

Hemoglobin C Disease Fact Sheet

What is hemoglobin C disease?

Hemoglobin C disease is a condition found mostly in the black population. Hemoglobin is the part of the red blood cells that carries oxygen through the body. The most common (“normal”) form is called hemoglobin A. Your child’s red blood cells contain a different hemoglobin called hemoglobin C.

How does someone get hemoglobin C disease?

Hemoglobin C disease is an inherited condition. It occurs in one out of 3,000 to 5,000 African Americans. If a child has hemoglobin C disease, it usually means both parents have hemoglobin C trait. The trait for hemoglobin C occurs in about 2-3% of all black people. Hemoglobin C trait causes no problems. *When both parents have C trait, each baby they have together has a 1 in 4 chance of inheriting hemoglobin C disease.*

What problems can hemoglobin C disease cause?

Most people with hemoglobin C disease have mild to moderate anemia (low blood count). Usually this low blood count does not cause serious symptoms or problems. Occasionally, especially during an infection, the blood count may drop even lower. Your child’s doctor may want to check the blood count in this situation.

Your child may develop an enlarged spleen, or jaundice (noticed by yellowness in the white part of the eyes). Older teenagers and adults with hemoglobin C disease also have a small risk of developing gallstones. However, many people with hemoglobin C disease have none of these problems.

Are there any special treatments for people with hemoglobin C disease?

Most people who have hemoglobin C disease do quite well. Iron and vitamins will not raise the blood counts. No other treatments or special precautions are necessary (although children who have a particularly enlarged spleen should avoid sports that involve heavy physical contact). In general, your child should be able to live a normal life despite this condition. Hemoglobin C disease is usually so mild that regular medical attention for the anemia is not necessary. Because it is a lifelong condition, however, you need to be aware of its existence in your child.

What about hemoglobin C-beta-thalassemia?

Hemoglobin C-beta-thalassemia is a milder form of the disorder. Affected people with this condition may have some of the features described above, but often to a lesser degree. Sometimes, repeat testing of individuals thought to have hemoglobin C-beta-thalassemia on newborn screening shows that they have hemoglobin C trait only.