



The Patient Perspective

June 2020



Reflections

Summer is finally here.

It's been quite a busy month here at EPF following the announcement of the EU4Health Programme as well as the Pharma Strategy. We started the month off with our Industry Roundtable where we discussed various 'hot topics' and presented our Strategic Plan and discussed improving reporting processes for patient organisations. We even launched our Impact Report 2020 (see below) to showcase the results of our work in 2019 and 2020.

Our Policy and Advocacy team has been quite busy with its work on Digital Health and Artificial Intelligence. We are also looking forward to virtually launching our Position Paper on 'The Value and Pricing of Innovative Medicines' on 1 July. More information on that below.

Our Projects team is looking ahead to hosting its first webinar for Data Saves Lives, also on 1 July while, EUPATI has just launched a survey to decipher the best methods for e-learning. More on that below.

Our Youth Group has been extremely active (online) and we are happy to announce that our very own Communications Officer, Emily Bowles, has initiated a new series for our newsletter - Patients in the Spotlight - focusing on the value of theatre and storytelling to develop more effective patient advocacy.

As borders slowly open and travel commences, we encourage you to stay safe and continue following health guidelines to ensure a pleasant start to the summer season.



News From the Secretariat

updates from the inside

The Forgotten Patients: COVID-19 and the impact on people living with non-communicable diseases

COVID-19 has shone a light on the weaknesses within our healthcare systems, and we fear that the impact on vulnerable populations will be long-lasting. Read full op-ed [here>>>](#)

EPF Launches its Impact Report 2020

Over the past year, EPF has driven innovation, whilst continuing to reinforce, and improve existing activities. This has made us stronger and ready to flourish in a fast-paced and ever-changing environment. Check out our latest Impact Report to see the influence and results of our work in 2019 while looking ahead to 2020 and beyond.

[Read the Impact Report 2020>>>](#)



Policy and Advocacy Corner

discussing the most relevant patient-centered policy and advocacy issues

"The Value and Pricing of Innovative Medicines" - Virtual Launch

In the context of current political priorities and goals to ensure access to affordable medicines and review Europe's pharmaceutical strategy a forthcoming new Pharmaceutical Strategy for Europe, EPF will be publishing and presenting its new position paper entitled 'The Value and Pricing of Innovative Medicines', during an event which will take place virtually on **1 July from 15h-17h**.

The event will be moderated by EPF President Marco Greco and co-hosted by MEPs Kateřina Konečná, Tomislav Sokol and Tiemo Wölken. Reactions from a panel of prestigious speakers will follow the presentation of EPF's paper and the event will feature a keynote speech by EU Commissioner for Health and Food Safety, Stella Kyriakides.

[Register here>>>](#) **(deadline is 29 June)**



COVID-19 and Brexit – Protecting patients across Europe from pandemics

EPF and a group of 17 pan-European healthcare stakeholders launched the statement “COVID-19 and Brexit – Protecting patients across Europe from pandemics” which highlights the importance of addressing health issues as part of the agreement on the future relationship between the EU and the UK. [Read Full Statement>>>](#)

EPF Salutes Prof Guido Rasi and Welcomes Ms Emer Cooke as EMA’s Executive Director

EPF would like to thank Professor Guido Rasi for his remarkable efforts and achievements during the last half decade. We would like to offer our sincerest congratulations and welcome to the EMA’s new Executive Director, Ms Emer Cooke. We feel that Ms Cooke’s extensive background in regulation, from the national to European and international levels will be an asset to the agency. [Read our Full Statement>>>](#)



Projects Portal

briefings on EPF’s ongoing projects

A patient perspective on managing multiple chronic conditions

On 17 June 2020, Raymond Nangle, a patient representative and member of the [COMPAR-EU](#) patient panel shared his inspiring journey to successfully self-manage three chronic conditions. In his blog post, Raymond shares the various health crises of both chronic and acute conditions that have affected him from his teenage years and into his fifties, some life-threatening. Raymond recounts how, after receiving discouraging news from his doctors and reaching an emotional low-point, he decided to take charge of his conditions and live better through self-management. Sharing experiences like Raymond’s is important for understanding the diversity of individual’s journeys, and the value that self-management can bring on improving someone’s life.

Read Raymond’s full account [here>>>](#)

Call for interest – EATRIS-Plus searching for patient advisory committee members

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 is open until to 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

Interested? You can learn more about what is expected, who we are looking for, and timelines for application at: www.eu-patient.eu/News/News/eatris-plus-patient-advisory/



Save the Date – Data Saves Lives Webinar on 1 July 2020

On **1 July 2020 at 13:00-14:00 CET**, Data Saves Lives will be hosting its first deep-dive webinar all about the initiative. The focus will be on explaining the health data challenge that DSL aims to tackle, as well as our mission, main activities, and how we are organised and governed.

This will be the first in a series of webinars aimed at raising awareness of 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.

To join the webinar, use this [link>>>](#)

Join us for our first WEBINAR!
Our panellists will be discussing:
All About "Data Saves Lives"

#DataSavesLives

Veerle de Wispelaere Terje Peetso Ania Henley Nicola Bedlington

DATE: 1 July 2020 TIME: 13:00 – 14:00 CET

Click the link to join, or follow with the hashtag #DSLWebinar

Data saves lives.eu

EUPATI Survey - E-learning Expectations

The future EUPATI learning platform will provide free access to all educational resources as well as an opportunity to obtain certifications for a fee on three levels. The lessons will be grouped into modules that do not rely on the completion of other modules to be taken.

As part of the future e-learning platform, we would like to hear from you about your expectations, ideas, and suggestions. This survey will be used to define the learners' interests, motivations, learning pathways and other essential aspects of the future activity of EUPATI. It should take you less than 15 minutes to complete this survey.



Member Focus
highlights from our member organisations



European Haemophilia Consortium (EHC) and EAHAD Joint Statement on:
Promoting hub-and-spoke model for the treatment of haemophilia and rare bleeding disorders using gene therapies

[read more >>](#)



European Haemophilia Consortium (EHC) held two webinars on women and bleeding disorders. Both webinars are now online and can be viewed on our YouTube channel.

[watch more >>](#)

EHC 2020 Conference goes virtual! However, we are pleased to inform you that the EHC will hold its 2022 Conference in Copenhagen. Meanwhile, the EHC 2021 Conference will be held in Zagreb, Croatia, as agreed by the EHC General Assembly.

[register now >>>](#)



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



Alzheimer Europe (AE) has published the 33rd



World Duchenne Organization completed their latest webinar on **Care in COVID times**. They invited Prof. Muntoni, Prof. Goemans, Dr. Wong and Dr. Cripe to answer questions on the risk of returning to Standards of Care now that countries are slowly opening up again.

[watch now >>>](#)

barriers to accessing care.

[take survey>>>](#)



European Federation of Neurological Association's (EFNA) #BrainLifeGoals Project Grants announced! EFNA will provide 10 grants of €3,000 each to selected organisations, working to address this theme. 26 applications were received from across Europe, all featuring exciting projects.

[see all winners>>>](#)

edition of its "Dementia in Europe" as an e-magazine. This decision was taken earlier in 2020, in light of some of the uncertainties around COVID-19 and its impact on service-providers.

[read the e-magazine](#)

[>>>](#)



June is Scleroderma Awareness month and June 29th is World Scleroderma Day. **Federation of European Scleroderma Associations (FESCA)**, have made a joint campaign spreading awareness of scleroderma, a rare autoimmune disease that affects the body by hardening connective tissue. Skin and internal organs can be damaged by this illness. It can be life threatening and currently there is no cure. However, successful treatments are available for individual organs.

[learn more >>>](#)



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>>>](#)



On July 24, 2020 Empowerment Webinar will be held by Mental Health Ireland in close partnership with **Mental Health Europe, ENUSP, HSE Mental Health Engagement. ENUSP** is going to organise a workshop as part of the event, called **"Empowering Recovery: A Human Rights Based Approach"**. The workshop will address different aspects related to a human rights based approach to mental health and how it contributes to recovery.

[register now>>>](#)



Youth Group

initiatives, stories and events from our most budding members

PATIENTS IN THE SPOTLIGHT:

Patient Advocacy through Theatre and Storytelling

Our very own Communications Officer, Emily Bowles, has combined her two passions: patient advocacy and theatre, into a blog series. In her first post, she discusses the benefit of utilising theatrical performance methods to assist patient advocates in telling their story more effectively. [Read Full Blogpost>>>](#)

EPF Youth Group (Virtual) Spring Meeting

by Erin Davies, EPF Youth Group Member

The EPF Youth Group's Spring Meeting took place on 13th-14th June. Though unable to meet up in person as planned, the Group's excitement at the prospect of welcoming new members, electing a new Vice President and planning for future endeavours was in no way compromised.

Since the Youth Group's Fall Meeting (September 2019), seven new members have joined the team, myself being one of them. Therefore, some of our key objectives were to get to know each other (albeit via Zoom!), to allocate new roles and build upon positive team dynamics. This was all achieved through creative activities, honest expression of interests and some virtual 'speed dating'! Anastasia Seaman was elected as Vice President of the Youth Group and roles were assigned within our Policy, Communication and Social Media teams.

Through the establishment of new working relationships, the Youth Group has developed what was already a strong foundation for the realisation of its goals. We would like to continue to support EPF in revising its youth strategy and hope to present the findings of last year's Work and Youth Strategy (WAYS) project in the near future. Results of the survey conducted on young patients' experience of the working world will be compiled and distributed along with key recommendations for change.

Thereafter, the Youth Group's focus will shift to our latest project. This will be an exploration into how chronic conditions, both mental and physical, might impact upon sexual health. The topic was keenly discussed by our members during the meeting and we look forward to working on this new project together.





Inside the Bubble

updates, stories and events around EU healthcare

Commission unveils EU Vaccines Strategy

The European Commission presented a European strategy to accelerate the development, manufacturing and deployment of vaccines against COVID-19. With this strategy, the Commission will support efforts to accelerate the development and availability of safe and effective vaccines in a timeframe between 12 and 18 months, if not earlier.

Re-open EU: Commission launches a website to safely resume travelling and tourism in the EU

The Commission is launching Re-open EU', a web platform to support a safe relaunch of travelling and tourism across Europe. It will provide real-time information on borders and available means of transport and tourism services in Member States. Re-open EU will also include practical information provided by Member States on travel restrictions, public health and safety measures such as on physical distancing or wearing of facemasks, as well as other useful information on EU and national tourism offers.

EUHealthSupport Study on the processing of personal health data across EU

As part of this study, we would like to invite you to participate in an online survey, aimed to collect the views of experts and organisations representing the wide range of stakeholders, including patients, care providers, industry, public bodies and researchers. The results of the study will be used to identify possible future actions to be developed at EU level, such as new legislation or codes of conduct for health data sharing for research or policy purposes, also in light of the current COVID-19 pandemic.

[Take the Survey>>>](#)

Commission puts forward 2021 budget proposal

The European Commission [proposed](#) spending €166.7 billion in 2021 under its new annual budget proposal. The proposal is considered a preliminary suggestion since the size and composition of the 2021-2027 budget framework and the recovery fund have yet to be decided.

A total €17.3 billion would go toward the Horizon Europe research program, of which €5 billion would come from the recovery fund. A proposed new health program would be allocated €1.19 billion, nearly all of which would be funded by recovery money. European leaders will meet in Brussels on July 17-18 in a bid to move ahead in negotiations over the bloc's long-term spending.

Emer Cooke selected as next EMA executive director

Emer Cooke, of the World Health Organization, was tapped as the next executive director of the European Medicines Agency by the agency's management board. Cooke, who is currently director of regulation of medicines and other health technologies at the WHO, was chosen by the EMA's management board this morning. Cooke will replace current executive director Guido Rasi, whose term ends in November 2020.

"Good health and good sense are two of life's greatest blessings."

Publilius Syrus



Calendar of Events

[Launch](#)

contact us

1 July (13:00-14:00)

[All about Data Saves Lives Webinar](#)

1 July (15:00-17:00)

[Virtual Launch of EPF's Position Paper on 'The Value & Pricing of Innovative Medicines'](#)

2 July (15:00)

[Webinar: 'How to address the medicine shortages in the EU'](#)

24 July

[Empowerment Webinar \(Mental Health Ireland with Mental Health Europe, ENUSP, HSE Mental Health Engagement & Recovery and Community Partners\)](#)

[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