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**House of Commons**

**London SW1A 0AA**

**All-Party Parliamentary Group on Baby Loss**

**Monday 10<sup>th</sup> December 2018**

**16:00 - 18:00**

**Committee Room 12, House of Commons**

## **MINUTES**

### **Members in attendance:**

Antoinette Sandbach MP (Co-Chair)

### **Guests:**

Aimee Middlemiss – University of Exeter

Alessandro Alagna - Parent

Clea Harmer – Sands

Dr Celia Burrell - BHRUT NHS Trust

Erin McCloskey – Canterbury Christ Church University

Francine Bates – The Lullaby Trust

Gillian Weaver – Human Milk Foundation/Hearts Milk Bank

Helen Kirrane – Bliss

Jane Goringe – Tamba

Jane Plumb – Group B Strep Support

Jane Scott - Imperial College NHS Trust

Jessica Faulkner – Office of Sharon Hodgson MP

Jo Dickens – University of Leicester

Karina Russell – Royal College of Obstetricians and Gynaecologists

Kate Mulley – Sands

Keith Reed – Tamba

Lauren Hutton – Imperial College Healthcare NHS Trust

Leanne Turner – Aching Arms

Menali Patel - Sands

Munira Oza – Ectopic Pregnancy Trust

Natalie Shenker – Human Milk Foundation

Paula Abramson – Child Bereavement UK

Penny Kerry – Miscarriage Association

Prof Neil Marlow - UCL

Sam Collinge – UHCW NHS Trust

Zeshan Qureshi – Great Ormond Street Hospital

Other guests may have been in attendance but were not captured on the sign-on sheet.

**Apologies received:**

George Howarth MP  
Lord Boswell  
Patricia Gibson MP (Vice Chair)  
Sharon Hodgson MP (Vice Chair)  
Victoria Prentis MP (Vice Chair)  
Will Quince MP (Co-Chair)

**1. Welcome and introductions (Co-Chairs of APPG on Baby Loss)**

Antoinette welcomed the guests, and said she welcomed being at this meeting after a tumultuous few days of Brexit debate.

*Note: all presenters' slides will be available on the APPG on Baby Loss webpage when this minutes are published.*

**2. Model of Care and Neonatal Transformation Review -  
Professor Neil Marlow, Chair of NHS England Specialised  
Commissioning Neonatal Critical Care Clinical Reference Group**

Antoinette welcomed Professor Neil Marlow. He is Professor of Neonatal Medicine at University College London, as well as Chair of NHS England's Specialised Commissioning Neonatal Critical Care Clinical Reference Group.

Prof Marlow has been leading the Neonatal Transformation Review, and has been preparing a set of recommendations on the basis of this work. Prof Marlow's colleague Dr Eleri Adams presented at the APPG meeting in March 2017 about the beginnings of this project. Antoinette welcomed Prof Marlow back to update on progress. (Slides will be available on the APPG webpage).

Prof Marlow explained that there had been a review in around 2003 about a set of standards around neonatal care, which was followed by some commissioning guidance in 2007. With the changes to specialised commissioning, he said that we have come back to this issue once again.

Prof Marlow that the NHS wants to ensure parents and babies have seamless and responsive services. His team ran the review which delivered a range of interesting results. The high spots of mortality and poor health did not at all match the areas of high deprivation, which suggested the NHS needed to address service quality as well. There are also issues with recruitment and retainment of nurses and paediatric professionals. Some of these issues could be attributed to training and career progression challenges. Prof Marlow added that we also need improvements in the reporting system, while the data collection system is relatively good.

As a result, the Programme set up a set of initiatives to improve these areas. These covered:

- delivering expert care – e.g. nursing workforce and training, allied health professionals (AHP) support
- developing capacity – e.g. strengthening local pathways
- enhancing parenting opportunity – e.g. parental accommodation at the neonatal unit

Prof Marlow said we also need to plug the resource gap identified.

The group has completed a final report, and has produced a version which will be released to the public soon. It is a highly ambitious programme of transformation, which is a good opportunity to get things right for the long term.

Antoinette thanked Prof Marlow. She asked whether the AHP support was going to be delivered in the community or in the acute setting. Prof Marlow said that he has no mandate to improve support in community settings. However improvements in acute support should help improve referrals (though as Antoinette noted, that depends on appropriate services being commissioned in the community).

Clea (Sands) asked who is managing the implementation. Prof Marlow said that there is a maternity transformation implementation board, and Prof Malow is aiming to set up a sub-group of that board to handle the implementation.

Antoinette asked how far back the team looked in the clustering data. Prof Marlow said they had been using current MMBRACE data. He said that you would expect clustering to appear around areas of high deprivation, but this is not the case – North-East and Manchester come up 'green', whereas some areas of Birmingham and Yorkshire are 'red'. Some of this is about quality and capacity, some is about changing attitudes around care.

### **3. Maternity engagement and reducing deaths in multiple births - Keith Reed, CEO, Tamba, & Jane Gorringe, Maternity Engagement Project Manager, Tamba**

Antoinette welcomed Keith Reed, Chief Executive of Tamba (Twins and Multiple Births Association), and his colleague Jane Gorringe, Maternity Engagement Project Manager. Jane presented on Tamba and the Department of Health and Social Care's Maternity Engagement Project. This worked with 30 maternity units across England to improve outcomes for families with multiple pregnancies.

This is a unique project, aimed to develop an audit tool to look at current practice vs NICE guidance, and provide support and resources on an ongoing process. Jane said that one of the key messages is that maternity units want to make changes, but you need third parties to go in to help support and drive improvements. In 2017, the team went into 30 units supported by 3 consultant midwives, audited case files, spoke to key staff members from midwifery, sonography and Obstetrics and reviewed patient outcomes. Among other support and engagement, the team put in place a multi-disciplinary care pathway and provided free access to a wide range of Tamba resources. 12 months later, the team undertook a second audit.

As a headline finding, at least 63 babies' lives could be saved per year if the changes could be applied across England. A full report will be coming out in March, but the majority of units in this programme had improved on a range of measures, including reducing the number of neonatal admissions which leads to huge cost reductions

This is a 3-year project and funding comes to an end in March 2019. There is currently nothing in place to enable the project to continue beyond March and multiple births are not explicitly included in the Saving Babies Care Bundle

Keith added that in order to take this forward, the cost would be about £130k per year for 30 units. Tamba are unable to fund this themselves, so are looking for funding support.

Antoinette asked whether Trusts could fund this programme, given the savings identified. Keith said there is no reason for them not to, if Trusts have the money and the will. Prof Marlow said that this would be a benefit to the whole service, not just to twins and other multiple births, but you have to persuade the Trusts to do it.

Keith said we could try to sell it to Trusts, but as it is not mandated by a national lever, that is a barrier to people funding it. Keith said that in all fairness the Clinical Director did present this to the Better Care Bundle expert team, but they rejected this proposal.

Antoinette asked whether a Trust would become legally liable if the NICE guidance is not followed. Keith said generally that may be the outcome, but judges will tend to look at these issues case by case.

Prof Marlow added that the provision of transitional care is one of the top 10 CNS criteria for Trusts. Many of these interventions are not special care, they are part of routine baby care in postnatal ward, and so the Trust should be encouraged to provide transitional care.

Francine (Lullaby Trust) asked what helped make the change in the project? Jane said it was the approach used: the collaborative aspect, sharing resources, and listening rather than just 'telling'. It was also important to identify together the things that were hard to overcome, and target these issues specifically. Keith said he felt it had been useful to be approached from a charity rather than NHS England, as they were seen as just there to help.

Antoinette said that would be good to work up a letter from the APPG and TAMBA to request funding from NHS England.

**Action: Drew and Keith to collaborate on a letter and send to Co-Chairs for sign-off**

#### **4. Lactation support for bereaved mothers – Gillian Weaver, Director of Hearts Milk Bank**

Antoinette welcomed Gillian Weaver, the Director of Hearts Milk Bank. She discussed lactation support for bereaved mothers and breastmilk donation.

Gillian said that women produce secretions from the breast typically very early in pregnancy, and are usually ready to lactate 22-26 weeks into pregnancy. This means that there is often a big group of mothers who may be lactating when they lose their baby.

Gillian highlighted the need to support bereaved mothers in a compassionate way when it comes to breast milk. To put it simply, “her breasts don’t know that the baby has died”. This applies to how breast milk is stored and then used. A conversation needs to be had with a mother about what happens to her milk, when and in what way. In the UK, donor milk is usually used in neonatal units, but is increasingly been used in the community as well.

This experience also has an impact on the whole family. Mothers have several choices when this situation arises. For instance, she can stop lactating as soon as possible (involution), slowly reduce and stop her milk support, donate her milk, and so on. There are some health advantages to the mother to continue lactating for some time, and some mothers can find this an important emotional link to their baby. Others may wish to donate their milk to help other babies. In practice, most mothers will want to stop lactating.

We need to know what the mother wants to do, and have an initial conversation with that mother within a few hours rather than a few days, which would cover a range of options, including donating milk. It is also right to offer further information and other support as time passes. Provision of a breast pump if the mother does not have one would also be sensitive. Medications can be used to stop lactation, but side effects should be explained to the mothers. No immediate decision is needed, and mothers should not be pushed to make a decision before they are ready.

Donating following a stillbirth can take place in some circumstances, and for some women giving their milk to help other babies can give comfort, and is seen as a tribute to their lost baby.

However, Gillian outlined that some mothers are not supported well and confronted with misunderstandings by families, friends and even some health professionals. Some have even been turned away by local milk banks. Gillian requested that this is an issue that is kept on the APPG’s agenda.

Natalia (Human Milk Foundation) said that she would be very keen to work with other organisations as means to break the taboo of donating milk in some areas and communities.

Leanne (Aching Arms) said that the approach outlined by Gillian was right and appropriate, following her experience.

Kate (Sands) said that there is a link to the National Bereavement Care Pathway (NBCP), and we want to open up some of the site to include good examples. It would be good to work together with the Human Milk Foundation on this issue.

Sam (UHCW NHS Trust) said that her Trust are looking at introducing some aspects of what Gillian had described in Coventry, but asked if there was any guidance on how to go about this. Gillian said there is some details in the Sands guidance for professionals but it does not have ‘conversation starters’ in it. Gillian said that this is the kind of resource the Human Milk Foundation would like to develop in collaboration.

Gillian thanked the Group for the opportunity to speak, and Antoinette thanked her for her presentation.

## 5. Review of Baby Loss Awareness Week 2018 – Dr Clea Harmer, CEO of Sands

Antoinette welcomed Dr Clea Harmer, Chief Executive of Sands. Clea gave an overview of the key results from Baby Loss Awareness Week (BLAW) 2018.

Clea began by expressing her profound thanks to everyone in the room for all their efforts for BLAW. She gave a key overview of some of the Westminster parliamentary activity that was involved. We had several displays in parliament, a launch event, a remembrance service, a debate in the House of Commons, with the Minister reaffirming support for the NBCP and committed to asking the Care Quality Commission to embed the pathway in their own monitoring. 107 attendees were at the launch event of which 36 MPs attended and engaged well. 3 MPs already have agreed to visit NBCP pilot programmes in their own constituencies.

Outside of Westminster, Clea recounted that the BLAW partners held a drop-in event in the Scottish parliament; a successful debate, as well as a remembrance event in the Wales Assembly. With the efforts of Will Quince MP's office in particular, we also produced a video montage of MPs and other politicians expressing their support for BLAW, which received wide viewership.

Across the UK, 180 buildings were lit up pink and blue, which is more than double the amount of buildings involved last time. The BT Tower joined the Wave of Light at the end.

Turning to social media, Clea said that just on the BLAW-specific social media channels, there was over 2 million reach on Facebook, with the custom-made BLAW animation video grabbing almost 250k views. ITV's Emmerdale, Loose Woman and BBC's Cbeebies all joined in the Wave of Light.

Conventional print, radio and TV coverage was again up on last year, with significant celebrity involvement.

Clea said that the BLAW partners also held a large number of events over the week, with 39 ribbon displays, 48 remembrance events, 42 wave of light events, and 10 other events.

There were also other opportunities that emerged. The retailer M&S supported BLAW with a special t-shirt, which sold out within 24 hours. More were printed as a result.

Clea added that the number of charities involved increased from 40 in 2017 to 70 in 2018.

Antoinette said this was a fantastic set of achievements, and thanked everyone for their hard work.

## 6. APPG work next year

Antoinette began a discussion with the Group on what business the APPG should consider in 2019.

Jessica Faulkner (Office of Sharon Hodgson MP - Vice Chair) and Helen (Bliss) requested that the Group arrange a joint meeting with the APPG on Maternity to discuss the issue of **parental leave for mothers who give birth to premature babies** requiring extended

hospital stays. As discussed briefly at the APPG meeting in July, this situation means that the maternity leave provided would be unlikely to be sufficient. This topic was also the subject of a Westminster Hall debate in November. Antoinette responded we should be able to organize this event.

**Action: Drew to work with APPG Co-Chairs to organise a joint meeting in 2019**

Antoinette proposed that the APPG's focus **should shift to the community**. Leanne (Aching Arms) welcomed this approach, and said she would like the APPG to look at what happens after parents go home. Clea agreed and said that some of the NBCP focus would shift to the community support too.

Kate (Sands) said it would be helpful to hear back on some of the **prevention initiatives** being undertaken by the government e.g. the next iteration of the Saving Babies Care Bundle. Alessandro agreed that putting more time into the reviewing and monitoring the progress towards the government target would be worthwhile. Jane Plumb (Group B Strep Support) said there is also new research that has come out, e.g. Each Baby Counts, to help prevent more of these cases, which would be worthwhile to highlight.

Antoinette agreed this would be a good issue for the group. Francine (Lullaby Trust) suggested inviting to the new Secretary of State Matt Hancock MP to come report on the Saving Babies Care Bundle, but also on the halving the number of stillbirths, which was welcomed by the Group.

**Action: Drew to arrange for a meeting next year**

There is also some work that would be useful to look at **inequalities in risk**. Antoinette asked whether that it is a research or implementation issue. Kate replied there seems to be a lot of the research done, so definitely a focus on the later.

Antoinette said we should probably prioritise one of bereavement care in the community or prevention. Leanne (Aching Arms) expressed a preference to keep developing the NBCP and move through the pathway into the community.

Drew raised that while there is limited time for issues to be included on the meeting agendas, much of the work of the Group and its partners takes place outside of the meeting. As such, while we should be selective on what to focus on, not everything needs to be 'squashed' into the 4 meetings per year.

Drew requested people to send through other specific agenda items if they would like these considered.

**Action: Guests to send through other agenda items before end January**

On the topic of the NBCP, Jane (Imperial) said that she and her colleagues lead the national bereavement midwife forum with 120 members and the charity 4Louis funding their meetings. She said that there has been some frustration with the NBCP because of a lack of clinical input; it feels like there hasn't been much consultation with their group. The NBCP is not mandated in Trusts, so if there is not a supportive head of midwifery, it may not be possible to obtain the support needed to imbed the pathway. Jane asked how Sands could get this more embedded.

Kate (Sands) said that it is true that the NBCP does not include clinical guidance. She said that Sands is clear they want this to be mandated, which was one of the asks during BLAW to NHS England, as well as ongoing conversations with the Care Quality Commission to incorporate the NBCP in its inspections. The NBCP partners are still pushing with NHS England to try to engage on this point.

Jane (Imperial) said that there was very little consultation with clinical partners in putting this together. Clea said there were a lot of stakeholder events, and that the Royal College of Midwives has been involved from the start. But she emphasised that this was always intended to be about bereavement care, not clinical care. Clea offered to discuss this in more depth with Jane and colleagues outside of the meeting.

**Action: Clea/Kate to discuss with Jane**

## **7. Any other business**

Drew passed on that Will has been elected as a Trustee of Sands.

## **8. Next meeting: Dates for 2019 tbc**

Dates will be confirmed with the APPG officers and shared with the group's mailing list at the start of next year. Antoinette said that we will need to be realistic given the events of today, so between now and the 29<sup>th</sup> March, MPs' time may be very pushed due to Brexit.

Antoinette also gave her thanks to Francine for all her work that they have done over the last couple of years, and for Lullaby Trust's funding for the secretariat of the group from the start. Francine is moving on.