



**Evelina Children's
Heart Organisation**

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

20pg ECHO
SPECIAL

Newsletter Summer 2009

BIG PLANS FOR THE FUTURE

We have just held our first Conference, AGM and Family Day on Saturday June 13th. This was the first time we had changed the format of our yearly AGM to include the whole family, and it was obvious by the phenomenal response we got to the invitation, that it was something that members wanted. Over 100 adults and 75 children attended to hear some fascinating and relevant presentations, attend workshops and to meet up with other ECHO and ETC members. A buffet lunch and lovely 3 course dinner were provided, and crèche facilities were available all day and in the evening. Activities were provided for the teenagers, day and night, by our wonderful ETC team – the kids all had an absolutely fantastic, memorable time, and the whole event proved to be a great opportunity for members young and old to relax and socialise together!

Details of our recent "Strategic Review" were discussed at the AGM. This review was carried out recently – a process which reviewed all our activities, took account of feedback from our members and hospital staff via focus groups, and this has resulted in a new 3-year business plan. This new, long-term plan sets out clearly how we intend to develop ECHO and become an even more effective, inclusive and professional organisation, but one which never loses sight of its core mission, to support heart-children and their families in

whatever ways we can. We are enclosing a copy of our "Annual Review" booklet with this newsletter, which summarises our achievements during the financial year 2008 – 9, the Strategic Review and our plans for this current year. I hope you enjoy reading it.

This comes at a time of change for ECHO – as you will see from page 3 we have recently lost two of our Trustees, and although we have been fortunate to have had other members waiting in the wings to take over in these important roles, we feel that in order to fulfil our plans for the future, it is vital for ECHO to attract further new Trustees and Committee members to the board. We are particularly looking for individuals with the following skills and experience:

- Fundraising
- Communications/PR
- Human resources
- IT
- Counselling

One of the most important strands of support that ECHO offers is the Pre-natal support to parents whose unborn child has been diagnosed with a heart condition. We are looking for parents who have experience of pre-natal diagnosis, giving birth at St. Thomas' and of a child receiving treatment at the Evelina, to take up the role of Pre-Natal support volunteers. The role will involve infrequent telephone support

and attending, on a rota basis, the six-weekly ECHO Ante-natal days run by the Specialist Tower Team midwives at St. Thomas' to talk to new parents about your experiences. Full training and induction will be given.

We are also looking for volunteers to carry out ward visits to Savannah Ward and PICU on a rota basis to spend some time (roughly 2 hours) chatting with and supporting families whose child is being treated there.

We know, from experience, that there is a wealth of talent, experience and skills amongst the ECHO membership, but that not everyone likes the idea of "joining a committee" (even though we think it's great fun!) or committing, longer term, to projects which they might not have time for. However, we would be happy to hear from you if you feel you can help us out on a particular project or if you have a skill which you might like to offer to us from time to time on an ad hoc basis.

If you would like to know more about how you could help our organisation, or would like to see an "Introduction to Volunteering with ECHO" pack, then please contact me, Jo Wilson, on director@echo-evelina.org.uk.

I look forward to hearing from you!

Jo Wilson

DON'T FORGET TO LET US HAVE YOUR EMAIL ADDRESS IF WE DON'T ALREADY HAVE IT, AND ALSO TO INFORM US OF YOUR NEW ADDRESS IF YOU MOVE HOUSE!

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ECHO Summer party, see details on page 3.

New South London Area Contact Eleanor Beardsley is holding a coffee morning on **Thursday 16th July, 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

Member **Rachael Cooper** is holding her annual garden party to raise funds for ECHO and Ronald McDonald House on **Sunday 26th July**, from midday (food available from 1pm) at **Beech Farm, Aslacton, Norfolk NR15 2ER**. There will be ploughman's lunch and deserts for £3.50 and afternoon teas for £2.50, a raffle, tombola, games and more. Rachael would love to see some ECHO members at the event. For more details please contact me and I will give you Rachael's contact details.



Dates for your Diary

CHILDREN'S HEART WEEK 2009



The ECHO stand with Jessica chatting to a GUCH patient, and Debbie Parker (Acting Head of Nursing for Guy's & St. Thomas' NHS Trust) with Hazel Greig-Midlane (founding member of ECHO and former Chairperson).]

As part of the Children's Heart Week awareness raising activities, we organised a small exhibition in the Central Hall area of St. Thomas' Hospital (right by Queen Victoria's statue). ECHO was joined by representatives from Little Hearts Matter, Children's Heart Federation, Down's Heart Group and Heartline, who all set up a table to display the leaflets and DVD's they have available. We were visited by lots of the Trust staff (from various departments throughout the hospital) and parents who'd come across from the Evelina to take a look at the information displayed

and chat to charity staff. It was a really interesting and worthwhile day, and we all felt that we had been able to raise awareness about CHD and about our support groups to a wide variety of Trust staff, parents, patients and the general public.

After the exhibition closed, we made our way to the House of Commons for a reception hosted by the Children's Heart Federation. The aim of the reception was to raise awareness of the issues heart-children face around participation in sport. Gerry Sutcliffe, the Minister for Sport gave a speech outlining his support for the campaign for equality of opportunity for heart-children in sporting activities, but he was definitely outshone by Harrison Steadman, a 10 year old who told those gathered about how he loves sport but struggles to participate because of his heart condition.



ECHO Golf Day

STOP PRESS! We now have a firm date for the inaugural **ECHO Golf Day**. This will be held on **7th September 2009** at the prestigious **Royal Blackheath Golf Club**, the oldest golf club in the world.

The day will begin after lunch with teams of 4 competing for the ECHO Golf Trophy and other prizes. These will awarded after a sumptuous three course dinner in the beautiful club house. Cost for entry is £125 per person including green fees, dinner, wines and minerals.

Please contact me for further details and entry forms. We already have a great deal of interest in what promises to be a fantastic day so book early as teams are limited to 20 in all. Further details and entry forms will be downloadable soon from the website.

Shaun Tel: 020 8295 1995 Email: shaun@shaungay.com

ECHO has a mobile phone.

To contact ECHO for support, advice or further information please call

07943 625 031

I work Monday, Tuesday and Thursday 9am-3pm. Please leave a message and I will return your call as soon as possible. **Jessica**

ECHO SAYS GOODBYE TO DANNY CARROLL AND JO RAO



Jo Rao

Sadly, ECHO must say goodbye to two of its Trustees this Summer!

Jo Rao, who many of you will know as Area Contact Coordinator and Prenatal

Support Volunteer, is moving up to the Birmingham area to be closer to her parents and family. Jo has been a very important member of the ECHO team (and dear friend) since 2000 and has befriended and supported so many families, that her contribution cannot be underestimated. She will, I am sure, be very sorely missed by all the members in her local area of South London, as well as by the Midwives who run the ECHO Ante Natal Days, which Jo attended regularly in her role as ECHO parent representative. All of us thank her from the bottom of our hearts and wish her, her husband Harish and children Kiran, Harry and Nina (pictured above) all the luck in the world with their exciting move. We dearly hope that they will stay in touch and still attend the odd party or too!



Danny Carroll

Danny Carroll has been Treasurer of ECHO for the past three years. Danny volunteered to become Treasurer at a time when we had been without one

for nearly a year, so as you can imagine he had a fairly daunting task ahead of him. Undeterred, he set about getting things up to date and even cleared a large backlog of vital Gift Aid claims. He then went on to set up a very clear, concise reporting system and has provided a sound, stable and sensible presence on the Board of Trustees ever since. Danny has decided to retire now, to spend more time with his wife Gill and their family as well as, I'm sure, even more time on the golf course (good for him!). We all wish Gill and Danny a very happy, healthy retirement and thank Danny for all his tremendous hard work and support during the past few years.

Jo Wilson

ECHO WELCOMES A NEW TREASURER!



Joanne Williams

It's not all bad news though – we are delighted to welcome a new Treasurer on board – she writes: "Hello. My name is Joanne and I am mum to Henry who is 2. Henry was born with Transposition of the Great Arteries and it is because of my son that I have volunteered to be the new Treasurer of ECHO. Henry

was born at St. Thomas's in April 2007 (his heart condition was diagnosed at the 20 week scan) and he had corrective surgery at the Evelina when he was 9 days old. After some initial setbacks we left hospital when Henry was 4 weeks old and since then he has gone from strength to strength. My husband Paul and I consider ourselves very lucky to have our healthy and happy little boy.

Until I went on maternity leave, I worked as a senior tax manager for a large firm of accountants in London. After Henry's arrival returning to the long working hours and long commute into London held no appeal, and so I now work part-time from home doing freelance bookkeeping, accounting and tax work, which I fit around looking after Henry.

I am very much looking forward to working with the ECHO team. My new role is a small way of saying thank you to the Evelina and ECHO for everything that they have done for my family over the last couple of years." **Joanne Williams**

Baby Breathing Alarm ECHO member Jackie Grant would like to donate a breathing monitor pad for a cot bed. It is a Babysense II model and is battery operated. It monitors breathing and movement so if a baby is slow breathing or not moving enough within a 20 second period it will go off. Jackie is happy to post it or if you live in the Maidstone/Ashford area you could collect it and Jackie would show you how it works. If you are interested then please email me at admin@echo-evelina.org.uk and I will pass your details on to Jackie. **Jessica Cattermole**

We are holding the 6th ECHO summer party on **Sunday 13th September, 2-5pm at Mountains Country House in Hildenborough, Kent**. We will have a barbecue, various bouncy castles, the farm animals visiting and the use of the swimming pool and grounds. The wonderful jazz band Dixie Ticklers will be performing and Alex and Matt, our two fantastic youth development volunteers will be there organising games and activities for the older kids to enjoy. If you would like to come and join in the fun and meet other families we would love to see you. The venue is very close to the M25 and, therefore, easily accessible from all directions, so we are hoping to see some of our more "far-flung" members there too! **Please note – as there is no charge to attend this event, it is open to ECHO members and their children only.**

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 **Summer Party**.

Please can you return this slip with a SAE and a £10 deposit (made payable to ECHO) to ECHO, PO Box 5015, Brighton, BN50 9JR. If you would like to have your cheque back you can collect it on the day from Jessica, alternatively you can donate it towards the cost of the party. **Please reply by Friday 17th July.**



Anna-Clare's story

Anna-Clare was born on 21 January 2007 at Darent Valley Hospital, Dartford. My husband Julian and I already had a son and were delighted to have a little girl to make our family complete. James was, as my midwife phrased it, a "textbook pregnancy and delivery" and he hit all his milestones to the day. We knew we had lucked out with him and quite possibly we were not going to be as lucky with Number Two. Julian and I were now "experienced" parents and we were going to hit everything in stride!

I remember that Anna popped out after two pushes. I had had no pain medication so I had a clear head and a responsive body so I did not register for about a minute that she weighed 5lbs 8oz. I was thinking, "is that maybe metric?"

"She's a little girl, that's all", said the hospital midwife, "girls tend to be smaller and she's got a fine set of lungs on her". I was thinking, "where's the rest of her"?

My pregnancy had been uneventful though I was smaller than I had been with James. Anna-Clare arrived four days past her due date and there had been no cause for worry during the forty-week pregnancy except that I had had a third scan at thirty-two weeks because my placenta had been low in an earlier scan. No sign of any cardiac anomalies had shown up in any of the scans....

Julian and I were extra-cautious in the days that followed. James was bouncing all over the place, I was excruciatingly tired and Anna's feeding was going pear-shaped. She seemed to eat eighteen hours a day in fits and bursts then fall asleep for twenty minutes then want more. Breast-feeding was not so bad as it was portable and immediate but I was shattered. To add to my maternal stress, she wasn't gaining any weight. The Health Visitors gave me as much advice as they could but nothing seemed to work. I put Anna on a few formula feeds a day, then on a "comfort" powder; I counted the ounces as they went in and drove myself mad with the worry.

Then the vomiting started. One hundred millilitres in; one hundred out. In a panic, we

went to the Medical Centre and the doctor who saw her essentially saved her life. He checked her over and realised that she had thrush on her tongue and surely it was painful for her to drink! He prescribed her with something and, just as we were walking out the door, relieved parents, he said, "let me listen to her chest in case she has an infection on her lungs". He opened her shirt and asked "is she always so mottled"?



Anna-Clare at the Evelina

"No, nothing sinister with her chest and of course you already knew about the heart murmur". Sorry? Say that again?

We were sent off with the caution that we should take her to A&E if she began to regurgitate more than half her feeds in a day. We were not sure whether to feel reassured or frightened. And we didn't have long to wait! That evening we took her to Darent Valley Hospital and our cardiac journey began. It was trance-like and it swept us along and took a course of its own. They fitted her with an NG tube and a cannula and



attempted an echo but the machinery was not suitable for 6lb infants and it did not happen. The Paediatric Consultant informed Julian and me that Dr Shakeel Qureshi did a cardiology clinic at the hospital once a month and that he would be coming down in a couple of weeks and would see Anna then. She would not be sent home until the feeding improved so we were to be prepared for a stay in hospital. Thank goodness I was on Mat Leave still and my mother-in-law was flying over from Ireland immediately to stay as long as we needed her to look after James.

The next morning a few more tests were done and just after lunch the Consultant returned and said that Anna's case had been discussed and that we were going to be transferred to the Evelina in an ambulance. What's the Evelina and why an ambulance? We had a nurse escort and we drove through south London at the height of rush hour. I felt relieved somehow because I knew Anna was going to get excellent care. The nurse was so kind and chatted to me about wanting to visit Canada, as that is where I am from. I remember thinking that the Canadian medical system has a lot to learn from the British NHS.

We arrived on Camel Ward late Wednesday evening and Dr Melanie was there waiting for us. She spent the better part of an hour doing a bedside echo and drawing diagrams explaining Anna's condition – a CONGENITAL HEART DEFECT. The words rang in my ears and my mouth dried up. I burst into a sweat and could feel the "fight-or-flight" instinct kick in. She told me that she had a VSD/ASD and that I was not to worry because they are the most common and easily treatable heart

defects. Unfortunately, we had missed the Wednesday meeting where all cardiac patients are discussed and we would have to wait a week until Anna's case could be put forward. She was started on her meds and the burden lifted. Though it was a horrible situation, I almost enjoyed that week! I met wonderful people with truly special children. I laughed with the nurses and got my fill of Tom's Café food. Our son James even came up for Gravesend one day and was allowed to go to the school downstairs and a kind porter gave him a leftover hot dinner as well. Anna was responding well to everything and we were just waiting for Wednesday.

It arrived – Wednesday, 14 March at 6pm. Nurse Thomas said that Dr Melanie had presented Anna's case to the Cardiac Team and that she was to be scheduled for surgery the next morning. Nil by mouth was begun immediately. Wow, I felt like I had been punched in the stomach; my breath left me. I'm glad they gave me no time to worry and fret about it. I just needed



hard to feed for long periods and the mere action of sucking was expending so much energy that it simply wore her out. I felt such pity for that poor girl and guilt too. "Failure to thrive" reflected on me and I felt like I had done something wrong. Thomas then took me for a tour around the operating area and the PICU so that I would know what to expect. I'm sure these men have done this hundreds of times but they need to know how necessary it was for those of us going through this for the first time.

The morning arrived and Julian, Anna and I were escorted down by Thomas. Seeing the white anaesthetic going into her tube and watching her disappear through another door was almost too much. Julian choked down a sob and I wept and Thomas told us to turn on our phones and leave the hospital. Strangely excellent advice even though at the time I thought it was crazy. Julian and I headed out into the bright March sunshine in the height of rush hour. People off to work and school who had no inkling of the emotional turmoil we were in. There were happy, healthy children running around and it occurred to me how skewed my sense of reality had become – I had been surrounded by sick and convalescing children and tired, worried parents for over a week and that this had become my new reality. I had almost forgotten how the rest of the world really turned. Julian and I had breakfast in an empty restaurant under one of the railroad arches by Waterloo Station. The Australian proprietor was moved by our situation and topped up our coffees and told us to come back for lunch as there was a lovely sunny atrium with lots of fluffy sofas on which to relax. We walked around behind Lambeth Palace then back to the Ward to await the news.

Success! Could we see her?

My baby had become a frog, puffed out beyond all recognition. Nurse Thomas had warned me but it still brought my stomach to my throat to see her in this condition. All the pumps administering life-given concoctions, a cling-film bandage, drains and tubes and bruises. A PICU nurse sat at the foot of Anna's bed in front of a large drafting desk monitoring SATs and levels and rates every quarter of an hour. A little "bypass pony" sat in her bed keeping her company. I yearned to cuddle her and that did not happen until about three days in. She had her ups and downs during her PICU stay. Increased heart rate and blood pressure which required some intervention but all worked out in the end. That waiting room is so dire! And my

hands were raw from the washing and sanitising!

The surgery was on Thursday and she was not released from PICU until the following Tuesday because there were not beds up on Camel. Anna was shifted from pillar to post; once I arrived back after dinner to find she was not where I left her but she had been moved over to a corner as she needed less and less intensive nursing care.

We did not stay long on Camel after that since Anna made a brilliant recovery. I loved giving her the formula as it increased from 1ml to 10mls and beyond. It was such a sense of accomplishment and I got stronger as she did. It amazed me how quickly her body recovered from such invasive surgery; I do not think we adults would bounce back like that! Oh, how we would whinge and complain!

We left on Saturday, 24 March. I was given prescriptions and schedules to follow and I did not think I could do it. But it is amazing what you can do if you have to. It was a regimen of feeds and medications but soon, the meds dropped off and the feeds increased. Anna was pink. Anna had cheeks. Dr Aphrodite checked her about a month later and was delighted. We attended Dr Qureshi's clinic at Darent Valley in July 2007 and he too thought that Anna was coming on brilliantly. He wrote a great note to give to her subsequent consultants because we emigrated to Canada a month later.

Anna turned two a couple of weeks ago and she is an incredible wee girl. She is running circles around James. She goes to daycare and sings and counts. She has just broken the 20lb barrier! We are beginning however to learn that Congenital Heart Defects seldom appear as a sole health anomaly. She has been tested here in Canada for various chromosomal deletions and endocrinal abnormalities and many questions still remain for her doctors over here. Luckily, we live in a part of Ontario that has two teaching hospitals and a legacy of medical excellence so Julian and I have faith that Anna's health hiccoughs will be discovered and treated. To us, she is a normal and happy toddler. Though she is meeting her physical milestones later than "normal", she is ahead of the game cognitively and socially and we adore her.

We are eternally grateful for the excellence of care we received at the Evelina and the post-surgical support from our local Healthcare providers. From the bottom of our hearts.

Amy Leeke

Fundraising



Shaun Gay

Shaun Gay is a Fundraising Consultant and Events Coordinator and also a long-time friend of ECHO. Many of our more long-standing members will remember Shaun's sterling efforts on fundraising projects in the past, amongst which he has organised 2 superb (and very profitable) raffles for ECHO. We have recently joined forces again and Shaun has agreed to help us increase our revenue during these difficult financial times. Shaun has written the following article about how you can all help...

It has been quite a few years since I last wrote in this publication and it seems that an awful lot has happened in that time. The children are getting older, and trickier to handle, the parents are also getting older and probably grumpier, and the new hospital is now not so new. I remember well visiting the Evelina when it was a building site and helping with the appeal. That visit seems like yesterday - however it was actually six years ago. The hospital opened at the end of October 2005. Where have those years gone?

One thing that has not changed over time is the fundamental need to raise funds in order that ECHO can continue to provide their most excellent support services to you and your children. Looking back to the fundraising report from 2003/04 we had a target the previous year of £15,000 and raised double that amount. This was achieved through sponsored events, parties, and the annual grand raffle. The report also mentioned "hearts4hearts" as a concept. We had already run a couple of pilots in local schools and it was a great success. As a reminder, or indeed for those of you who were not involved with ECHO six years ago the idea was that children would exchange a pound at school for a badge to wear and a chocolate heart to take home for Mum to tell her much she was loved. Or Dad if he was feeling left out. We have a vision to make this awareness and fundraising campaign a national event in 2010 with the support of one of the more popular newspapers. You will be kept fully informed as to progress.

There is another concept currently in the mix for later this year; an on-line treasure hunt. We are currently exploring the minefield of legal issues, technical criteria, artwork, branding and all the other aspects that need to be spot on for something of this magnitude to be a storming success. If we can get this

right it could be fantastic. We are also looking into a soap box derby but this is very much at the thinking stage.

We still have the die-hard supporters out there who are committed to the cause to such a degree that they will run marathons, jump out of airplanes or indeed, no names mentioned, decide it's a good idea to hang by a rope from the top of Guy's Tower. This ridiculous stunt is commonly known as abseiling and you wouldn't catch me doing it from that height for all the tea in China. So hats off to all those brave, foolhardy guys and girls for their fantastic efforts.

A more sedate way of raising much needed funds is to hold the first ECHO golf day. This will be open to both sexes and will hopefully be a celebrity based tournament in Kent followed by a gala prize-giving dinner. More details and entry forms will be sent out soon.

We are currently working in a very difficult climate. The impact of the recession has been colossal with no sector proving to be immune. The collective wealth of the 1,000 richest people in the UK fell by a staggering 37% in the last twelve months. For the charity sector all is not doom and gloom. The will to give can often be stronger in difficult times with people realising that philanthropy is even more important when the country as a whole is depressed. Although there will be very little virgin wealth to go after, managing the relationships with existing supporters will be key. Certainly individual giving will hold up a great deal better than corporate funding. Interestingly, in 2008 £207m more was given in donations to the sector than in 2007. There will always be donors out there we will just have to work that much harder to find them and secure their support. The most important thing is that we do not talk ourselves into a "giving recession".

In light of this we need to be a little more creative. You can all help by carrying on with the things that help with the ongoing core-funding of ECHO. However here are some ideas that might get the juices flowing:

- Get together a team of cyclists, pick a suitable destination about 100 miles away and ride there. You will be amazed at how much sponsorship a team of five or six can raise.
- Talk to your employers about payroll giving. We can help you set up a scheme via CAF Bank and offer advice as to how Give As You Earn functions.
- Ask your employers about any Charitable Foundations or Grant making schemes they may have for nominated charities. Larger companies often only accept nominations from charities put forward by their employees, so if you think your firm could help us in this way, why not think about nominating us. We can, of course, help you with any form-filling.
- Next time you sell something on eBay, donate a percentage of your profits to ECHO. ECHO is a certified and nominated Charity on eBay. Look at the eBay website for details. Promote this service via email to all your friends and colleagues.
- Be old fashioned and throw your coppers (or all loose change if you are feeling generous) into a jug or similar. Give it six months then resist the urge to take it to the supermarket where the machine takes 7.50% for various causes. Have the kids help you count it and then turn it into a donation. We also have ECHO collection boxes available - if you'd like one to keep on the kitchen table, just email admin@echo-evelina.org.uk
- Organising a party, ball or fundraising event? We will be delighted to help in any way we can.
- Don't forget that any personal donations will be increased by 28% if you sign the Gift Aid declaration. Forms can be downloaded from our website, or we can send one to you either via email or in the post. Just ask.

Good luck with all your efforts and thank you all so much for your continued support.
Shaun Gay

Any questions please do get in touch:
shaun@shaungay.com

How to raise funds online using Justgiving.com

What is Justgiving.com all about?

Justgiving.com is a website that enables you to raise money for your favourite cause online. ECHO has teamed up with Justgiving.com so that all our fundraisers can raise money quickly and easily online with their own personalised fundraising web pages. Setting up a fundraising page with Justgiving is free and the step-by-step process is very simple. If you tell your friends and family about your page they will be able to donate online with a credit or debit card (this is 100% secure) - so there is no need to use a paper sponsorship form, or chase cheques and cash after your event. Not only this is time-saving for fundraisers, but receiving donations from Justgiving is tax efficient for ECHO and reduces our administration costs - so everyone benefits!

You can use Justgiving to fundraise when you:

- take part in a **sponsored event** (whether

it is an organised event or one that you have set up yourself)

- celebrate your **wedding** or **birthday**
- wish to raise money **in memory** of a loved one

In addition, you can also use Justgiving.com to make one off, monthly or yearly donations.

Some tips on how to make the most of your fundraising page

- It's a good idea to personalise your page and to make it as eye-catching as possible - for example, add photos and write a personalised message. There is also a facility to link your fundraising page to your Facebook or MySpace page if you have one.
- Email your closest friends first - the people who you can really rely on to support you tend to be more generous. This will give other sponsors confidence in you and they may match the first few donations. This could make a big difference to the total amount you raise. Once your closest friends have sponsored you, email details of your page to everyone you know!
- Why not contact your local paper, radio and TV stations and tell them about your

fundraising efforts? If you would like a mention in the ECHO newsletter or on the ECHO website please let Jessica know.

- If you are completing an event, write to everyone again with an update on your activities as some donations on Justgiving come in after the event has taken place.
- If you receive donations from sources offline (ie not through Justgiving) you can still add these details to your Justgiving page so that people who visit your page can see how much you have raised in total. There are also web links (called widgets) that you can add to your page that show your target amount and how much you have raised so far. The widgets update each time you receive a donation and it's a great way to draw attention to the cause!

How to use Justgiving.com

To set up your page today visit www.justgiving.com/echoatguys/raisemoney or call **Justgiving.com** on **0845 021 2110** for more details.

Joanne Williams



How your donation could help ECHO

ECHO relies entirely on the support of our fundraisers to continue our work. Here are some ways in which you could help us:

How Individuals Can Support Us

- If you make a donation via Gift Aid we can add 28% at no extra cost to you - so a donation of £100 means ECHO receives £128.00.
- Take part in a fundraising event - from marathons and abseil events for the adventurous to coffee mornings and raffles, there is something for everyone!
- Set up a regular direct debit. This provides regular income that helps us to manage our projects effectively.
- Consider leaving a legacy in your will or donate in memory of someone.
- Use a special occasion such as a wedding or christening to ask family and friends for celebratory donations instead of gifts.
- Use the Giving Machine (www.thegivingmachine.co.uk) when you shop online and ECHO receives a donation without it costing you anything.
- Become a volunteer with ECHO - giving

up some of your time can mean that we can save money and time that could be better spent elsewhere.

How Companies Can Support Us

- Organise a fundraising event such as a corporate sports day or a dress down day.
- Hold a raffle or auction or organise a collection.
- Match the amount raised by your employees'
- Make us your Charity of the Year.
- Sponsor one of our events.
- Give employees a small amount of paid time off to volunteer or undertake fundraising activities.
- Payroll Giving is simple to set up and easy to administer and allows employees to donate regularly to ECHO from their salaries.

How your donation could help ECHO:

- £35 would pay for one night's accommodation at Gassiot House Patient Hotel for a family to stay with their child who is being treated at the Evelina.
- £60 would pay for the hosting and upkeep of the ECHO Website and Message Board for one month.
- £100 would pay for a selection of toys and play equipment for Savannah

Ward or the Cardiac Outpatient's department

- £200 would pay for one year's supply of discharge folders which are handed out to parents to keep their discharge summary and other papers and information in.
- £1,000 would pay for regular outings and events for the ETC youth group for one year, giving them the opportunity to socialise with other teens in a similar situation.
- £1500 would fund one issue of our free newsletter, including postage to all our members, associated health-care professionals and other related organisations.
- £1800 would fund the ECHO-sponsored Ante Natal Education Days (for parents whose unborn baby has been diagnosed with a heart condition) held at St. Thomas' Hospital, for one year.
- £3,000 would pay for our Summer Party providing entertainment for the children and a chance for families to meet others in similar situations.
- £6,000 would pay for a new database that would enable us to save money on administration in the longer-term and keep our records of members up to date effectively.

Fundraising

I would like to thank all our members and their friends and families for continuing to raise and donate money to ECHO. As always I am not able to mention all of you but would like to thank you all for your support over the last few months. I would like to share a few of our members fundraising efforts. You can find more fundraising ideas in Shaun Gay's article on page 6.

Thank you to **Tracy, Stuart and Freddie Wilson** for raising £190 in February. Tracy made boxes of cupcakes which she sold on Valentines Day. Tracy said "Please accept this cheque as a big thank you for all your kindness and support which has been so needed!!"

Thank you to **Debbie and Greg Westover** who have donated £1181. The money was donated by family and friends in memory of Greg's father Ricky Westover who sadly died in January. I would like to thank Greg's family for choosing to support ECHO. You can read some happier news for the Westover family on page 12.



The Westovers

Thank you to **Lorna Greig** for raising £1404. Lorna said "We raised £1404.30 through people sponsoring my step-dad running the Hastings full Marathon in December. We had a pub quiz in our local The Jenny Lind and a local business Penbuckles the



Jacob

cheesemonger had collection tins for us over the Christmas period. We also had a couple of people give large personal donations which was really generous of them. We wanted to give

something back to the charity as when we were in hospital with our son Jacob having his AVSD repair done it was great to have the family room, a little haven when you're so far away from your own home comforts. We hope the money we raised will go to supporting more families that have tough times ahead."



Oscar, the best man!

read about Kate and Steve's wedding on page 12.

Thank you to **Kate and Steve Archibald** for collecting £27.10 in an ECHO collection tin.

The **Preston NFU Ladies** have been very busy raising money for ECHO this year. Member **Pam Price** has explained what they have been up to!

"The president always chooses a charity (or two) to support for the year they are in office and then the fundraising efforts of the group go towards that. Mum as president from August 08 to May 09 chose ECHO and Little Hearts Matter obviously because of her connection via Matthew.

The events that have raised the money are:

- A pampered chef evening where the

profits from sales were donated

- A charity evening with a hat fashion show and Easter bonnet parade, numerous stalls and 2 raffles. Local business gave support by donating raffle prizes as did the ladies themselves.
- A safari lunch when approximately 70 people went to different locations for each of 3 courses people hosting up to 10 guests in their homes with everyone gathering in the same location for sweet and coffee where a raffle was then held. Again local businesses gave support.

Other monies have come from individual donations and the sale of a signed football shirt and handmade bird table. All the ladies especially the committee work very hard and give a lot of time into making the events successful. They are very proud of the wonderful amount they have raised this year – £2,300 split equally between both charities, matching previous years despite the economic climate!" Thank you to Pam and her family and to the Preston NFU Ladies for such fantastic fundraising.

Huge thanks to **Victoria Larkby** and her family for holding a Fun Day raising £1000. Victoria said "We all had a good day and it went really well although the weather wasn't great! On the day we had bouncy castles, face painting, a football tournament, a mini dog show, bbq, cake stand and much much more. All the locals from the village came to support us and everyone had a great day."

Thanks to **Kerry Wood** for raising £250 by running the Adidas Women's Challenge last September. We have a lot of places left for this years' Adidas Women's Challenge. You can find out more about the challenge and how to reserve a place in this issue. Kerry is also raising money for ECHO through car boot sales and has so far raised £130.

Jessica Cattermole



Matthew Price

London Marathon and Adidas Women's Challenge

Well done to this year's marathon runners. ECHO member **Victoria Bottomley** raised a fantastic £3152.38. Victoria said "I just wanted to thank you for the opportunity to run in the Flora London Marathon on Sunday last, I thoroughly enjoyed every minute of it and made it round in 4hours, 38 minutes and seven seconds. I have



Victoria and Alfie

just entered the ballot for next year I enjoyed it so much!" Well done Victoria and everyone else who ran for ECHO.

We have some places for the **Adidas Women's Challenge, a 5km run for women in Hyde Park on Sunday 6th September.**

For more information and to reserve a place please email me at admin@echo-evelina.org.uk

Jessica Cattermole

THE GRIM

We are delighted to add another event onto the ECHO calendar - The Grim Challenge! For those who think they can handle a bit of a challenge, it involves running, wading or crawling through 8 miles of mud on the grounds of an army base in Aldershot. This is a fantastic event and we are lucky enough to have some spaces on it. If you feel like you are up for the challenge, it is being held on December 5th and December 6th and we will be having a tent with some well deserved drinks and breakfast for the triumphant contestants. Please contact Jessica for further details and to register. www.grimchallenge.co.uk

MILES FOR SMILES - THE LONDON BIKEATHON 2009



As part of the exciting London Bridge Festival, Charles Wahab (pictured) is organising a Bikethon to raise funds for ECHO. The 50 mile cycle round London will take place on July 12th. The team are hoping to raise a few smiles by cycling with clown wigs and red noses!

If you are a keen cyclist and would like to take part in this fun event to raise funds for ECHO, please contact Charles by email: charles@londonbridgefestival.com for more details.

THANK YOU TO MEMBER MARTIN NEILL AND HIS EMPLOYER ACCENTURE FOR HELPING ECHO SECURE A GRANT FOR £25,000. WE APPLIED FOR THE GRANT TO ENABLE US TO MAKE A DVD FOR TEENAGERS, WHICH WE HOPE TO BE MAKING WITH THE HELP OF ETC MEMBERS.

ABSEIL DOWN GUY'S TOWER



We have just completed the first (of what we hope will be many) abseil events down Guy's Hospital Tower to raise funds for our charity. The event took place on Bank Holiday Monday with 35 mad abseilers descending 469 feet down the side of the world's tallest hospital building. The event was a huge success and great fun (easy for us to say from the safety of the registration desk on the ground

floor!) and most importantly, raised a huge amount for ECHO. At the last count we reached a staggering £31,000 (including Gift Aid), and that total might keep on growing! We hope to secure an abseil day for 2010, so if you or any of your friends and family are interested, please let Jessica know. In the meantime, look out for some wonderful photos and personal accounts of heroism in the next edition of the ECHO newsletter.

A huge thank you to **Cissy Adamou and Lily Glover** (pictured) for all their help and support with registration and admin during the day, as well as for designing and printing the lovely Abseil Certificates!

A big thank you also goes to **George de Naeyer** for videoing the abseilers (which will be put onto our website in due course) and to **Jack and Alice** for all their help on the registration desk too!



Charley's Story



It has taken me 3 years to write this story, but now I feel ready to come to terms with things and write about it.

When we found out I was pregnant we were so happy. My partner had had a vasectomy reversal only a few months before hand so we weren't sure if it would work and if so we're not expecting it so quickly. Even the surgeon could not believe it! My partner was desperate to tell the world, but I was reluctant as I was so worried something maybe wrong. I had told a couple of close friends and they said I was just worried as everyone does especially after it had been a long time since my eldest of 10 years. As time went on I just knew something wasn't right and I knew this was intuition speaking not normal Mum fears. The first scan was fine as they always are, but the second was when we found out there was a problem. My eldest, Bradley was there which was my worst nightmare. They did the scan, but said they could not see the heart, this they put this down to the baby laying the wrong way which I think is the same for most when there's a problem. I was to go home and come back in a couple of days. The same thing happened again though but, this time I knew. I asked the synographer if there was a problem as it was taking so long, she said she needed the consultant to view for a second opinion. Well that was it the tears came flooding. When it's gets to that point you just know. She advised us she could not see all

the four chambers of the heart and felt we needed a second opinion by a specialist. It was absolutely awful, she was trying to keep the tears back herself and comfort me and then there was poor little Bradley, he did not know what to think. My worst nightmare had come true, all what I had been fearing had become reality. This was to be the worst weekend of our lives. They were very good at the local hospital and got us an appointment for Monday morning, but what a lifetime that was. We went straight to my Mum's where Bradley told her the whole story and, so calmly. How funny kids are!

We had a student coming to stay with us from Spain that weekend for a month so we all had to put on a brave face and looking back now I think that's probably what got us through the times ahead. She was such a rock and didn't even know it.

Monday came and we went to Guy's. There we saw Mr Simpson and Sherida. Everything was explained to us after a detailed scan and it was confirmed our baby had Hypoplastic Left Heart Syndrome. We were told our options, but immediately knew we had to fight for our child. All what we had been through so far with getting pregnant the thought of not having him wasn't an option. We went away and tried to come to terms with it all. As we spoke to friends and family I could not believe their response. Not to have our baby. They felt that as we already had Bradley who has ADHD and other problems and we'd had a very tough time with him and then relationship issues we would be mad to go through with it. I could not believe what they were saying. How could they contemplate it? When I was younger (very young) I had had a termination so for me there was no way I could go through this again and was not prepared to regret losing another child. We had a reasonable chance to fight and that was what we were going to do. In time friends and family came round. I think because we came across as so determined and confident they then were too and between us all we knew we had to stick together and make good of a terrible situation.

It came to the time when I was due to have the baby. It was panned to be at St. Thomas' on 31 Oct 05'. I was so desperate for a child on that day as it would of followed on with two others in the family, but the baby seemed to

be quite happy where he was and I think he knew the Evelina was due to be opened that day so wanted them to have a chance to get settled in! 1st Nov just after 9am and our little boy arrived. Everything was as it should be apart from the fact that we barely got a cuddle before he went off to NICU and then onto PICU. It was awful I could not wait to be with him. Richard had gone down and it felt like a lifetime. Mum stayed with me and how quick can someone get themselves together after labour when your child needs you! I swear as well now, the less or no drugs through labour is so much better, you are so much more together and focussed after especially in a situation like this.

When we went down to see our baby I just could not believe it, where we were and what was happening, but I think then this is when adrenaline kicked in and you just keep going. We decided to name him after 3 days, Charley Rees Gavin. We really wanted a name that meant something and this did 'The strong man, The one who loves living, Hero!' Charley had his surgery at 4 days old, great success and went home 6 days after that. I'll never forget, Mr Anderson came round after surgery and said he wished all his patients were like Charley and that he should be speaking to others as he was the perfect patient.

Going home was so scary, a new baby is hard enough let alone one who had just had open heart surgery and all the risks that go with it and especially that it had all been so quick. I think though having had Bradley first who has always needed all my time, attention, medication etc helped. A blessing in disguise as they say! We got by as we all have to and I think in the end you just learn to deal with things, you have to.

The second lot of surgery, Stage 2 seemed to come round so quickly. Prior to this we had had MRI's and medication increases so we had been in hospital a couple of times which had helped, but still nothing prepares you for surgery each time watching your child go through this and you being so helpless. I think as a parent this is the worst situation you could be in because we are supposed to protect our children but when it comes to this we are helpless. I say it's like us women having babies, you do forget once you get home and get on with life, but it's always there and the minute you go back to that place you

realise you haven't forgotten at all. The second surgery, again, went well and we were only in days. Charley seems to be such a fighter and I believe is meant to be here and meant to help us as a family and get on with life. And as my Mum says we are the lucky ones despite the ups and downs, because we have been given this special child probably because another person couldn't have coped. After surgery at 6 months old things were good, Charley was doing well and I was expecting another baby which you could say was mad but is the best thing now seeing them so close and together all the time. Over the time Charley had always been reasonably well, not really any heart problems, your usual up's and downs with heart children of general illnesses prolonged and all the worries for us that go with it until,

how could this all be. I honestly thought this was it for us, his sats were down to 50 he couldn't virtually do anything, he looked navy constantly and was just so poorly. After waiting such a long time to come out of theatre we finally saw him. The team were pleased with how things went, up until the point they did an ECHO in PICU. Things had changed, the scan in theatre showed the leak had reduced but now it showed it hadn't made any difference at all. We were all gutted, all that time for nothing and still a very sick child. Mr Anderson couldn't even speak to us he was that upset. No-one new what to do next. I honestly thought this was it we were going to lose our special little boy. We waited and waited for them to make a decision. Finally later on that day they advised they were going to re-operate.



Christmas 2008 Charley and his family, Kerry, Richard, Bradley and Josh

Sept 07'. Charley woke up one morning with really puffy eyes. We saw our doctor and went to the local hospital and they all put it down to an allergy of some sort, could even have been air they said! We knew though things weren't right, he was tired more so than normal, blue, not really eating and things weren't getting better. We eventually got to the Evelina where they scanned him and advised he was in heart failure. The leak on the tricuspid valve had got worse and they would need to look at it further with an MRI. They did try increasing Charley's medication in the hope that that would help, but it didn't. We went in for the MRI and within a week were back in having surgery. They advised he could not wait passed Christmas for this. What an emotional and terrifying time. He had never had any real heart problems so

Charley had already been on bypass twice that day and I just couldn't imagine him getting through anymore. He looked so poorly and just not our happy little boy. Mr Anderson had looked at the ECHO and felt fairly confident he could change some of what he had done to the valve and get it to a better state. Wednesday morning came, Charley had been out for 48hrs and it was time for surgery. I think the only consolation to this was the fact that he wasn't aware of what was happening or going to happen, but I just wanted to give him the biggest cuddle and tell him I loved him and couldn't. Again we waited and waited, only a few hours this time though and Charley was back with us. This time the operation had been a success and the leak was now moderate from severe. Charley was back on the ward within no time

eating his Pringles and staying up chatting to the nurses! He's such a character and I couldn't believe how well he had done and that he was here with us. He is our world and the thought of anything happening to him just doesn't bare thinking about. We made it home just in time for Christmas and what a special one that was. Still a worrying time, but we so thanked our lucky stars he was here and we were all together.

As time went on we started to see a difference in Charley, he was actually able to do things, even just down to eating properly. He was still blue, but we knew hopefully this would be temporary until he had stage 3. The consultants advised that the leak had stayed at moderate and they would look at a possible repair again when they came to do stage 3 later on next year.

September just gone and Stage 3 was due with a tricuspid valve repair again. Each time it gets harder and harder. Charley is growing up now and understands what is going to happen to him and knows where he's going. He's so sweet though he associates the hospital with the people out the front (the statues). He always says now 'are we going to see the people?' He has not long had the surgery and is actually doing a lot better. I don't feel at the moment there is much change, but I'm sure this will just take time to show as its still early days. The consultants now say the leak has gone from moderate to mild plus and are really pleased. Although we don't know what the outcome will be and no-one can say how long this repair will last we are trying to just now get on with life and take each day as it comes. It does seem that a transplant is more so inevitable now that the valve has caused so many problems, but I'm sure as always we will get through and no that Charley is such a fighter. He was so brave this time in hospital and so grown up, like a different child and he really kept us going. I know Charley has been sent to us for lots of reasons and I know deep down he will be here fighting through to help and teach us the lessons we need to learn.

Our children are the best thing that's ever happened to us Bradley, Charley and Josh and we are so lucky to have such special children at that. I know we've had tough times with all of them and I'm sure there are more to come, but we will always stick together and get each other through. I would also like to say that without the support from our family and close friends who we have meet through LHM and ECHO we couldn't have got through these last couple of years without you. So thank you very much!

Kerry Gavin

In this issue we wanted to give you the opportunity to share your happy events and children's milestones with us. Thank you for all the lovely news and photos that you have sent in.

Kate Hepworth and Steve Barren were married on 14th February, Valentine's Day. Their son Oscar was his Daddy's best man and both he and his sister Grace looked absolutely gorgeous! Steve and Kate raised £2709 for ECHO, you can read how they managed to raise this fantastic amount on page 8.



Oscar and Grace



Luke, Lewis and Jake

Bam Saunders and Andy Grey tied the knot in October and here is a wonderful photo of their three boys Luke, Lewis and Jake. Congratulations Bam and Andy!

Congratulations to **Greg and Debbie Westover** on the safe arrival of their son Jack on 13th March, a little brother for lovely Mya.



Jack Westover

Mya and Jack Westover

Aimee Goodwin turned 2 years old in March. Her mum Kelly sent me this lovely photo of her in the garden. Kelly said "Aimee is a big fan of chocolate, Charlie and Lola and her big brother, Max - she's



Aimee Goodwin

so cute and lovely, we feel so lucky. So far she seems to be doing really well so we're really grateful to everyone who made that possible back when she had her coarctation repair at thirteen days old."

JJ Bird recently joined a 'Stagecoach' class on Saturday afternoons. Three hours of singing, dancing and acting. His mum Fru said "He enjoyed it so much and was so enthusiastic about it that he ran out at the end with energy to spare! Praise God!!!"



JJ Bird

Annie Davis made her First Holy Communion on Sunday 10 May 2009 at her local Roman Catholic Church. Mariette, her mum said "Annie looked the picture of



Annie Davis

Annie Davis

health, read the introduction and was chosen to lead the others. She went first because of her maturity and confidence. She took both bread and wine!

Annie is in the front row on the far right of the photograph. We had our annual cardiac review on 29th April and we were given a whole year before we have to go back so we felt in a really good mood for several reasons. We were, and always are, very proud of Annie!"

Luke Elborn has just started playgroup. His older brother Jack was allowed to go with him on his first day to help him settle in. The wonderful photo of Luke was taken the week before he started playgroup, at Centreparcs.



Luke Elborn

The photo below of **Conrad Moore** inspecting poppy wreaths laid at London's Cenotaph on Anzac Day was used by the New Zealand Herald newspaper to lead its report on UK commemorations. Conrad's grandfather, Bernard Madden, served with the New Zealand forces in the Middle East and Italy during World War II.

Thank you to all of you for your wonderful contributions to our milestones piece. **If you have a special event or milestone that you would like us to include in the next issue, then please email me, Jessica, at admin@echo-evelina.org.uk.**

Jessica Cattermole



Conrad Moore

DR. AARON BELL

I count myself as being exceptionally fortunate to have been recently appointed as a Consultant in Paediatric Cardiology at the Evelina Children's Hospital. The post I have been appointed to is a new one, with a special interest in MRI scanning and echocardiography, and is an expansion of the imaging service.

I was born and brought up in New Zealand and did my

undergraduate medical training there. After working there for 2 years I moved to the UK and settled in Scotland. It was in Glasgow that I started training in Paediatric Cardiology. Towards the end of my training I was lucky enough to join the Division of Imaging Sciences at Kings College London and gain extra training in congenital cardiac MRI there and at the Evelina Children's Hospital.

With a couple of young children at primary school, most of my spare time is spent running around after them! In the ideal world I would like to be doing lots of the active things

that kiwis are supposed to do, but currently am making do with the walk to the train station.

I like to think of myself as being pretty approachable and I am keen to teach medical students and junior doctors. I look forward to working closely with children and their families as well as the excellent team we have here at the Evelina.

Aaron Bell



CARDIAC MRI SCANNING AT THE EVELINA



Cardiac MRI scanning has been around for a number of years now, but it is still

fairly new when it comes to looking at the hearts of children and adults with congenital heart disease. It was first used in our unit by Dr Edward Baker in 1987. Dr Baker was the first to do this in Europe following on from the US experience, and that time the unit was unique in that children of all ages (including infants) were scanned. He was later joined by Reza Razavi, initially as a clinical fellow and then as a consultant. Together they developed the MRI service and introduced to the world MRI combined with cardiac catheter. Since then the service has continued to grow and following the move to the Evelina Children's Hospital the service has expanded rapidly.

We now have 4 Paediatric Cardiology Consultants involved in the Paediatric MRI Service and there is an additional Consultant in Adult Congenital Heart Disease who is also involved in the MRI Scans. Last year over 220 children had MRI scans at the Evelina Children's Hospital.

Within the UK there are only a few cardiac centres performing a small number of MRI Scans in children with congenital heart disease, with only Great Ormond Street and ourselves performing a large number of scans.

Why MRI, and why do we do it when other centres don't?

There are a number of reasons for that. The first is the type of information we get from an MRI. It gives us detailed 3d information and allows us to look at the heart in a way we haven't been able to before. It is especially good at looking at the blood vessels, which is something that can be tricky with echocardiograms. Also MRI gives us accurate information about the function of the heart and flow in the blood vessels, both of which are very important but difficult to get with other tests.

Secondly, we can get all of this information without using X-Rays. A lot of other centres still use Diagnostic Cardiac Catheterisation, which as well as being invasive involves a large X-Ray dose. We have found that for most children we can get most of what we need from an MRI, reserving cardiac catheter for specific interventional procedures.

Thirdly, we have great support from the other Cardiologists and our Cardiac Surgeons. Our interventional cardiologists find MRI really useful for planning catheters and the surgeons find that the MRI pictures are very useful when it comes to planning surgery.

Also we have a highly skilled team of radiographers, these are the people that run the scanner. MRI scanning of the heart can be difficult enough, and with all the variations of heart problems we see, scanning patients with congenital heart disease can be especially difficult.

How does the MRI Scanner work?

The MRI scanner is a giant magnet, strong enough to lift a car. The MRI scanner combines the magnet with radiofrequency waves which are beamed into the body, this excites some of the atoms in the body and then when they relax they emit a signal. We pick up this signal, stitch it all together and this gives us our images. We then use different 'sequences' which create different types of picture and allow us to look at things in more detail. It is a very complex machine and we have a lot of input from Philips Healthcare and a group of physicists to make sure the scanners run smoothly.

We are also very lucky to have a very strong Research Group that we work with. This is based in the Division of Imaging Sciences at Kings College London and is led by Reza Razavi. They have produced some very innovative sequences that give us fantastic information about the heart and allow us to get more information in a quicker time period.

Why do we sometimes use anaesthetic?

The scanner looks at everything in 3d, and it relies on things being still to get sharp images. This means the person in the scanner has to be completely still and have periods where you hold your breath. The scanner can be noisy (like roadworks) and some people don't like the enclosed feeling. The average scan takes just over an hour to do and some adults find it very difficult to lie this long.

Because we need the children to be completely still for an hour, the only way we can really do that safely in young children is with an anaesthetic given by our anaesthetic team. For older children (10 years or so) we can sometimes do the scan awake. This is very much up to the individual and some children are great and the scans are successful. But occasionally we find that although the children managed the scan they wiggled enough to make the scan pictures very blurry and they need an anaesthetic in the end.

Can MRI scans tell us everything?

The short answer is no. The main test is still an echocardiogram, and for lots of adults and children that is all that is needed. MRI scans and echo's are complimentary, with each type of scan giving different information to complete the whole picture. Sometimes when children are asleep for their MRI we take the opportunity to do a detailed echo at the same time and put the results of the two tests together.

Whats going to happen in the future?

We expect that we are going to be doing more and more cardiac MRI scans, especially as children grow up and have their scan awake. This is because it gives us such good information and we can do scans every few years without X-ray radiation. We are also continuing to develop sequences and do research that will allow us to get even better at scanning and give us more information about the best way to treat some of the complex heart conditions we see. **Aaron Bell**

Sophie's story

Sophie was born at Eastbourne Hospital on 15th November 2004. She was full term after a normal pregnancy. I had a quick delivery of just over an hour. Sophie was born with a stridor – noisy breathing and was whisked away as soon as she was born and intubated. Sophie was then transferred to N.I.C.U. at St Thomas' in London (there wasn't any room at P.I.C.U. at Guys at the time).

Sophie spent 6 weeks in N.I.C.U. During this time we found out as well as having serious breathing problems she also had a heart problem. Sophie had a double aortic arch with a right sided aorta (something her heart surgeon had not seen before). Sophie had heart surgery for this at 4 weeks old as this was causing some of her breathing problems.



Sophie after her spinal surgery

N.I.C.U. was a very calm, quiet unit and Sophie looked huge at 6lb 5oz up against all the tiny prem babies. Sophie's time at N.I.C.U. was very up and down medically. When Sophie was 2 weeks old she had hypocalcaemia and it was very touch and go for 3 days. Sophie had her heart surgery at Guys and spent a night in P.I.C.U. (that was very frightening as P.I.C.U. was so busy, children coming back from surgery, lots of

machines beeping and everyone rallying around). A baby died the night Sophie was there which was very sad. It was very different to the calm atmosphere of N.I.C.U. In P.I.C.U. Sophie was attached to more machines, had more lines put in and looked so poorly after surgery. After 24 hours she went back to N.I.C.U., the plan was to send her back to our local hospital after extubation and when she was well enough to learn how to feed as she had been on a ventilator all her life. Sophie and all the other babies and staff were put on erythromycin as a precaution as one of the babies had whooping cough. Sophie had a reaction and needed intubating again. Once again she was very poorly and once again we nearly lost her.

During our time on N.I.C.U. the doctors and nurses were wonderful, that first night my husband Simon and I were in total shock. This had not entered our minds that anything would be wrong with our baby. We could not believe our beautiful little girl was so critically ill and on a ventilator, it is every parent's worst nightmare. The doctors and nurses looking after Sophie were so calm and explained everything they were doing and everything that was going on with the machines. They not only looked after Sophie but they looked after us too. In N.I.C.U. parents are not allowed to be around at handover so it was explained to us that this was the best time to say goodnight and get some rest, which is what we did, we got into a routine of leaving at 7:30pm and returning at 7:30am the next day. We stayed at Ronald McDonald House at Guys.

Sophie returned to our local hospital at 6 weeks old with everyone thinking she had



been fixed, to try and establish feeding as this was now a big issue. Sophie spent her 1st Christmas at Eastbourne Hospital and we went home on Boxing Day. The next few days were a bit of a blur, lovely to be home but frightening as we didn't have any doctors or nurses at the end of Sophie's cot if it all went wrong. One of the community nurses phoned from our local hospital to see how her feeding was coming along and if it was getting any better. Sophie was having 20mls every 3-4 hours so we were called straight in. Sophie was put straight onto oxygen, her Co2 levels were very high and so she was returned to Guys P.I.C.U. More tests showed her aorta was causing her more problems, so at 8 weeks old Sophie had more heart surgery, an aortapexy -her aorta was stitched to her chest wall.

Again we thought we were going to lose her, we were back on that rollercoaster nobody wanted to be on. This time we brought our other 2 children; Ryan then 12 and Abbi then 9 up to Guys with us and they went to school there. We wanted them to get to know Sophie and for her to spend time with them in case she did die, she needed to have her brother and sister around. Abbi asked a lot if Sophie was going to die, I had to tell her I didn't know as she was very sick but the doctors were doing all they could to keep her alive. I just wanted them to get to know each other and to let Sophie know she was loved so much. Sophie still had problems after surgery and needed more surgery at 12 weeks; her subclavian artery was causing oesophageal compression and was removed. As a result of this Sophie has a very weak pulse in her left arm.

This time we had spent 12 weeks at Guys in and out of P.I.C.U. It was about the time of Sophie's second heart operation that the fish test was mentioned and the first time we had heard of 22q. We were devastated especially when we found out she did have it as it would be a life changing moment for all of us. Little Sophie who had had 3 heart operations in three months, we knew this would not be the end of her problems. Sophie still needed oxygen continuously and would do so until two and a half during the day and 3 years old at night. She only needed a trickle, but without it she would de-saturate very quickly.

every feed, Sophie turning blue, constipation, choking episodes was also a problem. I felt like some days I was feeding, washing clothes and clearing up vomit all day (that is because I was!). Sophie also suffers from reflux, is on medication, still vomiting and all the time she was poorly, but, a happy beautiful baby even if she was a bit blue! She had the most gorgeous smile and we all loved her to bits. We tried not to move Sophie for about an hour after a feed to help with the vomiting – it didn't always help. Sophie also suffered sensory aversions on foods and everyday items e.g. a hairbrush, cuddly toys, wet hair, fleece

the gastrostomy, but it was a good decision and she still has it (no worries trying to get meds down her!). We all plodded along trying to lead a semi-normal life. Sophie was and still is adorable and she has made a rough ride a lot easier to handle.

In early March 2006 Sophie had bronchilitis and spent a week at our local hospital, recovered and came home. At the end of March when Sophie was about 14 months old she was crawling, but not walking or talking (Sophie has vocal chord palsy), she caught a virus that her Dad and sister had. She was admitted to our local hospital and on Mothers Day in March stopped breathing; she was intubated at our local hospital and again returned to the Evelina (Guys). Sophie was critical – we got to P.I.C.U. and remember thinking she got here, she is safe now and she'll be fine. Sophie deteriorated further and was put on an oscillator, this didn't help, her lungs had collapsed – she needed ecmo, a lung bypass machine. She was transferred to GOSH, that ambulance journey was the worst ever as we had been prepared that she may not make the journey as she was so sick. It took 6 minutes. I remember the ambulance driver saying it was his best time ever. I was so grateful. Sophie went onto ecmo. They had to insert a long canula into her jugular vein, it kinked and they had to do it again. It wasn't looking good. Sophie spent ten long days on ecmo, we again thought there was a big possibility it would be too much for her.

This time I had her funeral plans in my head. This was a really bad time for us. Sophie's immunodeficiency was put to the test. It was discovered Sophie had human metopneumovirus – bird flu from years ago. Thankfully Sophie did recover and on the eleventh day returned to P.I.C.U. at the Evelina and spent the next 5 weeks there recovering. I was, and am still amazed by her and her inner strength. Sophie really wants to be here.

Again we go on with life, hospital visits in London . . . but Sophie was improving. Her milk had been changed to neocate; her stomach had been damaged by the virus. Changing to neocate was a good move as she stopped vomiting as much and started to put on weight. Everything had started to improve for her. Not needing oxygen was a huge step forward, at two and a half Sophie stopped needing it during the day and at three she stopped relying on it at nighttime. Sophie started to take a few steps (she is still



Sophie enjoying a swing!

We took Sophie home from Guys at four and a half months. Again Sophie had superb care throughout and we got lots of support from the doctors and nurses. Without their care Sophie would not be here today and we would not want her to go anywhere else. We have been very lucky and have 100% confidence in the care that Sophie receives.

We went home in March 2005 and had oxygen installed at home. Sophie was on a sats monitor, she came home with an ng tube as feeding was still a big issue. Vomiting was another big issue after nearly

blankets, these are just a few and she would vomit violently. She would do this with a whole range of foods too. Sophie is a very selective eater, she eats what she thinks is 'safe food', all rubbish really! Apart from egg, toast, noodles, chicken nuggets, she loves McDonalds, their cheeseburgers are very soft and easy to eat. Sophie grazes all day with little amounts, but she is eating and that is great.

Sophie had a gastrostomy at 9 months old as her weight was still an issue, glad to get rid of ng tube but at the time a bit scared of



I don't know what the future holds for her, here and now, what I want most for her is to enjoy every minute of life.

a bit wobbly now but it is getting better). Her sensory issues were not such a huge problem; she learned to avoid anything that would make her gag or vomit. Sophie did have choking episodes but they were not happening nearly as frequently. Chest infections were also less frequent. Things were much better for her apart from her scoliosis which was getting a lot worse. It was decided Sophie needed spinal surgery, her scoliosis was progressing fast and if she didn't have the operations she would not survive. Sophie would have titanium rods inserted and every 6 months have them lengthened until she reached seven years old when her spine would be fused. To do all of this it was decided Sophie needed a tracheostomy to keep her airway safe as she has vocal chord palsy and tracheobronchomalacia.

So in June 2008 Sophie had her trachey and in the July she had the rods inserted into her spine. Sophie once again pulled through

major surgery; it was very frightening for her. She has had many painful procedures.

It was very scary for all of us, we had a family holiday beforehand, and it was Sophie's holiday! If she didn't make it, we had the most wonderful memories of a fantastic holiday with her. If she did pull through I would be able to talk to her about it and we took lots of photos which I put into an album to take into hospital with us to help her recovery. I honestly didn't know if she was strong enough for the spinal surgery but there wasn't a choice.

It is now January 2009 and Sophie has had her trachey and spinal rods for 6 months. She has had a complete new lease of life, no more stridor, she is stronger, and her sats are the best ever.

As I am writing this she has just had her second stage of spinal surgery, lengthening of the rods. A P.I.C.U. bed was booked for her as she usually needs a lot of care after a

general anesthetic but not today – straight back to the ward where she was eaten toast and watched TV! Once again she has been amazing!!!!!!

Sophie is developmentally delayed, she is a like a 2-3 year old. Her fine motor skills are developing and everything is moving forward for her and she is enjoying life. Sophie loves people chatting to her even if she doesn't always understand what they are talking about, if they say it with a smile she nods as if she knows what they are talking about. Sometimes it's very funny to watch as she is nodding and hasn't got a clue what people are on about and they think she understand to ask her more questions. Sophie signs using simple makaton and can make noises and can make herself understood.

Having a child with Di George Syndrome can be heartbreaking, watching your baby so close to dying, we would not want anyone to go through what we have been through, but

Sophie is here, she has beaten all the odds. I don't know what the future holds for her, here and now, what I want most for her is to enjoy every minute of life. We are very lucky she is here. She has so many strengths; she is beautiful, very enthusiastic and extremely affectionate. She loves attention and is very happy. Sophie is a very visual child, she loves music and the television, Peppa Pig and In the Night Garden are driving me mad! Sophie has a lovely warm personality and is great fun; she loves to please people and always has her wonderful smile beaming from ear to ear.

We have been truly blessed with an extremely special daughter.

Sophie has a great community nurse who is always there for her. Sophie has lots of consultants, surgeons and nurses at the Evelina Children's Hospital we are so grateful to, as without them we would not have Sophie here with us today.

Sophie was also looked after by Sam the trachey nurse and Rachel the spinal nurse, they have both supported myself and Simon so much. We didn't take Sophie's trachey lightly, it was a big step but we know she had to have it. Sam was great and helped us through everything. I am quite a wimp when it comes to medical stuff (I don't change Sophie's gastrostomy on my own), Sam was very patient and Sophie took to her trachey so easily that it made it easier for me. You would do anything for your child, especially as we had to be competent in changing the tubes before we were allowed to take Sophie home. No myself and Simon change it weekly and

Sophie is comfortable with that. Rachel took care of Sophie's spinal wound, poor Sophie had a bad reaction to a lot of dressings used, so her poor back was red raw.

One last mention is about Andrew, the P.I.C.U. consultant who has done so much for Sophie and has been involved with her care from 6 weeks old. He did lots of research into her heart surgery. He has done so much for Sophie and has always been involved with her care and treatment and we will always value his opinion. He is truly Sophie's hero!

Caroline Tucker

I would like to say a huge thank you to all of the doctors, nurses and staff on N.I.C.U, P.I.C.U and Mountain ward, for the wonderful care Sophie has always received. Thank you for being so dedicated and caring as without you Sophie would not be here today.

Thank you to all of Sophie's consultants:

Mr Conal Austin Heart Surgeon

Dr Owen Miller Cardiologist

Dr Andrew Durwood P.I.C.U Consultant

Mr Blaney Ent Consultant

Mr Lucas Spinal Surgeon

Miss Agrawal General Surgeon

Dr Kanabar Paediatric Consultant

Dr Menson Paediatric Consultant

Dr Heath Immunologist Consultant

Sam Whetstone Trachy Nurse

Rachel Hunt Spinal Nurse



New resources for special educational needs

As many parents will testify, getting the right help and support for heart-children at school can often be a complicated and frustrating process. It helps to know what your child is entitled to and what the school and other organisations can do to help. The Children's Heart Federation have a fact sheet for parents called "Your Child and Special Educational Needs" which you can download from their website: www.chfed.org.uk or call 0808 808 5000 to order.

There are also a couple of new resources available to parents. Contact A Family have recently produced a podcast about S.E.N. which you can listen to – visit www.cafamily.org.uk. As well as going through what to do if you are concerned that your child has S.E.N., the podcast also has more information about how to request a "statutory assessment", the "statementing" process, how to make sure any provision best meets your child's needs, and what to do if you are unhappy or want to appeal against a decision.

The Advisory Centre for Education (ACE) has a number of useful advice booklets for parents, which are now free to download from their website. They cover a range of issues, including asking for a statutory assessment, disability discrimination, extra help in early years and getting the statement right. Visit www.ace-ed.org.uk for more information.

We will put direct links to all the above resources from our own ECHO website in due course – just keep checking the Information section.

Hi everyone,

Hope you are keeping well and happy that summer is pretty much upon us!

For those who do not yet know me, I'm Alex Bicknell and I'm looking after the ECHO Teen Club now along with Matt Wallace.

I want to build ETC into something great and I need your help to do this! Most importantly, please let me have your email addresses so I can stay in contact with you all and keep you updated on upcoming ETC events.

Alex Bicknell

Matt Wallace

We recently had a very successful Transition Day. The aim of this day is to help those of you who are approaching 16 years of age to become confident in dealing with your conditions and helping you prepare for entry into the adult cardiology departments. The day involves icebreaker games, role-plays and a forum where you can meet new people and have your worries or concerns answered. 2 ETC members who recently went on the Transition had some great feedback:

"The day was different to what I expected. I expected it to be just talking about moving to Adult congenital care and not as interactive. At the beginning of the day I was nervous and shy but as the day went on I got more and more confident. It was interesting to meet other children with heart conditions because I haven't had the chance of meeting any other children with heart conditions before. Overall the day was very informative to me and my mum. I would recommend it to anyone!" by Hannah Sturman

"I found the Transition Day to be very helpful. Not only did we learn about the change from child to adult services (which, by the way doesn't seem to be scary at all, so don't worry!), but also about how to cope better with any problems we might encounter, to do with our congenital heart disease.

Everyone was very easy to talk to, and any questions anyone had, were answered honestly, and in confidence.

Even better than the information though, was the chance to meet other people with congenital heart disease, and of course, have some fun as well!" by Josh Martin

As you can see, these events are meant to be fun as well as informative for you!

Coming up soon we have a number of activities which I hope you will enjoy:

AGM Day 13th June 2009

We have loads of activities and workshops designed especially for you, and possibly a trip to the Tower of London lined up also on the day. If the weather is good we can also head out for a game of rounders or football.

Over The Wall

'OTW' offers young people with heart conditions between the ages of 8 and 17, and their siblings, the chance to go on fantastic adventure holidays. The holidays are usually located in schools / residential camps and last about a week or so. It's an opportunity to make friends and take part in activities such as kayaking, archery, drama, crafts, and talent shows. It's all free and the feedback we have had so far from ETC members has been really positive, see Laurence Squire's piece on the next page. Definitely recommend it!

Evelina's Pride

ETC will be joining in with some of the fantastic events and outings that take place with the Evelina's Pride group. This is a group that meets regularly and is attached to the Evelina Children's Hospital. Let me know if you are interested in joining this.

CHF Trip to Portugal

CHF are sponsoring a holiday to Portugal from July 28th to August 1st. This will be free of charge for you and you will be joined by 10 or so other young people. I will be there, along with some other volunteers and there will be medical supervision. Again, let me know if you are interested in this also.

Bowling and Pizza day out

Apologies for having to postpone the ETC bowling and pizza night out last month. We will reschedule this for later in the summer, I promise!

As you can see there are loads of great events happening for you all, and it would be great to have as many of you come along as possible.

Finally, I am looking for volunteers to setup an ETC youth focus group. This will entail meeting up every so often (over a nice lunch of course!) and getting your ideas on which direction you want ETC to go, where you would like to go on outings and how ETC can generally help you. Please send me a message if you are interested in this.

Hope you see you all soon and don't forget to send in your email addresses to:

alex@echo-teen-club.org.uk

Alex Bicknell



BENEFITS FOR YOUNG PEOPLE AGED 16 PLUS

From the September following a young person's 16th birthday, they can claim benefit in their own right. It is only possible for parents and carers to carry on getting benefit payments for them as a dependent if they attend a full-time non advanced education or an approved training course.

Payments can then continue until their 19th birthday unless they stop attending the course or training before that date. Payments can be extended to their 20th birthday if they are completing a course they started before they turned 19.

If a young person has to have a break from their education or training, this can be ignored if the Department for Work and Pensions (DWP) accept it is a reasonable circumstance. Parents may still be able to claim benefits and tax credit for their son or daughter if the interruption to education or training is due to physical or mental illness or disability.

You may want to contact Ivy Bannerman-Wood, Cardiac Social Worker at the Evelina, if your son or daughter has been asked to leave education or training due to their health needs, for advice and support.

EMPLOYMENT AND SUPPORT ALLOWANCE (ESA)

On 27th October 2008, a new benefit Employment and Support Allowance (ESA) replaced both Incapacity Benefit and Income Support for people who are incapable of work. You will no longer get child benefit, tax credit and any other benefit payment for your son or daughter as part of your family if they claim ESA. Young people in full time mainstream education, aged 19 who do not receive DLA are unable to claim ESA.

Contact Ivy Bannerman-Wood for detailed advice on claiming benefits for 16 - 19 year old on **020 7188 9618** (Monday to Thursday 10:00 - 2pm).

A VISIT TO ST. THOMAS'S BY CHLOE MCCOLLUM



Chloe McCollum has written the following piece about her recent heart check up at St Thomas'.

I had a great time with Joyce when we went to St. Thomas's for a heart check-up. It was good getting there. The bus ride took us right to the door. The hospital was very big and busy and we saw lots of people there. Before I was a bit frightened of the doctors, the machines, having sticky things on me, and that horrible cold jelly. I especially didn't like the machine that squeezed my arm.

I'm now 26, and I had my operation: open heart surgery when I was 11 months old. When I was little I had check-ups at Guys Hospital and mostly didn't mind it. But as I got older it seemed more scary, and I haven't liked it for years. As I've been in good health and my colour is good then doctors would say from the little reading they could get things were ok, and come back in 2 years. But my mum thought I should have a proper check-up. She tried bribing me and even had a photograph album made to show me what would take place. I always say I'll be ok, but when I get there it's all too horrid. We don't go to Guys anymore and I'm too old to go to the Evelina which looks amazing, so off I go with the other grown-ups. This time I've taken my mum, but also my best supporter Joyce with me. ..and I really tried to be on my best behaviour. Everyone was very patient, and after creating a bit, I let my blood pressure be checked. When we went in for the ECG and ECHO, I was a little bit more relaxed. The jelly was warm, and the lovely technician let me move the tester along, and Joyce lied down next to

me. It took a long time, but the doctor could get a good picture of my heart. It looked like a video of ET's heart light pumping. We saw the consultant who said I was doing well and "it was a really good repair". And come back in two years. I now know the machines don't hurt me, and I hope I won't be scared again, but I really hope Joyce joins me next time as well.

Chloe McCollum

PS Mum's comments: Chloe was born in 1982 in Guy's Hospital in London. Shortly after her birth it was discovered that she had Down's Syndrome. Dr. Joseph suggested she have an ECG and an echocardiogram because of her colour and inability to feed well. It was then discovered that she had an AVSD artero-ventricular canal, and after monitoring and a catheter examination it was decided an operation was necessary and quite possible. Dr. Deverell performed the operation which went exceedingly well. Chloe never looked back. From being a very poor eater and quite a floppy little one, she immediately became a good eater and and physically very strong. Although her appetite still amazes us, she isn't overweight because she is an extremely active young woman. She swims, dances, goes bowling and to the gym; and also enjoys long walks. She has left college now, and works one day a week in a city farm, enjoys adult education courses; and sometimes performs at the Albany in Deptford with Heart and Soul. We've been talking about sharing her story for ages, and finally because she is really proud of managing her last appointment she agreed to writing it. Taking along someone (other than a parent) who really understands and communicates well with a person with learning difficulties seems such an important thing to do to help that person understand and cope with check-ups. I only wish I had thought of it earlier. We are really pleased and thankful that her repair went so well and know it will continually need monitoring, and hope the next appointment goes as smoothly.

Zelda McCollum

Laurence Squires went to an Over the Wall camp for siblings in April and has written the following piece about the fantastic time he had. Over the Wall Thank you Laurence for sharing your experience with us.



Laurence with his four volunteer helpers; Paul, "Scuba" Steve, Ben and Kat

I went to the Over the Wall camp for Siblings at Bryanston School in Dorset for the first time in April and it was a wonderful experience. At first I was really nervous whether I would make friends but in a few hours I'd made loads. In our group there were five volunteers and six campers, George, Tristian, Callum, Jack, Keegan and me. Every bedroom had its own en suite and in the corridor there was a bigger bathroom and toilets. First we unpacked and they took away our mobile phones, not that I needed it as I soon forgot all about my family! The activities were techno, swimming, sports, music, drama, arts and crafts, horse riding, climbing wall and photography. The food was delicious and they had a huge variety of things to choose from. You also had time to choose an activity. I did power kiting with Mark, my team leader and it was fun. He had three kites, the biggest being 5m across, which would lift him off the ground, even in really light winds. The best bit was making new friends, being silly and having fun! I'd really recommend going to an Over the Wall camp and I can't wait till I can go again next year! **Laurence Squires, 11 years**

Laurence's mum Barbara was very worried about Laurence going away, but she had no need to worry!!

I think I was more nervous about Laurence going away for a whole week, especially as he was going quite far away and with no one else that he knew. Although Over the Wall had said not to contact the children I sneaked a mobile phone in his bag so we could text if he was lonely. None of my texts were returned and I don't think he had a moment free to miss us anyway! We could, however, phone for news and I did this twice, each time being reassured and regaled with the activities he was having fun with.

Picking him up a week later, he was a different child. He's quite a confident boy anyway, but was much more assured and grown up. Strangely, the activities he was least looking forward to; the talent night and the disco, were the ones that he enjoyed the most in the end. The emphasis was on carefree fun and silliness. There are loads of songs and chants, forfeits and OTW rituals - it was like another world, with a different language. The children are put into small groups according to age, so he was Green Boys 1, with five other boys and five volunteers; a high ratio of care so lots of attention for them all. And the volunteers were so wonderful; I could tell they'd built up a special relationship with him when I collected him.

He can't wait to go again and he had such a great time, I'll definitely apply next year, both for him and his heart brother. Thanks Echo for giving him this wonderful opportunity. **Barbara Squires**

WE ARE HOPING TO START WORK ON A DEDICATED ETC NEWSLETTER VERY SHORTLY, BUT IN THE MEANTIME PARENTS, PLEASE SHOW THIS ETC SECTION TO YOUR TEENAGERS!

KEEP IN CONTACT

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

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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

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	