



europeanpatients' forum

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Issue 9: 7 May, 2007

Dear EPF members and friends,

Welcome to the fourth issue of the EPF internal mailing 2007. EPF has focused over the last month on our contribution, as associate partners, to two projects submitted in the framework of the seventh framework programme ([Read about these under section 5](#))

EPF also participated in the last month in several important meetings – IAPO's UN event in New York, the E-health week in Berlin, and a meeting in the European Commission on Health Equity ([Brief reports are included in this mailing – section 8, 9 & 10](#)).

An excellent planning meeting took place regarding our project Value +, to be submitted under the public health programme ([More details can be found in section 7](#)).

We will also be involved as associate partner in another PHP proposal which will work towards a European Patient Safety Network

Another major priority for EPF this month has been 'information to patients', you can follow EPF consultation and developments ([in section 3](#))

Regarding the adoption of the new Public Health Programme, to commence next year, the discussion on second reading in the European Parliament began earlier this month. EPF is campaigning hard with MEP allies to push to maximise funding, and the involvement and participation of patient organisation in the programme ([Read more in section 1](#)).

Final documentation will be circulated for the EPF Annual General Meeting on 9th May, a month in advance of the meeting. We are looking forward to meeting many EPF existing and to warmly welcoming new members there! It will be a good time to exchange views and practices between our organisations so that we know each other even better and to enhance the good working spirit in the European Patients' Forum.

Warmest regards,

Anders Olauson
President

Nicola Bedlington
EPF Director

European Parliament

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The next issue will be available on 5th June 2007. The deadline for articles/calendar additions is 31st May

1. Exchange of view in the European Parliament (ENVI committee) on Trakatellis' report on the Public Health Programme

On Wednesday 11 April 2007, Nicolas Pradalié represented EPF at the session of the Environment, Public Health and Food Safety Committee. The debate consisted in an exchange of view on the Antonios Trakatellis' report on the second Public Health Programme (2007-2013). This report was at the stage of a draft recommendation for the second reading in European Parliament.

A drastic cut in the health budget

As you are aware, following the agreement on Financial Framework, the budget of the programme was drastically cut (to €365.6 million). Consequently, the Commission had to streamline its revised proposal, which then formed a basis for the Council common position. The key issue for second reading is the budget. The Rapporteur Antonios Trakatellis proposes in his draft recommendation a budget increase of 10%, which would bring it to € 402.16 million.

Non-negotiable points from the Parliament

The margin for manoeuvre as regards the budget is limited. However, some flexibility is possible given the importance of the Health Programme. Parliament considered very important that the programme explicitly addresses health inequalities, criteria for NGOs eligible for direct funding from the programme, a Community system for cooperation between centres of reference and the establishment of a Europe-wide register on those cancers which are covered by the Council recommendation on cancer screening. Consequently, this should be mentioned in the aim and objectives of the programme.

Action by EPF

EPF has taken bi-lateral contact with a number of key MEPs in the Committee, reiterating the importance of the programme per se, and encouraging the adoption of recommendations on a budget increase, and the role and funding of patient organisations. A letter to this effect will be distributed to all MEPs in the Committee in advance of the second reading on 8th May 2007

Agenda

17th April: time for Amendments deposit

8th May: report scheduled for adoption in ENVI, 2nd reading

21st June 2007: deadline for opinion, 2nd reading

11th July 2007 probable part-session scheduled by the DG of the Presidency, 2nd reading

The Council wants an adoption before the summer break for an implementation for 1st January 2008

Draft Recommendation:

http://www.eu-patient.eu/doclibrary/newsletter/2007_05/659335en.pdf

Previous initial legislative document – Commission (6th April 2005):

<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52005DC0115:EN:HTML>

Initial legislative document – commission & council (24th May 2006):

http://www.eu-patient.eu/doclibrary/newsletter/2007_05/com2006_0234en01.pdf

All the documents related to the public health programme:

<http://www.europarl.europa.eu/oeil/file.jsp?id=5243402>

2. Outcome of the Advanced Therapies Vote in the EP

Following consultation with its members, EPF signed up to a one page statement prepared by EURORDIS and supported by a number of other patient groups to call on the European Parliament to secure early adoption of the EU Regulation on Advanced Therapies.

This Regulation is urgently needed to guarantee that ALL patients from the 27 European Member States have timely and uniform access to Advanced Therapy Medicinal Products which have undergone a robust evaluation process at the European level.

For a copy of the one page statement and information on the next steps for the Regulation and key dates in relation to adoption by the Council, please contact Flaminia Macchia: fmacchia@eurordis.org

For further information:

MEPs set out safer rules for innovative therapies - 25 April 2007

http://www.europarl.europa.eu/news/expert/infopress_page/066-5722-113-04-17-911-20070420IPR05538-23-04-2007-2007-false/default_en.htm

Advanced therapy: MEPs debate report Monday – 24 April 2007

http://www.europarl.europa.eu/news/public/story_page/057-2645-030-01-05-909-20070201STO02644-2007-30-01-2007/default_en.htm

Safer rules for innovative therapies - 18 April 2007

http://www.europarl.europa.eu/news/expert/briefing_page/5266-113-04-17-20070413BRI05265-23-04-2007-2007/default_p001c013_en.htm

Current status of the entire procedure

<http://www.europarl.europa.eu/oel/file.jsp?id=5291242>

For a good overview: Euractiv's website

<http://www.euractiv.com/en/health/advanced-therapies/article-117507>

Report on the proposal for a regulation - 7 February 2007

<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+REPORT+A6-2007-0031+0+DOC+XML+V0//EN>

Other relevant documents on the topic:

Document from the Commission - 16 November 2005

<http://europa.eu/rapid/pressReleasesAction.do?reference=MEMO/05/429&format=HTML&aged=1&language=EN&guiLanguage=en>

3. European Commission's consultation on information to patients

The deadline for the Commission's consultation on quality principles in relation to information to patients, and the Diabetes model is Friday 4th May. EPF will make its submission following the board meeting of Thursday 3rd, having consulted the membership on a draft proposal.

The Commission launched its consultation on the Commission report on information to patients on 19th April. The deadline is 30 June. EPF, in consultation with its members will prepare a draft, and will also convene a meeting with patient groups allies to agree a common document in early June. Further information will be sent shortly.

For further information on Commission's report:

http://www.eu-patient.eu/doclibrary/newsletter/2007_05/draft_infopatients2007_04.pdf

4. *Pharmaceutical Forum*

Susanna Palkonen will be representing the EPF at the next working group of the Pharmaceutical Forum, 10 and 11 May 2007.

EPF will also be arranging an event in the European Parliament to put forward the patients' perspective in relation to the report.

For a copy of our final input on quality principles, and the diabetes model, [please contact the Secretariat](#)

The Commission report can be downloaded on:

http://www.eu-patient.eu/doclibrary/newsletter/2007_05/draft_infopatients2007_04.pdf

Please contact the EPF Secretariat if you would like to participate in the EPF consultation meeting with other patient group allies in early June. Further details regarding the date will be made available as soon as possible

5. *EPF joins two project proposals under FP7*

EPF has joined, as associate partner, two project proposals submitted in the framework of the Seventh Framework Programme on Research and Development (FP7).

One project called EUROHEALTH, led by the Karolinska Institute in Sweden, focuses on the accessibility and information dissemination of health research project outcomes to diverse audiences, including patients' groups.

The second proposal called RESPECT, has two objectives: firstly to clarify the expectations and needs of children and their families who have participated or who might participate in clinical trials for new drugs in Europe. Secondly, to identify methods by which the expectations and needs can be translated into empowering and motivating participants in future clinical trials research. This project will be led by the University of Gothenburg, Sweden.

Both of these projects are highly complementary to the Value + proposal (see section...), and are in line with EPF's goal around meaningful involvement of patients. If funded, EPF will use its experience in these projects as 'case studies' to substantiate our policy work in this area.

For further information on both proposals, please contact Nicola Bedlington, nicola.bedlington@eu-patient.eu

6. FP7 – funding opportunities

Roxana Radulescu attended the Information Day “European Public Health Research in Action” on 25 April, in Brussels, organized by the European Commission's Directorate General for Research.

FP7 has entered into force at the beginning of 2007 and will run until 2013 and provides the strategic and legal background for research funding by the European Union. Participating countries outside the now 27 EU Member States include Croatia, Turkey, Iceland, Israel, Liechtenstein, Norway and Switzerland.

In comparison with the previous programme (FP6), FP7 focuses less on genomics and puts more emphasis on translational research, re-introduces biomedical technology and public health research and reinforces the health policy driven research. Also, participation of International Co-operation Partner Countries (from African, Caribbean, Pacific regions as well as from Asia, Eastern Europe and Central Asia, Latin America, and Mediterranean and Western Balkan) is strongly encouraged.

A new third pillar entitled “Optimizing the delivery of health care to European citizens” has been added to the Health Theme. Proposals must be submitted using a special web-based service - CORDIS

A few topics relevant for patients organizations:

Patient mobility and access to information (3.4.3.)

Self-medication and patients’ safety (impact of the risk of adverse events associated with self-medication (3.1.2)

Patients’ safety research network (3.1.3)

Better use of medicines (3.1.5)

Patient self-management (3.1.7)

Identifying patients' needs in the clinical trials context

Agenda

The publication of the second call for proposals has been postponed for 11 May (deadline for applications 18 September 2007).

For further information:

Health Research under FP7

http://cordis.europa.eu/fp7/cooperation/health_en.html

Call page that includes the Work Programme with the list of topics

http://cordis.europa.eu/fp7/dc/index.cfm?fuseaction=UserSite.CooperationDetailsCallPage&call_id=10

FP6-funded projects in the area of Scientific Support to Policies "Providing health, security and opportunity to the people of Europe":

<http://cordis.europa.eu/lifescihealth/ssp.htm>

7. EPF Project VALUE+

As informed in previous issues, EPF Secretariat is preparing a project proposal in the framework of the Public Health Call for proposals (deadline 21 May 2007) on involvement of patients' organizations in EU health related projects and research (VALUE+). The intention is to produce:

- A database of relevant EU health projects, partners and stakeholders linked to EU health related projects, and patient sponsored projects.
- Policy Recommendations targeted towards the European Institutions and Governments
- A handbook for project leaders and project proposers and for EPF members and patient group allies as a resource to share when they are approached to be involved in projects or leading a project themselves
- A resource kit for patients organisations to build knowledge and capacity to ensure they are able to engage as equal partners in projects

A Conference on patients' involvement and empowerment is planned under Swedish Presidency 2009. Two networking meetings in Bulgaria and Lithuania are also planned with the aim to promote multilateral cooperation amongst major players in the field of health in the 'new' Member States.

Several show case examples of patients' involvement and an analysis of the critical success factors will also be prepared.

Associate partners include: European Men Health Forum, the European Network for Users and Survivors of Psychiatry Empirica, The Spanish Patients' Forum, Retina Europe, Lithuanian Health Policy Centre, the Bulgarian Patient Platform, the European Institute of Women's Health.

For further information, please contact Roxana Radulescu, roxana.radulescu@eu-patient.eu

8. IAPO's meeting on patient-centred healthcare

On the 30th March, EPF's President, Anders Olauson, attended the International Alliance of Patients' Organizations (IAPO) meeting on Patient-Centred Healthcare: "Aligning Healthcare systems with patients' needs" which took place in the United Nations, New York.

The objective of the meeting was to discuss international issues affecting patients' organizations. On this occasion, IAPO presented a Declaration on Patient-Centred Healthcare which was including some overriding principles:

- Respect for patients unique needs and fundamental right to health care and their preferences for health care providers;
- Patient's choice and empowerment;
- Patient's involvement in health policy;
- Patients and their organizations must have access to safe services and support;
- Patient's right to access healthcare information.

Throughout the day, U.N NGO Health Committee members and representatives from international patients' organizations met with healthcare professionals, academics and other stakeholders to try to determine actions to help transform healthcare systems worldwide. Meeting attendees evaluated international case studies and reviewed best practices in advocacy of patient-centered healthcare.

Anders Olauson was invited to talk to the IAPO's Board on IAPO/EPF cooperation, based on a Memorandum of Understanding. This will be taken forward by the respective Secretariats in the near future with a meeting planned in London in July.

On behalf of the Agrenska Foundation and Academy, he was also invited to the White House in Washington to

discuss further cooperation with the First Lady, regarding young patients and empowerment.

For the presentation:

<http://www.patientsorganizations.org/showarticle.pl?id=774>

For the press release:

http://www.eu-patient.eu/doclibrary/newsletter/2007_05/iapo_press_release_-_united_nations.pdf

For the programme of the meeting:

http://www.eu-patient.eu/doclibrary/newsletter/2007_05/Meeting%20on%20PCH%20Programme.pdf

9. *Workshop on Health Equity*

Nicola Bedlington was one of three external experts to address a DG SANCO workshop on Health Equity, 18th April 2007. The workshop was the third of a "case study workshop" series, designed to think about the future challenges that DG SANCO will face in 2009-2014. The workshop discussed the challenges linked to health equity in light of four identified drivers of change (governance, confidence, changing society, and globalisation).

The main objective was to start reflecting and thinking of the potential implications for DG SANCO of the possible evolutions of health equity and how these should be adequately anticipated.

A discussion took place around key questions:

Can we afford equity in health? To what extent will equity in health outcome likely to be considered as part of or separate from equity in other areas of life (e.g. educational opportunities, income, working conditions)? Will health be considered in the future as one normal service (amongst others) considering the increase of promising new technologies for healthcare and also our European ageing society?

How are patients' attitudes and expectations changing? Can we talk about 'patient choice'? How social determinants of health (e.g. income, environment, education policy) will evolve and which elements will increasingly influence patients?

Will patients increasingly manage their health in a more pro-active way (empowered patients via Internet, self-medication trend, personalised treatment)? Is there a general trend towards this? Will it contribute to reduce the inequalities between patients or on the opposite increase it?

Three scenarios were developed to facilitate the discussion and a report will be prepared by DG SANCO.

For a copy of Nicola's presentation, [please click here](#).

For more information and a copy of the report please contact Nicola Bedlington, nicola.bedlington@eu-patient.eu

10. *eHealth Conference – From Strategies to Applications*

The conference was part of the eHealth week organised by the German Presidency of the EU and took place in Berlin between 17 and 19 April 2007. Member States and the European Commission have committed to take steps towards implementing a roadmap for cross-border eHealth services.

Member States representatives reported on the concrete progress made to implement the EC's Action Plan for a European eHealth Area, including ehealth initiatives in their national programmes. Presentations from public officials and industry representatives focused on the crucial importance of eHealth in improving healthcare provision to European citizens: eHealth will enable higher-quality, effective healthcare that is safe, empowering and accessible for patients and cost-effective for governments.

Six specific actions were proposed:

- Engaging in the initiative - MS will facilitate citizens', patients' and health professionals' mobility, with the support of integrated and interoperable eHealth initiatives.
- Organizing European-wide co-operation – MS will work to resolve legal and regulatory aspects, including the protection, confidentiality and security of personal and patient data.
- Building on national eHealth roadmaps – A European health information space can only be built on the basis of accepted and existing national systems that respect institutional, cultural, and linguistic national preferences.
- Creating innovative eHealth services: a deployment strategy that spans research to final adoption by patients and health professionals needs to be developed.
- Combining standardization and safety in eHealth: Patient safety needs to be improved dramatically. Key steps: development and coordination of eHealth standards on user identity, user authentication, technical criteria, and semantic concerns.

- Involving and supporting the eHealth industry and other stakeholders - eHealth business potential needs to be unlocked. Patients' and health professionals' organisations and health service providers are crucial for a full adoption and implementation of information-technology related to healthcare

Roxana Radulescu participated in the conference on behalf of EPF. In a workshop dedicated to patients' empowerment, she presented EPF's work and key policy areas, mission and goals, as well as key issues, from a patients perspective regarding eHealth:

- eHealth as potential to improve patients' safety (reducing medication errors, cross-border issues related to access to patients' electronic records, etc)
- eHomecare as a way to improve quality of life, reinforce care and reduce costs, consideration for health inequalities
- patients as masters the center of the of European Health Record (give consent to the sharing of personal information,)
- patients as key contributors in investigate the use of innovative methods and solutions and in implement incident reporting programmes
- the need to nationalize the debates on eHealth
- the need for consistency between policy statements and implementation.

For further information:

<http://www.ehealth2007.de/> and

<http://www.ehealthnews.eu/content/view/352/37/>

11. *EFPIA Think Tank Meeting*

The European Federation of Pharmaceutical Industries and Associations (EFPIA) think tank met on Friday 20th May. Key items on the agenda included information to patients, and animal testing (addressed at working groups in the morning). It was agreed that EPF will coordinate an independent position on behalf of the patient members of the think tank.

A presentation and debate also took place on counterfeit medicines, and the International Federation of Pharmaceutical Manufacturers and Associations (IFPMA) Clinical Trials Portal.

For further information or a copy of the presentations, [please contact the Secretariat](#)

12. *Notes on EPF Website accessibility*

EPF, with the support of our webmaster Žilvinas Gavėnas, takes the developing of the website very seriously. One of the most important steps is to create fully accessible website, which means, among other issues:

- Disabled users can gain access to all the same information that other users can.
- The website can be properly viewed on a variety of media, including PDA's and other handheld devices.
- The website will be technically robust, easier to maintain and can gain higher search engine rankings.

EPF website has been tested using professional accessibility tools. We are currently in process of it further.

For further information, please contact, Žilvinas Gavėnas, webmaster@eu-patient.eu

13. *News from our Members*

European Multiple Sclerosis Platform (EMSP) would like to announce its major conference - Multiple Sclerosis Information Dividend. Please visit dedicated section on the EMSP website:

<http://www.ms-in-europe.org/news/index.php?kategorie=whatsnext&cnr=5&anr=211>

EMSP is ALSO seeking an external evaluator for its European Project, Multiple Sclerosis, Information Dividend. For more information contact Project Coordinator Mairead O'leary mairead.oleary@emsp.org

14. *Forthcoming Board*

The EPF board have met on 3 May 2007. The key items of the agenda were:

- The follow up to the EPF Conference in March
- Preparation of the AGM in June, including new membership applications
- External Audit Report 2006
- Review of EPF's role in FP7 and public health programme project proposals
- Feedback on the EPF Annual Report 2006
- Preparation of the EPF training seminar in November 2007

A report on key outcomes will be included in the next internal mailing.

15. *Deadlines and EPF Agenda for May-June 2007*

Deadlines in Institutions

| Date | Event |
|------------|---------------------------------------------|
| 4 May 2007 | Consultation on Information to Patients |
| 8 May 2007 | Vote in ENVI on the Public Health Programme |

EPF Agenda, May 2007

| Date | Event |
|-------------|--------------------------------------------------------------------------------------------------------------------------------------------------|
| 10 May 2007 | <i>European Stroke prevention day in the European Parliament</i> Representative: <i>Nicolas Pradalié, Assistant Policy Officer</i> |
| 14 May 2007 | <i>Putting an end to drug counterfeiting in the EP</i> Representative: <i>Nicola Bedlington, Director</i> |
| 22 May 2007 | <i>Pharmaceutical Forum Steering Group meeting</i> Representative: <i>Nicola Bedlington, Director</i> |
| 24 May 2007 | <i>Chemical Ingredients of pharmaceutical and patient safety</i> Representative (Speaker): <i>Nicola Bedlington, Director</i> |
| 30 May 2007 | <i>European Multiple Sclerosis Platform Conference. Brussels, Belgium</i> Representative (Speaker): <i>Nicola Bedlington, Director</i> |

| Date | Event |
|-----------------|------------------------------------------------------------------------------------------------------------------------------------------------------|
| 4 June 2007 | <p><i>Compliance Conference in Geneva</i></p> <p>Representative (Speaker): <i>Nicola Bedlington, Director</i></p> |
| 4-5 June 2007 | <p><i>AEGSP Annual Conference, Warsaw</i></p> <p>Representative: <i>Anders Olauson, President</i></p> |
| 5 June 2007 | <p><i>Think tank</i></p> <p>Representative: <i>Nicola Bedlington, Director</i></p> |
| 6 June 2007 | <p><i>European Heart Network Conference</i></p> <p>Representative (Speaker): <i>Nicola Bedlington, Director</i></p> |
| 9-10 June 2007 | <p><i>EPF Annual General Assembly</i></p> |
| 12 June 2007 | <p>EP interest groups on carers and euro-carers</p> <p>Representative: <i>Roxana Radulescu, Policy Officer</i></p> |
| 13 June 2007 | <p>The European society of Radiology, MRI and EU Physical agents</p> <p>Representative: <i>Nicolas Pradalié, Assistant Policy Officer</i></p> |
| 18 June 2007 | <p><i>GIRP meeting</i></p> <p>Representative (Speaker): <i>Anders Olauson, President</i></p> |
| 18-19 June 2007 | <p><i>PGEU meeting, Vienna</i></p> <p>Representative (Speaker): <i>Nicola Bedlington, Director</i></p> |

| | |
|-----------------|----------------------------------------------------------------------------------------------------------------|
| 26 June 2007 | <i>Pharmaceutical Forum</i> Representative: <i>Anders Olauson, President</i> |
| 30 June 2007 | <i>New Horizons in Treating Cancer, Frankfurt</i> Representative: <i>Nicola Bedlington, Director</i> |
| 21-23 June 2007 | <i>IPI SO Meeting, Romania</i> Representative (Speaker): <i>Anders Olauson, President</i> |