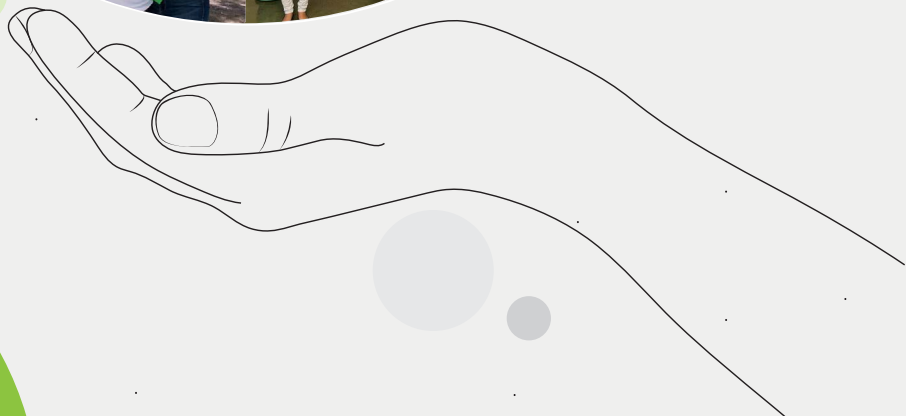


Access to care for all PID patients, everywhere

Let's make early diagnosis and timely access to quality treatment a reality worldwide

WORLD PI WEEK 2024 INFORMATION PACK



World PI Week

TEST • DIAGNOSE • TREAT

22-29

April 2024



About World PI Week

What is World PI Week?

World PI Week (22-29 April) is a global movement to raise awareness of Primary Immunodeficiency (PID) and related challenges; promote quality of life for people living with the disease, early diagnosis, availability and access to treatment and care worldwide; and stimulate communication and advocacy around primary immunodeficiency.

Where does it take place?

Thousands of events happen across the world during World PI Week. Through online/in-person events, public lectures, medical symposia, family activities, runs and walks, media interviews and many other actions, the global primary immunodeficiency community unites to bring about positive changes in healthcare systems and practices, in support of people living with the disease. The campaign has a strong online component, reinforced amid the COVID-19 pandemic.

Who can participate?

Everyone can get involved in World PI Week, from patients, carers and families, to healthcare professionals, medical societies, patient organisations, researchers, schools, policy makers, pharmaceutical industries, public health authorities and anyone interested to celebrate the week and spread awareness.

A little bit of history

The first World PI Week was celebrated in 2011 and since then, over 80 countries worldwide have joined the campaign, reaching thousands of people and generating wide media attention at local and international level. More information on past campaigns is available [here](#).

Why World PI Week?

There are more than 450 types of primary immunodeficiency¹, which occurs when a person's immune system is absent or does not function properly. Over 10 million people live with PI around the globe, and yet this rare disease is still widely unknown. Greater awareness, testing, diagnosis and improved access to treatment are needed.

- › For more information about World PI Week, please click [here](#)
- › Read more about primary immunodeficiency [here](#)

WORLD PI WEEK THEMES OVER THE YEARS

2012 – Access to Appropriate Treatment

2013 – Primary Immunodeficiency: Turning Hope into Action!

2014 – A call for new-born screening to test for severe combined immunodeficiencies

2015 – The importance of vaccination and immunoglobulin treatment for patients with primary immunodeficiency diseases (PID)

2016 – Into action: Improving access to optimum care for all primary immunodeficiency patients

2017 – Ensuring access to life-saving immunoglobulin therapies for people with primary Immunodeficiency

2018 – My future starts with early testing and diagnosis of primary Immunodeficiency

2019 – Putting primary immunodeficiency patients at the centre of their care

2020 – Celebrating 10 years of solidarity, successes and expectations for the future of primary immunodeficiency diagnosis, care and quality of life worldwide

2021 – Protecting and improving the lives of the millions of people living with primary immunodeficiency worldwide by supporting early diagnosis and access to care

2022 – Access to healthcare is a basic human right. People living with primary immunodeficiency worldwide depend on it. Each of them is entitled to the correct diagnosis, quality treatment and care.

2023 – Turning real-world data into knowledge for better PID care.

1. Tangye SC, Al-Herz W, Bousfiha A, Cunningham-Rundles C, Franco JL, Holland SM, et al. The Ever-Increasing Array of Novel Inborn Errors of Immunity: An Interim Update by the IUIS Committee. *J Clin Immunol* (2021) 41(3):666–79. doi: 10.1007/s10875-021-00980-1

World PI Week 2024: all about equal access to care

In 2024, the campaign focuses on eliminating barriers to access to care for everyone, everywhere.

ACCESS TO CARE FOR ALL PID PATIENTS, EVERYWHERE

Let's make early diagnosis & timely access to quality treatment a reality worldwide

According to the World Health Organisation, "Universal Health Coverage" means that all people have access to the full range of essential health services and quality treatments they need, where and when they need them, across the life course².

However, significant differences exist in the level of care available for patients with rare diseases in and across countries globally³.

Around the world, **80%** of primary immunodeficiency patients do not yet have access to adequate care⁴. Lack

of knowledge around PIDs, gaps in the availability and accessibility of diagnosis and treatments, lack of specialists & multidisciplinary care or shortages of the source material necessary to produce treatments leave individuals and families vulnerable.

It's time to shatter these barriers. Let's make universal access to early diagnosis & quality treatment a reality for all those living with PIDs. Together, we can raise awareness and bring about change.

Key messages

- » **Equal access to PID care should be a priority worldwide.**
- » **Every PID patient should have access to timely diagnosis, quality health services & treatment, independent of their type of PID, where they live, their age, gender, or socio-economic status.**
- » **Advancing awareness, education and research is crucial to reduce remaining knowledge gaps around PIDs, improve health outcomes and quality of life for all patients.**



2. World Health Organization. WHO Resolution WHA69.11 on Health in the 2030 Agenda for Sustainable Development" (2016). Available at: https://apps.who.int/gb/ebw/wha/pdf_files/WHA69/A69_R11-en.pdf

3. Leung D, Chua GT, Mondragon AV, Zhong Y, Nguyen-Ngoc-Quynh L, Imai K, Vignesh P, Suratannon N, Mao H, Lee WI, Kim YJ, Chan GCF, Liew WK, Huang LTM, Kanegane H, Muktiarti D, Zhao X, Santos-Ocampo FJ, Latiff AHA, Seger R, Ochs HD, Singh S, Lee PP, Lau YL. Current Perspectives and Unmet Needs of PI Care in Asia Pacific. *Front Immunol*. 2020 Aug 13;11:1605. doi:10.3389/fimmu.2020.01605. PMID: 32903579; PMCID: PMC7438539.

4. Meys I, Bousfiha A, Duff C, Singh S, Lau YL, Condino-Neto A, Bezrodnik L, Ali A, Adeli M, Drabwell J. Primary Immunodeficiencies: A Decade of Progress and a Promising



How to join World PI Week

Show your support and help us make 22-29 April 2023 all about PIDs!

Help raise awareness of PIDs

1. SPREAD THE WORD

- » **Share information about primary immunodeficiency** around you and online to inform your family, friends, neighbours, colleagues etc (e.g email, WhatsApp message etc) and invite them join the campaign. Use the resources available [here](#).
- » **Display the World PI Week poster** in your windows, at your workplace, in shops or other public venues around you.

2. GET ACTIVE AND JOIN THE CONVERSATION ON SOCIAL MEDIA

- » **Follow World PI Week** on [Facebook](#), [Twitter](#), [Instagram](#) and [LinkedIn](#)
- » **Change your profile** picture with the World PI Week frame
- » **Post the campaign banners**, poster and pledge card "I support World PI Week". *Find the materials [here](#).*
- » Before and during the Week, **communicate key facts** on PIDs (visit the World PI Week [website](#) to find information)
- » **Share a support message/video** with #WorldPIWeek
- » **Relay the World PI Week** videos, podcasts & roadshow series
- » **Strike a Y and send us your picture** via World PI Week social media accounts
- » **Repost the messages of the World PI Week Ambassador** in your region (visit the World PI Week website for more details)
 - › Use the official World PI Week hashtag: **#WorldPIWeek** to help build momentum
 - › More tips for social media are available [here](#)

Where to find World PI Week on social media

Facebook : @WorldPIWeekcampaign
Instagram : world_pi_week_
Twitter : @WorldPIWeek
YouTube : World PI Week
LinkedIn : World PI Week

3. SUBMIT A PICTURE FOR THE PHOTO CONTEST TO SHOW SOLIDARITY (22-29 APRIL)

- » **Strike a Y in support improved access to PID care for all PID patients, everywhere and get a chance to win a copy of the new World PI Week comic book!** Post your picture on Facebook, Twitter, Instagram or LinkedIn with **#PictureAwareness** and **#WorldPIWeek** from 22-29 April, or send it to us at info@worldpiweek.org.
- » You can also **challenge your colleagues, friends or schoolmates to participate**, and post a group picture (or collage) of everyone striking a Y!

4. Read and share the new World PI Week comic book (1-29 April)

- » **Embark on a cosmic PID journey** with the first ever World PI Week comic book, **find out more about advances, good practices, gaps and remaining challenges** in improving access to care for PID patients
- » Stay tuned for the full story: one chapter will be released each week from the 1st to 29th of April, **share these around you to help us raise awareness!**
- » More information will be available soon



How to join World PI Week

5. TELL YOUR STORY VIA #MYPISTORY

- » **Contribute to the #MyPIstory campaign:** you can upload a video, photo or testimonial on the World PI Week website, to share your own experience of living with PID, caring for someone living with a PID, treating patients with PID, doing research on PIDs etc.
- » *Story telling is a key tool to illustrate positive aspects related to PID care but also problems or areas where further improvement is needed. It allows us to communicate your learnings, concerns or recommendations with decision-makers, and help them relate to your experience or understand better how they can drive progress.*

6. VISIT AND CONTRIBUTE TO THE WORLD PI WEEK “WORLD MAP OF PID ADVANCEMENTS” HIGHLIGHTING SUCCESSES IN ADVOCACY FOR IMPROVED ACCESS TO CARE WORLDWIDE (LAUNCH ON 22 APRIL)

- » **Check out this repository on the World PI Week website to learn more about** initiatives that made a difference in various regions of the world and get inspired
- » **Pick your “favourite” examples and promote them on your social media channels and around you** – you can use the visual here
- » **Share with us examples of impactful and engaging policy and advocacy initiatives that supported greater access to care for people with PIDs in your region.** Send them via info@worldpiweek.org or on social media – they will be added to the map!
- » More information will be available soon

Go the extra mile

7. CONTACT THE PRESS

- » **Engage with your local/regional media,** give a TV/radio interview: if you are a patient, a specialist health professional or anyone that has expertise with PID, consider offering your testimonial/insights. Tips & tools for media engagement are available [here](#).

8. SUPPORT ADVOCACY

- » **Sign the World PI Week [call to action](#)** or endorse the [Policy Pledge](#)
- » **Contact your national/local representatives and policymakers** (mayor, member of Parliament, Minister etc): write a letter (template [here](#)) to invite them recognise World PI Week and take action; share your story and explain unmet needs and challenges in your country. You can also invite them to a meeting with you and/or the PID patient group or medical society in your region. You can find guidance and tools [here](#). Find policymaker invitation letter template [here](#).
- » **Approach celebrities in your country** to invite them to join the campaign and show support, by sharing a support message or post on social media with #WorldPIWeek.

9. GET INVOLVED IN AN (ONLINE) EVENT NEAR YOU OR ORGANIZE YOUR OWN ACTIVITY

- » **Take part in an event/activity*** in your country, or run for the PID cause. More information on local events [here](#).
- » **Contact the patient group, medical organization or hospital near you** to understand how you can help and join their World PI Week initiatives.
- » **Organise an event or activity:** an information stand at your hospital, a learning session on PIDs at your school, a run in your town, a photo booth with the World PI Week frame and educational material in a shopping mall etc. Find guidance and inspiration [here](#).

Safety comes first: make sure to follow the applicable guidelines from your health authorities when planning or organising an activity.

10. DONATE PLASMA

- » If you are an eligible donor, contact a centre near you to **donate plasma**.
- » *Read some inspiring examples to make the most of the World PI Week 2024 [here](#)*
- » *For more information on how to engage with World PI Week, please visit the page [here](#)*

Campaign materials



THE ESSENTIALS

Poster, e-banner, pledge card



ADVOCACY TOOLS

Policy pledge, call to action, template letter for policymakers



FOR LISTENING & WATCHING

Podcasts, videos, teaser films



Social Media Tools

SOCIAL MEDIA TOOLS

Data for PIDs, Picture frame, Facebook / Twitter covers, Instagram posts, GIFs



MEDIA TOOLS

Template press release, editable website post



TO LEARN ABOUT PID

Fact sheets, infographics, leaflets, stories, scientific articles



Click [here](#) to preview and download the 2024 campaign tools

World PI Week provides plenty of downloadable resources, from communications packages to scientific pieces, template social media posts, engagement toolkits, quizzes and more.

- » All materials are available in the resources section of the World PI Week website
- » Translations are available in the 'local resources' section. If you need an additional translation, please don't hesitate to get in touch.

For more information, please contact:
info@worldpiweek.org

www.worldpiweek.org



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