KAISER PERMANENTE®

INFORMATION SHEET

HEMOGLOBIN C TRAIT

Positive Carrier Screening Result

You have recently learned that you have hemoglobin C trait. Here is important information about being a trait carrier.

Everyone has two copies of a gene that makes hemoglobin. Hemoglobin is found in red blood cells and moves oxygen through the body. A person with hemoglobin C trait (Hb AC) has one copy of the gene that makes the usual hemoglobin (Hb A), and one copy that makes hemoglobin C (Hb C). Hb C is a type of hemoglobin that can cause an inherited blood condition when combined with a hemoglobin other than Hb A.

Hb C trait does not affect your health. Trait carriers will not develop a blood condition and usually have no signs of being a carrier. There is a 1 in 2 (50%) chance of passing this trait to any of your children.

If you are pregnant, the next step is to test your partner. **Both** parents must carry a hemoglobin trait to be at-risk for a baby with a blood condition. If your partner has a normal blood test result (Hb AA), the chance that a baby will have a blood condition is very small. Your partner can be tested at any Kaiser Permanente laboratory at no cost. A genetic counselor will let you know how to arrange testing.

Why test your partner?

- You want to know the chance that your baby could have a blood condition.
- You want to be prepared if your baby is found to be at-risk for a blood condition.
- You might consider testing the baby for a blood condition during pregnancy.

Why would you not test your partner?

- You do not want to learn about a risk for a blood condition during pregnancy.
- The result would not change anything you do during pregnancy.

What happens if my partner is a trait carrier? When both parents are trait carriers, there is a 1 in 4 (25%) chance for a baby to have a blood condition. There is also a 3 in 4 (75%) chance that a baby will not have a blood condition. If you are pregnant, you will be offered prenatal testing to find out if your baby has a blood condition. A procedure, such as amniocentesis or CVS, is able to diagnose blood conditions during pregnancy. Prenatal testing could help with pregnancy care and delivery plans. Some parents may use the results to consider whether to continue or end the pregnancy. You could also wait until after birth to test your baby through the newborn screening program.

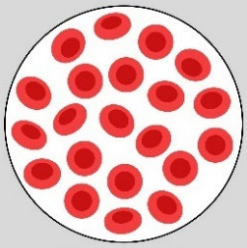
Types of blood conditions related to Hb C:

Hb SC disease - People with this condition inherit Hb C from one parent and Hb S from the other parent. This is a type of sickle cell disease and can cause many health problems.

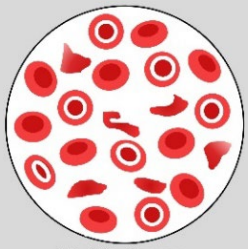
Hb CC disease - People with this condition inherit Hb C from both parents. This causes red blood cells to break down quickly and leads to anemia. Most people do not need medical treatment; however, they might develop gall stones or an enlarged spleen as they get older.

Hb C-Beta Thalassemia disease - People with this condition inherit Hb C from one parent and a beta thalassemia variant from the other parent. Severity can vary depending on the type of beta thalassemia variant. Further blood tests are needed to identify the beta thalassemia variant. People with Hb C-beta thalassemia disease have anemia and may need regular visits with a doctor. Most people do not need medical treatment; however, they might develop gall stones or an enlarged spleen as they get older.

More about Hb SC disease



Normal blood



Hb SC disease

A person with Hb SC disease has red blood cells that can change into unique shapes, instead of the usual round shape. Red blood cells that aren't round can get stuck in blood vessels. This causes pain and damage to any area where this occurs. This can happen in any part of the body, including bones, spleen, liver, heart, lungs, kidney, brain, and muscles. Blood cells that have changed shape also break down more quickly, which leads to anemia.

Signs of Hb SC disease can start in the first year of life. Symptoms are different for each person, but may include repeat infections, pain, and fatigue. Some treatments can be started in infancy. Treatments may include medications, frequent doctor visits, blood transfusions, and overnight hospital stays.

Research is being done to find ways to keep people with SC disease and other blood conditions as healthy as possible. Early diagnosis and treatment can help.

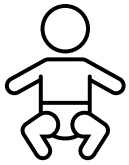
Testing Your Partner for Hemoglobin Traits

Anyone can carry a hemoglobin trait, even if there is no history of blood conditions in the family. Carrier screening detects most hemoglobin trait carriers. The chance for your partner to be a trait carrier depends on their ancestry or ethnic background.

- **Hb C trait (Hb AC)** is more common in people with West African, Mediterranean, and Middle Eastern ancestry.
- **Sickle cell trait (Hb AS)** is more common in people with African and Hispanic/Latino ancestry.
- **Beta thalassemia trait (Hb Aβ)** is more common in people with Chinese, Southeast Asian, Mediterranean, Middle Eastern, and Asian Indian ancestry.

People with these ancestries are more likely to be trait carriers, but it is possible for any person to carry a hemoglobin trait. The chance could be higher if there is any history of blood conditions in the family. Let your provider know if someone in the family has a blood condition or a hemoglobin trait.

Newborn Screening for Inherited Blood Conditions



In California, all babies are screened for inherited blood conditions in the first few days after birth. Newborn screening helps identify Hb SC disease, Hb CC disease, and Hb C-Beta thalassemia disease. If your baby has one of these conditions, a screening coordinator will contact you with the results. Newborn screening also identifies babies with Hb C trait.

Limits of newborn screening:

- Some babies with other inherited blood conditions may not be identified (this is rare).