

The European Patients' Forum newsletter – March 2019

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ANNOUNCEMENT: New Leadership at the European Patients' Forum Secretariat



The European Patients' Forum is delighted to announce the appointment of our new Executive Director, Usman Khan, who will join us from early May. Usman has an established record in European health policy and practice and has significant knowledge of and commitment to patient engagement at all levels.

Usman is currently Executive Director of the European Health Management Association. Usman commented: *"I am really looking forward to taking on the role of Executive Director of the European Patients' Forum. Nicola leaves a strong legacy and a vibrant organisation, and I am excited by the opportunity to lead EPF in its mission to ensure patient access, patient experience and patient involvement are core to health and social care provision across Europe."*

Nicola Bedlington has stepped down as Secretary General after 13 years and will continue to support EPF in a part-time advisory function. Nicola said: *"I am very pleased to pass on the baton on to Usman, to lead the team and support the board in taking EPF into the third decade of the 21st Century and an inspiring new era of change. I know he will do a terrific job."*

Commenting on the appointment Marco Greco, EPF President said: “Usman was selected following a rigorous equal opportunities recruitment process and I am confident, under his leadership of the secretariat, that EPF will continue to thrive and flourish. We are at an exciting crossroads, developing our new strategic plan, our relationship with the wider Europe, and a new Commission and Parliament. Much to achieve together!”

EPF Congress 2019

Interview with June Raine: “We have so much to gain from the Congress and to contribute to its outputs” →

This month, we asked Dr June Raine – Director of Vigilance and Risk Management of Medicines at the Medicines and Healthcare products Regulatory Agency (MHRA) of the UK and one of the ambassadors of the event, a few questions on what to expect from the Congress. [Read more here.](#)

European Parliament Elections 2019

Success story: #europeforpatients goes local as Malta Health Network gathers the support of 13 MEP candidates →

Our member Malta Health Network (MHN) gathered representatives from their 43 member organisations to discuss the future of health. These discussions were followed by 13 MEP candidates from all parliamentary groups, who pledged their support for our #europeforpatients Manifesto for the 2019 European Elections. The news was relayed in national newspaper [Malta Independent](#).

We are most grateful to MHN for helping us spread the message, and bring issues that matter to patients to the attention of all the MEPs and candidates who have signed our support card! We hope to receive similar levels of support from other Member States. To read more about MHN’s outreach strategy to MEP candidates in the pre-election period, [click here](#).

Find out more about our campaign and who are our supporters here: www.europeforpatients.eu and make sure you, too, get involved and support our five key asks, which matter most to patients!

Policy Update

[Letter to the BMJ Editor on medical implants →](#)

In response to an editorial published in the professional medical journal BMJ at the end of last year, EPF signed a joint letter with several patient and health professional organisations calling for increased transparency and access to incident reports on medical devices. The letter states that “transparency is important for informed decision making for both patients and doctors. For this reason, diminishing transparency to protect commercial secrets and to avoid scaring the public is an untenable argument.”

[New Roadmap Initiative tackles practical challenges of creating lay summaries of clinical trial results →](#)

EPF was actively engaged in the drafting of the new EU rules, and particularly on the importance of transparency of clinical trial results. Effective communication of scientific research to patients and the public, as we stated in our position paper in 2015, is a vital requirement of an open, inclusive and accountable system. We subsequently took part in a working group headed by the UK Health Research Authority, which developed an EU guideline for the drafting of lay summaries.

[EPF Continues Work on Vaccination for Patients with Chronic Conditions →](#)

Because of gaps in vaccination uptake among patients, and the important risks patients with chronic conditions face from vaccine-preventable diseases, EPF started an initiative in 2018 on providing information and supporting patient organisations' advocacy on the importance of vaccination. This year, we are continuing work on this important topic.

Projects

Data Saves Lives →

Data Saves Lives is an exciting new initiative hosted by the EPF secretariat, and managed by our newest colleague **Gözde Susuzlu Briggs**. Representatives from several organisations active in the field of digital health are combining forces to address the challenges and opportunities relating to health data.

IMI project IMMUCan has kicked off! →

EPF is pleased to be part of the IMI-funded IMMUCan project (which stands for "Integrated IMMUnoprofiling of large adaptive CANcer patients cohorts"), which officially launched on Monday 18 March at the European Organisation for Research and Treatment of Cancer (EORTC) headquarters in Brussels. The consortium is led by EORTC and includes 19 other partners, including 10 expert clinical centers.

CHRODIS+ project: EPF ensures the patient perspective in implementation pilot activities →

Read more about our recent activities as part of the CHRODIS+ project, a European Joint Action, which aims to support Member States through cross-national initiatives in order to reduce the burden of chronic diseases, while assuring health systems sustainability and responsiveness.

EUPATI is ready to launch a brand new industry training →

The engine is still running on the EUPATI front: this time it will bring in a brand new training module!

EPF Members

EUFAMI launches Schizophrenia Carer Playbook →

Being a carer is often far from easy, and can feel overwhelming at times. The internet provides a lot of information, and whilst this is

good, the sheer volume available can be confusing and not all of it is reliable.

In response to this, EUFAMI decided to develop the “Schizophrenia – Carer Playbook”, a project that provides guidance and advice to carers of those living with schizophrenia, helping them to navigate the struggles they may face. The content of this interactive document stems from the experience of patients, carers and healthcare professionals, and it aims at supporting those caring for the 21 million people worldwide who face schizophrenia. [**Read more about this initiative here.**](#)

[Cypriot patient organisation advances health literacy in schools](#)



The Cypriot patient organisation for rare genetic diseases “Unique Smiles”, a member of the Pancyprian Federation of Patients Associations and Friends, has made a major step towards improving health literacy in their country: the introduction of patients’ rights in the school curriculum. [**Read more here.**](#)

[EPF participates in international policy symposium](#)

[“Transforming the medical model”](#) →

Building on the success of previous conferences by ENOPE and partners, the Centre for Empowering People and Communities (CEmPaC), which EPF is involved in as a partner, is pleased to announce an international symposium on the theme: “Transforming the medical model”. [**Read more here.**](#)

EPF Youth Group

[International Experience Exchange with Patient Organisations \(IEEPO\)](#) →

The 11th edition of the [**IEEPO**](#) Congress organised by Roche was held in Rome on 5-7 March. The event aimed at encouraging exchanges and conversations between patient organisations and pharmaceutical companies. As a member of the French association AFA Crohn RCH

and an advocate for Inflammatory Bowel Diseases, Martin Mastrotto from the EPF Youth Group, attended this event to represent the interests of IBD patients in France and across Europe.

Read Martin's full report [here](#).

EURORDIS Winter School – international collaboration in the field of scientific innovations and translational research →

The EURORDIS annual Winter School took place in Paris from 11-15 March. This year's training focused on scientific innovations and translational research and gathered 30 patient advocates, medical experts and researchers. Jana Popova, patient advocate and member of the EPF Youth Group and European Alliance of Neuromuscular Disorders Associations (EAMDA) attended this event. Read Jana's full report [here](#)

EPF Secretariat

EPF welcomes Gözde, the new Data Saves Lives Coordinator →

Gözde Susuzlu joined EPF in March 2019 as the coordinator of "[Data Saves Lives](#)" initiative. A Turkish citizen residing in Belgium, she has a post-graduate degree in international communications from Vrije Universiteit Brussel - VUB. Before joining EPF, she worked for ten years as a web manager at an international organisation in Brussels. A warm welcome from all of us at EPF, Gözde!

Call for tender

We are currently looking for a Photographer/Videographer to undertake some communications work related to the EPF Congress 2019. [Read more here](#)

Events



European Health Parliament 4th Edition (last session)

2 April 2019 / Brussels, Belgium

EPF speaker: Nicola Bedlington

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