**EPF** newsletter

# European Patients' Forum Newsletter A strong patients' voice to drive better health in Europe



# //MARCH 2018 ISSUE

 $oldsymbol{W}$  elcome to the EPF newsletter. Another busy and exciting month for the EPF community.

The debate around the future of the EU priorities and the next EU budget is shaping up. EPF responded to the European Commission **consultation on the post-2020 Multiannual Financial Framework**, highlighting the views and needs of the patient community. Read about our key asks for health <u>here</u>.

On 6 March we took part in a policy roundtable debate "Building a sustainable policy framework for the biologic and biosimilar medicines in Europe" in the European Parliament, involving representatives from both the originators, the generics and biosimilars industry, policymakers, health professionals' organisations, patient organisations and other health NGOs in the room.

In recent times, vaccines have become a major topic of discussion and controversy Europe-wide. In 2018, **EPF is actively engaging on the topic of** vaccination, developing information materials for the patient community. We walk you through this project in this article. Within this context, we have also a 15-minute survey targeting patients, their relatives, their careers and patient representatives that you can fill in here.

We have just <u>published</u> a **new position statement on information to patients on food and nutrition**. This reflects our role as an agent for public health, alongside sister organisations, and given the particular interest of EPF members on this topic.

The first **face to face meeting of the third cohort of trainees following the EUPATI course** met in Madrid at the end of February. Almost 60 patient leaders from through Europe had the opportunity to exchange and consolidate their learning to date. <u>Read more here</u>. In our blog, EPF member EFCCA – the European Federation of Crohn's and Ulcerative Colitis Associations – presents the <u>findings</u> from its project "**Mapping** of innovative medicines and devices in EFCCA member countries" in which 31 countries participated.

This month also saw World Kidney Day, on 8 March. As it coincided with International Women Day, the topic of this year was Kidneys & Women.

Finally, there were <u>a couple of changes</u> in the EPF Secretariat: we are saying goodbye to Stefano and welcome Mathieu as the new project coordinator of PARADIGM.

Enjoy the reading!

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

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EU BUDGET: WE WANT AN AMBITIOUS EU HEALTH POLICY WITH PATIENTS AT ITS CENTRE



A SUSTAINABLE FRAMEWORK FOR BIOSIMILARS MEDICINES IN EUROPE



# SEE OUR VIDEOS ON OUR YOUTUBE PAGE

## **UPCOMING EVENTS**

10/04/2018 | First Open Forum on Patient Engagement

Brussels

11-12/04/2018 | SCIE - self care initiative summit

The debate around the future of the EU priorities and the next EU budget is shaping up. EPF responded to the European Commission consultation on the post-2020 Multiannual Financial Framework, highlighting the views and needs of the patient community.

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# VACCINES: INFORMATION IS KEY



One of the reasons for vaccine hesitancy is lack of high-quality, evidence-based information in patient-friendly language and accessible format. EPF has therefore included in its action plan 2018, a pilot project on vaccine information.

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We took part in a policy roundtable debate "Building a sustainable policy framework for the biologic and biosimilar medicines in Europe", co-hosted by MEPs Nicola Caputo (S&D, Italy) and Cristian Silviu Busoi (EPP, Romania), to bring forward the patients' position on the topic.

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#### EPF POSITION ON INFORMATION TO PATIENTS ON FOOD AND NUTRITION



Links between nutrition and health have been known since ancient times. Today, EPF publishes its new position statement on information to patients on food and nutrition. In line with its responsibilities as an agent for public health and given the interest of its members, EPF will work in the sphere of information to patients on nutrition, with a focus on medical nutrition.

#### READ MORE »

Self-care, health literacy collaboration

EPF attendance Kaisa Immonen

#### 14-15/04/2018 AGM and Leadership Meeting

#### Brussels

**EPF Members' Event** 

EPF attendance Elena Balestra

#### 17-18/04/2018 | EMA PCWP

London

Regular meeting

EPF attendance Kaisa Immonen

#### 18/04/2018 EMIF final event "LIBERATING EVIDENCE FROM EUROPEAN HEALTH DATA THE ACHIEVEMENTS AND CHALLENGES OF A FIVE-YEAR IMI PROJECT: EMIF"

#### Brussels

Presentation of project results

EPF speaker Valentina Strammiello

#### 24-25/05/2018 | PATHWAYS Project Final Conference

#### Brussels

Patient-MedTech Dialogue Workshops

EPF attendance Katie Gallagher

#### EUPATI FACE-TO-FACE TRAINING EVENT IN MADRID: 4 DAYS OF FUN AND HARD WORK



The first face-to-face meeting of the third cohort of trainees following the EUPATI course met in Madrid at the end of February. Almost 60 patient leaders from through Europe had the opportunity to exchange and consolidate their learning to date.

### **READ MORE »**

WORLD KIDNEY DAY 2018

#### WE WANT EQUAL ACCESS TO HEALTH FOR ALL!



The European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) has recently published the findings from its project "Mapping of innovative medicines and devices in EFCCA member countries" in which 31 countries participated.

#### **READ MORE** »

HELLO MATHIEU. GOODBYE **STEFANO!** 

EPF newsletter



World Kidney is held on the second Thursday in March every year. This year it was on March 8 and the topic was Kidney Disease & Women, to highlight the impact of kidney disease on women's health.



Over the last few weeks, we said goodbye to Stefano Tironi, EPF Financial Manager and welcomed Mathieu Boudes, PARADIGM Coordinator!

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



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