How can I help my child?

- Tell all your child's health care providers that your child has sickle cell trait.
- Take your child to all their medical appointments.
- Talk to a healthcare provider and a genetic counselor about sickle cell trait and sickle cell disease. Genetic counselors can help explain risks to children when planning a family.
- Teach your child about sickle cell trait.
- Know the warning signs or symptoms caused by exercise. People with sickle cell trait can safely exercise and play sports. Talk with a coach and a healthcare provider to plan for safe training. People with sickle cell trait should drink plenty of water when exercising and take breaks when needed. The National Collegiate Athletics Association (NCAA) currently requires that all student-athletes receive testing for sickle cell disease before trying out for, or playing, sports.
- People with sickle cell trait should tell their healthcare provider if they have symptoms like blood in their pee (urine). They should also report any eye injuries.

Where can I get more information about sickle cell trait?

- Talk to:
  - Your healthcare provider
  - Your baby's healthcare provider
  - A genetic counselor
- Helpful websites:
  - Centers for Disease Control and Prevention – What You Should Know About Sickle Cell Trait: https://www.cdc.gov/ncbddd/sicklecell/toolkit.html
  - Nemours® KidsHealth® – Sickle Cell Trait: https://kidshealth.org/en/parents/sickle-cell-trait.html
  - Health Resources and Services Administration Newborn Screening: Sickle Cell Trait: https://newbornscreening.hrsa.gov/conditions/sickle-cell-trait
  - National Collegiate Athletics Association – A Fact Sheet for Student Athletes: Sickle Cell Trait: https://www.ncaa.org/sports/2016/7/27/sickle-cell-trait.aspx

Newborn Screening Program
Wadsworth Center
New York State Department of Health
120 New Scotland Ave
Albany, NY 12208
nbsinfo@health.ny.gov
(518) 473-7552, Monday-Friday, 8:45am-4:45pm
www.wadsworth.org/newborn

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NEW YORK STATE | Department of Health

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SICKLE CELL TRAIT

The Family Connection

Information for Parents and Families

NEW YORK STATE | Department of Health

A newborn screening test shows that your baby has sickle cell trait. **Your baby DOES NOT have sickle cell disease.** This information can be useful for you and your family.

What is sickle cell trait?

Sickle cell trait is not a disease. Anyone can have sickle cell trait. It is passed down (inherited) from parent to child. People with sickle cell trait are most often healthy. People are born with sickle cell trait and will have it their whole lives. It cannot be "caught" from someone. Sickle cell trait does not turn into sickle cell disease.

What is the difference between sickle cell trait and sickle cell disease?

SICKLE CELL TRAIT

- Sickle cell trait usually does not cause health problems. Most people with sickle cell trait go through life not knowing they have it. In some rare cases, people with sickle cell trait may have symptoms during times of extreme stress on their body, such as:
  - Intense exercise or sports
  - Not enough fluid (dehydration)
  - Extreme changes in elevation, like deep-sea diving or mountain climbing
- Symptoms can include muscle pain, feeling tired, blood in their pee (urine), and/or breathing fast.

SICKLE CELL DISEASE

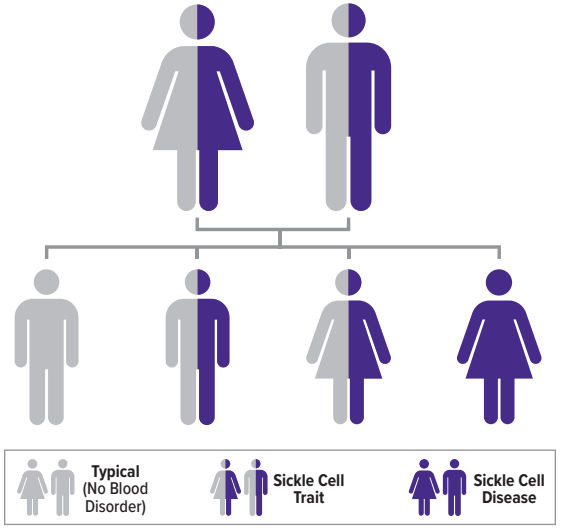
- Sickle cell disease is a serious blood disorder. People with sickle cell disease often have chronic pain and problems with their liver and spleen. They also have a lower number of red blood cells. This is called anemia. Anemia can cause people with sickle cell disease to be pale, short of breath, and easily tired. They have a high risk for severe infections and strokes. People with sickle cell disease need medical care throughout their life.

How does someone get sickle cell trait?

- Anyone can have sickle cell trait. All races and ethnicities can have sickle cell trait. Sickle cell trait is more common in people with ancestors from Africa, the Caribbean, Central and South America, Mediterranean countries, the Middle East, and/or India.
- All of us have genes (or DNA) that we get from both of our birth parents. A gene is a section of DNA that provides instructions for the body. Both sickle cell trait and sickle cell disease are caused by changes in a gene that makes a protein called hemoglobin. We have two copies of this gene, one from each parent. Hemoglobin helps red blood cells carry oxygen through the body.
- Sickle cell trait happens when a person is born with 1 normal copy and 1 changed copy of the gene. Many people do not know they have sickle cell trait. The best way to know if you have sickle cell trait is to ask your health care provider and have a blood test.
- Sickle cell disease happens when a person has 2 changed copies of the gene. Sickle cell disease is also called hemoglobin SS disease or sickle cell anemia. There are more types of hemoglobin disorders.

What does this test result mean for me and my family?

- If your child has sickle cell trait, it means that at least one of the child's parents also has sickle cell trait. It is important that both parents are tested. Ask your health care provider about testing for all types of hemoglobin disorders (not just sickle cell trait). You should discuss your results with a health care provider or a genetic counselor. Testing for sickle cell trait will help you understand your chances of having a child with sickle cell disease. People can be tested for sickle cell trait and other types of hemoglobin disorders at any age.
- A parent with sickle cell trait has a 1 in 2 or 50% chance of passing it to each of their children. This chance is the same as flipping a coin each time.
- Both parents must have sickle cell trait (or another hemoglobin trait) for a child to have disease.
- If both parents have sickle cell trait, they have a...
  - 1 in 4 or 25% chance of having a child with sickle cell disease
  - 1 in 2 or 50% chance of having a child with sickle cell trait
  - 1 in 4 or 25% chance of having a child without sickle cell trait or sickle cell disease



SOURCE: https://www.cdc.gov/ncbddd/sicklecell/documents/factsheet_sickle_cell_trait.pdf

- We cannot change our genes, and we cannot decide which genes get passed on to a child.

When was my baby tested for sickle cell trait?

- All babies born in New York State are screened for many disorders. This screening is done by the Newborn Screening Program. The screen is done using a few drops of blood taken from the baby's heel shortly after birth. One disorder the test screens for is sickle cell disease. This screening also finds babies who have sickle cell trait.
- This is a screening test. More testing is needed to confirm these results. Please talk to your baby's health care provider.