My first born, Johnny, was stillborn at 24 weeks gestation. Tests and autopsy identified that Johnny had a hypercoiled umbilical cord and I was diagnosed with MTHFR. The conclusion was that the hypercoiled umbilical cord combined with the MTHFR reduced the blood flow to Johnny and ultimately his heart stopped beating.

I was already considered to have a 'high risk' pregnancy, due to an unrelated issue (Unicornuate Uterus). This meant I was being closely monitored by my Obstetrician and was having regular scans to monitor fetal growth and my cervix.

I would like to address the following terms of reference:

1. coordination between Australian and international researchers;

   My son died due to a hypercoiled umbilical cord. At this time of his death, the research and diagnosis of hypercoiled umbilical cords was more advanced in the UK and was routinely scanned for. As mentioned, due to being 'high risk' I was closely monitored and was having regular scans however the hypercoiled umbilical cord was not detected. Further training of radiographers and improved technology, such as that in the UK would assist in the identification of hypercoiled umbilical cord.

2. consistency and timeliness of data available to researchers across states, territories and federal jurisdictions;
   As far as I am aware, there is not data on the rate of stillborn babies born to mothers with MTHFR. Research has identified that there is a link and based on my interactions with other Stillbirth Mothers, there is a high proportion who carry the MTHFR gene mutation. If data is available across the states, territories and federal jurisdictions, we would be able to identify just how much of an impact the MTHFR gene mutation has on the chance of stillbirth. This would potentially increase awareness and funding towards MTHFR screening and education.

3. sustainability and propriety of current research funding into stillbirth, and future funding options, including government, philanthropic and corporate support;

   Following my Sons death, I was diagnosed with MTHFR. This is not routinely screened for in Australia, however seems to be a commonality between other Stillbirth Mothers. There is not a lot known abut this gene mutation, especially my kind which is Compound Heterozygous. I am currently pregnant and am taking clexane daily (a painful blood thinning injection) 'just in case' as it has been shown to address other variations of MTHFR, however there is not enough research into my variation. I can't help but wonder why MTHFR is not routinely screened for, if it is such a common factor in stillbirth? Would my Son still be alive if I was diagnosed with MTHFR prior to his conception or during the early stages of pregnancy?