



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

Tuesday 8th November, 10.00am – 12.00pm, W2 Westminster Hall & Online

MINUTES

Members and representatives in attendance:

- Cherilyn Mackrory MP (Chair)
- Helen Morgan MP
- Representative of Sharon Hodgson MP
- Representative of Lillian Greenwood MP

Speakers:

- Rafi Cooper, Twins Trust
- Julie Jones, University of West London

Guests in person:

Megan Ball	Sands, APPG on Baby Loss Secretariat
Kate Mulley	Sands
Ben Curran	Parent Infant Foundation
Collette Murphy	Advocacy for All

Guests attending online:

Aimee Middlemiss	University of Exeter
Alexandra Mancini	Chelsea and Westminster Hospital NHS Foundation Trust
Alison Morton	Institute of Health Visiting
Angela Rice	Midwife, EPAU Nurse
Beth McCleverty	Bliss
Caroline Brogan	Irwin Mitchell
Cathryn Johnson	Royal London Hospital
Charlotte Hill	ONS
Clea Harmer	Sands
Diane Gaston	Royal College of Pathologists
Fiona Gosden	TimeNorfolk
Georgia Stevenson	Sands and Tommy's Joint Policy Unit
Jenny Chambers	ICP Support
Jessica Reeves	Sands

Julia French Somerset NHS Foundation Trust Kirri Gooch Lily Mae Foundation Leanne Turner Aching Arms Louis Pilard Sands University of Leicester Lucy Smith Matt Pearson JOEL The Complete Package Mehali Patel Sands Munira Oza The Ectopic Pregnancy Trust **Barnsley Maternity Voices Partnership** Natalie Joseph Richard Boyd **Twins Trust** Robert Wilson Sands & Tommy's Joint Policy Unit Ruth Bender Atik Miscarriage Association Sabina Patel **Muslim Bereavement Support Service** Sadia Haqnawaz University of Leicester Sara Fitzsimmons SiMBA Charity Sharon Darke Twins Trust Sian Ness Colchester Hospital Heidi Eldridge MAMA Academy Veronique Berman Chana Jewish Fertility Charity Zoe Jones ONS

Welcome & introductions (Cherilyn Mackrory)

Cherilyn opened the meeting and welcomed everyone attending both in person in Westminster and online over Teams.

Cherilyn also explained to the group that Jeremy Hunt has stepped down as Co-Chair due to his recent appointment in the Treasury. Cherilyn will be continuing as the sole Chair of the group, and we will update on any additional appointments when the group holds an AGM.

Cherilyn and the group would like to express their immense gratitude to Jeremy for his dedication and campaigning. We look forward to continuing to work with him, as we know it will remain a passion of his.

APPG on Baby Loss updates (Cherilyn Mackrory)

<u>APPG on Baby Loss & APPG on Maternity joint report into safe staffing</u> Cherilyn thanked all who were involved in the creation of this report, explaining that more would be discussed on this later in the meeting.

Baby Loss Awareness Week

Cherilyn paid tribute to Baby Loss Awareness Week 2022, the theme of which was 'stepping stones' to mark the different points in the journey of those affected by pregnancy and baby loss.

On Tuesday 25th October, the annual Baby Loss Awareness Week debate was held in Parliament. It was disappointing that time could not be found in the Main Chamber to host

this debate as it was last year, but a great debate was had with moving contributions from MPs from around the House.

Cherilyn outlined that the new Minister has been announced as Maria Caulfield MP, who the group has worked with before and she is certain will continue engaging with the APPG.

East Kent Report

Cherilyn outlined that on the 19th October, the independent investigation into East Kent Maternity Services, led by Dr Bill Kirkup, was released. The report found stark failings of a system where workforce culture allowed negligence to occur. If the situation had been different and safe care had been delivered, 45 babies would have survived.

Everyone involved in the APPG can only imagine how painful the results of the investigation will have been for the families involved. We look forward to hearing from the Government on how recommendations from the East Kent review will be implemented.

Cherilyn highlighted how little families were listened to and noted how important it is to rapidly fix this with culture changes within the NHS.

Action: Cherilyn follow-up with Minister on East Kent

Women's Health Strategy

Cherilyn outlined that the Women's Health Strategy was published in the summer, setting ambitions to tackle deep-rooted, systemic issues within the health and care system to improve the health and wellbeing of women and how women are listened to. Included in the Strategy is the announcement of Pregnancy Loss Certificates for those that experience a pre-24 weeks pregnancy loss. Cherilyn noted how much of a difference this will make to families.

The Strategy also outlined commitments to the Lancet 'Miscarriage Matters' series and stated that there would be more support for those experiencing miscarriage when the Pregnancy Loss Review is released. This is expected later this year. Cherilyn shared that she attended a recent Parliamentary roundtable, which called for updates on progress from the Strategy and ensuring that transparent timelines are available.

ACTION: Cherilyn to write to the Minister, Maria Caulfield MP, to invite her to a future APPG on Baby Loss meeting.

Update on Pathologist workforce crisis

Since the July meeting where the Royal College of Pathologists shared information on the current workforce crisis in perinatal pathology, NHS England has met with the College. They have agreed on a 3-step plan to reduce staffing gaps which includes:

- Plan & produce guidance to maximise existing resources
- NHS England funding announced to support 2 teams of people, including some from the Royal College of Pathologists Specialty Advisory Committee, to oversee curriculum design and resource development and demand management.

• Boost staff recruitment, including overseas recruitment, and working on current retention.

Cherilyn highlighted how this is fantastic news and asked the Royal College to keep the group informed.

Diane Gaston from the Royal College of Pathologists shared that NHSE has now published a statement on perinatal and paediatric pathology investigations and announced premia for pathology trainees. BBC Radio 4 will also be releasing a 'File on 4' investigation into the shortages in December. Diane shared that things are progressing well.

10.30: APPG on Baby Loss & APPG on Maternity Joint Report

Cherilyn thanked everyone that contributed to the call for evidence for the APPG on Baby Loss and APPG on Maternity's joint report into safe staffing. There were over 100 responses, and the <u>final report</u> was published on 13th October. The report was picked up by news agencies and received good coverage, including a <u>Parliamentary Question</u> by Lisa Nandy about the Government agreeing to consider the recommendations.

The report makes a series of recommendations to improve the state of staffing in maternity and neonatal services, which include:

- All recommendations on staffing set out in the Ockenden Review and the Health and Social Care Committee Report on the safety of maternity services in England are implemented as a matter of urgency. Including a multi-year, fully funded settlement for maternity and neonatal services
 - Cherilyn outlined how Government Ministers did accept Ockenden's recommendations immediately, so we are hopeful that we are pushing at an open door.
- Workforce planning for maternity and neonatal services must be firmly based on the needs of women, babies and families including when a baby dies
- The Department of Health, NHS England, and Health Education England (HEE) in partnership with the Royal Colleges should develop a national strategy for improving the retention of maternity and neonatal staff

The responses to the call for evidence were a clear cry for help. Cherilyn reiterated that the group will be following up with the Minister to make sure recommendations are implemented and asking how we can work with them to make sure this happens.

Action: Cherilyn to write to Ministers about the report and ask for a commitment to recommendations.

Alison Morton from the Institute of Health Visiting highlighted the pressure on health visiting and the requirement for a dedicated workforce plan. Alison outlined that a workforce plan has been submitted to key stakeholders, so assistance to roll this out further is appreciated.

Sara Fitzsimmons from SiMBA outlined the importance of pre-briefing and debriefing after crises and traumatic events to ensure both staff wellbeing remains supported, and learning can be made. Cherilyn agreed and highlighted the importance of exit interviews as well.

At this point, chairing moved over to Helen Morgan MP.

10.50: Twins Trust Bereavement Care Report (Sharon Darke, Twins Trust)

Helen introduced Sharon Darke, Senior Bereavement Support Officer, and Rafi Cooper, Head of Communications at the Twins Trust. The Twins Trust support the parents and families of twins, triplets and more babies with information and support. They also have a standalone section of the organisation which offers support for the deaths of multiples.

Rafi outlined that recent research by MBRRACE-UK shows the risk of neonatal death in pregnancies with multiples is 3x higher than singleton pregnancies, and the risk of stillbirth is doubled.

Sharon movingly shared the story of her twin boys, Charlie and Joshua, who were born in 1999 at 26 weeks. She outlined the work of <u>the bereavement care report</u> that Twins Trust conducted, which received 250 responses from parents that were recently and long-ago bereaved families. The findings include:

- Over 50% were not seen in a twins clinic
- Over 1 in 3 felt that they received poor care during pregnancy
- 44% felt their aftercare was poor or could have been improved
- Only 60% had counselling after bereavement

Rafi outlined the calls of the report, which include:

- Core, multidisciplinary teams of specialists within a dedicated multiple-pregnancy clinic
- Bereavement care pathways specifically for multiples
- Access to counselling as standard

Ruth Bender Atik from Miscarriage Association echoed the need for specific information for multiple pregnancies and losses in the National Bereavement Care Pathway.

Julie Jones from the University of West London highlighted the need for training on bereavement in multiple pregnancies to be included in midwifery training and echoed her support.

Julie also reiterated the need to include bereavement care training for multiple pregnancies where only one baby survives, as this is a unique experience. Collette Murphy from Advocacy for All shared her experience of this, and Sharon reiterated that Twins Trust does work on this.

11.10: Perinatal Loss Proficiency Framework (Dr Julie Jones, University of West London)

Helen introduced Dr Julie Jones from the University of West London. Julie has launched the Perinatal Loss Proficiency Framework (PLPF) as a part of her PhD, and the framework has implications for clinical practice to improve equity in bereavement care.

Julie outlined that the framework aims to fill the gap in existing midwifery training of a lack of references to physical and clinical care in delivering babies that have died, but doing so in an emotionally, sensitive way. The framework outlines training implementation over a three-year undergraduate course, and the themes covered in the framework are:

- Practical clinical skills
- Communication
- Emotional and spiritual support
- Paperwork

The full PLPF, including guidance on teaching topics, can be found here: <u>https://sands.org.uk/sites/default/files/Perinatal%20Loss%20Framework%20BOOKLET%2</u> <u>0AUG%202022%20v2%20PRINT.pdf</u>

Julie closed by highlighting that this framework can be adapted for any healthcare professional. She also shared that a potential Postgraduate certificate is being developed with Sands.

Sabina Patel from the Muslim Bereavement Support Service asked about embedding spiritual and cultural competencies in the framework. Julie asked for specialist support on embedding this to ensure it is inclusive. Both Sabina, and Veronique Berman from Chana Jewish Fertility Charity, stated that they would be in touch to share insight.

11.30: Any other business

Kate Mulley from Sands raised a query about the NHS introducing a triage policy for perinatal post-mortems to help alleviate workforce issues. Sands have some concerns about engagement with bereaved parents and healthcare professionals in communicating this policy and asked whether the APPG could support raising this query. Helen stated that the group would pick this up outside the meeting.

Action: Cherilyn to write to the Minister to ask officials to look into this

Helen closed the meeting and thanked all who attended and spoke. The Secretariat will be in touch in the New Year about the next meeting.