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# The Patient Perspective

March 2022



## Reflections

Welcome to our March Patient Perspective newsletter.

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

Our **Policy** team has been quite busy in March. They participated in different events, including EMA's Patients' and Consumers' (PCWP) and Healthcare Professionals' (HCPWP) Working Parties and the 10th Bulgarian National Congress of Patients' Organisations. They also just released a new survey on patient involvement in the continuing professional education (CPE) for healthcare professionals. We share the result with you below.

Our **Projects** team is organising a new Patient Engagement Open Forum session in April. They also share a new blog post from the DataSavesLives initiative and the recording of the latest #DSLCoffeeTalk.

There is a new sexual health and well-being project from the **Youth Group** that is currently collecting stories and experiences to open the conversation on this delicate topic.

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 April.

*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 neighboring countries. A resource page will soon be available on our website, and in the meantime we have highlighted a few initiatives here, you can find more information below.*



## News From the Secretariat

updates from the inside



# Continuing the *conversation* on digital transformation

DOUBLETREE BY HILTON  
BRUSSELS

23 - 24 JUNE 2022

## **SAVE THE DATE - The EPF Congress 2022 will be back on 23-24 June**

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.

The registration for the event will open on **4 April 2022**.

**More details, registration and preliminary programme will be available soon on our dedicated website [www.epfcongress.eu](http://www.epfcongress.eu).**

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CHECK BELOW FOR OPEN POSITIONS!



# JOIN OUR TEAM

Send your cover letter, CV and references to  
[recruitment@eu-patient.eu](mailto:recruitment@eu-patient.eu)

## We are hiring!

EPF is looking to hire three new positions:

- ✓ Finance Officer
- ✓ Policy Officer – Digital Health
- ✓ Head of Governance, Membership and Capacity Building (Maternity cover)

Take a look at the full job descriptions and how to apply below.

**If you know someone who is passionate about patients' rights in Europe, let them know about this unmissable opportunity!**

[Here you can find the full job descriptions](#)



Our brand-new season of the EU PATIENTS' Podcast started with a very special episode dedicated to #RareDiseaseDay, and a chat with Anna Kole, Public Health Policy Director at Eurordis.

Celebrated every year on 28 February, Rare Diseases Day was launched in 2008



On March 8 we celebrate the International Day of Women. This year for the occasion, we bring you a new episode of the EU Patients Podcast featuring a chat with Elizabeth Cunningham, Communications Manager for EFNA. We discuss EFNA's Advocacy Awards that this year will focus on Gender Equity in Neurology, and their newest survey, 'Assessing diagnosis and

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There are over 300 million people worldwide living with a rare disease. 72% of rare diseases are genetic, and of these genetic diseases 70% start in childhood. There is no cure for most of these disorders and few treatments are available for those who are affected. EURORDIS works towards more equitable access to diagnosis, treatment, care, and social opportunity.

EFNA's Advocacy Awards will take place in May 2022. These awards recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders in Europe. On this occasion, the awards will focus on the topic of 'Advocating for Gender Equity in Neurology'.

[Listen to the episode here>>>](#)

[Listen to the episode here>>>](#)



## Policy and Advocacy Corner

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

This month has been heavily marked by the aggressive military invasion of Ukraine. In a [statement](#), EPF expressed its **support for the Ukrainian people**. As a European patient organisation, it also showed concerns about the situation of people living with chronic diseases, who are vulnerable to the disruption of health services, medical treatment and medicines caused by war, and who are less likely to have the means to flee the conflict. EPF has surveyed the membership to understand their needs, and will work with its members with the aim of supporting patients and their organisations in Ukraine and neighbouring countries.

In March EPF participated in several events with other organisations to amplify the voice of the patient community. We spoke at the **10<sup>th</sup> Bulgarian National Congress of Patients' Organisations** organised by an EPF member, the National Patients' Organisation ([NPO](#)). During this event, we delved into the role of EPF as a key interlocutor of the EU institutions in channelling patients' voices into policy and legislative developments. The full keynote speech is available [here](#). We also participated in the **European Specialist Nurses Organisation (ESNO) 2022 Congress** and discussed the plans of specialist nurses for the next decade, highlighting the need to consider the patient perspective in health workforce policy. The digital transformation of healthcare is also an area where specialist nurses and patients can work together on coaching, shared decision-making and advocacy. You can watch the recording of the debate [here](#).

At the European Medicines' Agency, EPF participated in the joint March meeting of the **Patients' and Consumers' (PCWP) and Healthcare Professionals' (HCPWP) Working Parties** on 2 and 3 March. On the agenda were, among other things, the public stakeholder workshop on the EMA's new mandate, that will take place on 1 April, and the topics to be prioritised in 2022.

Finally, EPF continued to work on the implementation of the **Medical Devices Regulation** by participating in the European Commission's coordination group's sub-group on clinical investigations and evaluation. At the moment, our role in the group is that of an observer, monitoring the situation and anticipating the expected impact of developments for the patient community.

## Publication of the survey report on health professionals' continuing education

EPF is pleased to publish the results of its **survey on patient involvement in the continuing professional education (CPE)** for healthcare professionals. The results will



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participating in CPE activities.

Patient involvement in professional education is a crucial component of patient-centred healthcare. Not only is the transformation of our health systems by technological and scientific advances leading us to rethink the relationship and role of patients and healthcare professionals, but high-quality patient-centred healthcare requires that healthcare professionals have the right knowledge, attitude and skills.

The EPF survey collected 89 responses from individual patients, patient advocates or family members and patient organisations. The survey shows that, despite inherent shortcomings of current patient involvement in CPE activities, there is a willingness in the patient community to advance patient participation in CPE activities. The key findings and learnings of this survey will inform our policy and advocacy work in the coming months.

## Read our Survey Report on Patient Involvement in Continuing Professional Education



### Projects Portal

briefings on EPF's ongoing projects

#### WATCH 🎥 the #DSLCoffeeTalk on the Role of Medical Technology in Harnessing the Power of Personal Data

On 10 March, [Data Saves Lives](#) and [MedTech Europe](#) collaborated on a 1 hr panel discussion exploring the role of medical technology in harnessing the power of personal data.

The coffee talk style discussion featured speakers Uroš Bogdanović, a patient advocate living with Type 1 diabetes; Angela Bradshaw, Project Officer at [Alzheimer Europe](#); and Justine Vandenbosch, Chair of the Data Governance WG, [MedTech Europe](#). The discussion centred on the **importance of patient centricity** when it comes to developing medical technologies. In the discussion, Angela Bradshaw said, "***We're moving towards a situation now where companies and researchers are more aware of the importance of involving patients.***"

Curious to watch more?

**>>> [Watch the coffee talk here](#)**

#### New Data Saves Lives BLOG ALERT! 📢

[Data Saves Lives](#) has published its most recent guest blog post on the Benefits of a Personal Health Record (PHR), written by Fran Husson, Honorary Research Officer at [Imperial College London](#).

A Personal Health Record is a secure online record that stores information about a person's health, care and wellbeing. "***Data does save lives, but information quality is paramount to achieve successful outcomes and this, in my experience, cannot be achieved if patients are not full partners and agents in their care, using the right tool to do this,***" shares Fran Husson. In the blog, she explains why Personal Health Records are so important in achieving successful outcomes for patients.

**>> [Read the blog here](#)**

# #DataSavesLives

## Registrations are open 🚨 for PEOF 2022 April sessions

The **Patient Engagement Open Forum** (PEOF) is back for its 2022 patient-centred series of virtual events to shape and co-create stronger patient engagement across health systems. The next sessions will **take place on 12 & 14 April**, and will cover topics like:

- > Patient Engagement 2022 trends
- > Patient Experience Data
- > Patient Remuneration in patient-pharma interactions
- > Patient Engagement in Translational Research

Catch the 14 April session on ***Making Meaningful Patient Engagement in Translational Research the New Normal***, which will be chaired by Anne-Charlotte Fauvel (**EATRIS** Head of EU Affairs) & Valentina Strammiello (Head of Programmes at **European Patients' Forum**).

This is the 4<sup>th</sup> edition of PEOF, which aims to facilitate collaboration and co-creation of real solutions **for patients WITH patients** while providing a holistic perspective of patient engagement, its landscape, and actors. It has become THE place for the patient engagement community to foster innovation, network, share practices, build trust, acceptance, and awareness.

**>>> Register here**



The poster features a blue and green background. On the left, there is a circular logo with the text 'Patient Engagement open forum'. To the right, a laptop screen displays a video conference with four participants. Text on the right side of the poster includes: 'Towards Stronger Patient Engagement', 'April 14, 2022 #PEOF', '14:30 - 16:00 (CET): Making Meaningful Patient Engagement In Translational Research The New Normal', and a 'Register now' button. At the bottom, logos for 'Powered by' (Patient Focused Medicines Development), 'EUPATI' (European Union Patient Association), and 'EPF' (European Patients' Forum) are displayed.

Patient Engagement open forum

Towards Stronger Patient Engagement

**April 14, 2022 #PEOF**

**14:30 - 16:00 (CET): Making Meaningful Patient Engagement In Translational Research The New Normal**

**Register now**

Powered by

PATIENT FOCUSED MEDICINES DEVELOPMENT

EUPATI European Union Patient Association

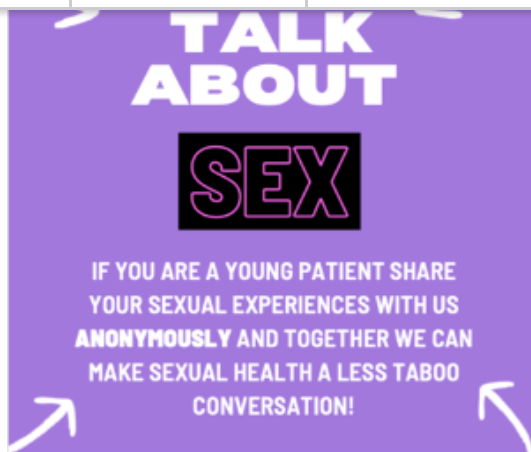
EPF European Patients' Forum



The banner has a blue background. On the left, there is a white icon of three stylized figures holding hands. To the right of the icon, the text reads: 'Youth Group', 'initiatives, stories and events from our', and 'most budding members'.

**Youth Group**

initiatives, stories and events from our most budding members

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Break the taboos around the sexual health of young patients, please support our project by submitting any of your experiences ANONYMOUSLY.

Some of the experiences will be selected and used in a video for our current project.

**Share your stories anonymously, [here>>>](#)**



The Summer Training Course for Young Patient Advocates (**STYPA**) is back for another edition in 2022. The topic for this year will be the sexual health and well-being of young people with chronic conditions, and the deadline for all applications is **15 April 2022**. The course will run from June until November 2022, and there will be both a face-to-face meeting in Strasbourg, France, and online and webinar workshop components. Please share this program widely with the young patients in your community (18-30 years old and based in Europe). Apply if you are:

- A Young Patient with a chronic and/or lifelong illness/condition who is not affiliated with a patient organisation,
- A Young Patient with a chronic and/or lifelong illness/condition who is affiliated with a patient organisation
- A Young Employee or volunteer of a patient organisation
- 18 – 30 years of age at the time of applying
- Live in Europe

You can find more information [here](#). Should you have any questions, comments or concerns, feel free to contact EPF Secretariat member Borislava Ananieva at [borislava.ananieva@eu-patient.eu](mailto:borislava.ananieva@eu-patient.eu).

**Apply now here!**

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## 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. In the coming weeks, **a resource page will be available on our website** as well.



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 neuromuscular disease that are affected by the Ukrainian war, as their community manager Nicoletta Madia travelled to the Czech Republic and other countries to interview 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](#).



## Member Focus

highlights from our member organisations



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**Diabetes Federation  
Europe**

## People living with Type 2 Diabetes and their Healthcare Professional - A Successful Team?

IDF Europe's newly established platform of people living with Type 2 diabetes (T2D) has identified the quality of the relationship between PwD and their main healthcare professional (HCP) as the key priority to be addressed by the platform. Being informed and supported, heard and understood, and empowered to take control of their care is the very first step for PwD not only to understand the condition they will live with for the rest of their life, but also to stay motivated to put their health first and self-manage their diabetes as best they can on the good and on the bad days. How can HCPs and people living with T2D work together to achieve optimal health outcomes and quality of life.

A dedicated working group is being set up to work on this relationship and we are looking for participants (people living with T2D, specialists working with people living with T2D, and primary care professionals) to share their experience and co-develop recommendations to support an open and effective dialogue between PwD and HCPs. Interested? Please contact us at [idf-europe@idf-europe.org](mailto:idf-europe@idf-europe.org). We look forward to hearing from you!

**IDF Europe website>>>>**



## 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


**EFA**

 European Federation of Allergy and Airways  
Diseases Patients' Associations

## EFA is looking for the next generation of patient advocates!

If you are aged 16-30 and want to connect with other young patient advocates across Europe and build your skills in pushing for patient-centred care – be a part of the **European Allergy and Asthma Youth Parliament!**

The European Allergy and Asthma Youth Parliament is a group of allergy and asthma patients and scientific advisors aged 16-35 who meet online regularly to bring the youth perspective to European policy consultations and develop their skills in patient advocacy. They have launched their own EU policy recommendations, contributed to consultations and represented young patients at the European Youth Event in 2021. You can visit their website [here](#).

Take a look at this [video](#), which features current members of the Youth Parliament who present their work and how others can get involved.

**Find out more  
about #AllergyAsthmaYouth >>>**



## CALL FOR PARTICIPANTS - WFIPP International Multistakeholder Workshop

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We invite clinicians from all around the world to the second online Grand Round session on Hydrocephalus with Dr. Benjamin Warf (Professor of Neurosurgery, Harvard Medical School, USA) on Friday April 8 2022 at 3PM Brussels time.

[Find more information and registration here>>>](#)



### **Alzheimer Europe publishes two new reports: One on sex, gender and sexuality in the context of dementia, and one on dementia-inclusive initiatives and communities**

Alzheimer Europe has launched a new report on sex, gender and sexuality in the context of dementia, targeted at health and social care professionals/providers, students and policy makers. The report was written during 2021, by a working group composed of experts in the fields of dementia, gender studies, ageing, ethics, psychology, service provision and the training of healthcare professionals.

Alzheimer Europe has also published its Dementia in Europe 2021 Yearbook, examining the subject of dementia-inclusive communities and initiatives. The information for this publication was gathered by Alzheimer Europe surveying its national member associations, about the work and activities taking place in their countries. A total of 27 members contributed, across 24 countries.

[Both publications can be found on the Alzheimer Europe website>>>](#)

and Infrastructures of Sustainable Continence Care (TISCARE2022) together with the Tampere University on 25-26 April 2022 in Tampere, Finland. Co-creating knowledge about holistically sustainable continence care.

The places go at first serve first come basis, so register quickly, and join the efforts to define first international definition for sustainable continence care.

[Find more information, full agenda and registration here>>>](#)



### **Introducing the EHC Think Tank**

The EHC Think Tank aims to find new ways of solving complex issues. One of these issues addressed is the future of patient registries. Based on a workshop, experts several key challenges regarding registries and data sharing, which is the first step towards finding achievable long-term solutions. Have a look at the paper and let us know your thoughts.

[Paper "Key challenges for patient registries – A report from the 1st workshop of the EHC Think Tank Workstream on Registries:">>>](#)

### **EHCucate - education about rare bleeding disorders at your fingertip**

The treatment landscape of inherited bleeding disorders is rapidly evolving with medical and technological advances. To help people living with bleeding disorders understand this fast-paced medical field, the European Haemophilia Consortium (EHC) has developed an educational app, EHCucate, explaining the science behind bleeding disorders and their treatment in simple language. This app is continuously being updated, and in March 2022, we published new material explaining the 'rebalancing of haemostasis.' The EHCucate app features diverse interactive features such as gamification elements, self-assessments, custom animations, medical illustrations, deep-dive resources, and personalised, quick reference



## The European Nutrition for Health Alliance Survey

In the past months, a survey was developed to map and understand the experiences of cancer patients and identify areas for improvement regarding nutrition in oncology in European countries.

With the outcomes of the survey, which will be shared with you, the European Nutrition for Health Alliance will all be better equipped to advocate for change, inform policymakers, implement optimal nutritional care with the aim to improve the lives of cancer patients.

The questionnaire has been designed to be short and patient-friendly, will take 15 to 20 minutes to complete and is open until May 31.

The survey was developed by the European Nutrition for Health Alliance (ENHA), Das Lebenshaus, the European Cancer Patient Coalition (ECPC) and cancer nutrition researchers from the Sapienza University of Rome, Italy and the University Hospital Jena, Germany.

Don't hesitate to contact ENHA at [secretariat@european-nutrition.org](mailto:secretariat@european-nutrition.org)

[Find the survey here>>>](#)



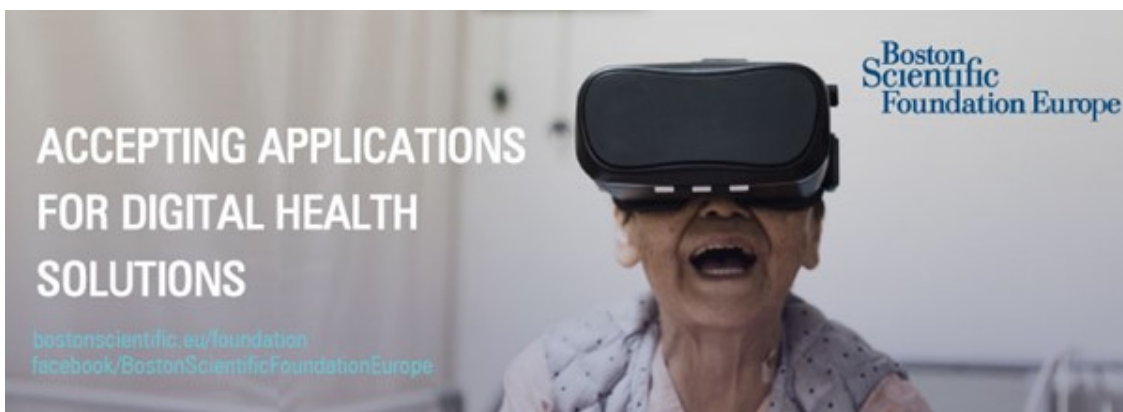
## Access to quality Health & care: Evaluate, Futureproof & Improve

The PACT-Patient Access Partnership is organising the webinar entitled: "Access to quality Health & care: Evaluate, Improve & Futureproof", which will take place online on Tuesday, March 22, from 10:00 to 11:30 CET.

This will be the opening event of a series of thematic webinars entitled "The Future of Health: Time to Act". The initiative is continuation of The Health PACT (the conclusion document of the Future of Health Conference - 2019).

The first event of the series will focus on the access findings within the State of Health in the EU report and the "FutureProofing Healthcare for all European citizens: A vision for building the EU's role in healthcare", a vision paper build up by the Expert Panel of the FutureProofing Healthcare Initiative, submitted to the portal of the Conference on the Future of Europe.

[Register here for the event>>>](#)



## Boston Scientific Foundation Europe – Improving wellbeing through digital innovation



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help prevent or manage diseases.

Specifically, the Foundation is an advocate of innovative digital projects, helping reach patients who are increasingly accessing their healthcare online. We believe that **digital has given us the potential to reduce health inequalities** by enabling people to access health information and tools to better manage their health and care.

Since establishing the Foundation in 2018, it has supported a variety of initiatives, from EURORDIS's 'Building Good Practices' webinar series that educates patient advocates to elevate the patient voice in Europe, to e-training in paediatric cardiology to train young doctors from Africa for the *Mécénat Chirurgie Cardiaque*, to online camps for children with chronic illnesses for the Bator Tabor Foundation, to name a few.

The BSFE accepts applications all year round. Visit the website if you have a digital health project and are looking for financial support, or [follow them on facebook](#) to see the stories of all their projects.

[The Boston Scientific Foundation Europe website>>>](#)



## Inside the Bubble

updates, stories and events around EU healthcare

### War in Ukraine, inflation threaten resilience of Europe's medicines supplies

Soaring prices for energy, fuel and raw materials, and now the war in Ukraine, are threatening Europe's medicines supplies — the latest endangerment to health services still recovering from COVID-19 and tackling backlogs as they take on the extra care needs of refugees.

The generic drugs sector, which manufactures most of the medicines prescribed in Europe, says it is facing unprecedented cost pressures. The industry, which sells cheaper copies of drugs whose patents have expired, depends heavily on energy to run manufacturing facilities day and night. But, last year alone, energy import prices in Europe more than doubled.

The industry also relies on a complicated global supply chain network, mostly consolidated in Asia, that is now being forced to divert shipments because the overland trade route via Ukraine is blocked.

### The European Union will release €3.4B to help with Ukraine refugee crisis

The money will fund investments in housing, education, health, employment and child care as Europe deals with its biggest refugee crisis since World War II.

"This is an unprecedented, historical challenge. And Europe's response has also been unprecedented," Commission Vice President Margaritis Schinas said, announcing the spending.

An estimated 3.5 million people have fled to the EU, by the Commission's reckoning. The funds will chiefly help the EU countries neighboring Ukraine — Hungary, Poland, Romania and Slovakia — that have taken in the most people.

### Pfizer and UNICEF reach deal for COVID-19 drug

Pfizer and the United Nations Children's Fund (UNICEF) announced on Tuesday an agreement for the pharma giant to supply up to 4 million treatment courses of its Paxlovid coronavirus therapy.

The agreement aims to improve access to the new treatment for 95 low- and middle-income countries, which the company said accounted for around 53 percent of the world's population. Paxlovid is an oral treatment to be taken for five days starting soon after the onset of symptoms.

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Not everything that's faced can be changed, but nothing can be  
changed that is not faced.

**James Baldwin**



## Calendar of Events

**2 April**

World Autism Awareness Day

[visit our website](#)

**7 April**

World Health Day

[contact us](#)

**11 March**

World Parkinson Day

**17 April**

World Haemophilia Day

**18 April**

European Patients' Rights Day

**22 April**

World Earth Day

**23 April**

EPF 2022 AGM

**24 - 30 April**

European Immunization Week

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