Lupus

Information for women with lupus 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 lupus?

Systemic Lupus Erythematosus (SLE, lupus) is a condition in which the immune system attacks various tissues and organs, mistaking the body tissues for foreign material. SLE can include any or all of the following symptoms:

- Fatigue
- Fever
- Joint pain, stiffness, swelling
- Butterfly rash, covering cheeks and bridge of the nose. Rashes also may occur elsewhere on the body
- Photosensitivity: Rashes that develop or worsen after exposure to sunlight
- Raynaud phenomenon: Fingers and toes turn white/blue upon exposure to cold to cold or during stressful periods
- Shortness of breath
- Dry eyes
- Headache
- Confusion or memory loss
- Chest pain

Some of these symptoms, such as fatigue or swelling also occur frequently during pregnancy.

How common is SLE during pregnancy?

Estimates of the prevalence of SLE vary greatly depending onthe population being studied. A conservative estimate puts the number of cases in the United States at greater than 160,000. Roughly, about 9 times as many females are affected by SLE compared with males and, since typically the

disease first appears from mid or late teenage years through the mid forties, SLE if fairly common during pregnancy.

How is SLE diagnosed during pregnancy diagnosed?

Based on a suspicion that a patient may have SLE, a rheumatologist can make a diagnosis of SLE using laboratory tests performed on blood samples. These tests tell doctors that the immune system is attacking specific types of tissues, cells, and molecules within the body.

Does SLE cause problems during pregnancy?

Yes. SLE can put a woman at very high risk due to several serious complications that can develop, whether or not her SLE is in the midst of a flare-up. There is a 5 10 percent risk that an SLE mother-to-be will develop serious blood clots that could put her life in danger. Additionally, she is at high risk of developing specific pregnancy complications, such as preeclampsia, eclampsia, and diabetes, all of which can be life-threatening. The risk is highest in women who suffer from high blood pressure prior to pregnancy, in women with a history of kidney complications from SLE, and in women whose immune systems manufacture what are called anti-phospholipid antibodies. However, all women with SLE carry an elevated risk.

Does SLE during pregnancy cause problems for the baby?

SLE increases the risk of what doctors call *fetal loss*, a term that includes spontaneous abortion, late miscarriage, and stillborn birth. The risk for these undesirable outcomes is highest in mothers whose immune systems produce anti-phospholipid antibodies, in those who have experienced miscarriages in the past, and in those whose SLE was flaring-up at the time of conception.

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

- The risks to yourself and your baby if you do not treat the SLE. These can be significant
- 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 SLE during pregnancy?

Virtually all of the effective medications against SLE are potentially harmful to the developing baby. However, certain medications are particularly toxic. Examples of the latter category include methotrexate, leflunomide, and COX inhibitors. There are additional categories of SLE medications that are thought to be potentially harmful to the developing baby but for which research has been very

limited. This includes biological agents, such as rituximab and other drugs that end with mab. On the other hand, there are some medications, such as azathioprine and low-dose aspirin, that are though to be only slightly risky in pregnant women with SLE. Corticosteroids, which can be administered for a short time to treat a flare-up and then tapered off, are used frequently with good results.

Who should NOT stop taking medication for SLE during pregnancy?

This is an extreme dilemma both for the pregnant patient and her doctors. Every drug used in SLE has benefits and risks. However, since there are so many drugs, often it is possible to replace one drug with another. Planning your pregnancy can make things much easier, both for you and your doctors.

What should I know about choosing a medication for my SLE during pregnancy?

If needed, a drug can be chosen to mitigate SLE flare-ups during and prior to pregnancy, while minimizing the risk to your developing child. However, all risks cannot be eliminated.

You may find Pregistrys expert reports about the individual medications to treat SLE here. Additional information can also be found in the sources listed at the end of the report.

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

The various drugs that are effective against SLE vary both in their ability to enter breast milk and in their potential harm to the nursing baby if they do get into the milk. In order to encourage breastfeeding, doctors study how quickly the drugs move through the mothers system. For certain drugs, this has led to ideas on "how to burn the candle at both ends", in a sense. For instance, it is known that the steroid prednisolone builds up in breast milk mostly during the first four hours after a dose is given. Consequently, some doctors who give this agent for rheumatologic disease flare-ups will suggest that the patient wait four hours after receiving each dose, then pump out her milk and discard it, then wait for new milk to accumulate and nurse the infant from that new milk. For some mothers is becomes more appealing to feed their newborn with infant formula.

What alternative therapies besides medications can I use to treat my SLE during pregnancy?

It is possible that fish oil supplements containing omega-3 fatty acids are beneficial for people with SLE, but studies to date are very preliminary. There are many people making claims about folk remedies, such as acupuncture and the like, but such claims are not supported by good studies.

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

Stay in close contact both with your rheumatologist and your obstetrician. Work with your doctors to choose a treatment strategy that minimizes risks for the fetus, but also protects both you and the fetus by mitigating your SLE.

Resources for lupus in pregnancy:

For more information about **lupus** during and after pregnancy, contact http://www.womenshealth.gov/ (800-994-9662 [TDD: 888-220-5446]) or read the following articles:

- Mayo Clinic: Lupus Information.
- US Centers for Disease Control and Prevention: Lupus Detailed Fact Sheet.

Last Updated: 07-09-2018

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.