Cure SMA Urges “Non-Screening” States to Make 2021 the Year They Implement SMA Screening for All Newborns

Year-end Progress Report Shows Two-Thirds of U.S. States Now Screen for SMA, Yet 1 in 3 American Newborns Still at Risk for Delayed Diagnosis

CHICAGO, ILLINOIS, UNITED STATES, December 21, 2020 /EINPresswire.com/ -- Cure SMA is ramping up efforts to urge non-screening states to expedite adoption and full implementation of newborn screening for spinal muscular atrophy (SMA)—the most common genetic cause of mortality for infants in the U.S. This is especially important given the availability of disease-modifying, life-saving treatments for SMA.

Despite a challenging year for the nation, 17 states started screening for SMA in 2020 — the largest recorded year ever since SMA screening implementation started in 2018. Building on that progress, the nonprofit is now focused on bringing along the remaining 17 states and the District of Columbia who have yet to take final action to protect newborns in their states.

This year, the following states started screening for SMA: Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Iowa, Kansas, Michigan, Nebraska, North Dakota, Rhode Island, Tennessee, Washington State, and Wyoming.

“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 or lapsed appointments with healthcare providers,” said Kenneth Hobby, President, Cure SMA. “We urge non-screening states to finalize action in 2021 and start ensuring early diagnosis for babies across the country.”

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 genetic blood test.

Cure SMA’s 2020 end-of-year progress report showed that two-thirds (33) of states have implemented screening for SMA as part of their newborn screening programs. However, the devastating flipside of the tremendous progress made in the last two years is that nearly 1 in 3 (32%) newborns born in the U.S. are still at risk of a delayed SMA diagnosis, which can lead to rapid and irreversible health effects.

Many families from these non-screening states have stepped forward to share their personal stories, and how an earlier SMA diagnosis with treatment may have dramatically changed the course of their babies' lives.

SMA is a serious, life-threatening, neuromuscular disease affecting a person's ability to walk, eat, 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 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, and with newborn screening often pre-symptomatically, can dramatically improve babies' breathing, muscle control, and ability to move independently.

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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