World Primary Immunodeficiency Week 2023

Turning real-world data into knowledge for better PID care

CAMPAIGN REPORT
About World PI Week
A global movement to drive change

The Week acts as a central platform to drive awareness as well as global and national advocacy.

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

**Aims**
World PI Week offers an opportunity to inform and educate health policy-makers, schools and families, and the general public about primary immunodeficiencies (PI) to drive the earliest possible diagnosis and optimal treatment.

**Vision**
Over 10 million people live with PI around the globe, and yet the condition is still widely unknown. Greater awareness, testing, diagnosis and improved access to treatment are needed.

Since its inception, World PI Week has been successful in stimulating awareness and advocacy efforts in all continents.
World PI Week by the numbers

- Over 80 countries across the globe
- Thousands of people reached
- Hundreds of events every year
- 14 committed organisations driving the campaign
- 13 years of campaigning
- 8 days to create momentum on PIDs
World PI Week in pictures
Our active network

Asian Pacific Society for Immunodeficiencies
Arab Society for Primary Immunodeficiencies
Immunodeficiency Canada
Clinical Immunology Society

European Federation of Immunological Societies
European Society for Immunodeficiencies
African Society for Immunodeficiencies
International Nursing Group for Immunodeficiencies
International Patient Organisation for Primary Immunodeficiencies

Jeffrey Modell Foundation
Latin American Society for Immunodeficiencies
Plasma Protein Therapeutics Association
South East Asia Primary Immunodeficiency Network
Immune Deficiency Foundation

A dynamic, multi-stakeholder and global community

SILVER SPONSOR

GOLD SPONSOR

BRONZE SPONSOR
Campaign resources & materials

Information & advocacy tools & activities

- Posters
- Toolkit
- Factsheet
- “Story sharing” visuals
- Social Media Assets
- Policy Calls to Action
- Media Tools
- Template letter for Governments
- Online engagement campaigns
- Videos
- Journal articles

Click here to download all materials
WORLD PI WEEK 2023 IN ACTION
A community milestone embraced worldwide

Patients, families and healthcare professionals participated in advocacy and awareness raising activities across the world to show support to those living with PID and improvements in care.

Through (virtual) runs, online webinars and workshops, social media campaigns, TV/radio interviews; by donating blood or plasma – World PI Week is for everyone!
This year, we outlined the value of real-life health data

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

Focusing on 4 key issues:

**Diagnosis**
Data helps improve knowledge & understanding of PIDs, which is crucial to ensure timely diagnosis.

**Treatment & Care**
Data allows to improve treatment & care leading to better patients' health outcomes and enhanced quality of life.

**Research & Innovation**
Health data informs efficient research & drives innovation. Research & innovation also help generate evidence to support change in policies and practices for the benefit of PID patients.

**Medical Education**
Evidence-based medical education and best practices exchange are critical to progress clinical care worldwide.

Improving access to diagnosis, treatment and care for PID patients through collaborative & real-world data use.
Preview of 2023 resources

A mix of advocacy, social media and other communication tools

The Essentials 2023
- Logo
- Poster
- e-banner
- Information toolkit
- Message house & policy calls
- Factsheet on Health Data

Social Media Tools 2023
- Picture frame
- Facebook cover
- Twitter cover
- Instagram post

Media Tools
- 2023 Template policymaker invitation
- Editable website/blog post
- 2023 Press Release

Click here to download materials
The 2023 'essentials'
Communications package

E-banners, posters, email signatures, sample website posts, press release & many more

Click here to download materials
Available in various languages

- French
- Dutch
- German
- Greek
- Italian
- Ukrainian
- Spanish
- Portuguese
- Turkish
- Mandarin
- Vietnamese

Click here to find all translated assets
A bespoke information toolkit

Everything you need to know about the 2023 campaign, how we marked the week and direct link to resources.

Click here to download toolkit
Launched in February, the “World PI Week Refresher on Data” explains:
- What health data is
- How health data is collected and used
- What real-world data (RWD) means
- What patient registries are
- The value of health data for primary immunodeficiencies

What is health data?
Health data is described as any personal data related to the physical or mental health of a person, including the provision of health care services (doctor referrals, medical examination reports, prescriptions, laboratory tests, etc.), which reveals information about that person’s health status, medical history, lifestyle, or environment. Health data are essential to understanding the state of health care delivery around the world and to improving the health information systems needed to accurately monitor health trends and inform decision-making.

How is it collected and used?
In general, information on a patient’s health and lifestyle can be collected by individuals or healthcare professionals, during a doctor or hospital visit, and is stored as health data in patient records. Researchers, clinicians, doctors and public health experts benefit from these patient records and use them to develop or improve diagnosis approaches, clinical care, medical & scientific research and strengthen medical education. This data can also be aggregated at a larger population level, cross checked from different sources, for broader knowledge purposes, and to improve overall health systems.

What do we mean by “real-world data” (RWD)?
Although there is no consensus definition for real-world data, it is understood for different types of health care data related to the effects of health interventions, that are not collected in conventional clinical trials. Such data come from various sources and include patient data, data from doctors, hospital data, data from pharmacies, and special data such as clinical and economic outcomes, patient-reported outcomes and health-related quality of life.

RWD can complement clinical trial data to support medicine assessment and authorization, as well as regulatory decisions in smaller patient populations like PIDs. It is valuable to strengthen understanding of the effectiveness and impact of a treatment or care pathway on the long-term.

What are patient registries (or databases)?
Patient registries are repositories—for one or more purposes—of standardized information about a group of patients who share a condition or experience. They may be organized either per disease or product-treatment.

Therefore, patient registries allow widespread clinical and laboratory data on selected patient populations to be gathered that can be used to foster advances in scientific research and ultimately improve patient care. They aim to collect and store data, and allow to collect such data in a coordinated way, using observational methods and following the same patients over time.

What is the value of health data in primary immunodeficiency (PIDs)?
Due to existing knowledge and awareness gaps and the complexity inherent to this field, the diagnosis and management of rare diseases such as primary immunodeficiencies (PIDs) can be challenging.

- **Diagnosis**: Collecting & sharing data can support greater knowledge about the disease and associated symptoms and signs, and the development of diagnostic tools and techniques.
- **Treatment & Care**: Data analyzed through registries provide important insights into patients’ impact, efficacy and duration of treatment or the right combination of treatments, as well as help decision makers improve health care systems.
- **Research & Innovation**: Turning data into evidence for novel treatments or new products and support to develop innovative therapies and new care pathways and make these accessible to all PID patients.
- **Health education**: improving awareness and education for healthcare professionals and specialists through evidence-based data that allow accurate diagnosis and treatment of PIDs.
Message House & Global Policy Calls

Our policy calls
What needs to be done worldwide

Leverages real-world evidence including patient-reported outcomes data to inform policies for researchers, regulatory agencies, and providers through follow-up on efficacy of treatments and health outcomes.

Link and use data from national PID registries & comparable collection of data in all countries – to provide necessary data for planning, service, monitoring public health, improves PID research, diagnosis and care.

Ethical, responsible and transparent use of patients' health data – ensures patient data is used to enhance understanding and care for PID.

Collaboration and sharing of research data & results in the academic sector and beyond among all network collaborations to benefit patients' health.

Worldwide efforts to strengthen the collection of data and to share collaborative health data anonymously to provide the healthcare vital for higher quality and more personalized care.

Using health data to facilitate innovation in healthcare delivery and treatments, and to enhance health systems and specialized care services for PID.

Click here to access the Message House
Campaign Teaser Video

Engaging video conveying a “build-up” message on the topic of data featuring:

- Rüdiger Krech, Director of the Department of Health Promotion, World Health Organization (WHO)
- Dr. Nizar Mahlaoui, Chair of IPOPI Advisory Panel

Click here to watch the teaser video
Global messages from organisations on “why data matters” to launch the 2023 campaign

+150 views on YouTube only

Click here to watch the launch video
This year, we invited the community to share their thoughts on why they think data is essential in improving care for Primary Immunodeficiencies

- +50 social media posts shared using #DataforPID - including patient representatives, carers, experts, industry partners
Patient-Clinician Coffee Talk

On 21 April, we hosted our first live & hybrid event to kick off the campaign week, featuring exciting conversations focusing on:

- Value of patient registries to advance knowledge & research
- Establishing and maintaining national PID registries
- Collection of health data on a day-to-day basis
- Kicking off WPIW 2023

Click here to watch the recording (start from 00:37)
New World PI Week Roadshow Series

5 new destinations of the Roadshow Series showcasing daily lives of a patient, a carer, a researcher, an industry partner and a nurse across the globe!

Destination #1
Argentina

Destination #2
Australia

Destination #3
Austria

Destination #4
Morocco

Destination #5
Canada

Watch the Roadshow Videos here
About World PI Week Roadshow Series

Roberta talks about how robust patient registries help improve PID care and lives of patients, families and carers.

Emily shares her views on how data accrued helps improve diagnosis & treatment as well as the importance of collecting data safely.

Thomas gives insights on why data is essential in epidemiology and pathogen safety for improved PID care.

Maria explains why registries are important in prevention of pathologies from a patient’s perspective.

Jessica delves into health data’s role in facilitating diagnosis, guidelines and management of rare conditions & improving medical awareness.

Tune into the Roadshow Destinations here
Photo campaign #PictureAwareness

Striking a “Y” on all continents to support the PID cause

- Participation on social media to mobilise and drive attention using #PictureAwareness
- Patients and supporters shared their pictures striking a Y to raise awareness of PIDs across the globe!

Click to access the photo campaign
Congratulations to MaricheLo Hernandez Ibarra from Mexico! Well done!

#PictureAwareness
Social media milestones

Driving conversations and mobilising to raise awareness of PIDs

This year, World PI Week reached its highest ever level of engagement on social media since the inception of the campaign!

Analytics for 22-29 April

April

Twitter

+100 followers
+150 posts shared
+26K impressions
+18K profile visits

Instagram

791 followers (+10%)
+42 posts shared
+90 stories shared
1,959 accounts reached (+444%)

Facebook

+48 followers
+40 posts shared
Most engagement from United Kingdom
Overall impressions & engagement

- 50% audience increase
- Tweet reach was the highest ever
- Highest engagement around coffee talk activity
- Best performing social channel

TWITTER: @WorldPIWeek

FACEBOOK: @WorldPIWeekcampaign

INSTAGRAM: @world_pi_week

WEBSITE: www.worldpiweek.org
Media coverage

World Immunodeficiency Week: More Than One Million Indians Have Immunodeficiency Diseases, Say Experts

In the United States, one in 2,000 live births is estimated to have primary immunodeficiency. On the back of this, experts estimate that more than one million Indians are likely to have the diseases.

More than 600 Romanians are today diagnosed with one of the more than 400 diseases from the family of primary immunodeficiencies, but due to the fact that very frequently, these diseases manifest as common infections, it is assumed that there are another 5,000–6,000 Romanians who have a disease belonging to this category, but are not diagnosed, or are misdiagnosed. Some of these conditions are so mild that they may go unnoticed until adulthood. Other types are so severe that they are discovered soon after birth.

In Romania, there are 600 patients diagnosed with primary immunodeficiencies, but it is estimated that the number of undiagnosed ones is 10 times higher.

National/local media coverage: Australia, France, Netherlands, US
Country involvement

47 countries reported participation to World PI Week 2023 as of May

- Argentina
- Australia
- Belgium
- Bolivia
- Brazil
- Canada
- China
- Ecuador
- France
- Greece
- India
- Ireland
- Italy
- Malaysia
- Mexico
- Netherlands
- Poland
- Portugal
- Romania
- Russia
- South Korea
- Spain
- United Kingdom
- United States
- Venezuela
- Vietnam
- Australia
- New Zealand
- Philippines
- Thailand
- Indonesia
- Japan
SNAPSHOTS OF NATIONAL EVENTS
AAPIDP (Association de Ayuda al Paciente con Immunodeficiencia Primaria)

- Conference on Nursing in Primary Immunodeficiencies at the Elizalde Hospital in Buenos Aires
- 3rd Virtual PID Patients Congress
  - 2 educational lectures
  - 1 advocacy lecture about access to treatment
- #MyPIStory testimonials
- Awareness-raising campaign on social media

AAPIDP (Asociación de Ayuda al Paciente con Inmunodeficiencia Primaria)
• New «Share Your Story» online campaign – mirroring WPIW campaign at global level
• Instructional video featuring Christine Jeffrey from Blue Wren Advocacy on Self Advocacy Toolkit
• Stakeholders’ discussions on the implementation of the 2022 National Immunology Strategy
• #WhereYouAre Social Media Competition.
  • Sharing a picture with a “Y” (symbolising the antibodies) to show support to PIDs
• Social Media engagement

Donate to Make a Difference to People Living with PI.
Primary immunodeficiencies are rare diseases which occur when a person’s immune system is absent or does not function properly. When a defect in the immune system is inherited (carried through the genes), it is called primary immunodeficiency.

By donating to IDFA, you will be helping us to:
• Raise awareness for PID, specifically importance of access to early testing and proper diagnosis.
• Help us contact with community members suffering or caring with someone with a PID around the country through support groups.

Social Media engagement

2022 WPIW REPORT
Recipient of IPOPI grant
IDFA – Immune Deficiencies Federation Australia

Share Your Story - for a chance to win 1 of 3 $100 gift cards.
On average, our members experience 5 years before a diagnosis and the journey is often overwhelming with a huge impact on quality of life and wellbeing. So, this year we invite everyone to share their story.

With your data and your stories, we can help raise awareness that early diagnosis benefits everyone, ourselves, our families including the health system.

Winner!

IDFA Australia • Apr 21
It’s next World PiWeek has officially begun. If you’re looking for ways to show your support, consider a donation by buying a raffle ticket or sharing your own experiences, #WorldPiWeek #Australia #WPIWeek #RaffleTicket #CreativeBreath #Immunodeficiency @WorldPiWeek

Immune Deficiency Foundation of Australia (IDFA)
April 29 at 4:22 AM

For World Pi Week in 2022, ASCIA and IDFA launched the National Immunology Strategy. Fast forward to this year, on the 28th and 29th of April 2023, we meet again, along with AusPIPS, IDFNZ and other stakeholders to discuss and progress the strategy with a detailed action plan for implementation over the next 12-24 months. Both Emily Edwards AusPips and Carolyn Devis IDFA CEO were in attendance to the event.

#worldpiweek WorldPiWeek AusPIPS Inc. Australasian Society of Clinical Immunology and Allergy (IDFNZ Kids Foundation)
Information updates

ASCIA events in World Primary Immunodeficiency Week - 22-29 April 2023

ASCIA has planned the following events, to coincide with World Primary Immunodeficiency (PID) Week (22-29 April 2023) and the International Day of Immunology (29 April 2023):

ASCIA Immunodeficiency Strategy Meeting
Sydney, Australia - Marly Pacific Hotel
Friday 28 April 2023

ASCIA TAPID (Transplantation and PID) Meeting
Sydney, Australia - Marly Pacific Hotel
Saturday 29 April 2023

ASCIA Advanced Training Immunodeficiency Meeting
Sydney, Australia - Marly Pacific Hotel
Sunday 30 April - Tuesday 2 May 2023

Australian Society of Clinical Immunology and Allergy

22 April at 0618

Did you know it’s World Primary Immunodeficiency (PID) Week?

“By providing fair access to genomic testing for PIDs, healthcare providers will be better equipped to identify and diagnose these conditions early, which will improve outcomes for patients and reduce the burden on the healthcare system. Early and accurate diagnosis ensures that people with Primary Immune Deficiencies receive the medical care they need to manage their condition which will prevent complications,” explains Professor Jo Douglass, clinical immunology/allergy specialist and co-chair of the ASCIA Immunodeficiency Strategy.

To learn about the ASCIA National Immunodeficiency Strategy go to https://www.nationalimmunodeficiencystrategy.org.au/

#ASCIA #PID #immunodeficiency #genomictesting
Austria

Coming Soon!

Recipient of IPOPI grant
Belarus

#MyPIStory Campaign – sharing patient stories

School of Patients with PID in Vitebsk

Took part in the Republican School-Seminar “Diagnostics of immunopathological conditions.

Social Media Engagement

Click to see more
Belgium

Bubble ID

- Bubble ID Family Day
- Donation campaigns

Click to see more

Thank you to everyone who attended our bubble ID family day 😊😊😊

See original · Rate this translation
Belgium

Belgian Patient Organisation for Primary Immunodeficiencies (BePOPI)

- Participation in Bubble ID Family Day

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Bolivia

FIDEP – BOLIVIA (The Primary Immunodeficiencies Patient Organisation)

- Experts Insights on PIDs (4 informative videos)
- Awareness raising campaign at the "Manuel Ascencio Villarroel" Children’s room at the City of Cochabamba at the Children’s Hospital
- PID Factsheet Posters & Awareness Raising campaigns

Recipient of IPOPI grant
Brazil

Associação Brasileira de Alergia e Imunologia (ASBAI)

- PID Testimonial Videos
- Covid-19 Vaccination campaign
- #plasmajabrazil campaign
  - Podcasts episodes
  - Social media engagement

Click to see more
Canada

- National walk with over 100 participants
- Awareness raising campaign called “Invisible No More”
- World PI Week Proclamations in 6 cities
- Fundraising Walk for Immunodeficiency
- 2023 National Immune Deficiency Patient Conference
- Social media engagement
- Fundraising

**Immunodeficiency Canada**

Recipient of IPOPI grant
Section 1

• Participation in international PID campaign via video testimonial (IPOPI)
• Patient & Families board meeting
• Virtual meeting with IPOPI representatives
• Social Media Engagement
China

PID Care China

- Kite-Flying campaign in 4 cities
  - 150 kites with QR codes for patient surveys to combine activities with data collection
- Social Media Engagement
- Actively inviting the community to engage in data related efforts

Jessie - PID Care China @Jessiequmeng • Apr 29
Celebrate spring in China with kite-flying and the #WorldPIWeek campaign! PID patients were encouraged to join the campaign through a kite-flying campaign organised by PID CARE CHINA. Patient Survey QR codes were printed on kites to collect important data from patients.

Click to see more

Jessie - PID Care China Retweeted
World Primary Immunodeficiency Week @WorldPIWeek • Apr 25
#WorldPIWeek Roadshow Destination#3 features Thomas Kreil, Vice President, Global Pathogen Safety at @TakedaPharma! Watch now to find out more about why data is so important in epidemiology bit.ly/3NbQGZW

Recipient of IPOPI grant
Columbia

Fundacion FIP (Fundacion Diana Garcia de Olarte) – Collaboration with Iniciativa ALAS

- Podcast episode on PIDs
- Social Media Engagement

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Cyprus

- Social media engagement
- Scientific Conference on PAAs in collaboration with Υπουργείο Υγείας Κυπριακή Δημοκρατία, Παιδιατρική Εταιρεία Κύπρου and under the auspices of Cyprus Alliance for Rare Disorders and Karaiskakio Ινστιτούτο / Karaiskakio Foundation
- Presence in National TV Channel on PIDs
- Translation of IPOPI statement into Greek
  - “A PID causing a heavy burden of disease must always be recognised as a disability.”
Ecuador

Foundation PIDE

- Social Media Engagement
- National Symposium "Talking about Primary Immunodeficiencies" for the World Week of Awareness
- Illumination of the Old Cathedral "Iglesia del Sagrario" in the city of Cuenca
- Training workshop, violation of rights in health
- Inaugural video

Recipient of IPOPI grant
Eesti Primaarse Immuunpuudullikkusega Patsientide Uhing (PIDESTONIA)

- Seminar-presentation at Tallinn University of Health and at Medicum
- Discussion round about “Primary Immunity” at Tartu University Clinic on 1st of June
- “A dream day” for a child with PID in cooperation with Minu Unistuste Minu Unistuste Päev.
- Social media campaign “Did you know?”
- Informative banners for medical students in Tallinn and Tartu
- Thank you letters to blood centers

Recipient of IPOPI grant
France

Association IRIS

- IRIS Connected Race #CourirPourIris
- Social Media Engagement

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IASO Children’s Hospital will have its 11th Scientific Seminar in Greek!

The lectures of the 3rd Session (4:30 – 16:00 [EET]) will focus on Primary Immunodeficiency Immune-mediated diseases.

As World PI Week approaches, more and more events take place globally. IASO’s Children Hospital is organizing its 11th Scientific Seminar (hybrid) in Greece! The 3rd session focuses on Primary Immunodeficiencies.

Chairs: Maria Varvarou, Stylianos Crakakos, Tania Telivitanidou – Kakourou

- Paraskevi Maggina: Complex Manifestations of Inborn Errors of Immunity / Primary Immunodeficiencies
- Joanna Barbounaki: Diagnostic Approach of Prolonged Fever and Recurrent Fever Episodes
- Lampros Fotis: Juvenile Dermatomyositis

Live streaming link: https:// intoxation.nowlive.events/88/node/95
Greece

Immune Deficiency Association of Greece (Galinos)

- Informational advertisement video on PIDs broadcasted on national TV, radio & internet
  - Featuring patients, board members sharing personal experiences

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Germany

- Live virtual event on PIDs
- "Boy in the Bubble" in Berlin
- Social Media Engagement

@ Immundefekt

Live-Event
26. April 2023 | ab 11 Uhr
> auf der Reichstagswiese in Berlin
Meeting with nurses at the Children's hospital and the Department of Immunology

Presentation of the Immunology departments new website

Educational material

Organising 2 meetings for November
  - Educational meeting for nurses, medical students & health workers
  - Meeting for parents of children with PID & adult patients
Indian Patients Society for Primary Immunodeficiency (IPSPI)

- IPSPI-Indian Patients Society for Primary Immunodeficiency in collaboration with Medicine and Pediatrics Department of Lady Harding Medical College, New Delhi - #WPIW2023 Conference
- a Sharing and Caring of IEI Patients and Family Event

Click to see more
Section 1

- Social Media Engagement
- PID Facts visuals
- Online Symposium

IDAI (Indonesian Pediatric Society)

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**Indonesia Primary Immunodeficiency Patients Society - IPIPS**

- Indonesia Registry Work Plan Launch to kick-off pilot for national registry (Timeline: 12 months)
- Family Day on May 28 with 50 participants including patients and experts
- Social media engagement
- Online article

**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

Recipient of IPOPI grant
Iran

Iranian Primary Immunodeficiency Association (IPIA)

- **14th International Congress of Immunodeficiency Diseases (ICID)** – 26-27 April
  - 28 Lectures
  - 11 countries

- Exhibition area at the Immunology Congress to increase awareness of healthcare workers on PIDs
Ireland

IPIA - The Irish Primary Immunodeficiencies Association

- Social media engagement
- Collaborating with hospitals to create & purchase posters, leaflets, goody bags, treats, emergency cards to distribute to PID patients

JOIN US

IPIA aims to enhance the quality of life and increase awareness among people with primary immunodeficiency. To further this cause, IPIA is collaborating with St. James Hospital in Dublin on April 27th and Children Health Ireland Crumlin in Dublin on April 26th.

Additionally, Beaumont Hospital, Bon Secours Hospital in Galway will also be joining.
Israel

Bubble Care

- Presentation to Immunologist doctors
- 2 videos on PIDs in collaboration with Takeda featuring Ruti Steinberg & Dr. Nufar Marcus
- 4 videos on patient stories
- Online articles
- Social media engagement including warning signs, podcast articles & testimonials

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Associazione Immunodeficienze Primitive & Federazione Italiana Associazioni Donatori di Sangue

- Brand new comic episode of Lino Globulino, the superhero of children with PIDs
- 2023 Stakeholders and Patients & Doctors Meeting
- Press Release
- Social media engagement

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Japan

NPO法人PIDつばさの会 PIDTsubasa-no-Kai

- Media conference in Tokyo on 6th of April
- Articles published in 6 media outlets
- Social media engagement
  - “10 warning signs”

Recipient of IPOPI grant
Kenya

PIDS Kenya

- Social media engagement
- Participation in International Video on PIDs (IPOPI)

"Seeing the numbers makes me feel less alone."
In the second video of our World PI Week campaign, we hear from Hellen Ayaga, a mother from Kenya whose child has... See more
Malaysia

MyPOPI - Malaysia Patient Organization for Primary Immunodeficiencies

- Organised a Blood Donation Campaign & Collaborate with the Ministry of Health of Malaysia to promote awareness of PID on MoH Online Portals.
- Dissemination of infographic
- Social Media engagement
- Participation in World PI Week 2023 with Patient-Clinician Coffee Talk

Recipient of IPOPI grant
Mexico

Fundación Mexicana para Niñas y Niños con Immunodeficiencias

- Visit to Papalote Children’s Museum
- 1st congress on PIDs led by specialists
- The Ball is in Your Court Public Policy Advocacy Campaign
- Social Media Engagement
- 1st Primary Immunodeficiency Podcast in Latin America

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Morocco

- Launch of new service dedicated to PID patients
- Award distribution for best medical student awareness video
- Blood donations
- Scientific conference on vaccination
- A party for children with PIDs
  - PID quiz
  - Meeting with nurses, doctors and parents
  - Gifts

Recipient of IPOPI grant
Stichting voor Afweerstoornissen (SAS) Foundation for Immune Disorders

- National Patient Day for PID Patients & Families
- Participation in International PID video (IPOPI)
- 4 Informative Videos in collaboration with Industry partner
- Launching of PID Expertise Network
- SAS Family Day with 130 visitors
  - Announcement of national PID empowerment event (23 September 2023)
- Social media engagement

Recipient of IPOPI grant
New Zealand

IDFNZ Kids Foundation

- PIE for PI Challenge
- World PI Week Quiz
- Warning signs posters available in multiple languages
- Social Media Engagement

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Philippines

Philippines Patient Organization for Primary Immunodeficiencies

- Social Media Engagement
- Comic strips on brochures, posters, leaflets and other promotional items
- Fundraising

Recipient of IPOPI grant
Poland

Association for Patients with Primary Immunodeficiencies (IMMUNOPROTECT®)

- Educational wobblers with 10 warning signs of PIDs for general practitioners

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Portugal

APDIP - Associação Portuguesa de Doentes com Imunodeficiências Primárias

- Social media engagement
- Family Reunion in Aveiro
- PID walk

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Puerto Rico

Puerto Rico Alliance of PID Patients (APIP)

- Family meeting with patients, families and doctors
- Launch of educational awareness campaign via social media

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Romania

Romanian Association of Patients with Primary Immunodeficiency (ARPID)

- Presence in WPIW Patient-Clinician Coffee Talk
- Virtual National ARPID Conference
- Regional patients-doctors-nurses meeting
- Social Media Engagement
- Participation to International PID Video (IPOPI)

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Recipient of IPOPI grant
Russia

Coming Soon!

Click to see more
Slovakia

Združenie pacientov s primárnou imunodeficienciou, o.z.

• Awareness raising video

Združenie pacientov s primárnou imunodeficienciou

26. April

Tento týždeň je pre nás veľmi dôležitý, lebo od 22 do 29 apríla sa koná "World PI Week" čiže v preklade Svetový týždeň pre primárne imunodeficiencie. Tento týždeň je venovaný hlavne zvýšovaniu povedomia o ochoreni a preto budeme radšie ak naše video podporíte zdjelãním. My sme pripravili 10 minútovú prezentáciu, ktorú odvysieliame v stredu o 18:00, a bude zároveň aj odprezentovaná na odbornom sympóziu pre primárne imunodeficiencie, kt. zastraňuje doc. MUDr. Peter Čiznár.

See translation
South Korea

- PID Korea regular families meeting

Recipient of IPOPI grant
Spain

Barcelona PID Foundation

- Foundation Members Videos
- Social media engagement
- Fundraising event
- Adult patient care seminar
- Educational activity at Grifols

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Spain

Asociación española de deficiencias inmunitarias primarias (AEDIP)

- Two walks in Gavilanes
- More than 100 inscriptions
- Information on PIDs
- Plasma donation borchures

Recipient of IPOPI grant
Sweden

• #GoZebra walk campaign
• Social media engagement

22 April
World Immunodeficiency Week and the #GoZebra campaign. News!
#ZebraRun
April 22 - April 29

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Thai patient Organization for Primary Immunodeficiency (ThaiPOPI)

- Souvenirs for donors to the Thai Red Cross Society
- Paper notes for people donating blood during WPIW
- Social media engagement
  - 10 warning signs
Turkey

Ulusal Alerji ve Klinik İmmünoloji Derneği (AID)

• #ThinkZebra kite flying in Gaziantep
• Q&A Seminar on PIDs with patients & families

Click to see more
Ukraine

Rare Immune Diseases

- Social advertising in metro lights in Kyiv (May 2023)
- Posters for PI signs
- Distribution of information booklets to hospitals
United Kingdom

Immunodeficiency UK

- Social media engagement
- Posters
- 2 patient stories on APDS and Complete Di George
- Sharing Community voices
- Patient survey in collaboration with Takeda (Launch on 8 June 2023)
- Donation campaigns

Recipient of IPOPI grant
United States

Immune Deficiency Foundation

- Social media engagement
- In-person advocacy campaign in Washington
- #WalkforPI campaign

PATIENT SAFETY & PROTECTION

By protecting each other with vaccination, we protect people with primary immunodeficiency
Vietnam

Vietnam PID Patient Support Group (Viet Pips)

- Social media engagement
Venezuela

IDP-Venezuela

- 1 hour radio interview featuring 2 immunologists
- Concert “Playing for PID” in theatre
- WPIW 2023 Hike
- “Approach to the patient with recurrent infections” conference
- 2 Webinars
- 5th Annual meeting on IEI
- Annual meeting with PID patients
- Social media engagement
- Expo PID

Recipient of IPOPI grant
Iniciativa ALAS

- PID Radio

Click to see more
Section 1

• Roundtable discussion in Madrid
• IPOPI World PI Week Campaign
  • Featured video interviews with individuals from France, Kenya, Netherlands, Chile, Indonesia,
  • Highlighted need for improved data collection, hurdles faced by patient organisations in data collections
  • Put a spotlight to IPOPI PID Life Index
• Health application 4ID
• Social Media engagement

Click to see more

Section 2

HOT TOPICS

• 2022 WPIW REPORT
International

Jeffrey Modell Foundation

- Regional Toolkits
- Social Media Engagement
- Patient Stories

Click to see more
Today kicks off #WorldPIWeek, a time to show our support for all those living with #PrimaryImmuneDeficiency. During World PI Week, we’ll be sharing resources, facts and stories from those living with PI. Learn more about... see more.

10 MILLION PEOPLE WORLDWIDE are living with Primary Immunodeficiency

World PI Week begins on April 22, and it is an important opportunity to help bring about change for Primary Immune Deficiency (PID) patients worldwide. This year, #WorldPIWeek focuses on turning real-world data into knowledge to improve access to diagnosis, treatment and care for PID patients. As part of the #DataForPIDs campaign, we invite you to join us in sharing why you think data is essential in improving care for Primary Immunodeficiencies: https://bit.ly/3XX31yY

Chiesi Global Rare Diseases @ChiesiGRD - 23 avr.
As we join with the global PI community in recognizing @WorldPIWeek, we invite you to listen to the story of Jakob and his parents, Andrea and Kamil, who found strength in their family’s journey with ADA-SCID: youtube.com/watch?v=AU-cn...
Thank You!

World PI Week 2022 was a success again!

PID awareness does not end with the campaign.

Continue to share information and engage worldwide, to drive positive change.

We thank our committed sponsors; without their support our campaign would not be possible.
Takeda (Gold Sponsor), CSL Behring (Silver Sponsor), Chiesi (Bronze Sponsor)