



**Evelina Children's
Heart Organisation**

Support for families of heart-children treated at The Evelina Children's Hospital

**24 page
special**

Newsletter Autumn 2011



ABSEIL DOWN GUY'S TOWER

On **Saturday 24th September** we held our fourth and final abseil down Guy's Tower. Nineteen brave people took part. Here's what they had to say about the day....

Debbie Hall and Tracey Wells, friends and colleagues of Trustee Jane Ward, abseiled along with 2 other colleagues, **James McGuirk** and **Michelle Walsh**. **Debbie** raised £470 and said, 'Well it was an experience and there were definitely moments when I questioned my sanity! However, I tried to focus on the money and all the great work you guys do and how my friends and family would never forgive me if I bottled it! Keep up the good work for the charity and many thanks for giving me the opportunity to feel like Spiderman for a few minutes!' **Tracey** was relieved to be able to say, 'I'm alive! I made £345 in total. Well what can I say: I'd been really nervous for the two weeks or so leading up to it, so when the day came I was a bag of nerves! It was a lovely sunny day and the guys from 'Over the Edge' were so laid back and friendly – they made me feel much better! It was all over (much quicker than I expected)!! I did manage to wave half way down to the crowd below, so it couldn't of been that bad!'

Melissa Adamou, aged 17 took part, and said the following about the experience! 'On the 24th of September I conquered my fear of heights by abseiling down the 469 foot Guy's Hospital Tower. I was absolutely

terrified on the day and I have no idea how I managed to do it! I raised over £300 for such a great cause! I wanted to do it because I knew that I was very scared of heights and doing the abseil would be a big challenge for me, which would be even more reason for people to sponsor! P.S I did enjoy it in the end and wouldn't mind doing some more abseiling in the future!'



Melissa Adamou

ECHO member **Emilly Carter** raised nearly £500 and said, 'I was the first down on Saturday and was rather apprehensive, but forgot most of that when I stepped out and saw the view - breathtaking! Thanks for the opportunity to give back something to ECHO as we have had support and made friends through the various functions like the Christmas party and the fab family conference day, it all makes such a difference, knowing we're not on our own'.

Harris Girls' Academy in Dulwich, put together a group of six staff and students to take part. To read more about the fantastic support we are receiving from the academy, turn to page 23.

Huge thanks to **all** of our brave abseilers and their friends and families who supported them.

Finally, I would like to say a big thank you to **Joanne and Paul Williams** for all their help in running the day.

Jessica Cattermole



The ECHO Abseil raised over £10,000!!!!
Over £5,500 of which was raised by Gary Ballard



Turn to pages 22 and 23 to read the latest ETC news!

Main photo: Gemma and Rosie see pages 18-21

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Kathy Turner, Area Contact for Surrey is holding a coffee morning at her home in **Epsom** on **Thursday 24th November**, 10am - midday, please email surrey@echo-evelina.org.uk.

New Area Contact for Suffolk **Angela May** is holding a coffee morning in **Sudbury** on **Wednesday 9th November**, please email suffolk@echo-evelina.org.uk.

Eleanor Beardsley, our Area Contact for South London, will be holding a coffee morning at her home in **Lewisham** on **Tuesday 22nd November**, 10am - midday, please email south.london@echo-evelina.org.uk.

I am holding a coffee morning at my home in **Brighton** on **Thursday 17th November**, 10am - midday, please email admin@echo-evelina.org.uk.

ECHO member **Emma Ormrod** has offered to hold an ECHO get together in Dobbies Garden Centre in Milton Keynes on **Monday 7th November**. She suggests meeting there at 11.30am for lunch at the restaurant at midday. For more information please email admin@echo-evelina.org.uk and I will pass your emails on to Emma.

The **ECHO Christmas Party** will be on **Sunday 4th December** 2-5pm at Millwall FC in London. Invitations will be sent to all members in November.



Dates for your Diary



ANGELA MAY

Hi, my name is Angela May and I am taking over as area contact for Suffolk. I am mum to

Holly, a beautiful 18 month old girl. Holly has an AVSD, Tetralogy of Fallot & Pulmonary Stenosis. She also has Downs Syndrome. Holly had OHS in February of this year and is doing so well. She is doing something new every day and never ceases to amaze me.

We found out at the 20 week scan that our baby girl had congenital heart disease. Initially she was written off and it was recommended we terminate the pregnancy. After requesting a second opinion we found ourselves at the Evelina Children's Hospital. What a difference! We were

given information about ECHO and I was able to talk to an inspirational ECHO mum. She let me ask lots of questions and answered honestly from her own experiences and those of her ECHO friends.

I will never forget how I felt after speaking to someone who was living in this alien world; she put things into perspective when the bottom had fallen out of my world. I would like to support others who are in that position or who have heart children and just want a chat or a cup of tea.

I would love to meet other ECHO members and would like to invite you to a coffee morning on Wednesday 9th November in Sudbury.

Angela May
suffolk@echo-evelina.org.uk

We would like to say a huge thank you to Teresa Buchanan who has been Area Contact for Suffolk for many years. Thank you Teresa, and love to you and your family.



ALEX BICKNELL

We are sorry to tell you that Alex Bicknell, ECHO Trustee with special responsibility for our ECHO Teen Club group (ETC) is stepping down from the ECHO board. He has been promoted by his company and will be moving to New York to take up an exciting new role within the organisation. Alex has been involved with ECHO for the past three years and has made a huge impact on our Youth services. His vision and drive have made a huge difference to the work we have been doing with our young people, and his empathy, understanding and fun-loving personality have made him a

firm favourite with not only our teenage members, but also the younger children too, who have all been excited about approaching their 11th birthday and being old enough to join ETC. We will all really miss Alex and his input on the Trustee board, but he's promised to keep in touch and come to any events which might be taking place during visits back to the UK! Good Luck Alex!



SUSAN BUXTON

As you will see from our ETC pages, we have a new Youth Development Manager. This is an exciting new role and

Susan Buxton joined the staff of ECHO on August 22nd. She has many years' experience working with young people and is really looking forward to

getting to know our own ECHO Teen Club gang. She will be sending out a newsletter to all young people aged between 11-18 in the next couple of weeks, so look out for exciting news, invitations and developments at ETC. We are all delighted to welcome Susan to the ECHO team and look forward to seeing how ETC grows over the next few years!

Emilia and Moving Forward



Emilia our brave little girl lost her battle for life in the summer. From the day of her antenatal diagnosis of Hypoplastic Left Heart Syndrome, Emilia has let everyone whose life she touched know she was a fighter. She was an inspiration to all. Her strength and determination to enjoy life was amazing. She made her family extremely proud.

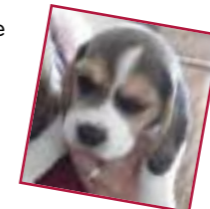
Emilia spent over 3 months this year at the Evelina, and was fortunate to meet and be cared for by all the wonderful staff, from Mary the cleaner to Mr Austin her surgeon. They ensured that Emilia's life was protected and the nurses on Savannah - Camel Ward, Clare Perrett (Play Specialist) and Alison Edgar (Ward School) brought many a smile to her day. We can not thank them enough.

I had spent those three months at the hospital, day and night, and I was taken aback by the generosity of care. I was more surprised and humbled though by how Emilia and many of the children I met coped emotionally with being in hospital, as

many parts of the day were not about being a child. There is already so much that is being done to try and protect the children and preserve their quality of life. However something was said by the Canon at Emilia's Thanksgiving Service that has made me look at how the future has to be. He said "look at what you have been given in life and think about how you can give back".

I have to give back and I have therefore set up a charity as Emilia's legacy named **Emilia's Little Heart Foundation**. Its aim is to protect and preserve children's emotional wellbeing whilst they are in hospital, by providing leisure and recreational activities, such as: creative arts; performances; and trips off the hospital site to the park etc. The fundraising has already started with: donate a book (boxes found on Beach and Savannah floor) - people donate their books and each one is sold for £1; a Golf Day; and a coffee morning. Emilia's Little Heart Foundation will be working in collaboration with ECHO. If you would like to see more the website is www.emiliaslittleheart.org.uk.

Just to let all those of you who knew that Emilia was being granted a wish for a puppy, that we granted her wish and Lulu the beagle is now very much part of the Webb family. Surprisingly and bizarrely, Lulu is like Emilia: she knows her own mind; enjoys spending time on her own but also likes a cuddle on the sofa with Dad.



Claire Webb



ECHO Family Day

On Saturday 18th June, we held our third ECHO Family Day at the Grange City Hotel in London, overlooking Tower Bridge and the Tower of London. The event was attended by over fifty families. Members enjoyed informative presentations, a buffet lunch, followed by afternoon workshops and then a three course

evening meal. While all the children were amused and entertained! It was a fantastic day, and a wonderful opportunity to learn, share experiences and socialise in a lovely environment.

I would like to thank **Amanda** and her team from **Creche on Location** for the great care given to the young children. **Alex, Melissa,**

Hannah and **John** for entertaining the older children so well. Our workshop facilitators **Melinda Edwards, Clare Perrett, Emily Ellis, Natali Chung** and members **Nick de Naeyer** and **Pippa Hodge**. Thanks also to **Mr Asif Hasan** and **Fiona Lynch** for their fascinating presentations.

Jessica Cattermole

A message for "ECHO" Grandparents

My name is Sue and I have a little grandson, Thomas, who is now 8 years old. Thomas is the eldest son of my youngest daughter, Liz, and her husband Leigh.



When Thomas was 6 weeks old he collapsed and was admitted to our local hospital as an emergency. After 3 days of tests and discussions with the Evelina, he was blue-lighted to the Evelina and diagnosed with critical aortic stenosis. This was a terrible time for us as a family, and as grandparents we had the double agony of watching our daughter and her husband coping with a critically ill baby, as well as watching our little grandson struggling for life. He underwent surgery and has made a wonderful recovery and now runs around like any other 8 year old.

I was very fortunate as a friend of mine had a "heart" grandchild and I was able to chat to her, which I found a great help. I think without that support it could have been quite an isolating and lonely place to be. For the past 3 years, I have been fortunate enough to accompany Liz to the ECHO family days. I think these days are very good in so many ways.

There are speakers in the morning, always on interesting topics, followed by a very nice lunch. In the afternoon, there are several workshops held, when you have the opportunity to share experiences or discuss various topics. Next year the plan is to hold a workshop for Grandparents. This would give an opportunity to share experiences of being the grandparent of a heart child

I would like to encourage you to come along to the next family day where you will have the opportunity to chat with other families and share experiences with other parents and grandparents. It can also be helpful to pick up the telephone and chat with someone who has "been there" and can in some way understand what you are going through. I have asked Jessica to pass on my number to any grandparents who would like a chat with me, and I hope to see you at the next Family Day in 2012.

Thank you Sue, for so kindly offering your support to ECHO grandparents. Any grandparents who have not yet joined ECHO and would like to, please join online at www.echo-evelina.org.uk or email me at admin@echo-evelina.org.uk. As a member you will receive your own copy of the newsletter and invitations to all our events.
Jessica Cattermole

IF YOU DO NOT RECEIVE REGULAR EMAILS FROM ME, PLEASE SEND ME YOUR EMAIL ADDRESS SO THAT I CAN ADD IT TO OUR NEW DATABASE JESSICA CATTERMOLÉ

Amber's story

At 41, I was glad to be going in to the Princess Royal University Hospital to be induced. My first born daughter was 2 weeks over due and had to be forced out, so why I had sat around since Christmas thinking this baby was going to be early I will never know as it was now three days before Valentines. The birth this time was a very different experience.

I had it quite bad first time round so when my second daughter finally made it into the world on 13th February at 22:22 I was glowing, ecstatic and yes, it did still hurt it but it was a far less stressful experience than last time. My first words when Steve told me it was a girl were, 'Thank god I never have to do this again.' (I had secretly wanted two girls). Then as always, luck is never on my side, the placenta got stuck! I ended up in theatre. Eight hours to deliver a baby, three hours to deliver a placenta!

Finally we got back on to the ward and quickly Steve said his goodbyes and headed home for rest. We hadn't yet decided a name from the short list and I promised I would by the time he returned. I held my baby all night. I wasn't able to do that with my first so stayed awake and enjoyed every second with her. In my head I only called her one name. She felt a little cold, so I kept us wrapped up in blankets and just looked at her all night. It was special. I had tried to breastfeed but with little success, she was trying.

The next day visitors came and went including her big sister who was over the moon she actually had the sister she had wanted so much. When Steve arrived at 11 am I was still deliberating over the name so I promised to decide by the time he came back at 3pm. I tried to feed again but this time she was too sleepy. My parents arrived at 2 pm and were having a cuddle when the Paediatrician came to do the usual baby check. Baby was ready to go, I wasn't! I had to be kept in for observation. Good or bad I can't ever be sure now. But what I am sure of is the fact that the doctor picked up the heart murmur was part one of saving my girls life. 'It happens in one in three babies. We have already had another one today; we just need to do some checks

up in SCBU. 99.9% of the time it's fine, so don't worry.' I looked at my mum raised my eyebrows and said, 'I feel like I have been read so many risks. Don't worry grab a coffee, see you soon'. Off I walked up to SCBU with the doctor pushing the cot for me. A slow walk and chat on the way, no emergency. Minutes later my world changed forever. We got into SCBU and a nurse started to run the checks by taking my baby's blood pressure. There was obviously a problem; I didn't know what but the next minute the nurse was waving an oxygen mask over my baby's face. In my naivety, I assumed she wasn't breathing, why else would she need oxygen? The nurse started to shout for help and said, 'Come on baby, come on baby.' I looked puzzled, shocked and as I started to realise something was badly wrong, they had taken her clothes off, she was in an incubator being wired up. I was saying, 'What's happening, what's going on?'.

I was feeling like jelly, my whole body shook from that minute on - I can't quite remember when it stopped. A doctor pointed to a flashing number on the screen. What I now know well is saturation levels; it read 38 and she said this number needs to double. I still assumed she wasn't breathing. They were putting wires and tubes all over her little body and I just shouted, 'I need my husband here'. It was terrifying. A nurse lead me to a phone I called him - voicemail, as always! I screamed, 'Get here now, something serious is wrong! I don't know what's happening'. I then phoned my mum. What a shock for them all too to receive those calls. My husband drove like crazy and left the car outside the hospital door. By the time he got up to the waiting room, he was as white as a sheet and I was a large jelly rocking back and forth pulling my hair, literally, saying, 'This can't be



Amber just before she needed her second catheter procedure. Looking like a very poorly Minnie mouse.

happening...why why why?' I remember physically shaking all over. Time stood still, looking back I wonder - was I too scared to stay with my baby? I would never leave her now. Was I just too scared or were we not supposed to be? I don't know.

We sat in the waiting room. Steve, my parents and I. The Dr and a nurse opened the door. I clung to Steve's arm still visibly shaking; I couldn't stop. They walked in the room, no eye contact. In slow motion they closed the door, turned around looking at the floor and sat down. Those motions and the silence seemed to last hours but it was seconds. I honestly thought, as did Steve, they were going to tell us our daughter had gone. They started to talk and told us very sincerely, the stress written over their faces our daughter was in fact in a critical state and seems to have a problem with her heart. Alive, alive, alive - is all I heard. The hours that followed were agonizing.

We were called in again to be told that a cardiologist happened to be on duty and had given her an echo scan. She had a blocked valve to her heart. At this point the doctor asked if we could give the baby a name to help communication. 'Amber Jayne' I said, without a doubt, the name I had called her all night in my arms. I remember thinking a blocked valve? Well surely that can just be unblocked? She's alive - it must be easy from here? How different was my knowledge then! The hospital had been liaising with St Thomas' who had advised to put Amber on prostin to keep her arterial duct open. They were sending a retrieval team to get her. Steve would have to drive across London as only one of us could go in the ambulance. I wanted to go with him. I was too scared to be in charge of Amber. I wasn't strong enough to

do this! Then I had a chat with myself. I am her mum; she needs me. She was inside me only hours ago and now she is in this scary world and surrounded by wonderful but scary doctors. I had to be strong, for her. When I next saw my baby it was hours after the oxygen mask incident. I was warned she was ventilated. She had tubes and wires all over, in every inch of her face and body. She was in a tiny bed, which I only describe as a box from outer space. I met Dr John Lily and the wonderful driver Kevin. I discharged myself against the advice of medical staff and made the journey looking at my very sick daughter, in a blue-light ambulance racing across London. This is when I started to realise the enormity of this - this is not a little problem; she is really sick. I was cold, shaking and terrified.

Once at St. Thomas' it felt almost instantly that we were told our daughter has a serious rare CHD called Pulmonary Atresia with intact ventricular septum. She also has a small hole. It took me four days to learn how to pronounce it properly. Dr Henry Chubb was so kind and understanding. He explained everything to us in a way that felt he had all the time in the world and what he was saying to us was the most important thing he had ever said. He also said something that we used to remind ourselves often and still do. He said it would be a roller coaster ride and Amber may get more poorly before she gets better. I am so glad he said that. He drew us a diagram of a good heart and then Amber's so we could understand it. He told us what could be done for her and the fact she was now stable meant we could get some rest to build strength for the morning. We held each other all night. It really was a living nightmare - something we repeated over and over in those first few weeks.

From that night, not hearing my phone ring during the night meant Amber was still alive every morning when I woke. We were actually managing to sleep through exhaustion. We were given a room at the Evelina for two nights and after that we decided to commute in daily while she was in PICU. We met Dr Krasemann who talked through the catheter procedure he would do. The plan was to open the valve with radio frequency perforation and widen with balloon valvotomy. Then to put a stent in her duct to keep it open, to allow blood flow to the lungs in a palliative way. As she grew she may or may not need it, there were options and lots of wait and see. We were with her as much as possible until the Friday of her operation. She was so tiny and helpless and we felt helpless too but all we could do is be there, try and understand what she had and what was going on. Initially, we had kept saying that although it was a horrific

shock to find this out after giving birth it wouldn't have changed it if we had known sooner so therefore didn't matter. Over time, our opinion has changed and we now know that it would have helped to a degree to be able to cope a little better. Whenever you find out, it would be a horrific time but having to deal with everything in one go - the birth, the shock, the condition, PICU and what was going to happen was an enormous trauma. I kept family up to date by text. We were too emotional to speak.

The first time we saw our older daughter she just said, 'Where's my baby, mummy?' I broke down. I just kept crying and crying. I felt like I was the only one falling apart in there but



A chubby Amber, now six and a half months. Sitting up and rolling over already.

realise now that was impossible. Every heart parent is breaking if not outside then inside. You crumble from within and just learn to hold it in with time. I call them my waves of emotions. I got so many a day back then, when reality would surface at unpredictable times. The first time I had to walk in the house without her and see all her things, I literally covered my eyes. I honestly didn't think we were ever bringing Amber home. I didn't know how we would ever get over this. I spent four days wishing it wasn't happening, thinking why me, why us, what did I do. But then something clicked, a chat with myself and I realised she is our baby, not the doctors. She needs us as much as we needed her. Dr Krasemann had said she is a child before a patient. We realised this is it, now let's deal with it for Amber's sake but one stage at a

time. We told ourselves not to think further than the next event otherwise we would lose our strength. The ifs/ buts/ maybes were too vast to even start to comprehend and still are. Today and tomorrow was as far as we could get. So the focus was her op, one step at a time. Everyone had questions for us beyond but we just kept saying one thing at a time. Amber couldn't cope with anymore than that. We couldn't cope with any more either.

The day of her operation was horrific. We had her baptised and then watched her be sedated and said our 'goodbyes' - a horrible choice of words, I was desperate to think of an alternative. Seeing her ventilated again was treacherous. We were told it would be

about three hours. We decided not to stay in the hospital. We ended up walking to Waterloo station and sat in Burger King reading the papers. It sounds a little bizarre but it helped our minds to keep ticking and stopped us going crazy. I read every paper front to back. I read each article in detail but realised when I had closed the paper I had not taken in a single thing. The news seemed strange. It felt like I was looking at things that had taken place months ago yet it was only five days old. The clock was ticking; surprisingly the first two hours went quite quickly. We started to have a slow walk back to the hospital. It felt like my feet were walking in thin air. I couldn't really feel my legs or the pavement beneath me. Once we got back we expected a call on the hour but we didn't get it. That extra hour was like torture. My insides

were twisting and cramping; my head was thumping, my heart was in my mouth. I was having a 'wave' every second. Finally, after four hours we got a call to say she was back in PICU. We both moved like lightening to get back in to her. She was OK! It went well. Dr Krasemann was pleased when he went in and believed her right ventricle was a good enough size to function by itself. He hadn't put in a stent! This was a big shock as we hadn't expected it but really good news. It meant her heart was functioning in a corrective manner. Just the valve would never work, but it was now open allowing blood flow to the lungs. She was still on a little prostin but this would be reduced and stopped over time. We were elated. Our Amber was so strong, a superstar. She got through it.

The next few days, we experienced the real roller coast ride Henry had warned us about. The 'waves' were still hitting me frequently. The enormity of what we were dealing with. They tried a few times to take Amber off the prostin but each time she seemed to still be heavily dependant. She was a cannula



Amber 17 hours after birth

nightmare and had to have at least one if not two a day changed. We were watching them like hawks. It made a huge difference to her sats. Once one started to fail, we knew her sats would drop. We sat watching those machines, as you do, day and night. We would have a level day and it felt good. I got to the point where I knew feeling good meant a crash was coming. That's how it went for days. Up and down. On the following Saturday after her op, she had a very level day. The four of us had been together at the hospital going through the routine. We had realised this was going to be life for a while. Steve was going back to work, Sienna was home and going back to school. We were given the indication this could be weeks. The doctors just didn't know, it all depended on Amber. Steve took Sienna home for tea and I stayed. I had planned to go home just so we could be with Sienna. Amber was on HDU so well looked after and she was OK. Then a terrible incident happened in the bed next to

me. At the same time Ambers sats started to drop and I was stressed, tired and assumed it was a cannula situation. I left for home eventually when I thought she was OK. Too late to be together for Sienna. When I got home I said to Steve she looked really grey (Amber never goes blue) and translucent. I then felt bad for leaving her but was traumatised and tired.

We got a call first thing to say Amber had gone back to PICU as her sats had dropped too much and the prostin had to be increased. She was up and down, literally that day from the ward to PICU but eventually we left her looking poorly on PICU that night. We had a call while sleeping that Sunday from Henry Chubb to say Amber was needing more and more prostin so she would need an urgent op in the morning to put the stent in. We have remembered this so many times and realise someone else lost their slot for her, thank you.

9am the following morning Steve dashed to the hospital. I sorted childcare and drove like crazy to get there. We sat with our girl. She looked terrible. So grey, shaking, she was now on the most prostin she had ever needed! The duct really was trying to close and fighting against the medicine. Off she went again. We felt a little better than the last time, if that is possible. We spent the three hours 'reading' papers again. Again the first hour went quite quickly, the last was agonising. The 'waves' coming thick and fast. I must have said 'please god' to myself about a million times. We got the call again and Dr Kraseman came to find us to say everything was good and Amber was coming round - phew, a relief. I kept our family up to date again via text. I did worry about everyone else. I had read in some literature that your parents feel about you the same way you feel about your own child. We knew that we were living this nightmare by second. Our families were sitting at home knowing nothing for hours. And then it was just a text. However we couldn't speak, it was too hard. We just about managed it with each other without breaking down. The texts gave me a job, a purpose and I felt I had to keep them informed as they loved and cared just as much. What happened in the next few days was remarkable. Amber's sats were high 90's, she was back on the ward in no time and with no tubes! She was monitored but it was obvious everyone was pleased with her and then they talked of home!! I wouldn't believe it until it happened and kept pessimistic so as not to build up my hopes. When the word was actually said for the first time we were ecstatic. However, reality meant no nurses, doctors, machines and we were nervous.

Amber had her first taste of fresh air at three

weeks old. It was a momentous occasion. I know we couldn't quite believe how quickly it then happened. As excited as we were anxious, the waves kept coming. This was not the homecoming we had expected, she is still ill, it will never go away, ever. However she was coming home and we have learnt to enjoy what we can. Having us all under one roof seemed like a distant dream at one point. When it actually happened I think it was the best day of my life. However, it came with terrible anxiety and checking her hands and feet to see if they were blue 100 times a day. We had our regular appointments at the great Evelina and all was good. Dr Krasemann had said after her first op that her valve may need re ballooning as she grows. This has happened and Amber had her third catheter procedure at five months. It was just as agonising, if not worse than the first two, as a different bond had formed but our superstar came through it with flying colours and was home before we could have imagined.

The roller coaster continues, it just gets easier with time. I only check her a couple of times a day and don't think of her heart every time I look at her now. I still have waves, anything can trigger them and the hard ones are when you least expect them. It's not about us though; it's about Amber. She has done all the hard work. It is her life of ifs/buts/maybes she has to face.

She is off Asprin now, this will close off the stent and allow her heart to function in a corrective manner. We are just waiting to see if that happens. We don't really know what's next for her until her heart develops more. We manage to live a normal life on a day to day basis so couldn't ask for more. Because one thing I know for sure when I see her smiles and hear her laughing with her sister-I would never swap her for anyone. She isn't just our heart baby, first and most importantly she is our Amber Jayne Florence, the special heart always comes second. She's the biggest inspiration and motivation in our lives

Thank you to everyone at the Evelina that has played a part in giving Amber a chance of a life. I will be attempting the 5k Hyde park fun run on Sept 11 th to raise money in support of ECHO - in my darkest hours and times of need I don't know what I would have done without the message board.

The beginning...

By Jo Rowe

Happy events and children's milestones

This is your opportunity to share your children's milestones and happy events. Thank you for sending such lovely photos and news.

Florence Embden sent this wonderful photo of her daughter Freya on her first day at Manor School in Uckfield. Florence says that she is loving it!



Freya

Amanda Prentice sent this photo of her daughter Lucy, aged 4, who started full-time school. In the photo Lucy is holding a spider called Mavis. Amanda said that Lucy is terrified of spiders so it was a major achievement for her, 'having small hands, she did the job perfectly!'.



Lucy

Neil Loughnane sent these pictures of his sons, Thomas and Connor, on their first day at school and nursery. Thomas started at St Fidelis Catholic Primary School on Thursday 8th September and Connor started at Little Stars Nursery on the 12th September. Neil says, 'Thomas makes his parents proud looking smart on his first day at St Fidelis Catholic

Primary School. His little brother Connor also brings a tear to our eyes ready for his first day at Little Stars Nursery.'

Our Treasurer Joanne Williams sent this lovely photo of her son Henry on his first day at St. Mary's Infants School in Baldock, she says he seems to be enjoying it so far!

Laura and Ben Cox sent this wonderful photo of their daughter Florence on her first day of school, with big sister Tilly. Floss had corrective surgery for TGA at 7 days old and has been fine since. She has settled well at school.

Eleanor Beardley sent this lovely photo of her daughter Elise, taken on her first day at her first day at Gordonbrock Primary School, SE London.

Jessica Cattermole



Thomas



Connor



Henry



Florence



Elise

SAFE AND SUSTAINABLE UPDATE

This is the latest news from the Safe and Sustainable review into Paediatric Cardiac Surgical Services in the UK:

An independent report has found quality is the public's top priority when it comes to shaping the future of children's congenital heart services. The report, compiled by independent experts, Ipsos MORI, on behalf of NHS Safe and Sustainable, provides a detailed analysis of more than 75,000 responses to a national consultation, one of the largest ever carried out by the NHS. The consultation included a large number of responses from the BME community (20% of total formal responses) and from children and young people (10% of total formal responses).

During the consultation, which ran from 1 March to 1 July 2011, people were asked to share their views on the key principles of the review, four configuration options which would pool surgical expertise into fewer larger centres, the development of congenital heart networks to bring care closer to home and new national quality standards.

The report demonstrates strong support for the key principles of the review and nine out of ten support the proposed national quality standards. There was significant support for ensuring excellent care – of those who responded 93% of individuals and 94% of organisations support these standards. An extremely high number of respondents supported the proposal to improve the collection, reporting and analysis of mortality and morbidity data – of those who responded, 85% of both individual respondents and organisations agreed with this proposal.

There was a strong belief among many respondents that quality should be the deciding factor when planning future services. People were also positive about proposals to develop

congenital heart networks that would deliver care closer to home - more than three quarters of both individual respondents and organisations supported this proposal. There was also significant support for the proposals that centres no longer providing surgery become children's cardiology centres.

Also, A report which was published recently concluded that children's respiratory services, including cystic fibrosis services and asthma services, would remain viable at the Royal Brompton Hospital if children's heart surgery services were moved to the Evelina and Great Ormond Street, as per the recommendations put before the decision making body, the JCPCT (Joint Committee of Primary Care Trusts). Contrary to the hospital's allegations about the impact of the Safe and Sustainable proposals on some of its other services, a panel of independent experts has unanimously agreed that children's respiratory services could continue to be delivered safely in the absence of an on-site paediatric intensive care unit (PICU).

The JCPCT is expected to announce its final decision by the end of 2011. Any changes to the provision of children's congenital heart services are expected to be implemented from 2013. A detailed implementation plan will be developed once a decision has been made.

For full information on the above reports and regular updates on the progress of the review, we suggest you visit the Safe and Sustainable website regularly: http://www.specialisedservices.nhs.uk/safe_sustainable/childrens-congenital-cardiac-services. In the meantime, as soon as we are informed about any final decisions we will communicate via email and a link on our own website.

Jo Wilson

FLU JAB TIME!

Yes, it's that time again... as the nights draw in we will all be turning our thoughts to avoiding and preventing coughs, colds and the dreaded flu virus. The general advice for parents direct from the Dept of Paediatric Cardiology at the Evelina are:

Current recommendations:

Flu-jab: recommended for cardiac patients with untreated or complex congenital heart disease.

Pneumococcal vaccine: now part of the standard immunisation schedule but essential to vaccinate and boost all children without a functioning spleen and with immunodeficiency associated with their cardiac disease.

RSV-vaccine: Only recommended for most high risk patients identified by the consultants.

Please visit the ECHO website for full details and recommendations and information:

<http://www.echo-evelina.org.uk/information/flu-jabs/>

WISH LIST PURCHASES

We have recently bought the following items for the Cardiac unit at the Evelina :

- 2 I-Pads for Savannah Ward (one for younger children, and one with 3G internet access for teenagers)
- 1 I-Pad for PICU
- Coin operated lockers for the parents' room on Savannah (with the very generous assistance and a donation from member Paul Mather and his company "Locker Storage Solutions").
- We have also provided funds for Jane Sivyer, Play Specialist on PICU to attend a training course on providing massage for babies and children, so that she can in turn teach parents various techniques to encourage calming, relaxation and bonding.

We are currently looking at the provision of various other small items of medical equipment which will be to the benefit of children staying on the ward and also to families in general once their child has been discharged. Details to follow in the next newsletter.

WHO'S WHO ON THE CARDIAC UNIT AT THE EVELINA, AND HOW TO IDENTIFY THEM!

Feedback from our Summer Conference and Family Day suggested that parents find it quite confusing to identify who's who on the Cardiac Unit at the Evelina and particularly which uniforms are worn by particular staff. We thought we'd try and help by producing a simple guide:

SAVANNAH WARD STAFF

Matron	Debbie Komaromy	Black uniform
Sister (acting)	Emily Ellis	Navy Blue Uniform
Senior Staff Nurses		Mid Blue Uniform
Staff Nurses	Ten in the team & counting!	Light Blue Uniform
Student Nurses		Light pinstripe Uniform
Health care assistants		Light Grey with blue trim
Clinical Nurse Specialists (Outreach)		Dark grey with white trim

CLINICIANS

Lead Clinician	Professor Shakeel Qureshi	
Surgeons	Mr David Anderson	Green "Scrubs" when operating

Cardiologists	Mr Conal Austin Mr Caner Salih Dr. Philipp Beerbaum	Dark Red "Scrubs" for procedures
	Dr. Aaron Bell* Dr. Gerald Greil Dr. Thomas Krasemann Dr. Owen Miller* Prof. Reza Razavi Dr. John Simpson* Dr. Gurleen Sharland – Consultant Fetal Cardiologist/Reader	
		*also Fetal Cardiologist

Registrars		Dark Red "Scrubs" for procedures
Play Specialist	Clare Perrett	Purple shirt/tee shirt

PICU – Same colour coding applies to Clinicians/Nursing staff/Play Specialist

In the next issue of the ECHO newsletter we will explain more about the different roles of the staff on the Cardiac Unit.

ECHO FUNDRAISING

Adidas Women's 5k Challenge - Sunday 11th September!!

Thank you to all the runners who took part in the Adidas Women's Challenge to raise funds for ECHO. ECHO member **Jo Rowe** took part and wrote the following....

'My sister and I looking red faced after completing the 5k Hyde park fun run without stopping! Having never jogged more than 3k, we shocked ourselves. The motivation was that we raised £1500 for ECHO. A small way of saying 'Thank you'. At 4k I said never again, however my sister is keen to keep running, we shall see after my back has recovered!'



Jo Rowe and her sister

Thank you to you and your sister Jo! To read Jo's daughter Amber's story turn to

pages 4-6.

And ECHO member **Zoe Huxley** wrote this account of the day.

'On Sunday 11th September, I stood in the warm Autumn sunshine surrounded by lots of amazing women ready to run the Adidas Women's 5K Challenge. The atmosphere was fantastic and everyone was so friendly. It didn't feel like a race but a huge get together of strong women who wanted to run/walk to raise money for their chosen charities. Everyone had a story and everyone was running for someone or something very close to their hearts. Many women created a real carnival atmosphere dressing up in brightly coloured feathers, ra ra skirts and even as 118 men with moustaches! I proudly wore my gleaming white ECHO T-shirt.

It was time for the warm up and 8999 ladies and myself jumped around to some very uplifting music. All raring to go we then lined up for the start. I must admit I did have butterflies in my tummy as I jiggled around waiting for the start. Following a minute' silence in memory of

9/11 we were off. I decided I was never going to catch the likes of Liz Yelling, former Commonwealth bronze medal winner and Justina Heslop, England 5000m champion so I set off at my own pace. Music played, people cheered and Hyde Park sparkled. The course snaked round Serpentine Road and Speakers Corner but as I battled through the wind and that final hill, the end was in sight! I felt great crossing the line under the huge time clock and I managed to finish in 24.04 minutes. The best feeling was I had raised some money for a cause very close to my heart.'

Zoe raised over £200. Thanks Zoe!



Fundraising

Thank you to all of you for your kind donations and wonderful fundraising over the last few months. We have received so many contributions that I am not able to thank you all, but here are a few that I thought I would share with you.



Jessica accepting a cheque from Lana

£200 through a cake and sweet sale. We also received a further £67.20 from a collection made on their Founders Day for Chaucer College.

2nd Crofton Guides held a Friendship Fayre and raised a fantastic £67.55. There were a number of stalls including soak the leader, and name the teddy. The guides voted for ECHO themselves after one member explained the work we do. Thank you girls!

ECHO member **Hannah Wilson**, raised £2312 and a further £380 on Justgiving through holding a coffee morning at her Parents in Law's home. Her event included a raffle, cake stall, handbag stall, name the teddy etc. 'We were blown away by how many people supported us and helped to make it such a success.' said Hannah. Her son Jack had open heart surgery at the Evelina in March, 'three months on and he seems to be recovering well, so fingers crossed he can look forward to life with a healthy heart.'



Jack's information table at mum Hannah Wilson's event

Thank you to **Dover Grammar School for Boys** for their fundraising activities raising £100 for ECHO. Events took place from Valentine's Day through to Easter with

donations being split between 6 charities. A non uniform day contributed a large sum, but students also made cookies and sold them around the school dressed as 'love fairies'. As well as stalls there was a range of raffles and competitions. Thank you to ECHO member **Amanda Monk Peak** for nominating ECHO.



Paul Quinn and his grandson, Callum

Thank you to **Paul Quinn and his family and friends** for their kind donations totalling over £1400 in lieu of gifts for Paul Quinn's birthday. Paul's grandson, **Callum Howarth**, is treated at the Evelina and is progressing well. Thank you also to the **Windsor Castle**

who also raised £50 in gratitude of the treatment Callum has received. Callum's mum **Claire Howarth** wrote the following. 'My little boy Callum was born on the 6th July 2009 and two days after birth was diagnosed with Hypoplastic Left Heart Syndrome and a few other complaints. We were transferred to the Evelina, from Manchester where Mr Anderson worked a little bit of magic but we did stay with them for approximately a month. We have also had the Hemi Fontan performed by Mr Anderson in November 2009 and are due to be back down there for the final stage in the not too distant future. We value all the support we have received from ECHO and will support the charity as much as we can.'

Member **Lucy Salmon's** friend **Rachel Bromley** ran the Bedgebury 10km for ECHO on 14th May and raised £385. Thanks Rachel!



Lucy's brother Tom holding Lucy's son Ashton, with Rachel Bromley and Neil Wyborn

Thank you to **Grace Community Church** for their kind donation of £700.

ECHO member **Kerry Funnell** raised a wonderful amount at a Fun Day held at her local pub, the **New Inn in Murston**, and donated half, £560, to ECHO. Thanks also to the **Sittingbourne and Milton Ladies Dart League** for raising £210 by holding a knock out darts match, to help Kerry with her fundraising

A close friend of ECHO member **Zoe Huxley**, **Emma McDiarmid**, ran the Edinburgh Marathon and raised a wonderful £638, through both sponsorship and by organising a coffee morning and raffle.

Elissa Holloway, ECHO member and volunteer, has been very busy fundraising for ECHO. She wrote the following update on her fundraising efforts!

'My friend **Caroline** was inspired to kick start our fundraising for ECHO when she came to visit us in PICU at the Evelina. She already knew we'd been through/were going through a lot but seeing us in PICU really hit her. Since we've been home she has allowed her house to be invaded by mums and kids by hosting two very successful coffee mornings raising nearly £500! Thanks



Elissa's fantastic fundraising!



Lee, Jack and Theo at the end of Day 1

to **Caroline** and all the bakers, (especially my mum and sister **Leanne**) this has been an amazing start to our fundraising campaign! **Caroline** has inspired another hostess, **Donna**, who hosted another coffee morning raising £260!

Theo's dad, **Lee** and brother **Jack** (15) have done a 50 mile sponsored walk over 2 days (16th & 17th July) to raise money across 2 charities, one being ECHO (the other **medicinema**). **Lee** works in the event industry so to attract sponsorship via business contacts they walked the 50 mile route from Farnborough's event venue, **FIVE**

to **Earls Court** in London along canal and river paths. They raised £500 for ECHO.

Finally, (for now anyway) another friend of ours, **Kyrsty** is the owner of our local (fleet) **Specsavers**. They like to run a charity event every year and this year they've chosen to work with me and **Theo** to raise money and awareness of echo. The event was held on the 27th August in store and was a day of family friendly activities like guess the number of sweets in a jar, a raffle etc, staff dressed in red and white and all personally baked cakes for the raffle! We raised £188.

So in total since March we've raised just over £1500 and now we've got the bug!

Huge thanks to you **Elissa** and to your friends and family for all your efforts.



Hannah's mum, Pauline Moynihan with the captain of the winning team

Thank you to **Verity Hoffman** and friends for holding a charity football match in memory of **Verity's** sister **Hannah Moynihan** on Sunday 1st May which raised a fantastic £2070. We also received many generous donations from **Hannah's** family and friends

when she passed away last September. **Verity** said that the charity day was a huge success and they had agreed to make it an annual event. The photos we have used are courtesy of **Danielle Emmerson**.



Memorial Day for Hannah

Sam Gubb's grandparents, for the second year running, held a charity BBQ on their farm in Devon and raised a fantastic £1,000. Thank you to **Sam's** grandparents and family for their continued support.

Thank you to **Yeliz Kasif** who won a jewellery making project last year, called **B-original**. **Katia Correia** from **Lilian Baylis Technology School**, said that **Yeliz** had won for her tenacity and great achievement. **Yeliz** asked that all profits from the project should

go to ECHO for the help she received when she was younger. Thank you and Congratulations **Yeliz!**



Bizz Thackray

Bizz Thackray is a good friend of **Cissy Adamou's** grandparents, and over the past few years she has become a good friend to ECHO too. She has raised over £500 from the proceeds of **Phoenix card sales** and most recently from a sale of beautiful scarves.

Thanks go to **Bizz** for all her hard work and support!



Cissy and Holly

Angela May's friends have been raising funds for ECHO.

Jaena, **Angela's** best friend, and manager of **Anglia Sunshine Nurseries** raised a fantastic £300 at their summer fete. Also **Angela's** friend **Lesley** who works at **Westchester House Nursery**, also raised

£300. **Jo Wilson** went to collect the cheque and wrote this about the day. 'On Wednesday 7th September, **Cissy** and I were lucky enough to visit **Westchester House Nursery** school in **Farnham, Surrey**. We had a lovely tour of the nursery, met the teachers and children, and were then presented with a giant cheque for £300 which the nursery pupils and staff had raised for ECHO. **Angela May** and her scrumptious **Holly** had introduced ECHO to **Lesley Hurst** the Deputy Nursery Manager, hence the donation, and were there to help us collect the cheque. Many thanks go to the management, staff, pupils and parents from **Westchester House**.'



Jo accepting cheque from Westchester Nursery in Farnham

Read more about **Angela's** new role for ECHO on page 2. **Jessica Cattermole**

Isaac Rush's story

I felt like I had pulled off the best stunt ever! I had just had a baby and no pain! I had dreaded the birth so much I had left a gap of 5 1/2 years between my two boys.

Because of the trauma around my older boy, Louie's birth, I was induced at 38 wks, with an anaesthetist standing by when they broke the waters. And only 3 hours and 8 minutes after they did break the waters, Isaac Ruben Freddie was born at 1 o'clock in the morning, on January the 15th 2010, weighing a healthy 6lb 13 oz. My husband Gavin and I were delighted. Isaac screamed a bit, just to liven the atmosphere, then settled quietly in my arms feeding happily if only for a brief while. As I was moved to my room the midwife noticed that he was 'grunting' a little. "He just wants feeding"...she said.

So I did my best for the next 16 hrs but he was mainly tired and wanted to sleep. The nurses were not too worried, they just said he obviously needed to sleep and would eat when he was hungry. I could see the same pattern as with Louie, and he was healthy and had no problems at all when born. So I had no reason to think anything was wrong.

I had hoped that they would let us come home that same day, but I had Group B strep when Louie was born. Because of this and that they hadn't had time to give me enough antibiotics before Isaacs birth, I was asked to stay overnight just to be sure.

I was reluctant and Gavin and Louie were very disappointed, but something told me that I should stay. I probably would have gone home had I not been fortunate enough to have my own room.

If we had insisted on going home, we would have lost Isaac that night. I have since that moment learnt to listen to my gut feeling...no matter what.

When the night shift of nurses came to say hello, I was just changing Isaac and had thought that wasn't it amazing that for someone so little, that hadn't eaten very much, he had such a big, round belly... One of the

nurses asked about his little noises he was making and I replied that we had been chatting on and off all day when he had been awake. Still thinking nothing of it. She asked if I would mind if a paediatrician from neonatal came to have a look, just to make sure all was fine. Five minutes later he was there, he had a quick look, left and came back after only a few minutes with another doctor....

I was told Isaac had to be moved to neonatal immediately!! The walk down the corridor took maybe 2-3 minutes, with Isaac in his cot under several blankets & a big woolly hat...when we arrived there his temp had dropped by almost 2 degrees. They very quickly got him in an incubator and put him on CPAP as his oxygen levels were low.

I couldn't understand what was happening...I stood there like a lost soul, clutching his baby grow that they had taken off him as they put him into the incubator.

A nurse came and put her arm around me and said that they thought that he might have a chest infection and they needed to stabilise him. Also then to do some chest x-rays and tests on him. I was told to go back to the ward and try to get some sleep....

I locked myself in the toilets just outside and rang Gavin. I don't think I made much sense, I was sobbing on the phone, distraught that Isaac might have a chest infection and maybe need a drip....little did I know...I did manage to get some sleep, somehow...

When I returned to neonatal first thing in the morning and was met by the doctor and a nurse they said, "We were just coming to get you. Let's go into this side room...." I just knew that something was really wrong at that moment!!

The doctor explained that they had found a very enlarged heart and liver when they had done the chest x-rays. She explained that



they had nearly lost him that night as his heart rapidly seem to be failing. By this time I found it hard to actually take anything in. What was happening? Nothing in my pregnancy had indicated that something was wrong. Yesterday, I had a healthy if yet a very sleepy baby in my arms or so I thought...I just wanted Gavin there with me. She explained that Isaac needed to be transferred to London (from our local hospital in Surrey). And that the South Thames Retrieval Team from Evelina Children's Hospital were on their way to us already.

One of the nurses rang Gavin and told him not to be worried but to get to the hospital as fast as he could without breaking the law....needless to say, it didn't take him long to get to us.

By the time the doctor had told Gavin everything she had explained to me earlier, the ambulance had arrived. Isaac was at that point so poorly that it took them over 2hrs to stabilise him enough to have a chance to manage the journey. He had been put on a ventilator in the night, and had lines going into both arms and feet. He was blue and terribly puffy. We were

beside ourselves. Luckily there was a space in the



Mimmi and Isaac



ambulance for me. Gavin said to the ambulance driver, "I'll follow you!" but the driver just shook his head and said, "No mate, I'll give you the postcode, you won't be able to keep up".

The retrieval team Sarah and Jo, were fantastic!! Making sure I was ok while keeping an eye on Isaac and all his monitors. And so was the ambulance driver, who's name we unfortunately never got.

That was the worst journey in my entire life. They had warned me about the sirens and that it could be a bit bumpy in the back, it was, but it was nothing compared to the low beeps and bleeps from all of Isaacs machines. It was all I could hear.

We made it up in 40 minutes going through every red light possible. Up on curbs and central reservations....It took Gavin 3 hrs....I had no idea what to expect. I can just remember feeling so terribly lost and out of place.

Once in PICU, there was suddenly at least 15 doctors and nurses swarming around Isaacs tiny little body. Somebody found me a chair and I just sat there watching in disbelief...I was watching somebody trying to put a line in his neck, struggling as he was so very poorly, she looked up and I realised that it was Jo from the Retrieval Team...She looked concerned but reassured me she was doing her best, and then asked the nurse next to her if anyone had seen if I needed anything.

Someone came up with a cup of steaming, sweet tea and asking if I was in pain...What did she mean about pain? I suddenly remembered that it was only 1 day ago I had given birth... I hadn't even been discharged from my local hospital before getting in the ambulance.

They didn't have the painkillers I needed, so one of the nurses got money from her own pocket and went down to the pharmacy and bought some. Everyone was so fantastic and cared so much for me as well as Isaac...I couldn't quite believe it...

Gavin joined me 2 1/2 hrs after I had first got there. I don't really know what happened that first afternoon and evening in PICU. I was just trying to take it all in. There were so many names and faces, trying to find out what was going on with Isaac. So many questions. Had I been unwell in my pregnancy? Did we have heart problems in the family? How had the birth been? Had they not mentioned anything on my 20wk scan? We had no answers that would shed any light on the situation. It all seemed a mystery.

Dr John Simpson was one of the Consultant Doctors on duty that weekend. He explained to us that -There was nothing wrong with the "plumbing" of Isaac's heart.... He was not in need of immediate surgery....Up until that time surgery hadn't even crossed my mind...I got so scared at that point-Heart surgery!!!

I think that was one of those moments when you just go-Aahhhaa! And the penny drops. That's when we really and truly understood how serious it was...Because even if he didn't need surgery, the enormity of what was happening was just dawning on us. Up until less than 24 hrs earlier we thought we had a totally healthy newborn baby.

At that point in time, they were mainly concentrating on getting Isaac stable, stronger- and surviving. They had seen on the echo that his heart was massively enlarged, it wasn't functioning well at all. They thought there was a clot somewhere in his heart, hanging on a thin thread, threatening to come loose and cause untold problems. And his liver was also very, very enlarged.

Isaac was ventilated, they had finally managed to stitch a line in his neck so he could have a special drug going in via a long tube almost straight into his heart. Connected to that was something I can only describe as a "spaghetti-junction", resting next to him by his head. It was one of those connections where about 6 lines went into the one main one...I was horrified. It took me a day or two to realise that it was less invasive as they could both take blood and give medicine without any further pain caused to my little baby.

He also had lines in both arms, a catheter... I was afraid to touch him. And at the same time all I wanted to do was to cuddle my baby, keep him warm, feed him and get to know him. But he was stripped down to his nappy, on nil-by-mouth and it was breaking my heart.

He was put on Milrinone and Dopamine straight away, together with high doses of Morphine, Furosemide(diuretics), potassium, aspirin and a sedative. And a few other things that now escape me, but he had 12 infusions going in to his little body within hours of arriving to Evelina. Isaac was so critical that we got one of the bedrooms on first floor of the hospital. So that we could be near at all times.

It was getting late and Isaacs lovely night nurse told us to go to our room and try and get some sleep and rest. Some one said to Gavin as we both hesitated, "Don't worry, go and get some sleep, we will call you if there is nothing else we can do..." I don't need to say, we didn't sleep very well. But we were both exhausted. It had been a lot to take in the last 4 days. Gavin's granddad, Fred, had passed away on Christmas Day and the funeral had been on the Wednesday. It had been very emotional. Thursday morning I was in hospital first thing, booked in to be induced. The induction hadn't started until late Thursday afternoon, so consequently Isaac wasn't born until early hrs of Friday. And as most mums will know, a maternity ward is hardly the place for catching up on sleep? Your own room or not.. And then the all the commotion started on Friday eve... Not the greatest build-up for coping with terrible stress.

In the morning when we got back to PICU, Isaac looked so unwell. He hadn't had a very good night, but he was a bit more stable. One of the Doctors came and spoke to us after the morning rounds. She was very direct in telling us exactly how ill Isaac was. They hadn't really expected him to survive the night. But she told us that they were very pleased that now they could "think in hrs" instead of "10 min slots"...That was positive, but very hard hearing.

Then our lovely nurse for the day, Harriet, said hello and showed us Isaacs hospital diary that they had started for him. Well that just blew me away. I couldn't read it without breaking down for a good few days. It is just such a wonderful thing for the staff to do... There were photos and the loveliest little "stories" from the nurses to Isaac.

As we had another child at home, Gavin had to leave later that day. It was so difficult, but it made me have to start taking everything in. So that whenever we spoke, I could tell him exactly what was happening.

My family is in Sweden, where I'm from, so I tried to get everything right, every comment, diagnosis and all medication, so that I could in long late night talks with my mum tell her what was happening. She would sit with Wikipedia and a big Medical book and translate it, and try to make sense of it all. Only to then have to re-iterate it to my dad who was away in Newfoundland on business.





Gavin, Isaac and Louie

Isaac was diagnosed with Dilated Cardiomyopathy, which meant his heart was very enlarged and not pumping anywhere near strong enough to support his body, his liver was thankfully only enlarged because of his poorly pumping heart. Fluid was trickling back through his heart and ending up in his liver. High doses of diuretics and keeping him on as little fluids as possible made the liver go back to what it should be within just over 4 days. His heart wasn't responding in quite the same way unfortunately. Daily scans showed very slow improvement, the right side a little bit more than the left.

We had been told right from the beginning that it was only a 40% chance that they would find out what had caused Isaac's Dilated Cardiomyopathy. So for the moment they could only medicate and see how Isaac reacted. Tests were being taken and sent to all around the country, and the world... We could only wait and see if anything came back positive.

Meanwhile, we found ourselves in a very surreal routine. Gavin came to hospital every other day, staying with me and Isaac and then going home to look after Louie the other nights. When Gavin was with me at Evelina, his dad looked after Louie. All our family rallied around to make Louie's life as normal as possible. And as much as he missed his mummy and knew that his precious new baby brother was in hospital desperately ill I honestly think he wasn't that affected by it all. It was a bit of an adventure having grandad for sleepovers every other night. Nana and Aunties taking him to school. And being spoilt rotten by everybody.

Slowly Isaac started to improve. I got to hold him for the first time since he arrived at Evelina. 3 days I had waited, and it was lovely! I felt like his mummy. Finally I could cuddle him and keep him warm (if only for a short while at a time). I still was not allowed to feed him, his heart was not strong enough to deal with eating and digesting food. He got really bad jaundice and looked like he had "been tangoed", and had to spend 2 1/2 days, naked, under phototherapy lights. Like he hadn't had enough at that point.

But he started to show us and all the Doctors in PICU just was he was made of...They were amazed to see the improvement he suddenly was making. After 4 1/2 days he was strong enough to come off the ventilator. I was so scared because every time they had disconnected the apnea machine to see how he was coping up to that point he kept forgetting to breath at times, but they felt the right time had come and he did very well off it, managing just fine. It was such a fantastic moment when he was allowed to start to feed. It was only through his NG tube in his nose, but it really didn't matter as it was my expressed milk. That just helped me so much. I had been disappearing off to the "breastfeeding" room every 2 hrs up until now, but only for the nurses to store it away for "a later date". Suddenly I had a real purpose, I could contribute to making him better, it was a good feeling.

After one week exactly after arriving at the Evelina, at one of the morning rounds Dr Murdoch and Dr Miller sprung the fantastic news that they wanted Isaac to move up to Savannah and Camel Ward. They thought he was strong enough. They said it was a long time since they had seen such a dramatic turn around. He was still not doing well but it was not such an instant worry anymore, it started to become a long term issue. We were out of immediate danger, now we just had to work on trying to get home and then take it from there.

The ward was so different from PICU. Isaac was at high infection risk (like most babies and children that had either just had surgery or just had a very poor functioning heart. But we didn't know that as we had come totally unprepared to hospital) and just felt like the transition from the clinical PICU where Isaac had his very own nurse at the bottom of his bed 24/7 to a ward where he was in a bay with four patients and 2 nurses, was very scary.

But it all soon started to sink in and it all felt much more normal. We got a room at Ronald

MacDonald by Guy's Hospital. Isaac couldn't breastfeed very well, he didn't have the energy and though the nurses were so lovely in encouraging me to continue, I was getting so stressed when they came around and weighed his nappies and him and telling me he just kept on losing weight, that I decided to express and bottle feed him. As all parents that have had children in hospital and have stayed with them knows that you get a terrible night sleep on the pull-down bed next to them. I decided to stay at Ronald MacDonald so at least I would get some sleep. It made me feel a little bit normal, Gavin and I could be together and Louie came up and stayed with us when he didn't have school.

The first time Louie came up to visit Isaac we were a bit worried that all the machines everywhere would scare him and maybe give him nightmares. Gavin had tried to prepare him as much as possible. Gavin's two older children, Yasmin 21 and Jordan 15, were also looking forward to meeting their new baby brother and came with Louie on that first visit. Isaac had been very "helpful" and pulled his NG tube out the night before the visit. That meant that he now didn't have any lines or tubes anywhere, which I think helped.

Louie took it all in his stride and after a few cuddles he went to the play area on the ward, making himself at home. At one point that afternoon, coming back from the bathroom I found him propped up on a chair leaning over Isaacs cot, putting a dummy in Isaacs mouth. My heart



Gavin Louie and Jordan

hands....Look no germs".

I could have cried, how did my little 5 1/2 year old boy get so grown up?

It was hard not knowing how long we would be in hospital for. We had got to know some wonderful parents on the ward, that made the stay so much easier to cope with, but with children that had surgery they all had an idea of how long they would be there for. But as Isaac was only improving slowly, and was still on a medicine that we were not allowed to administer ourselves, we could again just wait and see. After 5 days on the ward, they started him on a different heart medicine, one he would be OK to go home on. And after another 2 days, suddenly one morning after all his daily tests, we were told we were going home later that day.

Wonderful news that filled me with dread. How were we going to manage at home? Isaac needed medicine every 2 hrs. What if he stopped breathing? And what about all those dreaded germs? I was so worried about secondary infections.

Maybe parents with children that have had OHS think that we were panicking, but we had no idea what we were dealing with. We still hadn't got used to the fact that Isaac had a heart condition. We didn't know what the future would hold. Were we going to be lucky enough and he would maybe grow out of his condition or would he need medication for the unforeseeable future and possibly a pacemaker? We didn't know...the uncertainty was difficult to deal with.

The journey home from hospital was awful! Isaac has from the day he was born made very loud breathing noises, sometimes he sounded like he had swallowed a squeaker. We were on edge and nervous, Isaac was probably uncomfortable and made lots of strange sounds and screamed the whole way. It all felt very wrong, but we had to trust that the Doctors at Evelina knew what they were doing. Even though we just wanted to turn around and go straight back again.

stopped. All I could see was the germs on Louie's hands (I am ashamed to say). At that moment Louie looked up and must have read my mind. "Don't worry mummy. I did put that alcohol stuff on my

The first few days at home were not much better. Our fridge was covered in spreadsheets with all his medicine lists, so that we could tick every dose he had off. Slowly it all started to sink in, and we were getting used to it all. Gavin had to go back to work 8 days after Isaac had come home, and that day Isaac managed to bring all of one feed plus medication back up. I rang Camel Ward for advice what to do with his medication and was told that he needed to see a Doctor, I was told to ring an ambulance. I broke down, all the emotions came flooding up to the surface. But I knew deep down that though he might need to see a Doctor he really didn't need an ambulance. So Gavin made his way back home a.s.a.p and we drove to the hospital. After 3 hrs in A&E we got the all clear and could go back home again. That evening was a bit of a turning point for me and Gavin. We felt that we had past the first test and Isaac had managed well at home. We relaxed a bit more.

A week later we had our first check-up at Evelina, and there had been a little improvement, but at least he hadn't deteriorated. We were happy with that. Another month went by and we were up to see Dr Simpson again, this time it was much more positive. Isaac had put a whole kilo on in just a month - a good sign that he was getting strong enough to eat without any problems. His echo showed more improvement this time. We started to get hopeful that he might stand a chance to grow out of his condition, even if it was early days.

The next few appointments went in the same manner. But we still had no idea what had caused Isaacs heart to fail in the first place. So we got called to the Genetics team at Guy's Hospital. So far no tests had come back positive, but they wanted to test Isaac for Costello, Noonans and Cardio-Facial-Cutaneous-syndrome as he had showed a few signs that could possibly be connected to any of them. It took a long time to get the results but months later we got the news we were hoping for - tests came back all negative.

Meanwhile, we were watching Isaac with delight, going from strength to strength. We had a few more slightly scary visits to the A&E, but we never needed to stay longer than one night and it was more our local GP covering himself and sending us on.

In the middle of December, Isaac was due to go up to Evelina, we were ever so excited about this appointment in particular as we had been told that if Isaac had improved again he might be able to come off all medications. Then the snow hit London and West Sussex and it all got cancelled, but luckily they managed to schedule us in on the 16th of December. Isaac was 11 months and 1 day.

Dr Simpson delivered the news what we had waited to hear for the whole year...Isaac's heart

condition was now resolved!!!! And all his medicines were to stop from that day onwards. Well, that was the best Christmas present we ever could have been given.

We just wanted to pop into PICU, say Merry Christmas and drop off cookies and cakes that I had baked. We were only there for a short while and when we walked up to the lifts to take us back down, the doors opened and mine and Gavin's jaws just fell to the floor...In the lift was the same retrieval team, the same ambulance driver and the same "spacepod" with a very small baby in it. It was exactly 11 months to the hrs since that was us in that lift and Isaac in the "spacepod"....It felt like we had gone full circle.

Christmas was wonderful, the boys got spoilt rotten. Isaac had started to crawl so the Christmas tree didn't have much on the bottom branches.

Three weeks later was Isaac's first birthday. A very emotional day, that we at times in the last year just couldn't see that it would ever happen. It was fantastic to see him tumbling around amongst his presents and just beaming to us.

Our story is very different to most of the stories we have read or come across through ECHO. We feel extremely lucky that we can say that Isaac's Dilated Cardiomyopathy is now resolved. He still attends check-ups at Evelina, we are at the moment on 6 monthly visits. His heart is still noticeably uneven, the left side still bigger, but it functions so well that Dr Simpson and his colleagues are very happy with him and they are even thinking he might "grow into" it.

We have had a very frightening, uncertain, life changing first year in Isaac's little life. With many black, black moments. But we have come out the other end and we cannot believe our luck!!

Isaac is now nearly 20 months, running around not letting anything stop him. And we wouldn't change the past year even if we could, it has made us really re-evaluate everything and really appreciate the small things in life! A cliché but so, so true!!

And nothing else in the world could have got me and my step daughter, Yasmin, to do the abseil down Guy's tower as we HATE heights...Isaac was 4 months to the day and we were petrified but we did it!!! Raising lots of money with it!!!

Mimmi and Gavin Rush

Gavin, Mimmi & Isaacs journey

Our little Inspiration and Miracle

stories I had collated that were just notes in a diary gathering dust. My little black book is bursting with characters and stories just waiting to be brought to life. With some drive and passion I am determined to get these children's books published.

My intention is to donate a percentage of any profits to the children's hospital charities that we owe so much. I have realised very quickly that writing and illustrating is the easy part. Having publishing success is the difficult part. Any help and advice would be greatly appreciated.

It was 20 years ago when I started making stories up for my daughter Yasmin. When my second son Jordan was born 14 years ago they continued. When Louie was born, I started writing them down with the intention of writing and illustrating them one day. Then Isaac was born in January 2010. MY WIFE MIMMI'S & MY WORLD WAS TURNED UPSIDE DOWN. This was the moment when our perception of what is worry or stress or what irritates you in life changed. It is like a wake up call. Every time we look at all our children and especially Isaac we know something that special can never be taken for granted. To hand over your most precious baby to strangers in the hope they can make them well is a humbling experience. There was not a single person that we dealt with that we didn't have the utmost trust in and because of this we have dug deep to see how we can repay such a huge gratitude of debt. I will try and try again to have success with my books and one day I will succeed.

I am open to any suggestions or advice from people that know more than I do in how to get these books published. 'Pixly, the cheating tooth fairy', 'Tiddles, the caterpillar' and 'The Grumpy Lump' are three of my completed stories with The Grumpy Lump being the first that has been pushed into the laps of a publisher recently....fingers crossed. I want children all over the world to enjoy these stories.

Mimmi and I have been doing what we can in fundraising for ECHO including the famous abseil down Guy's tower, car boot sales and selling Mimmi's home made gifts, cooking and babies accessories. Let's hope with some luck, hard work and tenacity we can make this dream come true and start making a difference as a BIG THANK YOU!!! It is the least we can do. X



My wife Mimmi and

I have been privileged and blessed to have our little son Isaac on 15th January 2010. We would like to share some of our experiences and thoughts with the readers of the ECHO magazine.

There are so many amazing stories featured that we have read, some heartbreakingly sad and some with happy endings. Ours is a happy ending to which we are eternally grateful to everyone at The Evelina Children's Hospital that worked the miracles needed. My wife and I sometimes feel almost unworthy to be writing an article when there are so many families that have been through so much more than we did. Although when we look back now it really was the most sad and difficult time we have ever had. We felt totally helpless & dependent on all around us.

Little Isaac was born with Dilated Cardiomyopathy. He was retrieved to Guys & St Thomas hospital & PICU at the Evelina Children's Hospital. Without the expertise, equipment love and care given to Isaac by everyone involved in his care he would not have survived. This event affected every facet of our lives. Priorities & attitudes changed. Along with the desire to give back something to the hospital and staff as a thank you for the wonderful work they did for Isaac. I made the decision to start writing children's books. This was not a wild whim of an idea. In fact it has been a dream of mine to write and illustrate all the

If you have any information or ideas that could help Gavin then please email me, Jessica, at admin@echo-evelina.org.uk and I can put you in touch with Gavin.

Wendy Kemp Jewellery Update

Purchase from any of Wendy Kemp's Jewellery Collections in November to raise money for ECHO



Dear ECHO members,

Starting in November I am changing the way that I support ECHO and the other charities which benefit from Wendy Kemp Jewellery. For each month I will choose a certain charity to support and £1 from every sale for that month will go to that charity. I have decided that since ECHO holds a special place in my heart (no pun intended) to donate to your charity for 3 months each year. The first month is November. I have reluctantly had to make this change due to the astonishing increase in silver prices over the last 12 months and I simply can't sustain the 25% donation without a huge rise in my prices. This new method however does mean that all purchases from all my collections will benefit the chosen charity so you needn't feel that you have to purchase only from the ECHO Collection.

Thank you so much for your support and I will continue to support ECHO and help as much as I can.

Please email me at info@wendykempjewellery.co.uk if you would like to be added to my mailing list. I do not pass on any details to anyone else and will only email once a month with details of the chosen charities and other Wendy Kemp Jewellery News.

Please don't forget to put in your Christmas orders in early November!

Kind wishes
Wendy x

info@wendykempjewellery.co.uk
www.wendykempjewellery.co.uk

Wendy is such a loyal supporter of ECHO, and we would like to thank her for her continued generosity. Please take a look at Wendy's website to see all her collections. Her new personalised range is particularly beautiful, as you can see in these photos. Thank you Wendy! Jessica Cattermole



www.wendykempjewellery.co.uk

Rosie's story

When I fell pregnant we couldn't quite believe it, we had been trying for 5 months and were so excited as we wanted a baby so much! We paid to have a few private 3D scans from 8 weeks pregnant as we couldn't wait to see our little baby and to make sure everything was okay. We found out we were having a little girl at 16 weeks.

We went for our 21 week anomaly scan at our local hospital expecting everything to be okay. After lots of prodding and poking the sonographer told us that our baby was lying in an awkward position and she couldn't clearly see the heart so advised us that we'd have to make another appointment and come back. When I got home I had a really uneasy feeling so did some research on the Internet, I was concerned that something was wrong with our baby's heart but everyone told me to be positive and there would be nothing wrong, she was just lying in an awkward position. We paid for a private scan within a few days to check that everything was okay. The sonographer also said that the baby was lying in an awkward position, but from what she could see the heart flow appeared ok. The next two weeks until our next scan were pretty awful as I was so worried. When it came to the scan the sonographer spent a long time silently looking at the screen while scanning my belly, she then advised us that she was really sorry but she thought there was something wrong and that the baby appeared to have a hole in its heart. She was going to get a colleague for a second opinion. They tried to explain what they thought was wrong and then told us we had to wait to see a consultant who would try to explain things further and advise us of what would happen next. Our world fell apart and we couldn't believe this was happening.

We had to wait a couple of hours to see a doctor, in that two hours we made the decision that whatever was wrong we would have our baby and love and care for

her no matter what. The doctor was very nice and tried to explain what they suspected was wrong; 'Tetralogy of Fallot', but it was clear that we had to wait until we could be seen at Evelina at St Thomas' Hospital. It was a Friday so we had to go through the whole weekend until our appointment on the following Tuesday.

At our first appointment at Evelina it was explained by John Simpson that our baby had a Double Outlet Right Ventricle, suspected Coarctation of the Aorta, a large VSD and an abnormal Mitral Valve with suspected straddling of the Mitral Valve through the VSD. It was a lot to take in but the kindness and support from Evelina and ECHO helped us through. We were offered an amniocentesis, which would give a prenatal diagnosis of any chromosomal abnormalities, we asked if this would benefit the doctors in any way and give them a head start in helping our baby and were advised that it was purely a procedure for us to gain more information, so because we had already decided it was our baby and we wanted her more than anything we decided not to have the amniocentesis test. The doctors had discussed with us that none of the characteristics of our baby's heart condition necessarily pointed towards any chromosome abnormality and the scans showed that everything else looked normal.

We went through the rest of my pregnancy very excited about the fact we were going to have our little girl but I also felt very upset sometimes as I didn't think it was fair that she would have to go through so



much when she was born. After her birth we would have to wait and see if she would need any further operations as John Simpson told us that although they could plan so much of Rosie's operation some of it would have to be decided by the surgeon once they were operating. We had the opportunity to meet the surgeon Mr Anderson while I was still pregnant to discuss the operation Rosie would need and to ask any questions we had, it was very helpful and reassuring to meet with Mr Anderson.

It was at this point that I came across ECHO and was given a few contact details of parents of heart babies in my area. We contacted a few of them for some advice and support and ended up meeting one parent and their little girl for coffee who I have also seen since Rosie has been born. This was a great support to us, to have people to speak to who had gone through exactly what we were experiencing.

Throughout my pregnancy we had more scans that confirmed everything John Simpson had said in our first meeting with him but they also reassured us that Rosie was growing normally and she seemed very healthy and happy in my belly!

I was due to be induced at St Thomas' on Sunday 27th February at just over 38 weeks pregnant. I was told that the date may change as they had to make sure that everything was ready for Rosie when she was born and they had a cot available for her in NICU. We called St Thomas' on the Sunday morning and was told to call back later in the day, we spent the day feeling so nervous that either we would be going in to

have our baby that night or we would be postponed, we didn't know which was more terrifying! It turned out that everything was ready for us to go in that evening so we made our way to St Thomas' and arrived at the hospital birth centre at 21:00, we were very very excited!

We were shown to a room in the home from home birth centre as they didn't have any rooms available in the hospital birth centre which turned out to be a good thing as we had a fantastic view of Big Ben and The Houses of Parliament from our window. I was given Prostin Gel at about 23:00 that evening and as I was progressing quite nicely and there were no midwives available at that time it was 24 hours until they broke my waters at 23:00 on Monday evening when I was 3cm dilated. I thought I'd be in labour for at least the next 10+ hours but suddenly I started getting really strong and fast contractions. I didn't have time for any pain relief and when the midwife examined me at 00:15 I was fully dilated, Rosie's heart rate was dropping so I was told I had to get this baby out and fast! Our beautiful daughter Rosie was delivered at 00:45 on the Tuesday morning weighing 5lbs 14oz, when they put her on my chest I couldn't believe how perfect and tiny she was and Darren couldn't believe how pink and healthy she looked as we had been told that she might be born looking a bit blue. She was born crying very loudly and looking very very healthy and pink! The NICU team then took Rosie to make sure she was okay and they then took her to her cot in NICU, Darren went with her holding her head all the way, he said that she was looking around her the whole time taking in her first little journey. I felt upset that I wasn't with Rosie but felt so happy and relieved that she'd been born safely and was on her way with her Daddy to be looked after by the people who were going to keep her safe until she could have her first operation.

Darren came back down to see me after about 30 minutes and then we were given a picture of Rosie looking very comfortable and asleep. We both went to see Rosie at about 03:00 after I had had a cup of tea and was able to get into a wheelchair! Rosie was doing so well that she wasn't yet being given any drugs or any help with her breathing, we were so proud of her.

We had been lucky enough to be given a private room on the post natal ward so we got a few hours sleep and were back at

Rosie's bedside at 07:00. She had been put on Prostin by this point to keep her arterial duct open to help her heart and she was connected to a CPAP machine to help her breath. It was very upsetting seeing her connected to the CPAP machine

stayed on Prostin to keep her duct open but came off of the CPAP machine after only 36 hours and just continued to do so well! I was expressing breast milk for her which she was being tube fed when she was asleep or tired, she then started to be



Our beautiful daughter Rosie was delivered at 00:45am on the Tuesday morning weighing 5lbs 14oz.

and the monitors but we were still so pleased that she was doing so well as we didn't really know what to expect after she'd been born.

Rosie spent the next 9 days in NICU, she

fed by teat when she was awake and then the nurses asked me if I wanted to try to breastfeed her, I jumped at the chance as I didn't think this would be possible before her operation. She latched on pretty much

straight away and had a good feed which surprised everyone and made us so happy. The nurses said that they didn't think she'd actually feed straight away and then were concerned because she was supposed to be having limited feeds, they just thought it would be nice for us to have some skin to skin contact and for her to be near my breast to help us establish breastfeeding. From then on as long as she was awake and not too tired I managed to breastfeed her which was amazing.

We were staying at Ronald McDonald

We had a few small cuddly toys in Rosie's cot and her own blankets, although the cuddly toys seemed to grow and by the end of her hospital stay she had quite a few!

Because Rosie was doing so well instead of being in one of the big intensive care cots she ended up in one of the little old swinging cribs and we used to laugh that one day we were going to walk in and find her in a cardboard box in the corner of the room because she was doing so well she didn't need any help or special equipment!

the 11th anyway! It felt like fate and that her operation would be the start of her life as nature intended.

We spent the night before Rosie's operation on Savannah Ward where Rosie would eventually end up after she had come out of intensive care after her operation. It was nerve-racking being out of an intensive care ward with her only being connected to one small monitor, as by this point we were used to all the beeps and alarms of an intensive care ward, so much so that we would imagine hearing the beeps even



I read Rosie the same book every day in hospital that I still read to her at bedtime now. She smiles as soon as I start reading it.

House so we could spend the maximum amount of time at the hospital with Rosie. We were at Rosie's bedside first thing in the morning and stayed until very late every evening, we just didn't want to leave her. It was heartbreaking to leave her during the night but we had to get a few hours sleep and we called during the night every night to check on how she was doing. I read Rosie the same book every day in hospital that I still read to her at bedtime now. She smiles as soon as I start reading it.

Rosie's operation was postponed twice by a couple of days due to her good health and someone else being very poorly and needing to be operated on more urgently than Rosie. This was pretty difficult for us because although we were dreading the operation we knew Rosie had to have it done. Rosie's operation was finally set to go ahead on 11th March which was actually her birth due date! So we always see it that we had the first ten days with Rosie as extra special time to spend with her as she wasn't meant to be born until

when we weren't in the ward! The day of Rosie's operation was here and even though we knew this day would come it was so emotional, Rosie was prepared for her operation and dressed in her little operation gown. We went with her into the room where she would be anaesthetised, I held her while she was put very carefully to sleep and then we had to leave the room very quickly so they could start the operation. I remember one of Rosie's mittens falling to the floor just as we were

leaving the room but I kept hold of the other one and didn't let it go until we were back with her after her operation, I kept hold of it like I was holding onto her hand throughout the whole operation. We waited for six hours until we could see her again, we just sat in the parent's room in Savannah Ward drinking cups of tea, we just couldn't seem to move. When we were told that Rosie was through the operation and was doing really well I just couldn't believe how lucky we were and again how proud we were of Rosie. We rushed to go and see her in PICU. We had been prepared for how she might look after her operation, during my pregnancy and while she was in NICU. When we saw her I was just so pleased to see her that I hardly noticed anything else.

Mr Anderson had successfully completed an Arterial Switch procedure and Aortic Coarctation repair on Rosie. He advised us that it wasn't wise to try to close Rosie's VSD at this time because of the straddling mitral valve and that they would look to resolve this issue when Rosie was a bit bigger making the next operation a bit safer. He was happy with what they had succeeded in doing in this operation and was confident that Rosie could lead a normal, healthy life until they would need to operate again at about age one. It felt like we owed not only Rosie's life to Mr Anderson, but our own.

Rosie seemed to recover so quickly after her operation, she was only on a ventilator for 36 hours and every day more and more support was being removed (it seemed at an alarming rate to us) because she was doing so well. She was soon able to take breast milk again from a tube and every day she just seemed to be getting better and better. After four days she was moved to Savannah Ward where she had a little help with her breathing by being given the smallest amount of oxygen that the machines would allow, eventually she didn't even need this and after four days of being looked after in Savannah Ward they wanted to transfer her to our local hospital just so she could establish feeding properly after being tube fed for so long and then she could come home! They gave us some diuretic medication that Rosie ended up taking for 3 months but we couldn't believe that was all she needed after all she had been through. We were stunned at how quickly she had recovered from open heart surgery. Darren's boss later commented that she was our 'miracle

baby' and that is certainly what she is.

I went with Rosie in the ambulance and Darren drove and met us at our local hospital. I stayed up all night with Rosie breastfeeding her on demand determined that they would let us take her home the next day. When the doctor came to see us the following morning he was satisfied that Rosie was doing so well that she was allowed home, it was such a relief to hear this. We had to wait around for the next few hours but eventually we got out of the hospital and were on our way home! Darren had been home briefly the day before and had blown up pretty pink balloons and had put up a huge banner saying 'Welcome Home Rosie' which was lovely to see when we walked through the door.

We couldn't believe it when we finally got home. Our little girl had been through so much and here she was doing so well and finally at home. We were a little bit nervous as we were so used to Rosie being monitored twenty four hours a day by monitors checking her saturation levels, blood pressure and heart rate and the staff being around all the time. However, Rosie was so well and happy that she didn't give us any reason to worry, apart from normal parent anxiety!

We have since been back to Evelina and John Simpson's clinic for check ups three times since she was discharged and they are very pleased with how Rosie is doing. We have just been for our third check up and John Simpson advised us that at Rosie's next check up in the beginning of December they will start to discuss with the surgeons how and when they'll do her next operation. Most of the time I forget that Rosie has to have another operation because she is just as healthy as any other baby, but when I do remember I have to put it at the back of my mind for now and just appreciate all the time we spend with her and not take any day for granted. I have complete faith in the team at Evelina that Rosie's next operation will be a success and she'll recover just as quickly as she did the first time around.

We are so proud of Rosie, she is the happiest little girl who loves to smile and laugh. We are just so grateful that she is here to give us such happiness. We have now moved to the Cambridgeshire countryside where we take Rosie for long walks which she loves and smiles for every second of it, I'm sure it won't be long before she's running alongside us with us struggling to keep up with her!

**By Gemma and Darren Nesbitt
September 2011**



Darren, Rosie and Gemma



Hello, I hope you've had a fantastic summer... allow me to introduce myself... my name is Susan Buxton and I am the new Youth Development Manager for ETC. Over the next few months I will be developing our club to ensure that you get the support you need and lots of exciting opportunities to just hang out, have fun and make new friends.

Here's whats on offer for YOU:

- **One to one support**, in person, by email and phone.
- **Advice on Health, Education, Relationships and Lifestyles.**
- **Social events and regular meet ups.**
- **Fun activities and trips**, during school holidays.
- **Newsletters** every season.
- **Re-vamped ETC website.**
- **Facebook and Twitter** connecting you so you can follow us, keep in touch and up to date with the latest news.
- **Fundraising ideas.**
- **Volunteering opportunities**, our volunteers are very important to us and we do our best to ensure that we offer them useful and interesting projects.
- **ETC Sub Committee**, remember we are here to support YOU and for that reason our committee is run by YOU for YOU! So why not get involved, share your ideas about what you think the club should be doing and make important and exciting decisions about its future and how it develops, you could even write an article to be printed in one of our newsletters!

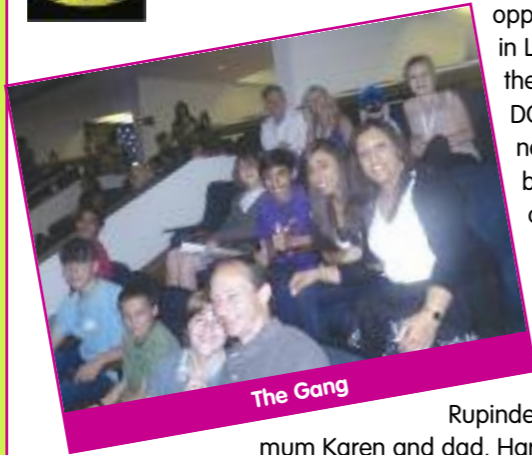
If you'd like more info and want to become apart of our sub committee, I'm happy to talk to you via phone or email, so please feel free to call/text me on:
07715 208 077 or send me an email to: susan@echo-teen-club.org.uk I'll look forward to hearing from you!



TRIPS



On Saturday 3rd September, some of our lucky members and their families had the opportunity to visit the O2 in London to see Batman the world's most popular DC Super Hero as he's never been seen before, in a live-action arena adventure! They were Melissa Adamou (volunteer helper), Karan, Simi and Savray Panesar with mum



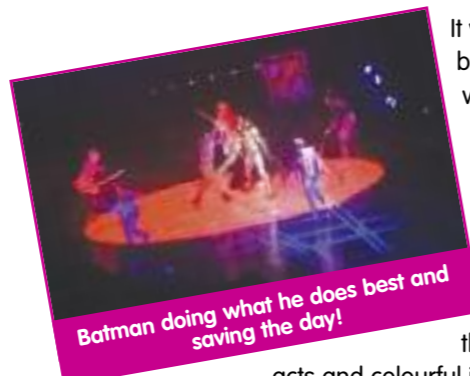
The Gang

Rupinder, Conrad Moore with mum Karen and dad, Harvey Dunn with dad Robin, Nathaniel Creasey, Evan Griffiths and Toby Bishop.



The Joker causing mayhem!

Gotham City was brought to life in a visually exciting way! Batman was joined on stage by Robin, their nemesis The Joker and other super villians such as The Riddler, Catwomen and The Penguin.



Batman doing what he does best and saving the day!

It was totally authentic, very bold and awe-inspiring, with lots of

WHAMS, BAMS, BOOMS AND POWS!!!

thrilling stunts, acrobatic acts and colourful illusions... a fantastic time was had by all! This is what Toby, age 12, had to say about Batman, "Susan was really nice and I enjoyed making new friends and seeing one that I had met before. I enjoyed the show and the sprite and crisps".



The marvelous Batmobile!

FUTURE EVENTS – Watch this space... Xmas event coming soon!!*****



Transition Day

On Saturday 24th September the fourth Transition Information Day was held at the Evelina. Over 12 young people and their parents attended the event which was run as a collaboration between the Department of Paediatric Cardiology at the Evelina, the Department of Adult Congenital Heart Disease (ACHD Dept) and ECHO with representation and assistance from GUCH (Grown Up Congenital Heart Disease Patients Association). The event was intended as an introduction and preparation for when it is time to leave the familiarity of the Paediatric team at the Evelina and move to the care of the Adult team at St. Thomas' at around the age of 16. The young people and parents were split up and took part in separate specially designed workshops which included "Transition – what, why, when an how?", "Worries and concerns" and "Living with congenital heart disease in adulthood", as well as taking part in ice-breaking or question and answer sessions with experts from the hospital such as Cathy Head and Natalia Chung, both Consultant Cardiologists from the ACHD dept and Melinda Edwards, Consultant Clinical Psychologist from the Evelina. The young people were also given the

opportunity to get to know each other and spend some time chatting and playing on the X-box together. Susan Buxton, our new Youth Development Manager, introduced the ETC DVD "ECHO Teen Club – You Ask The Questions", explained a little bit about what her vision is for the future of the group, and was delighted to meet some potential new ECHO Teen Club members. ECHO spoke to some of the parents there who thought the event was a really excellent way of preparing young people and their families for their move over to St. Thomas' and allayed some of their fears and anxieties about what to expect. ECHO is really grateful to all the staff from the hospital who gave up their Saturday to make this event such a worthwhile success, and to Jane Fewlass for all her hard work in organising it. It is hoped to run these ground-breaking days twice a year, and all Evelina patients aged around 15 will be invited to attend. If you would like more information or would like to book a place on the next event, please contact Jane Fewlass, Outreach Nurse with special interest in Transition: Jane.Fewlass@gstt.nhs.uk.

Susan Buxton
 Youth Development Manager
 Tel: 07715 208 077
 Email: susan@echo-teen-club.org.uk
www.echo-teen-club.org.uk

Like to join ECHO TEEN CLUB?

If you are over 11 and haven't already joined ETC (ECHO Teen Club) then don't delay, you might be missing out! Email your name, date of birth, postal address, email address and mobile phone number to Susan at susan@echo-teen-club.org.uk!

HARRIS GIRLS' ACADEMY HOPE PROJECT



Kaileigh Searles, 12 years old, in year 8

The Harris Girls' Academy in Dulwich has recently launched its "Hope" Project. Hope (Helping Others, Promoting Enterprise) encourages the pupils to use their design and practical skills to produce goods which they can sell through their own dedicated website to raise money for charity. ECHO has been successfully nominated by one of the pupils to be one of this year's lucky charities to



ECHO Cupcakes

benefit from the sale of their goods, and also from other collaborations and partnerships. Jo Wilson and Susan Buxton went along to the official launch of the project and were extremely impressed by the beautiful silk scarves and handkerchiefs which were on sale, as well as the absolutely delicious cupcakes (all hand-made by the girls). If you are looking for unique and inspirational Christmas presents or fancy some delicious cupcakes, please visit the Hope website: www.hope-harris.org and make your selection online. We are also delighted to tell you that the wonderful Harris Gospel Choir will be performing at our Christmas party! We are delighted to be collaborating with such an inspirational school and really look forward to working with the pupils!



Harris Girls - The Choir

KEEP IN CONTACT

Does ECHO have your email address?
Send it to Jessica on admin@echo-evelina.org.uk

AREA CONTACTS

AREA	NAME	TELEPHONE	EMAIL
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Surrey	Kathy Turner	07792 349 780	surrey@echo-evelina.org.uk
Norfolk	Molly Crisp	01362 860 488	norfolk@echo-evelina.org.uk
Pre-natal Support	via Admin Office	07943 625 031	prenatal@echo-evelina.org.uk
Bereavement Support	Cathie Shipton	Please contact Jessica for Cathie's contact details'	

THE ECHO COMMITTEE

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ECHO mobile 07943 625031

Don't forget to let us (and the hospital) know of any change in your contact details, i.e. address, phone number, e-mail address

Edited by Jessica Cattermole | Designed by Stanislaus Design [Please email kstanislausdesign@yahoo.co.uk](mailto:kstanislausdesign@yahoo.co.uk)

ECHO MEMBERSHIP FORM



To join ECHO, please complete the form and return to Jessica Cattermole at:

ECHO

PO Box 5015, Brighton BN50 9JR

Membership of ECHO is free, but if you would like to make a donation, however small, it would be gratefully received.

Name of Child	Child's Date of Birth
Parent(s) Name(s)	
Would you like to be put in contact with other families in your local area? Yes <input type="checkbox"/> No <input type="checkbox"/>	
Address	Postcode
Telephone	Email address
Child's condition	
Has he/she had surgery? Please give details	