

Guest Post! Over Coming Adversity – The Complex World of Autism and PANS



E's Journey: The Complex World of Autism and PANS

E was diagnosed with autism at 2.5 years. E developed a complex Motor Movement Disorder and Tourette like symptoms at 5 years. Intellectual disability followed.

My Journey:

When at high school many years ago, I always remember an English Assessment being "Overcoming Adversity". At the time I never knew the impact this very deep theme would have on me.

Age 5

Around age of 5 we noticed Enosh was tripping over more often.

We were noticing some increase in aggressive behaviours when Enosh would develop a virus. He would swear more, his anxiety would grow and he was more clumsy than usual. Enosh would then get over the virus and within 5-6 weeks he would return to his Autism baseline. I would question myself "Are we overreacting as parents?"

I started to track data and filming Enosh when he was sick,

(as further documentation for the doctors's). Enosh developed a movement disorder at 5 years of age. These included chorea-like movements, as well as tics, ataxia and tremor/s. He was hospitalised but with no real answers. Enosh's condition would wax and wane. As a result of this waxing and waning, making a formal diagnosis was difficult. Enosh had a relapse when he was 8 years old and he looked like he was having a stroke. We rushed him to hospital. The Doctors had no idea what was wrong as MRI presented normal.

From this point on, I decided to do more research and discovered the condition PANS. (Pediatric Acute-Onset Neuropsychiatric Syndrome)

March 2015

Enosh was presenting with neuropsychiatric symptoms and increased movements. We then did something that was probably goes against various health policies. We drove straight from Rockhampton to Brisbane (620 kilometres/ 8 hours) and turned up at Lady Cilento Childrens Hospital Emergency Department. Enosh was examined and I expressed my concerns that I believed Enosh had PANS. They took my concerns very seriously. Enosh was hospitalised and further testing was completed, though they couldn't validate my suspected diagnosis. Enosh was diagnosed with Complex Motor Movement Disorder, Tourette's, and again Autism.

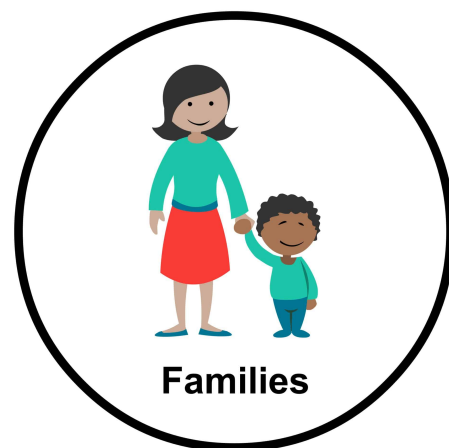
Within 6 weeks of discharge, I was not convinced with this diagnosis. I was still very concerned and pushed for a cognitive assessment to be completed on Enosh. His IQ was presenting very low. An IQ assessment confirmed extremely low range. I started again to tract all his school work and could see the cognitive decline. Enosh was losing memory. Enosh has always had very high thyroid antibodies. They were now sitting at 1500. Levels should be 5. I asked my GP to order bloods every 3mth. She agreed. My theory of Pediatric Acute-Onset Neuropsychiatric Syndrome was now very obvious and clear to

me. I just needed some concrete evidence.

I have a wonderful medical Professor knowing my every move. He never doubted me and encouraged me to keep tracking. The more I researched the more confident I became in presenting my case. Our Professor also had been watching Enosh closely and agreed he was not the same child he had meet 4 years ago on an outreach clinic to Rockhampton.

June 2016

The Professor suggested we see a world leader in autoimmune disease and the brain. However, one does not refer interstate unless necessary. The only issues was this Specialist was in Sydney; 1400km away. In June 2016 we made the long 4 day drive to Sydney as Enosh's anxiety was too high and he would not board a plane.



Within 30mins of consulting, the Neurology team believed in me. Further testing had to be completed which included a lumbar punch.

Within 6 weeks we had the answer. They were able to trace neopteriens double the level in his spinal fluid. This is a marker for inflammation in the brian.

I felt great relief that my years of research were going help Enosh's future. Having said that we have a long way to go.

Enosh commenced aggressive treatment within a week after seeing the neurology team in Sydney. Enosh has now had 10 massive steroid pulses to try slow his regression. He is also having IVIG infusions every 30 days, and more recently commenced mycophenolate (anti-rejection / immune modulating medication) This treatment will be ongoing.

The amazing part of the journey is that Enosh is now contributing towards Research in Children with Autism. Some children with Autism have an immune system that is dysregulated.

I will do my best to continue to represent Autism / PANS.

I am one of those fortunate people who knows that I go home knowing have I made a difference in my community through Advocating for my child.

To parents and carers. Never give up.

The best reward is having 2 boys with Autism.

I have overcome Adversity.

Thanking you.

You can follow Sonia's Journey here

You can find helpful information oh families, schooling and sibling support by clicking on their respective links.