

MORGAN

Morgan's GRI Story

Morgan was born 2 weeks early on 16th May 2003 with a normal delivery and there was no specific reason to see or think at that time there was anything wrong with her, weight 6lb- 7oz (same weight as I was when I was born). It was not until Morgan didn't reach her initial milestones in the coming weeks/ months that it became apparent that there was an issue. Morgan could not lift her head for too long, although she tried hard and she had very low muscle tone, she had difficulty taking a bottle, and was gaining weight very slowly. There was no real concern until about 6 months. Morgan slept well up until about 6 months and then was a very poor sleeper thereafter.

We were referred to a pediatric Doctor's clinic at Yorkhill, Glasgow for genetic testing, MRI and other tests, the genetic testing did not show anything (18 years ago) their conclusion, Morgan had Global Development Delay possibly attributed Angelman Syndrome again not conclusive but probably) or Cerebral Palsy. An opportunity presented itself in 2019 to re test genetics, then the pandemic delayed but by November 2022 Morgan was Diagnosed with GRIN 1 LOF at the age of 19 years.

Schools & after.....

Morgan attended a Main Stream/Additional Needs Nursery, Primary School and High School and now attends a Day Centre in Glasgow where she has fun every day with people her own age.

During schooling and at Day Centre Morgan is seen by Speech and Language, Physiotherapy and OT.

Morgan can sit unaided, stand with assistance, walk a little with assistance, uses a wheelchair or walker to get around and communicates through eye contact (or when people get to know her they know what she wants)

Family.

- Morgan lives at home with Mum, Dad, Sister Cienna and 2 Ragdoll Cats, Snow White and Simba and 2 Mainecoon cats Maleficent and Mufasa..



- Morgan loves her sister Cienna, and from the moment Cienna became aware of Morgan and her being extra special, she has helped Morgan and played with Morgan, having lots of fun together.



Morgan is a beautiful, happy and fun loving young lady who brings happiness to everyone she spends time with.



Health and Wellbeing

Morgan, to date, has not suffered from seizures, Morgan keeps in very good health often not even catching general colds and sickness bugs like the rest of the household (fingers crossed that this may continue) and aside from an accident in school when the carer left Morgan's brake off on her wheelchair, with the wheelchair going down hill off a pavement and Morgan falling on her face losing her front teeth, Morgan has never been in hospital.

Morgan slept well her first 6 months but thereafter does not sleep well at all and is up most of the night. Sleeping for short bursts.

What Morgan Loves

Morgan loves spending time with people, she loves Barney, Mr Tumble, The Wiggles and HI Five (some of which she has seen in concert a few times and loved), she loves all things sensory, including musical instruments, running water and messy play.

Hopes for the future

We would love if Morgan could communicate with us a bit better, to be able to tell us if she is in pain or what her needs or wants are. We would love to see a cure for this horrible Genetic Gene Disorder.

