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## Introduction

This submission is based on my own personal experience of stillbirth. I hope that the insight of my experience will provide beneficial and crucial insights on stillbirth and the effects this has as a new mother/mother, as parents, as well as extended family members.

I would like to thank all the Doctors, Specialists and Social Workers who had provided their best care and attention during my stay in Liverpool Hospital. Most of all, my deepest appreciation goes to the nurses who were beyond sympathetic, who monitored me throughout my whole time being there, and who provided the most sensitive care. They definitely do not get enough credit.

## Background

On the 19<sup>th</sup> December, 2016, I had learned [from a home pregnancy test] that I was pregnant with our first baby. My husband and I had so many emotions – elated, scared, nervous...but excited. We went to my GP to do a blood test to confirm if in fact I was pregnant, and sure enough, the next day I received a phone call to confirm that we were expecting our first baby. Up until 18 weeks, we did 3 scans. First one being the dating scan, the next one being the Nuchal Translucency Scan, and the last one being the Morphology scan.

Everything was going well. All the test results were coming back normal, the baby's growth was normal. We were becoming more and more excited as everyday counted down. I started to notice at 27 weeks that my baby's movement weren't as strong as what they typically were. I remember advising my GP as well as my mid-wife that although I could feel foetal movement, it wasn't as strong. Both proceeded to use the Doppler and check the heart rate which was reading a normal rate.

At exactly 28 weeks, I had been scheduled in for my Anti-D injection at Liverpool Hospital. Again, I mentioned to the Doctor and Nurses there that the movement was there but not as strong. Again they used the Doppler to check the heart rate which had a normal reading. They measured my blood pressure which was a little higher on the first reading, but after waiting 5 minutes, the second blood pressure reading came back normal.

That very night (approximately 10:30pm) going to bed is when I knew something wasn't quite normal. I felt a huge, significant movement which was out of the ordinary. A part of me thought the baby had just done a big flip to get comfortable, but in the back of my mind was a worrying thought.

The next morning I woke up, and noticed that my bump had dropped. Again, I thought maybe this is what happens at 28 weeks? Having breakfast, I was expecting the usual kicks and movements, but didn't have any response. Orange juice, mandarins, ice... nothing was waking my baby. I went to work with a racing heart and kept trying to reassure myself. Still no movement. At 9:30, I called Liverpool Hospital – Maternity Ward to speak to a nurse and could barely talk through the tears – I knew something wasn't right. My manager had driven me to hospital, and I rushed up to the ward where the nurses had taken me into the Foetal Maternal Unit, to where my biggest nightmare was confirmed. There was no heartbeat. The shock was not allowing me to register what had just been said to me, what was going on. After that, a lot of what happened had become a blur.

My husband was called in to the hospital from the city – an hour’s travel by train. There is nothing easy about telling your husband, a father to be, that his little baby had died. We barely had time to let this sink in and go through any of the emotions before a social worker was sent in to discuss the next steps. We were told that because the baby had died after 20 weeks, a funeral needed to be done, give the baby a name and register the birth with NSW BDM. All this information felt like it was crashing down on us without us even accepting what had just happened. Team that with being asked how we would want to deliver our child, it just felt like our whole world had just imploded on us. Our decision was to be induced and deliver the baby as soon as possible. The idea of carrying something lifeless in me was going to take over my life as well.

We were taken into a private room in the maternity ward. The sound of crying babies became deafening to us. A couple of hours after that, we were seen by Dr Alex, who explained to us all the different tests they could perform in order to get as many answers as possible. My husband and I agreed instantly that we wanted all the answers, and to go ahead with whatever tests and biopsies needed. He then proceeded to explain the procedures of induction. From what I can remember, I had taken all four procedures. Medication, tape, ball and finally on the drip. It took 3 days before I was actually in labour. My first experience in child birth has been completely tarnished and ruined. Although the nurses were wonderful and supportive, the whole process of delivering a child that wasn’t crying or breathing is something no mother should ever have to experience. Particularly being the first time. At 5:45pm, 5<sup>th</sup> of June 2017, we delivered our beautiful baby boy, Andjelko (Serbian for Angel).

During the three days, we weren’t advised what was going on with the baby, what had happened or why this had happened. It wasn’t until delivery that the nurse had informed us that the baby had a true knot in his cord, as well as it being wrapped around his neck three times. The biopsy revealed that his cord length was twice the normal size – at 28 weeks, a typical length is about 400mm. Andjelko’s cord length was 795mm. Everything else with his development had come back as normal.

After the trauma of burying our son, I spent my time trying to find more answers. I read books about mothers who had the unfortunate experience of stillbirth and child loss, how they coped and life after loss. What I realised from most of the mothers who suffered with stillbirth, was that they all experienced the same ‘significant movement’ I had experienced with my son. The most interesting book that I came across and that I could actually relate to the most, was called “Silent Risk: Issues about the Human Umbilical Cord” by Jason H. Collins. This book had everything I was looking for in Umbilical Cord Accidents. What became clear to me, is that there aren’t enough resources or research into UCA related mortalities.

I understand that there is little anyone can do with the baby in utero, particularly when it involves the cord. I understand that accidents happen, albeit traumatic. However what I had noticed, is that there is a large gap between check-ups and scans with expectant mothers. I am pregnant again with our second child, and had personally requested to have regular check-ups every three weeks. If I could, it would be every week. I’m sure I speak for all pregnant mothers, that there should be more frequent scans, more education into foetal movements and what’s deemed ‘normal’, and of course – there needs to be more research and studies not just into Umbilical Cord Accidents, but across the board for all stillbirth, miscarriages and child loss where a diagnosis is not available.

## Terms of Reference

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

The statistics on miscarriages, stillbirth and child loss has not changed in a little over 20 years. One in four pregnancies end in a miscarriage, stillbirth or child loss. In this day and age, with the technological advancements we have, I struggle to comprehend that this figure has not reduced in the slightest.

When we buried our son, I was visiting his resting place every day for weeks on end. Almost every week after that, there was a new burial in the baby section. This became more and more clear to me that the number of families experience this trauma just didn't seem right at all.

My husband and I set up a fundraising page to raise money for two charities that had helped us – Stillbirth Foundation Australia, and Bears of Hope. Our goal was to raise \$5,000 in total, and to be split between the two charities. We managed to raise just over \$5,000 in just a few weeks from the amazing generosity of family, friends and colleagues.

These are just two of the number of organisations that are out there to provide support for those dealing with loss. Each of these organisations rely on donations from individuals, companies and fundraising groups. What they need more of, is government assistance into the research of miscarriages, stillbirths and child loss so that each case has a diagnosis and an explanation as to "why".

### e. research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education;

We are in an age of personal devices that track everything from dietary intakes, to heart monitors, to mood trackers. We are now able to see our babies in 3D / 4D. There are tests that are able to detect chromosomal abnormalities. Although not something I support, you are now able to select your child's gender.

I fail to believe that there aren't enough advancements to detect foetal abnormalities, umbilical cord accidents, sudden deaths, etc. In the book "Silent Risk: Issues about the Human Umbilical Cord", there are ways to detect the cord location, blood flow, insertions, compositions, cysts....all the things that play a fatal risk on the development of the baby. This book also discusses how the cord should be addressed more closely during the 18 week (Morphology) scan. I believe it should be monitored throughout the pregnancy.

Pregnant mothers should be educated during the early days of pregnancy of risks to be aware of. No one knows their child better than its mother. However, in order to reduce the number of foetal deaths, educating a mother in the early days of foetal movements, understanding what to feel at what time, can help make some kind of a difference.

### f. communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy;

New parents should be made aware of all the potential risks associated with pregnancies. It's a wonderful experience to learn that you are bringing another life into this world, but it's a

responsibility a mother needs to learn from the moment the embryo is formed. Understanding foetal movements and recognising certain patterns, becoming familiar with baby's patterns and being in tune with its movement is crucial.

I am blessed to have not just my sister pregnant at the same time as me, but my best friend as well. As much as I didn't want to scare them, I felt I needed to make them aware of what's normal in foetal movements. It's important for all pregnant mothers to know that they can go to their OB or hospital if ever in a moment of doubt – something that I believe is not encouraged enough by Doctors.

*h. any related matters*

Now with my second pregnancy, I do experience anxiety about the wellbeing of my baby. I have a home Doppler for my 'peace of mind' but I know I cannot completely rely on that bit of technology.

At 17 weeks, I went to emergency at Liverpool Hospital as I had concerns with my baby. I had advised the nurses and doctors when I went in of my history. I waited in the waiting area for at least 4 hours before I had been seen. Once I was called in, I was met with a young Dr who proceeded to advise me that he had tried to get a midwife to come down with a Doppler, however because I was *under 24 weeks*, I wasn't considered 'high risk' enough. Personally, I took this as a major flaw in the hospital system (not just in Liverpool, but across the board). Any mother, irrespective of her pregnancy history, should be entitled to receive attention if they have any concerns with their pregnancy. Early detection in foetal activity is crucial information in order to reduce the number of pregnancy and child loss in Australia.

I would like to acknowledge the mothers, parents and families who have gone through such a heartbreaking ordeal for opening up and sharing their stories. It is never easy to re-tell the story, but every time we open up and speak about our angel babies, it helps us heal that little bit more. We shouldn't be shying away from our experiences, rather we should be educating. The more it's out there, the more awareness it will receive, and the more babies can be saved.