European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe

EPF European Patients Forum

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//JUNE 2017 ISSUE

Welcome to the latest issue of our Newsletter!

*In a unique move, a coalition of 39 health NGOs, co-led by EPF, signed a **letter to President Juncker** early June, expressing their view that health is absolutely and unequivocally part of the core business of the EU. The open letter **calls on the European Union to continue its action in the field of health collaboration**. Delivering results that make a tangible difference in the daily lives of its citizens is a prerequisite to re-establish people's trust in its institutions.*

*In an exclusive interview, **MEP Paul Rübig** (EPP, Austria) tells us his reasons for joining our campaign on Access to Healthcare as a champion for the area on quality of care. He details his vision and priorities as European lawmaker on this important topic for European patients. **#Access2030***

*It is our pleasure to introduce you to the new component of our Capacity Building Programme: the **Summer Training Course for Young Patient Advocates – Leadership Programme!** A 3-day training event aiming to empower young patient representatives, ensuring the sustainability and future of European patient advocacy.*

*We share some updates from the recent **HTAi Conference** which took place in Rome last week, and discussed a more globalised approach for health technology assessment (HTA), with patient involvement as a sine-qua-non condition.*

*Our **Capacity Building Programme** is taking shape in Poland! The first face-to-face training was held in Warsaw mid-June and offered training on strategic planning to 18 Polish patient organisations.*

*This month our Blog features three interesting posts from the latest survey on rare diseases by **EURORDIS**; the World Continence Week by the **World Federation of Incontinence Patients**; and the ECR Congress of the **European Society of Radiology**.*

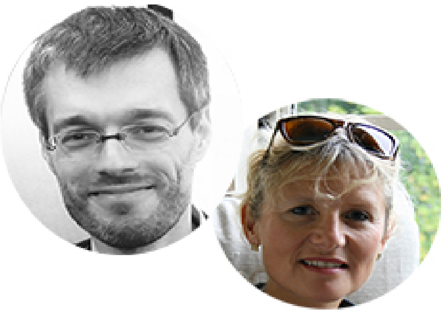
*Elected as full EPF member in April, **the European Congenital Heart Diseases Organisations** features in our* 'Under the Spotlight' *interview, sharing their priorities and challenges.*

*Lembe Kullamaa, from the **EPF Youth Group** reports on her experience as invited speaker at the European League Against Rheumatism (EULAR), where she presented the views of young patients on employment discrimination.*

*Finally, we are delighted to announce that **EPF is moving offices**! From 31st of July, you can find us at our new address: Chaussée d'Etterbeek, 180 B-1040 Brussels.*

Enjoy the reading!

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



#EU4HEALTH: EU HEALTH COLLABORATION IS CRUCIAL FOR EUROPE'S FUTURE

MEP RÜBIG: 'WE NEED A FRAMEWORK ENABLING MEMBER STATES TO PROVIDE THE BEST HEALTHCARE'

SEE OUR VIDEOS ON OUR YOUTUBE PAGE

UPCOMING EVENTS

03 - 05/07/2017 | Summer Training Course for Patient Advocates

On 6th June, a coalition of 39 health-related organisations, co-led by EPF, sent a letter to European Commission President Jean-Claude Juncker voicing their concerns about the future of health in European policies. Detailing the added-value of EU in health, this letter is the first step of a major public campaign.

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MEP Paul Rübig (EPP, Austria) is one of the 5 champion MEPs of the EPF Campaign on Access to Healthcare. A member of the Committee on Budgets at the European Parliament, Mr Rübig is supporting our work on quality of care across the EU. We take this opportunity to ask him a few questions on his priorities for this particular area of the campaign.

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JUST A FEW DAYS BEFORE OUR 1ST SUMMER TRAINING COURSE FOR YOUNG PATIENTS ADVOCATES!

Ensuring the sustainability and future of patient advocacy is very close to EPF's heart. By providing a 3-day training to young patients, our Summer Training Course will empower the next generation of patient's advocates and leaders. The first edition is just a week ahead!

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HTAI CONFERENCE: TOWARDS A GLOBALISED APPROACH AND PATIENT INVOLVEMENT

EPF participated in the latest HTAi Conference in Rome, where international experts discussed the way forward for health technology assessment (HTA) processes, including a more holistic and multi-criteria approach, with increased patient involvement.

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EPF CAPACITY BUILDING PROGRAMME - 18 POLISH PATIENT ORGANISATIONS TAKE THE FIRST STEPS TOWARDS LONG-TERM SUSTAINABILITY

On the 19th and 20th of June, EPF organised the first face-to-face training of the Capacity Building Programme in Poland. Over two days and under the guidance of a team of trainers, 18 Polish patient organisations took the first steps towards developing their own

WE ARE MOVING! EPF HAS A NEW ADDRESS FROM THIS SUMMER ON!

On the 31st of July, EPF will be moving offices into a modern and central address in the European neighbourhood.

Vienna

10/07/2017 | EIT Health Think Tank Meeting

Brussels

EPF speaker
Nicola Bedlington

11/07/2017 | [Research and Development in Health: pulling together efforts and ensuring public return for society](#)

Brussels

EPF attendance
Kostas Aligiannis

08/06/2017 | [Health systems for the future - Making EU health systems resilient and innovative](#)

Brussels

EPF attendance:
Kaisa Immonen

12/07/2017 | [Implementing the European pillar of social rights: obstacles and opportunities](#)

Brussels

EPF attendance:
Katie Gallagher

long-term strategy. The training also aims at fostering a collaborating culture between patient organisations and health stakeholders.

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(BLOG) EUROPEAN SOCIETY OF RADIOLOGY: INVOLVING PATIENTS FOR BETTER SAFETY

The European Congress of Radiology (ECR) took place in Vienna from 1-5 March 2017 providing a platform to discuss strategies towards improved patient safety and quality of care. Patients and healthcare professionals exchanged views on best practices in patient involvement.

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(BLOG) 5 QUESTIONS TO THE EUROPEAN CONGENITAL HEART DISEASE ORGANISATION (ECHDO)

Every month we put the spotlight on one of our members. Today, we are delighted to catch up with the European Congenital Heart Disease Organisation (ECHDO), who recently joined EPF.

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(BLOG) WORLD CONTINENCE WEEK - NO MORE STIGMA

Every year, the World Continence Week (WCW) raises awareness about incontinence-related issues. Coordinated by EPF member World Federation of Incontinent Patients (WFIP), this year's initiative offered plenty of activities and workshops to help understand the disease and lift the stigma.

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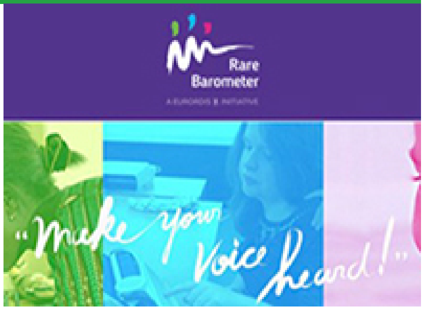
(BLOG) SURVEY SHOWS SUBSTANTIAL IMPACT OF RARE DISEASES ON DAILY LIFE



EURORDIS-Rare Diseases Europe ran the first Europe-wide survey on the social impact of rare diseases. Results demonstrate a serious impact on everyday life for over 80% of patients and families. More details on our blog.

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(BLOG) EULAR ANNUAL CONGRESS – PERSPECTIVE OF THE EPF YOUTH GROUP

Representing the EPF Youth Group, Lembe Kullamaa attended the yearly EULAR (European League Against Rheumatism) congress in Madrid on 14-17 June 2017. Speaking on employment issues for young patients, Lembe underlined the many challenges young people with chronic conditions face when entering the job market. Read her report on our blog.

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A STRONG PATIENTS' VOICE
TO DRIVE BETTER HEALTH IN EUROPE

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Please note that some links may not work anymore because the articles have moved, do therefore not hesitate to look at the news section where all the articles are archived or contact communications@eu-patient.eu for more information.