

# European Patients' Forum Newsletter

## A strong patients' voice to drive better health in Europe



//SEPT 2017 ISSUE

Welcome to the latest issue of our Newsletter!

Our campaign on Access to Healthcare is swiftly approaching its end with the closing meeting planned for 6th of December in the European Parliament, Brussels! Please save the date. In the meantime, read the **interview of MEP Sirpa Pietikäinen** on why she decided to champion the campaign area on sustainable investment in healthcare systems. **#Access2030**

Earlier this year, we launched the **EPF Breakfast Briefings**, video podcasts on current policy topics and useful information for the capacity building of patient organisations. Open to EPF Members only, the live sessions are then made available via our [YouTube](#) channel, as on demand podcasts. See here a small recap of the first episodes and subscribe to our channel for more updates!

As always, EPF representatives have been very busy attending various meetings recently. Two were particularly interesting as they will be a stepping stone towards future EPF policy initiatives: a upcoming statement on **nutrition** and its role in diseases management; and the new initiative of the **OECD on patient-reported outcomes and experiences**, fostering a patient-centred culture for health systems performance assessment.

Some news to share as well on the project portfolio: time to end the **PRO-STEP** tender project with a final conference in Brussels on the 23rd and 24th of October; while **CHRODIS Plus** gets under way pursuing the activities undertaken by its predecessor CHRODIS.

The **EPF Capacity Building Programme** is going from strength to strength, with recent training sessions in **Bulgaria** where participants receive tailored information on how to set up coherent, transparent and sustainable fundraising plans.

Endorsed this year as a new member of EPF, the **National Coalition of Disabled People of Greece** takes on our 5 questions-interview, sharing their priorities and challenges as patient organisation.

This month our Blog hosts the beautiful story of **Inge Vandellannoote**, an IBD patient, on how valuable the relationship between patients and nurses can and should be.

Finally, some news regarding the **EPF Youth Group**, with Andreas Christodoulou (EPF Youth Group and cancer survivor) sharing his experience on attending the Young Cancer Europe congress; and some updates on the group itself: happy to welcome two new members and to gather soon for their autumn annual meeting in Leuven, Belgium!

Enjoy the reading!

Marco Greco, EPF President and Nicola Bedlington, EPF Secretary General



MEP PIETIKAINEN: 'ONLY A LONG-TERM VISION CAN ENSURE SUSTAINABLE INVESTMENT IN HEALTH'

EPF BREAKFAST BRIEFINGS: A GREAT WAY TO START YOUR DAY!

**SEE OUR VIDEOS ON OUR YOUTUBE PAGE**

### UPCOMING EVENTS

**02-04/10/2017** | [Alzheimer Europe Conference - Care today, cure tomorrow](#)

Berlin, Germany

**04-06/10/2017** | [20th European Health Forum](#)



MEP Sirpa Pietikäinen (EPP, Finland) is one of the 5 champion MEPs of the EPF Campaign on Access to Healthcare. A member of the Committee on Economic and Monetary Affairs at the European Parliament, Mrs Pietikäinen supports our work on sustainable investment in healthcare across the EU.

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### NUTRITION: FROM BARE NECESSITY TO ESSENTIAL COMPONENT OF DISEASE MANAGEMENT



EPF is currently developing a Position Statement on information to patients on food and nutrition. The document will build on our previous work on the area of nutrition and will be a stepping-stone towards a closer focus in 2018.

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### PRO-STEP FINAL CONFERENCE – SHARING RESULTS ON SELF-MANAGEMENT IN PATIENTS WITH CHRONIC CONDITIONS



The final conference of the EU-funded PRO-STEP pilot project will take place in Brussels on 23 and 24 October 2017. Around 100 delegates are expected to attend the event where the projects' preliminary outcomes will be presented.



Earlier this year, EPF decided to propose an innovative way of communicating with members: the EPF Breakfast Briefings. These video podcasts are meant to help members to get the latest updates on European health policy and to receive practical advice to improve their organisation and skills.

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### OECD PARIS INITIATIVE: ASSESSING HEALTH SYSTEMS THROUGH THE PATIENT'S EYES



For several years, EPF has been calling for patient-centredness to be adopted as a key aspect of healthcare quality measurements and for appropriate indicators to be developed. For this reason, we were delighted to see the launch of the OECD Paris Initiative in January 2017, which does just that.

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### KICK OFF MEETING OF THE CHRODIS PLUS JOINT ACTION: IT'S TIME TO IMPLEMENT



From 18 to 20 September 2017, partners gathered in Vilnius for the official launch of the Joint Action CHRODIS Plus, which will aim to implement the initiatives identified in the previous CHRODIS Joint Action.

#### Gastein Valley, Austria

EPF speaker  
Nicola Bedlington

10/10/2017 | [Health Care Summit 2017](#)

#### Geneva

EPF speaker  
Nicola Bedlington

10/10/2017 | [Mental Health and Migration in Europe: Supporting refugees, migrants and asylum seekers' mental health - Mental Health Europe](#)

#### Brussels

EPF attendance:  
Katie Gallagher

11/10/2017 | [Mental Health promotion in the workplace, a multi-stakeholder dialogue - European alliance for mental health - employment and work event](#)

#### Brussels

EPF attendance:  
Katie Gallagher

16-18/10/2017 | [eHealth Conference – Health in the Digital Society](#)

#### Talinn

23-24/10/2017 | [Capacity Building Event Poland](#)

#### Warsaw, Poland

EPF attendance:  
Elena Balestra

25/10/2017 | [HTAi PCIG meeting](#)

#### Paris

EPF attendance:  
Valentina Strammiello

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### CAPACITY BUILDING IN BULGARIA: FUNDRAISING 101



In August EPF concluded the third module of its Capacity Building Programme in Bulgaria. 15 organisations, including 7 newcomers to the programme, developed their fundraising strategy and shared best practices.

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### EPF YOUTH GROUP: NEW MEMBERS, NEW IDEAS!



As the summer winds to an end, the EPF Youth Group is preparing for its annual Fall Youth Group meeting, which will be held from 29 September-1 October in Leuven, Belgium. On the menu of these two days: debriefing on the first Summer Training for Young Patient Advocates, brainstorming in preparation of next year's edition, advocacy planning, and group governance.

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### (BLOG) FROM NURSE TO EQUAL PARTNER: READ THE STORY OF INGE, IBD BELGIAN PATIENT

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### 5 QUESTIONS TO: THE NATIONAL COALITION OF DISABLED PEOPLE - GREECE



Every month we put the spotlight on one of our members. This month, we are delighted to catch up with our new member the National Coalition of Disabled People of Greece, represented by its President Ioannis Vardakastanis.

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### (BLOG) YOUTH CANCER EUROPE 2017 MEETING – 'PATIENTS ARE NOT ALONE'



Andreas Christodoulou (EPF Youth Group and cancer survivor) attended the recent congress of Young Cancer Europe held in Vilnius Lithuania in late August. A great opportunity for him to share his experience and learn best practices from fellow patients. Read his story on our blog.

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Read on our blog the beautiful story of Inge Vandelannoote, on how a nurse-patient relationship turned into a trusted and beneficial partnership. Full story here.

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

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