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Understanding Intrahepatic Cholestasis of Pregnancy (ICP): The power of women coming together

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By Jenny Chambers

In this article, Jenny introduces us to the work of the charity she founded thirty years ago, ICP Support,1 and illustrates the benefits of service users coming together to work on issues of common concern. With a shared goal of ensuring that all ICP babies are born safely, by improving the understanding of the physiology of intrahepatic cholestasis of pregnancy (ICP) across the maternity services and by improving the care of everyone affected by ICP, Jenny's account demonstrates the crucial importance of having 'experts by experience' at the table.

In 1991, I was diagnosed with intrahepatic cholestasis of pregnancy (ICP). ICP affects around 5,500 women a year in the UK and it is the most common liver disease specific to pregnancy. Its main symptom is itching, which can be so severe that some women have reported feeling suicidal2 ICP is also associated with spontaneous preterm birth, fetal distress and, in severe cases, stillbirth. When I was told I had ICP, I soon realised that no women – and only the odd health professional – knew about the condition. Because my own diagnosis had taken several pregnancies to establish, I wanted to raise awareness so that all women knew that itching in pregnancy wasn't always something to be dismissed. My plan was to do this

for a few years, after which I would be able to get back to a 'normal' life.

This year sees the 30th Anniversary of ICP Support, and I'm still very much involved. The information line I started in 1991 has developed into a registered charity of which I am now the CEO. I'm lucky enough to have been supported in making the transition from being a lay person with no medical background to working in research into ICP, and I am now a named author on numerous peer-reviewed academic papers on ICP. I am also the first author on several midwifery articles. I've given presentations on the condition at midwifery conferences and delivered lectures to midwifery students. I'm still involved because I discovered that scientific research takes far longer than I originally thought it would, and because not all health professionals have embraced learning about the condition, as I thought they would. It's been quite a rollercoaster of a journey.

But what I also discovered along the way was the sheer joy of being with other women who have had ICP. I've learned just how much can be achieved when we all come together and work towards a common goal. In the case of ICP, that goal has always been the safe arrival of babies, and over the years I have been humbled by what women have been prepared to do for research that will help to ensure that all ICP babies are born safely. From donating their blood, urine and faeces to donating their babies' cord blood and placenta (post birth), women have done so much.3 Some of them have also taken part in studies that have involved them eating standardised meals and having nine blood samples collected over a 7-hour time period; agreed to have electrode tabs put on their abdomen so that researchers can get an overnight fetal ECG recording of their babies;4 and donated samples of their white adipose tissue collected during their caesarean sections. Their willingness to do all these things has been quite outstanding.

Because of these women, we now have a risk threshold for stillbirth in ICP (3.44% when bile acids are >100 µmol/L) as established by Ovadia et al.5 This means that the 90% of women whose bile acids remain under this level throughout pregnancy can not only be reassured about the safety of their babies, but can also not have early induction (which has typically happened at around 37 weeks for ICP) if they want to (and if they can cope with the intractable itch that so many women with ICP have to endure).

Because of these women, Dixon et al6 were able to identify genetic changes associated with ICP (and there is further research on this due out soon), meaning that in time it may be possible for women who have had the disease to undergo genetic testing to see what variants they may carry. It may also mean that their daughters can be tested to see if they too carry the markers and how this will affect their chances of developing ICP: in this case, forewarned is most definitely forearmed!

And because of these women, researchers now have a better understanding of the longer-term impact of ICP for women,7 which includes an increased risk of developing a liver disease such as gallstones. We now realise that ICP is not just for pregnancy – it's for life.

But of course, none of this could have happened without researchers, and in the UK we are lucky that one such researcher, Professor Catherine Williamson, made ICP her research focus8 Catherine is the reason

I was able to make the transition from lay person to working in research and she's a terrific example of how PPI (Patient and Public Involvement) can work9 because she is committed to listening to women, which includes asking them to comment on the design and feasibility of studies. The ethos of ICP Support has always been that we are research-based, and I know (because they tell me) just how much women value being involved in supporting it; it is, after all, their condition! Our role as a charity is to be the conduit between women and the researchers, and we do this by posting surveys for them to complete (usually about new studies), by conducting polls, and by hosting focus groups. We also hold live 'meet the expert' Facebook sessions, which have proved very popular.

It's going to be an interesting 12 months as we look back and reflect on how much has changed with the diagnosis and management of what has turned out to be a very complex condition of pregnancy, but what I do know is that the research will continue, and that as it does, the women affected by ICP will be with us all the way.

Further information on ICP – www.icpsupport.org

Facebook group for health professionals – www.facebook.com/groups/ICPSupporthealthcareprofessionals

Facebook group for women – www.facebook.com/groups/icpsupport

Instagram – www.instagram.com/icpsupport

Author Bio: Jenny Chambers is the founder of ICP Support, and was only diagnosed with ICP after suffering a second stillbirth.

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[1] ICP Support website homepage: www.icpsupport.org.
[2] ICP Support website, 'Symptoms': www.icpsupport.org/about_symptoms.shtml.
[3] Geenes VL et al. (2011). 'A placental phenotype for intrahepatic cholestasis of pregnancy.' *Placenta* 32(12):1026–1032. https://pubmed.ncbi.nlm.nih.gov/22015023.
[4] Vasavan T et al. (2021). 'Fetal cardiac dysfunction in intrahepatic cholestasis of pregnancy is associated with elevated serum bile acid concentrations.' *J Hepatol*. 74(5):1087–1096. https://linkinghub.elsevier.com/retrieve/pii/S0168827820338253
[5] Ovadia C et al. (2019). 'Association of adverse perinatal outcomes of intrahepatic cholestasis of pregnancy with biochemical markers: Results of aggregate and individual patient data meta-analyses.' *Lancet* 2;393(10174):899–909.
[6] Dixon, PH et al. (2017). 'An expanded role for heterozygous mutations of ABCB4, ABCB11, ATP8B1, ABCC2 and TJP2 in intrahepatic cholestasis of pregnancy.' *Sci Rep 7*, 11823. www.nature.com/articles/s41598-017-11626-x.
[7] ICP Support website, 'After your baby is born': www.icpsupport.org/about_after.shtml

[8] ICP Support website, 'London research group': www.icpsupport.org/research_london.shtml.
[9] NHS Health Research Authority website, 'Public involvement': www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement.