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STOP PRESS – SAVE THE DATE

The EPF Spring Conference 2008 will take place in Brussels on 8, 9 April 2008. EPF members who are interested in joining a working group to develop the programme for this meeting should contact [Amanda Casey](#).

Dear EPF members and friends,

Welcome to the first autumn issue of the EPF Mailing. We hope you had a great summer and are looking forward to an exciting and challenging autumn. As you can see from the Policy Update, there are many EU health issues moving forward.

With this issue we say “good bye” to Nicolas Pradalie who has been working with EPF as a stagiaire/assistant policy officer since last October. We would like to thank Nick very much for his wonderful contribution to developing the office in Brussels, and being such a constructive and positive member of our small team. We also wish Nick the best of luck in his year at the College of Bruges and his future career. We will welcome a new stagiaire in October. We are pleased to announce that Amanda Casey, whom many of you will know from our conference is now also working closely with the secretariat as coordinator for the EPF Autumn Advocacy Seminar.

We are delighted to inform you that the project proposal “RESPECT” , under the Seventh Framework Programme for Research and Development in which EPF is an associate partner has been approved. The project will explore the expectations and needs of children and their families in relation to clinical trials for new drugs in Europe and how this should be translated into empowering and motivating participants in future clinical trials research. We will share more information on this project in the next issue of the Mailing.

You will note the slight change in format of the Internal Mailing to make it easier to read/scan. We hope you like this and please let us have your suggestions for further improvement. We would also take this opportunity to invite you to let us have the email address of other colleagues in your field who may find the EPF mailing useful; and finally as ever encourage you to contribute with news from your members and comment on articles etc.

Warmest greetings,

Anders Olauson, President

Nicola Bedlington, Director

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The next issue of the internal mailing will take place towards the end of October.
 Deadline for contributions is 19 October 2007.

1. Health Services

As informed previously, the European Commission is currently working on a proposal on health services to be adopted by the end of 2007, for a package of a legal instrument and non legal measures.

You may recall that in May, the French MEP Bernadette Vergnaud's Report presented a report in the Parliament on the impact and consequences of the exclusion of health services from the Directive on Services in the Internal Market and called for a directive on health services, in parallel with legislation on general interest social services, included in the objective, included in the objective of a framework directive on services of general economic interest.

The Secretariat will keep you informed with future developments.

2. The New European Health Strategy

As informed in previous Internal Mailing issues, the European Commission has committed to adopting a **Health Strategy White Paper** as part of its Legislative Work Programme for 2007. The aim of the new Strategy will be to put in place an overarching, strategic framework with measurable objectives for 2008-2017. The strategy will stress three key principles: (1) to take a value-driven approach, (2) to recognise the links between health and economic prosperity and (3) to integrate health into other policy areas. It should build on current attempts to improve coordination and integration of health protection within the Commission's services, under the leadership of DG SANCO.

The strategy will also put in place a new implementation system of structured cooperation, within which the European Commission will work with Member States to put in place indicators to monitor the progress of the Strategy.

For further information, please contact EPF's [secretariat](#).

3. Programme for Community Action in the field of Health (2008-2013)

As informed previously, this proposal replaces the initial proposal from 6 April 2005 for a *Community Programme for Health and Consumer Protection*. This came out following the European Parliament's first reading of the 2005 proposal and following the inter-institutional agreement from 17 May 2006 which decided on the budget (€365.6 million, about one third of the amount foreseen in the initial 2005 proposal).

The new programme has three main objectives:

- To improve citizens' health security
- To promote health for prosperity and solidarity
- To generate and disseminate health knowledge;

In terms of geographical coverage, the programme is open wider not only to EU Member States, EEA countries and EU accession countries, but also to the European Neighbourhood Policy countries and Western Balkan countries. Several financial mechanisms are foreseen: co-financement for projects, operational costs for non-governmental organisations or network (up to 60%), joint financing for a public body or a NGO by the European Commission and Member States (up to 50%) and joint actions with other Commission's programmes.

The Commission is currently working on establishing a set of selection and award criteria for organisations eligible for financial support from the EC.

For further information, please contact EPF's [secretariat](#).

4. E-health Inter-operability

The European Commission, DG Information Society is preparing a draft recommendation of e-Health Interoperability. EPF has provided an input from a patient perspective to the draft recommendation, emphasising the need to strongly and explicitly recommend the Member States to give real and equal opportunities to patients' organisations, including potentially marginalised and underrepresented patients, to share their unique and direct experience since the very onset of the policy process, from the design and planning to the monitoring and evaluation stage. EPF has also emphasised that, in the interoperability framework, the information should be transferred with patients' and, when necessary, with carers' consent.

EPF is actively contributing to the eHealth Users' Stakeholders Group, which is an Advisory Group of the i2010 Subgroup on eHealth, to the DG Information Society. The next meeting of the group will take place on 27 September.

For further information on the comments submitted to the Commission by the eHealth Users' Stakeholders Group, please contact [Roxana Radulescu](#).

5. Animal Testing

EPF has prepared a Statement from EPF's, members and allies on a patient perspective on the use of animals in biomedical research. We believe that properly regulated animal research continues to be essential in many aspects of medical research and a vital, legally required stage in the development of treatments for patients with unmet medical needs. In the Statement, we call for a proportionate, appropriate and transparent regulatory framework, designed with proper consideration of the rationale behind the research. This regulatory framework should prevent abuse, not compromise safety of products that may emerge, and not delay progress towards new therapies. We also advocate accelerated efforts into research into viable alternatives to animal testing.

REMINDER: We would highly appreciate any final comments from EPF's member to the statement before 28 September. Please, contact [Nicola Bedlington](#) on this issue.

6. Consultation on the future of pharmaceuticals for human use

The European Commission launched a consultation on 19th July on the [future of pharmaceuticals for human use](#). The Commission intends to improve the regulatory, non-regulatory and RTD framework for pharmaceuticals. Following this public debate, the Commission intends to address a Communication to the Council of the European Union and to the European Parliament on the future of the EU Single Market for Human Use. EPF has prepared a [draft response](#) that will be finalised for the deadline of 12th October.

Should you have any comments/proposals regarding this text, please send them to [Nicola Bedlington](#) as soon as possible. EPF members have received this request separately.

7. Cooperation with other NGOs

As informed previously, EPF is part of a Stakeholder Consultation Group on Information to Patients, which was set up by the European Public Health Alliance (EPHA). The aim of the group is to coordinate action with other health and consumer organizations for a common advocacy strategy to maintain public health concern in the debate on information to patients.

The Group has prepared a Joint Statement on Information to Patients: the Way Forward which is the first step of the advocacy strategy and which reflects the consensus achieved during the first two meetings. The Statement underlines general principles related to consumers' and patients' rights to access quality health information, empowerment of patients and potential users of health services, role of health professionals as a primary source of health information to patients and calls for a comprehensive analysis of existing initiatives, from diverse sources, of providing health information.

The next meeting of the group will be held on 17 September. Roxana Radulescu will represent EPF at the meeting

For further information, please contact the [secretariat](#).

8. EPF Funders' Briefing Meeting

On 12th September, EPF organised a briefing meeting for funding partners to give an overview of the key achievements over the last year and our plans and aims for 2008 and beyond. We welcomed 10 representatives from industry partners to the meeting, to which the EPF board also participated.

For a copy of the presentation made at the meeting, please contact [Nicola Bedlington](#).

9. EPF / European Standing Committee of Doctors (CPME) joint meeting

On 13th September, the EPF board and director held a creative workshop with the executive committee and Secretary General of CPME. The day resulted in a firm commitment for EPF and CPME to work together more closely, and to agree a set of principles and work plan to take this forward. EPF President, Anders Olauson said of the day “This is, in a way, a historic development – the start of a very exciting cooperation that will bring dividends for both our organisations and our members”.

A working group will be set up to develop the set of principles. If any EPF members would be interested in joining this working group, that will also be made up of selected board members from each organisation, please contact the secretariat.

Further details on the outcomes of the meeting will be send to the EPF members in due course. EPF will be exploring similar creative workshops with other health professional stakeholders in 2008.

10. EFPIA Think-Tank meetings

Christoph Thalheim (EMSP) chaired, on behalf of EPF, the EFPIA Special Think-Tank meeting on Funding for Patients' Organisations on 10th September. Roxana Radulescu represented EPF Secretariat at the meeting. A presentation on eligibility criteria for funding for European patient organisations under the EU Public Health Programme was given by Daniel Mann, from the European Commission DG SANCO. EPF representatives highlighted the importance of ensuring that the reference to 'independent of industry' is interpreted to include patient organizations that receive unrestricted funding from industry in accordance to strict independence and transparency rules.

A recent report on Access to funding and diversified resources for European patients' organisations was presented by Marc Dober (APCO), who introduced the general EU funding framework and the foundations funding framework. The report recommends that patients groups should position themselves as a voice of reference and that the outreach to the Commission should start immediately, based on sharing information and expertised with the EC. Also, patients' organisations should seek partnership opportunities and identify the differences and uniqueness of their own projects and also explore a "Round Table of Foundations" to establish a long-term cooperation.

Anders Olauson and Roxana Radulescu attended the afternoon think-tank meeting. The discussion included an update on progress in the High-Level Pharmaceutical Forum on information to patients, relative effectiveness and pricing and reimbursement, an update on the innovative medicines initiative and on the latest developments on animal testing directive, as well as an update on the WHO draft Global Strategy and Action Plan on Public Health, Innovation and Intellectual Property.

For more information or papers from this meeting please contact [Roxana Radulescu](#).

11. European Commission Patient Safety Working Group meeting

Roxana Radulescu represented EPF at the meeting of Working Group on Patient Safety of the European Commission, which was held on 12 September, in Brussels. Set up under the High Level Group on Health Services and Medical Care, this Working Group brings together representatives from 27 EU Member States, OECD, WHO, Council of Europe and key stakeholders representing patients (EPF), health professionals (CMPE, PGEU, EFN), and healthcare settings (HOPE). The meeting was an opportunity to explain the Commission's Patient Safety Initiative and the links with the Health services initiative and the Council Recommendation on the prevention and control of healthcare associated infections. The initiative is due for adoption in the second half of 2008, under the French EU Presidency. This will include an overview of the key elements and processes and a draft timetable for action.

For further information, please contact EPF [secretariat](#).

12. Round Table on Health Strategies in Europe

Roxana Radulescu attended the EU Portuguese presidency Round Table on “Health Strategies in Europe” on 12-13 July, in Lisbon. The conference brought together representatives of the European Commission, the Council of Europe, the European Parliament and the World Health Organisation, as well as academics and NGOs representatives and addressed questions like:

- What sort of framework can guide the development of a European Health Strategy and ensure coordination with Members States and with other international organisations?
- How can an overarching strategic framework help coordinate specific disease management strategies?
- How can we ensure a proper balance between the operation of the single market and the functioning of national health services systems contributing to European-wide health gains?

Parallel sessions on specific areas looked at the most effective approaches to address specific disease priorities - such as cancer, cardiovascular diseases, diabetes, gender-sensitive strategies, obesity, oral health and tuberculosis. Various patients' groups stressed the importance of having a Patient-centered EU strategy and the need to learn from the experience of patients themselves. Involving effectively NGOs in the implementation was also emphasised.

13. Meeting of the Health-EU Portal Editorial Board

EPF was represented by Roxana Radulescu at the 2nd meeting of the Editorial Board of the Health-EU Portal, which was held in Luxembourg on 28 June. The Editorial Board brings together participants from across EU Member States, NGOs and other parts of the Commission.

The Health-EU Portal started issuing a Newsletter, which is published in 20 European languages and hosts links to interactive features on public health. It aims to keep citizens updated on health-related events and publications, conferences and campaigns, while in each edition a topic would be dedicated to a European or international day of action in the field of health.

If you wish to receive the Newsletter you can register at:

http://health.europa.eu/newsletter/1/newsletter_en.htm

REMINDER:

A draft document summarizing some initial thoughts from EPF's Secretariat on improving the Health Portal was circulated to members of 15 August. Thank you very much to those who responded. E would greatly appreciate any other comments. Please send them to [Roxana Radulescu](#).

14. Note from Nicolas Pradalié

It has been a great pleasure and an honour for me to work for the European Patients' Forum. During these 11 months, I have been closely associated to the development of the organisation.

This year, I have notably been in charge of the reorganisation of the office's work, the internal mailing (partly), the European monitoring, the growing MEPs links, the representation in various meetings and the membership liaison - and I really appreciated to see that there was a feeling of community inside EPF and a will to build something together for patients.

I would like to thank very much to EPF's dedicated and competent Board and to EPF's Director for the trust given to me to my excellent colleagues for the positive working atmosphere. I will now spend the year to come studying at the College of Europe, in Bruges, for a Master of Arts in European Political and Administrative Studies.

Thank you and best wishes to you all,
Nicolas Pradalié

15. EPF Spring Conference Report available



The report from EPF'S Spring Conference 2007 is now available on [the EPF website](#).

Hard copies are also available from the EPF secretariat. To order one, please contact [secretariat](#).

16. EFPIA Code of Practice on relationships between the Pharmaceutical industry and patient organisations

EFPIA has recently developed a draft Code of Practice for its Federations and Companies regarding working with patient organisations. EPF has welcomed this development and given comments to the draft, which was based on the Code on relationships with health professionals. For a copy of the draft, together with EPF's comments, please contact the secretariat. The Code will become operational in June 2008. For more information please contact [Erica Poot](#).

17. European Patients' Forum Autumn Seminar, 27-28 November 2007, Hotel Sofitel Brussels Europe, Place Jourdan, Brussels

The European Patients' Forum constantly works to best represent the needs of our members at European level. We understand, from evaluations, that our training and advocacy seminars have proved an invaluable source of support, advice and information for all who have been involved.

This year we aim to continue this process and feel that the proposed agenda will provide delegates with an excellent opportunity to learn about the healthcare policy within the EU and to how you, as a patient representative group, can access and influence decision makers in the healthcare arena.

As you can see from the [draft agenda](#), the seminar addresses issues of great importance to patient groups across the European Union, such as the legislative process and working as a non-governmental organisation within this framework. The seminar will also provide you with the opportunity to meet with a Member of the European Parliament in small breakout sessions and will allow for constructive discussions concerning the impact of EU policy decisions at national and local level.

The seminar is aimed specifically at patient representative groups and will allow you the opportunity to meet with and discuss issues of relevance with your peers from all member states.

We hope that you will be able to join us in Brussels in November. Please contact our meeting coordinator, Amanda Casey at seminar2007@eu-patient.eu with any questions you may have regarding the event.

18. Patient Safety Research Conference – input from EPF's members needed

As informed in a special message to members, EPF has been invited to present a patients' perspective to a major conference on Patient Safety Research – Shaping the European Agenda, that will be held in Porto, during 24-26 September 2007. Issues to be discussed will be:

- What is the role of patient groups in building infrastructure and capacity on research for patient safety?
- How to create research partnerships that works;
- What are patients' needs for research on patients' safety, challenges and potential directions that we recommend?

The conference is indeed a crucial opportunity for EPF to express the solidarity of patients groups and to voice your views in front of an audience of researchers, key European policy makers and educational leaders.

We would highly appreciate any input from EPF's members on this topic. Please send this to [Roxana Radulescu](#).

For further information about the conference:

<http://www.patientsafetyresearch.org/index.html>

19. Diary for second half of 2007

DATE	EVENT	PLACE	ATTENDANCE
18 September	Launch Alzheimer Europe Exhibition In European Parliament	Brussels	Roxana Radulescu
20 September	Steering Group of the Pharmaceutical Forum		Nicola Bedlington
21 September	EMA Patients Working Party		Christoph Thalheim
25 September	FP7 High Level Advisory Meeting	Brussels	Anders Olauson
25-28 September	FEPI (European Federation Nursing Regulators) Conference	Catvat, Croatia	Nicola Bedlington
24-26 September	Patient Safety Research Conference	Porto, Portugal	Roxana Radulescu
27 September	eHealth Users' Stakeholders Group meeting	Brussels	Roxana Radulescu
2 October	Briefing on Information to Patients to Journalists		Nicola Bedlington
2 October	Pharmaceutical Forum Working Group on Relative Effectiveness		Nicola Bedlington
3 October	Briefing EP on "Pandemic preparedness: the importance of seasonal influenza vaccination in Europe"	Brussels	Roxana Radulescu
4-6 October	European Health Forum Gastein	Bad Gastein	Nicola Bedlington
10 October	Round Table on Patients's Rights and Ethics	Ljubljana	Roxana Radulescu
11-12 October	EPF Board meeting	Brussels	

15 October	Information to Patients Working Group Meeting	Brussels	Susanna Palkonen, Nicola Bedlington
18-19 October	8 th EPPOSI Workshop on "Partnering for Rare Diseases Therapy development"	Copenhagen	Anders Olauson
8 November	Health Care Compliance Packaging Council	Copenhagen	Anders Olauson Nicola Bedlington
9 November	EFPIA Think Tank meeting	Brussels	Nicola Bedlington
8-9 November	Patient Dialogue Forum	Karsruhe	Rainald von Gizycki
21 November	OECD Panel Discussion on Information Technology and Information to Patients	Paris	Nicola Bedlington
26-28 November	EPF Autumn Advocacy Seminar	Brussels	EPF members
6 December	Debate EP chaired by Jorgo Chatzimarkakis – For a Europe of Achievements: reinforcing patients' right to information	Brussels	Anders Olauson
6 December	EPF Board meeting		