europeanpatients'forum

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Dear EPF Members and Allies,

Welcome to the EPF Mailing on the eve of the European Parliament elections. During the last few months, EPF and many of our member organisations have been using the EPF Manifesto "150 million reasons to act" to campaign with current and prospective MEPs both here in Brussels and Strasbourg, in the final sessions of the last Parliament, and in particular at national level. Several members have translated the Manifesto and have been active with their national MPs and MEPs. Our main collective message is, of course, the need for more commitment to act in 3 fundamental areas to improve the quality of health care delivered across Europe:

- Equal and timely access to safe, effective diagnosis, treatment and support;
- Better information and resources for patients to be partners in determining their care – a comprehensive information strategy at EU level;
- A genuine patients' voice to be heard in Brussels and throughout the EU.

Our campaign does not stop with the election. EPF will work intensively with the new European Parliament to engage both newcomers and past supporters to champion our work on advancing high quality, patient centred, equitable healthcare across the EU, and to support our contribution to the various health related legislative proposals that will be on the agenda in the next EP term.

In this issue we give you an overview of the voting in the last session of the European Parliament on several issues affecting patients and likely next steps. We will also share with you EPF's positions on the Pharmaceutical Package (section 2), and developments on quality of care, patient safety (section 3), EMEA work (section 9), and the work of the EU Health Policy Forum (section 8).

We are delighted to announce the dates of the EPF VALUE+ Conference, that will take place on 9, 10 December 2009 in Sweden under the patronage of the Swedish EU Presidency. Please do save the date. The other key event in autumn is our regional advocacy seminar taking place in Sophia, Bulgaria, on 18, 19 September 2009. All EPF members will be contacted, to encourage them to send patient leaders from that region to the event (see section 20).

Many EPF members and allies attended the Conference "Delivering for patients" on the Pharmaceutical Forum Outcomes, co-organised by the Commission and EPF, and we are pleased to announce that the Conference Report and the streaming video are now available (section 5).

Also in this issue (see section 23) is a brief resumé of the first meeting of the new EPF board, that took place on 26 May 2009 – a major focus being the EPF planning in the context of the forthcoming EU Presidencies.

Warmest greetings,
Anders Olauson, President
Nicola Bedlington, Director

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The next issue of the EPF Mailing will be distributed 9 July 2009. The deadline for submission is 25 June 2009.

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EPF Mailing

Read EPF's regular update on EU health developments from a patients perspective – if you would like to subscribe please contact us

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European Patients' Rights Day

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1. DIRECTIVE ON PATIENTS RIGHTS IN CROSS BORDER HEALTHCARE

On 23 April 2009, the European Parliament voted on the first reading, under co-decision procedure, on the Commission's proposal for a directive on the application of patients' rights in cross-border healthcare. The proposal based on MEP John Bowis report was adopted by 297 votes in favour, 120 against, and 152 abstentions. You may find below some key aspects of interest for the patients' community and that reflect EPF's consistent work with the Members of the European Parliament.

The amended legal text:

- recognises the value of cooperation (bi-lateral cooperation, ehealth cooperation, aftercare cooperation) among Member States (MS) and providers, and encourages MS, particularly neighbouring countries, to conclude agreements with one another concerning the continuation or potential further development of cooperation arrangements.

  EPF called for further EU action to encourage and support Member States to cooperate on cross-border healthcare and consistently highlighted the benefit of sharing experiences and information.

- includes both quality and safety principles and provides for the involvement of patient organisations in drafting quality guidelines.

  EPF called for the principles of quality and safety of health care to be clearly embedded in the legal text and suggested that the Commission should take a lead role in ensuring the collection of information on key quality indicators across the EU. EPF equally called for MS to define clear quality standards for health care provided on their territory, ensure that information about this is publicly available and develop guidelines, in cooperation with patients and health professional groups.

- recognises that costs shall be reimbursed or paid by MS and invites the Commission to explore the feasibility of a clearing house. In the situation where prior authorisation is given, it asks for MS of affiliation to seek to transfer funds directly between the funders and the providers of care; the Directive also recognises the right to reimbursement of extra costs incurred by persons with disabilities and leaves open the option for MS to cover other related costs, such as therapeutic treatment, accommodation and travel costs.

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Importantly for patients, the Directive asks for workable, non-discriminatory prior authorisation systems, if included, based on clear and transparent criteria.

> *EPF strongly stated that it is not acceptable for patients to be asked to pay up-front for hospital treatment (in their country of affiliation or abroad) and called for Member States to work together to put in place mechanisms to pay health care providers directly and thus avoid the need for patients to advance funds.*

- provides for patients affected by rare diseases to have the right to access health care in another Member State and to get reimbursement even if the treatment in question is not among the benefits provided for by the legislation of the Member State of affiliation.

> *EPF called for patients affected by rare diseases to have the right to choose where to access health care without prior authorisation.*

- provides for a European Patients' Ombudsman who will treat patient complaints as regards prior authorisation, the quality of treatment, payments, etc, and which shall engage once all the complaint options within the relevant Member State have been explored.

> *EPF supported this ever since the Commission's consultations on patients' mobility in January 2006.*

- provides for clear, accessible information for citizens and patients and a transparent system as well as efficient contact points; asks the Member State of treatment to guarantee patients' access to their medical records, including electronic records; recognises the role of patient organisations in providing information.

> *EPF called for provision of relevant information for patients and involvement of patient organisations in this process.*

- provides for stakeholders' participation – including health professionals, patients, social partners, scientists and industry – in health technology assessment.

> *EPF fully supported this aspect.*

The Directive will be discussed at the Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council meeting on 8-9 June in Luxembourg.

For further information:
www.europarl.europa.eu/oeil/file.jsp?id=5661632

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2. PHARMACEUTICAL PACKAGE

Following extensive consultation with the EPF membership and other patient group allies, EPF's position on proposals put forward as part of the Pharmaceutical Package on Pharmacovigilance and Anti-counterfeiting, have been adopted and are being widely circulated. The International Association of Patients' Organizations (IAPO) played an important role in our response to the Anti-counterfeiting proposals, and they also indicated their support for both positions. Please visit the EPF website for more information.

It should be noted, however, that these positions on the legislative proposals are a starting point, and further in depth and detailed commentary and amendments reflecting the patients' perspective will be needed on an on-going basis as both proposals follow their legislative journey in the European Parliament and European Council.

EPF is in the process of setting up a policy advisory group on specific policy topics to support and contribute to such work. If you are interested in these particular topics, please contact the EPF secretariat.

Regarding the "Information to Patients" proposal, the EPF board has approved a final version of EPF's position that incorporates the feedback and suggestions from the EPF membership. It has now been sent out to EPF Members and Patient group allies to affirm their support. The final version, with signatories will be circulated widely to relevant players, in advance of the EPSCO Council on 8-9 June 2009.

For more information, please contact Nicola Bedlington.

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3. RECOMMENDATIONS ON PATIENTS SAFETY AND RARE DISEASES

The European Parliament voted on 23 April 2009 on a proposal for a Council Recommendation on patient safety, including the prevention and control of health care associated infections – based on MEP Amalia Sartori's report. The proposal was adopted by 391 votes in favour, 6 against, and 5 abstentions.

The Recommendation provides for:

- MS to embed patient safety as a priority issue in health policy and programmes and designate a competent authority responsible to patient safety on their territory.
- MS to empower and inform citizens and patients by involving patient organisations and disseminating information to patients.
- MS to set up or improve comprehensive blame-free reporting and learning system, in a constructive, rather than punitive way.
- MS to education and training of healthcare workers in patient safety.
- MS to consider the development of core competences in patient safety (core knowledge, attitudes and skills) for patients (– a very important move forward in the context of patients' health literacy).

The Recommendation is planned to be adopted during the following Czech EU Presidency meeting of the Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council (8-9 June 2009).

EPF is pleased with the Recommendation which reflects our input in the draft proposal during the discussions within the Patients Safety Working Group, set up by the European Commission. EPF has systematically called for further cooperation among MS on patient safety and particularly for information and education activities on patient safety aspects for patients and will continue to work for the promotion and implementation of the Recommendation across EU Member States.

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For further information: www.europarl.europa.eu/oeil/file.jsp?id=5737632

The proposal for a Council Recommendation on a European action in the field of rare diseases was also adopted by the European Parliament, also with a large majority of 383 votes to 116 and 15 abstentions. The Parliament called for financial support at European level for this Recommendation and for Member States to adopt a comprehensive and integrated strategy by the end of 2010 (rather than 2011). The Recommendation provides for:

- national plans to ensure rehabilitation for those living with the disease;
- priority actions within the national plan to contain substantial and clearly designated funding;
- MS to declare whether they have any specialised centres and compile a catalogue of experts;

and includes a series of new recommendations to Member States.

EPF's member EURORDIS has been very active in this area and called for reinforcement of some elements of the Recommendation, such as, for example, patients' involvement into the management and evaluation of the Centres of Expertise and the European Reference Networks concerning research on rare diseases.

For further information: www.europarl.europa.eu/oeil/file.jsp?id=5714652 .

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4. PATIENTS RIGHTS DAY AND NEXT STEPS

Readers will be aware of the work of Active Citizenship Network in promoting a "Patients' Rights Charter" and in this context a designated Day (18 April) in the annual calendar to celebrate Patients' Rights. EPF has supported this drive for patients' rights and encouraged our members' active participation.

This year, the Third European Patients' Rights Day took place on Saturday 18th of April with activities across the European Union. Please go to www.activecitizenship.net/content/blogcategory/60/144 for further information and contacts in your country.

Active Citizenship Network also organized a major Conference in Strasbourg during one of the final sessions of the European Parliament, on the day before the vote on patients' rights in cross border healthcare. Commissioner Vassilou addressed the meeting, entitled "Patients Rights – A growing European concern and framework for action", highlighting that "Patients' rights **reaffirm fundamental human rights in healthcare** – rights such as the protection of dignity and integrity and the promotion of respect for the patient." Please see http://ec.europa.eu/commission_barroso/vassiliou/speeches/s09_European_patients_rights_day_en.pdf for a copy of this speech.

Nicola Bedlington participated in this meeting and gave a presentation on EPF's perspective on patients' rights, supporting the petition campaign launched by ACN to gather a million signatures calling for the Institutionalisation of the Patients' Rights Day.

For more information on this, please contact the EPF secretariat.

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5. NEW CONFERENCE REPORT AVAILABLE - THE OUTCOMES OF THE PHARMACEUTICAL FORUM

EPF co-organised on 25 March the Conference on the outcomes of the Pharmaceutical Forum, a three year process involving the European Commission, the Member States and representatives from other stakeholders to explore the future of pharmaceuticals and public health in terms of information to patients, pricing and reimbursement and relative effectiveness. The conclusions and recommendations of the Pharmaceutical Forum received political endorsement during a high level ministerial meeting in October 2008. The Conference brought together 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 at a European and local level.

The final report of the Conference can be found on the EPF website. It contains summaries of the introductory speeches by Karin Johansson, State Secretary to the Minister of Health and Social Affairs, Sweden, and by EPF's president, Anders Olauson. The outcomes and deliverables of the three expert working groups "information to patients", "pricing and reimbursement" and "relative effectiveness" were presented briefly, as well as some case studies on how the outcomes of the Pharmaceutical Forum can be implemented at European and national level.

Some key statements of the session on "information to patients" were that it is urgent to invest into high quality and accessible information on diseases and treatment options and there is a need for a comprehensive information to patients' strategy at EU level that includes health literacy. Recommendations were that quality and accessibility of information should be enhanced inter alia through the use of the core quality principles developed by the Forum and the DARTS-principles for the identification of good websites; that accessibility and dissemination of information should be increased through effective communication taking account of local traditions and culture, healthcare systems and languages; that information can be generated through the involvement of all actors concerned.

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The session on "pricing and reimbursement" reiterated that decisions concerning pricing and reimbursement have to satisfy expectations of patients who need affordable access to health solutions, of manufacturers who want to be compensated for the time and money that they have invested into the research and those of the funding authorities who dispose of limited resources. New approaches to pricing and reimbursement were explored, drawing on cancer and orphan drugs as case studies.

The Commission should, in cooperation with relevant stakeholders, undertake a first review of progress on pricing and reimbursement within the next 2 years.

The sessions on "relative effectiveness" highlighted the importance of agreed good practice principles for relative effectiveness assessments should be implemented on European and national level; and the exchange of information on relative effectiveness assessments should be promoted in order to improve data availability and transferability. The importance of meaningful patient involvement in relative effectiveness assessment was also echoed, notable through an example put forward from the area of Alzheimer's disease.

The conference report and video streaming are available on the EPF and Pharmaceutical Forum's websites.

6. A WIN FOR PATIENTS AND RESEARCH IN THE EUROPEAN PARLIAMENT by Nick Meade, EGAN

Without animal research, scientists across Europe would be unable to make further progress in understanding the causes of ill health and progress towards developing new treatments for conditions without a cure or treatment would be halted. Medicines for diabetes, asthma and leukaemia and medical procedures such as blood transfusions and transplant surgery may not have been developed without animal research. This is why the review of Directive 86/609/EEC governing animal research in the EU is so important.

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Since the last mailing, the Committee on Agriculture and Rural Development (AGRI) has made a number of alterations to the Commissions proposals to review the directive. These changes were introduced by Neil Parish MEP, who took careful account of all of the stakeholders' views and prepared the AGRI report, which was largely very satisfactory for the patient and research community.

Following the publication of the AGRI report, it was submitted for plenary vote in the European Parliament. The Genetic Interest Group (GIG), and another UK group, the Association of Medical Research Charities (AMRC), organised an event the week before the vote where patients and carers could come to Brussels to speak to MEPs about the impact this Directive will have on them. They gave personal testimonies of what it is like to live with a serious disease or illness such as Alzheimer’s or Parkinson’s and how medical research using animals is bringing new hope and opportunities to improve their quality of life.

A balanced Directive is crucial to improving patient lives wherever they live in Europe; this was clear from the presence of so many pan-European patient groups. Joining the Genetic Interest Group (GIG) and the Association of Medical Research Charities (AMRC), who together represent over 250 UK patient charities, to meet MEPs were the European CanCer Organisation (ECCO), representing 24 European professional and patient organisations; the European Cancer Patient Coalition (ECPC), representing more than 270 European cancer patient organisations; the European Multiple Sclerosis Platform (EMSP), representing 33 European Multiple Sclerosis patient support groups; the British Heart Foundation (BHF), the UK charity fighting heart and circulatory disease; the Parkinson's Disease Society, the UK charity dedicated to providing support, advice and information for people with Parkinson's disease, their carers, families and friends; the Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP), the Dutch genetic alliance representing more than 60 disease specific support groups; and the Alzheimer's Research Trust, the UK's leading research charity for dementia; and of course the European Patient's Forum (EPF), representing 39 European patient umbrella groups.

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The plenary vote occurred on the 5th of May, and to our delight, was adopted with 540 in favour of the Parish report, 66 against and 34 abstentions. This massive majority represents a major victory for all who fought for the adoption of the report. Our work does not stop here. The European elections are imminent, and an unprecedented turnover of approximately 40% of MEPs is expected. One of the first issues of business for the new Parliament will be to vote on whether to accept the previous Parliament's progress on this issue, or whether to go right back to square one. Our opponents in this lobby have a vested interest in rejecting the previous Parliament's decision. We must therefore get back into action to communicate the value that the Review holds for patients in its current state, to ensure we win this vote too.

If your organisation would like to lend its support to this ongoing campaign, as so many have so far, please get in touch with Nick Meade (nick(at)gig.org.uk).

7. WORKING GROUP ON PATIENT SAFETY AND QUALITY OF CARE

As announced in previous EPF Mailing issues, with the growing emphasis on wider healthcare quality issues, the Commission extended the remit of the Working Group on Patient Safety to healthcare quality issues and therefore re-named it into Patient Safety and Quality of Care Working Group. The group is constituted of representatives of Member States, pan European healthcare stakeholders, international organisations such as the Council of Europe, WHO, and OECD, and serves as a platform for information exchange on existing and emerging issues, priorities and innovative solutions for safety and quality challenges.

From a broader policy perspective, the group will support the implementation of the current health strategy "Together for Health: A Strategic Approach for the EU 2008-2013", notably the strategic objective 2, "protecting citizens from health threats", and the strategic objective 3, "supporting dynamic health systems and new technologies", and will liaise with the Working Party on Public Health at Senior Level (informing the

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latter about the progress and outcomes of its work and preparing technical papers for discussions at senior level).

A first meeting was held on 28 April 2009, in Brussels, where the draft' Terms of Reference' for the group were discussed. It was decided that the group will continue its former strategic endeavours on patient safety and implementation of the Council Recommendation on Patient safety and health-care associated infections, and will examine the possible EU added value of action in the following dimensions of quality of healthcare:

(1) sharing of good practice in reducing outcome variability: to make sure that appropriate procedures are in place to ensure improved outcomes for patients;
(2) the creation of a patient-centred healthcare environment that respects the rights of patients and treats all patients and their families with dignity;
(3) an increase in the quality of life of the patient at every stage: including development of comparative data and quality improvement strategies in primary care, secondary care, mental healthcare, palliative care and disease prevention;
(4) an increase in patient involvement in healthcare: including the provision of clear and comprehensive information on efficacy and clinical outcomes; the building of health literacy; and support for self-management of chronic disease.

The group will focus its work on selected commonly adopted priorities and will identify possible actions at Member State and EU level. The intention is to develop a reflection paper by the end of 2009 that would subsequently be submitted to a wider public consultation in 2010.

Roxana Radulescu represents EPF in this group. Please contact her for any further information.

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8. EU HEALTH POLICY FORUM (EUHPF)

Nicola Bedlington represented EPF at the EU Health Policy Forum taking place on 14 May 2009. The main issues for the meeting were the EUHPF strategic priorities and work plan 2009/2010, follow-up to the Open Letter on the economic crisis and health, the implementation of the EU health strategy, update for stakeholders on the EU response to swine flu, and a detailed discussion on the Commission White Paper “Adapting to climate change: Towards a European framework for action”. There was also a Commission update on key policy issues including the Cross border healthcare directive, Patient safety, SANCO Stakeholder Dialogue Group, and a forthcoming Conference on Youth and Health on 9, 10 July.

For a copy of the presentations and meeting notes please send an email to secretariat(at)euhealthforum.org.

A number of useful websites relating to these issues have also been circulated within the EUHPF:

1. http://europa.eu/debateeurope/eu-elections/index_en.htm

2. http://ec.europa.eu/health-eu/youth/index_en.htm

3. http://ec.europa.eu/dgs/health_consumer/sdg/index_en.htm

9. EUROPEAN MEDICINES AGENCY (EMEA) PATIENT AND CONSUMER WORKING PARTY (PCWP) DEVELOPMENTS

The EMEA PCWP ad hoc working group of patient organisations has developed a **Code of Practice between Patient Organisations and the Healthcare Industry**. All patient groups are invited to adopt and sign up for the Code (see the end of this article) that is intended for guidance on relations between patient organisations and industry. It does not attempt to be exhaustive, but indentifies some challenges and solutions based on experiences, and defines a set of basic principles and recommendations. EPF took also part in the development of the Code. Organisations who sign up for the Code will be listed at the end of the document.

In January, EMEA held a workshop on their developing **transparency policy** and expectations of different stakeholders for such a policy, transparency being one of EMEA's priorities for 2009.
The presentations are available at:
www.emea.europa.eu/htms/human/transparency/TP_workshop_220109.htm

At the previous meeting of the PCWP on 5 March 2009, the results of the **satisfaction survey** 2008 of patients/consumers who are involved in EMEA activities were presented. There was an overall good level of satisfaction, similar to 2007. However, there are several areas to be improved, such as the level of feedback on the review of documents, the need for more training and the need to involve more patient and consumer organisations. Also the importance of timely and appropriate **involvement of patient groups in EMEA safety communications** in critical situations was discussed and the good **experiences in direct patient reporting on medicines safety** by PCWP members. David Haerry from the European AIDS Treatment Group and Albert van Zeijden from the International Alliance of Patient Organizations (IAPO) were selected to represent the PCWP as observers to the EMEA Pharmacovigilance Working Party (PhVWP) for a trial period (it is new that patient groups are involved).
The minutes of this meeting are available at www.emea.europa.eu/Patients/PCWP.htm
Susanna Palkonen, EPF's vice president represents EPF in the PCWP.

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10. CHILDREN AND YOUNG PEOPLE's RIGHT TO HEALTH – International and EU commitments and action

The Universal Children's Day takes place on November 20th. In 2009, it will also be the opportunity to celebrate the 20th anniversary of the United Nations Convention on the Rights of the Child (CRC or UNCRC), which lists the fundamental rights that every child should be able to benefit from without discrimination. EPF has drafted a background information document on this issue and the EU dimension, as part of its work on the rights of young patients. For a copy of this please contact the secretariat. A brief synopsis of this features below.

Drafted by the United Nations, the 54 articles of the Convention describe the rights of all children below 18 years and requires signature states to ensure that every child - regardless of nationality, origin, gender, religion or social status - receives the care, education, and protection it has a right to and is offered the opportunity to actively participate in the development of society. That means that in every issues that concerns the child, the child's best interest has to be considered. However, for the Convention to be applicable, the government of the country in question must ratify it.

In theory, it seems that children's rights, including the right of children to health, are recognized almost everywhere in the world. Governments agree that the children should have rights specific to their precise needs and reflecting their potential vulnerability. More...

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11. CONOCIMIENTO Y PACIENTES AWARD

Anders Olauson, on behalf of EPF was given the ConoCImiENto-y-PaCIENtes-award in the category Projects by the Fundació Josep Laporte. The Fundació rewarded organisations, institutions and people who have shown support and trust in the work and projects of the foundation over the last ten years.

Our president, Anders Olauson, was honored to accept the award in the name of the European Patients' Forum in April in Barcelona. The award is an acknowledgement of EPF's role as the patients' voice in Europe and its close collaboration with the Spanish Patients' Forum.

Whilst in Spain, Anders held a number of key high level meetings with the Spanish Health authorities, particularly in the context of the forthcoming Spanish EU Presidency.

12. EUROCARERS MEETING

Nicola Bedlington attended a Eurocarers' European Parliament Interest Group on 15 April 2009 that focused on the Commission Green Paper on the EU Workforce for Health. For a copy of the report please click here.

Marian Harkin MEP and Kathy Sinnott MEP stated that the meeting provided useful input for the Green Paper debate. The fact that the Commission recognises carers as part of the health workforce is a welcome step forward. Alliances between relevant stakeholders can help to better advocate the case for carers, as a joint voice is a stronger one.

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The European Parliament Interest Group is playing its role in continuing the debate with the various relevant parts of the Commission, and it is the intention to reconstitute the Interest Group after the European Parliament elections, and become even more active.

EPF and Eurocarers are developing a fruitful cooperation, and Eurocarers will collaborate in the framework of EPF's recent project proposal on telemedicine "Chain of trust".

13. CONFERENCE ON HUMANIZING HEALTH SERVICES WITH THE PARTICIPATION OF PATIENTS

The European Society for Quality in Healthcare (ESQH) in cooperation with CEREF (Center for Research and Training in Padova) organized, in cooperation with EPF and IAPO, an exciting international conference on humanizing health services across the EU with patients' participation (Rome, 23 April). The conference was generously hosted by the Italian Ministry of Labour, Health and Social Policy and provided an excellent opportunity to share research outcomes on patients' involvement, concrete example of patients' involvement at local level, as well as policy initiatives and strategies looking at patients' participation.

First, the Italian national programme for Promotion of Quality in HealthCare was introduced, then a series of interesting examples were presented looking at information initiatives for patients about their rights, existing services, treatment plans, interactive websites etc. in several Italian regions (Emilia Romana, Toscana, Veneto, Puglia and others).

EPF was represented by Roxana Radulescu who gave a presentation about EPF's work at EU level, with examples based on the VALUE+ project on patient involvement, as well as on EPF's advocacy work with the European Parliament and the Commission on issues like patient safety, patients' rights in cross-border healthcare, ehealth, etc.

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The principles of patient involvement in health care were outlined by IAPO's representatives, while the speaker of the Polish Federation of Patients' Organisations gave an example of the achievements and challenges encountered in Poland. Another presentation looked at barriers to progress and highlighted that patients' involvement should not be seen as cumbersome obligation but as fundamental to the quality management system of health care organisations.

An interesting and innovative angle was brought to the discussion by the presentation of the experience of Polish migrants with healthcare in Norway, while Denmark's representative talked about the result of a recent publication on recommendations for health care professionals on communication and interpersonal relations with patients in the Danish health services.

For further information, please visit ESQH website www.esqh.net or contact Roxana Radulescu.

14. CPME/ ENVI COMMITTEE WORKING GROUP ON HEALTH MEETING

On 23 April 2009, the European Parliament ENVI Working Group on Health held a debate on "What is the Added Value of EU Health Policies for National Health Systems?" During the discussions, there was a special emphasis on the financial crisis and its implications on the Health Gap between "Old" and "New" Member States. This event was hosted by MEP Georgs Andrejevs and organised in collaboration with the CPME, the Standing Committee for European Doctors. Commissioner Vassiliou opened the event with a powerful key note speech. CPME President Michael Wilks and EPF director Nicola Bedlington gave their organisations' perspective on the added value of EU health policies.

As a result of this meeting, the following call was adopted:
Creating opportunities for Healthcare

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During a period of economic recession, one of the most sensitive challenges for the EU and its Member States is providing the healthcare that people need.

In the area of health, inefficiency in terms of choices, policy making and performance management is not only tremendously costly, but can raise ethical questions as it deprives potential patients of the care they could benefit from. There is therefore a political need to promote, as soon as possible, health related actions because this sector runs the risk of being deeply challenged by the economic recession and budgetary constraints.

Member States do not have the choice whether to address health issues or not. Even before the onset of the economic crisis, Member States identified the need for adjustments of their social and health policies so as to ensure their long-term sustainability. The fact that Member States retain their competencies in organizing, providing and funding the healthcare of their citizens, should not preclude the EU from providing support.

The EU could play a role namely by: promoting policy sharing and benchmarks, patient safety, addressing the issue of health inequalities etc. The EU's added value has already been proven in addressing gaps in citizens' access to healthcare (e.g. HIV/AIDS, cancer, inequalities in health, cross-border care, rare diseases).

In the run up to elections for a new European Parliament and the establishment of the new European Commission, all parties involved should use all the means at their disposal to support Member States in providing adequate healthcare for all European citizens.

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15. FINANCIAL SUSTAINABILITY OF HEALTHCARE SYSTEMS CONFERENCE

Roxana Radulescu represented EPF at this conference which took place in Prague on 10-11 May and chaired a session on “How to manage public discussion on healthcare affairs”. Organised under the Czech EU Presidency, the conference brought together about 200 participants including Ministers of Health and high level officials from various EU countries, representatives of the European Commission, WHO, OECD, academic institutions, industry, NGOs. The aim was to foster the discussion on the sustainability of the EU financial systems, in the context of the current harsh economic climate, where EU health and welfare systems face significant financial pressure.

The discussions looked at shading light on the notion of “financial sustainability” which touches on a wide range of notions such as: increases in health spending due to technological progress, demographic change, consumer expectation; resource constraints caused by government inability or unwillingness to generate sufficient resources to finance the health care; or health expenditure (as a proportion of GDP) and growing at a faster rate than spending in other parts of economy.

It was highlighted that the way health care financing is organized has significant implications for the efficiency of health systems. For example, for countries that rely predominantly on employment-based compulsory health insurance contributions, it is possible to get more revenue by lifting any existing income or earning ceilings , as it is the case of Estonia or Hungary. For governments that are both concerned to stimulate employment while maintaining or increasing public spending on health, diversifying the source of public revenue for health may be an option. Germany, after moving to a unified national contribution rate of 15.5% of salaries, injected additional general tax revenues into the health insurance system. Other countries have undertaken efforts to address fragmentation: both Norway and Denmark have recently reduced the number of territorial health authorities responsible for pooling funds for the purchase of health care systems; in Estonia, Latvia, Lithuania and Poland separate health insurance funds were gradually consolidated into single national funds.

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The conference also looked at the impact of demographic change on public expenditure on health and long-term care and to the contribution of health technology assessment and chronic disease management to health system's sustainability. At the parallel session "How to manage public discussion on healthcare affairs", the presentations featured the cases of Czech Republic, Slovakia and Hungary and gave examples of ways of involving the health community and stakeholders in healthcare reforms.

For further information:
www.eu2009.cz/en/news-and-documents/news/ministerial-conference-on-the-financial-sustainability-of-health-systems-21811
www.euro.who.int/observatory
or contact Roxana Radulescu.

16. WORLD HEALTHCARE CONGRESS – EUROPE CONFERENCE, BRUSSELS, 14 MAY 2009

Nicola Bedlington represented EPF at this Conference on 14 May in Brussels and gave a presentation on the role of New Medical Teams in patient-centred healthcare. Also on the panel was CPME President Michael Wilks, presenting the health professionals' perspective.

For a copy of both presentations and further information on the conference please go to www.worldcongress.com/events/HR09015/index.cfm?confCode=HR09015 .

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17. IAPO PATIENT WORKSHOP: WORKING EFFECTIVELY WITH THE WORLD HEALTH ORGANIZATION

Nicola Bedlington was invited by IAPO to participate in a Patient Workshop on working effectively with the WHO on 18 May 2009 in Geneva, in the context of the World Health Assembly. An important overview was given with regard to the WHO's Non-communicable Disease Action Plan, that will also have implications for the WHO Europe Region. A specific section was also devoted to Counterfeit Medicines from the perspective of the WHO and the International Patients Community: this was particularly interesting given the EU legislative proposal on anti-counterfeiting throughout the European Union.

For a copy of the presentations made during the meeting, please contact IAPO:

www.patientsorganizations.org

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18. INTERNATIONAL CONFERENCE ON HEALTH PROMOTING HOSPITALS AND HEALTH SERVICES

EPF was invited to be part of the Panel in the Opening session 'Health care without walls – A vision for health promotion in health care' together with colleagues from health professional organizations of the Conference of the International Network of Health Promoting Hospitals (HPH) and the WHO Collaborating Centre on Health Promoting Hospitals and Health Care held in Crete, Greece, 6-8 May 2009. EPF was represented by Susanna Palkonen, vice-president. The Conference brought together around 700 participants from around the world to present projects, discuss and advance health promotion as part of high quality care. Our global partner, the International Alliance of Patient Organizations (IAPO), is a long term partner of the organizers, who are keen to work with patient organizations.

What is a health promoting hospital? It is a hospital that commits not only to care in a traditional sense, but also to active health promotion and prevention strategies as integral part of care. New technologies present new opportunities, but also challenges for health promotion.

Key points in EPF intervention:

- For potential patients, prevention is better than cure, for patients cure is better than care, BUT for patients with chronic diseases, cure does not often yet exist and access to high quality care is key.
- Holistic interpretation on health-care includes prevention, health promotion and the social, economic, environmental, cultural and psychological aspects of health.
- No thank you to shame, blame and deny care strategies.
- Patient and patient organizations should have a key role in decision making on care.
- E-health is an opportunity for patients but needs of patients with chronic diseases and their carers are very different from people in good health.
- E-health literacy offers new opportunities and challenges.
- Information to patients needs to be married with robust quality criteria.
- There has to be clarification on e-health records and their ownership.

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- There has to be a balance between electronic and human contact.
- Interactivity – e-health should not reinvent the old model of patients as passive recipients.
- Our work on e-health at EU level, and partnership with health professionals, including HOPE who was an active partner at the conference.

And finally, that health care without walls should also mean that all patients would have the same access and choice, no matter where they live.

EPF would like to thank the organizers, in particular the HPH President Yannis Tountas and Jürgen Pelikan, Director of the WHO Collaborating Centre for their kind invitation and hospitality, and congratulate for a very successful and dynamic conference and true interest in patient perspective.

www.hph-hc.cc

For more info: susanna.palkonen(at)efanet.org

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19. CAMPAIGN UPDATE ON EPF PATIENTS' MANIFESTO

EPF fervently continues the promotion of our Patients' Manifesto. In May and April, EPF has sent out info-packages to all our members, containing model letters to MPs and draft press releases to be used in their national campaign work. We equally addressed the health attachés of all 27 Member States and send letters and e-mails to the MEPs so that they may use the Manifesto in their campaigns for the European Elections in June. We will repeat this initiative in autumn after the new European Parliament is in place and raise awareness among the new MEPs for the importance to give patients in Europe a voice as well as convince them to sign up to the Manifesto. The latter has meanwhile been translated into French, German, Romanian, Lithuanian, Latvian, Estonian, Polish, Czech and Spanish which will enforce its impact at Member State level.

20. VALUE+ PROJECT

Since the last issue of the Mailing there are several updates we would like to inform you about.

Workshop with project coordinators and patients/representatives
The objective of VALUE+ is to exchange information, experiences and good practices among key stakeholders in relation to the meaningful involvement of patients' organisations in EU supported health projects at EU and national level.

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With that purpose in mind, VALUE+ proposed cooperation to a number of currently running projects with diverse extent of patient involvement. Some of these projects were invited to participate in a workshop; each project was represented by the project coordinator and a patient or patient representative.

The objectives of the meeting were to:
1. carry out a self assessment of patient involvement in the participating projects;
2. identify good practices, lessons learned, benefits and challenges related to patient involvement;
3. decide a number of measures – short and long term – to address challenges identified;
4. develop recommendations related to VALUE+ deliverables.

The projects were quite diverse in terms of activities, experience and level of patient involvement; however many of the issues identified were common to all of them.

Highlighted problems were: insufficient resources dedicated to involvement; difficulties due to the financing mechanisms of the EC programmes; underrepresentation of patients/organisations in the project management bodies; communication barriers; attitudes and values regarding involvement.

Some of the good practices shared were: working with patients/organisations as equal partners in a Win-Win approach; giving compensation and rewards; finding out patient priorities; involving patients/organisations in the management of projects; training and coaching for both patients/organisations and project coordinators as well as other actors involved in the project.

These reflections in mind, participants worked on an action plan for their individual projects, aimed at improving the identified gaps in patient involvement.

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In conclusion, a list of recommendations was elaborated for the tools and resources that VALUE+ will deliver: a Toolkit for patients/organisations; a Handbook for project coordinators; a database of projects with patient involvement and policy recommendations. All these resources are currently being developed.

The success of the workshop lies in the fact that a) for the first time participants had opportunity to reflect upon the involvement of patients/organisations in their projects following a structured approach; b) they were very committed to involvement and wished to further work towards strengthening it. All found this opportunity very beneficial not only for the current project in discussion but also for the future ones.

21. SAVE THE DATES – BULGARIA AND GOTHENBURG

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

On **September 18-19 2009**, EPF and the VALUE+ Consortium organise a seminar for patient leaders of patients' organisations from Bulgaria, Romania, Hungary, Slovakia, Croatia and Greece.

The seminar will take place in Sofia, Bulgaria, and is hosted by the Bulgarian Confederation "Health Protection" (KZZ).
To date five highly successful European seminars have taken place. These seminars have reached out through patient leaders to the patient community throughout Europe, and particularly the new Member States, to enhance knowledge on health issues at European Union (EU) level and to build capacity on how to engage.

The purpose of the seminar is to:

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

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- explore findings from the VALUE+ project and glean feedback from grassroots organisations as well as test some of the VALUE+ deliverables.

The seminar will have contributions from representatives of the European Parliament, the European Council, the European Commission, the Directorate General for Health and Consumers and its Executive Agency, and patient leaders.

A draft programme is available at www.eu-patient.eu/projects/valueplus/events/bulgaria-2009.php

For more information on the seminar or if you wish to register, please contact Liuska Sanna.

EPF Final VALUE+ Conference

The conference will take place on 9-10 December 2009 in Gothenburg under the patronage of the Swedish Government.

The conference on patients' involvement will be the final event of the EPF-led project VALUE+. It will provide the opportunity to present the results of the project and the deliverables and be a spring board for wide-scale dissemination and implementation. This event will be an important platform for fostering continued political commitment on patient involvement underpinned by the VALUE+ basic premise that the meaningful involvement of patients will enhance projects outcomes and results, which will then contribute more effectively to patient-centred policy making.

The target audience will be wide-ranging and will include representatives of the Swedish Presidency, European Commission and governmental officials, Members of the European Parliament and Council Representatives, key health stakeholders, research organisations, think tanks and policy units in Brussels, project leaders, patient organisations' representatives and the project partners themselves. Approximately 100 participants will convene in the Agrenska Centre, Gothenburg, Sweden.

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We expect to raise the awareness of the audience, especially political representatives, regarding the need to strengthen commitment to patient involvement with concrete means and actions and to make tools and information available on how to achieve meaningful involvement. We also aim for the policy recommendations made by VALUE+ to be included in the conclusions of the Swedish EU Presidency.

The programme will soon be available on EPF's website. For more information, or if you wish to register, please contact Liuska Sanna.

22. CHAIN OF TRUST PROJECT– UNDERSTANDING PATIENTS' AND HEALTH PROFESSIONALS' PERSPECTIVE ON TELEMEDICINE AND BUILDING CONFIDENCE AND ACCEPTANCE

EPF recently submitted a project application to the Call 2009 of the Public health Programme to address the following area:
3.2 Priority Area: Improve citizens health security
3.2.2.2 Improving patient safety through high-quality and safe health care
Implementation of the action set out in COM (2008) 689 on telemedicine for the benefit of patients, healthcare systems and society to foster collaboration between health professionals and patients in key areas for greater application of telemedicine as set out in that Communication, in order to develop specific recommendations on how to improve confidence in and acceptance of telemedicine, also taking into account ethical and privacy related aspects.

The "Chain of Trust" project will assess for the first time the perspective of the main end users of telemedicine services across the EU with the purpose of creating understanding, confidence in and acceptance of this innovative type of services. The vision informing the project approach is high quality, patient-centred, equitable health care for all patients throughout the European Union: good practice and challenging of bad practices; equitable access to treatment and care and health-related quality of life at

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European level and at member state level. The project will result in a unique and unprecedented assessment of the views, needs, benefits and barriers related to telemedicine from the perspective of patients and health professionals.

The project will focus on patients, doctors, nurses and at a more secondary level on pharmacists. Their leading representative EU umbrella organisations are partners in the project; thus the project Consortium is composed by the Standing Committee of European Doctors (CPME), the European Federation of Nurses (EFN), the Pharmaceutical Group of the European Union (PGEU), Thalassaemia International Federation (TIF), the Latvian Umbrella Body For Disability Organization (SUSTENTO), the European Men Health Forum (EMHF) and the Norwegian Centre for Integrated Care and Telemedicine (NST).

The collaborating partners represent leading umbrella organisations of health managers – the European Health Management Association, hospitals – the European Hospital and Healthcare Federation, and carers – Eurocarers.

An Advisory Board composed of the leading e-health networks at EU level, will ensure extensive dissemination and outreach to relevant target groups to raise awareness, and synergies between the projects and broader e-health developments at EU and international levels. An End User Interest Group composed of individuals from a broad cross section of the patient and health professional community will guarantee on an on-going basis insights on how telemedicine impacts in specific settings, how to involve users systemically in telemedicine developments, and general feedback on the project's processes and outcomes.

The project will increase substantially the knowledge and understanding of the specific perspective of health professionals and patients amongst various stakeholders. The findings and the recommendations will constitute a unique tool to inform policies and decision-making at various levels: in primis the EC, Member States health authorities, the EP, WHO, OECD, Council of Europe. This new knowledge base and awareness will be of significant added value for the implementation of the EC Communication on telemedicine that calls for recommendations from patients' and health professionals' groups. It will also contribute to defining the strategy and supporting the work of the EC Platform on telemedicine.

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23. EUNETPAS PROJECT

A project coordination meeting took place on 18 May 2009 in Copenhagen where the partners involved in the EUNetPas project (European Union Network for Patient Safety) had the opportunity to update each other on main project developments within each Work Package. The project is coordinated by the French Health Authority and brings together 27 MS, international organisations and a wide range of stakeholders in the field of patient safety (decision makers, healthcare professionals, patients, researchers). The main objective is to produce European added value of Member States collaboration by mutual support and exchange of ideas in order to accelerate progress in improving patient safety across the EU. Modelled on the EUNetPas platform, national patient safety networks have already been established in 13 MS and this will continue to be done in the future.

More specifically, a literature review and situation analysis have been carried out in Work Package (WP) 1 on instruments of assessing patient safety culture in healthcare organisations, while partners involved in WP2 have worked on a set of guidelines on education on patient safety for healthcare institutions. EPF has been particularly active with regard to including patients as recipients of education and training on patient safety.

WP3 partners have been involved in collecting so far 34 good practice examples on reporting errors and learning systems across MS and aim by June 2010 to propose an EU rapid alert system, facilitating the sharing of information among Member States concerning serious medical errors and most effective medical solutions.

In the framework of WP4, 5 to 25 hospitals have been selected in 11 MS to implement a medication safety pilot. Several good practices were, for example, identified: the safety vest (do not disturb nurses while they prepare medicines in wards), the sleep card (guideline to reduce unnecessary treatment with sleeping pills),

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bed dispensation (preparation and administration of medicines to the patient by the same person reduce risk), medication reconciliation at discharge (written discharge medication given to the patient and sent to the GP and community pharmacist).
EPF is also very much interested in the project process evaluation and will get further involved in this WP later this year.
For further information, please visit the project website www.eunetpas.eu or contact Roxana Radulescu.

24. BOARD MEETING – KEY OUTCOMES

The new EPF board met on 26 May 2009. Key items on the agenda included
- approval of the AGM minutes;
- approval of a revision to the Constitution on associate membership criteria (this will be tabled for adoption at the next AGM);
- accounts for the first quarter;
- roles and responsibilities of the new board;
- approval of the EPF position on information to patients;
- discussion on the Activity plan for 2010, including actions under the Spanish and Belgian EU Presidencies;
- two new membership applications from Bulgaria and Romania.

Discussion also took place on a financial reflections paper looking at the short term and long term financial sustainability of EPF as well as on the recently submitted EU proposal on telemedicine. Next steps were agreed with regard to EPF‘s work on young patients, revision of the EPF website and virtual meeting arrangements and the setting up of a policy advisory group to support EPF in the development of its policy and campaign work.
For further information, please contact our Director Nicola Bedlington.

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25. DIARY

Wed, Jun 3	AGRENSKA 20th Anniversary Conference - Future challenges for rare diseases Place: Gothenburg Attendance: Nicola Bedlington
Tue, Jun 9	The American Chamber of Commerce to the European Union (AmCham EU) Seminar on e-Health (Brussels) Attendance: Liuska Sanna
Wed, Jun 10	EFPIA Patients Think Tank Place: Brussels Attendance: Nicola Bedlington
Thu, Jun 11 -- Sat, Jun 13	RESPECT project Steering Committee meeting Place: Pavia Attendance: Liuska Sanna
Fri, Jun 12	European Federation of Allergies and Airways Diseases Associations (EFA) Annual Conference Place: Rome Attendance: Nicola Bedlington (speaker)
Mon, Jun 15	EFPIA meeting on the Commission’s anti-counterfeiting proposal Place: Brussels Attendance: Nicola Bedlington
Mon, Jun 15	EPF officers meeting 23 June (video conference)
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 Attendance: Anders Olauson

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