

SUPERHERO KIDS - JAMIE-LEIGH



My name is Rachel, I live in Darwin and Jamie-Leigh is my daughter. This is our story.



"We thought it was just a cold. Back at the end of July 2012, all symptoms of illness we saw in Jamie-Leigh said common cold. But that cold never went away. By the beginning of August, Jamie was getting tired very easily and still had a cold, so she went to the doctor. We were told it was bronchitis and she was given a course of antibiotics. These did nothing. She continued to go from a bright, bubbly, active child to a child who couldn't get through a school day without needing sleep and was in bed by 6.30 each evening after an afternoon nap on the couch. By now Jamie was also eating very little and had an almost constant temperature. On Sunday, August 19, 2012, things took a dramatic turn.

It was the day of Jamie-Leigh's party to celebrate her 7th birthday which would fall 3 days later. We took her and her friends to the local bowling alley. She seemed quite ok at the beginning, but by the time she had her 3rd turn, Jamie was just happy to sit and talk to her friends and allow someone else to take her turn in the game. She enjoyed the day, but it absolutely exhausted her. She fell asleep as soon as

we got home. We woke her to have dinner and about 10 minutes later, she vomited violently in the bathroom. When she came out, she was as white as a ghost except around her eyes

which were black as night with what looked like heat rash. We took her straight to the ED at Darwin Royal Hospital and the almost impossible happened ...the triage nurse took one look at Jamie and sent her straight through to the back. In the time it took to walk from her desk to the door, she had a team of doctors on standby. Jamie-Leigh was immediately admitted to the ICU. Her blood count had dropped so low, her organs were beginning to shut down. They didn't think she would last the night.

The next morning, we got the news no parent wants to hear, Jamie-Leigh had acute lymphoblastic leukaemia (ALL). She and her father were on a Careflight to the Adelaide Women's and Children's hospital by lunchtime. We were told she'd be there for about 6 weeks.

Once in Adelaide, things moved pretty quickly. She was instantly admitted to the oncology ward and the overload of information began. There was so much to take in and while half the family was in Adelaide, able to ask questions, the other half was sorting out things at home in Darwin, having the information relayed to them. It was frustrating and frightening. By the end of the week, things in Darwin were settled and brother and mother went to Adelaide. By this stage we'd been told that she would be there for at least 6 months and that they wanted the whole family there for the first 6 weeks. So while Jamie was in the hospital receiving the beginning of her treatment, we moved into Ronald McDonald House. This would end up becoming our home for the next 11 months.

The first couple of weeks of treatment went like clockwork, but then complications developed. One day we noticed Jamie was having trouble breathing. They took her to X-ray and found her lung had punctured. She was taken to surgery to re inflate it and discovered she had an aggressive fungal infection that was eating her organs. That night, September 12, Jamie-Leigh lost her upper palette, septum, 2 adult teeth, a portion of her right cheek bone and a couple of tear ducts. The fungus was also in her lungs where they couldn't operate. For the 2nd time in 3 weeks, we were told it was unlikely she would survive the night, then a 3rd time a week later when they had to operate again. But survive she did, and after 11 days in the PICU, Jamie finally returned to the oncology ward, the place that would be her home until early December.

Because of the fungal infection, her treatment for the ALL had to be put on hold for 4 months. We were incredibly lucky that she went into remission in the first couple of weeks of being in Adelaide and that she remained in remission. Once treatment was started again, it went reasonably normally and the family got into a routine of living in 2 different places with parents changing location between Darwin and Adelaide every 10 weeks. It wasn't ideal, but it did mean that Jamie's brother, Ashley, could have as normal a life as possible. Finally on July 20, 2013, exactly 11 months after arriving in Adelaide, Jamie-Leigh returned to Darwin. Life returned to normal almost instantly for her. She went straight back to school and the swimming lessons she loved. The only difference to her life was her skin was extremely sun sensitive due to the medication she was taking to fight the fungus so she had to use sunscreen, sunglasses and a hat every time she went outdoors. To us, life never went back to being the same. Even though she is in remission and completely back to her old self,

we are still always wary of ANY little sign that something has changed, not just in her, but in Ashley as well (much to his disgust). After walking on eggshells for so long, it's hard to stop.

Now, in March 2015, Jamie is about to travel back to Adelaide to have her palette repaired. She still has a long way to go, she won't be cleared of her ALL until 2017, and still has to have her septum repaired once she hits puberty, but she's not looking back. She's taking life full speed ahead and getting stronger every day and will hopefully do so for many years to come.”