

IN THREE YEARS, CURE SMA MARKS NATIONWIDE MILESTONE FOR 85% OF U.S. NEWBORNS NOW SCREENED FOR SPINAL MUSCULAR ATROPHY

The organization's grassroots efforts give thousands of families new hope by securing widespread, state-by-state screening for SMA at birth

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Within three years of spinal muscular atrophy (SMA) being added to the

federally recommended list of diseases to screen for at birth, [Cure SMA](#) is celebrating a significant milestone—85 percent of newborns in the U.S. are now screened for SMA, the leading genetic cause of infant death.

In total, 37 states now screen newborns for SMA—with South Dakota joining the ranks of screening states in the coming weeks—giving those diagnosed with SMA early access to disease-modifying, life-saving treatments that dramatically improve a child's quality of life. It takes the crucial combination of early detection and timely administration of treatment to prevent the rapid and irreversible loss of motor function caused by the disease, and ultimately, maximize healthy outcomes.

"This is a huge leap forward and represents the hard work and dedication of our advocates, parents, individuals with SMA, and healthcare professionals, who continue to share their personal stories and experiences with state leaders," said Kenneth Hobby, President, Cure SMA. "While this is good news, our work is not complete. Cure SMA won't rest until every baby born in this country has access to universal newborn screening, regardless of the state they're born in."

In early July 2018, the federal government added SMA to the Recommended Uniform Screening Panel (RUSP)—the list of suggested conditions that states should screen for within their statewide universal [newborn screening programs](#). Since then, Cure SMA and its advocates have made tremendous progress, with about three-quarters of all states screening for the disorder. By the end of 2021, Cure SMA estimates another 4 to 5 states will begin screening for SMA,



covering 9 in every 10 babies born in the U.S.

To recognize this anniversary and the incredible progress made by the SMA community, Cure SMA is releasing a [new report card](#) to celebrate its advocates and recognize their stories and testimonies that have led to responsive legislative action in expedited time over the past three years.

“Cure SMA applauds the swift action of states implementing SMA screening early on,” says Dr. Mary Schroth, Chief Medical Officer, Cure SMA. “It is abundantly clear, when we identify and treat SMA, often pre-symptomatically, we can dramatically improve a baby’s breathing, muscle control, and ability to move independently. Early screening is life-saving.”

To expedite this state-by-state rollout, Cure SMA organized a Newborn Screening Coalition in 2016 with its key partners to help implement newborn screening of SMA. Current members include Cure SMA, Novartis Gene Therapies, and Genentech. Cure SMA advocates are stepping up across the U.S. to engage their elected leaders in taking quick action on screenings – and making tremendous progress, in just a few short years.

About SMA

SMA is a progressive neurodegenerative disease that robs an individual of their ability to walk, eat, and breathe. SMA is the leading genetic cause of death for infants. Symptoms can surface within the first 6 months of life (Type 1, the most severe and common), during the toddler years (Types 2 and 3), or in adulthood (Type 4, the least common form). SMA affects 1 in 11,000 births in the United States each year, and approximately 1 in 50 Americans is a genetic carrier. There are now three highly effective treatments for SMA approved by the U.S. Food and Drug Administration (FDA) that make it possible for babies diagnosed with SMA to achieve developmental milestones and individuals with SMA to live full and productive lives.

About Cure SMA

Cure SMA is dedicated to the treatment and cure of SMA. Since 1984, Cure SMA has grown to be the largest network of individuals, families, clinicians, and research scientists working together to advance SMA research, support the full SMA community, and educate public and professional communities about SMA. The organization has directed and invested in comprehensive research that has shaped the scientific community's understanding of SMA, led to breakthroughs in treatment and care, and provides individuals and families the support they need today. For more information, visit <http://www.curesma.org/>.

Leslie Humbel

Cure SMA

+1 312-523-5016

leslie.humbel@curesma.org

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