



CARE INSTRUCTIONS

KAISER PERMANENTE

Ethnicity-Based Genetic Screening: Care Instructions

Your Kaiser Permanente Care Instructions



All of our genes come in pairs. We get a copy from each parent. Genes determine how we grow and function. They help control everything from our eye color to whether we get certain conditions. Genes that do not work right or that are missing can cause genetic conditions. These include cystic fibrosis, sickle cell anemia, and Tay-Sachs disease.

You can be a carrier of a genetic condition and not have symptoms. Instead, you "carry" one copy of a gene that is not working well. If someone in your family has one of these conditions, you may be a carrier. But many people who are carriers have no family history. If both members of a couple are carriers, they have a 1-in-4 chance of having a child born with the condition. So that means that there is a 3-in-4 chance that their child won't have the condition.

To have certain genetic conditions, a baby must get a copy of the changed gene from each parent. You can have a blood test to find out if you are a carrier. The results of this test can help you make choices about having children. If you test positive, your partner should be tested too.

Follow-up care is a key part of your treatment and safety. Be sure to make and go to all appointments, and call your doctor if you are having problems. It's also a good idea to know your test results and keep a list of the medicines you take.

Which conditions can genetic testing find?

You can be tested to see if you or your partner might pass down gene changes to your child. You may be tested for:

- **Inherited anemias.** This group of conditions affects red blood cells. It includes sickle cell anemia and thalassemia. They can lead to lifelong medical problems, such as infections. In some cases, they can cause death in childhood or the early adult years. Sickle cell disease occurs most often in people of African background. Thalassemia occurs most often in those of Asian, African, or Mediterranean background.
- **Cystic fibrosis.** This causes the lungs and digestion to not work right. Problems caused by this disease can be treated. But there is no known cure. On average, people who have it live into their mid-to-late 30s. The disease is much more common in non-Hispanic white people than in people of other races and ethnic backgrounds.
- **Tay-Sachs disease.** Babies with this disease have problems such as losing sight or not being able to eat or crawl. Children who have it do not live very long. It is more common in people of Ashkenazi Jewish, French-Canadian, or Cajun backgrounds.
- **Diseases that occur more often in people of Ashkenazi Jewish background.** These include:
 - Tay-Sachs disease.
 - Canavan disease.
 - Familial dysautonomia.
 - Cystic fibrosis.
 - Fanconi anemia group C.
 - Niemann-Pick disease type A.
 - Mucopolysaccharidosis IV.
 - Bloom syndrome.
 - Gaucher's disease.

Should you be tested?

People who are Caucasian or of African, Ashkenazi Jewish, Southeast Asian, French-Canadian, or Mediterranean background may want to think about testing. People in these ethnic groups are more likely to have children with certain genetic conditions. Some close-knit religious communities also have higher rates of certain genetic conditions. This includes the Amish and the Mennonites.

People with a family history of one of these conditions also may want to think about testing.

What should you think about when deciding about genetic testing?

- Your doctor may advise you to talk to a genetic counselor. He or she can help you understand the test and what the results could mean.
- Testing is not 100% accurate. But if you are in one of the above ethnic groups, testing is more accurate for certain diseases.
- You may choose to have testing if you are pregnant and the test results **will affect** whether you continue your pregnancy or will help you make choices about the care of your newborn child.
- You may choose not to have testing if you are pregnant and the test results **will not affect** whether you will continue your pregnancy.

Where can you learn more?

Go to <http://www.kp.org>.

Enter **Q084** in the search box to learn more about "**Ethnicity-Based Genetic Screening: Care Instructions.**"

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