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The Patient Perspective

February 2021



Reflections

February may be the shortest month but it's one of the busiest at EPF!

Our **Policy** team responded to several European Commission public consultation opportunities that will be fundamental to amplify the patients' voice in the EU. Our **Projects Portal** features some interesting articles and announcements, including a Call for Patient Representatives for the COMPAR-EU project. You can stay up-to-date on all ongoing matters by visiting our website [Projects Page](#).

Our **Capacity Building** Team finished the last episode of the HIVE-33 webinar series but is proud to announce the launch of the Summer Training Course for Young Patient Advocates (STYPA) 2021 edition. You will find all pertinent information on it below. Some of our members have important announcements and updates that you will discover in the **Member Focus** section. Meanwhile, our **Youth Group** launched its Strategy for 2021-2026 and gives some insight into their advocacy efforts throughout the pandemic.

There are several events, webinars and virtual conferences happening in March so please visit our **Calendar of Events section** at the end of the newsletter to register. Don't forget to check our [COVID-19 Resource Point](#) on a weekly basis.

Don't forget to SAVE THE DATE for the **EPF Congress 2021**, taking place virtually from 26-29 October, with a physical follow-up event in Brussels in Spring 2022. Registration opens in April.

Stay safe and enjoy the weekend!



News From the Secretariat

updates from the inside

New episodes of the EU Patients' Podcast 🎧

In February, we released three new episodes of the EU Patients' Podcast

- #4 - Beating Cancer Plan/World Cancer Day with Lung Cancer Europe (LuCE)

[Subscribe](#)[Past Issues](#)[Translate ▼](#)[#6 - Rare Disease Day with EURORDIS](#)

[All episodes of the EU Patients' Podcast>>>](#)

Don't forget to hit the **SUBSCRIBE** button. If you would like to participate or suggest a theme for an episode, reach out to dante.diiulio@eu-patient.eu



New episodes available on:



or wherever you get your podcasts!

SAVE THE DATE

EPF Congress 2021: Digital Transformation of Healthcare 26-29 October 2021

Join us for a 4-day virtual event to explore the digital transformation of healthcare driven by leading representatives of the patient community. Together, we'll explore what meaningful patient involvement means in a rapidly changing healthcare environment using new technologies, and why it is critical to successful innovation. Due to the current public health situation, the Congress 2021 will be held virtually, with a physical follow-up event in Brussels, in Spring 2022.

Registration will open in April with Programme Details to follow.

Visit [>>>](https://epfcongress.eu)

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took place on 28 January 2021.

Read the [Shot Callers Event Report>>>](#)Watch [Shot Callers Recording>>>](#)


SHOT CALLERS:
A VIRTUAL EVENT ON
COVID-19 VACCINES

JANUARY 28, 2021 | 15:00-16:15 CET

Moderated by:

Nicola Bedlington
Special Advisor
European Patients' Forum

Speakers include:

Marco Greco
President
European Patients' Forum

Prof. Jean-Michel Dogne
WHO Global Advisory Committee
on Vaccine Safety

Prof. Guido Rasi
former Executive Director
European Medicines Agency



Policy and Advocacy Corner

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

February in Review

This month was quite intense for the policy team, who responded to several European Commission public consultations. These were an opportunity to amplify the patient's voice in the European arena, making sure that they will contribute to the shaping of EU health policy in the months and years to come.

Firstly, EPF welcomed the publication of the European Commission's "**Europe's Beating Cancer Plan**". It has comprehensive approach, which aims to tackle the entire continuum of the disease, including survivorship. However, EPF suggested to take stronger actions in several areas, such as reducing access barriers to cancer diagnosis (among others). Patient involvement is key in developing and implementing the Cancer Plan. The full reaction to the Cancer Plan can be read [here](#).

The European Commission collected input on how to best **reinforce the mandate for its two public-health related agencies**: the [European Centre for Disease Prevention and Control \(ECDC\)](#) and the [European Medicines Agency \(EMA\)](#). To foster a more coordinated EU response the EMA's new proposed mandate will extend its abilities to better tackle cross-border health emergencies; and the ECDC will gain further competences to improve preparedness, surveillance, risk assessment, and early warning to future cross-border health threats. The EPF welcomed these changes but also argued that the mandate of these two agencies should be extended even further. The EMA should be granted powers to address the problem of shortages of medicines and certain medical devices, whereas the ECDC should be able to monitor the impact of chronic diseases. A more detailed explanation of EPF's input is available [here](#).

On **Digital Health**, there is an ongoing "data revolution" taking place at the EU-level. The proposed use and re-use of health data have the potential to improve the sustainability of Europe's health systems. EPF is strongly engaged in this debate. We provided input to two

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Governance Act (DGA). On the EHDAS, EPF called for an improved and harmonized health data access and control, a clear framework to improve transparency and trust, the build-up of best practices, and the use of patients' experience to address challenges and needs. Regarding the DGA, EPF addressed the set of elements included in the current version of the proposal that believes require further attention considering their potential. More information on these is available [here](#).

Finally, EPF also [provided input](#) to the evaluation of the **Directive on Cross-Border Healthcare** (2011/24/EU). Building in this previous work, several priorities were identified and included in the response to the consultation, such as ensuring that patients have a right to timely and affordable, and many others. Our work on this topic will continue in the coming months and will include a dedicated **information webinar for EPF members on 23 March** and more. Reach out at policy@eu-patient.eu to know more!



Projects Portal

briefings on EPF's ongoing projects

COMPAR-EU Blog: EPF looks ahead to 2021

On 22 February, the COMPAR-EU project published its latest blog post authored by Lyudmil Ninov and Estefania Cordero of the European Patients' Forum.

This month's post focuses on the patient empowerment activities in the year ahead, including EPF joining the Self-Management Europe Research Centre, the planned dissemination of lay-versions of key project documents, and EPF's continued work on the COMPAR-EU IT Platform.

COMPAR-EU 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 our [project page](#) to learn more about EPF's role in the project, and the value for patients.

[Read the blog post>>>](#)

Call for Patient Representatives for the COMPAR-EU project

EPF is planning to **expand and diversify** the group of patients and patient representatives involved in the COMPAR-EU patient panel. We invite you to express your interest today!

As part of its work in the [COMPAR-EU project](#), the European Patients' Forum has set-up a [patient panel](#). The patient panel is an informal working group composed of EPF members, individual patients and also patient advocates from across Europe. The group is involved in project activities through various channels and meets (online) for monthly webinars. The patient panel supports in the production of materials in lay language and development of other project outputs. In 2021, it will focus on the functionality of the COMPAR-EU IT platform and materials on cost effectiveness. All these activities will bring even more of a patient focus to COMPAR-EU, and showcase the direct benefits of patient involvement. The group is on voluntary basis, however, a compensation is foreseen.

Are you interested, or know someone that may be interested in joining the patient panel? You can reach out to EPF Senior Programme Officer, **Lyudmil Ninov**: lyudmil.ninov@eu-patient.eu



H2O: new project website

On 19 February 2021, the Health Outcomes Observatory (H2O) project launched its official website for the public. H2O, a project of the [Innovative Medicines Initiative](#), aims to equip patients with the tools to measure their outcomes in a standardised way, while giving them full control of their data. This is the first-ever attempt at scale to collect and incorporate patient outcomes into healthcare decision making at an individual and population level.

Head to the website to explore more about the project, the consortium participants, and the patient page, including a comprehensive FAQ on key health data topics

[Explore the website >>>](#)



EATRIS-Plus Annual Meeting: Patients in focus

On 3-4 February 2021, the EATRIS-Plus project held its first Annual General Meeting. Project partners gathered in a virtual two-day event to present the project's progress in the first year and look ahead to the planning and milestones of year two.

A highlight of the event included two keynote speeches from members of the Patient Advisory Committee (PAC), Oriana Sousa and Michela Onali. In their keynote addresses, Oriana and Michaela shared their personal journeys to becoming patient advocates. They highlighted the importance of early patient engagement, the important role that patients play in driving new research, and the need for full patient partnership, not just a 'tick-box' exercise. EATRIS-Plus has a PAC of seven members that drives patient empowerment at the heart of the project. PAC members inform project activities from a patient perspective, consult on key project outputs, and will support in the delivery of a patient involvement toolkit for translational researchers.

Additional keynote speeches were also delivered on the topics of Multi-Omics in Personalised Healthcare (by Alain Van Gool, Radboud UMC), and the challenges and opportunities in personalised medicine, delivered by Edward Abrahams of the Personalised Medicine Coalition.

To learn more about the project, visit the [EATRIS-Plus](#) website or head to our [dedicated project page](#) to learn more about EPF's role and why this matters for patients.

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Alain van Gool:
Multiomics in
Personalised Healthcare



Michela Onali:
developing a research
idea in full partnership
with patients



Oriana Sousa:
Patients triggering
research for new
therapeutic approaches



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 871096



Capacity Building Centre

a rundown on EPF's seminars and learning tools

Summer Training Course for Young Patient Advocates (STYPA) 2021

STYPA supports young patient advocates to develop their advocacy skills. Now in its fifth edition, this year we hope to have 60 young advocates taking part from across Europe. The course is based on interaction with other young patient advocates. We use a mixture of online learning, training webinars and group circles to connect the participants with other people on the course, the trainers and EPF.

[Learn more and apply>>>](#)



Episode 3 High Impact Virtual Engagements (HIVE-33) webinar series

The final episode of HIVE-33 webinar mini-series concludes with questions about technology, content & after-event reporting to determine the success of your virtual events. [Watch recording>>>](#)

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**The HIVE-33
WEBINAR
MINI-SERIES**

**Episode 3
05/02/2020 - 3:00 PM CET**

**The circle of seven concept:
7 main areas important for all event organisers**

Technology, content and after-event reporting

Powered by

EPF
European Patients Forum

gro
GLOBAL

PATIENT FOCUSED
MEDICINES DEVELOPMENT



Member Focus

highlights from our member organisations



EMSP is looking for a new Project Coordinator to join their team and to develop and coordinate EMSP projects, as well as to provide active support for daily activities and operations. Deadline is **5 March 2021**.

[apply now>>>](#)



EFNA has developed a series of elearning modules for patient advocates. These open-access courses aim to upskill participants on how they can effectively advocate in a virtual world by identifying and engaging key stakeholders, hosting



The **EHC** is currently developing an educational app on rare bleeding disorders and novel therapies (gene therapy, non-replacement therapies, clinical trials, ...) They have opened a call for testers for the beta version of '**EHCucate**', to collect feedback from the broad patients' community (patients, family members, caregivers, HCP,...) with as varied knowledge and interest as possible, in order to better finetune the final version.

[register to test>>>](#)



In Rare Diseases like Duchenne and Becker



Stroke Alliance for Europe has launched a series of free interactive events to build the life after stroke healthcare, research and stroke survivor community, to stimulate debate, improve life after stroke care and build interest for SAFE's 1st European Life After Stroke Forum on 11 March 2022. The opening session on **Friday 12 March 10.00-11.30 CET** is titled Life after stroke: priorities, challenges and ways forward.

[register now>>>](#)

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disseminating key advocacy messages.

[start learning here>>>](#)

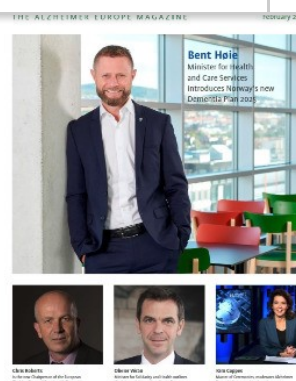


Lung Cancer Europe (LuCE) is hiring a new Executive Director.

[apply here>>>](#)

Strong patient communities plays a fundamental role [Duchenne Data Foundation](#) and the [World Duchenne Organization](#) launched their Duchenne Emergency & Capacity Building Program, to support local communities that struggle with finding tools and opportunities or are affected by emergency situations through strategic global capacity building.

[learn more>>>](#)



Alzheimer Europe has published a new edition of its "Dementia in Europe" policy magazine, in an electronic format.

[read now>>>](#)



Youth Group

initiatives, stories and events from our most budding members

Young Patient Advocacy during the Pandemic

Our Youth Group got together to share how they have continued their advocacy throughout the pandemic. [read full article>>](#)



Launch of the EPF Youth Group Strategy 2021-2026

The main aims of the EPF Youth Strategy are to make sure the young patient voice is effectively heard when shaping the policy and research agenda within Europe, build a strong core of educated and empowered young patient advocates, and ensure the future of patient organisations and patient representation within Europe.

[read the new Youth Group Strategy>>](#)



europeanpatients'forum Youth Group



Inside the Bubble

updates, stories and events around EU healthcare

EMA receives application for conditional marketing authorisation of COVID-19 Vaccine by Janssen

EMA has received an application for conditional marketing authorisation (CMA) for a COVID-19 vaccine developed by Janssen-Cilag International N.V. The Committee could issue an opinion by the middle of March 2021, provided the company's data on the vaccine's efficacy, safety and quality are sufficiently comprehensive and robust. This is the fourth CMA application for a COVID-19 vaccine since the start of the current pandemic. It comes after EMA's evaluation of vaccines from BioNTech/Pfizer, Moderna and AstraZeneca.

EMA starts rolling review of CureVac's COVID-19 vaccine (CVnCoV)

EMA's human medicines committee has started a rolling review of CVnCoV, a COVID-19 vaccine being developed by CureVac AG. Like other vaccines, CVnCoV is expected to prepare the body to defend itself against infection with COVID-19.

EMA starts rolling review of Novavax's COVID-19 vaccine (NVX-CoV2373)

EMA's human medicines committee has started a rolling review of NVX-CoV2373, a COVID-19 vaccine being developed by Novavax CZ AS (a subsidiary of Novavax, Inc.).

Commission proposes doubling EU funds in COVAX vaccine facility

European Commission President Ursula von der Leyen proposed doubling the EU's contribution to the COVAX facility, set up to share coronavirus vaccines with the developing world, by another €500 million, bringing its total financing to €1 billion. Currently, the EU budget is contributing €500 million to the pool set up by the World Health Organization, with another €350 million added by member countries.

EU draws up list of mutually recognized rapid coronavirus tests

The EU Health Security Committee has pulled together a common list of rapid antigen coronavirus tests that member countries have agreed to recognize. The committee, composed of representatives from the bloc's health ministries, has also created a common set of data that will be included in COVID-19 test results, building on the Council's [recommendations](#) from January 21.

"What drains your spirit drains your body. What fuels your spirit fuels your body."

– Caroline Myss

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Calendar of Events

28 February[Rare Disease Day](#)[visit our website](#)**3 March**[Digital Health Europe Workshop](#)[contact us](#)**8 March**[International Women's Day](#)**11 March**[VAC-PACT Regional Workshop #3](#)**23 March**[EPF webinar on Cross-border Healthcare \(TBD\)](#)**24 March**[World Tuberculosis Day](#)**26 March**[EMA public stakeholder meeting on the approval, safety monitoring and impact of COVID-19 vaccines in the EU](#)**30 March**[Data Saves Lives Webinar \(TBD\)](#)[view this email in your browser](#)

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