



Make today a breakthrough.

Testimony of
Hayley McDonald, Cure SMA Supporter
Boise, Idaho
Before the
Idaho Senate Health and Welfare Committee
on the
Implementation of newborn screening for
spinal muscular atrophy in Idaho

Chairman Martin, Vice Chair Riggs, and Members of the Committee,

Thank you for again inviting me to speak before the Health and Welfare Committee on Idaho's implementation of newborn screening of spinal muscular atrophy—or SMA.

I am Hayley McDonald from Boise. I am a lifelong Idaho resident and an active supporter of Cure SMA, the leading national organization that represents individuals with SMA and their families.

One year ago, on February 22, 2021, my husband, Bill, and I appeared before this committee to talk about the importance of newborn screening of SMA, a rare neuromuscular disease that affects the motor nerve cells in the spinal cord, impeding a person's ability to walk, swallow, and breathe.

I shared with you how this devastating disease took our precious little girl, Liv, from us in 2017 at less than 7 months of age. I told you about our joy in bringing Liv home after her birth on March 7, 2017. She was the most beautiful little girl who had the most expressive eyebrows. Her vital signs were normal, and she was released from the hospital following a routine delivery. But within 2 weeks, we started to see warning signs—first related to difficulty in feeding and then because of missed developmental milestones. This began our diagnostic journey that included several doctors' visits and a trip to the hospital. On May 26, 2017, Liv was diagnosed with SMA Type 1, the most common and severe form of SMA.

As I shared with this committee earlier, infants with SMA Type 1 lose 90% of the motor neurons needed for physical strength by 6 months of age. Once these neurons are lost,

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they cannot be regenerated. For Liv, the disease progressed rapidly. She died on October 6, 2017, 135 days after her SMA diagnosis and less than 7 months after she was born.

It is because of Liv that my family has been active in helping to ensure Idaho screens newborns for SMA.

Less than a year after Liv's death, the federal government approved adding SMA to what is known as the Recommended Uniform Screening Panel, or RUSP, which is a list of conditions that states should screen babies for at birth.

That was in 2018.

Over the next couple of years, I watched other states adopt and implement newborn screening for SMA—and I wanted to make sure Idaho was next. Newborn screening saves lives by giving parents of babies born with SMA with an immediate diagnosis so they can make timely decisions about treatment and other supports—before the rapid deterioration of the disease.

My message to this distinguished panel one year ago was: **please help**. I knew that with your leadership and support for our Department of Health and Welfare that Idaho would join the other states that were already screening for SMA.

Today, my message to you is simple: **thank you**. Thank you for your help in raising awareness of this issue and in supporting the Department of Health and Welfare in their work to finish the job in implementing newborn screening of SMA.

I especially want to thank and recognize **Senator Melissa Winthrop** for her personal advocacy, going all the way back to 2020, when I first connected with her for help on this important issue. And, finally, for the staff at the Idaho Department of Health and Welfare who took the steps necessary to make newborn screening for SMA a reality in our state.

Collectively, your actions will make a difference in the lives of children, like Liv, who are born with SMA. However, because of the early diagnosis through newborn screening and the advances in SMA treatment, their lives will look very different.

Thank you for your efforts and for inviting me to testify before the committee.