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

**Wednesday 12<sup>th</sup> September 2018**  
**16:30 -18:30**  
**Commons Committee Room 6**

**MINUTES**

**Parliamentarians**

Sharon Hodgson MP (Vice-Chair)  
Will Quince MP (Co-Chair)  
Antoinette Sandbach (Co-Chair)  
Patricia Gibson (Vice-Chair)  
Baroness Benjamin

**External guests**

Andrew Fellows – Office of Victoria Prentis MP  
Beth McClevery – Bliss  
Catharine Wozniak – Office of Victoria Prentis MP  
Daniel Ellis – Office of Will Quince MP  
Dr Celia Burrell, Queens Hospital  
Erin McCloskey – Canterbury Christ Church University  
Jane Denton – Multiple Births Foundation  
Jane Scott - Imperial College NHS Trust  
Julia Bueno – Pregnancy Loss Support/author  
Karina Russell – Royal College of Obstetricians and Gynaecologists  
Kate Mulley – Sands  
Keith Reed – Tamba  
Lauren Hutton – Imperial College Healthcare NHS Trust  
Leanne Turner – Aching Arms  
Lucy Smith – University of Leicester  
Mohammed Omar – Gardens of Peace  
Munira Oza – Ectopic Pregnancy Trust  
Natalie Shenker – Human Milk Foundation  
Natallie Hoare – Mama Academy  
Paula Abramson – Child Bereavement UK  
Penny Kerry – Miscarriage Association

Ruth Bender Atik – Miscarriage Association  
Ryan Jackson, Lily Mae Foundation  
Sam Warren – Department of Health and Social Care  
Vasita Patel – Office for National Statistics  
Zoe Clark-Coates – Mariposa Trust

## **1. Welcome and introductions (Co-Chairs of APPG on Baby Loss)**

Antoinette Sandbach MP welcomed the attendees. One amendment to the previous minutes was received: to add Mohamed Omar to the attendance list.

## **2. Legislation and initiatives update (Co-Chairs)**

- **Parental Bereavement (Leave and Pay) Bill**

Antoinette outlined that this Bill aims to make provision for at least two weeks paid leave for employees whose child has passed away (up to the age of 18). This has now passed the Commons and has successfully passed the 3<sup>rd</sup> Reading stage in the Lords. The Bill awaits Royal Assent tomorrow. This is the first time we will have paid bereavement leave in the UK.

Antoinette gave her thanks to Kevin Hollinrake MP who sponsored the Bill, and to Will who originally did a 10-minute Rule Bill in support of this issue.

- **Civil Partnerships, Marriages and Deaths (Registration Etc.) Bill**

Antoinette explained that the relevance of this Bill to the APPG: this 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 is awaiting its Report Stage and 3<sup>rd</sup> Reading in the Commons (i.e. final chance for amendments to be made), which is scheduled for 26<sup>th</sup> October.

Baroness Benjamin said that she will be taking a keen interest in the Lords when this Bill comes through, to ensure compatibility with her own 'Certificate of Loss' Bill.

- **Pregnancy Loss Review (Department of Health and Social Care)**

Antoinette outlined that following the presentations from the Co-leads of the Review at our last meeting, this Review is ongoing. We understand that the timeline has been extended. Antoinette asked Zoe Clark Coates (Mariposa Trust), one of the Review's co-leads in attendance, for a short update. Zoe said that the process is going very well, with the report being anticipated being delivered in January/February.

## **3. The whole family: support for the wider family and community**

- **Baby loss in Muslim families (Mohamed Omar, Gardens of Peace)**

Will Quince MP introduced Mohamed Omar. He been actively involved with community work in East London for the last 15 years. He works with various charities in these roles:

- Board member – External Affairs, Gardens of Peace Muslim Cemetery, based in Hainault Essex. This is the largest dedicated Muslim Cemetery in Europe and has a capacity for 10,000 graves and burials in accordance with Islamic Shariah
- Chair of the National Burial Council, an umbrella body for all Muslim Community dealing with burials and Deaths
- Vice Chair of Oaks Park High School in Ilford. Oaks park is a community school and the only PFI school in the borough
- Trustee of The Big Issue Invest, an organisation funding social enterprises that are not able to obtain funding from banks
- Trustee of Haven House Children's Hospice in Woodford

Mohamed is also a:

- Member of the Burial Cremation Advisory Group at the Ministry of Justice representing the Muslim Community
- Member of the advisory group on Counter Terrorism at Scotland Yard
- Executive Member of the Federation of Redbridge Muslim Organisations (FORMO)

Mohamed explained that the concept of discussing death is not something that is taboo or frightening within the Muslim community. For a Muslim, in any death, whether it is a stillbirth or a death later in life, there are many aspects of the faith that must be respected. Presentation slides are available from the APPG website, of which brief notes have been taken below.

For example, a quick burial is essential, including all foetal remains that come from the mother. Post-mortems are also restricted, as there is a belief that this desecrates the body. Mohamed said that the aim would be for non-invasive post-mortems.

The Muslim community is perhaps 3 or 4 more times likely to have a stillbirth than other communities. This is part of the reason that Gardens of Peace works on this issue, to work to identify and alleviate any underlying factors for this issue. Mohamed explained that Gardens of Peace have been working with Sands and other organisations to understand the factors involved, including social, health and cultural issues.

Gardens of Peace have created a tailored Muslim Bereavement Support Service. This is specifically offered for Muslim women at this stage, but will soon be extended to the whole community, with volunteers trained by professionals in order to support. Some communities still believe that a stillbirth or birth defect is the fault of the woman, a misconception is what Gardens of Peace is trying to combat. Gardens of Peace have also seen that men can be affected by baby loss as much as women.

Mohamed said that he has washed perhaps 1,000 people in preparation for burial, but the hardest experience is always to wash a child or baby. 46% of all Muslims who die in London are buried at Gardens of Peace, and almost 80% of Muslims who die in East London.

Antoinette asked what the facilities outside London are for Muslims. Mohamed answered that the majority of councils will hold a section of their local cemeteries for Muslims. Gardens of Peace are in touch with all councils to educate them about the proper means to honour the Muslim dead. An important aspect is to keep every grave identical – all are equal in death. He added that Gardens of Peace offer training to hospitals.

Baroness Benjamin asked if the Gardens of Peace cemetery is open to visit. Mohamed said all are welcome to visit.

Natalie Shenker (Human Milk Foundation) asked if there are any specific aspects that need to be considered in Islam when donating milk. Mohamed replied that according to Islamic law, babies should just be fed from the mother, but he says that this is often more flexible in practice. The Prophet himself was fed by a wet nurse.

Ruth Bender-Atik (Miscarriage Association) said that she had heard that there is a prohibition on photographing a stillborn or miscarried child. Mohamed said that with photography in general there are two schools of thought. The orthodox view says no photography at all, the more moderate view would say a photo is ok as long as you are not taking a photograph to use for worship.

Munira Oza (Ectopic Pregnancy Trust) asked to what extent does Gardens of Peace engage with the specific needs of the different Muslim communities? Mohamed answered that the Gardens work with each and every sector. We urge all who come to our cemetery not to preach about their own personal set of beliefs.

Keith Reed (Tamba) suggested that given the points made about the higher rate of stillbirth in Muslim community, this could potentially be a subject for a confidential government inquiry. Mohamed agreed, but stressed it would need to be considered carefully and handled sensitively.

Antoinette thanked Mohamed for his presentation. Mohamed extended the offer of a visit to the Gardens of Peace to all in attendance.

- Support for siblings after baby loss (Ryan Jackson, Lily Mae Foundation)

Antoinette introduced Ryan Jackson from the Lily Mae Foundation. She gave a short outline of his biography.

Ryan, along with his wife Amy founded The Lily Mae Foundation following the loss of their second child Lily Mae Jackson in February 2010. Formerly a PE teacher, Child Protection and Safeguarding Officer in Birmingham, Ryan chose to give up his job in teaching in December 2016 to put all his efforts into growing the charity across the Midlands. Along with the help and support of the Charities board of trustees, Ryan has been able to grow the charity and expand their services across the Midlands.

Ryan spoke about sibling grief, and the Lily Mae Foundation's siblingsgrieve2 campaign. He explained that we have an understandable impulse to shield children from painful realities. He wanted to protect his three-year old son Alfie (now 12) from what was happening when his daughter Lily died. However, Ryan said that we emphasise with children that they should be always be truthful, so we should be truthful with them too.

Children ask questions and want to know about what has happened. Alfie has recently become more involved in the charity. Freddie has grown up knowing that he had lost a sibling, but had never met her. Ryan said Freddie recently asked him: “what memories do I think about if I didn’t even meet her?”

To highlight the needs of siblings after baby loss, Ryan said that the Lily Mae Foundation is starting the #siblingsgrieve2 campaign. There are a range of charities that provide support for siblings, and they would like to work the other charities involved in the APPG. The Lily Mae Foundation is working with FreeRadio, the biggest radio station in the Midlands, to offer an activity day for children to go out with each other and remember their siblings. This will launch in November at Hatton Country World which has a range of activities. Ryan suggested this could run this as a carousel event, with various groups from the charities.

Drew said that he will put out an email to the APPG about the campaign when it launches, following notification from Ryan.

Antoinette thanked Ryan. She said that this work is incredibly important, and said she had received support on helping sibling support

#### **4. Charlie’s Law (Antoinette Sandbach MP)**

Antoinette introduced the discussion on Charlie’s Law, and seek input from the attendees.

Antoinette gave some background to the Charlie Gard case. At less than 2 months old, Charlie Gard was admitted to hospital at the end of September 2016 to treat a rare a serious mitochondrial condition. Three months after admission, his parents disagreed with the course of treatment offered by the hospital. This became a high-profile and controversial case. Charlie died on 28<sup>th</sup> July 2017.

Following the death of Charlie Gard, a proposed ‘Charlie’s Law’ seeks to achieve three things. Firstly, it aims to prevent disputes between parents and hospital staff going to court by giving access to mediation and clinical ethics committees. Secondly, to ensure that when disputes do go to court, that legal aid, advice and other support is offered to families. Thirdly, the proposed legislation would restrict court involvement to cases where there is a risk of ‘significant harm’.

Charlie’s parents have been working with high-profile medical professionals behind the scenes. Last week, two peers put down an amendment to a Bill going through the House of Lords which would encapsulate the aims of Charlie’s Law. Antoinette emphasised that this proposal is not about putting parental supremacy over decisions over medical advice, but changing the test on which these decisions are made.

Antoinette asked whether the attendees feel that the APPG should be involved in this debate.

Mohamed Omar (Gardens of Peace) said that he feels we should support Charlie’s Law. When the dispute moves into the legal arena, this can become more high-profile and detrimental to all involved. He also feels that some health professionals require more or different training to help in making these decisions as well as communicating with the families.

Will said that this is a highly worthy issue, but questioned whether this fits within the scope of this APPG. We have a great deal of work to do with our agenda.

Paula Abramson (Child Bereavement UK) said that it is really encouraging to hear that Charlie's parents are challenging this experience, but would agree with Will this may not be within the scope of this APPG. She recommended speaking to Dominic Wilkinson, Professor of Medical Ethics, who is an expert on this area. Antoinette thanked Paula and said she would contact him.

Kate Mulley (Sands) suggested that it would be useful to work with one of the Children's APPGs. Within the Children's Act, the concepts of significant harm and best interest work together. Francine Bates (Lullaby Trust) said that we could bring the APPG together with the APPG for Children to debate this issue.

Patricia Gibson MP suggested bringing in Prof Wilkinson to speak to a future meeting, if the parliamentary schedule allows. Events are progressing quickly as the amendment is in the Lords now.

Jane Scott (Imperial College) said the effect on the staff should also be taken into consideration. Some were intimidated and attacked over the Charlie Gard case. Antoinette said she had seen a similar impact with a similar case at Alder Hay Hospital closer to her constituency.

Antoinette thanked the attendees for their thoughts, and the APPG members will consider the best next steps based on their input.

## **5. Baby Loss Awareness Week 2018 update (Kate Mulley, Sands)**

Kate Mulley (Director of Research, Education and Policy at Sands) gave an update on the plans for Baby Loss Awareness Week, with input from Drew Lindon (Policy and Campaigns consultant) on Westminster activity over that Week.

Kate thanked the APPG members and the guests for all your work on this already. She explained that Baby Loss Awareness Week takes place from the 9<sup>th</sup>-15<sup>th</sup> October, involving over 60 charities in the UK. More information can be found on <https://babyloss-awareness.org/> There are a wide range of remembrance events taking place across the country, many for specific faiths, and many events which are not faith related. The Week culminating in the global Wave of Light, where parents light a candle at 7pm local time and leave it burning for an hour. People are encouraged to share pictures of their candle on social media at this time, so that the images spread across the world in a similar wave.

Kate explained that the Baby Loss Awareness Week alliance of charities have also prepared a set of packs for hospitals and NHS areas, as well as shops and business to help them create displays for the week. Sands are also collating a list of buildings and landmarks who will be lit up with pink and blue.

The alliance is also creating an animation to be launched at the beginning of the week, which aims to raise awareness of the scale and range of the people affected by the baby loss. The documentary Child of Mine, following three couples following their experiences of

baby loss, will be broadcast on Channel 4 on 8pm on 15<sup>th</sup> October, with some local screenings also organised.

Kate said that the policy focus this year is on the National Bereavement Care Pathway. We want people to get the best possible bereavement care wherever they live, whenever they need it. The Pathway is live in 32 NHS sites, and the team been developing and revising the documentation based on the feedback received. We have now also created 9 core bereavement care standards with the charities and other organisations involved, and will be publishing these in the Week with the backing of the APPG Co-Chairs. We will be asking people to push NHS bodies to adopt the National Bereavement Care Pathway locally. This is a really positive story about what has been achieved already, and what could be achieved for bereavement support if the Pathway is embedded everywhere.

Kate said that there is also a range of activity taking place in the legislatures across the UK nations.

In the Scottish Parliament, we have a drop-in event for MSPs on the 3<sup>rd</sup> October, sharing the standards and updating on progress. We are also seeking a debate.

In the Wales Assembly, we are also seeking a backbench debate in Wales Assembly, and will be holding a remembrance event

We are working with the civil servants in Northern Ireland to push forward on uptake of the Pathway (the Northern Ireland Assembly is currently not sitting). We will be briefing some Assembly members, and there will be a memorial walk on the 13<sup>th</sup> October.

Drew outlined the activity due to take place in Westminster:

- There will be a set of standing displays about baby loss, bereavement support and the Pathway in the House of Commons' Upper Waiting Hall display from Monday 8<sup>th</sup> – Friday 12<sup>th</sup> October
- The APPG has organized a backbench business debate on Baby Loss Awareness Week on the afternoon of Tuesday 9<sup>th</sup> October
- The APPG will host a drop-in launch event in the Jubilee Room, from 9:00 – 13:00 on Thursday 11<sup>th</sup> October. There will be speeches from 12:00
- Straight after the launch event, there will be a remembrance service held in the Undercroft Chapel from 13:00 – 13:45

Will added that the APPG and Sands are also putting together a set of vox pops videos; brief messages from MPs, Minister, Shadow Ministers, and some metropolitan Mayors expressing their support for the Week. We will share these on social media as well as pull together a single montage. We have recorded 28 videos in total so far.

Will added that his office is also writing to go to every local authority and place of worship asking them to light up their buildings.

Francine Bates (Lullaby Trust) said that the charities have also made an approach to the NHS Chief Executive to ask them to write to all NHS Trusts in England about the standards.

Antoinette gave her thanks to Sands and all the other charities in delivering the Pathway and these standards. On behalf of the APPG she said that she was very grateful for all their help and hard work.

## **6. Any other business**

No other business was raised.

**7. Next meeting:** 10<sup>th</sup> December, 16:00 – 18:00