



## Cushing's and my Miracle Baby – by Megan

My name is Megan, I am 32 years old and married with two children. I am a Cushing's Disease patient and this is my story.....

After high school I went to University to study my bachelor degree. I still say now that those 4 years were the best years of my life as far as fun, partying and meeting new people goes. Three quarters' of the way through my last year I became quite ill. I just put it down to stress of the very busy year I was having. My doctor called me back to her office after some blood tests and then referred me on to a specialist who tested me for Leukaemia. The tests came back negative and the end result was that they did not know what was wrong with me. I was diagnosed with ITP (Idiopathic Thrombocytic Popenia) - the reason for all of my bruises - and was told that I would probably have to have my spleen removed (thank god that never eventuated!!)

At age 22 it was discovered that I had really high blood pressure. This was very odd as I weighed 62kgs, was really conscious of what I ate and really enjoyed my sport. Several trips to the Cardiologist doing different tests did not reveal anything either. So my battle with Hypertension just continued on.... I was married just before I turned 23 and continued to pursue my career. At age 26, I came down with the Chicken Pox and as I didn't have them as a child, ended up with the Shingles as well. I was so sick.

Weeks later I was not recovering very well and was back at the doctor's. This was when I found out that I was pregnant with my first child. I was pregnant at the time that I had the Chicken Pox and was then told that there was a very great risk (50%) that my baby would have many deformities, problems etc. My life was put on hold for the next 3 weeks as I made the trip to Brisbane to have an Amniocentesis and wait for the test results. The results finally came back clear. I could not have been happier although I worried all throughout the remainder of my pregnancy that something could have gone undetected.

Throughout my pregnancy I was told that I had Toxaemia and as a result had to finish work 4 months before my due date. I put on a whopping 36kgs, developed lots and lots of huge stretch marks and found my muscles/movements weakened quite quickly. I was going to the hospital every day to be checked and on one of these days I was told that I was not going home. I was having this baby tomorrow.

The next morning I had a baby boy by caesarean section. Exactly one week after we took him home my husband rushed me to hospital which turned out to be a pulmonary embolism (blood clot in the heart). Two weeks after that I had a repeat of the same turn. This was again a time where I had what seemed to be every test under the sun. I was able to breastfeed my son until nearly 6 months then I was put back onto blood pressure medication. For some reason I just had to stop totally in one day. I was in so much pain (as any mother would know if they didn't get the chance to wean).

I was not losing any of my baby weight and the kilos started to pile on. My stretch marks were still as red as they were when I was pregnant and I was losing balance and falling quite often. I also noticed that I could not just get up off the floor anymore. I had to get onto all fours, lean onto something and then pull myself up. I could not believe how much pregnancy could wreck my body. Just after my son started walking my right foot was really sore and the pain would not go away. I had an x-ray done and the Radiologist told me to go straight back to the doctor. I had broken my foot. The doctor asked me how I did it and I could not tell him. The only thing I could say was that I might have dropped something on it. Whatever it was it didn't hurt otherwise I would have known. My leg was placed in a cast up to my knee. Well, what a mammoth effort trying to run after a toddler on crutches (when I think back now it's really funny)! After six weeks in the cast it was taken off but then another applied. My foot did not heal for 3 months.

In 2005 my baby sister asked me to be her matron of honour at her wedding. I was so happy and determined to lose this weight. I started Jenny Craig, employed a personal trainer/physiotherapist and used my treadmill one hour in the morning and one hour at night every night. For some unexplained reason (by all parties) the kilos just kept piling on. This is when I noticed my depression as I was trying EVERYTHING to get within a normal weight range and nothing would work. I ended up at my sisters' wedding in a size 18/20 dress.



***This is Me with Cushing's Disease***

At this point in time I just felt really crappy and no one could tell me a reason why. My son was the only reason that I would get out of bed in the morning and I spent my life at home too embarrassed to be seen 'this big' by anyone. When my son turned 2 my husband and I wanted to have another baby. After discussing it with my doctor he took me off the blood pressure tablets (?) and prescribed Diazepam to me 3 times a day. Even the chemist asked me if this could be right. It was terrible!! I was back in weeks to tell him how sick I was feeling. I was put back onto the blood pressure medication as my blood pressure was sky high.

In 2007 a lady I knew told me I needed to go elsewhere for an opinion and told me about the Lillian Cooper Centre in Brisbane. The doctor I saw referred me to a blood pressure specialist at one of the major hospitals. He took one look at me and told me he thinks I have a brain tumour called Cushing's Disease. My whole world crashed!! I was admitted to hospital and underwent all types of tests. After that week I was sent home. I cried and cried and cried thinking the worst and that I would be leaving my 2 year old son with no mother. I had to go back to hospital for another week of tests which at the end of it confirmed my worst nightmare. I did have Cushing's Disease.

To help my diagnosis, my endocrinologist took a look at the top of my back – yes a fat hump at the base of my neck. He asked me to squat down and stand up again – no I couldn't do it. He saw that I had bad stretch marks and most of my weight was carried around my middle etc. His comment was that I had all of the symptoms of a textbook case of Cushing's Disease.

I was prescribed Ketaconazole for the next 6 months before my surgery. On the 13<sup>th</sup> November 2006 I underwent transphenoidal surgery to remove my tumour. My neurosurgeon had to take all of my pituitary gland out with the tumour as he found more tumour in surgery than what my MRI showed.

• *To add a bit of humour to this story, at my expense, if you have had the same surgery how did you behave when you woke up? Apparently I couldn't put my right arm down and I was telling the theatre nurses to take me to the party ward. Low and behold they took me to Intensive Care where everyone was serious and no one smiled. I was telling a patient who was directly opposite me in the ward to smile and told him that it wasn't that bad. THEN I started singing "If you want my body and you think I'm sexy, come on baby tell me so." Once the anesthetic wore off then I crashed. I don't know anything about the psychology of this sort of procedure but all I know is that for the whole six months from my diagnosis until my surgery I was so worried about the doctors and nurses laughing at how fat I was when they got me on the theatre table (I know they don't and it was all just in my head) that I came out singing strange songs I think from the movie The Wedding Singer.*



***This is me post surgery.***

As a result of my surgery I developed Diabetes Insipidus for which I take Minirin twice daily and Secondary Addison's Disease for which I take total hormone replacement Hysone. The correct dosage I required was a big 'trial and error' for me as I suffered frequent Adreno Crisis' in the first few months. The emergency department got to know my medical file really well. Because the whole of my pituitary gland was removed it became apparent to me that I would not be able to fall pregnant again. Once again my world came crashing down as after everything I had been through I wanted this so bad. I felt like I went into a period of mourning and I carried this feeling with me for a long time.

In March/April 2007 I suffered heart attack–like symptoms which thankfully turned out to be an infected gallbladder. I had surgery to remove it, and then in September of the same year I went to hospital with Graves Disease (hyperthyroidism). I had to take a radioactive pill to kill my thyroid and then was told to take thyroxine for the rest of my life. I have just been through the same symptoms 2 years later as the rotten thing has come alive and started to partially work again (I can't win!!)

I didn't like it but I started to get used to the fact that I couldn't have anymore children and had to be happy that I had one healthy child who had his mother. In February 2008 my sister and family moved to my hometown and she announced to me that she was pregnant with her second child. I was so happy for her and so sad for myself. We are very close and she was coming around everyday describing her symptoms to me. Two days later I would be experiencing the exact same thing. I let these feelings go on for several weeks before starting to worry that my tumour might have come back. My doctor looked concerned and got me to go and do my full bloods (blood test everything). The following day my husband and I were driving to one of my specialist appointments and the receptionist rang to tell me my results. She casually told me that the pregnancy test that I had had come back POSITIVE!! Luckily I wasn't driving as I would have crashed the car.

I could not believe it and sometimes even though my baby daughter is 9 months old now it still seems surreal. Obviously I was really high risk the whole way through my pregnancy but I had not felt so good in such a long time. I was ON TOP OF THE WORLD spiritually, emotionally and physically (probably from the high level of hormones racing around my body). I am not able to breastfeed my daughter as I did not produce any milk but she is thriving just as well on formula. At my six week check-up I had another MRI and appointment with my Neurosurgeon (who didn't know I was pregnant). He could not believe that I fell pregnant. He kept looking at my films saying he took all of my pituitary gland out so it was NOT possible.

I am so much happier now that my family is complete and I feel like I have been given a reward at the end of everything I have been through.

To anyone out there who is going through a tough time in any way and does not see the end of the road. I am here to tell you that there are times in our lives when we will all feel the same but you do get there and miracles, just like my little miracle, do happen!!

I cannot finish my story without recognizing the Australian Pituitary Foundation. Just after my diagnosis I felt very alone and needed to talk to someone who had been through the same as what I was going through. I found the local coordinator from the APF and if it wasn't for her wonderful, caring support (through information and emotional support) I am sure my rollercoaster ride would have been a lot more unpleasant. The Foundation is the "Guardian Angel" of pituitary condition sufferers and I cannot thank them enough!!



***My family***