

ICP: How It Affected Me

Clare Johnson tells us about her experience with Intrahepatic Cholestasis of Pregnancy, or ICP.

Elliott (my gorgeous ICP baby, pictured) was born on 9th July, 2013.

I would like to share my experience of intrahepatic cholestasis of pregnancy (ICP) because I believe that many women (I was one of them) seem to be unaware of the condition and the symptoms to look out for. I found the lack of information very difficult, especially because, while some of the midwives were very proactive about my care plan, others were much less aware of the condition and the recommendations for managing it. Although there is a 60-90% chance that ICP will recur if I go on to have another pregnancy, I now feel better prepared to make informed choices about our care should this happen.

Other than a couple of weeks between my morning sickness finishing and pelvic girdle pain kicking in, I certainly wasn't one of those women who 'glowed' during

pregnancy! Despite being green around the gills and waddling from 18 weeks, I was fortunate enough to be having a low-risk pregnancy, with my only cause for concern being my own physical comfort.



When I was exactly 36 weeks, I began to itch unbearably. The onset was very sudden and I didn't even manage five minutes of sleep that night. My husband turned to Dr Google and informed me, at about 5am, that itching was a 'thing' in pregnancy and I ought to get it checked out. I'd never heard of this and felt sure that I would have done had it been deemed common or serious enough - after all, being a first-timer I'd downloaded every pregnancy app, read a range of books and signed up to numerous forums for expectant mums. I was clued up on the warning signs for pre-eclampsia and gestational diabetes

(amongst other things), but itching and intrahepatic cholestasis of pregnancy (ICP), or obstetric cholestasis (OC), as it's also known, had never made it onto my radar.



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Later that morning, I called maternity triage as I was at my wits' end with the itching and wondered if I could take any antihistamines. I assumed the most likely explanation was an allergic reaction to the new bubble bath I'd been using.

As my baby had been a little more sluggish with his movements than usual, triage asked to see me straight away. When I arrived, the midwife took some blood and hooked us up to a CTG monitor. The blood results came back while I was still on site and I was diagnosed with ICP based on my elevated bile acid levels.

I drove home alone and in tears, shocked that 'something that happens to other people' was happening to me, and feeling that I didn't know anything about this condition that I had. I'd just heard the words 'foetal distress' and 'increased risk of stillbirth' and without really knowing what they were going to be looking for, had promised to be at my appointment for more bloods, a growth scan and another CTG the next day.

I continued to itch night and day and can't really describe how it felt. For me it was all over my body: constant and like nothing I'd ever experienced. I researched what I could about the condition, but there seemed to be little definitive information available. I spoke to a close family member with a medical background who had never heard of ICP, and they went away to read up on it. We understood that the risk of stillbirth seemed lower when the condition was actively managed with medication and when labour was induced between 37 and 38 weeks.

The next few days passed in the same way: too itchy to sleep and visiting the day assessment unit for monitoring. I was given an appointment to see the consultant about the safest time to deliver, but never made it, as the doctors decided that they weren't comfortable with my

rising bile acid levels and the fact that the baby was having the odd period of reduced movement.

As it turned out, I was already dilating on arrival and one pessary and less than 12 hours later, at 37+1 weeks' gestation, Elliott was born! He spent five days in the neonatal unit due to some concerns about his breathing, but was generally healthy and well. I cannot believe that his first birthday is less than a month away!

For more information and support about the condition please visit ICP Support's website at www.icpsupport.org. ICP Support is a UK-based charity with the very powerful mission statement 'that every ICP baby is born safely'. They provide evidence-based information about the condition and offer support to those affected by it. They raise awareness of ICP and promote research into the condition. ICP Support have provided the following information:

ICP is also known as obstetric cholestasis (OC) and is the most common pregnancy-specific liver disease in the UK. It affects around 5,500 women a year in the UK and causes are thought to include:

- Hormones - it is a pregnancy condition
- Genetics - it is found in families
- Environment - there are more reported cases of ICP in winter

Although ICP is not generally harmful for the mother-to-be, it is associated with foetal distress for the baby, premature labour (spontaneous and induced) and, in severe cases, stillbirth.

The most common presenting symptom of ICP is itching. Many women do itch in pregnancy, but the itch in ICP is more typically noticed on the hands, feet, arms and legs, although it can be anywhere on the body. Women often report that the itch is more noticeable at night and can range from mild to so severe that it causes loss of sleep. It is more common for a woman to be diagnosed in the third trimester of pregnancy (28 weeks onwards), but it can present as early as seven weeks. Other symptoms of the condition can include:

- Dark urine
- Pale stools
- Jaundice (although this is not common)
- Tiredness, feeling generally unwell and loss of appetite

The diagnosis of ICP is made by excluding other causes of the itch, so screening is likely to include blood tests to check for auto-immune hepatitis, hepatitis C and other conditions, such as PBC (primary biliary cirrhosis). For more information, see: www.icpsupport.org.

The NCT has a shared experiences register for those with individual conditions - call 0300 330 0700, Mon-Fri between 9am and 7pm.