

September 17, 2013

Michael Glass  
Director, Newborn Screening  
Washington State Department of Health

**RE: Support for Amendment to Chapter 246-650 WAC Newborn Screening**

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.

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 Washington

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. In February 2012, the Washington Newborn Screening Advisory Committee concurred with the federal endorsement and voted to recommend the inclusion of SCID on the Washington newborn screening panel.

Sixteen states and the territory of 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. According to the Washington Department of Health, there are approximately 85,700 births per year in the state. That means one to two babies are likely to be born every year with this condition in Washington. Currently, these children have little chance at an early diagnosis and treatment. 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.

**IDF supports the amendment to Chapter 246-650 WAC Newborn Screening to add SCID to the list of mandatory conditions for newborn screening conducted by the Department of Health.**

Thank you for your time and consideration of this critical issue.

Sincerely,



Marcia Boyle  
President & Founder