Heart Link News

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

ECMO 25th Anniversary Edition

HEART LINK CHILDREN'S CHARITY

Issue 56 July 2014

Meet some of our ECMO Warriors inside

Part 2 of Iwan's Story

Stephanie's haircut raises £hundreds

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Chairman's Page

Dear All

I hope you are all looking forward to the summer months ahead, let's hope they are warm and sunny.

By the time you read this newsletter we will have had our day out at Twin Lakes. I hope those who attended enjoyed the day – we were very lucky with the weather. Many thanks to Christine who organized the day with over 300 people attending.

We are looking forward to the Teddy Bears Picnic on the 10th August, a special one this year as we are celebrating 25 years of the ECMO programme at Glenfield. Please fill in the enclosed invitation and return as requested, keeping the top part with your number on it as your family admission ticket on the day. Your ticket number will be entered into a draw for a special raffle prize.

We have a lot of requests for equipment coming from the staff in the near future, all very specialised, so please think of us if you are planning on doing some fundraising.

Our thanks as always go to the Coffin Scratchers Motor Cycle Club for their continued support and generosity, delivering Easter Eggs to the children on Ward 30 & PICU again this year.

The recommendations from the NHS England Children's Cardiac Services review which was due to be published in June of this year has again been put back until March 2015, so we still await the outcome. We continue to give our support to Glenfield and the staff and are confident of a successful outcome for services at the EMCHC. Don't forget you can read all the latest news about the review on John Holden's regular blog at:

www.england.nhs.uk/publications/blogs/john-holden/

email: england.congenitalheart@nhs.net telephone: 0207 932 9128

See you all at the Teddy Bears Picnic.

Love

Geoff W Smart MBE

@Heart_Link1

Find us on Facebook

Heart Link Glenfield

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If you no longer wish to be on our mailing list please write to the Members Secretary at the above address.

Heart Link AGM 2014


Geoff Smart
Chairman


Gill Smart
Treasurer

CHAIRMAN'S ADDRESS

Mr Smart welcomed everyone to the AGM.

"The past year, as the previous year, has left us still in the turmoil created by the Independent Review Panel. Throughout, the Safe & Sustainable proposals have seen to be flawed. We await the final N.H.S England decision. There are continued meetings we have attended both in London and at Glenfield. We feel more optimistic than before and would like to thank everyone working to help secure the future of Children's Heart services here at Glenfield.

Our financial position is still on a very sound basis. Our expenditure for the last twelve months was in excess of £223,000 and our income was over £330,000. This included a large legacy in excess of £100,000 from an anonymous benefactor.

The Annual trip to Twin Lakes, Our Teddy Bears Picnic & Christmas Party were, as usual, well attended and very successful. These events take a lot of organizing and I give thanks to all the people involved who make it all possible. A special thanks to Joanne and the team who organise the food at the Christmas Party – we couldn't manage without you!!
Our caravans are still very popular and well used – thanks to Jenny & Charlie for looking after them.
The "Heart Link News" is first class – thanks to Andrea and her team (mostly Chris!).

I thank the Heart Link management team – Vincent, our President, Chris – our Secretary, Gill – our Treasurer and Amanda – Membership Secretary and all our other Committee Members/Trustees for their continued support and commitment – long may it continue.

Richard French has taken on the role of Press Officer and has already formed a bond with the press and hospital administration team. My thanks to him for his perseverance – resulting in keeping Heart Link in the limelight.

Special thanks to Wayne and John for their continued support on the Tuesday and Friday "Coffee Nights" on Ward 30.

Thanks to all the hospital staff members for their support for us and their commitment to the patients – in my eyes Glenfield is still the best hospital in the country!!"

TREASURER'S REPORT

"Once again the year has been a good one. Money has been given to purchase much needed items for Ward 30 & the Paediatric Intensive Care Unit. Also, this year, we helped to fund a revamp and to create new parent's rooms on the Children's Ward at Leicester Royal Infirmary. We have also promised to help towards a further room.
As our Accounts show, the donations have been very good – a big thank you to everyone involved with helping to raise this money.

The Twin Lakes trip, Teddy Bears Picnic & of course the Christmas Party are a big part of Heart Link – just to see the children enjoying time out with their families is great. Once again thank you to everyone who helps in any way to make this possible.

From the Accounts you will see how much has been spent on Medical equipment and items for Ward 30 & P.I.C.U (£163,149.) – this includes all the sheeting Jenny buys for PICU!!! What more can I say – but my thanks to everyone who does their bit to make Heart Link a great Charity – Please keep up the good work!!"

Iwan's Story - Part 2

Part 1 of Iwan's story covered the time from his birth, through diagnosis of Tetralogy of Fallot to having his first intervention (a stent).

In the months that followed, Dr Duke and his team monitored Iwan and discussed with us the likely forthcoming treatments, which would be open-heart corrective surgery.

I think it is fair to say that we both approached Iwan's appointments with an amount of trepidation – nothing to do with the care I hasten to add – but because with him being so young and developing so fast we didn't know what had changed and what to expect.

There were a few areas of concern, particularly with the narrowing of the pulmonary arteries, but his sats were holding up and he was on the whole doing really well. However, as the months went by we noticed at particular times (ie when he had a cold) that his colour went from pink to blue/grey, only momentarily but it was noticeable.

During this period he underwent a second catheter procedure, which was investigatory and preparation for his surgery.

The more he grew the more his sats began to drop (to 60/70s prior to surgery) and looking back although a happy baby he was reluctant to move around. However he did get around this by developing an amazingly long reach for a little chap, something which he still uses today!

A date came through for his corrective surgery and it was a strange few days before we took him in. I found it very hard to concentrate at work knowing what was around the corner. Luckily for us Glenfield is on our doorstep, which meant that I could take Grace to see her little brother (and Mummy!) the evening before his big day.

Iwan was taken down to theatre and left in the very capable hands of Mr Lotto and his team whilst Sarah and I busied ourselves trying to pass the time. We can recommend the breakfast at the hospital canteen and also the fish & chip shop/restaurant at Beaumont Leys shopping centre! Sarah took some time to choose a coming home outfit for Iwan.

5-6 hours or so later we got the call from Mr Lotto and raced to meet him in PICU. All had gone well! Even as I write this some 18 months on the sense of relief is very hard to put in to words.

Seeing him for the first time in PICU, hooked up to a raft of machines, monitors and medicines was daunting. Lying there he looked so small and vulnerable. We took turns holding his hand. Immediately we saw the operation had done wonders for the colour and complexion of his skin. He was an excellent pink colour and up until this point he had suffered a bit from rashy skin, to the point where his GP had prescribed cream. But the rash had gone and (to date) hasn't come back. We mentioned this to the nursing staff who said that other parents had noticed similar results with their children.

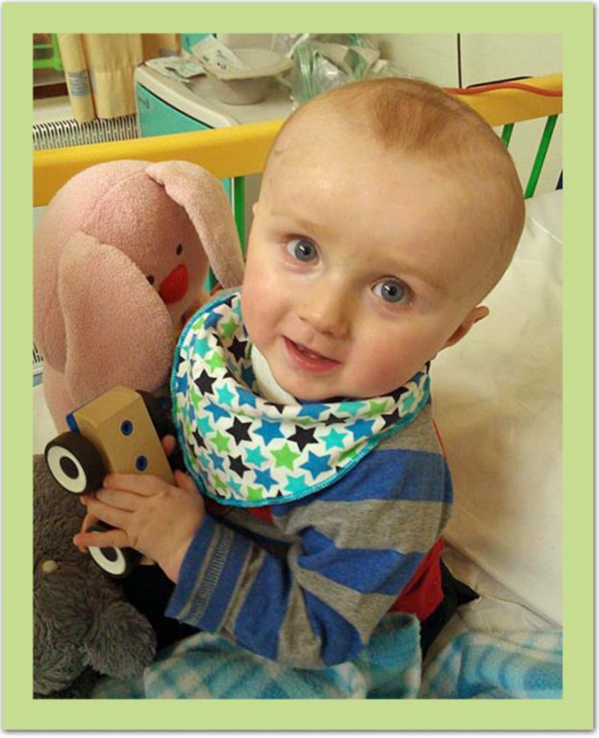
PICU is a very humbling place with so many lives coming together for a short time with so many stories to tell. The work done in that department and on Ward 30 is quite simply stunning.

Iwan was slowly brought back to consciousness and made good progress over the next couple of days. He even met a couple of the Leicester Tigers on their Christmas visit and was transferred back to Ward 30, where his recovery continued. Although he was diagnosed with a chest infection and what can best be described as a mini vacuum cleaner was deployed on a regular basis to clear mucus from his passages, something he hated.

There was some concern over the amount of fluid that was still draining from his chest and tests were done, which showed that a fat duct had been nicked during his op (not uncommon). This meant that he was put on a strict no/very low fat diet for a few weeks. Having to take notice of the fat content of food was an eye opener with some foods in particular being far higher than you would ever think.

Taking Grace to see her baby brother for the first time after his op was very special, as was seeing his first post op smile, which took a few days. Fully understandable after all he had been through, but he is naturally very smiley and it was strange to see him looking so fed-up.

Iwan is a tough little cookie and must have wanted to come home, as a few days after pulling his feeding tube out, he pulled out his remaining chest drain. Luckily no harm was done and we were able to bring him home. We had to go back to outpatients a few days later to check a small accumulation of fluid, but this was okay.



Dr Duke has explained to us that whilst the op was a great success there is still some narrowing of the sub-arteries that may need attention in time to come and he will probably need to have his pulmonary valve replaced at some point, all bridges to cross in the future, but we are so thankful to have a beautiful boy who, along with his sister, lights up our life every day.

Watching Iwan grow and develop is a privilege and something very special. He is now very much a typical 2 year old who is full of fun (and phonics!), a bit of a handful and thanks to Heart Link is very much looking forward to going to Twin Lakes and the Teddy Bears Picnic over the Summer months.

We hope his story can in some way help other parents who find themselves in a similar position.

God Bless All

Jason & Sarah Owen
Iwan's very proud parents

Zack Walker

So our story starts with me having a pretty straight forward pregnancy until our 20 week scan when we are asked to come back an hour later as the baby is sitting in an awkward position. So an hour walk around the hospital and a Mars bar later, the little one has decided to turn the right way for his full scan. Today we decided to find out the sex of our baby and we are overjoyed to find out we are having a baby boy. Our tears of joy soon turn into tears of fear and the unknown as we are told our baby's heart looks abnormal and we are to come back the next day to see a consultant. That night seemed like the longest night ever to find out what could possibly be wrong with our little boy.

The next day we returned to see the consultant who explained that she suspected the baby had Transposition of the Great Arteries and wanted us to see a specialist at the Glenfield hospital for a repeat scan and confirmation of diagnosis. A day later we were booked in to have a confirmation scan with Dr Shebani, we also were prepared that the baby could have Down's Syndrome but this could only be ruled out by having an amniocentesis which carries a risk of miscarriage, but we felt this was a risk worth taking so we could prepare ourselves for what the future might hold. This was found to be negative and the baby had been unaffected by the huge needle through my tummy apart from a little prick on his finger when he had tried to grab it!

After we had seen Dr Shebani it had been confirmed that the baby had multiple heart defects - Double Outlet Right Ventricle (DORV), Pulmonary Atresia and a large VSD, all of which were operative once he had been born. As a precaution we decided to give birth in Leicester as the baby may have not survived the trip from Nottingham.

We were given a date of 5th of June to head to the hospital for me to be induced and finally, after 38hrs, baby Zack arrived on the 7th of June! We were so happy to have seen him before he was whisked over to the Glenfield but sad that we did not get chance for a little hold and after a Caesarean knew that I may not see him for a couple of days.

In the meantime Zack had been taken for a scan at the Glenfield to confirm the extent of his heart defects. He was put on Prostin to ensure that his duct remained open because if this closed he would most certainly not survive as there was no path from his heart to his lungs.

We were given a plan that Zack would be operated on within 2 days as the duct should narrow enough for a stent to be fitted via a catheter which would allow us to go home until Zack was big enough to have his full repair.

Days turned into weeks and scan after scan confirmed that the duct was not closing and Zack was keeping this open by himself, it was unknown though how long this could happen for and potentially could close at any time. After 6 weeks of waiting it was decided that Zack would go for a catheter to try and balloon the duct to keep it open so we could go home. This procedure was cancelled maybe 3 or 4 times before it finally happened as there were more urgent cases which were rightly put in front of us, but finally on the 23rd of July Zack went for a cardiac catheter.

The 3 hours we waited seemed so long and when we finally got to see Zack it was such a relief, but we were shocked to be told that they had to stop the operation as the risks to Zack and his health was far too great so this could not be performed. Back to waiting for a plan whilst remaining on Ward 30! We made our regular visit to the Heart Link office to see Geoff for a coffee and a chat which was our 'get out' place, it's only when you leave hospital you realise how much those coffee and chats do help you!!

So after 13 weeks on Ward 30 it was decided that Zack was big enough to operate on and Mr Peek would do the 'full repair' on the 1st of September. Again we waited for what felt like eternity and 5 hours later we headed to see our baby boy. We were told the operation had gone according to plan and Zack had coped well after being taken off the bypass for the second time. That night we sat with Zack until late knowing when we left for bed he was in safe hands and recovering well.

Next morning things were a lot different! Zack had taken a turn for the worse and we were told by doctors that the next 48 hours were crucial to his survival. He had contracted severe sepsis which was attacking his body and was on a cocktail of drugs to try and control this as well as high ventilatory oscillation and Nitric oxide.

Little by little Zack responded to all of the medication and started to get better, 14 days later and narrowly escaping ECMO we were transferred back to Ward 30 and 2 weeks later we were packing our suitcases to go home!!

Eight months later we have been for a follow up appointment to be told things are looking good with the repair and we won't need to go back for 12 months which is fantastic news.

Zack will eventually need more surgery and we are keeping our fingers crossed it won't be for a while yet.

Written by Emma & Jonny Walker.

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Hello there from Walter Bear!

I hope you didn't get too much chocolate for Easter and are enjoying your last term of the school year before the big summer holidays, I know that I am!

I would just like to congratulate Charlotte, Natalya, Ellie, Benjamin, Samuel, Thomas and Cecily for taking part in the colouring competition. I received lots of fabulous entries and decided to be very generous and pick lots of winners this time, so a very big well done!!!

Who went to Twin Lakes for our annual day trip? I really enjoyed the trip seeing lots of your happy, smiley faces running around and having fun on the rides.

Also it's that time of year for summer holidays to start again. It would be lovely to see some of your holiday snaps this year, so please do send them in and they may feature in the next Walter's World.

We also have the Teddy Bears picnic just around the corner so let's keep our fingers crossed for some nice hot sun to go along with our barbeque, but do remember to keep applying lots of sun cream and don't forget to wear a hat and sunglasses too!

Until next time

Take care

Walter Bear xxx

Young Peoples Group

If you are a patient/sibling at the East Midlands Congenital Heart Centre we would like to invite you to come and join us for a chance to talk, meet other children who come to hospital, play games and have some fun!

We plan to run 6 sessions on alternate weeks and would hope that you could attend most weeks.

If you think you or someone you know might be interested please contact us for further details.

Liz Lee– Clinical Psychologist
Catherine Beck – Health Play Specialist

0116 250 2831 / 0116 295 2959

Letters

Happy New Year Heart Link,

Please find enclosed a cheque of £102 for Heart Link .

I work for UPS in the sales support dept. During November and December 2013 we have had a number of casual dress days on Fridays - whereby we donated a pound on each occasion. The total raised was £102. This would not have been possible without the support of my friends and colleague at work. So a big THANK YOU for helping me to support The Heart Link Children's Charity.

Heart Link supported my family back in September 2006 when my daughter Erin Reeves had her first heart surgery at only 5 days old - to repair a co-arctation of the aorta artery which was 80 % narrowed.

Erin's operation was a success but we still spent 7 weeks in hospital with Erin. Heart Link was an invaluable support providing the accommodation off Ward 30 at Glenfield hospital, and full kitchen facilities. This meant we could stay close to Erin during her stay at Glenfield. We also had the opportunity to speak to people connected with Heart Link and families in similar circumstances also.

Erin's second operation was at 7 months old to repair a complete AVSD. Again we spent 3 weeks at Glenfield. (The picture of Erin and Mum Diane in the Thomas the Tank playroom at Glenfield was in April 2007, the day of her second operation).

Both of Erin's operations were performed by Mr Peek.

After Erin's second operation her recovery was slow, but steady progress was made week on week month by month. Erin was still being tube fed for fluids until the age of two.

Erin's appointments to see Dr Khan slowly changed from 3 to 6 months then 9 and in the last few years became yearly, as at present. There is always the possibility Erin could require surgery in the future. We could not have asked for better help dealing with what Erin has gone through.

This is Erin now at Christmas 2013 - aged 7.

Many thanks again Heart Llink and all at Glenfield for your support - keep up the great work!

Kind regards

Wayne Reeves

Dear Heart Link

Firstly we would like to say a massive THANK YOU for agreeing to purchase the 24 hour ambulatory monitors and event recorders for us.

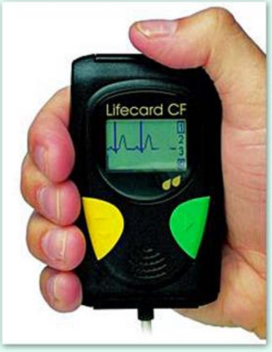
These monitors are a vital tool in the diagnosis and treatment of many arrhythmia's associated with congenital heart defects.

Ambulatory electrocardiography is used to detect, characterise and document cardiac arrhythmias in clinical practice. As some arrhythmias are infrequent or may occur only during certain activities (eg, sleep or exercise), it is essential to be able to record the electrical activity of the heart over a period of time, usually 24 or 48 hours.

Lifecard CF, the ambulatory monitors that we use, are capable of recording full disclosure ECG for up to 7 days. The modern technology delivers outstanding ECG quality for accurate analysis from the most challenging recording environments, which is why they are ideal for paediatric patients. This in turn provides the consultant with excellent quality ECG recordings of even the most complex of arrhythmias, allowing them to treat and manage these arrhythmias effectively.

The monitors are attached via 3 small electrodes placed on the patient's chest. The monitor can then be secured to the patient using the belt clip, this makes them more comfortable and less intrusive to wear.

These recorders are typically used for 24 or 48 hours to record events which might reasonably be expected to occur within that timeframe, i.e. frequent, or at least once a day symptoms.



The patient is asked to keep a diary of symptoms and records the time on the Holter clock when the symptoms occur, for later correlation with ECG abnormalities.

Long term ECG Event Monitoring is widely used for monitoring symptomatic patients over several weeks in order to capture transient or infrequent arrhythmias.

Due to the nature of some of the arrhythmias associated with congenital heart disease it is not always possible to capture an event over a 24 or 48 hour period. Event monitors allow the patient to take the device away for a number of weeks at a time and capture events as and when they happen. These monitors can either be attached via stickers or used by placing the device directly on to the skin.

When the symptoms occur the patient will activate the device themselves and document all symptoms into the diary card that would have been given to them when the monitor was attached. This allows for accurate correlation of symptoms and ECG recording.

If you require anymore information please feel free to contact us.

Once again, thank you.

From the Paediatric and Congenital Cardiac investigations team.

Leicester schoolgirl raises thousands to say thanks to hospital lifesavers

By Leicester Mercury | Posted: April 01, 2014
By Adrian Troughton

A schoolgirl has raised hundreds of pounds to say thank you to the hospital which helped save her life after she was born with a serious heart defect.

Stephanie Baum, 11, had her ponytail cut off to raise funds for Heart Link, a charity based at Glenfield hospital which supports children born with heart defects, and their families.

The youngster, from Stocking Farm, Leicester, nearly died after being born with Transposition of the Great Arteries, a condition in which major blood vessels are malformed.

Stephanie's parents have set up a charity web page to enable people to support Stephanie. It had a target of £50 which Stephanie set for herself, but it has already raised more than £660.

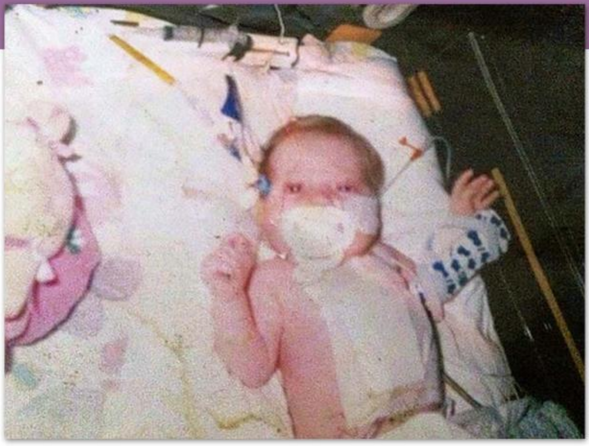
The Beaumont Lodge Primary pupil, who came up with idea herself, said she was very happy with the amount raised so far for Heart Link.

Stephanie is also donating her hair to the Little Princess Trust, which makes realistic wigs for young cancer patients.

"The children who have cancer need my hair more than I do and I wanted to raise money for the people who did so much to help me and my family," she said.
Mum Victoria, 32, said: "I had a scan at 20 weeks and they told me my baby was a girl and had a serious heart defect. They offered me a termination but me and my husband, Mike, didn't even consider it. The doctors said they were not sure what the exact defect was but there was a possibility she might not survive."

Stephanie was born on March 10, 2003, at Leicester General Hospital, weighing a healthy 8lb 3oz. Doctors transferred her immediately to Glenfield Hospital, said Victoria, where there is a specialist children's heart unit.

"They told us that, in layman's terms, Stephanie's main arteries were plumbed in wrong and she was not getting oxygenated blood pumped round her body.
"They operated straight away at Glenfield and then left her to recuperate. After a week, she had to be transferred to Birmingham Children's Hospital for more surgery.



Surgery: Stephanie's first two months were a battle

"The doctors warned me there was a chance Stephanie might die during the ambulance journey.

"There was no room in the ambulance for me as she was all wired up. Mike drove us over and it was the longest journey of our lives. When we got there they had already taken Stephanie down to the intensive care unit, but at least she had survived."

A week later, the surgeons operated, and four weeks after that Stephanie was transferred back to Glenfield Hospital.

She finally went home for the first time when she was eight weeks old.

Victoria said: "The doctors and nurses at Glenfield were amazing and helped save Stephanie's life”.

"The volunteers who work for Heart Link were incredible. They gave me and Mike so much support in our darkest hours. They were brilliant and we can't thank them enough."

Heart Link founder Gill Smart said she was delighted to hear of Stephanie's donation.

"It's always pleasing to hear that what we do helps people in this difficult situation," she said.

"It's a lovely thing for a young girl to do."

To donate to Stephanie's cause, go to:

www.justgiving.com/ victoria-Baum1/

Stephanie's haircut

Well done Stephanie, what a brilliant way to raise funds!
Thank you very, very much.

Meet the Team

East Midlands
Congenital Heart Centre

Karen Duncan
Senior Adult Heart Nurse

Hello….my name is Karen Duncan and I work in the East Midlands Congenital Heart Centre as the Senior Adult congenital Heart Nurse (ACHN) and we are currently a team of 2 nurses, although I work part time.

Prior to joining the team 5 years ago I have worked in a variety of roles all within the NHS. I qualified in Birmingham in the 1980's and my career has always been within the cardio-respiratory speciality.

Working as a staff nurse it was back in the day where we wore starched white caps and belts with buckles and doctors always wore a white (or not so white) coat. We took blood pressure recordings manually with a stethoscope and mercury filled thermometers were placed in patients mouths. Oh how things have changed!

During my nursing career I have been a ward sister, worked in education and practice development and was one of the first Modern Matrons in Leicester. Working as assistant head of nursing for a large directorate gave me much insight into the management and service development side of the NHS but my desire to work alongside patients and their families on a daily basis was a stronger pull.

Working as an ACHN is such a varied role and there really isn't a typical day. There is the structure of ward rounds, catheter meetings, clinics and we do travel across the network to do clinics in Nottingham, Derby, Kingsmill and Lincoln. However, an unexpected telephone call from a patient wanting to discuss their concerns around coming into hospital for a catheter procedure or surgery often means that must take priority. As we all know, planning work commitments, family needs of children and carers, financial matters, etc around a proposed date that can be changed, requires much co-ordination. It's this unpredictability and the complexity of needs that some of our patients experience that I really enjoy working in partnership to resolve.

My spare time is taken up largely by my sons aged 7 and 17. During the summer I can usually be seen driving my motor home called Bessie to the coast or a rock festival. I love to weight train and run and have completed 2 marathons and numerous half marathons for fun. I'm an active member of my church and community and am considering starting a PhD this autumn looking into aspects of adult congenital nursing care.

I look forward to meeting you and your children as they grow up and if you see me in the corridor or in clinic please feel free to say Hi……..

Cheers Karen

Dr S Sadagopan
Consultant in Congenital Heart Disease

I trained at Southampton, specialising in Paediatric Cardiology and Electrophysiology.

Previous roles include working as a Consultant at Southampton and Chennai before coming to Glenfield where I joined the Consultant team in January 2013.

My responsibilities include managing children with heart disease and I have a special interest in the management of children with heart rhythm disturbances (Ablation and Device based therapy). I also teach and train junior colleagues.

The most gratifying part of my work is to see sick children getting better and going back to their life.

I am ever so grateful to be part of a fantastic team that constantly thrive to achieve the best possible outcome for our patients.

Meet the Team

East Midlands
Congenital Heart Centre

Chris Thornborough
Adult Congenital Liaision Nurse

Hi, I'm Chris Thornborough and I work as an Adult Congenital Liaision Nurse at the East Midlands Congenital Heart Centre. I have been in this role for 4 years now and no one day is ever the same.

My job is very varied and whether I'm out at a peripheral clinic, working within outpatients or looking after the patients coming in for an interventional procedure or surgery, my focus is always about doing the best for our patients and delivering a high quality service. I love my job because it is so varied - no two days are ever the same and every day I learn something new. Karen Duncan and I work together as the dynamic duo.

Originally from Birmingham, I trained at Dudley Road Hospital (now the City Hospital) in the mid to late Eighties. In 1989 I moved to Leicester to work at the old Groby Road hospital and so began my love affair with the cardiac speciality. I looked after some of the first paediatric and adult ECMO patients on ITU there and continued working in the critical care environment until eventually becoming an ECMO specialist full time.

The opportunity arose in 2006 to work with Dr Bu'lock on a research study " Do genetic changes cause congenital heart disorders?" which afforded me the opportunity to work with both children and adults with congenital heart disease. I was an active campaigner throughout the Safe and Sustainable review and continue to follow the new NHS England review to ensure our centre stays well and truly on the map.

I've been married to my lovely but long suffering wife for 21 years and in my spare time my main passion is my garden and wildlife photography plus DIY which normally ends in a visit to A&E at some point!

Chris

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Thank you for your support

HEART LINK CHILDRENS CHARITY

Twin Lakes 2014

We had an amazing day @ Twin Lakes, thanks for organizing it :-)

OMG! Fab day at Twin Lakes. Lovely seeing so many families there. Great spending time with some great friends.

Thank you Heart Link for a brilliant day at Twin Lakes. Look forward to seeing you all at Teddy Bears Picnic x

Thanks for an amazing day out at Twin Lakes. Kids all had a great time and weather was brilliant again.

Brilliant day out thanks to Heart Link. Thank you so much xx

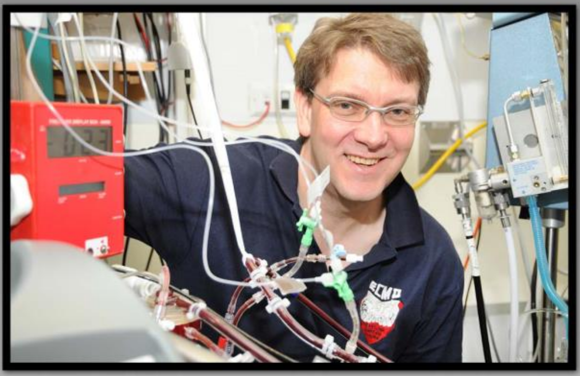
Lovely day today at Twin Lakes with Heart Link. You guys were there when our son got admitted over 3 years ago and supported us then and you're still there now!

Had a great day out at Twin Lakes thanks to Heart Link. It was great to see other heart families having fun too.

ECMO Feature

Celebrating 25 Years of the ECMO Programme

ECMO Explained by
Giles Peek Consultant in Cardiothoracic Surgery & ECMO



ECMO stands for Extracorporeal Membrane Oxygenation, what this means is the use of a machine, similar to the heart-lung machine used in the cardiac operating theatre, to take over the function of the lungs and/or heart for a period of days or weeks to give them a chance to recover. ECMO is only used when "normal" methods of intensive care are failing, it can be used in any situation where the lungs or heart are not working properly but have got a chance of recovery.

ECMO can therefore be used after a long, difficult and complex heart operation to support the function of the heart while it recovers. It could also be used in the case of someone who developed a severe lung infection with a virus such as the H1N1 virus (swine flu) to take over the function of the lungs to give the anti-viral drugs a chance to work.

In order to put a patient onto ECMO large pipes (cannulae) must be put into the blood vessels in the neck or groin, or sometimes directly into the heart itself, these allow blood to be drained away from the body to the ECMO machine where it is oxygenated before being pumped back into the patient. The tubing of the ECMO machine is made of plastic and this makes the blood try to clot, a drug called Heparin is used to prevent clotting, this means that patients are at risk of bleeding whilst they are on the ECMO machine.

Patients who are on ECMO are very sick and the machine is very complex to look after so an extra nurse called an "ECMO Specialist" is always there to help look after patients whilst they are on ECMO. Often machines to replace the function of the kidneys or liver are also required, these can be connected to the ECMO machine to help the patient recover. Patients receive drugs to keep them pain free whilst they are on ECMO they also receive feeds either through a tube in the nose or intravenously. Some older patients who need to be on ECMO for a long time may be slowly woken up so that they can breathe for themselves.

The survival rates for patients treated with ECMO depend on what the underlying problem is. For instance for a patient whose heart is too weak to allow them to come off the heart-lung machine at the end of a difficult heart operation the expected survival with ECMO is about 50%, but if ECMO was not available in this situation no patients would survive. In the case of a newborn baby with lung failure ECMO can save one extra patient for every 3 patients treated, and for adults with lung failure one extra patient is saved for every 6 that are treated, compared to continued treatment with "normal" intensive care.

If you child or loved one needs to go onto ECMO it can be very frightening and confusing as they seem to be lost behind a row of machines, tubes and wires. But be reassured that the ECMO Team are working very hard to give your child the best chance of recovery and that they understand how scared and confused you are. Keep asking questions and you will soon understand how everything works and then you will be less scared and more able to help in the care of your child and regain a sense of control by contributing to their recovery.

The Heart Link ECMO Centre
1989 - 2014
CELEBRATING 25 YEARS

ECMO History

Celebrating 25 Years of The ECMO Programme

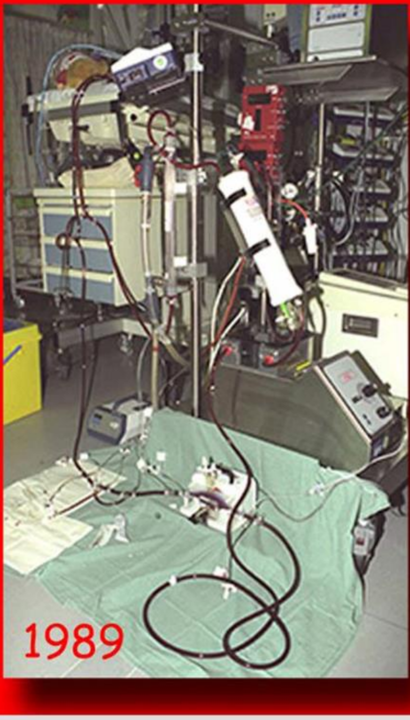
Heart Link are extremely proud to have funded the introduction of ECMO (Extra Corporeal Membrane Oxygenation) into Great Britain in 1989. This is a modern invasive life-support technique which can be used in patients with extremely severe respiratory (lungs) and cardiac (heart) failure. The treatment is very expensive and labour intensive and, in 1989, financial support from the NHS was out of the question.

Mr R.K. Firmin, Paediatric Cardiac Surgeon at Groby Road Hospital, Leicester, approached Heart Link and convinced us to finance the introduction of an ECMO programme. Mr Firmin and Dr Sosnowski learned the technique on visiting the University of Michigan U.S.A which is where Professor Bartlett, the father of ECMO, had developed the leading ECMO Centre. The Heart Link Committee, although not able to understand the technicalities, were convinced enough of the potential benefits by Mr Firmin, to launch another 'Appeal' which resulted in the ECMO programme being introduced to Glenfield Hospital.

Heart Link funded this together with all the relevant running costs, including paying the staff who worked on it until, after various 'trials' (and nearly bankrupting Heart Link), the NHS agreed it was a worthwhile treatment and took over the funding.

Since November 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.

Although ECMO is now financed by the NHS there is still enormous input from Heart Link as we continue to help fund ECMO research programmes, finance medical and nursing staff who attend scientific meetings and teaching sessions, plus purchasing any new equipment needed to ensure that the highest and most modern standard of care is given to all those patients requiring ECMO treatment.

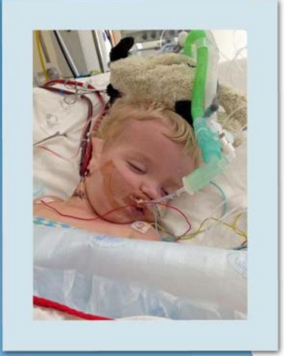

1989


Today

Here are some photos of our son Noah Brooker. He was born prematurely at 26 weeks in November 2012, and since discharge from SCBU in January 2013, he had been a picture of health.

He was 16 months old when he fell ill and put onto ECMO on 15th March 2014. He was on it for 5 days. He was so lucky that the team at Glenfield and the ECMO machine was only a few miles down the road as without it he would not be with us now! An amazing machine and team of people who operate it. We will always be eternally gratefully.

Noah has made a remarkable recovery since he came off ECMO and other than a few scars you would never know he was fighting for his life just over a month ago!

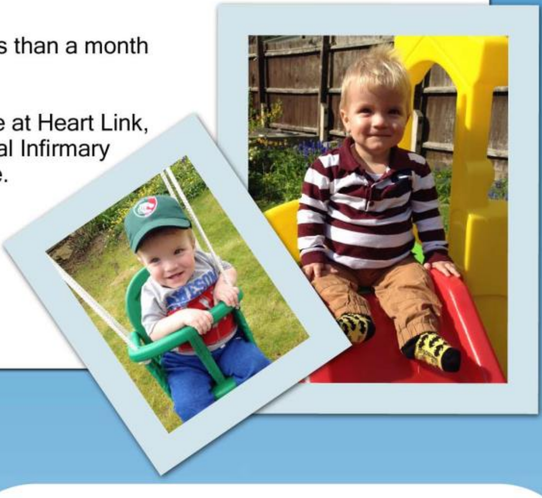


The after photos were taken less than a month after he came off ECMO!

We would like to thank everyone at Heart Link, Glenfield and the Leicester Royal Infirmary for saving our precious son's life.

Kind Regards

Clare Brooker



Harry on ECMO at 26 days old in July 2013.
Harry was on ECMO for 2 weeks.
And Harry now (April 2014).

Harvey George on ECMO 9 years ago following heart surgery. Look at him now!

Jackson on ECMO in September 2010 for 5 days of treatment for Meconium Aspiration.
Now a healthy 3½ year old.

Born 20.12.05 with Strep B and Meconium Aspiration Oliver was on ECMO which saved his life.
Now a brilliant 8 year old!

Tommy was on ECMO in December 2011.

Here he is now at 2½!

Anyone wishing to share their ECMO photos in the next issue of our newsletter, please email them to:
heartlink@hotmail.co.uk

The Heart Link ECMO Centre
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CELEBRATING 25 YEARS

Declan on ECMO in June 2010....... and now!

My son Jonah has HLHS and was on ECMO last January /February at 4 months old. He was quite poorly early in January so it was decided to do his Glenn and some repairs.

After the surgery, which took most of the day, he seemed to be doing OK. Early the next morning though, he arrested and was put onto VA ECMO within 24 minutes.

He remained very unstable for 24 days then it was decided to tunnel a cannula through his groin to change to VV ECMO so they could finally close his chest and see how his lungs coped. He lasted 3 days then had to be taken off due to a massive abdominal bleed. He had surgery, again.

After a very long stay in PICU and Ward 12 at the LRI, a Glenn reversed and a BT shunt, an Ileostomy and a Tracheostomy and numerous times being told he wouldn't make it, my boy came through!

Thanks to the surgeons, doctors, nurses and many more medical professionals and of course ECMO. Jonah is home and doing well at the minute.

Forever indebted and eternally grateful.

Joanne now aged 30!

Joanne on ECMO for 4 days in 1994 after heart surgery aged 10 years.

This is a photo of Ella Ewers aged one day and now aged 6 She's on ECMO and dialysis in this photo and has Super Cardiac TAPVD type 2

Bethany Rose Knight was born on 23rd June 2012 with Meconium Aspiration. After 5 days of ECMO at Glenfield Hospital she was transferred to the Children's Ward and then on to Queen's Hospital, Burton, where she was discharged on 17th July 2012. Without the fabulous staff and quick action she would not be here today.

Thank you for your fantastic work.

Niki & Justin Knight

This is our daughter Isabelle Grace Sankey (Beech), now 5 months. She was born on 11.12.13 weighing just 5lb 8oz by emergency C Section in Royal Shrewsbury Hospital. At just a couple hours old, Isabelle got rushed to Glenfield Hospital, Leicester, for ECMO treatment due to Meconium Aspiration which left her lungs not working. She was rushed into theatre as soon as she got to the hospital in the early hours. My partner rushed up there to be with her but unfortunately I couldn't be with them until I got discharged from Shrewsbury Hospital.

All the Staff at Glenfield are fantastic and we can't thank them enough. Everything the Staff and Heart Link children's charity do is brilliant and without them none of this would have been possible. We never thought we would get to see our little girl smile but thanks to everyone involved after 6 days being on ECMO Isabelle got transferred back to Shrewsbury.
She was in Shrewsbury for another 4 weeks but then came home, it was the happiest day!

Every day we look at her and think how lucky we are to have had the chance to have the ECMO treatment, if this wasn't available then Isabelle wouldn't have been with us today. We just want to thank you all so much for looking after us while we stayed in Glenfield and for everything you did for Isabelle. We will be doing all we can to make sure we raise some money for a charity so close to our hearts.

Thank you again for everything you're doing.

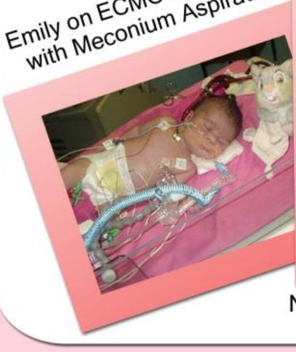
Thank you

Laura

Claudia on ECMO for 3 days in December 2012 with Meconium Aspiration

Claudia now aged 18 months old

Emily on ECMO for 10 days with Meconium Aspiration



Now aged almost 4 years!

Willow spent 10 days on ECMO in June 2013 with Dilated Cardiomyopathy.
She has just turned one!

Thank You!

Our daughter, Milly Elizabeth Hewitt was born at Birmingham Heartlands Hospital on 16th June 2013.

During birth, she inhaled meconium and she was fighting very hard for breath. She was quickly taken down to the Neo Natal ward, intubated and given 100% oxygen.

It was very hard for us as new parents to see Milly this way and we were extremely upset and frightened. Unfortunately, Milly's condition worsened over the next few hours and a specialist team of doctors and nurses were called from Leicester Glenfield Peadiatric Intensive Care Unit (PICU) to put her on an ECMO circuit. ECMO stands for: Extracorporeal Membrane Oxygenation. Basically, a heart and lung bypass machine.

The despair we felt at this stage is too difficult to put into words, except to say that the thought of losing our little girl was becoming more and more of a terrible possibility. Milly was rushed to Glenfield PICU and we spent the next few days there with her and other children and parents in far worse circumstances. The care we received at this unit is like nothing we have ever experienced in any hospital before. The compassionate way in which we were treated will be something we will remember for the rest of our lives. It was truly outstanding and we're thrilled to say it saved our daughter's life!

After three and a half days, Milly was able to come off ECMO and was given the all clear to return to the Neo Natal ward at Birmingham Heartlands Hospital to continue her recovery. After a further two weeks of incredible care, Milly was well enough to finally come home with us.

We, Milly's parents would like to take this opportunity to thank all of the fantastic staff at Glenfield PICU and Birmingham Heartlands Neo Natal ward for what they have done for us.

You are all nothing short of genuine heroes and the saviours of our daughter and countless other precious children. We are in absolute awe of the noble work you all do. You have given us our whole world back when we thought it was going to fall apart.

No amount of thanks could be enough to equal the happiness you have given us. All we can do is show you these pictures of her journey so that you can see how she has benefitted from what you have all done.

We are forever in your debt.

- Jeremy, Claire and Milly Hewitt

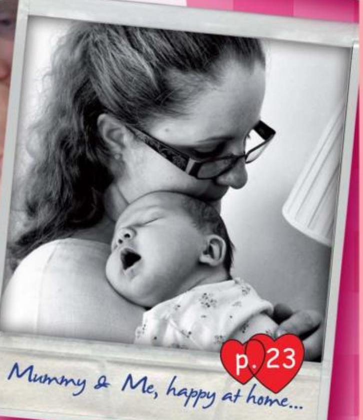
HEART LINK CHILDRENS CHARITY

heartlink-glenfield.org.uk

Meeting Grandad!

All better now!

Me and Daddy!



Mummy & Me, happy at home...

Thank you for your support!