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

Tuesday 30th April 2019
17:00 - 19:00
Commons Committee Room 15, House of Commons

MINUTES

Member attendance:

- Antoinette Sandbach MP

Member apologies:

- Victoria Prentis MP
- Patricia Gibson MP
- Sharon Hodgson MP
- George Howarth MP
- Lord Boswell

Guests:

- Andrew Fellows – Office of Victoria Prentis MP
- Carly Williams – Zephyr's
- Clea Harmer – Sands
- Drew Lindon – Drew Lindon Consulting Ltd. (minutes)
- Erin McCloskey – Canterbury Christ Church University
- Harriet Jordan – University Hospitals of Leicester NHS Trust
- Jane Denton – Multiple Births Foundation
- Jane Plumb – Group B Strep Support
- Jane Scott – Imperial College NHS Trust
- Jenny Ward – Lullaby Trust
- Jessica Faulkner – Office of Sharon Hodgson MP
- Jo Dickens – University of Leicester
- Jonny Tinsley – Office for National Statistics
- Josie Anderson – Bliss
- Kate Mulley – Sands

- Keith Reed – Tamba
- Laura Wetherley –Abbvie
- Marcus Green – APEC
- Michele Upton – NHS Improvement
- Munira Oza – Ectopic Pregnancy Trust
- Paula Abramson – Child Bereavement UK
- Rachel Arkell – BPAS
- Sarah Harris – Child Bereavement UK
- Sophie Alagna – Liberty’s Mother project
- Sophie Dodgeon – Rainbow Trust Children’s Charity

1. Welcome and introductions (Chair of APPG on Baby Loss)

Antoinette opened the meeting and welcomed the guests.

Antoinette reported to the Group that Will Quince MP has now been appointed as a Minister, specifically Parliamentary Under-Secretary for Family Support, Housing and Child Maintenance at the Department of Work and Pensions. While this is great news overall, unfortunately this means that he has had to step down from the Group, both as a member and as the Co-Chair, in order to be able to focus on his new Ministerial responsibilities. Will was a founder member of the APPG. He has worked tirelessly to push for more recognition of baby loss, the needs of bereaved parents and the means to prevent avoidable baby loss. Antoinette said she was sure those in attendance would join her to offering our profound thanks to Will for his passion and hard work for the Group, and wish him all the best in his new position.

Antoinette said that she will continue as Chair for the APPG. Our next meeting on June 17th is the APPG’s Annual General Meeting, where all Officer posts are offered for election.

2. Updates (Antoinette Sandbach MP)

• Apologies from Minister of State Jackie Doyle-Price MP

The Minister was due to present today, but gave her apologies for this meeting, due to schedule constraints. Antoinette said that the Group has extended an invitation to her for our next meeting on June 17th, for her to present on the same subject of the NHS Long Term Plan and baby loss prevention. We will be interested to discuss with her how existing baby loss prevention targets and initiatives will be incorporated and built upon through the new Plan’s implementation.

• Civil Partnerships, Marriages and Deaths (Registration, etc.) Act

Antoinette explained that we have discussed this Act previously at the APPG, when this was a Bill going through the Houses of Parliament. This is now passed both Houses so is now law. Among covering provisions around marriages and civil partnerships, the most relevant parts of the Act to this Group include:

1. A direction for the Secretary of State for Health and Social Care to make arrangements for the preparation of a report on whether, and if so how, the law ought to be changed to require or permit the registration of pregnancy losses. This report is currently being prepared through the Pregnancy Loss Review being undertaken by the Department of Health and Social Care. We have heard updates from the Review Co-Leads at previous meetings. As far as we are aware, the report is being drafted but we did not have a deadline for publication.
2. A direction for the Secretary of State for Health and Social Care to make arrangements for the preparation of a report on whether, and if so how, the law ought to be changed to enable or require coroners to investigate still-births.

This direction is being enacted, and currently the Ministry of Justice and Department for Health and Social Care are jointly holding a public consultation which is open now, and close on 18th June 2019. This consultation offers proposals to give coroners the power to investigate all full-term stillbirths, with the aim of helping provide parents with vital information on what went wrong and why, while ensuring any mistakes are identified to prevent future deaths.

We will be discussing this consultation later in this meeting.

• Neonatal Transformation Review

At our last meeting (10th Dec 2018), Professor Neil Marlow, Chair NHS England Specialised Commissioning Neonatal Critical Care Clinical Reference Group spoke about the Neonatal Transformation Review he was leading. Neil was unable to join the meeting this time around to give an update, but he has let the Group know that all the Neonatal Transformation Review recommendations are in the NHS Long Term Plan, which is really good news. A document to drive implementation is near completion and an official group to supervise implementation will meet in June.

3. Avoiding Term Admissions to Neonatal Units (Michele Upton, Head of Maternity and Neonatal Transformation programmes at NHS Improvement).

Antoinette welcomed Michele Upton, Head of Maternity and Neonatal Transformation programmes at NHS Improvement. Michele presented on the ATAIN (Avoiding Term Admissions Into Neonatal units) programme. Presentation slides will be shared with these minutes via email and then on the APPG webpage.

Michele began with thanks to everyone who has contributed to this programme over its operation. She explained that few fully grown babies should need neonatal services; however before the programme began rates of admission were rising exponentially. While the aim has been harm prevention rather than cost reduction, the programme has shown the potential for cost reduction benefits by reducing unnecessary intervention.

Michele said that we are all here today because we all believe in preventing loss. When a baby is admitted to a neonatal unit, they are separated from their mother. This can lead to long-term emotional harm both to the baby and mother though difficulties in bonding, as well as impact on the physiological stability of the baby. As such, we should be doing everything we can to keep mother and baby together where safe to do so.

Michele said the programme needed an evidence base to begin, so used a range of data sources including over 10,000 patient safety incident reports and an analysis of primary RfA using the NNRD.

A range of programme priorities were identified including improved and wider training of professionals and greater involvement of parents. The programme had an obstetric chair and a neonatal chair for the four working groups, to role-model effective working relationships across maternity and neonatal services and ensure expertise from the different professional groups.

Through the programme's analysis, for over 136,000 births over 3 years, around 8% of all live births resulted in a neonatal unit (NNU) admission. 20-30% of admissions were potentially avoidable; i.e. the intervention they received did not warrant them being separated from their mothers. This percentage translates into around 13,000 babies per annum. This finding prompted the recognition that there was a role for transitional care facilities that keep mother and baby together.

The programme created a resource pack for professionals, drew on and engaged in a range of national initiatives to disseminate and implement this learning, e.g. the 2016 Safer Maternity Care Action Plan, the 2017 NHS England Improving Value Scheme, among others. They also developed an e-learning programme. One of the main drivers for this programme has been the Clinical Negligence Incentive Scheme Years 1 and 2, aimed at driving improvements in safety in maternity services.

Michele reported that the programme is now seeing a reduction in term admissions, which they hope to see more of next year as resources begin to be implemented more widely.

Best practice is about getting it right first time around prevention, particularly with intrapartum care and babies who might be at risk of hypoxic brain injury. There are now a range of exciting and effective initiatives in place which are, or should be, leading to improvements and a reduction in avoidable term admissions to neonatal units.

ATAIN is now a national programme. We need to keep addressing this issue until it becomes unthinkable to admit babies who do not need to be separated from their mothers at birth.

Antoinette thanked Michele, and lauded the programme. Antoinette opened the floor up to questions.

Jane Scott (Imperial College) asked what kind of training to midwives receive for transitional care. Michelle said the elearning includes this topic, though training is locally determined and will differ from unit to unit. ATAIN has been influencing pre-registration training.

Jo Dickens (University of Leicester) asked what the mechanisms for monitoring outcomes are. Michele answered that monitoring outcomes should be done on a local level, but there is an opportunity to measure this via national data.

Jane Scott (Imperial College) raised that midwives do not receive any additional training before going onto the neonatal unit. She said that it should be mandatory to have at least a 6-week training module to ensure midwives are adequately supported. Michele said

there does seem to be quite a lot of local variation in training, and that she would be happy to pick up this discussion with Jane after the meeting. She said that the programme has made sure that in the CNST scheme that the models of care do include midwives.

Clea Harmer (Sands) thanked Michele. She said that on top of the results of the programme, Michele's presentation showed a really powerful model of introducing a programme, linking to other initiatives and frameworks, as well as engaging different sectors. Writing this up as a model of introducing a programme and delivering change would be very useful.

Antoinette thanked Michele again for her presentation. She said that would be very interesting to follow up on the outcomes on the programme at a later meeting.

4. Ministry of Justice consultation on investigation of stillbirths (general discussion – Antoinette to give APPG context, Kate Mulley from Sands to give overview of consultation)

Antoinette introduced this item by saying that the APPG is interested in submitting a response to this consultation, and so wanted to take the opportunity today to seek views from the guests. With support from Drew, the APPG will pull together its response in time for the 18th June deadline.

Antoinette then invited Kate Mulley (Sands) to give a brief overview of what the consultation covers, which is summarised below.

Kate thanked Antoinette, and gave an overview of the consultation. At present, coroners can only hold inquests for babies who have shown signs of life after being born. They cannot investigate where the pregnancy appeared healthy but the baby was stillborn. The consultation webpage reads:

“The joint consultation from the Ministry of Justice and the Department for Health and Social Care seeks a wide range of views, from bereaved parents, the organisations that support them or that provide advice to pregnant women, researchers, health professionals and healthcare providers, as well as those working for coronial services.

Under the system being proposed by the consultation:

- “Coroners will have powers to investigate all full-term stillbirths occurring from 37 weeks pregnancy
- The coroner will consider whether any lessons can be learned which could prevent future stillbirths
- Coroners will not have to gain consent or permission from any third party in exercising this power
- Coronial investigations will not replace current investigations undertaken by the hospital or NHS agencies”

The new system is proposed to help provide an independent assessment of stillbirth, improve parental involvement in the process, and contribute to system-wide learning. More information is available here: <https://www.gov.uk/government/news/new-powers-to-investigate-stillbirths> (a short version of the consultation is available here:

<https://consult.justice.gov.uk/digital-communications/coronial-investigations-of-stillbirths-short/>

Kate gave an overview of Sands' current position on the consultation. Sands sent a survey to parents in 2017, with over 500 responses received after only a few days. Kate emphasised that this does not offer a representative sample of all parents, just parents who responded to Sands' survey. 72% of respondents had had a stillbirth and 10% had had a neonatal death. A majority of those who responded to Sands' consultation (95%) felt that coronial involvement in stillbirths was a good idea overall. However, this view was heavily caveated, in particular by the view that coronial involvement should not reduce parental control or consent. As a result, if these changes are implemented, the question of how they are introduced becomes vitally important given the range in parental views.

Kate said that Sands had several points they will be raising via their consultation response. These included:

- Concerns about the impact of this process on bereavement care – will parents still have sufficient time with their babies?
- Unease about setting arbitrary cut-off periods, and inadvertently excluding certain parents from the process
- Concern about lack of capacity and expertise in the coronial system, and potential for long waiting times for investigations or post-mortem results
- A need to integrate with other processes – given the investment that has been made in improvements to review and investigation processes (such as the Perinatal Mortality Review Tool, or PMRT), it would be a problem if this change undermined these processes, or delayed parents' seeing results from hospital reviews for example, as a result of waiting for the coronial investigation to finish
- We still do not know why many babies die. Sadly even with coronial investigation, it may not still be clear what the cause of death may be, and this may lead to unintended consequences such as blaming or dashed hopes for parents if investigations are not sensitively managed from the start
- Sands welcomes the aim to learn and drive improvements, but it is not clear that the data will be collected on a national level to enable vital learning

Antoinette thanked Kate for her summary and Sands' position, and opened the discussion up to the floor.

Jenny Ward (Lullaby Trust) said that the Lullaby Trust does not work on stillbirths, but with SIDS cases which are all coronial cases. Jenny said SIDS deaths have a coronial process and child death review process. The coronial system is very legalistic, and does not always serve parents very well. There are implications of blame and lack of support.

Jenny went on to say that post-mortems are a key part of the coronial investigation. It has been very difficult for families to challenge or engage with some coroners on this issue. The Lullaby Trust has been engaged in a range of research in non-invasive post-mortems as an alternative, and families are very supportive of the opportunity to do non-invasive post-mortems. We could look at this as an option to offer.

Jenny said that the coronial system is quite overloaded. SIDS by definition do not have a known cause at the start, so tend to be the longer version of investigation – typical length is a year. While stillbirth investigations may not take that long, it is important to consider

how long these will take and the resources that will take. That said, having more investigations of stillbirths is a good thing overall.

Antoinette asked about the interaction between coronial investigation and bereavement care. She said that she was given the opportunity to make memories and see her son, and the investigation was completed very quickly, but she did not get the post-mortem results for about 6 months. Jenny answered that this is a common experience, and can be extremely difficult for families.

Antoinette suggested that it might be an idea that there should be some standards around keeping families informed, and realistic timescales for the family to be informed of the outcome. Jenny agreed.

Jane Scott (Imperial College) said that she and her colleagues had just run their regular bereavement midwife forum. Jane explained that the midwives involve all struggle with contacting coroners (often won't answer emails, or answer the phone even to them as health professionals), and are often frustrated with the length of the process. All coroners work independently, so there is no standard practice as far as she is aware.

Jane added that Perinatal Mortality Review Tool is really good, and there are external reviewers who look at every single case. This process can feel more thorough than a coronial investigation.

Antoinette asked whether an investigation should take place only at the request of the medical team and/or the parents. Jane responded that the parents can come along to the investigation at a Perinatal Mortality review. Antoinette asked how often parents do attend, particularly in cases where they may have concerns about the medical care provided. Jane said she understood that the process can feel intimidating for parents. Jane and her colleagues have offered at times to have meetings in different venues to the hospital, and that parents can bring along someone else for legal or emotional support, but this remains a challenge.

Paula Abramson (Child Bereavement UK) said that the coroner's offices would really benefit from specialist training. The Perinatal Mortality Review Tool (PMRT) is now mandatory.

Antoinette asked if any of the 3rd sector organisations present had already put in their own response. None had done at present. Antoinette encouraged the organisations, professionals and parents to put their responses in. Clea Harmer (Sands) seconded this idea. Clea added that while the consultation document is quite complex and lengthy, people should feel free to only respond to the parts they wish or feel able to answer.

Karen Todd (Department of Health) said that in addition to the consultation document, there are four consultation events coming up in mid-May.

Action: Karen to send these events details to Drew, who will circulate these to the guests.

Sophie Alagna said that as a parent, she would not find the consultation intimidating to fill in, but might find it quite impenetrable. Her overall view is that it is really important that there is equality within the law; what happens for children who died just after birth compared to others.

Carly Williams (Zephyr) said that she had had a post-mortem for her son, which did not find any results. This was presented by staff who did not seem to understand it, and the sense of guilt she felt was a challenge for her. Carly explained that at Zephyr's centre, there is a weekly drop-in with parents, and they all share a desire that they do not want this to happen again for other people. Having a sense of control if your baby has died may conflict with the mandatory approach proposed in the consultation.

Rachel Arkell (BPAS) said that BPAS been looking into the Northern Ireland experience, as they have similar laws to what is being presented. BPAS' impression is that it has not been a positive experience; police questioning bereaved parents in hospitals for example. Rachel pointed out that clearly this is within a different context with Northern Ireland's abortion laws, but it is worthwhile bearing in mind for any changes proposed for England.

Clea Harmer (Sands) said she agreed with Rachel. One of the issues with 'Axel's Law' in Northern Ireland was that the coronial system is hugely over-capacity, and it appears that the law this was implemented without thought for the consequences on the system.

Antoinette said that one option may be to suggest a pilot or series of pilots to see what the best approach would be, to learn what would be the best approach and improvement. She thanked all those present for their contributions.

Drew added that all guests should feel welcome to send any thoughts or consultation responses to him, in order to feed into the APPG's response.

Action: All to send on views on the consultation. Drew to draft consultation response on behalf of the APPG, for sign-off by the MP members.

5. Update on Baby Loss Awareness Week 2019 (Sands)

Kate Mulley (Sands) provided an update of how planning is progressing for Baby Loss Awareness Week 2019.

Kate said that Baby Loss Awareness Week (BLAW) is in its 17th year. It represents a collaboration between over 60 charities and thousands of families and takes place between 9th – 15th October each year.

This year, the Baby Loss Awareness Week coalition will be setting up a large number of commemorative events (aiming to increase on the events from last year) as well as promoting the annual 'Wave of Light'. Last year, the coalition doubled the number of buildings lit up 'pink and blue' compared with 2017, she is delighted that the APPG will be writing out again to public and private buildings this year.

Kate said that the group have just been through the process of determining the policy focus for the Week. Kate announced that the members has voted to focus on access to psychological therapies and appropriate mental health services for parents who have experienced pregnancy and baby loss. There is a key gap in that support within the UK, so a subgroup will be meeting very soon to look at how this goal can be turned into a positive vision for BLAW, building on what there is already.

The group have also been discussing plans for events in Westminster, and in the devolved legislations, in conversation with the APPG.

Looking back at last year, Kate added that we are about to see the evaluation of the Wave 2 pilot sites of the National Bereavement Care Pathway. This evaluation will be published next week along with a range of resources to help continue to spur development.

Jane Scott (Imperial College) added that Imperial now has Petals, the counselling service, included in their maternity budget. This counselling is provided to parents who have had very traumatic deliveries, so better support for parents around mental health is already happening in some areas.

Antoinette thanked Jane, and said it would be useful to feed into the BLAW group examples of where that support has been put in place, particularly in advance of the BLAW debate and BLAW as a whole.

Action: Guests to pass examples of good mental health practice around baby loss to the BLAW group members via Sands.

6. Liberty's Mother project (Sophie Alagna)

Sophie Alagna gave an overview of the Liberty's Mother project, due to be launched during Baby Loss Awareness Week 2019. Sophie performed her song 'I Can Love You From Here' at the Westminster Remembrance Service in October last year which she wrote for her daughter Liberty who was stillborn in January 2011. She was overwhelmed with the reaction she received. Sophie explained that she writes songs and teaches songwriting.

Sophie wrote the song for Liberty around 11-12 weeks after Liberty passed away. She has recorded the song, which she plans to release in October for BLAW as a one off artist project under the name 'Liberty's Mother' along with a four track EP to support it, recorded recently in Nashville. This would be entirely not-for-profit to raise funds and awareness for BLAW. They are also looking into some merchandising opportunities including printed lyrics to sell. Sophie said she will share this with anyone interested to ensure that it can be used and changed.

Sophie Alagna played the recording of her song to the APPG.

Following the song, Sophie explained she wanted to contribute to the idea of breaking the silence, following on last year's BLAW. She knows a number of other songwriters who have experienced baby loss. She is planning to recreate the 2018 'Break The Silence' video (which featured politicians talking about baby loss) by interviewing 15-20 notable people from the world of music who have experience of baby loss).

The EP will be released at some point either during or just before Baby Loss Awareness Week. Sophie will do gigs to promote this EP, and will play and attend as many of the memorial events as possible.

Antoinette thanked Sophie for updating the Group, and encouraged everyone to keep an eye out for the release.

Action: Sophie to send Drew details of the song/links when ready, and Drew to disseminate to the Group.

7. Any other business

- Antoinette explained that she has been contacted by a police officer from Avon and Somerset Police, who talked about a family who lost their unborn daughter Grace as a result of a road accident. However, while the police officer wished to charge the other driver with death by dangerous driving, the law does not allow a charge when a post-24 week old child in-vitro is killed in-utero through driving. The local MP has already been in touch with the relevant Justice Minister.

The police officer has asked the APPG to support a change in the law to enable this, and Antoinette sought perspectives from the attendees.

Harriet Jordan (University Hospitals of Leicester NHS Trust) said that as in her role as a bereavement midwife, she had a very similar situation with a patient. The police officer she spoke with felt that there should be a change in the law, and Harriet supports that view.

Kate Mulley (Sands) said that her organisation agrees that the law needs to be looked at as the Road traffic Act appears to be inconsistent with other parts of the criminal law.

Jane Scott (Imperial College NHS Trust) said that there could be many far-reaching implications of changing the law. She asked whether the change proposed would change the rights of unborn children. Kate (Sands) said that other relevant laws relating to a 'destruction of the child' are carefully worded to ensure that this does not conflict with existing law around terminations.

Antoinette said she will speak with the other officers on the group to consider the APPG's position.

- Marcus Green (Action on Pre-Eclampsia) said that there will be a 9th May debate in Parliament on pre-eclampsia, shortly before World Pre-Eclampsia Day on 22nd May.

8. Next meeting: 4-6pm, Monday 17th June. This will be the AGM.