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The Patient Perspective

May 2022



Reflections

Welcome to our May Patient Perspective newsletter!

Here's a recap of what we have been up to in the last month:

As the European Commission presented a proposal for a regulation to establish the European Health Data Space (**EHDS**), on May 3rd, the **Policy Team** has been working on an **overview of the draft regulation**, while focusing on key points for patient organisations.

Moreover, with the 2022 Congress rapidly coming up, the **Policy Team** invites us to **reflect on the impact of digitalisation and the healthcare professional/patient relationship**. You'll find a more comprehensive debate on the topic below.

The **Projects team** has been busy with travel, **together with patient advisors, for the EATRIS-Plus project, a Patient & Community Engagement day** for the EU-PEARL project, and **various surveys and consultations** to integrate the patient experience into our understanding of HTA processes, and patient recruitment for clinical trials.

The Youth Group is reuniting in Brussels, at the end of the month, for the first face-to-face Spring Meeting, since the pandemic. Ivett Jakab, former YG President, will be leaving the Youth Group. She shares some insights on her experience as a young patient advocate below.

Don't forget to check our **Calendar of Events** at the bottom to see the special days and events from us and our member organisations taking place in June.

We are deeply concerned by the situation that has been unfolding in Ukraine in the last few weeks. As a European patient organisation, we are particularly concerned about the situation of people living with chronic diseases, who are vulnerable to disruptions in healthcare services, medical treatment and medicines caused by war. For this reason we are working with our members to collect and amplify any initiatives our members launched to support the patient community in Ukraine and



News From the Secretariat
updates from the inside

2022 **EPF**
Congress

Continuing the *conversation* on **digital transformation**

DOUBLETREE BY HILTON
BRUSSELS

23 - 24 JUNE 2022

LESS THAN A MONTH AWAY TO THE EPF CONGRESS 2022!

The European Patients' Forum is pleased to announce the **EPF Congress 2022 – Continuing the conversation on digital transformation** will be held on **23 and 24 June 2022** in a live-streamed format.

This unique event will take place at the **DoubleTree by Hilton**, set in a prime location in the heart of Brussels, Belgium, with the option of participate online for those who wish to join us remotely.

Registration is now open for the in-person event. You can also join us virtually, for free. Please note that only the plenary sessions will be live-streamed, and you will have access to all EPF 2022 Congress content for "on-demand" viewing after the event.

Take a look at the programme >>>

Erika Landvik is EPF's new Finance Officer

Erika joined EPF in May 2022. As Finance Officer she is responsible for the day to financials tasks, financial policies and processes, audit compliance, budgeting, and reporting.

Before joining the EPF, Erika had extensive experience as a Finance Manager in both private and public sectors in Sweden and the United States. She worked the last ten years at Planned Parenthood, a non-profit organization that provides sexual healthcare in the United States and globally.

Erika has a Bachelor of Science degree in Accounting and a graduate certificate in non-profit management from Universities in the United States.



Policy and Advocacy Corner

*discussing the most relevant patient-centered
policy and advocacy issues*

Digitalisation and the healthcare professional/patient relationship

The digitalisation of our healthcare systems is creating high expectations and new opportunities for both patients and **healthcare professionals**.

From a patient perspective, digital tools could lead to better outcomes and improve their quality of life through self-management of chronic diseases and person-centred care. Digital health is also seen as a key tool to empower patients by providing them with more knowledge about their condition and facilitating their involvement in the care process alongside healthcare professionals. The EPF **survey** on Electronic Health Records (EHR) has highlighted that patients see EHR as a way to improve communication with healthcare professionals.

EPF has advocated for a partnership with patients to realise the full potential of technology, for example by using data with healthcare professionals to improve the quality of care and discussing the data and implications of new technologies.

From the perspective of healthcare professionals, digital tools also offer opportunities to improve clinical outcomes and increase efficiency. Digital health can, among other things, help healthcare professionals manage their workload and support their work through access to screening, device data or therapy. Telemedicine, for example, has the potential to be a useful additional tool in certain clinical scenarios, such as monitoring chronic

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Be that as it may, the deployment of digital tools and their real impact on the relationship between the patient and the healthcare professional remains uncertain.

Digital health literacy, both among health professionals and patients, is a prerequisite for the uptake of digital tools. At present, neither practising health professionals nor the generation in training is adequately prepared. Similarly, for patients, digital tools may exacerbate already existing inequalities and deepen the digital divide. Furthermore, if entering data to the system were to become an additional burden for healthcare professionals, they would be more reluctant to use digital tools.

There is no silver bullet to change the relationship between patient and health professional and advance patient-centred care. Digital tools can only be one part of the change to empower patients to manage their diseases and improve their quality of life. What is needed is a fundamental shift in medical culture from one of paternalism and hierarchy to one of partnership.

In this context, the underlying question is whether digital health is an enabler of this changing patient/healthcare professional relationship.

This is one of the many questions that will be addressed in the parallel session at the EPF Congress on the impact of digitalisation on the healthcare professional/patient relationship. In a workshop with key players from the health sector, we will explore the details of this relationship where digitalisation adds a layer of complexity. Whether you are a patient, a healthcare professional or a health enthusiast, please [join us!](#)

“ THE QUESTION IS WHETHER DIGITALISATION IS AN ENabler OF A MORE PARTNERSHIP-BASED APPROACH TO CARE.

THE EPF CONGRESS WILL EXPLORE THIS IN A SPECIAL SESSION. ”

Digital health technologies to address health inequalities – solutions for lower-income countries & marginalised groups' involvement?

Access to healthcare, including medicines, is recognised as a fundamental right and promoted as a common EU policy. However, health inequalities, especially in lower-income countries, still persist today in the EU. These are even deeper in marginalised groups within countries. This happens due to a variety of socio-economic reasons (e.g., being part of a minority or being excluded from the job market) which are frequently defined at the national and/or the regional level. Some of these have been worsened by the COVID-19 pandemic, as highlighted by EPF in the [survey](#) that it conducted among patients and patient organisations. Inequity in access is an important aspect of health inequalities and the European Parliament has recognised patients with chronic diseases as a group whose needs should be taken into special consideration when addressing health inequalities. [\[1\]](#) [\[2\]](#)

For people who are already subject to disadvantages and worse health outcomes, digital exclusion is a possible risk, too. As healthcare is increasingly digitalised, they are at risk of being left out with limited and unequal access not only to healthcare but also to the new digital technologies that are transforming it.

For those reasons, the EPF Congress will devote a session to exploring how reducing inequalities in access to digital technologies can help redress health inequalities. That is, to look at how digital health technologies may be designed and implemented specifically for addressing the needs of marginalised groups in lower-income countries. The session will involve several key experts in the field, who will share their perspectives and also moderate two break-out discussions with the audience.

Electronic Product Information: How patients can benefit from a digital version of medicine leaflets

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information (ePI) is intended to improve access to the up-to-date product information on medicines when and where it is needed".^[3] The use of ePI in parallel to paper-based information has potential benefits for the citizens and patients' community, as it has the potential to create efficiency gains for regulatory systems, it can make information available in all of the EU's official languages, it can complement the traditional paper package leaflet, and overall, it may benefit public health. However, it also has limitations which are not yet deeply explored, and requires meaningful patient involvement to ensure the tools and policies being developed will benefit patients

For that reason, the EPF Congress includes a dedicated session on this topic. It will include a varied panel of experts on the topic, including representation from the European Medicines Agency, the pharmaceutical industry, and academia. During this session, participants will be introduced to the concept of ePI and the biggest potential benefits for patients, including an example of an ePI app currently under development with patient involvement. Then, speakers will elaborate on the key aspects from their various perspectives and explore the limitations of ePI and hurdles that need to be overcome so that all patients can benefit equally. This session ends by discussing the priorities in the implementation of ePI to ensure that all patients can benefit equally.

^[1] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. "Solidarity in health: Reducing health inequalities in the EU". Brussels, 20.10.2009. COM(2009) 567 final

^[2] European Parliament resolution of 8 March 2011 on reducing health inequalities in the EU (2010/2089(INI))

^[3] Source: <https://www.ema.europa.eu/en/electronic-product-information-human-medicines-european-union-key-principles>



Projects Portal

briefings on EPF's ongoing projects

YOU'RE INVITED! To Patient and Community Engagement Day for EU-PEARL

The **EU PEARL consortium** invites patients, researchers, funders, and members of interested communities to join us for the EU-PEARL **Patient and Community Engagement Day**. The event is **taking place on 1 June, 14:00 – 16:40 CET**.

As part of the projects' patient engagement activities, this event will provide participants with an **introduction to platform trials and its potential benefits to participants, patients, and society**. We will then discuss the **requirements for informed consent** for participants in such trials to help build informational material that provides sufficient information without overwhelming them with unnecessary detail.

>> [Register here](#)

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**EU-PEARL
PATIENT & COMMUNITY
ENGAGEMENT DAY**

*Informed Consent in Platform Trials:
Finding the balance*

01 June 2022 2.00 - 4.30 pm CET

[More information and registration](#)

im innovative medicines efpia This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 853956. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and CHILDREN'S TUMOR FOUNDATION, GLOBAL ALLIANCE FOR TB DRUG DEVELOPMENT NON PROFIT ORGANISATION, SPRINGWORKS THERAPEUTICS INC.

EU-PEARL
EU PATIENT-CENTRIC
CLINICAL TRIAL PLATFORMS

NEW 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 (patients, 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!](#)

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How do Patients Perceive their Involvement in HTA Processes?



take the survey!



Bringing Patient Engagement to the EATRIS-Plus Annual Meeting

On 9 and 10 May, the **EATRIS-Plus project** held its annual meeting in Malaga, Spain. This was the first in-person meeting since the pandemic, where the European Patients' Forum was able to attend together with members of the project **Patient Advisory Committee (PAC)**. The **European AIDS Treatment Group (EATG)** also attended, in their capacity as coordinators of the PAC.

The team met face-to-face for a preparatory session on Monday morning, after two years of collaborating online. The group was debriefed on the progress so far, the results of the **previous PEOF April session on patient involvement**, and prepared for their intervention the next day.

At the consortium wide meeting, the PAC participated in a **Patient Engagement roundtable**, together with researchers from the consortium, to discuss **the challenges and resources needed to effectively and meaningfully engage patients in personalised and translational medicine research**. The roundtable featured a lively exchange, highlighting the importance of reminding researchers about the impact of their work, the patients' search for the *right* researchers, and concluded with a brainstorming exercise on future patient engagement in EATRIS-Plus. The day concluded with a closed meeting of the PAC to align on future actions, in particular the **forthcoming toolkit for patient engagement**.

>>[Learn more about our work on EATRIS-Plus](#), and the expected benefits to patients!

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Consultation on Shifting the Paradigm for Patient Recruitment: Needs, Options and Challenges for Trial Matching Solutions

YOUR VOICE MATTERS! On 13 June 2022 at 14:00 – 18:45, the **PharmaLedger** project will host a Virtual Open Consultation on **Shifting the Paradigm for Patient Recruitment: Needs, Options and Challenges for Trial Matching Solutions**. The consultation aims to explore why patients struggle to search for suitable clinical trials, and clinical trial investigators have difficulties finding the right patients.

Recruitment of patients remains the time-limiting factor in clinical trials. Matchmaking solutions exist, but none of them fully serve both parties' needs. That's why PharmaLedger, in collaboration with consortium partners the **European Forum for Good Clinical Practice** (EFGCP) and the **European Patients' Forum** (EPF) are hosting this **multi-stakeholder open consultation on how matchmaking solutions** for clinical trials could improve the patient recruitment process.

You can contribute by bringing your voice to the discussion on the pre-requisites for a clinical trial matchmaking solution that would improve the patient recruitment process, and your perspective on the potential of PharmaLedger's trial matchmaking concept to benefit all.

>> [Register here](#)

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PharmaLedger

EPF CCP EPF European Patients Forum

Shifting the Paradigm for Patient Recruitment: Needs, Options and Challenges for Trial Matching Solutions

Your voice matters!

13 June at 14:00 - 18:45 CEST (Virtual Open Consultation)



Youth Group

initiatives, stories and events from our most budding members



Youth Group Spring Meeting and a Farewell to Ivett Jakab

The Youth Group is meeting in Brussels this weekend, for a face to face event, the first one of this kind in the past two years. This event will also be a good opportunity for the YG members to say a warm farewell to Ivett Jakab, former President of the Youth Group and herself a rare disease patient living with a transplanted liver. Now Ivett is getting ready for the new challenges coming in her professional life.

As Ivett is leaving the Youth Group, she shared some of her thoughts with us:

"Dear EPF family and friends,

I am writing these lines on my way to Brussels for my last EPF Youth Group meeting. I cannot help but feel pride when I think of this bright-minded group of young people. I could go on and tell you how amazing, smart, and motivating they all are – but I won't. Instead, I urge you to sit down with them for a chat, so you can see for yourselves. Support them any way you can, because we need them in patient advocacy now, and we will need them in 20 years when they will have long years of experience. We need to make sure that the fire that brought them to this bumpy road keeps lightning bright. Mentor them, ask them what they need, invite them, hire them, LISTEN TO THEM and the future of patient advocacy will be in good hands.

Dearest Youth Group,

You are the coolest. Coming from different countries and different conditions, you still find what connects you and not what differentiates you. You have been working online with people you have never ever met in the past 2 and a half years while studying, working,

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your own definition of success – and if it is keeping yourself alive that day, let it be. My only hope is I left this group a tiny bit of a better place than I joined. I am definitely much better at being human because of you.

EPF, thank you for the purpose, the mentoring, all the friendships and fun!

*Your forever cheerleader,
Ivett"*



EPF Congratulates EUPATI on its 10 Year Anniversary!

EUPATI celebrated its 10th anniversary in a hybrid event gathering a total of 140 participants, among whom EUPATI Partners, National Platform representatives, EUPATI Fellows and key individuals who have contributed to EUPATI's success story over the years. Participants could reflect on EUPATI's key achievement as it evolved from an IMI project to a fully independent foundation since 2020. On the last day, participants could take part to workshops on "Diversity & inclusion in health literacy" and "Changing role of patient experts and needs for further training & education. EUPATI is thankful to everyone who have been involved in this celebration, whether it was online or in person in Brussels. For more information on EUPATI's 10th anniversary [click here](#).

The EUPATI Fundamentals training is ready to go back face to face! It will take place in Brussels next 7 July 2022. This training on patient engagement is co-designed and co-

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number of seats available:



Ukraine crisis

Our members' initiatives to support the patient community in Ukraine

The European Patients' Forum stands in solidarity with the people in Ukraine, who are facing an aggressive military invasion in violation of international law since 24 February 2022. As a European patient organisation, we are particularly concerned about **the situation of people living with chronic diseases**, who are vulnerable to disruptions in healthcare services, medical treatment and medicines caused by war. Patients with chronic diseases, especially those with multiple conditions and severe illness, are less likely to have the means to flee the conflict and access humanitarian aid.

EPF is working with its members to understand the needs and challenges to support policy decision-makers to address those needs. We are currently **collecting all the initiatives, projects, events** they have envisioned to support the patient community in Ukraine, a few of which are reported here below, and that can also be found on this [resource page on our website](#).



Alzheimer Europe has a new online resources page to help support people with dementia and carers, during the ongoing war in Ukraine.

You can access [Alzheimer Europe's resource page here](#).



European
AIDS Treatment
Group

EATG published a statement in solidarity with people living in Ukraine and those displaced by the war, that can be accessed [here](#).

They also created a [resource page](#) with information for donations targeted to people living with HIV and key affected populations in Ukraine.

In addition, EATG contributed to a piece published by POLITICO, that can be found [here](#).

Furthermore, they are in close contact with partner organisations and individuals in Ukraine and they are liaising with international organisations as well as pharma industry to ensure continuity of services and access to medicines.



WORLD
DUCHENNE
ORGANIZATION
UPPMD

The **World Duchenne Organization** set up a donation page to contribute the DMD Emergency Fund to aid families with Duchenne and Becker muscular dystrophy affected by the Ukrainian conflict. You can find it [here](#).

They are currently working on creating a documentary about people living with a

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refugees, patient organisations, and volunteers.

A trailer of a documentary titled 'Help has no borders' on the emergency in Ukraine is available [here](#).

This activity is part of the **DMD Emergency Program**. A life feed with all the updates can be found [here](#).



Neurological disorders become a major global health priority with adoption of Global Action Plan

The European Federation of Neurological Associations - EFNA, along with members of the **OneNeurology partnership** which EFNA co-founded, celebrates a major milestone for all those affected by neurological disorders today, with the adoption of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (GAP) at this week's 75th World Health Assembly.

EFNA fully endorse its aims, will support its implementation in Europe, and celebrate the positive impact it should have for those living with neurological disorders, their carers, the medical professionals who support them, and those researching scientific breakthroughs in prevention, diagnosis and treatment.

EFNA calls for a close alignment of the GAP with the EU NCD Initiative 'Healthier Together', expected to be adopted in June 2022. A conjunction of the NCD Initiative and the GAP couldn't be timelier. The European community is now presented with a unique window of opportunity to provide an integrated and cross-sectorial response to neurological health. Investing in this holistic model can bring measurable



The *Share4Carers project* comes to an end. The Good Practices Guide is available

EUFAMI has acted as a partner and representative of the **Share4Carers project** at European level throughout 2021 and until January 2022, when the programme came to a conclusion.

The Share4Carers project aimed to promote key solutions by uniting patients' organisations, academics, clinicians and carers from four different countries and to provide them with the skills and knowledge necessary to raise awareness on the societal impact of children of parents with mental ill health in Europe.

Representatives of the above groups met during the lifecycle of the project in order to share good practices and exchange perspectives on effective advocacy strategies and learn how to engage with decision-makers at national and EU levels.

The project fostered cooperation between seven different organisations by consistently promoting dialogue between patients, caregivers, scientists and society. The goal was to draw the attention of the academic and general public, as well as

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incidence of neurological disorders, improving survival rates, reducing complications and disability, lowering treatment costs and – ultimately – ensuring a better quality of life for all those affected.

Read more at <https://www.efna.net/gap-adoption/>

and clinical psychoeducation as well as key solutions in the prevention, early detection, intervention and support of children.

The Good Practices Guide can be viewed [here](#).



On 27 April 2022, the Global Heart Hub co-hosted an event in Brussels on 'Heart Valve Disease in Europe: Creating A Better Patient Journey'

This event highlighted the burden of heart disease in Europe and provided an opportunity for attendees to discuss recommendations for better patient journey. The event was co-hosted by Global Heart Hub and MEP Brando Benifei and moderated by Nicola Bedlington.

You can now read the summary report of the event [here](https://globalhearthub.org/Brusselsvhvdsummary): <https://globalhearthub.org/Brusselsvhvdsummary>



RBDCOV: the first clinical trial looking for a new COVID-19 vaccine is initiated

EATG is participating in RBDCOV, a project aiming to study a COVID-19 vaccine in children, adolescents and immunocompromised patients. Drawing from its experience in patients' advocacy and representation, EATG is contributing

3rd International Muscle-Bone Interaction in Duchenne Muscular Dystrophy Symposium: Moving beyond the 2018 international standards of care for osteoporosis management

This online symposium, organised in collaboration between the World Duchenne Organization and the International Conference on Children's Bone Health, will be held on November 3 and 14, 17:00-20:00 GMT. The event is aimed to clinicians and scientists who want to gain a deeper understanding of the impact of DMD on the growing skeleton and on endocrine outcomes. Patient advocates are also welcome.

The scientific programme is designed to address the following main aims:

1. Highlight the minimum standards of care for bone and endocrine management as laid out in the 2018 international standards of care consensus with particular focus on practical aspects of implementation in the clinic;
2. Share results of clinical research to support current management of osteoporosis in DMD;
3. Showcase new clinical and translational research to consider the path forward to prevent fractures and related bone morbidity in DMD.

[More info and event registration>>>](#)

EATG Annual Report 2021 is online

Check out EATG's 2021 activities in review: achievements in numbers, reporting from our programmes, highlights, figures for finances and membership and updates on communication and governance at a glance.

[Read the full annual report >>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

Russia takes first steps to withdraw from WTO, WHO

The Russian government is starting the process of unilaterally withdrawing from a series of international bodies, including the World Trade Organization and the World Health Organization, the Russian Duma's Deputy Speaker Pyotr Tolstoy said on Tuesday. "We have work to revise our international obligations, treaties that today bring no benefit, but instead directly harm our country. The Foreign Ministry sent a list of such agreements to the State Duma," Tolstoy said. "Together with the Federation Council, we plan to analyze them and to propose to withdraw," he added. Tolstoy singled out the international trade and health organizations, saying that "the next step is to withdraw from the WTO and the WHO, which have neglected all obligations towards our country." European WHO member countries voted on May 10 in favor of a resolution that forces the WHO to decide on the potential relocation of its European non-communicable diseases office out of Moscow as well as the temporary suspension of regional meetings in Russia. The resolution was slammed by Russia's Deputy Health Minister Andrey Plutnitsky who described it as a "gross violation of the constitution of the WHO."

European Commission to designate COVID-19 as workplace disease

The European Commission announced today it will be including COVID-19 on its list of recommendations on occupational diseases. The news comes after an agreement was reached yesterday between member states, workers and employers in the European Union Advisory Committee on Safety and Health at Work (ACSH), the statement said. "This agreement is a strong political signal to recognise the impact of COVID-19 on workers and acknowledge the crucial contribution of people working in health and social care, as well as other jobs that carry a higher risk of contracting COVID-19," said Nicolas Schmit, Commissioner for Jobs and Social Rights. The Commission had previously said it would include COVID-19 in its recommendation on occupational diseases by the end of the year.

WHO gives green light to coronavirus vaccine from China's CanSino Biologics

The World Health Organization has issued an emergency use listing for a coronavirus vaccine produced by China's CanSino Biologics, bringing the portfolio of jabs given the green light by the organization to 11. The listing is a prerequisite for a vaccine to be included in COVAX's supply and it also enables countries to speed up their own

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coronavirus. The vaccine was found to have 97 percent efficacy against symptomatic disease and 92 percent efficacy against severe illness, said the WHO. Two other vaccines from Chinese manufacturers have been given emergency use listing by the WHO — one from Sinopharm and another from Sinovac.

All the darkness in the world cannot extinguish the light of a single candle.
St. Francis Of Assisi



Calendar of Events

1 June
Patient & Community Engagement Day

[visit our website](#)

6 - 12 June
Carers Week 2022

[contact us](#)

13 June
PharmaLedger Open Consultation

14 June
World Blood Donor Day

20-26 June
World Continence Week

29 June
World Scleroderma Day

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