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House of Commons

London SW1A 0AA

The All-Party Parliamentary Group on Baby Loss

Inaugural Meeting

14:30 – 16:00, Wednesday 3rd February 2016

Room W2, Westminster Hall

MINUTES

Attendance

Members

Lord Boswell of Aynho	Non-affiliated
Sharon Hodgson MP	Labour
Victoria Prentis MP	Conservatives
Will Quince MP	Conservatives
Antoinette Sandbach MP	Conservatives (chairing meeting)

Non-members

Francine Bates	CEO, The Lullaby Trust
Catharine Gammie	Office of Victoria Prentis MP
Henry Lee	Office of Will Quince MP
Drew Lindon	Director, Drew Lindon Consulting (minutes)
Rebecca Montacute	Parliamentary Office of Science and Technology
Felix Parker-Smith	Office of Antoinette Sandbach MP
Isaac Spring	Office of Victoria Prentis MP
Daniel Tye	Office of Sharon Hodgson MP

1. Welcome and introductions

The attendees introduced themselves. Antoinette Sandbach MP explained the intended role of the group.

2. Election of Officers

In accordance with the Rules of All-Party Parliamentary Groups, the group nominated and elected:

Antoinette Sandbach MP	Co-Chair
Will Quince MP	Co-Chair

Victoria Prentice MP
Sharon Hodgson MP

Vice Chair
Vice Chair

3. Formal appointment of secretariat - Lullaby Trust

Antoinette proposed the group appoint the Lullaby Trust as the secretariat for the group. Francine Bates explained that the Lullaby Trust will retain the services of Drew Lindon (independent policy and campaigns consultant) to support the secretariat duties of the Lullaby Trust.

The group agreed to appoint the Lullaby Trust as secretariat. The Group conveyed its thanks to the Lullaby Trust for its ongoing support.

Antoinette asked for the value of the secretariat support for the coming year, to ensure the Group accurately reports this benefit in kind. Drew Lindon answered that Francine and he had discussed the estimated time required to provide secretariat support for four meetings over the year. This would amount to £6,300. This is significantly below the £12,500 limit for APPGs after which Groups are required to produce a detailed income and expenditure statement as part of their annual reporting.

Lord Boswell asked how this secretariat support will be resourced. Francine answered that the Lullaby Trust Board has approved this expenditure as a relevant use of charitable resources, as a means to help improve policy relating to SIDS as well as baby loss more generally.

Lord Boswell added that the group should not rule out additional support from other sources, which was agreed by all. Francine said that she would also hope to secure additional support in kind from other baby charities. Will suggested that we consider potential support from commercial sources, if appropriate.

Francine added that the secretariat support will be separate from other activities. For instance, Baby loss Awareness Week is coming up in October. Francine suggested that the Lullaby Trust and other baby charities may consider holding an event and reception, which the Group may need to declare, depending on the level of the APPG's involvement.

Lord Boswell said that it would be worth developing a media strategy for the Group, including activities such as an article in the House magazine, or holding a reception which includes media professionals. The group agreed. Antoinette added that there is significant interest in these issues; she has been recording a 12-minute piece that will be broadcast on the Victoria Derbyshire Show on 4th February. This will be online afterwards on the show's website.

All Officers agreed that they would be happy to talk on the media. Will Quince MP said that the radio station LBC (now broadcast nationally) is very keen to run a year-long campaign on this issue, following the bereavement suite debate. LBC would be interested in the progress of the APPG.

Antoinette asked whether the Lullaby Trust, as secretariat, would want to be the secretariat want to be the public enquiry point. Francine answered yes; the Lullaby Trust

will field queries relating to the group in the first instance. Francine passed contact details to Daniel Tye to add to the APPG's registration forms.

4. The Group's mission statement

The Group discussed their mission statement. After discussion, it was agreed that the original proposed text would be shortened to be more inclusive of all forms of baby loss.

Original:

A cross-party forum to develop policy that supports families dealing with the grief and loss of a baby, be it through miscarriage, stillbirth, premature/neonatal death or SIDS, and; raise awareness of what more can be done by Government and Parliament to help all those affected.

Agreed text:

A cross-party forum to develop policy that supports families dealing with the grief and loss of a baby, and raises awareness of what more can be done by Government, Parliament or other agencies to help all those affected.

The Co-Chairs-elect signed the forms for registration of the APPG, which will be sent to the Commissioner for Standards Office by Daniel.

Action: Daniel Tye to send on forms to Commissioner for Standards Office.

5. Action planning

The Group discussed upcoming issues and opportunities, to develop an action plan for the APPG's first year.

(a) Access and availability of bereavement suites

Antoinette has made a Freedom of Information (FOI) request to every NHS Trust in England on the availability, and policies on the use of bereavement suites. Today was the deadline for response, but only half of the Trusts have replied. Initial analysis of the results suggest that there is:

- confusion about what is meant by bereavement trained midwives
- a lack of consistency on guidelines or how they are applied
- variable access to bereavement suites
- lack of access for parents who present with a child who has passed away from Sudden Infant Death Syndrome (SIDS). In many cases parents will not be offered access to the bereavement suites.

The Group discussed the implications, and agreed one role for the Group would be to help define and promote what good practice should be.

Action: Antoinette Sandbach's office to chase up non-respondents to the FOI request, complete analysis of the results, and write letter outlining the findings to the responsible Minister (Ben Gummer MP) and the Department of Health. It was also

agreed that Antoinette consider 'naming and shaming' non-responding NHS Trusts in a future parliamentary debate.

(b) Ministry of Justice consultation on baby cremations

Victoria Prentis MP outlined that the Ministry of Justice is consulting on baby cremations, with a 9th March deadline for responses.

Action: Victoria's office will draft a response to MOJ consultation on baby cremations, and circulate to the group for comment.

(c) Informing stakeholders of the APPG's establishment

Victoria noted that Ben Gummer MP came to a previous meeting and was very supportive. Francine added that a group of baby charities are meeting with Ben Gummer MP on the 1st March to talk about the NHS maternity review.

Action: Antoinette Sandbach's office to write to Ben Gummer MP and the relevant opposition spokespersons to inform them about the APPG.

Lord Boswell asked whether there are any related APPGs with which the Group should open relations. Francine said that there were a range of relevant Groups, including the APPG on Children; APPG on the first 1000 days; APPG Maternity and Childcare, and so on.

Action: Secretariat to write letters to related APPGs informing them of our establishment and proposing future collaboration.

Action: Antoinette Sandbach's office to write to Caroline Dinenage MP (Parliamentary Under Secretary of State at the Ministry of Justice and Minister for Women and Equalities at the Department for Education) to inform her about the APPG's establishment.

Action: Will Quince MP's office to email all MPs about the Group, and put a notice in the All-Party Group meetings to inform peers.

(d) Office of National Statistics and baby deaths registration

Francine explained that the Office for National Statistics is currently consulting on proposals to halt collection of a range of statistics due to funding cuts, including details on baby deaths via death certificates. This does not include miscarriages before 24 weeks, as these deaths are not recorded at the moment.

Action: Francine to draft a letter from the Group in support of the Lullaby Trust's final response (shared with members post meeting), which will go to the Director of the Office for National Statistics.

Sharon Hodgson MP left the meeting at 14:55.

(e) Infant mortality and inequality

Francine said there is a wider public health agenda the APPG could consider. Most SIDS deaths are in poor families; in fact, there is a correlation between inequality and infant mortality more generally. The Group discussed and agreed that there is a clear need to address inequality and best to prevent deaths through public health measures. Antoinette agreed this topic needs to be a focus for the group, though it is a longer project.

(f) Baby loss awareness week

The members discussed ideas for how the Group could make best use of the opportunities presented by Baby Loss Awareness Week in October.

Action: Francine to confirm the exact dates of Baby Loss Awareness Week with members. *Postscript: Baby Loss Awareness Week will be held from the 9th – 16th October.*

Victoria suggested the Group could secure a backbench debate for the Baby Loss Awareness Week.

The Group agreed to launch a report on bereavement pathways in October. Victoria suggested that having a celebrity involved in some way would help promote this issue; for instance, a recent Hollyoaks storyline featured a stillbirth. The actress who portrayed the mother in this storyline would be happy to be involved. Rory Bremner has also offered his support to Victoria in the past. In addition, the Lullaby Trust and the other baby charities have supportive celebrities to whom they could speak.

Victoria also suggested the group could sponsor a remembrance service, for instance an early evening candlelit event at St Margaret’s (the church in Parliament). This could be a non-religious event, and invitations would go to both parliamentarians and parents. There would also be the opportunity to do an event at a national service's hospital chapel.

In response to a question from Francine, the members said that they would be very happy for other charity representatives to attend the Group. Will said it would be a great opportunity to showcase smaller charities too.

CLOSE OF MEETING

Appendix: Summary of Actions

Action	Responsible person/office
Send on APPG registration forms to Commissioner for Standards Office.	Daniel Tye (Office of Sharon Hodgson MP)
Chase up non-respondents to the FOI request, complete analysis of the results, and write letter outlining the findings to the responsible Minister (Ben Gummer MP) and the Department of Health. It was also agreed that Antoinette consider 'naming and shaming' non-responding NHS Trusts in a future parliamentary debate.	Office of Antoinette Sandbach MP
Draft a response to MOJ consultation on	Office of Victoria Prentis MP

<p>baby cremations, and circulate to the group for comment.</p>	
<p>Write to Ben Gummer MP and the relevant opposition spokespersons to inform them about the APPG.</p>	<p>Office of Antoinette Sandbach MP</p>
<p>Write letters to related APPGs informing them of our establishment and proposing future collaboration.</p>	<p>Secretariat (Lullaby Trust)</p>
<p>Write to Caroline Dinenage MP (Parliamentary Under Secretary of State at the Ministry of Justice and Minister for Women and Equalities at the Department for Education) to inform her about the APPG's establishment.</p>	<p>Office of Antoinette Sandbach MP</p>
<p>Email all MPs about the Group, and put a notice in the All-Party Group meetings to inform peers.</p>	<p>Office of Will Quince MP</p>
<p>Draft a letter from the Group in support of the Lullaby Trust's final response, which will go to the Director of the Office for National Statistics.</p>	<p>Francine Bates</p>
<p>Confirm the exact dates of Baby Loss Awareness Week with members. <i>Postscript: Baby Loss Awareness Week will be held from the 9th – 16th October.</i></p>	<p>Francine Bates</p>