Immune Deficiencies Foundation Australia

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**SCID Member Stories – Boris, SA**

My son Boris has Severe Combined Immune Deficiency – Adenosine deaminase (ADA). He is just about to turn 21, so ours is a success story but a long, bumpy and painful one.

Our first hospital admission was at about four weeks of age as Boris wasn't gaining weight. At six weeks he was admitted for a respiratory illness. At 10 weeks he was so sick he was readmitted for vomiting, failure to thrive and a swollen stomach. In hospital he became sicker and sicker. He ended up in intensive care intubated as he had staph abscesses in his throat that became so large he couldn't breathe. He also had abscesses on his kidneys. It was then that he was diagnosed with SCID.

I can still vividly remember being in the ICU when the infectious diseases lady came rushing up to me with her fifth batch of antibiotics that she had created and being told this was it, she was so excited. I still remember the talk I was given that if this didn't work he wouldn't survive the night. Well, he did. After that I don't really remember how long we were in hospital for but I do remember his first Christmas was there. He started enzyme replacement injections, antibiotics and IVIG infusions and then our journey really began. He was diagnosed with autism and an intellectual disability at about seven years of age. He also has some hearing loss.

We attended Great Ormond Street Hospital in London for stem cell gene therapy just before he turned 16. Boris is the oldest kid to have had this treatment so they were very interested in him. It was successful and he now has minimal medications and only sees an immunologist once a year.

For us, life is good now, but before his gene therapy he literally had well over a thousand enzyme injections, tonnes of infusions and antibiotics his whole life without mentioning his hospital admissions. I cannot put into words how difficult Boris' life has been and the impact it has had on mine. I am forever grateful for our wonderful doctors and the health system that got him through but it is undoubtable that with early diagnosis and treatment his life and mine would have been vastly different and the disability he lives with less severe. He is living proof that a small test at birth is not only in the patients' best interest but that a small amount spent early on saves the health system a massive amount of money in the long run.