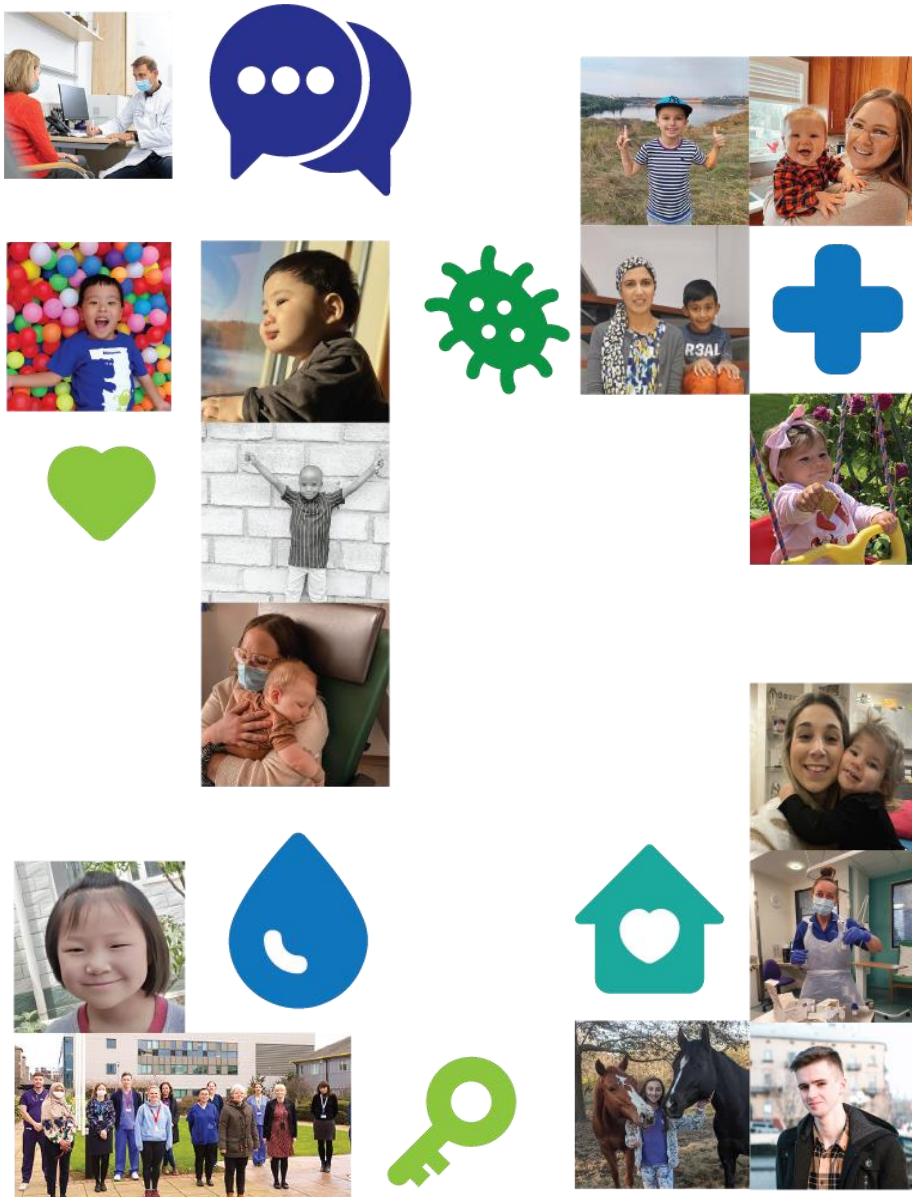




World Primary Immunodeficiency Week 2022

Together, bringing about change for
primary immunodeficiency patients
worldwide

CAMPAIGN REPORT



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.

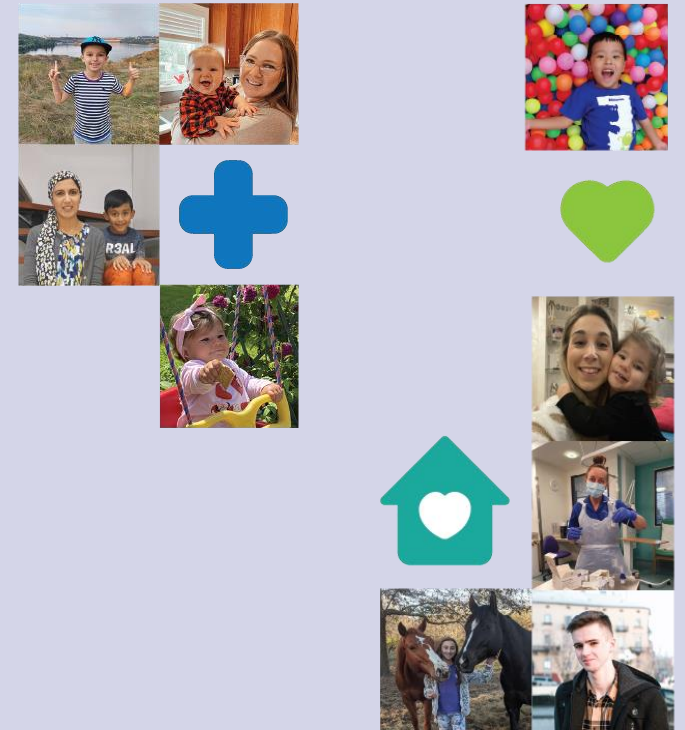


Aims

World PI Week offers an opportunity to inform and educate health policy-makers, schools and families, and the general 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, World PI Week has been successful in stimulating awareness and advocacy efforts in all continents



World PI Week by the numbers

Over 80 countries
across the globe

Thousands of people
reached

Hundreds of events
every year

12 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

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On the 25th of April, the 12th #IDP course for resident doctors and the 8th IDP course for nursing staff began. From the BCN PID Foundation we co-sponsor these courses, organized by Societat Catalana d'Immunologia and Societat Catalana de Pediatria. One of our objectives is to promote excellence in the knowledge, study, research and dissemination of IDPs and infectious etiology complications that may be presented to affect... See more

[Hide Translation](#) [Rate this translation](#)



Our active network



GOLD SPONSOR



SILVER SPONSOR



BRONZE SPONSOR



New 2022 partner



CONTRIBUTORS



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



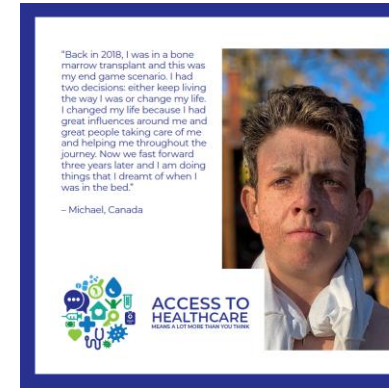
A dynamic,
multi-stakeholder
and global
community



Campaign resources

Information & advocacy tools

- Flyers
- Videos
- Scientific pieces
- “Story sharing” visuals
- PID quiz
- Messaging brochure
- Template press release and articles
- Template letter for Governments
- Template social media posts
- Policy Pledge
- Podcasts



Click here to download all materials



WORLD PI WEEK 2022 IN ACTION



Thousands showing support worldwide

People mobilized for the PID cause both online and in-person

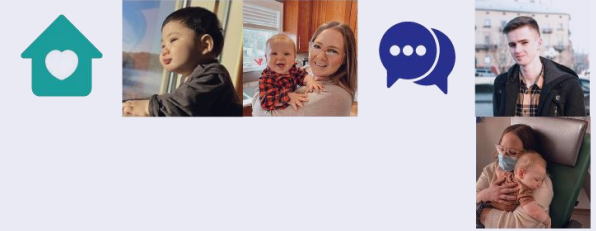
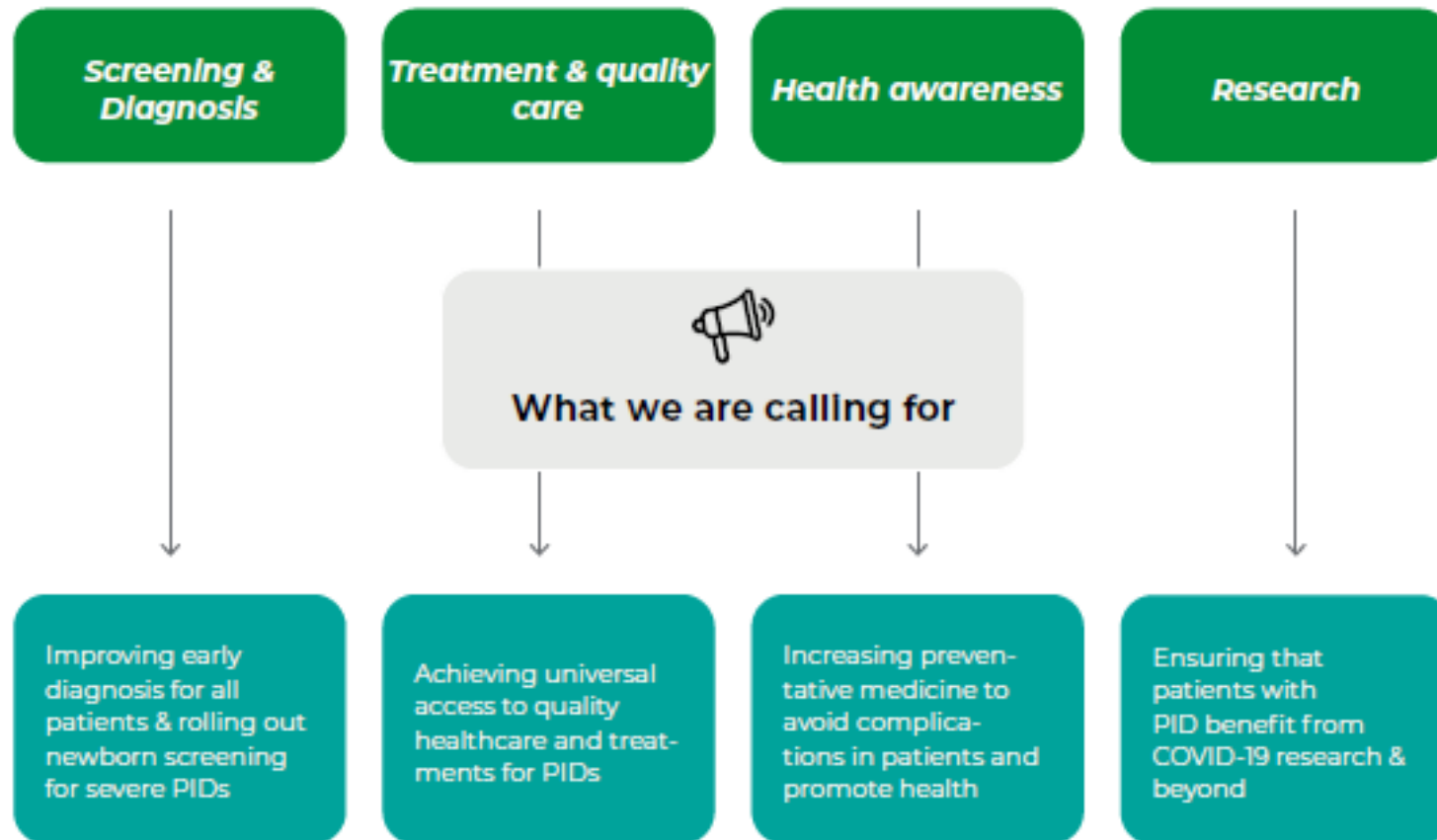


Through (virtual) runs, online webinars and workshops, social media campaigns, TV/radio interviews; by donating blood or plasma – World PI Week is for everyone!

In 2022, we showed that lives can be saved

Access to quality care saves lives.

Spotlight on 4 themes linked to improving access to care for patients



Access to healthcare is a basic human right. The millions of people living with PIDs worldwide depend on it. Each of them is entitled to the correct diagnosis, quality treatment & care.



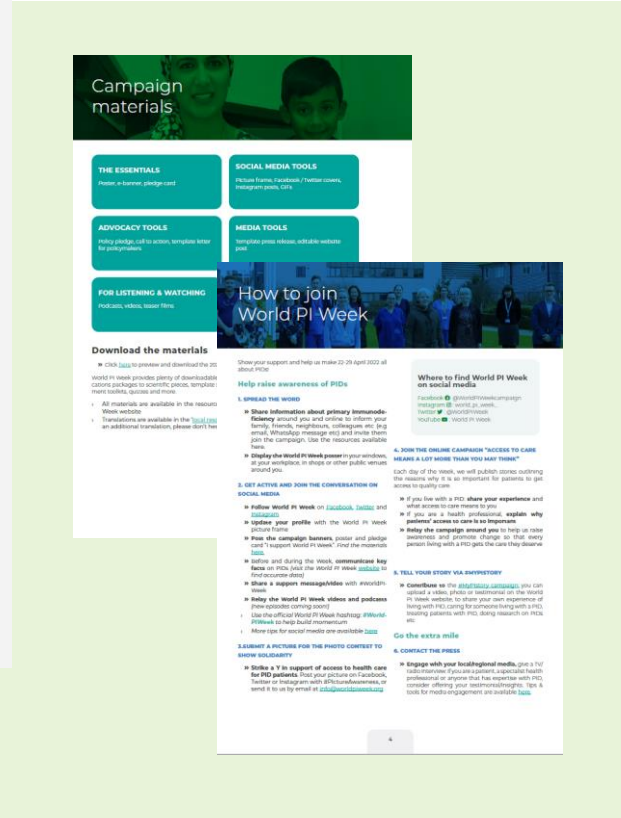
A bespoke information toolkit



Everything you need to know about the 2022 campaign, how to mark the week and direct link to resources.



Click here to download toolkit



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The 2022 'essentials'

Communications package



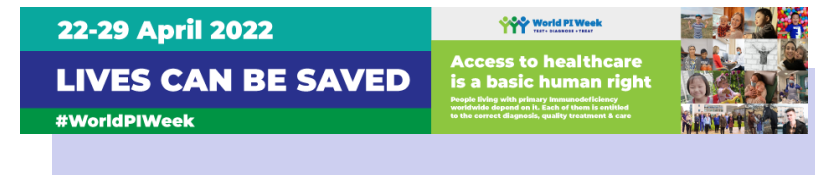
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Click here to download materials

Pledge card, e-banners, posters, email signatures, sample website posts, press release & many more



Available in various languages



**22-29 de
Abril de 2022**

**Se pueden
salvar vidas**

**El acceso a la
sanidad es un
derecho humano
fundamental.**

Las personas que viven con una inmunodeficiencia primaria dependen de ello. Todos tienen derecho a un diagnóstico correcto, a un tratamiento de calidad y a una atención adecuada.

#WorldPIWeek

**22-29
April 2022**

**Nyawa boleh
selamatkan**

**Memperoleh
penjagaan
kesihatan
adalah
merupakan
satu hak asasi
manusia**

Individu yang hidup dengan immunodefisiensi primer di seluruh dunia bergantung padanya. Setiap seorang daripada mereka berhak untuk mendapatkan diagnosis yang tepat, rawatan & penjagaan yang berkualiti.

#WorldPIWeek

Translations available in:

- Arabic
- Chinese
- Dutch
- French
- German
- Italian
- Malay
- Portuguese
- Spanish
- Swedish
- Thai
- Turkish

**22-29
April 2022**

**LEVEN
KUNNEN
WORDEN
GERED**

**Toegang tot
gezondheids-
zorg is een
fundamen-
teel mensen-
recht.**

Wersdaijd zijn mensen met primaire immunodeficiëntie ervan afhankelijk. Ieder van hen heeft recht op de juiste diagnose, kwalitatieve behandeling & zorg.

#WorldPIWeek

**22-29
Avril 2022**

**SAUVONS
DES VIES**

**L'accès aux
soins de
santé est un
droit humain
fondamental.**

Les personnes atteintes de déficits immunitaires primaires en dépendent. Chacune d'entre elle est en droit de recevoir un diagnostic précis, un traitement et des soins de qualité.

#WorldPIWeek

**22-29
Aprile 2022**

**POSSIAMO
SALVARE
DELLE VITE**

**L'accesso
ai servizi
sanitari è un
diritto umano
fondamentale**

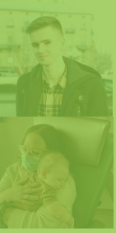
Le persone che vivono con una immunodeficienza primaria la sanno il mondo dipendono da questo. Ognuno di loro ha diritto a una diagnosi corretta e a trattamenti di qualità.

#WorldPIWeek

[world_pi_week_](#) [@WorldPIWeekcampaign](#) [@World PI Week](#)



Preview of 2022 resources



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22-29
April 2022


TEST • DIAGNOSE • TREAT



LIVES
CAN BE
SAVED

Access to
healthcare
is a basic
human right

People living with primary
immunodeficiency worldwide depend on
it. Each of them is entitled to the correct
diagnosis, quality treatment & care

#WorldPIWeek

The Essentials

Logo

Poster

e-banner

Pledge card "I support World PI Week"

2022 information toolkit

Zoom background

22-29
April 2022


TEST • DIAGNOSE • TREAT



LIVES
CAN BE
SAVED

Access to
healthcare
is a basic
human right

People living with primary
immunodeficiency worldwide depend on
it. Each of them is entitled to the correct
diagnosis, quality treatment & care

#WorldPIWeek

Social Media Tools

Picture frame

Facebook cover

Twitter cover

YouTube cover

Instagram post

Instagram story


TEST • DIAGNOSE • TREAT



#WorldPIWeek

Protecting and improving
the lives of the millions of
people living with primary

Media Tools

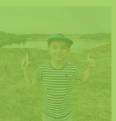
Template press release

Editable website/blog post



Click here to
download materials

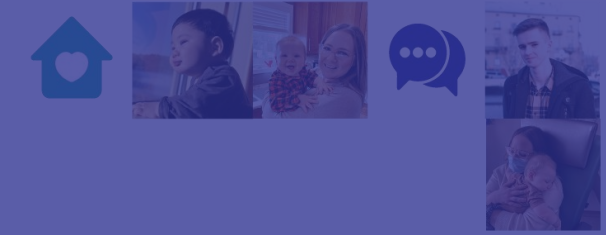
A mix of advocacy, social
media and other
communication tools



New campaign on access to quality care

Access to healthcare means a lot more than you think

Patients, healthcare professionals, supporters from all over the world participated in the online campaign #AccesstocareMatters



8 themes for 8 days:

- *Early diagnosis*
- *Newborn screening*
- *Genetic testing*
- *Access to specialist doctors*
- *Life-saving treatment*
- *Immunoglobulin therapy & access to plasma*
- *Transplantation*
- *Gene therapy*

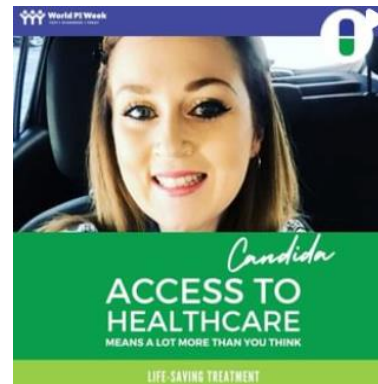
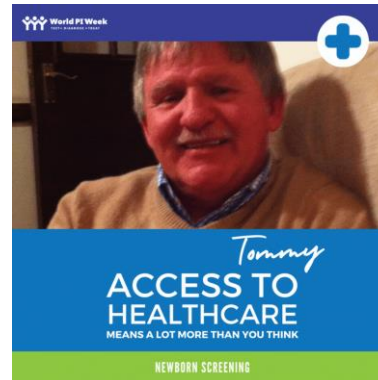


Access to care
campaign materials

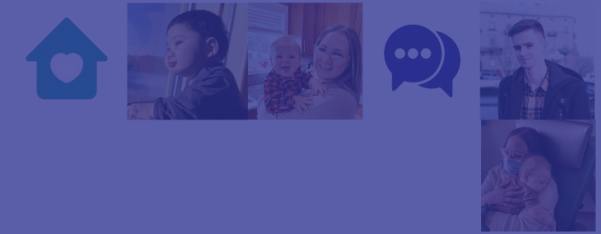


Explaining what access to care means

Real-life examples to show the impact it has on patients' lives

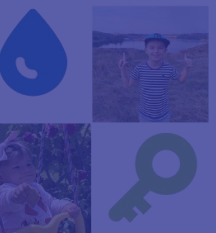


Access to care
campaign materials



Animated stories
were published
each day of the week
(one theme per day)

*The reasons why it is
so important
for patients to
get access to
quality care – across
the continuum of
care*



#AccesstoCareMatters by the numbers

+120

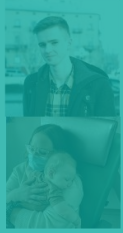
Stories submitted by the community before the campaign – from patients, health professionals, carers

31

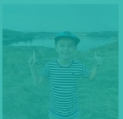
Stories published by World PI Week during the campaign, reflecting multiple experiences and from diverse countries

+240

Posts across social media platforms, relayed online by patients, patient groups, doctors and specialists, nurses, researchers, media, industry and more



The campaign remains open in the next months, submit your story via our website or engage with **#AccesstoCareMatters**

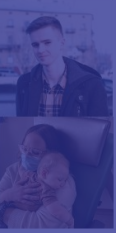


Pursuing the World PI Week Talks

4 new episodes to the podcast series by the World PI Week



Listen to the podcasts on your preferred platforms



EPISODE 1:
Early diagnosis & newborn screening



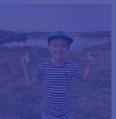
EPISODE 2:
Treatment & Care



EPISODE 3:
Research

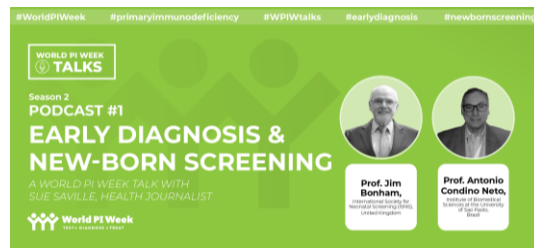


EPISODE 4:
Preventative Medicine



About World PI Week Talks Season 2

Health journalist Sue Saville talks PIDs with multiple experts and patients



- This podcast explores different issues surrounding diagnosis and screening of PIDs, including the **difference it makes** in the lives of patients, how neonatal screening is currently **implemented worldwide, obstacles and efforts** led by stakeholders across the globe to improve the situation.



- This podcast discusses how to achieve **universal access to quality healthcare** for PID and gives a brief overview of the **main treatment options**. It also provides a glimpse into the promise of **gene therapies** and explores the role of **transplantation** in PID care.



- This podcast sheds light on the **benefits of research** and its role and impact on patients, families, medical practices as well as society. It explores **existing challenges** related to research in PIDs, what the **future of research** may look like in the field, and the value of **international collaboration**.



- This podcast explores how **health awareness measures** and preventative medicine help people living with primary immunodeficiencies, including tools such as focus groups that are used to talk to patients about those aspects and the challenges in patients' access to **preventative medicine**.



Join the conversation on social media with #WPIWTalks

A new policy pledge on access to care



Access to quality care for those living with PIDs matters: it saves lives!



Together we pledge for

-  Early diagnosis and screening
-  Quality Care
-  Health Awareness for PID patients
-  Research



Launched on the last day of the campaign to keep momentum, the pledge focuses on the main topics of World PI Week 2022 and complements the call to action.

It outlines **priorities to make access to quality care a reality for all PID patients**, no matter where they live. It unifies organizations and individuals who are committed to improving awareness and recognition of PIDs; as well as addressing current challenges in access to quality care – understanding the complex realities of healthcare systems across the world.

Click here to access the policy pledge

Supporters of the policy pledge



Signatories



The pledge is **open for endorsement**, please click in the link [here](#) to endorse it

Engage with the pledge, **share it around you including with your local/national representatives**; and encourage them to support it

16 international organisations encouraging collaboration so that access to quality care become a reality for all PID patients



World PI Week at IPIC 5th Congress in Portugal, Vilamoura

27-29 April 2022

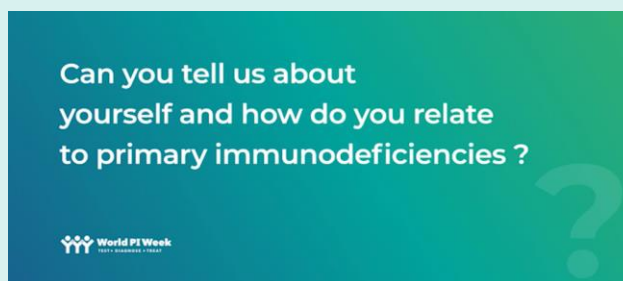
For the first time, World PI Week was at the International Primary Immunodeficiencies Congress (IPIC)!

World PI Week corner

- Visual background/gallery including stories of the online campaign on access to quality care
- Copies of WPIW material with link to online resources
- Photobooth/picture frame to "Strike a Y" for World PI Week
- Filmed interviews with patients & specialists



Click for more information on the congress



World PI Week Interviews

16 interviews with patients and experts during IPIC



What are the main treatments options for PIDs?



What difficulties have you experience in getting the right treatment?



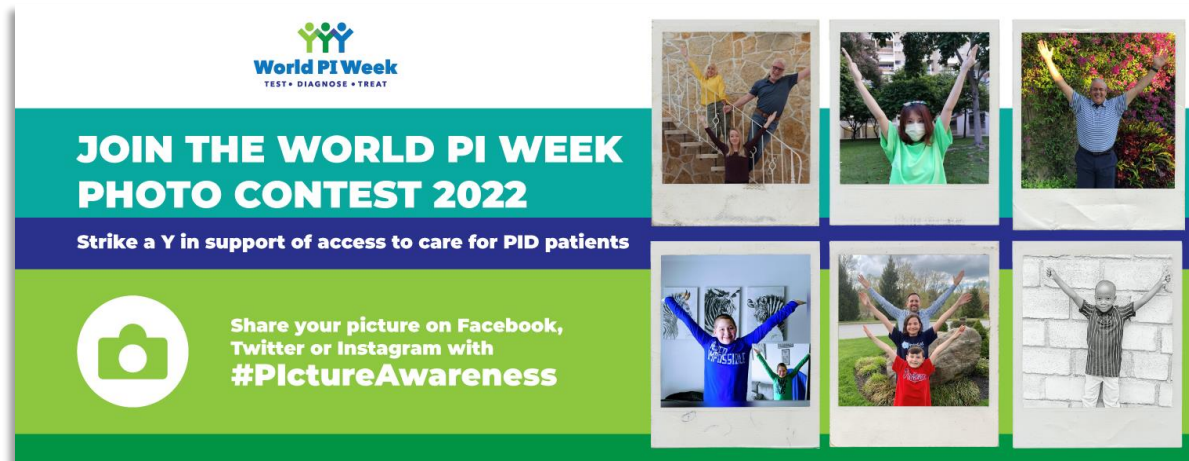
Interviews are being finalized and will be published soon, stay tuned!



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 in support of access to quality care for patients.



 Click to access the photo campaign

... and the winner is Arianti Ria!



Congratulations to Arianti Ria from Indonesia!



HOME



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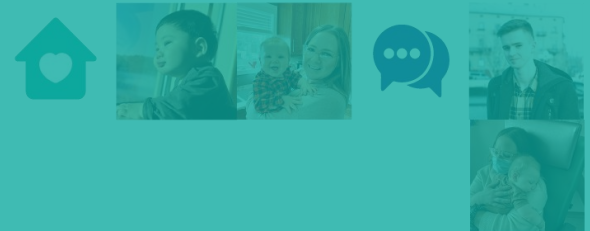
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Social media engagement



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AAPIDP @aapidp

La salud es un derecho humano, básico y universal. Por eso es vital lograr el acceso a la atención médica y a un tratamiento adecuado a tiempo para las **Immunodeficiencias Primarias**
[#SePuedenSalvarVidas](#) @world_pi_week_

#WorldPIWeek
 Translate Tweet

CTI Clinical & Translational Immunology @ClinTransImmuno

For World Primary Immunodeficiency Week we have made a Virtual Issue highlighting valuable research contributions in [@ClinTransImmuno](#) to studying this diverse group of diseases.
[onlinelibrary.wiley.com/doi/toc/10.100...](#)
[#WorldPIWeek](#) @WileyBiomedical @AusPIPS150 @Info4PI @WorldPIWeek @Openaccess

WILEY Clinical & Translational Immunology

Virtual Issue: 2022 World Primary Immunodeficiency Week

[Read here](#)

St James's Hospital @stjamesdublin

This week we're celebrating [@WorldPIWeek](#)!

Make sure to drop by the awareness stand in the concourse and show support for [#WorldPIWeek](#) [#AccessToCareMatters](#)

Katie Ridge @ridgek · Apr 25
 The SJH Immunology Nursing team promoting World Primary Immunodeficiency Week in @stjamesdublin today. A global campaign to raise awareness and improve diagnosis & treatment for people living with PID. @WorldPIWeek @ipopi_info

RARE Rare Revolution Mag @RareRevolutionM · 22 Apr

Today marks the start of [#WorldPIWeek2022](#) raising awareness of [#PrimaryImmunodeficiencies](#). IDf participates in worldwide initiatives to improve the recognition, diagnosis, treatment and quality of life of people with primary immunodeficiency diseases.
[primaryimmune.org/world-pi-week...](#)

Frontiers in Immunology @FrontImmunol · Apr 25

With this week being World Primary Immunodeficiencies week, we would like to highlight our article collections published in our dedicated Primary Immunodeficiencies section, covering various aspects of the field.

Learn more here [fro.nfers.in/NTvi](#)

[#WorldPIWeek](#)

Immunodeficiency Canada @ImmunoCanada · 22 Apr

Today marks the start of **World PI Week 2022**, a global campaign to raise awareness for PI. There are approx. 6 million people worldwide living with PI. Access to early testing and diagnosis can help prevent complications and greatly improve the quality of life.

[#WorldPIWeek](#)

IPOPI @ipopi_info · Apr 29

Its the last day of [#WorldPIWeek](#) as well as [#PIC5](#)! Come celebrate with IPOPI members and patient representatives to strike a Y in support of access to quality care for people with [#PIDs](#).

[#MyPhysicianAndI](#) [#PrimaryImmunodeficiency](#) [#PID](#) [#IEI](#)

Primary Immunodeficiency Adult Centre-Milan @PID_sauitMI

In the last day of [#WorldPIWeek](#) as well as [#PIC5](#) we presented our ongoing job on vaccination anti [#COVID19](#) in [#primaryimmunodeficiency](#)

Oxford Medicine @OUPMedicine · Apr 27

[#PIC5](#) attendees, don't miss the World [#PrimaryImmunodeficiency Week](#) Virtual Issue from [@CEIjournal](#) for the latest information in the field.
[@britsocimm](#) [#WorldPIWeek](#)
[bit.ly/38ur2ww](#)

Clinical & Experimental IMMUNOLOGY

PRIMARY IMMUNODEFICIENCY VIRTUAL ISSUE
[#WorldPIWeek](#)

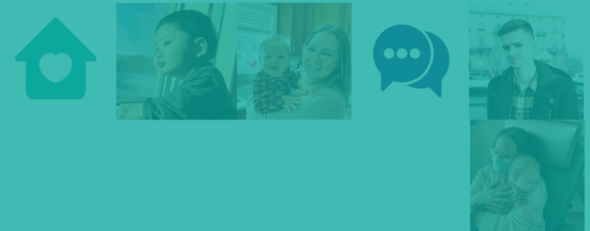
[Read now >>](#)

Katie Ridge @ridgek · Apr 25

The SJH Immunology Nursing team promoting World Primary Immunodeficiency Week in [@stjamesdublin](#) today. A global campaign to raise awareness and improve diagnosis & treatment for people living with PID. [@WorldPIWeek](#) [@ipopi_info](#)
[pic.twitter.com/dyuT9Rn57q](#)

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





Social media milestones

Driving conversations and mobilising to raise awareness of PIDs

Analytics for 22-29 April



April

- +65** new followers and likes
- 90%** increase in post coverage (22-29 Apr)
- 900** interactions per post (22-29 Apr)



April

- 682** followers (+13.6%)
- +57** posts shared
- +7.7K** impressions (+1,276%)
- 785** content interactions



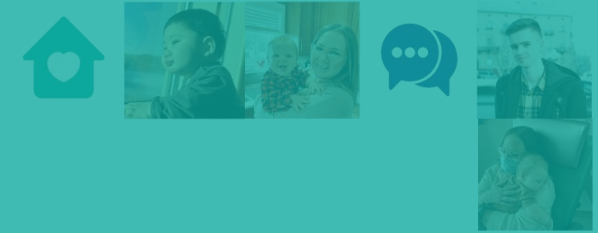
April

- +115** followers
- +107** posts shared
- +46.2K** impressions
- 21.4K** profile visits

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



Best-performing social media posts



Follow World PI Week:

FACEBOOK:

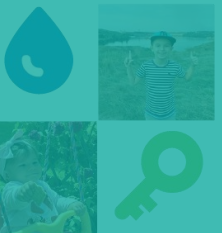
@WorldPIWeekcampaign

TWITTER:

@WorldPIWeek

INSTAGRAM:

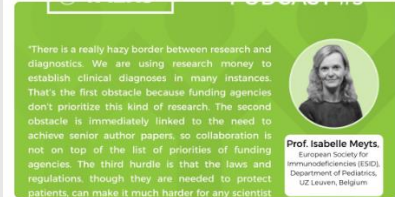
@world_pi_week_



Top Tweet earned 2,417 impressions

In our latest [#WPIWTalks](#) podcast, Prof. Isabelle Meyts [@ESIDSociety](#) [@KU_Leuven](#) talks about the research she is leading at her lab, and how this impacts patients, but also helps advance the understanding of the immune system and PID care.

bit.ly/3JDeuiZ pic.twitter.com/vYkD01rbLZ



1 4 15



2,417
Impressions

+50
Engagements



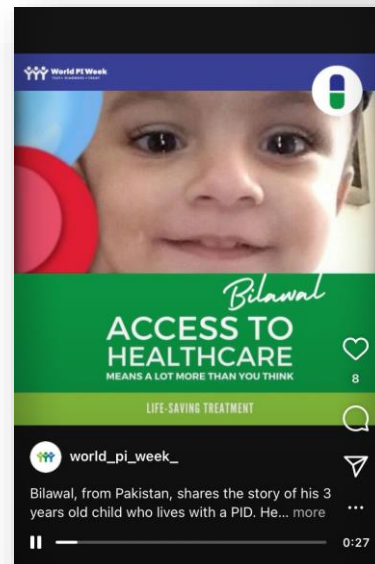
+68
Reactions

+925
Total engagements



187
Accounts reached

199
Impressions



Media coverage

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THE HealthSite.com

HEALTH A-Z DISEASES HEALTH SUMMIT 2022 DIET & FITNESS YOGA PREGNANCY VIDEOS

Home > Diseases Conditions >

World PI Week 2022: What Are Primary Immunodeficiency Diseases?



Miércoles, 8 de junio de 2022, 13:25



DIARIO ESTRATEGIA
EL DIARIO DE NEGOCIOS INDEPENDIENTE DE CHILE

INICIO NEGOCIOS & EMPRESAS ECONOMÍA & FINANZAS DINERO & INVERSIÓN AUTOMOTRIZ INTERNACIONAL TECNOLOGÍA

Conozca cuáles son los diez signos de alerta de las inmunodeficiencias primarias

Archivado en: Ciencia & Salud · inmunodeficiencias · inmunodeficiencias primarias · Dra. Raquel Aguilera Insunza · Red UC Christus

Estrategia On line | Lunes, 25 de abril de 2022, 06:59

Compartir 0

Twitter

La Semana Mundial de las inmunodeficiencias primarias (IDP), que abarca desde el 22 hasta el 29 de abril, es un movimiento mundial para crear conciencia sobre este grupo de más de 380 formas de enfermedades poco frecuentes que se estima afectan a 6 millones de personas en todo el mundo y que "ocurren cuando el sistema inmunológico de una persona tiene un defecto en su función, lo cual lleva a una baja en las defensas o a una desregulación de sus



Dr Sunitha Kayidhi
Consultant Rheumatologist and Clinical Immunologist, Yashoda Hospitals Hyderabad

THE TIMES OF INDIA

Opinion Times View Readers' Blog Times Evoke City India World Entertainment Sports Spirituality Business

NEWS / BLOGS / LIFESTYLE / What are primary immunodeficiency disorders?

LIFESTYLE

What are primary immunodeficiency disorders?

April 30, 2022, 5:42 PM IST / Dr Sunitha Kayidhi in Voices, Lifestyle, TOI

FACEBOOK

TWITTER

LINKEDIN

EMAIL

World Primary immunodeficiency week is observed from April 22-29 to raise awareness about primary immunodeficiency diseases (PID). PID is a group of rare disorders in which part of the body's immune system is missing or not functioning correctly. Genetic defects in the immune system cause these conditions. There are >400 types of PID identified so far. More than 90% of PID are still undiagnosed in India. Hence it is very important to know about the symptoms of these diseases. They can present in infancy, childhood, or adulthood, depending on the severity.

EDITION IN BRUSSELS 64°F
THE TIMES OF INDIA
City Noida Mumbai Delhi Bengaluru Hyderabad Kolkata Chennai Agra Agartala Ahmedabad Ajmer Allahabad

CITIZEN REPORTER SCHOOL AND COLLEGES WEATHER POLLUTION NEWS UP ELECTIONS EVENTS

NEWS / CITY NEWS / NOIDA NEWS / Infection in Your Ear For Long? It May Be Immunodeficiency

Infection in your ear for long? It may be immunodeficiency

TNN / Apr 26, 2022, 03:09 IST

SHARE

AA

TOI

TOP VOICES



Noida: An ear infection for more than four times a year, repeated sinus infections, two or more instances of pneumonia in a year and little effect of prolonged use of antibiotics could be symptoms of primary immunodeficiency diseases in children, doctors have warned.

Doctors at the Child PGI in Noida said that while most of the infections caused by primary immunodeficiency were not fatal, some could also cause cancer. They were speaking on the occasion of world primary immunodeficiency week, which

An improved website

Enhancing awareness of PIDs & engagement with the community



New features

- Rolling banners on home page to spotlight new initiatives and how to get involved
- Revamped "Get involved" section, clearer and with access to quick information about how to join the campaign, tips and inspiration to mark the Week
- Dedicated pages for the podcasts and policy pledge

+400k

Total impressions (Feb-June)

85%

New visitors

**Facebook +
Instagram**

Top social referrals

New and optimized sections to continue improve user experience

Country involvement



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Section 1

Section 2



41 countries reported participation to World PI Week 2022



SNAPSHOTS OF NATIONAL EVENTS



Argentina



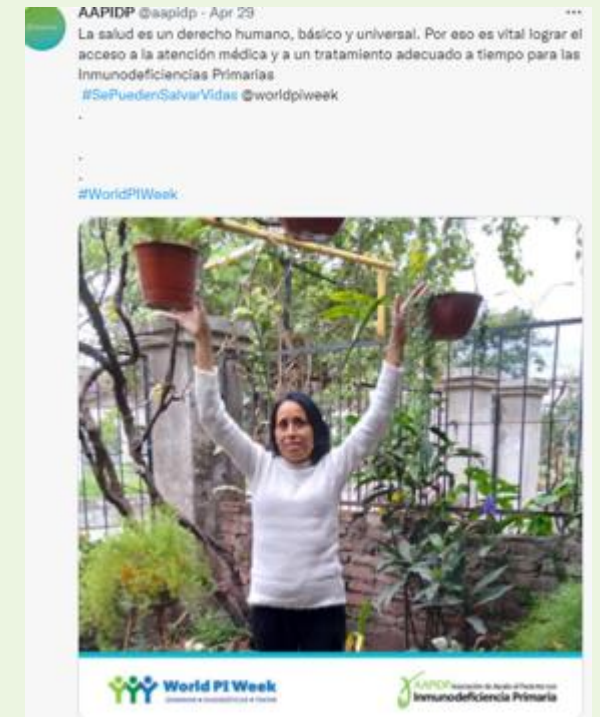
AAPIDP (Asociación de Ayuda al Paciente con Inmunodeficiencia Primaria)



- 2nd Virtual Congress for Patients with PIDs on 21st and 22nd of April
 - Overview of PIDs
 - Implication of Law
 - Covid-19 & Influenza Vaccines
 - Hematological & Oncological Manifestations
- #SePuedenSalvarVidas social media campaign
- “Strike a Y” Photo social media campaign
- Live TV presence at “Nuestra Salud” to talk about World PI Week + PID care



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Australia



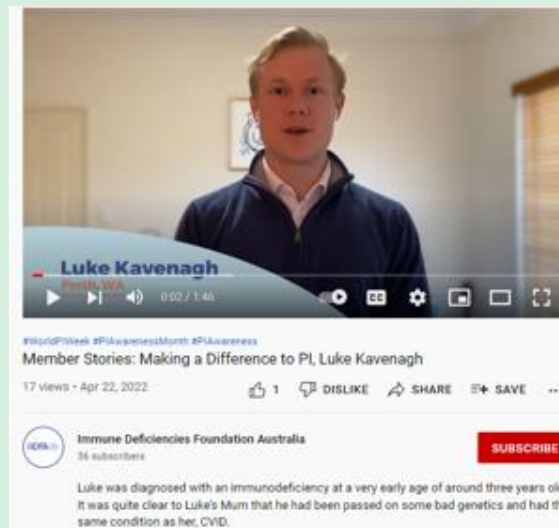
IDFA – Immune Deficiencies Federation Australia



- PI Education Program Webinars
- Patient testimonials
- Participation in #PictureAwareness Strike a Y social media campaign
- “Member Stories: Making a difference to PI” Booklet – digital storybook
- #RareAndPowerful, #PIAwarenessMonth, #LivingWithPI, #IDFACommunity



Click to see more



Don't miss out!

Making a Difference to PI

Tonight @ 7pm (AEST)
Online via Zoom

FREE TO REGISTER!
idfa.org.au/events



Australia



Australian Society of Clinical Immunology and Allergy (ASCIA)



- Launch of ASCIA Immunodeficiency Strategy for Australia and New Zealand



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ASCIA Immunodeficiency Strategy for Australia and New Zealand

29 April 2022



The ASCIA Immunodeficiency Strategy for Australia and New Zealand was developed by ASCIA, the peak professional body of clinical immunology and allergy specialists in Australia and New Zealand, in consultation with patient organisations (AusPIPs, HAE Australasia, IDFA and IDFNZ), and other stakeholders. Whilst the main content of the Strategy was completed in November 2020, the final version of the Strategy is now available, to coincide with the International Day of Immunology and World PID Week.

Belarus



Спасем иммунитет – Save Immunity



- #MyPiStory Campaign – sharing patient stories
- Republican Conference of Patients with PIDs
- Social media engagement
- Sharing World PI Week materials



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Belgium



Bubble ID



- Burst the bubble family and awareness raising event in Ghent



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Belgium



Belgian Patient Organisation for Primary Immunodeficiencies (BePOPI)



- Petition for patients with PID in a lockdown
- Educational animated video on PID
- Participation in #MyPhysicianAndI photo campaign led by IPOPI



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Mensen met PID leven in een lockdown - Les patients atteints de DIP vivent confinés



785 have signed. Let's get to 1,000

Tatiana S. signed 6 hours ago

Ietta V. signed 2 days ago

First Name

Last Name

What do you need to know about PID? Discover it in this video .
Help patients with PID; share this video and sign the petition .

<https://bit.ly/37yDafK>

Editing: Beeldman Design

Ipopi

#... See more

See original · Rate this translation

Wat is PID?



0:06 / 0:40



2

22 shares



Bolivia



FIDEP – BOLIVIA (The Primary Immunodeficiencies Patient Organisation)

- “10 Alarm Signs” Information Videos distributed throughout the week online, alongside other educational material



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Brazil



Hospital Pequeno Príncipe



- Workshop on Diagnosis and Treatment of Inborn Errors of Immunity



Click to see more

Semana Mundial das IMUNODEFICIÊNCIAS PRIMÁRIAS de 22 a 29 de abril



A informação é sua melhor aliada no diagnóstico precoce

O Complexo Pequeno Príncipe participa, desde 2014, da **Semana Mundial das Imunodeficiências Primárias (WPIW)**. Neste ano, a instituição promove um evento multidisciplinar com atenção ao tema da campanha de 2019: **"O Paciente no Centros dos Cuidados"**. Sua participação é essencial.

I Workshop de Diagnóstico e Tratamento: Erros Inatos da Imunidade
Parte da programação da Semana Mundial das Imunodeficiências Primárias – WPIW 2019

Data: 27 de abril (sábado)
Horário: das 8h às 12h30
Local: Centro de Simulação Realística
Rua Brigadeiro Franco, 2.879 – 2º andar

Vagas:
Medicina (10), Psicologia (10),
Biomedicina/Biologia (10),
Enfermagem (10) e Farmácia (10)

Inscrição:


Programação:

8h às 8h10	Abertura
8h10 às 8h30	Diagnóstico e Acompanhamento Clínico Integrado do Bebê com SCID (Carolina Prando, médica imunologista e pesquisadora do IPPP)
8h30 às 8h50	O Impacto Emocional do Diagnóstico de uma Doença Grave (Bruno Jardim Mader, psicólogo)
8h50 às 9h10	O Transplante de Medula Óssea em SCID (Euripedes Ferreira, médico e chefe do Serviço de TMO)
9h10 às 9h30	Coffee break
9h30 às 11h30	Oficinas (inscreva-se na atividade referente à sua área de atuação) Oficina 1 – Exames Laboratoriais no Diagnóstico de SCID
9h30 às 10h10	Citometria de Fluxo (Ana Carolina Inada, bióloga do IPPP)
10h10 às 10h30	PCR em Tempo Real (Bianca Pizanga, biotecnologista do IPPP)
10h30 às 11h30	Sequenciamento Genético (Laine Schildowski, bióloga do IPPP)
9h30 às 10h15	Oficina 2 – Reposição de Imunoglobulina em SCID – pré e pós-transplante
10h15 às 11h30	Prescrição de Imunoglobulina Intravenosa e Subcutânea (Carolina Prando, médica imunologista e pesquisadora do IPPP) Simulação de Infusão de Imunoglobulina (Carolina Prando, médica imunologista e pesquisadora do IPPP; Houda Izabela de Oliveira, enfermeira; Heloisa Arruda Gorn Barreto, farmacêutica; e Diego Bastos Guimarães, farmacêutico)
9h30 às 11h30	Oficina 3 – Psicologia nas Doenças Raras
11h30 às 12h	Resiliência e Enfrentamento: Promoção, Prevenção e Intervenção Psicológica nas Doenças Raras (Bruno Jardim Mader, psicólogo) Encerramento: A Importância da Pesquisa nas Imunodeficiências Primárias (Carolina Prando, médica imunologista e pesquisadora do IPPP)



Canada



CIPO - The Canadian Immunodeficiencies Patient Organization



- First Annual Walk for PI with 103 participants across the globe
- World PI Week 2022 Special Webinar "Ensuring Access to Treatment"
- Social media engagement
 - Sharing World PI Week material



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Canada



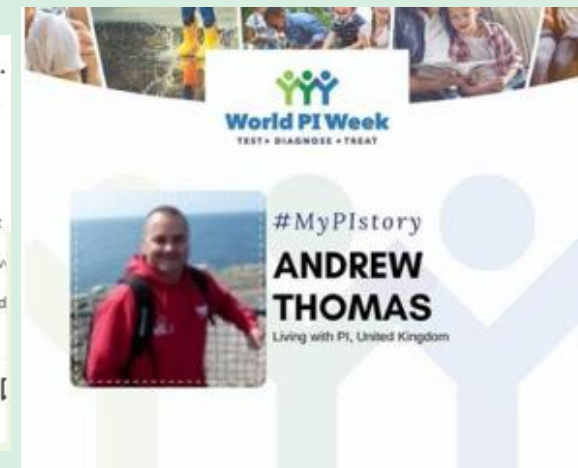
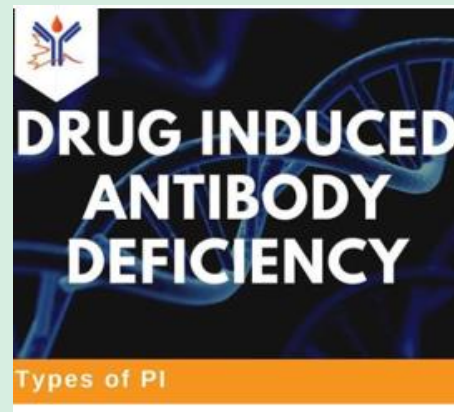
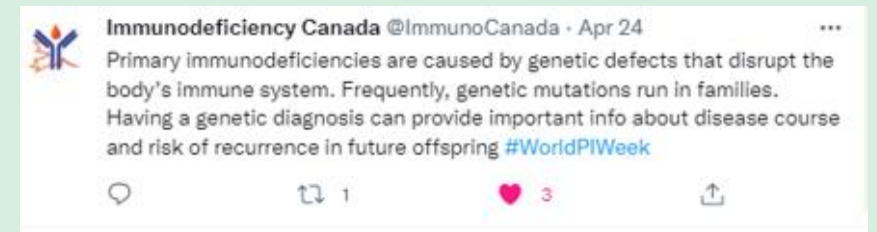
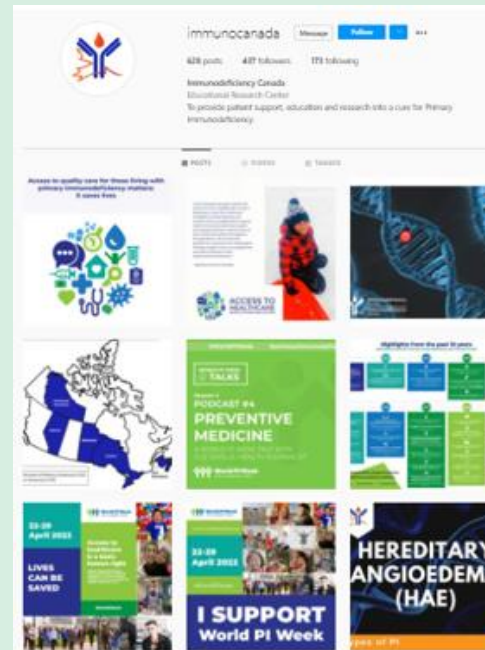
Immunodeficiency Canada



- Social media engagement
- #MyPIStory – patient stories
 - Relayed information and resources on PI
 - Shared patient testimonials



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Chile



Fundacion IDP Chile



- Picnic with the organisation community
- Virtual meeting to raise awareness of the organisation & PIDs



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China



PID Care China



- "Jump for PI" Campaign
- Sending out comfort toy designed for China's PID patients
- Contributed video stories/pictures with patient testimonials
- High involvement in the World PI Week "Strike a Y campaign)



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Columbia



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

- Social media dissemination of campaign material
- Online webinar on PIDs
- Expert discussion on PID treatments



Los invitamos hoy a las 9am a escuchar la entrevista al Dr. Eduson Morales s las 9am sobre el desabastecimiento de Gamaglobulina Humana #WPIW

We invite you today at 9am to listen to Dr. Eduson Morales' interview at 9am on the Dispute of Human Gamaglobulin #WPIW





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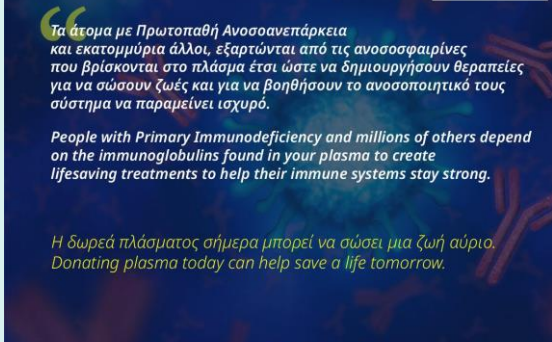
Section 1

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“Τα άτομα με Πρωτοπαθή Ανοσοανεπάρκεια και εκατομμύρια άλλοι, εξαρτώνται από τις ανοσοσφαιρίνες που βρίσκονται στο πλάσμα έτσι ώστε να δημιουργήσουν θεραπείες για να σώσουν ζωές και για να βοηθήσουν το ανοσοποιητικό τους σύστημα να παραμείνει ισχυρό.

People with Primary Immunodeficiency and millions of others depend on the immunoglobulins found in your plasma to create lifesaving treatments to help their immune systems stay strong.

Η δωρεά πλάσματος σήμερα μπορεί να σώσει μια ζωή αύριο.
Donating plasma today can help save a life tomorrow.



World PI Week
TEST • DIAGNOSE • TREAT

#WorldPiWeek2022
World Week dedicated to Primary Immune Deficiencies.

We would like to thank Simba Land kinder garden, for the support and for the organization the children prepared.

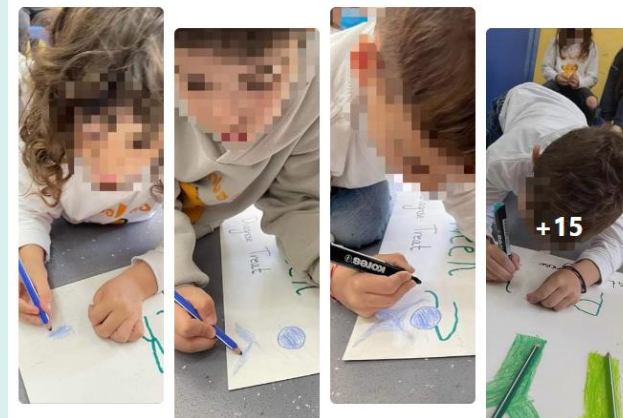
Their participation in vigilance and awareness of Primitive Immune Deficiencies!

💚💚💚

👉 Together, we are bringing change for patients with primary immune deficiency, no matter where they are!

#worldpiweek #primaryimmunodeficiency #ομαδατοπαιωνμεσυγγενηανοσοανεπαρκεια #2022
#worldpiweek2022 #WPIW #PIAwarenessMonth #primaryimmunodeficiencycyprus
#πρωτοπαθειαςανοσοανεπαρκειες #ΕΛΕΓΞΕ #ΔΙΑΓΝΩΞΕ #ΘΕΡΑΠΕΥΞΕ #ΠΑΑ

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Ecuador



Foundation PIDE



- "Velada de Torches" event in to commemorate World PI Week in collaboration with the Ministry of Health
- Call for Immunoglobulin therapies in city of Cuenca
- Educative webinar on Primary Immunodeficiencies with specialists



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Fundación PIDE, de Pacientes con Inmunodeficiencias Primarias Ecuador
27 April · 🌐

Día 5 de la Semana Mundial de Inmunodeficiencias Primarias.
Ponentes:
17H30 - Dr Jorge Cañarte
18h30 - Dra Kelly Calvo
19h30 - Dr Miguel Cedeño ... See more

Day 5 of World Primary Immunodeficiency Week.
Speakers:
5:30pm - Dr Jorge Cañarte
6:30pm - Dr. Kelly Calvo
7:30pm - Dr Miguel Cedeño... See more

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Today we had the audience in the city of Cuenca, to fight for normal human immunoglobulin to have a dignified life. We demand the state and the Constitutional Judge, favor us with the treatment that helps us stay alive.
#VidaDigna #Justicia #saludpublica #worldpiweek #cuenca

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Estonia



Immuunpuudulikkuse Selts



- Social media engagement
 - Sharing World PI Week material
- Presence at the IPIC Congress



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France



Association IRIS



- "Solidarity Run / Courir pour IRIS" with hundreds of people running, walking, cycling and more in support of PID patients
- Participation in IPIC Conference
- Interviews with PID patients and their families



Click to see more

🗣️ Cette semaine, l'Association IRIS est allé interviewer la famille de Livia dans le cadre d'une série de témoignages de patients que vous découvrirez bientôt...

👨‍👩‍👧‍👦 Si cette petite fille est là aujourd'hui, entourée de ses parents et de son grand frère, c'est parce que Livia a pu bénéficier du dépistage néonatal élargi, ces quelques petites gouttes de sang sur le test de Guthrie qui ont permis de révéler un DICS (Déficit Immunitaire Combiné Sévère).

😊 La suite de leur histoire bientôt en images...



Greece



For what you hold most dear.

IASO Children's Hospital - Paediatric Immunology Department

- Scientific Symposium in collaboration with European Society for Immunodeficiencies
- Hybrid Scientific Lecture "The effects of Microbiome and Immunoglobulin therapy on immune dysregulation"
- Social media engagement



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IASO Children's Hospital
For what you hold most dear.

World PI Week
TEST • DIAGNOSIS • TREAT

ESID
European Society for Immunodeficiencies

LIVES CAN BE SAVED #WorldPIWeek

Access to healthcare is a basic human right
People living with primary immunodeficiency worldwide depend on it. Each of them is entitled to the correct diagnosis, quality treatment & care.

SYMPOSIUM OF ESID SUMMER SCHOOL IN COLLABORATION WITH DOCTORS OF IASO CHILDREN'S HOSPITAL

"Update on Primary Immunodeficiencies - Inborn Errors of Immunity"

FRIDAY 06/05/22 | TIME: 14:30 - 18:30 p.m.
IASO Events Hall (37-39 Kifissias Ave, 151 23, Marousi)

Notably Invited Speakers:
Faculty of ESID Education Working Party

Scientific Directors:
Despina Moshous, Paris, France
Maria Kanariou, Athens, Greece

The One - Day Meeting will be carried out via live streaming @ attendance in person. PARTICIPATION IS FREE

Information:
Polina Valassi - Events & Conferences Coordinator | T: 210 6383906
37-39 KIFISSIAS AVE / 151 23, MAROUSI, ATTICA / TEL.: 210 6383000, 210 6383070-2 / FAX: 210 6383073
EMERGENCIES: 210 6383064, 210 6383065 / EMAIL: INFO@IASO.GR
www.iaso.gr

IASO Children's Hospital
For what you hold most dear.

World PI Week
TEST • DIAGNOSIS • TREAT

SCIENTIFIC LECTURE

"The effects of Microbiome and Immunoglobulin therapy on immune dysregulation"

THURSDAY MAY 12TH 2022
TIME: 13:00 - 14:00

IASO Events Hall
(37-39 Kifissias Ave, 151 23, Marousi)

Notable Invited Speaker
Prof. Andrew Gennery
Honorary Consultant, H&S,
The Newcastle upon Tyne Hospitals,
Paediatric Immunology, ID and Allergy,
The Great North Children's Hospital.

Scientific Director
Maria Kanariou
Paediatrician, Director of the Paediatric Immunology Department, IASO Children's Hospital.

Information
Polina Valassi
Events & Conferences Coordinator of IASO
Tel.: 210 6383906

Participation is free of charge
The Event will be carried out both via live streaming & attendance in person
37-39 KIFISSIAS AVE, 151 23, MAROUSI, ATTICA / TEL.: 210 6383000, 210 6383070-2 / FAX: 210 6383073
EMERGENCIES: 210 6383064, 210 6383065 / Email: info@iaso.gr
www.iaso.gr

Όμιλος ΙΑΣΩ
★ Αγαπημένα • 29 Απρ •

Το Ανοσιακό Σύστημα είναι η κύρια άμυνά μας 🌐, αλλά δεν λειτουργεί σε όλους μας αποτελεσματικά. Οι άνθρωποι... Δείτε περισσότερα

IASO Παιδών
Για όλη την παιδική ηλικία.

Διεθνής Ημέρα Ανοσολογίας
Παγκόσμια Εβδομάδα για τις Πρωτοπαθείς Ανοσοανεπάρκειες

522 2 σχόλια 6 κοινοποιήσεις

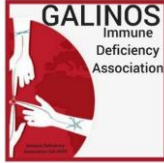
SYMPOSIUM OF ESID SUMMER SCHOOL IN COLLABORATION WITH DOCTORS OF IASO CHILDREN'S HOSPITAL

"Update on Primary Immunodeficiencies - Inborn Errors of Immunity"

FRIDAY 06 MAY 2022

14:30 - 14:40	Welcome and introduction Despina Moshous and Maria Kanariou	14:30 - 14:50	Inborn Errors of Immunity in Adults Emma C. Morris, London, UK
14:40 - 15:00	SCID in the era of Newborn Screening Manfred Hentig, Ulm, Germany	14:50 - 17:10	Warning signs of PID in Haematology/Oncology Eleonora Gambineri, Florence, Italy
15:00 - 15:20	From infection to immune deficiency Peter Oltbrich, Sevilla, Spain	17:10 - 17:30	Immune dysregulation Kathleen Sullivan, Philadelphia, USA
15:20 - 15:40	When to think about monogenic causes of CVID Pere Seler Palacin, Barcelona, Spain	17:30 - 17:50	A patient with immune dysregulation Vivian Maggina, Maria Kanariou, Athens, Greece
15:40 - 16:00	PIDs and cytoskeleton dynamics Fabio Candotti, Lausanne, Switzerland	17:50 - 18:10	The many faces of Haemophagocytic Lymphohistiocytosis Despina Moshous, Paris, France
16:00 - 16:30	Coffee Break	18:10 - 18:30	Discussion - End of the meeting

Greece



Immune Deficiency Association
of Greece - GALINOS



- Immune Deficiency Bracelet for members & patients
- Leaflet distribution with 10 warning signs & information of PID care in Greece



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 ΕΝΗΜΕΡΩΤΙΚΟ
ΦΥΛΛΑΔΙΟ

ΒΡΑΧΙΟΛΙ ΣΗΜΑΝΣΗΣ ΑΝΟΣΟΑΝΕΠΑΡΚΕΙΑΣ

Ο Πανελλήνιος Σύλλογος Ασθενών με Ανοσοανεπάρκειες Γαλήνος παρουσιάζει στους επαγγελματίες υγείας το βραχιόλι σήμανσης για τις ανοσοανεπάρκειες.

Το βραχιόλι αυτό σχεδιάστηκε με ευδιάκριτα στοιχεία και συνοδεύεται από QR code που κάνει ανακατεύθυνση σε συγκεκριμένο τομέα της επίσημης ιστοσελίδας του συλλόγου που περιέχει πληροφορίες για την πάθηση.

Στην μπροστινή όψη είναι χαραγμένο το σύμβολο του ιατρικού κηρυκείου και δίπλα η φράση IMMUNE DEFICIENCY PATIENT (Ασθενής με ανοσοανεπάρκεια στην αγγλική γλώσσα) ώστε να είναι εύκολα αναγνωρίσιμο από ιατρούς σε όλο τον κόσμο.

Στην πίσω όψη είναι χαραγμένο το σύμβολο του Συλλόγου ΓΑΛΗΝΟΣ που αποτελείται από χέρια που τέμνονται σε μια σταγόνα που συμβολίζει την στενά συνδεδεμένη σχέση της παθήσεώς μας με τις αιματολογικές παθήσεις αλλά και την θεραπεία της με γ-σφαιρίνη, ενώ αναγράφεται και η φράση Ασθενής με Ανοσοανεπάρκεια στα Ελληνικά.

Τα βραχιόλια διατίθενται σε δύο χρώματα μαύρο, και χρωματιστό με συνδυασμό τριών χρωμάτων (λευκό, μπλε, κόκκινο).





Hungary



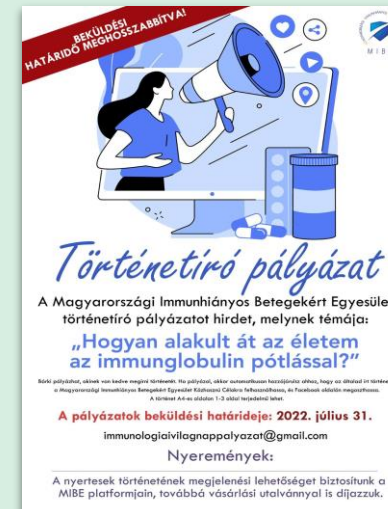
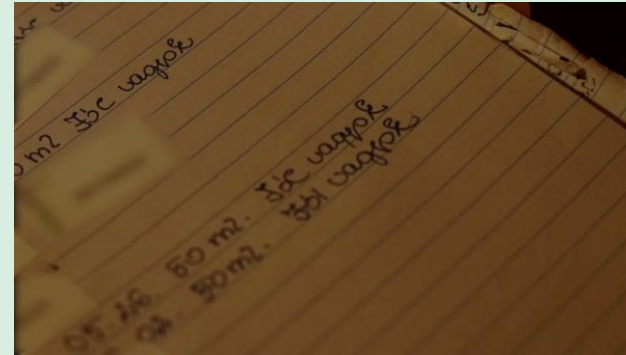
Magyarországi Immunhiányos Betegéért Egyesület



- Lectures about "The Way to the Infusion Chair"
- Short film on "Life rolls smoother with the right treatment"
- Charity donations to the Immunology Dept. and the Children Immunology Dept. of Debrecen University Clinical Centre
- Contest on patient stories



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India



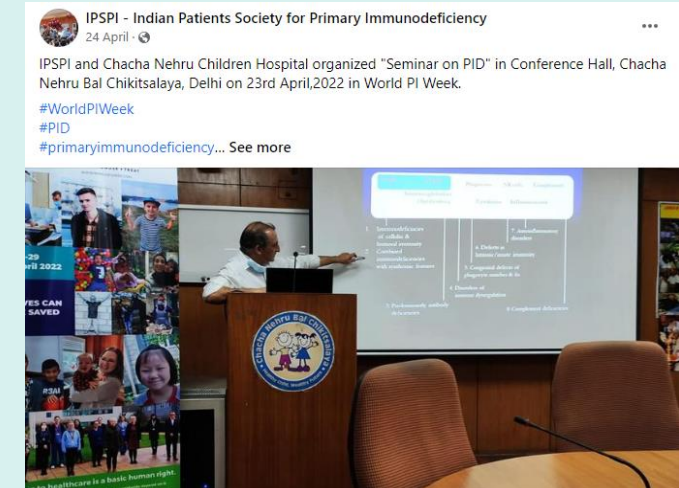
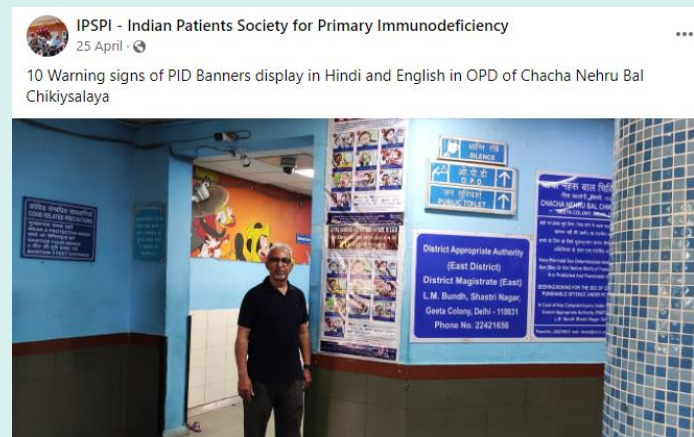
Indian Patients Society for
Primary Immunodeficiency
(IPSPI)



- Talk on PID in WPIW in Lady Hardinge Hospital
- Banner display in Chacha Nehru Children Hospital
- Seminar on PID in collaboration with Chacha Nehru Children Hospital



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Indonesia



IDAI

Indonesian Pediatric Society
Committed in Improving The Health of Indonesian Children



IDAI (Indonesian Pediatric Society)



- Awareness raising on social media
- Video launch on PIDs
- Online Symposium on PIDs



Click to see more



IDAI @idai_tweets · 20 Apr
Dalam rangka Pekan Imunisasi Dunia, IDAI menyelenggarakan Kompetisi Video Edukasi Imunisasi dengan tema "Sehatkan Anak dan Keluarga dengan Vaksinasi".
Batas pengumpulan video diperpanjang sampai tanggal 25 April 2022.
[#WorldImmunizationWeek2022](#)
[#KompetisiIDAI](#)
[#IDAI](#)



Indonesia

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PREVIOUS

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Section 2



Indonesia Primary
Immunodeficiency Patients
Society - IPIPS



- Launch of Parents Story
- WPIW photo competition to increase engagement
- Launch of IPIPS via live interview in the official channel
- Social media engagement



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Iran



Iranian PiA



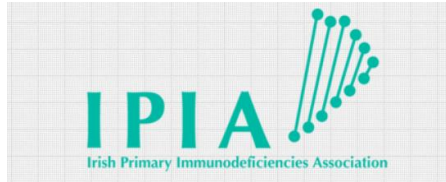
- In person meeting with patients, physicians and nurses
 - Entertaining shows for children and various activities in the meetings



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Ireland



IPIA - The Irish Primary Immunodeficiencies Association



- Social media engagement
- Awareness Stand display in collaboration with St James Hospital Dublin and Children's Health Ireland at Crumlin



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IPIA Ireland
@ipiainfo

@CHlatCrumlin @stjamesdublin @IPOPI
#WorldPIWeek Raising awareness among the patients' social environment, general public, medical professionals and policymakers helps improve understanding of the disease in support of people with primary immunodeficiency

Patient centred-care in primary immunodeficiency

5 KEY Principles

- Each individual is different: one-size-does-not-fit all**
Each individual is different: one size does not fit all. There are over 200 different types of primary immunodeficiencies, estimated to affect one in 10,000 people worldwide.
- Working with patients - not around**
During their journey many patients and carers are become familiar with the complexities of the disease. Involvement and benefits of the health care system are essential. Their input and experience is essential to successful medical management.
- Involving multiple actors**
A multi-disciplinary approach to patient care is required. It is a mix of all actors working together in care delivery from patients, families and carers to allied health care professionals, biologists and researchers and for legal health and social services.
- Creating value**
Patient benefit is the end goal of care.
- Genetic therapies**
Genetic therapies are not generic medicines and should be considered on a case-by-case basis. They are not available to all patients and are not available in all countries.

Genetic therapies can be a game-changer for some patients with primary immunodeficiency but are not available to all patients and are not available in all countries.

Advocacy, education and awareness are essential for all patients. Patients need to know and understand their condition, the available treatments and the support services available.

IPIA Ireland @ipiainfo · Apr 28

IPIA is so thankful for all the hard work that the Immunology Department @stjamesdublin and @CHlatCrumlin put in place during this WPIWeek. We hope to repeat this in the years to come. IPIA is grateful to have you on our team. Thank you for all that you do! #WPIWeek #IPOPI #PID

1 6

Israel



Bubble Care



- Launch of website and facebook page.
- Development of posters and brochures
- Films with English subtitles on PIDs
- Media articles on PIDs, gene therapy and awareness raising



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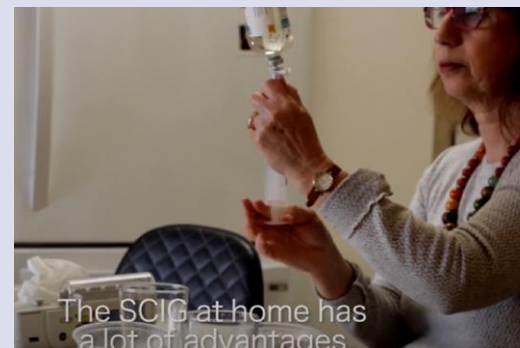
עמותת BUBBLE CARE

עמותה ללא כוונת רווח אשר פועלת למען מטופלי חסר חיסוני. מטרותיה הן-

- כנסים והסברה
- הדרכה לחולים ולבני משפחתם
- מימון אמצעי מניעה
- קידום חלופות טיפול

אנו שואפים ליצירת מענה לחולים ויחד כקבוצה נסייע אחד לשני בתמיכה ובקידום מטרותינו

צרו קשר דרך האימייל: info@BubbleCare.org.il בקרו אותנו באינטרנט: www.BubbleCare.org.il



בדקו את עצמכם:
אם אתם סובלים מדלקות חוזרות או ממושכות כמו דלקות אוזניים, סינוסים, ריאות, עור, מעיים.

70-90% של חולים בחסר חיסוני ראשוני עדיין לא מאבחנים

אולי אתם סובלים ממחלה של חסר חיסוני ראשוני? לכו לרופאים אימונולוגיים להיבדק.
primary Immune Deficiency - PID המחלה נקראת
שבוע מודעות למחלות של חסר חיסוני ראשוני 22-29 באפריל
עמותת באבל קר Bubble Care Bubblecare.org.il

עמותת באבל קר (Bubble Care) - עמותה ללא כוונת רווח אשר פועלת למען מטופלי חסר חיסוני. מטרותיה הן-

הקמת חלופות טיפול לרופאים (SCIG) - אמצעי למניעת נזקקים (Tablets) - אמצעי למניעת נזקקים (Tablets) - אמצעי למניעת נזקקים (Tablets)

23.1.2022

and to help improve patients' quality of life.



Italy



Associazione Immunodeficienze Primitive & Federazione Italiana Associazioni Donatori di Sangue

- Comics of the adventures of Lino Globulino for children
- IPIC presence
- 30th anniversary of AIP OdV



Click to see more



Beautiful day yesterday in Jesi with the Ancona group! It began with the shareholders' meeting that approved the financial statements and ended with a lunch to celebrate together the first 30 years of AIP OdV ❤️
#worldpiweek #ipopi #myphysicianandi #aipodv #insiemesipuò



aip ASSOCIAZIONE IMMUNODEFICIENZE PRIMITIVE O.d.V.

Incontro medici pazienti

Sabato 23 Aprile 2022
ore 11:00
Hotel Federico II
Via Ancona 100, 60035 - Jesi (AN)

Programma:
"Impatto del COVID sulla immunodeficienza comune variabile"
"Autoimmunità e poliautoimmunità nella COVID"
"Nutrizione e COVID"
Prof.ssa Maria Giovanna Danieli, Dr.ssa Cristina Mezzanotte, Dr. Daniele Fumelli
A.O.U. Ospedali Riuniti di Ancona

30 ANNI INSIEME

A seguire pranziamo insieme per festeggiare i nostri primi 30 anni!
Sei socio? Il pranzo lo offriamo noi.
Contributo per accompagnatori non soci € 20,00.
Puoi anche associarti sul posto. Bimbi sotto i 10 anni gratis.

Info e prenotazioni: info@aip-it.org - 351.0269978

Kenya



PIDS Kenya



- Social media engagement



Click to see more



Malaysia

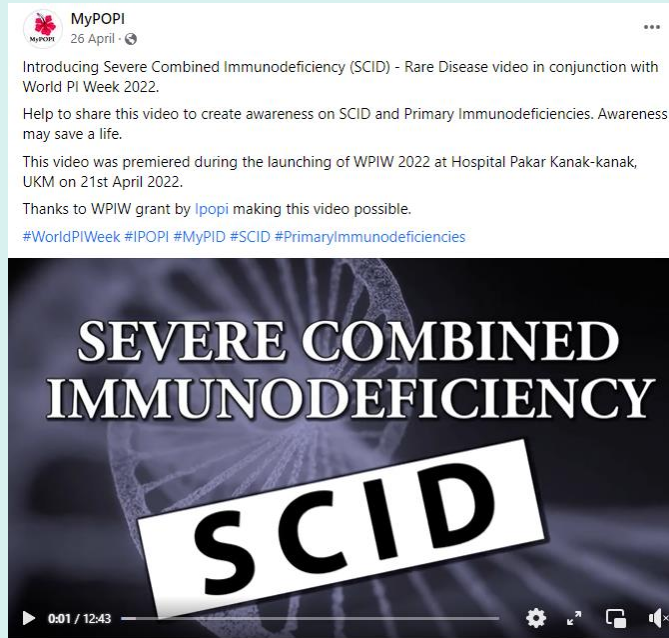


MyPOPI - Malaysia Patient Organization for Primary Immunodeficiencies

- Launch of rare disease video focusing on Severe Combined Immunodeficiency (SCID)
- Live interview on news channel and dissemination of WPIW campaign & MyPOPI material
- Awareness raising activities in collaboration with Child Passenger Safety Malaysia
- Charity exhibition sales



Click to see more



Thank you Child Passenger Safety Malaysia for partnering with us in World PI Week 2022 celebration by sharing awareness on Primary Immunodeficiency. Early diagnosis is key in improving quality treatment and care. Access to healthcare is basic human right!
#WorldPIWeek #MyPID



Morocco



Hajar



- Awareness raising campaign
- Education for families
- Vaccination training for doctors



Mexico



Fundación Mexicana para Niñas y Niños con Inmunodeficiencias

- Live Call to action to the government to promote detection of PIDs
- Social media engagement to share information on PIDs



INMUNODEFICIENCIA COMÚN VARIABLE (IDCV)



Es un trastorno caracterizado por los bajos niveles de inmunoglobulinas del suero (anticuerpos) y una mayor susceptibilidad a infecciones. Esta es una forma relativamente común de inmunodeficiencia, de ahí, la palabra "común". El grado y tipo de deficiencia de inmunoglobulinas del suero y la conducta clínica, varía de paciente a paciente, de ahí, la palabra "variable".

Pueden ocurrir infecciones frecuentes e inusuales durante la primera infancia, la adolescencia o la vida adulta. En la mayoría de los pacientes, el diagnóstico no se realiza sino hasta la 3era o 4ta década de la vida. Sin embargo, alrededor del 20% de los pacientes muestra síntomas de la enfermedad o deficiencias del sistema inmunológico antes de cumplir 16 años.

FACTORES GENÉTICOS Y HEREDITARIOS

Debido a la confusa naturaleza genética de la IDC, no se ha establecido un patrón hereditario claro. En algunos casos, hay más de un miembro de la misma familia con deficiencias de una o más clases de inmunoglobulinas. Por ejemplo, no es inusual que un miembro de una misma familia tenga IDC, mientras que otro padezca una deficiencia selectiva de IgA.

CUADRO CLÍNICO

- Tanto hombres como mujeres pueden padecerla.
- Los signos iniciales en la mayoría de los pacientes son infecciones recurrentes que afectan oídos, senos paranasales, nariz, bronquios y pulmones.
- Una tos frecuente por las mañanas que produce un esputo amarillo o verde sugiere la presencia de una infección crónica o bronquiectasias (dilatación, cicatrización e inflamación de los bronquios).
- Pueden presentar aumento de los ganglios linfáticos del cuello, pecho o abdomen.
- El aumento del tamaño del bazo es relativamente frecuente.
- En el 20% de los casos la primera manifestación es un nivel muy bajo de plaquetas en sangre o quizá una anemia grave debido a la destrucción de los glóbulos rojos.
- Artritis o trastornos endocrinos, como enfermedades de tiroides.
- Molestias gastrointestinales, como dolor abdominal, hinchazón, náusea, vómito, diarrea y pérdida de peso.
- Por último, los pacientes con IDC pueden tener un mayor riesgo de cáncer, especialmente de cáncer del sistema linfático, de piel y del tracto gastrointestinal.

TRATAMIENTO Y PRONÓSTICO

La terapia substitutiva con inmunoglobulinas en combinación con la administración de antibióticos ha mejorado enormemente las perspectivas de los pacientes. El objetivo del tratamiento es mantener al paciente libre de infecciones y prevenir la manifestación de enfermedades pulmonares crónicas.

FUMENI

Netherlands



Stichting voor
Afweerstoornissen (SAS)
Foundation for Immune
Disorders



- Video and podcast series
- Speech in the IPIC Conference
- Social media engagement

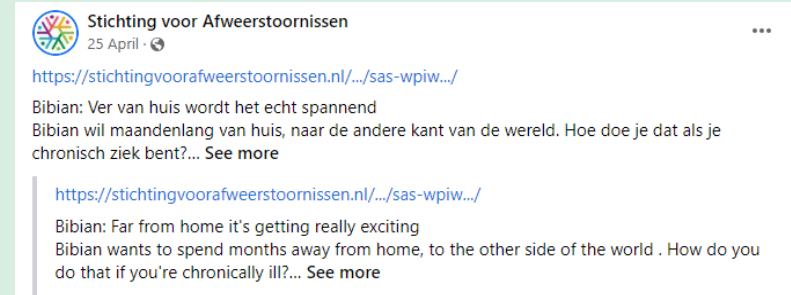


Click to see more

WPIW Week 2022

Watch all videos and listen to all podcasts published so far from the WPIW week.

1. Video – Why is the SAS coloring the Erasmus Bridge green?
2. Video – What does it mean to grow up with a primary immune deficiency?
3. Podcast – Thijs: I'm not pathetic, I want to party
4. Podcast – Bibian: far from home it gets really exciting
5. Podcast – Natalie: I'm just starting to live
6. Video – Treatment of PID
7. Video – Working together for a better quality of life



New Zealand



IDFNZ Kids Foundation



- World PI Week Quiz
- Content dissemination in different languages
 - Warning Signs
 - Information packs for general practitioners



Click to see more

Thank you for participating in World PI Week 2022

Remember – IDFNZ Warning signs posters are available to download free in English, Samoan, Maori, Mandarin, Tongan and Hindi.

https://idfz.org.nz/.../13/7_warning_signs_PID_POSTER_1.pdf

https://idfz.org.nz/.../23/7_Warning_Signs_Maori_PRINT.pdf

https://idfz.org.nz/.../7_Warning_Signs_Chinese_PRINT.pdf

https://idfz.org.nz/.../23/7_Warning_Signs_Tonga_PRINT.pdf

https://idfz.org.nz/.../23/7_Warning_Signs_Samoa_PRINT.pdf

https://idfz.org.nz/.../11/PID_Information_Order_Form.xlsx

Information packs for General practitioners can be ordered free from info@idfz.co.nz – we will post these out free on your behalf.

https://idfz.org.nz/.../2022/04/22/1778_001_0ZSxOw3.pdf

Join us in helping to raise awareness to support those living with PI. IDFNZ have a wide range of resources that are available free – help us to spread awareness by downloading and sharing these resources through social media, or print off posters to display at your workplace, school, or medical centre.

You can support the charitable work of IDFNZ with a donation

<https://idfz.org.nz/get-involved/make-donation/>

Organise a school multi day or Orange day to support IDFNZ – we can provide cool information packs and story books if you contact us at info@idfz.org.nz.

IDFNZ Kids Foundation
28 April · 📢

The Covid Pandemic has impacted on our vulnerable PID community.

In the inaugural IDFNZ 'Living with PID' series, we bring you the first of a collection of talks addressing the latest information for PID patients.

Listen to Dr Miriam Hurst speaking on PID and Covid, the New Zealand experience. (27 minutes).
Click Following Link to Start Presentation: <https://youtu.be/CfZ9wjEmtc>

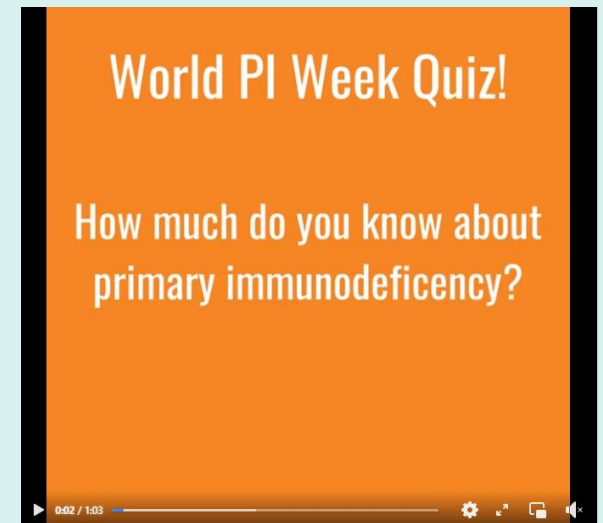
IDFNZ
Immune Deficiencies Foundation
of New Zealand

LIVING WITH PID
PATIENT EDUCATION SERIES

Session 1
PID & Covid in Adult Patients - New Zealand Update
Dr Miriam Hurst, MBChB, FRACP, FRCA
[Watch now](#)

IDFNZ Kids Foundation
We are a not for profit organisation dedicated to supporting New Zealanders o...

Call Now



Philippines



Philippines Patient Organization
for Primary Immunodeficiencies



- Disseminating WPIW 2022 content on social media



Click to see more



immunoprotect

- Live TV coverage of PIDs with patient representatives and experts
- Social media engagement
- "Resilience can be shared" campaign
 - Meeting with experts ahead of WPIW 2022

[Click to see more](#)



Szerzymy wiedzę! Nasza kampania w telewizji śniadaniowej. - Mądra Opieka
W ramach kampanii „Odpornością można się dzielić. Jak mogę pomóc?” dzielimy się wiedzą n...



Portugal



APDIP - Associação Portuguesa de Doentes com Imunodeficiências Primárias

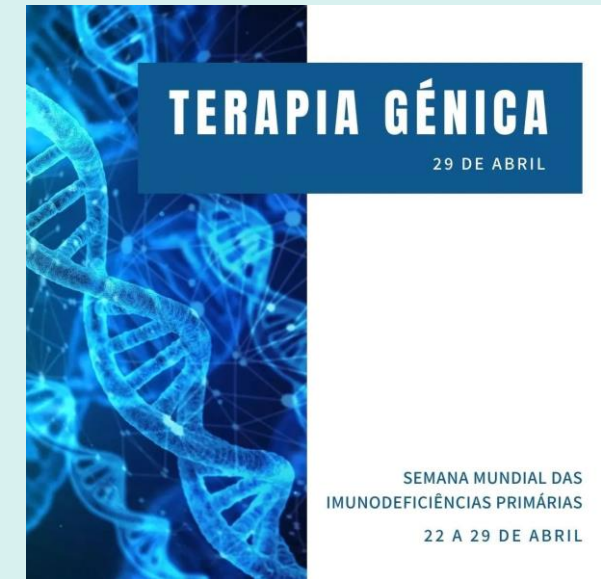
- IPIC presence
- Social media engagement
 - Awareness raising of different PID treatments



Click to see more

Na 5a. Edição do IPIC, reencontrámos alguns amigos, desta maravilhosa família, de quem já tínhamos saudades! É que bem que soube! #IPICS #IPOPI #wordpiweek #DP #PID

See translation



Romania

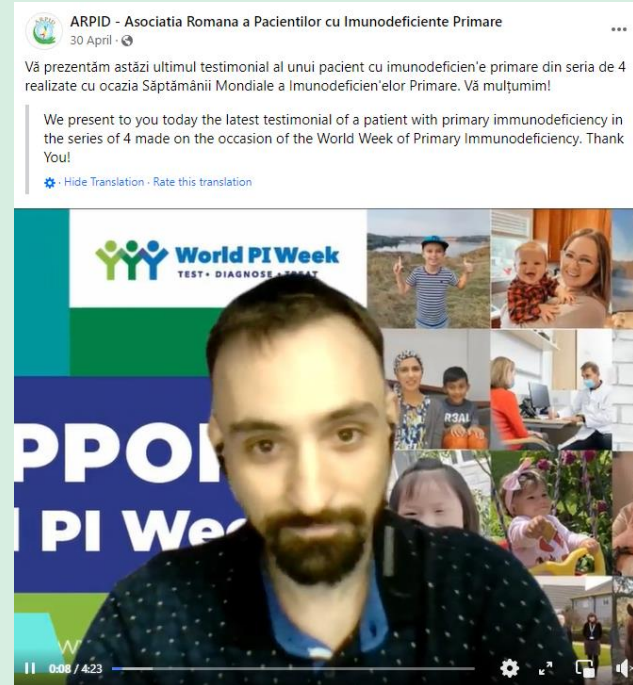


ARPID - Romanian Association of Patients with Primary Immunodeficiency



- Patient testimonials
- IPIC Presence
- Social media engagement
- Collaboration with Military hospital in awareness raising


Click to see more





SĂPTĂMÂNA IMUNODEFICIENȚELOR PRIMARE

22 - 29 aprilie 2022

SUSȚINEM

"Am primit cu entuziasm propunerea de a mă alătura echipei care se ocupă de îngrijirea pacienților cu imunodeficiență primară, în cadrul programului de diagnostic și tratament dedicat acestora. Domeniul imunodeficiențelor primare este unul dintre cele mai interesante, dinamice și de vârf din medicina actuală, în continuă dezvoltare. La acest moment, în secția noastră, beneficiem de cele mai noi tehnologii din domeniul geneticii, fapt ce ne permite diagnosticul bolilor rare și complexe, care până în urmă cu câțiva ani nu erau cunoscute. Satisfacțiile profesionale sunt extraordinare și sunt întrecute doar de bucuria că putem oferi, la timp, tratamentul corect pacienților noștri.

A fost și este un drum dificil, pavat uneori cu dificultăți, pe care, împreună cu pacienții noștri, încercăm să îl străbătem cu mult optimism!

Vom continua să fim alături de ei, indiferent de cât de anevoios va fi acest drum!

Doar împreună vom putea reuși!"

Dr. Anca Manolache
Medic primar medicină internă/ Secția Clinică Medicină Internă II
Spitalul Universitar de Urgență Militar Central "Dr. Carol Davila"

SUSȚINĂ SĂPTĂMÂNA IMUNODEFICIENȚELOR PRIMARE!

Spitalul Universitar de Urgență Militar Central "Dr. Carol Davila"

29 April -

South Africa



PINSA Primary Immunodeficiency Network of South Africa

- Social media engagement promoting "Being Different makes us stronger"



Click to see more

Join us in celebration of World Primary Immunodeficiency Week! Help us celebrate "Being different makes us stronger!" 🙌

Angie was diagnosed at only 10 months old and is now 13 🌸 By the age of 5 she had overcome more than 50 hospitalizations, countless blood tests, X-rays & 5 surgeries. Today she has done 451 life-saving infusions at home! She has survived TB, almost lost her vision, and been on continuous antibiotics for 8 years.

BUT our warrior princess has launched a book on Childhood TB in 2018 in The Hague, where she met 2 real life princesses! 🙌 She is smart, persistent, stubborn and creative; loves animals with all her heart and is an outstanding horse rider. She has overcome, and is a true shining light for others with PI 🌟 We are endlessly grateful to God for preserving her life, and so proud of our Warrior Princess ❤️

#WorldPIWeek

#primaryimmunodeficiency

#differentisok

Rare Diseases South Africa NPO 120-991

lpopi



PINSA
28 April · 🌐

Thank you [Coldplay](#) for helping us to realize that Being Different is okay.

Join us in celebration of Patients with Rare Diseases. This week is World PI week and we celebrate how being different makes us stronger. Our genetic immune systems might be weak but we tougher than you think.

Coldplay you inspire us, we thank you!

lpopi

#RareDiseasesSA

<https://www.youtube.com/watch?v=zvp3bvL8gMg>



South Africa



AFSA (Allergy Foundation South Africa)



- Social media dissemination of campaign material
- Awareness raising for PIDs on social media



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Spain



Barcelona PID Foundation



- "I have PID, I am not alone" video campaign
- PID course for nursing staff
- Hospital visit with the Ginebro School of Llinars del Vallès



Click to see more



YOUTUBE.COM

"Tinc IDP. Ja soc gran i no estic sol." - #WPIW2022

Amb molta il·lusió us presentem avui el vídeo del projecte d'atenció psicossocial d'adults, on m...

On the 25th of April, the 12th #IDP course for resident doctors and the 8th IDP course for nursing staff began. From the BCN PID Foundation we co-sponsor these courses, organized by [Societat Catalana d'Immunologia](#) and [Societat Catalana de Pediatria](#)

One of our objectives is to promote excellence in the knowledge, study, research and dissemination of IDPs and infectious etiology complications that may be presented to affect...
[See more](#)

[Hide Translation](#) · [Rate this translation](#)



Sudan



SOPPI - Sudanese Organization for Patients with Primary Immunodeficiency

- Online support to World PI Week campaign
- National News Coverage
- Event organisation to support PID patients



Click to see more

OTHER POSTS



Thailand



ThaiPOPI



- Delivering souvenirs and spray alcohol to the Thai Red Cross & to donors
- Social media engagement
 - Disseminating 10 warning signs fact sheets



Click to see more



Turkey



AID – Turkey International Allergy and Clinical Immunology Association

- Webinar on PID with experts



Click to see more

Dünya Primer İmmün Yetmezlikler Haftası 2022

Dünya Primer İmmün Yetmezlikler Haftası



28 Nisan
2022
Perşembe



19.30
20.30



Antikor eksikliklerine güncel yaklaşım:
Kimi, nasıl tedavi edelim?
Dr. Hasibe Artaç



Ağır kombine İY'de karşılaşılan sorunlar
ve çözümleri
Dr. Safa Barış



PIY tanısında hızlı ve pratik çözümler:
Yapay zeka teknikleri
Dr. Kazım Okan Dolu



Moderatör:
Dr. Şebnem S. Kılıç

www.aid.org.tr



Uganda

PIPO Uganda

@ Patient Organization for Primary Immunodeficiencies - PIPO

- Awareness raising campaigns in different locations
 - Patients & care takers
 - Health care providers



Click to see more



United Kingdom



Immunodeficiency UK



- Social media engagement
- Dissemination of information charts



Click to see more



NOW AVAILABLE

Ig Therapy Products & Risk Factor Chart

- FDA-approved Ig brands
- Dosing and administration
- Formulation differences
- Available sizes and storage
- Risk factors and interventions tear sheet

The Ig resource that you'll use daily! **Available FREE**

A graphic showing the Ig Therapy Products & Risk Factor Chart. It includes a table of FDA-approved Ig products, a section for dosing and administration, and a risk factor chart. The chart lists various risk factors and their associated interventions, such as "Do not use if you have a history of severe allergic reaction to any component of the product" and "Do not use if you have a history of severe allergic reaction to any component of the product".

United States



The CGD Association of America



- Educational video series on CGD



Click to see more

CGDAA Launches Educational Video Series on CGD for #WorldPIWeek

April 26, 2022 | CGD carriers, Patients with CGD

For World PI Week, CGDAA Launches a Special Educational Video Series on CGD, Featuring Dr. Harry Malech, a Globally-Recognized Expert in the Field



To recognize **#WorldPIWeek**, April 22-29, a global effort that aims to raise awareness for primary immunodeficiencies (PI), the CGD Association of America is pleased to share a video series featuring **Harry Malech, M.D.**, Chief of the Genetic Immunotherapy Section at the National Institutes of Health, a globally-recognized expert in Chronic Granulomatous Disease, and a member of the CGDAA's medical advisory board.

United States



Immune Deficiency Foundation



- Promoting World PI Week on social media
- "Walk for PI" campaign
- SCID knowledge survey
- Promoting donations



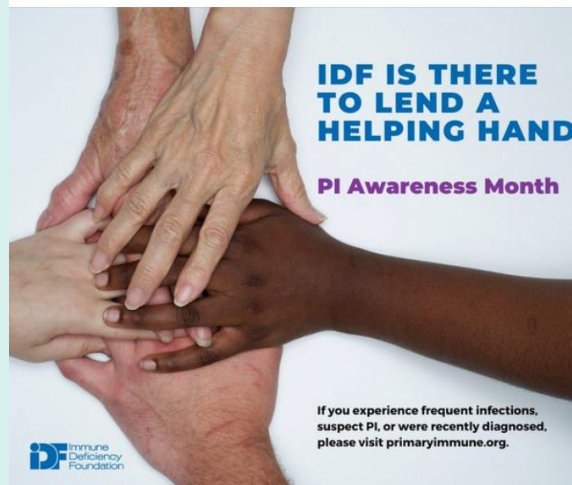
Click to see more

Feeling empowered and inspired by National PI Awareness Month? Continue to make a difference in the summer and fall by participating in IDF Walk for PI 2022. With every step you take, you create better lives for those affected by PI. Registration will open on Monday, May 16. Until then, learn more at <https://bddy.me/3vTb5Yz> | #WalkForPI



IDF Immune Deficiency Foundation
28 April · 🌐

Although #PIAwarenessMonth is winding down and there are only a few days left, remember that IDF is always there to lend a helping hand to the #IDFCommunity throughout the year. To find resources for #LivingWithPI, please visit our website at www.primaryimmune.org?utm_source=facebook&utm_medium=social&utm_campaign=awareness&utm_term=&utm_content=.



Survey explores provider SCID knowledge

News / Survey explores provider SCID knowledge

APRIL 25, 2022



Because of your generosity, kids like Maria could get the PI diagnosis they needed to receive proper treatment.

www.primaryimmune.org/pi-awareness

Venezuela

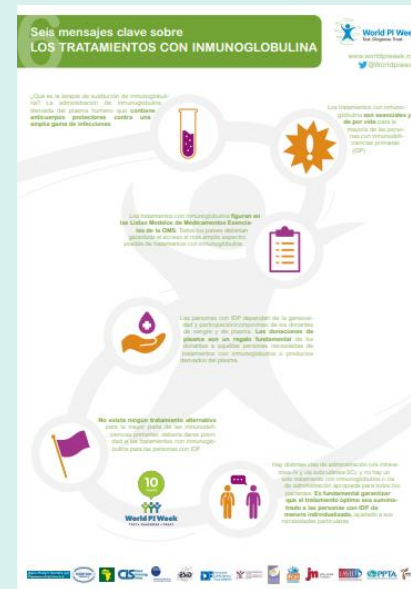


@ IDP Venezuela

- Social media dissemination of flyers
- Conference on 10 warning signs for general practitioners
- Virtual conferences for local paediatricians
- Webinar with immunologists on PIDs
- In-person meetings with patients & paediatricians
- Virtual 3rd IEI Meeting with national & international speakers



Click to see more



FUNDACION IDP Venezuela te INVITA AL:

ENCUENTRO DE PACIENTES, FAMILIARES Y AMIGOS DE IDP VENEZUELA

Día: Sábado 30 de Abril 2022
Lugar: Parque Ciudad de los Niños
Hora: de 9:00 am a 11 a.m

El evento será corto y dentro del horario establecido de 9:00 a.m a 11 a.m. Sea puntual. Llevar Tapaboca o mascarilla y gel antibacteriano. Durante el evento se cumplirá con las normas de bioseguridad.

ACOMPANANOS!!!!

International



International Patient Organisation for Primary Immunodeficiencies (IPOPI)



- IPIC 5th edition conference
- #MyPhysicianAndI picture campaign
- Social media engagement



Click to see more



Take advantage of regular registration rates until 18 April for #IPIC5 which has been accredited with 11 European CME credits.
Delegates will have access to all in-person congress sessions, lunches, welcome reception, and networking opportunities: <https://ipic2021.com/registration/>
https://www.youtube.com/watch?v=y_bLZxf4PD0



YOUTUBE.COM
IPIC 5th Edition, 27-29 April 2022
Regular registration is open until April 18th. For further information visit: <https://ipic2021.com/r...>

IPOPI
WORLD
PI WEEK
PHOTO
CAMPAIGN
2022

#MyPhysicianAndI



"Doctor-patient collaboration is essential for improving therapies and guaranteeing a better quality of life for our patients. Therapy on the sofa at home would not be possible without collaboration and dialogue with doctors. #MyPhysicianAndI"

Alessandro (Italy)



International



European Society for Immunodeficiencies (ESiD)



- “ESiD Grand Rounds Webinar” discussing diagnosis & access to care
- Social media engagement & sharing WPIW content



Click to see more



International



Latin American Society for Immunodeficiencies (LASID)



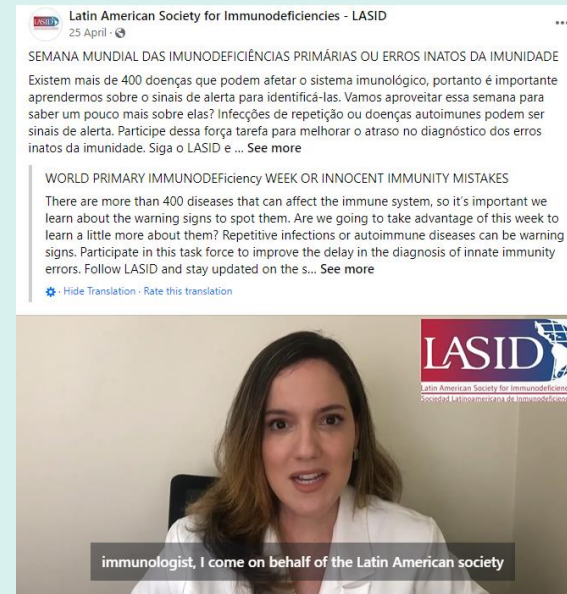
- PID Symposium
- Disseminating WPIW materials
- Awareness raising videos



Click to see more



12:31 AM · Apr 26, 2022 · Twitter for Android



Encuentro virtual y gratuito para profesionales

“Semana Internacional de las Inmunodeficiencias Primarias: cuando pensar en inmunodeficiencias más allá de las infecciones”

Jueves 28 de Abril de 18 a 19:30 hs.

PARTICIPAN DRA. SIGLEN AQUIRI, DR. IGNACIO URIARTE, DRA. ANA LAURA TOLIN, DR. LUCIANO URDINEZ, DR. JULIO ORELLANA.

COORDINA DR. VICTOR SKRIE

ORGANIZA Grupo de Inmunología de la SAP

Link para su conexión:
<https://us02web.zoom.us/j/81460327658>
 ID de reunión: 814 6032 7658 - Código de acceso: SAP

Por nuestra face en vivo: @soc.arg.ped

Por una vida y bienestar basados en un mundo mejor

International



Iniciativa ALAS

- Disseminating information on PIDs on social media

 Click to see more

26 April · 

IDENTIFICA + DIAGNOSTICA + TRATA
Semana mundial de las [#InmunodeficienciasPrimarias](https://iniciativaalas.org/)
Los pacientes con el Síndrome de Hiper-IgM (HIGM) son susceptibles a infecciones recurrentes y severas, y algunos tipos de este síndrome también son susceptibles a infecciones oportunistas y a un riesgo aumentado de cáncer. La forma más común es la heredada de manera ligada al cromosoma X. La mayoría de las otras formas son heredadas de manera autosómica recesiva y por lo tanto pueden afectar a niños y niñas. <https://iniciativaalas.org/>

See translation

¿Qué son las Inmunodeficiencias Primarias?
Se caracterizan por tener niveles disminuidos de IgG y niveles normales o elevados de IgM. Diferentes defectos genéticos pueden causarlo. La forma más común es la heredada de manera ligada al cromosoma X. La mayoría de las otras formas son heredadas de manera autosómica recesiva y por lo tanto pueden afectar a niñas y niños.

PRESENTACIÓN CLÍNICA
La mayoría de los pacientes con síndrome de HIGM desarrollan síntomas clínicos durante su primer o segundo año de vida. El problema más común es la susceptibilidad incrementada a infecciones, incluyendo las infecciones recurrentes de las vías respiratorias altas y bajas. Las molestias gastrointestinales más comunes son la diarrea y la mala absorción.
Algunos pueden desarrollar úlceras orales, inflamación del recto, infecciones cutáneas y riesgo de cáncer. Es frecuente observar el aumento de volumen de ganglios y bazo, resultando en adenoides y amígdalas que causan ronquido y apnea obstructiva del sueño.

DIAGNÓSTICO
Los síndromes de Hiper IgG se deben de considerar en cualquier niño que presente infecciones respiratorias severas recurrentes o una infección oportunista y que además tenga niveles bajos o ausentes de IgG y niveles normales o elevados de IgM.
El diagnóstico de las diferentes formas de HIGM se puede confirmar con el análisis de la mutación de los genes causantes conocidos de estas alteraciones. Este análisis de ADN se puede hacer en laboratorios especializados.

SOSPECHA - DIAGNOSTICA - TRATA

ABRIL

Mes de las

Inmunodeficiencias

Primarias

Semana del 22 al 29



 Iniciativa ALAS
14 April · 

IDENTIFICA + DIAGNOSTICA + TRATA
Semana Mundial - 22 al 29 de abril
Aunque las [#InmunodeficienciasPrimarias](https://iniciativaalas.org/) no se ven, estas son reales, pueden aparecer a cualquier edad y no son contagiosas.
<https://iniciativaalas.org/>

IDENTIFY + DIAGNOSIS + TREAT
World Week - April 22nd to 29th
Although [#PrimaryImmunodeficiencies](https://iniciativaalas.org/) are not seen, these are real, they can appear at any age and are not contagious.
<https://iniciativaalas.org/>
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Las Inmunodeficiencias Primarias (IDP) son una serie de enfermedades en las que, debido a una alteración genética, hay un funcionamiento inadecuado de las defensas del cuerpo. A consecuencia de ello, se padecen más infecciones de lo habitual, y además las infecciones se hacen más severas, más prolongadas, responden mal a los tratamientos habituales, y aparecen también con microbios relativamente inofensivos.

Las 10 señales de Alerta de las Inmunodeficiencias Primarias son la llave para tener acceso a un Diagnóstico Temprano.

1		Cuatro o más infecciones de oídos nuevas en un año
2		Dos o más infecciones de sinusitis graves en un año
3		Dos o más meses tomando antibióticos con pocos resultados
4		Dos o más neumonías en un año
5		Dificultad para aumentar de peso y crecer normalmente
6		Abcesos profundos y recurrentes en piel o en órganos internos
7		Aftas persistentes en la boca o en la piel después de la edad de 1 año
8		Necesidad de antibióticos intravenosos para aliviar infecciones
9		Dos infecciones profundas o más, incluida la septicemia
10		Antecedentes familiares de inmunodeficiencia primaria

International



Jeffrey Modell Foundation



- Public service advertising campaign
- Social media engagement
- Dissemination of awareness raising "Do Something" video



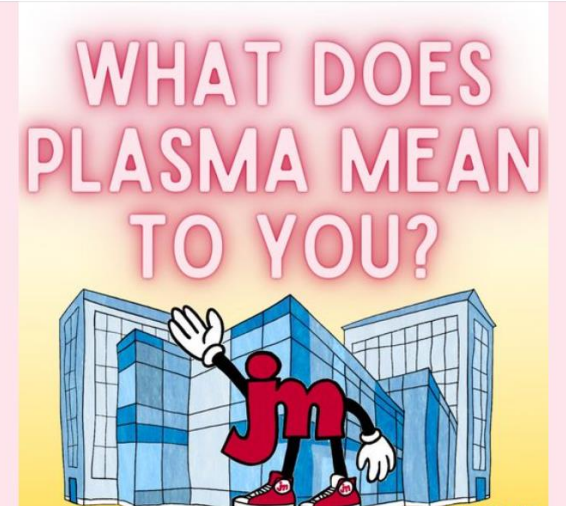
Click to see more



We invite you to meet our Founder, Jeffrey Modell. Watch his film, and learn how his call to action for his parents, , to "Do Something" has helped to shape the PI Journey for patients around the world. Watch "Do Something: The Jeffrey Modell Story" today to learn how Vicki and Fred Modell led the way to start World Primary Immunodeficiency Awareness Week and help us spread Primary Immunodeficiency awareness through this film. Available in seven languages! [Do Something: The Jeffrey Modell Story](#)

English: <https://vimeo.com/379050291>
Spanish: <https://vimeo.com/354651690>
French: <https://vimeo.com/355968857>
German: <https://vimeo.com/356405033>
Japanese: <https://vimeo.com/364062291>
Portuguese: <https://vimeo.com/355321285>
Simplified Chinese: <https://vimeo.com/354955025>

#info4pi #jmfworld #wpiw #worldpiweek #primaryimmunodeficiency #pi #pidd #awareness #education #film #documentary #dosomething #movie #journey #diagnosticjourney #global #worldwide



International



International Nursing Group for Immunodeficiencies (INGID)



- IPIC presence
- Social media engagement



Click to see more



Life Sciences Industry

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CSL Plasma



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 29

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 2022 was a success again!

PI awareness does not end with the campaign.

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