

Newsletter EPF - December 2019

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The European Patients' Forum newsletter – December 2019

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Dear readers,

We are drawing the curtains on 2019 and what a year it has been! We hope you enjoy this Christmas edition: a recap of our main highlights of 2020, not to mention our most successful newsletter articles!

This year called a great deal of our work focused on preparing for the first European Congress on patient involvement. The enriching contributions from speakers and participants, and overall fruitful outcome of all sessions gave us living proof that meaningful patient involvement is an esteemed and endorsed practice in many different fields. Working together is key: now is the time to act, and build from our own evidence and stories.

This is not the only 2019 highlight we will look back on in the months to come. The 5 key messages on our EU Elections manifesto truly resonated with many returning and new MEPs who signed it, pledging to commit to bring issues that matter to patients at the heart of EU policy.

The EPF team would like to wish our readers the happiest of holidays and a prosperous new year. We look forward to seeing you again in 2020!



Usman Khan (Executive Director)

Top 3 articles of 2019

We took a closer look on 2019. Here are the top three topics which caught your eye the most!

EPF Congress 2019: There's nothing for patients without patients



This month EPF hosted its first ever Congress on patient involvement entirely driven by the patient community.

Over 300 delegates, including patient advocates, healthcare professionals, health NGOs, academics, members from industry and national institutions made their way to the Crowne Plaza Hotel in Brussels, where the Congress was held. Joined by more than 60 speakers the Congress considered opportunities and barriers for meaningful patient, drawing upon a myriad of examples of effective practice.

"Nothing must be for the patients without the patients" said EPF President Marco Greco.

From a Hackathon on enabling patient involvement by balancing ethical considerations, to inspirational plenaries and constructive parallel sessions, the patient voice was fully in the spotlight as patients and patient advocates featured among both keynote speakers and panellists. Real life stories on self-management, added value, and teaching in medical school among others highlighted a different level of patient empower and perspectives from other stakeholders such as regulators, academics, members of industry, national governments, health NGOs and EU institutions all contributed with tangible ideas and measures to integrate patient involvement in our health systems.

EPF Congress 2019: registration for the first European Congress on patient involvement is now open



We are pleased to announce that registration for the first patient community-driven Congress is officially open. This unique event will take place from 12 to 14 November 2019 at the Crowne Plaza Hotel – Le Palace, in the heart of Brussels, Belgium. You may now register via [this link](#).

What is the EPF Congress? This event will provide an exceptional opportunity for dialogue and engagement with a wide range of health players are committed to making meaningful patient involvement a reality in their daily work. We will exchange best practices and knowledge to support positive change in different health environments, and the Congress will contribute to a patient-led framework for more structured and effective patient involvement across health systems and services.

More details, preliminary programme and speakers' information are available on our dedicated [website](#). Don't miss our [recent interview](#) with Usman Khan, who shared his thoughts on his upcoming position as EPF's Executive Director, as well as what to expect from the Congress.

The first European Congress driven by patients begins today in Brussels, Belgium.



"The patient is a hugely untapped resource in the health system. The Congress will stimulate debate and discussion, building on the premise that the patient's own unique experiential knowledge, can impact on various areas" [Marco Greco, EPF President].

Meaningful patient involvement is an underused resource in the development of innovative, patient-centred healthcare design and delivery. Yet developments at a European level remain piecemeal and limited in reach.

From 12 to 14 November 2019, the EPF Congress will aim to instigate a narrative of real and lasting change in attitudes, knowledge and resources for participants. Unlike others, this event will be entirely driven by representatives of the patient community themselves, which will result in tangible learning outcomes.

#1: EPF Congress

... no surprises there! From February until December articles featuring our Congress were the most popular.

Fun fact: the [interview with our president, Marco Greco](#), was the most read article related to our Congress!

More on #EPFCongress19:

- The #EPFCongress19 hashtag was the **Number 1 hashtag trending in Belgium** during the afternoon of Day 1!
- The top 3 most active accounts were
 - @ifsbh

- [@MichaelGeorgePR](#)
- [@MTParisotto](#)

A big thank you to them and anyone else who contributed to our Twitter feed!

Refresh your Congress memories by watching our [after-movie](#), scrolling through the official pictures and taking a look at our web-streaming links on our [Youtube channel](#). Take a look at our [recapitulative article](#), which includes some highlights and a list of external sources mentioning our Congress!

EPF Congress Pictures



#2: Transparency guidelines

EPF was proud to see that the Transparency Guidelines it published back in September was the article with the second highest number of downloads!

Take another look at our document, to see how health and patient organisations can be ethical and transparent with industry and their members

[Read our transparency guidelines](#)



#3: AGM 2019: farewell to our Secretary General, Nicola Bedlington and what lies ahead for EPF

The AGM and ur former Secretary General Nicola Bedlington was our third most popular article of the year.

On 13-14 April 2019, EPF members gathered in Brussels for EPF's 16th Annual General Meeting. During the event, members of EPF's Board and Secretariat reported on 2018 activities and gave an overview of our current and upcoming work for 2019-2020. The meeting also saw the election of new Board members and the approval of four new member organisations.

AGM 2019

Other highlights



#europeforpatients - Putting issues that matter to patients at the heart of EU policy

This year we campaigned to make health and what matters to patients key policy priorities for the new mandate following European elections in May this year.

A total of 60 MEP candidates signed our manifesto, pledging to commit to the following five points:

- 1. Accessing the healthcare we need with no discrimination*
- 2. Being empowered*
- 3. Driving the development of digital health*
- 4. Being a partner in driving better research*
- 5. Helping make better health policy*

Read our manifesto





**Summer Training Course for Young Patient Advocates (STYPA) 2019:
#Advocates4Health**

This year's edition of STYPA took place in Vienna, Austria with the theme "Shaping the future of patient advocacy", in July 2019

37 Participants from 20 European countries representing 26 different chronic conditions. All activities were aimed at developing the young patients' personal leadership skills and teaching how to achieve advocacy goals. This year's training was centered on the theme of ethics and conflict of interest.

Take a look at our [story in visuals](#) (#STYPA19), and [short trailer](#) of this year's STYPA edition!

Registrations for next year's edition will open in January: stay tuned!

More information

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