THE EPF European Patients Forum PATIENT PERSPECTIVE JUNE 2023

EDITORIAL

Dear reader,

A warm welcome to the June edition of The Patient Perspective. We look back on yet another busy month that was marked by the ongoing developments after the publication of the pharmaceutical legislation's revision, numerous important meetings and events, and a whole lot of interesting updates from our projects.

Some highlights? EPF was represented at the Health Technology Assessment international (HTAi) annual meeting in Adelaide, Australia. Valentina Strammiello and Julie Spony travelled across the globe for a number of interesting and important sessions. Another one for the books this June: PEOF! The Patient Engagement Open Forum took place in Northern Italy earlier this month and EPF joined various chats and panel discussions to discuss and co-create the way forward for valuable and meaningful patient engagement.

In policy news, this month, we put out a position statement in which we share three action points that require stronger action in light of the EU4Health work programme. You'll find more info and a link to the position statement below. And more or less right below *that,* you will read that the EPF Youth Group is recruiting two new members this and next month. If you know or are someone who'd be perfect for the role, reach out!

It has been a busy month for projects like Data Saves Lives and EATRIS Plus. At the same time, EPF is happy to announce the launch of a new project: IDERHA.

In our Member news section, you'll find plenty of updates from the European Institute of Women's Health, Europa Donna, Mental Health Europe, the European AIDS Treatment Group, Alzheimer Europe, European Multiple Sclerosis Platform, and EUPATI.

While we look back on June, we are also gearing up for next month in which we get ready for the face-to-face meeting of STYPA, our Skills Training for Young Patient Advocates. We are excited to have onsite chats, sessions, and presentations and to get into the ins and outs of the important topic of shortages with the participants. More soon!

What else is coming up in July? Stay tuned via our social media channels to keep up to speed.

Happy reading and until next month,

The EPF team

SECRETARIAT NEWS

June 24-28, 2023, Adelaide, Australia: Health Techonology Assesment international (HTAi) Annual Meeting

EPF’s Julie SPONY and Valentina Strammiello traveled to Australia for Health Technology Assessment international (HTAi)’s Annual Meeting - **#HTAi2023Adelaide**.

They joined various seesions, as Valentina moderated a workshop on patient involvement in HTA, harmonisation of approaches, and capacity building. Both Valentina and Julie were involved in a lot of debates and meaningful conversations, The in-person event brought together global HTA stakeholders to discuss and debate the role of HTA in leading health innovation. Discussions surrounded the meeting theme, on The Road to Policy and Clinical Integration.

Position statement: EU4HEALTH Priorities

The EU4Health programme is a unique opportunity to make a significant contribution to stronger, patient centred health systems that deliver for all, in all circumstances.

EPF calls for a patient-centered 2024 work programme. We have identified three areas where we would like to see stronger action:

➡️ A sustainable, accessible, and transparent funding scheme for patients and civil society organisations is essential to ensure that patient organisations can play their role in the health programme and other European legislation

➡️ Capacity-building programmes for patient participation in EU and national health policies: patients must have the necessary awareness of policy processes, training, and resources to participate in expert groups and advisory bodies.

➡️ Substantial investment in health literacy and patient information. Health literacy fosters access to health and puts citizens and patients at the centre of health and healthcare.

Read our entire position statement **here**.

meeting in Baveno, Italy

Earlier this month a part of the EPF team attended the 2023 face-to-face Patient Engagement Open Forum, that took place in Baveno, Italy.

Anca Toma, Valentina Strammiello, Milana Trucl, Gözde Susuzlu Briggs, Anne Rensma, and Ingrid Weindorfer represented EPF, led sessions on digital health literacy, education, HTA, and attended stakeholder specific discussions.

This year's on-site meeting summarised three full days of sessions, conversations, and presentations on patient engagement.

"A Strong Patients' Voice – The European Patients' Forum": An Interview with Anca Toma

Anca Toma joined **Susanne Meister** for a heartfelt conversation about EPF's 20th Anniversary Event and two decades of patient advocacy: "*The revolution that started with, not just with EPF, but with our founding members, was that patients became interlocutors, they became core participants in their own care*".

Listen to the **full episode of The Waiting Room**.

The countdown for STYPA 2023 has started!

The online kick-off meeting of the Skills Training for Young Patient Advocates (STYPA) 2023 took place on the 29th of June. During this first preliminary webinar STYPA participants had the chance to meet each other, to discuss with the trainers and get to know the EPF team.

STYPA is an exciting and unique opportunity offering a tailored high-quality course for young patients or representatives of young patients, providing the space to dive deeper into the important topic of shortages. Some of the focus topics include:
- Why do shortages happen in the first place?
- How can patients be a part of the access and shortages scene?
- What are the regulatory aspects that patients must be aware of?

This year's edition will take place in Riga, Latvia, between 13-16 July.

We will be back next month with fresh updates from the in-person training!

WHY YOU SHOULD JOIN THE EPF YOUTH GROUP AND NOT TO MISS A GREAT LEARNING OPPORTUNITY THROUGH YOUR PATIENT VOICE?

By: Blaž Urbanč

Some people say everything in daily life depends on political decisions. Such thinking prevails when general disappointment of people arises. However, advocacy activities and the European Patients Forum (EPF) Youth Group (YG) work complementary to them. Therefore as a group, we are aware of the strength to be united with different patients having their unique experiences and unifying different perspectives on what the future should look like for all. Ultimately, only by being united and by presenting diverse policy concepts, will our voices be heard. We are sure that our work and incentives can be perceived through many various projects that will be designed in the future. To be stronger and progressive with you, welcome to join us! Be the difference that you want to se!

Our members have shared with us the following of reasons and incentives for

To be involved in EPF YG is a privilege because it provides many educating and training activities so that you can disseminate new knowledge further. (Blaž Urbanč)

"Being part of YG has challenged me to think beyond my limits - my own reasoning, my disease area, my culture, my beliefs. It has enabled me to find my voice and work on matters that are of interest for me - young patients' rights. And it's also fun, I promise." (Cornelia Păuna)

"Being a part of the EPF Youth Group has empowered and driven me to not only continue to advocate for my own disease and knowledge areas, but for all young patients, whilst furthering my confidence in doing so. By communicating and collaborating with young patients from different disease areas and a range of stakeholders within different fields of

Have you ever wanted to express your attitudes related to patients' advocacy in an inclusive and open-minded environment? Would you like your voice to be heard and have an opportunity to attend diverse educational training? Would you like to meet young patients across Europe? If you answered "YES" to all rhetorical questions above, then we would like to encourage you to apply for a new member of our incredible and unique patient's advocacy family with awesome vibes. As an EPF YG member I really appreciate the opportunities that such membership offers, where you will never be overlooked by expressing your own opinions, concerns, needs and wishes.

advocacy and develop and learn about topics that I would not have otherwise. This is a place where I began as a solo young patient, to being a part of family and community of young empowered patients wanting and actively striving to make a difference." (Anastasia Semaan)

We have recently opened a recruitment call for new Youth Group members and we are looking forward to meeting and collaborating with them in the future. If you know someone who is a young patient or patient advocate and is affiliated with an EPF organisation spread the word.

PROJECTS PORTAL

Busy month for the EATRIS Plus project

- EATRIS Plus announces the launch of the **Annual Report 2022**
- The recently launch **Patient Engagement Resources Centre** (PERC) was presented at PEOF 2023
- The **Innovation Management Toolbox** (IMT) has been updated: see an interview with Anne-Charlotte Fauvel (EATRIS Head of EU Affairs) on meaningful patient involvement

Data Saves Lives presents the "Engaging with digital health tools" toolkit

As individuals, there are many ways in which personal health data can be collected, even when we are not being actively monitored in a medical setting. In the past, our health data was largely confined to medical records stored personally or in a family doctor's practice or hospital. Nowadays, digital healthcare devices have become an integral part of our daily lives. A significant number of individuals wear smartwatches or fitness trackers, which serve various purposes.

Individuals with specific medical conditions may use sensors to oversee vital signs like blood sugar or heart rate. Frequently, we use all sort of digital healthcare tools without considering the importance of safeguarding our data.

The Data Saves Lives toolkit highlights some of the issues associated with the use of digital health tools, providing advice on how to protect sensitive health data. **The toolkit is available here**.

IDERHA
integrating health data

IDERHA, a new project EPF is involved in, has officially started in June

This newly formed **Innovative Health Initiative (IHI)**-funded consortium aims to address the obstacles in accessing, integrating and analysing health data to maximize their value for patient care and research.

Focusing on lung cancer as a use case, IDERHA's pilot program will focus on key priorities of the Europe Beating Cancer plan, which include the improvement of early cancer detection and the quality of life of individuals with cancer. It will link and analyse diverse data stemming along the continuum of a lung cancer patient's journey: from early screening of citizens at risk to develop lung cancer to remote monitoring of late-stage patients to enable better care in an at home setting. Ultimately, the platform and policy recommendations will be disease independent.

If you're interested in the work of IDERHA, keep us close: more updates will follow soon!

MEMBER FOCUS

It has been over 60 years since the Treaty of Rome, where gender equality was enshrined into EU law and yet no country has succeeded in reaching gender equality; this is also reflected in healthcare. The **European Institute of Women's Health** (EIWH) calls on the EU to commit to the reduction of health inequalities and provide equitable health for all women, through the provision of an EU Strategy for Women's Health.

Some Facts and Figures on Women's Health:

- By 2050, the GDP in the EU will increase by 6-10% or €2-3 trillion if gender equality is improved.
- Women earn 13% less and receive pensions that are 29% lower than men.
- Women are the main the caregivers and perform the majority of household chores. In the EU 80% of care is provided informally (unpaid) and 75% of informal carers are women.
- Women are under-represented in medical research. Women have more than a 50% greater risk of developing adverse drug reactions compared to men.
- 500,000 women in Europe do not have access to care during the first months of pregnancy.
- 1 in 3 women in Europe have experienced physical or sexual violence in their lifetime and 8% have experienced violence in the last 12 months.
- Women are disproportionately affected by mental health conditions such as anxiety and depression.

An EU Strategy for Women's Health would ensure that women's health remains a policy and research priority. This strategy would address the societal challenges that lead to health disparities; improve data collection and analysis; harmonise current legislation; and ensure that women's voices and needs are embedded in all EU policies. With effective monitoring and evaluation measures, real progress can be made on gender equality in health.

You can read the full manifesto here. If you are a patient organisation wishing to support the manifesto please contact Aoibhinn **aoibhinn@eurohealth.ie**.

EUROPA DONNA announces the launch of The Cancer Currency Campaign

Metastatic breast cancer (MBC) is an incurable disease. Currently, those living with MMBC have been left to feel ignored and worthless. This campaign highlights the immense value people living with MBC still have to offer, however long they have left.

Mental Health Europe's response to the comprehensive approach to mental health

On 7 June 2023, the European Commission **unveiled its plan for a comprehensive approach to mental health** in Europe. Mental Health Europe (MHE) closely followed the development of the initiative, through **meetings with Commissioners and their cabinets**, a **response to the public consultation** and **coordination with partners** and **stakeholders**.

MHE's main recommendation has been, for a long time, to develop a European Mental Health Strategy, with a clear timeline, adequate budget, objectives, as well as indicators to monitor progress. This message has been echoed by **civil society**, the **Council of the European Union** and the **European Parliament**. Considering the limited time that the European Commission had to develop this initiative, expecting the publication of a comprehensive European Strategy would have fallen short of reality and risked producing an unambitious result. Still, all those who have been hoping for a mental health strategy may have been disappointed by the absence of any mention or any indication of plans to develop one in the Commission's communication.

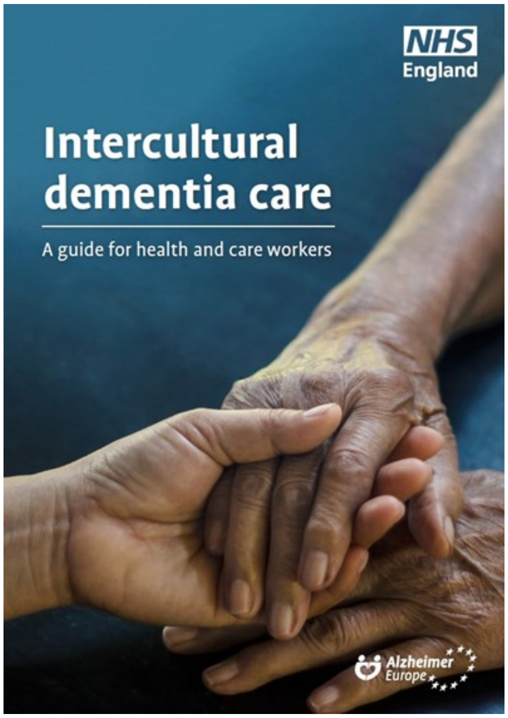
Read more **here**.

EA TG European AIDS Treatment Group

News and updates from EATG

can now donate once or subscribe to a monthly donation fast and easily. The donation pages are available via the EATG website

- EATG **Annual Report 2022** is launched
- EATG **joins POLITICO Live podcast** 'Severing the chain: How to end HIV transmission in Europe"
- EATG **presents initiative on 'Why People Living With HIV Must Be Included In Non-HIV Clinical Trials'** at ICAR 2023 conference
- SCOPE community e-meetings on HIV and STIs biomedical prevention pipeline and PrEP implementation are now streaming:
- In May and June, the European AIDS Treatment Group, along with European and local organisations came together to jointly organise community e-meetings on HIV and **STIs prevention pipeline** and **PrEP**
- STEP-UP 2022/2023 Training and Networking Weekend – the **Community of Practice Workshop**


NHS England
Intercultural dementia care
A guide for health and care workers
Alzheimer Europe

Alzheimer Europe: Intercultural Dementia Care

The number of people living with dementia from an ethnic minority background is expected to double by 2026 in England. Currently, people from ethnic minority communities often face delays in dementia diagnosis, barriers to services and there is insufficient culturally competent dementia care available. Working in partnership with Alzheimer Europe and the Royal College of Psychiatry, NHS England (NHSE) has


Alzheimer Europe
Muistiliitto
Register now!
33rd Alzheimer Europe Conference
New opportunities in dementia care, policy and research
Helsinki, Finland
16 - 18 October 2023
#33AEC

33rd Alzheimer Europe Conference agenda available online and new bursaries also available for early stage researchers

Alzheimer Europe and Muistiliitto (Alzheimer Society of Finland) would like to thank everyone who submitted abstracts for the 33rd Alzheimer Europe Conference (#33AEC), taking place from 16 to 18 October 2023, in Helsinki, Finland. A record number of 539 abstracts was received this year, which have all now been reviewed by our Scientific Committee and notifications have been sent to all applicants. The detailed programme for the conference is available to view on **their website**.

Exciting news, also, for early stage researchers wishing to attend this event, improve care for people living with dementia from an ethnic minority background.

NHSE hopes these new resources will help raise awareness of the challenges people from ethnic minority communities face when accessing dementia care and help narrow the health inequalities gap.

Check out the guide here.

to award ten bursaries of EUR 1,000 for early stage researchers wishing to attend and present at the Alzheimer Europe Conference. Please apply for these bursaries by sending in your abstract and a short bio by 30 June 2023 *via* the **abstract submission portal** under the topic "Dementia researchers of the future – Innovative approaches to dementia".

Impact of Multiple Sclerosis Symptoms (IMSS) Survey is LIVE

The **European Multiple Sclerosis Platform** (EMSP) is leading, alongside 25 MS Societies across Europe, on a pan-European survey to understand in depth the symptoms of Multiple Sclerosis and their impact on the quality of life, called **IMSS,** English abbreviation for **Impact of Multiple Sclerosis Symptoms**. The survey will be running until end of July 2023.

Why are they asking about MS symptoms? MS symptoms, their management, and how they are affecting people with MS are not well-documented. This information is needed to help us understand MS symptoms and their impact to prioritize symptom management and the need for proper, personalized, accessible, and timely care for MS symptoms.

Who can participate? People living with MS in the following countries can participate: Belgium, Croatia, Czech Republic, Denmark, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Netherlands, Norway, Poland, Portugal,

The IMSS survey is available here.

PATIENT EXPERT

Training Programme

Registration opens soon!

EUPATI
Open Classroom

EUPATI: Registrations for the 2023 - 2024 Patient Expert Training Programme are now open

EUPATI is delighted to open registrations for the next cohort of future EUPATI Fellows. the training is about the medicines development process and tailored for patients and patient representatives (e.g. caregivers and people working in patient organisations).

Programme is composed of

- 6 online modules
- 2 training events (4 days each, 1 online and 1 F2F event)
- All modules and events are compulsory
- Completing the programme usually takes 12 - 14 months
- Proficiency in English is required as training is provided in English

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.

Access information on the entire EUPATI Patient Expert Training Programme **here.**

contact us visit our website

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Our mailing address is:
European Patients' Forum
Chaussée d'Etterbeek, 180
Brussels 1040
Belgium

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