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Positive about Down syndrome

The Lived Experience: Heart surgery experiences

Positive about Down syndrome

Please note that there are images of little ones in intensive care which some parents may find distressing.

Introduction

We have collated these stories to give you an insight into some of the experiences of our little ones in the run up to surgery and during the hospital stay. Parents have shared their stories to hopefully enlighten and reassure you if your child is due to have heart surgery. These are produced by parents for parents, we hope you find them useful and informative.

In addition, PADS can provide you with a heart buddy - a parent whose child has been through similar surgery and happy to try to answer any questions, offer you support as your little one prepares for surgery, on the day and follow up. **If you would like to request a Heart Buddy, please fill in this form.**

There are many great resources on line if you are after more medical information, we include some links for your reference:

https://www.bhf.org.uk/informationsupport/conditions/congenital-heart-disease

https://dhg.org.uk/information/

https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/heart-problems-cardiac-disorders/?fbclid=IwAR0uf7fv5ytlwqV67_qCC-SrkbzLAvTHnxCk4rdo91mLBjr5-8NFTtLoeMo

https://www.tinytickers.org/?fbclid=IwAR1H3MnF75ZnOQj0gvapx1hxcAcIEncHuW8uHgiATUTMRm7-aVIzCpN5mI0

Parents Top Tips!

Here are a few practical pearls of wisdom from other parents who have been through heart surgery:

1. Keep a list of all the medical professionals involved in your child's care, together with contact details and relevant info like hospital numbers – you'll be asked for this information at various appointments and on admission to hospital so it's handy to have it all together.
2. It's helpful to take a couple of toys or rattles for distraction during scans and once they're feeling better after the op.
3. Check whether the hospital has a heart or parent support charity attached to it – if so, their website and facebook pages can be a really helpful resource – from finding local food options to other parent's experiences.
4. Little ones are unlikely to be dressed the first few days after surgery. During this time, they might get cold hands and feet so socks/booties/mittens are all very useful. Depending on the age of your little one, mittens/socks on their hands might also help to stop them pulling at tubes!
5. Once your little one is back in to clothes, they'll need easy access to their chest and they are likely to have various lines/tubes/monitors still attached so the vests with poppers down the side (from places like H&M, Next & M&S) and babygros with no feet come highly recommended.
6. Intensive Care Units are usually fairly warm places so whatever the weather outside, take light and comfortable clothes to wear in ICU.
7. Think about looking after yourself too - take a refillable water bottle, snacks and a good book with you! Also think about a few things that might give you comfort - chocolate, your favourite comfy jumper, fluffy socks, headphones to listen to music/watch netflix etc.
8. Remember there are lots of families in PADS groups who have been through this and are here to support you. Any questions you have, please post in our group.
9. PADS can also provide you with a heart buddy - a parent whose child has been through similar surgery and happy to try to answer any questions, offer you support as your little one prepares for surgery, on the day and follow up.

We are here to help - so just ask!

Lenny's Heart Story

By mum Vikki Rooney

HOSPITAL: ALDER HEY CHILDREN'S HOSPITAL

The second Lenny was born and I saw him for the first time I knew had had Down syndrome, he was perfect, breathed on his own, breastfed straight away, never had any time in the Neonatal Unit (NNU), his oxygen saturation test after birth was all normal, so when the doctors had said he would need a routine heart scan the day after birth, just to check for any heart defects, as just under half of babies born with Down syndrome have some kind of heart condition, I just thought well nothing was picked up at his 20 week scan so it will be all fine.

The next day I went to the NNU for the consultant to do his heart scan, and the doctor said he has 2 large holes in his heart and only one valve – a complete Atrioventricular Septal Defect (cAVSD) this was the first time I broke down crying as my little boy would need Open Heart Surgery (OHS), I was devastated, thoughts run through by mind, would he survive? When would he need the operation? How long would he be in hospital for? But he was currently very well and we were allowed to go home and Lenny was referred to our Local Children's Hospital Alder Hey in Liverpool.

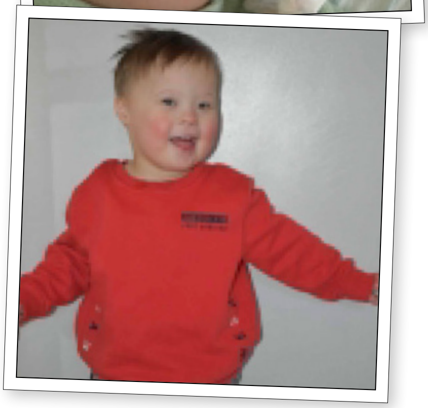
Lenny went into cardiac failure at three weeks old, he was struggling to breathe because of the build up of fluid on his lungs as the heart wasn't working as effectively, he was put on medication which worked well and the day he was 6 months olds was the day of his OHS, I was told to expect a 1 to 5 week hospital stay so I aimed for three weeks.

On Wednesday 3rd October we walked him down to theatre at 09:00 I kissed him goodbye, I held it together but my husband was in tears as we walked away, we had a 6 hour wait until the nurse called to say he was out of theatre and all went well, the operation lasted 4 hours and he had been in intensive care unit (ICU) for 2 hours before they called us.

I was told he would be ventilated and sedated for about 24 hours, but 3 hours after the operation he was waking up and trying to pull the ventilator tubes out, he was too strong for the sedation medication to work, so they had to take him off the ventilator, he didn't seem in any pain. I couldn't stay with him overnight in ICU, so I stayed in the Ronald McDonald House and continued to express breast milk for him overnight.

The next morning (Thursday 4th) Day 1 post surgery, I asked could I hold him, and the nurse helped me pick him up as he still had two chest drains in and some wires monitoring his heart and breathing. After 24 hours from the operation he was out of ICU and transferred to the Cardiac Ward. He was tube fed expressed breast milk, that day he slept most of it.

Day 2 (Friday 5th) he was smiling again, His chest drains were removed, I was allowed to breastfeed him again, the feeding tube was removed and his big sister even got to hold him.



Day 3 (Saturday 6th) he had a heart scan, all looked good, he just had one tiny hole at the bottom of his heart (VSD) ventricular septal defect, but I was told this should close fully on its own. His dressing was removed too.

Day 4 (Sunday 7th) Lenny was discharged home. He had monthly scans and after 6 months his little hole closed on its own, he has one valve which is slightly leaking so will need further surgery one day in the future, he is now 2 years old and has one heart check-up every year.

Isla’s Heart Story

By mum Jane Britton

HOSPITAL: BRISTOL CHILDREN’S HOSPITAL

Isla was born on the 7th Feb & we had no idea at this stage that she had DS or any heart issues. We had the DS diagnosis confirmed a few days later and as routine, she underwent heart scans in NICU which showed a small VSD & possible ASD which they didn’t think would be an issue but we would be referred to the cardiology team at Bristol children’s hospital for ongoing monitoring and we were allowed home.

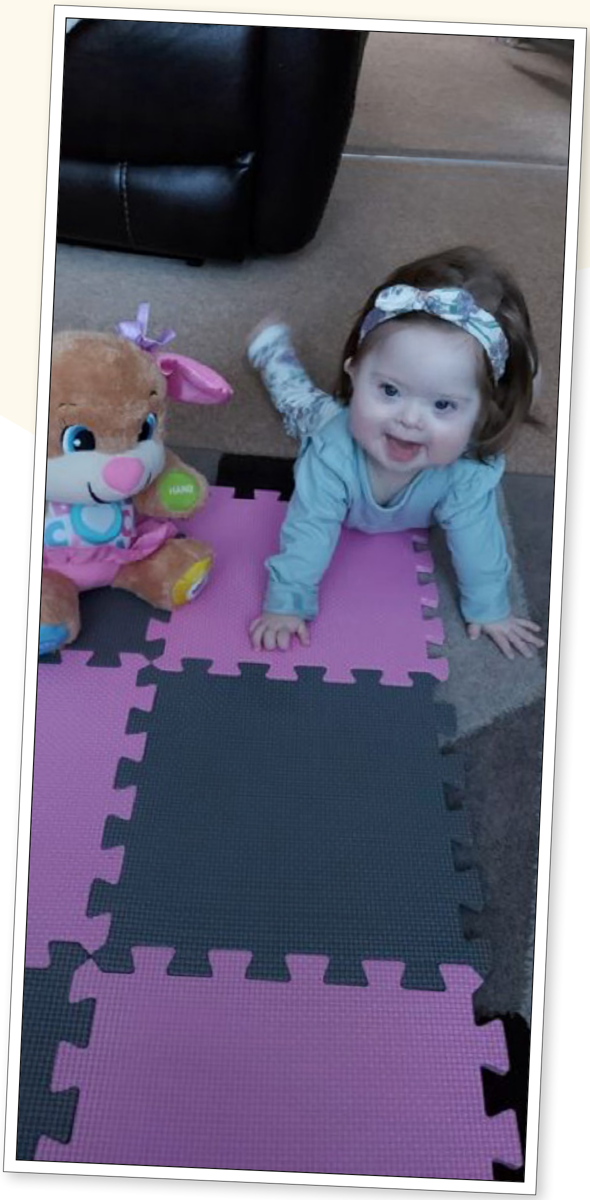
On 21st Feb Isla was admitted to hospital with breathing difficulties. After lots of tests we were given the news that Isla would need surgery for a large VSD, ASD & PDA litigation but she would need to be around 5kg for surgery to happen. She was currently 2.5kg and not gaining weight due to worker breathing. She was put on diuretics to help draw fluid off her lungs and blood pressure meds to help along with high calorie milk fed by NG tube.

Over the next few weeks her condition was deteriorating and she was in heart failure. Surgery was now the only option but she was still very small at only 2.9kg. Surgery was booked for Mon 9th March what we hadn’t prepared for was to be told on the morning that PICU was full so the op was cancelled. This happened 4 times and she finally had surgery on 13th March - 5 weeks old and weighing just 3kg.

The 6 hour wait during her surgery was the longest time ever and the relief when the surgeon rang to say she was OK and in recovery was overwhelming. Although we had been shown round PICU beforehand we just weren’t prepared for what we saw, Isla looked awful - so many tubes, wires, chest drains, ventilator and she was very swollen from the drugs. Within 24 hours the improvement was remarkable although her rate was controlled by pacing wires as she had no natural heart rhythm. She had a collapsed lung & an infection and was put on a Cpap machine.

After a week in PICU her heart was still not beating unaided, she had total heart block & they decided to operate again to fit a pacemaker all the while we were isolating at home due to me developing covid symptoms. It was a nightmare not being able to see her but the hospital was amazing calling us regularly with updates. Isla spent 12 days in intensive care and then transferred back to the cardiac ward. I was finally able to go back to the hospital but Isla was now being treated for Sepsis. She had another op to fit a Hickman line through her chest so they could give IV antibiotics.

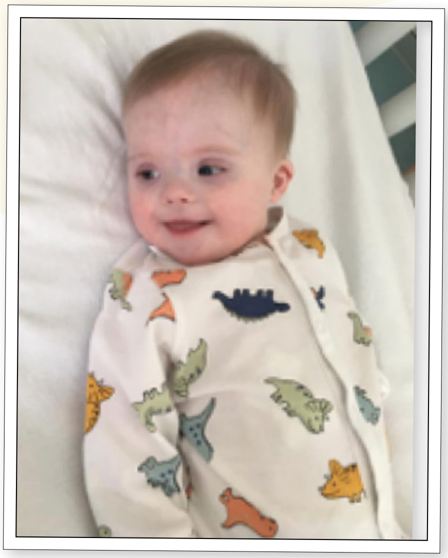
We were eventually allowed home on 3rd April but with hospital nurses visiting us every day for 6 weeks to continue the treatment for the Sepsis. It has been a long process and we have had 2 cardiac checkups at the hospital which they have confirmed she has a small residual VSD but this won’t require any further surgery. She will need another op in around 6 to 7 years time to upgrade the pacemaker but other than that she is doing amazing.



Freddie's Heart Story

By mum Catherine Ayres

HOSPITAL: ALDER HEY CHILDREN'S HOSPITAL



At our 20 weeks scan, our cheeky monkey was covering his heart - he obviously had something he wanted to hide! We got called back two weeks later (to be on the safe side). I was not concerned at all. At this point, all screening tests had come back 'low risk' and scans were just an opportunity for us to see our little baby again. Until, at 22 weeks, when we were ushered from one side of the hospital to the other as the sonographer was concerned. I will never forget that walk and that anxiety.

When we were scanned again, this time by a consultant, she noticed our baby had an extra SVC which to my understanding is the big vessel coming out of the heart. Everyone was calm and we almost joked that it was always good to have something 'extra' than something missing. But, we were sent to a fetal medicine unit just to make sure.

By this point, I was 23 weeks pregnant and the ultra high-tech scanners at the specialist hospital were able to see a lot more. It was here that the news was broken to us. We were sat in the quiet room (the one with the box of tissues) and we were told our little boy had a hole in his heart (or a complete AVSD for those of us in the know).

This news hit us like a ton of breaks as the doctor drew us diagrams and explained that surgery would be needed in the first 6 months of life.

Strangely, two different doctors had asked me the same question numerous times - 'have you had the screening for trisomies?'

I had no idea why they were asking me this until they explained the link with Down syndrome and offered me an amnio on the spot.

In that moment, finding out our unborn baby would need surgery was the biggest shock and you find yourself googling and researching everything as scaring yourself silly

Extra scans came and each time we would celebrate a little more. We were happy to see him grow, we were happy to discover the AVSD was balanced (meaning both sides of his heart were equal in size) and each scan we got to see our beautiful boy.

On 21st August 2018, I was induced at 38 weeks as this is quite common when a baby has a heart condition or a genetic condition (at this point we didn't know he had DS because we declined the further testing).

The hospital monitored his heart throughout labour to check he was doing ok. The thing I worried about the most was him being rushed off and not being able to see him or hold him but when he was born we got to spend the most amazing hour with him and he didn't need any oxygen. I was also worried he would be blue as so many people had told me about 'blue babies' but he wasn't and seeing him, you wouldn't think he'd had a heart condition.

His first few months of life, he had to have heart scans every few weeks. His VSD (the hole at the bottom two chambers) was smaller than they expected meaning they could postpone surgery a little longer. He was also managing to keep up with his feeds (although he did get tired a lot during them).

When he was a few months old, he was put on a small amount of medicine which we gave to him each day in a little syringe. He didn't mind it at all and it just became part of our routine.

The wait for open heart surgery is truly the worst part. We got sent for a pre surgery meeting where you meet the doctors and get shown around. Honestly, I recommend this for peace of mind. It really helped me to see where Freddie would be looked after and to ask any questions.

It also made me realise that these surgeons, doctors and nurses are complete experts and are used to doing these surgeries every day. They completely had my trust.

It wasn't nice to sit and hear all the statistics and possible complications I admit but I got comfort from the many families I had spoken to who had been through the same thing.

The worst day for us was the day we went in for Freddie's OHS and it was cancelled last minute. Please be prepared that this can happen. We were obviously understanding as emergencies obviously take priority but this was so hard for us to deal with as you built up to it so much and the drive back from the hospital that day was the toughest.

However, we didn't have to wait much longer and the day of the surgery came (March 22nd, the day after world DS day) Freddie was exactly 7 months old.

I had taken so much practical advice from the wonderful community and remembered the Vaseline (in case his lips got dry) H&M grow suits (with the poppers that made it easier for wires) and socks (to go over his hands to stop him pulling at them).

Passing Freddie over to the surgeons is one of the hardest things we have ever had to do and waiting for that phone call for the rest of the day was awful but we trusted that he was in good hands. I recommend trying to get some fresh air during the day and maybe going for a little walk.

Freddie came out of surgery and went straight into ICU for recovery. Be prepared for lots of wires and beeping machines. Seeing him lie there, he looked so different and helpless but I can tell you how wowed I was surprised by the speed of his recovery. Every time we would go to see him, a tube had been taken out or a medicine had gone. We were very lucky that he didn't hit any complications in his recovery and within 48 hours he was on the ward. I have attached a photo of him after 2 days.

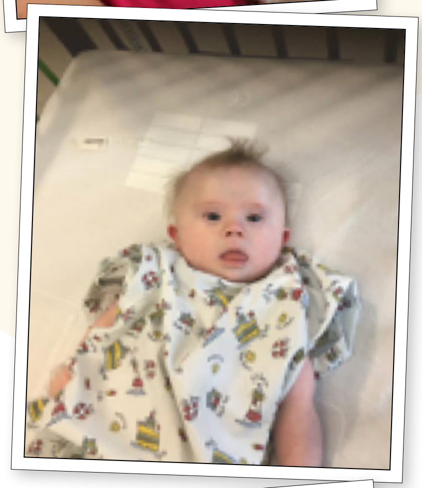
After just 6 days in hospital, Freddie was ready to go home (at this point, he wasn't even taking calpol) and we've never looked back. He's now a lively 2 year old, with barely a scar.

We have to go and have his heart checked each year and there may be a possibility of further surgery but I tell you what, he's a warrior and so is every other baby who goes through this.

Riley's Heart Story

By mum Gillian Hynde

HOSPITAL: QUEEN ELIZABETH HOSPITAL (GLASGOW)



I found out about Riley's complete AVSD when I was 28 weeks pregnant. I was devastated at the thought my baby was ill and I could lose him!!

Riley was diagnosed with Down syndrome on the day he was born but all I worried about was his heart!! I had a 7 year old at home and couldn't tell her as I didn't know how to answer the hard questions about if he was going to be ok after surgery.

We got the date for surgery on the 17th March. The hardest day ever was to take my little boy and put his life in the hands of strangers!! I was terrified and scared I was going to lose him, it made me feel so sick!!

I waited 9 hours to see him and that was like forever!!! When I got in to see him I broke down seeing how helpless he looked!!

5 months on and Riley is doing so well. He is gaining weight and eating all foods which he loves.

At the moment when you are told anything like this it destroys you and you pick yourself up and get on with it for your kids and your strength is there for them. Doesn't make it any easier as it's very scary. Now I get to enjoy my wee boy!!

Che's Heart Story

By mum Toni Holmes

HOSPITAL: BIRMINGHAM CHILDREN'S HOSPITAL

Che had a complete AVSD. He was taken for surgery at around 10am on the 20th Jan 2020. My husband had to hand him over as I was just not strong enough to do It. I had spent all week struggling, thinking that everything I did with Che might actually be the last time I did it. I was so terrified that he might not make it. At around 5:30 the surgeon came to see us and told us that everything had gone well but it had been a difficult surgery. The hole in Che's heart had been extremely large and she had needed to go back in a second time. That had meant stopping his heart twice.

We were taken into intensive care to see him! As we had already spent time on the ward we felt like we had a good insight into what the aftermath of heart surgery could look like but nothing could have prepared us for what we saw! Our tiny little baby covered in more wires and tubes than an electric box. We could hardly see him for all the wires! His body was lifeless and he was surrounded by nurses and doctors! The amount of machines he was connected to was also overwhelming.

We sat by his bedside as doctor after doctor came and looked at his SATs and then altered medicines. During that night the amount of doctors increased and we soon had three constantly watching over him. Eventually, we were told by the doctors that Che was very sick and that they had done all they could. When morning came the surgeon came to see him. She made the call to re-open Che's chest to help release pressure. This was done later that afternoon. We spent our second night by his bedside and were told once again that he was very sick and that the resuscitation team were on standby. By the next morning he had improved slightly and the surgeon decided to re-close his chest! This unfortunately went wrong. It was too much for Che and his heart went into the wrong rhythm and he had to have his heart shocked. He was left with his chest party closed.

As his chest was open he had to be heavily sedated and paralysed! This for us was one of the most horrific experiences of our whole journey. Our lifeless, unresponsive, little man fighting for his life.

In the days to come we struggled with fluid build up causing Che to swell like a big balloon. His kidneys also stopped working and he had to go onto a dialysis machine. Fluid also built up in his lungs causing a collapsed lung. Che also pulled out one of his drains causing blood loss meaning he needed a blood transfusion. Lines had to be taken out and replaced causing even more trauma. They also found he had a fractured rib. Che also had a strange black rash appear all over his legs which caused the need for more testing.

Thankfully, after two weeks our little man's body, with the help of the amazing doctors at BCH started to recover. Wire after wire came out, the drains were removed and Che came off the ventilator onto nasal oxygen. This meant we could go back to the ward. Once on the ward, medicines were weaned off! This had its own problems as Che had become addicted to some of them. We saw withdrawal symptoms and Che even had a fit. This meant more tests. Eventually after 3 long months, Che was ready to go home!

I really hope I have not scared or upset anyone with our story. Not all surgeries are as bad as Che's but I wanted to share the reality of how it could be, so that others can be as prepared as possible.

The photos show Che, just before surgery, just after surgery and celebrating his first heart day on the anniversary of his operation.

Darcy's Heart Story

By mum Francoise Warren

HOSPITAL: BIRMINGHAM CHILDREN'S HOSPITAL

Darcy was diagnosed with an AVSD at 20 weeks pregnant. We had already had Down syndrome confirmed at 10 weeks with a CVS test so my consultant was on the lookout for issues related to Down syndrome. We were referred to Birmingham Women's Hospital for further scans. It was confirmed that she would need surgery at around 3 to 6 months old. I had regular checks throughout the rest of my pregnancy.

At her birth neonatal staff were on hand in case of any problems & she was taken almost straight away down to nicu due to initial breathing issues. She quickly came off oxygen but then had to be treated for jaundice. A week in hospital & we were home. She breastfeed well at first but struggled to gain weight so we had to do formula top ups. A referral to the dieticians at Birmingham resulted in switching to a high calorie milk & she was put on meds to help her heart.

We were admitted for surgery in January at 3 & half months due to her poor weight gain. She was in surgery for 5 hours and her repair was successful. It was one of the hardest things I've had to do leaving her in the theatre after signing the consent form knowing there was a risk she may not survive. I cried buckets but knew it was necessary as she wouldn't survive without the surgery. The relief when I knew she was ok was overwhelming. It was hard seeing her on a ventilator with so many wires and tubes but the staff were amazing at explaining everything & talking about what would happen. One night in PICU & she was back on the ward. I was amazed at how quickly she recovered.

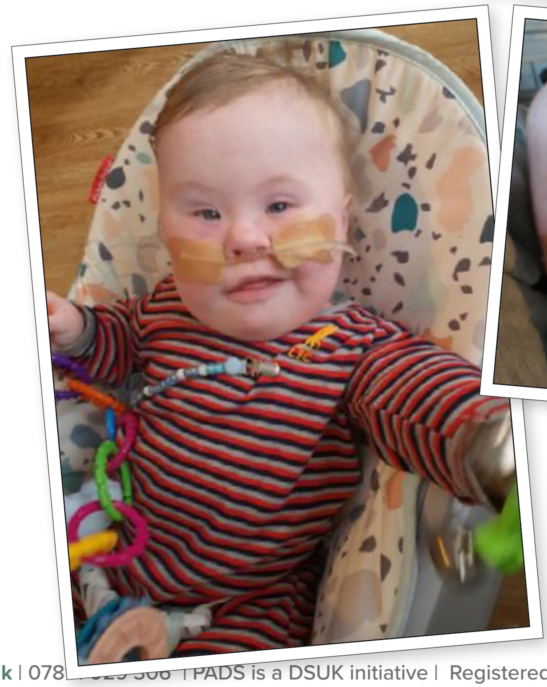
She had a chyle leak following surgery so we had to go on a fat free milk & I couldn't breastfeed any longer. We were home a week following her surgery and she has come on leaps and bounds. The staff and doctors at Birmingham Children's Hospital are amazing. We are still having check ups as she has a leaky valve but they've said as long as it doesn't deteriorate she won't need any further surgery. Happy to talk to anyone who is going through this.

Freddie's Heart Story

By mum Kelsey Lynch

HOSPITAL: ALDER HEY CHILDREN'S HOSPITAL

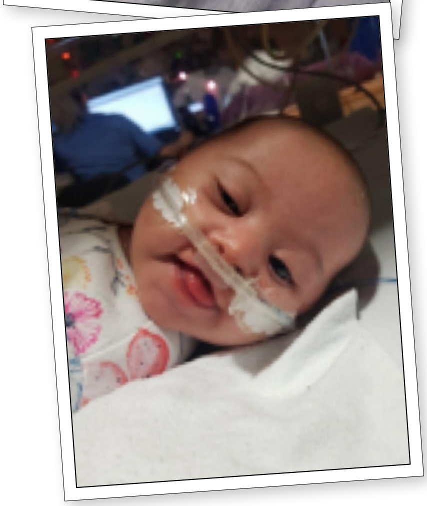
On the 3rd July our little Freddie went in for his heart surgery this was the scariest day of mine and my partners life my emotions were all over the place, all that I could think of was what if he doesn't make it. Freddie has a lot of other issues including chronic lung disease I was told his survival rate was a little less than average due to this. Freddie went on to have PDA repair and VSD repair - I was told his hole was "massive". He was in theatre for 7 long hours; it felt a lot longer but he made it and only spent 1 night in intensive care. He coped really well after the procedure and thrived after a 10 day stay in hospital he came home, doctors expected a longer stay for him but he decided otherwise. Freddie still has a small hole as they could not fully close it but it has no effect on him he has gained a lot of weight and recovered really well. Yeah it's a lot to take in and scary but our little ones are so strong and they really are an inspiration.



Poppy's Heart Story

By mum Leigh-Ann Barthram

HOSPITAL: EVELINA CHILDREN'S HOSPITAL



We had been trying to pregnant for a year and had suffered an early miscarriage the month before falling pregnant with Poppy. Early pregnancy was the usual, morning sickness, tiredness, excitement but fear too after our previous miscarriage....

Just before our 12 week scan I started obsessing about nuchal folds. No idea why, maybe I had an inkling that our baby was going to be that little bit extra! At our 12 week scan the nuchal fold was slightly bigger than the "norm" and a few days later my bloods came back as us having a 1 in 5 chance of our baby having down syndrome. We decided to have CVS to know for sure if our child did have an extra chromosome as we wanted to be fully prepared. Our results revealed that we were having a girl and she did have down syndrome. We knew her name immediately - Poppy Violet Coates!

As the diagnosis happened during pregnancy we were given specialist heart fetal scans. At 22 weeks a hole in her heart was picked up. It was located in the bottom chambers of her heart - ventricular septal defect (VSD). We continued to be monitored throughout our pregnancy but it was explained that until she was born and she was fully independent from me it wouldn't be known if she would need surgery, medication to manage it or it would close by itself.

When Poppy was born we had further scans and found out the VSD was in fact large and would require open heart surgery to close by the time she was 12 weeks as she had a lot of fluid on the lungs (we were told her lungs were saturated), and if she went over 12 weeks the damage to her lungs may be irreversible.

Poppy was prescribed diuretic medication to try and control the amount of fluid on her lungs and high calorie formula as where her heart was working too hard she was using up too many calories causing a lack of growth.

At 11 weeks I received a phone call from Poppy's cardiologist saying the hospital (The Evelina Children's Hospital in London) had an opening for Poppy to have the operation the very next day and could we pack bags and go to the hospital ASAP! We were expecting it to be a week later so didn't have anything prepared which in a funny way helped. There was no time to panic about the operation, no time to worry about what was going to happen. We had to focus on packing what we needed and getting to the hospital in time for Poppy to have pre surgical assessment!

We got to the hospital and checked in with the cardiology department. There she had another scan, an echo, bloods taken, weight and height measured and was checked over by a paediatrician to make sure she didn't have a cold or other illness preventing her from having the surgery. She passed through all that and we went to our room next to the hospital with instruction to be on the ward at 7am for Poppy to be taken for surgery.

It was once we got into our room that evening that it hit us. Our baby was going to have surgery. Open heart surgery. At 11 weeks and 5 days. We were scared but we also knew that there was no choice. Poppy needed this surgery to ensure she would live her life to her fullest potential. To ensure she had quality of life. To save her life.

The next morning we took her to the ward where she was assessed again and put into a surgical gown. Then the scary part. Signing the disclaimer if anything went wrong. Her heart would be on bypass so there was some risk of her not waking up, having brain damage etc. It was truly awful having to sign that bit of paper but ultimately we knew that there was no choice really because she would have no life without having the surgery.

We were allowed to take her into the anaesthetists and stay with her while she was put under but then we had to go. I remember thinking our girl was so strong because she was fighting the sleep so much! We left her at 8am and got a call from the surgeon at 12pm to say surgery had gone well but the hole was in fact massive and her heart was extremely dilated, which just hit home how much she needed the surgery.

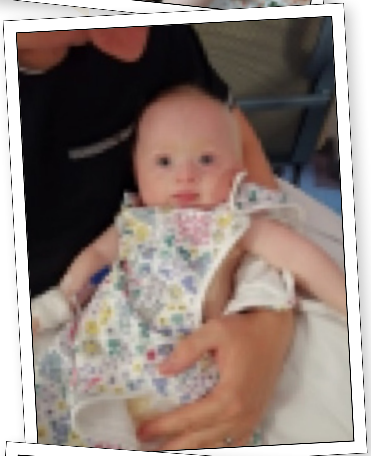
All in all we were in hospital for 6 days. I was allowed to stay with her on the children's ward and my partner was able to stay in Ronald Mcdonald housing which was very near to the hospital. She had to stay on diuretic medication until her next scan where her cardiologist said there were no residual holes and she was an advert for cardiac surgery!

Since the surgery she has gone from strength to strength. Before surgery she was simply surviving, too tired to do anything but pretty much as soon as she woke up (when the drugs wore off) she was a different child and oh my goodness so loud!! She is the most energetic, fun loving person I know and I will never be able to thank her cardiology team enough!

Hannah's Heart Story

By mum Sarah Bendell

HOSPITAL: SOUTHAMPTON HOSPITAL



Hannah was born with Patent Ductus Arteriosus (PDA) which is an opening between two major blood vessels leading from the heart. This usually closes on its own shortly after birth but as it didn't in Hannah this caused blood to flow in the wrong direction which made Hannah's breathing more laboured therefore impacting her feeding and energy levels. Hannah was closely monitored with regular heart scans and, because the open duct was quite sizeable and not closing on its own, at 8 months old a surgery was scheduled at Southampton hospital to close the open duct via a catheter going through the femoral vein and artery in her groin.

The hospital called us to tell us about the procedure and were so kind and helpful in talking to me about it and answering all of my questions.

We also had the extra complication of the potential of Hannah being allergic to anaesthetic (as this is a serious allergy my husband has) which makes any surgery more risky and extra precautions have to be put in place. However, our fears were quickly calmed as the head of anaesthetic at Southampton took the time to talk through all of the safety procedures that would be made.

We were very nervous when we first found out that the procedure would be taking place but we both have a strong Christian faith and after praying about it and sharing the situation with others, many of whom also prayed for us, we felt a strong sense of peace leading up to the day.

We were admitted into hospital the day before the procedure for Hannah to have heart scans and blood tests. We also met with the surgeon who talked through the procedure with us. Everything was very clearly explained to us and all of the staff were very friendly, all of which put us at ease. Hannah was scheduled to have the surgery first thing the next morning and I cuddled her close to me as we carried her into the theatre room. We laid her down on the theatre table and stayed with her while they put her to sleep. We were then able to give her a little kiss before leaving the room. That part was so hard! I kept turning back to look at her as we walked out. The waiting was the hardest part. We distracted ourselves by going for a walk and calling family members. After about two hours, we were able to see her in recovery. She was awake and desperate for milk! She spent the next few hours either sleeping or cuddled up with us. She then had a heart scan which confirmed that the procedure was successful and we were told we could go home that same day!

Much to our surprise, her recovery was immediate. The next day Hannah was happy, smiling and playing with toys. For two days after the procedure, she had longer sleeps and wanted slightly less food but then the difference was amazing! We instantly noticed that Hannah had more energy and was able to stay awake for longer between naps. She also started to make more playful noises and seemed to be more interested in things around her as well as having an increased appetite. Now it is a month later and Hannah is doing so well and has grown so much. We have had a check-up back in Southampton and her heart is looking great. We will go back in a year and if all is still well, she will be discharged. We are so grateful for the care and support we all received in hospital and we are so proud of Hannah. She has changed our lives for the better and we are so privileged to be her parents!

Ava's Heart Story

By mum Eleanor Baggaley

HOSPITAL: FREEMAN HOSPITAL

Having had a postnatal diagnosis of Down syndrome, we were asked to stay in at the RVI for a few days to monitor and observe Ava's feeding. She had been examined and her heart checked on more than one occasion, we were told everything looked ok and had just text friends and family to tell them so. Just as we were about to leave on day three, the nurse wanted to check Ava's heart again. This time she thought she heard something. We had the agonising wait, with all of our bags packed, our two older children in the room with us, about to celebrate our return home with their new baby sister. The consultant she called confirmed what she'd heard. It was a Saturday and they wouldn't be able to get someone from the Freeman Hospital over to this hospital. Knowing how desperate we were to get home they arranged for us to drive to the Freeman ourselves, we had to meet my family there to collect our older children there and take them home while we waited to find out what we were facing with Ava's heart. It wasn't the introduction to Ava that they had expected, short but sweet in a child swap. Within a few hours, lots of wires and machines later we were told Ava had a complete AVSD and would require heart surgery. We were then able to go home, it was such a relief to be back in our own space.

The next 4 months were spent in and out of the Freeman, including three hospital stays to balance medication for heart failure and get her on the right high calorie formula to help her gain weight. We had a bit of a battle with the nurses to remain breastfeeding with high calorie top ups but it was worth the battle as we'd find out during her recovery. In the appointment at the end of August the consultant confirmed that due to Ava's heart failure, we'd reached a point where surgery had to happen, she'd only just managed to get to 4kg (the weight they said they required) and she was about to turn 4 months (the youngest they wanted her to be). SIgning the consent form left me feeling a bit sick after they'd run through all of the things that could go wrong along with the chances of each thing occurring.

On 18th September 2018, we received the phone call telling us they had a date for surgery, we were to go in on the evening of 20th September for her pre-op, fortunately we were allowed to return home after, to spend time as a family, as we only lived half an hour away. We had to be back on the ward by 8.30am the next day.

It was a long wait after we arrived back on the ward, Ava was not the first on the list for surgery, she wasn't allowed any milk while we waited, it was the afternoon before it was her turn. I tried to remain positive and pictured taking her to her first day of school and imagining her back home post surgery. We had been told the night before that due to her size, when they operated that they may not be able to close her chest up if her heart was still quite swollen. We went upstairs to the operating theatres when they were ready for her. Handing her over to be carried into the room was one of the hardest things I have ever done. My husband waited outside, he didn't want his last memory of her to be lying on the table if anything went wrong. I stayed with her while they put her to sleep and then I was guided out. We were fortunate to have been given a room at Scott House (Sick Children's Trust) in the hospital grounds, so we took our stuff over before heading home to see our other children. We wanted to keep things as normal as possible for them, we had been told surgery could be up to 6 hours, when they called less than 4 hours later we didn't know whether that was to be a good sign or bad. She was out of surgery and we could go and see her. When we arrived the first question I asked was whether they'd closed her chest and they had been able to. We knew that would be a good sign as she would not need to be sedated for as long. She looked so helpless, lying in the bed, swollen with wires coming out of her. That's one thing I had not been ready for, I hadn't known what to expect post surgery.

We stayed by Ava's side as much as possible, leaving late at night and heading over first thing the next morning. The morning after surgery when we arrived she was covered in a red rash, which turned out to be an allergic reaction to the dressing, which had to be swapped for a sensitive skin one. Ava was doing really well, she came off the ventilator the following day and they steadily removed other drips and wires. Once she was able to she even pulled her NG tube out herself, that was the last time she ever had one. She started breastfeeding again 24 hours post surgery and she was ready to move out of PICU and on to the ward, unfortunately they didn't have a bed available so we had to stay on PICU a bit longer. By the time we left, 6 days later she wasn't on any medication, the first time since she was 1 month old.

We had regular check ups following her surgery, we knew she still had a slight leak to one of her valves as they hadn't wanted to make it too narrow. The holes had been completely fixed though and she was coping well with the leak. That was until our delayed appointment, due to Covid, in August 2020. It came out of the blue and it was the first appointment I'd attended alone, because of Covid restrictions. Ava's consultant said the words I'd hoped not to hear. She would require further surgery. The leak had got worse and we would have to monitor her again and watch for signs of heart failure returning. At least this time we know what we are looking for. That day I threw myself a pity party. The next day I pulled myself together, decided we couldn't change where we were and we would manage each day as it came. After all, Ava is doing amazingly well; she's in the early stages of walking, she communicates well using Makaton and has also started to speak. What more could we want?

Matilda's Heart Story

By mum Amy Roche

HOSPITAL: GREAT ORMOND STREET HOSPITAL

Matilda was born on July 21st 2020. We had a high chance screening but decided to carry on and see at the 20 week scan if there were any markers, I was mainly worried about any heart conditions but reassured all was well. When she entered the world we knew she had the extra chromosome but felt at ease knowing she was medically well, she stayed with me, fed, slept and filled her nappies, just as a new born did. She went for a routine heart scan at 2 days old and I was convinced all was ok and we would be going home that evening. When the dr asked if my husband was around to talk to us together, I felt my heart drop and I felt sick. He sat with a model heart in his hand and a leaflet and explained to us that she had a complete AVSD. He explained so calmly and was very reassuring that he knew the path she would follow and we put all our faith in this stranger, to do the best for Matilda and get her to operation day.

As the days turned to weeks and weeks to months everything he had told us that would happen on that day did happen. She became more breathless and worked harder with her breathing, she started on diuretics at 3 weeks old, had periods when she would be sweaty. But through it all she was a smiley, chilled out little girl.

She passed her target weight of 4.5kg at 12 weeks old and she just kept growing.

On December 15 at 21 weeks old weighing 6.4kg we went to GOSH for her operation. The day we arrived consisted of us having to meet the surgeon and sign the consent forms, have some bloods done, have her weight done and a covid test. We stayed in accommodation and attended the ward at 7:30 the next morning. As I walked her to theatre, I promised myself I would keep a smile and make her feel happy as she drifted off to sleep. The moment I walked out of that room the tears came down but that was ok. Me and my husband walked around a very deserted London (due to covid) and walked for miles. At 1 pm we phoned the theatre and was told all had been successful and she was being transferred to intensive care (flamingo ward).

When we got there, we both felt a little bit helpless, she had her tubes and wires and looked so peaceful. She was taken off the ventilator that evening and then the following day she slowly began to lose the wires and tubes. She was doing so well they transferred her to the recovery ward (bear ward) that evening.

As we were admitted to the ward the nurses said we would have a few day stay and I could stay in the room with her. We settled in and made ourselves comfortable.

In the morning of the 18th December. 2 days post op. The Drs doing ward round, said are you ready to go home! Home! She was comfortable, eating and playing, they were confident in our ability to continue her care at home and spoke with our community nurse who confirmed she would be there if we needed her. We also have open access at our local hospital but thankfully we never needed it.

Matilda has just celebrated her first Christmas and new year and has made amazing progress since her op. She is not quite 6 months but is just about sitting up, is a lot more alert and is making a lot of noise!

When people told me before her op you won't believe the difference in them, I thought they were just exaggerating or their babies were more poorly than Matilda was before hers, as she seemed well, but the difference is amazing!

If I can give any advice, it is try and remember that although they have to tell you the things that can go wrong, more often than not everything is fine, stay positive and be ready to enjoy the fun times ahead.

Sophie's Heart Story

By mum Rozie Haines

HOSPITAL: ROYAL BROMPTON AND EVELINA LONDON CHILDREN'S HOSPITAL

We knew Sophie had a high chance of Down syndrome prenatally from the NIPT test so we had additional scans. They identified a small hole between her ventricles and thought she had a 'partial AVSD'. We had a very sobering conversation about how to identify heart failure in a two week old but they didn't anticipate surgery would be needed.

When she was born, no-one could hear a heart murmur. We had a heart appointment at the Royal Brompton at 5 weeks thinking everything was looking positive but they found the hole was actually more than twice the size previously thought. We were told, quite bluntly unfortunately, that open heart surgery would be needed when she was between 3-6 months, which came as a big shock given how well she'd been doing.

Aside from a 6-day hospital visit for bronchiolitis, Sophie managed well until she was about 2 ½ months old. We felt she was working very hard on her breathing and she was admitted to our local hospital and started on diuretics – something we knew was highly likely. Over the next two months, she had her drugs increased and then had a feeding tube to help with weight gain. It was a tough time watching her slowly get more poorly, not helped by being in the throes of a global pandemic! We were told she was on the surgical list at the Evelina (because of Covid) and then we got the call that the surgery would be 5 days later.

Going through various pre-op checks at the hospital, so many kind doctors and nurses found very tactful ways to probe why we were there and to check if someone was aware of her very significant subcostal recessions – that really brought home how much she needed the surgery.

The first surgery slot ended up being cancelled due to an emergency – Sophie was ready in her gown so it was quite a big emotional rollercoaster but it meant we got to go home and see our 2 year old before starting it all again a few days later. Walking her down to the operating theatre after signing her consent form, and then leaving her sleeping and having to walk away was the hardest thing I've ever done. The 7 ½ hour surgery felt incredibly long – not helped by it being several hours longer than we were initially told but I think that is quite common.

We were not allowed to be on the ward or the Pediatric Intensive Care Unit (PICU) together because of Covid but they let us both in to PICU to see her just after the surgery. She was all wired up, swollen and sedated but I got to sit and hold her hand which was lovely. The nurses were all so kind and supportive – talking us through all the lines, drains and machinery. She came off the ventilator on day 2 but had issues the following day with fluid on her lungs and went back on it with a new chest drain too. I was with her when she started to really struggle and it was terrifying to have everyone come running but I was blown away by their professionalism, knowledge and care for her. Once the drain had got the liquid off her lungs, she steadily improved, leaving intensive care after 5 days and, amazingly, we were home only 8 days after surgery.

She started smiling again the first day we were back on the ward and she hasn't stopped since – she's been a different baby; happy, settled and thriving. It was definitely the toughest thing I've ever been through but I was also surprised at my ability to cope throughout. All the medical professionals she met were brilliant, they certainly knew their stuff and they treated her with such kindness and respect. I am filled with affection and gratitude to them for all they have done.

Elsie’s Heart Story

By mummies Emma & Kat

HOSPITAL: GREAT ORMOND STREET HOSPITAL

Elsie was born on 25th August 2019 in Bedford Hospital and although we knew that she has Down syndrome, we weren’t expecting any heart issues, as at her 20 weeks scan everything was OK. A couple of hours after Elsie was born she turned slightly blue and was taken to NICU. She needed oxygen to help her breath. She didn’t need large amounts of oxygen which was encouraging. While on NICU, Elsie had a heart scan and the cardiologist confirmed there was a tiny hole but nothing to worry about and we wouldn’t be discussing any heart surgery any time soon. After two weeks spent on NICU we were able to go home. Elsie didn’t need any oxygen at all and the doctors confirmed it was transitional.

We had our first outpatient cardiology appointment in October 2019 with the hospital’s cardiologist as well as a consultant from Great Ormond Street and at this appointment we were told Elsie had a partial AVSD. Mummy Kat had done a lot of research after we had been told Elsie had a small hole and we hoped with everything we had that it could be repaired using keyhole surgery but we were to be disappointed. Kat asked the question and we both waited holding our breath while the Consultant shook her head and told us it would have to be open heart surgery. The good news was that Elsie’s case was “the best case scenario” for what she had and so there was no need to make any plans for her surgery. If Elsie became symptomatic to contact them straight away but otherwise we would see them in 6 months time. We left the hospital and cried our eyes out but life went on and we somehow pushed it to the back of our minds.

In June 2020 Mummy Emma took Elsie to her follow up appointment (only one parent was allowed due to Covid restrictions) with GOSH and the hospital Cardiologist. At this appointment the consultant confirmed the previous advice that Elsie would need surgery and he would return to GOSH, meet with his colleagues to confirm they thought the same and providing they did he would call us to let us know the next steps. This time it seemed more real, it was happening we just didn't know when. So we waited with held breath for about 7 weeks and then the dreaded phone call came. The consultant had met with his colleagues, they all agreed Elsie needed surgery and he would pass her case over to the surgical booking team and they would be in touch to let us know the date.

If we thought the wait between her appointment and the call to confirm surgery was long then we didn't know what was going to hit us while we waited (impatiently) for the actual date. Elsie's 1st birthday came around on 25th August and we kind of forgot about it for a few weeks and on 15th September 2020 the phone rang and we were told surgery was scheduled for 13th October 2020. We were worried only one of us would be allowed to go as that had been the case in Great Ormond Street for months due to Covid. To be told we could both be there was such a relief.

So we had 4 weeks to wait, which doesn't sound like long and we have seen a lot of people want as much notice as possible, for us it was the opposite. We would have preferred to get a call on a Friday to go in on the Monday. The wait was horrendous, we cried, we were nervous as hell and we didn't know what to do with ourselves. We both had thoughts we didn't dare to say out loud (we had the conversation after) and all we wanted was for it to be done. A few days before the surgery (and we wish we had thought of it earlier) we reasoned that it couldn't get much worse than them stopping Elsie's heart and that was exactly what they were doing so we just had to convince ourselves it would all be OK.

The day before Elsie's surgery we made our way to Great Ormond Street, we had to be there for 1pm for her pre op tests so we arrived about 12pm, just to be sure ;0) That day was long but we were constantly on the move from one test to another and all of a sudden it was all done and we were given our instructions for that evening and the following morning. Elsie was not allowed anything to eat or drink for a set amount of time before surgery so we planned to the second what we would do with the morning and it all went to plan.

At Midday on Tuesday 13th October 2020 we carried our baby girl to the anaesthetic room and held her while they put her to sleep and then we had to lay her down on the operating bed. It was the hardest thing I think either of us has ever had to do and to say we never want to have to do it again is an understatement.

We waited for 4 hours before we got impatient and went back to where we had been that morning to ask if the nurse had any update. We were told Elsie was out of theatre and on her way up to Intensive care and we could go up but had to wait outside for someone to come and see us. We didn't wait for very long and the anaesthetist came out to tell us everything went well and he was happy with how Elsie had been during the surgery. He was followed by the surgeon who had a beaming smile on his face and told us everything went as he had wanted it to and Elsie would be fine. We

can't explain the relief. We just had to wait a little while longer while they got Esie set up and then we could see our baby girl. Walking into the Intensive care ward was hard because we knew we were about to see our little girl hooked up to a lot of machines and have wires coming out of her but we also couldn't wait to see her.

Seeing Elsie for the first time was emotional and the first thing we asked was why was she so swollen, her face was really puffy and the nurse explained it was a mixture of water retention and being pumped full of air during surgery and nothing to worry about.

Over the next few days Elsie went from strength to strength. She sat up when they removed her ventilator and was opening her eyes the evening of her surgery. We stayed in Intensive care for two nights and then we were moved up to the Cardiac ward. During our stay on Intensive care we saw so many different people who asked questions, gave advice and just generally made us feel like Elsie could not be in better hands. The Doctors, nurses, physios and family liaison teams of Great Ormond Street genuinely do not know their worth, they reassured us no matter the question and they took better care of Elsie (and us) than we could have.

Three days after Elsie's surgery, on Friday morning, the doctor completed his ward rounds and told us providing Elsie's thyroid levels had returned to normal we could go home, we could not believe it. We were told we would be in for between 7-10 days, we had booked a hotel room for one of us to stay in as we had been told only one could stay in the hospital on the ward and we had packed enough clothes to be there for a month (we like to be prepared!) It was a very scary thought but the nurse told us there was nothing medical that they were doing for Elsie that we couldn't do at home for her ourselves, so we listened, we believed her and we got excited about getting home.

Since having her surgery Elsie has amazed us all, she started crawling two days after we came home, she is cruising around all the furniture in the house with no problem and she absolutely loves taking her dolly for a walk in her pram, although not fully walking yet we know she will get there in her own time. We have had two check ups since surgery and the consultants at both have been more than happy with how Elsie has healed and we don't have to go back for eight months now.

Open Heart surgery was our biggest fear but it has now become Elsie's biggest triumph and we could not be prouder of how she handled it.