



Improving Access to Care for Patients with Primary Immunodeficiency

22nd - 29th April 2016
Test - Diagnose - Treat



CALL TO ACTION

World PI Week 2016: Improving Access to Care for patients with Primary Immunodeficiency.

Primary Immunodeficiency (PI) is a growing category of 300 different disorders resulting from some form of deficiency of the immune system. Primary Immunodeficiency can, if not treated, be chronic, serious and even fatal. Many PI disorders are considered 'rare diseases' which has meant that diagnosis and treatment have historically been difficult, but thanks to research and medical progress over the last 60 years, many of these conditions are now treatable. Yet because symptoms are similar to common and recurrent infections, PI often remain undiagnosed, misdiagnosed, or is diagnosed at a late stage.

In addition, despite life-saving treatments having been developed, access to care varies significantly across continents and even countries of the same region.

This year, we are raising our voices to call on policymakers, health authorities and healthcare funders to put in place the relevant mechanisms to ensure that all PI patients have access to safe, efficient and appropriate treatments and optimum care throughout the world.



European Federation of Immunological Societies





More specifically, we call on Governments, health authorities and payers to :

1. **Make immunoglobulin replacement therapies available to all PI patients by:**
 - **Putting in place funding mechanisms to ensure availability of several Ig products** to enable wide access to appropriate therapies.
 - **Ensuring optimal dosing of Ig therapy replacement** to enhance patients' quality of life, avoid further organ damage and save costs.
2. **Provide access to Hematopoietic Stem Cell Transplantation (HSCT) or gene therapy to Severe Combined Immune Deficiency (SCID) and other severe primary immunodeficiency patients**
3. **Ensure access to early diagnosis and quality specialist care by:**
 - **Setting up regional specialist centers** to enable equitable geographical access to medical and nursing expertise in these diseases
 - **Promoting expert treatment centers** with dedicated nursing staff to avoid side effects due to incorrect infusion techniques
 - **Putting in place patient registries** to help assessing the prevalence and incidence of PI
 - **Promoting professional networks** to peer-review specialist centers, patient registries, establish guidelines and raise standards of care.
 - **Establishing coordinated pathways to guide pediatric patients towards adult services** to ensure adequate planned transitional care.
4. **Ensure increased availability of immunoglobulin replacement therapies, HSCT and additional antimicrobial measures in developing countries by:**
 - **Establishing international collaboration mechanisms** to ensure countries lacking the financial or technical infrastructure can provide the necessary treatment through collaboration with established reference centers.
 - **Setting up international patient registries** to provide information to centers in countries in which there are no national networks.
 - **Promoting online networks** to discuss clinical cases and support physicians living far from specialized centers.
 - **Building appropriate facilities and providing expert training** to ensure a more efficient management of health care resources in developing countries (currently many SCID patients have to travel to developed countries for a BMT)
 - **Developing services for diagnosis and treatment alongside facilities for diagnosis and monitoring of HIV patients** or locate them with immunization centers, in countries where HIV is a pandemic disease.