



Media Toolkit

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About World PI Week

World PI Week aims to **raise Awareness** of the importance of primary immunodeficiency (primary immunodeficiency) diseases globally and **stimulate efforts** to improve the recognition, diagnosis, treatment and quality of life for people with primary immunodeficiency world-wide. The first World PI Week was celebrated on 22-29 April 2011 and focused on increasing the understanding of these diseases and promoting optimal diagnosis.

World PI Week takes place **every year on 22-29 April**. World PI Week offers a vital, visible **opportunity to inform and educate health policy-makers, schools and families, and the general public** about primary immunodeficiencies (primary immunodeficiency) to ensure the earliest possible diagnosis and optimal treatment.

The campaign focuses every year on a specific topic.→

Through events and activities promoting the warning signs of primary immunodeficiency, seminars, public lectures, video-diaries, and press conferences, the global primary immunodeficiency community can unite to bring about positive changes in healthcare systems and practices around the world in support of people living with primary immunodeficiency.

For more detailed information about World PI Week please visit the website: www.worldpiweek.org

Why engaging with the media?

Media can be **powerful allies to raise public awareness, and communicate on primary immunodeficiency reaching a wide audience**. Working with the media helps get high visibility and brings attention to primary immunodeficiencies, informs and educates target groups and **increases the impact** of the calls from the primary immunodeficiency community

Media outreach guidelines

HOW TO GET STARTED

- 1. Define your audience:** Who are your main target groups? Prioritize!
 - What do they read/watch/listen to? - How much does the audience know about primary immunodeficiency - What do you want them to do?
- 2. Familiarize yourself with the outlet you are contacting** - Check what kind of articles they publish/ reports they broadcast - Try and identify the health correspondent and research whether they have published any stories relating to primary immunodeficiency and rare diseases. - How much scientific and or technical information should you provide?
- 3. Define your message** - What is your objective? Do you want to raise Awareness on primary immunodeficiency? Issue a call for action? - Who will read the article? According to who you want to reach out to, identify the most appropriate lines of argumentation for that audience - Emphasize the most exciting story, try to find hooks: what would best raise the interest of the outlet's readers? E.g. story about SCID babies

World PI Week themes

2012 - Access to Appropriate Treatment

2013 - Primary Immunodeficiency: Turning Hope into Action!

2014 - A call for newborn screening to test for severe combined immunodeficiencies

2015 - The importance of vaccination and immunoglobulin treatment for patients with primary immunodeficiency diseases

2016 - Into action: Improving access to optimum care for all primary immunodeficiency patients

2017 - Ensuring access to life-saving immunoglobulin therapies for people with primary Immunodeficiency

2018 - My future starts with early testing and diagnosis of primary Immunodeficiency

2019 - Putting primary immunodeficiency patients at the centre of their care



4. **Ensure you have an available and prepared spokesperson** - Select a spokesperson comfortable with the topic (possibly several spokesperson for each key topic) - Make sure the spokesperson is briefed about the outlet and is ready to give an adapted answer to the journalist, taking into account the media angle, the level of technicality required etc. - Ensure your spokesperson is media trained or at least has practiced delivering the key messages prior to the interview
5. **Have background information ready to be sent** - A press kit - Patients case studies (and if possible, a patient who is fully briefed and ready to be interviewed) Look at the patient testimonials provided on the World PI Week website for guidance.

How to write press material

1. WRITING A PRESS RELEASE

A press release is a short written document prepared for the media that announces something newsworthy and aims to pique the journalist's interest. The structure:

- » Put the most **important information first**. Your headline should catch reporters' attention.
- » The lead sentence should **summarize what's most newsworthy**: When, Who, What, Where, Why
- » Next should be the **supporting facts and quotes** from spokespeople or experts to illustrate and liven your data.
- » State -more- at the bottom of each page, except for the last page where you put a ### or ENDS sign.
- » At the end of the release include **one-paragraph about World PI Week**.
- » Include **contact details** for further questions or possible interviews.
- » Always include general info on World PI Week and the website address at the bottom of the page.

2. WRITING AN INVITATION

If you want to involve the media to your World PI Week event, you need to send them an invitation. In many countries an invitation (also called a media advisory) is structured in the following way:

- » **WHAT**: stating the context and the agenda
- » **WHO**: the name and titles of the speakers
- » **WHERE**: the location name and address or login details
- » **WHEN**: Time and duration
- » **REGISTRATION**: who they should contact to register and possibly what they need to bring with them to the press conference or an exact web address and log in details

Don't forget to give contact details of your organization, to put the World primary immunodeficiency day logo and the World PI Week website address.

General tips

Include all necessary facts for reporters to file a story. Write in a fluent, journalistic style that conveys authority and fully covers the issue. Aim is for the reporter to rely on your release and key as they write their stories.

Keep it to one page or at the most where possible.

Use the World PI Week logo, available in the Material section of the website.

Include a patient/carer testimonial to capture the human side of PI

Insert quotes from an immunologist or other key thought leaders from your country.



Visit the "media information" page on the World PI Week website to see examples of press releases and media material!



3. WHAT TO INCLUDE IN A PRESS KIT

- » Fact sheets
- » Graphs/ statistics
- » Q/As on the issue
- » Patient testimonials and / or case studies. Possibly with an expert answering simple questions
- » Lexicon/glossary of terms
- » Pictures

Check out the World PI Week website for facts and figures on primary immunodeficiency!



IDEAS TO RAISE Awareness WITH MEDIA SUPPORT

- » **Newspaper** articles on primary immunodeficiency
- » **Adverts** in magazines
- » **Press** conference on primary immunodeficiency
- » **Publicity** spot in different TV and radio programs during the month of April



The World PI Week website provides helpful media material examples, as well as general materials about primary immunodeficiency and the campaign which can be useful supportive tools when engaging with the media.



Download the media toolbox here



In addition, many organisations from the primary immunodeficiency community develop regional and country-specific resources and tools, available to download at their websites.

Key World PI Week resources

World PI Week template press releases

On the World PI Week website you will find official press statements for Rare Disease Day, and the announcement of the start of the World PI Week campaign, for adaptation in your local language

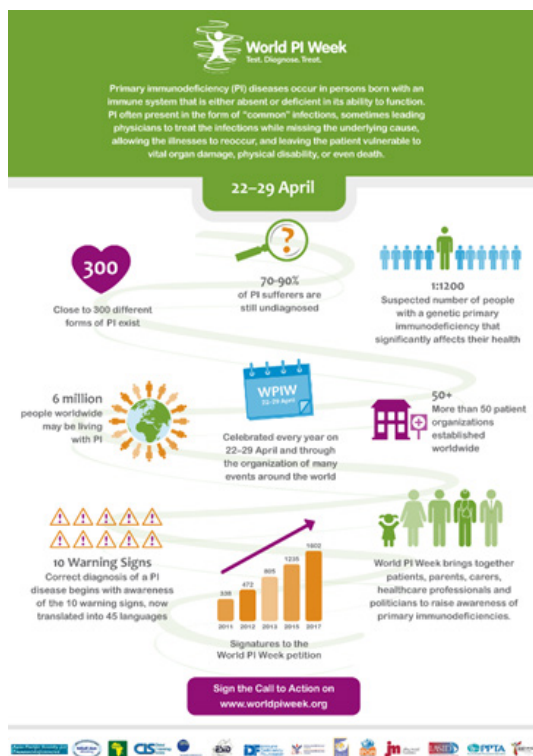
World PI Week video – available in 7 languages



World PI Week flyer



World PI Week infographic





Stories

"I was born with X-Linked Agammaglobulinemia, and I have always been very prone to develop infections. After many ups and downs during childhood and adolescence, my health got better when I started with the intravenous treatment and even better with the subcutaneous treatment. Today with 36 years old, I have a fully active lifestyle."

Nuno Urbano
Portugal

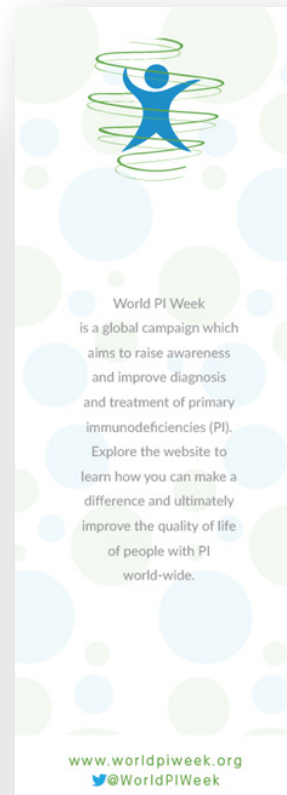
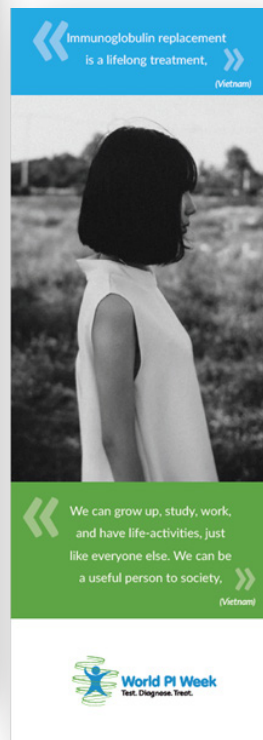
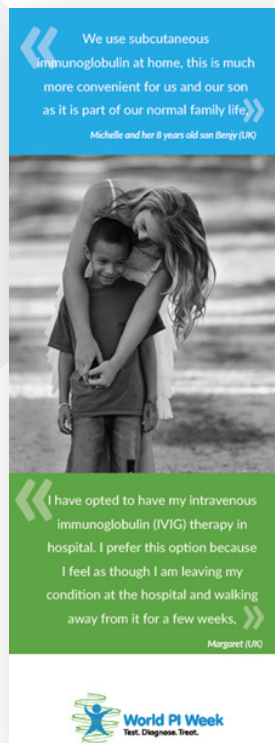
"I have been dealing with various illness for the past 10+ years. I finally found a doctor that had enough thought and compassion for me to test me.. I was finally diagnosed with CVID this year. We are still working out the kinks, as I am still getting sick, but I am a step closer to getting a little better. Not being sick every single day"

Donna Dunnican
United States

"I was diagnosed with Hypogammaglobulinemia as a baby later identified as X-linked Hyper IGM Syndrome. Have long term health problems but am currently really well. Switched to sub-cut nearly 4 years ago which I do weekly. Work full-time and try to live life to the full. Volunteer with PID UK in order to support other PID patients."

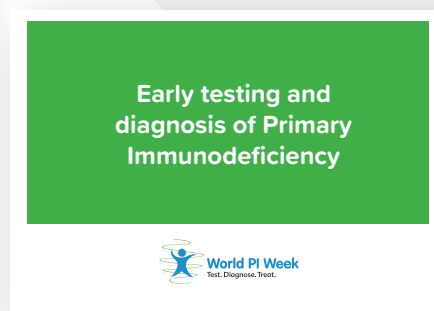
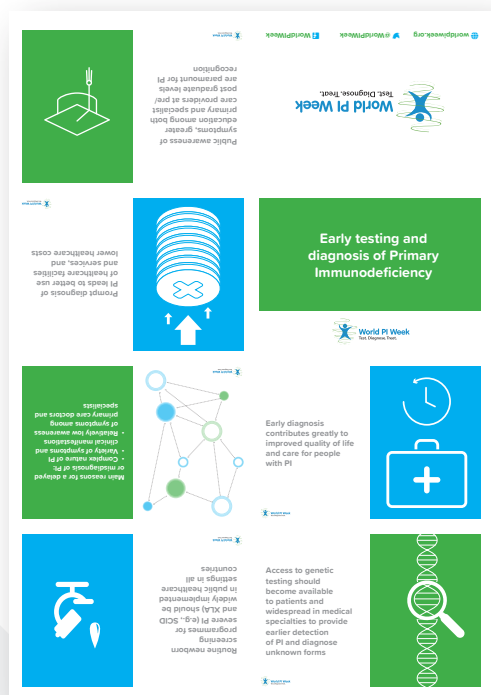
Andrew Thomas
United Kingdom

Bookmarks with patient testimonies about treatment for primary immunodeficiency





Brochure on early testing and diagnosis



Infographic - 6 key messages on immunoglobulin therapies

