

Pregnant and Healthy

Moms-to-be with lupus cope with the fears and risks

By: Mary Dixon Lebeau

Molly Phelps, a South Bend, IN, middle school music teacher, always knew she wanted to be a mother—someday. She and her husband, Bob, talked about raising a family in the future, but they were still newlyweds and busy establishing their careers.

Since being diagnosed with lupus four years ago, Phelps—who was a *Lupus Now* Dream Makeover winner last fall—knows firsthand that life doesn't always go as planned. Still, when the home pregnancy test showed a positive result, Phelps admits to being "a bit surprised and amazed."

"I had just had surgery seven months before because my doctor suspected I had endometriosis and I was taking birth control pills because of this," Phelps says. The surgery was successful, and Phelps was told she shouldn't have a problem conceiving when the time came.

She just didn't know the time would come so quickly.

"I was still on birth control after the surgery," Phelps recalls. "I hadn't had a period for two months, but even that didn't concern me, as I've always been very irregular. And I guess I assumed having lupus would make it harder for me to conceive."

But then the waves of nausea began. Still skeptical, Phelps took a second pregnancy test—with the same results. "I wasn't really convinced until my doctor gave me the results of the blood test. There was no mistake. I was pregnant.

"I was thrilled, confused, and afraid, all at once."

Most women facing motherhood understand those feelings. But women with lupus live with fears that other mothers-to-be may not have.

"When a woman with lupus considers pregnancy, she usually has three concerns," says Michael D. Lockshin, M.D., M.A.C.R., director of the Barbara Volcker Center for Women and Rheumatic Disease and professor of medicine and obstetrics-gynecology at the Joan and Sanford Weill College of Medicine of Cornell University.

"Am I going to be healthy during pregnancy? Will my baby be healthy? And will I be well enough to raise my child and see him or her grow up?"

B.C.-Before Conception

Because many people with lupus are young women, the issue of pregnancy is a major concern.

"Often a woman's first reaction to her diagnosis of lupus is, 'Does this mean I can't have

children?" says Jill Buyon, M.D., vice chairman of rheumatology at the Hospital for Joint Diseases, and professor of medicine at NYU School of Medicine.

"I tell my patients that most women with lupus can get pregnant and do well during pregnancy," Buyon says. In fact, more than 50 percent of all lupus pregnancies are generally normal although some may end prematurely, but without any serious consequences.

"The best time to get pregnant is when you're at your healthiest," Lockshin says. "Women in lupus remission have much less trouble than women with active disease. Such planning isn't always possible, but if a woman is even considering having children, she should follow the common sense rules of good health."

Remission, however, can be a tricky thing to determine. "I wouldn't want to scare someone into thinking she could never have a baby because she's never in remission," Buyon says. "Remission is hard to define, and it's a very individual definition. But common sense should prevail in that you don't want to have active organ involvement at the time you conceive."

Buyon notes that pre-pregnancy counseling is always the best way to begin. At that time, the woman's health is thoroughly evaluated, the medications are reviewed and changed as necessary, and blood is drawn for testing.

"I like to see someone come in right before she wants to get pregnant," Buyon says. "If a woman becomes pregnant before counseling, then immediate consultation is important. While we advise remission for at least six months, pre-pregnancy screening and discussion should be close to the timing of pregnancy since a flare that happens after an earlier consultation could change the test results."

The blood work will include two blood antibody tests. "Approximately one-third of women with lupus have antiphospholipid antibodies, which interfere with the function of the placenta," Lockshin explains. "These antibodies may cause blood clots in the placenta, which can affect fetal growth. If you have these antibodies, you may be treated with heparin and a small dosage of baby aspirin. With treatment, 80 percent of women will not miscarry."

The second test is for the anti-Ro (or anti-SSA) and anti-La (or anti-SSB) antibodies. "The anti-Ro antibody occurs in about 30 percent of lupus patients," says Buyon. (SEE BOX)

Although they may have no outward effect on the mother's health, about two percent of women with these antibodies will have a child with neonatal lupus, the only type of congenital abnormality found in children of mothers with lupus.

Neonatal lupus is not systemic lupus. Rather, this syndrome consists of several key features such as a skin rash and heart and blood count abnormalities. The most serious concern is the heartbeat abnormality known as congenital heart block. If the unborn child has heart block but is otherwise

doing well, no treatment may be necessary, or there may be steroids given to the mother. After birth, most babies with congenital heart block lead normal lives with no treatment.

The presence of anti-Ro and anti-La antibodies will help determine the risk of neonatal lupus to your child. If the baby is at risk, your doctor will monitor him or her carefully and treat as necessary.

Your Treatment

One important step in planning a pregnancy is evaluating what medications you take for your symptoms, and for any related conditions.

"Certain medicines shouldn't be taken at the time of conception or during pregnancy because they cause birth defects," says Michelle Petri, M.D., M.P.H., professor of medicine at Johns Hopkins University School of Medicine and director of the Hopkins Lupus Center in Baltimore, MD. "These include thalidomide, methotrexate, leflunomide, cyclophosphamide, and mycophenolate mofetil (CellCept). Other medications, such as ACE inhibitors and NSAIDs, are stopped when the pregnancy is confirmed."

Once a woman becomes pregnant, she can continue on certain medications to maintain her own health with minimal risk to the baby. "I usually maintain Plaquenil during pregnancy," says Buyon. "I explain to my patients that Plaquenil passes through the placenta, but the risk of eye or ear toxicity in the baby is quite low, and the risk of flaring up if you stop Plaquenil may be greater. It's a long conversation.

You and your doctor should have the "long conversation" about medications as soon as you decide to conceive. Managing a pregnancy and a chronic illness is a balancing act-and keeping the lines of communication open with your healthcare team is important to maintain your and your baby's health.

What to Watch For

Although the low incidence of problems offers hope, there are some risks that moms-to-be with lupus should understand. Experts agree all pregnancies with lupus involvement should be treated as "high risk" and be handled by high-risk obstetricians, perinatologists, or other appropriately trained medical personnel. You'll be seeing this doctor, as well as your rheumatologist, every four to six weeks, with visits coming more frequently as your due date approaches.

Women with lupus do have an increased risk of miscarriage. According to Petri, about 10 percent of lupus pregnancies end in miscarriage. First trimester miscarriages generally have no known cause or are associated with active lupus. Losses later in the pregnancy are often due to antiphospholipid antibodies.

Another risk you may face is preeclampsia. "About 20 percent of women with lupus will experience preeclampsia," says Lockshin. Preeclampsia symptoms include a sudden increase in blood pressure and increased protein in the urine that leads to edema, or swelling in the tissues. The risk of increased flares is a serious-and controversial-one.

"Most flares tend to be mild," Lockshin says. He adds that normal body changes during pregnancy could be hard to distinguish from the symptoms of a flare. For example, lupus rashes may appear to worsen during pregnancy, but women without lupus also complain of increased ruddiness of the skin (called the "blush" or "mask" of pregnancy).

Labor Day and Beyond

As Phelps nears her due date, she is optimistic about labor and delivery. "I plan to have as normal a birth as possible," she says.

"There are a few things you need to know going in," says Lockshin. "If you're on steroids, for example, you might need to get extra for labor and delivery." Lockshin explains that women taking corticosteroids have suppressed adrenal glands, and in times of stress such as labor and delivery, they cannot depend on their adrenal glands to give them the extra cortisone (steroid) they need, so it may be necessary to get a supplement intravenously.

Many mothers with lupus will deliver their babies by Caesarean section. However, the decision about the type of delivery is usually not made in advance-even in high-risk pregnancies, according to Lockshin. Your doctor will evaluate you once you're in labor and then both of you can make an informed decision.

Remember, though, that delivery marks the beginning of day-to-day parenting and this transition may be difficult while dealing with lupus.

"Couples should have a contingency plan if mom is sick," says Lockshin. "Make the grim assumption you may get sick, and plan for your baby's care at that time."

Phelps is making contingency plans along with decorating the nursery. "Some days I feel like I've been hit by a truck," she says, "But other days I'm just fine. I have a lot of support, and I know my little girl will be cared for even when I don't feel well."

If you work with your medical team, develop a support network of family and friends, and follow some common sense health rules, you'll also have peace of mind, knowing you're doing all you can to give your baby the best possible start.

What are Anti-Ro and Anti-La?

About 30 percent of women with lupus have antibodies to a part of DNA and its surrounding proteins known as anti-Ro (or SSA, for Sjögren's syndrome A) and anti-La (or SSB, for Sjögren's syndrome B). For reasons that are now beginning to be understood, these antibodies identify

women whose infants are at risk for the syndrome known as neonatal lupus. It is likely that the antibodies directly attack the baby's heart and skin. The babies of women who do not have these antibodies are not at risk for neonatal lupus, so testing would most likely bring peace of mind. Also, remember, few babies are affected. If a woman does have the antibodies, the risk of the baby developing a skin rash is less than 10 percent. The risk of the baby developing the heart problem is 2 percent, according to Jill P. Buyon, M.D.

Pregnancy Pointers

Your pregnancy test is positive? Congratulations! Just remember-common sense is key when dealing with lupus and pregnancy. Take a few minutes to read our doctors' advice on how to best keep yourself and your unborn baby healthy:

- **DO** make your doctor aware of your plans as soon as possible when you are ready to start trying to conceive. Some doctors are uncomfortable with caring for pregnant lupus patients. You'll want to know this up front.
- **DON'T** take or stop medications without seeking your doctor's advice. Some medications, including steroids like prednisone and prednisolone, may be allowed. Others may need to be adjusted, but some must be totally avoided. "Discuss all your medications, even aspirin, as early in the pregnancy as possible," says Buyon.
- **DON'T** worry about passing lupus on to your child. "The overwhelming majority of babies born to lupus patients do not have the disease," says Lockshin.
- **DO** keep an eye on your ankles. "Ankle swelling can be a part of normal pregnancy, but I would be very sure to check the urine under those circumstances," says Buyon. Ankle swelling could indicate preeclampsia or lupus nephritis, so contact your doctor immediately if swelling occurs.
- **DO** watch your salt intake. Salt can raise blood pressure.
- **DO** develop a support system of family and friends and keep them informed. "I like to have the whole family in," says Lockshin. "If your parents are involved, bring them in, as well as your significant other. Let's all be on board with what we're getting into."
- **DO** try to enjoy this time. Even with its difficulties, pregnancy marks a special milestone in your life!

This article is reprinted with permission of the Lupus Foundation of America, Inc., from Lupus Now, Fall 2005. Copyright 2005. All rights reserved.