

ADRIANA'S STORY

God sent Adriana to us in 1998 and we knew she was special in every way. At first we were scared because we didn't know what her future would hold for her. Adriana is now 12 years old and I can tell you she has been through so much. I am amazed that she has taught me so much, from her inner strength and courage.

Adriana was born with a rare condition called APERTS syndrome. One child in 160,000 births is born with this condition. This syndrome causes fused cranial sutures, a retruded mid face, fused fingers and fused toes. Adriana also has a moderate intellectual disability and a moderate hearing loss.

Dr Michael Freeland, our Campbelltown based Paediatrician, diagnosed Adriana with this condition at birth. We were in shock and could not believe that this was not picked up at the 18 week ultrasound. Adriana didn't have fingers, she had hooks for hands. Luckily, Dr Freeland was able to direct us to the best Cranio Facial Unit in Australia, Professor David and his team in Adelaide.

Adriana's first 12 months was spent in hospital with oxygen. If she went without oxygen, she would turn blue because of her narrow airways. Adriana's first major operation was at four months old. She had a frontal orbital advancement which gave room for her brain to grow. The doctors also gave her a palatal split to enable her to breathe more easily. Adriana's fingers were separated giving her three fingers and a thumb. Her fingers are still fused and stiff.

Adriana's first year of school was spent at the Royal Deaf and Blind Institute at Glenmore Park. There, the teachers helped her as much as they could.

Adriana started attending Mater Dei's School at five years of age. At first my husband, Joe, and I didn't want Adriana to go to a Special School because that would mean that we had to accept that Adriana was "different", but we soon realized that this was the best thing we have ever done for her.

Adriana loves Mater Dei. She comes home so happy and loves her friends (*pictured with Brenton*) and teachers; and she can't wait to catch her taxi to school in the mornings. The children love one another unconditionally and the love that the members of staff have for all of the children is incredible. Mater Dei

provides individualised programs for each student and also significantly helps their family in every way they can. We feel truly blessed to be part of the Mater Dei family.

Adriana's joints will start to restrict her mobility as she gets older. To date, she has had 29 operations during her short 12 years of life. Adriana will require more operations as she continues to grow. In May this year, Adriana had a major eight hour operation. She had a facial reconstruction. This required relocating our family to Adelaide for two months. Four distractors were placed in her skull and turned daily to bring out her forehead and mid face. Adriana didn't like her new face. She kept saying "I like the other Adriana".

Despite all the operations, the pain, the X-rays and numerous Doctors' appointments, Adriana never sees her condition as a disadvantage. Adriana knows she looks different and hates people staring at her.

Lately, she seems so much more confident. Adriana says she wants to be a doctor one day. She is a fighter and she is always so happy and bubbly. She is also very determined to try and do everything for herself. Adriana just loves life.

Adriana has two older sisters, Stephanie and Olivia, and two younger brothers, Domenic and Tony. We are blessed to be a very loving family and none of us would swap Adriana for the world. Adriana's brothers and sisters love her unconditionally and have said that they will always be there to guide her through life.

Having a child with special needs is not as bad as you initially fear. Sure it changes your plans, and you, but I feel it has made me and my family much better people. At first it didn't come easy, but now I thank God for our sweet angel from above and thank you, Adriana, for all that you have taught me. I love you in every way.... **Josie Gattelari**

