



Europeanpatients' forum

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Issue 3: 26 September, 2006

Dear EPF members and friends,

'Information to patients' has, quite rightly, dominated the EPF agenda in the last month, with meetings in the European Parliament (see section ---and a 'Friends of Europe' Debate on 20th September(see section----) .This is timely, on the eve of the Ministerial Pharmaceutical Forum on 29th September 2006, where EPF will be making a very clear statement on our position on how to move forward on 'information to patients'.

29th September also mark the launch of our brand new website. Please visit the site on www.eu-patient.eu and let us have your views and comments.

EPF is committed strongly to partnership with other NGOs and patient groups and during September, had the opportunity to meet with a number of number key players to discuss areas of cooperation and mutual support: We met the European Public Health Alliance, the International Diabetes Federation European Region, the European Heart Network, and the European Cancer Coalition. We are looking forward to working with these organisations in the future on common goals, and in the first instance, on EU health funding as a key area of concern to all of us.

The EPF board met on 8th September, and a number of key decisions were taken, particularly regarding finance and fundraising (see section...)

Within EPF, our three working groups: (A) Spring Conference preparation, (B) strategic planning and policy (C) campaigns. All met during September and the outcomes are included in this mailing.

Thank you for your feedback on action points and indeed, any articles, news or calendar dates that you would like to contribute to future issues.

Warmest greetings,

Anders Olason
President

Nicola Bedlington
EPF Director

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Date of the next issue: 24 October 2006
Deadline for input: 20 October 2006.

1. EPF strategic planning process - ACTION

The EPF strategic planning working group met on 7th September to agree terms of reference and develop a preliminary draft on EPF's vision, mission, Strategic goals and agree a consultation process with the EPF membership regarding the development of the plan.

The EPF membership has been invited to comment on this in advance of our next meeting at the end of October, when we will develop our work on core principles, the external environment, specific policy and programmatic priorities, timelines, resource implications.

For a copy of the preliminary draft, please contact the secretariat.

2. Date for the European Patients' Forum Spring Conference March 20, 21 March 2007 – INFO

A further working group meeting for the EPF Spring Conference took place on 21 September to advance the planning. A draft programme was discussed and the focus will be on the pre-requisites to empower patient organisations at all levels and the contribution that patient organisations themselves make to information to patients.

EPF will be recruiting a part time conference coordinator in January to manage this work.

3. EPF policy working group

The EPF policy working group held a teleconference on 6th September to agree the terms of reference and short term work priorities.

It was agreed that the focus will be addressing the EU health funding situation along with the importance of involving patient organisations in all EU health related projects.

Many thanks to those who responded with examples of good practice regarding involvement of patient organisations in EU health related projects. (We would welcome more to include in our background paper and position statement on this issue).

On the issue of involvement of patient groups in health related structural funded projects, EPF will be meeting relevant Commission officials in the coming weeks in relation to the National Framework Documents being submitted by the end of the year to the Commission by member states.

4. *EPF Board Meeting - INFO*

The EPF board meeting met on 8th September 2006.

1. A revised budget for 2006 was agreed,
2. An expenses and reimbursement policy discussed.
3. It was agreed to employ a stagaire in the secretariat from October onwards.
4. The board also reviewed developments within the EPF working groups.
5. A draft discussion document on formalising cooperation between IAPO and EPF was agreed and this has now been sent to IAPO to advance further discussions.

For a copy of the board minutes, please contact secretariat.

5. *EU consultation on drugs policy - ACTION*

Green Paper on the role of Civil Society in Drugs Policy in the European Union Action

The European Commission launched a wide consultation, by means of a Green Paper, to explore how best to organise a continuous dialogue with civil society organisations **active in the drugs field** to ensure their knowledge and expertise is taken account in the EU policy-making process, in particular the implementation of the [EU Action Plan on Drugs 2005-2008](#).

EPF has responded to meet the 30th September 2006 deadline.

The European Patients' Forum Full response can be viewed in the final [briefing paper](#).

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

In the last issue [Briefing info patients](#) outlining the background of the above subject was given. Major emphasis was given to the work of the three pillars: (1) Patient information, (2) Pricing and Reimbursement and (3) Relative Effectiveness of treatments and medicines.

In preparation for representation at the high level Pharmaceutical Forum on the 29th September a position paper on the three areas is being prepared [Briefing info patients 2/3](#).

Anders will present the position of the European Patients Forum at this meeting, with a strong statement on information to patients.

Those present, Health Ministers of the 25 member states, the Commission, Industry CEO's responsible for European Operations, EU Parliament

representatives and health care professional leaders will also outline respective positions.

7. *"Health Confidentiality and the Patient" – Interview Slovenian TV 7TH September 2006*

Don Marquis was interviewed by Tanja Fajon Correspondent for RTS following a case in Slovenia where government officials are allowed to review patient records without the consent of Patients' and/or health professionals. The interview was to find out what the European Patients' Forums views were on the subject.

The full briefing notes on confidentiality and the interview are available on [Briefing Patient Confidentiality](#) and [Slovenian TV](#).

8. *Briefing Service Directive – Health Framework – Patient Mobility*

The proposed Services Directive would guarantee service providers more legal certainty if they want to exercise two fundamental freedoms (freedom of establishment and freedom to provide services) enshrined in the EC Treaty.

Public and private healthcare were excluded from the services directive, the Commission has decided to set up a specific EU health services framework to guarantee cross-border access to health care.

Healthcare systems are organised by the member states but 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](#)

9. *Funding initiatives Baxter Healthcare Foundation*

As part of the European Patients' Forum [Business Plan 2005 - 2008](#) and Policy on diversity of funding streams an application has been made to the above Foundation and was submitted on the 12th September 2006, to review the document [Baxter Foundation 3](#)

A further two applications to different Foundations will be submitted between now and the end of November to enable capacity development and inclusive projects in 2007 -2008.

Further updates will be provided as work in progress in future editions.

10. Draft Code of Conduct and Ethics Review 2006

In recent months, we have witnessed a dramatic increase of the importance in the need for greater transparency of governmental and non governmental organisations in order to impact ethically on policies and advance initiatives that once were exclusive to governments and for-profit organisations. The European Patients Forum is committed to ensuring that its Conduct and that of the Board adhere to the highest standards of probity and due diligence with transparency in its decisions and overall operations.

The European Patients' Forum is in the process of reviewing its governance structures set in 2005 in the light of the transparency green paper.

The Briefing, [\(past newsletter\)](#) response to the Commission and the Draft Code of Conduct can be viewed and commented on [Written Response to The Green Paper on Transparency published on 3rd May 2006](#). (Includes draft code of conduct 2006)

11. Interview on Pharma Futures with Anders Olauson

On the 14th September Anders Olauson was interviewed by Sophia Tickell of Sustainability concerning the future of the Pharmaceutical Industry from a Patients' perspective.

"From a Patients' Perspective, the key components must be that we have trust and confidence not only in the products, but in all systems that are employed in their manufacture, distribution, compliance, safety and the ongoing monitoring of their effectiveness as part of the treatment for people with chronic diseases."

As one of the most massive and successful business sectors, the pharmaceutical industry has and is a potent force for good in the community, yet its behaviour is frequently questioned: could it serve society at large better than it has done in the recent past? Its own internal ethics, both in business and science, may need a careful reappraisal, as may the extent to which the law - administrative, civil and criminal - succeeds in guiding (and where necessary containing) it. The full briefing and response can be obtained here. [EPF pharma futures briefing AO](#)

12. *Pharma Questionnaire Response*

Most of you will be aware that a questionnaire has been forwarded to Patient organisations regarding their activities, income sources and various relationships and activities undertaken by the organisation.

EPF's response can be viewed on [Pharma questionnaire 2](#). The work is being carried out by Patients' View with the results being disseminated on the 10th and 11th of October 2006 to various audiences. The aim of the exercise is to evaluate and assess the organisations advocacy capacity and its "relative effectiveness" in terms of quality of outcome and value for money invested.

Nicola Bedlington and Don have been invited to a specific meeting to discuss the outcomes of the survey on 10th October 2006 in Brussels. A further report will be included in the next issue of internal mailing.

13. *Access to Health Association of Turkey*

The European Patients' Forum had six guests from this newly formed organisation which is pledged to setting up a patient advocacy platform. The aims of the organisation are to improve the health of patients and caregivers in terms of awareness and to activate patients and caregivers' participation in Turkish Healthcare policy making.

EPF welcomes this initiative and will provide support in whatever aspect it can to help develop this young and unique organisation in Turkey further. The presentation that was given can be found [EPF presentation AHA](#)

14. *Second Workshop Health Democracy*

Don Marquis attended the second workshop which produced from work streams power point presentations on stakeholders, inequalities, feedback, communication which were presented to R Madalin, DG Sanco. Full notes can be found on [Briefing Notes Health Democracy](#)

15. *European High Level Forum on Pharmaceuticals – European Parliament Life Science Circle 12th September*

EPF were invited as stakeholders along with commissioners, advertisers, professional organisations, consumer groups, pharmaceutical groups and other EU institutions. Don Marquis represented EPF at this first meeting

The European Life Science circle will meet at least four times a year, key note speakers will outline themes for each meeting with discussions

being moderated by a European Parliamentarian, Dr Jorgo Chatzimarkakis who is a member of the Pharmaceutical Forum.

The invited audience will have the opportunity of taking part in discussions concerning aspects of the challenges facing health systems in Europe.

“The intention of this grouping is to be the political motor behind healthcare reforms in Europe”. It is also intended to focus on improvements of patients’ with particular interest on patients’ rights to information and being given opportunities to exercise valued choices concerning their health and lifestyle.

It is envisaged that the “Life Science Sector” will be an important economic factor with critical importance in guaranteeing more growth and competitiveness in Europe, by bringing about more investment in research and innovation to become the premier Bio-Zone in the world.
[Full Briefing European life sciences](#)

16. Conference under the EU Finnish Presidency Nanotechnology, Helsinki, Finland

EPF was represented by Susanna Palkonnen at this important conference, the purpose of the conference was a meeting of minds on the issues facing this dramatic new technology that has the potential of benefiting patients and society as a whole. However it is important to ensure the health safeguards are in place to protect individual citizens and the environment as this technology is developed.

What is Nanotechnology?

Nanotechnology, which has been called "the manufacturing technology of the 21st century," refers to the study and design of systems at the scale of the atom (size from 0.1-10 micro- metres) or the nanoscale. At the most basic level, the manufacturing is actually the rearranging of individual molecules and atoms into complex "molecular machines."

A full briefing, press release and report are available at [Nanotechnology Briefing, press release, report](#)

17. Patient safety

A meeting of the Patient Safety working Group of the High Level Group on Health Services and Medical Care set out to agree.

- 1 The report to the high level group
- 2 Patient Safety Frameworks
- 3 Set Up Network
- 4 Drafting recommendations

All member states present agreed on the way forward with minor amendments to documentation to support funding. For the full context of the meeting notes and minutes can be found on [Patient Safety](#)

EPF was represented by Rodney Elgie at this meeting.
The next meeting will take place on 9th November

18. Friends of Europe's Café Crossfire lunch debate "EU policymakers' options on patient information" in Brussels.

"High quality reliable, validated, timely and accessible information for patients from a multiple range of sources is a fundamental human right.'
Nicola Bedlington debated the right for better validated information from a range of sources to patients with a panel of high-profile speakers.

The emphasis of the European Patients' Forum was that this information needed to be from validated source including stakeholders at a European Level so patients can be well informed, educated, knowing the information was trusted and that it would help lead to them making informed choices in the management of their care. [Programme](#) and [Nicola's brief introduction](#)

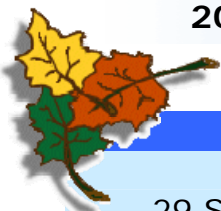
Also, used as part of the discussions was a report entitled [Information For Patients – The EU's Policy Options September 2006](#) by [David Watkiss](#) there are many quotes on EPF policy and approach following interviews with Don Marquis in March 2006.

19. EFPIA – EPF Think Tank.

The Think Tank was well attended with approximately 30 people attending. Presentations and discussions included Structural Funds and health, updates of the Pharmaceutical Forum, The decision by parliament on the 14th September not to approve the Directive on Advanced Therapies, the Eurodis Position Paper supporting Stem Cell research, a briefing on the pan European Innovative Medicines Initiative to support

the faster discovery and development of medicines through a Public Private Partnership arrangement.

20. EPF calendar for September/November 2006



Date	Event
29 September	High level Pharmaceutical Forum meeting Attendant: President Anders Olauson.
4-7 October	"European Health Forum Gastein" Salzburg, Austria. Exchanging of experience and networking Attendant: Nicola Bedlington
10 October	Pharma Questionnaire feedback session. Attendant: Nicola Bedlington
10 October	Roundtable on "Health Tourism in Europe" with Commissioner Markos Kyprianou & Dr. J. Chatzimarkakis MEP <i>What is 'health tourism' and how is it encompassed in European policies? What developments do European policy makers see in European health tourism services? Can Europe compete at a global level as an attractive health tourism destination?</i> Attendant: Don Marquis
18-19 October	Conference " New legislation – the right impact? " <i>The conference will look at how the legislator's original objectives compare with reality on the ground. This will facilitate the debate on areas where further guidance might be appropriate. It will also be the basis for developing concrete steps towards "better regulation" for non-prescription medicines in Europe.</i> Attendant: Member of EPF board
30 October	EPF working group on policy
7 November	EPF working group on conference
20, 21 November	And EPF EFPIA training seminar
5 December	And the board meeting

