



# Parley

Parents And Relatives  
Listening and Empathising  
with You

## Michelle's Story

I was 19 and pregnant for the second time I thought everything was going to be fine like last time, everything was until my 20week scan the hospital found something and I went back for a number of scan they done more test and that was that nothing was picked up.

My date came for my caesarean I was really excited at 9.18am my tiny baby boy was out, the doctors knew he wasnt the same as other babies he looked a bit different and he was born at 39weeks weighing 5lb 9oz but I still reckon to this day they got it wrong as he fitted in premature clothes and nappies, he was a poor feeder and was kept in hospital a week.

Back home all was going fine doctors didnt say anything then at 10weeks he was admitted to hospital for poor feeding after that he was admitted about 15times in the first year and a half for poor feeding, croup, vomiting and other things, even upto Great Ormand Street.

He had a number of test through out that time for downs syndrome, williams syndrome and some others cant remember them all then finally when he 1year 8months we got called to Great Ormond Sreet they diagnosed him with Nicolaides Baraitser syndrome he was only the 7th in the world at that time now theres 23 in world which proves more research is being done.

Callum didnt sit up until just before his first birthday, started crawling at a year and a half then didnt walk until he was nearly 2, he still cant talk and has been attending a special school since before Christmas, he is a proper little man. I love him so much he brings so much joy just the same as my other 2 children.

Callum has quite a temper, he is good towards his older brother and younger sister he sometimes get a bit to rough. It does get hard with him sometimes I feel I need a break but that never happens it's all part of motherhood.

Callum has met two little boys with the same syndrome as him he met one in November that little boy was 4 they looked so much alike, then we met the other boy who was 10 in the December Callum wouldnt leave him alone.

The geneticist has arranged a meeting for next week with 7 other families who have children like Callum it will be really good to meet them all and have a walk, the geneticist are going to talk to us about the syndrome was causes it and the more research there doing. It was only throughout my pregnancy something was picked up and Callum is still the youngest to have been diagnosed, most of the children are being diagnosed at 3+. He is very energetic and keeps me on my feet all the time but it's worth every minute.