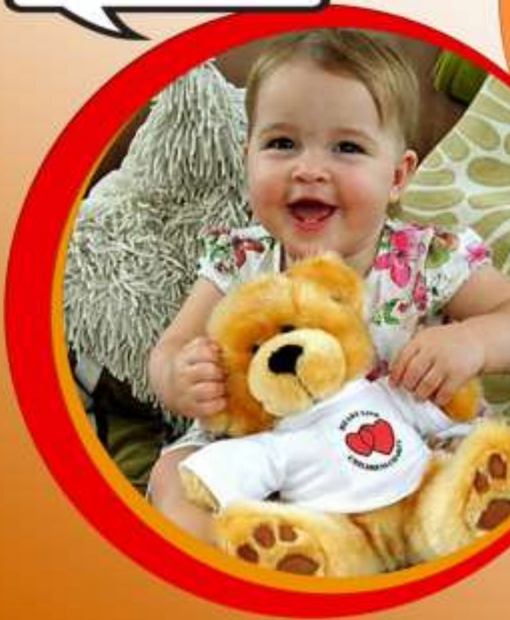
Heart Link News

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

Issue 54 2013

Wilf's Swim

Read Willow's Story



Ruben's Story Inside

Reply slip inside for the Christmas Party Please return URGENTLY!

Dixon-Woods Charity Show

2014 CARAVAN DATES AND BOOKING FORM INSIDE

Chairman's Page

Hello All

I hope you are all well and enjoyed the summer months.

The Christmas party is on the horizon and the invitations are included in this edition of the newsletter. Please make sure you fill in the reply slip and post it back straight away to give us time to purchase the presents and food as time is very tight this year! Unfortunately we cannot accept replies received after 18th November or replies by phone, email or Facebook.

Hope you all enjoyed the Teddy Bears picnic and even the weather was kind to us. Thanks once again for all the help given in organizing the event.

We have purchased a lot of new merchandise which is selling very well. Details are in this edition on page 6 and any queries can be made to: heartlinkmerchandise@gmail.com

John Rigby and myself attended a meeting in London, along with other charities, with NHS England, the people dealing with the new review of children's heart surgery. It was a positive meeting and they did seem to listen to our fears, concerns and comments. We will have to wait until June 2014 for their recommendations which takes away the threat of closure, for the time being anyway, and we are feeling a little more positive. However, we do urge you to forward your views to NHS England and keep up your support for Glenfield Hospital. All the latest news on the review can be found on John Holden's regular blog at:

www.england.nhs.uk/publications/blogs/john-holden/ or write to:

New Congenital Heart Disease Review
NHS England
Southside
105 Victoria Street
London SW1E 6QT

england.congenitalheart@nhs.net 0207 932 9128

Look forward to seeing you at the Christmas party!

Take care

Geoff W Smart MBE

@Heart_Link1

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Ruben's Story

It was a Saturday night when I finally went into labour - for real after two nights of pre labour! My doula Zita arrived and supported me, alongside my husband throughout the night until our beautiful baby boy was born at home in water on St. Patrick's Day. Everything went smoothly and I was soon cuddled up with him in bed to start our baby moon!

But two weeks and two days later everything was about to change...

On Tuesday morning, the 2nd April I got a little niggling feeling something wasn't quite right but brushed it aside as mummy paranoia.
As the day progressed I realised there really was something wrong. My baby boy was struggling to breathe. He was heaving just like I'd seen my oldest boy do when having an asthma attack.

When my husband Mike returned from work we took him to see our GP. I will never forget the look of sheer terror on Mike's face when the doctor said we should go to Hull Royal Infirmary but on second thoughts made the decision to call an ambulance as it would get us there quicker. On the way there we called Zita who came as soon as she could to support us yet again.

Ruben's oxygen stats were fluctuating between 65 and 95. After just shy of 36 hours in Hull HDU, the decision was made to transfer Ruben to Glenfield Hospital - a specialist paediatric cardiac unit. There was "something wrong with his heart". Words cannot describe the fear, the terror, the panic and distress... I was in shock and went into autopilot.

I contacted everybody I knew who could help me express my milk for Ruben as I wasn't allowed to feed him anymore. I'd never been able to express before but with the support from friends I managed.

Ruben had to be intubated for the transfer to help stabilise him and I had to leave the room. I kissed my boy goodbye and prayed I would see him again - alive. As we sat down in the other room I broke down and cried like I'd never cried before. The exhaustion finally took over and I fell asleep sobbing, curled up in Zita's arms.
Mike had to go back to the two older boys and Zita came with me to Glenfield where Ruben was diagnosed with a complex congenital heart defect - Transposition of the Great Arteries and two holes in his heart. He needed emergency surgery immediately. I signed the consent forms and broke down.

In the early hours of the morning on the 4th April we were finally allowed to see Ruben. He looked so peaceful despite his breathing tube. The operation had been a success and his stats had stabilised and were in the high 90's again!

After a couple of days he was taken off his breathing tube and I was able to hold him! Another couple of days later we were on the ward and I could finally start breastfeeding Ruben again and carrying him in my sling.

We got roomed in together and the next few days were spent in bed, cuddling, feeding, or pacing the corridors with Ruben in the ring sling, reconnecting and healing a little from the stress of the last week. I felt like the sling was keeping him protected. I was his safe haven for a short while at least. When he fed and fell asleep, milk drunk, he would smile in his half sleep and it melted my heart.

The day of his open heart surgery soon approached though, and once again we had to say goodbye to our son. This time Daddy carried him down to theatre. We laid him down on the table and kissed him and held his hand until he went to sleep. The image of his tiny body in his surgery gown is etched in my mind forever.

What followed was the longest wait of our lives.
The operation took all day and the relief when we got the call to say everything had gone well was immense. Unfortunately, this was short lived as the scan on his heart revealed a residual leak on one of the holes in his heart, which needed to be fixed, which meant more open heart surgery.

Between Monday the 15th of April (the day of his first OHS) and Friday the 19th (his second OHS) Ruben's chest was left open to avoid putting the heart under too much pressure. He went into acute renal failure and was put on a form of dialysis. He was fighting for his life.

Ruben's Story

The surgery on Friday went well. His kidneys started working again which was a relief! but he was still very swollen and needed to lose a lot of fluid before he could come off the ventilator.

On Tuesday, surgeons removed a line which measured the pressures in his heart but as they did so they discovered a clot in his heart. He was put on heparin, a blood thinner to hopefully dissolve the clot. This was not good news, but it got worse. They also put a chest drain into the pleural cavity of his left lung. He drained 250ml of fluid that had been building up and threatened to collapse his lung. The reason for the fluid was Chyle. Ruben had developed Chylothorax as a complication from open heart surgery. My world broke down around me once again. Not only could I not hold my baby but now, the one thing that I could do for him to help him get stronger, I couldn't do anymore. He couldn't have my breast milk anymore.

Chyle is made up of fats which are usually transported up in the lymphatic system and into the bloodstream. But his lymphatic ducts had been damaged and now this fluid was leaking out. He had to be put on a low fat diet for 6 weeks which, as standard, meant formula. All my friends rallied together to help find a way for him to have my milk and we got *this* close to achieving it. There *is* a way of skimming human milk in a centrifuge to give to babies with this condition. Unfortunately the dietician wasn't on board and in the end it all hung on her decision. I feel wracked with guilt that I didn't fight harder, that I didn't insist because I know that it has been done. The only consolation I have is that after lots of research I persuaded them to reduce the time to 4 weeks.

After Ruben was put on the formula and he had lost most of the excess fluid he was extubated and finally moved onto the ward again. He was put on more medication as he was struggling to digest the formula. The skin around his lips went dry and he had eczema on his cheeks. He had reflux and when he would fall asleep upright on me he would wake up after a short while, suddenly, and scream in pain...the medications eventually masked the symptoms of his body's struggle to digest the formula.

But once again the relief was short-lived as he developed an infection, was moved back to intensive care and was re-intubated for 24 hours to stop him from arresting.

He was put on aggressive antibiotics. All I could think was that there was never a time when a child of mine needed my milk more than ever before but couldn't have it. To see my vulnerable baby, almost skin and bones struggle through so much was heart-breaking. The Chyle stopped flowing at least, and the chest drains could be removed. At last I could cuddle him now without the drains causing him discomfort.

As he recovered from the infection the nurses and doctors tried to get him off CPAP - a type of breathing support which delivers continuous positive air pressure into the nostrils. After a few days of failed attempts they scanned him again to check that his diaphragm was working properly. The bad luck didn't want to end quite yet and we were told he would need yet more surgery to plicate his diaphragm, as the nerve had been damaged and the right hand side was paralysed.

More surgery! Once again we carried Ruben into theatre and watched him be put to sleep. Thankfully these few hours passed quickly and everything went alright. We didn't even see Ruben intubated this time as he protested about the tube so much they decided to take it out only half an hour after returning to the PICU.

Finally things were looking up. We spent another week on the ward and then transferred back to Hull.

Four weeks after his Chylothorax diagnosis we were back where our nightmare had started. But this time we were celebrating. Ruben had his last bottle of formula before we left Glenfield hospital. As soon as we arrived in our room in Hull Royal, I took Ruben out of his transfer pod, sat down and after 5 weeks I breastfed him again.

Five weeks of pumping. Eight weeks of ups and downs in hospital. Endless cups of coffee and conversations with other parents in the kitchen. Over 100 bottles of milk pumped. Too many tears! So much fear. But we made it! We came through it! I celebrated silently as I sat down in that chair in my room, lifted my top and Ruben latched on. A silent tear of relief and a smile on my lips. Now he could really start healing. Now our emotional healing could begin...

It is now 2 months since we left hospital. Ruben has been gaining weight beautifully and has gained over 7lbs since our discharge. The last time he was weighed in hospital he was just about to reach his birth weight again at 2 months old!!

I spent the first week making up for our babymoon that had been cut short. I spent most days in bed with Ruben feeding and building up my supply again. I carried him in his new sling, which friends had made for me. We cried and we cuddled and we stayed up late together as we relived those eight weeks.

We are still healing. But we are ever so grateful that we are home now and things are looking good.

While we were in hospital two other families were there too who I spent a lot of time with.

It breaks my heart to say that both of these families baby's grew wings.

Ruben's heart sister, Sienna, had the same condition as Ruben and the same complication - Chylothorax. Unfortunately she didn't respond to treatment and after three months the fight became too much for her.

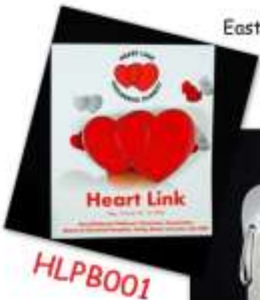
Her parents are raising funds to buy another light and sensory machine as Sienna liked looking at the lights so much.

I want to share their fundraising link too, in memory of all heart warriors who didn't make it.

https://www.justgiving.com/Michelle-Whittaker5

Heart Link Merchandise
Postal Order Form

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


HLPB001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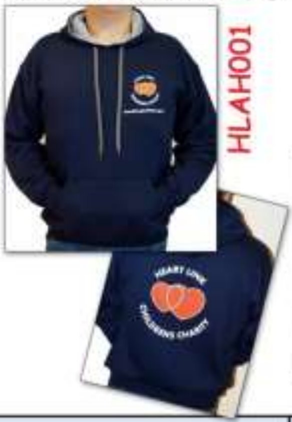

HLAH001


HLCB001

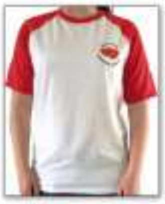

HLEB001

Product Code	Product Description	Price (incl. P+P)	Size/Col	Quantity	Total
HLAT001	Adult White T-shirt - Sizes: S,M,L or XL	£10.49			
HLAH001	Adult Navy Hoodie - Sizes: S,M,L or XL	£29.99			
HLCH001	Child Royal Blue Hoodie - Ages: 5-6, 7-8 & 9-11	£24.99			
HLSB001	Shopping Bag (Approx size 40 x 38cm)	£3.50	N/A		
HLSW001	Silicon Watch (Colour: Black or White)	£3.99			
HLPB001	Double Heart Pin Badge	£2.00	N/A		
HLDB001	Drink Bottle 400ml	£4.99	N/A		
HLLY001	Lanyard	£2.00	N/A		
HLTC001	Wishbone Trolley Coin Keyring	£2.99	N/A		
HLSB002	Silicon Wristband	£2.00	N/A		
HLEB001	Double Heart Elasticated String Bracelet	£3.00	N/A		
HLCB001	Collection Box (F.O.C. with any other item)	60p P+P	N/A		
				Grand Total =	


HLSB002


HLLY001


HLSB001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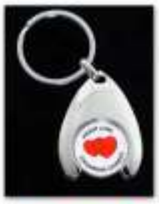

HLTC001


HLSW001

I enclose a cheque for £____________ made payable to '**Heart Link**'

Name:

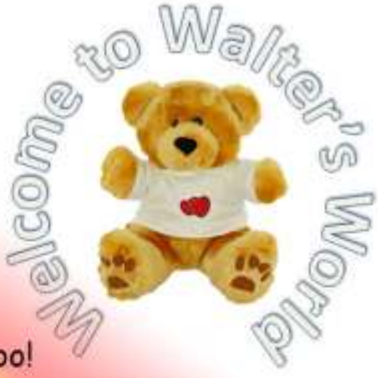
Address:

Postcode:

Phone No: Email:

Please return to: Heart Link Merchandise, C/O Marie Chaston, 9 Ridgmont Walk,
Clifton, Nottingham NG11 9JA. Email: heartlinkmerchandise@gmail.com

***********Please allow 28 days for delivery**********.*
Hoodies and T-shirts are special order, non-stock items and may take longer



Hello Everybody!

I hope you all had a lovely summer
and for those of you who are old enough
to go to school, I hope you are all enjoying
your new term with new teachers and some new friends too!

I had a lovely time at the teddy bears picnic and it was great to see so many of you there with your families, it was a fun day had by all with lovely weather too!!!

In the last newsletter, there was a spot the difference competition. Thank you to all of you who sent in your sheets.

I had one from a little girl named Shannon from Whittlesey, near Peterborough, but as there was no full address I could not send you your prize, so please write it down on a little piece of paper and send it to me here at Walter's World and I will post it to you.
Our other winners are Kayah Hall, Lennon Cufflin-Potter, Jessica Heritage and Louis Boorman!

Congratulations to you all, your prize is in the post!

Lastly, it's now less than 100 days to go until the big man with the beard comes down our chimney or uses a magic key to get through the back door, so I hope you're all on your best behaviour as Santa will be asking me if he should make a visit to your house!

I look forward to seeing you all at the Christmas party!!

Take care
Lots of love

Walter Bear xxx

Ben's Story

Ben was born on the 19th October 2012 at 10.45 am at King's Mill Hospital.

He arrived after a very quick labour. Once the midwife Dawn had cut the cord, Benjamin quickly went a very scary grey colour. We thought to begin with that there wasn't anything wrong with him and were told that he needed to warm up and have lots of cuddles, so Ben was placed under the heat lamp after they had told his dad to get him dressed.

Once I had been for surgery and come back, Ben had already been taken to NICU as they thought there was something wrong with his lungs and tried to get some oxygen into him. After a while, a team of doctors came to tell us that Benjamin had Transposition of the Great Arteries which, they explained, meant the main arteries were the wrong way around in his heart.

At that time it was hard to understand. They said he was very ill and may not make it through the night. They had called Glenfield and arranged for him to be transferred there as he would need an operation and some specialist care.

At around 5.30 pm they prepared Benjamin for the journey to Glenfield and at this point we were told to say goodbye. His dad had to follow him to Leicester as I needed to stay at King's Mill for the night.

Benjamin left and I was taken back to the maternity ward and given four very special pictures of him. Benjamin arrived at Glenfield at 7.15 pm and was given a balloon septostomy to keep the hole in his heart open and his dad was finally able to see him at around 9 pm. Benjamin was stable and his dad was given a parent's room to stay in. I followed up the next day (on the Saturday) and finally got to see Benjamin. It would be another 5 days before we could have our very first cuddle, but it was nice to be able to help with his cares and change nappies.

Benjamin was on PICU for 5 days as he had a chest infection, which meant he was unable to have the switch operation and at 6 days old he had a Tonic-clonic seizure (formerly known as grand mal seizure) which has left some areas of his brain with damage (but he has never let it affect him).

Finally, on the Friday, I got my first cuddle with Benjamin which was a very emotional time. Benjamin had lots of visits from his big brother Samuel (who is a very proud big brother), aunties, uncles, cousins and Grandparents. On the Friday we registered Benjamin and he became official! He then moved to Ward 30 so he could become a little stronger before his operation.

We were given a special goody bag from Heart Link with a Walter bear in who sleeps in Benjamin's cot and watches over him.

Benjamin was then allowed to start bottle feeding which was hard work for him. It took him a while to learn to get the hang of it, but he soon went from 10 ml to 70 ml and started to gain a little weight and get over his chest infection.

Benjamin dressed up for Halloween and enjoyed having his hands painted to make a ghost with the play leader on Ward 30. He also enjoyed being able to sit in a bouncy chair and under a play gym.

On Sunday the 4th of November, Benjamin had his pre-op and we met Benjamin's surgeon, Mr Lotto, who explained all about his switch operation.

Benjamin went down on Monday the 5th of November for his open heart surgery. The operation went very well and Benjamin was back up on PICU. We finally got to see him around 5.30-6 pm after a very long day. After the operation Benjamin had his chest closed and pacing wires out within 4 days and was doing really well. He moved beds in PICU as he found his lungs and started to cry louder, but Benjamin developed another chest infection and his lung collapsed.

We moved to Ward 30 on the 13th November to finish his recovery and Benjamin enjoyed his physiotherapy to help his lung get better. He also enjoyed extra special visits from family and loved receiving gifts.

Finally, on the 14th November, Benjamin came off oxygen and had his NG tube removed. By then he was completely bottle fed and we were allowed to go for a walk around the ward - so Benjamin got to explore the sensory toys in the play room!

On the Wednesday we were allowed a walk around the hospital and I was able to take him down to x-ray and for an echo myself.

On the 16th November we were allowed to take Benjamin home, so at 7pm we left Ward 30!

We will never be able to thank Glenfield and Heart Link enough for the amazing care given to Benjamin and our family.

Benjamin will be 1 on 19th October and it's been an amazing year so far!

Fundraising Story

After all the fantastic help and care Ben received from birth at Glenfield on both PICU and Ward 30, we decided to hold a fundraising event to raise money for Heart Link to help to carry on their good work helping other babies and children born with heart conditions.

We decided to hold a family fun night. We arranged a disco and band and wrote various different letters asking for raffles prizes. We received some amazing prizes; a signed Forest football, a book, tickets for LEGOLAND, Digger land, White Post Farm, Butlins, Wheel gate and Oceans of Fun, bottles of wine, a baby hamper and a hairdressing voucher. We also auctioned some lovely homemade cakes off (see photos below).

A fun night was had by all and the children received a goody bag from Ben and even a little Walter Bear came along!

Great fun was had all night by everyone who came. We raised £ 1,000 and went to Ward 30 to present a cheque to Heart Link.

Can't wait to hold another fundraiser next year!

Cheryl Hibbard

Letters

Dear Heart Link

21 years ago, in April 1992, I underwent E.C.M.O treatment after a complication in the womb. Without this treatment I would have certainly died.

Last month I graduated from the University of Sussex with a first-class degree in mathematics with economics - see the attached photo of my parents and me. Needless to say, this would have been impossible without the expert care you were able to give. I didn't realise until today that the treatment which saved my life wasn't available in the UK just 3 years before I was born!

I'd just like to take this time to thank you wholeheartedly for saving my life, giving me the opportunity to have a normal life, and achieve what I have done so far. I can never thank you enough, but hope you find my story heartening - no pun intended!

Thanks once again, and Best Wishes,

Jack Pape

Hi Heart Link

Way back in the October of 2000, my now eldest daughter was born with dilated cardiomyopathy, a slightly worrying time as she was born 8 weeks early and delivered by an emergency Caesarean. Up to birth she had been healthy (she has featured in your newsletter, but when she was little).

Over what has been an eventful 13 years, she has grown into a wonderful young lady. Last year she started high school.

We are so very proud of her and her amazing fight for life, it's an understatement to say how much you can become grounded by those you love being unwell, and how children get on with being so poorly as a matter of course.

This is to wish our amazing Ruby-Rose a fantastic 13th birthday on October 18th, and also another chance to thank the amazing teams at Glenfield and Derby hospitals on getting us here, and beyond.

We love you Ruby!

Mum, Dad and little sister Drew x

We want to say a big thank you to Heart Link for giving us the opportunity to attend the 'Dream Night' at Twycross Zoo. We all thoroughly enjoyed it.
There were lots for the children to do and it was great to be able to meet the keepers and get to ask questions about the animals.
The children wore their t-shirts so that other Heart Link members recognised us. We even met someone who had been on the ward when Arlo had his surgery last year.
I have enclosed some photos of Sofia, Lucille & Arlo. Feel free to post them on Facebook or use in the newsletter.

Kind regards,

Hannah Massarella.

Dear Heart Link

My name is Nathan Robertson. I'm 17 years old and I was born with a congenital heart defect (Bicuspid aortic valve).

Whilst I was young this defect never affected my health but I was seen routinely at Glenfield Hospital, Leicester. When I was 11 years old I began to feel tired and breathless. Scans revealed I had aortic stenosis (narrowing) which was caused by my defect.

I've since had 2 balloon dilations, one when I was twelve and one when I was 15 to help relieve the narrowing, which made me feel a lot better. I will need to have my aortic valve replaced soon to give me my health back.

In the summer my sister Callan and my Dad decided to do the Robin Hood Half Marathon to raise money for Heart Link, as they have supported myself and my family with accommodation and much needed equipment. This made my stay in hospital easier to cope with.

I will be transferring to adult cardiology in October as I will be 18. Myself and my family wanted to give something back to Heart Link so this worthy charity can continue to help others.

Having trained hard through the summer my sister and dad completed the half marathon on the 29th September in 2 hours 6 minutes and have so far raised just over £800! I'm so proud of what they have done and hopefully this will go towards helping other families.

Thank you

Nathan Robertson

One year ago today we took our 10 day old son Cyprian to the GP as he wasn't very well. By that evening he was in a hospital that we knew very little about, with a condition we had never heard of and in a situation we had never even dreamed about. Mr Lotto successfully operated on Cyprian two days later and after two weeks at Glenfield we were able to go home.

My husband and I would like to say a huge thank-you to all the staff and support team in PICU and Ward 30 and to the amazing Heart Link team. Your love and support across those two weeks kept us sane and the use of the parent facilities was amazing.

You are in our hearts and prayers forever,

James, Rebecca, Matthias and Cyprian Leatherland

Willow's ECMO Story

On Thursday the 27th of June this year our lives changed forever. Just a month after her first birthday, our daughter, Willow, was taken ill suddenly and a roller-coaster month started. We went from having a perfectly healthy baby to death's door in 24 hours, told she would probably need a heart transplant a few days later, had to learn complex medical conditions overnight and had the pain of seeing her heart stop three times in 24 hours, the last time for four minutes.

This is Willow's story:

Willow was taken into Northampton General Hospital on June 27 and was admitted on to the children's ward with a suspected chest infection. Within the next few hours Willow's condition rapidly deteriorated to the extent she was given emergency CPR twice after her heart stopped.

Willow was transferred to the Glenfield Hospital in Leicester and we were told that her heart was functioning at less than a quarter of the expected rate. She was diagnosed with dilated cardiomyopathy, although at this point we didn't know if it was congenital or viral.

Willow had another cardiac arrest, this time her heart stopped for four and a half minutes. The heart consultants told us they had no choice but to put Willow on an ECMO machine, which acts as an artificial lung and heart to oxygenate the blood outside the body and allows a patient's heart to rest and recover.

Doctors told us that Willow may require a heart transplant but they would wait to see if her heart showed any improvement while she was on the ECMO machine. The first week of treatment showed little encouragement, discussions were held with Great Ormond Street and Newcastle to see if a bed was available and to make them aware of Willow.

Great Ormond Street advised Glenfield that they had dealt with a similar case recently and that child had made a fantastic recovery after two weeks on ECMO. We were preparing for the journey to London or Newcastle fearing that a transplant would be inevitable.

After 10 days on the ECMO machine, Willow's heart began to show signs of improvement. She was trialled off the machine and subsequently taken into theatre to have the cannulae removed. A further Echo showed a marked improvement. During Willow's time on ECMO she had also been on dialysis. She was kept on dialysis and a ventilator for a further 48 hours before we finally got to see her awake again.

Another 48 hours on PICU and Willow was ready to go onto the ward; we felt we were almost home; just 45 minutes later, Willow started having seizures and she was taken back into PICU. She required an MRI which meant she needed to be intubated again and given a general anaesthetic. The MRI showed a large old bleed, possibly caused by the cardiac arrests and a smaller acute bleed. This was covering both the left parietal and temporal lobes. Willow continued having seizures for the next 48hrs, lasting from 20 seconds to 25 minutes.

Once the seizures were under control and the sedatives from her time on ECMO started to wear off we saw glimpses of our little girl coming back to us. She had been awake a full week before she managed a smile, a smile that broke our hearts - in a good way!

At the end of July Willow was finally discharged from Glenfield, on a regime of medication for both her heart and her head but coming home none the less.

Subsequent follow-up appointments have shown that Willow's heart is functioning "normally", she has not had a seizure for almost two months and the loving, cheeky little girl we thought we'd lost is showing little ill effect from the trauma she has suffered.

We have started fundraising for Heart Link to try to buy another ECMO machine. So far we have raised over £3,000 and completed Skydives on the 28th of September which have been paid for by Redrow Homes so that all the money we raised goes to Heart Link.

www.justgiving.com/willowsmountain

Wilf's Swim

Our thanks go to Wilf Smith and his family for swimming over 1,000 lengths earlier this year to raise money for Heart Link. An amazing achievement for which we are very grateful.

Wilf decided to celebrate his 80th birthday by persuading his family to join him in a sponsored swim for charity that saw them completing 1,020 lengths of his local pool in Ibstock.

Wilf was joined by daughter Jackie and son Michael, as well as grandchildren Vicky, Rachel, Erica, Katie and Holly, and great grandchildren Zach, Isla, Alfie and Evelyn. His wife Eileen cheered them on from the pool side.

He aimed to raise around £5,000 but has smashed that target with a fabulous final total of £8,343.68!

Healing Little Hearts

THE SCALE OF THE PROBLEM

Congenital heart disease is the most common major birth defect and affects millions of children around the world.

Every year 80,000 children in India are born with defects in their hearts requiring heart surgery.

Out of these 80,000, only 20,000 get any form of heart surgery, WHICH MEANS THAT EVERY YEAR, YEAR ON YEAR, 60,000 CHILDREN ARE DENIED A SIMPLE OPERATION WHICH WOULD BE LIFE SAVING.

90% of these children live in areas of India where appropriate medical care is inadequate or unavailable.

Time is also precious for these unfortunate children, AS THE LONGER SURGERY IS DELAYED; THEIR HEARTS BECOME IRREVERSIBLY DAMAGED AND ARE BEYOND HELP.

Can you imagine even for a second what it would be like if a child in your family needed life-saving heart surgery but it was not available to them either because of lack of funds or inadequate expertise, or poor access to appropriate healthcare?

To put it into context, the UK with a population of 60 million is served by 12 modern, fully functional children's heart centres, whilst India with a population of 1.2 billion has exactly the same number!

The gross inequity in healthcare is painfully and tragically obvious.

HOW DO WE HELP?

Healing Little Hearts was launched in 2007 with the primary objective of treating children with heart defects in India.

HLH was set up to make a contribution towards the tragic paucity of Health Care for a huge number of babies and children with correctable congenital heart defects in India.

HLH SENDS SPECIALIST MEDICAL TEAMS OF DOCTORS AND NURSES, EVERY 4 TO 6 WEEKS TO OUR ADOPTED BASE HOSPITAL IN INDIA, HOLY FAMILY HOSPITAL, MUMBAI, TO PERFORM LIFE SAVING OPERATIONS, PROVIDING STATE OF THE ART OPERATIVE INTERVENTION AND POST OPERATIVE CARE.

TO DATE HLH HAS OPERATED ON OVER 320 CHILDREN WITH A SUCCESS RATE OF OVER 94%.

Our mission at HLH is to give as many children as possible the chance of life, by continuously sending our specialist medical teams to provide the best standard care to the deserving children and their families.

HLH HAS NOW OPENED A 2ND CENTRE, AT THE ADITYA BIRLA HOSPITAL, PUNE, AND NEXT YEAR WILL BE OPENING A CHILDREN'S CARDIAC CENTRE WITH WADIA CHILDREN'S HOSPITAL

Healing Little Hearts

Healing Little Hearts
Give a child a new life

HOW YOU CAN HELP?

In this day and age in the 21st century, as the world is now a much smaller place, it is feasible to mobilise teams of doctors and nurses to fly out to India regularly to provide these life-saving heart operations.

HLH is fortunate to have many volunteers who donate their time to look after these desperately ill and desperately poor children.

However, this can only be done through the financial support of people and companies like yourselves.

Each trip costs £6,000 (air fares and accommodation) during which 10 to 12 children receive life-saving heart surgery. The HLH team are also training the local doctors and nurses with a hope of that in the fullness of time, they become self-sufficient. It is worth mentioning that there are NO ADMINISTRATIVE COSTS as HLH is run entirely by volunteers.

This effectively means that for a cost of £500 - £600 each, a child is literally given a new lease of life.

THIS IS WHERE WE NEED YOUR FINANCIAL HELP AND SUPPORT, TO FUND OUR CHARITY MISSIONS SO PLEASE HELP US TO HEAL THESE LITTLE HEARTS.

Website: www.healinglittlehearts.org.uk or find us on Facebook: www.facebook/HLHcharity

REGISTERED CHARITY NUMBER 1130194

DR.SANJIV NICHANI
CONSULTANT PAEDIATRIC INTENSIVE CARE AND HIGH DEPENDENCY CARE
University Hospitals of Leicester

Although Heart Link are not connected with 'Healing Little Hearts', we are including this article about the charity as it has been set up by Dr Sanjiv Nichani who will be known to many of you as one of the Paediatric Consultant Intensivists at Glenfield Hospital and the Leicester Royal Infirmary.
It highlights how treatment of children with heart defects in India differs so greatly from the UK.

Thank You Message Tree

We will be putting our Christmas tree, once again, in the Main Reception at Glenfield Hospital on Friday 29th November to raise funds for Heart Link.

Please buy a "tag" at £1 each and use it to send a special message to a Member of Staff, Ward or Department or anyone else you would like to thank.

Tags will be on sale at our Christmas Party or you can send your message and donation to - Heart Link, Freepost MID 25384, Leicester LE3 6ZJ.

William's Story

William was born in March 2010 as what appeared to be a healthy baby boy. It was only as the weeks went by that the problems and worry began. He didn't appear to be able to feed very well, taking only a very small about of milk at a time. He wasn't gaining weight properly and was rapidly falling below the healthy weight for his age.

We first saw a paediatrician when he was five months old. He was under medical investigation for a further seven months, in which time numerous tests and trips to hospitals were carried out. Unfortunately, his condition wasn't picked up.

With William approaching his first birthday, as parents, we still felt something wasn't right. He was skin and bones and had started becoming ill very regularly. William being our first child, we just thought perhaps it was normal for children to be ill so regularly. But after six months of constant illness, particularly severe chest infections, we knew it just couldn't be normal.

After a couple of trips to the local GP, a heart murmur was picked up. We tried not to get too worried and thought perhaps it might be innocent.

We finally got to the paediatrician appointment after William had just turned two. When she listened to his chest, she was very alarmed. She said there was an extremely prominent murmur and that he would need further investigation as soon as possible.

After various trips to the hospital and further heart scans, William was diagnosed with a large VSD, a hole in his heart. We were told it would be open heart surgery as soon as a place was available. As parents, we were devastated. We knew it was going to be the toughest journey of our lives.

In November 2012, William had a large VSD repair as well as a 'kink' in his aorta repaired. The operation took eight hours and was the longest, hardest eight hours of our lives. But William was very strong and the operation was successful.
He was out of intensive care in just a day and was making fantastic progress.

Twelve months on, and William is a happy boy, full of energy and free from the constant illness and chest infections. He can breathe better, has a healthier appetite and is now a healthy weight for his age.

We are delighted as parents and want to thank the charities Heart Link and Keep the Beat for their fantastic support throughout this hard time. During our stay at the Hospital, all the additional facilities, equipment and support groups provided by the charities were invaluable. We would also like to thank the wonderful, caring staff at the congenital heart unit in Glenfield Hospital, the vast surgical team and staff in the PICU. Their work and dedication is second to none. Particular thanks go to Mr Lotto, not only a brilliant surgeon but a caring person. We will never forget that his incredible skills have saved our little boy's life.

Left: William after his surgery.
Top right: William & Dad 4 days post-op
Bottom Right: William's first week back at home

William enjoying the beach in France August 2013

We know that William's health will have to be monitored for all of his life, but with such a fantastic hospital and caring charities, we know he is in safe hands.

A final thank you to William's Uncle and his colleagues at the University of Nottingham who carried out a 200 mile bike ride for the charities Heart Link and Keep the Beat in September.

Many thanks for reading William's Story.

Yours sincerely

William's parents - Sarah & Matt Smith.

Mr & Mrs Brown

Our thanks go to Peter & Karen Brown for accepting donations to Heart Link in leiu of wedding gifts. Their generosity stems from following the story of one of our young members, and a relative, Archie. Archie's Grandpop is Karen's Uncle and had the honour of giving the bride away on her big day. The wedding was held at the Hinckley Island Hotel on Sunday 8th September and the guests were very generous, raising a total of £760.00. Congratulations to you both and we wish you every happiness!

Karen, Uncle Mick & Archie

Mr & Mrs Brown
© David Brown Photography

Peter, Archie & Karen

Dee n Dek's Charity Night!

My Dad (& Ben's Grandad, Derrick Gordon) organized a Charity Event on 6th September at Brush Sports & Social Club, Fennel Street, Loughborough to raise money for Heart Link and Cancer Research.

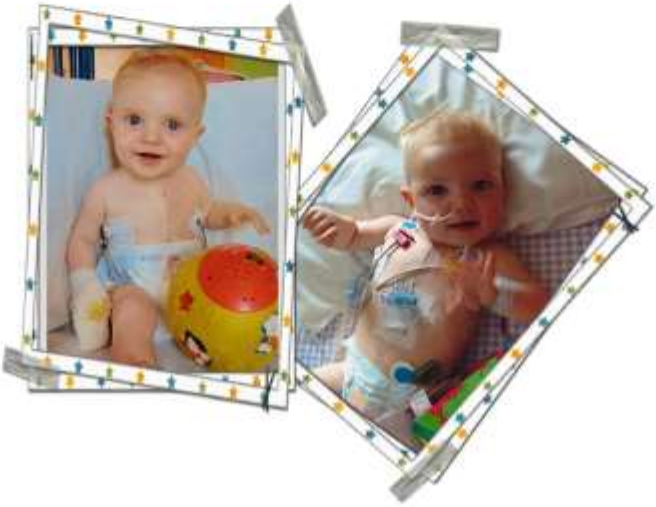
Around 250 people showed up on the night. After 6 weeks of preparation and practice the night was a huge success with "Dee n Dek" singing together and individually (ending with Frank Sinatra My Way). There was also a disco, a dance by "Nervous Elvis" and Ben playing drums to The Summer of '69. The crowd spurred Ben on and he did an impromptu drum solo – it was simply awesome! There was a huge raffle and other games to raise money too.
£1200 was raised and this has been split between Heart Link and Cancer Research.

The picture of the four people on stage are the organizers and entertainers; Nervous Elvis is Natalie – Dee's Daughter, Dee is dressed as Amy House Wine, Derrick is the singing DJ and Ben the little drummer.

Vocalist Dee Marie
& Me and Me Mate Disco Derrick
"The Singing DJ!"

Ben's story

We discovered Ben had Tetralogy of Fallots when he was 6 months old. We had been trying in vain to get GP's to listen to our concerns about Ben's "spells" (as we now know they were). At 6 months he was rushed into hospital and transferred to Glenfield where we would stay for the next 6 weeks. Ben was too poorly to come home as he was 'spelling' each day. Despite this, he never stopped smiling – he learned to give a little wave to the nurses and doctors each day with a big grin! Ben had surgery after 3 weeks. That was the hardest day my husband and I have ever known, watching our baby go through what he went through. When he came out of surgery he had a few complications, so stayed in PICU for longer than normal. We discovered he had Chylothorax so he was put on a strict diet of Monogen and low fat soft foods. Because of this he needed chest drains so it was not until 3 weeks after his surgery that he was finally allowed home – on his diet.



The doctors and nurses do their job and see lots of different faces, people and babies – but to us whom they have helped we can never forget anyone of them, and never fully express how thankful we are for their extraordinary care each and every day.

The support we received from everyone – nurses, doctors, CLN's and Heart Link was magnificent and we feel blessed to have such dedicated and caring people around us.

Without Heart Link I wouldn't have been able to stay with my baby during that time – Heart Link is an amazing charity set up by an amazing lady.

Ben is 8 years old now, we were told he would probably never be an athlete....but I think that's the one thing the doctors got wrong…as he never stops running around, playing with his friends, going for bike rides….and of course playing his drums like a star!

Ben has no pulmonary heart valve and will need to have one fitted in the future, but for now he has so much energy that I can't keep up with him!

Hayley (Ben's proud Mum!!)

Thank You....

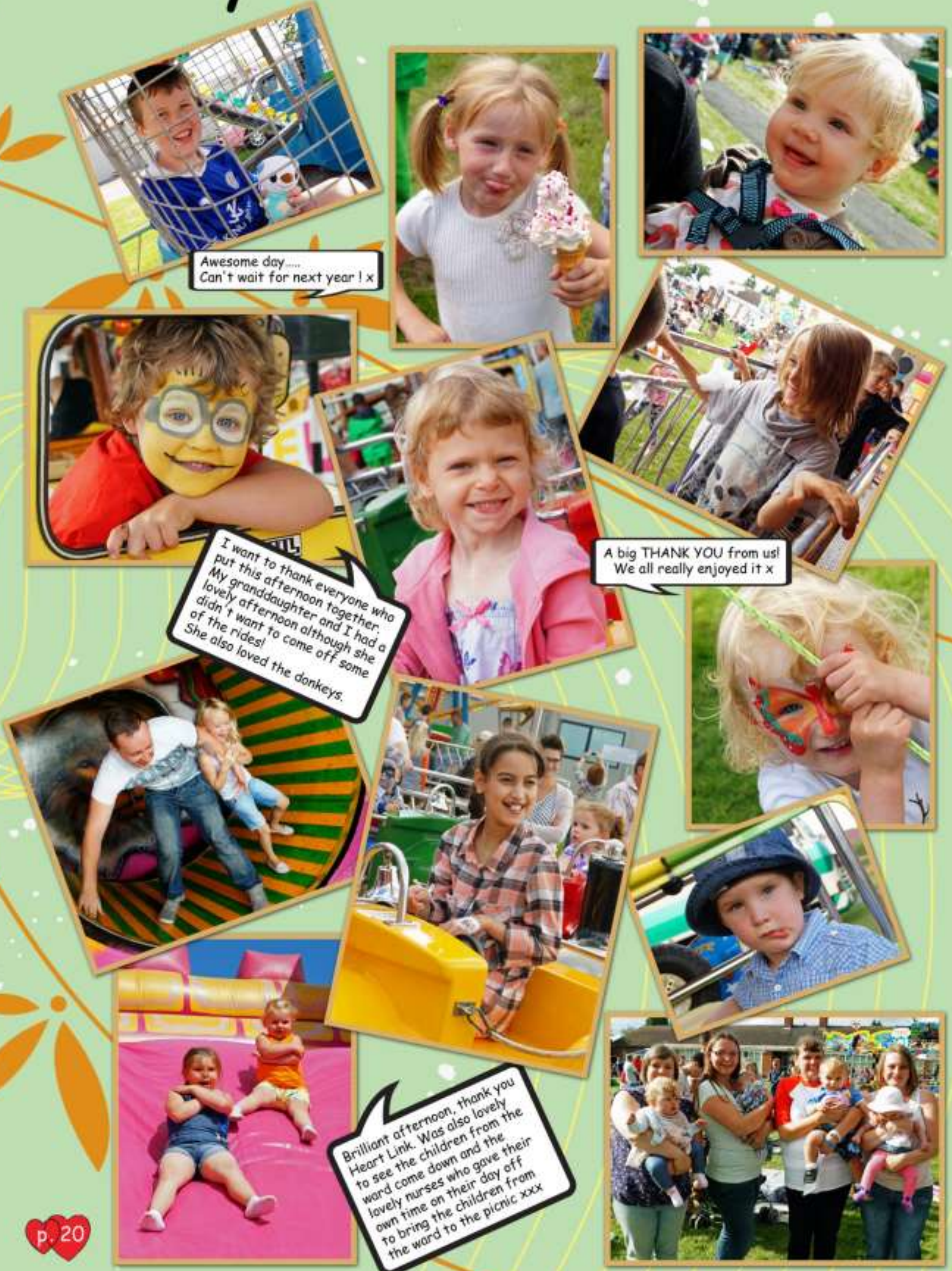
......to all of our fabulous fundraisers!

Connor Smith did a sponsored bike ride around Shipley Country Park and raised £178. Fantastic!
Well done Connor we are very grateful.

Melanie Finch, Ian Lockwood, Alan Cox & Andy Cox raised £820 plus gift aid of approximately £185 by cycling the Great Notts Bike Ride for Heart Link. Brilliant! Thank you so much.

Please share your fundraising stories, personal stories and achievements with us by emailing them to: heartlink@hotmail.co.uk

Teddys Picnic 2013

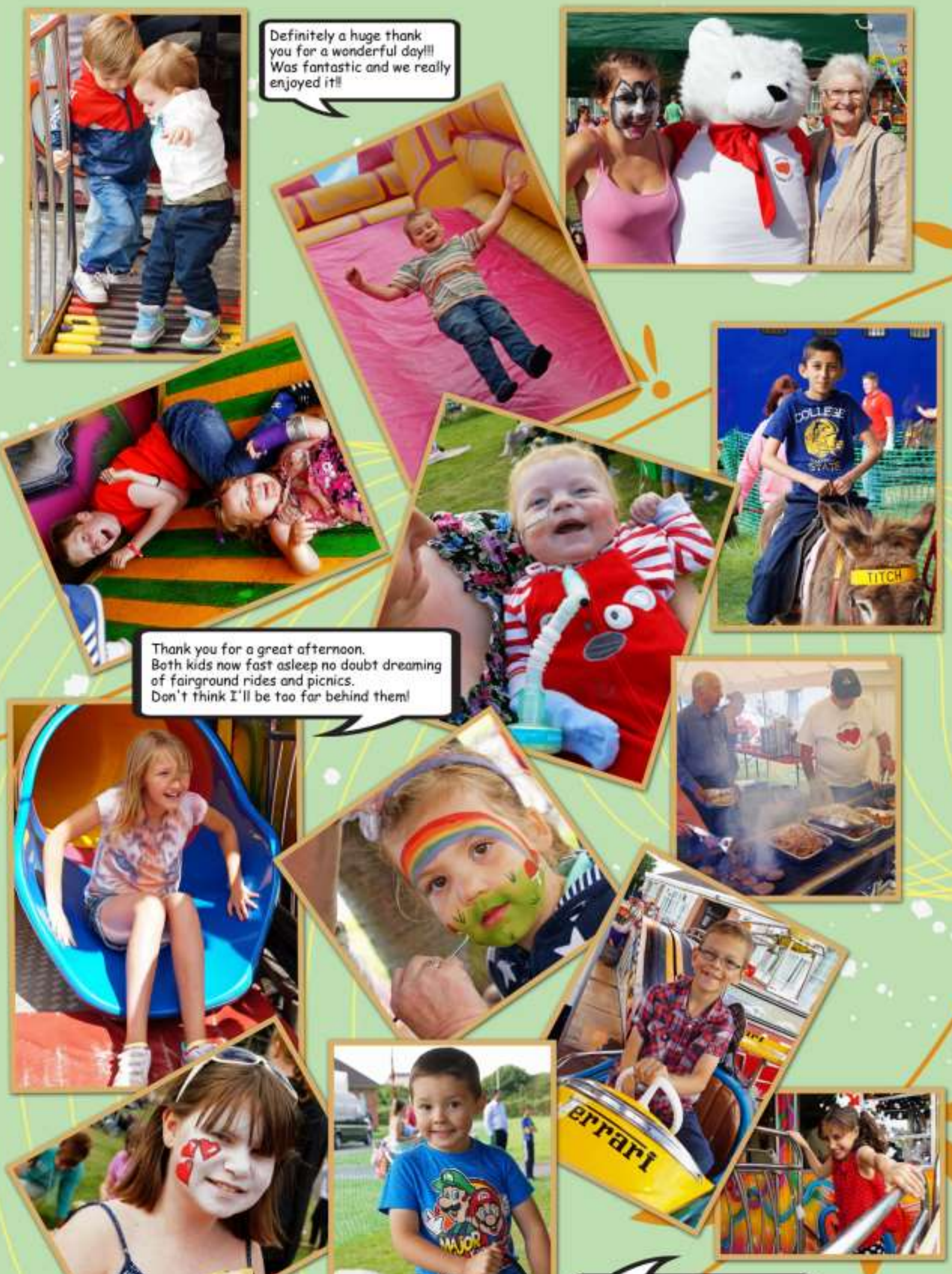


Awesome day.....
Can't wait for next year ! x

I want to thank everyone who put this afternoon together. My granddaughter and I had a lovely afternoon although she didn't want to come off some of the rides! She also loved the donkeys.

A big THANK YOU from us!
We all really enjoyed it x

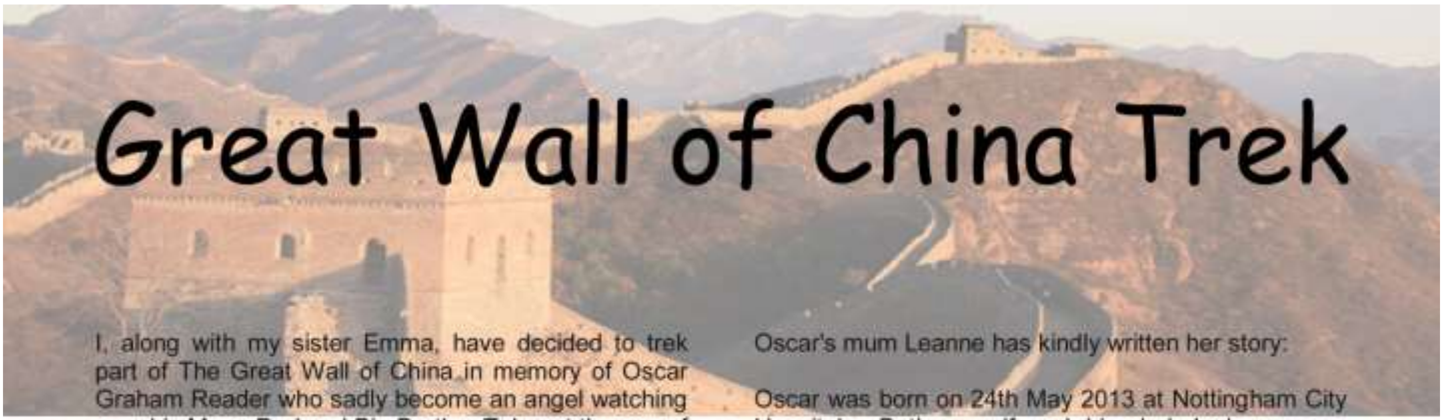
Brilliant afternoon, thank you Heart Link. Was also lovely to see the children from the ward come down and the lovely nurses who gave their own time on their day off to bring the children from the word to the picnic xxx



Definitely a huge thank you for a wonderful day!!! Was fantastic and we really enjoyed it!!

Thank you for a great afternoon.
Both kids now fast asleep no doubt dreaming of fairground rides and picnics.
Don't think I'll be too far behind them!

Want to say a big thank you to Heart Link for today.
My children really enjoyed themselves and the other parents were so friendly too x



Great Wall of China Trek

I, along with my sister Emma, have decided to trek part of The Great Wall of China in memory of Oscar Graham Reader who sadly become an angel watching over his Mum, Dad and Big Brother Toby, at the age of just 9 weeks and 1 day old, after a hard fought battle with many heart problems. Emma and I are both 30 something and VERY unfit. We are both full time child minders and each have two children. We are taking part in this trek to raise money for the wonderful children's charity - Heart Link.

We first got to know about this wonderful charity when my nephew William was admitted to Glenfield aged 2 weeks. William had surgery at 2 weeks old and then again at 15 months. Thanks to the great staff at Glenfield, William is now a fit and healthy 12 year old and lives a normal life. And thanks to the support of Heart Link and the facilities they have funded, my sister Emma and her husband had their time in hospital made so much easier.

This is Oscar with his big brother Toby. Such a handsome pair of boys!

We have been inspired to do this Trek by the very brave Oscar and his equally brave family so please visit our Just Giving page and give generously!

http://www.justgiving.com/ChinaWall

Thank you
Marie & Emma.

Oscar's mum Leanne has kindly written her story:

Oscar was born on 24th May 2013 at Nottingham City Hospital. Both myself and his dad Jack were so pleased to have a second son and baby brother for our two year old Toby. At birth it was identified that Oscar had some dysmorphic features. When put together this normally points to a genetic syndrome, however which syndrome was not known. After a few days it became clear that he wasn't well and was admitted to the Neonatal unit with breathing problems. Initially the doctors thought he had a respiratory infection, but over the course of a few weeks with lots of tests and heart scans, it was revealed that Oscar has multiple heart problems. The main causes of Oscar's problems were the hypertrophic cardiomyopathy (thickened heart muscle on both ventricles) and pulmonary valve stenosis (narrowed valve/artery leading to the lungs). He also had a small atrial septal defect (hole in the heart) and a left ventricle cavity obstruction due to the increased pressure in the left side meaning the septum of the heart was swollen.

Over the course of seven and a half weeks he was cared for fantastically well at Nottingham City Neonatal Unit by some amazing doctors, nurses and other healthcare professionals. He was just at the point when we were thinking we may be able to take him home with some extra support in place from oxygen and feeding tubes, however, at this time, Oscar's condition deteriorated and his heart began to beat in a very unsynchronised way. This was due to the pulmonary valve narrowing to a life threatening size. He needed an operation to stretch the valve. Oscar was transferred to Glenfield Hospital in Leicester and it was there that he received more potentially life-saving care although unfortunately for us, Oscar was just too poorly. He spent five days on Ward 30 at Glenfield with some fabulous nurses and we had a great parent's room, all provided by Heart Link. During the operation Oscar's heart stopped for 20 minutes and he had to be put on an ECMO (extra corporeal membrane oxygenation) machine to do the job of his heart and lungs. After four days on ECMO, it was clear that Oscar would not recover from the procedure and we lost him on 27th July.

Heart Link do a fantastic job of fundraising to provide lifesaving equipment like ECMO, monitors and all the parent room essentials such as a washing machine and fridge freezer.

On behalf of my gorgeous baby boy Oscar, Jack, Toby and all the children this money will go towards helping at Glenfield Hospital - THANK YOU SO MUCH!!!!
Leanne xxxx

Londres à Paris en vélo

London to Paris Diary 2013

Tuesday 13 August

All ready for the off tomorrow at 6am! We would like to say a big thank you to those that have sponsored us; we've hit the £2k target!

Wednesday 14 August

92 miles done to Dover. Now waiting two miles from the ferry, before another 8ish in France. WE MADE IT!!!!!!

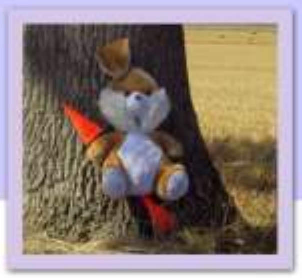
Thursday 15 August

Half way to Paris! 50 miles down so far today. Just lunching. Shoulders and feet hurt!

Dinner at Ibis hotel. Laura has eaten with just right hand due to having a numb left hand, good job it was lasagne!

Friday 16 August

Well over 200 miles cycling done. There have been so many hills this morning and rough road. It is hard but there's a good cause and good lunch to get us there. We follow the orange triangles :)



End of day 3 and our legs and other parts of our bodies know it, but we're nearly there. It was 65 miles today, hot, windy and bad tarmac. Smooth tarmac is like heaven! We've both struggled at times but we balance each other out. We were a group of 6 this afternoon and sang our way to the hotel in Beauvais. Couple of punctures in the group slowed us down but we got here. 244 miles down "just" 60 miles to Paris. P.S. Had words with ourselves up a hill today - we have not got off once and don't intend to!!!!

Saturday 17 August

We met some amazing people. Simon, cycling after 2 kidney transplants, the young lady who had donated a kidney to her sister, many cycling in memory of someone they had lost through accidents and illness and our own little Noah, who had his next operation 2 days after we reached Paris.

We've got £1385 in total for Heart Link (that includes the Just Giving) plus gift aid on top. Not bad as our target was £750 for each charity!

Thanks again to all of you who sponsored us, an amazing experience☺

Vicky and Laura

Dixon Woods Charity Show

Here are some pictures from the Dixon Woods Charity Show held on 15th September 2013 at The Peepul Centre in Leicester.

Dixon Woods School of Dance have been supporting Heart Link for many, many years for which we are extremely grateful.

Gill Smart awarded certificates to three of the dancers; Jessica Ward, Emma Cooke and Jack George. The Heart Link performance award went to Demi Hylands.

Thanks again for an incredible show of the highest standard!