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**House of Commons**

London SW1A 0AA

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

**Monday 15<sup>th</sup> March 2021, 16:00 - 18:00, Via Zoom**

## **MINUTES**

Members and representatives in attendance:

- Cherilyn Mackrory MP (Chair)
- Sharon Hodgson MP
- Patricia Gibson MP
- Jane Hunt MP
- Alicia Kearns MP
- James Sunderland MP

Other guests:

- |                         |  |
|-------------------------|--|
| • Alex Mancini          | Chelsea & Westminster NHS Foundation Trust |
| • Alyson Chorley        | Twins Trust                                |
| • Alyx Elliott          | Petals                                     |
| • Amneet Graham         | Willow's Rainbow Box                       |
| • Amy Braier            | Miscarriage Association                    |
| • Amy Overend           | NHS  |
| • Anita Rakhit          |  |
| • Professor Asma Khalil | St George's Hospital                       |
| • Belinda Champion      | Lewisham & Greenwich NHS Trust             |
| • Beth McCleverty       | Bliss                                      |
| • Beverley Radcliffe    | The Coroners' Courts Support Service       |
| • Celia Burrell         | NHS  |
| • Charlotte Bevan       | Sands                                      |
| • Chris Binnie          | MAMA Academy                               |
| • Clea Harmer           | Sands                                      |
| • David Monteith        | Grace in Action                            |
| • Dawn Brown            | CRADLE                                     |
| • Donald Mbeutcha       | Dope Black Dads                            |
| • Elizabeth Hutton      | Kicks Count                                |
| • Emily Lewis           | RCOG                                       |
| • Emma Pearson          | Joel the complete package                  |
| • Erin McCloskey        | Canterbury Christ Church University        |

- Gemma Quayle ONS
- Geoff Heaps The Lily Mae Foundation
- Gillian Weaver Human Milk Foundation
- Gwyneth Munjoma Tees law
- Hannah McConnell ONS
- Jane Denton Multiple Births Foundation
- Janet Scott Sands
- Jenny Chambers ICP Support
- Jenny Poirier Lullaby Trust
- Jenny Ward Lullaby Trust
- Jess Read NHSEI
- Jessica Reeves Sands
- Joanne Dickens University of Leicester and University  
Hospitals of Leicester NHS Trust
- Julia Bueno
- Karen Burgess Petals
- Kate Mulley Sands
- Laura-Rose Thorogood The LGBT Mummies Tribe
- Lauren Petrie Imperial College Healthcare NHS Trust
- Leanna Brace CRADLE
- Leanne Turner Aching Arms
- Lucy Smith University of Leicester
- Marc Harder Sands
- Marcia Jones The Lullaby Trust
- Marcus Green APEC
- Mehali Patel Sands
- Mohamed Omer Gardens of Peace Muslim Cemetery
- Molly Boydon BPAS
- Munira Oza The Ectopic Pregnancy Trust
- Niki Robins Imperial Healthcare NHS Trust
- Oliver Plumb Group B Strep Support
- Paula Abramson Bereavement Training International
- Penny Kerry Miscarriage Association
- Professor Gordon Smith Cambridge University
- Professor Philip Steer Imperial College London
- Rachel Corry
- Richard Boyd Twins Trust
- Ruth Bender Atik The Miscarriage Association
- Ruth Matthews University of Leicester
- Ryan Jackson The Lily Mae Foundation
- Sara Fitzsimmons SiMBA
- Sarah de Malplaquet Kit Tarka Foundation
- Sarah Harris Child Bereavement UK

- Sharon Darke Twins Trust bereavement group
- Sophie Dodgeon Rainbow Trust Children's Charity
- Steph Wild Beyond Bea Charity
- Tara Arnold Nova Foundation
- Thomas Maddox ONS
- Vicki Robinson Miscarriage Association
- Wendy Olayiwola NHS England

## **1: Welcome, introductions and updates (Cherilyn Mackrory MP, Co-Chair of the APPG on Baby Loss)**

Cherilyn Mackrory MP, Co-Chair of the APPG, opened the meeting and welcomed everyone. She gave apologies from Jeremy Hunt MP, Co-Chair of the APPG, who was unable to attend. Cherilyn explained that the meeting would include a discussion of the APPG's focus for 2021, alongside updates on legislation, data and relevant charity campaigns.

Cherilyn went on to update attendees on activity since the previous meeting. She noted that in December the Co-Chairs were pleased to contribute the foreword to the MBRRACE-UK second annual report on the National Perinatal Mortality Review Tool. This is an important tool for improving the quality of local reviews and incorporating parents' perspectives into reviews after the death of a baby.

Cherilyn further noted that in February the Co-Chairs joined a meeting organised by the APPG on Smoking and Health to mark the launch of a report from the Smoking in Pregnancy Challenge Group. A recording was taken of the meeting which is available to view online.

Cherilyn then updated attendees on actions from previous meetings. In relation to the National Bereavement Care Pathway, Cherilyn explained that conversations with Sands are ongoing as to how to continue support this important work.

In relation to funding for charities during COVID-19, Cherilyn noted that the APPG on Charities has been working on this issue, and encouraged attendees to make contact with that APPG if this is a relevant topic for them. She further noted that the Public Accounts Committee are conducting an inquiry into Government support for charities during COVID-19 which may be of interest to attendees. The deadline for submissions to this inquiry is 8 April 2021.

## **2: AGM**

Having established there was a quorum of five or more members of either House present, the AGM was held.

The newly elected Officers of the APPG are:

- Co-Chair: Cherilyn Mackrory MP (Conservative)
- Co-Chair: Jeremy Hunt MP (Conservative)

- Vice-Chair: Patricia Gibson MP (SNP)
- Vice-Chair: Sharon Hodgson MP (Labour)
- Vice-Chair: Sarah Owen MP (Labour)

#### **Actions:**

- The Secretariat to complete the APPG registration by informing the Office of the Deputy Registrar
- The Secretariat to publish on the APPG's webpage:
  - The minutes of the AGM
  - Changes to the group's membership list.

### **3: Updates (Chair)**

Cherilyn then provided an update on a number of relevant policy initiatives.

Cherilyn first opened a discussion on support for baby loss before 24 weeks. Sharon Hodgson MP noted that there has been a petition on this brought by a bereaved parent on providing support in the workplace. It was also noted that the Pregnancy Loss Review which includes consideration of registrations of baby loss is ongoing. Sharon discussed the impact of losses at every gestation and that families' feelings of grief are all important whatever the gestation at which they occur. Cherilyn agreed with Sharon and reiterated the importance of supporting people after a loss in the workplace.

Clea Harmer, CEO of Sands, commented to highlight the need to hear an update on the Pregnancy Loss Review soon. She further noted that many parents want the option to register the death of their baby, as well as needing access to the right support.

Ruth Bender Atik, Director of the Miscarriage Association, agreed that it was important that registrations be optional depending on the needs of families. She also called for further provision of support in the workplace, through ensuring there are miscarriage and pregnancy loss policies in place for employees.

**Action:** A representative from the Pregnancy Loss Review group to be invited to give an update at the July APPG meeting.

Cherilyn went on to note that the Department for Health and Social Care have launched a call for evidence to contribute to a Women's Health Strategy, the deadline is 30 May 2021. It was agreed that the APPG would look to submit a response to this consultation.

**Action:** The APPG to submit a response to the Women's Health Strategy consultation.

### **4: Safer Sleep Week (Jenny Ward, CEO, The Lullaby Trust)**

Cherilyn introduced Jenny Ward, CEO of The Lullaby Trust, the charity which aims to prevent unexpected deaths in infancy and to promote infant health. Jenny gave a presentation on the charity's work over the past 50 years, and their new research to mark Safer Sleep Week which started on 15 March.

Jenny began by explaining that the charity was started by a bereaved grandmother in 1971. She noted that the charity promotes safer sleep messages and provides bereavement support to families. She highlighted that over the past 50 years there has been a significant drop in rates of sudden infant deaths, including a reduction by over 80% since 1991 when the Back to Sleep message was launched in 1991.

She explained that 230 babies still die through sudden death in infancy (SIDS) each year. She went on to note that while the cause of infant deaths is not always known, there are certain practices that can help to prevent sudden death in infancy.

Jenny explained that Safer Sleep Week this year focuses on Dads. The charity's research has shown that 74% of new and expectant Dads are worried about SIDS, yet only 32% had been given safer sleep information by a health professional. She noted that the charity is working with Public Health England to help reach Dads with health advice. Jenny reminded everyone of the key safer sleep messages: to put babies on their back for every sleep; in a clear, flat sleep space; and to keep them smoke free day and night.

Cherilyn thanked Jenny for her presentation and asked what can be learnt from the success of public health messages to do with safer sleep. Jenny noted the importance of consistent information, and the need for continuing research to inform best practice.

Amy Overend commented to agree with the importance of safer sleep messages. She also noted the different products on the market which are advertised to parents of babies, and asked how these are regulated for safety. Jenny explained that this is an area the charity seeks to tackle, to ensure that products are safe and that parents are informed about what is best for their baby. She noted that there is a product guide available from Public Health England on this area.

## **5: Latest ONS data (Gemma Quayle, Senior Research Officer, Office for National Statistics)**

Cherilyn introduced Gemma Quayle from the Health and Life Events Division at the Office for National Statistics (ONS).

Gemma began by explaining that the ONS have recently published data on infant deaths that occurred in 2019 and which were registered up to 29 September 2020. She set out the overall trends for infant mortality in England and Wales, noting that the rate has remained fairly stable since 2014. She further noted that rates vary between the regions.

Gemma went on to discuss trends in neonatal mortality, the rate of which has not changed since 2017. She noted that the rate differs between babies born before or after 24 weeks gestation. The neonatal mortality rate for babies born before 24 weeks is higher than for babies born after 24 weeks. Further, the rate of neonatal mortality for babies born after 24 weeks has been declining.

Gemma then set out details of the statistics available on other factors, such as low birthweight. She lastly explained that new analysis on ethnicity should be available from the ONS at the end of May.

Gemma explained that the latest statistical bulletin is available online:

- Bulletin: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/latest>
- Accompanying tables:
  - Death cohort tables – with additional tables on gestational age: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/childmortalitystatisticschildhoodinfantandperinatalchildhoodinfantandperinatalmortalityinenglandandwales>
  - Birth cohort tables: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/infantmortalitybirthcohorttablesinenglandandwales>

Cherilyn thanked Gemma for her presentation and asked what her assessment was of progress against the National Ambition. Gemma noted that there is a mixed picture with some rates levelling off. She further noted that there is more commentary on this on the ONS website.

Clea Harmer commented on the importance of reporting rates of neonatal deaths including those both before and after 24 weeks gestation. She asked Gemma about what plans there are for reporting these together or separately in future. Gemma explained that ONS will continue to publish all available data, and will provide breakdowns for different factors such as gestational age.

## 6: Safe Delivery

Cherilyn explained that the next section of the meeting would focus on activity to reduce rates of baby loss. She noted that, while the APPG is proposing a particular area of focus for the rest of this year, the group will continue to work on a range of topics relating to baby loss. Cherilyn went on to note that, as set out by Gemma and the Office for National Statistics, the latest available data shows that while some rates of baby loss are falling, other rates remain stable. She further noted that despite the best efforts of all to meet the Government's 'Halve It' ambition, there is more that can be done.

Cherilyn explained that the APPG is proposing a campaign focused on encouraging evaluation of which interventions can help reduce rates of baby loss and driving progress towards the National Ambition. The APPG proposes calling on the Government to assess what works and what is already contributing to falling rates of baby loss to ensure this continues. The APPG also proposes calling for evaluation of new interventions, to ensure that all potential tools in the toolbox are evaluated in order to be used to save babies' lives.

Cherilyn noted that interventions to reduce rates must be evidence based, and must be considered in partnership with women and families. Further, interventions must also be supported by funding for the training, equipment and workforce required for implementation, and there must be equity to ensure that impactful interventions reach all women, including those living in poverty and women from ethnic minorities. Cherilyn concluded by saying that the APPG supports women's rights to decline any interventions, and to make informed choices about their place and mode of delivery.

## 7: Guest speakers

Cherilyn explained that the next section of the meeting would hear from scientists who are working on different interventions that could help to reduce rates of baby loss. Some of the interventions are already approved for use, but are not being universally delivered. Others are new proposals which must be fully evaluated before being considered for implementation.

### **ECM testing for Group B Strep**

Cherilyn introduced Professor Philip Steer, from Imperial College London, who spoke about ECM testing for Group B Strep. Cherilyn noted that ECM testing should already be in use throughout England, but there is thought to be variation in how it is being applied.

Professor Steer explained that Group B Strep is the most common cause of infections in newborn babies, effecting 800 babies a year in the UK and causing about 50 deaths. Up to 90% of cases could be prevented through the use of antibiotics. He described the different ways to detect Group B Strep infections, and that the method recommended by the Royal College of Obstetricians and Gynecologists is ECM testing. This is recommended for women who were diagnosed with Group B Strep in a previous pregnancy. However, he noted that data from Freedom of Information requests show that testing procedures are not universally being followed.

### **NIPT for multiple pregnancies**

Cherilyn introduced Professor Asma Khalil, from St George's Hospital, who spoke about Non-Invasive Prenatal Testing (NIPT) for multiple pregnancies. NIPT is not currently used as standard practice in this way.

Professor Khalil set out research which shows that rates of stillbirths differ between singletons and twin pregnancies, with twins having a higher rate. She went on to explain the current practices for screening for chromosomal abnormalities. She set out her research into using NIPT in multiple pregnancies as a first line test, showing this could lead to results being available earlier, reduce risk of miscarriage and pre-term birth, and impact on parents' experiences.

### **Scans for breech presentation**

Cherilyn introduced Professor Gordon Smith, from Cambridge University, who spoke about scans for breech presentation. Scans for breech presentations are currently being reviewed by the National Screening Committee.

Professor Smith explained that his research indicates that up to 50% of breech presentations are currently not identified. He noted that this means that conversations about place and mode of delivery are not able to happen in advance, with implications for parents' experiences and patient safety. He set out his research into using universal scans for breech presentation at 36 weeks, suggesting this would lead to a reduction in emergency caesarean sections and prevent five to 10 babies' deaths each year.

Cherilyn thanked the three speakers for their presentations and invited questions on their research. Marcus Green, from Action On Pre-Eclampsia, asked why some Trusts do not use ECM tests for Group B Strep. Professor Steer noted that some Trusts may have hesitancy around the cost or resource required for the tests, but that this can be solved once the details of the tests are explained. Cherilyn emphasized the importance of Trusts

becoming involved with the GBS3 Trial, and supported the work the Minster has been doing in this area.

Cherilyn then asked Professor Smith what research is available on what training would be required to implement scans for breech presentation. Professor Smith noted that this is a priority for research, but he felt that the skills for scanning can be learnt by a range of healthcare professionals and that new technologies mean scanners are more portable.

Professor Khalil further commented on whether NIPT should be offered to all pregnancies as a first line test. She noted this is not currently recommended, but that her research focuses on benefits for twin pregnancies specifically.

Clea Harmer welcomed the focus on tools for prevention of baby loss. She noted the importance of working to reduce smoking in pregnancy and latest data on smoking at the time of delivery. She highlighted interventions that can help to address this, such as CO monitoring and smoking cessation services. These should already be happening but implementation varies, partly due to the pandemic.

Jenny Ward agreed that small interventions can add up to make a significant difference to saving babies' lives, and also to help ensure women are informed about their choices.

Dawn Brown from Cradle asked which Trusts have signed up for the GBS3 trial. In correspondence after the meeting it was noted that four Trusts had signed up as of October 2020, with others having expressed an interest:

- North West London University
- Nottingham University Hospitals
- Royal Devon and Exeter
- University Hospitals Coventry and Warwick

Cherilyn closed by reiterating her thanks to all the speakers for sharing their research and for their work on seeking to prevent baby loss.

## **8: Closing remarks**

Cherilyn concluded the meeting by noting that the APPG proposes focusing on a prevention campaign for the remainder of 2021. This will involve engaging with the Minister and Secretary of State, and Parliamentary activity. She noted that Jeremy Hunt MP, Co-Chair of the APPG, is also Chair of the Health and Social Care Committee which will be publishing a report on this area in the coming months.

Cherilyn then closed the meeting. The next meeting of the APPG is planned for 5 July 2021, via Zoom.