

SARAH'S STORY

Our beautiful 17 year old daughter, Sarah, affectionately known as "Blondie" by her family and friends, does more around the house than most girls her age, makes birthday cards for the majority of the school and her artwork hangs in many of the shops in our local area. She is a shining example of Mater Dei's inclusion in the community philosophy. Currently in Year 11, she is dreaming of working in the local post office or any job that can satisfy her love for all things paper and stationery.

We've come so far as a family since 1994 when doctors told us Sarah had had a stroke in utero and probably wouldn't live. It was crushing news for Ian and I as new parents but Sarah has prevailed.

The early years were toughest. Despite Sarah's numerous health issues, months in and out of hospital and appointments with a barrage of therapists, we did not get a diagnosis until she was six. Sarah has Prader-Willi Syndrome, or PWS, a genetic abnormality that affects about 1 in 15,000 people but is rarely inherited. As a baby Sarah couldn't suck due to extremely low muscle tone and needed to be fed by gavage or special teats. She took longer to reach developmental milestones and her position had to be changed from sleep to sleep. PWS babies sleep a lot so we had to make sure she received a lot of stimulation when she was awake. We used the Jolly Jumper baby exerciser, baby walker, and trampoline to encourage her to take her weight through her feet. Sarah did not walk until age two and a half.

Around two years old, though Sarah's diet remained the same, her weight started to balloon. PWS sufferers have a compulsion to eat, they do not know when they are full and hunger is painful. If they don't restrict their diet and follow an exercise program, 95% will face life-threatening obesity. Sarah's other symptoms include learning difficulties and poor balance but the hardest issues for us to deal with are her dramatic mood swings and tantrums.

Mater Dei has been breathtakingly successful in helping Sarah manage these problems. She has been part of the Living Skills Program for the last four years where she is learning to be an independent adult. On weekends and school holidays she attends Illawarra Interchange where she catches up with old primary school friends and enjoys everything from dining in restaurants to horse riding and going to the movies.

Sarah is much loved by people in the village of Gwynneville where we live and adored by her family, 14 year old sister Emma who attends St Mary's College Wollongong and 12 year old brother, Thomas, who goes to St Francis Xavier's School Special Education unit. Tom is epileptic and displays autistic spectrum disorder. Yes, two of our three children have special needs and it has been an exceedingly difficult journey but we are winning against the odds.

Go Blondie we are all behind you. Much love from Mum, Dad, Emma, Thomas, "Wishbone" and "Maxi".

