

Lucy and Amelia's Story

PRENATAL AND NEW BABY

For new parents Lucy and Roberto, the birth of their beautiful baby Amelia should have been a time of joy and celebration, but with negative messaging from medical professionals about a Down syndrome diagnosis, their pre-natal experience was tinted with fear and uncertainty.

Lucy recalled the moment they received the results from a Genetic Counsellor, who shared the news as if it was a devastating, terrible outcome. Instead of saying congratulations to the expectant parents, the medical staff said they were sorry – “I remember thinking my baby isn't dying, why is everyone so sorry?”

Instead of providing useful, accurate and up-to-date information, the Genetic Counsellor went on to describe what they should expect of a baby with Down syndrome, stating that the baby would have moderate intellectual disability and describing physical features including small ears and stature. It all sounded like a warning.

Until changing hospitals, their early experiences continued to be negative. For their 20-week scan, they saw an obstetrician who said she had noted some suspected abnormalities in the heart and due to a minor intestinal obstruction, the amniotic fluid was building up, due to this there was a very good chance their baby's heart could stop at any moment. Lucy recalls this conversation; “She then, in the most insensitive tone possible asked if we wanted to terminate. I was a mess; my partner was furious. He frustratingly asked if she had anything positive to say? She just stared at us, and we got up and walked out.”

Lucy and Roberto spiraled into a very dark place after this. All the joy, excitement and celebration of becoming new parents had been taken from them.

A week later, now at a new hospital, the staff could see how distressed they were and quickly put their minds at ease that their baby's heart could not stop due to the buildup of amniotic fluid. Furthermore, they identified that she was perfectly safe, and her heart was functioning normally. There were no abnormalities with her heart, she had a minor intestinal obstruction which would require surgery after birth but everything else relating to the pregnancy was normal.



Knowing that her baby was safe, Lucy could now finally relax. But the fear she'd felt all week that she might at any point lose her baby had made that period of their lives one of the darkest and most challenging for their family. Not only did it impact their relationship, creating unnecessary added stress and worry, but it was also deeply traumatising for their parents and siblings.

>>> Lucy and Roberto would like to see the medical professionals involved in their early care to be better equipped with up to date information to be able to offer them positive and constructive information so new parents could feel empowered and educated and enter this beautiful journey the right way so that we can give our children the best opportunities and support for the best life possible.

Connecting with Down Syndrome NSW was a turning point for their family. They were visited by staff with a shared lived experience, who were able to pass on positive and encouraging messages about their own children's achievements and challenges. With the right advice and information provided, Lucy and Roberto found comfort and support in the Down syndrome community.

Now, at 6-months old, Amelia is a thriving, happy, and beautiful baby girl. She loves playing on her play mat, she is active and strong. She can roll over onto her belly and looks so proud of herself when she does. She gives Lucy and Roberto endless smiles and sweet giggles and has enriched their lives beyond belief. Most importantly, they are so proud that she is their daughter.

"Knowing that they were just a phone call away was and is so helpful and we are very thankful for such a supportive and proactive organisation for our loved ones. We can't thank Down Syndrome NSW enough. We've already learned so much and met some amazing people who are part of this community. I really enjoy the online fortnightly New Parent sessions and got so much out of the sign language course we participated in during pregnancy. It is so wonderful that there are so many educational sessions made available to us and I really enjoy receiving Emily's organisation updates so we can plan ahead and feel so positive about Amelia's future. To know that DSNSW and so many inspiring people are advocating for our loved ones really means the world to us."