

My name is Dr. Mary Schroth. I am the Chief Medical Officer for Cure SMA, a patient advocacy organization which represents Nevada residents affected by spinal muscular atrophy or SMA. I speak in **strong support** of the newborn screening regulation being considered today.

SMA is a devastating neurodegenerative disease that results in severely weakened muscles in every part of the body. Infants with SMA lose the ability to swallow, breathe and move independently. Throughout my 25-year career as a lung specialist for children, most babies with SMA died before reaching their second birthday.

That has changed because there are now **treatments** for SMA. But these medications are most effective when given before the symptoms of SMA begin. And these medications coupled with **newborn screening for SMA has dramatically changed the outcome for those babies.**

Babies born today with SMA are living full and normal lives—**but only if** they can access treatment right after birth and before permanent nerve damage begins.

These success stories are happening everywhere **except Nevada.**

98% of all U.S. newborns are screened for SMA and can access a treatment before SMA symptoms start.

But not newborns in Nevada.

Nevada is one of only 2 states that has not implemented newborn screening for SMA.

Why? Because the newborn screening regulation has been delayed due to a larger debate over health privacy and patient and family choice.

I worked with patients and families daily for over two decades. I respect their choices and take their privacy seriously. But this debate has delayed this rule and has hurt the health and well-being of Nevada children.

While babies born with SMA in every neighboring state are thriving, children in Nevada are developing irreversible, permanent disabilities that will affect their entire lives. Irreversible and costly lifetime disability.

Only because they were born in your state.

This health challenge has a simple solution. It's newborn screening of SMA. Please meet the needs of children in your state by approving the newborn screening rule.

Thank you.