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The Patient Perspective

June 2022



Reflections

Welcome to our June Patient Perspective newsletter!

June has been extremely busy for us at the EPF Secretariat and full of big events. Here's a recap of what we have been up to in the last month.

We've wrapped up the **EPF 2022 Congress!** The two-day event fostered meaningful dialogue and explored answers to some of the most burning questions, in terms of digital healthcare transformation. You find out more about our Congress by continuing reading the newsletter.

We are happy to share that EPF was appointed as a member of the European Commission's HERA Civil Society Advisory Forum.

Our President, Marco Greco, has been reappointed to **European Medicines Agency's** Management Board, for another three years.

We signed an open letter, together with 300+ civil society organisations for a EU Civil Society Strategy in the European Commission 2023 Work Programme.

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 July.



News From the Secretariat

updates from the inside

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EPF Congress 2022 is a wrap!

Between the **23rd and 24th of June**, The European Patient Forum hosted the second in-person European Congress. The event took place at the DoubleTree by Hilton Hotel, in Brussels (Belgium). The Congress' plenary sessions had the option of being attended online.

Having in mind the experience and lessons learned from the 2021 online Congress, this year's event included a **wide audience** of patient representatives, policymakers, health systems experts, healthcare profession representatives, academics, and industry representatives, from Europe and beyond.

We welcomed the **first keynote speech given by Stella Kyriakides**, European Commissioner for Health and Food Safety, who was livestreamed virtually into the Congress. Stella Kyriakides established the context for and introduced the principles of **European Health Data Space (EHDS)**, which aims to establish the right for patients not only to have digital access to their own health data, but to control how it is used, which parts are shared, see who has accessed their health data and help correct any inaccuracies.

We hope that the dialogue initiated during the Congress will bring coherence to the concept of patient involvement in digital health, while extensively exploring patients' needs in terms of medical data sharing and security, data-driven personalised healthcare, AI usage in healthcare, and the role of new technologies in health literacy.

[You can re-watch the live-streamed plenary sessions here!](#)

[Read a comprehensive Congress update here](#)

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The European
Health Emergency
Preparedness and
Response Authority

#SOTEU



The European Patients' Forum was appointed as a member of the HERA Civil Society Advisory Forum

We are pleased to announce that the European Patients' Forum was selected to be a member of the Civil Society Forum as a sub-group of the HERA Advisory Forum. This sub-group will help to ensure that the HERA Advisory Forum will receive regular input, views and opinions from civil society stakeholders. Along with the Joint Industrial Cooperation Forum, it will provide the Advisory Forum with observations and assessments from a diverse range of stakeholders. This will support the work of the Advisory Forum and contribute to its informed opinions and conclusions.



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Marco Greco, EPF President, Reappointed for Another Term on the EMA Board

On 13 June 2022 the Council of the EU **adopted** a **proposal** to **reappoint** four civil society representatives as members of the **European Medicines Agency** Management Board. The European Patients' Forum (EPF) welcomes the reappointment of our President Marco Greco for another three-year term on the EMA Board.

Alongside Marco Greco, other appointments to the EMA Management Board include Ms Virginie Hivert (**EURORDIS**), Mr Denis Lacombe (**EORTC**) and Ms Despoina Iatridou (**Federation of Veterinarians of Europe**, FVE).

The new mandate of the EMA Management Board started on 15 June 2022.



EPF represented in the Final Plenary of The European Health Parliament

Our colleagues, Anca Toma (Executive Director), Estefania Guzman Cordero (Communications and Outreach Officer), and Juan Jose Fernandez Romero (Policy Officer) represented EPF during the Final Plenary of the European Health Parliament, which took place on the 29th of June.

[>> Listen to the recommendations](#)



While Estefania Guzman Cordero took the floor during the Committee for Wellbeing of Healthcare Workers Policy Recommendation discussions, Anca Toma was invited to a debate on the state of future health policies in Europe, together with Sandra Gallina, Director-General of Health and Food Safety at the **European Commission**, Tomislav Sokol, Member of the **European Parliament**, and Eleonora Varntoumian, President of the Seventh Edition of the European Health Parliament (EHP).

[>> Watch the debate](#)

"Patients and NGOs should be vital in working toward a

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This is EPF's answer to the question addressed during the launch on the European Health Union Network: "What is the vision for a European Health Union?". Our Director of Policy, Kaisa Immonen, attended the event and delivered EPF's view on shaping healthcare systems that work for patients.



The event took place on the 30th of June, at the European Parliament.

WE'RE HIRING!



BE OUR NEW COMMUNICATION OFFICER.

Send your cover letter, CV and references to
recruitment@eu-patient.eu

We're looking for a Communications Officer!

Purpose of the role

The Communications Officer is responsible for helping develop and deliver excellent communications on EPF's work.

The deadline for applications is **10 July 2022, 23:59**.

Key tasks

- You manage digital communications channels on a daily basis, developing and designing relevant and interesting content;
- You create designs for social media campaigns and design templates for other communication channels;
- You manage EPF's weekly internal and external newsletters in a consistent and timely manner;
- You monitor information relevant to EPF's priorities and network, and ensure its rapid dissemination;
- You produce and support content preparation for various EPF communications channels/purposes (such as the Annual Report);

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- You make sure that EPF's databases and mailing lists are maintained and up to date;
- You understand partnerships that directly and indirectly affect the organisation;
- You may also be expected to undertake other duties to meet the needs of the department and the organisation (including preparation of EPF's events).

[Check the job description here](#)



Closing of the Horizon 2020 PERMIT Project

The PERMIT project, a **Horizon 2020** funded project, has come to an end after 2,5 years of collaboration. On 16 and 17 June 2022, the European Patients' Forum (EPF) team travelled to the **Istituto di Recherche Farmacologiche Mario Negri** in Milan, together with project partners and other stakeholders, to hold the project closing conference.

The project's 70+ recommendations were presented, including a discussion of the process, outcomes, and key lessons learned from each working group. Monika Frenzel, of the **ICperMed** and **French National Research Agency**, provided the key note address, in which she highlighted the creation of the new European Partnership in personalised medicine, and outlined what aspects identified in the PERMIT project could contribute to a cohesive network for personalised medicine.

Other topics covered at the closing vent included the regulatory landscape in Europe, as well as dissemination and training efforts for the recommendations encompassing the breadth of the personalised medicine pipeline. In the next phase, **PERMIT project** partners aim for the recommendations to live on to inform decision making in personalised medicine, and improve implementation and communication.

EPF is proud to have participated in the **PERMIT project**. Personalised medicine has enormous value for patients, potentially reducing trial and error treatments, enabling better choices for medications, and managing rising healthcare costs. By participating in this project, EPF ensured that the patient perspective and journey were considered throughout the workshops and recommendations put forth by the expert groups.

[>> Learn more about the project and the closing event](#)



Label2Enable project on quality labels for health apps kicks-off!

On 1 June 2022, a new two-year **Horizon Europe** project called 'Label2Enable' has kicked-off. The project aims to develop a **quality label for health and wellness mobile applications**.

Label2Enable will do this by promoting the trust, use, and adoption of **the ISO/TS 82304-2**, a technical specification and quality label for health and wellness apps, developed by the **International Organization for Standardisation**. Label2Enable will better inform citizens (patients, carers) using health apps, healthcare professionals that wish to recommend them, and health/ regulatory authorities looking to approve and reimburse apps.

The European Patients' Forum will be involved in the workstream on **Patients, Citizens and Carers**, and will lead the work in establishing a patient, citizen and carer advisory group that will contribute to the project work, and will help to ensure the label is useful and impactful. The project brings together 14 partners from 7 countries (Belgium, Croatia, Germany, Italy, Lithuania, the Netherlands, and Spain).

You can learn more about Label2Enable **on its website** (live soon), and by **following the project on Twitter**.

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PharmaLedger Consultation on Shifting the Paradigm for Patient Recruitment

On 13 June 2022, the **PharmaLedger** project, including EPF's Project Coordinator Hannes Jarke, hosted a Virtual Open Consultation on **Shifting the Paradigm for Patient Recruitment: Needs, Options and Challenges for Trial Matching Solutions**.

The multi-stakeholder open consultation explored: Why patients struggle to search for suitable clinical trials, and conversely, why clinical trial investigators have difficulties finding the right patients. It also explored how **matchmaking solutions** for clinical trials **could improve** the patient **recruitment** process and **patient experience**.

The insights gleaned will inform PharmaLedger's work on a clinical trial matchmaking concept, and further discussions on how to propel the paradigm shift for patient recruitment.

>> **Watch this space for the full recording in the future!**

Active poll 16

#18 - Do you find it important that a trial-matching solution offers human support to the matching process?

Response	Percentage
Yes, it might be helpful for some patients	38%
No, entering my health data should anyway be super easy and intuitive	38%
Yes, I think it is essential	25%
No, I would not want an unknown person's involvement	0%

Join at **slido.com**
#2592 217

Ingrid Klingmann

NEW SURVEY 🗳️ Experiences with Patient Involvement in Health Technology Assessment (HTA) in Europe

SHARE YOUR EXPERIENCE! Following the **12 May introductory webinar** on how patients perceive involvement in HTA processes, the **360 HTA Patient Involvement** partners have launched a survey to better understand how patients are

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All stakeholder groups (patients, carers, industry, academics, health care providers, HTA agencies) who have experienced patient involvement in HTA in any European country **are invited to share their experiences** in a 20 to 30 minute survey.

The survey is completely anonymous, and was co-created by patient organizations and HTA experts, **and is available in six languages (English, French, German, Italian, Spanish, Polish)**. The aggregated results and insights will be shared on the project website, as well as through our social media channels and dedicated webinars, or you may register to receive the report.

Learn more about the work of the patient and citizen involvement interest group (PCIG) of HTAi, the European patients forum (EPF), and the European Patient Academy On Therapeutic Innovation (EUPATI), on the **360° HTA PATIENT INVOLVEMENT** project.

>> [Link to the survey; select your language!](#)

How do Patients Perceive their Involvement in HTA Processes?

take the survey!

HTA

HTA

HTA

HTA HEALTH TECHNOLOGY ASSESSMENT INTERNATIONAL

EPF European Patients Forum

EUPATI European Patient Academy on Therapeutic Innovation



EUPATI launches a new module on the Open Classroom!

The Open Classroom is a free-to-use online learning platform on which users will find multiple modules on Regulatory Affairs, Non-Clinical Development, Health Technology Assessment, etc. and study at their own pace.

More information about the module is available [here](#)

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The EUPATI (European Patients' Academy on Therapeutic Innovation) Patient Expert Training Programme is a training programme about the medicines' development process. It covers the entire lifecycle of medicines research and development (R&D) (see roadmap here), from design and execution of clinical trials to regulatory processes and Health Technology Assessment (HTA). In addition to detailed information on each step of the process, the training also describes how patients can be involved at each stage. The overall objective of the programme is to obtain a thorough understanding of the medicines R&D process, the patients' role within and build capacity among the patient community to take on an active role in collaboration with the other involved stakeholders

The seats are limited, so make sure you register in time!

Check out more information about the programme



The European Patients' Forum stands in solidarity with the people in Ukraine, who are facing an aggressive military invasion in violation of international law since 24 February 2022. As a European patient organisation, we are particularly concerned about **the situation of people living with chronic diseases**, who are vulnerable to disruptions in healthcare services, medical treatment and medicines caused by war. Patients with chronic diseases, especially those with multiple conditions and severe illness, are less likely to have the means to flee the conflict and access humanitarian aid.

EPF is working with its members to understand the needs and challenges to support policy decision-makers to address those needs. We are currently **collecting all the initiatives, projects, events** they have envisioned to support the patient community in Ukraine, a few of which are reported here below, and that can also be found on this [resource page on our website](#).



Alzheimer Europe has a new online resources page to help support people with dementia and carers, during the ongoing war in Ukraine.

You can access [Alzheimer Europe's resource page here](#).



EATG published a statement in solidarity with people living in Ukraine and those displaced by the war, that can be accessed [here](#).

They also created a [resource page](#) with information for donations targeted to people living with HIV and key affected populations in Ukraine.

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Furthermore, they are in close contact with partner organisations and individuals in Ukraine and they are liaising with international organisations as well as pharma industry to ensure continuity of services and access to medicines.



**WORLD
DUCHENNE
ORGANIZATION**
UppMD

The **World Duchenne Organization** set up a donation page to contribute the DMD Emergency Fund to aid families with Duchenne and Becker muscular dystrophy affected by the Ukrainian conflict. You can find it [here](#).

They are currently working on creating a documentary about people living with a neuromuscular disease that are affected by the Ukrainian war, as their community manager Nicoletta Madia travelled to the Czech Republic and other countries to interview refugees, patient organisations, and volunteers.

A trailer of a documentary titled 'Help has no borders' on the emergency in Ukraine is available [here](#).

This activity is part of the **DMD Emergency Program**. A life feed with all the updates can be found [here](#).



Member Focus

highlights from our member organisations



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

The International Federation for Spina Bifida and Hydrocephalus (IF) together with partners from international organisations, medical and academic institutes is leading a campaign for a global action on preventable birth defects. Food fortification with folic acid is urgently needed to achieve the objectives of the 2010 World Health Assembly Resolution on Birth Defects and achieve the sustainable development goals (SDGs).

On May 23 2022 the joint publication titled '**Preventing birth defects, saving lives, and promoting health equity: an urgent call to action for universal mandatory food fortification with folic acid**' was published in **The Lancet Global Health**. You can read the publication [here](#).

EUROPA UOMO

The Voice of Men with Prostate Cancer in Europe

A New Chairman for Europa Uomo

Last weekend, Europa Uomo had its annual General Assembly in Leusden, The Netherlands. 46 representatives from 23 European countries attended the meeting.

The Dutch patient organization, ProstaatKankerStichting - PKS, celebrated its 25th anniversary with a fantastic donor's day in the AFAS theater in Leusden which we used as a MasterClass session where the presentations were simultaneously translated into English for our EUomo members. Highlights were the presentations of Prof. Monique Roobol and Prof. Hein Van Poppel on 'early detection

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European
AIDS Treatment
Group

EUOMO study.

RBDCOV: the first clinical trial looking for a new COVID-19 vaccine is initiated

EATG is participating in RBDCOV, a project aiming to study a COVID-19 vaccine in children, adolescents and immunocompromised patients. Drawing from its experience in patients' advocacy and representation, EATG is contributing to the studies through community insights and outreach.

EATG Annual Report 2021 is online

Check out EATG's 2021 activities in review: achievements in numbers, reporting from our programmes, highlights, figures for finances and membership and updates on communication and governance at a glance.

[Read the full annual report >>>](#)

During the EUomo General Assembly on Saturday, June 11, 2022, the accounts 2021 as well as the budgets for 2022 & 2023 were approved. Günther Carl and Ioannis Vanezos were, after ending their first term of 3 years (4 years instead due to Covid condition), reinstated into the new Board. We said goodbye to André Deschamps and John Dowling, both ending their second term. André Deschamps will be connected to the Board as Past-President advising them for at least one year. We also welcomed two new Board members, namely Steven Lerys (France) and Paulius Rakstys (Lithuania). Most important is that Günther Carl (Germany) was elected as the new chairman of Europa Uomo. He thanked André for his job done in the Board in the last 7 years and that he is exited to work on the heritage of André.

A copy of the EUomo Annual Report 2021-2022 is available on our EUomo website: www.europa-uomo.org

Introducing COVIRNA

COVIRNA is a patient-centred Innovation Action aiming to generate a diagnostic tool to identify COVID-19 patients at risk of developing fatal cardiovascular complications.

Although lungs are the main organs involved in COVID-19, one of the major systems affected by the virus is the cardiovascular system. It is estimated that 20% of patients infected with COVID-19 do not die from pulmonary but cardiac problems. *This is precisely the issue that the COVIRNA project is trying to address.* The project will generate a diagnostic tool to identify COVID-19 patients at risk of developing fatal cardiovascular complications. The novel diagnostic tool will help healthcare providers improve individualised surveillance, care and follow-up of COVID-19 patients.

To get updates from the project team, you can subscribe [here](#).

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EUROPEAN AI FUND

The European AI Fund is running a new Open Call for 2022!

The European AI Fund is now inviting applications for core funding of between €50,000 and €250,000 over two years that will support organisations to build policy and advocacy capacity. The deadline for applications is 25 July 2022.

[Here's more information on how to apply](#)



Inside the Bubble

updates, stories and events around EU healthcare

A European Health Union

On 23 June, a deal on the serious cross-border threats to health regulation was announced. This was the final piece of the Health Union package, which also saw an

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abilities to prepare and respond to serious health threats (like the pandemic), and would enable the European Commission to declare EU-level health emergencies. Crucially, it also has provisions for joint medicines and vaccines procurement, as well as transparency stipulations so that MEPs can access procurement contracts.

European Commission announces Non-Communicable Disease Initiative

On 22 June, the European Commission has announced its Non-Communicable Diseases (NCD) Initiative, which aims to tackle NCDs in a systemic and comprehensive way through prevention, detection and treatment. The initiative pledges €156 million of funding managed through the EU4Health programmes, to improve citizens' health and wellbeing, and address the leading causes of preventable premature death in Europe. The NCD Initiative will identify effective actions in legal and financial tools, centred around five thematic (condition) areas and their contributing factors which are: cardiovascular diseases, diabetes, chronic respiratory diseases, mental health and neurological disorders. The initiative was welcome by a number of disease and patient advocacy groups.

Commission Also Announces a Push for Banning Heated Tobacco

The European Commission has also published a report in response to its consultation for the evaluation of the Legislative Framework for Tobacco Control, which received over 24,000 responses. In response, the Commission has announced it aims to ban the sale of flavoured tobacco products, push for stronger action to reduce tobacco consumption, including stricter enforcement and regulation of new products, in particular those marketed to younger people.

Latvia Push for Patients Rights

On 29 June, the Latvian health ministry discussed potential changes to law that would see patient rights strengthened and protected. The meeting was convened following the results of a working group. The proposals call for a plan for how patients' rights will be implemented, and clarifications on the rights and obligations of patients and medical staff to strengthen the status of patients in medical treatment, and define administrative responsibilities.

"Nothing is built on stone; all is built on sand, but we must build as if the sand were stone."

Jorge Luis Borges



Calendar of Events

1 July - 31 July

Sarcoma Awareness Month

[visit our website](#)

14 July - 17 July

The Summer Training Course for Young Patient Advocates (STYPA)

[contact us](#)

28 July

World Hepatitis Day

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