

WORLD PI WEEK CAMPAIGN REPORT

**Access to care for all PID
patients, everywhere**

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


World PI Week
TEST • DIAGNOSE • TREAT
22-29 April 2024



2024

CHAPTER 1

ABOUT WORLD PI WEEK



A global movement to drive change



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.



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.



Aims

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

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

Since its inception in 2011, World PI Week has been effectively promoting awareness and advocacy initiatives across all continents.



World PI Week by the numbers

54 countries
across the globe

Thousands of people
reached

Hundreds of events
every year

13 years of
campaigning

13 committed organisations
driving the campaign

8 days to create
momentum on PIDs



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World PI Week in pictures



Our active network

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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

Information & advocacy tools

- Fact Sheets & Infographics
- Podcasts
- Videos
- Scientific Articles
- Policy Pledge
- Call(s) to Action
- Press Releases
- Template Letters for Governments
- Social Media Assets



Click **here** to download all materials



CHAPTER 2

WORLD PI WEEK 2024
IN ACTION

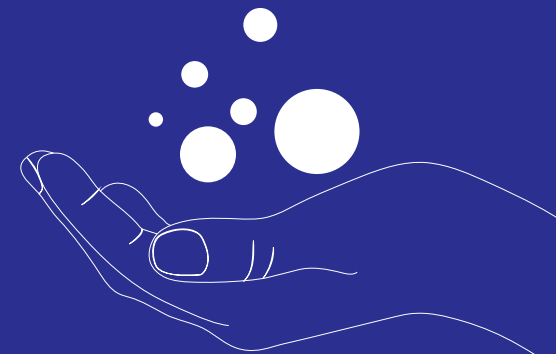


Remembering Vicki Modell

This year, the World PI Week campaign was dedicated in the memory of Vicki Modell whose passion, dedication, and unyielding spirit were instrumental in propelling the foundation to the forefront of the fight against primary immunodeficiency.



*“Remembering Vicki Modell,
global patient advocate and co-
founder of World Primary
Immunodeficiency Week”*

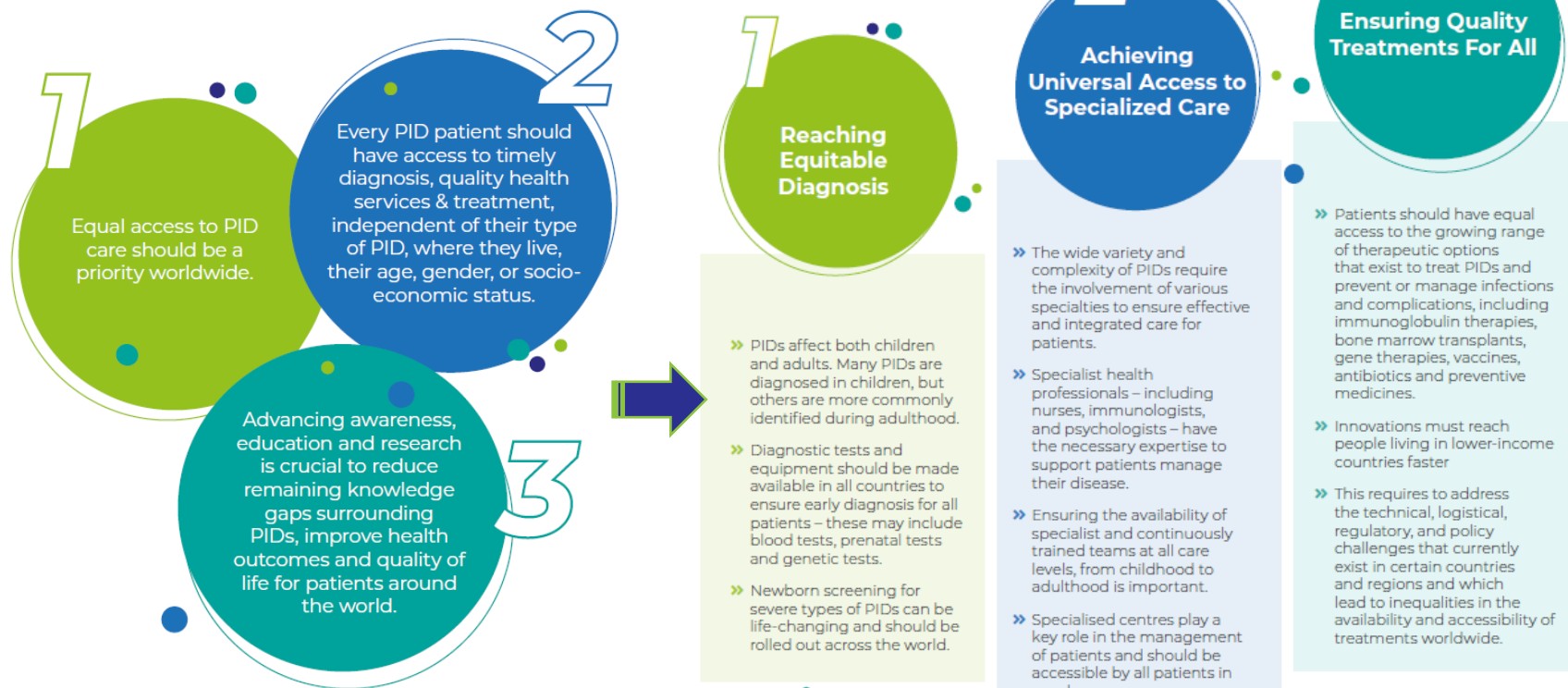


In 2024, we focused on equal access to care

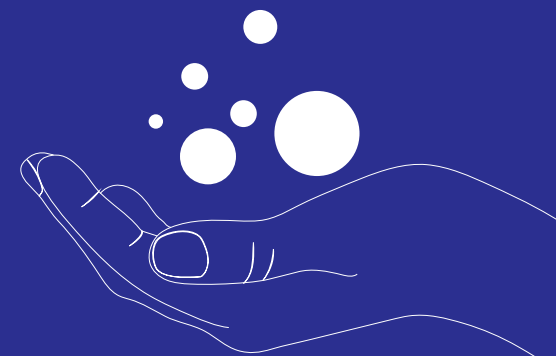
Access to care for all PID patients, everywhere.

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

Main campaign messages



This year, the campaign highlighted disparities in access to care worldwide and mobilized the community around the common goal of ensuring equal access to care globally

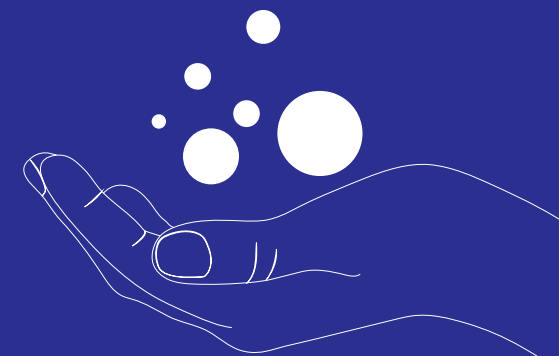


Thousands showed support worldwide

People mobilized both online and in-person to raise awareness, show support to those living with PIDs and advocate for change.



Many marked the campaign – from patients and families, specialist clinicians, research institutes, medical students, industry, to children at school, elected officials and the public – World PI Week is for everyone!



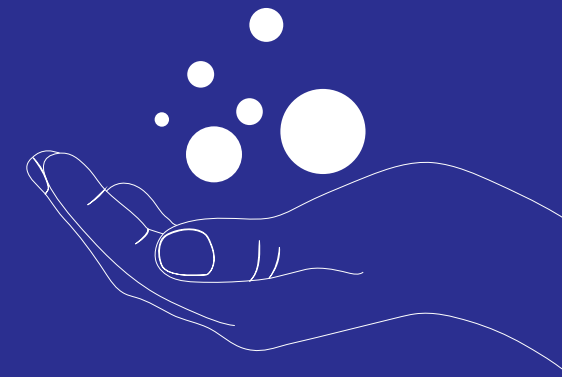
Diverse activities were held over the week

A glimpse into the dynamism of World PI Week.

- **Patient-family days** (mix of recreational activities, educational sessions, roundtable discussions)
- **Hospital open days** & information stands
- **Educational lectures/symposia for health professionals** & clinicians
- **Awareness-raising webinars/events** on PIDs (for the public)
- **'Review series' on PID research** issued in medical journals
- **Solidarity 'PID walks' and runs**
- **Blood & plasma donation drives**
- **Patient-story sharing campaigns** (digital) – videos, podcasts etc
- **Media/TV & radio interviews** with specialists or patients
- **Meetings with policymakers** (local/regional/national levels)



A variety of successful activities were observed across countries



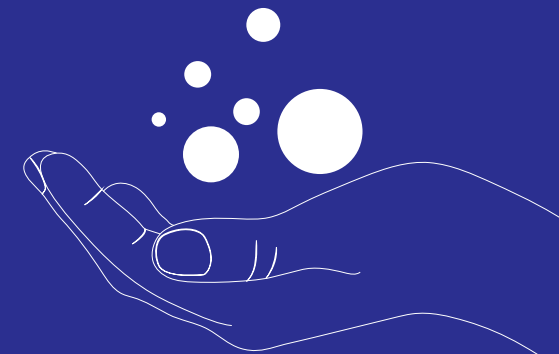
Spotlight on some inspirational initiatives

Here is a snapshot of some creative ways to mark the campaign.

- **Canada:** 13 cities & mayors showing official support to World PI Week
- **France:** one-week bike tour across main cities, to raise awareness of PIDs – **projection of a documentary film on PIDs and open debate** with the public in each city.
- **China:** awareness day at university campus for medical students
- **Türkiye:** tree-planting in several cities to raise awareness & support the PID cause
- **Colombia:** a symbolic **butterfly release** to mark World PI Week on a poetic note
- **Uganda:** Organised **media collaborations** through interviews, panels and discussions on local & national TV channels.



Innovative thinking is at the heart of the campaign!



A bespoke toolkit as a main source of information and guidance

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Access to care for all PID patients, everywhere

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

WORLD PI WEEK 2024 INFORMATION PACK



World PI Week
22-29
April 2024



Click [here](#) to download toolkit

World PI Week 2024: all about equal access to care

ACCESS TO CARE FOR ALL PID PATIENTS, EVERYWHERE

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

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

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

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

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

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

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

Key messages

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

Key priorities



² World Health Organisation. *World Health Organisation (WHO) on health in the 2030 Agenda for Sustainable Development (SDG)*. Available at: <https://apps.who.int/iris/handle/10665/131050>
³ <https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage>
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How to join World PI Week

5. TELL YOUR STORY VIA #MYPISTORY

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

6. VISIT AND CONTRIBUTE TO THE WORLD PI WEEK "WORLD MAP OF PID ADVANCEMENTS" HIGHLIGHTING SUCCESSIONS IN ADVOCACY FOR IMPROVED ACCESS TO CARE WORLDWIDE (LAUNCHING ON 22 APRIL)

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

Go the extra mile

7. CONTACT THE PRESS

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

8. SUPPORT ADVOCACY

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

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

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

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

10. DONATE PLASMA

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

Providing all necessary information about the 2024 campaign, ways to celebrate the week and access resources.

The 2024 'essentials'

An overview of the communications package

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Access to care for all PID patients, everywhere

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

Remembering Vicki Modell, global patient advocate, and co-founder of World Primary Immunodeficiency Week.

www.worldpiweek.org [@world_pi_week](#) [@WorldPIWeek](#) [@WorldPIWeekCampaign](#)



World PI Week
TEST • DIAGNOSE • TREAT
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April 2024



Click **here** to download materials

Our Global Policy Calls

World PI Week
TEST • DIAGNOSE • TREAT
22-29 APRIL 2024

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www.worldpiweek.org [@world_pi_week](#) [@WorldPIWeek](#) [@WorldPIWeekCampaign](#)

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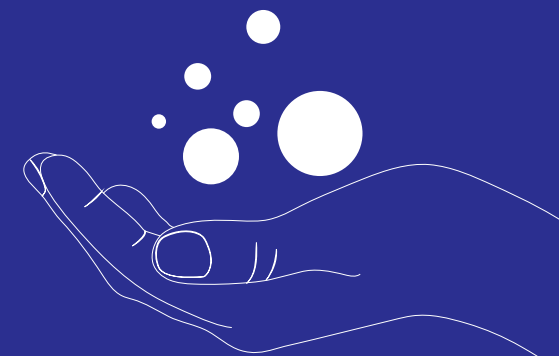
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www.worldpiweek.org [@world_pi_week](#) [@WorldPIWeek](#) [@WorldPIWeekCampaign](#)

Campaign poster, digital banners, animated social cards, press releases & more



Fostering engagement through the increased accessibility of campaign resources globally



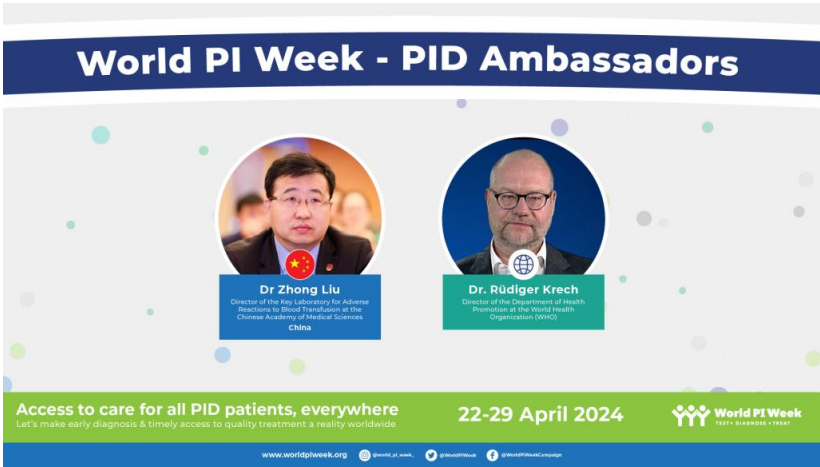
Translations available in 19 languages

- Arabic
- Chinese
- Dutch
- French
- German
- Greek
- Hindi
- Italian
- Japanese
- Malay
- Russian
- Spanish
- Swedish
- Thai
- Turkish
- Ukrainian
- Vietnamese
- Romanian
- Portuguese



Focus on the 2024 Ambassadors

World PI Week received the official support of influential voices championing the PID cause



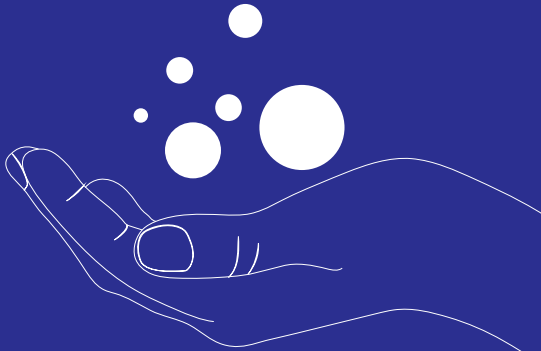
Dr Rüdiger Krech, *Director of the Department of Health Promotion, World Health Organization (WHO), Global*

Dr. Zhong Liu, *Director of the Key Laboratory for Adverse Reactions to Blood Transfusion, Chinese Academy of Medical Sciences, China*

Click on images below to watch the video messages shared by this year's PID Ambassadors!



Thanks to their work and visibility, Ambassadors help shine a spotlight on PIDs, on the unmet needs of patients and their families, while promoting solutions and fostering greater understanding across sectors and stakeholder communities



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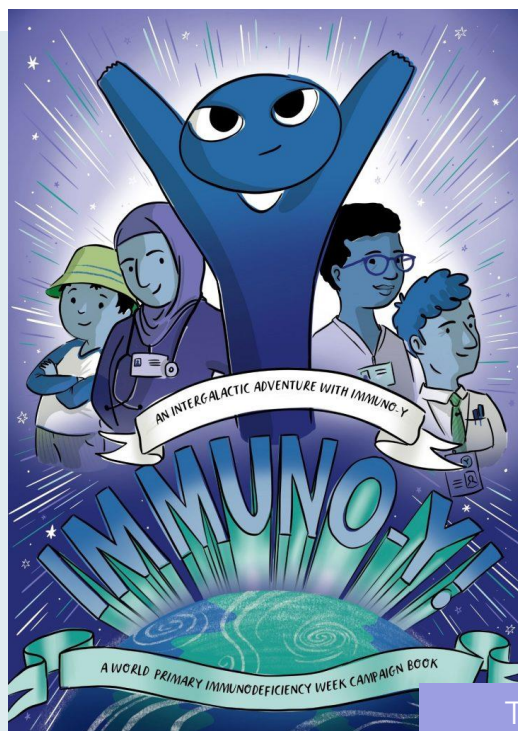


Click **here** for more in PID Ambassadors

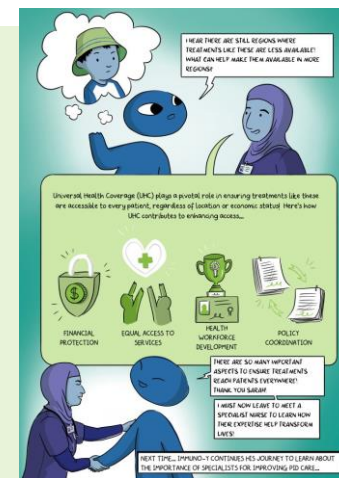
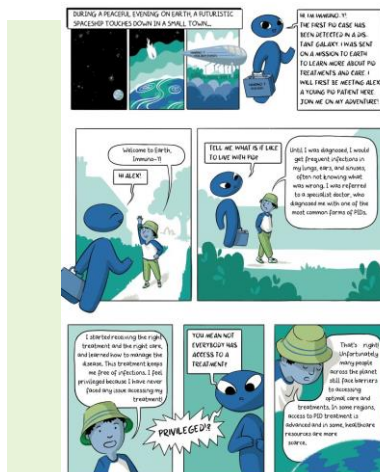
Flagship Initiative: the First Comic Book

An Intergalactic Adventure with Immuno-Y

World PI Week offered the opportunity to embark on an intergalactic journey through a digital comic book exploring access issues.

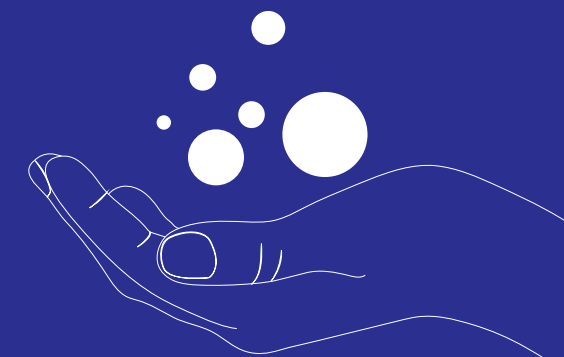


This book consists of 5 chapters, released in the lead up and during World PI Week.



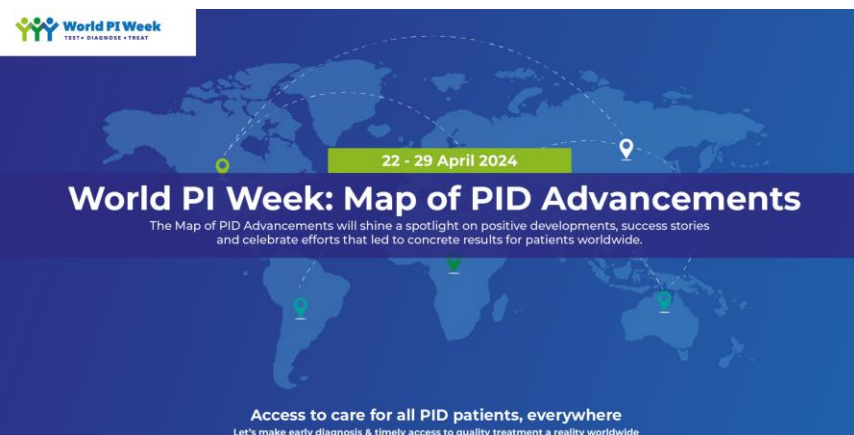
Click [here](#) to read the full comic book

Through this comic book, meet our new hero Immuno-Y as he embarks on an intergalactic journey, learning about access to treatment and care on Earth



Flagship Initiative: Map of PID Advancements

Case studies were featured daily on World PI Week social media channels.



Highlights from:

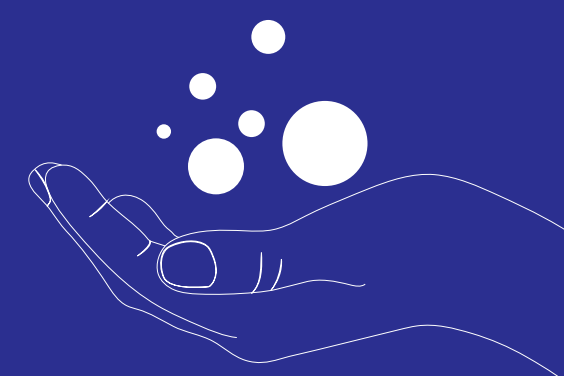
- Canada
- The United States
- Mexico
- Latin America
- Argentina
- United Kingdom
- Australia & New Zealand
- The Netherlands
- Moldova
- Morocco
- Bangladesh
- Malaysia
- Indonesia



Click here to access
Map of Advancements

*** While it does not capture the entirety of initiatives happening across the globe, this map offers a glimpse into the collective journey undertaken by stakeholders worldwide in recent years. It underscores the invaluable contributions of countless initiatives that help to improve PID care on a global scale.*

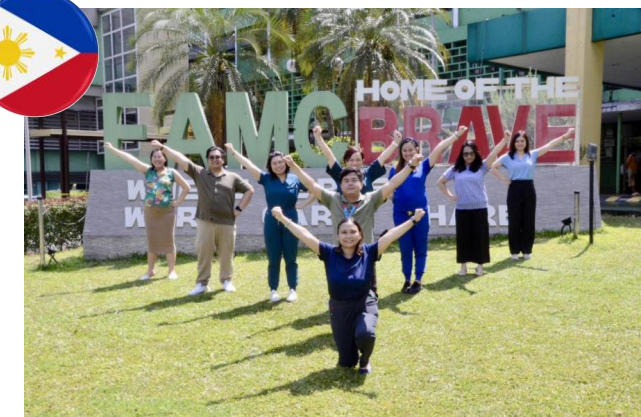
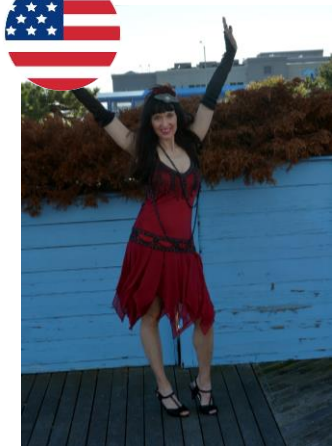
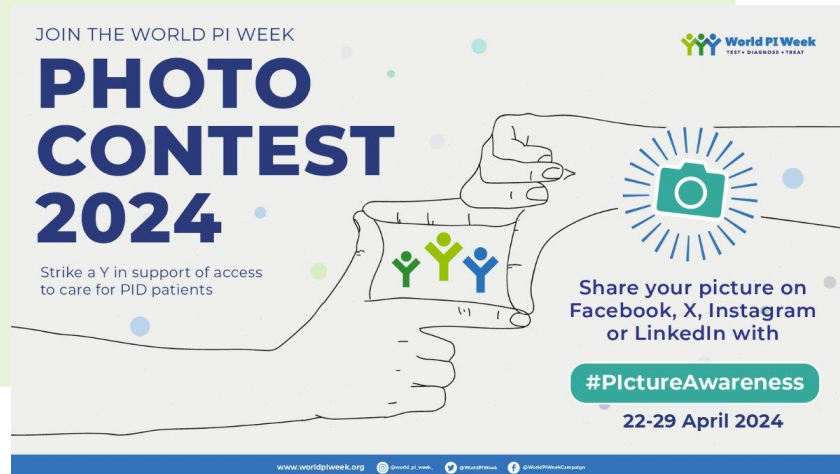
The Map of PID Advancements serves as a window into a variety of examples of best practices in awareness raising, advocacy, and policy advances that have contributed to improving access to care for individuals with PID across regions of the world.



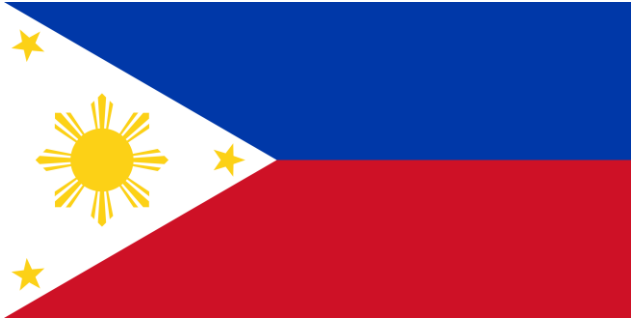
Striking a Y for World PI Week: #PictureAwareness Contest

Over the campaign week, individuals took part in the #PictureAwareness campaign, striking a Y pose to raise awareness and show support for equal access to PID care worldwide.

Let's take a look at some of the submissions!



And the winner of 2024 is: Dra. Karla Borjas



**Congratulations to
University of Santo Tomas Hospital Section of Allergy,
Asthma and Immunology from Philippines!**

*Thank you for participating and showing support to
Primary Immunodeficiency!*

#PictureAwareness



CHAPTER 3

WORLD PI WEEK 2024
DIGITAL PRESENCE



World PI Week Joins the LinkedIn Community

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PREVIOUS
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Section 1

Section 2



Access to care for all PID patients, everywhere

World PI Week
22-29 April 2024

World PI Week
TEST • DIAGNOSE • TREAT

World PI Week
22-29 April 2024

World PI Week

World PI Week (22-29 April) is a global movement to raise awareness of Primary Immunodeficiency, stimulate advocacy.

Health and Human Services • 147 followers • 51-200 employees

Message

Following

Home

About

Posts

Jobs

People

Insights

Overview

World PI Week, celebrated every year during 22-29 April, offers an opportunity to inform and educate health policy-makers, schools and families, and the general public about primary immunodeficiencies (PI / PID) to drive the earliest possible diagnosis and optimal treatment.

Through events and activities promoting the warning signs of PI, the global PI community can unite to bring about positive changes in healthcare systems and practices around the world in support of people living with PI.

Website
<http://www.worldpiweek.org/>

Industry
Health and Human Services



Click here to access LinkedIn page

World PI Week
147 followers
1mo •

Reflecting on the incredible ways we celebrated World PI Week 2024! 🎉
Here's a glimpse of what we achieved:

Access to care for all PID patients, everywhere

World PI Week
22-29 April 2024

Campaign messaging

#WorldPIWeek

Summary narrative

World PI Week - PID Ambassadors

Thomas R. Kreil and 5 others

1 repost

World PI Week
147 followers
1mo •

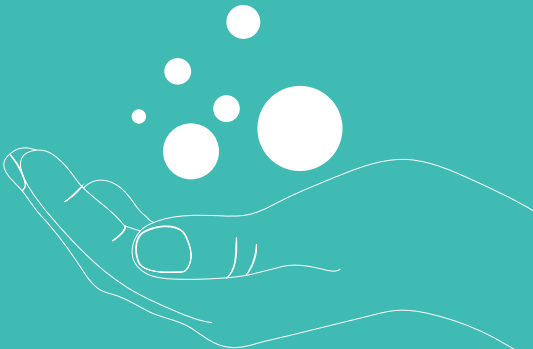
Chapter 3 of our #WorldPIWeek comic book is HERE! 📖
Join Immuno-Y on his intergalactic adventure as he meets Elena, a spe ...see more

IMMUNO-Y

IMMUNO-Y

Yves Brand and 11 others

This year, to maximise reach and galvanize global awareness, World PI Week launched a dedicated page on LinkedIn. Follow the campaign online!



An Overview of Social Media Milestones

Driving conversations, knowledge and mobilising to raise awareness of PIDs throughout and beyond the campaign.



Section 1

Section 2



+50 new followers
2.2K likes
1.5K page visits
2.7K average reach per day



+120 followers
+300 posts shared
+8,885 impressions (97,4% increase)
+15K profile visits



+9,5% new followers
+52 posts shared
+80 stories shared
+15,6K reach in April



+147 followers
+76 posts shared
+6,753 impressions
+200 profile visits

In 2024 World PI Week reached a great level of engagement on social media since the inception of the campaign!



Campaign Website: Increased Performance



+5.6K New Users

+300k Total impressions

+15 News Updates Shared

Twitter + Instagram
Top social referrals

The World PI Week website provides a dynamic platform for the community to access latest updates, download essential materials, share their personal stories; and for the general public to learn more about PIDs and ways to mark the Week.

World PI Week 2024 in The Media

PID issues and patient stories were covered in local and national print and online media outlets during and around World PI Week.

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Bellenblazen voor personen met afweerstoornis: "Aandacht vragen voor elke onzichtbare ziekte"



Wim De Geest in de Londense National Gallery met zijn dochter Mirte die met het onzichtbare Vervyckt

Awareness is key for aiding early diagnosis, treatment of Primary Immunodeficiency Disorders in children: experts

In line with World Primary Immunodeficiency Week observed from April 22 to 29, doctors of Apollo Cancer Centres in Chennai raised the need for awareness and delved into the challenges posed by PIDs

April 30, 2024 04:05 pm | Updated 04:05 pm IST - CHENNAI



Partner

Unmasking Primary Immune Disorders: ACC spearheads raising awareness and the battle against PIDs

Early diagnosis and treatment can help PIDs-affected children to lead a good quality life



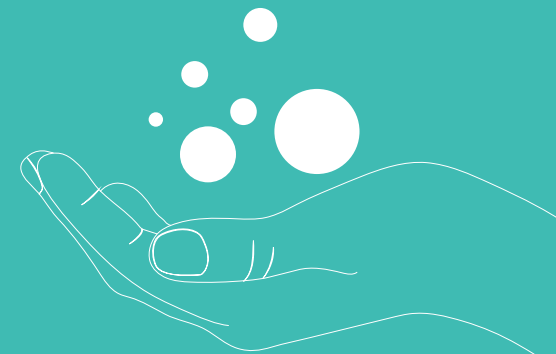
CHU : une soirée ciné-débat sur les déficits immunitaires primitifs le 22 mai

Matteo Pellegrinuzzi viendra présenter un documentaire poignant sur le déficit immunitaire primaire, une maladie grave qui empêche l'organisme de se défendre contre les virus, bactéries et microbes.

Le Progrès - 13 mai 2024 à 06:00 - Temps de lecture : 2 min



Matteo Pellegrinuzzi parcourt la région à vélo pendant une semaine afin de présenter le film dans plusieurs grandes villes. Photo fournie par Matteo Pellegrinuzzi



Country Involvement Globally

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54 countries reported participation to World PI Week 2024 as of May



CHAPTER 4

SNAPSHOTS OF NATIONAL EVENTS



Algeria



PREVIOUS



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COMING SOON!

Argentina



Association de Ayuda al Paciente con Inmunodeficiencia Primaria (AAPIDP)

- 4th Virtual Congress covering the issues of vaccination and guaranteeing access to health care in current times.
- Social campaign with a new video of warning signs, QUIZ, key testimonials from patients, care givers and also educational awareness material
 - Shared with #MiHistorialDP, #MYPIStory



Click to see more



Australia



Immune Deficiency Foundation of Australia (IDFA)



- Radio interview with Carolyn Dews, IDFA CEO, on ABC Illawarra to increase awareness of PIDs.
- Community Insights Event to exchange experiences “Your Story”
- Social media presence



Click to see more

Buy your ticket to Make a Difference to People Living with PI during World PI Week!

Your donation will help us raise awareness about immunodeficiencies, promote access to early testing, and support community members suffering or caring for someone with immunodeficiencies through support groups.

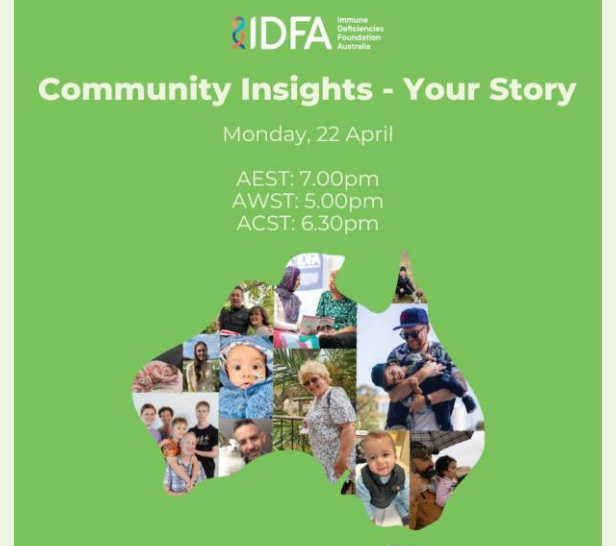
Primary immunodeficiencies are rare diseases that occur when a person's immune system is absent or does not function properly. When a defect in the immune system is inherited (car... See more



RAFFLES.BOLSTA.CO

The Immune Deficiency Foundation of Australia Limited

Buy raffle tickets for your chance to win



Australia



Immune Deficiency Foundation of Australia (IDFA)



- Radio interview with Emily Edwards, Vice President of AusPIPS Inc. and Dr. Shane to increase awareness on PIDs
- Raffle to raise awareness and promote access to early testing
- World PI Week Raffle to collect donations
- Social media presence



Click to see more



AusPIPS Inc.
29 April · 🌐

Today marks the Day of Immunology learn abit more about the immune system and how it is different in Primary Immunodeficiency with the [World PI Week](#) comic.



WORLDPIWEEK.ORG

Comic Book - World PI Week

Discover our comic book: An intergalactic adventure with Immuno-Y In our first comic book for World PI Week, we invite you to join Immuno-Y as he delves into the world of Primary Immunodeficiency. After the discovery of the first PID case in a distant galaxy Immuno-Y embarks on a quest to unravel th...



AusPIPS Inc.
28 April · 🌐

Today our Vice president a medical researcher in the field of Primary Immunodeficiencies joined Dr Shane on Triple R - 3RRR 102.7FM Einstein ago go to raise awareness of this rare disease as part of World Primary Immunodeficiency Week. [#WorldPIWeek](#) Immune Deficiency Foundation of Australia (IDFA) IDFNZ Kids Foundation Australasian Society of Clinical Immunology and Allergy



RRR.ORG.AU

Shared moment from Einstein A Go-Go – 28 April 2024 — Triple R 102.7FM, Melbourne Independent Radio

Austria



ÖSPID - Österreichische Selbsthilfegruppe für primäre Immundefekte

- Hosted an information session for the public and aimed at sparking a discourse on PIDs
- Story sharing campaign – spotlight on personal stories



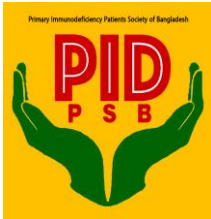
Click to see more

April 2024

Worldwide Immunodeficiency Week. We were on site in Villach and, in addition to many personal conversations, were once again able to clarify and provide information.



Bangladesh

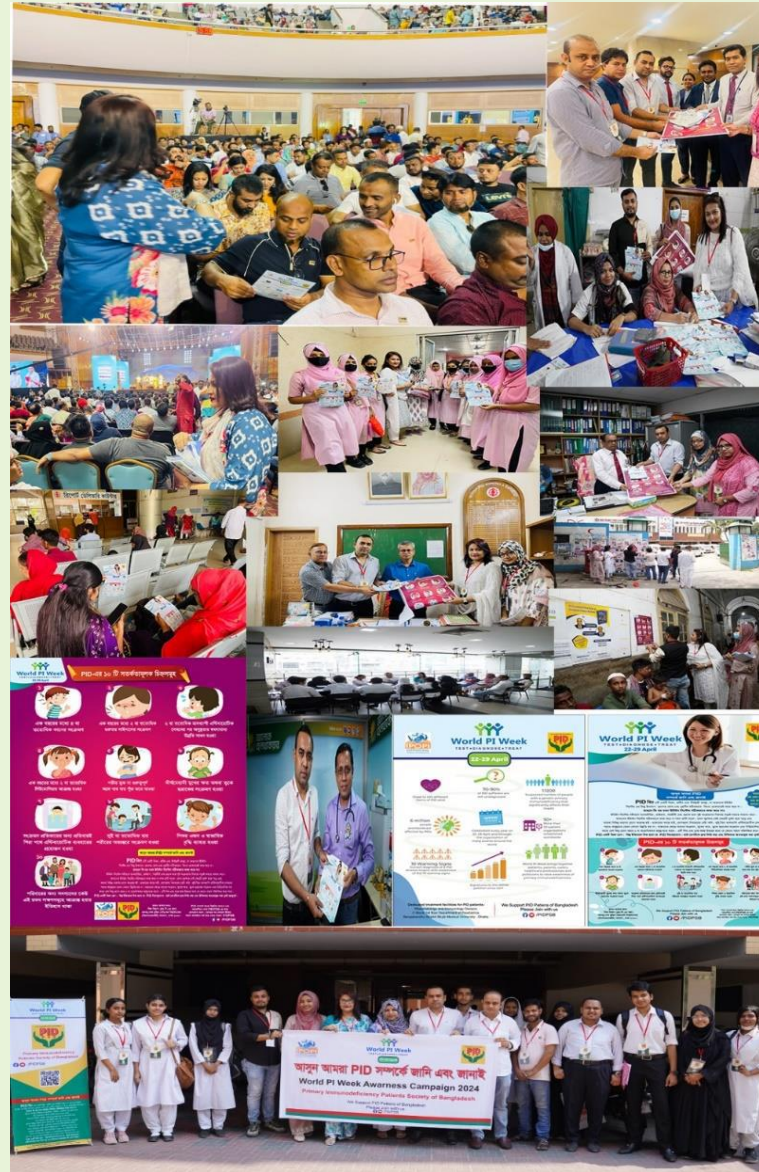


Primary Immunodeficiency Patients Society of Bangladesh (PIDPSB)

- Tour of 52 hospitals, dispatching over 3000 flyers, 1000 posters
- Featured a campaign in bringing 2000 professionals of Bangladesh
- Produced materials featuring doctors, artists, PID patients for social media platforms
- Distributed 6000 copies of the « 10 warning signs of PIDs » across Bangladesh
- Series of discussions on PIDs with influencers, healthcare professionals



Click to see more



Belarus



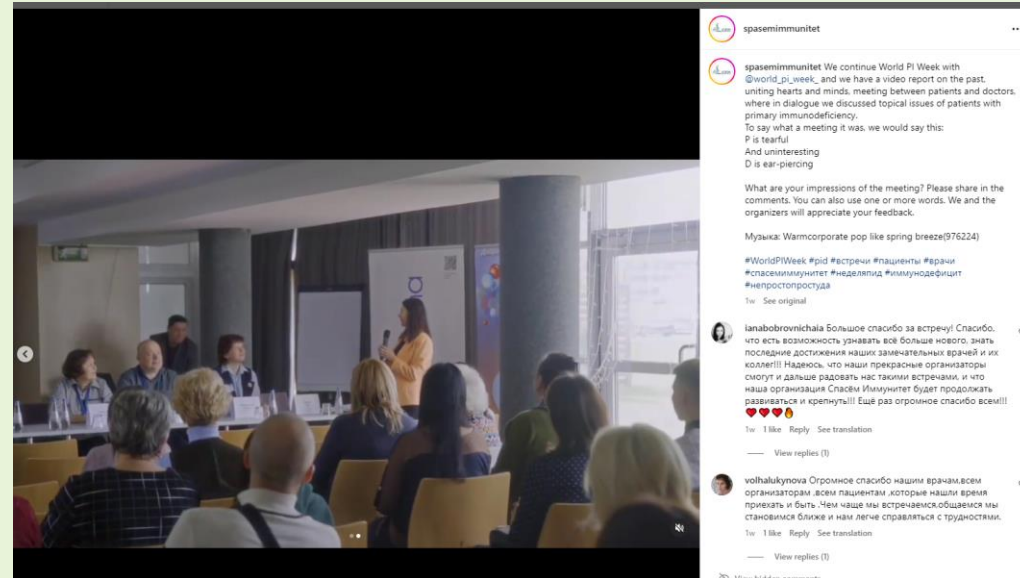
Спасем иммунитет – Save Immunity



- Annual patient meeting including healthcare professionals, organisation presidents and patients
 - Included a master class on painting for children
- Social media campaign about PID



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Belgium



Bubble ID



- Information stands at hospitals around in Belgium
 - With doctors and specialists to answer questions
 - Fundraising activities
- PID family day bringing together patients and families and to increase knowledge on PIDs.



Click to see more



Belgium



Belgian patient organisation for
primary immunodeficiencies



**Belgian patient organisation
for primary
immunodeficiencies (BePopi)**



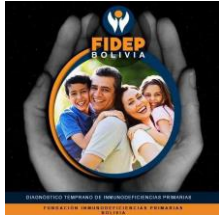
- Held a campaign called #Burstthebubble where patients, medical staff, friends and family blew bubbles in 6 hospitals in key cities.
- Piloted the first PID Cafe in Brussels where patients, family & friends received information on PIDs through lectures and in writing.
- Established a chat group for supporting each other and started the first close-knit offline PID community in Belgium.
- Disseminated interviews about on PID on social media



[Click to see more](#)



Bolivia



FIDEP – BOLIVIA (patient organisation)



- Educational campaign on PI with awareness-raising videos
- Planning of the 5th International Days of Primary Immunodeficiencies (23-24 May 2024)
- Open information day



Click to see more



VI JORNADAS INTERNACIONALES DE INMUNODEFICIENCIAS PRIMARIAS
Resolución ministerial N° 0109

Auditorio UNIVALLE
Ing. Gonzalo Ruiz Martínez
Torre Académica América
Av. América N° 165
Cochabamba - Bolivia

DIRIGIDO A

- Pediatras
- Médicos Generales
- Médicos internistas
- Inmunólogos
- Alergólogos
- Bioquímicos
- Estudiantes de medicina y Residentes

TEMAS

- ¿Dónde se encuentra y cuál es la función del Sistema inmunológico?
- Enfermedades autoinmunes y auto inflamatorias
- Nuevas herramientas diagnósticas para inmunodeficiencias primarias Autoinmunidad y alergias
- Manifestaciones gastrointestinales, dermatológicas, oftalmológicas y respiratorias
- Presentación de casos clínicos

Registro:

MÉDICOS DISERTANTES INTERNACIONALES

QR Pago:

Confirmar asistencia a: fidep.bolivia@gmail.com
Teléfonos de contacto: 751 191 19/ 72768765/
SE ENTREGARÁ CERTIFICADO DE ASISTENCIA CON CARGA CURRICULAR Y RESOLUCIÓN MINISTERIAL

panzyga **octapharma** **Bagó**

What are Primary Immunodeficiencies?
IDP's Global Campaign
FOCUS ON IT!
#WorldPIWeek
#IPOPI
#semanamundialidp
#primaryimmunodeficiencies
#primaryimmunodeficiency
#InmunodeficienciasPrimarias
* See original · Rate this translation



Brazil



ASBAI - Associação Brasileira de Alergia e Imunologia

&

BRAGID - Grupo Brasileiro de Imunodeficiências

- ASBAI-BRAGID Online Day Event with expert panels, lectures and more
- ASBAI: Article on expert answering questions on plasma



Brazil



Eu Luto Pela Imuno Brasil (ELPIB)

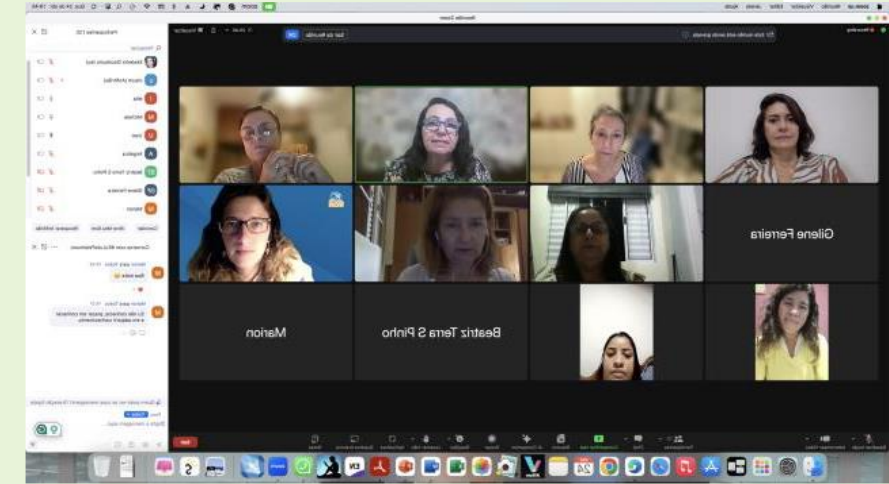
- Each association member received a set of 10 IPOPI educational booklets translated into Brazilian Portuguese which are available also on their website.
- Held an online meeting to inform patients about the association activities.
- Galvanized great movement on social media throughout April with informative posts and patient testimonials



Click to see more



Bom dia !!! Gratidão acabei de receber 🥰



Canada



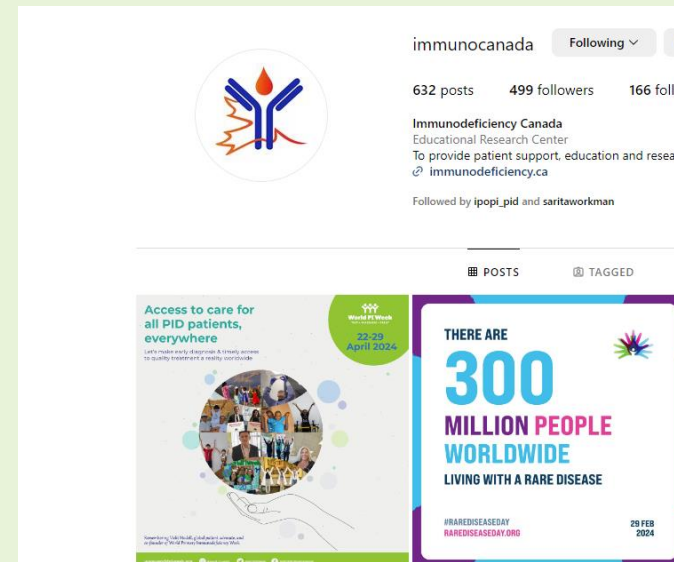
Immunodeficiency Canada



- Hosted online Awareness raising events (webinars) to increase understanding of PIDs
- World PI Week Access Campaign Webinar
- National CommUnity Connect Groups (connecting patients and families/caregivers to share experiences and support)
- Social media presence



Click to see more



Canada



ImmUnity Canada



- Worked with volunteers to obtain official declarations of WPIW in 13 cities and 1 province across Canada
- The executive Director hosted a webinar on advocacy and getting involved to support the community
- Initiated a campaign for members to talk about the importance of access which will continue throughout the year at their regional education events and community walks.



[Click to see more](#)



Chile



Fundación IDP Chile



- Organized a virtual meeting with patients, doctors and the foundation
- Distributed IPOPI flyers in different hospitals in Santiago and created a box for patients with a medical agenda along with informative pamphlet on PID
- World Primary Immunodeficiency Week – Access Campaign Webinar
- Hosted an in-person meeting for the patients.



[Click to see more](#)



China



PID Care China

- Hosted a public education campaign at the China Pharmaceutical University.
 - The student union designed PID promotion for university public welfare campaigns to educate medical students
- Positive coverage by 15 Chinese media outlets
- Held a quiz with 10 questions on PID and offered gifts to attendees with correct answers
- Opening of "Disease Awareness Week" at the Xiangyao Building of the Jiangning Campus of China Pharmaceutical University
 - Jointly organised by the Koude Rare Disease Center and the PID Fuel Baby Care Center
 - Included exhibition of people in plastic 'bubbles' (in reference to the "Bubble Boy")



Colombia



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

- “Transforming Lives” community activity to celebrate World PI Week
- Butterfly Release activity Celebrating World PI Week
- Video on PIDs featuring experts in collaboration with Jeffrey Modell Foundation



Click to see more



Cyprus



Ομάδα Ατόμων με Συγγενή Ανοσοανεπάρκεια και Φίλων

- Information Event "Rare Diseases - Patient Experiences"
 - the speakers were given the opportunity to give the stigma about the prevailing situation in the field of rare diseases in Cyprus
- The adult ensemble of the conservatory organised an event with the Music Café "All Together We Can" where music was played for 6 hours covering Greek songs.
- Social media presence through sharing rare disease patients' experiences



Click to see more



Ecuador



Fundación PIDE, de Pacientes con Inmunodeficiencias Primarias Ecuador

- Held the 2nd National Symposium "Talking about PID in Ecuador" involving medical students, specialist doctors, PID patients & families and the Ministry of Public Health of Ecuador
- Conducted dissemination workshops in third-level hospitals & universities in 4 cities.
- Created short films with medical students from the Central University of Ecuador with 9 PID patients.
- Social media campaign patient testimonials attracting the attention of major universities



Click to see more



El Salvador



Fundación Escudo de Amor para las IDP El Salvador



- Social media presence



Click to see more



Estonia



Eesti Primaarse
Immuunpuudulikkusega
Patsientide Ühing



PIDESTONIA – Eesti Primaarse Immuunpuudulikkusega Patsientide Ühing



- Held a display of WPIW in 4 libraries to raise awareness
- Held 6 presentations on PID in 2 higher education institutions teaching healthcare professionals where association president shared her personal experiences.
- Held an important meeting with the Social Committee of the Parliament discussing the supply of medicines & treatment of each PID patient, highlighting ways to address challenges.
- Social media campaign: Information campaign PID



Click to see more

PRIMAARSE IMMUUNPUUDULIKKUSE 10 OHUMÄRKI

2 või enam kuud
antibiootikumiravi
olulise efektita.



Korduvad sügavad
naha- ja siseorganite
mädapõletikud.

Infektsioonide
kontrollimiseks
vajalik ravi
veenisiseste
antibiootikumidega.

4 või enam ägedat
keskkõrvapõletikku
aastas.



2 või enam ägedat
põskkoopa põletikku
aastas.



RAVI

Immuunpuudulikkusega **patsientide elu on suuresti doonorite kätes**. Ravis asendatakse kõige sagedamini antikehi, **manustades doonoriverest valmistatud immunoglobuliini-preparaate**.

Immunoglobuliinid ehk IGD valmistatakse inimese plasmasest. **IG-d asendavad immuunsüsteemis puuduvaid kaitsvaid antikehi**, ilma milleta oleksid patsiendid alati korduvatele ja rasketele infektsioonidele. Neid võib manustada kas intravenoosselt või subkutaanselt.

#WORLDPIWEEK



France



Association IRIS

- "Connected run" – encouraging people to run, walk, cycle in support of people living with PIDs
- Projection of a documentary film on PIDs titled "Immunity" at the University Hospital
 - Stories of 4 PID patients, who share their fears and fights, and discuss how PID impacts their family, social and work lives.
- Public debate with the President of IRIS, who did a bike tour across several French cities during the campaign, to organise conversations and raise awareness of PIDs.



Click to see more

Du 22 au 29 avril
Semaine mondiale des DIP

Course
connectée

2024

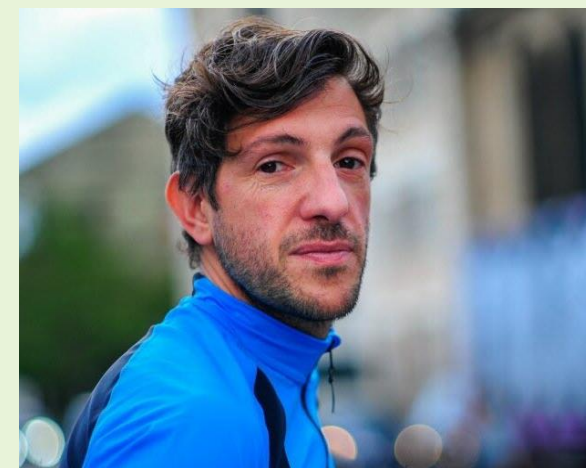


soutenir

Semaine mondiale des DIP

World PI Week
TEST • DIAGNOSE • TREAT

Chaque année du **22 au 29 avril** se tient la semaine mondiale des DIP. Il s'agit d'un mouvement international qui vise à **sensibiliser** à la maladie et à **promouvoir** la qualité de vie des patients. En 2024, l'accès aux soins, à un traitement adapté et au diagnostic précoce a été érigé en slogan. Toutes les organisations mondiales mobilisées pour les DIP s'associent à cette semaine importante. Du côté d'IRIS, c'est l'occasion de faire du bruit et de rendre visible nos maladies par le biais de la course connectée !



Germany



Defektes Immunsystem?
Starke Patientenorganisation!



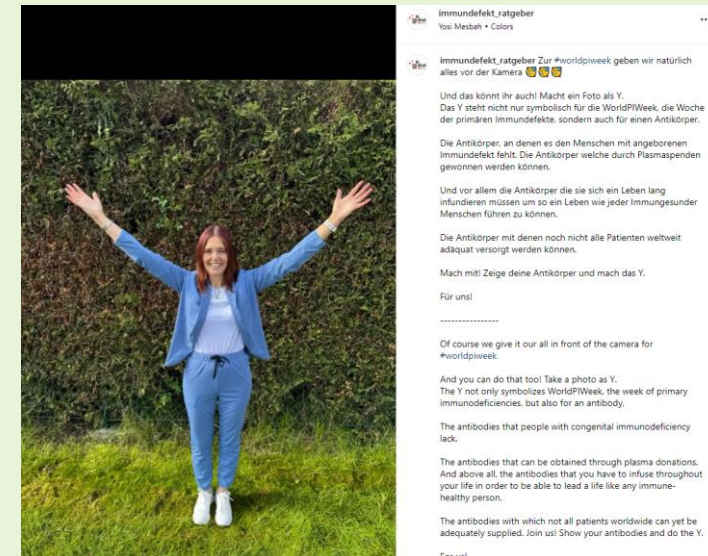
Immundefekt - dsai e.V. hilft



- “Immunity explained” cartoon.
 - A short video explaining what PIDs are.
 - Posted on their Facebook page.
- Social media campaign
 - Sharing practical information online
 - Sharing patient stories



Click to see more



Greece



GALINOS – Immune Deficiency Association of Greece



- Organised a 2-day conference on PIDs where over 60 patients & families, physicians, pharmaceutical & local government representatives participated.
 - Theme: “The Patient at the centre of the solution”
 - Panel discussion on the value of genetic testing in patients with PI
 - Discussion and exchange of experiences of living with PID
- Received local TV coverage with interviews



[Click to see more](#)



Honduras



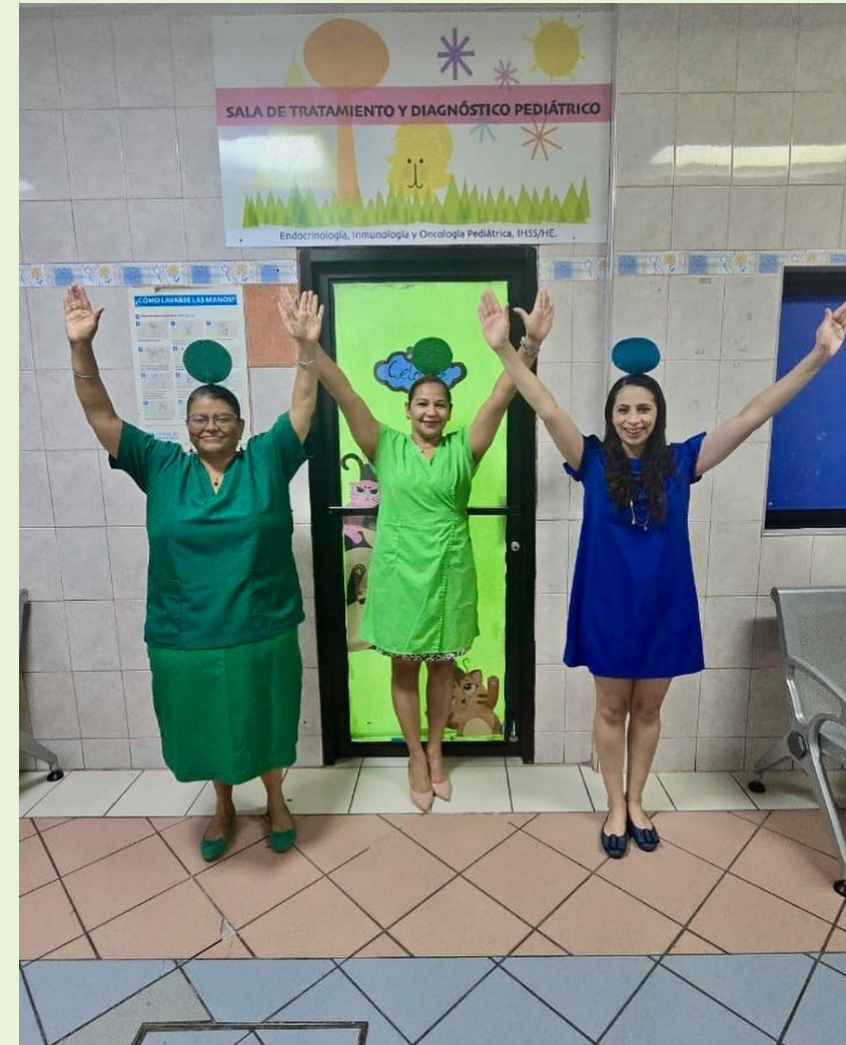
Hospital Infantil Privado



- Participation in #PictureAwareness contest by Dr. Karla
 - Selected as the winner of the 2024 campaign



Click to see more



Hungary

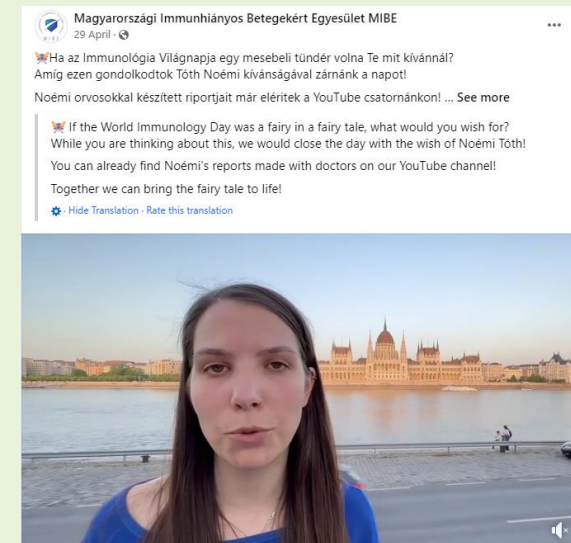


Magyarországi Immunhiányos Betegekért Egyesület MIBE

- Disseminated educational materials to introduce treatment in clinics & centres in different regions in Hungary.
- Filmed a series of videos on multiple PID related topics featuring specialists.
 - Connected the community of patients with doctors via a Q&A session.
- Commemorating plasma donors
- Social media presence



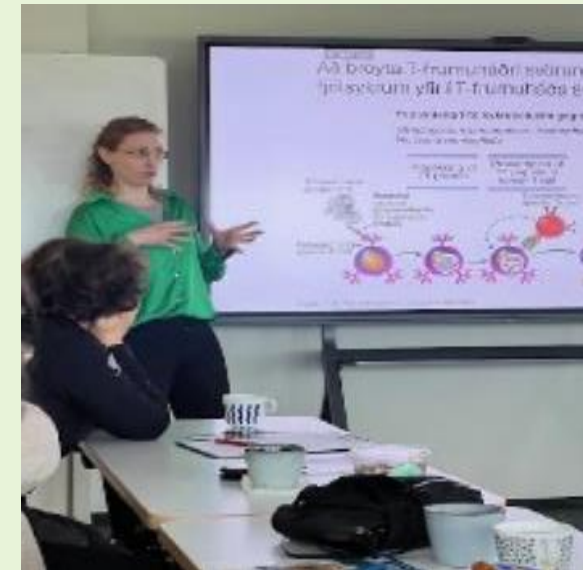
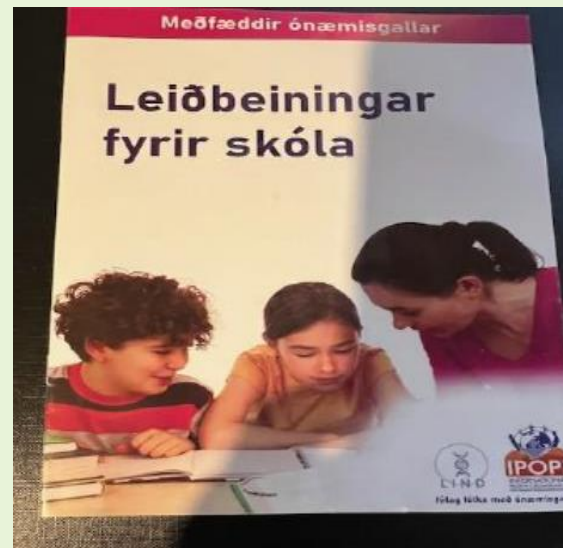
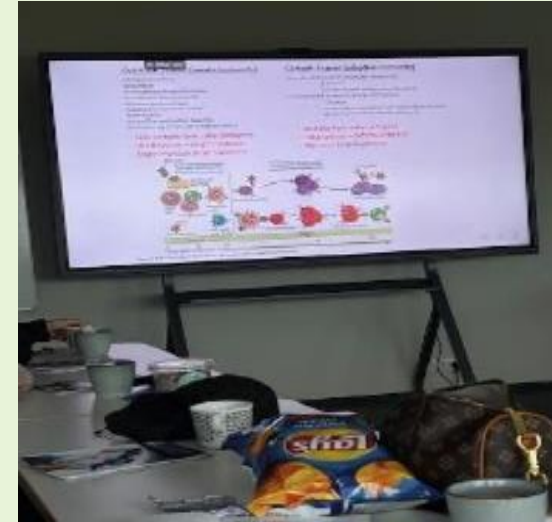
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Iceland

Lind Iceland

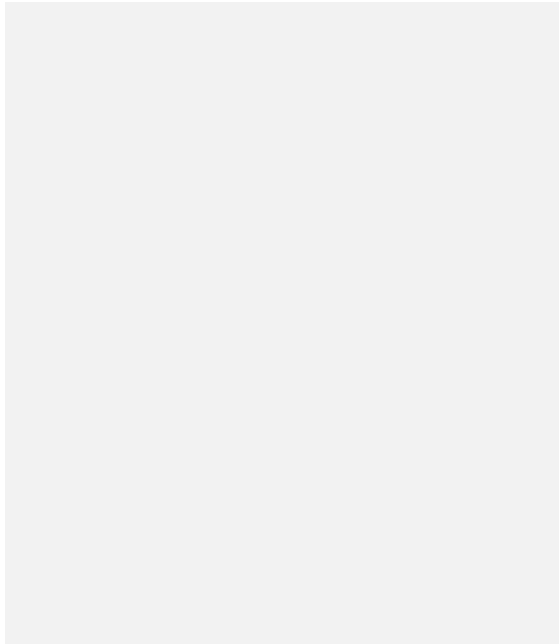
- Held educational meeting for practical nurses covering two sessions on:
 - What is immune system and how it works
 - Treatments & care
- Published a brochure guide for schools and distributed it to all school nurses & children departments in the hospitals.



India



**IPSPI - Indian Patients Society
for Primary Immunodeficiency**



COMING SOON!

Indonesia



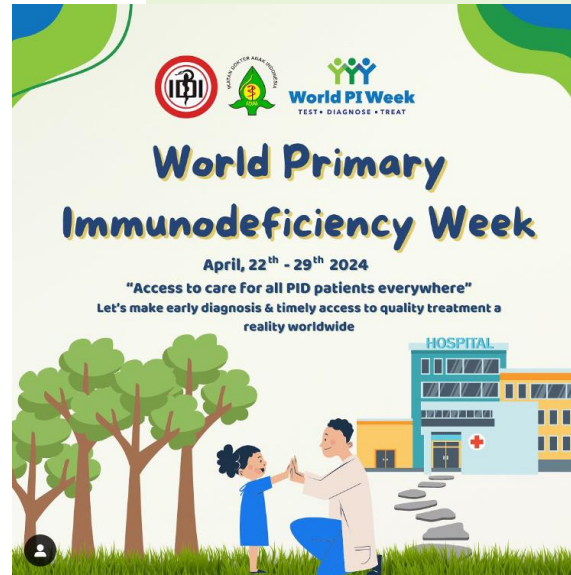
IDAI Ikatan Dokter Anak Indonesia
Indonesian Pediatric Society
Committed in Improving the Health of Indonesian Children

IDAI - Ikatan Dokter Anak Indonesia

- Organised online symposium on Primary Immunodeficiency




Click to see more




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

Primary Immunodeficiency: Beyond Infection

Narasumber


dr. Rizqi Amalia, Sp.A(K)
Anggota UKK Alergi
Imunologi IDAI

Moderator



dr. Endah Citraresmi, Sp.A(K)
Pengurus Pusat IDAI

Rabu, 24 April 2024
13.00–14.00 WIB

Daftar pada tautan berikut:
<https://idaismo.id>
Tutorial: bit.ly/idaismo_tutorial

Acara ini dapat diikuti oleh dokter umum dan dokter spesialis anak

Scan disini:



Iran



Immunodeficiency Patients Advocacy Association (IDPA)



IDPA – Immunodeficiency Patient Advocacy Association



- Interview with the vice president of the Immunology, Asthma and Allergy Research Center on the occasion of the WPIW– answering questions about their activities, and about PID



Click to see more



Iran



@ Iranian Primary Immunodeficiency Association (IPIA)

- Held the 15th International Congress on Immunodeficiency Diseases for paediatric immunologists, paediatricians, nurses, students, patients & families.
 - Featured 51 lectures in 2 days
 - Celebrated 25th year of IPIA where 400 delegates attended
 - Announced the new had of the association.

15th International Congress on Immunodeficiency Diseases (ICID)

April 25,26- 2024
Children's Medical Center,
Tehran, Iran

In-person Congress

rcidcong.tums.ac.ir
info.rcidcong@gmail.com
+98 (21) 66129187

Research Center for Immunodeficiencies (RCID)



Ireland

Sláinte Leanaí Éireann
ag Sráid an Teampaill



Children's Health Ireland
at Temple Street



Children's Health Ireland



- Awareness raising campaign
 - 10 warning signs
 - Focus on children



Click to see more



Children's Health Ireland
@CHI_Ireland

Follow

It is [#WorldPIWeek](#)! CHI is raising awareness for Primary Immunodeficiencies.

PI are rare diseases that cause children and adults to have infections that come back frequently or are unusually hard to cure.

Here are some warning signs of PI [ipia.info/10-warning-sig...](https://ipia.info/10-warning-signs/)



newchildrenshospital and 8 others

3:57 PM · Apr 27, 2023 · 4,822 Views

Ireland



Irish primary immunodeficiencies association (IPIA)

- Children and adult patients were visited by their immunologists at Main Dublin Hospitals
- Hosted activities in a stand at James' Hospital where promotional items including tattoos, treats, brochures, balloons and posters were distributed.



[Click to see more](#)



Israel



Bubble Care

- PID short video series featuring patients and health care professionals
- Held the first ever PID patients' conference bringing together 70 participants including immunologists, PID patients, carers.
- The lectures at the conference were filmed to be made available online.
- Published an article in a popular magazine
- Social media presence
 - Created the association presence in Youtube



Click to see more





San Raffaele Telethon Institute for Gene Therapy (SR-Tiget)

- Patient story sharing – focus on the journey to receiving a gene therapy treatment
 - Story of an Argentinian family with twins, who both live with PID
 - Explains the family journey of finding a suitable treatment and the experience of receiving a gene therapy at the San Raffaele Telethon Institute for Gene Therapy in Milan.



Click to see more



Two Twin Girls, Same Destination: The Future

San Raffaele Telethon Institute for Gene Therapy (SR-Tiget) on LinkedIn • 4 min read



Associazione Immunodeficienze Primitive (AIP)

- Created a new comic episode of "The Adventure of Lino Globulino"
 - Explained the functioning of Newborn Screening
 - Published on the association website and social media platforms.
- Disseminated a press release via emails and association website.



Click to see more



Japan



PID Tsubasa no Kai

- Organised an “in-person” family day which was attended by 12 participants
- “What are people doing?” themed patients & families meeting to increase awareness.
- Social media presence
- Advocacy campaign to encourage blood/plasma donations
 - Video featuring patients expressing their thoughts on plasma donations and why these are important



Click to see more



NPO法人PIDつばさの会 PIDTsubasa-no-Kai @PID_Tsubasa · Apr 29

【献血にご協力ください】一部のPID患者の治療に使われる免疫グロブリン製剤は献血によって支えられています。献血にご協力いただいている方へ心より感謝申し上げます。PID患者の献血に対する思いをこちらの動画でお聞きたいだけです。 youtu.be/F7gLn33lg9w?fe... #WorldPIWeek



youtube.com

献血の先にある、感動を知っていますか？【ダイジェスト】
確認用のため限定公開善意の献血から作られる”血漿分画製剤”という「くすり」について紹介していま...



2

7

234



NPO法人PIDつばさの会 PIDTsubasa-no-Kai @PID_Tsubasa · Apr 27

【患者会】PIDつばさの会は、PID患者と家族を支援する会です。日頃のちょっとした「他の人はどうしているのかな？」という疑問から情報交換まで患者や家族が気軽に交流できる会を目指しています。ご興味ある方はホームページのお問い合わせフォームよりご連絡ください。 #WorldPIWeek



Kenya



PIDs Kenya – Primary Immunodeficiencies Association Kenya

- Webinar: “Rare but there – Primary Immunodeficiencies Demystified”
- Social media presence



Click to see more

KNH - UoN Webinar

Rare Disease Series



Thursday 25th April 2024 | 2:00pm- 3:30pm (EAT)

RARE BUT THERE - PRIMARY IMMUNODEFICIENCIES DEMYSTIFIED



Speaker

Dr. Anne Barasa
Pathologist & Lecturer, UoN.
President, African Society for Immune Deficiencies



Speaker

Hellen Ayaga
Lawyer, Patient Representative and
Mother to a child with a primary immunodeficiency



Moderator

Cynthia Olotch
Infrastructure Lawyer & Founder,
Primary Immunodeficiencies Association, Kenya

Discussions & Insights

- Introduction to PIDs
- Diagnosis of PIDs
- Treatment strategies
- Patient Perspectives





Event is CPD Accredited

[Click Here to Register](#)

Follow Us on Our Social Media Platforms    @knhresearch

Lithuania



Lithuanian society for primary immunodeficiencies (IMUNAS)



- Prof. Laura Malinauskienė was interviewed at the TV show “Good Morning” at the state TV channel LRT as well as was hosted at the radio show “Experts Suggests”
- Held the annual patients’ meetings in Vilnius featuring lectures held by medical advisors.
- Organised a live press conference “Primary Immunodeficiencies – a verdict or a possibility?”
 - The conference had a wide media coverage including a press release.



Malaysia

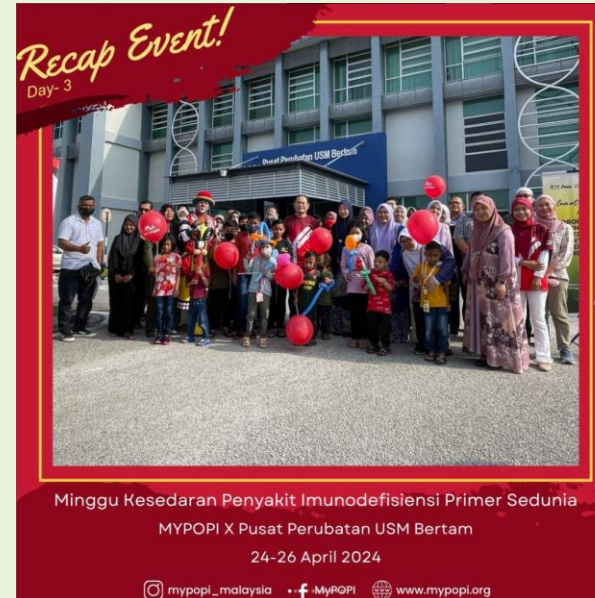


MyPOPI - Persatuan Pesakit Imunodefisiensi Primer Malaysia

- 3-day collaboration with the USM Bertam Medical Centre and the Ministry of Health Malaysia
 - Educational meetings
 - Exhibition Booth
 - Series of learning webinars for doctors
 - Blood collection stand
- Social media engagement



Click to see more



Minggu Kesedaran Penyakit Imunodefisiensi Primer Sedunia
MYPOPI X Pusat Perubatan USM Bertam
24-26 April 2024

mypopi_malaysia • MyPOPI www.mypopi.org

Program Minggu Kesedaran Penyakit Imunodefisiensi Primer Sedunia Pusat Perubatan USM Bertam (PPUSMB) 2024		
24 th hingga 26 th April 2024		
Pengenalan		
Pusat Perubatan USM Bertam terus berkomitmen dalam membantu masyarakat dengan menawarkan Perkhidmatan Rawatan dan Diagnostik Penyakit Imunodefisiensi Primer (PID). Penyakit ini merupakan sejenis Penyakit Kurang Daya Imun sejak lahir disebabkan beberapa faktor antaranya genetik hingga menyebabkan penghidapnya mudah jatuh sakit, sekarang terdedah kepada sebarang kuman dan virus. Difahami, seorang pesakit akan berhadapan dengan penyakit ini bagi setiap 58,000 kelahiran. Di Malaysia tidak banyak hospital yang menawarkan perkhidmatan PID dan PPUSMB menjadi tempat pakar rujukan serta mempunyai fasiliti dalam membantu masyarakat. Menyedari masih ramai yang tidak mengetahui mengenai penyakit ini boleh memberi ancaman maut jika tidak diubati maka Program minggu Kesedaran Penyakit PID Sedunia dianjurkan, bertujuan untuk meningkatkan kesedaran orang ramai terhadap penyakit PID. Bersama kita meningkatkan kesedaran berkaitan penyakit ini.		
TARIKH	MASA	AKTIVITI
24 th April 2024 (Rabu)	1230 - 1330	Online Webex Webinar CME Tajuk : Introduction to Primary Immunodeficiency Disease (PID) Penceramah : Dr. Sangeetha Srinivas Consultant in Pediatric Infectious Disease and Immunology Hospital Tunku Azizah (Women and Children Hospital Kuala Lumpur) Moderator : Dr. Intan Juliana Abd Hamid Paediatrician, Immunology and Allergic Specialist Pusat Perubatan USM Bertam (PPUSMB) Universiti Sains Malaysia
25 th April 2024 (Khamis)	1230 - 1330	Online Webex Webinar CME Tajuk : Current Advance in PID Management Penceramah : Dr. Marina Binti Md Sham Consultant in Pediatric Infectious Disease and Immunology Hospital Tunku Azizah (Women and Children Hospital Kuala Lumpur) Moderator : Dr. Intan Juliana Abd Hamid Paediatrician, Immunology and Allergic Specialist Pusat Perubatan USM Bertam (PPUSMB) Universiti Sains Malaysia
26 th April 2024 (Jumaat)	0900-0930	Lokasi Program Ruang Lobi Pusat Perubatan USM Bertam Persembahan dan Pelancaran Sambutan Minggu Kesedaran Penyakit Imunodefisiensi Primer Sedunia dan Kaya Tulen penayrah IPPI bertajuk Penyakit Imunodefisiensi Primer (an 1)
	0930-1030	Ceramah : Pengenalan kepada Persatuan Pesakit Imunodefisiensi Primer Malaysia (MyPOPI) Penceramah : Mr Bruce Lim Presiden MyPOPI
	1030-1100	Ceramah : Pengenalan kepada rawatan Subcutaneous Immunoglobulin (CSL) Forum : Sesi perkongsian pengalaman bersama "PID survivors" (Dr. Intan & Dr. Zainna)
	1100-1215	



PID WEEK WEBINAR

25 APRIL 2024
1230 - 0130PM

Current Advance in PID Management

Dr. Marina Binti Md Sham
Consultant in Pediatric Infectious Disease and Immunology
Hospital Tunku Azizah (Women and Children Hospital Kuala Lumpur)

Moderator :
Dr. Intan Juliana Abd Hamid
Paediatrician, Immunology and Allergic Specialist
Pusat Perubatan USM Bertam (PPUSMB)
Universiti Sains Malaysia

Mata CPD Disediakan



Mexico



FUMENI - Fundación Mexicana para Niñas y Niños con Inmunodeficiencias Primarias



- Produced Podcast episode together with Iniciativa Alas to commemorate Vicky Modell, co-founder of JMF and World Pi Week Steering Committee Member who was also a mother activist fighting for a better life for those with primary immunodeficiencies
- Social media presence



Click to see more



FUMENI @FumeniAC · Apr 22

Inicia Semana Mundial [#InmunodeficienciasPrimarias](#) [#WPIW](#) Nos unimos con [@AlasIniciativa](#) al [#Homenaje](#) a [#VickyModell](#) quien junto a su esposo Fred creo la [@Info4PI](#) Fundación Jeffrey Modell apoyando a 90 países para salvar vidas de quienes nacen con [#IDP](#)



open.spotify.com

Vicky Modell, una vida cumpliendo los sueños de salud
Listen to this episode from Radio Alas on Spotify.
Rendimos homenaje a Vicky Modell, una madre ...



↻ 1

♡ 2

📊 36



Mexico



Asociación Mexicana para pacientes con inmunodeficiencias primarias (AMPIP)

- Continued to provide knowledge about PIDs.
 - Conferences and experiential talks by patients, family members and a multidisciplinary team on understanding PIDs.
 - Family meeting with patients to encourage mutual support



[Click to see more](#)



Morocco

Hajar

- Raised awareness on the importance of bone marrow transplantation
- Organised training for doctors
- Raised awareness among the students of a primary school about PID
- Celebrated WPIW with the patients



Netherlands



Stichting voor Afweerstoornissen (SAS)



- Bonus episode of their podcast on WPIW
- Organised the SAS Family Day
 - Featuring educational & fun day for members
 - Included presentations by healthcare professionals and interactive sessions
 - Visitors could check the PID information market where various organisations could offer their products / services.
- Social media presence



[Click to see more](#)



Nepal

Nepal Primary Immunodeficiencies and Inborn Errors Initiative

- Program aimed at awareness raising among the general public and healthcare professionals.
- Speakers: Dr Dharmagat Bhattarai and medical professionals shared insights on PIDs. Parents of children with PIDs shared personal stories and challenges.
- Topics Covered: Understanding PIDs, Importance of early diagnosis and available treatment options, Strategies for managing life with PIDs, including available support systems.
- Activities: Educational sessions and presentations by Dr Dharmagat Bhattarai and Sandip Paudel. Interactive Q&A sessions to address concerns.



New Zealand



IDFNZ – Immune Deficiencies Foundation of New Zealand



- Awareness raising – translated and distributed information pamphlets to reach as many New Zealanders as possible



Click to see more

庆祝4月29号世界免疫日

学习自己的免疫系统和原发性免疫缺陷是怎样影响我们社区中的人们。

7种警示信号

什么时候怀疑患上原发性免疫缺陷

需要治疗异常大面积感染
需要治疗和其他感染相关的异常症状
异常生物种类引起的感染
感染发生在非同寻常身体部位
孩子不如预期中身高，或者长体重
感染对于治疗的反应不如预期中的效果
家族史中有免疫缺陷或异常感染

IDFNZ 新西兰免疫缺陷基金会协助新西兰患有原发性免疫缺陷的人们。

想了解更多信息，请浏览 www.idfnz.org.nz

Te Whakanui i te RĀ O TE AO MŌ TE MĀTAI PŪNAHA AWHIKIRI i te rā 29 o Āperira

Ākona ētahi atu mōhiotio mō tō pūnaha awhikiri, ā, ka pēhea te pā atu o ngā kōpaka awhikiri matua ki ngā tāngata ki ō tātou hapori.

7 Ngā Tohu Whakatūpato e

Ahea me whakaaro atu ki te kōpaka awhikiri matua

Ētahi atu tohumata rerere e hāngai ana ki ngā potenga
He potenga i hua mai i ngā momo rauropi rerere
He potenga ki ngā wāhi rerere
He potenga kōroa e unapare i te whakamāmatanga e ai ki tō rā e hūmanatohia ana
He potenga kōroa e unapare i te whakamāmatanga e ai ki tō rā e hūmanatohia ana
He potenga kōroa e unapare i te whakamāmatanga e ai ki tō rā e hūmanatohia ana

IDFNZ Kei te tautoko a IDFNZ i ngā tāngata ki Aotearoa e noho ana me ngā kōpaka awhikiri matua.

Mō ētahi atu mōhiotio, toro ki www.idfnz.org.nz

Celebrating WORLD DAY OF IMMUNOLOGY on the 29th April

Learn more about your immune system and how primary immune deficiencies affect people in our communities.

7 Warning Signs

When to suspect primary immune deficiency



An unusually large number of infections requiring treatment



Any other unusual symptoms related to infections



Infections caused by unusual types of organisms



Infections in unusual places



A child that does not grow, or put on weight as expected



Infections that do not respond to treatment as expected



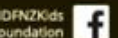
Family history of an immune deficiency or abnormal infections



IDFNZ supports people in New Zealand living with primary immune deficiencies.



For more information, visit www.idfnz.org.nz



Poland

immunoprotect

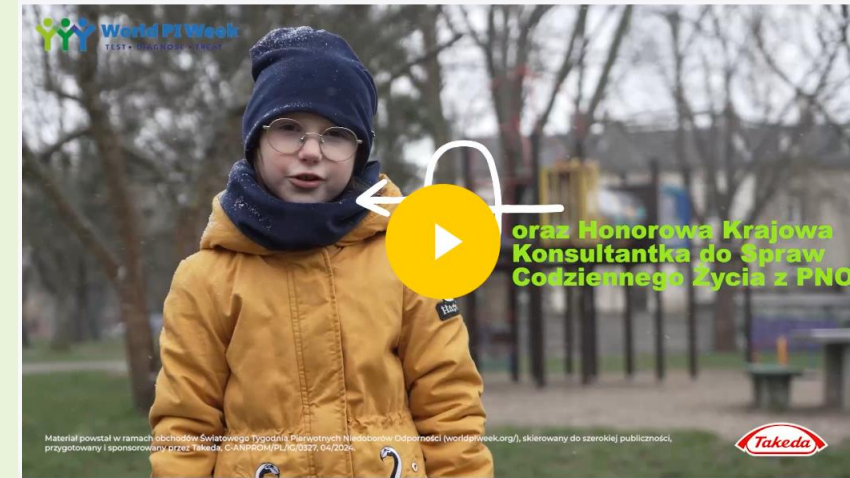
10 lat
Stowarzyszenia

Immunoprotect

- Disseminated patient stories
- The fourth in the series of five educational films on PIDs
- Social media presence
- The XI Conference of the Polish Working Group where topics related to improving the diagnosis of PID, screening tests, education of first contact doctors regarding PID were discussed
- Provided camera covers with the association logo & 10 warning signs of PIDs in polish medical centres



Click to see more



Portugal

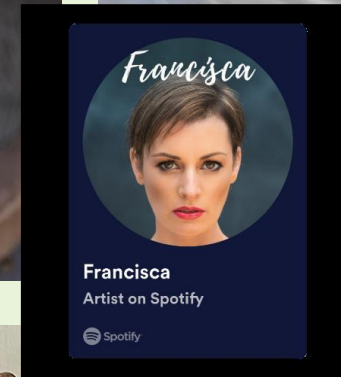


APDIP - Associação Portuguesa de Doentes com Imunodeficiências Primárias

- Organised a guided tour of the UNESCO World Heritage site “Convento de Cristo”
 - Organised an acoustic concert by Francisca, creating an intimate atmosphere
- “In WPIW We Wear the Sweater”: photo campaign on social media
- Social media presence



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Romania

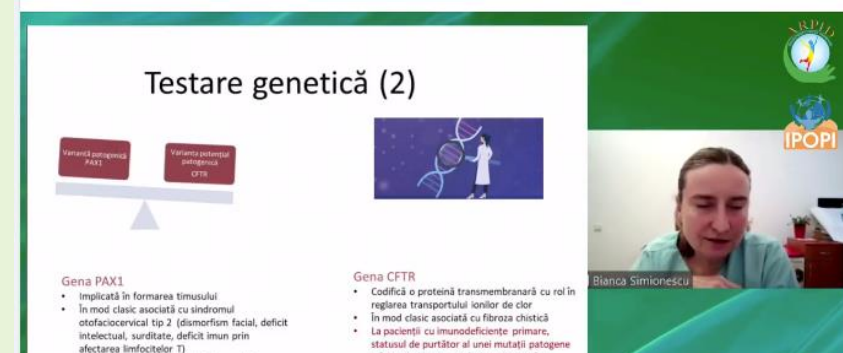


ARPID - Asociatia Romana a Pacientilor cu Imunodeficiente Primare

- Held the 2nd regional patient-doctor-nurse meeting
- Also held the 7th Romanian Annual Conference of Patients with PIDs, under the theme: "Access to care for all primary immunodeficiency patients, everywhere" bringing together 7 doctors and 50 patients.
- Held a press campaign to highlight challenges by patients.
- Discussing unknown errors of immunity and autoimmunity with Mrs. Prof. Dr. Deleanu Diana
- Participation in #PictureAwareness contest
- Social media presence



Click to see more



Russia



Association for PID patients (OPPID)

- Educational video featuring experts on PID treatments
 - 6 broadcast episodes covering diverse topics on PIDs
- Organised a children's drawing competition
- Hosted a joint press conference with Russian State Foundation: Circle of Kindness in the Civic Chamber of Russian Federation
- Patient stories
- Social media presence



Click to see more



Oppid Ru ✓
28 Apr at 12:09 pm

«Терапия подкожными иммуноглобулинами (ПКИГ)»

Берсенева Наталья – вице-председатель МБОУ ОППИД

Родина Юлия Александровна –
к.м.н., зав.отделением иммунологии ФГБУ «НМИЦ ДГОИ им. Дмитрия Рогачева»

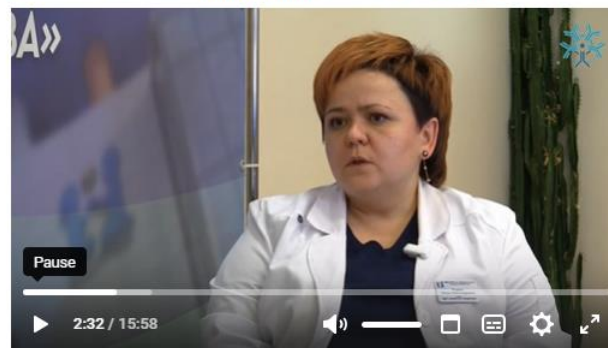
? ПКИГ – особенности терапии, преимущества и эффективность подкожного введения иммуноглобулинов по сравнению с внутривенным введением;

? Нежелательные реакции на заместительную терапию;

? персонализированный подход при выборе терапии для пациента.

♥ Смотрите ролик и принимайте участие в неделе ПИД! Делайте репосты, делитесь своими историями!

#неделяПИД #первичныйиммунодефицит #здоровье #иммунитет



Movie007.mp4



Всемирная неделя Первичных иммунодефицитов 22 - 29 апреля 2024 года

Выступления экспертов в области иммунологии



Щербина А. Ю.



Продеус А. П.



Родина Ю. А.



Дерипапа Е. В.



Латышева Е. А.



Балашов Д. Н.



Творческий конкурс



«Круг добра»

South Africa

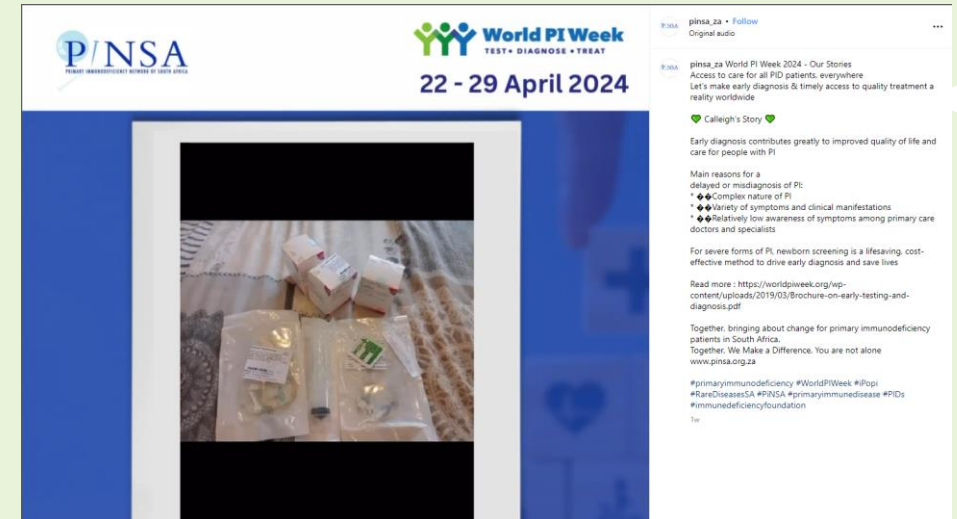


PINSA – Primary Immunodeficiency Network of South Africa

- Social media campaign with patient stories
- Social media engagement to educate about PIDs



Click to see more



Spain



Asociación Española de Déficits Inmunitarios Primarios (AEDIP)



- Organised the PID Solidarity Walk focusing on recruiting participants & providing them information.
 - Set up an information stand
 - Distributed a pamphlet on PIDs
- Social media campaign on PIDs & Presence



Click to see more



Sudan



Sudanese Organization for Patients with Primary Immunodeficiency - Soppi

- Social media presence



Click to see more



Sweden



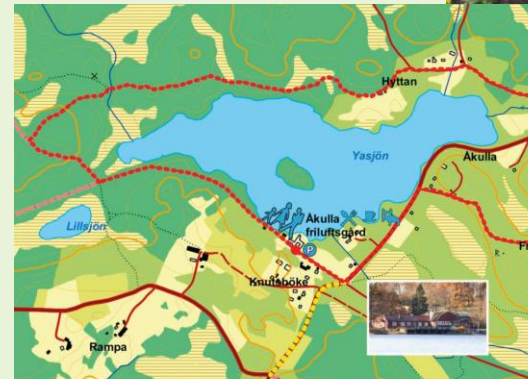
PIO – Primär immunbrist organisationen



- #GoZebra campaign – walking tours organised to raise awareness and funds for the organization
- Organised 3 hybrid lectures focusing on different topics on PIDs enabling conversations amongst patients & family members
- Hosted interviews at the local radio station
- Social media presence



Click to see more



Primär immunbrist organisationen, PIO

April 29 at 11:13 AM · 🌐

Världsimmunbristveckan och kampanjen #GoZebra 22–29 april.

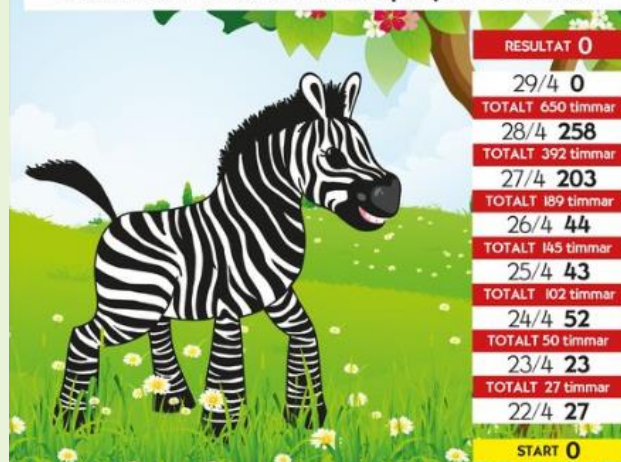
Nu är det såååå spännande! 🐾 När söndagens promenader är räknade har vi tillsammans promenerat 650 timmar! 🥳

Idag är det sista kampanjdagen – så nu spurtar vi mot målet på 700 timmar! Heja, heja! ❤️🐾❤️

Via promenaderna samlas pengar in till PIO, via stöd från kampanjens samarbetspartners samt via appen Guided Heroes, som fördelas mellan PIOs forskningsfond och informationsmaterial för att sprida mer kunskap om primär immunbrist.

Varmt tack till er som promenerar/joggar/springer och samlar in tid! #GoZebra och #ZebraRun 🥳

Världsimmunbristveckan 22-29 april 2024 Insamlade timmar under kampanjen #GoZebra



Via #GoZebra-promenaderna samlas pengar in till PIO, via stöd från kampanjens samarbetspartners samt via appen Guided Heroes #ZebraRun. Tack för att du hjälper till och bidrar med din tid!

Türkiye



AİD – Türkiye Ulusal Alerji ve Klinik İmmünoloji Derneği

- Tree planting activities in different cities to raise awareness on PIDs



Click to see more



Tunisia

معهد باستور
Institut تونس
Pasteur de Tunis



Institut Pasteur de Tunis -
معهد باستور تونس



- Awareness day for children with PIDs with animated presentations
- Visit to laboratory with children



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Uganda

Dove Primary Deficiency Patients' Organization limited (DPIDPO)

- Organised media collaborations through interviews, panels and discussions on local & national TV channels.
 - Main discussion topic was the availability of immunoglobulins
- Amplified messaging via social media presence
- Organised a PID awareness walk on April 28th

NBS TV INTERVIEWS, UGANDA.



PIDD AWARENESS WEEK.



Ukraine



RID – Rare Immune Diseases



- Educational event together with All-Ukrainian Association of Children's Immunology, International European University, and other NGOs
- Shared & broadcasted flyers and animated film with features of PID in regional hospitals.
- Created a flyer on neonatal screening with information for mothers



Click to see more



Rare Immune Diseases

2. Mai um 08:21 · 🌐

До Всесвітнього тижня первинних імунodefіцитів представники ГО РІЗ Зоя і Арсеній Попові та Оксана Стрельникова взяли участь у навчальному заході, який проводився рядом фахових організацій #Всеукраїнська асоціація дитячої імунології, #Міжнародний європейський університет, #ГО Міжнародна міждисциплінарна асоціація медичних професіоналів для лікарів різних спеціальностей міста Чернівці і області а також обласних імунологів України. Так, 26 квітня пацієнтська організація РІЗ розповіла про свою діяльність за останній рік і найголовніше - озвучила історії пацієнтів, їх складний шлях пошуку діагнозу, відчуття батьків під час встановлення і першого етапу лікування дітей і пацієнтів з первинними імунodefіцитами.



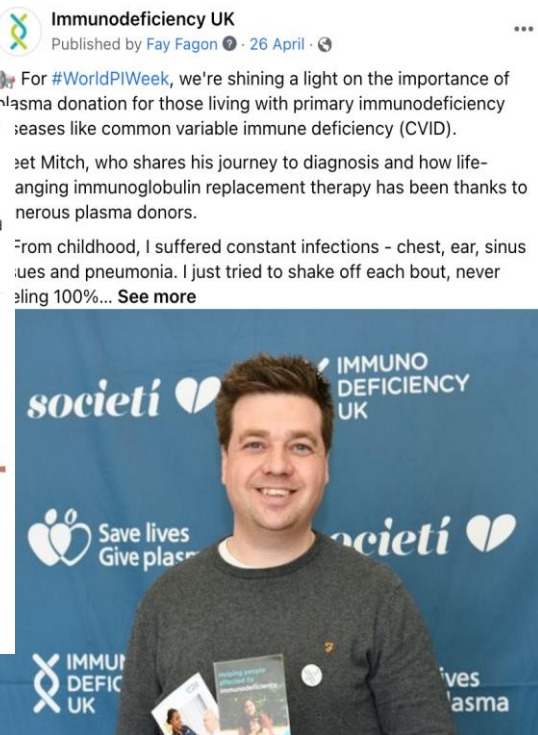
United Kingdom



Immunodeficiency UK



- Patients' stories (social media campaign) – focusing on plasma donation and other treatments
- Information campaign on social media – encouraging the public to donate plasma
 - a custom video was developed emphasising why plasma is so vital. The video reached over 2,500 people, over half of whom were non-followers successfully engaging people outside of our community.
- Awareness campaign on the importance of immunoglobulin therapy to drive plasma donation.
 - Shared plasma donation related patient stories further hammering home the importance of Plasma in PID treatment.



10 warning signs of Primary Immunodeficiency



Primary Immunodeficiency (PID) causes children and adults to have infections that come back frequently or are unusually hard to cure. Two or more of these warning signs could indicate the presence of an underlying PID. If you or your child have any of these symptoms, it's important to talk with your doctor. He or she might refer you to a specialist, such as an immunologist.

- Four or more new ear infections within 1 year
- Two or more new sinus infections within 1 year
- Two or more months on at least two antibiotics with little effect
- Two or more pneumonias within 3 years
- Failure of a baby or child to gain weight or grow normally (failure to thrive)*
- Need for intravenous antibiotics to clear infections.
- Persistent thrush or fungal infection (more than six months) on the skin or elsewhere
- Frequent deep skin or organ abscesses
- Two or more deep-seated infections, including septicaemia (blood poisoning), within three years.

A family history of a PID.

There are many reasons for failing to thrive and PIDs are a rare but important cause.

People with PID rely on a range of different treatments being available. These include:

- Immunoglobulin therapy
- Antibiotics
- Anti-fungals
- Anti-virals
- Corticosteroids
- Haematopoietic Stem Cell Transplant (BMT)
- Enzyme replacement therapy
- Gene therapy
- Thymic transplant
- Immunosuppressive therapies
- Targeted therapies such as monoclonal antibodies



Click to see more

United Kingdom



**Great Ormond Street Children
Hospital NHS Foundation Trust**



- Participation in World PI Week
#PictureAwareness Contest



[Click to see more](#)



United States



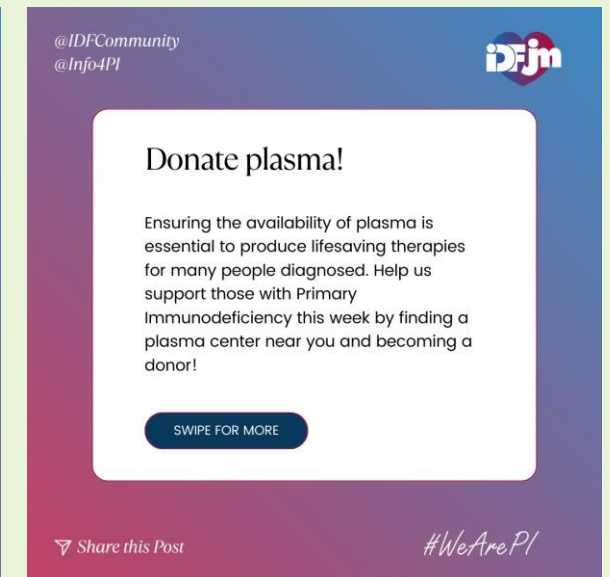
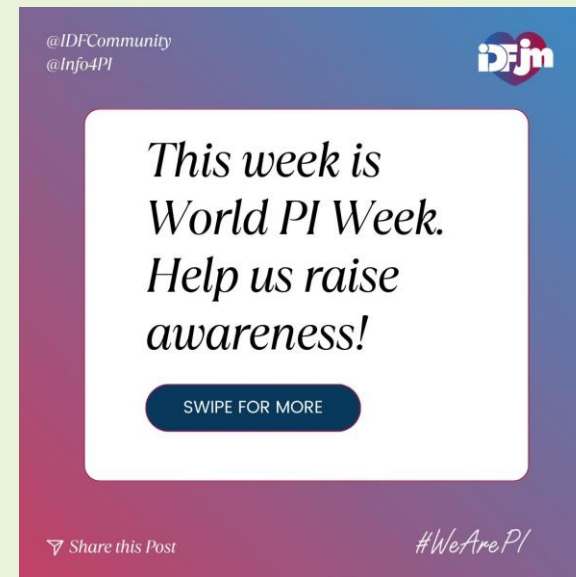
IDF – Immune Deficiency Foundation



- Organized and Advocacy Day – bringing advocates from the PI community to promote policies to U.S. legislators
- Awareness raising and social media promotion – encouraging the public to donate plasma



Click to see more



Venezuela



Immunodeficiencias Primarias Venezuela (IDP)

- Distributed campaign material at Otorhinolaryngology Unit and Pediatric Service and to medical students in the Faculty of Medicine
- Hosted a conference “We can do more to identify patients with PID” for healthcare professionals.
- Held the annual meeting on IEI.



[Click to see more](#)



Vietnam



VIET PIPS

- Participation in World PI Week #PictureAwareness Contest
- Social media presence



[Click to see more](#)



International Latin America

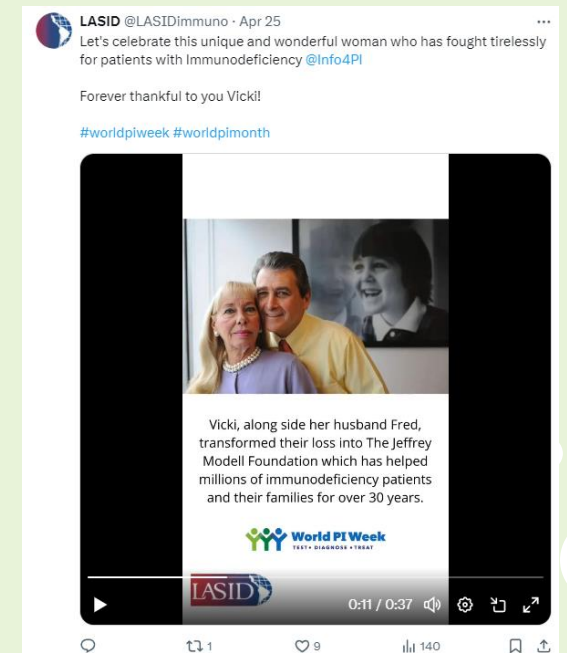


LASID – Latin American Society for Immunodeficiencies

- Social media campaign
 - Raising awareness through informative videos and patient testimonies



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International INGID



International Nursing Group
for Immunodeficiencies



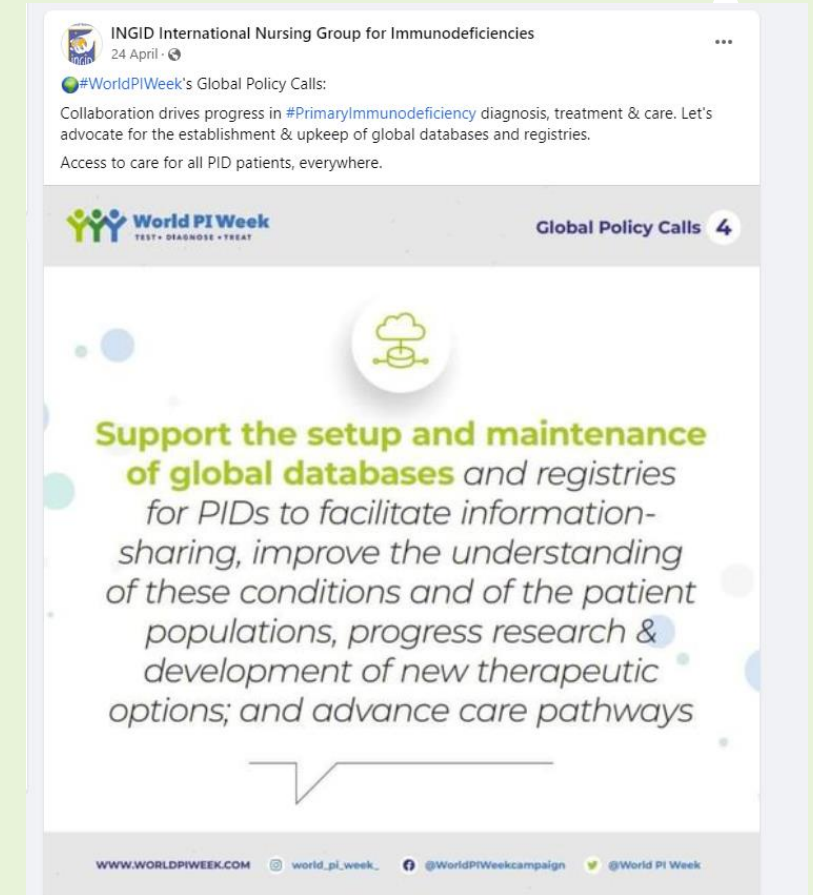
INGID – International Nursing
Group for Immunodeficiencies



- Social media presence



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International Jeffrey Modell Foundation



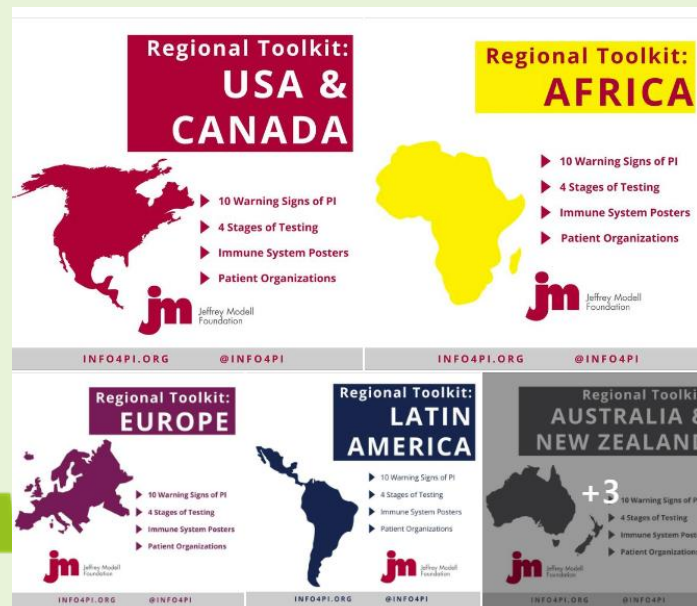
JMF – Jeffrey Modell Foundation

- Celebrating World PI Week with a video collecting messages from across the globe
- 10 Warning signs of PID in more than 60 languages.
- Sharing regional information toolkits on PID.
- Social media presence



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World PI Week
is being celebrated
all over the world



We're celebrating [#WorldPIWeek](#) with gratitude for the incredible doctors, brave patients, and passionate advocates worldwide who stand tall in the face of Primary Immunodeficiency. Your strength, resilience, and dedication inspire us all to raise awareness, foster understanding, and strive for a world where PI is recognized, diagnosed, and supported with compassion. Together, let's continue to shine a light on PI and empower every individual on their journey towards better health and well-being. ❤️🌟🌍

[#WPIW](#) [#INFO4WPIW](#) [#PrimaryImmunodeficiency](#) [#RareDisease](#) [#Immunology](#)



Jeffrey Modell Foundation
28 April · 🌐

The Jeffrey Modell Foundation team presents to you: The 10 Warning Signs of PI in honor of [#WorldPIWeek](#) ❤️ An essential part of our mission is educating the healthcare community about [#PrimaryImmunodeficiency](#) and how to properly diagnose it.

Did you know that you can find and share the 10 Warning Signs of Primary Immunodeficiency in more than 60 languages on our website? You can find them here: <https://bit.ly/3w3Z5rv>
[#INFO4WPIW](#) [#WPIW](#) [#PrimaryImmunodeficiency](#) [#RareDisease](#) [#Immunology](#)



10

WARNING SIGNS
of Primary Immunodeficiency

SEÑALES DE PELIGRO
de la Inmunodeficiencia Primaria

SIGNES D'ALARME DES
déficits Immunitaires primaires

International IPOPI



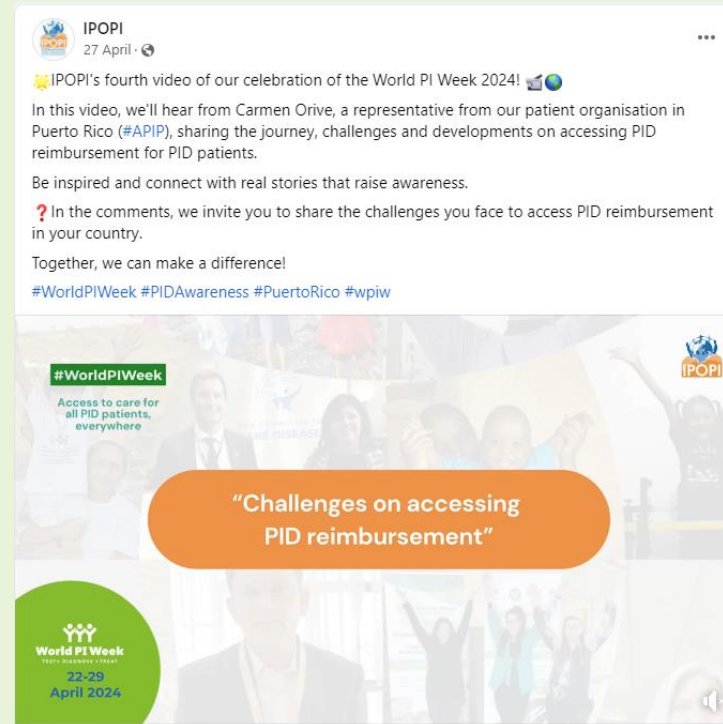
IPOPI - International Patient Organisation for Primary Immunodeficiencies



- Patient-representatives testimonial video series on the challenges and development of accessing PID care
- Participation in World PI Week #PictureAwareness Contest
- World PI Week Closing video by Martine Pergent, President of IPOPI
- Social media presence



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Life Sciences Industry

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Section 1

Section 2



CSL Plasma
@CSLPlasma

Liz M. is currently an Operational Excellence Manager. She has been with CSL Plasma for 10 years, and began as a part-time Donor Service Technician.

Learn more about Liz' career journey with CSL Plasma: bit.ly/3vCO4sL

#DotheAmazing #PromisingFUTURES



KORU Medical Systems @korumedical - Apr 28
On this last day of #WorldPIWeek, Jessica shares her PI story with us, explaining how she went on for 5 years without answers and that her diagnosis was one of the best days of her life!

Read Jessica's story here: korumedical.tumblr.com

#CVID #WPIW2022 #PrimaryImmunodeficiency



Jessica's PI Story

WORLDPIWEEK.org #WORLDPIWEEK

CSL Plasma
@CSLPlasma

On average, it takes more than 12 years from symptom onset for a #primaryimmunodeficiency disorder to be diagnosed in an individual in the United States.

Learn more about PI and how you can help those affected: bit.ly/37E3i93

#WorldPIWeek #PIAwareness



Primary Immunodeficiency Awareness CSL Plasma

Takeda @TakedaPharma - 26 Apr
#DYK? #PrimaryImmunodeficiency (#PI) is usually inherited, which means it runs in families. This #PIAwarenessMonth, we're raising awareness for the many types of PI disorders. Learn more about PI: bit.ly/3Mxw4ak #PIAwarenessMonth

What is (PI)? Primary immunodeficiency



PI isn't a single condition. It's an umbrella term used to describe

0:09 203 views



X4 Pharmaceuticals @X4Pharma - Apr 27
#ICYMI we partnered with the @IDFCommunity to host the first session of the Diagnosis-Specific Lunch & Learn series where we discussed challenges of diagnosing #WHIM syndrome, a primary #immunodeficiency. Listen to the webinar here:

Pathogenesis in WHIM Syndrome



Binding Site @TheBindingSite - Apr 22

#HappyFriday! At Binding Site, we head into the weekend focusing on a #disease that is close to our hearts.

April is National #PrimaryImmunodeficiency Awareness Month, but today marks the start of #worldPIweek.

BPL-USA @bpl_usa - Apr 22
Today is the first day #WorldPIWeek, where @WorldPIWeek shares the stories of patients around the world and we join in with them to speak up in support of access to care that brings diagnosis and hope. Follow along with us in the coming days as we share patient stories.

Chiesi Global Rare Diseases @ChiesiGRD - Apr 25
We're looking forward to attending #IPIC5 this #WorldPIWeek! Our team at #ChiesiGlobalRareDiseases will spotlight opportunities to support the management of ADA-#SCID, a rare #primaryimmunodeficiency. bit.ly/3B4tPqb @ipopi_info



Thank You!

World PI Week 2024 was a success again!

PID awareness does not end with the campaign.

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