

In October 1998 Leanna was admitted to hospital suffering pneumonia whereupon her right arm began to twist involuntarily up behind her back. The Specialist Doctors were astounded, as they'd never seen anything like this before. One Doctor said at the time that in his 25 years of practising paediatric neurology he'd never witnessed anything like it.

Leanna's birth was normal as was her first (almost) 4 years of life. She was born on 27/12/94 at 38 weeks gestation weighing 2650kg. This bout of pneumonia was the first inkling that there was a problem with her health. Leanna already had two healthy siblings, Katey, who was born on 26/11/92 and Bethany who was born on 20/9/96. At the time of Leanna's admittance to hospital for pneumonia Michelle, Leanna's mother, discovered she was pregnant with their fourth daughter, Olivia who was born on 6/6/99. With the events unfolding the decision to continue with this pregnancy was not an easy one.

The next few months were spent visiting numerous specialists in Newcastle and Sydney to find a diagnosis.

Then late in 1998 Leanna's younger sister, Bethany then aged 2 ½ years, developed a "sore" leg. Visits to Doctors ensued but the "sore" leg miraculously disappeared. Then one night in March 1999 Bethany suffered from an hour or two of generalised vomiting and diarrhoea before falling asleep. She awoke 8 hours later and ceased to be able to walk. A specialist doctor was disbelieving and accused the family of lying regarding the circumstances of the previous 12 hours.

The next 12 months were somewhat of a blur of visits to specialist doctors and a multitude of medical procedures. What started with a variety of blood tests soon progressed to CT Scans, MR scans, skin biopsy, nerve deduction test, eye test, Hip biopsy, liver biopsy, rectum biopsy and spinal tap. In fact nearly every part of Leanna's body underwent biopsies and the results distributed worldwide in an effort to find a diagnosis.

Nick and Michelle even ventured overseas in their quest to find answers, including one trip to Great Ormond Street Hospital in London in August 1999 and another trip to Specialist Doctors in New York, USA in March 2000. Only with the assistance of Richard Branson (Virgin Airlines), family and some close friends were the family able to raise the much needed funds for these trips to the UK and USA.

The Doctors in London claimed that the condition was related back to the "Jewish days" whilst the majority of the doctors in New York claimed not to have any idea. However one paediatric neurologist in New York questioned immunisation, which both girls had undergone as a routine health measure carried out in Australia, as being the root cause of the health problems being suffered by both girls. At this point Olivia, Leanna and Bethany's youngest sibling was approximately 12 months of age and the decision was made by Nick and Michelle to cease all childhood immunisation for Leanna, Bethany and Olivia.

In the meantime Leanna and Bethany's symptoms continued to worsen. Video footage taken around this time shows Bethany using her head as a foot as she was so twisted and bent over that this was the only way she could move around on the floor.

Nick, Leanna and Bethany's dad questioned whether someone was trying to kill his family. Psychologists became involved after Nick relayed his fears to the medical staff at Westmead hospital in Sydney. It seemed they were questioning Nick and Michelle's role in their daughters illness.

High doses of a mixture of medication usually used in the treatment of Parkinson's Disease became the norm for both Leanna and Bethany and for a period of time, they found their symptoms easing to the point where both girls could stand upright enough to be able to walk (albeit aided).

In summary the majority of doctors have agreed that although a diagnosis and prognosis was not forthcoming the primary symptom being suffered by both girls was "Primary Dystonia – Generalised as Dystonia". The majority of specialists also believe that it is of a genetic, metabolic nature. As a result the girls were given a multitude of medication to combat the symptoms with the intention of making their lives more comfortable.

The stigma for the family saw Nick, Leanna and Bethany's dad arrested for poisoning his two daughters, friendships were lost as many believed the unknown condition being suffered by Leanna and Bethany to be contagious. Discrimination was rife highlighted by one particular incident whereby Leanna's 7th Birthday party was cancelled because none of the 20 children she had invited were allowed to attend as a result of their parents attitudes and fear for their children.

In August 2004 Bethany's health suddenly deteriorated to the point whereby Doctors questioned whether she would live for more than a few more weeks. It eventuated that the local chemist whilst filling what had become a routine script, a mistake had been made with the dosage and the wrong dosage was issued and then given to Bethany over the course of a week prior to her deterioration. The effects were profound and the sudden deterioration mystified her local specialist for 4 weeks before the mistake was discovered. By then it was too late – there never was a reversal of the deterioration. At this point she ceased to walk or have any type of motor skills.

It was around this time on one particularly "bad" night that Nick (Leanna and Bethany's father) at his wits end, contemplated taking things into his own hands and ending Bethany's suffering the only way he knew how to, by giving her an overdose of medication.

Fortunately soon after Patti Gratten-Smith, Leanna and Bethany's specialist in Sydney at Randwick Children's Hospital told Nick and Michelle about a Doctor in France that he'd heard an international seminar that may have a procedure called "Deep Brain Stimulation" that could halt the progression of this devastating condition. This procedure was specifically able to assist sufferers of dystonia and although not a cure it was something he believed may alleviate some of their suffering. This gave them some hope!

Again fundraising ensued and well known local identities soon became involved which led to interest of a national TV program "A Current Affair" and their reporter Ben Fordham. Following a segment shown Christmas Eve 2004 on this program asking for support Nick's phone did not stop ringing for 4 days and nights. \$120,000 was raised which meant Bethany was on her way to France! It gave the family some hope. Richard Branson from Virgin Airlines continued to assist the family by reducing flight costs and has since met with Nick, Michelle, Katey, Leanna, Bethany and Olivia whilst visiting Sydney in late 2005.

On 21 March 2005 Bethany, accompanied by Nick, Michelle and Leanna underwent the risky and radical brain operation in Montpellier in France with Professor Phillipe Coubes. But this was not without its dramas as when the family finally arrived in Montpellier and met with the Professor a few days preceding the operation the Professor questioned Bethany's primary symptom as being

dystonia. The Professor suggested that the multitude of medication be cut back over the next two days in case it was the medication masking the dystonia symptoms. Nick decided to cut back the medication more dramatically than what the professor had suggested. Within 12 hours Bethany's body was so twisted that the operation for the following Monday was given immediate "go ahead".

"Deep Brain Stimulation" involved the implantation of two electrodes into the patient's brain. From these electrodes run two leads under the skin down to the abdomen into two separate battery packs implanted in the patient. The electrodes are then "stimulated" in a way that interrupts the messages travelling from the brain to parts of the body telling the body's muscles to involuntarily twist and contort. In effect the muscles are forced to relax.

Thankfully the operation was a resounding success and within 24 hours Bethany was able to walk (with difficulty) and wanted "pizza" for dinner! Over the next few months her high dosage medication was reduced to nothing.

Soon after Leanna returned to Australia leaving Bethany in France to continue her recovery from the operation. As Leanna suffers severely from travel sickness a doctor in London had prescribed "patches", to combat motion sickness, to place behind her ears to make her journey back to Australia more comfortable. Upon arriving home it was obvious that Leanna was hallucinating and had suddenly lost her ability to walk. She was rushed to the local John Hunter Hospital in Newcastle where her condition continued to deteriorate. The next day, Easter Sunday, her local specialist realised that it was these "patches" that were affecting her. It transpired that these travel sickness patches although legal in the UK were actually banned in Australia due to their side effects. Like Bethany who deteriorated following the mistake in her medication, Leanna too never recovered from this event.

During the next few months Leanna continued to deteriorate and in November 2005 she too travelled to Montpellier in France with Nick and Michelle for the same operation.

Unfortunately Leanna's outcome was not as successful as Bethany. Even though following the operation Leanna was able to walk (albeit aided) it was very haphazard and she was still quite unsteady on her feet. During 2006 specialist Doctors in Australia unsuccessfully attempted to increase her response to the procedure by changing the settings in her electrode. And so the decision was made by the Doctors in France to have Leanna brought back to France for a prolonged period to see if they could assist.

From August to early November 2006 the entire family (Nick, Michelle, Katey, Leanna, Bethany and Olivia) lived in Montpellier France whilst the Doctors assisted Leanna. Unfortunately there was little they could do, as it would seem that Leanna was one patient who was not responding as would have been expected for whatever unknown reason. However what they did discover was the "Deep Brain Stimulation" was assisting Leanna, if only in a small way!

Since returning to Australia it would appear that Leanna's body has continued to be relatively unresponsive to the "Deep Brain Stimulation" procedure and still requires vast amounts of medication.

For the immediate future both girls need regular 6 monthly visits to the specialist doctors in France to monitor and maintain the medical equipment now implanted into their bodies however their long-term future is unknown.

To be continued.....