



Make today a breakthrough.

February 22, 2021

Dear Oregon Leader:

As Oregon residents and supporters of Cure SMA, an organization that advocates for individuals living with spinal muscular atrophy (SMA), **we respectfully ask that you act during the 2021 Legislature to ensure that newborn screening of SMA is implemented by January 1, 2022.** We support House Bill 3107 or the addition of newborn screening funds in Oregon Health Authority's (OHA) budget to ensure Oregon newborns are screened for SMA, historically the most common genetic cause of infant death.

SMA is an inherited neurodegenerative disease that robs individuals of physical strength, taking away their ability to walk, eat, and breathe. SMA impacts 1 in 11,000 births in the United States. **In Oregon**, more than 83,800 residents are SMA carriers, according to Cure SMA estimates. 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.

With three effective U.S. Food and Drug Administration-approved SMA treatments and advances in SMA care, individuals with SMA are achieving unprecedented milestones and 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 access to these life-saving treatments. Newborn screening is the most effective way for babies with SMA to access timely treatments and available supports.

House Bill 3107, which was introduced by Representative Rob Nosse and supported by Cure SMA, would ensure that Oregon meets the 2018 federal recommendation to screen babies born in our state for SMA. Alternatively, newborn screening of SMA could be accomplished by adding newborn screening funds to the OHA budget. Cure SMA and the undersigned Oregon residents support whichever action is most likely to win final approval and be signed into law during the 2021 Legislative Session. As you may know, Oregon's newborn screening advisory committee of healthcare experts unanimously recommended last February that SMA be added to the state's list of screened conditions. Immediate action by the 2021 Legislature would carry out this unanimous recommendation and ensure that newborn screening for SMA is implemented in Oregon as quickly as possible. Currently, 33 states, including Washington and Utah, already screen for the disorder, covering nearly 70% of all newborns in this country.

HB 3107 or OHA newborn screening funds for SMA must be finalized during the 2021 Legislative Session so that Oregon newborns are screened for SMA and that their families can make timely decisions related to available treatments and evidence-based care. Babies born with SMA Type 1 lose 90% of their motor neurons needed for physical strength by six months of age. And once these neurons are lost, they cannot be regenerated, making action this legislative session on newborn screening of SMA so critically important.

Thank you for your consideration.

Sincerely,

Cure SMA Oregon Families and Supporters

Rose	Ahn	Amity	OR	Brigid	Koeppen	Astoria	OR
Holly	Corwin	Ashland	OR	Chris	Laman	Astoria	OR
Nathaniel	Corwin	Ashland	OR	Kiley	Laws	Astoria	OR
Kizzie	Adams	Astoria	OR	Kevin	Leahy	Astoria	OR
Evandro	Almeida	Astoria	OR	Dana	Lewis Allen	Astoria	OR
Jon	Altheide	Astoria	OR	Breanne	Libertad	Astoria	OR
Tiffany	Ambiel	Astoria	OR	Jared	LuCore	Astoria	OR
Jeremy	Annat	Astoria	OR	Julie	LuCore	Astoria	OR
Courtney	Awes	Astoria	OR	Katarina	LuCore	Warrenton	OR
Cody	Baughman	Astoria	OR	Keifer	LuCore	Warrenton	OR
Don	Bohn	Astoria	OR	Melton	LuCore	Astoria	OR
Maddie	Boyle	Astoria	OR	Coraleen	Mathews	Astoria	OR
Chris	Breitmeyer	Astoria	OR	Loran	Mathews	Astoria	OR
Ashley	Brewer	Astoria	OR	Tabatha	Miller	Astoria	OR
Paula	Brownhill	Astoria	OR	Lisa	Minnear	Astoria	OR
Meche	Brownlow	Astoria	OR	Lillian	Morrell	Astoria	OR
LaDonna	Cary	Astoria	OR	Kirsten	Norgaard	Astoria	OR
Mark	Cary	Astoria	OR	Thor	Norgaard	Astoria	OR
Djordje	Citovic	Astoria	OR	Cade	O'Brien	Astoria	OR
Trudy	Citovic	Astoria	OR	Patrick	O'Brien	Astoria	OR
Sarah	Cobb	Astoria	OR	Vicki	O'Brien	Astoria	OR
Bruce	Conner	Astoria	OR	Erika	Olsen	Astoria	OR
Suzie	Conner	Astoria	OR	Emily	Olson	Astoria	OR
Ryan	Eccles	Astoria	OR	Matt	Phillips	Astoria	OR
Amanda	Engleman	Astoria	OR	Audrey	Poindexter	Astoria	OR
Jon	Englund	Astoria	OR	Fred	Pynes	Astoria	OR
Kurt	Englund	Astoria	OR	Pat	Pynes	Astoria	OR
Brett	Estes	Astoria	OR	David	Reid	Astoria	OR
Nancy	Ferber	Astoria	OR	Cathryn	Roe	Astoria	OR
Sally	Fox	Astoria	OR	Kenna	Roman	Astoria	OR
Todd	Fox	Astoria	OR	Luke	Roman	Astoria	OR
Denise	Gagnon	Astoria	OR	Bonnie	Ross	Astoria	OR
Susan	Hansell	Astoria	OR	Jackson	Ross	Astoria	OR
Blair	Henningsgaard	Astoria	OR	Jeanette	Sampson	Astoria	OR
Hannah	Henrichs	Astoria	OR	Elizabeth	Schimpf	Astoria	OR
Jackie	Higginbotham	Astoria	OR	Caitlin	Seyfried	Astoria	OR
Hailey	Hoffman	Astoria	OR	Jackie	Spencer	Astoria	OR
Craig	Hoppes	Astoria	OR	Nicholas	Stephens	Astoria	OR
Bryce	Hutchinson	Astoria	OR	Caroline	Travers	Astoria	OR
Megan	Hutchinson	Astoria	OR	Dan	Travers	Astoria	OR
Debbie	Inman	Astoria	OR	Carol	Van Dusen	Astoria	OR
Will	Isom	Astoria	OR	Daniel	Van Dusen	Astoria	OR
Tyler	Johnson	Astoria	OR	Fatima	Van Dusen	Astoria	OR
Bruce	Jones	Astoria	OR	Jan	Van Dusen	Astoria	OR
Esther	Jones	Astoria	OR	Rachel	Van Dusen	Astoria	OR
Deb	Kaup	Astoria	OR	Sydney R.	Van Dusen	Astoria	OR
Doug	Kaup	Astoria	OR	Willis	Van Dusen	Astoria	OR
Jacob	Kaup	Astoria	OR	Willis	Van Dusen II	Astoria	OR
Barrett	Koeppen	Astoria	OR	Rachel	Whisler	Astoria	OR

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Kristin	Zedwick	Astoria	OR	Stephen	Marin	Cloverdale	OR
Matthew	Zedwick	Astoria	OR	Guy	McCormick	Cloverdale	OR
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Rebecca	Barron	Beaverton	OR	Mar'quis	Bryant-Morgan	Corvallis	OR
Marcos	Hernandez	Beaverton	OR	Sarra	Hawash	Corvallis	OR
Gary	Joaquin	Beaverton	OR	Valeria	Heredia	Corvallis	OR
Mark	Kliewer	Beaverton	OR	Malissa	Larson	Corvallis	OR
Renee	Kliewer	Beaverton	OR	Lynn	Russell	Corvallis	OR
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Cheryl	Millard-Nutt	Beaverton	OR	Kimberly	Kirkwood	Donald	OR
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Krystal	Brown	Bend	OR	Howard	Davis	Eugene	OR
Gina	Chylak	Bend	OR	Gayle	Del Grosso	Eugene	OR
Ellen	Eisman	Bend	OR	Elizabeth	Fairlamb	Eugene	OR
Karen	Green	Bend	OR	Angela	Fuchs	Eugene	OR
Melinda	Hampton	Bend	OR	Megan	Haight	Eugene	OR
Amy	Howell	Bend	OR	Mary	Hinman	Eugene	OR
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Blair	Jenkins	Bend	OR	Carole	James	Eugene	OR
Marcia	Koff	Bend	OR	Mark	James	Eugene	OR
Stacy	Koff	Bend	OR	Rae	Karp-Curtis	Eugene	OR
Chelsea	Sanford	Bend	OR	Peter	Keyes	Eugene	OR
Susan	Shepardson	Bend	OR	Tanya	McDaniel	Eugene	OR
Jared	Shucha	Bend	OR	Candace	Miller	Eugene	OR
Janine	Stassen	Bend	OR	Letty	Morgan	Eugene	OR
Anne	Van Dusen	Bend	OR	Sandra	Olson	Eugene	OR
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Dylan	Knutson	Clatskanie	OR	Matthew	Halsen	Gearhart	OR
Jordan	Knutson	Clatskanie	OR	Sarah	Spalding	Gearhart	OR
Tracey	Knutson	Clatskanie	OR	Sean	Spalding	Gearhart	OR
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Michael	Gabriel	Happy Valley	OR	Michael	Herbel	Neskowin	OR
Astrid	Melton	Happy Valley	OR	Marge	Jozsa	Neskowin	OR
Melanie	Tran	Happy Valley	OR	Candice	Miller	Neskowin	OR
Benjamin	Maney	Helix	OR	Gregory	Miller	Neskowin	OR
Julie	Maney	Helix	OR	Katherine	Oullette	Neskowin	OR
Patrick	Maney	Helix	OR	Russell	Oullette	Neskowin	OR
Trudy	Maney	Helix	OR	Judie	Rubert	Neskowin	OR
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Jill	Woodward	Lake Oswego	OR	Lukas	Arnerich	Portland	OR
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William	Bayne	McMinnville	OR	Krista	Basis	Portland	OR
Winona	Bayne	McMinnville	OR	Renee	Becerra	Portland	OR
Siria	Larmay	McMinnville	OR	Tara	Bernhardt	Portland	OR
Martha	Arciga	Milwaukie	OR	Jennifer	Besaw	Portland	OR

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Stefan	Bird	Portland	OR	Marsha	Henry	Portland	OR
Amanda	Blitzer	Portland	OR	Ana	Herrera	Portland	OR
David	Blitzer	Portland	OR	Holly	Hess	Portland	OR
Briana	Booth	Portland	OR	Mika	Hilbers	Portland	OR
Abby	Boudouris	Portland	OR	Steven	Hilton	Portland	OR
Zeljka	Boyd	Portland	OR	Stephanie	Hinkle	Portland	OR
Kelsey	Brown	Portland	OR	Molly	Hiro	Portland	OR
Sarah	Burns	Portland	OR	Brandi	Horikawa	Portland	OR
Morgan	Cain	Portland	OR	Eryn	Hughey	Portland	OR
Coleen	Carey	Portland	OR	Rami	Jabaji	Portland	OR
Earenya	Chapman	Portland	OR	Kristen	Jessie-Uyanik	Portland	OR
Nickole	Cheron	Portland	OR	Roopa	Karia	Portland	OR
Rebecca	Christiansen	Portland	OR	Kimberly	Kenney	Portland	OR
Megan	Coleman	Portland	OR	Anne	Kim	Portland	OR
Kara	Cooper	Portland	OR	Romila	Kim	Portland	OR
Carole	Cooperman	Portland	OR	Keith	Kreuz	Portland	OR
Jessica	Curtis	Portland	OR	Lynn	Kreuz	Portland	OR
Constance	Dalla Gasperina	Portland	OR	Christine	Kurz	Portland	OR
Bruna	Dalla Gasperina	Portland	OR	Jared	Kurzawa	Portland	OR
Jody	Dalla Gasperina	Portland	OR	Katie	Larson	Portland	OR
Lucio	Dalla Gasperina	Portland	OR	Chelsea	Lay	Portland	OR
Maddie	Dalla Gasperina	Portland	OR	Meganne	Leach	Portland	OR
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Jennifer	Downer	Portland	OR	Amanda	LeCrone	Portland	OR
Celeste	Dryer	Portland	OR	Barbara	Leese	Portland	OR
Sara	Eide	Portland	OR	Spencer	Leese	Portland	OR
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Penny	FitzMaurice	Portland	OR	Mary	Liedel	Portland	OR
Jamee	Freeland	Portland	OR	Rick	Lorenz	Portland	OR
Joni	Fusick	Portland	OR	Heather	Lorenzen	Portland	OR
Jordan	Geller	Portland	OR	Tracey	Lorts	Portland	OR
Natalie	Geller	Portland	OR	Nicola	Lowe	Portland	OR
Laura	Gill	Portland	OR	Shar	Ludwig	Portland	OR
Jasmine	Gilmore	Portland	OR	Kendra	Lwebuga	Portland	OR
Sarah	Glathar	Portland	OR	Max	Macdonald	Portland	OR
Jennifer	Gould	Portland	OR	Mariah	Madigan	Portland	OR
Cheryl	Grabham	Portland	OR	Margaret	Maes	Portland	OR
Drew	Grabham	Portland	OR	Sylvia	Mann	Portland	OR
Darcy	Grant	Portland	OR	Mia	Matusow	Portland	OR
Rebecca	Gundle	Portland	OR	Becky	McBrayer	Portland	OR
Frances	Hall	Portland	OR	Brook	McCall	Portland	OR
Marnie	Hanel	Portland	OR	Kim	McClaskey's	Portland	OR
Christina	Hanson	Portland	OR	Pauline	McCourt	Portland	OR
Andrew	Hanto	Portland	OR	Mark	McIntire	Portland	OR
Aryka	Hanto	Portland	OR	Alicia	McVey	Portland	OR
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Nora	Heard	Portland	OR	April	Mikan	Portland	OR

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Sarah	Ming	Portland	OR	Laura	Vega	Portland	OR
Martha	Moore	Portland	OR	David	Vogel	Portland	OR
Suzanne	Mylet	Portland	OR	Erin	Wallace	Portland	OR
Elizabeth	Neel	Portland	OR	Dana	Wazny	Portland	OR
Emma	Newton	Portland	OR	Thomas	Wells	Portland	OR
Natalie	Nixon	Portland	OR	Jennifer	Wilde	Portland	OR
Lauren	Ogden	Portland	OR	Cailie	Yates	Portland	OR
Lauren	O'Neil	Portland	OR	Mitch	Yoder	Portland	OR
Natalie	O'Neil	Portland	OR	Justin	Yuen	Portland	OR
Laura	Oxley	Portland	OR	Todd	Benson	Redmond	OR
Joy	Paquette	Portland	OR	Margaret	Bishop	Salem	OR
Jessica	Patton	Portland	OR	Pam	DeLong	Salem	OR
Jessica	Pederson	Portland	OR	Charles	Dye	Salem	OR
Dolan	Personke	Portland	OR	Lorraine	Dye	Salem	OR
Kimberly	Peterson	Portland	OR	Britta L	Franz	Salem	OR
Meghan	Phelps	Portland	OR	Pat	Grimmett	Salem	OR
Caroline	Pittman	Portland	OR	Janet	Halstead	Salem	OR
Deb	Pleva	Portland	OR	John	Halstead	Salem	OR
Deb	Pleva	Portland	OR	Rebecca	Hesedahl	Salem	OR
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Janelle	Rasmussen	Portland	OR	Anmolpreet	Kaur	Salem	OR
Ellyas	Razaqi	Portland	OR	Constance	Ledbetter	Salem	OR
Dustin	Razo	Portland	OR	Amy	McCollum	Salem	OR
Rebecca	Rice	Portland	OR	Ian	McCollum	Salem	OR
Megan	Rickert	Portland	OR	Jason	Plume	Salem	OR
Michelle	Riney	Portland	OR	Sherree	Rodriguez	Salem	OR
Teresa	Robinson	Portland	OR	Cathryn	Teal	Salem	OR
Carrie	Salehiamin	Portland	OR	Gerry	Thompson	Salem	OR
Pat	Scheans	Portland	OR	Susan	Thompson	Salem	OR
Andrea	Schlechter	Portland	OR	Diane	Trevett	Salem	OR
Mark	Schlechter	Portland	OR	Ivan	Vejar	Salem	OR
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Camden	Schobert	Portland	OR	Earl	Ming	Sandy	OR
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Lindsey	Soter	Portland	OR	Pam	Holmes	Seaside	OR
Mindy	Stone	Portland	OR	Kevin	LaCoste	Seaside	OR
Nsncy	Strening	Portland	OR	Sally	LaCoste	Seaside	OR
W	Stroud	Portland	OR	Kirstin	Lent	Seaside	OR
Christine	Sverkovich	Portland	OR	Tiah	Nelson	Seaside	OR
Erin	Thomas	Portland	OR	Greg	Peterson	Seaside	OR
Christine	Tomlinson	Portland	OR	Bill	Teeple	Seaside	OR
William	Tomlinson	Portland	OR	Kathleen	Teeple	Seaside	OR
John	Tyson	Portland	OR	Sydney	Van Dusen	Seaside	OR
Patricia	Tyson	Portland	OR	Julia	Weinberg	Seaside	OR
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Greg	Unwin	Portland	OR	Renee	Arnold	Siletz	OR

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Joshua	Breese	Tigard	OR
Diane	Chellis	Tigard	OR
David	Dalla Gasperina	Tigard	OR
Macy	Fox	Tigard	OR
Cameron	James	Tigard	OR
Nikki	James	Tigard	OR
Chelsea	Jepson	Tigard	OR
Kevin	Lesley	Tigard	OR
Rebecca	Lesley	Tigard	OR
Laura	Mann	Tigard	OR
Diana	Montgomery	Tigard	OR
Shawna	Randall	Tigard	OR
Michael	Stevens	Tigard	OR
Sarah	Wiechec	Tigard	OR
Carol	Knutson	Tolovana Park	OR
Cassie	Smith	Troutdale	OR
Kelly	Gallagher	Tualatin	OR
Daniel	Kawamoto	Tualatin	OR
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Amy	Atkinson	Warrenton	OR
Julie	Balzer	Warrenton	OR
Leslie	Cameron	Warrenton	OR
Alana	Kujala	Warrenton	OR
Mark	Kujala	Warrenton	OR
Cathy	Leinassar	Warrenton	OR
Jeffrey	Leinassar	Warrenton	OR
James	McGee	Warrenton	OR
Randy	Stemper	Warrenton	OR
Sharon	Visser	Warrenton	OR
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Matthew	Bevacqua	West Linn	OR
Virginia	Carr	West Linn	OR
Lisa	Ledson	West Linn	OR
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Christine	Getman	Wood Village	OR
Cathy	Ming	Wood Village	OR
Kim	Fahey	Wilsonville	OR
Melissa	Kitowski		OR