SMA STATE FACT SHEET

Maryland

Est. individuals living with SMA: 226
Est. babies born with SMA annually: 6
Est. number of SMA carriers: 120,854

Estimates for incidence, prevalence, and carriers are based on 2018 birth and population data for the state of Maryland.

TYPES OF SMA

There are four primary types of SMA that are based on the age of onset and highest physical milestone achieved. Type 1 is the most severe and most common, affecting 60 percent of those with SMA and is typically diagnosed during an infant's first 6 months of life.

Type 1 SMA
Onset: Before 6 months
Milestones: No sitting

Type 2 SMA
Onset: 6 - 18 months
Milestones: Sitting, not walking

Type 3 SMA
Onset: Childhood after 12 months
Milestones: Walking

Type 4 SMA
Onset: After 30 years old
Milestones: Normal

ABOUT SMA AND CURE SMA

Spinal muscular atrophy (SMA)—the number one genetic cause of death for infants—robs people of physical strength by affecting the motor nerve cells in the spinal cord, taking away the ability to walk, eat, or breathe. SMA is caused by deletion or mutation of the survival motor neuron gene 1 (SMN1). In a healthy person, this gene produces a protein that is critical to the function of the nerves that control our muscles. Without it, those nerve cells cannot properly function and eventually die, leading to debilitating and often fatal weakness of muscles used for breathing, crawling, walking, head and neck control, and swallowing.

Cure SMA is the largest network of families, clinicians, and research scientists working together to advance SMA research, support individuals and families impacted by SMA, and educate the public and professional communities about SMA.

MARYLAND CHAPTER INFORMATION

Cure SMA has 36 volunteer-led chapters across the U.S.
To find and contact the Maryland chapter, visit www.curesma.org/chapters.

CURE SMA CARE CENTER NETWORK

The Cure SMA Care Center Network is the centerpiece of our efforts to address the changing landscape of SMA. The goal of the Network is to develop an evidence-based standard of care that will improve the lives of all those impacted by SMA.

Care Center located in Maryland:

Currently there are no Care Centers in Maryland at this time.

NEW HOPE FOR TREATING SMA

Thanks to the dedication of our community and the ingenuity of our researchers, we now have treatments that target the underlying genetics of SMA. Currently, there are multiple treatments for SMA approved by the U.S. Food and Drug Administration (FDA)—Evrysdi, Spinraza, and Zolgensma. All are SMN-enhancing treatments.

But our work is not done. We know what needs to be done to develop and deliver effective therapies that target other systems, pathways, and processes impacted by SMA. Our goal is a combination of therapeutic approaches that can be tailored to each individual's age, stage, and type of SMA. These breakthroughs will continue to change the course of SMA for everyone impacted—from infants to adults—and eventually lead to a cure.

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NEWBORN SCREENING FOR SMA IN MARYLAND SAVES AND IMPROVES LIVES

Early diagnosis and treatment for spinal muscular atrophy (SMA) can lead to improved, long-lasting developmental outcomes for individuals living with SMA. In addition, clinical data shows that SMA treatments and care are more effective when delivered early and delivered early and especially when pre-symptomatic. Newborn screening is the most effective and efficient way for babies with SMA to access timely treatments and available supports.

SMA INCLUDED ON NATIONAL RECOMMENDED NEWBORN SCREENING PRIORITY LIST

In July 2018, the U.S. Secretary of Health and Human Services added SMA to the national recommended list for newborn screening—known as the Recommended Uniform Screening Panel or RUSP.

Each state determines what conditions to include in its screening panel, and how to add conditions to this panel. The RUSP is an important guideline for the states in this process, and after being included, several states have taken action to adopt and implement newborn screenings for SMA.

CURE SMA'S GOAL: UNIVERSAL SCREENING FOR SMA

Cure SMA has made implementation of universal screening for SMA—as recommended by the federal government—a top priority. Thanks to the advocacy of individuals and families impacted by SMA and the leadership of state officials, **well-over half of all states have implemented newborn screening for SMA, representing nearly 7 in every 10 babies born in this country**.

Despite the progress in screening newborns for SMA, the U.S. remains well short of the goal of 100 percent universal newborn screening for SMA. Several states are still not screening babies born in their state for the leading genetic cause of death among infants.

THANK YOU, MARYLAND!

All babies born in Maryland are screened for SMA! Cure SMA applauds Maryland for being an early adopter of newborn screening for SMA. The state started screening newborns for SMA in 2019. Maryland parents of newborns with SMA now have the information they need to make timely decisions about care and treatment for their child.

For more information, contact the Cure SMA Advocacy Team at advocacy@curesma.org *Last revised on August 2020*

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