

**Submission to National Assembly for Wales' Health and Social Care Committee is undertaking a one-day inquiry into stillbirths in Wales**

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Member of the Board of the International Stillbirth Alliance, a non-profit coalition of organizations dedicated to understanding the causes and prevention of stillbirth 2009 – present.

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2011 to present.

1. SANDS are providing written evidence around the burden (social, societal, economic, health) of stillbirth. My major focus of professional activity around stillbirth is in the area of research. Hence the focus of my submission will relate to research.

2. A key approach to reducing the number of stillbirths is to reduce the rates in women who lack strong risk factors. The majority of stillbirth babies do not have a lethal congenital or genetic anomaly. The majority of mothers experiencing stillbirth do not have a major pre-existing medical condition (e.g. diabetes, connective tissue disease etc). Therefore, in order to reduce the overall burden of stillbirth, it will be necessary to focus efforts on women who might ordinarily be regarded as “low risk”.

3. In the absence of a major pre-existing medical condition, most maternal characteristics associated with stillbirth are not sufficiently important or discriminating to allow clinically

useful intervention. For example, it is known that advanced maternal age is associated with an increased risk of stillbirth. One of the papers from the recent Lancet series pooled existing studies and concluded that women >35 years of age had a 65% increased risk of stillbirth. This may be taken as an argument for focusing on these women. However, the background rate of stillbirth is approximately 0.5%. Hence, women aged >35 have a <1% chance of having a stillbirth or, put another way, have a >99% chance of not having a stillbirth. Between 6% and 8% of all stillbirths were attributed to the increased risk among women aged >35. Hence, even if a programme of intervention reduced the rate of losses among this group by 50%, the overall rate of stillbirth would be minimally reduced.

4. The current methods of screening women are virtually unchanged in recent years. The National Institute of Clinical Excellence Antenatal Care guideline suggested serial measurement of a woman's bump with a tape measure (technically called the symphysis-fundal height) as the sole method of assessing fetal well being among low risk women. A number of other methods, such as serial ultrasound scanning, were evaluated. They were not recommended as there is no evidence that the routine use of ultrasound reduced the number of losses. The evidence is from pooled analyses of randomised trials including tens of thousands of women.

5. The current methods of screening the low risk population for stillbirth are extremely crude compared with the methods used screening for Down's syndrome. In contrast to the point above, the protocol for screening for Down's is as follows:

*Screening for Down's syndrome should be performed by the end of the first trimester (13 weeks 6 days), but provision should be made to allow later screening (which could be as late as 20 weeks 0 days) for women booking later in pregnancy. The 'combined test' (nuchal translucency, beta-human chorionic gonadotrophin, pregnancy-associated plasma protein-A) should be offered to screen for Down's syndrome between 11 weeks 0 days and 13 weeks 6 days. For women who book later in pregnancy the most clinically and cost-effective serum screening test (triple or quadruple test) should be offered between 15 weeks 0 days and 20 weeks 0 days. When it is not possible to measure nuchal translucency, owing to fetal position or raised body mass index, women should be offered serum screening (triple or quadruple test) between 15 weeks 0 days and 20 weeks 0 days.*

i.e. there is a panel of 6 possible biomarkers (blood tests) to assess Down's syndrome risk, but no recommended biomarker screening for stillbirth risk.

6. The relative lack of emphasis on screening for stillbirth occurs despite the fact that it is one of the most common of the serious complications of pregnancy. Death of babies due to prematurity affects about 1 in 1000, Down's syndrome affects about 1 in 700-800, whereas stillbirth affects about 1 in 200. This is equivalent to all infant deaths (i.e. deaths of liveborn infants in the first year of life) put together, a category which includes areas of intense research and public health interest (e.g. sudden infant death syndrome, congenital anomaly, prematurity, infection, trauma and abuse).

7. There is a relative lack of focus of research funding to address the problem of stillbirth. Although SANDS are starting to raise and distribute funds for research, there is no major charitable funding devoted to stillbirth which is comparable in scope to Cancer Research UK or the British Heart Foundation. The UK government's Medical Research Council (MRC) has funded specific projects relevant to stillbirth research. However, there is no MRC Unit or Centre in the country which is devoted to stillbirth or has stillbirth as a major focus of research.

8. It is plausible that good biomarkers could impact on the burden of the disease. Although routine ultrasound scanning does not reduce perinatal mortality among low risk women, it does reduce losses in high risk pregnancies. Hence, identification of high risk pregnancies using, for example, blood tests, could lead to interventions to improve outcome. Moreover, of the >4000 stillbirths in the UK in the last national report, almost one third (~1200) occurred at or after 37 weeks of pregnancy. Induction of labour carries a low risk of short or long term problems when performed at 37 weeks. If babies at high risk of stillbirth at term could be identified, induction of labour would be a plausibly effective intervention.

9. Conclusion: Stillbirth is a relatively ignored problem which accounts for the potentially preventable loss of large numbers of babies. There are aspects of stillbirth which indicate that the relatively high levels could be reduced by novel methods of screening coupled with safe and effective intervention.