

Sickle Cell Trait

Information for women who have sickle cell trait while pregnant or breastfeeding

The information provided below is for readers based in the United States of America. Readers outside of the United States of America should seek the information from local sources.

What is sickle cell trait and how does it differ from sickle cell disease?

Sickle cell trait (SCT) is a genetic condition involving the hemoglobin in red blood cells. People with SCT carry a defective copy of a gene for a section of the hemoglobin molecule called the beta chain, but they also carry a normal copy of the same gene. This makes them carriers for a very serious blood condition called sickle cell disease (SCD). **Normally, people with SCT have no symptoms, but in recent years doctors, genetic counselors, and policy makers have been growing increasingly aware of complications that can result from SCT when the body is put under stress.** Stressful environments that can put a person with SCT in danger include high altitude, dehydration, and intense sports, and there is concern that the physical stresses of pregnancy may also do the same. Though less common than SCT, SCD also can occur during pregnancy, because an increasing number of children with SCD are living to reproductive age.

How common is SCT during pregnancy?

Genes for sickle cell hemoglobin are common in populations of humans from regions of the world where malaria is common, or was common until recently. This includes people with origins in Africa, Mediterranean regions, and parts of south Asia. Among African Americans, about 1 in 12 pregnant women has SCT. SCD is much less common, but more than 300,000 children are born with this condition around the world each year. Since survival has been increasing for children with SCD over the past few decades, SCD has become more common during pregnancy.

How are sickle cell conditions during pregnancy diagnosed?

SCT is diagnosed through laboratory tests conducted on samples of your blood. The tests include analysis of your hemoglobin as well as genetic tests to see whether you carry a sickle cell gene. The tests are the same for SCD, but in virtually all cases SCD is diagnosed in early childhood, and thus you

would know about it before getting pregnant.

Do SCT and SCD cause problems during pregnancy?

SCD has been shown to cause several problems during pregnancy, notably preterm delivery, and a serious complication called preeclampsia, plus it can lead to blood clots, strokes, and problems with internal organs (called sickle cell crisis) that can be fatal. SCT may cause infections in the amniotic fluid that may or may not affect your pregnancy. However, if you have SCT and you ascend to high altitude, you are at serious risk for a sickle cell crisis.

Do SCT and SCD during pregnancy cause problems for the baby?

SCD puts the developing baby at high risk for preterm delivery, low birth weight and size, and death. SCT may slightly increase the risk of fetal death. If you and the baby's father both have SCT, the baby has a 25 percent (1 in 4) chance of being afflicted with SCD as well as a 50 percent (1 in 2) chance of being a carrier like yourself. If the mother has SCT, but the father does not, the baby still has a 50 percent chance of being a carrier for SCD (having SCT), but is not at risk of having SCD.

What to consider about taking medications when you are pregnant or breastfeeding:

- Any risks to yourself and your baby if you do not treat the SCT or SCD.
- The risks and benefits of each medication you use when you are pregnant
- The risks and benefits of each medication you use when you are breastfeeding

What should I know about using medication to treat SCD during pregnancy?

Women who have SCD are often treated with a medication called hydroxyurea. Studies on how using this drug during pregnancy affects the patient's own developing baby have been very limited. Consequently, there is no strong evidence that children born to such mothers have any negative effects, but there is concern that future studies may reveal that hydroxyurea is dangerous to the developing child. There are two reasons for this. First, hydroxyurea belongs to a class of drugs that is used against cancer, because the drugs interfere with the reproduction of cells. The second reason has to do with that fact that hydroxyurea's beneficial effect in SCD is that it causes your bone marrow to stop making adult hemoglobin and to restart production of the type of hemoglobin that your body made when you were a fetus. Fetal hemoglobin attracts oxygen more strongly than adult hemoglobin does. This is what enables the developing baby to draw oxygen from your blood in the placenta, where the maternal and fetal blood vessels come into close contact. However, if a large portion of a mother's hemoglobin gets converted to fetal hemoglobin, the baby, theoretically, would lose the advantage in

drawing oxygen. As noted earlier, studies thus far do not proven that this actually happens, but it is something that doctors have in mind.

Who should NOT stop taking medication for SCT/D during pregnancy?

Women with SCT do not need medication for this. For those with SCD, the situation is complicated. In very serious cases, the risk of a sickle cell crisis outweighs the risk of harmful effects of hydroxyurea.

What should I know about choosing a medication for my SCT/D during pregnancy?

You may find Pregistrys expert reports about the individual medications to treat SCD [here](#). Additional information can also be found in the sources listed at the end of this report.

What should I know about taking a medication for my SCD when I am breastfeeding?

The jury is still out on whether taking hydroxyurea is harmful to the nursing infant. Until more is known, it is prudent to refrain from breastfeeding and feed the child with infant formula.

What alternative therapies besides medications can I use to treat my SCT/D during pregnancy?

For those with SCT, staying hydrated by drinking plenty of fluids, and avoiding high altitudes, are excellent ways to prevent a sickle cell crisis. For those with SCD, in addition to hydroxylurea, the condition is often treated with transfusion of red blood cells if/when the person becomes severely anemic.

What can I do for myself and my baby when I have SCT during pregnancy?

Cooperate your health care providers and heed the advice of your genetic counselor.

Resources for sickle cell conditions in pregnancy:

For more information about **sickle cell trait and disease** during and after pregnancy, contact <http://www.womenshealth.gov/> (800-994-9662 [TDD: 888-220-5446]) or visit the following links:

- March of Dimes: [Sickle Cell Disease and Pregnancy](#)
- Center for Disease Control and Prevention: [What You Should Know About Sickle Cell Disease and Pregnancy](#)

General information

It is very common for women to worry about having a miscarriage or giving birth to a child with a birth defect while they are pregnant. Many decisions that women make about their health during pregnancy are made with these concerns in mind.

For many women these concerns are very real. As many as 1 in 5 pregnancies end in a miscarriage, and 1 in 33 babies are born with a birth defect. These rates are considered the background population risk, which means they do not take into consideration anything about the health of the mom, the medications she is taking, or the family history of the mom or the baby's dad. A number of different things can increase these risks, including taking certain medications during pregnancy.

It is known that most medications, including over-the-counter medications, taken during pregnancy do get passed on to the baby. Fortunately, most medicines are not harmful to the baby and can be safely taken during pregnancy. But there are some that are known to be harmful to a baby's normal development and growth, especially when they are taken during certain times of the pregnancy. Because of this, it is important to talk with your doctor or midwife about any medications you are taking, ideally before you even try to get pregnant.

If a doctor other than the one caring for your pregnancy recommends that you start a new medicine while you are pregnant, it is important that you let them know you are pregnant.

If you do need to take a new medication while pregnant, it is important to discuss the possible risks the medicine may pose on your pregnancy with your doctor or midwife. They can help you understand the benefits and the risks of taking the medicine.

Ultimately, the decision to start, stop, or change medications during pregnancy is up to you to make, along with input from your doctor or midwife. If you do take medications during pregnancy, be sure to keep track of all the medications you are taking.