

Issue 4: 26 October, 2006

Dear EPF members and friends,



As many of you are aware, this month has been overshadowed greatly by the sudden death of our colleague and friend, Don Marquis. A spirited campaigner for patients' rights, Don will be sadly missed... He made a huge contribution to the European Patients' Forum over 18 months of consultancy and development work and was set to move to Africa next year to work on childrens' rights.

The board and the secretariat are determined to continue to build on the foundations laid by Don and others during EPF's beginnings. We know we can count on the support and commitment of you, the members and those of you who work closely with us.

This mailing is, for obvious reasons, briefer than usual as the secretariat is re-organised to cover Don's responsibilities. We ask for your tolerance, and promise that it will be business as usual as soon as possible, just as Don himself would have wished.

For personal messages of condolence to Don's family and friends in the UK, please send these to the secretariat and we will forward them on. A commemoration to honour Don will take place at the EPF offices on 30th October to which you are all very welcome. Please notify the secretariat if you are able to attend.

Warmest greetings,

Anders Olauson
President

Nicola Bedlington
EPF Director

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Date of the next issue: 28 November 2006
 Deadline for input: 23 November 2006

1. Health priorities of the upcoming German Presidency presented at the Health Forum Gastein, 4-7 October 2006 - INFO

At the European Health Forum Gastein, the health attaché of the German Permanent Representation to the EU, Frank Niggemeier, as well as Mr. Schulte and Mr. Kummel of the German Ministry of Health announced the upcoming German Presidency priorities. The German Presidency (January 2007 – June 2007) will be the first one that is part of a “team presidency”. This means that three countries, namely Germany, Portugal and Slovenia (whose Presidencies follow Germany’s), will work together over the 18 months period. This new approach seeks to build in continuity as regards the content of strategies and policies. As such, the team members will work together on various issues and will jointly organise conferences and events.

Attached Document: [Full Report Health priorities of the upcoming German Presidency presented at the Health Forum Gastein, 4-7 October 2006.](#)

Attached Document: [Speech of EPF Director Nicola Bedlington](#)

2. EPF Meetings with Industry Partners - INFO

Over the past few weeks, EPF has held a number of meetings with industry partners to review our work and explore future opportunities for sustainable support and cooperation, based on our transparency and ethical codes of conduct (see the EPF website)

These partners include Baxter, Bristol Meyer Squibb, GSK, Merck, Novartis, Phrma, Pfizer, Schering, UCB,

Meetings have also been held with AEGSP, PhRMA and EFPIA to exchange information and discuss future cooperation on common priorities and how to work as effectively as possible.

For further information on these developments, please [contact Nicola Bedlington](#)

3. EPF Board Meeting – INFO

The EPF board met in Brussels, 30 September, 1 October. A team- building session, led by President Anders Olauson resulted in important reflections on the future direction of EPF that will be fed into the strategic planning working group due to meet at the end of this month.

The Board also agreed a draft budget for 2007 and gave the green light to launch an equal opportunities recruitment procedure to employ a policy officer to support the secretariat from early next year. A detailed discussion also took place on the Pharmaceutical Forum and implications for EPF's workload in the coming months. It was agreed that particular emphasis must be placed on preparations around the next information to patients working group in December with firm proposals on the way forward.

An agreement also took place that EPF would continue to be actively seeking funding from non-pharma sources, including foundations based on work initiated by Don Marquis and this would be a priority in 2007.

For further information, please [contact Nicola Bedlington](#)

4. Review of EU Pharmaceutical Legislation & Information on medicines from pharmaceutical companies to consumers – ACTION/INFO

Anders Olauson (EPF President) presented the position of the European Patients Forum at the meeting of the 29th September with a strong statement on the three pillars ([see attached – Briefing Statement](#)) from the patients' perspective.

Those present: Health Ministers of the 25 member states, the Commission, Industry CEO's responsible for European Operations, Parliament representatives and health care professional leaders also outlined respective positions.

Summary of conclusions: ([Full Document – Briefing Outcomes of High Level Pharmaceutical Forum 29th September 2006](#))

Information to Patients':

This initiative will cover different topics that could help improve electronic and non-electronic information for patients and, in particular, develop a model for a Public Private Partnership that could implement the recommendations in an effective and sustainable way. It will also explore the feasibility of establishing a database of comprehensive and easily accessible information.

Progress:

The Forum's Working Group on Information to Patients was established in January 2006. It has developed the following three work streams to:

- a) Develop a model package of information on diseases (using diabetes as a first example);
- b) Consider areas for more harmonised action on information on medicines at an EU level; and
- c) Improve patient access to good quality health information in healthcare environments (pharmacies and hospitals and ways to enhance access more generally).

Underpinning the work is a questionnaire that has been issued to all participants (Member

States and stakeholders) seeking details of the main mechanisms for distributing information on medicines and related health issues in each Member State.

Pricing and Reimbursement:

To examine alternative pricing and reimbursement mechanisms to support Member States in fulfilling their commitment towards the G10 recommendations, as well as towards the public health objectives of offering an equal access to medicines at an affordable overall cost.

Progress:

Structured within four work streams which allow a more focused approach:

- Control of expenditure, including use of price control and the variety and impact of national cost-containment strategies in line with Member State responsibilities for pricing & reimbursement decisions and ensuring the sustainability of their health systems.
- Access to medicines, for all patients within Europe, including availability and affordability issues.
- Market and trade, including organisation of distribution and cross-border trade of medicines.
- Transparency of pricing and reimbursement data, exchanged between Member States.

Relative Effectiveness:

To support Member States apply relative effectiveness systems in order to allow containment of pharmaceutical costs as well as a fair reward for innovation. Relative Effectiveness systems are relatively new for many Member States and rather complex.

Progress:

Circulation of questionnaires to all participants to get an overview of different relative effectiveness practices in Member States. This served as basis for discussions on definitions and further objectives. This was supplemented by a further questionnaire focusing on the availability and use of different sources for information and data.

The Pharmaceutical Forum requests the Working Groups to report back on the implementation of their work plans prior to the next meeting in 2007.

5. *Briefing Service Directive– Health Framework– Patient Mobility– Consultation*

In the last internal mailing we outlined how Healthcare systems are organised by the member states and how they have become increasingly interconnected in recent years as the EU's internal market rules, which are designed to facilitate the free movement of people, have increased mobility of patients seeking healthcare in countries other than their own. For the briefing with references click [Service Directive and Public and Private Healthcare Exclusion from the Directive – Summary Patient Mobility](#).

The EU has launched a public consultation on the future EU framework for health services, to know where greater legal certainty is needed and how to support co-operation between national health systems.

The Commission has adopted a [Communication for consultation](#) regarding the establishment of an EU framework on healthcare services to ensure cross-border access to safe, high-quality and efficient care. The focus is to provide legal certainty for cross-border patients and help co-operation between member states' health services.

The [Consultation regarding Community action on health services communication](#), adopted on

26 September 2006, launches a public consultation seeking input from member states, the European Parliament, patients, health professionals, healthcare purchasers (social security institutions) and providers, as well as regional and national health authorities. The Commission is asking for comments on nine specific questions to know:

- Where greater legal certainty is required;
- Areas where EU action could support more member state co-operation and the tools to do so, and;
- The impact of cross-border healthcare for both 'sending' and 'receiving' countries.

[Public consultation on the Commission communication is open until 31 January 2007.](#)

The European Patients' Forum will be undertaking its own consultation with members and stakeholders during late October until November 20th 2006.

EPF will also be represented at a meeting entitled – Benefits and Challenges of Enhanced Patient Mobility in the European Union, Ghent, 26 and 27 October 2006.

6. Pharma Questionnaire Response – INFO/ACTION

Nicola Bedlington represented EPF at a meeting hosted by Barston- Marsteller, 10th October 2006, regarding a survey on future priorities for industry engagement undertaken by Patient View on behalf of PhRMA. 40 Pan European patient groups responded to the European questionnaire. 49 German Groups and 53 Italian groups responded to national surveys in their member states.

The purpose of the meeting was to discuss [the results of the research, and implications for patient/ health advocacy in the EU](#).

A constructive debate took place between 10 patient organisation representatives and industry partners on expectations and potential around industry/patient group relationships at both EU and national level.

Summary conclusions of the meeting and follow up will be available from the EPF secretariat shortly.

7. Third Workshop Health Democracy – Building Stakeholder Involvement - INFO

Don Marquis attended the third workshop which produced from work streams power point presentations on stakeholders, comotology, feedback, communication which where presented to R Madalin, DG Sanco.

Full notes can be found on [Briefing Notes Health Democracy](#).

8. *European Health Forum Gastein - INFO*

Nicola Bedlington represented EPF at the European Health Forum Gastein, and presented a paper on Health Democracy.

The meeting was an excellent opportunity to meet with other European patient organisations such as the European Aids Treatment Group, the European Cancer Coalition, and the European Section of the International Diabetes Federation and discuss future cooperation.

Very useful 'state of the art' info and debate took place on current EU policy priorities, in particular a future EU health policy strategy, and patient mobility

Nicola Bedlington also participated in a highly interesting work shop on health literacy entitled 'navigating health care, and seminar on long term conditions led by the European Men's Health Forum

For more information on this year's European Health Forum Gastein, please visit www.ehfg.org

9. *Important information from EMEA, the European Medicines' Agency*

At the last meeting of EMEA's Patients' and Consumers' Organisation Working Group (POWG) to which EPF participated, it was highlighted that EMEA would welcome new applications from organizations' wishing to participate in POWG activities.

If your organization is interested in becoming involved, please [click here](#) to EMEA website, where you will find more information on how to participate and criteria for membership.

10. EPF calendar for October/November/December 2006

Date	Event
26 October	<i>EPF Strategic Planning Working Group</i>
30 October	<i>EPF working group on policy</i>
1 November	<i>Health Democracy Stakeholder Meeting</i>
7 November	<i>EPF working group on conference</i>
7, 8 November	<i>Pharmaceutical Forum - Pricing and Reimbursement Working Group</i> Representative: Christoph Thalheim
9 November	<i>Patient Safety Working Group</i> Representative: Rodney Elgie
20, 21 November	<i>EPF EFPIA training seminar</i> This meeting involves several members of the EPF board and members <i>Health Policy Forum</i>
22 November	Representatives: Anders Olauson Nicola Bedlington <i>EFPIA Think Tank</i>
4 December	Representatives: Anders Olauson Nicola Bedlington
5 December	<i>EPF board meeting</i>

