



World Primary Immunodeficiency Week 2023

Turning real-world data into knowledge
for better PID care

CAMPAIGN REPORT

About World PI Week

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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



14 committed organisations driving the campaign



8 days to create momentum on PIDs



Over 80 countries across the globe



Thousands of people reached



Hundreds of events every year



13 years of campaigning



World PI Week in pictures



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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



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



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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:

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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

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The Essentials 2023

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

 [Click here to download materials](#)

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

A mix of advocacy, social media and other communication tools

The 2023 'essentials'

Communications package



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'immunodéficiences 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 [@WorldPIWeek](#) [@WorldPIWeek](#) [@WorldPIWeek](#)

This banner features a globe with a network of connections and circular icons representing various medical and scientific concepts like DNA, a lightbulb, and a person. It also includes small photos of children and healthcare professionals.

Μετατροπή των δεδομένων πραγματικού κόσμου σε γνώση για καλύτερη περίθαλψη της πρωτοπαθούς ανοσοανεπάρκειας (ΠΑΑ).

Επεξιδύση της πρόσβασης στη διάγνωση.



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

 [Click here to download materials](#)

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



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

This banner features a globe with a network of connections and circular icons representing various medical and scientific concepts like DNA, a lightbulb, and a person. It also includes small photos of children and healthcare professionals.

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

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The toolkit includes:

- Information Pack:** Turning real-world data into knowledge for better PID care. Improving access to diagnosis, treatment and care for PID patients through collaborative & real-world data use. 22-29 April 2023.
- World PI Week 2023 at a glance:** Tagline: "Turning real-world data into knowledge for better PID care". Themes: Improved access to diagnosis, treatment and care for PID patients through collaborative & real-world data use. Includes a video from Dr. Michael J. Kuehn.
- How to join World PI Week:** Step-by-step guide to spreading awareness, getting involved, and getting active. Includes a video from Dr. Michael J. Kuehn.



[Click here to download toolkit](#)



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



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

The screenshot shows a slide titled "World PI Week Refresher on Data". The slide is divided into several sections: "What is Health Data?", "What are patient registries (or databases)?", "How is it collected and used?", "What is the value of health data in primary immunodeficiency (PIs)?", and "What do we mean by "real-world" data (RWD)?". Each section contains descriptive text and small images related to healthcare and data analysis.

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 means information about that person's health and medical status.” 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 adequately monitor health trends and inform decision-making⁵.

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/treatment⁶. 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 care⁷. 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 time⁸.

How is it collected and used?
In general, information on a patient's health and identity can be “collected” by individuals or healthcare providers annually, 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 epidemiology purposes and to improve overall healthcare systems.

What is the value of health data in primary immunodeficiency (PIs)?
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 (PIs) 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 tests.
- Treatment & Care:** Data analysis through registries provide important information about patients, the impact, efficacy and durability of treatments to strengthen their care, as well as help decision-makers improve healthcare systems.
- Research & Innovation:** Turning data into evidence help advance understanding of PIs and is crucial to develop innovative therapies and new care pathways and make these accessible to all PIs 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 PIs.

What do we mean by "real-world" data (RWD)?
Although there is no consensus definition, real-world data is an umbrella term for different types of health care data related to the effect 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 media – such as clinical and economic outcomes, patient reported outcomes and health-related quality of life.

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



[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.

Treatment & Care
Data can be used to care for patients and deliver improved care more efficiently, leading to better patient health outcomes and enhanced quality of life.

Research & Innovation
Patient data informs and drives scientific and medical research & innovation. Improved & innovative treatments generate additional resources to support changes in care and practices for the benefit of PID patients.

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

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 learning lessons, monitoring public health, improving PID research, diagnosis and care.
- Ethical, responsible and transparent use of patients' health data – to ensure data obtained from patient vigilance is used to advance safety to improve understanding and care for PIDs.
- Collaboration and sharing of research data & results in the academic sector and beyond among different 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 base 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](#)



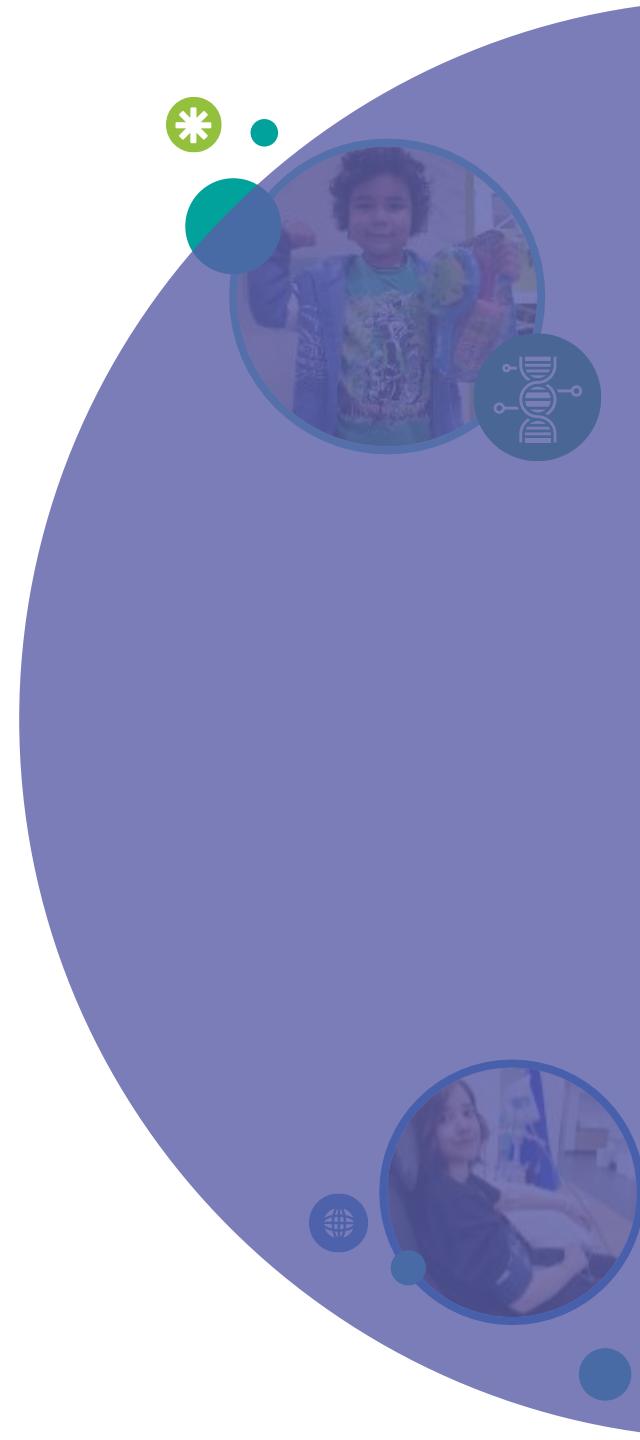
Campaign Teaser Video

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



[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



[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

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!

JOIN OUR ONLINE CAMPAIGN
"Data for PIDs"
Quotes received will be published on our website

Share your views:
"Why is data important in improving PID care?"

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/3yWc321

Rashann Fontenot
Data makes the difference between patients receiving timely, accurate diagnosis and care – or contending with the very serious consequences of undiagnosed, untreated PID. Doctors can't recognize, diagnose or treat what they don't know about.
– Denise Reich, CVID patient

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

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 Tekedia, 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. Ultimately, we hope to use data to help identify and address unmet needs and improve the lives of patients in a holistic way.



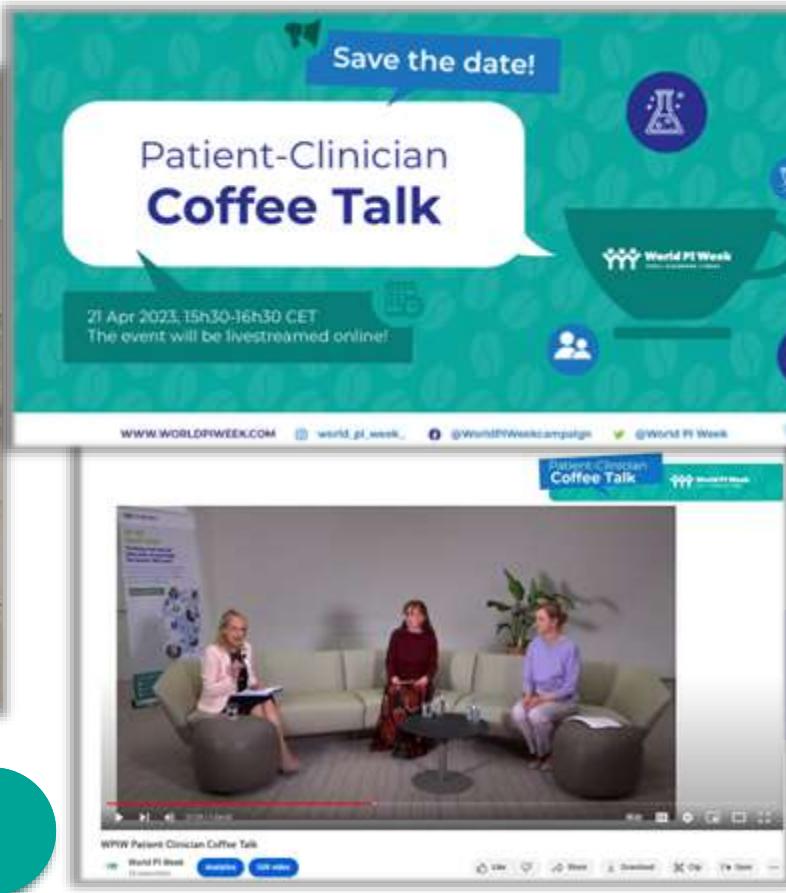
Click here to participate in
#DataforPIDs campaign



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



Save the date!

Patient-Clinician
Coffee Talk

21 Apr 2023, 15h30-16h30 CET
The event will be livestreamed online!

www.worldpiweek.com world_pi_week_ @WorldPiWeekCampaign @WorldPiWeek

Participants: [redacted]

WPIW Patient Clinician Coffee Talk



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!



[Watch the Roadshow Videos here](#)

Destination #1
Argentina



Destination #2
Australia



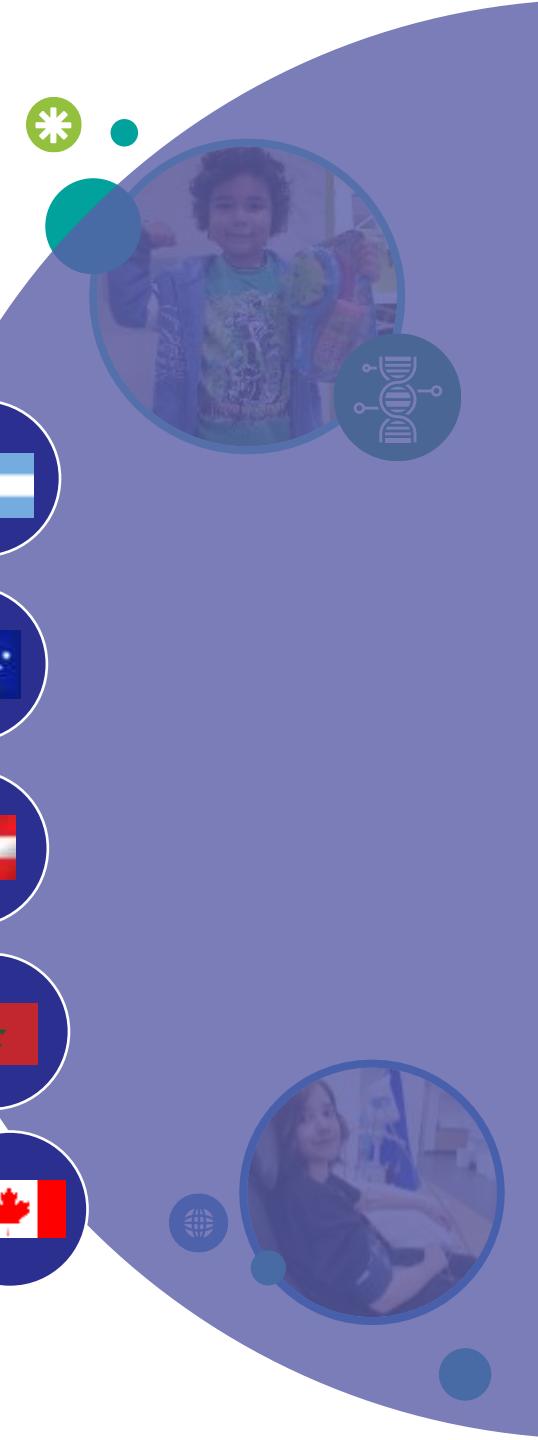
Destination #3
Austria



Destination #4
Morocco



Destination #5
Canada



About World PI Week Roadshow Series

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Destination #1

WITH
ROBERTA ANIDO DE PENA
Mother of Patient & President of the Argentinian Association for Primary Immunodeficiencies Patients (AAPIDP) – Argentina

www.worldpiweek.org

Destination #2

WITH
EMILY EDWARDS
Research scientist at the Alfred Hospital and Monash University & Vice President of AusPIPS – Australia

www.worldpiweek.org

Destination #3

WITH
THOMAS KREIL
Vice President, Global Pathogen Safety, Takeda – Austria

www.worldpiweek.org

Destination #4

WITH
MARIA ANEBANE
Vice-President, Hajar (Patient Association for PID Patients) – Morocco

www.worldpiweek.org

Destination #5

WITH
JESSICA WILLET PACHUL
Clinical nurse specialist in Immunology, Hospital for Sick Children – Canada

www.worldpiweek.org

- 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**!

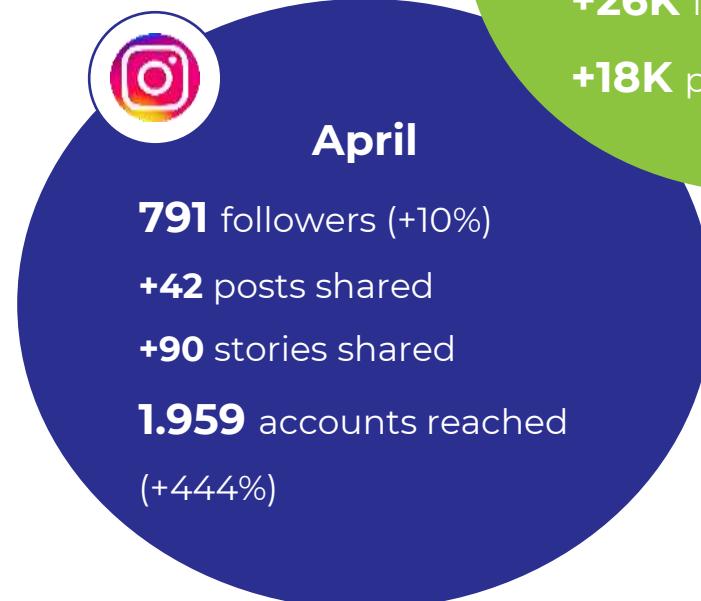
Well done!

#PictureAwareness

Social media milestones

Driving conversations and mobilising to raise awareness of PIDs

Analytics for 22-29 April



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/4D46lg2
pic.twitter.com/y4V4eRAFWe

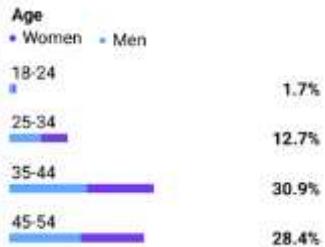


- ✓ 50% audience increase
- ✓ Tweet reach was the highest ever
- ✓ Highest engagement around coffee talk activity
- ✓ Best performing social channel

TWITTER: @WorldPIWeek



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



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

INSTAGRAM: @world_pi_week_



Overview Report
Visitors **4893** ↑300% vs Previous 30 Days
Pageviews **9589** ↑320% vs Previous 30 Days
Avg. Session Duration **33s** ↑202% vs Previous 30 Days
Total Users **3,570** ↑202% vs Previous 30 Days



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

WEBSITE: www.worldpiweek.org



Media coverage

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SPECIALIST
De actualiteit voor de arts-specialist

Data for better care in primary immune deficiencies (PID)

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

This data can be converted into knowledge to better PID care, or as it sounds, it's about improving access to diagnosis, but also improving treatment and care for PID patients through [Genomics and Real-world](#) [Data](#).

THE

Friday, April 28, 2017, 11:30

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 • [Healthnews.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.



abp LIVE

HOME ▾ ▶ IPL NEWS ▾ BUSINESS ▾ ENT ▾ IDEAS OF INNOV ▾ ▶ SCI & TECH ▾ OFFBEAT ▾ ▶

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 [Rakesh Kulkarni](#) | Updated on 28 April 2017, 11:30



L'EST

Actualité ▾ Négoce ▾ Faits divers ▾ Sport ▾ Culture-Société ▾ Magazine ▾ Services ▾

Iris, la voix des patients atteints de déficits immunitaires primaires

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

DÉBAT DÉBATS ▾ 20 Avril 2017 à 20h30 - Théâtre du Closa | 1 entrée



The Sydney Morning Herald

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

Angela Thompson
April 23, 2017 – 3:03am

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 (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



[Click to see more](#)

Conoce la historia de Romina
#MyPIStory
World PI Week IPOPI

#InmunodeficienciasPrimarias #SemanaMundialIP #WorldPIWeek
#PrimaryImmunodeficiencyawareness #PrimaryImmunodeficiency #PrimaryImmunodeficiencies
#Immunodeficiency #Immunoglobulins #PIDcare #PID

Voir la traduction

#PIPStoriesDF World PI Week

no genera las defensas necesarias

6 MILLONES de personas en todo el mundo viven con inmunodeficiencia primaria.
Esa es más que la población total de Dinamarca o Nueva Zelanda o la población combinada de Gambia y Namibia.

Programa Jueves 27 de abril

18:00 - 18:05 Palabras de bienvenida
Dra. Beatriz Araceli Páez - Presidente

18:05 - 18:40 Actualización y recomendaciones en vacunas en IDP
Dra. María Andrea Urtubia
Coordinación: Dr. Miguel Gallegos

18:40 a 19:15 Espacio de preguntas y respuestas
Actualización y recomendaciones en gammaglobulina endovenosa y subcutánea
Dra. Agustina Llarena
Dra. María Andrea Urtubia

Segura de la mano de los expertos

3er. CONGRESO VIRTUAL PARA PACIENTES CON INMUNODEFICIENCIAS PRIMARIAS

Recipient of IPOPI grant

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



Click to see more

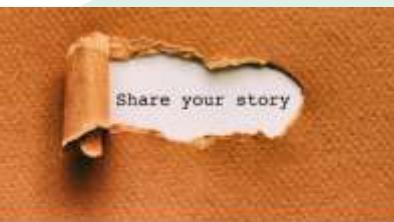
Donate to Make a Difference to People Living with PI.

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 across 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



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 #PawAwareness #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



Recipient of IPOPI grant

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

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

ASClA 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):

ASClA Immunodeficiency Strategy Meeting

Sydney, Australia - Manly Pacific Hotel
Friday 28 April 2023

ASClA TAPID (Transplantation and PID) Meeting

Sydney, Australia - Manly Pacific Hotel
Saturday 29 April 2023

ASClA 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, ASClA President and paediatric clinical immunology/allergy specialist.

www.nationalimmunodeficiencystrategy.org.au
#ASClA #PID #immunodeficiency #genomictesting

Austria

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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



Спасем иммунитет
22 April at 10:10 ⓘ

The World Week of Primary Immunodeficiency (PID) is traditionally held from April 22 to 29. The task of PID Week and our patient community is to draw attention to this orphan disease. [What is this event, and why is it worth knowing about it?](#)

PID Week is a time when the spotlight is on patients with primary immunodeficiency, and concerned organizations, doctors, patients and simply caring people come together to draw public attention to these problems, raise awareness and... [See more](#)

• See original | Rate this translation

22–29 апреля
Всемирная неделя Первичных
иммунодефицитов
Участвуйте в распространении
информации о ПИД



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

20–21 апреля
2023
Национальный научно-исследовательский центр детской онкологии и гематологии
Республиканский школа-семинар
Диагностика иммунопатологических состояний. Врожденные дефекты
иммунной системы



Belgium

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Bubble ID

Bubble ID

- Bubble ID Family Day
- Donation campaigns



Click to see more

Bubble ID
26 April at 15:25 ·

Thank you to everyone who attended our bubble id family day ❤️❤️❤️

Bubble ID
€ 5,50 per stuk
Bestellen via FB bij
Haerens Shanna

Alle opbrengsten gaan integraal
naar Bubble ID

B & S Design
www.bs-depicti...
Haerens Shanna

Alle opbrengsten gaan integraal
naar Bubble ID

Belgium

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Belgian patient organisation for primary immunodeficiencies

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 patiënten met een primaire immuunodeficiëntie, 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



Recipient of IPOPI grant

Bolivia



FIDEPE – 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



Click to see more



Fidep-Bolivia
3 May at 23:11 ·

Global Campaign on Primary Immunodeficiency. Awareness week about these diseases. There are people who are heartless and have a heart of gold. Today in the city of Cochabamba at the Children's Hospital "Manuel Ascencio Villarroel" a room was enabled so that our children with Primary Immunodeficiencies can comfortably receive their Immunoglobulin treatment every month. Heartfelt thanks to the protagonists who made this possible.
Nelia Lizbeth Guillen Rocha @Cecilia Camacho @Limer López Cárdenas ❤
#Popi
#WorldPIWeek
#Primaryimmunodeficiency
#Fidepbolivia
[See original · Rate this translation](#)



INMUNODEFICIENCIAS
PRIMARIAS
Y LA IMPORTANCIA DE DARSE CUENTA

DATE CUENTA! #FidepBolivia #Popi World PI Week #InmunodeficienciasPrimarias
#SemanalMundialDP #primaryimmunodeficiency #Primaryimmunodeficiencies

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



Brazil



ASBAI

Associação Brasileira de Alergia
e Imunologia (ASBAI)



Section 1

Section 2

- PID Testimonial Videos
- Covid-19 Vaccination campaign
- #plasmajabrasil 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 #plasmajabrasil #alergia #Imunologia #WorldPIWeek #ASBAI

Dra. Cristina Maria Kokron
Médica de Dey*, Clínico de Erros Inatos da Imunidade ASBAI - CRM: 48868/SP - RG: 492362

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 #plasmajabrasil
bit.ly/podcast_plasma

#imunodeficienciasprimarias #EII #plasma #plasmajabrasil #Imunologia #WorldPIWeek #ASBAI

#plasmajabrasil

ASBAI @ASBAI_alergia · Apr 29
Imunidade baixa ela existe mesmo?

#imunodeficienciasprimarias #EII #Imunidade #plasma #plasmajabrasil #alergia #Imunologia #WorldPIWeek #ASBAI

9 vê

COVID-19
REFORÇO DA VACINA
BIVALENTES PARA
GRUPOS PRIORITÁRIOS.

Vacina é vida. Vacina é pra todos.
Informe-se, procure uma Unidade Básica de Saúde
e complete seu esquema vacinal.

gov.br/vscimacao

SUS

MINISTÉRIO DA SAÚDE

BRASIL

LUTA E RESISTÊNCIA

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



Chile

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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 de padres y amigos
Con inmunodeficiencias primarias

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 exp... See more



Recipient of IPOPI grant



Celebración semana de la IDP

Sabado 29
Abril

Parque
Intercomunal
de la reina

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

Te invitamos a nuestro 2º 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 @Jessiequumeng · 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



Fundacion FIP (Fundacion Diana Garcia 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

World PI Week

**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 Karaiskakio 1όρυμα / 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.”



Click to see more

Ιμάνθα Ατόμων με Συγγενή Ανοσοανεπάρκεια και Φίλων
28 April at 12:00

World PI Week 2023

Our aim is that our campaign has encouraged efforts to enhance the well-being of those with PID globally.

Μαζί φέρνουμε την αλλοιγή για τους ασθενείς με πρωτοπορική ανοσοανεπάρκεια, όπου και στην Ευρώπη

#PrimaryImmunoDeficiency
#ανοσοανεπάρκεια
#Ευρωπαϊκή Ημέρα Ανοσοανεπάρκειας
#WorldPiWeek2023 #PIDPie #IPOPI #PrimaryImmunoDeficiencyCyprus
#Πρωτοπορική ανοσοανεπάρκεια
#Ευρωπαϊκή Ημέρα Ανοσοανεπάρκειας

See highlights



World PI Week
TEST • DIAGNOSE • TREAT

Έγκαιρος έλεγχος και διάγνωση της Πρωτοπαθούς Ανοσοανεπάρκειας

Η έγκαιρη διάγνωση και θεραπεία μπορούν να απατρέψουν τις επιπλοκές των λοιμώξεων και να επιτρέψουν στον έχοντα ΠΑΑ να ζει μια «φυσιολογική» ζωή

Together, bringing about change for primary immunodeficiency patients worldwide
www.ipopi.org | www.wpiweek.com



Ecuador



FUNDACION PIDE
Para pacientes con inmunodeficiencia.
Primericia - 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

The collage illustrates the various activities organized by Foundation PIDE for the World Week of Awareness. It features promotional materials for the 'World PI Week' and 'SEMANA IDP DEL 22-29 DE ABRIL', including a calendar of events and a speaker at a podium. The collage also shows a night view of the Iglesia del Sagrario cathedral, which was illuminated during the event.

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



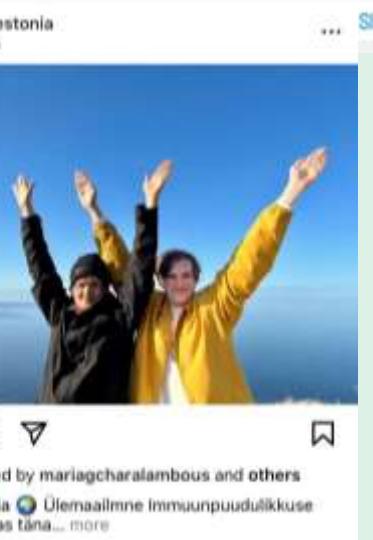
pidestonia Liked by spasemimmunitet and others
pidestonia As part of the ongoing World Immune Deficiency Week, the leader of our association Kersti spoke to the good staff of Medicum Special Medical Aid and to the awesome students of the Kohtla-Järve structural unit of Tallinn Health Care College about primary immunity deficiency through her experience with two sons - Kristopher and Robin, also known as the Lion Hearts Brothers.

Kersti's message at both seminars was positive - despite the difficulty of the journey, the diagnosis doesn't stop you from dreaming big! Estonian patients have been lucky because the treatment is

@world_pi_week_kampaania teises videos kuuleme Hellen Ayagat, Keenast 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.



Recipient of IPOPI grant

France

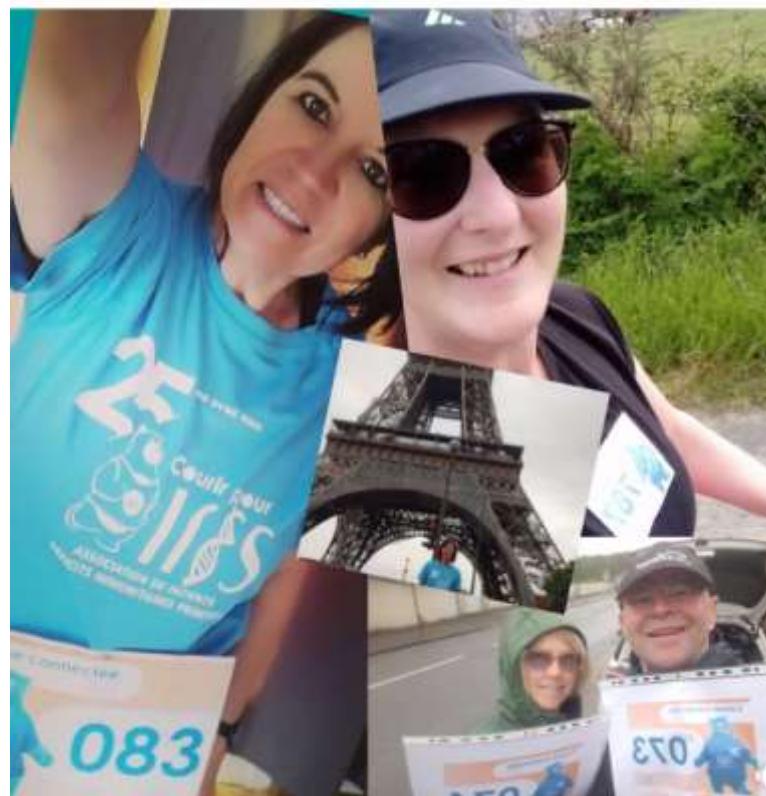


Association IRIS

- IRIS Connected Race #CourirPourIris
- Social Media Engagement



[Click to see more](#)



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 – 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 – Immune-mediated diseases

Chairs: Maria Kanariou, Stylianos Grafakos, Tali 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://evolution.nowlive.events/all/node/95>

Greece



HOME



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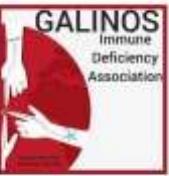
Immune Deficiency Association
of Greece (Galinos)



- 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

A circular graphic for the "Boy in the Bubble" campaign. It features a boy sitting inside a large transparent bubble. The text "Boy in the Bubble" is at the top, and "Live-Event 26. April 2023 | ab 11 Uhr > auf der Reichstagswiese in Berlin" is in the center. The dsai logo is in the top right corner. Below the main graphic is a smaller image of a poster for the campaign.

Immundefekt - dsai e.V. hilft is 😊 feeling joyful.
20 April at 13:13

2 more days until World PI Week and 9 days until International Immunology Day! The dsai is coming along... stay tuned and keep sharing our posts. To improve diagnosis, treatment and to raise awareness of congenital immune deficiencies in the public.
IPOPI World PI Week

See original · Rate this translation

World PI Week
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

World PI Week updated their cover photo.
13 April at 13:21

A graphic for World PI Week showing a globe with many small circular icons representing people connected by a network of lines, symbolizing global collaboration.

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 #plazmaspende #bith #berlin #PIWeek #WorldPIWeek IPOPI

See original · Rate this translation



Immundefekt - dsai e.V. hilft at Moosburg a. d. Isar.
28 April at 11:28 · Moosburg an der Isar, Germany

We need your support! 🙏
Open event for all affected and interested parties, to which we cordially invite you.
This event will be broadcasted via Zoom: <https://zoom.us/j/9640782562>

#dsai #Immundefekt #web #setzeneinkrankungen #thundertag #aufklarung #feierlicher #worldpiweek #moosburganderisar *

See original · Rate this translation

ladung zur Veranstaltung am 02.05.23:
tene Erkrankungen Bayern
Klungkampagne zu Immundefekten

A poster for an event on May 2, 2023, at Moosburg a. d. Isar. It features the dsai logo and text about rare diseases in Bavaria and a campaign against immunodeficiencies. It includes a QR code and a QR code.

Iceland



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

Section 1

Section 2



Click to see more



Forsíða Sjúklingar / Aðstandendur Deildir og þjónusta

Sjúklingar / Aðstandendur

Fagfólk

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

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Section 1

Section 2



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

IPSPI - Indian Patients Society for Primary Immunodeficiency
3 May at 10:59 ·

#IPSPI-Indian Patients Society for Primary Immunodeficiency in collaboration with Medicine and Pediatrics Department of Lady Harding Medical College, New Delhi organised CME on Inborn Errors of Immunity on 29th April,2023 in Auditorium, Academic Block, LHMC, New Delhi



IPSPINDIA.ORG
#WPIW 2023 CME on Inborn Errors of Immunity
#IPSPI-Indian Patients Society for Primary Immunodeficiency in collaboration with Medicine an...



Indonesia



IDAI (Indonesian Pediatric Society)

- Social Media Engagement
- PID Facts visuals
- Online Symposium



Click to see more

The collage consists of three vertical panels. The top panel shows a tweet from IDAI (@idai_tweets) on April 24, 2023, about Primary Immunodeficiency with an infographic. The middle panel shows another tweet from IDAI (@idai_tweets) on April 23, 2023, about an online symposium for World Primary Immunodeficiency Week. The bottom panel is a promotional banner for the same online symposium.

Top Panel (IDAI @idai_tweets - Apr 24):

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

#IDAI
#IndonesianPediatricSociety
#worldprimaryimmunodeficienyweek

Middle Panel (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 dselenggarakan pada:

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

Bottom Panel (Promotional Banner):

Online Symposium Ikatan Dokter Anak Indonesia dalam rangka World Primary Immunodeficiency Week

Recognizing Primary Immunodeficiency in Resource-limited Country

Narasumber: dr. R. A. Myrna Alia, M.Kes, Sp.AKO
Anggota UKK Alergi Imunologi

Moderator: dr. Endah Citraresmi, Sp.A(K)
Pengaruh Pusat IDAI

Rabu, 26 April 2023
13.00-14.00 WIB

Dafatar pada tautan berikut:
<https://bit.ly/OSDIA21April>

Scan di sini:

Akses ini dapat dilihat oleh dokter umum dan dokter spesialis anak

Indonesia

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Section 1

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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



Click to see more

IPIPS
19 April at 03:06 ·

Hi Parents, welcome World PI Week 2023, join us to continue to raise awareness of primary immunodeficiency in Indonesia.

This year's theme is "Turning real-world data into knowledge for better PID care". Comprehensive patient data can later help physicians to better understand the causes, provide a diagnosis, and provide the treatment that is best suited to patients' needs.

#WorldPIWeek #LivingwithPID #primaryimmunodeficiency #imunodefisiensiprimer #PID #WorldPIWeek2023 #IPIPS

[See original · Rate this translation](#)

World PI Week

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: Freepik

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 di dunia. Blaya pertengahan dan perawatannya pun juga 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

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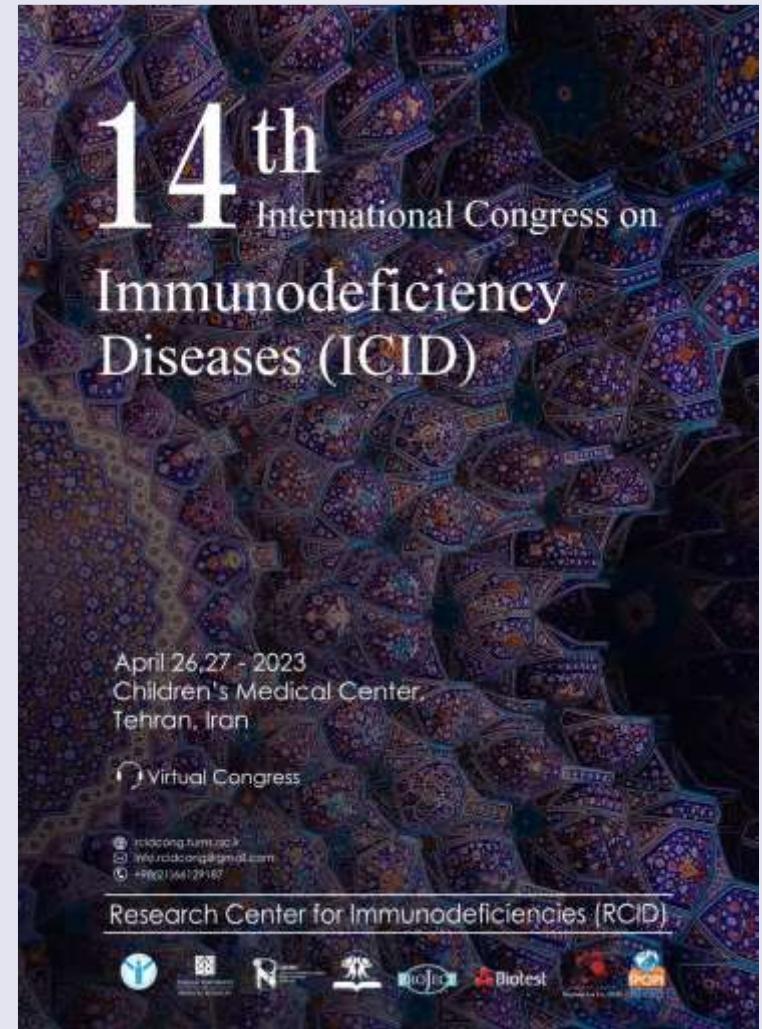
Iranian Primary
Immunodeficiency Association
(IPIA)



- [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

Section 1

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Ireland

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Section 1

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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 Ross Maria Carrizo — Leave a Comment



...

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



ipainfo



Israel



HOME



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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, podcasts, articles & testimonials

[Click to see more](#)



SIX KEY MESSAGES ON IMMUNOGLOBULIN THERAPIES

What is immunoglobulin replacement therapy? This administration of life-saving immunoglobulin therapies derived from human plasma which are proteins against a broad range of infections.

Immunoglobulin therapies are absolutely essential, lifelong treatments for many of primary immunodeficiencies.

Bubble Care קר
65 likes · 85 followers



Recipient of IPOPI grant

Italy



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

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**Assemblea AIP 2023
e incontro medici pazienti**
Sabato 22 Aprile 2023
Aula Magna "Vida", Padiglione 11, IRCCS Azienda Universitaria-Ospedaliero di Bologna

09:00 AssemMed Soci AIP O.d.V. – Riservata ai soci
Incontro medici pazienti*
Moderatore: Prof. Andrea Pessioni

10:00 Ulteriori congegni dell'immunità: ieri e oggi, generazioni e confronti
10:20 Vaccini: aggiornamento sulle indicazioni nell'era post-COVID19 (Dott.ssa S. Cicali)
10:40 Screening neonatali: la realtà della Regione Emilia-Romagna (Dott.ssa S. Cicali)
11:00 Coffee break
11:20 Multidisciplinarietà nelle IDP: creazione di percorsi assistenziali dedicati (Dott.ssa S. Cicali)
11:40 Dalle immunoglobuline alla terapia maturata (Dott.ssa Conti, Dott. Gerosa)
12:15 Storie bolognesi: i pazienti si raccontano
12:45 Discorso e chiusura del tavolo

Seguire un pranzo e momento conviviale!
Per info: info@ip-italy.org

AIP - Associazione Immunodeficienze Primitive O.d.V.
Fondazione da Silvia Cicali il 22 aprile 1994 (IASI)

Inizia oggi, sabato 22 aprile, la Settimana Mondiale delle Immunodeficienza Primitive 2023! La World PI Week è un evento di portata mondiale istituito nel 2012 con l'obiettivo di promuovere la consapevolezza relativa alle Immunodeficienze Primitive. Durante l'intera settimana hanno luogo tantissimi eventi e attività online e in presenza in tutto il mondo.

#WorldPIWeek #LinoGlobulino

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 immunocompromissione le riconosca.

**10 CAMPANELLI DI ALLARME
DELLE IMMUNODEFICIENZE PRIMITIVE**

AIP O.d.V. - ASSOCIAZIONE IMMUNODEFICIENZE PRIMITIVE O.d.V.
www.ip-italy.org | info@ip-italy.org | +39 051 201000

CORRISpondere
AIP O.d.V. - ASSOCIAZIONE IMMUNODEFICIENZE PRIMITIVE
I CAMPANELLI D'ALLARME E IL RUOLO DELLA RICERCA NELLA CURA DELLE IDP

Il Supereroe dei bambini Lino Globulino allo scoperto delle terapie per combattere le IDP nelle sue nuove avventure "La gita nel futuro", pubblicata da Telethon.

Le Immunodeficienze Primitive sono malattie congenite rare che colpiscono circa 1 persona ogni 500. In esse le difese preziose e all'avanguardia tempestive 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 immunocompromissione le riconosca.

Consigliando Immunodeficienze Primitive italiane e internazionali le risorse scientifiche per un inserimento più facile e preciso di tutte le varietà di IDP. Oggi grazie allo sviluppo tecnologico è possibile individuare, anche ad alto patologico, anche le immunodeficienze consolidate e rare (NDS). Con l'obiettivo di migliorare la tenacità della diagnosi, che finora non è mai stata così più elevata in grado di influenzare la progettazione e le aspettative di vita. AIP O.d.V. è attiva nelle diffusione, attraverso i suoi canali digitali, di contenuti scientifici, di "Glossari comprensivi di IDP", un database che raccolge i termini più comuni per cui ha individuato oltre una trentina di IDP italiane e internazionali.

IL PROGETTO LINO GLOBULINO:
AIP O.d.V. mette il contributo tecnologico di Telethon e in collaborazione con la TV per la realizzazione creativa e grafica, ha ideato il personaggio di "Lino Globulino". Un supereroe che insieme ai compagni globulini porta in campo le IDP e magia nel futuro! Un supereroe che trasmette messaggi positivi e conforto alle IDP e magia nel futuro!

LA NUOVA AVVENTURA "LA GITA NEL FUTURO": I 10 NUOVI CAMPANELLI D'ALLARME DI LINO GLOBULINO
Lino Globulino e i suoi alleati tranno già affioranti molti importanti risultati e raccomandi. Di nuovo vero tempo di innovazione e ricerca. Per questo è nata la nuova avventura "La gita nel futuro", Globulino porta in campo le IDP e magia nel futuro. Ancora più giovane in programma nella fine di 2023. Il nuovo fumetto "Lino Globulino e la gita nel futuro" è patrocinato da Telethon.

Lino Globulino aderisce campionariamente per la diffusione del "Glossario comprensivo delle Immunodeficienze Primitive" (grande e un nuovo e numeroso poster). Ogni anno dal centro di conoscenza delle Immunodeficienze Primitive viene riedita una diversa avventura raccontata da Globulino e presentata sul suo sito e sui social www.ip-italy.org.

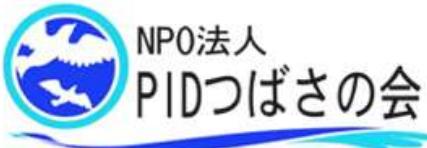
Eugenio Alfai - Presidente Internazionale AIP O.d.V.
Dott. Pierpaolo Cicali - info@ip-italy.org - +39 051 201000

Gloria Comunicazione AIP O.d.V.
Dott. Annalisa Cicali - comunicazione@ip-italy.org
Dott. Annalisa Cicali - comunicazione@ip-italy.org



Recipient of IPOPI grant

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の徵候」が参考になります。
小児用⇒ [takeda.co.jp/patients/pidna...](https://takeda.co.jp/patients/pidna/)
成人用⇒ [takeda.co.jp/patients/pidna...](https://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ごち...
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...

HELSKAEAD+ ハルカスヘルスケア+ UVER WORLD
TOP 新着記事 病気 症状 地域 予防 病院 開業医 コラム 常識

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



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



ANGIE 心地よき・楽しさ・私らしさを追求する
女性たちのためのマガジン ANGIE(アンジー)
TOP ファッション 美容 愛愛 ダイエット ライフ

HOME > 繰り返す中耳炎や副鼻腔炎、気管支炎…それってPID（原発性免疫不全症）かも？

2022年04月19日

繰り返す中耳炎や副鼻腔炎、気管支炎…それってPID（原発性免疫不全症）かも？

LIVE会員登録 LINE会員登録 Twitter会員登録

Kenya



PIDS Kenya

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



[Click to see more](#)

Primary Immunodeficiencies Association Kenya
23 April at 16:51

IPOPI
23 April at 11:01

"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

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



Mexico

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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 Niñas y Niños con Inmunodeficiencias
April 24 at 7:58 PM - 1
Radio ALAS, el 1er Podcast en América Latina donde ponemos las #InmunodeficienciasPrimarias al Aire !!
Escúchalo y sigue nos en Spotify <https://spoti.fi/2VtRk0z>

Radio ALAS

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



Fundación Mexicana para Niñas y Niños con Inmunodeficiencias
April 26 at 10:51 PM - 1
Semana mundial de los #InmunodeficienciasPrimarias
Existen más de 400 tipos de inmunodeficiencias primarias, he aquí 10 de los 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 imunoglobulina, 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.

SCENICIA SELECTIVA DÍGIST DE SUBCLASES DE
mutación de tipo IIb implica la alteración del dominio de la inmunoglobulina A (IgA), lo que implica la alteración de la actividad de IgA. La mutación de tipo IIa implica la alteración de la actividad de IgG.

+7
FotoLife

Morocco

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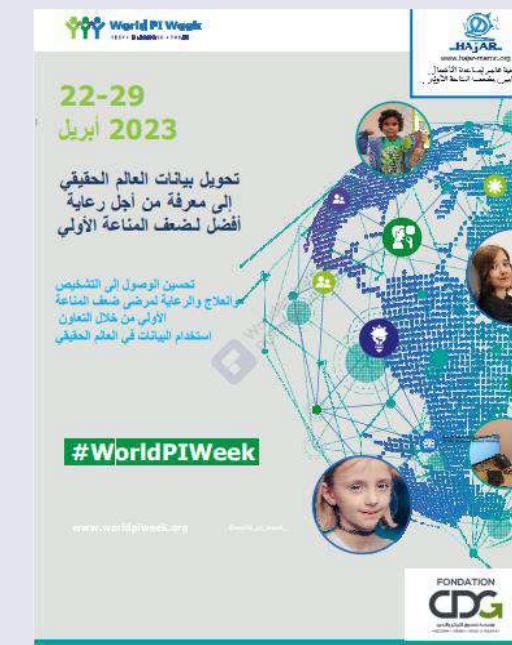


Hajar



- 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

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Netherlands



Stichting voor
Afweerstoornissen (SAS)
Foundation for Immune
Disorders



Section 1

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- 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



Click to see more

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 Tibeta Nederland. Keep 23 September free and register via the link above.

#WorldPIWeek #wpw #pidnaarmimmunodeficiëntie #internmedicinity #samenwerking #event

See original · Rate this translation

Margo Dona
Bestuurslid SAS

IPOPI

Hear Jose Versteegen from Stichting voor Afweerstoornissen about the data collection activity they are launching during #WPW. As part of our World PI Week campaign series, we're data collection for rare diseases. We're thrilled to see patients in this crucial area.

<http://pidlifeindex.ipopi.org>

#WorldPIWeek #PIDlifeIndex

The Foundation for Resistance Disorders has developed four informative videos together with CSL 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 #pidnaarmimmunodeficiëntie #immunoglobulinen #plasmauwleders #plasmatherapie

See original · Rate this translation

CSL Behring

Het product



PID EXPERTISENETWERK



ZATERDAG 23 SEPTEMBER 2023 JAARBEURS - UTRECHT

Op zaterdag 23 september organiseert de stichting voor Afweerstoornissen het PID-event. Een evenement 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 long-in-lab sessies en je laten inspireren tijdens een sessie over de gecreëerde trends, technologieën en innovaties in de zorg.

Als slaper op de avond is er de PID-show over alles met betrekking tot PID onder inspiratie van een bekende Nederlander. Denk daarbij wie dat is? Hou onze sociales de komende tijd dan goed in de gaten.

Gedurende jaren zelf een plekje en schriftje je vandaag nog in!



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



Click to see more

The screenshot shows a video player interface with the title "World PI Week Quiz!" displayed prominently. Below the title, the text "How much do you know about primary immunodeficiency?" is visible. The video player has a progress bar at the bottom showing "0:02 / 100".

The screenshot displays a section titled "PI Awareness Month" with the sub-section "PI Week Challenge". It features a call to action "Enter our 'Pie for PI' competition" with a photo of a child and a woman. Below this, there is a "Take a Pie in the face for PI and support IDFNZ" section featuring a photo of Laura Harrold and a challenge summary. On the right, there is a "PIE for PI Challenge" summary box showing "\$235.00 donated" towards a goal of "\$2,000.00". At the bottom, there is a section titled "Know the 7 Warning signs of Primary Immune Deficiency (PID)" with several small illustrations related to PID symptoms.

Philippines

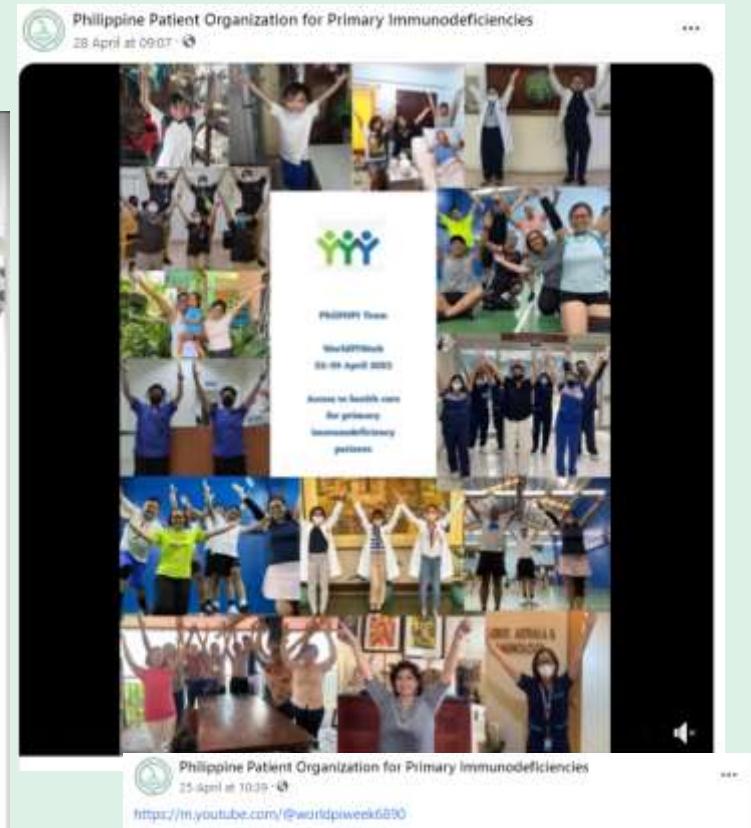


Philippines Patient Organization
for Primary Immunodeficiencies

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



Click to see more



YOUTUBE.COM
World PI Week - YouTube
Share your videos with friends, family, and the world

Like Comment Share



Recipient of IPOPI grant

Poland

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Stowarzyszenie na rzecz osób z niedoborami odporności

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 (PIPs) 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 (PID) 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](#)

World PI Week
PORTUGAL CHAPTER

22 a 29 de Abril de 2023

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



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Puerto Rico

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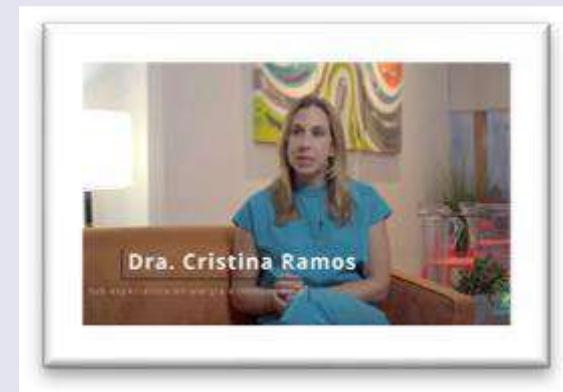


Puerto Rico Alliance of PID Patients (APIP)

- 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



ARPID - Asociația Română a Pacientilor cu Imunodeficiențe Primare was live.

29 April at 14:05

Cum pot fi îngrijite mai bine IMUNODEFICIENȚELE PRIMARE. Medici renumiți ca Dr. Ciprian Juric, Dr. Mihaela Bătăleanu, Dr. Irina Pintea, Dr. Bianca Simionescu sau Dr. Cristina Stăicu explică pe interesul tuturor la Conferința Națională a Asociației Române a Pacientilor cu Imunodeficiențe Primare. Un eveniment ARPID în Săptămâna Mondială a Imunodeficiențelor Primare.

See translation

World PID Week

**IMUNODEFICIENȚELE
PRIMARE**
pe înțelesul
pacientului
03:05:17 PM

Conferința Națională 2023 - Asociația Română
a Pacientilor cu Imunodeficiențe Primare

▶ 2:56 / 3:26:00

Imunodeficiențele Primare
explicații de la MEDICI - Conferința Națională 2023



Pacientul 2.0



VIATA
MEDICALA

Patru medici se reunesc să ajute pacienții cu imunodeficiențe primare

DE SORINA NEAGU - 28 APRILIE 2023



Patru medici români se reunesc vineri, 28 aprilie, ca să explice mai bine imunodeficiențele primare pacienților și celor care li îngrijesc.

HotNews.ro

HOME ULTIMA ORA

SANATATE Vineri, 28 Aprilie 2023, 19:38

În România trăiesc 600 de pacienți diagnosticați cu imunodeficiențe primare, dar se estimează că numărul celor nediagnosticati este de 10 ori mai mare

Alina Neagu • HotNews.ro

Peste 600 de români sunt astăzi diagnosticați cu una dintre cele peste 480 de boli din familia imunodeficiențelor primare, dar, din cauza faptului că, foarte frecvent, aceste boli se manifestă ca niște infecții comune, se presupune că există alți 5.000 - 6.000 de conaționali care au o



Recipient of IPOPI grant

Russia



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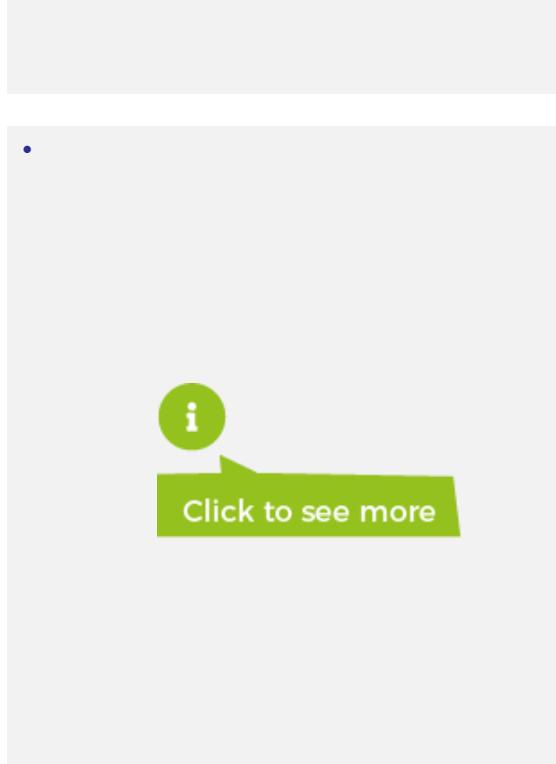


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Coming Soon!

Slovakia



Združenie pacientov s primárnoch imunodeficienciami, o.z.

- Awareness raising video



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IMUNODEFICIT.SK

Združenie pacientov s primárnoch imunodeficienciami

Trieste stretnutie pacientov s poruchami imunity

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



Združenie pacientov s primárnoch imunodeficienciami

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

See translation

South Korea

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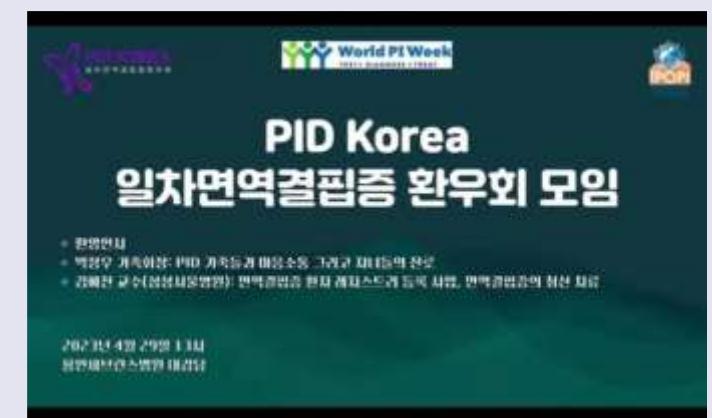
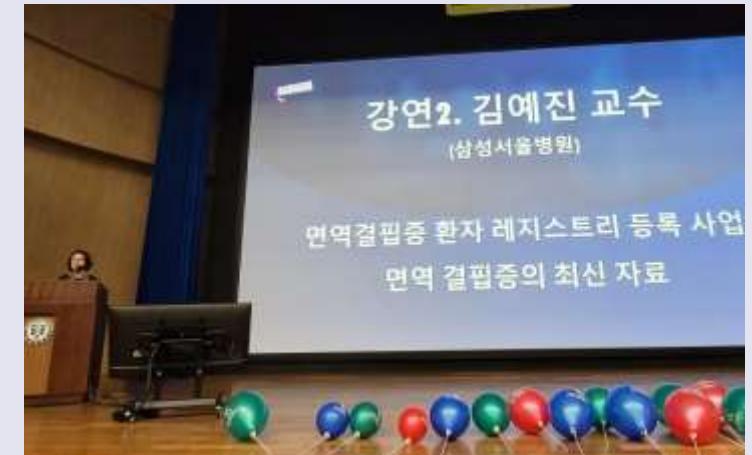
NEXT



PID Korea



- PID Korea regular families meeting



Spain



Barcelona PID Foundation

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



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BCN PID Foundation @bcnpidfound · Apr 25

Us presentem l'Andrea, membre del patronat de la @bcnpidfound pediatra immunòloga de la UPIP 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 patrò la BCN PID Foundation i pediatra immunòlog



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



Activitats emmarcades en la Setmana Mundial de les IDP 2023

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



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

Spain



Asociación española de déficits
inmunitarios 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 IDP **no se detectan a simple vista**, necesitan de un análisis minucioso de los sangres 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 contagiado 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 sigan la curva que tiene.

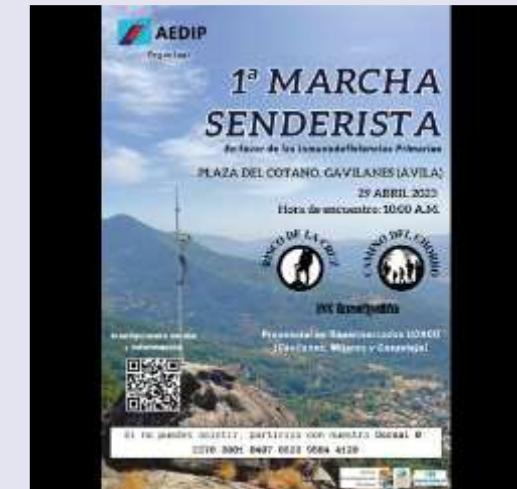
DONA PLASMA, DONA VIDA

Fuente: AEDIP. Concurso Español por la suficiencia de plasma y su tratamiento. Febrero 2012.

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 pacientes. El **plasma obtenido a partir de las donaciones de sangre no es suficiente para abastecer las necesidades**, a lo que debe sumarse que la donación directa de plasma, denominada plasmáteresis, 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 (plasmáteresis)** 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.



Sweden



Primär
immunbristorganisationen

- #GoZebra walk campaign
- Social media engagement



Click to see more

22

April

World Immunodeficiency Week and the #GoZebra campaign. News!

#ZebraRun

April 22 - April 29



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 İmmünloloji Derneği (AID)

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



Click to see more

22-29 Nisan Dünya Immün Yetmezlikler Haftası kapsamında bu yıl da farklılık kutlamasında renkli görüntülere eğlenceli etkinlikler. Immün yetmezliklere farkındalık işgi tutmak amacıyla tüm hastalarımıza şifa dileklerimizi balonlar ile gökyüzüne uçurduk.

#ThinkZebra #WorldPIWeek #MUPAJ #IMYED #IPOPI #JeffreyModellFoundation

See translation



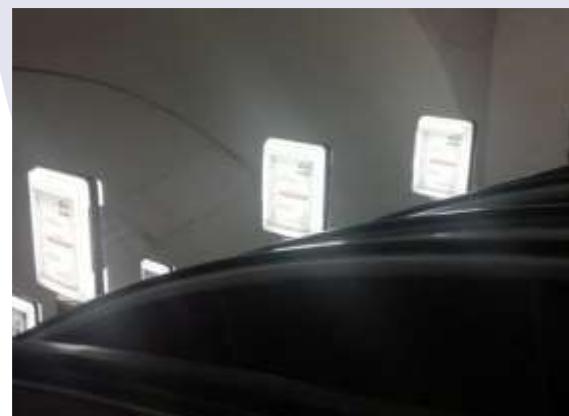
Ukraine



Rare Immune Diseases



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



United Kingdom

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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

Immunodeficiency UK
29 April at 15:24 ·

This #WorldPIDWeek 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....> See more



IMMUNODEFICIENCY
UK

World PID Week

Visit our website at www.immunodeficiencyuk.org

Immunodeficiency UK
29 April at 12:46 ·

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.

NHS

#PlasmaDonationWeek



Recipient of IPOPI grant

United States

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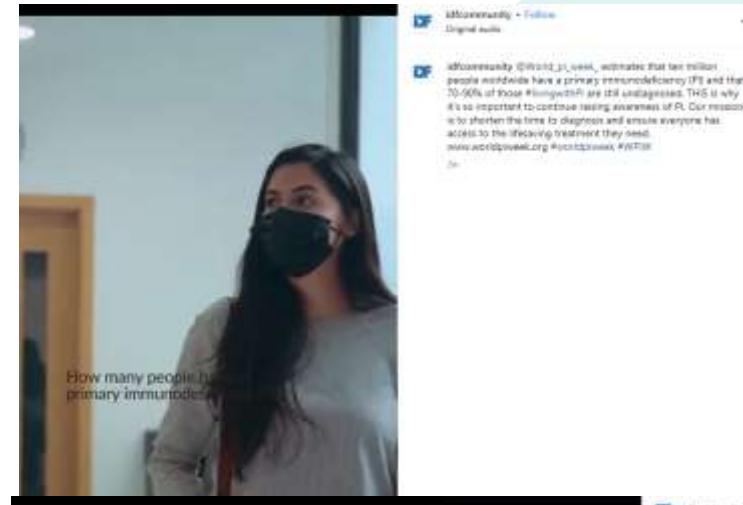
Immune Deficiency Foundation



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



Click to see more



PATIENT SAFETY & PROTECTION

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



World PI Week
HELP • STRENGTHEN • TREAT

#WorldPIWeek worldpiweek.org

112 views
1 day ago



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



Click to see more



Latin America



Alianza de Asociaciones de Immunodeficiencias Primarias



Iniciativa ALAS



- PID Radio



Click to see more

Radio www.ALAS.org

ALAS

Escúchanos y entérate que se necesita en Argentina, Colombia y México para diagnosticar las inmunodeficiencias primarias.

Faisuly Gaviria
ALAS Colombia

Mayela Garcia
ALAS Mexico

Laura Doldán
ALAS Argentina

INICIATIVA ALAS

ONLINE

¡ESTRENO!
PODCAST

Radio ALAS

Inmunodeficiencias Primarias ¡Al Aire!

INVITACIÓN

ABRIL
22

World PI Week

INICIATIVA ALAS

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

Click to see more



GET TO KNOW THE
NEW FEATURES
4ID.IPOPI.ORG



IPOPI
28 April at 12:00 ⓘ
Our final video in the World PI Week campaign series is here! ⓘ
This time, we hear from Dimas Sugiharto from the Indonesian Primary Immunodeficiency Patient Society (IPIPS) about the critical role patient organisations play in collecting data.
We hope this series has highlighted the importance of data collection for rare diseases ⓘ and inspired more patient organisations to start collecting data. ... See more



IPOPI
29 April at 11:00 ⓘ
Exciting news! This Friday, World PI Week is hosting a live event featuring three of our very own IPOPI representatives: Otilia Stanga and Bruce Lim from our Board of Directors and Dr. Nizar Mahlaoui, Chair of our Medical Advisory Panel.
Tune in on World PI Week's YouTube channel at 15:30 CEST for a discussion on the power of data ⓘ and patient registries to improve #PID care globally.
👉 <https://bit.ly/3ofwQ4B> ... See more



International



Jeffrey Modell Foundation

- Regional Toolkits
- Social Media Engagement
- Patient Stories



Click to see more



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 ❤️

The screenshot shows the 'NEW ZEALAND' toolkit page. It features a map of New Zealand and links to '10 Warning Signs of Primary Immunodeficiency', '4 Stages of Testing', 'Immune System Posters', and 'Patient Organizations'. Below this is another section titled '4 Stages of Testing for Primary Immunodeficiency'.



The screenshot shows two side-by-side sections. On the left is the 'Regional Toolkit: AFRICA' page, featuring a map of Africa and links to '10 Warning Signs of PI', '4 Stages of Testing', 'Immune System Posters', and 'Patient Organizations'. On the right is the 'Regional Toolkit: ASIA' page, featuring a map of Asia and similar links. Between the two pages, there is a photograph of a man in a suit and a woman in a red dress standing in front of a framed certificate or plaque.

Life Sciences Industry

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CSL
200,973 followers
1mo • 

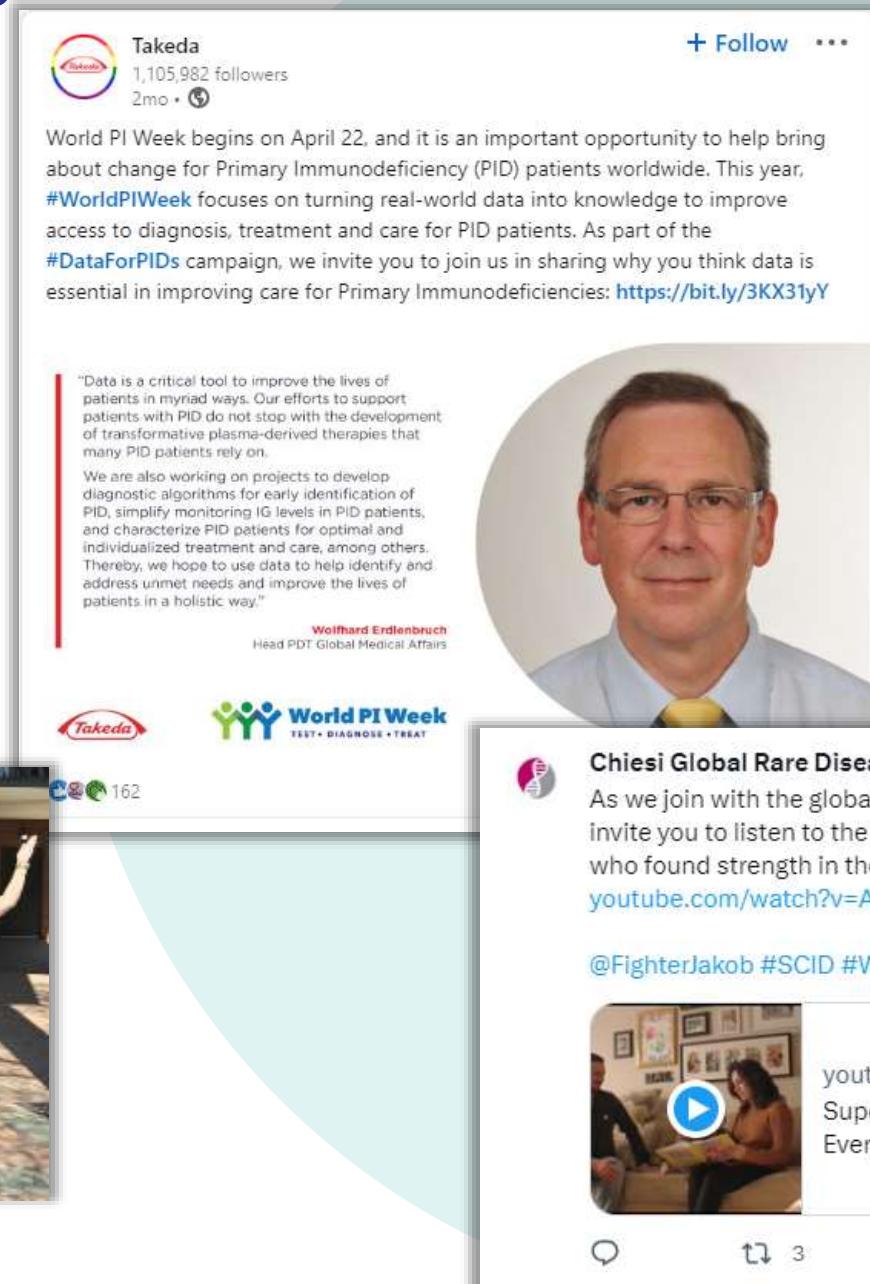
+ Follow

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 abou ...see more

10 MILLION
PEOPLE WORLDWIDE
are living with
Primary Immunodeficiency

CSL

A large group photo of CSL employees standing outdoors with their hands raised in a celebratory pose.



Takeda
1,105,982 followers
2mo • 

+ Follow ...

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."

Wolfhard Erdlenbruch
Head PDT Global Medical Affairs

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A circular portrait of Wolfhard Erdlenbruch, Head PDT Global Medical Affairs.



XORO Medical Systems
22-29 April 2023

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 Immunodeficiencies by sharing patient stories. [#WorldPIWeek](#)

To submit your story, send us a DM or visit [#WorldPIWeek](#), enter your info and "Share your Patient Story" to be featured on our page during World PI Week... See more

#WorldPIWeek

World PI Week
TEST • DIAGNOSE • TREAT
22-29 April 2023

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

Share Your Story!



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-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)*