

Health and Social care Committee

Inquiry into stillbirths in Wales

SB 2 – OC Support

# OC Support

Registered charity number 1146449



Committee Clerk  
Health and Social Services Committee  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

23 May 2012

Dear Sirs,

I am writing to you as a representative of OC Support to submit evidence for the committee's inquiry into stillbirths in Wales. I would like to draw your attention to a relatively unknown condition of pregnancy which I believe may contribute to the unexplained stillbirth figures for Wales and the rest of the UK.

Obstetric cholestasis (OC), also known as intrahepatic cholestasis of pregnancy (ICP), is a liver condition specific to pregnancy. It is typically associated with itching, abnormal liver function tests (LFTs) and elevated bile acid levels, neither of which has an alternative cause and both of which resolve after birth. It is associated with fetal distress, spontaneous premature labour and, in severe cases, stillbirth<sup>(1,2,3)</sup>.

OC Support was founded as a support group in 1991 after its founder, Jenny Chambers, suffered a second stillbirth and was subsequently diagnosed with OC. We became a UK registered charity in March 2012. Our aims are to provide support and information to people affected by OC, raise awareness of the condition and promote research into it.

It is thought that OC affects around 5000 pregnancies across the UK every year<sup>(3)</sup> and although stillbirths are still occurring<sup>(4)</sup> research suggests that with active management of the condition (i.e. treatment, weekly blood tests and choosing to induce the baby around 37–38 weeks) the risk of stillbirth in an OC pregnancy is thought to be the same as that for a normal pregnancy<sup>(2)</sup>.

Itching is often thought of as a normal part of pregnancy. However, OC Support believes that it is vital to raise awareness of this condition and in doing so will empower women to report their symptoms for further investigation. We often hear from women through our support services that they thought itching in pregnancy was normal or that they had never heard of the condition prior to diagnosis. To date no one has been able to publish accurate perinatal mortality rates for the condition, but research literature has reported it to be as high as 10–15%.<sup>(8,9)</sup> OC Support believes that by raising awareness of this condition it is possible that the stillbirth rate from OC could be reduced.

Whilst the Geenes review of *Intrahepatic Cholestasis of Pregnancy* (2009) reports that there are several case reports of normal CTG and/or normal fetal movements in the hours preceding fetal loss, OC Support encourages women to be aware of their baby's movements and report any changes to their health professional in line with other research<sup>(5)</sup>.

Obstetric cholestasis has not been shown to be linked to intrauterine growth restriction, with several studies showing there is no increase in the number of small for gestational age infants born to women with OC<sup>(6,7)</sup>.

In conclusion, OC Support believes that the provision of information and support to women during pregnancy is of the utmost importance in an effort to protect unborn babies and would encourage the Welsh Assembly Government to inform women about the importance of ensuring that any itching in pregnancy is reported to their health professional.

Yours sincerely,

Jenn Deasington

OC Support Forum & Helpline Manager

References

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