

The Lived Experience:
Heart Surgery

DSUK Down Syndrome UK | Positive About Down Syndrome Community

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The Lived Experience

This is a collection of parents' stories about their children with Down syndrome going through heart surgery. 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 and we hope you find them useful and informative.

In addition to this document, DSUK also provides support for parents whose children require heart surgery by matching you up with a Heart Buddy (further details on page 6) and through peer support through the New Parent or Pre-schoolers closed Facebook groups (see page 5).

Please note this document includes photos of little ones in intensive care which some people may find upsetting.

We have had a lot of feedback from parents following surgery that being prepared for seeing their child post-surgery was helpful and we have therefore included a labelled post-surgery photo on the last page. If you have any questions about this picture and the details is shows, please speak to the Heart Buddy Coordinator or your Heart Buddy.

Cardiac Hospitals

Paediatric heart surgery takes place at 11 cardiac centres across the UK. In addition, patients in Northern Ireland may travel to Dublin for surgery. You may also have appointments at more local hospitals where they run clinics on behalf of the cardiac centres but surgery will take place at one of these hospitals:

Birmingham Children's Hospital
Bristol Royal Hospital for children
Children's Health Ireland at Crumlin, Dublin
Royal Hospital for Children, Glasgow
Leeds General Infirmary
Leicester Royal Infirmary
Alder Hey Children's Hospital, Liverpool
Evelina Children's Hospital, London
Great Ormond Street Hospital, London
Royal Brompton Hospital, London
Freeman Hospital, Newcastle
Southampton Children's Hospital

Many of these hospitals have either cardiac, paediatric or hospital wide charities that support parents. Some have facebook groups that you can join to speak to other parents who have been through heart surgery at those hospitals.

Useful Resources

Books about heart surgery

The following books have been recommended by other parents about heart surgery:

- **Zip-Line by David Humpherys**
- **Ava the mermaid goes to hospital by Eleanor Baggaley**
- **Patch the brave heart lion by Natalie Halls-Jones and Karen Horsell**
- **Little Panda and her super heart by Marta Almansa Esteva and Silvia Romeral Andrés**
- **Getting ready for my heart surgery by Fr. Fei Sheng-Ward and Moch. Fajar Shobaru**
- **BHF Going to Hospital for surgery**

Other organisations that can help

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

British Heart Foundation
Tiny Tickers
Children's Heart Federation
Little Hearts Matter
Pyjama Fairies

Join the New Parents Closed Facebook Group

Join the Preschool Parents Closed Facebook Group

13102

Who are DSUK Heart Buddies?

The DSUK Heart Buddies scheme was set up in March 2021 to support the parents of children with Down syndrome who need heart surgery. Our Heart Buddies provide dedicated one-to-one support from parents who have been through their own child's surgery.

Parents are matched up with one or two 'Buddies' – wherever possible, we try to match up on the basis on the little one's heart condition and cardiac hospital so the Heart Buddies' experience is as relevant as possible.
Parent can sign up at any time on their little one's heart journey – from initial cardiac appointment through to the week of the surgery and our Heart Buddies can virtually hold their hands throughout.

We take the lead from the parents on how much support they need – our Heart Buddies are there to help as much or as little as needed. During the worry and uncertainty in the pre-op period, our Heart Buddies can help reassure and provide advice around appointments, issues with feeding and weight gain, and what to pack in the hospital bag. During the hospital stay itself, our Heart Buddies are there to offer a space to talk, providing support and cheering on our little heart warriors.

We find that many of our parents who have benefitted from having a Heart Buddy go on to sign up to support others which shows how helpful they've found the scheme.



“Having a Heart Buddy gave me so much support and insight into what would happen in the run up during and post heart surgery for my son. It’s like they are there holding your hand through the hardest day of your life. Having been through it themselves, they know how it feels which helps you not feel so alone. I couldn’t recommend the scheme highlight enough – so much so I would like to give back and have volunteered myself.”

Jo, mum to Issac

DSUK's Heart Buddies Scheme is coordinated by Rozie Haines, whose daughter Sophie had heart surgery at 5 months old to repair a partial AVSD. You can read their story on page 49.

You can contact Rozie with any questions or to request a Heart Buddy via the Facebook groups (see Page 5) or at heartbuddies@downsyndromeuk.co.uk

Top Tips

Here we would like to share some of the Top Tips from other parents who have been through heart surgery with their little one:

General

Take videos of your little one's breathing and chest recessions (with their top off) at different stages – if any issues arise, it's really helpful to be able to show the doctors what has changed.
Marcia, mum to Tahlia

From the very beginning, scan every letter with either appointment or results in the file name and create a directory for different specialists in Google Drive or similar. There will be a lot of paperwork and it can be hard to keep track of what you need and when, so having it all in the cloud means you can pull it up anywhere, anytime.
Ruth, mum to Lucy

If you're struggling to keep track of appointments, get a small diary specifically for writing in those appointments and keep it with your little one's red book.
Alicia, mum of Liara

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. Keep it in a folder with all relevant hospital appointment letters and reports.
Bernie, dad to Sophie

I would be conscious to consider yourself part of your child's care team. You are the one person who knows everything about your child, and what various specialists they have seen to this point.
Kate, mum to Thomas

Getting ready for your hospital stay

Check whether the hospital has a heart or parent support charity attached to it – if so, their website and facebook pages/groups can be a really helpful resource – from finding local food options to other parent's experiences.
Rozie, mum to Sophie

Before you go into hospital for surgery, create a WhatsApp group or couple of groups to update friends and family in bulk. That way, you don't have to write the same message multiple times and can provide news at times that work for you, rather than constantly fielding lots of individual messages and questions.
Camilla, mum to Beatrix

If you're on medications, it might help to get a full prescription before you to into hospital. Explain your situation to your GP and then you know you'll have enough. Hospital pharmacies get very busy and some don't take non-hospital prescriptions.
Alicia, mum to Liara

It's helpful to plan what you can in advance – look into parking etc and think about how you'd like to keep busy while your little one is in surgery as distraction really helps the time to pass. Some parents like to go for a walk, shopping, out to lunch or meet a friend. Or take films or a good book and some biscuits to keep you busy in your accomodation (if it's available).
Rozie, mum to Sophie

What to pack

- [ ] 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 or socks on their hands might also help to stop them pulling at tubes! Once your little one is back into clothes, the doctors and nurses will 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.
Rozie, mum to Sophie

- [ ] Take **chapstick or vaseline** – it's not something I usually carry on me but I find the hospital environment really dries your skin out. Plus, when your baby is off oxygen, they lips are quite dry too so it's good for them as well. And a water bottle to keep yourself hydrated.
Hayley, mum to Robin

- [ ] Take your own **plate, knife, fork** and a **travel mug** to use whilst on the ward – sometimes there aren't any.
Sharon, mum to Olivia-Grace

- [ ] Don't forget to think about you – **comfy clothes** (the ICU units can be quite warm), **good book, water bottle, earphones** so you can watch something or listen to music for a bit, chocolate or your favourite treat as it all helps.
Rozie, mum to Sophie

- [ ] Some wards have laundry facilities and so do some of the hospital accomodation so being a **small box of your own washing powder/softener**.
Alicia, mum of Liara

- [ ] You will constantly be having to wash your hands in the hospital so take **hand moisturiser**.
Kate, mum to Thomas

- [ ] Take a diary, so you can keep notes of your own. Some **change in case you need it to pay for facilities** like washing machines and slippers to wear on the ward.
Emily, mum to Lexi

- [ ] Take a **long charging cable** for phones/pads etc.
Margaret, mum to Hannah

- It's helpful to **take a couple of noisy or light up toys for distraction** during scans and once your little one is starting to feel a bit better.
  Bernie, dad to Sophie

- If you like **filter coffee or a certain type of tea**, bring it with you to use in the kitchen on the ward. It will be a small thing each day that you can enjoy and have control over.
  Hannah, mum to Reya

- It's pretty noisy on the ward so bring some **headphones/earbuds and an eye mask**!
  Kate, mum to Thomas

The hospital stay

Mums, if you are breastfeeding/expressing, you're entitled to being fed on the ward – I do recommend bringing drinks and snacks with you.
Alicia, mum of Liara

Take photos during your hospital stay – it may seem a strange thing to do but when you and your baby are out the other side, those pictures will mean so much to you.
Ruth, mum to Lucy

Try to look after yourselves and make yourselves comfortable in whatever accomodation you have. If you don't eat and sleep, you won't be able to look after your child as well.
Camilla, mum to Beatrix

Go outside and get some fresh air and natural light. You'll be surprised how much better you'll feel for it.
Hayley, mum to Daisy

Consider asking a family member or friend to visit you while your little one is recovering. Go for a coffee or cake and lots of hugs. It will help you get away from the ward for a bit, which is so important.
Hannah, mum to Reya

Make sure you look after yourself too – it can be very intense. I used to leave my husband with my son whilst I went and had a brew in the coffee shop for half an hour away from the ward. That bit of peace made a huge difference to my mental health whilst in there.
Maria, mum to Samuel

It can be really hard not being able to care for your baby in the same way that you have been doing when they have wires and tubes everywhere. Take your favourite stories to read to them while you sit with them and take any opportunity the nurses give you to do caringn things, however small – like putting a wet sponge on their lips, putting mittens on their hands, helping change a nappy etc.
Ruth, mum to Lucy

If your child is on medication set an alarm in your phone at medication times. It's busy on the ward and sometimes one nurse to 6 babies means things can slip. Again – advocate for your child at all times.
Kate, mum to Thomas

In the unlikely event it happens, if you any reason you don't feel comfortable with or feel unhappy with a particular nurse taking care of your child, don't be afraid to speak up. Talk to the Nurse in Charge, you can request a different nurse. Don't feel like you have to be okay with it – you have to be happy with the care your child is receiving,
Alicia, mum to Liara

Help the nurses with your child's daily cares (washing, hair brushing, nappy changing etc) while they are in intensive care – it helped us feel involved at a stage when there was very little else we could do to help.
Ross, dad to Beatrix

You will have lots of questions, try to note them down on paper or your phone so you have them handy when the consultant comes to your child's bed.
Ruth, mum to Lucy

Make yourself part of the conversations when the team do their walk rounds and discuss your child in front of you. Don't be afraid to ask questions and challenge to gain further understanding. You're your child's advocate – remember that.
Claire, mum to Sienna

Don't be afraid to talk to the staff. The doctors and nurses would rather you ask questions and you'll be there a while so no point having some niggling though in the back of your mind.
Emily, mum to Lexi

Being on the ward means there are other specialists like Physios, Dieticians, SALT around. We found raising concerns on the ward an invaluable way to be referred to services we had otherwise struggled to get into.
Kate, mum to Thomas

Remember there are lots of families in DSUK groups who have been through this and are here to support you. Any questions you have, please do reach out via email or and post in the closed Facebook groups if you feel comfortable to do so.

DSUK 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 – see page 6 for more details.

Looking after yourself

Supporting your child through heart surgery can be a very stressful and overwhelming experience. It's so easy to put ourselves last as parents but, during this period, it's so important to prioritise yourselves as well. From all the uncertainty and worry during the pre-surgery stage, through the hospital stay and afterwards too – it isn't just your little one who needs to recover!

- **Keep talking to your partner, friends and family about how you're feeling.**
- **Most hospitals can offer psychological support for parents so do reach out to your Cardiac Nurse Specialist / Cardiac Liaison Nurse.**
- **You can self-refer to your local NHS Talking Therapies service online and they will prioritise parents of babies under 1 year.**
- **DSUK offer a counselling service to support parents too.**
- **Make a plan for how to keep busy during the surgery itself.**
- **Don't forget to think about yourself when packing for your hospital stay and take things that will bring you comfort and keep you busy at the bedside.**
- **Make sure you take time out to eat and drink during your hospital stay and prioritise time to sleep when you can.**
- **Taking photos and keeping a diary during your hospital stay can help you process the experience afterwards.**
- **Don't forget that crying is coping!**

Ian & Andrew

Hospital: Alder Hey Children's Hospital



After 7 years of trying and 2 failed IVF attempts, the wonderful day finally arrived of finding out we were pregnant. We were absolutely elated and the journey to our little baby arriving had begun.

We excitedly went to our 12-week scan and agreed to screening tests. After the scans we were taken into a room and were told our little miracle had a high risk of Down's Syndrome due to our age and other factors.

Due to this result, we were offered an NIPT test which we agreed to. We were contacted a week later and told the test result confirmed that we were high risk and how did we want to proceed?

From the absolute high that we were going to be parents, we were suddenly thrust into a universe of facts and figures. All the questions and answers being distilled into "1 in so many chance" statements, countless percentages and causal links. We were asked whether we wanted a diagnostic test (amniocentesis/needle test) to absolutely confirm whether our little one had Down Syndrome. We refused.

At the 20-week scan we were taken into a room and the consultant started the conversation with words that haunt me to this day "I'm sorry guys, it's bad news". We were told our little boy (Steph couldn't wait) had a complete AVSD and unfortunately one side of his heart was larger than the other. Bearing these issues in mind and the high probability of Down's Syndrome, we were told it was highly unlikely they would operate. They would refer us to cardiac specialists, and we needed to prepare ourselves.

The Alder Hey staff met us in Liverpool Women's, they did numerous scans and they said to wait in a room, and somebody would be in to see us. The consultant came in and stated our boy had a complete AVSD, handed us a piece of paper with a diagram he'd drawn and explained exactly what this meant and how they could fix it. "Are you going to fix it?" we asked, "Of course, why wouldn't we?...

Ian, dad to Andrew

This may seem like a big thing to you but don't worry, we're doing this every single day" was the reply. We couldn't have been happier that our little boy would be given a chance, the two halves of his heart were equally sized, so it was 'just' the complete AVSD to deal with. We were told exactly what to expect over the first 6-12 months of his life.

The rest of the pregnancy journey was a blur of scans, monitoring and nervous excitement. We were told that due to excessive pressures in the umbilical cord it was likely that Steph's placenta was failing and with all the other factors, we needed to get him out and be induced at 37 weeks.

Liverpool Women's Hospital monitored his heart throughout labour, it stopped several times and each time this happened there was a dread that maybe we'd pushed him too hard. We wondered if he'd need any assistance, would we get to hold him straight away, a million concerns and worries flying through both of our minds. We needn't have worried, Andrew entered the world unimpressed, screaming and grabbing anything he could!

After several hours of being in the world, Andrew had a set of observations taken. His temperature was down and his oxygen saturation levels were poor. After several staff arrived and double checked the figures, Andrew was wheeled to NICU and put into an incubator with the associated wires and machines.

He was given additional oxygen and placed on antibiotics to cover all bases in case of infection. Alder Hey informed the staff that due to the complete AVSD, saturation levels may be lower than expected. After a day, his saturation levels were improving and the oxygen was removed, however Andrew developed jaundice. After a week of treatment, we were discharged from NICU and placed in transitional care to get Andrew's feeding sorted. This took another week, and we were finally allowed home!

For the first few months of his life, we attended Alder Hey for regular scans to see how Andrew's heart was growing. Sometimes holes can close or become smaller which means surgery can be postponed for a bit longer. With Andrew, surgery would need to be done at around 6 months, nothing was fundamentally altering with regards to the situation. From these scans, Andrew was put on a small amount of medicine (diuretic) to help protect his lungs from a build-up of fluid.

As the 6-month mark was approaching we were noticing Andrew was struggling when playing, he was panting/breathless and every day we'd rush to the door when the mail was delivered looking for the letter confirming his heart surgery. We were then invited to an online appointment where the surgery was discussed, the chances of complications and what to expect. Once again, we were in a world of facts and figures but ultimately there wasn't a choice, he needed the operation.

Steph also found Heart Buddies at this time via the PADS Facebook group, we were introduced to Rozie via WhatsApp and she was there all through the process. We would recommend Heart Buddies to other parents; it was great to have someone just a text away who understood what we were going through.

Ian, dad to Andrew

We were given some rough dates as to when the surgery was likely, however at the pre-op assessment, surgery was brought forward after scans were showing signs of heart failure. We had everything packed and ready to travel over and then we got a phone call. An emergency had taken priority, so the operation had been delayed until the next day.

We travelled over to Alder Hey and had some final checks, bloods taken, met the anesthetist and finally checked into Ronald McDonald house. Andrew was scheduled to have his operation on the 20th of June, and he was the only one in the afternoon. We were told to go to the cardiac ward early morning and Andrew would be taken from there to the operating theatre.

The waiting on the ward was terribly difficult. Knowing what was ahead, knowing there weren't any certainties regards outcomes, the facts and figures spinning around constantly in your mind and then you hear the nurse "Come on, it's time to go."

Steph carried Andrew and we all walked down the corridors to the operating theatre, walls, ceilings, doors, they all looked the same. At this point, Andrew decided to have a fit of the giggles and wouldn't stop laughing. We finally got to the theatre and met the staff and they got to work connecting everything up.

The anesthetist said to give kisses and say goodbye, we had been warned some babies don't go under easily... Andrew screamed, fought and swung until he finally fell asleep. All that went through my mind is I hope that's not the last memory I have of my little boy. We were told to wait for the phone call which would come once he'd reached ICU, it would be around 7-8 hours.

Me and Steph wandered Alder Hey aimlessly, we walked back to Ronald McDonald House and kept ourselves busy as best as we could. We eventually ended up back at Alder Hey playing quiz games on Steph's phone in the restaurant area so when the phone call came, we could see Andrew in the quickest time possible. The phone call came through, Andrew had arrived in ICU. We ran up the stairs, sanitized hands and walked briskly down the corridor to the pod he was in. We walked through the doors and there was our little boy, wires everywhere, machines everywhere but unmistakably our little baby boy amongst it all. One of the surgeons told us everything went as planned and "he's fixed"!

The days in ICU were fast paced, each time we would visit another wire and/or medicine would be getting removed. One morning we arrived and there was a mass of activity around Andrew, our hearts sank, what had happened? The staff explained Andrew had proved to be a "sedation challenge" and had woken up overnight and tried to pull his wires out. He had three nurses calming him down and seemed pretty happy with this arrangement.

Ian, dad to Andrew

We met the surgeon who performed the miracle work on our little boy, he told us “He just needs time to recover, he’ll be fine”, Andrew’s recovery was slightly hampered by a collapsed lung but before we knew it he was discharged to the cardiac ward. We started giving Andrew small amounts of milk, he was beginning to find his voice again and he was smiling once again. From here Andrew got progressively stronger and stronger, we were moved several times until we had another ECG and heart scan, the person informed us it was a “pre discharge” scan. The next day we were given all the information for ongoing care and our discharge papers!

Andrew is going from strength-to-strength, he’s still getting regular heart scans but so far, the consultants are stating he won’t need any further surgery. Our lives would not be complete without him.



Rhea & Jacob

Hospital: Birmingham Children's Hospital



Well, what can I say about Jacob Thomas Meanwell? He is amazing. He makes us proud everyday. He is our heart warrior. He completes our family. Quite simply he is perfect and we wouldn't change a thing. He has certainly kept us on our toes even before he was born.

The 20-week scan, the one time my husband Chris couldn't be with me. I got told they couldn't see all 4 heart chambers and we needed a more detailed scan in Birmingham. They thought it might just be because of the way he was laying but wanted to be sure.

At 22 weeks, on our older son Noah's 4th birthday, after 90 minutes of scanning we were told our unborn baby had a significant heart defect, markers for Downs Syndrome (short long bones, larger head, heart defect) making it 80% likely he would be born with it and was showing signs of Hydrops which is fluid collection around organs which meant he may survive the pregnancy but not long afterwards. We were told the heart could be fixed, Downs Syndrome was something that not all parents were willing to live with and Hydrops would be fatal.

We fell apart. We were immediately offered a termination. We were adamant - NO! We were advised to think about it. Again, we said - NO! We were told to go home and think about it. Then reality kicked in. Our son was at home waiting for us so he could have a tea party for his 4th birthday, we had to pull it together and deal with this later. We went home in a fog, put our best faces on and somehow got through a tea party that neither of us can remember.

The rest of my pregnancy was chaos. I went from too much fluid to not enough. Jacob went from being very active to spending the last 9 weeks in the breach position. Poor dopplar readings led to 3 scans a week in case we had to make the decision for an early delivery. Luckily the signs of Hydrops went away so that was one less worry.

Due date was 23rd March but on 4th March we went for a check up in Birmingham Women's Hospital and were told we have a bed for you, a cot for baby, you aren't going home. 5.30pm Jacob was born by C-section and whisked off to NICU.

Rhea, mum to Jacob

5 days later he was transferred to Hereford SCBU where 10 days later he was allowed home on meds and tube fed.



Fast forward to 11th June, and after months of rigourous feeding, medication, three weekly scans and amazing support from the team at Birmingham Children's Hospital, Jacob had his complete AVSD heart repair surgery. 8 hours without our boy, waiting and praying. We got the call, all fine, you can come and see him. We didn't recognise our baby boy, swollen from being on bypass with more tubes and wires than we could count. 2 days later Jacob was smiling and laughing, stronger than we could imagine and stronger than any of us. Slowly all the tubes and wires were removed and thanks to the amazing team at Birmingham Children's Hospital, a week later we took our boy home, his heart now properly formed but with three leaky valves which would need future surgery. His medical team were amazing and looked after all of us not just Jacob.

In September 2020, he had his second surgery to adjust his leaky valves and remove a blockage that had developed in his aorta. It was COVID times so it was just him and I so added worry. However, after 9 hours of surgery and a 4 day stay, Jacob amazed us again and was discharged. He still has leaks on his valves but they are stable, his heart is strong, he's on no medication and he is checked every six months in Birmingham. Again, the team were so supportive and we couldn't have got through it without them.

Every day since Jacob has thrived, developed, grown and amazed us. He is doing things we were told he would never do. He attends a local mainstream primary school and is living his best life. He can charm the birds from the trees with his amazing smile. The bond he has with his big brother Noah is a joy to behold. We cannot believe the love we have for our gorgeous boy, he brings us such joy. He is a cheeky little monkey with a right character. He has more strength than any of us. His smily face is what gets us through the tough days.

Having Down Syndrome and a heart condition does not and will not ever define him. It is part of him and what makes him so amazing, the same way that his "zipper" from his heart surgery (as his brother calls it) is a part of who is. We know there may be challenges ahead, but he's a tough cookie, our warrior and will no doubt continue to prove people wrong. It's been one hell of a rollercoaster so far and we wouldn't change a thing.

Claire & Sienna

Hospital: Bristol Royal Hospital for Children



Sienna's heart story began in December 2020 when we had a surprise postnatal diagnosis of Trisomy 21. Knowing that children with an extra chromosome often had heart conditions, we were over the moon with the 'big win' that her heart was 'normal'. That was until two days before Christmas when we were sent a letter with an appointment to see a cardiologist.

Unbeknown to us, Sienna actually had a complete Atrioventricular Septal Defect (AVSD) which required surgery when she was 6-months old. Her ECG hadn't been checked by a senior paediatrician, yet she had signed it off as being normal.

We were absolutely devastated. It was a struggle to get her to the ideal weight of 5kgs as she was becoming more symptomatic; becoming breathless when feeding was the most obvious. The dreaded day arrived but we also felt that it couldn't have come sooner as we knew Sienna needed this life-saving surgery. What had becoming extremely hard for us was that Sienna was born during the Covid pandemic which meant appointments had to be just one of us with her. It was a blur - taking in and trying to process the cardiologist's observations was so difficult.

We broke our hearts saying goodbye to Sienna as she was put to sleep, but we knew this was the chance to fix hers. We were advised that the surgery would take 4-6 hours. We left her at 8am and by 4pm, we still hadn't heard and we were both becoming very anxious about it. As a distraction and wanting to give our eldest daughter (who was 3 ½ years old at the time) our focused attention, we spent the day with her. Being silly in the park with her certainly occupied our minds for a short while. At 5.30pm, the surgeon called to say there were some complications but Sienna was ok - a huge relief was an understatement.

Claire, mum to Sienna

Sienna was in total heart block so had a temporary pacemaker fitted. Seeing her for the first-time post-surgery made me collapse - I was petrified of seeing her for the first time post-surgery and her little chest with the wound.



Our little girl was surrounded by medical professionals, had tubes everywhere and machines beeping. It was heartbreaking for us but she proved to us that she is a true fighter. Her temporary pacemaker was only able to support her little, bruised heart for 10 days maximum. Each day, we watched the cardiologist turn down her pacemaker, her little face wincing with discomfort, to see if her heart kicked in. She still needed the pacing wires.

There were conversations about her having a permanent one fitted. Until one evening, whilst her daddy sat by her side in PICU, he downloaded the instruction manual for her pacemaker. This was now day 10. He then had a conversation with a different cardiologist and suggested they reduced the sensitivity of the pacemaker to give her heart the opportunity to beat by itself. He agreed. The red 'pace' light changed to a green 'trace' light. My husband and I looked at each other in utter disbelief and trying hard not to get too excited. We had seen the same thing - her little heart had kicked back in! From this point on, Sienna grew from strength to strength and once she had been discharged from HDU, she absolutely thrived. The difference in her behaviour, appearance and stamina were so obvious.

We anticipated Sienna's recovery in hospital to be 7-10 days. However, due to her having total heart block with a temporary pacemaker fitted then discovering she had gallstones, we ended up staying for 21 days. Unsurprisingly, the gallstones created an additional complication as to whether she had surgery at another hospital to have them removed, and whether it would be before or after having a permanent pacemaker fitted. Never to be underestimated, our little heart warrior escaped having both done!

In her post check-ups, and as a result of her surgery, the cardiologist noted that there was some regurgitation and increased pressure. In September 2023, we were advised that Sienna needed further open-heart surgery to relieve her of an aortic obstruction

Claire, mum to Sienna

As she was growing, the passage was becoming narrower which would only become worse and more of an issue for her. The thought of going through open heart surgery again filled us with fear but we knew that we were now so much better informed, educated and prepared for it.

After three last-minute surgery cancellations due to emergencies and theatre staff shortages, Sienna finally had her second open-heart surgery in March 2024. This surgery was considered less complicated than her previous one and she was in theatre for a shorter period of time. Once Sienna was back in PICU, she took a bit longer to come around after her general anaesthetic, however, once she had woken, she showed her resilience and amazing personality once again. Fortunately, she had the same incredible cardiac surgeon who went beyond his role; he checked on Sienna and her progress daily, even visited her on his rest days. Sienna had an unbelievable recovery and was home within six days! We will be forever grateful for how he has looked after our precious, little heart warrior.

Since her second surgery, Sienna is totally thriving with her development and growth. Her cardiac review in April 2026, suggested possible further surgery in 4-6 years however, for now, she is happy, well and a very strong little girl so we will take that.

From one parent to another, please try and involve yourself in the conversations when the medical team do their walk rounds to discuss YOUR child. Have the strength and courage to ask questions, challenge plans and be your child's advocate. It totally changed the direction of Sienna's recovery journey and for the better. If you are offered emotional support from the psychologist on the wards, please accept and embrace it.

At the time of Sienna's first surgery, I wasn't aware of PADS Heart Buddies, however, I felt that I could offer advice and supportive words to parents who were also facing this rollercoaster with their little one so I became a Heart Buddy. If I can walk beside another parent who is watching their child go through heart surgery, be a listening ear to their concerns before, during and after surgery, provide strength and supportive words, then it gives me great comfort and pride knowing a Heart Buddy has helped them with their journey.



Linzi & Matilda

Hospital: Our Lady's Children's Hospital, Dublin



When Matilda was born in July 2019, we were shocked to discover when she was 8 days old that she had a serious heart condition that required emergency surgery.

Matilda was diagnosed with a Coarctation of the Aorta which basically means a narrowing of the aorta. It forces the heart to pump harder to move blood through the aorta.

As surgery wasn't available in the North of Ireland, we travelled down to Dublin where at 13 days old & weighing just over 4lb in weight they operated on Matilda's heart.

The operation, around 4 hours long was a success & Matilda recovered for a few days in Dublin before being transferred back up to our local hospital to finish her recovery.

Unfortunately, around 1 week post surgery Matilda was diagnosed with suspected Necrotising enterocolitis (NEC) which is a serious condition that can affect newborn babies, where tissue in the bowel (small and large intestines) becomes inflamed. This meant Matilda's recovery was a lot harder and slower as she was pumped full of antibiotics to clear the infection and wasn't able to feed for almost two weeks.

Finally at 6 weeks old we were able to take our little girl home. The first few months were difficult with feeding issues post surgery and it meant very little physio with matilda as her wound healed.

After a few checkups in the months post surgery, it was found that Matilda also had a leaky mitral valve. Over the course of a few years the valve leakage slowly worsened, her symptoms became more noticeable with mottling of her skin & her hands and feet always seemed to have a purple tint, however it didn't seem to affect her physically as she always seemed to have a burst of energy all day!

Linzi, mum to Matilda

But due to the leak becoming more severe, Matilda had open heart surgery in April 2023 just a few months before her 4th birthday.

The surgery was different to her first surgery, this time requiring a heart & lung bypass machine but thankfully it went without any major side effects and one-week later Matilda was back home causing mischief!

Matildas heart conditions have never stopped her living her life to the fullest!

She's participated in gymnastics, horseriding, walks, runs and climbs anything she can get her hands on! She is now aged 6 in Primary 1 and attends weekly gymnastics & swimming lessons, including swimming unaided in her breast stroke! Her checkups remain good and we are hopeful that she won't require any more surgery in the future.

It's a journey we never planned, but it hasn't stopped Matilda living her best life!



Whitney & Austin

Hospital: Evelina London



Austin was diagnosed with Down syndrome the day after he was born. To say it was a complete shock would be an understatement. We were completely floored, suddenly worrying about the future and what this would mean for our beautiful baby boy.

At the time, we didn't know what the road ahead would look like.

As much as we were broadly aware of what a diagnosis of Down syndrome could mean, we had little to no knowledge of the immediate health issues Austin might face. Possible heart defects were the furthest thing from our minds.

While the doctor ran through a laundry list of possible health issues, the increased risk of heart defects was mentioned but also that it didn't seem likely for Austin, as his scans had been clear and no murmur could be heard. However, we would get a referral to double check.

At two weeks old, we travelled to London for an appointment at the Cardiology Rapid Access Clinic at the Evelina Children's Hospital. It was there we found out that Austin had a complete AVSD (Atrioventricular Septal Defect - two holes in his heart and a common valve), which would require open heart surgery. It was explained to us that although this was major surgery, it's now considered routine with high success rates and would typically be carried out when he was 3–6 months of age. Given he was breastfeeding and thriving, the aim was to delay surgery for as long as possible to help him grow stronger, but he would be seen in clinic every two weeks until surgery. By his next appointment, Austin was beginning to struggle with breastfeeding, and his weight had barely increased. Babies with heart issues often need a lot more calories as their hearts and lungs are working so much harder.

Whitney, mum to Austin

He was prescribed high-energy formula to supplement breast milk and a diuretic to help reduce the pressure on his lungs. We had to set alarms to ensure he was feeding every four hours. However, getting anything into him started to become a real struggle, he was tiring easily and beginning to throw up after every feed.

By his 3rd appointment, Austin was falling off the growth chart. His work of breathing and tracheal tug (signs of struggling to breathe) were very evident. He was classified as failure to thrive, no words any parent ever wants to hear, secondary to CHD, and we were admitted straight from clinic.

The plan was for an NG tube to be fitted to help with feeding, and we hoped we'd be in for the weekend to be trained and then go home. Unfortunately, Austin picked up a virus and ended up in HDU on IV medications and breathing support for almost three weeks.

The juggle was awful. The Evelina is over an hour from our house, and we had a 3-year-old at home.

While I was on maternity leave, my husband was working full time (though his company was very supportive during this time) so we had to work out a way to split our time between home with our eldest and being in hospital with our youngest. Luckily, the Evelina has a Ronald McDonald House nearby and we were able to get a room, so one of us could stay with Austin while the other could be at home or working.

Being constantly separated from one of my children, and often my husband, was incredibly hard.

It took a while, but we found a routine that worked for us. We were even able to bring Oscar up at weekends so we could be together.
The team at the Evelina could not have been more supportive. The nurses encouraged us to take breaks, go for a walk or a drink, and try to find some normality in the chaos.

That support made a huge difference to us. We even took our eldest to the London Aquarium to make those unexpected London weekends feel like an adventure for him.

After almost three weeks, we were finally able to go home again. Our own sofa had never felt so good. However, Austin's medication needs had increased dramatically, and alongside tube feeding, we needed to be up every 90 minutes in the night.



Whitney, mum to Austin

The relief of being home was short-lived. After a few days, it became clear Austin was declining and we were readmitted, with the decision made to stay in hospital until surgery. Unfortunately, Austin picked up another virus and we quickly ended up back in HDU on breathing support.

The decision was made to move us into isolation to minimise infection risk, and to move him to continuous pump feeding and breathing support to conserve his energy. We stayed in that room so long the consultants joked about renaming it "the Austin room." Three months was the earliest they were prepared to do Austin's surgery (to give the valve tissue more time to mature), but he also needed to be gaining weight. Over the next four weeks, Austin kept spiking temperatures, and no one could find a reason why. The waiting was incredibly difficult. We had no idea when surgery would be, and every day was another day our family was split. Eventually, the decision was made to operate at 13 weeks. But the day before, he spiked another temperature, and as it was a Sunday, no one could confirm if surgery would go ahead.

On Monday morning, November 26th, we were given a surgical gown to change Austin into still not knowing if the surgery would happen. Fifteen minutes later, we were told it would. Before we knew it, we were walking him down to theatre.

Handing him over and kissing him goodbye was one of the hardest things I've ever had to do. The wait felt endless. The surgeon told us to expect a call in 4–5 hours, but one of the nurses suggested adding another 1–2. She was right. The call came after six hours, the surgery had been a success.

Even though we'd spent the last seven weeks in HDU, and had been shown around ICU beforehand, it was still a shock to see him there, swollen and surrounded by wires and tubes. However, within 24 hours, Austin was doing amazingly and they were able to remove his breathing tube. He had a small setback that night, picking up another infection and needing oxygen again, but three days later we were back on the ward. Within 48 hours, we were home.

The speed of Austin's recovery was unbelievable. Before surgery, he had been grey, so unwell. One of the nurses had said, "just wait, he'll be pink after surgery." She was right. He looked like a different baby. He was still very underweight and weak, but within weeks he was gaining strength; holding his head up, rolling over, and starting to catch up.

The surgery was a success. He still has a small amount of leakage around the valve, but nothing that causes concern and now has two-yearly outpatient reviews. He's grown into a thriving little boy who loves sports, horse riding and playing with his older brother and now, younger sister.

Those eight weeks were some of the hardest of our lives. Keeping everyone updated felt overwhelming, so we set up a WhatsApp group. It ended up being an eclectic mix of people, family, friends, colleagues, even bosses, who rallied around us, helped with our older son and dog, visited us, and encouraged us to take breaks. They still call themselves Team Mohawk (Austin had an amazing natural mohawk as a baby). It became a real source of strength for us. You realise just how many people are there for you, often the ones you least expect.

Katrina & David

Hospital: The Freeman Hospital



We discovered David had Down's Syndrome (DS) at 15 weeks pregnant following an amniocentesis. Following the DS diagnosis this triggered a Fetal Medicine (FM) scan at 16 weeks to focus on David's heart due to the high chance of a Congenital Heart Defect (CHD). We were advised at this scan that they couldn't see everything as well as they wanted to but they could see David had a complete Atrioventricular Septal Defect (cAVSD). We were advised that this would usually result in Open Heart Surgery (OHS) at approximately 4-6 months of age. It was during a later scan that we got the unbalanced cAVSD diagnosis. The doctor explained that this would mean the repair which had been previously discussed would not be possible because the new discovery would mean we would need to go down the Single Ventricle Route (SVR).

David was born in the early hours of the morning and following paediatrician assessments it was determined that he did not need to be admitted to the NICU ward but he would need an urgent Echocardiogram (Echo) to confirm diagnosis and determine next steps. We met with a cardiology doctor from the Freeman Hospital in Newcastle at 19:30 that night. It was at this point we discovered that he had a Hypoplastic Aortic Arch which complicated matters further and would mean he would need surgery imminently. Following this diagnosis David was transferred to the Freeman Hospital from the RVI to be monitored closely to enable them to give medication to keep his heart function stable until his operation.

David had the first stage OHS known as the Norwood Procedure when he was 4 days old. This was one of the hardest and scariest days of my life because of how young he was plus there was little to no information regarding the successful outcome of this procedure for patients with DS. We had been advised that there were three possible outcomes from this operation. The best outcome would be for David to come out closed chest, second outcome would be for David to come out open chest and the worse outcome would be for him to be on ECMO which is a form of life support used temporarily to give his heart a rest to allow it to recover.

Katrina, mum to David

Following the operation thankfully David came out of the operation closed chest which made the doctors very confident the operation was successful and there would be a quick recovery for David. When we got to see David following his operation, we were shocked at the sight that greeted us. David looked extremely bloated and jaundiced but we were reassured by doctors and nurses in PICU that this was not an unusual sight and did not indicate an adverse outcome or a prolonged recovery. The next few days were full of ups and downs due to David contracting a chest infection, pneumonia and also a blood clot from the central line. This resulted in him requiring a PICC line being inserted in his neck directly into his heart to allow medication to be administered to help his heart function. However, David fought through it all and 2 days after the PICC line was inserted he was transferred to the HDU ward because he was improving so quickly.

David spent a further 5 weeks in HDU due to the amount of medication he needed to be weaned off and his need for vapo-therm which produced a high-pressure flow of room air to keep his oxygen saturations stable and at a level the doctors were happy with. Which in David's circumstances were to be between 75% and 85%. He was investigated by ENT and Respiratory to determine if there were any complications they could determine any cause and to assess if he needed a tracheotomy. Both specialists gave the all clear and advised that it was just going to be a slow process and there was a possibility he may need to go home with vapo-therm if reliance could not be rectified.

Eventually it was the sister on the ward who argued with the doctors to allow them to take David off the vapo-therm as a trial and monitor him closely. On the first day he was able to manage without vapo-therm for the full day but this was reintroduced overnight due to dips in his oxygen levels. On the second day he managed without vapo-therm during the day and the sister left direct instructions that vapo-therm was not reintroduced unless ordered by a doctor. He never needed vapo-therm again after that and was transferred to main ward 2 days later.

He improved rapidly following this but was unable to take much milk at a time and we were able to take him home using an NG feeding tube, an oxygen saturation monitor for regular checks on his saturations and hospital scales for biweekly weigh in sessions. We had a weekly telephone call with the liaison specialist nurses to monitor his weight gain and symptoms. We also had checkups with his cardiology consultant in clinic every 5 weeks until it was determined he was ready for his second stage operation. The indicators that pointed to him being ready for the second stage operation was he began looking increasingly mottled, his oxygen saturations began to drop lower and got to the stage where they were struggling to remain above 75% and he began to struggle to maintain his weight gain which resulted in him plateauing out at the same weight for several months.

After several last-minute cancelled operations due to emergencies needing his PICU bed, David finally had the second stage operation at the end of January 2021. This time we felt a lot more prepared and less anxious and stressed than what we had done the first time around. This was largely since he was a lot older and had a lot more weight behind him to help recovery. We felt confident that everything was going to go well and he would recover a lot quicker this time around. Unfortunately, we couldn't have been more wrong.

Katrina, mum to David

At first things seem to be going well and they reduced sedation and extubated him in the afternoon of day two after the operation. David seemed ok at first apart from signs of pain and discomfort but as the hours passed, he seemed to get increasingly unsettled and this resulted in his sedation levels being increased. Eventually his sedation was increased so much overnight they had to re-intubate because he couldn't breathe on his own. They carried out various tests over the course of next 24-48 hours and all they could find was a chest infection, but this would not be causing all of the complications. The following day his temperature plummeted to 34.7 degrees for no apparent reason and no matter how many blankets he was under it would not raise. Following blood works it was determined he had sepsis which meant his immune system was overreacting and would begin to attack his body organs if they could not get it controlled. He was switched to extra strong IV antibiotics at that point and the doctors admitted things would be touch and go depending on whether the antibiotics worked and could help stop his immune system from overreacting. This was really scary but on the other hand it wasn't the first time David had suffered with sepsis this had happened on his 16-week-old needles and we have the confidence the antibiotics had worked quickly on that occasion. Thankfully overnight his infection markers reduced massively and his temperature increased. Later that day they tried to reduce the use of the ventilator but David still seemed to struggle to manage himself so he was booked in for a CT scan the following afternoon.

It was discovered the connection made in the previous operation was too narrow and this was causing the distress David was feeling when they reduced the sedation. David was booked in for an emergency operation the following morning which was Saturday to rectify this. We were also told that they believe they may need to insert a stent in his pulmonary artery at the same time. The main concerns were whether his heart would handle the second operation so soon after the first and also whether there would be any complications arise due to the sepsis and chest infection but they did not believe David would have a great chance of survival without it. It was a long 6 hours wait but eventually we got word that David was back on PICU, and the surgeons were ready to talk to us. Thankfully all went well, and they were confident the operation was successful, and the connection was now wide enough this time around.



Katrina, mum to David

Within 24 hours David was overriding the ventilator and breathing for himself much of the time and soon he went from strength to strength and within three days he was transferred to the main ward rather than PICU. We thought this was a sign that everything would be plain sailing and we would have him home soon. However, due to the various complications David had been on morphine long term and it would take a long time to wean him off it. He also had a suspected blood clot again which we were waiting for a scan to confirm this but they had already started treatment due to his history of blood clots after the first operation. Additionally, he was on oxygen so they would need to try to wean him off this also. Gradually he was weaned off the morphine over the next two weeks and his oxygen was reduced to low flow but they were struggling to get him off it completely. It got to the point where they tried to take him off it for a portion of each day with the plans to increase this gradually hoping to stop his dependency on it.

A few days later things took a bad turn and a chest x-ray showed his lung had collapsed and he had diaphragmatic palsy which meant his diaphragm was not moving when he was breathing and as a result he was increased to high flow oxygen again. No change after 24 hours so they introduced a c-pap ventilator machine to see if this would help and he was transferred to HDU ward. 48 hours later there was no improvement and the decision was made to transfer him back to PICU for further help and investigation.

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In June 2024 David had his third stage operation which is called the Fontan procedure and is the final stage operation for Single Ventricle Patients. At this point we felt like we knew everything to expect and although we were worried about the risks we believed we were professionals dealing with the routine and waiting period which we had been advised would be around 6 hours. When we hadn't heard anything after 8-hours we began to worry and contacted PICU to see if they could get an update. They were advised that he was still in surgery and it would be a while longer yet. When it got to 11-hours we were really scared but finally after 12 hours we got the phone call to say he was back from theatre and the surgeon was ready to talk to us.

We rushed to PICU and was told by his surgeon that things did not go to plan they had to put him on bypass which they had been hoping to avoid and they struggled to get him off it which meant he was on longer than he should have been. We were told that he was in critical condition but they would see how he went and hope for the best. Within 24 hours he was put on dialysis as he ended up with Acute Kidney Injury from the prolonged period on bypass. The staff all grew concerned because he was still on a lot of medicine for his blood pressure after 72 hours and after further investigation a decision was made to take him.

back to theatre and reopen his chest with the belief that he may need to go on ECMO. However, when they reopened his chest his blood pressure stabilised and they decided to not proceed to ECMO at that point.

Over the next few days his blood pressure recovered and he started to improve but he still needed continuous dialysis. 5 days after reopening his chest they closed it up again and his blood pressure remained stable and he slowly seemed to be recovering. 5 days later they tried to take him off dialysis and his temperature spiked due to an unknown infection and sepsis. The dialysis had hidden the infection due to the blood cooling when it was being filtered outside of the body. He was put back on dialysis and given antibiotics. It was touch and go for a further 5 days while the antibiotics back to theatre and reopen his chest with the belief that he may need to go on ECMO. However, when they reopened his chest his blood pressure stabilised and they decided to not proceed to ECMO at that point.

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Unfortunately, when David was first born or even during his second stage operations the PADS Heart Buddy programme was not running or I would have jumped at the chance to get the support and learn experiences from other mums who had been through OHS. When the programme was introduced, I knew straight away I wanted to be a Buddy to offer support to other parents starting out on their CHD journeys. I don't always go into great detail about all of David's ups and downs but this is mainly because his journey has been very difficult and is seen as the exception rather than the rule.

Katrina, mum to David

As a result, I don't want to increase any fears parents have of complications arising but my journey has put me in a good position to support parents through their worries and concerns and help allay some of their fears because of the fact that David had overcome so much and bounced back amazingly. Additionally, due to spending so much time on the cardiac ward and PICU I met a lot of families and learned a lot about many different CHD's not just the one David was diagnosed with.



Caroline & Hope

Hospital: Royal Hospital for Children, Glasgow



Hope was born in January 2020 with Trisomy 21. This brings with it a list of possible medical issues, including heart defects and so she was given many scans at a just a day old. The scans revealed that Hope had a partial ASD and it was left to hopefully close up by itself. We were therefore discharged from hospital, much to the delight of her two older sisters; Rachel (12) and Laura (9). But by the 1st of February Hope's feeding had deteriorated mainly because she was sleepy all the time and was vomiting a lot. We took Hope to A&E and were admitted to the cardiac ward on the 9th of February.

Further scans revealed that Hope had a complete AVSD and a nasal gastric tube was inserted to help with her feeding. Finally, after establishing a feeding pattern, Hope was discharged from hospital on the 21st February.

Hope attended clinic early and it was decided to plan surgery for when she would be four or five months old. In the end Hope was already six months of age when she finally underwent surgery on the 10th July, during the 2020 pandemic.

Hope developed hydrothorax after her operation, which was something we had been warned could happen, this delayed her recovery, but despite this, she did amazingly well and was home by the 21st July.

There were a few things we had been prepared for because of meeting another mum whose baby had her repair while we were in hospital in the February. This helped a lot, but there were still a few things that took me by surprise and like everyone else who goes through this I found it heartbreaking to see my baby in pain.

Hope's valves are still a little leaky but they are really happy with how she is doing. Her consultant, Dr Ilina mentions in her report that "Hope is going from strength to strength and does not have any cardiac symptoms whatsoever". Such good news.

Caroline, mum to Hope

She does have a tiny residual inter-atrial shunt but this may not need attention as a child but they aren't worried.

I'm so thankful for the operation and that there continues to be advances in treatment for cardiac differences.

Hope is enjoying mainstream primary, heading into Primary 2 in August. She is a bubbly character and full of so much love and strength, although there are days where she falls asleep in the quiet corner!

We are so happy with the amazing work of the doctors and nurses in PICU and Ward 1E. We are looking forward to the future with lots of cuddles and smiles from Hope.



Sarah & Rheagan

Hospital: Great Ormond Street Hospital



When I was pregnant with our daughter, Rheagan, we were told there was a high chance she had Down's syndrome and that she might also have a heart defect. Throughout the pregnancy I required frequent hospital monitoring due to premature contractions, gestational diabetes, thyroid problems and concerns about Rheagan's wellbeing.

By 32 weeks it was considered safest for me to remain in hospital until she was born.

Rheagan was delivered by planned caesarean section in April 2019. Although she initially appeared well, a heart scan at just two days old confirmed she had a large ventricular septal defect (VSD) and atrial septal defect (ASD). We were told she would eventually need open-heart surgery but hoped this would not be until she was around 7–8 months old.

Within two weeks, however, Rheagan was already showing signs of heart failure. Feeding became exhausting, she struggled to gain weight and we found ourselves repeatedly admitted to hospital. Despite the challenges, we continued to breastfeed alongside high-calorie formula to help prepare her for surgery.

Following assessment at Great Ormond Street Hospital, doctors confirmed that Rheagan had Tetralogy of Fallot, a complex congenital heart condition made up of four separate heart abnormalities. Further imaging also revealed she had a single-origin coronary artery, an uncommon finding that added further complexity to her surgery.

Sarah, mum to Rheagan

At just three months old, Rheagan underwent life-saving open-heart surgery at Great Ormond Street Hospital. Handing our tiny baby over to the surgical team was the hardest thing we have ever done, but we knew it was the only chance to save her life.

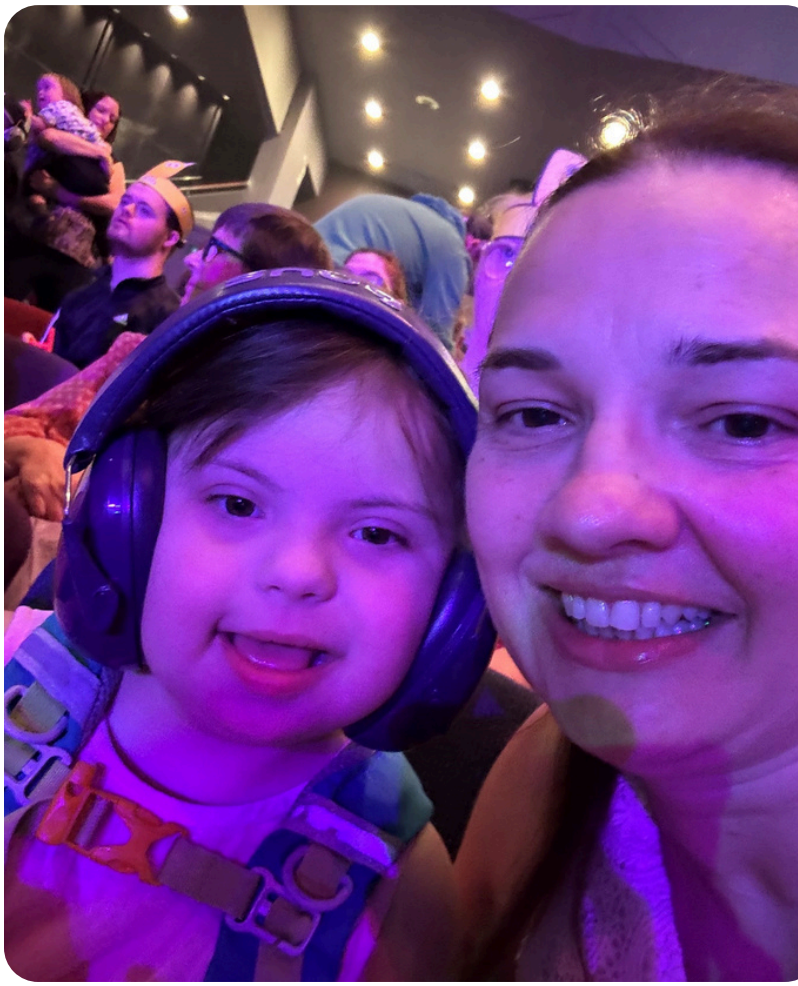
The operation was a success and, after several days in cardiac intensive care, Rheagan made remarkable progress. Just as we thought the worst was behind us, she developed severe breathing difficulties following discharge and became critically ill. She was transferred to Nottingham Children's Hospital, where she was diagnosed with tracheobronchomalacia, laryngomalacia and subglottic stenosis, alongside multiple respiratory infections. She spent weeks in intensive care, underwent further airway surgery and faced a long recovery.

That experience taught me one invaluable lesson: as a parent, you know your child better than anyone. I knew something wasn't right long before the seriousness of her airway problems became clear. Since then I have always trusted my instincts, and our local medical team have come to recognise how well I know Rheagan's baseline.

Eventually, when Rheagan was around 18 months old, the decision was made to stop oral feeding completely and move to tube feeding. The difference was life-changing. Her chest infections reduced dramatically and she finally began to thrive.

Today, Rheagan is a happy, energetic little girl who attends a specialist school and loves every minute of it. Her cardiologists are delighted with her progress and, following excellent echocardiogram results, now only need to review her heart every three years.

Looking back, our journey was frightening and unpredictable, but we will always be grateful to the incredible teams at Northampton General Hospital, Great Ormond Street Hospital and Nottingham Children's Hospital, whose expertise and compassion gave our daughter the opportunity to grow into the amazing little girl she is today.



Alexandra & Holly

Hospital: Leeds General Infirmary



When I was pregnant with Holly, we had no idea she was going to have Down syndrome. We had to have some extra scans as she was measuring small. I was booked in for an induction due to lack of movement. I went into labor quicker than with my daughter Lily and, as it was Covid, Neil wasn't able to be with me until I was going to the delivery suite, he missed the birth.

As soon as I had Holly, Neil arrived. I thought everything was ok and when I held her, I didn't realise anything was different. Neil then held her and he said to me that she looked like she had Down syndrome. I looked again and said yes I think she does, I don't know if I was a bit out of it from the gas and air or I didn't realize myself as I didn't expect it.

The nurse said that she wanted a doctor to have a look at Holly and we waited about 4 hours for him to come. I said to Neil I wanted to call my mum as it had been hours since I said I was going to delivery. I told her that Holly had Down syndrome and cried a lot as it was quite a shock and I didn't understand what that would mean for her.

Holly's Oxygen level originally tested ok but later on they said they were concerned and wanted to take her to neonatal and she was given oxygen. I didn't really understand what was happening and was on the maternity ward alone which was quite upsetting as the other mums on the ward had their babies with them. The nurse said I could go and see Holly. And the next day, I think it was, they did a heart scan and found that she had two holes in her heart, one being quite large so they said it was unlikely to repair itself. We were later told she was also missing a rib, that she had an unsafe swallow and much later found she had a floppy airway so it was quite a difficult time.

Alexandra, mum to Holly

Holly spent a total of 8 weeks in hospital following her birth, she required oxygen and diuretics to help with her heart condition. I felt quite scared about the surgery even though it is something that is done very regularly. She was so young and small. Biweekly weight checks became very important to me as we needed her to be as strong as possible.

The doctors and nurses were always very positive and supportive of Holly. She was born at St James Hospital in Leeds and had a couple of trips to the LGI for heart scans.

As we were not able to go home after having her, we gave her her first bath there, read books, had cuddles and did her cares and feeds. Due to her being on neonatal and her heart condition making it tiring for her she was given an ng tube to feed. We had to learn how to feed her through a tube which was a bit daunting at first but you soon adapt.

We kept hoping to take Holly home prior to the surgery as they said it would probably be about three months away. Each time we were close to home her oxygen would deteriorate. And at about 6 weeks old Holly went into heart failure. I noticed she was working harder and the doctors and nurses rushed to move her into another room and use a cpap machine to support her more.

They had a meeting about the heart patients including Holly and said they would operate as soon as possible. And that they would do the full repair not the band repair. I was happy it would just be one surgery but still very scared. I cried when the doctor told me it would be the next week as it became very real.

Holly was transported to the LGI and they did a scan to assess how her heart was now looking and found that the two holes were now three. This was because the large hole had closed partly making it two holes. There was a concern about where the holes were that might have made it more difficult to repair. Hearing a detailed explanation of what would be involved in the surgery was daunting. I had never been through anything like this before.

When they took her up for surgery I cried when we left her and then tried to fill up the next 7 hours and slightly distract myself. Shortly before they called, I made tea but just couldn't eat. Just after I got the call that all had gone as planned, I was so happy! I called my family to let them know and they were so happy it had all gone ok. They had still not met Holly due to Covid rules.

I rushed to the hospital to see her, and the recovery room was quite daunting. She was originally on a lot of machines and had tubes and a pacing wire coming from her. She was still sedated so laid fairly still. It was a lot to take in. I had no idea what to expect and was still quite emotional seeing this. After a few days I think, she was moved to the ward yet still required oxygen which I imagined she wouldn't if her heart had been repaired. This could be due to her floppy airway, but we didn't know this at the time.



Alexandra, mum to Holly



Holly was on the ward for about a week to wean her off the oxygen and recover enough to go home. Her scar seemed to heal well, and they were happy with her progress. It was quite scary to take her home. 8 weeks felt incredibly long even though I know some children are there much longer.
I was always so upset that we didn't get to go home prior to her surgery but looking back I am so glad we were in the hospital when she went into heart failure, and they were able to help her straight away.

She stayed on the diuretics for a while and has regular heart checks. Holly is now five years old and loving life! She wants to learn more and do everything! I couldn't be prouder of her! I am now a Heart Buddy and have been matched with quite a few families so far who I hope I have helped during their journey.

Becky & Maddox

Hospital: Glenfield Hospital, Leicester



Maddox's heart issues were picked up at our 12-week scan alongside markers for DS. We were then under fetal medicine until Maddox was born.

At 16 weeks pregnant I had a scan by the cardiac team at Leicester where they diagnosed pulmonary stenosis and noticed his heart wasn't growing/forming typically. He was subsequently diagnosed with a complete AVSD.

Being first time parents, and all these diagnosis and medical terminology thrown at us, our concern was what quality of life would Maddox have – as tough as it was to think about. To be told these are common things seen in babies often with Down syndrome put our minds at ease.

I was monitored couple of times at Leicester before Maddox was born, and miraculously the pulmonary stenosis sorted itself out, so we were left with the complete AVSD.
As soon as Maddox was born via emergency C-Section he had his first ECG and Echocardiogram so the medics could get a clearer look at his heart.

Whilst in NICU, we were told what signs to look out for regarding heart failure so should Maddox become ill we knew with specific symptoms to get to A&E ASAP.
When Maddox was 2 months old, he became poorly and was admitted to hospital, where they had another check of his heart, and it was then he was put on various medications for his heart that were administered via his NG tube.

The surgery for Maddox's complete AVSD repair had been penned for the age of 6 months, or a specific weight to be over and to be carried out at Glenfield Hospital.

Becky, mum to Maddox

We had an 'unofficial' heart buddy, as at the time I wasn't on FB and wasn't aware of all the extra support the wonderful team at PADS can offer. Speaking with Lea-Anne (Betsy's mum) really helped, from asking things like what to pack, how long they were in and speaking about there experience helped my nerves somewhat, although it is very daunting knowing what is upcoming.

So, we had a date for Maddox's surgery, but unfortunately it was pushed back due to Maddox being in hospital battling bronchiolitis for just short of a month and needing oxygen, nebulizers and suctioning and having low sats.

The day before we were due in, I was upset at the thought of Maddox having scars from surgery, but they are his wonder lines and show how strong he has been.

The time comes for surgery, at hospital the day before having all pre-op checks and a run through of everything that will happen and signing the paperwork to consent to Maddox having the surgery. This must be the hardest paperwork to sign, especially when you're feeling all the emotions.

Day of surgery comes, the surgery took a lot longer than anticipated due to the complete AVSD being a lot worse than scans had shown, main thing was Maddox was safely back with us on PICU. Seeing him so swollen and hooked up to what seemed like so many wires was upsetting to say the least and intubated and with three drains attached also.

Day one of recovery and Maddox was showing signs of complete heart block, and the external pacing machine was working the ventricles. This can be typical in some recovery from such a large surgery, and it can take the heart a few days to normalise once any excess swelling and fluid has gone down.

Things took a turn for the worse during recovery on PICU, and subsequently Maddox had another surgery a week later for a permanent pacemaker to be fitted.

As the days passed, after what felt like a lifetime on PICU (3 weeks) Maddox had his final drain out and was moved to the day ward. Still having daily physio come in and OT and dieticians.

What a relief it was to be discharged, then at our follow up a week later back in Leicester we were told things weren't right still, so we were back on the day ward for another two weeks while they tweaked Maddox's medication and doses and closely monitored him.



Becky, mum to Maddox

The following year, Maddox went in as a 48-hour case to have a TOE (Trans-oesophagal echocardiogram) and heart catheterization to get a more in depth look at his heart than a typical ECHO shows.

We were on 3-monthly cardiac review appointments, Maddox currently has Left AV Valve stenosis and leaking valves.

We have a device at home that monitors and sends data daily to the pacemaker team so they can monitor its usage, battery life. Should we need an emergency hospital dash, we hit a button on the pacemaker wireless device, and it will send the latest copy of information about Maddox's pacemaker to the hospital.

The next surgery for Maddox is looming over us as we don't know when it will be. It could result in valve replacements – this is something we won't know until the surgery is happening.

It was decided to stop Maddox's diuretic medication, which was daunting to say the least as he has been on it since 2 months old, and just monitor how he goes.

When Maddox turned 3 and he started to crawl – and he is fast! Vocalisations are a lot more with babbling and noises, he has also started to pull to stand on furniture and working on his first steps.

Age 4 Maddox mastered walking, and loved taking is K walker everywhere. He became so confident with it, in the end he started to carry it around – this is when we started to encourage independent steps & he absolutely loves zooming around on his TryBike.

Cardiac reviews went from 3 monthly to 6 monthly, still heart medication free. Maddox's heart is stable which is a huge relief, surgery is still on the cards - it's just a case of when Maddox shows signs, unless anything is picked up on his echos.

Age 5 now, Maddox has started school & cardiac reviews have gone from 6 monthly appointments to annual appointments, yes I feel nervous but the saving grace is the cardiac team are contactable any time with any concerns or worries night or day.

We have annual pacemaker checks still, to make sure it's at the right setting and to monitor the battery life too as this will need replacing.

You would never know to look at Maddox he has been through so much so young and he is thriving.

Our warrior, Maddox.



Cate & Charlotte

Hospital: Leicester Royal Infirmary

Charlotte had a post birth diagnosis of Trisomy 21. Shortly after she was born, she had an appointment for a full review with the paediatric consultant which included an echo as she had a heart murmur. This is when it was discovered that she had a large Patent Ductus Arteriosus (PDA) and a small VSD. I was told that she would need surgery for the PDA when she was older but was too small at that time, so would be monitored closely. It was explained that the preferred method of PDA closure was via keyhole surgery entering through the groin, but that Charlotte would have to grow considerably before this would be possible. She commenced Diuretic medication to help prevent fluid overload and to help the heart and lungs from having to work too hard. Despite the medications, she always seemed to be working hard with her breathing, she had a significant chest muscle tug and was very sleepy all the time. She would also get breathless when feeding and often fall asleep before finishing her bottle, so she wasn't putting on much weight.

We went for monthly check ups with the cardiology team, and gradually her heart was becoming more enlarged, her symptoms were worsening and she was showing early signs of heart failure.



It was decided that she could not wait any longer, and that closure by ligation would be necessary. This method is when surgeons access the heart through the ribs and close the PDA with clips. I remember being told that they would like to do surgery the week after and feeling really numb. This was when I joined the DSUK's Heart Buddies and was paired up with our buddy Liz, who was a massive support. I don't think anything can quite prepare you for the rollercoaster of emotions and the exhaustion whilst in hospital, but practical advice like what to pack, the best type of vests / sleep suits to allow for drains and lines etc and what to expect in recovery makes a huge difference.

Cate, mum to Charlotte

We were admitted to Leicester Royal the evening before surgery and we were first on the list for the next morning. The staff and all the team on the ward were amazing! The surgery lasted about 2 hours (feels like forever when you're waiting) and then she was kept on a ventilator for another 24 hours after that. That was probably the hardest part to see, but again the staff were incredible! Once she was weaned off all the sedatives and drains removed, she was transferred back to the ward. It's really hard to believe how fast the recovery is from such major surgery. The improvement in her breathing was immediately evident, and she began taking her milk much better straight away. Because the surgeons have to break ribs with this kind of repair surgery, I was shown how to pick Charlotte up in a way that would not hurt her. I couldn't pick her up under her arms, I had to scoop her up, and she couldn't be placed on her tummy for approximately 6 weeks.

From a cardiac point of view, she made a really quick recovery and medications were stopped immediately. Ordinarily we would have been discharged 2 days later, but unfortunately, Charlotte got a blood clot from the central line in her femoral artery. Apparently, this is really rare and we were just unlucky. This meant she had to go onto a Heparin infusion and we ended up having to stay in hospital 12 days and be discharged on anticoagulant injections twice a day for 6 months. Despite this complication, Charlotte made a really quick recovery and her cardiac function has returned to how it should be.

We had 12 monthly checkups with the cardiology team, but they are happy with how she has progressed and have now discharged her from cardiology. The VSD closed on its own and no further treatment was required.



Kate & Thomas

Hospital: Royal Brompton Hospital, London



Our little Heart Warrior Thomas was born in October 2022 at Watford General. Everything was a surprise. Soon after birth we were told they suspected he had Down Syndrome. The next morning, we were told the risk of heart issues in babies with Down Syndrome, and he needed a scan to determine if one was present. The scan confirmed a suspected hole in his heart so we were booked to see the Cardiologist from the Royal Brompton who was visiting Watford General in two weeks. At this appointment Thomas had a detailed echo and it was confirmed he had a VSD – a hole in the wall between the bottom two chambers of his heart.

We were given a lot of information and told they would expect the newborn high pressures in his heart to drop in the coming weeks after which it was likely he would go into heart failure. When this happened, he would be put on diuretics and put on the list for surgery. It was all very intimidating at the time but the consultant from the Royal Brompton could not have been more reassuring.

Thomas was then seen weekly at the Royal Brompton as we were waiting for his pressures to reduce. After about 10 weeks there was a concern that these pressures should have reduced but hadn't so we were referred for a CT scan, respiratory checks, dietician, sleep study – all to establish if there was any underlying cause for the high pressures remaining. A concern was raised that one reason could be Pulmonary Hypertension but this was rare and many other reasons could be attributing to the delay.

On the day of the CT scan an echo was also carried out that showed the pressures had begin to drop and also Thomas was beginning to fall into heart failure. This was both a relief and a worry as it meant Pulmonary Hypertension was much less likely now, but also that surgery would be required very soon.

Kate, mum to Thomas

We had been told that ideally they don't operate on babies under 5kg and Thomas was about 4.8kg at this time. Although through PADS, we have learnt that it really isn't uncommon for babies to have surgery earlier than this.

We were then given a date for surgery and a large amount of information on email about the surgery and staying in the hospital. We were warned that many things could mean the surgery would be cancelled – not enough beds in PICU, strikes, an emergency case coming in on the day, or Thomas being unwell on the day of surgery. To reduce the risk of the latter we kept our older daughter off nursery the week before and both worked from home to isolate Thomas as much as possible.

The day before surgery, we came into the hospital and had a briefing with both the surgeon and the anaesthetists. The surgeon was incredibly reassuring. He basically said I understand this may be the hardest day of your life but to me this is quite routine. He explained that although Thomas' hole was very large, being a VSD it is the easiest of holes in hearts to repair. He explained how he would close the hole (using a bovine patch to cover the hole), how long Thomas would be on the heart and lung bypass machine (around 50mins) and how long he expected the surgery to take in total (4-5hours).

I had found the day before leaving home for the surgery incredibly emotional and difficult, particularly when my sister-in- law came to pick up our elder daughter.



I found I just couldn't stop crying. However, surprisingly, I felt very calm the day and night before the surgery in the hospital. I had found the conversation with the surgeon particularly reassuring. As a result, both Thomas and I slept well that night on the ward. I woke up early keen for it to get started as the sooner it started the sooner it would be over.

On the ward, the nurses gave us a special body wash to bath Thomas with that thoroughly cleaned him pre-surgery. This was a nice thing to be able to do for him and to be involved in some way. We were very lucky as the surgery wasn't subject to cancellation so we went down with him to the anaesthetic room at the scheduled time. This room was next door to the actual theatre so we didn't see where the operation would actually take place. There were a lot of people in the room – maybe 5 or 6. We had been briefed the day before on what would happen.

Kate, mum to Thomas

We watched and held Thomas' hand as he fell to sleep with the mask over his face. I'm sure there is more to putting him fully under than that but that is the bit the parents can stay for. We were then led out of the room. As advised by our Heart Buddies, we then left the hospital as soon as possible – this was the best piece of advice we received!

We went for breakfast and a walk around the area, read the paper. Did as much to distract ourselves as possible. I cannot stress enough how important I think leaving the hospital was. However calm I was the night before, I was incredibly anxious and at times upset during the hours of the operation. It wasn't pleasant but being out of the medical setting I'm absolutely certain helped.

Exactly 4 hours after we left Thomas we had a call from PICU saying he was on his way up and to come over to the ward in about 45 minutes. The relief was overwhelming.



When we saw Thomas for the first time after the operation, I was not shocked by the machines and dressings but his dad was. I had looked at pictures of babies post op through PADS. I am very glad I had as it had prepared me for what he would look like. There was also a brilliant poster in the PICU that showed what all the lines into the body did and made it "interesting" rather than unknown and scary. I also spoke to the PICU nurses and they explained everything to us which helped.

In the afternoon, the surgeon came to see us and told us that the operation had gone completely to plan which was reassuring.

After surgery, a drain will be in place removing fluid from the baby's chest into a container by the bed. Thomas' drain was removed after 2 days. We were advised to leave PICU for this which we did and I'm pleased we did. Thomas' dad was there when another baby's drain was removed. He said it was quite distressing – to such an extent that one of the trainee nurses had fainted during the procedure so I recommend not staying in the room for it!

After the operation, physios came round daily to help him clear the congestion in his chest that just builds up from being laid down all the time. They were lovely and also taught us about how to hold and carry him to protect his sternum which is broken during surgery to get to his heart.

Thomas stayed in PICU for 9 days and was discharged completely after 12 days. He was in for a bit longer than some due to a couple of post op complications. These were as follows:

Kate, mum to Thomas

Fluid on the lungs: After the drain was removed Thomas developed fluid on the lungs. They gave him diuretics to reduce this and with a plan to add a new drain if it didn't reduce in the coming days. Luckily it did reduce and the additional drain wasn't needed.

Blood clot: When on the ward I noticed Thomas had a VERY cold left foot. I said this to the doctors during their rounds. We were told it could be the sign of a clot. A scan was carried out at his bedside and found a blood clot in his femoral artery. He was prescribed a blood thinning drug twice a day. We had to inject him with this two at home for 6 weeks post surgery. A mini cannula was installed when he was discharged that I then injected the needle into. The community nurse team came to change this cannula twice a week and take bloods which monitored the levels to ensure the medication was working. After 6 weeks, he had another scan that showed the blood clot was gone and he could come of the medication. Injecting him at home wasn't much fun at first but became routine. For the two or three days before discharge, the nurses taught me to do it and stood over me while I did it until they were completely confident I could do it alone. They had said if I never got to that place the last resort is I could take him to our local hospital daily to have the injections.

Rib sublaxation: 3 months after surgery Thomas developed a sticking out lump where his sternum is. We went back to have it reviewed. An ultrasound was carried out and we were told the rib has detached from the sternum.

This is called Subluxation. It's fairly uncommon but it currently causing no pain or complications. The surgeon said we can just "open him back up and secure it down"....! He said unless it starts to cause paint though it's not required and would only be to resolve the appearance. As we want to avoid surgery unless required, we have said no to further surgery. We are keeping an eye on it though and I will be asking for another ultrasound of it at his next cardiology appointment to ensure it isn't creating any internal risk.

6 weeks after surgery Thomas came off diuretics. Within one week of this he gained 1kg in weight! We were seen as an urgent case at the Royal Brompton due to this. He was monitored but over time it slowed, and it was assumed the gain was purely due to coming off the diuretics.

Thomas is now 3.5yrs old and is thriving. He still has the rib subluxation, but it has never caused him an issue I'm happy to say the whole experience is now a distant memory and we are down to cardiac reviews just every two years at the Brompton.

Rozie & Sophie

Hospital: Royal Brompton Hospital and Evelina Children's Hospital

We knew Sophie had a high chance of having 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 5 weeks thinking everything was looking positive but they found the hole between her ventricles 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 then 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 the first lockdown of the global pandemic! We were told she was on the surgical list 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.

Rozie, mum to Sophie

I was worried before the surgery that I wouldn't be able to hand her over, that I'd have a panic attack or something as I just couldn't imagine doing it. When we were settling her in at the hospital though, it hit me that everyone had their job and mine was to be calm for Sophie, to use my body and voice to reassure her and help her feel calm and safe. That really helped me put one foot in front of the other and get through the hospital stay.

Walking her down to theatre, after signing her consent form, then leaving her sleeping in the theatre 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 that is quite common. Finally we got the call that it had gone well and we could come up to PICU to see her.

We were not allowed to be on the ward or PICU together because of Covid but they let us both into 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 of 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 was a different baby, happy, settled and thriving. Sophie is now at school and her heart doesn't hold her back at all!

It was definitely the toughest thing I've ever been through but I came away amazed and proud at how well both Sophie and I had coped with it. 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.

There is an image of Sophie on the last page, showing her just after surgery with some explanation of the various tubes and wires for you to look through when you are ready.



Laura & Caleb

Hospital: Evelina Children's Hospital

We found out about Caleb's heart condition, Tetralogy of Fallot, when I was 14 weeks pregnant. There were also several markers for Down syndrome picked up during our weekly scans — shorter femurs, a larger nuchal fold measurement, and overall small size. We were closely monitored throughout the pregnancy, and after Caleb was born, a genetic blood test confirmed he had Down Syndrome. He had many cardiology appointments leading up to his heart surgery at six months old.

In early March 2024, Caleb had a planned Bronchoscopy, Microlaryngoscopy, and CT scan under his first general anaesthetic. While he was recovering in hospital, we were told the next day that there had been a cancellation and it was likely his open-heart surgery would take place the following day. It was a massive shock, and we felt so many emotions, but we knew this was something Caleb desperately needed.

On the day of surgery, we waited for hours, as Caleb didn't go down to theatre until 3pm. Until that moment, we weren't even sure whether the surgery would go ahead. Walking him down to the anaesthetic room was incredibly tough and emotional, but we knew he was in good hands and that this was something we couldn't do for him ourselves. We placed him in the care of a wonderful, talented surgeon and surgical team.



My husband and I tried to stay busy. We went for a walk and had something to eat. Being out of the hospital helped, though we kept our phones close, waiting anxiously for the call. The operation took five hours. We were relieved to hear it was over and that everything had gone to plan — including a transannular patch over the hole in Caleb's heart and the release of vascular aortic ring.

We went straight to see him once we were told he was out of theatre and settling into PICU. It was a shock to see how swollen he was, and to take in all the tubes and wires. The nurses were fantastic, and we are so grateful for the care they gave him. We were told to expect extubation within 24 hours, but Caleb had a difficult recovery. He remained intubated for seven days while fighting a chest infection and experiencing irregular heart rhythms.

Laura, mum to Caleb

It was incredibly hard not being able to hold him and watching his little body struggle. But eventually, he turned a corner. The breathing tube was removed, and we were slowly transferred to the ward. I remember seeing him smile again, watching the swelling go down, and seeing our beautiful, strong little boy looking more like himself. Seeing oxygen levels of 99 and 100 was something we had never witnessed before — before surgery, we had to make sure his levels stayed above 75.

While Caleb was in PICU, I was thankful to have a room at the Ronald McDonald House down the road. It was big enough for my husband and our other three children to stay at the weekend. It was such a welcoming place with friendly staff, and I appreciated having somewhere to rest and recover before returning to Caleb each morning. Hospitals are wonderful places, but they can be draining, emotional, and busy. Once Caleb was back on the ward, I was able to stay with him and sleep by his side.

Discharge day felt amazing. We had regular home visits from the local children's community nurses, who checked Caleb's wound and redressed it, as he had developed an infection in hospital. We had to be careful picking him up while he healed, but everything slowly became easier, and it felt more normal being home together as a family. We administered diuretics for the first couple of weeks, and his previous heart medication (Propranolol) was no longer needed.

Heart surgery was tough, but we knew it was necessary. We could finally see our little boy begin to thrive, gain weight, and show huge improvements in his overall health.

We went from eight hospital admissions in the first six months of his life to only two in the last two years.

I really appreciated being part of DSUK's Heart Buddies group. Having people who truly understood what we were going through was amazing. The WhatsApp group became such a source of support, and I'm grateful it was put in place.



Jennifer & Isabella

Hospital: Great Ormond Street Hospital



Isabella was born by emergency Caesarean section at Hinchingbrooke Hospital on 17th March at 11:38pm, weighing 8lb 4oz.

Shortly after she was born, Isabella was transferred to the Neonatal Intensive Care Unit (NICU), where we were told that she had Down syndrome and two holes in her heart. It was an incredibly emotional and overwhelming time, and all we wanted was for our little girl to be okay.

During the first six months of her life, Isabella was in and out of hospital because of her heart condition. When she was around two to three months old, Great Ormond Street Hospital (GOSH) became involved in her care following another hospital admission. She was started on medication which we truly believe saved her life. From that point, a plan was put in place to continue her medication and begin preparing for the surgery she would eventually need.

Throughout this journey, we were supported by our wonderful cardiac nurse, Jess, from GOSH. She checked in with us every week, guided us through each stage of the process, and was always there to answer any questions we had. Every step of Isabella's care was explained to us in detail, and we were always encouraged to ask questions, which gave us so much reassurance during such a frightening time.

The team planned for Isabella's surgery to take place when she was around six months old, as they wanted her to be as strong as possible beforehand. Because of her heart condition, Isabella found feeding very difficult and wasn't able to take enough milk on her own, so she had a nasogastric (NG) tube to ensure she received the nutrition she needed and could gain enough weight for surgery. We followed a very strict feeding plan to help her grow and prepare for the operation.

On 30th September, we travelled to London and stayed overnight in the hospital accommodation. The following day, 1st October, Isabella underwent open heart surgery. She was in theatre for four hours before being transferred to the intensive care unit. Finally, being able to see her afterwards, knowing she had come through the operation, was an enormous relief.

Jennifer, mum to Isabella

We stayed at Great Ormond Street Hospital for ten days in total. Although it was one of the hardest experiences of our lives, every member of staff treated us with such kindness, compassion and professionalism. They made an incredibly difficult situation feel as manageable as possible, and we will always be grateful for the care Isabella, and our family, received.

Today, Isabella is 15 months old and thriving. Her NG tube is no longer needed, she is eating and drinking independently, and she continues to amaze us every single day. She takes everything in her stride, and we couldn't be prouder of the incredible little girl she has become.



What does the future look like after heart surgery as a baby?

We thought it might be helpful to include the story of Heidi Crowther, who is one of DSUK's Patrons who underwent heart surgery as a baby.



Mum Liz says:

"29 years ago, when Heidi was born with Down syndrome, she had a heart scan which showed a large AVSD. She was admitted to the Birmingham Children's Hospital at about 4 weeks old.

The doctor wanted her to grow to a decent weight but sadly she didn't, so had the surgery when she was two and a half months – with only a day's notice! The surgery was successful and the difference in Heidi was immediate – she had more energy and was much more awake and responsive!

After a few days she was discharged and hasn't looked back – she was left with leaky valves in her heart. At first, she had medication for this but gradually that was removed. The promised surgery to repair the valves at age 2 or 3 has still not been necessary and she is still not on medication for her heart.

Heidi is now living a full, vibrant, happy and semi-independent life."

Heidi says:
"I had heart surgery as a baby – I don't remember it of course but I regularly have heart check up's – which are great fun! I love watching the heart scans. I don't have any issues with my heart at the moment. I can't have piercings or tattoos or too much caffeine but I can cope with that!

I have an amazing life and one of my favourite things is being a Patron of PADS and working with babies and children with Down syndrome in local support groups."



Post surgery

Based on our personal experience, and a lot of feedback we have received from other parents, we know it can be helpful to prepare yourselves by seeing photos of other babies post-surgery. We know this can be a very overwhelming so we have included this image on the last page so you can look at it when you are ready.

Firstly, introductions – on the next page is Rozie's wonderful daughter Sophie a few hours post surgery in the Paediatric Intenstive Care Unit (PICU). She was still very heavily sedated but held onto her mummy's finger which meant so very much at that point in time. As well as being quite swollen (which is very common initially), Rozie's main observation was how calm Sophie's body was – Sophie had had significant sub-costal recessions (sucking in under the ribs) all her life and by the time it got to surgery, you could really see how much work she was putting into each breath.

You will see some descriptions of the various tubes and wires – the wonderful PICU nurses will talk you through everything, including the various medications and explain what the monitors are showing. A lot of the medications are on a constant drip feed managed by machines and stored in racks by the bed. Sophie is attached to a ventilator to help with her breathing, meaning that her body can get as much rest as possible. She is also attached to monitors that beep a lot! Do ask the nurses to talk you through what the monitors are showing and what is a good 'trace' – if the monitor isn't getting a good reading, the machine will beep but it doesn't mean something is actually wrong!

The PICU nurses will answer any questions and help support you too so please feel confident to ask if you aren't sure what something is for. Throughout recovery, the number of tubes and wires gradually reduced.

"Here is Sophie now – a happy, healthy and thriving 6-year-old! We can now look back on the day of her surgery as being both a tough day but also as being the best of days, as it was the day her heart was mended, leaving her able to live life to the full."

Rozie x




Clamp for holding various lines in place
Very cute mohican hair that even OHS can't flatten!
Feeding tube
Swelling post surgery
Line in for medications, such a morphine, and for taking blood samples
Surgery site covered in dressing
Oxygen via ventilator
Pacing wires
Chest drains
Line in for medications, such a morphine, and for taking blood samples
Stickers for electrocardiogram (ECG)
Identity band
Catheter
Line in for medications, such a morphine, and for taking blood samples
Oxygen monitor
Thermometer

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