European Patients' Forum eNewsletter A strong patient's voice to drive better health in Europe



// MAY ISSUE

A WORD FROM EPF PRESIDENT AND EPF DIRECTOR

10 years towards active patients' involvement in healthcare

EPF turns 10 this year. To mark the occasion, we will celebrate this important milestone with a major conference under the EU Irish Presidency on Thursday 23 May. Featuring the 2013 European theme *Year of Citizens* dedicated to the rights that come with EU citizenship, the event will translate what this means for patients.

In 10 years patients' role in healthcare has transformed. We are moving from being passive recipients to active and responsible actors of our own health management. We can no longer be considered as being the cost-driver in health, but as a crucial part of the solution towards sustainability and quality in health systems.



Patients are willing and able to contribute individually and collectively to improving the quality, effectiveness and sustainability of healthcare services. However to be empowered patients need to have the skills, information and adequate support to take an active role in the co-management of their disease.

Over recent years EPF has managed to become an important interlocutor with key stakeholders on health issues. This would not have been possible without our member organisations which have contributed so much to these ten years' achievements. In the next issue of this newsletter you will receive our 2003-2013 timeline leaflet that outlines key highlights year by year.

We would like to thank all those people who have been working with us on a daily basis over the past ten years. Together we have contributed to advance patient-centred, equitable healthcare in Europe. And only by continuing to working together will we be able to engineer the changes needed for empowerment, quality and sustainability.

We hope you enjoy this issue of the Newsletter.

Anders Olauson, EPF President and Nicola Bedlington, EPF Director

EPF TO CELEBRATE THE EUROPEAN MONTH OF THE BRAIN UPDATE ON THE DRAFT REPORT ON MEDICAL DEVICES

UPCOMING EVENTS

22/05/2013 | EPF Annual General Meeting

Dublin, Ireland EPF members will elect four new members in the Board and will take important decisions on the budget, on membership requests and on important documents agreements.

EPF attendance: EPF Secretariat, Board & Members



May 2013 is the European Month of the Brain. It is important for all neurological disorders to use this Month to champion their cause. We also welcome Audrey Craven, the current President of the European Federation of Neurological Associations (EFNA), on our blog to share her experience of living with migraine.

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REPORT FROM THE EUPATI ANNUAL CONFERENCE



The EUPATI conference was held in Rome, Italy, on 19 April 2013. More than 180 delegates attended the event coming from 28 countries. It was the occasion, 14 months after the launch of this EPF-led EU project, to hear about the plans under way and to look ahead at the future challenges.

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MORE PATIENTS' INVOLVEMENT IN THE MEDICAL DEVICES WORLD



Rapporteur Dagmar Roth Behrendt MEP (S&D, Germany) published on 12 April the draft report on the proposal for a Regulation on Medical Devices. It takes on board some of the key concerns we have expressed in our position on medical devices but some gaps remain.

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"LIVING WITH DIABETES IS LIKE BREATHING"



Andrew Zammit McKeon is a young student diagnosed with diabetes. He is also member of the EPF Youth Group. On 8-11 July, he will have the occasion to put forward young patients' expectations under the EMPATHY project's seminar. He shares his experience as a young patient on our blog ahead of the event's session "a day in patients' shoes" and provides his opinion on two event's focuses: data protection and discrimination.

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CALL FOR ABSTRACTS: PATIENTS TO CHANGE THE FACE OF HEALTHCARE

23/05/2013 | <u>10th Anniversary</u> Conference Towards active patients' involvement in healthcare

Dublin, Ireland

EPF will celebrate its 10th Anniversary in 2013 and will mark this important milestone with a Conference under the Irish EU Presidency on 23 May featuring the European theme Year of Citizens and the Month of the Brain awareness.

EPF attendance:

EPF Secretariat, Board & Members

24/05/2013 | Conference on Effective Health Care Requires Good Nutritional Care

Dublin, Ireland

EPF will partner with the Patient Network for Medical Research and Health (EGAN), the Irish Patients' Association in cooperation with the Irish EU Presidency, the European Nutrition for Health Alliance (ENHA) and the Irish Society for Clinical Nutrition & Metabolism (IrSPEN) for the organisation of this conference on the added value of appropriate nutritional care for effective disease pathways.

EPF attendance: EPF Secretariat, Board & Members

27 & 28/05/2013 | Conference on "Healthy Brain: Healthy Europe"

Dublin, Ireland

This invitation-only conference, Healthy Brain: Healthy Europe - A new horizon for brain research and healthcare, is the final event of the European Month of the Brain.

EPF attendance: Kaisa Immonen-Charalambous

28/05/2013 | <u>"Recipes for Sustainable</u> <u>Healthcare Conference"</u>

Brussels, Belgium

The conference is a multi stakeholder public debate hosted by AbbVie, Philips and the European Public Health Association.

EPF speaker: Nicola Bedlington

30/05/2013 | Wokshop on Patient Safety

Brussels, Belgium

The Committee on Environment, Public Health and Food Safety (ENVI) of the European Parliament is organising this workshop where EPF will speak about the rights of patients.

EPF speaker: Cristina Padeanu



EPF has signed a Memorandum of Understanding (MoU) with Eucomed, the European medical technology industry association. Such agreement will define a new phase of dialogue on mutually relevant issues.

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On 19 April 2013, a group of health experts from the European Union launched in Brussels the report on Clostridium Difficile Infection (CDI). Cristina Padeanu, project officer, represented EPF at the meeting. This initiative is part of broader efforts on the part of the European Union to address patient safety issues such as antimicrobial resistance

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The Careum Congress 2014 will take place on 17-18 March 2014 in Basel, Switzerland. The event will be entitled "The power of patients 3.0" to explore ways to engage patients in future healthcare systems. You are invited to contribute to the event's themes through a call for abstracts.

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FRENCH CITIZENS' VIEWS ON THE CROSS-BORDER HEALTHCARE DIRECTIVE



On 18 April 2013, the French health associations group (CISS, Collectif inter associatif Sur la Santé), member of EPF, published a survey barometer on the right of patients in France. The survey focuses on the knowledge of French citizens regarding the new European Directive on Cross-Border Healthcare.

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31/05/2013 | Shaping the future of healthcare in Greece

Athens, Greece

The conference is organised by the Financial Times and will provide a thorough assessment of Greece's present status and will illustrate innovative practices and services, leading to health and economic growth.

EPF speaker: Nicola Beldlington

31/05 & 01/06/2013 | IOF Worldwide conference of osteoporosis patient societies

Helsinki, Finland

The IOF Worldwide Conference of Osteoporosis Patient Societies (IOF WWC), held every two years, is an important forum for the development of the global osteoporosis patient movement.

EPF speaker: Kaisa Immonen-Charalambous

05 & 06/06/2013 | Pioneers in Healthcare: World Research Congress

Brussels, Belgium

The World Research and Innovation Congress aims to bring together key stakeholders in healthcare research to discuss the most important issues impacting our efforts to address the 'Grand Challenges' of tomorrow.

EPF speaker: Nicola Bedlington

10 to 14/06/2013 | Men's Health Week

Brussels, Belgium

Our Director will attend the Roundtable meeting on men's health and primary care on 11 June. Primary healthcare services are central to strategies to improve men's health in terms of prevention, early diagnosis and treatment.

EPF speaker:

Nicola Bedlington

26/06/2013 | Health Inequalities in the new EU member states and candidate countries

Brussels, Belgium

Entitled "Equity Of Access To Quality Healthcare", this conference is organised by the National Patients' Organisation of Bulgaria (NPO), with the support of Dr. Andrey Kovatchev, MEP and EPF.

EPF speaker:

Kaisa Immonen-Charalambous



A STRONG PATIENTS' VOICE, TO DRIVE BETTER HEALTH IN EUROPE

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