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The European Patients' Forum newsletter – February 2019

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#EuropeForPatients takes to the European Parliament - A day of action organised in parallel of a PACT event in Brussels on 20 February 2019.

Dear readers,

We are pleased to send you the February issue of the EPF monthly newsletter. As you will see, the shortest month of the year has not proved to be less eventful!

Among the many developments in our policy and project work, our campaign for the 2019 European Elections is building

momentum and starting to gather the support of many MEPs, both future and non-candidates.

With over 150 million people living with chronic conditions in the European Union (EU), we need to make sure health will be a priority in the EU post-2020, and that patients acquire a central and active role in EU policy. Patient involvement and empowerment can only be achieved with the support of the political leaders of the EU, the Parliament and the future Commission – and patients and their families expect clear and concrete actions from EU policy-makers in all policies that affect their lives.

The above video looks back at a day of campaigning, and promising discussions on the future of health in Europe. Feel free to share it far and wide and get involved with our campaign via www.europeforpatients.eu

Thanks for taking action and enjoy the reading!

Marco Greco, EPF President

Nicola Bedlington, EPF Secretary General



EPF Congress 2019

[Interview with Marco Greco →](#)

The EPF Congress 2019 is the first ever European Congress on patient involvement driven by leading representatives of the patient community in the capital of the EU. It is aimed at exchanging ideas and good practices on patient empowerment and involvement, moving forward on much-needed policy commitments in this area, and gaining a greater and genuine understanding of the wealth of knowledge and expertise that patients bring to the design and strengthening of health

systems.

We asked Marco Greco, President of EPF 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

[EPF takes #europeforpatients to the European Parliament →](#)

On Wednesday 20 February, the European Patients' Forum took to the European Parliament to present and gain support for our EU elections campaign #europeforpatients. EPF is calling on political leaders of the EU, Parliament candidates and the future Commission, to take action and ensure health is an EU policy priority. "Patients want and expect EU collaboration in health and a strong European health policy," said Nicola Bedlington, Secretary General at EPF.

Policy Update

[EPF's take on the opportunities and challenges of electronic medicines information →](#)

On 28 November, EPF participated in an HMA/EMA workshop on electronic product information, a follow-up from a July 2018 preparatory meeting hosted at the Spanish Medicines Agency. Following this event, the EMA has launched a public consultation on its "key principles" for electronic product information, with a deadline of 31 July. EPF has been actively contributing to the EMA events, and we will consult our membership on a response to the consultation.

[OECD – PaRIS international survey tender is out & new Patient Safety working group looking for patient representatives →](#)

EPF has been actively working with the OECD in the last few years, contributing to its work on outcome indicators and in particular, to the shaping of the proposal for PaRIS – the comparative cross-country survey of patient-reported outcomes and patient experiences in

healthcare.

[Falsified medicines – new EU rules come into application →](#)

The EU falsified medicines directive (FMD) is finally in application, since 9 February 2019 – almost seven years since it was adopted.

[Two more steps towards a patient-centred health system in Portugal →](#)

The participation of patient and healthcare user organisations in health policy and decision-making was in the spotlight in Portugal this month, with two key events marking the health agenda.

[“Patients should be at the centre of healthcare systems in all Member States” says Antonio Tajani, President of the European Parliament →](#)

The European Health Parliament (EHP) and its six partners, including EPF, received a letter from European Parliament President, Antonio Tajani, who endorsed recent efforts in advancing health policy, in the framework of the latest EHP edition on Wednesday 6 February.

[EPF responds to European Ombudsman Inquiry on EMA pre-submission activities →](#)

The European Ombudsman's recent inquiry focuses on the level of transparency in the European Medicines Agency's pre-submission activities, and the appropriate extent of the use of "firewalls" in marketing authorisation applications. Having been involved in various strands of the work of the EMA for many years, EPF is highly committed to the work of the Agency and familiar with its processes. [Read our response to the inquiry here.](#)

Projects

[EPF and EUPATI at the DIA Europe 2019 Conference – Partnership in practice →](#)

Earlier this month, DIA held its annual European conference in Vienna,

Austria. Some of our collaborators attended the event. Here is a summary.

EPF Members

[SAFE introduces Stroke Support Organisation Faculty Tool →](#)

EPF member Stroke Alliance for Europe (SAFE) introduced the Stroke Support Organisation Faculty Tool (SSOFT), an online eLearning tool that provides knowledge and training on how to create effective advocacy campaigns to deliver positive change at a local and national level on stroke prevention, treatment and care.

[The European AIDS Treatment Group names new Executive Director →](#)

EPF member, the European AIDS Treatment Group (EATG) is delighted to introduce its new Executive Director, Pieter Vanholder. Pieter will be starting his term as Executive Director of the EATG on 5th March, 2019. He will be based at the EATG Office in Brussels.

[Read more here.](#)

Call for tender

[Consultant to develop a "Patient Guide to Vaccination" →](#)

Are you passionate for health and communications? Are you able to convert technical texts into lay-friendly language? We're looking for a consultant to develop a "Patient Guide to Vaccination".

Events



[European Congress of Radiology 2019](#)

2 March 2019 / Vienna, Austria

EPF speaker: Nicola Bedlington

Addressing the hidden burden of migraine

European Migraine and Headache Alliance

20 March 2019 / Brussels, Belgium

EPF attendance: Emily Bowles

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