After the birth

Once you have had your baby there are a few things you need to know.

It is important that you have your blood checked again after having your baby. Usually in ICP your liver function and bile acid tests will return to normal by around 6–12 weeks following the birth of your baby. However, for some women the results of these tests may continue to be abnormal. It's important to know if they are, so that doctors can either continue to monitor your bloods or refer you to a liver specialist if necessary.

The only methods of contraception that are likely to cause problems for women who have had ICP are those containing hormones. However, there have been no large studies regarding the use of contraception following an ICP pregnancy, so it may be possible to take the oral contraceptive pill. Speak to your doctor about this and visit our website for more detailed information.

You will have a higher chance of developing liver disease, including gallstones (and some women develop these even before an ICP pregnancy), so it's a good idea to have a liver function test once a year.

Research has shown that girls born to women who have had ICP also have a greater chance of developing the condition in their pregnancies. It has also shown that boys as well as girls can pass the genetic changes



linked to the condition down through their families.

There is further evidence to show that children (and their mothers) may be more affected by metabolic disease such as Type 2 diabetes in later life, but this needs more research.

The charity

ICP Support was originally set up in 1991 and is a vital point of contact for thousands of women and their families.

The information we provide about ICP is researchbased, as we work closely with one of the largest ICP research groups in the world (headed by Professor Catherine Williamson), and two of the charity's founding members work in ICP research.

Our aims are to:

- Provide information and support to people affected by ICP
- → Raise awareness of ICP
- → Promote and fund research into ICP

We work closely with hospitals and other organisations, such as the Royal College of Midwives, as we believe that collaboration is key if we are to achieve our vision:

That every ICP baby is born safely

A regular donation of just £2 a month can make all the difference

Contact www.icpsupport.org and help make that difference

ICP Support

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With thanks to Professor Catherine Williamson, Dr Peter Dixon and Dr Caroline Ovadia of King's College London for their help in writing this leaflet. Photographs © ICP Support. Thanks to Pooja Chavan-Prabhu, Elizabeth Kendell and Bianca Webb for allowing us to use their photos.

ICP Support

Pregnant and itching? Call your midwife!

www.icpsupport.org

Support for you

Around 20% of women itch in pregnancy, and only a small number of these will have intrahepatic cholestasis of pregnancy (ICP). But it is important to let your health professionals know that you are itching so that they can perform the right tests to see if you have the condition.

If you are being tested for the condition or have been diagnosed with ICP we know how distressing this can be. This leaflet is aimed at giving you some basic facts about the condition as well as signposting you to more detailed information and forms of support.

The positive news is that recent research suggests that 90% of women who have ICP can be reassured that their babies are free from the risk of stillbirth due to the condition. With careful management the 10% of babies who are at risk because of ICP can be born safely.

Whether you have mild or severe ICP we are here to support you and provide you with the most up-to-date information in the world on this very complex condition.

For further information about ICP and to see tips on how to cope with the condition please visit our website: **www.icpsupport.org**.

To speak to someone about ICP, ring our information and support line – details are on the website.

To meet other women who have ICP join one of our many Facebook groups – again, details are on the website.



www.facebook.com/icpsupport/

icpsupport



What is ICP?

ICP (intrahepatic cholestasis of pregnancy, also known as obstetric cholestasis) is the most common liver condition specific to pregnancy. ICP affects around 5,500 women in the UK each year and is caused by a combination of:

- → Genetics it has been found to run in some families. Genetic changes associated with ICP occur in approximately 25% of all women and this remains an area of active research
- → Hormones women expecting more than one baby or who have had fertility treatment appear to have a higher chance of developing ICP
- → Environment more cases are reported in the winter, and diet may affect the condition, but this has not so far been proven

The main symptom is **itching**, usually on the hands and feet, but it can be anywhere on the body. It may be mild or severe, and most women with ICP say that it's worse at night.

Diagnosis, treatment and management

Your doctors will want to make sure that nothing else is causing the itch, so your blood needs to be tested for other conditions as well as ICP. **The most important blood test to diagnose ICP is a bile acid test.** If the bile acid test is normal but you continue to itch, you must be tested again, because research shows that you can itch for many weeks before your bile acids become abnormal.

Treatment and management of ICP includes the use of medicines, regular blood tests and possibly an early birth for the baby, depending on bile acid levels (anywhere from 35–39 weeks of pregnancy).

If you have had ICP in one pregnancy you have over an 80% chance of developing it in a future pregnancy.

Why is ICP a problem?

ICP is known to be associated with an increased risk of:

- → Baby passing meconium (poo) before birth
- → Spontaneous premature birth
- → Admission to a neonatal unit
- → Stillbirth (this small risk applies to the 10% of women who have severe ICP)

The exact cause of stillbirth in ICP has not been fully proven, but the latest research suggests that very high bile acid levels (over 100 micromoles per litre, which you will usually see written as μ mol/L) may cause the rhythm of the baby's heart to change (known as heart arrhythmia) and make it stop working. This theory is still being researched, and until more is known most experts recommend regular bile acid testing and an earlier birth for those babies whose mums have bile acids over 100 μ mol/L.

lt's important to ask your hospital to give you your bile acid results within 24 hours, as they can rise suddenly (they can fall equally quickly). Bile acids above 100 μmol/L may mean that you will need to have your baby before 39 weeks.

If your bile acid levels have always been below 100 µmol/L, but your itching is so severe that you cannot face waiting until 39 weeks to meet your baby, talk to your doctors about the possibility of an earlier birth. Your baby will be considered to have reached term from 37 weeks onward, and while some babies have needed additional care when born at this stage in pregnancy, most will not need any extra help.

