

# Overview of WPIW campaign tools

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# Introduction to WPIW campaign tools

- Campaign slogan: Test. Diagnose. Treat.
- A different campaign theme each year:
  - 2019: “Putting primary immunodeficiency patients at the centre of their care” // theme: patient centred care
- WPIW provides materials and awareness tools annually
- All materials are global, templates can be modified and translated to serve national purposes

# Introduction to WPIW campaign tools

- On [www.worldpiweek.org](http://www.worldpiweek.org) you can find all relevant campaign information, resources, materials as well as ideas how to participate
- It is possible to join the campaign:
  - as an organisation/society: through organising events, fundraising, workshops, awareness booths, speaking at events.
  - as an individual: using social media / online awareness, joining national WPIW events, signing the global call to action.

# Theme 2019: Patient centered care

- Why?
  - PID patients are all different
    - individual needs should be considered in their care pathways
  - PID patients as partners
    - health care providers should include patients in the decision making related to their own care.
  - Health care systems designed with patients' benefit as main focus
  - A multi-disciplinary approach
    - involving all stakeholders playing a role in PID care delivery

# WPIW e-Blasts

## - Stay updated!

- Sent throughout the year to IPOPI's members mailing list.
- News and updates on the campaign materials and activities.
- Invitations to join social media campaign's



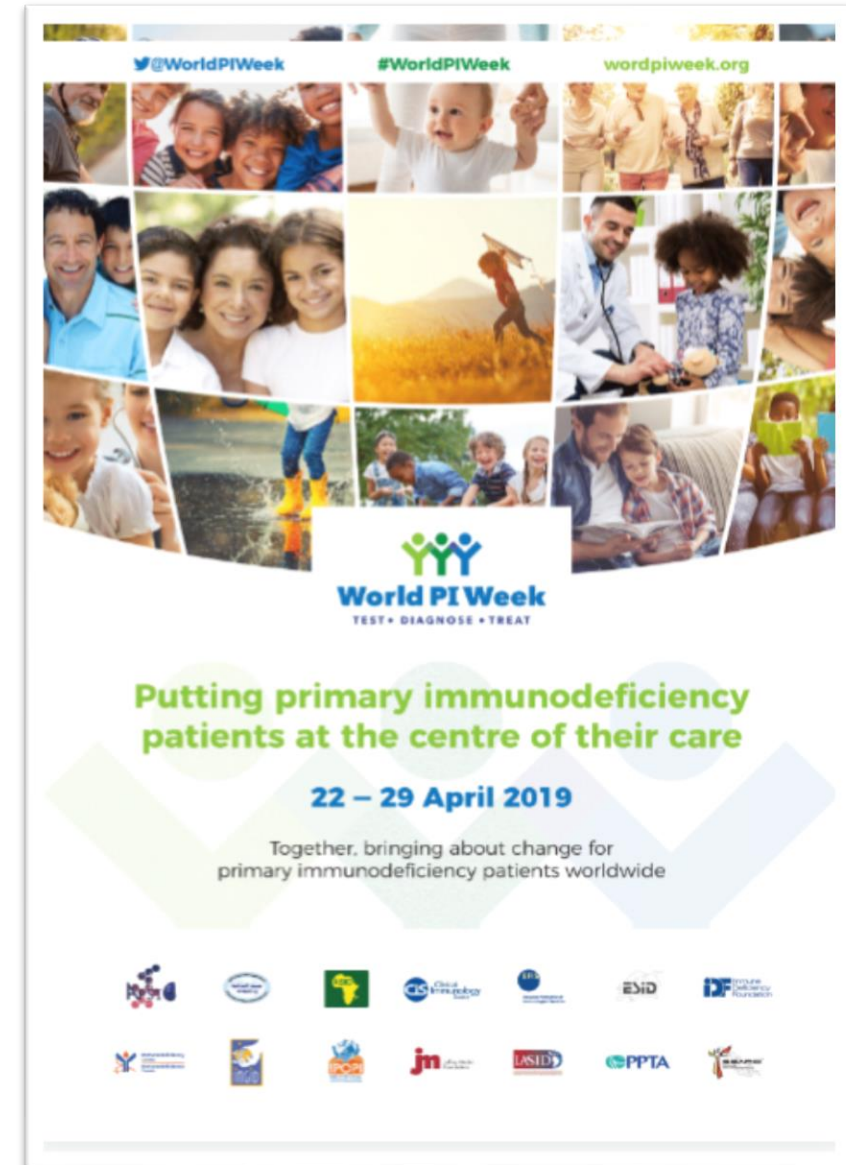
## World PI Week has a new look and new website!

Dear World PI Week supporter,

World PI Week is starting in 2 months! On this occasion, we are excited to launch the **new visual identity** of the campaign and the **new website**. We are also announcing the **theme of the 2019 campaign**!

# Campaign package

- World PI Week poster
  - Can be translated into local language, send to [julia@ipopi.org](mailto:julia@ipopi.org)  
2018: Arabic, Portuguese, German, French, Hindi, Italian, Romanian and Spanish
  - Can be adapted for national purposes





# Campaign package

- Logos
- E-banners for website, email signature and social media use
- Campaign flyer
- Sample blog or website post

All ready to use as they are or translated and modified to better serve local purpose!



70 to 90% of #PrimaryImmunodeficiency sufferers remain undiagnosed. Help raise awareness of PI. Celebrate @WorldPIWeek on 22-29 April [CLICK TO TWEET](#)

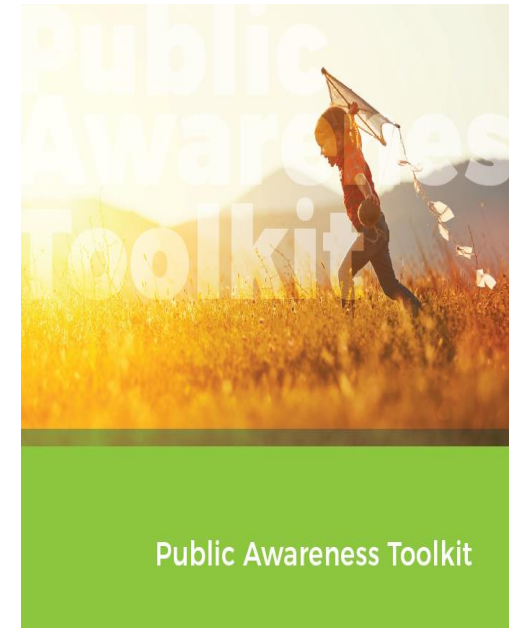
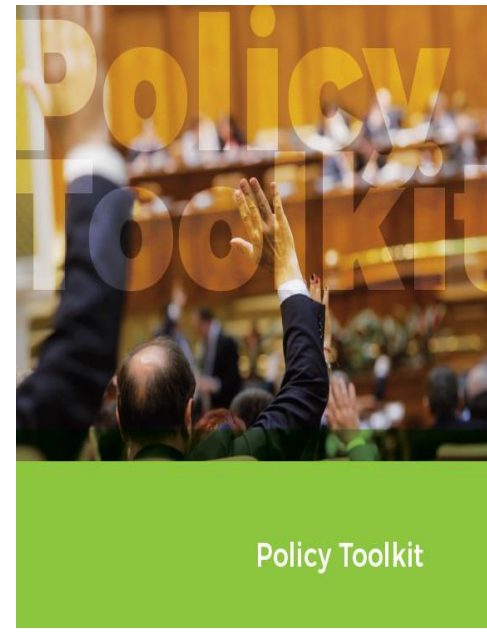
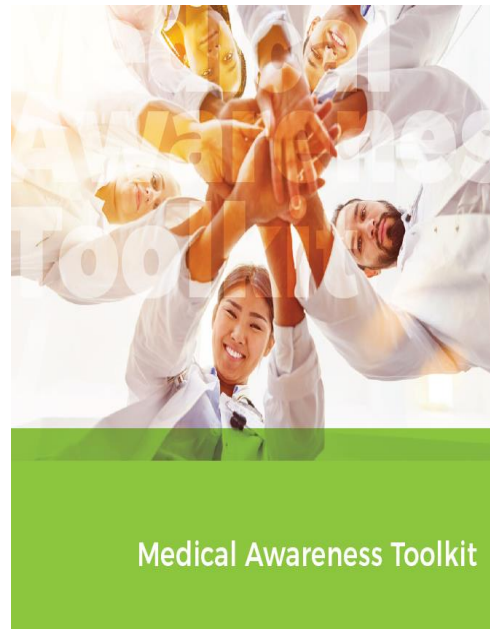
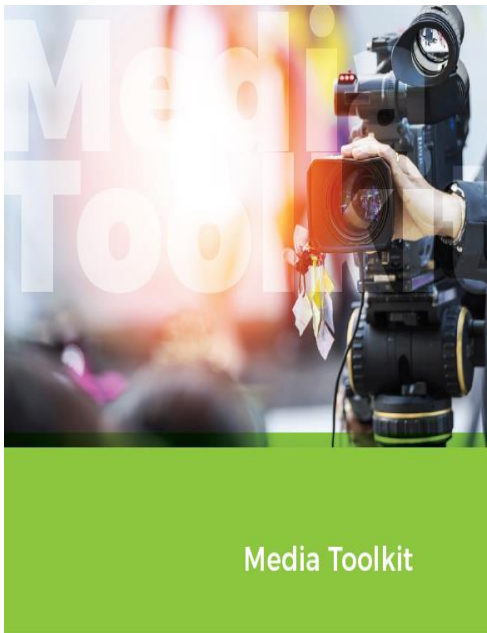
# Engagement toolkits

- NMOs have different priorities
- Toolkits for 4 types of campaigning during WPIW:
  - Media toolkit – materials towards raising awareness through media
  - Policy toolkit – advocacy materials to get visibility among policy makers
  - Medical awareness toolkit – materials for raising awareness among medical professionals
  - Public awareness toolkit – materials for raising wider public awareness



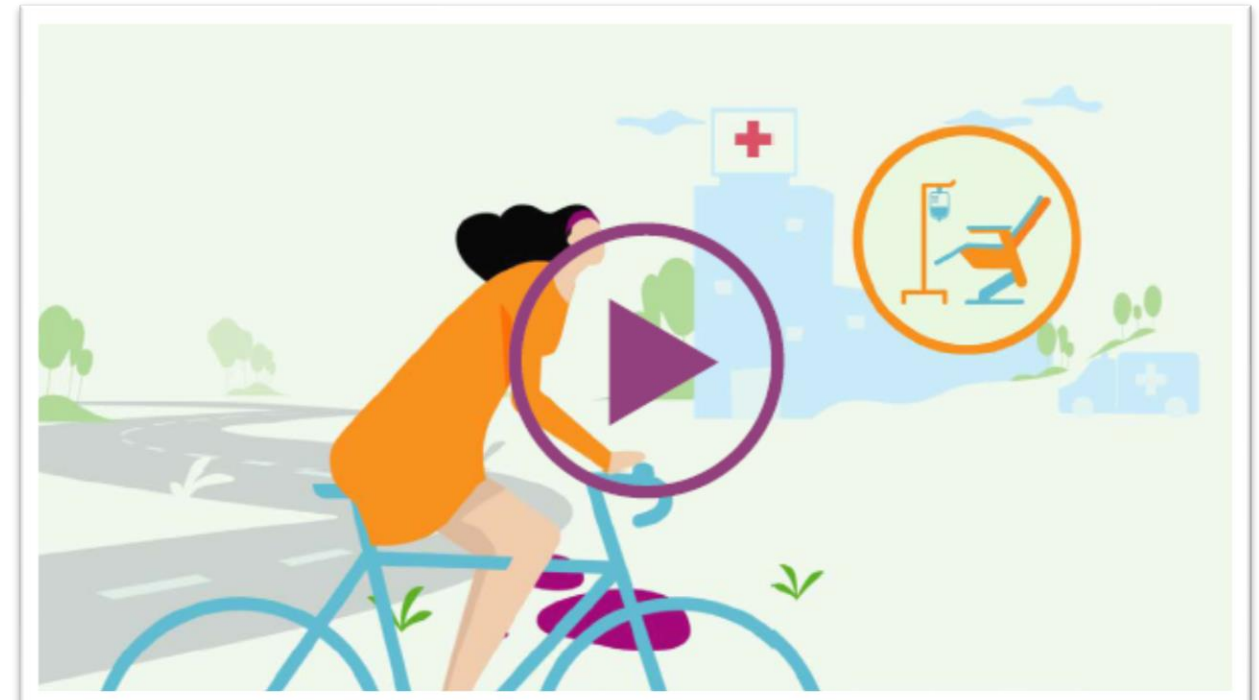
# Engagement toolkits

- Different resources depending on the toolkit
- All available at [www.WPIW.org](http://www.WPIW.org)



- World PI Week video to show at events, use on social media etc
  - Can be translated into local language (subtitles), just ask IPOPI
    - Available now in French, Spanish, Italian, Portuguese, Vietnamese, Russian
- Infographics

2018



# WPIW Press Releases

- In 2019 3 press releases:
  - on Rare Diseases Day (28 Feb).
  - during WPIW (22 April).
  - after campaign outcomes (in June).
- Freely available to use for reaching media coverage nationally
- Can be translated into other languages



Research in hope for early diagnosis, treatment and care of Primary Immunodeficiency

Brussels – 28 February 2018

Today the Primary Immunodeficiency (PI) community joins forces with rare disease advocates in celebrating Rare Disease Day 2018 around the theme of research. On this important occasion, the World Primary Immunodeficiency Week (WPIW) outlines the importance of medical research and encourages Governments, Health authorities, and investors in all countries to further support and stimulate rare disease research to change the lives of people with PI.

70-90% of people with PI worldwide remain undiagnosed. Because Primary immunodeficiencies - which are rare, genetic diseases occurring in people with an absent or deficient immune system - often manifest themselves in the form of recurring and "common" infections in individuals, diagnosis is complex. General practitioners and healthcare professionals may face difficulties in making an early and appropriate diagnosis due to those commonalities between PI symptoms and other recurrent infections. Furthermore, lack of scientific knowledge of the diseases contribute to a delayed diagnosis.

**« Research is hope for early diagnosis, treatment and care of PI »**

This year, World PI Week (22-29 April) will gather the PI community around the theme "My future starts with early testing and diagnosis of PI" highlighting how testing and diagnosis are essential first steps in the care pathway and are life-enhancing for patients with PI and other rare diseases.

Therefore, on Rare Disease Day, the PC community invites under the World PC Week to encourage policy-makers, health regulators and investors to: maintain and further support PC research, by *exchange of scientific knowledge and good practices worldwide in the collection of data as well as by developing new, effective care models and treatments*; to recognise the central role that patients play in research processes hence to fully engage them; these can be achieved by prioritising research in political agendas and funding schemes. In the context of political discussions on the financial framework for research post 2020 in the European Union (EU), the World PC Week especially invites EU decision-makers to ensure that research funding is not withdrawn nor reduced, but rather increased to meet rare disease research needs. This will ultimately benefit the population and sustain the tireless efforts of medical researchers.

# represent more than 350 of the 6,000 recognised rare diseases, and as the significant research and medical progress of the past decades testify, research remains the backbone of any improvements in the diagnosis, treatment and care of patients worldwide.

For more information on Rare Disease Day 2018: [www.rare-disease-day.org](http://www.rare-disease-day.org)

For more information on World PT Week 2023: [www.worldptweek.org](http://www.worldptweek.org)

Like World PI Week [Facebook page](#) | Follow World PI Week on Twitter: [@WorldPIWeek](#)

What if I need them to sponsor?



World PI Week 2018: Early testing and diagnosis of Primary Immunodeficiency makes a world of difference

Brussels, 22<sup>nd</sup> April 2018 - Today, the Primary Immunodeficiency (PI) community invites people of around the globe to join forces during the "World Primary Immunodeficiency Week" (21-29<sup>th</sup> April) to raise awareness about PI and advocate for positive changes that will ensure a timely testing and diagnosis of the diseases.

It is a growing category of over 350 forms<sup>1</sup> of rare, genetic deficiencies of the immune system, increasing one's susceptibility to a wide range of infections that can be life-threatening and affect different parts of the body including the skin, ears, lungs, intestines.

Celebrated for the first time in 2016, the global awareness campaign, World PI Week, gathers patients and patient organisations, families, health care professionals, scientists, industry and policy-makers on all continents to enhance the understanding and political recognition of these rare diseases. The 2018 edition, starting today, focuses on early testing and diagnosis of PI, which are crucial first steps for a successful care pathway and management of these diseases, estimated to affect over six million people worldwide.

Although medical research and progress over the last six decades have led to the development of life-saving treatments, such as immunoglobulin replacement therapies, bone marrow transplantation, gene therapy, and contributed to greater understanding and knowledge of the diseases, it is estimated that around 70-90% of people living with the different forms of  $\beta$  remain undiagnosed.<sup>2</sup>

Diagnosing PI is complex due to the similarity of symptoms with those of common infections. The relatively low awareness of PI among healthcare professionals and the general public, the lack of

**« Early testing and diagnosis of PI makes a world of difference »**

the world

<sup>1</sup> Bouvff-Ak A, Jeddane L, Picot C, Alif F, Bobbe Grasper R, Al-Hazri M, Chakla T, Crow YL, Cunningham-Rundles C, Djalali A, Frensch J, Holland SM, Klein C, Maier T, Oishi HK, Okonkwo E, Puck J, Tang M, Tangre S, Tangre T, Casanova JL, Sullivan KE. The 2017 G3S Phenotypic Classification for Primary Immunodeficiencies. *J Clin Immunol*. 2018 Jan;38(1):129-1

143. doi: 10.1007/s12075-017-0463-8. Epub 2017 Dec 11.

<sup>1</sup> N. Besser and G. Primary Immunodeficiency Disorders: Definition, Diagnosis, and Management, Second edition, Springer, 2012.



**Actions speak louder than words:  
8 days of recognition of Primary Immunodeficiency (PI) around the world**

fracture, 24<sup>th</sup> of June 2012 (World Blood Donor Day) – imagine living with a rare disease that prevents your immune system from fighting common infections – it would dramatically impact your life. But early testing and diagnosis, as well as, appropriate treatment could change this reality and allow you to live a healthy and productive life. This was the takeaway message of the many grass-roots actions that took place during the eight days of April that marked the 8<sup>th</sup> World Primary Immunodeficiency Week (WPIW).

30-60% of people living with Primary immunodeficiency (PI) worldwide still remain undiagnosed. However, responding to the PI diagnostic challenge can change lives. Fighting for early testing and diagnosis of PI was the key message of the PI community during the campaign week which ran from the 22<sup>nd</sup> to 29<sup>th</sup> of April. National PI organizations, patients, families, physicians, experts and partners in over 40 countries mobilised with campaigns, patient specialist meetings, educational conferences, public lecture, TV and radio interviews to put the spotlight on the importance of early recognition of PI, under the theme "My future starts with early testing and diagnosis of PI".

Telling the world about how life with PI is: Have you ever wondered how your life would be without a fully functioning immune system? In many countries that engaged in World PI Week, the focus was on storytelling, to raise awareness of how an early testing and diagnosis of the disease makes a world of difference for patients with PI. Many patients and their carers invited people to enter their world via video clips in [France](#), [Malaysia](#), and with 'screenlife' messages in [New Zealand](#) or [Russia](#).

There is no health without knowledge – enhancing knowledge on PI diagnosis and treatment. World PI Week was the occasion to inform patients and healthcare professionals, from medical students, primary care doctors to nurses,

**« Actions speak louder than words: 8 days of recognition of PI around the world »**

was held in Romania, and a free hotline to consult with immunologists was made available in Russia.

**Connecting the dots:** Several countries organised 'get connected' sessions between blood donors and patients, where people with PI rely on the generosity and commitment of plasma and blood donors, and these donations are an essential input to develop life-saving immunoglobulin treatments and other plasma-derived medicinal products. Blood donation days in Malaysia and Morocco reached high donation rates.

Meaningful efforts were placed on raising public awareness: Press conferences, TV reports and TV interviews with specialists in immunology were organized in all regions of the world, from Bolivia, Mexico, Canada to Germany, Belarus and Iran. Radio shows and interviews on PI were live on national radio channels in several countries, and national TV webcasts ran in Canada, as a learning opportunity for physicians and the general public. In Russia, live TV-ads were broadcast on national TV, while for the first time awareness-raising activities were conducted at the workplace to spread the word about PI "without borders", in partnership with third party businesses and private companies.

The successful World PI Week initiatives were diverse [link to WPTW report], but raising awareness of PI and driving public and political action is a never-ending process, and in the lead up to the 2019 World PI Week campaign, the PI community will continue to stimulate understanding and advocate for a better diagnosis, treatment, care and quality of life for the estimated 6 million people living with PI worldwide, and their families.





# Social Media activities

- Throughout the year (Twitter, Facebook)
- Increased communication during rare disease day (28 Feb), World PI Week and WHO world immunization week
- PID Quiz on social media
- WPIW stories
  - Share your story via worldpiweek.org or using [#MyPIStory](#) on social media
  - Stories will show on website and are used for future campaign materials

**#WorldPIWeek**  
**#WPIW2019**  
**#PID**  
**#Plawareness**  
**#primaryimmunodeficiency**

## #MyPIStory

### SHARE YOUR STORY

Watch videos. Read stories. Join the movement #myPIstory.  
Share your story.

You can write about your experience as well as submit photos or a video testimonial.

We look forward to hearing from you.

Your name \*

Your story \*



**Maria João Mousinho**

Living with PI  
Portugal

[More...](#)



**Janet Grab**

Family carer  
South Africa

[More...](#)



**Ana Posea**

Living with PI  
Romania

[More...](#)

# Stay informed

- Follow WPIW on social media
- Read IPOPI e-blasts
- Visit [www.worldpiweek.org](http://www.worldpiweek.org)

## *During the campaign*

- Use the WPIW hastags on social media #WorldPIWeek
- Send your campaign info to **julia@ipopi.org**

## *After the campaign*

- Send us your photos, articles and updates!

# Three things to take with you

- 1) All countries can do something – small or big!
- 2) WPIW is a unique opportunity to raise awareness in Africa
- 3) We invite you to join our global community

**Let's work together!**

Questions? → [Julia@ipopi.org](mailto:Julia@ipopi.org)





# Have a great World PI Week 2019!

[www.ipopi.org](http://www.ipopi.org)  
[www.worldpiweek.com](http://www.worldpiweek.com)

#WorldPIWeek  
#WPIW2019  
#PID  
#PIawareness  
#primaryimmunodeficiency  
#MyPIStory



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