All-Party Parliamentary Group on Baby Loss

- **Date:** 4th December 2025
- **Time:** 14:00-16:00
- **Location:** Committee Room 12, Palace of Westminster

Members and representatives in attendance:

- Andy MacNae MP
- Bobby Dean MP
- Lizzi Collinge MP
- Tessa Munt MP

Apologies:

- Alison Bennett MP
- Mark Francois MP

Speakers:

- Dr Clair Evans, Chair of the Speciality Advisory Committee for Prenatal, Perinatal and Paediatric Pathology, The Royal College of Pathologists.
- Katie Wheeler, Campaign for Gigi
- Jenny Ward, Chief Executive, The Lullaby Trust
- Heidi Eldridge, Founder and CEO, MAMA Academy
- Emily Butler, Lead Midwife, The Perinatal Institute
- Keelie Grindley, Lead Midwife for Equality, Diversity and Inclusion, UHNM NHS Trust and Founder, Nya Birth Collective
- Racheal Crane, Baby Loss and Bereavement specialist

Attendees:

- Adelaide Di Maggio, Catholic Bishops Conference of England and Wales
- Amneet Graham, Willow's Rainbow Box
- Angela Thompson, UHDB
- Angelie Balalingam, Sands and Tommy's Joint Policy Unit
- Angie Rice, Midwife and Bereavement Counsellor
- Ayesha Anandji Demetriou, bereaved parent and Sands campaigner
- Benjamin Landsberry, Footprints Baby Loss
- Diane Gaston, Royal College of Pathologists
- Elizabeth Duff, NCT
- Emily Cannon, Office of Michelle Welsh MP
- Gareth Wallace, Catholic Bishops Conference of England and Wales
- Holly Brooker, Luther Pendragon
- Jane Sondall, Kings College London
- Jessica Reeves, Sands
- Jo Dickens, Perinatal Safety and Review Midwife
- Kate Mulley, Sands
- Kath Abrahams, Tommys
- Laura Corcoran, Dignity Care
- Laura Levy, Max's Legacy
- Louisa Hendrickson, Zion's Lighthouse
- Maninder Hayre, Child Bereavement UK
- Maya Parkin, Bliss
- Mike Indian, Royal College of Midwifes
- Olivia Boschat, Bolt Burdon Kemp
- Olivia Davies, EGA IFWH UCL
- Owen Riley, Office of Andy MacNae MP
- Rachel Burn, Royal College of Midwifes
- Rory Mosseveld, Nursing and Midwifery Council
- Sam Collinge, Co-Chair of the Independent Pregnancy Loss Review and Lead Bereavement Midwife
- Sian Ness, Cuddle Cot
- Sienna Teague, EGA IFWH UCL
- Susie Holder, Chana Charity
- Suzie Scofield, Footprints Baby Loss
- Tiffany Jones, Max's Legacy

1. Welcome & introductions

Andy opened the meeting and welcomed everyone attending.

He started with an overview of the meeting agenda and introduced the speakers.

2. APPG on Baby Loss updates

Round up of the year

Andy reflected that this year we have continued to face serious challenges around baby loss but also seen significant opportunities and areas of progress.

There is a clear feeling of political will and cross-party collaboration on this issue, evidenced by the growth of the APPG.

He thanked all the members who have been involved over the year and welcomed our three new members: Amanda Hack MP, Bobby Dean MP and Freddie van Mierlo MP following the baby loss debate.

Andy reflected on some of the key political moments and policy developments this year:

Baby Loss Awareness Week

This year's Baby Loss Awareness week debate saw over 40 MPs stay in the chamber until after midnight and was attended by the Secretary of State for the first time.

Andy reflected on the importance of breaking the cycle of investigation, report and recommendations, and the need for tangible actions.

Andy thanked all the bereaved families who travelled to watch from the gallery, the MPs who shared their own and their constituent's stories of baby loss, and everyone across the country who marked Baby Loss Awareness Week.

NBCP included in the NHS Planning Framework

Andy shared that following the APPG event on the importance of bereavement care in October, the National Bereavement Care Pathways for stillbirth and neonatal death have now been included in the NHS Medium Term Planning Framework.

This means that all ICBs are now expected to take immediate action to improve bereavement care and ensure that parents are listened too following a stillbirth or neonatal death. This marks a significant step forward in ensuring that all families receive high quality bereavement care loss.

The APPG will continue to advocate for all pathways of the NBCP to be mandated and that the standards are fully embedded across England.

Men's Health Strategy

Andy outlined that last month the Government published the Men's Health Strategy which we were pleased to see recognise the need for specialist mental health services to be available to fathers and partners following baby loss.

The APPG will continue to raise the importance of specialist mental health support for all bereaved parents and will hold a mental health focused meeting next year.

Public Office Accountability Bill

Lizzi Collinge MP updated the meeting on the progress of the Public Office Accountability Bill, also known as the Hillsborough Law, which will introduce a legal duty of candour from all public bodies, new offences for misleading the public and new requirements for cooperating with processes such as inquests.

Lizzi highlighted the relevance of this Bill and the importance of transparency in public organisations.

Look at the year ahead

Maternity investigation

Andy confirmed the revised timelines for the National Maternity Investigation:

- **Initial update – December 2025**, will reflect on the evidence heard so far and outline the themes that the investigation will focus going forwards.
- **Initial findings report – February 2026**, will follow the conclusion of site visits and include the publication of Trust reports. It will also include initial findings on the review of previous recommendations, the legal framework for coronial review and the compensation system for clinical negligence.
- **Final report and recommendations** – **Spring 2026**. The report and recommendations will then be used by the taskforce to develop the national action plan.

The call for evidence will be launched in January. Anyone wanting to contact the investigation can email: matneoinvestigation@dhsc.gov.uk

Bereavement leave for pregnancy loss consultation

Andy shared that the consultation on proposals to introduce new bereavement leave for pregnancy loss has now been launched and the APPG would like to congratulate everyone who has campaigned on this.

The Government have proposed that anyone who experiences a bereavement, including pregnancy loss, should be entitled to at least one-week unpaid leave as part of a wider consultation on leave for different types of bereavement.

The consultation is open for responses to the end of January, and the APPG encourages everyone to feedback on this proposal.

GMC consultation

Andy outlined that the accountability of regulators is a crucial part of improving maternity safety and protecting patients from harm.

We are expecting a three-month consultation on the secondary legislation around the GMC reforms to launch before the end of this year, which will act as a blueprint to reforms to other regulators.

The APPG will share further information on this consultation when it is available and encourage all bereaved and harmed families to submit a response.

3. Presentations

Paediatric and perinatal pathology workforce report

Speaker: Dr Clair Evans, Chair of the Speciality Advisory Committee for Prenatal, Perinatal and Paediatric Pathology, Royal College of Pathologists.

Clair began by explaining the role of paediatric and perinatal pathologists, who specialise in investigating and diagnosing diseases in babies and children. This includes post-mortem examinations, cancer diagnosis, and placental histopathology to understand pregnancy-related conditions.

She outlined new findings from the Royal College of Pathologists workforce report, which revealed a 37% shortfall in consultant posts and a looming crisis as 25% of current consultants are expected to retire within five years.

She stressed that recruitment is extremely challenging due to a lack of trained doctors, with only 13 resident doctors in training compared to the estimated need for 31 additional funded training posts.

Barriers to recruitment include:

- Minimal exposure to paediatric/perinatal pathology in undergraduate medical education.
- Lengthy GMC processes for curriculum and exam changes (taking 2–3 years).
- Separate subspecialty recruitment after two years of histopathology training, which deters applicants.
- Reluctance of trainees to relocate due to family and other life commitments.

Clair noted that international recruitment drives in the late 1990s temporarily alleviated shortages, but those consultants are now retiring. She emphasised the negative impact of workforce shortages on bereaved families, including delays in investigations and reduced quality of care.

Clair summarised that consultant numbers need to rise from 52 to around 90 to maintain service levels and called for systemic changes in training pathways, recruitment processes, and funding to ensure sustainability.

She also highlighted the growing challenge of uneven distribution of paediatric pathologists across the UK, noting that regions such as Northern Ireland, the Midlands, and the South West have none. This results in significant delays and distress for families, as babies requiring post-mortems must be transported long distances.

She explained that demand for paediatric pathology services is increasing, driven by rising surgical pathology cases, more placental examinations, and greater complexity due to advances in genetics and personalised medicine.

Clair described temporary mitigation strategies, such as NHS England's mutual aid programme, which arranges for babies to be transferred to centres that can perform post-mortems. Unofficial mutual aid also occurs, with departments informally covering each other's workloads.

The Royal College has published guidance documents and tissue pathways to prioritise clinically relevant cases and reduce workload, but these measures only partially alleviate pressure.

Recruitment incentives have also failed: NHS England introduced a £20,000 "golden handshake" for trainees, but the scheme was cancelled after little impact, as candidates were motivated by interest in the specialty rather than financial reward.

New initiatives to tackle the workforce challenges, such as upskilling biomedical scientists to undertake placental histopathology are expected to launch in 2026.

Clair outlined several solutions to the workforce issues in pathology:

- Increasing the number of resident doctors in training and creating alternative entry points earlier in training.
- Fully funding conversion fellowships for consultants in related specialties (e.g., histopathology, neuropathology, forensic pathology) to retrain in paediatric pathology.
- Exploring new routes for international recruitment, acknowledging Brexit's impact on workforce retention.
- Addressing IT infrastructure issues to enable digital pathology and remote case sharing between centres, reducing reliance on physical specimen transfer.
- Incentivising and retaining the consultant workforce through cultural change and improved working conditions.

Clair concluded that without systemic changes in training, recruitment, and technology, the service will remain fragile, leaving bereaved families vulnerable to delays and inequities.

She went on to describe the growing challenge of training residents within an apprentice-style model, which relies heavily on one-to-one mentorship from consultants. Without

creating protected time for training, the pipeline of future consultants will be compromised, placing long-term service sustainability at risk.

Clair acknowledged the positive steps taken by NHS England, noting that they have established a working group to collaborate with consultants on mitigation strategies and workforce planning. However, she cautioned that these efforts require greater institutional support and wider awareness to ensure that proposed solutions can be implemented effectively

Clair also highlighted the importance of accurate and timely data collection to inform workforce planning and workload management. She called for the development of a centralised, proactive system for gathering and analysing workforce data to support strategic decision-making.

Andy moved to questions for the room:

Angie Rice highlighted the emotional impact on families, noting that delays in post-mortem examinations take time from parents who want to spend time with their babies before funerals. She recalled that five years ago, the wait was around four weeks, but now delays are even longer due to severe workforce shortages.

Laura Corcoran provided an update on the Miscarriage Collection Cradle, which is currently being trialled at several hospitals and can support sample testing and diagnostic processes.

Sam Collinge described the severe impact of workforce shortages on families and staff in Birmingham. She stressed that delays also affect the completion of post-mortem reports, sharing examples of families waiting for reports from April, causing significant distress, mental health struggles, and delays in planning future pregnancies.

Sam asked whether any qualitative research has been conducted into the values and motivations behind choosing paediatric pathology as a career.

Clair acknowledged the complexity of the issues and confirmed that current delays are unacceptable. She explained that post-mortem timing varies between centres, with significant delays due to workload and resource constraints. Ideally, babies should be returned within one to two weeks, and post-mortem reports should be completed within six weeks to align with follow-up clinic appointments. Coroner's cases typically take longer due to more extensive investigations and referrals to external experts, which adds further delays.

Clair highlighted the urgent need for systemic changes to address these issues and provide better services to bereaved families.

<u>Campaign for Gigi</u>

Speakers: Katie Wheeler, Mother of Genevieve Meehan, and **Jenny Ward,** Chief Executive, The Lullaby Trust

Katie began by sharing the story of her daughter Genevieve, who was born on 18th July 2021, describing her as a vibrant, happy child who brought immense joy to the lives of Katie, John and her big sister.

When **Katie** returned to work, she researched local nurseries, asked fellow parents for recommendations, reviewed OFSTED reports, and checked staff continuity.

Katie recounted the events of the 9th May 2022, when she dropped Gigi off for her first full day at nursery. Later that afternoon, **Katie** received a phone call informing her that Gigi had been found unresponsive. Despite resuscitation efforts, they were told at the hospital that Gigi had died.

Initially, **Katie** and John were told that her death appeared to be sudden infant death syndrome. However, a police investigation revealed that Gigi had been placed face down, swaddled tightly, and strapped to a beanbag for ninety minutes, which led to her suffocating.

During the investigation CCTV footage uncovered multiple instances of child abuse at the nursery over a seven-day period, resulting in one staff member being convicted of unlawful manslaughter and others charged with ill-treatment of children.

Katie expressed deep distress that similar cases have since occurred in other nurseries, highlighting systemic failures in safeguarding. A BBC documentary that found a significant increase in serious childcare incidents reported to Ofsted between 2019 and 2024.

She also cited data from a law firm showing that legal claims involving injuries to children in nurseries have increased tenfold over the past decade.

On the 9th May, **Katie** and John launched Campaign for Gigi with support from **Tom Morrison MP.** The campaign goals are:

- Compulsory CCTV in all nursery settings.
- Routine unannounced Ofsted inspections with increased frequency.
- Mandatory review of CCTV footage during inspections.
- Clear statutory safe sleep requirements for early years settings.
- Mandatory safe sleep training for all nursery staff and Ofsted inspectors.
- Regulation of sleep products used in nurseries.

Katie stressed that if these measures had been in place, Gigi's death would have been prevented. She emphasised that parents should be able to trust that their children are safe while they work, especially as government policies expand funded nursery places and add pressure to the system.

Since launching the campaign, the Ofsted inspection cycle for early years settings has been reduced from six years to four years, and the Government has committed to strengthening the early years framework on safe sleep.

Katie encouraged attendees to support the campaign and asked MPs to sign Early Day Motion 1191 and attend a drop-in session on the 19th January in Portcullis House.

Andy and Tessa Munt MP praised Katie's courage and pledged their support to the campaign.

Jenny Ward thanked Katie and John for their bravery and advocacy.

Growth charts and avoidable deaths

Speakers: Heidi Eldridge, Founder and CEO, MAMA Academy**, Emily Butler,** Lead Midwife, The Perinatal Institute

Emily declared her interest as an employee of the Perinatal Institute, a not-for-profit organisation working to prevent stillbirth and improve the detection of small babies.

She outlined that poor foetal growth is commonly caused by a poorly functioning placenta, which severely limits the baby's ability to thrive in utero. The only treatment in such cases is delivery which presents a delicate balance, avoiding delivering the baby too early while also ensuring timely intervention to reduce the risk of stillbirth.

Emily stressed that early and accurate detection of growth restriction is therefore critical to improving survival rates and reducing adverse outcomes.

Emily described the Growth Assessment Protocol (GAP), a comprehensive programme designed to improve the detection of small-for-gestational-age (SGA) babies. It incorporates the use of personalised growth charts that are tailored to each pregnancy based on characteristics including height, weight, and ethnicity.

She noted that these customised charts were first recommended by the Royal College of Obstetricians and Gynaecologists in 2002 and became a central element of NHS England's Saving Babies' Lives Care Bundle in 2015. An independent study of 19 NHS Trusts demonstrated that implementing GAP increased SGA detection rates from 15% to 59% and reduced stillbirth rates by 20%.

Emily expressed concern about recent changes following updated RCOG guidance in 2024, which made no recommendation on which growth chart should be used. This has led many Trusts to switch from Grow charts to Intergrowth charts, which assume a universal standard for foetal growth.

She explained that this approach is problematic because Intergrowth does not account for the UK's diverse population and tends to underestimate growth restriction, resulting in lower detection rates.

However, **Emily** emphasised that there is no evidence to support the effectiveness of Intergrowth and the decision appears to have been driven by convenience and cost. Intergrowth charts are available free to Trusts whereas GAP costs £2 per pregnancy.

Emily shared findings from a Freedom of Information survey undertaken by bereaved parents Sherena Corfield and Jack Devlin following the death of their daughter Maia. The survey revealed that approximately 130,000 births per year are now managed using Intergrowth charts. The data shows that after switching to Intergrowth, the rate of SGA detection dropped by half.

This decline correlated with an increase in stillbirths in regions that adopted Intergrowth charts. In North East and North Cumbria, where eight trusts switched in April 2024, analysis of ONS data revealed that while stillbirth rates remained stable or slightly declined in Trusts using GAP, those using Intergrowth experienced a significant rise. This equated to 27 additional stillbirths in the region.

NHS England have confirmed that they will be issuing a national patient safety alert advising Trusts to stop using Intergrowth charts.

Heidi introduced herself as the founder and CEO of MAMA Academy, which aims to prevent stillbirth and improve pregnancy outcomes.

She shared that her son Aidan was stillborn 16 years ago due to undetected growth restriction. She was not informed about the risks associated with foetal growth restriction and she emphasised that many parents are still not told about the risks.

Heidi highlighted that financial pressures have led some hospitals to abandon customised growth charts, stressing that these decisions are being made without proper oversight or understanding of the consequences.

She outlined the campaign's key asks, which include:

- Reinstating GAP protocols and establishing a national standard for foetal growth assessment.
- Creating a national website and monitoring system to ensure consistency and transparency.
- Implementing a mandated audit of key processes and outcomes related to foetal health and well-being.
- Providing centralised and direct support for all NHS trusts to follow national guidance and receive feedback on their performance.
- Ensuring transparency and accountability in reporting progress and outcomes to parents and stakeholders.

Heidi concluded by inviting attendees to join the campaign and learn more about how they can prevent avoidable stillbirths and improve maternity care.

<u>Equitable maternity care</u>

Speaker: Keelie Grindley, Lead Midwife for Equality, Diversity and Inclusion, University Hospitals of North Midlands NHS Trust and Founder, Nya Birth Collective.

Keelie outlined that her primary responsibility in her roles is to improve outcomes for marginalised communities and families who are disproportionately affected by poor maternity outcomes, including maternal deaths, severe morbidity, baby loss, and neonatal complications.

She began by acknowledging that baby loss is unimaginably painful for anyone who experiences it. She clarified that her focus today would be on racial disparities in maternity outcomes, emphasising that this does not diminish the experiences of other families but aims to address systemic inequalities to make maternity services equitable and accessible for all.

Keelie highlighted that the largest part of her work is education, because “when we know better, we do better,” tackling structural issues in care which lead to stark disparities in maternity outcomes.

Keelie explained that research from organisations such as Birthrights, the NHS Race and Health Observatory, Five X More and The Motherhood Group consistently shows that Black women’s concerns are not taken seriously.

She cited an example where Black mothers repeatedly reported signs of jaundice which were missed because healthcare professionals lacked knowledge of how the condition presents in melanated skin. The 2023 MNSI report documented an increase in catastrophic late diagnoses of jaundice in Black and South Asian babies.

Keelie emphasised that these harms could have been prevented if clinicians were trained to assess conditions across all skin tones. She identified the midwifery curriculum as a major contributor to disparities, explaining that textbooks and teaching materials are overwhelming based on a white norm, with no mandatory modules on cultural safety or racial inequalities.

This means students can qualify without learning how conditions present differently or how structural racism affects outcomes. **Keelie** outlined that the curriculum must be decolonised, with equality, diversity, and inclusion embedded throughout the degree.

Keelie explained that her teaching explores anti-racism in maternity care and unpacks historical myths rooted in slavery which still negatively influence care today. She also focuses on cultural safety and building trust with communities, as well as the importance of adapting care systems to meet people’s needs.

Her training looks at case studies where cultural bias has impacted care and talks about the importance of mitigating language barriers. At her Trust for example, a case with a poor outcome led to a change in the triage system, introducing a lower threshold for support when a language barrier is present. This change has already shown impact, reminding that equity saves lives.

Keelie affirmed that all families should start on an even playing field, and she will be educating, advocating and pushing for change until this is realised.

Andy moved to questions from the room:

Mike Indian thanked Keelie for her work and highlighted the RCM's work on a decolonising midwifery education toolkit, calling for workforce plans to reflect the protected training time needed to ensure equitable care.

Ayesha Anandji Demetriou asked where parents can go to find information about disparities in maternity care and conditions which disproportionately affect Black and South Asian women.

Heidi flagged the MAMA Academy pregnancy passports and **Kath Abrahams** highlighted the Tommy's Black and Black Mixed-Heritage Helpline in partnership with Five X More.

Keelie highlighted the importance of cultural competence in the NHS, ensuring that midwives are confident in having culturally sensitive conversations with parents, as well as the need for better access to interpreting services.

Max's Legacy

Speaker: Racheal Crane, Baby Loss and Bereavement Specialist

Racheal introduced herself as maternity support worker and the founder of **Max's Legacy**.

She explained that in 2022 she took part in the Nursing, Midwifery and Allied Health Professionals Scholarship programme to create a service inspired by the loss of her son Max. She undertook research into baby loss and created a monthly baby loss support group for staff and families.

Racheal described her role as providing dedicated bereavement care, sitting with families during their darkest moments, helping them make memories, guiding them through difficult decisions, and continuing support long after they left the hospital.

She emphasised that her work extended beyond immediate loss, offering emotional, practical, and holistic support for weeks, months, and even years afterward. She stressed that repeated trauma and inconsistent support remain common because the system lacks the time and resources to provide continuity of care.

Racheal outlined her vision to establish Max's Legacy as a national charity, working alongside NHS Trusts to strengthen clinical teams. Her goal is to ensure every family, regardless of location, has access to compassionate, trauma-informed, person-centred care after baby loss.

She called for protected spaces within NHS hospitals for early pregnancy losses, such as private, quiet rooms staffed by trained professionals so parents never receive devastating news in a busy corridor or sit beside expectant parents while losing their own baby.

Racheal concluded by stating that Max's Legacy was created to offer dignity, compassion, continuity, and hope and urged attendees to support her mission to build a future where bereavement care is consistent across the UK.

Andy reflected on the importance of bereavement care, and the need to ensure consistent implementation of the National Bereavement Care Pathways.

Kate Mulley noted that it is only the pathways for neonatal death and stillbirth which have been mandated in the NHS Planning Guidance, meaning there is more work to be done to improve support around early pregnancy losses. She also highlighted the need for the new guidance being communicated to Trusts.

Sam Collinge emphasised the importance of the role of maternity support workers in helping bereaved families through loss.

4. Meeting close

Andy thanked those who attended the meeting and the speakers for their presentations.

He shared that we are currently planning the work of the APPG for 2026. The APPG will have a meeting focusing on mental health and hope to secure time with Baroness Amos around the investigation.

Please contact the Secretariat if there are any other topics you would like highlighted next year.