NORTH DAKOTA
DEPARTMENT *of* HEALTH

NEWS RELEASE

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A Baby's First Test – The Answers Might Save a Life

BISMARCK, N.D. – The North Dakota Department of Health (NDDoH) is pleased to announce that July 1 marked an important step in saving the lives of babies born in North Dakota. The state newborn screening program expanded their newborn screening panel to include a disorder called Severe Combined Immune Deficiency (SCID).

SCID, also known as "Bubble Boy Syndrome," is a rare, but serious primary immune deficiency characterized by lack of a functioning immune system. Newborns with SCID often appear healthy at birth, but are at increased risk to develop infections that may become severe. If not identified early through newborn screening, babies with SCID often die by age 1. "Early detection and treatment saves lives and improves outcomes for SCID and all disorders included on the newborn screening panel," said Joyal Meyer, Newborn Screening Program Director.

Treatment for SCID includes a bone marrow transplant, which is often done within the first few months of life. "The five-year survival rate for infants diagnosed with SCID who receive treatment by three and a half months of age is approximately 94 percent," according to Dr. Chris Cleveland, Pediatric Immunologist at Sanford Health in Fargo and SCID Medical Consultant for NDDoH.

Newborn screening is done by taking a few drops of blood from a baby's heel 24 to 48 hours after birth. The blood is tested for 51 rare, but serious disorders. All of the disorders screened for can be treated, and most babies, if identified early, can grow up to be healthy with normal development.

The newborn screening program recently partnered with families to develop videos to help educate the public on the importance of testing. The main video can be found at https://youtu.be/weJAz9o74Cw.

For more information, contact Joyal Meyer, North Dakota Department of Health, at 701.328.2493.

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