

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// FEBRUARY ISSUE

A WORD FROM EPF PRESIDENT AND DIRECTOR

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

We are looking forward to our forthcoming Cross-Border Healthcare Conference on 7-9 April 2014 in Athens, Greece ([link](#)). It will be a key opportunity to take stock of how Greece, Cyprus, Malta and Italy are implementing the EU Directive through the eyes of patients' representatives, based on the results of the first conference organised with their Belgian, Dutch, French and Luxembourg peers ([link](#)).

We encourage national patient organisations to work with the Directive and provide constructive critique and guidance to ensure that patients really benefit from it at the end of the day.

Patient organisations can also contribute to the effectiveness of the National Contact Points by ensuring dissemination of information to the grassroots level.

Some of the other key highlights of the last month include the European Commission's Agenda on Patient Safety and Quality of Care, the Data Protection dossier which is now in the Council's hands, the revision of the Medical Devices Directive, a report of the Artic-Light eHealth Conference, and the World Cancer Day celebrated on 4 February.

The 22-25 May EU elections draw closer and our campaign is stepping up a gear with a new campaign video that strongly reflects a patients' movement of solidarity. We hope it will be a significant and positive component of our campaign encouraging politicians to include the patient perspective as they set new policy agendas – please share it as widely as possible.



We will hold a major EPF EU election exhibition at the European Parliament in Brussels (Forum Area, 3rd floor) from 17- 20 March, involving also our member organisations. Please do not hesitate to step by. More details on a special event linked to the exhibition on 19th March will be sent in the next week.

It is our pleasure to welcome Brooke Aksnes, our campaign assistant and volunteer, who will be supporting the 2014 EPF campaign work during the elections season.

Warmest greetings, Anders Olauson, EPF President and Nicola Bedlington, EPF Director

A PATIENT JOURNEY THROUGH
EUROPE

OUR CAMPAIGN FOR THE 2014
EU ELECTIONS

UPCOMING EVENTS

05/03/2014 | [EuropaColon 10th Anniversary Lunch](#)



With the Cross-border Healthcare Directive, the rules on patient access to healthcare have been clarified and are now in force. EPF organised a first conference on this Directive in December, which Dr. Cees Smit, policy advisor of EGAN, has reported on our blog. EPF is preparing the second regional conference that will take place on 7-9 April in Athens, Greece, under the auspices of the Greek Presidency of the Council of the European Union.

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SETTING THE EU PATIENT SAFETY AND QUALITY AGENDA FOR 2014



On 14 February, the Commission Patient Safety and Quality of Care Working Group met for the first time this year to develop the EU patient safety and quality agenda for 2014. This Group brings together representatives from all 27 EU countries, EFTA countries, international organisations and EU bodies.

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PATIENTS AND DISCRIMINATION: WHY IT'S TIME TO GET INVOLVED?



With the European Elections every five years European voters get the opportunity to have a say on what is important to them. 2014 is the year we ask politicians to break down access barriers to healthcare to empower patients to be part of healthcare solutions and build health systems that are more effective and quality-oriented.

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DATA PROTECTION: HEALTH RESEARCH OVERLOOKED BY DECISION-MAKERS



The Data Protection dossier is now in the Council's hands and the Commission anticipates that an agreement by end of the year is possible. On 27 January EU Justice Commissioner Viviane Reding expressed her wishes to see "full speed" on this dossier.

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INFORMAL MEP DISCUSSION ON EQUITY OF ACCESS TO QUALITY HEALTHCARE

Brussels, Belgium

EuropaColon will celebrate its 10th Anniversary featuring the European Colorectal Cancer Awareness Month with the Health Commissioner Tonio Borg as a guest of Honour.

EPF attendance:
Camille Bulot

[11/03/2014 | Launch of the ESR Patient Advisory Group](#)

Vienna, Austria

Collaboration between patient organisations and the European scientific community led to the creation of this ESR Patient Advisory Group where EPF is represented by our Executive Director.

EPF speaker:
Nicola Bedlington

[11/03/2014 | "Medicines, public Health and Patients' Protection"](#)

Strasbourg, France

Workshop organised by the European Directorate for the Quality of Medicines & HealthCare (EDQM) and reserved to journalists. EPF will lead a session entitled "To be a patient today: the concerns in terms of quality of care, access to healthcare and reimbursement".

[13/03/2014 | EuropaBio Patient Dialogue](#)

Brussels, Belgium

The focus will be on next generation genomic sequencing and its implications for patients.

EPF attendance:
Kaisa Immonen-Charalambous

[17-18/03/2014 | 2014 Careum Congress/2nd ENOPE Conference](#)

Basel, Switzerland

The 2014 Careum Congress, which is also the second conference of the European Network on Patient Empowerment (ENOPE), in which EPF is also a partner, will be entitled "The power of patients 3.0" to explore ways to engage patients in future healthcare systems.

EPF speaker:
Kaisa Immonen-Charalambous

[17 to 20/03/2014 | EPF Exhibition at the European Parliament](#)

Brussels, Belgium

EPF is bringing the EPF Campaign for the 2014 EU Elections to the heart of European democracy by presenting an exhibition in the hall of the European Parliament in Brussels on 17-20 March 2014 (Forum Area, 3rd Floor) hosted by MEP Dagmar Roth-Behrendt (S&D, Germany). A cocktail reception will celebrate this exhibition on Wednesday 19 March 2014.



Our membership identified tackling discrimination as a new goal in our strategic plan for 2014-2020. The discrimination which patients encounter in various areas of their life is increasingly of concern to patient organisations. The financial and economic crisis has also led to further discrimination of vulnerable groups in accessing healthcare.

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WORKSHOP ON THE REVISION OF EU MEDICAL DEVICES DIRECTIVE (MDD)



On 27 January, the MedTech industry association Eucomed and EPF held together an interactive workshop to have an open exchange of views on the EU Medical Devices Directive.

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BLOG : BULGARIAN CHILDREN BATTLE FOR TREATMENT



Equal access to affordable, available,



EPF speaker:
Anders Olauson

[18/03/2014 | EU Conference "Health in Europe, making it fairer"](#)

Brussels, Belgium

The conference addresses the issue of improving fairness and equity in health in Europe, improving access to health and combatting discrimination in health.

EPF speaker:
Robert Andrew Johnstone

[21/03/2014 | Patient MedTech Dialogue](#)

Brussels, Belgium

This bi-annual event provides a constructive platform of exchange between patients' organisations and the MedTech industry.

EPF speaker:
Nicola Bedlington

[25-27/03/2014 | DIA Annual EuroMeeting](#)

Vienna, Austria

The DIA's Annual EuroMeeting is organised by DIA, the Global Forum for Therapeutic Innovation & Regulatory Science.

EPF speaker:
Nicola Bedlington

[22-25 /05/2014 | 2014 EU Elections](#)

Europe

On 22-25 May 2014, we will get the opportunity to vote and therefore have a say on what is important to us with the European Parliament Elections and new Commission. Support our campaign to vote for patients' friendly candidates who commit to a healthier Europe where patients are part of the solution to make health systems more effective and quality-oriented.

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"PATIENTS' EMPOWERMENT SHOULD BE THE LEITMOTIV OF THE E-HEALTH AGENDA"



The fourth edition of the Arctic-Light e-health Conference, ALEC 2014, took place in Kiruna (Sweden) on 4-6 February. Around 200 participants gathered around the theme of patient involvement in e-health.

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THE EUROPEAN CANCER PATIENT'S BILL OF RIGHTS



The 4 February 2014 marked the

and high-quality healthcare is a basic EU-citizen right. Unfortunately, this is not the reality for many living in the EU. Our member in Bulgaria, the National Patient Organization (NPO), is making strides to close the gap in equal access for patients living with chronic illness. Here is the story of Alexander and his parents' battle for treatment.

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World Cancer Day. Patient advocacy organisations, healthcare leaders and Members of the **European Parliament against Cancer (MAC)** have chosen this day to launch the European Cancer Patient's Bill of Rights, in the European Parliament in Strasbourg.

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WELCOME BROOKE!



EPF welcomed Brooke N. Aksnes in February 2014. She will be working as a volunteer assistant for the EPF 2014 EU Election Campaign until the end of June 2014.

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

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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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