



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

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

Why engaging with policy-makers and governments?

Policy-makers, governments and health authorities hold the key for policy action and change to the benefit of primary immunodeficiency patients. Engaging with them help increase their awareness of the challenges surrounding primary immunodeficiency and the critical need to manage the diseases well, as well as better understand the needs of people living with primary immunodeficiency. This heightened awareness can in turn help increase testing and diagnosis, safeguard treatment option and ensure access to optimal care.

Engaging with policy-makers also allows to share personal patient or healthcare professional stories, but also the experience of your organisation, the work you are doing and its successes.

Better health outcomes for patients with primary immunodeficiency is the primary goal of engaging with policymakers. A collaboration over the long term is important to build a foundation of mutual trust and confidence, and ultimately drive policy change which often do not happen overnight and require a long-term vision.

How to engage?

There are many different ways to engage with policy-makers, from face-to-face meetings, written correspondence for instance via emailing and letters,

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



or by engaging in the scope of awareness-raising events and activities. At parliamentary level, organisations often partner with a specific member of Parliament to conduct a policy roundtable or event, ultimately aimed to a wider policymaker audience.

A few preparatory steps before engaging

KNOW THE LANDSCAPE & YOUR AUDIENCE

It is particularly relevant to know for instance whether your country has a rare disease plan, what guidance or policy programmes and actions exist around primary immunodeficiency, whether your Government or the policymaker you engage with participates in Rare Disease Day or World PI Week, what are the current priorities on the public health agenda and if there are any activities currently planned which could benefit the primary immunodeficiency community.

PREPARE IN ADVANCE YOUR MESSAGES AND CONCRETE POLICY ASKS

Policymakers often have busy schedules and may not have time for a long discussion, or reading a detailed letter. It is important to make your points clear by **sharing key, straightforward messages**. Those should pinpoint concrete policy asks or suggestions of how policymakers/governments can help improve the situation in your country or region; or a call to action. You may also discuss the vehicle by which that change will take place: for instance via a regulation change, a Parliamentary decision, a new research project, scientific guidance, a national action plan or programme etc.

Also, it is important to briefly set the scene again when engaging with policymakers - reminding of the situation of your country, challenges and needs - to be able to explain concrete asks.

SUGGESTIONS OF AWARENESS RAISING ACTIVITIES AND EVENTS WITH POLICYMAKERS

- » A **policy forum or roundtable discussion** to discuss the status of rare disease law, or a country-specific challenge and possible actions
- » A **parliamentary reception/event** and launch of a new publication
- » An **awareness exhibition** hosted in a parliamentary or governmental building

4 key tips

Use simple wording which is easily understandable

Share short and concise messages, tailored to your policy audience

Do not hesitate to **share good practices of policy action/ interventions** from other countries/regions of the world as examples

Sharing stories and experiences of patients, health-care professionals is always an effective way to engage



On the World PI Week website, you will find useful guidance and tips to organise successful activities & events.





You will find below relevant materials for policy-makers audiences or to help you engage with policy-makers. In addition, you will find on the World PI Week website a handful of materials to raise awareness and inform about primary immunodeficiency or specific challenges, including access to immunoglobulin therapies, or early testing and diagnosis.

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



Download the policy toolbox here



Template government letter

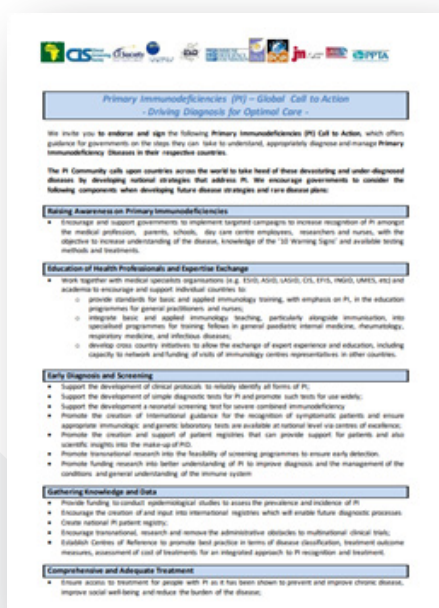
This template letter aims to help you contact government officials, ministries and other policymakers. You can tailor it to your situation and national specificities.





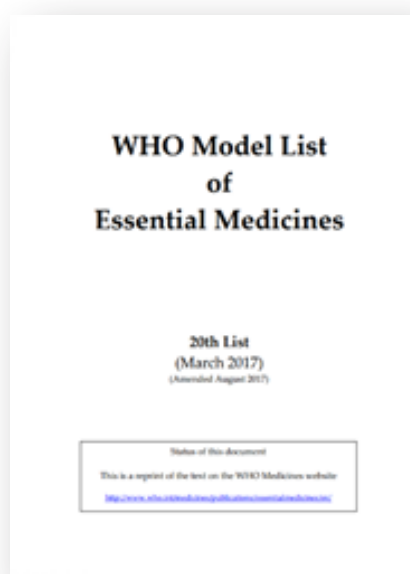
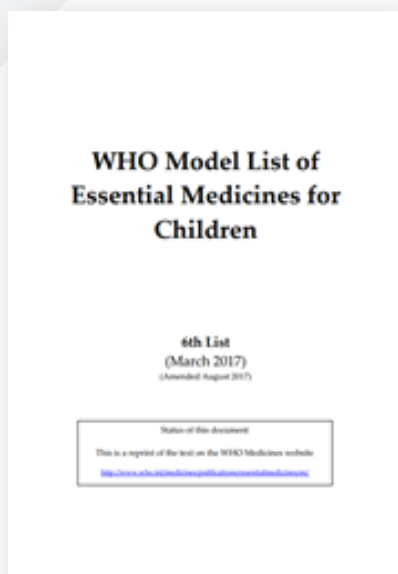
World PI Week call to action

The World PI Week global call to action includes a list of concrete policy asks. The World PI Week has also developed a specific call to action around ensuring access to immunoglobulin therapies for people with primary immunodeficiency.

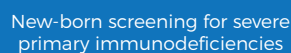
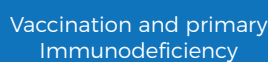


WHO Essential Medicines Lists

Immunoglobulin therapies for primary Immunodeficiencies are included in the World Health Organisation (WHO) Essential Medicines Lists both for adults and patients, which means all countries should provide access to the broadest spectrum of immunoglobulin therapies possible.



Each year, World PI Week develops specific scientific editorials around primary immunodeficiency issues, which provide scientific evidence and concrete suggestions for change to policy makers.





Patient 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."

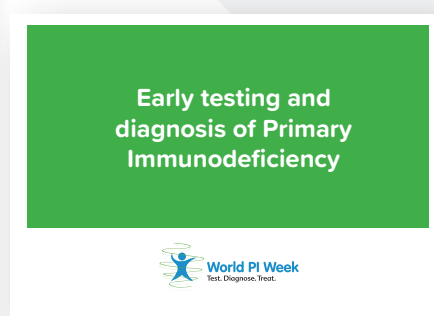
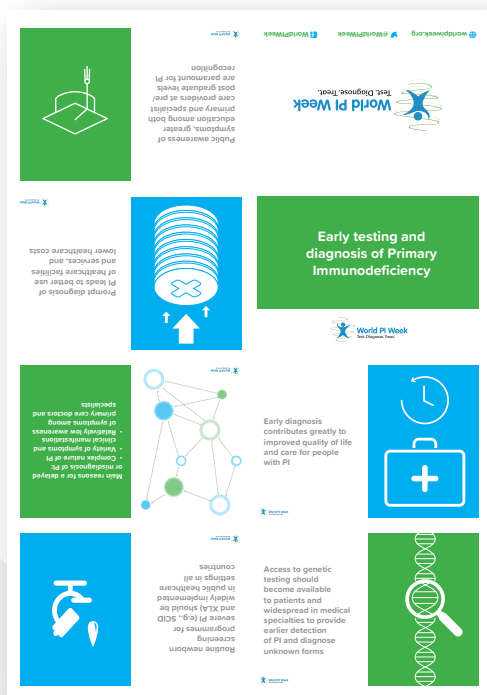
Andrew Thomas

United Kingdom

World PI Week video – available in 7 languages



Brochure on early testing and diagnosis



Infographic - 6 key messages on immunoglobulin therapies

