



The Patient Perspective

April 2020 edition

Reflections

It has been another whirlwind month here at EPF as our team has continued to respond and take a leading role with regard to the COVID-19 pandemic. We launched the [COVID-19 Resource Point](#), to ensure that you are kept abreast of the most relevant and reliable information regarding the COVID-19 pandemic

Given the profound concerns of EPF member organisations regarding the impact of COVID-19 on their communities, EPF shared an [Open Memo](#) to health industry representatives outlining the main challenges for patients with chronic diseases and our expectations regarding their on-going commitment and contribution in these unprecedented times. Since we underlined the important role and responsibilities of industry as we perceive them, we have received several responses from Industry players (**EFPIA, Medicines for Europe, Med-Tech Europe, AEGSP, EUCOPE, COCIR and EuropaBio**), which you can read [here](#).

We thank everyone for their participation in this endeavour. We will look very carefully at the detailed replies and will **continue our dialogue with industry and other stakeholders** to help to ensure the best possible outcomes for patients and their families across Europe.

In other news, we just finished conducting our **first-ever virtual Annual General Meeting** (AGM) this past weekend, with flying colours. More below on that. We take a look at how our Policy, Projects and Capacity Building teams have adapted and conducted themselves over the past month during the lockdown and focus on some of the COVID-19 work of our Members.

We are all in this together, and only with vigilance and diligence, can we surpass this obstacle.

As William Shakespeare once wrote: **"Things done well and with care exempt themselves from fear."**

News from the Secretariat

updates from the inside



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



Recap of EPF's (virtual) Annual General Meeting (AGM)

On 25th April 2020, EPF Members gathered online for the 17th Annual General Meeting. This was the first ever virtual AGM for EPF, adapting to the current COVID-19 circumstances while upholding fundamental governance standards for EPF and its members. During the event, members of EPF's Board and Secretariat reported on 2019 activities and gave an overview of our current and upcoming work for 2020-2021. EPF's Annual General Meeting (AGM) has always played a key role in the democratic and governing process of the organisation. The annual report and the financial report for 2019, as well as the budget and work plan for 2020 were all approved during the meeting.

Based on live voting, we are happy to congratulate and offer a warm welcome to the three **new three FULL members** of the EPF Family:

1. [Digestive Cancers Europe](#)
2. [Lung Cancer Europe](#)
3. Greek Patients' Association

1. Elisabeth Kasilingam ([European Multiple Sclerosis Platform](#))
2. Brian West ([European AIDS Treatment Group](#))
3. Marzena Nelken ([Federation of Polish Patients](#))
4. Michal Rataj ([EAMDA](#))
5. Jana Popova ([European Young Patients](#) rep)

This year, we have launched our **Ethics Committee** to issue opinions or advice upon written request from the Board and review any internal guidelines or procedures if such guidelines or procedures have a direct or indirect impact on matters in its scope. We are happy to announce the newly elected members of the Ethics Committee are:

1. Amanda Bok ([European Haemophilia Consortium](#))
2. Anita Arsovska ([Stroke Alliance for Europe](#))
3. Birgit Dembski ([BAG SELBSTHILFE](#))
4. Stella de Sabata ([International Diabetes Federation Europe](#))
5. Mateja Kržan ([European Network of Fibromyalgia Associations](#))

We would like to warmly thank all other candidates and outgoing Board Members for all their efforts. While we would have preferred to embrace all of our members in person, the virtual AGM was the best option to unite us together during this tumultuous time. Nevertheless, we hope that everyone enjoyed our day together and we look forward to seeing you all again in person in the very near future.

Read the [Full Report on the 2020 AGM here>>>](#)

#WorldHealthDay2020

**#SupportNursesAndMidwives
#COVID19**

7 April 2020

World Health Day



EPF and its Members Shine a Spotlight on Nurses during World Health Day 2020 (7 April)

This year's theme was centred on nurses and midwives and serves as a reminder of the critical role they play in healthcare.

EPF has over the years strengthened its partnership with organisations representing nurses and European level, such as the **European Federation of Nurses (EFN)** and the **European Specialist Nurses Organisation (ESNO)** to foster cooperation on patient-centred healthcare. EPF led the first ever EU-funded [project](#) to assess the perspective of the end-users of e-health services – patients, doctors, nurses and pharmacists across the EU, and we regularly contribute to events and activities, including through the European Medicines Agency's [joint meetings](#) of patients and health professionals' organisations.

As pan-European umbrella for disease-specific organisations and national patient coalitions, EPF's priority is to strengthen and amplify its members' diverse yet unified messages. On this occasion, we **asked our members to help us gather patient testimonies** on the subject of nurses and midwives.

You can read those testimonies [here>>>](#)



Our beloved Anna Trzcinska is moving on

We are sad to announce that our lovely Event Coordinator has left EPF to become the Office & Event Manager at Heinrich Böll Foundation in Brussels. We'll definitely miss her solutions-based demenour, quirkiness and her unique method of sneezing. Best of luck on your new adventure and we hope to see you soon!

Policy & Advocacy Corner

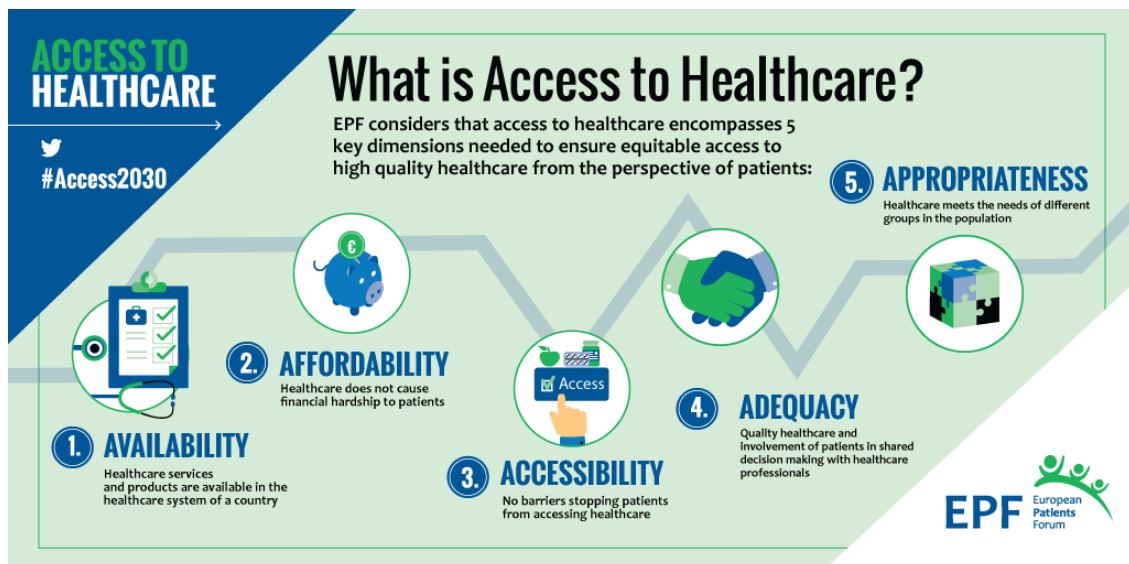
discussing the most relevant patient-centred policy and advocacy issues



EPF Statement on the Postponement of the Application of the Medical Devices Regulation (MDR)

The COVID-19 outbreak and the associated public health crisis has created extraordinary circumstances that demand substantial additional resources, as well as an increased availability of vitally important medical devices. Those extraordinary circumstances have a significant impact on various areas covered by the **Medical Devices Regulation (EU) 2017/745**, such as the designation and work of notified bodies and the placing on the market and making available on the market of medical devices in the Union.

On 22 April, the Council approved the European Commission's [proposal to postpone the application of the Medical Devices Regulation](#) to prioritise the fight against coronavirus. Considering this situation, the **European Patients' Forum (EPF)** welcomes the [postponement by the European Commission](#) of the date of application of the Medical Devices Regulation (MDR) by one year to 26 May 2021, in order to alleviate pressure on key actors and ensure effective implementation of the regulation and the changes that patients need. You can read our [Full Statement here>>>](#)



EPF's working group on universal access to healthcare meets virtually

Members of the group proposed that EPF may be able to support with a statement which would go into more detail on a few aspects of our [initial COVID-19 statement](#), notably home delivery/local pharmacy delivery of medicine, telemedicine and virtual consultation and an emphasis on the protection of people with chronic conditions during this pandemic. Following this request, on 8 April, EPF published the statement [“Now is the Time to Protect Patients and Safeguard Access to Care”](#) in close collaboration with the working group, whose members endorsed the statement.

The working group's **work plan for 2020 was also discussed and adopted** during the meeting. In particular, the group discussed forthcoming activities related to the European Semester, medicine shortages and the affordability of and access to medicines. In 2020, the working group will contribute to several specific tasks relating specifically to medicine shortages and affordability of and access to medicines, as per the EPF work plan. The working group will also contribute to EPF's next Strategic Plan, support the Patient Access Partnership's activities, and contribute to the work of SDG Watch Europe as and when appropriate.

For any further questions about the working group, please contact katie.gallagher@eu-patient.eu

Projects Portal

briefings on EPF's ongoing projects

EPF Projects during the COVID-19 Lockdown

COVID-19 has shined a new light to the work of the EPF Projects team, and the impact of infectious diseases on patients with chronic conditions will not be perceived the same again. For our team, this unprecedented time has reaffirmed what we already knew – **multi-stakeholder collaboration across countries is incredibly important** and at the centre of everything we do.

The Projects team doesn't work despite COVID-19, COVID-19 is now fully a part of our work, both through building up new projects and/or already ongoing projects. Equally, we have been very impressed with the renewed commitment from our partners. Of course, the deadlines for some of our projects have been impacted with minor delays, and we have even begun to **integrate COVID-19 as a proof-of-concept** into some of our work.

Of course, we miss the hum of everyday life – coming into the office, seeing friends and colleagues, going about our weekends like we used to. Just like everyone, we are adapting to new ways of working from home, replacing the large consortium meetings with project partners to online spaces where we sometimes make jokes about turning off the microphone, or catch glimpses of family or pets in the background. We are most of all reminded that we are all trying to do our best during a very challenging time, and are uplifted by the impressive growth in community spirit and support that we have seen.



COVID-19

**Rapid Collaboration Call for data partners
wanting to map their COVID-19 patient data
to the OMOP common data model**

- Mapping performed by **EHDEN Task Force**
- Up to **50 000 €** grant to cover expenses
- Rapid evaluation & turnaround

April 16th - May 14th

APPLY NOW
[BIT.LY/EHDENCovid19](https://bit.ly/EHDENCovid19)

EHDEN launches a COVID-19 Rapid Collaboration Call for Data Partners

On 16 April 2020, the **European Health Data & Evidence Network (EHDEN)** announced an extraordinary COVID-19 Rapid Collaboration Call, which is open until 14 May 2020. EHDEN published the call to support the work of patients, clinicians, scientists and governments worldwide to learn more about characterising COVID-19 patients, managing their care, and deciding on safe and effective treatments.

Obtaining data insights and evidence is critical to improving decision-making during the COVID-19 pandemic; but real-world health data is often patchy, divided in systems that cannot work together, and is difficult to work with. To change this, EHDEN proposes to assist potential partners with relevant COVID-19 clinical data with financial and technical support to streamline the data to a common model. The aim is also to **link partners and researchers together** to facilitate faster open science in the study of COVID-19.

Interested? Interested partners can apply by filling in a short application template through this [portal](#). A panel of experts will then assess all applications, and will respond quickly with their decision. For this call, EHDEN is **offering a sub-grant of up to €50,000**.

Capacity Building Centre

a rundown on EPF's seminars and learning tools

Adapting our Programmes to the COVID-19 Pandemic

Every year, EPF offers a variety of learning opportunities to its members and the European patient community at large.

At the beginning of this year, EPF launched the 2020 edition of its *Empowering Leadership and Positive Governance Module* as well as the third year of the *Summer Training Course for Young Patients Advocates (STYPA)*. Both capacity building modules typically have an online and physical component.

The COVID-19 health crisis has put us, and many organisations, in the position of deciding to postpone or abstain from offering learning opportunities or be creative and find a way of digitalising the courses without compromising the quality and cutting on the vital human/peer learning dimension that is a key element of our offer. **Being EPF, we decided to take on the challenge!** [Read more>>>](#)

Member Focus

highlights from our member organisations

MAY

Calendar of Events



EURORDIS - Rare Diseases Europe have published a statement addressing EU policymakers to bring to their attention the concerns and needs of people living with a rare disease, their families and carers during the current crisis. They have even created their own designated COVID19 resource centre.

May 1

Labour Day

May 4

Mental Health Awareness
Week

May 5

Global Hand Hygiene Day

May 8

IMMUcan Executive
Board meeting (by
invitation)

May 9

European Public Health
Week

May 10

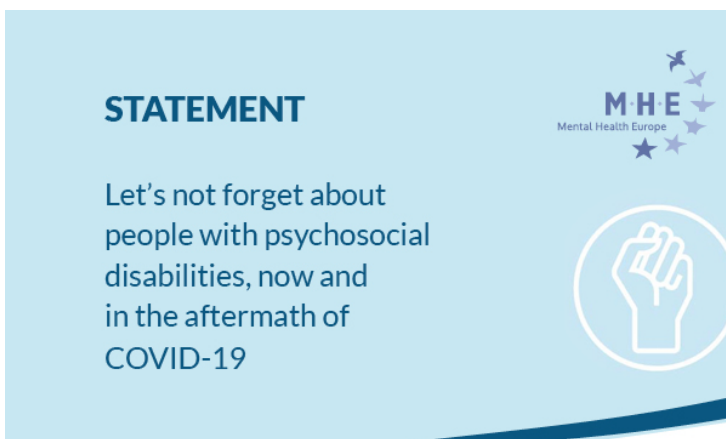
Mother's Day

May 11



The ECRD 2020 theme “**The rare disease patient journey in 2030**” recognises that the next decade holds great potential for improvement and that while we cannot predict the future, we all have a role in preparing for it. As the EU shapes its future policy and spending frameworks, ECRD 2020 serves as an opportunity to press the ‘pause button’ and take the time to co-create policy options today that can lead to a better patient journey in 2030.

[Register Now](#)



Mental Health Europe have published a statement to remind national and EU policymakers of the critical role that human rights compliant mental health services play in contributing to a public health response during COVID-19 pandemic. They have also published tips on [how to look after your mental health](#) during COVID19.

[Read their Statement](#)

May 12

OECD Healthcare Quality and Outcome working group (HCQO)

May 14

[Virtual European Conference on Rare Diseases \(ECRD\)](#)

DigitalHealthEurope Webinar: “Citizens’ secure access to and sharing of health data across borders”

May 15

Launch of STYPA

May 18-20

[Virtual ISPOR 2020](#)

May 19

World IBD Day

May 22

Bank Holiday (BE)

May 28

[EUPATI Fundamentals Online Training](#)

WELCOME ABOARD

EPF would like to welcome two new members to its Secretariat.



Michele Calabro is EPF's new Policy Advisor.



The **European Multiple Sclerosis Platform** have issued a blog piece based on global recommendations, and useful resources for people with MS to inform our communities about the relationship of the virus and Multiple Sclerosis. The blog is updated on a daily basis.

Read their Blog

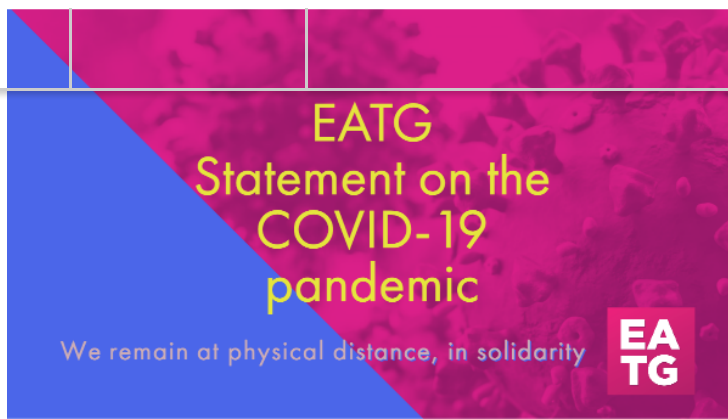


ENUSP have expressed concerns for the mental health community, with regard to people with psycho-social disabilities and their vulnerability to the COVID-19 outbreak. The statement outlines their concerns and calls national and local governments to action.

Read their Statement

management of projects, policy and communication at the European Health Management Association (EHMA) and he worked as European Semester Officer Assistant at the European Commission Representation in Malta. Michele holds a Bachelor degree in Public Administration and a Master degree in European Studies and International relations (University of Turin, Italy). He is also a member of a number of health policy professionals network, including the Young Forum Gastein Task Force, of the Young Coalition for Prevention and Vaccination and of the European Health Parliament alumni group.





The **European Aids Treatment Group (EATG)** have created a Facebook group to collect and share evidence related to the ongoing COVID-19 epidemic in regards to HIV and co-infections. They have also published results of their recent Rapid Assessment, undertaken to document perceptions from the HIV community of the way COVID19 is impacting their health, well-being and access to HIV related prevention, treatment and care.

Read about their Rapid Assessment



The **European Federation of Neurological Association (EFNA)** has collected resources from a number of our member organisations that are relevant to the disease areas they represent. These, along with other general information from trusted health authorities, are available in EFNA's new **COVID-19 Resource Hub for Neurology Patients**.

See their Resource Hub for Neurology Patients

Youth Group

initiatives, stories and events from our most budding members



An Historical Moment for the EPF Youth Group at the 2020 AGM

by Jana Popova

This year's EPF Annual General Meeting (AGM) was organised online on 25 April, because of the complicated situation with COVID-19. In spite of the circumstances, many members of EPF were able to attend the meeting and to share their valuable experience. The meeting provided interesting discussions on important topics and contained a historical recognition for the EPF Youth Group.

For the first time in the history of EPF, the Youth Group representative, **Jana Popova, was elected to the EPF Board with full voting rights.** This happened, because of the changes in the EPF constitution, approved during the previous AGM. Having a Youth Group representative on the Board is proof that EPF values young patients' empowerment and supports next generation of patient advocates. Jana shared the following: *"I would like to thank EPF and EPF Secretariat for this honour! This is great recognition for the hard work of EPF Youth Group. I also would like to thank all current and former Youth Group members for their inspirational work and devotion to patient community! I am looking forward to working with the EPF Board and to present Youth Group in the best possible way."*

During the AGM, Ivett Jakab, Youth Group President, presented the latest updates about WAYS project (Work and Youth Strategy) and provided a sneak peak of the next Youth Group project on sexual health/education. Ivett underscored that the the main goal is to enhance the cooperation with other youth associations in Europe. Also, EPF Youth Group is going to be involved in the fourth edition of the Summer Training Course for Young Patient Advocates (STYPA). The 2020 AGM proved that there is a strong collaboration between the EPF Secretariat and the EPF Youth Group.

Inside the Bubble

updates, stories and events around EU healthcare

An EU approach for efficient contact tracing apps to support gradual lifting of confinement measures

EU Members States, supported by the Commission, have developed an [EU toolbox for the use of mobile applications for contact tracing and warning](#) in response to the coronavirus pandemic. This is part of a common coordinated approach to support the gradual lifting of confinement measures, as [set out in a Commission Recommendation](#) last week.

Since the outbreak of the coronavirus pandemic, Member States, backed by the Commission, have been assessing the effectiveness, security, privacy, and data protection aspects of digital solutions to address the crisis. Contact tracing apps, if fully compliant with EU rules and well coordinated, can play a key role in all phases of crisis management, especially when time will be ripe to gradually lift social distancing measures. They can complement existing manual contact tracing and help interrupt the transmission chain of the virus.

The EU Commission have released a joint roadmap towards lifting COVID-19 containment measures

The Commission, in cooperation with the President of the European Council, has developed the present roadmap responding to the call of the [European Council of 26 March](#) for a coordinated exit strategy. It takes into account the expertise of the European Centre for Disease Prevention and Control (ECDC) and the panel of scientific experts advising the Commission on the coronavirus.

In parallel, the Commission continues to mobilise **funding to foster research** on the development of vaccine, treatments and medicines. The Commission is also working with the European Medicines Agency to **streamline regulatory steps**, from clinical trials to marketing authorisations. It will also foster **international cooperation** as a priority.

[Download roadmap here>>>](#)

EU Commission issues guidance on clinical trials during pandemic

The European Commission published guidance to keep clinical trials running during the coronavirus outbreak. The guidance is meant to harmonize “simple and flexible” measures that ensure patients in clinical trials receive their medicine. Read their [Guidance here>>>](#)

The Last Word

"Three things in life: your health, your mission, and the people you love.
That's it."

