

Cure SMA Urges Arizona to Make 2021 the Year It Starts to Screen All Newborns for Spinal Muscular Atrophy

While Two-Thirds of U.S. States Now Screen for SMA, Arizona Newborns Are at Risk for Delayed Diagnosis

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Building off its most impactful year in state newborn screening for spinal muscular atrophy (SMA), [Cure SMA](#) is

urging Arizona to complete implementation in 2021 of [newborn screening for SMA](#)—the most common genetic cause of mortality for infants in the U.S. This is especially important given the availability of three effective disease-modifying treatments for SMA. As it stands, without statewide screening, newborns in Arizona are at risk of a delayed diagnosis and profoundly less effective treatment results.

In 2020, a record [17 states started screening for SMA](#), including Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Iowa, Kansas, Michigan, Nebraska, North Dakota, Rhode Island, Tennessee, Washington State, and Wyoming. Building on that progress, Cure SMA is now focused on bringing along Arizona, the other remaining 16 states, and the District of Columbia to take final action in 2021 to protect newborns in their states.

Cure SMA notes that two-thirds (33) of states now screen for SMA. However, the flipside of the tremendous progress made in recent years is that nearly 1 in 3 (32%) newborns born in the U.S. are still at risk of a delayed SMA diagnosis—including all newborns in Arizona—which can lead to rapid and irreversible health effects.

Many families from these non-screening states have stepped forward to share their personal stories with public health officials, describing how an earlier SMA diagnosis with early treatment may have dramatically changed the course of their child's life. One example is the Sirak Family, of Mesa, Arizona.

"Our family, along with others impacted by SMA in the state, has been strongly advocating for newborn screening of SMA in Arizona since 2018," said Cassandra Sirak, whose son, Junior,



received a delayed diagnosis for SMA at 6 months old. “We are so hopeful that 2021 will be the year that Arizona joins other states in the region in screening newborns for SMA.”

The early diagnosis and the early treatment of SMA—often pre-symptomatically in the case of diagnosis through newborn screening—is essential to maximizing a child’s health outcomes from this debilitating disease. The earlier these life-saving treatments are administered, the better. An early diagnosis can dramatically improve a child’s quality of life while reducing the total cost of care over a lifetime.

“The urgency to screen newborns for SMA in Arizona has increased dramatically during the pandemic, where we are seeing nationwide declines in symptomatic diagnoses, likely due to missed symptoms during virtual wellness checks or lapsed appointments with healthcare providers,” said Kenneth Hobby, President, Cure SMA. “We urge Arizona to implement in 2021 to ensure Arizona babies born with SMA receive an early diagnosis and can access the treatment and care appropriate to them.”

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. The good news is that 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 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 www.cureSMA.org.

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