

During Newborn Screening Awareness Month, Cure SMA Urges “Non-Screening” States to Expedite SMA Screening

Nationwide Report Card Shows Two-Thirds of U.S. States Now Screen for SMA, While Leaving 1 in 3 American Newborns Still at Risk for Delayed Diagnosis

CHICAGO, ILLINOIS, UNITED STATES, September 1, 2020 /EINPresswire.com/ -- With Newborn Screening Awareness Month, [Cure SMA](#) is ramping up efforts to urge non-screening states to expedite adoption and full implementation of newborn screening for SMA. This is especially important given the availability of disease modifying, life-saving treatments for SMA.

It has been over two years since the federal government added SMA to its Recommended Uniform Screening Panel (RUSP) list of conditions states should screen for as part of their state universal [newborn screening programs](#). This is done by administering a simple genetic blood test.

Recently, Cure SMA released a [new report card](#), highlighting that nearly two-thirds (32) of states have implemented screening for spinal muscular atrophy (SMA) as part of their newborn screening programs. The flipside of the tremendous progress made in the last two years, however, is that nearly 1 in 3 (32%) of newborns born in the U.S. are still at risk of a delayed SMA diagnosis, the most common genetic cause of mortality for infants in the U.S.

To date, 18 states and the District of Columbia have yet to take final action to protect newborns in their state. In an effort to encourage these states to take action, families from these non-screening states have stepped forward to share their personal stories, and how an earlier SMA diagnosis with treatment would have dramatically changed their babies' lives.

“The urgency to implement newborn screening of SMA in all states has increased dramatically during the pandemic, where we are seeing declines in symptomatic diagnoses likely due to missed symptoms during virtual wellness checks,” said Kenneth Hobby, President, Cure SMA. “The good news is that even during the pandemic, we have seen states like Florida, California, Illinois, and Washington implement newborn screening of SMA. We urge other states to also finalize action.”

SMA is a serious, life-threatening, neuromuscular disease affecting a person's ability to walk, swallow, and breathe. Thanks to important medical breakthroughs, there are now three effective

SMA treatment options that can save babies' lives, delivering dramatically improved prognosis and quality of life.

The early diagnosis and the early treatment of SMA is absolutely essential to maximizing a child's health outcomes from this debilitating disease. The earlier the treatment is 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 difference is profound. Identifying and treating SMA as early as possible, even pre-symptomatically, can dramatically improve babies' breathing, muscle control, and ability to move independently. Not to mention it alleviates the physical, emotional, and financial burden this disease takes on patients, their families, and communities.

About SMA

SMA is a progressive neurodegenerative disease that robs an individual of their ability to walk, swallow, 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 highly effective FDA-approved treatments for SMA that make it possible for individuals with SMA to achieve developmental milestones and 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 for individuals and families living with SMA, 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 provided individuals and families the support they need today. For more information, visit www.cureSMA.org.

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