

Jo's Story



Cissy swimming

I have worked with ECHO for many years now, as a Committee member, Vice Chair, Chair, and now in my current role as Chief Executive. I've been lucky enough to meet many of you at some of our wonderful parties and events, but I thought I'd write a little piece for the newsletter about my own heart-baby (Cecilia or "Cissy"), how the experience of our baby having Congenital Heart Disease led me to get involved with ECHO and why I believe parental support, through groups like ours, is so vital.

On April 9th 1999 my life changed forever. I was 20 weeks pregnant and my partner Vas and I went to our local hospital for a routine anomaly scan. It was a glorious Spring day, and we had decided to take our daughter Melissa with us (who was 5 at the time) so she could see her new brother or sister for the first time on the screen. We had plans to find out the sex of the baby and were so excited. Even though I was an older mum, and had heard about the risks of having a child with Down's Syndrome or other abnormality, nothing could prepare either of us for the shock we felt when the sonographer stopped the scan and went to fetch a colleague to check on what she was seeing (or not seeing, it turned out!). I think I knew, even before anything was discussed or confirmed, that something serious was wrong. Her colleague came in, checked and then broke the news to us that they "couldn't see the septum of the baby's heart", and that we would need to be referred immediately to a Fetal Cardiologist for a heart scan to confirm their suspicions. An appointment was made for the following Monday morning at 9.00 am for us to attend Guy's Hospital to see Dr. Gurleen Sharland. We were absolutely shattered, and I can still remember walking away from the hospital, clutching poor Melissa's hand (who was wondering what on earth was going on, and why Mummy was crying), convinced that we were going to lose our long-awaited second baby.

What seemingly started with a slight tummy upset quickly developed into something which seemed more sinister – she would scream uncontrollably and inconsolably for a long time, her face turning a terribly bluey-grey colour, before falling into an almost unconscious sleep.

After an agonising weekend of tears and worry, we turned up at 8.00 am for our appointment with Dr. Sharland (an hour early!), hoping against hope that our local hospital had got it all wrong and that our baby's heart was perfect after all. It was not to be. After the scan (which seemed to take an absolute eternity) we were escorted into the Counselling Room (we knew things were really bad then!) and were told, very gently, that our baby had a very serious heart condition – one which would require at least one major open-heart operation and lifelong follow-up. We were given a diagnosis of Complete AVSD, Pulmonary Stenosis and Left Atrial Isomerism, just for starters, and some other anomalies, which added up to a very serious, very complex heart condition. Our world fell apart. It is now eight years since that shocking news was given to us, but even now it brings tears to my eyes to recall how devastated and frightened we were. I remember Sherrida Rollings, the Counsellor, telling us that we would probably feel like we were on an emotional rollercoaster, and to this day I think that is probably the best description of the world we inhabited just after our baby was diagnosed. I have spoken to many, many parents since, and most agree that the day of diagnosis is among the worst days of their lives and one which they will never, ever forget.

I remember leaving the hospital, with normal life rushing past me in a blur. I couldn't think about anything else; I felt sick with worry and fear. I couldn't understand how people could carry on their busy lives all around us whilst our hearts were breaking and our lives were falling apart. As is usual, we had been given the option to terminate the pregnancy, and spent a terrible night discussing the unthinkable alternative, but I knew in my heart that I could never, ever have taken away the chance of us spending even five minutes with our precious baby. When I got into bed that night, the baby seemed to be kicking me so much more vigorously than it had before, and I just felt it was saying to me "don't give up on me – give me a chance". My mind was made up, even before we attended an appointment at the Fetal Medicine Centre at Kings College Hospital for a full and detailed anomaly scan (deemed necessary because the scan I had been having at my local hospital had never been completed once they detected the heart problem). After a very long and detailed scan, where they counted fingers and toes, checked all the organs and we saw an amazing image of our baby's face, we were finally given a glimmer of hope; they couldn't find any further obvious problems, and although they recommended I had an amniocentesis, they hadn't found any pointers to any chromosomal disorders. Once the amnio had been performed (much less stressful and painful than I had anticipated), we were told that we would (amazingly) receive the results in 3 days. Sure enough, three days later, we were telephoned and told that they had not found any chromosomal defects, and, to our joy, that our baby was a girl.

This was more positive news which gave us a little bit of strength to carry on until the August due date.



Cissy, with big sister Melissa

However, I had the rest of my pregnancy to get through, which was not easy. I felt isolated and alone; I couldn't relate to other pregnant women because they did not have the terrible worries I had, and decided not to go to any of the offered ante natal classes. One of my closest friends was also pregnant at the same time, and although she was a huge support to me and at times kept me sane, even she couldn't really understand the torment and fear I was suffering - not even really knowing whether my baby would survive her birth, or whether she would need surgery immediately she came into the world.

After 18 stressful weeks, Cecilia Joy Sylvia Adamou finally put in an appearance after a long and stressful labour. Vas held her immediately and put her face next to mine so that I could kiss her, before she was whisked off to Special Care to be checked. Vas disappeared off with her, whilst I lay there, dazed, not knowing whether I'd ever see her alive again. I was taken to the Post Natal ward to rest. It seemed like an eternity before Vas' grinning face came round the door and he said "she's breathing on her own, she's pink and so far they seem quite pleased with her!" What a relief! We both shed tears of joy. After about six days in hospital, we were, amazingly, allowed to take our new baby home because, in the words of the doctors, she was, for the time being anyway, "balanced" (i.e. the pulmonary stenosis was counteracting the effects of the A.V.S.D.), but we were warned that she would need a "BT shunt" to alleviate the stenosis within six to eighteen months.

We left hospital, pleased to be going home, but without the joy and excitement that parents usually feel when taking their new baby home. However, Cissy thrived, despite her heart condition, fed well (unusual for a heart-baby) and put on weight. We had lots of support from family, friends and a lovely health visitor, as well as a wonderful Outreach team, but still I felt alone, depressed and fearful - terrified of losing the precious little girl we had already all fallen head over heels in love with. There were good times though, and we never lost sight of the fact that we were very lucky to be living an almost normal life with her, and only having to visit the hospital for infrequent Outpatient checks.

When Cissy was six months old, she suddenly deteriorated over the course of a weekend. What seemingly started with a slight tummy upset quickly developed into something which seemed more sinister – she would scream uncontrollably and inconsolably for a long time, her face turning a terribly bluey-grey colour, before falling into an almost unconscious sleep. After two visits to our local Children's Casualty department, they finally decided to keep her in overnight for observation. When, at 3.00 in the morning, her sats dived to 42%, all hell broke loose with doctors and nurses flying everywhere. It was obvious they weren't quite sure what to do with her and I was terrified we were going to lose her. Now they finally believed me that there really was something wrong with her, and quickly arranged for us to be transferred, by ambulance (with lights flashing and sirens wailing) to Guy's.

I walked through Rothschild Ward (the then Paediatric Cardiac ward in Guy's Hospital) for the first time on that cold, miserable February evening with my darling Cissy in my arms, I looked around and it dawned on me ... we weren't alone – our baby wasn't the only one with a heart defect! It sounds absolutely ridiculous now, but I had felt so isolated and, yes, I suppose, victimised, that I'd failed to realise that there were lots of other families going through what we were going through, and I saw them now, sitting by their children's beds, I saw their children recovering from surgery and thought for the very first time "maybe, just maybe, we can get through this".

The following morning I was told that Cissy would need surgery (a BT Shunt) immediately to alleviate the Pulmonary Stenosis, which was causing the "spells" she was experiencing, and that it would take place over the next few days. I decided to give her breakfast but no sooner had I put a spoonful of Weetabix to her lips than it was pulled away by the nurse taking care of her, who told me that they'd found a surgery slot for her that morning and she was going to be next on the "list". Vas arrived after spending the night at home with Melissa and getting her to school in the morning, to find me in tears – dreading the surgery our precious little baby was about to undergo.

Nothing can prepare parents for the terrible experience of carrying their baby or child down to an operating theatre. It had been bad enough taking our older daughter Melissa in for minor surgery on her eyelid when she was two, but to be taking Cissy down to an operation which could pose a serious threat to her life (albeit ultimately to save her life) was the hardest thing I'd ever had to do. I was almost hysterical until Conal Austin, her surgeon came into the anaesthetic room and spoke to us in such a reassuring way. I remember asking him to please take good care of her because she was so precious to us and I will never forget his reply "she's very precious to us too, you know". We knew she was in good hands.

To our joy and total relief, Cissy recovered very well from her operation and was discharged after about 8 days. We left hospital, taking a new pinker Cissy with us and a copy of the ECHO newsletter, which I'd found on the ward. As soon as I got home, I sent off my application form to become a member and not long after that volunteered to join the Committee. We were so grateful for the fantastic care Cissy had received from her Cardiologist, John Simpson, her Surgeon, Conal Austin, and all the wonderful doctors and nurses at the hospital, and I felt I wanted to give something back, by helping other parents who were going through what we had gone through. I did not want any other parents to experience the loneliness and isolation which I had felt through my pregnancy and Cissy's early months, and resolved to try and improve accessibility to ECHO and contact and communication between parents and members.

I was really fortunate that when I joined the ECHO Committee a number of other "new faces" did too and the fresh blood in the organisation meant new ideas and fresh challenges were undertaken with

enthusiasm. Since then ECHO has grown and grown, and has developed into a much more cohesive and structured (and I think/hope professional organisation). We offer support in many ways, including this wonderful newsletter which goes out, free, to all our members four times a year. We also leave lots of copies at the hospital (on the ward and in the Outpatients Dept.) as well as at Outreach clinics, so that parents who haven't heard of us can read about us and, if they wish to, join. We also have a comprehensive Contact Database with named Area Contacts, which allows parents to be put in contact with other parents in their local area and attend coffee mornings and other social events. Our website is used constantly, and the message board has proved to be a vital and important way of allowing parents to give and get on-line support – just reading through the messages each day is inspiring; no parent ever goes unanswered and we have many regular contributors who make sure that cries for help are always answered. That is priceless and goes to the heart of what ECHO, and indeed, parental support is all about. Members of the ECHO team and other volunteers carry out ward visits too, to sit with parents and chat, offering a friendly ear and, sometimes, more practical support whilst their child is recovering from surgery or other procedure.

For me, apart from the absolute terror associated with everything involved with the surgeries that my gorgeous little girl has had to undergo, the most difficult time was when I was pregnant, when I had no way of making contact with other parents in the same boat. From speaking to parents, we know that most mothers who are expecting a “heart-baby” don't want to go to normal Ante Natal classes, as they worry they will feel “different” and have far more serious concerns to deal with. Bearing this in mind, two years ago, ECHO initiated a unique series of Ante Natal Days (in conjunction with Midwives from the Thames Team at St. Thomas'), which are held every six weeks, and which are open, free of charge, to all parents whose heart baby will go on to be treated at the Evelina. These classes offer a specialised look at labour, pain relief, giving birth, breast-feeding and post-natal care, as well as a tour of the NICU ward and a talk by a representative from ECHO about their own experiences of having a heartbaby. The response to these special days has been overwhelmingly positive, not only because parents are able now to attend an Ante Natal class where they feel they “belong”, but also because they are able to meet and talk with other parents-to-be, who are in exactly the same position as they are in, who have all the same fears and anxieties. For me, I believe this project, running alongside the availability of our two Pre Natal support volunteers to speak to parents on the phone, has been one of the most important and valuable developments ECHO has undertaken because it means we are able to support parents almost from the moment their baby is diagnosed.

ECHO has evolved over the years into a successful support group, now so much so that it has had to employ two part-time staff (albeit on a consultancy basis) to ensure that we continue to grow and develop, as well as offer the core support that is so important to our members and all parents. This has meant that both myself and our lovely Jessica Cattermole are very fortunate to be able to actually work for a wonderful organisation that we truly believe in. Through ECHO, I have been inspired by the people I have met, parents who despite tragedy and sorrow in their own lives, or worries over their child's deteriorating health or impending surgery still find time and space in their hearts to help others. I think that is humbling and at the same time restores one's faith in human nature.

As for my own precious little Cissy – eighteen months after her first operation, she had to undergo major open-heart surgery. We were devastated to learn that it was not possible to repair the AVSD or correct the Pulmonary Stenosis, due to the very unusual anatomy of her heart, and a Glenn Shunt was performed instead. This would mean that as she grew she would probably need further surgery to complete the Fontan circulation, but none of this would cure her heart defect. She is now seven and a

half years old and, to date, we've managed to stave off the inevitable third bout of surgery, (or I should say she has!), but for how long, we don't know. She absolutely loves school and indeed life in general, and does far more than she probably should be doing with sats in the mid - lower 80's! She is a fantastic swimmer, specialising in a killer backstroke, an accomplished ballet dancer and gymnast and even plays in goal when playing football at lunchtime. You can imagine our pride, when, at her recent Parents' Evening, her sports teacher told us she couldn't believe there was anything wrong with her heart!

Jo Wilson