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THE EPF European Patients Forum PATIENT PERSPECTIVE

JULY 2023

EDITORIAL

Dear reader,

Welcome to the July Patient Perspective! In this edition, we are excited to share a plethora of engaging content, from exciting updates on our policy work, recent projects and initiatives to inspiring stories from our community members, we hope to fill your heart with inspiration and enthusiasm.

The revision of the pharmaceutical legislation represents a once in a generation opportunity to shape the future of European healthcare. EPF sees this as the perfect opportunity to pave the way for a more patient-centric regulatory framework. To reach this goal, some steps have yet to be taken - our position paper reflects EPF's recommendations for the revision of the pharmaceutical legislation.

We invite you to a brief overview of STYPA 2023 and some reflections shared by the EPF Youth Group regarding the event. In this edition, we also invite you to tune in to our newest podcast episode, featuring our member AOECS.

Claudia Louati, our Head of Policy, reports back from the EMA's Patients' and Consumers Working Party.

We would also like to share with you the results of one of EPF's latest studies which assesses AI awareness among patient organisations.

Two of our running projects - Label2Enable and Prophet - are running surveys, so please submit your contribution, while EATRIS-Plus welcomes summer with a fresh issue of its quarterly newsletter.

Our members have been keeping busy throughout this summer season, so make sure to scroll down and read updates from Europa Donna, EATG, and EFNA. Make sure not to miss EUPATI's announcement of open registration for the Patient Expert Training Programme.

Until next month, make sure to follow us on social media!

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The EPF team

SECRETARIAT NEWS

The European Patients' Forum Calls for A Patient-Centred Revision of the EU Pharmaceutical Legislation

The revision of the pharmaceutical legislation proposed by the European Commission is a once-in-a-lifetime opportunity to shape the future of healthcare in Europe. At EPF, we see this as a perfect chance to achieve fair and equitable access to medicines and to pave the way for a more patient-centric regulatory framework in the EU.

To ensure the effective enforcement of this new proposal, some steps have yet to be taken.

Head to our website to learn more about **EPF recommendations**.

STYPA 2023: A Brief Recap

This year's face-to-face module of the **Skills Training Course for Young Patient Advocates** (STYPA) took place in Riga, Latvia, from 13 to 16 July.

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 medicine shortages.
Some of the debated topics included:
- 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?

There's even more to come from STYPA, as follow-up webinars are foreseen for the participants throughout the rest of the year.

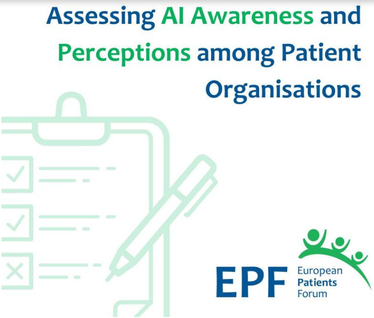
The EU Patients' Podcast Welcomes Katre Trofimov

Listen to this brand-new episode of The EU Patients' Podcast, in which we talk to Katre Trofimov from EPF member **AOECS**.

We discuss underdiagnosis, the issues that arise from inflation and higher food prices, marking Coeliac Disease Awareness Day, and much more.

Tune in!

And Perceptions Among Patient Organisations



EPF began **engaging in Artificial Intelligence (AI) in healthcare** in 2020, from both a policy and a capacity building perspective. Given the rapid increase of interest in AI in healthcare and in view of upcoming policy activities, EPF has decided to reinforce its engagement on this matter to ensure that the patients' views, needs and values are adequately represented in future discussions and EU-level debates.

We did this with a survey on AI awareness and perceptions.

Read the results of the survey **here**.

EVENT REPORT

EPF participates in the EMA's Patients' and Consumers Working Party (PCWP)

On June 27-28, Claudia Louati, EPF Head of Policy, participated in the EMA's **Patients' and Consumers Working Party (PCWP)** and **joint PCWP and Healthcare Professionals (HCPWP) Working Parties**.

EMA provided updates on a number of initiatives. On **mis/disinformation**, EMA is using the experience of the COVID-19 pandemic to develop a framework based on three pillars: monitoring, actions (e.g. increased communication and transparency, health media literacy, etc.), and outreach (e.g. joint campaigning). Further discussions will follow with interested organisations on experiences, strategies, and best practices to tackle mis/disinformation.

EMA also presented the results of its 2022 communications' **perception survey**. While most respondents were positive about EMA's communication activities, areas for further improvement include enhancing the user-friendliness of EMA's website and translating content. EMA welcomes continuous feedback on how to increase its reach and engagement across EU countries.

Participants were impressed with the progress made with the implementation of **DARWIN EU®.** This initiative aims to deliver real-world evidence from across Europe on diseases, populations, and the uses and performance of medicines. In this context, patient and HCP engagement is instrumental. Stay on the lookout for EMA workshops and opportunities to collaborate in developing patient communication strategies and materials on registries.

Related to this, next steps on how to promote inclusion of **patient experience data (PED)** in all aspects of medicines development and regulation were discussed. A key EMA deliverable is a reflection paper on the best approach to generating and collecting PED, with a planned public consultation by Q1 2024. EMA is also contributing to an ICH guidance on PED. Collaboration of multi-disciplinary experts is needed to make meaningful progress in this area.

Finally shortages remain a top priority. EMA is tweaking its **pilot** on reporting of shortages by eligible patients and HCP organisations. Finding the right level of reporting – at national vs EU level – can be challenging. EMA calls on patient and HCP organisations to continue

Other presentations related to the **EU Recommendations on Decentralised Elements in Clinical Trials**, the **EMA 2019-2022 report on pharmacovigilance tasks**, EMA **activities linked to N-nitrosamines**, the outcomes of the **kick-off meeting of the ACT-EU stakeholder platform**, and the **satisfaction survey** on the EMA's Human Medicines' Highlights Newsletter.

The next meetings of the PCWP and PCWP/HCPWP will take place on September 19-20.

YOUTH GROUP UPDATES

2023 STYPA EXPERIENCE IN A BALTIAN COUNTRY AS A NEW BEGINNING OF ADVOCACY ADVENTURE

By Cornelia Păuna, Konstantina Boumaki, Leonie Wollscheid, and Blaž Urbanč

As a part of the European Patients' Forum Youth Group (YG), we are aware of the significance of educating ourselves in the field of patient advocacy. By taking part in training sessions, seminars and open discussions, we tend to feel better equipped with diverse knowledge and skills. It is always a privilege to be a part of training opportunities such as the Skills Training Course for Young Patient Advocates (STYPA), which is dedicated to

It has been highlighted on several occasions how important is the involvement of the local government, patients and patients' organisation at the national level. We also found out how complex shortages can be, that they are divided in temporary stock-up shortages and shortages of molecules. This created a big need, so we now have a new regulation in place - (EU) 2022/1232, which provides the EMA with a framework members and patient advocates participated within STYPA this year, and they were all inspired by experience. Cornelia, Konstantina and Leonie together have shared with us below some important event highlights from the face to face part of the STYPA training.

This year's STYPA was focused on shortages and took place in Riga, Latvia. During the program we talked about what shortages are, how they can be categorised and what certain institutions and organisations are doing to prevent them.

We witnessed a very inspiring presentation from a passionate Latvian patient advocate (in her own words) where we saw that a patient's voice and determination can make a difference. At the same time we also received several pieces of advice from her experience; among them: shortages are not a one day solution, and nothing happens in isolation.

We had experts from *Medicines for Europe*, *European Medicines Agency*, *European Federation of Pharmaceutical Industries* and *Associations and Standing Committee of European Doctors* which helped us navigate through the lifecycle of a medicine.

With all the information we've received we already started working on our future advocacy projects which we'll better define and work on in the next few months. Besides this, it's always a great thing to meet new people, let alone meeting new people who are advocating and making a difference in their countries. We are so inspired by everyone we met during STYPA, by their ideas, their experiences and their work in advocacy!

As Leo Buscaglia once said "Change is the end result of all true learning", we all know that training and furthering one's knowledge is a prerequisite to changing the current world. On behalf of the EPF YG members, we have our own vision of a world we want to live in, so that we will take advantage of every single opportunity to get new skills in the future as well.

PROJECTS PORTAL

Translational Trends. Quarterly Updates From EATRIS-Plus

Curious to read about the latest updates, news and activities in translational medicine from the EATRIS community and beyond? **EATRIS-Plus** has issued its newest quarterly newsletter.

You can **read it here** and don't forget to **subscribe**!

PROPHET

a PeRsOnalized Prevention roadmap
for the future HEalThcare

New Survey: Barriers, Challenges, and Enablers for the Adoption of Personalised Prevention Strategies

Personalised prevention is possible only if citizens, policymakers and health professionals are aware of the impact they can have and are provided with the resources to act on this knowledge.

PROPHET.EU, in collaboration with its partners InstitutoNacional de Saúde Doutor Ricardo Jorge, Università Cattolica del Sacro Cuore, and Karolinska Institutet, has launched a survey aimed at mapping the barriers, challenges, and enablers for the adoption of personalised preventive approaches in health systems in Europe

To take the survey, **follow this link**. Don’t miss the chance to contribute!

LABEL2
ENABLE

Label2Enable: Survey on Value Propositions for Health App Assessments

Are you a health app developer, healthcare provider or represent a health authority, health technology assessment body, or health insurer?

Label2Enable developed a survey to support the selection of a suitable business model for the CEN-ISO 82304-2 health app certification and the draft of the European Health Data Space (EHDS) Regulation, which includes labeling of apps.

Follow this link to take the survey.

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**.

MEMBER FOCUS

Making Neurology A Public Health Priority - BHNC MEP Interest Group

The **European Federation of Neurological Associations** (EFNA) is proud to present their meeting of the Brain Health and Neurological Conditions MEP Interest Group with the European Association of Neurologists (EAN) to highlight that despite the knowledge that almost one in three people globally will develop a neurological disorder at some point in their lifetime – Neurology is still not treated as a public health priority.

Neurological disorders are the leading global cause of disability-adjusted life years (DALYs) and the second leading cause of death yet the impact of neurological conditions are often overlooked due to their complexity. There is no clear public health prioritization for neurological conditions.

Watch the full replay & read the event report.

EUROPA DONNA: MBC Advocacy Webinar 2023

The 6th Europa Donna's **MetastaticBreastCancer** webinar was held on June 16th and featured advocates, patients and specialists, among the 57 attendants from 27 countries, invited to share in on updates in the #MBC (Metastatic Breast Cancer) field, supplying them with advocacy strategies & solidarity to continue the speaking up.

Among the experts in attendance were: Dr. Fatima Cardoso, Dr. Alexander Eniu, Dr. Javier Cortes, Dr. Maria Die Trill and Barbara Wilson from Working with Cancer UK. The Morning session was dedicated to the latest developments and research into MBC while also providing keys to emotionally cope with diagnoses, both for patients and caregivers. In the afternoon it dove deeper into navigating the workplace with MBC and provided communication and advocacy tips & tricks to demand changes at a national level.

The webinar also helped launch **The Cancer Currency campaign** which features 5 Europa Donna advocates living with metastatic breast cancer, sharing their stories and struggles all with the joint message: we are still here, alive and we have a voice & value to give.

PATIENT EXPERT

Training Programme

Registration opens soon!

EUPATI
Open Classroom

EUPATI 2023 – 2024 Patient Expert Training Programme now open for registrations

Registrations for the 2023 - 2024 Patient Expert Training Programme are now open **here.**

We are 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.**

Downloadthe new porgramme brochure **here.**

EA
TG
European
AIDS Treatment
Group

of Practice Workshop in Porto

EATG joined POLITICO Live podcast recording. **Here are their takeaway messages** from POLITICO Live's podcast taping "Severing the chain: How to end HIV transmission in Europe"

BLOGS:
SCOPE: **Study Trip from Apoyo Positivo (Spain) to PrEPster (UK)** – by Juan Francisco Cabrera Solano

SCOPE: **Study Trip from Association Xenon (Georgia) to Gaïa** - Paris Association (France) – by Tedo Bigvava

PUBLICATION:
Discussion Paper: Community-based HIV & Mental Health Care –The role of community-based services within the continuum of HIV and mental health care

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