THE EPF European Patients Forum
PATIENT PERSPECTIVE
FEBRUARY 2023

EDITORIAL

Dear reader,

February may be the shortest month of the year, but it was chock-full of activities and happenings here at EPF.

Policy-wise, we focused our efforts on two noteworthy legislative projects: the ongoing review of the pharmaceutical legislation and the European Health Data Space (EHDS), both of which carry a powerful impact for patients. We were pleased to learn that several of our proposals regarding a patient-focused EHDS were taken into consideration for the ENVI and LIBE draft report on the Regulation.

Recently, the Committee of Ministers from the Council of Europe adopted a recommendation about equitable access to medical products and equipment when in short supply. It emphasises that people should not suffer from lack of proper care due to shortages. Earlier this month, European Parliament Members voted to establish a new and permanent subcommittee on public health, which will be part of the Committee on Environment, Public Health and Food Safety.

The Secretariat has some exciting news to share! EPF and ALTEMS Università Cattolica have joined forces to bring you the master programme in International Patient Advocacy Management, now open for enrolments. To help those just starting out with patient advocacy, we have created the Advocacy 101 course. This free, online course is tailored to younger patients and representatives and provides them with exceptional advice on this subject.

This month, Yevheniia Zhyla joined us as Office Coordinator and we are proud to have her on board. We are currently in search of another team member to fill the vacancy for a Capacity Building Assistant.

The EPF Youth Group held a final event, to mark the end of the Sexual Health and Wellbeing Project. Anastasia Semaan, EPF Youth Group president, reports back with some reflections and insights.

For Projects, February marked the launch of a new call for tender: IMMUcan is looking for design assistance. The Periscope Talks, our podcast mini-series dedicated to the work of the Periscope project, is back with a discussion on tools and practices for addressing the challenges of a pandemic.

- On the 28th of February, we will observe, alongside EURORDIS, Rare Disease Day.
- EFA has launched a European Prize to recognize achievements in digital health for asthma and COPD.
- World Duchenne Organization has opened the registrations for Duchenne Centers Accreditation.
- Plataforma de Organizaciones de Pacientes and Malta Health Network have published a guide on labor inclusion and chronicity.
- Among other updates, EATG announces a new publication.

Till we meet again, keep in touch with our work:

Facebook | **Twitter** | **LinkedIn** | **Anchor**

Happy reading!
The EPF team

POLICY CORNER

February in Review

February was perhaps the shortest but not the least intense month for the Policy Team. This month was split between our two major legislative dossiers: the ongoing review of the EU pharmaceutical legislation and the European Health Data Space (EHDS).

At the beginning of February, the expected proposal of the European Commission for the revision of the pharmaceutical legislation was obtained by several media outlets, well before the expected publication date. Naturally, EPF has taken note of the leaked documents containing updates on, for example, the level of patient involvement included in the regulatory process for the approval of new medicines, incentives proposed for the development of new antibiotics, drug shortages, and security of supply. While recognising the fact that leaks are often subject to substantial changes before final publication, our main objective is to continue to consult with EPF members through our working groups on recommendations for the final version of the proposal, which will probably be released in March.

On the digital health front, we have continued our advocacy strategy to put patients at the centre of the EHDS Regulation. The ENVI and LIBE co-rapporteurs have published their **draft report** on the Regulation which includes many of our **recommendations** for a patient-centred Regulation, including meaningful involvement of patients and their representatives. As we have repeatedly stated, harnessing the power of EU health data can help deliver better care and ultimately improve patients' lives, but only if it is designed with and for patients.

EU NEWS

COUNCIL OF EUROPE'S COMMITTEE OF MINISTERS ADOPTS RECOMMENDATION:

"EQUITABLE ACCESS TO MEDICINAL PRODUCTS AND MEDICAL EQUIPMENT IN A SITUATION OF SHORTAGE"

EPF European Patients Forum

Committee of Ministers adopts Recommendation on "Equitable Access to Medicinal Products and Medical Equipment in a Situation of Shortage"

On the 9th of February, the Council of Europe's Committee of Ministers adopted the Recommendation on "Equitable access to medicinal products and medical equipment in a situation of shortage". Equitable access to medicines across Europe is a key policy topic for EPF. In reducing health inequalities, shortage prevention is essential for continuity of care and patient safety.

Consult the full Recommendation document **here**.

UPDATE

MEPs vote in favour of creating new Public Health subcommittee

14 February 2023: MEPs agree to create a new permanent subcommittee for public health under the umbrella of the Committee on the Environment, Public Health and Food Safety (ENVI)

The European Parliament voted the creation of a dedicated subcommittee, to address public health issues. It will deal with programmes and specific actions in the

Prevention and Control.

More details in the EP's **press release**.

SECRETARIAT NEWS

EPF European Patients Forum

MONTHLY ROUNDUP

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

Here's a highlight from our work on patient engagement:

📍 31 January: **Gozde Susuzlu Briggs** joined **EUPHA - European Public Health Association**'s round table webinar on "The Change in Demand and Consumption of Health Information", calling for patient engagement in data use in healthcare: *"The sparked thirst for health information highlights the need for patient organisations to be meaningfully involved in the implementation of a well-functioning system that puts patients at the very centre."*

📍 16 February: **Milana Trucl** gave an interview to the **European Artificial Intelligence and Society Fund** and spoke about **EPF's capacity building work on AI** and the benefits AI could entail for patients: "*Artificial Intelligence in healthcare has the potential to bring great benefits to patients, but only if it is coupled with acceptance and trust.*"

Read the full interview **here**.

MASTER IN INTERNATIONAL PATIENT ADVOCACY MANAGEMENT

EPF European Patients Forum | Università Cattolica del Sacro Cuore ALTEMS ALTA SCUOLA DI ECONOMIA E MANAGEMENT DEI SISTEMI SANITARI

The master in International Patient Advocacy Management is kicking off in March!

The master programme in International Patient Advocacy Management, developed by EPF in collaboration with **ALTEMS Università Cattolica**, is open for admissions.

The course will provide to students the management skills required for a successful coordination and development of patients' organizations' activities in the reference healthcare scenario. The programme is addressed to those who already have a master's degree and aims to provide a professional training to develop management skills for patients' organisations working at local, national and international level.

The teaching activity is then divided into ten modules, from March 2023 to May 2024. The lessons are a mix or fully remote self-learning, hybrid or in presence lessons. The courses will span from healthcare management, European legislation on health, patient involvement, fundraising, strategic communication, planning and bookkeeping, stakeholder management, and more.

See the full curriculum and the course calendar **here** and head to our **dedicated website page** for detailed information!

EPF European Patients Forum

ADVOCACY 101 TRAINING COURSE

The main objective of the Advocacy 101 training course is to provide participants with the strategic skills to make their mark as patient advocates. Participants will be able to use their learnings to engage in public awareness and advocacy actions, both in national contexts and on the European level. Next to this, they will gain in-depth knowledge of representative skills and discover how they can be applied in patient advocacy.

Some of the programme's key questions are:

- What is patient advocacy?
- What is the difference between advocacy, lobbying, and being a patient representative?
- How do you make and use an advocacy map?
- Where do experts get their expertise from?

"*Advocacy 101 is a great course if you want to learn the basics of health literacy to help the patient community. It was engaging, quick, and interesting*", said one of the participants. Does that make you curious to find out more about the topic?

Read more and register **here**!

The Secretariat welcomes Yevheniia Zhyla!

Yevheniia joined EPF in February 2023. As Office Coordinator and part of the Operations team, she is responsible for the daily running of the office, supports the team during and in the lead-up to events, and takes on HR-related tasks, while being of general assistance to EPF's Senior Management Team. Yevheniia is a philologist – she studied English at the National University in Kyiv. Previously, she worked as assistant to the director at the International School in Odesa. In her free time, Yevheniia enjoys spending time with animals, reading, baking, and visiting museums.

We're looking for a new colleague: Capacity Building Assistant

The purpose of the role is to assist in the sustainable growth of the EPF Capacity Building programme by supporting learning activities for patients around Europe.

different facets of patient organisations' advocacy work, with a focus on supporting the organisation of the Cattolica University master on International Patient Advocacy Management, the **Data Saves Lives initiative**, and the Artificial Intelligence project.

- Full-time (100%) position - CDI
- Deadline for applications: 12 March 2023, 23:59
- To start as soon as possible

Find more information about the role and the full job description **here**.

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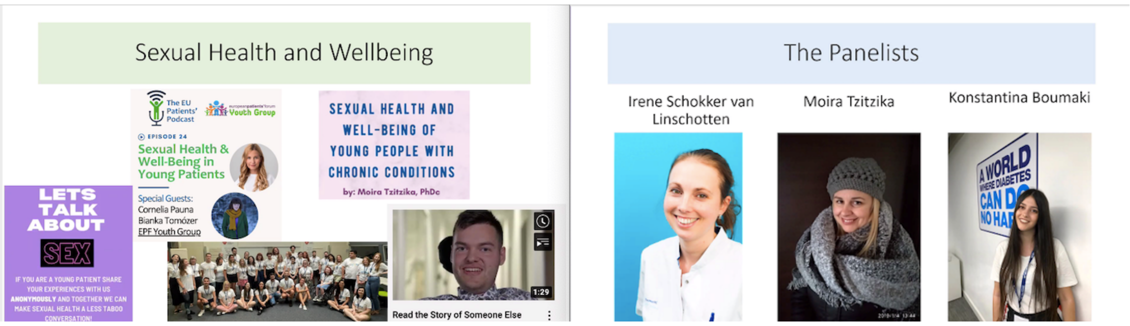
europeanpatients'forum Youth Group



A Reflection Sexual Health and Wellbeing Project & on our Final Event: "Let’s get Provocative! – EPF's Youth Group Discusses Sexual Stigmas

by Anastasia Semaan - EPF Youth Group President

On February 9, 2023 we as the European Patients’ Forum (EPF) Youth Group held our final closing event for our Sexual Health and Wellbeing Project where we aimed to get provocative and discuss certain stigmas around the sexual health of young patients. During our event titled **“Let’s get Provocative! – EPF's Youth Group Discusses Sexual Stigmas”** we invited three speakers, Irene Schokker - van Linschoten, Moira Tzitzika and our very own Youth Group member Konstantina Boumaki, each from different backgrounds, to discuss three topics that had come about from our **overall project**.

The project began by us as a Youth Group

Additionally, it was highlighted that patients and doctors should not hide behind having conversations about sex because they are “taboo topics”, “too personal”, or “due to fear or discomfort”, as it is a natural topic and a part of life. Ultimately, for the stigma around sexual health to be minimized, conversations need to happen between different stakeholders, but always involving the patients, as the choices that are made in the end belong to the patients.

After the Roundtable Discussion we asked our speakers to share a final takeaway for our audience to remember regarding this topic, based on their experiences, and Moira stated that:

specifically beginning the discussion around sexual health for young patients. We initially created and disseminated a survey to young patients about their experiences regarding their sexual health, and provided them with the opportunity to send anonymous "stories". This was intended for us to gain an insight about their journey regarding their sexual health and about any conversations they may or may not have been having. After gathering our data, we consolidated it by analyzing the experiences of different people with different conditions and disease areas. From this we created a **video** whereby as a group we filmed some of these experiences, and during this process we also held an **interview with a sexologist**, and recorded a **podcast episode**, both around the Sexual Health and Wellbeing of Chronic Patients. However there were still some survey findings that were very thought provoking and not included within the video. Hence, from the experiences and areas within sexual health that we believed needed to be addressed we defined them as three "Topic Discussions", and aimed to host a Roundtable Discussion, where the three panelists and the audience could discuss the statements and share their different beliefs around them. The three 'Topic Discussions' were:

1. Some patients should not have children
2. It's hard to talk about sex
3. Treatment plans should consider sexual and reproductive health

This **Roundtable Discussion** brought to the surface multiple conclusions, including the importance of ensuring that patients know about all of the options that are possible for them regarding their sexual lives. It is crucial that communication and collaboration happens between the patient and their doctors and families, and that time is taken to discuss openly, for each decision, the risks involved and what the patient's abilities are.

the capacity to give and receive love and pleasure, although creative problem-solving is sometimes necessary to find avenues for intimate expression. Understanding how symptoms or medications might affect intimacy and sexuality represents a crucial step towards overcoming obstacles effectively. Whether one is newly diagnosed, physically disabled, young, mature, single or in a committed relationship, chronic health conditions do not diminish the universal human need to give and receive love and intimate pleasure".

Irene highlighted that:

"By being engaging with each other, we are making clear that sexuality is important, disregarding the disorder. In this context an open discussion on sexuality is crucial to be able to take the next steps and learn from best practices."

Overall, we began this project with an empowering initiative of wanting to make a change for the young patient community around sexual health. Even though the project may have ended, we all recognize in the group that the message we aimed to promote around empowering young patients regarding their sexual health is a journey that takes constant reminding and not to not be fearful of "being provocative" and to "make bold statements". Therefore, it is of utmost importance that we continue to have these conversations that may seem "taboo" at first, and contribute to normalizing them within society, but especially for the young patient community.

Congratulations to all our members who worked so persistently and diligently on this project, and we thank the audience, speakers and EPF team who have supported us. Follow us on **Facebook**, **Twitter**, and **Instagram** to keep up to date with our current projects.

PROJECTS PORTAL

Call for tender for design work for the European project, IMMUcan

EPF is looking for a designer within a new call for tender to produce high-quality, engaging, and accessible communications assets, including a brand kit, as part of its work on the **IMMUcan project**.

IMMUcan is a **highly technical project**; it aims to study the tumor microenvironment to better understand how the immune system and cancer cells interact at the molecular level. Some concepts central to the project are not easily understood by non-expert audiences.

The **purpose of this call for tender is to facilitate lay audiences' understanding** of how the project works, how patient tumour samples are used, how this benefits patients, and the ultimate contribution of IMMUcan to cancer research.

IMMUcan is a **Innovative Medicines Initiative 2** project (Grant Agreement 821558). EPF leads the work on dissemination and communication, and will be the point of contact. This call for tender concerns the creation of:

> A brand kit for the project
> Ongoing design work on visual aids including GIFs, videos, and infographics, to support lay audiences' understanding of the more technical aspects of IMMUcan.

Does this sound like it is within your expertise, or the expertise of someone you know or have worked with?

Applications must be sent in by **15 March 2023, 23:59.**
Full details here >>

This work has received support from the EU/EFPIA/ Innovative Medicines Initiative [2] Joint Undertaking ([EHDEN] grant n° [806968]; and from the EU/EFPIA/Trial Nation/ JDRF Innovative Medicines Initiative [2] Joint Undertaking ([H2O] grant n° [945345-2]

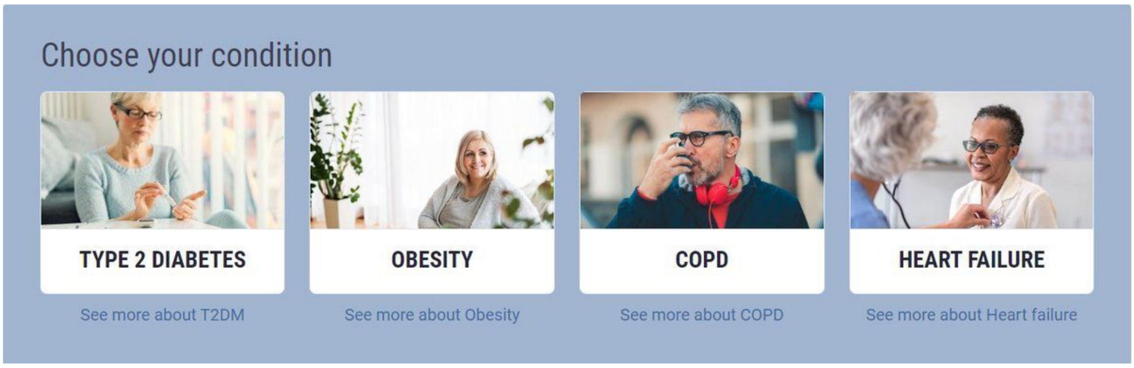
NEW 📢 EHDEN and H2O Collaborate on a Lay-Language Course on Patient Reported Outcomes

EHDEN (European Health Data & Evidence Network) and **H2O** (the Health Outcomes Observatory) projects launched their lay-language course collaboration on Patient Reported Outcomes. This is the 4th course in the series of introductory-level courses on the **EHDEN Academy**, which have been co-produced in partnership with the European Patients' Forum.

This introductory course is designed to familiarise non-experts with the basic concepts around Patient Reported Outcomes, or PROs. The MOOC-style course uses animated content and accessible examples to explain what 'outcome' means in healthcare, why PROs are important and how they are gathered, why it is beneficial to share PRO data, the safeguards in place, and more.

Course 4 builds on the foundational concepts explored in courses 1-3, and sets the stage for a further module.
You can access the course, plus many other free training materials at the **EHDEN Academy**.

Or access the course via this link > >



The COMPAR-EU project has ended; the platform is live

The **COMPAR-EU project** came to an end in December 2022, but the core work of the project lives on in the project **platform to support decision-making on self-management interventions (SMIs) for different end users** for the four relevant chronic diseases of the project.

The platform collects and collates the different results obtained in the project's life. The

1) summary of findings tables, aimed at guideline developers and healthcare professionals to find and understand the main results regarding the effectiveness of SMIs
2) evidence to decision frameworks to support policymakers and managers to make decisions about SMIs
3) Patient Decision Aids, designed to help reach a shared decision between a healthcare professionals and a patient regarding SMIs, tailored to patient preferences regarding specific outcomes or the interventions' characteristics
4) repositories of randomised controlled trials, tools, and interventions to support researchers and clinicians by presenting the information synthesised in the project in different ways

Curious to learn more? Head to this link >>

The Periscope Talks: Tools and Practices for Addressing Pandemic Challenges

The Periscope Talks is back with the second episode of Season 2! It focuses on the **Massive Open Online Courses** (MOOCs), developed by the PERISCOPE project partners, that are available on Coursera's e-learning platform. These courses aim to offer insights into the COVID-19 pandemic and propose new ways forward for better crisis response.

Our guest for this episode was **Laure Guillevic**, Policy Officer at the **Federation of European Academies of Medicine** (FEAM).

after the successful conclusion of all its modules.

Listen to the episode **here**.

MEMBER FOCUS

ARTICLE 'ESTIMATING CUMULATIVE POINT PREVALENCE OF RARE DISEASES: ANALYSIS OF THE ORPHANET DATABASE', EUROPEAN JOURNAL OF HUMAN GENETICS (2019)

#RAREDISEASEDAY
28 FEBRUARY 2023
RAREDISEASEDAY.ORG

Rare Disease Day 2023 - 4 days left!

Rare Disease Day is observed every year on 28 February (or 29 in leap years) - the rarest day of the year.

Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease.

Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse but united in purpose. Rare Disease Day was set up and is coordinated by **EURORDIS** and over 65 national alliance patient organisation partners.

Show your support for this great initiative and get more details **here**!

EURORDIS is offering fellowships for up to 40 patient advocates to attend the ***EURORDIS Membership Meeting (EMM) 2023*** taking place 25-27 May in Stockholm, Sweden. The EMM 2023 will provide the opportunity for engaging discussions on the road towards holistically addressing patient needs and ensuring their full inclusion in society. Selected fellows of EMM 2023 will receive free registration, travel, and accommodation. For details, please contact: **anja.helm@eurordis.org**.

EFA launch European prize to recognise achievements in digital health for asthma and COPD

The **European Federation of Allergies and Airways Diseases** (EFA) has launched a Prize to welcome applications from innovators whose digital products improve the lives and health of asthma and chronic obstructive pulmonary disease (COPD) patients in Europe.

The EFA Patients' Digital Prize is set to recognise digital health solutions addressing asthma and COPD patients' needs while empowering them to manage their care. As a patient initiative, the Jury will be especially looking for innovations that embed patients' input from development to implementation, are accessible for patients' use, and facilitate dialogue between patients, healthcare professionals, and the digital sector.

The application is open until 27 March 2023. More information is available **here**.

World Duchenne Organization announces that the applications for Duchenne Centers Accreditation are now open

up to date care for everyone living with Duchenne muscular dystrophy.

Accredited Duchenne Centers provide comprehensive care according to the international care considerations and consensus guidelines. To be eligible for application, Duchenne centers must provide multidisciplinary care, which may be delivered either by one center, or shared with other locations.

Read more about the application process in WDO's **press release**.


Managing people with chronic diseases in the work environment

A practical guide for companies and employers

PLATAFORMA DE ORGANIZACIONES DE PACIENTES
MHN MALTA HEALTH NETWORK
Funded by the European Union

Plataforma de Organizaciones de Pacientes and Malta Health Network publish guide on labour inclusion and chronicity

In Europe, 1 in 3 people of working age have a chronic disease that impacts their personal, family, social, and work life. These people are able to work and they want to do it. However, many of them are concerned about the consequences of the impact of their disease on the performance of their work.

created "Managing people with chronic diseases in the work environment" with the aim of giving visibility to the situation of people living with a chronic disease and contributing to their full labour and social inclusion. The organisations have developed this guide aimed at companies and employers with the purpose of informing about the impact of chronicity on employment and the needs of these workers, and guiding them on the possible adjustments to be implemented that contribute to favouring the inclusion of people with chronic disease in the workplace.

Read the publication **here**.

EA TG European AIDS Treatment Group

News and updates

- The **European AIDS Treatment Group** (EATG) shares **mental health priorities for people living with and affected by HIV** in response to European Commission's call
- PROMise project launches **Community Activist Toolbox**
- EATG reports from **RBDCOV's second face-to-face meeting** in Barcelona
- **Red Ribbon Istanbul**: update on the natural disasters in Turkey and donation options

New publication

Trajectories: AIDS Activism in Western Europe

The comic book ***Trajectories: AIDS Activism in Western Europe*** aims to illuminate the struggles of campaigners from diverse social backgrounds in their fight against HIV and AIDS, as well as against the stigma attached to people living with AIDS. EATG has read earlier versions of the comic book and provided the authors and the cartoonist with our feedback, which has helped shape the final iteration of the book.

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