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The Patient Perspective

April 2021



Reflections

April was quite a busy month at the European Patients' Forum.

We finalised our Annual Report 2020, which recapped our efforts in 2020 and was presented at our Annual General Meeting (AGM). We outlined our objectives of our Policy, Projects and Capacity Building teams for the upcoming year as well. You will see find their efforts during the past month below.

There are several special theme days and virtual events such as **Mental Health Awareness Week** and **our joint webinar with DG SANTE on the European Health Data Space** happening in May 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 or listen to the latest episodes of the [EU Patients' Podcast](#).

We're now officially six months away from the **EPF Congress 2021** so stay tuned for the launch of registrations within the next weeks.

Stay safe and enjoy the weekend!



News From the Secretariat

updates from the inside

Annual General Meeting Recap

On 17th April 2021, EPF Members gathered online for the 18th Annual General Meeting (AGM). This was the second virtual AGM for EPF due to COVID-19 circumstances. Despite being apart for the second year in a row, the mood was light and happy as all members got to bask in the wonderful efforts from the past year and look forward to what's next.

[Read our AGM recap>>>](#)

Annual Report 2020 Published Online

The European Patients' Forum's Annual Report 2020 has been published. Our Annual Report outlines the work and achievements made in the areas of empowering and enhancing the patient voice in 2020.

ANNUAL REPORT 2020



We're Hiring!

EPF is looking to hire three (3) new positions:

- a Director of Operations,
- Senior Finance Officer
- an EU Policy Advisor - Pharmaceuticals and Medical Devices.

Please share amongst your networks.

[Full Job Details & Deadlines>>>](#)

CHECK BELOW FOR OPEN POSITIONS!



**JOIN OUR
TEAM**

Send your cover letter, CV and references to
recruitment@eu-patient.eu

New Episodes of the EU Patients Podcast

In April, the EU Patients Podcast published several new episodes. Listen below:

- [#8 - European Health Union Manifesto with Dr. Vytenis Andriukaitis](#)

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New episodes available on:



or wherever you get your podcasts!

EPF celebrates World Health Day

On 7 April 2021, we called for action to eliminate health inequities, as part of a year-long global campaign to bring people together to build a fairer, healthier world.

On this year's World Health Day, we asked our Members and patient communities **what is needed to build a fairer and healthier world.** [Read their responses>>>](#)

WORLD
HEALTH DAY
2021



Building a fairer, healthier world for everyone



Policy and Advocacy Corner

discussing the most relevant patient-centered policy and advocacy issues

April in Review

On 27 April, EPF [published its response](#) to the European Commission Roadmap Consultation on the revision of the EU general pharmaceuticals legislation.

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new medicines, and making the medicines supply chain more efficient. While welcoming the Pharmaceutical Strategy's objectives that directly affect patients, in our response we stressed the importance of reducing inequity in access. We also provided our views on some of the elements identified in the European Commission Roadmap, such as the need of defining the concepts of "unmet needs" and "added therapeutic value", the regulatory landscape, incentives, competition and transparency. Patients' perspective should be meaningfully embedded in the ongoing pharmaceuticals legislation revision.

Furthermore, you can now access recording and materials from our webinar Evaluating the Cross-Border Healthcare Directive – Have patients' rights improved a decade on? The webinar, hosted by EPF in collaboration with the European Commission, was organised to facilitate engagement the patient community with the evaluation process of the Directive and its next steps, including the [upcoming European Commission's public consultation](#). If you could not attend the webinar or if you want to re-watch the discussion, you can now read our brief recap and access the event recording and the presentation [here](#).

If you want to know more about EPF's policy work please reach out to the Policy Team at policy@eu-patient.eu.

VAC-PACT

The **VAC-PACT pilot project** aims to improve uptake and confidence in vaccines for patients with chronic diseases, families and supporting communities. As part of its activities, VAC-PACT coordinated **3 regional workshops** to enable us to engage and work with representatives at national levels within Central and Eastern Europe, Southern, and Western Europe. [Read our Recap>>>](#)



Projects Portal

briefings on EPF's ongoing projects

Kick-Off Meeting for CORE-MD project

On 16 April 2021, the Coordinating Research and Evidence for Medical Devices (CORE-MD) project held its virtual kick-off meeting.

CORE-MD is the first formalised group of stakeholders in Europe working together to identify ways to enable the scientific, fair, and systematic evaluation of medical devices. The project will translate expert evidence on study designs for evaluating high-risk medical devices into advice for EU regulators. Advice will be provided on ways to extract maximum value from real-world evidence including medical device registries and clinical practice. The aim of CORE-MD is to achieve a balance between innovation, safety, and effectiveness.

EPF will support the consortium in identifying the best suited patient-reported outcome measures (PROMs) to discriminate between well-performing and under-performing high-risk medical devices and how to adapt them. They will ensure that patient engagement is part of this task from the very beginning of establishing PROMs.

The project, is led by the European Society of Cardiology and the European Federation of National Associations of Orthopaedics and Traumatology, and comprises a consortium of 22 partners.

CORE-MD receives funding from the European Union Framework Programme for Research and Innovation under Grant Agreement No 965246.

[Learn more about CORE-MD on the dedicated project page >>>](#)



Coordinating Research and Evidence
for Medical Devices

DSL Call for Patient Stories

The Data Saves Lives initiative aims to raise wider patient and public awareness about the importance of health data, improve understanding of how it is used and establish a trusted environment for multi-stakeholder dialogue about responsible use and good practices across Europe.

To help us achieve this aim **we're looking to share individual patient stories to highlight personal experiences** of being involved in health data research projects or initiatives. We would like to share these personal experiences on a new 'Patient Stories' section of the Data Saves Lives website (<https://datasaveslives.eu/>).

Would you or your members be interested in taking part?

[Learn more about Patient Stories >>>](#)

#DataSavesLives

4th Data Partner Call of 5 million euros - largest to date!

The European Health Data & Evidence Network (EHDEN) has launched its fourth open call for [Data Partners](#) to map their patient data to the [OMOP common data model](#) to enhance and accelerate research and healthcare decision-making.

The aim is to harmonise more than 100 million health records utilising the services of EHDEN-certified SMEs. For this reason, EHDEN is inviting all data custodians (keepers) of Electronic Health Records, Claims, Hospital and Registry data across Europe to participate in its next open call. After 3 open calls, EHDEN is now working with [61 Data Partners](#), 26 trained and certified Small-to-Medium Enterprise-sized (SME) companies across Europe.

The current call is a general call across therapeutic areas and diverse types of health data. But countries not yet (or minimally) represented in the EHDEN Network will be especially welcome, as well as datasets with granular data:

- Oncology, especially solid tumours (e.g., breast, lung, pancreatic, prostate)
- Diabetes Mellitus
- Including, but not exclusively Patient Outcomes, e.g., PROs/PREMs/HRQoL
- Including, but not exclusively Claims, resource utilisation.

If you wish to know more about what data partners mean and their role in this project, you can also listen to our podcast at "[All about EHDEN, Part 2: Data Partners](#)"

The current open call will run from April 15 to May 13 2021

[>>> Head to the EHDEN website for more details](#)

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DATA PARTNER CALL

4th Open call for data partners wanting to map their patient data to the OMOP common data model to enhance and accelerate research and healthcare decision-making.

- Work with one of 26 EH DEN Certified SMEs for mapping your data
- Up to **100 000 €** grant for mapping cycle
- Rapid evaluation & turnaround

April 15th - May 13th

EHDEN.EU

NEW COMPAR-EU blog: Prolonging lives with self-management

On 30 March, the COMPAR-EU regular blog series published its latest update.

In the blog post, Pieter van Baal and Meg Perry-Duxbury of the Institute for Medical Technology Assessment (iMTA) review the findings of two recently published papers on how to integrate the impact of future costs into cost-effectiveness analyses. The term "Future Costs" refers to the medical care and other goods and services that a person can participate in (or 'consume') as a result of them living longer thanks to self-management interventions (SMIs).

[Read the full blog here >>>](#)

SELF-MANAGEMENT BLOG

PERISCOPE Monthly Talks #2 - EU COVID-19 Forecast Hub with ECDC's Helen Johnson

On this episode of the PERISCOPE Monthly Talks, we speak with Helen Johnson from ECDC to discuss the importance of data forecasting in relation to the #COVID19 pandemic. [listen now >>>](#)

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MONTHLY TALK

EPISODE > 2

with
HELEN JOHNSON

about
EU Forecast Hub

20 APRIL 2021

The EU Patients' Podcast

Capacity Building Centre
a rundown on EPF's seminars and learning tools

Patient Advocates Seminar 2021 - Recap

From February to March 2021, EPF along with The Good Lobby held its Patient Advocates Seminar. Its an online course composed of four online interactive trainings on patient advocacy aimed to give participants from EPF member organisations stronger knowledge of the European decision-making process, as well as enhanced advocacy skills and strategies and increased cooperation between different organisations. Special attention was paid to the impact of COVID-19 on the health advocacy space.

With the success of these online courses, we asked a few participants to tell their story and give their feedback on the Patient Advocates Seminar.

[Read their testimonials>>>](#)

Member Focus
highlights from our member organisations

WORLD IBD DAY 19 MAY

EFCA

IBD and Well-being

#worldibdday2021 #breakthesilence

EFNA GRANTS 2021 - APPLY TODAY!

Personalised Health and Social Care

Total grant fund of €30,000

www.efna.net/grants2021

EFNA

The **European Federation of Neurological Associations (EFNA)** has launched a call for applications to its 2021 grants scheme. This

EHMA
European Health Management Association

EMHA launched a **European survey** to understand the difficulties and cost there are to get a good treatment for

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awareness on Inflammatory Bowel Disease (IBD) throughout the month of May. Under the theme "Break the silence – IBD and Well-being" EFCCA wants to shed a light on the various aspects of the disease. In particular we want to start a dialogue and discussions on how IBD affects people not only physically but also psychologically.

[join now>>>](#)

World Haemophilia Week, culminating in **World Haemophilia Day** on Saturday 17 April. We mark the celebration with daily podcasts on various topics that might be of interest to the broader patients' community. We would suggest sharing our webpage with all the podcasts and background information (it will be complete with all the posts by Saturday 17 April) with the EPF community.

[listen now>>>](#)

organisations in the area of 'personalised health and social care'. In 2021 EFNA will fund up to 10 projects from a total grant fund of €30,000.

[apply now>>>](#)

The European Multiple Sclerosis Platform (EMSP) will gather the European Multiple Sclerosis community virtually between 9-11 June at the **#EMSP2021 Conference** addressing the topic of "MS Care in a Changing World". Registration is FREE for patients, nurses, carers, MS societies and patient advocates.

[register now>>>](#)

EURORDIS, Rare Diseases International (RDI) and NGO Committee for Rare Diseases are leading a global campaign calling for the first UN Resolution on Persons Living with a Rare Disease (PLWRD) and their Families. They are urging UN Member States to adopt measures to promote the full participation of PLWRD and their families in society and protect their human rights.

[join the campaign>>>](#)

survey is available in 11 languages

[read the survey>>>](#)

EMHA hosted a webinar and released a **Policy Paper** that looks at 5 important aspects of women and migraine which can instruct future policy makers' decisions: disease prevalence, sex-specific factors, the impact of migraine on women's work-life and personal life, and gendered stigma.

[read the policy paper>>>](#)

The European Liver Patients Association (ELPA)'s **COBALT study** is taking place across Europe to urgently address this question by measuring responses to vaccination in liver patients. It is designed to report back quickly to inform patients and policy-makers, although further support is needed to accelerate this process and allow policy decisions to be made rapidly.

[learn more>>>](#)

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

Recapping our Activities in April

This past month, the EPF Youth Group was very busy, partaking in several events that allowed members to engage and provide the young patients' perspective. The Youth Group hosted its annual Spring Meeting, attended the EPF AGM and participated at the Patient Engagement Open Forum. [read full article>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

Parliament approves COVID-19 certificate position

The European Parliament adopted its position on the "digital green" certificates Brussels wants to use to reboot travel by proving holders got a jab, a test, or have antibodies following a coronavirus infection with a broad majority. The votes cement Parliament's push to prevent EU countries from imposing additional travel restrictions for people with a certificate, and its demand that tests for travel be offered free of charge — two elements lawmakers argue are essential for the certificate to make a difference for citizens.

EU, Roche sign deal for COVID-19 antibody cocktail

The European Commission has signed a deal for the supply of Roche/Regeneron's monoclonal antibody cocktail to treat COVID-19, Roche said today. The joint procurement framework contract for the supply of casirivimab and imdevimab — antibodies that mimic the body's own response to coronavirus infection — was signed on April 1.

Increase in vaccine manufacturing capacity and supply for COVID-19 vaccines from BioNTech/Pfizer and Moderna

EMA's human medicines committee has adopted two important recommendations that will increase manufacturing capacity and supply of COVID-19 vaccines in the EU. EMA is in continuous dialogue with all marketing authorisation holders of COVID-19 vaccines as they seek to expand their production capacity for the supply of vaccines in the EU. The Agency provides guidance and advice on the evidence required to support and expedite applications to add new sites or increase the capacity of existing sites for the manufacture of high-quality COVID-19 vaccines.

EMA, ECDC team up to monitor coronavirus vaccines

The European Medicines Agency (EMA) and the European Centre for Disease Prevention and Control (ECDC) announced they have joined forces to coordinate and oversee studies on the safety, effectiveness and impact of authorized COVID-19 vaccines.

A new joint advisory board to support this work held its first meeting today. The board comprises representatives of the European Commission, the EU/EEA National Immunisation Technical Advisory Groups collaboration organized by ECDC, members of the EMA COVID-19 pandemic Task Force and EMA's committees on human medicines (CHMP) and safety (PRAC). The board will meet regularly and advise on the prioritization, design,

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“Remain calm, because peace equals power.”
Joyce Meyer



Calendar of Events

5 May

Global Hand Hygiene Day

[visit our website](#)**10-16 May**[European Mental Health Awareness Week](#)[contact us](#)**17-23 May**

European Public Health Week

19 May

World IBD Day

20 May[2nd Life after Stroke webinar: "Intimacy and sex after stroke"](#)**21 May**Joint Webinar with European Commission (DG Sante) & EPF
Shaping a European Health Data Space for patients and with patients**27 May (15:00 - 16:30)**EPF & CEMPAC Webinar
“Changing healthcare – partnerships for patient empowerment”.**28 May**[International Day of Action for Women's Health](#)[view this email in your browser](#)

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