



Test. Diagnose. Treat

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

22nd – 29th April 2017

Raising Awareness for Diagnosis and

Treatment of PI Together!



CALL TO ACTION

We must ensure access to life-saving Immunoglobulin Therapies for People with Primary Immunodeficiency

In 2017, we, the PI Community, raise our voices to call for assured access to life-saving immunoglobulin therapies for people with PI.

We call on policymakers, health authorities, payers and healthcare professionals to put in place the relevant mechanisms to ensure that all people with PI throughout the world have access to safe, efficient and appropriate treatment options which will reduce mortality and morbidity and allow a better quality of life.

Classified as “rare diseases”, primary immunodeficiency diseases (PI) are hereditary and genetic disorders of the body's immune system which is partly or totally missing, or does not function properly. These deficiencies lead to increased susceptibility to a wide range of infections affecting different parts of the body including the skin, ears, lungs, intestines, etc; and are often chronic, persistent, and debilitating. While antibody deficiencies are the most commonly diagnosed type of PI, over 300 forms exist, and because they often present themselves in the form of “common” infections, practitioners may just treat these infections while missing the underlying cause. This situation means infection can reoccur and leave the individual vulnerable to permanent organ damage, physical disability or even death. However, once recognized, these rare disorders are treatable and in some cases curable.

Despite life-saving treatments have been developed over the past decades, availability and access vary significantly across regions of the world but also across countries of the same region.





Together, the PI Community urges policy-makers, health authorities and healthcare funders to address the barriers that prevent access to the best suited immunoglobulin replacement therapy for each individual with PI, and especially by:

1. **Putting in place adequate funding systems to ensure the availability of Ig therapies, including:**
 - **appropriate supply of immunoglobulins on the national healthcare systems and proper reimbursement of the therapies** to ensure equal access for all individuals
 - **introduction of alternative funding schemes** to guaranty the availability of several Ig therapies

2. **Ensuring optimal dosing of Ig therapy replacement** to enhance patients' quality of life, avoid further organ damage and save related costs to the healthcare systems:
Treatment strategies shall be individualised and a personalised regimen (dosage and treatment route) must be developed for each patient and modified as necessary to achieve treatment goals and meet the needs of each person, taking into consideration possible disease-associated complications.

3. **Giving primary consideration to the supply of immunoglobulin therapies for people with PI:**
As Immunoglobulin therapy remain the main and only treatment option for most people with PI, national clinical guidelines for immunoglobulin use shall recommend administration to people with PI and prioritize indications giving primary consideration to PI.

4. **Incentivise initiatives including awareness-raising campaigns addressed to the general public for voluntary plasma and/or blood donations,** considering that Ig supply is dependent upon plasma availability.