

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// APRIL ISSUE

A WORD FROM EPF PRESIDENT AND DIRECTOR

A warm welcome to the April issue of the EPF Newsletter.

As we enter the last crucial weeks before the 2014 EU Elections we are delighted to report on the support of key decision-makers that promised to commit to a patients' perspective in their work for the next parliamentary mandate. We also share with you the important testimonial of Katie Murphy, one of the patient/actresses featured in our 2014 campaign video. Katie lives daily with Cystic Fibrosis and was able to offer us some valuable insight into the real need for a stronger patients' voice in Europe.

We were also pleased to see the Clinical Trials Regulation moving from the European level debate towards implementation at member state level. Other crucial dossiers were formally adopted by the European Parliament on Medical Devices and on In Vitro Diagnostics (IVD) Devices. We commend MEP Roth Behrendt's efforts towards ensuring safer devices and more transparency, and we welcome overall the report drafted by MEP Peter Liese (EPP, Austria) but have some concerns regarding provisions on genetic testing.

We took stock of how Greece, Cyprus, Malta and Italy are implementing the EU Directive on Cross-Border Healthcare with patient leaders from these countries at our highly successful second regional conference on this topic that took place on 7-9 April 2014 in Athens, Greece.

Access to healthcare was a core theme at several European Conferences this month and we are pleased to sense a heightened concern about existing barriers and how to overcome them. We represented the patients' perspective at major events such as the Chronic Disease Summit, the DIA EuroMeeting and the WHO consultation on coordinated and integrated care.

Key highlights of the last month also include advances in our Patient-led Academy, EUPATI project, the Joint Action on Patient Safety and Quality of Care (PASQ) and our Capacity Building Programme.

We hope you enjoy reading more on all of this in this Newsletter.

Warmest greetings,

Anders Olauson, EPF President and Nicola Bedlington, EPF Director

[LAST RUN UP TO THE 2014 EU ELECTIONS!](#)

[KATIE MURPHY BLOG ON 2014 ELECTIONS CAMPAIGN](#)

[CALL FOR TENDERS - TRAINING ON FUNDRAISING](#)

UPCOMING EVENTS

Today | [InterQuality Final Conference](#)

Brussels, Belgium

The purpose of the conference is to present the main findings of the Project and their health policy implications, with a focus on the recommended financing models for



With the EU elections fast approaching on 22-25 May 2014, we showed we are also part of the action and the solution. More than 40 Members of the European Parliament and national candidates have signed our Campaign Manifesto "Patients + Participation = Our Vote For a Healthier Europe" and therefore committed to include a patients' perspective in their work. Some quotes.

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SECOND REGIONAL CONFERENCE ON PATIENTS' RIGHTS IN CROSS-BORDER HEALTHCARE



Earlier this month, EPF organised our second three-day regional conference on patients' rights in cross-border healthcare. This time patient leaders from Cyprus, Greece, Italy, and Malta met in Athens, Greece, on 7-9 April to understand the details of this legislation and its transposition at national level.

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LONG-TERM ACCESS TO QUALITY HEALTHCARE IN EUROPE



EPF is collaborating closely with the



EPF talked Katie Murphy, one of the actresses featured in our 2014 campaign video, about our 2014 European Elections Campaign. Katie lives daily with Cystic Fibrosis and was able to offer us some valuable insight into the real need for a stronger patients' voice in Europe.

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VOTE OF THE CLINICAL TRIALS REGULATION



The European Parliament has voted through the revised Clinical Trials Regulation on 20 April 2014 by an overwhelming 594 votes in favour to 17 against and 13 abstentions. The vote means that EPF's efforts long and active engagement on this dossier will enter a new phase.

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EUROPEAN PARLIAMENT OFFICIALLY ADOPTS THE REPORT ON MEDICAL DEVICES



On 2 April 2014, the European

different areas of healthcare.

EPF attendance:
EPF Secretariat

25/04/2014 | Access to healthcare services

Brussels, Belgium

Final workshop of the "Access to healthcare services in times of crisis" series

EPF speaker:
Nicola Bedlington

28/04/2014 | Experts meeting on patient Safety and Quality of Care

Brussels, Belgium

EPF will participate in this European Commission Working Group as an expert representing the voice of patients in Patient Safety and Quality of care

EPF speaker:
Nicola Bedlington

28/04/2014 | Health Literacy and Self-Management: New Challenges

Barcelona, Spain

This conference is organised by the Global Institute of Public Health and Health Policy (IGS) of the Universitat Internacional de Catalunya (UIC), in line with its objective to develop training strategies for self-management skills, aimed both at patients and health professionals. It will be organised with the Spanish Patients' Forum and the European Patients' Forum.

EPF attendance:
Camille Bullot

29/04/2014 | EPF Board Meeting

Brussels, Belgium

EPF is administered by a Board of Members elected by the Annual General Meeting for a term of two years and meet five times a year to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the annual work programme.

EPF attendance:
EPF Board

05/05/2014 | "Towards Better and more Affordable Healthcare: Incentives, Game Theory, and Artificial Intelligence"

Paris, France

The workshop will help identify research

National Patient Organisation of Bulgaria (NPO) to put in place a multi-stakeholder partnership on access to healthcare. The partners met on 20 March 2014 and EPF also hosted the conference "Long-term Access to Quality Healthcare in Europe" as a fringe meeting during the EU summit on Chronic Diseases held on 3-4 April 2014 in Brussels.

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7TH PATIENT MEDTECH INDUSTRY DIALOGUE



On 21 March in Brussels, EPF and the MedTech Industry association EUCOMED held a 7th Dialogue meeting, with 19 participants from their respective memberships. An important item on the agenda was the development of patient-centred models for companies and patients' involvement in the medical devices sector.

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EUPATI: YOUR HEALTH. YOUR KNOWLEDGE



More than 150 representatives from patients' organisations, industry, academia and the world of regulation met in Warsaw on 2-3 April 2014 to plan the next stage of our patient-led Academy, EUPATI. At the heart of the discussions: how to reach at least 100,000 European citizens with an interest in health?

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Parliament formally adopted in plenary the report on Medical Devices that was discussed in October 2013 by 541 votes to 19, with 63 abstentions. MEPs also adopted the report on in vitro diagnostics devices, where we are more concerned by provisions on generic testing.

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BUILDING CAPACITIES WITH OUR NATIONAL AND EUROPEAN MEMBERS



The 4-5 April was an important milestone for the Capacity Building Programme in Hungary; the nine patient organisations involved took part in intensive two-day training on operational planning. EPF will also train 10 EPF European Full Members over the summer to strengthen their capacity in fundraising.

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BEST PRACTICES FOR PATIENT SAFETY AND QUALITY IMPROVEMENT



The workshop focusing on good practices in relation to Patient Safety and Quality of Care took place on 27 March 2014 in Bucharest, Romania. The event is part of the Joint Action on Patient Safety and Quality of Care Exchange Mechanism which aims at exchanging knowledge related to Good Organisational Practices and Patient Safety Practices.

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gaps, concrete use, long term research strategies, and potential projects under the framework of the WE CARE project.

EPF attendance:
Valentina Strammiello

[12- 13/05/2014 | EPF Annual General Meeting](#)

Brussels, Belgium

Following last year's meeting dedicated to the celebration of EPF's 10th Anniversary, this Annual General Meeting marks the start of the effective implementation of our Strategic Plan 2014-2020 with our members.

EPF attendance:
EPF Board & Secretariat

[26/08/2014 | EPF Training on Fundraising](#)

Brussels, Belgium

The Training on Fundraising is delivered within the EPF Capacity Building Programme that was launched in 2012. The objective of the training is to strengthen the capacity of 10 EPF European Full Members in fundraising.

EPF attendance:
EPF Secretariat

[THE EU SUMMIT ON CHRONIC DISEASES](#)



On 3-4 April 2014 EPF participated to the Chronic Disease Summit organised by the European Commission's DG SANCO at the initiative of Tonio Borg, Commissioner for health (pictured). The event aimed at developing a set of policy recommendations for action on how the medical, social and economic burden of chronic diseases should be tackled in the European Union now and in the years to come.

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[FIGHTING ALZHEIMER'S DISEASE AND DEMENTIA TOGETHER](#)



Our member Alzheimer Europe met with MEPs and Commission officials on 1 April 2014 to discuss the growing threat of Alzheimer's and other dementia-related conditions. The conference was hosted by MEP Marina Yannakoudakis (ECR, UK) who is also vice-president of the European Alzheimer's Alliance.

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[PATIENTS' ROLE IN COORDINATED AND INTEGRATED HEALTH SERVICES DELIVERY](#)

[PATIENTS PLAYED A KEY ROLE AT DIA EUROPE MEETING](#)



This year the DIA Europe Meeting took place in Vienna on 25-27 March and attracted over 3000 participants from industry, research, academia, regulators and industry. Our member EURORDIS manages the DIA Patient Fellowship Programme and patient advocates participated actively as session speakers and as members of the planning committee.

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[ROMANIAN PATIENTS TACKLE THE ACCESS TO HEALTHCARE ISSUE](#)



The fifth meeting of the National Forum of Patients' Organisation took place in Bucharest, Romania, on 28-29 March 2014. The event was organised by our member, the Coalition of Patients' Organizations with Chronic Diseases from Romania (COPAC).

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WHO European Region consulted stakeholders on 1 April 2014 in Brussels, Belgium, on the Framework for Action towards Coordinated and Integrated Health Services Delivery (CIHSD). Our Senior Policy Adviser Kaisa Immonen-Charalambous had a chance to share how integrated care can be realised from the patients' point of view and what role we can play.

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CONTACT US

EUROPEAN PATIENTS' FORUM

Rue du commerce 31
1000 Brussels
BELGIUM

Phone : +32 (0)2 280 23 34

Email : info@eu-patient.eu

www.eu-patient.eu | eu-patient.org/blog



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