

GLOBAL CALL TO ACTION ON PRIMARY IMMUNODEFICIENCY

The Primary Immunodeficiency (PI) Call to Action offers guidance for governments on the steps they can take to understand, appropriately diagnose and manage primary immunodeficiency diseases in their respective countries, to improve patients' quality of life.

The primary immunodeficiency community calls upon countries across the world to recognize and take heed of these rare and under-diagnosed diseases by developing national strategies that address primary immunodeficiency. We encourage governments to consider the following components when developing future disease strategies and rare disease plans:

Raising Awareness on Primary Immunodeficiencies

Encourage and support governments to implement targeted campaigns to increase recognition of primary immunodeficiency amongst the medical profession, parents, schools, day care centre employees, researchers and nurses, with the objective to increase understanding of the disease, knowledge of the warning signs and available testing methods and treatments.

Education of Health Professionals and Expertise Exchange

Work together with medical specialists organisations (e.g. APSID, ARAPID, ASID, LASID, CIS, EFIS, ESID, INGID, SEAPID, UEMS, etc) and academia to encourage and support individual countries to: provide standards for basic and applied immunology training, with emphasis on primary immunodeficiency, in the education programmes for general practitioners and nurses; integrate basic and applied immunology teaching, particularly alongside immunisation, into specialised programmes for training fellows in general paediatric internal medicine, rheumatology, respiratory medicine, and infectious diseases; develop cross country initiatives to allow the exchange of expert experience and education, including capacity to network and funding of visits of immunology centres representatives in other countries.

Early Diagnosis and Screening

- Support the development of clinical protocols to reliably identify all forms of primary immunodeficiency;
- Support the development of simple diagnostic tests for PI and promote such tests for use widely;
- Support the development and implementation of neonatal (newborn) screening for severe combined immunodeficiency;
- Promote the creation of international guidance for the recognition of symptomatic patients and ensure appropriate immunologic and genetic laboratory tests are available at national level via centres of excellence;
- Promote the creation and support of patient registries that can provide support for patients and also scientific insights into the make-up of primary immunodeficiency;
- Promote transnational research into the feasibility of screening programmes to ensure early detection;
- Promote funding research into better understanding of primary immunodeficiency to improve diagnosis and the management of the conditions and general understanding of the immune system

Gathering Knowledge and Data

- Provide funding to conduct epidemiological studies to assess the prevalence and incidence of primary immunodeficiency;
- Encourage the creation of and input into international registries which will enable future diagnostic processes;
- Create national or regional primary immunodeficiency patient registry;
- Encourage transnational, research and remove the administrative obstacles to multinational clinical trials;

- Establish Centres of Reference to promote best practice in terms of disease classification, treatment outcome measures, assessment of cost of treatments for an integrated approach to primary immunodeficiency recognition and treatment.

Comprehensive and Adequate Treatment

- Ensure access to treatment for people with primary immunodeficiency as it has been shown to prevent and improve chronic disease, improve social well-being and reduce the burden of the disease both on individuals, families and healthcare systems;
- Ensure that safe immunoglobulin treatments are available to all patients who require antibody replacement; and ensure the adequate and high quality supply of human plasma;
- Recognise the social needs of primary immunodeficiency patients and their families and facilitate access to adequate support services, as well as the coordination of health and social care services;
- Ensure the reimbursement of orphan drugs according to their medical efficacy for the patient and not according to the price of the product.

About the Call to action

This United Call to Action was developed by the primary immunodeficiency community in 2010 and updated in 2019 to reflect new realities. With over 1,600 signatures of support to date, it provides a common perspective on unmet needs in primary immunodeficiency globally and opportunities for change, with the understanding that countries and regions of the world have additional specificities.

