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House of Commons
London SW1A 0AA
All-Party Parliamentary Group on Baby Loss

Monday 27th January 2020

16:00 - 18:00

Commons Committee Room 6, House of Commons

MINUTES

Members in attendance for the AGM:

- Victoria Prentis MP
- Stuart Anderson MP
- Siobhan Baillie MP
- Fiona Bruce MP
- Adam Holloway MP
- Cherilyn Mackrory MP
- Angela Richardson MP
- William Wragg MP

Other guests:

- Alex Mancini - Chelsea and Westminster NHS Trust
- Dawn Brown - Cradle
- Caroline Stickland - The Lullaby Trust (minutes)
- Cheryl Gadsby
- Chris Reid - Teddy's Wish
- Christina Rolles - The Lullaby Trust
- Clea Harmer - Sands
- David Monteith - Grace in Action
- Dean Lomas - The Lily Mae Foundation
- Elizabeth Hutton - Kicks Count
- Emma Brooke - ONS
- Erin McCloskey - Canterbury University
- Fiona Rankin - Rainbow Trust
- Francesca Day - DHSC
- Gemma Quayle - ONS
- Jane Denton - Multiple Births Foundation
- Jane Plumb - Group B Strep Support
- Jenny Ward - The Lullaby Trust

- Jess Faulkner – office of Sharon Hodgson MP
- Jess Read - NHS England
- Jess Reeves - Sands
- Josie Anderson - Bliss
- Karen Burgess - Petals
- Leanne Turner - Aching Arms
- Marc Harder - Sands
- Marcus Green - Action on Pre-eclampsia
- Natalie Casey - The Lily Mae Foundation
- Paula Abramson - Bereavement Training International
- Richard Boyd - Twins Trust
- Sam Collinge - UHCW NHS Trust
- Sarah de Malplaquet - Kit Tarka Foundation
- Sarah Harris - Child Bereavement UK
- Sophie Daniels - Liberty's Mother
- Zoe Clark-Coates - The Mariposa Trust
- Zoe Moulton - RCOG

1. AGM

- Election of a Chair and a total of at least four officers

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:

- Chair: Victoria Prentis MP (Conservative)
- Vice Chair: Sharon Hodgson MP (Labour)
- Vice Chair: Jeremy Hunt MP (Conservative)
- Vice Chair: Patricia Gibson MP (SNP)
- Vice Chair: Cheryl Mackeray (Conservative)

Actions:

- The Secretariat to complete the APPG registration form for Victoria's sign off, and submission to the Office of the Deputy Registrar before Monday 10th February
- The Secretariat to publish on the APPG's webpage:
 - The minutes of the AGM
 - The date of future meetings
 - Changes to the group's membership list.

2. Welcome and introductions (Victoria Prentis MP, Chair of APPG on Baby Loss)

Victoria opened the meeting and welcomed everyone. She explained that she has been a member of the APPG since it was founded in 2016, initially as a Vice-Chair. She noted that this is a particularly effective APPG, with wide cross-party support, and welcomed that it is already being joined by new colleagues.

3. Updates on guidance and legislation

- Pregnancy Loss Review (Review Co-Leads)

Sam Collinge and Zoe Clark-Coates, Co-Leads of the Pregnancy Loss Review, gave an update on the status of the Pregnancy Loss Review. They explained that the Review was set up to consider the impact of the current process on families, and to consider how to improve practice. They have worked with DHSC to undertake wide engagement, and have drafted a report. Publication has been delayed due to workforce issues at DHSC which has pushed back the editing required before the report can be made public. [The Minister later confirmed the report would be published in Spring/Summer 2020.]

- Coronial investigations of stillbirth (Chair)

DHSC have informed the APPG that officials have been analysing the responses to the consultation on giving coroners new powers to investigate term stillbirths and consulting further with stakeholders. DHSC are preparing advice to Health and Justice Ministers and, subject to their agreement, they plan to publish a Government response sometime in the Spring or early Summer. It was agreed that the APPG will continue to seek updates on this legislation and its impact.

- Parental Bereavement (Pay and Leave) Act (Chair)

The Government recently announced that the provisions of this Act will come into place in April this year.

Known as 'Jack's Law', the new law will ensure that all parents whose baby dies through stillbirth or neonatal death will be entitled to two weeks' paid leave, in addition to their parental leave entitlement. Parents can take the leave as a single block of two weeks, or as two separate blocks of one week each. The leave can be taken any time during the first year after the death of the baby or child.

The pay element will be available to parents who have been employed in their job for six months or more, in line with other parental leave entitlements. This new provision makes the UK one of very few countries to offer this level of support to bereavement parents. Victoria congratulated all those who have worked hard to achieve this success. It was agreed that the APPG will continue to monitor the impact and uptake of this legislation to ensure it is helping parents, and will help to promote the launch of the entitlements in April.

Action: APPG members to promote the new entitlements once they become active in April. To consider the APPG's presence on social media for events such as this.

4. AOB – update from Erin McCloskey

Due to a technical hitch, a point of AOB was taken from Erin McCloskey, PhD student at Canterbury University. She is studying the support available to, and needed by, communities of colour after experiencing baby loss. She is looking to make connections in different communities and would welcome contact on e.mccloskey544@canterbury.ac.uk.

Sam Collinge noted that the work of the Pregnancy Loss Review had involved engaging with different faith communities so she may be able to help. Victoria highlighted the engagement with churches across the UK that happens with Baby Loss Awareness Week remembrance services.

5. Review of the work of the APPG so far and priorities for 2020

Victoria introduced a presentation detailing the work of the APPG since it began in 2016. The presentation was given by two of the charities who support the APPG, Jenny Ward, CEO of The Lullaby Trust, and Clea Harmer, CEO of Sands.

Jenny began by setting out the history of the APPG, which was formed by a group of MPs and Peers in 2016. It had some core aims of supporting families and raising awareness, and it took a broad approach by encompassing pregnancy and baby loss at all stages.

In October 2016 the group published their report, 'Beyond Awareness to action: Tackling baby loss in the UK' which set out four key goals – prevention, commissioning, clinical care and support.

On prevention, Jenny noted that the APPG has had a significant impact by raising awareness of baby loss, which is the first step towards prevention. Since 2016 the group has grown its external membership, now comprising 106 supporters representing 58 organisations. She noted that there have been four moving Baby Loss Awareness Week debates in Parliament led by the APPG so far, with 24 MPs contributing to the most recent one in 2019.

On commissioning, Clea noted that the APPG have been instrumental in securing the introduction of the National Bereavement Care Pathway for pregnancy and baby loss. The pathway seeks to reduce inequity in the bereavement care experience by parents. It was initially trialed in 32 pilot sites and is now active in 56, with a further 72 exploring using it. The next steps will be to establish the pathway and ensure that support and resources are available so that it can be properly delivered. There is a further need to embed the nine standards of the pathway in CQC frameworks at every stage, as is currently done in maternity services. Cherilyn Mackrory MP asked about care in the community after pregnancy or baby loss, and whether this is a part of the pathway. Clea explained that the pathway does not include this element, but it is recognized as an issue and will need a concurrent, integrated effort to address it. Leanne Turner (Aching Arms) asked whether the focus was on securing 100% of Trusts, or starting to look at community support, and Clea said that both were equally important.

Action: To consider how the APPG can encourage the Trusts who are not yet fully active with the NBCP to get more involved.

On clinical care, Clea explained how the APPG had played a key role in holding the Government and NHS England's feet to the fire, in particular on the National Ambition to halve rates of stillbirths, neonatal and maternal deaths, and brain injuries occurring during or soon after birth, by 2025. This target was initially set for 2030. The focus must now be on ensuring progress against the target is reviewed so that the most effective actions to reduce baby loss can be identified and promoted. It was noted that there are two different possible data sets, ONS and MBRRACE, so it is important to be consistent in which figures are used. Tracking the National Ambition uses ONS data. Victoria noted that

recent press stories have highlighted very sad cases where it appears lessons may not have been learnt. It was also noted that 2020 marks the mid-point for the ambition and is a good time to take stock. Cherylyn asked what exactly have Trusts been asked to do in order to meet the Ambition, and Clea explained that there are multiple different initiatives, but the challenge is understanding what is working where in order to focus on these. Clea also highlighted the importance of having the data to track progress towards the National Ambition.

Action: APPG to write to DHSC to ask for a mid-point update on progress against the Ambition and plans for the next five years, and for the response to be discussed at the next meeting of the APPG.

At this point Victoria left to speak in the chamber, and Clea took over as Chair.

On support, Clea noted Nadine Dorries' commitments during Baby Loss Awareness Week 2019 to provide funding for mental health support for parents who have experienced pregnancy or baby loss as an example of the APPG's impact. The working group for the development of maternity outreach clinics have also been asked to consider the mental health needs of those who experience pregnancy or baby loss. She also highlighted the success of the Parental Bereavement (Pay and Leave) Act that was championed by former APPG Co-Chair, Will Quince MP. There was a discussion on mental health support and how it is a fragmented and challenging area to navigate, but that the focus on it in Government provides an opportunity to secure more support. Karen Burgess (Petals) commented that the Minister had been interested in their recent report on mental health support. It was also noted that mental health support should consider losses at every stage of pregnancy and baby loss.

Clea went on to present the APPG's key ask for 2020, to call upon DHSC to continue its support for the roll out of the NBCP, and the adoption of the nine bereavement care standards in all NHS Trusts in England, and to ensure sustainability for the future into the new financial year.

There was then a wide discussion of what else the APPG may want to focus on over the period of the 2019-2024 Parliament. Some key themes included:

- Support in the community, after parents have left hospital and in the longer term
- Mental health support across all stages of loss
- Support for rainbow pregnancies
- Baby loss in BME communities, both support and prevention
- A greater focus on prevention more generally
- What we can learn from data to inform actions to improve prevention
- How information provision can help prevention
- Monitoring the impact of legislation like Jack's Law, and programmes such as HSIB, changes to MBRRACE data collection
- Linking up with other APPGs to highlight cross cutting issues such as patient safety.

It was noted that charities, individual Trusts, and NHS via the Maternity Transformation Programme were all doing important work across many of these areas. The APPG has a role in bringing together Parliamentarians, charities, parents and the NHS to join these up.

Action: The APPG to incorporate these ideas into its planning for this Parliament.

6. Neonatal Palliative Care project (Alex Mancini, Chelsea and Westminster Hospital)

Alex Mancini, Pan London Lead Nurse for Neonatal Palliative Care, gave a presentation on her recent project. For the past five years she has been working in collaboration with teams in hospitals, hospices and in the community to review the optimal care for families and babies in these settings.

Her role and the project have been funded by two charities, and hosted by Chelsea and Westminster NHS Trust. She noted that palliative care is different to bereavement care, and is about working with parents and keeping them informed so that they can make decisions.

The project sought to train healthcare professionals who are involved with neonatal care. Over 3 years free training was provided to 1,330 staff over 88 sessions. An audit of palliative care provision in 27 neonatal units showed increased knowledge among staff, but that gaps remain in accessing psychological support for both families and staff.

Alex noted that the recent BAPM guidance on extremely pre-term babies will likely lead to more babies having a requirement for neonatal palliative care in future, and so it is important to develop policy and practice in recognition of this.

Next steps include consolidating this work in the London region to ensure sustainability, and transferring the model to Neonatal Operational Delivery Networks nationally.

The immediate recommendations of the project are:

- To review the BAPM categories for palliative care with a consensus decision including multi-disciplinary professionals and parents
- For new data items to be added to the Neonatal Dataset (badgernet system), ensuring data is collected to enable service planning
- That neonatal palliative care must be put on the national agenda
- For NHS England to recognise the care required to support babies and their families
- That national policy is required for this vulnerable group of babies who have an uncertain future and premature death.

7. Update from the Minister (Nadine Dorries MP, Minister for Mental Health, Suicide Prevention and Patient Safety)

Nadine Dorries MP joined the meeting to introduce herself to the APPG. She explained that maternity safety is a key priority for her, including the Pregnancy Loss Review, the National Ambition, and work on maternity safety. She particularly highlighted the maternity safety training fund as an area that was being reviewed in order to understand the evidence base. She also discussed continuity of carer in maternity services, and the different regional barriers that can exist in delivering this.

Currently budgets are being set so there is less clarity about work areas, but she would like to return to the APPG in April to provide more details then.

The Minister then took a number of questions from attendees. She discussed her commitment to making changes in relation to Group B Strep. She spoke about the

Government's commitment to providing 50,000 more nurses, and said she hoped that these could be directed to important areas such as neonatal care. She explained that the imminent NHS workforce plan would help guide this. She was asked about how nurses could be encouraged to return to practice, and said she would consider this. She was further asked about workforce culture for staff who may encounter pregnancy and baby loss, and how they can be best supported. It was acknowledged that Trusts have an obligation to support their staff but there are different ways of doing this. She was further asked about commitments during the Baby Loss Awareness Week debate last October when the Minister agreed to write to the lead of the working group responsible for setting up perinatal mental health community outreach clinics to ask them to consider whether the clinics could be available to those bereaved by a child death. The Minister confirmed she had heard back and would share the response with the APPG.

Clea thanked the Minister for coming to speak to the APPG and for sharing her priority areas.

8. Next meeting: 16.00-18.00, Monday 27th April