

Dear Jordan,

On behalf of **more than 175 Nevada supporters and families with spinal muscular atrophy (SMA)**, Cure SMA is pleased to share the attached letter of support for the final steps the Nevada Department of Health and Human Services and the Nevada State Public Health Laboratory needs to take to implement newborn screening of SMA, as required by law.

Cure SMA and our supporters across Nevada respectfully ask that the Nevada Legislative Committee approve the State Board of Health regulation establishing provisions related to newborn screening in the state. The Commission's action is critical in ensuring that Nevada joins Idaho, Utah, and the 42 other states that have already added SMA to its newborn screening panel.

Please reach out if you have any questions. Thank you for your consideration of the view of Nevada residents.

Thanks, Maynard

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Maynard Friesz | Vice President, Advocacy

Cure SMA | Make today a breakthrough.



Make today a breakthrough.

April 25, 2022

Dear Nevada State Leader,

As Nevada residents and supporters of Cure SMA, an organization that advocates for individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **we fully support efforts by the Nevada Department of Health and Human Services to implement newborn screening of SMA**, historically the most common genetic cause of infant death.

SMA is a genetic disease caused by a mutation in the survival motor neuron gene 1, or SMN1. In a healthy person, this gene produces a protein that is critical to the function of the nerves that control our muscles. Without it, those nerve cells cannot properly function and eventually die, taking away an individual's ability to walk, eat, and breathe. 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. Approximately 3 Nevada babies are born each year with SMA, according to Cure SMA estimates.

The discovery of three effective SMA treatments make it possible for individuals with SMA to achieve unprecedented milestones by stopping or slowing the degenerative course of the disease. In addition, data indicates that these motor and developmental gains are sustained, which could lead to reduced future need for intensive health care and specialized supports, such as ventilators. However, these dramatic outcomes are only possible with early diagnosis and timely access to these treatments. Newborn screening is the most effective way for babies with SMA to access life-saving treatments and available supports.

We are appreciative of the work of the Department of Health and Human Services and the Nevada State Public Health Laboratory to implement newborn screening of SMA in Nevada, as required by the state legislature. Today, 44 states, including Idaho and Utah, already screen for SMA, covering nearly 95 percent of all babies born in this country. With your support and final action on regulatory approval and other steps, Nevada will be among the next states to screen for SMA, giving those Nevada families of children born with SMA the information they need to make timely decisions related to available treatments and evidence-based care.

Thank you for your consideration.

Sincerely,

Cure SMA Nevada Families and Supporters

Kristen	Aleman	Henderson	NV	Tera	Robinson	Henderson	NV
Denielle	Farrow	Henderson	NV	Kayla	Senters	Henderson	NV
Sara	Huff	Henderson	NV	Korina	Woods	Henderson	NV
Linda	Lopes	Henderson	NV	Michelle	Abrera	Las Vegas	NV
Jason	Rivas	Henderson	NV	Alexis	Alcalan	Las Vegas	NV

Angelica	Alcantar	Las Vegas	NV	Eric	Melendes Medina	Las Vegas	NV
Leslie	Alcantar	Las Vegas	NV	Monica	Mendoza	Las Vegas	NV
Priscilla	Alcantar	Las Vegas	NV	Maria	Meza	Las Vegas	NV
Alexander	Alvarez	Las Vegas	NV	Adriana	Montano	Las Vegas	NV
Brianna	Alvarez	Las Vegas	NV	Jessica	Montes	Las Vegas	NV
Sarriah	Arizola	Las Vegas	NV	Mayte	Morales	Las Vegas	NV
Lourdes	Avila	Las Vegas	NV	Leticia	Natividad	Las Vegas	NV
Rachel	Bannister	Las Vegas	NV	Wendy	Nelson	Las Vegas	NV
Karen	Barcenas	Las Vegas	NV	Brian	Nepomuceno Vega	Las Vegas	NV
Rebecca	Barraza	Las Vegas	NV	Kayla	Nottingham	Las Vegas	NV
Karen	Bravo	Las Vegas	NV	Mayra	Olivares	Las Vegas	NV
Michaela	Burns	Las Vegas	NV	Annette	Ortiz	Las Vegas	NV
Katia	Cabada	Las Vegas	NV	Maria	Osuna	Las Vegas	NV
Monica	Carbajal	Las Vegas	NV	Lesley	Perez	Las Vegas	NV
Eduardo	Castro	Las Vegas	NV	Melissa	Perez	Las Vegas	NV
Araceli	Cendejas	Las Vegas	NV	Sharon	Pettis	Las Vegas	NV
Yessenia	Cerpa	Las Vegas	NV	Luz	Quijada	Las Vegas	NV
Danny	Chavez	Las Vegas	NV	Carmen	Ramirez	Las Vegas	NV
JaNiya	Darling	Las Vegas	NV	Jaqueline	Ramos	Las Vegas	NV
Anna	Dembik	Las Vegas	NV	Lisbet	Ramos	Las Vegas	NV
Edward	Diaz	Las Vegas	NV	Shane Annika	Reyes	Las Vegas	NV
Betzabet	Elizarraras	Las Vegas	NV	Jasmine	Rios	Las Vegas	NV
Maureen	Femenella	Las Vegas	NV	Jacqueline	Rivas	Las Vegas	NV
Cambria	Frazier-Hudson	Las Vegas	NV	Amanda	Rivera	Las Vegas	NV
Brianna	Freema	Las Vegas	NV	Kelsey	Rodrigues	Las Vegas	NV
Angela	Frisby	Las Vegas	NV	Joanne	Rodriguez	Las Vegas	NV
Patricia	Frye	Las Vegas	NV	Tylese	Ross	Las Vegas	NV
Alicia	Gallegos	Las Vegas	NV	Ashley	Salazar	Las Vegas	NV
Courtney	Garcia	Las Vegas	NV	Jimena	Salazar	Las Vegas	NV
Sonya	Hanson	Las Vegas	NV	Anthony	Serrano	Las Vegas	NV
Rachel	Hardman	Las Vegas	NV	Brenda	Soto	Las Vegas	NV
Mia	Heng	Las Vegas	NV	Robyn	Taube	Las Vegas	NV
Liliana	Hernandez	Las Vegas	NV	Maria	Thulin	Las Vegas	NV
Victor	Hernandez	Las Vegas	NV	Gresya	Ureno	Las Vegas	NV
Yessica	Hernandez	Las Vegas	NV	Osvaldo	Vargas	Las Vegas	NV
Ana	Ibarra	Las Vegas	NV	Andrew	Vargas Osuna	Las Vegas	NV
Corina	Iturrios	Las Vegas	NV	Lori	Velasco	Las Vegas	NV
Leslie	Jauregui	Las Vegas	NV	Josue	Viramontes	Las Vegas	NV
Alexis	Jimenez	Las Vegas	NV	Sarah	Weiss	Las Vegas	NV
Kelly	Jimenez	Las Vegas	NV	Angel	Acosta	North Las Vegas	NV
Deidre	Leyva	Las Vegas	NV	Marshae	Aikens Butler	North Las Vegas	NV
Santa	Limon	Las Vegas	NV	Anthony	Alcantar	North Las Vegas	NV
Daniela	Lopez	Las Vegas	NV	Delia	Alcantar	North Las Vegas	NV
Isela	Lopez	Las Vegas	NV	Hector	Alcantar	North 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

Litzy	Avila	North Las Vegas	NV	Poleth	Rodriguez	North Las Vegas	NV
Edelmira	Barrera	North Las Vegas	NV	Heather	Rojas	North Las Vegas	NV
Henoc	Barrera	North Las Vegas	NV	Alejandra	Soto	North Las Vegas	NV
Armando	Becerra	North Las Vegas	NV	Tyra	Stovallhao	North Las Vegas	NV
Angela	Berg	North Las Vegas	NV	Paula	Szpyy	North Las Vegas	NV
Conner	Bobay	North Las Vegas	NV	Selene	Tabares	North Las Vegas	NV
Jesus	Bravo	North Las Vegas	NV	Arlett	Tovar	North Las Vegas	NV
Yajairy	Cabrales	North Las Vegas	NV	Sheila	Valladares	North Las Vegas	NV
Leslie	Cardenas	North Las Vegas	NV	Emely	Vasquez	North Las Vegas	NV
Heidy	Carrillo	North Las Vegas	NV	Peony	Vazquez	North Las Vegas	NV
Aileen	Chaidez	North Las Vegas	NV	Yamell	Vazquez	North Las Vegas	NV
Alfonso	Chavez	North Las Vegas	NV	Joanna	Velazco	North Las Vegas	NV
Jennifer	Contreraa	North Las Vegas	NV	Olivia	Williams	North Las Vegas	NV
Guadalupe	Corona	North Las Vegas	NV	Brenda	Wilson	North Las Vegas	NV
Mariam	Dias	North Las Vegas	NV	Sidney	Wilson	North Las Vegas	NV
Alicia	Garcia	North Las Vegas	NV	Trinity	Wolkenhauer	North Las Vegas	NV
Betzi	Garcia	North Las Vegas	NV	Alicia	Young	North Las Vegas	NV
Daniela	Garcia	North Las Vegas	NV	Kathleen	Gates	Overton	NV
Jimmy	Garcia	North Las Vegas	NV	Suzanne	Hughes	Pahrump	NV
Brittney	Gonzalez	North Las Vegas	NV	Monika	Campbell	Reno	NV
Fabian	Guerrero	North Las Vegas	NV	Jamie	Huck	Reno	NV
Nidia	Guzman	North Las Vegas	NV	Heidi	Svenningsen	Verdi	NV
Shantel	Hall	North Las Vegas	NV				
Andrea	Hernandez	North Las Vegas	NV				
Fatima	Ibarra	North Las Vegas	NV				
Powell	Kathryn	North Las Vegas	NV				
Alejandra	Lara	North Las Vegas	NV				
Jason	Leiva	North Las Vegas	NV				
Araceli	Leyva	North Las Vegas	NV				
Karen	Lopez	North Las Vegas	NV				
Victoria	Loy	North Las Vegas	NV				
Abrianne	Luna	North Las Vegas	NV				
Jessica	Luna	North Las Vegas	NV				
Chelsea	Medina	North Las Vegas	NV				
Javier	Menchaca	North Las Vegas	NV				
Yadhira	Mendez	North Las Vegas	NV				
Emily	Mitre	North Las Vegas	NV				
Tyra	Mondragon	North Las Vegas	NV				
Jasmin	Morrill	North Las Vegas	NV				
Sasha	Mujica	North Las Vegas	NV				
Arman	Nadjarian	North Las Vegas	NV				
Daisy	Pena	North Las Vegas	NV				
America	Perez	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				