



alig.gilroy@gmail.com

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## WHAT YOUR PATIENT IS THINKING

### Please tell me what the long term effects might be

Ali Gilroy explains what it was like to be diagnosed with intrahepatic cholestasis of pregnancy, and how discovering the long term effects was unexpected

Ali Gilroy

I was 34 weeks pregnant when I first experienced an unexplained persistent itch. I couldn't pin down any reason for it. It felt deep under my skin and was all over my body. Scratching didn't help, but I couldn't stop. I vaguely remembered reading about itching during pregnancy in a handout I'd been given, so I looked on the NHS website and discovered intrahepatic cholestasis of pregnancy (ICP). After reading that ICP was associated with an increased risk of stillbirth and preterm birth, I contacted my maternity assessment unit.

The medical team confirmed a diagnosis of ICP and I was given a management plan. An induction was planned for 37 weeks and I was reassured that my itching would stop soon after I had given birth. Owing to my increased bile acids and worries for my baby's outcome he was delivered earlier at 36+4 weeks.

#### The long term effects

Luckily, he was fine, and my itching stopped after I gave birth. I thought that would be the end of my ICP health concerns. However, shortly after giving birth I discovered the ICP Support website while searching online. I learnt there may be long term health implications for women with ICP, such as being at greater risk of developing other conditions. I could also pass on the genetic changes of the condition to my children. This all came as quite a shock.

I appreciate that before giving birth the priority was the safe arrival of my baby, and that discussing the longer term health implications may not have been appropriate. But I wish I had been signposted to ICP Support during my discharge from hospital, or during my postnatal checks. I wish I'd had the opportunity, while I was pregnant, to hear the experiences of women with ICP who had safely delivered their babies. This would have been invaluable.

#### Planning for the future

I learnt I had a very high chance of developing ICP again in any future pregnancies, which worried me. Whether or not we should have any more children was something my husband and I seriously considered. I believe being able to access a pre-pregnancy planning consultation would have been hugely reassuring, especially to discuss my previous experience of ICP and to plan for a future pregnancy.

Since my pregnancy I volunteered with ICP Support and joined the team as a member of staff earlier this year. I hope that sharing my experience will help other women feel reassured and supported. I am

currently pregnant with my second baby and I haven't yet been diagnosed with ICP. I hope this continues but it's hard not to worry about developing it again.

#### What you need to know

- Sharing information about the long term impact of ICP is just as important as information about managing the condition during pregnancy
- ICP Support offers valuable resources to help women feel reassured and informed. Hearing other women's experiences is also hugely helpful
- Pre-pregnancy discussion and planning for any future pregnancies would help relieve some of the worries about ICP in the future

#### Education into practice

- How can you ensure that you share the long term effects of ICP as well as managing it during pregnancy?
- What resources and information could you share with someone experiencing ICP?
- When might you discuss future pregnancy planning with someone who has previously had ICP?

#### Additional information

- Online support: [www.icpsupport.org](http://www.icpsupport.org)
- iLearn module link: <https://bit.ly/ICPi-learn>
- Health Professionals ICP Support Facebook group: <https://bit.ly/HPsICP>

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