



Make today a breakthrough.

September 23, 2022

Legislative Commission  
Nevada State Legislature  
401 S. Carson St.  
Carson City, NV 89701

Dear Legislative Commission Members,

On behalf of Nevada residents and families with spinal muscular atrophy (SMA), **Cure SMA strongly supports the newborn screening rule developed by the Nevada Department of Health and Human Services (DHHS) and being considered by this distinguished panel.** Approval of this important rule will allow DHHS to implement newborn screening for SMA and provide Nevada families of babies born with SMA with the information they need to make timely decisions about treatment and care.

SMA is a progressive neurodegenerative disease that causes debilitating muscle weakness that can result in underdeveloped lungs, compromised breathing, and respiratory failure. Historically, babies born with SMA Type 1, the most common and severe form of the disease, died before reaching their second birthday. SMA impacts 1 in 11,000 births in the United States. **In [Nevada](#), more than 62,000 residents are carriers of the SMA genetic mutation.** If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender.

**Due to treatment and care breakthroughs, babies born today with SMA—and identified soon after birth through newborn screening—are achieving unprecedented developmental milestones and thriving in their communities.** The U.S. Food and Drug Administration (FDA) has approved three treatments for SMA—Spinraza (2016), Zolgensma (2019), and Evrysdi (2020)—that are helping babies born today with SMA Type 1 to sit, stand, and even walk. Clinical [data](#) shows these treatments are most effective when delivered early, and especially when delivered pre-symptomatically. Data also indicates that motor and developmental gains are sustained, which could lead to reduced future need for intensive healthcare, specialized supports and care, and medical devices, such as ventilators. These dramatic outcomes are only possible, however, with early diagnosis and timely access to treatments.

Because **Nevada is one of only three states that does not screen for SMA**, Nevada families are unaware when their child is born with SMA. As a result, these infants and their families experience the frustration of delayed diagnosis and missed opportunities for better outcomes because they did not receive a diagnosis at birth through newborn screening and were unable to access an SMA treatment before SMA symptoms and irreversible damage occurs.

A Nevada boy named Aidan was born in January 2021. He had limited arm movement and poor reflexes, which the doctors initially believed was related to the delivery. However, his parents suspected something more. At their 5-day check-up, the doctors noticed Aidan had weakened further and started tests to determine the cause. It would take another two weeks before the family received a diagnosis: Aidan had SMA Type 1. The family immediately pursued treatment, but it would take another several days before Aidan was approved and received an SMA treatment. He was one month and five days old. By then, Aidan stopped moving his arms and legs, could not

swallow, and his breathing grew very labored, requiring surgery to insert breathing and feeding tubes. Today, Aidan is 19 months old, and his health has improved since receiving the SMA treatment. However, treatments do not reverse damage caused by SMA during the time it took for Aidan to receive his diagnosis and access treatment. *"Time is everything with SMA, and we lost valuable time because Nevada does not screen for SMA,"* Aidan's mom said, *"While approval of the newborn screening regulation and implementation of newborn screening of SMA will not directly benefit Aidan, it will help other Nevada families of children born with SMA."*

**Newborn screening is the most effective way for babies with SMA to access life-saving treatments and available supports before the permanent damage of SMA.** Cure SMA agrees with DHHS's [assessment](#) of the public benefit of the rule *"to empower families to make the best decisions for their child by providing information and education"* and that the rule will *"ensure proper referral and care for infants suspected of or diagnosed with specific preventable or inherited conditions."* Approval of this rule and implementation will also ensure that Nevada joins the other 47 states that already screen their newborns for SMA. One state and Washington, DC will add SMA newborn screening by the end of the year leaving Nevada as possibly the last state to implement. Cure SMA and our Nevada supporters—including the more than 175 Nevada residents who signed onto a letter in support of newborn screening of SMA—fully support this rule and hope its approval leads to immediate implementation of newborn screening of SMA.

Thank you for considering our views. Please do not hesitate to contact Cure SMA if you have questions or need additional information. Cure SMA can be reached through Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at [maynard.friesz@curesma.org](mailto:maynard.friesz@curesma.org) or 202-871-8004. Thank you for your consideration.


Sincerely,



Kenneth Hobby  
President



Mary Schroth, M.D.  
Chief Medical Director



Maynard Friesz  
Vice President, Policy

**Cure SMA Nevada Families and Supporters**  
**(signed April 25, 2022 letter to the Legislative Commission)**

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Leslie	Alcantar	Las Vegas	NV	Monica	Carbajal	Las Vegas	NV

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Yesenia	Cerpa	Las Vegas	NV	Luz	Quijada	Las Vegas	NV
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Yessica	Hernandez	Las Vegas	NV	Osvaldo	Vargas	Las Vegas	NV
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Sarah	Lopez	Las Vegas	NV	Maria	Alcantar	North Las Vegas	NV
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Brenda	Wilson	North Las Vegas	NV				