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The European Patients' Forum newsletter – October 2018

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Putting what matters to patients at the heart of EU health policy

The European Patients' Forum launched its 2019 European Parliament election campaign to ensure that what matters to patients is prominent in the upcoming European elections. During a special event on 9 October at

our offices in Brussels, we launched a [Manifesto](#) which sets out five key demands for the next term of the European Parliament. We are seeking advances in access, patient empowerment, digital health, and meaningful involvement of patients in driving better health policy. These five key asks have been translated into [five powerful video testimonials](#) of patients and were presented during the launch event.

Among the keynote speakers, two strong patients' advocates from the Netherlands and from Denmark, talked about their experiences and how they would like to see health cooperation evolve at EU level. Commissioner for Health and Safety, Dr Vytenis Andriukaitis, who closed the event, gave a rousing speech on the importance of the EU for patients, while endorsing EPF's five key messages for the 2019 European elections. EPF Secretary General, Nicola Bedlington, placed a special emphasis on the need to ensure that this campaign goes well beyond Brussels and emanates in all EU countries at local and regional level.

Patient advocacy in the European elections is crucial to drive positive change for patients. With 74 member organisations, representing the interests of an estimated 150 million people with chronic diseases, EPF amplifies the voice of a high proportion of voters. Over the next weeks and months, we will be working hard with members and supporters to engage patients and citizens on issues that matter to them and to encourage candidates to adopt the Manifesto nationally as well.

To coincide with the launch event, a dedicated website was launched, which brings together information about the elections and the vital issues at stake, including our manifesto and the five videos. It can be found at www.europeforpatients.eu.

Policy Update

[European Health Forum in Gastein](#) →

This year, EPF was represented by Nicola Bedlington, EPF Secretary

General. In addition to her role as member of the Advisory Committee of the forum, Nicola also spoke on numerous occasions on innovative medicines, vaccines for all and the value of evidence in outcomes-based healthcare. Katie Gallagher, EPF Policy Advisor also participated in the forum, speaking on personalised medicines and health literacy.

[Update on the Multi-Financial Framework →](#)

The European Patients' Forum has been following a number of those files in order to make sure that the needs of patients are appropriately reflected.

Projects

[EUPATI reaches 1 million users →](#)

Impact matters to EPF and we are delighted to be able to report on this significant milestone for EUPATI, the Public Private Partnership ran under the auspices of EPF, driving education on medicines R&D for patients.

[Peer-Reviewed EUPATI Guidance published in Frontiers in Medicine →](#)

The EPF-led European Patient Academy on Therapeutic Innovation (set up by the IMI-EUPATI project in 2012-2017) has published guidance for patient involvement in key areas of medicines research and development.

[Measuring Impact in patient-centered drug development conference →](#)

Humanising key performance indicators to make patient engagement in medicines R&D a greater reality: a report of the DIA-organised conference on 'Measuring the impact in patient-centered drug development', by Mathieu Boudes, PARADIGM coordinator.

EPF Members & Youth Group

[EPF Patient Advocates' Seminar - Be an EU lobbyist for a day →](#)

On 20-21 October, 30 representatives of patient organisations from more than 20 countries across Europe gathered in Brussels for the first EPF Patient Advocates' Seminar. The aim was to show how the European legislative process works and to learn how to advocate effectively at all levels, for better outcomes for patients in Europe.

[How sex and gender impact the health of women and men →](#)

This month, EPF talked to Peggy Maguire from the European Institute of Womens Health (EIWH) and one of EPF's member organisation, about how sex and gender impact the health of women and men. Here is her insight on the matter.

[EPF Youth Group Fall Session in Sofia →](#)

The European Patients' Forum Youth Group held its second meeting this year on 12-14 October in Sofia, Bulgaria. This fall session was an exciting three-days full of creativity, positive vibes, brainstorming on future projects and setting strategic objectives for 2019 and beyond.

Blog

[47th Annual General Assembly of EAMDA →](#)

An inspirational experience for people with Neuromuscular disease.

Events



Launch of Children's Tumor Foundation Europe

7 November 2018 / Brussels, Belgium

European Health Parliament 1st Plenary

7 November 2018 / Brussels, Belgium

EPF attendance: Nicola Bedlington

ISPOR Europe 2018

10 - 14 November 2018 / Barcelona, Spain

EPF speaker: Nicola Bedlington

Optimal Nutritional Care for All

12 - 13 November 2018 / Sintra, Portugal

EPF speaker: Katie Gallagher

ESR Annual Leadership Meeting

16 November 2018 / Berlin, Germany

EPF speaker: Nicola Bedlington

Amgen Patient Advocacy Day

21 November 2018 / Paris, France

EPF speaker: Nicola Bedlington

COMPAR-EU General Project Meeting

22 - 23 November 2018 / Utrecht, The Netherlands

EPF attendance: Lyudmil Ninov

ENHA Members Meeting

27 November 2018 / Brussels, Belgium

EPF speaker: Katie Gallagher

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