

World PI Week Report 2020

Celebrating 10 years of solidarity, successes and expectations for the future of primary immunodeficiency diagnosis, care and quality of life worldwide

10
YEARS



World PI Week
TEST • DIAGNOSE • TREAT

Together, bringing about change for primary immunodeficiency patients worldwide



About World PI Week



An 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 worldwide



10 years of
campaigning



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3



Our active network

i New 2020 partner



GOLD SPONSOR



SILVER SPONSOR



BRONZE SPONSOR



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 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



Campaign resources

Download all materials at www.worldpiweek.org

Plenty of resources available in various languages

- Flyers
- Videos
- Scientific pieces
- “Story sharing” visuals
- Template social media posts



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 | @WorldPIWeek

What?
World PI Week is a global movement to raise awareness of Primary Immunodeficiency (PI) and hidden challenges for the quality of life for people with primary immunodeficiency, early diagnosis, availability of access to treatment and care, healthcare and advocacy, communication and education, patient primary immunodeficiency.

Where?
Worldwide events are taking place across the world during World PI Week, including regional events, conferences, webinars, seminars, and more. Some events are held in person, while others are held online. The World PI Week is open to all people of all ages.

Who?
Everyone can get involved in World PI Week. From patients, carers and families to healthcare professionals, medical students, patient organizations, schools, and more. World PI Week is a global movement for the science, education, patient health, advocacy and anyone interested in supporting the work of the World PI Week.

About
World PI Week was created in 2010 and since then, many activities have taken place in over 20 countries worldwide. We are proud to have many people and families who have been inspired to join the World PI Week.

Primary immunodeficiencies are rare diseases, which occur when a person's immune system is absent or does not function properly. There are over 300 types of primary immunodeficiency, ranging widely in severity. All remaining in children, people are living with primary immunodeficiency worldwide. 1 in 10,000 of people with primary immunodeficiency are with autoimmune worldwide.



HOME

PREVIOUS

NEXT

Section 1

Section 2

Section 3

Educative materials

Shareable resources to inform and raise knowledge of primary immunodeficiency



HOME

PREVIOUS

NEXT

Section 1

Section 2

Section 3



World PI Week messages



About primary immunodeficiency

- Primary immunodeficiency (PID) are rare diseases which occur when a person's immune system is absent or does not function properly. When a defect in the immune system is inherited (passed through the genes), it is called primary immunodeficiency. There are over 300 forms of primary immunodeficiency (PI) or PID ranging widely in severity.
- Primary immunodeficiency often presents in the form of 'common' infections, sometimes leading physicians to treat the symptoms, while missing the underlying cause, allowing the infections 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.
- 10% of people with primary immunodeficiency are still undiagnosed worldwide.
- A number of different signs and symptoms can help identify primary immunodeficiency as they occur commonly in many types. The most common are severe, persistent and recurring infections such as ear, sinus, or skin infections, as well as inflammation in the lungs, liver and intestines. Although it varies from mild to life-threatening and often difficult to diagnose, these signs can enable doctors to refer the patient for further medical examinations. It is also important that family, carers and the public are aware of symptoms to act as an early indicator in case of 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 urine tests, reviewing medical and family history, physical examinations. The initial testing is usually performed in a clinical setting, followed by further tests at the laboratory setting. Genetic testing is often needed to identify the particular form of primary immunodeficiency and the appropriate care pathway, however it is not yet available in many countries.
- For severe forms of primary immunodeficiency, newborn screening is a promising and effective method to allow early diagnosis and save lives. Routine newborn screening programs for severe primary immunodeficiency (e.g. SCID and BCG) should be widely implemented in public healthcare settings in all countries.

World PI Week messages



Care & treatment

Routine access to care and appropriate treatment helps to prevent serious and life-threatening complications in people with primary immunodeficiency.

Treatment options: Treatment for primary immunodeficiency depends on the type of disease and other factors. Several treatment options exist, which include immunoglobulin (Ig) therapy, haematopoietic stem cell transplant (HSCT) or BMCT, gene therapy, gene/cell/cell-based therapy (e.g. CAR-T), and other advanced treatments such as anti-fungal prophylaxis, antibiotics, intravenous Gamma globulin or PEG adalimumab (Humira) among others. Immunoglobulin therapy is the accepted protocol for a wide range of primary immunodeficiency, which can reduce the number of acute infection episodes, prevent permanent damage to the lungs, eyes and neurological system, facilitate protecting the patient's long-term health while improving the quality of life.

About Immunoglobulin (IG)

Immunoglobulin (IG) is a protein that helps the body fight off infections. It is made by white blood cells called B cells. There are several types of IG, each with different functions. IG is used to treat people with primary immunodeficiency (PID) who have low levels of their own IG. IG therapy can help reduce the number of infections and improve the quality of life. IG is also used to treat people with other conditions, such as Kawasaki disease, certain types of cancer, and certain types of autoimmune disease. IG therapy is usually given through an intravenous (IV) drip. It is important to follow the doctor's instructions carefully when receiving IG therapy.

Quality of life

- Early diagnosis and appropriate treatment can prevent complications and have considerable impact on the lives of people with primary immunodeficiency and their families.
- As a result of new therapies, greater social awareness, and better access to information, many patients are leading more normal and productive lives – going to school, work, playing sports, enjoying social activities and a better quality of life.
- Patients may face difficulties coping with the early medical experience, treatment regime and personal life as well as the psychological aspects of living with a chronic disease.
- Having awareness among the patient's social environment, general public, medical professionals and policy makers helps improve understanding of the disease in support of people with primary immunodeficiency.

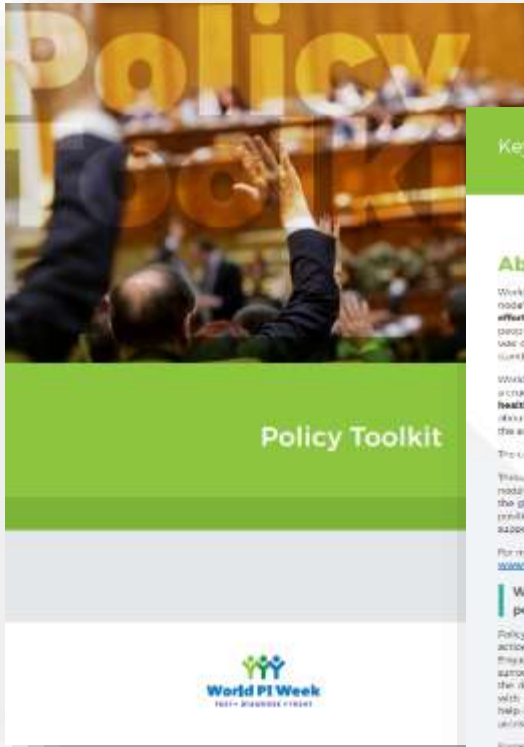


World PI Week Quiz

How much do you know about primary immunodeficiency? Take this quiz to find out!

- How many people are estimated to live with primary immunodeficiency worldwide?
 - 500,000
 - 6 million
 - 25 million
 - 1 billion
- Is primary immunodeficiency an infectious disease?
 - Yes
 - No, it's a hereditary genetic disease
- How many different types of primary immunodeficiency exist?
 - Less than 10
 - 15-100
 - 100-300
 - Over 300
- How many people living with primary immunodeficiency are undiagnosed worldwide?
 - Around 5%
 - About 50%
 - 70-80%
- Which of the following are potential signs and symptoms of primary immunodeficiency? (more than one is correct)
 - Often and severe infections of ear, sinus or skin
 - Pneumonia
 - Inflammation of liver and intestines
 - Scoliosis

Engagement toolkits



Key considerations

About World PI Week

World PI Week aims to raise awareness of the implications of primary immunodeficiency (primary immunodeficiency) diseases 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 22-28 April 2017 and focused on increasing the understanding of the condition and promoting optimal diagnosis.

World PI Week takes place every year on 22-28 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), its causes, the earliest possible diagnosis and optimal treatment and care.

The campaign focuses on a specific theme each year:

Through events and activities promoting the working spirit of primary immunodeficiency, seminars, public lectures, video dramas, and press conferences, the global primary immunodeficiency community can unite to bring about positive changes in healthcare systems and society around the world in support of people living with primary immunodeficiency.

For more detailed information about World PI Week please visit the website: 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 overcome 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 ensure access to optimal care.

Engaging with policy-makers also allows to share personal patient or healthcare professional stories, but also the experience 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 develop a framework of medical care and continuous, and ultimately drive policy change with or without legislative and regulatory support in a long-term vision.

How to engage?

There are many different ways to engage with policy-makers, from face-to-face meetings, written correspondence to organized or unorganized activities.



Resources

World PI Week themes

- 2024 - Access to appropriate treatment
- 2023 - Primary immunodeficiency: Turning hope into action
- 2022 - A call for newborn screening to test for severe combined immunodeficiency
- 2021 - The experience of survival and immunoglobulin replacement for patients with primary immunodeficiency diseases (PID)
- 2020 - Into action: Empowering people to optimize care for all patients with primary immunodeficiency
- 2019 - Making access to life-saving immunoglobulin therapies for people with primary immunodeficiency
- 2018 - My future starts with early testing and diagnosis of primary immunodeficiency
- 2017 - Putting primary immunodeficiency patients at the center of their care

Download the policy toolbox here

Template government letter

This template letter can be adapted to your national government officials, ministers, and other policymakers. You can take it to your doctor and healthcare providers.



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

- HOME
- PREVIOUS
- NEXT

- Section 1
- Section 2
- Section 3





WORLD PI WEEK 2020 IN ACTION

A special year, all about celebrations

Celebrating a decade of successes and expectations for the future

10 years of collaboration and awareness raising across the globe

Celebrating life and what keeps the primary immunodeficiency community moving forward

Celebrating the lives of patients and carers, and their expectations for the future

Celebrating positive research outcomes and the never-ending search for innovative diagnostics, treatments and cures

Celebrating an ever-growing understanding of primary immunodeficiencies and patients' needs for specialised treatment

Celebrating the efforts undertaken worldwide to improve outcomes for people living with the diseases

Celebrating the aspirations of a community that, together, thrive for greater awareness of primary immunodeficiencies, early diagnosis, availability and access to treatment and care worldwide, resulting in better quality of life



Celebrating the 10th anniversary of the campaign



HOME



PREVIOUS



NEXT

Section 1

Section 2

Section 3



World PI Week 2020 amid COVID-19

A special 10-week effort



The campaign was extended to allow anyone participate in the campaign while protecting public health and the health of PID patients




World PI Week started on 22nd of April 2020 and ran for 10 weeks, until 1st of July, in reference to the 10th anniversary



A virtual campaign week with emphasis on online awareness raising and advocacy



Recognizing World PI Week came with additional meaning in the COVID-19 context: everyone experienced the omni-present risk of getting a life-threatening infection and conceived how life is with an immune system that is not able to protect from such infection

 [Read World PI Week COVID-19 statement](#)

10 weeks of campaigning to mark the 10th anniversary



HOME

PREVIOUS

NEXT

Section 1

Section 2


Section 3



The first-ever World PI Week webinar

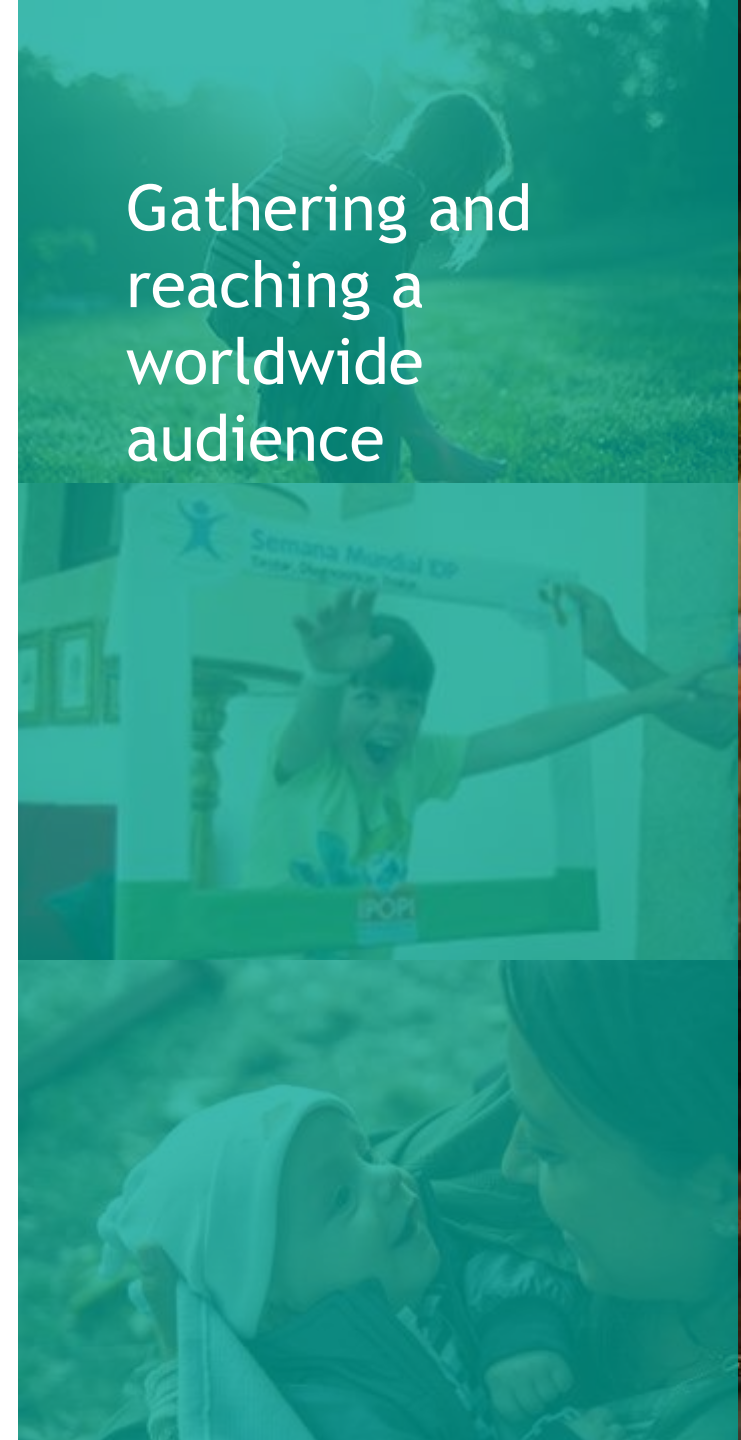
Kicking-off the 2020 campaign as a community

- Launch of a new global video
- Expert insights from Prof. Isabelle Meyts (*UZ Leuven, Belgium; President, European Society for Immunodeficiencies - ESID*) on recent and future advances in primary immunodeficiency
- Overview of available campaign resources and ways to engage
- Spotlight on 2020 campaign activities across different continents

 Webinar recordings available on YouTube



Gathering and reaching a worldwide audience



PREVIOUS



NEXT

Section 1

Section 2

Section 3



Communications collaterals



E-banners, posters, email signatures, sample website posts & many more, translated in local language



PREVIOUS



NEXT

Section 1

Section 2

Section 3



« Facts » visuals

Series of 5 visuals to raise awareness online

www.worldpiweek.org #WorldPIWeek

There are **over 400 forms** of primary immunodeficiency ranging widely in severity and falling into **nine main groups**.

Together, bringing about change for primary immunodeficiency patients worldwide!

10 World PI Week

www.worldpiweek.org #WorldPIWeek

1870 • Primary immunodeficiencies were initially classified in 1970 by a committee of the World Health Organization.

1998 • At the time, 16 types were identified. By 1998, the number had reached 50.

2018 • In 2018, more than 400 have been categorized.

Together, bringing about change for primary immunodeficiency patients worldwide!

10 World PI Week

www.worldpiweek.org #WorldPIWeek

6 people worldwide are living with primary immunodeficiency. That's more than the entire population of Denmark or New Zealand or the combined population of Serbia and Nigeria.

MILLION

Together, bringing about change for primary immunodeficiency patients worldwide!

10 World PI Week

www.worldpiweek.org #WorldPIWeek

70-90% of people with primary immunodeficiencies are still **undiagnosed worldwide**.

Together, bringing about change for primary immunodeficiency patients worldwide!

10 World PI Week

www.worldpiweek.org #WorldPIWeek

Every year it takes about **150 plasma donations** to treat **1 person** with a primary immunodeficiency.

Together, bringing about change for primary immunodeficiency patients worldwide!

10 World PI Week



A new global video



Thank you to Jucaira, Dew, Gustavo, John Paul, Ricardo; Brenda Reid and Prof. Fabio Candotti.



Click to watch the video on YouTube

Bringing insights into the lives of patients across the globe, hearing from patients and healthcare professionals about their expectations for the future

New advocacy material: infographic



👍 One printable version and one version for online use



Outlining key milestones and achievements in primary immunodeficiency over the past decade

- HOME
- PREVIOUS
- NEXT

- Section 1
- Section 2
- Section 3



Press announcements



World PI Week, COVID-19, Rare Disease Day

HOME

PREVIOUS

NEXT

Section 1

Section 2

Section 3



PRESS RELEASE

Embargoed until 22/04/2020, 9.00am CET

World PI Week 2020: 10 weeks of campaigning around primary immunodeficiency

Brussels, 22nd April 2020 – The 10th World Primary Immunodeficiency (PI) Week campaign starts today with one watchword: *celebrations*. Celebrating life and what keeps the primary immunodeficiency community moving forward. We celebrate solidarity and positiveness, much needed in the context of the current pandemic.

Focus on celebrations

This year, the World PI Week campaign celebrates its 10th anniversary. Ten years of collaboration and awareness-raising across the globe. For the first time ever, World PI Week will run for ten weeks, from 22nd April to 1st July. Ten weeks of campaigning and advocacy to put primary immunodeficiency on the spotlight.

There are over 400 different types of primary immunodeficiencies, affecting over 8 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 auto-inflammation. In the current COVID-19 situation, raising awareness of these genetic, hereditary defects of the immune system takes on an even greater significance.

World PI Week 2020 is an opportunity to join a global movement outlining successes and expectations for the future of primary immunodeficiency diagnosis, research, care and quality of life, in support of patients and their families around the world.

Raising awareness to bring about change

Considering the circumstances, emphasis will be placed on online awareness raising and advocacy. To mark this special milestone, people on all continents will connect and show support to the primary immunodeficiency cause through webinars, virtual campaigns, TV/radio interviews, "medical expert" podcasts, celebrity talks; or by donating blood or plasma.

World PI Week is open to everyone. Join the campaign to celebrate the efforts undertaken worldwide to improve outcomes for people living with the diseases. Important breakthroughs have been made in the last decade, but many more advances are to come and are needed.

Sharing is caring: spread the messages of a community that together can foster greater awareness, earlier diagnosis, availability and access to treatment and care worldwide, resulting in better quality of life.

Drawing on a 10-year history and a dynamic network, the World PI Week 2020 builds momentum for another decade of progress in primary immunodeficiency.



Brussels – 19th March 2020

COVID-19 and its implications for the World PI Week 2020: 10 weeks of campaigning for the 10 years' anniversary

In light of the COVID-19 pandemic, the World PI Week Board has taken the decision to extend in time the World Primary Immunodeficiency Week campaign (22-29 April) to protect public health and the health of patients living with primary immunodeficiency. World PI Week will run until 1st July 2020. All campaign supporters are encouraged to join online activities wherever in-person events are not advisable in their regions.

COVID-19 and primary immunodeficiency

Any respiratory virus that can be spread from person-to-person may be a risk for patients with primary immunodeficiency diseases (PID)¹. While there is no tangible evidence to date, it is believed that PID patients might be at higher risk for this infection or a more severe course of the disease². The World Health Organisation (WHO) and the Center for Disease Control and Prevention provide recommendations to reduce exposure to and transmission of COVID-19. Patients and their relatives need to take extra care to prevent from getting this infection³, and should closely keep track of developments in their region and applicable advice from health authorities. For further information, please refer to the [joint statement](#) from IPOPI, ESID, INGD, APSID, ARAPID, ASID, CIS, LASID and SEAPID on the COVID-19 epidemics.

Implications for the World PI Week 2020 resulting from the outbreak

World PI Week is an important milestone for the primary immunodeficiency community. In particular, this year marks the 10th campaign anniversary. Momentum needs to arise from the campaign while ensuring that none of the actions undermines public health nor the health of primary immunodeficiency patients joining the celebrations.

Extension in time: 10 weeks of campaigning

For this reason, this year, the campaign will be extended. World PI Week 2020 will start on 22nd of April and will run for 10 weeks, until the 1st of July 2020, in reference to the 10th anniversary.

World PI Week encourages all individuals and organizations contributing to the campaign to closely monitor the situation in their regions and adhere to the guidance of health authorities when considering next steps regarding their participation or the conduct of their operations in relation to the campaign. This is critical as the epidemiological situation and the management of the pandemic might differ from one country to another. Protection measures should be taken when carrying out activities, as [recommended by](#) the WHO.

This extension in time will provide more flexibility and the possibility to postpone on-site activities and physical meetings where necessary. In-person activities to mark World PI Week are also encouraged later in the year, depending on the health situation.

Increasing online celebrations on 22-29 April

From the 22-29 April (the original campaign dates), emphasis will be placed on online awareness raising and advocacy. All campaign supporters, including patients and patient organizations, healthcare professionals and medical societies, industry partners, policymakers and everyone interested in supporting primary immunodeficiency awareness are invited to join these efforts. More information on online forms of engagement in the campaign can be found on the World PI Week website [here](#), together with the many educational and informative materials [available](#) to spread the word. Further news will be shared soon.

¹ Joint statement on the current epidemics of new Coronavirus SARS-CoV-2 – COVID-19. From: IPOPI, ESID, INGD, APSID, ARAPID, ASID, CIS, LASID, SEAPID. Available at: https://opoi.org/wp-content/uploads/2020/03/COVID19_Mar13v1_EN.pdf

² Item 1

³ Item 1

World Primary Immunodeficiency Week
Email: info@worldpiweek.org | www.worldpiweek.org | @WorldPIWeek
Together, bringing about change for primary immunodeficiency patients worldwide



Brussels – 29 February 2020

Although Rare, we - the Primary Immunodeficiency Community - are Many. Strong and Proud!

On the occasion of Rare Disease Day 2020 – a special day as it falls on a leap year – the primary immunodeficiency community joins forces with rare disease advocates to promote the spirit of celebrating 'Rare'.

Primary immunodeficiencies, a group of inherited and genetic defects of the immune system, are considered rare but still they are estimated to affect over 6 million people worldwide, with infants and children more commonly having serious forms of the disease.

When living with a primary immunodeficiency, the patient's immune system is compromised. This can lead to recurring infections as well as autoimmune, autoinflammatory, allergy diseases and cancer. Primary immunodeficiency patients are more susceptible to a wide range of infections, affecting many different parts of the body, which are often chronic and debilitating in nature. Primary immunodeficiency significantly influences patients' quality of life, and may limit working ability and engagement in physical and social activities.

2020 represents a very unique year for the primary immunodeficiency community, as it honours the 10th anniversary of the World PI week campaign (22-29 April). As such, this year's theme is all about celebrations: celebrating ten years of outstanding collaboration and awareness-raising efforts across the globe to put primary immunodeficiency on the map.

Equity, the theme of the 2020 edition of Rare Disease Day, is inherent to those who live with primary immunodeficiency. The World PI week aspires to fight inequalities in rare diseases which unfortunately persist, to ensure that people living with primary immunodeficiency have the same access to early diagnosis, treatment and care worldwide, as anyone else.

Through this year's celebration, we will help to spread awareness about what it means to be living with or be affected by a rare disease, such as primary immunodeficiency. This will help the public to better understand the unmet needs of this 'Rare' community to ensure no individual with primary immunodeficiency nor any other rare disease is left behind.

Although we still have a long way to go, the 2020 World PI week campaign will take stock of achievements and celebrate life: celebrate the lives of patients and carers, positive research outcomes, an ever-growing understanding of primary immunodeficiencies and aspirations for the future.

Please join us in celebrating Rare Disease Day 2020 and World PI Week 2020 to ensure that the voices of millions of people living with primary immunodeficiency are heard.

For more information on **Rare Diseases Day 2020**: see [here](#)!

World Primary Immunodeficiency Week
Email: info@worldpiweek.org | www.worldpiweek.org | @WorldPIWeek
Together, bringing about change for primary immunodeficiency patients worldwide

Opinion article



“Primary immunodeficiencies: a decade of progress and a promising future”

Isabelle Meyts, Carla Duff, Surjit Singh, Yu Lung Lau, Antonio Condino-Neto, Liliana Bezrodnik, Adli Ali, Mehdi Adeli, Aziz Bousfiha, Jose Drabwell

- Reflecting on the many successes and achievements in the field of primary immunodeficiency to date, and on future advances and unmet needs
- Providing insights on the learnings from COVID-19, the implications and impact on patients and “how to build back better”
- Highlighting how the COVID-19 has paradoxically helped increased awareness of these genetic, hereditary defects of the immune system and how multi-disciplinary collaboration has taken on an even greater significance



The opinion is available in [Frontiers in Immunology here](#)

Published in
*Frontiers in
Immunology* in
December 2020



Section 1

Section 2

Section 3




Social media activities & successes

Engaging the community, driving conversations to increase awareness & understanding

- Building an active and ever-growing network worldwide
- Informing about World PI Week activities and spreading primary immunodeficiency/rare diseases news
- Raising awareness about primary immunodeficiency
- Fostering the exchange of experiences and stories



 Click on the icons to visit social media channels

Social activities have taken a new dimension during COVID-19, becoming a unique way to interact with the community and raise awareness

HOME

PREVIOUS

NEXT

Section 1

Section 2

Section 3



Photo contest #PictureAwareness

Striking a “Y” in support of the primary immunodeficiency cause

- Participants from all regions of the world showed their solidarity
- People were inspired by the visuals encouraging them to share photos with a Y pose, just like the World PI Week logo



The « Y » shape refers to the shape of an antibody but it also symbolises the community



Social media support campaign

Making World PI Week viral on social media

- Supporters could celebrate the campaign virtually in a variety of ways
- Engagement was the highest on Facebook with a World PI Week 'Twibbon' being displayed across the profiles of users that supported the campaign



PREVIOUS



NEXT

Section 1

Section 2

Section 3



Social media engagement

- HOME
- PREVIOUS
- NEXT

Section 1

Section 2

Section 3

Expresso Show @expressoshow · 1h
Annual @WorldPIWeek has been extended from 22 April to 1 July 2020 due to the #COVID19 crises. The aim is to raise awareness about primary immunodeficiency disorders. Do you know someone with an immunodeficiency disorder? Visit worldpiweek.org for more #ExpressoShow



Celebrity support in South Africa

WeStudentNurses @WeStudentNurse · Apr 22
#WeWonder - World PI Week (Primary Immunodeficiencies)

Today is the start of World PI Week & the campaign is in it's 10th year, find out more about the campaign here ow.ly/kQZF30qzGtB

Have u come across PI in your learning or maybe even out on placement?

#WeStNs

Broad reach within nurses students' groups

World Primary Immunodeficiency Week @WorldPIWeek · 1 mei

A message from Gustavo, from Brazil: "It is very important for the government to nationally implement an early diagnosis for primary immunodeficiencies: with a really simple test, we can save moneys and lives" bit.ly/2SjQZ74 #WorldPIWeek



Adrian Liston @LabListon · Apr 23

Our new work on Sec61a1 and #neutropenia is out now in @jacionline!

Another new #pid gene discovered by our team - couldn't be prouder of the great scientists I work with! Just in time for #WorldPIWeek and #Primaryimmunodeficiency awareness month

liston.babraham.ac.uk/blog/2020/4/23...



22 2020 WPIW REPORT

Research community energized the Week

Takeda @TakedaPharma · Jun 29

People with #primaryimmunodeficiency may face many difficult challenges but they can come out stronger. Hear how Pawel found his motivation #LivingWithPI #WorldPIWeek



My PID journey: Finding motivation as a young adult ... Finding what motivates and excites you can help change your life for the better when living with PID. ... youtube.com

RarasNoInvisibles @NoInvisibles · Jun 18

Este año q es 10º aniversario de la Semana Mundial de las #InmunodeficienciasPrimarias, la visibilidad comenzó el 22 d abril durará hasta 1 d Julio #WorldPIWeek #WPIW10years

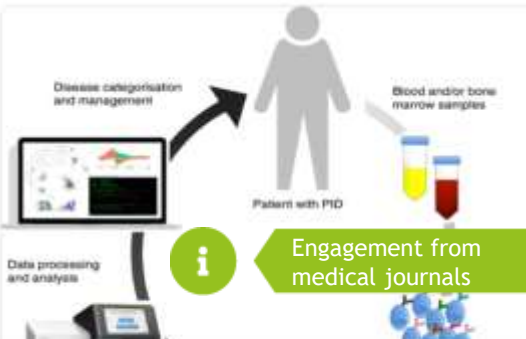
Un estudio español analiza la calidad de vida en niños con #IDP. Gr. @SEICAP pacientes.seicap.es/es/un-estudio-...

12 señales de alarma de inmunodeficiencias primarias

Un estudio español demuestra una pobre calidad de vida en niños con IDP

Immunology @immjournal

It's #WorldPIWeek! Take a look at this review from Johannes Trück et al. @KispiZuerich on #Bcell receptor repertoire sequencing in patients with primary immunodeficiency buff.ly/2zgTeBc



Engagement from medical journals

Patients at the frontline of awareness efforts

Children's Hospital @ChildrensPhila · 16h

#WorldPIWeek is a time to recognize those with primary immunodeficiencies. Learn more about some of our patients who have helped us make strides in the fight against PI: bit.ly/3eOkibB



High-impact communications from healthcare providers

« Words of inspiration » campaign for the 10th anniversary

One message per week from the World PI Week Board

Words of Inspiration - #WPIW10years

« The past 10 years have brought great advancement for both diagnosis and care for primary immunodeficiency patients, let's come together to celebrate this success and continue the journey as a community. »

Martine Pargent, Chair, International Patient Organization for Primary Immunodeficiencies (IPOPI)

« There is a lot to celebrate, but there is still so much to do: we need to continue and raise awareness, to battle for equal access to diagnosis and treatment, to maintain plasma product supplies, to develop more innovative treatments and to foster a collaborative network towards a better diagnosis pathway. It is important to celebrate and keep thinking forward together. »

Prof. Isabelle Meyts, President, European Society for Immunodeficiencies (ESID)

« In the past 10 years, we have seen great advancements in the diagnosis, treatment, and care of patients living with primary immunodeficiencies. As a community, let's join together to celebrate this milestone and continue to improve as we move forward. »

Carie Duff, President, International Nursing Group for Immunodeficiencies (INGID)

« The Primary Immunodeficiency community's strength, courage, and resilience is like no other! We cherish this extraordinary group of people and will always be proud to celebrate this global village during World PI Week and always! »

Vicki and Fred Medell, co-founders, Jeffrey Medell Foundation


« PID affects patients emotionally and can be life-threatening but working together to improve their condition and increase disease awareness is key to improving their quality of life and well-being. Let's work together as a team to support patients and maximize their well-being. »

Dr. Mehdi Adeli, Arab Society for Primary Immunodeficiency (ARAPID)

« As a community, we continue to meet and surpass key milestones: Newborn Screening for SCID now enables early identification and treatment, our understanding of the genetic causes of CVID has broadened the available medications for managing autoimmune aspects, and for many other immunodeficiencies: Gene Therapy is available or on the horizon. Under the cloud of COVID-19 there is much sunshine on the PI front! »

Leadership team, Immunodeficiency Canada

Country involvement

 Click on the name to see the report



HOME
PREVIOUS
NEXT

Section 1

Section 2

Section 3



SNAPSHOTS OF NATIONAL EVENTS

Argentina



AAPIDP (Asociación de Ayuda al Paciente con Inmunodeficiencia Primaria)



- Release of two World PI Week videos: one educational video & one ‘thank you’ video
- Social media campaign
 - Raising awareness on social media and joined the #PictureAwareness challenge




Click to see more



Argentina

Laboratorio de Hemoderivados (National University of Cordova)

-  Social media awareness campaign with educational videos on primary immunodeficiency

 Click to see more



Australia

Children's Hospital in Philadelphia

- Videos of patients and healthcare providers celebrating World PI Week and inviting everyone to stay safe in the Covid-19 context
- Article by Kathleen E. Sullivan (MD, PhD, Chief of the Division of Allergy and Immunolog) about PI and including patients' stories



Two recent patients we've helped are:

- **Elijah**, who was diagnosed with CD40LG duplication-associated autoimmune disease, a new, never-before-seen gene mutation, and
- **Audrey**, who was diagnosed with severe combined immunodeficiency and treated with a bone marrow transplant

Join us as we celebrate World PI Week and recognize:

- The lives of our patients and caregivers




Elijah

Click to see more



Australia

IDFA (The Immune Deficiency Foundation of Australia)

-  Social media campaign
 - Informative infographic on PI
- Webinars on lifestyle factors and life with PI during Covid-19 in partnership with CIRCA (The Clinical Immunogenomics Research Consortium Australia)

 [Click to see more](#)



Immune Deficiencies Foundation
www.idfa.org.au Australia

Illuminating Immunology
Join us for this FREE webinar

**COVID-19 AND PRIMARY IMMUNODEFICIENCY
A GLOBAL PERSPECTIVE**

THURSDAY 25TH JUNE 2020 | 5.00-6.30PM

Speaker: Professor Stuart Tangye
(Lab Head - Immunology & Immunodeficiency, Garvan Institute of Medical Research)

IN PARTNERSHIP WITH
THE CLINICAL IMMUNOGENOMICS RESEARCH
CONSORTIUM AUSTRALASIA (CIRCA)



Australia



AusPIPS and Monash University



- Online public forum for PI patients
- Radio interview about primary immunodeficiency with experts and families of patients
- Social media communications to encourage blood donations



Click to see more

11am 26th April, Melbourne
Tune into Einstein A Go-Go on 3RRR 102.7FM

Featuring
A/Prof Menno Van Zelm
Monash University



For World Primary
Immunodeficiency Diseases
Week (22-29 April)

 AusPIPS
presents
an online patient forum entitled:

“COVID-19 and Primary Immunodeficiency”

Thursday 14th May 2020
4.30-6pm AEST

with talks by Medical Advisory Board Members
Prof Jo Douglass (Clinician), A/Prof Menno van Zelm (Researcher),
Mr Richard Hession (Physiotherapist), committee member Dr Bianca Holzer (Psychologist)
and the National Blood Authority

Register at:
<http://auspips2020.eventbrite.com>

If you have any queries email:
info@auspips.org.au

 AusPIPS Inc.
Posted by Jackie Murphy
14 mins · 🌐

AusPIPS is very pleased to announce that there is a radio interview tomorrow morning about primary Immunodeficiency on radio 3RRR on Einstein A Go-Go between 11 am and 12 noon Australian Eastern Standard Time.

This is in honour of World PI week, to help raise awareness of this rare disorder of which still sees lives lost and damaged by infections.

Menno van Zelm, along with one of our committee members Louise Driscoll will be interviewed along with Louise's daughter Mae.




RRR.ORG.AU
Programs: Einstein A Go-Go — Triple R 102.7FM,
Melbourne Independent Radio



Belarus



Save Immunity

-  • New booklet to raise awareness about PIDs, available in various formats



Click to see more



Всемирная неделя первичного иммунодефицита
22-29 апреля

10 years

В центре внимания - забота о пациентах с первичным иммунодефицитом

Республиканское общественное объединение пациентов (родителей) с первичным иммунодефицитом «Спасем иммунитет»

НЕДЕЛЯ ПИД

Здесь вы можете скачать презентацию для проведения информационных встреч в рамках Недели ПИД.

В ФОРМАТЕ PDF

В ФОРМАТЕ PPT



Recipient of IPOPI WPIW grant



Belgium



Bubble ID

- Celebrations at the hospital in collaboration with Kloen with the immunorap and bubble bursting
- Social media campaign to raise awareness about PI and warning signs



 **infobubbleid** @infobubbleid
In het UZ Gent sloten Bubble ID en Kloen de wereldweek van PID af met de immunorap en het symbolisch bellen-blaas-moment! Burst the Bubble!
bubble-id.org
kloen.be/nieuws/wereldw...

HOME

PREVIOUS

NEXT

Section 1

Section 2

Section 3

 Click to see more



Belgium



VIB (Vlaams Instituut voor Biotechnologie)



- Social media campaign highlighting research efforts in the field of PI, notably around early diagnosis



Click to see more



PREVIOUS



NEXT

Section 1

Section 2


Section 3



Bolivia

Fidep-Bolivia



-  Social media communications
- Webinar on the effect of Covid-19 on rare-disease patients organised in collaboration with two hospitals

 Click to see more



Fidep-Bolivia
23 juin, 19:30 · 🌐

Webinar "Efecto COVID-19 en personas con Enfermedades poco frecuentes" organizado por el Hospital Garrahan de Buenos Aires y Hospital Sant Joan de Deu de Barcelona.
Viernes 26 de junio, a las 12:00 hora Bolivia.

[Voir la traduction](#)

FADEPOF
Federación Argentina de Enfermedades Poco Frecuentes



ALIBER
23 juin, 18:40 · 🌐

FADEPOF comparte: "Efecto de la COVID-19 en personas con enfermedades poco frecuentes"

FADEPOF hace extensiva una iniciativa global sobre un registro de person... [Afficher la suite](#)

[Voir la traduction](#)

Brazil



ASBAI (Associação Brasileira de Alergia e Imunologia)



- Articles and a series of videos from experts to raise awareness of the warning signs of PI in adults and children
- Series of educational activities for healthcare professionals



Click to see more

Bragid
14 April at 15:59

No mês de abril, em que ocorre a semana mundial das imunodeficiências primárias, o programa de Educação continuada da ASBAI vai liberar aulas sobre Imunodeficiências. Só entrar no site e se inscrever!
See translation

Programação completa de Abril

MÓDULO IMUNODEFIÊNCIA

1. Investigação dos defeitos de anticorpos para polissacarídeos
Dra. Ekaterini Simões Goudouris | CRM-RJ: 52.494090
2. Suspeita e diagnóstico de IDP no idoso
Dra. Carolina Sanchez Aranda | CRM-SP: 126819
3. SCID: diagnóstico e tratamento
Dra. Helena Fleck Velasco | CRM-RS 33933
4. Deficiência de IgA como achado laboratorial: o que fazer?
Dra. Mayra de Barros Dorna CRM-SP: 108318

Conteúdo novo toda sexta-feira.

INICIATIVA: **ASBAI**
Associação Brasileira de Alergia e Imunologia

APOIO:

World PI Week
TEST • DIAGNOSE • TREAT

Mais de 400 doenças representam as imunodeficiências primárias

As imunodeficiências primárias (IDP) são doenças genéticas em algum nível do sistema imunológico que prejudicam a capacidade de defender infecções comuns da forma recorrente, como gripes, pneumonia, sinusite, otite média, infecções graves ou por organismos oportunistas. Embora seja raro, com o passar dos anos, as IDP podem levar a danos graves e até à morte. Com o passar dos anos, há uma incidência de 400 doenças genéticas associadas com as IDP, com prevalência variando ao redor do mundo. Devido ao seu caráter raro, muitas vezes há dificuldades de diagnóstico de erro de amostragem, levando a cerca de 10% das primeiras amostras não sendo diagnosticadas.

Esta comemoração em 10 anos da Semana Mundial de Imunodeficiências Primárias coincide com o mês de conscientização sobre o HIV, ocorrendo em 23 de abril e em setembro em 01 de julho, sendo 10 semanas com ênfase na educação sobre imunodeficiências primárias.

Objetivos - Criar campanhas de diagnóstico das IDP, promover a educação dos profissionais de saúde, educar a população sobre as doenças imunodeficientes e suas causas, promover a educação dos profissionais de saúde, educar a população sobre as doenças imunodeficientes e suas causas, promover a educação dos profissionais de saúde, educar a população sobre as doenças imunodeficientes e suas causas.



Brazil



BRAGID (Brazilian Group for Immunodeficiency)



- Social media communications, including awareness campaign on the warning signs of PI
- Launched a series of videos from experts on the themes of “immuno sufficiency”, COVID-19 etc on the occasion of the World PI Week
- Animation video to promote the campaign and encourage participation



Click to see more



Brazil



Hospital Pequeno Príncipe



- Educational videos and podcasts about the immune system, the importance of early awareness and diagnosis with immunologist Carolina Prado

Complexo, Doe, Faculdades, Gols Pela Vida, Hospital, Instituto de Pesquisa

Semana Mundial das Imunodeficiências Primárias: diagnóstico precoce é fundamental

Celebrada de 22 a 29 de abril, a data é importante para reforçar a necessidade de prevenção em tempos de pandemia

22/04/2020



A importância do diagnóstico precoce é o alerta necessário nesta Semana Mundial das Imunodeficiências Primárias, celebrada entre 22 e 29 de abril. Em tempos de pandemia do



Click to see more

Canada



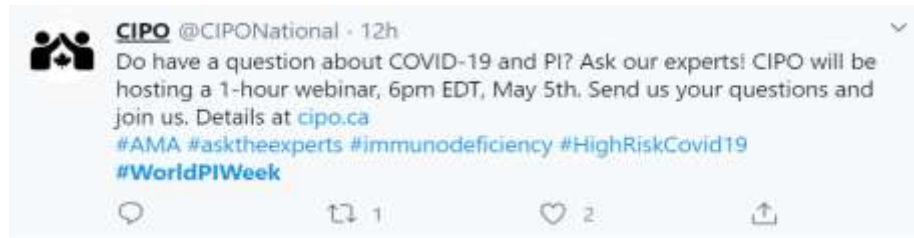
CIPO (Canadian Immunodeficiencies Patient Organization)



- Online webinar on COVID-19 and PID with experts
- Virtual patients meeting every
- Blog articles and press release to celebrate the campaign



Click to see more



CELEBRATE WORLD PI WEEK!

by Whitney

Posted on April 21, 2020 Uncategorized

CIPO is proud to celebrate World PI Week! This year, the World PI Week campaign celebrates its 10th anniversary. Ten years of collaboration and awareness-raising across the globe. For the first time ever, World PI Week will run for ten weeks, from 22nd April to 1st July. Ten weeks of campaigning and advocacy to put primary immunodeficiency on the spotlight.

There are over 400 different types of primary immunodeficiencies, affecting over 5 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 auto-inflammation. In the current COVID-19 situation, raising awareness of these genetic, hereditary defects of the immune system takes on an even greater significance.

World PI Week 2020 is an opportunity to join a global movement outlining successes and expectations for the future of primary immunodeficiency diagnosis, research, care and quality of life, in support of patients and their families around the world.

Drawing on a 10-year history and a dynamic network, the World PI Week 2020 builds momentum for another decade of progress in primary immunodeficiency.

Read the complete press release [World-PI-Week-Press-Release-2020](#)

HOME

PREVIOUS

NEXT

Section 1

Section 2

Section 3

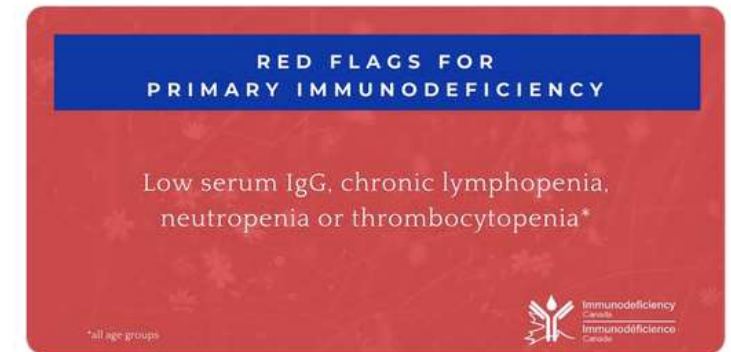


Canada

Immunodeficiency Canada

- Social media campaign with facts and figures about PI

 Click to see more




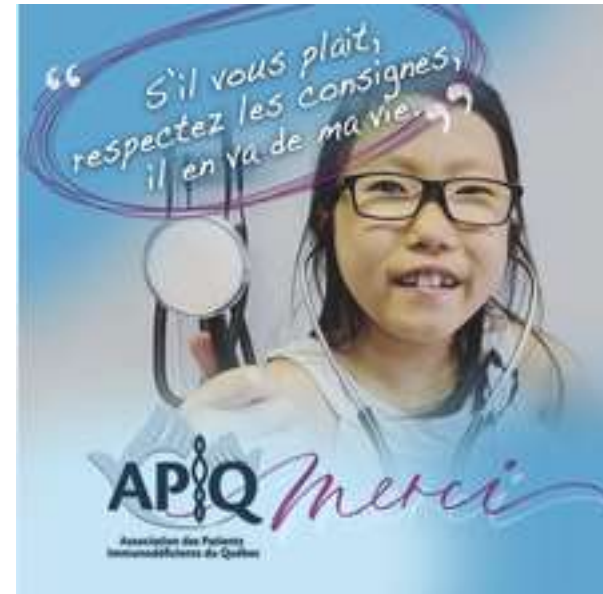
4:29 PM · 29 juin 2020 · Twitter Web App



Canada

APIQ (Association des Patients Immunodéficients du Québec)

-  Distribution of toys to children with PI as part of « I have my teddy » awareness campaign
- Awareness campaign encouraging everyone to stay at home and protect PID patients



 [Click to see more](#)



China



PID Care Organisation



- Social media awareness campaign
- Launched “Amber”, a new logo mascot and comfort toy for children with PI
- Published a new PID brochure for the paediatric care centre

 Click to see more



PID十大警告体征

如果您或您身边的人,有以下两个或更多的警告体征,请尽快与您身边的免疫专家联系,警惕PID的发生



Recipient of IPOPI WPIW grant

Columbia



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



- Promotion of the campaign on social media
- Co-organization of the 10th national PID symposium
- Webinar on PIDs and COVID-19 organized with LASID
- “Stay at home” campaign with a series of videos from PID patients



Semana Mundial de las Inmunodeficiencias Primarias
Abril 22 – 29 de 2020

World PI Week
Not Dismissed Year

X Simposio Nacional de Inmunodeficiencias Primarias JMC -ACAAI

Hotel Spiwak
Cali- Colombia
Abril 18 de 2020
8:00 am – 5:00 pm

Invitan:

LASID, jmcn, Asociación Colombiana de Alergia, Aama e Inmunología, FECOER, INICIATIVA ALAS, jmcn Jeffrey Modell Cariters Network, IDPNet, IPOPI, FIP

Informes: fundacionfip@gmail.com
Tels: (4) 311-8121 • (314) 864-6956
Entrada libre con inscripción previa en www.fundacionfip.org.co



Click to see more

HOME

PREVIOUS

NEXT

Section 1

Section 2

Section 3

Ecuador



Fundacion PIDE



- Suite of videos from PID patients with messages on universal health coverage, personalised treatment and encouraging everyone to stay at home during COVID-19
- Promotion of World PI Week and campaign materials on social media



Click to see more

Qué es?

La Semana Mundial de IDP es un movimiento global para **generar conciencia** sobre las **Inmunodeficiencias Primarias (IDP)** y los retos relacionados a ellas; promover la calidad de vida para las personas con IDP, diagnóstico temprano, acceso y disponibilidad de tratamiento y cuidados en todo el mundo, y promover la comunicación y defensa de estas enfermedades.



Acerca

La Semana Mundial de IDP se creó en 2010 y desde entonces, se han realizado un sinnúmero de actividades en **cerca de 80 países** alrededor del mundo, alcanzando a miles de personas y generando amplia atención en los medios a nivel local e internacional.



El Salvador




Click to see more



Fundacion Escudo de Amor para las IDP



- Dissemination of World PI Week materials to raise awareness



Brussels – 29 February 2020

Although Rare, we - the Primary Immunodeficiency Community - are Many, Strong and Proud!

On the occasion of Rare Disease Day 2020 – a special day as it falls on a leap year – the primary immunodeficiency community joins forces with rare disease advocates to promote the spirit of celebrating 'Rare'.

Primary immunodeficiencies, a group of inherited and genetic defects of the immune system, are considered rare but still they are estimated to affect over 6 million people worldwide, with infants and children more commonly having serious forms of the disease.

When living with a primary immunodeficiency, the patient's immune system is compromised. This can lead to recurring infections as well as autoimmune, autoinflammatory, allergy diseases and cancer. Primary immunodeficiency patients are more susceptible to a wide range of infections, affecting many different parts of the body, which are often chronic and debilitating in nature. Primary immunodeficiency significantly influences patients' quality of life, and may limit working ability and engagement in physical and social activities.

2020 represents a very unique year for the primary immunodeficiency community, as it honours the 10th anniversary of the World PI week campaign (22-29 April). As such, this year's theme is all about celebrations: celebrating ten years of outstanding collaboration and awareness-raising efforts across the globe to put primary immunodeficiency on the map.

Equity, the theme of the 2020 edition of Rare Disease Day, is inherent to those who live with primary immunodeficiency. The World PI week aspires to fight inequalities in rare diseases which unfortunately persist, to ensure that people living with primary immunodeficiency have the same access to early diagnosis, treatment and care worldwide, as anyone else.

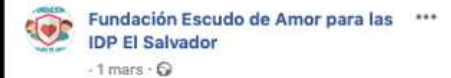
Through this year's celebration, we will help to spread awareness about what it means to be living with or be affected by a rare disease, such as primary immunodeficiency. This will help the public to better understand the unmet needs of this 'Rare' community to ensure no individual with primary immunodeficiency nor any other rare disease is left behind.

Although we still have a long way to go, the 2020 World PI week campaign will take stock of achievements and celebrate life: celebrates the lives of patients and carers, positive research outcomes, an ever-growing understanding of primary immunodeficiencies and aspirations for the future.

Please join us in celebrating Rare Disease Day 2020 and World PI Week 2020 to ensure that the voices of millions of people living with primary immunodeficiency are heard.

For more information on **Rare Diseases Day 2020: see [here](#)**

World Primary Immunodeficiency Week
Email: info@worldpiweek.org | www.worldpiweek.org | @WorldPIWeek
Together, bringing about change for primary immunodeficiency patients worldwide



La declaración de la organización de la Semana Mundial de las IDP en el día de las enfermedades raras
[Voir la traduction](#)


1 1 partage

J'aime Commenter Partager

Votre commentaire...

France

Iris (Immuno-Deficience Primitive: Recherche, Information, Soutien)

-  Contest with the chance to pre-view a documentary on immunity and chat live with the film director
- Information sharing on Covid-19 and World PI Week on social media

 [Click to see more](#)



Association IRIS
@AssociationIris

Des informations très intéressantes concernant entre autres le #COVID_19 et la semaine mondiale des DIP.

#WPIW #DIP #MaladiesRares #MaladiesGénétiques
#SystèmeImmunitaire #AssociationDePatients #Patients
#PID #Sante

IPOPI @ipop_info - 31 mars
IPOPI Spring e-News is out!
Read all about #COVID19 and #PID, the upcoming #WPI for the Global PID Patients Meeting.

We are now on Instagram as well, meet us there - detail:
e-news.ipopi.org

Birmingham, UK

From the President's desk
Under the current circumstances, the thoughts immediately in my mind go to all the people who SARS-CoV-2, the health professionals who fight it, those who contribute to maintaining life in remote locations where confinement is required. We're going there where every hour who are knowledgeable as we they don't know and where our patient comes



CONCOURS

10 personnes gagneront l'opportunité de voir le documentaire
IMMUNITY
en ligne en avant-première !

5 gagnants tirés au sort sur Facebook.

Pour jouer : Aimer cette publication, être adhérent à jour en 2020 et suivre la page @AssociationIris

Semaine mondiale des DIP
Du 22 au 29 avril 2020


World PI Week
TEST • DIAGNOSE • TREAT

IPOPI
INTERNATIONAL
PRIMITIF DEFICIENCY
ASSOCIATION



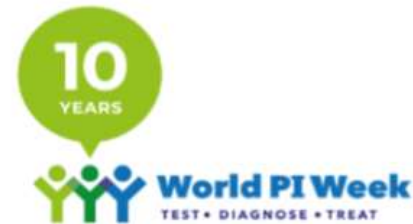
Greece

 **APMONIA** (Association of Greek Friends for Paediatric Immunology - Primary Immunodeficiencies)

-  Dissemination of World PI Week material on communications platforms
- Educational videos on primary immunodeficiency

 [Click to see more](#)

Νέα & Ανακοινώσεις



[Διεθνής Εβδομάδα για τις Πρωτοπαθείς Ανοσοανεπάρκειες](#)



Διεθνής Εβδομάδα για τις Πρωτοπαθείς Ανοσοανεπάρκειες
Έλεγχε. Διάγνωσε. Θεράπευσε.




[Δείτε το video](#)

Hungary



HOPI (Hungarian Organization for Patients with Immunodeficiencies)

-  Organization of a virtual run from 17th of August - 7th of September (replacing a run initially planned on 25th April)
- Webinar on 29 August with key experts, focusing on COVID-19 and PIDs



 Click to see more



India

Aster CMI Hospital, FPID center of Excellence for the diagnosis and management of primary Immune Deficiency - Dr Sagar Bhattad

- Social media communications
- Awareness raising video on Youtube

i
Click to see more

Dr. Sagar Bhattad, MD, DM @DrSagar_Bhattad · 29 avr.
En réponse à @DrSagar_Bhattad
Every month, around 4 - 5 new children are being diagnosed to have a Primary Immune Deficiency in the Pediatric Immunology Department at Aster CMI hospital, Bangalore. The following graph shows the numbers for the last 3 years (2017 - 2019).

Dr. Sagar Bhattad, MD, DM @DrSagar_Bhattad · 29 avr.
This, however, is only the tip of the iceberg! Hundreds of children remain undiagnosed and suffer for months, and at times, for years. Raising awareness is the only way forward and the observation of the [#worldPIweek](#) (April 22 - 29) is one step further in this direction!

Number of PIDs diagnosed at/referred to the Department of Pediatric Immunology, Aster CMI Hospital, Bangalore, India

Year	Number of PIDs
2017	25
2018	30
2019	65



What is Primary Immune Deficiency? - Dr Sagar Bhattad - Aster CMI Hospital.
209 vues · 29 avr. 2020

HOME
PREVIOUS
NEXT
Section 1
Section 2
Section 3

Indonesia



IDAI (Indonesian Pediatric Society)



- Dissemination of World PI Week materials on social media
- Information campaign on PIDs in Indonesia
- Series of webinars with PID specialists organised throughout the week under the theme "Immunization for All"



Click to see more

ONLINE SYMPOSIUM
Menjawab Pertanyaan Orangtua Seputar Imunisasi dalam Masa COVID-19

Hari dan Tanggal: **Senin, 27 April 2020**
Pukul : 12.30-13.30 WIB

Narasumber: Moderator:

Dr. Mei Neni Sitaresmi, Sp.A(K), PhD Dr. Ade Djanwardi Pasaribu, Sp.A

Acara ini terbatas untuk Dokter Spesialis Anak.
Harap login pada website idai.or.id menggunakan NPA yang telah terdaftar.

WEBINAR
Bagaimana Melaksanakan Imunisasi dalam Masa COVID-19

Hari dan Tanggal: **Jumat, 24 April 2020**
Pukul : 14.00-15.30 WIB

Narasumber:

Prof. DR. Dr. Imoedjanto, MP, DTM&H, Sp.A(K) Prof. Dr. Cissy B. Kartasasmita, M.Sc, Ph.D, Sp.A(K) Dr. Nina Dwi Putri, Sp.A(K), MSc(TropPaed)

Moderator:

Prof. DR. Dr. Hartono Gunadi, Sp.A(K)

Tanya IDAI di IG Live
"Imunisasi untuk Semua"

Hari dan Tanggal: **Kamis, 30 April 2020**
Pukul : 12.00-12.20 WIB

Narasumber: Moderator:

Prof. DR. Dr. Kusnandi Rusmil, Sp.A(K) Dr. Catharine M. Sambo, Sp.A(K)

Acara ini terbuka untuk seluruh Sobat Instagram IDAI.



Replying to @idal_tweets

Dalam Rangka Pekan Imunisasi Dunia yang jatuh pada tanggal 24-30 April 2020. Ikatan Dokter Anak Indonesia menyelenggarakan rangkaian acara dengan Tema "Imunisasi untuk Semua" yang dapat diikuti selama #dirumahaja (2) #ImunisasiUntukSemua #PekanImunisasiDunia2020 #WIW2020



Ireland



IPIA (Irish Primary Immunodeficiency Association)



- Virtual run between 2-9 August
 - Participants invited to walk, jog, run, tread mill, cycle for 5 kms
- Social media campaign

Register now!

IPIA very first Virtual 5km fundraiser



Click to see more



Irish Primary Immunodeficiency Association - IPIA a ajouté un évènement.
26 juin, 12:43 · 🌐



DIM., 2 AOÛT ET 7 AUTRES DATES
IPIA very first Virtual 5km fundraiser
Participant decision
Fitness

☆ Ça m'intéresse



Irish Primary Immunodeficiency Association - IPIA
26 avril · 🌐
#WPIW #Plasma #PrimaryImmunodeficiency #IPIA
Its World PI Week - A big THANK YOU to all those people that donate Plasma! primary immunodeficiency patients count on plasma donations to be able to live a healthy life! Help us make this possible!



Irish Primary Immunodeficiency Association - IPIA
25 avril · 🌐



ipopi
22 avril · 🌐
Martine Pergent, IPOPI president, closes the #countonyou global flash campaign. Many thanks for the fantastic turnout and ...
Welcome to World PI Week 2020 🎉

World PI Week 10th Anniversary from 22nd – 29th April 2020 – Come and celebrate with IPIA


February 28, 2020 By Rosa Maria Catralo — Leave a Comment



Recipient of IPOPI WPIW grant

Italy

AIP (Associazione Immunodeficienze Primitive) and PID Adult Centre-Milan

-  • Dissemination of World PI Week materials
- Social media communications and promotion of World PI Week in communications outlets



Il COVID-19 non ferma la Settimana Mondiale delle Immunodeficienze Primitive!

World Primary Immunodeficiencies Week 2020
<http://www.worldpiweek.org>

La decima campagna della Settimana mondiale delle PI dal titolo **"BRINGING ABOUT CHANGE TOGETHER"** inizia con una sola parola d'ordine: celebrazioni. Celebrare la vita e ciò che fa avanzare la comunità delle immunodeficienze primarie. Celebriamo la solidarietà e la positività, molto necessarie nel contesto dell'attuale pandemia. "Insieme, guidando il cambiamento per i pazienti con immunodeficienza primaria in tutto il mondo". È questo lo slogan della settimana 2020. Una sfida per tutti in tutto il mondo.

Alla luce della pandemia di COVID-19, il World PI Week Board ha deciso di estendere nel tempo la campagna per proteggere la salute pubblica e la salute dei pazienti con PID. La World PI Week 2020 iniziata il 22 aprile 2020 termina il 1 luglio:

10 settimane di campagne di comunicazione per il decimo anniversario. La Settimana mondiale, quest'anno in modalità extended, offre l'opportunità di **informare e educare i responsabili delle politiche sanitarie**, le scuole e le famiglie e il pubblico in generale sulle immunodeficienze primarie (PI) per sensibilizzare ad una diagnosi quanto più precoce possibile ed ottenere un trattamento ottimale della patologia.

La settimana WPIW 2020 promuove tre obiettivi fondamentali:


- Test e diagnosi precoce.
- Cura e trattamento personalizzati di qualità e innovativi.
- Qualità di vita per i pazienti e i caregivers.

 Click to see more



Italy

FIDAS Nazionale (Federazione Italiana Associazioni Donatori di Sangue)


-  Social media campaign to encourage plasma donations and highlight the value of plasma derived medicinal products for PID patients and other rare disease patients

 Click to see more



Malaysia

MyPOPI (Malaysia Patient Organization for Primary Immunodeficiencies)

-  Launch of webinar series, exploring various important topics for PID patients in Malaysia
- Live PID parent sharing session
- “Stay at home” campaign with videos from children with PI asking people to stay safe and respect social distancing

 [Click to see more](#)




The collage features several promotional materials for MyPOPI events and campaigns:

- Top Left:** "SESI PERKONGSIAN PID" poster for a live session on August 22, 2020, featuring speaker Firdaus Farhani Binti Abu Bakar and moderator Bruce Lim. The topic is "JOM KETAHUI Rawatan IVIG: APA JANGKAAN ANDA?".
- Top Right:** "SESI PERKONGSIAN PID" poster for a live session on September 12, 2020, featuring speakers Zariah Tharneem Zainuddin and Siti Aminah Bt Amir. The topic is "Dari Titisan Darah kepada Diagnosis".
- Bottom Right:** "PID PARENT SHARING SESSION" poster for a live session on August 15, 2020, featuring speaker Dr. Intan Juliana Abd Hamid and moderator Bruce Lim. The topic is "GET TO KNOW: IMPORTANCE OF IMMUNOGLOBULIN THERAPY".
- Center:** A Facebook post from MyPOPI dated April 27, 2020, announcing a message from twins Adib and Aniq regarding COVID-19 safety.
- Bottom Center:** A video frame showing two children, Adib and Aniq, holding signs that say "ADIB..." and "ANIQ...".

Mexico

Fumeni (Fundacion Mexicana Para Niñas e Niños con Inmunodeficiencias Primarias)

-  Social media campaign with video clips and animations

 Click to see more



FUMENI @FumeniAC · 22 abr.

Hoy más que nunca celebramos 10 años de trabajar por la #Salud de niñas y niños con #IDP, con imaginación, colaboración, alianzas, educación, difusión, creando comunidades fuertes y solidarias. #WorldPIWeek #SaludSinDiscriminación #AccesoATratamiento



by Modell Foundation (JMF) et 9 autres



FUMENI @FumeniAC · 18 juin

#InmunodeficienciasPrimarias son enfermedades genéticas que afectan el sistema inmune de personas quienes no pueden defenderse adecuadamente de virus, bacterias, hongos, parásitos. Si no se diagnostican, las personas pueden perder la vida por complicación de estas infecciones.



0:11 72 vues



FUMENI @FumeniAC · Apr 22

Iniciamos la #SemanaMundial de las #IDP hoy más que nunca para difundir la situación de quienes viven con alguna de estas enfermedades que afectan gravemente su sistema inmune. #SaludSinDiscriminación #DiagnósticoOportuno #AccesoATratamiento #NadieEsMenos @WorldPIWeek @Info4PI



0:14 131 views



Mexico



AMPIPI (Asociación Mexicana para Pacientes con Inmunodeficiencias primarias)



- Conference on “COVID19 in patients with PIDs” on 8 June
- Plasma donation campaign via WhatsApp
- “Stay at home” campaign



#QuédateEnCasa
#PorEllosPorTodos
AMPIP México



#QuédateEnCasa
#PorEllosPorTodos
AMPIP México



#QuédateEnCasa
#PorEllosPorTodos
AMPIP México



#QuédateEnCasa
#PorEllosPorTodos
AMPIP México

Hajar



- Online scientific lecture by pediatrician and specialists about COVID-19 and PIDs
- Online PID patient meeting on COVID-19
- Blood donation drive
- Contribution to a webinar and online Q&A session on 23rd of April with PID experts
- Dissemination of World PI Week materials and participation in online awareness raising

Hajar's activities during the World of Primary Immunodeficiency week

المناعة الأولي و ذلك بالمشاركة في الندوة التي ستقام يوم 23 أبريل حول COVID-19 برئاسة الدكتور نزار محلاوي من CEREDIH بمستشفى نيكرو، و الدكتورة جاكلين كير من معهد Paul-Ehrlich. هذه الندوة عبارة عن أسئلة و أجوبة حول COVID-19 و أيضا سيتم التركيز بشكل خاص على التجارب السريرية للعلاجات والقاحات المضادة للفيروسات.

عبر الويب يتأسها كل من ذ بوصفيحة و ذ. أيلول
 • تنظيم لقاء المرضى عبر الويب لتحسيسهم بفيروس COVID-19
 • حملة للتبرع بالدم.
 • تقديم قفة للأسر المتضررة من جائحة كورونا.
 • دعم الفيدرالية الدولية لضعف المناعة الأولي في الاحتفال بالذكرى 10 للأسبوع العالمي لضعف

هذه السنة وعلى غرار جميع جمعيات العالم المختصة في ضعف المناعة الأولي، ستحتفل هاجر بالذكرى العاشرة للأسبوع العالمي لضعف المناعة الأولي وستكون الأنشطة كالتالي:
 • تنظيم محاضرة علمية توعوية، تحسيسية لفائدة أطباء مستشفى الأطفال حول فيروس COVID-19



Netherlands



Stichting voor Afweerstoornissen



- Social media campaign
- Blogs on PID with Dr. van Montfrans
- Online bingo
- Dissemination of materials on Covid-19 and primary immunodeficiency




Click to see more




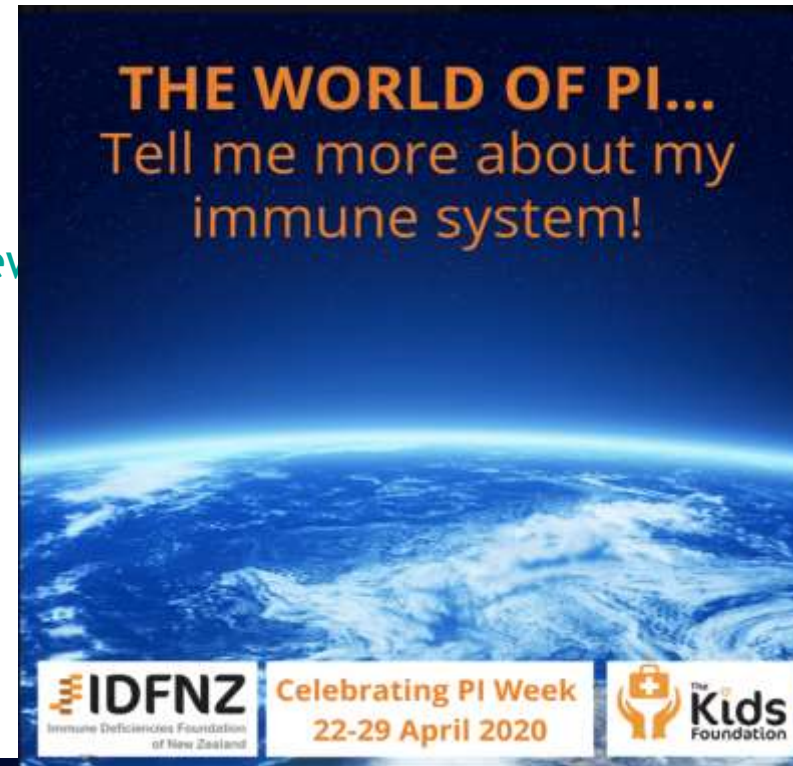
Recipient of IPOPI WPIW grant

New Zealand

IDFNZ (Immunodeficiency Foundation of New Zealand)


-  Online campaign about PIDs “be a detective”
- Launch of educational resources that explain immunology

 [Click to see more](#)



Be a detective

Learn more about how the body protects itself from germs.
What is the Body's alarm system?
What are the body's defences?
How do they work?



The Immune System



Poland

Immunoprotect

- “Stay at home” campaign with patients’ videos
- Interview of Dr Sylwia Koltan on PIDs

Click to see more

Immunoprotect
23 avr. · 🌐

Mija drugi dzień World PI Week. W związku tym zachęcamy do przeczytania wywiadu z konsultantem krajowym w dziedzinie immunologii klinicznej, dr hab. n. med., prof. UMK Sylwią Koltan na temat sytuacji epidemiologicznej w kontekście pierwotnych niedoborów odporności.

[Voir la traduction](#)



RP.PL
Sylwia Koltan: Pacjenci z pierwotnymi niedoborami odporności są szczególnie narażeni


👍❤️ 45 1 commentaire 88 partages

Immunoprotect
25 avr. · 🌐

World PI Week trwa i chociaż kampania #CountOnYou dobiegła końca to wciąż nie brak nam Waszych filmików i zdjęć, dlatego na naszym profilu Światowy Tydzień Niedoborów odporności będzie też Immunoprotectowym tygodniem pacjentej wspólnoty 🌱

Bardzo dziękujemy wszystkim za zaangażowanie, jesteśmy dumni i przeszczęśliwi na wasz odzew. Jutro znowu niespodzianka.

Trzymajcie się ciepło ❤️... [Afficher la suite](#)
[Voir la traduction](#)



am Szymon from Poland
By applying social distancing you protect ME from COVID-19 !!

👍❤️ 2 3 partages




Portugal



Associação Portuguesa de Doentes com Imunodeficiências Primárias
APDIP é uma associação sem fins lucrativos com o propósito de apoiar os doentes com imunodeficiências primárias em Portugal.

 **APDIP (Associação Portuguesa de Doentes com Imunodeficiência Primária)**

-  Launch of a new guide on how to live with PI
- PID awareness campaign on social media



Click to see more

Semana Mundial das IDPs 2020



APDIP Imunodeficiência Primária @apdipt · Apr 23
Uma das acções da Semana Mundial das Imunodeficiências Primárias 2020, que este ano vai prolongar-se até Junho. Junte-se a nós! 🥰 #WorldPIWeek #WPIW2020



APDIP Imunodeficiência Primária @apdipt · Apr 23
Criámos um guia destinado a apoiar os doentes que lidam diariamente com imunodeficiências primárias (IDPs) #saude #idp #imunologia #imunoalergologia #guia #kedrion #imunoglobulina vitalhealth.pt/ebook/IDP/page...




Recipient of IPOPI WPIW grant

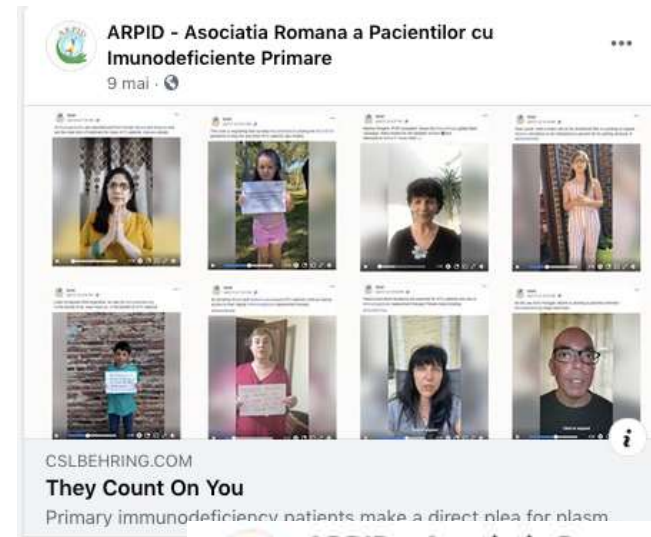


Romania

 **ARPID (Romanian Association for Patients with Primary Immunodeficiencies)**

- 
- Dissemination of materials and information on PIDs on social media
 - Online conference to advocate for plasma donation in Romania


 [Click to see more](#)

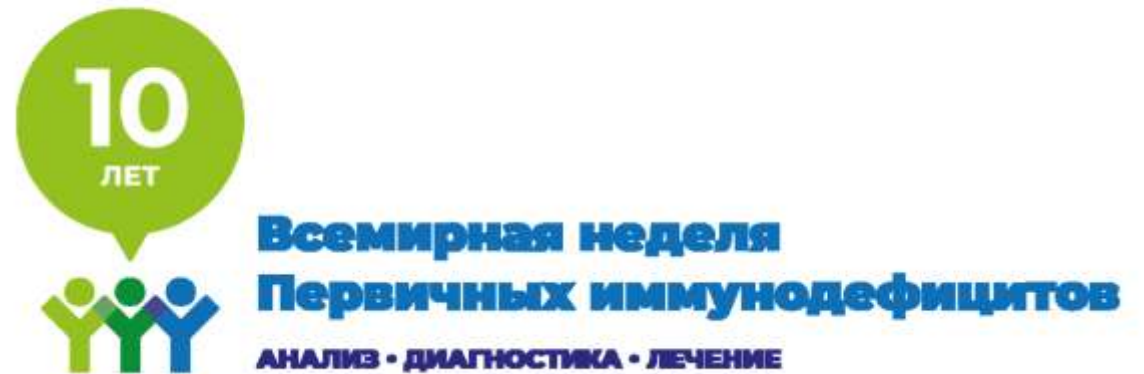


Russia



 **ARPID** (Romanian Association for Patients with Primary Immunodeficiencies)

-  • Dissemination of materials and information on PIDs on communication channels



HOME

PREVIOUS

NEXT


Section 1

Section 2

Section 3



POsPID (Podrška Osobama sa Primarnim Imunodeficitima)

-  • Dissemination of World PI Week material on social media
- Release of an online book for children on PIDs and COVID-19, written by a doctor and psychologist

 [Click to see more](#)



Slovakia



Slovak Association of Patients with PIDs
(Združenie pacientov s primárnou imunodeficienciou)



- New educational video launched and promoted on Facebook, to raise awareness of PIDs in Slovakia
- Highlighted the changes needed in Slovakia: introduction of newborn screenings for rare diseases and plasma donation centres to be opened
- Media interview



Click to see more




IMUNODEFICIT.SK
ZDRUŽENIE PACIENTOV S PRIMÁRNOU IMUNODEFICIENCIOU



South Africa

PINSA (Primary Immunodeficiency Network of South Africa)

-  Virtual Game Show initiated by Rare Diseases South Africa
- [Press release](#) on PIDs and underdiagnosis
- Dissemination of World PI Week materials

 [Click to see more](#)



Our next challenge is one the whole family can participate in – no fitness required. This coming **SatUrDaY 9 MaY at 16:00** we will be hosting our first ever **VirTuaL GaMe ShOw**.

Our theme is **MaD HaTTeRs TeA PaRtY**, so we encourage you to dress as creatively as you can to earn yourself some bonus points. Entry is **R100 PeR tEaM** (your team can be just yourself or all the members of your household – your furry friends are welcome to get involved too).

All you need is a laptop, an internet connection and your competitive spirit. Once you've purchased your entry via our [online store](#), you will be sent an email with pdf instructions to register on Zoom. Zoom is the online platform we will be using to host the game show.

 **PINSA**
@PiNSA_ZA

Press Release: Children and adults who fall ill with recurrent underdiagnosed and underreported. World Primary Immunodeficiency Disease Week has been extended to 10 weeks, and will now run from 22 April to 1 July 2020, due to the added concerns arising from the threat of Covid-19



Press Release
21 April 2020


World Primary Immunodeficiency Week extended to 10 weeks due to Covid-19 concerns

Children and adults who fall ill with recurrent or more severe infections may suffer from an undiagnosed, underlying primary immunodeficiency (PID) disease – which is of increased concern during the Covid-19 pandemic.

This is the word from Professor André van Niekerk, Paediatric Pulmonologist and Chairman of the [Allergy Society of South Africa \(ALLSA\)](#) who adds that these conditions often go underdiagnosed and underreported. *World Primary Immunodeficiency Disease Week has*

South Africa

AFSA (Allergy Foundation South Africa)

-  Interview in main media (TV and radio) with PID expert Prof Claudia Gray
- World PI Week logo broadcast on high-audience TV channel



 Click to see more

Cape Talk – Primary Immune Deficiency Awareness Interview – Prof Claudia Gray With Bianca Resnekov





AAPIDP (Asociación de Ayuda al Paciente con IDP)



- Participation in the World PI Week #PictureAwareness photo contest
- New educational video about PIDs, promotional video about World PI Week
- Dissemination of World PI Week materials
- Position statement from the organisation on PIDs and COVID-19 and raising awareness about the campaign



Click to see more



ABRIL 30, 2020

¿Sabés qué son las Inmunodeficiencias Primarias?

Desde AAPIDP hemos realizado este video para concientizar y difundir las Inmunodeficiencias Primarias.



Spain



AEDIP (Asociación Española de Déficit Inmunitarios Primarios)



- Dissemination of information about PIDs on social media and WPIW materials



Click to see more



Aedip
3 mai · 🌐

Este año, aunque estemos en estas circunstancias tan complicadas y excepcionales por la Pandemia COVID-19, también celebramos la X SEMANA INTERNACIONAL DE LAS INMUNODEFICIENCIAS PRIMARIAS.

Es una buena oportunidad para hacer visible esta enfermedad a la sociedad. Quizá ahora se comprenda mejor la situación de los Inmunodeficientes y la fragilidad de salud en la que viven toda la vida.

En esta edición, los actos programados por AEDIP para celebrar la X Edición de la Semana ... **Afficher la suite**

Cette année, même si nous sommes dans ces circonstances si compliquées et exceptionnelles par la pandémie COVID-19, nous célébrons également la X SEMAINE INTERNATIONALE DES IMMUNODÉFICIENCES PRIMAIRES.

C ' est une bonne occasion de rendre cette maladie visible à la société. Peut-être que la situation des immunodéficients et la fragilité de santé dans laquelle ils vivent toute leur vie sera mieux comprise maintenant.

Dans cette édition, les actes prévus par l'AEDIP pour céléb...
Afficher la suite

[Masquer l'original](#) · [Notez cette traduction](#)

10 YEARS
World PI Week
NEXT GENERATION - TODAY
22 APRIL >
01 JULY 2020

Celebrating 10 years of solidarity, successes and expectations for the future of primary immunodeficiency diagnosis, care and quality of life worldwide

worldpiweek.org | [@worldpiweek](https://twitter.com/worldpiweek) | [www.youtube.com](https://www.youtube.com/channel/UC...)

Spain



Hospital la Fe



- Social media communications by the first multi disciplinary PID committee in the community of Valence (set up in March 2020)



Click to see more




Pedro Moral @PedroMoral16 · 9h

En la Semana Mundial de las IDP queremos recordar que desde el Comité Hospitalario de IDP del Hospital La Fe seguiremos trabajando para mejorar la atención y la calidad de vida de nuestros pacientes.



Spain

ACADIP (Catalan Association of Primary Immunodeficiency)

-  Awareness raising campaign on the warning signs of PI
- Dissemination of World PI Week materials



SIGNES D'ALERTA QUE HAN DE FER SOSPITAR UN DÈFICIT DEL SISTEMA IMMUNITARI

- 1- Més de 2 sinusitis greus en menys d'un any
- 2- Més de 2 pneumònies confirmades radiològicament en menys d'un any
- 3- Infeccions de la pell greus i/o abscessos profunds recidivants
- 4- Estancament o retard de pes i alçada malgrat una correcta alimentació
- 5- Dues o més infeccions greus
- 6- Més de 8 otitis greus en un any
- 7- Infeccions per fongs a la boca després del primer any de vida
- 8- Complicacions després de l'administració de vacunes i/o infeccions per microorganismes que normalment no provoquen malalties
- 9- Infeccions que no es curen amb els tractaments habituals i precisen l'administració d'antibiòtics intravenosos per eradicar-les
- 10- Antecedents familiars de malalties amb alteració del Sistema Immunitari

La suma de dos o més signes d'alerta en un pacient augmenta el risc que es pateixi una IDP

22 - 29 Abril 2020 - Setmana Mundial IDP
World Primary Immunodeficiency Week - WPIW
RESEARCH TO LIVE BETTER





ACADIP
ASSOCIACIÓ CATALANA DE DÈFICITS IMMUNITARIS PRIMARIS

10 YEARS

World PI Week
TEST • DIAGNOSE • TREAT

 Click to see more



Seis mensajes clave sobre LOS TRATAMIENTOS CON INMUNOGLOBULINA

La teràpia amb immunoglobulines derivades del plasma humà, que conté anticossos, protegeix contra una àmplia gamma d'infeccions.

Existeixen diferents tipus d'administració, Immunoglobulina intravenosa i subcutània.

Les donacions de sang i plasma son un regal essencial dels donants als pacients IDP. Gràcies per la vostra generositat! No hi ha teràpia alternativa per a molts dels nostres pacients.

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

 **ACADIP**
ASSOCIACIÓ CATALANA DE DÈFICITS IMMUNITARIS PRIMARIS



Spain

BCN PID Foundation, Vall d'Hebron Hospital Campus

- “Bubble from home” campaign to raise awareness about PIDs via pictures disseminated online
- Series of training courses for students, by resident doctors and nurses
- PID awareness online campaign

 Click to see more

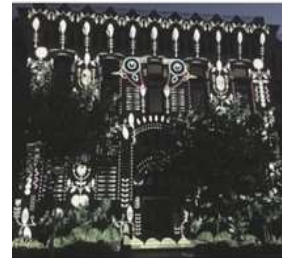


CN PID Foundation @bcnpidfound · 25 avr.
Des del 2010, 500 alumnes han pogut gaudir dels cursos en formació en IP de metges residents i de personal d'infermeria, organitzats pel grup IDP de @SCPed i @SCImmunologia, en els que col·laborem anualment. Els cursos d'enguany s'han posposat. @Info4PI @ACADIP @WorldPIWeek



Bubbles from home
May 2020

Step by step we are going out into the street and leave behind the days of lockdown. But what about bubble boys and buses



BCN PID Foundation @bcnpidfound · 20 mai
Bufem #bombollesdesdecasa per tots els nens bombolla que han de seguir vivint en condicions d'aïllament i protecció a causa de la seva #IDP. Compra el teu bomboller a @AbacusCoop i estaràs col·laborant en la recerca d'aquestes malalties minoritàries a @vallhebron @bufalabombolla



Spain



AEPap (Asociación Española de Pediatría de Atención Primaria)



- Dissemination of World PI Week materials on social media and online



Click to see more



GPI AEPap @GPI_AEPap · 28 abr.

Esta mes Abril tiene dos efemérides importantes: la campaña de la **#WorldPIWeek** 2020 y la SEMANA MUNDIAL DE LA INMUNIZACIÓN. En tiempos **#COVID19**, ¡no olvidemos el importante papel de las vacunas! **#LasVacunasFuncionan #VaccinesWork for All | @scoopit**



World Immunization Week 2020 #VaccinesWork fo...
Celebrated in the last week of April, World Immunization Week aims to promote the use of ...
[who.int](https://www.who.int)



3

5



GPI AEPap @GPI_AEPap · 28 abr.

Esta semana es el 10 aniversario de la celebración de la Semana Mundial de las Inmunodeficiencias Primarias. ¡No te olvides de ellas! **#WorldPIWeek** 2020 **#WPIW10years #primaryimmunodeficiency | @scoopit**



Our 2020 campaign - World PI Week
**In light of the COVID-19 pandemic, the World PI Week Board has taken the decision to extend in ti...
[worldpiweek.org](https://www.worldpiweek.org)



1

6



Sweden



PIO (Primär immunbristorganisationen)



- Series of podcasts on living with a primary immunodeficiency
- #GoZebra fundraising campaign and virtual walks



This is a special edition in English regarding covid-19, from the podcast "Så Sjukt – a pod about life with primary immunodeficiency". A longer version of this episode is available in Swedish. [#SoundCloud soundcloud.com/sasjukt/avsnit... #coronavirus #covid19 #primaryimmunodeficiency](#)



Click to see more

Dags att sammanfatta årets Världsimmunbristvecka och kampanj #GoZebra.

Skrivet av Admin | 30 april, 2020

Nationellt

Nu har vi räknat ihop gårdagens minuter – då flera familjer/företag/kompisgång registrerade promenader för hela veckan och...vi ramlade nästan av kontorsstolarna! Totalt har vi tillsammans promenerat nästan 48 dygn dvs 7 veckor – på en vecka! 68820 minuter = 1147 timmar! WOW! 🤩 Och vi har aldrig tidigare varit så många personer som promenerat! Stort och varmt tack till alla som varit med i kampanjen och bidragit till att PIO nu får 35.000 kr från kampanjens samarbetspartners för att sprida mer information om primär immunbrist! ❤️ Stort tack också för fina foton från promenader och glada och trevliga meddelanden som vi fått under veckan! Vi ser redan fram emot nästa års #GoZebra-kampanj! ❤️ #GoZebra #WPIW #WorldPIWeek



Sudan

i Sudanese Society for Allergy and Clinical Immunology and Soppi (Sudanese Organization for Patients with Primary Immunodeficiency)

- a** • Dissemination of World PI Week materials on social media
- Communications about the campaign online

i
Click to see more




Sudanese organization for patients with primary immunodeficiencies And Sudanese Society of Clinical Immunology and allergy are celebrating #WPIW

HOME
PREVIOUS
NEXT
Section 1
Section 2
Section 3

Turkey

 **IMYED (İmmün Yetmezlik Derneği - Immune Deficiency Association)**

-  Video with drawings of children living with PID illustrating World PI Week celebrations
- Engagement campaign with members



 [Click to see more](#)



United Kingdom



PID UK



- Series of videos from PID patients sharing their stories and experiences
- Questions & Answers online campaign to raise awareness on primary immunodeficiency



FAQ

Q. I have just heard something about multisystem inflammatory syndrome. What are the symptoms and are children with a primary immunodeficiency more vulnerable?

Thank you for taking the time to answer my questions and to find answers to those you weren't sure of. You have made me a great deal calmer about the whole situation and enabled me to talk to my husband about it. He now understands a little about how I've been feeling. Therefore, thank you from him also.
CVID patient, Lancashire



CGD Society liked

PID UK @primaryimmuneuk · 1h

Meet our amazing supporter Mark 😊

▶ Watch his inspiring video, describing his journey, what he has learnt along the way and how we want to help others affected by PID's. #WorldPIWeek

Thank you for sharing Mark ❤️

Time of Reflection in Stressful Times
A video made to invite all who would like help & support in these challenging times based on my ...
youtube.com

 Click to see more



PID UK @primaryimmuneuk · Apr 26

Today we are #celebrating with our PID community friends, the incredible achievements made over the last 10 years. #WorldPIWeek

#primaryimmunodeficiency #raredisease #livingwithpids #pidcare

10 World PI Week
22-29 April 2020
Celebrating 10 years of history, success and expectations for the future of primary immunodeficiency diagnosis, care and quality of life worldwide



PID UK @primaryimmuneuk · Jun 1

"Receiving my diagnosis was validating and life-affirming."

Thank you for sharing your story Charlotte ❤️

piduk.org/whatarepids/pa...

#primaryimmunodeficiency #raredisease #livingwithpids #pidcare



PID UK @primaryimmuneuk · 13h

As part of #WorldPIWeek, we want to share your stories. By doing so, we hope to help bring strength and comfort to our community. Send us your stories in text or video. Thank you, we can't wait to hear your story 😊

#primaryimmunodeficiency #raredisease #livingwithpids #pidcare

your story...

What advice would you give to other families?

What was your PID

United Kingdom

Liston Laboratory at the Babraham institute

- Launched research results during the World PI Week
- Social media awareness efforts

 Click to see more



Adrian Liston
@LabListon

Our new work on Sec61a1 and #neutropenia is out now in [@jacionline!](#)

Another new #pid gene discovered by our team - couldn't be prouder of the great scientists I work with! Just in time for #WorldPIWeek and #PrimaryImmunodeficiency awareness month

liston.babraham.ac.uk/blog/2020/4/23...



7:06 PM · Apr 23, 2020 · Twitter Web App



HOME

PREVIOUS

NEXT

Section 1

Section 2

Section 3



United Kingdom



Bubble Foundation



- Book with messages and stories from PID patients
- Social media awareness campaign

 Click to see more



Bubble Foundation

@TheBubbleUK

Save the lives of babies born with no immune system & accommodation. #WorldPIWeek

[Traduire la biographie](#)

Newcastle-Upon-Tyne [bubblefoundation](#)

A rejoint Twitter en juillet 2012

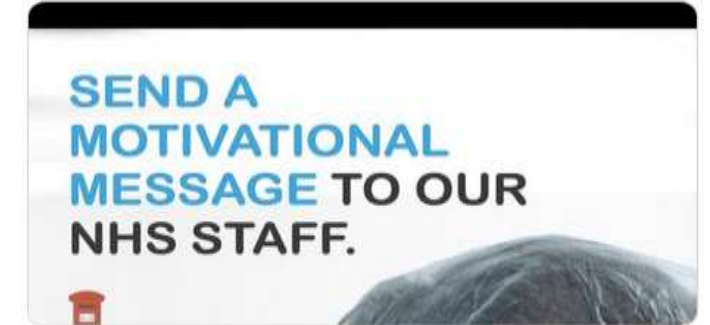
558 abonnements 3 833 abonnés

Suivi par aucune des personnes que vous suivez



Bubble Foundation @TheBubbleUK · 29 mars

Ask the bairns to send a surprise message to our hospital. This can be a drawing, picture or even a poem of why our staff are doing such a fantastic job. We've got a wall waiting to be filled with your positive messages!



1 3 1



Bubble Foundation @TheBubbleUK · 29 mars

Post them to Ward 3, Great North Children's Hospital, Queen Victoria Road, Newcastle Upon Tyne, NE1 4LP and let us know who they're from!

- if you were a PID patient, your PID messages could be included in our book for #WorldPIweek! #SaveOurNHS #WereInThisTogether #isolationtips

3 4



United States



Immunoglobulin National Society



- PID awareness on social media
- Online campaign to encourage plasma donation

 Click to see more



Immunoglobulin-National-Society @IgNSorg · 12h

It's [#worldpiweek](#). Every year it takes 130 plasma donations to treat ONE patient with PI. Think about it. Then take action. Say it with us: [#ItsMyTurn](#) [#donateplasma](#) [#igns](#) [#ignsorg](#)



Every year it takes about **130 plasma donations** to treat **1 person** with a primary immunodeficiency.

Together, bringing about change for primary immunodeficiency patients worldwide!



HOME
PREVIOUS
NEXT

Section 1
Section 2
Section 3



United States



IDF (Immune Deficiency Foundation)



- Virtual event with a “PI Champions panel” of patients and PID specialists
- Online campaign with educational material about PID and podcasts
- IDF walk for PI




Click to see more



Venezuela

AC IDP Venezuela (Venezuelian Primary Immunodeficiency Association)

-  • Release of campaign with two Hero-series: highlighting PID patients and highlighting medical professionals that work in the PID field
- Dissemination of campaign materials and scientific articles to doctors and the healthcare community (online)





Regional to Global



Latin America



LASID (Latin American Society for Immunodeficiencies)



- Webinar co-organized with Iniciativa ALAS
- Social media awareness campaign with dissemination of educative materials



La inmunodeficiencia primaria (Primary Immunodeficiency; PI) hace que los niños y los adultos tengan infecciones que reaparecen con frecuencia y que son inusualmente difíciles de curar. 1.500 personas están afectadas por uno de las inmunodeficiencias primarias conocidas. Si usted o alguien a quien usted conoce está afectado por dos o más de las siguientes señales de peligro, hable con un médico acerca de la posible presencia de la inmunodeficiencia primaria subyacente.



Estos signos de alarma han sido desarrollados por The Jeffrey Modell Foundation Medical Advisory Board. Se recomienda la consulta médica con expertos en Inmunodeficiencias Primarias. ©2013 Jeffrey Modell Foundation

www.INFO4PI.org



HOME

PREVIOUS

NEXT

Section 1


Section 2

Section 3



Latin America

Iniciativa ALAS

-  Online meeting with PI advocates
- Webinar on PI and Covid-19 with Dr Francisco Espinosa
- “Stay at home” campaign with a series of videos from PID patients
- Social media communications to raise awareness about PI



Europe



PPTA Europe



- Interview with IPOPI Executive Director
- Social media communications to raise awareness about PIDs and the importance of plasma donation



PPTA @PlasmaProteins
We are glad to promote the great work of @WorldPIWeek and to support the essential commitment of plasma donors and dedication of donation center staff. #PlasmaDonorsSaveLives – learn more at donatingplasma.org.



PPTAEurope @PPTAEurope · May 6
In the last 10 years, there have been great advancements in diagnosis and treatment of #PID, yet the work continues as we seek to improve the lives of #patients and their families. #WorldPIWeek Test Diagnose Treat!
@martinepergent #WPIW10years



Europe & International



IPOPI (International Patient Organisation for Primary Immunodeficiencies)



- Clinical care webinar on PID and cancer with the contribution of the President of ESID Prof Isabelle Meyts
- PID awareness campaign on social media and communications channels
- Supported national patient organisations to maintain awareness raising and advocacy activities during World PI Week
- Video with IPOPI staff celebrating World PI Week



World Primary Immunodeficiency Week et 3 autres



USA & International



JMF (Jeffrey Modell Foundation)



- Online PID awareness campaign, with educational material and “When I grow up” series
- Support to awareness raising in various hospitals, PID centres and to patient groups across the US and internationally
- Plasma donation campaign amid COVID-19



Click to see more

Tweet épingle
Jeffrey Modell Foundation (JMF) @Info4PI · 11 juin
Can YOU Spy the 10 Warning Signs of #PrimaryImmunodeficiency?

Click below & look around to “spy” the different warning signs... and just like a PI diagnosis, sometimes the warning signs are tricky to spot.



Jeffrey Modell Foundation (JMF) @Info4PI · 29 avr.
If you can, please please please #donateplasma.

Your donation can save a life!!

Iniciativa ALAS @Alasiniciativa · 29 avr.
La sangre de personas recuperadas de #Covid19 es fuente de #PlasmaEnriquecido que podrá ayudar a personas a defenderse de esta infección. Si tú eres de esas personas, #Felicidades, tienes una gran oportunidad. Comunícate con tus médicos y agenda una cita para #SalvarVidas.



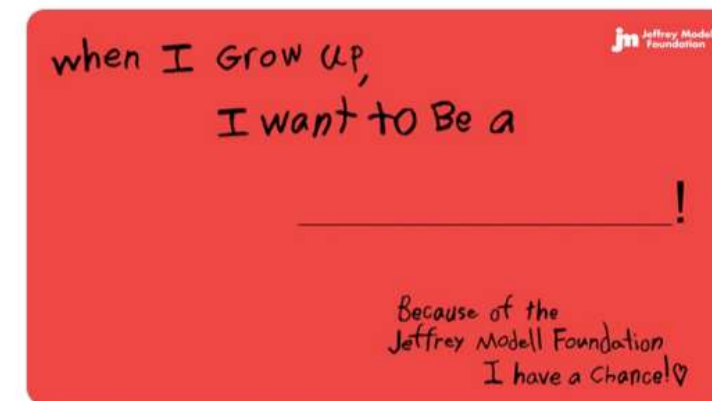
Jeffrey Modell Foundation (JMF) @Info4PI · 22 avr.
Happy #WPIW! Let's always remember to spread awareness about #primaryimmunodeficiency, encourage our community to reach for the stars, to dream, and that their potential is limitless!

#worldpiweek @WorldPIWeek #immunodeficiency #immunocompromised info4pi.org/wjmf/breaking-...



Jeffrey Modell Foundation (JMF) @Info4PI · 29 avr.
Now you can make your own "When I Grow Up..." poster!!

Happy @WorldPIWeek!! #JMF #info4pi #PrimaryImmunodeficiency #worldpiweek #wpiw #FlattenTheCurve #stayhome #staysafe #StayAtHomeAndStaySafe #stayathome #kidsactivities #activitiesforkids #kidfun #funactivities #funathome



USA & International



INGID (International Nursing Group for Immunodeficiencies)



- PID awareness on social media
- Dissemination of World PI Week materials and information on activities organized worldwide to mark the campaign



10th edition of the global awareness campaign World PI Week

Thursday, 2 April, 2020

INGID members will be all too aware that we are immersed in a global pandemic currently;

In light of the COVID-19 pandemic, it has been decided to extend in time the **World PI Week** campaign. Instead of the usual week long celebration (22-29 April), **WPIW 2020** will run for 10 weeks, from April 22 to July 1, 2020.

The aim is to help protect public health and the health of patients living with primary immunodeficiency while also highlighting the work and achievements of PI globally.

This year, we will be celebrating a decade of collaboration and progress for primary immunodeficiency stakeholders worldwide. The objective this year is to highlight and celebrate important milestones from the past 10 years as well as emphasize the expectations and work that still lies ahead.

Despite everything else that is distracting us right now, if possible we should all take time to celebrate our achievements for patients and their families.

INGID would love to hear from you.

HOME

PREVIOUS


NEXT

Section 1

Section 2

Section 3





Thank you for making World PI Week
2020 a success!

PI awareness does not end with the campaign.

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