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# The Patient Perspective

March 2021



## Reflections

In the words of the prolific writer Jean Hersey, "In March, winter is holding back and spring is pulling forward. Something holds and something pulls inside of us too." As we look back at our work in March, we feel this push and pull between past, present and future.

Our **Policy team** focused on several key areas for the upcoming months, specifically the Cross-border Healthcare Director and the EU4Health programme. We also collaborated with our Spanish member **Plataforma de Organizaciones de Pacientes** to advance patients with chronic conditions into the priority group in Spain's vaccination strategy. More about that in our **Member News**.

Our **Projects Portal** continues with a Call for Patient Representatives for the COMPAR-EU project and happily announces the launch of **two podcast mini-series for the PERISCOPE and EHDEN** projects. You can have a listen to them both below.

For all young patient advocates, we are still accepting applications for **STYP21** and we're happy to announce the addition of four (4) new members to our Youth Group.

There are several special theme days and virtual events such as **World Health Day** and the **Patient Engagement Open Forum** happening in April so please visit our **Calendar of Events section** at the end of the newsletter to register. Don't forget to check our [COVID-19 Resource Point](#) on a weekly basis.

We're now officially seven months away from the **EPF Congress 2021** so don't forget to **SAVE THE DATE** as registration will open up by the end of April.

Stay safe and enjoy the weekend!



## News From the Secretariat

*updates from the inside*

**EPF is looking for a new Director of Operations and a Senior Finance**

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EPF is looking to hire two new positions: a Director of Operations and a Senior Finance Officer.

The Director of Operations will support EPF's Executive Director by coordinating the EPF Secretariat operations and delivery of the EPF work plan, while the EPF Senior Finance Officer will carry out the financial operations of EPF.

The deadline for applications is **Sunday 11 April 2021**. [Apply now>>>](#)



WE'RE HIRING FOR 2 POSITIONS!

# DIRECTOR OF OPERATIONS SR. FINANCE OFFICER.

Send your cover letter, CV and references to  
[recruitment@eu-patient.eu](mailto:recruitment@eu-patient.eu)

## 7 Months Away!

**EPF Congress 2021: Digital Transformation of Healthcare**  
**26-29 October 2021**

We're officially **seven (7) months away** from the start of our EPF Congress 2021.

Together, we'll explore what meaningful patient involvement means in a rapidly changing healthcare environment using new technologies, and why it is critical to successful innovation. Due to the current public health situation, the Congress 2021 will be held virtually, with a physical follow-up event in Brussels, in Spring 2022.

Registration will open by the end of April with Programme Details.  
Visit [>>>](https://epfcongress.eu)

# 2021 EPF Congress

## EPF celebrates International Women's Day 2021

For this year's International Women Day, EPF stood in support with our Members in their efforts to improve women's health: [read more>>>](#)



### Policy and Advocacy Corner

*discussing the most relevant patient-centered policy and advocacy issues*

## March in Review

In March 2021, the Policy team of EPF focused its activities on setting the scene for engagement in key dossiers and policy areas for the months to come.

On 23 March, EPF ran the webinar '[Evaluating the Cross-Border Healthcare Directive: have patients' rights improved a decade on?](#)', organised in collaboration with the European Commission DG Sante. The webinar, joined by over 50 EPF members and representative from their broader patients' communities, focused on the evaluation and consultation work on the **Cross-border healthcare Directive** (2011/24/EU). Following an introduction on EPF's work in this policy area, European Commission representatives presented the key

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be available in the coming weeks and will be shared through our communication channels.

On 24 March, our Acting Executive Director Elisabeth Kasilingam, presented EPF's views on the **EU4Health programme** during a dedicated [public virtual workshop](#) organised by the European Commission. Elisabeth's presentation, which will be soon available together with the session's recording and material on the European Commission website, built on our [recent work](#) on the topic. EPF's intervention highlighted key expectations from the patient's community on the Programme's policy areas and focused on the essential role of patient organisations in shaping and delivering the Programme going forward. This should be enabled by inclusive and meaningful consultation processes and adequate resources to assist organisations in carrying out their crucial activities.

The Policy team is also working on two key webinars taking place in April and May. On 14 April, EPF will organise a joint event with **CEmPaC** (the Centre for Empowering Patients and Communities) 'Changing healthcare – partnerships for patient empowerment'. Finally, on 21 May, in collaboration with the European Commission, we will run a webinar on the European Health Data Space dedicated to our members. Information on both events will be shared soon, stay tuned!

## Shaping and delivering EU4Health with patients



### Meaningful patient involvement is still an underused resource:

Patients' organisations and the wider civil society **must be fully involved in shaping and implementing the EU4Health Programme** to ensure that the needs are met and their voices heard.



Ensure and implement **inclusive and meaningful inputs in the consultation** processes foreseen in the EU4Health Programme governance.



Ensure adequate resources for patient organisations to enable their key role through the **adoption of a more inclusive operating grants approach and enhanced funding opportunities**.

“ A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE ”



## Projects Portal

*briefings on EPF's ongoing projects*

## Call for Patient Representatives for the COMPAR-EU project

EPF is planning to **expand and diversify** the group of patients and patient representatives involved in the COMPAR-EU patient panel. Do you live with **Type 2 Diabetes, Obesity, COPD or Heart Failure**, or have experience in these diseases and are interested in joining an online group? We invite you to express your interest today!

As part of its work in the [COMPAR-EU project](#), the European Patients' Forum has set-up a [patient panel](#). The patient panel is an informal working group composed of EPF members, individual patients and also patient advocates from across Europe. The group is involved in project activities through various channels and meets (online) for monthly webinars. The patient panel supports in the production of materials in lay language and development of other project outputs. In 2021, it will focus on the functionality of the COMPAR-EU IT platform and materials on cost effectiveness. All these activities will bring

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Are you interested, or know someone that may be interested in joining the patient panel? You can reach out to EPF Senior Programme Officer, **Lyudmil Ninov**: [lyudmil.ninov@eu-patient.eu](mailto:lyudmil.ninov@eu-patient.eu)



### **Data Saves Lives webinar: Developing more meaningful health interventions through the use of patient-reported outcomes (PROs) in health research**

Do you represent a patient group or patient community interested in finding out more about how you can shape health research? Or do you work in clinical or academic health research and want to understand more about how to harness the patient experience to improve outcomes? **JOIN DATA SAVES LIVES** for this 90 minute webinar on **30 March at 13 - 14:30 PM** to:

- Understand how patient groups can work with commercial and academic organisations to help shape clinical research that focuses on what really matters to patients
- Learn from positive examples of where patient-reported outcomes have been used as measures of success in existing research
- Consider current and future opportunities to promote patient-led health data collection in health research

This largely discursive webinar will be led by introductory keynote presentations by x3 expert panellists from the fields of patient engagement, pharmaceutical research and academia.

[Register & read more about the expert panel >>>](#)



## Developing more meaningful health interventions through the use of patient-reported outcomes (PROs) in health

featuring keynote speakers:



**Hannah Staunton**  
Roche



**Dr Alexandra Wyke**  
PatientView



**Dr James Harmsworth King**  
Evergreen Life

DATE:

**30<sup>th</sup> March**

TIME:

**13:00 – 14:30 CET**

### 🎧 EU Patients' Podcast launches the PERISCOPE Monthly Talks

In March, we launched the first episode of our new monthly podcast mini-series - the **PERISCOPE Monthly Talks**.

We speak with PERISCOPE project coordinator Paolo Giudici about **the role of data and data analysis** in understanding the effects of the COVID-19 pandemic.

[Listen now>>>](#)

The poster for the first episode of the PERISCOPE Monthly Talks podcast. It features a blue background with a large white circle containing a portrait of Prof. Paolo Giudici. To the left of the circle, the text reads: "The Role of Data Analysis in Understanding the Effects of COVID-19" and "16 MARCH 2021". Below this, a short biography of Prof. Giudici is provided. The top left corner features the European Union flag. The top right corner displays the "EPF periscope MONTHLY TALKS" logo and "EPISODE > 1". The bottom of the poster shows a colorful illustration of a diverse group of people, some wearing face masks, representing the patient community.

**The Role of Data Analysis in Understanding the Effects of COVID-19**

**16 MARCH 2021**

Prof. Giudici specialises in Statistics and of Financial Data Science. Supervisor of about 180 Master's students and of 18 Phd students, currently working as academic researchers, in the financial sector and in IT/consulting companies. He is also the author of several scientific publications. He is the Coordinator of 12 funded scientific projects, PERISCOPE is one of them.

**PROF. PAOLO GIUDICI**

### 🎧 The launch of the All About EHDEN mini-series - Part 1

series, All About EHDEN.

In this episode, we are joined by EHDEN project coordinator Peter Rijnbeek to help us understand some **basic health data concepts** central to EHDEN and helps us to frame why a project like EHDEN is crucial to harnessing the insights and evidence available from real-world clinical data at scale. [Listen now>>>](#)



The EU Patients' Podcast presents:

# All About EHDEN

mini-series

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Part 1

**An introduction to EHDEN**  
with Peter Rijnbeek

EPF European Patients Forum

EHDEN EUROPEAN HEALTH DATA & EVIDENCE NETWORK

prefer.  
PATIENT PREFERENCES

### Patients and Researchers in Partnership: PREFER project

On 5 March 2021, the [PREFER](#) project launched an intensified patients' communications campaign. Together with three other patient organisations participating in the project, the European Patients' Forum aims to ensure that what is done for patients, is also understood by patients.

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reviewing project materials, helping to ensure that patient focused materials are created in a patient-friendly manner and ensuring that they are in accessible language. Lastly, the core group of four patient organisations, including EPF, the European Cancer Patient Coalition, Muscular Dystrophy UK, and the International Alliance of Patient Organisations, will begin the crucial work to ensure that the project's scientific reports and researcher's publications results are also accessible to patients.

[Click here to learn more about the PREFER patient engagement activities >>>](#)

PREFER is a project of the [Innovative Medicines Initiative](#) (IMI) working to provide a set of systemic methodologies and recommendations to assess, engage and include patient perspectives during the development, approval and post-approval of new therapies, providing a better understanding of recommended best-practice approaches.



## Capacity Building Module on Fundraising and Engagement 2021

The Fundraising and Engagement topic of this year's capacity building module arises from the uncertainty and difficulties that patient organisations are put through, during the COVID-19 pandemic. Patient organisations are under great pressure to keep running their day-to-day work as well as respond to the new emerging needs from their members. The pandemic crisis has made it difficult for many to secure funding from membership fees, and attend in-person fundraising events and conferences.

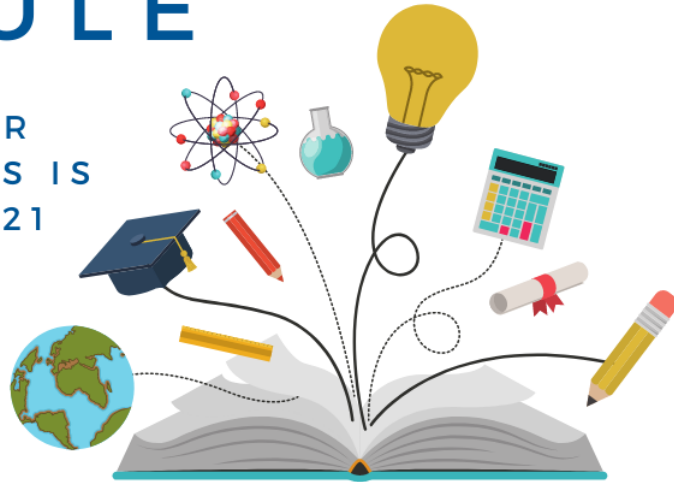
In 2021, the economic crisis is starting to impact patient organisations, as funding is diverted towards other beneficiaries, leaving patient organisations to seriously rethink their fundraising strategy. In this framework, supporting the fundraising and engagement strategy is key to ensure the sustainability of patient organisations.

**Registration is now closed but the Module will proceed in three phases from April to November.**



# CAPACITY BUILDING MODULE

DEADLINE FOR  
APPLICATIONS IS  
25 MARCH 2021



## Summer Training Course for Young Patient Advocates (STYPA) 2021

There is still time to apply to newest edition of our Summer Training Course for Young Patient Advocates! With #STYPA21 you will have the opportunity to network with other young patients, learn from tailored webinars and develop your own advocacy project!

Geared towards young adults aged 18-30, our trainers will fully support you in your new patient advocate journey and maximise your leadership potential. **Application deadline is 18 April 2021.**

[Apply for #STYPA21 now>>>](#)



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## highlights from our member organisations



The Executive Council of **WFIPP** is excited to present the 'Support InContinence' platform which is intended to act as a helpful resource for all stakeholders, patients, families, carers, HCPs and institutions who are in some way involved in the patient pathway relating to incontinence.

[support now>>>](#)



PLATAFORMA DE ORGANIZACIONES DE PACIENTES

On 11 March 2021, EPF wrote a letter in tandem with its partner, **Plataforma de Organizaciones de Pacientes**, advocating to the Spanish Minister of Health, Hon. Carolina Darias, to include patients with chronic conditions as a priority group in Spain's COVID-19 Vaccination Strategy. We are very pleased to inform you that following this letter, it was agreed in the Health Committee that **high-risk group will start vaccination at the same time as the 70-79 age group.**

[read the letter>>>](#)



European  
**AIDS Treatment**  
Group

**EATG** has co-signed and shared this call for global vaccine equity, initiated on the side of one of the flagship annual conferences on retroviruses, CROI. The call is open for signatures of support.

[sign the letter>>>](#)



**EHMA** is pleased to launch the **Call for Abstracts** for the EHMA 2021 Annual Conference. Participate in the EHMA 2021 Annual Conference by sharing your research with the full health management ecosystem. Submit your abstract by **Monday, 3 May 2021.**

[submit here>>>](#)



## Youth Group

*initiatives, stories and events from our most budding members*

### Our New Youth Group Members

After our recent recruitment call, as the EPF Youth Group is very happy to welcome four lovely new members to our Youth Group Family. They all come from different geographical backgrounds and represent a variety of patient communities. As a board, we are also very excited to work with these new members and work on current projects as a team.

Welcome to **Cornelia Pauna** (Romania), **Blaž Urbanc** (Slovenia), **Bianka Tomózer** (Hungary) and **Rositsa Malinova** (Bulgaria). [read full article>>>](#)

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## Inside the Bubble

updates, stories and events around EU healthcare

### EU moves to fast-track vaccine approval for new coronavirus variants

The Commission announced plans to imminently introduce new provisions in EU legislation to fast-track approval of booster vaccines that could target new variants. Under the HERA incubator, which aims to solve the threat of new coronavirus variants that can bypass current vaccines, the Commission's fast track procedure will mean that companies can submit a smaller data set to the European Medicines Agency for booster vaccines — that is, shots that have been adapted from already approved vaccines. The Commission also proposed an additional €345.2 million from the EU budget to fund existing and new coronavirus initiatives this year, with part of this funding going to HERA's work on sequencing variants. €100 million would be available for urgent initiatives. However, the funds still need to be agreed by Parliament and the Council.

### Joint HTA proposal to proceed to negotiations with Parliament

The long stalled proposal for EU-wide joint health technology assessment has received backing from the EU's member countries, clearing the path for negotiations with the European Parliament, an EU diplomat said today. The latest [proposal](#) was presented to member country representatives at a meeting for Coreper, where it received a mandate to proceed to trilogue.

### MEPs vote to fast-track coronavirus travel pass

MEPs have agreed to fast-track voting on the European Commission's plan to create a bloc-wide travel pass that confirms coronavirus vaccination, immunity or testing status. The Commission unveiled its proposal for the so-called digital green certificate, which is supposed to help re-start robust travel across the bloc. It has pushed to roll out the certificates swiftly, with plans to have the pass operational by June.

"Every negative belief weakens the partnership between mind and body."

Deepak Chopra



## Calendar of Events

**2 April**

World Autism Awareness Day

[visit our website](#)

[Subscribe](#)[Past Issues](#)[Translate ▼](#)**11 April**

World Parkinson's Day

**14 April (15:00 - 16:30)**

EPF &amp; CEMPAC Webinar

"Changing healthcare – partnerships for patient empowerment".

**14-15 April**[Patient Engagement Open Forum 2021 \(PEOF\)](#)**17 April**

World Haemophilia Day

EPF Annual General Meeting

**18 April**

STYP21 Application Deadline

**19-25 April**

World Primary Immunodeficiencies (PI) Week

**22 April**

World Earth Day

**26 April**

Registration Opening for EPF Congress 2021

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