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THE **EPF** European Patients Forum
PATIENT PERSPECTIVE
AUGUST 2023

EDITORIAL

Dear reader,

A new month, a new edition of The Patient Perspective. As the summer is coming to an end, we are gearing up for September and for the final quarter of 2023. The latest in the world of patient advocacy? This was August.

In the approaching autumn's back-to-school spirit, we present the second edition of the **master's degree on International Patient Advocacy Management** in collaboration with ALTEMS/Università Cattolica. This new programme focuses on topics, such as healthcare management, patient involvement, HTA, and much more.

We are delighted to share that two **new EPF staff members** have joined the Secretariat over the summer! Meet Sibel and Estefanía.

On the projects side, we share **updates from EATRIS-Plus and PERISCOPE**, the latter facing the lead-up to its conclusion with a final conference taking place on 8 September, in Brussels. EATRIS-Plus was recently featured in a Project Spotlight episode of EPF's The EU Patients' Podcast, in which we spoke to Oriana de Sousa, patient advocate. In other news, EATRIS is involved in organising the TMex - Translational Medicine Explained winter school - scroll down if that sounds right up your street.

Hadn't caught up with EPF's recommendations for the revision of the EU pharmaceutical legislation? Scroll down and learn more about what **#ItsAboutPatients** means to us.

Until next month!

The EPF team

In the meantime, make sure you follow us on social media:
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SECRETARIAT NEWS



JOIN THE NEW MASTER'S ON INTERNATIONAL PATIENT ADVOCACY MANAGEMENT



Master's update! The programme on International Patient Advocacy Management is opening for applications again

EPF, together with ALTEMS/Università Cattolica, presents the second edition of the engaging and important master course on International Patient Advocacy Management. Topics and classes range from healthcare management, patient involvement, and health technology assessment to communication, fundraising, and bookkeeping.

Are you ready to send in your application? Find more information [here](#).



Hello, Sibel (l) and Estefanía (r)! The EPF Secretariat welcomes new Office Manager and Membership and Governance Officer

We are delighted to announce that two new EPF colleagues started work at the Secretariat in the past two months.

Sibel joined EPF in July 2023. She currently works as Office Manager. In this role, she supports the Director of Operations with HR, and provides support to the Executive Director, Special Advisor and Senior Management Team on administrative tasks. She holds a master's degree in Neurosciences and Cognitive Psychology from Strasbourg University in France and worked for years in various private sectors such as tech, marketing or education.

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provides active support to the Board of Directors and the Ethics Committee. Esterania is originally from Colombia, and currently resides in Brussels. She has a multidisciplinary background in Anthropology and Psychology and holds two master's degrees, one in Public Health from Andalusian School of Public Health and the other one in Governance and Leadership in European Public Health from Maastricht University. Before joining EPF, she worked as a trainee in DG SANTE at the European Commission, and in Health Research for Javeriana University.



The graphic is a promotional image for a podcast episode. It features a green and blue background with a white play button icon and the text 'EPISODE 6'. The EPF logo (European Patients Forum) is visible. The main title is 'PROJECT SPOTLIGHT' followed by 'eairis+' in a stylized font. Below this, it says 'Special guest: Oriana de Sousa Patient advocate'. On the right side, there is a portrait of Oriana de Sousa, a woman with long dark hair wearing a black lace top. In the top right corner, there is a logo for 'THE EU PATIENTS' PODCAST' featuring a green microphone icon.

New podcast alert: listen to the EATRIS-Plus project special with patient advocate Oriana de Sousa

This new episode brings one of our longstanding projects, **EATRIS-Plus**, into the spotlight. EATRIS-Plus aims to build further capabilities and deliver innovative scientific tools to support the long-term sustainability strategy of EATRIS as one of Europe's key research infrastructures for personalised medicine.

As the project will come to an end in December 2023, we invited Oriana de Sousa to sit with us and reflect on how meaningful patient engagement took shape throughout all the activities of the project.

Oriana is a Patient Advisory Committee representative for the EATRIS+ project. A survivor of rare cancer, she's now a patient advocate and EUPATI-certified Patient Expert. Oriana recently completed training in Scientific Innovation and Translational Research with EURORDIS. Her advocacy focuses on childhood, AYAs, and small cells ovarian cancer. She's part of the Rare Tumors of the Ovary network and Genomics in Oncology Patient Expert

approach.

Listen to the episode [here!](#)



Position Paper | Read our recommendations for the revision of the EU pharmaceutical legislation

READ IT HERE | EPF calls for a patient-centred revision of the EU pharmaceutical legislation - [#ItsAboutPatients](#)

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](#).

YOUTH GROUP UPDATES

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Meanwhile, don't forget to follow the EPF Youth Group on social media for the latest on the amazing work they've done and what is yet to come!



PROJECTS PORTAL



LEARNING OPPORTUNITY | Join "Translational Medicine Explained", a 5-day winter school!

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This program was designed for PhD candidates, master's degree students, and postdocs in biomedical research to learn about the job profiles of scientists in Industry and other sectors.

The course includes a 12-hour online introduction and a 5-day in-person workshop from 13 to 17 November 2023, hosted at Bayer's facility in Berlin.

Experts will address topics such as:

- Target product profiles
- Research and development of biologics
- Clinical trials
- Regulatory support
- Science communication
- Patient-driven research and personalised medicine

Several innovation sessions will take place, covering new drug delivery methods and academia-biotech-industry collaboration.

For details and registration, visit [this page](#).



The poster features a pink and blue background with a white sun icon in the 'periscope' logo. A small European Union flag is in the top right corner. The main text is in white and blue. At the bottom left, there is an illustration of a woman in an orange shirt and dark pants holding a green megaphone. To her right are icons for a calendar, a location pin, and a person, followed by the event details. A blue button with white text 'SAVE YOUR SPOT' is centered at the bottom, with the website URL below it.

periscope

FINAL CONFERENCE

POLICY CONFERENCE

From Data Science and Socio-Economic Research to Policy and Technology - Learning from COVID-19 to build better Health and Care in Europe

FRI SEP 8TH, 2023
09:00 - 19:00 CET

BRUSSELS, BELGIUM
CEPS - PLACE DU CONGRÈS 1, 1000

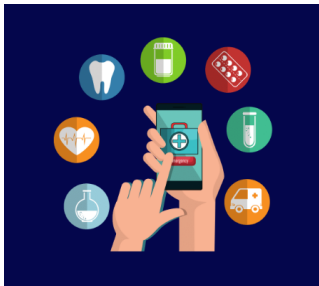
SAVE YOUR SPOT

www.periscopeproject.eu

After more than two years investigating the impact of the COVID-19 pandemic, PERISCOPE will share key results in its final conference - **From Data Science and Socio-Economic Research to Policy and Technology - Learning from COVID-19 to Build Better Health and Care in Europe**.

The event will delve into the socio-economic and behavioural impacts resulting from the policies implemented in response to the pandemic and examine how policy responses have influenced the path towards better health outcomes in Europe. Over the course of the project, PERISCOPE's team has been at the forefront of data science, economic research, and technological innovations in response to the COVID-19 pandemic. Now, as the project nears its end, it is time to reflect on the collective efforts and the valuable lessons learned.

This full-day conference will present the project's policy recommendations and will gather researchers, policymakers and representatives from medical institutions.



Do you work at a **health app developer, healthcare provider, health authority, HTA body, or health insurer?**



Please share your opinion on value propositions for health app assessments!

[EMP.ONL/L2ESURVEYASSESSMENT](https://emp.onl/l2esurveyassessment)



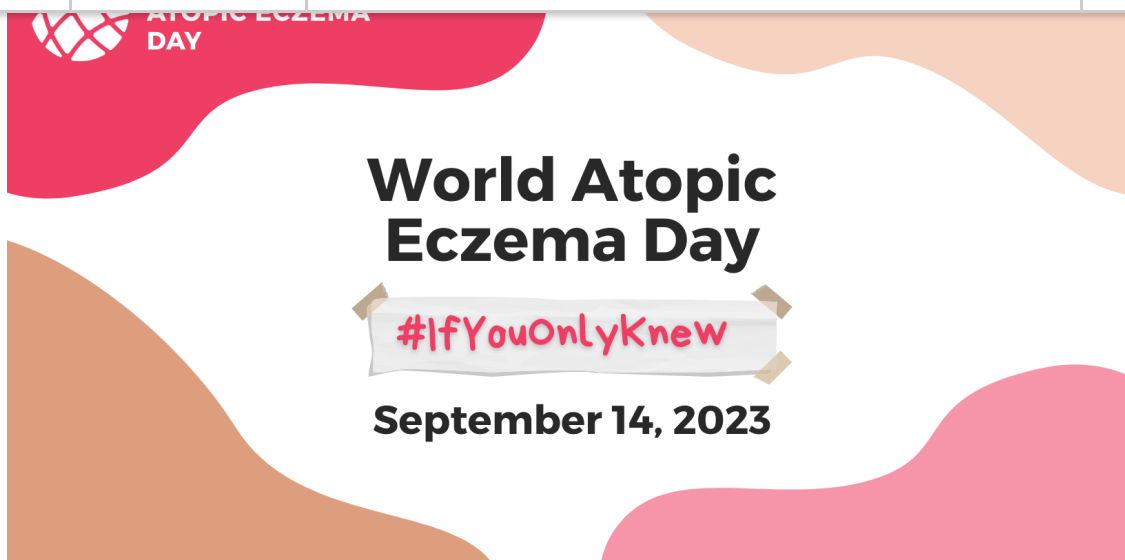
Label2Enable is looking for respondents: survey on value propositions for health app assessments

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.

MEMBER FOCUS



EFA: World Atopic Eczema Day 2023: #ifyouonlyknew the burdens on children and youth living with Atopic Eczema

Patient communities join forces to empower their youngest members and their carers

On September 14th, World Atopic Eczema Day, patient communities across the globe join forces to raise awareness on the **psychosocial burden of children and youth** living with Atopic Eczema (AE). Also known as atopic dermatitis (AD), atopic eczema is one of the most prevalent skin diseases in the world. It is a non-communicable and chronic skin disease that usually develops during childhood. It affects body and mind of over 230 million people worldwide, whereby approximately 43 million are aged 1-4, which shows the startlingly high incidence in young children.

Often dismissed as “just a skin condition”, it requires instead a full multidisciplinary team to be properly managed, also to tackle stigmatization and its consequences on the most vulnerable. For this reason, together with partners from GlobalSkin, EFA launches World Eczema Day 2023 campaign to support those who live with atopic dermatitis every day, bringing to the center patients’ feelings and appealing to the audience sensitivity. A social media campaign will pivot on the hashtags **#ifyouonlyknew** and **#AtopicEczemaDay**, implying that there is an amount of invisible consequences regarding what happens in a patients’ life and in affected teens’ and their carers’ emotions.

Young patients from different countries have actually contributed in developing the messaging of the international campaign, providing their thoughts on their fears, concerns and desires for their life, also opening a route for the empowerment of their peers dealing with similar conditions.

Join EFA’s campaign and the growing global community to empower young people with AE and encourage health systems to address the full range of atopic eczema’s impact. To be part of the online conversation on channels like Twitter, Facebook, Instagram and LinkedIn, use the hashtags: **#ifyouonlyknew** and **#AtopicEczemaDay**.

More info on World Atopic Eczema Day 2023 is available on EFA's [website](#).

PATIENT EXPERT Training Programme Registration opens soon!



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

Registrations for the 2023 - 2024 Patient Expert Training Programme are now open [here](#).

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](#).

Download the new programme brochure [here](#).

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