



**Evelina Children's
Heart Organisation**

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

Newsletter Winter 2010



A BIG THANK YOU TO THE STUARTS



Tim and Karen Stuart

The Stuarts have been fantastic supporters of ECHO over the past few years.

Some of you may remember in 2007, aged nine, Josh Stuart became our first 'Junior Fundraiser of the Year' when he raised over £100 by running a Warhammer painting competition and through doing chores for his mum! His brother James recently sold some toys raising £40 and at Christmas we regularly receive donations from their company Windsor Food Machinery in lieu of Christmas cards.

Earlier this year Karen Stuart held a balloon launch at her son James's school, Ashford Friars Prep School. This

is the fourth year running that Karen has been able to fundraise for ECHO at the school, so thank you so much to Head Teacher Richard Yeates and Deputy Head Penny Willetts.

But as well as all the above fundraising, in July this year Karen and Tim held a Live and Silent Auction at their Silver Wedding celebration and raised an amazing £18,718.63! Karen said "We had a fantastic party and as a result 120 guests are now more aware of ECHO and the amazing work it does to help 'heart' families".

Thank you so much Karen, Tim, Josh and James for all your support over the years.

Jessica Cattermole



James Stuart

Looking up high



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Coffee morning in Kent at Charlotte Hummel's home in Etchinghill, nr Folkestone on **Thursday 27th January 2011**. Please contact Charlotte at charlotte@echo-evelina.org.uk Charlotte introduces herself on page 2.

Coffee morning in Surrey at Kathy Turner's home in Epsom on **Friday 28th January 2011**. Please contact Kathy at surrey@echo-evelina.org.uk for more details. You can read about Kathy our new Area Contact for Surrey on page 2.

Coffee morning in Brighton at my house on **Tuesday 1st February 2011** at 10am-midday. Please email me at admin@echo-evelina.org.uk for more details.

ECHO AGM and Family Day at the Tower Grange Hotel in London on **Saturday 18th June 2011**.

Put the date in your diaries, more details in the Spring.

Transition Day 22nd January 2011, read more about this on page 17.

Dates for your Diary



Kathy and Amy

Your Area Contacts

News from Surrey

I would like to introduce our new Area Contact for Surrey, **Kathy Turner**.

Bev Jowsey has been Area Contact in Surrey for many years and as her children are growing up and life and work getting busier, Bev is happy to pass on her role as Area Contact to Kathy.

I would like to thank Bev for all the support she has given families over the years and to welcome Kathy to the role!

I'm Kathy Turner and I joined ECHO in 2008 after spending time "living" at the Evelina with my husband, Mark, whilst our new baby, Amy, had surgery for Transposition of the Great Arteries. Amy's heart condition was not detected ante-natally, so it was a total shock after a difficult labour when she was transferred to the Evelina when she was hours old. It was a very long 36 hours before I saw my baby girl again, and by that time she had already had her first surgery. She had her major open heart surgery, the switch operation, when she was 5 days old and we will be forever grateful to Mr Anderson and team at the Evelina for doing such a great job. She is now a happy 2.5 year old and you would never know!

We discovered ECHO whilst browsing in the parents room on Savannah ward. It was wonderful to realise that we were not alone and that there were a lot of families going through the same as us. ECHO gives us a chance to meet and talk to other families and we have valued attending events and particularly seeing other heart children. It has been amazing for me to realise how much our heart children and their families do go through, and I would like to be able to support other families. I would love to meet local ECHO members and would like to invite you to a coffee morning at my house in Epsom. **Kathy Turner**

Kathy will be holding a coffee morning at her home on Friday 28th Jan 10am - 12 noon. If you would like to join Kathy then please email her at surrey@echo-evelina.org.uk.

News from Kent

We have a huge number of members in Kent and as it is such a large county with so many members we have decided to enrol another Area Contact to help **Fran Wintour**.

Fran and her lovely family live in Eynsford, and Fran will continue to support members near to her. **Charlotte Hummel**, one of our wonderful ward

visitors, has offered to support members who live the other side of Kent! Charlotte lives in Etchinghill near Folkestone. Charlotte will be holding a coffee morning on **Thursday 27th January 2011** and would love to meet you. You can contact Charlotte at charlotte@echo-evelina.org.uk.

Hi, my name is Charlotte Hummel. I joined ECHO in 2009 following the birth of my daughter Esme in 2008. Esme was diagnosed postnatally and had surgery at 12 weeks for a Complete AVSD repair and a mitral cleft valve repair. This was a really tough time for all our family as Esme's condition was not picked up until very late so diagnosis and surgery happened within weeks.

I heard about ECHO when Esme left hospital through a friend whose daughter was also treated at the Evelina. ECHO has become a big part of our lives and we really appreciate all the support, advice and especially new friends we have made.

I am also a ward visitor at the Evelina once a month. I find this role very rewarding and for parents to be able to talk to another parent who understands what they are going through can really make them know and feel they are not on their own.

We are unsure whether Esme will require more surgery in the future but what we do know is that we have the support of ECHO behind us and we will not be on our own. **Charlotte Hummel**

I would also like to say a huge thank you to our other Area Contacts, **Kerry Auger** in Essex, **Di de Naeyer** and **Mandy Webster** who share North London and Hertfordshire, **Molly Crisp** in Norfolk, **Eleanor Beardsley** in South London, **Teresa Buchanan** in Suffolk and **Rosie Wheldal** who shares Sussex with me.

Just to let you know, you don't have to be an Area Contact to hold an event. Any members are welcome to hold coffee mornings or local events to meet other members near to them. If you would like to do this then please get in contact with me and I can arrange for your event to be advertised in the newsletter and can email members in your area.

For Sussex members, or any members who want to come to Brighton, I will be holding a coffee morning on **Tuesday 1st February 2011**. You can find details on all upcoming ECHO coffee mornings and events in Dates for your Diaries on page 2.

Jessica Cattermole

Charlotte and Esme



Jo, Cissy and Vas

As many of you will know, our 11 year old daughter Cissy has recently had a heart transplant at the Freeman Hospital in Newcastle, after suffering complications following heart surgery at the Evelina in April.

It has been a terrible, nightmare rollercoaster ride for the past seven months, but hopefully the worst is over now and she is on the (very long and

Update on Cissy

winding) road to recovery. We are hoping to be transferred back to the Evelina at some point in the not too distant future to complete her rehabilitation and recuperation.

One day, when I have some time and feel I can face it, I shall write Cissy's story for the newsletter (it'll need to be a 32 page edition I think!), but in the meantime I would like to thank you all SO much for all your good wishes, prayers, candles lit in her name, cards, presents and, particularly, that special brand of ECHO love that has sustained us through such dark times. I hope we will be back with you soon, and Cissy will take up her rightful place as a member of ETC now she's 11!

Lots of love to you all, Jo, Vas, Melissa and Cissy Adamou xxx

Thank you to all of our volunteers!

I would like to say a huge thank you to all our volunteers who do such a wonderful job of supporting our members. As well as our fantastic Trustees and Committee, we are very lucky to have such a lot of members who offer their support to other members.

We have our pre-natal supporters who are on an on call rota to offer telephone and email support to parents who find out they are expecting a baby with a heart condition. I would like to thank **Joanna Blewett, Tahira Shah, Julie Jackson, Claire Wilkie, Marion Alston and Debbie Houghton** for the help and support you have offered these parents over the past year. I would also like to welcome **Caroline Jeal** to the role.

A huge thank you also to **Tahira, Marion, Claire and Joanna** who also attend the ante-natal days run by Thames Team midwives, sponsored by ECHO, for the Saturdays that they give up throughout the year to offer this

invaluable support.

We also have ward visitors who visit the ward on a regular basis to offer support to those people in PICU and Savannah ward who want a chat. Thank you to **Charlotte Hummel, Julie Jackson, Ros Carter, Ben Wilkie and Richard Parsons**.

Then there are those of you who I call on to offer support to members who are expecting a baby with the same condition as your child. There are too many of you to mention but you know who you are, and I am so pleased that I can call on you so thank you.

And not forgetting our fantastic Area Contacts who do an amazing job supporting members living near to them, you can read more about our **Area Contacts** on page 3.

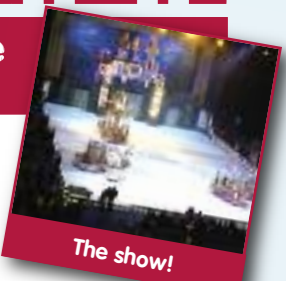
If you would like to find out more about volunteering for ECHO then please email me at admin@echo-evelina.org.uk

Jessica Cattermole

New ECHO Database

We have invested in a new database thanks to a very generous donation from **The Lakehouse Charitable Trust**. The new database will make communicating with our members much easier. If you don't receive regular emails from me then please can you let me know your email address so I can make sure that it is added to the new database. Also if you joined before 2007 please can you email your phone number to admin@echo-evelina.org.uk. Thank you!

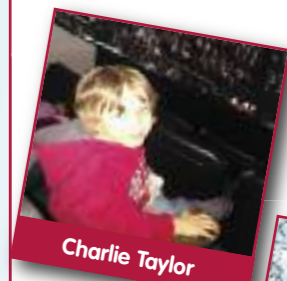
Disney on Ice at the O2



The show!

ECHO member **Viki Stapleton** very kindly donated a 15 seater box at the Disney on Ice performance of '100 Years of Disney Magic' at the O2. Viki was offered complimentary use of the box by **The National Sporting Club**. Thank you so much to The National Sporting Club and to Viki for donating this wonderful opportunity to our members.

We had a huge response to my email offering tickets so we had to pick families out of a hat and on Saturday 23rd October six families were able to enjoy the show and they all had a fantastic time. Thank you Viki!



Charlie Taylor



Oscar Baker

Jade's Story

This time last year I had a perfectly healthy normal 10 year old daughter who was into sports, swimming, playing out in the park with her friends and generally running around enjoying life. Or so I thought.



Two days into the new school year my daughter Jade suffered chest pain whilst playing tennis, she had experienced chest pain on and off for about a year, and I had taken her to our GP who assured me it was very rare for a child to suddenly develop heart disease at her age and that it was probably a bit of asthma.

The day she played tennis I had planned to go to the local supermarket nearby and come back and catch the end of the match, but for some unknown reason I changed my mind and decided to stay and watch the match. Thank goodness I did, almost at the end of the match Jade suddenly went very pale and lent over her racquet, and I instantly knew it was her heart, I could barely feel her pulse which was very weak and thready, Jade described her legs and eyes going funny, and I noticed she was grey and clammy.

Within half an hour Jade was propped up in our local A&E department wired up to an ECG and heart monitor. No-one mentioned anything other than she had suffered an ischemic attack. Every doctor and nurse who came near us kept asking me what I thought it was and I told them that I honestly thought she was going into a full cardiac arrest. I think I must have answered that question a hundred times. Yet I still thought we would be going home later that night and all would be fine.

But the fantastic staff on CCU knew something was wrong. Jade was transferred to the children's ward and wired up for the night. I don't remember much from that night, but I vividly

remember the next day.

Early the next morning another ECG was recorded and taken over to CCU. I guess there was no easy way to tell me that Jade had Cardiomyopathy. It's funny how despite being a nurse and having worked in cardiology I was racking my brains to remember what it was, what the treatment was and what the prognosis was. My grown up daughter and teenage daughter were with me and both of them looked to me to explain, all I could do was walk over to the window and silently weep. Literally 24 hours previously I thought I had a perfectly normal daughter, now here I was with the huge responsibility of getting my family through this. Being a single parent with no father of my children around to support me I was used to coping with whatever life threw at me, but I felt totally overwhelmed with this. The ward staff told me they were transferring Jade to the Evelina Hospital, I felt totally numb, confused and devastated.

Within the next few hours Jade was transferred to the Evelina Hospital. She spent a week having every cardiac investigation possible. Every day my brain went into overload with all the information I was being given. I had to tell family, friends and work colleagues of all the updates. I had to text everyone except my two older children; they were the only people I could speak to without crying, as I knew I had to be strong for them. I remember texting my manager to tell her I would be off sick and explaining that I was texting her because if I phoned her I

wouldn't be able to speak for crying.

I also had to explain to my 10 year old daughter what condition she had and what the implications were, I knew from nursing experience that children cope better with the truth, so I told her everything that I knew and explained everything in simple terms. Jade was fantastic, although understandably very worried, but between us we managed to put everything into perspective.

I explained to Jade that she had Atypical Hypertrophic Cardiomyopathy and that she was in fact one of the lucky ones as we now knew she had it and could learn to cope with it. I explained that there were many more young people that didn't know they had it until they collapsed. I don't think either of us believed we were the lucky ones but have convinced ourselves since.

Jade and I became a lot closer during that week and I think as a family we became even closer still. Jade's siblings had to be screened for the condition, but I knew that they didn't have it, although it was a worrying time for them.

Jade's school were wonderful and sent her a huge card with lots of little presents, we had lots of phone calls from her friends who had taken the time and trouble to find out the number of the ward and phone her, this meant a lot to both of us, and my friends visited me to keep me company as life on the ward can be very lonely, particularly as most other mums were very young and had tiny babies. Both Jade and I felt isolated on the ward

as we had no other older children and parents who had only just found out about the heart condition, other parents told me they assumed we were old timers at it. I have since learnt of a previous colleague who has found out that her son has the condition but thankfully does not experience any symptoms.

Eventually after a week Jade was discharged home on medication, she was told to self limit her exercise and not to take part in competitive sports. Jade's life had suddenly altered beyond all recognition. She could not return to school until a health care plan was in place and all staff were told about her condition and the implications. We were told in hospital that she was at increased risk of sudden cardiac death. Although Jade attends the largest junior school in this part of the UK with over 800 children, the head teacher was more than fabulous, within 24 hours he had informed every member of staff and all six classes of children in year 6 of Jade's condition and symptoms of chest pain. From then on Jade had virtually the whole school watching out for her. Sometimes she found it frustrating, but mostly was grateful for some very good friends at school, and I was extremely grateful to the staff that had to learn to cope with Jade's episodes of chest pain which she was now experiencing on a daily basis. At least Jade was able to attend school and experience some normality.

Jade had to remember she couldn't run, walk fast or do anything that normal children of her age do. She often forgot and went running off with her friends whilst in the playground, every time she forgot she suffered chest pain, she was now experiencing chest pain 3-4 times a day lasting for over 10 minutes at a time.

Inevitably within three weeks Jade was back in the Evelina hospital having experienced an episode of chest pain that lasted for over an hour. Once again cardiac investigations were performed and medication changed, and after ten days we were home again. This time I had taken my teenage daughter in with us and we stayed at the Ronald McDonald house, I felt she coped better with this as she was too worried to stay at home with her older sister, and during Jade's first hospital stay she had been very tearful at school and home. Both of them went to the hospital

school and I think Jade felt better having one of her sisters there with her to argue with.

During this stay we had to talk to Jade about what kind of work she could do when she was older, Jade asked about having children, having sex, living a normal life, she asked the consultant what would happen if she was bullied at school and chased, she asked me what would happen if she had a child and it started to run towards the road, how would she run after it? I found it amazing that at her age she was wondering about all this. It was during this stay we met the social worker, Ivy, and were advised to apply for disability living allowance. Although I'm grateful for her advice it was a devastating blow to now have a child who is registered disabled.

As the year progressed Jade's quality of life worsened, I had to buy a wheelchair for her to use if we wanted to walk more than a few hundred yards, as the cold weather increased she needed to use it more, eventually the cardiologist suggested that Jade be referred to GOSH as they have a specialised Cardiomyopathy unit.

Earlier this year Jade was seen as an outpatient at GOSH and admitted for change of medication, she was discharged from the Evelina hospital, something which I was totally unsure of to begin with as they were my heroes and I trusted them with my daughter's life.

As a nurse I could never understand how patient's hero worshipped doctors and nurses, I now fully understand. The staff at the Evelina became my heroes that I depended on, I felt safe as long as Jade was being treated there, and so when it was suggested that Jade be referred to GOSH for a second opinion, I was scared but understanding of the rationale behind the decision.

Jade is now treated solely at GOSH, and we are pleased with the progress she has made on new medication. The specialist cardiac nurse, Sarah, is wonderful, and she has become our new hero. Jade's quality of life has certainly improved, she will never be 'normal' again, but we have all learnt to adapt to her condition, its limitations, and the fact that she will always have to take tablets, visit hospitals and endure medical investigations for the

rest of her life. Thankfully because she has showed symptoms, which is rare, I can sit here and type those words – 'the rest of her life'.

Jade starts at secondary school in September, we are both sorry for her to be leaving Ocklynge School, the staff have been truly magnificent in their care for Jade, and it will be something we both never forget. I have completed a new health care plan for Jade at her new school, and all staff have been informed, it was a very worrying time initially, but Ratton School have dealt with it in a professional caring way that has instilled confidence in Jade and me for her future years there. Jade wants to teach English when she grows up, and thanks to her chest pain she may now achieve that dream.

Unbeknown to me, soon after Jade was diagnosed with HCM she wrote the following poem at school. **Julie Allistone**

In my head

I have nightmares in my head

Endless hospitals

Frowning doctors

Smiling nurses

Tubes that wind

Through me like rivers

Machines that beep

Needles that pierce

Attached monitors

And tests and drugs and corridors

The hope that soon

A cure will be found by Jade

Happy events and children's milestones

This is your opportunity to share your happy events and milestones with us. I would like to thank you all for the lovely news and photos you have sent in.



Lucy

fell off the Abbey ruins and Lucy fell down the toilet!! In spite of these things, the day was a great success. I got the nice natural looking shots that I had wanted- a "Day in the life" kind of thing. Laurie was a fabulous photographer and I was happy to let her use her judgement on what photos to take and where.

I would really recommend Littlest Heroes Project to any of my heart friends. The service they provide is great!! A big, big thank you to LHP and Laurie."

Michael Panayi celebrated his first birthday in August, his mum Leonie writes "Congratulations to Michael Panayi who celebrated his 1st birthday back in August in true English style... in a tent in the rain....but with lots of cake

of course! He's very nearly toddling now and is a bigger handful than we ever could have imagined - we're having the 'terrible twos' early - however, we're so glad he's healthy enough to be a menace that we're not going to complain!!"

Oscar Barren has started school. His mum Kate said "He started school on the 15th September and I thought I would send a picture of him looking so grown up in his uniform. He loves it and despite being very tired he can't wait to



Oscar Barren's first day at school!

go in! We are due to see Dr Miller soon and Oscar has told me he is going to tell Dr Miller to be 'quick sticks' because he has to 'dash' back to school!!! Not sure he's realised that its for ever now!!!"

Helen Reeve sent me this gorgeous photo of her twins **Albie and Stanley** and said "It will be one year since Albie had his surgery this Saturday (9th October). Both my boys have started walking too and, in fact, Albie was first to take steps.....the first thing he's been first to do, Stanley usually gets in first with everything so it was lovely

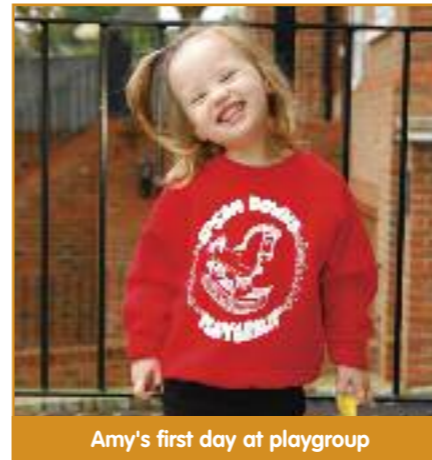


Albie with brother Stanley

that Albie did it before Stan."

Kathy Turner's daughter **Amy** started playgroup on 1st November.

To read more about Kathy, her family and her new role in ECHO turn to page 2.



Amy's first day at playgroup

Daniel Archer started pre-school on 6th September, a couple of weeks before his third birthday. His mum Katherine said "We are very proud of Daniel, he is such a lovely little lad, very even tempered and always wanting to please. Despite his tough start (co- arctation of the aorta) we count our blessing every day that it was diagnosed pre-natally as he probably wouldn't have made it had we not known before he was born. He has a seeming inability to walk anywhere, he has to run EVERYWHERE....."

Paul and Rosie Bartlett sent me these two lovely photos of their daughter **Sophie** at her 1st Holy Communion and her first sports day at her new school - held at Thames Valley Athletic Centre.



Sophie at sports day



Sophie at her 1st Holy Communion



Sam Richardson

Sam Richardson age 3 years and 6 months started Holy Cross Nursery in Uckfield in September. His mum Frances said he has a great time there and loves playing with the sand and water.

Jessica Cattermole



Daniel with his sister Madeleine and brother Caspian



Katie and Lucy

Amanda Prentice's daughters **Lucy** aged three and **Katie** aged six were chosen to take part in the Littlest Heroes Project, LHP. LHP is a non-profit organisation made up of professional photographers and provides complimentary photo shoots for children who suffer from any type of illness. Amanda's daughter Lucy was born with Tetralogy of Fallots. Amanda said "My girls love to be photographed, so I knew the day was going to be great.....well, it was certainly a day to remember!! Katie



Katie and Lucy



Michael Panayi



Katie



Michael Panayi, the Bootsale baby!

Cameron's Story

Our journey started in February 2006, when we went to the West Suffolk Hospital for our 20 week scan. Up to that point the pregnancy had been straight forward with no problems. The scan started off well and then the sonographer went quiet and said she couldn't see the heart properly, so she went to get someone more senior to take a look.

They were also having problems and decided to stop the scan, and said that they would like us to go to the Evelina Children's Hospital in London; we were taken to a counselling room whilst they made the arrangements, not knowing what was going on. Upon their return they had made us an appointment with Dr Owen Miller, a Fetal Cardiologist for the next day.

In the morning we made the one and a half hour journey by train from Norfolk to London, managed to find our way across the underground and to this amazing hospital. We met Dr Miller and he made us feel as relaxed as he could. The scans took what felt like hours, he confirmed that our baby had a complex form of Congenital Heart disease; he then had to rush off to theatre whilst we took in the news and went to have a drink.

Once Dr Miller returned he went through the complicated diagnosis and what treatment he could offer. The diagnosis was Tricuspid Atresia, Severely Hypoplastic Right Ventricle, VSD, Transposition of the Great Arteries and Hypoplastic Aortic Arch, this meant nothing to us and he explained it by drawing pictures of square hearts! The next bomb shell was the treatment options, the first was a termination, which was not an option for us and couldn't believe that he told us the termination rate for a baby with a condition like ours was about 97%, the second was to continue with the pregnancy and let him pass away

naturally after birth, the last option was to put him through three lots of open heart surgery and give him the best quality of life he could have. We looked at each other and said the only option was to give him chance and put him through the surgery, not knowing what the future would hold.

The week after being told this heart breaking news we went back to the West Suffolk hospital to have the original 20 week scan completed. They confirmed that we were having a baby boy, who we named Cameron.

We spent the rest of the pregnancy going to and from London for regular scan and checks; we got to know Dr Miller very well, and met the Thames Team Midwives who would be looking after me during my labour. They wanted me to have Cameron in St Thomas' hospital so he could be transferred straight to PICU at the Evelina. The date of the induction was decided and booked in but due to bed shortages in NICU in St Thomas' we had to wait 5 days for a bed to become available, on the 23rd June 2006 we made our final train journey down hoping that when we come home we would have Cameron with us. The induction was really quick and labour started straight away, but after a long 21 hours and with Cameron struggling with the contractions it was decided an emergency C-section was the best option. On the 24th June 2006 Cameron came into the world weighing in at 7lb 9oz, he was taken straight to NICU



followed closely by his dad, Colin, and once stable he was transferred to PICU at the Evelina, again followed by dad, and then my parents (Cameron was their first grandchild). I was unable to see Cameron until the next day due to recovering from the surgery, but the nurses took a lovely photo of him for me.

The next day I got to hold my baby boy, who at that time only had a few tubes and wires, he looked perfect although a bit blue. He was stable for two days and then needed intense photo therapy for jaundice and on the fourth day we took our first walk to theatre, where we handed him over to Mr Miller and Mr Anderson's team. This was the longest eight hours and we decided that it was best to keep busy; I discharged myself from the post natal ward and moved in with Colin into one of the family rooms on level one. After what felt like forever we thought we would head back to PICU to see if there was any news, little did we know that they were then bringing Cameron back to PICU and would have been called once he was settled. The operation they did was a modified version of the Norwood procedure and they reconstructed parts of his Aortic Arch. We were expecting him to look busied and puffy but he was perfect just with a lot more tubes, wires and the ventilator. We were able to help with cleaning him, and hold him (even with all the tubes and wires) and as he got stronger they started to remove pieces one at a time. After a week we were moved to the ward, and a week later we

were transferred to the West Suffolk Hospital to establish feeding, and get used to the medication he was to take (Aspirin, diuretics and pain relief). We finally got home when he was just under 3 weeks old.

Over the next few months we were monitored by the team at the Evelina, our health visitor and GP, who are fantastic and see us at the drop of a hat. Cameron was a relatively easy baby; he slept most of the day and was feeding really well. Then at one of our check-ups we mentioned that he was sleeping more and getting bluer than normal when feeding, they decided to do an MRI and when Cameron was 5 months old they decided to do the second lot of surgery.

On the 14th December 2006 we made the journey down to London, ready for Cameron to have surgery on the 15th. We were first on the list and at 8am we walked down to theatre again, and handed him over to Dr Miller and Mr Anderson's team. We couldn't stay in the hospital so we went for a walk and moved into the Ronald McDonald House. Eight hours later we got the phone call, and went straight to PICU. Once again he was ventilated and had many tubes and wires. The surgery they had done was the Norwood stage 2 and reconstructed his Aortic Arch for the second time. Although the surgery was a success and off the ventilator within hours, and sitting supported so he could eat yoghurt, we later found out that they had to move his nerve to his left vocal cord to enable them to do the extensive reconstruction to the Aortic arch, which they hoped would only cause temporary damage. That evening we were moved up to the ward and the recovery was straight forward until on the Sunday (the same day as the Christmas party!) he caught an infection and needed emergency chest x-rays and IV antibiotics for three days and then oral antibiotics. He also caught a sickness bug and was put in isolation until we were discharged. On the 23rd December they discharged us with a whole bag of drugs (Aspirin, diuretics, antibiotics and pain relief). This should have been a fantastic first Christmas as a family, but Cameron was still not 100% and then Colin was ill, so Christmas was cancelled.

We had a check-up at the Evelina just after New Year and mentioned that his voice had not yet returned to normal, they were concerned that he had left vocal cord palsy and referred us to the ENT department in St Thomas' to get it checked out. Apart from this complication they were very happy with the surgery. They managed to get an appointment with ENT for the next day, and they confirmed (by putting a camera down Cameron's throat), that he had left vocal cord palsy and that it was stuck in such a way that it was partially blocking his airways. They told us that they wouldn't know if it was permanent for at least two years (that's how long the nerves take to



recover!!). We were told to watch his feeding as his airways couldn't close properly and so milk could be going to his lungs. Within a week Cameron was having problems feeding and was choking and then refusing to take any milk at all, after a trip to the GP who then sent us straight to the West Suffolk Hospital for assessment, Cameron ended up with a NG Tube. We sent the next six months tube feeding him, having regular ENT and Cardiac check-ups to monitor the situation, and many trips to the hospital to have the a new tube put in. We finally managed to start to get Cameron taking small amounts of food and milk by mouth and after a special x-

ray at the Evelina, which confirmed that he was swallowing normally we were able to remove the tube and start to lead a normal life. It was during the last six months that the community nurse recommended that we apply for DLA, (we didn't know we would be entitled to this), and to our surprise we were awarded the top rate without any problems.

Cameron progressed very well and was having cardiac check-ups every six months with Dr Krasseman at the West Suffolk Hospital, he had started to sit up and crawl and by 14 months he was able to take his first steps. Heart wise his progress continued until he was nearly two years old, we went for a check-up,

although they were reasonably happy with his heart, he was sleeping a lot. They decided to do an MRI to assess him for the last lot of surgery. During this time we also found out that Cameron's vocal cord palsy was permanent, although it didn't affect his ability to eat and drink, it did make his breathing very noisy and he got breathless very quickly. Within a month we had his MRI appointment for September. Down to London again, this time with a toddler who was starting to understand what needles were and didn't want to be poked and prodded. The MRI went well and we were discharged that afternoon. The surgical team discussed his case very quickly

after that and he was booked in for the Fontan procedure for the end of October 2008, the evening before we were due to go we received a phone call. Mr Anderson had to take emergency leave and they had to postpone the surgery. Finally on the 6th November 2008, aged 2 years 5 months, we went down to London ready to the surgery on the 7th.

As normal they did all the bloods, ECHO and ECG on the 6th November and just as we were getting Cameron to sleep at Gassiot house we got a phone call to say there was a problem with his bloods and they needed to repeat them. Back we go to have more bloods take (with a very grumpy and sleepy Cameron!!). After a reasonably good night's sleep we went back to the ward and waited to make the walk to theatre again. Once again we couldn't stay in the hospital so we walked all the way to Tower Bridge and back waiting for the phone call. Eight hours later the call came, we rushed straight to PICU and this time the surgery went well but they were having problems stabilising the rhythm of his heart and he was wired up to an external pace maker. They also kept in on the ventilator longer than normal because they didn't want to cause any further damage to his vocal cords. After 24 hours they removed the ventilator, but he was still on the pace maker. Later that day they decided to turn off the pace maker to see what would happen; although his heart was not in sinus rhythm he was stable (they left the wires in just in case). Later that day we were moved to the ward, where he progressed well. Then ward was shut to visitors due to sickness and diarrhoea for a few days (luckily enough not in our bay). Cameron was able to get up and walk around with his chest drains still in after a few days and as I was there alone (Colin had to go home to make sure the house and the dog were OK), the nurses allowed my mum to visit for the day. This was when they removed the chest drains and pacing wires, his heart had sorted itself out and was settling down. Then he started to sweat and go all sleepy and was setting the monitors off every five minutes, he had an infection. IV antibiotics were started and we were moved to an isolation room. After a couple of days Cameron had improved and they put him on oral

antibiotics and discharged us, we couldn't believe that his saturations were at 92% and have been since.

We had a fantastic Christmas; Cameron was getting stronger every day and was so excited by it all, this was the first proper Christmas that Cameron was able to enjoy properly.

In March 2009 Cameron managed to catch German measles, although he is vaccinated against everything. After a trip to the GP and in isolation at home for a week he was fine. A month later he started Pre-School, we were lucky enough to get funded one to one for him. To start with he only went one day a week and over the next 18 months with continued funded one to one support we managed to get him to attend five mornings a week. During this time it was also recommended that we get him assessed by the Wheel chair services for a bigger buggy. He has never been able to walk as far as other children, without getting out of breath, but he also suffers from unexplained painful legs and finds walking hard. In July 2010 Cameron finished Pre-School and was getting ready to start primary school.

In September 2010 the big day arrived my little boy was going to 'big' school, and although the council are disputing the schools request for one to one funding, the school are funding it themselves and he has his lady Mrs Hall around all morning. He manages to do five mornings a week, although he is very tired and we can't do much in the afternoons or at weekends he loves it. The hope is that he will eventually be able to do all day and the school are hoping to be able to get funding for him to have continued one to one support. We have also been given a wheel chair by wheelchair services to give him more independence, he loves his chair and it didn't take him long to learn to steer it.

Health wise Cameron has gone from strength to strength since his third surgery, although he has also been diagnosed with Asthma, Sebo-psoriasis (skin condition) as well as his vocal cord palsy, painful legs and his heart condition, you really wouldn't know that he had all these conditions if you look at him. We see various different doctors in different hospitals but none of this

bothers Cameron and he happily has scans and tests done. We continue to see several different doctors (in different hospitals!) and a physio for all of his conditions, but he is happy to go and play and have jelly on his belly!

Looking after a heart child has its challenges, I still get up several times a night for him to have a drink of milk (he doesn't always know when he needs a drink during the day), and when he is tired he can't always control his bodily functions or understand that there are times when he can't do things that other children can do. He gets very cold in the winter and wears several layers of clothing, and has a cold all winter. He gets out of breath easily and we have to take his wheelchair everywhere, and when we go out it takes us half an hour to get out of the house making sure we have spare clothes, drinks and of course snacks! But he leads a 'normal' happy life and we have always made sure that he believes that he is no different than any other child.

We are so proud of how far Cameron has come over the last four years and how big and strong he has become. In the last six months he has learnt to ride his bike (with stabilisers), he loves bouncing on his trampoline, digging in his grandparents vegetable garden, helping his grandpa with his tractors and visiting Banham Zoo on a regular basis. We are also proud to say that in December we are expecting our second son, who looks to be heart healthy, and we can't thank that Fetal Cardiologist team enough for their support during this pregnancy. Cameron can't wait to become a big brother and is looking forward to bathing and changing nappies!!!!

Since Cameron's diagnosis in 2006 we have been members of ECHO and since then the family have held an annual fundraising garden party for ECHO and the Ronald McDonald House. These have become bigger and bigger every year and the whole family are involved, from Cameron's grandparents, Great Grandparents to uncles and aunties. We have a fantastic day and the support from family friends is overwhelming and we can't thank them enough.

Rachael Cooper

ECHO Heart Jewellery The Perfect Christmas Gift



ECHO Heart Jewellery by Wendy Kemp is the perfect gift for friends and family this Christmas.

Whether you choose some Silver everyday ECHO Heart Earrings or the stunning ECHO Heart Crystal Quartz and Silver Necklace for that special Christmas party, there are three pages of ECHO Heart Jewellery on Wendy's website to choose from. Wendy has also designed some contemporary men's jewellery with carved masculine abstract hearts.

Wendy's enthusiasm to support ECHO is reflected in her beautiful jewellery and her commitment is shown in the new designs which are regularly added to the ECHO Heart Collections.

25% of all sales from the ECHO Heart collection is donated directly to ECHO.*

*For Gold and Gold Vermeil Jewellery, 10% is donated to ECHO.

"Thank you to everyone who have purchased items from my ECHO Heart collection and I'd also like to thank you all for your lovely comments. The ECHO Heart collection has now raised over £1,000 and I'm looking forward to a busy Christmas period to add to this figure." **Wendy x**

"Thank you so much for sending it all so quickly! The jewellery is all beautiful and I will definitely be back for more at some point soon. I have decided that all the females I know will be getting ECHO jewellery for Christmas this year! Thanks again." **Sarah Libralato**

Wendy has already donated a fantastic £1,200 to ECHO this year.
Thank you so much Wendy!

www.wendykempjewellery.co.uk



Wendy Kemp

Nathaniel's Story

When we found out I was pregnant with our second child I was so ecstatic as I was due for surgery at the time for endometriosis but fortunately fell pregnant just before...

When going for the 20 weeks scan we were told by the sonographer that she couldn't see a specific part of the baby but didn't go in to any further detail other than to suggest that we go and take a walk and hopefully baby should have moved, by the time we return. By this stage I said to my partner Dan that something is up we didn't have this for our daughter Daisy. When we arrived back the sonographer took another look but again couldn't get close enough so advised us that we would be transferred to Kings College for another scan.

At this stage I was crying thinking what is going on. We were

fortunate that Kings College had an available appointment the following day, although that night was a long one... Dan was going to meet me at the hospital, but was running a little late so I went in and had my scan. The professor said, "do you have anyone here with you?" At that moment my heart sank and I said my partner was on his way. We were told that our unborn baby had a coarctation of the Aorta and would almost certainly have to have surgery within the first week of his life. The shock left me dumbstruck and I really struggled to take in what the professor was saying.

We told our families and they held it all together for us, and gave us so much support. I carried on through my pregnancy as normal, just like I did with our daughter. Whilst it was always in the back of my mind about what was going to happen, I am a firm believer of how you feel your child would feel the same so I was just carrying as normal and trying not to stress out.

We initially didn't want to find out the sex of our baby but because of chromosome testing, we went ahead and found out the baby was going to be a boy.

We had regular scans to see how our son was doing,

to see if there were any changes or miracles!! But unfortunately there were not. I was told at 38 weeks that I would be induced. On the 3rd of November (Dan's birthday) I had to go in to hospital as the baby was lying side ways and they felt it was dangerous as if I went into labour the baby umbilical cord could wrap round his throat! In the end the baby's head moved into position, so I was allowed home. I spent time with Daisy. She didn't know what was going on and was staying with my parents and sister.

The day came for delivery and I have always wanted a normal delivery as with Daisy I had emergency c-section. I was induced and was told to walk to bring labour on, I walked and walked came back and said to Dan that nothing is happening. The next minute I was in labour!! The midwife came in and moved us to the delivery room. I remember nearly falling off the wheelchair as I was in so much pain. I was hyper stimulating. At 4cm dilated I was told I would have to have an emergency c-section as the situation wasn't good for the baby (or for me!!). It seemed like a whole lifetime in the theatre room, I said to Dan I can't hear baby crying, I started to feel unwell. We could hear that they had to get another surgeon in. Our son was finally delivered but I just gave him a kiss and was taken to NICU. Later on I was told that they could not get through to our son and an incision was made on my bladder. Dan came back up and showed me the picture of our precious baby and I had two names Nathaniel or Sebastian and he really looked like a Nathaniel.

Nathaniel stayed in NICU for 7 days we were told by Mr Austin that Nathaniel was going to have an operation to repair the coarctation of the aorta the following week. He also had a VSD, but this was too small to do anything about.

I was still in hospital with a bag attached to my bladder! The day came for Nathaniel's surgery and I was in a state, going to the theatre and seeing your child being put to sleep was just awful, not knowing if he was going to come out alive. It was a very long day and my mum came to meet us and we sat outside PICU as we waited for Nathaniel

to be wheeled by.

We saw him and I was just in tears. Andreas told us everything went well and we could come in 15 min and someone would call us. That 15 minutes was a long one. I was crying my mum and Dan said "He is fine, remember the Doctors had said so". I said "No he is not". At this stage a consultant came out and told us Nathaniel had a cardiac arrest, but they had managed to stabilise him and we could come in and see him.

Seeing my baby wired up in pain, I just wanted to take all that pain away from him I felt useless. I would just sit there and cry. We were told to go and have some rest, I was still on the ward, Dan was going to see our daughter who I hadn't seen for nearly two weeks. I was in the maternity ward at St Thomas when I then received a call from a nurse in PICU. Nathaniel was in a bad way and at this stage the consultants suggested he go to Great Ormond Street for ECMO. Panicking I went straight over to PICU and was told miraculously after four days of no improvement Nathaniel had picked up a little bit and we were staying where we were.

A mother came and spoke to me and said go and talk to Nathaniel like how he was in your stomach and be positive. This helped so much. I felt I really picked myself up and I felt that Nathaniel started to respond to me speaking and my positive energy.

I remember popping out of PICU to get some food and said to Dan that I need to go back and tell Nathaniel that I was just popping out for a moment. I went back in and the curtains were drawn about Nathaniel's bed. Nathaniel was having another cardiac arrest.

The brilliant doctors managed to resuscitate Nathaniel again and he started to make slow progress. We went up to Savannah ward. I was concerned that it was too soon. That night Nathaniel was poorly and taken back down to PICU. Nathaniel was in PICU for a while and then went up to the ward for a few days and we were told we could go finally home!!

I was anxious not knowing what I needed to look out for, but we were finally home as a family. Nathaniel suddenly became ill at home after being at home for only two days. The ambulance was called and we were taken to our local hospital. Unfortunately we didn't feel that Nathaniel was getting the right care at the local hospital and after pestering them for about 6 hours we finally got transferred back to Evelina as we were

told he had a bug. In the end this turned out not to be case and the sample he had taken was contaminated.

We were all trying to figure out what was wrong with Nathaniel, as usually following the coarctation repair things should be working okay. We were going to be discharged but this time I didn't feel Nathaniel was well and upon further investigation and an andiogram they found an obstruction to the aortic valve had risen and he had a blood clot in one of the coronary arteries, probably as a result of one of his cardiac arrests.

We were told he would need another operation to attempt to widen the aortic valve. I felt more positive for Nathaniel just seeing how much he fought. This stage it was Christmas and we were told that Nathaniel had 50-50 survival. He was so ill again after surgery and was told again he may need ECMO. This time I spoke up and said to one of the consultants to look at the slow recovery from his last surgery and see how long it took for him to improve, she agreed they will wait and hold fire on the ECMO. My baby boy I would say to him "Keep fighting you are a very strong boy". We all went to PICU on Christmas day and spent the morning with Nathaniel and Daisy.

Nathaniel slowly improved and finally we were again discharged. After being at home a month Nathaniel collapsed again on us and went very pale. We were taken to another local hospital and Nathaniel was put back on to the ventilator. We were then transferred back to Evelina. This time I said "The next time Nathaniel will have a cardiac arrest on me please do something". I started to become run down and was unable to come and see Nathaniel in the hospital but wanted something done. Feeling better I had a meeting with the cardiologist and MRI scan was suggested and Nathaniel went for the scan the next morning. During that morning Nathaniel's heart rate started to slow down and we were called in fearing the worst. True to form he then picked up. A rollercoaster doesn't even begin to describe this!! MRI results came back and Nathaniel needed to have surgery the next day as the aortic valve was leaking and the narrowing was causing back flow. The valve would need to be replaced.

We prepared ourselves for yet another operation. They estimated that surgery would last for about 5 hours. You could imagine our shock when after an hour of surgery one of doctors came in to the

parents room and said the surgeon wanted to see us!!

With thoughts of fear racing through our heads, the surgeon informed us that the donor aortic valve they had was too big and suggested that they perform the Ross operation, switching his pulmonary valve in to the aortic position and using a donor pulmonary valve which, if everything went well meant that Nathaniel would not have to have further surgery in a years time.

Whilst the operation was more risky on a baby of his size we thought we had no choice but to go for it.

When Nathaniel came out of surgery all the medications were prepared for low blood pressure, as historically this was a problem for him after surgery. True to form this time it Nathaniel had high blood pressure!

Nathaniel gradually started to make progress but suddenly one morning I came in and he looked awful he was incubated again. They wanted him to rest and it did him good. Progress was suddenly showing and we were all happy but we knew in this game that if you have high hopes it can suddenly change.

Nathaniel was finally allowed to come home in May after virtually 6 months in hospital. It is fantastic to have all of us back home as a family. Touch wood since the last surgery in April he has done well. He is putting on weight and is now very active. Our precious son is a very happy baby who is a true fighter. He is one year old on 11th November and it brings a lump in my throat, as I never thought it would happen.

In April one of Dan's work colleagues Barry Vickery ran the London Marathon for ECHO and raised a fantastic £7,352. Barry managed to complete the marathon in a time of 3 hours and forty five minutes, this was despite turning his ankle on a discarded water bottle at the ten mile mark!! We would like to say a huge thank you to Barry for his fantastic efforts.

Priscilla Anenden



Barry in action!

Fundraising

Thank you all for your fantastic fundraising and kind donations over the last few months. As always we have received too many contributions to be able to mention you all here but I would like to share a few with you.

Member **Emma Goulding** nominated ECHO to the Charity Committee at her work and we received a cheque for £500. Thank you to Emma and to her employer SCA Hygiene Products UK Ltd for this very generous donation.

Thanks to **Antonia Mudunkotuwe** and her parents **Robin and Mary Field-Smith** for their kind donation of £715. Antonia's daughter Esther had the Arterial Switch operation in April. Antonia's parents celebrated their 40th wedding anniversary this year and asked their guests to donate to ECHO rather than bringing gifts. Robin and Mary said "Esther is now a picture of health and we wanted to express our gratitude for all the help and support we received." Congratulations Robin and Mary and thank you very much!

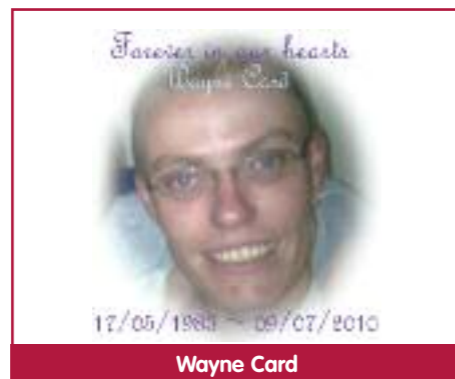
Sarah, John, Charlie and Sam Gubb raised a fantastic £1,000. Sarah and John said "Our 22 month old son has Pulmonary Atresia with VSD. We held a charity event on Sam's grandparents farm in Berrynarbor in Devon on 12th June. The event included a live band, a bonfire, and a hog roast (and plenty of beer to loosen people's pockets!) A fantastic night was had by all, made so much better by knowing where the money was going. We know the money will be put to fantastic use in helping families just like us. Thanks for all you do."



The Gubbs

Rachael Cooper raised a total of £1324 at her annual garden party and split the money between ECHO and Ronald McDonald House. Thank you for your continued support of ECHO Rachael. You can read all about Rachael's son Cameron on pages 8-11.

Kerry Card's brother Wayne Card very sadly passed away on 9th July. Wayne had always helped out with Kerry's charity events for ECHO. Kerry said "It was his my mothers wish that a collection be made in my brothers memory to donate towards ECHO. My brother will be so proud to have been able to do his little bit for ECHO even after his passing." Thank you to Kerry and her mum for thinking of ECHO at this very sad time and for donating a wonderful £230.



Wayne Card

In the last issue of the newsletter we advertised **Helen Reeve's** exclusive film screening of Marmaduke that she had organised to raise money for ECHO. Helen's event raised a total of £808.96. Helen said "I'm so pleased that I was able to do this and give a little something back after the great work that the hospital did for my son Albie and the continued support that ECHO offers to us and many other families." Thanks to Helen and to her employer, Empire Cinemas in Basildon, for holding such a successful event.

Thank you to **Angela May** who recommended ECHO to her employer **Kids inc nurseries** who donated £400, the proceeds of their summer fete, to ECHO which they held on July 16th 2010

Don Tester walked from Brighton pier to Eastbourne pier to celebrate his 70th birthday on 8th August and raised £720.16 for ECHO. Thank you Don, what an achievement!

Robin Ware collected £530 at his father's memorial service in April. Robin said "Thank you for all that you do. My dad loved his granddaughter Rebekah dearly and would have been delighted to see so many give to an organisation that supports 'heart' children and their families."

Thanks to **Kirstin and Ben Guy** for donating £478.55 in memory of Kirstin's mother Elaine Susan Slack, my thoughts are with you and your family at this sad time.

Thank you to **Rose Parmar** who raised £87 by organising a cake sale at St Martins Hospital in Canterbury where she works in the admin building. Rose said "I would like you to accept this cheque on behalf of my nephew and his family, **Matthew, Louise and Hendrix MacKay** and all of us at the Eastern and Coastal Area Office at St Martins Hospital in Canterbury. My nephew's little baby has recently been treated at the Evelina and I wanted to do something as a way of thank you in you for the wonderful treatment they have received." Thank you Rose.

ECHO's Area Contact for Kent, **Fran Wintour**, very kindly asked for donations in lieu of flowers at her mum's funeral and donated £440. Thank you Fran and family for thinking of ECHO at this sad time.

Huge thank you to **Anna Scott, Evie Scott, Manon Hagger and Hetty Taylor** who raised £100 by selling unwanted toys and games. The girls all live in Weybridge, Surrey and are great friends of Cissy Adamou. It is the second time that Anna and Evie have raised money for ECHO, so thank you so much girls!!

Thank you all so much for your fantastic contribution.

Jessica Cattermole

Joanna Blewett's Run to the Beat Half Marathon

In November of last year we had been home from the Evelina for a few weeks after Thomas' Fallots repair, when I started to think of ways I could raise some funds for ECHO. ECHO had and continue to be a huge support to my family and I and helped to ease some of my anxiety at being a heart mum. So along with fellow heart mum Caroline Jeal I signed up for the Run to the Beat Half Marathon for September 2010 - I'd never ran further than 10k pre-pregnancy. It gave me almost a year to train, easy I thought - I think I forgot I had a 4 month old baby to look after!

Training was a bit hit and miss and didnt really start until I stopped breastfeeding and we had moved house in March of this year. Motivation was easy but trying to find the time was difficult around my husband Matt's long working week, but eventually, with a few 7 mile runs and one 10 mile run under my belt come the big day I felt I could complete it and that was all that mattered.

The day itself was grey and cold but thankfully dry. Thomas came to cheer me on along with Matt, my parents and a couple of close friends. It was a hilly and slightly boring course around south London, but I was consistent. Every time I turned another corner and was faced with yet another incline or if my legs niggled I thought of all of our brave heart children and how almost a year to the day we were



Joanna Blewett

sitting in Camel ward at the Evelina wishing our beautiful boy well. I dug deep and kept going. I would not let Thomas down - if he could endure open heart surgery, Mummy could run 13.1 miles!!

I kept to my 10 min a mile pace and thankfully completed the course without walking or stopping in 2 hours and 29 mins! Even better I managed to raise £1245 for ECHO via Just Giving! Almost £100 a mile - thank you to all our family and friends who sponsored me. Your support means a lot to me, Thomas and especially ECHO.

Will I be running another half marathon? Never say never... Will it be in the near future? I doubt it. Now I'm going to take it easy and concentrate all my efforts on our beautiful boy Thomas.

Thank you Joanna for raising such a fantastic amount for ECHO and also for all the pre-natal support you offer our members, you do a wonderful job!

Joanna's friend and fellow ECHO member Caroline Jeal had this to say...

Along with my good friend and fellow heart mum Joanna Blewett, I took part in the Run To The Beat Half Marathon on 26th September 2010. My daughter Keira was born in June 2009 with TGA. I finished in a time of 1 hour 58 minutes and 45 seconds and raised £150 for ECHO. I'm saving my big fund raising effort for The London Marathon which my husband Damian and I are running in April 2011! Let the training begin!!

Good luck with all the training and fundraising Caroline!

Jessica Cattermole

An Update on ECHO Finances

This year is shaping up to be another fantastic year for ECHO financially. We are on track to match, and perhaps even exceed, last year's income - and that was the second most successful year in ECHO's history. No mean feat in the current economic climate!

We have seen an increasing number of regular donations being made by standing orders or through tax-efficient Give As You Earn schemes operated by members' employers. These regular donations are a great way for the committee/trustees to budget spending as we know what money is coming in and we would like to thank everyone who has set up these arrangements.

ECHO could not of course exist without the fundraising efforts and donations of members, so the committee/trustees are always interested in hearing members views of how money could be spent - if you have any thoughts please let us know! In this way, money raised can be used in the best way possible to offer and expand services and support to our members. This might be particularly relevant where, for example, money is donated in memory of a loved one or to celebrate a special event. In these circumstances we could look to use the money you have raised for a specific purpose if that is something that you would like. In this case, it is helpful if you could let us know your thoughts on this in advance so that we can plan accordingly.

If you have views on fundraising issues you would be more than welcome to join the committee! The role does not need to be time-consuming and can fit around other commitments - a lot of what we do is dealt with via emails. Making a contribution in this way, however small, can mean that we save money that can be better spent providing support to members.

Finally, a small plea - if you are using a paper sponsorship form (instead of, or in addition to, a Justgiving website page), please could you ensure that donors complete their full name and full address. We can only reclaim the gift aid from HM Revenue and Customs if this information is included and there are often situations where these details are incomplete and so we cannot make the claim. Gift aid is currently worth 28p for every £1 donated and so it makes a real difference to our numbers if we claim it and it really only takes a second or two to fill in the form.

Thank you!

Joanne Williams ECHO Treasurer



Joanne Williams

Are you stuck in your comfort zone? Would you like a huge challenge in 2011?

Abseil 450 ft down Guy's tower and raise money for ECHO at the same time!

Date of event: Saturday 9th April 2011 or Monday 2nd May 2011 (Bank Holiday Monday)
Time: 9.00am to 4.00pm (timed slots)
Age restrictions: Over 16
Minimum Sponsorship required: £250

Places are strictly limited - £25 registration fee will be required to guarantee your place.

Please contact Jessica Cattermole without delay by e-mail admin@echo-evelina.org.uk or phone 07943 625031 to book a place, or for more information.

FOR THOSE LESS ADVENTUROUS AMONGST US WHY NOT LOG ONTO www.echo-evelina.org.uk TO FIND OUT HOW YOU CAN SPONSOR AN ABSEILER OR DONATE TO ECHO ONLINE!



Transition to Adult Services

Many teenagers with congenital heart disease and their parents have concerns about their future care when they reach the age to move to the adult services.

A newly formed transition group consisting of staff from the Evelina Children's Hospital and the Adult Congenital Heart disease team from Guys and St Thomas', together with the support of ECHO, the parents' support group for Congenital Cardiac patients at the Evelina are organising this day with a focus on informing and supporting you and your parents as you approach the time when you may start to consider this important step

The day will involve information from relevant health care professionals as well as patients who have made the transition to the adult congenital heart disease service. You will have the opportunity to meet health care professionals from the adult team who will be involved in your future care.

There will also be a representative from ECHO and the GUCH Patients association who will be able to offer their help and advice.

We would like to ask for a little help from you and your family, for your views on how we can make transition days helpful, supportive and informative.

The next transition day will be held 22nd January 2011. If you would like to attend this day please contact Anne Levaste, Clinical Nurse Specialist, Adult Congenital Heart Disease Service at St Thomas' Hospital on 020 7188 9712 or at anne.levaste@gstt.nhs.uk



The ETC room on Beckett Ward

In September, the ECHO Teen Club made a donation to Guys & St Thomas' Hospital to create a new room in Beckett Ward specifically for our ETC members who have entered into the transition phase and are now part of the Adult Hospital.

We recognised that there was a need for you to have some space and chill out by yourself or with other people of similar ages. That is why the room has a sofa, fast computer, big LCD tv and DVD player for you to enjoy!

We really hope you enjoy the room and make full use of it. If you have any feedback please do let us know. **Alex Bicknell**

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 Jessica on admin@echo-teen-club.org.uk

Meet@teenheart Weekend Stunner



Tom, Matt, Josh, George and Jack!

A group of our ETC members **Josh Martin, Matt Squires, Jack de Naeyer, George Daly** and **Tom Sexton** went away on a British Heart Foundation weekend called Meet@teenheart Weekend Stunner from 28th - 31st October at Hautbois House in Norfolk.

The British Heart Foundation arrange these weekend events every two years at different venues across the country and they are packed full of fun activities for young people with heart conditions.

Matt Squires wrote this fantastic report about his time away:

I really enjoyed the BHF Weekend Stunner. On Friday we went to BBC Norwich and made a short chat show programme. This was lots of fun and there were a variety of roles so everyone could get involved. I was one of the cameramen and learnt how to film which was tricky at first but eventually I got the hang of it. We all thought this was a very enjoyable experience.

On Saturday we had a blogging workshop where we learnt about the various ways that we can contact other people with heart conditions. We split into five groups, two groups did a written blog, two made an audio blog and one a video blog. I was in the last group and we created a video about whether God exists or not and whether or not he loves us. One of the arguments was, if he does love us, then why do we have heart conditions? I found it very interesting to talk about an unusual subject and to be able to put my point of view across.

After this we had a go at archery and zip-wire which were entertaining and exciting. We also had a quiz night which stimulated competition between everyone, but my team, Yeh-boi, won. On the final night we had a party, but I am not at liberty to disclose any details about that! I was glad that I went and made lots of new friends.

And **Josh Martin** has kindly shared the following with us:

The activities were great, but it would have been worth it alone to meet all the people I did - we all had an amazing time together. It was great fun to make our own chat show, at BBC Norwich - it was definitely a new experience for me! The leaders were all very friendly and made everyone feel comfortable and welcome - a big thank you to all of them.

Thanks Josh and Matt, sounds great fun!

Harley's story

Being nineteen and pregnant was hard, being nineteen and having a baby with CHD is harder. I would never change Harley, I feel blessed that I have him.

On the 12th of February Harley Bonwick was born at 1.30am weighing a healthy 7lb11oz. 12 hours later myself and my partner took a healthy little boy home to meet our families. At 1 day old Harley was jaundiced and was not feeding well. Ten days went by and I had been seen by three different midwives who all gave me different ways to get Harley to feed but none of them worked, he wouldn't take more than 30mls of milk.

On Friday the 22nd of February I had a visit from a midwife who had looked after me during my pregnancy, she weighed Harley and it was clear he had lost weight. At this point I knew something was obviously not right with him, so she asked me if I would like to take him to my local hospital in Brighton or wait until the Monday and she would return to weigh him again. Without hesitation, me and my mum took him straight up the hospital.

After the doctors examined Harley they suspected an infection so they took him to the treatment room and went ahead with a lumbar puncture to check what infection he had. Suddenly doctors rushed past me and my mum. Soon after we realised they were working on Harley as he had 'collapsed' as they were taking the fluid from his spine. Soon after my partner and his family arrived. The doctors told us they suspected Harley had a heart problem and was being transferred to PICU on a ventilator and he was fully sedated. We were then told we were waiting for the Evelina to send an ambulance down to take him back up to London.

After a few hours (which seemed like a life time) the ambulance arrived and rushed Harley to London. The ambulance crew said if anything happened to Harley's condition they would get the police to close the motorway so they could get to the hospital quicker. Myself, my partner Luke and both our families shot down to London, by this time it was past midnight so it didn't take too long to get there. On the way I had a phone

call from the ambulance crew saying that they had arrived and Harley was stable in PICU.

When we arrived we were met by a consultant who explained the diagnosis which was large muscular VSD and juxta-aortic forestation type severe. Basically this meant he had a large hole in the centre of his heart and the aorta had closed which made him ill. He also said that if we had left him any longer at home he would deteriorate and would have been too ill to operate on. Something that day told me to take Harley straight to the hospital otherwise I don't know what would have happened.

We were told Harley would need surgery ASAP or he wouldn't make it. As it was the weekend they tried Harley with a medicine to help the blood flow through his aorta to prolong surgery until the Monday. A few hours later on the Saturday, the medicine hadn't helped so their only option was to operate that day which meant they had to call in the surgeon on his day off. We finally met Mr Conal Austin who explained everything. He explained that as Harley's hole was so big he wouldn't make it through the procedure. He explained he would have to close the hole at a later date. He described Harley's heart as an ice cream cone and said that Harley's hole was at the bottom of the cone which makes it a lot harder to close. So they were going to repair the aorta by cutting out the closed part of the aorta and stitch it back together. They would also put a band on it to restrict the blood flow.

The surgery was successful and we only spent two days in intensive care before being transferred to the camel ward. We spent a further four days in the ward before being discharged home.

Harley was at home for a week before his scar on his left shoulder from the aorta repair became infected. I spent a further week in the Evelina while the doctors were

using honey to heal the scar. After another week at home he was admitted to my local hospital for feeding problems and vomiting issues. Overall, he spent seven weeks in my local hospital trying to put weight on for his next surgery. On the 7th week, I was transferred back to the Evelina for scans as his breathing was rapid. They told me his heart was squashing his left airway making him pant. After a week up the Evelina I went home with a feeding tube and weekly appointments. I had to give him ten doses of medicine a day and feed him three times hourly which was very tiring. Every day Harley would pull out his feeding tube so I would have to take him back up for another one.

After two weeks, I decided enough was enough and I put my foot down. I told the nurse he was having no more feeding tubes and I was going to let him use the bottle. I promised her that if he didn't take enough fluids I would bring him straight back for another tube, but Harley was fine on the bottle and started to put on weight. At the beginning of 2009 I told my family, the Evelina and my local hospital I didn't want to know the date of his second surgery as I didn't want it playing on my mind. I wanted to be strong for Harley and I knew I wouldn't sleep or cope knowing the date and time of his surgery, and everyone agreed.

In August I planned to take Harley away to a holiday camp with my friend and her little boy as going abroad wasn't an option. Two weeks before I was due to go my mum rang me to say that the holiday camp had overbooked and they only had space at that time so we went a few days later. When I returned my partner Luke took me to one side and told me Harley had to go up to London for his second surgery the following day. I was shocked as I had it in my head he wouldn't be having any surgery until 2010, then my mum told me that she cancelled my holiday as it clashed with Harley's surgery date.

Not knowing the date and having a day to prepare was a good decision for me as I had no time to think about the surgery. Once

we had settled in at the hospital we were greeted by Mr Conal Austin again (who is now my hero) and he explained the operation to us which involved open heart surgery and he was going to use an artificial material to close the hole. It took just under 6 hours. His surgery went very well and within a week I was back at home.

Harley has had a few problems after but none of them due to his heart. He now has yearly check ups with his consultant Dr Miller at the Evelina. He is being seen at the Royal Alexandra regularly with respiratory problems and has recently been seen by Great Ormond Street, as his heart is an abnormal size and it's still pushing his left airway. He also has an immature voice box which leaves him with loud noises.

I was nineteen when I had Harley and was very inexperienced with babies so having Harley (thinking he was healthy) was frightening enough, but when he was rushed to hospital with heart problems I was even more scared. But somehow I've forgotten about his problems and am treating him normally at home which has made me a stronger person.

Now Harley is two and a half and is a very confident and happy little boy. I am so proud of him with everything he has been through. He is a blessing to me and the best thing that has ever happened.

Myself and Luke would like to take this opportunity to thank all our family, our health visitor, Jane Epthorp and everyone at the Evelina and the Royal Alex for all their support and help with Harley. We wouldn't have been able to go through what we have without you.

Kerry Wood



Harley after his first open heart surgery



Harley following his second open heart surgery



Harley with his mum and dad

Safe and Sustainable Paediatric Cardiac Surgical Services Programme - Update

The National Steering group met a few weeks ago. The results of the scoring of the units seemed to have been leaked to the media and there was some discussion as to who could be leaking this highly sensitive and confidential information. An independent body has been tasked to develop a system of options, and at present there are 12 or more different permutations, each reducing the current number of units (11) down to 8,

7, 6 or 5. Recommendations will be made to the Joint Primary Care Trust Committee for a smaller number of options and these will then go out for public consultation by 26th January.

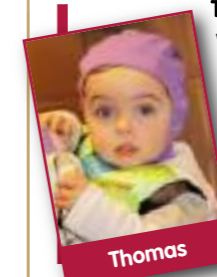
Please keep up to date on Safe and Sustainable by checking the home page of our website where you can read regular updates and details of the Safe and Sustainable website.

The Evelina Children's Hospital 5th Birthday Bash!

On Sunday 24 October, more than 40 children got the opportunity to dress up as their favourite superhero at a fancy dress party, followed by a trip on the London Eye. The event was to celebrate the 5th birthday of the Evelina Children's Hospital at St Thomas' and one of the special guests invited was ECHO member

photo of her superhero!

Oliver Parsons also attended with his parents Richard and De-Ann and De-Ann wrote the following. **He goes by the name Oliver, he is a SuperHero but doesn't need the title. All can see, including the judges at the Evelina's 5th birthday party, that Oliver is Wow! Oliver won the category Best Overall SuperHero Outfit and was rewarded with a Meerkat and medal. Being the modest SuperHero he is, Oliver quickly removed the medal and threw the Meerkat aside, embarrassed by the recognition! Well done Oliver!**



Thomas

Thomas Blewett. It was a very special day for Thomas and his family as it was exactly a year after he had been discharged from the Evelina. Joanna Blewett sent me this lovely

Coffee mornings on Camel Ward

From **Thursday 4th November** Clare Perrett the new play specialist on Camel Ward and Emily, a pre-admissions nurse have very kindly been holding coffee mornings in the Parents' Room on Savannah Ward from 2-3pm.

These coffee mornings will be held every Thursday afternoon giving parents the opportunity to meet other parents on the ward in a relaxed atmosphere. Tea and cakes are served!!

20th Anniversary of World's first catheter valvotomy

The 20th Anniversary of the world's first catheter valvotomy for pulmonary valve atresia by a laser at Guy's Hospital in April 1990 was celebrated at the Evelina on Saturday 11th September 2010. It was developed by Dr Shak Qureshi and Professor Mike Tynan. Many patients and parents attended this event as well as Patricia Moberly and Professor Tynan.

FLU JAB TIME!!!

Please make sure you read the up to date advice (direct from the Evelina) about vaccinating your children against flu in the run up to Winter on the home page of our website.

KEEP IN CONTACT

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

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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	