

"In my words: My story with Down Syndrome"

by Sally Fetouh

I open my still sleepy eyes to the gentle words, "Huggy mummy?" I feel tiny arms wrap around me and a warm kiss planted on my cheek. I smile, and Jana asks, "Are you happy, mummy?"

Yes, I'm happy, Jana. I couldn't be happier.

Six years ago, it was a time of confusion and grief. My pregnancy was mostly smooth, but it was the last trimester when everything got a bit erratic. Scans seemed to reveal excess fluid around the baby. One scan would reveal a problem with the baby's heart. The next week it would be okay but would show a problem with the baby's stomach. None of the doctors could explain what was going on. It was a source of massive stress. We were referred to the Maternal-Fetal Medicine Department at the Royal Women's Hospital in Randwick. It was my first exposure into the world of Down syndrome through the most amazing, kind and nurturing midwives, who had seen many babies with Down syndrome during their time. They were an immense source of comfort during those few weeks before Jana was born and after.

Jana was born by natural delivery. The doctors took one look at her at birth and told us that they think she has Down syndrome. The words dropped in our laps like lead. We didn't have time to celebrate or feel joy. It was a time of ignorance and grief. A blood test confirmed the diagnosis a few days later.

We knew nothing about Down syndrome and we thought it meant a death sentence to us. Confused, sad and shocked, little did we know that this was the best piece of news we could ever receive. Jana spent five days in the hospital nursery for observation and then we were discharged to start our lives together. Her stomach was fine, her heart was fine except for a small hole that cardiologists said would heal on its own. She was doing great.





Knowing what I do now, I look back at this time with tremendous empathy, a tiny bit of shame but a great deal of understanding. Since that day, Jana has graced our lives with endless blessings. **She touches the lives of everyone she meets. In the six years since she was born, we have had richer and more fulfilling lives than our whole life before her.** She continues to surprise us every single day with her charm, wit, cheekiness, innocence and beauty. We cannot imagine life without her, nor how we lived before her. We are excited by the future.

During that time of confusion, I had often wondered how she would be perceived in the community, how she would be accepted in school, work and life. Two years ago, we were celebrating World Down Syndrome Day at Jana's mainstream preschool. I had gone into her classroom to read to the children a book about Down syndrome. **The children were so open and curious. They asked questions and were very accepting and loving of Jana. It was heart-warming to see, and had I still had any doubts, I knew then and there that our fears, worries and concerns for the future were unfounded.**

Jana continues to lead us down her spectacularly amazing path. We have met some beautiful people along the way. She makes friends wherever she goes. We are experiencing a different flavour of life that many do not have the privilege to experience. There is kindness, humanity and raw beauty. That is how I would describe Down syndrome and the community, and I know that it will only get better.

