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The Patient Perspective

July 2022

EPF European Patients Forum

Reflections

Welcome to our July Patient Perspective newsletter!

July has been busy for us at the EPF Secretariat. Join us for a recap of what we have been up to in the last month.

But first, we'd like to heartly thank all of you for being a part of the EPF community and for subscribing to our newsletter. We are very proud to share with you that the number of people who read the **Patient Perspective** had almost tripled, compared to the same time last year!

Between the 14th and 17th of July we had the extraordinary change of getting to know 40 inspiring young patient advocates, from all across Europe, during STYPA 2022.

Following a consultation with our members, EPF drafted and published a response to the European Commission's call for feedback on the **European Health Data Space** (EHDS).

To summarise our response, we believe that:
1. Patients must be in control of their electronic health data.
2. Safeguards should be in place for the re-use of electronic health data.
3. Patient organisations should be part of the governance of the EHDS.
4. The functioning of the EHDS with pre-existing mechanisms should be clarified.

This month's issue of the Patient Perspective covers our response in more detail, as you'll see below.

The **EPF Youth Group** shares with all of us some important advice: we are all dedicated to pouring our heart and passion into making positive changes in our communities, but it's important that we are not pouring from an empty cup!

As usual, our **Projects** team is extremely active in embedding the voice of patients across all of our initiatives.

It has also been a productive summer for our members, who shared with us exciting updates on their activities. Make sure to read more details under the Member Focus section.

See you in August!

The EPF Team

News From the Secretariat

updates from the inside

THE EUROPEAN HEALTH DATA SPACE

“Meaningful involvement of patients in shaping the European Health Data Space is fundamental to bringing the unique experience of patients, responding to their needs and concerns, and addressing ethical challenges in a more harmonised and coherent way”

EPF's response to the European Commission's call for feedback on the European Health Data Space

We are pleased to publish our response to the European Commission’s call for feedback on the **European Health Data Space** (EHDS). The Commission will summarise all feedback received and present them to the European Parliament and the Council of the EU to inform the legislative debate.

The EPF response, drafted in collaboration with member organisations, welcomes this overarching framework for the exchange and sharing of health data while stressing the need for a European Health Data Space **shaped with and for patients**. This is a unique opportunity for EPF and its members to play an enabling role in data quality and trust, which should be reflected in the regulation.

As this call for feedback only allowed a limited response, EPF will develop a more extensive position statement on a patient-centred EHDS to engage with relevant stakeholders throughout the legislative process.

For more information on the consultation, click **here**.

>>> **Read our full response**

STYPA 2022 is a wrap!

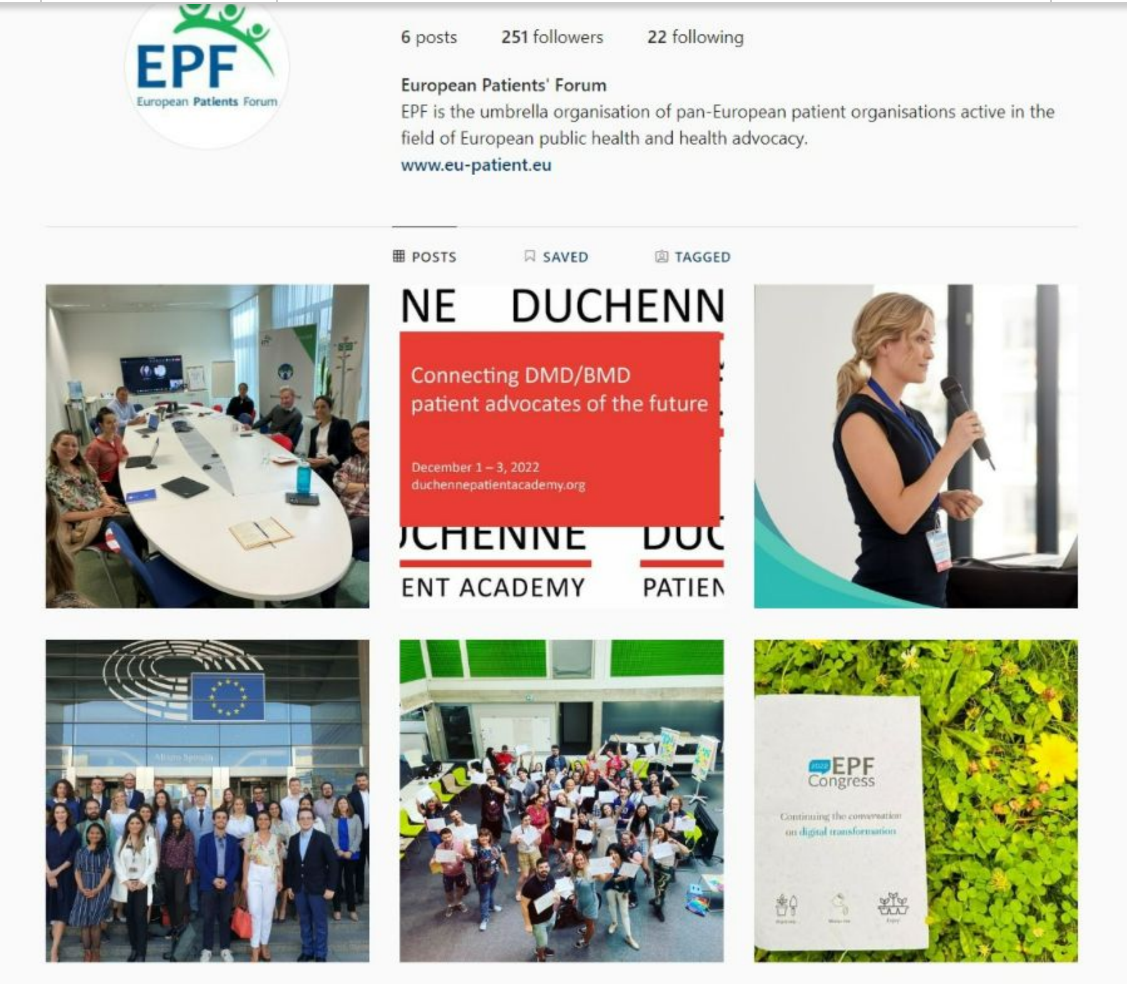
As we said goodbye to the 40 participants of this year's sixth edition of the Summer Training Course for Young Patient Advocates (STYPA), our team reflected on the extraordinary opportunity we had to interact with such an inspiring group of young people.

The young patient advocates met face to face in Strasbourg, between the 14th and 17th of July. They worked together with our trainers to dive deeper into the topic of sexual health and well-being for young people with chronic conditions to provide key recommendations to their fellow peers on the topic.

Throughout the course, the participants had the opportunity to be a part of workshops and interactive games focusing on the importance of communication with HCPs, partners and potential partners on this delicate topic.

The group will meet again virtually, this fall, for follow up webinar.

We are confident that a new generation of young patient advocates is ready to drive social change and improve the communities they live in!



6 posts 251 followers 22 following

European Patients' Forum
EPF is the umbrella organisation of pan-European patient organisations active in the field of European public health and health advocacy.
www.eu-patient.eu

Did you know you can follow us on Instagram?

Click on the button below and let's explore the world of Instagram together!

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europeanpatients'forum
Youth Group

In the **EPF Youth Group**, we understand very well that patient advocacy can take its toll, especially as a lot of us who are advocates live with a chronic or long term health condition ourselves. So, while we are dedicated to pouring our heart and passion into making

If you are reading this as a patient advocate or you're not sure how to fit advocacy work around other commitments, here are our top 3 tips on maintaining a healthy balance between advocacy, work, life and health:

Prioritise and don't over-commit! We know this is really hard to do, but something we say in the EPF Youth Group is that advocacy is always tertiary to our primary and secondary responsibilities and needs - whether those are life, health or work commitments. Always make sure you are meeting your primary needs first and foremost. Put your own oxygen mask on first, as the saying goes!

Plan and organise - for example, set timelines and deadlines and block one or two hours a week - however much time is realistic for you - to focus on advocacy work. Knowing and communicating how much time and energy you are able to commit to advocacy will also help you to set boundaries and prevent over-committing and burnout.

Communicate and ask for help! If you are working on an advocacy or volunteering project with other people, don't be afraid to ask for help or adjustments if you are struggling or need to take a break - the more you communicate your needs, the better your peers will be able to support you. We cannot stress enough the importance of looking after yourself first

With that being said, we will be taking the summer off to recoup and recharge, before we return to working on our **Sexual Health and Wellbeing** and Young Patient Involvement projects - in the meantime, feel free to message us any tips we may have missed via our Instagram page **@epfyouthgroup** or **Twitter**! If you have any questions or would like any more information about the EPF Youth Group and how to get involved with our work, email us at **youthgroup@eu-patient.eu**.

Take care of yourselves and we will see you on the other side with updates on what we'll be working on after the summer break!

Projects Portal

briefings on EPF's ongoing projects

The COMPAR-EU platform launched

COMPAR-EU consortium partners are delighted to announce the launch of an **information technology platform** to support decision making on SMIs for different end users with the four

COMPAR-EU Final Research Conference – Call for Poster Abstracts

Ahead of the project closing, the **COMPAR-EU consortium** has announced a call for submissions of poster abstracts for the COMPAR-EU final research conference. The research obesity, COPD and heart failure.

This interactive **COMPAR-EU** platform hosts several products to support decision making on self-management interventions, including interactive Summary of Findings tables, Evidence to Decision frameworks and recommendations, Patient Decision Aids, as well as repositories of randomised controlled trials (RCTs), among others.

The platform also offers recommendations for four chronic diseases – type 2 diabetes, obesity, chronic obstructive pulmonary disease, and heart failure.

Curious to learn more?
Visit the platform

Spain.

Partners will **present the key findings**, and will **launch the main product of the project**, an innovative information technology platform featuring self-management tools. **Leading researchers** will be invited as keynote speakers, **young researchers** are particularly encouraged to submit their work in a poster session. The objective of the poster session is to **foster research and to promote and exchange new ideas** in the area of self-management, self-management support and chronic diseases.

Interested to learn more or submit a poster abstract? **Follow this link**

Closing of the Horizon 2020 PERMIT Project - Podcast episode

> 2,5 years of collaboration
> 70+ Personalised Medicines recommendations
> Huge value for patients

The **PERMIT project,** a **Horizon 2020** project focusing on personalised medicine trials has ended. In the latest EPF podcast we spoke with Paula Garcia Lobato of **ECRIN-ERIC** to understand more about the project, its aims, impact for patients & next steps.

EPF is proud to have participated in the **PERMIT project**. Personalised medicine has enormous value for patients, potentially reducing trial and error treatments, enabling better choices for medications, and managing rising healthcare costs. By participating in this project, EPF ensured that the patient perspective and journey were considered throughout the workshops and recommendations put forth by the expert groups.

🎧 **Listen to the Podcast**

SURVEY ✍🏽 Experiences with Patient Involvement in Health Technology Assessment (HTA) in Europe

SHARE YOUR EXPERIENCE! Following the **12 May introductory webinar** on how patients perceive involvement in HTA processes, the **360 HTA Patient Involvement** partners have launched a survey to better understand how patients are involved in HTA currently, and how to do it better in the future.

All stakeholder groups (patience, carers, industry, academics, health care providers, HTA agencies) who have experienced patient involvement in HTA in any European country **are invited to share their experiences** in a 20 to 30 minute survey.

The survey is completely anonymous, and was co-created by patient organizations and HTA experts, **and is available in six languages (English, French, German, Italian, Spanish, Polish).** The aggregated results and insights will be shared on the project website, as well as through our social media channels and dedicated webinars, or you may register to receive the report.

Learn more about the work of the patient and citizen involvement interest group (PCIG) of HTAi, the European patients forum (EPF), and the European Patient Academy On Therapeutic Innovation (EUPATI), on the **360° HTA PATIENT INVOLVEMENT** project.

>> Link to the survey; select your language!

Member Focus

highlights from our member organisations

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Grand Rounds for Clinicians Working with Spina Bifida and Hydrocephalus

The **International Federation for Spina Bifida and Hydrocephalus** (IF) facilitates meaningful discussions and opportunities for medical education among healthcare professionals working with individuals with Spina Bifida and or Hydrocephalus through Grand Rounds.

IF invites clinicians from all around the world to the third online Grand Round session on the topic of Fetal Surgery with **Dr. Agnieszka Pastuszka** (Pediatric, urologist and fetal surgeon, Medical University of Warsaw - Poland) on Friday, August 12, 2022 at 3PM (CEST).

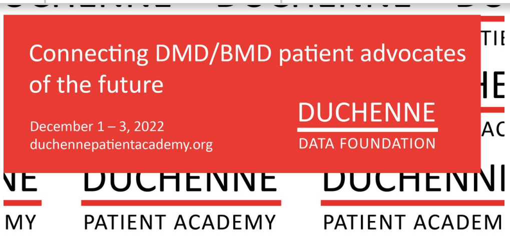
EA TG European AIDS Treatment Group

It was a productive month at **EATG**. Here are some updates on their activities!

EHVA project initiated a clinical trial to test a candidate therapeutic HIV vaccine and immunotherapy medicine. EATG is the community engagement partner of the project. A multilingual set of Q&A sheets about the trial was also launched.

EATG, **ESWA** and **Legebitra** have launched an **youth activist toolbox** to support online peer-training. The e-MPOWER toolbox is intended for youth advocates, volunteers, trainers, and those who work closely with youth, who want to deliver an online sexual health and rights training programme.

EATG is present at the **24th International AIDS Conference** taking place in Montreal, Canada and online from the 30th of July until the 2nd of August.



World Duchenne Organization is organising a new edition of the Duchenne Patient Academy

The 6th edition of the **Duchenne Patient Academy** will take place online, between the 1st and 3rd of December, 2022. The event is the result of a collaboration between the World Duchenne Organization and Duchenne Data Foundation.

Duchenne Patient Academy aims to inspire and equip patient advocates to become change makers and build a better future for people living with dystrophinopathies. So far, it has trained over 500 DMD/BMD patient advocates from 52 countries.

Applications for Duchenne Patient Academy will open mid-September.

event for all stakeholders working in the field of HIV/AIDS around the world.

Fifty years of Pride: EATG's place in the fight for equality. This year, the European AIDS Treatment Group turns 30. It's an important opportunity for the organisation to reflect on their wins and losses as well as on the future challenges, regroup with members, communities, and allies. **Read the second article** from a series of blogs, to be released each month from June 2022 onwards, forming part of **EATG's 30th Anniversary Campaign** running from June to December 2022. The blogs, together with a publication of stories and reflections to be released around World AIDS Day, will document the impact of EATG, its activities, and the views of members and allies, over the 30 years

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EKPF Annual Summit and General Assembly 20th-21st October in Athens

The **European Kidney Patients Federation** announces that the executive committee has decided at its last meeting that the Annual Summit and General Assembly (AS & GA) will be held on 20-21 October in the beautiful city of Athens.

The venue is an amazing location, very close to historical and archaeological attractions. An exciting opportunity for all organizations to come together to discuss and learn about the issues that matter to us in chronic kidney disease.

EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

Communications for Patient 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 and Personalised Healthcare.

The 'Communications for Patient Advocacy' series is presented by Melissa Curley, owner of communications training company SocialBe. The series is divided into three modules – Communicating with impact, Communicating persuasively and Presentation skills for public speaking.

Over 60 minutes, Melissa shares key insights, tools and strategies that will empower you to communicate with confidence, poise and clarity, so that you can successfully advocate for yourself or your community.

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.

EFNA's e-learning modules are free to access, though registration is required.

Introducing COVIRNA

COVIRNA is a patient-centred Innovation Action aiming to generate a diagnostic tool to

Although lungs are the main organs involved in COVID-19, one of the major systems affected by the virus is the cardiovascular system. It is estimated that 20% of patients infected with COVID-19 do not die from pulmonary but cardiac problems. *This is precisely the issue that the COVIRNA project is trying to address.* The project will generate a diagnostic tool to identify COVID-19 patients at risk of developing fatal cardiovascular complications. The novel diagnostic tool will help healthcare providers improve individualised surveillance, care and follow-up of COVID-19 patients.

To get updates from the project team, you can subscribe **here**.

My HeART is **GAMIAN-Europe**'s inaugural art competition that was launched earlier this year.

The project aims at exhibiting the talent

As part their suicide prevention in young men project, **GAMIAN-Europe** has followed up its two in-depth workshops with a second visual part of the campaign.

have chosen to submit.

During the summer, judges will evaluate their work and three winners will be announced in September.

The top submissions will be displayed across GAMIAN-Europe's website and social media channels to give artist members maximum exposure.

Watch this space!

interactive toolkit for young men looking for help or those wanting to help them, plus other engaging social media assets.

These will be released on World Suicide Prevention Day (September 10).

Find out more information on the project **here**!

14 June: Alzheimer Europe hosts European Parliament Lunch Debate examining EU and WHO policies on neurological conditions

On 14 June 2022, **Alzheimer Europe** held its first in-person European Parliament Lunch Debate since February 2020, which focused on "Neurological conditions and mental health in EU and WHO Europe programmes". The event was attended by approximately 70 people, including representatives from Alzheimer and dementia organisations across Europe, from civil society and from industry, as well as European policy makers.

Apply today!

The Alzheimer Europe Anti Stigma Award

will be given to an outstanding initiative aimed at combating stigma and promoting a positive image of dementia and people living with dementia. We will present it during our Annual Conference in Bucharest (October 2022)

More information and application form can be found at: bit.ly/AEAntiStigmaAward

Anti Stigma Award

#AEAntiStigmaAward

With the support of: The Alzheimer Europe Foundation, Biogen, Lilly, Roche

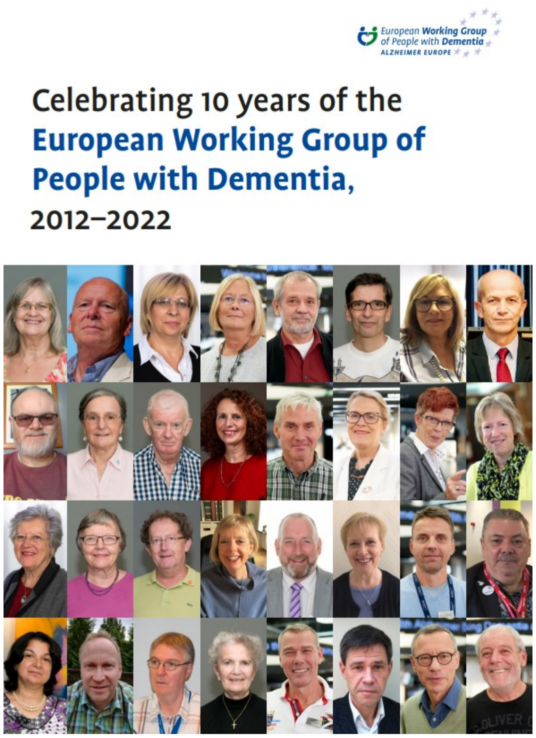
Alzheimer Europe

Alzheimer Europe invites applications for its new Anti-Stigma Award

On 22 June 2022, Alzheimer Europe announced a new award, recognising an outstanding initiative aimed at combating stigma and promoting a positive image of dementia and people living with dementia. The Alzheimer Europe Anti-Stigma Award will be presented at the closing of the upcoming Alzheimer Europe Conference in Bucharest.

The award is open to individuals and organisations established in a **member country of Alzheimer Europe** and which has been developed and/or implemented in the past three years (2019-2022). It can be for projects, campaigns, films, videos, publications or books which aim to address the stigma attached to dementia.

Find out more about the award!



European Working Group of People with Dementia
ALZHEIMER EUROPE

Celebrating 10 years of the
European Working Group of People with Dementia,
2012–2022

Special publication celebrates 10 years of the European Working Group of People with Dementia

Alzheimer Europe has launched a special publication, to celebrate 10 years of the inspirational work of the European Working Group of People with Dementia (EWGPWD). Congratulations to the group on its 10th anniversary!

Here's a **full recap of the launch**!

You can download the celebratory publication, **here**.

Inside the Bubble

updates, stories and events around EU healthcare

Upcoming deadline for applications for HaDEA's new action greant under the EU4Health Programme

HaDEA has launched a new action grant under the EU4Health programme to support the European Health Emergency Preparedness and Response Authority (HERA).

Stemming from the COVID-19 crisis, this action supports one of the EU4Health programme priorities to protect European citizens from serious cross-border health threats and strengthen the responsiveness of health systems to cope with these.

The action grant aims to establish a pilot network of top-class laboratories and research institutes with the expertise and capacities to support HERA in identifying emergent pathogens and ensuring the availability of medical countermeasures for improved health preparedness and response. In a health emergency outbreak, the network will have to support HERA in providing a timely, targeted, and tailored input on the identified health threat.

All interested parties are invited to send their applications by **18 August 2022, 17:00 (CEST)**.

Budget: € 25 000 000
Learn more about the call and apply on the Funding and Tenders Portal.

The European Commision in partnership with the European Disability Forum invites cities to apply for the 2023 Access City Award

The **2023 Access City Award** competition is now open for applications. This EU award recognises cities that have done outstanding work to become **more accessible for persons with disabilities.** As mentioned by Commissioner Dalli in this video, the efforts of these cities are essential to build a Union of equality. The award is organised by the European Commission in partnership with the European Disability Forum. The winner and runners-up receive a monetary prize:

- **1st place: €150 000**
- **2nd place: €120 000**
- **3rd place: €80 000**

The winners will be announced on **25 November 2022**, with first, second and third place prizes and up to four special mentions being awarded.

How can my city apply?

Cities across the EU with over 50 000 inhabitants are eligible to apply. If a country has fewer than two cities with so many inhabitants, two or more smaller cities in the country can join to apply if together they have more than 50 000 inhabitants.

Applications must be made by completing and submitting an online application by **8 September 2022** (up until 23:59 CEST) at the latest.

A guidance note for applicants and the participation rules are available in all official EU languages on the official Access City Award website.

WHO declares monkeypox outbreak a global emergency

The World Health Organization declared the monkeypox outbreak a public health emergency of international concern, the health body's highest level of alert. The decision on Saturday (22nd of July) from WHO chief Tedros Adhanom Ghebereyesus came as the organization's emergency committee was unable to reach consensus on whether the outbreak constituted such a global emergency.

Commission launches once in a generation overhaul of blood, tissues and cells rules

On the 14th of July, The European Commission has launched a plan to improve the safety and quality standards for people treated with substances of human origin (SoHO), donors, and children conceived through medically assisted reproduction. It has laid it all out in a 118-page proposal, set to replace the current two decades-old blood, tissues and cells legislation.

> **"If you have knowledge, let others light their candles in it."**
>
> **Margaret Fuller**

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