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The Patient Perspective

August 2022



Reflections

Welcome to our August Patient Perspective newsletter!

August 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. With autumn closing in and with a lot of events coming our way, join us and read insightful updates about what's happening in the world of patient involvement in healthcare.

Speaking of events, EPF will host the COMPAR-EU Final Conference Advocacy Event, to mark the end of the project. It will take place in Brussels, on the 15 and 16 November, 2022. This advocacy conference marks 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 Policy Team has advanced their work on on going policy files. You can read more details about their work below.

The **EPF Youth Group** shares with all of us some insights and impressions from the **EPF Congress 2022**. They've also shared some news on an upcoming project. We're looking forward to hearing more about it!

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 month for our members, who shared with us exciting updates on their activities. Make sure to read more details under the Member Focus section.

We hope you enjoyed your summer and are back refreshed and well rested!

The EPF Team



updates from the inside



Updates from EPF's Policy Team

The month of August has been a busy one for the Policy team. For the most part, we have continued advancing work on previous policy files.

To start with, we are currently compiling a report on the **European Semester 2022 Spring Package**, analysing all of the **Country Reports**. This year, unlike in previous editions, the status of healthcare systems is looked at for every country, including a series of tailored recommendations on how to improve current challenges and long-term sustainability. In addition, a brief analysis is also included in each Country Report on how the analysis country is performing regarding the United Nation's **Sustainable Development Goals**.

We are also continuing our input to EU projects. For example, in the PERISCOPE project: in the following days, you will receive a communication from us encouraging you to participate and disseminate two surveys (one for individual patients and another for patient organisations) on the continuous impact of the COVID-19 pandemic. These will be the follow-up of the survey that we conducted between September and October 2022 (its report is available [here](#)).

Another topic we have worked on is the summary of the **European Society for Clinical Nutrition and Metabolism** (ESPEN) nutritional guidelines for Inflammatory Bowel Syndrome patients. We are currently looking into the development of a lay-language summary which includes some visual elements.

Finally, should you have any questions on our ongoing work or any other related matters, please feel free to reach out to us at policy@eu-patient.eu.

Meet Milana Trucl: EPF's new Policy Assistant

Milana Trucl joined our team in July 2022 as Policy Assistant. In this role, she supports EPF's policy and advocacy work, including monitoring policy developments, conducting background research and assisting the policy team

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focus on digital health.

Prior to joining the EPF, Milana's work focused on monitoring and analysing EU health and social policies. She holds an MA degree in European Studies obtained at the University of Trento, Italy.

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The **European Patients' Forum Congress 2022** was attended by a wide audience ranging from patient representatives to policymakers, healthcare representatives and academics to discuss ideas and solutions for digital transformation and patient involvement. Our very own Konstantina Boumaki from the **EPF Youth Group** also attended the event as a youth group representative. Konstantina had positive thoughts to share on the event and beneficial impact of collaboration:

"I loved that there were participants from different places; there were patient advocates, associations, federations and pharmaceutical companies and we had good discussions. I participated in panel discussions even though I don't usually take part in them because it was so open and everyone had an opportunity to take part. I loved the discussions about health data and the breakout rooms where we played a board game about the patient experience and modernisation of health data.

I love that EPF is bringing people from so many different backgrounds together, it's opening my mind to think in a different way. People wanted to be there, they were all listening, all participating and open to meeting new people and forming new networks and connections. If we can have open discussions and share ideas and solutions, we can change the world to be a better place."



Anastasia Semaan, president of our EPF Youth Group, highlights the importance of including, and collaborating with, young patients at such events:

"It is so important for young patients to be represented at these events, because it justifies the importance of the youth voice. How can action be taken to support young patients and ensure that their rights are being adequately met, without personally acknowledging their wants and needs? The inclusion of young people in practice provides a confidence-boosting opportunity for them and its value should not be disregarded - from the side of the organizer and the participant. For change to happen, do we not need to understand the root of the problem from those who experience it? Age should not be a

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Indeed, we as the EPF Youth Group are incredibly grateful for the opportunities that EPF has provided to raise our voices and communicate our community's needs and expectations as young patients. In fact, our next project - aptly named the 'Youth Collaboration Project' - will support patient organisations to develop and incorporate effective youth group structures and programmes to ensure the youth voice is included and elevated in their work! Watch this space for more news on this project and how you can get involved!



Projects Portal

briefings on EPF's ongoing projects

Save the Date – COMPAR-EU Final Conference Advocacy Event

The European Patients' Forum is pleased to announce that it will host the **COMPAR-EU Final Conference Advocacy Event**, to mark the end of the project.

This advocacy conference marks 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 aim is to gather ~70 stakeholders to exchange experiences and expertise on self-management (SM) best practices, share the lessons learned from the implementation of SM policies, and discuss how to best integrate and incorporate the project's findings across various settings. Other topics, like the **Self-Management Europe Initiative**, project lay-language materials, and self-management policy implementation practices will also feature in the programme.

The conference will take place in Brussels, and will feature patient representatives from across Europe, EU policy makers, other EU health stakeholder organisations, COMPAR-EU project partners, and national public health representatives.

Key information:

- 📅 15 & 16 November, 2022
- 📍 Brussels, Belgium
- ✉️ On site attendance via invitation only
- 🔗 Livestream link to follow

Stay tuned to our channels for incoming updates!

Background: Learn more about the **COMPAR-EU** project, **EPF's involvement, and the value for patients.**

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Deadline Extended to 11 September! 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 conference will take place from **26-27 October 2022 in Palma de Mallorca, 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](#)



NEW COMPAR-EU blog: The EPF Team Prepares for a Successful End of COMPAR-EU

On 3 August, the **COMPAR-EU** blog published its latest edition featuring updates from the **European Patients' Forum** (EPF) team. With the end of the COMPAR-EU project foreseen for end of the year, EPF team has begun its preparations for further outreach efforts, and a big event to close our collaboration on this project at the end of the year.

Hit the link below to learn more about how we are leveraging audio-visual content to support our uptake efforts, what to expect in 2023 from the project, and the announcement for an advocacy event in Brussels.

[Read the blog here](#)



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#Label2Enable is preparing its month three milestone for early September: the project website! Your place to stay updated on the CEN-ISO/TS 82304-2 #HealthApp label assessment, use and adoption, relevant events and discussions.

Don't miss the launch!

You can already follow the project updates on [twitter, at this link >>>](#)



The banner features the 'LABEL2 ENABLE' logo in blue and green, with a green medical icon. Below the logo is the text 'Project Website'. A central image shows a laptop displaying the website's interface, which includes sections for 'Healthy and safe' and 'Easy to use'. To the right of the laptop, the text reads '...launching early September!'. At the bottom left, there is a logo for the European Union with the text 'Funded by the European Union'. At the bottom center, a search bar contains the URL 'www.label2enable.eu'. The banner is decorated with a stylized starburst graphic on the left and right sides.

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](#)

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 PATIENTS PODCAST

▶ EPISODE 4

PERMIT project comes to an end

Special Guest:
Paula Garcia, ECRIN



Member Focus

highlights from our member organisations




The 29th International Conference on Spina Bifida and Hydrocephalus
Diverse Needs, Same Rights

Programme Book
5th - 9th September 2022

The 29th International Conference on Spina Bifida and Hydrocephalus - Diverse Needs, Same Rights

The **International Federation for Spina Bifida and Hydrocephalus**

DID YOU KNOW ...  #WDAD2022

The date of the World Duchenne Awareness Day (7/9) refers to the 79 exons of the Duchenne (DMD) gene.

WORLDUCHENNE DAY.ORG

DID YOU KNOW ...  #WDAD2022

The average time it takes to get a diagnosis (diagnostic delay) for Duchenne is 2,5 years.

WORLDUCHENNE DAY.ORG

World Duchenne Awareness Day 2022: Women and Duchenne

September 7 is World Duchenne Awareness Day or WDAD. Each year, an annual campaign aims to increase awareness of **Duchenne and Becker muscular dystrophy**. World Duchenne Awareness Day raises awareness and

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Blind and Hydrocephalus – Diverse Needs, Same Rights that will take place between September 6 to 9, with on September 5 a pre-conference workshop for youth with disabilities only. The aim of the conference is to bring together academics, researchers, healthcare professionals and SBH associations to discuss best practices of all aspects of SBH. A special highlight will be the Conference Day September 7 where we focus on Prevention including speakers from WHO, Micronutrient Forum, Food Fortification Initiative, and more.

Registration links and Conference Programme are available [here](#).

muscular dystrophy.

On September 7, the **World Duchenne Organization** will be hosting an online event. During this event, experts share their stories and experiences surrounding women and girls in the field of DMD/BMD. This year's focus is women and Duchenne.

[Find out more about this event >>>](#)



FH Paediatric Screening. Moving Prevention From Evidence to Action: Overcoming the Barriers to Implementation

FH Europe together with Diagnoza FH, its Czech Network member organization, will hold an event under the auspices of the **Czech Presidency of the EU** titled **"Paediatric screening - moving prevention from evidence to action: overcoming the barriers to implementation"**. The event will take place on the 6th of September, in the Czech Senate, in Prague, with speakers including the Czech Minister of Health and Deputy Minister, representatives of the European Commission, WHO, key public health European institutions, scientific and medical experts, and patient ambassadors.

FH Paediatric Screening was recognized as public health **Best Practice by the European Commission** and added to the EC Best Practices Portal. In line with the **Healthier Together initiative FH Europe is also invited to the Best Practice Marketplace two days after the Prague meeting to present to the EU Member states.**

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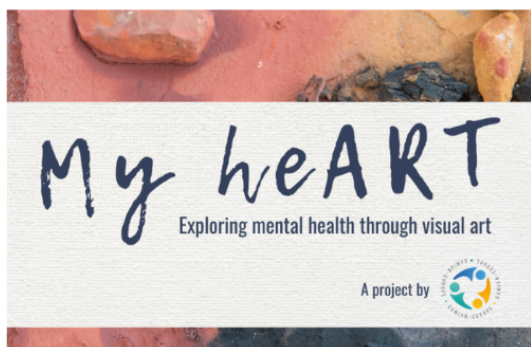
EUROPEAN MEDICINES AGENCY

DEADLINE 1 SEPTEMBER - Help EMA conduct an evaluation of a new medicine
 The **European Medicines Agency (EMA)** is looking at the evaluation of a new medicine intended to treat moderate to severe acne in children and adolescents from 9 years to 18 years of age.

There are other acne medicines already available containing only one or two of these substances but EMA's Paediatric Committee (PDCO) is discussing the added value of a proposed 3-in-1 combination gel to treat acne and would like to gather the views of young people who have experience of acne or their parents.

If you are a young person up to the age of 18 struggling with acne or the caregiver of a child or a teenager with moderate to severe acne, please provide your input to **EMA's survey** by **1 September 2022**.

[>> Click here to participate](#)



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.

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and their own views on the pieces they 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!

their own suicidal ideation experiences, an 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).

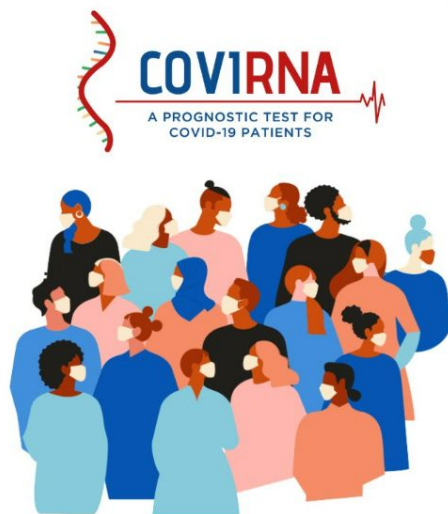
Find out more information on the project [here!](#)

Introducing COVIRNA

COVIRNA is a patient-centred Innovation Action aiming to generate a diagnostic tool to identify COVID-19 patients at risk of developing fatal cardiovascular complications.

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](#).



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#EU4Health: Calls for Tenders

The [European Health and Digital Executive Agency](#) (HaDEA) announces its current #EU4Health open calls for tenders:

1. Training and networking of Substances of Human Origin (SoHO) Competent Authorities' staff for oversight. Deadline: 20 September 2022, 16:00 (CEST)
2. EU Preparedness: Planning, Reporting and Training Programmes for Health Specialists. Deadline: 23 September 2022, 16:00 (CEST)
3. Multiple Framework Contracts in cascade for support services to manage expert groups in the field of health. Deadline: 07 October 2022, 16:00 (CEST)



The [European Commission](#) in partnership with the [European](#)

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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.

[EU countries given go-ahead for monkeypox vaccine dose-sparing.](#)

The European Medicines Agency has given the green light for countries to carry out a dose-sparing strategy as limited supplies of the monkeypox vaccine leave people unable to get jabbed.

[COVID can impair brain function, large study suggests](#)

Researchers from Oxford University combed through more than a million patient files and discovered that, two years after infection, patients who had recovered from COVID-19 were at a higher risk of psychosis, dementia and "brain fog" when compared with patients who recovered from other respiratory diseases.

**"In the midst of winter, I found there was, within me, an invincible summer."
Albert Camus**

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