

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



// MAY ISSUE

A WORD FROM EPF PRESIDENT AND DIRECTOR

A warm welcome to the May issue of the EPF Newsletter!

Last week, we had the opportunity to cast our votes for the 2014-2019 European parliamentary representatives. We look forward to working with the new elected Members of the Parliament who have committed to our Campaign Manifesto to ensure that patients' rights have the right place on the healthcare agenda and in the next Health Commissioner's portfolio.

We share with you on our blog the testimonial of Dimitris Kontopidlis, Cystic Fibrosis (CF) patient and chronic-disease activist who was a candidate for the European Parliament. We deeply share his hope to increase patient participation in shaping healthcare policy and lay the foundations for a fair and healthy Europe, free of inequalities.

This year, our Annual General Meeting provided our members with a new format which gave the opportunity to meet, exchange and celebrate their being part of the European Patients' Movement. We are proud to welcome four new Full Members; one new Associate Member and also our new Board Members who will stay for a two year term.

In May, the Spanish Patients' Forum paid a moving tribute to Albert Jovell who died in November 2013. He was among EPF's pioneers as he has been Member of the EPF Board for two terms since the Spanish Patients' Forum joined EPF in 2007. We thank him wholeheartedly for his invaluable contribution to shaping EPF and his huge contribution in our world.

We are finally delighted to welcome Stefania Laferte and Leah Cozens, our new part-time administrative assistants, dedicated to support the Secretariat to ensure its good running to drive together better health for patients in Europe.

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

Warmest greetings,

Anders Olauson, EPF President and Nicola Bedlington, EPF Director



THE VOTES ARE CLOSED, AND THE CAMPAIGN GOES ON

BLOG: PATIENT AND CANDIDATE FOR THE 2014 EU ELECTIONS

UPCOMING EVENTS

TODAY | [World Multiple Sclerosis Day](#)

World

Multiple Sclerosis (MS) is one of the most common chronic neurological conditions and the leading cause of non-traumatic disability in young adults. The European Multiple



Last week, we had the opportunity to cast our votes for the 2014-2019 European parliamentary representatives. We are delighted to see that some of our Patients Rights Champions made it into the European Parliament. We look forward to working with them to ensure that patients' rights have the right place on the healthcare agenda and in the next Health Commissioner's portfolio.

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REPORT OF OUR ANNUAL GENERAL MEETING



Our 2014 Annual General Meeting took place in Brussels on 12-13 May. This year again, we provided our members with the opportunity to meet, exchange and celebrate their being part of the European Patients' Movement.

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EPF EXCHANGES VIEWS ON MEDICAL DEVICES WITH THE EUROPEAN COMMISSION



Dimitris Kontopidlis, Cystic Fibrosis (CF) patient, vice-president of the Hellenic Cystic Fibrosis Association and chronic-disease activist, was a candidate to the European Parliament in the 2014 EU Elections. He hoped to increase patient participation in shaping healthcare policy and lay the foundations for a fair and healthy Europe, free of inequalities.

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NEW BOARD, NEW MEMBERS



The Annual General Meeting is also the occasion to approve new memberships and for our members to redefine the structure of the EPF Board. We therefore welcomed four new Full Members; one new Associate Member and elected new Board Members for a two year term.

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EPF JOINS EFFORTS TO COMBAT SUPPLY SHORTAGES OF MEDICINES

Sclerosis Platform (EMSP) is a Member of EPF.

[03/06/2014 | EMA Patient Consumer Working Party](#)

London, UK

At this event we will contribute to provide recommendations to the European Medicines Agency and its human scientific committees on all matters of interest to patients in relation to medicinal products.

EPF attendance:
Kaisa Immonen-Charalambous

[10/06/2014 | EPF Policy Advisory Group](#)

Brussels, Belgium

The Policy Advisory Group advises the EPF Board and Secretariat on policy topics prioritised by EPF's annual general meeting and issues which, because of their complex, controversial and/or highly political nature, require detailed and in-depth discussion.

EPF attendance:
Laurène Souchet

[12/06/2014 | PaSO Exchange Mechanism Conference. Sharing Good Practices to improve Quality of Care and Patient Safety in the EU.](#)

Madrid, Spain

The Conference aims to promote the exchange of knowledge and experiences of good organisational practices and patient safety practices around quality of care regarding patient safety and patient involvement/empowerment.

EPF attendance:
Cristina Padeanu

[13/06/2014 | Clinical documentation symposium](#)

Basque Country, Spain

EPF will present developments in the area of electronic health records and patient access to their records under the SUSTAINS project.

EPF speaker:
Walter Atzori

[17/06/2014 | "Does innovative research for allergy and respiratory disease in the European Union benefit patients?"](#)

Brussels, Belgium

Our member, the European Federation of Allergy and Airways Diseases Patients Associations (EFA), is organising this event to discuss EU research on allergy, asthma and chronic obstructive pulmonary disease (COPD), latest results, activities and plans.



EPF wrote a letter in late April to Consumers Affairs Commissioner Neven Mimica to ensure the Commission's support of the Parliament's first reading position adopted on Medical Devices. His office reassured us that patient safety and transparency were well taken into account in the review process.

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INTERQUALITY CLOSING CONFERENCE "SPEND NO MORE BUT SMARTER"



Since December 2010, the InterQuality project investigated the effects of financing systems on the quality of healthcare. The knowledge gained from the 4-year research provides input for European countries to choose the right financing mechanisms in different areas of their healthcare systems, according to their needs and resources, and to pay not more, but smarter.

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LOOKING AT HEALTH LITERACY AND SELF-CARE WITH OUR SPANISH COALITION



EPF has signed the common position between Patients', Consumers' and Healthcare Professionals' Organisations on supply shortages of medicines. At this stage the coalition is collecting signatures to prepare a meeting with the European Commission.

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"WECARE" ABOUT BETTER AND AFFORDABLE HEALTHCARE!



The WeCare Project Consortium "Towards Better and More Affordable Healthcare" met on 5 May in Paris, France. This workshop was organised to outline a research roadmap for the incorporation of game theory and algorithms into healthcare solutions to help address expanding European costs in this sector.

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CELEBRATING THE INTERNATIONAL CLINICAL TRIALS' DAY!

*EPF speaker:
Anders Olauson*

19/06/2014 | [European mHealth Conference](#)

London, UK

Against the backdrop of the European Commission's recent Green Paper on mHealth, this high-level one day conference will bring together top level stakeholders for an interactive cross-sectoral debate on the way forward in developing a European strategy to unlock the potential of mHealth, and the challenges and opportunities that it brings.

*EPF speaker:
Robert Andrew Johnstone*

24/06/2014 | [ENOPE meeting](#)

Malmö, Sweden

EPF is member of the European Network for Patients Empowerment (ENOPE) whose goal is to promote patient empowerment in Europe.

*EPF attendance:
Kaisa Immonen-Charalambous*

27/06/2014 | [AIM disease management workshop](#)

Bruges, Belgium

This is a workshop on "Challenges in Chronic Disease Management" in the framework of the General Assembly meetings of AIM.

*EPF speaker:
Kaisa Immonen-Charalambous*

07 to 09/07/2014 | [Cross-Border Healthcare Regional Conference III](#)

Ljubljana, Slovenia

Patient organisations' representatives from representatives from Austria, Czech Republic, Hungary, Slovakia and Slovenia will learn and share experiences about how the Directive works for patients and how they can contribute a strong patient's perspective. This is the third Regional Conference, one last event will be organised by the end of 2014 in another EU country.

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



Our Membership Officer Camille Bullo attended the conference entitled "Health Literacy and Self-Care: new challenges" on 28 April 2014 in Barcelona, Spain. This event was organised by the Global Institute of Public Health and Health Policy at UIC (Universitat Internacional de Catalunya), in collaboration with our Member, the Spanish Patients' Forum.

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EUROPEAN SUMMIT ON HOSPITAL PHARMACY



Change is a constant in the modern world, and the European hospital pharmacy profession not only wishes to keep pace with it, but to lead it and ensure that patients are the ultimate beneficiaries. Accordingly, the European Association of Hospital Pharmacists (EAHP) called an international Summit on 14 & 15 May 2014, to set out the future direction of the profession.

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International Clinical Trials Day is held on 20 May each year since 2005 to commemorate the day that James Lind began his famous trial. The objective is to make this moment a focal point for international communication events, meetings, debates, and celebrations of clinical research.

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WELCOME STEFANIA AND LEAH



EPF is happy to expand our Secretariat with two part-time Administrative Assistants: Stefania Laferte and Leah Cozens. Welcome aboard and all the best for you!

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10 EPF European Full Members in fundraising.

*Corrigendum: in the last edition of our newsletter, we misspelled the name of former MEP Roth-Behrendt and we wish to apologise for this mistake.

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



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