Elodie by Danielle

Elodie was born via a planned C-section, due to breech positioning, at 10:33am on 30th July 2019, weighing 7lb 1oz. From the moment she was born we knew something was wrong. She didn't cry and rather than my husband being asked to come and take some photos, like with our first, he was instead asked to wait behind the curtain and I could hear people saying "Come on baby! Come on baby!" I felt confused, and the C-section was putting me to sleep so I couldn't process what was happening very well but I wasn't panicking as my gut was telling me she was fine. And she was! She needed some help to get going but eventually she did start to breath on her own. We were told she would need to see a specialist team as she was so lethargic and floppy and I had to wait, what felt like a lifetime, to finally see her whilst I was put back together again.

They brought Elodie over to meet me and she was such a perfect, tiny, dinky dot! A very quiet dot!

Nurses and Doctor's umm'd and ahh'd over her, some of them disagreed amongst themselves regarding whether there were any concerns. But finally, after being referred to a consultant who deemed her floppiness to be down to a muscular issue that would fix itself, we were sent home on day 3.

We only had her home for a day when, whilst sleeping on her dad, her face went blue. We called an ambulance which led to us spending the next 3 weeks in hospital. She had loads of blood tests, an MRI scan, a heart scan and eventually genetic testing. All of her tests were coming back fine. Elodie had 3 more blue episodes during her hospital stay, due to this the doctor's thought her health was deteriorating, and, along with her very low muscle tone, they suspected she had Spinal Muscular Atrophy (SMA). She was transferred to the Intensive Care Unit where she stayed in an incubator. She was on a CPAP machine to assist her breathing and had wires all over her body. Our local hospital transferred Elodie to GOSH for specialist treatment and we were told to prepare for the worst. By this point my life didn't feel real any more, I was robotically doing what I had to do and I felt numb and detached.

Whilst Elodie was in GOSH's Intensive Care Unit, the specialists that examined her felt that she more than likely had Prader-Willi Syndrome (PWS). She was then sent back to our local hospital.

At 3 weeks old the genetic test results came back and confirmed that Elodie did indeed have PWS. Our story is different to

most others on diagnosis day, as understandably receiving this diagnosis is a shocking and difficult time. But for us, this day was a relief because compared to SMA, PWS was so much better! Our daughter would live and we would take her home!!

Elodie was finally discharged once we had been trained on NG tube feeding, which Doctor's felt necessary due to fears that her blue episodes may have been caused by her aspirating her bottle feeds. She came home with monitoring machines, emergency oxygen and many referrals were made to various departments for her ongoing care.

At a hip check Elodie was then diagnosed with hip dysplasia and will undergo 2 hip operations. Her first one is due when she is 9-10 months old and she will wear a hip spica for 12 weeks after each one.

Elodie is now 5 months old, she hasn't had any more blue episodes. She is still fed by NG tube, but is starting to have purées orally which she loves! Her tone is still low for a baby of her age, but she can now support her head whilst in an upright position. And with lots of hard work at physio, she has begun to be able to support her head during tummy time! She takes a lot more interest in toys and each step of progress comes with a huge sense of pride!

Elodie has some complex problems to face, yet she is such a joy and is always so happy, I've never met a more contented baby. I love watching her grow and reach her own milestones.

I struggle when it comes to her needing hospital stays and I am anxious about her upcoming operations, but having support around you is key and I am really lucky to have such supportive family and friends, The PWSA and the PWSA Facebook group are a huge part of that support network, use them!

Our Growth Hormone journey should begin shortly as she has recently had a sleep study and I am excited to see how much this treatment benefits her.

Although there are challenges with having a child with special needs my husband and I could honestly say we wouldn't change Elodie for the world, she has already taught us so much about what's important in life and any bad days are far outweighed by the good.

With lots of promising research being done a future with PWS looks brighter than ever.

Danielle