

planning a family



Gauchers
ASSOCIATION

Registered charity number 1095657
www.gaucher.org.uk

Men

For men there should not be any Gaucher related reasons that will affect your ability to father a child. You should still discuss this with your medical team as whilst ERT is thought to be safe, the impact of SRT (Cerdelga/Zavesca) is not currently known. Should your partner become pregnant whilst you are taking either medication it would be helpful to share this information with your clinical team.



Women

Planning your pregnancy is the best way to ensure the health of you and your baby. Pregnancy carries its own risks and has the potential to exacerbate your Gaucher disease, so it is sensible to try to achieve the best control of your Gaucher before conceiving.

Contraception: there are no Gaucher-specific reasons to choose one form of contraception over another and you should discuss this with your family doctor to find the solution that is right for you.

Unplanned pregnancy: DON'T PANIC. Contact your specialist team as soon as you know and they will talk through the options with you.

Fertility: fertility is not generally thought to be reduced in patients with Gaucher disease. It is sometimes easier to conceive when you are physically and emotionally well. Make sure you stop smoking, minimise alcohol consumption and start taking folic acid supplementation. Try to keep your weight within the healthy BMI range. If you are finding it difficult to conceive do talk to you specialist team so they can ensure you receive the appropriate help.

Pregnancy: contact your specialist team as soon as you know so that you can discuss the best way forward regarding your treatment and the likely impact on your health. Your clinical team will take into account any other health problems you may have and the severity of your Gaucher disease when offering you advice. A risk-benefit treatment assessment is recommended for each pregnancy.

If you would like to have children it is advisable to talk to your clinical team about this.

risks

To You (without treatment):

There is an increased risk of bone problems, anaemia and bleeding – particularly important at the time of delivery

To the baby (with treatment):

The impact of ERT on the baby has not been examined in clinical trials but no harmful, ERT-related outcomes have been reported to date

Medication

Enzyme Replacement Therapy

Cerezyme

Limited experience from 150 pregnancy outcomes (primarily based on spontaneous reporting and literature review) is available suggesting that use of Cerezyme is beneficial to control the underlying Gaucher disease in pregnancy. Furthermore, these data indicate no malformative toxicity for the fetus by Cerezyme, although the statistical evidence is low." Cerezyme SPC 17/8/16

VPRIV

There are no or limited amount of data from the use of velaglucerase alfa in pregnant women. Animal studies do not indicate direct or indirect harmful effects with respect to pregnancy, embryonal/fetal development, parturition (birth) or postnatal development. VPRIV SPC 26/10/16

Substrate Reduction Therapy

Cerdelga

There are no or limited amount of data from the use of Cerdelga in pregnant women. Animal studies do not indicate direct or indirect harmful effects with respect to reproductive toxicity. As a precautionary measure, it is recommended to avoid the use of Cerdelga during pregnancy. Cerdelga SPC 13/06/17

Zavesca

There are no adequate data from the use of miglustat in pregnant women. Studies in animals have shown reproductive toxicity, including dystocia. The potential risk for humans is unknown. Miglustat crosses the placenta and should not be used during pregnancy.

Zavesca SPC 22/09/2016



other information

Bisphosphonates

This is a group of drugs used to treat osteoporosis and other related bone diseases. There are known risks regarding its use in pregnancy and you should discuss this with your specialist doctor if you are taking any of these. It is often advised to stop taking these for some time before starting a family as these drugs can remain in your bones for many years.

Birth

It is currently recommended that you deliver your baby in the hospital setting because of the slightly increased risk of bleeding. There is no specific need for you to have a caesarean section - you should discuss the options for delivery with your midwife/obstetrician when you create your birth plan.

Breast feeding

You should ensure any medication you take is safe in breast feeding as you did during your pregnancy. If enzyme replacement therapy is present in breast milk it is likely to be broken down safely in the baby's stomach. The effect of substrate reduction therapy is unknown and is at present not recommended for use. The long term impact of breast feeding on your bone health is not clear but many experts suggest limiting breast feeding to about 6 months.

Finding out you are pregnant can be a very exciting time and there are lots of resources out there to help you.

Your specialist centre will review you regularly and will be able to provide information about Gaucher disease to your obstetrician and midwife to help keep you safe and well through pregnancy and delivery.

