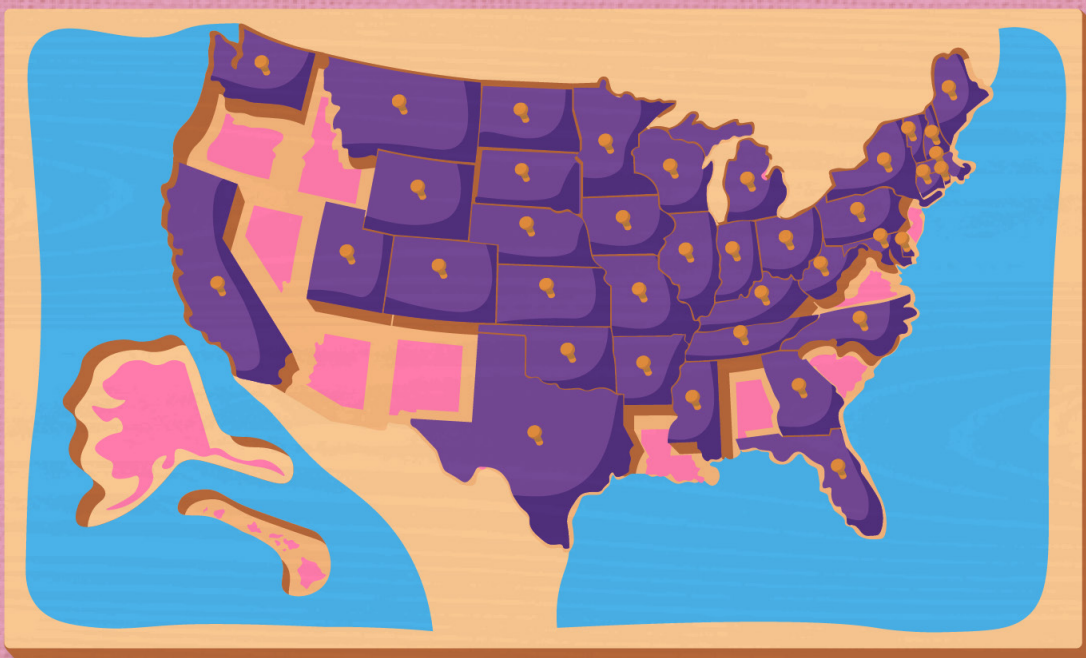


Thanks to you, we're almost there!

Does Your State Screen Newborns for SMA?



Help Us Complete the Puzzle!

Within three years of spinal muscular atrophy (SMA) being added to the federally recommended list of diseases to screen for at birth, Cure SMA is celebrating a significant milestone in 2021 — 85 percent of newborns in the U.S. are now screened for SMA, the leading genetic cause of infant death.

Spinal muscular atrophy is the leading genetic cause of infant mortality, affecting one in every 11,000 live births in the U.S. It is a serious, life-threatening, neuromuscular disease impacting a person's ability to walk, swallow, and breath. Thanks to important medical breakthroughs, there are multiple, effective SMA treatment options that can save babies' lives, delivering dramatically improved prognoses. But, it takes the crucial combination of early detection and timely administration of treatment to prevent the rapid and irreversible loss of motor function caused by the disease and, ultimately, maximize healthy outcomes.

Universal newborn screening is the best way to ensure every child with SMA is diagnosed and treated early, and has the best possible chance at a healthy life.

In total, 38 states will be screening newborns for SMA through permanent or pilot programs, giving those diagnosed with SMA early access to disease-modifying, life-saving treatments that dramatically improve a child's quality of life.

In July 2018, the federal government added SMA to the Recommended Uniform Screening Panel (RUSP)—the list of suggested conditions that states should screen for within their statewide universal newborn screening programs. Since then, Cure SMA and its advocates have made tremendous progress, with approximately three-quarters of all states screening for the disorder. By the end of 2021, Cure SMA estimates another 4 to 5 states will begin screening for SMA, covering 9 in every 10 babies born in the U.S.

We're almost there, and it's all thanks to you, our advocates. Your activism, your stories, and your dedication have paved the way.

With your continued help, we will complete our newborn screening puzzle so that every baby born in the U.S. is screened for SMA.

THANK YOU!

YOUR IMPACT IN JUST 3 YEARS



Braedon

Braedon was born in 2020 and diagnosed with SMA via newborn screening. He and his family live in upstate New York, a state that began screening for SMA in 2016 through a pilot, which helped lead to the condition being added to the RUSP.

"No one in our family had ever heard of SMA prior to Braedon's diagnosis, but our pediatrician was positive and emphasized the importance of early detection. It's absolutely crucial in the preservation of motor neurons that a child be diagnosed as soon as possible, and we were fortunate to have access to early treatment."

- Amanda, Braedon's Mom



Avery

Avery was born in 2019. She and her family are from Alabama, a non-screening state; however, Avery was born in Georgia where she was screened and diagnosed with SMA within a few weeks of birth.

"I felt both blessed and angry for our situation. Blessed she was born at the exact right time and the first baby in Georgia diagnosed with SMA through newborn screening, but angry at what could have been our family's fate had we chosen a hospital in Alabama where she would not have been screened."

- Shannon, Avery's Mom

IMPLEMENTED

Arkansas
California
Colorado
Connecticut
Delaware
Florida
Georgia
Illinois
Indiana
Kansas
Kentucky
Maine
Maryland
Michigan
Minnesota
Mississippi
Missouri
Montana
Nebraska
New Hampshire
New York
North Carolina
Oklahoma
Pennsylvania
Rhode Island
South Dakota
Tennessee
Texas
Utah
Vermont
Washington
West Virginia
Wisconsin
Wyoming

PILOT

Iowa
North Dakota
Massachusetts*
Ohio**

ACTION REQUIRED

Alabama
Alaska
Arizona
Washington, DC
Hawaii
Idaho
Louisiana
Nevada
New Jersey
New Mexico
Oregon
South Carolina
Virginia

* Opt-in Pilot

** Population study



To learn more about SMA and the value of newborn screening, visit www.curesma.org.