



The Patient Perspective

September 2020



Reflections

“It is crystal clear: We need to build a strong European health union.”

This was a key message from Commission President Von der Leyen in her State of the Union speech, underlining that ‘now is the time to make it happen’. EPF is, of course, fully supportive of the recognition that health must be an urgent European and global policy priority and we have outlined our perspective in recent statements on the **EU4Health Programme** and **EU Pharmaceutical strategy**.

Our Projects team has been busy at work with several virtual webinars and online conferences, while our co-led **PARADIGM project** recently presented its Patient Engagement Toolbox and Monitoring and Evaluation Framework. A **Digital Health Europe Workshop** and the **CHRODIS+ Online Conference** will take place in October and you are very welcome to join us.

We have a lot of news and updates from our members and our **Youth Group** has shared their experiences during lockdown and this very unusual summer. We encourage you to check out all of the upcoming October events below.

We strongly urge you to continue following the advice of your local health authorities and stay safe !

Enjoy your start to Autumn!



News From the Secretariat

updates from the inside

EPF recognised with the 2020 Patient-Centred Health Award at the Annual RAPS Awards

We are pleased to inform you that EPF has been awarded with the [Regulatory Affairs Professionals Society \(RAPS\)](#) Patient Centered Health Award for “making a significant impact to advance patient-centered policy, product development or regulatory decision making”. We would like to congratulate our Secretariat and members for their incredible



Our dear Emily is leaving us.

After nearly two years at EPF, we are sad to say goodbye to our Communications Officer Emily Bowles, who is leaving us to pursue another professional opportunity. We would like to sincerely thank Emily for putting her heart into her work in ensuring steady and solid communication at EPF, especially before and during our very Congress on patient involvement, last year. We wish her the best of luck in her future endeavours!



EURACTIV: Teach health literacy at school to combat fake news

EPF President Marco Greco discusses how social and traditional media, patient organisations and policymakers all have a role to play in providing clear messages when it comes to public health. But without proper investments in health literacy at school, fake news cannot be combatted. [Read article here>>>](#)



EPF celebrates World Patient Safety Day with its Partners

17 September celebrated World Patient Safety Day 2020. Patient safety is a strategic priority for EPF and goes to the heart of our work for equitable, patient-centred healthcare systems across the EU. The COVID-19 pandemic has added further strain to our healthcare systems, bringing more danger both for patients and healthcare workers!

See below for our video messages with our members **Mental Health Europe** and **European Federation of Neurological Associations** for World Patient Safety Day!



World Patient Safety Day 2020



EPF SURVEY - COVID-19 Impact on Patients and Patient Organisations

EPF invites you to take part in a survey to gather more information on the lived experience and impact of the COVID 19 pandemic on patients with chronic conditions, their communities and on patients' organisations. The survey includes two separate sets of questions for:

1. Individual patients with chronic or long-term conditions, their family members or informal carers and;
2. Patient organisations

Click [this link](#) to access the survey. It will take no more than 15-20 minutes to complete.
Survey Deadline is 11 October 2020.

EPF proposes a progressive and patient-centred EU4Health Programme

Amidst the ongoing COVID-19 crisis, attention has been turned towards enhanced European collaboration to ensure our health systems emerge from it stronger, more prepared and more people-centred. EPF believes this is a move in the right direction as health is not only a national matter – it is an urgent European and global health policy priority. [Read our official statement>>>](#)

EPF Statement in response to the written consultation on the WHO European Programme of Work

The European Patients' Forum welcomes the ambitious and timely European Programme of Work of the World Health Organisation (WHO). Its determination to address health inequalities and to leave no one behind aligns well with the UN SDG3 on health. We believe that the empowerment and meaningful involvement of patients and communities – i.e., the people the health systems aim to serve – at all levels will be critical to the shaping and the delivery of the EPW, but the concept is not entirely elaborated in the document. [Read our full statement>>>](#)

EPF responds to the EU Pharmaceutical Strategy Consultation

We believe that embedding meaningful patient involvement in everything that affects the patients' own access to medicines and care, will be key in tackling medicines shortages, and in evaluating medicines appropriately. Tackling shortages requires a range of tools, and it will be critical to understand patients' experience on shortages and their impact. Patients should also be able to report shortages to national and EU competent authorities. [Read our full statement>>>](#)

PHARMACEUTICAL STRATEGY FOR EUROPE



Learning from COVID-19, towards a crisis-resistant system



Ensuring accessibility and affordability of medicines



Supporting sustainable innovation, emerging science and digitalisation



Reducing medicines shortages and securing strategic autonomy

#EUPharmaStrategy



Q&A: Fanni-Laura Mäntylä – Chair of Mental Health & Healthy Workforce Committee for the European Health Parliament (EHP)

Following the European Health Parliament's (EHP) Virtual Plenary on 9 September, EPF had the chance to speak with **Fanni-Laura Mäntylä**, the Chair of the Mental Health and Healthy Workforce Committee. We discussed her patient advocate experience as well as her committee's resulting recommendations and their intended impact in the near future. [Read the full interview>>>](#)



Projects Portal

briefings on EPF's ongoing projects

Video Recap of "Lessons learnt from the COVID 19 pandemic and future of HTA collaboration at EU level" co-hosted by EPF, EURORDIS and MEP Tiemo Wölken



Online Event Recap: "Lessons learnt from the COVID 19 pandemic and future of HTA collaboration at EU level" co-hosted by EPF, EURORDIS and MEP Tiemo Wölken

REGISTER & SAVE THE DATE - Data Saves Lives TweetChat & Webinar

TWEETCHAT (2 October at 13:00 CET) DSL will host its second tweet chat on how patient organisations can help to close the data gap between West and Central/East Europe. Anyone can participate – just log on to Twitter at 13:00 on 2 October, and tweet your questions using the hashtag #DSLChat.

WEBINAR: 'COVID-19 and beyond: what is the role of governments in tracking their population's health and how can we support them?' (20 October at 13:00-14:00 CET)

Register at: https://zoom.us/webinar/register/WN_LDHJ04wPQDuv-eCuwDjV0w

To learn more about the Data Saves Lives initiative, head to datasaveslives.eu/ or you can find us on twitter at the handle twitter.com/DataSaves_Lives.

A banner for the Data Saves Lives initiative. It features four circular logos of partner organizations: Federacja Pacjentów Polskich, npo_Bulgaria, EHTEL, and iHD. Below each logo is the organization's name and Twitter handle. At the bottom, an orange bar contains the event date and time: "DATE: 2nd October" and "TIME: 13:00 – 14:00 CET".

Federacja Pacjentów Polskich
@FederacjaPP
Federation of Polish Patients

npo_Bulgaria
@npo_Bulgaria
National Patient Organisation, Bulgaria

EHTEL
@ehtel_ehealth
EHTEL (European Health Telematics Association)

iHD
@iHD_HealthData
European Institute for Innovation through Health Data

DATE:
2nd October

TIME:
13:00 – 14:00 CET

COMPAR-EU General Consortium Meeting

On 14-16 September 2020 the [COMPAR-EU project partners](#) dialled in to the annual consortium meeting. The partners met over three days to discuss the progress made so far on assessing the evidence for self-management interventions, their cost-effectiveness and

European Patients' Forum (EPF) also presented its work done over the past year– including creating a mechanism to account for patient's views, gender and socioeconomic dimensions throughout the project, increasing patient involvement by setting up a patient panel, and preparing lay-summaries of two key project outputs. Two representatives of this patient panel attended the consortium meeting as well. EPF secretariat members have been actively involved in the interactive IT platform design and development process this year. Stay tuned as more news will be available soon!

COMPAR-EU receives funding from the European Union's Horizon 2020 research and innovation programme under grant agreement #754936. The project aims to identify, compare, and rank the most effective and cost-effective self-management interventions for adults living with four high-priority chronic diseases today. Head to <https://www.tinyurl.com/y3gywx9b> to learn more about EPF's role in the project, and the value for patients.



PARADIGM presents Patient Engagement Toolbox and Monitoring and Evaluation Framework

The PARADIGM project, co-led by EPF, aims to make patient engagement easier for all is coming to an end. During the last session at the Patient Engagement Open Forum, co-organised with PFMD and EUPATI, the consortium presented two main outputs of the projects, the Patient Engagement Toolbox and the Monitoring and Evaluation Framework with metrics. [Read full article>>>](#)



EUPATI announces new co-Chairs and Board of Trustees

A [Board of Trustees](#) has been formed and the new [EUPATI Board](#) elected by the [Sustaining Partners Assembly](#), now also including the EUPATI National Platforms.

The new EUPATI Board is led by EPF's Anders Olauson as the Chair and Kay Warner from GlaxoSmithKline (GSK) as the Co-Chair. Both Anders and Kay have a long track-record in patient engagement and patient education and have contributed to EUPATI since the start. They are picking up the baton from EPF's Nicola Bedlington and Matthias Gottwald (Bayer)



Registration is open – 5 & 6 October 2020 Digital tools for patient empowerment and person-centred care - Workshop

On 5 October 2020 from 13:30 – 17:30 CET and on 6 October from 9:30 – 12:30 CET, EPF will host a two-day multi-stakeholder online workshop on Digital Tools for Patient Empowerment and Person-Centred Care. The workshop will be a mix of plenary and breakout sessions so that all participants can contribute their views and shape the discussion. **Registration closes on 28 September 2020.**

Register here: <https://eupatient.wufoo.com/forms/k1udbtc51vuihc4/>



**REGISTER NOW
JA CHRODIS PLUS Online Conference on Chronic Diseases
27 October 2020**

Over its 3-year lifespan the aim of CHRODIS PLUS Joint Action (2017-2020) has been to support member states in overcoming the burden of chronic diseases by promoting policies and practices that have proved successful in the past.

CHRODIS PLUS will hold its **closing online conference on 27 October 2020.**

[Register here>>>](#)



ONLINE CONFERENCE ON CHRONIC DISEASES

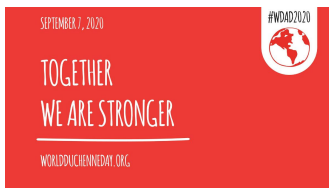
CHRODIS PLUS PROJECT CO-FUNDED BY THE EU

Making Europeans happier, healthier and more active by implementing good practices



Member Focus

highlights from our member organisations



September 7 was World Duchenne Awareness Day. On this day, **World Duchenne Organization** raised awareness for Duchenne and Becker muscular dystrophy (DMD and BMD) around the globe. This year the special theme was Duchenne and the brain. A general awareness campaign video was created to show that even in the COVID emergency, *Together, we are stronger*

[learn more>>>](#)



EATG published the **third installment in its COVID-19 Rapid Assessments** series. They now offer a bilingual version of their newsletter, as the impact of COVID-19 on PLHIV in Eastern Europe and Central Asia may be harsher, added to the already vast shortcomings in HIV services delivery.

[read the 3rd assessment>>>](#)



EFNA has launched of a new art competition **'Me and My Brain' Art Competition**. Create a drawing, painting, collage or digital illustration that represents your relationship with your brain. Your work might explore your hopes, your frustrations, or the day to day impact a neurological disorder has on your life. Entries will be judged on both artistic merit and how well the artwork reflects the theme. The winner will be awarded €500 and four runners up will each be awarded a €125 prize. **The deadline for entry is Monday, 7 December 2020.**

[enter here>>>](#)



Youth Group

initiatives, stories and events from our most budding members

How we spent our Summer

by Anastasia Semaan, EPF Youth Group Member

For all patients, from different patient communities the lockdown and social distancing has taken higher extremes and more precautions needed to be taken. However, within all of this it has not changed the role of each of our patient advocates within the EPF's Youth Group. Some of our YG members have described how they have spent their time in lockdown and what measures they each felt was important to take: [Read full article>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

Coronavirus Global Response: the Commission's contribution to the COVID-19 Vaccine Global Access Facility (COVAX)

The European Commission confirmed its participation in the COVAX Facility for equitable access to affordable COVID-19 vaccines, following its expression of interest on 31 August and its announcement of a contribution of €400 million. In a joint effort between the European Commission and the 27 EU Member States, Team Europe will contribute with an initial €230 million in cash through a loan from the European Investment Bank, backed by the same amount in guarantees provided by the EU budget. A contribution of €230 million is equivalent to reserves or options to buy 88 million doses and the EU would transfer these to eligible Advanced Market Commitment (AMC) countries. This contribution is complemented with €170 million in financial guarantees from the EU budget.

Commission inks a second coronavirus vaccine deal, with Sanofi-GSK

The European Commission announced that it has closed its second contract for a possible coronavirus vaccine, this time with French drugmaker Sanofi and Britain's GlaxoSmithKline, following a similar deal with AstraZeneca. The deal allows EU countries to purchase up to 300 million doses of the vaccine candidate that is being jointly developed by the two companies. The shot is currently in a Phase 1/2 study and is expected to enter a Phase 3 clinical trial by the end of 2020, the Commission said in its public statement. Should these be successful, the vaccine could become available in the second half of 2021, the Commission added.

The European Centre for Disease Prevention and Control published today [guidelines](#) for testing to help public health authorities across Europe. The report, created at the request of the European Commission, sets out five key objectives for coronavirus testing: Controlling virus transmission; monitoring its rate and severity; managing the impact of COVID-19 on health care systems; finding new clusters of outbreaks; and stopping re-introduction of the virus where it has been eliminated.

European Parliament passes resolution calling for greater pharma resilience

The European Parliament today adopted a resolution calling for the reshoring of the production of drugs and medical equipment to boost the security of their supply in the wake of the coronavirus outbreak. Noting that a majority of active ingredients for medicines are imported from external producers, Parliament called for creating financial incentives to encourage manufacturers to relocate to the bloc. Included in the resolution is a call on the Commission to introduce a directive creating minimum standards for health care systems in the EU, as well as the creation of a European pharmacy for emergency medicines that would function as a stockpile of strategic drugs to help avoid shortages.

Von der Leyen: 'It is time' for a 'strong European health union'

It's time for the European Union to bolster its health competence, European Commission President Ursula von der Leyen said during her first annual speech on the state of the EU to the European Parliament. "It is crystal clear: We need to build a strong European health union," von der Leyen said. "It is time to do that." One of her key proposals is creating a European version of the U.S. Biomedical Advanced Research and Development Authority (BARDA) to help the EU better respond during emergencies relating to cross-border threats. Furthermore, she noted, there's a need to "reinforce" existing European health agencies such as the European Medicines Agency (EMA) and the European Centre for Disease Prevention and Control (ECDC). Von der Leyen said, she will convene a global health summit in Italy next year, when Italy will head the G20 Presidency.

"If you want others to be happy, practice compassion. If you want to be happy, practice compassion."

Dalai Lama



Calendar of Events

2 October

[Mental Health Europe's "The Future of Mental Health, Rights and Recovery Europe"](#)

[DataSavesLives TweetChat 'Closing the health data gap between West and Central/East Europe' \(13:00 CET\)](#)

3 October

[EPF's Extraordinary General Meeting \(EGM\)](#)

10 October

World Mental Health Day

visit our website

contact us

14-21 October

International Infection Prevention
Control Week

15 October

Global Handwashing Day

20 October

[DataSavesLives \(DSL\) Webinar:
'COVID-19 and beyond: what is the
role of governments in tracking their
population's health and how can we
support them?' \(13:00-14:00 CET\)](#)

27 October

[CHRODIS+ Online Conference](#)

28 October

[POLITICO's online event "Health
care systems post-COVID 19" feat.
EPF President Marco Greco](#)

[view this email in your browser](#)

Copyright © 2020 European Patients Forum, All rights reserved.

You are receiving this email because you opted in at our website www.eu-patient.eu

Our mailing address is:

European Patients' Forum
Chaussée d'Etterbeek, 180
Brussels 1000
Belgium

[Add us to your address book](#)

Want to change how you receive these emails?
You can update your preferences or unsubscribe from this list.

This email was sent to <<Email Address>>
[why did I get this?](#) [unsubscribe from this list](#) [update subscription preferences](#)
European Patients' Forum · Chaussée d'Etterbeek, 180 · Brussels 1040 · Belgium