

Beyond The Diet Fad: My Gluten Journey Through Pregnancy, Life

As it turns out, I'm not crazy nor am I a hypochondriac! After decades – and I mean more than 30 years – of bouts of severe constipation and diarrhea, fatigue, joint pain, migraines, skin rashes and infertility, I finally received the news that I have celiac disease. Oddly enough, it was only after adopting a sickly cocker spaniel named “Peanut” from the Humane Society that the mystery of my symptoms was solved. When our vet suggested that Peanut eat gluten-free food, I bought her some gluten-free pretzels as a treat. After eating some myself, I noticed fewer tummy issues; that feeling of the “kink” in my intestine and the bloating pain didn't happen!

I contacted my physician, whose first response was, “You don't have celiac disease, you would have already known it by this time.” She tested me anyway and, when the blood test for **transglutaminase antibodies (tTG-IgA)** was positive, she sent me to a gastroenterologist for an endoscopy (a scope of the intestines), which also indicated celiac disease. It had taken countless trips to countless physicians, but at the age of 55, my health took a turn for the better after starting a diet without gluten.

In my case, it was unfortunate that the diagnosis took so long because for years I struggled to have children. I feel lucky to have gotten pregnant five times and was able to carry two pregnancies to term. My boys are now wonderful adult men and I feel blessed to have them in my life! I'll never know if my undiagnosed celiac disease contributed to my pregnancy losses or my harder time in getting pregnant, but as an information specialist with the MotherToBaby Utah program and over 20 years' experience talking to mothers and health care providers, here's what I do know from reviewing the published information about celiac disease...

What is Celiac Disease?

Celiac disease is inherited, meaning it runs in families. When people with this auto-immune disease have contact with gluten, it causes inflammation or swelling and can damage the small intestine. Over time, the damage to the intestine causes serious health concerns, including an increased risk of colon cancer and lymphomas (cancer of the lymphatic system, such as Hodgkin's). It is estimated that 1 in 100 people worldwide have celiac disease. Many are never diagnosed.

With celiac disease, food that is eaten is quickly released from the body with little time for nutrients to be absorbed by the body. That's because the finger-like tubes in the small intestine, called villi, are flattened from the swelling.

Celiac Disease and Pregnancy

For women who want to get pregnant or who are pregnant with celiac disease, it can be a nutritional nightmare and may lead to anemia (low iron) and other vitamin deficiencies, lactose intolerance (unable to eat dairy), and osteoporosis (weak and brittle bones). It is rare that people have only one autoimmune problem and, for many people with celiac, thyroid disorders and diabetes go hand-in-hand. A recently published study looking at 24 articles on 'reproductive' issues found women with celiac disease have a harder time getting pregnant, as well as a higher risk for miscarriage, prematurity, babies born small for their age and with low birth weight. With other autoimmune disorders, such as rheumatoid arthritis, multiple sclerosis, and Lupus, we see the same types of negative pregnancy outcomes. More studies are needed to confirm if celiac disease increases any risks.

Hope

The good news is that studies also show that when moms stay on their gluten free diets, the problems almost always go away! So, to my 'Celiac Sisters' there is hope! Here are a few suggestions to have a healthy pregnancy:

- **Avoid gluten, of course!** Not only is gluten in foods, but gluten hides in make-up (be extra careful with lipsticks), hair products, soap and even in sheetrock. Never lick an envelope or a stamp, because there is gluten in glues!
- **Take your Multivitamin Before, During and after Pregnancy.** A multivitamin will help balance nutritional deficiencies from celiac disease. Make sure your vitamin has at least 400mcg of folic acid.

- **Control the Other Maladies that Come with Celiac Disease.** Rarely will someone just have celiac disease. If you have thyroid problems, diabetes or hypertension, it is important to stay on your medications and control these issues before you try to have a baby.

Ultimately, if you control the symptoms from celiac disease, you can be healthy during your pregnancy. It takes some work to avoid gluten, but I promise you will feel better! In retrospect, the veterinarian really saved two lives that day...Peanut is also doing great on a gluten-free diet!

Julia Robertson, CPM, is the program manager for MotherToBaby's Utah affiliate, a program with the Utah Department of Health and University of Utah that aims to educate women about medications and more during pregnancy and breastfeeding. Along with answering questions from women and health providers regarding exposures during pregnancy/breastfeeding via MotherToBaby's toll-free hotline (866-626-6847) and email counseling service, Julia has authored several peer-reviewed publications focusing on maternal medication consumption and the effect on the developing fetus.

MotherToBaby is a service of the international non-profit Organization of Teratology Information Specialists (OTIS), a suggested resource by many agencies, including the Centers for Disease Control and Prevention (CDC) and the Food and Drug Administration's (FDA) Office of Women's Health. If you have questions about medications, diseases, vaccines or other exposures, call MotherToBaby toll-FREE at 866-626-6847 or visit www.MotherToBaby.org to browse a library of fact sheets and to find your nearest affiliate.

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May is Maternal Mental Health Awareness Month

By Elizabeth Salas, MPH, Teratology Information Specialist, MotherToBaby California

If you are feeling anxious during your pregnancy, you're not alone. It seems every year there are more articles and news stories on the latest health hazards. Whether you read it online or in a medical journal, hear it on the news or from friends and family, there's no shortage of information on health concerns. This seems especially true during pregnancy.

Having Questions Vs. Having Anxiety

It's normal to have questions and concerns during pregnancy. Every woman has them. Every woman also deserves to have her questions answered and concerns addressed. Beyond having questions about what's safe to eat, products to use, or medications to take, pregnant women must balance their normal activities and responsibilities with scheduling prenatal appointments and preparing for their baby's arrival. With so much to think about, it's not unusual for pregnant women to feel a little bit anxious. So what's the difference between having questions and having anxiety? How much anxiety is too much during pregnancy?

The month of May is Maternal Mental Health Awareness Month, and a great time to tackle these questions, raise awareness, and talk about mental health.

What Are Anxiety Disorders?

While stressful events in our lives can cause anxiety that is mild and temporary, anxiety disorders are different in that the fear and anxiety can be excessive and/or persistent over time and can interfere with a person's ability to function in their daily life. It is estimated that 13-18% of American adults or up to 40 million people each year experience an anxiety disorder.¹⁻⁶ Anxiety disorders include generalized anxiety disorder (GAD), panic disorder, post-traumatic stress disorder (PTSD), social phobia, and other phobias. These conditions can cause individuals to experience a great deal of worry or fearfulness. Anxiety disorders can cause physical symptoms such as difficulty sleeping, fatigue, headaches, muscle aches, irritability, lightheadedness, dizziness, trembling, hot flashes, feeling out of breath, and nausea among other symptoms.⁶

Anxiety Disorders And Pregnancy

While more attention has been given to the study of anxiety disorders during pregnancy in the last decade, information is limited. Screening tools for anxiety disorders during pregnancy, such as those used to screen for depression during pregnancy and postpartum, have not been well studied and are not used regularly in obstetric clinics.² Without screening being part of routine prenatal care, it is up to pregnant women to express their concerns about anxiety to their healthcare providers. It also means that some women might not get the help they need.

Anxiety disorders during pregnancy are estimated to affect from 4%-39% of women.³ While some studies suggest that pregnant women are more likely to have anxiety disorders than non-pregnant women, other studies found that pregnant women are just as likely than non-pregnant women to have an anxiety disorder.⁴ How many women develop anxiety disorders during pregnancy is not well understood. A woman with a preexisting anxiety disorder may find that her condition is worse during pregnancy, but for others symptoms may stay the same. While gaps in our knowledge remain about anxiety disorders in pregnancy, the importance of maternal mental health is receiving more attention.⁵

What If I'm Having Problems With Anxiety?

Whether starting a new job, dealing with financial stressors, or struggling with a relationship or health complications, we have all experienced anxiety at some point in our lives. If your anxiety is affecting you more than usual or if you're concerned you may be experiencing an anxiety disorder, talk to your healthcare provider right away. Your provider will ask about your symptoms and may give you a screening questionnaire to fill out. If you are having symptoms they will

talk to you about your options and may refer you to a mental health provider. Depending on a woman's diagnosis and the severity of her condition, she and her providers may decide to treat her condition with talk therapy, behavior modification, medications, or a combination of these. Many pregnant women take medications for anxiety during pregnancy and deliver healthy full-term babies.

Since anxiety disorders can cause significant physical symptoms and stress in a person's life, these conditions require attention and treatment just like any other medical condition during pregnancy. Every woman and every pregnancy is different. Working together with your provider to keep you healthy during pregnancy isn't just important for your health; it's important for the health of your developing baby too.

WHERE CAN I GET MORE INFORMATION?

California Maternal Mental Health Collaborative

To learn more about maternal mental health disorders, access a self-quiz, and obtain a list of resources that can help, visit the California Maternal Mental Health Collaborative website.

<http://www.2020mom.org/mmh-disorders/>

<http://www.2020mom.org/get-help/>

National Institute of Mental Health

To learn more about anxiety disorders, check the National Institute of Mental Health website and their Anxiety Disorders information booklet.

<http://www.nimh.nih.gov/health/publications/anxiety-disorders/index.shtml?rf=53414>

http://www.nimh.nih.gov/health/publications/anxiety-disorders/nimhanxiety_34436.pdf

MotherToBaby

At MotherToBaby, we answer questions about exposures during pregnancy and breastfeeding. We receive questions on everything from hair dye to medications used to treat anxiety and depression and much more. Our service is free, confidential, and provides information that is evidence-based. Most importantly, our service is available to you and your healthcare providers. To speak to a MotherToBaby expert, you can call toll free at (866) 626-6847 or visit us online. <https://mothertobaby.org/>



Elizabeth Salas is the Lead Teratology Information Specialist for MotherToBaby California, a non-profit that provides information to healthcare providers and the general public about medications and more during pregnancy and breastfeeding. She is based at the University of California, San Diego, and is passionate about the work MotherToBaby is doing to promote healthy moms, healthy pregnancies and healthy babies.

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Beyond The Diet Fad: My Gluten Journey Through Pregnancy, Life

By Patricia Olney, MS, CGC, Genetic Counselor & Teratogen Information Specialist, MotherToBaby Georgia

Emily's call to MotherToBaby came in late at night. Her voicemail message sounded a bit garbled, almost as if she had been crying. I returned her call the next day and heard her anxious voice say, "My psoriasis flared up last week...it's been several years. I'm really worried because I just found out I'm pregnant." I replied calmly, "Emily, I'm glad you called MotherToBaby for information. We care about you and your baby!"

How did Emily find me? I'm a pregnancy risk specialist at MotherToBaby, which is a service of the Organization of Teratology Information Specialists (OTIS). MotherToBaby provides FREE, up-to-date, evidence-based information about exposures during pregnancy and breastfeeding. Exposures may include prescription or over-the-counter medications, chemicals in the environment, alcohol, illicit drugs, and viral or maternal illnesses, like psoriasis and psoriatic arthritis. After spending a lot of time searching the Internet for answers to her questions, a frustrated Emily found our website and our toll-free phone number and I was able to provide her with the information she needed.

Psoriasis is a life-long skin disease, but symptoms can come and go. The most common is chronic plaque psoriasis, the type Emily was diagnosed with at the age of 14. Emily described her life since being diagnosed as an emotional

rollercoaster. As a teenager, she was self-conscious about how she looked, and often felt depressed. In college she studied by herself and avoided social gatherings. It wasn't until she met her future husband that she began feeling more in control of her life. He helped her find a specialist in dermatology with experience in treating psoriasis. After trying a variety of treatments, a combination of topical corticosteroids, moisturizers, and medications helped to control her symptoms. Compared with other family members, she described the severity of her psoriasis as mild to moderate. In her late twenties, she had several flare ups which often required medication or UVB phototherapy.

During Emily's first pregnancy, she told me her psoriasis improved, and she was hoping for the same during her next pregnancy. But the week before calling me, Emily had worked long hours on a project with a tight deadline. She came home late in the evenings, feeling stressed and discouraged. By the end of the week, she noticed the all too familiar red, scaly plaques on her elbows, knees and scalp.

The evening Emily called, she had taken a home pregnancy test. She and her husband planned to have another child, but were surprised how easy it was to conceive. This time, however, she was not prepared to face the possibility of a psoriasis flare up during the first few weeks of pregnancy. I reassured her that she was not alone, and many women face the same uncertainty with pregnancy.

So what can a woman with psoriasis and/or psoriatic arthritis do to prepare for a healthy pregnancy?

Every woman who is planning pregnancy should avoid drinking alcohol and smoking cigarettes, reduce stress, exercise, eat a healthy diet, and take prenatal vitamins with folic acid. In some women with psoriasis, alcohol, cigarettes or stress may trigger a flare up or aggravate her disease.

Approximately 30% of individuals with psoriasis will develop psoriatic arthritis, characterized by pain and swelling in the joints. Psoriatic arthritis can be a side effect of psoriasis that's triggered by an interaction of genetic and environmental factors. Medications similar to those that treat psoriasis can improve psoriatic arthritis as well (1).

Women who require medication to treat their psoriasis/psoriatic arthritis should discuss pregnancy planning with their healthcare provider. Some treatments may require a period of time to clear from the body before conception, and certain medications should be avoided during pregnancy.

Will psoriasis and/or psoriatic arthritis go into remission during pregnancy?

This can be hard to predict, and it varies from person to person and even from pregnancy to pregnancy. In approximately two-thirds of pregnant women who have psoriasis, their psoriasis symptoms spontaneously improved during pregnancy due to the increase of estrogen hormones. Others, however, reported that their symptoms got worse during pregnancy. In addition, inflammatory flare-ups can occur 1-2 weeks after delivery (2). If your psoriasis symptoms get worse during your pregnancy or after you deliver, be sure to talk with your doctor. In 2012, the National Psoriasis Foundation published guidelines for treating psoriasis during pregnancy and lactation (3). For example, caution is advised when applying topical steroids to the breast to avoid passing the medication to the baby while nursing.

How can MotherToBaby help?

MotherToBaby counselors are here to help answer any questions or concerns about exposures in pregnancy or while nursing. If you have questions or concerns about psoriasis/psoriatic arthritis - and the medications used to treat these conditions - during pregnancy, call us toll-free at (866) 626-6847. Our service is FREE and confidential. MotherToBaby also conducts research on psoriasis/psoriatic arthritis during pregnancy. This research is observational, meaning participants are not asked to take any medications or to change their daily routine. To learn more about our research program, please contact one of our MotherToBaby Pregnancy Studies experts at (877) 311-8972.

After our call, Emily felt a lot more confident that she was on the right track to having a healthy pregnancy. However, her fear over how a psoriasis flare could affect her pregnancy was quickly followed by questions about how her psoriasis could be safely treated during pregnancy.

 Online resources for individuals with psoriasis/psoriatic arthritis:

National Psoriasis Foundation (<http://www.psoriasis.org>)

TalkPsoriasis Support Community (<http://www.inspire.com/groups/talk-psoriasis/>)

Talk Health Partnership (<http://www.talkhealthpartnership.com/talkpsoriasis/>)



Patricia Olney, MS, is a certified genetic counselor and pregnancy risk specialist at MotherToBaby Georgia, Emory University. She received her masters degree at the University of California, Berkeley and has practiced genetic

counseling for more than 25 years.

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Beyond The Diet Fad: My Gluten Journey Through Pregnancy, Life

By Elizabeth Salas, MPH, Teratology Information Specialist, MotherToBaby California

If you have Multiple Sclerosis (MS) and are currently pregnant, breastfeeding, or planning a pregnancy, where do you go when you have questions about MS or MS treatments? In this day and age, the first place you might go is the Internet. With no shortage of information at our fingertips, it may seem the answers to all of our questions are just a web search away. But when it comes to chronic conditions and treatments in pregnancy, reliable and accurate information isn't always easy to find, and the answers may not be so simple. So let's try a different approach, shall we? First, let's start with the facts!

The Good News

Studies about MS and pregnancy are encouraging. To date they show MS does not affect a woman's ability to get pregnant. For most women with MS, they are less likely to have a relapse during pregnancy especially in the 3rd trimester. Research shows pregnancy does not worsen MS or the progression of the disease¹. MS during pregnancy also does not increase the risk for birth defects, and does not increase the risk of major complications in pregnancy, during delivery, or for the newborn². In fact, some studies suggest pregnancy may have a protective effect for women, by slowing down or reducing the progression of MS – although more research is needed to confirm this finding³.

Making Progress in Treating MS

Ten years ago only a handful of treatments were available to treat MS. These medications, such as Betaseron® (Interferon Beta-1b) or Avonex® (Interferon Beta-1a), are called disease modifying medications because they slow down the natural course of MS while reducing the number and severity of relapses. Today there are twice as many disease modifying medications available – but the big question here is what do we know about these treatments during pregnancy or lactation?

The somewhat frustrating answer is that there is very little information about the safety of the newest medications during pregnancy or lactation. For this reason, standard practice has generally suggested women with MS stop treatment with disease modifying medications at least 1 menstrual cycle prior to attempting to conceive⁴. Older medications used to improve symptoms during a relapse, such as Solu-Medrol® (methylprednisolone) or prednisone, have been around since the 1950s⁵ and much has been published on their use in pregnancy⁶. (For more information about prednisone/prednisolone in pregnancy and lactation, see our **Fact Sheet**.) Regardless of which medications you may be taking, it's important for women with MS to plan their pregnancies and discuss treatment and options with your doctor *before* trying to become pregnant.

But what if your pregnancy, like nearly half of all pregnancies in the United States, was not planned? You may still have many questions about how your MS – and any medication you may be taking to treat it – could impact your pregnancy, such as: Could my medication have an effect on my developing baby? Will additional tests be needed during pregnancy to make sure my baby is all right? Should I continue taking my MS medications during pregnancy? If I stopped my medication, when can – or when should – I start taking them again? Can I breastfeed while taking these medications? The questions may seem overwhelming, but the good news is there are specialists who can answer your questions and they are just a phone call away!

Making The Call

Hello and thank you for calling MotherToBaby. We're here for you!

I am a counselor with MotherToBaby, a group of experts dedicated to providing women, healthcare providers, and the general public with accurate and up-to-date information on exposures during pregnancy and breastfeeding. We answer questions about everything from medications and cosmetics, to chronic conditions, like multiple sclerosis. Our service is FREE, confidential, and available for you. To speak to a counselor, call us toll free at (866) 626-6847.

Making A Difference

Every pregnant woman wants a healthy pregnancy. After personally talking to pregnant women with chronic conditions for nearly a decade, one thing has become very clear: we need better answers about how medications affect pregnancy. MotherToBaby has a follow-up program for pregnant women with MS, regardless of whether they are currently taking medication. We are learning more every day thanks to pregnant women with MS who are sharing information about their experiences. If you'd like to know more about current programs on MS and pregnancy, please contact one of our MotherToBaby Pregnancy Studies experts toll free at (877) 311-8972. You can help us make a difference, and together we can find the answers.



Elizabeth Salas is the Lead Teratology Information Specialist for MotherToBaby California, a non-profit that provides information to healthcare providers and the general public about medications and more during pregnancy and breastfeeding. She is based at the University of California, San Diego, and is passionate about the work MotherToBaby is doing to promote healthy moms, healthy pregnancies and healthy babies.

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*Interested in more information about MS and pregnancy? Check out MotherToBaby's March 2014 blog, "**MS: The Diagnosis that Doesn't Mean Missing Out on Motherhood!**"*

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

"I just found out I'm pregnant, and while I am glad, I'm also pretty overwhelmed," lamented Marian, a never-pregnant, newly-married woman who had struggled with Crohn's disease since her teenage years but was finally in semi-remission. "I'm not sure I'm comfortable taking my medications now, even though my doctors say they are fine. I can't even sleep! I am worried I'm harming my baby. I wonder if there will be long-term effects. I don't even know if it's OK to breastfeed and still take my medications, but I've had a terrible time in the past when my insurance changed and I didn't have access to these drugs."

"Your concerns are the concerns of every pregnant woman who takes medication for a chronic health condition," I told her gently. "This is the hallmark of motherhood, when a mother puts her baby's concerns above her own. However, in your case, you'll need to carefully consider the risks vs. the benefits of taking or not taking your medication. The goal is to keep your Crohn's disease from flaring so as to ensure as healthy a pregnancy as possible. Let me share some information with you. Once you have that knowledge, you will feel empowered, and you'll be able to sleep soundly knowing that you are making the best choices for both yourself and your baby."

How did Marian find me? I am a counselor at MotherToBaby Pregnancy Studies, conducted by the Organization of Teratology Information Specialists. Here at MotherToBaby, we help pregnant women, their partners, and their doctors by providing up-to-date information about exposures in pregnancy. What do we mean by "exposures"? Exposures could include prescription medications, over the counter medications, herbal supplements, caffeine, alcohol, fever, hair dye...you name it, and the question has probably been asked and answered to the best of our ability by someone in our global network of counseling services.

Half of all pregnant women in the U.S. take at least one prescription medication in pregnancy.¹ For many of these women, taking their medication isn't a choice; it's vital to their health and well-being. I'm talking about women who take medications to control seizures, to treat psychiatric illness, to treat pain, to treat asthma, or to delay the progression of diseases such as Multiple Sclerosis or Rheumatoid Arthritis. Depending on the severity of your Inflammatory Bowel Disease (IBD), you may fall into this category too. It may be that NOT treating your Crohn's or Colitis will worsen your symptoms, and could lead to a situation where both you and your baby would be threatened. Lengthy hospitalization, severe pain, blood loss, surgery - all may outweigh the risk of taking the very medication that could prevent these grim developments.

And while many women plan ahead to get pregnant, consult with their doctors, consider their medication use in advance, and start or stop medications in anticipation of conception, over 50% of pregnancies in the U.S. are unplanned.² However pregnancy happens for you, it's important to learn about your medications and what others who take them have experienced with regard to pregnancy. Some medications were approved long ago by the Food and Drug Administration and we have years of good data on their use in pregnancy. Others, particularly newer biologics used to treat autoimmune diseases like IBD, may only have been on the market for a few years at the time you inquire, so there may not be a lot of information available about the use of the drug in pregnancy - which means you will need to weigh the risks of taking or not taking the medication to both you and your baby. Your doctor can help you assess those risks, and so can information specialists like me at MotherToBaby.

It will also be important to ask whether or not there could be any impact of your IBD medications to a breastfeeding baby. Undoubtedly, breastfeeding is far more beneficial to a baby than using commercial formula, but inquiring about actual infant experience with a mother's medication use will be valuable information for you and your baby. The American Academy of Pediatrics, and your pediatrician, can tell you if there are concerns for your newborn.

If you've given yourself the luxury of time by planning your pregnancy, speak with your gastroenterologist and your obstetrician or family doctor about your medications and your plans for a future pregnancy. Gather a team of experienced physicians who will support you in your choices, and avail yourself of their advice to ensure you will be healthy when the time comes to begin trying to get pregnant. Studies show that conceiving when your disease is in remission decreases your risk of having pregnancy complications and ongoing IBD flares.³ Also, now is a good time to begin taking a multivitamin or prenatal vitamin with folic acid to ensure the best start for your baby.

What if you aren't planning pregnancy this year? Then use this article as a starting point for considering the future. If you are of reproductive age, every sexual encounter presents the chance of becoming pregnant. It's important to know what you might face in terms of medication risks were you to unexpectedly become pregnant. Ask your prescribing doctor or the pharmacist about the research on your medication in pregnancy, or call MotherToBaby at our toll-free number 877-311-8972 and ask to speak with a counselor.



Beth Kiernan is a Teratogen Information Specialist with MotherToBaby Pregnancy Studies, a non-profit that conducts observational research about exposures in pregnancy and provides information to healthcare providers and the general public on medications and more during pregnancy and breastfeeding. She is based at the University of California, San Diego, and is the married mother of four children ages 12 to 23 years.

MotherToBaby is a service of the international Organization of Teratology Information Specialists (OTIS), a suggested resource by many agencies including the Centers for Disease Control and Prevention (CDC). If you have questions about medications, vaccines, diseases, or other exposures, call MotherToBaby toll-FREE at 866-626-6847 or call the Pregnancy Studies team directly at 877-311-8972. You can also visit MotherToBaby.org to browse a library of fact sheets, including one on IBD in Pregnancy, and find your nearest affiliate.

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Questions? Call 866.626.6847 | Text 855.999.3525 | Email or Chat at MotherToBaby.org.

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