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THE EPF European Patients Forum

# PATIENT PERSPECTIVE

## JANUARY 2023

## EDITORIAL

Dear reader,

To be in the position of looking back on two decades of transforming the role of patient organisations in healthcare practices and policies together feels like an overwhelming honour. 2023 is marked by 20 years of highly effective advocacy campaigns. 20 years of unique multistakeholder collaboration. 20 years of ensuring that patients have a seat at the table in the design of medicines, technologies, practices, care, and the overall strengthening of healthcare systems.

We celebrate EPF's 20<sup>th</sup> anniversary in awed recognition of the cross-disease umbrella organisation we are today, linking communities across the continent and driving policy issues that affect all patients. Nothing of the kind would have been possible without our strong community of members, partners, readers, and advocates!

We have no intent to rest on our laurels. If anything, this celebratory time is an exciting and inspiring incentive to keep up the pace in shaping the future of patient engagement together! The foundational theme for this anniversary year is based on just that: the future, with a particular focus on a new generation of young patient leaders. On 28 April 2023, our Anniversary Policy Event will celebrate key achievements, draw learnings, and co-design a collective vision for the future of the European patient community.

It is safe to say that 2023 is already shaping up to be one for the books. Before we fully immerse ourselves in the exciting things to come, we look back on 2022 one last time. Indeed, we owe you a recap. The Secretariat in Brussels is happy to share their updates with you.

EPF's Policy team, for example, mentions three notable topics that stood out in their busy schedules, containing highlights on their work on digital health and the European Health Data Space, the pharmaceutical legislation proposals, and the Medical Devices Regulation. The Membership, Governance, and Capacity Building team discusses their work with the EPF Youth Group, STYPA 2022, and our AI Knowledge Hub. For team Communications, you will read all about our (social) media presence, events, and more. The Projects team puts PERMIT, PharmaLedger, COMPAR-EU, and Data Saves Lives centre stage.

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on the H2O project, and a link to the episode below. And, last but certainly not least, please do not forget to register for the Data Saves Lives AI Bootcamp by 31 January.

Scroll down for more monthly news from the EPF community. Do make sure you know your way to the latest EPF updates via our social media channels.

[Facebook](#) | [Twitter](#) | [LinkedIn](#) | [Anchor](#)

Happy reading!  
The EPF team

## POLICY IN 2022

The EPF Policy team looks back on a busy year. Shifting between various legislative processes impacting the European patient community resulted in multiple policy areas and issues to be addressed at once. Which topics stand out?

### **EHDS**

For a large part, 2022 was dedicated to digital health, with in particular the preparation of the advocacy strategy on the European Health Data Space (EHDS). Following member consultations, EPF released a position [statement](#) on the European Commission's proposal on 28 November, with 19 proposed [amendments](#). EPF's recommendations put patients at the heart of this initiative and focus on trust, transparency, meaningful patient involvement, security, and data protection. The statement and suggested amendments guided EPF's advocacy strategy and shaped the interactions with the co-legislators during the last months of 2022.

### **Pharmaceutical legislation**

Secondly, team Policy worked extensively on reviewing the Commission's foreseen pharmaceutical legislation proposal, which was originally due to be published in December 2022. In line with the most recent updates, the legislative proposal is now expected to be published towards the end of March 2023. Anticipatorily, the Policy team prepared an advocacy strategy, joined relevant events, and consulted members on how to achieve patient-centred legislation, promoting equitable and fair access to innovative medicines. The Policy team continues to engage with key stakeholders and publish position papers and amendments (as per our current member call for input).

### **MDR (Medical Devices Regulation)**

December was marked by a focus on the "new" [EU Medical Devices Regulation \(2017/745\)](#) (MDR). The MDR entered into force on 26 May 2021, setting a new framework of rules for the authorisation process of all medical devices to enter the Single Market. Technically, by 26 May 2024, all medical devices must comply with this new set of rules, but concerns have been raised and reported about disruptions to the availability of many medical devices in the EU. EPF [called for action](#): a lack of capacity of Notified Bodies to certify and re-certify devices and the reported high cost of certification could result in devices to be withdrawn from the market, for example, threatening patient safety and continuity of care.

Early 2023, following repeated calls for action, the Commission published proposed amendments introducing new deadlines of 3 to 4 years for compliance with the MDR, depending on the risk class of the medical devices. EPF supported a one-year postponement, but raised the concern that the three-year postponement and other deadline changes announced by the Commission should not lead to a lower level of

## MEMBERSHIP, GOVERNANCE AND CAPACITY BUILDING IN 2022

### Understanding AI: Webinar Series

Following EPF's successful application for the **NEF EU AI Fund**, EPF launched the Understanding AI webinar series for its members. The overall objective of the webinar series is to shed light on AI in healthcare. In 2022, EPF continued the series with three more webinars focusing on EU Legislation on AI, AI in Medicines Innovation, and Patients, Healthcare Professionals and AI. All the recordings can be found [here](#). Overall, the webinar series was a great success, with more than 320 participants registering for the series. EPF has also updated [the AI Knowledge Hub](#) where its work on AI as well as key publications are stored for the benefits of its members and the patient community at large.

### The sixth edition of STYPA (pictured left)

In 2022, EPF held the Summer Training Course for Young Patient Advocates (STYPA) in Strasbourg, France with over 38 young patients participating and representing various disease areas and coming from all over Europe. The purpose and nature of STYPA 2022 was to support and build the capacity of young patient advocates or representatives of young patient advocates who are motivated to learn more about sexual health and wellbeing as well support them in developing communication principles for their peers on young patients and their sexual health. The principles and more information about the course can be found [here](#).

### The EPF Youth Group (pictured right) *Sexual Health and Wellbeing Project*

After consulting the wider young patient community back in 2021 about the key topics surrounding sexual health they would like to discuss, the EPF YG has been actively publishing more and more content on the project. Such as:

- An [article](#), interviewing Moira Tzitzika – a psychologist and psychosexologist certified from the European Society of Sexual Medicine.
- A [podcast episode](#), diving deeper into the results of the survey and interests of the wider young patient community.
- A [series of short videos](#), featuring the YG reading out loud the anonymous stories of young patients, concerning their sexual lives with a chronic condition.

### *The YG Spring and Fall Meetings*

The group met twice in 2022, in Brussels, Belgium. During the spring and fall meetings, the members of the Youth Group can discuss and progress on their focus topics, future projects, and events. The few days of collaborative work, task allocation and planning are a great way to advance on their hard work and represent the young patient perspective.







## PERMIT Comes to an End

**PERMIT**, a **Horizon 2020** project focusing on personalised medicine (PM) trials, ended in 2022. EPF is proud to have participated in PERMIT. PM has immense value for patients, potentially reducing trial and error treatments, enabling better choices for medications, and managing healthcare costs.

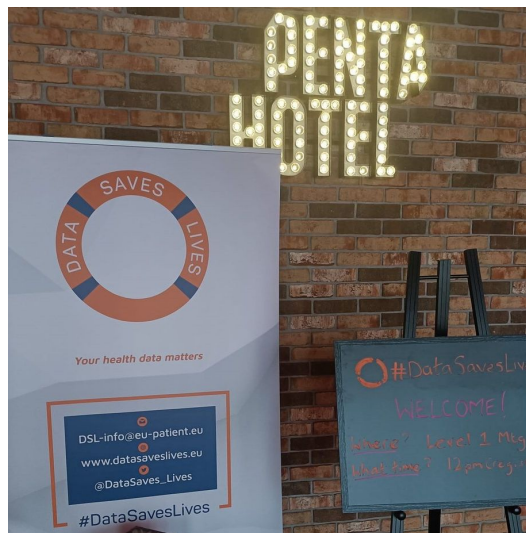
EPF ensured that the patient perspective and journey were integrated throughout the workshops and 70+ recommendations produced in the project. [Listen to our podcast](#) marking the end of the project.



## Beyond PharmaLedger

**PharmaLedger**, an IMI project aiming to drive the early-adoption of blockchain technology in healthcare, came to an end in 2022, with a closing event in Madrid.

Patient perspectives are crucial in blockchain-enabled healthcare and the development of its applications. This is why, EPF and the project's patient representatives **joined the conversation** at the closing event, to discuss the project results and future outlook. The work of the project will be continued through **the PharmaLedger Association**



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The European Patients' Forum hosted the **COMPAR-EU Final Conference Advocacy Event**, to mark the end of the project.

This advocacy conference marked the culmination of **5 years of interdisciplinary work** to identify, compare, and rank the most effective and cost-effective self-management interventions for adults in Europe living with high-priority chronic conditions. The conference took place on 15 & 16 November 2022 in Brussels.

Read the evidence on self-management interventions at **the new COMPAR-EU Platform**, and **don't forget to read the lay-summaries prepared by EPF**.

2022 was a key year for the EPF-led initiative, Data Saves Lives (DSL). 17 ambassadors joined the inaugural training boot camp, which took place on 10 & 11 October in Prague. The boot camp equipped participants with an understanding of key health data terminology, an overview of European legislation, and confidence to handle challenging questions. **Read the boot camp reflections here.**

The year closed with the formal launch of the **Data Saves Lives Germany** initiative. DSL Germany is the first offshoot of this campaign and it will adapt the DSL guiding principles to provide tailored support to patient groups across Germany. Show your support by following the #DSLDE **Twitter** and **Instagram**.

## COMMUNICATIONS IN 2022

A busy and exciting 2022? The EPF Communications team concurs! Read the main highlights.

2022 was the year almost 4000 people joined our overall social media following. We are so pleased to see all of you getting involved in our mission to advance patient empowerment and we warmly welcome you to the online EPF community. We started several social media periodicals in 2022, including a weekly recap post that highlights speaking and policy engagements and a dedicated section to share our members' updates, celebratory moments, and key happenings.

The **European Patients' Podcast** welcomed twelve inspiring guests this year, sharing important and topically relevant stories with us on, i.e., AMR, young patients and sexual wellbeing, Rare Disease Day, and much more. We also welcomed a number of expert speakers from our membership network, and we started with a new subseries that spotlights the projects we work on and are proudly involved with.

In June, **EPF's 2022 Congress** took place, in which we continued the conversation on digital transformation with over 300 registrants, of which 150 people joined us onsite. In four plenaries and a number of parallel sessions, 40 speakers explored a palette of topics with us, covering the EHDS, the ethical implications of AI, real-world data and evidence, and much more. During this two-day event that ran from the afternoon of 23 June to the following afternoon on the 24<sup>th</sup>, #EPFCongress2022 became the number two most trending hashtag on Twitter, testifying of our participants' engagement and solidifying our communications efforts in the lead-up to the congress. Afterwards, we created a post-congress video with highlighted speakers, built a short-running social media campaign around the recordings of the plenary sessions, and published an in-depth **report**.

On the media front, we are happy to report that the press consistently finds its way

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article featuring Anca Toma in *Polder de Sanitate*, a quote in the French political reporter *Contexte*, and mentions in POLITICO's Morning Healthcare updates.

As of last year, EPF's Communications team underwent some change, and the team's efforts are currently led by [Flavia](#), [Estefania](#), and [Anne](#). Click on our names to get to know us! We look forward to being in touch with and working with you in 2023.

## SECRETARIAT NEWS



## MONTHLY ROUNDUP

Our agendas are usually very busy! We attend various policy and stakeholder events during which we voice the patient perspective.

Here are some highlights from our work on patient engagement:



📍 On 12 January, [Anca Toma](#) attended the Brussels-held workshop on the topic of "Sustainable Ways to Support Pharmaceutical Innovation", where she joined a panel stressing that citizens' needs should be put first and that "economics should never be a barrier between patients and the healthcare they need".

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Opportunities in the European Parliament on 11 January, **Milana Trucl** voiced the need for concrete and meaningful involvement of patients in the governance structures of the EHDS: "Patients must continuously be at the very heart of decisions taken by the co-legislators to ensure that the EHDS is built in a way that promotes trust and transparency, delivers better care, and improves patients' lives."



📍 During the Coalition for Vaccination Conference on 17 January, EPF's **Juan José Fernández Romero** joined the late-morning panel discussion on improved collaboration to increase vaccine confidence and uptake: "Many diseases are vaccine-preventable, and even though the benefits of vaccination are evident, hesitancy remains. Patient organisations are key stakeholders in liaising with patient communities to raise awareness when it comes to the efficiency, safety, and efficacy of vaccines."



📍 25 January: **Kaisa Immonen** joins "Future of Clinical Trials and Health Data in Europe". Kaisa spoke at this event calling for meaningful and valued involvement of patients in clinical trials: "Innovation in healthcare is meaningless if patients do not get to experience the benefits from it. The objective of clinical trials is to ensure better treatments, so they need to be backed by robust evidence of patient benefits. Patients' priorities and involvement need to be embedded in research and development processes."

## Let's Get Provocative!

EPF Youth Group's final event on 9 February 2023

WITH:

**IRENE SCHOKKER-VAN LINSCHOTEN**

Children's nurse at Erasmus MC





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Registrations for "Let's Get Provocative!" are now open. The event will take place on 9 February, 18:30 CET.

This online event gathers young patients, families and carers, advocates, and healthcare professionals from across the continent to discuss misconceptions, beliefs, and stereotypes when it comes to sexual health for young people with chronic conditions.

The Youth Group welcomes panellist Irene Schokker-Van Linschoten, children's nurse at Erasmus MC Sophia Kinderziekenhuis in the Netherlands, to talk about (and break down) some of the stigmas young patients face.

Join the conversation and [register here!](#)

## CALL FOR EVIDENCE

# "A comprehensive approach to mental health"

Share your views and contribute to developing this EC initiative before 15 February

## CALL FOR EVIDENCE | Share your thoughts on the Commission's initiative for "A comprehensive approach to mental health"

The European Commission has opened a call for feedback and would like to hear your views on their mental health initiative that "seeks to promote a comprehensive, prevention-oriented approach to mental health as a public health issue and to mainstream mental health into EU policies".

The call's document describes the need for EU action on the topic as follows:

*"The overall aim of the comprehensive EU approach to mental health is to improve mental health by integrating mental health into all relevant EU policies and to maximise the added value of EU policies in national and local efforts. Mental health is a determining factor in the effectiveness of EU policies as well as in the health, stability and prosperity of our societies. It is therefore essential to ensure that the EU adds maximum value to the coordinated efforts undertaken by Member States and others to help promote mental health, prevent poor mental health, treat mental health problems and deal effectively with the consequences."*

In short, this initiative sets out:



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- How mental health considerations should be factored into a wide variety of resilient EU and national policies for the benefit of people across the EU

The feedback period runs until 15 February, so be sure to submit your input [here](#) before that time.

## PROJECTS PORTAL

The graphic features a blue background with an orange wave-like shape on the left. At the top, the text 'Data Saves Lives Ambassador Training Bootcamp 2023' is written in large, bold, orange and white letters. Below the text, there are several icons: a white cross on an orange background, a blue bar chart with a line graph, a green bar chart, a green circle with a white cross, a pie chart with green and grey segments, and a donut chart with orange and blue segments. At the bottom, there is an illustration of a diverse group of six people (three women and three men) standing together. In the bottom right corner, the 'Data Saves Lives' logo is displayed, consisting of a blue and orange circular icon and the text 'Data Saves Lives' in white, with the hashtag '#DataSavesLives' below it.

# Data Saves Lives

## Ambassador Training Bootcamp 2023

#DataSavesLives

**FINAL WEEK | Register for the Data Saves Lives Ambassador Bootcamp on Artificial Intelligence (AI)!**

AI in healthcare is a trend that is here to stay, the question is: is your patient organisation ready to fully embrace it?

We are offering organisations the chance to send one representative to our [Data Saves Lives](#) AI Bootcamp event, which will be delivered over two days in **Lisbon, Portugal** from **Tue 28 - Wed 29 March**. Delegates will gain:

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- An understanding of the role of patient groups in influencing how AI is designed to improve the lives of their members
- Confidence to handle challenging questions concerning AI and health data from patient group members and wider stakeholders
- An opportunity to workshop their own ideas surrounding the promotion of and education about the use of AI, with data and communications experts

Please register your interest via the application form [here](#) by **Tuesday 31 January** if you meet the following criteria:

- Are part of an organisation that is a member of the EPF or a member of an EPF member organisation
- Have intermediate knowledge about health data
- Are able to attend the event in-person

All training costs, two nights' accommodation and food will be covered by the EPF, with a further €300 contribution towards travel.  
See you there!

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## EPISODE 1



## Project Spotlight: H2O: Strengthening the Patient Voice in Health Care

Special guests:  
Linetta Koppert  
Jolanda Koenders



### Project Spotlight on H2O: Strengthening the Patient Voice In Healthcare

The European Patients' Podcast has kicked off its third season with a Project Spotlight on the **Health Outcomes Observatory (H2O)** project.

H2O is a project of the **Innovative Medicines Initiative**; it's a public-private partnership drawing together patients, providers, researchers, industry, and policy makers who share an interest in putting patients at the heart of healthcare.

H2O is set to transform the use of patient-reported information in healthcare, enrich the interaction between patients and healthcare providers and, as a result, **drive better outcomes for patients**.

In this episode, EPF speaks with Linetta Koppert of the **Erasmus Medical Centre** and Jolanda Koenders of **Takeda**, H2O country leads for the Netherlands, to learn more about how H2O is strengthening the patient voice in healthcare.

Listen to the episode [here](#).

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### Reminder! Label2Enable survey is open for all (future) health app users

The **Label2Enable project** has published a survey for European patients, informal caregivers and citizens. The survey aims to study health app use, adoption, trust and preferences across the European Union.

The survey is available in 26 languages, and consists of 11 questions, lasting approximately 5 minutes to complete.

Label2Enable is a Horizon Europe project which aims to promote the **ISO/TS 82304-2** health app assessment framework and label to support the development and implementation of an EU quality label for health and wellness apps. Learn more about EPF's involvement and the impact for patients **[on our dedicated site](#)**.

Would you like to share your experience, and support the EU project Label2Enable find out about health app use in the EU? **[Take the survey!](#)**

## MEMBER FOCUS



### Europa Donna Booklet on Genomics, Genetics and Personalised Medicine in Breast Cancer

Genetics and genomics hold the key to unlocking unique combinations lying within



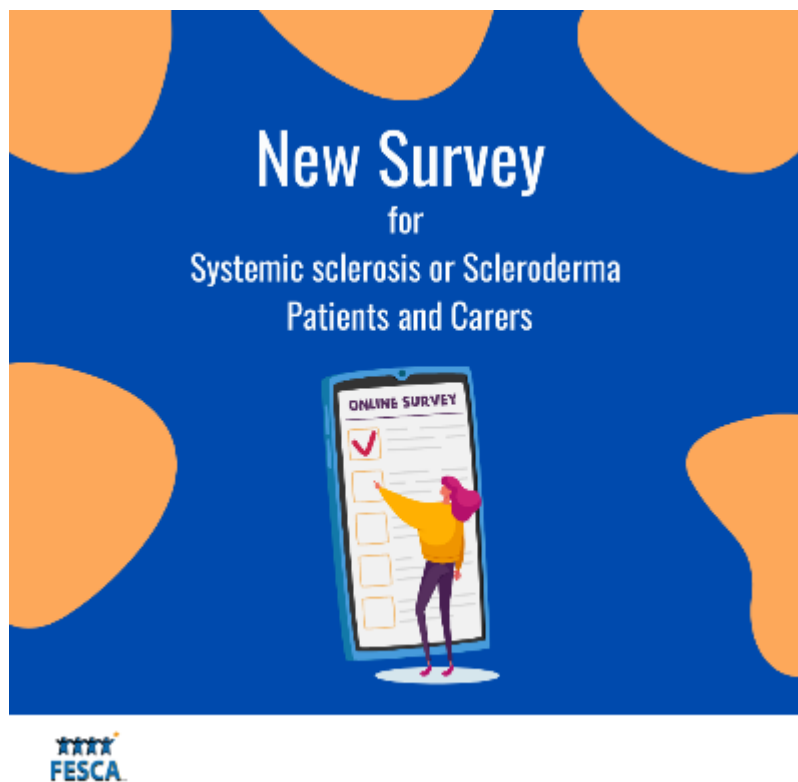
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imperative for advocates and patients to understand this information as it could hold the future of breast cancer therapy. For this reason, Europa Donna – The European Breast Cancer Coalition has developed and published a new 12-page booklet on the topic of *The Advocate's Guide to Genomics, Genetics and Personalised Medicine in Breast Cancer*.

Using scientifically accurate language that is at the same time understandable to the layperson, topics covered include: genetic and genomic testing, genetics and hereditary breast cancer, genetic testing for hereditary breast cancer risk, breast cancer subtypes and biomarkers, genetic and genomic testing of tumour tissue, genomics and biomarkers in metastatic breast cancer, and precision medicine.

The booklet also tackles the basics for advocacy in this area, including why advocates need to understand the role of genetics and genomics in breast cancer, why this topic is important to Europa Donna, inequalities and areas for action, and what to advocate for.

The publication is available on the [Europa Donna website](#).



## **FESCA's Patient and Carer Survey on systemic sclerosis or scleroderma is out!**

The [European Federation of European Scleroderma Associations \(FESCA\)](#) is launching a Patient and Carer Survey on systemic sclerosis or scleroderma across 20 European countries. The surveys will be translated into 16 languages to gather the perspective of patients and their carers on the socio-economic burden of the disease as well as the obstacles along the care pathway.

The surveys have been developed in collaboration with medical experts and patient representatives. The results of the surveys will inform FESCA's Report identifying gaps where further attention and interventions from policymakers and health authorities are needed. Stay tuned for the launch of the Report on World Scleroderma Day, taking place on 29 June 2023!

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complete the survey to help us to continue working to improve the lives of the scleroderma patient community!

### [Access the Patient and Carer surveys here!](#)

On the FESCA website, select if you are a patient or a carer. Once you have access to the survey platform, use the drop-down menu at the top left-hand corner to change to your preferred language. The survey will be available in the following languages (translations are in the process of being uploaded): Croatian, Czech, Danish, Dutch, Finnish, French, German, Greek, Hungarian, Italian, Portuguese, Romanian, Spanish, Swedish, Norwegian, and Turkish.



### **Upcoming event: Emergency Medicine Day**

On the 27th of May it's Emergency Medicine Day. The **European Society for Emergency Medicine** (EUSEM), initiated this campaign to raise awareness on the lack of staff and resources in the emergency departments (EDs), and a lack of recognition of the importance of a well established emergency care system.

This year's campaign is dedicated to patient and professional safety. When an ED is understaffed or the professionals are on the brink of burnout, you can imagine they can't provide the care that a patient needs. This is really a threat to the health care system in many countries.

Under the "Your safety - our priority" slogan, EUSEM believes it is of the utmost importance to provide concrete data to the relevant stakeholders to reflect our distress and how this can threaten the safety of both patients as professionals.

EUSEM invites patients to respond to this five-minute survey and provide information about their experience in the ED as patient or the accompanying person of a patient.

The survey is open till **27 February**.

Background information on this initiative is [available here](#).

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### *Black Pearl Awards*

On Tuesday 21 February in Brussels, EURORDIS will be hosting the 12th edition of our *Black Pearl Awards*. The awards aim to highlight the outstanding work of all those who advocate for the rare disease community. The ceremony will be held both online and in-person, but tickets are selling fast, so make sure to **book your spot** by Monday 6 February! Also, don't forget to submit your entry to the **EURORDIS Photo Award** by Sunday 22 January.

### *Rare Disease Day – Join the campaign!*

The dedicated **Rare Disease Day website** provides a wide array of resources which can support your organisation's involvement in the campaign. The site hosts a **global map and calendar of events** taking place and a large **downloadable collection of campaign materials** you can print or use on social media. On 31 January, Rare Disease Day will also **hold a webinar** on: '*How to raise awareness among healthcare providers*'.

### *For a patient-driven evolution of the Orphan Medicinal Product Regulation: Addressing unmet needs*

On Wednesday 8 February, MEP Frédérique Ries – in collaboration with EURORDIS – will **host an event** in the European Parliament reflecting on how the EU can ensure that more and better treatments are available, accessible and affordable for people living with rare diseases. The live-streamed event will take place within the framework of **Brussels Rare Disease Week**, and will seek the perspectives of patients, clinicians, regulators and developers.

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**EHC is looking for a new CEO**

Apply by 12 February 2023  
More info at [www.ehc.eu](http://www.ehc.eu)

### **Job opportunities with the [European Haemophilia Consortium](#)**

The European Haemophilia Consortium (EHC) is looking for a new CEO. This is an exciting opportunity to represent a European patient community affected by rare and chronic conditions. You will be heading the Brussels office and helping to shape the advocacy strategy to ensure better access to treatment and care.

The EHC is also looking for a part-time Communications Assistant to support the EHC communications strategy.

Find out [more information here!](#)



### **[EUFAMI](#) Position Paper on Coercive Practice**

Coercive practice, such as involuntary admission and coercive measures, such as seclusion, restraints and forced medication, are used in mental health services in all European



Grounds for compulsory admission often include an identified need for treatment to which people are unable or unwilling to consent, and which cannot safely and effectively be delivered in the community. Concerns are often expressed that some people may be at risk of self-harm, or harm to others, if coercive measures are not enforced. Although regulated by national law, involuntary admission and coercive measures conflict with treatment based on informed consent, shared decision-making and recovery-focused care.

EUFAMI believes that coercive practice, even when used as a necessary last resort based on national law, is essentially the failure of mental health services to respond with non-coercive alternatives.

In order to minimize coercive practice in mental health, training should be mandatory on topics of de-escalation skills, human rights, medical ethics, mental health legislation, alternatives to involuntary admission and use of coercive measure as well as on recovery culture. Coercive practice should only occur as a last resort in circumstances when no less restrictive alternative will respond adequately to the risk of physical harm to the person themselves or others.

***If you wish to view the full paper on EUFAMI's position on Coercive Practices in Mental Health Services, please click [here](#).***



European  
AIDS Treatment  
Group



EATG has launched the **Europe and Central Asia HIV & Mental Health Platform**.

This new online space is intended to foster collaboration and experience exchange across Europe and Central Asia in addressing the mental health needs of people living with and affected by HIV.

How does ideal combination prevention look like to you? — EATG **survey is online**. Survey findings will be used to create a tool for monitoring HIV prevention services at community-level in relation to community-defined quality standards. The survey closes on 15 February 2023.

**EATG project reports: PROMise + STEPS 8 reports are now available.** In 2022, EATG held a stakeholder workshop on patient-reported outcome measures (PROMs) in HIV research and development (R&D), as a follow up recommendation on the ongoing consultations and research of the EATG PROMise Project. Participating stakeholders included HIV community members, academic clinicians and

New TINA eLearning course aims to improve engagement in health research

The European Federation of Neurological Associations (EFNA) has launched a new eLearning course on the theme of research, with modules on 'Patient and Public Involvement in research', 'Overcoming the barriers to clinical trials access' and 'Data generation: Surveys to support policy and advocacy'.

The course is the latest in EFNA's digital '**Training Initiatives for Neurology Advocates**' (TINA) programme, which also includes courses on topics such as EU Funding, Communications for Advocacy and Personalised Healthcare.

The modules are video-based and divided into sections that can be watched independently at times that suit the viewer. Each module includes supporting notes, as well as the option to take a quiz on the content and receive a personalised certificate of completion.

Courses are in English, but subtitles in other languages can be enabled.

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