



europeanpatients' forum

www.europeanpatientsforum.org

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Issue 1: 13 July, 2006

Welcome to the new **EPF Internal Mailing** for EPF members and representatives of other networks and NGOs working closely with EPF. It will be sent to you from the EPF secretariat on a monthly basis, and will update you with news, requests for action, and information that may be of interest. The secretariat will only send ad hoc emails to you on matters requiring immediate attention. If you would like to add your own information to the mailing, please forward it to the secretariat and it will be included in the next issue. If you feel other colleagues or networks should also receive this mailing, please inform us. This way of communicating within EPF is a trial, and an attempt by the new secretariat not to overburden you with information and help you to sort out 'action' from 'important documents' from 'good to know reference material'. It would be great to get your comments on ways to improve.

Thanks very much for taking the time to read and take action where needed. Your input as members and close partners is very important to the development of EPF!

We wish you all a very happy summer break!

Warmest greetings

Anders Olason
President

Nicola Bedlington
EPF Director

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Date of the next issue: Thursday, 22 August, 2006

The next issue will include a brief report from a meeting of AESPG in Athens on OTC medicines, and a meeting of GIRP (pharmaceutical wholesalers), in Budapest in June. EPF was represented by its President Anders Olauson at both meetings.

1. EPF new office address and contact details –*INFO*

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2. EPF Annual General Meeting key outcomes and summary notes – *INFO*

The EPF Annual General Meeting met in Brussels on 22 June 2006. Sixteen European member organisations convened to agree the EPF work plan of the next few months including its input in the High Level Pharmaceutical Forum, and longer-term strategic objectives.

The increasing emphasis on including health in all aspects of EU policy, driven also by the Finnish Presidency, was seen as a highly welcome development.

EPF's immediate campaign thrust will be to ensure that this new emphasis on health includes appropriate mechanisms for partnership, consultation and information to patients at all levels. As part of its advocacy work EPF will be analysing and developing policy input and position papers on

- Health Economics and the patients 'agenda
- A patients' voice in mainstreaming health
- A patients' perspective in the health component of the Seventh Framework Programme on Research and Development, and the Structural Funds
- Core funding for umbrella patients groups to be effective consultative partners
- Including vulnerable patients' groups

Members were concerned by recent draconian funding cuts to the new Health Programme and the potential implications of this for patients' driven work. EPF has identified this as a key priority in the coming months.

The meeting also devoted a specific session on transparency and independence, to prepare the ground for EPF's response to the European Commission's Green Paper on Transparency.

On the governance side, Anders Olauson (EURORDIS) was re-elected as President, Jean Georges (Alzheimer Europe) was elected the new Vice President. Mike O'Donovan (European Multiple Sclerosis Platform) was elected as EPF's new Treasurer, Astrid Scharpantgen (EuropaDonna) and Susanna Palkonen (European Federation of Allergy and Airways Diseases Patients' Associations) were welcomed as board members without portfolio.

Rodney Elgie (GAMIAN), Mara Maccarone (European Forum for Psoriasis Associations), Christoph Thalheim (European Multiple Sclerosis Platform) and Colin Webb (European Coalition of Positive People) were thanked warmly by all members for their enormous contribution as board members to EPF since its inception in 2003. The European Coalition for Positive People was also applauded for its major in-kind contribution to EPF to help to set up the secretariat. **Please see attached summary notes of the meeting.** If you have any queries on these do [please contact the secretariat](#).

3. EPF's new board meets -*INFO*

EPF's new board met in Brussels on Tuesday 4th July 2006 together with the secretariat. Key decisions included:

- The development of a new website to be launched just before the Pharmaceutical Forum September 29. The address of the new website will be www.eu-patient.eu and further information on this will be given in the next issue of the mailing
- Roles and responsibilities of new board members and working procedures
- Development of three working groups for EPF
- Dates of meetings until the end of the year. (8 September, 30 September, 1 October, 21 November)

Should you wish to include an item on a future board agenda, please email Anders Olauson, with a short background paper at least week before the meeting.

4. Reminder re EFPIA/ EPF training seminar in November –*ACTION*

Although the secretariat has received some nominations for this event, there remain many members that have not responded. The deadline has now been extended to the end of July. For those who have not sent the names of people they would like to attend from their organisation, we would be pleased if you could do this as soon as possible. For more information on the event please go to the calendar 2006 on www.europeanpatientsforum.org

5. Workshop on Health Democracy -*INFO*

EPF was represented at a workshop on Health Democracy, organised by DG Sanco. The following report is an overview of work in.

Background:

In autumn 2005 DG SANCO launched a project looking at ways to develop the stakeholder involvement and improve the stakeholder engagement.

The goals are:

1. Improve the quality of better regulation and the governance processes.
2. Empower stakeholders and improve the dialogue
3. Address issues of asymmetry of information and its access.

A peer review group has been formed to assist DG SANCO in identifying best practices in consultations and reviewing findings to define standards for stakeholder engagement and empowerment.

The peer review group will meet four times from June – December 2006 to discuss the report on ***Building Stakeholder Involvement in DG SANCO.***

The Issues to be addressed through the Process:

General:

- ❖ Who are DG SANCO stakeholders?
- ❖ How to solve asymmetry of information and means between industry and NGO's.
- ❖ Stakeholder planning and mapping.
- ❖ Timeframes for consultation.
- ❖ Access to information and feedback

Issues related to the functioning of DG SANCO:

- ❖ Stakeholder database needed?
- ❖ Consultation Coordinator?
- ❖ Improve intra SANCO coordination
- ❖ Increased transparency and comitology
- ❖ Creation of common DG SANCO website for all stakeholder consultations.
- ❖ Creation of internal operational guidelines.

Meeting of the 13th June 2006

A wide range of stakeholders from governmental organisations, industry across the board and various NGO's involved in civil society. This introductory meeting focused on the outline of the project, reviewing the Commission Papers on Governance and Minimum Standards for Consultation.

Six work groups considered actions necessary for increased communications and dialogue. The conclusions will be written up for consideration at further meetings.

Future Meetings:

- 7th September 2006 (14 .30 – 17.30)
- 11th October 2006 (14 .30 – 17.30)
- 1st December 2006 (14.30 – 17.30)

6. Report from the Pharmaceutical Forum –*INFO*

A brief reminder on what is the High Level Pharmaceutical Forum?

The starting point for this Forum is the G10 process. The high level Pharmaceutical Forum has been set up by the EU Commission to address concerns expressed by Community Policy Makers that Europe's research based Pharmaceutical industry is losing competitiveness with respect to its main competitors and that Europe is losing its major base as a centre for research and development.

Policy Makers are also concerned in relation to the costs of medicines within differing member states, the equity and access to "safe" medicines for citizens across member states, and the information that should be available to Patients', Health Professionals and the Healthcare Industry that is transparent and informative, thus providing opportunities for an informed citizen with the available choices to safe, appropriate, cost effective and new treatments.

The High level Pharmaceutical Forums Work will be conducted over three years and will rely on strong representation in the four working groups it

has set up to explore and make recommendations on Pricing, Information, Relative Effectiveness, Transparency.

The Pharmaceutical Forum and the individual working groups representation consists of; The Commission, Healthcare professionals, Healthcare Industry, A Pan European Patients' Organisation, Member State representation and "independent" Consultants.

Current state of play

At the last steering group on 3 July, the draft conclusions of the work of the various working groups were presented and discussed. These will form the core of the High level Pharmaceutical Forum meeting on 29th September 2006. These draft conclusions give a very good overview of work in progress and future developments. Please visit www.europeanpatientsforum.org/?lm1=AXIPQNVMFMVB for the latest information.

In relation to EPF's representation in the Forum, please see below:

Anders Olauson - EPF official representative to steering group and pharmaceutical forum meeting in September

Susanna Palkonen - EPF official representative to working group on info to patients. Susanna will be supported and substituted where necessary by

Mike O'Donovan

Christoph Thalheim to continue as EPF official representative to the 'Pricing' working group

Jean Georges - EPF official representative to the 'Relative Effectiveness' working group.

Please do not hesitate to contact any of the representatives above, via the secretariat, should you wish further information or input.

7. Update re. Medical Devices directive –ACTION

Members will recall the request to contribute to EPF's position on the Medicinal Devices Directive. Very few responses were received, however a briefing was submitted to the European Parliament Reporter. Mrs Jäätteenmäki. An exchange of views on her draft opinion took place on 10/11 July and the deadline for amendments is 14 July 2006. The secretariat is monitoring this process and will keep you informed. If however you would like to become more actively involved, please contact Don Marquis who is overseeing this work: dfmarquis@fsmail.net

8. Health Priorities for the Finnish Presidency and German Presidency – a brief overview –*INFO*

The Finnish Presidency health has identified 'health mainstreaming' as a priority during the coming six months - the issue of including health in all areas of EU policy. A specific meeting on this issue will take place in Helsinki on 20 and 21 September to which EPF will be making a written contribution on behalf of its members. A list of other relevant meetings including health ministers' meetings can be found on the official Presidency Website <http://www.government.fi/eu/suomi-ja-eu/2006/en.jsp>

Hill and Knowlton have produced a very useful guide to the Finnish Presidency. Please contact the EPF secretariat if you would like a copy of this electronically.

With regard to the German Presidency, expected legislation in relation to health includes 'Advanced Therapies' (tissue engineering); the review of the Directives on Medical Devices; a decision on the Health Programme 2007 –2013; a Sectoral Directive in the field of health and / or and European Framework for safe and efficient health services; and provisions in relation to health insurance regulations.

Discussions will also focus on OTC health and long-term care, and the health dimensions of the Lisbon process, Sustainable Development Strategy and the European Social Model.

Priorities for the German Federal Ministry of Health include: strengthening the pharmaceutical industry in the EU; HIV/AIDS prevention, health insurances in Europe; and E – health. Work will also take place on an action plan on illegal drugs, and strengthening international cooperation in this regard.

In consultation with its members EPF will be in contact with the German Presidency in the coming weeks with regard to a patients' dimension in relation to the above areas and will report back in future issues of this mailing.

9. Join EPF working groups –*ACTION*

The AGM agreed to set up three working groups to advance our work plan in 2006/ 2007, and this was further discussed by the recent board.

The working groups are as follows:

Conference working group

- To plan a major conference in early spring next year, linked to an internal EPF pre-conference workshop in autumn 2006

Strategic planning working group

- To facilitate a strategic planning and consultation process with the wider membership and to develop a 5 year strategic plan for EPF by the end of 2006

Policy and campaign working group

- To support EPF's policy and campaign role, in accordance with priorities identified in the plan. Particular emphasis in the early autumn will be placed on a campaign on the health budget cuts.

Several members have already volunteered to be a member of the various working groups, and a list will be sent in the next mailing. Should you be interested in being involved in any of these groups, [please contact the secretariat](#).

10. Consultation on transparency–EPF's internal consultation process –*ACTION*

Those present at the AGM afternoon session will remember the discussion on transparency and independence that we hope will feed into the Commission's Green Paper on Transparency.

The starting point for our response is EPF's code of ethics that is posted on the website. Please see www.europeanpatientsforum.org - [transparency section](#).

Other key points will include in the response such as the importance of consultation at the very beginning of an EU initiative, at a 'non paper' stage to input ideas from the perspective of patients and citizens, not purely at a penultimate stage; and reiterating the importance of timing – ensuring sufficient time to enable umbrella organisations to consult their member organisations at national level and their members, and to collate responses.

Should you have any specific points you would wish to include in the EPF response, please forward these to the secretariat. A draft response will then be developed and circulated for consultation with members by the end of July. A final response will be sent, incorporating these comments to the Commission just in advance of the deadline of 31 August 2006.

11. Brief Report from EFPIA meetings in Prague –*INFO*

Nicola Bedlington, EPF director represented EPF at the EFPIA meetings in Prague 28,29 June 2006 where she was a panellist in a workshop on information to patients, and a panellist in conference entitled ' Medicines Research Health and Wealth in Europe'.

Please see attached press release regarding the workshop. More information on the events is also available on the EFPIA website www.efpia.org

During the information to patients' workshop, Nicola stressed that information to patients was of primary concern to EPF and transcends much of the policy and campaign work we, and our members do. She highlighted key aspects of EPF's position paper on information to patients, as a fundamental and legitimate human right. During the 'Health and Wealth Conference she stressed the importance of partnership in achieving health, wealth **and** equity; the role of patients as researchers; the relevance of the knowledge based economy from the perspective of patients; the importance of a sustainable economy, including the economic, environmental and **social** tenets; and the human capital potential of an effective healthcare workforce and, where desirable and possible, enabling patients to remain in work and continue to be active citizens.

Nicola said 'The meeting in Prague was a really timely opportunity to meet key people from government and industry, and colleagues and allies from the European patients' community. Both panels resulted in some interesting ideas on the way forward and EPF will continue to be involved in this dialogue'.

12. Mental Health Green Paper –*INFO*

EPF was represented at a Public Hearing in the European Parliament on the Mental Health Green Paper. For more information please visit John Bowis' website: www.johnbowis.com/health_mentalhealth.htm

13. Calendar -*INFO*

A calendar for autumn will be included in the next issue of the EPF mailing. Should your organisation have events and/or news to announce, please send these to the [EPF secretariat](#).