication, Patient Needs and Ethics & Societal Impact.

After an introduction of participants, there was a review and discussion of the topics to be explored by each working group. The plenary continued with an update of communication, management and coordination issues and then the working groups' members met separately.

EPF will be active in the Patient Needs group chaired by Alastair Kent, Director of the Genetic Interest Group (UK) and Chairman of the European Platform for Patients' Organisations, Science and Industry (EPPOSI).

The main points discussed at this first meeting of the WG are:

- Need to establish whether nanotechnology is any different from other aspects of new technology in medicine, and if so how and to what extent?
- This main question leads to a series of further questions on ethical issues; use of nanotechnology in current clinical practice; risks versus benefits; regulations; access; clinical preparedness and equity
- Since nanomedicine will impinge on diagnostics and therapies, the group will take two case studies and use these as the basis to address the above questions. One of these will be drawn from the field of novel diagnostic technology and the other is hoped to be an innovative therapy that is well advanced in clinical development and which is likely to receive a license in the coming year.
- An online questionnaire will be circulated to members of selected patient groups where an identified nanotechnology derived therapy is available, to canvas patient and family views on relevant issues.

The dates for the next Working Group meetings are 22-23 April and 2-3 September.
The final meeting of the Round Table will be in Brussels on 16-17 November.

For further information we invite you to contact Liuska Sanna.

11. US CHAMBER OF COMMERCE TO THE EU – NEW COMMITTEE ON HEALTHCARE, 20 JANUARY, BRUSSELS

The US Chamber of Commerce to the European Union (AmCham EU) has recently set up a new healthcare committee focusing on enhancing the relationship between health and wealth, promoting the benefits of e-heath, informing the debate on cross border healthcare and raising the profile of healthcare issues in transatlantic relations. To mark the launch of the committee, a plenary session on healthcare took place on 20 January. Nicola Bedlington participated on behalf of EPF in a panel presenting the Patient's Perspective on Healthcare. Industry representatives presented the Industry Perspective on Innovation and Cross-Border Healthcare and on E-Health. Transatlantic Relations on Innovation was presented by Robert Connan, Minister Counselor for the Department of Commerce at the US Mission to the EU. The panel was followed by a lunch debate with keynote speakers, Head of Cabinet Vassiliou, Philippe Brunet and MEP John Bowis.

For further information on the new committee go to the AmCham EU website www.eucommittee.be

12. EU HEALTH POLICY FORUM, 21 JANUARY 2009, BRUSSELS

Nicola Bedlington represented EPF at the EU Health Policy Forum Meeting on 21 January. The main items on the agenda were: the presentation and adoption of a renewed mandate for the Health Forum, the presentation of a document on strategic priorities for the EUHPF, the adoption of a resolution on civil society and regional role in civil society. There was also an update from the Commission on key health initiatives within the Commission's legislative work programme 2009; the EU Platform for Action on Cancer; a proposal for Commission initiative on Alzheimer; Communication on Solidarity in Health: Reducing Health inequalities in the EU and a Communication on combating HIV/AIDS in the EU and the neighbourhood – strategy and second action plan (2010 – 2014). There was an update regarding the "Europe for Patients" campaign and the next steps focusing on a prize for health journalism.

Significantly, the members of the Forum, on the proposal from the IAPO representative agreed to draft an open letter to governments and policy makers regarding the importance of continuing to invest in health during the economic down-turn.

For further information on the EUHPF and the above meeting, please contact the EUHPF secretariat secretariat (at) euhealthforum.org

13. EHMA PATIENT SAFETY ROUNDTABLE, 22 JANUARY, BRUSSELS

Nicola Bedlington spoke on behalf of EPF at a Round Table organized by the European Health Management Association. The aim of the Round Table was to inform key stakeholders on EU policy development impacting on health outcomes and health care delivery and to facilitate dialogue and debate between key stakeholders and engage them in EU policy development.

Robert Madelin (Director General DG SANCO) presented the Commission Communication and proposal for a Council Recommendation on patient safety. Prior to coming forward with the proposal on 15 December 2008, the EU has been involved with patient safety in a number of ways until now, more specifically by means of the Patient Safety Working Group of the High Level Group on Health Services and Medical Care (running between 2005-2008), and co-funded patient safety projects.

The Commission proposal for a Council Recommendation addresses patient safety as well as HCAI's in one single document and focuses on the following issues:

At Member State level:

- Support the development of national patient safety policies and programmes.
- Empower and inform citizens and patients.
- Establish or strengthen reporting and learning systems on adverse events.
- Include patient safety in the education and training of health professionals.
- Develop and promote research on patient safety.
- Classify, codify and measure patient safety.

At EU level:

- Develop and promote research on patient safety.
- Classify, codify and measure patient safety.
- Share knowledge, experience and best practice at European level.

The proposal was transmitted to the Council for discussion in December, and, once adopted, Member States need to report to the Commission within 2 years on how the Recommendation has been implemented. In relation to HCAI, the ECDC will assist Member States, e.g. by developing guidance, by helping to set up or further strengthen surveillance systems.

Nicola Bedlington provided an overview of EPF's comments on the Commission proposals. EPF's vision is high quality, patient-centred, equitable healthcare for all patients across the EU, and it is clear that patient safety is central to this. Therefore, EPF welcomes the Communication and Proposal for a Council Recommendation as a significant step forward. EPF particularly welcomes the fact that Member States are recommended to embed patient safety in their health policy and programmes as well as designate a competent authority responsible for patient safety. In addition, the proposal explicitly acknowledges the role of patients' organizations in contributing to the development of policies and programmes on patients' safety. The fact that Member States are recommended to set up or improve blame-free reporting and learning systems, in a constructive, rather than punitive way, also reflects the spirit of the EUNeTPAS project in which EPF is involved. Education and training of healthcare workers in patient safety is strongly promoted and Member States are encouraged to consider the development of core competences in patient safety (core knowledge, attitudes and skills) for patients. This is an important move forward, not least within the context of health literacy.

EPF will work with its member organisations and patients allies to make the Recommendation known and understood at national level, with the EPF Patients' Manifesto Campaign "150 million reasons to act" as an integral pillar to the work carried out on this issue. The EPF also works with the IAPO to promote their Patient Safety Toolkit. For a detailed report of the roundtable debate please contact the European Health Management Association.

14. MEETING OF THE HEALTH-EU PORTAL EDITORIAL BOARD, 6 FEBRUARY 2009, LUXEMBOURG

Nicola Bedlington represented EPF at a meeting of the Health EU Portal Editorial board on 6 February. The meeting discussed the progress to date on the Health Portal that is shortly approaching its third birthday. The outcomes of an external evaluation have pinpointed some core issues for reflection. We also discussed an action plan, recent achievements, and statistics on visitors, actions on multilingualism, and a discussion on a project looking at setting up a database of EU health related projects funded under FP5 and FP6. The portal has been extended recently with a specific section on "A Europe for Patients" and in the near future a special section will be set up on Youth and Health.

Three workshops took place to explore how to advance the Health Portal, specifically: Working together: NGO database and social networking; Content you can trust: referencing NGOs and International Organisations; Promote our Portal: how to increase visibility and users.

For full details of the meeting and a copy of the presentations please visit the Health EU Portal.

15. EFPIA PATIENT THINK TANK MEETING, 9 FEBRUARY, BRUSSELS

Nicola Bedlington represented EPF at the EFPIA Patients Think Tank Meeting on 9 February. The agenda focused on the Commission's Communication and Council Recommendation on Patients' Safety, published on 15 December and the Pharmaceutical Package. Lee McGill from DG SANCO gave an overview of the Communication and the Proposal and responded to questions. EPF has welcomed the proposal, and would like to see additional clarity regarding mechanisms for patients to report adverse events.

EFPIA representatives gave an overview of the Pharmaceutical Package and its three key elements: information to patients, pharmacovigilance and anti-counterfeiting, welcoming in essence the three proposals, whilst identify certain areas that required further refinement from an industry perspective. In the dialogue that followed Nicola described the work undertaken to date by EPF on the Package (see special feature) and outlined next steps for EPF, centred on the development of a draft position for discussion and agreement at the EPF Annual General Meeting and our collaboration with IAPO on the issue of counterfeiting.

Regarding the Innovative Medicines Initiative, EFPIA highlighted the disappointing number of successful Consortia involving patient organisations in IMI. EPF reiterated the importance of encouraging the involvement of patient organisations by making this a key criterion for funding, as discussed in previous meetings. EPF will continue to work with EFPIA to encourage the active participation of patient organisations in future Calls.

An update was given on the Animal Testing Directive (see section 5) and Nick Meade (EGAN) gave an update of lobbying activities within the European Parliament. Other patient representatives expressed their desire to support EGAN which is leading the interested EPF membership on this issue.

Nicola Bedlington gave updates on cross border healthcare and telemedicines proposals discussed in previous meetings.

For further information and presentations from the think tank, please contact the EPF Secretariat.

16. VALUE + PROJECT - PLANS FOR 2009

At the end of January Value+ completed its first year of implementation. The end of last year was marked by the seminar for patients' leaders we organised in Lithuania. The report of that event is now available in our website.
The beginning of 2009 has been focused on making detailed work plans for 2009.

During the first months we will continue gathering information on the involvement of patients in health-related projects. Apart from continuing to collect questionnaires sent to the projects, we will organise a focus group in March. The participants will be project coordinators and patients or patients' representatives from a number of projects currently running. The purpose is to share experience on good practices, challenges, benefits and lessons learned related to patient involvement in these projects. We will also hold interviews with some stakeholders involved in the projects identified.

The project Steering Group will assess progress at a meeting planned in mid-April where the main point for discussion will be the framework for analysing the body of information collected.
The outcome of such analysis will be used to develop the project deliverables. The process will start in the spring and will be finalised through various reviews. Some key review opportunities will be a focus group with patients at the beginning of summer and a seminar for patients' leaders to take place in Sofia, Bulgaria on 18-19 September.

We foresee to complete the project with a final conference under the patronage of the Swedish Presidency. The conference will be held in the second week of December.

Should you wish to know more about VALUE+, please contact Liuska Sanna.

17. RESPECT PROJECT – EPF SURVEY

EPF's role in RESPECT, in addition to being a member of the project Steering Committee, is to seek the views of its members in relation to clinical trials performed with children and adolescents. The more we can voice the needs and concerns of young patients participating or likely to participate in clinical trials, the better chances we will have that they become subjects and not only objects of research and that treatments and drugs are better tailored to their specific conditions.

The methodology to be used will include a survey, interviews and focus groups with members' representatives.

The survey has been launched very recently through a questionnaire and we expect to get an insight on what the members think on a number of issues: ethical aspects, current status of trials in their disease, ideas for motivating and empowering children, what role patients' organizations should play in this area.

We will be able to share the results in April 2009.

We invite other patients' organizations and other bodies and individuals who have experience or expertise in the field of paediatric clinical trials from a patient perspective to contact us. More views will enable us to better understand how to empower young patients.

The contact person for this project is Liuska Sanna.

18. EPF ANNUAL GENERAL MEETING, 26 MARCH, BRUSSELS

The EPF Annual General Meeting is taking place on 26 March 2009 at the Borschette Centre, one of the facilities kindly offered by the European Commission.

The meeting will be a one day event starting at 9.00 h and finishing at 16.00 h. Two different sessions have been planned: a Business Session and a Policy and Programme Session. This AGM aims at providing EPF members and observers with a wide overview on the management of the association, on its position on key policy issues and the developments on the going projects and initiatives, such as the launch of the EPF Manifesto “150 Million Reasons to Act”.

The AGM will be an important opportunity to get feedback and direction from our membership on all of these issues.

For further information on the EPF AGM, please contact the EPF Secretariat.

19. EPF BOARD MEETING – KEY OUTCOMES, 10 FEBRUARY, LONDON

The EPF Board met in London on 10 February. The day before, an informal meeting took place with the co-chairs of the umbrella patients' organisation in the UK "National Voices", EPF member in the UK. Jeremy Hughes, CEO of Break Through Breast Cancer, and Mike O' Donovan (also EPF Treasurer) shared recent developments in the UK and together with the EPF board explored opportunities for further collaboration between EPF and National Voices in the UK.

The Board Meeting was devoted to the preparation of the AGM, with the adoption of the Annual Report and accounts for 2008, to be presented for adoption at the Annual Meeting, and the adoption of the Work Plan and Budget 2009.

First steps for the EPF project "The Status of Patients in the European Union" were agreed, and the next phase of the EPF "Young Patients" project was also agreed.

The Board agreed an overhaul of the website to facilitating uploading of documents swiftly and some new procedures for application for EPF membership. Other items on the agenda included the preparation of EPF's 4 major European events this year, our perspective on Health Technology Assessment developments, and medium term financial planning, reflecting our commitment to diversification of funding including industry, Commission and foundation funding; agreement on the European Union Health Policy Forum Strategic Priorities and preparation of the EU Presidencies in 2010.

For further information on the Board Meeting outcomes, please contact Nicola Bedlington.

20. DIARY

Tue, Feb 3 -- Thu, Feb 5	**Meetings with Patients Groups in Poland** Place: Poland Attendance: Anders Olauson
Mon, Feb 9	**Meeting with co-chair and CEO of National Voices UK** Place: London
Mon, Feb 9	**EFPIA Think-Tank** Place: Brussels Attendance: Nicola Bedlington
Tue, Feb 10	**EPF Board Meeting** Place: London Attendance: EPF Board
Tue, Feb 17	**European Voice Health Debate** (acting as promotion parter) Place: Brussels Attendance: Nicola Bedlington
Wed, Feb 18	**Conference "Patients' Rights in a Diverse Europe"** Place: European Parliament, Brussels Attendance: Nicola Bedlington (speaker)
Wed, Feb 18 -- Thu, Feb 19	**eHealth Conference 2009** Place: Prague Attendance: Anders Olauson (Speaker and Chair), Roxana Radulescu
Wed, Mar 25	**Conference on the outcomes of the Pharmaceutical Forum** Delivering for Patients Place: European Commission, Brussels Attendance: EPF Board, EPF Secretariat
Thu, Mar 26	**EPF Annual General Meeting** Place: Brussels Attendance: EPF Members
Tue, Apr 21	**Patients' Right Day** (EPF acting as partner)