

Global Resolution

Jeffrey Modell Centers Summit – June 8th -12th, 2016

275 Immunologists from Jeffrey Modell Diagnostic and Research Centers in 52 countries were brought together by the Jeffrey Modell Foundation for a four day Global Summit in Los Angeles, California, U.S.A. The physician experts, including two Nobel Laureates, represented the world's leadership and are authorities in the diagnosis, treatment and management of Primary Immunodeficiencies. At the conclusion of the Summit, the physicians agreed to the following guiding principles:

Whereas Primary Immunodeficiencies are defects of the immune system that cause severe, recurring and sometimes life threatening infections, if not diagnosed and treated appropriately.

Whereas Primary Immunodeficiencies are estimated to affect at least 1 - 2% of the world population.

Whereas experts have identified more than 300 specific genes that can cause serious Primary Immunodeficiency diseases.

Whereas infants born with Severe Combined Immunodeficiency (SCID) and related T cell Lymphopenia suffer from serious life threatening infections and will likely not survive their first year without curative treatment.

Whereas SCID can be screened using the TREC Assay which is inexpensive. This will identify the condition before irreversible organ damage or death, allowing children a chance to grow up and lead a normal life.

Whereas all 50 states in the United States, Navajo Nation, District of Columbia, Puerto Rico, Taiwan, Israel, and several provinces in Canada have implemented population based newborn SCID screening.

Whereas there is an existing global network of established, dedicated and specialized treatment centers for affected patients to be managed and receive care, which may include immunoglobulin therapy, bone marrow transplantation, gene therapy and emerging new treatments.

Resolved by the undersigned, calling for continuing encouragement and support of physician education and awareness of Primary Immunodeficiencies directed to physicians, health ministries and the public. This should include dissemination of the 10 Warning Signs of Primary Immunodeficiencies now available in more than 60 languages.

Resolved by the undersigned, calling for improved access to care, treatment and diagnostics for patients with Primary Immunodeficiencies.

Resolved by the undersigned, calling for implementation of newborn screening for Severe Combined Immunodeficiency (SCID) and related T cell Lymphopenia allowing newborn babies with SCID to be detected, treated and survive.

Resolved by the undersigned, calling for development and advancement of preventative and personalized medicine for patients with Primary Immunodeficiencies.

Resolved by the undersigned, calling for application of new technology to clinical care, identifying the gene causing disease and developing treatments for patients with Primary Immunodeficiencies.

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Please sign and scan back copy to Vanessa@jmfworld.org

NAME	CITY	COUNTRY

