



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

**Tuesday 12<sup>th</sup> September, 10.00am – 12.00pm**  
**Chairs: Cherilyn Mackrory MP & Helen Morgan MP**  
**Online**

**MINUTES**

Members in attendance:

- Helen Morgan MP (Co-Chair)
- Cherilyn Mackrory (Co-Chair)
- Olivia Blake MP
- Theo Clarke MP

Speakers:

- Dr Srin Annavarapu, Chair of the Specialty Advisory Committee of Paediatric and Perinatal Pathology, Royal College of Pathologists
- Janet Scott, Head of Saving Babies Lives, Sands
- Jane Scott, Divisional Bereavement Project Lead Midwife
- Alex Mancini, National Lead Nurse for Neonatal Palliative Care
- Laurellie Staples and Julia Clamp – parent speakers
- Karen Middleton – Maternal Mental Health Alliance

Guests attending online:

Janine	Aldridge	RCPATH
Jenny	Angliss	Child Bereavement UK
Owen	Arthurs	Great Ormond Street Hospital
Lydia	Baker	Epsom and St Helier University Hospitals
Emma	Barritt	East Kent Hospitals University NHS Foundation Trust
Ruth	Bender Atik	Miscarriage Association
Joanna	Bennett	

Andrew	Bocking	
Stuart	Bonar	RCM
Lauren	Braithwaite	Petals Charity
Laura	Bridle	Guys and St Thomas' NHS Foundation Trust
Caroline	Brogan	Irwin Mitchell
Adrian	Brown	Sands
Sam	Browse	
Jessica	Burley	Cambridgeshire Community Services NHS Trust
Celia	Burrell	Barking, Havering and Redbridge University Hospital
Owen	Cartey	Office of Cherilyn Mackrory MP
Joanne	Cookson	West Midlands Neonatal Operational Delivery Network
Sharon	Darke	Twins Trust
Kara	Davey	Dr Davey Coaching
Jane	Denton	Multiple Births Foundation
Sharon	Duke	
Heidi	Eldridge	MAMA Academy
Zahra	Famili	Guys and St Thomas' NHS Foundation Trust
Clea	Harmer	Sands
Sophie	Harrold	Mossbourne Community Academy
Leila	Hobart	Little Wings of Hope
Sara	Hunt	Farrer&Co
Ryan	Jackson	Lily Mae Foundation
Matt	Joel	Bristol Community Health CIC
Zoe	Jones	Office for National Statistics
Sarah	Kiely	Salford Clinical Commissioning Group
Nicky	Lyon	Baby Lifeline
Molly	Mantle	Sands
Beth	McCleverty	Bliss
Angela	McConville	NCT
Natalie	McKie	Lullaby Trust
Aimee	Middlemiss	University of Plymouth
Karen	Middleton	Chartered Society of Physiotherapy
Munira	Oza	Ectopic Pregnancy Trust
Louis	Pilard	Sands
Jane	Plumb	Group B Strep Support
Oliver	Plumb	Group B Strep Support
Hannah	Putley	UK Civil Service
Jessica	Read	NHS England
Jess	Reeves	Secretariat
Alex	Richardson	NHS Manchester Trust

Zoe	Russell	Royal College of Obstetricians and Gynecologists
Suzie	Scofield	Bereavement Midwife
Anna	Stewart	Torbay and South Devon NHS Foundation Trust
Natalie	Tasker	Barnsley Maternity Voices
Jenny	Tata	Oxleas NHS Foundation Trust
Michelle	Tolfrey	Talking Heads
Leanne	Turner	Aching Arms
Alexandra	Twemlow	Office of Helen Morgan MP
Georgie	Vestey	Dead Honest Podcast
Jenny	Ward	Lullaby Trust
Gillian	Weaver	Human Milk Foundation
Abigail	Weller	
Laura	Williamson	NHS Highland
Rob	Wilson	Sands & Tommy's Joint Policy Unit

## **Welcome & introductions** (Cherilyn Mackrory MP)

**Cherilyn** welcomed everyone attending the meeting which is being held fully online. Cherilyn informed those attending the meeting that there will be a chance for questions after each agenda item.

### **1. APPG on Baby Loss updates** (Cherilyn Mackrory MP)

#### Pregnancy Loss Review

**Cherilyn** updated the group that the Pregnancy Loss Review was published in July. **Cherilyn** explained the Government's immediate response to the Review included the introduction of a voluntary pregnancy loss certificate for parents who have had a pregnancy loss at any gestation under 24 weeks, recommendations relating to the storage of sensitive storage, and to consider the outcome of the pilot into the Graded Model of Care advocated by the Miscarriage Matters series in the Lancet.

#### Government's full response to East Kent Maternity Investigation

**Cherilyn** informed the group that at the end of July the Government set out its full response to the independent investigation into maternity and neonatal services at East Kent. **Cherilyn** outlined the response which included a new National Oversight Group chaired by the Minister for Women's Health, Maria Caulfield and Dr Kirkup to work with healthcare partners to help ensure teams in maternity and neonatal care across England can work together.

#### Maternity workforce follow up

**Cherilyn** updated the group on the APPG's Safer Staffing Campaign, informing them of the publication in June of the NHS Long Term Workforce Plan. The commitments of the plan included the growth of midwifery education and staffing, expansion of apprenticeships and greater investment in retention of existing midwives.

### APPG on Birth Trauma

**Cherilyn** informed that Theo Clarke MP has set up the APPG on Birth Trauma and is looking forward to working with the APPG as there is much crossover.

### Trial and verdict of Lucy Letby

**Cherilyn** voiced the APPG's support and condolences for the families involved in the case of Lucy Letby's recent trial and verdict, as well as other bereaved parents and families.

### Baby Loss Awareness Week Debate

**Cherilyn** stated the application for the Baby Loss Awareness Week Debate has been submitted, which will focus on progress of the Ockenden Report published in 2021.

## **2. Perinatal Pathology**

**Cherilyn** introduced the session, explaining the focus will be on how workforce and staffing issues in perinatal pathology are impacting bereaved parents and their families.

### Janet Scott - Head of Saving Babies Lives at Sands

**Janet** started the presentation by emphasising the importance of listening to parents' experiences of perinatal pathology services at a time of crisis. **Janet** outlined the national context of the crisis explaining that there is a critical shortage across the UK of special perinatal pathologists, regional disparities and a shortage of Anatomic Pathology Technicians. There is a new interim NHS perinatal post-mortem policy which was introduced in 2022 and a permanent policy is due imminently.

**Janet** explained Sands have conducted two parent surveys in March and June of this year from parents whose babies died in 2020. 690 parents responded to the questions regarding post-mortems.

The survey found five themes:

#### Consenting

- Reports of parents being denied a post-mortem
- Parents not understanding decisions about post-mortem and 'ceiling consent'

#### Waiting for the post-mortem report

- Many parents waited over 12 weeks for post-mortem report, with some waiting over six months or even over a year

#### Transporting a baby's body

- Regional disparities mean more babies are being transported to pathology centres far away

#### System Failures

- Babies sent for post-mortems without consent, babies' bodies being left and not taken to the mortuary for several days and tissue samples being forgotten resulting in samples becoming too old for pathology examination

#### Communication

- The need for clear information and interaction for parents throughout the experience

**Janet** concluded by explaining that Sands is working alongside NHS England to develop their programme, specifically the triage policy. **Janet** expressed the importance of a parent pathway to sit alongside the triage policy, to lay out clearly parents' choices and guidance in the case of an agreement not being reached. In addition to the imperative need for revised information resources for parents and healthcare professionals and an active communication strategy.

#### Jane Scott & Alex Mancini

**Jane** began by thanking Janet for her presentation and expressed her support for the issues Janet had raised. It was then highlighted that there is a need for a single point of contact, currently there are no lead bereavement midwives for each region and no one is overseeing midwives for the clinical work they do. **Jane** stated that the National Bereavement Pathway is not substantial enough to make sure all these fundamental issues are being covered. Further emphasising there is such limited support for bereavement midwives.

**Jane** handed over to **Alex Mancini**.

**Alex** reiterated that communication makes a vast difference, but emphasised the importance of funding to put people in post and deliver the change that is needed.

**Jane** informed the group that midwives are spending a lot of time chasing up post-mortem reports and not getting updated to be able to inform parents.

306 bereavement midwives and 142 neonatal nurses shared how the waits of post-mortem reports have impacted their services:

- Doncaster & Bassetlaw to Sheffield Pathology = PM 12 weeks, Histology 6 months
- Wrexham Park & Frimley Park to Oxford Pathology = PM 12-16 weeks, Histology 12 months
- Worcester Royal to Birmingham Pathology = PM 6-10 months (HSIB 12 months)
- Aneurin Bevan UHB (Wales) = PM 6 months
- University Hospital Coventry & Warwickshire to Birmingham = PM 6-12 months
- The Dudley Group to Birmingham/Alder Hey Pathology = PM 8 months (recently improved from 10-12 months)
- Nottingham University Hospital = PM 5 months +
- South Tees Hospitals to Newcastle Pathology = PM 6-7 months, Histology 5 months

**Jane** further added that there are extensive delays and poor communication in Coroner cases, which NHS England do not oversee. In addition to midwives reporting that the Ockenden Report money has still not been received by some hospitals.

**Action: Jane to keep the APPG updated on funding issues with regards to the Ockenden Report. Cherilyn to attend the South Bank Forum, Directors of Neonatal Nurses on 8<sup>th</sup> February 2024.**

Laurellie Staples – Parent Speaker

**Laurellie** shared her own personal story, where she lost her baby at 18 weeks on 17<sup>th</sup> September 2022. Spontaneous labour was the cause of death. **Laurellie** shared the wait time for the post-mortem results was an enormous problem, she was informed it would be about three months, but it took 22 weeks to find out the sex of their baby who died, and 40 weeks to get the post-mortem report. It was noted that Laurellie received very good follow up care and saw a consultant every two weeks. However, the lack of results made it challenging to know what the consultant should look out for in her next pregnancy. **Laurellie** stated that the wait for the post-mortem results made the grieving process even more challenging and affected her most recent pregnancy.

**Laurellie** stated her main plea is for a time frame to be set out, ensuring that no parent must wait nine months to receive post-mortem reports like she had to.

Julia Clamp – Parent Speaker

**Julia** shared her own personal story, where she gave birth to her first son, Alvin, on 11<sup>th</sup> May 2023 but tragically discovered that Alvin was unresponsive in his cot 48 hours later. Julia shared that the pathologist indicated the wait is 9 to 10 months to receive the post-mortem report, which will be February to March 2024. This wait has put Julia and her partner in a confusing period of grief, as the report could help them process what has happened and help them plan for the future, including family planning.

**Julia** acknowledged the perinatal pathologist crisis is a complex problem but called for action to be taken now. The injustice of the waiting time of post-mortem results being a post code lottery was also discussed.

**Cherilyn** thanked Laurellie and Julia for sharing their stories and commended their bravery. Cherilyn handed over to Helen Morgan MP to chair the remaining of the meeting.

**Helen** reiterated Cherilyn's words and condolences to Laurellie and Julia. Following this, Helen explained that NHS England had been invited to the meeting but have been unable to send anyone to this meeting but will attend a future one and have provided a statement she will read later.

Dr Srin Annavarapu Chair of the Specialty Advisory Committee of Paediatric and Perinatal Pathology, Royal College of Pathologists

**Dr Sri** explained the crisis is a system failure. These problems have been known for 15 years.

**Dr Sri** explained that a post-mortem report is complex, it is not just a simple blood test but involves histology and genetics testing. These tests take place in different labs and due to the complexity of these procedures, they require a specialist who has been trained for 3 to 5 years. There are currently only 55 pathologists in the country.

**Dr Sri** explained the reasoning behind the short-term measures of Perinatal Autopsy Guidance and Placental Tissue Pathway, stating it was an emergency measure as there are so few perinatal pathologists. It was also raised that there are certain circumstances where a post-mortem will not help understanding the death of a baby, if it is already known that there is a genetic abnormality.

For medium term measures, **Dr Sri** discussed mutual aid for hospitals who do not have any perinatal pathologists, stating Alder Hey Hospital is an example of this, covering Northern Ireland, North Wales and Birmingham.

**Helen** opened the meeting for questions and focussed the discussion on what can be done to solve the issues raised. **Helen** then read the statement received by NHS England:

'NHS England is working collaboratively with Sands, the perinatal pathologists' services directly, NHS workforce including college and health education including the GMC and NMC Path who come together under a perinatal pathology steering group co-chaired by Mathew Jolly. The steering group has several work streams in place, including work to progress international recruitment linked to the work force challenges the service has.'

**Julia Clamp** asked if there are particular areas, such as genetic testing, which are causing delays in post-mortem reports. **Dr Sri** responded that genetic testing takes about 6 to 8 weeks and this can often bring up other findings which need to be investigated. The pathologists are waiting for all these results to come back. **Jane Scott** added sometimes the results are ready but there are no consultants available to relay the results. **Dr Sri** followed up by stating there is an international recruitment drive which involves a three-year training programme for Biomedical Scientists, approved by the Royal College and NHS England Fellowship Programme. The diploma will be in Placental reporting.

**Lydia Baker** queried whether there is a way to only send the placenta to a Perinatal Pathologist without the baby. **Dr Sri** emphasised the importance of the placenta in cases of late still birth to find out why the baby has died and added this is the key reasoning behind investing so much in the Diploma; the programme will teach the students to be experts in placental histology.

**Clea Harmer** drew attention to why NHS England failed to attend the meeting. Helen agreed and stated she will speak to Cherilyn and Jess Reeves regarding this. **Dr Sri** explained Anthony Prudhoe is aware of the crisis and has worked to ringfence £200,000 for producing educational material for training programmes.

**Action: Helen and Cherilyn to invite NHS England to the next meeting once the Secretary of State has responded to the letter on perinatal pathology services.**

**Joanne Cookson** drew attention to the development of a e-learning for Health Perinatal Post-Mortem Consent Training Package in conjunction with her local Perinatal Pathology team, they are working towards updating the package and stated would value any feedback.

### **3. Spotlight Session**

Karen Middleton - Head of Campaigns and Policy, Maternal Mental Health Alliance – 'Specialist perinatal mental health care in the UK 2023' report

**Karen** opened the session by stating the Maternal Mental Health Alliance is a network of over 120 national organisations who work to ensure all women and families can access compassionate, comprehensive and compassionate mental health care. **Karen** explains 1 in 5 women develop a mental illness during pregnancy or within the first five years after having a baby, with mental illness being one of the leading causes of death in the perinatal period. **Karen** noted there are disparities for black and minority ethnic communities, young parents and those facing additional adversities such as domestic abuse, which correlates with the evidence for baby loss too.

**Karen** informed there has been progress in specialist perinatal mental health services between 2015 and 2022, due to national focus and commitment (Five Year Forward View and NHS England Long Term Plan) and essential resourcing and funding alongside this. However, progress is still uneven and a postcode lottery remains.

**Karen** highlighted there is an issue that at a national level money has been allocated, but locally teams are still having to fight for services. It was identified national and local commitment are needed to progress and enable the possibility of preventing perinatal mental health care.

**Jane Scott** expressed frustration as despite establishment of Trauma and Loss Care Service, all referrals have been rejected unless the patient had a pre-existing mental health condition. **Karen** acknowledged this has been an underfunded area for so long, the funding only begins to help the problem. **Jane** added that the mental health of the father should be considered and resources should be in place to support them. **Karen** agreed and explained there is not one model, therefore, there is local variation.

**Laura Bridle** highlighted in South East London, the Trauma and Loss Care Service opened in April 2023 and have had 170 referrals, with the majority not possessing pre-existing mental health problems. It was then highlighted there are huge disparities with post codes.

**Cherilyn Mackrory MP** queried about why partners are not included how funding money can be traced and suggested this is a wider conversation that needs to be had amongst parliamentarians. **Karen** agreed that there is a frustrating lack of data transparency.

**Jane Scott** enquired why the Mental Health Services are not the same across the UK. **Karen** explained Mental Health Services have been set up at separate times and one model has not been proposed, MMHS are seeking to understand and learn from these different models.

#### **4. Close**

**Helen** thanked all who attended and spoke. The Secretariat will be in touch about the next meeting in January.