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The Patient Perspective

August 2021



Reflections

As August comes to a close, we take a look back at some of the exciting initiatives we engaged with during the past month.

Our **Policy** team has been busy with their advocacy work on the EU4Health Programme and the possibility of restoring Operating Grants for NGOs. They also responded to a European Commission's Public Consultation on the revision of EU rules on medicines for children and rare diseases, and expanded their work on the Pharmaceutical Strategy for Europe.

Our **Projects** team put some time aside to lay out EPF's Project Strategy for the future. You will find all the details below.

Our **Membership and Capacity Building** team is working very hard to launch the first ever EPF's Members' Circle, an exclusive online gathering with EPF members to explore different topics and learn new opportunities. If this sounds interesting, you should check out more details below.

Registration is OPEN for our virtual **#EPFCongress2021**. The online event is free for EPF Members while patient advocates and health NGOs are eligible for free registration before 1st September. For more information regarding registration, programme and exhibitor booths, please visit epfcongress.eu.

Stay safe and get ready for September!



News From the Secretariat

updates from the inside

EPF Congress 2021 - Last few days for patient advocates and Health NGOs to register for free

We would like to remind you that the event is free for EPF members and we are offering free registration to patient advocates and health NGOs before 1st September.

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Visit epfcongress.eu for all registration and programme details

Digital *transformation* of **healthcare**

Virtual event
OCT 26-29, 2021

New episode of the PERISCOPE Monthly Talks

In August we published a new episode of the **PERISCOPE Monthly Talks**, this time to take a look at the effects of the pandemic on mental health. To discuss this topic, we've invited Professor Walter Osika. He is co-founder and director of the Center for Social Sustainability, as well as an Associate Professor at the Department of Clinical Neuroscience, in Karolinska Institutet, Sweden. He is also a physician specialised in Internal Medicine, Cardiology & Psychiatry, and a Consultant at Northern Stockholm Psychiatry.

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EPF

periscope
MONTHLY TALK

E P I S O D E > 5

9 AUGUST 2021

The EU Patients' Podcast

WALTER OSIKA

about
Mental Health
Impact of
COVID-19



Policy and Advocacy Corner

discussing the most relevant patient-centered policy and advocacy issues

EPF's Policy Team Activities

During the last month, EPF's Policy Team has been conducting advocacy work on the EU4Health Programme and the possibility of restoring Operating Grants for NGOs. **The EU4Health 2021 Work Programme's proposed abandonment of the core funding for health NGOs risks undermining the independence of civil society organisations.** More importantly, it risks denying Europeans their voice in EU policy-making while losing decades of expertise that civil society has built up in the field of public health. Last 30 July, we met with Commissioner Stella Kyriakides to discuss this topic. During the meeting, Commissioner Kyriakides acknowledged the importance of the issue and committed to exploring a positive solution within the framework of the EU4Health Programme Regulation. Commissioner Kyriakides also affirmed the importance of patient organisations and health NGOs as key partners of the European Commission, in particular at such a crucial juncture for the future of health in the EU. More details on the joint CSOs asks and position on EU4Health are all available [here](#). We also responded to a European Commission's Stakeholders' Targeted Consultation on EU4health related priorities, strategic orientations and needs. Together with our response, we attached an **accompanying statement**.

In a different vein, we also responded to a European Commission's Public Consultation on

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with EPF's Youth Group. In our response, we advocated for increased access of young and paediatric patients to medicines and treatments, as well as encouraged the European Commission to foster research in those areas. You may see our response [here](#).

Finally, we continue working on the Pharmaceutical Strategy for Europe. At the moment, the members of the European Parliament's Committee on the Environment, Public Health and Food Safety (**ENVI**) are providing written comments on the first draft of a report providing amendments to the original European Commission proposal. We provided a series of comments to that report, advocating for the inclusion of the patient perspective in the strategy, which is currently being discussed. The "final" report will be voted in Plenary in the 22-25 November session.



“ We urge the European Commission to resume the support to civil society organisations in the field of health through operating grants. As similar mechanism are still active in other fields, it is essential that the EU does not forget health. ”



Projects Portal

briefings on EPF's ongoing projects

EPF's Projects Strategy

Anticipating the launch of both Horizon Europe and EU4Health, respectively the new EU Research and Health Programmes, and having in mind the growing patient community involvement in EU-funded projects, in 2020 EPF developed a strategic approach to our involvement in projects, which carefully defines our criteria for engagement. EPF's **current project portfolio**, and prospective project involvement act as a **cross-cutting platform** which **underpins our advocacy, education and communication** pillars. Our aim is to maintain a relevant and impactful project portfolio, which:

- is strongly aligned to our EPF **key values, strategic goals**, and **priority topics** to the patient community;
- has a **demonstrable link with our advocacy** and/ or educational objectives;
- is open to **co-create a meaningful role for Patient Organisations** through early engagement in the proposal phase, and throughout implementation;

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involvement in projects;

- and provides an **adequate allocation of resources** to enable meaningful contribution.

To get in touch about one of our ongoing or completed projects, or if you would like to reach out about a future collaboration, please send a message to: projects@eu-patient.eu



Capacity Building Centre

a rundown on EPF's seminars and learning tools

Join the first ever EPF Members' Circle!

The Members' Circle will be an informal online gathering, with a **limited attendance**, where you can get together with our fellow members to discuss areas of importance to you. In a comfortable and confidential environment, you will be able to share your learnings, your failures, your successes and hear from other EPF members. Sharing is not only caring, it is a great way of learning and looking at things with a different perspective! We will connect for our first ever **Members' Circle on Thursday, 16th of September at 15:00 CET**. For the first edition we will focus on the topic of **Capacity Building for patients' organisations**.

You can register for it following [this link](#).

Don't think twice to register, we have a very limited availability and we are granting the spots on a first come first served basis.

For more information on the topic, do not hesitate to contact Desislava.ekzarova@eu-patient.eu!

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Member Focus

highlights from our member organisations



EURORDIS Black Pearl Awards

Start looking for your hero! **Nominations for the Black Pearl Awards are open until September 10th**, so be sure to keep an eye out for someone going the extra mile for the rare disease community. Help them get the visibility they deserve!

[nominate your star of the rare disease community>>>](#)



ENHA will be hosting a Joint Policy Seminar at the ESPEN Conference on September 13 11.45-13.00 CET. The event will review the latest evidence regarding the impact of nutritional issues in cancer, the barriers that patients face in accessing nutritional care across Europe, what must now be done at European and country level to implement a fully integrated model of nutritional care in cancer,



World Atopic Eczema Day 2021: Unite for atopic eczema! Our members **EFA** and **Global Skin Alliance** will come together on September 14th to raise awareness for the disease, to speak up about the burden it has on patients and caregivers, and to recognise the need for care and treatment that is

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WHO Europe consultation on Future Generations: Young allergy and asthma patients' priorities

WHO Europe has launched a survey for youth organisations of all sizes across Europe to gather their input on how they want to see health and healthcare treated in a post-COVID Europe. EFA's European Allergy and Asthma Youth Parliament, a platform for young patients living with allergy and asthma to advocate for their needs, submitted a response outlining their priorities. With help from EFA, they advocate for a "youth in all policies" approach and raise awareness for the needs of young people living with chronic conditions. This included addressing inequalities in health and increasing access to digital healthcare tools.

[more info >>>](#)



On 20 September 2021, 16.00 - 17.30 PM, the **European Institute for Women's Health** is organising a webinar to launch their "**Women's Health in Europe:**

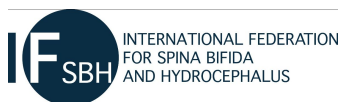
more info on the event>>>



We are proud to endorse the **Workshop on Healthy Living with HIV**, organized by **Virology Education** and the **European Aids Treatment Group**. This annual workshop is designed to build a community of HIV-treating expert care providers focusing on promoting a full and healthy life for all patients.

Join this program from 1-2 October 2021 and contribute towards building a community of HIV-treating expert clinicians focusing on promoting a full and healthy life for all PLWH!

[more info and registration>>>](#)



The **International Federation for Spina Bifida and Hydrocephalus (IFSBH)** organizes the first online **Conference on Multidisciplinary Care for Spina Bifida and Hydrocephalus from September 14th to 17th 2021**. One of the reasons to organize this conference was the recently published report presenting the work from an exploratory study on the best practices of multidisciplinary care. Since this conference covers a variety of aspects of care for individuals with Spina Bifida and or Hydrocephalus (SBH),

disease. The theme for this year is **#UniteForAtopicEczema**, aims at patients, carers, healthcare providers and policymakers.

Join World Atopic Eczema Day 2021>>>



The **World Duchenne Organization** is organizing an online educational event on **Adult Life & Duchenne**. The free event on **September 7** will be accessible for everybody via Zoom, and is available with live Spanish interpretation.

Speakers include Prof. Ros Quinlivan, Dr. Jos Hendriksen, Nicoletta Madia, Elizabeth Vroom and Hlawulani Mkhabela. Apart from these, Duchenne adults from different parts of the world will share their experience of living with Duchenne.

Register here for the 'Adult Life & Duchenne' Conference>>>

On July 15, the World Duchenne Organization organised a meeting on **the use and development of digital outcomes in Duchenne and Becker**. A scientific report is currently being drafted, and the meeting was deemed very valuable from all stakeholders.

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

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Report . The event will be hosted by Ms. Sirpa Pietikäinen, MEP. To register contact info@eurohealth.ie

SAVE THE DATE >>>

applications, such as ageing, urology, parenting and transition, incontinence management, optimizing care and more, anyone interested in future progress in optimizing management and care should not miss.

get the Conference Book>>>

The European Health Forum Gastein will be back from 27 September to 1 October 2021 for a full week of digital sessions and networking, and understanding how we can rise from this crisis as more resilient, smarter, and more equitable societies.

Find out more >>>



Inside the Bubble

updates, stories and events around EU healthcare

A major study into the risk of blood clots from COVID-19 and vaccines is conclusive: vaccine benefits outweigh the risks.

A study, recently [published on the British Medical Journal](#), of nearly 30 million people in England who've received either the Oxford/AstraZeneca or the BioNTech/Pfizer vaccine indicates that the risk of blood clots after contracting coronavirus is many times larger than the risk presented by either vaccine.

Scientists welcome the U.K.'s first monoclonal antibody therapy for COVID-19

News that the U.K.'s medicines regulator approved the use of Regeneron/Roche's antibody cocktail — casivirimab and imdevimab — to treat COVID-19 was welcomed recently by the research community. The antibody therapy has demonstrated it can prevent hospitalizations when given early to people at risk of severe disease. The RECOVERY trial demonstrated that the treatment could save six lives for every 100 patients treated among people who haven't generated any natural immune response to infection — and are seronegative. However, it wasn't approved for a subgroup of vulnerable patients who become hospitalized with COVID-19.

Wealthy countries are going full steam ahead with plans for boosters, ignoring the WHO's call for a moratorium on third jabs.

The World Health Organization may have called for a moratorium on boosters until the end of September but wealthy Western nations are blatantly ignoring the global health institution. France, Germany, the U.K., Israel and Hungary have set out plans for third doses, or are already rolling them out. The U.S. government is also planning to encourage coronavirus boosters for most Americans, and the administration there has already recommended a third shot for immunocompromised people.

It's not just that countries are going against the WHO's call for increased vaccine equity. The need for third doses is disputed by some scientists who believe that there isn't enough evidence to support their rollout yet. That includes the EU regulator — up until now, the European Medicines Agency has said that it is too early to confirm whether boosters will be needed.

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Ovid



Calendar of Events

7 September

World Duchenne Awareness Day

[visit our website](#)

17 September

World Patient Safety Day

[contact us](#)

[view this email in your browser](#)

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