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House of Commons

London SW1A 0AA

All-Party Parliamentary Group on Baby Loss

16:00 – 18:00, Monday 11th December 2017

Room CR15, House of Commons

MINUTES

Attendance list

APPG members:

Will Quince MP (Co-Chair)
Victoria Prentis MP (Vice-Chair) - attended from 16:30 - 17:30
Patricia Gibson MP (Officer) - left at 17:15
Antoinette Sandbach MP (Co-Chair) - attended from 17:30

Guests:

Aimee Middlemiss (University of Exeter)
Alex Mancini (Pan London Lead Nurse for Neonatal Palliative Care)
Beth McClevery (Bliss)
Celia Burrell (Barking, Havering and Redbridge University Hospital NHS Trust)
Cheryl Gadsby
David Monteith (Grace in Action)
Drew Lindon (Drew Lindon Consulting Ltd; APPG secretariat on behalf of Lullaby Trust) - minutes
Eleanor Dyer (Newcastle University)
Elizabeth Hutton (Kicks Count)
Emily Harris (Office of Victoria Prentis MP)
Francine Bates (Lullaby Trust)
Georgina Vestry (Action on Safer Births)
Jane Plumb (Group B Strep Support)
Jane Scott (Imperial College NHS Healthcare Trust)
Judith Rankin (Newcastle University)
Lauren Hutton (Imperial College NHS Healthcare Trust)
Leanne Turner (Aching Arms)
LeighAnne Wright (Little Things & Co)
Matt Wright (Little Things & Co)
Nicola Crawley (St Thomas' Hospital)
Paula Abramson (Child Bereavement UK)

Penny Kerry (Miscarriage Association)
Sam Collinge (UHCW NHS Trust)
Vanessa Higham (Office of Antoinette Sandbach MP)
Zeshan Qureshi (NCPCH)
Mohamed Omer (Gardens of Peace)
Sam Richards (The Lily Mae Foundation)
Ryan Jackson (The Lily Mae Foundation)

Other guests were in attendance but not captured on the sign-in sheet. For contributions where guests spoke but were not identified, they are referred to simply as 'guest'.

16:00 Welcome and introductions (Co-Chairs of APPG on Baby Loss)

Will Quince MP welcomed attendees and introduce MP members of the APPG in attendance. He conveyed Antoinette Sandbach MP's apologies for the start of the meeting, as she was in the Chamber to ask a question on the Brexit negotiations.

16:05 Review of Baby Loss Awareness Week (BLAW)

- Presentation from Francine Bates (CEO of Lullaby Trust) & Drew Lindon (policy and campaigns consultant)

Drew Lindon and Francine Bates gave an oral presentation on some of the key statistics and achievements of the Week, as well as outlined activity on bereavement care that has taken place subsequently.

Speaking in the place of Clea Harmer (Sands CEO), Francine said that Clea wanted to convey how positively the Week had gone, and that this was a real cooperative, team approach by charities large and small, local and national. The Week brought together around 50 charities, as well as many, many more parents and health professionals. Francine ran through some of the key figures from the Week:

Social media

- #waveoflight trended top in UK Twitter trends between 7:55-8:15pm approximately on 15 October.
- BLAW Facebook posts - 2.4m users reached, 141k likes and shares
- Sands Facebook posts - 2.1m users reached, 128k likes and shares
- BLAW Twitter - 160k impressions 6k engagement
- Sands posted a live video of a wave of light candle on Facebook at 7pm for an hour, which was the first time this had been done. This reached 1.6m people.

Press and broadcast

There were at least 79 pieces of coverage across national and regional print, broadcast and online media. This included coverage in The Observer and The Sun's Fabulous magazine on the eve of BLAW.

The main local print media coverage focus was on Wave of Light events where local groups had contacted their local media directly. There was also a good pick up on stories of buildings being lit pink and blue (the BLAW brand colours).

Local events and lighting buildings

There were 71 known local events across the UK – mainly but not all were remembrance services and Wave of Light gatherings on 15 October.

Coincidentally, there were also 71 buildings and landmarks were lit up pink and blue in the UK, Channel Islands, Isle of Man, and the Moorish Castle in Gibraltar. Photos were shared on the BLAW and individual charity social media accounts.

Fundraising and merchandise

Sands sold and distributed just over 18,800 pin badges – approximately a 24% increase on 2016. They also sold 2000 heart shaped candle tins.

There were a range of other events which had a fundraising focus during the Week too. , such as the Lullaby Trust's bake sale in their London office.

Parliamentary activity

Drew spoke about the events held in the UK parliaments during BLAW. Within Westminster, there was:

- a Backbench debate (Tues 10 Oct) – 38 MPs attended, with 23 speaking (33 attended in 2016)
- a Parliamentary event (Weds 11 Oct) – 33 MPs and 69 external guests (23 MPs and 3 peers in 2016)
- a Remembrance service (Weds 11 Oct) – 65 attendance (44 in 2016)

There were a range of actions asked of MPs, including writing to Ministers and supporting the Week via social media. The Prime Minister mentioned BLAW, Sands and the National Bereavement Care Pathway during Prime Minister's Questions on 11th October.

In total, 99 MPs took some form of action (either coming to an event, speaking, posting about BLAW on social media, or other), compared to roughly 50 MPs in 2016, or almost a 100% increase. 15% of all MPs did something for BLAW.

There was a Scottish Parliamentary event on 5th Oct with 46 attendees and the First Minister wore a BLAW pin badge during First Minister's Questions. Scotland are now setting up a cross-party parliamentary group similar to APPG and a conference for healthcare professionals in 2018.

There was a remembrance service in the Senedd (Welsh Assembly), though this was not well attended. We have booked a room again for next year and will work to improve attendance for BLAW 2018.

National Bereavement Care Pathway

Drew added that the National Bereavement Care Pathway pilots were launched in 11 NHS Trusts in England at the start of BLAW. The interim report from the pilots will be available in April 2018, with a final in June/July. A second wave of pilots is likely to be announced in April, and the aim is to have other pilots in the devolved nations too.

Following the Week, charity partners continue to push the key asks around bereavement care, and are working with the Care Quality Commission in England to look at how our Pathway might be integrated into the assessments they undertake of health and care services. Drew outlined that he is separately working with Sands to develop their ongoing outreach to supportive MPs, Peers, MSPs, and other elected representatives at the devolved legislatures.

The Stakeholder Group of charities created as part of planning the Week will remain in place to help develop next year's events.

- Discussion - reflections from the APPG members, guests and ideas for next year

Will thanked Drew and Francine for their presentation. He said that BLAW 2016 had been a hard one to match, but we did it. He spoke about his experience organising a vigil at Colchester Castle in his constituency. Overall, BLAW 2017 was a huge success. Will opened up the floor to ideas for next year, and suggested that we could have some form of light display on a boat just by Parliament.

Mohammed Omer suggested that we could publicise Baby Loss Awareness Week through wider channels, and would be happy to offer his expertise particularly with reaching Muslim audiences. Mohammed sits on a joint Muslim Council comprising many UK organisations, so he could seek ideas there as well. Mohammed also offered a meeting space at Gardens of Peace, should the APPG wish to convene out of London at some point in 2018. Will thanked Mohammed, and said his offers of support were greatly welcomed. **Action: Mohammed to contact Drew about useful media or other channels.**

David Montieth supported Mohammed's point about reaching more diverse audiences. He suggested we could use other channels to reach Black British communities, such as the Voice. He added that it would be great to see more video content as part of the BLAW 2018, as a means of attracting even greater audiences. **Action: David to contact Drew with suggestions for channels and relevant contacts.**

Zeshan Quershi said that personal stories are always the most powerful. He suggested incorporating more success stories in 2018, perhaps links to the changes that have been made by the National Bereavement Care Pathway. Secondly, Zeshan proposed we make greater links with the paediatric and obstetric community during the Week. Thirdly, there may be opportunities to engage on these issues in schools, via Personal, Social and Citizenship Education.

Jane Plumb said we could link up with the Church of England and other religious institutions to reach even more people. If we were to develop a toolkit for the different faith institutions that could be used to raise awareness, develop events, this could be sent out via MPs, or via interfaith groups, such as the Interfaith Council of London. The toolkit or pack could ask religious leaders set aside five minutes during services to reflect on the Week, and what it means. This would enable people to have conversations as part of their religious community. Leanne Turner said it would be great to have a similar toolkit for

midwives in hospitals, to help them put on displays and events. Sam Collinge agreed, and said there had been a display in her hospital.

Cheryl Gatsby agreed with Jane's point; this would fit well with the Care for Family, a Christian organisation local to her. Returning to Zeshan's point on stories, she said that one problem is that charities often will ask parents to write their stories in 100 words or fewer, and that is insufficient to describe your experience. She said that Twitter and Facebook are great, but we need to also draw people into the longer stories, and give parents the opportunity to speak more fully.

Will said this was a good point. It is important to strike the right balance, to attract as much interest as possible through short content as well as offering longer, more detailed accounts for those wishing to know more. Both short and longer stories are needed. Cheryl agreed, and said she would welcome more video content. Ryan Jackson suggested that it might be worth including stories from siblings within video content.

A guest asked whether it would be possible to fund a short TV advert, if we get decent video content. Will said that we would definitely want to produce creative and interesting content, but the costs of buying TV ad time are prohibitive. However, if we produce decent video which is then picked up by TV, we can often get a similar impact.

Ryan Jackson said that while the charities are very good at bringing up stillbirths and neonatal deaths, he hears less about termination due to medical abnormality. Celia Burrell added that parents are not getting the aftercare following termination for foetal abnormality, and we need more specialist clinics for this support. Will said that he was conscious of this, and explained that his own son had a foetal abnormality. Francine said the charity ARC (Antenatal Choices and Results) are part of the National Bereavement Care Pathway team and BLAW week stakeholders, so have been involved in shaping the asks. She agreed we could collectively highlighting this topic more.

Jane Scott said that the common language of loss at conferences is often about 'trauma', 'devastation', but often parents don't have trauma counselling after the event. Leanne agreed, saying that the support she received from ARC saved her life, and prompted her to set up the charity Aching Arms. Leanne added that the trustees of Aching Arms were all 'ARC mums'.

The discussion turned to arranging vigils for BLAW, which appeared to attract broad support. Leanne requested that there to be some non-faith vigils too. Victoria Prentis asked whether it would be ok to hold a non-faith vigil, but within a church. Leanne said that for some parents this would be fine, and for others no. Will said that the local vigil in his constituency was non-faith specific, held outside, and had a range of poems read. lights and poems. It is good to have a variety of events to be suitable for all parts of the community.

Jane Scott said that it is really important that we do not just rely on charities for the support. As part of this APPG, we are pushing, and must continue to push, for NHS to provide essential support. This point was agreed. Will emphasized we need to keep making the case to government, as well as build the business case for the National Bereavement Care Pathway.

Victoria added that we should book the Upper Waiting Hall in Parliament early in the New Year, in order to offer a display during BLAW.

Action: APPG to book Upper Waiting Hall for BLAW 2019.

16:30 Review of APPG work over the year

- Overview of meeting topics and progress

Will gave an overview of the Group's meetings and work this year. In summary, the Group has welcomed 15 guest speakers over the last three meetings, including 2 ministers and 2 shadow ministers, and held two joint meetings with other APPGs. That is unheard of for most APPGs. Will gave an overview of what, other than the Baby Loss Awareness Week events, our meetings have covered:

March:

- Maternity Transformation Programme (Presentation by Dr Matthew Jolly, Clinical Director for Maternity, NHS England)
- Neonatal Review (Presentation by Dr Eleri Adams, Vice Chair of NHS England Neonatal Critical Care Clinical Reference Group)

July: (Joint meeting with APPG on Smoking and Health)

- Launch of Smokefree Skills: An assessment of maternity workforce training
- Speakers from ASH, NHS England, Royal College of Midwives, Lullaby Trust, Royal College of Obstetrics and Gynaecology, Public Health England
- Presentations from Steve Brine MP, Public Health Minister, and Sharon Hodgson MP, Shadow Public Health Minister, on the government's Tobacco Control Plan

September: (Joint meeting with APPG on Maternity)

- Presentations from Philip Dunne MP, Minister of State for Health, and Justin Madders MP, Shadow Minister of State for Health, on the future for maternity safety
- Patient speakers from *Zero Harm First Time*, *Nobody's Patient* initiative, and Royal College of Midwives.
- Proposals for 2018 activity and meetings

Will outlined a set of issues under consideration for the Group to look during 2018:

(a) Bereavement care, of which items may include:

- National Bereavement Care Pathway as a standing item – interim report is due in April 2018, with full report in July 2018 on first pilots as second set of pilots begin
- Parental Bereavement Leave Bill (due for Committee Stage on 17th January)
- Baby Loss Awareness Week (standing item from May/June)

(b) Prevention

- Monitoring of government's Maternity Safety Strategy initiatives
- Neonatal Review for England – update
- Maternity Transformation Programme – update
- Any relevant clinical research findings

(c) Other – to discuss or ‘note’ at meetings

- Powers of coroners to investigate stillbirths – relevant with Civil Partnerships, Marriages and Deaths (Registration Act) 2017 – 19, due for Second Reading on 2nd February), as well as Jeremy Hunt’s announcement that his Department will be considering enabling coroners to investigate full-term still-births.
- Lactation support for bereaved mothers (requested by The Hearts Milk Bank)
- Sands Awareness Week (June)
- Group B Strep Awareness Month (July)

(d) Potential additional activities to consider (budget dependent)

- Members’ visit to National Bereavement Care Pathway pilots
- Holding one APPG meeting outside of London, given that many attendees travel in - e.g. in the Midlands, make this an event on a Friday

- Discussion

Will opened up the discussion to contributions from the floor.

Lactation support

Gillian Weaver suggested lactation support, and looking at how to encourage mothers to donate their breast milk. There is a dearth of research around this issue, and the Hearts Milk Bank is working to fund a specialist consultant.

Coroners and stillbirths

Patricia Gibson MP said she would be really interested to look at the issue around enquiries following stillbirth, and see what information parents are given in the aftermath.

Georgina Vestry said Action on Safer Births would welcome the opportunity to address the Group in January on stillbirths and coroner’s inquests, given the upcoming Bill. Victoria said that she has been working on this issue, and requested the members’ permission to continue to lead on this issue on behalf of the APPG. She explained her background in coronial law, and has been asked by the Bill authors to feed in her experience of working on deaths in combat. She said the authors want to make sure that the coronial system is not overwhelmed in the way it was when changes were brought in around combat deaths.

Georgina offered that Action on Safer Births could also bring in an expert coroner to give their thoughts on the issue to the Group. Victoria clarified her view that the APPG may not have time for a specific meeting on this issue before the Second Reading. However, she suggested that it would be helpful for the APPG to gather views on this issue via email from the charities, health professionals and parents who attend, and then for us to develop the APPG’s position. Victoria confirmed with the other members of the APPG that the overall perspective at the moment was that the coroner’s investigation should not necessary be the norm in the case of stillbirth, but an option. It was agreed by the MP members present that Victoria will have authority to continue her meetings and conversations with Tim Loughton on behalf of the APPG.

Action: APPG to develop a set of questions to share with APPG attendees, and Victoria to develop with an APPG position based on this input. Drew will involve Sands and Lullaby

Trust to support this work. Will clarified that the deadline would be end January/early February, but potentially we have more time for greater detail, as the Committee Stage of the Bill where a line-by-line examination takes place is yet to be scheduled.

Action: Victoria to share House of Commons briefing on coronial powers/baby loss.

Bereavement support in the community

Cheryl proposed an issue for next year would be aftercare post hospital, particularly with the focus around trauma discussed previously. Will agreed, but said that we also need to maintain to focus also on National Bereavement Care Pathway within hospitals. The next set of pilots would look at support in community, so that might be another opportunity to cover this element, including bereavement counselling.

Jane Scott said that would be useful, but we need to be careful to when pushing for more bereavement support to understand wider implications or precedents; for example, why would a parent who has lost an older child not have the same support offered as a parent who lost a baby?

Sibling support

Ryan said he would like to cover sibling support next year. The Lily Mae Foundation are in the process of putting together a siblings' kit in addition to the grandparents' kit they have.

Fetal dopplers

Aimee Middlemiss said she had been researching use of home fetal dopplers by parents who had used these devices before fetal movement had started, and have found that the harm is less than what some reports have suggested. Antoinette said that her Private Members Bill is looking at this issue, but it is unlikely the APPG would have a meeting before the second reading of the Bill. Will said this could come back to a later meeting for a discussion. **Action: Aimee to share research with the group in the meantime.**

Smoking in pregnancy

Francine suggested it would be good to return to reducing smoking in pregnancy as a meeting topic, so we can monitor the impact of the Smoking Prevention plan.

Research

Will said that he and Sharon Hodgson MP (Vice-Chair) were in China about six weeks ago, and visited a mother and child medical centre who are doing a big project with pregnant women who are opting into a comprehensive monitoring kit, which feeds back to the hospital in real time. The monitoring does not just cover pregnancy, but the first 18 months of the baby's life. Will said it would be useful to pick up on the results with the UK universities who are partnering with this project.

Scheduling and venues

There was broad support to hold a half- or full-day event for the APPG, gives us the opportunity to talk about some topics in more depth, at some point during the year.

Ryan said that Lily Mae Foundation would be open to hosting an event in the Midlands.

17:45 Any other business

David said that when the Health Minister (Philip Dunne MP) spoke at the last meeting, he perceived that the 'temperature in the room' rose particularly for those NHS staff who

attended who did not agree with the Minister's assessment of staffing levels. How does the reporting get to the Minister, and how can he have the impression that staffing is better than staff on the ground perceive?

This issue was debated at length. Antoinette said that all Serious and Untoward Incidents are reported to directly to the Minister, but the responsibility of reporting falls to local NHS Trust. Celia said that as part of her role she has assessed 10% of all the baby deaths in the country, and knows that there is a staffing problem. Antoinette said all attendees are welcome to engage with Philip Dunne directly, and she is happy to help arrange a meeting if needed. She said that the APPG recognise the issue.

Antoinette added that the point of the Perinatal Mortality Review Tool's point is to gather the common reporting issues and risks, which could include staffing. Jane Scott said that we need the tool to be mandatory, to ensure better identification of risks. Antoinette said that her understanding was that is the intent, though is not clear whether the Tool will be mandatory initially, or will be piloted first.

It was proposed that the APPG could hold an evidence session on the staffing issues, and invite NHS Trust Chairs and the Minister back to discuss.

Will thanked everyone for their contributions and attendance, and closed the meeting.

Next meeting of APPG on Baby Loss: TBC, 2018 dates to be agreed.