



# NEWBORN ESSENTIALS

## Does Your State Screen for SMA?

Spinal muscular atrophy (SMA) 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 affecting 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 prognosis and quality of life.

But early diagnosis and early treatment of SMA are key. **Universal newborn screening is the best way to ensure every child diagnosed with SMA has the best possible chance at a healthy life.**

The U.S. Department of Health and Human Services agrees, adding SMA to the federal Recommended Uniform Screening Panel (RUSP) in 2018 and strongly encouraging that EVERY newborn be screened across the country.

**Does your state make the grade? Keep reading to find out.**

### SMA Facts to Know

- SMA is the most common genetic cause of mortality of kids under age 2 years
- Approximately one child a day is born with a form of SMA
- One in every 50 Americans is a genetic carrier of the SMA gene

With new, lifesaving treatments now available, and others on the horizon, we hope you will join us in changing the outcome for so many young children and their families.



**Make today a  
breakthrough.**

## SCREENING STATES

Since 2018, 32 states have implemented permanent or pilot SMA newborn screening programs, assuring that every baby born in their states is screened. This provides parents the information they need to make the rights decisions about treatment and care if their child is diagnosed with SMA.

### EARLY IMPLEMENTER STATES (27)

These states have implemented permanent screening programs for SMA and have led the way in newborn screening. Today, because of their hard work, they have helped achieve Cure SMA's goal of reaching half the country within 2 years of the federal recommendation for SMA screening!

**Fun fact:** California, Illinois, and Washington are the latest to join the ranks as "Early Implementer" states.

### PILOT STATES (5)

These states screen newborns in their state through a pilot program or population study. They've taken the first step in promoting healthy newborns and must now finalize their work toward permanent implementation of newborn screening for SMA.

**Fun fact:** approximately 68% of babies born in the U.S. are screened thanks to "Early Implementer" and "Pilot" states!

## NON-SCREENING STATES

Despite the progress in screening newborns for SMA, **the U.S. remains well short of the 100% implementation target.** [Cure SMA](#) urges these states to expedite adoption and full implementation of newborn screening for SMA. This is especially important given the availability of disease modifying, life-saving treatments for SMA.

### ALMOST THERE STATES (2)

These states are in the final steps toward permanent implementation of newborn screening of SMA. They have made strong progress and are taking final steps to implement their SMA newborn screening program, but every day counts as they work to ensure babies born in their state are screened for SMA.

**Fun fact:** after full implementation by the "Almost There" states later this year, more than 7 in 10 babies in the U.S. will be screened for SMA.

### ACTION REQUIRED STATES (17)

Two years following the federal recommendation, these states are still not screening their newborns for SMA. Many of these states have taken promising steps while other states are at-risk of being the last adopters of newborn screening of SMA in this country. Additional action is required to catch up with the screening states.

### EARLY IMPLEMENTER

Arkansas  
California  
Colorado  
Connecticut  
Delaware  
Florida  
Georgia  
Illinois  
Indiana  
Kansas  
Kentucky  
Maryland  
Michigan  
Minnesota  
Mississippi  
Missouri  
New Hampshire  
New York  
Pennsylvania  
Rhode Island  
Tennessee  
Utah  
Vermont  
Washington  
West Virginia  
Wisconsin  
Wyoming

### PILOT

Iowa  
North Carolina\*  
North Dakota  
Massachusetts\*  
Ohio\*\*

### ALMOST THERE

New Jersey  
Virginia

### ACTION REQUIRED

Alabama  
Alaska  
Arizona  
Washington, DC  
Hawaii  
Idaho  
Louisiana  
Maine  
Montana  
Nebraska  
Nevada  
New Mexico  
Oklahoma  
Oregon  
South Carolina  
South Dakota  
Texas

\* Opt-in Pilot  
\*\* Population study