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The Patient Perspective

February 2022



Reflections

Welcome to our February Patient Perspective newsletter!

Here's a recap of what we have been up to in the last month:

Our **Policy** team has been quite busy in February. Not only they continued to monitor the developments on digital health, but also they organised the webinar on the evaluation of the EU's Blood, Tissues and Cells Directives. Moreover, they keep up their work with several other EPF members and public health civil society organisations on the topic of Operating Grants under the EU4Health Programme.

Our **Projects** team is organising a coffee chat with Data Saves Lives and MedTech Europe, and they also launched a tender for the design work on the COMPAR-EU project.

Our **Youth Group** is welcoming its newest members, and it is already preparing for their first face-to-face meeting since 2019, that will be held in May 2022.

Don't forget to check our **Calendar of Events** at the bottom to see the special days and events from us and our member organisations taking place in March.



News From the Secretariat

updates from the inside



EPF is pleased to announce that Anca Toma will join us as our new Executive Director as of 7 March 2022.

"I am honoured to have been appointed as Executive Director of the European Patients' Forum, an organisation I have known and admired since the beginning of my career in Brussels. It will be a privilege to be part of this team of very talented professionals working every day to advance the voice of all patients in Europe", Anca Toma says.

Anca is a public health advocate working in tobacco control, with expertise in European public health policy and advocacy, and brings with her an extensive knowledge and experience of EU policy and institutions, advocacy strategies, policy campaigns and project management. Anca has led the Smoke Free Partnership for the past four years, in addition to her 10 years' working on pan-European campaigns in SFP.

[Read the announcement on our website.](#)



We are hiring!

EPF is looking to recruit a new Finance Officer. The deadline for applications is 28 February 2022.

If you know someone who is passionate about patients' rights in Europe, let them know about this unmissable opportunity!

[Here you can find the full job description.](#)



discussing the most relevant patient-centered
policy and advocacy issues

February has been a busy month for EPF's Policy Team!

Over the past month, EPF continued to lead work in collaboration with several other EPF members and public health civil society organisations on the topic of **Operating Grants** under the **EU4Health Programme**. In January, the European Commission confirmed the reinstatement of operating grants under the EU4Health Work Programme 2022 with increased funding. This is a significant achievement, as the Commission had previously excluded operating grants for civil society organisations as a funding mechanism. We hope the changes will enable more patient organisations to be funded under the Health Programme and contribute towards the EU4Health policy objectives. EPF and fellow civil society health NGOs continue to engage in a dialogue with the Commission to resolve outstanding issues where there is still lack of clarity, such as whether there will be a multi-annual funding scheme in future years, and how the financial eligibility criteria can be made more viable for patient organisations.

EPF also engaged in the **revision of the EU legislation on blood, tissues and cells (2002/98/EC and 2004/23/EC)** – commonly known as BTC legislation. The European Commission will publish its proposal for the revised BTC legislation in the first quarter of 2022. EPF organised a Members-only webinar on 9 February entitled "*The evaluation of the EU's Blood, Tissues and Cells Directives – what is at stake for the patient community?*". The purpose of this webinar was to explain to the patient community the ongoing work being carried out by the European Commission evaluating the BTC legislation to identify issues of importance to patient organisations and potential engagement needs and opportunities for EPF and its Members. If you could not attend the webinar or want to re-watch the discussion, you can access the event recording [here](#).

On 21 February, we participated in the **multi-stakeholder workshop on "Implementing Good Lay Summary Practice"** led by the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the European Forum for Good Clinical Practice (EFGCP) and presenting the Roadmap for implementing the previously developed European guidance on planning, developing, translating and disseminating lay summaries of clinical trial results. EPF has been closely involved in this project since its initiative in 2015. As lay summaries for all trials will be required by the EU Clinical Trials Regulation (**536/2014**), the Roadmap for implementation comes very timely. EPF will engage its membership in this initiative over the coming months to promote awareness, partnership opportunities and more patient organisation involvement in developing lay summaries.

Lastly, EPF's Policy Team continued to closely monitor the developments on digital health, in particular on the **European Health Data Space (EHDS)** and artificial intelligence (AI). On 2 February, EPF attended the high-level conference on "Citizenship, ethics and health data" where the French presidency of the Council of the European Union (EU) presented **16 principles for ethics in digital health** adopted by the **eHealth network** – a network of Member State representatives responsible for digital health. The team further continued its AI work supported by the European NEF Fund on AI. More information on the latter is available [online](#).

The upcoming second edition of the COVID-19 survey

From 18 September to 18 October 2020, EPF conducted a survey to gather more information on the experience and impact of the COVID-19 pandemic on patients with chronic conditions, their communities and on patients' organisations.

The results were clear: patients and patient organisations have experienced many severe challenges due to the ongoing pandemic. Treatments have been delayed, access to healthcare professionals has been hindered, communication has not always been clear, funding opportunities for organisations have decreased, and more.

Ultimately, this survey demonstrated that, even as funding opportunities have decreased,

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of patients and their carers. The full survey report, as well as an infographic summarising its key conclusions and recommendations, are all available [online](#).

As part of the PERISCOPE project and in collaboration with other project partners, EPF will continue to investigate the impact of the pandemic on the broader patients' community and prepare the second edition of the COVID-19 survey during the second and third quarters of 2022. More information on this is upcoming.



Projects Portal

briefings on EPF's ongoing projects

NEW #DSLCoffeeMorning: Role of Medical Technology in Harnessing the Power of Personal Data

Data Saves Lives and **MedTech Europe** are collaborating on a 1 hr. panel discussion exploring the role of medical technology in harnessing the power of personal data.

The aim is to inform and educate the patient & multi-stakeholder health community about how **the medical technology industry generates insightful health data**, what is the potential of this data and how this can data be used to support health and scientific research to meet the needs of patients and address the challenges faced by our healthcare systems.

Speakers include:

- Uroš Bogdanović, diabetes advocate living with Type 1 diabetes
- Angela Bradshaw, Project Officer at Alzheimer Europe
- Justine Vandenbosch, Chair of the Data Governance WG, MedTech Europe

The discussion will take place on **10 March 2022, 01:00 PM CET**.

[>>> Register here](#)

Join us for a **COFFEE CHAT** on:

**The Role of Medical Technology in
Harnessing the Power of Personal Data**

Featuring keynote speakers:



Justine Vandenbosch
MedTech Europe



Angela Bradshaw
Alzheimer Europe



Uros Bogdanovic
Diabetes advocate

DATE:

10th March

TIME:

13:00 – 14:00 CET

On 15 February 2022, the European Patients' Forum published a new call for tender to produce attractive and accessible **leaflet and video designs** as part of its work in the **COMPAR-EU project**.

COMPAR-EU is a Horizon 2020 project aiming to identify, compare, and rank the most effective and cost-effective self-management interventions in four chronic conditions. In this project, EPF leads the workstream that aims to identify what outcomes are most important to patients, and ensure that their views, gender, and socioeconomic dimensions are taken into account.

As part of this work, **we have developed lay summaries and leaflets to adapt the technical reports** of the project into **language that is accessible for lay-users** including patients, but also the wider public. These materials – the leaflets and videos – must also be **visually appealing in a way that facilitates their readability**.

Does this sound like it is within your expertise, or the expertise of someone you have worked with?

Applications must be sent in by **11 March 2022, 23:59**.

>>> Further details and the full call here



Registrations open for HAS symposium – Together for HTA in Europe

On **7 March 2022, 10:30 – 16:30 CET** the **French National Authority for Health (HAS)** will hold an international conference on the entry into force of the European regulation on health technology assessment (HTA).

The HTA regulation brings a new era of greater cooperation between HTA agencies in different European states. The objective of this cooperation is to ultimately **facilitate access to innovations** with a clinical benefit, **in the interest of patients**. However, key questions remain.

This conference will explore **questions like how to meet HTA objectives** without departing from the **stringent quality, safety and transparency standards** required for any health technology assessment? And what are the factors for success, both in times of crisis and in the long term?

Speakers include **EPF's own Head of Programmes, Valentina Strammiello**, as well as others like **Olivier Veran**, French Minister of Health and Solidarity; MEP **Tiemo Wölken**; **Andrzej Rys**, Director for Health Systems, Medical Products and Innovation, DG

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This event is organised as part of the programme of the [French Presidency](#) of the Council of the European Union.

[>>> Register here](#)



Welcome to the Youth Group....and Our Monthly Updates

By Anastasia Semaan

At the end of 2021, we the EPF Youth Group (YG) opened a call for new members to join our family, and we are very happy to announce the welcoming of our two new members Konstantina Boumaki, who is from Greece, and is a representative of the International Diabetes Federation, and Leonie Wollscheid, who is from Germany and is representing the International Bureau of Epilepsy. We loved getting to know more about them and introducing them to the rest of the group during our Monthly Call in February, and we are looking forward to collaborating with them from now on. Further introductions about them, their backgrounds and their hopes and goals whilst being within the Youth Group will be coming soon, so make sure to follow us on Facebook, Instagram and Twitter!

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We are very excited to announce that in May 2022 we (at least up until this point in time) will be meeting face-to-face for our Spring Meeting, and this will be the first time that we will be meeting face to face since 2019 as a current youth group. We are not only looking forward to working with each other in a face-to-face setting and making progress on our current projects, but to get to know more about each other and develop our team dynamic on a holistic level. As the Spring Meeting of the EPF YG is fast approaching we are very excited to continue our progress on our Sexual Health and Wellbeing Project, and to plan our goals for the face-to-face meeting. Currently the project has highlighted the importance of breaking the taboos and stigmas around talking about the sexual lives of young patients and is in process of gaining an insight on the experiences that young patients have had regarding this topic, and how they want to be supported.

Do not forget to follow us on our social media platforms to find out more about our new members, for more interesting content from our YG, for our progress on our projects and how you can get involved and support our team, or email us at youthgroup@eu-patient.eu with any questions!



Member Focus

highlights from our member organisations



European
AIDS Treatment
Group

Webinar: "U=U=U and I can do more!"

EATG held its webinar "U = U = U and I can do more! – An exploration of what we can do more to get the message across" on Friday, 18 February 2022 with a good attendance.

EATG will launch the report with results of the



Share Your Colours on Rare Disease Day 2022

For Rare Disease Day 2022, everyone is invited to **Share Your Story** and **#LightUpForRare** at home at 7 pm on 28 February 2022, to show your solidarity and help to raise awareness for people living with a rare disease!



Registration is now open for the first event in the **European Life After Stroke series 2022** that will take place on Friday **11 March**.

With two plenary sessions, the event will cover the important topics of self-management and communications after stroke. There will be a mix of presentations from

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promote the undetectable=untransmittable message from around the world



Find more information on the webinar>>>>



EATG has also been coordinating the community meetings on the side of the CROI 2022 conference. It is the second year they are using the Margarita/Breakfast concept to highlight the time-zone difference that virtual conferences of global interest bring.

You can find more information on the Margarita Breakfast Clubs at CROI 2022 on EATG's website>>>



EMSP Annual Conference 2022

Join the European Multiple Sclerosis Platform for their first-ever hybrid annual conference either in Madrid or virtually on 29-30 April 2022.

The theme of this year's conference is "A Holistic Approach for Personalised MS Care". Registration will be opening soon.

Find more info on the EMSP Annual Conference>>>

The power of international cooperation.

Learn how to establish fruitful cooperation with other rare disease patient groups around the globe in **EURORDIS' new online course!**



300 words to showcase your achievements.

Let the whole community know the outcomes of your research project on rare diseases or public health, at the **European Conference on Rare Diseases - ECRD2022.**



New EURORDIS Rare Barometer Diagnosis Survey: strengthen your advocacy work with robust figures! Join EURORDIS on Thursday 17 March at 14:30 CET for the launch of their new survey on diagnosis! Which new indicators will be available to strengthen your advocacy work? How can you encourage your network to participate? These are some of the questions we will be answering during the webinar. **Register now**

across Europe.

Learn More and register>>>



2nd International Conference on Rare Diseases

On 1-2 March 2022, the Greek Chapter of the **International Conference on Rare Diseases** will host its annual event. The theme this year will focus on **"The Balancing Act between Equity and Sustainability."**

The conference is organized by **Health Daily** and **BOUSSIAS**, in cooperation with **95 Rare Alliance Greece**, under the patronage of **Rare Diseases Europe (EURORDIS)**. **Register here.**



EUPATI celebrates its 10 years anniversary

EUPATI was launched in February 2012 as an **#IMI** project, paving the way for an innovative education programme to enhance the engagement of patients in medicines R&D.

10 years later, EUPATI is now established as an independent foundation. In 2022 they will celebrate key achievements and display new objectives for improving patient engagement through education and training.

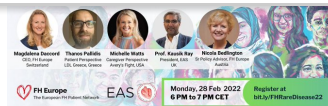
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Global Heart Hub invites you to their next Inspire patient advocacy session!

Date: Monday, March 7
Time: 14:00 - 15:00 GMT
(15:00 - 16:00 CET)
Cost: FREE!

[Register now>>>](#)

Dr Durhane Wong-Rieger is President & CEO of the Canadian Organization for Rare Disorders and Chair of the Canadian Heart Patient Alliance.



On Rare Disease Day 2022, **FH Europe - The European FH Patient Network** will host a multi-perspective discussion on HoFH.

The event "Leaving no-one behind: creating a better future together for all people living with rare and severe FH" will be held on 28 February at 18.00 CET.

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

On 25 January EUPATI launched its newest collaborative project, EUPATI Connect. EUPATI Connect is a place where both EUPATI Patient Experts and research can build new connections, create synergies and mutually beneficial opportunities to enhance patient engagement. Thanks to a matching algorithm, researchers are able to submit their project requests online (i.e. protocol reviews, focus groups, speaking opportunities, patient advisory boards, ethical committees, regulatory processes) while EUPATI Patient Experts can log in to view, edit their profiles and indicate their availabilities to participate in various projects.

[Find out more on EUPATI Connect website>>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

EMA backs Moderna jab from aged 6, Pfizer booster from aged 12 The European Medicines Agency recommended wider use of mRNA COVID-19 vaccines in children and young people as countries seek to expand protections in the face of waning immunity and stubbornly high case rates, while at the same time relaxing measures. The EMA's medicines committee CHMP advised that Moderna's COVID-19 vaccine can be given to children aged six to 11. It's the second vaccine to be available for younger children after the BioNTech/Pfizer jab was extended to those aged five and older in November.

First batches of Novavax's COVID-19 vaccine arrive in Europe from India

Germany, Austria and France are the first countries in Europe to get their hands on shipments of the latest COVID-19 vaccine — Nuvaxovid — which was approved for use in December. Italy, Spain and others are likely to receive theirs by the end of the week, with the U.K. also on the delivery list. The fifth jab on the block comes just as the Omicron and Delta peaks have passed and countries from East to West are opening up. The doses also arrive as countries from Finland to Romania are reporting a vaccine surpluses, with Finland debating how to handle excess doses while Romania has announced it is donating 1.1 million shots. Nonetheless, there's still demand for Novavax's jab in Europe, Silvia Taylor, senior vice president, global corporate affairs, told a media briefing on Wednesday.

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A report by the Parliament's Special Committee on Beating Cancer (BECA) has been adopted. It makes important recommendations on preventable risk factors linked to cancer and chronic diseases across the lifecycle, with a focus on inequalities. It further aims for stronger tobacco prevention, EU-harmonised nutritional profiles and labelling, health and digital health literacy, and addressing commercial determinants of health. The report also calls for a new EU childhood obesity strategy and a stock-taking prevention summit.

Without courage we cannot practice any other virtue with consistency. We can't be kind, true, merciful, generous, or honest.

Maya Angelou.



Calendar of Events

1 March

Zero Discrimination Day

[visit our website](#)

1-2 March

2nd International Conference on Rare Diseases: Greek Chapter

[contact us](#)

3 March

World Hearing Day

7 March

HAS symposium – Together for HTA in Europe

8 March

International Women's Day

10 March

Data Saves Lives & MedTech Europe Coffee Chat

30 March

World Bipolar Day

14 - 20 March

Brain Awareness Week

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