

PRESS RELEASE

PIDs included in WHO List of Essential Diagnostic Tests

Cornwall, UK

July 10, 2019

FOR IMMEDIATE RELEASE

Primary immunodeficiency (PID) diagnostic tests have been included in the World Health Organization (WHO)'s Essential Diagnostics List (EDL) published by WHO on July 9, 2019. The inclusion of PID diagnostics tests follows a successful joint application by IPOPI and IUIS (International Union of Immunological Societies).

The second publication of the [Model List of Essential In Vitro Diagnostics*](#), also called Essential Diagnostics List (EDL), now includes a new disease specific section on primary immunodeficiencies (PIDs) as well as a mention of PIDs, in general, for clinical laboratory diagnosis.

The WHO Strategic Advisory Group on In Vitro Diagnostics (SAGE IVD) considered several diagnostic tests submitted by IPOPI and IUIS as important, including, white blood cell count, HIV 1/2 antibody (anti HIV Ab), immunoglobulin plasma levels (IgG, IgA and IgM) and Lymphocyte Subtype enumeration. Whilst some tests applied for by IPOPI and IUIS were not included at this stage and some tests will necessitate the submission of further evidence, this is a major step towards increased diagnosis of PIDs worldwide. This inclusion is also a great complement to the WHO List of Essential Medicines ([21st version recently published](#) and [7th version for children](#)) which includes immunoglobulin replacement therapy for the treatment of PIDs.

As diagnosis is the first step to timely access to treatment, a great advance has been made. IPOPI is committed to continue to work with the WHO as the EDL develops over the years, to ensure people living with a PID can be spared the diagnostic odyssey they too often have to face and its disastrous consequences. The more visibility we give to PIDs, the more we will diagnose and the more we will treat or even cure!

IPOPI wishes to thank Professor Helen Chapel, Professor Kathleen Sullivan, Professor Stuart Tangye, Dr Dilani Arnold, Dr Nizar Mahlaoui, Prof Surjit Singh, Dr Monika Esser, Dr Adli Ali, Dr Wim Dik and the many other medical experts for their precious help and support. We also wish to thank the professional societies and associations that have supported this joint application including the African Society for Immunodeficiencies, the Arab Society for Primary Immunodeficiencies, the Asia-Pacific Society for Immunodeficiencies, the Clinical Immunology Society, the European Reference Network for Immunodeficiency-Autoinflammatory-Autoimmune Diseases, the European Federation of Immunological Societies, the European Society for Immunodeficiencies, the Immune Deficiency Foundation, the International Plasma and Fractionation Association, the Jeffrey Modell Foundation, the Latin American Society for Immunodeficiencies, the Plasma Protein Therapeutics Association and the South East Asia Primary Immunodeficiency Network.

** The Essential Diagnostics List (EDL) recognizes that IVDs are essential for advancing universal health coverage, addressing health emergencies and promoting healthier populations. It is expected to provide guidance and serve as a reference for member states that are developing and/or updating national EDLs for interventions within universal health coverage and for selecting and using IVDs. It will also be informative for United Nations agencies and nongovernmental organizations that support selection, procurement, supply, donation or provision of IVDs and will inform the private medical technology sector about the diagnostic priorities and the IVDs necessary to address global health issues.*

About IPOPI: IPOPI is the leading advocate for primary immunodeficiencies' patients worldwide working in collaboration with patients, doctors, politicians, regulators, pharmaceutical industry and other relevant stakeholders. IPOPI is the Association of national PID patient organisations currently representing 67 countries.

More: www.ipopi.org, [Facebook](#), [Twitter](#)

Contact: IPOPI – Magda Lourenço, Communications Manager info@ipopi.org - T. +351 916174909