



The Patient Perspective

July 2020



Reflections

As we approach August, we take a look back at the very fruitful month of July.

The recent decision of the European Council to drastically cut funds from the EU4Health programme was surprising and regrettable. Despite a lack of clarity on some elements, the new standalone programme proposed by the Commission was a very welcome step towards more resilient health systems in the post-COVID-19 era. However, the Council's decision and the **revised EU4Health budget**, dropped from €9.4 billion to €1.7 billion, goes in the opposite direction: a real step back for health at European level. EPF is working closely with allies and the European Parliament on if and how this might be addressed.

From the Policy and Advocacy team, we present the Summary Report from the virtual launch meeting of our position paper on '**The Value and Pricing of Innovative Medicines.**' We have a lot of news from our Projects team, including the announcement of **CHRODIS PLUS' online conference on 27 October**. Data Saves Lives continues its online campaign while EHDEN has recently announced its collaboration with the European Medicines Agency to address COVID-19.

You will find the second issue of '**Patients in the Spotlight**' by our Communications Officer Emily Bowles in addition to some updates from our Youth Group and the latest initiatives and statements from our Members.

We all still need to play our part and work together to emerge from this crisis stronger and more resolute. Thank you all for working with us.

Enjoy the summer break !



News From the Secretariat

updates from the inside

Saying Goodbye and Good luck to Zuzanna!

After two years as EPF's Operations Assistant, Zuzanna Skowronek will be departing from

our team to pursue other interests in her native Poland. We would like to sincerely thank Zuzanna Zfor her incredible work in coordinating and organising all EPF events and

meetings while leading several initiatives internally to the benefit of the organisation. We wish her the best of luck in all future endeavours and will definitely miss her upbeat and pleasant attitude at the office.



Are you our new Executive Director?

EPF is looking for a new Executive Director. Overall, you are responsible for keeping the organisation mission focused, you act as our main external spokesperson and you lead our programmes, short- and long-term strategic planning and community outreach. In addition to leading our fundraising efforts you will also bring experience of leading a busy team in a non-profit environment whose mission is to influence health related initiatives from a patient perspective.

View application details and role requirements [here>>>](#)



Policy and Advocacy Corner

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

"The Value and Pricing of Innovative Medicines" - Summary Report

On 1 July 2020, the European Patients' Forum published and presented its position paper on 'The Value and Pricing of Innovative Medicines.' during an event which took place virtually on 1 July. The event was moderated by EPF President Marco Greco, co-hosted by MEPs Kateřina Konečná, Tomislav Sokol and Tiemo Wölken and featured a keynote speech from European Commissioner for Health and Food Safety, Stella Kyriakides.

[Read the Full Event Summary Report>>>](#)



COVID-19 crisis: the time to invest in a healthy future is now.

EPF and several other health organisations expressed their concern and disappointment with the EU Council's recent decision to cut the recently allocated EUR 9.4 billion for the 'EU4Health' programme down to 1.8 billion.

The 'EU4Health' health programme was conceived in order to boost the EU's preparedness for future cross-border health threats and to strengthen national health systems in the long-term. In other words: it is supposed to represent the EU's response to the COVID19 pandemic, with people's health and well being lying at the heart of all EU policies. And yet the recent cut suggests a will to drive Europe in the opposite direction, despite the backing of the European Commission and European Parliament. [Read our full reaction here>>>](#)

EPF responds to WHO European Regional Office's new European Programme of Work

The WHO European Regional Office has published a new [European Programme of Work](#) (EPW), titled "United Action for Better Health". This programme aligns with and supports the WHO's 13th General Programme of Work (GPW13). It sets out a vision for how WHO/Europe can better support countries in meeting citizens' expectations on health for the future.

EPF responded to the public consultation on the EPW by submitting a written statement (attached below). We also had an opportunity to give initial comments in an online consultation meeting between the WHO European Office team and non-state actors on 18 June. EPF gained accredited non-state actor status with the European Regional Office in 2019. [Read EPF's Statement>>>](#)

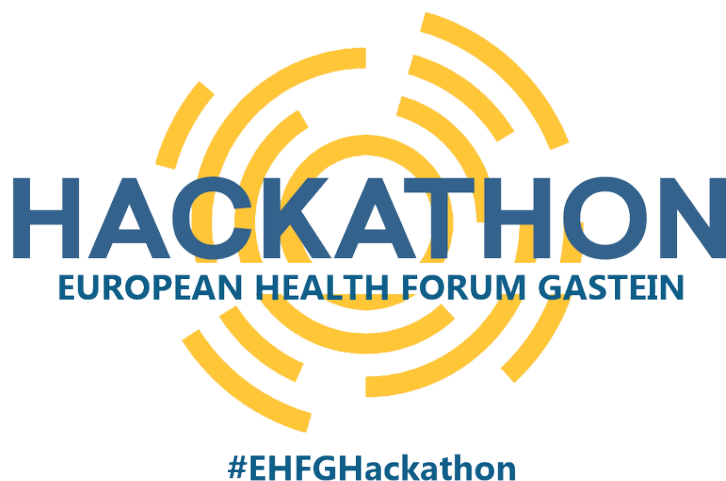
European Health Forum Gastein (EHFG) Hackathon CALL FOR APPLICATIONS

The third annual EHFG Hackathon will take place digitally from **25 - 27 September 2020** within the framework of the EHFG 2020 conference. Jointly organised with [EIT Health](#), this year's event will challenge participants to create innovative and implementable **digital solutions to support continuity of care during times of crisis**.

The 2020 hackathon aims to virtually bring together up to 100 experts from a variety of backgrounds and cultures for a 40-hour marathon of intense solution-oriented collaboration. Competing teams will receive guidance from high-level professionals across various fields who will act as mentors throughout the process. At the end of the 40-hour period the teams will present their solutions in front of an expert jury panel and three finalist teams will be selected to go forward and present their pitches to the audience during the Closing Plenary of the EHFG 2020 conference on **2 October 2020**. Two prizes, a jury prize and an audience prize, **amounting to €25.000 will be awarded to the**

Applications are open to all with an interest in health policies. If you are a health professional, an IT expert, a business specialist, a designer, or other – at any rate an open-minded, creative thinker who enjoys working under pressure in teams with the goal of arriving at a joint solution, we are looking for you!

Want to apply? Please complete the [application form](#) and share your CV and a passport copy with (chloe.maher@ehfg.org). We are looking forward to receiving both your individual and team applications before midnight **2 August 2020**.



Projects Portal

briefings on EPF's ongoing projects

SAVE THE DATE

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. Further refinement and EU cross-border sharing of these tested policies and good practices has been the core idea behind this pan-European project.

CHRODIS PLUS has implemented *21 pilot projects* aimed at testing tools and good practices for certain chronic diseases, and held *17 policy dialogues* (15 national and 2 EU-level ones). It has brought together *over 50 partners* from *21 European countries*.

All good things come to an end: CHRODIS PLUS will hold its **closing online conference on 27 October 2020**.

This conference will illustrate the impact that CHRODIS PLUS has had on public health systems across EU member states over the past 3 years. It will focus on showing how the good practices, models and tools implemented by the project can be tailored to various national and local settings across Europe.

The conference's presentations and roundtable discussions will be structured around the project's key focus areas:

- *Health Promotion & Primary Prevention*

- *Fostering Quality Care for People with Chronic Diseases*
- *ICT-based Patient Empowerment*



ONLINE CONFERENCE ON CHRONIC DISEASES
CHRODIS PLUS PROJECT CO-FUNDED BY THE EU

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



Data Saves Lives wants to hear from you!

Share with us your quotes on responsible health data sharing and your views on why data saves lives. Your quote will be featured on the Data Saves Lives social media pages, and will help us in our goal to promote greater awareness of how health data can be used in trustworthy ways to improve health and care, and to establish a trusted environment for dialogue about responsible health data use and good practices across Europe.

Interested? Directly **send us your quotes** or **get in touch** for questions at: dsl-info@eu-patient.eu

All about Data Saves Lives Webinar

On 1 July 2020, Data Saves Lives (DSL) held its first deep-dive webinar all about the initiative. The webinar featured a panel of experts from the four DSL working groups, which presented the initiative from their perspective. At the end of the webinar, attendees had the opportunity to ask the panel of speakers questions, which led to a lively exchange of views. The discussions from the Q&A will be published in a blog post on the DSL website in the coming days.

Did you miss the webinar? You can watch a video of the highlights [here](#).

This will be the first in a series of webinars aimed at raising awareness about the importance of responsible data sharing, supporting patient organisations to communicate about the value of health data, and further stimulate discussions about health data issues with wider audiences. Watch this space for the next DSL webinar, planned for this Autumn.



Data Saves Lives

EHDEN to collaborate with EMA to address COVID-19

On 22 July, the European Health Data and Evidence Network (EHDEN) announced its collaboration with the European Medicines Agency ([EMA](#)) to establish a research framework and network to conduct multi-centre group studies on medicines for COVID-19 patients.

The purpose of EHDEN is to create an international **open science** network in Europe based on common and standardised data models and tools; this will be critical for the development of medicines that real world, observational research can evaluate on effectiveness alongside repurposed medicines. To this end, the EMA-funded project includes **standardised data** sources from across eight European Countries.

You can learn more about EHDEN on the project [website](#), and learn more about EPFs' role by following this [link](#).



LAST CALL - EATRIS-Plus patient advisory committee applications

In cooperation with EATRIS, EPF is pleased to announce a call for patient representatives for a Patient Advisory Committee (PAC) for the EATRIS-Plus Project. **The call closes on 7 August 2020.**

The PAC will inform EATRIS-Plus activities from a patient perspective and will identify mechanisms for meaningful patient involvement and input throughout the project. We believe engaging patients at the heart of EATRIS-Plus activities will be key to the success of this project.

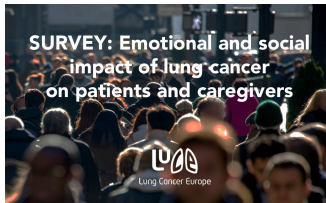
Interested? You can learn more about what is expected, who we are looking for, and timelines for application [here](#).

eatris+



Member Focus

highlights from our member organisations



Lung Cancer Europe (LuCE) is looking for volunteers to help us with this research by completing an online survey. The objective of this survey is to explore patients' and caregivers' experiences about the emotional and social impact of lung cancer, and to identify main barriers to accessing care.

[take survey>>>](#)



European AIDS Treatment Group (EATG) released a statement asking for a Common Public Good approach that places respect, protection and promotion of human rights at the centre.

[read statement>>>](#)



The **EURORDIS**-led CETF has created an infographic setting out the patient journey to diagnosis. The infographic demonstrates the diagnostic odyssey many people experience on a daily basis and presents existing resources from



European Haemophilia Consortium (EHC) released a Position statement on AAV8-based ASPIRO clinical trial.

[read more>>>](#)



To assist the broader patient community, **EHC** recorded a Facebook live of exercises with a physiotherapist focused on the ankle

[watch recording>>>](#)



Alzheimer Europe calls for urgent action to address the impact of COVID-19 on dementia research. Following engagement with its national members, research funders and industry partners, Alzheimer Europe issued a position statement highlighting the pressure on dementia research as a result of COVID-19.

[read statement>>>](#)



Nominations for the **EURORDIS Black Pearl Awards 2021** are now open until 11 September 2020. Awards are presented to patient advocates, organisations, policy makers, scientists, companies and media for their major achievements and their outstanding commitment to the rare disease cause. Nominations are submitted by the general public and shortlisted by an ad hoc committee.

[register now>>>](#)



To mark World Brain Day 2020, **EFNA** has published the results of its recent survey on stigma and neurological disorder. 1373 responses to the survey were received from 37 countries. Responses came from a diverse range of neurological conditions, with the greatest numbers coming from the areas of Myalgic Encephalomyelitis (ME), dystonia, migraine or headache and chronic pain.

[download the report>>>](#)

organisations
to support patients on this
journey.

[view the patient
journey>>>](#)



Youth Group

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

PATIENTS IN THE SPOTLIGHT: Telling and Becoming the Story

by Emily Bowles, EPF Communications Officer

Our very own Communications Officer, Emily Bowles, has combined her two passions: patient advocacy and theatre, into a blog series. In her second post, she discusses how telling a personal story can sometimes even have a more therapeutic effect on the patient as the storyteller. The story itself can potentially become a vehicle for building inner strength and mental health, because it affects and increases levels of creativity, presentation, resilience and other life skills.. [Read Full Blogpost>>>](#)

A Bright Future With The Patient Engagement Open Forum

by Sally Hatton, EPF Youth Group Member

Last week I attended my first webinar as part of the Patient Engagement Open Forum, a series of online multi-format events taking place between June and November this year. The aim of the Forum is to turn patient engagement into reality and the session I attended included three quick-fire presentations on the key topics of Sustainability in Patient Engagement, Patient Engagement Agreements, and work on Patient Engagement in Central and Eastern Europe.

Although these topics may seem diverse, I found a strong theme throughout the session on not only the value of patient engagement, but the importance of recognising that it doesn't need to be a far out or idealised concept, and that there are real, achievable, and tangible steps that can be taken to make patient engagement work for everyone. I was impressed by how well all of the speakers were able to take the complexity of the issue and use their own real world experiences and subsequent data to lay out the different proven ways in which stakeholders - from government organisations, to researchers, to patients organisations - can work together to drive change. Plus, they all also provided useful resources to be used going forward.

The sessions left me really enthused and inspired for the forum and what it is trying to achieve in collaboration with EUPATI, Patient Focused Medicines Development, and the Paradigm Project, with which EPF are also involved. As a result, I've now signed up through their website to attend as many of the further sessions as possible.



Inside the Bubble

updates, stories and events around EU healthcare

EU leaders agree on €1.82T budget and coronavirus recovery package

EU leaders agreed early Tuesday on a groundbreaking plan to jointly borrow €750 billion to respond to the coronavirus pandemic, which has killed 135,000 people around the bloc and sent economies across the Continent into a tailspin. The EU's recovery fund, to be composed of €390 billion in grants and €360 billion in loans, will be attached to a new €1.074 trillion seven-year budget, the Multiannual Financial Framework (MFF), on which heads of state and government also reached unanimous agreement — bringing the total financial package to €1.82 trillion. [Read Full Plan>>>](#)

Pharmaceutical Strategy: Commission launches open public consultation

The European Commission launched an online public consultation on the Pharmaceutical Strategy for Europe. Coming in the wake of the COVID-19 pandemic, the Strategy will aim to ensure Europe's supply of safe and affordable medicines to meet patients' needs and support the European pharmaceutical industry to remain an innovator and world leader. The consultation, launched on 16 June, will last three months. DG SANTE will organise, on 14 and 15 July, an online workshop with stakeholders on the Strategy: Registration open until 3 July. [Read Consultation>>>](#)

The European Commission publishes Coronavirus guidance on second wave

The European Commission published new guidance on what the EU should do to prevent a second wave of coronavirus cases. The document discussed a host of issues, including contact tracing apps, the upcoming flu season and containing localized outbreaks. Commission Vice President Margaritis Schinas and Health Commissioner Stella Kyriakides stressed the need for member states and citizens to remain vigilant.

[Read New Guidance>>>](#)

“A sad soul can be just as lethal as a germ.”

John Steinbeck



Calendar of Events

1 August

World Breastfeeding Awareness
Week

[visit our website](#)

12 August

International Youth Day

[contact us](#)

[view this email in your browser](#)

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