



# World PI Week 2021

Together, bringing about change for primary immunodeficiency patients worldwide

CAMPAIGN REPORT



## About World PI Week



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# A global awareness-raising effort

## Mission

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

## Aims

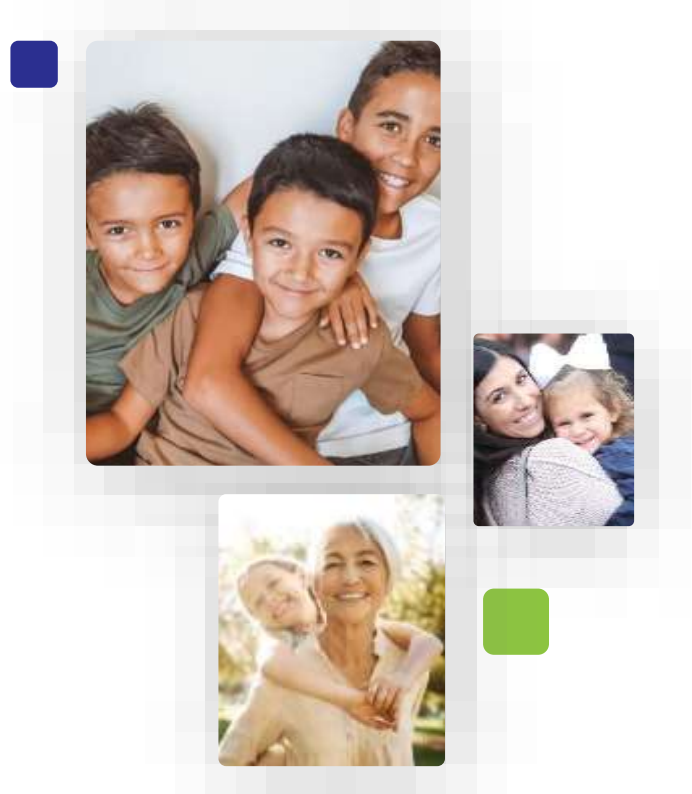
World PI Week offers an opportunity to inform and educate health policy-makers, schools and families, and the general public about primary immunodeficiencies (PI) to drive the earliest possible diagnosis and optimal treatment.

## Vision

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

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





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# World PI Week by the numbers

Over 80 countries  
across the globe

Thousands of people  
reached

Hundreds of events  
every year

11 years of  
campaigning

13 committed organisations  
driving the campaign

8 days to create  
momentum on PIDs





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# World PI Week in pictures





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Our active network

## A devoted World PI Week Steering Committee



Asian Pacific Society for Immunodeficiencies



Arab Society for Primary Immunodeficiencies



African Society for Immunodeficiencies



Immunodeficiency Canada



Clinical Immunology Society



European Federation of Immunological Societies



European Society for Immunodeficiencies



International Nursing Group for Immunodeficiencies



International Patient Organisation for Primary Immunodeficiencies



Jeffrey Modell Foundation



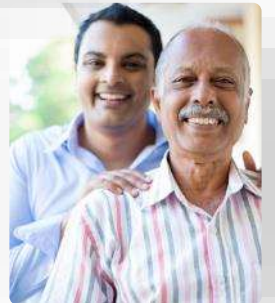
Latin American Society for Immunodeficiencies



Plasma Protein Therapeutics Association



South East Asia Primary Immunodeficiency Network



A dynamic, multi-stakeholder and global community



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Our committed partners



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SILVER SPONSOR



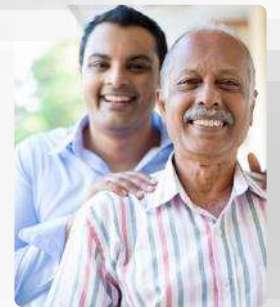
BRONZE SPONSOR



CONTRIBUTORS



New 2021 partners



Thank you for supporting the World PI Week campaign



# Campaign resources

## Informative tools available in various languages

- Flyers
- Videos
- Scientific pieces
- “Story sharing” visuals
- Template social media posts
- PID quiz
- Messaging brochure



Download all materials at [www.worldpiweek.org](http://www.worldpiweek.org)



My life has changed tremendously with immunoglobulin therapy. No more pneumonia, bronchitis, no more infections. I am alive. I got through school and college, got married, have two very healthy boys and a job. When I was diagnosed with primary immunodeficiency at 13 years old, I never thought any of that would happen.

Cheryl (US/Canada)



**World PI Week**  
TEST • DIAGNOSE • TREAT

Together, bringing about change for primary immunodeficiency patients worldwide

World PI Week 22-29 April

[www.worldpiweek.org](http://www.worldpiweek.org) | [#worldpiweek](https://twitter.com/worldpiweek)

**What?**  
Primary immunodeficiency (PID) is a group of rare genetic disorders that affect the immune system. It is caused by a defect in one or more of the genes that code for the proteins that make up the immune system. PID can be life-threatening and often requires lifelong medical treatment.

**What?**  
World PI Week is a global campaign to raise awareness of PID and to encourage people to get tested for the condition. The campaign runs from April 22-29, 2021.

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World PI Week messages

**About primary immunodeficiency**

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Primary immunodeficiency often presents in the form of "chronic" infections, sometimes leading physicians to treat the infections while missing the underlying cause, allowing the infection to recur and leaving the patient vulnerable to vital organ damage, physical disability, and even death.

**Early testing and diagnosis**

It is estimated that 6 million people worldwide are living with primary immunodeficiency.

70,000+ of people with primary immunodeficiency are still undiagnosed worldwide.

A number of different signs and symptoms can help detect primary immunodeficiency as the most common are severe persistent and/or recurring infections such as ear, sinus, or skin infections, as well as infections in the lungs, liver and intestines. Although it varies from individual to individual and from disease to disease, these signs can prompt doctors to refer the patient for further medical examinations. It is also important that family doctors and the public be aware of symptoms to visit an immunologist in case of a suspicion.

The first step in diagnosing primary immunodeficiency is a detailed evaluation of the immune system through several types of testing including blood and/or sputum tests, measuring medical and family history, physical examinations. The initial testing is usually performed via blood testing, followed by further tests of the immune system. Genetic testing is often needed to identify the particular form of primary immunodeficiency and the appropriate care pathway, however it is not available in many countries.

For severe forms of primary immunodeficiency, newborn screening is a laboratory test offered routinely to some early diagnosis and care (e.g. Routine newborn screening programs for severe primary immunodeficiency (e.g. SCID) and PID) should be widely implemented in public healthcare settings in all countries.







HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Engagement toolkits



Policy Toolkit



## Key considerations

### About World PI Week

World PI Week aims to **raise awareness** of the importance of preventing, managing, and treating primary immunodeficiency disease globally and **stimulate efforts** to improve the recognition, diagnosis, treatment and quality of life for people with primary immunodeficiency worldwide. The first World PI Week was celebrated on 22-26 April 2013 and focused on increasing the understanding of these diseases and estimating optimal diagnosis.

World PI Week takes place **every year on 22-26 April**. World PI Week offers a crucial, visible opportunity to **inform and educate health policy makers, healthcare professionals, schools and families, and the general public** about primary immunodeficiency, (primary immunodeficiency), to ensure the earliest possible diagnosis and optimal treatment and care.

The campaign focuses on a specific theme each year:

Through events and activities promoting the various types of primary immunodeficiency, seminars, public lectures, video diaries, and press conferences, the global primary immunodeficiency community can unite to bring about positive changes in healthcare, schools, and families in support of people living with primary immunodeficiency.

For more detailed information about World PI Week please visit the website: [www.worldpiweek.org](http://www.worldpiweek.org)

### Why engaging with policy-makers and governments?

Policy-makers, governments and health authorities hold the key for policy action and change to the benefit of primary immunodeficiency patients. Engaging with them helps ensure their awareness of the challenges surrounding primary immunodeficiency and the critical need to manage the disease well, as well as better understand the needs of people living with primary immunodeficiency. This heightened awareness can in turn help increase testing and diagnosis, safeguard treatment options and secure access to optimal care.

Engaging with policy-makers also allows to share personal patient or healthcare professional stories, but also the experiences of your organization, the work you are doing and its successes.

**Better health outcomes for patients with primary immunodeficiency is the primary goal of engaging with policymakers.** A collaboration over the long term is essential to face the numerous levels of medical, social and professional, and ultimately drive policy change which often do not happen overnight and may be a long-term strategy.

### How to engage?

There are many different ways to engage with policy-makers, from face-to-face meetings, written correspondence to social media outreach and writing.

### World PI Week themes

- 2013 - Access to Adoptive Treatment
- 2014 - Primary Immunodeficiency: Turning Hope into Action
- 2014 - A call for newborn screening to test for severe combined immunodeficiency
- 2015 - The importance of vaccination and immunoglobulin treatment for patients with primary immunodeficiency disease (PID)
- 2016 - Improving access to optimal care for all people immunodeficiently patients
- 2017 - Seeking access to life-saving immunoglobulin therapies for people with primary immunodeficiency
- 2018 - My future starts with early testing and diagnosis of primary immunodeficiency
- 2019 - Making primary immunodeficiency a priority of the future of health care



## Resources

The World PI Week should visit our policy-maker action plan to help you engage with policy-makers. In addition, you will find on the WPIW website a list of resources to raise awareness and inform about primary immunodeficiency specific challenges, including access to immunoglobulin therapies, or early testing and diagnosis. In addition, many organizations from the primary immunodeficiency community develop region- and country-specific resources and tools, available for download on their websites.

[Download the policy toolkits here](#)

### Template government letter

This template letter aims to help you contact government officials, ministers, and other policymakers. It can be adapted to fit your situation and national context.



# Audience-specific toolkits with guidance on how to engage with media, policymakers, medical professionals and the general public





## WORLD PI WEEK 2021 IN ACTION



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Focus on what matters most to the community

## Spotlight on three main themes that are all the more relevant in the COVID-19 context:

**PATIENT SAFETY & PROTECTION**

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



1

**QUALITY OF LIFE & HEALTH OUTCOMES**

Research, early diagnosis and better access to treatment help improve patients' quality of life




2

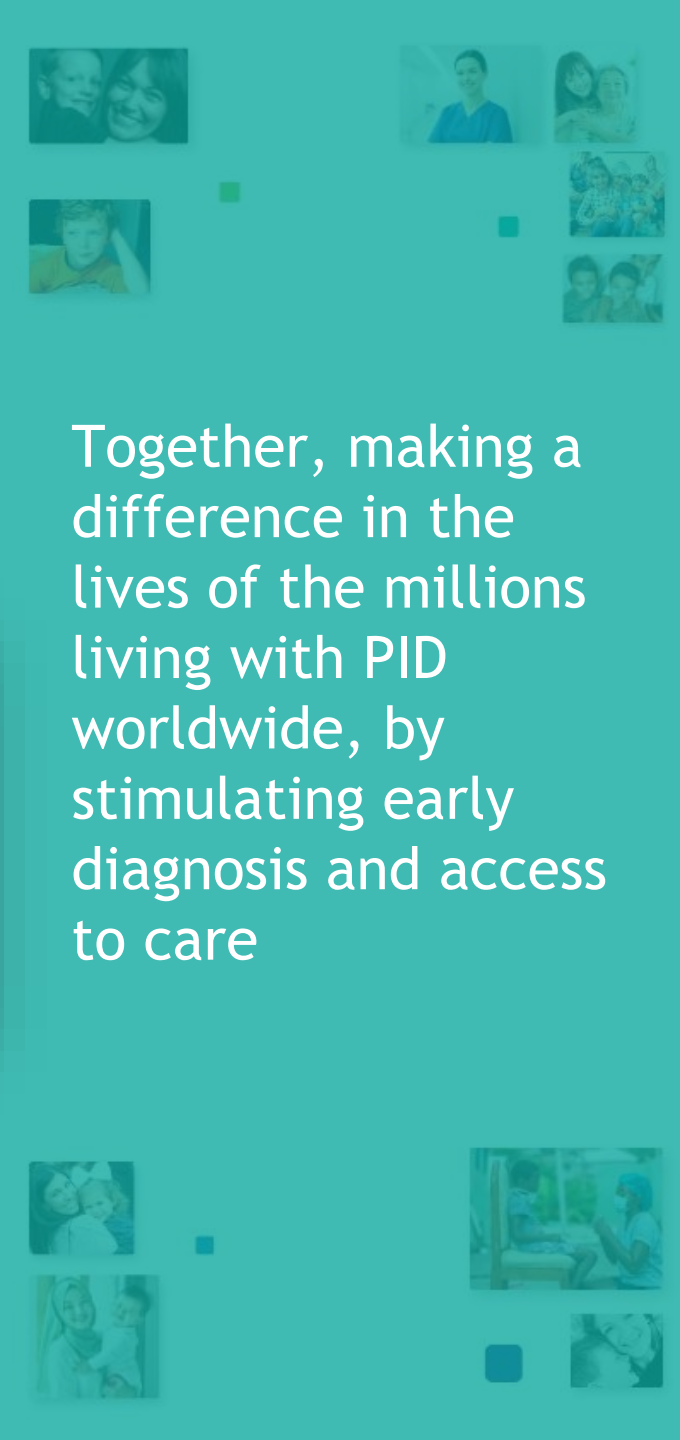
**PLASMA AVAILABILITY**

Ensuring the availability of plasma is essential to produce life-saving therapies for many patients



3

 [Learn more about the 2021 campaign messages](#)





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Thousands showing support towards the PID cause worldwide

## World PI Week is for everyone



Through virtual runs, online webinars and workshops, social media campaigns, TV/radio interviews; by donating blood or plasma





PREVIOUS



NEXT

Section 1


Section 2

Section 3

# Launching the campaign together

## Opening webinar

- Video message from the World Health Organisation (*Dr Ruediger Krech*)
- The immune system, PIDs & COVID-19 learnings (*Prof Fabio Candotti, Lausanne University Hospital, European Society for Immunodeficiencies - ESID*)
- *Patients' experiences during COVID-19 (Julia Nordin, International Patient Organisation for Primary Immunodeficiencies - IPOPI)*
- Overview of new campaign initiatives and how to mark the Week

 Webinar recordings available on YouTube





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Communications « package »

From the 'essentials'...



...To the tools for « social media gurus »



Click to download materials



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

Available in various languages





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# A series of new campaign teaser videos...

## 3 video clips providing insights on:

- availability of plasma and plasma-derived medicinal therapies
- changes in quality of life of patients before and after treatment
- mental health impacts that can arise following a PI diagnosis and emotional aspects of living with a PID
- the importance of protecting those who are immune compromised and the role of vaccination

WATCH AND SHARE THE  
**3 WORLD PI WEEK CAMPAIGN VIDEOS FEATURING PATIENTS, POLICYMAKERS AND PID EXPERTS**  
 #WorldPIWeek

Click to watch



Featuring patients and parents of children with PID from all over the world and all walks of life; as well as PID specialists and policymakers

*Available on YouTube and social media*







HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# ... amplified on social media to spread the word



+5,270  
Total views

Help share the powerful video messages around you with these bespoke quote cards





HOME



PREVIOUS



NEXT

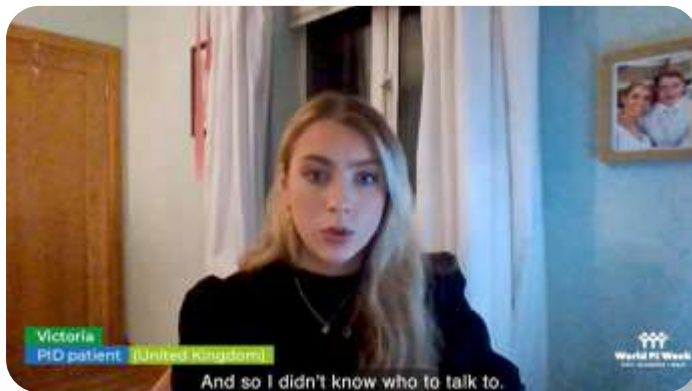
Section 1

Section 2

Section 3

## « Insights » videos

16 standalone video messages of policymakers, parents and PID patients



More videos to come in June and July 2021, stay tuned!

*Find all videos on the [World PI Week YouTube channel](#)*





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3




# Introducing the World PI Week Talks

A new podcast series by the World PI Week campaign



Listen to the podcasts on your preferred platforms



-  EPISODE 1:  
Plasma availability
-  EPISODE 2:  
Vaccination
-  EPISODE 3:  
Mental health





PREVIOUS



NEXT

Section 1

Section 2

Section 3

# About the World PI Week Talks

## Health journalist Sue Saville talks PIDs with multiple experts and patients



- > What is plasma? Why is it so important for many people with rare diseases like PIDs?
- > What are the challenges around plasma availability and how to address these? What is the impact of COVID-19 on plasma supplies?
- > Why donating plasma and how?



- > Discussing routine immunization, the role of vaccination in the case of PID patients, vaccines awareness and innovation in the field



- > Being diagnosed with a chronic disease like PIDs and coping with it in daily life can be challenging.
- > Everyone's situation is unique and there is no single way of dealing with emotions. Seeking help or an attentive hear is very important

Join the conversation on social media using #WPIWTalks



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Policy « asks » in the spotlight

## What Governments across the world should achieve

THE MAIN GOAL FOR GOVERNEMENT WORLDWIDE



### PATIENT SAFETY & PROTECTION

- Promote immunization, properly implement immunization strategies and ensure **access to safe vaccination for all**
- Ensure continuous **access to safe, high-quality treatment** and care for all patients
- Guarantee a **high level of safety** for all health workers

 #WorldPIWeek worldpiweek.org

THE MAIN GOAL FOR GOVERNEMENT WORLDWIDE



### QUALITY OF LIFE & HEALTH OUTCOMES

- **Invest in research and data collection** to help innovate, progress clinical practices and ultimately improve patients' outcomes
- Ensure **availability and access to diagnosis and treatment** for all PID patients
- Foster **heightened awareness of PIDs** at policy, medical & societal levels
- Promote **good mental health**

 #WorldPIWeek worldpiweek.org


THE MAIN GOAL FOR GOVERNEMENT WORLDWIDE



### PLASMA AVAILABILITY

- Ensure a **sustainable, high-quality supply** of human plasma - in collaboration with relevant groups
- Support **increased plasma collection** including by boosting initiatives to promote safe donation
- Ensure **access to plasma derived immunoglobulin therapies** for PID patients, in accordance with the WHO Model List of Essential Medicines

 #WorldPIWeek worldpiweek.org

 Animated and static formats



A suite of animated visuals with “policy calls to action”, to help advocate beyond the campaign week!





# An improved website to communicate about PIDs

New and optimized sections to continue improve user experience

## New features

- Rolling banners on home page to spotlight new initiatives and how to get involved
- Revamped video section

**14,148**

Page views (April)

**77%**

New visitors

**Facebook + Instagram**

Top social referrals



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Press announcements



## PRESS RELEASE

Embargoed until 22/04/2020, 9.00am CEST

### **World PI Week 2021: Will you be striking a “Y” to support the primary immunodeficiency cause?**

**Brussels, 22 April 2021** – Millions of people around the world are living with a compromised immune system due to a genetic defect. Together, we can make a difference in their lives by stimulating early diagnosis and access to care. This is the headline message of the 2021 World Primary Immunodeficiency (PI) Week campaign, starting today.

#### **Focus on what matters most to the community**

This year, World PI Week (22-29 April) embraces three themes that are all the more relevant in the COVID-19 context: patient safety and protection with a focus on vaccination; plasma availability; and quality of life.

There are more than 430 different types of primary immunodeficiencies (PIDs), affecting over 6 million people worldwide. Primary immunodeficiencies occur when a person’s immune system is absent or does not function properly, which leaves individuals more prone than other people to infections and predispose them to auto-immunity, allergy, malignancy, or inflammation. For this very reason, raising awareness of the defects of the immune system such as PIDs takes on an even greater significance amid COVID-19.

While across the world all eyes are on the COVID-19 vaccination progress, World PI Week 2021 aims to remind that by protecting each other with vaccinations, we protect people with a compromised or weak immune system, such as those living with PIDs – also, during routine immunization. Further, although the availability of plasma is essential to produce life-saving therapies for many patients, the pandemic has impacted supplies in many parts of the world. This is a reminder that during COVID-19 and beyond, plasma donation is vital.

The spirit of this global endeavour is all about collaboration, awareness, investment and action to ensure that research, early diagnosis and better access to treatment are given greater visibility and feature high on health policy agendas, in order to improve patients’ quality of life.

#### **Striking a Y together to drive momentum, mobilise and bring about change**

In solidarity with those living with primary immunodeficiency, thousands of people from all continents will connect digitally and show their support towards the PID cause, through virtual runs, online webinars and workshops, social media campaigns and TV/radio interviews; or by donating blood or plasma.

World PI Week is for everyone. Join the many patients, policymakers, healthcare professionals including immunologists and nurses, researchers, journalists, company representatives and other partners that come together on 22-29 April to shine the light on what living with a PID means, and how to deliver change.

Joining World PI Week 2021 means helping make a difference, in support of patients and their families around the world.

More information about World PI Week: [www.worldpiweek.org](http://www.worldpiweek.org)



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Social media milestones

## Driving conversations and mobilising to raise awareness of PIDs

Analytics for 22-29 April



+96 followers

+5.4K impressions

600 page views



+160 followers

+100K impressions

7,185 profile visits

HIGHEST ENGAGEMENT REACHED



+18.5% followers (+102)

+9.5K impressions (+614%)

678 content interactions



+300 new viewers

+2.3K impressions

2,000 total views

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



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Best-performing social media posts



**26,783**  
Impressions

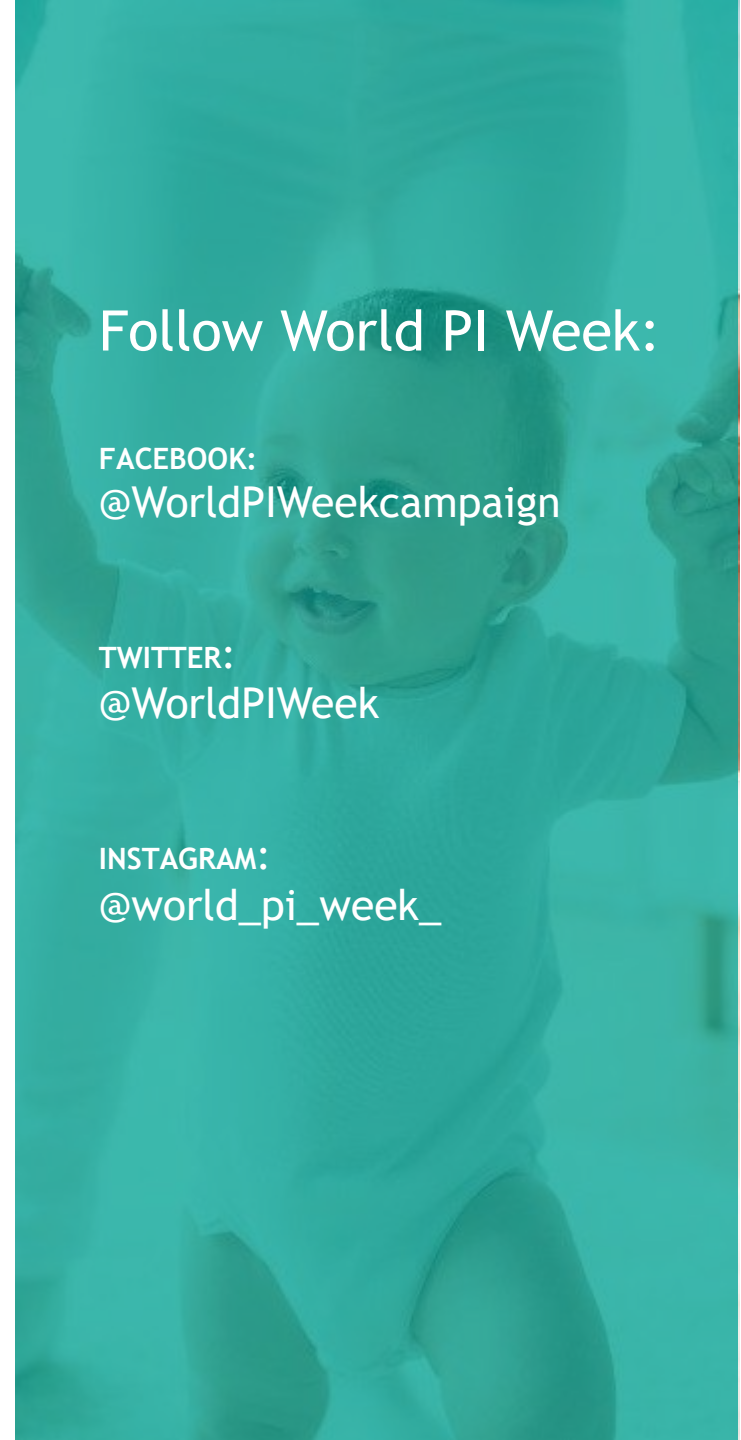
**+100**  
Engagements



**2,500**  
Impressions

**+79**  
Reactions

**+157**  
Total engagements



## Follow World PI Week:

FACEBOOK:  
[@WorldPIWeekcampaign](#)

TWITTER:  
[@WorldPIWeek](#)

INSTAGRAM:  
[@world\\_pi\\_week\\_](#)





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Photo contest #PictureAwareness

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

- Participation on social media to mobilise and drive attention
- Going “green” in reference to the campaign’s key colour but also the importance of outdoor environments for good health



**World PI Week**  
TEST • DIAGNOSE • TREAT

**JOIN THE WORLD PI WEEK PHOTO CONTEST 2021**  
Strike a Y in support of the PID cause - in GREEN!

Share your picture on Facebook, Twitter or Instagram with [#PictureAwareness](#)

The Y pose refers to the shape of an antibody, but it also symbolizes the community - just like the World PI Week logo. Green is one of the main identity colours of the campaign.





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# ... and the winner is...

## Congratulations to UMAE Hospital De Pediatria CMN in Guadalajara (Mexico)!



# WINNER!

Strike a Y Contest



Congratulations to  
UMAE Hospital de Pediatria CMNO,  
Guadalajara (Mexico)





HOME



PREVIOUS



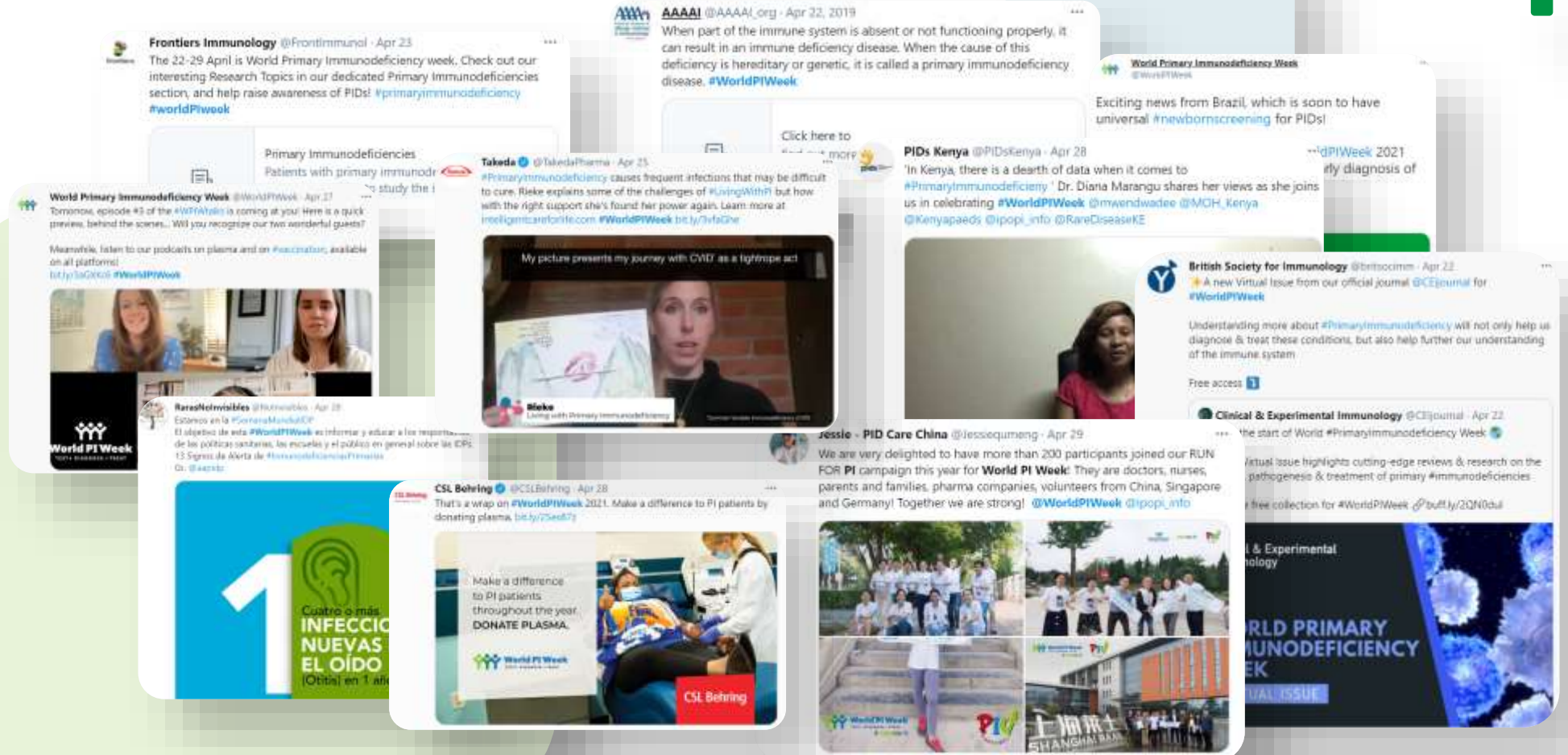
NEXT

Section 1

Section 2

Section 3

# Social media engagement







HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Media coverage & press clippings

Primary Immunodeficiencies: "The Challenge for a Timely Diagnosis"



### Queen Sofia Treats More than a Thousand Andalusians with Immunodeficiencies

The goal of the center is to obtain diagnoses in a shorter timeframe

M.J. Sotillo

22-04/21 | 9:01 EL | Updated on 7:12 a.m.



One-Year Masters Programs

**murcia.com / Salud**

murcia.com website navigation menu including: Cover, Murcia, Cartagena, Liria, region, Mar Menor, Business Guide, advertising, contact, economy, national, employment, international, travel, Bless you, culture, technology, sport.

Berliner Woche FROM THE KEEZ CALENDAR SWEEPSTAKES E-PAPER ADVERTISING WITH US

SERVICE

Angela Kerschke

New Topic

Apr 22, 2021, 9:07 AM | 50 reads

PROF. DR. VOJTES PAVEL, IMMUNOLOGIST AT THE DWITZ, STRESSES THE IMPORTANCE OF PLASMA DONATION

### Why blood plasma donation is so important



HaberDenizli

Denizli'de Gecenin Yarısı Giddetli Deprem

SOM BAKIYA Alacak varacak hangısında 1 kişi yaralandı

### Her Bir Balon Çocuklara Umut Olsun

Her yıl 22-29 Nisan haftası dünyada Primer İmmün Yetmezlik haftası olarak kutlanmaktadır. PAÜ Hastanesi olarak ağız alında balonlar uçurarak etkinlik düzenlenerek çocuklarımız sevindirildi.

26.04.2021, 15:00



Latest News

World Primary Immunodeficiency (PI) Week April 22-29, 2021: Immune Deficiency Foundation (IDF) SCID Campaign

World Primary Immunodeficiency (PI) Week April 22-29, 2021: Immune Deficiency Foundation (IDF) SCID Campaign

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World Primary Immunodeficiency (PI) Week April 22-29, 2021: Immune Deficiency Foundation (IDF) SCID Campaign

World Primary Immunodeficiency (PI) Week April 22-29, 2021: Immune Deficiency Foundation (IDF) SCID Campaign





Click on the name to see the report

# Country involvement



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3



47 countries reported participation to World PI Week 2021



## SNAPSHOTS OF NATIONAL EVENTS

# Argentina



AAPIDP (Association de Ayuda al Paciente con Inmunodeficiencia Primaria)



- 1st Virtual Congress for Patients with PIDs with over 265 participants, covering:
  - › living with PID in a pandemic
  - › COVID-19 vaccines and PIDs
  - › emotional aspects of PIDs
  - › nutrition
  - › access to PID care
  - › future challenges
- Video messages of speakers
- #MiDerechoEs campaign for patients with PIDs on social media
- Media engagement (92.700 people reached)



Click to see more

1º CONGRESO VIRTUAL PARA PACIENTES CON  
INMUNODEFICIENCIAS PRIMARIAS

## VACUNAS COVID-19 E INMUNODEFICIENCIAS PRIMARIAS

Vacunas disponibles y sus diferencias. ¿Puedo vacunarme? ¿Qué debo saber al momento de vacunarme? ¿Debo suspender mis tratamientos? ¿Cuándo reanudarlos?



Dra. Analía Rearte

Dra. Andrea Uboldi

Coordinadora Dra. Diana Liberatore

Coordinador Dr. Miguel Galicchio

EN VIVO YouTube / Facebook / I/E

23 DE ABRIL - 18:40



## Sumá tu voz

SUBÍ TU FOTO UTILIZANDO EL HASHTAG



1º CONGRESO VIRTUAL  
PARA PACIENTES CON  
INMUNODEFICIENCIAS PRIMARIAS



23 Y 24 DE ABRIL

SAVE THE DATE



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Australia



IDFA - Immune Deficiencies Federation Australia




- Fundraising Activities
- Production of bespoke video for digital campaigning in collaboration with members



Click to see more



 Immune Deficiency Foundation of Australia  
29 April at 05:00 · 🌐

These are the voices of Australians living with primary immunodeficiency (PI). On this final day of World Immunodeficiency Day, we recognise and celebrate these rare disease warriors.

YOU CAN SHOW YOUR SUPPORT BY...

- ★ Sharing our video to help us raise awareness of our community.
- ★ Make an appointment to donate plasma at your nearest [Australian Red Cross Lifeblood](#) centre... See more







HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Belarus



Спасем иммунитет - Save Immunity



- Awareness raising video - Myths about primary immunodeficiency, outlining the differences between primary and secondary immunodeficiencies, and the importance of early diagnosis
- 6<sup>th</sup> international conference: Primary immunodeficiency issues



Click to see more



Спасем иммунитет

29 April at 09:48 · 🌐

“ Let’s save immunity ” takes part in the VI international conference  
 “ Primary immunodeficiency issues are relevant ”.

⚙️ · See original · Rate this translation



# Belgium



Bubble ID



- Testimonial videos (story sharing)
- Youth theatre performance



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HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Belgium



Vlaams Instituut voor  
Biotechnologie (VIB) - Belgian  
Research institute



- Launch of a documentary on PIDs, featuring patients' stories



Click to see more



**dit is biotech** @ditisbiotech · Apr 28

Dit zijn Lucy (6 jaar) en Thieu (10 jaar), Zij kampen net als vele andere kinderen in ons land met een primaire immuundeficiëntie. Zij vertellen in eigen woorden welke impact dit heeft op hun leven @WorldPIWeek #PIDAwareness #WorldPIWeek [piddocu.sites.vib.be/nl](http://piddocu.sites.vib.be/nl)







HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Belgium



UZ Leuven University



- Awareness raising on PIDs and psychosocial care for children living with PIDs
- Website article, informing about the work of the University to support paediatric populations with PIDs, including the CARE4KIDS project



Click to see more

**JZ Leuven** @UZLeuven · Apr 22

Kinderen en jongeren met een primaire immuundeficiëntie (#PID) hebben vaak nood aan psychosociale ondersteuning en informatie op maat, ook voor hun omgeving. Precies daarover gaat het #CARE4KIDS-project van @UZLeuven. #worldPIweek



UZ Leuven zet in op psychosociale ondersteuning  
Kinderen en jongeren met een primaire immuundeficiëntie moeten al erg  
[uzleuven.be](https://uzleuven.be)





# Bolivia



FIDEP - BOLIVIA (The Primary Immunodeficiencies Patient Organisation)



- First PID symposium for healthcare professionals - focusing on symptoms, types of PIDs and treatment modalities
- › Launched a series of short videos with PID experts, addressed to healthcare professionals, covering various issues surrounding PID care:
- › [Dr. Patricia Alfaro](#), Dermatologist-Pediatrician - *Manifestations on the skin in patients PID.*
- › [Dr. Edgar Cordero](#), Specialist in Pediatric Allergy and Clinical Immunology - *Treatments in patients with PID.*

**INMUNODEFICIENCIAS PRIMARIAS**  
Diferentes formas, tipos y defectos

Dr. Matias Oleastro  
Jefe de Clínica en Inmunología  
Servicio de Inmunología y Reumatología  
Hospital Garrahan  
Buenos Aires, Argentina

World PI Week IPOPI FIDEP

**1er Simposio Virtual de INMUNODEFICIENCIAS PRIMARIAS**

viernes 23 de abril  
19:00 horas

**Dirigido a:**

- Inmunólogos
- Alergólogos
- Pediatras
- Infectólogos
- Hematólogos
- Neumólogos
- Oftalmólogos
- Otorrinolaringólogos
- Gastroenterólogos
- Dermatólogos
- Médicos Internistas
- Bioquímicos
- Residentes y estudiantes



Click to see more



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Brazil



Hospital Pequeno Príncipe



- Webinar on 'Treatment of Primary Immunodeficiencies: Present and Future'



Click to see more

## Semana Mundial das Imunodeficiências Primárias Erros Inatos da Imunidade 22 a 29 de abril

### O presente e o futuro do tratamento das imunodeficiências primárias

Desde 2014, o Complexo Pequeno Príncipe participa da Semana Mundial das Imunodeficiências Primárias (WPIW). Neste ano, a instituição promove um evento multidisciplinar on-line, por meio da plataforma Zoom, para discutir as formas de tratamento das imunodeficiências primárias. Contamos com a sua presença!

• Data: 28 de abril (quarta-feira) • Horário: das 8h às 9h30

Para acesso ao webinar  
CLIQUE AQUI



#### PROGRAMAÇÃO

"A construção de um serviço de referência em Erros Inatos da Imunidade: clínica e pesquisa" – Carolina Prando, médica imunologista do Hospital Pequeno Príncipe e diretora de Medicina Translacional do Instituto de Pesquisa Pele Pequeno Príncipe.



"Resultados do Serviço de Transplante de Medula Óssea do Hospital Pequeno Príncipe para portadores de Imunodeficiências Primárias/Erros Inatos da Imunidade" – Gisela Loth, médica hematologista do Serviço de Transplante de Medula Óssea do Hospital Pequeno Príncipe.



"Resultados do transplante de timo do Great Ormond Street Hospital e University College of London" – Alexandra Kreins, médica do Departamento de Imunologia do Great Ormond Street Hospital for Children. Pesquisadora em Biologia do Timo, University College of London.



"Terapia gênica para Imunodeficiências Primárias/Erros Inatos da Imunidade no Great Ormond Street Hospital e University College of London" – Kritika Chetty, médica do Departamento de Imunologia do Great Ormond Street Hospital for Children. Pesquisadora sênior em Terapia Gênica, University College London.





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Brazil



ASBAI - Brazilian Association of Allergy and Immunology



- Social Media #PlasmajaBrazil campaign and facts about PI
- Suite of PID information videos, featuring various experts sharing latest insights on PIDs, promoted on social media



Click to see more

**ASBAI** @ASBAI\_alergia · api. 29

Are we going to recall the main points of World Primary Immunodeficiency Week / Innate Immunity Errors? Pass the images to the side and accompany them in the infographic.

#plasmajabrasil #imunodeficiencias #errosinatosdaimunidade #semanaidp #WorldPIWeek #plasma #imunoglobulina

The infographic consists of six panels arranged in a 2x3 grid. Each panel has a circular icon and a text box. The top row panels are: 1. 'por imunogramas vacuolares' with a green bar chart; 2. 'VACINAÇÃO' with a green circle; 3. 'Porém, um estudo brasileiro, que está em andamento, aponta que o COVID-19 pode ser mais grave em pacientes com algumas imunodeficiências.' with a green bar chart. The bottom row panels are: 4. 'vacinação' with a green circle; 5. 'VACINAÇÃO' with a green circle; 6. 'A saúde mental dos pacientes é tão importante quanto sua saúde física.' with a green bar chart. The text in the panels discusses genetic defects, the importance of vaccination, and mental health.

**ASBAI** @ASBAI\_alergia

#plasmajabrasil #imunodeficiencias #errosinatosdaimunidade #semanaidp #W #ASBAI #alergia #imunologia #vacinacovi #imunizacao #plasma #imunoglobulina

ASBAI | Mensagem final da Semana Mu...

ASBAI | Mensagem final da Semana Mundial das IDPs/EII  
Por Dra. Ekaterini Simões Goudouris, coordenadora do Departamento Científico de Imunização da ASBAI.  
youtube.com

#plasmajabrasil





PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Canada



CIPO - The Canadian Immunodeficiencies Patient Organization



- Social media campaigns
  - > *World PI Week Through the Years*
  - > *World PI Week Patient Profiles*
- Plasma Donation Awareness Campaign featuring patients' stories



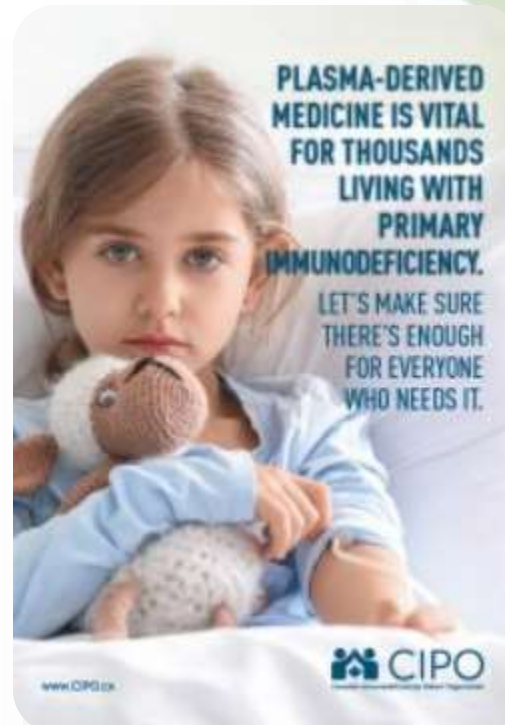
Click to see more

## PI THROUGH THE YEARS 2018

Stem Cell Transplantation for Immunodeficiencies in Europe registry (SCETIDE) now encompasses data on more than 4800 patients with SCID or other PIDs

## PI THROUGH THE YEARS 2018

All PID diagnoses have working definitions for clinical diagnosis and registration in the ESID Registry



The Canadian Immunodeficiencies Patient Organization - CIPO

28 April at 14:01 · 🌐

Today's *World PI Week* profile is Tara! She is powered by plasma and without donors she wouldn't be able to do her favorite things #piawareness #plasmaawareness #worldpiweek

WORLD PI WEEK PATIENT PROFILES  
MEET TARA (SHE/HER)



TARA WAS DIAGNOSED WITH CVID AND USES HIZENTRA FOR TREATMENT. SHE LIKES GOING OUTDOORS, READING, MAKING ART, AND GARDENING. SHE IS A GRYFFINDOR. HER GO TO MIDNIGHT SNACK IS CHOCOLATE AND HER FAVORITE COFFEE DATE IS HER HUSBAND







PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Canada



Immunodeficiency Canada



- Social Media #MyPIStory Campaign and facts and figures about PID



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HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# China



PID Care China



- “Run for PI-Run for Love” solidarity campaign
- 2021 promotional video
- Photos from various healthcare professionals and patients supporting World PI Week, including the Division of Immunology - Children’s Hospital of Fudan University China
- Awareness raising in public venues and digital campaigning activities



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HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Columbia



Fundacion Diana Garcia de Olarte



- Conference for PID patients with Q&A time via live chat between patients and healthcare professionals
- Social media campaigning
- Promotion of educational material on PIDs



Click to see more



**Do Something: The Jeffrey Modell Story** is with Fundación Fip.  
25 April at 15:00

Vamos a continuar celebrando la Semana Mundial de la Inmunodeficiencia Primaria, compartimos acceso complementario



# Columbia



Sociedad Colombiana de Pediatría



- Dissemination of PID awareness campaign materials



Click to see more

## Semana Mundial de las Inmunodeficiencias Primarias (IDP)

Cada año durante los días 22 al 29 de Abril

Las IDP son enfermedades hereditarias que afectan al sistema inmunitario. Pueden deberse a la alteración de un solo gen, varios genes o pueden representar la interacción de determinadas características genéticas y factores ambientales o infecciosos. Los pacientes con IDP son reconocidos más frecuentemente por su susceptibilidad a diversas infecciones de gravedad variable. Sin embargo, su importancia no solo radica en esta susceptibilidad aumentada a infecciones, sino por su asociación frecuente a cuadros de autoinmunidad y neoplasias (especialmente del tejido linfoide), con una frecuencia mucho mayor a la población general que, de no ser tratadas en forma adecuada, pueden ser fatales y/o dejar secuelas que empeoran la calidad de vida de los pacientes.

Recuerden que las inmunodeficiencias, sobre todo las menos severas, se manifiestan clínicamente con síntomas respiratorios y por ello forman parte del diagnóstico diferencial de un niño con problemas respiratorios. Característicamente, son recurrentes, persistentes, debilitantes, crónicas y causadas por diferentes tipos de microorganismos que en gran parte son patógenos no habituales.

En el espectro de las inmunodeficiencias primarias en Colombia, según un reporte del año 2002 del Centro Nacional de Referencia Jeffrey Modell para diagnóstico e investigación en inmunodeficiencias primarias (CJM-IJDEA) la frecuencia y prevalencia en Colombia son similares a las estimadas en la población mundial, — 1:2.000 nacidos vivos y ~1:10.000 individuos población general respectivamente. Sin embargo, los datos de este reporte demostraron que esta información es equivalente a sólo el 15 % de la población potencialmente afectada, lo cual revela un subregistro muy significativo.

Para más información sobre la sospecha de inmunodeficiencias primarias, puede consultar el siguiente estudio:

[http://www.sgi.com.co/presscop-alel/pw/2\\_Recomiendado.pdf](http://www.sgi.com.co/presscop-alel/pw/2_Recomiendado.pdf)

**Referencia:**  
Pérez, J. A. (2002). Espectro de las inmunodeficiencias primarias en Colombia. Reporte del Centro Nacional de Referencia Jeffrey Modell para diagnóstico e investigación en inmunodeficiencias primarias (CJM-IJDEA). Unidad de Neumología, Medicina Universidad de Antioquia. (2011). Pérez, J. A. et al. (2017). Prevalencia y características clínicas de las inmunodeficiencias primarias en Colombia. *Revista Colombiana de Neumología, Inmunología e Infectología*, 18(4), 175-184. <https://doi.org/10.1016/j.rcn.2017.08.001>

10  
SEÑALES

DE ALARMA DE LAS INMUNODEFICIENCIAS PRIMARIAS (IDP)

EN NIÑOS

Las IDP pueden causar infecciones recurrentes en niños. Uno de cada 500 individuos puede tener una IDP. Si usted conoce a alguien que este siendo afectado por 2 o más de las siguientes señales, consulte a su profesional de la salud sobre la posibilidad de ser diagnosticado con una Inmunodeficiencia Primaria.



Referencia:  
L. Jeffrey Modell Foundation, Medical Advisory Panel.





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Cyprus



## Ομάδα Ατόμων με Συγγενή Ανοσοανεπάρκεια και Φίλων



- PID workshop involving patients
- Recreational activities for children including painting of the 'Y' shape of the antibody and symbol of the World PI Week
- Social media educational activities and campaigning/advocacy towards the Health Ministry for the implementation of newborn screening for SCID in Cyprus
- Sharing patient testimonials on social media



Click to see more



## Ομάδα Ατόμων με Συγγενή Ανοσοανεπάρκεια και Φίλων

29 April at 20:28 · 🌐

Today is the last day of awareness for Primary Immunodeficiencies. Our Association actively participated in patient alert for a clear diagnosis, where early diagnosis with proper treatment not only is key to the patient's life and quality of life but also his family.

- On April 22 we participated in the launch of World PI Week
- On April 23 we went to Simba Land Kindergarten Kindergarten, where children painted the Y shape of our antibody symbol
- On April 25, we participated in the " Συλλογος Ανοσοανεπαρκιας ΓΑΛΗΝΟΣ. Immunodeficiency Association Galinos " workshop, our club president Maria Charalambous, talked about her own experience, the research she took part in and how the Association was made in Cyprus!

We wish there was a shorter road to early diagnosis, as well as we optimize for our efforts to deal with the Ministry of Health and with the support of the [Cyprus Alliance for Rare Disorders](#) Pancyprian Rare Disease Alliance, for technical agreement with the Center Reporting abroad to come immunologist in Cyprus for patients with Primary Immunodeficiencies.

We wish to follow in Cyprus the newborn inspection for Protopathi Immunodeficiency especially SCID Severe Combined Immunodeficiency



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Ecuador



## Foundation PIDE



- PID awareness video - promoting the warning signs of PIDs to improve early detection
- Video campaign featuring healthcare professionals and specialists to raise awareness of PIDs (see [here](#))
- “COVID-19 safety kits” distributed throughout the week



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PREVIOUS



NEXT

Section 1

Section 2

Section 3

# El Salvador



Fundación Escudo de Amor para las IDP



- Social media communications
- Radio interview with PID specialist



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HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Estonia



## Immuunpuudulikkuse Selts



- Social media campaigns through real life patient stories and expert insights
- Media interview with PID specialist



Click to see more

This world immune deficiency week is dedicated to quality of life. What the quality of life means to the immune deficient and how it affects our lives. Today Anne-Mari tells her story, whose diagnosis is the general variable immunodeficiency. How does this affect life and what does Anne-Mar have on life?  
 " I was diagnosed as a young adult and a mother of one child. So I know what life is like before treatment pretty well - infinite inflammations and poor feeling.  
 What has ch... See more

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



**Immuunpuudulikkuse Selts**  
 27 April at 16:47 · 🌐

Üks meie seltsi asutajaliikmetest Dr Krista Ress jagas Immuunpuudulikkuse nädala raames laiemale üldsusele teadmisi selle kohta, mis üldse on primaarne immuunpuudulikkus ning kuidas seda kahtlustada. Artikkel on täies ulatuses loetav ent jagame siinkohal mõned olulised punktid intervjuust Kristaga.  
 🙌 Teada on üle 400 erineva immuunpuudulikkuse vormi ning kõiki neid vorme arvesse võttes esineb primaarset immuunpuudulikkust keskmiselt ühel inimesel 500st  
 🙌 Enamasti on immuunpuu... See more

[See translation](#)



TERVISE.GEENIUS.EE  
 Dr Krista Ress: immuunpuudulikkuse sümptomid ilmnevad sageli varases lapseas, kuid haigus võib avalduda ka...



# France



ASSOCIATION DE PATIENTS  
DÉFICITS IMMUNITAIRES PRIMITIFS



Association IRIS



- « Solidarity Run » with hundreds of people running, walking, cycling and more in support of PID patients



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PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Greece



The Immune Deficiency Patient Association



- Event on immune deficiencies in the age of COVID19
- Social media campaigning with promotion of educational material



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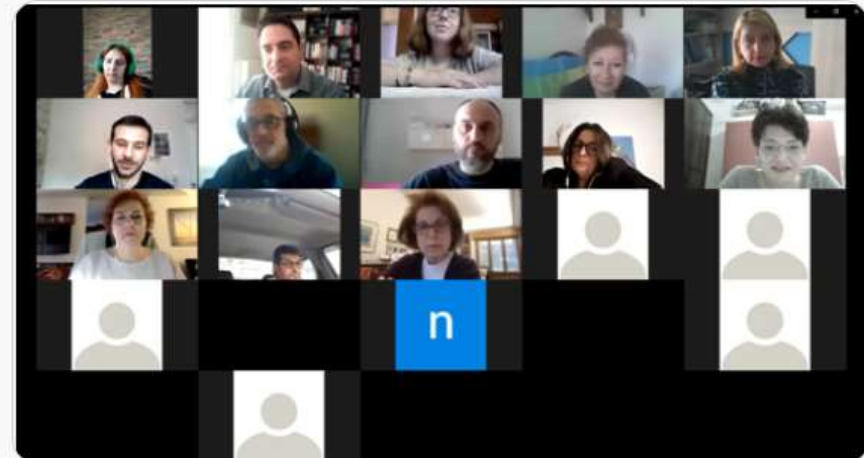


PIDGalinos Retweeted



**PIDGalinos** @PidGalinos · Apr 29

As part of the World Week of Primary Immune Deficiencies, GALINOS Association organized a conference on: "Immune Deficiencies in the era of covid-19" which took place on Sunday April 25 2021 \_10:00-14:30. We thank all for their participation. [#WorldPIWeek](#) [#PrimaryImmunodeficiency](#)





PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Hungary



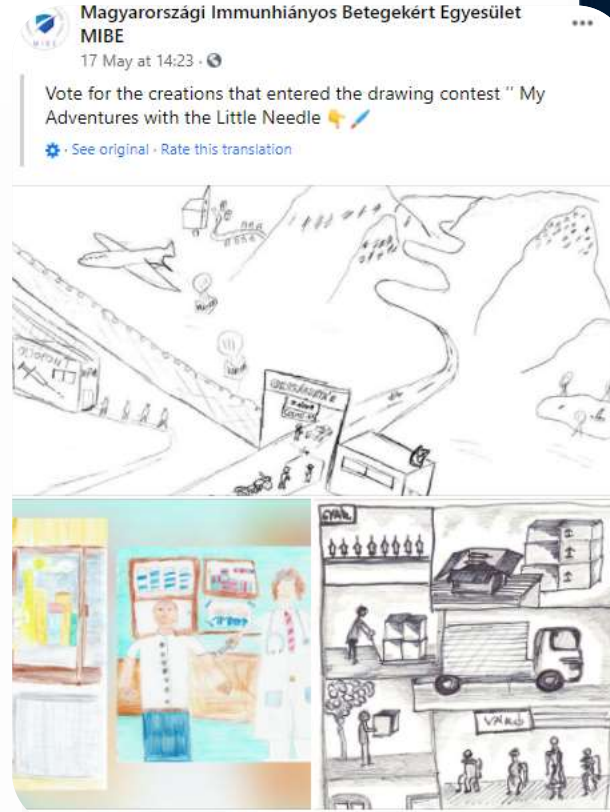
Magyarországi Immunhiányos Betegekért Egyesület MIBE



- “The Little Needle” drawing contest for pediatric and young PID patients
- Webinar on “The Impact of the Covid Pandemic on Immunoglobulin Supply”



Click to see more



**COVID pandémia hatása az immunglobulin ellátásra**

**Tisztelt Meghívottak!**

A Magyarországi Immunhiányos Betegekért Egyesület, a Primer Immunhiányos Betegek Egyesülete, valamint a Magyar Allergológiai és Klinikai Immunológiai Társaság szeretettel meghívja Önt a

**COVID pandémia hatása az immunglobulin ellátásra**  
című webkonferenciájára

Dátum: **2021. április 23.** (péntek) 15.00 - 17.00

ESEMÉNY HOZZÁADÁSA A NAPTÁRHOZ

**SAVE THE DATE!**

A webkonferencia az Immunológia Hete 2021 (World PI Week 2021) rendezvény része.

MIBE Magyarországi Immunhiányos Betegekért Egyesület  
PIBE Primer Immunhiányos Betegek Egyesülete  
Magyar Allergológiai és Klinikai Immunológiai Társaság

A webkonferencia támogatója:

**CSL Behring**  
Biotherapies for Life™  
CSL Behring Kft.  
1123 Budapest, Árkótsík utca 53. D. ép. 4. em.  
Tel.: +36-1-213-4288  
www.cslobehring.hu

#ANR02HESZVA/2021/0306 | 2021.03.26.



# India



## Indian Patients Society for Primary Immunodeficiency (IPSPI)



- A webinar session on understanding PIDs
- Educational material on PIDs

A webinar session on  
**THINK ZEBRA !  
UNDERSTAND PID...**

24<sup>th</sup> & 25<sup>th</sup> April 2021  
Saturday & Sunday  
Starts at 5 PM onwards

**SPEAKERS**



**Dr. Sagar Shafiq**  
MBB Pediatrics, DNB Pediatrics, DNB Child Immunology & Rheumatology, JGIM, CMU, JSSR, Coimbatore, Bangalore



**Dr. Stalin Ramprakash**  
MBB Immunology, JGIM, CMU, JSSR, Coimbatore, Bangalore  
IPSPCI Consultant Pediatric Immunology, All India Institute of Medical Sciences, New Delhi, India

SPONSORED BY: **PLASMA GEN BIOSCIENCES**

SUPPORTED BY: **IPSPCI** and **IPSPI**

**CATCH IT LIVE**





PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Indonesia



Indonesian Paediatric Society (IDAI)



- Distribution of informative material on PIDs
- Awareness raising online throughout the Week



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PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Iran



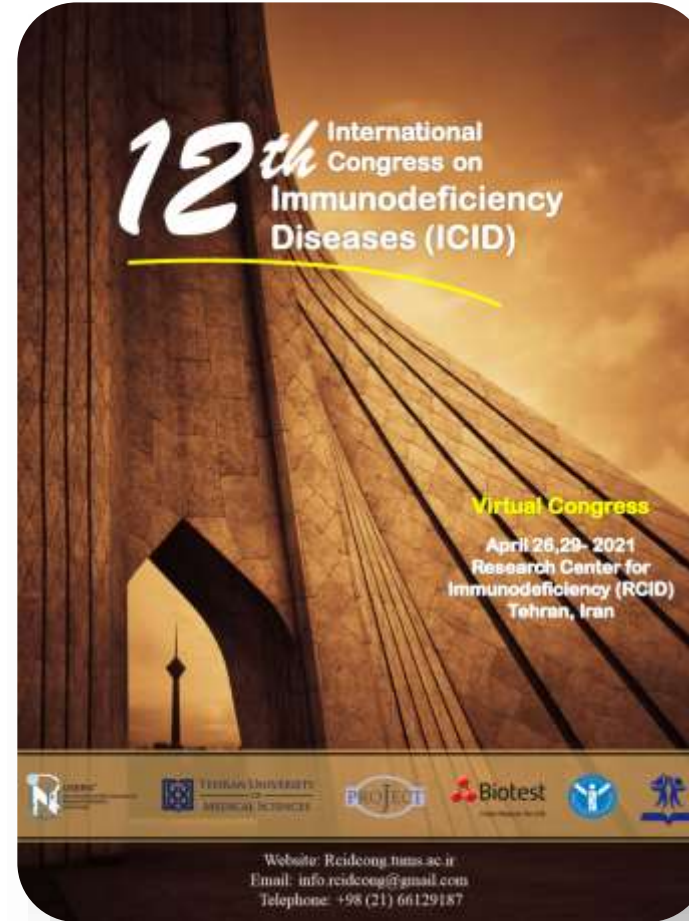
Research Center for Immunodeficiency (RCID)



- 12th International Congress of Immunodeficiency Diseases (ICID) from 26-29 April, focusing on updates in the diagnosis and treatment of PID patients



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PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Ireland



IPIA - The Irish Primary Immunodeficiencies Association



- Virtual 5K Run 2021



Click to see more



Irish Primary Immunodeficiency Association - IPIA

19 April at 11:55 · 🌐

JOIN US TODAY!! #WPIW #PID #IPIA

<https://mailchi.mp/284cc83e.../ipia-5k-virtual-run-wpiw-2021>



MAILCHI.MP

**IPIA 5K VIRTUAL RUN WPIW 2021**

We are a small Irish Association and we need all the help we can get to support our Immunodeficiency's Patients. Your help and...



IPIA Ireland @ipiainfo · Apr 29

Thank you Víctor Hugo Catraio for participating and helping IPIA in their supporting PID patients #PID #WorldPIWeek

kilometres

4'42"

Avg. Pace

47:02

Time

691

Calories

96 m

151



169



# Italy



Associazione Immunodeficienze Primitive & Federazione Italiana Associazioni Donatori di Sangue



- Social media campaign
- Plasma donation campaign
- Message from FIDAS President Giovanni Musso encouraging blood donations during World PI Week



Click to see more

**AIP - Associazione Immunodeficienze Primitive O.d.V**  
2 May at 18:57 · 🌐

On the occasion of World Primitive Immunodeficiency Week **World PI Week** the **#WPIW21** Podcasts were born on Spotify here's the link! 🎧

Happy Listening! 🎧 <https://spoti.fi/3u6NQbr>

⚙️ - See original · Rate this translation

**AIP - Associazione Immunodeficienze Primitive O.d.V**  
28 April at 19:00 · 🌐

📣 World Week for Primitive Immunodeficiency **#WorldPIWeek** is aimed at spreading information and knowledge about Primitive Immunodeficiencies.

📌 Today we want to share with you the view of Ruedy Krech, [World Health Organization \(WHO\)](#)

👉 ... See more

⚙️ - See original · Rate this translation

YOUTUBE.COM  
Dr Ruediger Krech World Health Organization

**FIDAS** | HOME | ABOUT US | DONATING BLOOD | FEDERATED | PAPERS

**EVENTS**

**World Primitive Immunodeficiencies Week 2021: Life-saving therapy from plasma donation**

APRIL 22ND, 2021

**I SUPPORT World PI Week 22-29 April 2021**

We often talk about the importance of plasma donation, but not everyone knows the many reasons why this type of donation is indispensable for many patients. It helps us to clarify the theme an important event: the World Week of Primitive Immunodeficiencies that in 2021 occurs from 22 to 29 April.





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Kenya



PIDs Kenya



- Series of experts videos sharing insights on multiple issues surrounding PIDs to help increase awareness as well as outline unmet healthcare needs in Kenya
- Social media communications
- Participation to World PI Week strike a “Y” photo contest



Click to see more



PIDs Kenya @PIDsKenya · Apr 22

Join us in celebrating #WorldPIWeek



Rare Disorders Kenya @RareDiseaseKE · Apr 22

Join us in celebrating #WorldPIWeek from today 22nd upto 29th April.

Let's support early diagnosis and access to care for PID patients!

Test. Diagnose. Treat.

#PrimaryImmunodeficiencyDisorder  
#PIDWeek  
#RareDiseaseKE

PIDs Kenya @PIDsKenya · Apr 27

'Children with severe, recurrent or unusual infections may have a Primary Immunodeficiency' Dr. David Kiptum tells us more as he joins us in celebrating World PI Week #WPIW2021 @RareDiseaseKE @MOH\_Kenya @KenyaPaeds @ipopi\_info





PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Malaysia



MyPOPI - Malaysia Patient Organization for Primary Immunodeficiencies



- Coverage on national TV news (RTM TV) including interview with PID specialist Dr Sangeetha and Mr Saravanan



Click to see more



MyPOPI

27 April at 14:34 · 🌐

Thank you very much RTM2 TV TamilSeithi for helping us to raise awareness on Primary Immunodeficiency Disease (PID) amongst the Indian community in Malaysia, in conjunction with World Primary Immunodeficiency Week 2021.

We are honoured to have Dr [Sangeetha Siniah](#) and [Saravanan Saran](#) to share on behalf of MyPOPI and the PID community.

<https://www.facebook.com/rtmtvtamilnews/videos/788885852056389>



# Mexico



Fundación Mexicana para Niñas y Niños con Inmunodeficiencias



- Virtual “connect” meeting with families, medical personnel and health officials
- Social media campaigns through videos and quote cards featuring patients’ stories
- Launch of educational video on PID



Click to see more







Section 1

Section 2

Section 3

# Mexico



Mexican Association for PID Patients (AMPIP AC)



- Organised a conference from 21 to 28 April, serving as a meeting point between the association and members, which covered the following topics:
  - › *Mindfulness and mental health*
  - › *Late diagnosis, COVID-19 complications*
  - › *Vaccines & COVID-19*
  - › *Adherence to treatment*
- Raffle, prizes were two nebulizers that can be used in the preventive treatment of some diseases and treat emergency cases of patients with bronchiectasis
- Information sharing on social media



Click to see more





# Mexico



UMAЕ Hospital De Pediatria CMN



- Virtual workshop with patient groups and healthcare professionals
- World PI Week picture frame at the hospital encouraging people to get pictured to raise awareness
- Dissemination of information on PIDs online and at the hospital



# Morocco



Hajar



- Children's party (digital, via Zoom)
- Children's party (with limited number of children)
- Blood donation drive
- New children video



# Netherlands



Stichting voor Afweerstoornissen (SAS) Foundation for Immune Disorders



- Educational webinars
- Creative workshops, baking session
- “The perfect PID picture” photo contest
- Roundtable discussion on “Positive and negative effects of COVID-19”
- Games, escape room, pub quiz
- ‘Meet & Greet’



Stichting voor Afweerstoornissen

12 April at 17:36 · 🌐

What we at the SAS are doing?  
Processing all applications for the workshops, games and webinars of the WPI week 🥳!  
The signing up deadline will close soon, so grab your chance and register! We look forward to meeting you



Click to see more





# Netherlands



UMC Utrecht



- Raised awareness through the voices of UMC Utrecht PhD candidates investigating PIDs - series of messages circulated throughout the week on social media

 Click to see more

**Infection & Immunity UMC Utrecht** @lenl\_UMCUtrecht · Apr 29  
Our PhD candidates investigating PID:  
"I want to find new leads for treatment of Primary Immune deficiency  
Stephanie van Dam investigates underlying mechanisms for severe  
inflammation in PI.  
[@worldPIweek](#) [@UMCU\\_Intl](#) [@CTI\\_UMCUtrecht](#) [@UMCU\\_CMM](#)  
[@UMCURRCI](#)



**Infection & Immunity UMC Utrecht** @lenl\_UMCUtrecht · Apr 26  
Our PhD candidates investigating PID:  
Making optimal use of available healthcare data' - The PhD research  
of Marianne Messelink [@UMCUtrecht](#) aims to reduce the diagnostic  
of primary antibody deficiencies.  
[@worldPIweek](#) [@UMCU\\_Intl](#) [@CTI\\_UMCUtrecht](#) [@UMCU\\_CMM](#)  
[@UMCURRCI](#)



**Infection & Immunity UMC Utrecht** @lenl\_UMCUtrecht · Apr 28  
Our PhD candidates investigating PID:  
"I hope to find better alternatives to blood tests for young children with PID"  
Mischa Koenen investigates the mucosal immunological function of children  
with IgA deficiency  
[@worldPIweek](#) [@UMCU\\_Intl](#) [@CTI\\_UMCUtrecht](#) [@UMCU\\_CMM](#)  
[@UMCURRCI](#)



**World PI Week**  
Test. Diagnose. Treat.





PREVIOUS



NEXT

Section 1

Section 2

Section 3

# New Zealand



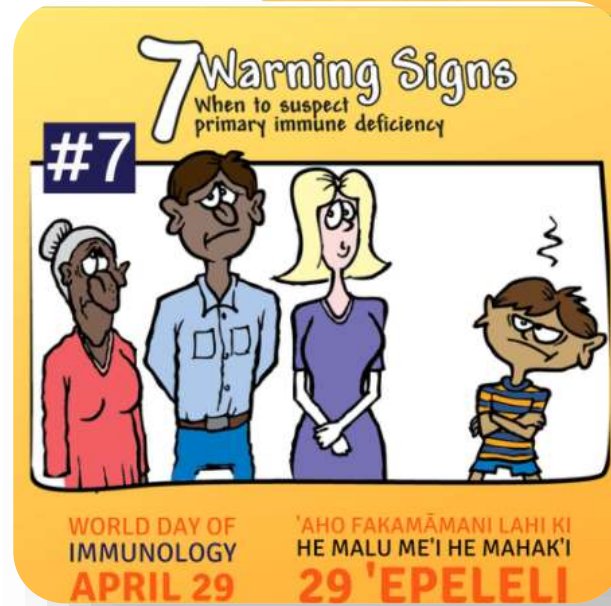
IDFNZ Kids Foundation



- Dissemination of PI facts and awareness raising content on social media
- Story sharing campaign with patients' testimonials



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HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Nicaragua



Nicaragua Association of Patients with PIDs



- Dissemination of PI facts and awareness raising content on social media
- Story sharing campaign with patients



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PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Philippines



Philippines Patient Organization for Primary Immunodeficiencies



- Communications about PIDs and World PI Week, on social media and other digital platforms
- Developed an online toolbox with resources on PIDs to help people raise awareness



Click to see more



**PhilPOPI Pres** @caragcolly · Apr 15

sharing facts on Primary Immunodeficiency (PI) as we support World PI Week this April

[drive.google.com/drive/mobile/f...](https://drive.google.com/drive/mobile/f...)





PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Poland



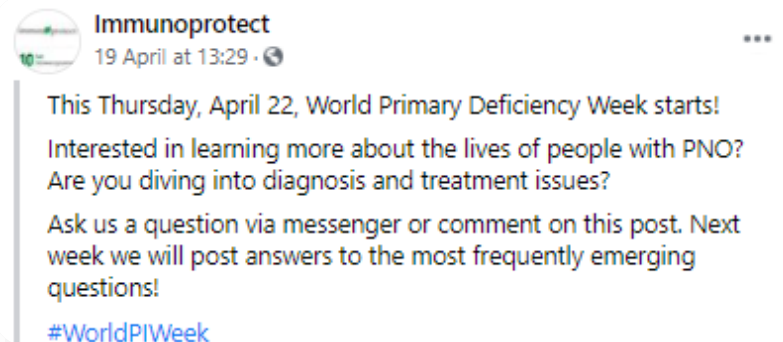
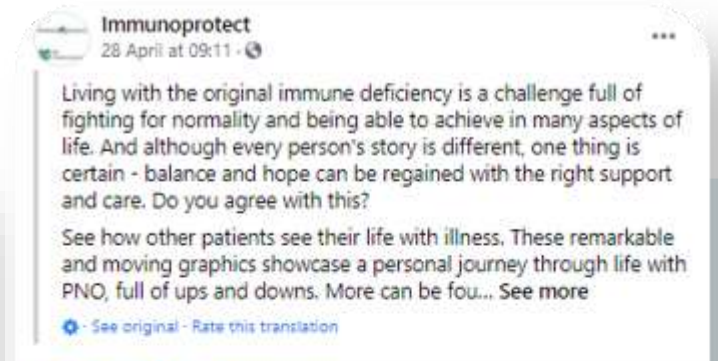
Immunoprotect



- Awareness raising on social media and online platforms
- Live Q&A chat on social media



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PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Portugal



APDIP - Associação Portuguesa de Doentes com Imunodeficiências Primárias



- Celebrity support from Daniela Mercury, a PID patient, raising awareness about PIDs in the press
- Digital campaigning including blog post and social media engagement



Click to see more



**APDIP Imunodeficiência Primária** @apdiptt · May 7

Daniela Mercury falou aos seus fãs sobre a Semana Mundial da Imunodeficiência Primária #WPIW #WPIW2021



lifestyle.sapo.pt

SAPOLIFESTYLE

Daniela Mercury explica como é viver com imunodeficiência primária - ...  
A cantora, de 55 anos, descobriu sofrer desta doença após ter sido doente repetidamente.  
lifestyle.sapo.pt

## Semana Mundial das Imunodeficiências Primárias 2021

22 Abril, 2021 por Ricardo Pereira



A Semana Mundial das Imunodeficiências Primárias começa hoje! De 22 a 29 de abril, pessoas de todo o mundo reúnem-se para trazer visibilidade e compreensão da imunodeficiência primária. Este ano, queremos mostrar que juntos podemos fazer a diferença na vida de milhões de pessoas que vivem com IDP e suas famílias em todo o mundo, ... Ler mais



**APDIP Imunodeficiência Primária** @apdiptt · Apr 30

The World PI Week Talks, a nova série de podcast da @WorldPIWeek, está agora disponível em todas as principais plataformas de podcast.

Já saíram 3 episódios sobre temas muito interessantes:

- plasma humano
- vacinação
- saúde mental



World PI Week Talks - World PI Week  
open.spotify.com

# Romania



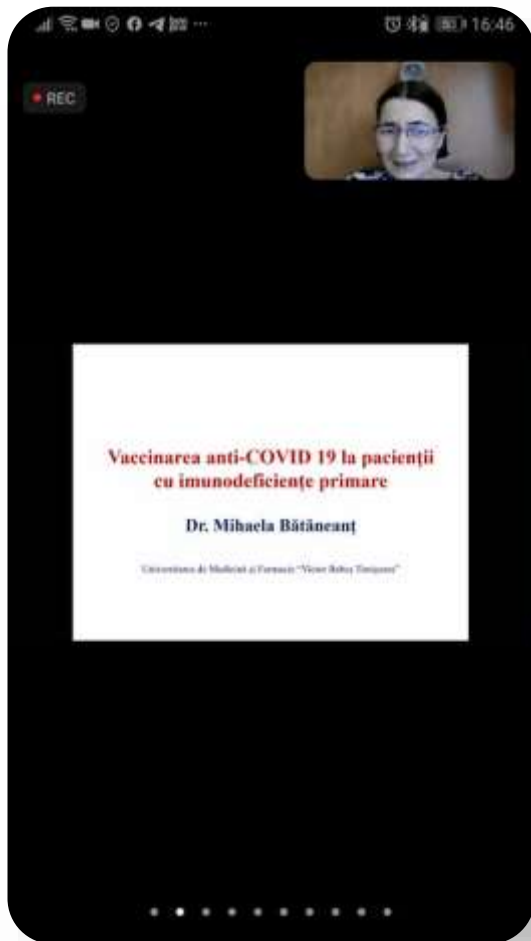
ARPID - Romanian Association of Patients with Primary Immunodeficiency



- National conference for patients with PIDs (virtual)
- Educational content on social media to raise awareness of PIDs



Click to see more







HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Russia

## ОППИД

Общество пациентов с первичным иммунодефицитом



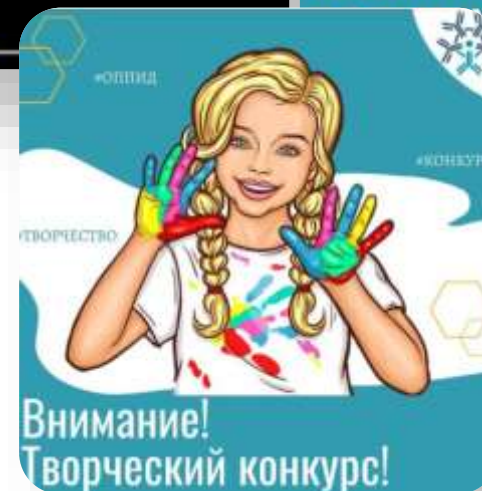
OPP ID



- Support video clip
- Live broadcast series covering various issues surrounding PIDs throughout the campaign Week
- Creative work contest



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HOME



PREVIOUS



NEXT

# Singapore

Section 1



Individual PID patients



- Participation to 'Strike a Y' photo contest
- Awareness raising online

Section 2

Section 3



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Jessie - PID Care China  
@Jessiequmeng

Another Y photo from Singapore PI patients!  
[@WorldPIWeek](#) [@ipopi\\_info](#)



7:23 AM - May 1, 2021 from Central Region, Singapore - Twitter for Android



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Slovakia



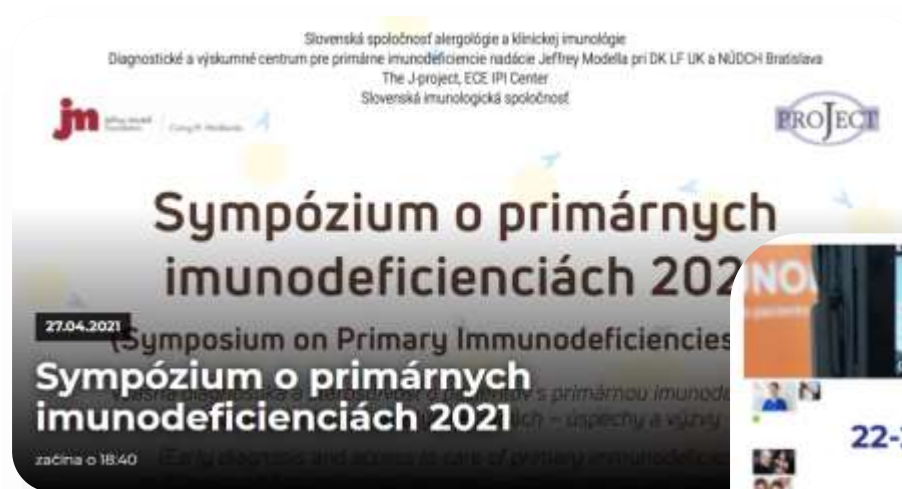
Združenie pacientov s primárnou imunodeficienciou



- PID Symposium including expert talk on immunoglobulin substitution therapy and plasma donation
- Educational video about PIDs promoted on social media with participation of patients of all ages



Click to see more



Združenie pacientov s primárnou imunodeficienciou

22 April at 01:00 · 🌐

In the wake of the world Primary Immunodeficiency Week 2021, we are sending you our video for raising awareness of primary immunodeficiency disease and we want to share two messages, one good and one bad... more in the video.

For people who first hear about this disease and ask what is immunodeficiency? So immunodeficiency is a compulsive condition, which is due to a disorder of some component of the immune system. A disorder may affect immunity natural or specific, may be p... See more

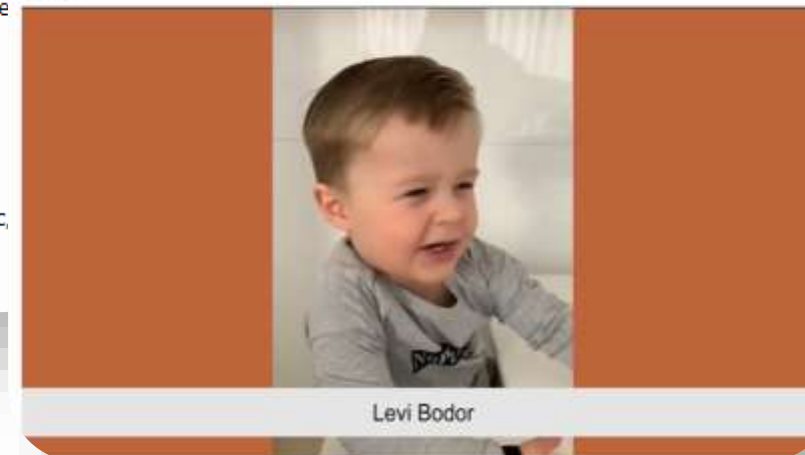
🔗 See original · Rate this translation



V rámci svetového týždňa primárnej imunodeficiencie 2021 Vám zo združenia posielame naše videjko pre zvyšovanie povedomia o ochorení primárnej imunodeficiencie a chceme sa s Vami podeliť o dve spravy, jednu...

Pre ľudí, ktorí prvýkrát počujú o tomto ochorení a pýtajú sa, čo to je imunodeficiencia? Tak imunodeficiencia je chorobný stav, ktorý je dôsledkom poruchy niektorých zložiek imunitného systému. Porucha môže postihovať imunitu prirodzenú alebo špecifickú, môže byť primárna, t.j. podmienená geneticky, alebo sekundárna, získaná počas života. Viac o imunodeficiencii si prečítate tu na našej stránke imunodeficit.sk

Video





# South Africa

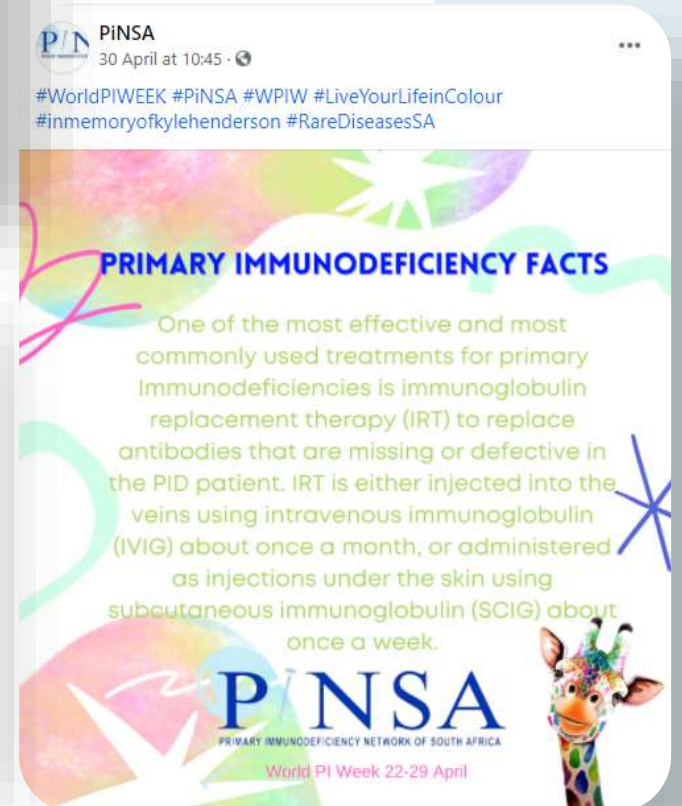


PiNSA Primary Immunodeficiency Network of South Africa



- “Live your Life in Colour” campaign - putting the spotlight on mental health and emotional impact of living with a rare disease such as PID
- PID facts sharing

 [Click to see more](#)



### PRIMARY IMMUNODEFICIENCY FACTS

One of the most effective and most commonly used treatments for primary immunodeficiencies is immunoglobulin replacement therapy (IRT) to replace antibodies that are missing or defective in the PID patient. IRT is either injected into the veins using intravenous immunoglobulin (IVIG) about once a month, or administered as injections under the skin using subcutaneous immunoglobulin (SCIG) about once a week.

**PiNSA**  
PRIMARY IMMUNODEFICIENCY NETWORK OF SOUTH AFRICA  
World PI Week 22-29 April

# South Africa



Micklefield School

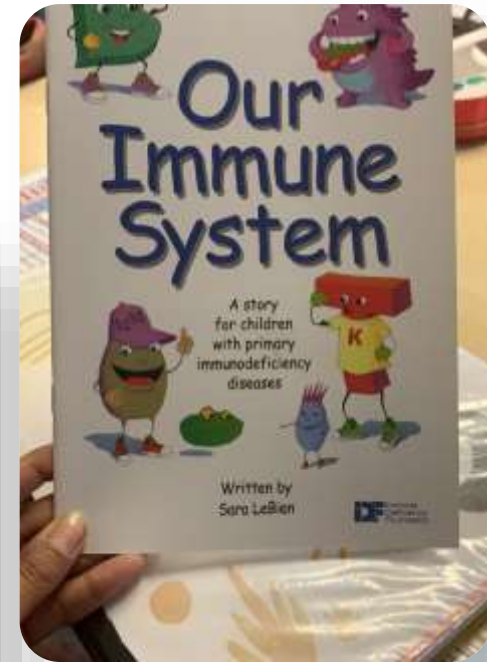


- Awareness / education session at school
- Distribution of informative leaflets on PIDs

Section 1

Section 2

Section 3







PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Spain



AEDIP - Asociación Española de Déficit Inmunitarios Primarios



- Press Release on PI
- Event on PID in adults
- Medical symposium with Hospital Gregorio Marañón
- PID awareness campaign on social media



Click to see more

**Aedip**  
26 April at 10:42 · 🌐

AEDIP with International Primary Immunodeficiency Week. This year three are the themes we put on the table:  
1.- Patient Safety and Protection (vaccination),  
2.- Quality of life for patients  
3.- Plasma Availability.

⚙️ · See original · Rate this translation



**Aedip**  
19 April at 09:50 · 🌐

Good morning,  
On April 28, the Catalan Association of Primary Immune Deficits (ACADIP) hosts an event on Primary Immunodeficiencies in Adults. We encourage you to participate.  
<https://acadip.org/es/agenda/>

⚙️ · See original · Rate this translation

ACADIP.ORG  
**Agenda | Acadip**  
Cada año se celebra la Asamblea anual de soci@s en la cual, a parte de aprovechar para vernos, se aprueba el acta de la anterior...

**Associació Déficit Irr**

**Aedip**  
26 April at 10:52 · 🌐

Press News published on Primary Immunodeficiencies:  
<https://www.infosalus.com/.../noticia-aedip-advierte...>

⚙️ · See original · Rate this translation

INFOSALUS.COM  
Aedip advierte de la caída de donaciones de plasma por la pandemia y del problema de que España no sea...



# Spain



## BARCELONA PID FOUNDATION



- Social media campaign
- “Pictures” support campaign with healthcare professionals



Click to see more



**BCN PID Foundation** @bcnpidfound · Apr 26

Les professionals que treballen al nou Hospital de Dia Polivalent Pediatric (#HDPP) de @vallhebron i que atenen als pacients amb Immunodeficiències Primàries (#IDP), donen suport a la Setmana Mundial de les IDP! 🙌  
#WPIW2021 @WorldPIWeek



**World PI Week**  
TEST • DIAGNOSE • TREAT



**BCN PID Foundation** @bcnpidfound · Apr 27

L'Abril ha fet el treball de Recerca de 2n de Batxillerat sobre la immunodeficiència primària del seu germà Pol, La Síndrome #SAVI

Des de la BCN PID Foundation volem agrair el suport que tots els germans i germanes donen als seus germans/es amb #IDP!

@WorldPIWeek #WPIW2021



**World PI Week**  
TEST • DIAGNOSE • TREAT

# Sudan



SOPPI - Sudanese Organization for Patients with Primary Immunodeficiency



- PID Workshop with involvement of PID experts
- Video message from specialists distributed online to raise awareness of PIDs



Click to see more



### Speakers & Moderators:



SOPPI @SOPPI95893248 · May 1  
Now ! it is happening PID workshop #worldpiweek

**Primary Immunodeficiency Diseases (PIDs) Workshop**

**Speakers & Moderators:**

Time	Topic	Speakers
12:00 - 1:00 pm	Opening Remarks	
02:00 - 02:30 pm	1st Session (Diagnosis)	Dr. Salma Elmahall
03:30 - 04:00 pm	2nd Session (Management in Diagnosis PIDs)	Dr. Salma Elmahall
04:00 - 04:30 pm	Workshop Training in PIDs	Dr. Salma Elmahall
04:30 - 05:00 pm	Workshop	
05:00 - 05:45 pm	Closing Remarks	
<b>Second session (Treatment)</b>		
06:00 - 06:30 pm	Opening Remarks	
06:30 - 08:00 pm	Immunoglobulin Replacement Therapy in PIDs	Dr. Fawaz Sadeh
08:00 - 08:30 pm	Human Stem Cell Transplantation in PIDs	Prof. Shabazz K. Hashim
08:30 - 09:00 pm	Closing Remarks	

**Sponsored by:** IPOPI, World PI Week

**Sponsored by:** IPOPI

# Sweden



PIO - Patient Organisation for Primary Immunodeficiency



- #GoZebra campaign
- Social media communications



Click to see more



Primär immunbrist organisationen, PIO

28 April at 15:29 · 🌐

Now yesterday's walks are counted and in total we have walked 512 hours together! 🐾🐾🐾 #GoZebra Tomorrow April 29th the campaign ends - so now we're putting in the final sprint! 😊👏

Register your walks here: <http://pio.nu/varldsimmunbristveckan-22-29-april-2021/>





HOME  
PREVIOUS  
NEXT

# Turkey

Section 1

Section 2

Section 3



İmmün Yetmezlik Hastaları Dayanışma Platformu (Primary Immunodeficiency Patient Platform Turkey)



- Awareness campaign 'put on your orange mask' to protect people with PIDs
- Dissemination of educational material on PIDs, informative posters on hospital walls
- Social media campaign with video messages from patients



Click to see more

el Hskl @veys\_hkul · Apr 21  
 iün yetmezlik hastaları için kampanya başlattık bize destek olun  
 incu maske takarak fotoğraf veya video ile bize destek olun..  
 İmmünYetmezlik @drfahrettinkoca @GulsanSucak @RTErdogar  
 bestepe @TCMalatyaV @MalatyaHaber\_



@WorldPIWeek @ipopi\_info  
 This is our campaign. Put on your orange mask, notice the  
 immunodeficiency disease  
 Greetings from Turkey 🇹🇷🇹🇷🇹🇷🇹🇷  
 #ImmunDeficiency





HOME



PREVIOUS



NEXT

# Uganda

Section 1



Individual patient



- Testimonial video from a patient's family to increase awareness
- Participation in the photo contest "Strike a Y"

Section 2

Section 3



Click to see more



Primary Immunodeficiencies Association Kenya

26 April at 20:23 · 🌐

Test, diagnose, treat - Lucky, a mother from Uganda shares her experience as she joins us in celebrating #WorldPIWeek





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Ukraine



Vinnytsia National Medical University



- 5<sup>th</sup> Regional School of Immunology & Allergology (virtual) on “Modern opportunities for diagnosis, treatment and management of patients with primary immunodeficiency”



Click to see more

Науковий організатор - Вінницький національний медичний університет ім. М.І. Пирогова



Співорганізатор - ГО "Рідкісні імунні захворювання"



Технічний організатор - ТОВ "Фьорст Ван Груп"



Спікери школи:



**Ольга Бондарчук**  
к.мед.н., доцент ВНМУ ім. М.І. Пирогова, експерт терапевтичного профілю з питань клінічної імунології та алергології Департаменту ОЗ і реабілітації Вінницької ОДА.



**Валентина Чоп'як**  
д.мед.н., професор, лікар імунолог, алерголог, завідувач кафедри клінічної імунології та алергології Львівського національного медичного університету імені Данила Галицького, Експерт МОЗ України.





PREVIOUS



NEXT

Section 1

Section 2

Section 3

# United Kingdom



Immunodeficiency UK



- Awareness raising video on the importance of diagnosis
- Article with *The Northern Echo* to raise awareness about PI
- Social media campaigning



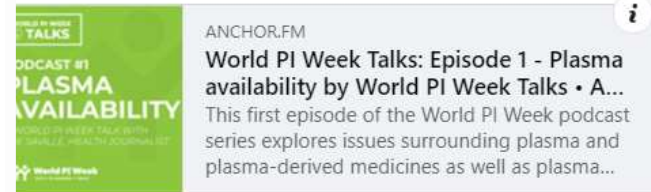
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The World PI Week campaign have created a podcast series, the World PI Week Talks.

Facilitated by Health Journalist Sue Saville, it explores a variety of topics surrounding primary immunodeficiencies (PIDs), rare and genetic diseases that occur when one's immune system is absent or deficient, with potential life-threatening health consequences without early diagnosis and proper care.

Listen to the first three episodes, launched during World PI Week 2021 (22-29 April) in whi... See more



4





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# United States



Immune Deficiency Foundation



- Promoting World PI Week on social media



Click to see more





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# United States



UCLA Health Academic Medical Centre



- 'World PI Awareness' Webinar with Prof. Manish Butte, Dr. Garcia-Lloret, including Q&A session



Click to see more



**Manish Butte** @ManishButte · Apr 27

To celebrate #WorldPIWeek at @UCLAHealth, @manishbutte and Dr. Garcia-Lloret will team up tomorrow with expert immunoglobulin pharmacist Dr. Marks from Care Fusion Rx to give a webinar and Q&A.  
[#PrimaryImmunodeficiency](#)



Welcome! You are invited to join a webinar: UCLA I...  
 Join Us: This webinar is for primary immunodeficiency patients, caregivers, family and ...  
[zoom.us](#)





HOME  
PREVIOUS  
NEXT

# Venezuela



AC IDP - Inmunodeficiencias Primarias Venezuela Asociación



- Awareness Raising campaign on social media
- Zoom conference “De las Inmunodeficiencias Primarias a los Errores Innatos de la Inmunidad” with PID specialists



Click to see more

Section 1

Section 2

Section 3

**SEMANA MUNDIAL DE LOS ERRORES INNATOS DE LA INMUNIDAD (EII) 22 al 29 de ABRIL 2021**

Protegiendo y mejorando las vidas de personas que viven con Errores Innatos de la Inmunidad -en Venezuela- ayudando al diagnóstico precoz y a tratamientos oportunos

idpvenezuela@gmail.com

**SEMANA MUNDIAL DE LAS INMUNODEFICIENCIAS PRIMARIAS 22 al 29 de ABRIL 2021**

**ACTIVIDAD PARA LOS PACIENTES**

**Como podría afectar el COVID-19 a los pacientes con Inmunodeficiencias Primarias?**

**PUEDES INFECTARTE? Habla con Nosotros**

Fecha: Miércoles 28 de Abril  
Hora: de 4:00 pm a 8:00 pm

**A través de este Whassap, médicos de IDP-Venezuela responderán a tus preguntas sobre la enfermedad COVID-19 EN LOS PACIENTES CON IDP**

Panel de Médicos:  
Dra. Maritza Nava  
Dra. Morella Bouchard  
Dr. José Angel Cova

**PARTICIPA!**

**Semana Mundial de las Inmunodeficiencias Primarias**

**De las Inmunodeficiencias Primarias a los Errores Innatos de la Inmunidad**

Patrocinado por:

**Dra. Marielly Herrera  
Dr. Joselit Torres**

**Ayudemos a nuestros pacientes a tener una mejor calidad de vida**

**Via Zoom**  
Martes 27 de abril 6pm  
ID: 795842685 Clave: 285655





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Vietnam



Viet Pips



- Social media campaigning and awareness raising
- Promotion of World PI Week materials



Click to see more

**#WorldPIWeek**

**Bảo vệ và cải thiện cuộc sống của hàng triệu người bệnh suy giảm miễn dịch tiên phát trên toàn thế giới bằng cách khuyến khích việc chẩn đoán sớm cũng như tiếp cận điều trị**

**Chào mừng Tuần lễ Suy giảm miễn dịch tiên phát thế giới #WorldPIWeek 2021**

22-29 Tháng 4 năm 2021

www.worldpiweek.org @WorldPIWeek world\_pi\_week\_ @WorldPIWeekcampaign





HOME



## Regional to Global





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Africa



Arab Society for Primary Immunodeficiencies (ARAPID)  
African Society for Immunodeficiencies (ASID)



- Social media communications
- Promotion of educational material on PIDs



**African Society For Immunodeficiencies (ASID)** @African... · Apr 27 ···

Celebrating the world primary immunodeficiency week [#WorldPIWeek](#)  
[@ipopi\\_info](#)



**I SUPPORT**  
**World PI Week**  
**22-29 April 2021**



[www.worldpiweek.org](http://www.worldpiweek.org) [#WorldPIWeek](#)





HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# Europe



European Society for Immunodeficiencies (ESiD)



- Contribution of President-Elect Fabio Candotti to World PI Week2021 opening webinar discussing COVID-19 learnings on PIDs and the immune system
- ESiD Grand Rounds webinar on managing COVID-19 in adults with antibody deficiency



Click to see more



European Society for Immunodeficiencies - ESiD

April 21

We are more than happy to invite you to the # ESiD Grand Rounds webinar - Join us to learn more about case studies demonstrating the challenges of managing # COVID19 in adults with # Antibody Deficiency .

🕒 When: Monday, April 26th, 5:30 PM (CEST)

📍 Where: <http://ow.ly/CB4Y50EuavO>

# primaryimmunodeficiency # PID # WorldPIWeek

# Latin America



Latin American Society for Immunodeficiencies (LASID)

Iniciativa ALAS



- [Series of 21 video clips](#) from experts and patient representatives throughout the Week to mark World PI Week
- Spotlight on the work of patient groups in Argentina, Brasil, Chile, Colombia, Ecuador, El Salvador, Guatemala, México, Nicaragua y Perú
- [Video Teaser](#) with messages from Patients and experts
- Launch of 6 new initiatives at ALAS: “Tu Voz Cuenta” [platform](#), [Story blog](#), series of 14 [webinars](#) and 14 [educational videos](#), online App to register PID Patients and new Patient Academy

Latin American Society for Immunodeficiencies - LASID  
April 28

el dr. Ricardo Sorensen y su video conmemorativo de la semana Mundial de las Inmunodeficiencias PI Week, que hicimos en conjunto con Iniciativa ALAS muchas gracias a todos los participantes.



Initiatives ALAS  
April 30

Semana Mundial de las # InmunodeficienciasPrimarias # WPIW . El 60% de niñas y niños con # IDP , como # Dylan , necesitan reemplazo anticuerpos con # Gammaglobulina para sobrevivir. Las instituciones de # Salud en # Latinoamérica deben garantizar el acceso a este tratamiento sin ninguna restricción. # GammaglobulinaYA Iniciativa NADIE ES MENOS Jeffrey Modell Foundation, Do Something: The Jeffrey Modell Story



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HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3

# International



International Patient Organisation for Primary Immunodeficiencies (IPOPI)



- Distribution of educational material and patient stories
- IPOPI Board of Directors contributed to a GPS art to mark World PI Week
- Contributed to World PI Week opening webinar sharing insights from IPOPI survey on patients' experiences during COVID-19



Click to see more



# International



Jeffrey Modell Foundation



- Digital campaign to communicate about PIDs
- Distribution of educational material on PIDs



Click to see more

Jeffrey Modell Foundation (JMF) @Info4PI · Apr 28

The #PrimaryImmunodeficiency community is closer than ever & we're coming together to let the world understand PI... Our Voice is Only One Voice. Together, with all of our voices, we are stronger! So, let's keep going!  
#jmfworld #info4pi #awareness #worldpiweek #education #community



Jeffrey Modell Foundation (JMF) @Info4PI · Apr 22

It's kick off @WorldPIWeek with Vicki & Fred Modell as they join PPTA's President/CEO of PPTA in their "Plasma is Life" Podcast!

#jmfworld #wpiw #plasma #DonatePlasma #awareness #podcast #primaryimmunodeficiency #PlasmaProteins @PPTAEurope



Plasma is Life podcast series episode 4: Vicki  
In the latest episode of Plasma is Life, PPTA President & CEO Amy Efantis is joined by the  
[youtube.com](https://www.youtube.com/watch?v=...)

Jeffrey Modell Foundation (JMF) @Info4PI · Apr 19

3 more days until #WorldPIWeek! What are you most looking forward to & how will you create #awareness?!

#info4pi #jmfworld #jmf #jeffreymodellfoundation #primaryimmunodeficiency #test #diagnose #treat #hope #advocacy #action #education #celebration #wpiw #celebrate #livingwithpi



# International



International Nursing Group for Immunodeficiencies (INGID)



- Awareness raising of PIDs on digital platforms
- Participation to World PI Week photo contest “Strike a Y”
- Contributed to World PI Week podcast series and World PI Week videos



Click to see more

INGID @INGID\_Tweets - Apr 22



world\_pi\_week\_

## Ways to join World PI Week 2021

World PI Week is for everyone. There are many ways to mark the World PI Week!

### QUICK STEPS THAT CAN MAKE A DIFFERENCE:

- Join the **photo contest**: Strike a Y in green and post your picture on Facebook, Twitter or Instagram with #PictureAwareness. [More information here.](#)
- Update your social media profiles with the World PI Week frames and banners
- [Share your experience](#) on our website or via [#MyPIstory](#) campaign
- Spread information on PIDs around you and on social media, relay the campaign [hashtag](#)







PREVIOUS



NEXT

Section 1

Section 2

Section 3

# International: The life science industry marks World PI Week

**KORU Medical Systems** @kionomedical - Apr 29  
 PI patients like Susan rely on IG treatment to live a better quality of life.  
 #WorldPIWeek #WPIW2021 #pid #piawareness #piweek#primaryimmunodeficiency #CVID

**Binding Site** @TheBindingSite - Apr 28  
 Patients and their families should be partners of healthcare providers in the decisions related to their own care and treatment plans. Join #WorldPIWeek to bring about change towards #patientcentredcare

**Rocket Pharmaceuticals** @RocketPharma - Apr 22  
 During @WorldPIWeek, we recognize the millions of people who live with a compromised immune system and the urgent need to cure #LAD1 and other Primary Immunodeficiencies.  
 #WorldPIWeek #PIAwarenessMonth #PIAwareness #WPIW

**CSL Behring** @CSLBehring - Apr 25  
 70 to 90% of #PrimaryImmunodeficiency patients remain undiagnosed. Raise awareness during #WorldPIWeek. bit.ly/3esSnhQ

**BPL-USA** @bpl\_usa - Apr 28  
 As #WorldPIWeek continues today, we are proud to be a part of the fight to recognize this patient community and bring them quality treatments every day. Get involved in the fight, here: worldpiweek.org

**WORLD PRIMARY IMMUNODEFICIENCY AWARENESS WEEK**  
 6 MILLION people worldwide are living with PI diseases.

**70 - 90%** of Primary Immunodeficiency patients remain undiagnosed.  
 Follow #WorldPIWeek 2021 and raise awareness about PI.

**70-90%** of people with primary immunodeficiencies worldwide are still undiagnosed.  
 Help spread the word about these rare diseases with us.  
 #PIAwareness #PIAwarenessMonth

**X4 Pharmaceuticals** @X4Pharma - Apr 26  
 Meet Kirsty, a woman who is living with #WHIM Syndrome. Watch this video to hear more about Kirsty's journey to diagnosis, her experience connecting with other patients & her hope for a more effective treatment: bit.ly/3bQe8u7. #WorldPIWeek #MyPIStory

**Mustang Bio** @Mustang\_Bio - Apr 22  
 #WorldPIWeek is here! Mustang Bio is committed to raising awareness around early diagnosis and access to care for people living with primary immunodeficiencies. #SMBIO

**Takeda** @TakedaPharma - Apr 23  
 This #WorldPIWeek, our #PrimaryImmunodeficiency (PI) ambassadors have created moving artworks representing their individual journeys #LivingWithPI. To hear more stories from the ambassadors and to help us raise awareness watch bit.ly/2QTWNWI #MyPIStory

**WHIM SYNDROME VOICES: KIRSTY'S STORY**

**I SUPPORT World PI Week 22-29 April 2021**  
 www.worldpiweek.org #WorldPIWeek

**Gary, Diagnosed with PID at Age 13**

**Chiesi Global Rare Diseases** @ChiesiGRD - Apr 23  
 This #WorldPIWeek, we're showing our support for patients and families living with ADA-SCID. Head to @SCIDAngels, @IDFCommunity and @Info4PI to learn more about primary immune deficiency diseases. #SCID



# Thank You!

**World PI Week 2021 was a success again!**

Primary immunodeficiency awareness does not end with the campaign.

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