

Press Release

São Paulo, Brazil, 5 Oct 2017

Primary immunodeficiencies in Latin America Call to Action: Equal access to lifesaving treatments

The Latin American patients with Primary Immunodeficiencies (PIDs) and health care professionals' community have launched a **Call to Action** calling Governments to improve the quality of life of PID patients through access to life-saving treatments and equal care across the region. They held a meeting during the Latin American Society for Immunodeficiencies (LASID) Congress, São Paulo, Brazil, on 5-6 October 2017, and took collaborative action to address the urgent needs of PID patients in the region. The National Patient Organisations in Latin America will address this Call to Action to their national governments urging them to develop supportive health policies for the care of PID patients across the region.

The Call to Action highlights the urgent and essential needs of PID patients that are yet to be met by the health authorities in Latin American countries. The document states the following crucial priorities to be implemented by the governments:

- *Early detection and diagnosis* through clinical protocols, reference networks and newborn screening programmes
- *Adequate and sustained treatment* through availability and access of treatment options such as immunoglobulins, antibiotic and anti-fungal prophylaxis, and including PIDs in social security and health insurance schemes
- *Education of healthcare professionals* by including PIDs in the Medical Doctors' and nurses' curricula and through collaboration with medical societies
- *Promotion of research and data gathering* by implementing national PID registries, expanding the number of reference centres and supporting collaboration among medical professionals
- *PID awareness* by supporting campaigns of the PID community and spreading the availability of diagnostic and therapeutic methods.

"The PID Community in Latin America prepared this Call to Action in the hope of bringing the most important challenges and steps that need to be taken to Governments' attention so that patients in Latin America can have a better quality of life. The patient community calls upon decision makers to implement these urgent and essential steps!"

Roberta Anido de Pena, President of Argentinean Patient Organisation AAPIDP and a mother of a PID patient.

"The Latin American Society of Primary Immunodeficiencies fully supports this Call to Action for the benefit of patients with primary immunodeficiencies and their families. Ultimately our aim is to increase diagnosis rate, improve treatment and reduce the burden of disease. We truly hope our governments take seriously this cause and join us in this action"

Prof. Antonio Condino-Neto, President of Latin American Society of Primary Immunodeficiencies LASID.

"The International Nursing Group for Primary Immunodeficiencies offers its full support towards this Call to Action. Our goal is to provide education and support to nurses caring for patients with primary immunodeficiencies. Our hope is that this Call to Action will aid in the diagnosis and treatment of patients living with primary immunodeficiencies in Latin America."

Carla Duff, Nurse practitioner, President of International Nursing Group for Primary Immunodeficiencies INGID

Primary immunodeficiencies (PIDs) are a large and growing group of over 350 different disorders caused when some components of the immune system do not work properly. When not diagnosed and treated accurately, people with PIDs suffer from recurrent and severe infections, and are often treated for them instead of the underlying cause. This takes a toll on both patients' quality of life but also the government budgets. In Latin America, around 125,000 people have their lives impacted by these chronic conditions. **Still 80% of people with PIDs remain undiagnosed and untreated.**

To read and sign the Call to Action, visit [<http://chn.ge/2yDvyS3>]

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