



House of Commons
London SW1A 0AA

AGM of All-Party Parliamentary Group on Baby Loss

16:00 – 18:00, Monday 11th June 2018
Wilson Room, Portcullis House

MINUTES

Attendance:

MPs and Peers

Antoinette Sandbach MP (Co-Chair) (joined later in the meeting)
George Howarth MP
Huw Merriman MP
Jackie Doyle-Price MP (Parliamentary Under-Secretary of State for Health & Social Care)
Jim Shannon MP (joined later in the meeting)
Lord Boswell MP
Sharon Hodgson MP
Victoria Prentis MP
Will Quince (Co-Chair) MP

Apologies were received from Patricia Gibson MP.

External guests

Aimee Middlemiss – University of Exeter
Alex Mancini – Pan London Neonatal
Alison Ismail - DHSC
Andrew Fellow – Office of Victoria Prentis MP
Carrie Heitmeyer – Department of Health and Social Care
Catharine Wozniak – Office of Victoria Prentis MP
Claire Dunn – Royal College of Obstetricians and Gynaecologists
Clea Harmer – Sands
David Monteith – Grace in Action
Gillian Weaver – Hearts Milk Bank
Helen Kirrane – Bliss
Professor Jacqueline Dunkley-Bent OBE - NHS England
Jane Denton – Multiple Births Foundation
Kate Mulley - Sands
Kayleigh Blackstock – The Lily Mae Foundation
Kelley Ireland – Royal College of Obstetricians and Gynaecologists

Leanne Turner – Aching Arms
Nicola Crawley – St Thomas Hospital
Paul Abramson – Child Bereavement UK
Penny Kerry – The Miscarriage Association
Rabiya Nasir – Office for National Statistics
Ruth Bender Atik – The Miscarriage Association
Sam Collinge - University Hospital Coventry
Sam Richards – The Lily Mae Foundation
Sian Goss – Department of Health and Social Care
Zoe Clark-Coates - Mariposa Trust

Other guests were in attendance, but did not receive/sign the attendance sheet.

1. AGM

- Election of officers

Will Quince introduced the AGM, and explained there are two standard items of business for the AGM:

- Elect at least four officers
- Approval of income and expenditure statement

Officers needed to be elected by a quorum of parliamentarians (five Members in attendance including at least one MP). In attendance at this point were:

- Lord Boswell
- Sharon Hodgson MP
- George Howarth MP
- Tim Loughton MP
- Huw Merriman MP (left after AGM)
- Victoria Prentis MP
- Will Quince MP

The current officer holders were:

Co-Chairs: Will Quince MP and Antoinette Sandbach MP

Vice-Chairs: Patricia Gibson MP, Sharon Hodgson MP, and Victoria Prentis MP

All Officers had expressed their wish to stand again in their current roles. The parliamentarians voted to approve the Officers for another year.

- Approval of income and expenditure statement

Will explained that all APPGs which receive more than £12,500 in money or in kind from outside Parliament in its reporting year need to prepare, approve and submit an income and expenditure statement. This has been shared with the Group's officers.

Will reported that the Group has not received income nor spent any money directly. However, the Group has received over £12,500 in benefits in kind through the support

provided by the Lullaby Trust, for a total of £16,500 – £18,000 (reporting is required to fit within a set of pre-determined bands).

The statement was signed off by the parliamentarian members.

2. Welcome and introductions (Co-Chairs)

The AGM concluded, Will formally opened the APPG meeting and welcomed the guests.

3. Legislation update

- Fetal Dopplers (Regulation) Bill

Will gave an update on this Bill submitted by Antoinette Sandbach MP, which would regulate the sale and use of fetal dopplers. This is currently scheduled for a 2nd Reading in the Commons on 15th June, but has already led to a review by the Department of Health & Social Care into fetal dopplers currently available for consumer purchase in the UK, with a specific focus on the contents of instructions for use. As a result, Will said that this has it has largely already done its job. As with most 10-minute rule bills, it is difficult for this to become law.

- Parental Bereavement (Leave and Pay) Bill

Will updated on this Bill, sponsored by Kevin Hollinrake MP, which aims to make provision for at least two weeks paid leave for employees who have a child who has died. This Bill has been passed by the House of Commons, and due for Second Reading in the Lords on a date to be confirmed. Lord Boswell is taking this forward in the Lords.

<The Parliamentary Under-Secretary for Health and Social Care Jackie Doyle-Price MP arrived at this point>

- Civil Partnerships, Marriages and Deaths (Registration Etc.) Bill
 - o Coronial investigations
 - o Registration of pre-24 week loss

Will outlined that this Bill was discussed at the last meeting, chiefly around the coronial investigations element. Among other issues, the relevance of this Bill to the APPG is that it proposes changes to allow the registration of stillborn deaths pre-24 weeks gestation, as well as giving coroners the power to investigate stillborn deaths. This Bill has gone through the 2nd Reading in the Commons, and we await a date for the Committee Stage (*postscript: the Committee Stage took place on 18th July, and the Report and 3rd Reading Stages are scheduled for 26th October 2018*).

At the moment, parents whose babies are stillbirth after 24 weeks gestation can receive a certificate of registration of stillbirth, as well as register their baby's name. If a pregnancy ends before 24 weeks gestation, there is no formal process for parents to legally register the loss.

Will invited the Bill's sponsor, Tim Loughton MP, to speak.

Tim explained that this is a Private Members Bill, and there can only be one private members bills in Committee at one time. There are four in the queue ahead of this Bill. Tim and Sharon Hodgson MP are also part of the Pregnancy Loss Review (next item) both, but at this point had not yet been able to attend one of the meetings.

Tim said that it was the wish of the Secretary of State for Health and Social Care that we change the law that pre-24 week stillbirths. There is a degree of opposition on the Committee about how we do that, with discussions on going. Tim added that it would be likely that his Bill will receive amended to add details as time go on.

The Minister Jackie Doyle-Price MP responded that it was the government's intention to move forward with this Bill, and it was the Secretary's aim to make this law. She added that the Pregnancy Loss Review's remit is much wider than just looking at registration, so it would be useful to consider how the Review and its leads engage with Tim and his Bill going forward.

4. Department of Health & Social Care Pregnancy Loss Review

(introduction by Jackie Doyle-Price MP, Parliamentary Under-Secretary of State for Health and Social Care; presentation by Co-leads for Review: Sam Collinge, Midwife and Maternity Bereavement Service Manager at University Hospital Coventry, and Zoe Clark-Coates, Co-Founder, Mariposa Trust)

Will explained that the Department of Health and Social Care has announced a review on registration of pre-24 week loss, which will produce a report 'Pregnancy Loss - Care and Support when Baby Loss Occurs Before 24 Weeks Gestation'. The review will be co-led by the co-leads of the review, Sam Collinge and Zoe Clark-Coates.

Will welcomed the speakers, and invited the Minister to say a few words.

The Minister said that it is always a pleasure to work with this group, and that in its short lifetime, it has achieved so much. She explained that in the spirit of this continued joint work, the Department has commissioned this Review, which is intended to be absolutely patient-centred.

Sam Collinge and Zoe Clarke-Coates then offered a presentation on the Review. Slides will be made available on the APPG webpage when minutes approved, but key points from the first two slides are reproduced below for information

Background

Registering babies born without signs of life before 24 weeks gestation

- *The Births and Deaths Registration Act 1953, as amended, provides for the registration of babies born dead after 24 weeks' gestation, which is the legal age of viability. Parents of babies who are stillborn after 24 weeks gestation receive a medical certificate certifying the stillbirth and, upon registration, can register the baby's name and receive a certificate of registration of stillbirth.*
- *Parliament supported a change to the stillbirth definition from "after 28 weeks" to "after 24 weeks" in 1992, following a clear consensus from the medical profession at that*

time that the age at which a foetus should be considered viable should be changed from 28 to 24 weeks. Medical opinion does not currently support reducing the age of viability below 24 weeks of gestation.

- *The Department of Health and Social Care is aware that some parents find it very distressing that they may not register the birth of a baby born before 24 weeks. However, it is important to recognise there may also be parents distressed at the possibility of having to do so. When a baby is born dead before 24 weeks gestation, hospitals may issue a local certificate to commemorate the baby's birth.*
- *On 2 February 2018, Health and Social Care Secretary of State Jeremy Hunt announced the Government's intention to conduct a review of whether the law should be changed to allow registration of late miscarriage, and more broadly on what might be done to improve the care and support for parents who experience pregnancy loss before 24 weeks gestation.*

The Terms of Reference state the Pregnancy Loss Review will consider:

- a) The impact on families of the current threshold of 24 weeks gestation for formally registering a late miscarriage.*
- b) Whether it would, on balance, be beneficial to amend existing primary legislation to allow parents to register a late miscarriage.*
- c) Options to improve NHS gynaecology and maternity care practice for parents who experience a miscarriage and other causes of baby loss.*

Abortion Law: *The review will not consider any changes to abortion law.*

Devolution: *While health is devolved, registration systems apply to both England and Wales and the Review will need to be mindful of any impact on Wales as well as, more broadly, cross-border issues (for example, when a woman from Wales delivers or experiences a pregnancy loss in England and vv.)*

Sam said that the Review is also looking at terminology as well, as well as options to improve gynaecological and maternal care for all women who experience pre 24-week loss. The Review Group is also mindful of the work of the National Bereavement Care Pathway.

Sam outlined the 6-month timeline for the Review. They are at the halfway point now. She explained that Zoe and herself have been given one day per week from their own work. The draft report will be submitted to Ministers in about 6 weeks, with the final document about the beginning of October, coinciding in with the start of Baby Loss Awareness Week. However, Sam added that there is so much more to cover than was initially thought, so it is a challenging timeline and may be worth extending.

Sam said that the co-leads and Departmental team have been meeting with and listening to parents; understanding how parents feel is really at the heart of what the Review is doing. They are also looking at practice in other countries, and currently working on a survey for bereavement midwives to inform the review.

Will thanked Sam, and lauded the work that is taking place. He invited questions from the floor.

Faith groups

Mohamed Omar asked whether the Review had consulted with cemeteries about what requirements there are for burial, and whether there was any representation from a faith. Perspective on the Advisory Panel.

Sam responded that the Review is looking at in regards to registrations is more about parents being able to obtain a certificate to recognise their child. If this went ahead, this would likely be voluntary, and possibly back-dated. It is possible that it would also be optional to provide evidence of whether there was a pregnancy. Zoe added the panel is made up of health experts from their field, not specifically around faith.

The Minister added that she appreciated the point made about faith groups, and that the Review needs to look at how to engage with faith groups. Sam said that this was an open process, and that she would like to meet after the meeting with Mohamed to discuss further.

Funerals

Will said that lots of companies offer free funerals for stillbirths, but not for miscarriages. He asked whether the Review was considering this disparity?

Zoe responded that the Review is looking at this issue, and some hospitals and companies do offer funerals for miscarriages.

Voluntary process and evidence requirements

Lord Boswell asked for clarification that any registration process would be voluntary and evidence requirements would also be flexible/voluntary. He gave the example that if a loss took place 18 years ago, there would likely be less evidence available. He said that it would be very emotionally difficult for a parent to be rejected on the lack of evidence.

Zoe answered that having a voluntary registration process is one of the options being considered. On the certificate it may be the case that there is an option for evidence or not.

Will said that registrars charge £4 for registration. He asked if there would be a charge for pre-24 weeks registration. Zoe answered that the Review has not looked at this point.

Victoria Prentis MP asked if the Review was going to look at maternity leave issues? Zoe said that the Review is looking at those issues.

Sharon Hodgson MP asked if medical terminology would be looked at by the review, as the term miscarriage particularly for close to pre-24 weeks can be very hard to hear.

Sam answered that the co-leads are very keen to look at terminology to make sure it is more sensitive, e.g. "evaluation of retained products" can be very distressing to hear.

Zoe added that a key challenge for the Review was the time limit for the project. She said that both she and Sam felt that this could be a 2-3 year piece of work. Their hope is that the timeline for the Review can be extended.

Kate Mulley added that she wanted to commend the co-leads for how they have constructed the Review in a kind, sensitive, and generous way for parents.

5. Meeting the ambition: halving stillbirths and neonatal deaths by 2025 (introduction by Jackie Doyle-Price MP, Health Minister; Professor Jacqueline Dunkley-Bent OBE, Head of Maternity, Children and Young People, NHS England; and Alison Ismail, Deputy Director for Resolution, Patient Experience and Maternity, DHSC)

Will welcomed the speakers, and said that the APPG had been to see the Government make the commitment to halve stillbirths and neonatal deaths by 2025. He explained that last year, the APPG welcomed presentations from Ministers and senior civil servants on the Maternity Transformation Programme, the Neonatal Review for England, and on the wider Maternity Safety Strategy. He said that the group was looking forward to hearing some more of the detail of how NHS England and the Department for Health and Social Care are currently working to achieve these goals, and how the APPG and their partners can help sustain momentum on this work. Will invited the speakers to introduce themselves.

Alison Ismail explained that she is the Deputy Director for Resolution, Patient Experience and Maternity in the Department of Health and Social Care.

Professor Jacqueline Dunkley-Bent OBE said that she is currently Head of Maternity, Children and Young People at NHS England, essentially national maternity safety champion working in close partnership with Matthew Jolly as national clinical lead.

The Minister added that the Secretary of State is very passionate about this agenda. She said that the Government are on course to meet the targets set, but that is not a reason to rest on our laurels.

Alison began her presentation (*slides available on the APPG webpage when minutes approved*). She said that the Secretary wants to make sure we leave no stone unturned on preventing baby loss tragedies, learn from any times when this is unavoidable, and offer as much care and support to families affected by loss.

The Maternity Safety Strategy, refreshed in November 2017, works across the whole health system to support women, their babies, families and the services that care for them throughout their lives to achieve the best health outcomes and to realise the national ambition to halve the rates of stillbirths, neonatal and maternal deaths and brain injuries that occur during or soon after birth by 2025 (updated from a prior 2030 target).

The key issues are to make sure that we have high-quality, independent investigation when things do go wrong, make sure staff have the resources to do as much as possible to help support families, and that better data surveillance is offered.

Jacqueline took over the presentation at this point. She explained that there are 134 Maternity providers in England which we must engage. There is also a big push around cultural change as well, to make sure that patients and staff in clinical settings are not just seen as 'numbers'.

She outlined that the Maternity Transformation Programme aims to 'join the dots' between all the key bodies - NHS England, NHS Improvement, Royal Colleges and so on - to effect change within all their programmes and areas of expertise.

Jacqueline explained that this is a pragmatic programme. We are trying nationally to achieve continuity of care for every woman involved in maternity; the evidence says that if you have someone known to you throughout the process, you are 24% less likely to have a pre-term birth. The single, most modifiable risk factor in premature births and miscarriages is smoking. Women are also more likely to disclose domestic violence and other issues to someone they know and are comfortable with.

Jacqueline laid out that there is national challenge on consistency of incident reporting and investigations. We need to do more to engage with women and their families when incidents occur. One stream is the Perinatal Review Tool, developed by MMBRACE, for which we have 100% sign-up for use of this tool by providers. This will help to enable and empower clinicians to undertake appropriate, high-quality investigations, so that the root causes are investigated and we have rapid learning across England.

Will thanked Jacqueline and Alison, and invited questions from the audience.

Harm reduction

Lord Boswell said that the programme and strategy were splendid ideas. He said that it was very important that harm reduction is included into the support for people.

Continuity of Care

Mohamed Omar asked how the programme aims to ensure continuity of care with the challenge of high turnover of staff. He also asked whether the team are working with coroners to investigate stillbirths as well.

Jacqueline responded that there is much discussion about the number of midwives we have to provide maternity care. She said the Secretary has made a commitment to increase midwifery numbers by 3,000, which will take time to come through. Some of the challenges are also about prioritization. Jacqueline is travelling round the country to talk to organisations who face the challenges, so we can provide the highest intervention in areas of high multiple deprivation. She added that the team was not working with coroners directly, but are working closely with the Health Safety Investigation Branch to improve practice in this area.

Neonatal inclusion

Helen Kirrane asked if the Neonatal Critical Care Review is included in the Programme. She explained that a lot of Bliss' work is with the neonatal work force, and they are feeding into that Review. Bliss feels there is a looming workforce crisis in neonatal services, so it is important to address this challenge.

Alison said that the Neonatal Care Review does feed into this programme, and that they be publishing their report in the Autumn. It is clear from what has been shared from the Review so far is that there is the shortage of neonatal nurses and others. She added that the NHS has a moral imperative to 'grow our own' staff teams rather than potentially relying on recruitment from overseas.

Continuity and clinical negligence

Alex Mancini reiterated the need for continuity in neonatal work as well as midwifery. She said it is vital to ensure these teams work together better and share information.

Jacqueline agreed. Part of the Programme aims to integrate maternity into neonatal care. In addition, she explained that the Clinical Negligence Scheme for Trusts (CNST), an incentive scheme can help to encourage improvements. This scheme offers an insurance premium rebate to well-performing providers, based on meeting 10 criteria.

Alison said that her department also has responsibility for clinical negligence in the NHS and work on birth injuries. CNST is a pot which Trusts pay into for protection/payment to resolve some cases of clinical negligence. The Early Notification Scheme helps to identify when injuries are sustained. Injuries are notified within 30 days from the incident, which helps build up a pattern of data so we can understand how better to predict and reduce these tragedies.

Reporting

Victoria Prentis asked the speakers what happens to a Trust when they fail to report. Alison said that reporting isn't perfect, and Trusts are still getting their heads around the requirement. There is another issue about streamlining reporting too, so there is a long way to go on improving this process. However, working within the criteria set by the CNST is a condition of cover. We are at the beginning of exploring how far you could go with that criteria to push for compliance. The Minister added that the team would reflect on this point.

Coordination of multiple workstreams

Clea Harmer said that Sands is passionate about these workstreams, and are involved in many of them. She described that there was a large number of Reviews that have been mentioned as well as related work going on, and questioned whether there was potential overlap.

Jacqueline said she absolutely understood. She said that the ongoing reviews will need to continue for now, but she is working very closely to try to streamline reporting and integration of these Reviews; use of infographics has helped.

Will handed back over to the Minister for a few final words. The Minister said that as the group could see, the Government has some great help and skilled people working on this agenda. She committed to keeping the APPG updated.

Will thanked all the speakers.

6. Maternity leave for premature births (Sharon Hodgson MP)

Sharon raised the current situation on maternity leave for parents with premature births, in light of the recent debate on the Parental Bereavement Leave Bill. She said that discussion of this issue would fit within the APPG on Maternity's remit too, but explained she wanted to check with the 'collective wisdom in the room'. She explained that she had received an enquiry from a constituent who had started maternity leave but whose baby was born premature and will need additional care. As such, the maternity leave provided is unlikely to be sufficient. This issue is likely to affect many parents.

Helen explained that Bliss had produced a report previously entitled 'Not a Game', which argued that mothers of premature babies should have more maternity leave. There has also been a charity campaign in London called the 'The Smallest Things', advocating for one extra week's leave for every week a baby is in neonatal care.

Sharon said that she will raise this issue with the APPG on Maternity, and see if we can address this shortfall, drawing from a previous Bill which did not pass a few years ago. Victoria suggested this group could have a joint session with the APPG on Maternity to consider a joint approach.

It was raised that Waltham Forest Council has a provision for all its staff in case of premature births.

Lord Boswell said that the Group could put out a call for evidence. Will added that Ben Gummer (a former MP) did a lot of work on this topic, so he will pick this up with Ben separately.

The Minister said that it would be very good to highlight good practice, and show to employers how to be sensitive and flexible in order to drive up standards. She cited Stonewall's best practice 'stamp' for good LGBT business policies, which she said has been so successful that employers actively apply to receive it.

Helen said that Bliss would very much welcome APPG's support on this issue. There may also be an opportunity with the Department for Business, Energy and Industrial Strategy (BEIS) report on shared parental leave coming later this year to put a spotlight on the needs of parents with babies in long-term neonatal care.

Kate (Sands) and Leanne (Aching Arms) agreed this would be a valuable issue for the APPG to consider. Kate suggested that if we could have a joint meeting with APPG with Maternity, we could look at the aspects that employers could do well, and establish what 'good looks like'.

Lord Boswell expressed his support, but cautioned that we have to be careful with what approach we take with small and medium-sized businesses (SME).

Action: Develop joint meeting with APPG on Maternity on this issue for the future, plus potential Ask for Evidence, prior to looking at legislative options/campaign. Will to contact Ben Gummer re: his previous work on this issue.

7. Any other business

Victoria Prentis MP emphasised that Baby Loss Awareness Week is coming up, and that she will need to book things soon if needed. Will agreed, and explained that he, Antoinette, Drew and Sands had a planning meeting last week.

8. Next meeting: 10th September, 16:00 – 18:00

Will said that it been raised that the 10th and 11th September are Rosh Hashanah, the Jewish New Year. As such, we will look at rearranging the meeting for later in that same week. (*postscript: meeting date was rearranged to 12th September, 16:30 – 18:30*).