



# The Patient Perspective

May 2020 edition

## Reflections

As the month of May comes to an end, we take a look back at the incredible amount of work we have accomplished together with our members and allies - despite working from the confines of our homes.

The big news of the day is the confirmation that the EU will once again have a **dedicated health programme** – and this time with a significant boost of resources. The [announcement](#) by the European Commission, as part of its revised work programme and budget proposals, answers a call EPF has been making for some time: that **the Union needs a strong and coherent health policy**.

Our statement, published yesterday, reiterates this vision and states it is “**High time for enhanced European coordination and competence on health**”. You can find the full statement below, as well as news about complementary initiatives.

Earlier this month, our President and senior team members met with **EU Commissioner for Health and Food Safety Stella Kyriakides on line** to discuss challenges faced by patients during COVID-19. You can also read her response to our March 27 letter [here](#). The Commission plans to involve EPF in further dialogue during the coming weeks.

Following extensive consultation with our members, we released our **Response to Europe's Beating Cancer Plan** as well as co-authored a few statements revolving around healthcare systems during the pandemic. You can also read our statement in response to the public consultation on the **EU's Data Strategy**. Several of our projects have recently launched interesting initiatives.

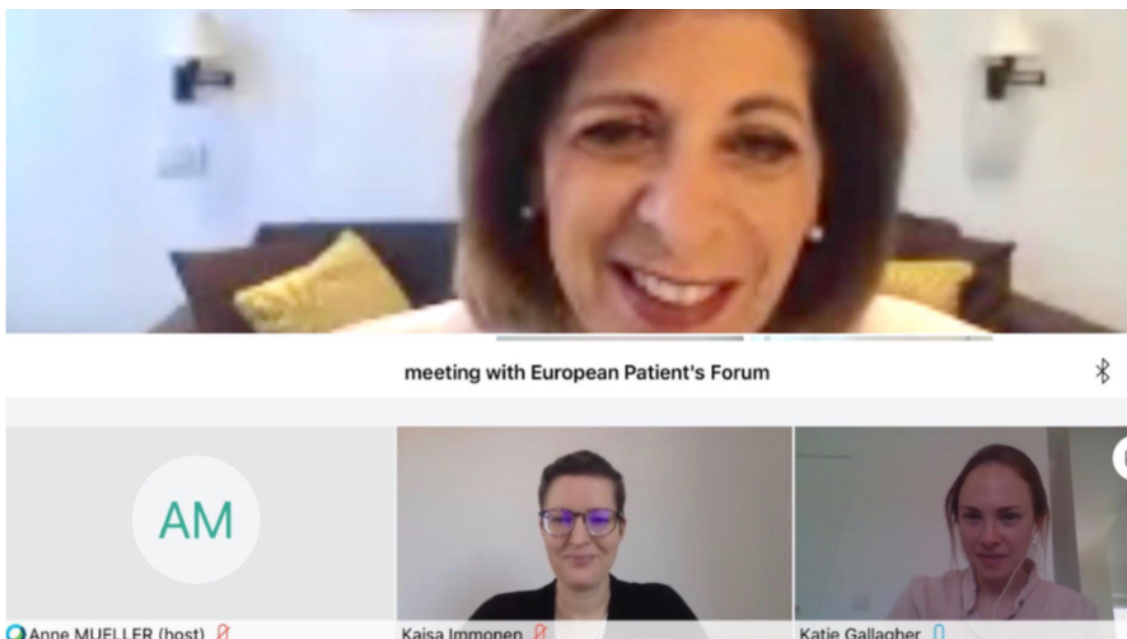
We are greatly looking forward to our **Industry Roundtable on 5 June** where we will present our **Strategic Plan 2021-2026**, discuss topical issues with industry leaders, including the COVID-19 response, and showcase the impact of our work over the last year.

As lockdown restrictions begin to ease and borders slowly open up, we kindly recommend you continue to follow local guidelines. We need to continue to be vigilant, particularly for our patient communities across Europe.

As we continue to flatten the curve and edge closer to summer, we encourage you to be optimistic, as, in the words of the Dalai Lama, "it feels better."

## News from the Secretariat

*updates from the inside*



### EPF's Conference Call with EU Commissioner Kyriakides

On Thursday 7 May, EPF met virtually with EU Commissioner for Health and Food Safety Stella Kyriakides to discuss challenges faced by patients during COVID19. This much needed meeting stemmed from the Commissioner's concern that **"no chronic patients should be left behind"** during these unprecedented times, and in the long term that "patients need to be at the centre of the decision-making process", which EPF strongly welcomed.

The meeting dealt with the Commission's response to the pandemic, while EPF outlined the main challenges for patients with chronic conditions as highlighted by our members, such as treatment delay, discontinuation, general lack of clarity or appropriate guidance;

[Read Full Recap>>>](#)

# Policy & Advocacy Corner

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



## **Preparing the EU for Digital Health**

Health is an area where Europe can undoubtedly benefit from during the data and Artificial Intelligence revolution. The COVID-19 pandemic has demonstrated how accurate and quickly accessible data is fundamental in the management of cross-border public health emergencies. Nevertheless, the road to fully exploit the potential benefits of data and AI in health is only partially built, still extremely fragmented and not yet developed with patients' views at the centre. To strengthen the patient community voice on digital health, over the past few months EPF has been working on several initiatives and publications addressing some of the most important updates in this field. [Read more about Digital Health>>>](#)

## EUROPE'S BEATING CANCER PLAN STRENGTHENING OUR APPROACH AT EVERY STAGE



### EPF's Response to Europe's Beating Cancer Plan Public Consultation

EPF welcomes the roadmap on **Europe's Beating Cancer Plan** and more generally the ambitious approach taken by the European Commission in tackling cancer. Our **response** has been developed in a consultative process together with our members and highlights several issues which are not addressed in the public consultation questionnaire, but which in our view warrant inclusion in the plan. EPF welcomes the opportunity to provide input to the development of the EU's Beating Cancer Plan, an initiative which affects many of our members. We hope the Commission will consider our recommendations when defining its priorities for the plan. [Read our Full Response here>>>](#)



# NEW STATEMENT

### "High time for enhanced European coordination and competence on health"

EPF believes now is the time to end the debate on whether health is an EU competence. Citizens and patients have clearly voiced their expectations for the EU to do more on health. In many cases, the EU already can do more: it simply needs a united political will and the necessary resources. We urge EU decision-makers to ensure that the Union exercises the full extent of its powers and instruments in the field of public health to do more now, while evaluating whether the health competences contained in the Treaties will be sufficient to ensure it has the capacity to not only cope with future pandemics but to deliver a healthy and cohesive future for its people. [Read Full EPF Statement>>>](#)



# EU4health

**COVID-19 has shown EU action on health is more urgently needed than ever**

[www.eu4health.eu](http://www.eu4health.eu)

## **9 ways the European Institutions and Member States should respond to the COVID-19 pandemic**

Shaping the future of health in the EU together has therefore never been more urgent. To this end, members of the **EU4Health** coalition, which EPF is co-leading together with EPHA, have pooled their strengths together in a joint EU4Health statement, calling to act now for a stronger and more ambitious European health policy. [Read Full Statement>>>](#)



## **Joint Statement from the European Parliament Interest Group on Equitable Access to Healthcare and the Patient Access Partnership (PACT)**

This statement - **co-written by PACT, of which EPF and our Bulgarian member NPO are founding members** - nails down the critical immediate challenges for access to health care, and how they can be addressed fairly, collaboratively and with the needs of patients and citizens at the forefront. It also looks forward, and the imperative to learn from, and address the political, policy and financial bottlenecks that have impeded our response to the COVID -19 pandemic. [Read Full Statement>>>](#)

## **Projects Portal**

*briefings on EPF's ongoing projects*



# Patients are at the center



## EU PEARL: A plan to foster patient engagement gets off the ground

Patient centricity is at the centre of EU PEARL's mission. That is why we are engaging with patients from the start to co-design the platform trial framework, thus bringing on board more patient-relevant outcomes. One of the ways we are ensuring that patients remain active and at the centre of everything we do is by inaugurating two consultative bodies – a **Patient Advisory Group (PAG)**, and an **Expert Advisory Group (EAG)** – which will consult on the work of EU PEARL and the design of the platform. [Read more>>>](#)



## Inauguration of EATRIS-PLUS Project in Personalised Medicine

EATRIS-Plus will deliver innovative scientific tools to the research community to accelerate the progress of personalised medicine. The project will aim to improve the understanding, data-sharing and clinical needs of how gene, protein, mRNA and metabolite analysis will directly **impact Personalised Medicine Solutions**.

EPF will lead on Stakeholder Engagement. We will deliver a **Patient Advisory Committee** to drive patient empowerment at the heart of EATRIS operations and develop a patient involvement toolkit for translational researchers. To learn more about the project, you can head over to the [EATRIS-PLUS webpage](#). For more on EPF's role and the benefits for patients, visit our [dedicated project page](#).



## 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 PAC will inform EATRIS-Plus activities from a patient perspective and 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.

[Find out more and apply here>>>](#)

## Member Focus

*highlights from our member organisations*

## JUNE

Calendar of Events



### June 1

International Children's Day

### June 2

National Cancer Survivor's Day

### June 3

17th eHealth Network meeting

### June 4

[@DataSaves\\_Lives](#) tweet chat 'How patient groups can best communicate about health data during our current crisis.'

Life after stroke is a key priority within SAFE's strategy, recognising the need to consider this neglected area of the care pathway in a holistic fashion. This first European Life After Stroke Forum is driven by the need to implement the Stroke Action Plan for Europe and to create a network of stakeholders involved in professionally researching, advocating and providing evidence for improved life after stroke care.

### More Info on 'Life After Stroke Forum'



The first exclusively virtual **European Conference on Rare Diseases & Orphan Products** (14-15 May) was a huge success with 1,500 registrants from 57 countries. For anyone that already registered you can access the content via the online platform until May 2021. For anyone that missed the conference - new special rates are available to access all content for a year after the conference.

### Access Sessions Recordings



**Plataforma de Organizaciones de Pacientes** updated us on how they have been working to minimize the effect of COVID19 on patients with chronic conditions.

Patient Federation,  
Alzheimer Europe  
and International  
Niemann-Pick Disease  
Registry.

**June 5**

EPF's Industry  
Roundtable  
World Environment Day

**June 6**

[EIT Health Alumni  
Hackathon](#)

**June 8**

Carers Week

**June 14**

World Blood Donor Day

**June 16**

[DMEA Connecting Digital  
Health conference](#)

**June 22**

[HTAi General Annual  
Meeting](#)

**June 25**

[Patient Engagement  
Open Forum 2020 -  
Open Plenary.](#)

**June 26**

[Patient Engagement  
Open Forum 2020 - Panel  
Sessions](#)

**June 29**

World Scleroderma Day

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**Lung Cancer Europe's (LuCE)** new board was elected during its general assembly in May.

[See LuCE's New Board](#)



Following recent advocacy actions, led by the **European Federation of Neurological Associations (EFNA)** and partners, WHO agreed to expand its work on epilepsy to look at its 'neurological synergies'. Published in advance of the World Health Assembly [WHA], the 'Consolidated report by the Director-General', included five pages outlining the prevalence and burden of neurological disorders based on the latest available data.

[Read Overview of EFNA's Advocacy](#)





**Alzheimer Europe's** 30<sup>th</sup> Annual Conference #30AEC will now be a virtual conference from October 20-22, under the banner "Dementia in a changing world". This decision was taken by the Alzheimer Europe Board at an online meeting on 19 May 2020, in light of the continuing COVID-19 pandemic. It was also decided by the Board that the Bucharest conference "Building Bridges" would move to 29 November to 1 December 2021. All delegates who have already registered for the Bucharest conference will be reimbursed by Alzheimer Europe.

#### More Details about 2020 Conference



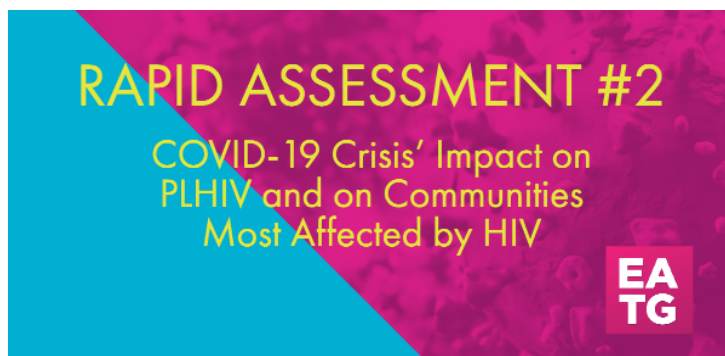
**International  
Diabetes Federation  
Europe**

**International Diabetes Federation (IDF) Europe** is looking for two interns to join its team.

- Communication intern
- Advocacy intern

**See Full Internship Posting**





This is the second COVID-19 rapid assessment bulletin by the **European AIDS Treatment Group**. The rapid assessment surveys aim to document in a structured manner the perceptions of people living with and affected by HIV and that of organisations providing services to affected communities about the way in which COVID-19 impacts their health, well-being and access to HIV related prevention, treatment and care.

**Read EATG's 2nd Rapid Assessment**



**Open Letter: Act now to boost mental health policy** In the wake of the coronavirus pandemic, the [Coalition for Mental Health and Wellbeing](#) sent an open letter to the European Commission and Council calling for increased efforts to protect the mental health of EU citizens now and beyond the crisis. Specific recommendations include public communication initiatives, investing in mental health literacy and ensuring access to mental health services.

**Read their Open Letter**



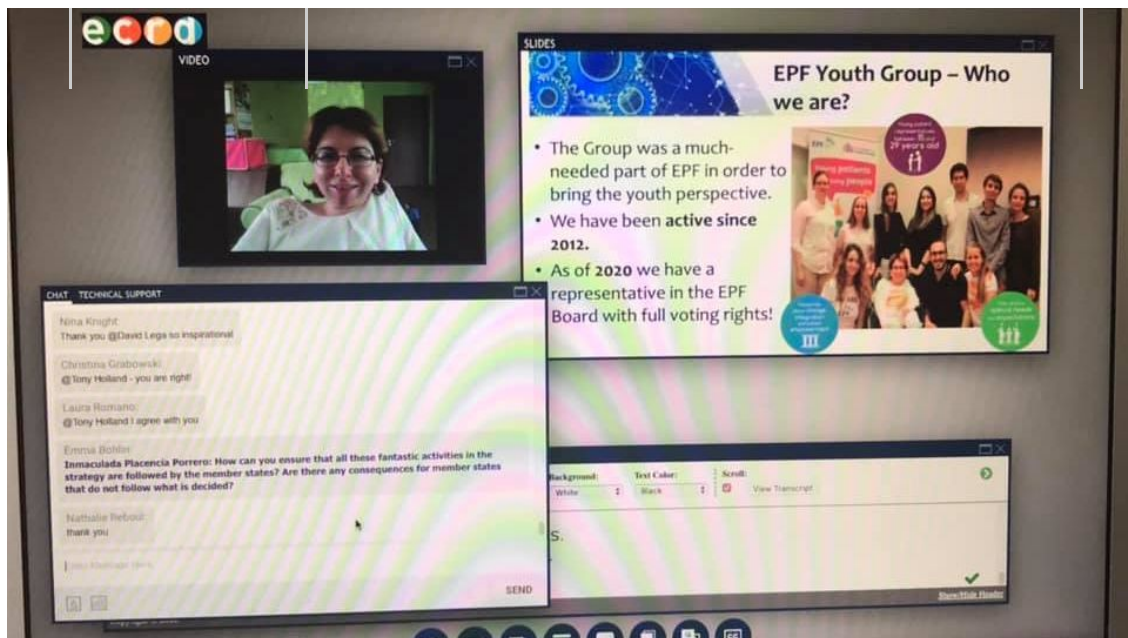
5th of May is celebrated as the **World Pulmonary Hypertension Day** since 2012. This year 26 member associations from Europe and many more from all over the world raised the awareness of PH. Due to COVID-19 big sport events and public gatherings were cancelled, which were, originally, our main target and sphere of activity.

**PHA Europe**, with the support of ERN-Lung, kicked-off a **patient COVID survey** - the survey is endorsed by PHAROS, ERS Assembly 13 and ESC Working Group Pulmonary Circulation & Right Ventricular Function. The survey has been already translated to 19 languages and expect more to come in the coming weeks. Many non-member associations joined this effort from Europe and beyond (eg. Canada). The questionnaire will be open until 21/06.

**Take the Survey**

## Youth Group

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



## ECRD 2020 - International Collaboration in Rare Diseases

*by Jana Popova*

On 14 and 15 May, I had the great honour to participate as a speaker in the **European Conference on Rare Diseases and Orphan Products (ECRD)**, representing EPF Youth Group and European Alliance of Neuromuscular Disorders Associations (EAMDA). Due to COVID-19, this year's conference was organised virtually. Nevertheless, ECRD proved once again to be a globally recognised patient-led event that provides diverse opportunities for collaboration.

The conference began with an Opening Session, moderated by Lise Murphy – patient advocate from the Swedish Marfan Association. There were warm welcomes offered by Terkel Anderson, president of EURORDIS, Dr. Ana Rath, director of Orphanet, Maria Montefusco, president of Rare Diseases Sweden and HRH Crown Princess Victoria of Sweden. They all underscored the fact that in these challenging times, we should **focus more on cooperation in the field of rare diseases**. This was the best start of two amazing days, full of inspirational sessions about the development of diagnosis, implementation of patients' rights, transformative practices for cure and care, achievements in digital health and progress of accessible and affordable treatment for people with rare conditions.

On the second day, I had the honour to present **EPF Youth Group's project in the field of job employment – WAYS**. Our survey was recognised as an important source of information about the challenges young patients face in the labour market. The survey underlined that young patients are young people and their involvement in employment is fully possible. Our presentation concluded with a constructive dialogue on how to increase inclusion of young patients in the labour market. These discussions ultimately proved that together we are stronger as a patient community and mutual collaboration is a key factor for success.

## Commission proposes €9.4 billion budget for health program

The European Commission's proposed standalone health program, EU4Health, will have a budget of €9.4 billion, based on a [Commission document](#). Up until now, the EU's health budget has been part of the European Social Fund. The Commission laid out a number of health-related aspects in its Multiannual Financial Framework and Recovery Instrument proposals, including investing more in health systems; improving coordination between countries; and fighting medicine shortages.

## Commission announces €9.5B haul in coronavirus pledging drive

The Coronavirus Global Response Pledging Conference has raised €9.5 billion. The Commission's goal was to raise €7.5 billion, or roughly \$8 billion. But that sum includes money pledged toward the coronavirus response from January 30 to [May 23](#).

## EMA prepares for coronavirus vaccine to come to market

The European Medicines Agency has commissioned research to ensure that a potential coronavirus vaccine works in the real world and not just in clinical trials. The EMA [announced](#) it has commissioned Utrecht University to carry out research into how best to monitor the safety, effectiveness and coverage of a future coronavirus vaccine once it's in circulation. The first results of the research are expected in August, with the project to be completed by the end of the year.

## EU ends export controls on masks and protective gear

The EU lifted controls on exports of masks and other protective gear, meaning EU countries are no longer supposed to restrict such exports outside the bloc. Under the scheme, EU producers of masks, protective spectacles and garments were required to ask their national governments for an export authorization before selling such products outside of the European Union. The original measures were prolonged to May 25, with a more limited number of protected items.

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### The Last Word

"Health is not valued until sickness comes."

**Thomas Fuller**



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