

Little Hearts Matter Newsletter

Winter 2010



ECMO Treatment

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LHM AGM & Open Day

Come and join us at this year's AGM and Open Day on Saturday 13th March 2009.



We would like to invite you all to our Open Day and Annual General Meeting.

It is to be held on Saturday 13th March 2010 at Bretby Conference Centre, Burton-Upon-Trent. This will be our fourth year here but as well as being located centrally it can't be beaten for price and facilities. The Open Day will consist of talks and workshops for the adults, young adults and the children. And as always, there will be the fully qualified

crèche which we have used for the past eight years.

We are delighted to announce that we have Jeremy Glyde, from the Safe and Sustainable Services team, coming to talk about the review of future service provision for congenital cardiac surgery within England. Other workshops will be How to Cope with Medical Conditions in Secondary and Primary School, Careers, Pacemakers, DLA applications and life with a baby with congenital heart disease.

On the Saturday evening there will be a social at the centre, with food and a chance to get together with other families to chat. There is accommodation at Bretby for those of you who would prefer to stay and have a relaxing weekend.

More details about the day and a draft agenda and application form will be sent out separately to all our member families. There will also be details and prices for bed and breakfast at Bretby Conference Centre. We hope to see you there.

NEWS

Suzie's News



It has been lovely having the Little Hearts Matter Lights of Love tree in my garden all over the festive period. It was also very special to have a brass band and carol singers on the patio the night that we switched the lights on. Thinking about the children and other friends of the charity depicted by beautiful shining lights has been very special.

As we switched the lights off on the 6th of January we were looking forward to adding more lights next time, although we might try to do it on a less windy day unlike last time. My son Fred and husband Rod had me directing them, safe at the bottom of the ladder, as they swayed above!

I hope that you like the pictures on the website. Sadly they are never as good as the tree in real life. Next year, come and join us at the switch on, the date is the 5th of December.

As we move into 2010 the charity is moving into its third decade. Excitingly we plan to continue to build our services. You come up with new ideas for information or events and we will try to incorporate as many of them as we can into our work this year. Projects that we are already working on include sex education information for our teenagers, a detailed Fontan information booklet and building Network services.

Jon is undertaking a new piece of research that is seeking the views of our young members asking what is it like to live with their heart problem and what would make it easier. He will be mixing his collection of this information with opportunities to meet up with as many youth members as possible. Watch out for more information from Jon.

Deb and Gwen have been working on the front page of the website. Go and have a look

and tell us what you think www.lhm.org.uk. From there you can now link to the youth website. As a non-member you can see the main pages but only the young members can travel into the message and picture sections. If you are the parent of one of the youth members remember that you have to give us permission for your child to join the message boards. Fill in the permission sheet and send it back to Jon. If it got lost in the Christmas wrapping just give us a ring and we will send you another one.

Kevin needs your help again this year. He has to raise £270,000 to enable us to do all the things that you have asked of us. If you have any ideas for fundraising events, large or small, just give him a ring.

He would also love to hear from you if you work for a business that might like to link with a children's charity. We always do better with companies if we know someone who works for them.

Finally I would just like to say that we are here. If any of you need any support or information we are only a phone call or an email away. We will always try and help if we can.

Wishing you all a peace-filled and happy 2010.

Suzie Hutchinson
Chief Executive

On Your Marks for Little Hearts
Mote Park, Maidstone
28th March 2010

With all that Christmas pud to shift (!) what better way to help shed a few pounds than to support your own charity by taking part in the 5 or 10km walk/run around Mote Park in Maidstone this March. Following the success of our first South East event last year it is really hoped that many more of you will join us. There is so much to do in the park, why not bring your family and friends for a day out? You can choose to either run, walk or crawl 5 or 10km round the historic gardens. Register now at www.lhm.org.uk or call 0121 455 8982.

LHM In The Media

with
Emma Pelling
emma@pellingpr.co.uk
0207 624 7533



As I write this we are experiencing the big freeze in the first week of the New Year - we are well and truly in Winter now.

The last part of 2009 saw many of our young members speaking out. This is an area that we would very much like to develop in the future. It is so important that the voice of the young person is listened to. This is exactly what happened at the end of October with a Question Time debate at the House of Commons about issues that affect young people with health conditions. Carys Allen and Sarah Haselgrove travelled to London and took part in the debate. This resulted in a great flurry of media coverage - particularly in Shropshire and Kent. The highlight saw Sarah invited on the sofa for the live BBC Politics Show for the South East.

Other media work included discussions around Safe and Sustainable Services. The issues and future changes around services are central to Little Hearts Matter and, alongside Suzie, I am ensuring that we are ready to respond to the media when appropriate.

The New Year looks like it will be no less busy. Our next big event is On Your Marks on 28 March in Maidstone, if you live in Maidstone or the surrounding area and would be happy to do media work on behalf of the charity, please get in touch.

Please do keep me in touch with your news and I can always be contacted on the numbers below. I look forward to catching up with many of you



Carys Allen (13) pictured left and Sarah Haselgrove (17) right at the House of Commons Question Time



Ask the Experts

Here we ask professionals to answer some of the common questions asked by our members.

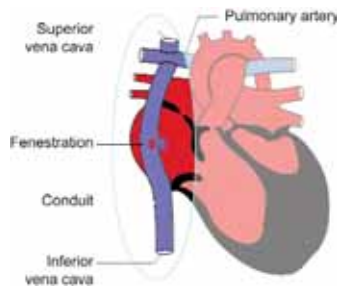
Suzie Hutchinson
Chief Executive



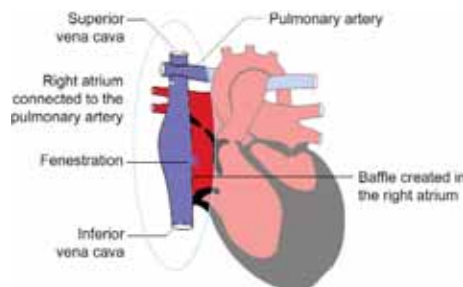
What is a fenestration and why do children need them?

Fenestration - means to create a window.

Surgical fenestrations may form part of the surgical treatment during a Fontan procedure.



External Fontan



Internal Fontan

The aim of the Fontan operation is to re-route blue (deoxygenated) blood straight to the lungs without it taking its usual path through the heart.

Following surgery the flow of blue blood no longer has a ventricular pump behind it. This sometimes causes the flow to slow causing a

back pressure down the major blood vessels especially the vein that brings blood from the lower body up to the heart (Inferior Vena Cava). This back pressure can cause the blood flow in the liver and the gut to slow down affecting the way that food is absorbed and the way that the liver supports the making of blood components and the removal of blood waste.

To support the smooth flow of blood through this new system it is common for a hole (fenestration), to be created in the tubes that take blood to the lungs, occasionally the surgeon may decide that a fenestration is not necessary. This fenestration works like a pressure valve, similar to those found in a boiler and central heating system.

If the back pressure from the lungs is high some blue blood passes through the fenestration into the red (oxygenated) blood circulation.

The effects of a fenestration

- The back pressure down the veins leading to the lungs is relieved.
- The flow of blood to the lungs is smoother.
- The children have separate circulations following the Fontan but a small amount of blue blood will mix with the red oxygen-filled blood. This is no problem for the children but does cause their oxygen saturations to be less than 100%.

Will the fenestration be needed forever?

As the children grow, their blood vessels get

bigger and their general activity helps to create the push that is needed to return blood to the lungs so gradually they may no longer need their fenestration.

If the fenestration has been a small one it will close itself - clever! As the body grows and makes new tissue it will gradually grow over the hole, closing it over.



Septal Occluder

If the fenestration is a big one, and it is no longer needed, the doctors may decide to close it. This is done during a cardiac catheter using a device that closes both sides of the hole.

Sometimes the fenestration begins to close before the body is ready so the cardiologists place a stent (a wire mesh) in the hole to keep it open. This is done during a cardiac catheter.

Next time your child has an echo ask the doctor to show you their fenestration.

If you have a question about fenestrations just ask your doctor or give us a ring in the LHM office.



Medical

The article below looks at ECMO, a process sometimes used after a major heart operation.

Written by
Mr Giles Peek
Consultant in Cardiothoracic Surgery and ECMO
Glenfield Hospital, Leicester



Over the last ten years Paediatric Intensive Care Units and cardiac surgical teams have been developing new ways to support a child in the precarious post surgery period.

Some children are unable to cope with supplying their body with oxygen because their pump, their heart, is still too tired to function

well after surgery.

The development of ECMO has been the result of many years of work - it is used in an increasing number of units to support children after their open heart surgery if recovery is slow. Mr Peek explains more.



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

Archie's Story

Our son Archie was due to have his Fontan completion and to complicate matters and add to the risk, his main pulmonary artery had become massively dilated (42 mm) and needed reducing in size and wrapping to contain it, and hopefully stop it dilating again. This is very unusual and Archie is currently under a Geneticist who is checking his DNA for a connective tissue disorder.

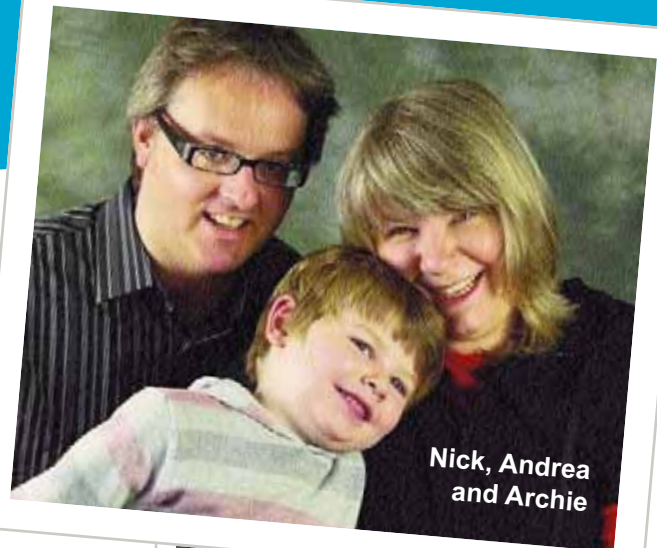
He was admitted on 21st June 2009 - Father's Day - not the best his daddy has ever celebrated!

Archie went down to theatre first thing on 22nd June and we left him in the capable hands of Dr Moore the Anaesthetist - that bit never gets any easier!

We were called to see the surgeon, Mr Peek, at around 4p.m. He told us that Archie was coming out of theatre on ECMO. My stomach hit the floor. We

had narrowly avoided it after his stage 2 - Glenn shunt and Damas-Kaye-Stansel procedure. The problem was with his blood pressure - or lack of. His heart was beating fine but there was no vascular resistance so the blood was not going around his body. Mr Peek thought that, with a rest on ECMO, it would recover. He said he was "concerned but not overly worried". He might not have been too worried but Nick (my husband) and I were wretched with worry!

While we were waiting in the parent's room we saw Archie being wheeled back into PICU. We had never seen a patient surrounded by so many doctors and nurses and connected to so much equipment. When we eventually saw Archie settled in PICU it was like seeing a tiny body amidst a sea of tubes and machines - he looked like a corpse - not our Archie at all.



Nick, Andrea and Archie



Archie receiving ECMO

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 asleep and pain free whilst they are on ECMO. They



also receive feeds either through a tube in the nose or intravenously.

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 three patients treated, and for adults with lung failure one extra patient is saved for every six that are treated, compared to

continued treatment with 'normal' intensive care.

If your 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.

We knew the dangers of ECMO, of clots forming or extensive bleeding. The ECMO machine had its own nurse checking the tubes constantly with a torch watching the blood flowing through.

Archie's chest had been left open whilst on ECMO and the day following his operation one of the ECMO Specialists told us that he had problems with bleeding and they wanted to flush his chest out to see if they needed to add any stitches anywhere to stop the bleed. They would also give him Novo7 a drug to stop the bleeding if there was nowhere apparent to stitch, which they did end up giving him. What a juggling act for the doctors! Keeping the blood thin enough to flow through the tubes of the ECMO without clotting but not too thin that the patient bleeds to death. I think the years of experience helped get the balance right!

Archie spent two days on ECMO in all and Mr Peek was the one who took him off it. He spent the morning tweaking and fiddling with the ECMO machine and chatting to Nick and I. Around lunchtime he announced "Do you realise Archie has been off ECMO for the last 40 minutes?" After a few more hours he was taken

off it for good and his chest was closed.

We had another scare not long after Archie was taken off ECMO when his BP started dipping again but this time he responded to drugs. Archie also developed an extensive clot in his IVC but this was treated successfully by an IV infusion of TPA and he continues to have a higher INR range of 3-4 on Warfarin.

We did have a long stay of 25 days in PICU and then a further 20 days on the ward. It was quite a roller-coaster of highs and lows with re-intubation along the way due to a nasty chest infection.

We believe that having the rest on ECMO saved Archie's life and we are glad that he was in the unit which has the most experience of ECMO in this country. It's not what you would wish for your child but no-one can predict how a child reacts to open heart surgery. It's such a massive trauma on a little body. ECMO may even be seen as a last resort but as a parent you'll take it over the alternative!

Thank you to Glenfield's ECMO team, PICU and Mr Peek for our son's life.

Andrea Harris,
mum to Archie, aged 5 years.



Fundraising

Well we are all in the grips of the coldest spell in the country for 30 years and battering down the hatches just to keep warm at the moment.

But as we do, it's great to say that some members are already at work planning fundraising activities for 2010 and some are doing them right now.

Dad Tim York from Kettering and four of us are busy planning and training to do the Hadrian's Wall walk in February and I know that many of you in the South East are looking forward to coming to Maidstone in March to take part in the second 'On Your Marks for Little Hearts' walk or run, so that's great too.

The two walk and run events in 2009 raised over £35,000, all of which has been used to provide services that you as members asked us for, wonderful news for everyone.

I tell you every edition of the newsletter that I get so motivated by you all, especially the children, but this month I was moved so much by a young expectant mum who was organising events during her pregnancy and into the future who said to me last week during a conversation, "Got to go now Kev, off to Bristol to have my baby girl, will be in touch very soon". You are so wonderful.

Some of you may know that I worked for BHF in a past life and they do a fantastic job, of that there is no doubt, but the beauty of LHM is that it is your charity and you influence what we do and we all interact every day which is so nice. You really can see the difference that your

Kev's News



kevin@lhm.org.uk

involvement in what I am trying to do actually makes.

Thank you for your support and thank you for inspiring me to try that bit harder for you all.

The diary of Fundraising Events is now in place so please look on the website and see if you can get involved, or please feel free to do your own thing. Please remember that it is your involvement that keeps the charity going and

allows it to grow for everyone. I will highlight a few events in these pages but please have a look at the details of our first Forget Me Not walk to be held in the South West in May.

Please join with others and have a look at the fundraising pages on the website, there are lots of fun things to read about and you can meet Barnaby Bear there too of course!

Can I thank all of you for taking part in the alternative Christmas Card idea, we had a great response and the money is now coming in.

Many of you also purchased a light or lights on our first Lights of Love tree and some of you managed to attend the lighting ceremony where we had a brass band supplied by Peter Groves, one of our Trustees, and we sang carols, had loads of mince pies and mulled wine, but more importantly spent a while with our own thoughts of love at Christmas time. Thank you all.

The Tree has raised over £1,200 in its first year. Again, all this money is turned around to provide services which you have asked for.

Finally it is so difficult to feature everyone in the newsletter or on the website, I do try but please accept my apologies if your story does not feature. It does not make your efforts any less important.

Best wishes for a very happy New Year to you and all your loved ones.

Kev Bazeley
Fundraising Manager



Fundraising Events and Ideas

FORGET ME NOT WALK
Ashton Court Estate, Bristol -
Sunday 9th May 2010, 2pm

May is always a lovely time of year, with the cold behind us and summer flowers bursting into life all around us.

Why not join with others and enjoy the start of summer as we hold our first sponsored 'Forget Me Not' walk in Bristol. Set within the grounds of beautiful Ashton Court there are walks, all of which are suitable for buggies and wheelchairs so all the family can take part.

For application and sponsorship details contact the office on **0121 455 8982** or apply on-line at www.lhm.org.uk.

BIG FUN RUN
Various Dates and Locations

Thank you to everyone who took part in the Big Fun Runs across the country last year for us. Darren and Amy Smith did and they raised over £400 - thanks guys.

There are more runs in 2010 - visit our website www.lhm.org.uk and click on **Charity Events & Diary** for more details.

SUMMER BALL 2010
Moor Hall Hotel, Sutton
Coldfield - 11th June 2010

With Christmas & New Year now behind us it's time to look forward to our Summer Ball being held at the Moor Hall Hotel in Sutton Coldfield and hosted by St Joseph's RC



Doing the Great Scottish Run for LHM



LHM...!

"Being a bit of a couch potato, I was thrilled to run my first half marathon in September as part of Glasgow's Great Scottish Run. I'm also a friend of Gill and Pete Smith; recently they and Olivia and Michael came to stay with us, and when Gill found out I was going to run, she talked me into doing it for

LHM...! The training was quite different as I live in inner-city London and running round Peckham Rye in the heat and humidity of summer was very tough. I quickly realised that running for LHM not only helped the charity but was keeping me going too; the temporary pain and discomfort was easily put into perspective by the knowledge of the endless strain and heartbreak endured by families who have a child with one of the devastating conditions they deal with.

The actual race felt reasonably comfortable as my home city didn't let me down and produced cool weather and copious amounts of rain on the day. And I was delighted to raise £855 for Little Hearts Matter."

Valerie MacLeod

A Great Grandpa says Charlie!

I remember a long time ago when I was a little boy my Grandpa was a magical figure who always did great things with me. He was my best mate.

Well the same went for little Charlie Turner and his Grandpa. I am told by mum Alison that her Dad who passed away at the end of last year was totally dotty about his little 'Charlie Barley' and that Charlie felt the same way.

Friends and family of Charlie's Grandpa raised



Grandpa, they all are you know!

School. Selected as the school's charity for 2010 this prestigious event has almost sold out already with **only 10 tickets left for LHM members.**

So with the date set for Friday 11th June and plans now taking shape, music and food on order, it promises to be a fabulous evening and a great chance for many of us to get together and all in support of the children and the services provided by Little Hearts Matter.

For more information about Moor Hall Hotel have a look at www.moorhallhotel.co.uk. If you would like to grab one of the remaining 10 tickets (£40 per person) please call me or email without delay kevin@lhm.org.uk.

CLOTHING BINS

With four bins now firmly established in communities in Birmingham and a small income now coming in from them it would be great if we could spread this initiative across

Kev says "In partnership with BCR Global Textiles we hope to site bins across the UK as another way of raising much needed funds to support the vital family services provided by LHM. And in addition to fundraising, the bins will also help to raise our profile. The bins are in effect bill boards to show that we are here and to highlight our work via the website".

YOU CAN HELP - help us to find sites.

Why not approach your local supermarket, council or anywhere people get together and ask if we can have permission to site a bin.

You are our daily ambassadors, if you think you may be able to help, please try. The more bins we site, the more funds we can raise and the more services we can provide for you all.

You find me a site and I will get a bin there - it costs us nothing!

Little Hearts Matter Ice-cream!

Wow, Janet Jones and friends raised over £365 when they produced and sold LHM ice-cream last October.

It sounds really yummy, Janet's grandson Charlie has HLHS and family and mates have rallied around to help raise funds for your charity with this and other projects like a giant gingerbread man which raised over £300. Thank you the Jones family, you are great - any chance of some ice-cream?



Charlie enjoying sailing lessons

White Water Rafting

Inspired by your stories and conversations with members, Gwen who many of you chat to each week decided to put a team together and take on the Olympic White Water Rafting course in Nottingham. So joined by Deb and 6 mates they did just that (see website for more pictures).

Congratulations to the whole team, who to date have raised an incredible £1,200.



Outstanding Fundraiser Puts Best Foot Forward

Runner Neil Simpson inspired by the story of five year old Tom Smith from East Rainton, near Sunderland, has decided to run 50 miles to help Tom and children just like him suffering from HLHS. He will be taking on four running events to raise funds for your charity.

Hearing about Tom's plight after a chance meeting with dad Andy, Neil decided to do all he could to help. The dad of one said, "I've done runs for charity in the past but learning about Tom and the charity pulled on my heart strings a lot."

"I have a 21-month-old boy myself, and it would crucify me if he was ill."

Neil's first event is a 16.3 mile kilomathon from Nottingham to Derby, the first race of its kind in the world.

In each of his four events Neil will attempt to break his personal best records in his drive to raise funds for us.

To sponsor Neil please go to www.justgiving.com/neil-simpson



ROUND UP

So many of you have helped to raise funds for your charity in December with Lights of Love, the alternative Christmas card as well as running, walking, swimming, selling logs, holding raffles, concerts and so much more, here are a few of you.

Donna & Steven Grainger took part in Walkabout UK and raised £172.

Hannah Jordan sold logs! and sent us £100.

Alison and Michelle Hendry took part in the Shugborough run/walk and trotted to a total of £566 - brilliant.

Also running the Shugborough Run and making a handsome donation was **Andrew Shaw and his family.**

Mrs Brenda Watts donated a moving £525 in memory of her dear husband Alf.

Christine Garrens danced with her wild west pals and £500 came line dancing our way.

There were many more of you helping at the end of the year so thank you to you all.

Personal Story

Below Kerry shares with us their family story.

Written by
Kerry Gavin

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

When we found out I was pregnant we were so happy. My partner had had a vasectomy reversal only a few months beforehand so we weren't sure if it would work and if so, we were not expecting it so quickly. My partner was desperate to tell the world, but I was reluctant as I was so worried something may be wrong. I had told a couple of close friends and they said I was worrying as everyone does, especially as it had been a long time since my eldest of 10 years.

As time went on I just knew something wasn't right and I knew this was intuition speaking not normal mum fears. The first scan was fine as they always are, but the second was when we found out there was a problem. My eldest, Bradley was there which was my worst nightmare. They did the scan, but said they could not see the heart, this they put down to the baby lying the wrong way which I think is the

same for most when there's a problem. I was to go home and come back in a couple of days. The same thing happened again though but this time I knew. I asked the sonographer if there was a problem as it was taking so long, she said she needed the consultant to view for a second opinion. Well that was it, the tears came flooding. When it gets to that point you just know. She advised us she could not see all four chambers of the heart and felt we needed a second opinion by a specialist. It was absolutely awful, she was trying to keep the tears back herself and comfort me and then there was poor little Bradley, he did not know what to think.

My worst nightmare had come true, all that I had been fearing had become reality. This was to be the worst weekend of our lives. They were very good at the local hospital and got us an appointment for Monday morning, but what a lifetime that was. We went straight to my mum's where Bradley told her the whole story and so calmly. How funny kids are!

Monday came and we went to Guy's. There we saw Mr Simpson and Sherrida. Everything was explained to us after a detailed scan and it was confirmed, our baby had Hypoplastic Left Heart Syndrome.

We were told our options, but immediately knew we had to fight for our child. All that we had been through so far with getting pregnant, the thought of not having him wasn't an option.

We went away and tried to come to terms with it all. As we spoke to friends and family I could not believe their response - not to have our baby. They felt that as we already had Bradley who has ADHD and other problems and we'd had a very tough time with him and then relationship issues we would be mad to go through with it. I could not believe what they were saying. How could they contemplate it? When I was younger (very young) I had had a termination so for me there was no way I could go through this again and I was not prepared to



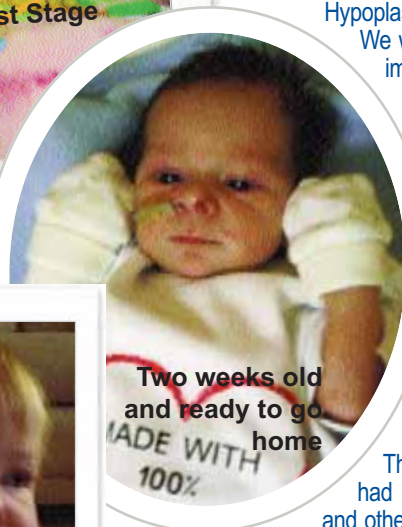
regret losing another child. We had a reasonable chance to fight and that was what we were going to do. In time friends and family came round. I think because we came across as so determined and confident they then were too, and between us all we knew we had to stick together and make good of a terrible situation.

It came to the time when I was due to have the baby. It was planned to be at St. Thomas' on 31st October 2005. I was so desperate for a child on that day as it would have followed on with two others in the family, but the baby seemed to be quite happy where he was and I think he knew that the Evelina was due to be opened that day and wanted them to have a chance to get settled in!

1st November, just after 9 a.m. and our little boy arrived. Everything was as it should be apart from the fact that we barely got a cuddle before he went off to NICU and then on to PICU. It was awful, I could not wait to be with him. Richard had gone down and it felt like a lifetime. Mum stayed with me and it's amazing how quickly someone can get themselves together after labour when your child needs you! I swear now, few or no drugs through labour is so much better, you are so much more together and focused after - especially in a situation like this.

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

Going home was so scary, a new baby is hard enough, let alone one who had just had open heart surgery and all the risks that go with it and



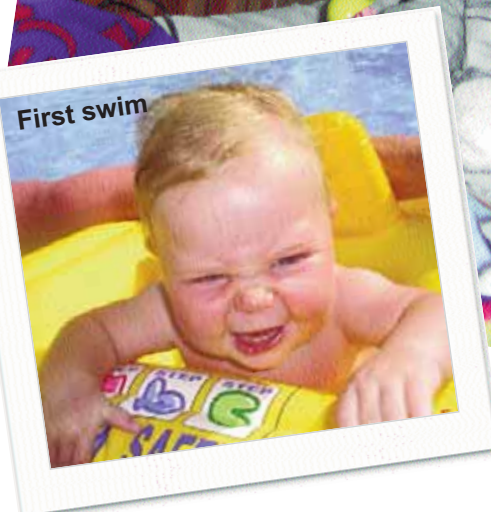
especially when it had all been so quick. I think though having had Bradley first who has always needed all my attention, medication, etc helped. A blessing in disguise as they say! We got by as we all have to and I think in the end you just learn to deal with things.

Stage 2 seemed to come round so quickly. Prior to this we had had MRI's and medication increases so we had been in hospital a couple of times which had helped, but still nothing prepares you for surgery each time, watching your child go through this and feeling so helpless. I think as a parent this is the worst situation you could be in because we are supposed to protect our children but when it comes to this we are helpless. The second surgery again went well and we were only in for a few days. Charley seems to be such a fighter and I believe is meant to be here and meant to help us as a family get on with life. And as my mum says, we are the lucky ones despite the ups and downs, because we have been given this special child probably because another person couldn't have coped.

After surgery at six months old, things were good. Charley was doing well and I was expecting another baby which you could say was mad but is the best thing now - seeing them so close and together all the time. Charley has always been reasonably well, not really any heart problems, your usual ups and downs with prolonged general illnesses and all the worries that go with it until September 2007.

Charley woke up one morning with really puffy eyes. We saw our doctor and went to the local hospital and they put it down to an allergy of some sort, could even have been air they said! We knew though that things weren't right, he was more tired than normal, blue, not really eating and things weren't getting better. We eventually got to the Evelina where they scanned him and advised us he was in heart failure. The leak on the tricuspid valve had got worse and they would need to look at it further with an MRI. They did try increasing Charley's medication in the hope that that would help, but it didn't. We went in for the MRI and within a week he was back in having surgery. They advised that Charley could not wait until after Christmas for this. What an emotional and terrifying time. He had never had any real heart problems so how could this all be. I honestly thought this was it for us, his sats were down to 50 and he virtually couldn't do anything, he looked navy constantly and was just so poorly.

After waiting a long time for him to come out of theatre, we finally saw him. The team were pleased with how things went, up until the point they did an echo in PICU. Things has changed, the scan in theatre showed the leak had reduced, it now showed it hadn't made any difference at all. We were gutted, all that time for nothing and still a very sick child. Mr Anderson couldn't even speak to us he was that upset. No-one knew what to do next. I honestly thought this was it, were were going to lose our special little boy. We waited and waited for them to make a decision. Finally later on that day they advised us that they were going to re-operate. Charley had already been on bypass twice that day and I just couldn't imagine him getting through any more. He looked so poorly and was just not our happy little boy.



Mr Anderson had looked at the echo and felt fairly confident he could change some of what he had done to the valve and get it to a better state. Wednesday morning came, Charley had been out for 48 hours and it was time for surgery. I think the only consolation to this was the fact that he wasn't aware of what was happening, but I just wanted to give him the biggest cuddle and tell him I loved him and couldn't. Again we waited but only for a few hours this time though and Charley was back with us. This time the operation had been a success and the leak was now moderate. Charley was back on the ward and in no time eating his Pringles and staying up chatting to the nurses! He's such a character and I couldn't believe how well he had done and that he was here with us. He is our world and the thought of anything happening to him just doesn't bear thinking about. We made it home just in time for Christmas and what a special one that was. Still a worrying time, but we thanked our lucky stars he was here and we were all together.

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

September 2008 and Stage 3 was due with a tricuspid valve repair again. Each time it gets harder and harder. Charley is growing up now and understands what is going to happen to him and knows where he's going. He's so sweet

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

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



Feature

Below some of LHM's fantastic volunteers share why they give up their time to help the charity.

Written by
 Louise Hall, Olivia Hutchinson,
 Amanda Gardener, Lynne Carney & Tim York

When Little Hearts Matter was first formed it was run purely by volunteers. Fifteen years later the charity has developed and grown and is now lucky to have six members of staff, but LHM still cherishes our volunteers, we would not be able to continue to offer all our support and information services without their time and experience which they so kindly give to the charity.

These pages feature some of the wonderful people who volunteer their time and expertise to the charity and explains why they have chosen to do so.

If you would like to help please contact us, we particularly need volunteer network support leaders, but if you are interested in any area that the charity deals with, such as information provision or fundraising we would also love to hear from you.

Please call us to chat through what you would like to do and how we can offer you the support to do so.

Youth Volunteering Olivia Hutchinson

I've been involved with LHM for so long I can't even remember when I began. As most of you will know Suzie is my Mum and so she's been asking me to help out with events for almost as long as she's been working for the charity. Every time I'm asked I come back. This isn't because if I didn't she'd get cross (which I can assure you is something you should try to avoid :) but because I really love working with such a fantastic group of people. I enjoy meeting up with everyone to catch up with people, some of whom I've known for years, and find out how everyone is. I think the events that LHM puts on are invaluable for so many reasons and I'm so happy to be a part of them and to help out in whatever way I can.



One of the main reasons I get asked to events is to run drama workshops and this is what I love doing the most. Acting and drama are my passions and so being able to share what I love with a group of enthusiastic, (some more than others), kids is so exciting, especially when I can see them enjoying themselves.

LHM is a family and that's why I love helping out. Everyone gets together, united for one reason, and even if they haven't seen each other for months you would never be able to tell. I feel privileged to be a part of something so special.



As LHM's longest serving trustee, this is a valid question. Why have I spent the last 13 years trundling up and down the M6 to meetings, conferences, interviews? Why do I still volunteer to take on a variety of daunting tasks often involving hours of preparation? Why do I want to be part of an organisation that is constantly changing in response to the needs of the members and the outside world? The short answer is easy: because I want to! The long answer needs a little more thought...

13 years ago almost to the day, I drove down to Birmingham from Cheshire to my very first LHM meeting. This took place in a tiny room hidden away in the back corridors in the old Birmingham Children's Hospital. I had been

asked to attend by Suzie Hutchinson, then Cardiac Liaison Sister at Birmingham, as I was very keen to establish some sort of support network for families diagnosed antenatally with Hypoplastic Left Heart Syndrome (HLHS): my son's diagnosis at 18 weeks' gestation had left me floundering for help and I had had to find people to talk to through my own contacts. I was lucky to meet 2 women who lived close by who had experienced something of what we were going through and their support and understanding was invaluable. LHM was just beginning, but parent-to-parent support was not easily available outside Birmingham (then one of only two treatment centres for HLHS). Once my son, Ben, had successfully got through his first 2 surgeries, I approached Suzie with a view to co-ordinating some antenatal support and, before I knew it, there I was, sitting in a meeting with like-minded people!

Why am I a Trustee? Louise Hall

LHM has grown beyond recognition in the intervening years. Lottery grants, inspired fundraising and careful management have enabled us to develop the service beyond the dreams of any of us in that little room. We have a full-time working office staffed by a fantastic team; we provide high class information to the medical, educational and social work profession; we have a distinct and positive profile in political and media circles; we help fund award-winning research; and, most importantly, we provide a safe haven for all those families (now including all single ventricle disorders) who need support.

I am proud to have been part of the development of Little Hearts Matter and love being in a team of committed, thoughtful people who are striving to improve the lives of all our children. So, why am I a trustee? Because it's great!



Why we joined the LHM Support Network

Amanda Gardener & Lynne Carney



Amanda says

"This is me with my husband James, seven year old son Thomas and Annabelle who has just turned four. We live in South West Surrey and my involvement with Little Heart's Matters (LMH)

began when I was expecting Annabelle, our hospital Consultant told us it was a good organisation to use to get information and support.

Annabelle's first year was difficult, however as she reached about 3 things started to get a bit more stable. So I felt the time was right to see if I could help out a little.

In November 2009 I went on a training weekend, along with a small group of other new volunteers which was led by Suzie Hutchinson. The weekend was really social and informative. To be a Volunteer Network Support Leader was not as daunting as I

imagined and the team are so friendly and helpful.

It has been a comfort for me to know that there are other children with similar heart problems and their families out there and a charity to help us. I hope by volunteering that I may in a small way be able to give something back."

Lynne says

"My second daughter, Carys was diagnosed with Hypoplastic Right Ventricle along with several other defects when I was 26 weeks pregnant. Although that was nearly 14 years ago I can still remember the rollercoaster of emotions as we struggled to understand the diagnosis, make a decision about what to do next and come to terms with what life might be like with this baby who would be so different from what we expected.

I remember Suzie (who was our Cardiac Liaison Nurse at the time) put us in touch with a couple who had a gorgeous one year old with a similar set of defects, and talking to them and meeting their little one helped me put it all in

context and gave us hope.

A little while ago I answered one of Suzie's calls for volunteers to help provide support to other parents and when she suggested I help on the antenatal support line I was really pleased to be able to do something to help other parents find a way through that awful fog.

My role is simply to be able to answer questions about what life with this condition can be like as a parent and how it impacts on family life. I have now spoken to several parents and they all had similar and different questions and concerns. I hope just a little of our experiences throughout Carys' life has been helpful if only in the smallest way."



Fundraising

Tim York

Actually organising an event and taking part in order to raise money for a good cause has always sounded like a lot of hard work. It is also something that I thought that other people, who are better organised and more focussed than me, take part in.

So why do I find myself just a few months away from leaving my perfectly warm house in Northamptonshire to set off and walk the whole length (84 miles, coast to coast!) of Hadrian's Wall (in late February!)? Well as some of you may know, our son, Solomon, was born with Tricuspid Atresia. He has already undergone open heart surgery (Glenn Shunt) in the first year of his life and he is certain to need further open heart surgery (Fontan) over the next few years. Like many families with children with 'half a heart' conditions, we have found ourselves feeling confused and anxious on numerous occasions, not knowing what to expect with various elements of coping with Solomon's condition (e.g. surgery, feeding, general health, etc.).

LHM has been such a useful and valuable resource to us providing us with the kind of specialist information that it is difficult to get from elsewhere. Without LHM's help we would have struggled to

understand the surgical procedures facing Solomon and we wouldn't have been able to successfully complete the minefield that is the DLA application form! As part of the annual conference, LHM have also provided us with access to important seminars with key doctors/spokesmen from the Cardiac Surgery world that we would otherwise not have had access to. They also provide a brilliant website and forum which allows us to be in contact with other parents who are going through similar experiences.

Since we get all those mentioned benefits (and more) from LHM without paying a penny, I thought it would be a good idea to try and raise some money so that they can continue to provide this fantastic support to all of us that are affected by these heart conditions. Therefore, I contacted a few old friends and suggested doing a decent length sponsored walk ... which soon developed into the Hadrian's Wall challenge that we are due to undertake next February/March. To my surprise, it has been really good fun organising the event and has been nowhere near as complicated to arrange as I thought. Of course, organising a big event is only one way of fundraising but another way Hannah, my partner, has raised funds for LHM is by donating the payments received from her making cakes for friends' and families' celebrations. Fortunately, Hannah has got a real talent for making just about anything in cake form, and really enjoys the challenge of doing so, so people are more than happy to make their donations to LHM at Hannah's request.



I know our family have taken so much from LHM so I think it is only right to try and assist in fundraising to keep the charity doing what it does best. I encourage anyone who is thinking of doing anything to fundraise for LHM (and even those that aren't!) to bite the bullet and do it. You'll find that it is really rewarding to organise and isn't nearly as difficult as you'd expect (since lots of people are willing to help!). I also know that when Solomon is a little older and needs to hook up with other kids that have gone through similar experiences, I want LHM still around to be able to provide that service for him.

If I can do, anyone can!

Now I just need to dig out those walking boots, get in a bit of practice and take out some shares in a 'blister plaster' company ...

Shameless plug:

<http://www.justgiving.com/hadrianswall2010>



Zipper Zone



Jon gives an overview on some of the things he has been working on with our young members and what is planned for early in 2010.

Written by
Jon Brunskill

To get in touch to discuss anything email jon@lhm.org.uk or call 0121 455 8982/07590



ZipperZone: Where are we now?

I have a feeling that 2010 is going to be the year of change. Since I've been at the charity, I think that there has already been a shift in the way that we think. My position has meant that the young people that we support have had a chance to have their voice heard.

Let's have a look back at the highlights of what Little Hearts Matter is doing to help young people with a single ventricle heart condition:

- ☺ We have a fantastic Youth Website: www.zipperzone.org.uk
- ☺ If you are over 13, you can join our Facebook page to chat with other young

people with a heart condition like yours.

- ☺ We are undertaking a piece of research into how having a heart condition affects adolescents.
- ☺ The Little Hearts Matter Youth Council grows in strength, volume and influence.
- ☺ The Youth Newsletter offers information, advice, and a chance for you to connect with all of the other Zippers across the country.
- ☺ Our Open Days, Youth Forums and Activity Weekends have got hundreds of young people together to have fun and make new friends.

What will the future be?

In many ways, all of the work up to now has been groundwork. We have collected evidence and heard directly from you what ticks you off, and the best ways that we could help.

Now the real work can start, but we need your help. We are receiving more and more calls from parents of teenagers in need of information, support and advice. Please do get in touch so that we can build a huge, active community of families working together to give children with only half a heart the best chance at having an independent, fulfilling adulthood.

HIGHLIGHTS OF EARLY 2010

FEBRUARY	
How I Feel: Research Project	To help lobby for change with government, we need hard data. Many parents have asked if we can visit you at home with the Questionnaire. We can do this, please get in touch to arrange a date.
MARCH	
LHM Open Day 2010	This year we have a fantastic Youth Programme set up which will be looking to the future, and helping young people with advice and information on BIG issues. All the topics that we explore have been asked for by either our young members or their parents. Last year we had over 30 young people, don't miss out!
APRIL Onwards	
Confidence Building Workshops	One of our key aims in 2010 is to empower all of our young members. We want all of the young people that we support to be happy and safe, and we think that building confidence will help to do so. Look out for Music Workshops and DVD projects from April onwards!

Introducing Nicky Pope, the Transitional Nurse at Birmingham Children's Hospital

"Hi, I'm Nicky Pope and I have just started as the new GUCH Transitional Nurse Specialist for University Hospitals Birmingham (UHB). My post has been funded by the British Heart Foundation as both UHB and BHF recognise the importance of having a good transition from paediatrics to the adult services.

My role is to help you and your parents make the move as smooth and stress free as possible. I will hopefully meet you in your last clinic at BCH and so be a familiar face for you when you attend the clinics over at UHB or if you have to be an inpatient there. Also I will be a point of contact if you need any help or information. I am hoping to come and meet some of you at Little Hearts Matter in the near future so we can talk about some of your feelings or anxieties.

I have worked at BCH for 20 years, I know from experience how daunting and stressful it is moving and having to get to know new doctors and nurses and saying goodbye to those you have known for years. But it can also be an exciting time, a new beginning towards independence.

I'm looking forward to meeting you."



Feature

'Communications Tree' - members share their experiences of using a network of people to keep others updated with hospital news.

Written by
Gill Cloke



Have you used a 'Communications Tree' - whether or not you called it this? Used while a child's in hospital, this is a spreading network of folk who keep each other in touch with your news. We've had positive experiences of this, so we thought we'd write about it; it can be hard to keep updating people yourself, and this can turn out to be a real help.

I can say this because I've had this done for me and done it for others. When my son was diagnosed antenatally, we were inundated with well-wishers, all saying 'DO keep in touch'... So many that it would have taken hours and cost a packet. And back in that day (2004), networking sites weren't much used, we didn't blog, my husband could barely even e-mail. And I thought it would be tough trying to do that all myself in hospital, while dealing with heart surgery for our child...

But we found we had an avalanche of volunteers desperate to do something for us, to support us in any way they could - help with the house, packing and preparing - whatever. So having a communications network was a no-brainer for me. My friends were keen on the idea, willingly organised themselves into contact groups and offered to help forward e-mails, and communicate the contents to others not on e-mail. It took some time and care setting it up - the thing I most worried about was that this would be terribly burdensome to whoever 'moderated' it for us. But my friend Marjory, a godparent-to-be, was caring, committed, and above all organised!..

Marjory says: *'When Michael was diagnosed with HLHS, everyone in his parents' lives experienced the feeling readers will recognise: what can I possibly do to help? Just doing something reduced that feeling of helplessness we all suffer from round serious illness. So when I was asked to run a 'communication tree' I was relieved to be able to do something practical. So Gill and Pete, during the many weeks of hospital stays and absence from home, kept in personal touch with me and as often as necessary (in the first couple of weeks more than once a day, and after that daily) phoned me or sent a text message with an update. My job was then to turn that into an e-mail message to the whole tree, who'd then pass it on.*

'The challenge in this is communicating with people who are mostly strangers, so the style of what's passed on has to be very carefully judged

to avoid confusion and distress. I tried to report clearly and gently, with reassurance about what was going on - but still trying to convey the mood of the family and also tell of some of the lighter moments in their adventure. In this, it helped being slightly detached. The raw emotion and exhaustion the parents experience is hard reading for those more distant from the scene; it's good for messages to be prepared by someone who can focus on that task and take time over the wording.

'This system really lightened the load for the family for a few weeks, while reassuring them that everyone was being kept informed. I would recommend to families who are going to have a hospital stay, that they take the time, as soon as they can, to set up a system like this.'

About receiving (and passing on) the messages, **Joan says:** *'I can say that as a consumer, I found it incredibly helpful. It gave me the information without having to bother you while you were at the hospital. I was reluctant to phone you in hospital, and the email gave me what I needed to know. And when we did speak, it meant those calls could be spent actually talking about how you were, as I already knew what was happening. I don't think I ever dreaded reading them... People really do want to know how things are going, and it gives folk the information without worrying, "who can I ask"? I honestly can't think of a down side to doing this. I know it took a while to set it up initially, some emails bounced back etc., but I also know that people want to be able to help and it was something we could do for you. I would assume that most people would have at least one friend who was computer literate and for whom setting it up and sending things on wouldn't be a bother.'*

Because we'd felt so helped by this, when I found our friend Andrea was proposing to do her own updates when her son went in for Stage 3, I had no hesitation in offering to run a communication tree for her. Here's what **Andrea says:**

'When our son was due to have his Fontan op, Gill offered to do email updates for us to all our friends. At first I was reluctant to accept her offer as I felt it would be a lot of work for her, but then thought back to when Gill's own son had his Fontan and how grateful I was to her friend for her email updates. I accepted the offer - who better to update than someone who had been there and

got the t-shirt!

'For those friends without email I gave my Mum's phone number to ring for updates. Although most hospitals now allow use of a mobile phone, it is difficult to reply to lots of messages as you are in a very stressful situation and emotionally drained. It is far easier to send one update to a few recipients by text and let them spread the word.

I asked a few friends for their thoughts on the updates:

"It was very helpful to get updates and be able to ask questions if I didn't understand what was happening. She took the time to reply to my questions so I didn't need to bother you with them".

"Before I visited the hospital it was handy to ask advice on what gifts to bring - ones that would be useful".

"I came to rely on it and hoped for daily news. I was glad to hear that Archie had got through another day".

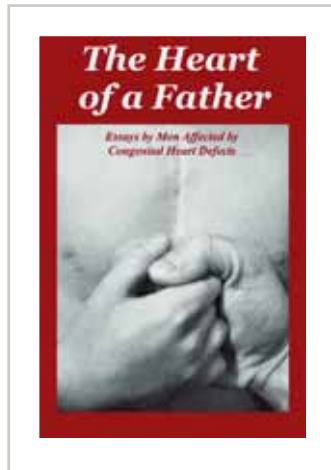
"It felt like there was a bond between everyone, thinking of you all and hoping together".

'It was a brilliant idea which worked really well. We are grateful to Gill and then to Isabel (who took over when Gill went on holiday) for sending out the updates. Even though, at times, things were pretty grim and desperate at the hospital end, they didn't scare or worry our friends unduly as they kept the updates upbeat and were able to draw on their own experiences to reassure everyone.'

You do need to think about the commitment before taking it on: in the event, it was quite stressful because Andrea and Nick had a number of dramatic upsets in their son's recovery curve. We seriously worried about sending out bad news - people who take this on need to be aware that this is always a possibility. But it all came right in the end, and it was best of all sending that news. And though it was worrying, somehow it helped me too, to be able to process what had happened to us the year before. I don't know why, but going through it side-by-side with another family, from more distance, helped us put it in perspective, and use our own experience to some good effect.



The Review



Every issue we feature a review of a book or website or film that our members may find interesting. In this issue, Paul Mullan reviews the book 'The Heart of a Father'

Written by
Paul Mullan



The Heart of a Father is a father's perspective on the experiences of having a child with a congenital heart defect. Its scope is broad, from birth to death, and is at times both affirming and heart wrenching: no one experience is the same. There is something in this book for everyone, and that is the book's strength, pooling a wealth of experience from over 20 contributors, mainly drawn from America, and combining them into one volume. Some people might question whether one can separate the experiences of fathers and mothers: the publication of this book successfully makes the case that you can.

The book is split into a number of headings: *Determination*, *Inspiration*, and *Dignity*. Each heading contains a number of chapters all written from the experience of a father. This approach does not always work for me as some chapters could have easily been put under another of the headings.

Determination covers the hospital experience, the care options for children, the experience of becoming a father, and the impossible choices that we are faced with as fathers and partners. *Inspiration* covers marriage, special needs, faith and lives cut short. *Dignity* deals with experiences beyond the US, reflection, being a grandfather and the experiences of adults with congenital heart disease.

This is a very broad scope for a book, but somehow it is all pulled together with success. Some of the personal stories work better than others. Some chapters spoke directly to me, and my own experience, while elsewhere I just feel for the pain of the writer and I am thankful for a very different experience. The book is, for

all of those reasons, worth putting effort into reading in its entirety. There will be parts I will certainly want to read again.

I am thankful that it has avoided, in the main, some of the sentimentality that can afflict, in particular, the American website associated with congenital heart disease. Most of the writers tell their stories straightforwardly and honestly.

There are some very clear outlines given of the hospital experiences, when children are undergoing their various operations. This in particular will benefit those parents who are just about to embark on that particular journey. But I also found that it helped me remember my own experience of that time. Perhaps I also should have tried to capture that very personal experience as it happened? Reliving that experience through the eyes of another has helped me connect again with what my son went through, and why he is so special.

I was particularly taken by the chapters which dealt with the conflicting emotions that can be experienced when, for example, trying to balance normal life with the trauma of operations, or the terrible wait for a transplant. Some of the stories told are very sad, the break-up of a marriage, the lack of support from in-laws, the fight for insurance cover; determination is written through them all. Heart parents do not give up!

Thankfully because of the NHS, insurance is not an issue here; and this is something that we should celebrate every day. The fear that some American families have of losing insurance cover is not an experience we have to face. On a personal note, I just cannot believe the resistance to President Obama's

necessary health reforms on the ground.

Particularly difficult pages are those which deal with the life and death choices that many of us have had to face when choosing the care options for our children. I found myself becoming furious when reading about choices being made on bad, biased or limited information. Again I am thankful for the honest frankness of my son's consultant at the Children's Hospital in Belfast and the inspirational team at the Princess Diana Hospital in Birmingham.

While *The Heart of a Father* covers quite broad ground and does not hide from exploring difficult issues, it is, overall, a very positive book. There is lots of good advice to be found, but more than anything it works for me by including me in a very wide community who have gone through experiences that I can identify with. It underlines the point that no-one should feel isolated through thinking that their experience alone is unique. It also emphasises the importance of cherishing family and nourishing relationships, particularly between couples who could so easily lose touch with each other at any point on the difficult journey of being the parent of a heart child, and it does not admonish those couples that do.

The Heart of a Father was published in America in June of last year and is a follow up to *The Heart of a Mother* which was published in 2000.

Both books can be bought on Amazon or from the website: www.heartfather.com in book or in eBook format.



Noticeboard

NATIONAL COOKIE BAKE 2010

Little Hearts Matter
Half a heart
...not half a life

TV Chef Lesley Waters tucking into a heart shaped cookie along with Ben Hall and Lucy Pearson

Combine healthy eating and fundraising together in a fun-filled project that supports children born with half a heart.

To get your cookie bake pack call us on 0121 455 8982 or email info@lhm.org.uk

Your Newsletter

Thank you so much to everyone who has contributed to this newsletter - it has been wonderful to receive all your stories and photos and ideas. The next issue is expected to be completed and will be distributed in May 2010. If you would like to send your ideas and stories/photos for the next edition please send them to Deb - deb@lhm.org.uk by the beginning of April. Also if there is something you would like to see in the newsletter do let us know. **We very much look forward to hearing from you.**

LHM Publications

Little Hearts Matter now has the following publications and packs available free of charge to members - to get your copy just call the office on 0121 455 8982 or email info@lhm.org.uk or visit www.lhm.org.uk.

- Antenatal Information Booklet
- Preparation for Hospital Booklet
- Preparation for Hospital Pack - to borrow for a period of weeks.
- Benefits - a guide for parents
- Feeding at Home - a guide for parents.
- Early Years and Infant School Education Booklet
- Junior School Education Booklet
- Dental Care
- Fundraising Pack

DIARY DATES

LHM Open Day & AGM
Saturday 13th March 2010
Bretby Conference Centre, Burton upon Trent

On Your Marks For Little Hearts

Sunday 28th March 2010
Mote Park, Maidstone

Sunday 3rd October 2010
Shugborough Hall, Staffordshire

Forget Me Not Walk

Sunday 9th May 2010
Ashton Court Estate, Bristol

'Lights of Love' Tree Switch On

Sunday 5th December 2010
West Midlands



Little Hearts Matter
 11 Greenfield Crescent, Edgbaston
 Birmingham, B15 3AU
 Telephone: 0121 455 8982;
 Email: info@lhm.org.uk

Over To You

This page is just for you – the members of LHM. We want you to tell us what you've been up to! Send us your pictures or stories – achievements, things that have made you proud – however big or small. If your child has swum a length of the baths, conquered the bouncy castle, or gone off to their first day at school or nursery, we want to know about it! We also want to include any of your ideas to make life easier or recipes for foods to tempt the children! This is YOUR page – if there's something you'd like to see – let us know.

Email your pictures, stories, recipes and ideas to info@lhm.org.uk



Barnaby's Great Adventure

Can you help us to help Little Hearts Matter's Barnaby Bear on his 'Big Adventure'?



LHM's new bear Barnaby has set off on his 'Big Adventure' to tell the whole world about the work of Little Hearts Matter and to see how the children supported by LHM live, go to school, play and of course go to the doctor's sometimes.

In November Barnaby visited Lanzarote on the first leg of his trip and managed to get a bit of sunbathing in as well as read the odd book or two. He really enjoyed his first flight with Tina from the LHM office, she took him to see lots of interesting things and of course everyone wanted to know all about him and the charity. He has also been on his first train journey and had his first snowball fight!

Barnaby is back in Birmingham and now that his passport has arrived (YES PASSPORT) he is planning his next trip which is to Paris with one family and it looks like he may go to South Africa with Suzie later this year.

WOULD YOU LIKE TO HELP?

If you think you could take Barnaby on holiday with your family or perhaps on your next unusual day trip or to a big school event, then why not get in touch with the LHM office and invite Barnaby to come along.

It's a great way of telling the world about LHM and the children. All we ask is that you send him back armed with great pictures of your adventure. You and your family can feature in the photos too and they will be posted on the website and may also feature in the newsletter.

Let's see if we really can get Barnaby right around the **WHOLE WORLD!!!**

- RIGHT: Thomas Hooks (4) and Charlie Turner (6) visiting Santa on the Severn Valley Santa Train.
- BELOW: Morgan Davies (2) and his sister Erin enjoying the snow on Christmas Eve.
- BELOW RIGHT: Matthew Baumber (7) and his sister Rachel and baby brother Thomas looking forward to Christmas.

