

The European Patients' Forum newsletter – December 2018

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Dear readers,

2019 is already nearly in and we are, of course, all looking forward to the holiday season, but looking back at 2018, it has been a very important year for us with many, many achievements that we are proud to share with you. This last newsletter of the year will show highlights of what we have been up to in our policy and advocacy work, projects, capacity-building and working with our membership, as well as the Youth Group.

We could not have been so successful without the help and support of our valued members, sponsors and partners. Thanks to them – to you – the policy environment in the EU has become a little more friendly for patients, though much remains to be done.

Our members are the beating heart of EPF. Without their support, we would not be able to address our next goals in 2019, especially the [campaign for the European Parliament Elections](#) in May and our [very first Congress](#) on patient involvement in November. 2019 will also mark a major change in the leadership of our organisation. We invite you to [read more about the announcement here](#).

The EPF Board and Secretariat wish you a restful and happy festive break with your family and friends. We look forward to working with you again in 2019!

Marco Greco, EPF President
Nicola Bedlington, EPF Secretary General



EPF would like to announce a change within the EPF secretariat

Nicola Bedlington who, as many of you will know, joined EPF in 2006 to establish the secretariat in Brussels, will step down as Secretary General in Spring 2019.

Nicola said: “I have had 13 wonderful years with EPF – working with truly inspirational leaders committed to the strength of a united patient voice to transform the way that patients are perceived, and healthcare is delivered. With an excellent team in Brussels, EPF is stronger than ever, despite a very challenging

year. I am proud to pass on the baton to a new leader who will help to craft the new strategic plan and to take EPF forward into the next decade.”

She will continue to work very closely with Marco Greco, our President, in an advisory capacity, with a specific focus on the EPF Congress, our patient engagement strategy and interactions with key partners.

The recruitment process for Nicola’s successor has commenced and we would invite you to [share this link](#) with potential candidates.

Policy

[EPF active on medicines and medical devices →](#)

This year EPF has again been active in bringing a patient perspective into debates on medicines and medical devices at European level.

[EPF calls for patient-centred EU framework on HTA →](#)

This year we welcomed the publication of a legislative proposal on a future EU framework on health technology assessment (HTA). As our position paper adopted in May explains, this is an important step towards more equitable access to effective healthcare for all patients across the EU.

[The importance of vaccination for patients →](#)

Because of gaps in vaccination uptake, and the important risks patients with chronic conditions face, EPF started an initiative in 2018 on providing information and supporting patient organisations’ advocacy on the importance of vaccination.

[New initiatives in the area of digital health →](#)

This year laid the groundwork for many promising new initiatives in the area of digital health. Many thoughts and ideas we had around the topic became concrete plans.

[Shaping the future EU policy framework for health →](#)

This year has been crucial for influencing the future EU funding programmes – we had called it the year of the EU budget – even if major decisions are still pending finalisation in 2019.

[EPF strives to make equitable access and universal health coverage a reality →](#)

While universal health coverage is a well-recognised goal for all healthcare systems in the EU, this basic right is not yet a reality for all patients. In 2018, EPF focused its efforts on building awareness and capacity of patient communities on these topics.

[EPF promotes better inclusion of people with chronic conditions in the workplace →](#)

In 2018, EPF intensified its advocacy for the development and implementation of policies and initiatives that eliminate discrimination, reduce stigma and promote the inclusion of patients with chronic diseases in healthcare, employment and society at large.

[Better information to patients on food and nutrition →](#)

In 2018, EPF has made significant progress advancing the awareness and application of meaningful patient involvement in clinical nutrition, information for patients, and raising awareness of the role of nutrition and diet in managing long-term conditions.

Projects

[EUPATI's main achievements in 2018 →](#)

2018 has been an enthusiastic year and we would like to thank everyone that has contributed to that. We are looking forward to collaborating with you in the next year!

[A year into PARADIGM to advance patient engagement in medicines development →](#)

Since the launch of the EUPATI project almost a decade ago, the long-term vision at EPF is that patient education, training and

empowerment are intertwined with patient engagement during the development of medicines. In line with this strategy, to create an ecosystem fostering patient engagement in R&D, EPF co-leads with EFPIA the IMI-funded project PARADIGM.

[Sharing results of the PRO-STEP project →](#)

A Pilot project on Promoting Self-management for Chronic Diseases in the EU.

Completed in January 2018, the PRO-STEP pilot project on self-management of chronic conditions marks a major achievement for EPF to gain a deeper insight in aspects strongly related to patient empowerment.

Capacity Building

[Capacity Building Programme and Patients Advocates' Seminar](#)

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2018 was again a significant year in the development and implementation of EPF's Capacity Building Programme, contributing further to our mission to support patient organisations and to strengthen their role as equal players in the healthcare environment.

[3rd edition of EPF Summer Training for Young Patient Advocates](#)

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EPF is happy to share with you an exciting opportunity for the 3rd edition of the Summer Training for Young Patients Advocates. Next year's theme is 'Shaping the Future of Patient Advocacy'. The training will take place on 7-10 July 2019, in Vienna Austria. Deadline for applications is 1st March 2019.

Youth Group

[Young patients talking to the EU →](#)

2018 was an exciting and challenging year for the EPF Youth Group. The Group improved its capacity and joined forces with young patients across the EU. But most of all, in the light of the upcoming EU elections next year, the Youth Group is focusing all its strengths to bring young patients' needs on the agenda of the EU.

Members

New EPF Members in 2018

And last but not least, this year in April, we were delighted to welcome two new members to the EPF family – one of which (Plataforma de Organizaciones de Pacientes) – has been confirmed as EPF full member! Keeping the organisation growing and strengthening our representation by adding the voice of several countries and diseases to EPF's, it is our pleasure to count as new members:

- *Full Membership:* **Plataforma de Organizaciones de Pacientes**, which brings together the main groups that represent patients, people with chronic diseases and symptoms in Spain.
- *Associate Membership:* **SAFE**, an umbrella organisation for national and regional organisations representing a range of stroke patient across Europe that were affected by stroke.

Our membership is our *raison d'être*, our members are the backbone of our work: their feedback bring an inestimable added value to our policy and advocacy activities. With these new members, EPF now represents 72 patient organisations throughout Europe, making it the strongest cross-disease patients' voice at European level.

Events



Workshop on innovative solutions for research in healthcare
European Parliament - Panel for the Future of Science and Technology (STOA)

10 January 2019 / Brussels, Belgium

EPF speaker: Mathieu Boudes

EPF attendance: Kaisa Immonen

Public Hearing on "Digital Health literacy"

European Economic and Social Committee (EESC)

30 January 2019 / Brussels, Belgium

EPF attendance: Kaisa Immonen

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