

European Patients' Forum eNewsletter

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



// SEPTEMBER ISSUE

A WORD FROM EPF PRESIDENT AND EPF DIRECTOR

Welcome to the EPF Newsletter. In this issue we are delighted to share with you the outcomes of our Youth Meeting in Malta in late August. Special thanks to EPF board member Philip Chircop for his fantastic support in organising this. We are also very happy to report on two recent major meetings linked to the European Patients' Academy (EUPATI) which EPF is leading on. You will find a brief update on current on-going projects and the events to which EPF has contributed. The patient's role in primary care, and demography and aging are in focus this month. Please do not hesitate to come back to the EPF secretariat should you wish to learn more about this work.

Our warmest wishes,

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



A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

UPCOMING EVENTS

20 & 21/09/2012 | [1st Conference of Health inequalities in new EU Members States](#)

Sofia, Bulgaria

Two-Days conference organised by National Patients' Organisation of Bulgaria (NPO) and supported by EPF focusing on health inequalities from a perspective of Patients with chronic disease

EPF attendance:
Nicola Bedlington, Tomasz Szelagowski

20 - 23/09/2012 | [2nd European Festival of Psychiatric Nursing](#)

Stockholm, Sweden

Anders Olauson's keynote speech will explore the fundamental importance of the meaningful involvement of patients, of users of mental health services in care planning and delivery, to ensure that their voice is heard.

EPF attendance:
Anders Olauson (speaker)

24/09/2012 | [Panel discussion on clinical trials](#)

Brussels, Belgium

Organised by European Voice to discuss the new legislative proposal

EPF attendance:

EPF TO SUPPORT THE HEALTH INEQUALITIES CONFERENCE



This month EPF is supporting closely the [National Patients Organisation](#) in Bulgaria in a long-term strategic initiative on health inequalities with particular emphasis on the new Member States and Candidate countries. The aim is to encourage collaboration and exchange of good practice and know-how, and most importantly, to identify and communicate the needs of patients, how they are 'living' health inequalities, and their views on moving forward. A [conference on 21-22 September in Sofia](#) marks the start of this important process.

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PATIENTS' ACADEMY: MANY VIEWS, VARIED IDEAS, ONE VISION



With its first public workshop kick-off event on 5th of September 2012 in Frankfurt, the [European Patients' Academy \(EUPATI\)](#) provided an open forum for stakeholders from all over Europe. More than 120 registered participants from 24 countries attended this event, demonstrating the broad interest and real need for more patient involvement when new treatments are being developed.

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EPF YOUTH GROUP TO SHAPE THE EMPATHY PROJECT



The Youth Group laid the foundations of its work for the next months during its second Annual Youth Meeting. This year's meeting served as the springboard of the annual meeting of the Youth Group and as the kick-off meeting of the first youth project "EMPATHY: Europe Meets Young Patients".

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JOINT ACTION ON PATIENT SAFETY AND QUALITY OF CARE



The European joint action on patient safety and quality of care (JA PaSQ) formally started in April 2012, with a kick-off meeting taking place at the end of May. During the last months, the partners have developed the detailed work plans of the different work packages, developed a glossary of terms and conceptual framework as well as draft questionnaires were gathering information.

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"2022 – 10 YEARS TO SHAPE THE DEMOGRAPHIC SHIFT"

CHAIN OF TRUST PROJECT'S FINDINGS: FOLLOW-UP WITH NATIONAL ROUNDTABLES



After one year and a half, it is time for the two year telehealth user-led [project Chain Of Trust](#) to review on its state of progress. The project team has carried out a series of activities including a literature review, an online survey, six national workshops and four European focus groups. The results of these activities are presented in a report which is set to be published very shortly. Follow-up roundtable will follow.

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"PRIMARY CARE IS THE ENTRANCE POINT OF HEALTHCARE FOR PATIENTS"



Our President, Anders Olauson, attended the [4th Biannual Conference on the Future of Primary Care in Europe](#), organised by the [European Forum for Primary Care](#), on 3-4 September in Gothenburg, Sweden. During his keynote address, he entered the hearth of the matter: "Primary Care plays an absolutely crucial role for patients with chronic diseases as it is the entrance point in healthcare."

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TESTIMONIAL: 'HEALTHY AGEING AND THE CHALLENGE OF COMORBIDITY'

Kaisa Immonen-Charalambous

[24 & 25/09/2012 | EMA Patients & Consumers Working Party](#)

EMA, London

Joint meeting with Health Professionals Working Group

EPF attendance:
Susanna Palkonen

[26 & 27/09/2012 | Joint EFGCP/DIA/EMA Medicines for Children Conference](#)

EMA, London

Conference on paediatric drug development

EPF attendance:
Susanna Palkonen

[27/09/2012 | Workshop on Biosimilars](#)

Brussels, Belgium

EPF will attend in order to look at some of the core issues for patients in relation to biosimilars

EPF attendance:
Nicola Bedlington

[28/09/2012 | EFPIA Think Tank](#)

Brussels, Belgium

Patients' organisations and the pharmaceutical industry as consumers and producers of pharmaceutical products set up a joint Think-Tank in order to have a dialogue on EU policy issues in the area of health and innovative medical research.

EPF attendance:
Kaisa Immonen-Charalambous, Nicola Bedlington

[03 & 06/10/2012 | European Health Forum Gastein](#)

Bad Hofgastein, Austria

Focus on "Crisis and Opportunity – Health in a time of Austerity". Gastein 2012 will address the core question of how health policy and healthcare systems are going to be shaped in the upcoming decades.

EPF attendance:
Anders Olauson, Robert Johnstone, Nicola Bedlington

[03 - 05/10/2012 | JA PaSQ coordination meeting](#)

Madrid

2nd coordination meeting of WP 4, 5 and 6

EPF attendance:
Kaisa Immonen-Charalambous

[08 & 09/10/2012 | EMA workshop](#)

London

"Pharmacogenomics: from science to clinical care"



Nicola Bedlington attended the [World Demographic and Ageing \(WDA\) Forum](#), on 28 – 30 August, St Gallen, Switzerland, as part of a delegation of the Philips Think Tank on Ageing Well in the framework of [Philips Centre for Health and Well Being](#). A ten year time perspective framed the discussion at this year's WDA Forum: "2022 – 10 Years to Shape the Demographic Shift".

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EU HEALTH PROGRAMME: THE LIST OF NATIONAL FOCAL POINTS IS UPDATED



On 29 August 2012, DG SANCO has updated its [list of National Focal Points participating in the EU Health Programme](#). The focal points are typically the competent national authorities that help the Executive Agency for Health and Consumers (EAHC), entrusted by the European Commission, to implement the Health Programme.

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EPF posted a [new entry on its blog](#): a testimonial from Cees Smit on how to incorporate the challenge of comorbidity in the "healthy ageing" concept. Cees Smit is policy advisor for EGAN, the European Patients Network for Medical Research and Health, member of EPF.

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EPF CALL TO SUPPORT WOLD ARTHRITIS DAY!



Join the 2012 "Waving" campaign and be part of the bigger picture! It is fun, physical and in a great cause. As part of the "Move to Improve" initiated by the World Arthritis Day team, this year they are asking people around the world to send a picture of people waving.

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EPF attendance:
Kaisa Immonen-Charalambous

[10 & 11/10/2012 | IPPOSI Information Day - Health Technology Assessments](#)

Dublin, Ireland

This event is an IPPOSI Information Day for Patients' Organisations, Scientists and Industry members. It will introduce IPPOSI members to the principles of pharmacoeconomics and the methodology used in the HTA process in Ireland and elsewhere.

EPF attendance:
Nicola Bedlington

[16/10/2012 | Policy Dialogue on the Role of ICT in supporting active healthy ageing](#)

EPF will bring the patients' perspective to the debate on the role of eHealth and ICT in promoting active and healthy ageing.

EPF attendance:
Nicola Bedlington, panelist

[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

EPF attendance:
Liuska Sanna, Nicola Bedlington, Özgün Ünver

[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 attendance:
Kaisa Immonen-Charalambous (speaker)

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

Brussels, Belgium

Save the date! This hearing will put the spotlight on mental health and homelessness.

LOOK AT EPF NEWS !



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MEMBERS ?**



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

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