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Issue 2 (15): 13 March, 2008

Dear EPF members and patient group allies,

Welcome to the second issue of the EPF Mailing 2008. As we go to press, the EPF secretariat is moving offices. We are relocating to Rue Belliard 65 – to our own accessible office space, See section 21 for our new contact details.

As readers will know, EPF's Annual General Meeting and Spring Conference will take place on 8 and 9 April 2008 in Brussels – for those patient groups who have not yet registered, we urge you to contact Amanda Casey, conference coordinator (conference2008@eu-patient.eu) immediately.

In this issue, there is a special feature on the Patients Rights' Day on 18th April (section1). Mike O'Donovan, EPF treasurer will speak at a Conference in Gorizia to celebrate the Day, that will focus on cross-border services. Patient groups throughout Europe will also celebrate the Day at local, regional and national level. EPF is supporting a move to "institutionalise" the day - i.e to ensure that the EU institutions recognise on an on-going basis the 18th April at the Patients' Rights Day.

Since the last mailing a large number of health related policy meetings have taken place in Brussels particularly in the sphere of Information to patients. (see policy update) The VALUE + project held its first steering group meeting in Brussels on 27 and 28 February, (section 19) and EPF participated in the launch of the EUNETPAS patient safety project in Utrecht on 28 and 29 February (section 15) we hope this issue gives you a clear overview of work in progress and next steps. Please do not hesitate to contact the secretariat should you need more information.

Finally, the European Commission has launched a call for proposals for projects and core funding in the field of Public Health. EPF attended the Information Day on 12 March and has also prepared a check list of helpful hints for our members in preparing applications based on previous experience, see section 17. We wish those patient group colleagues applying much luck in their applications and would be delighted to help in any way possible.

Warmest greetings – for the many of you attending our spring conference we are looking forward to seeing you soon to advance our common work on "health literacy" - a theme that is central to the empowerment of patients!.

Warmest greetings,

Anders Olauson, President and Nicola Bedlington, Director

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The next issue of the Internal Mailing will take place at the end of April 2008. The deadline for contributions is 22th of April.

1. EUROPEAN PATIENTS' RIGHTS DAY - 18 APRIL 2008

EPF is working closely with Active Citzenship Network regarding the European Patients' Rights Day, 18 April. We congratulate ACN and welcome this initiative: We will be present at the flagship event in Gorizia (see below) and are promoting the institutionalisation of the Day. The following article, by Melody Ross gives some background and info on the importance of the Day and how different patients' organizations throughout Europe will be celebrating the Day this year:

Patients' Rights a European Issue

Patients' rights are becoming an increasing concern of EU institutions and stakeholders.

In 2002, Active Citizenship Network (ACN) www.activecitizenship.net together with a group of European citizens organisations drafted a European Charter of Patients' Rights that includes the following 14 rights.

www.activecitizenship.net/documenti/European_Charter_of_Patients_Rights_Final_Draft.pdf

The 14 Patients' Rights

The fourteen patients' rights seek to make the fundamental rights mentioned in the Charter of Nice, applicable and appropriate to the current transition process in health services. These rights all aim to guarantee a "high level of human health protection" (Article 35 of the

14 Patients' Rights

1. Right to Preventive Measures
2. Right of Access
3. Right to Information
4. Right to Consent
5. Right to Free Choice
6. Right to Privacy and Confidentiality
7. Right to Respect of Patients' Time
8. Right to the Observance of Quality Standards
9. Right to Safety
10. Right to Innovation
11. Right to Avoid Unnecessary Suffering and Pain
12. Right to Personalized Treatment
13. Right to Complain
14. Right to Compensation

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Charter of Fundamental Rights) and assure the high quality of services provided by the various national health services. They must be protected throughout the entire territory of the European Union.
The reinforcement of patients' rights will become effective only with the cooperation and commitment of all healthcare stakeholders in every EU country. It is thus essential to increase awareness regarding the importance of patients' rights and everyone's responsibilities in guaranteeing their respect.

For that reason ACN believes that celebrating a European Patients' Rights Day every year in all EU Member States would greatly contribute to that goal. It would be a common occasion to inform, discuss and take commitments to improve patients' rights in Europe.

A European Event celebrating cross-border care and patients' rights: Gorizia, Italy.
ACN will organize a European conference in Gorzia, a small town on the Italy-Slovenia border to celebrate the 2nd European Patients' Rights Day European event. ACN is expecting some 100 representatives from the participating organisations and countries together with European Parliament members and representatives from other European institutions. Together, they will share what is happening in their countries as well as specifically address the issue of patients' rights and cross- border care. For more information check the ACN website www.activecitizenship.net

Join In
If your organisation would like to join this Europe wide effort and celebrate the European Patients' Rights Day in your country download a participation form from the ACN website and send it in immediately. It is still not too late. www.activecitizenship.net/projects/project_europe_chart_1.html

Read a full article here.

2. NEW HEALTH COMMISSIONER NOMINATED

On 28 February 2008, Ms Androula Vassiliou was nominated by the Republic of Cyprus as successor to Mr Markos Kyprianou, who has resigned from the Commission to become Foreign Minister in Cyprus.
Ms Vassiliou started her career as a lawyer. She was an elected Member of the House of Representatives of Cyprus for two terms (1996-2001 and 2001-2006). She served among others on the European Affairs Committee and on the Joint Parliamentary Committee of Cyprus and the EU. She was an Alternate Representative of the Cyprus Parliament to the Convention for the Future of Europe (2001-2003). She was also Vice President of the European Liberal Democrats and Reform Party (ELDR, 2001-2006) and as such chairperson of the European Liberal Women's Network. Since 2002, she serves as chairperson of the board of trustees of the Cyprus Oncology Centre. She was also President of the Cyprus Federation of Business and Professional Women.

EPF President, Anders Olauson has written to Ms Vassilou, congratulating her on the appointment and inviting her to give a keynote address at our forthcoming Spring Conference.

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3. HEALTH STRATEGY

A seminar on Implementing the new Health Strategy organized by EuroHealthNet – the European network of national health promotion agencies - in cooperation with the IUHPE (International Union for Health Promotion and Education), was Brussels, on 13 March. Participants came together to share a critically constructive look at the new EU Health Strategy. The aim was to propose concrete actions needed to turn a strategic paper into real progress for EU citizens.
Although unfortunately, no EC official was able to be present at the meeting, the organizers informed that DG SANCO has started the next steps and that expert advice and suggestions on concrete actions are very much welcome from Member States and stakeholders.
While applauding this first coherent EU approach, participants expressed concerned that health had however a poor influence inside the Commission itself and among other DGs.

Also, the point was raised that Member States were still reluctant to allow use of Commission's key powers in the field of health, the reason behind being sometimes too little evidence of the added value of EU. Participants felt there was a real need to take action in this direction.

Another key point highlighted was that there is an urgent need for ministers in charge with structural funds across Member States to be made aware of the health component of these funds.

Several speakers made a plea for much more efficient cooperation between Member States and the European Commission on building on each other's strengths.

For more information contact Roxana Radulescu. A further report on the EU health strategy developments and the contribution EPF is making will be included in the next EPF mailing.

4. CROSS BORDER HEALTH CARE – THE CURRENT STATE OF PLAY

At a debate held in the European Parliament on 4 March, organized by Ludwig von Mises institute-Europe and entitled "Patients Rights for cross-border health care – freedom for patients and providers", Philippe Brunet, Head of Cabinet for the recently appointed Health Commissioner Androula Vassiliou informed that the Commission had to rethink the schedule for issuing a directive for patients' rights in cross-border health care. The directive was expected for April this year, but in this context it would be delayed again.

Mr Brunet reiterated that there was a need for a positive legal act to codify the rulings of the European Court of Justice in respect of the principles of the Council of universality, equity, solidarity and stressed that patients should be aware of their rights and entitlements, but also about what they can realistically expect and what they cannot.

While presenting Active Citizenship Network's work on Patients' Rights, Charlotte Roffiaen, highlighted that the case-law of the European Court of Justice is often not applied by national administration and that there is a urgent need to simplify the administrative procedures - which are often the main obstacles to patients' access to cross-border health care – and to establish strict deadlines for authorisation.

EPF strongly argues that patients should have the right to receive safe and high-quality care all over the Union, and to have the fullest information in order to make informed choices. When necessary or by choice, patients must be able to receive care abroad and their rights and the quality of their treatment must not be compromised. On the 8th of February EPF and CPME (the Standing Committee of European Doctors) issued a press release stating that patients and medical doctors decided to unite their voices and are calling for an EU directive on health services in the context of patients' cross-border mobility.

5. PHARMACEUTICAL FORUM DEVELOPMENTS

Three meetings of the Pharmaceutical Forum took place at the beginning of the year; they focused on the main core working areas: Information to Patients (ITP), Pricing and Reimbursement and Relative Effectiveness. The following are brief reports of the meetings and main outcomes.

Information to Patients Working Group

Susanna Palkonen, EPF Vice President represented EPF at the working group meeting on 1 February 2008. Regarding the different work streams reported in the last issue of the EPF Mailing, progress is being made in all of these.

- Access to ITP in different health care settings - Ivana Silva (PGEU) gave a presentation on behalf of CPME and HOPE. EPF will consult during our AGM and Spring Conference regarding the barriers and opportunities identified from the perspective of patients.
- Implementation of the quality principles - Austria made a presentation on how these principles could be applied in practice in specific settings
- Public Private Partnerships Sweden - Austria and France gave examples of where public private partnerships in relation to information to patients have been effective. Sweden gave a presentation on ethical issues linked to this.
- Key elements of an ITP package prepared by EPF - Susanna Palkonen made a presentation and comments were given.

EPF was nominated co-leader with the Commission in the fourth work stream on future strategy, and PGEU,CPME, EMEA, AIM and Sweden will contribute to this work. EPF has developed a very preliminary bullet point document for the next working group meeting on ITP on 14 March 2008. Following this meeting EPF together with the partners above will work together to develop this document. EPF will also consult its members and patient group allies in a specific briefing on the meeting that will reach you before the Easter break.

Pricing and Reimbursement Working Group

The Working Group on Pricing and Reimbursement of the Pharmaceutical Forum held a meeting in Brussels on 13 February.

Member States representatives provided new comments and updates to the papers "From assessing innovative value of pharmaceuticals to pricing and reimbursement decisions" and "Risk-sharing practices and conditional pricing of pharmaceuticals" that were discussed also in the previous meeting from 12 December.

A representative of the Pharmaceutical Benefits Board in Sweden gave a presentation about cost-effectiveness in the Swedish reimbursement process, explaining, among others, the main steps of the reimbursement decision process: starting with the reimbursement application from the company, going through an evaluation carried out by the Assessment Team which refers the application to the Board - with a proposal for a decision – and ending with the decision taken by the Board. The Board is made up of 11 members who are medical doctors, health economist and patients' organisations representatives.
A company perspective was given by a speaker from EFPIA who described the challenges to translate the concept of value of medicines into actual costs.

The group further discussed the proposal of generics and free price competition and provided several comments to the questionnaire prepared by Forschungs und Planungsgesellschaft mbH (on behalf of the Main Association of Austrian Social Insurance Institutions) in order to map the current use of tendering of pharmaceuticals in Europe.
Throughout the discussions, EPF highlighted the need to take on board the patient's perspective in these processes.

For further information, please contact: Christoph Thalheim / Roxana Radulescu.

Relative Effectiveness Working Group

The working group on Relative Effectiveness (RE) met on 28 January in order to assess the progress made in the three work packages within this working area and to review the documents developed by the correspondent sub-groups. In the previous meeting it had been agreed that mandates would be prepared for each work package by the leaders of the subgroups and these mandates were adopted.
With regard to the development of principles of good practice for relative effectiveness, while most of the principles developed were agreed, the group decided that some of them need to be re-worked. General comments were made on the scope of the principles which should relate to RE assessment and not the entire drug evaluation process. More specific comments were made on issues related to the Transparency Directive, market authorisation issues and the importance of ensuring the relationship of the RE assessment process and national decision making which in some countries are separate and in some others not. As regards the development of a toolbox, it was agreed that it is not a simple task and would therefore need to be addressed at a later stage once work package 2 has also finalised its work.

The leader of the second working package, which aims at looking at how RE assessments are done in the Member States explained the process for collecting this information. Some aspects of the process were discussed and agreed: the focus of the exercise will be on relative effectiveness and not cost effectiveness; in order to be able to compare information across countries the same categories of centrally authorized drugs will be used. The questionnaire for interviews at MS level will be re-worked based on these comments and finalized.
For the working package on networking, in which EPF is playing an active role, there are two levels of action: mapping existing networks and collaborations and developing a proposal/recommendation on ways to develop further European collaboration on relative effectiveness assessment. The draft questionnaire developed for the mapping exercise was reviewed and adjustments will be made. It was agreed that the working group would not only look at existing networks and provide a general overview but would also prepare a forward looking paper on possible objectives, tasks, functions of European level collaboration on this area and present it to the next meeting.

For further information, please contact: Nicola Bedlington.

6. EPF'S RESPONSE FOR EUROPEAN COMMISSION CONSULTATION ON PHARMACOVIGILANCE

EPF welcomed the public consultation on a legislative proposal 'to strengthen and rationalise the EU system of pharmacovigilance' launched by the European Commission with the deadline of 8 February.

EPF submitted its response, adopted by the EPF Board on 7 February, to the European Commission and underlined the importance of building EU health policy from a patients' rights perspective. EPF highlighted three key points and made specific proposals in this regard.

- The lack of patients' involvement in pharmacovigilance processes;
- Equity and access to safe medicines concerns: the need for binding provisions and post-authorisation structured from a patient's perspective;
- The fundamental importance of Information to patients in relation to effective pharmacovigilence.

Please go to the EPF website for a copy of EPF's response.
For further information, please contact: Nicola Bedlington.

7. ANIMAL TESTING

Patient Groups stand up for Animal Research, by Nick Meade, European Genetic Alliance Network (EGAN)

The last time that European animal research regulations were updated was more than twenty years ago in 1986. Since then many advancements have been made, both in methods for which animals may be used for research and in their care and treatment.

The 3Rs: Replacement, Refinement, and Reduction of the use of animals in research, a movement that started more than fifty years ago, has made significant progress which needs to be reflected in regulations governing the use of animals in biomedical research. Fewer animals need to be used in less severe tests to provide scientists with the evidence necessary to progress with drug development than at the time the current European regulations were brought into effect.

New regulation would take account of more streamlined animal research methods, as well as entirely new uses of animals in research, such as genetically modified animal models, which provide more insight into the mechanisms behind medical conditions than were previously available.

The review of Animal Directive 86/609 is due to start in early summer. During this debate, likely to run for many months, every aspect of the use of animals in biomedical research will be examined in fine detail. There will be calls for a ban of certain methods or certain types of animals.

Patients are the direct beneficiaries of biomedical research. Biomedical research exists both to develop treatments and cures for health conditions, and to investigate the causes and mechanisms behind health conditions. It is imperative that patients make their voices heard in this important debate. The European Patients' Forum has a position statement on animal research on its website.

EGAN is leading the work in relation to animal research. As fellow- members of the EPF, you will receive further details of this important debate via email in the coming months, including advice and information on how to make your group's voice heard in this debate. It is imperative that we stand together to ensure continuation of good quality biomedical research, and the necessary accompanying animal research, in the European Union.

8. PATIENT SAFETY

Roxana Radulescu will attend the next meeting of the High Level Patient Safety Working Group on 12 March. A detailed report will be given in the next Mailing – please contact Roxana Radulescu directly if you have any specific questions at this stage.

9. E-HEALTH USERS' STAKEHOLDER GROUP

EPF participated in the first meeting in 2008 of the eHeath Users' Stakeholder Group which was held in Brussels on 21 February. This group is an advisory group of the i2010 Subgroup on eHealth, working under the coordination of DG INFSO.
The aim of the meeting was to debrief on various actions that the group's members have been undertaking since the last meeting in September 2007 and to plan the group's participation in the upcoming eHealth Conference in Slovenia (6-8 May 2008).
Information was given on a large-scale project called SOS (Smart Open Services) eHealth, which brings together Member States under the leadership of the Swedish Health Authority with the aim of developing a practical eHealth framework and ICT infrastructure. The objective is to strengthen the cooperation among MS in better coordinating eHealth cross-border services. enable and secure access to patient health information between European healthcare systems.

The CALLIOPE project was also introduced to the group (see section 16).
Helene Richardsson, the Group's chair and ICT strategist for the Swedish Association of Local Authorities and Regions, informed that the Group was extended the invitattion to participate in the eHealth 2008 conference http://ec.europa.eu/information_society/newsroom/cf/itemdetail.cfm?item_id=3698) and to lead on the session dedicated to users. The theme of the conference is eHealth without borders. The group brainstormed on topics to be possibly included, from both a geographical and thematic perspective, and decided to look at the positive aspects and benefits of eHealth services in the context of patients' mobility and cross-border health care.
EPF will be present at this conference. Further information will be provided in the next IM issue.

For further information, please contact Roxana Radulescu.

10. PUBLIC HEARING ON RARE DISEASES IN THE EUROPEAN PARLIAMENT

EURORDIS – the European Organisation for Rare Diseases – an EPF's member, organized a Public Hearing on Rare Diseases co-hosted by MEPS Frédérique Ries and Jules Maaten, on 4 March 2008 to celebrate the Rare Disease Day - which was set on 29 February!

EURORDIS' president, Terkel Anderson informed about a series of events organized by patients' organisations from all European countries and not only, in order to raise awareness among decision-makers about the need to consider rare diseases as a public health priority and to improve coordination at European level.

Nick Fahy, from DG SANCO informed the participants that more 600 responses were received to the recent public consultation on "Rare diseases: Europe's Challenge" and stated that this was a record response to a public consultation on health. A Commission Communication on Rare Diseases, which will take into account these responses, is expected to be presented to the Council and European Parliament in November this year.

The latest funding opportunities for rare diseases research under the 7th Programme for Research (FP7) – Health, were described by Manuel Hallen, DG Research.
Lesley Greene, former president of EURORDIS and founder of CLIMB UK, closed the event with a moving testimony of her daughter's long-battle against the metabolic disease Cystinosis and made a plea to the policy-maker "to listen to the patient".

EPF would like to warmly congratulate EURORDIS for this initiative and to offer its support for any future action.
For further information: www.eurordis.org/secteur.php3?id_rubrique=1

EPF has welcomed the Commission's consultation on rare diseases and has strongly supported EURORDIS' contribution to this consultation. Key points highlighted in the response:

- There is a need for European cooperation on rare disease.
- Education and training should be ensured at different levels of society to improve the quality of life of people living with rare diseases.
- Community action should tackle discrimination faced by people with rare diseases and disabilities, with regard to social exclusion, lack of access to adequate healthcare, employment opportunities, etc.
- EPF supports EURORDIS' proposal for Specialised Social Services for rare disease patients and welcomes the idea of a European Agency to specifically address issues of concern for patients with rare diseases and their families.
- Patient's mobility should be facilitated and supported when necessary and Centres of Expertise and European Reference Networks for Rare Diseases should be established.
- Patient-centered research on rare disease should be developed at EU level
- EU action should support accessibility of patients with rare diseases to orphan drugs.

11. EMEA TRAINING FOR PATIENTS' AND CONSUMERS' ORGANISATIONS

EPF was represented by Mike O'Donovan, EPF Treasurer and Roxana Radulescu in the Training for patients and consumers' organisations carried out by the European Medicines Agency (EMEA) on 29 January, in London.

The meeting was attended by 26 patients' and consumers' organisations' representatives, operating at EU level or at national level. Participants were first given an introduction to the methodology of review of both the Package Leaflets (PL) and the European Public Assessment Report (EPAR). EMEA's team equally made a presentation on the analysis of the documents reviewed in 2007 by patients and consumers and the feed-back received.

Comments from patients' organisations looked at using more the lay words rather than scientific ones, to making sure that the translations are as accurate and user friendly as possible, to the need for pharmaceutical companies to involve patients' organisations' representatives in the user testing procedures and no randomised people.

Participants were subsequently involved in practical exercises to review the PL and EPAR for a set of new medicines, while being asked to make sure that the information included is clear and understandable for patients. They were also explained how to use the "Eudralink" database in order to continue this review process on line.

A training manual for involvement in the review of documents addressed to patients was distributed to participants on hard copy and CD. Should you wish a copy of this, please contact EPF' Secretariat.

EPF was invited to activate an account on Eudralink database and to support the review process.

For further information, please contact Roxana Radulescu.

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12. EFPIA PATIENTS THINK-TANK, 26 FEBRUARY 2008

Nicola Bedlington represented EPF at the EFPIA think tank meeting on 26 February and gave brief feedback on current developments with the health strategy, health services and information to patients, from the perspective of patients. Presentations included an update regarding the running of the EFPIA Patients Think Tank, Animal Testing, and a new project by EGAN on the involvement of patients in clinical trials, that will link up with the VALUE + project.

Please contact the EPF secretariat for more details or a copy of any of these presentations.

13. IAPO CONGRESS

Nicola Bedlington represented EPF at the International Alliance of Patients Organisations (IAPO) Congress in Budapest on 21 February. Nicola led a session on EU policy developments on information to patients. The Congress was highly successful on all fronts and a very good opportunity to see the EPF/IAPO Memorandum of Understanding at work in practice and to work together with the main IAPO patient leaders from through the world.

Please go to IAPO website www.patientsorganizations.org for more information.

14. EULAR WORKSHOP ON PROJECT APPLICATION

The European League Against Rheumatism (EULAR) - the organisation which represents patients, health care professionals and scientific societies of rheumatology from across all European countries - held a workshop for its members on 5 March, in Brussels, on preparing an application for the Public Health Call for Proposal 2008.

EPF was invited to share its experience on this. Roxana Radulescu gave a presentation about the preparation of the VALUE+ project application and the experience of working with the Public Health Executive Agency and with project partners, from preparing a concept paper, preparing the actual project proposal, negotiating with the Agency and finally to signing the project contract.

15. EUNETPAS PROJECT MEETING

EPF participated in the launch of the EUNetPAS (European Union Network for Patient Safety) project in Utrecht, the Netherlands on 28 and 29 February.

As informed earlier, the project is supported by the European Commission within the 2007 Public Health Programme. Coordinated by HAS (French National Authority for Health), its purpose is to establish an umbrella network of all 27 EU Member States and EU stakeholders (CPME, EPF, PGEU, HOPE, EFN) to encourage and enhance their collaboration in the field of Patient Safety (culture, reporting and learning systems, medication safety and education).

The meeting in Utrecht brought together all associated and collaborative partners and looked at clarifying their roles and responsibilities.

As an associated partner, EPF will be involved in the WP2 on Structuring Education & Training in Patient Safety, which will collect and organise existing knowledge on curricula, Continuing Professional Development programmes, standards, etc. The aim is to propose a recommendation to the Network on a set of core competencies for all (doctors, nurses, managers, patients) and on learning interventions and quality and accreditation programmes. Institutions that would be prepared to test these patient safety education programmes will be identified and supported.

EPF will also be involved in the evaluation of the project and will interact with WP4 on Pilot Implementation in Medication Safety.

For further information, please contact Roxana Radulescu.

16. CALLIOPE PROJECT – 1ST CONSORTIUM MEETING

On 22 February Liuska Sanna participated on behalf of EPF to the first meeting of the Consortium of the CALLIOPE project, which stands for InterOPErability: Creating a European coordination network for eHealth interoperability implementation, with the aim of ensuring that patients' perspective is fully integrated. The Network is composed of 17 health authorities, bringing into the network an equal number of national stakeholder groups and of 10 organisations representing networks of physicians, community pharmacists, patients, industry, health insurers and payers.

The main objectives of the CALLIOPE Thematic Network for the first 30 months of operation are to:

- Objective 1: Establish itself as a competent, self sustainable mechanism for experience sharing and consensus building for eHealth Interoperability in Europe;
- Objective 2: Provide an open forum and "a think tank" for current and emerging challenges which could lead to the description of potential future pilot projects and future partnerships;
- Objective 3: Provide targeted support for activities requiring broad convergence across Europe, such as LSP eHealth projects, the EU Interoperability Recommendation and implementation of open, common interoperable service solutions;
- Objective 4: Propagate, disseminate and create grounds of good knowledge and understanding of important policy EU level documents supporting interoperability, amongst its members, through training and dissemination events.

The ultimate goal of the project is to - after the first 30 months of operation - turn the CALLIOPE Network into a sustainable mechanism, able to address emerging challenges in support of EU level interoperability, using the inherited Governance, Infrastructure and Network Management mechanisms. The project is still in the negotiation phase with the Commission and if everything goes well a final approval is expected in March.

This first meeting was not only a good opportunity for all the partners to meet, but it was also useful for establishing common starting points, for positioning CALLIOPE among other initiatives, for finalizing the work plan and partners' commitments and for planning immediate steps. EPF is very pleased of being part of this network as it is an important platform for voicing the needs and rights of patients in the eHealth arena. It is EPF's intention to be actively involved especially in the work areas related to the strategic aspects of defining a Common European Road Map for Interoperability and contributing to the EC Iop Recommendation.

This project will be most probably launched at the eHealth event promoted by the Slovenian presidency and taking place in Slovenia in May. A project website will also be soon available. More information will be provided in the future issues of this mailing and you can also contact Liuska Sanna for more details.

17. HEALTH PROGRAMME 2008-2013. INFODAY ON CALL FOR PROPOSALS 2008

On 12 March Liuska Sanna attended in Luxembourg the first of two Infoday events on the 2008 Call organised by PHEA. This article aims at providing information that complements what can be found in the PHEA's website and was provided during presentations and by answering to participants' questions. The day was structured in specific sessions to present the three strands of the call; to explain how and share best practices on writing grant applications; to provide financial and contractual information and finally looking at the IT aspects of the application.

The new elements of this call were highlighted:

Objective 1 – Improve citizens' health security

- Particular focus on cross-border health threats
- Evelopment of Community reference laboratories
- Action on patients safety through high-quality healthcare

Objective 2 – Promote health – including the reduction of health inequalities

- Regional policy as key factor in reducing health inequalities
- Focus on health ageing and children's health
- Cooperation between health systems

Objective 3 – Generate and disseminate health information and knowledge

- Target 'added value' issues e.g. gender, children's health, rare diseases, mental health
- Focus on citizen-friendly means of dissemination

The financing mechanisms of this second Health Programme are wider than previously:

- GRANTS
  - Projects: can be granted to a single beneficiary or multiple ones (public or private bodies); they cannot last longer than 3 years ; the budget available is EUR 28 541 003
  - Operating grants (new) : can be granted to a single beneficiary only (NGO or specialised network) for one year; the budget available is EUR 2 300 000
  - Conferences (new): can be granted to a single beneficiary only (public or private bodies) for one year maximum; the budget available is EUR 700 000
  - Joint actions; the budget available is EUR 2 300 000
- CALL FOR TENDERS - the budget available is EUR 9 300 000.

Some highlights from the day:

- The total budget of the Call will be evenly distributed between the three objectives;
- Compared to the 2007 Call there is no obligation anymore for each individual partner to financially contribute for at least 40% of its part of the budget; the minimum requirement of 40% co-financing applies only at the project level;
- Whereas main and associated partners have to be from the EU 27 MS, Croatia or the EFTA/EEA countries, sub-contractors and collaborating partners may originate from Third countries, when necessary for the good implementation of the project;
- The maximum EC contribution will be 60% of the total budget applied for. This can be up to 80% in cases 'of exceptional utility'. It was said that this will be for outstanding actions in terms of impact and added value at the level of EC policies.
- Strong emphasis was put on the fact that applicants should avoid proposing actions that duplicate actions already implemented in the past or currently implemented; it is the responsibility of applicants to look at what has been already done;

- It was recommended to use European data when developing proposals; this will add value to the proposal as it will enable the Commission to better integrate the project into existing initiatives
- With regard to the objective on health security, projects that translate research into risk management systems and processes will be considered as having added value;
- For operating grants and conferences a pre-proposal can be submitted by 11 April; the final deadline for all types of applications is May 23;
- It is possible to submit another proposal even if already funded by PHEA; this is possible also if receiving operating grants from other DGs as long as the funds are used for different activities
- Recommendations were repeatedly made to start planning and preparing the proposal as soon as possible; especially the discussions with partners and collecting of documents should be a priority
- PHEA will communicate the final results of the call in October.

The second Infoday will be hold on 17 March and there will also be national Infodays in a number of countries. Further information can be found in the following websites:
PHEA: http://ec.europa.eu/phea
DG SANCO http://ec.europa.eu/health/ph_programme/programme_en.htm

For more information you can also contact Liuska Sanna.

18. 'EUROPE IN WIDE SCREEN', A CAMPAIGN LED BY THE MEP'S AGAINST CANCER AND THE PARLIAMENT MAGAZINE

MEPs Against Cancer joined together with the Parliament Magazine and held a meeting on the current state of cancer screening in Europe. Population based screening programmes is one of the most effective way to prevent cancer and also to detect cancer at an earlier stage. This could reduce significantly the number of death caused by cancers. Although the screening programmes have been developed in several EU countries, disparities and inequalities in accessibility and implementation among them remains an important issue.

The progress made since the Council Recommendation on screening in 2003 was reviewed. The European Parliament Health Committee has adopted a draft Cancer Resolution last January, providing the green light for the Resolution to be adopted by the full EP plenary during the week of 10 March 2008.

Moreover, the discussion highlighted the need for a political commitment from the Member States and stronger cooperation between all the stakeholders and the added value of an EU approach. The Slovenian Presidency highlighted the need for civil society to be included in the process of monitoring and evaluating the work.

EPF welcomes the initiative of the MEPs campaign against Cancer and the opportunity given to the patients' organization to discuss with MEPs, the Slovenian Presidency and other stakeholders from different Member States. Many of these developments have been driven by the European Cancer Patient Coalition.

For further information, please contact: Elisabeth Kasilingam.

Link to the Council recommendation:

http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2003:0230:FIN:EN:PDF

19. VALUE + KICK OFF MEETING

On 27-28 February the first meeting of the project Steering Group (SG) was held in Brussels. Participants to the meeting were representatives from the 7 associate partners and some of the collaborating partners.

Not all the participants present had personally participated in the development of the project and quite some time had passed from the application to the final approval from the Commission. Therefore, expectations for this meeting were for a common understanding of the project components and an agreement on implementation; a conceptual framework and a methodology for the approach to some specific components and clarity on the roles and responsibilities of each partner.

With this purpose in mind, we looked together at the project objectives and components with an overall approach first and then tackled the specific work packages. Very intense discussions around the work package related to the assessment of patients' involvement in EU health projects animated the group. This is one of the core components of the project and each participant brought a unique perspective on the topic, which was extremely enriching but also challenging for reaching a common understanding. Nonetheless, we were able to channel the conceptual and theoretic views on definitions of patient, health and patients' involvement into a concrete reference framework for the preliminary information collection of projects. We have defined the first steps and preliminary tools for conducting this research and this will keep us busy until June when the first phase of this work is expected to be completed.

VALUE+ is also about supporting concretely patients' involvement in projects and we explored this second work area keeping in mind the linkage with the previous one. As we intend to accompany and support a

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few currently implemented projects aspiring to patients' involvement, we had to agree on how to identify and select these projects and the approach and methodology we would use. The conclusion we came to is that we need in the short term to identify them and, based on their needs, define at a later stage how to best work with them.

Since projects require also coordination, internal and external communication, reporting, monitoring and evaluation, we spent some time on these issues. We agreed on terms of reference for recruiting an external independent evaluator whose task will be to assess the project progress and outcomes. We brainstormed on the project's website and EPF's website will soon have a specific section on VALUE+ with its own logo and useful content on the project and resources on patients' involvement.

At the end of the two days all partners left with the feeling of having their expectations on the meeting fulfilled and also, since it was the first opportunity for us to meet all together to finally be shaping a true partnership. The next SG meeting will take place in mid- June.

20. WORK IN PROGRESS, EPF SPRING CONFERENCE 8-9 APRIL 2008, (Hotel Silken Berlaymont, Brussels)

We are now only one month away from this year's annual conference, the theme of which is Health Literacy. Given its inclusion in the Health Strategy, we feels 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.

The response to the conference as been very positive and we have a high number of registrations to date. The closing date for registrations is 14th March 2008 and we would invite you to forward your registration form to our Conference Coordinator, Amanda Casey, at conference2008@eu-patient.eu.

This year also gives the opportunity for EPF member organisations to share their ongoing work and projects with their colleagues during a poster session. Enquiries should be forwarded to Amanda at the above email address.

Further information regarding the conference programme is available at:
http://www.eu-patient.eu/conference2008

21. NEW EPF CONTACT DETAILS

EPF has moved to a new office, which is located in the same "European Institutions" area as before: very close to the European Parliament and Luxembourg Station.

Please note our **NEW** postal address:

Rue Belliard 65
1040 Brussels
Belgium

For a detailed map view, click here.

All other contact details - email addresses, telephone and fax numbers are not changed. You can find that on our website: www.eu-patient.eu/about_us/contact_us.htm

We will also keep you informed about new fax and telephone numbers.

22. DIARY

	Mon, Mar 3 -- Tue, Mar 4	**DIA Meeting on Information to Patients** Place: Barcelona Attendance: Nicola Bedlington
	Thu, Mar 6 -- Fri, Mar 7 (Postponed)	**European Voice Conference** Place: Brussels Attendance: Nicola Bedlington
	Tue, Mar 11	**Presentation at the Irish Federation of Pharmaceutical Companies** Presentation at the Irish Federation of Pharmaceutical Companies setting up an Irish Patient Think Tank Place: Dublin Attendance: Nicola Bedlington
	Wed, Mar 12	**Information Day, Public Health Executive Agency** Place: Luxembourg Attendance: Liuska Sanna
	Wed, Mar 12	**GSK Advisory Group** Place: London Attendance: Nicola Bedlington
	Thu, Mar 13	**Patient Safety Working Group Meeting** Place: European Commission, Brussels Attendance: Roxana Radulescu
	Thu, Mar 13	**EuroHealthNet Seminar "Implementing the EU Health Strategy"** Place: Brussels Attendance: Roxana Radulescu
	Fri, Mar 14	**Information to Patients Working Group meeting** Place: Brussels Attendance: Susanna Palkonen (speaker), Roxana Radulescu
	Tue, Mar 25	**CHES meeting** Place: Brussels Attendance: Nicola Bedlington
	Thu, Mar 27	**Compliance and Packaging Conference** Place: Amsterdam Attendance: Nicola Bedlington (speaker)

	Thu, Apr 3	**Steering Group of the Pharmaceutical Forum** Place: Brussels Attendance: Nicola Bedlington
	Tue, Apr 8	**EPF Annual General Meeting** Place: Brussels Attendance: EPF Members
	Tue, Apr 8 -- Wed, Apr 9	**EPF Spring Conference on Health Literacy** Place: Brussels
	Tue, Apr 15	**Meeting with HSO Sweden** Place: Brussels Attendance: Nicola Bedlington, Elisabeth Kasilingam
	Fri, Apr 18	**Patients Rights Day Conference** Place: Gorizia, Italy Attendance: Mike O'Donovan (speaker)
	Tue, May 6 -- Thu, May 8	**May eHealth Conference** Place: Porto Roz, Slovenia Attendance: TBC
	Fri, May 9 -- Sat, May 24	**U.S. Meetings** Attendance: Anders Olauson
	Wed, May 28	**EFPIA Patients Think Tank** Place: Brussels, Attendance: Anders Olauson, Nicola Bedlington
	Fri, May 30	**European Health Policy Forum** Place: Brussels Attendance: Anders Olauson, Nicola Bedlington
	Mon, Jun 2	**Steering Group meeting of VALUE +** Place: Brussels
	Mon, Jun 2	**GIRP (Full Line Wholesalers) Annual General Meeting** Place: Brussels Attendance: Nicola Bedlington
	Fri, Jun 6 -- Sat, Jun 7	**Board meeting** Place: Brussels
	Wed, Jun 11	**AEGSP Conference** Place: Brussels Attendance: Anders Olauson
	Wed, Jun 25	**High Level Advisory Board on FP7** Place: Brussels Attendance: Anders Olauson