

Family Planning Options for People with Sickle Cell Trait or Sickle Cell Disease

If you have sickle cell disease or trait, you have choices for how to start your family

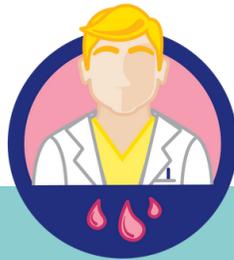
*Note: All underlined words are defined in the glossary

The first step in family planning is learning if you and your partner carry genes that lead to a chance of having a child with sickle cell disease (SCD). It takes genes from both parents to have a child with SCD. You can get a blood test to check (hemoglobin electrophoresis). Ask your doctor to order this test and to explain your results. If the test shows there is a chance your future child could have SCD, and you want to learn more, there are many people who can talk to you about your options.



Reproductive Endocrinologist (Fertility Doctor)

Knows the steps, risks, and cost of medical options



Hematologist (Blood Doctor)

Knows what to expect with SCD and your child



Genetic Counselor

Explains your child's risk for having SCD and helps you think about your options



Spiritual Advisor

May help guide your family planning choices to fit your values

Who can help?

Some of your choices are:

- Pregnancy from
 - Having sex
 - Donor egg/sperm
 - In vitro fertilization and Preimplantation genetic testing (IVF+PGT)
- Adoption
- Surrogacy

In Vitro Fertilization + Preimplantation Genetic Testing is one option to have a child for people who want to lower the chance their child will have SCD. Some benefits and risks are:

Benefits

- Child has genes from you and your partner
- Can lower chance your child will have SCD

Risks

- Pain and discomfort
- Sometimes very high cost (depends on insurance)
- Can be very stressful

The back of this pamphlet has details about IVF+PGT.

summary:

1. Ask your doctor to order a hemoglobin electrophoresis blood test for you and for your partner to check for the most common types of abnormal hemoglobin. A blood doctor (hematologist) can help you figure out if you have an abnormal hemoglobin other than sickle hemoglobin. Other abnormal hemoglobins also cause a form of SCD if paired with a sickle hemoglobin gene.
2. Adoption, donor egg/sperm, and IVF + PGT lower the chance that your child will have SCD. If that is one of your goals, ask your doctor to send you to a genetic counselor or fertility doctor (reproductive endocrinologist) to learn more.
3. IVF + PGT lets you combine egg and sperm from you and your partner in a lab to make embryos. Lab workers can test the embryos for SCD before putting one in the female's womb.
4. Visit Sickle Cell Reproductive Health Education Directive (SC RED)'s website at www.sicklecellred.org for more resources.

Next step: have a visit with your primary doctor or blood doctor (hematologist) who can refer you to other team members

In Vitro Fertilization (IVF) and Preimplantation Genetic Testing (PGT): how does the process work?

1. Ovarian Stimulation: The doctor gives medicine to release the female's eggs

The female gives herself shots one or more times daily for about one to two weeks to help her grow many eggs at once. When the eggs are big enough, she will give herself a shot to cause them all to mature at the same time.



shots are taken to grow eggs

2. Retrieval: The doctor removes the eggs from the ovaries

The doctor uses a long, thin needle to remove eggs through the vagina using an ultrasound as a guide. The female is asleep, and she may feel some cramping after.



doctor takes eggs from ovaries (yellow)

3. Fertilization: The eggs and sperm are combined in the lab.

On the day the eggs are removed, the male gives a sperm sample. The eggs and sperm are combined to form embryos with genes from both the male and female.



eggs and sperm make embryos

4. Culturing: The embryos grow in the laboratory

The embryos grow for about five days. They are scored based on how healthy they are. Parents get information about the embryos as they grow.



embryos grow in a lab

5. Preimplantation Genetic Testing: Cells are tested for SCD

A few cells are taken from a part of the embryos that will not form the baby and are sent to a lab, where they are tested for genes that cause SCD. Results come in 1-2 weeks. The test is wrong less than 1% of the time (less than 1 time in 100 tests).



lab tests genes from embryos

6. Embryo Selection: Parents and doctors choose which embryo to use

Parents get a report about the health of the embryos and which ones have SCD. The parents and the doctor choose an embryo to put in the female's womb. They may pick one without SCD if they want to lower the chance their child will have SCD. There is a chance that all the embryos will have the genes that cause SCD. Some people have concerns about how to pick an embryo or what to do with unused ones. You can talk to people you trust, like family, friends, and spiritual advisors.



embryo is chosen based on health and genes

7. Transfer: An embryo is placed in the female's womb

This is a procedure that uses ultrasound. The female is awake and often feels no pain. If the embryo attaches to the womb, the female becomes pregnant. You can try again with extra embryos, and you can also freeze them to use later.



embryo can grow into a baby in the womb

glossary

Donor egg/sperm: using egg or sperm from a person without the gene that causes SCD. Prevents the child from having SCD. The child will be biologically related to one parent.

Embryo: an early stage of fetal growth where the baby is a handful of cells with genes from the male and female parent.

Hemoglobin electrophoresis: a blood test that tells you about the building blocks that make up your blood cells, called hemoglobin. The test will show the most common types of abnormal hemoglobin in your blood, which put your child at risk for a form of SCD.

In vitro fertilization: a process that helps a female get pregnant. The process where a female gets shots to grow eggs and embryos made in the lab are placed inside the womb. You cannot have PGT without IVF.

Preimplantation genetic testing: can add to IVF. Checks for gene changes in an embryo before putting it in the womb.

Sickle cell disease: a group of diseases that affect a part of the red blood cells, called hemoglobin. Many different gene pairings can cause SCD. Some possible problems SCD can cause are pain, strokes, lung infections, and organ damage. Learn more at www.sicklecellred.org.

Surrogacy: a family planning choice where a male and female who want to be parents make an embryo in the lab, and it is put in a different person with a uterus to carry the pregnancy.