

**PRESS RELEASE**

**REPRESENTATIVE GREGORY F. MURPHY, M.D.**

9th House District

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**Lawmakers Expand Newborn Screening Panel to Cover Three Additional Abnormalities and Follow Federal Recommendations**

Representatives Greg Murphy, Josh Dobson, Nelson Dollar, David Lewis, Donny Lambeth, and Senator Ralph Hise are proud to announce that S99 will expand newborn screening testing to include Pompe disease, Mucopolysaccharidosis type 1 (MPS 1), and X-linked Adrenoleukodystrophy (X-ALD). Additionally, North Carolina’s newborn screening tests will continue to expand as the United States Department of Health and Human Services adds disorders to the federal Recommended Uniform Screening Panel (RUSP).

HIGHLIGHTS

-SB99 will add the following disorders to the North Carolina Newborn Screening Panel:

* Pompe disease
* Mucopolysaccharidosis type 1 (MPS 1)
* X-linked Adrenoleukodystrophy (X-ALD)

-Screening is not required when the parents or the guardian of the infant object to such screening.

*- “We are proud to announce that North Carolina will continue its legacy as a leader in Medicine,” said Rep. Greg Murphy, M.D. “We as a people value life and will continue to seek ways to make it healthier for everyone.”*

*- “I am proud to be a part of this effort to give every child the best possible chance at a healthy life,” said Rep. David Lewis.*

*- “Our daughter, Kirra, was diagnosed early with spinal muscular atrophy mainly because we knew she was at risk since two of our older children, Jocelyn and Nathan, had been diagnosed with SMA. Her treatment began soon after she was born. Watching the progress she has made is amazing. She is meeting all her milestones on time. Newborn screening would give all children born with SMA the same opportunity Kirra has gotten," said Jennifer Lee, SMA mom and advocate.*

*- “My diagnosis with MPS I took 38 years. I spent the majority of my life searching to find out why I wasn't well. If I had this diagnosis as an infant, I would have had the chance for more years with an existing approved treatment. This is my hope for all babies born with MPS I,” states Adele Kary of Flat Rock, NC.*

- “*Adding MPS I, Pompe and Adrenoleukodystrophy to the state’s newborn screening panel is an important move that will help save families from the heartbreak of losing a child or losing precious time where treating their child could result in better outcomes. These additions are the result of hard work by many people including concerned parents and public health officials. We thank them for their efforts, said Terri Klein, President/CEO National MPS Society.”*

*- “Newborn screening has the power to improve health outcomes for all children regardless of location, race, ethnicity or socioeconomic status, making this proposed legislation a win-win for children, their families and North Carolina,” said Sharon King, chair of the North Carolina Rare Disease Coalition. “Improved newborn screening and early intervention for the treatment of rare diseases will create life-changing benefits, and we are pleased that North Carolina is taking this step.”*

BACKGROUND

RUSP

The Secretary of the Department of Health and Human Services maintains the Recommended Uniform Screening Panel (RUSP). Disorders on the RUSP are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments. Spinal muscular atrophy (SMA), the leading genetic cause of death in infants, was recently recommended for the RUSP, and additional conditions are expected to be added in the coming years as medical advances continue.

Insurance Coverage

Additionally, Non-grandfathered health plans are required to cover screenings included in the HRSA-supported comprehensive guidelines without charging a co-payment, co-insurance, or deductible for plan years beginning on or after the date that is one year from the Secretary’s adoption of the condition for screening.