



SPINAL MUSCULAR ATROPHY (SMA)

FAMILY FACT SHEET

What is a positive newborn screen?

Newborn screening is done on tiny samples of blood taken from a baby's heel 24 to 36 hours after birth. The blood is tested for rare disorders that may affect a baby's health and development. A **positive newborn screen** means that a baby may have one of these disorders. More testing is needed to know for sure.

Your baby had a positive newborn screen for spinal muscular atrophy (SMA). Your baby's primary care provider or the Newborn Screening Program will notify you to arrange for more testing.

What is SMA?

SMA is a genetic disorder that affects a person's ability to control muscle movement. It is caused by the loss of special nerve cells in the spinal cord called motor neurons.

Individuals with SMA do not make enough of a certain protein needed to keep motor neurons healthy. As a result, the motor neurons stop sending signals to the muscles. Over time, muscles become weak and smaller from not being used.

SMA is passed on (inherited) from parents to a child. Both the mother and father of an affected child carry a gene change that can cause SMA. Parents usually do not know they carry the gene change because it does not cause health problems for them.

What problems can SMA cause?

There are four types of SMA that vary in severity and age at which symptoms begin. Symptoms can be mild or severe and can begin in infancy, childhood, or adulthood. A blood test may help predict which type of SMA a child has.

A child with SMA may develop:

- Muscle weakness
- Inability to sit, crawl, stand, or walk
- Curved spine
- Breathing difficulties
- Swallowing or feeding difficulties

It is very important to follow the doctor's instructions for testing and treatment.

What is the treatment for SMA?

There is no cure for SMA. Treatment is life-long and can include:

- FDA approved treatments that help the body make more of the protein needed for motor neurons
- Physical and occupational therapy
- Respiratory therapy
- Nutritional support

Children with SMA should see their regular doctor. They should also see a doctor who specializes in SMA as part of a special care team.

Specialized treatment helps children with SMA live the healthiest lives possible.

It is very important to get follow-up testing as soon as possible.

Michigan Resources and Support

Michigan Newborn Screening

Nurse Consultant

Toll-free: 1-866-673-9939 newbornscreening@michigan.gov

SMA Newborn Screening Coordinating Center

734-647-8938

Children's Special Health Care Services

Toll-free: 1-800-359-3722

Online Resources

Genetics Home Reference

<https://ghr.nlm.nih.gov/condition/spinal-muscular-atrophy>

National Organization for Rare Disorders

<https://rarediseases.org/rare-diseases/spinal-muscular-atrophy/>

Baby's First Test

www.babysfirsttest.org