

When Primary Immunodeficiency awareness and political advances meet

Public and Government eyes on Primary Immunodeficiency (PI) during World PI Week 2017 leads to political action

Brussels, Belgium, 17th July 2017 - Intravenous immunoglobulin (IVIG), a life-saving treatment for a majority of people with Primary Immunodeficiencies (PI) added as treatment for PI in the list of essential medicines in Mexico, extensive media coverage of PI in Malaysia and PI being included in the national list of rare diseases in India... here comes the success of the 2017 edition of the World PI Week global awareness-raising campaign.

From the 22nd to 29th of April, the Primary Immunodeficiency community celebrated “[World Primary Immunodeficiency Week](#)” (WPIW) 2017 under the theme “*ensuring access to immunoglobulin (Ig) therapies for people with PI*”. Patients, family carers, physicians, nurses, scientists, policy-makers and pharmaceutical industry joined forces for the seventh consecutive year to hold awareness-raising activities across five continents, with the aim, this year, to drive attention to the need for ensuring access to safe and effective Ig therapies in all countries. Over 48 countries participated to draw attention to primary immunodeficiency diseases and access to life-saving immunoglobulin replacement therapy.

A Sampling of Successes around the World:

In **Mexico**, intravenous immunoglobulin (IVIG) replacement therapy was included in the national list of essential medicines of the Mexican Social Security Institute (IMSS) as treatment for PI on the 18th of May. IVIG is now officially recognised as a priority medicine, meeting the health care needs of people with PI and paving the way for better access to treatments in the country. This occurred as a result of the [Mexican Foundation for Children with PI \(Fumeni\)](#) organizing a medical symposium on PI in adults, in partnership with the IMSS, presenting the epidemiology and the economic impact of PI in the Mexico. This meeting came along with other awareness raising activities including a [press conference about PI paediatric care](#) during which physicians, parents and children with PI gave voice to the patients’ needs in the presence of the local government.

The **Malaysian** Patient Organization of Primary Immunodeficiencies ([MyPOPI](#)) conducted massive public awareness activities at community-level, with broad press coverage. “PI roadshow” were organised in universities and shopping malls to drive attention to PI across the country. Malaysian leading English newspaper “The Star,” with a reach of 1.41 million readers, featured PI in Malaysia for the first time.

In **India**, primary immunodeficiency diseases were included in the national list of rare diseases, a key step in the recognition of this group of over 300 inherited conditions which result in a defect in the body’s immune system, causing increased susceptibility to infections. This resulted from the advocacy of the Indian Patients Society for Primary Immunodeficiency (IPSPI) and national rare diseases organisations advocating for a national policy on rare diseases toward the Government during World PI Week.

But [the list of successful stories does not stop here](#). National PI organisations across the globe joined by many partners championed the PI cause during World PI Week 2017, with the aim to drive public and political leadership to improve the diagnosis, treatment and quality of life of people with PI, estimated to be over six million worldwide.



About Primary Immunodeficiencies:

Primary immunodeficiencies (PI) are a large and growing group of more than 300 disorders caused by some form of deficiency of the immune system, increasing one’s susceptibility to infections. PI are generally recognised as rare disorders but some are more common than others, and it is estimated that six million people worldwide live with a PI. When PI are left underdiagnosed or are misdiagnosed, the immune system remains defective, leaving the patient vulnerable to illness, physical disability, vital and permanent organ damage, or even death. [More information on PI.](#)

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