



Make today a breakthrough.

Testimony of

**Kristen Aleman, Cure SMA Supporter
Henderson, Nevada**

In support of

Newborn screening rule that would implement newborn screening for spinal muscular atrophy in Nevada

My name is Kristen Aleman. I live in Henderson with my husband, Charles, and our daughter, Juliana. As a Nevada resident and a mother to a child with spinal muscular atrophy, or SMA, **I strongly support the newborn screening rule being considered by the Legislative Commission.** Approval of this rule will help ensure that newborn screening of SMA will finally be a reality in Nevada.

When our daughter was diagnosed with SMA in February 2013, my husband and I were not aware of SMA, a rare genetic disease that robs individuals of physical strength and, for many, their ability to walk, eat, and breathe.

Our daughter was born on her due date: June 1, 2012. She was a cute, little baby with a full head of hair. She was also a very happy baby.

Within just a few months of her birth, Juliana was able to sit up, play with her toys, hold her feet, and roll over. She was even holding her bottles to feed herself. Everything seemed normal—my version of normal.

It was at my daughter's 6-month wellness check-up, in December of 2012, that our pediatrician noticed something unusual. She had Juliana sit up while she examined her, testing her arms first, and then her legs next. When our doctor checked her knee reflex, she hesitated and then checked it again. There was still no reflex, which concerned our pediatrician and started us on our journey to diagnosis.

We were referred to a pediatric neurologist in Las Vegas who saw us the next month, in January of 2013. He ordered several tests, including blood work and a muscle biopsy, and scheduled us to return following the test results. It was at that follow-up appointment in February that the doctor told us that Juliana had SMA Type 2, a form of SMA where symptoms first appear during the toddler years.

I remember him telling us about the survival rate, where babies born with the most severe form of the disease often do not live past their 2nd birthday. It was scary and confusing—we were freaking out. The rest of the appointment was a blur.

Following the appointment, I learned more about the disease on the Internet. That is how I first got connected with Cure SMA, a national organization dedicated to finding treatments and a cure for SMA. Shortly after that connection, our family received Cure SMA's newly diagnosed care package that included SMA information and useful items, such as a blanket, children books, and SMA-appropriate toys.

There was not an SMA treatment available at the time. Typically, babies and toddlers with SMA begin to lose motor neurons needed for physical development. Juliana was still able to sit up on her own at 13 months of age, but we started to see her lose that ability as she got older. She never really had leg movement, but she maintained some arm and hand strength. In December of 2016, the first SMA treatment was approved by the U.S. Food and Drug Administration. Juliana started that treatment, which has improved her energy level, head control, and arm and hand strength.

Today, Juliana is an almost 8-year-old who will start third grade in the fall. She excels at her schoolwork, especially spelling and science, and she loves reading. Her current favorite is the *Sarah, Plain and Tall* book series. Juliana is very social, loves being outside in her powerchair, and is a caring person. She never complains and has shown my husband and I what strength truly is. We are better people because of her.

Our journey has been stressful and challenging, especially as we waited for her eventual diagnosis. However, with early identification through newborn screening and access to one of the two SMA treatments that exist today, no other Nevada family should have to face that same uncertainty that our family did.

That is why I am here today, in support of this newborn screening rule, which will allow Nevada to implement newborn screening of SMA. In 2018, the federal government recommended that SMA be added to state newborn screening panels. Nevada is one of only three states that does not screen for SMA.

I urge you to support his newborn screening rule. Newborn screening of SMA would give Nevada parents the information they need to make decisions about treatment and care. It is the right thing to do.

Thank you for considering my views.