Is Lupus Hereditary or Not?

by BARBARA LEECH

Is Lupus Hereditary?

Last night, after my eight-year-old son drifted off to sleep, I returned to his room to check on him. Thanks to lupus, this is not a “fix his blankets” kind of visit, but rather a desperately worried monitoring, where I feel compelled to watch him breathe to reassure myself that he is all right and his heart, despite its slow and unsteady beat, is doing its job.

I actually sat in the dark by his bed and placed my ear to rest on his little chest. I heard the slow beat and then I heard the pause; the skip in his slow rhythm. I am so afraid, and this is not the first time.

I had undiagnosed lupus in pregnancy with my son. In my seventh month, I left my desk in the newsroom, where I was editor of two newspapers, to go to my regular prenatal checkup. I never returned to work — ever.

While I was on the examining table chatting with my doctor, she grew silent. She was not answering me but focusing on sliding the monitor around my large belly so we could hear the baby’s heartbeat.

“Something is wrong,” she suddenly said. “Dear God, something is not right.”

Those words would not sink in, not fully, until I found myself minutes later in the maternity department upstairs being prepped for an emergency C-section and hearing my doctor and nurses say over and over again that they could find no heartbeat.

It was like a nightmare from which I could not awake. He was dead. He had been kicking my belly against my desk at work an hour before. But now, nothing.

Then suddenly, the faint sound of heartbeat came through the monitor; slowly, like a train pulling away from a station, increasing back up to a normal, miraculous beat that filled the room.

The nurse next to me began shouting, “There it is! He’s alive!” and tears were streaming down her cheeks as well as mine. I heard my doctor in the corner of the room thanking God. I love her for that. In those moments, she was just a human — as raw and desperate as the rest of us in the room.

This continued about three times every 24 hours until he was born. I was sent to a hospital that specialized in neonatal care and watched helplessly as the same scenario unfolded over and over, day and night, each time with the heartbeat returning.

A special pediatric cardiologist did tests and everything looked normal. Eventually, I was sent home on bed rest, but had to go into the hospital every day to be monitored for a few hours.

While at home, I was to note any time that movement stopped for more than an hour. It was terrifying.

My husband and I had a little toy duck that quacked when you squeezed it, which helped provoke movement if we placed it near my belly. But there were long moments when we held our breath, that stupid yellow duck quacking, beckoning for kicks that seemed to take a lifetime to come.

It was a very long three months of constant fear. But at 38 weeks, I went into labor and my son was born, healthy, and they said with no signs of heart issues.

Here We Go Again

Fast forward to last week, he was at school when he suddenly felt chest pains. He went to the school nurse, something he never does, and she listened to his chest. His heart was not beating normally.

Our pediatrician agreed with her findings. It was an irregular arrhythmia and he ordered an EKG, which found a bradycardia, or a very slow heart rhythm.

Next page: Barbara looks for answers on "is lupus hereditary?"

Here We Go Again

Now we are waiting to see a pediatric cardiologist next week to determine the extent of the issue, cause, and treatment is required. But the fact that he has that history in utero, and that I had undiagnosed lupus at that time, will be closely examined.

According to the Mayo Clinic, bradycardia occurs when the heart's electrical signals slow down or are blocked, and lupus can do this to the unborn baby of a mother with lupus.

Bradycardia is one several factors that can affect any part of the heart's conduction system, including the SA node and the AV node. The SA node is the pacemaker of the heart, while the AV node conducts the electrical impulse from the atria to the ventricle.

Maternal lupus can lead to congenital heart block (disruption of the signal impulse) due to the presence of maternal antibodies that crossed the placenta. Now, the real question is: Is this why my son's heart stopped beating in utero? Could it have rebounded enough that doctors never caught an issue until now?

Heart to Heart

As we wait, I am in flashback mode. His doctor says there is no urgent need to rush or panic about this, but, desperate to be understood that I am not some overly worried helicopter mother, I explained that this is not a new worry.

"I spent three months laying in a hospital bed listening to that boy's heart, praying and bargaining with my own life every time it slowed to a terrifying stop," I said. "This is a hauntingly familiar feeling I am having, doctor. So, yes, it is urgent."

And I blame myself for having this horrible disease, and four children, before I was ever diagnosed. What have I passed on to them? What will their health be like?

My daughters both have exhibited symptoms (rashes, sun sensitivity, pain all over and Raynaud's syndrome) and one has a positive ANA but is not officially diagnosed.

It took me decades to get a diagnosis and I fear for all of them, not only for getting the disease, but the lack of knowledge many medical professionals seem to have. You spend your time wondering, is it really OK or are the doctors actually missing what is really going on inside?

When I asked my son’s pediatrician about the possibility of lupus being the cause, I was grateful he at least admitted that his knowledge about lupus was limited. He believes there would have been no doubt as soon as my son was born, because the issue is so severe.

Yet, I have read that there are varying degrees of this kind of signal block, from mild to complete. When I said this, he admitted he really did not know for certain. I respect that.

So many doctors never admit that they just don’t know all there is to know about lupus. And I pray that my son’s cardiologist is someone who knows what lupus is capable of, but will also probe to learn more if that is what is required.

If You're a Lupus Mom...

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:

- **Get any symptom of lupus you discover in your children checked by their doctor.** If your gut says the doctor does not appear educated about lupus, get a second opinion from one who is.
- **Don’t be afraid to advocate for your child’s best and most thorough care.** The squeaky wheel gets the grease. Ask for the blood tests that check ANA levels and for any clotting issues.
- **Educate yourself on all the symptoms of lupus and other autoimmune diseases.** If you have one autoimmune disease, the odds increase to get another. This means that genetically your child is more prone to get any of the autoimmune diseases — they are open to the full autoimmune menu.
- **If you are pregnant or considering it, educate yourself on all the risks.** Find a high-risk OBGYN doctor who has a solid knowledge about lupus.