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**Dear EPF members and friends,**

Welcome to the last issue of the EPF Mailing for 2007. It has been an extremely busy and successful year for EPF. Our latest event: the EPF Autumn Advocacy Seminar, that brought 40 leaders of patients' organisations from over 20 different countries of the EU, was a great way to round off the year – with some important insights into what really concerns patients throughout the European Union and how EPF can and should respond. Read more on the EPF Autumn Advocacy Seminar [in section 10](#).

With 2008 around the corner, the EPF board met on 6<sup>th</sup> December to discuss and agree the EPF work plan and budget for 2008. Read more on the outcomes of the Board meeting in section and our priorities for 2008.

One of the big issues we will address in 2008 is the preparation of a European Patients' Manifesto in advance of the European Parliament elections in 2009. EPF members are invited to become part of a working group to lead this campaign, chaired by EPF President.

We will also launch our EU project VALUE + in January 2008.

EPF is co-organiser, together with the Spanish Patients' Forum of a major European Conference on Patient Education in Barcelona in January; and our own Spring Conference taking place in Brussels, 8 and 9 April will focus on Health Literacy. Both these events will provide an important backdrop to current EU developments on Information to Patients – our wish for 2008 is a legislative proposal that makes a difference for patients throughout the EU who do not access the high quality, up-to date, objective information they need to manage their disease effectively. Watch [this space](#).

We take this opportunity to thank all readers for their interest in and support for EPF over the last year. We are very much looking forward to continuing our common work to move forward together on patient –centred equitable health care in the European Union.

Our warmest greetings for a very happy holiday season and a peaceful new year!

**Warmest greetings,**

Anders Olauson, President

Nicola Bedlington, Director

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The next issue of the Internal Mailing will take place at the end of January 2008. The deadline for contributions is 25th of January.

## 1. European Health Policy Forum

Anders Olauson and Nicola Bedlington attended the European Health Policy Forum where the agenda included:

- a presentation on DG SANCO's "Future Challenges 2009 – 2014" paper ([http://ec.europa.eu/dgs/health\\_consumer/events/future\\_challenges\\_paper.pdf](http://ec.europa.eu/dgs/health_consumer/events/future_challenges_paper.pdf)) that, based on three contrasting socio-political and economic scenarios, outlines key challenges for DG SANCO,
- a presentation on the new EU Health Strategy "Together for Health" ,
- a new initiative on Patients' Safety,
- and an overview of the new EU Directive on Health Services and Cross Border Healthcare.

The Consultation on the Commission's Communication on reforming the budget, 'Changing Europe' ([http://ec.europa.eu/budget/reform/library/issue\\_paper/consultation\\_paper\\_en.pdf](http://ec.europa.eu/budget/reform/library/issue_paper/consultation_paper_en.pdf)) was also presented.

A small working group was set up to develop draft proposals for endorsement by the Forum: this is a crucial opportunity to re-orient the future EU budget and create realistic resources for EU health.

The other very important theme addressed by the European Health Policy Forum is its revised mandate and future work programme in the light of the new Health Strategy. In concert with several other health NGO members, and reflecting crucial health developments at EU level, EPF supports a stronger, more pro-active and political health policy forum where the expertise and experience of all members can be fully utilised.

For a copy of these documents and EPF's briefings on the key policy developments, please contact the EPF secretariat.

The next EU Health Policy Forum will take place on 30 May 2008.

## 2. European Commission New Health Strategy (2008-2013)

The European Commission DG SANCO has recently published the white paper “Together for health”: a Strategic approach for the EU 2008-2013 ([http://ec.europa.eu/health/ph\\_overview/strategy/health\\_strategy\\_en.htm](http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm)). The White Paper follows the consultation at the beginning of 2007 and identifies three key challenges: population ageing; threats to health and new technologies and sets strategic objectives and actions for the EC and Member States. Four fundamental principles are pinpointed: (1) a strategy based on shared values; (2) health is the greatest wealth; (3) health in all policies (HIAP); (4) strengthening the EU’s Voice in global health. EPF welcomes the strategy and we are pleased to see that a lot of the points that we raised in the response to the consultation have been taken on board. The Strategy acknowledges that the patient is becoming more and more an active subject rather than a mere object of healthcare. Citizens’ empowerment is outlined as a core value. Also, there is an explicit recognition of citizens’ and patients’ rights as a key starting point for Community health policies. There is an explicit reference to and an acknowledgment of the fundamental importance of health literacy.

EPF recommends that:

1. A stronger emphasis should be put on mental health and well-being. The Strategy should clearly integrate patients’ mental health and well-being.
2. The role and contribution of families and carers to the health care and social system should be recognised.
3. Indicators provided by patient organizations should be included in the system of European Community Indicators.
4. With regard to the ‘healthy life years’ core indicator, we support the inclusion of a reference to quality of life indicators, alongside healthy life years.
5. Health NGOs, including patients’ organizations should be meaningfully involved in establishing indicators (both quantitative and qualitative) for monitoring and evaluating the strategy and in the impact assessment.

### 3. European Commission Directive on internal market of healthcare services

The European Commission will propose a legal instrument ensuring the protection of basic rights for patients travelling to other EU Member States in receiving medical treatment. Following the public consultation, the Commission has drafted a directive on "safe, high-quality and efficient cross-border healthcare".

The directive concerns EU citizens "travelling to another member state with the purpose of receiving health care there." The key principles of the directive are:

- Equal healthcare provision throughout Europe: Mobile patients should at least receive health care similar to what they would have been entitled to in their home country. Member States are in charge of ensuring the quality and safety standards thereof.
- Costs: Patients' home countries should carry the cost for health care abroad up to at least the price they would have been charged had the patient been treated at home.
- Information: Member states should provide all the relevant information "to enable informed choices by patients" concerning availability, prices and outcomes of the health care they provide. This concerns in particular the question of liability and procedures to be followed in the event of medical malpractice.
- Co-operation: Member States should work together, using, among other things, telemedicine services, in order to assure cross-border exchange of patient data, while respecting privacy rights.

As a result of the draft directive, Member States would have to establish rules concerning the EU-wide definition of treatment methods, including hospitalisation, and on the cross-border recognition of prescriptions.

Once the directive has been published (anticipated date 19 December 2007), EPF will prepare in consultation with its members regarding an official response and a strategy to move forward.

## 4. EU Patients' Safety Initiative

The Commission is preparing a Patient Safety Initiative for 2008 which will include a proposal to address general patient safety issues and more specifically EU actions to try to improve the control of health care-associated infections and strengthened collaboration and cooperation on patient safety at the EU.

So far, there has been working on a draft patient safety recommendation which will be the Commission's proposal's starting point in 2008. The recommendation provides a possible European framework towards improving patient safety in all sectors of healthcare in Member States and identifies key areas where patient safety action is most effective and should be promoted at national and European level.

EPF welcomes this important focus on patient safety and looks forward to being involved, also through the EUNetPas (European Union Network on Patients' Safety) project.

For further information, please contact [Roxana Radulescu](#).

## 5. Pharmaceutical Forum – Information to Patient Working Group

Following up the last mailing, EPF has been requested to prepare a draft on the key elements of an information package. We will draw on consultations documents previously agreed by the EPF membership, however if any EPF member would wish to contribute specifically to this, please contact Nicola Bedlington. The deadline for the initial draft is 4 January 2008. EPF will consult all its members on the draft in advance of the next meeting on information to patients (1 February 2008).

Work is also underway in the other two strands as mentioned in the previous mailing, specifically access to information in specific healthcare settings (led by CPME – primary health care settings, HOPE – hospital settings and PGEU – community pharmacists). EPF is working closely with these organisations with regard to delivering a strategy on ITP in specific healthcare settings during the early part of 2008.

Austria is leading the work strand in relation to the practical implementation of quality criteria, and EPF will be invited to comment, from a patients' perspective on proposals submitted in early January 2008.

EPF members or readers who wish to receive further information or become specifically involved, in addition to the consultation in January, please contact [Nicola Bedlington](#).

## 6. Pharmaceutical Forum: Pricing and Reimbursement Working Group

Christoph Thalheim is the EPF representative on this working group. The following is his brief report on the last meeting, 12<sup>th</sup> December 2007.

### **Agenda Item “From Assessing Innovation to Pricing and Reimbursement”.**

The Andalucian School of Public Health gave an overview and introduction to the subject looking at good practice of six EU countries. The countries assessed were France, Netherlands, Belgium, Sweden, United Kingdom and Germany. The presentation of the Andalucian School of Public Health was purely a descriptive one, not presenting any recommendations for potential changes or improvement. The Belgian authority responsible for “Pricing and Reimbursement” (RIZIV-ENAMI) then presented a more detailed outline on “Innovation and Therapeutic Value of Medicines in Belgian Reimbursement Decisions”.

From the presentations it was clear that innovation is made explicit from a payer perspective by considering (added) therapeutic value using well defined criteria. The reimbursement procedures in Belgium, France and the Netherlands have five therapeutic value criteria in common. Disappointing from the patients point of view is the fact that in the Belgian Commission of stakeholders developing recommendations to the Ministry of Health for each reimbursement decision, there are seven academics, eight sick funds representatives, four physicians association representatives, three pharmacist association representatives forming the 22 voting members, and there are three ministry representatives, one person from ENAMI-RIZIV and two from pharma umbrella organisations forming the six non-voting members. The most important stakeholder, the end user and patient is not represented at all; when asked, why this important stakeholder is not represented, the answer was that the patients are represented by the sick funds!!! The overall conclusion on this first point ‘From assessing innovation to pricing and reimbursement’



was: No single price is possible and no common assessment approach is possible in Europe because of different value systems being established in the Member States.

### **Agenda Item “Orphan Drugs”.**

After a short introduction into the subject from an economic point of view by the European Commission the patient’s perspective was outlined in detail by Yann Le Cam, CEO of Eurordis. The payer perspective followed on the same subject as well as the company perspective represented by Europa Bio. As in the previous point, the Commission indicated their intention to come up with a draft summary report on the issue and invited Eurordis on behalf of the patients’ side plus several other stakeholders to contribute to this summary document.

### **Agenda Item “Pilots on Guiding Principles – Risk Sharing”.**

The introduction with an overview of some practices identified in the Member States came from the European Commission and included risk sharing schemes such as the one on Multiple Sclerosis developed a couple of years ago in the UK for the interferons as Disease Modifying Drugs. Another example for risk sharing schemes practiced in some member States, the Commission mentioned Velcade, a drug for relaxed multiple myeloma, which was not considered cost effective by ‘NICE’ and the National Health Service in the UK called for more research. J and J and the National Health Service agreed on a money-back guarantee if the cost effectiveness cannot be proven by 2010. The Netherlands presented a country specific example of such schemes through evidence based funding of ‘expensive hospital drugs’ in the Netherlands. As before for the other key points, a summary document was decided to be developed by the European Commission for consultation through the Members of the Pricing and Reimbursement Group.

Two proposals for further investigation and presentation of the results to this working group were presented:

- a) A proposal from the European Generics Association for the subject “Generics and Free Price Competitions”.
- b) A proposal from the European Social Insurance Platform “ESIP” on the subject of public procurement/tendering procedures used in the Member States for services and therapies to out-patients.

Then a proposal from a group of stakeholders was made to put the issue of “Trade and distribution of drugs in Europe” back on the Agenda with the intention to go into more detail on the basis of a short questionnaire.

Finally Christoph Thalheim made the participating stakeholders aware of the current consultation process organised by the United Nations: “Human Rights Guidelines for Pharmaceutical Companies in Relation to Access to Medicines”. The comments to this draft document of the United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health can be sent by 31st December 2007 to [rkhosl@essex.ac.uk](mailto:rkhosl@essex.ac.uk).

**IMPORTANT:** The indicated summary documents which are mentioned earlier in this report should come from the European Commission within the coming weeks or months and provide an important opportunity to make the patients’ voice heard. Specifically the request for more patients’ participation in decision making processes on national level need to be included as well as the main conclusions on the issue of Orphan Drugs as provided by Eurordis.

**Attached documents:** [Agenda of 9th Meeting of the Working Group on Pricing of Pharmaceuticals](#), [Proposal for the Pilot project](#), [Proposal to the Working Group Pricing on Trade and Distribution](#), [Deliverables for 2007 – 2008](#)

## 7. “Analysis of differences and commonalities in pricing and reimbursement systems in Europe”, study funded by DG Enterprise and Industry

The study on Pricing and Reimbursement in the EU, developed in the margins of the Pricing Working Group during the last year is now available. The focus of the report was on assessing the impact of pharmaceutical policy practices. In order to do so, it draws a detailed and comparable picture of present policy practices in EU Member States. It also aims to build an in-depth understanding of certain selected practices as implemented in different countries (set-up risks, success factors and impact on expenditure, reward for innovation and patient access). The study is based on a review of the literature on the impact of the policy practices and a survey with country representatives in the Working Group on Pricing of the Pharmaceutical Forum.

The study is available on:

[http://ec.europa.eu/enterprise/phabiocom/docs/study\\_pricing\\_2007/andalusian\\_school\\_public\\_health\\_report\\_pricing\\_2007\\_incl\\_annexes.pdf](http://ec.europa.eu/enterprise/phabiocom/docs/study_pricing_2007/andalusian_school_public_health_report_pricing_2007_incl_annexes.pdf)

## 8. EFPIA Code of Practice on Relationships between the Pharmaceutical Industry and Patient Organisations

The EFPIA Board has endorsed the EFPIA Code of Practice on Relationships between the Pharmaceutical Industry and Patient Organisations. EFPIA has developed the code for its members, in order to enhance transparency and to ensure ethical relationships between the pharmaceutical industry and patient organisations, whilst recognising the independence of patient organisations.

The code sets out standards related to transparency, use of written agreements, non-promotion of prescription medicines, diversified funding of patient organisations, use of patient group logos, editorial control and hospitality.

The code will be implemented across Europe by 1 July 2008, and will be enforced by EFPIA's national industry associations. Each member association will have national procedures and structures to process complaints and impose sanctions in case of breaches of its national code.

The code requires that by the end of March 2009 at the latest, pharmaceutical companies will make the names of patient organisations supported by pharmaceutical companies and the nature of that support publicly available once a year.

The code is available on the EFPIA website at: <http://www.efpia.eu/content/default.asp?PageID=151>

EPF welcomes the Code of Practice and has commented on draft versions.

## 9. Guide to the Slovenian Presidency of the EU (by Hill & Knowlton)

On 1 January 2008, Slovenian Presidency will take over the Presidency of the EU from the Portugal. Hill & Knowlton provides a guide to present Slovenian Presidency upcoming objectives and works.

The guide is available at: <http://www.hillandknowlton.be/docs/SlovenianPres.pdf>

## 10. EPF Autumn Advocacy Seminar

This year's seminar, held in Brussels at the Sofitel Hotel during 26-28 November 2007, was very well attended and we again benefited from the active participation and enthusiasm of our member organisations, both new and old. 20 EU countries were represented composed of 15 pan European groups with 15 individual organisations representing specific national patient groups or disease specific groups. The support of high level speakers and a number of MEPs allowed for delegates to meet with and discuss issues of relevance to their organisations at a one to one level and added to the experience of all who attended.

As ever, the workshop sessions on the final day, proved to be of huge practical benefit for all involved and gave all delegates a clear focus for their ongoing work of representing their members both at national and EU level.

Equally important was the opportunity for delegates to meet with each other and share valuable experiences and helpful hints. As agreed, all presentations will be made available on the EPF website in the coming weeks, and feedback will be used to plan future seminars.

For further information, please contact the meeting coordinator, Amanda Casey at [seminar2007@eu-patient.eu](mailto:seminar2007@eu-patient.eu).

## 11. IAPO seminar

Nicola Bedlington represented EPF at a seminar on public health and intellectual property organised by IAPO in Geneva on 6 November 2007. The seminar was timed to coincide with 2nd meeting of the Intergovernmental Working Group (IGWG) on Public Health; Innovation and Intellectual Property. The Seminar provided an introduction to the IGWG process, to understand collectively the patients' voice. Readers will recall that EPF has supported the IAPO's response to the WHO proposed Global Strategy on Public Health, Innovation and Intellectual Property and will work closely with IAPO to support its work in an EU context. For further information on the seminar papers please go to [www.patientsorganizations.org](http://www.patientsorganizations.org).

## 12. European Patients' Congress

Anders Olauson gave a key note address at the European Patients' Congress in Madrid, Spain- 20th November 2007 that convened 400 participants mainly from throughout Spain. His specific focus was information to patients and current EU healthcare developments. He also had a meeting with the President of the European Parliament Committee for Health and Consumer Affairs.

For a copy of Anders' presentation, please contact the [EPF secretariat](#).



### 13. OECD Meeting on Information Communication Technology (ICT in Health Care)

In the context of the OECD project on ICT in health, BIAC (Business and Industry Advisory Committee to the OECD) organised, in cooperation with the OECD, an expert meeting on 21 November 2007. The meeting took place, back-to-back with the meeting of the OECD Health Committee to facilitate the participation of member countries. The objective of the meeting was to provide a business and industry perspective on topics of relevance to the OECD project, and provide a platform to engage in constructive dialogue to increase the understanding of both the success and failure factors of the introduction of ICT in health care. It was intended to shed light on specific challenges the industry faces in the design and implementation of ICT projects and present practical experiences from which lessons could be learnt. A major challenge in ICT implementation is the appropriate alignment of goals and objectives across participating actors. EPF was invited to present an EU patients' perspective on ICT and health, based on our work at EU level. Also presenting were representatives from EFPIA, on behalf of industry; the OECD Health Committee Member on behalf of Government and CPME on behalf of doctors.

For more information on the outcomes of the meeting, and proposed follow-up, or a copy of the meeting report, please contact [Nicola Bedlington](#).

## 14. Royal College of Physicians - Meeting on the EU Health Strategy

Mike O'Donovan attended the presentation of the new EU Health Strategy by Dr Bernard Merkel (Head of Health Strategy, European Commission) at the Royal College of Physicians, London on 27th November, followed by a debate.

For more information, please contact Paul Belcher, EU Advisor, Royal College of Physicians, [pbelcher@euhealth.org](mailto:pbelcher@euhealth.org).

## 15. CHES Roundtable – A new public health strategy for the EU

A Roundtable, addressing the recent Commission White Paper 'Together for Health: A Strategic Approach for the EU 2008-2013' was held on 6 December at the Madariaga European Foundation and was organised by the Center for Health, Ethics and Society (CHES).

Robert Madelin (Director General DG SANCO) presented the content and context of the Strategy. He explained that the implementation mechanism will be put in place in 2008-2009 and that, most likely, it will not be the same as the Open Method of Coordination (OMC). The most important issue is to make sure that stakeholders find themselves in the Strategy's objectives and then develop the best process for delivery.

Jeni Bremner (Director, European Health Management Association) provided an overview of EHMA's main comments on the strategy. Roxana Radulescu presented EPF's comments to the Strategy (see above) and underlined EPF's commitment to be a constructive partner in implementing the strategy and making it more visible at Member States level and at regional level.

For the full report, please contact [Roxana Radulescu](#).

## 16. EMEA Working Party with Patient Organisations had quarterly meeting in London, 7 December 2007

The Working Party with Patients' and Consumers' Organisations (PCWP) of the European Medicines Agency (EMA) met for its quarterly meeting in London on 7 December 2007. At this meeting, the PCWP:

- Received a performance report on the involvement of patients and patients organisations in EMA activities in 2007,
- Discussed proposals for further interaction between patient organisations and the scientific committees and working parties of EMA,
- Was updated on the activities of the European Network of Centres in Pharmacoepidemiology and Pharmacovigilance (ENCePP),
- Had an exchange of views on the progress of the working group on information to patients of the Pharmaceutical Forum,
- Discussed recommendations for insulin naming, for the wording of antidepressant medicines for package leaflets and the naming and labelling of medicines for medicines for paediatric use.

EMA Executive Director Jean Georges represented the European Patients' Forum at this meeting, as Christoph Thalheim our usual representative was unavailable.

## 17. Healthcare Compliance Packaging Council Conference – Drug Packaging – the prescription to success

EPF President, Anders Olauson and Nicola Bedlington participated in the HCPC 2007 Conference held in Copenhagen, on the 8th of November, and gave a presentation on 'EU Healthcare developments – A patient centred perspective'. Interesting discussions took place on strategies to ensure that drug packaging supports both adherence and patient safety. There was also the opportunity to discuss informally enhanced cooperation between HCPC and EPF in relation to concordance issues.

For a copy of the presentation please contact [Nicola Bedlington](#). For more information on HCPC, please visit [www.hcpc-europe.org](http://www.hcpc-europe.org)

## 18. The EFPIA Think Tank with Patients Groups

Nicola Bedlington represented the EPF at the EFPIA Think Tank with Patients Groups on the 9th of November : A special morning session took place on 'an introduction to Brussels Media Relations'. For a copy of the presentation given during this session, please contact the EPF Secretariat.

The afternoon meeting focused on an update of the EFPIA Code of Good Practice on Relationships between the Pharmaceutical Industry and Patient Organisations, an update and exchange of views on EU policy developments including : the High Level Pharmaceutical Forum, the Commission consultation on the future of Pharmaceuticals, the Innovative Medicines Initiative and the health services/ health strategy developments at EU level. Flaminia Macchia gave a presentation on access to medicines for rare diseases, and highlighted some of the barriers and fundamental ethical versus economic issues in this arena, based on two case studies. Should you be interested in learning more about EURODIS's work in this area, please contact Flaminia: [fmacchia@eurordis.org](mailto:fmacchia@eurordis.org)

For background papers on all of the issues raised at the EFPIA meeting, please contact [EPF Secretariat](#). The next meeting of the EFPIA think tank is Tuesday 26 February 2008.

## 19. The European Association of Pharmaceutical Wholesalers Autumn Conference

EPF was invited to make a presentation on “Continuous Access to Safe Medicines” – What does it mean to European Patients’ (Brussels, 20 November). Nicola Bedlington gave an overview regarding the work of EPF in relation to the promotion of safe medicines, specifically within the Pharmaceutical Forum, and the role of pharmacists and wholesalers. She discussed the value of efficient distribution systems in providing the whole spectrum of medicines needed by patients; she also raised some of challenges linked to the counterfeiting of medicines:

For a copy of Nicola’s presentation, please contact [EPF Secretariat](#).

## 20. Launch of the report by the Centre for European Policy Studies on “Asthma in the EU: Towards Better Management and Regulation of Public Health Issues”

The event took place on Tuesday 20th November, in the European Parliament and was hosted by Liz Lynne MEP. The report (by Jorgen Mortensen and Andrea Renda) identifies gaps and inconsistencies in EU policymaking and argues for more concerted efforts in order to improve the situation of patients across the EU.

The prevalence of asthma has doubled in the last ten years and continues to rise, particularly among children. Asthma patients receive suboptimal care in most EU Member States. A better regulation is needed to provide an appropriate management of Asthma: competences should be clearly defined for pharmacovigilance (especially more transparency should be ensured). The conclusions also underline the lack of consultation of the patients. Their role should be strengthened through the creation of forum where all the stakeholders could be involved.

The Commission welcomes this report as an opportunity of research on public health issues.

For further information please contact [Elisabeth Kasilingam](#).



## 21. MSD seminar

Nicola Bedlington attended a symposium organised by MSD on Access, Innovation and Affordability of Medicines in Munich on 29th November. The seminar celebrated the opening of MSD's EMEAC offices in Munich.

Albert Jovell, [EPF board member](#) and President of the Spanish Patients' Forum gave a presentation on 'Access to healthcare – a European Patients' Perspective'

## 22. The informed patient- What the European Union has to do?

On 6 December, Anders Olauson and Roxana Radulescu attended this event which was co-hosted by MEPs Jorgo Chatzimarkakis and Dagmar Roth-Behrendt.

As one of the invited panellists, EPF's President Anders Olauson stressed that it is simply unacceptable that the level and quality of information to patients varies so dramatically across the European Union and he conveyed EPF's key message, which is that patients want high quality information and not marketing. It is a question of equity and patients' rights. "We urge the EU Institutions to accelerate their work and ensure that an appropriate legislative proposal is on the table with minimal delay. We feel that the end of 2008 is really very late, given the new Commission and new Parliament in 2009", said Anders Olauson.

Other panellists included representatives of the European Consumers' Organisation (BEUC), Standing Committee of European Doctors (CPME), Pharmaceutical Group of the European Union (PGEU) European Federation of Pharmaceutical Industries and Associations (EFPIA), Association of the European Self-Medication Industry (AESGP). One of the key conclusions were that EU needs a comprehensive health information strategy to enhance citizens' and patients' access to high-quality health and medicines information from a variety of sources.

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

### 23. Meeting of the Working Party on Health Systems

Roxana Radulescu attended the 9th meeting of the Health Systems Working Party, held in Luxembourg on 19-20 November. This Working Party has been set up to provide advice and assist the DG SANCO on information and knowledge for monitoring policies in the field of health systems and to facilitate the exchange of information about key aspects of health systems in the EU Member States, including cross-border care, pharmaceuticals, quality of care, eHealth, etc. Updates were provided about the eHealth 2020 working paper, the Lead Market Initiative and the Recommendation on Interoperability, the Glossary of the Health System Working Party, as well as health care available data available at Eurostat. This was completed with further information on the Patient Safety Initiative 2008 and the new Health Programme (2008-2018).

In February 2008, the Public Health Work Plan 2008 will be published together with several calls for: (1) projects, (2) operational costs for European NGOs/networks, (3) joint co-financing for public body/NGO by EC and MS, (4) lump sums for specific actions (ex. conference), as well as calls for tenders.

For further information: <http://www.nivel.eu/EC/WPHealthSystems>

## 24. Meeting of the Working Group of Patients' Safety of the High Level Group on Health Services and medical Care

Roxana Radulescu attended this meeting on behalf of EPF. The meeting was held in Brussels on 22 November. Several informative presentations on projects in the areas of patient safety were made: One of the main conclusions of the MARQuIS project (<http://www.marquis.be/Main>) was that patient safety strategies could contribute to broader quality improvement strategies to maximise their impact. There was not a need for one EU quality improvement system, rather each Member State should develop its own system to suit its own national needs. The cross-border aspects of these strategies did, however, require specific attention.

The SImPatIE project (<http://www.simpatie.org/Main>) showed that EU cooperation on patient safety does have added value. Member State should consider the national applicability of SImPatIE's work. The partners involved in the SImPatIE project could look to develop some of its work further as partners in the new EC funded EUNetPaS project. For example, one key area for further action is the development of patient safety indicators, towards establishing a common set for use by all EU Member States. The group also discussed the draft patient safety initiative 2008 specifically aspects related to the open web-based public consultation and the impact assessment of the proposal.

For further information, please contact [Roxana Radulescu](#).

## 25. WHO Guide on Quality and Safety Strategies

On 16 November 2007, the WHO Regional Office for Europe held a consultative meeting with experts on the document “National health system quality and safety strategies: guidance for WHO Europe members states”. EPF was not been able to be present at the meeting, but welcomed this comprehensive and high quality document and provided comments in written.

While highlighting safe quality care as a human right, the document integrates patient safety as part of quality and gives equal balance to patient professional and management quality.

The guide provides also a comprehensive presentation of methods and approaches of working on quality and a detailed description of national quality and safety strategies, among which those aimed at patients. We have welcomed this and stressed the importance of explicitly mentioning the need to provide adequate resources for patients organisations in order to enable them to participate meaningfully by: giving feed-back about quality, identifying gaps and needs, working with providers in order to improve quality, contributing to choosing priority for actions and supporting public health interventions. EPF has also recommended that the guide encourages exchange of information and good practices about patients' participation in national quality and safety strategies across WHO/EURO countries.

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

## 26. EPF Board Meeting

The EPF Board Meeting met in Brussels on 6 December 2007. The Board agreed the work plan and budget for 2008. This included an external communications strategy and work plan for the board. Our policy priorities next year will be: patients' safety, information to patients, the Health Services Directive and its legislative path, the new EU Health Strategy and ICT and health.

The meeting also reviewed the work plan for 2007 in accordance with performance criteria, and cashflow/financial overview for 2007. Two new membership applications were discussed and it was agreed that, as they both meet the criteria for full membership, the Federation of Polish Patients, and the European Federation of Associations of Patients with Haemochromatosis should become provisional members until their applications are formally accepted by the EPF Annual General Meeting. The Board also approved the revised budget and proposal on VALUE + in advance of the negotiations with the European Commission in Luxembourg on 12 December 2007.

Should you wish to receive further information on any of these issues, or a copy of the EPF work plan 2008, please contact [EPF Secretariat](#).

## 27. Conference on "Pharmaceutical Products in the Environment: Trends Toward Lowering Occurrence and Impact"

A conference is organised, in February 2008, in Nimes, in France, in the framework of KNAPPE project ([www.knappe-eu.org](http://www.knappe-eu.org)). The conference aims to identify new developments and future trends that will facilitate limitation of pharmaceutical products in environmental waters, and to promote an integrated approach by gathering actors involved with all of the various stages in the life cycle of pharmaceutical products (from manufacture to release in the environment) and providing a forum for discussion. Four scientific sessions dealing with pharmaceutical by products, new industrial practices, and regulatory and stewardship will be organized.

## 28. EuroMeeting 2008

The Drug Information Association (DIA) organises the next EuroMeeting in Barcelona, from 3 to 5 March 2008. This meeting brings together all interested parties involved in drug development and regulatory affairs and is an opportunity to learn about latest drug developments, innovative therapies, clinical trials, public health regulations, and ethics and to network with professionals from policy making bodies, academia and industry.

EURORDIS (European Organisation for Rare Diseases) and the DIA initiated a fellowship programme to enable 42 patient representatives to participate in the EuroMeeting. Nicola Bedlington will be give a presentation at the meeting.

The detailed programme is available at:

<http://www.diahome.org/DIAHome/resources/content.aspx?type=eopdf&file=%2fproductfiles%2f13603%2f08101diaweb.pdf>



## 29. EPF Spring Conference on health literacy, 8-9 April 2008, Brussels

Planning is now well underway for next years' annual conference, being held at the Hotel Silken Berlaymont, Brussels on 8-9 April 2008. The theme of next years' meeting is Health Literacy, highly topical given the current focus on Information to Patients. Health Literacy also features prominently in the new EU Health Strategy 'Together for Health'. We are putting together a wide and diverse agenda and are confident that we will continue to attract delegates from all sectors of the healthcare arena in the EU. The 2007 conference was very well received and has provided the EPF with a strong and clear framework for its work, as a patient advocate, at European Level.

Further information, with a preliminary agenda for the meeting will follow in early 2008.

For further information, please contact our conference coordinator, Amanda Casey at [conference2008@eu-patient.eu](mailto:conference2008@eu-patient.eu)

### 30. 2nd European Patients' Rights Day – 18 April 2008

The 1st European patients' rights day, which took place on the 29 March 2007, was a major event that brought together different stakeholders (national institutions, private sectors, pan-European networks of professional associations, patients' organisations, consumer associations, etc.) This event aimed at reinforcing patients' rights with the cooperation and commitment of all healthcare stakeholders in every EU country.

The 2nd European Patients' rights day will be celebrated on the 18th of April 2008 in all 27 EU countries. This will be an opportunity to give greater visibility to the issue of patients' right and increase its impact on national authorities and stakeholders. The main objective is to disseminate the European Charter of Patients' Rights among the general public as well as raise the awareness of the various actors of national health care systems to discuss common strategies to improve the implementation of patients' rights in each country.

Organisations interested on participating to this event could download the call for participation: [http://www.activecitizenship.net/projects/project\\_europe\\_chart\\_1.html](http://www.activecitizenship.net/projects/project_europe_chart_1.html).

## 31. Diary

DATE	EVENT	PLACE	ATTENDANCE
8 January	Information to Patients	Brussels	Nicola Bedlington
9 January	Eurocarers, EP	Brussels	Nicola Bedlington, Roxana Radulescu
14-15 January	Patient Education meeting	Barcelona	Mike O'Donovan, Roxana Radulescu
21 January	GSK Advisory Seminar	London	Nicola Bedlington
22 January	The Pharmaceutical Parliamentary Day	Stockholm	Anders Olauson
24 January	Patient Involvement and Empowerment – Making an impact	Manchester	Anders Olauson
25 January	European Health Services Directive	Brussels	Nicola Bedlington (speaker)
28 January	Relative Effectiveness Working Group Meeting	Brussels	Albert Jovel
29 January	EMA Training on the review of Package Leaflets and EPAR summaries	London	Roxana Radulescu, Mike O'Donovan
5 February	EPF meeting with EDF	Brussels	Nicola Bedlington, Anders Olauson
6 February	EPF Board Meeting	Brussels	EPF Board
21-22 February	IAPO Conference	Budapest	Nicola Bedlington
26 February	EFPIA Think Tank	Brussels	Nicola Bedlington
End of February	Pharmaceutical Forum meeting	Brussels	Nicola Bedlington
3-4 March	DIA Meeting	Barcelona	Nicola Bedlington
6-7 March	European Voice Conference	Brussels	To be decided
8 April	EPF Annual General Meeting	Brussels	EPF Members