



THE EPF
European Patients Forum

PATIENT PERSPECTIVE

OCTOBER 2023

EDITORIAL

Dear reader,

Patient centricity in Early Feasibility Studies (EFS) for Medical Devices is key.

The four-year IHI project "Harmonised Approach to Early Feasibility Studies for Medical Devices in the EU (HEU-EFS)" was recently launched and we consider this a perfect opportunity to put patient engagement at the centre of EFS. The European Patients' Forum joins this initiative led by Bocconi University and Edwards Lifesciences and is teaming up with patient organisation Global Heart Hub (GHH).

In recent years, regulators in various countries have been taking a closer look at how health technologies get approved for the market. Attention has been paid to the quantity, type, and quality of evidence needed for the approval of medical devices, which has been traditionally considered weaker than for drugs and sometimes insufficient to fully ensure patients' safety, especially for implantable, high-risk medical devices. For this reason, EU Regulations on medical devices, in-vitro diagnostics, and Health Technology Assessment (HTA) were established to promote a stricter process for clinical evidence generation before medical devices can enter the market and be used by patients.

This is where EFS come in. EFS are small-scale research studies or tests done in the very early stages of developing a medical device or treatment to see if it is practical, safe, and worth pursuing further. EFS help assess whether an idea or concept has potential before investing more time and resources into full-scale development and testing.

Currently, there are no standardised procedural rules or guidelines for conducting EFS in the EU. The ambition of the HEU-EFS project is to create a harmonised framework for the EU EFS programme. This programme is a crucial opportunity to introduce patient perspectives early on, benefitting all stakeholders involved in the development and use of medical devices.

EPF and GHH's efforts to advance patient centricity in the project will contribute to three key positive outcomes.

Firstly, patient engagement in EFS will allow for an efficient lifecycle planning of medical devices. Relevant data must be collected from patients early in the product conceptualisation stage to inform the business case, increasing the chances of developing innovative, cost-effective, and safe medical devices. This benefits not only patients but also end users, payers, and policymakers.

Additionally, patient centricity can help minimise late-stage pipeline failures and market access failures, saving resources (time, budgets, etc.) by aligning new technology with patients' needs and early knowledge on future endpoints. Evidence shows that most market access failures can be attributed to a lack of adequate understanding of the market and patients' needs, making some products redundant.

Finally, involving patients aligns with current healthcare transformation trends. It supports patients' active role in managing their own health, co-creating healthcare solutions. It also

Through meaningful patient engagement, we expect EFS to foster timely access to innovative and safe medical devices that improve patients' health.



EPF PROJECTS TEAM

VALENTINA STRAMMIELLO & YASEMIN ZEISL

Until next month!

The EPF team wishes you a great month of November.

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

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POLICY CORNER

October in review

October began with the publication of the draft reports by the European Parliament's two Rapporteurs on the EU pharmaceutical legislation. Following a first analysis, EPF issued a [statement](#) welcoming the greater patient involvement throughout the regulatory process, the improvements to the patient information leaflet, and the inclusion of quality of life criteria in the definition of "unmet medical need". On the other hand, we are also concerned about the lack of balance between innovation and access and call on the European Parliament to support measures that will help address the current inequalities in patients' access to medicines.

October also saw the finalisation of two position papers on key notions of the EU pharmaceutical legislation - [paediatrics](#) and [unmet medical needs](#). With regard to paediatrics, EPF is concerned about the disappearance of the EMA's Paediatric Committee (PDCO) and fears that the proposed change may lead to an unintended deprioritisation of paediatric medicines. Regarding the notion of unmet medical need, the cornerstone of the revision, EPF advocates extending the definition of unmet medical need to criteria of the utmost importance for patients with chronic conditions, such as the appropriateness of existing treatments and impacts on quality of life.

On the digital health front, October marked the finalisation of an important content work on Artificial Intelligence (AI) in healthcare. In our recently published [position paper](#), EPF explores the applications, benefits, and challenges associated with AI in healthcare from a patient perspective, and provides key recommendations for responsible deployment of AI solutions, such as respecting human dignity and addressing data quality and integrity.

Finally, in October, the policy team conducted advocacy activities towards the European Parliament's rapporteurs and representatives of DG SANTE and the EMA, in order to publicise the above-mentioned papers and statement. Our views on the EU pharmaceutical legislation, and in particular on access and security of supply of critical medicines, were also defended by our Executive Director at a hearing of the European Parliament's SANT Committee

SECRETARIAT NEWS

ARTIFICIAL INTELLIGENCE IN HEALTHCARE

Advancing Patient-Centric Care
through Co-design and
Responsible Implementation

October 2023

NEW! Read our latest paper on AI in Healthcare

Our recently published AI position paper explores the applications, benefits, and challenges associated with Artificial Intelligence (AI) in healthcare from a patient perspective, and provides key recommendations for a responsible deployment of AI solutions.

The considerations and recommendations presented in this paper are based on a survey conducted by EPF in Spring 2023, targeting patient organisations and individual patient advocates, and the discussions with participants of a bootcamp on Artificial Intelligence conducted by the [Data Saves Lives](#) initiative that took place in March 2023.

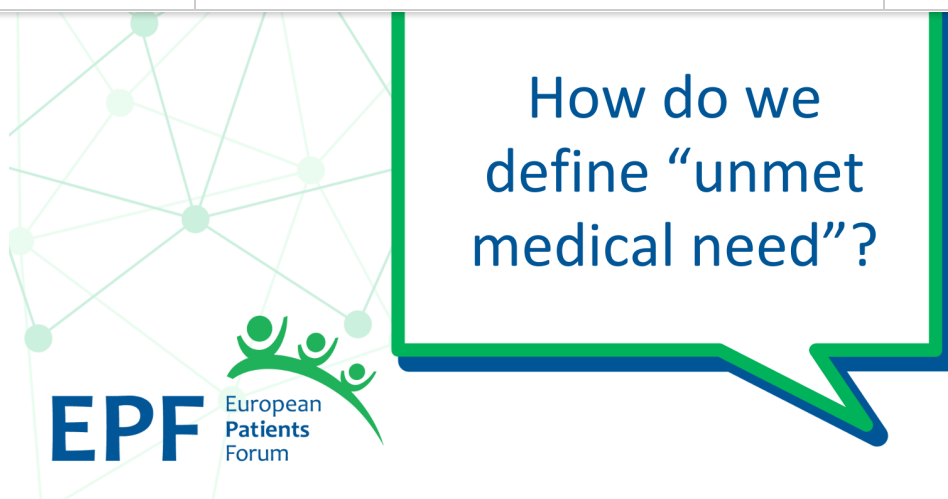
Their valuable insights, coupled with the expertise of [EPF's Digital Health Working Group](#), EPF's members, and Secretariat, have shaped our recommendations.

This paper is addressed to policymakers, developers, and research partners who play a vital role in legislating, developing, and deploying AI solutions in healthcare.

Our goal is to communicate with this diverse group of stakeholders about the importance of developing AI solutions in healthcare that genuinely benefit patients by upholding the principles of patient safety, transparency, privacy, human autonomy, co-design, accountability, and education.

In our recommendations, we advocate for the application of 9 guiding principles. We want to make sure that artificial intelligence is applied in healthcare to improve efficiency, fairness and, ultimately, patients' lives.

Check out the full position paper, read more [here](#).



"Unmet medical need": what does EPF recommend? Read our new position paper

EPF perceives the current Commission's definition of "unmet medical need" as restrictive, offering only a limited scope for genuine health innovation. EPF expresses not just concern but a resounding call for patient involvement in drawing up the definition.

Ultimately, the concept of "unmet medical need" should aim to distinguish innovative medicines that provide real and significant added therapeutic value for patients from other new medicines.

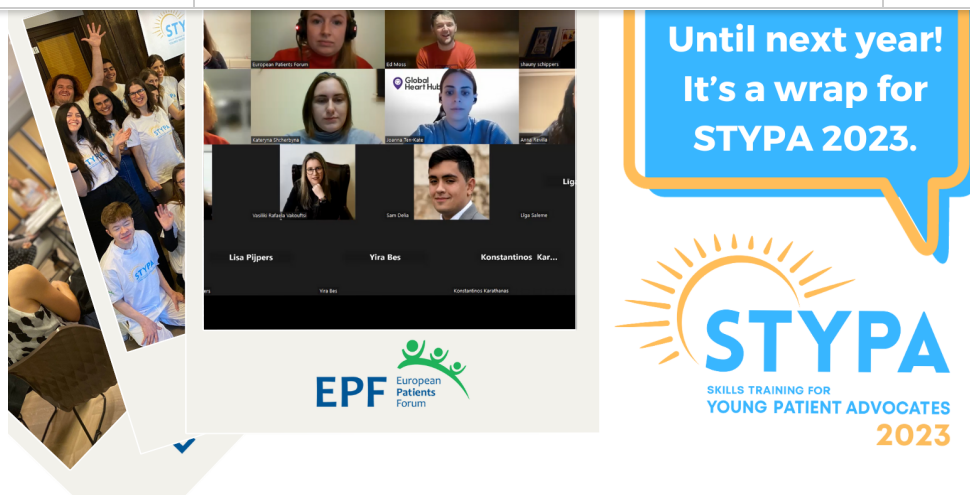
EPF proposes a future framework to characterise "unmet medical need" as part of the revision of EU pharmaceutical legislation. This framework should:

- Apply to medicinal products intended to treat, but also medicinal products intended to prevent or diagnose a disease, or to restore, correct, or modify physiological functions as per the definition of medicinal products in the EU.
- Acknowledge both immediate therapeutic needs perceived by patients that are unmet by current treatments and longer-term societal needs, including the impact on caregivers and potential public health concerns.
- Embrace inclusivity, recognising that many chronic diseases, while not life-threatening, substantially burden patients, caregivers, and healthcare systems. It should take into account not only mortality and morbidity but also their broader impact on patients' lives and health-related quality of life.
- Assess patients' therapeutic needs based on various criteria, encompassing the impact of the condition on life expectancy, the appropriateness of current standards of care, and patient experience data (PED), including their quality of life and any mental health implications.

In conclusion, the journey to define "unmet medical needs" starts with listening to patients and understanding the profound impact of their conditions and treatments on their lives.

Collaboratively shaping legislation and definitions with patients at the heart of the process fosters true health innovation, ensuring that medicinal products are developed and evaluated in ways that genuinely enhance patients' lives.

Read our full position paper [here](#).



That's a wrap! STYPA 2023 on the topic of "shortages" is officially over

It's official: STYPA 2023 is over! We rounded up this year's Skills Training for Young Patient Advocates with a final webinar session in October, which means that the course has now reached its end.

Thank you so much to all our participants, you were wonderful and we are delighted to have shared interesting and necessary discussions on the topic of shortages with you.

Throwback! What did we discuss?

STYPA 2023 was 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 focal points 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?

Next to the webinar series, we met in Riga for a face-to-face meeting, in which our two trainers, wonderful speakers, and EPF staff members joined the participants in a journey towards understanding, working with, and strategising around the topic of shortages.

Interested to learn more about STYPA? Curious to join next year? Find more information [here](#).



Our agendas are usually very busy! We attend various policy and stakeholder events and appear in publications, always voicing the patient perspective.

Here are some highlights from our work on patient engagement:

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the complexities of AMR and the need for better stewardship by decoupling revenues from sales volumes. They should also ensure that R&D efforts focus on areas of highest needs, in cooperation with patients."

Last week, at the **Global AMR R&D Hub** Annual Meeting, EPF's **Julie Spony** discussed innovative ways to tackle antimicrobial resistance. By decoupling revenues from sales volumes and engaging patients as partners, we can pave the way for a more sustainable and effective strategy.

"To make this a reality, we need to actively involve patient organisations, empower them, and provide the resources they require to contribute meaningfully. Only then can we navigate the challenges of antibiotic resistance and ensure a healthier future, for all."

At the European Parliament SANT subcommittee hearing, EPF's **Anca Toma** intervened on medicine shortages and re-affirmed the need to involve patients when formulating new policy solutions in healthcare.

"Availability issues are a significant public health problem and can harm patients' health and safety, quality of care, professionals' ability to deliver care, and health system functioning. Their impact on patients ranges from having no treatment at all to having to use an alternative treatment that may not be equally suitable, creating safety issues."

Only by establishing a true European Health Union can we improve access to and security of supply. To play their critical role in this initiative and in health policy more generally, patient organisations need to be publicly supported and have access to the resources they need.





recognise that accessing one's own health information does not diminish the role of healthcare professionals in any way. Instead, it has the potential to enrich the conversation between the professional and the patient. Crucially, that conversation must still exist.

Through having access to and control over one's data (to add and even correct information where necessary), an individual can be empowered to play a more active role in making informed decisions when it comes to their health – just as we have seen on a smaller scale through the use of wearable devices."

EPF's **Gözde Susuzlu Briggs** created a guest blog in **MedTech Views** from MedTech Europe on the importance of patient involvement in health data questions. Read it [here](#).

EU NEWS



'COMBINE' project

- analysing the regulatory landscape for combined studies on the IVDR/MDR/CTR interface

European Commission aims to provide clarity on clinical trials with the newly launched 'COMBINE' project

The **European Commission** recently launched the COMBINE project, which aims to provide guidance and clarify regulatory requirements on the design and submission of clinical trials involving both a medicinal product and a medical device/in-vitro diagnostic device.

This follows complaints, from industry stakeholders in particular, about the complex interaction of procedures under the clinical trials regulation and the new medical devices regulations, resulting in delays in conducting these combined studies in the EU. The European Patients' Forum will become part of the stakeholder reference group and contribute to the upcoming meetings of the group.

If you have experience with combined studies and have faced particular challenges in recent years, please reach out! Ahead of the upcoming meetings, we are collecting experiences and reflections on potential solutions.

Contact policy@eu-patient.eu.



HTA Info Day event: Overview of EU Regulation with Stakeholders from Spain, Italy, Malta, and Portugal

Join the European Commission on 22 November, in Seville, for a half-day stakeholder event on the EU **Health Technology Assessment Regulation**. Together with stakeholders from Spain, Italy, Malta, and Portugal, this event will provide an overview of the new legislative package on HTA and how civil society can contribute to an optimal implementation.

This session is part of a series of regional information gatherings scheduled for 2023 and 2024 across the EU. It is co-organised by the European Commission's **Directorate General for Health and Food Safety** (DG SANTE) and the Heads of **HTA Agencies Group** (HAG), in collaboration with national HTA agencies.

During this event, the European Commission will present an overview of the new EU HTA Regulation, followed by panel discussions featuring health experts on key topics related to the implementation of the regulation. The event will be conducted in English, with online interpretation services available in Italian, Spanish, and Portuguese.

Event details:

- Date and time: Wednesday, 22 November 2023, 10:30 – 14:00 CET
- Limited onsite spaces, but online registration available for all stakeholders
- Web streaming link will be provided upon registration

For further details, please reach out to contact@hta-info-day.eu.

Read more and register [here!](#)

YOUTH GROUP UPDATES



EUROPEAN PATIENTS' FORUM YOUTH GROUP: FALL MEETING & GOALS ACHIEVEMENT

By: Blaž Urbanč

The Fall Meeting of the European Patients' Forum Youth Group (YG) was highly successful, marked by high productivity and the achievement of all pre-set goals.

One of the key outputs of the meeting was the finalization of the "Young Patient Involvement in Patient Organisations" concept note. This document is a crucial part of our ongoing project, aimed at enhancing youth involvement in patient organizations and consequently their participation.

Anastasia, our EPF YG President, took a moment to reflect on the Fall Meeting activities and said:

"After this Fall Meeting I am feeling extremely rejuvenated and positive. It was very motivating to work collaboratively together as a team in person because often this "hands on togetherness" can feel lost when working heavily online. Ultimately, we as a group strive for quality and to take on thought-provoking topics and I feel that we achieved this through the Fall Meeting because of our efforts to improve our planning for our current Youth Group project. Now that we have taken the time to step back and reflect on the realities of what it takes to fulfil this project in the quality that we are aiming for, we have been able to set clear goals that we want to achieve, and most importantly we were able to highlight why we want to achieve them."

The fact that we have accomplished this was an important goal from us on the Youth Group board, therefore I am very happy and confident moving forward. Currently our aim is to submit our Concept Note for the Young Patient Involvement project and hopefully for it to be approved by funders so we can then move on to creating the necessary material for the project itself. I am so excited for all that is coming and knowing that we have now welcomed two new members into our team, it only increases my spirits for what lies ahead in the youth group."

We were delighted to welcome virtually two new members to our group, Eimear, and Aedan. Their enthusiasm and fresh perspectives will enrich our discussions, and we look forward to their contributions in future meetings and upcoming steps of ongoing project.

Aedan described some of his feelings:

"The Fall Meeting left me feeling hopeful and optimistic about the future of the EPF Youth Group. I am confident that by working together we can make a real difference to the healthcare landscape for patients. I was particularly impressed by the diversity of the group and the range of perspectives that were represented. I believe that this diversity is one of the group's strengths and it makes it possible for us to have more informed and inclusive discussions about healthcare and patient advocacy."

My first impression of the EPF Youth Group was that it is a warm and welcoming community of young people who are committed to making a difference. I was immediately struck by the group's passion and dedication to healthcare and patient advocacy. I was also impressed by the group's professionalism and organization. The meeting was well-planned and executed, and the speakers were all knowledgeable and engaging."

group. We are excited about the progress made and are eager to continue our work in improving patient involvement across Europe.

To find out what project steps we are taking in the upcoming months, follow us on our social media channels on [Facebook](#), [Twitter](#) and [Instagram](#) and stay tuned!!!



PROJECTS PORTAL

periscope

The PERISCOPE project is coming to an end. This is what you should know

PERISCOPE is a project funded under Horizon 2020 to investigate the broad socio-economic and behavioral impacts of the COVID-19 pandemic and contribute to better EU preparedness and resilience for future threats. The European Patients' Forum (EPF) was part of a multidisciplinary consortium bringing a broad range of experiences and expertise to assess the impacts of the crisis, from socio-economic to epidemiological and clinical aspects.

As the project draws to a close on October 31, we look back at the key findings and the

the particular challenges faced by patients in accessing healthcare and receiving adequate information.

EPF also produced a range of podcasts to raise awareness of the results, which are available here. The **latest one**, with CEPS project coordinator Andrea Renda, looks back on the origins of the project and main contributions.

As the aftermath of the COVID-19 pandemic is still reverberating across Europe and beyond, the PERISCOPE project has uncovered valuable insights into the multi-faceted impact of COVID-19 and has offered practical measures to pave the way for a more resilient and prepared continent.

The lessons learned from COVID-19 must serve as a blueprint for building stronger, more interconnected public health systems across Europe – there is no time to waste in implementing it.

7 December 2023, 12:30 CET

SAVE THE DATE | WEBINAR:
**“IT’S TIME WE TALK ABOUT
PATIENT ENGAGEMENT”**

 This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 871096

 **EATG** European AIDS Treatment Group

 **EPF** European Patients Forum

 **eatris** European infrastructure for translational medicine

 **eulife**

"IT'S TIME WE TALK ABOUT PATIENT ENGAGEMENT" - Will you join the webinar on 7 December?

EATRIS, the European AIDS Treatment Group, EU-Life-Alliance, and EPF are organising a webinar on patient engagement on 7 December 2023, 12:30 CET.

This webinar will serve as an introduction to researchers who are new to patient engagement and curious to learn more about good practices. While academic researchers are gradually involving patients and citizens in their research, meaningful patient engagement practices are challenging to develop in academia for various reasons such as lack of human and financial resources or limited awareness of the tools and services available to guide researchers in their patient engagement journey.

Register [here](#).

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for the future HEaTHcare

If you are a...



Citizen or Patient



Health professional



Policy-maker



Researcher



It will take 15 minutes of your life!

We need your collaboration!

Please take part on the [survey](#) about the **challenges** to the adoption of **personalized prevention strategies**.

You can share this survey with your family, friends and colleagues.

Preventing disease based on our own information may lead to a **longer healthy life!**



Exciting opportunity: Partake in PROPHET's survey on personalised prevention strategies

Participate in the online **PROPHET** survey that aims to map the barriers, challenges, and enablers for the adoption of personalised preventive approaches in health systems in Europe. "Personalised prevention strategies are only possible if citizens, health professionals, researchers, and policy makers are all aware of their potential and have the knowledge and resources to design and implement them."

To complete the survey scan the QR code in the visual or partake [here](#).

MEMBER FOCUS



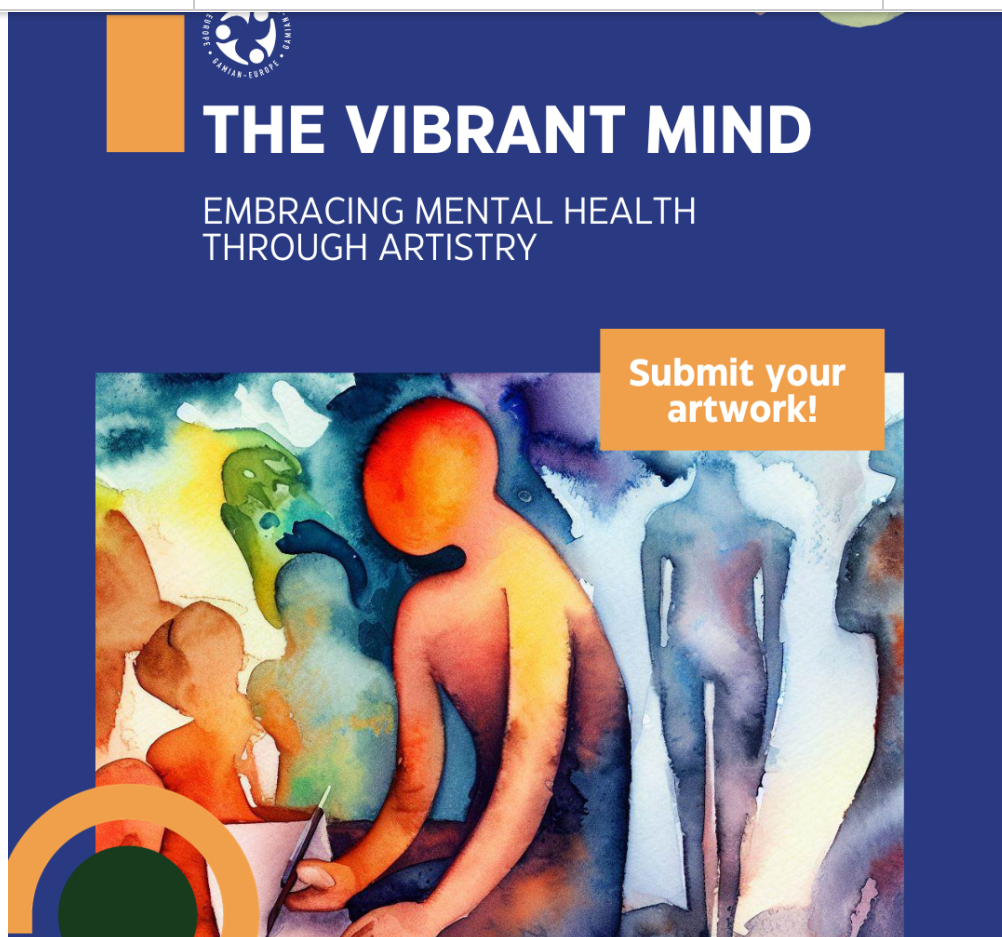
HEALTHY LIFESTYLE *for Breast Health*

ENGAGING IN PHYSICAL ACTIVITY, MAINTAINING A NORMAL BODY
WEIGHT AND EATING A HEALTHY DIET CAN HELP YOUR BREAST HEALTH



EUROPA DONNA – The European Breast Cancer Coalition (ED) celebrated its 16th annual Breast Health Day in October

On the 15th of October, **EUROPA DONNA – The European Breast Cancer Coalition** (ED) celebrated its 16th annual Breast Health Day to share tips on breast health and raise breast cancer prevention awareness across Europe. This year ED launched a charming new video featuring live cartoon drawings by visual scribing artist **David Vignolli** to highlight the importance of making daily *#HealthyLifestyle* choices for your breast health. Breast Health Day at ED is a coalition-wide event where member countries highlight the day by organizing local awareness-raising activities. "Our video is being shared by our 47 member countries across Europe to their communities. Please help us continue to spread the word by sharing the video, which is available at Europa Donna's **Facebook**, **Twitter** and **YouTube** social media channels or directly via this [link](#) to the video!"



a project by



Updates from GAMIAN-Europe

(R) Save the date: 15 November 2023 | 14:00 – 15:45 (CET)! As part of the GAMIAN-Europe **Peer Support project**, the mental health patient's organisation is thrilled to host a series of workshops. Don't miss the next one, aimed at exploring vital aspects of peer support work, training, and supervision. Register [here](#) to be part of the conversation.

(L) GAMIAN-Europe, in collaboration with EMHA, has released a groundbreaking report. Explore this vital topic by watching the informative webinar recording: youtu.be/FynLW6zpTg0?si=Ib40U_ZThHiU09u5. For an in-depth understanding, access the complete report, 'Migraine and Mental Health in Women: Addressing the Challenge,' [here](#). Don't miss the chance to broaden your knowledge on this critical subject!

(TOP) "The 'Vibrant Mind'" art competition is in full swing! Join GAMIAN-Europe in celebrating the connection between art and mental health. The organisation is accepting artworks from mental health patients until 10 December 2023, for a chance to be part of a European exhibition, featuring the top 30 pieces across multiple European countries. Submit your artwork [here](#).



Fertility Europe hosts event on 7 November in the EP - register to join!

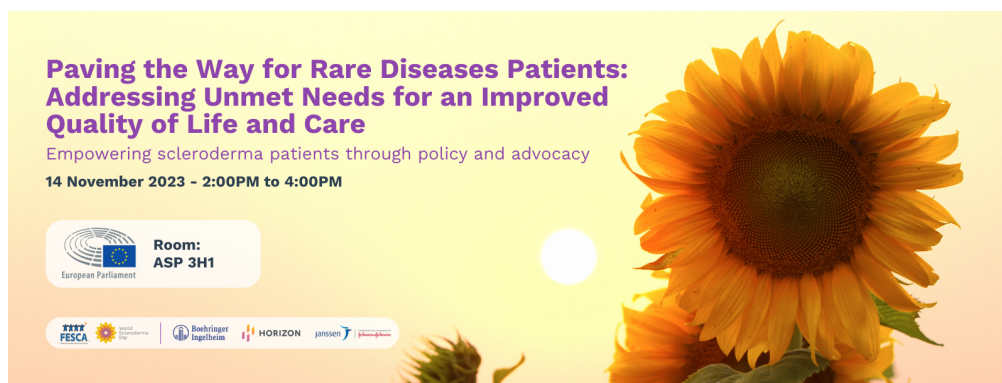
Fertility Europe, the European umbrella organisation representing over 30 national patient associations in the field of infertility, will hold an event entitled: "Minds Matter: Empowering Infertility Patients with Psychological Support". It is scheduled on November 7, 2023, from 3 to 4:30 PM in the European Parliament in Brussels.

This hybrid event will be a part of our annual European Fertility Week (EFW) during which our organisation, members, and supporters raise awareness of infertility and advocate for equal access to safe and efficient treatment.

This year's edition is dedicated to infertility as a comorbidity to mental health issues and the need for psychological support services across Europe for all individuals facing infertility and struggling with emotional burdens and distress. It will feature interventions from patients, healthcare professionals, and policymakers. We will take the opportunity to present the results of our latest survey on Psychological Support around Infertility with over 2,500 responses from across Europe and patients' recommendations on access to mental healthcare based on the survey outcome. We aim to push the process of easing the emotional burden of infertility and encourage much-needed conversations about all aspects of psychological support throughout the infertility journey, notably the importance of post-treatment support and destigmatising infertility.

This presentation will be followed by a Q&A session allowing ample time for debate.

To join us in person or virtually, please register through this [link](#).



The Federation of European Scleroderma Associations (FESCA) is thrilled to invite you at the event "Paving the way for rare diseases patients: Addressing Unmet Needs for an Improved Quality of Life and Care"

Building upon the momentum of 2022, FESCA has continued its successful ["Find the](#)

quality of life.

As part of the "Find the Light to Bloom" campaign, FESCA has been looking into the challenges faced by those living with this rare and life limiting disease, from limited access to treatment and care to the impact on people's emotional and mental wellbeing as well as their performance and independence at work. Lack of public access to non-drug treatments including psychological support, adequate labour market policies, as well as affordable and accessible care services remain key challenges that people living with scleroderma must overcome on a daily basis.

In this context, MEP Patrizia Toia (S&D, IT) is hosting an [event](#) that will look into the current unmet needs of the rare diseases patient community and how these can be addressed through existing policy initiatives. The event will take place on 14 November 2023 from 14:00-16:00 CET in the European Parliament (room 3H1).

Our confirmed speakers include:

- Ms. Patrizia Toia, Member of the European Parliament (S&D, IT)
- Ms. Donata Meroni, Health Monitoring and Cooperation, Health Networks Head of Unit, DG SANTE, European Commission
- Ms. Izabela Taborska, Medicines: Policy, Authorisation and Monitoring Unit, DG SANTE, European Commission
- Mr. Victor Maertens, Government Affairs Director, EUCOPE

If you are interested in joining FESCA on 14 November, please register [here](#) by Friday 3 November.



Updates from EURORDIS

Conference on Rare Diseases and the European Reference Networks

The European Reference Networks (ERNs), established in 2017, have showcased the effectiveness of EU-level solutions in addressing national healthcare challenges. These 24 networks, specialising in rare and complex diseases and funded by the EU budget, have been pioneers in cross-border healthcare.

At the recent *Conference on Rare Diseases and the European Reference Networks* in Bilbao, Spain, EU policymakers, including the Commissioner for Health and Food Safety Stella Kyriakides, commended the ERNs for their exceptional progress and efforts. In anticipation of the conference, EURORDIS and the ERNs jointly composed an [open letter](#) to EU policymakers, emphasising their achievements and advocating for continued support for them.

Rare on Air: Should more diseases be screened for at birth?

In the latest episode of *Rare on Air*, Julien Poulain returns to the topic of newborn

3,500 responses in Europe) from across the global rare disease community about health systems' practice of screening at birth for health conditions.

Before exploring the results of the survey, Julien talks to Iuliana Dumitriu, the mother of Victor, an eight-year-old boy living with Coffin-Lowry Syndrome in Romania. Iuliana, who is also the President of the Coffin-Lowry Syndrome Association shares with Julien the story of her family's torturous, yet determined, seven-year journey toward receiving a diagnosis for Victor. Reflecting on Iuliana's story, Julien also speaks to EURORDIS Social Policy Director, Jessie Dubief, who shares insights into the results of the recent EURORDIS Rare Barometer survey on newborn screening and the views of people living with rare diseases.



Prostate cancer affects partners and caregivers as well as those receiving treatment. What could be done to help them? Learn more about Europa Uomo's study and survey

Europa Uomo has launched a new study looking at the experiences of partners of men with prostate cancer, and the physical and psychological burdens the disease imposes on them. It will help define unmet needs and provide an agenda for action.

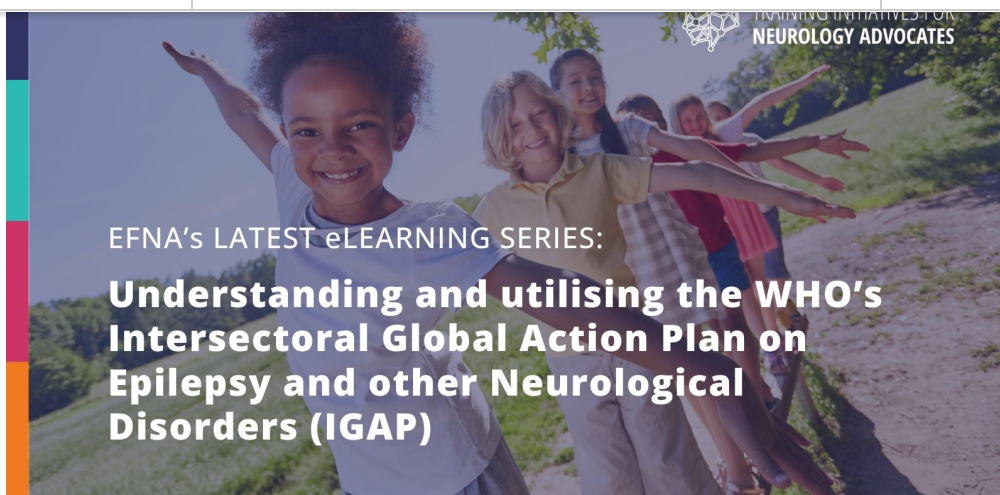
The study, named EU-PROPER (Europa Uomo Prostate cancer Partners in Europe Research), is centred on an online survey available in 17 languages asking simple questions about how the partner's disease has affected this group.

"This unique study is examining the experiences of partners of men with prostate cancer. It will measure the burden that the disease imposes on caregivers' lives and define unmet needs.

All the responses collected will be anonymously, but together they will present a valuable picture of the issues being faced by those close to men with prostate cancer – and provide an agenda for action"

EU-PROPER builds on the knowledge gained from previous Europa Uomo studies about patients' quality of life after treatment for prostate cancer (the EUPROMS studies). These have gone some way to identify the burden of prostate cancer on the daily lives of affected men, but the effect on partners and caregivers can also be considerable. Finding out what would really help partners, could have a significant impact on the type of support provided after diagnosis.

Go to euproper.org to complete the survey.



New e-learning series explores WHO's Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders

The European Federation of Neurological Associations (**EFNA**) has launched an e-learning series that explores the WHO's Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP) - a powerful, patient-centred and inclusive tool to aid the neurology community's advocacy efforts. Modules cover the guiding principles and strategic objectives of the WHO's IGAP, explore other global frameworks and introduce policy, and advocacy tools that can turn advocacy plans into action!

EFNA's e-learning modules are free to access, though registration is required. Participants will be able to access personalised certificates of completion following each module.

Learn more and register at: www.efna.net/elearning



CF Europe is hiring - apply this weekend!

CF Europe is hiring a Team Coordinator to support the implementation of projects and events aimed at engaging with CF patient organisations and key stakeholders in the cystic fibrosis community.

"Cystic Fibrosis Europe (CFE) is the federation of patient organizations for people with cystic fibrosis (CF) in Europe, with member organizations in 39 countries. CFE focuses on community building and representation, putting the needs of people with CF at the heart of its policy and research work. We advocate for access to optimal care for all people with CF. CF Europe has a small, dedicated and friendly team, this means you will be able to be closely involved in the work of your colleagues, learn about our projects, research, policy and communication work."

Learn more [here](#).

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Stroke Alliance for Europe (SAFE) organises the European Life After Stroke Forum (ELASF)

On 11 and 12 March 2024, SAFE organises **ELASF**.

"Please join us at the European Life After Stroke Forum, where stroke survivors, caregivers, healthcare professionals, researchers, and advocates will come together to address life after stroke issues. Our 2024 event in Dublin promises to be a vital platform for sharing insights, discussing the latest research, and delving into best practices in this often under-researched topic."

Registration for the event: <https://bit.ly/45PuA5b>

Abstract submissions: <https://bit.ly/3Lud2mW>



Updates from **EATG**

(L) **Stigma-Free: EATG launches campaign on intersectional stigma faced by people living with HIV and affected communities**

On World Mental Health Day (10 October), EATG launched the '**Stigma-Free**' campaign. The campaign aims to raise awareness among healthcare professionals and community around intersectional stigma and discrimination faced by people living with HIV and affected communities and the impact it has on their mental health and health outcomes. In addition, we aim to contribute towards the recognition and integration of non-medicalised services and peer-led programmes in the response to mental health issues affecting people living with HIV. #StigmaFree

(R) **Webinar: Mental Health within HIV Guidelines (9 November 2023)**

Jointly with the Stigma-Free campaign, **Mental Health within HIV care guidelines** is a follow-up **webinar** to explore some of the issues involved in updating existing standards

[Subscribe](#)[Past Issues](#)[Translate ▼](#)[RSS](#)**(TOP) EATG at EACS 2023 conference (Warsaw, 18-21 October 2023)**

EATG successfully participated at the **19th European AIDS Conference** in Warsaw from the 18th until the 21st of October. The biennial conference organised by the **European AIDS Clinical Society (EACS)** is a key event for all stakeholders working in the field of HIV/AIDS in Europe. This year, EATG hosted a special session focusing on harm reduction and mental health at the main **scientific programme** and also curated an acclaimed **Community Corner programme** at the Exhibition area. At the Exhibition, delegates visited EATG's booth. Check the stories via #EATGatEACS2023 and #EACS2023

**Join WFIPP's webinar next week**

Get vital updates and expert insights from the new UROwebinar **"(Data-driven) Shared Decision-making (SDM) in the management of incontinence"**, which is organised by the European School of Urology (ESU) in collaboration with the EAU Patient Office (EAU PO), and the World Federation of Incontinence and Pelvic Problems (WFIPP).

Moderator: Mrs. M.L. Van Poelgeest-Pomfret (NL)

Speakers: Mrs. J. Ghith (US), Mr. J. Phillips (GB), and Dr. M.R. Van Balken (NL)

Save the date: Tuesday, 31 October 2023

Time: 18:30 - 19:30 CET

This UROwebinar intends to clarify the value of (data-driven) Shared Decision-making (SDM) in the management of incontinence.

The learning objectives of the UROwebinar are:

- The benefits and value of data-driven SDM
- How can urologists facilitate (data-driven) shared decision-making with their patients?
- The need for patient-reported outcomes in the management of incontinence

Registration is necessary to join the webinar. Anyone can **create a 'My EAU' account** free of charge.

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