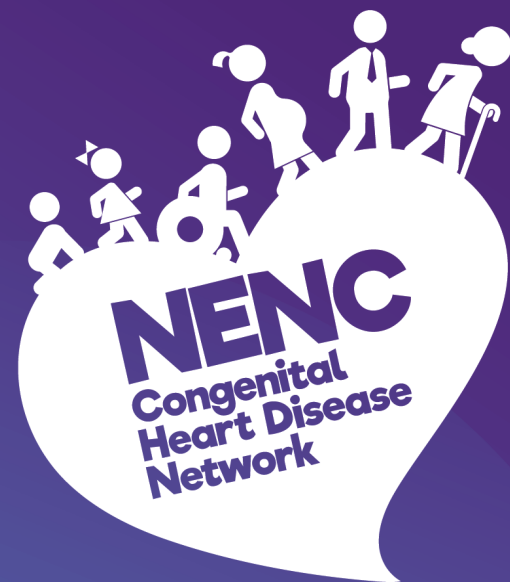


AULEY'S STORY



PATIENT AND FAMILY ENGAGEMENT GROUP

Hi everyone. On the 22nd July 2020 my gorgeous baby girl Auley was born weighing 8lb 10oz and she was perfect in every way. I had a planned c-section with me having gestational diabetes and I had regular scans every 4 weeks which is where they saw she was going to be a big baby. At my 20 week scan the sonographer couldn't see all the 4 chambers of the heart but I was told everything was fine on a repeat scan.

The day after she was born a doctor came to do Auley's newborn checks and did her oxygen saturation check. He asked me if I noticed anything about my baby to my reply 'yes she isn't breathing correctly and she's a tinge on blue'.

He checked her sats which were 78. He went away for another sats machine and again were still 78%, he then got a consultant which informed me that my baby was going to scbu. We were rushed off the maternity ward to scbu where they put Auley into an incubator and turned the oxygen up to 80%. Her colouring came back to what I would call normal but Auley was struggling more to



breath. The Consultant came in to inform me he thought it was a heart condition but didn't know what exactly until she had an echo to check and told me he'd put her on Prostin. I felt like I was dreaming.



I had gone from what I thought was a healthy baby but in the back of my mind I knew something was wrong to be told my baby was quite poorly. They sent a team from neonates to take Auley up to the Freeman hospital in Newcastle safely. Auley was diagnosed with pulmonary artresia with a ventricular septal defect. At 6 days old Auley had 2 stents placed which she then was in intensive care and straight away Auley was a "normal" colour she wasn't sucking her chest under her ribs I couldn't believe it! Auley was in PICU for 2 nights then back on

the ward where she was doing amazing. She was a different baby. We were told that we would need training and Auley would be on a care programme so we could take her home. As parents we were trained in CPR and went on a programme to monitor her saturations daily at home and to weigh her Monday, Wednesday and Friday and write down how much feed she took orally or down her ng tube. They said she will need another operation at about 6 months to completely mend her heart which will mean our little girl will be a lot better and a massive improvement again with her.

If she didn't have her new born checks I was told Auley wouldn't be here today. I will never forget the Sister on the unit saying 'a Mother's instinct is always right' and I feel I should of been listened to quicker. The staff at the Freeman have listening to our concerns and acting upon them and reassuring us. Auley has a long road of surgeries ahead but is full of smiles



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