



Make today a breakthrough.

October 18, 2022

Interim Finance Committee
Nevada State Legislature
401 S. Carson St.
Carson City, NV 89701

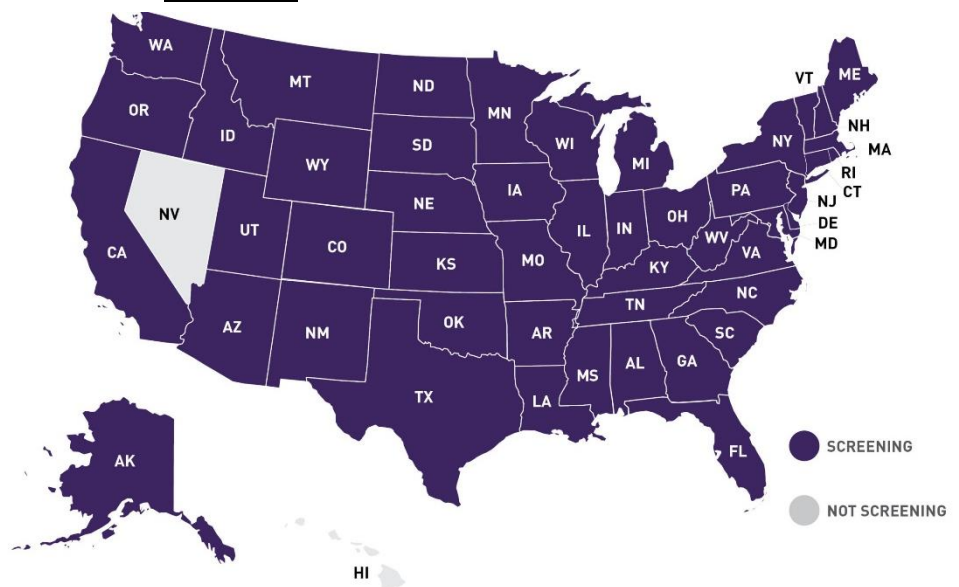
Dear Interim Finance Committee Members,

On behalf of Nevada residents and families with spinal muscular atrophy (SMA), **Cure SMA is pleased to support the proposal to provide the Nevada Department of Health and Human Services (DHHS) with funds for newborn screening testing and reporting. We urge that the Interim Finance Committee direct DHHS to use these and other available funds to immediately implement newborn screening of SMA.**

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. However, because of new U.S. Food and Drug Administration (FDA) approved [treatments](#) for SMA, babies born with SMA Type 1—and who receive these treatments shortly after birth, before symptoms arise—can meet key milestones such as sitting, standing, and walking and live independent and healthy lives.

Unfortunately, these unprecedented developmental milestones will not happen for babies born with SMA in Nevada unless the state implements newborn screening of SMA. Current SMA treatments are [most effective](#) when delivered early, and especially when delivered pre-symptomatically. In 48 states, babies are screened for SMA at birth through newborn screening, which puts them on a path toward timely [access](#) (typically, less than a month after birth) to a treatment. Motor and developmental gains of babies with SMA who are diagnosed and receive treatment shortly after birth are sustained and could lead to reduced future need for intensive healthcare, specialized supports and care, and medical devices, such as ventilators.

Nevada is one of only two states that does not screen for SMA. Based on Cure SMA estimates, approximately [three babies](#) are born with SMA in Nevada each year. Also, **more than 62,000 Nevada 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.



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 begins. In 2019, the Nevada Legislature approved and the Governor signed into law [legislation](#) that would ensure that Nevada newborns were screened for diseases, such as SMA, within **4 years** of the condition being added to the federal Recommended Uniform Screening Panel (RUSP). SMA was added to the [federal RUSP](#) in July 2018. The state should have implemented SMA by July 2022, as mandated by the [2019 law](#). **However, Nevada families still do not receive an SMA diagnosis for their child through newborn screening.** As a result, Nevada babies with SMA and their families continue to experience the frustration of delayed diagnosis and missed opportunities for better outcomes. They do not receive timely access to an SMA treatment before SMA symptoms and irreversible damage occurs, only because those infants were born in Nevada rather than any other nearby state.

The Interim Finance Committee will consider [two proposals](#) during your October 20th meeting related to newborn screening. Specifically, proposals 29 and 30 would provide the DHHS Division of Public and Behavioral Health with resources “to fund newborn screening testing and reporting enhancements”:

*29. Office of the Governor - COVID-19 Relief Programs - FY 2023
Transfer of \$2,795,700 from the Reserve category to the American Rescue Plan Act (ARPA) Public Health category and transfer of \$1,157,989 from the Loss Revenue Reserves category to the ARPA Public Health category to support an allocation to the Department of Health and Human Services, Division of Public and Behavioral Health to fund newborn screening testing and reporting enhancements. Requires Interim Finance approval since the amount transferred to the ARPA Public Health category exceeds \$75,000. RELATES TO ITEM D.30. Work Program #23FR132788*

*30. Department of Health and Human Services - Public and Behavioral Health - Maternal Child and Adolescent Health Services - FY 2023
Addition of \$3,953,689 in American Rescue Plan Act (ARPA), Coronavirus State Fiscal Recovery Funds transferred from the COVID-19 Relief Programs account to fund newborn screening testing and reporting enhancements. Requires Interim Finance approval since the amount added to the ARPA Newborn Screening and Testing category exceeds \$75,000. RELATES TO ITEM D.29. Work Program #23FR322202*

Cure SMA and our Nevada supporters—including the more than 175 Nevada residents who signed onto a letter in support of Nevada newborn screening of SMA—urge the Interim

Finance Committee to approve these funds and to direct DHHS to use these and other available funds to immediately implement newborn screening of SMA. Implementation of newborn screening of SMA will provide Nevada families of babies born with SMA with the information they need to make timely decisions about treatment and care. It is time for Nevada to catch up with the rest of the country when it comes to the health and well-being of its newborns.

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 [REDACTED] or [REDACTED]. Thank you for your consideration.

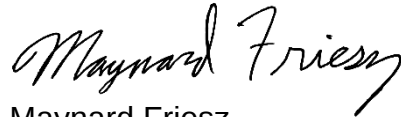
Sincerely,



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)

Kristen	Aleman	Henderson	NV	Danny	Chavez	Las Vegas	NV
Denielle	Farrow	Henderson	NV	JaNiya	Darling	Las Vegas	NV
Sara	Huff	Henderson	NV	Anna	Dembik	Las Vegas	NV
Linda	Lopes	Henderson	NV	Edward	Diaz	Las Vegas	NV
Jason	Rivas	Henderson	NV	Betzabet	Elizarraras	Las Vegas	NV
Tera	Robinson	Henderson	NV	Maureen	Femenella	Las Vegas	NV
Kayla	Senters	Henderson	NV	Cambria	Frazier-Hudson	Las Vegas	NV
Korina	Woods	Henderson	NV	Brianna	Freema	Las Vegas	NV
Michelle	Abrera	Las Vegas	NV	Angela	Frisby	Las Vegas	NV
Alexis	Alcalan	Las Vegas	NV	Patricia	Frye	Las Vegas	NV
Angelica	Alcantar	Las Vegas	NV	Alicia	Gallegos	Las Vegas	NV
Leslie	Alcantar	Las Vegas	NV	Courtney	Garcia	Las Vegas	NV
Priscilla	Alcantar	Las Vegas	NV	Sonya	Hanson	Las Vegas	NV
Alexander	Alvarez	Las Vegas	NV	Rachel	Hardman	Las Vegas	NV
Brianna	Alvarez	Las Vegas	NV	Mia	Heng	Las Vegas	NV
Sarriah	Arizola	Las Vegas	NV	Liliana	Hernandez	Las Vegas	NV
Lourdes	Avila	Las Vegas	NV	Victor	Hernandez	Las Vegas	NV
Rachel	Bannister	Las Vegas	NV	Yessica	Hernandez	Las Vegas	NV
Karen	Barcenas	Las Vegas	NV	Ana	Ibarra	Las Vegas	NV
Rebecca	Barraza	Las Vegas	NV	Corina	Iturrios	Las Vegas	NV
Karen	Bravo	Las Vegas	NV	Leslie	Jauregui	Las Vegas	NV
Michaela	Burns	Las Vegas	NV	Alexis	Jimenez	Las Vegas	NV
Katia	Cabada	Las Vegas	NV	Kelly	Jimenez	Las Vegas	NV
Monica	Carbajal	Las Vegas	NV	Deidre	Leyva	Las Vegas	NV
Eduardo	Castro	Las Vegas	NV	Santa	Limon	Las Vegas	NV
Araceli	Cendejas	Las Vegas	NV	Daniela	Lopez	Las Vegas	NV
Yesenia	Cerpa	Las Vegas	NV	Isela	Lopez	Las Vegas	NV

Sarah	Lopez	Las Vegas	NV	Maria	Alcantar	North Las Vegas	NV
Ivette	Martinez	Las Vegas	NV	Stephanie	Alcantar	North Las Vegas	NV
Sadie	Martinez	Las Vegas	NV	Vicente	Alvarez	North Las Vegas	NV
Yotsy	Martinez	Las Vegas	NV	Ashley	Amaya	North Las Vegas	NV
Heaven	Meko	Las Vegas	NV	Merlyn	Arellano	North Las Vegas	NV
Eric	Melendes Medina	Las Vegas	NV	Litzy	Avila	North Las Vegas	NV
Monica	Mendoza	Las Vegas	NV	Edelmira	Barrera	North Las Vegas	NV
Maria	Meza	Las Vegas	NV	Henoc	Barrera	North Las Vegas	NV
Adriana	Montano	Las Vegas	NV	Armando	Becerra	North Las Vegas	NV
Jessica	Montes	Las Vegas	NV	Angela	Berg	North Las Vegas	NV
Mayte	Morales	Las Vegas	NV	Conner	Bobay	North Las Vegas	NV
Leticia	Natividad	Las Vegas	NV	Jesus	Bravo	North Las Vegas	NV
Wendy	Nelson	Las Vegas	NV	Yajairy	Cabrales	North Las Vegas	NV
Brian	Nepomuceno Vega	Las Vegas	NV	Leslie	Cardenas	North Las Vegas	NV
Kayla	Nottingham	Las Vegas	NV	Heidy	Carrillo	North Las Vegas	NV
Mayra	Olivares	Las Vegas	NV	Aileen	Chaidez	North Las Vegas	NV
Annette	Ortiz	Las Vegas	NV	Alfonso	Chavez	North Las Vegas	NV
Maria	Osuna	Las Vegas	NV	Jennifer	Contreraa	North Las Vegas	NV
Lesley	Perez	Las Vegas	NV	Guadalupe	Corona	North Las Vegas	NV
Melissa	Perez	Las Vegas	NV	Mariam	Dias	North Las Vegas	NV
Sharon	Pettis	Las Vegas	NV	Alicia	Garcia	North Las Vegas	NV
Luz	Quijada	Las Vegas	NV	Betzi	Garcia	North Las Vegas	NV
Carmen	Ramirez	Las Vegas	NV	Daniela	Garcia	North Las Vegas	NV
Jaqueline	Ramos	Las Vegas	NV	Jimmy	Garcia	North Las Vegas	NV
Lisbet	Ramos	Las Vegas	NV	Brittney	Gonzalez	North Las Vegas	NV
Shane Annika	Reyes	Las Vegas	NV	Fabian	Guerrero	North Las Vegas	NV
Jasmine	Rios	Las Vegas	NV	Nidia	Guzman	North Las Vegas	NV
Jacqueline	Rivas	Las Vegas	NV	Shantel	Hall	North Las Vegas	NV
Amanda	Rivera	Las Vegas	NV	Andrea	Hernandez	North Las Vegas	NV
Kelsey	Rodriguez	Las Vegas	NV	Fatima	Ibarra	North Las Vegas	NV
Joanne	Rodriguez	Las Vegas	NV	Powell	Kathryn	North Las Vegas	NV
Tylese	Ross	Las Vegas	NV	Alejandra	Lara	North Las Vegas	NV
Ashley	Salazar	Las Vegas	NV	Jason	Leiva	North Las Vegas	NV
Jimena	Salazar	Las Vegas	NV	Araceli	Leyva	North Las Vegas	NV
Anthony	Serrano	Las Vegas	NV	Karen	Lopez	North Las Vegas	NV
Brenda	Soto	Las Vegas	NV	Victoria	Loy	North Las Vegas	NV
Robyn	Taube	Las Vegas	NV	Abrienne	Luna	North Las Vegas	NV
Maria	Thulin	Las Vegas	NV	Jessica	Luna	North Las Vegas	NV
Gresya	Ureno	Las Vegas	NV	Chelsea	Medina	North Las Vegas	NV
Osvaldo	Vargas	Las Vegas	NV	Javier	Menchaca	North Las Vegas	NV
Andrew	Vargas Osuna	Las Vegas	NV	Yadhira	Mendez	North Las Vegas	NV
Lori	Velasco	Las Vegas	NV	Emily	Mitre	North Las Vegas	NV
Josue	Viramontes	Las Vegas	NV	Tyra	Mondragon	North Las Vegas	NV
Sarah	Weiss	Las Vegas	NV	Jasmin	Morrill	North Las Vegas	NV
Angel	Acosta	North Las Vegas	NV	Sasha	Mujica	North Las Vegas	NV
Marsha	Aikens Butler	North Las Vegas	NV	Arman	Nadjarian	North Las Vegas	NV
Anthony	Alcantar	North Las Vegas	NV	Daisy	Pena	North Las Vegas	NV
Delia	Alcantar	North Las Vegas	NV	America	Perez	North Las Vegas	NV
Hector	Alcantar	North Las Vegas	NV	Giselle	Ponce	North Las Vegas	NV

Josefina	Ramirez	North Las Vegas	NV
Michelle	Rangel	North Las Vegas	NV
Heather	Ribarsky	North Las Vegas	NV
Tiffany	Robledo	North Las Vegas	NV
Brianna	Rodriguez	North Las Vegas	NV
Poleth	Rodriguez	North Las Vegas	NV
Heather	Rojas	North Las Vegas	NV
Alejandra	Soto	North Las Vegas	NV
Tyra	Stovallhao	North Las Vegas	NV
Paula	Szpyy	North Las Vegas	NV
Selene	Tabares	North Las Vegas	NV
Arlett	Tovar	North Las Vegas	NV
Sheila	Valladares	North Las Vegas	NV
Emely	Vasquez	North Las Vegas	NV
Peony	Vazquez	North Las Vegas	NV
Yamell	Vazquez	North Las Vegas	NV
Joanna	Velazco	North Las Vegas	NV
Olivia	Williams	North Las Vegas	NV
Brenda	Wilson	North Las Vegas	NV
Sidney	Wilson	North Las Vegas	NV
Trinity	Wolkenhauer	North Las Vegas	NV
Alicia	Young	North Las Vegas	NV
Kathleen	Gates	Overton	NV
Suzanne	Hughes	Pahrump	NV
Monika	Campbell	Reno	NV
Jamie	Huck	Reno	NV
Heidi	Svenningsen	Verdi	NV