SMA STATE FACT SHEET

Alaska

Est. individuals living with SMA: 32
Est. babies born with SMA annually: 1
Est. number of SMA carriers: 14,749

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

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.

ALASKA CHAPTER INFORMATION

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

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 SMA Care Center Network is to develop an evidence-based standard of care that will improve the lives of all those affected by SMA.

Care Center located in Alaska:
Currently there are no Care Centers in Alaska 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 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.

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

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Early diagnosis and treatment of 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 pre-symptomatically. Newborn screening is the most effective and efficient way for babies with SMA to access timely treatments and available supports.

**NEWBORN SCREENINGS FOR SMA IN ALASKA CAN SAVE AND IMPROVE LIVES**

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 of SMA.

**ALASKA NEWBORNS NOT CURRENTLY SCREENED FOR SMA**

Alaska has not adopted or implemented statewide newborn screenings for SMA.

**PROCESS TO GET SMA ADDED:**

Alaska is contracted with the Iowa State Hygienic Lab. They do not consider new conditions until their contracted lab adds a condition to their panel. It may then be reviewed by the Newborn Bloodspot Screening Advisory Committee, with the final decision made by the Director of Public Health and the Chief Medical Officer. The Advisory Committee reviews the incidence rate in Alaska, sensitivity and specificity of testing, cost of screening, treatment availability and funding for treatment, access to specialty care in Alaska and whether adding the condition aligns with their programmatic goals. They do not automatically consider conditions that are added to the RUSP. If adding a condition necessitates increasing the NBS fee, it would at minimum require a regulatory change, which is a separate approval process subject to public review and comment and may necessitate legislative action.

**ALASKA FAMILIES IMPACTED BY SMA SEEK ACTION ON NEWBORN SCREENINGS**

Alaska residents and families impacted by SMA, supported by Cure SMA, seek immediate action on:

- Adoption and implementation of statewide newborn screening for SMA; and
- Support for federal funding for rare disease basic research and newborn screening activities.

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