

**PE1505/C**

Petitioner Email of 10 June 2014

Dear Sirs,

Thank you for the opportunity to contribute to the discussion about awareness and prevention of group B Streptococcal (GBS) infection in babies in Scotland. My granddaughter died from GBS infection and, had testing and information been widely available, we believe this would not have happened. The death of any baby is heart-breaking. I know. My family knows. My daughter, her partner and all of our families think of Lola every day and will never get over her death. And it's all the more heart-breaking because her death could have been prevented, if only we had known. If only we had been told. We want everything to be done that is possible to spare other families the pain and suffering caused by these usually preventable and treatable infections. I just don't understand why more is not being done about this when so much could be.

I want to see in Scotland –

- Every pregnant woman offered screening for GBS
- Whenever testing for GBS carriage is undertaken in pregnant women for the 'gold standard' Enriched Culture Medium (ECM) method to be used and
- All pregnant women and their health professionals to be provided with full information about GBS, including preventing these infections in newborn babies
- All new parents and their health professionals to be provided with full information about identifying signs and symptoms of GBS infection in babies, and what action to take

Thank you for the opportunity to comment on the responses from the UK National Screening Committee and the Scottish Government:

### **1. Scottish Government Response to the Public Petitions Committee Questions**

It seems to me the responses given in this letter raise more questions than they answer.

**1.1 PPC Question - Will the Scottish Government ensure that information is routinely given to all expectant mothers in Scotland on Group B Streptococcus and on how to undertake tests and screening privately?**

The Royal College of Obstetricians & Gynaecologists' GBS guideline states that: "Routine bacteriological screening of all pregnant women for antenatal GBS carriage is not recommended." The guideline does not mention testing for women in high risk situations. So what does the Scottish Government mean when they write "*Women will have testing for the presence of Group B streptococcus if they fall into the high risk categories as advised in the recent RCOG guidance*"? Would they explain what is being done?

And when testing for GBS is done, does this follow Public Health England's UK SMI B58, which describes the 'gold standard' enriched culture medium (ECM) test to be used for the identification of GBS? And, if not, will they press for this as the 'standard' tests are not designed to detect GBS exclusively, and will fail to detect it in about 50% of the cases when GBS is present, meaning perhaps half of the women carrying GBS when the 'standard' test is done will be incorrectly told they are *not* carrying GBS. Is such advice not potentially dangerous?

Most pregnant women do not know about GBS and need to be informed – it is recognised as the most common cause of severe infection in newborn babies, more common than many of the other things pregnant women are told about, yet there is silence about it. GBS prevention policies at maternity hospitals vary considerably and I don't think there is any guidance or requirement for midwives to discuss it with pregnant Mums. A UK survey from 2013 reported two out of every five women had not heard of GBS and, of those who had, the source of information was outwith their midwife or doctor for four out of every five women. Without knowing about GBS, women can't make informed decisions - will the Scottish Government commit to an awareness-raising campaign which will include guidance for health professionals on discussing the issue with pregnant women?

Information also needs to be provided to new parents about the signs of GBS infection in their babies, plus what action to take should any such signs arise. This would mean babies would get earlier treatment, particularly those who have been discharged from hospital as the parents would be knowledgeable and empowered to get urgent medical attention for their baby. If my daughter had known she carried GBS and what signs to watch for in babies, Lola would have been properly treated for GBS infection much earlier and in all likelihood would have made a full recovery. As it was, she didn't get that that chance. She died.

Will the Scottish Government ensure all of the above issues are addressed in information developed for Scotland?

**1.2 PPC Question - Will the Scottish Government review its policy on the screening of all expectant mothers for Group B Streptococcus?**

The advice given by the UK National Screening Committee (NSC) in 2012 relates to the whole of the UK, not specifically for each of the nations of the UK. The guidance against introducing antenatal screening in 2012 was not universally agreed with – of 212 responses received during the public consultation process, **over 90% were in favour of screening.**

Why has no assessment of the situation concerning GBS prevention specifically for Scotland been made? The rate of GBS infection reported in babies in Scotland is significantly higher than the rate reported in England, Wales and Northern Ireland: **30% higher in babies aged 0-6 days, and 54% higher in babies aged 7-90 days.**

Rate of babies with GBS infection per 1,000 live births:

|  | <b>GBS infection 0-90 days 2012</b> | <b>Early onset GBS infection (0-6 days) 2012</b> | <b>Late onset GBS infection (7-90 days) 2012</b> | <b>Source</b> |
|--|-------------------------------------|--|--|---------------|
| <b>Scotland</b>                              | 0.81                                | 0.47   | 0.34   | HPA Scotland  |
| <b>England, Wales &amp; Northern Ireland</b> | 0.58                                | 0.36   | 0.22   | PHE 2013      |

In addition, the rate of early-onset GBS infections has **more than doubled in Scotland** since an enhanced surveillance study was conducted in 2000/1, compared with a small fall in the UK as a whole – in 2000/1 the rate in Scotland was 0.21 per 1,000 live births for early onset GBS infection, compared with a UK & Republic of Ireland rate of 0.48 per 1,000 live births for early onset GBS infection. In 2012, the rate in Scotland had increased to 0.47 per 1,000 live births for early-onset (while the rate in England, Wales & Northern Ireland was 0.36 per 1,000 live births).

Research from other countries has shown that screening with antibiotics given in labour to women carrying GBS significantly reduces the risk of GBS infection developing in the baby. Approximately 10% of babies who develop GBS infection die and around 5% of the survivors suffer long term problems, including brain damage, cerebral palsy, deafness and blindness. We can easily prevent many of these infections and we should.

**I ask the Scottish Government to review the evidence for antenatal screening for GBS in light of the higher and rising rate of these infections in**

**Scotland.** Health is a devolved issue and we can and should take more action to prevent these infections locally.

### **1.3 PPC Question - What is the current policy on instances where an expectant mother requests testing or screening for Group B Streptococcus from the NHS?**

Having read the response, I am still unclear what the current policy is on instances where an expectant mother requests testing or screening for GBS from the NHS. They refer to the RCOG guideline which does not make a recommendation in this situation (see 1.1 above).

Women should be given the facts about GBS and be able to choose to be tested if they want to. If that is outside the service offered by the NHS, then information on how to go about it should be available for health professionals to provide for families especially concerned about GBS. Don't we want pregnant women to be able to make an informed choice about their care?

## **2. UK National Screening Committee Response to the Public Petitions Committee Question**

### **PPC Question - What are the potential “harms” from screening for Group B Streptococcus, and what data or evidence is there on the incidence of “harms” resulting from screening for Group B Streptococcus?**

I can't find much evidence or data quoted in the response. The little data quoted seem either to minimise the benefits of screening programme:

- Stating “*screening tests cannot distinguish between women whose babies would be affected and those which [sic] would not*” implies a screening test would be expected to do this. It would not - screening tests identify risk, they are not diagnostic tests, and should not be judged as such.
- Focussing on the fact that most babies born to women carrying GBS will not become infected fails to address the impact on families and health services for those babies who do develop GBS infection, where it results in invasive treatment in Special Care or Neonatal Intensive Care Units, with a small but significant minority of these babies dying or surviving with long term disabilities.
- Every death of a baby is a tragedy, even more so when that death could have been prevented. The NSC, using its own estimates, suggests that 5-7 deaths a year from GBS are preventable – aren't these deaths worth preventing? The NSC recommends screening for Maple Syrup Urine Disease, a condition which they estimate affects (*affects*, not kills) around one

in every 100,000 babies – why is detecting Maple Syrup Urine disease recommended when preventing babies dying from preventable GBS infection is not? Plus the NSC fails to take into account how many GBS infections overall could be prevented – around 90% of babies who develop GBS infection when given prompt and aggressive treatment, usually in special or intensive care facilities, will survive, although half of the babies who recover from GBS meningitis will suffer long-term problems. The emotional cost of all of these infections is massive, particularly when many are preventable. The financial costs to the state – the NHS, social care and education – are also huge. Screening could and would reduce these costs substantially.

- Whilst the NSC is correct that in 2000/1 the rate for early onset GBS infection in Scotland was 0.21 per 1,000 live births, they fail to mention that the rate since then has **more than doubled** to 0.47 per 1,000 live births in 2012, despite the RCOG's introduction of risk-based guidance in 2003 (as described in 1.2 above). The current approach is clearly not working, especially in Scotland. US guidelines for early-onset GBS disease prevention, first issued in 1996 and updated in 2002, were associated with a nearly 80% decline in the incidence of early-onset GBS disease in the United States. Why should we not expect a significant decline if screening were introduced here?
- The current risk-based strategy is not a good predictor of carriage in labour, identifying fewer women carrying GBS than screening. Screening is better at identifying both women who are carrying GBS and those who are not, so it better identifies babies who are truly low-risk. This means decisions around birth can be made with the knowledge of a Mum's GBS status. Mums who are not carrying GBS do not need to be offered antibiotics in labour (unless other risk factors develop, such as fever in labour), whilst Mums who carry GBS can be offered the antibiotics in labour to change the risk of GBS infection developing in their newborn baby from higher-risk to low-risk.
- Increasing resistance to clindamycin for women allergic to the first line antibiotic (penicillin) is of concern. However, most women are not allergic to penicillin which is the first-line agent against EOGBS infection and, as the NSC states, penicillin remains *effective* "*there have been no confirmed cases of penicillin-resistant isolates in the UK to date*". Concern about resistance to one antibiotic should surely not mean that we do not consider treatment that we know is effective. We mustn't throw the baby out with the bathwater. Just because clindamycin is increasingly ineffective does not mean we should withhold using penicillin or other appropriate antibiotics when their use has been shown to prevent death and disability in babies.
- The NSC quotes data from the Northern Ireland audit which found 5 cases of allergic reaction to antibiotics in 2011/2. However, **all** of these allergic reactions were to a different antibiotic (co-amoxiclav) given for a different

reason (following the delivery of the baby after Caesarean sections). They were not to penicillin or clindamycin given during labour against EOGBS infection. A study of the first 1.8 million women in the USA given intravenous penicillin for GBS carriage reported no deaths and stated that severe reactions are rare. Any serious adverse reaction is a cause for concern, but the risk is extremely low, and to quote these cases whilst not explaining that they did not relate to GBS prevention and they were using a different antibiotic is scaremongering. For completeness of context, it is interesting to note that for the same period there were 17 cases of EOGBS infection voluntarily reported to the Health Protection Agency in Northern Ireland <sup>vii</sup>.

## Finally

Screening tests for maternal GBS carriage are routinely used in many developed countries to identify an increased risk of GBS infection developing in the baby. They cannot identify which babies definitely will develop infection (they are screening tests, not diagnostic tests), evidence shows that offering antibiotics in labour to women where GBS has been detected is highly effective at reducing the rate of GBS infection in their babies. We can and should be offering the same in Scotland.

The RCOG's risk factor approach cannot identify all the babies who will develop GBS infection – using risk factors identifies a similar proportion of women whose babies are at raised risk of GBS infection as antenatal screening, but most of these mothers will not be carrying GBS <sup>xi</sup>. Using the RCOG approach, antibiotics are given to women whose newborn babies are not at risk of GBS infection, whilst the majority of women carrying GBS and have no risk factors are offered no protection for their babies. The key risk factor for offering antibiotics in labour identified by RCOG's guideline is GBS having been detected during the current pregnancy – without testing for it, how will women know they're carrying it?

Screening programmes have reduced the rate of GBS infections in newborn babies in other countries – in the USA, by over 80%<sup>x</sup>, in Spain by 86%, in Australia by 82% and in France by 71%. In the US, the rate of early onset GBS infection reported in 2012 was 0.24 per 1,000 live births (0.34 for late onset GBS infection) .

Data current available suggest that the rate of early onset GBS infection in babies in England, Wales and Northern Ireland has not changed since the introduction of the RCOG's risk-based prevention strategy in 2003, although the rate has increased dramatically in Scotland. Other countries have seen the benefit of introducing screening programmes. I would like Scotland to consider introducing screening as a

matter of urgency. Then families and their babies can be spared the dreadful trauma GBS can bring. As the grandma of a baby who died from GBS, I am calling for:

- Every pregnant woman to be offered screening for GBS
- Whenever testing for GBS carriage is undertaken in pregnant women for the 'gold standard' Enriched Culture Medium (ECM) method to be used and
- All pregnant women and their health professionals to be provided with full information about GBS, including preventing these infections in newborn babies
- All new parents and their health professionals to be provided with full information about identifying signs and symptoms of GBS infection in babies, and what action to take

Concerns of course exist about potential negative side effects of a screening programme, but these need to be balanced against the proven and huge benefits – saving babies' lives, preventing life-long disabilities, preventing serious infection and avoiding the trauma which can blight the families lives forever.

My family and I welcome research into future prevention. But we need something done now - too many cases of preventable GBS infection are occurring in Scotland now, this month – we need urgently to introduce steps that have been tried and tested, and proven to be safe and effective.

Nothing can bring Lola back, but we can and should stop these preventable infections affecting other babies and their families.

Yours faithfully

Jackie Watt (Mrs)