

# A Dad's Story



# The Story of Isabel Begins

- Born 6<sup>th</sup> December 2003
- Alder Hey to see Ophthalmologist at 3 days old
- Cataract surgery & contact lenses
- Andrea's retinal detachments
- At 6 months old, physical difficulties became more apparent. CP diagnosis
- Around 12 months diagnosed with severe epilepsy called infantile spasms



# Infantile spasms



- Early treatment not successful
- Alder Hey started to use the term “refractory epilepsy”
- Was having major impact on learning – kept forgetting skills
- Told she would never walk, talk and would be blind
- Referral to Dr Martland @ Manchester Children’s Hospital
- Achieved decent seizure control around 3, fully controlled about 4-5
- Then made further progress with development

# What Worked

- My employer (small robotics company)
  - Flexibility
  - Psychological support for me
- Online forums / mailing lists
- Families United
- MACS (Microphthalmia, Anophthalmia and Coloboma Support)
- There was no WarrPAC then!

# Growing Up

- Once seizures were well controlled Izzy continued to make slow but steady progress
- Always some ongoing medical / care issues but definitely calmed down from school age onwards
- Izzy became more active and took up gymnastics, dance and cycling. All challenging for her but she really enjoyed them.
- Diagnosed with COL4A1 genetic mutation



# Andrea

- Found it difficult to cope in the early days and was diagnosed with Post Traumatic Stress
- Recovered well with treatment (& time)
- Became trustee of FUn
- Parent rep at WarrPAC
- Had always said she could never cope with a disabled child.
- Look at her now! Is actively engaged in range of activities for SEND children and great support to others

# My own health

- Back severely damaged by an osteopath 4 years ago
- Still significant impact on day-to-day activities



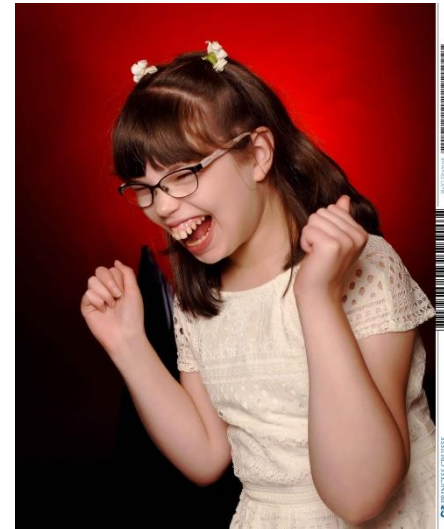
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- Can't be the husband and father I want to be
- In the early days I looked after Andrea & Izzy. Now it's Andrea who looks after Izzy and I

# Present Day

- Izzy has come such a long way!
- Is now 14 and doing well at Green Lane School
- Is very determined (& bossy!)
- Very loving and affectionate
- Continues to amaze me every day with the progress that she makes





# Challenges Ahead

- Physical difficulties
- Won't ever be able to live independently
- What to do when too old for school
- Loves “hands on” activities such as cooking and gardening
- **No matter what life throws at her she is always happy. As a parent, that's what really matters**

