



Help Daniel

Daniel is a little boy of six. Until two years ago, Daniel was just like any other healthy, fun-loving, happy little boy. He loved to climb trees and ride his bike. Then overnight, his world was turned upside down when he started to have massive and recurrent epileptic fits. Today, Daniel faces the prospect of neuro-epileptic surgery to give him a chance in life.

Daniel before he fell ill.

Sheena tells her son's story.....

When Daniel was born I looked at my perfect son and never dreamed that he would have to suffer.

Daniel's problem started in October 2011 when overnight he started having severe seizures. He was incorrectly diagnosed with Herpes simplex encephalitis and spent three weeks in hospital on an IV drip, twenty-four hours a day. Not having medical aid at the time resulted in some hefty bills.

In January 2012 Daniel started attending Hillcrest Pre-Primary and was relatively stable until July 2012 when he started having complex partial seizures. These seizures occurred up to 10 times a day and resulted in him being withdrawn from school for the rest of the year.

After consultation with his specialist it was recommended that Daniel attend Brown School – a school for children with special needs. He has a full time facilitator who is employed to aid Daniel's general well-being and safety whilst at school.

Daniel is currently on five different types of anti-convulsant drugs,

and has been on a strict Ketogenic diet for six months. Neither of these treatments has been successful in stopping Daniel's seizures. He is never left unattended, and cannot ride his bike or scooter without having a seizure. Play that most children take for granted, such as climbing trees, jumping on a trampoline or playing on a jungle gym, have to be strictly supervised.

Daniel is a very intelligent child but cannot function in everyday life. He is regressing in his physical motor skills and social skills, as often there are behavioural problems stemming not only from the seizures but the neurologically altering drugs.

Daniel's condition, 'Cortical Dysplasia', is not uncommon. People can live their entire life not knowing they have it. In layman's terms, Daniel suffers from a congenital cortical malformation. His brain tissue didn't form properly as a foetus or embryo. It is like having a birth mark or scar tissue on the brain.

Unfortunately it is the entire right temporal lobe of Daniel's brain that is affected.

The doctors' prognosis

To date Daniel has been under the care of specialist paediatrician, Dr John Flett, and paediatric neurologist, Dr Anthony Crutchley. They have identified Daniel's problems to be cortical dysplasia (right temporal lobe) and intractable epilepsy resulting in complex partial seizures, behaviour and concentration problems, and social intellectual regression. Despite management and multiple medications to control the complex partial seizures (Epilim twice daily; Topamax twice daily; Rivotril three times daily; Keppra twice daily; Pyridoxine twice daily) he has shown neurodevelopmental regression, having up to ten seizures per day.

Without consideration of Neuroepileptic surgery, Daniel will continue to have intractable seizures requiring hospitalization and acute seizure management with complete neurodevelopment regression and specialized remedial schooling with clinical global assessment functioning on the Axis 5 diagnostic criteria.

Daniel's specialists recommend that he be referred to Dr James Butler and Dr R Melville at Constantiaberg Hospital in Cape Town for

assessment of his epilepsy and cortical dysplasia, with a view to epilepsy surgery. This treatment will involve a 72 hour video E.E.G. (with inpatient admission of 3 - 7 days), a cortical E.E.G., possible neurosurgery (admission 1-2 weeks), a high definition M.R.I., a neuropsychological profile, and possible focal lesionectomy or Palliative Corpus Collosotomy.

The costs involved

Daniel comes from a normal family like yours or mine. Mum, Sheena, and Dad, Pete, are self-employed. He has a little brother, Joshua. To date, Daniel's medical bills have cost R350 000. Pete and Sheena now have to find a further R250 000 to fund advanced treatment and possible brain surgery in Cape Town, as well as travel and accommodation costs. Medical Aid has turned down their appeal for pre-authorisation.

What we can do

We, Daniel's friends and family, would like to help them find this money. If 500 people contributed R500 each we would be able to ensure that Daniel gets the treatment he needs. We would know that we have helped Pete and Sheena give their precious child a chance.



Daniel in 2013 with Dad, Mum and new brother, Josh.

To make a donation please use Peter's bank account:

P. Camp
Standard Bank SA
Hillcrest Branch
Branch Code: 045726
Acc. No. 256692270
Swift Code: SB ZA ZAJJ
Reference: Help Daniel