



Information Pack

Turning real-world data into knowledge for better PID care

Improving access to diagnosis, treatment
and care for PID patients through
collaborative & real-world data use

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 year-on-year

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.

1. Tangye SG, 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 2023 at a glance

Tagline

In 2023, World PI Week focuses on the importance of data in PID care. [Read more here.](#)

TURNING REAL-WORLD DATA INTO KNOWLEDGE FOR BETTER PID CARE

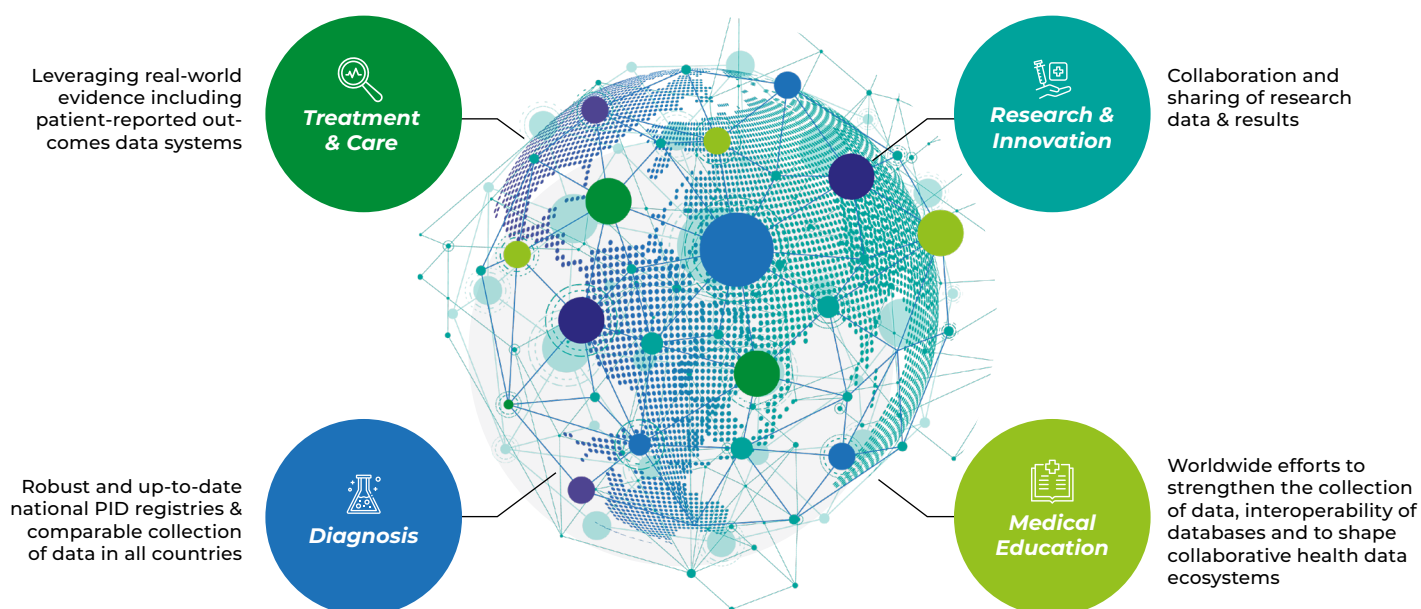
Improving access to diagnosis, treatment and care for PID patients through collaborative & real-world data use.

Join World PI Week 2023 to learn more and help make a difference!



Themes

The 2023 campaign embraces the following topics:



For a quick recap on the 2023 theme, watch our the World PI Week 2023 teaser [here](#).



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.
- » **Share our Factsheet for 2023** to shine a spotlight on this year's theme and help us spread awareness.

2. GET ACTIVE AND JOIN THE CONVERSATION ON SOCIAL MEDIA

- » **Follow World PI Week** on [Facebook](#), [Twitter](#) and [Instagram](#)
- » **Update your profile** with the World PI Week picture 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 accurate data*)
- » **Share a support message/video** with #WorldPIWeek
- » **Relay the World PI Week videos and podcasts** (*new episodes coming soon!*)
 - › *promote our new teaser 2023*
 - › *watch and share our kick-off video (released on our channels on 21st April)*
 - › *engage with the World PI Week roadshow videos "a day in the life of..."*
 - › *watch the patient-clinician coffee-talk (recording / live broadcasting on 21st April)*
- » **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

3. SUBMIT A PICTURE FOR THE PHOTO CONTEST TO SHOW SOLIDARITY

- » **Strike a Y in support of better PID care for patients through data.** Post your picture on Facebook, Twitter or Instagram with #PictureAwareness and #WorldPIWeek from 22-29 April, or send it to us at info@worldpiweek.org, we will relay it on our channels.
- » You can also **challenge your colleagues, friends or schoolmates to participate**, and post a group picture (or collage) of everyone striking a Y!

4. Join the online campaign "Data for PIDs"

- » **Share your thoughts on why data changes lives**, using the quote card generator on the World PI Week website – it will allow you to create a visual asset with your message, that you can use to support the campaign. If you post it on social media, use the dedicated campaign hashtag #DataforPIDs
- » **Relay the campaign around you:** throughout the week, we will publish content to outline the importance of data, which you can share on your social media channels to help us raise awareness and promote change, so that real life data translates into knowledge for better PID care for every person living with the disease.

[More information here](#)



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. JOIN THE PATIENT-CLINICIAN KICK-OFF COFFEE TALK

- » **Tune in** to the Patient-Clinician Kick-off Coffee Talk for a one-hour discussion between a selected group of patients, specialists, researchers sharing experiences on the importance of data. Listen and share your thoughts on webstream comments on the real value of data to improve knowledge of PIDs and engage with the community. (Link to join to be announced)

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](#).

- » **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 2022 [here](#)*
 - » *For more information on how to engage with World PI Week, please visit the page [here](#)*

Campaign materials

22-29 April 2023

Turning real-world data into knowledge for better Primary Immunodeficiency (PID) care

Improving access to diagnosis, treatment and care for PID patients through collaborative & real-world data use

#WorldPIWeek



THE ESSENTIALS

Poster, e-banner, pledge card

Social Media Tools



SOCIAL MEDIA TOOLS

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



ADVOCACY TOOLS

Policy pledge, call to action, template letter for policymakers



MEDIA TOOLS

Template press release, editable website post



FOR LISTENING & WATCHING

Podcasts, videos, teaser films



TO LEARN ABOUT PID

Fact sheets, infographics, leaflets, stories, scientific articles



Click here to preview and download the 2023 campaign tools

Join World PI Week and
help bring about change for
primary immunodeficiency
patients worldwide

