

European Patients' Forum Newsletter

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



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// JUNE ISSUE

A WORD FROM EPF PRESIDENT AND DIRECTOR

EPF celebrates ten years

Commissioner Borg and Irish Minister for Equity, Kathleen Lynch, joined EPF and our members in Dublin last month to celebrate [10 years of EPF](#). It was the occasion to reflect on our past achievements and challenges and also look forward to our role and responsibilities in the future. Our AGM also endorsed unanimously a new and ambitious strategic plan for the next EU programming period.

Our members applauded our new logo during our ten year anniversary's celebration. This new visual identity reflects our development in recent years and our commitment to a new strategic vision and goals for the future as well as the changing role of patients.

The new logo mirrors this positive growth. It visualises three different and dynamic figures who gather together to shape a forum. Together they are empowered to become active players that make the voice of European patients heard widely and loudly. And all of them are equally included in this forum to demonstrate the need for equal access to healthcare, regardless of disease or background.

Our logo conveys our ideals, motives and objectives — a sense of what we are all about. Our appearance has evolved with time, but our essence remains: we are a strong patients' voice to drive better health in Europe.



For more information about the new logo, please [visit our website](#) and watch it [on video on YouTube](#).

We hope you like our new visual identity and you enjoy this issue of the newsletter.

Anders Olauson, EPF President and Nicola Bedlington, EPF Director

EPF'S ANNUAL MEETING

CONFERENCE TOWARDS ACTIVE

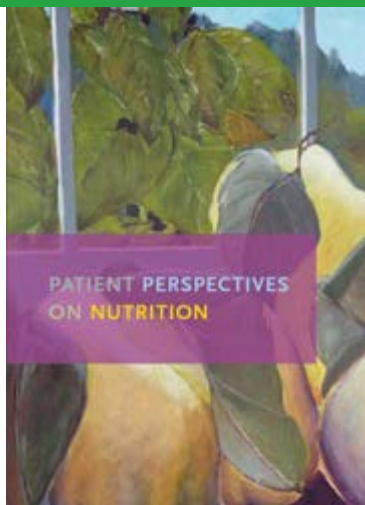
WELCOMES SIX NEW MEMBERS AND ELECTS FOUR NEW BOARD MEMBERS



Brussels, 22 May 2013 – The 2013 EPF Annual General Meeting (AGM)'s assembly welcomed six new members - two Full Members, three Associate Members and one new Provisional Member and (re-)elected four members of the Board for a two year term.

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FIRST BOOKLET PROVIDING PATIENTS' PERSPECTIVES ON NUTRITION



Patient groups and international nutrition experts across Europe pooled their knowledge together to produce the booklet "Patient perspectives on nutrition". This document explores nutrition from a relatively new angle: it demonstrates that nutrition has a key role to play in the management of diseases, to improve health outcomes and quality of life of patients.

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PATIENTS' INVOLVEMENT IN HEALTHCARE



We celebrated our 10th Anniversary on 23 May 2013 with a major conference in Dublin under the EU Irish Presidency and Commissioner Tonio Borg and Irish Minister for Equity, Kathleen Lynch as special guests. Featuring the 2013 European Year of Citizens dedicated to the rights that come with EU citizenship, the event translated what this means for patients while championing the European Month of the Brain.

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CONFERENCE ON EQUITY OF ACCESS TO QUALITY HEALTHCARE



On 26 June 2013 a conference on "Equity of Access to Quality Healthcare" will take place at the European Parliament. The National Patients' Organisation of Bulgaria (NPO), with the support of Dr. Andrey Kovatchev MEP and EPF's collaboration, will tackle for the second time the issue of health inequalities.

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EPF FROM 2003 to 2013
Watch it on YouTube!

UPCOMING EVENTS

19/06/2013 | [EFPIA Think Tank](#)

Brussels, Belgium

EFPIA's Think-Tank serves as a forum for both Efpia members and European patients' organisations.

EPF speakers:

Nicola Bedlington, Kaisa Immonen-Charalambous

25 & 26/06/2013 | [ENOPE "European Network on Patients' Involvement"](#)

Utrecht, The Netherlands

The goal of ENOPE is to promote patient empowerment in Europe through evidence based programmes which focus on living with chronic disease.

EPF attendance:

Kaisa Immonen-Charalambous

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:

Nicola Bedlington

02/07/2013 | [The launch of Guiding Principles Promoting Good Governance in the Pharmaceutical Sector](#)

La Hulpe, Belgium

The List of Guiding Principles Promoting Good Governance in the Pharmaceutical Sector was created under the Platform on Ethics and Transparency. This list establishes the governance necessary to guide interactions in the pharmaceutical sector between patients, physicians, competent authorities and pharmaceutical industries.

EPF speaker:

Nicola Bedlington

5 & 6/07/2013 | [Colorectal Cancer Patient Conference \(CCPC\) 2013](#)

POSITIVE MOVE TOWARDS A MORE PATIENT-CENTRED CLINICAL TRIALS EU FRAMEWORK



EPF welcomes the recent vote in the European Parliament on the legislative proposal for a Regulation on clinical trials. The ENVI Committee unanimously approved the draft report of Glenis Willmott (S&D, UK), adopting important amendments to the Commission's proposal.

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EMPATHY SEEN THROUGH MEDICAL STUDENTS' LENS



The EMPATHY project or "Europe meets Young Patients" is a four-day seminar that will take place in Brussels on 8-11 July. Young patients will have the chance to address their needs to various health stakeholders. The European Medical Students' Association (EMSA) will attend this event that they consider as an "amazing opportunity where direct contact with young patients involved".

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LAUNCH OF THE UNDER PRESSURE WEBSITE

SMARTCARE: FIRST MEETING OF THE USER ADVISORY BOARD



The SmartCare project, launched in 2012, aims to use Information Communication technology (ICT) to integrate both healthcare and social care to tailor these services to individual needs of older patients. The project's User Advisory Board (UAB) met for the first time on 5 June 2013. EPF is member of this Board to ensure the project takes into consideration the interests of older patients.

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HOW TO CREATE BETTER PATIENT INFORMATION LEAFLETS FOR PATIENTS?



The European Commission will soon report about the shortcomings of the current Product Information leaflets and make recommendations for improvement. A EuroDia Meeting session on 3-4 March 2013 in Amsterdam took the opportunity to look at how to create Product Information that meets the needs of the customer -patient, carer or healthcare professional.

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GET BREATHLESS FOR PULMONARY HYPERTENSION

Barcelona, Spain

The purpose of CCPC 2013 is to sustain EuropaColon's efforts to combat the disease across Europe, to engage, educate, inform and support colorectal cancer patients alongside all relevant stakeholders.

EPF speaker:
Kaisa Immonen-Charalambous

[09/07/2013 | Launch event of the WHO 2013 "Priority Medicines for Europe and the World"](#)

Brussels, Belgium

Presentation of the 2013 report and perspectives from the various stakeholders that participated in the update process.

EPF speaker:
Kaisa Immonen-Charalambous

[28 & 29/10/2013 | Save the Date! EPF 6th Regional Advocacy Seminar](#)

Zagreb, Croatia

The event is open to patients organisations' leaders from Croatia, Serbia, Montenegro, Macedonia and Turkey (the EU acceding and candidates countries) and will look at the link between policy-making at EU and member state level and advocacy skills for patient advocates. Draft programme and online registration form will be soon available on EPF website.

LOOK AT EPF NEWS !



DISCOVER EPF PROJECTS & INITIATIVES



FIND MORE ABOUT EPF POLICY WORK



WHO ARE EPF MEMBERS ?





The European Multiple Sclerosis Platform (EMSP) launched, on May 29 - World multiple sclerosis (MS) Day 2013 – the Under Pressure website. The multimedia platform aims to reveal discrepancies in the treatment, employment and empowerment of people with MS across Europe.

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PATIENTS' EMPOWERMENT TO SHAPE THE FUTURE OF HEALTHCARE



The conference “Shaping the future of healthcare in Greece” was organised by the Financial Times on 31 May in Athens, Greece. It was the occasion to illustrate innovative practices and services, leading to health and economic growth. Nicola Bedlington talked about the patient being part of the solution to sustainable healthcare.

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THE IMPACT ON HEALTH PROFESSIONAL'S MOBILITY ON PATIENTS' RIGHTS



EPF approved several new membership requests at our Annual General Meeting on 22 May. Amongst them, we welcomed the European umbrella organisation for Pulmonary Hypertension (PHA Europe) as a full member, which is. On 5 May they celebrated the world PH Day with the campaign “Get Breathless for PH”.

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5TH 'PATIENTS – MEDTECH DIALOGUE' MEETING



Patient leaders from EPF's membership and representatives from the medical technology industry convened their 5th MedTech Dialogue Meeting on 5 June in Brussels. The Memorandum of Understanding and Terms of Reference for this group was presented briefly to contextualize the work of the day.

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A SURVEY ON RISKS AND BENEFITS FOR PATIENTS AND FAMILIES



MEP Minodora CLIVETI and MEP Nessa CHILDERS organised a meeting on 14 May 2013 on "The rights of the patients and the health professional mobility in the EU". They wanted to look at the effects of health professionals' migration, mainly in Romania and Ireland, the countries they represent in the European Parliament.

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The Welsh Institute for Health and Social Care (University of South Wales) and Genetic Alliance UK work in partnership on a second Risks and Benefits project. This work will ensure that the patients' perspective is understood and valued as part of regulatory decision making processes for new medicines.

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IOF WORLDWIDE CONFERENCE



Kaisa Immonen-Charalambous, EPF Senior Policy Adviser, spoke at the IOF Worldwide Conference of Osteoporosis Patient Societies which took place in Helsinki on 31 May – 1 June 2013.

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TO DRIVE BETTER HEALTH IN EUROPE**

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This e-newsletter arises from the EPF 2013 Work Programme, which has received funding from the European Union, in the framework of the Health Programme.

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