

European Patients' Forum eNewsletter

A strong patient's voice to drive better health in Europe



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// MARCH ISSUE

A WORD FROM THE EPF PRESIDENT AND EPF DIRECTOR

Dear EPF members and allies,

Welcome to the March issue of the EPF Newsletter!

This month we have been very focused on the consultation process linked to our new Strategic Plan, our application to the European Commission for operational funding in 2014 and our involvement in a new Joint Action on Chronic Diseases which will also start in 2014 and where we will play a key role driving empowerment and health literacy.

We are looking forward greatly to our AGM and 10th Anniversary Conference in May in Dublin, under the Irish EU Presidency. As May is also the month of the brain it is an honour and privilege to work closely with our member organisations representing patients from the neurological and mental health arena in this event which promises to be a key milestone for our organisation.

In this issue we describe policy developments in relation to data protection, some project news on SUSTAINS and patient safety and quality of care and we report on meetings attended in the context of eHealth, mHealth and the European Patient Academy on Patient Innovation (EUPATI). The first EUPATI conference will take place on April 19th in Rome, Italy and we will explore our common vision for 2020 regarding patients' knowledge and involvement in the drug development process.

Warmest greetings,

Anders Olauson, EPF President and Nicola Bedlington, EPF Executive Director

“A STRONG
PATIENTS' VOICE
TO DRIVE BETTER
HEALTH IN
EUROPE”

A NEW JOINT ACTION ON CHRONIC DISEASES IN SIGHT



A new Joint Action on Chronic Disease will take place in 2014. The project has been submitted under the Public

EPF PREPARES RECOMMENDATIONS ON DATA PROTECTION



Rapporteur Jan Albrecht MEP (Greens/EFA, Germany) published in December 2012 the draft report on the

UPCOMING EVENTS

27/03/2013 | [Health Literacy Launch Event](#)

Brussels, Belgium

Our Director will co-chair a Panel Discussion on “How can Health Literacy make a difference?” This event will launch the first-ever blueprint for Business Action on Health Literacy and explore synergies between business, EU institutions and health-related stakeholders in the area of health literacy and health promotion

EPF speaker:
Nicola Bedlington

09/04/2013 | [EPF Board Meeting](#)

Health Programme and is pending approval. EPF will play a key role in the Joint Action, together with partners comprising member states and other stakeholders.

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SUSTAINS'S USER REQUIREMENTS REPORT IS OUT!



EPF has been coordinating a series of user requirements focus groups under the SUSTAINS project. This is part of the key role we play to identify patient requirements and to assess patient empowerment as a result of using patient-accessible Electronic Health Records (EHR). A report emerges from these meetings and provides recommendations associated with the use of these services.

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EPF PROMOTES PATIENTS INTERESTS IN MHEALTH



Mobile health or 'mHealth' is a component of eHealth. EPF contributed to the seminar "mHealth – making a positive difference to End Users" at the Mobile World Congress on 28 February in Barcelona, Spain. This was an opportunity for us to share some of EPF positions developed through our global eHealth-related work and most recently through the Chain of Trust project.

proposal for a General Data Protection Regulation. EPF will soon provide recommendations from the patients' perspective on this draft presented by the European Parliament's Committee on Civil Liberties, Justice and Home Affairs (LIBE).

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FIRST PHASE OF DATA COLLECTION COMPLETE



EPF coordinated the collection of data process under the [European Union Network on Patient Safety and Quality of Care \(PaSQ\) Joint Action](#). This first phase ended on 28 February 2013 and compiled a good number of practices.

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EUPATI PROJECT LOOKS TO THE FUTURE



The [EUPATI project](#) held an afternoon session during the final day of the [DIA EuroMeeting 2013](#) in Amsterdam on 6 March. The project consortium provided a [progress report on its first year](#), outlined activities underway to achieve near term objectives and prepared for its annual conference on 19 April in Rome.

Brussels, Belgium

The EPF Board Members 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:
Board Members

[10/04/2013 | Meeting on the transparency of results for non-commercial clinical trials](#)

Brussels, Belgium

The meeting will be a full and open discussion about the merits and practicalities of providing transparent results, specifically for non-commercial trials, and there will be plenty of time for audience participation in the discussion.

EPF attendance:
Kaisa Immonen-Charalambous

[11/04/2013 | European Patients Rights Day](#)

Brussels, Belgium

The meeting organised by Active Citizenship Network will be entitled "European citizens' rights: patients' involvement and Cross Border Care" in relation with the 2013 European Theme

EPF speaker:
Nicola Bedlington

[11 & 12/04/2013 | Knowledge on participation by EU Health Consumers and Patients in research, quality and policy](#)

The Hague, The Netherlands

Organised by ZonMw, the Netherlands Organisation for Health Research and Development

EPF attendance:
Kaisa Immonen-Charalambous

[18/04/2013 | Annual Conference on eHealth](#)

Warsaw, Poland

This conference is organised by the Polish Healthcare Journal and the German-Polish Health Association and focuses on cross-border healthcare. EPF will talk about "Patients and cross-border healthcare: opportunities and threats"

EPF speaker:
Tomasz Szlagowski

[19/04/2013 | EUPATI Annual Conference](#)

Rome, Italy

EUPATI's first Europe-wide conference will look to 2020. The question theme will be "How will the tools and knowledge provided through EUPATI make a difference to patients' advocates, patients' organisations and the public?"

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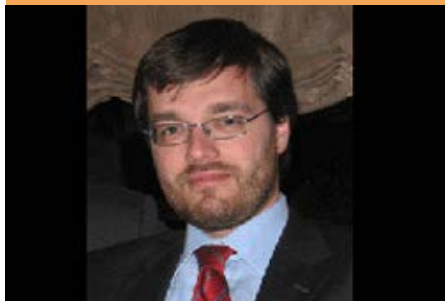
EPF ATTENDED REGULATORY WORKSHOP ON MEDICATION ERRORS



Healthcare providers and patient groups widely recognise that errors in medication are major public health issue. Our Senior Policy Adviser, Kaisa Immonen-Charalambous, attended the Regulation Workshop on Medication errors that took place at European Medicines Agency (EMA) in London last month.

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COMMISSION NOMINATES PATIENT REPRESENTATIVES IN PHARMACOVIGILANCE COMMITTEE



On 28 February 2013 the Commission appointed representatives of patient organisations and healthcare professionals to the [Pharmacovigilance Risk Assessment Committee \(PRAC\)](#) of the European Medicines Agency (EMA). EPF is proud to see one of our board member sitting on this Committee responsible for assessing and monitoring safety issues for human medicines.

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EPF WELCOMES VALENTINA, OUR NEW PROJECT OFFICER!

[READ MORE »](#)

PATIENT SAFETY SURVEY REMAINS OPEN UNTIL 30 APRIL 2013!



EPF needs the help of our members to answer to the Council Recommendation of 9 June 2009 on patient safety. To do so, we have initiated a survey that focuses specifically on patient organisations awareness and involvement in patient safety measures. EPF played a key role in the drafting of the Council recommendation.

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REPORT ON MULTIPLE DISCRIMINATION IN ACCESS AND QUALITY OF HEALTHCARE



On 11 March 2013, the European Union Agency for Fundamental Rights (FRA) published a new report on "Inequalities and multiple discrimination in access to and quality of healthcare". The report looks at some of the practical barriers and experiences of unequal treatment in accessing healthcare that people may face because of a combination of their traits (e.g. ethnic origin, gender, age and disability).

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EPF WELCOMES SARA, OUR NEW MEMBERSHIP OFFICER!

*EPF speaker:
Nicola Bedlington, Anders Olason, Jan Geissler, Liuska Sanna, Walter Atzori*

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 and members*

23/05/2013 | [10th Anniversary 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 and 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 and members*

LOOK AT EPF NEWS !

DISCOVER EPF PROJECTS & INITIATIVES

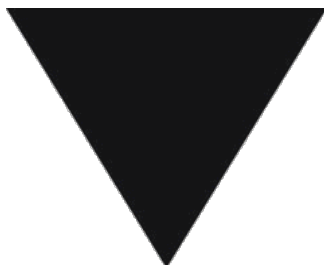
FIND MORE ABOUT EPF POLICY WORK



Valentina Strammiello joined EPF in late January 2013. She holds a BA in International Relations and a Master's Degree in European Studies. She will work as Project Officer, supporting the Programme Manager and Senior Programme Officer, while providing occasional assistance to other members of EPF staff.

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NEW BLACK TRIANGLE SYMBOL FOR MEDICINES SUBJECT TO ADDITIONAL MONITORING



A black inverted triangle '▼' will shortly appear on the package leaflet of certain medicinal products on the EU market. This symbol will flag to patients and health care professionals that a medicinal product is subject to additional monitoring, and its accompanying text will encourage them to report any adverse reaction through national reporting systems.

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Sara Bensaude De Castro Freire joined the EPF Secretariat in March 2013 as Membership Officer. EPF created this new position recently to be able to respond better to the needs of our growing membership. She will also provide ongoing support on the issues that matter to our members and enable them to optimise the benefits of being part of the European Patients' Movement through EPF.

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WHO ARE EPF MEMBERS ?



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

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