**Written submission from a member of the public (ANI0339)**

**Introduction:** My name is [name]. I am writing to the committee to share my own story of my beautiful daughter, [name], who was born with [condition]. [Name] only lived for a very short time, but the time we had with our little angel was so precious, and having that time with her helped us hugely in coming to terms with our terrible loss. Losing her is the hardest thing I have ever had to go through – other families in this situation need the loving answer of perinatal hospice care to allow them invaluable time with their babies. Abortion ends the life of these special babies, and robs families of the chance to meet their beautiful babies. The law in Northern Ireland should continue to protect babies like [name] from being aborted, and more funding should be given to proper medical services like perinatal care.

**Executive Summary:**

- My daughter [name] was born with a syndrome called [condition], on [date].
- [Name] weighed [weight] and had [0-5] precious hours on this earth.
- Sadly, some parents are told that their baby may not live for long after birth, or might not make it to birth at all.
- These parents need our full support and love - and proper medical services so that they can make every moment count.
- Abortion is not a realistic or compassionate solution for families like ours
- In contrast to the loving answer given by perinatal hospice, abortion ends the life of these babies by lethal injection or worse.

**Testimony:**
My precious daughter [name] was born with a syndrome called [condition] on [date]. This is the second most common syndrome in the UK after [condition]. The third syndrome is [condition].

This was something I had never heard of until the day my daughter was born and although throughout my pregnancy I knew that she had some problems with her kidney and bowel, I never expected the outcome! It all started when I was 20 weeks pregnant and so I was told that [name] had an enlarged kidney, I was brought back at 24 weeks to learn that it was slightly bigger and so they were going to keep an eye on this. At 28 weeks I was scanned again and was told she had dilated bowel loops and so I began to panic. Like most worried mothers I was scared as I had [0-5] normal straightforward healthy pregnancies before and so this all came as a terrible shock. At 30 weeks I was scanned again and was told that although she has gained some weight from the 28 week scan, she was under the average weight.

I also was then told there was a little fluid on the back of her brain and this is when I completely lost control and was inconsolable, I was so scared of what was going to be and so I was offered an amino test as the doctors predicted that this was chromosomal or genetic related. They give a few days to think about it, but I decided not to have it as I was told there was a very small chance I could go into labour after having this procedure. I thought with my luck I would be the one to go into labour, and because I was told my baby girl was underweight, I thought I was doing better by keeping her tucked up safe and warm and gaining weight and continuing on with my last 10 weeks; little did I know what lay ahead.

Like I say, I had [0-5] other children previous to [name] who were all healthy weights and sizes and so this made me panic more as I carried [name] smaller and didn’t feel her move as much as the others. I convinced myself that she was just going to be a wee petite and tiny baby that may have needed extra care or maybe an operation or medicine to fix her problems when she was born.
On the [date] this year I went to bed normal and lay waiting to feel her move and felt very little movement, I done this on the [date] also and got up on the [date] with a mothers instinct that something wasn’t quite right. It was like my body was telling me something’s wrong. I was petrified! So I decided to go to the hospital just to hear her heartbeat that would have put my mind at ease that everything was ok.

I arrived in hospital at [time] and explained my concerns, so I was given yet another scan. The doctor scanning me explained that I was 34 weeks pregnant and that my baby girl was very tiny indeed and that she would like me to have amino test that day and receive the results in 2 days. At this stage I still didn't have a clue what [condition] was. So at [time] I had the amino by a different doctor. By this stage, myself, my husband and my mum were so scared, as we discovered on another scan that [name] had a hole in heart also. I thought I was going to pass out and faint – I was screaming and my heart sank.

Before I knew it, I was told that I was being rushed for an emergency Caesarian. I was not mentally or physically prepared for this and so by this stage I was in a terrible state. I got taken to delivery suite at [time] and at [time] my baby girl was here. I was shocked, scared, excited, all these things rolled into one. A doctor brought her to me and she lay looking at me with her beautiful blue eyes and I was then told she was going to the neo-natal unit. I couldn’t stop crying and begged them to get me back together as quickly as possible so that I could go to be with her. Seconds felt like hours.

The doctor then came back to me with tears in his eyes and said that [name] had [condition]. I began to say, “well that’s good you know what it is so you can fix it now” but he shook his head at me and suddenly my world and hopes and dreams of my baby [number] began to crumble. What he was telling me I couldn’t and didn’t want to believe. He said he was going to take me to be with her as things weren't good. So I was wheeled round and immediately wanted my skin to skin with my baby girl. By this stage, all our family was with us, I lay there looking at this perfect and amazing baby on my chest wanting the moment to never
ever end. She looked at me as if to say 'mummy I wanted to meet you as much as you wanted to meet me'.....at [time] [name] grew a set of angel wings and went on her endless journey to heaven

I wanted to share this with whoever takes the time to read it to testify to the preciousness of every baby – no matter how short a life may be, every baby deserves to feel love and to be protected. I made a promise to my angel that her memory will live on and on forever and ever and she will always be talked about every day. Losing her is the hardest thing I've ever dealt with, and so as this condition is quite common but a lot of people know nothing about it. After [name] passing, I decided to make a Facebook page and make my angel proud. If this helps some other parent of a [condition] child, I feel it may do some good sharing my story.

**Recommendations for Government:**

Sadly, some parents are told that their baby may not live for long after birth, or might not make it to birth at all. These parents need our full support and love - and proper medical services so that they can make every moment count. Most children diagnosed with these conditions like anencephaly and trisomy 13 do, in fact, live beyond birth - and some continue to astound their families and doctors.

For example, 70% of babies with anencephaly live after birth - and 30% of children born with Trisomy 13 live for longer than a month. These children have a right to their life, however short that life may be, and however severe their disability. You can see some of their beautiful stories

These children do not suffer in the womb or after birth. This claim is untrue and is upsetting to parents. Palliative care manages any discomfort or pain the baby may feel after birth, and before birth, baby is protected from any pain in the womb. Parents in this situation deserve much more than our sympathy however – they need us to put professional support systems in place. Perinatal hospice services provide
counselling, services and support to parents, who are then able to spend every moment possible with their child.

This hugely helps parents with healing and recovery from loss. Photographs and mementos of their child become very important. These services are not expensive to provide and make an enormous difference to parents.

Since [name] passing and hearing about the attempts to legalise abortion on babies like her, I have read a lot into this and the effects abortion has on the families of babies with life-limiting conditions. Mothers of babies with severe or fatal disabilities often suffer great trauma after abortion. Research has shown that aborting a baby with birth defects can be a “traumatic event…which entails the risk of severe and complicated grieving.”

One long-term study found that, for mothers who had aborted babies with fatal diagnoses, “a substantial number...showed pathological scores for post-traumatic stress.”

In contrast to the loving answer given by perinatal hospice, abortion ends the life of these babies by lethal injection or worse.

The right to life of all children with disabilities would be seriously impacted by allowing children to be aborted because life we deem their lives too short, or ‘too disabled’ for our world. Where then do we draw the line? In other countries, such as Britain – which 45 years ago legalised abortion for ‘severe disabilities’ - this has led to the terrible situation today where up to 90% of unborn children diagnosed with [condition] are killed.

Thanks for reading this. All for my angel [name], born [date] weighing [weight].

December 2018