



europeanpatients' forum

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**Dear EPF members and friends,**

Welcome to the first issue of the EPF Mailing for 2008. Key features include a report on the European Patients' Education meeting in Barcelona on 14 -15 January that we co-organised with the Spanish Patients' Forum ([see section 5](#)), our on – going work on information to patients ([see section 2](#)), the current state of play regarding the Health Services Directive ([see section 3](#)) and our response to the European Commission's consultation on pharmacovigilance ([see section 4](#)).

We are delighted to welcome our new colleague [Liuska Sanna](#) who joined the EPF secretariat team on 18th January as EPF Programme Officer. Liuska will be responsible for coordinating the VALUE + project and leading other projects that EPF is involved, or will become involved in. The VALUE + partners will hold their first meeting on 20, 21 February ([see section 15](#)).

Work is also well underway to organise EPF's Annual General Meeting 2008 that will take place just prior to our Spring Conference on Health Literacy in Brussels on 8 April. We are looking forward to a number of patient organisation observers also attending this meeting. The EPF board will meet on 6 February to prepare the AGM and agree our Annual Report and Accounts for 2007. The work-plan and budget 2008 was agreed shortly before Christmas.

A major highlight fast approaching for the patients' movement is the European Cancer Patient Summit held under the Slovenian Presidency in early February. EPF is delighted to participate in this meeting and support the excellent work of the European Cancer Coalition. It is perhaps a little late to wish you a happy new year – as by now we are all well into the challenges and opportunities of 2008 – however we do wish to share our warmest greetings for a successful and rewarding year ahead.

**Warmest greetings,**

Anders Olauson, President

Nicola Bedlington, Director

**EU Policy Update**

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The next issue of the Internal Mailing will take place in Mid-March 2008. The deadline for contributions is 4th of March. Special Feature: Patients' Rights Day 18 April 2008

## 1. DG SANCO – FUTURE CHALLENGES

EPF gave a preliminary response to the document presented by the European Commission that identifies future challenges 2009 – 2014 for DG SANCO. [This was in the form of a letter from EPF President to Robert Madelin just before Christmas.](#)

The Commission will convene a meeting in the course of 2008 with a view to taking forward the 'Future Challenges' document.

EPF will be organising a board retreat in May where we will be exploring "Future challenges" from the perspective of patients' organisations in the light of the new Commission and European Parliament in 2009.

## 2. INFORMATION TO PATIENTS

On 20 December 2007, the European Commission adopted a Communication to the European Parliament and Council on current practices with regard to the provision of information to patients on medicinal products. ([http://ec.europa.eu/enterprise/pharmaceuticals/pharmacos/docs/doc2007/2007\\_12/inf\\_to\\_patients\\_com\\_2007\\_862\\_en.pdf](http://ec.europa.eu/enterprise/pharmaceuticals/pharmacos/docs/doc2007/2007_12/inf_to_patients_com_2007_862_en.pdf) )

This Communication is supported by a Commission Staff Working Document ([http://ec.europa.eu/enterprise/pharmaceuticals/pharmacos/docs/doc2007/2007\\_12/comm\\_native\\_sec\\_2007\\_1740\\_1\\_en\\_documentdetavail.pdf](http://ec.europa.eu/enterprise/pharmaceuticals/pharmacos/docs/doc2007/2007_12/comm_native_sec_2007_1740_1_en_documentdetavail.pdf)

The report highlights that the Commission intends to propose to the European Parliament and the Council amendments to the current rules on the provision of information to patients by the end of 2008. This proposal will put the interests of patients first and with this perspective should aim at reducing differences in access to information and should ensure the availability of good-quality, objective, reliable and non promotional information on medicinal products. The following main policy objectives will be pursued by this legal proposal:

- (1) Establishing a framework which provides citizens of EU Member States with understandable, objective, high-quality and non-promotional information about the benefits and the risks of their medicines, and which maintains the confidence of citizens, regulators and healthcare professionals.
- (2) Maintaining the ban on direct-to-consumer advertising of prescription medicines, making sure that there is a clear distinction between advertising and non-promotional information.
- (3) Avoiding unnecessary bureaucracy, in line with the principles of Better Regulation.

In accordance with Better Regulation practices the proposal will be substantiated by an impact assessment of the different policy options. In this regard, EPF was interviewed on 22 January 2008, and an impact assessment questionnaire will be sent to all EPF members in the near future.

Within the Working Group on Information to Patients, EPF has prepared a draft document on the key elements to be included in any information package on information to patients; and has also been invited to draft a strategy document looking to the future, in relation to future actions needed alongside legislation. The next meeting of the working group will take place on 1 February 2008.

Linked to this EPF has also been working closely with other health NGOs with regard to taking forward the [Joint Statement on information to patients](#). A further meeting on the implementation of the concrete proposals within the Joint Statement, convened by the European Public Health Alliance, will take place on 26 February.

Regarding the other Pharmaceutical Forum Working Groups on Pricing and Reimbursement and Relative Effectiveness – further meetings will take place in February and will be reported in the next issue of the Internal Mailing.

### 3. EUROPEAN COMMISSION DIRECTIVE ON CROSS-BORDER HEALTHCARE

The draft Directive ensuring the protection of basic rights for patients travelling to other EU Member States in receiving medical treatment was due to be launched by the Commission on 19 December 2007. This was unfortunately delayed for political reasons.

It was widely reported in EU press however that Commission president José Manuel Barroso is said to have feared political disagreements during the very sensitive period of ratifying the Lisbon Treat, and thus running the risk of jeopardising the EU's institutional reform (as was the case with the Bolkenstein Directive followed by the negative referendum on the EU Constitution from France and Netherlands).

There has been also an internal disagreement within the Commission, with several Commissioners' cabinets expressing reservations about the proposal, as well as heavy criticism from some MEPs. Some felt that the Commission proposal did not have enough support from the two other institutions, the European Parliament and the Council to be adopted and called for more thought and reflection to be put into the proposal, in particular the reimbursement system and its consequences.

Socialist MEPs argued that the Commission should reconsider the proposal, warning that the directive in its current form would create political chaos in some Member States and that such an important decision should be taken a day before the Christmas break.

Several Member States representatives expressed fears that the directive would endanger their national health insurance systems and their budgets. The Slovenian Presidency of the EU stated that, although the process was delayed, it is not possible to ignore the subject, even if a consensus between Member States looks difficult to find.

Healthcare employers and workers argued that while healthcare should be organised on the basis of European social values including solidarity, social justice and social cohesion, it was not for the European

institutions to impose market rules and/or competition mechanisms on the health care sector, which could lower standards and increase costs of healthcare systems and thus diminish accessibility to care.

Social NGOs denounced the lack of solidarity approach taken and expressed concern that only a small group of well-off citizens would be able to take advantage of such a system, while putting under stress the healthcare systems in both, the patient's home country as well as the host country.

EPF calls for an EU action that will provide greater clarity on access to healthcare across Europe and will strengthen patient's rights. The EU legislative framework should move towards the highest common denominator for high-quality and accessible health care services for patients – **all** patients- throughout the European Union. We will be discussing the way forward – from a patient's perspective- with all the players mentioned above and this will be reported in future mailings.

#### 4. EUROPEAN COMMISSION CONSULTATION ON PHARMACOVIGILANCE

EPF welcomed [the public consultation](#) on legislative proposal “to strengthen and rationalise the EU system of pharmacovigilance” launched by the European Commission.

EPF [submitted its response to the European Commission](#) and underlined the importance of building EU policy on pharmacovigilance from a patients’ rights perspective. We highlighted three key points:

- The importance of patients’ involvement in pharmacovigilance processes and reporting of adverse drug events
- Equity and access to safe medicines concerns: the need for binding provisions and post-authorisation surveillance structured from a patient’s perspective
- The fundamental link between the debate on information to patients and pharmacovigilance.

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



## 5. EUROPEAN PATIENT EDUCATION AND HEALTH LITERACY CONFERENCE, 14-15 January, Barcelona

The conference was organised by Josep Laporte Foundation and the Spanish Patients' Forum ([EPF member](#)), with the support of Stanford Patient Education Research Centre, Harvard and EPF.

The Conference provided an excellent opportunity to revisit the background and understanding of the concept of health literacy. Several examples of programmes and initiatives of patient education in Spain, Catalonia, UK, Sweden as well as the Stanford patient self management courses were presented. They showed how patient education contributes to the improvement of the quality of health systems and the promotion of a modern health care. A clinician perspective - from the Bellvitge hospital in Barcelona - and a policy making perspective - from the Department of Public Health of Catalonia - were also given. Roxana Radulescu gave a presentation about EPF and the advocacy work that EPF has been carrying out on information to patients.

While acknowledging the need to improve patients' and citizens' skills and competences in health, participants also stressed the need to increase health professionals' communication skills. It was generally agreed that this would contribute towards reducing the burden on the health care systems. From this perspective, patients' organizations, adequately supported, have a key bridging role to play between health administrators, health professionals and patients and families.

Related link: [www.fbjoseplaporte.org/epec](http://www.fbjoseplaporte.org/epec)

## 6. EUROPA BIO PATIENTS ADVISORY GROUP, 9 January

Nicola Bedlington attended this preliminary meeting to explore the potential role and added value of the Patient Advisory Group, and working procedures. The meeting gave an introduction to Biotech at EU level, the EuropaBio Health Care Council, and their healthcare manifesto and patients' charter. It is envisaged that the Patient Advisory Group will take place twice a year.

## 7. MEETING OF THE INTEREST GROUP ON CARERS IN THE EUROPEAN PARLIAMENT, 9 January

The meeting of the Interest Group on Carers took place on Wednesday 9 January in the European Parliament. It was hosted by MEP Kathy Sinnott and brought together several MEPs, the Director general of DG SANCO, representatives of various health related organizations. The issue of the special importance of carers was addressed, especially in relation to the new Commission White Paper: “Together for health – a strategic approach to EU”. Speakers highlighted that in the context of demographic change, aging population and challenges to health and social care services across Europe, the role of carers is more crucial than ever. It was stressed that carers are themselves at risk for their physical and mental health and also under increasing pressure to combine caring and paid work. The debate looked mainly at issues like: the need for measuring the economic value of carers; establishing partnership between health professionals, carers and patients; the need for training courses for carers and the importance of mainstreaming the carers’ perspectives in other policies.

EPF looks forward to cooperating with EUROCARERS a new organisation set up specifically to advance the interests of carers. For further information contact [EPF Secretariat](#).

## 8. JOINT PRINCIPLES BETWEEN EPF AND THE STANDING COMMITTEE OF DOCTORS

CPME and EPF convened a further meeting on 6 December to draft a “joint principles” document which will be submitted for approval by our respective boards and Annual General Meeting in 2008. EPF was represented by board member Albert Jovell and Nicola Bedlington. A working group will then develop the terms of reference for a specific joint project to be launched in 2008.

## 9. PATIENT INVOLVEMENT AND EMPOWERMENT CONFERENCE, UK

### MAKING AN IMPACT ON SERVICE IMPROVEMENT AND CLINICAL PRACTICE

Patient involvement was the core subject during the whole day conference held in Manchester, UK on January 24th. EPF had the privilege to chair the meeting. Once again the UK demonstrated a very strong ambition to put the patient in a central role in managing their health.

The day started by two powerful speakers using their own life stories to show the importance of having the patient him/her-self in centre. After that different ways forward were presented, where the projects "LINK's" and '18 weeks' were described.

The remainder of the day was devoted to the mental health implications of chronic disease or illness, and again it was reiterated that the individual patients who have experience and expertise themselves have to be part of the process otherwise one important perspective will always be missing. The conference ended on a positive note that patients involvement is for sure here to stay in UK, and we all look forward to seeing similar developments in other EU-member states.

For more info contact the secretariat or [Anders Olauson](#).

## 10. PHARMACEUTICAL PARLIAMENT: THE POWER OVER PHARMACEUTICAL INFORMATION – WHO SHOULD BE IN CONTROL?

On January 22nd the second “Pharmaceutical Parliament” was held in Stockholm. The conference convened more than 500 people representing the whole area of health in Sweden to discuss ‘Information to Patients’ as “top of the agenda” in all EU Member States.

EPFs president Anders Olauson was invited to give the patient perspective from both EU level and the Swedish level. Anders presented EPF’s position on Information to Patients and our work on the Pharmaceutical Forum ITP working group.

The day started with presentations by the four general directors (who also are also the founders of the Pharmaceutical Parliament) for The National Board of Health and Welfare, the Pharmaceutical Benefits Board, The Swedish Council on Technology Assessment in Health Care and the Medical Products Agency). They gave their views and their responsibility on information to patients.

The current status of the deregulation of the monopoly that Apotekbolaget (Pharmacia company) was also presented. Finally, the Minister of Health Mr. Göran Hägglund took the floor and presented the Swedish governments perspective in health and the right to information for patients.

For more info contact either [Nicola Bedlington or Anders Olauson](#).

## 11. PREPARATIONS FOR EPF AGM, 8 APRIL 2008

Preparations are underway for the EPF Annual General Meeting (AGM) that will take place on **8th April**. The EPF Annual Report and Audited Accounts for 2007 will be presented. There will be elections for 4 new members of the board, a presentation on our Child and Adolescent Patient project, and the adoption of joint principles between EPF and CPME.

## 12. EPF SPRING CONFERENCE, 8-9 APRIL 2008

A major focus for the secretariat is this year's annual spring conference, the theme of which is Health Literacy. Given its inclusion in the Health Strategy, we feel this is a hugely relevant topic and are looking forward to an exciting and informative meeting, bringing together EPF members, representatives from patient organisations across the EU and stakeholders from all areas of the health care arena. We hope that the recommendations from this conference will help to embed health literacy as a policy and programmatic priority in all EU member states. The EPF President will present the outcomes of the Conference to the Slovenian Health Minister in advance of the next Health Council in May.

There has already been significant interest in the event and registrations and enquiries are continuing. The second invitation mailing will be circulated this week, including a preliminary programme and invitations and enquiries are invited to our Conference Coordinator, Amanda Casey, at [conference2008@eu-patient.eu](mailto:conference2008@eu-patient.eu)

This year's event will also give patient organizations an opportunity to share their work and projects on health literacy with colleagues during a poster session.



### 13. EVALUATION SUMMARY OF EPF ADVOCACY SEMINAR, 26-28 NOVEMBER 2007, BRUSSELS

Many thanks to those delegates who completed and returned evaluation forms from the November Seminar. As ever, they have proved very useful to us in planning future events to best suits your needs and address issues of importance to all of our members. The feedback from the seminar was very positive and contained very helpful information regarding the structure and content of future events.

A full summary of the evaluation report will be available on the EPF website in the coming weeks.

EPF plans to hold our next major advocacy seminar in one of the new EU Member States, again in November.

Further news on this in our next mailing.

## 14. NEW PROGRAMME OFFICER



We are happy to announce that the recruitment process for the Programme Officer is completed and we welcome in EPF Secretariat Liuska Sanna. Liuska – of Italian origins – has a BA in Philology (English, French and Russian languages and literatures) and a MA in management of non-profit organizations.

Her work experience has matured very much in NGOs; after an internship at the European Women's Lobby (gender issues) she worked for more than six years with the European Network of the International Planned Parenthood Federation in the field of sexual and reproductive health. Here she developed her experience in project and programme coordination - in particular managing multi-partner regional projects; project development; monitoring and evaluation; capacity building and provision of technical assistance.

Her main tasks at EPF will focus on the management of the Value + project as well as of the Respect and Calliope projects. We are confident that her expertise will strengthen our team. We wish her much success and fulfilment in her work in EPF.

For further information, please contact [Liuska Sanna](#).

## 15. STARTING A NEW EU SUPPORTED PROJECT: VALUE+

As anticipated in the December issue, we have launched the VALUE+ project promoting patients' involvement in EU supported health-related projects. Now that the Programme Officer is in place and the contract is up for signature, the start-up work is under way. Here follows a brief overview of the project. The basic premise of VALUE+ is that patients' meaningful involvement enhances health project results which can contribute more effectively to policy towards patient-centred, equitable healthcare throughout the EU. Current EU health policy reflects this premise, but a concerted strategy is needed to achieve patient involvement in reality.

The objective of the VALUE+ project is thus to exchange information, experiences and good practices among key stakeholders in relation to the meaningful involvement of patients' organisations in EU supported health projects at EU and national level.

Coordinated by EPF, the key patients' interlocutor at EU level, in partnership with 7 associate partners with expertise in patients' advocacy, and health related awareness- raising, research and policy, the VALUE+ project will achieve, for the first time:

- A comprehensive evidence-based overview of current practice and trends regarding patient involvement in EU health projects and expansive database of organisations and institutions involved
- An extensive analysis and reflection regarding critical success factors, challenges and hurdles regarding patient involvement
- The identification of showcase examples of patient involvement to inspire and motivate key players at policy, programme and policy level
- The nurturing of selected EU projects running concurrently with VALUE+ to demonstrate how involvement of patients can be achieved in practice.
- The development of very specific targeted resources including:

- VALUE + policy recommendations for policy makers,
  - VALUE + Handbook for project leaders and promoters,
  - VALUE + Resource Kit for patient organisations themselves to facilitate patient involvement in future projects.
- A flagship Conference under the Swedish EU Presidency in 2009, to re-affirm political commitment and review these resources.

**Associated partners:** EPF, Empirica Research Institute (Germany), European, Network of (Ex-) Users And Survivors Of Psychiatry, European Men's Health Forum, European Institute of Womens' Health, Spanish Patients' Forum, Health Policy Center of Lithuania, Confederation "Health Protection Bulgaria"

**Collaborating partners:** European Multiple Sclerosis Platform (EMSP), European Federation of Allergy and Airways Diseases Patients' Associations (EFA), Retina Europe, Agrenska Foundation, Mental Health Europe

### **Work Packages (WP)**

**WP 1:** Coordination of the Project

**WP 2:** Dissemination of the project results

**WP 3:** Evaluation of the Project

**WP 4:** Make an overview of patients' involvement in EU health-related project; analyse the information gathered and identify showcase examples demonstrating the added value of patients' involvement

**WP 5:** Encourage and accompany patients' organisations involvement in ongoing health related projects

**WP 6:** Conference on patients' involvement under the auspices of the Swedish Presidency

Deliverables: VALUE+ Database, VALUE+ Handbook, VALUE+ Resource Kit, VALUE + Conference – Sweden, Two information dissemination meetings (Lithuania and Bulgaria), 6-8 show case examples of patients' involvement, Report summarizing the findings of the data collection exercise.

For further information, please contact [Liuska Sanna](#).

## 16. EPF MEMBERS SURVEY – INTERIM REPORT

On December 2007, EPF asked its members to respond to a questionnaire to evaluate the extent of EPF representation at EU level and national level in terms of prevalence of disease and in terms of direct membership of patients' organisations. EPF welcomes the contributions of its members and is expecting to complete the evaluation by the upcoming days. This will be circulated to the board and then uploaded on the EPF Website. For those members who have not yet responded in full – we would request you to do so as soon as possible – your input is vital.

## 17. DIARY

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| Tue, Jan 8                 | EPHA, Information to Patients<br>Place: Brussels<br>Attendance: Roxana Radulescu   |
| Wed, Jan 9                 | Eurocarers, European Parliament<br>Place: Brussels<br>Attendance: Roxana Radulescu   |
| Mon, Jan 14 -- Tue, Jan 15 | European Patient Education Conference<br>Place: Barcelona<br>Attendance: Roxana Radulescu, Mike O'Donovan                          |
| Mon, Jan 21                | POSTPONED GSK Advisory Seminar<br>Place: London<br>Attendance: Nicola Bedlington   |
| Tue, Jan 22                | The Pharmaceutical Parliamentary Day<br>Place: Stockholm<br>Attendance: Anders Olauson   |
| Thu, Jan 24                | Patient Involvement and Empowerment – Making an impact<br>Place: Manchester<br>Attendance: Anders Olauson                          |
| Fri, Jan 25                | POSTPONED European Health Services Directive<br>Place: Brussels<br>Attendance: Nicola Bedlington (speaker)                         |
| Mon, Jan 28                | Relative Effectiveness Working Group Meeting<br>Place: Brussels<br>Attendance: Liuska Sanna  |
| Tue, Jan 29                | EMA Training on the review of Package Leaflets and EPAR summaries<br>Place: London<br>Attendance: Roxana Radulescu, Mike O'Donovan |

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| Fri, Feb 1                 | Pharmaceutical Forum ITP working Group<br>Place: Brussels<br>Attendance: Susanna Palkonen, Nicola Bedlington                        |
| Tue, Feb 5                 | POSTPONED EPF meeting with the European Disability Forum<br>Place: Brussels<br>Attendance: Nicola Bedlington, Anders Olauson        |
| Wed, Feb 6                 | EPF Board Meeting<br>Place: Brussels<br>Attendance: EPF Board   |
| Wed, Feb 13                | Pharmaceutical Forum Pricing and Reimbursement Working Group<br>Place: Brussels<br>Attendance: Christoph Thalheim, Roxana Radulescu |
| Thu, Feb 21 -- Fri, Feb 22 | IAPO Conference<br>Place: Budapest<br>Attendance: Nicola Bedlington (workshop leader)   |
| Thu, Feb 21                | IAPO Conference<br>Place: Budapest<br>Attendance: Nicola Bedlington   |
| Tue, Feb 26                | EFPIA Think Tank, EPHA meeting of NGO health statekholders<br>Place: Brussels<br>Attendance: Nicola Bedlington                      |
| Wed, Feb 27                | Pharmaceutical Forum meeting<br>Place: Brussels<br>Attendance: Nicola Bedlington  |
| Thu, Feb 28                | EuroNetPas Launch meeting (Patients' Safety)<br>Place: Utrecht<br>Attendance: Roxana Radulescu                                      |
| Mon, Mar 3 -- Tue, Mar 4   | DIA Meeting on Information to Patients<br>Place: Barcelona<br>Attendance: Nicola Bedlington   |
| Thu, Mar 6 -- Fri, Mar 7   | European Voice Conference<br>Place: Brussels<br>Attendance: Nicola Bedlington   |

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|--------------------------|--|
| Sun, Mar 16              | Pharmaceutical Forum ITP working Group<br>Place: Brussels                |
| Tue, Apr 8 -- Wed, Apr 9 | EPF Spring Conference 2008<br>Place: Brussels                            |
| Tue, Apr 8               | EPF Annual General Meeting<br>Place: Brussels<br>Attendance: EPF Members |