

Our Story

Debbie and Ricky Belcher



Ricky and his beloved companion Sarge

Ricky was born in January 1990, a healthy baby boy and developed normally. He was always healthy and was introduced to Teeball when he was in year one and so started his love for sport. From that introduction, Rick played some kind of sport all year round - teeball, baseball, softball, Aussie rules football. Our weekend was filled with one game to the other. At school, he was champion swimmer every year as well as interschool champion or runner up right to the year he became unwell. He was also the athletics champion, represented his school in almost every sport they had a team for. He represented clubs in teeball championships, pee wee baseball championships and finally represented Western Australia in baseball for 6 years in a row, 2 while he was ill. He also represented Western Australia in the Schoolboys baseball team every year at high school. And finally he graduated as Dux of the school for sport when he completed high school in 2007.



Ricky pitching for WA in 2006

Looking back, our journey with Wegeners Granulomatosis (GPA) started towards the end of 2005, when he seemed to be really prone to injuries, especially in his pitching arm, which proved very frustrating. Lucky he was still able to play at top level, playing 1st base in order to rest his shoulder. Early 2006, he started with what we thought was some sort of allergy which caused him to get the worst rhinitis our GP had ever seen. He often had nose bleeds, but had been prone to those throughout the years, only these were becoming more frequent. In around May 2006, he came home from baseball training with his dad and when he came inside he could hardly walk on his ankle. Thinking he had rolled it during training, I asked what had happened and he said it was fine before the drive home (approx. 45 minutes drive) and he couldn't recall hurting it. I iced it and strapped it for the night. The next morning the swelling had disappeared but there was slight bruising, which I thought was unusual (my RN background kicking in). This happened again a few nights later, this time being his

other ankle. At this time, Ricky was bruising easy, blood noses were more frequent, he looked drained and pale. After his ankle swelling, he would have a swollen elbow, then a swollen knuckle.....each day somewhere different, causing pain, but almost gone by the next day. Again, my mind was going overtime, so I booked him into the GP, but by this time I had convinced myself that he had some type of leukaemia. The doctor ordered blood tests, and I sat at home waiting for a dreaded phone call telling us to go in urgently, but the phone call didn't come. After a few more days of roving swellings and pain I took him back to the doctor, who said his tests were reasonably normal, but he ran some more tests. This time he did call and said he thought he knew what was wrong with Ricky. We went in and was told his Rheumatoid Factor had come back positive so he has Juvenile Rheumatoid Arthritis and referred him to a rheumatologist at Princess Margaret Hospital, the large children's hospital here in Perth. August 2016, once under the Rheumatologist, she did a battery of blood tests and confirmed the diagnosis of RA. I questioned the diagnosis, again due to my nursing background, this did not present as normal RA - the swellings lasted overnight instead of weeks, normally very debilitating, yet Ricky was still playing baseball at elite levels, then there was the blood and crusty nose and bruising, but was basically told that I was in denial. He was put on prednisolone, Methotrexate and quinine and went for regular blood tests which only included liver function tests and not kidney function tests. Things seemed to settle somewhat, and Ricky went off to represent Western Australia in baseball in January 2017. On returning, the Rheumatologist agreed that he was a puzzling case as she had never actually seen a swelling (usually gone by the time he saw her), so she decided, at the end of January, to stop his Methotrexate and start weaning the prednisolone. Rick seemed to be ok until Easter 2017.

He had gone camping with his friend, he was having a great time, but Monday he rang and said he was not feeling very well but he would see me the next day. The Tuesday morning, when he woke up, his face was so swollen, he could hardly open his eyes. His friend drove him home and as he got inside he collapsed. The swelling in his face had gone, but his knee was swollen, he was weak and running a high temperature. I rang the rheumatology nurse and told her I was bringing him straight in. He was really ill. I got him to the clinic where the nurse drew bloods and sent them off urgently. By the time the doctor got in the results were in and were not good at all. He was admitted and I was asked to come and meet with some doctors. It was the worst day of my life!! I walked in to a room of doctors, nurses and the ward manager to be told that Ricky was in renal failure - he only had 25% kidney function. They wanted to perform a kidney biopsy but felt that this was irreversible. The biopsy was performed, when we found Ricky was allergic to Pethidine and it caused terrible agitation - so did not make the procedure easy!! Interim and then final reports showed this crescentic scarring in most of his glomeruli meaning the damage was in fact irreversible. Ricky will need a transplant - probably within 6 months. I then found out that the original batch of blood tests when first seen at PMH (August 2016) included a kidney function test, which showed slightly abnormal levels, unfortunately that test was never repeated until he collapsed and arrived at PMH in April 2017. Blood tests for ANCA-C came back positive and a diagnosis of Wegeners Granulomatosis was made. Rick was given 3 pulses of Methyl pred to quench the inflammation and commenced on cyclophosphamide and .

because of his age, they only wanted him on for 3 months. After the methyl pred he was put on high doses of prednisolone. He went from 60kg to 80kg in a matter of a few weeks. He was meant to represent WA for schoolboys in May 2017, and continued to hassle the doctors until they said he could go. It was heartbreaking for him, as for the first time in his life, his body was not responding as normal, and his speed had left him as well as his energy levels had gone. He still managed to play an inning here and there and was grateful to be there being his last year at schoolboys. He battled through his last year at school, suffering from nausea, vomiting every day and extreme fatigue, but managed to graduate at the end of the year. After the 3 months of cyclophosphamide, 6 weeks later the ANCA - C levels started to rise so his immunologist said he had no option but to give him another 6 months, but after that he would be at the maximum lifetime dose. The ANCA levels were not dropping, so arrangements for approval for this "new" drug, Rituxan, were set in motion and was approved but in the 11th hour, Ricky went into chemical remission. He did not need the Rituxan. They placed him on Myfortic Mofitel and he tolerated them well.

Ricky's renal care was transferred to Fremantle Hospital and his immunologist actually worked from both PMH and Fremantle Hospital so was able to see him there. Ricky tried to get work, but due to his morning nausea and vomiting, it proved too hard, but he managed to work on and off during the years. He was lucky to get a disability pension during the times he could not work. We looked after his kidneys, making sure we were feeding him good renal diet food, although he was allowed take away here and there, especially on weekends when he was with his friends. His dream growing up, was to go play baseball in the USA, either on a college scholarship or if lucky be signed to a professional club.....that went out the window, but even more sad, he had to watch all his friends fulfilling his dream.

I can remember asking his immunologist to explain to me how a perfectly healthy, fit young man can just suddenly get this awful disease. He turned and said to me "We really don't know the cause of auto-immune diseases, even though there are so many different types". I was like "right.... I will go to university and find out why this happens!" So, in January 2011, at the grand age of 48, I started a double degree in Biomedical Science and Molecular Biology - I needed to understand this disease and hopefully get into research to help find a cure!

I was tested to see if I was a match to give Ricky one of my kidneys and we were compatible. Well, that was one worry out of the way, when the time came!! Rick was doing well and then in 2011 his kidney function started deteriorating.....we got 4 good years out of them instead of only 6 months!! They rushed me through all the tests, and decided to perform the transplant before he needed dialysis and set a date for 20th November 2011 - great! I would have finished my exams and have nearly 3 months to recover before going back to Uni in the February. Unfortunately, less than a week before the transplant was to take place, the specialists had a meeting and had decided that because I had multiple vessels in my kidneys, both arteries and veins, they all agreed that it would be too risky for me, and not ideal for Ricky as parts of the kidney would die off from lack of blood to certain areas giving him a non fully functional kidney.....the second worst day of my life. Problem was that Ricky really needed dialysis soon and they decided to do peritoneal dialysis rather than haemodialysis. So

they rushed him in to get a PD catheter placed, but this needed at least 4 weeks to heal. On Boxing day 2011, Ricky returned from his girlfriends house and was really really pale, oedemic and his girlfriend whispers to me " he has been coughing up blood". So I rushed him over to Fremantle hospital where he was to spend almost a month in NSU and with us nearly losing him a few times. He had lots of fluid retention, shadows in the lungs, anaemic and short of breath. They were not sure if he was having a flare, or whether it was due to fluid around the lungs so they decided to just treat him for everything. They were taking the chance to start the peritoneal dialysis (PD) and hope the membrane had healed, they were going to start the Rituxan and he needed a blood transfusion because he was so anaemic. He was under close watch in NSU and after a few days he appeared to be a bit better. Then 1st January he had been transferred back to the renal ward with the possibility of going home the next day. I had actually gone home early that night, and he rang and said his blood pressure was really high and he had a bad headache. I rang the ward nurse and she told me she had already called the doctor and was waiting for him to review Ricky. 1am on the 2nd January, Ricky suffered a grand mal seizure lasting almost 10 minutes and was rushed back up to NSU. It was a result of PRES syndrome (Posterior Reversible Encephalopathy Syndrome) and we were lucky we never lost him that night. The seizure caused the peritoneum to tear, so we were no longer able to do PD for a few days and his breathing became worse, so much so they had him on the CPAP machine and he could not be off oxygen even to have a shower. He also developed tophi gout due to uric acid build up, but so bad you could see the crystals through the swollen areas around his 2 big toes. He was in a lot of pain, he could not walk. Eventually they got permission to give him a drug infusion of Rasburicase which was a miracle drug and worked almost instantly. The crystals turned to liquid and actually oozed out from the swollen areas around the joints. He was finally able to come home at the end of January 2012, on peritoneal dialysis, and I was trained on how to drain and refill his fluid every 4 hours. But now we were back to square one - to find another donor!! It was a bad start of the year with multiple stays in hospital, so I landed taking a semester off university. My mother, Ricky's grandmother, decided she wanted to donate a kidney. She was 68 turning 69, but as fit as a fiddle, healthy as an ox and as determined as a mule!!! She was getting tested, and that was that! Well, she was compatible and when they did all her tests, could not believe just how healthy she was, especially her kidneys. So they decided they would do the transplant, exactly a year after the one booked for me, the 21st November 2012. On PD Ricky had slowly stacked on the weight, weighing around 85-90 kg due to the glucose base of the PD fluid - the body had access to copious amounts of glucose 24/7. He was still on Myfortic and prednisolone, and looking back was not in the most healthy condition.



Rick and his Nana post transplant

21st November 2012, the transplant went ahead as schedule. It was a long day and started by my mum going down to theatre at 8am. We said our tearful goodbyes and then went up to say good bye to Rick. We waited and waited, mum came back to the ward at around 3pm, what a hero!! How can you thank someone for giving your son the gift of life??? My mum is our hero and we will never be able to repay her. Rick came back to the ward at about 7pm, a smile on his face, and a bag full of urine hanging on the side of the bed. Nana's kidney had started making urine before he was even sewn up!!!! Ricky started feeling so much better almost immediately and could not wait to get back home to start his "normal" life - a life away from dialysis!! The first few weeks after he came home entailed of early morning blood tests, then checkups with the registrar. All was going well until around week 6 when the creatinine was up and down, so they performed a kidney biopsy and waited for results. Initial results showed microscopic clots which was a small concern but were keeping a close eye. Ricky had to go for day surgery to get the PD tube removed as well as the stent from the operation, keeping the ureter open.. The day after he woke up in terrible pain in the abdomen and was really unwell. So off to emergency, and by now he was almost delirious with pain. When they tested his blood glucose, the glucometer could not read it, the levels were so high. Bloods show he had pancreatitis, due to HUS (Haemolytic Uraemic Syndrome), the microscopic blood clots seen in the kidney biopsy. He was very ill once again and then they got further bad news, the biopsy showed Rick had contracted the BK virus and because he was immunosuppressed for so long he had no way of fighting it and this virus was killing his new kidney. Equal to the worst day of my life, the Professor told me they have to remove the transplanted kidney in order to save his life. So exactly 8 weeks after he had received this precious gift, we had to agree to remove it to save his life. The HUS was presumed to be a side effect from the Tacrolimus, an anti- rejection drug. The specialists decided that due to the pancreatitis Ricky would no longer be allowed to have PD due to the high glucose content which would put a strain on the pancreas and he would have to start Haemodialysis. We were very fortunate that his pancreas recovered and he did not become diabetic. So they had to operate and form a arteriovenous fistula in his right forearm but had to use a hickman line in his chest until such time the fistula matured enough to mature.

We had a few ups and downs over the next few months with abscesses forming at the site of the transplanted kidney, further surgery to the fistula and finally in July 2013 we were able to start home haemodialysis. Fresenius provided all my training, the dialysis machine, provided plumbers and electricians to set up the dedicated dialysis room at home, and once a month deliver all the stock required for the month. We set up the room with recliners, TV, Foxtel and PS4 for him to get through the 3 hours a day, 6 days a week, hooked up to a machine. Oh it was so nice not to have to travel to the hospital three times a week and spend up to 7 hours (between waiting for a bed and 4 hours dialysis) unable to do much, but wait. At home I have a baby monitor in his dialysis room which frees me to be able to be able to do normal household duties while he is on the machine. I handle all his dialysis as well as take his monthly bloods and administer his IV iron and EPO meds through the machine.

After all these hiccups, I was lucky enough to graduate in July 2014 with a Bachelor of Science majoring in Biomedical Science and Molecular Biology as well as a minor in Forensic Science.

During my time of study, I encouraged Ricky to try to enter University, he was getting bored with his life, his friends were all falling away, enjoying their own lives, partying, travelling - all things Rick was not able to participate in. He was always interested in joining the police force, but obviously now he would never pass the medical. But if he obtained a degree in Forensic Science and Toxicology, he could get into the Crime Scene investigation department without actually becoming a police officer. So as I finished my degrees, he started.

It has been a juggling act between classes, studying and dialysis, but he has now finished his second year. The support and help he gets from the university is amazing and his degree will take an extra semester to complete his unit requirements, but he is doing it at his own pace. He is hoping to follow on with a Masters after graduation. As for me, I am not working or studying at the moment as most of my time is focused on my son.

Ricky has been on the organ donation list now for 2 years, apparently he is right near the top, but they are waiting for the "perfect" kidney - one from a young male preferably, so we just have to be patient.....often easier said than done. They stopped all his immunosuppressants after he lost his transplant, he is back to 68kg, was able to start playing baseball again and is much healthier in himself. We had to get him in the best condition before the next transplant. Looking at him now, you would not know he was ill, he is as tough and strong as his nana and giving up is not an option.

WG has already taken 10 years of the most important fun years of his life and we hope that the next transplant comes soon and lasts a long time. Through my studies, I do believe that within 10 years, there will be alternatives to dialysis, they are already almost at clinical trial stages with an implanted artificial kidney, but even better yet, will be the day when they can grow organs using your own stem cells.

I will get into research once Ricky is off dialysis, but right now I am his mother, his best friend, his nurse, his carer, his tutor and most of all his advocate.

Debbie