



Grace

LIVING WITH DIGEORGE SYNDROME, ALSO KNOWN AS 22Q11.2 DELETION SYNDROME

We were abandoned until she was 17. There's quite a lot of catching up to do!

“We hope she will find a job assisting in childcare, which is her dream. And perhaps live outside the home, in some shape or form, some form of assisted living. She needs it, we need it, her brother needs it.”

Grace, our daughter, was born in February 2002. The weeks, months and years that followed will always be etched in our memories. A straightforward pregnancy, slow labour and there she was, a 9lb2oz, fine sized baby! However there was a silent moment in the delivery room when the nurse asked the Doctor who was listening to her heart " is there a problem?" That line sent our world into chaos!

It took 24hrs to establish there really was a problem, a big problem. No interest in feeding, a pale colour, a lip that turned blue for a split second.... We found ourselves following an ambulance to Crumlin in the early hours of the following morning.

Without going into the nitty gritty, we had a week there, and were sent home with a very poor prognosis and a very sick baby. We were brought back a month later

for a month. She needed two major surgeries and several smaller procedures, but they patched her up well, and we were slightly more optimistic.

Grace has a variant of Fallots Tetralogy, a very complex anatomy, we were told by the brilliant cardiologist and heart surgeon, but they were hopeful. She underwent major repair surgery at 2 1/2 years of age. Thankfully it went well and Grace was able to lead a full and normal life.

This is where things began to get even more complicated... She struggled to meet her milestones, never really reacted strongly to things, and rarely smiled. She was too quiet. But as she grew and started school, she was just like any other little girl; a bit of a scamp and full of fun, especially when her little brother arrived.

She struggled in school and needed help with language.

We thought it was the result of her many stays in ICU and that was hard to watch. We thought it would be a miracle if she came out of ICU unscathed in some way. We were encouraged to be told that 'heart children' do sometimes catch up on their peers.

Grace became very ill in 2013 with Endocarditis resulting in a very long hospital stay, but she kept her spirits up and recovered.

It wasn't until she became a teenager that we noticed she was a bit different. I noticed her eyes; they were more slanted than ours or her brother's. Her mouth and teeth were different. I was becoming concerned.

She found Secondary School a nightmare. The rough and tumble, the crowded locker room in particular, the canteen. As I teach in the same school, I observed her body language She was utterly miserable. She found it hard to make friends. She had two, but eventually they left her. She was becoming quieter and quieter.

School was weighing her down, suffocating her, until after her Mock JC exams, where she performed very badly. She had a breakdown.

She was hearing voices, was paranoid and psychotic. She wouldn't leave our side and even slept in my bed. She was 16.

Grace stopped speaking. Our GP referred her to CAMHs, where they prescribed medication and recommended a stay in a Mental Institute for teens in Dublin. We didn't go through with that part, as I wanted her at home. She came through that, but is still on the meds.

Our cardiologist recommended she take a test for DiGeorges/22Q...we discovered when she was 17, she indeed has 22Q. While we are very angry that we didn't know until very late in her life, we were a little relieved that maybe we can understand her 'condition'. But nobody has heard of it! Nobody I know anyway! Even many medical professionals we spoke to have never heard of it! How ridiculous is that!

So here we are 2022 - Grace is suffering from mental health issues, anxiety and low self esteem. She did not complete the JC or the LC. She has been doing courses in NLN, has tried some others but her lack of confidence gets the better of her each time. She has no

friends. They've all moved on.

She has a quirky sense of humour and is witty. She is fiercely determined and works hard. She hates to disappoint, which also causes anxiety.

Physically she is doing well. She sometimes complains of a sore back or legs, but her Cardiologist is happy. It is her mental health we are most concerned about at the moment. The worry about her future is ever present.

We hope she will find a job assisting in childcare, which is her dream. And perhaps live outside the home, in some shape or form, some form of assisted living. She needs it, we need it, her brother needs it.

We will continue to work and strive to achieve this in the coming months and years.. we were abandoned until she was 17..there's quite a lot of catching up to do!