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House of Commons

London SW1A 0AA

The All-Party Parliamentary Group on Baby Loss

14:00 – 16:00, Wednesday 14th December 2016

Commons Committee Room 20, House of Commons

MINUTES

Confirmed attendees:

APPG members:

- Antoinette Sandbach MP (Co-Chair) – Conservatives
- Will Quince MP (Co-Chair) – Conservatives
- Sharon Hodgson MP (Vice-Chair) – Labour
- Lord Boswell – Non-affiliated

Other parliamentarians:

- Patricia Gibson MP - SNP

External guests:

Speaking:

- Elizabeth McLaren, Statistician, Vital Statistics Outputs Branch, ONS
- Professor Tom Bourne, Adjunct Professor (Imperial College) and Consultant Gynaecologist, Queen Charlotte's and Chelsea Hospital

Attending:

- Aimee Middlemiss, Postgraduate Student studying MRes Science and Technology Studies, University of Exeter
- Alessandro Alagna, Parent
- Amy Jackson, Parent
- Caroline Brocklehurst, Campaign Manager, Bliss
- Caroline Star, CMV Action
- Catherine Woznick, Office of Victoria Prentis MP
- Chris Reid, Trustee, Teddy's Wish
- Dr Clea Harmer, CEO, Sands

- Daniel Ellis, Office of Will Quince MP
- Drew Lindon, Director, Drew Lindon Consulting Ltd (Minutes)
- Emily Harris, Office of Victoria Prentis MP
- Francine Bates, CEO, Lullaby Trust
- Ryan Jackson, Trustee, Lily Mae Foundation
- Gillian Weaver, International Human Milk Banking Specialist and Consultant Co-founder and Co-Director, The Hearts Milk Bank
- Keith Reed, CEO, Tamba
- Leanne Turner, Coordinator/Trustee, Aching Arms
- Munira Oza, Director, Ectopic Pregnancy Trust
- Paula Abramson, Head of Training, Child Bereavement UK
- Penny Kerry, Chair, The Miscarriage Association
- Ryan Jackson, Parent
- Samantha Collinge, Bereavement Support Specialist Midwife, University Hospitals Coventry & Warwickshire NHS Trust
- Vanessa Higham, Office of Antoinette Sandbach MP
- Veronica Spibey, Penine Acute Trust

Apologies:

- Arlene Honeyman, Rainbow Trust Children's Charity
- Andy Langford, Director of Operations, Cruse Bereavement Care
- Annika Dowson, Parent
- Gabrielle Osrin, Trustee, Lullaby Trust
- Jane Denton, CEO, Multiple Births Foundation
- Jane Plumb, CEO, Group B Strep Support
- Marcus Green, Interim Chief Executive, Action on Pre-Eclampsia
- Mark Jermyn, Parent
- Shabira Papain, Director of Operations, Best Beginnings
- Victoria Prentis MP (Vice-Chair)

1. Welcome and introductions

The Co-Chairs welcomed the attendees.

2. Actions from last meeting

- Approval of minutes

The Group approved the minutes.

3. Review and response to Baby Loss Awareness Week

- Results of the week
- Maintaining momentum and planning for future

Antoinette gave some statistics from the APPG and supporting organisations activity during Baby Loss Awareness Week (BLAW).

- 84 people joined the Speakers' House reception, including 26 parliamentarians and 2 ministers
- 33 MPs contributed to the backbench debate on Baby Loss (with additional MPs attending but not speaking)
- Over 16 million Twitter accounts were reached by the Twitter Digital Debate, where Antoinette and Will held a Twitter Q&A at the start of the Week.

As such, Antoinette said she felt that there had been a great impact in terms of raising awareness of baby loss both in Parliament and publicly.

Lord Boswell agreed; from his experience of APPGs and their work, he said that he genuinely did not think that he had been as impressed by anything as much as the salience of that Week. Lord Boswell said that the efforts of the APPG and the organisations and individuals supporting it engaged more people in Parliament than he had ever seen before from similar events, including up to the Secretary of State for Health. He was also impressed to see the cross-party involvement within the Group and in attendance at the reception event. He emphasised the need to keep up the momentum to deliver the change we seek.

The Group discussed their experiences of BLAW. Clea (Sands) said that Sands had also seen significant on a number of awareness indicators. 15,500 Baby Loss Awareness Week pins were sold, more than double the amount from last year, and Sands acquired 200,000 new Facebook followers. She also saw many organisations using the pink and blue branding for BLAW. City Hall in Cardiff was pink and blue all week, several local councils raised flags to mark the week, and many National Trust properties used this colouring in creative ways.

Leanne (Aching Arms) agreed the Week had been a success in raising awareness. Through October, Aching Arms received at least three times the requests for their comfort bear in comparison to October 2015. Similarly, fundraising pledges received were about three times the amount from last year, and their Facebook likes "went through the roof". Leanne also recounted that the Week had provided an opportunity for her and her organisation to build links with her local MP (Eric Pickles MP).

Penny (The Miscarriage Association) said that they had seen the biggest involvement in the online 'Wave of Light' event, and more contacts made through October than ever before in previous years.

Caroline (Bliss) said that their organisation had reached over 100,000 people through Facebook, so the Week had a massive impact in terms of awareness.

Antoinette also reflected that the messages were reaching everyone; as an example, on her way to a BBC interview during the week, 4 out of the 10 people she spoke to on the journey told her about their own personal loss of a child.

Will said that the Week went really well from his perspective. The APPG reception hosted both the Minister of State and the Secretary of State for Health, which is very rare. The BBC also ran a baby loss story with his and Antoinette's interview for two days on their homepage. He said that we have to keep the pressure up for next year to achieve

change. We will need to have a session at a future APPG to think about how to make the BLAW bigger and better next year in Parliament. It might also be useful to set up a WhatsApp group or similar for charities to tell the APPG members what they are doing that Week, so the members can tweet about what's going on.

Antoinette continued that she and Will were looking at tabling debates in the New Year to focus on specific issues raised in the last debate, which might include smoking, public health, perinatal mental health, and so on.

Patricia agreed, and said that we will need to engage as many MP and Peer colleagues as possible for future events, to build the awareness. She added that it is vital to have a national view across the whole UK.

Antoinette said that in January, it is anticipated that the Secretary of State for Health will be bringing forward a Bill to establish a new NHS investigative unit (not baby loss incident specific), which may present a real opportunity for highlighting and addressing systemic issues. Gillian (Human Milk Bank Foundation) suggested one topic might be able the use of breast milk, as per the work of the Human Milk Bank Foundation.

Closing this item, Antoinette asked attendees to enter people or organisations for the Butterfly Awards. Ryan (Lily May Foundation) agreed, and emphasised the value of the Awards; the Lily May Foundation were fortunate to be awarded 'best support organisation' in the first year of the Butterfly Awards.

Antoinette thanked all guests and organisations present for their hard work bringing together the events and activities around BLAW, and made special mention of Drew Lindon (Drew Lindon Consulting) for pulling the APPG's report 'Beyond Awareness to Action'.

4. ONS and baby loss statistics (Elizabeth McLaren, Statistician, Vital Statistics Outputs Branch, ONS)

Elizabeth presented on the information the Office of National Statistics (ONS) collects around baby deaths, and what the ONS intends to collect in future (slides shared with members and guests following the meeting).

Every birth and death is recorded in England and Wales, and the ONS collects data from registered offices across these countries, as well as coordinate with their colleagues in Scotland, Northern Ireland and Europe. Whenever a baby is born, they are assigned an NHS number and other information is collected as well. ONS also undertakes a range of data processing, coding, and analysis on deaths information. It is vital to know what is happening over time in terms of infant statistics in order to identify issues for policy-makers to address.

Elizabeth spoke about stillbirth statistics. In the UK, stillbirth is defined as occurring after 24 weeks. There were over 3,000 stillbirths last year, but the stillbirth rate has been improving over time. In comparison to other European countries, England and Wales do not have the worst stillbirth rate, but certainly not the best. However, it can be difficult to compare across countries, given different types of stillbirth registration and definitions used.

The ONS publishes data on stillbirth and the stillbirth rate every July. This year they have provided stillbirth by local authority for the first time, and later in the year they provide further details on stillbirth characteristics. The ONS is now publishing 'explorable data' sets, enabling anyone to download data and pick tailored tables based on a limited set of variables. Currently, they provide data on stillbirth correlated with a selection of variables, e.g. socio-economic status, ethnicity, etc.

ONS is reviewing the types of analysis they undertake and provide publicly, as well as the format in which they provide this information. ONS have over 70 data tables relating to infant death at present, some of which are similar, meaning it can be difficult for people to find what they want. Likewise, there are some limitations in what data can be provided; particularly for stillbirth and neonatal deaths, it is not possible for ONS to code for the underlying cause of death due to how the data is collected.

ONS is also undertaking some new analysis linking different data sources to track potential correlations. For example, does birth time of day correlate with survival rates? What is the relationship between infant deaths and parental education status? Elizabeth also said there are some changes that could be made to how the ONS could give more access to data (some relevant elements are featured in the Digital Economy Bill currently under discussion in Parliament).

Concluding her presentation, Elizabeth asked the Group what statistics the group would need from the ONS in future, to inform their consultation next year (expected in February/March). In particular, she asked the Group to consider what data presentation they would need to show progress towards the Government's 2020 stillbirth target.

Keith (Tamba) lauded the work of ONS. He agreed that accessibility could be improved and enabling linkages with death causes data would be really helpful.

Lord Boswell observed that it would be worth the ONS speaking with the Economic and Social Research Council, particularly to look at the correlations with social deprivation, dietary habits, and geography. Elizabeth agreed, and said that lifestyle and census data is on her list of data to look at integrating.

Aimee Middlemiss (University of Exeter) asked whether the ONS collects data on live births prior to 24 weeks, which Elizabeth confirmed.

Clea (Sands) said that the cause for many stillbirths is still unknown, making analysis of existing data limited. She added it would be helpful if the ONS could separate stillbirth data into terms and pre-term.

Tom (Imperial College) said that we need health professionals to collect more antenatal information. Though each stillbirth is a tragedy, given that there are relatively few that occur national wide, he suggested it would not be onerous for people to collect more information to better help services and policy-makers.

Francine (The Lullaby Trust) expressed her thanks to ONS (and to their predecessor organisation) as their work helped greatly reduce incidences of sudden infant death syndrome (SIDS). She explained that ONS had also identified the number of young parents who experience SIDS deaths, which has assisted The Lullaby Trust and other organisations to target their messages to those parents. Francine added that this year there were the fewest SIDS cases ever recorded in the UK.

Antoinette brought the section to a close, saying that the APPG and supporters would be very keen to feed into the ONS consultation when it comes out.

5. Psychological impact of early baby loss (Professor Tom Bourne, Imperial College London)

Tom presented on his recent study on the psychological impact of early baby loss, published shortly after Baby Loss Awareness Week (slides shared with members and guests following the meeting). This pilot study researched mothers' post traumatic stress disorder (PTSD), anxiety and depression following miscarriage or ectopic pregnancy.

The initial study sample was 186 women, who were sent a questionnaire at one month, three months, and nine months after the loss of their baby. The researchers also followed up with the mothers' partners. This was not a randomised trial.

Tom reported that 32% of women surveyed had mild to severe PTSD at one month, with 43% of all women surveyed at three months. At one month, 32% of women had anxiety and 16% of women had depression, but these symptoms tended to resolve at three months. However, Tom explained that the PTSD symptoms persisted, and PTSD tends to be a more intractable condition resistant to treatment, if patients receive treatment at all.

Tom emphasised the seriousness of these conditions; symptoms include flashbacks, avoidance, major impacts on work, relationships and more.

Tom provided an extrapolation of the results for the Group. 250,000 women lose a baby a year, so these figures on PTSD suggest serious societal cost, as well as the psychological impact on individual women. 38% would equate to 95,000 women a year. He argued that we need to deal with the costs of this issue, potentially through relevant screening and interventions, because it is impossible to reduce baby deaths to zero.

Tom and his research colleagues are now following up with 800 women and 300 partners, and hope to publish the wider study soon. He said that the emerging results appear to be in line with those of the pilot study.

Chris (Teddy's Wish) responded that much of what Tom had said resonated with him. When he and his wife Jen lost their child (as a result of SIDS not stillbirth), the first response from the doctor was to "offer Jen some pills." Chris argued that it is vital to understand the difference between anxiety, depression and PTSD. Jen and Chris also attended an annual baby loss conference shortly afterwards, and what had struck them was the taboo around loss. Chris said that no one wants to talk about the loss, which undermines people's ability to deal with that loss. He said it is up to all of us to find a means and language to talk about loss in the same way - responsibly without scaremongering - and help build compassionate dialogue in society.

Antoinette asked whether the Department of Health had been in touch with Tom since publication of his research. Tom answered no, and said he would pass this on. Antoinette said it would be useful to aid evidence-based policy-making.

Will said that he undertakes a lot of work on parental bereavement, and would be interested in the data on early stage miscarriages, particularly if Tom had collected any data on how much time people took off work. Tom said that unfortunately the study had

not asked respondents about that issue, but he could look into the qualitative data received to see if this issue was raised. Tom also suggested this is a topic that could be included in his upcoming study.

Antoinette asked Clea (Sands) whether it was worth Tom feeding into the bereavement care pathway project, which Clea agreed. Clea added that the project is concerned to make sure we are offering the right support/services to people who have lost babies at different stages, so it would be useful to have Tom's engagement.

A longer discussion was held about the cut-off time of 24 weeks or earlier for different types of bereavement; Clea and Tom agreed that this distinction is frustrating, seems nonsensical, and means different types of loss do not receive the same acknowledgement. It was agreed that the strongest voice for change on definitions would come from patients, though this would require a change in legislation.

Antoinette said that this is something the group could discuss and consider in future, but cautioned that this is a controversial issue as it does enter a topic space which is highly contested by abortion and anti-abortion groups.

Aimee (University of Exeter) suggested that it is worth thinking about how we can help women to define their own pregnancies, in the same way we define their own abortions.

Munira (Ecotopic Pregnancy Trust) welcomed the points made. In relation to ectopic pregnancies, she said that often the loss is not acknowledged, as it is seen as a medical procedure. She said that many women had contacted her organisation who had been heartened by the baby loss debate in Parliament, where ectopic pregnancies were acknowledged as a loss.

Leanne (Aching Arms) expressed her thanks to Tom for his research. She recounted that she had lost her baby at 23 weeks, and self-diagnosed with PTSD, but that no medical professional had helped her with her anxiety following the loss. She said that it was great to hear the acknowledgement that this is a real issue that affects many bereaved women. She offered her help to Tom on future research.

Antoinette closed the section by explaining that there has been a commitment from government of £385 million to support perinatal mental health. She said that this is a positive move, a relatively small amount once it is distributed to local NHS organisations. However, this demonstrates that the issue of perinatal mental health has been acknowledged by the government, so there is an opportunity for the APPG and Tom to feed into their programme.

6. Bereavement care pathway update

Clea (Sands) updated the Group. The project is to create a Pathway that all professionals can use to guide bereavement care wherever parents are seen in the UK. This needs to be parent-centred, and flexible to individual needs.

The core group working on the Pathway includes: ARC, Bliss, The Miscarriage Association, Sands, The Lullaby Trust, The Royal College of Obstetricians and Gynaecologists, and The Royal College of Nurses. However, Clea emphasised that the project seeks input from all.

The Group has held an initial stakeholder group, which has confirmed some of the Pathway's intended shape. It has been agreed that the Pathway will begin at 'confirmation of pregnancy' up to a 'year', to ensure all infant loss is included. The Pathway will include hospital and community care, and is intended to link into additional care needs for each subsequent pregnancy following a loss.

Clea added that the Pathway project has hosted a learning event in Edinburgh to hear from Scottish professionals, and has also received 25 existing relevant pathways in response to a call for evidence and templates. Clea said that there is a lot of useful work being done out there, so they will be reviewing these pathways to ensure the group does not 'reinvent the wheel'.

The group has engaged 60 healthcare professionals in the process so far, mostly midwives but also obstetricians and other professionals. They are aware they need wider representation from other groups including chaplains, police, coroners, and more, in order for the eventual Pathway to be as comprehensive as possible.

The next big step is to talk to parents. Clea explained that the project group is putting together two stakeholder meetings for parents, one to be held in Manchester and one in London.

Clea reported that people involved have been really excited and engaged with the project so far. There has been a slight delay on obtaining the funding, which is now resolved, but that has led to a minor delay. The group will recruit a project lead in January, which will help move forward to the next step.

Clea finished by saying the group would hope to launch the initial pathway next summer, and have a year to trial the material. It will probably take three years to have a final version, after lots of testing, consultation and feedback.

Aimee (University of Exeter) and Antoinette asked whether the launch of the pathway could take place in Parliament during new Baby Loss Awareness Week? Clea said that this would be a good idea. However, this would naturally be dependent on project progress. Clea also made the point that the key audiences for the pathway are not necessarily parliamentary.

Antoinette said that her office has written to every CCG previously under the Freedom of Information Act, and would be happy to do so again if this would support this project.

Keith (Tamba) suggested that it would be useful for the project group to engage with the Maternity Transformation Council, to discuss how they would incorporate the pathway into their work. He added that it may be helpful for the Co-Chairs to invite some of the Council members (such as Sarah James or Matthew Jolly) to attend a future APPG meeting.

Keith also suggested pushing for progress from NHS England, and bringing the implementers to the APPG meeting as well. Francine seconded this point; these public servants may also find it helpful to talk about what they are doing as well with the attention of the APPG.

7. Any other business

- **Future meeting topics:** Will and Antoinette said that they have recently written to Nicola Blackwood MP (Health Minister) about impact of smoking during pregnancy, so it would be useful to invite the minister to a future meeting.
- **Avoiding Yom Kippur in future:** Paula (Child Bereavement UK) said she was really proud to be part of the APPG, and everything that was achieved during BLAW. For next year, she requested a point for inclusivity – the date of the reception event this year coincided with Yom Kippur, the holiest day in the Jewish calendar and as such she was unable to attend. She requested that the APPG chose a different date for events in Parliament next year.
- **Scope of APPG:** Alessandro (parent) asked on whether the scope of this Group extended to the prevention of baby loss. Antoinette answered that prevention is a core aim of the group, and gave Alessandro a copy of the APPG's 'Beyond Awareness to Action' report as an overview. She added that some of the policy announcements that the Secretary of State for Health made following BLAW were informed by the work of this Group.

Antoinette explained that the Group's aim in creating 'Beyond Awareness to Action' and raising awareness over BLAW was to lay out our aims for the future, and ensure we can hold the Secretary of State to account. Once our stated goals are achieved, the APPG can turn its attention to other important issues around baby loss, such as research, perinatal mental health, and others.

8. Close

Date of next meeting TBC.