SMA U.S. FACT SHEET

Est. individuals living with SMA: 12,053
Est. babies born with SMA annually: 344
Est. number of SMA carriers: 6,543,349

Estimates for incidence, prevalence, and carriers are based on 2018 birth and population data for the United States.

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. The disease is caused by a mutation in the survival motor neuron gene 1 (SMN1). Without enough of the SMN protein, nerve cells cannot function properly and eventually die, leading to debilitating and often fatal muscle weakness.

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

CHAPTER INFORMATION

Cure SMA has 36 volunteer-led chapters across the United States.
To find and contact the a chapter near you, visit www.curesma.org/chapters

CURE SMA CARE CENTER NETWORK

SMA Care Center Network is the centerpiece of our efforts to address the changing landscape of SMA. The goal of the Cure SMA Care Center Network is to develop an evidence-based standard of care that will improve the lives of all those affected by SMA.
To learn more, visit www.curesma.org/sma-care-center-network/ or find a Cure SMA Care Center Network by searching at www.curesma.org/find-a-location/

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 two treatments for SMA approved by the U.S. Food and Drug Administration (FDA) – Spinraza and Zolgensma. Both 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 affected 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 affected—from infants to adults—and eventually lead to a cure.

Find an event at www.curesma.org/cure-sma-events
Become an advocate at www.curesma.org/advocacy/
Donate at www.curesma.org/donate

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 six months.

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

Last revised on February 2020