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House of Commons

London SW1A 0AA

All-Party Parliamentary Group on Baby Loss

Monday 7<sup>th</sup> December 2020, 16:00 - 18:00, Via Zoom

## MINUTES

Members and representatives in attendance:

- Rt Hon Jeremy Hunt MP (Chair – first hour)
- Cherilyn Mackrory MP (Chair – second hour)
- Dr Rosena Allin-Khan MP
- Millie Beaver, representing Victoria Prentis MP
- Adam Smith, office of Jeremy Hunt MP

Other guests:

- |                          |                                       |
|--------------------------|---------------------------------------|
| • Alyx Elliott           | Petals                                |
| • Ann Chalmers           | Child Bereavement UK                  |
| • Belinda Champion       | CRADLE                                |
| • Beth McCleverty        | Bliss                                 |
| • Beverley Radcliffe     | The Coroners' Courts Support Service  |
| • Chloe Stevens          | ONS                                   |
| • Christina Rolles       | Lullaby Trust                         |
| • Clea Harmer            | Sands                                 |
| • Daniel Brett-Schneider | Sands                                 |
| • Emma Brooke            | ONS                                   |
| • Gemma Quayle           | ONS                                   |
| • Geoff Heaps            | Lily Mae Foundation                   |
| • Gillian Weaver         | The Hearts Milk Bank                  |
| • Hannah McConnell       | ONS                                   |
| • Jane Denton            | Multiple Births Foundation            |
| • Jane Plumb             | Group B Strep Support                 |
| • Jenny Chambers         | ICP Support                           |
| • Jenny Kurinczuk        | MBRRACE-UK                            |
| • Jenny Ward             | Lullaby Trust                         |
| • Jenny Poirier          | Lullaby Trust                         |
| • Jessica Reeves         | Sands                                 |
| • Karen Burgess          | Petals                                |
| • Lauren Hutton          | Imperial College Healthcare NHS Trust |
| • Leanna Brace           | CRADLE                                |
| • Leanne Turner          | Aching Arms                           |
| • Marc Harder            | Sands                                 |
| • Marcus Green           | Action on Pre-Eclampsia               |

- Munira Oza Ectopic Pregnancy Trust
- Nadine Baynes CRADLE
- Oliver Plumb Group B Strep Support
- Paula Abramson Bereavement Training International
- Rich Boyd Twins Trust
- Roopal Shah Babyloss Support LLR
- Ruth Bender-Atik Miscarriage Association
- Ryan Jackson The Lily Mae Foundation
- Samantha Collinge University Hospitals Coventry & Warwickshire NHS Trust
- Sara Fitzsimmons SiMBA
- Sarah de Malplaquet Kit Tarka Foundation
- Sharon Darke Twins Trust
- Sophie Dodgeon Rainbow Trust Children's Charity
- Veronique Berman Chana
- Vicki Robinson Miscarriage Association
- Vicky Nevin NSPCC

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

Jeremy Hunt MP, Co-Chair of the APPG, opened the meeting and welcomed everyone. He explained that the meeting would include a review of Baby Loss Awareness Week, a roundup of the APPG's activities during 2020, and a look ahead to plans for 2021. He noted that the guest speakers for this meeting focused on learning from data, which is key to the APPG's core aims – both improving bereavement support, and prevention of baby loss.

Jeremy went on to update attendees on actions from previous meetings. He noted that the APPG has written to Lord Bethell, Health Minister, in relation to MBBRACE-UK and the national data opt-out, requesting a meeting to discuss this further. However unfortunately the Minister is not currently in a position to facilitate a meeting. Jeremy further noted that the Health and Social Care Committee, which he Chairs, have been enquiring into this, and they received a letter from the Secretary of State stating that the opt-out for MBBRACE would be further considered in order to reach the "appropriate position". It was agreed that this continues to be an area of interest for the APPG.

## **2: Overview of the year for the APPG on Baby Loss, and plans for 2021 (Chair)**

Jeremy provided an overview of the APPG's activity during 2020, explaining that some of the activity occurred prior to him and Cheryl Mackrory MP taking up their roles as Co-Chairs. He noted that since December 2019 there has been one general election, two General Meetings of the APPG to elect a new Chair and then two new Co-Chairs, and three online meetings since the move to virtual working.

He noted that the APPG has continued to hold regular meetings to inform members of the key themes and topics relating to baby loss, such as the most recent meeting on baby loss and BAME communities. The group also worked to review the impact of COVID-19 on people experiencing pregnancy and baby loss. This culminated in the publication of the APPG's report on the pandemic, which was circulated to key stakeholders and which was discussed in parliament in a Westminster Hall debate in November. Jeremy highlighted that at the debate it was incredibly powerful to hear MPs from all parties sharing their own experiences and raising issues on behalf of their constituents.

Looking ahead to 2021 Jeremy explained that the APPG is seeking to choose an area of focus for the APPG. The group will continue to campaign on and discuss a range of issues beyond this, however it would be helpful to have a particular key area. Jeremy introduced a discussion on ideas for the core overarching theme for the year for the APPG to focus on, which had grown from discussions between the Co-Chairs and key stakeholders in NHS England. These are:

- Continuity of carer for all women

Jeremy explained that continuity of carer is important from the earliest point in a pregnancy, helping to improve safety, better support women and identify those who may be high risk. It was noted that continuity of carer can also lead to better bereavement support. It was further noted that while NHS England are working towards a target for providing continuity of carer for particular groups of women, there is no commitment to provide it to all women at present.

- Additional screening for possible breech birth

Jeremy noted that there is some expert opinion that an additional scan to identify breeches may help with earlier identification, meaning a plan can be put in place. This could reduce the need for emergency c-sections and improve outcomes.

- All women and their partners to have access to proper bereavement support

Jeremy explained that bereavement care has been a key focus of the APPG since it was established, but there continues to be variation. For example, access to bereavement suites may vary geographically.

Cherilyn Mackrory MP, Co-Chair of the APPG, then set out her perspective on the three proposed areas of focus. She noted that continuity of carer has a key role in identifying wider issues that may impact on women and babies, such as domestic violence. She noted the importance of women communicating with their maternity teams about any concerns, and highlighted how continuity of carer can help to facilitate this. She went on to note the interesting research in relation to breech birth and the importance of considering the evidence relating to this. Cherilyn concluded by explaining that bereavement care and support are close to her heart after her family's own experiences. She particularly noted the role of bereavement care and support for partners after a loss.

Jeremy then introduced Dr Rosena Allin-Khan MP, Shadow Health Minister. The Shadow Minister applauded the contributions of everyone who took part in the recent Westminster Hall debate to mark Baby Loss Awareness Week. She also explained her personal and professional experiences of pregnancy and baby loss. She noted the impact of trauma, and the role of continuity of carer in helping mitigate this. The Shadow Minister further noted the importance of bereavement support for partners, and that it is vital this is offered in a timely way. She went on to outline her interest in the role of extra scans in helping to identify risks.

Jeremy noted that the Health and Social Care Select Committee will be discussing issues in this area next week. Jeremy then invited others to join a wider discussion. Ryan Jackson from the Lily Mae Foundation supported a focus on mental health of partners, noting that in particular men may find it hard to access services. Veronique Berman from Chana noted that the COVID-19 pandemic may be impacting on continuity of carer, making this harder to deliver. Beverley Radcliffe from the Coroners' Courts Support Service talked about the importance of continuity carer for women experiencing baby loss. She further noted the importance of non-religious bereavement care being available, and the value of bereavement suites that were separate from delivery wards. Ruth Bender-Atik from the Miscarriage Association noted that a focus on continuity of carer may not reach those who experience loss in the first twelve weeks of pregnancy, although it can help to support those women who then go on to be pregnant again. She further noted that provision of bereavement support needs to be aligned with ensuring everyone is able to access it. Vicky Nevin from NSPCC highlighted research showing that continuity of carer has challenges in reaching every woman in person. Jenny Kurinczuk from MBRRACE-UK noted that the National Screening Committee will likely be examining the evidence in relation to additional scans and their impact. Finally, Clea Harmer from Sands explained how continuity of carer can help provide bereavement support, so these two areas are very interlinked.

Jeremy thanked everyone for their contributions and said that he would work with Cheryl and other members of the APPG to work up a plan to be brought to a future meeting of the APPG.

**Action:** The Co-Chairs to finalise plans for the APPG for 2021 and to share these at the next meeting.

### **3: Guest speakers: Learning from data**

Jeremy introduced the next section of the meeting which looked at learning from data in relation to baby loss. This is a key focus for the APPG, as data can help to inform work on both prevention and bereavement support.

He went on to introduce Gemma Quayle and Hannah McConnell from the Health and Life Events Division at the Office for National Statistics (ONS) who explained their work in relation to data on baby loss, and their plans for future data collection.

Gemma talked through the ONS' responsibilities in collecting data on births, stillbirth and infant mortality. She noted that they do not collect data on miscarriages. She set out the different data captured, and explained the difference between data sets on birth registration, death registration and birth notification. She demonstrated how these different data sets can be used to identify different risk factors. Gemma further provided an overview of the ONS' different publications in relation to baby loss and what was included in each one.

Hannah explained the ONS' new work on data linkages, expected in February 2021, which will lead to more detail on gestational age and ethnicity in relation to baby loss. She went on to present the ONS' publication on births in 2020, published earlier in the day, which examined data from during the pandemic. She noted that there had been slightly fewer

births than usual, in line with trends, and also slightly fewer stillbirths again in line with recent trends. Hannah also noted a small reduction in pre-term births, again in line with trends. She noted that the data for this review was at a national level for England and Wales.

Hannah also set out an aim for future work on child and infant mortality, and how the ONS were working with the National Child Mortality Database in this regard. Finally, Hannah explained the future work the ONS plans to carry out on ethnicity and baby loss. This includes evaluating the quality of ethnicity data available to them, and to work further on categorisation of the data.

Jeremy thanked Gemma and Hannah for their presentation, and asked about the impact of COVID-19 on baby loss. Hannah noted that their work on COVID-19 mortality has focused on the population as a whole. Gemma highlighted the role of the National Child Mortality Database in helping to review this. Jenny Kurinczuk shared the details of research that found no evidence of neonatal deaths resulting from COVID-19. Jeremy again thanked the speakers and passed on his gratitude for the important role of the ONS during the pandemic.

Jeremy then introduced Marc Harder from Sands, who set out data from an evaluation of the National Bereavement Care Pathway (NBCP). The pathway has been supported by the APPG on Baby Loss for many years and is an important tool in ensuring all families have access to the best bereavement care.

Marc explained how parent feedback has helped to design and develop the NBCP. He noted that parents have been involved in workshops since 2017, and their experiences showed the need for a pathway to tackle variations in care. He said that the core principle of parent-centred working is at the heart of the pathway.

Marc noted that the 2018/19 evaluation of the NBCP sought to look at its impact and effectiveness by surveying newly bereaved parents. He noted that the evaluation led to the development of nine bereavement care standards, three focusing on parents, three focusing on professionals, and three on processes.

Marc went on to present data collected in relation to the NBCP during the COVID-19 pandemic. This found that parents had good support in hospital, but less good experiences of community care and communication between healthcare professionals into the community. He further explained that a survey of healthcare professionals found they had struggled most to facilitate partners attending scans, to refer parents to support, to support and train healthcare professionals, and to ensure follow up was provided.

Marc noted that future plans for the NBCP include increased training, especially for community practitioners, sharing good practice and maintaining the profile of bereavement care. 2021 would also see more e-learning resources and a continued rollout in Scotland.

Cherilyn thanked Marc for his presentation and asked what more the APPG could do to support the spread of the NBCP. Marc explained that while the Department for Health and Social Care strongly urge Trusts to take part in the NBCP, there could be a role for mandating the pathway and the nine standards. Clea Harmer agreed and noted that mandating may lead to greater time, funding and resources being available to healthcare professionals to deliver the standards. There was a discussion as to how much funding might be required to meet the gap.

**Action:** Sands and the APPG to discuss opportunities to support the NBCP further.

Cherilyn then invited others to join a wider discussion. Munira Oza from the Ectopic Pregnancy Trust asked what level of granularity was captured in the data presented by Marc, as there is a lack of good data on early pregnancy loss, and it was noted that data is not broken down to that extent.

#### **4: Review of Baby Loss Awareness Week 2020 (Jess Reeves and Daniel Brett Schneider, Baby Loss Awareness Alliance)**

Cherilyn introduced Jess Reeves and Daniel Brett-Schneider from the Baby Loss Awareness Alliance who provided a review of this year's Baby Loss Awareness Week (BLAW) that took place in October. Cherilyn noted the success of the moving Westminster Hall debate that marked the week, explaining that this showcased Parliament at its very best.

Daniel reminded everyone of the key objectives of BLAW, to support bereaved families and commemorate babies' lives, to raise awareness about pregnancy and baby loss, and to drive change and improvements in care and support. He noted that in 2020 the week focused on a theme of isolation, with each day shining a light on a different topic. Daniel noted the different ways that people got involved, included wearing a pin, turning the UK pink and blue, organising an event, or showing support on social media. He further presented highlights of the social media and traditional media activity, both of which saw higher engagement than in previous years. Also new this year were the online panel discussions in partnership with the Natwest Group.

Jess talked through the parliamentary activity that ran during BLAW. This included an evidence gathering e-action which focused on access to maternity appointments and scans. She also discussed the Westminster Hall debate for BLAW which took place on 5 November, noting it was a powerful debate with excellent contributions from MPs. She also noted the Minister's response that it is a priority for access for partners to be reintroduced as soon as possible whilst maintaining safety.

Daniel concluded by sharing further highlights from the week, including a moving video of the wave of light candle lightings. He noted that raising awareness of baby loss does affect people and so it is important to seek support when needed.

Cherilyn thanked Jess and Daniel, and went on to note that she hoped next year's debate could be back in the main chamber, and highlighted that this view had been shared by the Minister, Nadine Dorries.

#### **5: Any other business and close of meeting**

Cherilyn noted that one item of additional business had been received in relation to language used for coding the National Emergency Care Data Set, however this was not discussed. It was decided that this would be discussed offline.

Cherilyn invited other items of AOB. Ryan Jackson raised two items of business. First, in relation to funding from DCMS for charities during the COVID-19 pandemic, and the challenges some charities had encountered in accessing these. Second, in relation to the availability of a directory of services and whether one could be produced to capture the services provided by external supporters of the APPG.

**Action:** The Co-Chairs to consider how to take these items of business forward.

Cherilyn then closed the meeting. The next meeting of the APPG is planned for March 2021, date to be confirmed.