March 4, 2014

Nebraska Department of Health and Human Services
Division of Public Health
Lincoln, NE 68509-5026

RE: Support for Amendment to Regulations found in Title 18, Chapter 2 of the Nebraska Administrative Code: Newborn Screening for SCID

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 200 primary immunodeficiency diseases. Severe Combined Immune Deficiency (SCID), also known as “bubble boy” disease, 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. 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 Nebraska.

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, thereby recommending that all states screen newborns for this devastating disease. In August 2011, the Nebraska Newborn Screening Advisory Committee concurred with the federal endorsement and voted to recommend the inclusion of SCID on the state newborn screening panel.

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. According to the Nebraska Department of Health and Human Services, there are approximately 26,000 births per year in the state. That means one baby is likely to be born every two years with this condition in Nebraska. 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 Regulations found in Title 18, Chapter 2 of the Nebraska Administrative Code: Newborn Screening for SCID

Thank you for your time and consideration of this critical issue. For more information about SCID and newborn screening, please see our website at http://primaryimmune.org/idf-advocacy-center/idf-scid-newborn-screening-campaign/.

Sincerely,

Marcia Boyle
President & Founder