

# European Patients' Forum eNewsletter

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



// OCTOBER ISSUE

## A WORD FROM EPF PRESIDENT AND EPF DIRECTOR

Welcome to the October's EPF newsletter. As we go to press, we learn that Vice-President Maroš Šefcovic takes temporary charge of health and consumer portfolio until a new Maltese Commissioner is appointed – we will keep you informed of any developments through our [website news](#). In this issue read about EPF's contribution to the European Health Policy Forum Gastein, our position on the Transparency Directive and events attended in the context of the Clinical Trials Regulation. EPF's HTA survey reports are now on line – we also share our plans for next steps in patient involvement in HTA. EPF has been active in a number of other key meetings, including a conference of nurses working in the mental health field across the European Union and an eHealth Conference in Denmark. We hope you enjoy this issue of the EPF Newsletter!

Warmest greetings,

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



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

### REGIONAL ADVOCACY SEMINAR: LET'S GO!



EPF's 5th Regional Advocacy Seminar will commence this week in Lisbon, Portugal, on 25-26 October. Focussing on financing of patient organisations and fundraising, the Seminar will bring together 50 patient leaders from Greece, Italy, Portugal, and Spain to look at strategies to fund patient groups during times of austerity. A full report will be given in the next issue of the EPF newsletter.

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GASTEIN 2012: FUTURE

### FIRST CONFERENCE ON HEALTH INEQUALITIES



The adoption of a Resolution by the participants concluded the First Conference on Health Inequalities in the New EU Member States. The conference, organised by the National Patients' Organisation in Bulgaria and supported by EPF, was a first step taken towards creating and implementing a comprehensive, continuous strategy for tackling health inequalities as patients are 'living' them, in the new EU Member States and candidate countries.

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A FLAVOUR OF EPF'S POSITION ON

### UPCOMING EVENTS

**21 & 24/10/2012** | [World Health Summit 2012](#)

#### Berlin, Germany

Under the theme "Research for Health and Sustainable Development", the event will focus on issues and possible solutions for non-communicable diseases and conditions of global concern

*EPF speaker:*  
Tomasz Szlagowski

**25 & 26/10/2012** | [5th EPF Regional Advocacy Seminar](#)

#### Lisbon, PT

Theme: "Fundraising: Resourcing Patient Organisations for a Strong Patient Movement". Capacity building seminar for patient organisations from PT, EL, IT, ES on fundraising

**25 & 26/10/2012** | [3rd Pan European Conference on Haemoglobinopathies & rare anaemias](#)

#### Cyprus

Our Board Member, Philippe Chircop, will give a presentation entitled "Towards a more patient-centred healthcare system & effective services" at 14.30-16.00 session on 26 October

**HEALTHCARE MODELS NEED TO INCORPORATE PATIENTS**



The current global financial, economic and social crises have resulted in substantial cuts in healthcare budgets. EPF reiterated at the [15th edition of the European Health Policy Forum Gastein](#) that we believe that the slashing of health budgets should halt as a knee jerk response to the crisis. The crucial element to be incorporated in future health care models is: the patient.

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**A STREAMLINED PROPOSAL TO FACILITATE CLINICAL TRIALS**



On 24 September 2012 EPF attended a [lunch debate organised by European Voice on the European Commission's legislative proposal for a Regulation on clinical trials](#). At this event, EPF highlighted three issues of concern to our members that were not explicitly addressed by the other discussants: information to patients and informed consent; patients' access to results of clinical trials; and patient involvement in clinical trials.

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**THREE REPORTS TO SHAPE PATIENT INVOLVEMENT IN HTA**

**THE MEDICAL DEVICES PROPOSAL**



Susanna Palkonen, EPF vice president, gave a foretaste of our position on the Commission's proposal on Medical Devices at the MedTech Forum, on 11 October in Brussels. She highlighted that, in EPF's perspective, the future regulation should aim at achieving a high level of patient safety and quality of care together with improved transparency and information for patients.

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**"EPF TAKES A STAND ON THE EU TRANSPARENCY DIRECTIVE"**



National measures on pricing and reimbursement of medicines have a direct impact on patients' access to therapies. This is why on 1 October we released our position statement on the so-called Transparency Directive ([Council Directive 89/105/EEC](#)). Overall, EPF welcomes the Commission's proposal as it marks a step forward for more transparent and effective processes. However further steps are needed to strengthen good governance and improve patients' access to therapies.

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**EUROPEAN PATIENTS' ACADEMY: UP, RUNNING AND REAL**

*EPF speaker:*  
*Philip Chircop*

[25 & 26/10/2012 | International conference on Cross border health care](#)

**Bled, Slovenia**

University Medical Centre Ljubljana (Slovenia) organises this conference to stress the importance of changes that await us with the introduction of a new European Directive (2011/24/EU), which governs patient rights in cross-border treatment.

*EPF speaker:*  
*Kaisa Immonen-Charalambous*

[29/10/2012 | The Economist Conference on "New responses to non-communicable diseases"](#)

**Geneva, Switzerland**

The theme of the conference is "Strengthening health systems, changing behaviours". Our Director will take part in the panel "How to incentivise and empower patients to manage their care and to adopt healthy lifestyles?"

*EPF speaker:*  
*Nicola Bedlington*

[13/11/2012 | Setting standards - Discussing health inequalities in the context of the European Year of Citizens](#)

**Brussels, Belgium**

This hearing will put the spotlight on mental health and homelessness

**LOOK AT EPF NEWS !**

**DISCOVER EPF PROJECTS & INITIATIVES**

**FIND MORE ABOUT EPF POLICY WORK**

**WHO ARE EPF MEMBERS ?**



Health Technology Assessment (HTA) is a multidisciplinary tool that ideally should involve patients' perspectives; however, in reality there is still a long way to go in achieving meaningful patient involvement in HTA. EPF has just released three consecutive reports to help patients gaining a foothold in the HTA process.

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#### REPORT "REDESIGNING HEALTH IN EUROPE FOR 2020"



As member of the EU Task Force of high level advisors on e-Health, our President Anders Olauson has presented the [Task Force's report "Redesigning health in Europe for 2020"](#) at the Danish eHealth Observatory's Annual Meeting on 9 September. In this report the group has identified five levers for change and formulated five recommendations for action.

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The [European Patients' Academy for Therapeutic Innovation \(EUPATI\)](#) has released a [report](#) about its first steps towards the development of pan-European and national infrastructures after its inaugural regional workshop, held in Frankfurt, Germany, on 5 September 2012. On the agenda: National Liaison Teams and National Platforms, network and communication opportunities, the collection of educational material and the delivery of trainings.

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#### PATIENTS' VOICE HEARD AT THE HORATIO FESTIVAL ON PSYCHIATRIC NURSING



Anders Olauson addressed a keynote speech at the 2nd Horatio Festival 2012, the festival of the European Psychiatric Nurses, on 23 September in Stockholm, Sweden. The event was entitled "Vision, Knowledge and Practice" and our President has decided to change the order of these words to illustrate the patients' voice in mental health issues.

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**BIOLOGICS AND BIOSIMILARS  
EXPLORATORY MEETING IN  
BRUSSELS**



On 27 September, EPF attended a meeting bringing together health professionals and patient groups to discuss the challenges and potential of biologics and biosimilars, particular in the current economic climate and some of the pharmacovigilance and safety issues linked to biosimilars.

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**NEW WEBSITE FOR THE PASQ  
JOINT ACTION!**



The European Union Network for Patient Safety and Quality of Care (PaSQ), launched in April 2012, is a three-year Joint Action co-financed by the European Commission under the Health Programme. A [new website](#) has been launch to provide information about the project and the partners but also about latest updates thanks to news and event sections.

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**POLICYMAKERS SUPPORT EPDA'S  
CONSENSUS STATEMENT**

**EFPIA PATIENTS' THINK TANK  
MEETING**



The [European Federation of Pharmaceutical Industries and Associations \(EFPIA\) Patients' Think Tank](#) meeting took place on 28 September in Brussels. This regular event is the occasion for Patients' organisations and the pharmaceutical industry to have a dialogue on EU policy issues in the area of health and innovative medical research.

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**LAUNCH OF THE EURO HEPATITIS  
CARE INDEX**



The European Liver Patients' Association (ELPA) announced the launch of the Euro Hepatitis Care Index in the context of a high-level multi-stakeholder workshop on 6 November in Brussels, Belgium.

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The European Parkinson's Disease Association (EPDA)'s The European Parkinson's Disease Standards of Care Consensus Statement, has been read, supported and endorsed by European policymakers since its launch last year in the European Parliament.

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

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