THE EPF European Patients Forum
PATIENT PERSPECTIVE
JULY 2024

EDITORIAL

Strengthening the European Health Union: A Call to Action

This month, the European health ecosystem has been dominated by several key topics, reflecting Europe's concerted efforts to address both immediate and long-term health challenges.

With Ursula von der Leyen commencing her second mandate as President of the European Commission and newly elected MEPs settling into their roles, the European Patients' Forum (EPF) reflects on the future of the European Health Union. On 11th July 2024, the EU4Health Civil Society Alliance, which includes EPF, published a letter to President von der Leyen, calling for the appointment of a Vice-President for Health, Wellbeing, and Social Rights.

We urge the new Commission to prioritise investment in this vision for health, ensuring appropriate funding in the next multi-annual financial framework (2028-2034) to further strengthen the European Health Union. Health policy impacts everyone, from facilitating equitable access to healthcare across countries to addressing cross-border health threats. The EU plays a crucial role in these efforts.

Patients are at the forefront in the fight against antimicrobial resistance (AMR). They spend time in healthcare settings where resistant bacteria spread, undergo procedures requiring antibiotics, and are more susceptible to infections. This highlights the importance of patient engagement in combating AMR. On 20th June, the first of three webinars, jointly organised by the EPF and The AMR Narrative, provided a platform for dialogue among patient groups to encourage advocacy efforts on AMR. Details on registering for the upcoming webinar (29th August), "How do we use our voices to reach a wider community for AMR?" are provided below.

AMR was also the focus of this year's Skills Training for Young Patient Advocates (STYPA). During the training on 4th-7th July, young participants engaged in critical discussions on AMR, sharing their insights and experiences.

draft Implementing Act on HTA cooperation with the European Medicines Agency (EMA). We strongly support close interaction between regulators and HTA bodies to enable faster patient access to medicines. Although the EMA's assessment is distinct from the HTA process carried out at the EU level, the two are closely interlinked and affect the entire medicine lifecycle, including determining whether a medicine provides significant benefits.

EPF stands ready to support policymakers in implementing a European Health Union based on patient-centred healthcare systems. Our focus remains on addressing unmet patient needs, enhancing health literacy, improving patient access, and recognising the indispensable role played by patient organisations.

SECRETARIAT NEWS

CALL FOR PATIENTS WHO HAVE EXPERIENCED ANTIMICROBIAL RESISTANCE (AMR)

As part of the European Antibiotic Awareness Day on 18th November, EPF is collaborating with the European Centre for Disease Prevention and Control (ECDC) and Health First Europe (HFE) to launch a new series of patient stories highlighting the critical issue of Antimicrobial Resistance (AMR).

If you are a patient or know of any patients who have experienced AMR, and would like to submit a patient story, find more details here.

REGISTER TO THE WEBINAR: "HOW DO WE USE OUR VOICES TO REACH A WIDER COMMUNITY FOR AMR?"

On 29th August (3pm CEST), join the webinar: "How do we use our voices to reach a wider community for AMR?". **Register here.**

In collaboration with The AMR Narrative, EPF is organising a webinar series to create an exchange space for diverse groups of patients, carers, survivors and civil society organisations impacted by Antimicrobial Resistance (AMR) who want to advance advocacy efforts.

Participate in the discussion on:

- How can we define patient advocacy for AMR?
- What could work well in terms of reaching a wider community for AMR?
- How to communicate such a complex topic like AMR in an engaging way?

FEEDBACK ON THE IMPLEMENTING ACT ON HTA COOPERATION WITH THE EUROPEAN MEDICINES AGENCY

On 23rd July, EPF submitted a response to the European Commission's public consultation on the Implementing Act on Health Technology Assessment (HTA) cooperation with the European Medicines Agency (EMA). **Read our feedback here.**

THE EU4HEALTH CIVIL SOCIETY ALLIANCE CALLS FOR THE APPOINTMENT OF A VICE-PRESIDENT FOR HEALTH, WELLBEING AND SOCIAL RIGHTS

On 11th July, the EU4Health Civil Society Alliance, which EPF is a member of, published a letter to the European Commission President Ursula von der Leyen calling for the appointment of a Vice-President for Health, Wellbeing and Social Rights. **Read the letter here.**

europeanpatients'forum
Youth Group

A REFECTION ON THE SKILLS TRAINING FOR YOUNG PATIENT ADVOCATES 2024

BY ANNA REVILLA BRUÑOL

From the 4th to 7th of July, a group of around 30 young patient advocates from across Europe travelled to Brussels to participate in *The Skills Training for Young Patient Advocates* (STYPA) 2024. This year's topic was on antimicrobial resistance (AMR).

We learnt that AMR occurs when bacteria, viruses, fungi and parasites no longer respond to antimicrobial medicines.

During STYPA, we had the opportunity to hear inspiring stories from AMR patients like Vanessa Carter, a story that motivated us all to continue our advocacy journey and fight against AMR.

We also took part in the Agora. These were sessions where experts from different backgrounds (pharma, politics and organizations) were present and after a short presentation we had the opportunity to ask them questions.

At the same time as we were learning and gathering all the information, either from EPF or the experts, we were working on projects, thinking about the meaning of AMR and working in groups to try to understand why we are becoming more vulnerable to infections

Finally, we worked on our own advocacy plans to combat AMR, so that we can share the lessons we have learned from STYPA with our local communities.

As I reflect on my time at STYPA, it was a fantastic opportunity, but in the end the best thing was that we had the chance to meet all these fantastic people from different backgrounds; where we had the chance to talk to each other, share experiences and knowledge, have fun together, and even try the typical Belgian fries and waffles as we were in Belgium.

As we approach the inspiring finale of our remarkable ongoing project on the importance of involving youth in patient organisations, you are invited to follow us on our exciting social media platforms including **Facebook**, **X**, **Instagram** and **LinkedIn** to find out more about our activities and for more interesting content from our YG. And if you have any questions, don’t hesitate to reach out via email at youthgroup@eu-patient.eu. Let’s continue make this journey unforgettable together!

PROJECTS PORTAL

EUCAPA aims to give patient representatives the knowledge to participate in the Health Technology Assessment (HTA) meaningfully.

Enroll in the EUCAPA Extended Training, an in-depth training program designed to deepen your knowledge of the principles and methods of HTA, health decision sciences, and patient involvement. Learn how you can help ensure patients have access to crucial technology evaluations for their care!

👉 **Sign up here**. Registrations will close soon.

LABEL2
ENABLE

Label2Enable will release a series of educational videos

Soon coming to an end, the EU project **Label2Enable** will publish a series of educational videos on **CEN-ISO/TS 82304-2**, the EU quality label for health apps.

Label2Enable is a project launched by the European Commission to promote the adoption of **CEN-ISO/TS 82304-2**, a technical specification that provides a framework for the quality and reliability of health and wellness apps. A common European standard to evaluate health apps and ensure patient safety is crucial to improving the quality, effectiveness, interoperability and productivity of healthcare across Europe.

Label2Enable aims to raise public awareness and encourage the widespread adoption of this quality label, ultimately contributing to a more robust and efficient healthcare system.

In the upcoming editions of this newsletter, we will provide more information on the informative videos.

👉 Stay tuned and visit **their website** to learn more!

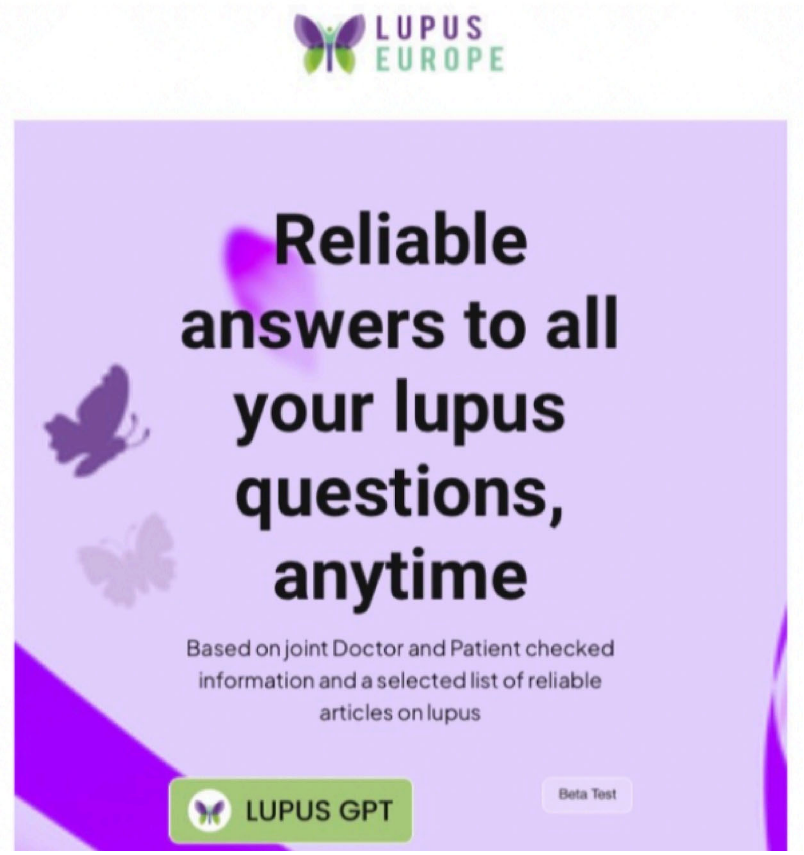
Estonia

EUCAPA continues the series on "HTA in Europe" with Meelis Joost, Chairman of the **Estonian Chamber of People with Disabilities**.

Given his experience as a patient advocate in the Estonian healthcare system, he reported back on the Information Day organised by the **European Commission** in Riga, Latvia. He also shared his knowledge of how HTA is carried out in Estonia.

✏️ Read the full interview **here**.

MEMBER FOCUS



Try out LUPUS GPT

Lupus GPT is a new online AI tool developed by LUPUS EUROPE. The tool operates by accessing a restricted, carefully vetted library of documents on lupus, ensuring that all responses are sourced from trustworthy and reliable information. This not only guarantees the quality of the information provided, but also allows for the database to be continuously enriched as new validated data becomes available.

responds to the specific questions posed by users, rather than providing pre-set answers. This allows the tool to address peoples' specific questions about lupus, offering a more personalised and relevant experience and enhancing therapeutic patient education.

Lupus GPT is in its final testing phase, ensuring it is widely and easily accessible to everyone. This initiative represents a significant step forward in using technology to support therapeutic patient education and fight health misinformation on lupus online.
Try the tool!

If you have any feedback on Lupus GPT, contact **secretariat@lupus-europe.org**.

Patient Session on Gamete Donation at ESHRE2024

One of the standout sessions at ESHRE 2024 was the patient session on gamete donation titled "Donation: a 360° view". Fertility Europe speakers, Ana Galhardo, Timo Ramu and Maciej Smiechowski walked the audience through the meanders of gamete donation from various perspectives, i.e. a psychologist, a donor-conceived individual and a patient and recipient.

The session was well-attended, reflecting the growing interest and importance of this topic in the reproductive health community. The feedback was positive, with participants praising the informative and engaging nature of the discussion. This session highlighted the need for ongoing dialogue, comprehensive education, and essential reforms in regulations and approaches to gamete donation in fertility treatments.

Fertility Europe Annual General Meeting (AGM): Welcoming New Members

This year's Annual General Meeting (AGM) was a notable event, marked by productive discussions and important decisions.

A highlight of the AGM was the acceptance of new members from France, Serbia and the UK into the community. The previous candidate member from Jersey was approved as an effective member. Milana Trucl (EPF) conducted a training on the advantages and disadvantages of AI in healthcare. This session provided insights into how AI can be implemented in healthcare while addressing potential challenges and limitations.

European Federation of Allergy and Airways Diseases Patients' Associations

Join patients on World Atopic Eczema Day 2024, 14th September – toolkit now available!

The atopic eczema community will unite once again for the **7th World Atopic Eczema Day**.

The **European Federation of Allergy and Airways Diseases Patients' Association (EFA)** is actively working to raise awareness about this disease and highlight the significant burden it places on patients and caregivers.

#AtopicEczemaUnfiltered, the 2024 campaign theme, revolves around real, untold stories of patients and carers living with the disease.

For more information, visit **EFA's campaign website**.

EFA responds to the EMA review of the first critical medicines list of the EU

In June, the **European Federation of Allergy and Airways Diseases Patients' Association (EFA)** responded to the European Medicines Agency (EMA)'s consultation which reviewed the first Union list of critical medicines.

EFA thoroughly reviewed the EMA list of over 1500 medicines that are under review in 2024, and focused on identifying the essential medicines for patients with allergy, asthma, atopic eczema and COPD. The list is an important step towards a patient-centric approach to ensure security of supply and prevention of shortages of critical medicines in the EU.

Read the full EFA's response here.

CF Europe Board elects new President, Vice-President and Secretary

Thierry Nouvel will take up the important task of President of the CFE Board, guiding the organisation through the new strategic plan. Renate Kos, who has been serving as a board member since 2023, has taken on the role of Vice-President of the CFE Board. Stefan Joris, who is Director of Muco and President of RadiOrg, the Belgian rare diseases federation, since 2019, continues to serve as Secretary.

News from EUPATI

The EUPATI team recently uploaded the course content on the **EU Health Technology Assessment Regulation to the Open Classroom**. This marks a significant milestone in preparing patients for the new EU HTA process set to commence in 2025.

The course content is freely accessible, requiring no registration. However, those interested in obtaining official certification can do so by paying a small fee. By 2025, the course will also be available in Czech, French, German, Greek, and Spanish, broadening its reach and accessibility. Start learning about the EU HTA Regulation through EUPATI's online courses available **here**.

For those interested in deeper engagement, EUPATI offers online training sessions from September 2024 to September 2025. Register your interest for these sessions **here**.

contact us **visit our website**

view this email in your browser

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

Add us to your address book