



North Carolina Signs Legislation for Newborn Screening to Support RUSP Alignment

Durham, NC

November 19, 2021 - The National MPS Society shares excellent news of the signing of [HB 736](#) in North Carolina. The law is recognized as Recommended Uniform Screening Panel (RUSP) alignment legislation and provides a three-year timeline for the State to begin screening a newborn for a life-threatening condition. These are conditions that were recommended by the Department of Health and Human Services. This forward-thinking legislation implements a platform to save the lives of more than 500 babies each year.

According to the State Health Department, North Carolina screens for 32 of the current 35 conditions on the RUSP. As new conditions are added to the RUSP, NC will begin screening newborns for those conditions as well.

The Society would like to thank Governor Roy Cooper for signing this into law and recognizes with great gratitude the representatives who sponsored this bipartisan legislation: Representatives William Brisson (Bladen, Sampson), Michael Wray (Halifax, Northampton), and Becky Carney (Mecklenburg, primary). This will change outcomes for babies and families throughout the state. Newborn screening provides direct health benefits and the opportunity for life-saving interventions and treatments.

Advocacy efforts of Society members brought forth direct change and support for this key effort. North Carolina is the fourth state to adopt RUSP alignment legislation in 2021, joining Ohio, Arizona, and Georgia. California and Florida adopted this in 2016 and 2017.

This starts the screening process for MPS I in the state. President/CEO Terri Klein states: "This law addresses the critical element of time and will provide babies screened for treatable rare diseases a chance at life before it is too late. These terminal diseases are progressive, and time cannot be reversed. The sooner we can provide therapy to an infant, the better their outcome. The FDA approved Aldurazyme™, a life-saving therapy for MPS I, 18 years ago. Five years ago, MPS I was added to the RUSP, and it has been three years since North Carolina passed the legislation to add MPS I to its newborn screening program. Thanks to this law, babies born in North Carolina will finally have access to screening for MPS I."

Partnerships and countless hours of support from organizations including [EveryLife Foundation for Rare Diseases](#), [Rare Disease Innovations Institute](#), and [Taylor's Tale](#) helped to make this goal a reality for the people of North Carolina. In 2022, the National MPS Society will continue to work with organizations to pass RUSP alignment legislation in other states as we work to make newborn screening accessible to all babies in the country.