Global Resolution
From the Jeffrey Modell Centers Network:
As of: November 2019

Whereas The Jeffrey Modell Centers Network consists of 821 expert physicians at 379 academic institutions, in 294 cities, and 86 countries, spanning 6 continents and growing.

Whereas the Network of expert physicians, including two Nobel Laureates, represents the world’s leadership as authorities in the diagnosis, treatment and management of Primary Immunodeficiencies.

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’s population.

Whereas experts have identified more than 400 specific defects described as a serious Primary Immunodeficiency disorder.

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 additional laboratory methods are still being developed, but, the current method of screening using the TREC Assay has the specificity and sensitivity to accurately identify affected newborns, with better than 99% accuracy.

Whereas the U.S. Secretary of Health and Human Services recommended that ALL newborns be screened for SCID and related T cell Lymphopenia, characterizing SCID screening using the TREC Assay as “The National Standard for Newborn Screening Programs”.

Whereas all 50 states in the United States, Navajo Nation, District of Columbia, and Puerto Rico have implemented population based newborn SCID screening, and more than 27 million babies have been screened to date.

Whereas 22 countries are currently conducting population based SCID screening or piloting in select areas of the countries.

Whereas there is an existing global network of established, dedicated and specialized treatment centers for affected patients to be expertly managed and receive appropriate care, which may include immunoglobulin therapy, stem cell transplantation, gene therapy and emerging new treatments.
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Resolved by the undersigned, calling for continuing encouragement and support of physician education and public awareness relating to all Primary Immunodeficiencies that should be directed to physicians, health officials 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 for diagnosis and clinical care, including genetic sequencing, identifying the genes causing disease and developing treatments for patients with Primary Immunodeficiencies.