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 with SMA.

OREGON CHAPTER INFORMATION

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

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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—from infants to adults to families.
NEWBORN SCREENINGS FOR SMA IN OREGON CAN SAVE AND IMPROVE LIVES

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

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

GOAL: All States; All Babies

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 with SMA and their families and the leadership of state officials, more than three-quarters of all states have implemented newborn screening for SMA, representing close to 9 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.

TIME TO ACT, OREGON!

Despite the 2018 federal recommendation, babies born in Oregon are still not screened for SMA. Infants will develop symptoms of SMA before being diagnosed, simply because they are born in a non-screening state. These infants and their families will experience the frustration of delayed diagnosis and missed opportunity for better outcomes from access to effective SMA treatments. Cure SMA urges Oregon to expedite adoption and full implementation of newborn screening of SMA.

For more information, contact the Cure SMA Advocacy Team at advocacy@curesma.org

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