The Risks of Lupus and Pregnancy

by BARBARA LEECH

Lupus and Pregnancy: A Rollercoaster Ride

My doctor believes I have had lupus since I was 17. Diagnosed in my 40s, I spent many years struggling to find answers as to what was happening to me. This means all of my pregnancies had an increased risk that I was unaware of at the time.

Luckily, though my pregnancies were not exactly easy or carefree (and I did have two miscarriages for no apparent reason) I somehow managed to become the mother of four amazing kids.

Here's what you need to know about lupus and pregnancy.

Lupus Means Risks

Being pregnant with lupus has increased risks. In fact, women with lupus have a greater chance of miscarrying, which explains my two lost pregnancies.

Lupus can also elevate your risk of early delivery and increase blood pressure during pregnancy (a condition known as preeclampsia). I experienced both: preeclampsia with the pregnancy of my first-born, and my last child was born three weeks early and also threatened to arrive much sooner.

I never knew why these things happened to me. It seemed that all my life I had had “mysterious” medical conditions hit me out of nowhere.

Pancreatitis (swelling of the pancreas), stomach ulcers and digestive issues, pleurisy of the lungs (again unexplainable swelling), rashes, lupus hair loss, blood flow issues, swelling and fluid around my heart, and complete exhaustion. All of my sudden physical issues and conditions were a mystery until I was diagnosed with lupus a year after the last baby’s birth.

But there were so many other signs, and pregnancy seemed to be a trigger for trouble.

With my third child, following a routine checkup in my seventh month where my son’s heartbeat could not be found, I was admitted for an emergency C-section. I was rushed straight from my OBGYN’s office into the maternity ward and just before they began the procedure, the doctor heard the heartbeat return.

The emergency situation vaporized when suddenly his heartbeat filled the room and it sounded completely normal. But something had occurred, that was certain.

I spent two days on constant monitors where we learned my son’s heart would slow to a near stop four to five times in every 24-hour period. It was a rollercoaster of horrible moments followed by relief.

I would lay there as nurses rushed in, calling doctors to set up the operating room as they turned me this way and that (believing that maybe laying on the opposite side might help), all the while I heard my baby's heart slow to a stop and that horrible silence would fill the room. Then it would slowly return to normal.

After a few days of this and certain I needed to deliver soon, the doctors transported me from my regular hospital to one with a specialized neo-natal unit, and the routine continued there with at least three occasions where they prepped me for an emergency C-section.

The heartbeat always returned and action was put on hold. Ultrasounds of my baby's heart and numerous tests found nothing abnormal. The whole thing seemed like a giant mystery.

After two weeks, I was sent home on modified bed rest and required to check into the maternity ward for a two-hour monitor test of the baby's heart every single day until I gave birth.

The Good News

AJ was born at 38 weeks, six pounds and seven ounces, with no obvious health issues. He later had seizures at four weeks old and some developmental issues he has since completely overcome (no idea if those were related) but his heart is actually healthy and strong.

I am well aware how lucky I am. I had lupus at the time and nobody knew my risks — and there are many.

In some cases, babies of moms with lupus can be born with a condition called neonatal lupus, which causes the fetus to develop problems in the heart, skin, liver, and/or blood. The most common manifestations are heart block, where the heart rate is abnormally slow, or a rash, most often seen around the eyes.

Somehow, my baby was born fine and nothing was detected.

But last year the risks seemed to return to him and me. At eight years old, my son AJ was diagnosed with a heart issue (his heart was misfiring and pausing).

Was lupus to blame for this and something had gone undiagnosed in him until now? That was my greatest fear.

Next page: The facts about lupus and pregnancy, and more.

The Facts, the Mystery and the Return of Good News

Maternal lupus (also known as neonatal lupus) can lead to congenital heart block (disruption of the signal impulse) due to the presence of anti-Ro and anti-La maternal antibodies that crossed the placenta. Recent research has actually narrowed it down so a woman with lupus can be screened before getting pregnant and know if she is at risk of her baby developing it.

But screening was not available for me when I was pregnant with AJ, and even if it was, I had three years to go before I would be diagnosed with lupus.

Heart block can be mild and almost undetectable (level one) to severe (level three). It can be progressive, and children don't usually survive with level three.

Naturally, my fear was that my son was level one at birth and things went undiagnosed, just like my lupus did. My fear was now that doctors detected a missed beat in his rhythm, he had a condition all along and now it was getting worse.

I was terrified what might happen if his condition progressed. I contacted experts and researchers in New York to learn everything I could about undiagnosed heart block. I became relentless in my search for answers.

I would go into his room at night to watch my son sleep and check on him. This was not for one more kiss and to fix his blankets, but rather I felt compelled to watch him breathe to reassure myself that his heart, despite its slow and unsteady beat, was doing its job.

I actually sat in the dark by his bed and put my ear to his little chest. I heard the slow beat and then I heard the pause; the skip in his slow rhythm, then an extra beat like it was trying to catch up.

I needed answers. I needed a miracle.

My good news (my miracle, really) is that after a year of tests, and stress and fear, in March of this year, his cardiologist conducted a 24-hour monitor test and the heart issue my son clearly had a year ago could not be detected.

It was heard in January, gone in March. Again, the doctor had no great explanation other than my son grew out of it, but the doctor could not explain the sudden speed of the recovery. He called him my miracle baby.

Child of My Heart

I, of course, blamed myself for whatever heart issue AJ had. I feel maybe there is something happening within him the doctors are not seeing and it is lupus-based in origin.

I blame lupus and what I may have passed on to my children. It took me decades to get a diagnosis and I honestly fear for all of them, not only about getting lupus, but the lack of knowledge about it within the medical profession.

You spend your time wondering if it is it really OK, or if the doctors are actually missing what is really going on? That is how it is for me on a daily basis and that is how I feel about AJ's heart condition that threatened his life then suddenly vanished.

When I asked my son's pediatrician about the possibility of lupus being the cause, he at least admitted his knowledge about lupus is limited. We later learned my own blood work done when I was first diagnosed with lupus did not indicate I was at any risk of having a baby with heart block.

So, other than bad luck, there is no solid explanation of why my son developed a heart issue, or why it resolved itself. Now we wonder, are they missing the connection?

Is it lupus related? Will it return?

If you are a lupus mom, you probably share in my feelings of desperation and worry. Here is what I have to share with you:

- If you are pregnant or considering it, educate yourself on all the risks and find a high-risk OBGYN doctor who has a solid knowledge about lupus and checks for presence of anti-Ro and anti-La maternal antibodies.
- Get any symptom of lupus you discover in your children checked by their doctor and if your gut says the doctor does not appear educated about lupus, get a second opinion from one who is.

If you are a parent with lupus, you must be an advocate for your child's health and medical conditions too. Ask questions, keep your faith, and never let small, odd little symptoms get brushed aside.