



American-born **SUSAN BIGGAR** was all set for an exhilarating life of globetrotting with her exotic husband from the other side of the world. She did get to see the world, but her life didn't turn out quite the way she planned. In her memoir, **The Upside of Down**, she writes about the challenges of raising children with demanding health conditions and her life lived across six countries.

In my final year of secondary school, my friend was voted by classmates as having 'the best legs'. I, on the other hand, was voted 'most likely to work at the UN'. I turned out to be well prepared for my international life, but I was completely unprepared for the crash-course in medicine that life would demand of me.

I grew up in the suburbs north of San Francisco. My three older sisters studied nursing; I avoided health, instead getting a degree in international relations. After two years of working in Germany, I headed to Stanford University to get a master's in international policy.

That's where I met Darryl. He was a good-looking, athletic Kiwi, working on his PhD. Given my history, it's probably unsurprising I decided to marry someone from the other side of the world. Looking back, things might have been less complicated had I found a local boy, one with a different genetic make-up. But love isn't like that.

Upon finishing our degrees, we moved to London to take up jobs. We were footloose, working hard but travelling and filling our house with over 75 guests in two years. Maybe it was all those visitors, or my 12 moves in 12 years, or that hitting 30 startled my body

clock out of its stupor, but I began wanting a family. The black soot under our fingernails and vomit on the Underground convinced us London was not where we wanted to raise our children. By this time Darryl was homesick, so when a phone call from Wellington dropped a job in his lap, we took it as an omen, farewelled our housemates and headed for the world's southernmost capital city.

Until now, I had exerted a measure of control over life decisions, leading me to naively believe that I could choose the course of my life. The reality of parenting was soon to challenge this concept. Nearly giving birth (seven weeks early) at a rural gliding field a few hours north of Wellington should have provided warning that change was in the air. But I'm not that quick with hints, so it wasn't until Aidan was diagnosed with cystic fibrosis (CF) shortly after birth that my understanding of the world changed.

With no medical background and not a gram of that intrinsic mothering know-how many women seem to cultivate, I felt unfit for navigating my sweet son through a serious, life-threatening illness to a healthy future. It was clear that the first thing I had to do was upskill in my understanding of CF.

I learned that CF is a genetic condition, and that Darryl and I both carry the gene. About one in every 25 Caucasians is a carrier. The

biggest risk for people with CF is cumulative damage to their lungs, leading to increasingly reduced lung function. There is currently no cure. When Aidan was diagnosed we were told that his life expectancy might be 30.

Living with the threat of illness changed us. Initially it was our daily routines, such as getting my young son to take so much medication – 20 to 25 pills a day. We also had to build chest physiotherapy into our life and, once he was old enough, serious exercise to keep his lungs clear. The biggest adjustment, though, was learning to live optimistically every day with a tough condition that continually throws unexpected curve

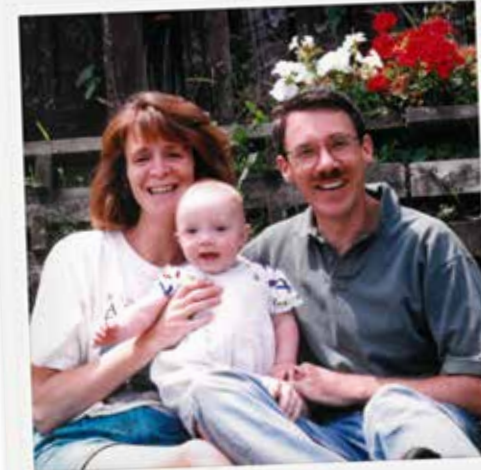
balls. On the outside Aidan appeared completely normal, learning to walk, squawk and talk and like any other child. But his lungs were under threat.

We couldn't accept the dismal prognosis, though it would take years to learn how to mount a proper battle.

One night when Aidan was almost two, the phone rang. It was a job offer for Darryl in Paris. We grabbed it. Within two months we had sold our house,

taken a much-too-short course in French and were on our way to a new life.

We loved our five years living in France, though there were some surprises. The arrival of Oliver – our second son, also born with



*Susan, Aidan and Darryl,
Wellington, NZ, 1996*



*Aidan and Oliver playing doctors,
Paris, France, 2000*

CF – was one of those surprises. Jean-Pierre was another. At our first visit to the hospital within weeks of arriving in Paris we were assigned

Jean-Pierre as our physiotherapist. He came to our flat six mornings and five evenings a week to do physio with Aidan and Oliver, working his way into our daily routine and our hearts. He was a gentle giant who loved rugby, fine French food, exotic travel and keeping our kids healthy. But the French health system was not what we would now call ‘patient and family centred’, and we struggled to have a voice in the kids’ care. At one point Oliver spent a month in the hospital; Aidan wasn’t allowed on the ward to visit, Darryl and I weren’t welcome to stay overnight – and by the end of the month I was pricing plane fares to get out of France forever. We stayed on, but those years marked the beginning of a new understanding for us about the importance of patients and their families having a say in decisions about their own health.

In 2002, when our boys were six and three and I was pregnant with our third child (Ellis, who doesn’t have CF), there was another one of those phone calls for Darryl. This call came from Melbourne, and by then we both knew we were ready to leave France. We stopped in Auckland to give birth to Ellis; I wasn’t

going to give birth in Australia where I had nowhere to live and no furniture, so I stayed with Darryl’s family in New Zealand for a few weeks while he went on to sort out things in Melbourne.

Darryl and I always believed that aerobic exercise would be important for protecting our sons’ lungs. Australia was the perfect setting for encouraging this. By the time the kids could lace up their shoes we were doing family runs, swims, soccer games and trampolining competitions. Before finishing primary school, both Aidan and Oliver were impressive runners, qualifying

repeatedly for zone and state cross-country events – and keeping themselves much healthier in the process. In Year 12, Aidan finished 7th in the nation in the 2km steeplechase, despite his lung condition.

The Upside of Down began as a book about the challenge of raising kids across different countries and of the intensity and pleasure of experiencing different cultures. But it became a story of

fighting for good health and patient-centred health care, and of learning that sometimes joy is a decision. **gr**

The Upside of Down by Susan Biggar is published by Transit Lounge, rrp \$29.95.



Aidan in the lead



Oliver, Ellis and Aidan, Hawaii

