

Gaucher Disease

This sheet is about having Gaucher disease in pregnancy or while breastfeeding. This information is based on available published literature. It should not take the place of medical care and advice from your healthcare provider.

What is Gaucher disease?

Gaucher disease is a genetic condition that causes low levels of an enzyme that helps to break down fatty substances in the body. Without enough of this enzyme, fatty material builds up in parts of the body including the liver, spleen, lungs, bone marrow, and sometimes the brain. This build-up of fatty material causes these organs to stretch and not work well. Common symptoms of Gaucher disease include thinning of the bone (osteopenia), bone pain/fractures, enlarged liver (hepatomegaly), enlarged spleen (splenomegaly), lack of healthy red blood cells (anemia), fatigue (low energy), low blood platelet levels (thrombocytopenia), and easily bruising.

Symptoms can range from mild to severe and depend on the type of Gaucher disease a person has. The 3 major types of Gaucher disease are called Type 1, Type 2, and Type 3; and there are 2 subtypes.

I have Gaucher disease. What should I talk about with my healthcare team before I get pregnant?

It is important to talk to your healthcare team (including your obstetrician, anesthesiologist, hematologist, and Gaucher disease specialist) about plans for treating your condition before and during pregnancy, during delivery, and after delivery. If possible, talk with your healthcare team before getting pregnant. If your pregnancy is unplanned, contact your healthcare providers as soon as you find out you are pregnant.

Things to talk about with your healthcare team include:

- Ways to monitor your pregnancy and your Gaucher disease symptoms.
- Any medications or vitamins you should take during pregnancy. Women with Gaucher disease might not have enough of certain vitamins and nutrients, such as Vitamin D or calcium.
- Checking your bones. Pregnancy can increase the chance for severe bone pain (bone crisis).
- Getting any necessary vaccines before and during pregnancy, especially if you have had your spleen removed. Many vaccines can be given in pregnancy. For more information, please see the MotherToBaby fact sheet on vaccines at <https://mothertobaby.org/fact-sheets/vaccines-pregnancy/>.
- Any other questions or concerns you have.

Can having Gaucher disease make it harder for me to get pregnant?

Gaucher disease is not expected to make it harder to get pregnant.

Does having Gaucher disease increase the chance for miscarriage?

Miscarriage is common and can occur in any pregnancy for many different reasons. Gaucher disease might increase the chance for miscarriage.

Does having Gaucher disease increase the chance of birth defects?

Every pregnancy starts out with a 3-5% chance of having a birth defect. This is called the background risk. Gaucher disease is not expected to increase the chance of birth defects above the background risk.

Would having Gaucher disease increase the chance of other pregnancy-related problems?

A small number of studies have not found a higher chance of other pregnancy-related problems, such as preterm delivery (birth before week 37), low birth weight (weighing less than 5 pounds, 8 ounces [2500 grams] at birth), high blood pressure, or gestational diabetes among women with Gaucher disease.

Some women who have Gaucher disease start to have new symptoms during pregnancy. They also have a higher chance of bleeding, infection after delivery, and bone disease.

Some women with Gaucher disease can develop anemia and thrombocytopenia during pregnancy. Having severe thrombocytopenia and/or clotting disorders increases the chance of bleeding around the time of delivery, and can increase the chance of complications with medications used for anesthesia. It is important to talk with your healthcare team about your plans for delivery, including the use of anesthesia.

Does having Gaucher disease in pregnancy affect future behavior or learning for the child?

Studies have not been done to see if Gaucher disease can cause behavior or learning issues for the child.

Breastfeeding while I have Gaucher disease:

Gaucher disease does not appear to affect the ability to breastfeed. However, breastfeeding for more than 6 months may not be recommended for some women with Gaucher disease who have low bone density. This is because most women will lose 3-7% of their bone density while breastfeeding. Although the lost bone is usually regained after breastfeeding stops, this loss might be too much for someone who already has low bone density. Be sure to talk to your healthcare provider about all of your breastfeeding questions.

If a man has Gaucher disease, can it make it harder to get a woman pregnant or increase the chance of birth defects?

Studies have not been done to see if Gaucher disease could affect a man's fertility or increase the chance of birth defects above the background risk. In general, exposures that men have are unlikely to increase risks to a pregnancy. For more information, please see the MotherToBaby fact sheet Paternal Exposures at <https://mothertobaby.org/fact-sheets/paternal-exposures-pregnancy/>.

Please click here for references.

Questions? Call 866.626.6847 | Text 855.999.3525 | Email or Chat at [MotherToBaby.org](https://mothertobaby.org).

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