



europeanpatients' forum

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Issue 5: 30 October, 2006

Dear EPF members and friends,

Thank you very much for all the support and friendship you have shown EPF during the last few weeks as we have been dealing with the emotional and professional implications of Don Marquis' sudden death in October. We truly appreciate it. The Commemoration held for Don on 30 October was an important time for all of us to remember and honour him. And his memory lives on in our continued work on patients' rights.

This issue of the Mailing outlines a number of key recent developments. All three of our working groups have met since the last Mailing, and a brief resume of the outcomes can be found in [section 6](#).

We are very pleased with developments linked to our Spring Conference 2007, and further news is available under [section 2](#)

Two working group meetings of the Pharmaceutical Forum met to which EPF was represented by Jean Georges (Relative Effectiveness) and Christoph Thalheim (Pricing and Reimbursement). EPF has also been working towards preparing the next working group meeting on Information to Patients, to which Susanna Palkonen will participate on EPF's behalf. [Section 2](#) outlines developments in all these areas.

Another major policy issue is of course the European Commission Consultation on Health Services. EPF was represented at a conference on Ghent on this issue, and our strategy to date on this crucial area is outlined under [section 4](#).

A very constructive meeting was held in early November with the European Standing Committee of Doctors (CPME) that bodes well for future cooperation, and the European Federation of Nurses Regulators.

Within the secretariat, interviews took place for the post of EPF policy officer following an equal opportunities recruitment procedure and considerable interest from throughout the European Union. Selection will take place in early December.

Please note that the EPF secretariat staff have new email addresses ([see section 10](#))

And finally a special appeal for you to complete and return the very brief questionnaire on this internal mailing and your organisation's potential specific contribution to EPF's policy work. [See section 3](#). It is only by knowing both our members on-going needs and their expertise will we be able to be as effective as possible as an umbrella body.

Very many thanks and warmest greetings,

Anders Olauson
President

Nicola Bedlington
EPF Director

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There will be no Internal Mailing during December, but rather individual updates on policy developments.

The next issue will be Thursday, 25 January 2007

1. Save the Dates – EPF Spring Conference -INFO



You will know that EPF's Spring Conference will take place on Tuesday 20, Wednesday 21 March 2007. The themes are empowerment of patients, looking to the future, and the sustainability of patient organisations. As readers of the EPF internal mailing you will receive further specific information on this in early December, but please reserve the dates in your diary now.

2. Pharmaceutical Forum - ACTION

Jean Georges represented EPF at the last working group meeting on Relative Effectiveness in October. Please see [notes](#) of this meeting, and a [draft framework report](#). Should you be interested in any further specific feedback please contact Jean Georges.

Christoph Thalheim attended the working group on pricing and reimbursement. He has made a special request that EPF members and allies forward to him, via the EPF secretariat information concerning lack of access to essential drugs in your disease areas, to identify specific EU member states where it is particularly difficult, in terms of availability and/ or affordability. Please do not hesitate to contact Christoph Thalheim directly on this, for more information. The deadline for this input is the end of January in advance of the next working group meeting on pricing and reimbursement.

EPF has submitted our membership list, and contact details for a number of our patient allies regarding a questionnaire on how patient organisations perceive innovation. This will be sent by the Commission in the coming weeks.

The next meeting on information to patients will take place on 7th December 2007. In order to

make an effective input in this meeting, EPF has invited its members and patient group allies to comment on and give input to a draft reference paper on developments within the working group and EPF 's positioning. A final draft will be circulated at the end of November once all feedback has been included in a revised version.

Nicola Bedlington held a preliminary meeting Mr Rui do Santos, who is the commission official responsible for drafting the Commission report on information to patients to be submitted to the European Parliament and European Council by April 2007. This was a useful opportunity to put forward the broad patients' perspective on information to patients, in accordance with EPF's agreed position paper.

A formal consultation on this report is due to take place at the end of 2006/ beginning of 2007 and EPF will be following this process very carefully and informing our members of developments.

3. EPF Questionnaire to members and allies

You will find annexed to this internal mailing a questionnaire to EPF members and allies, regarding the Internal Mailing, and also regarding specific interest, expertise and experience in the key policy areas in which EPF is engaging or is likely to be engaging in the future. We would be extremely grateful if you could respond to this short questionnaire. The deadline for this is 31 December 2007.

4. *The Health Services Consultation - Patient Mobility – Ghent Final Conference - INFO*

On 26th-27th October, EPF was represented by our Assistant Policy Officer, Mr. Nicolas Pradalié. at the Conference on "*Benefits and Challenges of Enhanced Patient Mobility in the European Union*" in Ghent,

150 participants gathered to learn the main results to the research project "Europe4Patients", funded under the European Union's 6th European Research Framework Programme. The objective of the research project was "to provide clearer view and understanding of the phenomenon of cross-border patient mobility in Europe and to support policy-making on this issue at both national and EU level".

(For more information on this final conference: www.europe4patients.org/conference).

Patient Mobility is a marginal phenomenon: it concerns very few people (58,000 people/ year – 1.6% of the contributors – in Austria for instance) and it takes up less than 2.75€ on average per inhabitant per year, however there is no reliable data for a comparison at European level.

The 'Europe 4 Patients' work has identified five main drivers that motivate people to opt for cross-border care: familiarity, availability of care, perceived quality, financial costs and (bio)ethical

legislation, but also stresses that most patients prefer to be cared near home, surrounded by their family.

As Nick FAHY (from DG SANCO) emphasised it, no decision have been taken by the Commission as to the appropriate legal instrument to address Health Services, to which Patient Mobility is related. It will be decided following the consultation on health services in the European Union (31st January 2006; the consultation has started on 26th September).

Attached document: [here](#)

EPF's draft response and explanatory note to the Health Services Consultation will be sent to members for their comments and contribution on 5th December, with request for input by 15 January 2007.

Please consult our former internal mailing ([issue n°4, 26 October – pages 8-9](#)) for more information on health services and on the Commission consultation.

5. Feedback from EFPIA-EPF Training Seminar - INFO

On the 20th and 21st November, EPF organized its 3rd seminar ("*Strengthening Patient Groups in the EU; Exchange of good practice between patient groups*") with the support of EFPIA. The purpose of this seminar was to provide participants with comprehensive information on the EU Institutions, and how to campaign effectively in Brussels, together with good practice examples on EU advocacy in the field of public health. As in previous years, all full members of the European Patients' Forum were invited to select two representatives from their member organisations – ideally some members who had not been involved in previous seminars – to participate in this event. Altogether, the event convened over 60 participants from 19 different countries.

The seminar started with a visit of the European Parliament building and the plenary session hemi-cycle, after a first presentation of how the parliament works and of the decision-making process in the European Union.

One of the crucial aspects of the seminar was the opportunity given to the participants to meet an MEP from their country with a specific interest in health. 19 MEP meetings took place with 14 different countries in a 3 hours schedule on Monday. All delegates highlighted how valuable this opportunity was, to raise patient issues of concern at national and European level.

The MEPs that were unable to receive a delegation expressed an interest in the work of EPF and willingness to support EPF in future initiatives.

On the morning of Tuesday 21st November, the seminar continued with a plenary session during which some members of the three main European institutions (Commission, European Parliament and European Council) explained their role in the definition of European health policy. The afternoon was dedicated to workshops in small groups on media training (how to be a good communicator) and advocacy skills (how to campaign effectively).

Feedback to date indicates that this seminar was very useful for the participants, and EPF is currently reflecting on the best way to organise similar events in future years.

The full report of the seminar will be available on the website in early 2007.

6. EPF Working groups - Feedback

The EPF working group on strategic planning took place on 26 October, and looked at the strategic planning framework and the outcomes of the board team – building meeting in late September. A revised single document will be prepared for the next meeting on December 11th and then circulated to the wider EPF membership.

The EPF working group on policy and campaigns met on 30 October. Key outcomes included the development of an 'open' mailing list to enable EPF members to circulate quickly policy information and developments, the proposal to circulate a questionnaire to members to get a better understanding of their respective policy priorities and interests and their experience and expertise. This is with a view to being able to set up specific clusters of interested members on key policy areas, to contribute to consultation documents for the wider membership. Detailed discussion also took place on strategies around the involvement of patient organisations in projects and policy making and document on this issue will be developed in the near future. It was agreed that the working group's primary task should be campaign rather than policy work, and this will be discussed further by the board in December 2006.

The conference group met on 7th November to agree a draft programme and budget. EPF will be appointing a temporary conference coordinator from January to April 2007 to manage the logistics of the spring conference. Please [contact the secretariat](#) should you know of potential candidates.

7. 2nd Pan Hellenic Congress on Health Management, Economics and Policy - INFO

EPF Board member, Susanna Palkonen participated on behalf of EPF in this major conference in Greece. She spoke in the session of 'The Great Alliance of Health' on 'Patients as Stakeholders in Health-Care Planning'. See attached presentation.

There were around 600 participants at the meeting, mainly from Greece, policy makers, healthcare planners, healthcare workers, patient representatives, industry.

There is a growing alliance of patient groups in Greece and the EPF is now in contact with this alliance to explore possible opportunities for collaboration.

8. Commission Work Programme 2007, Health Policy Strategy - INFO

The European Commission has recently launched its work programme for 2007. You will note that one of the listed priorities is Making Europe a better place to live where it is said that: 'Central to people's well-being is their health, a high quality environment and the services they can rely upon. A White Paper on *health strategy* will set out how the European level can contribute to health and help to shape health policy in Europe to best effect, facing up to the challenges of pandemics, improving food security, promoting health and contributing to future competitiveness.'

The work programme for 2007 can be found [here](#).

The EU health policy forum 22 November 2006 held a workshop on an EU Health Strategy. Please see attached [background paper](#). The workshop focused on 5 key questions, and it is possible for stakeholder to respond to these questions until January 2007.

- How could methods for involving stakeholders be improved? How can we create innovative partnerships with stakeholders?

- What should we realistically aim to achieve in practice? What broad objectives should we

set for the short term and long term – 5 years and 10 years? What criteria should be used to set objectives and determine priorities? Would Healthy Life Years serve as a key criterion?

- How can we ensure that progress is made and that objectives are met? For example, should indicators, benchmarks or milestones be used? What measures or indicators could show real *short term* change, within the early years of the Strategy?

- Are there issues where legislation would be appropriate? What other non-legislative instruments should be used – for example, how can we make better use of Impact Assessment? Would it be useful to have a process like the Open Method of Coordination to monitor progress?

Please send eventual replies to this to Sanco-Future-Health-Strategy@ec.europa.eu

EPF will also be sending a formal response in early January and a draft will be circulated to EPF members in early December for their deliberations.

9. News from EPF members - INFO

Alzheimer Europe

On the occasion of the centenary of Alois Alzheimer's discovery of the disease that was to bear his name, Alzheimer Europe launched the "**Paris Declaration on the political priorities of the Alzheimer Movement**" and a report entitled "**Dementia in Europe**" at a meeting in the European Parliament hosted by Astrid Lulling, MEP (Luxembourg).

The Alzheimer Europe Yearbook "Dementia in Europe" which was also launched at the meeting provides comparative data on the numbers of people with dementia, the reimbursement systems and provision of home care in 31 different European countries.

Astrid Lulling, MEP, commented: *"As European politicians, we welcome these important contributions by Alzheimer Europe. The Yearbook provides much needed information on the numbers of people affected by Alzheimer's disease and other forms of dementia. With the ageing of European populations, these numbers are of course expected to grow substantially over the coming years and we need to make dementia a European public health priority right now".*

Similarly, Jean Georges, Executive Director of Alzheimer Europe stressed: *"100 years of Alzheimer's disease gives us little reason to celebrate. Nevertheless, we are encouraged to see the growing commitment of European and national policy makers to give Alzheimer's disease the priority it so justly deserves. We now expect clear actions on a European and national level. In our Yearbook, we provide essential information on the situation of people with dementia in 31 countries and we hope that national governments will have a close look at this data, compare the situation in their country to others and learn from existing best practices elsewhere to improve the quality of life of people with dementia and their careers."*

Jean Georges concluded by calling on policy makers and concerned individuals to support the Declaration and call for action of the organization on its newly launched website: www.dementia-in-europe.eu.

European Federation of Allergies and Airways Diseases (EFA)

The European Council and Parliament have reached a compromise agreement (unofficial), which is widely supported by the Parliament regarding FP7 and allergic and respiratory diseases are now included as major diseases in the following manner.

- 'respiratory diseases including those induced by allergies'

Allergy continues to be in the food safety priority – and the compromise was that the other allergic diseases would be covered there.

On World COPD Day at 10.00 Scottish MEP Catherine Stihler launched a COPD Declaration at the European Parliament in Brussels calling upon the EU and Member States to pay more attention to this under-recognized and under funded condition. European COPD patients and pneumologists mark World COPD Day and welcome the launch.

See the [joint press release of EFA, European Respiratory Society \(ERS\) and European Lung Foundation \(ELF\)](#).

10. *EPF Website development*

After the testing period, we have launched our new email addresses:



Secretariat: info@eu-patient.eu

Director, Nicola Bedlington: nicola.bedlington@eu-patient.eu

Assistant Policy Officer, Nicolas Pradalié: nicolas.pradalie@eu-patient.eu

Webmaster, Zilvinas Gavenas: webmaster@eu-patient.eu

Notice, if you find broken links, information which is out of date, emails are bouncing back or you have any other troubles on the website, please bother our webmaster. ☺

11. EPF calendar for December 2006 / January 2007

Date	Event
	<i>EFPIA Think Tank</i>
4 December	Representatives: Anders Olauson Nicola Bedlington
	Meeting with IAPO President and Director
4 th December	Representatives: Anders Olauson Nicola Bedlington
5 December	<i>EPF board meeting</i>
6 th December	CHES meeting on health services consultation
	Information to Patients Working Group
7 th December	Representatives: EPF Board Member Susanna Palkonen and EPF Director Nicola Bedlington
11 th December	EPF working group on strategic planning
12 th December	EPF working group on conferences
22 December	EPF secretariat closes.
8 January 2007	EPF secretariat reopens
29 January 2007	EPF board meeting