

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



//MARCH 2017 ISSUE

Welcome to the latest issue of our Newsletter.

It is our pleasure to share with you the report of the successful kick-off meeting of our campaign on Access to Healthcare, which took place in the European Parliament on the 27th of February. The meeting offered the opportunity to explore and discuss the campaign's objectives and focal points. MEPs, stakeholders, and patients' representatives all shared ideas for avenues to achieve Universal Health Coverage by 2030. #Access2030

In the course of 2016, EPF ran a **survey** among patients' representatives to understand their perception of **quality of care**. The report, featured in this issue of our newsletter shows how the image of quality very much depends on the context where healthcare is provided and that it encompasses many dimensions of health and social care. The survey's results are telling and should encourage policy-makers to invest in more qualitative methods to capture patients' feedback.

As you may remember from previous Newsletters, a "new" **EUPATI** programme is moving forward under the direction of EPF maintaining the spirit of a Public Private Partnership, and with a newly-formed EUPATI Management Team. Now is the time for an official introduction! You may recognise familiar faces from the EUPATI network but there are a few big changes too.

Some updates on the many projects in which EPF is participating: the **PISCE** final conference took place in Brussels this February, gathering many partners and stakeholders. You will see in our report that cultural barriers still represent a big obstacle to the progress of **self-care**.

The EPF Newsletters are also a platform to share info from our members, so this month you will read how the European Federation of Allergies and Airways Diseases Patients Associations (**EFA**) set up a new blog with support information for **oxygen-dependent patients**; a report on a recent event organised by the European Headache Alliance (**EHA**) on the little-known **cluster headache** condition; and finally, some information on a new project on patient engagement in **Alzheimer's disease**.

And to wrap-up this March's issue, read the unusual story of Matthew Michael Attard who joined the EPF Secretariat in Brussels at the beginning of March, as an intern representing the **EPF Youth Group**.

Enjoy the read!

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



EPF ACCESS CAMPAIGN –
CONCRETE IDEAS TO ACHIEVE
UNIVERSAL HEALTH COVERAGE



EPF SURVEY RESULTS - WHAT
DOES QUALITY CARE MEAN TO
PATIENTS?



[SEE OUR VIDEOS ON OUR YOUTUBE PAGE](#)

UPCOMING EVENTS

10-11/04/2017 | EPF AGM & Leadership Meeting
Brussels

Annual General Meeting and Leadership Meeting

11/04/2017 | [European Kidney Health Alliance - Annual EU Kidney Forum](#)

On 27 February, the kick-off meeting of the EPF campaign on Access to Healthcare gathered more than 75 participants representing a wide range of health stakeholders. The opportunity to deliver some key proposals on how to achieve Universal Health Coverage for all by 2030!

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During 2016, EPF surveyed patient representatives on how they perceive “quality” in healthcare and what matters most to them. A rich resource of information and patients’ testimonies, the survey report makes fascinating reading.

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Brussels

The Forum will focus on the Patient Choice of Treatment, how to shift from ‘patient compliance’ to ‘treatment compliance’.

EPF speaker:
EPF Secretariat

20-21/04/2017 | [EORTC - 4th Quality of Life and Cancer Clinical Trials CEORTC](#)

A platform to discuss new developments in cancer research

26-26/04/2017 | [The International Forum on Quality and Safety in Healthcare](#)

London

Themed Igniting Collective Excellence, this year’s programme focuses on how the power of collaboration can inspire all parties, including patients, families, new healthcare professionals and improvement leaders to deliver top quality, person-centred care in a sustainable framework.

EPF attendance:
Kaisa Immonen

MEET THE NEW EUPATI MANAGEMENT TEAM!



The five-year EUPATI project funded under the Innovative Medicines Initiative (IMI) ended in January 2017, a “new” EUPATI programme is moving forward under the direction of EPF and a newly-formed EUPATI Management Team. Time has come for an official introduction!

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PISCE FINAL CONFERENCE - CULTURAL BARRIERS STILL A BIG OBSTACLE TO SELF-CARE



The final conference of the EU-funded PISCE tender project took place in Brussels on 17 March 2017. Around 100 delegates came together to present and discuss the study’s main results.

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(BLOG) NOT EVERYONE IS WELCOME ABOARD: OXYGEN-DEPENDENT PATIENTS ARE FACING DISCRIMINATION WHEN TAKING A PLANE



More than 3.5 million people need medical oxygen in Europe and many are advised to travel to regions with temperate climates that will ease the symptoms of their disease. Our member the European Federation of Allergies and Airways Diseases Patients Associations (EFA) set up a new blog compiling all necessary information for patients travelling with oxygen. Read it on our blog.

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(BLOG) CLUSTER HEADACHES – NOT JUST ANOTHER HEADACHE



"A searing pain like a red-hot poker piercing through your eye that prevents you from remaining still or from lying quietly in a darkened room" - this is how patients describe Cluster Headaches

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(BLOG) MOPEAD: PROMOTING PATIENT ENGAGEMENT IN ALZHEIMER’S DISEASE

(BLOG) MORE THAN MEETS THE EYE



Alzheimer’s disease (AD) has been recognised as one of the biggest health and societal challenges of our times. The number of people directly affected by the disease will continue to rise and put the sustainability of healthcare services to the test.

Matthew Michael Attard joined the EPF Secretariat in Brussels at the beginning of March, as a trainee representing the EPF Youth Group. A patient with chronic conditions himself, Matthew will coordinate the activities of the Youth Group. Read below his truly uncommon story.

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