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The Deadly Itch:

How My Midwives Saved My Babies' Lives

by Kim Gallina Viscio

Intrahepatic cholestasis of pregnancy (ICP) is a pregnancy-related liver disorder in which there are abnormalities in the flow of bile. These abnormalities lead to a build-up of bile acids in the mother's blood, resulting in symptoms such as severe skin itching. —March of Dimes definition of Intrahepatic Cholestasis of Pregnancy

Before I got pregnant, I contemplated going to a midwife instead of an obstetrician. I had never been to a midwife before, but the thought of one was appealing. I imagined something more human than clinical. More cozy than cold. Something deeper than a typical patient-doctor relationship. A close friend had given birth to her first child under the care of an OB, but used a midwife for her second baby. Her midwife advocated for her as a woman, patient and mother in a way that her OB had not. That sealed the deal for me. Little did I know how much this advocacy would mean to me and the life of my unborn babies.

I turned to trusty Google to find a midwife in my area. Advanced Wellness Solutions in Doylestown was at the top of the search. The second I stepped into their waiting room, I knew I had found what I was looking for. There were sofas, welcoming chairs and a huge selection of toys. I wasn't called until they were ready and I didn't have to sit awkwardly in an open gown on an exam table. Instead, I sat on another comfy couch while JoAnne Ruth, CNM, sat across from me in an equally comfy-looking chair. It felt like we were in her living room instead of a doctor's office.

I didn't meet my husband until my mid-thirties and so I fell into the category of advanced maternal age right from my very first pregnancy. That pregnancy had signs of problems from the beginning, such as low HCG levels and the fetus measuring small for dates. But I was not prepared for the missed miscarriage that was discovered on my 37th birthday. My midwives hugged

me, treated me with a delicate kindness and helped me understand how common miscarriage is for a first pregnancy.

My husband's birthday, a few months later, delivered much happier news. I was pregnant again! However, the naivety and excitement of my first pregnancy was replaced by paranoia and fear. I became the boy who cried wolf, constantly calling my midwives about something.

In the beginning, I panicked when I saw my progesterone results and asked to be put on supplements so I would not miscarry. At 14 weeks (which happened to be both Father's Day and my first wedding anniversary), I started bleeding and I called my midwives in a panic. They tried to calm my fears, but suggested I go to the ER if that would make me feel better, which, in my hyper-sensitive state, it did. The baby was fine. Weeks later, I read about incompetent cervixes and, suddenly, thought I had one. I didn't have an incompetent cervix, but I did have an anterior placenta so sometimes I couldn't feel my baby's movements. JoAnne offered to hook me up to her fetal Doppler anytime I needed reassurance. She was so patient and understanding.

Once I hit the third trimester, I finally let out a huge sigh of relief. I joked with JoAnne about my previous craziness and said I could finally enjoy the rest of my pregnancy. I couldn't have been more wrong.

Around 30 weeks, I noticed something odd. My feet became quite itchy. At first I thought I was having an allergic reaction to my new sheep fur-lined boots. But then the palms of my hands became itchy as well. Then my back and my arms. I didn't have a rash so I couldn't figure out what was going on. I tried lotions, Bena-dryl, cold showers instead of hot showers. Nothing helped. I went to my old friend Google and typed in, "Pregnant. Itchy. No rash." The results that appeared scared me to death.

Intrahepatic Cholestasis of Pregnancy

My search led me to information about intrahepatic cholestasis of pregnancy (ICP). Symptoms of ICP include itching without a rash (most often on the soles of the feet and palms of the hands), upper right quadrant pain, dark urine and light stools, among other things (Mayo Clinic 2014). Google also told me that ICP has a high rate of fetal demise (Reid et al. 1976). I became nauseous and my head started spinning. "One to two out of 1000 pregnancies are diagnosed with ICP" (CHOP 2014). My husband saw these odds and said, "This is so rare. I doubt you have it." My gut said otherwise.

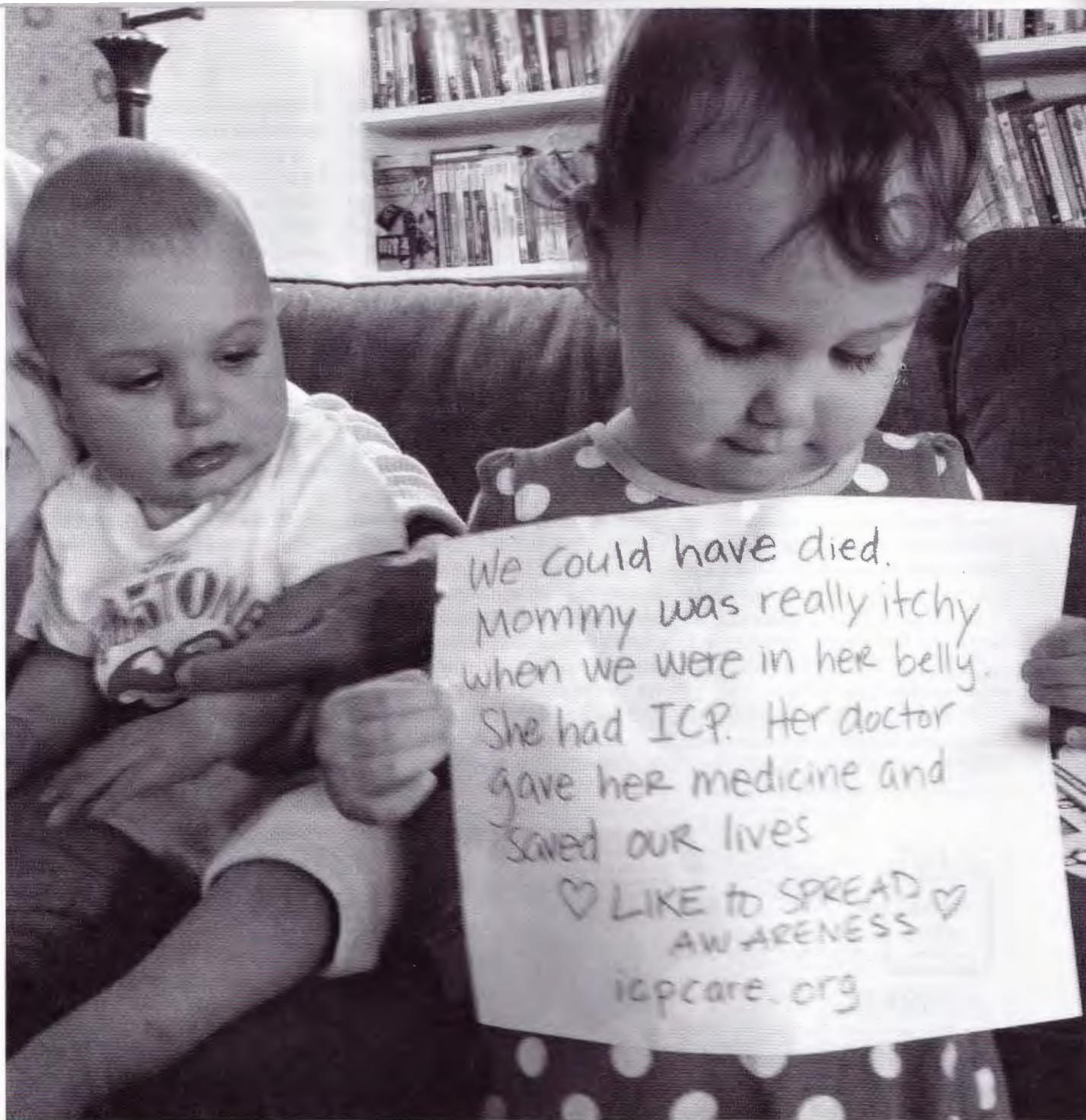
I called my midwives. I didn't want to sound like the hypochondriac they had come to know and love, so I simply said, "I'm really itchy and I don't have a rash." They told me to come in immediately for blood work.

They drew my blood and sent it out to test my bile acid levels. With ICP, the pregnant woman's liver secretes bile acids into her bloodstream, leading to a buildup of bile acids in the baby. These bile acids are toxic to the baby and can cause stillbirth.

JoAnne didn't want to worry me. Instead of going into scary details, she tried to keep me calm. Even when the results came back a week later, confirming my cholestasis, she was level-headed and compassionate.

In a bizarre twist of fate, she had several cases of ICP that year. "Doctor D calls me the cholestasis expert!" she said with a reassuring smile.

A confirmed diagnosis of ICP is total bile acids over 10 (Society for Maternal Fetal Medicine 2014). My levels were 103.9. JoAnne told me that Ursodiol (URSO) had worked wonders in her other patients (for more on URSO, see Rigby et al. 2014). She put me on it immediately. Not only should it help with the uncomfortable itching, but most importantly it would protect the baby.



The author's children, Alex (left) and Gemma (right)

She explained that the safest course of action was to be induced at 37 weeks because, even if my bile acids returned to normal, they tend to spike towards the end of pregnancy when hormone levels are out of whack (Rigby et al. 2014). When babies pass away from ICP, it is typically around or after 38 weeks gestation. At the time of my ICP diagnosis, it took a week (or longer) for bile acid results to come back from the lab. So, by the time results were in, they were already obsolete.

In addition to the 37-week induction and medication, she scheduled an appointment with a perinatologist and arranged for me to have twice weekly non-stress tests and a weekly biophysical profile. Another risk of ICP is sudden fetal demise. The constant monitoring was in the hopes of catching any signs of an issue before it escalated into something deadly.

It was so much information to process. I was 33 weeks along and would be giving birth in four short weeks instead of the

seven or so I thought I had ahead of me. Most frightening was the chance that my sweet baby would not make it. To have come so far and have this hovering over my head was just unbearable. I cried and cried and cried. Each time I saw JoAnne, she assured me that everything was going to be okay.

JoAnne continued to monitor my bile acid levels. Two weeks after my initial blood draw (and a week after starting URSO) my levels had gone from 103.9

all the way down to 13.5. A week later, they were within normal range at 5.8. However, the plan for induction did not change and I stuck to my medication. I think this is particularly important as my blood was measured one last time, a week later, and my levels had increased to 14.5. I don't know what my levels were for the remainder of my pregnancy, but I can't even fathom what they would have been if I had gone full term.

My midwives knew how important a drug-free, natural birthing experience was to me. But they also knew it was not an option for my high-risk condition. When 37 weeks arrived, I was instructed to arrive at the hospital around six in the evening. First cervadil was placed on my completely undilated cervix. Within minutes, I had consistent cramping that quickly became too much for me to take. It was an endless cycle of intense cramps for one minute straight, relief for the next minute, cramping, relief, and on and on. My drug-free hopes went out the window right then and there.

By morning, I had been given a pain-killer narcotic three times. By the third dose, it had hardly worked at all. When JoAnne went to check my cervix I recoiled and let

out a scream that took us both by surprise. It was the worst pain I had ever felt (and this is coming from someone who has had kidney stones!).

I was exhausted, in constant pain and hardly dilated at all. JoAnne and I discussed additional pain relief and she suggested I get an epidural so I could finally relax. She could then continue to check my cervix, and my body could do its thing. I was so thankful she didn't judge me for the epidural. For some reason I thought that all midwives would be anti-epidural. It was a relief to know she was simply pro-me and whatever my birth experience needed to be. By 7:00 pm, my body was ready. Forty-five minutes later, my beautiful daughter Gemma was born.

She was completely perfect aside from some jaundice. At first, I thought I was in the clear as well. The itching went away immediately. Although I had third-degree tears, I was thankful for my healthy baby girl. One final surprise came at my six-week postpartum checkup when JoAnne discovered I had preeclampsia, which I didn't even think was possible after giving birth. Luckily, I did not require hospitalization and my body returned to normal within a few more weeks.

Thirteen months later, I was surprised to discover that I was pregnant again!

I wasn't sure if I was just paranoid at first, but I kept feeling itchy. This time, I visited with both midwives at the office, JoAnne and Capri. Both took my concerns seriously, but also tried to keep me calm. I don't think any of us really believed I could get this rare condition twice.

Ninety percent of women who are diagnosed with a severe case of ICP will get it again in a subsequent pregnancy (Society for Maternal Fetal Medicine, 2014).

I started communicating with women on the icpcare.org "Itchymoms" Facebook page. All of the moderators had suffered from ICP. Some had lost their precious babies, including the founder of ICP Care, Donna Benavides. Donna's doctors didn't diagnose her until 36 weeks. Two days before her scheduled induction, she lost her son Jordan at 37 weeks.

When I posted questions to the page, I tagged Donna and other group moderators for expert information. I was on the lookout for any early signs of ICP. Whatever I learned, I shared with my midwives. JoAnne drew my blood to get a baseline. The results showed normal bile acid levels, but my liver function numbers were rising.

ONSET
Typically third trimester, as early as eight weeks.

FOOD FOR THOUGHT
If your doctor does not have experience with ICP, seek a perinatologist or a Maternal Fetal Medicine Specialist who does.

1-2 pregnancies
in 1000 is affected by ICP in the USA (Latina at 5.6%)

After intervention and proper treatment, **chance of stillbirth is less than overall rate of stillbirth** 0.301% v. 1%

SYMPTOMS
A back scratcher won't stop the itch or ICP
GET TO A DOCTOR

- Intense Itching (palms of hands, soles of feet or all over itch)
- Right Upper Quadrant Pain
- Dark Urine
- Pale Stool
- Fatigue/Malaise

A FEW LESSER-KNOWN FACTS

- Even if bile acids are initially normal, you may still have ICP.
- You will need to be retested every 1-2 weeks as long as you are experiencing symptoms.
- Severity of itching does not correlate with bile acid levels.

RISKS
Fetal Distress and abnormal heart rhythm (21-44%), Meconium Staining (as high as 50%), Preterm Labor, Respiratory Issues, Stillbirth (as high as 15%), Hemorrhage

DIAGNOSIS

- 1 Ask your doctor for a fractionated bile acid test.
- 2 If your total bile acids are over 10 $\mu\text{mol/L}$ or cholic acid is over 3.1 $\mu\text{mol/L}$ THEN you have ICP.

60%
of women with ICP will have elevated liver enzymes.

10%
of those will have elevated bilirubin, which can cause jaundice, or yellowing of the skin.

90%
of severe cases will get ICP in a subsequent pregnancy.

THE ONLY CURE for ICP is delivery

TREATMENT

MEDICATION: Ursodeoxycholic acid (Recommended dosage 600-2000mg per day)
EARLY DELIVERY: Between 36-37 weeks
MONITORING: Twice weekly NST (non stress test) and weekly BPP (bio physical profile)

LIVER FUNCTION TESTS
The most important measurements in this test for ICP are the levels of the enzymes AST and ALT. Levels above 40 IU/L can be used to help diagnose ICP. These tests are readily available and you can expect results quickly, often within hours.

DEFINITION
Intrahepatic Cholestasis of Pregnancy (ICP) is a liver disorder of pregnancy that leads to elevated bile acids in the blood and poses risks to the unborn baby.

ICPcare
Your baby's life is in your hands. Push for proper diagnosis and treatment of ICP.

For more information, links to studies or support from other itchy moms, please visit www.icpcare.org

Sixty percent of women with ICP will have elevated liver enzymes (Society for Maternal Fetal Medicine, 2014).

Based on the articles posted to the Itchymoms Facebook group, I knew this was a sign, so I asked to have my blood drawn on a regular basis. Capri informed me she couldn't draw my blood unless I was actually symptomatic (due to health insurance policies). I didn't want to be the boy who cried wolf all over again, but I needed to know what was going on inside my body. I was more afraid of ICP arriving under the radar at the end of the pregnancy when it could have deadly consequences.

The itchiness came and went. At one point JoAnne instructed me to take some Benadryl so we could make a decision right then and there. If the Benadryl worked, it wasn't ICP. If it didn't work, she would put me on URSO just to be safe. It didn't work, she put me on URSO proactively and my ICP was confirmed via a bile acid test a week later.

This time, my bile acids were only 14. And so, after consulting with Dr. D, JoAnne told me the plan was not to let me go past 40 weeks. I felt my stomach sink along with an overwhelming urge to burst into tears. Based on all that I had read, no one with ICP should go past 38 weeks, regardless of their bile acid numbers.

I asked JoAnne if I could e-mail her a study by ICP researcher Dr. Jonathan Mays, director of Obstetrics and Maternal Fetal Medicine at Metropolitan Center Hospital in New York. Dr. Mays recommends induction for all ICP cases between 37-38 weeks (Mays et al. 2011).

This stands out as a defining moment for me. I've learned that many patients are shot down by their OBs who are opposed to them overstepping into medical expertise territory. Of course, this is understandable. We are patients, not doctors. And in the case of pregnant women, we're not always the most rational folks on the planet. But we, as moms-to-be, deserve a listening ear. And, in some cases, we are indeed the experts. Because we have researched and read and learned about our conditions, we are armed with information. I was so lucky that JoAnne was not only open, but also interested in reading what I had read.

After JoAnne checked out the article, she agreed that a 37-week induction

was best. Although some providers fear NICU time for these early births, others, like JoAnne, will say, "I'd rather [have] breathing problems than a stillbirth." Yes, so would we moms.

With kindness, support and understanding, my midwives guided me through my second ICP birth experience. This time, I was dilated enough to avoid cervadil. Instead, I arrived early in the morning and was given Pitocin. I was even able to labor for several hours on a birthing ball. I was hoping to make it without an epidural, but that didn't happen.

Sometimes I wonder...*If I didn't have to be constantly hooked up to monitors, could I have managed labor without painkillers? What if I didn't need Pitocin in the first place? What would a waterbirth have been like?* I'll never know. But I do know what it's like to have a rare, frightening condition and to be blessed with two healthy babies.

My adorable son, Alex, was born after only five minutes of pushing. Capri laughed as she pulled him out and he peed all over me. It felt metaphorically like the pop of a celebratory champagne bottle.

I was so thankful, so fortunate to have my second ICP baby born with no problems whatsoever. I thank God, the universe, icpcare.org and my wonderful midwives for saving my babies' lives.

I am done having children. One part financial, one part age and one part ICP.

As of today, there is limited research for this deadly condition. We fight to raise

awareness and spread the word for proper treatment. Please listen to your patients. And remember that an itch may not just be an itch. It may be the deadly itch of ICP.

For additional information about ICP please go to icpcare.org.

Download a helpful infographic (see p. 40) with embedded links at icpcare.org/images/ICPinfographic.pdf.

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