



My Name is Carmen Miller; this is not my history but that of my 6 year old little boy.

My son Tylor was born a healthy normal little boy on 17 February 2004, or at least so we thought. After about three months of his birth I started noticing something strange in Tylor's behaviour in the early hours of the mornings. Being a first time mum I had no idea what to look for much less what to be aware of.

What seemed to be happening like clockwork every morning at around 1am and 2am turned out to be PPH, something I never even imagined would be a possibility. Each morning Tylor would let out a cry which is still constantly playing in my head. It's a cry which I cannot explain and one which people don't tend to understand until heard by their own ears. After a few minutes of this cry he would push his tiny clenched fists against my chest and then go absolutely limp, blue, sweaty and cold. At first they said it might be colic – “we know how babies can sometimes be” they said. At first I accepted this because I guess I just didn't know better – maybe I was just afraid of knowing.

I'll never forget the first night he'd stopped breathing – he just lied there like a limp ash grey doll. Luckily I was able to revive him and as soon as he started breathing again we rushed him off to the hospital in a panic. Tylor had by the time we reached the Hospital gotten his colour back and was his chirpy little self again. They admitted us but discharged us without doing any sort of investigation into the “episode”. Somehow whenever we were kept in hospital for “observation” Tylor was fine. I put the word observation in inverted commas because we were mostly left to our own devices and not really observed. We were practically in the emergency ward every morning for about 3 months before I simply refused to leave and refused to listen to the nurses snide comments “that there was absolutely nothing wrong with my child and that I was just worrying about nothing” – eventually Dr Madi from Mulbarton Hospital said they would do a scan on Tylor. Shortly after the scan/x-ray Dr. Madi said that Tylor's right part of his heart looks slightly bigger and that he would be transferring us to Sunninghill where we would see a paediatric cardiologist immediately. Just before the ambulance arrived to transport us to Sunninghill Tylor suffered another episode - “finally someone other than my mother and me had witnessed what was going on” “finally someone would help my baby”.

On arrival at Sunninghill Dr. Dansky was waiting for us in the Neo Natal ICU because DR. Madi had called ahead and explained what happened. And so we did a Sonar – once again nothing, Dr. Dansky had said there is absolutely nothing wrong with Tylor, that there are no heart defects – we were discharged again.

As a last hope we visited a paediatrician in Garden City Hospital – Dr. Miles Bartlet. After consulting with us he agreed to admit us into hospital and run every test until he could tell us what the problem was. Tylor spent about 2 weeks in hospital undergoing every test imaginable (MRI's, EEG's, Stomach and swallowing tests) – everything came up “clean”. Our last test would be a visit to the ENT – after the ENT examination the ENT sat me down and told me in no uncertain terms that Tylor was not sick and that I was making him sick, that I needed to take my baby home and learn to cope with motherhood.

After our ENT visit all I wanted to do was take my baby home and not see another doctor ever again. That same evening Dr. Bartlet was running late on his rounds and only came by the ward at around 19h00. He came to confirm that they had found “nothing” and that we would be discharged in the morning. It’s like Tylor heard him – because he started fitting, foaming, vomiting and then went into cardiac arrest. Dr. Bartlet rushed off to the “procedure room” and disappeared with Tylor for what seemed like a life time. Eventually when he emerged from the operating room he said that he had to revive Tylor 4 times already and that he had never ever seen anything like Tylor’s episode. Once Tylor was stabilised and placed on oxygen and nitro’s oxide machines he was transferred to the NEO Natal ICU downstairs. He just lied there on that cold hard bed not moving with pipes coming out everywhere while being doped up with morphine. The next day Dr. Dansky was called back in to look at Tylor’s heart. Dr. Dansky discovered that Tylor had PPH – PPH is not easily diagnosed he said – “it’s a very rare, one in a million condition”. I think at that stage I was angrier than anything else and it felt like I wanted to strangle the man. What they couldn’t figure out was why Tylor was fitting – why the epileptic attack – was it the epilepsy that aggravated the PPH or was it the PPH that caused the fits – and to this day they still do not know.

After his diagnoses in late September 2004 Tylor was only discharged from hospital in mid November 2004. During Tylor’s stay in hospital we almost lost him more times than I wish to remember. We called the priest in so many times fear still runs through my bones every time I talk to or think of one.

After Tylor’s diagnoses Dr. Bartlet prescribed Viagra for Tylor on an four hourly basis together with eight hourly epilym. Tylor eventually came off the machines and recovered nicely– my little soldier. Upon discharge Dr. Bartlet stated that we should stay with Dr. Dansky as he was the best in his field – and so we kept Dr. Dansky as Tylor’s treating doctor. We were also told that we cannot keep Tylor on Viagra indefinitely and that we should systematically wean Tylor off the Viagra – and after a period passed without a episode we increased the period of time between Tylor’s dosages – from 4 hourly then to six hourly then to 8 hourly. And every time we increased the time period between Tylor’s dosages he suffered an attack and every time the doctors would say increase the medication back to 4 hourly but indicated that we would need to wean him off slowly to see what the correct dosage is and “see what happens”. I could never understand how a doctor could say “let’s see what happens” to a mother. We saw so many doctors in the first two years and every doctor we saw seemed to know less and less. Eventually I just stopped searching the internet for answers, I stopped going to other doctors and focused on taking Tylor only to Dr. Bartlet and Dr. Dansky in order to create some sort of normality and stability for Tylor – all these doctor visits we taking a toll on Tylor as eventually it seemed like he could smell the doctor coming from a mile away and he would start screaming his head off.

Eventually I just didn’t listen to the instructions to wean Tylor off – I just kept him on four hourly medication. After a while his condition stabilised and I simply said I would wean him off to the doctor but never in did. Don’t get me wrong both Dr. Bartlet and Dr. Dansky are brilliant doctors and I am so grateful to both of them for saving my son on so many occasions – I guess it’s just the circumstances of it all that creates great anger within me.

From 9 November 2008 to 6 January 2010 Tylor suffered no “episodes” apart from the occasional tiredness after a busy day. The medical aid required a update from Dr Bartlet as well as Doctor Dansky in November 2009. Dr. Dansky “suggested” that 4 hourly was to stressful for both Tylor and myself and so we decided that we would increase the amount of Viagra and increase the period between dosages. I was far too afraid to do this until I could be at home with Tylor for a while to

make sure nothing happens to him while he is at crèche. So during my leave in December 2009 just before Christmas I implemented the change in the dosage of the medication. On 6 January 2010 on the second day after my return to work Tylor suffered a really bad episode and stopped breathing. His back on his 4 hourly medication now and doing well.

Through everything Tylor has been such a strong happy little boy – looking at him gives me strength. I just hate looking into his eyes after his had an episode – he always looks up at me as in to say “why is this happening to me, why do I feel so ill, why can’t I run with my friends” – I cannot look at his eyes after his been sick because I cannot answer the questions that are in his eyes, in my heart and constantly on my mind. I think it’s the not knowing what’s going to happen next, how long we still have and the not knowing what to say to Tylor that is the scariest – I sometimes wonder if I’ll be less fearful of tomorrow if I knew those answers but something tells me that I might fear tomorrow more after knowing what tomorrow might bring.

I wanted so much more than this for Tylor – I hate thinking of him as developmentally slow, I hate thinking that he will never run like the other kids – live a life like other kids. I hate this decease and I would do anything to take away my sons pain and give him a full and certain future.