

World Primary Immunodeficiency Week 2023

Turning real-world data into knowledge
for better PID care

CAMPAIGN REPORT





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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.

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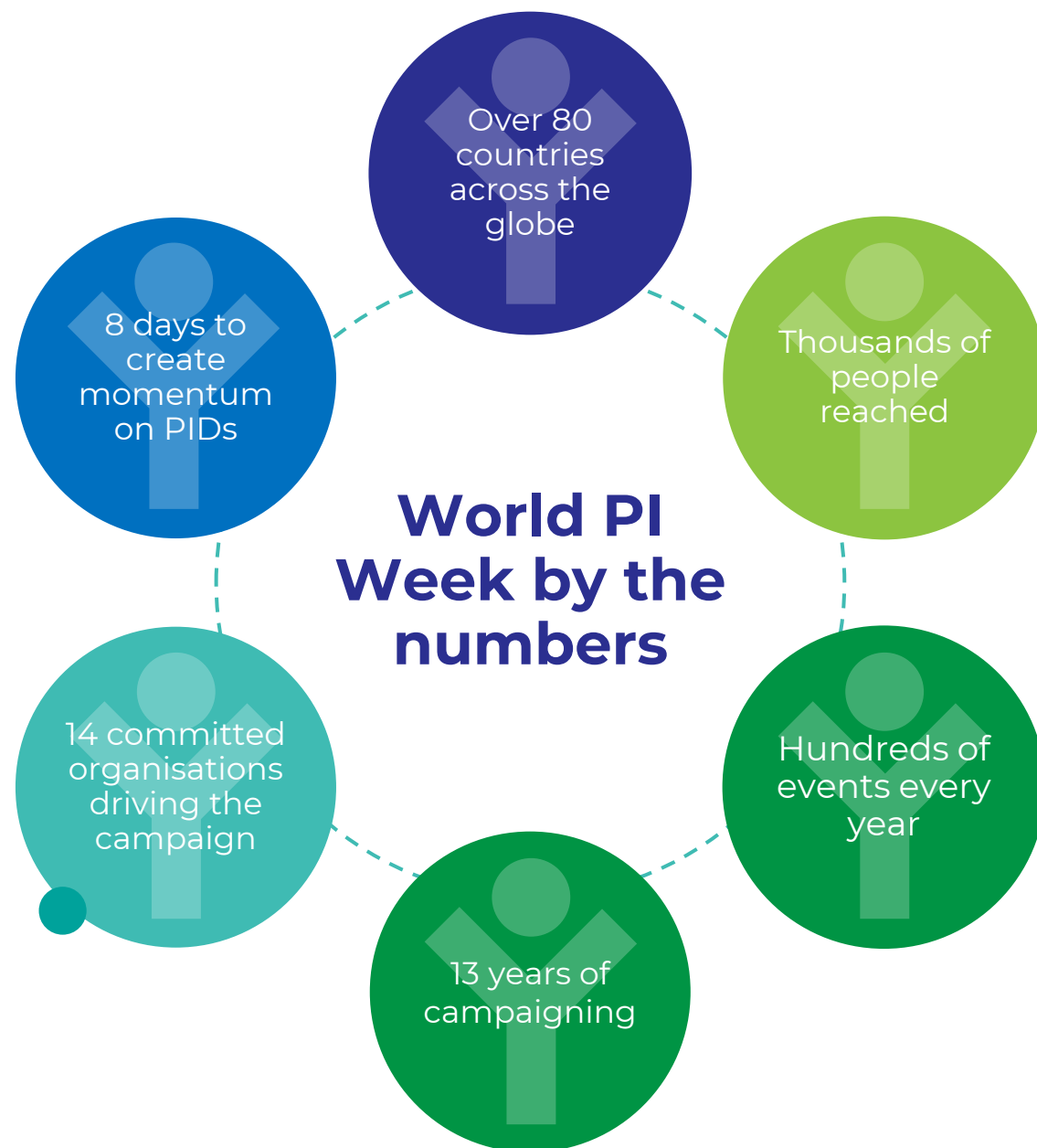
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World PI Week by the numbers



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



GOLD SPONSOR



SILVER SPONSOR



BRONZE SPONSOR



A dynamic,
multi-stakeholder
and global
community



Information & advocacy tools & activities

Information & advocacy tools & activities

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](#)



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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 PIDs 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

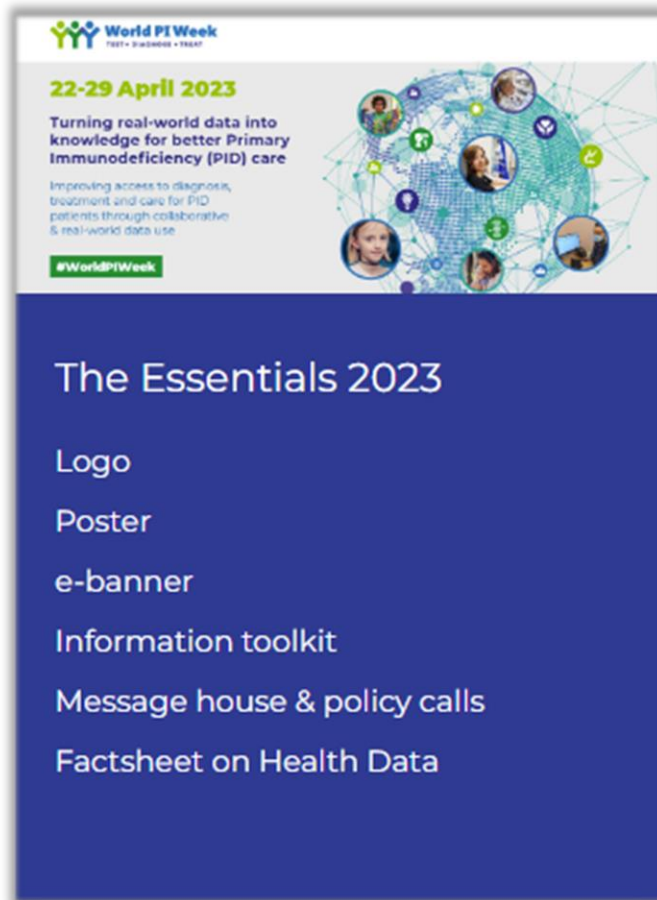
Medical Education

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

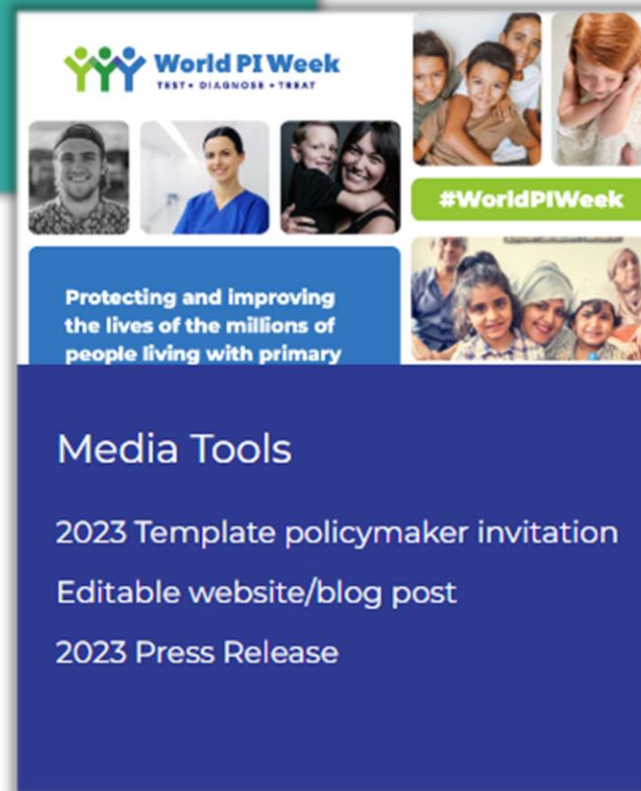


Preview of 2023 resources



Social Media Tools 2023

Picture frame
Facebook cover
Twitter cover
Instagram post



A mix of advocacy, social media and other communication tools

[Click here to download materials](#)

The 2023 'essentials'

Communications package



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



World PI Week
TEST • DIAGNOSE • TREAT

**22-29
Avril 2023**

Transformer les données du monde réel en connaissances pour une meilleure prise en charge des l'immunodéficience primaires (PID).

Améliorer l'accès au diagnostic, aux traitements et aux soins pour les patients atteints d'immunodéficience primaire (PID) grâce à l'utilisation de collaborative des données du monde réel.

#WorldPIWeek

www.worldpiweek.org @world_pi_week @WorldPIWeek WorldPIWeekCampaign

Takeda

World PI Week
TEST • DIAGNOSE • TREAT

22-29 April 2023

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

#WorldPIWeek



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Available in various languages

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French

Dutch

German

Greek

Italian

Ukrainian

Spanish

Portuguese

Turkish

Mandarin

Vietnamese

...tan alınan verileri
...nütürerek Primer
...yetmezlik (PID)
...lerini geliştirebiliriz.

World PI Week
TEST • DIAGNOSE • TREAT

2-29 April 2023

Het omzetten van Real-World
Data in kennis voor betere zorg in
Primaire Immunodeficienties (PID)

Verbetering van de toegang tot diagnose,
behandeling en zorg voor PID-patiënten
door middel van samenwerking en
gebruik van Real-World Data

#WorldPIWeek

in Wissen für eine bessere
PID-Versorgung umwandeln

besserer Zugang zu
nose, Behandlung und
für PID-Patienten
gemeinsame und
e Datennutzung

4月22日至29日

世界的的数据
识, 使原
缺陷病患
好的照顾

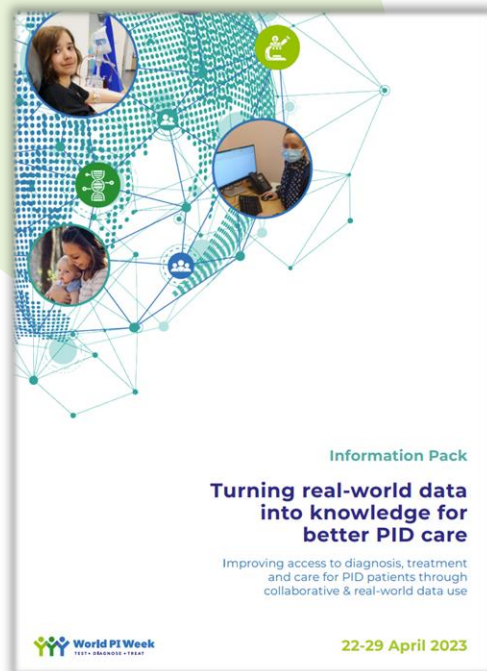
协作以及对
的数据运
对原发性免
患者的诊
和护理水平

PIWeek



[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](#)

A Health Data Factsheet

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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

World PI Week Refresher on Data

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 and medical status.”² Reliable health-related statistics are essential to understanding the state of health care delivery around the world and many countries lack the health information systems they need to accurately monitor health trends and inform decision-making³.

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 healthcare systems.

What do we mean by “real-world” data (RWD)?

Although there is no consensual definition, real world data is an umbrella term 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 clinicians, hospital data, data from payers, and social 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 authorisation, as well as regulatory decisions in smaller patient populations like PIDs. It is valuable to strengthen understanding on 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 organised either per disease or product (treatment)⁴. 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.⁵ Patient registries are an important source of real-world data, and allow to collect such data in a coordinated way, using observational methods and following the same patients over time⁶.

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 difficult.

- **Diagnosis:** Collecting & sharing data can support greater knowledge about the disease and boost testing and early diagnosis; and the development of efficient diagnostic tools.
- **Treatment & Care:** Data analyzed through registries provide important information about patients, the impact, efficacy and durability of treatment to strengthen their care, as well as help decision makers improve healthcare systems.
- **Research & Innovation:** Turning data into evidence help advance understanding of PIDs and is crucial to develop innovative therapies and new care pathways and make these accessible to all PID patients.
- **Medical Education:** Improving awareness and education for healthcare professionals and specialists through evidence-based data is important to strengthen expertise, which will allow accurate diagnosis and treatment of PIDs.



[Click here to access the police pledge](#)



Message House & Global Policy Calls

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Diagnosis

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



Globally, over 6 million people are affected by primary immunodeficiencies, among which 70 to 90% remain undiagnosed¹. Collecting & sharing data on PIDs can support greater knowledge about the disease and facilitate testing and early diagnosis, and the development of efficient diagnostic tools. For instance, the analysis of national registries and health records data may allow to identify affected individuals within the general population and study specific populations at risks. Interconnected databases are crucial to improve genetic testing and help make better informed decisions about PID care across regions.

¹ Mayhls L, Blauw-Peas A, Duff C, Singh S, Lau YL, Corbino-Neto A, Ben-El-Mechaieq H, et al. A global survey of primary immunodeficiencies: A Decade of Progress and a Promising Future. Front Immunol. 2021 Feb 18;12:625703. doi: 10.3389/fimmu.2021.625703. PMID: 33679794 PMCID: PMC7933502.

Research & Innovation

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



Global collaboration and data sharing is the key to enhance understanding of PIDs and develop new successful treatments to improve patients' lives. Data from clinical trials and other sources help advance understanding of PIDs. Data collection and sharing is crucial to develop innovative therapies and make these therapies accessible to all PID patients. Global collaboration on data sharing will help address remaining unmet needs of PID patients across regions.

Treatment & Care

Data allows to enhance care and deliver improved or new treatments, leading to better patients' health outcomes and enhanced quality of life.



Turning quality data into clinical insights and medical evidence contributes to more efficient, higher quality, safer and more personalized care, and help advance treatment options. Data collected and analysed through registries and other sources provide important information about patients, the impact, efficacy and durability of treatment overtime to strengthen their care, as well as help decision makers improve health systems.



Medical Education

Evidence and science-based medical education and best practices exchange are essential to progress clinical care worldwide.

Data helps reduce the knowledge gap among primary care physicians and specialists and help reduce disparities in PID awareness across the globe. Improving awareness and education for health professionals and specialists through evidence-based data is important to strengthen expertise, which will allow accurate diagnosis and treatment of PIDs. Continuous medical education is fundamental as it helps align practice with the evolution of scientific and medical knowledge.

Robust, quality health data is critical to enhance disease knowledge, healthcare delivery, medical research and development, support policy and regulatory decisions, and ultimately benefit patients as well as societies.

In rare diseases like PIDs, data is all the more vital to provide more efficient, higher quality, safer and more personalised care.

Data can change lives by speeding up diagnosis, improving patient care, and fostering research into new treatments.

World PI Week 2023 is shining a light on the value of data in the field of PIDs, for the diagnosis of PIDs, treatment and care, research, innovation and medical education.

Our policy calls

What needs to be done worldwide



Leveraging real-world evidence including patient-reported outcomes data to inform priorities for research, regulatory decisions, and monitoring & follow-up on efficacy of treatment and health outcomes



Robust and up-to-date national PID registries & comparable collection of data in all countries – to provide necessary data for planning services, monitoring public health, improve PID research, diagnosis and care



Ethical, responsible and transparent use of patients' health data – to ensure data obtained from patient registries is used and shared safely to improve understanding and care for PIDs



Collaboration and sharing of research data & results in the academic sector and beyond among all relevant stakeholders, to benefit patient's health.



Worldwide efforts to strengthen the collection of data and to shape collaborative health data ecosystems – to provide the knowledge vital for higher quality and more personalized care



Using health data to facilitate innovation in diagnosis, treatment and research; and to **enhance health systems** and specialist care services for PIDs



[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*

2023 Campaign Teaser



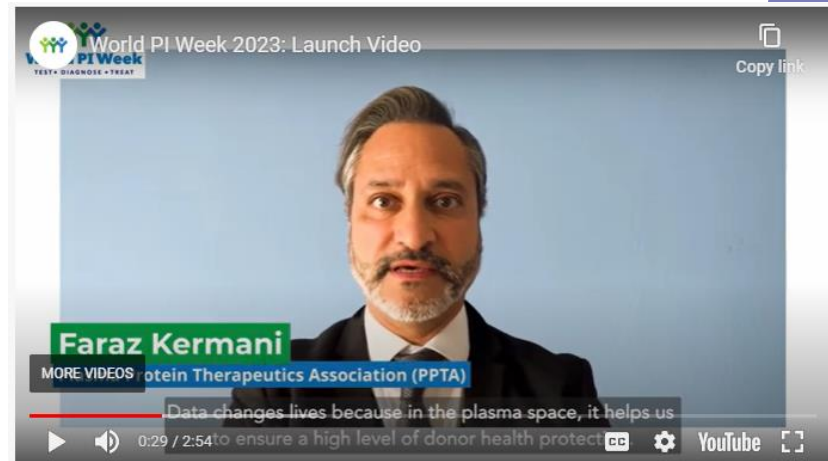
[Click here to watch the teaser video](#)

Campaign Launch Video

Global messages from organisations on “why data matters” to launch the 2023 campaign

+150 views on YouTube only

2023 Campaign Launch Video



[Click here to watch the launch video](#)

New online campaign #DataforPIDs

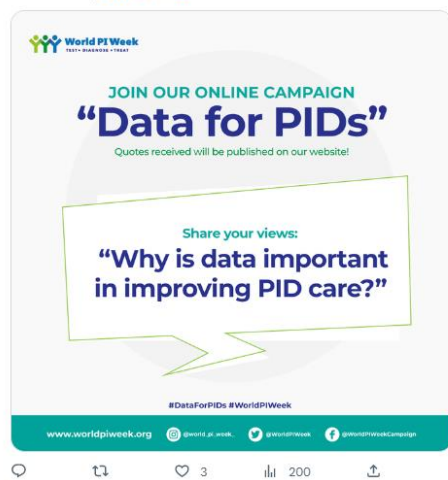
This year, we invited the community to share their thoughts on why they think data is essential in improving care for Primary Immunodeficiencies

- **+50** social media posts shared using #DataforPIDs - including patient representatives, carers, experts, industry partners



[Click here to participate in #DataforPIDs campaign](#)

World Primary Immunodeficiency Week @WorldPIWeek · Mar 22
Today at 15h00 CET, our online campaign #DataforPIDs goes live to ask:
"Why is data important in improving PID care?"
1. Submit your quote
2. Receive the email update that it's published
3. Download the template to enter your quote
4. Share & Tag @WorldPIWeek!



World Primary Immunodeficiency Week @WorldPIWeek · 41m
International collaboration in health data sharing helps close regional disparities; improve diagnosis, treatment & care for #PID patients worldwide!

For Rashann also, health data means improved diagnosis for #primaryimmunodeficiency. #DataforPIDs

bit.ly/3yVw3Z1



May 3, 2023

Rashann Fontenot

Data can help the quality of life for PID patients because; currently the average time to be appropriately diagnosed takes too long. By the time most PID patients are diagnosed, they can already experience irreversible damage.



April 25, 2023

Tonya Henry

Data is important because as data increases, so does the accuracy of treatment. Many PID patients take years to get diagnosed because there is a lack of data on early testing and information for the pediatrician.



April 14, 2023

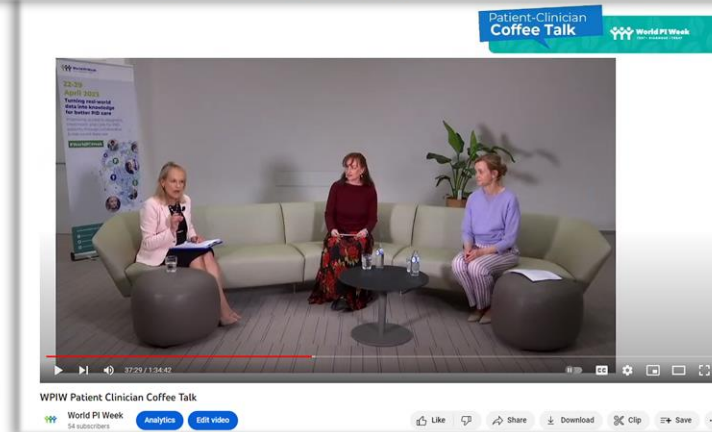
Wolfhard Erdlenbruch

Data is a critical tool to improve the lives of patients in myriad ways. Our efforts to support patients with PID do not stop with the development of transformative plasma-derived therapies that many PID patients rely on. At Takeda, we are also working on projects to develop diagnostic algorithms for early identification of PID, simplify monitoring IG levels in PID patients, and characterize PID patients for optimal and individualized treatment and care, among others. Thereby, we hope to use data to help identify and address unmet needs and improve the lives of patients in a holistic way.

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:

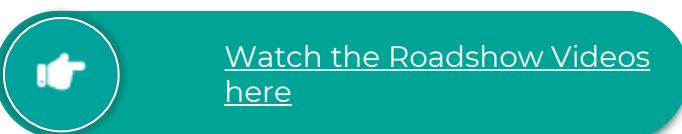
- Value of patient registries to advance knowledge & research
- Establishing and maintaining national PID registries
- Collection of health data on a day-to-day basis
- Kicking-off WPIW 2023



[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



About World PI Week Roadshow Series

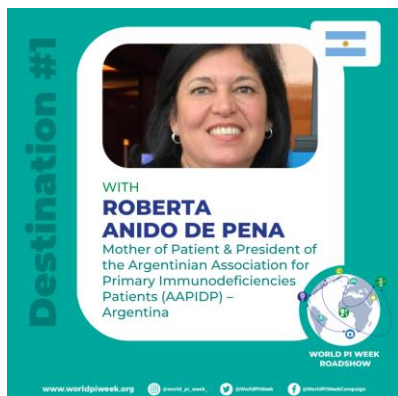
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- › Roberta talks about how robust patient registries help improve PID care and lives of patients, families and carers



- › 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

And the winner is from Mexico!



Congratulations to **MaricheLo Hernandez Ibarra** from **Mexico**!

Well done!

#PictureAwareness

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Social media milestones

Driving conversations and mobilising to raise awareness of PIDs

Analytics for 22-29 April



April

791 followers (+10%)
+42 posts shared
+90 stories shared
1.959 accounts reached
(+444%)



April

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



April

+48 followers
+40 posts shared
Most engagement from
United Kingdom



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



Overall impressions & engagement

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Tweet impressions
26.2K ↑331.6%

Profile visits
5,794 ↑54.3%

Top Tweet earned 2,250 impressions

SAVE THE DATE!

Friday, 21 April 2023, 15h30-16h30 CET,
#WorldPIWeek will host its 1st hybrid live
event "Patient-Clinician Coffee Talk" to kick-
off the campaign week! ☕
Link to the livestreaming & speaker info will
be shared soon! More info 📄 bit.ly/4046lg2
pic.twitter.com/y4V4eRAFWe



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

TWITTER: @WorldPIWeek



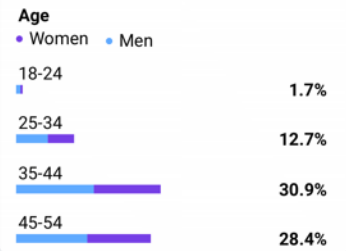
Performance ⓘ See all

Reach

3.6K +996%
from previous 2...

Engagement

837 +5480%
from previous 2...



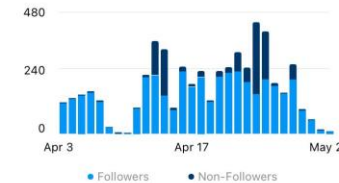
- ✓ Highest audience engagement around Roadshow Series
- ✓ More active patient community
- ✓ 'Peak' of engagement at start of WPIW and at +4 days

FACEBOOK: @WorldPIWeekcampaign



Account insights See all

1,242 accounts reached in the last 30 days
834 are non-followers

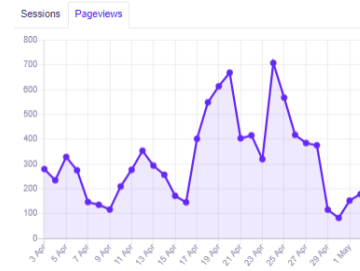


Reach



- ✓ High reach amongst non-followers (new audience)
- ✓ Highest engagement around coffee talk activity

INSTAGRAM: @world_pi_week_



- ✓ 'Peak' right before and at start of WPIW
- ✓ Nearly 10,000 website views

WEBSITE: www.worldpiweek.org

Media coverage

De SPECIALIST®
De actualiteit voor de arts-specialist

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Home » News » Health » Data for better care for primary immune deficiencies (PID)

Data for better care in primary immune deficiencies (PID)

© April 26, 2023 by GO

The 'World PI Week' started on Saturday, a worldwide campaign to draw attention to PID. This year, the emphasis is on the importance of working with real-world data.

That data can be converted into knowledge for better PID care, or so it sounds. It's about improving access to diagnosis, but also improving treatment and care for PID patients through [collaborative and real-world data use](#)

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

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

In the United States, one in 1,200 live births is estimated to have primary immunodeficiency. On the basis of this, experts estimate that more than one million Indians are likely to have the diseases.

By: Radfan Kabir | Updated at : 30 Apr 2023 10:10 AM (IST)



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

Alina Neagu • HotNews.ro

More than 600 Romanians are today diagnosed with one of the more than 480 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.



L'EST Actualité Régions Faits-divers Sport Culture - Loisirs Magazine Services

Santé

Iris, la voix des patients atteints de déficits immunitaires primitifs

C'est le moment ou jamais de parfaire votre culture et tenter de comprendre ce que sont les DIP. Représentant les patients atteints de ces maladies génétiques rares, affectant le système immunitaire, l'association Iris organise, le 18 avril au Citéa, une soirée-débat autour d'un documentaire évoquant le quotidien de malades.

Didier HUMBERT - 28 mars 2023 à 05:00 - Temps de lecture : 3 min

Vu 341 fois

The Sydney Morning Herald

National NSW Health

Archie waited 32 years for a diagnosis. His nephew waited two months

Angus Thomson
April 23, 2023 - 5:00am

Save Share

Australia is no closer to having a national genomic testing program for people with undiagnosed rare genetic conditions 18 months after a federal parliamentary committee warned failing to establish such a program would leave patients missing out on life-saving treatment.

People with primary immunodeficiencies are spending years searching for diagnoses that would lead them to effective treatments due to Australia's patchy and disconnected access to genetic testing, Melanie Wong, a paediatric immunologist at Westmead Children's Hospital, said.

Country involvement



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



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SNAPSHOTS OF NATIONAL EVENTS



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Argentina



AAPIDP (Asociación de Ayuda al Paciente con Inmunodeficiencia 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



Click to see more



6
MILLONES

de personas en todo el mundo viven con inmunodeficiencia primaria.

¡Eso es más que la población total de Dinamarca o Nueva Zelanda o la población combinada de Gambia y Namibia!



3º Congreso Virtual para Pacientes con Inmunodeficiencias Primarias

Jueves 27 de abril

18:00 - 18:05	Palabras de bienvenida Disertante: Roberta Anido de Pena - Presidente
18:05 - 18:40	Actualización y recomendaciones en vacunas en IDP Disertante: Dra. María Andrea Uboldi Coordinación: Dr. Miguel Galicchio
Espacio de preguntas y respuestas	
18:40 a 19:15	Actualización y recomendaciones en gammaglobulina endovenosa y subcutánea Disertante: Dra. Agustina Llares Disertante: Dr. Miguel Galicchio

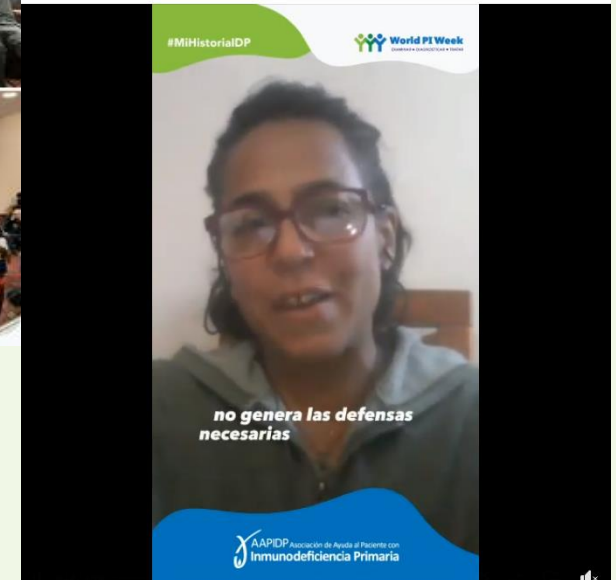


Conocé la historia de Romina

#MyPIStory
World PI Week IPOPI

#InmunodeficienciasPrimarias #SemanaMundialIDP #WorldPIWeek
#primaryimmunodeficiencyawareness #PrimaryImmunodeficiency #PrimaryImmunodeficiencies
#Immunodeficiency
#Immunoglobulins #PIDcare #PID

Voir la traduction



Australia



IDFA – Immune Deficiencies Federation Australia



- 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
- #YWhereYouAre 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 connect with community members suffering or caring with someone with a PID around the country through support groups.

[Donate Now](#)



Share Your Story - for a chance to win 1 of 3 \$100 gift cards.

On average, our members experience 9 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.

[Share Your Story](#)

Thank you to all of the wonderful entrants in our World PI Week #YWhereYouAre Social Media Competition.

We loved seeing your creative view of the letter 'Y'. So why the “y” shape? Because the Y shape refers to the shape of an antibody within the immune system. People living with PI are missing the antibodies that help protect it from many different types of infection.

This entry highlights the sad truth that the majority of our members often receive a late diagnosis for t... [See more](#)



Winner!



IDFA @IDFAustralia · Apr 21

It's here! World PI Week 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](#) [#Piawareness](#) [#RareDisease](#) [#ChronicIllness](#) [#Immunodeficiency](#) @WorldPIWeek



22-29 April 2023

Turning real-world data into knowledge for better Primary Immunodeficiency



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 Dews IDFA CEO we're in attendance to the event.

[#worldpiweek](#) World PI Week AusPIPS Inc. Australasian Society of Clinical Immunology and Allergy IDFNZ Kids Foundation



[Click to see more](#)

Australia



Australian Society of Clinical Immunology & Allergy (ASCIA)



- ASCIA Immunodeficiency Strategy Meeting
- ASCIA TAPID (Transplantation and PID) Meeting
- ASCIA Advanced Training Immunodeficiency Meeting
- Social media engagement



Click to see more

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 - Manly Pacific Hotel
Friday 28 April 2023

ASCIA TAPID (Transplantation and PID) Meeting

Sydney, Australia - Manly Pacific Hotel
Saturday 29 April 2023

ASCIA Advanced Training Immunodeficiency Meeting

Sydney, Australia - Manly Pacific Hotel
Sunday 30 April - Tuesday 2 May 2023



Australasian Society of Clinical Immunology and Allergy

28 April at 23:00 · 🌐

"World Primary Immunodeficiency Week and International Day of Immunology provide an opportunity to raise awareness about PIDs and advocate for fair access to medical care for all Australians," believes Associate Professor Theresa Cole, ASCIA President and paediatric clinical immunology/allergy specialist.

www.nationalimmunodeficiencystrategy.org.au

#ASCIA #PID #immunodeficiency #genomictesting



Australasian Society of Clinical Immunology and Allergy

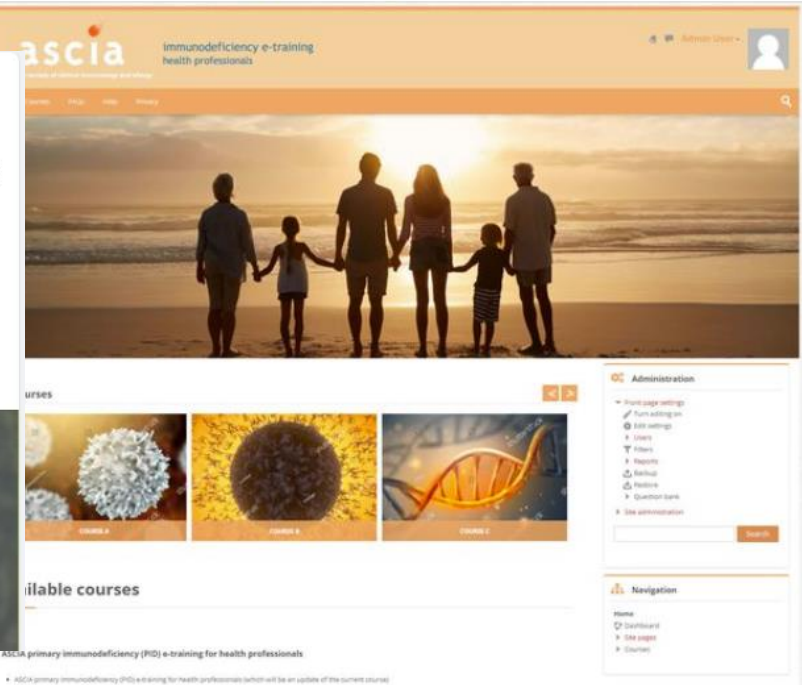
22 April at 06:18 · 🌐

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



Section 1

Section 2



Coming Soon!



Belarus



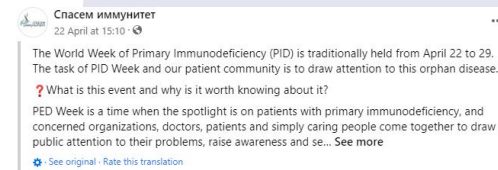
Спасем иммунитет – Save Immunity



- #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



School of patients in Vitebsk

In early April, "Save immunity" with the support of octapharma conducted a School of Patients with PID in the city. Vitebsk. The seminar was attended by patients from Vitebsk and Vitebsk region, as well as from Mogilev and Minsk. Natalya Ivanovna Yarosh, an immunologist doctor, told about how medical care is provided for patients with PID in the Vitebsk region, and Oksana Vladimirovna Ishchenko, a professor. m. n. Head of the Department of Aller... [See more](#)

[See original](#) · [Rate this translation](#)



20-21 апреля проходит школа-семинар на базе Центра детской, онкологии, гематологии и иммунологии

20-21
апреля
2023



Республиканская школа-семинар
Диагностика иммунопатологических состояний. Врожденные дефекты иммунной системы

Партнеры мероприятия:



Belgium



Bubble ID

- Bubble ID Family Day
- Donation campaigns



Belgium



Belgian Patient Organisation for Primary Immunodeficiencies (BePOPI)



- Participation in Bubble ID Family Day



Click to see more

**BePOPI - Belgian patient organisation for primary immunodeficiencies**
17 April at 22:35 · 🌐

Kom naar de patiëntendag van Bubble ID en beleef een dag vol plezier en informatie! Deze dag is speciaal bedoeld voor patiëntjes met een primaire immuundeficiëntie, maar ook hun broers, zussen, ouders, vrienden, familieleden en sympathisanten zijn van harte welkom. 🍀 Er is een leuk programma voorzien met activiteiten die speciaal zijn afgestemd op kinderen en tieners. In de voormiddag ontdek je zelf meer over PID via een wetenschapsmarkt en in de namiddag geniet je van een in... [See more](#)

[See translation](#)



**BUBBLEID.BE**
Familiedag BUBBLE ID op ZONDAG 23 APRIL
Bubble ID nodigt kinderen, jongeren en volwassenen met PID, hun (groot)ouders, familie en vr...

Bolivia



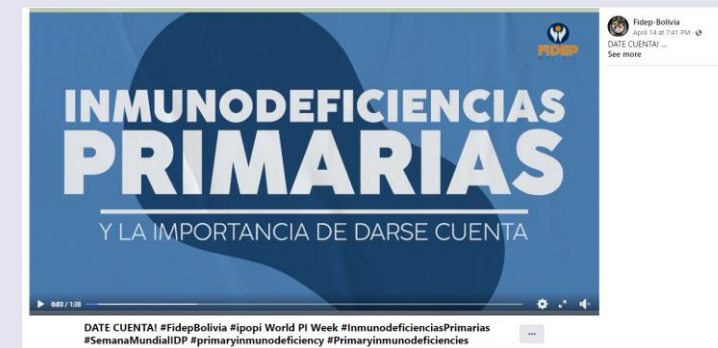
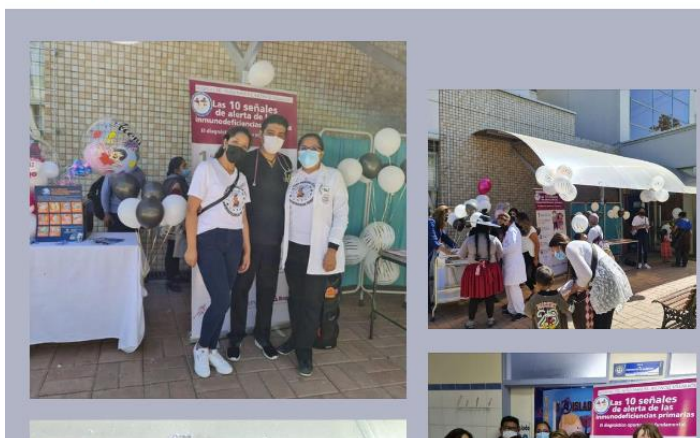
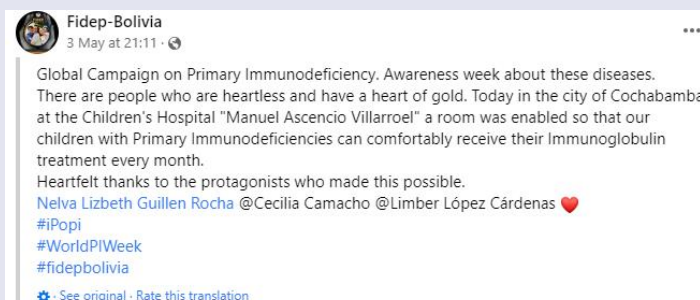
FIDEP – BOLIVIA (The Primary Immunodeficiencies Patient Organisation)



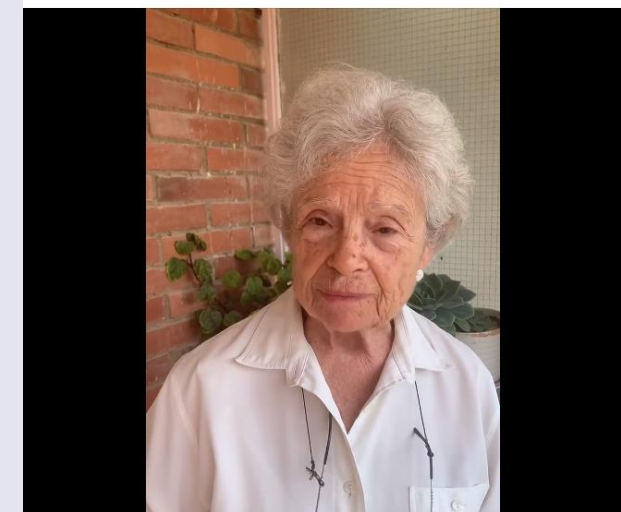
- Experts Insights on PIDs (4 informative videos)
- Awareness raising campaign at the "Manuel Ascencio Villarreal" Children's room at the City of Cochabamba at the Children's Hospital
- PID Factsheet Posters & Awareness Raising campaigns



Click to see more



Dr. Teresa Español, Immunologist-Pediatrician tells us about Primary Immunodeficiencies. REALIZE IT!!
World Primary Immunodeficiency Week.
#iPopi
#WorldPIWeek
#Primaryimmunodeficiency
#FidepBolivia
[See original · Rate this translation](#)



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



ASBAI @ASBAI_alergia · Apr 29

Você sabia que 70% dos novos casos de erros inatos da imunidade são diagnosticados em pessoas acima de 15 anos?

#imunodeficienciasprimarias #EII #imunidade #plasma #plasmajabrazil #alergia #imunologia #WorldPIWeek #ASBAI



ASBAI @ASBAI_alergia · Apr 27

Você sabe qual é a importância do plasma para os pacientes com erros inatos da imunidade?

Confira o episódio especial e não deixe de usar a #plasmajabrazil

bit.ly/podcast_plasma

#imunodeficienciasprimarias #EII #plasma #plasmajabrazil #imunologia #WorldPIWeek #ASBAI



ASBAI @ASBAI_alergia · Apr 29

Imunidade baixa ela existe mesmo?

#imunodeficienciasprimarias #EII #imunidade #plasma #plasmajabrazil #alergia #imunologia #WorldPIWeek #ASBAI



Canada



Immunodeficiency 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



Click to see more

April 22, 2023 - April 29, 2023

Get ready for the PI Awareness Week!

As part of our awareness-raising campaign called Invisible No More, we are requesting that members from across Canada help us...

[Go Back](#)

As part of our awareness-raising campaign called **Invisible No More**, we are requesting that members from across Canada help us to ensure that municipalities across the country proclaim **World Primary Immunodeficiency Awareness Week April 22nd - 29th 2023**. This will help let our supporters as well as the general public know more about the world of primary immunodeficiencies.

Please message the Programs Manager David Josey (david@immunitycanada.org) who will provide you with all the information you will need and support the application process if you are interested in participating. We are already working with mayors from St. Johns, Victoria and Vancouver.

During World Primary Immunodeficiency Week, we hope that many mayors will recognize the importance of being Invisible No More. We are also hoping for some local and national media coverage of our Walk for Immunodeficiency happening in Ottawa Saturday, April 15th, 2023.

We estimate that...
so if you can get...
this happen.

Date

April 22, 2023 - April 29, 2023

Time

All Day Event

A purple poster for the 2023 National Immune Deficiency Patient Conference. It features the text "2023 NATIONAL IMMUNE DEFICIENCY PATIENT CONFERENCE" in large white and orange letters. Below this, it says "NEW TOPICS | INTERNATIONAL SPEAKERS | THREE-DAY EVENT". The dates "APRIL 14-16" are listed, along with the location "OTTAWA DELTA CITY CENTRE". The registration fee is "\$50". A QR code is provided for registration, with the text "REGISTER HERE" above it. At the bottom, it mentions a "DELTA HOTEL SPECIAL RATE" and "BOOK BEFORE MARCH 16, 2023 UNDER 'CIPO' NAME". The Takeda logo is at the bottom left, and the website "www.immunitycanada.org" and email "info@immunitycanada.org" are at the bottom right.

immunity canada

2023 NATIONAL IMMUNE DEFICIENCY PATIENT CONFERENCE

NEW TOPICS | INTERNATIONAL SPEAKERS | THREE-DAY EVENT

APRIL 14-16

OTTAWA DELTA CITY CENTRE

REGISTRATION FEE \$50

DELTA HOTEL SPECIAL RATE
BOOK BEFORE MARCH 16, 2023
UNDER "CIPO" NAME

REGISTER HERE

This conference is sponsored by: www.immunitycanada.org info@immunitycanada.org

Being
#InvisibleNoMore
is important
to me because...



Chile



Fundacion IDP Chile



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



Click to see more

Fundación IDP Chile
30 April at 05:09 · 🌐

Proud to represent Chile ❤️❤️

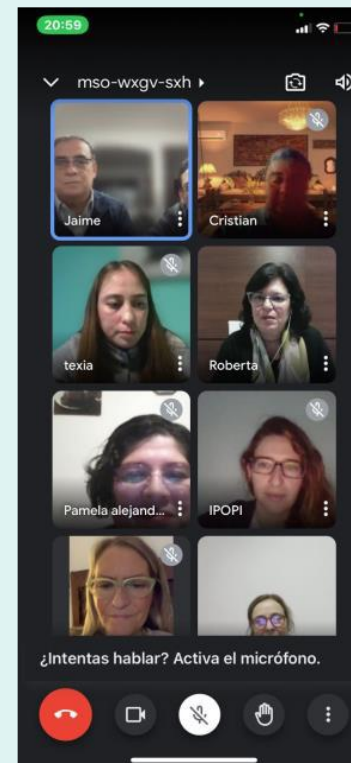
⚙️ · See original · Rate this translation



IPOPI

26 April at 12:00 · 🌐

We applaud [Fundación IDP Chile](#) for overcoming obstacles and embarking on collecting valuable data on primary immunodeficiency. 🙌 Jaime Brianson shares their experience... See more



Celebración semana de la IDP

Sábado 29
Abril

Parque
Intercomunal
de la reina

Desde las
12:00 hrs a
16:00 hrs.

Te invitamos a nuestro 2° evento
para celebrar la semana de las
inmunodeficiencias primarias

Para mayor Información visita nuestra web:
www.fundacionidpchile.cl



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



Click to see more



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.



You and IPOPI

↻ 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/3Nb0QZW

Columbia



Fundación FIP (Fundación Diana García de Olarte) – Collaboration with Iniciativa ALAS

- Podcast episode on PIDs
- Social Media Engagement



Click to see more



Fundación Fip

24 April at 16:56 · 🌐

Esta semana en todo el mundo estamos conmemorando la semana mundial de las Inmunodeficiencias Primarias, hacer conciencia de la importancia del diagnóstico temprano es primordial en nuestro país, pero aun mas importante es lograr el acceso a tratamiento para todos nuestros pacientes. Contamos contigo!

See translation



22-29 de abril de 2023

Convirtiendo los datos en conocimiento para mejorar la atención a las inmunodeficiencias primarias (IDP)

Mejorando el acceso al diagnóstico, el tratamiento y la atención de los pacientes



Cyprus



Ομάδα Ατόμων με Συγγενή Ανοσοανεπάρκεια και Φίλων

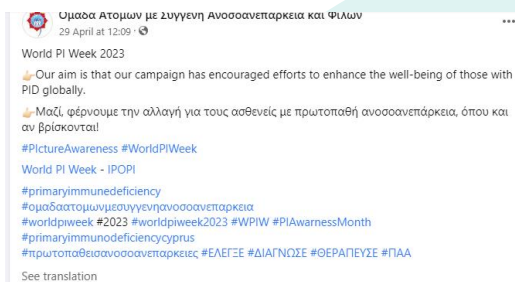


- Social media engagement
- Scientific Conference on PAAs in collaboration with Υπουργείο Υγείας Κυπριακή Δημοκρατία, Παιδιατρική Εταιρεία Κύπρου and under the auspices of Cyprus Alliance for Rare Disorders and Karaïskakio Foundation
- Presence in National TV Channel on PIDs
- Translation of IPOPI statement into Greek

- *"A PID causing a heavy burden of disease must always be recognised as a disability."*



Click to see more



Ecuador



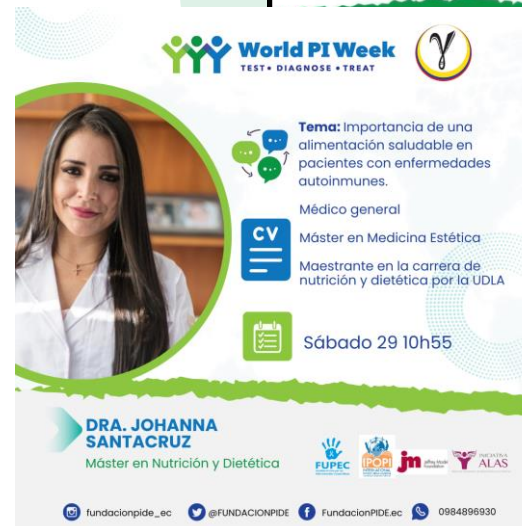
Foundation PIDE



- 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



Click to see more



Estonia



Eesti Primaarse Immuunpuudulikkusega Patsientide Ühing (PIDESTONIA)

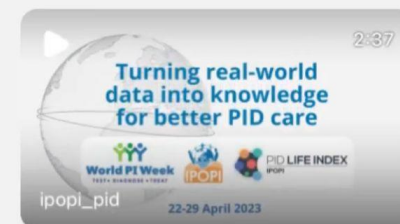
- Seminar-presentation at Tallinn University of Health and at Medicum
- [Discussion](#) round about “Primary Immunity” at Tartu University Clinic on 1st of June
- “A dream day” for a child with PID in cooperation with Minu Unistuste Minu Unistuste Päev.
- Social media campaign “Did you know?”
- Informative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



Click to see more



@world_pi_week kampaania teises videos kuuleme Hellen Ayagat, Keeniast pärit ema, kelle lapsel on esmane immuunpuudulikkus.



Hellen räägib andmete kasutamise tähtsusest muutuste toomiseks ja miks tema patsientide organisatsioon Primary Immunodeficiencies Association Kenya otsustas koguda andmeid IPOPI andmetööriista PID Life Index jaoks.



France



Association IRIS



- IRIS Connected Race #CourirPourIris
- Social Media Engagement



Click to see more



Course connectée 2023
DU 22 AU 29 AVRIL



Greece



For what you hold most dear.



IASO Children's Hospital -
Paediatric Immunology
Department



- 11th Scientific Seminar (3rd Session focuses on Primary Immunodeficiencies – Immune-mediated diseases)



Click to see more

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



For what you hold most dear.

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

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

Chairs: Maria Kanariou, Stylianos Grafakos, Talia Tsivitanidou – Kakourou

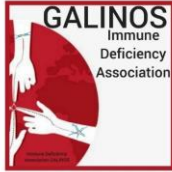
Paraskevi Maggina: Complex Manifestations of Inborn Errors of Immunity / Primary Immunodeficiencies

Ioanna Barbounaki: Diagnostic Approach of Prolonged Fever and Recurrent Fever Episodes

Lampros Fotis: Juvenile Dermatomyositis

Live streaming link: <https://avolution.nowlive.events/all/node/95>

Greece



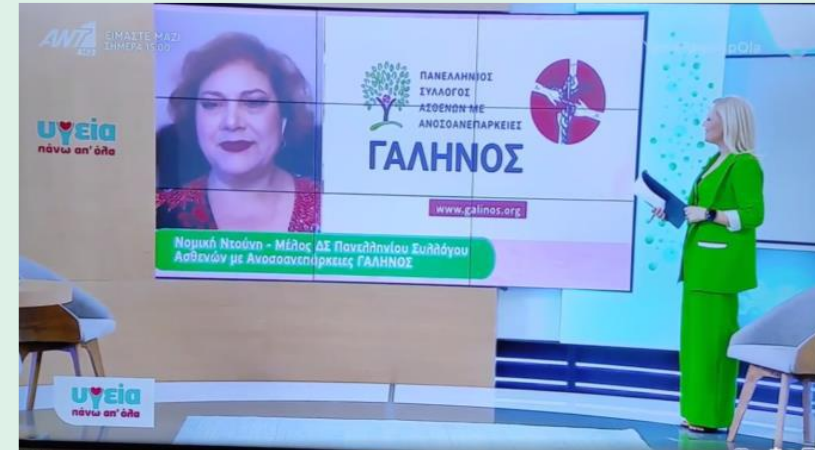
Immune Deficiency Association of Greece (Galinos)



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



Click to see more



Germany



Immundefekt



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

 Click to see more



Live-Event
26. April 2023 | ab 11 Uhr
> auf der Reichstagswiese in Berlin



! In order for affected people to live an almost normal life, they need medication made from blood plasma. Supply must be crisis-proof, supply shortages must not worsen. Politics is in demand here!

! On the occasion of World PI Week, the dsai was happy to support the action including a press conference and thanks all participants of the initiative: <https://boy-in-the-bubble.com/>

#dsai #immundefekt #plasmaspense #bitb #berlin #PIWeek #WorldPIWeek IPOPI



Iceland

HOME

PREVIOUS

NEXT

Section 1

Section 2



Lind Iceland



- 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



Click to see more



Sjúklingar / Aðstandendur

Fagfólk

Forsíða > Sjúklingar / Aðstandendur > Deildir og þjónusta >

Ónæmisfræðideild

Meginhlutverk deildarinnar er að vera leiðandi hvað varðar rannsóknir, greiningu, meðferð og eftirlit ónæmis- og ofnæmissjúkdóma á Íslandi. Auk þess veitir deildin alhliða þjónusturannsóknir á sviði gigtar-, bólgu- og sjálfsofnæmissjúkdóma

YFIRLÆKNIR

Sigurveig Þ. Sigurðardóttir
veiga@landspitali.is

India



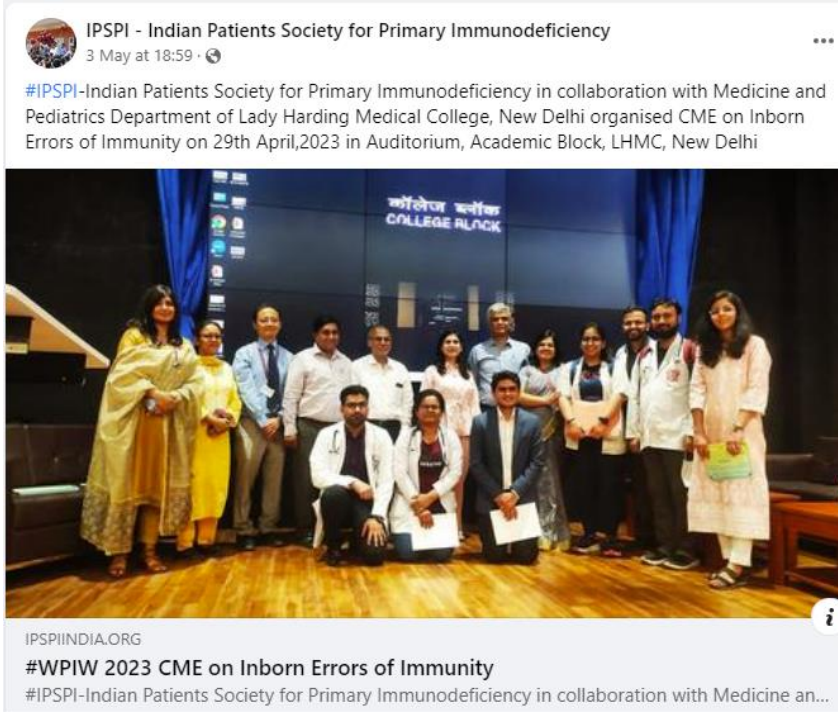
Indian Patients Society for Primary Immunodeficiency (IPSPI)



- #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



Indonesia



IDAI Indonesian Pediatric Society
Committed in Improving The Health of Indonesian Children



IDAI (Indonesian Pediatric Society)



- Social Media Engagement
- PID Facts visuals
- Online Symposium



Click to see more



IDAI @idai_tweets · Apr 24

Simak informasi lebih lengkap mengenai Primary Immunodeficiency dalam infografis berikut ini.

#IDAI

#IndonesianPediatricSociety

#worldprimaryimmunodeficiencyweek



IDAI @idai_tweets · Apr 23

Ikuti Online Symposium Ikatan Dokter Anak Indonesia dalam rangka World Primary Immunodeficiency Week "Recognizing Primary Immunodeficiency in Resource-limited Country" yang akan diselenggarakan pada:

Hari: Rabu, 26 April 2023
Pukul: 13.00-14.00 WIB.



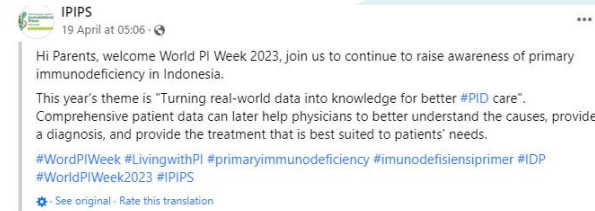
Indonesia



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

 Click to see more



**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



Sumber: Freepress

Kebutuhan tumbuh kembang anak dengan penyakit langka seperti imunodefisiensi primer (IDP) sebenarnya tidak jauh berbeda dengan anak pada umumnya. Bedanya, mungkin Anda—sebagai orang tua—dan anak Anda memiliki pengalaman dan beberapa kebutuhan yang jarang didapatkan oleh keluarga lain.

Anak dengan penyakit langka seperti IDP membutuhkan perawatan medis dan terapi khusus dan dalam waktu lama. Apalagi, tenaga dan lokasi medis untuk penyembuhannya masih tergolong langka ditemui. Biaya penanganan dan perawatannya pun jadi cukup besar.

6 Hal yang Dapat Dilakukan Orang Tua ketika Anak Memiliki Penyakit Langka IDP

Diagnosis IDP pada anak dapat memberikan pengalaman luar biasa untuk seluruh keluarga. Sebagai orang tua, mungkin awalnya sulit untuk mengetahui ke mana harus meminta bantuan penyembuhan dan dukungan.

Beberapa langkah berikut dapat menjadi pegangan untuk memastikan anak dengan penyakit langka menerima penanganan dan perawatan terbaik. Sehingga, Anda dan



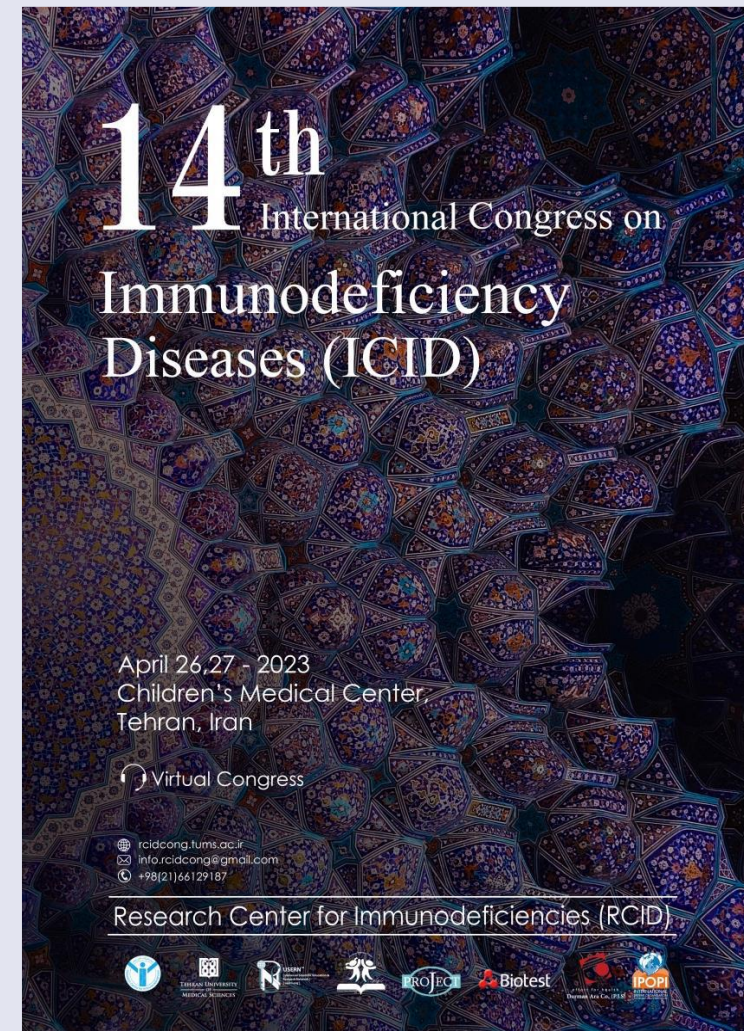
Iran



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



Click to see more

World PI Week 2023 Celebration

April 12, 2023 By Rosa Maria Catraio — Leave a Comment



Facebook



Twitter



Google+



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



ipiainfo



Israel



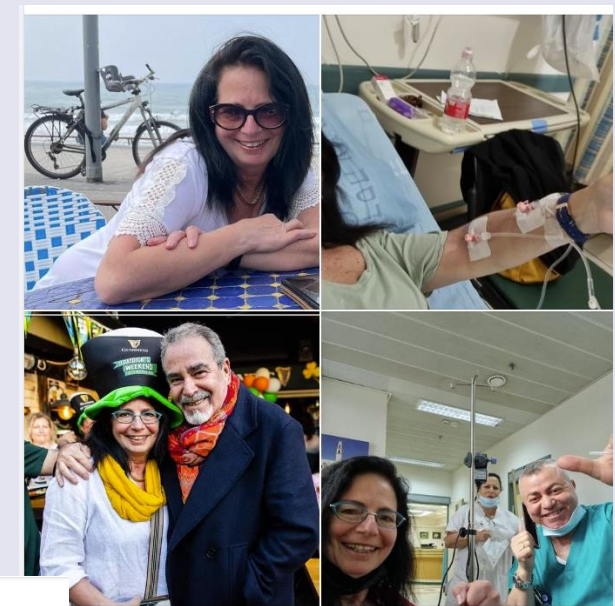
Bubble Care



- 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



Click to see more





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



Click to see more

Assemblea AIP 2023 e incontro medici pazienti

Sabato 22 Aprile 2023
Aula Magna "Viola", Padiglione 11, IRCCS Azienda Universitaria-Ospedaliera di Bologna

9.00 Assemblea Soci AIP O.d.V. - Riservata ai soci
Incontro medici pazienti*
Moderatore: Prof. Andrea Pession

10.00 Disordini congeniti dell'immunità: ieri e oggi, generazioni a confronto
10.20 Vaccini: aggiornamento sulle indicazioni nell'era post-COVID19 (Dott.ssa...)
10.40 Screening neonatale: la realtà della Regione Emilia-Romagna (Dott.ssa...)
11.00 Coffee break
11.20 Multidisciplinarietà nelle IDP: creazione di Percorsi Assistenziali dedicati (Dott.ssa...)
11.40 Dalle immunoglobuline alla terapia mirata (Dott.ssa Conti, Dott. Grasso)
12.15 Storie bolognesi: i pazienti si raccontano
12.45 Discussione e chiusura dei lavori

*Evento formativo per medici in formazione specialistica
Seguirà un pranzo e momento conviviale!
Sei socio? Il pranzo lo offriamo noi.
Contributo per accompagnatori non soci € 20,00 (puoi associarti sul posto)

Per info e info@aip-it.org

LE AVVENTURE DI
GLOBULINO

Lino Globulino e i suoi alleati aiutano i bambini a riconoscere i 10 campanelli d'allarme delle Immunodeficienze Primitive

Le Immunodeficienze Primitive sono malattie congenite rare che colpiscono circa 1 persona ogni 500. Grazie a una diagnosi precoce e all'attivazione tempestiva di un percorso di terapia, i pazienti con IDP hanno una qualità di vita al pari delle persone immunocompetenti. Tuttavia, si stima che solo il 30% di bambini e adulti affetti da immunocompromi... See more



COMUNICAZIONE STAMPA

AIP O.d.V. - Associazione Immunodeficienze Primitive
I CAMPANELLI D'ALLARME E IL RUOLO DELLA RICERCA NELLA CURA DELLE IDP

Il supereroe dei bimbi Lino Globulino allo scoperto delle terapie per combattere le IDP nella sua nuova avventura "La gita nel futuro", patrocinata da Telethon

Le Immunodeficienze Primitive sono malattie congenite rare che colpiscono circa 1 persona ogni 500. Si sa che una diagnosi precoce e all'attivazione tempestiva di un percorso di terapia, i pazienti con IDP hanno una qualità di vita al pari delle persone immunocompetenti. Tuttavia, si stima che solo il 30% di bambini e adulti affetti da immunocompromi... See more

L'associazione Immunodeficienze Primitive sostiene e promuove la ricerca scientifica per un riconoscimento più rapido e preciso di tutte le varianti di IDP. Oggi grazie alle screening neonatali è possibile individuare, oltre ad altre patologie, anche le immunodeficienze combinate e severe (ICDS).

Con l'obiettivo di migliorare la tempestività della diagnosi, che finisce con l'aspettativa di vita, AIP O.d.V. è attiva nella diffusione, attraverso i suoi canali internazionali, anche online, dei "Dieci campanelli d'allarme", un videomateriale che racchiude i sintomi più comuni per una più facile individuazione di una Immunodeficienza Primaria.

IL PROGETTO LINO GLOBULINO
AIP O.d.V., con il contributo non condizionato di Telethon e in collaborazione con i partner TV per la realizzazione creativa e grafica, ha ideato il personaggio di "Lino Globulino", un supereroe che insieme ai compagni globulini lotta per sconfiggere le IDP e insegnare ai bambini affetti da Immunodeficienza come poter vivere felici e circondati da amici.

LA NUOVA AVVENTURA "LA GITA NEL FUTURO" E I DIECI CAMPANELLI D'ALLARME DI LINO GLOBULINO
Lino Globulino e i suoi alleati hanno già affrontato molte importanti missioni e raccontato di diversi temi centrali, come la vaccinazione e la donazione di sangue. Con la nuova avventura "La gita nel futuro", Globulino parlerà ai bambini della ricerca, delle sfide e delle conquiste in prima linea nella lotta alle IDP.

Il nuovo fumetto "Lino Globulino e la gita nel futuro" è patrocinato da Telethon. Lino Globulino scenderà in campo anche per la diffusione dei "Dieci campanelli d'allarme nel bambino", grazie a un nuovo e rinnovato poster. Ognuno dei sintomi di riconoscimento delle Immunodeficienze Primitive richiama alle diverse avventure raccontate da Globulino presenti sul suo sito a lui dedicato www.linoglobulino.it/.

Settimanale Affari - Relazioni e Istruzioni AIP O.d.V.
Dott. Filippo Cristofari - info@aip-it.org - Tel 047 986 3838

Ufficio Comunicazione AIP O.d.V.
Dott.ssa Silvia Cesari - comunicazione@aip.it
Dott.ssa Chiara Pagnoni - comunicazione@aip.it

AIP O.d.V. - Associazione Immunodeficienze Primitive - Organizzazione di volontariato
Ente del Registro Regionale del volontariato (Reg. Tribunale di Bologna del 19/01/2010) - 011 - Immatricolata - n. 015400010
Sede operativa: Via degli Indipendenti, 36 - 40138 Bologna
Tel. 051 485 1010 - www.aip.it e info@aip.it e www.aip.it

Japan



PID Tsubasa no Kai



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



Click to see more



NPO法人PIDつばさの会 PIDTsubasa-no-Kai @PID_Tsubasa · 4月28日 ...

PID (#原発性免疫不全症候群) の特徴は「繰り返す感染症」です。

どのような時に #PID を疑うか、チェックシートである「10の徴候」が参考になります。

小児用⇒takeda.co.jp/patients/pidna...

成人用⇒takeda.co.jp/patients/pidna...

#WorldPIWeek #10WarningSigns



takeda.co.jp

乳幼児～15歳未満のお子さんのご家族の方はこち...
乳幼児～15歳未満のお子さんのご家族の方専用の、PIDの可能性があるかどうかを簡単に確認できる...



TOP 新着記事 病気 症状 治療 予防 病院 医病記 コラム 著者

日刊ゲンダイヘルスケア+ > 新着記事 > 記事

繰り返す気管支炎、肺炎、中耳炎…「原発性免疫不全症」かもしれない

公開日:2023年04月19日 更新日:2023年04月19日



東京都では4月1日から「拡大新生児スクリーニング検査」が開始された。日本では公費で20の病気に対して「新生児スクリーニング検査」が行われているが、対象外の7つの病気に対して、有料でスクリーニング検査が行われ...



Kenya



PIDS Kenya



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



[Click to 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



Click to see more

Ending our World PI Week 2023 with a picture collage of supports from Malaysia 🇲🇾

#PictureAwareness
#wpiw2023
#WPIW
#... See more



Mexico



Fundación Mexicana para Niñas y Niños con Inmunodeficiencias



- 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



Click to see more

Fundación Mexicana para Niños y Niños con Inmunodeficiencias
April 24 at 7:58 PM · 🌐

Radio ALAS, el 1er Podcast en América Latina donde ponemos las #InmunodeficienciasPrimarias al Aire !!
Escúchalo y síguenos en Spotify 🎧
<https://spoti.fi/3V0fk0z>



OPEN.SPOTIFY.COM
Radio Alas
Listen to Radio Alas on Spotify. Primer podcast en América Latina q...



Fundación Mexicana para Niños y Niños con Inmunodeficiencias
April 26 at 9:51 PM · 🌐

Semana mundial de las #InmunodeficienciasPrimarias
Existen más de 400 tipos de inmunodeficiencias primarias, he aquí 10 de las más frecuentes
<https://fumeni.org.mx/tipos-de-inmunodeficiencias/>

INMUNODEFICIENCIA COMÚN VARIABLE

La inmunodeficiencia común variable (CVID) implica disfunción de las células B y niveles bajos de inmunoglobulina, lo que lleva a infecciones frecuentes.

Si bien se han identificado varias mutaciones genéticas relacionadas, en la mayoría de los casos se desconoce la causa específica de CVID.

CIENCIA SELECTIVA DE TgA	DEGICIT DE SUBCLASES DE	IMPACTO EN LA SELECCIÓN DE
encia selectiva de TgA implica la presencia aislada de subclases de inmunoglobulina A (IgA) que son niveles bajos de uno o más de IgG.	encia aislada de subclases de inmunoglobulina A (IgA) que son niveles bajos de uno o más de IgG.	encia aislada de subclases de inmunoglobulina A (IgA) que son niveles bajos de uno o más de IgG.

www.fotolife.mx



Morocco

Hajar

- 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



Netherlands



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

Stichting voor Afweerstoornissen
28 April at 08:29 · 🌐
www.pidevent.nl
"Working together for a better quality of life" For us the work doesn't stop with World PI Week. We are determined to continue our commitment to better care.
This year, the Foundation for Disorders is organizing a national patient day for PID patients and their loved ones in cooperation with Takeda Nederland. Keep 23 September free and register via the link above.
#WorldPIWeek #wpiw #primaireimmunodeficientie #inbornerrorsofimmunity #samenwerking #event
🔗 See original · Rate this translation



Stichting voor Afweerstoornissen
27 April at 08:37 · 🌐
<https://stichtingvoorafweerstoornissen.nl/.../hoe-land.../>
The Foundation for Resistance Disorders has developed four informative videos together with [CSL Plasma Behring](#) for the World PI Week about the production of plasma drugs. In the coming days new videos will appear on the website of the Foundation for resistance disorders. Watch video 4 now and follow us for the next videos in the process of "Donor to Plasma Medicine"
#WPIW #CSLBehring #primaireimmunodeficientie #immunoglobulinen #plasmaasvieslives #plasmahero
🔗 See original · Rate this translation



Click to see more

Stichting voor Afweerstoornissen
27 April at 17:53 · 🌐

IPOPI
27 April at 17:00 · 🌐
Hear Jose Verstegen from Stichting voor Afweerstoornissen about the data collection activity they are launching during
👏 As part of our World PI Week campaign series, we're data collection for rare diseases. We're thrilled to see patient lead in this crucial area.
<https://pidlifeindex.ipopi.org>
#WorldPIWeek #PIDLifeIndex

PID EVENT

Een initiatief van
Stichting voor Afweerstoornissen

ZATERDAG 23 SEPTEMBER 2023 JAARBEURS - UTRECHT

Op zaterdag 23 september organiseert de Stichting voor Afweerstoornissen het PID-event. Een event dat je niet wilt missen!

Speciaal voor PID patiënten van 12 jaar en ouder en hun naasten is er in samenwerking met artsen en verpleegkundigen een interessant programma samengesteld. Je kunt je inschrijven voor interactieve break-out sessies en je laten inspireren tijdens een sessie over de grensverleggende trends, technologieën en innovaties in de zorg.

Als klap op de vuurpijl is er de PID-show over alles met het leven met PID onder begeleiding van een bekende Nederlander. Benieuwd wie dat is? Hou onze socials de komende tijd dan goed in de gaten.

Garandeer jezelf van een plekje en schrijf je vandaag nog in!

PID EXPERTISENETWERK



New Zealand



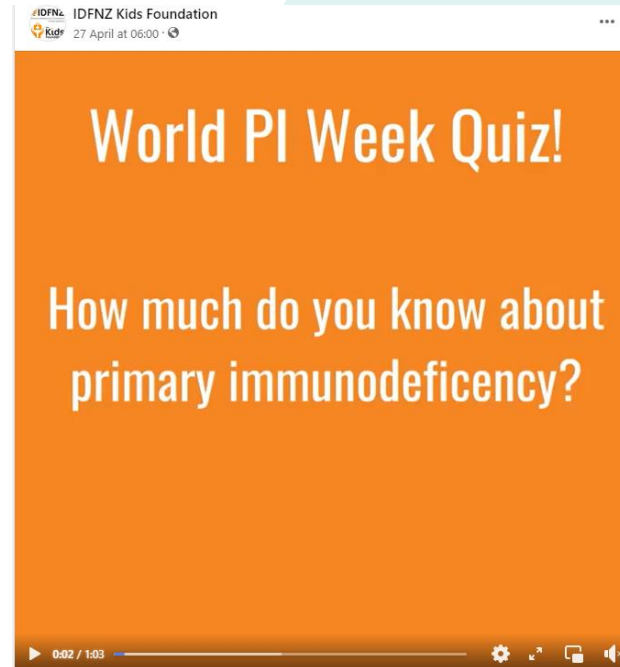
IDFNZ Kids Foundation



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



Click to see more



Looking for a FUN way to support IDFNZ?

Enter our **'Pie for PI'** competition



Take a **Pie in the face** for PI and support IDFNZ

Laura Hannah, PID member from Nelson, is issuing a challenge to all IDFNZ and KIDS Foundation members, clinical teams, and supporters, to film yourself taking a 'Pie for PI' on your mobile phone and posting this on our Facebook page. (We can help post this if you email your video clip to us or share from your own social media page). Laura has a target of raising \$2,000. We are giving away IDFNZ t-shirts as prizes for the clips with the most 'likes'.

Like the idea but don't feel up to this challenge?
You can still help by donating to the work of IDFNZ by visiting our givealittle page <https://givealittle.co.nz/cause/pie-for-pi-challenge> and issuing a friendly 'challenge' to friends and family to 'Take a Pie' or 'Make a donation' to the cause. Help Laura with this fun challenge to raise awareness and funds for IDFNZ.



PI Awareness Month

PI Week Challenge

A FUN way to support IDFNZ to raise funds and Awareness

Enter our 'Pie for PI' competition.

A great team building challenge for your workplace, school, or individual IDFNZ supporters.

Take a Pie in the face for PI and support IDFNZ.

Donate here:

PIE for PI Challenge

\$235.00
donated
\$2,000.00
goal



Know the 7 Warning signs of Primary Immune Deficiency (PID)



Visit idfnz.org.nz for more information.



Philippines



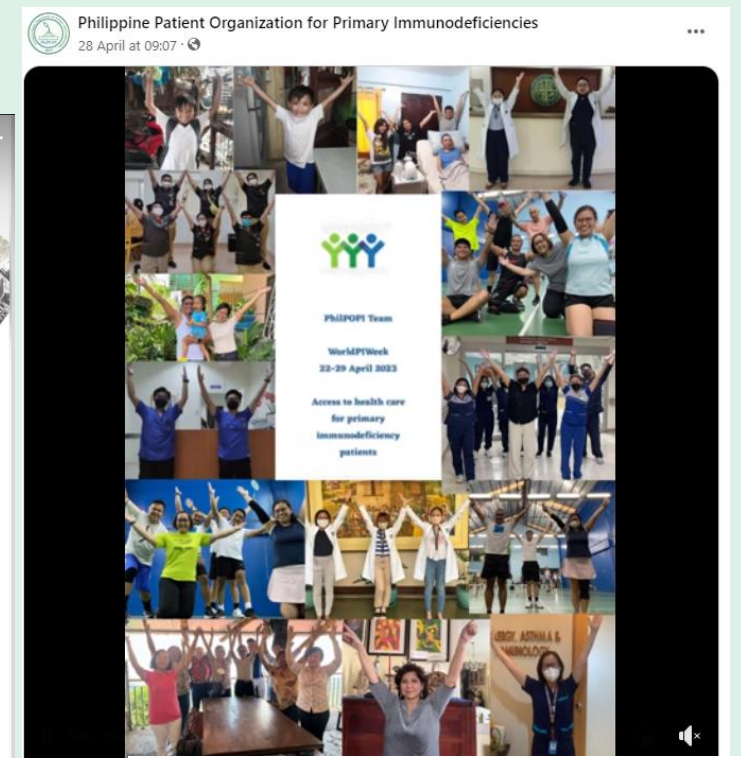
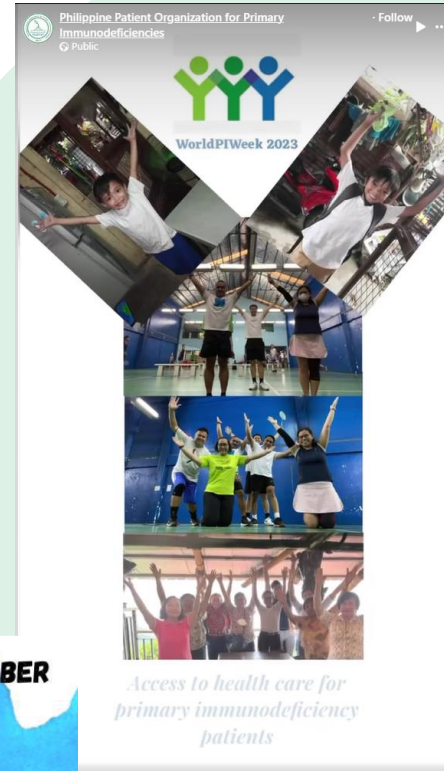
Philippines Patient Organization
for Primary Immunodeficiencies



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



Click to see more



Poland



Association for Patients with
Primary Immunodeficiencies
(IMMUNOPROTECT®)

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

 Click to see more



Portugal



APDIP - Associação Portuguesa de Doentes com Imunodeficiências Primárias

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



Click to see more

APDIP - Associação Portuguesa de Doentes com Imunodeficiências Primárias
24 April at 12:49 · 🌐

This week is dedicated to raising awareness in our society about Primary Immune Deficiencies (IDPs) to diagnose as early as possible and ensure optimal treatment. This year's theme relates to the importance of national rare disease data records. Having access to real-world data is key to improving primary immunodeficiency (IDP) care for several reasons, such as better understanding of the disease, personalized treatments, early diagnosis, development of new drugs, health poli... See more

⚙️ · See original · Rate this translation



22 a 29 de
Abril de 2023

Transformar dados actuais
em informacao para
melhores cuidados de
Imunodeficiencia Primaria.



29 de Abril

Vem caminhar 5 km



Puerto Rico



Puerto Rico Alliance of PID Patients (APIP)



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



Click to see more



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)



Click to see more



Russia



Section 1

Section 2



Click to see more

Coming Soon!



Slovakia



Združenie pacientov s primárnou imunodeficienciou, o.z.

- Awareness raising video



Click to see more

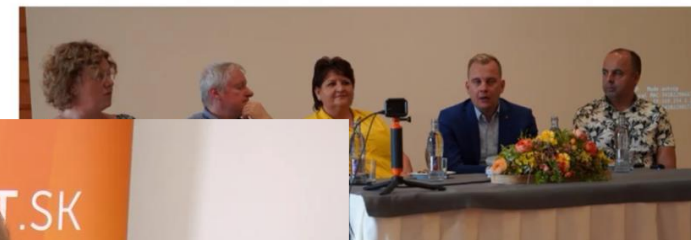


IMUNODEFICIT.SK

Združenie pacientov s primárnou imunodeficienciou

Tretie stretnutie pacientov s poruchami imunity

- ✓ Porozprávať sa medzi sebou
- ✓ Porozprávať sa s odborníkmi aj mimo ordinačných hodín



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 zvyšovaniu povedomia o ochorení a preto budeme radi ak naše video podporíte zdieľaním. My sme pripravili 10 minútovú prezentáciu, ktorú odovysielame v stredu o 18:00, a bude zároveň aj odprezentovaná na odbornom Sympóziu pre primárne imunodeficiencie, kt. zastrešuje doc. MUDr. Peter Čížňár.

See translation

South Korea

HOME

PREVIOUS

NEXT



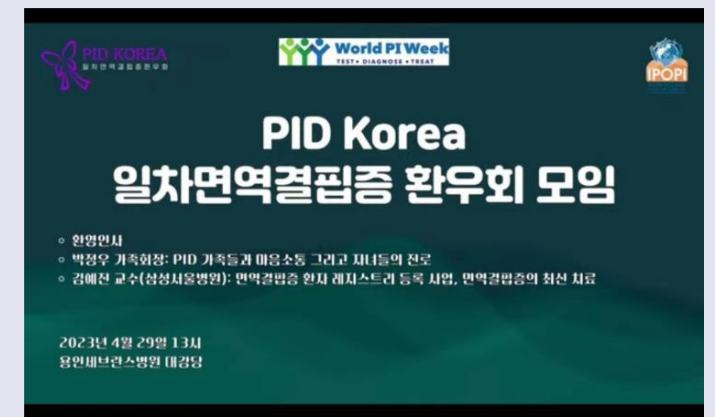
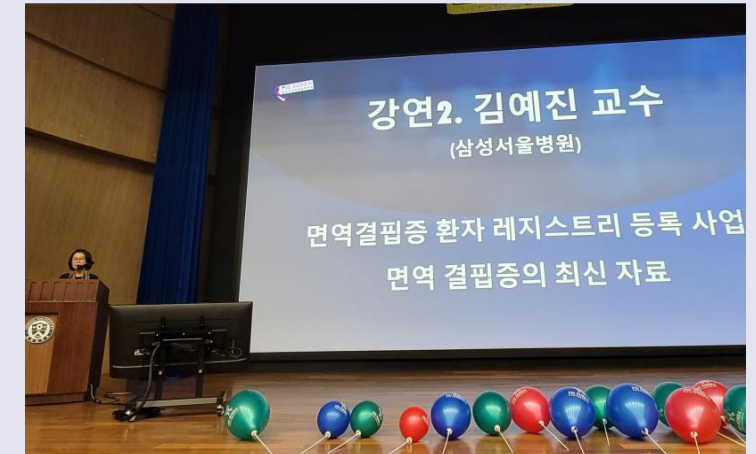
PID Korea



- PID Korea regular families meeting

Section 1

Section 2



Spain



Barcelona PID Foundation



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



Click to see more



BCN PID Foundation @bcnpidfound · Apr 25

Us presentem l'Andrea, membre del patronat de la @bcnpidfound, pediatra immunòloga de la UPIIP de @vallhebron. Gràcies pel seg que fas dels pacients pediàtrics amb #IDP i la implicació amb la Fundació! 🙌

#WPIW2023 #WorldPIWeek @WorldPIWeek



youtube.com

Membres de la BCN PID Foundation - Andre:
Us presentem a l'Andrea, membre del patror
la BCN PID Foundation i pediatra immunòlog



2



60



BCN PID Foundation Retweeted



Medhionine @medhionine · Apr 25

#WorldPrimaryImmunodeficiencyWeek from April 22-28 aims to raise awareness of the importance of early #PID diagnosis. In Medhionine, we want to encourage initiatives and organizations that improve access to PID treatment and early diagnosis. @bcnpidfound



1

Formació

- Curs SCP/SCI per a residents
- Curs IDP SCP/SCI per a infermeria

2

Difusió

- Publicació de 13 vídeos amb l'objectiu de conèixer els membres i professionals vinculats a la BCN PID Foundation

3

Activitats per a pacients i famílies

- Sortida educativa per a pacients i famílies al museu i planta Grifols
- Excursió matinal a la Mola+picnic



Anunciarem les dates de les activitats i horaris a les nostres XXSS

Activitats emmarcades
en la Setmana Mundial
de les IDP 2023



Spain



Asociación española de deficits
immunitarios primarios (AEDIP)

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



Click to see more



¿QUÉ SON LAS INMUNODEFICIENCIAS PRIMARIAS?

1 Son un grupo de enfermedades congénitas que se manifiestan cuando no trabaja adecuadamente alguno de los componentes del sistema inmunitario. Estas se suelen manifestar en la infancia.

2 Las IDPs no se detectan a simple vista, necesitan de un análisis minucioso de la sangre del paciente por parte de un especialista, el **inmunólogo**. Este será el encargado de llevar su historial clínico y de vigilar todas aquellas anomalías que encuentre, porque hasta un simple resfriado puede provocar dificultades.

3 Estas enfermedades no pueden ser curadas, lo único que se puede hacer es trasplante de médula, si fuera un caso grave, y ponerse un tratamiento de inmunoglobulinas cada x tiempo que suplan la carencia que tienen.

AEDIP

DONA PLASMA, DONA VIDA

Fuente: AEDIP. Consenso Español por la suficiencia de plasma y sus derivados. Sevilla 2022

1 Para miles de personas que padecen una IDP, los medicamentos hemoderivados son esenciales para mantener una vida normal. Estos tratamientos son especiales porque tienen un origen exclusivo biológico, no se puede fabricar el plasma sanguíneo humano.

2 En la actualidad existe un problema de dependencia y, en muchos casos, de limitación en la disponibilidad de los hemoderivados imprescindibles para miles de personas. El plasma obtenido a partir de las donaciones de sangre no es suficiente para abastecer las necesidades, y lo que debe sumarse que la donación directa de plasma, denominada plasmáferesis, es muy escasa.

3 Por ello queremos informaros desde AEDIP, que podéis donar plasma directamente, que en la gran mayoría de **Centros de transfusiones hay máquinas especializadas (plasmáferesis)** para este tipo de donación, la cual es totalmente segura, permite repetirla cada 15 días y tiene menos efectos adversos que una donación de sangre.

AEDIP

AEDIP
Organiza:

1ª MARCHA SENDERISTA

En favor de las Inmunodeficiencias Primarias

PLAZA DEL COTANO, GAVILANES (ÁVILA)

29 ABRIL 2023

Hora de encuentro: 10:00 A.M.

PUERTO DE LA CRUZ CAMINO DEL CHORRO

33 Inscripción

Inscripciones online e información

Presencial en Supermercados UDACO (Gavilanes, Mijares y Casavieja)

Si no puedes asistir, participa con nuestro Dorsal 0:

ESTO 3081 0407 0926 9584 4120

Sweden

22
April

World Immunodeficiency Week and the #GoZebra campaign. News!
#ZebraRun

🕒 April 22 - April 29



Primär immunbristorganisationen



- #GoZebra walk campaign
- Social media engagement



Click to see more



Thailand



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



Click to see more



Turkey



Ulusal Alerji ve Klinik
İmmünoloji Derneği (AİD)



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



Click to see more

22-29 Nisan Dünya İmmün Yetmezlikler Haftası kapsamında bu yıl da farkındalık kutlamasında renkli görüntülere eşlik ettik. İmmün yetmezliklere farkındalık ışığı tutmak amacıyla tüm hastalarımıza şifa dileklerini balonlar ile gökyüzüne uçurduk.
#ThinkZebra #WorldPIWeek #MUPAI #IMYED #İPOPI #JeffreyModelFundation
[See translation](#)



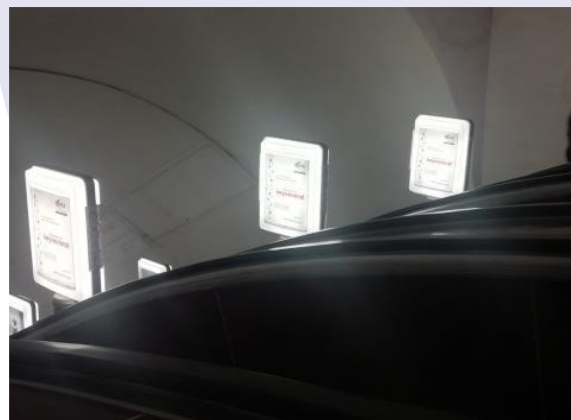
Ukraine



Rare Immune Diseases



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



United Kingdom



Supporting families affected by primary and secondary immunodeficiency



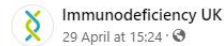
Immunodeficiency UK



- 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

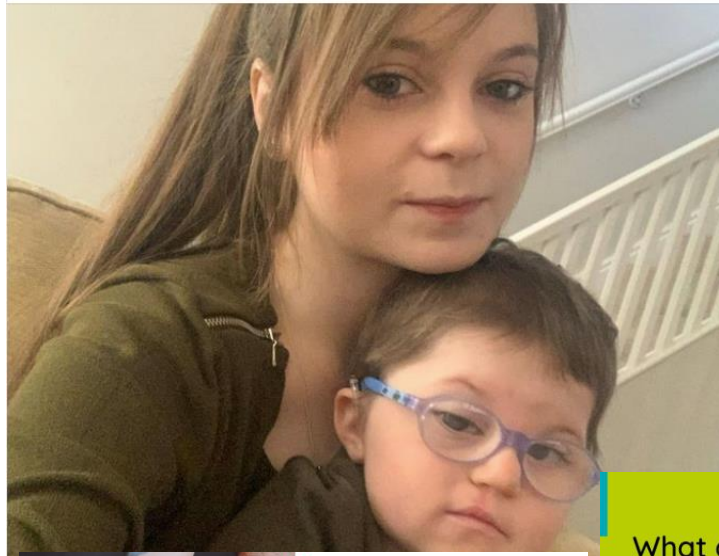


Click to see more



This #WorldPIWeek we'd like to highlight the story of Oscar and Bryony. Oscar was born with the primary immunodeficiency Complete Di George syndrome, genetically diagnosed as CHARGE syndrome.

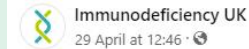
He received a ground-breaking thymus transplant at Great Ormond Street Hospital to treat his immunodeficiency when he was just a few months old. Here, his mother Bryony shares the story of Oscar's diagnosis and treatment and reveals how Oscar is doing now.
<http://www.immunodeficiencyuk.org>... See more



Immunodeficiency UK is here to lend a helping hand.

World PI Week.

Visit our website at www.immunodeficiencyuk.org



Someone with an immune disorder needs around 130 donations a year to help save their life. People with PID rely on the generosity and commitment of plasma and blood donors. Plasma donations are an essential gift to people in need of immunoglobulins and other plasma-derived medicinal products.

This Plasma Donation Week please share this post with your friends and family and ask them to head to <https://www.blood.co.uk/plasma/where-to-donate-plasma/> to sign up.



This Plasma Donation Week, be proud to be a plasma donor

Search 'donate plasma' to register now.



#PlasmaDonationWeek

What are primary immunodeficiencies (PID's)

PID's are a group of over 450 rare, chronic conditions that affect how the body's immune system works.

People affected have parts of their immune systems missing or not working.



#WorldPIWeek



United States



Immune Deficiency Foundation



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



Click to see more



How many people have primary immunodeficiency?

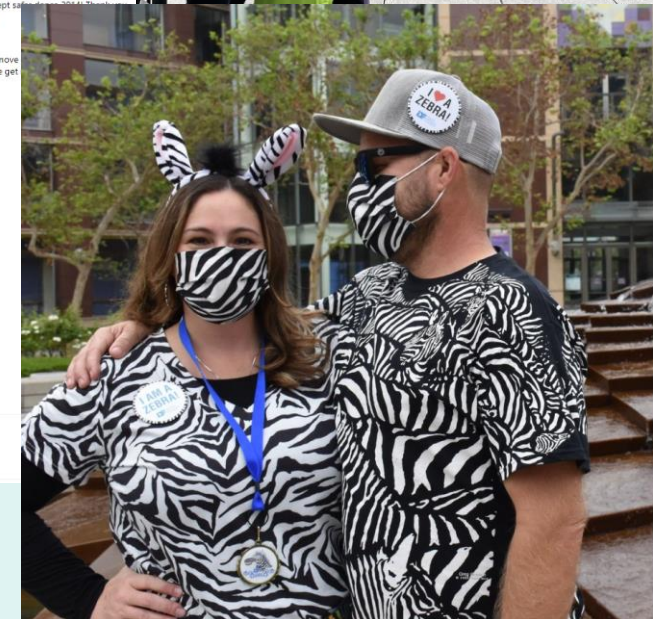
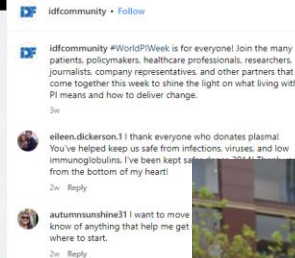


PATIENT SAFETY & PROTECTION

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



#WorldPIWeek worldpiweek.org



Vietnam



Vietnam PID Patient Support Group (Viet Pips)

- Social media engagement



Click to see more



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



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Latin America



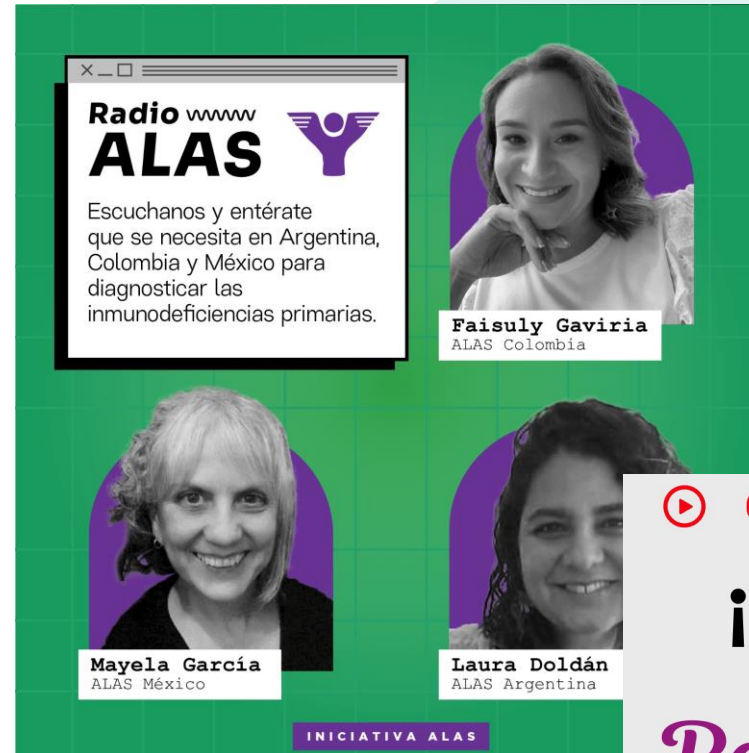
Iniciativa ALAS



• PID Radio



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International



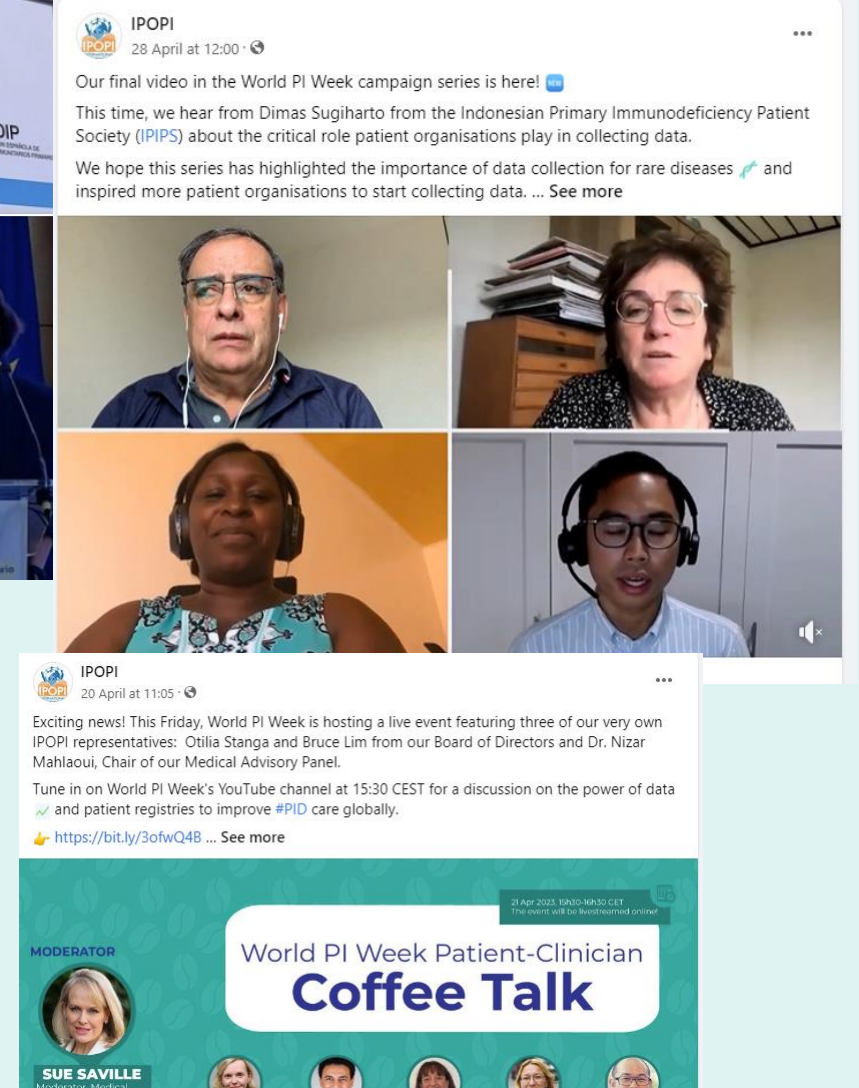
International Patient Organisation for Primary Immunodeficiencies (IPOPI)



- 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



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International



Jeffrey Modell Foundation



- Regional Toolkits
- Social Media Engagement
- Patient Stories

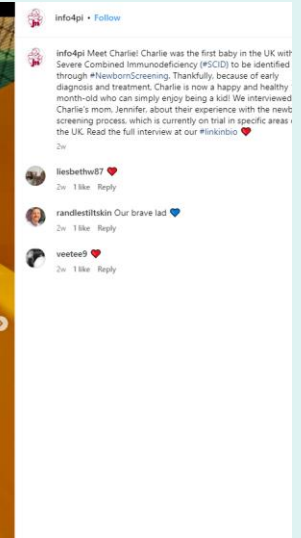


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Jeffrey Modell Foundation (JMF) @Info4PI · Apr 29

It's the last day of #WorldPIWeek & time for our final stop: Australia & New Zealand! 🌍🇦🇺 Our regional toolkits aim to ease the diagnostic odyssey for PI families worldwide by directing them resources in their regions. Find all of our toolkits at l8r.it/QWJW ❤️



Life Sciences Industry

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Today kicks off **#WorldPIWeek**, a time to show our support for all those living with **#PrimaryImmunodeficiency**. 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



Takeda
1,105,982 followers
2mo •

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World PI Week begins on April 22, and it is an important opportunity to help bring about change for Primary Immunodeficiency (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/3KX31yY>

"Data is a critical tool to improve the lives of patients in myriad ways. Our efforts to support patients with PID do not stop with the development of transformative plasma-derived therapies that many PID patients rely on.

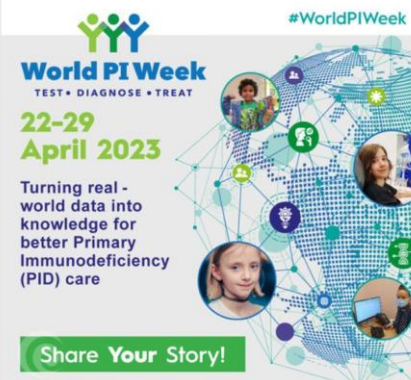
We are also working on projects to develop diagnostic algorithms for early identification of PID, simplify monitoring IG levels in PID patients, and characterize PID patients for optimal and individualized treatment and care, among others. Thereby, we hope to use data to help identify and address unmet needs and improve the lives of patients in a holistic way."

Wolfgang Erdlenbruch
Head PDT Global Medical Affairs



Today marks the start of World PI Week, an annual global campaign that aims to raise awareness and improve the diagnosis and treatment of primary immunodeficiencies (PID). We hope to contribute to the campaign's efforts and bring awareness to Primary Immunodeficiency by sharing patient stories, like yours!

To submit your story, send us a DM or visit bit.ly/korusinsider, enter your info and "Share your Freedom story!" to be featured on our page during World PI Week... See more



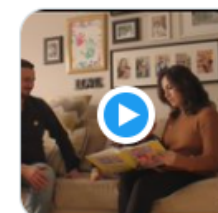
162



Chiesi Global Rare Diseases @ChiesiGRD · 23 apr.

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-cnw...

@FighterJakob #SCID #WorldPIWeek



youtube.com
Super Jakob: Bubble Boy, Little Fighter | Behind Every Superhero...



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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)*