



Parley

Parents And Relatives
Listening and Empathising
with You

Niamh's Story

My daughter Niamh is 8 years old Niamh has several rare and unusual medical conditions all totally unrelated. It is very lonely being a parent where your child has a rare condition and hopefully parley can help to overcome this.

Niamh has had various medical problems throughout her life a short description of these is pasted below.

Niamh has had various health problems since early childhood. She was born with a condition known as CHOANAL ATRESIA which meant that at birth she was unable to breathe through her nose. This meant that at one day old she needed surgery to help her breathe. Over the next 3 and a half years she had 9 more operations on her nose and was eventually able to breathe through it.

At that time we thought that Niamh had had her share of health problems. However in November 2005 when she was aged 5, she woke up one morning completely blind. We spent several weeks in hospital where they diagnosed a type of optic neuritis that basically means inflammation of the optic nerves. At the same time they also found a type of brain tumour called a PINEAL GLAND TUMOUR. This was monitored by the doctors and isn't requiring treatment at present. They were unsure if this was connected to the vision loss.

Niamh returned to mainstream school and started learning Braille in January 2006 and has coped well with her problems. Her eyesight did begin to improve but in May 2006 she had a second attack of OPTIC NEURITIS. Niamh is registered blind and has no sight in her right eye and partial vision in her left eye. She copes really well with this and is also learning to touch type as well as use a cane of mobility.

In August 2006 she suddenly developed paralysis of her lower limbs and was readmitted to hospital. The doctors then linked her vision problems with this paralysis and diagnosed a very rare type of MS NEURO MYELITIS OPTICA also known as DEVICS DISEASE. Her

condition has gradually improved after a several relapses . She has however made good progress; she is back at school and fully mobile again. She is on a cocktail of drugs to keep her condition under control including steroids and immunosuppressants. She also has regular check ups and blood tests.

It has been a very scary few years for us but she has coped so well and adapted to everything. She truly is a little star and an inspiration to us all.

