



europeanpatients' forum

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Dear EPF members and friends,

EPF is very pleased to share with you some exciting news in this issue. Our EU project proposal submitted under the European Public Health Programme "VALUE +" has been approved! Readers will recall that "VALUE +" addresses both at policy and programme level strategies to involve patients organisations meaningfully in EU health related projects ([see section 18](#)). This goes to the heart of EPF's work on promoting patient-centred equitable health-care throughout the European Union and we are very much looking forward to launching "VALUE +" with partners in early 2008. We were also delighted to learn that "EURONETPAS" project, led by France and focusing on setting up a European Patient Safety Network has also been approved. Alongside the Member States and several other health stakeholders, EPF is an associate partner in this project. EURONETPAS marks an important step in ensuring that "patient safety" remains high on the EU agenda.

The EPF secretariat welcomes our new stagiaire this month, Elisabeth Kasilingam from France. Elisabeth has a legal background and is especially interested in patients/ human rights. We are looking forward to working together with her over the next 9 months. EPF has also launched an equal opportunities recruitment procedure to employ a programme officer from early 2008. ([see section 19](#))

EPF representatives contributed to several major EU health meetings. Brief reports on these meetings feature in this issue – including our work at the European Health Forum Gastein and the European Conference on Patient Safety Research in Porto.

Our Autumn Advocacy Seminar here in Brussels is fast approaching and we look forward to seeing many of our patient representatives there from throughout the EU. If you cannot attend personally, please contact the secretariat and we will ensure you get all the information/speeches and interactive sessions on CD-ROM.

Warmest greetings,

Anders Olauson, President

Nicola Bedlington, Director

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The next issue of the Internal Mailing will take place towards the beginning of December. The deadline for contributions is 5 December 2007.

1. Pharmaceutical Forum developments

EPF was represented at recent meetings of the Pharmaceutical Forum where the focus was taking forward a work plan in each of the three core areas (Information to Patients, Relative Effectiveness, and Pricing and Reimbursement) based on the Conclusions of the High Level Pharmaceutical Forum back in June 2007. Readers will recall that this is the final year of the Pharmaceutical Forum with the final High Level Ministerial Meeting scheduled to take place in September 2008.

There have been particularly interesting developments in the area of Information to Patients, where EPF was represented by Susanna Palkonen, EPF Vice President at its latest meeting on 15 October. Three work streams were agreed: developing a strategy in relation to information to patients in specific healthcare settings (community pharmacists, hospitals, and primary health care settings); exploring methodology around the application of quality principles on information to patients; and partnership in developing ITP pilots at national level. Given the fundamental importance of all these areas, EPF has committed to be as active as possible in contributing to each from a patients' perspective. Other good news is that the Joint Statement on Information to Patients, coordinated by the European Public Health Alliance (EPHA) and signed by 21 health organisations including EPF has been well received by the Commission. The Statement makes the case for in-depth analysis and research based on existing materials and sources, exploration of good practice examples of public private partnerships in relation to ITP, strategies to optimise the impact of EMEA networks and Eudrapharm, promoting health literacy and using the structural funds to the maximum extent possible. The signatory organisations will meet again in the near future to examine how to advance on these actions in concrete terms and EPF is very pleased to contribute to this work.

The information to patients' working group also learned that a legislative proposal will be made by the end of 2008 in relation to article 88A of Directive 2001/83/EC, which called on the Commission to submit a report in 2007 and "if appropriate, put forward proposals setting out an information strategy to ensure good quality, reliable and non promotional information on medicinal products and other treatments and shall address the question of the information source's liability".

This proposal will be developed on the basis of an impact assessment from an economic, environmental, public health and social perspective. Key stakeholders will be consulted on these developments through interviews in November and December. EPF will report further on this in the next Mailing.

With regard to developments in relation to Pricing and Reimbursement, the working group met at the beginning of October and agreed to fine-tune the guiding principles on pricing and reimbursement, following pilot work with volunteer Member States and companies, and evaluation of their impact on cost-containment, access to patients and reward for innovation. Further debates will take place on the value of innovation, with a survey across the European Union on good practice; and continued exchanges of information around pricing. EPF will continue to input on all of these areas from the perspective of patients. It was also agreed that the Pricing and Reimbursement working group would explore in further depth trade and distribution, including the themes of parallel trade and trade and distribution margins.

The Relative Effectiveness working group has agreed to pursue work in relation to the development of principles to establish good practice for relative effectiveness assessments and a tool box; to explore the availability of data by using real life examples, and the development of networking and collaboration. EPF has joined a sub-group on networking and our contribution will be in relation to the added value of involving stakeholder groups, including patients, in post Pharmaceutical Forum developments.

For further information on developments within the Pharmaceutical Forum please contact [Nicola Bedlington](#) or consult the European Commission website: http://ec.europa.eu/health/ph_overview/other_policies/pharma_forum_en.htm

2. EU Patient Safety Network Project approved

We are pleased to let you know that project EUNetPaS (European Union Network for Patient Safety) has been officially recommended for funding by the Public Health Executive Agency.

The project aims to establish an umbrella European network to improve cooperation between EU Member States in the field of patient safety (culture, reporting and learning systems, education) and avoid effort duplication in developing patient safety programmes at Member State level.

The project is led by Haute Autorité de Santé in France and involves partners from all Member States and a broad range of stakeholders. EPF is one of the partners.

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

3. Animal Testing

The [EPF Statement on animal testing](#) has now been approved, by the vast majority of EPF's organisations. EPF will be distributing this statement widely during forthcoming debates in the EU Institutions on the Animal Welfare Directive.

For more information please contact [Nicola Bedlington](#).

4. European Commission Future Challenges Paper: 2009 –2014

DG SANCO (Health and Consumer Protection Directorate General) has recently published a paper entitled Future Challenges: 2009-2014 based on several different workshops and future scenarios.

Nicola Bedlington was invited to present EPF's perspective on health equity to contribute towards this work. The four core challenges identified through this process are governance, globalisation, changing society and confidence. The paper will be widely distributed as the draft vision of the main challenges to be addressed under the lifespan of the next Commission. EPF alongside other stakeholders, has been invited to give feedback on this by the end of December.

The paper can be downloaded [here](#).

5. European Commission consultation on the Future of Pharmaceuticals for Human Use

EPF submitted its [response to the Commission Consultation Paper on the Future of Pharmaceuticals for Human Use](#). We also had the opportunity to present the key challenges on the future of pharmaceuticals, as identified by the EPF membership at a parallel session devoted to pharmaceuticals at the European Health Forum Gastein.

If EPF members would like to become more actively involved in the follow-up to this consultation, please contact [Nicola Bedlington](#).

6. PES Manifesto for June 2009

EPF has received a letter from Poul Nyrup Rasmussen, President of the Party of European Socialists, requesting our input in a broad public consultation with civil society and other stakeholders this autumn as part of a process for elaborating a PES manifesto for the European elections of June 2009. The consultation will run until June 2008 and will focus on gathering the best political ideas and proposals on four main themes: Save our Planet (climate change, energy and sustainable development agenda); New Social Europe (particularly the social, economic and employment agenda); European Democracy and Diversity (on how to improve democracy and fundamental rights in the EU); and Europe in the World.

For further information please go to <http://manifesto2009.pes.org/en/>

EPF will be conducting its own work with our member organisations throughout the EU during the course of 2008 regarding a patients' manifesto for the European Parliamentary elections and will distribute this to all of the European Parties. For more information please contact [Nicola Bedlington](#).

7. ALDE campaign for EU Patients' Rights

The Alliance of Liberals and Democrats for Europe (ALDE) supports EU citizens and their rights to health care; especially for a fast access to high quality and safe health care, regardless of state borders, and a free access to the achievements of European science for all EU citizens. The ALDE launched a campaign to make sure the Charter of Patients' Rights will be included in the future Community frame for health services.

We would like to encourage EPF members to give their support to this initiative. The petition is available on their website: <http://www.alde.eu/index.php?id=alde4patients>

8. EESC: own-initiative opinion on Patients' Rights approved

In the plenary session of the 26-27 of September 2007, the European Economic and Social Committee approved the own-initiative opinion on Patient's rights, by 108 votes to none, with two abstentions.

The opinion, presented by M. Bouis, underlines the need for changes in relations between all health professionals and healthcare structures and patients on a daily basis. The place of the patient has to be re-thought in her/his interaction with the system, so that a solid relationship between professionals and patient can be built and the patient's empowerment can be ensured.

The EESC considers that three rights are preconditions for others rights: the right to information, the right to free and informed consent and the right to dignity. The EESC also welcomes [the European Charter of Patients' Rights](#) and calls on the European Commission to establish a European Patients' Rights Day, as proposed by the European Citizenship Network.

The EESC opinion is available on http://www.eesc.europa.eu/documents/opinions/avis_en.asp?type=en

9. World Health Organization Global Strategy and Plan of action on Public health Innovation and Intellectual Property

EPF has given its support to the response prepared by the International Alliance of Patient Organizations (IAPO) on the WHO Global Strategy, that focused specifically on three key themes: innovation and access; patient safety; and neglected diseases and neglected patients. EPF will be participating in the event organised by IAPO around the next meeting of the Intergovernmental Working Group in early November in Geneva.

10. EMEA Brainstorming meeting on the provision of information to its stakeholders

The meeting was held in London on 20 September and gave an overview of EMEA current communication tools and information practices. EMEA website includes information on all “centrally authorized” medicines (medicines that have been granted a single “marketing authorization”) for use in EU countries.

Participants raised several points for restructuring the website for better accessibility. It was highlighted that most of the current website visitors are regulators and industry representatives and that there was a need to provide easier access to information for health professionals and patients.

For more information, please contact [EPF Secretariat](#).

11. Third Annual Conference of the European Federation of Nursing Regulators – FEPI

This Conference “Placing the patient first - Effective Nursing Regulation in Europe” (25-28 September 2007, Dubrovnik) focused on three thematic areas: provision of quality nursing services in the internal market, recognition of professional qualifications and nursing education and competences.

Nicola Bedlington represented EPF at this meeting and gave a presentation on patient-centred health care in Europe. Useful discussions took place on the value of cooperation between FEPI and EPF, particularly with regard to concrete projects such as the “TUNING Project” on tuning educational structures in Europe. ([see previous Mailing](#))

For more information on FEPI, please go to www.fepi.org

12. Patient Safety Research Conference - Shaping the European Agenda

The conference (24-26 September, Porto) looked in depth at how research into patient safety incidents can provide a scientific basis for measures to improve healthcare safety and quality.

This was a crucial opportunity for EPF to express the solidarity of patients groups and to put forward the message that there should be no patient safety research without involving patients.

EPF was represented by Roxana Radulescu who made a presentation in the session “Research commissioning: Developing capacity and partnerships”. She highlighted the need for a meaningful involvement of patients’ organisations as a critical success factor for research on patient safety. Patients can not only help identifying the right research topics but also ensure this are better targeted and therefore more likely to be used. Patient associations and self help groups can play a critical role in participating in research, as well as in disseminating the results through their networks and facilitating the dialogue between researchers and policy-makers.

The Conference conclusions formed a ten-point Call for Action that was distributed across European health authorities for urgent implementation.

We are very pleased to see that one of the recommendations is to develop strategies to involve patients in patient safety research programmes and activities.

For further information: <http://www.patientsafetyresearch.org/psnews.htm>

13. European Journalists' Centre Training

On 2 October 2007 Nicola Bedlington gave a presentation on information to patients to a group of health journalists from throughout the EU, convening in Brussels at the European Journalists' Centre.

For a copy of Nicola's Bedlington presentation, please contact the [Secretariat](#).

14. European Health Forum Gastein 2007 – 10 Year Anniversary

Nicola Bedlington attended the European Health Forum Gastein (4- 6 October 2007) on behalf of EPF and chaired a parallel session on “Pharmaceuticals and the EU: looking back and forth”. Nicola presented a statement at the beginning of the session on 9 key challenges from a patients’ perspective.

For a copy of this and other presentations made during the session please go to www.ehfg.org

15. Are patients sufficiently informed nowadays? Rights and ethics

Roxana Radulescu gave a presentation on EU developments on information to patients and EPF's position on the Commission's report on information to patients on medicinal products at a conference in Ljubljana, on 10 October.

Organised by the Forum of International Research and Development Pharmaceutical Companies, the conference brought together representatives of chronic patients' associations, doctors, pharmacists, lawyers and representatives of government institutions and pharmaceutical companies. This was organised in the context of the Bill on Patients' Rights in Slovenia being currently under adoption in the Slovenian Parliament.

For further information, please contact the [Secretariat](#).

16. HAI Open Seminar – Ensuring Independent Medicines Information in Europe

This seminar was held in Brussels on 12 October. The keynote presentation “You say information, I say advertising...” by Barbara Mintzes and Teresa Alves explained the potential implications for public health of the widespread promotion of medicines to health professionals and increasingly to the public, with the example of the recent experience of the arthritis drug Vioxx. This launched a lively and interesting debate, with a wealth of information from various perspectives. Speakers included representatives of the European Consumers’ Organisation (BEUC), Association Internationale de la Mutualité (AIM), healthcare professionals organisations, European Commission, pharmaceutical industry, drug regulators, MEPs, patient organisations and independent society drug bulletins.

All presentations will be soon available on HAI website www.haiweb.org

17. Board Meeting Outcomes

The EPF Board met on 11 and 12 October 2007. Key issues on the agenda were the draft work programme and budget for 2008, the final approval of EPF's response to the Commission Consultation on the future of Pharmaceuticals for Human Use, discussion on criteria on getting involved in EU projects, becoming a member of other organisations, and representation at external meetings. It was agreed to launch a recruitment process for a programme officer, and to launch a survey before the end of the year among the EPF members to determine the number of patients EPF currently represents. The next meeting of the board will take place on 6th December 2007.

For more information, please contact the [Secretariat](#).

18. European Commission approves VALUE + Project

We are delighted to announce that our project proposal to the Public Health Executive Agency together with several members and other partners has been successful.

The VALUE + Project (Promoting Patients' Involvement in EU-supported health-related Projects) aims to exchange information, experiences and good practice among patients' organizations and other key stakeholders to encourage the meaningful involvement of patients' organizations in EU-supported health projects at EU level and at national level.

The project will develop a set of specific targeted resources: (1) a Resource Kit for patient organisations to facilitate patient involvement in future projects, (2) a Handbook for project leaders and promoters, (3) Policy recommendations for policy makers.

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

19. EPF recruits Programme Officer

EPF has just launched a recruitment process to employ a Programme Officer. The deadline for application is 20th November 2007.

To download the recruitment pack, please go to the EPF website: www.eu-patient.eu

20. Call for members of Working Group regarding cooperation between EPF and CPME (European Standing Committee of Doctors)

Readers will recall that EPF and CPME leaders met on 13 September to discuss how to work more effectively in the future ([see attached press release](#)). It was agreed that a set of joint principles will be agreed, together with concrete projects. A working group is being set up, and any EPF member who would like to join this group is invited to contact the secretariat. A series of teleconferences will take place prior to a working group meeting on 6th December to review the work.

21. Forthcoming Events

EPF Autumn Seminar 26-28 November 2007, Sofitel, Place Jourdan, Brussels

The European Patients' Forum constantly works to best represent the needs of our members at European level. We understand, from evaluations, that our training and advocacy seminars have proved an invaluable source of support, advice and information for all who have been involved.

As you can see [from the draft agenda](#), this years' seminar addresses issues of great importance to patient groups across the European Union, such as the legislative process and working as a non-governmental organisation within this framework. The seminar will also provide you with the opportunity to meet with a Member of the European Parliament in small breakout sessions and will allow for constructive discussions concerning the impact of EU policy decisions at national and local level.

The seminar is aimed specifically at patient representative groups and will allow you the opportunity to meet with and discuss issues of relevance with your peers from all Member States.

The EPF General Meeting will take place on 8 April 2008 am in Brussels.

Further information will be sent to EPF members and prospective members before Christmas.

EPF Spring Conference 8-9 April 2008, Hotel Silken Berlaymont, Brussels

Preparation has already begun on the annual conference, being held in Brussels on 8-9 April 2008. The theme of this years' event is Health Literacy and its implications and we are planning a wide and diverse agenda to attract delegates from all sectors of the healthcare arena in the EU. The 2007 conference was very well received and has provided the EPF with a strong and clear framework for its work, as a patient advocate, at European level.

Further information, with a preliminary agenda for the meeting will follow in due course.

Please contact our meeting coordinator, Amanda Casey at seminar2007@eu-patient.eu with any questions you may have about either event and we look forward to working with you in the coming months.

22. Diary

DATE	EVENT	PLACE	ATTENDANCE
6 November	IAPO meeting linked to the WHO global strategy on public health, innovation and intellectual property	Geneva	Nicola Bedlington
8 November	Health Care Compliance Packaging Council	Copenhagen	Anders Olauson Nicola Bedlington
9 November	EFPIA Think Tank meeting	Brussels	Nicola Bedlington Roxana Radulescu
8-9 November	Patient Dialogue Forum	Karlsruhe	
20 November	GIRP (European Association of Wholesalers) Meeting	Brussels	Nicola Bedlington
21 November	OECD Panel Discussion on Information Technology and Information to Patients	Paris	Nicola Bedlington
29 November	MSD Symposium on Access, Innovation and Affordability of Medicines	Munich	Nicola Bedlington
26-28 November	EPF Autumn Advocacy Seminar	Brussels	EPF members
6 December	EP Debate chaired by MEP Jorgo Chatzimarkakis – For a Europe of Achievements: reinforcing patients' right	Brussels	Anders Olauson Roxana Radulescu
6 December	EPF Board meeting	Brussels	EPF Board members