



Medical Awareness Toolkit

Contents

Key considerations 3

About World PI Week	3
Why raising awareness of primary immunodeficiency amongst the medical community?	3
How to raise medical awareness?	3

Resources 5

WHO Essential Medicines Lists.....	5
World PI Week editorials	6
World PI Week video – available in 7 languages	7
Brochure on early testing and diagnosis	7
Infographic - 6 key messages on immunoglobulin therapies.....	8
Key statistics and additional resources.....	9

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

Why raising awareness of primary immunodeficiency amongst the medical community?

Awareness-raising and informing about primary immunodeficiency to healthcare professionals will **help ensure earlier diagnosis and help identify proper treatments and care**. The primary healthcare providers, such as paediatricians and general practitioners are the first entry point for patients to help make a proper diagnosis, and are key players in the care pathway. Increasing awareness of primary immunodeficiency will improve knowledge about the different forms of primary immunodeficiency, warning signs and facilitate referral to specialists. In addition, **the voice of healthcare professionals is a strong complement of the patients' voice to make improvements in healthcare systems** happen when engaging with policymakers.

How to raise medical awareness?

There are various ways to inform medical audiences about primary immunodeficiency and raise awareness of related challenges. Whether you are a patient, a healthcare professional yourself or a family carer, this can be done via lectures and talks at scientific conferences or medical congresses, distributing educative materials about primary immunodeficiency (flyers, infographics) in hospital settings or at scientific conferences and congresses, writing pieces in scientific journals, sharing information on social media, disseminating information materials in medical universities and for post-graduate medical students etc

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





IDEAS TO RAISE AWARENESS

- » Get in contact with the primary immunodeficiency society or paediatric society
- » Offer to bring the patient perspective in a symposium
- » Visits of paediatricians and lung specialists in hospitals or medical schools/universities
- » Distribution of awareness materials in hospitals and pharmacies and instructions for referral to the division of Immunology of the hospital.
- » Printing posters and brochures for circulation in doctor rooms, clinics and hospitals
- » Distribution of primary immunodeficiency leaflet to members of patient organisations to distribute to their family doctors, distribution to lung specialists, ear-nose-throat specialists and gastroenterologists.
- » Organization and establishment of a primary immunodeficiency committee in the hospital, with involvement of paediatricians, haematologists and immunologists
- » Get in contact with your local or national immunodeficiency society or your local or national immunodeficiency foundation to find out how you can participate in initiatives, help disseminate information and become further involved

Scientific symposiums

- » (Web streamed) scientific conference with a group of physicians on World PI Week in hospitals
- » Webinar on primary immunodeficiency by experts aimed to a healthcare professional audience
- » A scientific symposium to discuss clinical, diagnostic and therapeutic tools for primary immunodeficiency (including case discussions and a summary of the research in primary immunodeficiency)

Consensus meetings

- » Joint patient/medical event: the objective is to brief and bring awareness of primary immunodeficiency to local community and to the medical world
- » Consensus Meeting on primary immunodeficiency in the country. Meeting dedicated to primary immunodeficiency will bring Immunologists to discuss further on the disease, cases & developments; bring other target groups (paediatricians etc.) to increase awareness; initiate the establishment of national treatment guidelines; help understanding country treatment levels better
- » Regional meetings powered by key opinion leaders and local physicians to a target group (general practitioner, Family Medicine Specialist, Internist, Paediatricians etc.) in selected regions where there are no immunologists



The World PI Week website provides materials to raise awareness of primary immunodeficiency. It is a multimedia toolbox for primary immunodeficiency awareness.



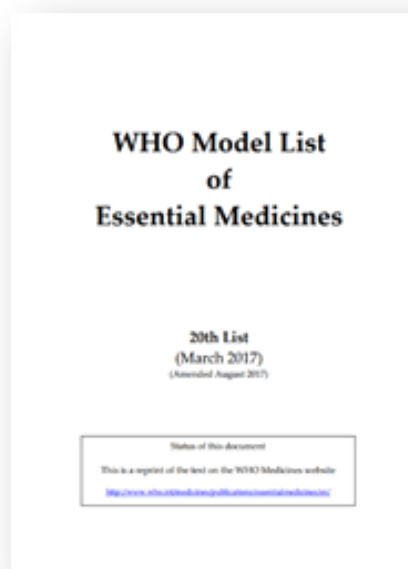
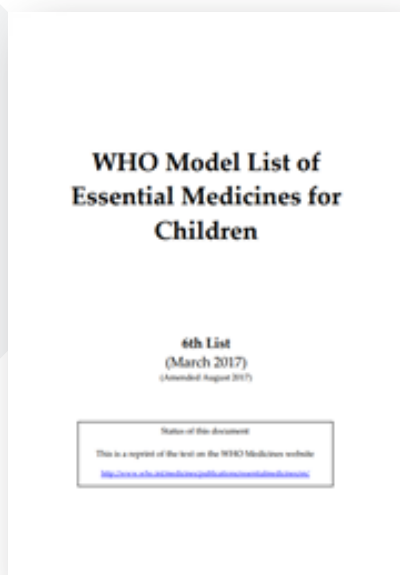
Download the toolbox here



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

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.



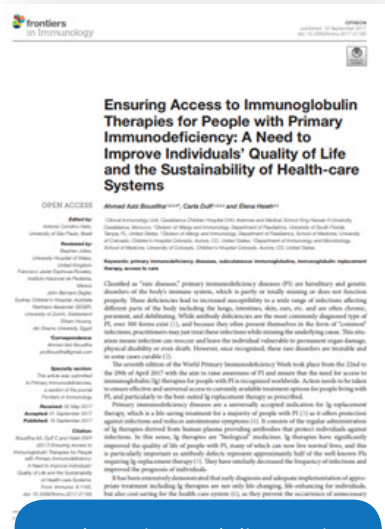


World PI Week editorials

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.



Early testing and diagnostic



Early testing and diagnostic



Access to optimum care



Vaccination and primary Immunodeficiency



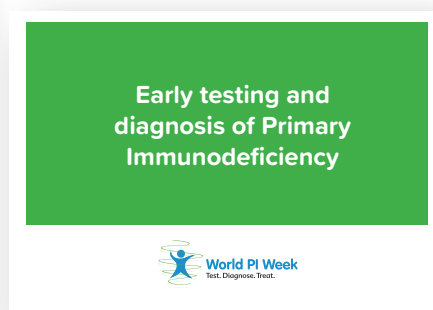
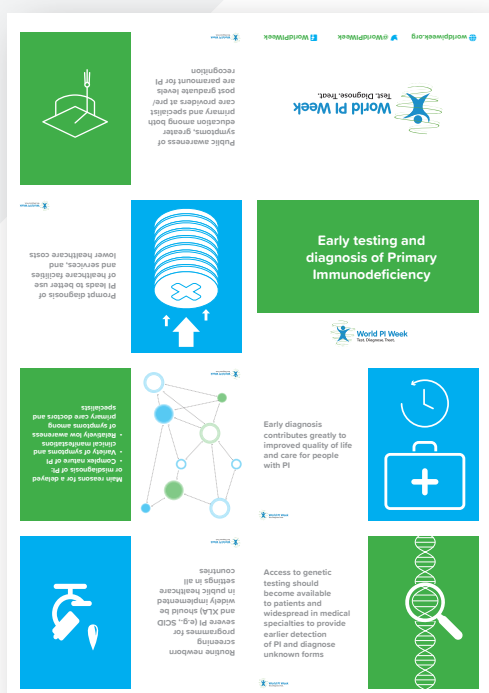
New-born screening for severe primary immunodeficiencies



World PI Week video – available in 7 languages



Brochure on early testing and diagnosis





Infographic - 6 key messages on immunoglobulin therapies





Key statistics and additional resources

INTERNATIONAL

- + [Inborn Errors of Immunity \(IEI\) Classification Table](#)
- + [2017 International Union of Immunological Societies \(IUIS\) Phenotypic Classification for primary Immunodeficiencies](#)
- + [IPOprimary immunodeficiency PID Map - Country data on estimated number of patients, availability of diagnostics, SCID newborn screening, treatment options\)](#)
- + [International Patient Organisation for primary Immunodeficiencies \(IPOprimary immunodeficiency\) publications](#)
- + [Jeffrey Modell Foundation - Physician Education Materials](#)

EUROPE

- + [European Society for Immunodeficiencies \(ESID\) Registry - List of diseases and genes](#)
- + [European Federation of Immunological Societies \(EFIS\)](#)

AMERICA - CANADA

- + [Immune Deficiency Foundation \(IDF\) Resource Centre for healthcare professionals](#)
- + [American Academy of Allergy, Asthma & Immunology \(AAAAI\)- PID resources](#)
- + [Clinical Immunology Society \(CIS\) resources](#)
- + [Latin American Society for Immunodeficiencies \(LASID\) resources](#)
- + [Immunodeficiency Canada - resources for healthcare professionals](#)

AFRICA

- + [African Society for Immunodeficiencies \(ASID\) resources](#)
- + [Arab Society for primary Immunodeficiencies \(ARAPID\) resources](#)

ASIA - INDIA

- + [Asia Pacific Society for Immunodeficiencies](#)
- + [Primary Immunodeficiency Database in Japan](#)
- + [Indian Society for Primary Immune Deficiency \(ISPID\) resources](#)