



**Evelina Children's  
Heart Organisation**

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

# Newsletter Autumn 2009



## 5TH ECHO SUMMER PARTY

On Sunday 13th September we held our 5th ECHO Summer Party at Mountains Country House in Hildenborough. It was a fantastic day, and the weather as always was kind to us! It was lovely to see so members catching up with old friends as well as many new members meeting for the first time.

I would like to thank **First Choice Inflatables** for the fantastic bouncy castles and the human football table which they supply every year. Also a big thank you to **Nesta Goldsworthy** and her family for bringing their farm animals, which the children always love. Thank you to **Henrietta Donovan** for providing the excellent food and huge thanks to

**Beverley and John Lawson** for their hard work and help leading up to the party and throughout the day as always.

Thank you to the **Dixie Ticklers** who entertained us with their fantastic music. You can find out more about them and buy their wonderful CD of nursery rhymes at [www.dixieticklers.co.uk](http://www.dixieticklers.co.uk)

I would also like to say a big thank you to my cousin **Phil Gallagher** AKA Mister Maker for coming to the party and talking to the children and their parents! He said he had a great time meeting you all!

**Jessica Cattermole**



**FOR ETC NEWS AND EVENTS, PLEASE READ PAGES 18 & 19**

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Christmas party  
invite on page 3**

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Our South London Area Contact **Eleanor Beardsley** is holding a coffee morning on **Friday 27th November** from **10am-midday** at her home in **Lewisham**. If you would like to join Eleanor then please email her at **south.london@echo-evelina.org.uk**.



**Dates for your Diary**

### Youth workers and admin help needed for ETC

Do you have experience working with older children and teenagers? Do you have some time, enthusiasm and commitment to spare? If so, why not volunteer to help our small but fast growing team at ECHO Teen Club (ETC)?

ETC is carrying out vital work supporting young people as they grow up with their heart condition, empowering them and building their confidence through social events, activity breaks, newsletters and collaborative activities with other similar groups – you can read more about the work we are doing on the special ETC pages of this newsletter (page 18 and 19).



If you are over 18 and feel you have something to offer this really special group of teenagers please do get in touch by calling **Jo Wilson** on **07921 775795** or email **director@echo-evelina.org.uk**.

### ECHO Committee

Following the article in the last newsletter, we had a fantastic response to our request for new volunteers. Thank you very much to those members who contacted us to offer their services, particularly on ward visits, prenatal support and offering other vital skills and attributes, many of whom are now going through the induction process and will be actively working with ECHO very soon. However, due to a number of Committee members moving on, we find ourselves now looking for some new faces to join our friendly and vibrant team on the Management Committee. If you have some spare time and might be interested, why not contact Jo Wilson (**07921 775795** or **director@echo-evelina.org.uk**) and she'll send you an "Introduction to Volunteering with ECHO" pack which contains all the information you might need.

### Margaret Arnell



Margaret Arnell and family

We are very sad to tell you that Margaret Arnell, Vice Chair of ECHO, her husband Nick, and son Aaron (10) are moving to Australia at the beginning of November. Many of you will know Margaret Arnell or will have met her during the past nine years, as she has supported so many parents both over the phone and in person, as well as on the website forum, and has undoubtedly made a huge difference to so many people through her unflinching commitment and dedication to

ECHO. Margaret and Nick have not been without tragedy in their own lives, but despite all their sadness and sorrow have managed to find space in their hearts to help other people and for that reason have made even more of an impact on their friends, colleagues and fellow members at ECHO. They will all be sorely missed (Margaret, we're keeping that chair at the conference table free for you, as it could never be filled!), but we wish them all the luck and love in the world for their adventure on the other side of the world. We know that they will keep in touch, and remain members of ECHO, so we will keep you posted, through the newsletter, on what they are up to down under! **GOOD LUCK DEAR MARGARET, NICK AND AARON!!!**

P.S. Who's going to make the sandwiches for the Christmas party this year???

### A night at the Opera

We are delighted to announce a really exciting evening of music being held to raise funds for ECHO. Four opera stars of the future will be singing much loved songs and arias from operas and musicals at the historic St. Olave's church in the heart of the City of London.

Details are as follows:

**Date: Wednesday 25th November**

**Time: 7.30 pm**

**Venue: St. Olave's Church, Hart Street, London EC3R 7NB**

**Ticket Price: £20.00 adults/£7.00 children and students (includes mulled wine, soft drinks & home-made mince pies).**

We will also be launching heart-shaped sky lanterns in the church courtyard after the concert to send a message of love and hope to all our heart-children. These will cost £5.00 each and all profits will go to ECHO. Why not come along, watch this fantastic spectacle unfold in the night sky and send your own message?

If you would like tickets for this wonderful event, please send a cheque, made payable to ECHO to **Jessica Cattermole, PO Box 5015, Brighton, BN50 9JR** by no later than **9th November** with a note stating how many adult and children/students tickets are required. **Tickets are limited to 75 people so don't delay!**



### School Engagement

ECHO is committed to developing more structured relationships with Schools in order to develop events and activities that support both fundraising and raising awareness of congenital heart disease. We are looking for a volunteer, ideally a member of ECHO, to lead and co-ordinate our efforts. This will include developing a programme of events and activities and co-ordinating the means by which we engage with schools. This is a critically important programme for ECHO and it an important part of our future strategy. If you have the enthusiasm, some spare time and a good knowledge of how to engage well with schools we would love to hear from you.

Please contact **Grant Taylor** (details on the back page of this newsletter)

### SAVE THE DATE - ECHO Conference and family weekend 2010

Following the resounding success of this year's AGM and Conference in June, we have decided to book next year's nice and early so that you can "save the date".

We have reserved **Saturday 12th June 2010**, and will once again be returning to the Grange City Hotel, near Tower Bridge, who looked after us to splendidly last year. We will be sending out formal invitations in the early Spring but in the meantime please make a note in your diary!

**ECHO Christmas party Sun 6th Dec**

We are holding the **ECHO Christmas party on Sunday 6th December 2-5pm at Millwall Football Club in South London**. There will be lots for the children to enjoy at the party: an entertainer, a disco, magic, arts and crafts and even a visit to Santa in his grotto!

We would love to see you all, so if you would like to come please complete the slip below and return to me with a **SAE and a £10 deposit cheque** made payable to ECHO to **ECHO, PO Box 5015, Brighton, BN50 9JR** by **Friday 13th November**. If you would like your deposit cheque returned please see me at the party otherwise we will treat it as a donation towards the cost of the party.

Full Names of adults

Full Names and ages of children

Full Address

Postcode

Telephone

Email address

I would like \_\_\_ adult tickets and \_\_\_ children tickets for the **Christmas Party**.



We are searching for a **Father Christmas (or two to share the role)** to hand out presents at our Christmas party. Please contact Jessica if you know a suitable person to take on this important role. Thank you.

Please note that this event is open to ECHO members and their children only. Please reply by **Friday 13th November 2009**.



# Emilia's Story

Emilia is an inspiration to all who know her. Her strength and determination to enjoy life is amazing, and she makes us so proud to be her parents.



Emilia enjoying bath time!

Relaxing on the sofa, I often pinch myself that I have a beautiful daughter asleep upstairs in her own room. How my life is very different now! Becoming a mum is amazing, but being the mummy of a heart baby is every day, another day I get to enjoy her smile and see her grow and live her life. It sometimes feels so unreal that she is even here.

Reading other children's stories I often remember our own experience. The 21 week anomaly scan that confirmed there was a problem with our baby's heart was also the scan that gave our daughter her name, Emilia Hope Webb. From that day she has let us know she is a fighter!

I often remember finding the dove feather later that day, and my husband saying there is our sign that our little girl will be safe. A weekend of worrying followed about what would be found on

the Monday at Foetal Cardiology at the Evelina Children's Hospital. The Monday could not come quick enough in some ways. When the scan was over, all of our fears were more profound when we were told by Dr Sharland that our daughter had Hypoplastic Left Heart Syndrome. I just wanted someone to tell me that she had a chance, however big or small. Dr Sharland explained the surgery that could be performed and the risks they entailed. There was a chance for our baby girl; we knew we had to remain positive. The next few months seemed to be filled with hospital checks and preparations. At home we fought with emotions of carrying on as normal like other first time parents; with the fears of will we be bringing our baby home.

It was soon Sunday 27th January 2008 and we arrived at St Thomas' Maternity Ward for me to be induced. When they checked me over it was discovered that Emilia was already on her way, another sign that she wanted to be here. Monday 28th January 2008 at 1.14pm, Emilia Hope Webb weighing 6lb 6oz came screaming into the world. When she squeezed my finger so tight I knew she was saying don't worry mummy I will make you proud of me. She was a perfect colour, and was wriggling all over the place. That was the one time that I thought there is nothing to show

that she has a heart condition, maybe they made a mistake.

After 2 days in PICU care Emilia had the Norwood Stage One procedure. The days following are a blur with moments of real highs when she seemed to be improving, to times of worry when her future seemed quite bleak. The PICU team were faultless in their care, and Emilia enjoyed many a night time cuddle with one of the nurses. After a week, she improved enough to transfer to Camel Ward. She continued to improve over another week, and we were told that she would be transferred to our local hospital. I was extremely happy to be moving closer to home, but was also very nervous about leaving the security of the Evelina. We had gradually been weaning ourselves off of watching the monitors all the time, and on the last day Emilia was detached from them completely. It was so exciting to see her free of all the canulars and tubes. We had our daughter again, and it was fantastic to see what she really looked like.

When we were transferred to our local hospital, her daddy said I am bringing my girls home on Valentine's Day. Emilia must have been listening as he got his wish. The months seemed to pass by and with the support of family and friends we coped with being first time parents. It was difficult sometimes



Emilia in hospital

because you didn't want to be a neurotic parent but also you knew that protecting her from infections was your utmost priority. I felt quite lonely not being able to take her to play groups like other mums were doing. I was fortunate though to have a good health visitor who put me in contact with a lovely group of first time mums, who have and continue to be good friends and are a great support.

Emilia's health started to deteriorate in

August 2008, and in September she had her second operation. She only spent a day in PICU and then she was transferred to Camel Ward again. It seemed strange to be pleased to see nurses and consultants you knew from last time, but it was a great comfort to know they knew Emilia. Emilia made a quick recovery and she was home within a week.

I think she changed her mind about being at home though, and was

missing the friends she had made, because 10 days after returning home she was admitted back into hospital after they found fluid around her heart and lungs. The fluid was what they call Chylothorax, which is a fatty fluid. They put in a drain to take away the majority of the fluid and then the rest was controlled by a 1g of fat a day diet. She was soon home again.

Emilia took it all in her stride and by the November was ready to make real steps forward. She went from not even sitting up on her own before the second surgery to at 13 months taking her first walk across the room. There is no stopping her now, she runs around with her friends, and does not stop talking all day. You would never know the fight she has had on her hands in the first year of her life. It will be a few years before her final stage of surgery, so we are now enjoying being able to be a normal family. We are off to Spain for our first family holiday in the next few weeks. We can't wait!

Emilia is an inspiration to all who know her. Her strength and determination to enjoy life is amazing, and she makes us so proud to be her parents. She brings such laughter to our family, and is our special little girl. She is a gift that always brings us joy and happiness every day. **Claire Webb**

# Fundraising

I would like to thank all our members and their family and friends who have raised and donated such a fantastic amount over the summer months. As always I am unable to mention all of you but I would like to share with you a few of our members fundraising efforts.

Thank you to **John Moynihan** who took part in a charity bike ride and raised a total of £958. He chose to support ECHO as earlier this year his granddaughter Evie Moynihan greatly benefited from ECHO's support. "As a team of 5 riders, we started our ride from the Church of Scotland office in Edinburgh on the 24th June and on the first day rode down to Corbridge in Northumberland. On the second day we rode down through York and stopped overnight in Scunthorpe. From Scunthorpe on day three we rode through Lincoln and stopped overnight near Cambridge. On the final day, we rode down to Ware and the Lea Valley before finishing at the Church of Scotland in Convent Garden in London. The overall distance completed by the whole team was 422 miles and I rode 140 miles over the four days. The weather was very good apart from some rain on Friday afternoon and a huge thunderstorm on Saturday as we entered London. Fortunately, I wasn't riding either of these stages." Well done to all of the brave cyclists! John is pictured third from the left and the photo was taken when they finished in Covent Garden, London.



John Moynihan

Thank you to **Margaret Beardsley** who raised £100 from car boot sales. "My granddaughter Elise McCarvill has benefitted from the care and expertise of the Evelina Children's Hospital and she and her family have received invaluable support from

belonging to this organisation, not to mention the special days you arrange when everyone can get together and enjoy themselves. Keep up the good work – it is so appreciated by grandparents as well as everyone else." Thank you Margaret.

ECHO member **Fiona Gilman** ran the Bupa 10k in London and raised over £1400. Well done Fiona!

Another ECHO member **Nathaniel Scott Cree** also ran the Bupa 10k to raise funds for ECHO. "On a drizzly day last May, I ran the Bupa London 10k on behalf of ECHO. Until that point in time, my experiences of gyms consisted of making meagre membership enquiries via e-mail, and as for running, making the bus or the last train left me short of breath and sweating to an embarrassing degree. But last November I felt inspired to do something which would involve raising funds for ECHO. A run seemed like the obvious start.

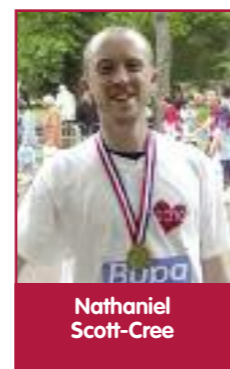
Our daughter, Lucy, had been looked after at the Evelina roughly eighteen months previously, and as a family we had joined up with ECHO and were looking forward to attending the Christmas party. Running a distance of ten kilometres seemed to be a sensible start, but as I found out when I began training, it was more than a fair distance to complete in one go.

And so, I ran a couple of times a week, and around March of this year, I created a page on the Just Giving website and began the process of telling all and sundry of my exploits. I was immediately overwhelmed by the response. Within a week I had raised the best part of a thousand pounds. Everyone we knew wanted to give money to ECHO because they understood what it meant.

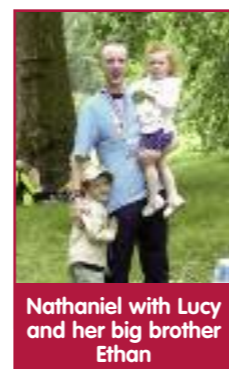
Race day finally arrived and I set off early for St James' Park proudly wearing my ECHO t-

shirt. With 12,000 other runners there was a fantastic atmosphere and I was instantly hooked. Coming along The Mall with the finish line in sight, I caught sight my family off to the left cheering me on. It was a wonderful feeling. Even better than that was my finish time of 50:48 and the medal around my neck.

The final total raised was in the region of £1600. I was delighted. Next year, I aim to go a step further and run the Royal Parks Half Marathon. The year after that? We'll see! Perhaps you will be wanting one of our entries for the 2011 London Marathon Nathaniel!!



Nathaniel Scott-Cree



Nathaniel with Lucy and her big brother Ethan

Thank you to class 7HB at **Guildford High School** for raising £86.23 through a cake sale.



Sophie at the Mexican Feast

At Sophie Bartlett's school, **St Bernard's Preparatory School** her teachers Ms Underwood and Mrs Gabb organised a "Mexican Feast" to raise money for ECHO. They also collected money at the school play called "The Goblin Next Door". They raised a total of £146.86.

ECHO member **Rachael Cooper** raised a fantastic £654.27 at her annual Garden Party. Thank you so much Rachael.

**Paul Conn** raised over £700 running the Edinburgh marathon "This is for one little boy, his mum and dad Kate & Steve and little sister Grace and his Grandparents who love him very much, especially Peter and Christine who have provoked me to action by

their dedication to him." Paul told me that he nearly won but was narrowly beaten finishing 2 hours after the winner!!

ECHO member **Grace Malpass** and **Jon Bevan** requested donations rather than wedding gifts and raised a total of £800 at their wedding. You can read more about their wedding on page 12.

Thank you to **The Lake House Charitable Foundation** for their very generous donation of £5,000.

ECHO members **Alison and Kevin Botten** said "Our 2nd son Liam was born in March 2008. Queen Mary's Hospital had identified a heart murmur but wanted to check if there were any other issues. They arranged an appointment at the Evelina for Liam the following week. We went to the appointment and Liam was diagnosed with Tetralogy of Fallots. At the time we were very upset and could not believe he would have to go through a heart operation. Everyone at the Evelina was very kind and made sure that we had a lot of support. They gave us contact details so we could call if we needed to ask anything. The Evelina monitored Liam monthly until his surgery was due. While Liam was in hospital having his treatment and recovery we found out how wonderful the Evelina and ECHO was, and how much support they offered to families. Liam is now doing really well and we would like to thank all that helped him." Kevin and his friends recently completed the London to Southend bike ride and raised £810 for ECHO.



from left - Stephen McCrorie, Stephen Corkery, Liam & Kevin Botten

Thank you to Pam Price and her brother for nominating ECHO to receive £290 from the **West Lancashire Metal Detecting Club**. Pam said "A few weeks ago a group of metal detecting enthusiasts contacted my brother to ask if they could hold a rally on his farm land and in exchange they would donate money to his chosen charity. My brother passed the charity nomination form on to me and naturally we chose ECHO"

Thanks to **Matt Davies** who held a coffee

morning on 2nd October and raised a fantastic £500. Matt said "I choose ECHO as my charity choice, as a result of the wonderful support my brother and his family received when my niece Caitlin was treated at the Evelina Hospital in January 2009. The support my brother, his wife and the whole family received helped ease the anguish and anxiety experienced by all. Needless to say, my niece Caitlin has not stopped since leaving Evelina's and has recently started nursery in the Isle of Mann.

We all praise the hospitals, doctors and nurses and will always appreciate their excellence but I wanted to thank ECHO for the support they offered my brother and his wife when they needed it. I decided to do this by hosting a dress down day and coffee morning event in my place of work (the International Baccalaureate) which also included a prize raffle draw with some unusual gifts to say the least. It was an excellent event, and even though it was only 30 minutes away from their desks, the mountains of cakes and biscuits soon disappeared. So I hope that the money raised will help to support other children and families who need it, because there is always light at the end of the tunnel. My niece Caitlin and many other children are evidence of that".

Finally a huge thank you to **Lauren Robbins**. Lauren and her friends raised a fantastic £100 for ECHO. "We raised the money by holding a cake sale at Chalford Hill School on Friday the 19th June, having it at playtime and at home time. We wanted to give something back to Evelina Children's hospital as a big thank you for looking after my brother Charlie so well when he had his heart surgery. I hope to organise more fundraising events in the future as it was lots of fun". Thank you so much Lauren and friends Lottie, Emma, Hannah and Maddy!



Lauren Robbins cake sale

Jessica Cattermole

## The Grim Challenge 09

Have you got what it takes to run, wade and crawl this 8-mile off-road challenge?

ECHO has 50 guaranteed places for **Saturday 5th December**, so if you're mad enough (and fit enough!) why not take part in this gruelling but fun event? Take a look at their website: <http://www.grimchallenge.co.uk/grim-original/> and if you'd like a place, please email [admin@echo-evelina.org.uk](mailto:admin@echo-evelina.org.uk) or call Jessica on **07943 625031**.



## Phoenix Greetings Cards

Two separate independent traders of Phoenix Greetings cards have recently donated the proceeds of card sales to ECHO. Bizz Thackray (<http://www.phoenix-trading.co.uk/web/bizzthackray>) has nominated ECHO to receive a percentage of all her sales, whilst Joanna Haines (who many of you will have seen at the ECHO Summer party) donated a percentage of the sales of a special heart greetings card to us, as well as from sales at the Summer party. A huge thank you goes to both ladies for their generosity!

A message to all our fantastic fundraisers. Please could you always get accurately completed sponsorship forms and please remember to remind your sponsors/donors to tick the Gift Aid box if applicable. If you are collecting money without a sponsor form you can download a gift aid form from our website at [www.echo-evelina.org.uk/how-you-can-help/donate-offline/](http://www.echo-evelina.org.uk/how-you-can-help/donate-offline/) Thank you.

# Fundraising

## The Shoemith family ECHO fundraising shenanigans

Our involvement with ECHO started 7 years ago when our daughter Holly was diagnosed with Aortic Stenosis and had her first treatment at Guys when she was 8 weeks old.

ECHO have always been there and have always been fantastically organised and helpful so we have always looked for our own opportunities to do our little bit to give something back. OK we don't have the backing of big business or the availability of corporate sponsors but raising the profile of heart children and perhaps a few extra quid is the priority.

On 6th September Carol and our other daughter

Caitlin (who has just turned 11) ran the Adidas women's 5k run at Hyde Park to raise funds & awareness for ECHO. It should have been a straight forward sunny Sunday jog with the odd 10,000 other women but it had taken a bizarre twist back in June when Carol had an unfortunate accident at a friends wedding when she turned her ankle with the assistance of 4" heels and a step (no alcohol was involved...genuinely). Carol's participation was in doubt for a long time as she had torn ligaments and was on crutches for ages. But she soldiered on and gritted her teeth and completed the run. The girls did a fantastic job and are proud to say that they came in a bit behind the Kenyan 10,000 meter world champion but a little way in front of Jo Brand!

Dad, Bob has raised money for ECHO before by laying on a rock concert in Hastings and not to be outdone by Carol decided to do the same again at Hasting Police station Social Club (Carol is a Police Officer). So, on the 19th September the club was decked out in heart shaped



Carol and Caitlin Shoemith



The Undecided and Holly Shoemith

balloons, tickets sold and some amazing raffle prizes were drummed up by Hastings beat officer PC Paul Eastes from local stores. The only downside was always likely to be that the club only held a limited amount of people, but the denizens of Sussex Police and their families did the event proud and filled the room. The band (made up of Bob and various other musically minded constables) called The Undecided played for the evening and the beer and raffle tickets flowed. It was a very good night.

So far our fund raising is over the £400 mark and as I write donations and pledges from various places are still coming in which will push the total, hopefully a bit higher. **The Shoemiths**

**Thank you very much Carol, Bob, Caitlin and Holly!**

## Adidas Women's Challenge Autumn 2009

I would like to thank all our members and their family and friends for taking part in the Adidas Women's 5km Challenge on Sunday 6th September in Hyde Park, London. I have received some lovely stories from some of the runners and wanted to share them with you.

Louise Davies took part in the run and raised over £1,000. "I wanted to do something to raise money for ECHO as my God Daughter Mia was about to go for further open heart surgery and I just felt completely helpless. My original intention was to run the London Marathon 2010 as I really enjoy running however last month I found out I was pregnant so thinking that my original plan was a bit ambitious, I decided to sign up for the Adidas Women's 5k instead!

Mia is an inspiring toddler who has shown more strength and bravery than I ever thought possible. I felt that running for ECHO was the most positive way to help little Mia and other children in similar positions. ECHO has provided an amazing amount of support for Mia's Mum Laura and I hope the money I've raised helps this good work to continue. So far I have raised £1025 and have further charity events planned for this year. I still have plans to run the London Marathon for ECHO in the future so watch this space!" Thank you Louise!

ECHO member Natasha Goldsworthy also ran in the race and raised a fantastic £2,000. "My fiancée and I chose ECHO

because of the wonderful care and support we received when our baby Sonny was diagnosed with a heart problem. Their care and understanding helped us through a



Natasha (right) and her friend Kate Lee

bad time in our lives. We would like to say an extra special thanks to Annette and Dr Miller who helped us through this time." Thank you to Natasha and Steven and Natasha's running partner Kate Lee!

Julie Hitchings took part with ECHO member Sam Elborn. Julie said "I completed the London 5k run in September. I managed to raise £75.00 mainly through office donations as I hadn't got myself organised to raise sponsorship properly! Both Sam and I saw a few ECHO runners at the event which was great fun as usual. I hope that the event managed to raise both awareness for your charity and much needed funds. We will both be

back next year as this is becoming a regular for Sam and I!" Thank you Julie and Sam.

Thanks also to Keelie and Sharon Goodwin for taking part. Keelie said "We didn't run together as Sharon is a lot faster than me - I think she did it in 27 minutes. I didn't time myself but I was caught up in people traffic so didn't go as fast as I would've liked! I raised about £100 and Sharon raised a similar amount. Her company, BUPA will be part-matching the amount she raised." Thank you Keelie and Sharon and to everyone who ran for ECHO!

If you would like to take part in next year's Adidas challenge, please email me and I can send you a runners pack next year.

Jessica Cattermole



Louise Davies

## LAST CHANCE TO ABSEIL DOWN GUY'S TOWER!

We are delighted to have been able to confirm another charity abseil down Guy's Tower next year on **Saturday 15th May 2010**. This will be the last year ever that Guy's Tower will be "abseilable" as the Trust is refurbishing the exterior of the building starting in 2011, so this will be your last chance to play Superman/Wonderwoman and raise money for ECHO at the same time. Last year, we managed to fill the 35 places in no time at all, with a waiting list at the end, and raised a colossal £31,000 in the process, so if you'd like to have a go next year, and are confident you can raise £200 or more sponsorship, please reserve your place as soon as possible by emailing **Jessica Cattermole** on [admin@echo-evelina.org.uk](mailto:admin@echo-evelina.org.uk).



# Ben's Journey

On 23rd December 2004 at my 23-week scan my husband and I were given the devastating news at our local hospital that our baby had a heart defect.

We then had an agonising wait over the Christmas and New Year break for an appointment at Guys where we were told the news that our baby had a very serious heart problem. The next few weeks were a total blur trying to deal with this life changing news, we were given the option to terminate the pregnancy but we both agreed we had to give our baby a fighting chance. We visited Dr Simpson at Guy's each month for prenatal scans which indicated our baby had a 95% chance of being born with Hypoplastic Left Heart Syndrome (which is where the left side of the heart doesn't grow). We then visited the surgeon Mr Anderson who explained our baby would require 3 open heart surgery procedures within the first 2 years of its life to try to correct his heart function. To try to come to terms with this scary diagnosis my husband and I spent many hours on web trying to gain as much information as we could, This is where we first came across the ECHO website, it suddenly made us both realise that hundreds of other families had travelled this path before us and that our fears and worries were the same as every other parent. It was a great comfort to know we were not alone.

On my previous pregnancy with my daughter I had ended up needing a caesarean, I knew this time round our baby would be rushed across London to Guys PICU straight away so I was determined to give birth naturally, I desperately needed to be mobile. After 38 long hours of labour at 15.38 on 12th April 2005 baby Ben was born naturally at St Thomas – he looked just perfect, it didn't seem right he could be so unwell. I was



Ben two days after surgery

able to give him a quick cuddle before my husband accompanied him in the ambulance to Guy's. He was given his first ECHO and we were told like a miracle that thankfully Ben had beaten all the odds and his left ventricle, although smaller than normal, did function, he no longer had HLHS. He was now diagnosed with Critical Aortic Stenosis and had a damaged mitral

valve. At 24 hours old he was given his first balloon dilatation to open his aortic valve, as anyone knows who's been there, it's the hardest thing in the world to hand over your child and not know if they'll make it through the operation. Thankfully Ben did and after 2 weeks we were able to take him home for the first time.

6 months later Ben needed 2 more balloon dilatations, one of which

unfortunately went wrong when the balloon burst inside him. It was such a scary day, just waiting and waiting for news, then being taken into the family room to be told something had gone wrong during the operation. We were reassured that Ben was ok, but they needed to keep him under very close observation in PICU. A vascular surgeon was called in from Kings College to assess Ben - they knew

he still had pieces of the burst balloon in his veins and they needed to decide if they should operate to remove them. After much discussion between the heart team and vascular surgeon it was decided not to operate, but to monitor closely. Ben recovered quickly, he was back in the ward the following day and home the day after. Thankfully the burst balloon has not given him further problems.

Ben returned home and apart from the 6 monthly hospital check ups life over the next 18 months was pretty normal and Ben grew from a baby into a cheeky toddler. Most of the time you would never even know Ben had a heart problem, but sometimes when he raced around chasing his friends he would get tired and very hot and sweaty. We knew that the dreaded day of further surgery was getting closer and a scan just after Ben's 2nd Birthday showed that indeed his aortic valve had narrowed. Mr Anderson spoke with us to explain he would need open heart surgery the following month, we both knew this day would one day come, but nothing prepares you for how fearful it makes you feel.

On 10th May 2007 Ben was admitted to Savannah Ward at the Evelina, his first stay in the new hospital ready for heart surgery the following day. That night I lay in the pull-out bed next to him watching him while he slept, treasuring every moment and praying everything would be ok. Morning eventually came and, with a feeling of dread only us parents know, it was time to take him down to theatre. Holding Ben as he fell asleep in my arms and kissing him goodbye was one of the hardest things any parent can do, but reassured as we knew Ben was in the capable hands of Mr Anderson and his team. The next 5 hours were the hardest hours of our lives and seemed to drag on forever, then

eventually we got the call to say Ben was ok, the surgery had gone well and he was on his way back from theatre, the relief we felt was overwhelming and so emotional.

Although we'd had seen photos of children after heart surgery and thought we'd prepared ourselves for seeing Ben with all the tubes and wires I don't think anything can truly prepare you when you see your own child laying there. Mr Anderson arrived explaining he was very pleased with the way the surgery had gone. He had widened the aortic valve and repaired the mitral valve to such an extent he hoped it could last Ben until his teenage years, this was the best news we could ever have hoped for. Ben's recovery from the surgery was amazing, he was sitting up in 2 days, out of IPCU in 5 days and back home in 8 days, just incredible!

Ben is four years old now and achieved his first big milestone this month - his 1st day of school!! To be totally honest there's been times over the past 4 years we wondered if this day would ever come. Both Ben's school and the Evelina have been fantastic. Ben's head mistress, never having a heart child in her school before, wanted to ensure both her and her staff were fully aware of Ben's restrictions so invited Catie Chou (Ben's Outreach nurse at Evelina) to meet with her team so Catie could explain exactly what signs physically to look out for in Ben and which activities he

should and shouldn't do. The school found this meeting very beneficial and now have Ben's picture up in their staff room so everyone knows who he is and can act if he starts exerting himself too much!

Ben's recent scans have shown that his aortic valve is starting to narrow again and there is talk that he may need further surgery within the next 2-3 years, but we'll deal with that bridge if and when it happens. In the mean time we are just enjoying life as a family, watching Ben go from strength to strength in everything he does, blissfully unaware of what a special brave little boy he really is.

Debbie & Kevin Houghton



Ben with his sister Charlotte on his first day of school in September

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 that you have sent in.



Cutting the cake made by Mandy from Timeless Treats who is a fellow member of ECHO

ECHO member Grace Malpass celebrated her wedding in June and wrote the following for us to share with you. "I married Jonathan Bevan on 19th June 2009 at St Lawrence Church, Bidborough. I was born with a congenital heart defect and my

family and I have benefitted greatly from the help and support of ECHO over the years. As a thank you to ECHO, Jon and I decided that instead of wedding gifts, we would ask our family, friends and loved ones to make a donation to ECHO and we raised £800 for the charity. As a child with a serious heart defect, my family and I were never sure what the future would hold. I am so grateful and lucky to have been given the opportunity by the brilliant cardiac team at Guys and St Thomas', to enjoy my life. ECHO helped my parents so much when I was little, their support and care gave them a strength that we all needed. I have found a wonderful, kind, caring man and I appreciate everything I have. Our wedding was a beautiful day filled with so much love, laughter and happiness. To have raised such a lot of money for ECHO really was the icing on the wedding cake!"

Miriam and Johnny Roberts son Lenny was born in July with TGA and a VSD. Miriam sent this wonderful photo of Lenny and wrote "Lenny is nearly 9 weeks old now and he is fab and doing fine. Thanks so much to all the amazing staff at St. Thomas and the Evelina. We are so grateful for the way both we and Lenny were looked after during our time there, also for the support that we received from echo members during the pregnancy. Thanks to everyone"



Lenny Roberts



Sophie Bartlett



Freya Embden-Kane



Jack with his sister Mia



Ewan Grant

Mel Fidge couldn't resist sending this picture of Jack and his sister Mia. Jack has started full-time nursery and is going to start reception in January. A wonderful photo, thank you Mel!

Sophie Bartlett won a "highly commended at an Irish Dancing competition (or "Feis" in Gaelic) which she recently took part in. Well done Sophie!

Freya Embden-Kane started nursery school in Uckfield in September and she absolutely loves it! I would like to wish Florence, Paul and Freya good luck in their new home. Brighton members will miss you but at least you have not moved too far away and can still make my ECHO coffee mornings!!

Jackie Grant sent us a photo of her two and half year old son Ewan who started preschool in September, half a day twice a week. Jackie said "This was taken on his return from playgroup on the first day. Just before he threw a tantrum because he wanted to go back to nursery!"

Thank you all for your lovely contributions to our happy events and milestones piece. If you have any special news you would like us to include in the next issue then please email me at [admin@echo-evelina.org.uk](mailto:admin@echo-evelina.org.uk)

Jessica Cattermole



Grace and Jon

## Seasonal & Swine Flu Vaccination Programmes 2009

The following information has been provided by Dr. Esse Menson, Consultant in Infectious Diseases, Evelina Children's Hospital:

Every year, children with severe or complex heart conditions are advised to have the seasonal flu vaccine because they are at risk of severe or complicated disease if they get flu. The same applies this year, and your GP should contact you as soon as the seasonal flu vaccine becomes available. If you are not contacted you should call your GP's surgery instead.

In addition, this year, the H1N1 swine flu vaccination will initially be offered to those at highest risk of severe disease from flu, that is children (over 6 months of age) and adults with underlying health conditions including severe, complex or uncorrected heart conditions. The seasonal flu vaccine will not protect your child against swine flu or vice versa, so to be protected against both these types of flu your child will need to have both vaccines.

The seasonal flu vaccine is likely to be available first this autumn/winter and the swine flu vaccine a little later, but the seasonal flu and swine flu vaccines can be given at the same time as other vaccines and they can be given together. The recommended schedule for swine flu vaccination in children is 2 doses, 3 weeks apart.

If your child has had **confirmed** swine flu they do not need to have a swine flu vaccination. If your child is **thought** to have had swine flu but it was not confirmed by samples from nose or throat processed in a laboratory, then you cannot be certain that it was swine flu – it may have been a different respiratory virus – and it is best for them to have the swine flu vaccine. If your child has severe egg allergy, discuss with your specialist as attention may need to be given to which swine flu vaccine preparation they are given. The Evelina has an excellent allergy service that can also advise and assist in difficult cases.

You may be interested to know that there is a clinical trial for swine flu vaccines in children (run by the Health Protection Agency) through a number of hospitals and vaccine research centres: St. George's London, Southampton, Royal Devon & Exeter, Bristol and Oxford; visit

[www.swineflutrial.org](http://www.swineflutrial.org) for more information. This trial is open to all children (healthy children and those with underlying health conditions) between the ages of 6 months and 12 years (before 13th birthday) who meet the trial conditions, so you may like to use this as a way to get your children vaccinated against swine flu sooner than would otherwise be possible.

### Medication to prevent or treat Swine Flu

Aside from the swine flu vaccination programme, there is still effective medication to prevent swine flu (prophylaxis) or to treat it – this is usually Tamiflu. The advice remains unchanged for using Tamiflu to prevent illness in those with long term heart conditions if they have direct close contact with someone with swine flu, either in their household or at school. If children with severe or complex heart conditions are exposed to swine flu in this way, they should be offered Tamiflu as soon as possible to prevent them getting flu, rather than waiting for symptoms to develop. Discuss this with your child's GP or Cardiologist.

The current up to date guidelines from the hospital regarding swine flu diagnosis, prevention and treatment are contained on our website: [www.echo-evelina.org.uk/information/swine-flu](http://www.echo-evelina.org.uk/information/swine-flu).

### RSV Vaccination

Remember that this winter many colds and flu-like illnesses may not be caused by swine flu, but by the range of respiratory viruses that normally cause these illnesses. RSV (or Bronchiolitis) is one of the common viruses which can affect babies and young children. There is a special vaccine against RSV which can help certain babies and infants with severe lung disease and also a few with complex or severe heart conditions. Your child's Cardiologist will advise if your baby or infant needs this vaccine.

There is a very good information sheet on the ECHO website, written last winter by Dr. Esse Menson and Dr. Thomas Krasemann, which can be used in conjunction with the above guidelines.

Just visit [www.echo-evelina.org.uk/information/flu-jabs](http://www.echo-evelina.org.uk/information/flu-jabs)

14TH OCTOBER 2009

## Safe and Sustainable Paediatric Cardiac Surgery Services



You will all have recently received, either by post or by email, a survey, sent out by the Children's Heart Federation, relating to the Safe and Sustainable Paediatric Cardiac Surgery Services review currently taking place in the UK. I hope as many of you as possible were able to relay your views and concerns via the survey, which will be used as an important tool to ensure that the needs of heart-children and their families are paramount in any changes which might result from the work being undertaken.

A set of draft minimum standards has recently been circulated to clinicians, managers and parent/patient representatives for comment and feedback, which in turn we have sent to as many of our member families as possible. All comments will have to be submitted by 10th November and this will drive the final set of Standards to which all hospitals will have to comply in order to maintain their status as Specialist Centres for Paediatric Cardiac Surgery. Once the standards are applied it will make it possible to identify hospitals which fall short of those deemed necessary to safeguard heart-children, and will probably result in reconfiguration of the service creating fewer but larger centres.

I have been involved in the process leading to this point for many years, representing ECHO and all Evelina families on a Paediatric Congenital Cardiac Services Review Working Party, so I am pleased to see that the work undertaken over the years in preparation for these final stages is finally reaching fruition. I will continue my involvement through the remainder of the review and implementation process, with a view to safeguarding all Evelina's heart-children and their families, and the services which they rely on and hold dear.

**I will endeavour to keep you updated through emails and through the newsletter, but if you would like any further information or background to the programme, please contact me on [director@echo-evelina.org.uk](mailto:director@echo-evelina.org.uk).**

Jo Wilson – Chief Executive

# Catriona's story

**My second pregnancy took me by surprise. Not the fact that I was expecting a second baby – but the fact that I wanted another child at all. Only a few months previously my husband and I had been quite convinced that we were happy to remain a little family of three. But as our daughter Abby started pre-school, we found ourselves wondering what another child would be like and we couldn't resist.**

We were immediately excited at the prospect of our new baby, due in August 2007. I felt well and had no real anxieties. Although I did fret to Ed, my husband, about the implications of having an August baby: 'It'll always be the youngest in its class at school.' Ed, an August baby himself, raised an eyebrow and observed that it hadn't done him too much harm.

I knew straight away that I wanted to have this baby at St Thomas' – our second closest hospital. We went for the 12-week scan feeling like old hands. The scan, although technically the 12-week one, actually took place during the fourteenth week – too late for the nuchal test to determine the risk for Down syndrome and other chromosomal abnormalities. The sonographer recommended that I go for a blood test instead. But I didn't bother. I couldn't see what use the information would be: I had no intention of having anything so invasive as amniocentesis, and I already had a perfectly healthy child. I didn't know anyone who had a child with a serious medical condition or a disability, so it wasn't on my radar at all.

When the time came for the 20-week scan – at 21 weeks – we took Abby along with us. We had told her all about the baby, and we thought it would be interesting for her to see the earliest pictures of her unborn brother or sister. But the sonographer said that she wasn't getting very good pictures of the baby's heart, and asked me to go for a walk to see if it would move into a more obliging position. So we walked around, and

waited to be called back in, and waited some more. Waiting patiently isn't really my thing, and I almost didn't stay – Abby was getting bored, it was a sunny Friday afternoon, and I didn't see the need to tick every box in the scan. We were called back in before I stomped off to the bus-stop – but I wonder what would have happened if I had?

The sonographer told us that she couldn't see four chambers of the baby's heart, and that we should have a specialist cardiac scan, just to be on the safe side. I asked what it might mean, if she couldn't see four chambers – but it wasn't her job to give us that kind of information. She mumbled something unclear about a single atrium, gave us a date ten days away for the cardiac scan, and said goodbye. I cursed in the lift at the inadequacy of the information we'd been given, and at the limitations of the NHS, which was going to make us wait an agonising ten days to find out what the problem was. Then I stood outside St Thomas' Hospital and cried – the first of many occasions I stood in the same spot and did the same thing.

At home, I hit the internet. I didn't know what to search for, but I finally found a phrase I thought I understood – 'hole in the heart'. So our baby might have a hole in its heart. Well, that wasn't so bad – lots of people had holes in their heart that corrected themselves. Not too much to worry about. Was there?

But the next ten days of uncertainty were hard to get through. Ed reassured me that all was probably fine, that the baby



had simply been lying the wrong way in the scan. But I knew from the sonographer's demeanour that she wasn't referring us for a cardiac scan simply as a formality. As we entered the Evelina for the first time on 23 April 2007, the world as we knew it changed.

Emerging from the scan, we were shown into a small room, with tissues on the table. We were offered a cup of tea. Tea and tissues – how bad could it be? The situation outlined to us by Dr John Simpson was complex. Some of our baby's heart problems were clear; some were not. There was an AVSD; there was a high chance of coarctation of the aorta; the left side of the heart was under-sized. We were trying to digest this, and trying to focus on Dr Simpson's sketches of how the heart works, when he told us that this type of condition is often associated with chromosomal abnormality. All I could hear in my head was 'Down syndrome'. And I could at that point imagine nothing worse than having a child with Downs – even though, in truth, I knew very little about what it really meant. But I feared for the impact of a disabled child on our family, doubted our ability to cope with such a child, and above all grieved for what it might mean for Abby, who was so excited about

having a playmate. How could we change her life forever with a sibling who might always be highly dependent?

Suddenly amniocentesis didn't seem unacceptably invasive any more. This time we only had hours rather than days to wait for the test. Then an interminable 48 hours while we waited for the first set of results. But we had no idea what we would do if we were told our unborn child had Down syndrome or some other abnormality. Ed and I talked about it, but reached no conclusions. I did more searching on the internet; went numbly to work; tried to imagine having a severely disabled child or having a termination at 23 weeks. Neither was imaginable.

So when the call came, and I was told that no chromosomal abnormalities had been detected, I allowed myself to relax. Our baby would need surgery, but we would get through it.

It was hard to stay relaxed though. I became preoccupied with whether the baby was growing properly and what other problems he or she might have. One of my consistent concerns was how still the baby seemed to be, how little it moved, and I wondered to Ed whether this baby would ever walk.

I felt like I was on a different planet to other expectant mothers. Finding ECHO was a big relief at this time, and the antenatal day we attended made us feel much less isolated. Being able to talk about what was happening with other people who were in the same situation helped us get through the final weeks, and I began to feel excited again. Another thing that helped was finding out that our unborn baby was a little girl. I needed a bit of help with thinking of this baby as a proper person and not just a collection of heart problems. And I figured that we'd have enough suspense on the day she was born. I was delighted to know that we were having another daughter, and it renewed my determination to do all I could to make everything come right for her.

Amy's arrival was strangely low-key. I had a planned caesarean due to her refusal (or perhaps, in retrospect, inability) to move out of breech position, and everything was in place – we put the date in our diaries, booked my mother to look after Abby, and took the bus to the hospital. It was all very

different to the chaos of Abby's birth at another south London hospital. Walking to theatre at 10.00am on 13 August 2007 and climbing onto the operating table, I was as ready for this moment as I could ever be.

Ed told me afterwards that the soundtrack in theatre was Babybird's 'You're gorgeous' as Amy was lifted out into the world. She appeared immediately above the screen, moving her hands together as if she was about to burst into applause. It was an amazing moment – and even though I knew she couldn't stay with me for long before going to intensive care, I had an overwhelming feeling that all would be well.

Our baby girl looked perfect to us in every way, and she was soon deemed to be the healthiest baby in NICU. She didn't need immediate surgery, and she quickly moved to SCBU where she lay in her cot looking totally self-contained and serene. We were amazed at her, and took her home at four days old with optimism outweighing our anxiety about her heart. Her cardiologist told us that he wanted her to grow a bit before surgery, and that he'd review her again in a few weeks.

But Amy was only nine days old when we

noticed how fast she was breathing after feeding. We wanted to believe that it wasn't significant, but our instincts took us back to St Thomas'. The rain poured down as I stood outside A&E, awash with tears and milk, as inside the hospital a junior doctor bent our tiny girl's hand in a fruitless effort to insert a cannula. We were admitted to Savannah ward for the first time, and had our first opportunity to appreciate the calmness and kindness of the specialist nurses. Amy's lungs were overloading as they struggled to cope with the volume of blood going back there, instead of pumping to the rest of her body. Diuretics were prescribed; Amy began to respond, and we gathered her up and went home. But now our peace of mind had gone – we were unable to relax fully around her, and we were constantly anxious. We began to realise that a big part of the challenge of being parents of a 'heart-child' is learning to manage anxiety and live with uncertainty.



As the weeks turned into months, Amy had further hospital admissions – there were further episodes of breathlessness, problems with feeding, and she was admitted twice with gastroenteritis. She had regular cardiac reviews, and we were aiming for 10kg as a target weight before surgery. But progress towards this goal was painfully slow. I came to dread the weekly weighing sessions at the local baby-clinic, where my baby remained tiny and floppy while others flourished. I



Now that I understand how difficult it is for Amy to do what other children take for granted, I see her in a whole new light.

dreaded people asking me how old Amy was, and I could never decide how much information about her heart condition I needed to share with casual enquirers. I felt profoundly isolated – as if I was carrying a burden that no-one else could begin to understand. The support from other ECHO parents helped, but when I heard the news that two of the babies whose parents had attended the same antenatal day as us had died shortly

after birth, I felt guilty for not enjoying my baby more when other people had lost theirs.

Amy was oddly 'distant'. She was slow to do things – smiling, reaching out for things, kicking her legs, 'talking' to us. She was hard to engage: she loved being cuddled, but didn't always make eye contact. She looked at what was going on around her, but she didn't seem to want to make herself a part of it, by reaching or rolling or grabbing. If I

coaxed her to hold something in her hand, she didn't hold it for more than a few seconds. When she finally sat unsupported at nine months, I cheered – she's getting there, I told myself, it's just going to take her a little while.

Our GP referred us to various specialists at the Evelina, but their focus was mainly on the impact of Amy's uncorrected heart condition and her persistent reflux, not on her delayed development. Everyone

we saw expressed the hope that once she'd had her heart surgery, she'd catch up. We hoped so too, but the anxiety remained.

When Amy was just over a year old, her cardiologist recommended her for surgery, even though she was still a long way off the 10kg target. It felt like her whole life thus far had been building up to that point. The night before her operation I held her in my arms, watched dawn break, and felt – just as I had on the day of her birth – that I was as prepared for this as I could ever be.

Hours later, I reflected that no wait for the phone to ring – for a job to be offered, or a boyfriend to call – had ever been like waiting for the call to say that Amy was out of theatre and in PICU. I marvelled at the strength of our child and at the skill of the surgeon and other professionals who looked after her during and after surgery, which had resulted in a successful repair of her AVSD. And we were amazed at her progress in the first 24 hours, as she paid attention to her surroundings, tried to pull out her arterial line, guzzled several bottles of milk, and even ate some food.

Amy continued to improve on Savannah ward, where she had more energy than she'd ever had before. She was still a bit of a puzzle, though, to the experienced nurses: she 'jittered' inexplicably, for hours, and she had developed a squint (intermittently, in both eyes) that hadn't been there before. The duty neurology registrar was called in the middle of one night; she wasn't overly concerned. And the cardiac registrar assured us confidently that if anything were amiss neurologically, 'she wouldn't be able to suck her bottle'.

The first weekend that Amy was home after surgery was like starting life with her anew. It felt like her battery had been changed. She seemed so much more energetic and engaged; she wriggled and rolled and grabbed for things; for the first time ever she put a little weight on her feet. She drank her milk, ate huge quantities of food and kept it all down. She gained a kilo in weight in the first month or so, and we couldn't believe the transformation.

But it didn't last. I can't pinpoint the exact moment when we went back to where we'd been pre-surgery, but only a few

weeks after her operation Amy started vomiting again, struggled to eat, showed less interest in her surroundings, and stopped trying to put any weight on her feet. We had an appointment with a geneticist at Guy's Hospital, requested before Amy's surgery by a paediatrician at the Evelina who suspected that something 'linked together' her various problems. The geneticist was reassuring. Examining Amy, she could see no sign of a chromosomal syndrome. She explained that AVSD could cause significant developmental delay, and her instinct was that Amy would catch up 'eventually'. We walked home from Guy's with a spring in our step – Amy would be fine, we just had to give her some time.

But she wasn't fine. An echo showed that her mitral valve had become leaky, but that wasn't the cause of the problem. She was as floppy as a rag-doll, and remained a passive spectator in our family life rather than becoming an inquisitive toddler. Sometimes her face appeared 'clouded', like an older person with dementia who is trying to make sense of their world. I began to search the web obsessively, focusing on the numerous syndromes associated with congenital heart disease, and I recognised Amy in many of the descriptions I read. But further chromosomal tests found no abnormality.

'Have you ever heard of Rett syndrome?' Those were the words of the consultant neurologist who observed Amy during a routine appointment with the medical feeding team at the Evelina in December 2008. I hadn't heard of it. None of my internet searches had led me in that direction, because I always started with Amy's heart, and there is no known connection between Rett syndrome and CHD. The neurologist went on to say that he thought it was unlikely, but he mentioned that there was a test that could be done. He also wanted Amy to have an MRI scan of her brain, to see if there was any identifiable reason for her developmental delay, such as cerebral palsy.

I left the hospital with my head in a whirl. I was reassured in some ways that the neurologist recognised straight away what I had been sure of for months – that there was 'something wrong' with Amy that went beyond her heart defect. But I found myself back to where I'd

been on the day we were given Amy's cardiac diagnosis before she was born – I could cope if I had to with an acutely ill child, but a permanently disabled one? I wasn't sure at all. The thought of cerebral palsy filled me with fear. And what was Rett syndrome anyway?

I soon found out. The Contact A Family website spells it out starkly: 'People with Rett syndrome are almost always profoundly and multiply disabled and totally dependent on others for all their needs throughout their lives.' We were stunned. None of the other syndromes we'd heard about sounded anything like this. We looked at dozens of websites, read the list of signs and symptoms, and decided that Amy didn't really fit the description. Nonetheless, now that the seed had been planted in our minds, we wanted Amy to have that test the neurologist had talked about. I contacted him to ask when it might be; he told me that he didn't communicate with parents outside clinic appointments.

We settled down to wait, and in the meantime Amy finally started physiotherapy and joined the waiting list for speech and language therapy and occupational therapy. We applied for Disability Living Allowance and joined the local branch of Contact A Family. Even though Amy had no firm diagnosis beyond CHD and 'developmental delay', we were entering the world of special needs. I wanted to resist, to cling to the belief that Amy was a 'normal' child neurologically who would catch up eventually – but in truth it helped to acknowledge that Amy needed help, and to seek out the things that would help us all as a family.

We waited five long months for the MRI scan, which in the end showed no abnormality in the structure of Amy's brain. In the meantime, we revisited the information we had about Rett syndrome, and realised that Amy was showing more signs of it as time passed. Although many children with Retts appear to grow and develop normally in the first year of their lives, it usually becomes apparent in the second year, as the brain fails to develop. That's why it became clearer as Amy got older that this was the elusive underlying factor explaining her inability to move independently, bear weight, use her hands or communicate verbally. It also explains other things, like her endless



problems with eating, her 'floppiness', and her tiny, cold feet. The chances are that she won't learn to walk or talk, and we will need to find ways of understanding her and helping her communicate.

We wanted a diagnosis, and in the end it came as a relief. It enabled us to explain to ourselves and other people why Amy is the way she is; to understand her better; and to love and appreciate her fully. The fact that this condition is caused by a random genetic mutation at the point of conception is good enough for me as a 'reason why'. It wasn't because of the glasses of wine I drank while I was pregnant, or because I forgot to take my folic acid, or because I put her in a forward-facing buggy when she was tiny. Now that I understand how difficult it is for Amy to do what other children take for granted, I see her in a whole new light. I feel better able now to applaud her achievements, accept her limitations, and adapt to her needs.

On the day that Amy was born, I felt and believed that all would be well. And although our family is very different to the way we ever imagined or expected it to be, all is still well. Amy is a beautiful girl who loves her family and friends, smiles at the sun and the wind in her face, and shares jokes and laughter with us. We can't know what the future holds, but we will do everything we can to make Amy's world the best place it can be.

**Catriona Moore**

Welcome to ETC - ECHO Teen Club!



Alex Bicknell

As some of you are aware, the Childrens Heart Federation funded a holiday to Portugal for 10 teenagers back in July. One of our ETC members, Hannah Sturman, was lucky enough to be chosen out of lots of applications and I was very fortunate to be invited along as a volunteer. It is fair to say that the holiday was amazing!!

Activities included Kayaking, raft-building, x-bugging, banana-boating, swimming and lots and lots of laughing! CHF's objective was to create a Youth Forum and to understand the needs and concerns of teenagers and by having no parents around we felt that teenagers were really able to open up and share their experiences with their peer group. All the young people who

came on the trip really bonded, and it was great to see some really good friendships being formed, so here's hoping they all continue to stay in touch in the years to come!

This is likely to be an annual event, and when the time comes again next year I urge as many of our ETC members as possible to complete the application form, so make sure you keep your eyes peeled in the ETC pages of the newsletter next year.

Alex Bicknell



Don't bother Alex, he's tied up!



Portugal Trip July 2009

Collaboration with other teen groups

During the recent amazing CHF trip to Portugal, all the group leaders there decided that it would benefit everyone if there was more collaboration and joint working between different groups (like ETC, Little Hearts Matter, GUCH - Grown Up Congenital Heart, and CHF). This exciting move would mean that ETC members would have the chance to get to know other young people with heart conditions from all over the country, and to attend joint events and activities as well as those organised by the other groups too!

We have now had chance to meet up and discuss how we can take this

forward, and have decided that we will get the ball rolling by publishing a dedicated Young People's newsletter. All the contributing groups will write two pages and that means we need some help from our members. If you have ICT skills or have had any experience editing or writing for your school or student magazine and would like to help us, please ring me or text me, Alex, on **07792 592731**. We also hope to repeat the Portugal trip next year and even increase the number of places offered to young people from each group, so watch this space!

ETC DVD

Really exciting news - we were really lucky to get a grant to make a short film about being a young person with a heart condition; about the issues and concerns you all have but also about enjoying life to the full and learning to face all the challenges in a positive way. We've found a great production company to work with, who already have lots of experience making TV films for children and young people, but what we really need is **YOU!** We need you to tell us what the film should include, what

style it should be in and most importantly, we need some stars of the future to appear in it!

If you'd like to be involved in this exciting project and have lots of influence about how the film turns out, please call me, Alex, on **07792 592731** as soon as possible. You will need to be able to travel to London once or twice, at least, to attend a meeting or two and if you want to appear in the film you'll have to be available for that too (we'll make sure it's always out of school hours!).

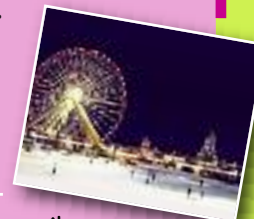


Like to join ECHO TEEN CLUB?

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!**

Up and coming events

December 2009 - ETC Christmas outing to Winter Wonderland in Hyde Park



Details to follow by email - make sure we've got your correct email address!

February 2010

Your chance to take part in the once in a lifetime "Sleepover at the Natural History Museum!"



Details will be sent out to you once we have them.

Transition Education Day on Saturday 27th February 2010

They just keep getting better! If you're 15 or over and haven't already been to one, you will receive an invitation from the hospital. If you don't receive one by Christmas please contact Thomas Witter on **Thomas.Witter@gstt.nhs.uk.**

Have we got your details right?

If you're already a member and have either moved house or changed your mobile number or your email address lately, don't forget to let us know, otherwise we can't get in contact! Email Jessica on **admin@echo-teen-club.org.uk** or text **07943 625031**

# KEEP IN CONTACT

Does ECHO have your email address?  
Send it to Jessica on [admin@echo-evelina.org.uk](mailto:admin@echo-evelina.org.uk)

## AREA CONTACTS

AREA	NAME	TELEPHONE	EMAIL
<b>North London/Herts</b>	Mandy Webster	0208 202 0713	north@echo-evelina.org.uk
	Diane de Naeyer	020 8441 3644	north.london.herts@echo-evelina.org.uk
<b>East London/Essex</b>	Kerry Auger	01702 559 335	east.london.essex@echo-evelina.org.uk
<b>South London</b>	Eleanor Beardsley	020 8690 6804	south.london@echo-evelina.org.uk
<b>Kent</b>	Fran Wintour	01322 864 350	kent@echo-evelina.org.uk
<b>Sussex</b>	Jessica Cattermole	07943 625 031	sussex@echo-evelina.org.uk
	Rosie Wheldal	01424 442 816	east.sussex@echo-evelina.org.uk
<b>Suffolk</b>	Teresa Buchanan	01473 659 360	suffolk@echo-evelina.org.uk
<b>Surrey</b>	Beverley Jowsey	01737 246 709	surrey@echo-evelina.org.uk
<b>Norfolk</b>	Molly Crisp	01362 860 488	norfolk@echo-evelina.org.uk
<b>Pre-natal Support</b>	via Admin Office	07943 625 031	prenatal@echo-evelina.org.uk
<b>Bereavement Support</b>	Cathie Shipton	07932 812 931	cathie@missfoundation.org

## THE ECHO COMMITTEE

NAME	TELEPHONE	EMAIL
<b>TRUSTEES</b>		
<b>Nick de Naeyer</b> Chair	01992 534 200 / 07889 570 784	chair@echo-evelina.org.uk
<b>Margaret Arnell</b> Vice Chair	020 7237 1745	vicechair@echo-evelina.org.uk
<b>Joanne Williams</b> Treasurer	01462 490 266	treasurer@echo-evelina.org.uk
<b>Jane Ward</b> Trustee	020 8655 0660	jane@echo-evelina.org.uk
<b>Grant Taylor</b> Trustee	07958 690184	grant@echo-evelina.org.uk
<b>CONSULTANTS</b>		
<b>Jo Wilson</b> Director	01932 864 893 / 07921 775 795	director@echo-evelina.org.uk
<b>Jessica Cattermole</b> Deputy Director	07943 625 031	admin@echo-evelina.org.uk
<b>ECHO TEEN CLUB</b>		
<b>Alex Bicknell</b> Youth Development Volunteer	07712 654 607	alex@echo-teen-club.org.uk
<b>Matt Wallace</b> Youth Development Volunteer	07932 664 520	matt@echo-teen-club.org.uk
<b>MEMBERS</b>		
Barbara Squires	01689 829 080	barbara@echo-evelina.org.uk
Catriona Moore	020 7252 7534 / 07939 527 753	catriona@echo-evelina.org.uk
Saleha Kabir	020 7701 5917	sal@echo-evelina.org.uk

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

Designed by Stanislaus Design Please call Kim on 07949 253 920 or email [kim@stanislausdesign.co.uk](mailto:kim@stanislausdesign.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	