When was my baby tested for hemoglobin C trait?

- All babies born in New York are screened for many disorders through the Newborn Screening Program. The screen is done shortly after birth, at the hospital, using a few drops of blood taken from the baby's heel.
- This is a screening test. Please talk to your baby's health care provider. More testing may be recommended by your health care provider or genetic counselor.

How can I help my child?

- Tell all your child's health care providers that your child has hemoglobin C trait.
- Take your child to all their medical appointments.
- Talk to a health care provider and a genetic counselor about hemoglobin C trait and hemoglobin diseases. Genetic counselors can help explain risks to children when planning a family.
- Teach your child about hemoglobin C trait.

Where can I get more information about hemoglobin C trait?

- Talk to:
  - Your health care provider
  - Your baby's health care provider
  - A genetic counselor

Helpful Websites

Hemoglobin C Trait
St. Jude Children's Research Hospital

together.stjude.org/en-us/medical-care/inherited-risk-genetic-testing/hemoglobin-c-trait.html

Information Sheet:
Hemoglobin C Trait

mydoctor.kaiserpermanente.org/ncal/Images/GEN_HEM_hgbC_tcm63-818620.pdf

Health Resources & Services Administration Hemoglobin Trait | Newborn Screening

newbornscreening.hrsa.gov/conditions/hemoglobin-trait

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
wadsworth.org/newborn

NEW YORK STATE | Department of Health
Wadsworth Center

4503 12/25

HEMOGLOBIN C TRAIT

The Family Connection

Information for Parents and Families

A newborn screening test shows that your baby has hemoglobin C trait. This means your baby is a carrier for hemoglobin C disease. **Your baby DOES NOT have hemoglobin C disease or hemoglobin SC disease (a type of sickle cell disease).** This information can be useful for you and your family.

NEW YORK STATE | Department of Health
Wadsworth Center

What is hemoglobin C trait?

Hemoglobin C trait is not a disease. Anyone can have hemoglobin C trait. It is passed down (inherited) from parent to child. People with hemoglobin C trait are most often healthy carriers. People are born with hemoglobin C trait and will have it their whole lives. It cannot be “caught” from someone. Hemoglobin C trait does not turn into hemoglobin C disease or hemoglobin SC disease.

What is the difference between hemoglobin C trait, hemoglobin C disease, and hemoglobin SC disease?

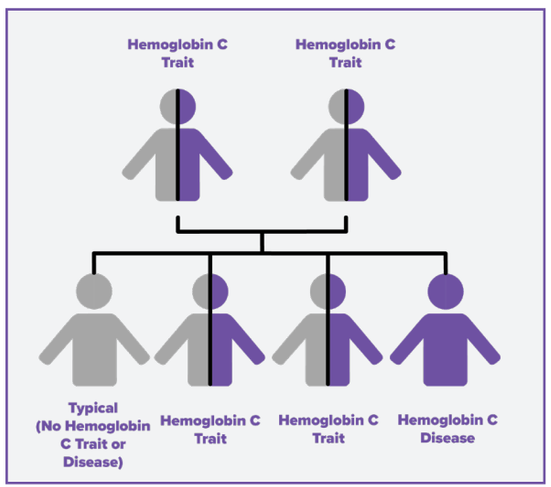
- **Hemoglobin C trait** (also known as being a carrier of Hemoglobin C disease) usually does not cause health problems. Most people with hemoglobin C trait go through life not knowing they have it.
- **Hemoglobin C disease** can cause people to have a lower number of red blood cells. This is called anemia. Some people with hemoglobin C disease may have yellowing of the skin (jaundice), deposits in the gallbladder (gallstones), or an enlarged spleen.
- **Hemoglobin SC disease** is a serious blood disorder. Hemoglobin SC disease is a type of sickle cell disease. People with hemoglobin SC disease often have chronic pain and problems with their liver and spleen. They also have more severe anemia than hemoglobin C disease. This can cause people with hemoglobin SC disease to be pale, short of breath, and easily tired. They have a high risk for severe infections and strokes. People with hemoglobin SC disease need medical care throughout their life.

How does someone get hemoglobin C trait?

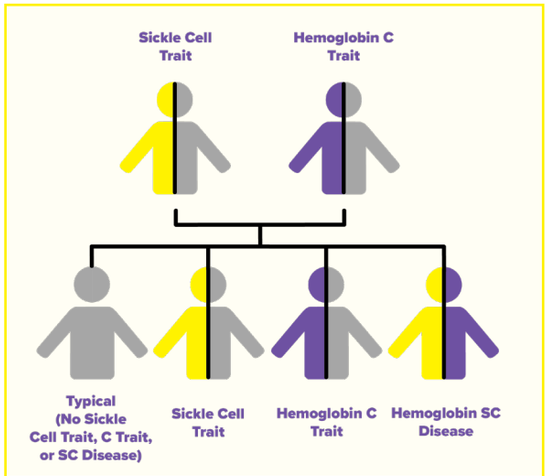
- Anyone can have hemoglobin C trait. People of all ancestries, races, and ethnicities can have hemoglobin C trait. Hemoglobin C trait is more common in people with ancestors from Africa, the Caribbean, Central and South America, Mediterranean countries, and the Middle East.
- All of us have genes (or DNA) that we inherit from both of our birth parents. A gene is a section of DNA that provides instructions for the body. Hemoglobin traits and diseases 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.
- Hemoglobin C trait happens when a person is born with 1 normal copy and 1 changed copy of the gene. This means they are a carrier of Hemoglobin C disease. Many people do not know they have hemoglobin C trait. The best way to know if you have hemoglobin C trait is to ask your health care provider and have a blood test.
- Hemoglobin C disease and hemoglobin SC disease happen when a person has 2 changed copies of the hemoglobin gene. There are also other types of hemoglobin disorders.

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

- If a child has hemoglobin C trait, it means that at least one of the child’s parents also has hemoglobin C trait. It is important that both parents are tested. Ask your health care provider about testing for all types of hemoglobin disorders (not just hemoglobin C trait). You should discuss your results with a health care provider or a genetic counselor. Testing for hemoglobin C trait will help you understand your chances of having a child with a hemoglobin disorder. People can be tested for hemoglobin C trait and other types of hemoglobin disorders at any age.
- A parent with hemoglobin C 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.
- A parent with hemoglobin C trait can have a child with a hemoglobin disease. Both parents must have hemoglobin C trait (or another hemoglobin trait) for a child to have disease.



- If both parents have hemoglobin C trait, they have a...
  - 1 in 4 or 25% chance of having a child with hemoglobin C disease
  - 1 in 2 or 50% chance of having a child with hemoglobin C trait
  - 1 in 4 or 25% chance of having a child without hemoglobin C trait or disease



- If one parent is a carrier of hemoglobin C trait and the other parent is a carrier of sickle cell trait (also known as hemoglobin S trait), they have a...
  - 1 in 4 or 25% chance of having a child with hemoglobin SC disease (a type of sickle cell disease)
  - 1 in 2 or 50% chance of having a child with hemoglobin C trait or sickle cell trait
  - 1 in 4 or 25% chance of having a child without hemoglobin C or sickle cell trait or disease
- We cannot change our genes, and we cannot decide or predict which genes get passed on to a child.