I am number 17
Nicola's Experience

Over my lifetime I have suffered with my hearing. As a child, every other year I went to Sheffield Children's hospital to have wax removed as I suffered with glue ear. Grommets were fitted to help me.

At sixteen years old I underwent a mastoidectomy I was then transferred from the children's services to the adult services in Barnsley. At around the age of twenty-four I developed a severe inner ear infection which turned into meningitis.

Part of the Feingold syndrome are abnormalities of the fingers and toes. I suffer from the shortening of my fifth finger that curves inwards, and also have webbed toes.
These I call "freaky fingers" as I could never do the sign properly at brownies and "duck feet" as I was often bullied at school because of them. I remember once asking my mum if I could have my toes cut open, so that I could look like normal people.

I struggled as a teenager relating to friends, once you have the label of "freak" that label sticks and I became more withdrawn. Consequently, upon leaving school my mental health took a nosedive and I found it difficult to build and maintain relationships, both with friends and work colleagues. With the support of my parents I undertook counselling and attended support groups to enable me to progress. This took a while but was well worth the journey and enabled me to get my life back on track.

As part of my recovery I studied and gained a Cache Diploma level 3 in childcare and education. It was at this point I found out that I was dyslexic. In 2014 I became pregnant for the first time; it was at the twelve-week scan where the abnormality was picked up. I was expecting twins. Further scans revealed one of the twin's brain was forming outside the skull and had a cleft lip and one of their feet and hand were deformed. This baby was terminated for the safety of the other twin and me.

At 15 weeks pregnant, a doctor tried to perform the termination process using keyhole surgery but could not due to William actually lying in front of her, (protecting his sister).
They tried again at 17 weeks, where they were able to complete the process. I was told that Layla would simply "disappear / dissolve". At 19 weeks I felt a sharp pain and was rushed into hospital where I delivered a still born baby who I named Layla.

At 26 weeks, William was born, weighing 728g, born in his sack and a natural birth. Due to being born so prematurely and having a duodenal atresia* (double bubble) unfortunately William never gained enough weight or strength to have the operation he only survived 58 days. We had our babies tested through genetics, the first baby was a girl, nothing was found at that time and told "it was one of those things and that future pregnancies should be alright". William and Layla are buried together.

I fell pregnant again and discovered that this baby also had a duodenal atresia. This time I was being looked after by Leeds General hospital. This was where I found out about Feingold syndrome. Edward was born, weighing 4lb 4oz, a healthy enough weight to have an operation at two days old to connect his bowel.

I was also tested for Feingold syndrome which came back positive for Feingold syndrome type 2, Edward has inherited Feingold syndrome type 1. My parents were also tested with a negative result.

Edwards father and I separated when Edward was seven months old. I have been with my new partner for three years and we were offered IVF, as I was given a 50/50 chance of any future baby having Feingold syndrome. Luke my other son is now 11 months old and the health visitor calls him a "textbook baby" and weighed at birth just under 9lb.

** Intestinal atresia is a broad term used to describe a complete blockage or obstruction anywhere in the intestine.*

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