Letter of support to IPOPI's and IUIS’ application on in-vitro diagnostics for PIDs

As medical experts, researchers and scientific societies in the diagnosis and management of primary immunodeficiencies (PIDs) brought together by the International Patient Organisation for Primary Immunodeficiencies (IPOPI) and the International Union of Immunological Societies (IUIS), we would like to stress the vital importance of early diagnosis of persons living with PIDs in the world.

PIDs are a group of inherited and genetic defects of the immune system, when the latter is partly or totally missing or does not function properly. Persons with PIDs are more prone to a wide range of infections affecting different parts of the body. When left undiagnosed and untreated, PIDs are chronic, debilitating conditions and, in severe cases, they may lead to permanent organ damage and even death.

Early diagnosis is key to avoid a diagnostic odyssey that is distressing to the family, damaging to the patient and wasteful of health-care resources. We call upon the World Health Organisation to include the tests described in the application as essential in-vitro diagnostics. We strongly believe that such inclusion in the WHO list of essential in vitro diagnostic tests would greatly optimize access to essential PID diagnostics across continents and regions, thereby significantly improving the care of persons with PIDs throughout the world.

Signed

Johan Prévot
Executive Director
IPOPI

Prof Stuart Tangye
Chair
IUIS Expert Committee on Inborn Errors of Immunity
Supported by:

Dr Mehdi Adeli
President
Arab Society for Primary Immunodeficiencies (AraPID)

Dr Roshini Abraham
President
Clinical Immunology Society (CIS)

Prof Andrew J. Cant
ERN RITA Coordinator
European Reference Network for Immunodeficiency, Autoinflammatory and Autoimmune Diseases (ERN RITA)

Prof Andrew J Cant
President
European Society for Immunodeficiencies (ESID)

John G. Boyle  
President & CEO  
Immune Deficiency Foundation

Dr Paul Strengers  
Executive Director  
International Plasma and Fractionation Association (IPFA)

Vicki and Fred Modell  
Co-founders  
Jeffrey Modell Foundation (JMF)

Jan M Bult  
President and CEO  
Plasma Protein Therapeutics Association (PPTA)