



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

Wednesday 15th December, 09.30-11.00, via Zoom

MINUTES

Members and representatives in attendance:

- Cherilyn Mackrory MP (Co-Chair)
- Rt Hon Jeremy Hunt MP (Co-Chair)
- Sharon Hodgson MP
- Sarah Owen MP (+ Representative)
- Angela Crawley MP (+ Representative)
- Representative of Victoria Prentis MP

Speakers:

- Ros Bragg, Maternity Action
- Dr Clea Harmer, Sands and BLAW Alliance

Other guests:

Aaron Nathaniel	Sands
Aimee Middlemiss	LSE
Alex Mancini	Chelsea & Westminster NHS Foundation Trust
Alia Hussain	Sands
Ann Chalmers	Child Bereavement UK
Becki Crook	University Hospitals of Leicester NHS Trust
Beth Duffell	Twins Trust
Beverley Radcliffe	The Coroners' Courts Support Service
Caroline Brogan	Irwin Mitchell Solicitors
Charlotte Hill	ONS
Dawn Brown	Switch Lanes Life Coaching
Emily Barnes	DHSC
Emily Lewis	Royal College of Obstetricians and Gynaecologists
Fauzia Paize	Liverpool Women's Hospital NHS Foundation Trust
Gemma Quayle	ONS
Geoff Heaps	The Lily Mae Foundation
Gillian Weaver	Human Milk Foundation
Jane Fisher	ARC UK
Jane Plumb	Group B Strep Support
Jenny Chambers	ICP Support

Jenny Ward	The Lullaby Trust
Jess Reeves	Sands
Jo Bennett	Chelsea & Westminster NHS Foundation Trust
Karen Burgess	Petals
Kate Mulley	Sands
Kate Putman	NHS
Katie Smith	Greater Manchester Mental Health NHS Foundation Trust
Kirri Gooch	
Laura Atherton	Memory Milk Gift Initiative
Lindsay Oliver	Aching Arms
Lisa Cooper	JOEL - The Complete Package
Louise Bowman	Twins Trust
Louise Zeniou	CRADLE
Lucy Smith	University of Leicester
Marc Harder	Sands
Mehali Patel	Sands
Murina Orza	The Ectopic Pregnancy Trust
Natalie McKie	The Lullaby Trust
Nicky Lyon	Campaign for Safer Births
Oliver Plumb	Group B Strep Support
Paula Abramson	Bereavement Training International
Rich Boyd	Twins Trust
Roopal Shah	Babyloss Support – Leicester, Leicestershire & Rutland
Rosie Allen	DHSC
Ruth Bender Atik	Miscarriage Association
Ruth Matthews	University of Leicester
Sharon Coaker	Petals
Sian Drinkwater	Maternal Mental Health Alliance
Sian Ness	Mid and South Essex NHS Foundation Trust
Surindar Nagra	Coventry and Warwickshire Partnership Trust
Veronique Berman	Chana Charity
Vicki Robinson	Miscarriage Association
Zoe Jones	ONS

09.30: Welcome & introductions (Cherilyn Mackrory MP, Co-Chair of the APPG on Baby Loss)

Cherilyn opened the meeting and welcomed everyone.

09.35: APPG updates (Cherilyn Mackrory MP, Co-Chair of the APPG on Baby Loss)

Cherilyn provided some updates on APPG Activity since the last meeting, and over 2021:

Screening for Breech presentation – update from Professor Gordon Smith

Cherilyn outlined that The National Screening Committee and the National Institute of Health Research Health Technology Assessment have agreed to fund a study on the training of midwives to perform 36-week presentation ultrasounds, with applications open until 30th March 2022. Cherilyn noted that this is positive, and things are going in the right direction and that it would be good to keep an eye on progress and ensure the rollout is not delayed. She also fed back to the meeting that screening has already been rolled out as the 'gold standard' procedure in several maternity units across the UK.

Maternity Charging

Cherilyn outlined that this update would be covered further in the next agenda item led by Maternity Action

Response to the Health and Social Care Select Committee report on the safety of maternity services in England

Cherilyn noted that a Government response on the above report has been received and that the APPG will look to pick this up in business in the New Year.

Baby Loss Awareness Week Debate in the Main Chamber

Cherilyn highlighted to huge success and importance of being able to have the Baby Loss Awareness Week Debate in the Main Chamber.

09.45: Maternity Charging (Ros Bragg, Director of Maternity Action)

Cherilyn introduced Ros Bragg and noted Maternity Actions work in supporting pregnant women, new mothers and their families with maternity rights, as well as their new report, 'Breach of Trust'.

Ros explained the work of Maternity Action to support pregnant women with advice relating to employment, social security and access to NHS healthcare, supported by lawyers. Maternity Action also do activity on NHS charging, notably their work promote access, cancel debt and bills where women have been wrongly charged, and secure write-offs for women unable to pay. Ros also outlined the demographics reached by Maternity Action – 85% minority ethnic, 78% on an income of less than £10,00 p.a., and over half have insecure immigration status included undocumented women and failed asylum seekers.

Ros gave a short explanation of how NHS Charging works, outlining that charges apply to those 'not ordinarily resident' in the UK and that there are exemptions. Maternity care is chargeable, but it is classed as immediately necessary so care should not be refused or delayed due to charging. The Breach of Trust report found

that NHS Trusts made errors in assessing immigration status, meaning women were often incorrectly charged. Trusts often refused to write off debts or accept payment plans and used an aggressive approach to demanding payments, including debt collectors. Women were found to be experiencing high levels of stress and anxiety around charging, were deterred from attending maternity care appointments, and went without food and essentials to repay debts to Trusts.

Ros explained Maternity Action's key asks— ideally, the immediate suspension of charging for NHS care. However, in the meantime, the focus should be on changing poor practice and adopting proper guidance on charging.

Cherilyn asked how the APPG can support this issue, and if there is any more that the Department for Health & Social Care (DHSC) could do to support as well. Ros outlined that raising to the DHSC and NHS England will help guarantee that Trusts across the country have information on the correct practice.

Angela Crawley MP asked a question regarding the implementation of charging across the UK, and good guidance in practice. Ros outlined that Maternity Action receives much fewer calls from Wales, Scotland and Northern Ireland and that she does not think 'good practice' is present anywhere, simply that there is better compliance with the rules.

Becky Crook asked if charging still occurs if a baby is stillborn or if a neonatal death occurs. Ros outlined that this is the case.

Actions: The APPG will raise the issue of maternity charging with the relevant Minister.

10.05: Miscarriage Leave (Sarah Owen MP, Vice-Chair of the APPG on Baby Loss)

Jeremy outlined that unfortunately the Minister for Small Business, Consumers & Labour Markets, Paul Scully MP, was unable to attend this meeting, however, that the APPG will take any outstanding questions to the department.

Jeremy outlined that currently, parents that experience the loss of a child between twenty-four weeks of pregnancy and up to 18 years of age receive two weeks of paid bereavement leave under the Parental Bereavement (Leave and Pay) Act 2018.

Sarah explained the remit of her 10 Minute Rule Bill which would extend two weeks of paid bereavement leave to those experiencing baby loss or miscarriage before 24 weeks. Sarah outlined that emotional and physical wellbeing after a miscarriage

must be supported by workplaces and that public campaigning has brought this into the spotlight.

Sarah outlined next steps to progress this and secure an amendment for extending Bereavement Leave. She recommended look at future legislation, noting the new Employment Bill or potential further legislation on Worker's Rights. She also noted the need to ensure we are not relying on good employers for this, as this may miss those most vulnerable in our society.

A question was received from the floor asking whether the Government would lead the way on this legislation, introducing this Leave to their employees. Jeremy gave his support for this idea and suggested speaking to the Minister for Patient Safety and Primary Care, Maria Caulfield MP, about this at a future meeting. Cherilyn noted work that she has been doing with Minister for Small Business, Consumers & Labour Markets, Paul Scully MP, and how a meeting with stakeholders would be a good next step.

Sarah noted another question that has been received from the floor, asking if her Bill includes losses due to TOPFA (Termination of Pregnancy for Foetal Anomaly). Sarah responded that this would be the case.

Actions: The APPG will raise the Miscarriage Leave Bill with the relevant Minister and look to organise a stakeholder meeting.

10.30: Baby Loss Awareness Week follow up (Dr Clea Harmer, BLAW Alliance/Sands)

Jeremy introduced Dr Clea Harmer, Chief Executive of Sands, and Chair of the Baby Loss Awareness Week Alliance.

Clea updated on Baby Loss Awareness Week (BLAW) 2021. Over 100 charities took part, with over 34,000 visitors to the BLAW website (84% of which were new), and 200 buildings lit up pink & blue. BLAW also had a fantastic media reach, with over 1,200 mentions of BLAW across TV, radio, newspapers, and news or consumer media websites and 112.1m opportunities to see BLAW activity.

Clea highlighted the success of the BLAW 2021 Debate in Parliament and thanked the APPG for the support, particularly Cherilyn and her office. 3,000 people took part in an e-action to encourage their MPs to attend, and half of the MPs that did attend the debate were new to BLAW. There was also an increase in men speaking, those involved who were not directly affected by baby loss, and speakers on a wide range of topics. Clea also noted the positive response from Maria Caulfield MP, and that a formal response is expected.

Clea ended her presentation by informing everyone that next year is the 20th anniversary of BLAW, so asked anyone with any ideas for commemorating the special anniversary to please get in touch.

10.40: Any other business

Jane Plumb from Group B Strep Support asked a question relating to the use of ECM (Enriched Culture Medium) testing in the NHS to detect Group B Strep, and if there is any progress on making this standard practice.

Marc Harder, National Bereavement Care Pathway Lead for Sands, asked a question relating to bereavement care, and when we can expect a response from the Government on this.

Nicky Lyon from Campaign for Safer Births asked if there could be an update via email on the timescale of the Breech presentation study. The APPG Secretariat will circulate this.

Ruth Bender Atik from The Miscarriage Association asked if there was an update on the Pregnancy Loss Review, especially regarding optional registration for pre-24 week losses.

Actions: The APPG Co-Chairs will write to the Minister, Maria Caulfield MP, to raise the following questions and issues from today, as well as invite her to the next meeting.

Cherilyn closed the meeting and thanked all for attending and speaking. The next meeting will be in the New Year.