



## Public Awareness Toolkit

# Contents

## Key considerations ..... 3

About World PI Week .....	3
Why raising public awareness of primary immunodeficiency? .....	3
How to raise public awareness? .....	3

## Communicating on social media..... 6

Using Visuals .....	6
Sharing real stories .....	6
Joining primary immunodeficiency discussions .....	6
Finding the primary immunodeficiency community on social media ..	7

## Resources ..... 8

Key World PI Week Ressources .....	8
World PI Week infographic.....	8
World PI Week video – available in 7 languages .....	9
Patients stories.....	9
World PI Week information flyer.....	10
Bookmarks with patient testimonies about treatment for primary immunodeficiency .....	10
Brochure on early testing and diagnosis .....	11
Infographic - 6 key messages on immunoglobulin therapies.....	11

## 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 crucial, visible **opportunity to inform and educate health policy-makers, schools and families, and the general public** about primary immunodeficiencies (primary immunodeficiency) to drive the earliest possible diagnosis and optimal treatment.

The campaign focuses on a specific theme each year.→

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

### Why raising public awareness of primary immunodeficiency?

awareness-raising aims to educate and inform the general public on primary immunodeficiency and related challenges, to **enhance knowledge and ultimately drive change in practice or policy**. It helps get high visibility or attention on primary immunodeficiency disease and increase the impact of the calls from the primary immunodeficiency community. Raising public awareness of primary immunodeficiency will ultimately have **positive effect on other audiences** such as policymakers, making primary immunodeficiency an important topic, or family carers of patients, who might feel empowered and supported.

### How to raise public awareness?

Raising public awareness can take various forms. By simply telling the world around you about primary immunodeficiency, you can make a difference. Everyone can play a part in informing and spreading knowledge about primary immunodeficiency

**As an organisation**, it will be important to define a plan and strategy to raise awareness, building on different means of action, from social media communication, public events/activities to media engagement.

**As an individual**, you can contribute to raising awareness by sharing information on primary immunodeficiency with friends, family, colleagues, either directly or by indirect channels such as social media networks.

### 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 (PID)

**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





## COLLABORATION WITH MEDIA

Working with the media is an efficient penetration tool which enables to reach out to populations amongst the general public who are not familiar with rare/genetic diseases, primary immunodeficiency and the immune system. The media usually has a broad scope of reach which enables to approach a large spectrum of the population.

## SOCIAL MEDIA COMMUNICATION

As a collective of online platforms for interaction, discussion and content sharing, social media has quickly become an essential element of any communications strategy and has changed the way we communicate with one another. A large proportion of the population worldwide is interconnected via social media networks, as well as stakeholder groups including primary immunodeficiency patient groups and organisations, immunology societies and many more. Therefore, raising awareness on social media is a productive way to engage broad audiences and enables the primary immunodeficiency community to interact and join forces to inform about primary immunodeficiency. Raising awareness has a tremendous cascading effect when implemented at a large scale through engagement with the media or on social media, but anyone can help raise awareness at various degrees!

## ORGANISING AWARENESS-RAISING ACTIVITIES AND EVENTS

Awareness-raising activities and events are an effective way of informing the general public about primary immunodeficiency and spread the word. Below are a few examples and suggestions of awareness-raising activities.

- » Awareness campaign in public and private hospitals, general public, medical university students, schools, patients and families: distributing educational material on primary immunodeficiency
- » Awareness march, distribution of flyers and posters
- » National survey to the population on the knowledge of primary immunodeficiency
- » Distribution of primary immunodeficiency awareness brochures/postcards and posters
- » A concert to introduce primary immunodeficiency to the general public
- » Distribution of translated version of the "10 warning signs of primary immunodeficiency"
- » Mobile caravan to circulate in the city during the world primary immunodeficiency week to increase awareness of the local community about the existence and symptoms of primary immunodeficiency
- » Family day with fun activities around primary immunodeficiency (quiz, drawing competition, toy mascot etc)
- » Organising a blood/plasma donor day and distributing information about the importance of plasma-derived products for people with primary immunodeficiency

### Awareness activities to children and schools:

- » Launch of a comic cartoon or interactive game on primary immunodeficiency for children and schools
- » Full day program organized by patient organisations to increase awareness, together with teachers and students of a high school specialized in educating students with future orientation to health care professions
- » Activities for children in front of paediatric hospitals by caregivers

## 5 key tips

**Use** simple wording which is easily understandable for non-expert audiences

**Share** short and concise messages

**If** you are a patient, a family carer or a healthcare professional with a personal experience, sharing your own story of primary immunodeficiency helps raise awareness with a more human aspect

**Using** visual content gets much more attention

**Make** sure to always check sources and use reliable sources of information



On the World PI Week website, you can find useful guidance and tips to organise awareness-raising events and activities.



## IDEAS TO RAISE AWARENESS

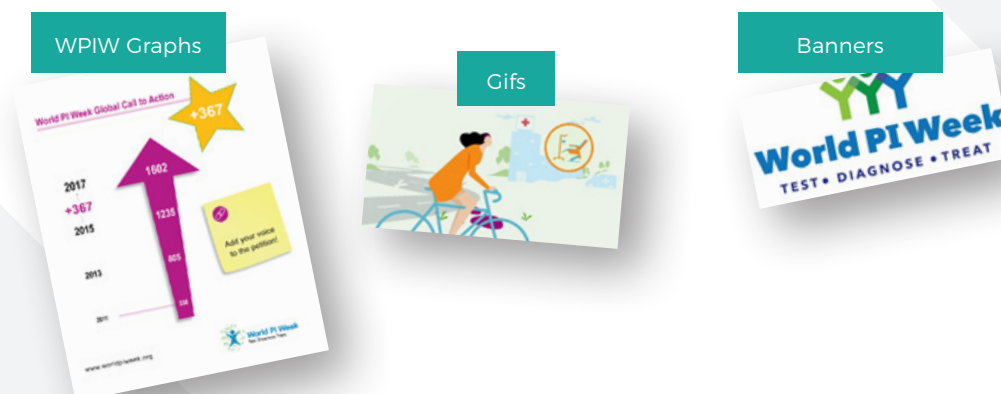
- » Join the World PI Week group on Facebook and the annual World PI Week event page
- » Publish about primary immunodeficiency and World PI Week on Facebook and Twitter, or relay publications of the primary immunodeficiency community
- » Put the World PI Week poster in public or private settings such as the lobby of your company, of your hotel, or waiting room, at your school, at the entrance of your daily grocery shop, at your insurance company or bank, at your sport club etc
- » Have a primary immunodeficiency educative class in your local school or library
- » Talk about primary immunodeficiency to your colleagues and friends
- » Ask your post office company to create a World PI Week stamp
- » Broadcast World PI Week video, images or poster on a screen in a pharmacy or public transportation
- » If you have a website or blog, post an article about primary immunodeficiency
- » Show a banner of World PI Week at the start of a football match or sport competition
- » Encourage friends, family and colleagues to donate blood/plasma and explain why this is important for people with primary immunodeficiency and other rare diseases in need of plasma-derived therapies



## Using Visuals

Sharing different types of visual elements on social media is a great way for people to engage in the campaign. Visual content (pictures, illustrations, graphics, videos, animations such as GIFs - animated visuals) catches the eye much more than other content and makes social media users more willing to engage. It can also help audiences better understand messages. But it is important to share high quality images!

You will find various downloadable visual materials and illustrations for social media use on the World PI Week website.



## Sharing real stories

The World PI Week website contains an online repository of testimonies from the primary immunodeficiency community. You can also share your own story if you are a primary immunodeficiency patient, a family carer, a friend or a healthcare professional.

## Joining primary immunodeficiency discussions

The primary immunodeficiency community has used a variety of specific key words on social media, in particular on Twitter to share primary immunodeficiency related content and engage audiences. On Twitter, these are preceded by a hash, and called “hashtags”. They are a “tracking tool” helping interested people follow the conversation by clicking on the hashtag and interact by sharing the content on their own profiles for instance (so called “retweeting”).

As an organisation, it is important to plan content in advance, by developing for instance a social media content calendar. This helps ensure coherence and consistency of messages; and build on hooks and news opportunities to spread the word. We encourage you to share World PI Week resources!



As an individual, you can share existing content and publications from reliable sources and accounts (i.e. by “retweeting” on Twitter), but also disseminate World PI Week materials. It is important to always check the facts and figures you communicate about.

On the World PI Week website, you will find a “campaign materials package” with the World PI Week logo, electronic banners, email signatures, sample blog/website posts as well as template profile pictures, selfie poster frames and banners to use on social media (Facebook and Twitter) to help you raise awareness!

## Finding the primary immunodeficiency community on social media

### KEY TWITTER HASHTAGS

- » #WorldPIWeek
- » #primaryimmunodeficiencyawareness
- » #PrimaryImmunodeficiency
- » #PrimaryImmunodeficiencies
- » #Immunodeficiency
- » #Immunoglobulins
- » #PIDcare, #PID

### KEY TWITTER HANDLES

- » @WorldPIWeek
- » @ClinImmSoc (CIS)
- » @EFIS\_Immunology (EFIS)
- » @ESIDSociety (ESID)
- » @IDFCommunity (IDF)
- » @ImmunoCanada (Immuno Canada)
- » @Info4primaryimmunodeficiency (JMF)
- » @INGID\_Tweets (INGID)
- » @ipopi\_info (IPOPI)
- » @PlasmaProteins (PPTA)

### FACEBOOK

- » @WorldPIWeekcampaign
- » @Bragid (Brazil)
- » @ClinicalImmunologySociety
- » @ESIDmeeting
- » @ImmuneDeficiencyFoundation
- » @ImmunoCanada
- » @ImmunodeficiencyPrimate (Romania)
- » @IPIAINFO (Ireland)
- » @ipopipid
- » @JMFworld
- » @lasid.org
- » @MyIpopi (Malaysia)
- » @primaryimmuneuk (UK)

And many more! If you would like to know more about the PID organisations in your region or country active on social media, please get in touch.



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

## World PI Week infographic





## World PI Week video – available in 7 languages



## Patients 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."

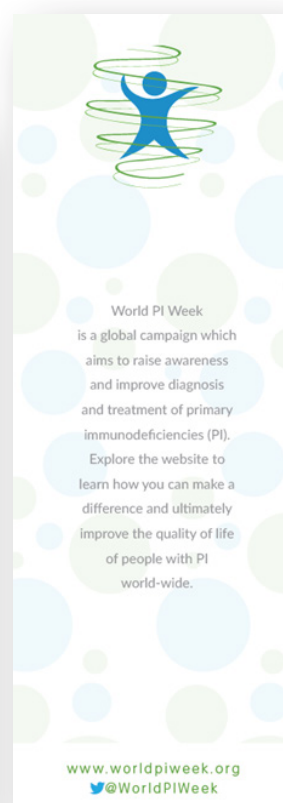
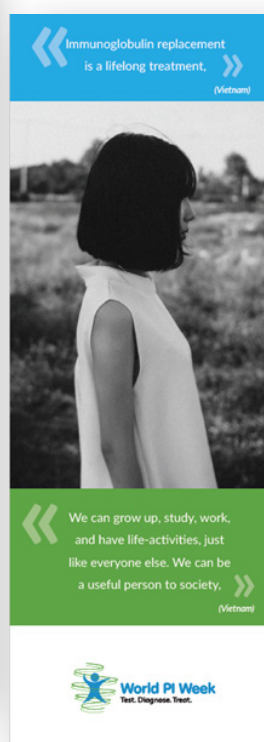
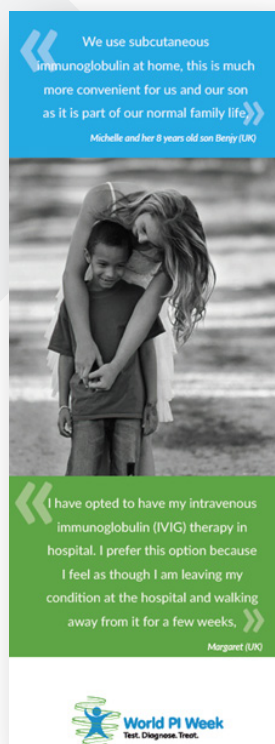
**Andrew Thomas**  
United Kingdom



## World PI Week information flyer

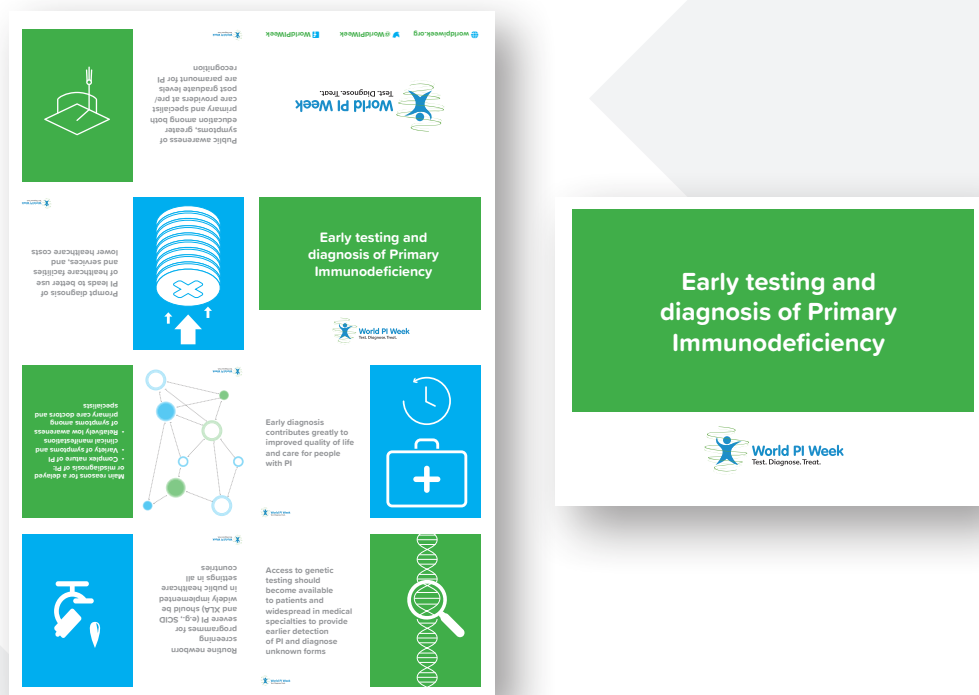


## Bookmarks with patient testimonies about treatment for primary immunodeficiency





## Brochure on early testing and diagnosis



## Infographic - 6 key messages on immunoglobulin therapies

