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

**15:00 – 17:00, Wednesday 20<sup>th</sup> April 2016**  
**Room T, Portcullis House**

**MINUTES**

**Attendees:**

APPG members:

1. Antoinette Sandbach MP (Co-Chair) – Conservatives
2. Will Quince MP (Co-Chair) – Conservatives
3. Sharon Hodgson MP (Vice-Chair) - Labour
4. Lord Boswell of Aynho - Non-affiliated

External guests:

5. Catharine Gammie – Office of Victoria Prentis MP
6. Cheryl Titherly - Improving Bereavement Care Manager, Sands
7. Drew Lindon - Director, Drew Lindon Consulting (minutes)
8. Francine Bates - CEO, The Lullaby Trust
9. Gabrielle Osrin – Trustee, Lullaby Trust
10. Jane Denton – CEO, Multiple Births Foundation
11. Jane Fisher – CEO, ARC
12. Jane Plumb – CEO, Group B Strep Support
13. Julie Ellison – Child Bereavement UK
14. Karen Burgess – Petals Charity
15. Keith Reed – Tamba
16. Leanne Turner – Coordinator/Trustee, Aching Arms
17. Munira Oza – Director, The Ectopic Pregnancy Trust
18. Paula Steele – St Georges Hospital (StGH)
19. Penny Kenny – Chair, The Miscarriage Association
20. Rupal Kantaria – Oliver Wyman
21. Sam Collinge – Bereavement Support Specialist Midwife, University Hospitals Coventry and Warwickshire NHS Trust (UHCW Trust)
22. Shona Cleland – Senior Policy and Public Affairs Officer, Bliss
23. Vanessa Higham – Parliamentary Assistant to Antoinette Sandbach MP
24. David Mowat MP – Conservatives

**Apologies:**

- Victoria Prentis MP (Vice-Chair) - Conservatives

- Annika Dowson
- Helen Lyons – Elise Ever After

## 1. Welcome and introductions

Antoinette Sandbach MP welcomed the attendees and asked all attendees to introduce themselves.

She explained that the All Party Parliamentary Group (APPG) had its inaugural meeting in February for the parliamentary members. However, this is for all intents and purposes the first full meeting.

## 2. Actions from last meeting

### • Access and availability of bereavement suites (Antoinette Sandbach MP)

Antoinette updated that her office has received responses from most hospital Trusts in England, following her Freedom of Information request relating to bereavement suite facilities. Headlines from the analysis include:

- 25% of hospital Trusts who responded did not have bereavement suites.
- For those who do have bereavement suites, 55% would allow parents who turn up to the hospital with a sudden infant death to use these suites, while 45% would not.
- 56% of the Trusts which offered suites locate these on the labour ward, which Antoinette and Will highlighted as inappropriate.
- Several questions were asked about specialist posts; however, the responses received from Trusts are not clear-cut. For example, many Trusts said they had trained midwives, which is not the same thing as a specialist.
- Where available, trained bereavement counsellors had very varied waiting times.

Overall, there is a huge variety in the type of support available from place to place, and lack of clear guidance on what support and signposting can be given.

Jane Fisher (ARC) expressed concern about Trusts' confusion and inconsistency around signposting. She said that with every best intention, often parents are signposted to pregnancy emergency services, which often have distinct agendas that may be inappropriate for this situation.

Sam Collinge (UHCW Trust) added that specialist midwives are very different to bereavement midwives. There is massive variety on the availability of this role across the country. There has been a dedicated specialist midwife role in Coventry for years, but not in neighbouring Warwick.

Cheryl Titherly (Sands) outlined that Sands have been commissioned by NHS England to undertake a Care Provision Audit, looking at the overall support structure, and produce a set of guidance by September. This work will be launched at a joint conference with Bliss in September.

Munira Oza (Ectopic Pregnancy Trust) said that her organisation often respond to cases where the emotional aspect of the bereavement isn't even acknowledged by health teams. It is often a very clinical approach, and the emotional needs are not taken into account.

Will Quince MP said that despite the issues we need to work on, this Freedom of Information of research was encouraging in some ways, as there was more suites available than the Group expected to find. That said, he found the variation particularly concerning. Will said that a key point is that parents are not being offered the opportunity to be involved in discussions to investigate deaths as a means to learn and prevent SIDS in future. Cheryl (Sands) informed the Group that Sands has produced a post-mortem consent package to help health professionals with that difficult conversation.

Shona Cleland (Bliss) explained that the variation shown by the Freedom of Information research was also reflected in neonatal care. There is often a lack of access to bereavement counseling, and it's also important to remember that parents whose children survive a traumatic birth may also need support or counseling.

Lord Boswell asked to raise two questions for the Group to consider as it delves into this information. Firstly, is there any correlation with the size of the maternity unit and its throughput? He suggested some units with a larger number of births might have more expertise in dealing with baby loss. Secondly, he highlighted that when it comes to baby loss, this is a situation where many professionals will have some level of involvement in the role. When the Group moves onto developing a comprehensive pathway, we will also need to get buy-in from all these types of professionals.

Jane Denton (Multiple Births Foundation) added that pathology services should be part of this picture too. There is a huge lack of, and therefore pressure on, maternal pathology services and perinatal pathologists.

David Mowatt MP asked whether the Group's focus is on bereavement rather than prevention? Antoinette answered that long term we want to look at prevention, but at this point, we want to address the issues around bereavement.

Lord Boswell remarked that it is great to have the range of professionals and expertise with the Group today. He suggested that this could help create a working alliance, or augment those that already exist. Lord Boswell has worked well with the Anaphylaxis Alliance to push forward positive change. Francine Bates (Lullaby Trust) responded that many of the national baby charities currently meet regularly (including the Lullaby Trust), so will look at how to involve and work with others via the Group.

- **Ministry of Justice consultation on baby cremations (Catharine Gammie, Office of Victoria Prentis MP)**

Catharine Gammie explained that the Ministry of Justice has held a consultation on infant cremations, and the Group's response was sent at the beginning of March. The Group has received an acknowledgment from Caroline Dinéage MP (Parliamentary Under-Secretary, Ministry of Justice). Victoria has also had discussions with Caroline on this topic. We anticipate a summary of responses will be published shortly, although are not privy to any specific information. Given the Minister is aware of Victoria's interest in this matter, it may be that we are given some advance warning, but we are not anticipating that.

- **Informing stakeholders of the APPG's establishment (Secretariat)**

Drew Lindon (Drew Lindon Consulting) reported on actions from the last meeting. Will's office wrote to all MPs via the Notices to notify them that the APPG has been established.

Drew also sent letters to the Chairs of 18 relevant APPGs. So far, 20 MPs have responded to say they would be interested in joining the group, of which 5 are APPG Chairs interested in collaboration, which Will listed:

- Kevin Hollinrake MP – Conservatives (APPG on Poverty)
- Stephen McPartland MP - Conservatives (APPG on Child Health and Vaccine Preventable Diseases)
- Fiona Bruce MP - Conservatives (APPG on Alcohol Harm; All Party Parliamentary Pro-Life Group)
- Tim Loughton MP - Conservatives (also Chair of APPG on Children; APPG on First 1000 days)
- Sir David Amess MP - Conservatives (also Chair of APPG on Maternity)

Will said that we need to write to Peers as well, and asked Lord Boswell for the best approach, as there does not seem to be a full list of contact details available. Lord Boswell suggested that rather than writing to all Peers, the Secretariat could talk to the House of Lords library for lists of Peers' specialist interests.

**ACTION: Secretariat to contact House of Lords library, develop list of key peers, and prepare letter from co-Chairs.**

Drew added that the APPG webpage is also up at <http://www.lullabytrust.org.uk/all-party-parliamentary-group-on-baby-loss>. We will post minutes and papers from the Group's meetings on this page from now onwards.

Will added that the issue of baby loss has also received a lot of media interest (not least from Antoinette's appearance on the Victoria Derbyshire show on 4<sup>th</sup> February), which keeps the pressure on the Department of Health

Antoinette said that her office was also contacted by the Parliamentary Health Select Committee, as a result of the Freedom of Information request, and asked for copies of the FOI. The Committee may be considering a specific inquiry on this issue. If so, the APPG will consider submitting evidence and invite the organisations around the table to submit as well.

- **Office of National Statistics and baby deaths registration (Francine Bates)**

Francine (Lullaby Trust) updated the Group; at the time of our last meeting, the Office of National Statistics (ONS) was consulting on whether to cut out a range of statistics relating to baby loss. Antoinette and Will wrote to ONS to express our concerns, which has had the desired result – ONS will continue to collect and publish this work.

### **3. Developing a bereavement care pathway (All)**

Antoinette outlined that the Group would like to explore developing a bereavement care pathway for the UK long-term, and invited members to feed in their ideas and perspectives.

Cheryl (Sands) welcomed the focus on a bereavement care pathway. As outlined previously, Sands are scoping out what is there already. For example, there are good examples pathways in Manchester and with the Strategic Clinical Network in North

Yorkshire. Sam (UHCW Trust) added that there are other networks that would be useful to be included, such as the West Midlands Strategic Clinical Network, in which all the bereavement midwives meet every quarter.

Cheryl continued that part of the issues is that lots of health organisations are starting from scratch on similar projects regionally, so SANDS is trying to bring them together to share and collaborate, with the aim of putting together a national bereavement pathway. However, Cheryl explained that while Sands are passionate about this aim, the key issues for Sands and other charities is a lack of resources to achieve this aim. In fact, just understanding how to approach this pathway and develop a clear process for creating this pathway is a big job as well.

In response to a query from Antoinette, Cheryl explained that the Care Provision Audit project for which they have been commissioned by NHS England does not include developing a pathway. Sands would be happy to share their provisional findings with the APPG. It would also be useful for Sands to have a soft copy of the Freedom of Information analysis Antoinette tabled at the meeting.

**ACTION: Sands to share provisional findings from Care Provision Audit with Group when available.**

**ACTION: Antoinette's office to share analysis of Freedom of Information work with Sands**

Antoinette outlined there are two broad areas to consider: what happens in hospital, and what happens when you leave hospital. She asked Cheryl whether Sands work covers both these areas. Cheryl (Sands) explained this Audit just covers the hospital context, so that leaves a knowledge gap.

Paula Steele (StGH) said that there is a need for bereavement counselling for parents available everywhere. Will added there is often no provision for siblings, who can also be impacted by the death of a baby.

Francine (Lullaby Trust) said that some of the baby charities were looking at a funding for a project to consider these issues. Bliss, Sands and the Lullaby Trust put in a funding bid for a feasibility study on what a joint bereavement service would look like, delivered by the three charities. However, the Department of Health rejected this bid recently. The three charities are looking to resubmit their bid to a charitable trust, but this is likely to take some time, even if the bid is successful. Francine said that the 'the dream would be to have one portal' for parents.

Leeanne Turner (Aching Arms) explained the role of her charity; the charity is run by parents who offer a hand of friendship to other parents who have lost a baby, but they are careful to direct parents to charities for other types of support. A list of charities and other support would be really helpful to have, to make sure that Aching Arms are confident they are signposting people onto the right kind of support.

Antoinette remarked that there is a small charity in her constituency, who have found that bereavement support is only provided via hospices. To access this bereavement support, you need to have had contact with the hospice already, which is often not the case for many parents (and no support is offered for siblings).

Antoinette suggested that a bereavement pathway would need to take into account three key areas:

- Bereavement suites
- Pathway into hospitals
- Pathway out of hospitals

Will said he would like the pathway to include a point around dads. Most of the contact with the bereavement counsellor is for the mum at present, and rightly so, but fathers may also need support during this time.

Karen Burgess (Petals Charity) said that Petals are delivering a lot of what is being discussed. She explained that the charity is Cambridge-based, working with St Mary's and Addenbrookes. They have established a free counselling model, to help parents process the trauma of their loss, as well as go on to support parents in their next pregnancy. Parents are reporting good results from the support, and Petals feels that this model fits in very well with the specialist midwife role. However, Petals have many enquiries for support from all over the country, but they are unable to do more due to lack of funding.

Karen (Petals Charity) added that Petals want to advocate for good online support; they have had great support from ARC as well as online support. In addition, Child Bereavement UK has a national helpline, through which parents can receive 6 sessions of telephone counselling. But it is difficult for parents to know what they might need at that traumatic time.

Penny Kenny (Miscarriage Association) said there is also a gap in support pre-24 weeks. Bereavement suites usually only provide support after 24 weeks of pregnancy, so if miscarriage happens before this, parents can miss out on support they may need.

Antoinette observed that there seems to be lots of great work going on with the charities out there, but there could also be duplication of costs. She asked whether the charities represented were looking at more collaboration. Francine (Lullaby Trust) answered that Bliss, Sands and the Lullaby Trust do collaborate already, but have begun to look into how what else they could do to share resources (though scoping this out is a piece of work in itself).

Jane Plumb (Group B Strep Support) commented that her organisation was very grateful to the national charities; as they provide a range of information and support, this helps Group B Strep Support to keep a specific focus, without 'reinventing the wheel.'

Antoinette suggested that a step forward, outside of a pathway, would be an accessible online resource or directory of support, which doesn't seem to exist at this point except on a local level. She proposed that the Group could write to the Department of Health/NHS England to assess what coverage there are for bereavement services outside of the hospital setting, to identify gaps and recommendations.

Jane (ARC) said that while that would be useful, a key challenge would be to ensure quality; i.e. that this does not become a portal where anyone can simply 'advertise' their services without some form of monitoring or quality control.

Returning to the topic of the bereavement pathway, Francine (Lullaby Trust) said that with the joint effort of groups and individuals now involved in the Group, it may be possible to identify the key principles that would underpin a bereavement care pathway, drawing on

research previously undertaken. This would be a great tool for commissioners to use in developing services and support for their area, prior to the creation of a full pathway. This would be a big piece of work, but not quite as challenging in time or resources as putting together a bereavement care pathway. Francine suggested that this set of principles could then be presented to the Minister by the Group Chairs, potentially during Baby Loss Awareness Week.

Catherine (Office of Victoria Prentice MP) agreed, and said many of themes discussed were included in the Group's response to the recent Ministry of Justice consultation. It will be interesting to see the Ministry's response.

Rupal Kantaria (Oliver Wyman) offered pro-bono support from her consulting firm (Oliver Wyman) to support this project. Antoinette and Francine thanked her for this offer.

**ACTION: Francine (Lullaby Trust) to organise a project to establish the key principles for a bereavement care pathway, and engage other charities and individuals present. Francine to speak to Rupal about the potential support from Oliver Wyman.**

**ACTION: Antoinette to inform Ben Gummer MP (Health Minister) that this work has been 'commissioned' by the APPG, once Francine has clarified expected timelines.**

Antoinette thanked the members for their contributions. She said that part of the Group's role can be putting pressure on the Department of Health and NHS England.

#### **4. Baby Loss Awareness Week 9<sup>th</sup> – 16<sup>th</sup> October**

Antoinette explained that at the prior meeting, the Group had discussed a number of ideas for how it could support Baby Loss Awareness Week. The purpose of this item was to flesh out these proposals and set down clear actions.

Francine explained that there has never been any parliamentary activity around Baby Loss Awareness Week previously. The Lullaby Trust and Sands said that their organisations coordinate Baby Loss Awareness Week, and they would welcome having a public event in Parliament. The aim would primarily be about awareness, and improve the recognition of the issue. Francine said that she has been in touch with a charity called 'Teddy's Wish' who have agreed to support an event in Parliament that week. Lullaby Trust has some resources therefore to help deliver, and need to set a date (Monday 10th, Tuesday 11th or Wednesday 12th October are potentials at the moment).

Catharine added that at the last meeting, Victoria Prentice MP had agreed to help arrange a remembrance service during the week, at the Chapel in Parliament, but which would be non-denominational. Francine agreed that this would be a fitting event, which also ties in closely with the 'Wave of Life', an international activity during Baby Loss Awareness Week where parents are encouraged to light a candle for those they have lost and share a photo on social media.

Will agreed, and said that we should plan to ensure other MPs are informed and promote this. For instance, if we can produce pins/badges for MP and Peers to wear, and hold the event on Tuesday or Wednesday, MPs will be more likely to wear the pins at Prime Minister's Questions, which increases the chances of increasing awareness via TV

coverage. Will highlighted that the more 'noise' we can make in Parliament, the more likely Ministers will take action on our issues.

Antoinette summed up the discussion and agreement; we will aim for a launch event at the start of the week, probably Tuesday, and then follow this up with a non-denominational remembrance service either later that day or later that week. The event is likely to include:

- the launch of our bereavement pathway principles (giving us a clear ask for government), subject to confirmation on timelines from the baby charities involved.
- findings from the Freedom of Information requests on bereavement suites
- any other relevant materials, such as the results of Sands' Care Provision Audit

**ACTION: Francine (Lullaby Trust) and Cheryl (Sands) to coordinate the Baby Loss Awareness Week events, involving APPG members as appropriate.**

Will said that the Speaker is very supportive of our issue, and he might even offer us his apartments (which would have no booking fee).

**ACTION: Will to ask the Speakers' office about booking his apartments.**

**ACTION: Catherine Gammie (Office of Victoria Prentice) office to look at chapel availability for the service during the week, aiming to hold this on the day after our launch event.**

**ACTION: Once venue and date confirmed, APPG Chairs to invite Ben Gummer MP and/or Jeremy Hunt MP to event.**

## **5. Any other business**

- It was agreed that the next meeting date for the Group would need to be before Baby Loss Awareness Week (ideally before Summer), booked in a bigger room.

**ACTION: Drew to book bigger room for next meeting of Group in July.**

- Jane Fisher (ARC) asked the Co-Chairs whether the Group has an England-wide or UK-wide remit? Antoinette answered that the Group is UK-wide, but to get changes across, we need to engage with the four different health systems across the four nations. One of the best ways to promote change is to engage with NICE in England, as their guidance can apply across the UK. Will added that the Group has two SNP MPs who are also interested in becoming involved, which should help keep the Group updated on developments in Scotland. Will said that if anyone has particular concerns on provision or practice in any of the four nations, please let the Co-Chairs know.
- Catherine Gammie (Office of Victoria Prentis MP) said that Victoria wrote to the Chief Coroner to inform him of the Group, and he would be happy to meet the Group in future.

**ACTION: Group to consider inviting Chief Coroner to next meeting**

- Several members asked whether there was a hashtag they could use to tweet about the Group. It was agreed to use #APPGbabyloss on this occasion, but the Group would look at potentially setting up a Facebook page and Twitter feed.



**ACTION: Group to consider setting up a Facebook page and Twitter feed.**

Leanne Turner (Aching Arms) said thank you to the Co-Chairs and members for standing up and speaking about this difficult issue. This means a great deal to the parents Aching Arms represent. Other attendees also gave their thanks.

Antoinette closed the meeting, saying that she and Will were so grateful to all the attendees for giving up their time, and thanked everyone for coming.

**CLOSE**

**Appendix: Summary of Actions**

<b>Action</b>	<b>Responsible person/office</b>
<ul style="list-style-type: none"><li>• Contact House of Lords library, develop list of key peers, and prepare letter from co-Chairs.</li><li>• Book Group's next meeting for July.</li></ul>	Drew Lindon (Secretariat/Drew Lindon Consulting)
<ul style="list-style-type: none"><li>• Share provisional findings from Care Provision Audit with Group when available.</li></ul>	Cheryl Titherly (Sands)
<ul style="list-style-type: none"><li>• Organise a project to establish the key principles for a bereavement care pathway, and engage other charities and individuals present.</li><li>• Speak to Rupal about the potential support from Oliver Wyman for the above project.</li></ul>	Francine Bates (Lullaby Trust)
<ul style="list-style-type: none"><li>• Coordinate the Baby Loss Awareness Week events, involving APPG members as appropriate.</li></ul>	Francine Bates (Lullaby Trust) & Cheryl Titherly (Sands)
<ul style="list-style-type: none"><li>• Inform Ben Gummer MP (Health Minister) that the project to establish key principles for a bereavement care pathway has been 'commissioned' by the APPG, once Francine has clarified expected timelines.</li><li>• Share analysis of Freedom of Information work with Sands</li></ul>	Office of Antoinette Sandbach MP
<ul style="list-style-type: none"><li>• Ask the Speakers' office about booking his apartments.</li></ul>	Office of Will Quince MP
<ul style="list-style-type: none"><li>• look at chapel availability for the service during the week.</li></ul>	Catherine Gammie (Office of Victoria Prentice)
<ul style="list-style-type: none"><li>• Once venue and date confirmed, to invite Ben Gummer MP and/or Jeremy Hunt MP to event.</li></ul>	APPG Chairs
<ul style="list-style-type: none"><li>• Consider inviting Chief Coroner to next meeting</li></ul>	Co-Chairs
<ul style="list-style-type: none"><li>• Consider setting up a Facebook page and Twitter feed.</li></ul>	Group / Secretariat