



europeanpatients' forum

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Dear EPF members and friends,

Welcome to the second issue of the internal mailing in 2007. Highlights of the last month include [the EPF board meeting](#), participation in a major [EU conference in Helsinki](#) on financing sustainable health care systems, [EPF's proposal to the public health programme](#), and our high level [meeting with the European Standing Committee of Doctors](#) (CPME).

EPF's spring conference is fast approaching, and the working group and secretariat are very much focused on preparing this meeting addressing empowerment, information and sustainability of patients' organizations ([section 6](#))

As many of you know, EPF will be holding its Annual General Meeting, 9 and 10 June in Brussels. In addition to the formal business session, there will also be an open forum for EPF members to exchange good practice and key developments in their organizations that fellow EPF members may be interested in. More information on this meeting will be made available at the end of March 2007.

Formal requests have been received this month from the International Diabetes Federation- European Section, and the French National Platform of Patients Organisations, CISS to join EPF. EPF is also in close contact with the National Platforms of Patient Organisations in Bulgaria and in Romania, as these organizations have also expressed a wish to join EPF. We are very much looking forward to enlarging our membership and building up strong relationship with these important patient groups.

Please note information on EPF's proposal to the recently launch Call under the European Public Health Programme ([see section 4](#)) should you be interested in joining us in this project, please [contact us](#) as soon as possible.

As ever, we encourage you to participate in this Mailing with news and views from your own organizations, or comments on our articles. Very many thanks and warmest greetings,

*Anders Olauson
President*

*Nicola Bedlington
EPF Director*

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The next issue will be available on 5th of April, before Easter 2007. The deadline for articles/calendar additions is 30 March.

1. EPF 5 Years Strategic Planning

The EPF strategic planning working group submitted a draft strategic plan to the EPF board at the end of January 2007. The draft has now been finalised following input from board and has been circulated to the wider EPF membership for their written approval by the end of May 2007, in advance of our Annual General Meeting.

Should you like a draft copy of the strategic plan, please [contact the EPF secretariat](#).

2. EPF Board Meeting

The [EPF Board](#) meeting met on 29 January 2007.

Key issues included:

- The adoption of the EPF Strategic Plan;
- The adoption of the budget and work plan for 2007;
- The decision to set up a branch of EPF in Belgium, as required under Belgian law (EPF is currently registered in Luxembourg);
- Review of major current policy areas including the Pharmaceutical Forum, the Response to the Health Services Consultation, the response to the Health Strategy Document and the upcoming EMEA meeting.

For more information on the board meeting please [contact EPF Director Nicola Bedlington](#).

3. EPF Policy Working Group Meeting

The EPF Policy Working Group met on 30 January in Brussels. Key issues included: the EPF project proposal to the EU Public Health Programme Call for proposals 2007; updates on the work with the European Parliament; and updates on the EPF Policy priorities.

The group brainstormed on submitting a project proposal looking at promoting meaningful involvement of patients in EU funded health-related projects (possible title VALUE +), while bearing in mind EPF's vision of a patient-centred, equitable healthcare throughout the EU ([please see the next article for further information](#)).

The discussion looked also at the intention to organise an event in the European Parliament in early May to raise EPF's profile and build our core group of champions in the European Parliament. The topic will be EPF's response to the information to patients report.

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4. *European Commission Public Health Call for Proposals 2007 – EPF's Project Proposal on Involvement of Patients*

As you may already know, on 16 February 2007, the Public Health Executive Agency published a Call for Proposals to implement the priority actions defined in the Work Plan for 2007. Patients-related issues are reflected mostly under strand 2.1.1. Health Information – especially under:

2.1.1.4. Developing strategies for information exchange and responding to non-communicable health threats

- support for disease knowledge projects, related to their occurrence, treatments, risk factors, risk reduction strategies;
- support for European networks of reference for rare diseases to establish guidelines on best practice for treatment;
- data collection on the volume and impact of cross-border healthcare .

2.1.1.5 eHealth

- development of reporting on patients and health professionals' behavioural and perception changes resulting from introducing eHealth solutions, modelling of the safety and risk implications of information and communication technology-related changes.

- promotion and dissemination of pilot projects on patient summaries, patient, staff and object identifiers, ePrescription, etc.
- analysis of legal, medical and ethical issues of confidentiality; ownership and access to data arising from the use of eHealth tools, in particular in relation to exchange of electronic health records in cross-border settings.

2.1.1.7. Supporting the exchange of information and experiences on good practice

- promoting patient safety and quality of health services - e. exchange of best practices including patient safety (...), developing a better understanding of patients safety interventions and economic implications of unsafe services and medical errors.

The deadline for submitting project proposals is 21 May 2007.

If your organization is interested in submitting a project please [go to this website](http://ec.europa.eu/phea/calls/call_for_proposals_en.html) (http://ec.europa.eu/phea/calls/call_for_proposals_en.html) for more details.

EPF to submit a project proposal – call for partners

EPF will be submitting a project proposal on the meaningful involvement of patient as partners in EU health projects and the added value of this regarding project outcomes and relevance for the broader health policy debate.

The main objectives will be

The overall objective of the project will be to promote the meaningful involvement of patients' organizations in EU supported health projects, bearing in mind EPF's vision of a patient-centered, equitable healthcare throughout the EU.

The specific objectives will be:

- to map and analyse patients' organisations' involvement in and contribution to date to EU health related projects and research.
- to identify 'showcase' examples of excellence from throughout the member states demonstrating the added value of meaningful involvement of patients.
- to monitor concurrently during the lifetime of the project other projects funded under the Public Health Programme to explore good practice, key challenges and hurdles in relation to involvement of patients.

Based on this analysis and evaluation, to arrive at

- A database and detailed report on the above;
- A handbook for relevant Commission directorates/Government Departments on using involvement of patients as a core criterion for project funding, and indicator for monitoring and evaluation;

- A set of recommendations and resources for project leaders to facilitate and ensure effective patient involvement in projects and indicators to measure this and its impact;
- A 'toolbox' for patients' organizations to support them in becoming an effective partner in health related projects.

As the deadline is 21 May 2007, we must move very quickly to develop the project proposal and identify the partners that would like to participate. If your organization would like to express an interest in becoming a partner in the project, please let the secretariat know **by 14 March 2007** at the latest. We will then organize an opportunity around the Spring Conference to hold a briefing meeting on:

- a) the implications of partnership in terms of resources and benefits
- b) next steps

5. *The European Commission Consultation for a Health Strategy – EPF's response*

EPF has responded to the discussion document for a Health Strategy: *Health in Europe: A Strategic Approach* by highlighting a number of key points from a patients' perspective:

1. Patients' involvement and citizens' involvement should be given a high priority in the Strategy.
2. The Strategy should provide the framework to mainstream health in EU policies and equally importantly should monitor and evaluate the mainstreaming process.
3. Patient organizations should be involved in effective dialogue related to health at the very onset, as a key partner.
4. It is important to make meaningful participation of patient organisations a criterion for European Health related funding at all levels.
5. The Strategy needs adequate funding in order to be effective. Process and outcome evaluation are crucial; indicators should be both quantitative and qualitative and agreed by all stakeholders including patients' organizations. Quality of life indicators, alongside healthy life years should be included.
6. It is vital that the Strategy sets the framework for core funding for a number of European platforms representing civil society organisations, patients organisations included.
7. The Strategy should feature clear communication mechanisms and effective use of the

EU Public Health Portal to disseminate information, facilitate the exchange of good practice across Member States.

8. EPF would welcome the reflection and inclusion of EPF's vision - of a patient-centred, equitable healthcare in Europe - and our key goals over the next five years, in the broad objectives of the Strategy.

9. EPF strongly encourages the implementation of the Open Method of Coordination methodology.

10. EPF would welcome further European action and cooperation on cross-sectoral policies between various Commission Directorates-General.

11. EPF encourages the complementarity of EU action with the work of the World Health Organization.

For further information, please visit EPF's website: www.eu-patient.eu

On 14 February, Nicola Bedlington and Roxana Radulescu met Bernard Merkel, Head of the Strategy Unit in DG SANCO and Tuuli-Maria Mattila, Policy Officer, for a debriefing on EPF work and response to the Health Strategy Consultation.

6. EPF 2007 Spring Conference – “Empowerment, Information, Sustainability”, 20-21 March 2007, Brussels



Approximately 100 participants have registered for the EPF Spring Conference 2007 from a wide range of stakeholders. The conclusions of this Conference will be included in the next issue of Internal Mailing.

Should you need more information on the conference please contact conference coordinator Amanda Casey conference2007@eu-patient.eu or

visit the website: www.eu-patient.eu/conference2007

7. Pharmaceutical Forum – Steering Group and Information to Patients WG

Anders Olauson, EPF President will be representing EPF at the Pharmaceutical Forum Steering Group and will make a statement on behalf of the members regarding developments in the three working groups (Information to Patients, Pricing and Reimbursement and Relative Effectiveness)

EPF has also finalised its reference document on information to patients that will be circulated to all participants of the next working group meeting on 6 March 2007. A report on the outcomes of this meeting will be included in the next issue of the Mailing.

The Commission has not yet launched the Consultation on papers from the working group on information to patients, not the draft Report to Parliament on Information to Patients that was anticipated before Christmas. As soon as this happens, EPF will prepare a draft response and circulate it to members for comments.

8. Working Group on Relative Effectiveness – 14th February 2007

On the 14th February 2007, a meeting of the Working Group on Relative Effectiveness was organised by the European Commission. Relative Effectiveness is one of the three working groups of the Pharmaceutical Forum. Anders Olauson attended on behalf of EPF and Nick Pradalié attended as an observer.

The Working Group on Relative Effectiveness has as its mission to support Member States to apply Relative Effectiveness systems in order to allow containment of pharmaceutical costs as well as a fair reward for innovation. The initial expected outcome was to help identify the most valuable medicines (both in terms of clinical efficiency as of cost-effectiveness) and set a fair price for these medicines. This Working Group is bringing together experiences from many stakeholders, and the Member States.

The meeting of the 14th discussed the Commission "Summary of the working group's report on data and methodology in relation to relative effectiveness". Some of the participants wanted to come back on the difference between their working group and the Pricing and Reimbursement. There was also a focus on whether to include cost-effectiveness in the remit of the Relative Effectiveness Working Group. The Commission recalled that the aim of the Working Group was to

generate consensus and to identify best practices. Above all, the group is set up to promote the production and collection of better data (for comparisons) to be used for Relative Effectiveness Assessment.

Anders Olauson on behalf of the European Patients' Forum stressed the patients' view on Relative Effectiveness Assessment. The patients' quality of life must also be taken into account in the methodology since drugs have not only medical implications, but also on patients' overall life situation. Today's patients are usually aware of what is going on in their own disease area via Internet, but also through their own networks. Patients do not wish to see that a better drug is available elsewhere. They are concerned both with availability and reimbursement. EPF then submitted a few suggestions:

- 1) The methodology must be broader and include the quality of life-perspective
- 2) There should be the same criteria for Relative Effectiveness Assessment in all countries
- 3) The price is of course important. So, there is a relation between Relative Effectiveness Assessment and Cost-Effectiveness.

9. Report on EFPIA Meeting

The EFPIA Think Tank Meeting took place on 12 February 2006, chaired by Anders Olauson.

Key areas covered included

- Presentation of the results of the survey on the Think-Tank
- Presentation on review of Directive 86/609 on animal welfare (by Magda Chlebus, EFPIA) and a document with links to websites with useful information on animal welfare
- Presentation on public information on animal experiments in the Netherlands (by Cees Smit, SID)
- Presentation on recent developments animal testing politics in the UK (by Nick Meade, GIG/EGAN)
- Presentation on the EU health policy strategy (by Nicola Bedlington, EPF)

For a copy of any of these presentations please [contact the EPF secretariat](#).

10. *EMEA Meeting - Patients' and Consumers' Organisations Working Group*

The European Medicines Agency (EMA) held a meeting of the Scientific Committee's Working Party with Patients' and Consumers' Organisations (PCWP) on 16 February in London. Christoph Thalheim (European Multiple Sclerosis Platform) represented EPF at this meeting.

The meeting was particularly important, as a co-chair from patient representatives was elected and we congratulate Nikos Dedes from the European Aids Treatment Group (EATG) on his election.

Other key issues on the agenda included the composition of subgroups and identification of topic leaders. Subgroups include: risk communication and pharmacovigilance; dissemination of information (websites and other tools); Commission report to the Council and the Parliament. Another session was dedicated to the Dutch National Authority experience of interaction with patients' organisations.

For more information please [contact EPF Policy Officer Roxana Radulescu](#).

11. *Cooperation with CPME*

Anders Olauson, EPF President and Nicola Bedlington, EPF Director met Daniel Mart, President and Lisette Tiddens, Secretary General of the European Standing Committee of Doctors (CPME) in Luxembourg on 13 February. A fruitful discussion took place on strategies to enhance the patient–doctor relationship in the wake of current developments on information to patients, and how our respective organisations could work together more effectively. A joint exploratory meeting between our respective Boards will take place on 13 September 2007, to agree on the way forward.

12. *EPPOSI – 8th Workshop on Rare Diseases Therapy Development*

Roxana Radulescu, EPF Policy Officer attended an organizing meeting for the 8th Workshop on Rare Diseases Therapy Development that will be held in Copenhagen, on 18-19 October. This year the workshop will be dedicated to the use of health economic methods and health technology assessment on the evaluation of orphan medicines.

The objectives of the workshop will be:

- Promote dialogue with multiple stakeholders on role of economic evaluation in creating a stable and sustainable access to and marketplace for orphan medicines.
- Evaluate the impact of current application of health economics on the field of orphan medicine policy, research and funding.
- Discuss the basis for differentiating the clinical and economic assessment of orphan medicines from the assessment of common disease medicines with specific consideration to rarity, innovation, and social values.

- Identify areas of further research to help identify and address shortcomings of current health economic methodology and develop criteria for application of health economic evaluation to inform resource allocation decisions.
- Involve all stakeholders in collaboration to advance policy and funding for orphan medicines.

The organization of the workshop is coordinated by the European Platform for Patients' Organisations, Science and Industry (EPPOSI), which is a European-wide partnership of patients, academic science and industry aiming to advance health-care policies for the prevention and treatment of serious diseases. EURORDIS, EPF member is actively involved in this.

13. *Report on a Conference – Financing Sustainable Care, 7 February, Helsinki - Finland*

Susanna Palkonen, EPF Board Member attended this conference, which aimed to launch and discuss with stakeholders the report “Financing Sustainable Healthcare in Europe: New Approaches for New Outcomes – Conclusions from a collaborative investigation into contentious areas of healthcare”.

The report has four main areas, which were introduced alongside with some case studies across the world:

- Are competition and choice compatible with an equitable and efficient delivery of healthcare?
- Innovation and financing in healthcare: The role of health technology management (HTA) in managing the tensions
- Improving efficient health outcomes by empowering patients
- Issues affecting the sustainability of health financing in several Balkan countries

As the EPF delegate, Susanna Palkonen stressed that the empowered patient should be seen as an opportunity, not a threat to healthcare systems and their financing as it will improve efficiency and that information to patients should take a holistic approach were the need for better and equal access to high quality information on all aspects of the disease, including medicines is important,

accompanied by patient education programmes. Also, patient organisations talk about true partnership between the patients and their treating healthcare professionals, with mutually agreed written self management and emergency plans with follow up. This concept recognises the professional as expert in medical aspects and the patient as expert in the experience of and living with their disease.

About 200 participants attended the meeting, most of them high level representatives of health and finance ministries across Europe and of the European Commission DG SANCO, ENTERPRISE and Information Society. EPF was the only patient representative together with a handful of Finnish patient groups.

For further information please visit www.sustainhealthcare.org

14. *Report on KNAPPE project meeting, 5 February, Brussels*

Policy Officer Roxana Radulescu participated in the kick-off meeting of the European project "Knowledge and Need Assessment on Pharmaceutical Products in Environmental Waters" (KNAPPE).

Supported by DG Research, the project aims to identify priority actions to be taken in order to reduce presence, impacts and risk of certain pharmaceutical products in environmental waters.

Several studies have highlighted the presence of various pharmaceutical products in different aquatic environmental compartments. Only pharmaceutical products covering active pharmaceutical ingredients for humans (such as antibiotics, antiseptics, antiepileptics, analgesics and anti-inflammatories, β -blockers and lipid regulating agents) will be investigated.

The project is coordinated by the research institute ARMINES (France) and will pull together results of previous and ongoing EU supported projects and published data from both governmental sources and scientific literature. It will look at issues like: relevant pharmaceutical products for the aquatic environment, indicators for supporting environmental managers and health authorities, efficiency of urban and industrial sewage treatment plants, regulatory approaches, prevention actions, use of ecopharmacostewardship approaches, as

well as better communication of methods of good practice.

EPF was invited as one representative of the public and was warmly invited to liaise with patients organisations and input in the project debates, especially in terms of patients compliance with medicines.

For further information, please contact EPF Secretariat or the project co-ordinator, Benoît Roig, Benoit.Roig@ema.fr.

15. *Report on a Workshop on a European Registry on Organs, Cells and Tissues (EUROCET), 7th February, Brussels*

Roxana Radulescu attended a workshop in the European Parliament which presented new database and portal on a European Registry on Organs, Cells and Tissues. This is the outcome of a European project, supported by the e-Ten Programme, which aimed to collect and publish official and updates figures on organs, tissues and cells donation and transplantation activities. The project is coordinated by the Italian National Transplant Centre and brings together 20 partners coming from 15 European Members States.

EUROCET portal is intended to help medical professionals to improve patient care while also bringing about common standards within different regulatory and cultural environments, and being an useful tool for patient organizations and for citizens, providing them with information related to the transplant process.

In the first part of the meeting, the features of the portal were explained, while the second session was dedicated to a debate on organ exchange and patient mobility across Europe and application of 23/2004 EU Directive on tissues and cells and Research on transplantation in the European Union.

For further information: www.euroget.org (under construction at the moment) or contact Paola di Ciaccio - paola.diciaccio@iss.it

16. *Call support for MRI scan campaign*

The European Society of Radiology has started the "Alliance for MRI" in order to campaign against the potentially negative impact of a European directive on the future use of MRI technology.

The [enclosed position](#) will be formally launched at the ESR Congress on 9 March and the society would like to call on other organisations and key opinion leaders to join this alliance.

If your organisation wishes to join this campaign please contact laura.batchelor@fipra.com

17. *EPF Calendar for March-June 2007*

| Date | Event |
|------------------|---|
| 1 March 2007 | <p><i>Workshop on Pharmacies (European Commission, Bureau of European policies Advisers)</i></p> <p>Representative: <i>Nicolas Pradalié, Assistant Policy Officer</i></p> |
| 6 March 2007 | <p><i>Pharmaceutical Forum – Information to Patients Working Group</i></p> <p>Representatives: <i>Susanna Palkonen, Board Member and Nicola Bedlington, Director</i></p> |
| 8 March 2007 | <p><i>Rodney Elgie to attend a Patients Safety High Level Meeting</i></p> <p>Representatives: <i>Rodney Elgie and Roxana Radulescu</i></p> |
| 19-21 March 2007 | <p><i>European Voice Conference</i></p> <p>Representative: <i>Anders Olauson, President</i></p> |
| 20-21 March 2007 | <p><i>EPF Spring Conference “Empowerment, Information, Sustainability”</i></p> |
| 30 March 2007 | <p><i>Meeting in Bulgaria with the umbrella platform</i></p> <p>Representative: <i>Susanna Palkonen, Board Member</i></p> |
| 30 March 2007 | <p><i>Meeting on health services organised by the European Health Management Association</i></p> <p>Representative (Speaker): <i>Nicola Bedlington, Director</i></p> |

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| 30 March 2007 | IAPO Annual Conference Representative: <i>Anders Olauson, President</i> |
| 16-17 April 2007 | European Public Health Alliance (EPHA) Conference on Health and EU Enlargement, Bratislava Representative: <i>Nicola Bedlington, Director</i> |
| 17-19 April 2007 | eHealth Conference 2007, Berlin Representative: <i>Roxana Radulescu, Policy Officer</i> |
| 22 May 2007 | Pharmaceutical Forum Steering Group meeting Representative: <i>Anders Olauson, President</i> |
| 24 May 2007 | Meeting on chemical ingredients of pharmaceuticals and patient safety, Berlin Representative (Speaker): <i>Nicola Bedlington, Director</i> |
| 4 June 2007 | Compliance Conference in Geneva Representative (Speaker): <i>Nicola Bedlington, Director</i> |
| 4-5 June 2007 | AEGSP Annual Conference, Warsaw Representative: <i>Anders Olauson, President</i> |
| 9-10 June 2007 | EPF Annual General Assembly |

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| 18 June 2007 | <i>GIRP meeting</i> Representative (Speaker): <i>Anders Olauson, President</i> |
| 18-19 June 2007 | <i>PGEU meeting, Vienna</i> Representative (Speaker): <i>Nicola Bedlington, Director</i> |
| 21-23 June 2007 | <i>IPI SO Meeting, Romania</i> Representative (Speaker): <i>Anders Olauson, President</i> |