‘Benefiting Other Moms Like Me:’ Why One Mom Chose Research Over Fear

By Beth Kiernan, MPH, Interviewer & Teratogen Information Specialist, MotherToBaby

“When my RA started flaring 6 or 7 weeks postpartum, I got to the point that I could barely lift my own baby….We need more research on medications used in pregnancy as well as during breastfeeding!”

I want you to meet Mariah, a participant in our MotherToBaby Rheumatoid Arthritis Study. I chatted with Mariah to learn about her experience being pregnant with a chronic medical condition and to find out what motivated her to participate in our study. As a Baby Blog reader, you are probably aware that MotherToBaby provides information on exposures during pregnancy and breastfeeding. What you might not know is that we also conduct observational research on certain heath conditions and their treatments, with the goal of providing moms like Mariah (and like you!) with better information about health and medications in pregnancy. This month’s Baby Blog focuses on the role of research at MotherToBaby and puts a spotlight on those who make our program possible: the women who decide to share their pregnancy experience with us.

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BETH: Mariah, thank you so much for talking with me about pregnancy research and your involvement with MotherToBaby! As an advocate for moms with rheumatoid arthritis (RA) and the creator of the popular blog, Mamas Facing Forward, you are inspiring women with chronic illness across the globe who are or want to become pregnant.

MARIAH: I’m so glad to be here and to talk more about pregnancy research! Since being diagnosed with RA, I’ve taken an interest in medical research–both personally and professionally. It’s been interesting to see my RA treatment options expand dramatically between my first pregnancy and my third, which were only about six years apart.

BETH: In general, the medical community knows little about the effects of taking most medications in pregnancy, because pregnant women are often not included in studies that determine the safety of new medicines. What initially interested you about MotherToBaby Pregnancy Studies?

MARIAH: Medication use during pregnancy needs to be studied because of the potential risks for the developing baby! Professionally, I cover developing research for Rheumatology Network so I have a good understanding of the different types and stages of medical research. But even with this background, when I first joined MotherToBaby’s study, I didn’t understand what “observational research” meant. My biggest concern was: Would I have to take a study drug–or change my usual treatment in any way?

BETH: This is the most common question–or confusion–that I hear from women! How would you describe what observational research is and what would you say is the difference between a clinical trial and observational studies, like MotherToBaby’s pregnancy registries?

MARIAH: I’ve learned that observational means the study “observes” what a participant does, but doesn’t advise or require a treatment course or change. There is no tested drug or placebo like in a clinical trial. A pregnancy registry is a study that collects health and medication information from pregnant women and their newborns, and then compares outcomes to unexposed women and their babies. While in the study, I made my own treatment decisions with my doctor, which is logical since she knows my health history best. But because MotherToBaby provides evidence-based information about medications in pregnancy, you also helped me learn more about my medications and specific pregnancy data, which then guided the conversations I had with my doctor before pregnancy and during the flare I had at about 23 weeks.

BETH: I’m glad that we were able to help you during this flare! So what ultimately motivated you to join a MotherToBaby Pregnancy Study?

MARIAH: I’ve actually participated in two research studies through MotherToBaby, and my main motivation was due to the lack of information on medications during pregnancy. At the beginning of my second pregnancy, I wasn’t taking any medications to control my RA and I ended up flaring very badly—to the point where I was having difficulty caring

for myself and my then almost two-year-old son. Though I know oftentimes TNF inhibitors are discontinued in the third trimester (call MotherToBaby to find out why!), my rheumatologist and I made the decision to use one so we re-started Enbrel near the end of my second trimester and continued through the remainder of my pregnancy. After making such a difficult decision, I called MotherToBaby right away to enroll in the study because I wanted future moms to have the benefit of my data when it came time for them to make a similar difficult decision.

While planning to become pregnant again, my rheumatologist, perinatologist, and I decided to switch me from Rituxan to Cimzia prior to conception, and decided that I would remain on Cimzia through my entire pregnancy and while nursing. I joined the Cimzia & Pregnancy Study as soon as I found out I was pregnant with my third baby. I'm still involved, in fact, my third baby just turned one and we just got a birthday card in the mail from MotherToBaby! I think it's fantastic to have such a caring group of researchers committed to providing better information for pregnant women living with chronic illnesses.

BETH: Did you have any initial hesitations about joining a MotherToBaby study?

MARIAH: At first, I wondered if study participation would take too much time. I had a toddler at home, I worked, and I was pregnant again**.** I found out that typically a woman spends about two hours total in phone interviews in the first year, and then just ten minutes per year by phone if enrolled in a multi-year study.

My husband was concerned about privacy. I asked how my personal information would be safeguarded, and who would have access to my medical records. I asked if the study collected my insurance information or social security number–it does not. Results will be published but without revealing my identity. The studies are coordinated out of the University of California San Diego, and their Human Research Protections Program oversees the privacy and security protocols, so there is an extra layer of oversight and protection. Also, pharmaceutical companies are required to sponsor this research but they don't have access to my personal data, and all research is done independently.

Women may feel wary about the idea of participating in research during pregnancy. What has made me feel even more secure is that doctors familiar with MotherToBaby have recommended joining your studies. The studies are not experimental so I didn't find any likely risk, nor is there any cost to me. So this, coupled with the research benefiting other moms like me, made me feel like it was something that I could support pretty easily.

BETH: What was the process of enrolling like for you?

MARIAH: I answered questions about my health history, prenatal test results, some demographic info, and then made a list of exposures during the pregnancy, such as prescription and over-the-counter medications, caffeine, illnesses and other environmental exposures.

BETH: I know you've mentioned the main reason for your enrollment was due to the lack of information about medications during pregnancy. Can you tell us more about how you and your healthcare team navigated your treatment options during pregnancy?

MARIAH: As I mentioned before, my treatment options changed dramatically between my first and third pregnancies. During my first, I spoke to my obstetrician and rheumatologist about my RA medications. I didn't do much research on my own at the time (there were fewer online resources, blogs, and social media connections then too!) but rather I trusted the information being given to me by my doctors. My obstetrician knew almost nothing about RA treatments and deferred completely to my rheumatologist. Based on the data available at the time, I used nothing but prednisone during that pregnancy.

When my RA started flaring 6 or 7 weeks postpartum, I got to the point that I could barely lift my own baby. At three months, I made the heartbreaking decision to wean my son so that I could re-start Enbrel, because at the time my rheumatologist did not think there was enough data available for it to be safe enough to breastfeed while taking that medication. I did manage to find one blog at the time where a mom talked about making the decision to use Enbrel while nursing, but as much as I personally wanted to continue breastfeeding I couldn't find adequate information to make me comfortable with the idea.

BETH: I'm so sorry to hear about your struggle breastfeeding. Unfortunately, this experience is very common. We also provide information to moms about breastfeeding exposures, and many of our research participants also provide a sample of breastmilk to Mommy's Milk so we can learn more about medications and breastfeeding.

MARIAH: Yes, we need more research on medications used in pregnancy as well as during breastfeeding! So jump forward to two years later during my second pregnancy, my rheumatologist and I decided that the data had improved

enough–and that the uncontrolled inflammation I was experiencing was a greater risk to me and my baby than the potential risk of the Enbrel. I used Enbrel during the end of that pregnancy and through three months of breastfeeding. Though I must say that I made this decision under a fair amount of duress because I was feeling very, very poorly at the time. I assumed I would manage my second pregnancy the same way I managed my first, so when I started flaring badly I did not have a treatment plan in place. This was another situation where I more or less trusted my rheumatologist's advice. Unfortunately, Enbrel lost its effect for me after my second pregnancy and I weaned my second son at three months as well, and began to search for another treatment option.

For my third pregnancy, I consulted my rheumatologist and a perinatologist prior to trying to conceive. I also did a lot more of my own research. I looked to what MotherToBaby had to say about the medications we were considering and found some research studies to read. I was lucky to have doctors who also did their research. My perinatologist didn't know much about Cimzia so she researched it before meeting with me. She shared her research with me and explained how the molecular structure of Cimzia was missing the part that is responsible for crossing the placenta, making it one of the better options for use during pregnancy.

BETH: Wow! That is a lot to navigate –for you and your healthcare providers. As you have shown us, every pregnancy and treatment plan is different! What is one thing you would like pregnant women or moms dealing with a chronic illness to learn from your experience?

MARIAH: When it comes to considering the use of medications during pregnancy, public opinion tends to push the idea that a woman ought to "sacrifice" herself for the sake of her baby during a pregnancy, so it can be difficult for many women to dodge that pressure and to consider medication at all while pregnant. MotherToBaby can help illuminate both the potential benefits and potential challenges of taking a drug while pregnant or breastfeeding. I'm glad to talk about these issues, and recommend paths to women that may make their decisions easier!

BETH: Thank you so much for talking with us today and for sharing your experience, Mariah. I think many women will be interested in hearing how you navigated pregnancy and motherhood while living with a chronic illness. So many women grapple with medication questions during pregnancy, and whether they decide to participate in our studies or not, we are glad you are here to help them through it on your blog and as an RA patient advocate. Any last words about pregnancy & research?

MARIAH: I recommend you ALL THE TIME – and have benefited firsthand from the research studies!

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If you are pregnant and interested in participating in a study, contact MotherToBaby to see if you qualify! We enroll pregnant women taking certain medications or living with chronic health conditions like rheumatoid arthritis, psoriasis, psoriatic arthritis, ankylosing spondylitis, Crohn's and ulcerative colitis, multiple sclerosis, asthma, high cholesterol, and eczema. We also enroll women without any of these conditions or medication exposures. You can view a list of all our ongoing studies here: https://mothertobaby.org/ongoing-studies. We look forward to speaking with you!

Beth Kiernan, MPH, is a Teratogen Information Specialist with MotherToBaby Pregnancy Studies, a series of observational research studies about medications and health conditions during pregnancy. The studies are conducted by the non-profit Organization of Teratology Information Specialists (OTIS). Beth is based at the University of California San Diego, and is a married mother of four children.

About MotherToBaby

***MotherToBaby** is a service of the Organization of Teratology Information Specialists (OTIS), and a suggested resource by many agencies including the Centers for Disease Control and Prevention (CDC). If you have questions about exposures during pregnancy and breastfeeding, please call MotherToBaby toll-FREE at 866-626-6847 or try out MotherToBaby's new **text information service** by texting questions to (855) 999-3525. You can also visit **MotherToBaby.org** to browse a library of fact sheets about dozens of viruses, medications, vaccines, alcohol, diseases, or other exposures during pregnancy and breastfeeding or connect with all of our resources by downloading the new MotherToBaby free app, available on **Android** and **iOS** markets.*

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