



Pregnant? What you will want to know about testing for sickle cell disease

“My husband and I just found out we both have sickle cell trait. Since I am pregnant, there’s a chance our baby could be born with sickle cell disease. This disease could cause the baby to have anemia, bad infections, severe pain, and other life-long health problems.

Sickle cell is a serious disease that can mean blood transfusions and hospital stays. We are very scared—but we also want to know what we may be facing. I am going to get a test called CVS next week.”

When **one or both** parents have sickle cell trait, there is a chance their baby will be born with normal blood, sickle cell trait, or sickle cell disease. Prenatal testing (testing done while you are pregnant) can tell you if your baby will be born with sickle cell disease. Read this handout to learn more about the testing.

Why do women get tested?

Some women get the test so they will be prepared. They want to know what to expect in caring for a baby who will have sickle cell disease. If you do not think you will abort the pregnancy, your doctor may advise you to wait until the baby is born and test at birth.

Other women want to know the results of the test so they can terminate the pregnancy. This is a very personal decision. If abortion could be an option for you, you may want to get the prenatal testing done as soon as possible. It may take a while to get the test results.



When is testing done?

Your doctor will test you early in your pregnancy. The doctor will get a sample of tissue from your unborn baby. Then, the doctor will send the results to the lab.

There are two forms of prenatal testing for sickle cell disease:

- **Chorionic villus sampling (CVS for short)** can be done as early as the 10th week of pregnancy. It tests a sample of the baby's cells from the placenta—the organ that links your baby to your womb.
- **Amniocentesis (amnio for short)** can be done as early as the 16th week of pregnancy. It tests a sample of the baby's cells floating in the amniotic fluid—the fluid that surrounds your baby in the womb.

Can this testing hurt me or my unborn child?

It is a good idea to talk to your ob-gyn doctor about any problems from having the CVS or amnio. For the most part, these tests are considered quite safe and have a very low chance of health risks for mother or unborn child. There is a very small chance of miscarriage with both tests.

Does insurance cover the testing?

Call your insurance company to find out if the tests are covered. These are common prenatal tests that are often covered by health plans.

How can I learn more about prenatal testing and sickle cell disease?

- Talk to your OB-GYN about testing.
- Contact the SCDA (Sickle Cell Disease Association of America) at **800- 421-8453**. Or, go to our website: **www.sicklecelldisease.org**

