Maternal Alloimmunization: Protecting My Baby from My Body

A Guest Blog by the Allo Hope Foundation's Bethany Weathersby

I grew up in a large family, loving both the chaos and the built-in friendships that came with having four siblings. My mom had five normal pregnancies and five healthy children, and I always (naively) assumed my experience would be the same.

Seven weeks ago my dream of having five kids — just like my mom — became a reality when I delivered my fifth living child, a beautiful 8-pound boy we named August. But while my mom's path to five children was smooth and uneventful, my journey to five kids was painful, rocky and tumultuous. I found myself faced with a question I never expected I would have to answer: what do I do when my baby is attacked by my own immune system?

The Diagnosis

My first two pregnancies were free of complications as I carried and birthed two healthy boys, Liam and Asher. It was when I was 9 weeks pregnant with my third child — our first girl — that my obstetrician gave me the news I was not expecting. My first trimester blood work came back positive for anti-Kell (or anti-K) antibodies, and I now had a condition called maternal alloimmunization.

Maternal alloimmunization, commonly known as Rh disease or isoimmunization, occurs when a woman makes red blood cell antibodies after being exposed to a blood type different from her own. This exposure to a foreign blood type usually occurs during a blood transfusion or a previous pregnancy. The woman's immune system views the foreign blood as a threat and creates antibodies to destroy it. This can be a serious problem if the woman becomes pregnant with a baby who has the offending blood type. In these cases the antibodies can cross the placenta in the second or third trimester and destroy the baby's red blood cells. This is called hemolytic disease of the fetus and newborn (HDFN). HDFN can have devastating consequences for the baby, including anemia, fetal hydrops and even death.

I knew about the more common anti-D antibodies or Rh disease, which can be prevented with the administration of Rhogam, but I had never heard of anti-Kell antibodies. Anti-Kell is one of the many other red cell antibodies that are similar to anti-D, but cannot be prevented. The more I learned about my diagnosis, the more discouraged I became. I realized that while my body was growing and nurturing my daughter, it was simultaneously trying to destroy her. I felt desperate to protect her from my antibodies.

Options and Questions

I immediately began researching treatment options. I learned that women with red cell antibodies should be closely monitored and treated by a maternal fetal medicine (MFM) specialist. Antibody titers show how many antibodies are in the mother's blood. Titers are checked regularly until they reach the critical level. Once titers are critical it means that

there is a risk of the baby developing severe fetal anemia. The baby can be monitored for anemia by special ultrasounds called MCA doppler scans. These scans measure how quickly the baby's blood is flowing through the middle cerebral artery in the brain. If it is flowing too quickly, the doctors know the baby is anemic and in need of a blood transfusion. Blood transfusions can be done in utero if the baby becomes anemic before birth.

The critical titer for Kell is 4. My titer was 1,024 right from the start of the pregnancy. My husband and I were terrified thinking through the possibilities.

I was referred to an MFM an hour away. In the online research I'd done to try to understand my diagnosis, I came across information about treatments called plasmapheresis and IVIG. These treatments had been used in severe cases to protect the baby from the mother's antibodies until the fetus was big enough for an intrauterine blood transfusion.

I printed off a copy of the study I found showing the efficacy of the treatments and brought it to my MFM appointment at 16 weeks. I asked if we should start the treatments to protect my baby in case she was becoming anemic. The MFM said the treatments were unnecessary and considered experimental. He also explained that they would not be checking the baby for anemia until further along in the pregnancy because nothing could be done to help anemic babies before 20 weeks. The smaller the baby, the more difficult and dangerous intrauterine blood transfusions are.

I left my appointment feeling uneasy, not knowing whether or not my baby was anemic. My mind buzzed with anxiety as I thought through my unanswered questions. I had read other women's accounts of successful intrauterine blood transfusions as early as 16 and 17 weeks gestation. Why did my doctors think that nothing could be done for my baby before 20 weeks? Why couldn't we be proactive and try the plasmapheresis and IVIG treatments I had read about online?

My fears grew day by day as I worried about my baby girl. I wanted to know exactly what was happening inside my body. Was my daughter safe and thriving? Or was my womb an unseen battleground where she fought for her life, unaided by all of us here on the outside?

I finally convinced my MFMs to do an MCA scan at 18 weeks to check our baby for fetal anemia. The results were devastating. The scan confirmed that our girl was extremely anemic and had started to develop fetal hydrops as a result. Our MFMs were not very hopeful about the outcome since the anemia was already so severe. They attempted an intrauterine blood transfusion the next day, but our little girl, Lucy Dair, died a week later at 19 weeks gestation.

Grief

Lucy was beautiful. She weighed one pound and was 9 inches long. My husband and I were completely overcome with grief. There is no pain in the world like losing a child.

To make matters worse, we not only lost our beautiful daughter Lucy; we also lost our hopes for future children all in one day. We were told that we could not have any more biological children since the antibodies tend to become more aggressive with each subsequent pregnancy.

Trying Again

Even after the doctors warned us of the dangers of future pregnancies, I could not let go of my dream for a big family. Five kids. How could we try again knowing that my own immune system would attack and possibly kill my next baby? I felt guilty for still wanting to grow my family despite having two living children while desperately wishing for better treatment options for alloimmunized women.

The plasmapheresis and IVIG treatments that we hadn't tried during my pregnancy with Lucy kept coming to mind. Could they be effective in a future pregnancy?

After many months of research, discussion and prayer, my husband and I decided to try again for another baby. This time we had a plan: we would use a different team of MFMs in a different state, and we would start plasmapheresis and IVIG treatments early in the pregnancy. Intrauterine blood transfusions can actually be done as early as 15 weeks so we would start weekly MCA scans at 14 weeks to monitor for fetal anemia.

We traveled 11 hours to Houston, Texas to find an MFM who was an expert on alloimmunized pregnancies. It turns out many women have to travel to other cities, states and sometimes even other countries in order to find MFMs who have experience treating alloimmunization and HDFN.

Our new team of doctors was extremely cautious and proactive, monitoring the baby carefully week after week. Our hope grew as the treatments seemed to be working, and, we found out we were having another baby girl.

The treatments kept her safe from my antibodies until 24 weeks when she became anemic and needed her first intrauterine blood transfusion. In total, our daughter had five intrauterine blood transfusions and was born healthy at 38 weeks. We named her Nora Juliet, our little light bringing joy back into our family. But she was also a reminder of the outcome that we could have had with Lucy if we had received the same care during my first alloimmunized pregnancy.

We went on to have two more little boys with the help of plasmapheresis and IVIG treatments as well as the help of our incredible MFMs. Our third son, Callum, had 3 intrauterine blood transfusions and was born at 34 weeks and our fourth son, August, was born at 37 weeks after seven intrauterine blood transfusions.

Hope and Advocacy

Over the years I have become an advocate for other women around the world who are facing alloimmunization and HDFN. I have seen familiar stories play out in their families: the shock of the unexpected complication, the terror that comes with a new diagnosis and the fear of not knowing how to protect their children.

Unfortunately, due to the rarity of alloimmunization and the variation in care practices around the world, well-managed pregnancies and ideal infant outcomes are not universal, but I have hope that they can be. Treatment options are improving for families facing alloimmunization. New clinical trials are underway to hopefully provide less invasive treatments for babies threatened by HDFN. In 2019, I started a non-profit organization called The Allo Hope Foundation in order to bring awareness to the disease and provide support and education to families facing alloimmunization and

HDFN.

If I could go back in time to the moment I first learned about my antibodies and if I could tell myself anything it would be this: You are your baby's best advocate and you have to be her voice. With the right medical care there is hope for your baby and it is up to you to find the doctors who will provide that care. Research, learn and speak up. These antibodies do not have to determine the size of your family.

To learn more about maternal alloimmunization and HDFN visit https://allohopefoundation.org.