NORTH CAROLINA NEWBORN SCREENING PROGRAM

Spinal Muscular Atrophy Fact Sheet for Parents

All babies born in North Carolina are screened at birth to look for certain medical conditions which if caught early can be treated. The newborn screen result showed it is possible your baby has spinal muscular atrophy. Your baby will need a second test as soon as possible to tell for sure.

What are the signs and symptoms of SMA?

Spinal muscular atrophy, or SMA, is a condition that affects the nerves in the spinal cord. When these nerves don't work, muscles can't do their job and become very weak. There are different types of SMA that are based on the age that symptoms begin and their severity. For babies with SMA Type 1, signs may appear within the first few weeks to months of life. Babies with SMA Types 2, 3, or 4 may not show signs until later in childhood or even adulthood. Symptoms may include trouble breathing, problems with feeding or swallowing, difficulty in meeting motor milestones, and/or muscle weakness. If left untreated, these symptoms will get worse over time.

Is SMA treatable?

Yes, there are different types of treatment that are available. If your baby does have SMA, a doctor will review the treatment options and together you will decide on what is best for your baby and family. Treatment should be started as soon as possible since babies with SMA tend to have better outcomes with early treatment.

What should I do next?

- The pediatrician or family doctor will refer you and your baby to a pediatric neurologist, which is a doctor who specializes in muscle and nerve problems.
- The pediatric neurologist will order the test to find out if your baby has SMA. The pediatric neurologist will also do an exam to check your baby for any early symptoms.
- You and your baby may also see a geneticist or a genetic counselor who will help you understand what SMA means for your baby and your family.
- Please check in with your baby's pediatrician or family doctor if you haven't heard from the geneticist or neurologist within 3 days.

Where do I go for more information?

Genetics Home Reference:
https://medlineplus.gov/genetics/condition/spinal-muscular-atrophy/

Cure SMA:
www.curesma.org/newborn-screening-for-sma/

Muscular Dystrophy Association:
www.mda.org/disease/spinal-muscular-atrophy

If you have questions, please contact the Newborn Screening Follow-up Program at 919-218-6460 or the Children with Special Health Care Needs Help Line at 1-800-737-3028.

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