

# From Bliss, To Barely Breathing: Finding The Light Again After Infant Loss

*By Ginger Nichols, Certified Genetic Counselor at MotherToBaby Connecticut*

Oprima aquí para el Baby Blog en español

Twelve years ago I was still blissfully 24 weeks pregnant, unaware that in a couple days I would be admitted to the hospital for two hellishly long weeks of bed rest listening to the constant beeps of the fetal heart rate monitor; feeling alone and terrified for the health of my unborn baby. My son, Lincoln, was delivered at 26 weeks, weighing only one pound. He was in the NICU in preemie diapers that were too big for him, and I was by his side for one week listening to the constant beeps, whirs, and alarms of his monitors. Sounds that will haunt me to the end of time. Lincoln died in my arms a week after he was born, and while I wasn't exactly aware of it at the time, thus began my post-traumatic stress disorder (PTSD). After grieving, my husband and I agreed to try again. We experienced several miscarriages, which were also heart breaking in similar and yet different ways from the death of Lincoln. Then, I finally had my miracle baby and gave birth to a healthy daughter. The day I brought her home from the hospital I realized



My daughter, a.k.a "Miracle Baby"

just how high my anxiety was. I wondered how I could manage without the help of the nurses. And I was terrified that she would stop breathing. 10 years later, she is still breathing fine. (I might even admit to the fact that I may still check on her once in a while in the middle of the night. And maybe, just maybe, I am considering the reality that I will still want to check to see if she is breathing even when she is off to college).

## **October is Pregnancy and Infant Loss Awareness Month.**

I know through my work as a prenatal genetic counselor and experiences of friends and family that, unfortunately, I am not alone in facing pregnancy and infant loss. For those of you who have ever experienced a pregnancy loss or the death of a newborn, we are gut wrenchingly sorry.

We know, and research has confirmed, that women who have experienced a pregnancy or infant loss will experience many of the same grief stages that anyone does after the death of a family member. There may be some who don't understand how a miscarriage can be so upsetting, but, for those of us who have had one, we know that the moment we saw that positive pregnancy test we were already planning maternity leaves, nursery décor, baby's hair color, and colleges s/he would attend someday.

We can feel numb after a loss, but we can also feel many things, one after the other. Several strong emotions can be felt at once, such as shock and denial, sadness, grief, anger, or helplessness. However, for pregnancy loss there may

be other feelings, such as feeling betrayed by our bodies (*Why couldn't I carry a term pregnancy?*), to guilt over the possibility that we did something wrong (*Was it the toothpaste I used?*). And let's not even talk about how many happy pregnant women you suddenly see **everywhere** and how the number of diaper and baby commercials seems to have **tripled** after you've lost a baby or newborn!

### **Women with previous losses are a vulnerable population in their subsequent pregnancies.**

There is no real "normal" in grief, and we all respond to stressors in unique ways. Our pregnancy stories vary and we will experience loss and grief in individual ways; however, there are some common themes. Research has shown that women who have had any type of pregnancy loss are at risk for depression, anxiety, excessive worry, stress, sadness, and / or lack of enjoyment in future pregnancies. We may also feel guilty about the times that we do feel happy. We worry about experiencing another loss, and wonder how we would ever survive that emotional pain again.

### **Depression or Post-traumatic Stress Disorder during pregnancy.**

Research shows that women who have experienced pregnancy or perinatal loss can be 4 times more likely to develop symptoms of depression and 7 times more likely to suffer from PTSD than women who have never experienced a pregnancy or perinatal loss. This same research showed that most women with depression or PTSD don't receive any type of treatment. Depression during pregnancy has been associated with an increased chance for miscarriage, preterm labor, preterm delivery, low birth weight, diabetes, high blood pressure, preeclampsia (dangerously high blood pressure), cesarean section, and post-partum depression/mood disorders. Similarly, some studies looking at pregnancies in women with PTSD have suggested that there might be an increased chance for ectopic pregnancy (egg implanting in fallopian tube rather than uterus), miscarriage, hyperemesis (extreme morning sickness), high blood pressure, preterm contractions, preterm deliveries, or low birth weight.

For more information, you may also want to read the MotherToBaby fact sheet on **depression in pregnancy** found at <https://mothertobaby.org/files/Depression.pdf> or **stress in pregnancy** at: <https://mothertobaby.org/files/Stress.pdf> .

Finding healthy ways to help you feel better is important. Your health care team may be able to refer you to a local therapist who specializes in working with women who have had pregnancy losses. The earlier you seek help, the better you may do. You don't have to go through this alone. Sometimes medications can be discussed, but often therapists can help teach you coping techniques with breathing exercises, meditation, or baby safe yoga. Each person's treatment plan should be personally designed after discussion with their health care provider.

### **Signs and symptoms of depression.**

Remember, there is no "one size fits all". Meaning signs and symptoms of depression can be different among people, and they might change over time. Most people will not have all the symptoms at once. Having a "bad" day or two now and again is normal and is not true depression or anxiety. Women with depression and or anxiety have symptoms that are present most of the time, last for at least 2 weeks or longer and make day to day life hard to enjoy.

1- Feeling **overwhelmed**.

2- Feeling **guilty** about not being able to juggle all that life is throwing at you. You feel like someone else could do better than you are doing so far.

3- Feeling lost or not able to understand what is happening or why or how to change it. Scared to talk about it or reach out for help out of **fear of judgement** or worse.

4- Feeling **angry** and short tempered or **easily irritated**. You have **less patience** than ever before and can't seem to get into check. You may resent all those around you including your spouse. Rage is a good description of your emotions on a regular basis.

5- Feeling **numb** or empty.

6- Feeling a level of **sadness** you have never felt before.

7- Feeling **hopeless, helpless, and weak**.

8- Changes in **sleep** (too much or too little).

9- Changes in **eating** habits (too much or too little).

10- Lack of **concentration** and focus.

11- Feeling like you are **disconnected** from everyone and everything.

12- Feeling like you should be feeling better - except **you still aren't feeling right**.

13- Feeling like **you want to escape** and run away from your life.

14- Feeling **suicidal** or wanting to harm yourself.

### **Finding brightness in a dark situation and moving toward the light.**

I think one important step in recovery is to find a health care provider that you trust for your next pregnancy. My OB team would let me just sit in their office and cry, and never once did they look at their watches and make me feel like I was taking up too much of their time. I also remember that instance when I voiced my concern about being a “Nervous Nellie” since I worried about every little thing. My doctor held my hand and said, “Not so, research has shown us how mothers with pregnancy and newborn losses can develop PTSD, and we understand.” For these compassionate moments, I am thankful. In my line of work, I have found that many OB teams do understand. Some OB groups are likely to allow quick ultrasound peaks for Moms to see the baby’s heartbeat, which might ease some of the anxiety in future pregnancies. **MotherToBaby** can also help ease stress when it comes to questions about medications, diseases and other exposures during pregnancy.

I hope reading this blog doesn’t trigger heightened anxiety, but, instead, motivates you to build an important mental health support system around

you. Be gentle with yourself, and maybe eat some chocolate. Because when life throws you a curve ball full of grief, a good support system with great listening ears and shoulders to cry on can be a comfort. Life will never be the same, but remember you are not alone and there is hope.



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**By Chris Colón, Certified Genetic Counselor at MotherToBaby Arizona**

During pregnancy, many women make changes in their lives in order to have the best chance to have a healthy baby. I know I did during both of my pregnancies. These changes can involve their diet, exercise habits and other lifestyle factors. After birth, new moms may consider adding back some of the things they cut out over the last 9 months, including drinking alcohol. But is adding it back in that simple? During September's Fetal Alcohol Spectrum Disorders (FASD) Awareness month, I thought I'd examine the topic of alcohol in breastmilk a little more closely for you. It's a question I get frequently from the women who contact our service. As you probably know, for years, experts have been saying there is no known safe amount of alcohol use during pregnancy, but does alcohol affect a breastfeeding baby?

### **Before you raise your glass of favorite vino, here's what research says...**

Studies have shown that alcohol passes into the breast milk. The concentration of alcohol in the breast milk is close to the concentration of alcohol in the woman's bloodstream. Alcohol can pass back and forth from the bloodstream into the breast milk. It's a common myth that pumping and discarding breast milk will remove the alcohol from breast milk. Even if you discard pumped breast milk after drinking, alcohol still remains in your blood for a period of time, depending on how much you had to drink. The only way to get rid of alcohol from your system is to wait for your body to break it down and get rid of it. It takes about 2 to 2.5 hours for each standard drink to clear from breast milk. (A standard serving is considered to be 12 ounces of beer, 4-5 ounces of wine, or 1.5 ounces of hard liquor.) For each additional drink, a woman must wait another 2-2.5 hours per drink. Pumping and discarding, drinking water, taking caffeine, or exercising do not help your body get rid of the alcohol faster, because only time can reduce the amount of alcohol in the breast milk.

### **More misconceptions...**

Another common misconception is that drinking during breastfeeding is recommended to help produce more breast milk. It used to be believed that beer raised levels of prolactin, a hormone in the body that plays a role in making breast milk. However, alcohol may actually reduce the amount of milk you produce. It is now known that alcohol lowers the release of another hormone called oxytocin. Lower oxytocin levels can affect the amount of milk that is released from the breast, meaning a baby may get less milk.

### **Alcohol's known effect on baby**

Many people wonder if alcohol affects a growing baby. Effects on infants from alcohol in breast milk are not well studied. There are some reports that babies whose mothers drink alcohol while breastfeeding may eat less and/or experience changes in their sleeping patterns. One study suggested problems with motor development following exposure to alcohol in breast milk, but other studies did not show the same results. There are many factors that can play a role in how alcohol can possibly affect a developing baby. Differences in genetics and metabolism of alcohol by both the mother and the baby may result in a wide range of risk. The risk may be different even in different babies from the same mother. At this time, it's not clear how alcohol in breast milk can affect a developing baby.

Depending on the amount of alcohol you drink and the frequency with which you drink, you may not need to stop breastfeeding if you drink alcohol. You can speak with your health care provider as well as the baby's pediatrician about how much alcohol you are drinking as well as all your choices for breastfeeding. You can also contact a MotherToBaby counselor at (866) 626-6847 to talk about alcohol and other exposures during breastfeeding.

**Chris Colón is a certified genetic counselor based in Tucson, Arizona and proud mother of two. She currently works for The University of Arizona as a Teratogen Information Specialist at MotherToBaby Arizona, formerly known as the Arizona Pregnancy Riskline. Her counseling experience includes prenatal and cardiac genetics, and she has served as MotherToBaby's Education Committee Co-chair since 2012.**

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# From Bliss, To Barely Breathing: Finding The Light Again After Infant Loss

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

“Do women really eat their placenta after delivery?” I was asked many years ago when a coworker mentioned a famous celebrity had talked about it during an interview. I had never heard of the practice before. As I await the birth of my first child, I got to thinking about this question again. I mean, the placenta-eating crowd has really created some demand over the last couple of years! Today, you can easily find services that will encapsulate your placenta, countless articles on the web, and even websites that offer placenta recipes. What’s next? Seeing it on a menu? Imagine hearing at your favorite dine, “I’d like a burger, fries and a placenta pop, please!” Bottom line, women are talking about it, asking about it, and yes, eating their placenta.<sup>1</sup>

## **The human placenta is an amazing organ, but what exactly does it do?**

The placenta is a temporary organ that develops during pregnancy to connect mom and her developing baby. The placenta provides oxygen and nutrients, removes substances or waste that could be harmful, and protects the baby from mom’s immune system.<sup>2</sup> The placenta also produces hormones that play an important role in pregnancy and the baby’s development.<sup>3</sup> When there are problems with the placenta, this can cause serious complications for mom and baby. Furthermore, as our knowledge of the placenta continues to grow, research suggests that problems with the placenta may give us clues or even cause future disease in mom or baby.<sup>4</sup>

## **What do we know about placentophagy?**

The term placentophagy refers to the consumption of the placenta. Among mammal species, animals commonly eat raw placenta immediately after the delivery of their offspring. It has been theorized that animals instinctively consume the placenta for its nutritional benefit to the mother animal, or to prevent predators from being attracted to the location of their newly born offspring.<sup>5</sup> Human placentophagy however, does not consist of eating the raw placenta immediately after delivery. Typically the placenta is processed and consumed in small quantities in the weeks or months after delivery. Some cultures practice consumption of the placenta, but according to studies of cultures around the world this is a rare practice.<sup>6</sup>

## **Are there benefits to consuming the placenta after delivery?**

Supporters of placenta consumption point to several possible benefits for mom. Iron is an essential element needed by our bodies for blood production.<sup>7</sup> When a woman delivers, it is normal to expect some blood loss. Since the placenta is rich in iron, consuming placenta may replace some of the iron lost during birth. The placenta also produces a substance called placental opioid-enhancing factor (POEF) which may aid in pain relief after delivery. Placenta consumption has also been suggested to improve milk production and decrease the chance of postpartum depression. The placenta contains a hormone called placental lactogen which can stimulate milk production. It also contains the hormones progesterone and corticotropin-releasing hormone (CRH). Women with low levels of these hormones may be more likely to develop postpartum depression. Therefore, it is thought that consuming placenta containing these hormones could possibly decrease the risk of depression.<sup>8</sup>

While the practice of consuming placenta has gained popularity and the possible benefits may be worth investigating, the practice is mainly supported by individual cases or personal stories. Well controlled studies have not been conducted to investigate the safety of placentophagy or its efficacy in aiding with pain management, milk production, or reducing postpartum depression.<sup>9</sup> Most of the studies published on placentophagy have focused on surveying both men and women regarding the practice and their attitudes towards it.

## **Have any concerns been raised regarding placenta consumption?**

There is currently no regulation of the processing or consumption of human placenta. If the placenta is prepared by an outside party, how can a new mom be assured of sanitary practices and handling? How does she know she has received her own placenta back? Since the placenta is a blood product and tissue, there are concerns that

consumption can transmit infectious diseases. There is also a possibility of contamination that may occur in the hospital or during the process of storage, preservation, or preparation.<sup>8</sup>

Some commentators suggest that due to the processing of the placenta which may include preservation, cooking, drying, or freezing of the tissue, there would be little or no nutritional health benefits. Individuals or companies that process the placenta may add herbal products which consumers should be aware of in case there is a sensitivity or allergy to these products. Some have also suggested that because the placenta acts as a filter of some environmental toxins, eating the placenta could expose mom to higher levels of harmful substances. Finally healthcare providers have also expressed concerns that women experiencing postpartum depression may not seek help or may refuse treatment with medications proven to be effective because they are self-treating at home with placenta.<sup>9</sup>

### **What can I do if I'm concerned about postpartum depression or milk production?**

If you are concerned about developing postpartum depression or think you may be experiencing symptoms, contact your doctor right away. Postpartum depression has serious consequences for both mom and baby, but help is available and symptoms should never be ignored. To learn more about Depression During and After Pregnancy, check out the following fact sheet: <http://www.womenshealth.gov/publications/our-publications/fact-sheet/depression-pregnancy.pdf>

You can also learn more by visiting the following links:

<http://www.postpartum.net/learn-more/pregnancy-postpartum-mental-health/>

<https://www.womenshealth.gov/mental-health/illnesses/postpartum-depression.html#pubs>

If you have recently delivered or are getting close to delivery, and have concerns about producing enough milk, talk to your pediatrician, a lactation consultant, or attend a breastfeeding support group. Making small modifications during breastfeeding can make a big difference. To learn more about solutions to common challenges that come up when breastfeeding visit the following womenshealth.gov page:

<http://www.womenshealth.gov/breastfeeding/common-breastfeeding-challenges.html>

For more information on breastfeeding support, information, and resources visit the following links:

<http://www.womenshealth.gov/breastfeeding/finding-breastfeeding-support.html>

<http://www.womenshealth.gov/breastfeeding/breastfeeding-resources.html>

### **Is it safe to breast feed while consuming placenta?**

No studies have been published to accurately evaluate safety of consuming placenta during breastfeeding. Among the things a mom consumes in her diet or the medications she takes, some substances pass more easily into breast milk and can reach the breastfed infant. Because every woman's placenta is slightly different, some placentas may contain substances that others do not or they may contain very different levels of a particular substance compared to another placenta. Without testing individual placentas, it would be difficult to evaluate how they differ and how safe mom's consumption might be for babies who are breastfed.

### **Where can I get more information about the safety of exposures during breastfeeding?**

MotherToBaby experts are ready to answer all of your questions on exposures during breastfeeding. We also answer questions about exposures in pregnancy for women who are currently pregnant or planning a pregnancy, as well as their healthcare providers. You can speak with a MotherToBaby counselor through our free and confidential service. Call us toll free at (866) 626-6847.

**Elizabeth Salas, MPH 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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# Light Again After Infant Loss

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By Robert Felix, President, MotherToBaby

Gardens are blooming, kids are out of school, beaches and parks are crowded, and the sun is shining. Ahhh....Summer is here again! With more skin showing during these warm summer months, it's important to protect our skin from the sun by wearing sunscreen. But what do we know about the safety of sunscreen products during pregnancy? Should pregnant moms avoid sunscreen? What if the day is overcast and cloudy? These are questions I'm getting often these days as a teratogen information specialist at MotherToBaby. So let me share with you what I tell women who contact our service...

First, there's a misunderstanding that when the sun is not directly shining, like when it's overcast, we are protected from the harmful effects of the sun's ultraviolet rays (UV-A and UV-B). So let me shine a light on the issue (no pun intended). Because the sun's ultraviolet rays penetrate clouds, everyone - including children and pregnant women - is vulnerable to sunburns, even on cloudy days. Damage to our skin that is caused by the sun can lead to long-term issues, including premature aging as well as skin cancer.. Prevention is key. Seeking shade, wearing protective clothing and using sunscreen are all important in reducing the risk of sunburns and skin cancer.

## **So what about sunscreen safety during pregnancy?**

Sunscreen alone is not fully protective. However, it certainly can provide added protection for the skin and reduce the risk from sunburn. In fact, the American Academy of Dermatology (AAD) recommends everyone use sunscreen. Pregnant or not, choose a sunscreen that protects against both UVA and UVB rays. Water resistant with a high sun protection factor (SPF) really helps, too; the AAD recommends using a sunscreen with a SPF of at least 30, which blocks 97% of the sun's rays.<sup>1</sup>

The ingredients in sunscreen products in the U.S. have to go through a specific approval process. They must be reviewed by the U.S. Food and Drug Administration (FDA) for their safety before they hit shelves. Unfortunately, there is not one preferred choice for pregnant women. However, it is reassuring that to date there is no published information suggesting that sunscreens cause an effect to the developing fetus/unborn baby. Additionally, sunscreen use can help prevent blistering sunburns, which can become easily infected and lead to other complications for a pregnant woman.

So what do our counselors at MotherToBaby recommend that pregnant women do? Before you head out the door, cover up with cool, breathable long sleeve clothing; wear a hat to protect your head and face; apply sunscreen on any areas of your skin that are exposed; and try to stay under shaded areas, when possible. Our last bit of advice? Enjoy your summer!

**Robert Felix is a teratogen information specialist at MotherToBaby California, a non-profit affiliate of the international Organization of Teratology Information Specialists (OTIS). Robert is the current president of MotherToBaby and is based at UC San Diego's Center for Better Beginnings. MotherToBaby CA answers questions over the phone as well as via live chat and email through [www.MotherToBabyCA.org](http://www.MotherToBabyCA.org).**

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- American Academy of Dermatology. Sunscreen FAQs. Available from, <https://www.aad.org/media-resources/stats-and-facts/prevention-and-care/sunscreen-faqs> Accessed July 6, 2015.

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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.**

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**Questions? Call 866.626.6847 | Text 855.999.3525 | Email or Chat at [MotherToBaby.org](https://www.MotherToBaby.org).**

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