Lupus

This sheet is about the effects of lupus during pregnancy and while breastfeeding. This information should not take the place of medical care and advice from your healthcare provider.

What is lupus?

Lupus is formally known as systemic lupus erythematosus (SLE). It is an autoimmune disease that affects many different parts of the body. Autoimmune diseases occur when the body’s immune system attacks its own cells or organs.

I have lupus and I am thinking about getting pregnant. Is there anything I should know?

People with lupus can have healthy pregnancies. However, those with lupus have a higher chance for complications during pregnancy. Healthcare providers believe that pregnancy outcome is better if the disease is well controlled for at least six months before becoming pregnant. It is important to speak with your healthcare team before trying to get pregnant or as soon as you know you are pregnant.

Will having lupus make it harder for me to get pregnant?

Lupus itself is not expected to affect a person’s ability to get pregnant. However, some people with high disease activity have reported missing periods, which might make it harder to get pregnant. Also, some medications used to treat lupus can affect how the ovaries work, and this might make it harder to get pregnant. People with kidney disease may also have a harder time getting pregnant.

Will pregnancy affect my symptoms?

It is not clear if pregnancy increases the number of lupus flares or new symptoms of lupus. Some studies have suggested a small increased chance for flares, with symptoms that ranged from very mild to severe. There were also some reports of flares within the first few months following delivery. The chance for symptom flares during pregnancy may be lower if lupus is not active within the six months before getting pregnant.

Does having lupus increase the chance for miscarriage?

Miscarriage can occur in any pregnancy. Lupus appears to increase the chance of miscarriage in pregnancy. Other factors, such as previous miscarriage, kidney disease, and the presence of certain antibodies (such as antiphospholipid) have been associated with a higher chance of miscarriage in people with lupus.

Does having lupus increase the chance for birth defects?

Every pregnancy starts out with a 3-5% chance of having a birth defect. This is called the background risk. Based on the studies reviewed, having lupus has not been linked with a pattern of birth defects.

Does having lupus increase the chance of other pregnancy-related problems?

People with lupus have a higher chance of developing high blood pressure and preeclampsia (a pregnancy-related condition that has several symptoms including a dangerous rise in blood pressure). People with lupus also may have a higher chance of late miscarriage, preterm delivery (delivery before week 37), and poor growth of the developing baby. In a small number of people, lupus can lead to blood clots, which can cause lung problems and possibly a stroke. Sometimes, blood clots can form in the placenta and, in rare cases, can be fatal.

Increased lupus activity, especially during conception and early in pregnancy, increases the chance for these complications. Kidney disease and having high blood pressure before pregnancy can also increase the chance for these complications.

Does having lupus cause other problems for the baby?

Lupus in the person who is pregnant can lead to symptoms of lupus in the baby. This is called neonatal lupus erythematosus (NLE). NLE is seen mostly in children that were exposed to certain antibodies (anti-Ro and/or anti-La) during pregnancy. Signs of neonatal lupus include rash, blood abnormalities that only show up on a blood test, and
liver problems. These may be temporary and often disappear by six months of age.

The most serious complication of neonatal lupus is a heart rhythm problem called congenital heart block. Congenital heart block can cause death in up to 30% of infants. Most babies born to people with lupus do not have heart block. Your healthcare provider may do a special ultrasound of the baby's heart called a fetal echocardiogram. This type of ultrasound is usually done between 18-24 weeks of pregnancy to look at the function and structure of the baby's heart.

I am taking medication for lupus. Can I take my medication during pregnancy?

Some medications used to treat lupus are not thought to increase risks to a pregnancy. Other medication may increase the chance of birth defects or other issues. For information on specific medications contact MotherToBaby and see our medication fact sheets at https://mothertobaby.org/fact-sheets-parent/.

Sometimes when people find out they are pregnant, they think about changing how they take their medication, or stopping their medication altogether. However, it is important to talk with your healthcare providers before making any changes to how you take your medication. Having lupus is associated with a higher chance of pregnancy complications. It is important to keep the disease as inactive as possible. Stopping some lupus medications during pregnancy may lead to worsening of lupus symptoms, which could increase the chance of poor outcomes. Your healthcare providers can talk with you about the benefits of treating your condition and the risks of untreated illness during pregnancy.

I would like to breastfeed my baby. Can I take my medications while breastfeeding?

Just like in pregnancy, some medications are of low concern, while others may be of more concern. For information on specific agents see our medication fact sheets or contact MotherToBaby. Talk to your healthcare provider about all of your breastfeeding questions.

If a male has lupus, could it affect fertility (ability to get partner pregnant) or increase the chance of birth defects?

Studies have suggested that lupus and certain medications used to treat lupus might affect fertility. In general, exposures that fathers or sperm donors have are unlikely to increase the risks to a pregnancy. For more information, please see the MotherToBaby fact sheet Paternal Exposures at https://mothertobaby.org/fact-sheets/paternal-exposures-pregnancy/.

MotherToBaby is currently conducting a study looking at lupus and the medications used to treat lupus in pregnancy. If you would like to learn more, please call 1-877-311-8972 or sign up at https://mothertobaby.org/join-study.

Please click here to view references.