

**Only a doctor can diagnose and treat Epilepsy!**



## Our Son - Kieron (A love that is so strong) by Nick Jago

Hi all, our family is made up of myself (Nick), my wife Sue and 3 children, Kieron 10 yrs, Aaron 8 yrs, and Thomas 2 yrs. We live in Sydney Australia, and we were welcomed to the E Support Community in August 2001. can still see it in my minds eye.

Kieron suffers from a rare form of Epilepsy called Continuous Spike & Wave Syndrome (CSWS) which is a variant of Landau Kleffner Syndrome (LKS). Both are predominantly a Speech and Language Disorder with a range of symptoms varying from severe behavioural difficulties to quite significant Autistic tendencies.

Kieron was initially diagnosed with Epilepsy in March 1997 aged 6 after having several Tonic Clonic seizures whilst I was away with my work. This was certainly very scary for Sue. Kieron was placed on Epilim.

During his early childhood, (mainly his pre school year), it was noted by his Teacher and caregivers that Kieron was slightly delayed in both speech and development, but we unfortunately didn't take this issue too serious until after the initial diagnoses.

Approximately 18 months later after a move to Canberra, Kieron had major difficulties at school. We began to see a Paediatrician, who was fantastic. He gave us a lot of information and started the process of getting a thorough diagnosis. After a sleep deprived EEG in Sydney and Speech and Neuropsychological Assessments, Kieron's Paediatric Neurologist, at the Sydney Children's Hospital, diagnosed Kieron with LKS.

On return to Canberra we started Kieron on a course of steroids. He started on a very high dose of 50mg per day, to try and assist in the reduction of the spike waves in his brain. This was a long battle, and Kieron went from 18 kg to 35 kg in just on 8 weeks. The benefits of the steroids become very obvious at school, socially.

It took a further 3 years to totally wean Kieron off the steroids. Every time we tried, his seizure activity would increase to dangerous levels.

### **The Queensland Years**

After several years in Canberra we were moved to Brisbane, Queensland because of my employment. We prayed that the Education Department and the medical professionals in Brisbane could provide for such a complex child like Kieron. Kieron's Neurologist in Sydney referred Him to a Paediatric Neurologist at the Brisbane Childrens Hospital.

Frustration and anger are the two feelings we experienced whilst dealing with the Queensland Education System. It took over 16 months for them to determine what support Kieron needed, even after coming from Canberra with all the reports and having being placed in Special Education there. They threw Kieron to the lions. He went into a Mainstream class with 2

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teachers and 55 students, with no support at all. The class was often left with only 1 teacher the entire class. Kieron went downhill very fast and began going completely bonkers (putting it politely).

We placed Kieron & Aaron into before and after school care as Sue and I were working full time. The before & after school facility was run by the schools P & C Association. We also experienced difficulties with this childcare facility because of Kieron's particular special needs, so we organised funding through the Government for 1 on 1 care for him. The hassles continued with this arrangement and Kieron was eventually thrown out of the before & after school program.

Unfortunately it was at this stage that Sue had to quit work after 13 years with the Public Service, as there was no one available in the area to care for Kieron before and after school. Sue was getting phone calls from the school at least 3-4 times a week and from the before & after school care facility nearly every day to come and get him because neither could seem to handle him.

At the same time, I was deployed with the Army to East Timor for 6 months; unfortunately the school took advantage of this and really drove the nails into Sue whilst I was away. I was recalled from East Timor after Kieron was hospitalised, to find my wife a wreck and my family in a very bad state of stress. It was then that we decided we would look for a posting back to Sydney, where we knew the medical system and the Education System would be better equipped.

During our time in Queensland, Kieron was hospitalised nearly around 8 times with severe psychotic episodes, called Rage Seizures. At no time did his Neurologist have any idea what to do, and was simply guessing. He showed little interest in helping Kieron, mainly because we think he knew that the problem lay with the school and were causing these problems. Kieron's Neurologist placed him on the drug Resperidone that is used mainly in adult Schizophrenic patients.

### **The Move and Change that has changed our lives forever**

The first change in our lives was on the 8th August 2001 when we met this group of wonderful and caring people in a chat room on E Support. Janey, Tigger and Solo, you 3 have given us a new lease on life since that night, we are forever in your debt.

In January 2002 we were posted to Sydney, back to Kieron's Paediatric Neurologist, at the Sydney's Children Hospital, and Speech Pathologist and Neuropsychologist who have dealt with him before and prepared to make a commitment in his well being.

We found the school Wattle Grove Public, and boy, what a shock. The Principal knocked us off our feet with the open arms and assistance he was prepared to give us and Kieron. Kieron now has a full time aide and will continue until Tertiary Studies at which time we will have to look at a Special Education placement.

Kieron is advancing every day, making large steps, even being let out in the playground during lunch, by himself, which is a major step for this little boy. His speech is improving, and generally his academic level is slowly, but steadily increasing, his intellectual level is still around a 6-7 year old.

Nick

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