



Primary Immunodeficiencies (PI) – Call to Action - Driving Diagnosis for Optimal Care

WHO WE ARE: We are representing the Primary Immunodeficiency (PI) Community in Africa and Worldwide. The **Jeffrey Modell Foundation** (JMF - www.info4pi.org), a global organization dedicated to early and precise diagnosis, meaningful treatments, and ultimately cures of Primary Immunodeficiencies together with the **African Society for Immunodeficiencies**(ASID - <http://www.asid.ma>) a society that has placed Africa solidly in the concert of nations that understand and promote the knowledge and treatment of Primary Immunodeficiencies.

OUR GOAL: The PI Community DOES NOT seek financial contribution from the governments of Africa. **Our goal is to encourage the recognition and prioritization of PI at the national government level.** The PI Community requests the support, encouragement and guidance of the governments of Africa on steps that can be taken to assure understanding, earliest possible diagnosis, appropriate treatment, physician education and public awareness of Primary Immunodeficiency diseases in their respective countries.

This initiative builds on the success of a dedicated “Call to Action” campaign in the European Union in April 2010 and Latin America in October 2011. These initiatives have been endorsed and signed by EU and Latin American decision makers including the Members of the European Parliament, the European Commission, the European Member States, Health Ministers in Latin America.

ABOUT PRIMARY IMMUNODEFICIENCIES (PI):

Primary Immunodeficiencies (PI) are hereditary and genetic defects in the immune system that cause increased susceptibility to a wide range of infections, affecting the skin, the ears, the lungs, the intestines and other parts of the body. These infections are often chronic, persistent, recurring, debilitating, and in some cases, fatal. To date, more than 200 specific conditions have been identified.

There are a significant number of un-diagnosed and under-diagnosed patients with PI in Africa. If PI is not diagnosed, the immune system is compromised leading to chronic illness, disability, reduced working capacity, permanent organ damage or even death. In undiagnosed or misdiagnosed patients, treatments are focused on the frequent and long term use of high dose antibiotics. Improved diagnosis of PI could therefore have a positive impact on the reduction in use of antibiotics, better use of health facilities and a better quality of life for patients and their families.

THE SIZE OF THE PROBLEM:

Experts estimate that between 70–90% of all PI patients remain undiagnosed, and the true incidence of PI within the general population could be as high as 1:250-500 [*Prof. L. Notorangelo and Prof. L. Hammarstrom presenting to European Parliament Scientific and Technological Assessment Unit, March 2004*]. The condition is more common than childhood Leukemia and Lymphoma combined, and four times the incidence of Cystic Fibrosis.

A recent peer-reviewed study documenting the financial impact associated with early diagnosis and management of PI found that each undiagnosed patient with an underlying PI costs the healthcare system an average of \$138,760USD annually. After diagnosis and treatment the average cost to the healthcare system is \$30,297USD annually; yielding an average savings of \$108,462USD per patient per year. (<http://www.springerlink.com/>)

WHAT AFRICA CAN DO:

The unnecessary suffering and subsequent burden that PI places on already over-stretched healthcare systems has already been recognized by the US Congress, CDC, NIH, and the European Union Committee of Experts on Rare Diseases. A dialogue between government decision-makers and the medical and patient community is urgently needed in the African region which will drive better recognition and optimal diagnosis and treatment of these devastating diseases. Such community action will serve to address the significant disparity of care within and across African countries, alleviate patient suffering and free up hospital resources.



Primary Immunodeficiencies (PI) in Africa

A Call to Action

AIMS AND OBJECTIVES

The African Primary Immunodeficiency Community including the Jeffrey Modell Foundation (JMF) and the African Society for Immunodeficiencies (ASID)) invite African governments to **endorse and sign** the following Primary Immunodeficiencies (PI) **Call to Action**. We call on Africa's governments to take heed of these devastating and under-diagnosed diseases by developing national strategies that address PI.

We encourage governments to consider the following components when developing future disease strategies and rare disease plans which offers **guidance** on the **steps** that can be taken to understand, appropriately diagnose and treat PI and increase public awareness of PI in their respective countries.

A.F.R.I.C.A. 5 Point Plan

Appropriate awareness raising for Primary Immunodeficiencies (PI):

- Encourage and support governments to implement targeted campaigns to increase recognition of PI amongst the medical profession, parents, schools, researchers and nurses, with the objective to increase understanding of the disease, knowledge of the '10 Warning Signs', SPUR and available testing methods and treatments.

Foster Education of Health Professionals:

- Work together with medical specialist's organizations, such as ASID and academia, to encourage and support basic and applied immunology teaching into educational programs for medical students, generalists, pediatricians, and subspecialists including: rheumatologists, pulmonologists, neonatologists and nurses.
- Develop initiatives to allow the exchange of expertise and education, including networking with immunology centers and representatives in other countries.

Research, Data Collection and Collaboration:

- Encourage input into the ASID Registry, which will enable future processes to improve diagnosis and treatment through networking.
- Continue to expand Centers of Excellence with advanced technology to promote best practice in terms of disease classification, treatment outcome measures, assessment of costs, and an integrated approach to PI recognition throughout Africa.
- Establish and encourage a working network in each of the African countries, bringing together the best quality research and care in both the public and private healthcare systems.

Identify through Early Diagnosis and Screening:

- Encourage and support African countries to develop clinical protocols to reliably identify all forms of PI.
- Support availability of specialized testing facilities to ensure provision of wide-spread use of simple diagnostic tests for PI at regional level.
- Support implementation of newborn screening programs ensuring better coverage for screening/diagnostic tests by both governmental and private health plans.



Comprehensive and Appropriate Treatment:

- Encourage the development of Centers of Excellence with advanced technology and regional services specialized in the care of PI patients.
- Encourage African governments to facilitate an equal access to adequate support services both in the public and private hospital systems; as well as choice of site of care, whether it is in hospital, or clinic, physician office, or home.
- Ensure the inclusion of PI in the list of standard of care programs.
- Encourage and secure high quality supply of human plasma and safe and appropriate immunoglobulin treatments (including: intravenous (IV), Ig, or Subcutaneous (Sub-Q) Ig).
- Encourage African governments to develop and utilize a standard VIS (Vaccination Information Sheet), to reduce potential adverse events in the childhood vaccination program.
- Ensure appropriate reimbursement for life sustaining, lifesaving treatments.

for... **AFRICA**

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