



europeanpatients' forum

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Dear EPF members and friends,

Welcome to the third issue of the EPF internal mailing 2007. The highpoint for EPF over the last month was clearly our Spring Conference, 20, 21 March 2007. We were delighted with the level of participation from our membership, umbrella patient groups across the EU, and health stakeholders in Brussels. "Moving forward together" described well the mood of the meeting, and indeed the core actions agreed by the Conference on empowerment, information and sustainability ([see section 1 for more details](#)).

Preparation are now well underway for our project submission VALUE +, in the framework of the Public Health Programme on involvement of patients in EU projects: a planning meeting will take place 3-4 April for those EPF members which have expressed an interest in being involved and selected external partners. The outcomes of this will be distributed just after Easter.

Work is also underway to prepare the EPF Annual General Meeting, which will take place over the weekend of 9-10 June 2007. Apart from the business session, an "open space" session will be organised to enable EPF members to explore together themes and issues common to all of us, and exchange experience and good practice.

Another key date in late Spring will be an event in the European Parliament when EPF will present our members' perspectives on Information to Patients, at this critical time in the debate ([see section 5](#)).

Anders Olauson has been in the States this month representing EPF at the IAPO (International Alliance of Patient Organisations) General Assembly, and at UN meetings. Susanna Palkonen attended a major meeting of the Bulgarian Coalition of Patient Groups, which is to join EPF. Reports on these will be included in the next Mailing.

We look forward to working closely with you on all of these developments, and wish you a great springtime!!

*Anders Olauson
President*

*Nicola Bedlington
EPF Director*

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The next issue will be available on 3th of May. The deadline for articles/calendar additions is 27 April 2007.

1. The EPF Spring Conference - "Moving forward together"



The EPF Spring Conference 20-21 March 2007 convened 120 participants, including the EPF membership, patient representatives from across the EU member states, key health stakeholder groups and federations in Brussels, the European Commission, European Parliament and National Government health representatives. The Conference resulted in key action points for EPF to take forward in the areas of empowerment, information and sustainability, in close cooperation with other stakeholders. Representatives from national patient platforms and umbrella groups expressed a keen interest to work more closely with EPF in the future, and joining EPF as members.

[The programme, outcomes and powerpoint presentations from the meeting are now available on the EPF website.](#)

The conference report and further recommendations from the working groups will be available in mid May 2007.

2. EPF Board Report

The [EPF Board](#) met on 19th March 2007. The main issues were:

- Approval of the accounts for 2006, which will be audited and presented to the Annual General Meeting in June 2007.
- Approval of a procedure to extend the EPF board through elections at the Annual General Meeting. Nomination forms will be circulated shortly to EPF members and applicant members.
- Discussion on the EPF project submission VALUE +, and our involvement in the EuNetPas project on Patient Safety (see section 8)
- The current state of play regarding 'information to patients' (see section 5)
- Agreement to sign up to the Advanced Therapies Position Paper led by Eurordis.
- Discussion on financial planning for EPF in 2008 and beyond, and arrangements for a sponsors meeting in mid September.

3. *Resolution of the European Parliament on Healthcare cross-border*

On the 15th March, the European Parliament adopted a Provisional Resolution (P6_TA-PROV(2007)0073) urging the European Commission to enhance community action on the provision of cross-border healthcare and to provide a legislative framework for cross-border aspects of healthcare. The European Parliament is thus welcoming the earlier Commission's initiative to propose a consultation ([see EPF's response in our Internal Mailing, 2007, Issue 6](#)) on the best form that Community action should take in this field.

The EP work on the issue

On the 24th January, Mr Karl-Heinz Florenz MEP asked an oral question to the Commission on cross-border health care to know what its plans were on the issue. In the meantime, Ms Bernadette Vergnaud MEP was appointed Rapporteur on health services by the European Parliament to assess the impact and consequences of the exclusion of healthcare services from the scope of Directive 2006/123/EC.

Ms Vergnaud recommended three directives: one on health services, one on Social Services of General Interest (SSGI) and a framework directive on Services on General Economic Interest. She asked for five clarifications to the Commission:

1. On the rules of healthcare services with social support (Disabled or elderly people);
2. On the definition of hospital or non-hospital healthcare;

3. On the “undue delay” concept;
4. On Responsibility in case of problem;
5. On reimbursement conditions and procedures when a cross-border care is provided.

On the 12th March, there was a debate in Parliament on “the Community action on the provision of cross-border healthcare”. Mr John Bowis MEP underlined that it is not up to the lawyers in Europe to decide on patient mobility since “no poet ever interpreted nature as freely as a lawyer interprets the truth” (Jean Giraudoux). Now, politicians of Europe should tackle the issue and state a position on the issue.

The Resolution's provisions

In its Resolution, the European Parliament highlighted that cross-border aspects of healthcare that should cover both patient mobility and the mobility of healthcare professionals, as well as the provision of healthcare from another country; the important EU's role in improving the availability of information for patients on cross-border mobility (their rights and obligations) by coordinating cooperation between Member States; the creation of a mechanism for appeals on malpractice in cross-border healthcare; the need to incorporate a common charter of patient; the opportunity to empower European citizens as patients...

EHMA conference

On 30th March, the European Health Management Association Conference (“shaping the future

for Community action in health services”) also concentrated on the issue. EPF was represented by Nicola Bedlington who participated in a stakeholder panel and Nicolas Pradalié. It was highlighted that the initial analysis of the consultation on health services will be discussed at an informal Health Council in Aachen, Germany in mid- April.

For further information on the outcomes of this meeting, please visit: <http://www.ehma.org>

Plenary session's summary – 19th March

http://www.europarl.europa.eu/news/expert/briefing_page/4038-071-03-11-20070309BRI03996-12-03-2007-2007/default_p001c016_en.htm

Resolution adopted by EP- 15th March - Strasbourg

<http://www.europarl.europa.eu/sides/getDoc.do?Type=TA&Reference=P6-TA-2007-0073&language=EN>

Debate in EP – 12th March

<http://www.europarl.europa.eu/sides/getDoc.do?objRefId=140028&language=EN>

Motion for a Resolution – 8th March

<http://www.europarl.europa.eu/sides/getDoc.do?type=MOTION&reference=B6-2007-0098&language=EN>

Draft Report – 6th March

http://www.eu-patient.eu/doclibrary/newsletter/2007_04/health_services_en.pdf

Parliamentary Question – 24th January

<http://www.europarl.europa.eu/omk/sipade3?OBJID=135885&L=EN&NAV=X&LSTDOC=N>

4. *European Commission BEPA Workshops on the Single Market – Pharmacies*

On the 1st March, Nicolas Pradalié represented EPF at the Workshop on Pharmacies (liberal professions), the first workshop organized by the Bureau of European Policy Advisers (BEPA – reporting directly to the European Commission's President, Mr José Manuel Barroso) The meeting took place in the broader context of the current Single Market Review: the review is a major reappraisal of the Single Market twenty years after the initial White Paper and the Single European Act.

“The workshop on pharmacies focused on the experience of users with the current provision of service, the barriers to further development of these services of both a regulatory and economic nature and the proper role and degree of EU regulation on the liberal professions”.

Patients' perspective

Three national patients' organisations (plus EPF) were convened, but the participants were invited to speak on their own behalf, rather than on the one of their organisations (Chatham House Rule). They were encouraged to answer questions pertaining to “users of pharmacies” (one of the three main themes of the discussion).

Main points that came out of the discussion

The “users” believe the quality and availability of information provided by pharmacies are crucial. According to patients groups, it appeared that physical accessibility of

pharmacies is in general not problematic, except in some rural areas.

The opening times (notably evenings and week ends), the availability of certain medicines and the need to order drugs are more substantial issues for the users. The price of medicines can be a problem too when the latter are poorly, or not at all reimbursed, or when these medicines are very new.

The discussion then addressed ICT (Information & Communications Technology) in the context of patient records and electronic prescriptions. It was highlighted that both aspects have the potential to provide benefits for users and providers of services. Technical problems (data security) can be overcome; the main issues are: trust among stakeholders and who controls the process.

Conclusion of the workshop

The impact of the Single Market on Pharmacies has been rather limited so far. Some liberalisation in the fields of entry on the Pharmacies market and sale of pharmaceutical products could be organised so as to extend patients' rights and to open up restrictions when not warranted by the public interest.

The BEPA:

http://ec.europa.eu/dgs/policy_advisers/index_en.htm

The Single Market Review: http://www.eu-patient.eu/doclibrary/newsletter/2007_04/single_market_yesterday_and_tomorrow_en.pdf

5. *Information to Patients*

EPF has prepared a draft response to the Commission Consultation, in the framework of the Pharmaceutical Forum, on quality principles and the diabetes model. EPF has also updated its baseline position on Information to Patients. These have been sent to the EPF membership for their input by the end of April. The deadline for this consultation is 4th May 2007.

Should readers be interested in receiving a copy of these documents, please [contact Nicola Bedlington](#).

Susanna Palkonen will be representing EPF at the next working group on information to patients 10-11 May 2007.

EPF has also agreed with the three MEPs involved in the Pharmaceutical Forum to hold an event in the European Parliament to outline their members' views on the above, and more specifically the Commission Communication to be presented to the European Parliament and Council in April on Information to Patients. The specific date for this event is yet to be set, pending the release of the Communication, but is likely to take place in May or early June. An invitation will be sent to all readers of the Internal Mailing.

6. *Diagnosing our Future – European Voice Conference 19-20 March 2007*

Nicola Bedlington represented EPF at the European Voice Conference “Diagnosing our Future” and took part in a panel session on future perspectives, including the Health Services follow up, the EU Health Strategy, and Pandemic Preparedness.

Please go to *European Voice* for full details of the programme and the conference report.

<http://www.europeanvoice.com/ev/info.asp?id=1788>

7. EPF Project VALUE +

EPF is currently preparing a project proposal in the framework of the Programme of Community Action in the field of Public Health, Call for proposals 2007, on involvement of patients in EU projects (VALUE +).

http://ec.europa.eu/phea/calls/call_for_proposals_en.html

The project will look at mapping and analyzing patients organisations' involvement in and contribution to EU health related projects and research. (for example Public Health Programme, FP6, Structural Funds etc), as well as at identifying "showcase" examples of excellence across EU Member States demonstrating the added value of meaningful involvement of patients.

A planning meeting is taking place on 3-4 April in Brussels for those EPF members which have expressed an interest in being involved and for interested external partners. The meeting will be an opportunity to work on the role and responsibilities of project partners and to define the content of the work packages. The outcomes will be distributed just after Easter.

8. EUNetPaS Project

EPF will participate as an associate partner in a major EU project submission on patients' safety that will be submitted by HAS in France (Haute Autorité de la Santé) in response to the Public Health Call for Proposal 2007.

The project EUNetPaS 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), thus avoiding effort duplication in developing patient safety programmes at Member State level. Most of the project partners will be Ministries of Health or social affairs in the EU, as well as research institutes, universities or organisations such as EFN (European Federation of Nurses), CPME (European Standing Committee of Doctors) and HOPE (Hospital and Healthcare Federation).

EPF will be involved in several Work packages, which look at: mapping good practices, discuss model core curricula and patient safety modules, raising awareness and dissemination of project results and evaluation of project outcomes.

For further information, please contact [Roxana Radulescu, EPF Policy Officer](#)

9. Workshop on paediatric medicines

In the context of the Seventh Framework Programme for Research (FPF), a workshop was organised by the European Commission on adapting off-patent medicines to the specific needs of paediatric population (14 March, Brussels).

The debate looked at the expectations of the EU Paediatric Regulation which aims at improving the health of children by increasing high quality, ethical research into medicines for children and information on and availability of authorised medicines for children. The Regulation entered into force on 26 January 2007 and is directly applicable to Member States. http://www.eu-patient.eu/doclibrary/newsletter/2007_04/I_37820061227en00010019.pdf

The discussion focussed especially on the new type of Marketing Authorisation, the Paediatric Use Marketing Authorisation (P.U.M.A.) that will be applied for new off-patent medicines specifically developed for children.

Participants explored possibilities of applying to the FP7 call for proposals to carry out further research in the area.

EPF was represented by [Roxana Radulescu, EPF Policy Officer](#), please contact her for further information.

10. *E-Health Users' Stakeholders Group*

EPF has got involved in the Commission e-Health Users' Stakeholders Group, which is an advisory group of the i2010 Subgroup on e-Health, working under the coordination of the Information Society and Media Directorate-General. The group provides advice for the progress on the eHealth Action Plan in Europe, concentrating on areas such as:

- interoperability of electronic health records,
- identification management
- legal and regulatory issues
- reimbursement schemes for eHealth
- certification and accreditation issues in eHealth
- deployment of health information networks including broadband, wireless, Grid technologies
- and appropriate deployment aspects of the Seventh Framework Programme eHealth future research agenda, etc.

A meeting was held in Brussels on 22 March in which EPF participated.

For further information, please contact [Roxana Radulescu, EPF Policy Officer](#)

11. *European Alliance for Access to Safe Medicines*

The European Alliance for Access to Safe Medicine (EAASM) is a new pan-European patient safety initiative, campaigning for the exclusion of counterfeit and substandard medicines from the supply chain. The Alliance aims to represent all interested parties – patient groups, health professionals, academics, NGOs, the pharmaceutical industry and policy makers. EAASM is registered in UK and its setting up has been supported by Pfizer.

EPF attended the first meeting of EAASM, which was held on 27 March in Brussels. The meeting generated reflections and discussions on the Alliance's strategy and aims and the best way to move EAASM forward.

We would like to encourage EPF members to share with EPF Secretariat any information and experience on use of counterfeit and substandard medicines

For further information on counterfeit and substandard medicines, please see the WHO factsheet N°275 from November 2003

<http://www.who.int/mediacentre/factsheets/2003/fs275/en/>

For further information on EAASM, please contact [Roxana Radulescu, EPF Policy Officer](#).

12. *European Patients' Rights Day*

The European Patients' Rights Day was launched on 29 March by Active Citizenship Network (ACN) with a seminar in the European Parliament, which aimed at establishing the European Patients' Day as an annual event, while fostering the debate on patients' rights, their respect and exercise.

The report Patients' Rights in Europe – Civic Information on the implementation of the European Charter of Patients' Rights was presented. The report features the main findings of a study which has monitored the process of implementation of the European Charter of Patients' Rights in 14 old EU Member States.

The seminar was very well attended by 7 MEPs, representatives of the Health Commissioner Markos Kyprianou cabinet and of the European Economic and Social Committee, of health care providers organizations and by large number of patients organizations.

EPF was represented by Nicola Bedlington and Roxana Radulescu.

To download the report: http://www.eu-patient.eu/doclibrary/newsletter/2007_04/patients_rights_report_final.pdf

To download the European Charter on Patients' Rights:
http://www.activecitizenship.net/documenti/European_Charter_of_Patients_Rights_Final_Draft.pdf

13. *The Seventh Framework for Research – funding opportunities*

Two calls for proposal have been published by the European Commission, DG Research under the Health theme of FP7 (deadlines 19 April and 18 September). Basic and applied collaborative research projects are supported in 3 main areas: (1) biotechnology, generic tools and technology for human health, (2) translating research for human health and (3) optimizing the delivery of healthcare to citizens. Two horizontal issues that should be addressed across all activities are child health and the health of the ageing population.

<http://cordis.europa.eu/fp7/dc/index.cfm?fuseaction=UserSite.FP7CallsPage>

14. *EPF Calendar for April-June 2007*

Date	Event
16-17 April 2007	<p><i>European Public Health Alliance (EPHA) Conference on Health and EU Enlargement, Bratislava</i></p> <p>Representative: <i>Nicola Bedlington, Director</i></p>
17-19 April 2007	<p><i>eHealth Conference 2007, Berlin</i></p> <p>Representative: <i>Roxana Radulescu, Policy Officer</i></p>
10-11 May 2007	<p><i>EC Working Group on Information to Patients</i></p> <p>Representative: <i>Susanna Palkonen, EPF Board Member</i></p>
22 May 2007	<p><i>Pharmaceutical Forum Steering Group meeting</i></p> <p>Representative: <i>Anders Olauson, President</i></p>
24 May 2007	<p><i>Meeting on chemical ingredients of pharmaceuticals and patient safety, Berlin</i></p> <p>Representative (Speaker): <i>Nicola Bedlington, Director</i></p>
4 June 2007	<p><i>Compliance Conference in Geneva</i></p> <p>Representative (Speaker): <i>Nicola Bedlington, Director</i></p>
4-5 June 2007	<p><i>AEGSP Annual Conference, Warsaw</i></p> <p>Representative: <i>Anders Olauson, President</i></p>

6 June 2007	European Heart Network Conference Representative (Speaker): <i>Nicola Bedlington, Director</i>
9-10 June 2007	EPF Annual General Assembly
18 June 2007	GIRP meeting Representative (Speaker): <i>Anders Olauson, President</i>
18-19 June 2007	PGEU meeting, Vienna Representative (Speaker): <i>Nicola Bedlington, Director</i>
21-23 June 2007	IPISO Meeting, Romania Representative (Speaker): <i>Anders Olauson, President</i>