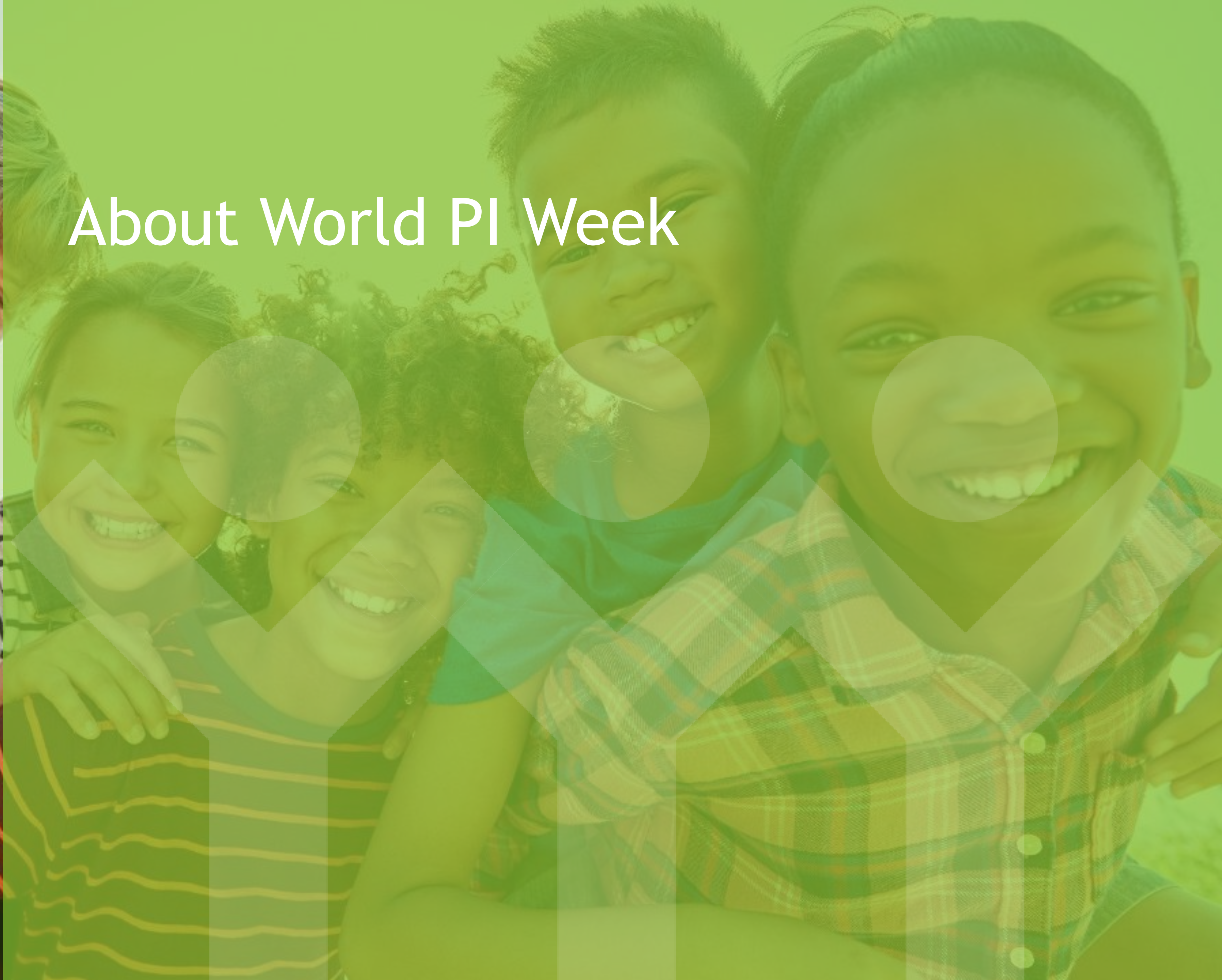
World PI Week Report 2019

Putting primary immunodeficiency patients at the centre of their care

World PI Week

TEST • DIAGNOSE • TREAT



About World PI Week

An awareness-raising effort

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Mission

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

Vision

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

Aims

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

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

Since its inception, World PI Week has been successful in stimulating awareness and advocacy efforts in all continents

Our active network

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Gold 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 Society for Immunodeficiencies

International Nursing Group for Immunodeficiencies

International Patient Organisation for Primary Immunodeficiencies

Jeffrey Modell Foundation

Latin American Society for Immunodeficiencies

Plasma Protein Therapeutics Association

South East Asia Primary Immunodeficiency Network

A Dynamic, Multi-Stakeholder and Global Community

Campaign resources

World PI Week
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Together, bringing about change for primary immunodeficiency patients worldwide

World PI Week 22-29 April

www.worldpiweek.org | @WorldPIWeek

What?

Where?

Who?

About

World PI Week
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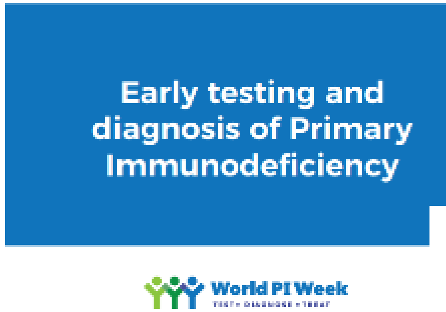
Materials

How can I get involved?



Early testing and diagnosis of Primary Immunodeficiency

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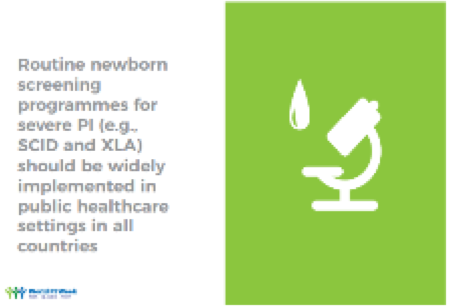
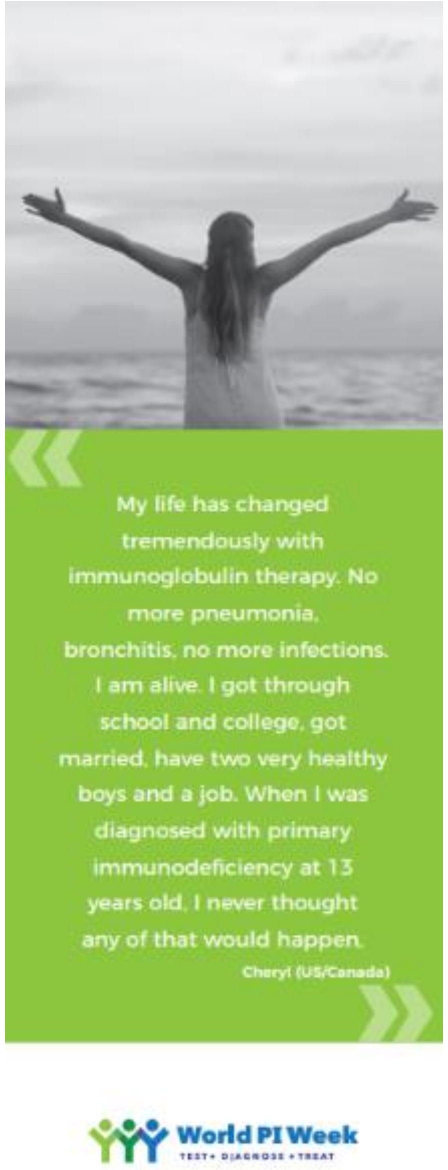


Routine newborn screening programmes for severe PI (e.g., SCID and XLA) should be widely implemented in public healthcare settings in all countries



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)

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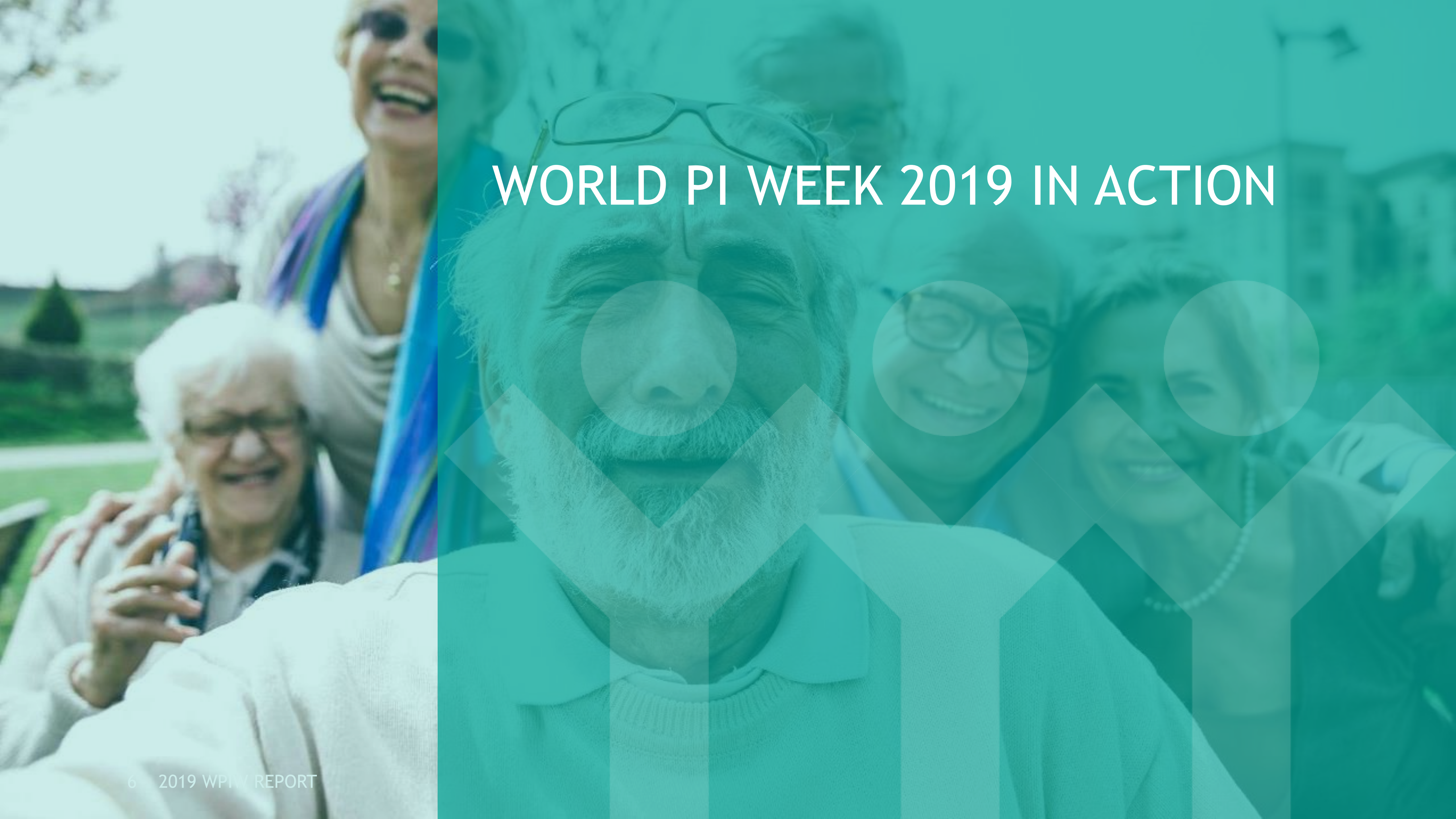
WORLD PI WEEK 2019 IN ACTION



Website rebuilt

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Launch of a new, user-friendly campaign website

- Stories of the PI community: for patients, healthcare professionals, carers and other players to submit testimonials in video, written or audio format
- “Join the movement ***#MyPIStory***”: social media campaign for story sharing & exchange of experiences
- Clear guidance on how to engage and support the campaign, how to organise an event or activity
- Calendar of World PI Week events around the world

A global campaign which aims to raise

Here are many ways you can join the campaign and make a difference.

Click to visit the World PI Week website

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Visual identity refresh

2019 brought a new image to the campaign

- Blue & green remain the World PI Week signature look
- The new logo reflects both the immune system, at the centre of PI, and the sense of togetherness
- New tagline that encapsulates the overall mission

The immune system: The Y shape symbolises an antibody and the circle an antigen that an antibody has pursued and attached itself to, preparing to take it to the white blood cell for destruction.

World PI Week

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Together: The Y and circle symbol also represent people – together and connected within support networks. Colour is used to represent the different groups affected by PI, with the patient in the centre.

Bringing about change together

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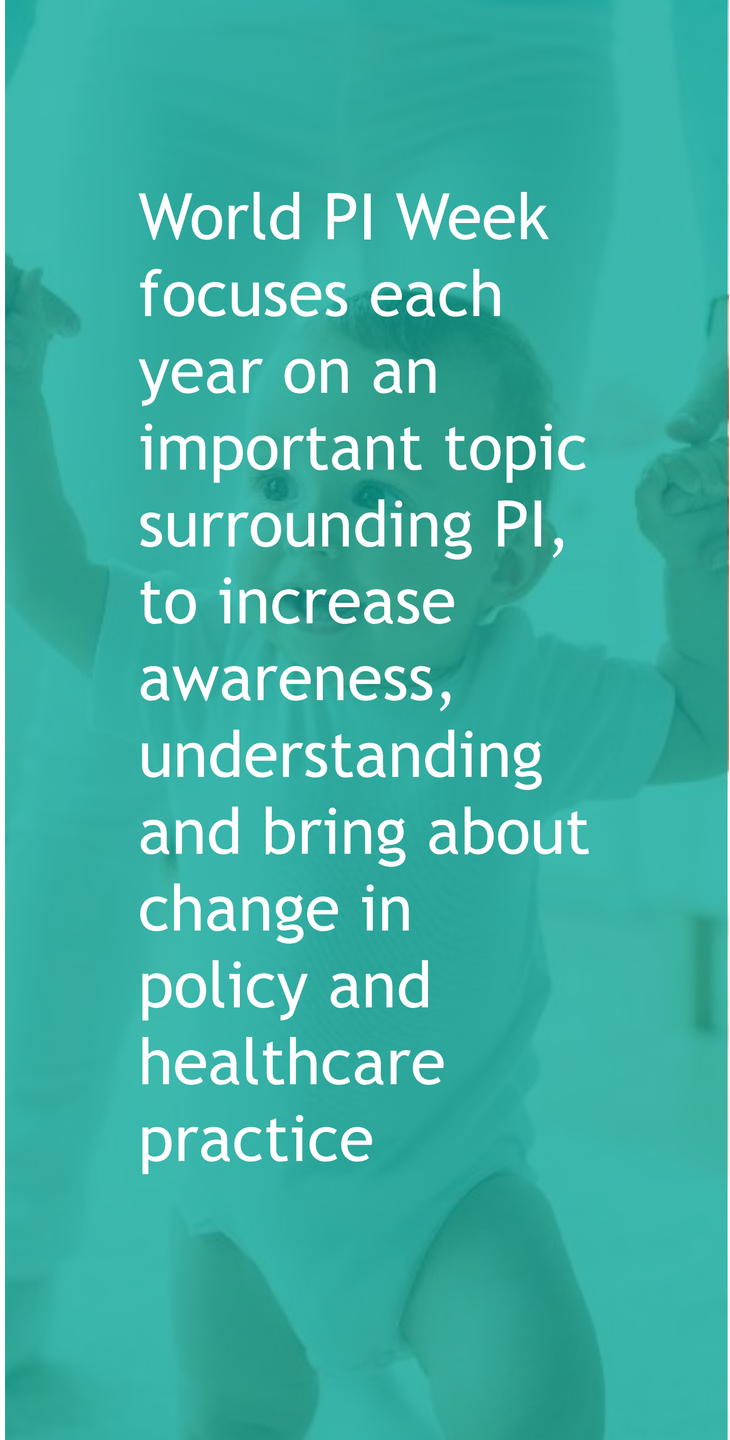
Patient-centred care on the spotlight

"Putting primary immunodeficiency patients at the centre of their care"

Patient-centred care was at the heart of the 2019 campaign, in order to improve the care and quality of life of patients and their families around the world.

- There are over 380 different types of primary immunodeficiencies which are estimated to affect over 6 million people worldwide. Each type of disease requires a customized treatment approach
- People with PI are all different: their specific health needs should be taken into consideration in their care pathway
- Patients and their families should be partners of healthcare providers in the decisions related to their own care and treatment plans
- Healthcare and healthcare systems should be designed to ultimately benefit patients
- A multi-disciplinary approach to the care of patients is inclusive of all actors which play a role in care delivery, from patients and doctors to allied healthcare professionals, biologists and researchers.



World PI Week focuses each year on an important topic surrounding PI, to increase awareness, understanding and bring about change in policy and healthcare practice

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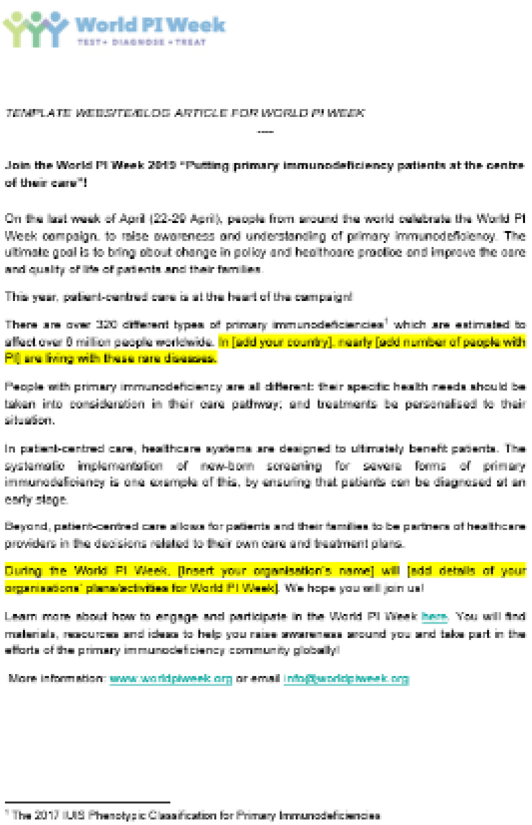
Communications collaterals



TEMPLATE WEBSITE/BLOG ARTICLE FOR WORLD PI WEEK

Join the World PI Week 2019 "Putting primary immunodeficiency patients at the centre of their care"!

On the last week of April (22-29 April), people from around the world celebrate the World PI Week campaign, to raise awareness and understanding of primary immunodeficiency. The ultimate goal is to bring about change in policy and healthcare practice and improve the care and quality of life of patients and their families.

This year, patient-centred care is at the heart of the campaign!

There are over 320 different types of primary immunodeficiencies[1] which are estimated to affect over 6 million people worldwide. In [add your country], nearly [add number of people with PI] are living with these rare diseases.

People with primary immunodeficiency are all different: their specific health needs should be taken into consideration in their care pathway; and treatments be personalised to their situation.

In patient-centred care, healthcare systems are designed to ultimately benefit patients. The systematic implementation of new-born screening for severe forms of primary immunodeficiency is one example of this, by ensuring that patients can be diagnosed at an early stage.

Beyond, patient-centred care allows for patients and their families to be partners of healthcare providers in the decisions related to their own care and treatment plans.

During the World PI Week, [Insert your organisation's name] will [add details of your organisations' plans/activities for World PI Week]. We hope you will join us!

Learn more about how to engage and participate in the World PI Week here. You will find materials, resources and ideas to help you raise awareness around you and take part in the efforts of the primary immunodeficiency community globally!

More information: www.worldpiweek.org or email info@worldpiweek.org

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[1] The 2017 IUIS Phenotypic Classification for Primary Immunodeficiencies

Click to download materials

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

A wealth of new educative materials

World PI Week messages

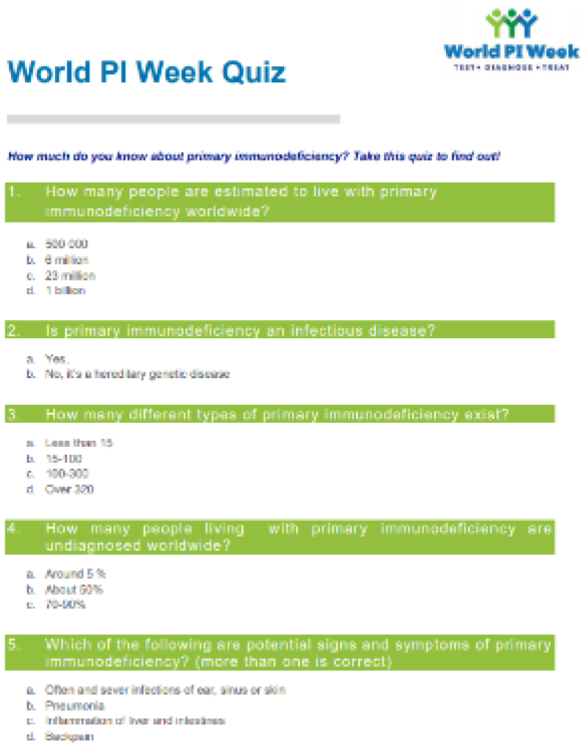
About primary immunodeficiency

Early testing and diagnosis

World PI Week messages

Care & treatment

Quality of life



World PI Week Quiz

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

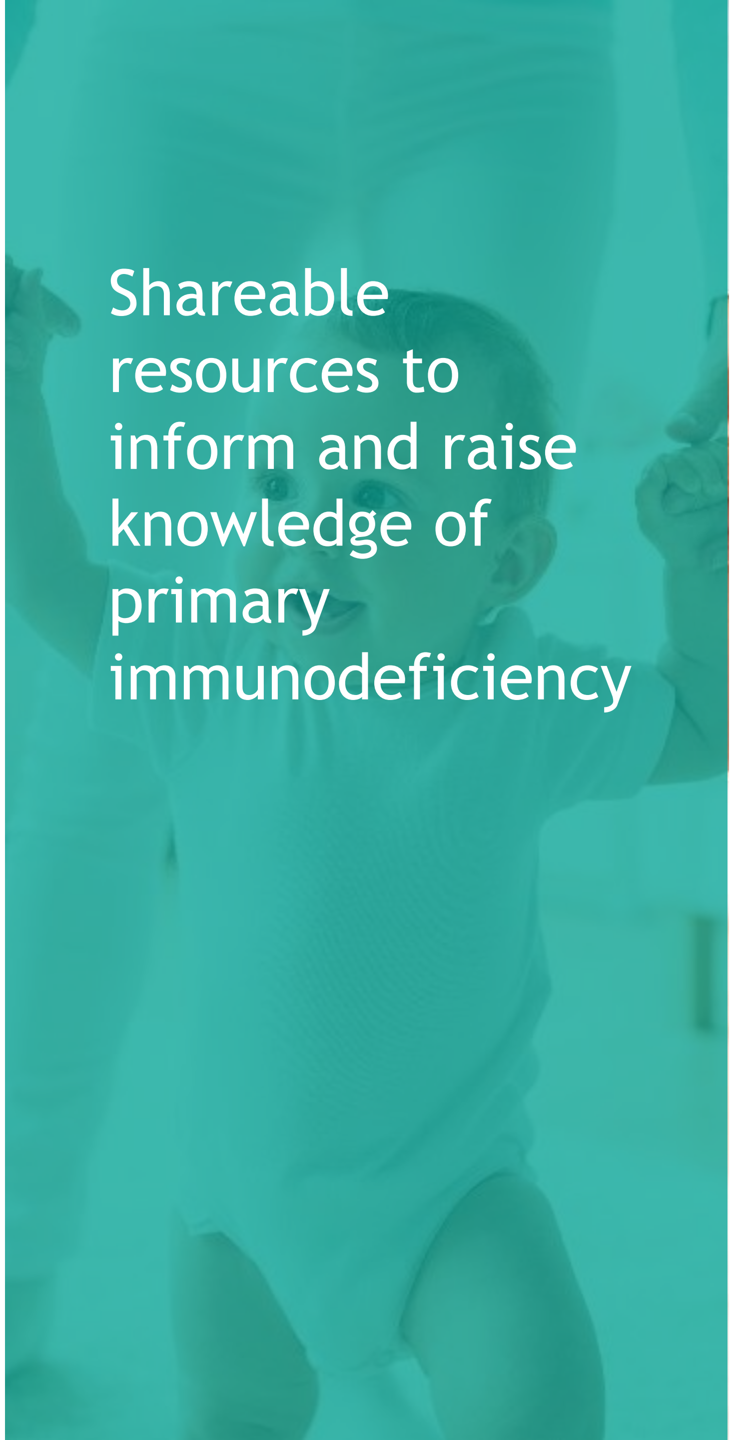
1. How many people are estimated to live with primary immunodeficiency worldwide?
   a. 500 000
   b. 6 million
   c. 23 million
   d. 1 billion

2. Is primary immunodeficiency an infectious disease?
   a. Yes.
   b. No, it's a hereditary genetic disease

3. How many different types of primary immunodeficiency exist?
   a. Less than 15
   b. 15-100
   c. 100-300
   d. Over 320

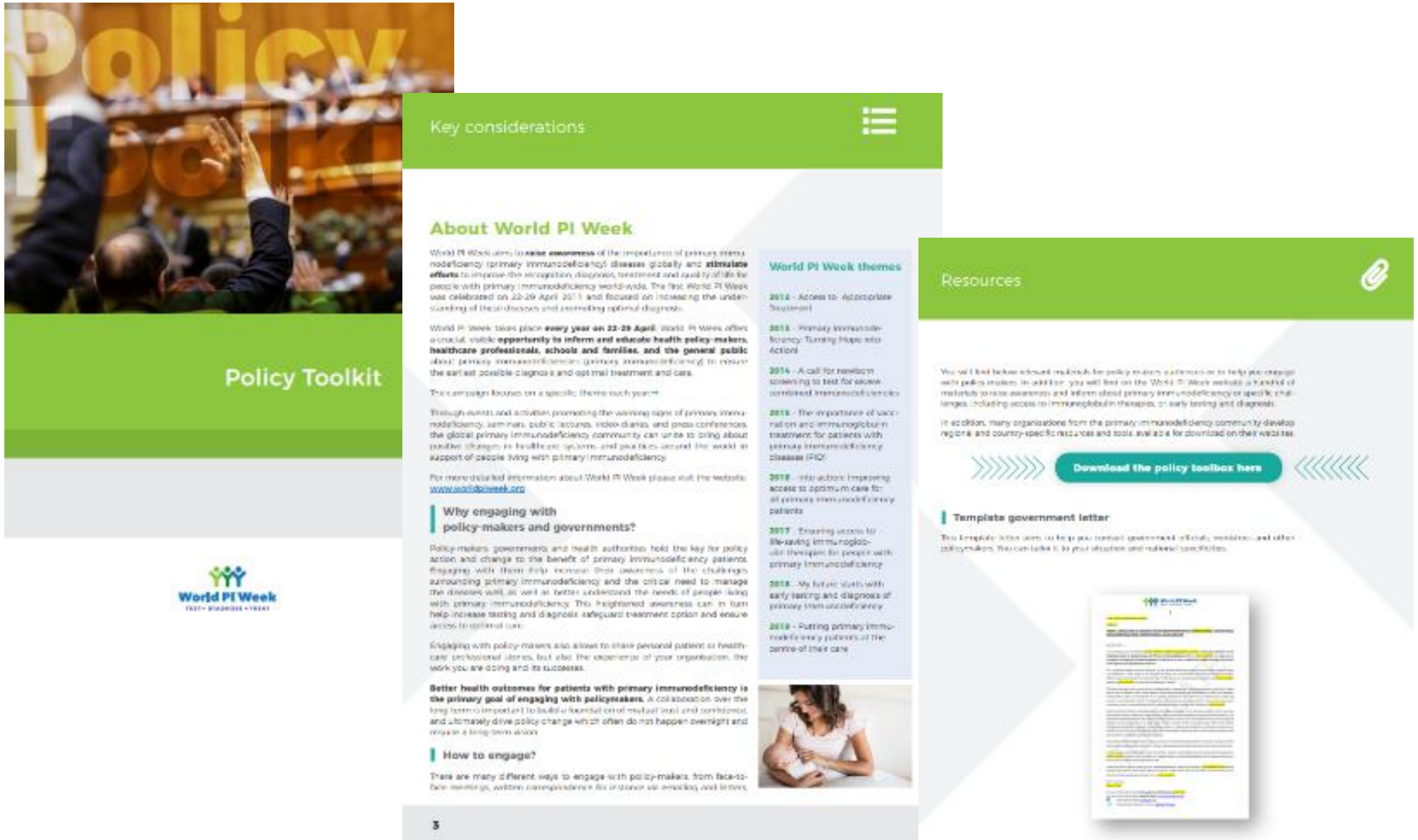
4. How many people living with primary immunodeficiency are undiagnosed worldwide?
   a. Around 5 %
   b. About 90%
   c. 70-90%

5. Which of the following are potential signs and symptoms of primary immunodeficiency? (more than one is correct)
   a. Often and sever infections of ear, sinus or skin
   b. Pneumonia
   c. Inflammation of liver and intestines
   d. Backpain



Shareable resources to inform and raise knowledge of primary immunodeficiency

Audience-specific toolkits



Policy Toolkit

World PI Week

Key considerations

About World PI Week

World PI Week themes

Why engaging with policy-makers and governments?

How to engage?

Resources

Download the policy toolbox here

Template government letter

Four toolkits providing advice and guidance on how to engage and communicate with media, policymakers, medical professionals and the general public

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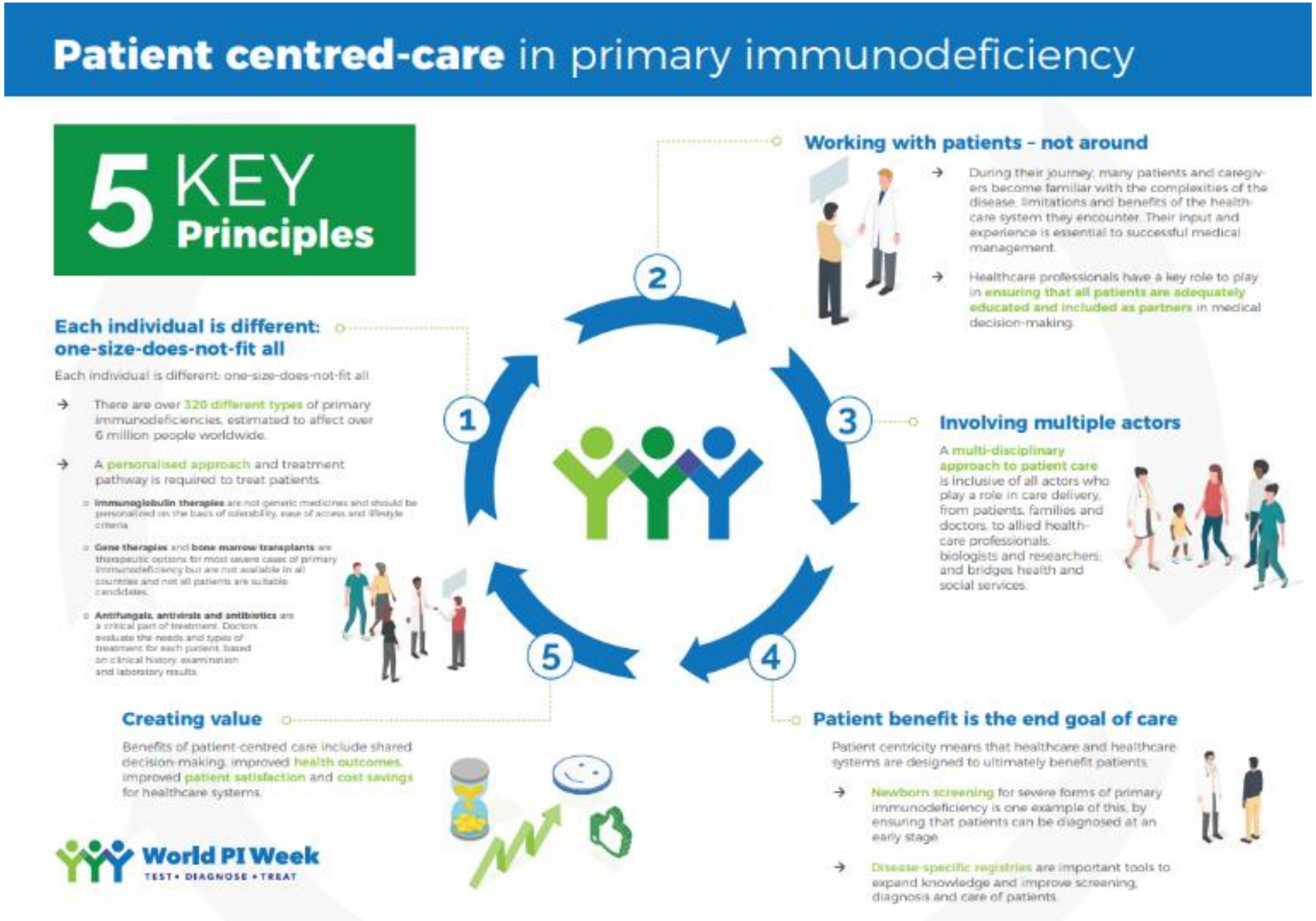
New advocacy materials



Patient centred-care in primary immunodeficiency

5 KEY Principles

1 Each individual is different: one-size-does-not-fit all

Each individual is different: one-size-does-not-fit all.

→ There are over **320 different types** of primary immunodeficiencies, estimated to affect over 6 million people worldwide.

→ A **personalised approach** and treatment pathway is required to treat patients.

- **Immunoglobulin therapies** are not generic medicines and should be personalized on the basis of tolerability, ease of access and lifestyle criteria
- **Gene therapies** and **bone marrow transplants** are therapeutic options for most severe cases of primary immunodeficiency but are not available in all countries and not all patients are suitable candidates.
- **Antifungals, antivirals and antibiotics** are a critical part of treatment. Doctors evaluate the needs and types of treatment for each patient based on clinical history, examination and laboratory results.

2 Working with patients – not around

→ During their journey, many patients and caregivers become familiar with the complexities of the disease, limitations and benefits of the healthcare system they encounter. Their input and experience is essential to successful medical management.

→ Healthcare professionals have a key role to play in **ensuring that all patients are adequately educated and included as partners** in medical decision-making.

3 Involving multiple actors

A **multi-disciplinary approach to patient care** is inclusive of all actors who play a role in care delivery, from patients, families and doctors, to allied health-care professionals, biologists and researchers, and bridges health and social services.

4 Patient benefit is the end goal of care

Patient centricity means that healthcare and healthcare systems are designed to ultimately benefit patients.

→ **Newborn screening** for severe forms of primary immunodeficiency is one example of this, by ensuring that patients can be diagnosed at an early stage.

→ **Disease-specific registries** are important tools to expand knowledge and improve screening, diagnosis and care of patients.

5 Creating value

Benefits of patient-centred care include shared decision-making, improved **health outcomes**, improved **patient satisfaction** and **cost savings** for healthcare systems.

World PI Week
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Specific tool with key messages on patient-centred care

Revised global call to action

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GLOBAL CALL TO ACTION ON PRIMARY IMMUNODEFICIENCY

The Primary Immunodeficiency (PI) Call to Action offers guidance for governments on the steps they can take to understand, appropriately diagnose and manage primary immunodeficiency diseases in their respective countries, to improve patients' quality of life.

The primary immunodeficiency community calls upon countries across the world to recognize and take heed of these rare and under-diagnosed diseases by developing national strategies that address primary immunodeficiency. We encourage governments to consider the following components when developing future disease strategies and rare disease plans:

Raising Awareness on Primary Immunodeficiencies

Encourage and support governments to implement targeted campaigns to increase recognition of primary immunodeficiency amongst the medical profession, parents, schools, day care centre employees, researchers and nurses, with the objective to increase understanding of the disease, knowledge of the warning signs and available testing methods and treatments.

Education of Health Professionals and Expertise Exchange

Work together with medical specialists organisations (e.g. APSID, ARAPID, ASID, LASID, CIS, EFIS, ESID, INGID, SEAPID, UEMS, etc) and academia to encourage and support individual countries to: provide standards for basic and applied immunology training, with emphasis on primary immunodeficiency, in the education programmes for general practitioners and nurses; integrate basic and applied immunology teaching, particularly alongside immunisation, into specialised programmes for training fellows in general paediatric internal medicine, rheumatology, respiratory medicine, and infectious diseases; develop cross country initiatives to allow the exchange of expert experience and education, including capacity to network and funding of visits of immunology centres representatives in other countries.

Early Diagnosis and Screening

- Support the development of clinical protocols to reliably identify all forms of primary immunodeficiency;
- Support the development of simple diagnostic tests for PI and promote such tests for use widely;
- Support the development and implementation of neonatal (newborn) screening for severe combined immunodeficiency;
- Promote the creation of international guidance for the recognition of symptomatic patients and ensure appropriate immunologic and genetic laboratory tests are available at national level via centres of excellence;
- Promote the creation and support of patient registries that can provide support for patients and also scientific insights into the make-up of primary immunodeficiency;
- Promote transnational research into the feasibility of screening programmes to ensure early detection;
- Promote funding research into better understanding of primary immunodeficiency to improve diagnosis and the management of the conditions and general understanding of the immune system

Gathering Knowledge and Data

- Provide funding to conduct epidemiological studies to assess the prevalence and incidence of primary immunodeficiency;
- Encourage the creation of and input into international registries which will enable future diagnostic processes;
- Create national or regional primary immunodeficiency patient registry;
- Encourage transnational, research and remove the administrative obstacles to multinational clinical trials;
- Establish Centres of Reference to promote best practice in terms of disease classification, treatment outcome measures, assessment of cost of treatments for an integrated approach to primary immunodeficiency recognition and treatment.

Comprehensive and Adequate Treatment

- Ensure access to treatment for people with primary immunodeficiency as it has been shown to prevent and improve chronic disease, improve social well-being and reduce the burden of the disease both on individuals, families and healthcare systems;
- Ensure that safe immunoglobulin treatments are available to all patients who require antibody replacement; and ensure the adequate and high quality supply of human plasma;
- Recognise the social needs of primary immunodeficiency patients and their families and facilitate access to adequate support services, as well as the coordination of health and social care services;
- Ensure the reimbursement of orphan drugs according to their medical efficacy for the patient and not according to the price of the product.

About the Call to action

This United Call to Action was developed by the primary immunodeficiency community in 2010 and updated in 2019 to reflect new realities. With over 1,600 signatures of support to date, it provides a common perspective on unmet needs in primary immunodeficiency globally and opportunities for change, with the understanding that countries and regions of the world have additional specificities.

The call offers guidance for governments on the steps they can take to understand, diagnose and manage primary immunodeficiency in their respective countries

Press announcements

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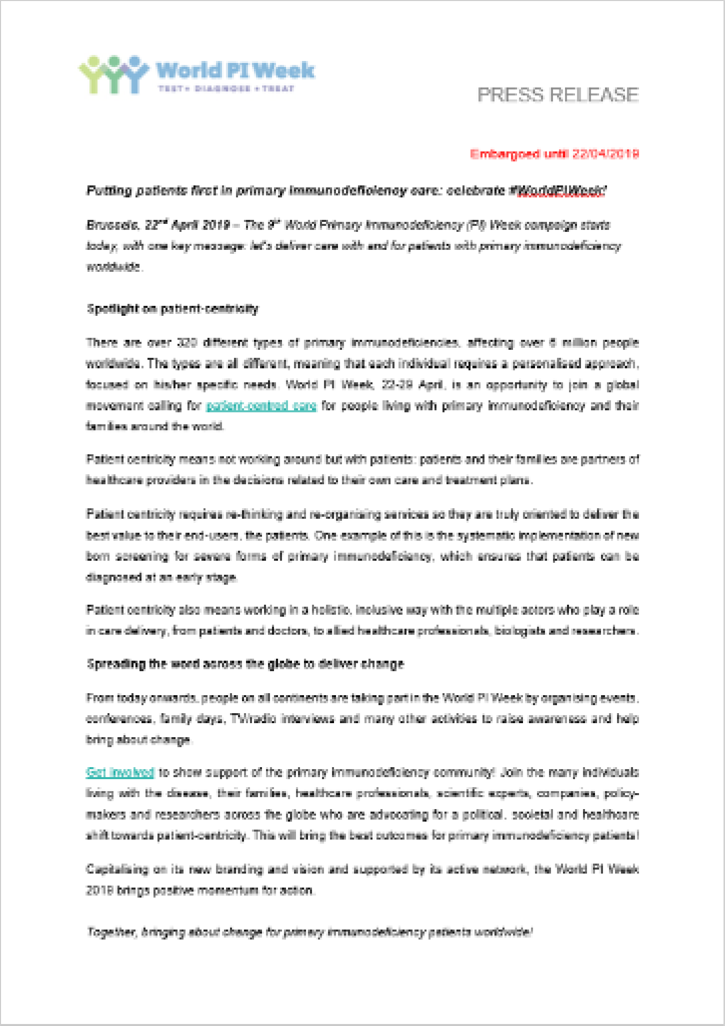

PRESS RELEASE

Embargoed until 22/04/2019

Putting patients first in primary immunodeficiency care: celebrate #WorldPIWeek!

Brussels, 22nd April 2019 – The 9th World Primary Immunodeficiency (PI) Week campaign starts today, with one key message: let's deliver care with and for patients with primary immunodeficiency worldwide.

Spotlight on patient-centricity

There are over 320 different types of primary immunodeficiencies, affecting over 6 million people worldwide. The types are all different, meaning that each individual requires a personalised approach, focused on his/her specific needs. World PI Week, 22-29 April, is an opportunity to join a global movement calling for patient-centred care for people living with primary immunodeficiency and their families around the world.

Patient centricity means not working around but with patients: patients and their families are partners of healthcare providers in the decisions related to their own care and treatment plans.

Patient centricity requires re-thinking and re-organising services so they are truly oriented to deliver the best value to their end-users, the patients. One example of this is the systematic implementation of new born screening for severe forms of primary immunodeficiency, which ensures that patients can be diagnosed at an early stage.

Patient centricity also means working in a holistic, inclusive way with the multiple actors who play a role in care delivery, from patients and doctors, to allied healthcare professionals, biologists and researchers.

Spreading the word across the globe to deliver change

From today onwards, people on all continents are taking part in the World PI Week by organising events, conferences, family days, TV/radio interviews and many other activities to raise awareness and help bring about change.

Get involved to show support of the primary immunodeficiency community! Join the many individuals living with the disease, their families, healthcare professionals, scientific experts, companies, policy-makers and researchers across the globe who are advocating for a political, societal and healthcare shift towards patient-centricity. This will bring the best outcomes for primary immunodeficiency patients!

Capitalising on its new branding and vision and supported by its active network, the World PI Week 2019 brings positive momentum for action.

Together, bringing about change for primary immunodeficiency patients worldwide!

PRESS RELEASE

ABOUT WORLD PI WEEK

World PI Week is a global movement to raise awareness of primary immunodeficiency and related challenges; promote quality of life for people with primary immunodeficiency, early diagnosis, availability and access to treatment and care worldwide; and stimulate communication and advocacy around primary immunodeficiency.

ABOUT PRIMARY IMMUNODEFICIENCY

Primary immunodeficiencies are rare diseases which occur when a person's immune system is absent or does not function properly. When a defect in the immune system is inherited (carried through the genes), it is called primary immunodeficiency. There are over 320 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 infections while missing the underlying cause, allowing the infections to reoccur, and leaving the patient vulnerable to vital organ damage, physical disability, and even death.

For more information, please visit www.worldpiweek.org, follow us on Twitter @WorldPIWeek.

Press contact:
Bénédicte Faure, campaign manager : info@worldpiweek.org

28th February 2019

Bridging health and social care in support of rare disease patients: Show You Care

Today, the Primary Immunodeficiency community worldwide celebrates Rare Disease Day 2019 to raise awareness worldwide of the challenges concerning rare diseases and to advance change in policy and practice to benefit patients.

Rare Disease Day 2019 puts the spotlight on bridging health and social care. People living with a rare disease, such as a Primary Immunodeficiency and their families require a combination of different health, social and local services in daily life. Therefore coordination and communication between those services is of utmost importance to improve patients' quality of life.

Many people with rare diseases and carers find care pathways complex and difficult to manage, while in most countries social services are still not adequately prepared to respond to their needs[1].

A holistic approach to the care of people with rare diseases is inclusive of all actors which play a role in care delivery, from patients and doctors, to allied healthcare professionals, biologists and researchers. But it also goes beyond healthcare, breaking silos with the social sector to deliver services which are truly integrated: this enables patients and their families to combine daily life with the exigences of living with a rare disease, juggling between care and a variety of social and community support services, and to act as active contributors to the society.

Bridging health and social care also underpins a political, societal and healthcare shift towards patient-centricity: re-thinking and re-organising services so they are truly oriented to deliver best value to their end-users, the patients.

Such a person-centred approach to care will be at the heart of the 2019 World Primary Immunodeficiency Week (World PI Week) campaign from 22-29th April, which will focus on "putting primary-immunodeficiency patients at the centre of their care". There are over 320 different types of primary immunodeficiencies[2] which are estimated to affect over 6 million people worldwide. But those are all different, meaning that each individual requires a customized approach, focused on his/her specific needs. This cannot become a reality for all patients without better coordination of all the aspects of care.

We should not miss the opportunity to improve the care and quality of life of rare disease patients and their families around the world: let's break silos between medical and social care!

World PI Week shows its rare, as we do care! #ShowYourRare

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[1] Results from Eurordis survey initiative Rare Barometer
[2] The 2017 IUIS Phenotypic Classification for Primary Immunodeficiencies

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

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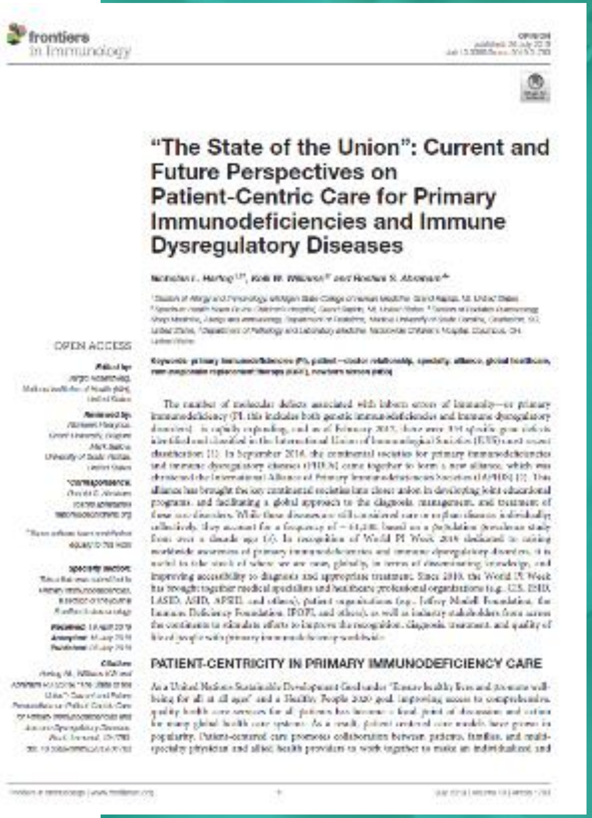
Opinion article

"The State Of The Union": Current And Future Perspectives On Patient-Centric Care For Primary Immunodeficiencies And Immune Dysregulatory Diseases"

Nicholas L. Hartog, Kelli Williams, Roshini S. Abraham

- Value of patient centricity in primary immunodeficiency care
- Links between patient-centred systems and timely access to care and treatment
- Overview of unmet needs in access to specialist care and to various treatment options; implementation of new-born screening for SCID worldwide
- Benefits of country and region-specific disease registries
- Spotlight on existing awareness initiatives and clinical research collaborations in various regions of the world
- Importance of global partnerships between developed and developing nations in improving education and access; and in achieving patient-centred care

Publication in *Frontiers in Immunology* on 26th July 2019



frontiers in Immunology

OPEN ACCESS

"The State of the Union": Current and Future Perspectives on Patient-Centric Care for Primary Immunodeficiencies and Immune Dysregulatory Diseases

PATIENT-CENTRICITY IN PRIMARY IMMUNODEFICIENCY CARE

Social media activities

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A hub for dialogue, story sharing and increasing awareness

- Online engagement & ongoing dialogue between individual patients, patient groups, medical societies, individual experts, media, industry and policymakers
- Vehicle to share pictures and information on World PI Week activities
- Driver for story/experience sharing
- Information sharing, rare-disease related and primary immunodeficiency related news updates
- Key tool to promote awareness and understanding of primary immunodeficiency

> 3,000 profile visits during World PI Week on Twitter

+ 100 followers on Twitter from 22-29 April

+ 100 likes on Facebook during World PI Week

Average of 1,500 people reached per Facebook post

Highest engagement around patient-centred care

> 60K impressions during April 2019

Click on the icons to visit social media channels

World PI Week is active on Facebook, Twitter and Instagram – follow us!
Join discussions using #WPIW, #WPIW2018, #WorldPIWeek or #PIawareness

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Photo contest #PIctureAwareness

Raising awareness of primary immunodeficiency, engaging the community

- Driver of social media activity
- Greater visibility of the World PI Week campaign

Congratulations to APIP for their colourful participation in the World PI Week photo contest and their dynamism during the campaign!

Social media engagement

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SEICAP @SEICAP

La mayoría de niños con inmunodeficiencias primarias #IDPs son diagnosticados con retraso. #WorldPIWeek. seicap.es/es/la mayor%C3 ... @WorldPIWeek

Translate Tweet

World Primary Immunodeficiency W... @WorldPIWeek

#WorldPIWeek 2019 is focusing on #PatientCenteredCare. Today we are launching a new infographic! Share it to educate and spread #Piawareness and put #patientsfirst. bit.ly/2ZIOPFJ

Rare Revolution Mag @RareRevolutionM · Apr 23

Putting patients first in primary immunodeficiency care: celebrate #WorldPIWee #primaryimmunodeficiencies World PI Week: buff.ly/2IR8FTx

Newcastle Hospitals @NewcastleHosps

Families of children cared 4 on world-renowned 'Bubble Unit' @GreatNorthCH support World PI Week by highlighting early warning signs of PIs inc. recurrent infections & running a very special drawing competition. Check it out! ➡ bit.ly/2IWX19D

Immunodeficiency CA @ImmunoCanada · Apr 27

People around the world is celebrating @WorldPIWeek , like @TheBubbleUK & @NewcastleHosps.

Check out this article from them. that includes a few inspirational stories from PI patients

#primaryimmunodeficiency #piawareness #PIDcare #raredisease #MyPIst

Newcastle Hospitals @NewcastleHosps

Families of children cared 4 on world-renowned 'Bub Unit' @GreatNorthCH support World PI Week by highlighting early warning signs of PIs inc. recurrent infections & running a very special drawing competit

Show this thread

NIAID News @NIAIDNews · Apr 23

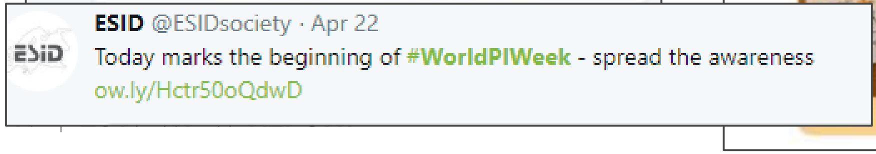
ICYMI: #GeneTherapy can safely correct the immune systems of infants newly diagnosed with the rare #PrimaryImmunodeficiency X-linked #SCID, researchers reported last week in @NEJM. bit.ly/SCIDGeneTherapy #WorldPIWeek #WPIW #PID

IPOPI @ipopi_info · Apr 21

JMF @Info4PI · Apr 26

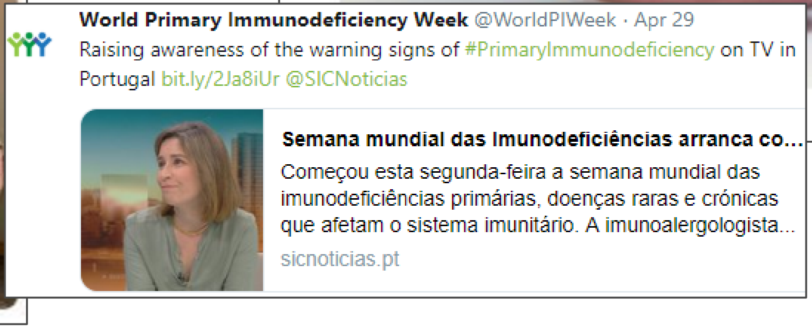
What a perfect way to celebrate @WorldPIWeek!! JMF Co-Founders welcome the newest Jeffrey Modell Diagnostic and Research Center at Nationwide Children's Hospital🏥 in Columbus, Ohio!! @nationwidekids

#JMF #info4pi #PrimaryImmunodeficiency #WPIW #testdiagnosetreat #worldpiweek



ESID @ESIDsociety · Apr 22

Today marks the beginning of #WorldPIWeek - spread the awareness ow.ly/Hctr50oQdwD



World Primary Immunodeficiency Week @WorldPIWeek · Apr 29

Raising awareness of the warning signs of #PrimaryImmunodeficiency on TV in Portugal bit.ly/2Ja8iUr @SICNoticias

Semana mundial das Imunodeficiências arranca co...

Começou esta segunda-feira a semana mundial das imunodeficiências primárias, doenças raras e crónicas que afetam o sistema imunitário. A imunoalergologista...

sicnoticias.pt

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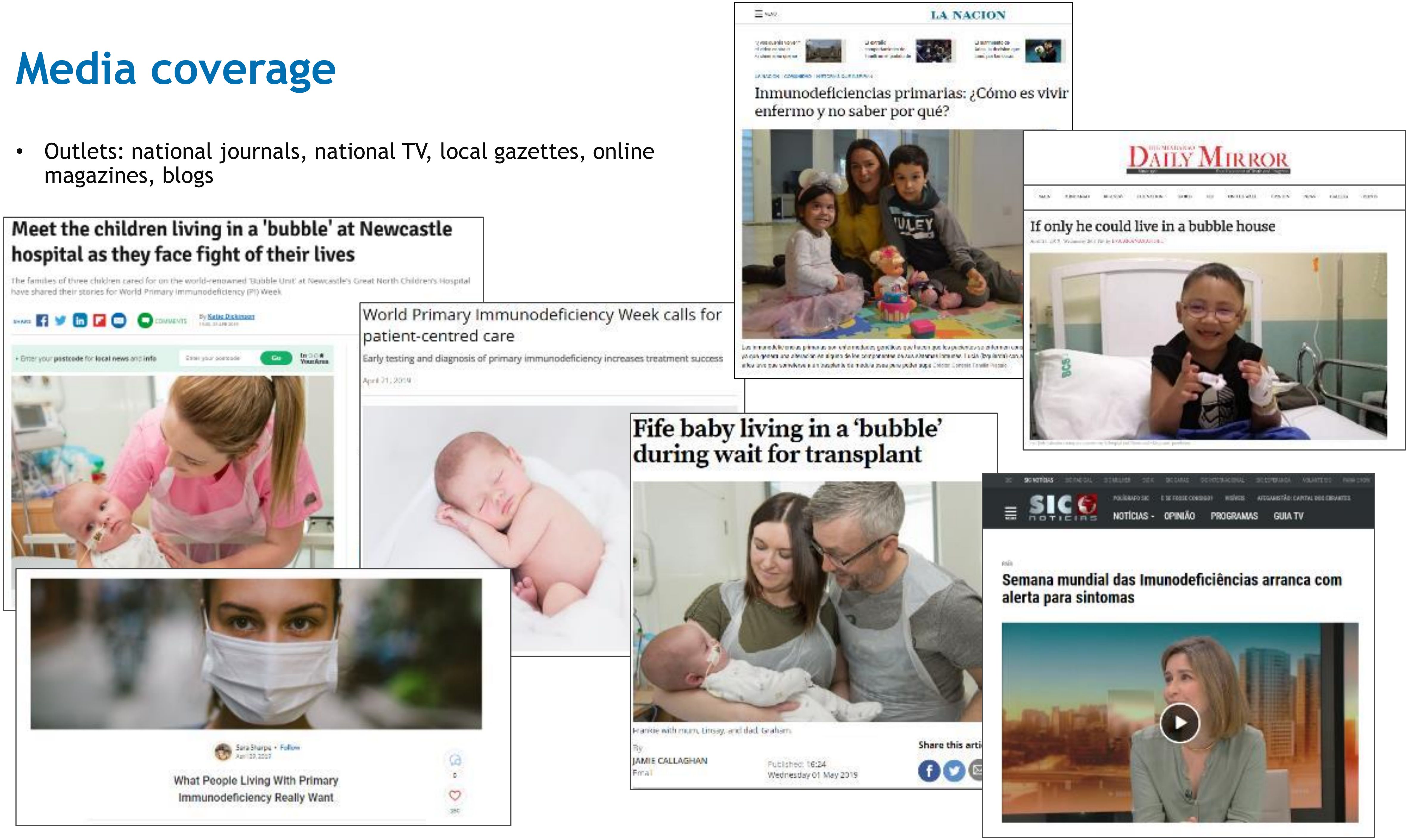
Media coverage

- Outlets: national journals, national TV, local gazettes, online magazines, blogs



Meet the children living in a 'bubble' at Newcastle hospital as they face fight of their lives

The families of three children cared for on the world-renowned 'Bubble Unit' at Newcastle's Great North Children's Hospital have shared their stories for World Primary Immunodeficiency (PI) Week

By Katie Dickinson

COMMENTS

Enter your **postcode** for **local news** and **info**

Go

World Primary Immunodeficiency Week calls for patient-centred care

Early testing and diagnosis of primary immunodeficiency increases treatment success

April 21, 2019

Sara Sharpe • Follow

What People Living With Primary Immunodeficiency Really Want

LA NACION

Inmunodeficiencias primarias: ¿Cómo es vivir enfermo y no saber por qué?

DAILY MIRROR

If only he could live in a bubble house

Fife baby living in a 'bubble' during wait for transplant

Frankie with mum, Linsey, and dad, Graham.

By
JAMIE CALLAGHAN
Email

Published: 16:24
Wednesday 01 May 2019

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SIC NOTÍCIAS

NOTÍCIAS - OPINIÃO PROGRAMAS GUIA TV

Semana mundial das Imunodeficiências arranca com alerta para sintomas

Country involvement

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Click on the flag to see the report

SNAPSHOTS OF NATIONAL EVENTS

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AAPIDP Asociación de Ayuda al Paciente con
Inmunodeficiencia Primaria

Argentina

AAPIDP (Asociación Ayuda al Paciente con Inmunodeficiencia Primaria)

- National Patients’ Meeting bringing together 180 people from several provinces across Argentina
    - Medical talks
    - Sessions on PI care and treatment, physio and dietary support
    - Psychological support workshop with teenagers
    - Recreational activities (art, games and magic shows) and outdoor activities
    - Closure with musical performance

Click to see more

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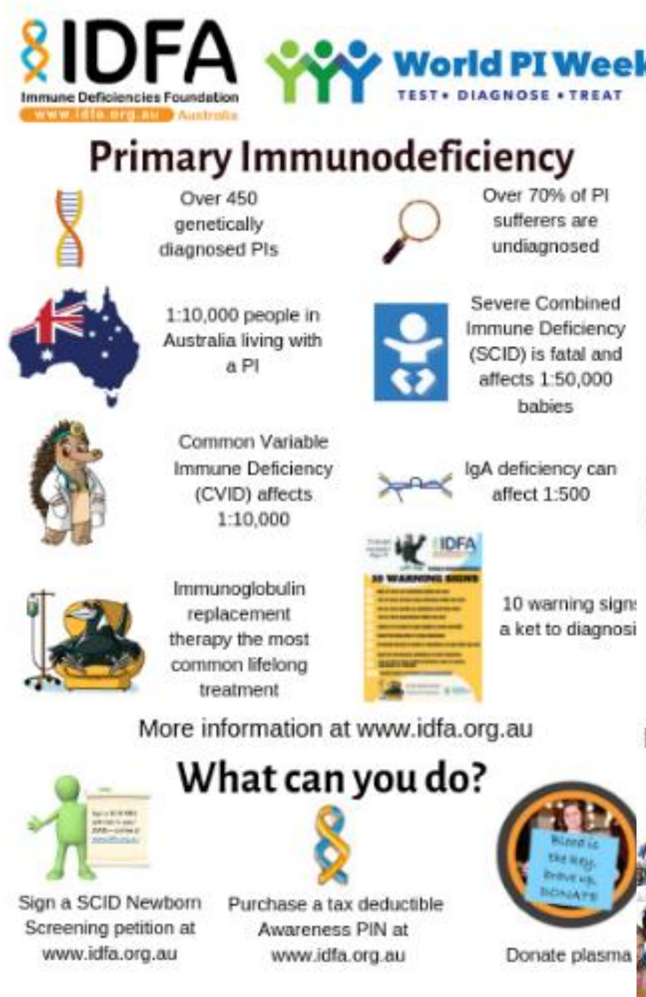
Australia

IDFA (The Immune Deficiency Foundation of Australia)

- Awareness campaign amongst Members of Parliament
- SCID Newborn Screening State Petitions
- Social media campaign
- IDFA patient and carers’ storybook, in partnership with CIRCA (The Clinical Immunogenomics Research Consortium Australia)
- Launch of new infographic
- World PI Week School Zebra Day fundraisers & quilt raffle fundraiser



IDFA Immune Deficiencies Foundation www.idfa.org.au Australia

World PI Week TEST • DIAGNOSE • TREAT

Primary Immunodeficiency

Over 450 genetically diagnosed PIs

Over 70% of PI sufferers are undiagnosed

1:10,000 people in Australia living with a PI

Severe Combined Immune Deficiency (SCID) is fatal and affects 1:50,000 babies

Common Variable Immune Deficiency (CVID) affects 1:10,000

IgA deficiency can affect 1:500

Immunoglobulin replacement therapy the most common lifelong treatment

10 warning sign a ket to diagnosi

More information at www.idfa.org.au

What can you do?

Sign a SCID Newborn Screening petition at www.idfa.org.au

Purchase a tax deductible Awareness PIN at www.idfa.org.au

Donate plasma

CIRCA

IDFA Immune Deficiencies Foundation www.idfa.org.au Australia

A: PO BOX 969 PENRITH NSW 2774 P: 1800 100 198 E: info@idfa.org.au

What can you do this World PI Week?

Add your story to our Storybook
Email your story and photos to info@idfa.org.au

http://www.idfa.org.au/world-pi-week-22-29-april/

Together, bringing about change for primary immunodeficiency patients worldwide

World PI Week TEST • DIAGNOSE • TREAT

22 – 29 April 2019

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Austria

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ÖSPID (Österreichische Selbsthilfegruppe primärer Immum Defekte)

- Cycling for a good cause
- Release of film about a PID patient meeting with her doctor
- Movie from a PID patient‘s life
- PID-balloon challenge
- Life-saving folders to all plasma centers in Austria

Click to see more

Recipient of IPOPI grant

Belarus

“Let’s Save the Immunity“ - The republican public organisation of patients/parents with primary immunodeficiency

- Awareness of the 10 warning signs of primary immunodeficiency
- Patient day

Recipient of IPOPI grant

Belgium

ASBL BOPPI (Belgian Patient Organisation for PID)

- WPIW: Family day « Technopolis », with recreational and educative activities
- 02/11/2019: DIP MARATHON indoor cycling

Click to see more


SAVE THE DATE

28 AVRIL 2019
TECHNOPOLIS - MECHELEN

BOPPI


DATE À BLOQUER
2 NOVEMBRE 2019

MARATHON D'INDOOR CYCLING

BOPPI

DIP MARATHON INDOOR CYCLING

Recipient of IPOPI grant

Belgium

KU LEUVEN
UNIVERSITEITSFONDS

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KU Leuven University (KID Fonds)

- “Get together” day with psychologists, hospital administrators, scientists, physicians, the play team and the music group “de Arkonauten” and families of children affected by PI
- Recreational activities for children organized, together with exchanges

Click to see more

Celebrating 5y PID charity fund at KU Leuven (KID Fonds) with World PI Week and JMF. Psychologists, admins, scientists, physicians, play team and music group « de Arkonauten » join hands for families and children affected by PID. @WorldPIWeek @Info4PI

Bosnia

POsPID (Podrška Osobama sa Primarnim Imunodeficitima)

- Online awareness raising on PI and warning signs

Click to see more

10 ZNAKOVA UPOZORENJA ZA PRIMARNU IMUNODEFICIJENCIJU

Svetska nedelja PID 2019

UČINIMO DOSTUPNOM TERAPIJU osobama sa primarnim imunodeficijencijama - PID (urođenim poremećajem imunog sistema)! Unapredimo kvalitet njihovih života i održivost zdravstvenog sistema!

Razvrstana u "retke bolesti" Primarma imunodeficijencija (PID) je nasledni genetski poremećaj telesnog imunog sistema, koji se ogleda u tome što je imuni sistem odsutan delimično ili potpuno, ili ne funkcioniše kako bi trebalo. Ovaj nedostatak je uzrok čestih i veoma različitih infekcija u različitim delovima organizma kao što su koža, uši, pluća, stomak itd.; infekcije su često hronične, uporne i iscrpljujuće. Obzirom da je najčešće dijagnostikovan oblik PID manjak/nedostatak antitela, obzirom da sada već postoji više od 300 oblika PID, da se najčešće javlja kao „obična" infekcija, praktičari ih često i tretiraju na tom pojavnom nivou, ne ulazeći u potencijalne uzroke infekcija. Zato se one ponavljaju i razvijaju trajna oštećenja pojedinih organa, invalidnosti i čak smrti. Ukoliko su na vreme prepoznati, ovi poremećaji se mogu lečiti a u nekim slučajevima i izlečivi.

Ove godine se Svetska nedelja PID od 22 do 29 aprila obeležava jedanaesti put, sa ciljem da se podigne svest javnosti o PID i da se širom sveta prepozna važnost dostupnosti imunoglobulinske (Ig) terapije za osobe sa PID. Samo organizovana akcija može da obezbedi efektivni i univerzalni pristup terapiji za osobe koje žive sa PID, pristup najboljoj terapiji za svakog pojedinca.

Od suštinske je važnosti da se na svim nivoima naprave određeni pomaci, obezbedi puna podrška i optimalna nega osobama sa PID kao i da se imunoglobulinska terapija definiše kao prioritetna za osobe sa PID, u odnosu na druge indikacije i oboljenja.

Brazil

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ASBAI- BRAGID

- **Immersion course in primary immunodeficiencies:** Immunologists from different regions of Brazil gathered together in São Paulo to discuss diagnosis and treatment, through panel debates and presentations.
- Interview with specialist doctor on the importance of early testing
- Awareness raising on social media

Colocar os pacientes com imunodeficiências primárias no centro dos seus cuidados

22 – 29 April 2019

Click to see more

Bragid
28 April

Interview with Dr. Gesmar second in CBN about the week of the primary imunodeficiencias / errors of the imunodade and the importance of the test of the

https://cbn.globoradio.globo.com/media/audio/257864/importancia-do-teste-do-pezinho-para-o-diagnostico.htm

See original · Rate this translation

About This Website

CBN.GLOBORADIO.GLOBO.COM

A importância do 'teste do pezinho' para o diagnóstico de deficiências imunológicas

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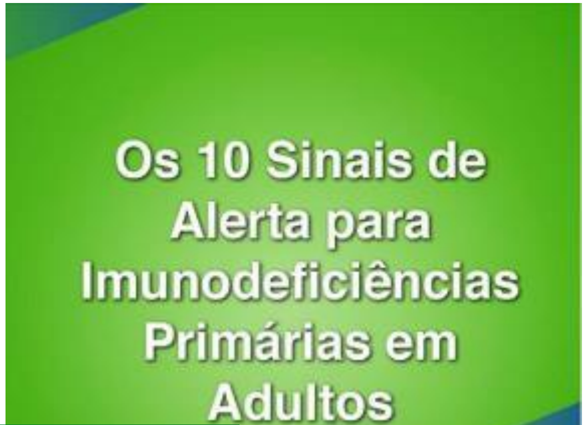
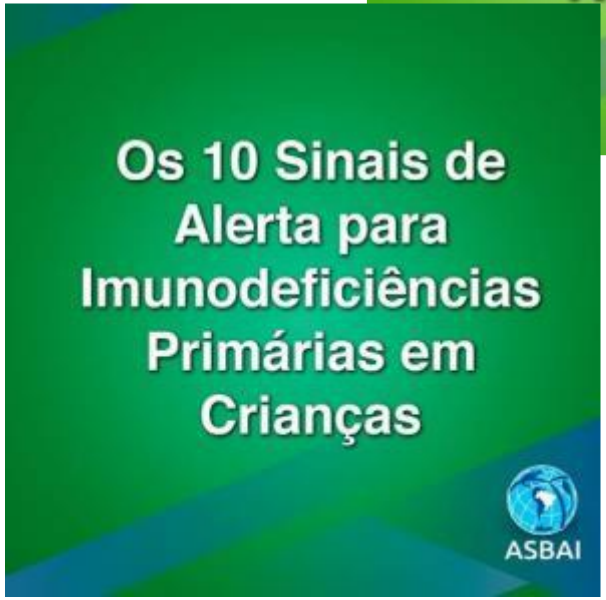
Brazil

ASBAI


World PI Week
TEST• DIAGNOSE •TREAT
ASBAI
Associação Brasileira de Alergia e Imunologia
www.asbai.org.br
@asbai_alergia ASBAI Alergia @ASBAI_alergia


Os 10 Sinais de Alerta para Imunodeficiências Primárias em Adultos
ASBAI


Os 10 Sinais de Alerta para Imunodeficiências Primárias em Crianças
ASBAI

- Video series release featuring member of the scientific department of immunodeficiencies from ASBAI, highlighting the importance of World PI Week under the theme: *"The Immunodeficiency Patient at the center"*
- Awareness raising campaign on the warning signs of PI in adults and children

Click to see more

Did you know ?

A video produced by ASBAI regional in Rio de Janeiro, captures the actions developed during World PI Week

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Brazil

Hospital Pequeno Principe

- Educational videos about the immune system and the importance of early awareness and diagnosis with immunologist Carolina Prando
- Workshop and lectures on Diagnosis and Treatment: Innate Errors of Immunity, attended by several health professionals (psychologists, nurses, doctors, pharmacists, biologists and biomedicians) with a focus on patient-centred, integrated care
- Project *"Ad Cordis: Rhythms of the Heart"* brings the group Jazz Gypsy Quintet to the Little Prince

Click to see more

Did you know ?

A video produced by Hospital Pequeno Principe highlights the activities of the World PI Week.

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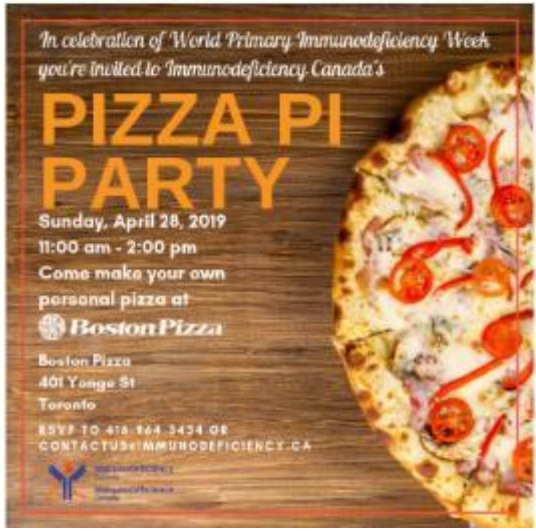
Canada

Immunodeficiency
Canada
Immunodéficience
Canada

Immunodeficiency Canada

- “Pizza PI Party” gathering healthcare professionals, patients, family and friends, to make their own personal pizza in celebration of the many different types of PI
- Dissemination and promotion of World PI Week materials on social media

Click to see more


In celebration of World Primary Immunodeficiency Week
you're invited to Immunodeficiency Canada's

PIZZA PI
PARTY

Sunday, April 28, 2019
11:00 am - 2:00 pm
Come make your own
personal pizza at
Boston Pizza

Boston Pizza
401 Yonge St
Toronto

RSVP TO 416 964 3434 OR
CONTACTUS@IMMUNODEFICIENCY.CA

Canada

CIPO
Canadian Immunodeficiencies Patient Organization

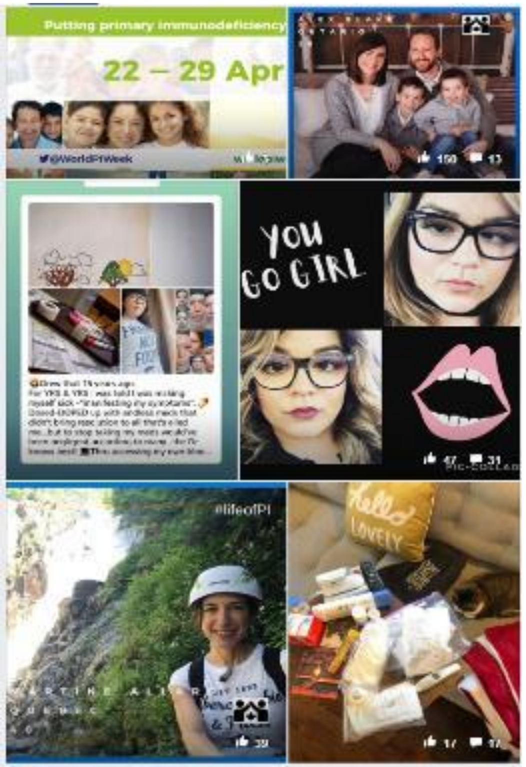
CIPO (The Canadian Immunodeficiencies Patient Organization)

- Participated in the World PI Week “myPIstory” campaign, highlighting patients’ daily life with PI

Click to see more


CIPO
@CIPONational
Following

Happy Friday Everyone! Now it may be the weekend but remember to keep checking in to catch up with our herd's stories which will be running throughout #worldpiweek 🌎 Today Tonya will be sharing her #lifeofPI journey 🗣️🦓❤️ bit.ly/2ISVWzQ



Canada

APIQ Association des Patients Immunodéficients du Québec

APIQ (Association des Patients Immunodéficients du Québec)

- Series of informational videos with interviews of healthcare professionals released on social media (on diagnostic, warning signs etc)
- Family day with distribution of plush toys to children with PI as part of « I have my teddy » awareness campaign, children and family activities

Click to see more


APIQ
24 April

"Diagnostiquer l'immunodéficience, c'est trouver une rareté parmi la normalité"
- Oleksandra Lepeshkina, infirmière clinicienne au CHUL

#worldpiweek #apiq #immunodéficience

See Translation


APIQ
24 April

Vanessa et Maude du CHU Sainte-Justine nous décrivent les signes cliniques à surveiller !

PARTAGER = AIDER AU DIAGNOSTIC PRÉCOCE !

#worldpiweek #apiq #immunodéficience

See Translation

China

PID Care China

- **Mental Health Event,** including a lecture for PID patients and caregivers with psychologist Ms. Jiang Qian Li
- Group counselling for patients and their families

Recipient of IPOPI grant

China

复旦大学附属儿科医院
市红十字儿科医院

Children’s Hospital of Fudan University

- Event to raise PI awareness and improve disease diagnosis and treatment standards in China, with Prof. Wang Xiaochuan, Director of Immunology

Recipient of IPOPI grant

Fundación Diana García de Olarte
para Inmunodeficiencias Primarias

Colombia

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FIP (Fundación Diana Garcia de Olarte)

- Promotion of World PI Week materials on social media
- IDP National Symposium held in collaboration with Colombian Association of Allergy, Asthma and Immunology (ACAAI)

Click to see more

Fundación Fip
26 April ·

Semana mundial de las Inmunodeficiencias Primarias WPIW

See Translation

World PI Week
PRUEBA • DIAGNOSTICA • TRATA

Propiciando el cambio para pacientes con inmunodeficiencias primarias en todo el mundo.

Semana Mundial de Inmunodeficiencias Primarias
22 - 29 abril

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.

Dónde?

Quiénes?

Semana Mundial de las Inmunodeficiencias Primarias
Abril 22 – 29 de 2019

IX Simposio Nacional de Inmunodeficiencias Primarias JMC·ACAAI 2019

Avances en Diagnóstico y Manejo
de los Errores Innatos de la Inmunidad

Abril 27 de 2019
Hotel NH Teleport (Bogotá)
Calle 113 No. 7-65
8:00 am - 5:30 pm

Invitan:

Apoyan:

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

Ecuador

Fundación PIDE

- National Meeting of patients with PIDs
- Training workshops
- Support material
- Developed an informative video about PI and warning signs

YOUTUBE.COM

Qué son las IDP y los signos de Alarma

Video informativo acerca de las Inmunodeficiencias Primarias y los signo...

Recipient of IPOPI grant

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El Salvador

FUNDACIÓN ESCUDO DE AMOR
PARA LA INMUNODEFICIENCIA PRIMARIA

Fundación Escudo de Amor para las IDP El Salvador

- Family Day and awareness raising on the 10 warning signs together with the National Pediatric Hospital Benjamín Bloom
- TV and radio interviews on PI with a specialist doctor, pediatrician and immunologist


Fundación Escudo de Amor para las IDP El Salvador a retweeté
Hospital Bloom @hospitalbloom · 26 avr.
El HNNBB y Fundacion Escudo de Amor: conmemoran la semana mundial de las inmunodeficiencias primarias.
Traduire le Tweet


Pencho y Aida @PenchoyAida · 25 avr.
Hablamos sobre la Inmunodeficiencia Primaria con el Dr. Héctor Eduardo Guidos, del @hospitalbloom y Héctor Rafael Amaya, de la Fundación @EscudoAmor.

#PenchoyAida
penchoyaida.com
Traduire le Tweet

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Estonia

Estonian Patient Society for Primary Immunodeficiencies

- Conference on immunodeficiency, exploring:
  - ✓ clinical manifestations such as gastrointestinal troubles or skin rashs
  - ✓ CIVD
  - ✓ vaccination in PI patients
  - ✓ cytokines and immunodeficiency

World PI Week
TEST • DIAGNOSE • TREAT

IMMUNODEFICIENCY CONFERENCE

Dear colleague,
We kindly invite you to the Conference on 24.04.2019 from 9:30 to 16:00 in the Conference Centre of Swissotel Tallinn

9:30 – 11:20 I SESSION
Immunodeficiency – What is it? Who? Where? – Krista Ress, East-Tallinn Central Hospital
Secondary Immunodeficiencies – Mariken Ross, North Estonia Medical Centre
Lung Manifestations in Primary Immunodeficiency – Maria Mikkal, East-Tallinn Central Hospital

LUNCH
12:00 – 13:40 II SESSION
Recidivating Angioedema – Krista Ress, East-Tallinn Central Hospital
Abscess and Immunodeficiency – Mare Suigom, East-Tallinn Central Hospital
Gastrointestinal manifestations in PIDDs, with a special emphasis on CVID – *Mikko Seppänen, Helsinki University Hospital*

COFFEE BREAK
14:20 – 16:00 II SESSION continues
Skin rash – when to suspect Immunodeficiency? – Tiia-Linda Okas, East-Tallinn Central Hospital
Cytokines and Immunodeficiency – Kai Kisand, University of Tartu
Vaccination in patients with Immunodeficiency – Maire Link, Pärnu Hospital

REGISTER HERE

The seminar will provide 8 training points.
Registration ends on 15th April 2019 or until seats on the East-Tallinn Central Hospital website **www.itk.ee** are filled.
The participation fee is 20 euros, for residents and doctoral students 10 euros. After registration we kindly ask you to transfer the participation fee to the SEB bank account No. EE771010220022885015 of East-Tallinn Central Hospital. Please add a note to the bank transfer with following information: The Immunodeficiency Conference 24.04.2019: participant / participants' name / names.
Received participation fee confirms registration.

Recipient of IPOPI grant

Finland

Liity jäseneksi

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Immuunipuutospotilaiden yhdistys r.y (Finnish Patient Organisation for Primary Immunodeficiencies)

- Awareness day targeting healthcare professionals, association members and general public.
- Annual Meeting and Patient Seminar on diagnosis and treatment, with specific sessions on:
  - ✓ diagnosis and identification of PI in pediatric populations
  - ✓ personalised care
  - ✓ subcutaneous treatment
- Peer support session and mental coaching

Click to see more

Immuunipuutos-potilaiden yhdistys

Potilasseminaari Tampere

27.04.2019

Ohjelma:

klo 13.00	Lounas
klo 14.00	Miten immuunipuutosgeenejä diagnosoidaan, uusia metsästetään ja varmennetaan LT, lastentauteihin erikoistuva lääkäri Juha Grönholm
klo 14.45	Yksilöidyt hoidot Teija Saari, Nordic Infucare AB
klo 15.00	Kahvitauko
klo 15.30	Tämän päivän subkutaanihoito Outi Halttunen, Steripolar Oy
klo 15.45	Kun sairaus hiipii mieleen Työnohjaaja, valmentaja Markku Salminen
klo 16.30	Videoesitys Saimi Hoyer & Minna Wilska-Sundström Punkaharjulla , Vertaistukiasiaa

France

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IRIS (Immuno-Deficience Primitive: Recherce, Information, Soutien)

- Online PID quiz disseminated through facebook, IRIS website, mailing to networks
- 104 participants: 85 women & 19 men

Click to see more


Association IRIS a partagé une publication.
Admin · Publié par Marion Schaefer · 25 avril, 10:16 · Ajouter des sujets

Participez au quizz spécial semaine mondiale des DIP, et tentez de remporter une visite à l'institut imagine !

Association IRIS
Publié par Marion Schaefer · 22 avril, 09:32

Pour cette semaine mondiale des DIP, l'association IRIS organise un quizz sur les DIP du 22 avril au 29 avril 2019 avec plusieurs lots à gagner :

1er gagnant : ...

Afficher la suite


QUIZZ Semaine mondiale des DIP

Pour cette semaine mondiale des DIP, l'association organise un quizz sur les DIP du 22 avril au 29 avril 2019 avec plusieurs lots à gagner :

- 1er gagnant: Visite de l'Institut Imagine avec une nuit à Paris pour deux personnes
- 2ème et 3ème gagnants : Goodies (t-shirt + sac + mascotte peluche + livre gourmandises de blogueurs + clé USB)
- 4ème et 5ème gagnants : Goodies (t-shirt + clé USB + bloc-note + stylo)

Les personnes ayant eu le meilleur score seront tirées au sort pour le premier lot. Ensuite un autre tirage au sort sera réalisé pour choisir les gagnants des lots 2 à 5. Ils seront choisis parmi les participants ayant le plus haut score.

Envie de participer ? Cliquez sur ce lien :
https://associationiris.typeform.com/to/T67IN|

Ensemble pour agir, informer, aider et protéger !

Documents officiels :

Rapport Général CAC2017 IRIS signé.pdf
Rapports IRIS 2017.pdf

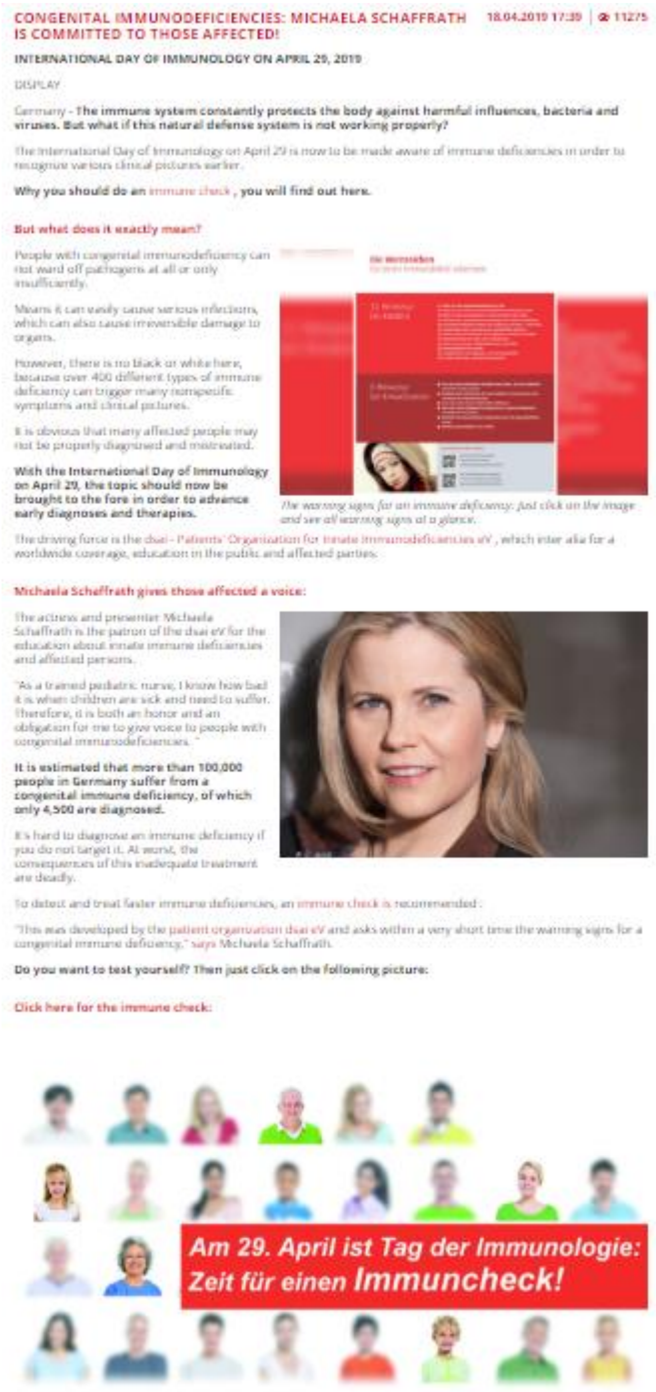
Recipient of IPOPI grant

Germany

Dsai - (Patients' Organization for Innate Immunodeficiencies eV)

- Balloon launch – Luftballon-Aktion zur WPIW
- Creation and promotion of immune check in support of early diagnosis
- Awareness raising and promotion by celebrity Michaela Schaffrath on TAG24
- Social media activity

Click to see more



CONGENITAL IMMUNODEFICIENCIES: MICHAELA SCHAFFRATH IS COMMITTED TO THOSE AFFECTED! 18.04.2019 17:39 | 11275

INTERNATIONAL DAY OF IMMUNOLOGY ON APRIL 29, 2019

DISPLAY

Germany - **The immune system constantly protects the body against harmful influences, bacteria and viruses. But what if this natural defense system is not working properly?**

The International Day of Immunology on April 29 is now to be made aware of immune deficiencies in order to recognize various clinical pictures earlier.

Why you should do an immune check, you will find out here.

But what does it exactly mean?

People with congenital immunodeficiency can not ward off pathogens at all or only insufficiently.

Means it can easily cause serious infections, which can also cause irreversible damage to organs.

However, there is no black or white here, because over 400 different types of immune deficiency can trigger many nonspecific symptoms and clinical pictures.

It is obvious that many affected people may not be properly diagnosed and mistreated.

With the International Day of Immunology on April 29, the topic should now be brought to the fore in order to advance early diagnoses and therapies.

The warning signs for an immune deficiency: Just click on the image and see all warning signs at a glance.

The driving force is the dsai - Patients' Organization for Innate Immunodeficiencies eV, which inter alia for a worldwide coverage, education in the public and affected parties.

Michaela Schaffrath gives those affected a voice:

The actress and presenter Michaela Schaffrath is the patron of the dsai eV for the education about innate immune deficiencies and affected persons.

"As a trained pediatric nurse, I know how bad it is when children are sick and need to suffer. Therefore, it is both an honor and an obligation for me to give voice to people with congenital immunodeficiencies."

It is estimated that more than 100,000 people in Germany suffer from a congenital immune deficiency, of which only 4,500 are diagnosed.

It's hard to diagnose an immune deficiency if you do not target it. At worst, the consequences of this inadequate treatment are deadly.

To detect and treat faster immune deficiencies, an immune check is recommended:

"This was developed by the patient organization dsai eV and asks within a very short time the warning signs for a congenital immune deficiency," says Michaela Schaffrath.

Do you want to test yourself? Then just click on the following picture:

Click here for the immune check:

Am 29. April ist Tag der Immunologie: Zeit für einen Immuncheck!

Defektes Immunsystem?
Starke Patientenorganisation!

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Greece

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

- Scientific meeting on PI and paediatric immunology, discussing patient needs, treatment, newborn screening and genetics
- Dissemination of World PI Week material

Click to see more


Τμήμα Ανοσολογίας-Ιστοσυμβατότητας
Ειδικό Κέντρο & Κέντρο Αναφοράς για
Πρωτοπαθείς Ανοσοανεπάρκειες -
Παιδιατρική Ανοσολογία
Νοσοκομείο Παίδων "Η Αγία Σοφία", Αθήνα

Επιστημονική Εκδήλωση
για τις
Πρωτοπαθείς
Ανοσοανεπάρκειες-
Παιδιατρική Ανοσολογία

20 Απριλίου 2019
Κτήριο "Κωστής Παλαμάς"
Ακαδημίας 48, Αθήνα

Πρόγραμμα


www.paed-anosia.gr

Scientific Meeting
on Primary Immunodeficiencies
Paediatric Immunology

20th April 2019
"Kostis Palamas", UoA
Athens - Greece


Έγκαιρος έλεγχος και διάγνωση της Πρωτοπαθούς Ανοσοανεπάρκειας

Recipient of IPOPI grant

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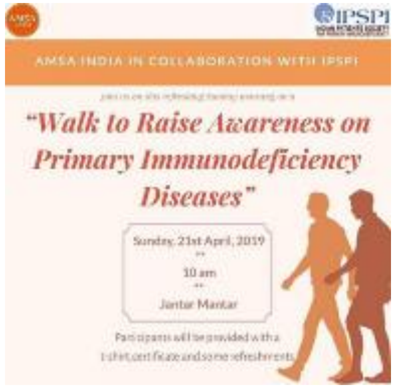
India

IPSPI (Indian Patients Society for Primary Immunodeciency)

- Seminar on PID in Maulana Azad Medical College, LN Hospital (New Delhi)
- PI awareness walk in collaboration with AMSA India at Jantar Mantar, New Delhi to mark the launch of World PI Week 2019
- CME programs on PI and interactive session for doctors & PI patient families

Click to see more



AMSA INDIA IN COLLABORATION WITH IPSPI

"Walk to Raise Awareness on Primary Immunodeficiency Diseases"

Sunday, 21st April, 2019
10 am
Jantar Mantar

Participants will be provided with a t-shirt, certificate and some refreshments

Recipient of IPOPI grant

Indonesia

IPIPS (Perhimpunan Pasien Imunodefisiensi Primer Indonesia)

- Online social media campaign, including story sharing
- Family day (50 attendees) – watch highlights of the meeting here
- Sharing sessions with doctors and patients, fellowship trainees session

Click to see more

Kumpul Keluarga Yayasan Pasien Imunodefisiensi Primer Indonesia (IPIPS) April 2019

Peringatan Hari Imunodefisiensi Primer Dunia 2019

28 April 2019 | 10.00 - 14.00 wib

Restoran Papparich,
Jl. Panglima Polim Raya No. 57-59

Didukung oleh

YOUTUBE.COM

Family Day Indonesia Primary Immunodeficiency Patients - Primary Immunodeficiency Week 2019

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Iran

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IPIA (Iranian Primary Immunodeficiency Association)

- 11th International Primary Immunodeficiency Conference (ICID), which focused on updating the medical community on diagnosis and treatment of patients with PI
- Ceremony in appreciation of PI patients and theater show at Children’s Medical Center Hospital
- Participation in several TV and media interviews

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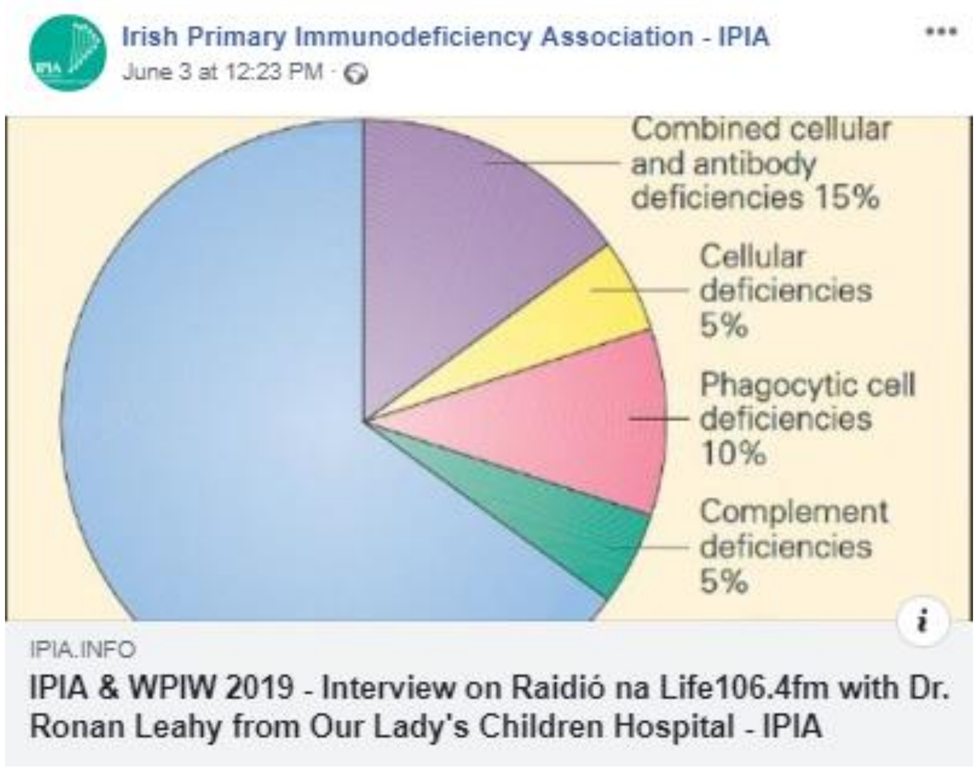
Ireland

IPIA (Irish Primary Immunodeficiency Association)

- Dissemination of World PI Week materials on social media
- Interview on local radio with Dr. Ronan Leahy on early diagnosis and PI information

Click to see more



Irish Primary Immunodeficiency Association - IPIA
June 3 at 12:23 PM ·

IPIA.INFO
IPIA & WPIW 2019 - Interview on Raidió na Life106.4fm with Dr. Ronan Leahy from Our Lady's Children Hospital - IPIA

Italy

ASSOCIAZIONE IMMUNODEFICIENZE PRIMITIVE ONLUS

A.I.P. (Associazione Immunodeficienze Primitive)

- Awareness raising activities during AIP congress, including flashmob, dedicated event to promote knowledge and procedures to doctors regarding PI, with multi-disciplinary teams involved
- Shared experiences from patients and insights on managing life with the disease
- Launch of a new awareness campaign on PI, with the mascot “Lino Globulino“
- Social media activities around the need for plasma donation, prevention, newborn screening

Click to see more

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Kenya

PIDs Kenya (The Primary Immunodeficiencies Association Kenya)

- Presentation in the context of the first A-Project in Kenya, raising awareness on PI from a patient perspective
- Establishment of a PI working group, comprising both patient support groups (PIDs Kenya and the Rare Diseases Society of Kenya) as well as doctors

Click to see more

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Malaysia

My POPI

MyPOPI (Malaysia Patient Organization of Primary Immunodeficiencies)

- National Walk-About across 7 states (Kelantan, Penang, Perak, Selangor, Kuala Lumpur, Malacca and Sabah), in collaboration with 6 Asian Medical Students' Association (AMSA) Universities to raise awareness amongst general public
- Participation of 117 medical students
- "W" hand sign movement to raise awareness of PI and show support to PI warriors & online photo campaign

Click to see more

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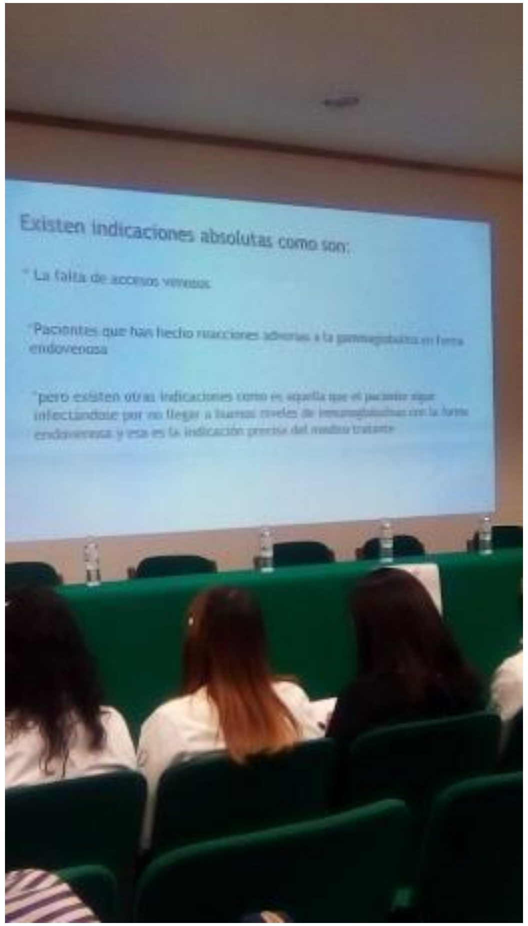
Mexico

AMPIP (Mexican Association for Primary Immunodeficiency Patients)

- Workshop on intravenous immunoglobulin treatment (prevention, reactions, testing, administration etc) – watch highlights of the session here

Click to see more



Mexico

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

- Online awareness raising, particularly on bone marrow transplantation and the need for donations "Bethematch"
- Continuous campaign on children' rights to access to healthcare
- Family day with theatre performance, painting – watch highlights of the day here
- Radio interview on early diagnosis and importance of access to treatment

Click to see more

Fundación Mexicana para Niñas y Niños con Inmunodeficiencias
30 April

Concluye la #SemanaMundial de las #InmunodeficienciasPrimarias #WorldPIWeek, y en #Fumeni #VamosPorMás por el #Derecho a la #Salud

See Translation

Fundación Mexicana para Niñas y Niños con Inmunodeficiencias
26 April

#SemanaMundial de las #InmunodeficienciasPrimarias. #Bethematch #FUMENI

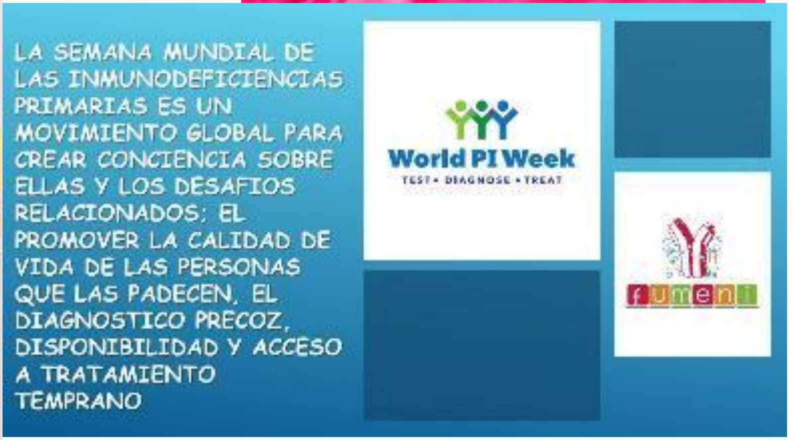
See Translation

TRASPLANTE DE CÉLULAS MADRE

¿Porqué es importante encontrar un donador compatible?

Este primer problema se conoce como rechazo de injerto

+7



LA SEMANA MUNDIAL DE LAS INMUNODEFICIENCIAS PRIMARIAS ES UN MOVIMIENTO GLOBAL PARA CREAR CONCIENCIA SOBRE ELLAS Y LOS DESAFIOS RELACIONADOS: EL PROMOVER LA CALIDAD DE VIDA DE LAS PERSONAS QUE LAS PADECEN, EL DIAGNOSTICO PRECOZ, DISPONIBILIDAD Y ACCESO A TRATAMIENTO TEMPRANO

Mexico

UMAE Pediatric Hospital CMNO IMSS

- Recreative activities for children with primary immunodeficiency and their families

Morocco

جمعية هاجر لمساعدة الأطفال المصابين بضعف المناعة الأولي
HAJAR Association to help children with Primary Immunodeficiencies
Association HAJAR d'aide aux enfants atteints de Déficits Immunitaires Primitifs

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Association Hajar de Soutien aux patients atteints de deficits immunitaires Primitifs

- Blood donation day, with over 400 donations
- Day trip for Hajar's children to the Zoo
- Training day on primary immunodeficiency for doctors and nurses

Recipient of IPOPI grant

Netherlands

SAS (Stitching voor Afweerstoornissen)

- Patient family day with with clinicians around patient-centred care
- Promoted YouTube Video series "A Rare Condition (PID)" featuring testimonials of patients
- Social media activity

Click to see more

YOUTUBE.COM
A Rare Condition (PID) | Chapter One: "What's wrong with me?"

YOUTUBE.COM
A Rare Condition (PID) | Chapter Five: "I will not give up"
Living with Primary Immunodeficiency Disease (PID) can be challenging....

YOUTUBE.COM
A Rare Condition (PID) | Chapter Four: "Life is an emotional rollercoaster"

YOUTUBE.COM
A Rare Condition (PID) | Chapter Three: "We'll find a way through"

Patient Centered care
Patient in het middelpunt van de zorg
Zaterdag 20 april
van 10.00 uur tot 16.45 uur
Locatie: Boerderij de Boerinn, Mijzijde 6, 3471 CM Kamerik
Workshops met medewerking van
Informatie en opgeven via:
info@stichtingvoorafweerstoornissen.nl

New Zealand

Immune Deficiencies Foundation of New Zealand

IDFNZ (Immunodeficiency Foundation of New Zealand)

- Online awareness raising through social media, including the warning signs of primary immunodeficiency

IDFNZ Kids Foundation updated their cover photo.
22 April

It's World PI Week. This is an important day for us here at the Immunodeficiency Foundation of New Zealand (IDFNZ) since a number of our patient members suffer from a Primary Immunodeficiency (PI).

World PI Week focuses internationally on an important topic or challenge surrounding PI, to increase awareness, understanding and bring about change in policy and healthcare practice. This year, patient-centred care is at the heart of the campaign.
There are over 380 different types of primary immunodeficiencies which are estimated to affect over 6 million people worldwide. Each type of disease requires a customized treatment approach.

Judith Dickson, Sonja Willcox and 7 others 6 shares

IDFNZ Kids Foundation
24 April

⚠Understand the Warning Signs of Primary Immunodeficiency with the help of children and adults relating their symptoms to each sign. Primary Immunodeficiency occurs when the immune system is broken or missing from birth. There are treatments that can help individuals lead a normal everyday-life.

YOUTUBE.COM
10 Warning Signs That Every Parent Should Know
This video of the 10 Warning Signs of Primary Immunodeficiency was made with the help of...

Judith Dickson, Rochelle Watson and 1 other 1 comment 1 share

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Philippines

PhilPOPI (Philippine Patient Organization for Primary Immunodeficiencies)

- Daily run of PI infographics video in drug store counters
- Newspaper publications on PI
- Radio interviews and TV broadcastings
- Public display of banners and distribution of brochures and educational items on PI
- Dialogue on Universal Health Care with the Philippine Health Insurance Corporation (PhilHealth) and the Department of Health of the Government

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Poland

immunoprotect
Stowarzyszenie na rzecz osób z niedoborami odporności

Immunoprotect (Association for Patients with Primary Immunodeficiencies)

- PI patient meeting
- Distribution of immunobags with educational leaflets in English and Polish
- Interview on national TV on access to healthcare building on patient story

Click to see more

Immunoprotect
22 April

Nie zapominajcie, że oprócz Śmigusa Dyngusa świętujemy także rozpoczynający się dzisiaj Światowy Tydzień PNO!!!!

See Translation

@WorldPIWeek #WorldPIWeek worldpiweek.org

World PI Week
TEST • DIAGNOSE • TREAT

Pierwotny niedobór odporności: pacjenci ośrodkiem leczenia i opieki zdrowotnej

22 – 29 April 2019

Razem, zmienimy życie pacjentów z pierwotnym niedoborem odporności na całym świecie

Recipient of IPOPI grant

IPOPI
INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES

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Portugal

ASSOCIAÇÃO PORTUGUESA
DE DOENTES COM
IMUNODEFICIÊNCIAS
PRIMÁRIAS

APDIP (Associação Portuguesa de Doentes com Imunodeficiência Primária)

- Family Day, with sessions on patient-centered care and neonatal screening for SCID
- Walk of Health, stretching session
- Awareness campaign through TV shows and social networks
- Distribution of educational material on PI

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INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES

Puerto Rico

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APIP (Puerto Rico Alliance of PID patients)

- Family day with lectures on treatment, new technology (app), CVID and Q&A about PI
- Awareness Campaign including:
  - ✓ Walk of Health
  - ✓ 10 digital billboards and radio ad in 12 stations
  - ✓ Health fair at the University of Puerto Rico and in Culebra
  - ✓ Community events in schools
  - ✓ Distribution of educational material at medical congresses, with information table
- Facebook campaign
- Press announcement

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Romania

ARPID (Romanian Association for Patients with Primary Immunodeficiencies)

- Timotion – Fundraising Marathon for PID children's summer camp
- National PI Conference and patient meeting in Zarnesti
- Public survey regarding the willingness of plasma donation and a press conference about the necessity of plasma donation in Romania
- Patient stories at NoRo –radio show dedicated for rare diseases
- Press release

Click to see more


RADIONORO.RO

Povestea Saptamanii - Stela Parvu | Radio NoRo

Emisiunea Povestea săptămânii Data Mar, 30/04/2019 - 13:00 Autor...

Recipient of IPOPI grant

Russia

Sunflower Charity Foundation (Association for Primary Immunodeficient Patients)

- Patient congress coinciding with World PI Week
- Awareness online about PI and warning signs
- Projection of animated film

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Saudi Arabia

King Faisal Specialist Hospital and Research Centre (KFSHRC)

- Campaign to increase awareness and access to primary immunodeficiency treatment at the hospital, with doctors, nurses, patients and families

Click to see more

الحملة التوعوية
لأمراض نقص المناعة الوراثية

تعرف . افحص . شخص . عالج

٢٣ أبريل ٢٠١٩م - ١٧ شعبان ١٤٤٠هـ

٩ صباحاً - ٤ عصراً

بهو البرج الشمالي

Senegal

ASDIP (Association sénégalaise des déficients immunitaires primitifs)

- A scientific meeting in partnership with the African Center of Excellence for Maternal and Child Health (CEA-SAMEF, the Senegalese Society of Pediatricians (SOSEPED) and the Senegalese Society of Immunology (SSI), with 50 participants
- Coverage in local media

Recipient of IPOPI grant

Serbia

POsPID-Support of Persons with Primary Immunodeficiency

- Awareness raising on social media

Click to see more

Pospid podrska osobama s primarnim imunodeficitom
23 April

Dragi prijatelji, od 22 do 29 aprila traje Svetska nedelja primarne imunodeficijencije ili urođenog nedostatka imuniteta. Osobe koje žive sa ovom retkom bolešću izložene su velikim rizicima od avih vrsta infekcija, a njihov organizam nema odbranu. Zato su prinuđeni da se celog života leče pre svega mesečnim dozama imunoglobulina, ali i operacijama, transplantacijama, biološkim i genetskim terapijama (gde je to moguće). Lekari koji leče ove pacijente moraju biti visoko subspec... See more
See Translation

South Africa

PINSA (Primary Immunodeficiency Network of South Africa)

- Seminar on PI and Patient Meeting, in collaboration with doctors
- Radio interviews
- Collaborative press release with Allergy Society of South Africa and Allergy Foundation South Africa
- PiNSA's poster advertised in Child Mag
- School presentation on PI and genetic marking by Dr Brigitte Glanzmann, Postdoctoral Fellow at Stellenbosch University
- Coverage of World PI Week in local media

Click to see more

Call for 'patient centricity' with World Primary Immunodeficiency Week

Affecting six million people worldwide, there are more than 320 forms of Primary Immunodeficiency (PI or PID), ranging widely in severity.

April 17, 2019

Patient centricity means working with patients in the decisions related to their own care and treatment plans.

PINSA
PRIMARY IMMUNODEFICIENCY NETWORK OF SOUTH AFRICA

Recipient of IPOPI grant

Spain

AEDIP
ASOCIACIÓN ESPAÑOLA DE DÉFICIT INMUNITARIOS PRIMARIOS

AEDIP (Spanish Association of Primary Immune Deficits)

- Day of diffusion and advances in PI, directed to health personnel at University Hospital of León
- RoundTable on PI and educational booth at the Hospital Universitario Virgen del Rocío (Sevilla), with information on diagnosis and treatment – in collaboration with the Andalusian Group for Infectiology and Paediatric Immunopathology (GAIP)
- Creation of an expert group for the management of PI in the University Hospital of Canarias
- Press coverage and call for genetic diagnostic


PISANDO FUERTE

VI SEMANA MUNDIAL DE LAS INMUNODEFICIENCIAS PRIMARIAS

Pisando Fuerte.
¿Cómo avanzar en el diagnóstico y tratamiento de las inmunodeficiencias primarias?

Sevilla (España), miércoles 24 de abril 2019
- Hospital Universitario Virgen del Rocío de Sevilla-

¡VEN A CONOCERNOS!

10:00-13:00 STAND informativo en el VESTÍBULO DEL HOSPITAL INFANTIL.

¡Que fácil es ayudar. Si quieres hacerte donante de médula ósea o plasma de la forma más fácil y rápida, pásate por nuestro stand!
Porque tú... puedes salvar una vida

¡TODOS JUNTOS!

Colaboran:
- Sección Infectología, Reumatología e Inmunología Pediátrica (SIRIP)
- Centro de Transfusiones Sanguíneas de Sevilla
- Grupo Andaluz de Infectología e Inmunopatología Pediátrica (GAIP)
- Asociación Española de déficit inmunitarios primarios (AEDIP)

Te explicamos:
- Que son las inmunodeficiencias primarias
- Cómo se diagnostican ahora y en un futuro no tan lejano
- Cómo se tratan y como se curan
- Cómo nos puedes ayudar a facilitar el diagnóstico y el tratamiento de pacientes con IDP

Os enseñamos:
- Mil maneras para ayudarnos: Desde difundir información hasta ser protagonista en el tratamiento y curación de las IDPs.


SESIÓN CLÍNICA HOSPITALARIA 2019

ABRIL
24
MIÉRCOLES

Creación del Grupo de Expertos para el Manejo de Inmunodeficiencias Primarias en el HUC (GEDIP)

Dra. Yvelise Barrios del Pino,
Médico Adjunto de Inmunología. Coordinadora del GEDIP

MODERA: Dr. Víctor Matheu Delgado,

Aula 25 Aniversario
13:45h.

COMPLEJO HOSPITALARIO UNIVERSITARIO DE CANARIAS


VI SEMANA INTERNACIONAL DE LAS INMUNODEFICIENCIAS PRIMARIAS

Jornada de difusión y avances en las IDP,s -dirigido a personal Sanitario- (*)

El Hospital de León urge el diagnóstico genético en secuenciación m...
Más de mil leoneses con inmunodeficiencias tendrían un diagnóstico exacto y tratamiento personalizado con una máquina de análisis genético «que p...
diariodeleon.es

Click to see more

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Spain

ACADIP Associació Catalana de Dèficits Immunitaris Primaris

ACADIP (Catalan Association of Primary Immunodeficiency)

- PI training course for resident doctors, organized in collaboration with the IDP group of the Societat Catalana de Pediatria i la Societat Catalan Immunology
- PI Patient Day with physicians and other reference professionals to discuss psychological support, integrated care, nursing support for home treatment. Presence of Josep Perpinyà, mayor of the Sant Just Desvern Town Hall who opened the event – watch video highlights here

Pere Soler-Palacín
Cap de la Unitat de Patologia Infecciosa i Immunodeficiències de Pediatria Vall d'Hebron

YOUTUBE.COM
Jornada Pacientes ACADIP 7/4/19
Jornada para Pacientes ACADIP, celebrada el 7 de abril de 2019 en Sant...

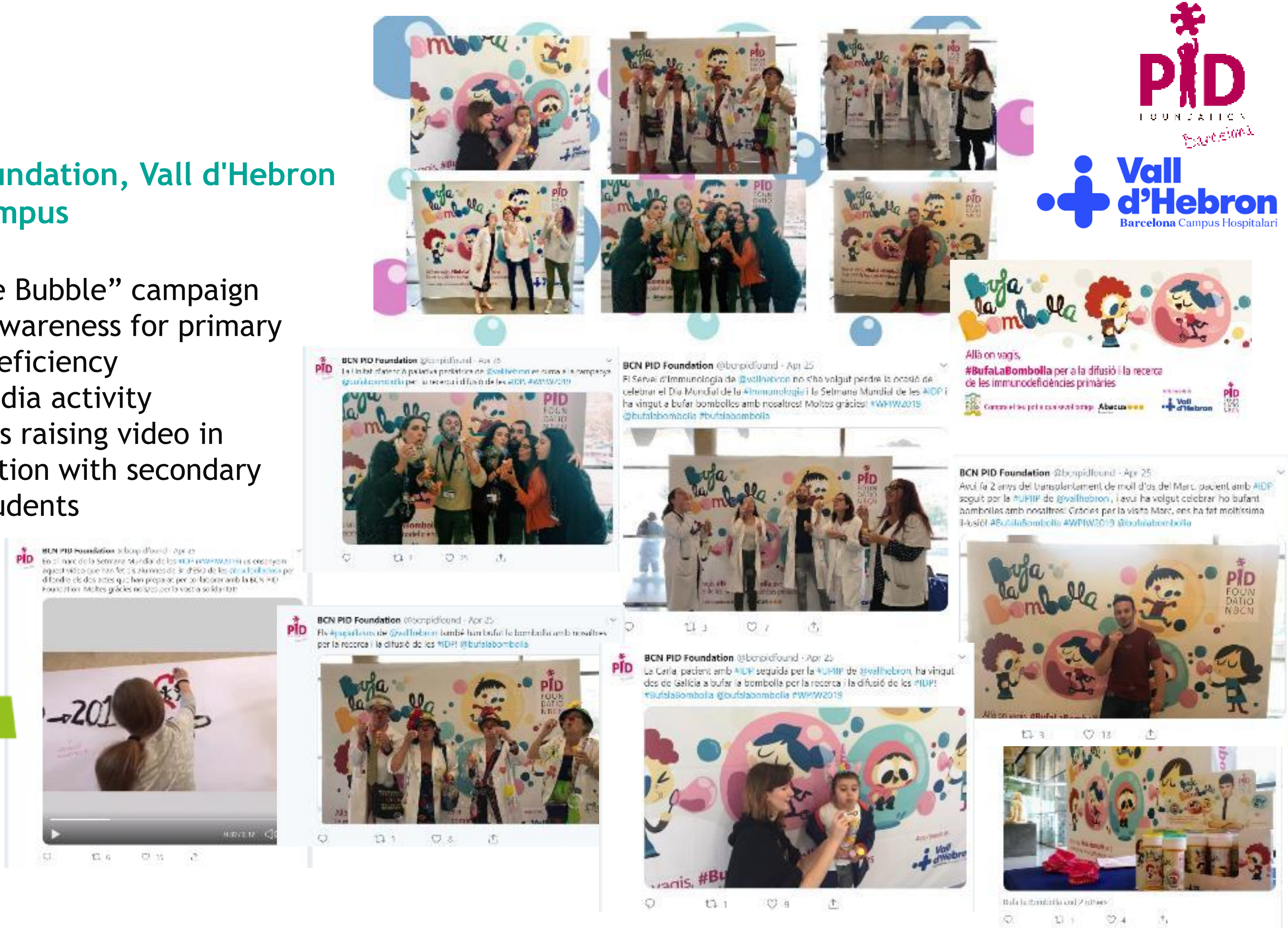
Click to see more

Spain

BCN PID Foundation, Vall d'Hebron Hospital Campus

- “Blow the Bubble” campaign to raise awareness for primary immunodeficiency
- Social media activity
- Awareness raising video in collaboration with secondary school students

Click to see more



BCN PID Foundation @bcnpidfound · Apr 25
El Servei d'Immunologia de @vallhebron no s'ha volgut perdre la ocasió de celebrar el Dia Mundial de la #Immunologia i la Setmana Mundial de les #IDP i ha vingut a bufar bombolles amb nosaltres! Moltes gràcies! #WPIW2019 @bufalabombolla #bufalabombolla

BCN PID Foundation @bcnpidfound · Apr 25
Avui fa 2 anys del transplantament de moll d'os del Marc, pacient amb #IDP seguit per la #UFIIP de @vallhebron, i avui ha volgut celebrar-ho bufant bombolles amb nosaltres! Gràcies per la visita Marc, ens ha fet moltíssima il·lusió! #BufaLaBombolla #WPIW2019 @bufalabombolla

BCN PID Foundation @bcnpidfound · Apr 25
La Carla, pacient amb #IDP seguida per la #UFIIP de @vallhebron, ha vingut des de Galícia a bufar la bombolla per la recerca i la difusió de les #IDP! #BufalaBombolla @bufalabombolla #WPIW2019

Allà on vagis, #BufaLaBombolla per a la difusió i la recerca de les immunodeficiències primàries

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Sweden

PIO Primär immunbrist organisationen

Ju mer man kan om sin sjukdom desto större möjlighet till god livskvalité.

PIO (Primär immunbristorganisationen)

- #GoZebra fundraising campaign and “zebra walks”
- Information tables in hospitals and corporate fairs
- Awareness raising on social media

Did you know ?

The Swedish Parliament approved an extension of newborn screening to SCID in May 2019. More information here

Världsimmunbristveckan genomförs varje år för att öka kunskapen om primära immunbristsjukdomar runt om i världen. Målet är att alla barn och vuxna med primär immunbrist ska få rätt diagnos och bästa vård och behandling för att kunna leva ett så bra liv som möjligt.

Recipient of IPOPI grant

Thailand

สภากาชาดไทย
The Thai Red Cross Society

THAIPOPI
Thai Patient Organization for Primary Immunodeficiency

ThaiPOPI (Thai Patient Organisation for Primary Immunodeficiency) and **Thai Red Cross Society**

- Awareness raising activities under the theme of blood donation
- Blood donation day with lecture on the importance of blood donation, recreational activities and Thai culture show
- Informative and educational material provided to donors on primary immunodeficiency

Recipient of IPOPI grant

Uganda

PIPO (Primary Immunodeficiencies Patient Organisation)

- Seminar on PI with case presentation at Kabale University Medical School (South Western Uganda) and Gulu University Medical School (Northern Uganda)
- Consultative seminar with officials from the Ministry of Health, Uganda Aids Commission and members from Sickle cell and Hemophilia associations, Consultant Pediatricians and PID parents/patients

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Ukraine

Rare Immune Diseases Ukraine (RID)

- Information Day during World PI Week, with sessions on vaccination, clinical manifestations and warning signs, diagnostic, life with PI and immunoglobulin treatment

Click to see more

Всесвітній тиждень первинних імунодефіцитів 22 – 29 квітня 2019 року

Школа з імунології/алергології

23 квітня о 17^{00}

«ПЕРВИННІ ІМУНОДЕФІЦИТИ В ПРАКТИЦІ СІМЕЙНОГО ЛІКАРЯ»

Вінницький молодіжний центр «Квадрат»
м.Вінниця, вул.Театральна, 15

Всесвітній тиждень первинних імунодефіцитів 22 - 29 квітня 2019 року

Школа з імунології/алергології для медичної спільноти
проводить конференцію присвячену Всесвітньому тижню первинних імунодефіцитів
за темою:

«ПЕРВИННІ ІМУНОДЕФІЦИТИ В ПРАКТИЦІ СІМЕЙНОГО ЛІКАРЯ»

Дата проведення: 23 квітня 2019 року Початок: 17.00

«Первинний імунодефіцит – шлях до діагнозу»
Доцент НМАПО Бондаренко А.В. – 20 хв

«Замісна імунотерапія первинних імунодефіцитів – реалії сьогодення»
Доцент ВНМУ Бондарчук О.Б. – 20 хв

«Вакцинація імуноскомпроментованих осіб: міфи та факти в практиці сімейного лікаря»
Доцент ВНМУ Богомолов А.Є. – 20 хв

«Гіпер IgE-синдром, як прояв первинного імунодефіциту»
Доцент ВНМУ Корицька І.В. – 20 хв

«Персистуючі інфекції, як основний прояв первинного імунодефіциту»
Доцент ВНМУ Кириченко Л.М. – 20 хв

«ГО «Рідкісні імунні захворювання»: шлях до життя»
Регіональний представник ГО «РІЗ» Ярмілко Н.М. – 15 хв

Запитання, відповіді, обговорення, вручення сертифікатів – *20 хв*

Місце проведення: Вінницький обласний молодіжний центр «Квадрат»
за адресою: м.Вінниця, вул.Театральна, 15

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«ПЕРВИННІ ІМУНОДЕФІЦИТИ В ПРАКТИЦІ СІМЕЙНОГО ЛІКАРЯ»

Дата проведення: 23 квітня 2019 року Початок: 17.00

Артемій Богомолов
К.мед.н., доцент курсу клінічної імунології та алергології
ВНМУ ім. М. І. Пирогова, Вінниця

Тема: "Вакцинація імуноскомпроментованих осіб: міфи та факти в практиці сімейного лікаря "

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United Kingdom

UK-PID (Primary Immunodeficiency UK)

- Awareness raising on social media throughout the week
- Promotion of #myPIstory and #PIctureAwareness! campaign
- Encouraging sharing of experiences with PI, video series of World PI Week materials with patient stories

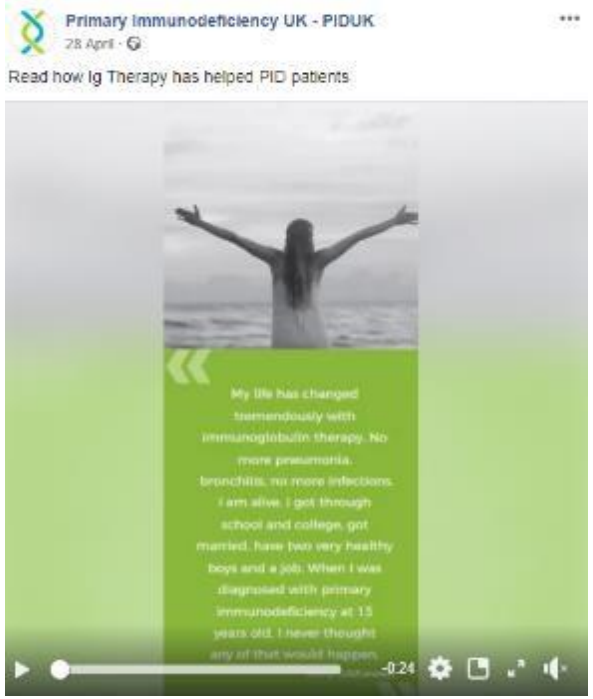
Primary Immunodeficiency UK - PIDUK
26 April

Patient Centred Care is so important for PID patients

PID UK
Supporting families affected by primary immunodeficiencies

Primary Immunodeficiency UK - PIDUK
28 April

Join our call to improve early diagnosis, appropriate treatment, and management of #PrimaryImmunodeficiency. Celebrate #WorldPIWeek on 22-29 April



Primary Immunodeficiency UK - PIDUK
28 April

Read how Ig Therapy has helped PID patients

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 15 years old, I never thought any of that would happen

Primary Immunodeficiency UK - PIDUK
23 April

For an adult, frequent debilitating illnesses can make it more difficult to pursue a career or enjoy family life. There can be psychological problems, too. Feeling isolated, the fear of losing one's income, or the anguish of caring for a sick child, can take its toll. #WorldPIWeek

Primary Immunodeficiency UK - PIDUK
24 April

Multidisciplinary teams of medical professionals look after the care of people with PIDs and are led by a consultant Immunologist. Specialists are needed because the disorders are rare, they can cause severe complications and complex treatments are often needed

Click to see more

United Kingdom

Bubble Foundation UK

- Repeat offender drawing campaign offered kids the opportunity to have their pictures brought to life through animation

Bubble Foundation UK
April 18

Here's Kieon at our stall in the GNCH. He was super happy to see his drawing displayed and brought to life through animation!

You still have time to draw and submit your repeat offender for #WorldPIweek over easter and have the chance to get it animated next week! See link here https://www.facebook.com/donate/1095523537316567/

Kieon from Sunderland Aged 10 Started Ig therapy aged 3 Diagnosed with X Linked Agammaglobulinaemia following repeated chest infections. We were lucky enough to find his repeat offender early enough to treat him.

Bubble Foundation UK
April 22

Today marks the start of #WorldPIweek! Here's a selection of drawings that we have received so far. All drawings sent in by the 25th have the chance of getting animated this week! Don't forget to send yours in! #repeatoffenders of the immune system.

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United Kingdom

Great North Children's Hospital - Newcastle

- Exchange of experiences and stories to mark World PI Week
- Participated in Bubble Foundation UK drawing competition
- Press coverage

Meet the children living in a 'bubble' at Newcastle hospital as they face fight of their lives

Fife baby living in a 'bubble' during wait for transplant

Frankie with mum, Linsey, and dad, Graham

By
JAMIE CALLAGHAN
Email

Published 18:24
Wednesday 01 May 2019

Share this article

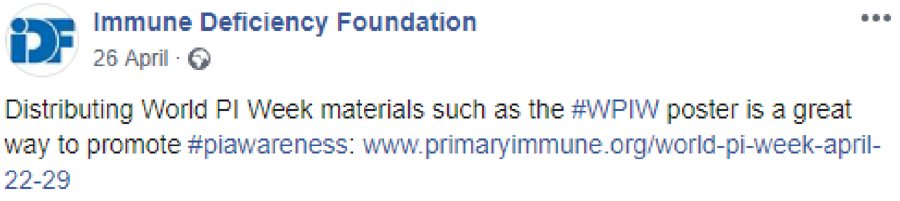
Click to see more

United States of America - USA

IDF (Immune Deficiency Foundation)

- Awareness raising efforts during National PI Awareness Month and World PI Week: sharing stories of patients and testimonials, educational material and information about PI

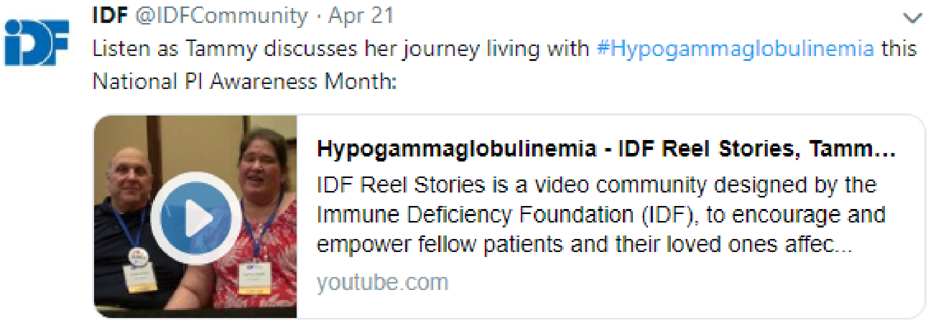
Click to see more



Immune Deficiency Foundation
26 April ·

Distributing World PI Week materials such as the #WPIW poster is a great way to promote #piawareness: www.primaryimmune.org/world-pi-week-april-22-29

IDF @IDFCommunity · Apr 22
It's the first day of World PI Week! Follow @WorldPIWeek and help promote #piawareness around the globe! #worldpiweek



IDF @IDFCommunity · Apr 21
Listen as Tammy discusses her journey living with #Hypogammaglobulinemia this National PI Awareness Month:

Hypogammaglobulinemia - IDF Reel Stories, Tamm...
IDF Reel Stories is a video community designed by the Immune Deficiency Foundation (IDF), to encourage and empower fellow patients and their loved ones affec...
youtube.com

Venezuela

IDP Venezuela (Inmunodeficiencias Primarias Venezuela)

- Psychiatrist meeting for PI patients, families and friends about daily life with PI
- Educational visits for patients to: pediatrics health services, pediatrics emergency, family medicine, otolaryngology and pneumonology, with general practitioners, internal medicine specialists, nurses and students




Recipient of IPOPI grant

Regional to Global

USA & International

JMF (Jeffrey Modell Foundation)

- Awareness raising online about PI
- Promotion of the Jeffrey Modell Story video, launched in June 2019
- Support to awareness raising in various hospitals across the US and internationally
- Launch of a new JMF Diagnostic and Research Centre at Nationwide Children's Hospital in Columbus

Click to see more

JMF @Info4PI · 23 avr.
#WorldPIWeek is about #Awareness! How have you brought awareness to others? Share how and what you do to spread awareness about #PrimaryImmunodeficiency to the people in your life!

#JMF #info4pi #WPIW #WPIW2019 #testdiagnosetreat @WorldPIWeek

Traduire le Tweet

JMF a retweeté
Do Something: The Jeffrey Modell Story @dosomethingdoc · 24 avr.
Jeffrey Modell was born with a confusing mysterious disease called #PrimaryImmunodeficiency.

Do Something: The Jeffrey Modell Story – JUNE 11 on digital & VOD platforms worldwide. youtube.com/watch?v=x3ceqr...
#love #family #storytelling #documentary #truestory #reallife #immunesystem

Traduire le Tweet

Do Something: The Jeffrey Modell Story — What is ...
Doctors explain what Jeffrey Modell's illness, Primary Immunodeficiency, is and his mother, Vicki, explains how each day could be completely different from t...
youtube.com

JMF @Info4PI · 26 avr.
What a perfect way to celebrate @WorldPIWeek!! JMF Co-Founders welcome the newest Jeffrey Modell Diagnostic and Research Center at Nationwide Children's Hospital 🏥 in Columbus, Ohio!! @nationwidekids

#JMF #info4pi #PrimaryImmunodeficiency #WPIW #testdiagnosetreat #worldpiweek

Traduire le Tweet

Europe & International

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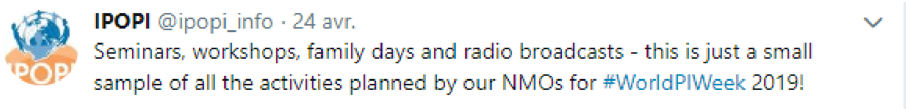
IPOPI (International Patient Organisation for Primary Immunodeficiencies)

- Awareness raising online
- Supported 31 national patient organisations worldwide to carry out grass root awareness and advocacy activities in celebration of the World PI Week

22 - 29 April 2019
IPOPI Board wishes you a happy and successful World Primary Immunodeficiencies Week

IPOPI @ipopi_info · 22 avr.
Today marks the start of #WPIW! Tell us what you have planned to bring cha
to #primaryimmunodeficiency patients across the world @WorldPIWeek

Click to see more



IPOPI @ipopi_info · 24 avr.
Seminars, workshops, family days and radio broadcasts - this is just a small sample of all the activities planned by our NMOs for #WorldPIWeek 2019!

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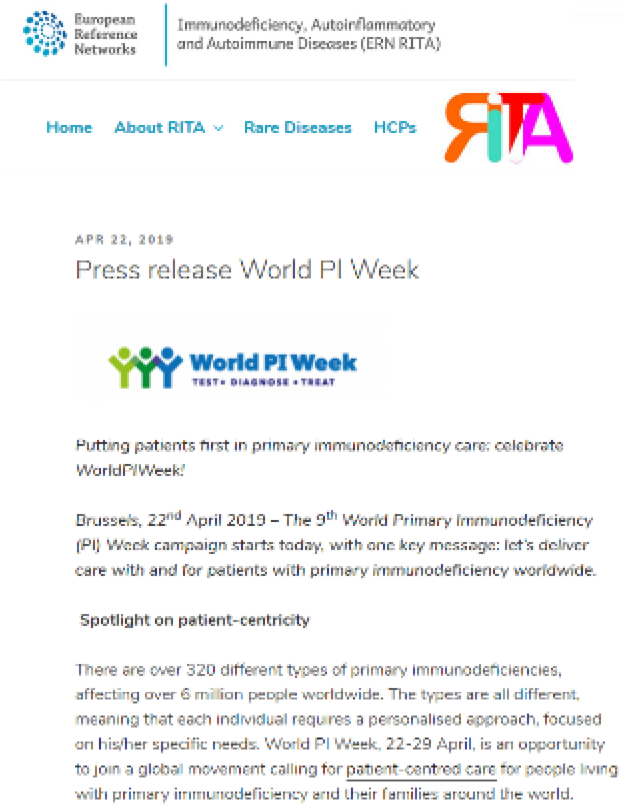
Europe

European Reference Networks | Immunodeficiency, Autoinflammatory and Autoimmune Diseases (ERN RITA) | RITA

European Reference Networks for Rare Immunodeficiency, Autoinflammatory and Autoimmune Diseases (RITA)

- Communication support, dissemination of the World PI Week press release and information amongst European medical experts

Click to see more



APR 22, 2019

Press release World PI Week

Putting patients first in primary immunodeficiency care: celebrate WorldPIWeek!

Brussels, 22nd April 2019 – The 9th World Primary Immunodeficiency (PI) Week campaign starts today, with one key message: let's deliver care with and for patients with primary immunodeficiency worldwide.

Spotlight on patient-centricity

There are over 320 different types of primary immunodeficiencies, affecting over 6 million people worldwide. The types are all different, meaning that each individual requires a personalised approach, focused on his/her specific needs. World PI Week, 22-29 April, is an opportunity to join a global movement calling for patient-centred care for people living with primary immunodeficiency and their families around the world.

APR 22, 2019

Join the World PI Week 2019!

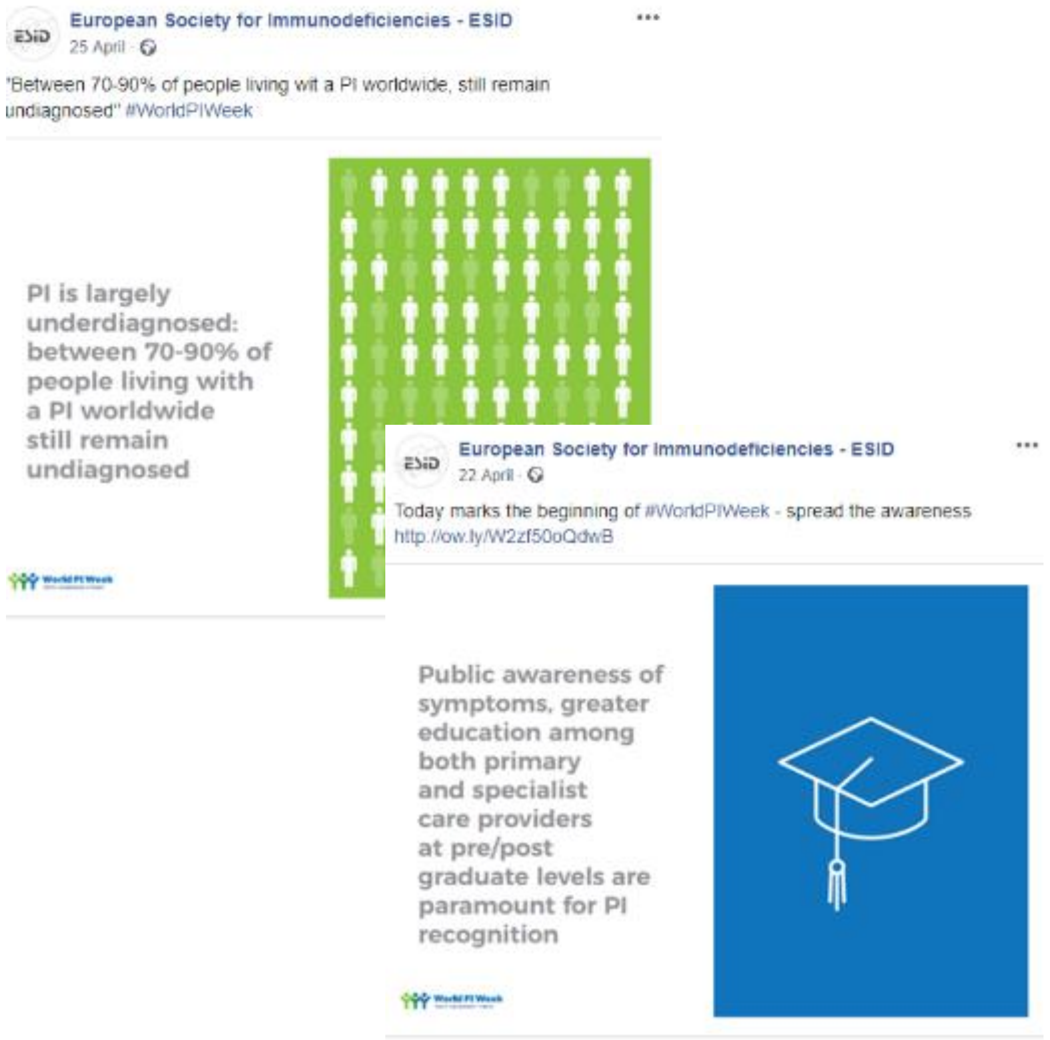
Join the World PI Week 2019 "Putting primary immunodeficiency patients at the centre of their care"!

Europe

ESID
European Society for Immunodeficiencies

ESID (European Society for Immunodeficiencies)

- Awareness raising on social media, dissemination of World PI Week material, facts and figures about PI



European Society for Immunodeficiencies - ESID
25 April

"Between 70-90% of people living wit a PI worldwide, still remain undiagnosed" #WorldPIWeek

European Society for Immunodeficiencies - ESID
22 April

Today marks the beginning of #WorldPIWeek - spread the awareness http://ow.ly/W2zf50oQdwB

European Society for Immunodeficiencies - ESID
10 April

People with #PrimaryImmunodeficiency are all different: their specific health needs should be taken into consideration in their care pathway. Join #WorldPIWeek on #PatientCentredCare on 22-29 April http://ow.ly/QVRb50oQffG via @WorldPIWeek

WORLDPIWEEK.ORG
Bringing about change together - World PI Week

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Latin America

Latin American Society for Immunodeficiencies
Sociedad Latinoamericana de Inmunodeficiencias

LASID (Latin American Society for Immunodeficiencies)

- Awareness raising online on social media, with dissemination of educative materials, facts & figures about PI
- Supported national and regional patient groups, medical societies and hospitals in Latin America hold PI workshops, medical workshops and other awareness raising activities during World PI Week

Latin American Society for Immunodeficiencies - LASID
30 April
https://www.youtube.com/watch...

Latin American Society for Immunodeficiencies - LASID
25 April
WORLD PI WEEK: 22 29 april 2019.

International

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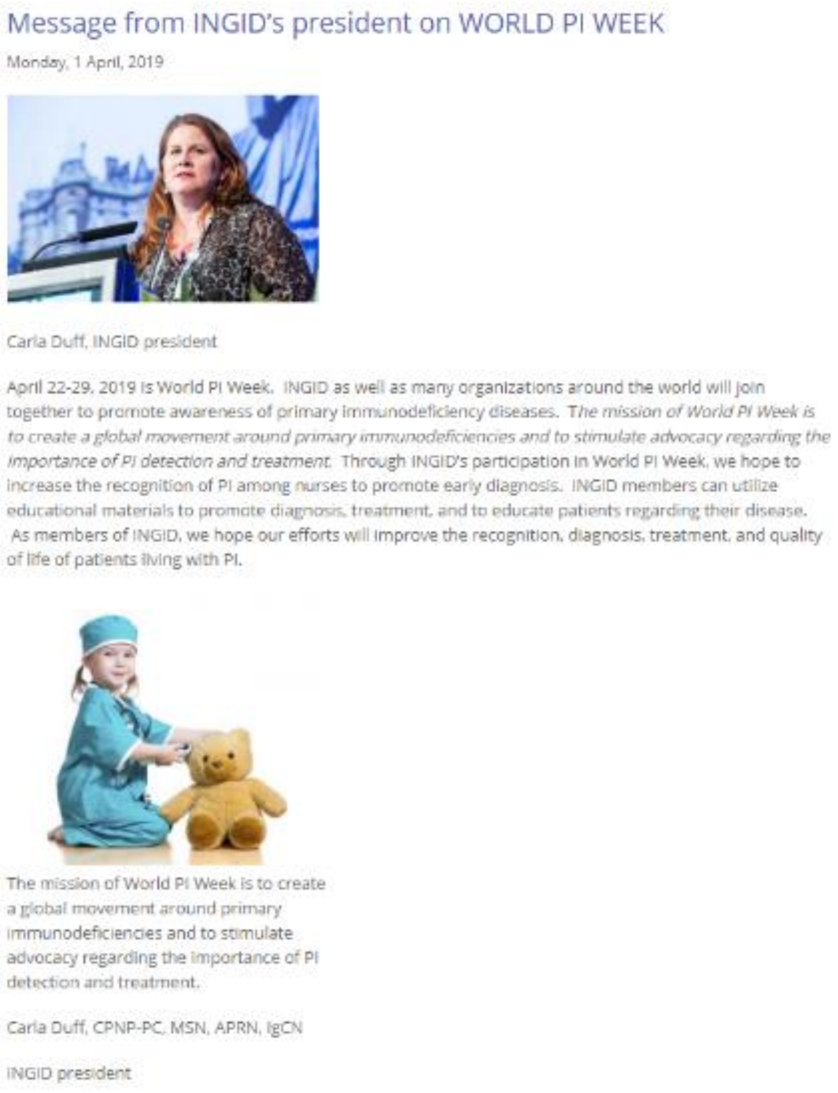
INGID (International Nursing Group for Immunodeficiencies)

- Supported dissemination of World PI Week materials and information about PI
- Awareness raising on social media and dissemination of activities organized worldwide to celebrate the campaign

INGID International Nursing Group for Immunodeficiencies
26 April

Primary Immunodeficiency UK - PIDUK
26 April

Patient Centred Care is so important for PID patients



Message from INGID's president on WORLD PI WEEK

Monday, 1 April, 2019

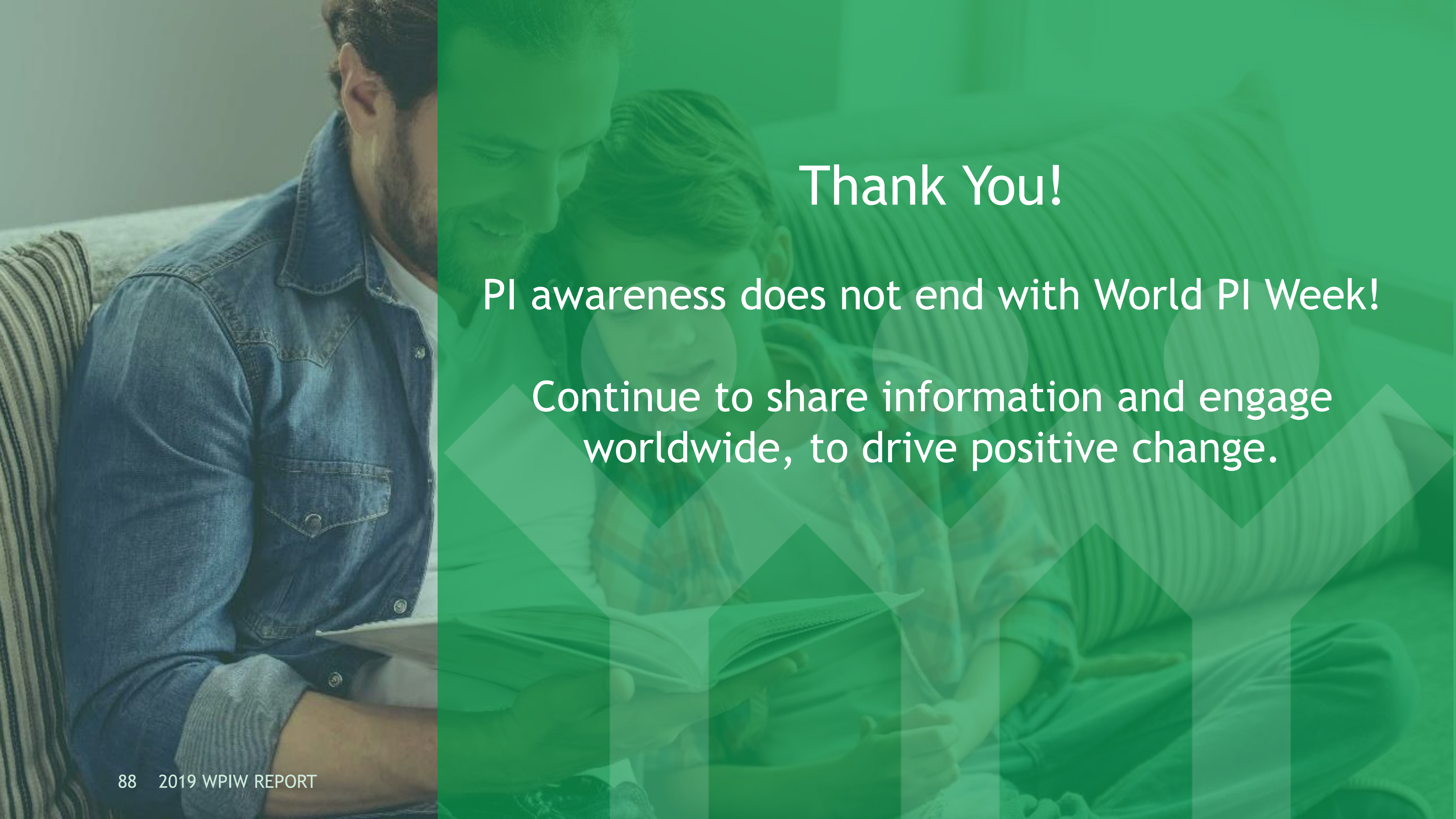
Carla Duff, INGID president

April 22-29, 2019 is World PI Week. INGID as well as many organizations around the world will join together to promote awareness of primary immunodeficiency diseases. *The mission of World PI Week is to create a global movement around primary immunodeficiencies and to stimulate advocacy regarding the importance of PI detection and treatment.* Through INGID's participation in World PI Week, we hope to increase the recognition of PI among nurses to promote early diagnosis. INGID members can utilize educational materials to promote diagnosis, treatment, and to educate patients regarding their disease. As members of INGID, we hope our efforts will improve the recognition, diagnosis, treatment, and quality of life of patients living with PI.

The mission of World PI Week is to create a global movement around primary immunodeficiencies and to stimulate advocacy regarding the importance of PI detection and treatment.

Carla Duff, CPNP-PC, MSN, APRN, IgCN

INGID president



Thank You!

PI awareness does not end with World PI Week!

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