

Unique Family Stories

Robert's Story

Robert age 9 months

Sailing through a trouble free pregnancy with no sickness by 9 months Rob was still in breech position, so was delivered at 38 weeks by elective caesarean section. Rob was born with a dimple at the base of his spine and a hole in the heart (small VSD), which had closed by the age of 6 months. Robert slept a lot and most of the time I had to wake him up to feed him. He was however a very colicky baby for about four months. At Rob's 9-month clinic check he failed all the tests, so was referred for blood tests. We finally got the diagnosis by his paediatrician two weeks after his first birthday. Rob was diagnosed with Inverted Duplication of Chromosome 15, now known as Isodicentric 15 or Idic15. He is not your regular idic15 though; He has a 48 chromosome karyotype (two identical markers).



At the time of diagnosis Rob could only lay on the floor. He wasn't able to roll over/ sit/ stand or crawl. We were referred to all sorts of different professionals: Physiotherapist, Occupational therapist, Speech therapist. Suddenly our lives became an endless round of appointments. It was like being on a roller coaster ride that just kept going round and round. By the time Robert was 18 months old, the help that we had been given by these professionals was starting to improve Robert's life. He started to crawl. He spent a long time trying to pull himself up the furniture and eventually succeeded. He started to walk at the age of three although he couldn't understand how to get back up from the floor to the standing position and this took him about another 4 months to work out.



Robert age 6 years

When he was 18 months/ 2 years he had some strange episodes of staring and dropping to the floor and went into hospital for investigation, but this was shown to be inconclusive. However, 3 days after his ninth birthday he developed seizures and he now requires medication. An MRI when he was 6 years old showed that at some point (probably in-utero) he

had a brain haemorrhage. Rob has severe dorsiflexion, his joints bend backwards and sometimes can be in danger of dislocating his hips or shoulders, he is also hypotonic.

Robert age 11 years in 2006

Rob is now almost 12 years old and goes to a special school. He likes school and loves Swimming and Horse Riding. He likes his food and drink. He loves being outside and going for walks, I have to take his wheelchair because he tires easily and because of the seizures I need to be able to transport him. He rarely cries and is very content most of the time. He is not able to speak and can only sign 'please'. Rob has very poor fine motor skills. He has severe learning difficulties. Rob is a climber, climbs on anything and everything, he bangs on the windows, switches lights on and off constantly, opens and shuts doors, tries to escape out of doors and windows. He loves water, and bath-time is a favourite, but you have to watch him constantly around any sort of water, he is constantly turning on taps and letting the water run. Despite the challenge of having a son with idic 15, I have to say he is a lovely loving boy who likes a cuddle. I am so glad he is mine, I wouldn't be without him. He is a very special boy.



The day we were given Rob's diagnosis, we were lucky enough to be told about Unique. I joined within 3 weeks and have never regretted it. Unique is like a big family that keeps growing and growing, I feel privileged to belong and no longer alone.

I have been a part of Unique for 11 years and have watched it grow and grow from the little acorn it was when I joined to the great oak tree it is today. Please help us to keep the tree growing.

If you are wondering why you should support Unique, please consider this:

- **Our children are very unique.**
- **Often parents are isolated because their child is the only one with that particular disorder.**
- **Unique is able to link families who feel alone so that they no longer feel isolated.**