



January 17, 2018

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James Eckman, MD, Chair
NBS and Genetics Advisory Committee
Georgia Public Health Laboratory
1749 Clairmont Road
Decatur in GA 30033

Re: NORD Support for Adding Spinal Muscular Atrophy (SMA) to the Georgia NBS Panel

Dear Chairman Eckman and Members of the NBS Advisory Committee:

On behalf of the 1-in-10 Georgians with one of the nearly 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes in support of adding Spinal Muscular Atrophy (SMA) to the State's Newborn Screening (NBS) panel. NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Spinal muscular atrophy (SMA) is a group of inherited disorder characterized by a debilitating loss of nerve cells in the spinal cord. The progressive effects of the various forms of this disorder are devastating, causing a weakening of basic motor functions that often leads to death. These effects can onset from birth which is why SMA is the leading genetic cause of death for infants. Fortunately, there is finally hope for families in the form of new treatments to improve motor functioning for patients with all types of SMA. Combined with successful pilot studies showing the effectiveness and reliability of newborn screening for SMA, it is now possible for states to ensure the rapid identification and treatment of this disorder in all births.

As you are well aware, the timely statewide adoption of newborn screening is vital to making this hope a reality. By adding SMA to its NBS panel, Georgia will be implementing a critical public health intervention to protect the approximately 1-in-11,000 newborns that will be affected by the forms of this disorder. NORD is ready to assist in this effort in any way we can. If there's further information that we can provide please do not hesitate to contact us.

Thank you for your consideration of this letter and your ongoing dedication to supporting the rare disease community in Georgia through the advancement of newborn screening.

Sincerely,

Tim Boyd, MPH
Director of State Policy