

Highlights from the past 10 years

Celebrating successes in primary immunodeficiency over the past decade

2010



The US Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) casts unanimous vote to add SCID for universal screening of all newborns in the US



"Save immunity" is founded to support and represent people affected by primary immunodeficiencies in Belarus

2011



The Indian Society for Primary Immune Deficiency (ISPID) comes to life



The "Slovenian Society for patients with immune disorders" is founded to support and represent people affected by primary immunodeficiencies in Slovenia

2012



Taiwan starts implementing newborn screening for SCID



60th anniversary of the landmark paper by Dr. Bruton, credited as the recognition of the first human primary immunodeficiency and beginning of the modern era in the study of PI

2013



MyPOPI is setup to support and represent people affected by primary immunodeficiencies in Malaysia



First International Plasma Awareness Week to encourage plasma donation in support of people treated with plasma derived medicinal products such as immunoglobulin therapies for primary immunodeficiencies



Ontario is the first Canadian region to start implementing newborn screening for SCID

2014



U.S. Congress passes the Newborn Screening Saves Lives Reauthorization Act allowing states to receive assistance in improving and expanding their newborn screening programs



"PID Korea", "ThaiPOPI" and "Rare Immune Diseases" are founded to support and represent people affected by primary immunodeficiencies in Korea, Thailand and Ukraine

2015



The South East Asian Network of PID and the Arab Society for Primary Immunodeficiencies (ARAPID) are set up



Council of Europe adopts Resolution CM/Res(2015)2 on Principles regarding Immunoglobulin Therapies for Immunodeficiency and Other Diseases



Israel starts implementing newborn screening for SCID



"FIDEP Bolivia", "APIP", "ASDIP" and "Immunodeficit" are founded to support and represent people affected by primary immunodeficiencies in Bolivia, Puerto Rico, Senegal and Slovakia

2016



The Asia Pacific Society for Immunodeficiency (APSID) is launched followed by the International Alliance of Primary Immune Deficiency Societies (IAPIDS), as a global alliance of clinical immunology societies



The first ex-vivo stem cell gene therapy is authorised to treat patients with ADA-SCID in Europe



"Aspana IDP Paraguay" and "VietPIPS" are founded to support and represent people affected by primary immunodeficiencies in Paraguay and Vietnam

2017



Iceland is the first European country to screen universally for SCID

New Zealand and the region of Catalunya in Spain start implementing newborn screening for SCID



The European Network on rare primary immunodeficiency, autoinflammatory and autoimmune diseases (ERN RITA) is launched to harmonize diagnostic and therapeutic guidelines across Europe, resulting in access to diagnostic tests and therapies



The PID Genius companion app, a personal assistant to PID patients, is launched to support patients manage their health information



The first 10 Warning Sign Video for Primary Immunodeficiency produced and distributed in Canada is launched



"PID Care China", "Fundación Escudo de Amor para las IDP El Salvador" and "PhilPOPI" are founded to support and represent people affected by primary immunodeficiencies in China, El Salvador and Philippines

2018



Norway becomes the second European country implementing newborn screening for SCID



Stem Cell Transplantation for Immunodeficiencies in Europe registry (SCETIDE) now encompasses data on more than 4800 patients with SCID or other PIDs



All states of the United States perform newborn screening for SCID



Netherlands starts an implementation pilot study (SONNET) for newborn screening of SCID



All PID diagnoses have working definitions for clinical diagnosis and registration in the ESID Registry



"ARAY", "PIDs Kenya", "AtunDIP" are founded to support and represent primary immunodeficiency patients in Kazakhstan, Kenya and Tunisia

2019



Primary immunodeficiency diagnostic tests are added to the World Health Organization (WHO)'s Essential Diagnostics List



Rare diseases are included for the first time in the UN political declaration on universal health coverage



Switzerland together with Germany and Sweden start implementing newborn screening for SCID; Alberta becomes the 5th Canadian region to screen newborns for SCID



"ANIPIDP" is founded to support and represent primary immunodeficiency patients in Nicaragua

Together, bringing about change for primary immunodeficiency patients worldwide

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10 YEARS

World PI Week
TEST • DIAGNOSE • TREAT