February 24, 2014

Representative Heather Carter
Committee on Health
Arizona House of Representatives
Phoenix, AZ 85007

RE: Support for HB 2491

Dear Chairwoman Carter:

Founded in 1980, the Immune Deficiency Foundation (IDF) is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education, and research. These diseases occur in persons born with an immune system that is either absent or hampered in its ability to function. These diseases are caused by hereditary or genetic defects and can affect anyone, regardless of age or sex. The World Health Organization recognizes more than 185 primary immunodeficiency diseases. Severe Combined Immune Deficiency (SCID) is one of the rarest and the most devastating of these diseases.

Thank you for introducing HB 2491, an act amending section 36-694, Arizona revised statutes; relating to the newborn screening program. HB 2491 includes a provision that would allow the department of health services to adopt rules regarding adding severe combined immunodeficiency testing to the newborn screening program and requires the department to perform a cost analysis on the addition of SCID screening.

Infants affected by SCID lack T lymphocytes, the white blood cells that help resist infections due to a wide array of viruses, bacteria and fungi. These genetic defects lead to extreme susceptibility to serious illness. As a result, the condition is fatal in infancy unless treated, usually with bone marrow transplantation. Transplants done in the first months of life have the highest success rate. A survey of more than 150 patients commissioned by IDF found that SCID patients who were diagnosed early and treated by 3.5 months had a 91% survival rate; those treated after 3.5 months had a 76% survival rate. If diagnosis is late, even a successful bone marrow transplant can still leave a patient with persistent health problems. The diagnosis of SCID very early in life is a true pediatric emergency, and the decision to screen for SCID will literally save the lives of infants in Arizona.

SCID screening in newborns became possible just a few years ago with the development of the TREC test that can detect SCID in the dried blood spot filter cards that are currently collected from all babies to screen for a variety of inborn conditions. The Secretary of Health and Human Services, Kathleen Sebelius, recognized the need to take action toward ensuring the health of these babies by adding SCID to the Recommended Uniform Screening Panel in May 2010.

Eighteen states and the Navajo Nation have already implemented newborn screening for SCID. Based on the screening done in these states, SCID is estimated to occur in approximately 1 in 40,000 to 1 in 70,000 births. Native American populations, especially those of Athabascan origin, have the highest incidence in the world for SCID, and Arizona has one of the highest Native American and Athabascan populations in the United States. While babies born on the Navajo Reservation have been tested for the disorder since 2006, one-third of Native American babies are born in surrounding cities, not on the reservation according to the Indian Health Services. Arizona babies will be best served by implementation of this test universally. Newborn screening has led to the identification and treatment of dozens of infants with SCID and many more with other kinds of T lymphocyte
deficiencies in those states that are screening. All of these babies will now have the opportunity for early treatment and the chance of a normal, healthy life because they had early detection.

Thank you again for your introduction of HB 2491 and for your support of Arizona’s most vulnerable individuals.

For more information about SCID and newborn screening, please see our website at http://primaryimmune.org/idf-advocacy-center/idf-scid-newborn-screening-campaign/. Should you have any questions please contact Emily Hovermale, Director of Public Policy, at 443-632-2544 or at ehovermale@primaryimmune.org.

Sincerely,

Marcia Boyle
President & Founder