EPF's Mailing

www.eu-patient.eu
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Dear EPF Members and Allies,

Welcome to this spring issue of the EPF mailing. We are delighted to report on two recent major events for EPF – the Conference we co-organised with the European Commission on the outcomes of the Pharmaceutical Forum on 25 March 2009 (see Special Feature) , and our Annual General Meeting on 26 March. This issue also includes a number of very important updates on both the policy and programme front, including funding opportunities for patients' organizations. We apologise therefore for the amount of reading but we need to share with you critical developments in several areas of EU policy that will impact greatly on Europe's patients.

Our Annual General Meeting welcomed three new members to EPF, LUPUS Europe, and the national platforms of patients' organizations from Cyprus and Estonia. We also said good bye to two board members who did not stand for re- election – Albert Jovell, President of the Spanish Patients Forum and Christian Saout, President of the French Patients' Platform "Le Ciss". Both board members have contributed significantly to the development of EPF over the last 2 years, and received a very warm vote of thanks from the AGM. The Annual General Meeting voted in four new board members, Vida Augustinienė from the National Patients' Platform in Lithuania, Guadalupe Morales from Gamian Europe, Maria Navarro from the Spanish Patients Forum, and Timo Nerkko CEAPIR. We are also extremely pleased to welcome these new board members who have a wide-ranging knowledge and experience on patients' rights from both a European and national perspective (see section 19).

We are delighted to include an article on Alzheimer's, charting the progress and plans this year where the European Commission has made it a priority, alongside rare diseases (featured in our last issue) and HIV Aids (see section 7).

You will all be aware that the European Parliament elections are just around the corner. Our AGM was a very good opportunity to review our members' work on the EPF Manifesto and to rally further support for continued campaign work before and indeed after the elections. Please go to section 6 to see how you can contribute. And thank you again to all our members and allies for your support so far. This is vital - to set the scene for a better, more patient-centred, equitable health focus in next European Parliament and new European Commission.

Warmest greetings,
Anders Olauson, President
Nicola Bedlington, Director

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The next issue of the EPF Mailing will be distributed 29 May 2009. The deadline for submission is 14 May 2009.

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1. CONFERENCE – THE PHARMACEUTICAL FORUM – DELIVERING FOR PATIENTS

On Moving from agreed principles to good practice and positive change across Europe

Can the Pharmaceutical Forum deliver for Patients?

This was THE question in the Conference co-organised by the European Commission and the European Patients' Forum that took place in Brussels on 25 March 2009.

The Pharmaceutical Forum was a three year process involving the Commission, the Member States and representatives from other stakeholders to explore the future of pharmaceuticals in terms of 'information to patients', pricing and reimbursement and relative effectiveness. A number of very important principles and practical tools in each of these areas were developed during that period that creates **a new dynamic between equity of access, cost containment and reward for innovation.** The conclusions and recommendations from the Pharmaceutical Forum received political endorsement during a high level ministerial meeting in October 08.

The conference convened 130 patient organisation leaders and other health stakeholders from across the European Union to explore critically the outcomes of the Pharmaceutical Forum and how to use these effectively from European to local level.

This Conference was a key milestone in moving forward on the achievements of the Pharmaceutical Forum. It enabled participants to share knowledge on the tangible outcomes of the Forum and to examine in very concrete terms how the conclusions and recommendations of the Pharmaceutical Forum could and should be translated into reality by the whole range of stakeholders in their own organisations and in their own contexts. More...

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2. DIRECTIVE ON PATIENTS RIGHTS IN CROSS BORDER HEALTHCARE (AMENDMENTS IN EP)

On 31 March the European Parliament Committee for Environment, Public Health and Food Safety (ENVI) adopted the Rapporteur's, John Bowis (UK, EPP-ED), report on the proposed Directive on the application of patients' rights in cross-border healthcare. The final compromise included 25 compromised amendments. The report was adopted with 31 in favour, 3 against and 19 abstentions. Since February, several other Committees in the Parliament have given their opinions on the Directive: Women's Rights and Gender Equality (FEMM), Industry, Research and Energy (ITRE), Employment and Social Affairs (EMPL), Economic and Monetary Affairs (ECON) and Environment, Public Health and Food Safety (IMCO). All opinions were adopted.
EPF sent letters to MEPs supporting a series of amendments of interest to patients and proposed a voting list. Our key messages referred to the following:

- The need for stronger cooperation between Member States on cross-border healthcare and exchange of information and good practices
- embed the principles of quality and safety of health care in the legal text and explicitly uphold the Council's commitment to the overarching values and principles for healthcare systems (June 2006)
- put in place cooperation between MS in place mechanisms to pay healthcare providers directly and thus avoid the need for patients to pay upfront
- in MS who choose to set up prior authorisation systems, this should be done in a transparent and effective way
- set up mechanisms for patients with rare diseases to access healthcare in another Member States without prior authorization

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- set up a European Patients' Ombudsman who will treat patient complaints as regards prior authorisation, the quality of treatment, payments
- involve patients organizations in provision of information to patients and drafting and adopting guidelines on information to patients,
- involve patients in the European health technology assessment network.

Letters including the same messages were sent to Ministers of Health from all EU countries, health attachés and permanent representatives. The vote in the European Parliament plenary sitting is planned for 23 April. In the Council, the Ministers of Health and Employment will discuss the Directive on 8-9 June. EPF will keep you undated with further policy developments in the parliament and the Council.

For further information, please contact Roxana Radulescu.

3. THE PHARMACEUTICAL PACKAGE

EPF and its member organizations discussed the Commission's pharmaceutical package, comprising proposals on information to patients, pharmacovigilance and anti-counterfeiting at our Annual General Assembly on 26 March 2009. A consultation paper has been circulated to members for their comments and input by the 30 April 2009. Our starting point is that we welcome the objectives of the pharmaceutical package and broadly support the proposals. There are however a number of elements that require re-think and or clarification in order to make the proposals really work for patients. In the context of the information to patients proposal we are very clear that this is very narrow in scope, and should in fact be only one, albeit important, part of a much broader comprehensive EU strategy on information to patients that includes health literacy.

A collective EPF position will be circulated widely in early May. Based on the discussions at the AGM, EPF is, in the meantime, meeting the European Parliament Rapporteurs in each of the three areas to discuss our

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respective positions. It is unlikely that any major work will happen on the proposals within the European Parliament until after the European Parliament Elections. Initial discussions however indicate that the proposals are being welcomed by MEPs.

EPF has also been in close contact with the European Commission Unit responsible for the proposals and also of course, the Council and in particular representatives of the Council Working Group working on the proposals under the leadership of the Czech Presidency.

A number of other meetings have taken place over the last few weeks that have explored the proposals in greater depth and looked at respective viewpoints. An important meeting was hosted by EFPIA that bringing together major health NGOs on 19 March that focused on “information to patients”. TOPRA, the organization for professionals in regulatory affairs arranged a meeting on 25, 26 February that looked at a “renewed European Strategy for Pharmaceuticals in Europe”. The life science circle, led by MEP, Jorgo Chatzimakarkis held a meeting on Health Education in Europe – Turning Europe into the Healthiest Society on 4th March. EPF was present and active in all of these discussions -please contact the secretariat if you would like further reports.

EPF will keep our membership informed of developments linked to the Pharmaceutical Package on an on-going basis. If you would like further detailed information in the meantime please do not hesitate to contact Nicola Bedlington (for information to patients) or Roxana Radulescu for pharmacovigilance and anti-counterfeiting.

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4. PATIENTS' SAFETY

The proposal for a Council Recommendation on patient safety including the prevention and control of healthcare associated infections was discussed, under consultation procedure, in the European Parliament Committee on Environment, Public Health and Food Safety. The rapporteur, Italian MEP Amalia Sartori (EPP-ED) highlighted that the European institutions and the Commission in particularly have to play a leading role to facilitate the exchange of data and good practices in these areas. She specifically called for the Commission to produce a document aimed at patients on the prevention of nosocomial infections and submit it to the Parliament and the Council.

The report was adopted in the Committee sitting on 31 March. Sartori's report and the amendments tabled are available on the European Parliament's website:
www.europarl.europa.eu/meetdocs/2004_2009/documents/pr/765/765642/765642en.pdf
www.europarl.europa.eu/meetdocs/2004_2009/documents/am/771/771247/771247en.pdf

At the same time, in view of the discussions with the Czech Presidency and the Council on the proposal, EPF provided the Commission with examples of information and education interventions tailored for patients on patient safety aspects that have been developed in various Member States. These include in particular the handbook for patients on patient safety developed by the Danish Society for Patient Safety, Patient Handbook: A patient guide to a safer hospital stay which aims at preventing communication errors with health professionals, medication errors, by offers safety tips for patients. And the Patient University Project – run by the University of Barcelona in cooperation with the Spanish Patient Forum and Joseph Laporte Library for patients with chronic conditions and their families and carers - courses and information tool kits about specific chronic diseases and the disease self management.
In terms of legislative timeline, the Recommendation is planned to be adopted during the following Czech EU Presidency meeting of the Employment, Social policy, Health and Consumer Affairs Council (8-9 June 2009).

For further information, please contact Roxana Radulescu.

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5. GREEN PAPER ON EUROPEAN HEALTH WORKFORCE

EPF welcomed the European Commission's Green Paper on the European Workforce for Health and expressed, in its recent response, support for the European Commission to encourage and back up Member States in sharing good practices and information about most effective ways of tackling workforce challenges. EPF first highlighted that an efficient public health work force, equipped with the right skills, and with sufficient capacity to carry out activities effectively, is essential for quality, safety and equitable healthcare throughout the EU. Key messages of our response:

- Involve patients' organisations in the health policy and planning process, both at national and EU level.
- support chronic disease management practices and long term care provision closer to home or in a community setting, in close cooperation with patients;
- explore the reasons why health workers leave the profession and why its attractiveness as a career choice is decreasing, as well as addressing the issues of low pay and working conditions;
- support continuous professional education of health professionals, including a gender perspective; develop training and communication courses for health workforce in order to provide clearer and more complete information to patients; use the quality principles agreed during the Pharmaceutical Forum process, and the strategy document on accessing information in different health settings to underpin European efforts in this direction;
- recognise the contribution of families and carers and recognise and resource their work;
- use structural funds to improve skills and competences of the health force, including communication skills to interact with patients;
- elaborate an EU comprehensive information strategy that embraces health literacy as a concept, and promote health literacy as a policy and programmatic priority at Member State level.

For further information, please contact the EPF Secretariat.

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

The EPF Annual General Meeting was a good opportunity to review progress on the EPF Patients' Manifesto Campaign. Readers will recall that the Manifesto was launched on 17th September at the European Parliament where a number of 'health MEPs' confirmed the importance of the Manifesto and their support.

- Copies of the Manifesto were sent out to the entire membership together with a campaign guide.
- The Manifesto was translated into French and used at a number of events under the French Presidency last year.
- It was a key topic during EPF's regional advocacy seminar in November in Lithuania. This has resulted in significant campaign work in the five countries involved in the seminar. The manifesto has been translated and our member organisations from the five countries concerned are working closely with current and prospective MEPs and their national governments.
- We have had requests from Croatia and Turkey, where patients' organisations have requested permission to translate and use the document as their own manifesto with their own governments.

A number of other initiatives have been taken on the Manifesto and we use it as a basis for all our policy and public work. A good example and a direct result of the Manifesto was the Written Declaration on Health Literacy - launched in November 2008 by MEPs Bulzesc, Maaten and Busoi - calling for wider distribution of quality health information to citizens and patients and further training for health professionals to improve their communication with patients. More...

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7. DEMENTIA ON THE EU POLITICAL AGENDA

By Annette Dumas, Alzheimer Europe

Since 2006, when Alzheimer Europe launched the Paris Declaration outlining the organisation's political priorities, European and national policy makers have become more aware about Alzheimer's disease and its challenges. This has led to a cascade of far-reaching EU policy recommendations.

In September 2008, the EU Competitiveness Council fulfilled two of the Paris Declaration priorities: 1) it recognised Alzheimer's disease as a public health priority. The conclusions call for Members States to combat neurodegenerative disease and specifically mention Alzheimer's disease. 2) In the field of research, the Council called for closer and stronger collaboration between key actors active in the field of research.

Then, in October 2008, the French EU presidency conference on Alzheimer's disease also responded to the Paris Declaration priorities : 1) it recognised the urgency to respond to the specific needs of an ageing population as well as the health and social challenges posed by Alzheimer's disease. 2) It called for European action on Alzheimer's disease.

In December 2008, the Health and Social Affairs Council conclusions took into consideration the French Presidency conference recommendations and called on the European Commission to adopt an initiative on Alzheimer's disease, reinforce collaboration in the field of research and exchange best practices in the field of prevention, early diagnosis, treatment, social support and rehabilitation.

At the opening of the EU Health Forum in December 2008, Health Commissioner, Androulla Vassiliou, announced a European Commission initiative on Alzheimer's disease initiative for 2009.

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And in February 2009, the European Parliament, the third major EU institution, adopted a Written Declaration on Alzheimer's disease. The Declaration was signed by 465 MEPs from all Member States and all EU political groups. It calls on the Member States, European Commission and Council to recognise Alzheimer's disease as a public health priority and develop a European action plan for the disease. The plan should promote pan-European research on the causes, prevention and treatment of Alzheimer's disease, improve early diagnosis, simplify procedures for patients and carers and improve their quality of life.

The awareness and political campaigns led by Alzheimer Europe and its members since 2006 have yielded tangible outcomes: more and more Member States are now putting Alzheimer's disease on their agenda with national plans or strategies.

At European level, the political recommendations of the Council and European Parliament are already producing some concrete results. Following the lead of the French EU Presidency, Member States have agreed to form, on a voluntary basis, a network that will pool efforts in the field of Alzheimer's disease, to avoid duplication and waste of resources. To-date, some 12 Member States have agreed to participate.

The European Commission has already started work on the promised Alzheimer strategy.

And at European level, on an exploratory basis, some discussions are also taking place around ethics, another Paris Declaration priority.

These promising developments are the results of a coordinated and engaged collaboration between Alzheimer Europe, its members and the EU policy makers. Alzheimer Europe will endeavour to continue this collaboration with the new European Parliament and Commission and ensure the needs and expectations of the people they represent are fully met.

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8. PATIENTS' RIGHTS DAY

The "3rd European Patients' Rights Day" celebration will be held on the 22 April 2009 at the European Parliament in Strasbourg in the presence of Commission Vassilou.

The 1st European Patients' Rights Day was organised by Active Citizenship Network (ACN) in 2007 at the European Parliament in Brussels with over a 180 delegates from 25 countries. Last year, the 2nd European Day was celebrated in 26 EU countries with a European Conference in Gorizia, Italy focusing on cross-border care.

The European Patients' Forum has participated actively in these events and is very supportive of ACN in its strive towards institutionalising the Day at EU level, also calling for this in our EPF Manifesto "150 million reasons to act". The institutionalisation of the Day will be a key focus on the event in Strasbourg and EPF has been invited as a speaker.

A number of patients and citizens' organisations are arranging patients' rights activities on and around that period in their own countries. If you would like further information on what is going, and how to contribute please contact Melody Ross (m.ross (at) activecitizenship.net).

ACN says "In the present European context patient's rights are a growing concern for citizens as well as a framework for common action. Every public survey shows their health is at the top of citizens' concerns, and many will take it into account in forthcoming EU wide elections. In addition on 23 April in the Strasbourg Parliament a number of important initiatives regarding patients rights that are planned to be voted on in plenary for example: proposal for Council recommendations on Patient Safety and the Directive on Patients' Rights in cross-border care. For that reason, the 3rd European Patients' Rights Day European event will be an opportunity for NGOs, public officials and other important stakeholders to be able to interact, and to hear each other's opinions on the concrete situation of patients' rights and the challenges being faced in a continually growing and changing Europe".

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9. TACKLING HEALTH INEQUALITIES - CONSULTATION

The European Commission launched earlier this year a consultation document on Tackling Health Inequalities – this is part of the EU Health Strategy “Together for Health”. EPF in consultation with its membership has developed a response to this, framed around our vision of high quality, patient centred, equitable healthcare across the European Union and our strategic goals on equity, empowerment and inclusion.

Our response identifies the key challenges, and strategies needed at EU level from a patients’ perspective. The EPF response (see attached) also explores opportunities for action by patient organisations in providing quality information targeted at patients vulnerable to social exclusion, and also approaches to ensure patients’ organisations are as inclusive and as representative as possible.

We will be reporting in future issues of the EPF Mailing the outcomes of the Consultation and next steps envisaged by the European Commission. If you would like further information on this important area of work, please contact Nicola Bedlington.

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10. STRUCTURAL FUNDS

On An important item of the EPF Annual General Meeting Agenda was 'The Structural Funds - Opportunities for Patients Organisations'. Rostislava Dimitrova from DG SANCO gave a comprehensive presentation on ways in which patient organisations can apply for structural fund monies, and particularly European Social Fund. As Rostislava made clear, these funds are awarded and administered at national level. If EPF members or your member organisation is interested in finding out more about the opportunities in your country, and how to go about making application, it would be important to contact your national contact point. You can do this by visiting the following website. http://ec.europa.eu/employment_social/esf/index_en.htm that is available in your language, and can also tell you more about the priorities your government has identified and where health fits in.

Should you need more general information or advice, please do not hesitate to contact Rostislava on the following email Rostislava.DIMITROVA (at) ec.europa.eu

As readers will be aware, EPF is also cooperating closely with the European Federation of Nurses (EFN), representing national associations of nurses across the European Union. They are attempting to use structural fund monies to support projects in the fields of patient safety and continued professional training in communications. EFN is very keen to get patients organisations involved in such projects and would welcome expressions of interest from your side to cooperate. If you would like to know more about this action, please contact the EPF secretariat and we will gladly put you in touch with EFN and their representative member in your country.

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11. EUROPEAN VOICE EVENT “ACCESS TO TREATMENTS – WHICH RIGHTS FOR PATIENTS”, 17 FEBRUARY 2009, BRUSSELS

Nicola Bedlington represented EPF at a European Voice event on health on 17 February 2009, in which EPF was also a promotional partner. The event “Access to Treatments – which rights for patients” took the form of a panel discussion between John Bowis, MEP and EP rapporteur on the proposed Directive on patients’ rights to cross border healthcare, Alistair Kent, President of the European Genetic Alliances Network, Dr Schuurmann, Chair of the Medicines Advisory Committee (MEDEV), And Pr Finn Borlum Kristensen, Project Leader at the European Network for Health Technology Assessment (EUnetHTA). Moderated by Phil Hammond, a lively and wide ranging debate took place on all aspects of the proposed Directive. Much positive discussion also took place on the importance of patients’ involvement in Health Technology Assessment process, which EPF is following up on.

For a full report of the event, please go to www.europeanvoice.com

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12. ALDE SEMINAR ON “PATIENTS RIGHTS IN A DIVERSE EUROPE”, 18 FEBRUARY 2009, BRUSSELS

Hosted by Cristian Busoi, MEP and Jules Maaten, MEP, this event took place on 18th February and addressed the EU Directive on Cross Border Healthcare. Opened by Graham Watson, leader of the ALDE group, presentations were given by Andzrej Rys, Director European Commission DG health and consumers, Nicola Bedlington for EPF, Axel Rahmel, Medical Director at Eurotransplan, and Dr Sorin Marian Paveliu, former member of the European Parliament and Mr Alexandru Teodorescu, TV producer of a Romanian talk show.

A discussion then took place on the state of play in the European Parliament, although clearly the debate has moved on since this meeting but this event was a very important opportunity to get across key messages to the ALDE Group on the importance of the Directive and indeed why EPF supports it.

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13. SUSTAINABILITY CONFERENCE, 17 -18 FEBRUARY, 2009

Anders Olauson, EPF's President, participated in the Conference on "Securing Europe's Healthcare Future" that took place in Prague on 18th February 2009 under the auspices of the Czech Presidency of the EU Council.

The conference marked the culmination of an investigation launched in Luxembourg in 2005 to provide policymakers with new research indicating practical solutions to sustainability challenges in healthcare. Following the first set of reports published in 2007, two more in-depth studies were undertaken:

Managing Chronic Disease in Europe - Dr. Reinhard Busse, Berlin University of Technology
The Future of Health Technology Assessment in Europe - Dr. Panos Kanavos, London School of Economics

The conference brought together a select group of politicians and regulators at national, European, and supra-national levels (EU 27 member States, Eastern European countries, US) and representatives of civil society to debate these issues.

For further information, please visit the conference website : www.sustainhealthcare.org

On the same topic, which is a priority for the Czech Presidency of the Council of the European Union, a Ministerial Conference on the Financial Sustainability of Health will be held in Prague on 10-12 May. Anders Olauson will represent EPF at this event. The conference will include new definition of financial sustainability with respect with efficiency and solidarity and long-term care, its finances and increasing demand for its services and impact of population ageing for health systems.

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14. E-HEALTH CONFERENCE, 18-20 FEBRUARY 2009, PRAGUE

The seventh in a series of annual conferences organised since 2003, the eHealth conference 2009 was held in Prague under the auspices of the Czech Ministry of Health in cooperation with European Commission. With the aim to support dissemination of eHealth best practices, the conference focused on three main themes: eHealth for individuals, eHealth for society and eHealth for the economy with featured a rich and valuable set of examples of good practice.

Anders Olauson, EPF's President gave a keynote speech at the pre-session "Users Perspectives on eHealth and Ethics. He highlighted that ehealth will only work for patients, society and the economy IF there is appropriate recognition of the ethics around e-health in terms of patients' meaningful involvement in all stages of ehealth solutions development, Patients' access to information and patients' informed consent, respect of patients' dignity and of ehealth literacy needs of patients, citizens and health care professionals. The session was attended by about 60 participants and enabled a rich and interesting exchange of ideas.
The sessions dedicated to the relation between ehealth and individuals summarized good practice examples of use of ICT tools in communicating to EU citizens, as well as benefits and challenges of cross-border healthcare provision and what eHealth can do to foster it.

At the session on ehealth and society, the idea of Health Literacy of patients and the need to support trust and interaction between patients and doctors was strongly promoted by Michael Wilks, CPME's President. The Patient's charter for e-health was presented by David Garwood, EHTEL, who highlighted the significant need to communicate the benefits of ehealth to patients and to involve patients in ehealth projects since the very beginning.

In the session dedicated to ehealth and economy, the discussions looked at possible solution for sustainability of eHealth within the health delivery ecosystem, in particular working consistently towards

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value for money across all of healthcare spending budgets while acknowledging that eHealth is an enabler, not an end in itself.

In the Prague Declaration, adopted at the end of the conference, the Member States and the European Commission committed to facilitate the building of a European eHealth area which will enable access to healthcare for all citizens. It was highlighted that continued efforts are needed, particularly in the areas of telemedicine services deployment, interoperability as well as Europe-wide cooperation and exchange of best practices. Member States are encouraged to adapt their national eHealth strategies so that the individuals (patients and healthcare professionals), society and economy are all the beneficiaries of eHealth's positive effects.

For further information, please visit the conference website.

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15. STROKE PREVENTION MEETING, 3 MARCH 2009, BRUSSELS

Nicola Bedlington represented EPF at a meeting looking at Stroke Prevention in Atrial Fibrillation and how to develop a policy initiative in this area. Atrial fibrillation (AF) is the most common type of arrhythmia in adults. It is associated with increased morbidity and mortality and has negative impact on the patient's quality of life, mainly due to stroke and heart failure which are linked with this condition. The rate of death due to stroke is nearly 2-fold higher in men and 3-fold higher in women with AF compared to those without AF.

AF prevalence is strongly age dependant. The phenomenon of aging in western populations contributes to the rising number of AF cases. In Europe 5% of the population will develop AF during their lives. The inevitable rise in AF prevalence has significant implications on general public health and health systems and its association with other conditions, such as high blood pressure and diabetes, means that AF is one of the key health issues of the 21st century. In 2006, the total direct and indirect costs associated with stroke were estimated at approximately 25 billion euros per year in Europe.

This meeting, co-chaired by Dr Ian Ragan, Executive Director, European Brain Council and Professor Paulus Kirchhof, Senior Physician and Consultant, Medical Hospital and Outpatients Clinic, Münster University Medical Centre brought together a wide range of experts covering the fields of cardiology, neurology, health economics, policy and the patient perspective, to look at possible action in an EU context and the development of a policy document outlining the extent of the problem and its impact on patients, healthcare systems and economies in general terms. The meeting provided a valuable opportunity for EPF to meet a representative of a leading European patient organisation working in this field and agree collaboration.

For more information, please contact Nicola Bedlington.

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16. EMEA AD-HOC EXPERT MEETING ON OSTEONECROSIS OF THE JAW, 19 MARCH 2009, LONDON

Roxana Radulescu participated in a meeting on bisphosphonates and osteonecrosis of the Jaw (ONJ) organized by the EMEA. The meeting was convened in the margin of the March meeting of the Committee for Medicinal Products for Human Use. Experts in dental surgery and oncology from various Member States attended the meeting to discuss about suspected association between the use of bisphosphonates and osteonecrosis of the jaw. The aims of this meeting were to obtain a better understanding of the pathophysiological mechanisms and to reach agreement on a definition of ONJ, to be able to rate the risk between products and patients and to be able to implement evidence-based preventive measures.

It was highlighted that cancer patients treated with bisphosphonates should undergo a dental assessment at a specially trained oral surgeon preferably before the treatment is started. As regards osteoporotic patients with poor dental health, a dental examination prior to treatment may be needed.

It was commonly agreed that a pan-European database on ONJ is highly needed to gather further information on the risks of ONJ and possible risk minimisation measures. Roxana raised the point of the need for to inform adequately the patients about the treatment and procedures, as well as risks associated with the medication. The choice of the treatment should be a common decision, shared between the physician and patients. Also, from a patient perspective it would be of advantage if multidisciplinary teams would be set-up and family doctors/GPs would be involved more often. Raising awareness of this issue with relevant patient organisations would also be helpful.

For further information, please contact Roxana Radulescu.

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17. EMEA WORKING GROUP ON THIRD COUNTRY CLINICAL TRIALS, 27 MARCH 2009, LONDON

The group discussed the challenges of meeting international ethical standards in clinical trials in countries outside EU. Clinical trials are increasingly conducted in low and middle income countries because of lower costs and faster recruitment. However, patients who are involved in these trials are more vulnerable and their rights are less secured than in high income countries. Conditions such as poverty, illiteracy, poor health systems and inadequate research ethics committees are factors that lead to international ethical standards not being met. Examples of rights violation were given: patients were not adequately informed, consent may not have been fully informed and freely given, serious adverse events were not reported, and ethical review committees were not fully independent.

It was highlighted that European authorities reviewing the application for marketing authorization of medicines cannot simply rely on these regulatory systems or on the statements made by the applicants themselves that clinical trials were conducted in an ethical manner. Further cooperation between European regulators (medicine agencies and inspectors) and regulators in the concerned countries, as well as WHO is needed.

The group divided in 3 sub-groups who work further in the coming months on specific topics: (1) clarify the practical application of ethical standards for clinical trials, in the context of EMEA activities; (2) determine the practical steps to be undertaken during the provision of guidance and advice in the drug development phase; (3) determine the practical steps to be undertaken during the marketing authorisation phase; (4) international cooperation in the regulation of clinical trials, their review and inspection and capacity building in this area.

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The patients' perspective was represented at the meeting by Roxana Radulescu (EPF) on behalf of Albert van der Zeijden, and Nikos Dedes - European Aids Treatment Group (EATG). The International Alliance of Patients Organisations (IAPO) is also involved in this work. Patients' organizations main concerns relate to the need for adequate information and education for patients, transparency of clinical trials procedures, preventive measures, but also sanctions to combat unethical research.

For further information, please contact Roxana Radulescu.

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18. MS-ID PROJECT CONSENSUS MEETING & EMSP SEMINAR, 14-15 MAY 2009, BRUSSELS

In 2007, the European Multiple Sclerosis Platform launched the MS-ID Project (co-funded by the European Commission).

The main objectives of this project are:

- the analysis and comparison of Multiple Sclerosis (MS) data collection systems in Europe with the aim of developing and piloting a European Register on MS,
- and the activation of the European Code of Good Practice on the quality of life for MS patients.

The outcomes of the MS-ID project should contribute to an increased awareness across the EU on MS at political level, to a better understanding of the major inequalities of MS treatment and care across the European Union, as well as to the utilization of high quality comparable data on MS to positively impact the health policy in Europe so that citizens affected by MS can participate as full and equal citizens in society today.

EMSP will hold a Consensus Meeting on the 14th May 2009 to present the results of the research done in the framework of developing a European Register on MS, both from a medical and a statistical perspective. A specific attention will be drawn upon the European Code of Good Practice in MS and its role to raise the standards throughout the European Union, the MS Barometer - EMSP's tool for making effective policy - and the added value of the MS-ID project in the context of the EU Public Health programme. The next day will be followed by a seminar on EU impact on the life of people with MS.

The program and practical details on those events are available on www.ms-in-europe.org
For further information, please contact: christoph.thalheim (at) emsp.org, EMSP Secretary General.
For further information on the project itself, please visit: www.ms-id.org

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19. EPF ANNUAL GENERAL MEETING HIGHLIGHTS

More than 50 representatives participated in the EPF AGM, either as members or as observers from patient groups who wish to join EPF or cooperate closely. In the governance session in the morning, the minutes from the previous AGM in April 2008, the annual report, financial accounts and auditors' report for 2008 were approved. Three new organisations joined EPF as full members: Lupus Europe and national patient platforms from Cyprus and Estonia. Four new board members were elected Vida Augustiniene from the National Patients' Platform in Lithuania, Guadalupe Morales from Gamian Europe, Maria Navarro from the Spanish Patients Forum, and Timo Nerkko from CEAPIR. The budget and work plan for 2009 were approved as were a revised framework on funding and a code of ethics.

An important discussion took place on EPF membership criteria, particularly associate membership criteria and the EPF Constitution and by- laws will be revisited in this respect.

The importance of including explicitly reference to families and carers in all our work was reiterated during the AGM.

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Both these debates illustrate the genuine interest and contribution by our members with regard to how EPF works and is developing as an organisation.

The afternoon session was devoted to policy and programme developments. A very good discussion took place on the Pharmaceutical Package on the basis of an explanatory note that was circulated to members in advance of the meeting. The importance of achieving consensus with regard to our response to the Commission's proposals was stressed, and members committed themselves to responding to a consultation note from EPF by the end of April.

Participants received a comprehensive update on other key policy priority areas for EPF particularly in the areas of patients' safety, e-health, cross border healthcare, health literacy and health inequalities. They were also given an update on the Value+ project and achievements to date.

EPF members approved an initiative to set up policy advisory groups for EPF and a 'terms of reference' document will be developed by the board and circulated shortly.

Participants also learned about opportunities for funding of patients organizations in the framework of the Structural Funds and sign posted to where to find additional information and support at national level.
Finally, a session took place on the EPF Manifesto "150 million reasons to act" and representatives outlined how they are working with the Manifesto at national level.

The meeting closed on this high note and EPF President, Anders Olauson, thanked all participants for their excellent input and for their continued and ongoing commitment and investment in EPF.

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20. NEW COMMUNICATION ASSISTANT JOINS EPF

EPF's new Communication Assistant joins EPF on 8th April 2009. Sabine Lobnig is of Austrian origins and has already had an internship experience at the EU Representation Office of Carinthia in Brussels where she was researching for new EU funded projects on regional development, worked on working papers and had some communication tasks.

Sabine holds a BA in translation in French, Japanese, English and German at the University of Vienna and is currently enrolled as student in the Master Programme in International Management (University of Liverpool).

At EPF Sabine will focus on internal and external communication strategy as well as on online communication.

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21. CALL FOR PROPOSALS – EPF ACTIONS

This is a period of the year when many organizations are occupied with developing project proposals to apply to different funding programmes of the European Commission.

The same goes for EPF and we are in the process of developing and participating in selected applications that will support our policy priorities.

In the context of the recently launched Call for proposals 2009 of the Public Health Programme, EPF will lead a proposal submission focused on Telemedicine. One of the strands under the patients' safety topic clearly aims at implementing the EC Communication on Telemedicine. EPF in cooperation with health professional allies will address the need to increase acceptance of Telemedicine by patients and health care providers.
A preparatory meeting is scheduled for the 8th of April in Brussels. A number of organizations have expressed their interest to attend. There is still an opportunity to join the project, if you have an interest or expertise in Telemedicine. Please contact EPF Secretariat.

In addition to this initiative, EPF has been invited to be partner in other two projects. The first one is led by the European Federation of Nurses and the subject is Quality of Care. The concept is currently being discussed.
The second one is on Health Technology Assessment and it consists in the second phase of the EU Network on Health Technology Assessment.

Our participation in both areas will be subject to board approval.
We are very excited about these initiatives that are important steps in the continuum of EPF work on those topics. Overall they all aim at achieving our primary strategic goal of ensuring equitable access to high-quality patient-centred health care across the EU.

Should you like to know more about developments in these projects do not hesitate to contact Liuska Sanna.

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22. RESPECT PROJECT

Member of the project Steering Committee, EPF is also an associate partner in the project.

Our role is to collect the point of view of its members in relation to clinical trials performed with children and adolescents. For the moment, the focus is on the info collection, which purpose is to investigate needs, motivation, barriers and identify good practices. We want to understand why children and families participate or not in clinical trials.

For that purpose, we finalized a survey that we sent to our members. The objective is two-fold: to get their general opinion on clinical trials on children and identify those members with experience in the field in order to have a more-focused second phase through interviews and focus groups.

We have sought the authorization of our members to spread the survey as widely as possible among their members. We receive regularly completed survey. Please, do not hesitate to return us the survey even if the deadline is exceeded!

We intend analysing the findings of this survey mainly with a qualitative analysis approach.
As these are all open questions, we aim at get an idea of views, perspectives and trends. We plan to share with all participants the outcome of the survey.

The contact person for this project is Liuska Sanna.

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23. CALLIOPE PROJECT

Roxana Radulescu represented EPF at CALLIOPE project second meeting of WG 5 which was held in Prague, on 18 February. The objectives of the meeting were to validate the proposed mission statement and work programme of the group and to develop the next stage of activities to be undertaken.

Work group 5 is involved in providing strategy support to CALLIOPE project partners and to the Commission services. Its scope is to contribute to the assessment of the eHealth Interoperability Recommendation published by the European Commission. An important part of work group 5 is to develop a user-centric process in relation to eHealth interoperability and a clear understanding of what is needed in the European Union and its Member States in terms of a stakeholder engagement approach that has to be encouraged, accepted, and mandated (legally if necessary).

Three very interesting presentations were given refer to eHealth interoperability (political/legal; organisational; semantic; technical; education and training):

- HPRO Card: European Health Professional Card: Contribution to Health Professional Identification
- identifying citizens and patients in Europe: eEHIC/EHIC project
- eHealth in Sweden, 1999-2009: stakeholder involvement? The “National Strategy for eHealth in Sweden” www.sweden.gov.se/content/1/c6/06/43/24/f6405a1c.pdf

Further discussions looked at the possibility to undertake a European-wide survey of methods and stage of maturity of stakeholder engagement in the European Union.

For more information, www.calliope-network.eu

Anyone who wishes to become a member of working group 5 should approach info@calliope-network.eu

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24. HEALTH LITERACY PARTNERSHIP APPRECIATED

The European Patient's Forum is committed to contribute actively in strengthening the health literacy component of the EU Health Strategy – "Together for Health" by working in partnership with the European Commission and other stakeholders.

This commitment was very clear at the Kick-Off meeting in March 2009 on the HLS-EU project, the comprehensive health literacy survey in Europe, which will take place 2009-2011. In the Kick-Off meeting programme officer Liuska Sanna represented the European Patient's Forum as collaborating partner and emphasized the patient's perspectives during the conceptual discussions of health literacy in terms of developing a survey tool. The survey will be carried out in the autumn and the results are ready by summer 2010.

The HLS-EU is a project coordinated by Maastricht University in the Nederland with a consortium of associated partners in eight countries in Europe and a global group of collaborating partners, among others the European Patient's Forum. The project receives funding from the European Community. The aim is to measure health literacy with a survey in the participating countries Austria, Bulgaria, Germany (NRW), Greece, Ireland, the Nederland, Poland and Spain and to ensure the dissemination of the results through establishment of national advisory task forces on health literacy in the involved countries. Setting up a health literacy network to benchmark, stimulate and promote good practices is also one of the aims of the HLS-EU project.

Maastricht University, coordinator highlighted "The fact that the European Patients' Forum is a front runner in terms of addressing the theme of health literacy and creating a broader awareness of the concept across Europe makes EPF a valuable knowledge partner to have on board in the HLS-EU project, and the contribution highly appreciated."

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For more information please contact: Kristine Sorensen, researcher and project coordinator, k.sorensen (at) inthealth.unimaas.nl or +31 43 38 81717

Project partners involved in the implementation of the HLS-EU project

Ludwig Boltzmann Gesellschaft GmbH, Vienna, Austria
Medical University, Sofia, Bulgaria
National School of Public Health, Athens, Greece
Landesinstitut für Gesundheit und Arbeit des Landes Nordrhein-Westfalen, Düsseldorf, Germany
Fundació Biblioteca Josep Laporte, Barcelona, Spain
National Institute of Public Health and the Environment (RIVM), the Nederland
UCD School of Business, Dublin, Ireland
Instytut Kardiologii, Warsaw, Poland.
Maastricht University, the Netherlands

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25. DIARY

Tue, Apr 7 -- Wed, Apr 8	Meeting with Health Ministry and Patients Groups Place: Budapest Attendance: Anders Olauson
Wed, Apr 8	Planning meeting on EU Proposal on Telemedicine Place: Brussels Attendance: Nicola Bedlington-chair, Liuska Sanna-moderator, Roxana Radulescu
Wed, Apr 15 -- Thu, Apr 16	Value+ steering group Place: Brussels Attendance: Liuska Sanna -moderator, Nicola Bedlington for policy session
Wed, Apr 15	Eurocarers Interest Group Place: Brussels Attendance: Nicola Bedlington
Tue, Apr 21 -- Thu, Apr 23	Meeting with Health Ministry and the Spanish Patients Forum Place: Barcelona and Madrid Attendance: Anders Olauson
Tue, Apr 21 -- Thu, Apr 23	Patients Rights Day and EP Plenary Session Place: Strasbourg Attendance: Nicola Bedlington
Thu, Apr 23 -- Fri, Apr 24	ESQC Conference Accelerating Patient Participation Place: Rome Attendance: Roxana Radulescu
Fri, Apr 24	EPF Officers meeting Place: Paris Attendance: Anders Olauson, Susanna Palkonen, Mike O'Donovan, Nicola Bedlington
Tue, Apr 28	Patient Safety and Quality of Care Working Group Place: Brussels Attendance: Roxana Radulescu
Mon, May 11 -- Tue, May 12	Conference on the Sustainability of Health Systems organised under the Czech Presidency Place: Brussels Attendance: Anders Olauson

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Wed, May 13	Health World Conference Place: Brussels Attendance: Nicola Bedlington -speaker
Thu, May 14	EU Health Policy Forum Place: Brussels Attendance: Nicola Bedlington
Fri, May 15	EMSP Conference- Opportunities for Healthcare Infrastructure by Structural Funds and other Examples for an EU Impact on the Life of PwMS Place: Brussels Attendance: Roxana Radulescu - speaker
Mon, May 18	EUNETPAS coordination meeting Place: Copenhagen Attendance: Roxana Radulescu
Tue, May 26	EPF Board meeting Place: Brussels Attendance: EPF Board
Wed, May 27	European Commission's Forum on the Patient Safety Place: Berlin Attendance: Roxana Radulescu (speaker)
Wed, Jun 3	AGRENSKA 20 years celebration Attendance: Nicola Bedlington
Wed, Jun 10	EFPIA Patients Think Tank Place: Brussels Attendance: Nicola Bedlington
Fri, Jun 12	EFA Conference Place: Rome Attendance: Nicola Bedlington -speaker
Mon, Jun 15 -- Tue, Jun 16	PGEU Annual General Meeting Place: Stockholm Attendance: Anders Olauson -speaker
Thu, Jun 25	DG Research Advisory Council FP7 Place: Brussels Attendance: Anders Olauson -member
Wed, Jul 29	Swedish EU Presidency Conference on the follow up of medicinal products

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