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

**Monday 17<sup>th</sup> June 2019**  
**16:00 - 18:00**  
**Commons Committee Room 11, House of Commons**

**MINUTES**

Members in attendance for the AGM:

- Antoinette Sandbach MP
- David Amess MP
- John Baron MP
- Kevin Hollinrake MP
- Neil O'Brien MP
- Sharon Hodgson MP

Other guests:

- Alexandra Mancini – Chelsea and Westminster Foundation Trust & Trust Colours Trust
- Carly Williams - Zephyr
- Clea Harmer – Sands
- Drew Lindon – Drew Lindon Consulting Ltd (minutes)
- Erin McCloskey - Canterbury University
- Jackie Doyle-Price MP- Minister of State, Department for Health and Social Care
- Jane Denton – Multiple Births Foundation
- Jane Plumb – Group B Strep Support
- Jane Scott – Imperial College NHS Trust
- Jenny Ward – Lullaby Trust
- Josie Anderson – Bliss
- Karen Burgess – Petals
- Kate Mulley – Sands
- Keith Reed – Tamba
- Laura Wetherley –Abbie
- Lauren Hutton – Imperial College NHS Trust
- Leanne Turner – Aching Arms
- Marc Harder, NBCP Project Lead, Sands
- Marcus Green – Action on Pre-eclampsia

- Mohamed Omer – Gardens of Peace
- Paula Abramson - Child Bereavement UK
- Penny Kerry – The Miscarriage Association
- Sam Collinge – University Hospitals Coventry
- Sophie Bond-Jones – Office of Victoria Prentis MP
- Tara Arnold – Nova Foundation

## 1. AGM

- Election of officers
- Approval of income and expenditure statement

Having established there was a quorum of 5 or more members of either House present, the AGM began.

All current officers of the APPG were re-nominated and re-elected by the MPs present. The APPG officers are:

Chair: Antoinette Sandbach MP (Conservative)  
 Vice Chair: Sharon Hodgson MP (Labour)  
 Vice Chair: Patricia Gibson MP (Scottish National Party)  
 Vice Chair: Victoria Prentis MP (Conservative)

The MPs present also signed off the APPG's income and expenditure statement.

### Actions:

- **Drew to complete the APPG registration form for Antoinette's sign-off, and submission to Office of the Deputy Registrar before close of play on Monday July 15<sup>th</sup>.**
- **Drew/Lullaby Trust to publish on the APPG's webpage:**
  - **the minutes of the AGM,**
  - **the group's income and expenditure statement,**
  - **the date of our future meetings, and**
  - **any changes made to the group's membership list.**

After the AGM was completed, Antoinette Sandbach MP welcomed all guests to the APPG's meeting.

## 2. Update on Ministry of Justice consultation on investigation of stillbirths (Antoinette Sandbach MP)

Antoinette passed on her thanks to all the organisations and individuals who sent on their responses and thoughts to Drew, who drafted the APPG's response to this consultation.

Antoinette reminded the attendees that the deadline is 18<sup>th</sup> June for anyone wishing to submit their own responses.

### **3. National Bereavement Care Pathway (Marc Harder, NBCP Project Lead, Sands)**

Antoinette welcomed Marc Harder who presented on the Wave 2 evaluation of the National Bereavement Care Pathway (NBCP) sites. The presentation will be shared on the APPG's website along with these minutes.

Marc begin by giving a big thank you to everyone for their hard work on this programme, including the Department of Health and Social Care who provided funding initially.

The uptake in sites which have adopted the NBCP has been very positive. Marc said that in the course of the initial two waves, they expanded the number of pilot sites to 38, and new early adopter sites in Scotland are due to be announced soon.

On May 10<sup>th</sup> the NBCP Evaluation report was released on the NBCP website, and offered the opportunity on their website for new Trusts to join the programme. Parents and professionals from the pilot sites were interviewed as part of the evaluation. A selection of the results included:

- 92% of parents agreed they were treated with respect
- 89% of parents felt the decisions they made in the hospital were at the right time
- 79% of the professionals (up from 66% at the outset of the programme) said they felt more able to communicate with parents
- 92% of professionals (up from 88%) felt supported to deliver good quality bereavement care

The process for new Trusts to join the Pathway programme is via the NBCP website, which among other steps includes an expression of interest, a self-assessment, and provision of resources for Trusts to create an action plan to improve bereavement support provided. The NBCP programme team is also putting together a peer support network and e-learning resources, and an accreditation framework for all Trusts involved in the programme.

Marc highlighted that there is work to be done to sustain the existing sites, as well as engaging new Trusts too.

In terms of the numbers, Marc outlined that there were 75 sites engaged in Easter. The programme now has 104 sites engaged: 32 as part of original programme, 48 more (not 46 as per presentation slides, as 2 more have come on board since then) have submitted a formal expression of interest, and 26 sites are also engaged at early stage or have been invited to attend a workshop.

Antoinette thanked Marc and gave a huge thank you to all parents, Trusts and third sector organisations who have supported and worked on this too. She said that this has been a great piece of work, which has also affected her area and the North of England. It's fantastic what this has achieved in just 3 years.

#### **4. NHS Long Term Plan and baby loss prevention (Jackie Doyle-Price MP, Minister of State, Department for Health and Social Care)**

Antoinette welcomed Jackie Doyle Price MP, Minister of State back to the Group. Following the publication of the NHS Long Term Plan at the start of this year, she explained the Group was keen to understand how this new direction for the NHS would continue, and hopefully build upon existing baby loss prevention projects and targets.

The Minister thanked Antoinette, and lauded the APPG for making significant inroads in its short life so far. She said that with the NBCP, it was great timing that the APPG came with a constructive solution at the time at the Department for Health and Social Care (DHSC) was looking at this issue.

The Minister spoke about how the NHS Long Term Plan would help address the four priorities of the Pregnancy and Baby Charities Manifesto:

- (a) England to be the safest country in the world in which to have a baby

DHSC has set out some key targets to help achieve this goal. The Minister said that the direction of travel has been good. In recent years there has been a 19% reduction in stillbirth, a 6% reduction in neo-natal death, and 8% reduction in maternal death. However, she cautioned that there are still significant regional variations, as well as a need to tackle pre-conception health.

The Minister said that she expected the Saving Babies Lives Care Bundle to be implemented in all Trusts by 2020. The Department is also looking at new interventions to reduce pre-natal issues.

The Minister also highlighted the ATAIN programme for dealing with key issues in birth issues, and keeping mothers and babies together immediately after birth as best practice.

- (b) To give women a maternity guarantee that their birth clinic will be personalised.

The Minister emphasised the importance of personalising care to what is needed. We need a targeted, continuity of care model. Much of this aim is based upon building good relationships over time between parents and medical professionals, being supportive of parents in vulnerable circumstances and building trust.

The Minister drew the Group's attention to the work ongoing to build internal medicine networks to ensure women have access to specialist advice and treatments as needed. The Minister also highlighted new training and more places for maternity professionals, and the Department's commitment to digitalisation of medical information for pregnant women, so they can access their own notes and take more control of their medical treatment

- (c) To give sick and premature babies the best chance of survival and quality of life.

The Minister said that the Long Term Plan commits to provide more intensive care costs, and improved triage in maternity units so that this care is available to the family as close to their home as possible. The Minister said she recognised that there are pressures in provision at present.

(d) The need to provide every family with bereavement care after pregnancy or baby loss

The Minister said she agreed that all parents should be able to expect the same high quality of care following a loss. She said she was really pleased to see the Care Quality Commission will include aspects of the NBCP in their inspection regime.

The Minister ended her presentation by talking about the Pregnancy Loss Review. She explained that the report has been delayed in part because of Brexit (some staff were moved off this project to work on Brexit-related activity, but some have now been returned now). The Minister said that she was hoping to that the report could be submitted to Ministers by Autumn, and be signed off by the end of the year. The Minister said this process has got to work for everyone, so we want to make sure people have the ability to have choices about what they wish to do, and have the support they feel they need around bereavement.

The Minister thanked the group again for all their energy and efforts in this field. Antoinette thanked the Minister for her presentation, and invited questions from the guests.

Marcus Green (Action on Pre-eclampsia) thanked the Minister presenting today and for joining the parliamentary debate on pre-eclampsia a few weeks ago. He asked if there was any news on any progress on Scotland and Wales on early testing for pre-eclampsia. The Minister responded that she couldn't speak on behalf of those nations, but in general the devolved nations and England tend to 'compete' – when one nation has a new service or treatment, the others will aim to provide it too.

Mohamed Omer (Gardens of Peace) asked the Minister about her figure of the 19% drop in stillbirths, and whether there is a breakdown by community, ethnicity for these figures. The Minister said that the Department has the racial disparity audit which looks across the board at how different conditions affect different groups in society. The Minister said she would be happy to discuss these issues with Mohamed in more depth personally if that would be of use, to which Mohamed welcomed.

Mohamed also requested that the APPG have more people to come along to the meetings to represent the views of other ethnic, religious or cultural groups. Antoinette said that the APPG is open to all, so if there are other professionals, parents or organisations who wish to come along or others would recommend attending, the APPG would very happy for any and all to attend, and would welcome different voices.

Keith Reed (TAMBA) welcomed the wide range of activities detailed by the Minister for dealing with stillbirth. He welcomed the Minister's own personal commitment as well. He asked how all these activities might be coordinated to understand the overall contribution to addressing the needs identified. He recalled that there had been talk of an annual report on progress. The Minister agreed that it was vital to how to hold the system accountable. She said that we need to find the best way to measure the outcomes on a more regular basis, and formalise this process. The Minister will look into this issue.

Alex Mancini (Chelsea and Westminster Foundation Trust & Trust Colours Trust) said that she welcomed the stated priorities of improving capacity and neonatal care. However, she said the overarching issue is of workforce. We currently have a 25% vacancy rate for nurses in London, and this is an aging workforce as well. She asked whether there are any

plans to refocus on building the future workforce. Minister answered that workforce planning is key. We need to look at investment in the new, but also how we retain skilled staff as well, and this is a challenge that affects the NHS as a whole.

Josie Anderson (Bliss) said that Bliss have some concerns around meeting the neonatal death target. She said that new research came out today showing the reduction is plateauing. She asked what more the Department can do to maintain the momentum on meeting this target. The Minister replied that we need to work to make continuity of care a reality, to ensure interventions can be made at the earliest possible time. This depends on changing work practices and working culture .

Jane Scott (Imperial College NHS Trust) drew attention back to staff retention. She said that the recent M-RESE report details that a huge proportion of baby deaths are due or related to a lack of resources or staff. She said she did not know what other evidence we are waiting for before things change and workforce issues are addressed. She also detailed the pressure her and her colleagues were under, and the retention problems related to pay and workload; many of her colleagues need to take on second jobs.

The Minister said that when we talk of continuity of care, we are talking about continuity of care teams, not necessarily that a patient will see exactly the same person each time. In terms of retention, there are different behaviours and situations in different Trusts, as well as career opportunities. We need to make sure we are giving the best possible support and encouragement to staff, and need to give training and encouragement. There are a different set of challenges in London compared to other parts of the country, and this is needs to be considered.

Jane responded that she founded the National Bereavement Midwife Forum, and have hosted midwives from across the country. She agreed there are differences in retention issues in different areas, but there is a general consensus among this staff group that there is not the support or understanding needed. Antoinette said that there is regional disparity, and one of the issues around pay in London is the cost of living which makes things more difficult. The NBCP should also help with the staff support needed by staff working on bereavement.

Antoinette thanked the Minister for coming and for updating the Group on the work of the Department.

## **5. Panel discussion: Expanding focus to the community**

- Carly Williams (Project Manager, Zephyr)
- Paula Abramson (Head of Training, Child Bereavement UK)
- Jane Scott (Senior Bereavement Midwife, Imperial College NHS Healthcare Trust)

Antoinette introduced a panel discussion on bereavement support in the community. She explained that this aims to be an initial discussion to establish what the current challenges are with support for baby loss in the community, following support in the hospital/in-patient settings as covered by the NBCP. This is an opportunity to identify key ideas for future activity by the APPG and others to move this agenda forward.

Antoinette invited the panel speakers to introduce themselves and their background, before opening this up to a discussion with the floor.

Paula Abramson (Child Bereavement UK) said that in terms of NHS support outside of a hospital setting, the bereavement care that GPs provide is usually restricted to counselling under the IAPT service. This is better than not being offered anything, but provision is limited – both by waiting list, region and by the nature of needs presented.

Paula went on to say that there are many charities offering some form of support, including 54 children's hospices in the UK. Child Bereavement UK offer a helpline and information, as well as a database of bereavement support services in the UK. However, support in the community tends to be limited. It's important to understand that while every parent should be able to have access to support, including psychological service, not every parent wants or feels they need this support.

Carly Williams (Zephyr) explained that she is a bereaved mother, and runs the charity Zephyr offering space in a local hospital to provide support and counselling, with input and support from consultants. They have a specialist bereavement counsellor available for parents, and have had 2,000 visits to the centre in the 3 years they have been opened by parents and children. She said it is vital to have a place to belong, to talk openly about what's happened, and it is really valued by parents.

Jane Scott (Imperial College NHS Trust) said that she came to the APPG today representing 130 bereavement midwives from across the UK. She has set up the Bereavement Midwife Network to provide support. She said that the Network has people calling them every other day for psychological and other support that is not available elsewhere. They work to share information to be able to standardise and improve their practice. The Network meets every three months, with funding kindly provided by the charity 4Louis.

There are 200 stillbirths every year in the areas that she and her colleague Lauren cover. Jane said that we need trauma counselling for parents, in addition to the (very welcome) provision that the NBCP sets out it. She added that they are lucky to have Petals (counselling charity) in their Trust, which can offer that service now to all of their parents now that funding for this service has been added into their maternity budget. She also argued that there needs to be more focus on BME groups. She said that 50% of our stillbirths occur in Muslim families, and services need to be able to have the ability to provide the right services for their beliefs, including rapid burials. To make the NBCP a reality, this depends on how seriously how your maternity management takes this as a priority.

Antoinette said that Great Ormond Street and Alder Hey hospitals will take referrals for counselling from across the country, but it is not right that people need to wait. Antoinette added that we have talked about the possibility of creating a central portal for bereavement support at the APPG before, which could be useful. She then opened up the floor to questions for the panel.

Alex Mancini (Chelsea and Westminster Foundation Trust & Trust Colours Trust) said that there are 54 children's hospices in the UK, but funding is being cut. This is absolutely devastating for people. Antoinette said that it would be useful for families to write to their MPs to ask them to talk about how this affects their care. It would be good to have this

done for the forthcoming debate for Baby Loss Awareness Week in October, so we can raise these issues.

Sam Collinge (University Hospitals Coventry) agreed that not every parent needs counselling, but they definitely need the information. Her role is to go and see parents at home, but she thinks that her role is pretty unique. It is also important to provide support for the next pregnancy as well.

Karen Burgess (Petals) spoke about funding for counselling services. Petals are based in a number of hospitals, four of which provide NHS funding, so this can be achieved despite being 'dammed hard work'. We need to be looking at CCGs for counselling funding, but everywhere budgets are tight. Karen said that Petals have a model and template they can replicate, and are trying to link into the perinatal mental health pathway. She added that the demand for counselling support is incredible; Petals have to turn people away regularly, which is very hard.

Leanne Turner (Aching Arms) said Aching Arms offer direct support to providers, but they cannot deliver the psychological counselling needed for the trauma experienced by many parents.

Carly Williams (Zephyr) observed that from some parents' perspectives, counselling is almost seen as a 'fix'. It is valuable, but it is also important to be able to offer a space to 'express' as well, and a place simply to 'be'.

Kate Mulley (Sands) said access of psychological therapies will be a focus for Baby Loss Awareness Week (BLAW). She said that the BLAW partners are looking for examples of best practice, including how funding might be sought via CCGs in the way that Zephyr has done, so Kate made a request to all present to feed this information in advance of BLAW in October.

Mohamed Omar (Gardens of Peace) said that almost two-thirds of hospice funding comes from charities, so if core funding gets cut, they are vulnerable. Donations are also dwindling. He asked if there was a way to get funding ring-fenced from the NHS or other sources. Antoinette said there is another APPG on Hospices that would be good to be involved in this discussion.

Clea Harmer (Sands) said that part of the problem is people do not get signposted to the right type of support. What is missing is that tool to help both professionals and parents to understand what is available and how to get it. She proposed that we should be working with perinatal mental health services to develop this kind of tool. Sands are looking at this issue, particularly considering the interface between the NBCP and the community.

Antoinette finished the discussion with a request for guests to write to her and to other local MPs with your stories in advance of Baby Loss Awareness Week.

Antoinette thanked the panel for their contributions.

## **6. Update on Baby Loss Awareness Week 2019 (Kate Mulley, Director of Research, Education and Policy, Sands)**

This item was skipped as Kate indicated there were no further updates following the previous meeting.



## **7. Update on parental leave and prematurity (Josie Anderson, Senior Policy and Parliamentary Officer, Bliss)**

Josie Anderson, Senior Policy and Parliamentary Officer at Bliss gave a short update on this issue last discussed at the APPG's December 2018 meeting.

Josie explained that current parental leave laws offer no flexibility when babies are born premature or requiring significant neonatal care. This means that many parents may spend months by an incubator in the hospital, with very little time left of leave when and if the baby is then discharged.

Around 740 parents responded to Bliss' survey on this topic, and Josie shared some of the results. Two-thirds of Dads had to go back to work while their baby was still in hospital, while 1 in 10 partners dropped out of the workforce all together.

At the end of 2018, following input from Bliss, Rachel Reeves MP (Chair of the Business, Energy and Industrial Strategy (BEIS) Select Committee in Parliament) and David Linden MP met with Kelly Tolhurst MP (Minister at BEIS) who agreed to review this issue. Josie reported that we are still waiting on the findings of the review to be released, originally due to be released in January, so the two MPs have chased this by letter recently. No response has been received as yet, but Bliss will keep the Group updated.

**Action: Bliss to update the APPG in due course.**

## **8. Any other business**

Erin McCloskey (Canterbury University) made a request to the Group's guests for links to grassroots groups based in London offering peer support particularly to parents from black, Asian and other BAME parent groups.

**Action: Drew to send on Erin's request to the APPG mailing list**

Antoinette explained that this was Drew Lindon's last meeting providing the secretariat support for the Group on behalf of the APPG, as he is moving on to other projects. Antoinette thanked Drew for all his hard work from the start of the APPG until now, and said his support had been invaluable. Antoinette presented a gift to Drew from the APPG and the charities and partners represented.

**9. Next meeting: 4-6pm, Monday 9<sup>th</sup> September.**