Heart Link News

East Midlands Children's Heart Care Association
Registered Charity No. 513946

Issue 55 April 2014

Reply slip inside for the Twin Lakes Summer Trip

2014 CARAVAN DATES AND BOOKING FORM INSIDE

Chairman's Page

Hello Everybody

I hope you are all well and enjoyed the period over the New Year, but looking forward to warmer, and hopefully, drier weather.

What did you think of the Christmas party? I hope you enjoyed yourselves as much as we did seeing you there. This year's party is already booked at the same venue for Sunday 7th December. Thanks once again to our wonderful helpers.

As you may have heard in the press, the review which was to give us a decision on our future at Glenfield has again been put back another year to June 2015. But we press on regardless and continue to purchase specialist equipment. At the start of 2014 we committed approx £55,000 on three items alone. During our March meeting we agreed another £54,000 to purchase some very hi-tech equipment and refurbishment of areas in various locations which we hope will help keep up the standard of treatment, which is already high thanks to our dedicated Doctors and nursing staff.

Please think of us and keep up the wonderful fundraising. Thank you!

It's our AGM again on 1st May in the Clinical Education Centre at 8.00pm. Everyone is welcome to attend. Should any parents or guardians wish to become Heart Link committee members, we would welcome you to our meetings on the first Thursday of each month, again in the Education Centre at Glenfield Hospital. Please come along, we need your support.

The Twin Lakes Summer Trip is our next day out on 8th June and you will find the invite included in this issue of our newsletter. Please remember to include a stamped addressed envelope with your reply for us to send tickets back out to you.

Please do not forget we have our two 8-berth caravans at the Butlins, Skegness site. There are still dates available with booking forms included in this edition.

Finally we must express our extreme gratitude to Sanjesh Sharma at New Ways to Learn for all his hard work on the re-design of our website. We hope you all like it as much as we do! Take a look: www.heartlink-glenfield.org.uk

Take care

Geoff W Smart MBE

@Heart_Link1

Find us on Facebook

Heart Link Glenfield

www.heartlink-glenfield.org.uk

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Freddie's Fundraiser

Our son, Freddie, was born with Coarctation of the Aorta on 21st August 2011. His story featured in issue 49 of the Heart Link Newsletter.

Thanks to the efforts of the medical staff at Nottingham's City Hospital and Leicester's Glenfield Hospital, Freddie was discharged on 14th October that year. The first three months of our son's life were extremely traumatic. We were told to prepare for the worst when he was first born as there were just so many things wrong with him.

He was strong enough to have heart surgery at Glenfield on 29th September 2011. Mr Lotto carried out a successful Coarctation repair.

Freddie is two and a half now. He is a strong little boy in every way. He only has to attend the Congenital Heart Centre at Glenfield once a year now for his scans as he is doing so well. We were always convinced he was a little fighter when he clung to life in those early days and his fighting spirit is still as strong. He is a toddler not to be reckoned with!
His favourite thing is music. He absolutely loves putting his music player on and bopping away to CBeebies theme tunes or a bit of One Direction!

Another of his favourite pastimes is playgroup.

We have been going to our local playgroup (St Luke's in West Bridgford) since Freddie was very young. On Thursday 13th February 2014 we held a fund raising morning in aid of Heart Link at playgroup. Some children dressed in red or pink for the occasion and we had a cake sale which went down a treat! We raised a total of £237.50.

Everyone was so generous and there were some seriously delicious homemade cakes brought in for the sale. I can't thank everyone at St Luke's Playgroup enough for a fantastic morning and for raising a significant amount of money for such a worthy cause.

We are so proud of our 'little' Freddie and very grateful to Heart Link for all of the wonderful work they do and support they provide to families such as ours.

Aimee Sawyer

Harvey George

Hello, one and all, Harvey George Malpas here.

After a long time (9 years) I finally got round to sharing my story with you, I hope you are sitting comfortably ……..

The whole drawn out process started in August 2004 when Mummy went for a 20 week scan at QMC, Nottingham and the nice Dr Twining was having a good look at me. He hovered over my heart for what seemed a long time. Finally he said that Mummy and Daddy should sit down as he had something to tell them. This was when he first explained TGA (Transposition of the Great Arteries) and he said that he suspected that this was the diagnosis. Luckily Dr Bu'lock was at QMC that afternoon and she confirmed the initial thought, that I had complications with my heart and would need surgery in the first few weeks of life.

After I had left the comfort of my first home, into the waiting arms of the medical staff at the LRI, Mummy and Daddy told them that my name was Harvey George and they were told that I weighed 9lb and was born at 10.39pm on 21st December 2004. The staff whisked me off after a couple of minutes (just enough time for a little scream for Mummy and Daddy) and that was it. I didn't see Mummy and Daddy for quite a long time and kept asking everyone I saw if they had seen them. Eventually they were allowed to see me, and me them, for the first proper time. Bit of a let down for me but not for them they assure me! After a few breathing difficulties and my first drug I was settled and was waiting for transfer from LRI to Glenfield.

I had a "Septostomy" within the first couple of hours after arriving – this is where a balloon makes a hole in the heart so that I could oxygenate myself until my operation. I was on a ventilator for a while and then moved onto the dreaded CPAP. This was to help my breathing but was very uncomfortable – it blew air up my nose very quickly and was like trying to breathe with my head out of a car window (as everyone kept telling me). Then one morning I met, for the first time, James, he was really laid back. He told me that it was Christmas Day and something very special was going to happen..
When Mummy and Daddy arrived he told them that I was going to the Ward. So Christmas Day was spent with Mummy and Daddy eating turkey on the Ward with some of the other parents, with me lying only a few yards away.

Operation dates were being talked about but nothing was certain and so we were told that we could go home for a few days. After 4 days at home (it was a Friday) we got a phone call – we were to go in on Monday as the operation was to be on the Tuesday.

For the next part of my life Mummy and Daddy have had to tell me as I wasn't aware of what was happening for the majority of it.

I went in at about 10am and after an hour with the anaesthetists I had my open heart surgery, now known as a 'simple' switch! Mummy and Daddy had been told that I would be in for about 4-6 hours and things were seemingly OK. They waited for a while but still I didn't come back – they thought that something wasn't right. I eventually came out on an ECMO machine, surrounded by lots of people in hats and masks. The machine was breathing for me, circulating my blood for me and completely keeping me alive. I had two blood lines going into my neck to do the job of my heart and oxygenate my blood for me and I had a massive range of different drugs, pacing wires (with a pacemaker) and lines going into my arms, legs and stomach as well as my big scar down my front that had been stapled shut. I wasn't looking my best! Mummy and Daddy were told that the operation had been very difficult (I had 3 hours worth of stitching on my heart) and I was ill as ill could be and that things were going to continue to be very difficult.

After a week on my very expensive machinery I was trialled off ECMO and after two hours it was said that I could stay off it. For the next number of weeks I stayed in a very similar position – my blood gases were very up and down and that meant that I was not coming off my ventilator or off some of my drugs. After a few more weeks I was allowed to have a cuddle with Mummy and Daddy. I had to lie on a cushion and 2 nurses had to move all my wires and ventilator tubing but I felt the most comfortable I had for a long time and had a lovely sleep.

Unfortunately I still continued to have too much fluid around my lungs and I had to be swapped from my ventilator onto another shiny machine called an oscillator. This gave me 596 breaths a minute. It made my body vibrate and shook my head. It was very noisy but I slept really well. Mummy and Daddy joked that when I am older they would find me asleep on the washing machine during its spin cycle! After a day my lungs looked much better – everyone seemed quite relieved. My ventilator was trialled off successfully and many of my drugs were weaned down. I even had a heart scan and my valve leak had reduced. My feeds were increased and everyone was talking about me going back to the Ward in a few days.

However, this relief was short lived. I had been on full feeds for a couple of days and an x-ray, whilst sitting up, showed that my lungs were pure white again. I was struggling to breathe and the doctors said that they would need to drain the fluid again in the morning. As the night continued I was struggling more and more.

My oxygen sats were 77% instead of 100% and it was decided that CPAP would help – Oh great! It didn't work so they decided to bring in a surgeon during the early hours of the morning to insert a drain. They woke Mummy and Daddy up at about 3am and they came to Intensive Care to see me. When they got there, they were told that there had been a major complication with the drain and my lung had been punctured and collapsed as a result.

I had had a respiratory arrest and my heart had stopped working, but they had given me adrenalin and my heart was now functioning. The drain showed that the fluid was chylothorax and that I had to be given milk that had medium chain fats called monogen. Mummy was told that I could no longer be given her breast milk.

Once on this new milk I went from strength to strength. My recovery after my arrest was amazingly quick and that night became a bad dream. After less than a week we were on our way back to the Ward. We were put in a side room so that we could all sleep together. I was having lots of cuddles and was doing well. The only problem seemed to be my lack of appetite. I was fed through an NG tube but this made me cry a lot. The doctors thought that I had a reflux. One night after an NG feed I was sick through my nose and mouth and stopped breathing. I was rushed back to Intensive Care. They thought that I had aspirated some milk into my lungs. The x-ray was clear and after several nebulizers, to open my airway, and lots of oxygen, my blood gases returned to normal. We went back to the Ward the next morning and they said that it was a one-off freak occurrence. However, after a week I started having these quite regularly and after tests for airway (bronchoscopy), reflux and angina there seemed to be no answer to my problems. I was now put onto a bottle and this really seemed to help and the episodes did not happen so Mummy and Daddy were taught how to use the nebulizers and oxygen. Grandparents and Auntie Nick had CPR training.

Finally the day came for me to go home. They packed all that I would need including my oxygen etc. and we set off in my pram.

It wasn't a very nice day and when Mummy transferred me to my car seat I stopped breathing again. The doctors had to come and fetch me back and we hadn't even left the car park! We were all very upset but after all we had been through we were not going to let this beat us. The next day I left the Ward in my car seat with a cover over it. Hooray no problems. I returned to the hospital after the weekend and at last I was finally discharged after 4 1/2 months.

I am now 9 years and 3 months and loving life. I became a big brother to Jacob Oliver in 2010 and couldn't be prouder of him.

I enjoy going to school, dancing lessons and have recently joined Cubs. I have to wear a hearing aid to help me and have dyspraxia but this doesn't stop me smiling and singing all the time! I have to admit I am a huge fan of "X-Factor" and "Dancing on Ice".

I know I wouldn't be here without the dedication of the staff at Glenfield and that is why my Auntie Nick ran the Virgin London Marathon last year. She wanted to raise money to say thank you for helping me and my Mummy and Daddy. Without the charity 'Heart Link' they would have not been able to stay at the hospital with me for those four long months in a room of their own. I was lucky enough to go down to London to watch her, I rang her in the morning and told her how much I loved her and that I was very proud. She told Mummy that, if she was struggling to run, she would think about me on ECMO and that would keep her going. Auntie Nick ran with a red heart shaped balloon so we could see her and I was so excited when she crossed the finish line in just 5 hours 44 mins. She raised £1350 for Heart Link. I went with her to present the cheque to the staff to say thank you once again. I know as a family we will continue to raise money and remain in contact with the people who cared for me.

Thank you for reading!

Lots of love

Harvey George x

Phoebe

Posted by
Jenny Green in
From The Heart
on Tuesday 24
September 2013

'A heart is not judged by how much you love; but by how much you are loved by others.' The Wizard of Oz.

I haven't been on here for a fair while. To be honest, I didn't realise quite how long I'd been absent for until I saw the date of my last post. The reason I have been somewhat absent is because in March, I gave birth to a beautiful baby girl called Phoebe. Since then, things have been pretty hectic. I do realise that having a baby doesn't automatically disable one's ability to write and type, but there is no shying away from the fact that blogging has taken a back seat.

For any first time mother, having a baby initiates a spectacular concoction of emotions. All the clichés are true. You feel an overwhelming sense of responsibility, tiredness, terror and most of all, love. As much as you don't know what you're doing and feel like Mary Poppins is going to hunt you down and show you who's boss, what you do know is that you'd do anything for your little one and will love them unconditionally. I expected the sleep deprivation, the odd crying fit (from both of us) and that her first bath would be a logistical challenge. What I didn't expect was to be told that she had a heart condition when she was three days old.

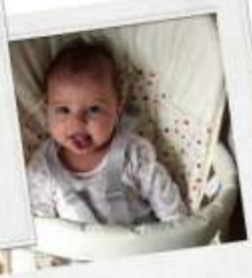
March 2013

Her condition, we were told, was called Tetralogy of Fallot. This meant her heart had four anatomical abnormalities and she would eventually need open heart surgery in order to correct them. At 4lb 12oz, my little Phoebs seemed delicate to say the least. Adding a congenital heart condition to the equation made me feel she was made of glass. I was terrified.

We were referred to Glenfield Hospital for an outpatient appointment when she was eight days old. The three of us met her consultant who explained more about her condition and what needed to be done to correct it. Like most parents, our heads were full of questions. Why was she born with a congenital heart condition? Was it something we'd done? How old would she be when she'd have the corrective operation? Would we be able to stay with her? Was her condition common?

We were told that children with her condition are usually operated on at approximately a year old and that she'd be closely monitored in the meantime. As someone whom is hardly au fait with the world of paediatric cardiology, it was a swift lesson that made my new world of motherhood seem all the more daunting.

April 2013



July 2013

Over the months, Phoebe progressed beautifully and exceeded her cardiologist's expectations. It took us a while to get our heads around things, but at home, we just kept calm and carried on. Apart from having a little machine that enabled us to carry out spot checks on the oxygen levels in her blood, things were fairly normal. Throughout the day, Phoebs and I would read together, watch films, have snuggly lie-ins, cuddles and naps. Once the evenings became warmer and lighter, my husband and I would often pop Phoebs in her pram and take the dogs to the park for a long walk. Although we had a few more hospital appointments to attend than most parents, her condition didn't interfere with our day-to-day lives or her development. She blossomed into a lively, smiley, little lady and we loved being a family.

On 19th August, we took Phoebs to Glenfield for a CT scan, which would determine whether she'd need a keyhole procedure before the big op, or whether she'd be big enough for the 'full monty.' Following her scan, her oxygen saturations remained low, so we were told she would be admitted and have the full corrective surgery the following week. Eight days later, we dressed Phoebs in a little gown and took her down to theatre. Watching my five month old baby go under anaesthetic was the hardest, most heart-wrenching thing I have ever had to do and I think it will haunt me for a long time.

Unsure of what to do whilst she was being operated on, we decided to go and buy Phoebe some presents. Armed with an array of clothes and toys, we headed back to our parent room at Glenfield and waited to hear from her surgeon. After an agonising couple of hours, we were finally told that Phoebe had come out of surgery and that we could head to PICU (Paediatric Intensive Care Unit) to see her. Although I knew Phoebs would initially be on a ventilator after her operation, nothing prepared me for how she looked. Her face was swollen and puffy, her chest had been left open to let the swelling of her heart go down and she had roughly a dozen chemicals being fed into her. She just didn't look like my baby. One of the most difficult things to get my head around was the fact that on the morning of her operation, she was happy and smiley. Although her heart needed repairing, she wasn't visibly poorly. To see her lying sedated with a ventilator just eight hours after she'd been beaming at me was so distressing I can't even begin to describe it. It's almost ironic that seeing your baby after corrective heart surgery somehow breaks your heart.


After surgery

As the days went on, Phoebs begin to show signs of progress. Her chest was closed 48 hours after surgery and her chest drains came out the day after that. Once her ventilator was removed, we were finally allowed to cuddle her, which felt wonderful. She still looked far from her old self, but it felt like she was making small steps in the right direction.

Six days after her operation, Phoebe was discharged from PICU and was allowed to go back to Ward 30, where we'd spent the week before her surgery. Despite initially seeming well, Phoebs began to show signs of respiratory distress and had an X-ray, which showed signs of fluid around her lungs. She went back to PICU during the night and was fitted with another ventilator. For me, this night was one of the hardest. Not only was seeing her distressed extremely upsetting, I felt emotionally battered and exhausted.

The following morning, Phoebs had another drain fitted and approximately 250ml of blood was removed from her chest. To us, it was a real turning point because she was visibly more comfortable and began to look much more like herself. That evening, she had her ventilator removed again and the following morning, she smiled at me for the first time since her surgery.


Smiles!

It was amazing to see. Later that morning, we were back on Ward 30 and three days later on 7th September, she was discharged and we were allowed to take her home.

Today will be four weeks since her operation and she is looking completely gorgeous and better than ever. She has a 'zip-line' of a scar on her chest along with some marks where her chest drains were, but she is as smiley, happy and lively as ever.

There is no doubt that the three weeks we spent at Glenfield were perhaps the hardest we have ever experienced. Along with the anguish of seeing our baby going through the physical traumas of open heart surgery, I also found myself worrying about other aspects of her operation. Silly as it might sound, I was nervous that her personal traits and characteristics would somehow wear off with the anaesthetic and that she'd be different afterwards. I also found myself missing her. Yes, my husband and I spent hours next to her bed, but that week there was a massive gap where her big smiles would usually be, and I found that very hard.

Although emotions ran high throughout our time in hospital, it must be said that it was a humbling experience. When you see so many babies, some of whom are days old, recovering from open heart surgery, your perspective changes. Every day, brave children in PICU are going through what no baby should have to and it makes you realise what a waste of energy all of life's trivial concerns really are.

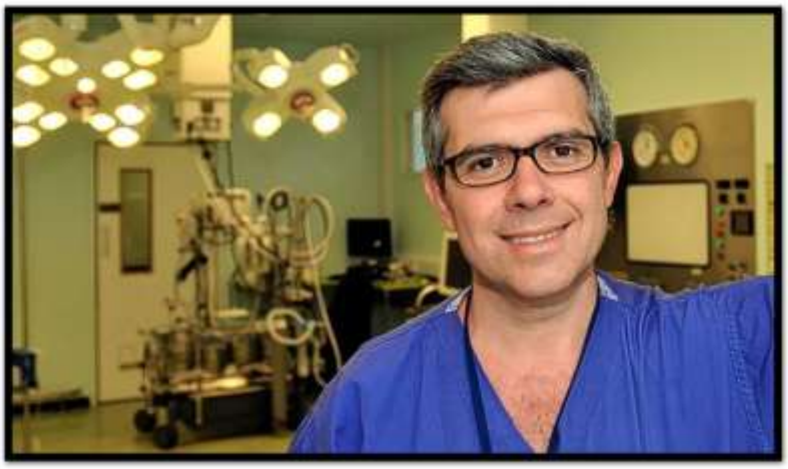
Of course, no account of our Glenfield stay would be complete without mentioning the team of people responsible for the care of our baby girl. The nurses in PICU and Ward 30 looked after all of us as a family unit and the surgical team work what I consider to be modern miracles every day. The team at Glenfield really are an inspiration and we are eternally grateful to them. We heart you all.


December 2013


January 2014

Heart Link to fund study at Leicester's Glenfield Hospital into children's heart problems

By Leicester Mercury | Posted: January 10, 2014
By Cathy Buss



Seeking recruits: Glenfield Hospital Consultant Children's Heart Surgeon Attilio Lotto

A charity is funding a £25,000 pilot study looking at the effect of kidney injury on children born with heart problems.

The study will be carried out at Leicester's Glenfield Hospital by Consultant Children's Heart Surgeon Attilio Lotto and Professor Gavin Murphy, British Heart Foundation Professor of Cardiac Surgery at the University of Leicester and a Consultant Cardiac Surgeon at Leicester's hospitals.

It is being funded by Heart Link, the Leicestershire charity that supports children born with heart defects.
The aim of the study is to learn more about the effect of kidney inflammation in patients who have had heart surgery.

Mr Lotto said: "We want to look at the relationship between kidney damage and children with heart failure.

We will be measuring blood samples to see if we can find a link as to why some children and some neonatal patients suffer kidney injury, why some recover and why, with others, it seems to trigger other events, such as multi-organ failure.

If we can find the links, it will help us to know which care pathway the patient should follow.

We see about 300 congenital heart patients a year and we are hoping to recruit about 50 to take part in this pilot study.
It is very early days and we still have to get final approval to go ahead, but we hope to be able to start recruiting patients in about September.

This recruitment could take about year."

The study is being done in collaboration with the University of Milan.

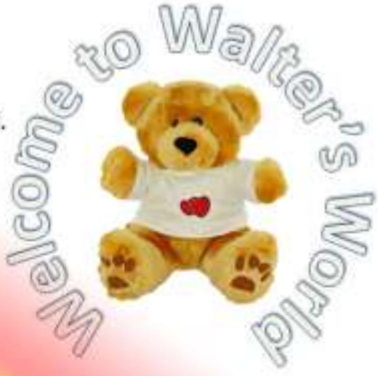
Mr Lotto said: "This study is quite exciting for us as a research group and we are grateful to Heart Link for funding the project."

Richard French, a spokesman for Heart Link, said: "We have a long history of supporting research at Glenfield Hospital which began nearly 25 years ago when we helped to bring ECMO – Extra Corporeal Membrane Oxygenation – treatment to Britain.

We also funded a study, about 16 years ago, looking at a special device for patients with a hole in the heart. It led to a procedure which eliminated the need for open heart surgery for certain types of defects. This procedure is now used regularly with great success. We hope this latest study will, in the long run, help children with congenital heart problems."

In addition to raising money for research, Heart Link, which was formed in 1981, has bought thousands of pounds worth of equipment for the children's heart centre at Glenfield, as well as paying to create accommodation for parents to stay near their children along with indoor and outdoor play areas.

For more information or to donate to Heart Link, go to: www.heartlink- glenfield.org.uk



Hello everyone

Hope you all had a fabulous Christmas and weren't as spoilt as I was. I had lots of lovely presents.

Did any of your parents see me on the television on BBC2 in January? The programme was following poorly children from all over the country and one child came to stay at Glenfield Hospital. The BBC's team were interested in what Heart Link do at the hospital and filmed me too. It was all very exciting!!!

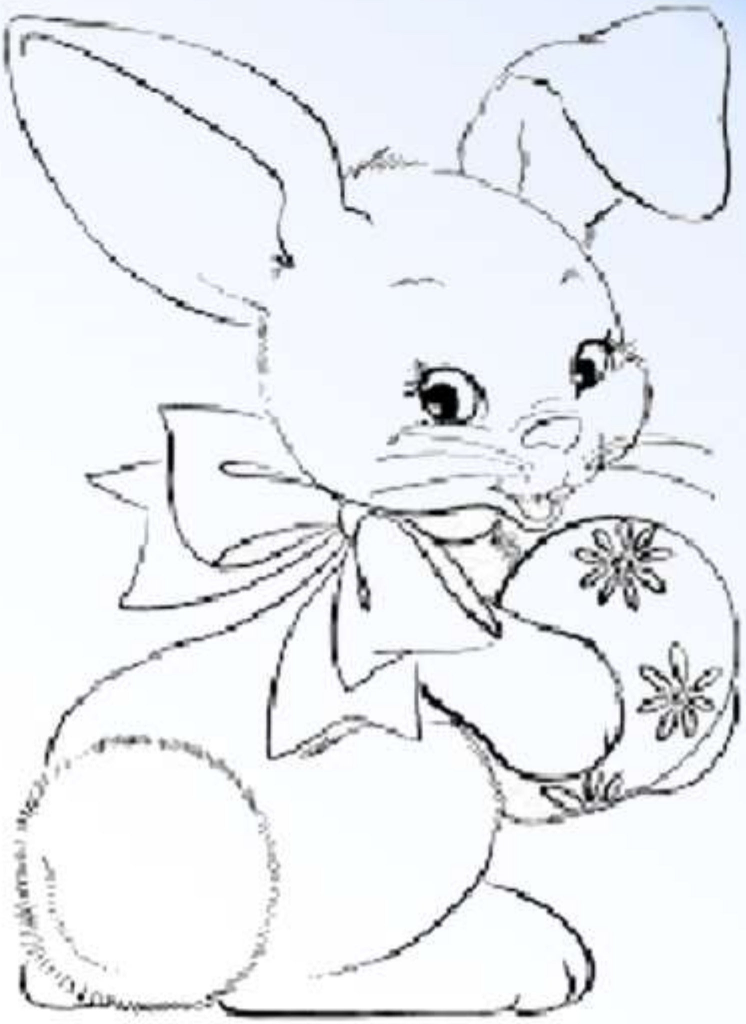
As you all know Easter is just around the corner so I thought that I would run a colouring competition of an Easter bunny for you all to participate in. Once you have coloured the bunny, please send it to me at the address below.

I am looking forward to Easter so much as chocolate is my favourite thing to eat after lots of pancakes on Shrove Tuesday!

I hope you all have a lovely Easter and are enjoying your new terms at school.

Take care

Walter Bear
xxxxxxx



Walter's World, C/O 27 Harrison Close, Glenfield, Leicester LE3 8EY

Letters

Family and friends gathered at The Leicester Railwayman's Club, East Park Road on Friday 1st November 2013 in order to raise money for the Children's Heart Unit at Glenfield (Heart Link) and Children's Diabetes Charities.

Aoife had a heart procedure and Lewis has type 1 Diabetes.

£1,300 was raised, split between the two charities.

Hi, I have followed your page on "facebook" and seen your status to email my experience.

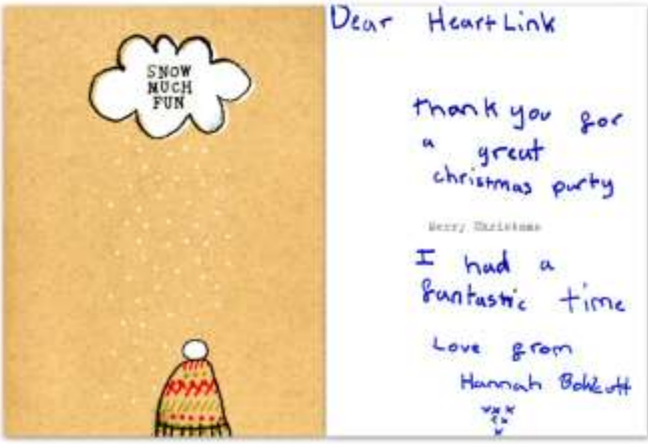
I am a young mum. Aged 19, I gave birth to my daughter Kaitlynn on 11/01/14. The day after she was born she had her 24 hour check and that's when they found a murmur in her heart. Scans showed that she has 2 holes in her heart (ASD & VSD).

Me and my partner were devastated with the news. We have recently been back to Glenfield Hospital for more scans and it has shown that the holes are getting smaller. So relieved!

This experience may have only been a minor problem but, with hearing great reviews about the hospital, it helped keep us strong for our daughter whilst waiting for the appointment. Nothing can describe how fearful I was. We have an appointment in 9 months' time to see how the holes are doing and I am feeling a lot more confident knowing that my daughter is in good hands.

Jasmin Bean

and a lovely thank you card from Hannah:



Dear Heart Link

thank you for a great christmas party

Merry Christmas

I had a fantastic time

Love from
Hannah Bokkott
xxx
xx
x

The Pelsall Ladies Choir who, in 2013, celebrated their 50th anniversary under the same Musical Director.

Pelsall is a small village between Lichfield and Walsall. In the ladies' anniversary year they nominated Heart Link as their charity, as in 2011 the Grandson of one of the members received ECMO as part of the successful treatment of an overwhelming acute infection.

A cheque for £2000 was recently sent.

Dear Heart Link

In the October Half Term, Abbie and I (Tiger) once came up with an idea to do some fundraising for charity and I suggested Heart Link for one of our charities. The reason for this was because my sister, Holly, went through treatment and she survived, so if it wasn't for you she wouldn't be alive. You are very important to my family and friends.

Abbie and I chose the idea all by ourselves to walk from Anson Road to John Storer House in Loughborough, a total of 9 ½ miles. We have raised just over £250. We wore face paint and our t-shirts and my Grandad walked with us to show us the way and take some photos.

Thank you

Tiger and Abbie

Heart Link Summer Trip 8th June 2014

Free Car Park & Picnic Areas

Melton Spinney Rd, Melton Mowbray Leicestershire LE14 4SB
www.twinlakespark.co.uk

Our Special Price for Heart Link Members	£5 each
Other Family & Friends	£10 each

Under 95cm FREE

Indoor and Outdoor Fun!

(a) Please complete the ticket order form below

(b) Enclose a cheque made payable to Heart Link

(c) ***<u>Please also enclose a stamped addressed envelope</u>***

Post to: Mrs C. Rigby, Heart Link Trip, C/O 39 Sparkenhoe, Croft. LE9 3EP
Tickets will be ordered on 13th May and posted out to you a week before the event

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SUMMER TRIP Twin Lakes

Name of Patient & their Brothers/Sisters

---Age-----------------

---Age-----------------

---Age-----------------

---Age-----------------

---Age-----------------

---Age-----------------

Adults (max.2) ________ Children ________@ £5 each = __________

Number of Other Family & Friends

Adults _______________ Children ________@ £10 each = ___________

TOTAL ENCLOSED £ _________

Iwan's Story - Part 1

Iwan Thomas Owen came into the World on 20th January 2012. His Mum, Sarah, and I were, naturally, over the moon to have a bonnie little boy and a baby brother to big sister Grace who was born two years previous.

Iwan was a good weight - 7lb 5oz and fed well. We were all set to bring the little fella home until, 3 days after he was born, the paediatrician detected a murmur. "Don't worry, a lot of new born babies have this" seemed to be the general consensus. So rather than going home an ECG was arranged for the following day.

Following the ECG Iwan was taken to the Special Care baby unit for an Echo Cardiogram which seemed to take forever, with the doctor very quiet. I should say that Iwan looked perfectly healthy, was a good pink colour and had sats of 98%+ so surely there must be "nothing to worry about, right?" The doctor conferred with a colleague, disappeared off for a few minutes and I was thinking "come on let's get this out the way and we can all be home for tea…"

The doctor reappeared with his colleague and Sarah and I were ushered into a side room, where we were given the news. I cannot remember the exact words but they were along the lines of "your son has a number of defects with his heart, which look to be similar to a serious condition called 'Tetralogy of Fallot'. I have made arrangements for him to go straight to Glenfield Hospital". We were shocked to say the least and couldn't hold back our tears, fearing the worst. It was with very raw emotions that Sarah and I went back into the Special Care baby unit to get back to Iwan and to wait for the ambulance.

I would like to add that we are forever thankful to the paediatrician who detected the initial murmur as without his vigilance it could have been a very different story.

We were met at Glenfield by a team of doctors and nurses and Iwan was taken away for tests. Sarah and I were taken into a separate room where we were given a lot of empathy and information by cardiac liaison nurse Mary McCann. Mary gave us a crash course in the workings of the heart and, when "Tetralogy of Fallot" was the confirmed diagnoses, explained the condition to us. I wished I had paid more attention in biology classes at school! Sarah and I understood that there are treatments available and that there is increasing hope for children with heart conditions. The feelings of utter despair that we experienced earlier were being replaced with hope. It was here that we first had contact with Heart Link as with a bit of trepidation I thumbed through a copy of the magazine. The content, particularly the stories and pictures, was of great comfort and gave us a further boost and we realised we were not alone. We met Dr Duke who explained that Iwan was a "pink fallot" and was okay to go home, with an appointment made for a few weeks later.

The next few weeks passed and Iwan fed well, slept okay and seemed to be doing well. There were a couple of times we were worried about his colour, but the light would change and he would be as pink as ever. We took him back to Glenfield for his first appointment, fully expecting to be told to come back a few weeks later. However, the sats monitor started to beep. Iwan however still looked quite pink and remained as responsive as ever, so another monitor was fetched which did just the same. Suddenly the room was alive with doctors, nurses and Dr Duke. Iwan was 'spelling'.

With saturation levels of 40% Iwan was rushed to Ward 30 where he was stabilised. He was kept in for monitoring and all seemed okay until he 'spelled' again a couple of days later. It was decided he needed an intervention. Typically it would have been a BT Shunt, but Dr Duke and Dr Taliotis explained to us that they would prefer to try a catheter/stent procedure, which is far less invasive -however it was quite a new procedure for babies. They pulled out all the stops and a few days later performed the procedure with assistance from Dr Stumper (from Birmingham).

Signing the consent papers with the dreaded "Risk of Death" written on them was hard, but not has hard as taking Iwan down to the catheter lab, watching his tiny eyes close and giving him a kiss once he had been anaesthetised.

After pacing around the grounds for what seemed like an eternity, Dr Duke arrived with the fantastic news that all had gone well and a short while later Iwan was back on the Ward. Now I am not one for kissing people I hardly know, but I could have done there and then. Luckily for the doc I was able to refrain!

It was during this time in hospital that we became aware of the brilliant work Heart Link do and without their input you can't help but think that Ward 30 would be as sparse and barren as your typical NHS hospital ward. Sarah stayed in one of the Heart Link funded parents rooms and Grace made good use of the "Tommy Room" as she calls it. I made decent use of the kitchen, sharing conversations with other families with children on the Ward. It does become like a surreal second home with a reality far different to most peoples.

With his stent fitted Iwan's condition stabilised and he continued to feed well and put on weight, but we knew that sometime within his first year he would need his full open heart corrective surgery.

Jason & Sarah Owen, Iwan's very proud parents

Part 2 of Iwan's story will appear in the next issue.

Scarlett's Story

On 5th December 2011 myself and my partner found out that we were expecting a baby. A surprise, but a happy one.
Everything progressed normally, and our 20 week anomaly scan soon came around. The scan showed everything was normal. We were having a baby girl, who we would call Scarlett.

At 38 weeks I was induced in our local hospital, Kingsmill, due to my own medical reasons. On Friday 3rd August 2012 at 6:03pm our baby girl arrived, after a forceps delivery, weighing 9lb 7oz. Overnight Scarlett became unsettled and started bringing back feeds. A paediatrician finally came to have a look at her on Saturday morning and decided that as she was being so sick she would need to be seen on NICU. Her blood sugars were dropping slightly low, nothing to be worried about, but, because she couldn't keep feeds down, she would need something to help sustain her blood sugar whilst we got to the bottom of the problem.

Whilst on NICU receiving glucose and attempting to feed, Scarlett had routine bloods done which showed up an infection. We were told she would need 5 days' worth of antibiotics. At this point a doctor mentioned that he could hear a slight heart murmur but it was probably nothing to worry about, and fairly common in newborns.

Scarlett received her antibiotics and her reflux calmed down. On the Thursday we were told that we could take her home Friday evening or Saturday morning. We went off home to do some washing and prepare for her arrival. Returning to NICU to be with Scarlett, we were greeted by two radiographers scanning our baby which we later found to be an Echo. In the time we had been gone Scarlett had taken a turn for the worse. We waited for what seemed like hours for someone to explain what was happening. Finally a consultant took us into the relatives room and explained that Scarlett's heart was swollen and that they suspected she had cardiomyopathy, which meant that her body was having to work extra hard and her blood pressure was dangerously high.

The Doctor explained that she had spoken to colleagues at Glenfield and Scarlett was booked in for a more detailed Echo the next day, but not to worry as she suspected that we would return to Kingsmill after the scan.

The next day came, Friday. Scarlett was taken to Glenfield and we followed. After our 50 minute trip we arrived on Ward 30 where Scarlett was already being scanned. After a very "silent" 10 minutes, we were informed that she needed to go to PICU immediately. Upon arrival on PICU Dr Bu'lock came to speak to us. She explained that Scarlett did have neonatal cardiomyopathy, but it wasn't a straight forward case. She had both dilated and hypertrophic cardiomyopathies and the cause needed to be found. My medical records were discussed but there was nothing of concern there. A neonatologist, Dr Curry, came from LRI to look at Scarlett's scans and suggest possible reasons. All of which were eventually ruled out. Karyotypes were done to rule out any genetic problems as were metabolic tests. These would take weeks to return so treatment began in the hope that it would work. Two days later Scarlett's lactate levels were very high as a result of her body struggling and the heart breaking decision to ventilate her was taken. As Scarlett didn't need surgery it was decided that she would be transferred to LRI, where she stayed for 5 days.

In this time she developed a clot in her leg due to a line. Anticoagulant medication was administered and, a few hours later, her consultant Simon broke the news that there had been a drug error, only a very small one, but still there was a minute chance that this may cause a bleed on her brain. Our already poorly baby faced another battle. Luckily all was fine and, even better, the clot dispersed, meaning her leg was saved.

Scarlett was extubated after 4 days and was well enough to return to Ward 30 the next day where repeat Echoes showed her heart function was improving.

After another weeks' stay on Ward 30, and still not knowing the cause of Scarlett's illness, we were transferred closer to home - QMC. An overnight stay was all that was required. We could take our baby home, with monthly visits back to Glenfield to check on her progress. In this time all tests came back normal, and her heart function returned to what it should be. After Christmas 2012 we were told Scarlett has "perfect" heart function and her heart anatomy is now '"normal" - so no lasting damage. We now attend a satellite clinic at Kingsmill with Dr Bu'lock every 6 months. The last lot of medication is due to stop in March.
Scarlett is now a happy healthy 18 month old little girl, who is described as ahead in milestones by paediatricians and health visitors. Recently she has become a big sister to her baby brother, who thankfully was born healthy. We will never know what caused Scarlett to be so ill but we are eternally grateful for the brilliant care and treatment that she received from every single member of staff at Glenfield and LRI. She may have baffled them all, but they never gave up treating her and exhausted every avenue of investigation.

This year we returned to Glenfield as a family at Christmas to hang a bauble on Heart Link's tree, and will continue to do so for many years to come. The least we can do for a place that helped our family so much.

Meet the Team

East Midlands
Congenital Heart Centre

In each edition of our newsletter we will feature different members of the team at the EMCHC.
In this edition, meet Nancy & Joanna!

Joanna Wykes
Children's Nurse

Q Where did you train and where else have you worked before joining the EMCHC?

A I trained at De Montfort University, Leicester and qualified three years ago. I worked on Ward 28 at LRI (Paediatric General Medical) and then in Paediatric Diabetes for a year.

Q When did you join the EMCHC and what does your role involve?

A I joined EMCHC in January 2014. I am a staff nurse, so my role involves preparing children for theatre or cardiac catheter. I also care for children once they have had their surgery.

Q What do you most like about your job at the EMCHC?

A I like talking to the patients and their families, finding out about the different heart defects. I like the pace of ward 30, and the fact that you can take the time to talk to parents and reassure them. I think Ward 30 has a lovely calming atmosphere, and the parents accommodation makes a difference to the children and their families stay in hospital.

Q What do you like to do in your spare time?

A I am part of an amateur dramatics group, we do plays and pantomimes, and we're just about to stage a production at the end of March. I also go to the gym, I swim and enjoy going out for meals.

Q Anything else you would like to share?

A I am very happy to be part of a fantastic team on Ward 30, and I look forward to many years here!

Nancy Reed
Service Manager

Q Where else have you worked before joining the East Midlands Congenital Heart Centre?

A I joined the NHS in 2004 as a graduate trainee in the East Midlands. I have worked in a variety of management roles, mainly in large hospitals in Nottingham, Cheshire, Manchester and London. My first contact with the EMCHC was on a personal level as my brother was a patient here with multiple health issues, including a heart defect.

Q When did you join the EMCHC and what does your role involve?

A I joined the service in November 2013, taking over the role of Service Manager from Elizabeth Aryeetey, who has moved into a Deputy Head of Nursing / Lead Network Nurse position. I have had a very warm welcome from the team of consultants and nursing staff.

My role is to support service development in partnership with my clinical colleagues and represent the service across the Trust. Essentially, a Service Manager is responsible for effective day-to-day operations, ensuring there is high quality patient care within the resources available. At the moment a large part of my role is to support EMCHC service development in line with the NHS England New Congenital Cardiac Review standards.

Q What do you most like about your job at the EMCHC?

A My role is very varied, no two days are the same. I enjoy working with clinical colleagues and support staff who provide very high quality care and enabling them to continue to give that excellent service. I'm new to cardiac services so it has been a quick and steep learning curve for me. Joining the EMCHC at this time is very interesting with the national work underway at the moment and I want to make sure the service is protected for the future. I love the passion from everyone involved with the EMCHC from the parents, children and charities, through to the clinical and support teams.

Q What do you like to do in your spare time?

A I enjoy spending time with my husband and young son at home in Melton Mowbray. I am a very keen swimmer and a few years ago I took part in a relay swim across the Channel to raise money for Rainbows Children's Hospice in memory of my brother James.

Christmas Toy Run

Our thanks once again to the Coffin Scratchers MCC for their generosity towards the children staying on Ward 30 & PICU, bringing Christmas presents for all, as they do year after year.

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Text: ECMO25 and your amount to 70070
Thank you for your support

Oliver Inspires Cycle to Paris

Oliver was born on 20 January 2012. He had a normal birth and, up until that point, all his scans had been fine. However, within an hour of being born, Oliver turned blue while taking his first feed. After a check up by the paediatrician, we were told he had a heart murmur that would need monitoring over the coming days.

Oliver at a few days old

This was monitored closely by the neonatal ward at Leicester General Hospital as Oliver had also developed jaundice that required phototherapy. A few days later, Oliver had his first of many heart scans, which revealed a thickening of his pulmonary valve. We were referred to Glenfield Hospital where he had another scan performed by Doctor Duke and his team. The severity of Oliver's heart issue was now starting to hit home. A week after he was born, Oliver was allowed to leave hospital, but he had to continue to be closely monitored by the team at Glenfield.

Oliver at a week old with sister Evie

We tried our best to return to normal family life over the next few weeks. Together we celebrated the third birthday of Evie – Oliver's big sister – but it was hard to forget Oliver's condition. In the back of our minds we knew he would need further treatment; we just didn't know what or when.

After eight weeks we had the answer. Oliver was booked in on Mothering Sunday for Balloon Angioplasty treatment on his pulmonary valve. The operation was to take place the following day.

I'm sure some people reading this will know the feeling of signing consent forms and kissing your child goodbye before surgery. It's a feeling that will certainly stay with us forever. Oliver had the balloon treatment on Monday 19 March and it was unsuccessful. We were told that the thickening was too substantial and he would need corrective surgery – and soon. We can't thank the team at Glenfield enough for recognising how important it was for Oliver to be operated on quickly. They moved surgery around so he could be operated on just three days later.

The day of Oliver's operation was probably one of the worst and best days of our lives. It was the worst for obvious reasons and the best in that the surgical team did a fantastic job of repairing Oliver's pulmonary valve. After waiting eight long hours we were allowed to see him again.

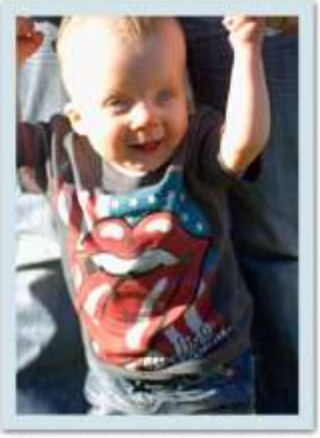
Oliver after surgery

We were told that the operation had gone well but further surgery could not be ruled out in years to come. Over the coming days, Oliver slowly came round and was allowed out of Intensive Care and back into Ward 30. During the five days that he was in Children's Intensive Care, my wife and I had the pleasure of getting to know the fantastic staff on the ward. At first I had been dreading going into the Ward, but from the moment we walked in we got a really warm feeling from the staff. It was amazing. Every nurse or doctor we met went out of their way to make sure we knew what was going on with Oliver's recovery and what the next stage for him would be. They really are an excellent team.

Once back on the Ward, Oliver had further scans that revealed just how well the operation had gone. He was allowed home eight days after surgery.

Oliver 3 days post surgery

Since his operation, Oliver has been diagnosed with Noonan's Syndrome. This has given us some answers as to why he was born with his congenital heart issue. Oliver continues to be assessed by the genetics team at the Leicester Royal Infirmary and is developing well in all areas.



Oliver a year after surgery

18 months later and Oliver has had three or four visits to the Children's Ward at Glenfield. Each time we have come away with really encouraging news. At our last appointment in July, we were told he would only need annual check ups and that we should treat Oliver like a normal little boy. It's probably the best thing we've ever heard!

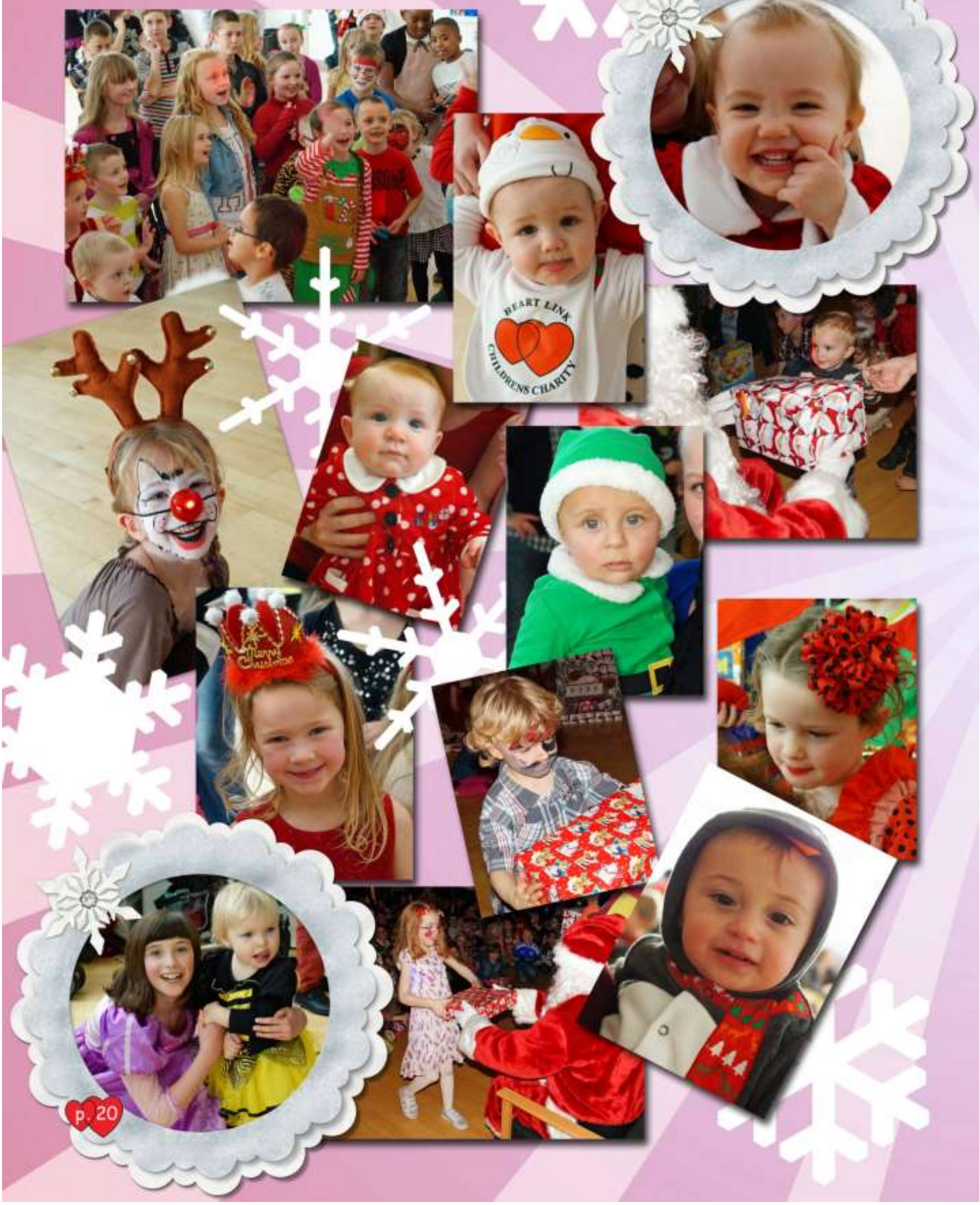
As a small thank you to the team at Glenfield for what they have done for my family, my brother and I took up a cycling challenge in June from London to Paris to raise funds for Heart Link. We had a great trip with 70 like-minded cyclists and were greeted under the Eiffel tower by Oliver and the rest of our family.

So far we have raised £4,400 for Heart Link.

Oliver & Dad before London to Paris ride

Oliver with his Dad and Uncle under the Eiffel Tower

Christmas Party 2013




JUNIORS GROTTO

Rhys

On Monday 28th November 2011 Gareth and I became the proud parents to Rhys. There were some small concerns during pregnancy but nothing that suggested any problems with his heart and after (an eventful!) delivery all appeared well. I had become unwell after the birth and Rhys and I were kept in at the Leicester Royal Infirmary. On the Wednesday I was feeling better (it's amazing what the adrenalin of being a new mum can do) and was hoping to be allowed home to start our new adventure into parenthood. That morning Rhys had his new born checks with a doctor on the ward. As we awaited the news of whether we could go home, the doctor returned with a colleague who wanted to check Rhys' pulses again. We were told that he had weak femoral pulses and we were sent to the neonatal unit to await further checks where it was explained to us that they suspected Rhys could have a heart defect. In the neonatal unit Rhys was given an Echo and it was confirmed that he had Coarctation of the Aorta. Coarctation of the Aorta is a narrowing of the aorta that restricts the flow of blood to the lower half of the body. We were told that Rhys needed to go to the Glenfield Hospital to be monitored and to assess if he needed surgery. We were devastated. One minute we were contemplating going home and the next we were being told our baby boy may need heart surgery. As I had not yet been discharged, I was told that I couldn't go with Rhys to Glenfield and therefore Gareth and Rhys would have to go without me. I begged for them to discharge me but they would not let me leave. I had only just met my baby and now he was being taken away potentially for a major operation. I gave him a feed, said goodbye and cried all night. Gareth travelled alone to Glenfield and joined Rhys on the Ward. Being a new dad is a daunting experience under normal circumstances but to be on his own at the hospital was very scary. The nurses however were wonderful and helped him to feed and care for Rhys.

The next day I convinced the Maternity Ward to allow me to travel to Glenfield to be with Rhys on the premise that I would return in time for the ward round and hopefully be discharged. At Glenfield the Consultant Cardiologist explained that Rhys would need surgery and it was agreed that it would be the next day. We were in complete shock. I was discharged from the LRI later that day and we both took up residency in the parent accommodation at Glenfield.

It was explained to us that Rhys' operation would be Friday afternoon and would be performed by Mr Lotto. On the day it was a long wait because there was a big case in theatre in the morning and we were finally called for at 3pm.

We waited in the anaesthetic room while they put him to sleep and gave him a big kiss. We roamed the corridors and walked around the outside of the hospital to try to pass the time. I remember going to the canteen and it was very quiet with the exception of some Christmas music playing in the background and a member of staff singing along. It felt very surreal and nothing like Christmas!

At around 6:30 we were called to PICU where Mr Lotto explained that the procedure went very well and Rhys would be coming out of recovery soon. At around 7:30 we were able to see Rhys on PICU. He looked so tiny in amongst all the machines. There is no scarier sight than seeing your baby with wires and tubes but the nurses were great. They explained everything to us, every wire, every tube, and all the lines and numbers on the machines. We sat with him until after midnight and came back early in the morning. We were told to prepare for him to be in PICU for up to 48 hours but by mid-afternoon we were on the Ward.

The Heart Link funded parents accommodation meant that we could be with him constantly and when he was ready I could begin feeding him myself again. Rhys recovered brilliantly and despite being told we could be in hospital for a week, we were able to go home on Wednesday, 5 days after his operation!

I think back now to how we felt when we set off from home in the early hours of the morning on November 28th. We were so excited that our baby was coming. At that point we didn't have a clue what was about to happen and that we wouldn't walk back through the door for 9 days and the rollercoaster of emotions we would go through in between. They say life changes when you have a baby but an experience like this changes you as a person too. It was relief to be home from hospital but the months that followed were very tough and emotional. At the time we got through the whole experience on adrenalin but once we were home and trying to settle in to normal family life the reality of what happened really hit us.

Unlike many other families we didn't have to travel far to Glenfield Hospital as we actually live in Leicester, in fact in the village of Glenfield. Also unlike other families the hospital was not an unfamiliar place to us. I work as an accountant for the Trust that runs Glenfield Hospital, in fact at the time I was the accountant for Paediatric Cardiac Services. As part of my role I had seen the Ward, PICU and theatres before. I had also met managers and clinical staff. This however felt very different. The walls and the corridors seemed like a different place. It was very strange to see places and people that I knew but from the perspective of a patient and parent. It's very easy in my job to forget that you are part of such an important service and I was probably guilty of seeing patients as numbers rather than people. I certainly never expected to experience the service first hand and these days I think my perspective is very much at the other end of the spectrum. I find it hard to detach myself and I think it's probably a good thing that I no longer support Paediatric Cardiac Services as the emotional attachment would probably make my job difficult. It is such a terrifying experience for a parent and we were lucky that the familiarity of the surroundings probably made the experience slightly less traumatic.

We are eternally grateful to all the staff involved in Rhys' care and also for looking after us too. They did a fabulously professional job whilst also taking the time to care and support us through the experience. We particularly want to mention Elizabeth Aryeetey who was the Service Manager and Lead Nurse for Paediatric Cardiac at the time. I already knew Elizabeth in a professional capacity but soon she was to see me at my most vulnerable. She was supportive, informative and most of all a shoulder to cry on. Elizabeth is no longer my colleague but a very special friend to the whole family.

We are also very grateful that the defect was picked up before it caused Rhys any problems. Many babies with his condition go home and it is not known they have the defect until they become symptomatic. It was a traumatic experience for us to go through so soon after childbirth but we were very lucky that it was found so early and we never had to experience Rhys becoming ill. It was however hard for us to get our heads around our baby going for such a major operation when he didn't appear unwell. If it was meant to be that Rhys had a heart defect then we are in the best situation we could be. Everything to date has been preventative, Rhys has never been affected in any way by his defect and he is being monitored and cared for by the best unit.

We have found out since that Rhys also has a bicuspid heart valve and a sub-aortic membrane. These are of no concern at the moment and are being monitored but will probably need surgery at some point in the future. As with his Coarctation, the surgery will hopefully be performed before they begin to cause him any problems.

We also discovered that Rhys' defect was caused by a chromosome disorder called microduplication of chromosome 22. This is a relatively newly recognised syndrome and, where patients have been identified, their characteristics have varied widely. We therefore have limited information on what to expect but we do know that, aside from birth defects, the disorder has been linked to developmental issues. As a result Rhys has been under the care of a Paediatrician but luckily he is developing really well and doesn't appear to show any signs of a delay.

Rhys is now 2 years old and a happy and very cheeky little man. We are so incredibly proud of our amazing and very special boy. We are equally as grateful to the wonderful team at Glenfield for making sure that he has the health and energy to cause all the trouble that a 2 year old should.

Thank you!

Jennie & Gareth

Heart Link Milestones

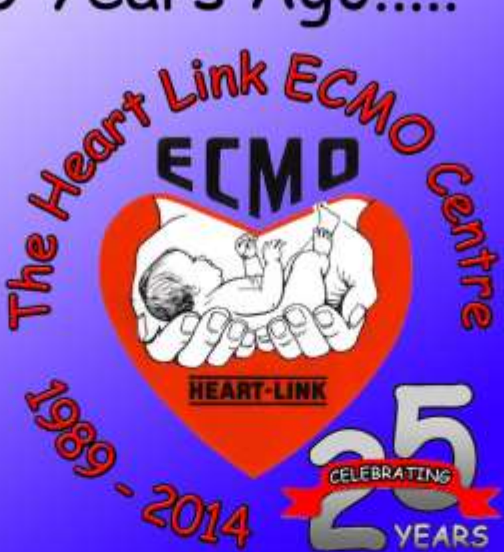
10 Years Ago.....

In 2004, we funded the 'Heart Link Garden'. This is a quiet, landscaped area with plenty of seating. It is situated near to the Education Centre and is available for anyone to use as a place of quiet reflection and contemplation. There is even somewhere to sit if it rains.

20 Years Ago.....

In 1994, the Children's Cardiac Unit was transferred to its present site at Glenfield Hospital. Although newer and more up to date, it lacked something we considered very important for the wellbeing of both young patients and their siblings - a play room! We raised £230,000 to build a purpose built two storey play room with outdoor play area which is accessed directly off the Children's Ward. A lift takes you downstairs to see and play on Thomas the Tank Engine, a great favourite with everyone!

25 Years Ago.....



Heart Link are extremely proud to have funded the introduction of ECMO (Extra Corporeal Membrane Oxygenation) into Great Britain in 1989.

This is a modern invasive life-support technique which can be used in patients with extremely severe respiratory (lungs) and cardiac (heart) failure. The treatment is very expensive and labour intensive and, in 1989, financial support from the NHS was out of the question.

Since 1989 the Heart Link ECMO Centre (this is the official name of the ECMO programme) has treated numerous patients, not only babies but older children and adults. The Heart link ECMO Centre is now known world-wide as a very successful Unit.