

Little Hearts Matter

Newsletter

Spring 2011



Future Pregnancies



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On Your Marks for Little Hearts

Sunday 22nd May 2011

On Your Marks For Little Hearts

This year's southern 'On your Marks for Little Hearts' race is being held in sunny Worthing.

Sign up...sign up... On Your Marks for Little Hearts Run. Worthing Sea Front, Sunday 22nd May.

It's time to dust off your runners and start training for the On Your Marks events, 2011. We are extremely pleased to be running a new event along the beautiful Worthing coast in May. The weather forecast looks good and we expect to have a great turn out! Many of our members have asked for a run in the south of England and we are hoping that everyone will encourage their family and friends to sign up and come along and enjoy the day. Those who know the area will appreciate just how stunning it is and what a delight it will be for visitors, situated between the beautiful South Downs National Park and five miles of award winning coastline, the town welcomes visitors with its attractions, friendly restaurants and fabulous shopping by the sea. It is easily accessible by road and public transport. We look forward to seeing you on the 22nd May.

Our annual On Your Marks for Little Hearts Shugborough will take place this year on the **25th September**, where we hope to have over 300 runners and autumn fayre, with children's races, face painting, toy, book and cake stalls along with tombolas and massages! Come and join us by running, walking, volunteering or cheering.

**This edition has
been kindly
funded by**



"Whilst we take our fundraising and our charities very seriously we insist on having lots of fun while raising as much money as we can for this very worthwhile organisation."

Katie Shanahan, Finance, Admin and Recruitment Manager.
[www. synectic-solutions.com](http://www.synectic-solutions.com)

News



Suzie's News

2011 is going to be a year of challenge and change.

For the charity's membership there will be the challenge that comes from the treatment of their child and the rollercoaster that is life managing the complexities that having only half a heart can bring.

Our young members will face a year of achievement mixed with frustration as they come to terms with the restrictions that their heart condition brings.

There will be the challenge of ensuring that a truly representative voice will be heard from LHM members as the need for change within medical care is discussed and formulated.

For Little Hearts Matter there will be the challenge of meeting the members' needs with a restricted budget and the need to raise much needed funds for this year's work, but also to create a reserve for the future.

So, which area is LHM's priority this year?

Well all of them.

We are working to strengthen our membership service. Our new Antenatal Information pack is being handed out in many units around the country. This has introduced parents to LHM and the vital, unbiased support and information given by the office and parent team. Helping parents to

have the confidence to make decisions about their unborn child is so important. The charity does not favour any one antenatal treatment path but works to ensure that every caller has the support they need to make their difficult decision.

The Education packs and DVDs have been a very highly praised service with many families being empowered to go into their child's school to work with the school staff to encourage the best for their children.

Our new project for the year is the Fontan pack. I have written it. Some families have been asking why I write a great deal of our material, I used to be a Cardiac Liaison Sister who specialised in supporting and informing families who had children with single ventricle heart problems both in the hospital and at home. To keep myself up-to-date, I visit many units and attend medical meetings. Oliver Stümper our Medical Advisor has verified the facts, our parent information team have tweaked it to ensure that it meets parents' needs and it is now in the capable hands of Deb who will make it look good. One of the charity's member families, the Robinsons, have funded the project so it is full steam ahead and we hope to have the new book ready to support families through the third stage of surgery by the end of the summer.

The teenagers are currently looking at their next project especially as their Secondary school DVD has been such a hit. Teachers have been phoning the office for more copies because they think that it is so useful. One of the events that the teenage group would like is another activity weekend but this will have to wait for a while because events like this cost an arm and a leg and this year's push is to stabilise the funds. We will be looking to build some more youth-to-youth support services though, as many of our young members have asked to be linked with each other.

The whole team are working on the Safe and Sustainable project with a huge emphasis on getting members to take part and voice their concerns about a change in service. Look at page 4 for more details of how you can get involved. I will be at nearly all of the events and at most there will also be

an LHM Trustee and the local network leader. If you are going, do come and say hello. LHM will be there listening to all of the comments and taking them forward as part of the charity's consultation response.

Many of our youth members are now speaking for themselves, in as many forums as possible. Their voice is especially important throughout the Safe and Sustainable process as it is the service that they need that must be the plan for the future.

And of course we work very hard to raise the funds that we need to continue to be here for you when you need us. You are so wonderful at supporting the charity, not only with your fundraising, which is essential, but also with your volunteering. Some of you offer vital parent-to-parent support, others speak at meetings and help with our information production. New volunteers are about to start being fundraising ambassadors, so many of you run local fundraising events for us. A huge THANK YOU to all those who get involved. We couldn't do what we do without you, but I have yet more to ask of you.

Although the first three months of the year have seen a nice regular income we have another nine to go. Any ideas that you have for raising funds will be gratefully received. Do you have any contacts in small or large businesses? If we ring a company that don't know anything about us we get nowhere, but if one of our families introduces us we have a way in. Everyone likes Little Hearts Matter and everything that we do but if we can't get to talk to people they will never know how much our families need their help.

Do you know any celebrities that might support us? Just their photo and a few words of support makes such a difference. If you tell us about them we will do the rest.

We need your stories. Emma Pelling 'our PR whizz' is looking for new stories that she can use to get people to understand what it is like to live with complex heart problems and to raise the profile of LHM and the support we can offer. Read Emma's piece (right) to get an update on what areas she is working on at present.



Finally I have some wonderful news. We have a new Vice-President.

As you know our Patron, President and Trustee Valerie Howarth, or to give her her full title, Baroness Howarth of Breckland has many friends in the House of Lords. Through her talking about the charity she has gained the interest and support of another member of the House, Baroness Rendell of Babergh. Most of you will know her better as Ruth Rendell the famous writer of detective fiction. We are so excited to have her on board.

"I have a soft spot for charities that help children. When I think about Little Hearts Matter and what they do I try putting myself into the shoes of these children's parents. I have, as you might guess, a pretty active imagination and though I don't come near to entering into their fear or feeling with their love, I do manage a degree of empathy. That empathy doesn't make me feel humble or ashamed. It makes me feel lucky. It brings me to an enormous admiration for these brave children and their even braver parents."



I hope to see many of you at the Safe and Sustainable regional consultation events. Please remember that the LHM team are here if we can help in any way.

THANK YOU

Many of you may have noticed that we have updated our logo. We would like to express our sincerest thanks to Sarah Durkin, who is a member of LHM and whose daughter Cerys has a single ventricle heart condition, and her sister 'Aunty Sharon' who have so very kindly donated their design skills and redesigned the LHM logo voluntarily.

They are also designing a brand new 'Journey to Independence' brochure and helping us look at all of our rebranding.

Thank you so much Sarah, Sharon and Cerys, we really appreciate all your help and work, and love what you are doing.

LHM In The Media



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

It was lovely to meet up again with so many of you at the Open Day in March. I'm always surprised at how much the children have grown since I last saw them! It was also great to meet new families and talk to them about how they can support the charity through media work.

As you all know, the Safe and Sustainable review of children's heart services has been high on the agenda over the past few months and I have been working consistently with the media. Firstly, I'd like to say a big thank you to all of you that have offered to support this process by showing your interest in talking to the media about your experiences. It is so important that your views are heard and I am working hard at getting your voices aired as widely as possible.

During February we were featured prominently in the Independent newspaper. Louise Hall was interviewed for this piece and talked clearly about the need for change (many of you would have also heard Louise talking about this at the Open Day). As we go out to consultation there will be on-going media interest and I

will be focussing on regional media over the coming weeks.

Looking back to the last part of 2010, highlights included Hannah Palmer speaking at an event at the House of Commons with the most amazing clarity and focus about three main aspects of her life and about the need for politicians and NHS teams to always keep children and young people born with heart conditions high on the priority list for care. The event was to give MPs the opportunity to meet with members of the Cardio and Vascular Coalition, a collection of some 47 cardiac or vascular charities who represent users of cardiac services. Over the Christmas period Paige Laight kindly put her name to a Birmingham based Christmas appeal on behalf of Little Hearts Matters. Thank you Paige!

The awareness team is continuing to work on the shaping of the Journey to Independence which will be our key communication focus for this year.

As always, please send me your news and I look forward to being in touch with many of you soon.



Hannah Palmer, Suzie Hutchinson, Jon Brunskill at the House of Commons



News continued...

Safe and Sustainable Consultation Programme ends on the 1st July 2011

Over the past few weeks the Little Hearts Matter team have been sending out copies of the NHS's Safe and Sustainable Children's Congenital Cardiac Surgical Services Consultation document.

We urge you to make sure that your voice is heard within this consultation process as the changes suggested may change the way surgery is offered to your children in the future. If you have concerns or you agree with the changes proposed, make sure that your voice is heard.

There are a number of ways that you can get involved.

The NHS consultation response

- Enclosed with this copy of the newsletter is the NHS Questionnaire. Using your consultation guide complete the questionnaire and send it back to Ipsos Mori in the envelope provided or go on-line and complete the NHS Questionnaire, www.ipsos-mori.com/safeandsustainable
- Attend one of the regional consultation events.

The Little Hearts Matter consultation response.

The Little Hearts Matter Consultation

Review team are drawing together a response about the shape and service provision set out in the NHS consultation document. Please let the LHM team know what service provision you are looking for by completing the LHM questionnaire that you have been sent or by going to the LHM website www.lhm.org.uk and completing the attached Word document.

If you have any worries or concerns that you would like to speak to LHM about don't hesitate in contacting us. Either leave a message on the LHM website, email us at info@lhm.org.uk or give us a ring on 0121 455 8982.

Regional Consultation Events

Location	Date & Time	Venue
Birmingham	4th April 2011, 6 - 8pm	Maple House
Cardiff	5th April 2011, 6 - 8pm	Cardiff City FC Stadium
Newcastle	7th April 2011, 6.30 - 8.30pm	Discovery Museum
Birmingham Youth Event	9th April 2011, 11am - 1pm	Maple House
Oxford	4th May 2011, 6 - 8pm	Kassam Stadium
London	7th May 2011, 11am - 1pm	Emirates Stadium
Warrington	9th May 2011, 6 - 8pm	Halliwel Jones Stadium
Leeds	10th May 2011, 6 - 8pm	Royal Armouries Museum
York Youth Event	14th May 2011, 11am - 1pm	The Royal York Hotel
Gatwick	19th May 2011, 3 - 5pm	Copthorne Effingham Park
Cambridge	23rd May 2011, 6 - 8pm	De Vere University Arms Hotel
Southampton	24th May 2011, 6 - 8pm	The Guildhall (part of the Civic Centre)
Taunton	7th June 2011, 3 - 5pm	Taunton Racecourse
Leicester	16th June 2011, 6 - 8pm	Walkers Stadium

Help your MP understand Safe and Sustainable

Many Members of Parliament are currently being lobbied to support their local cardiac hospital. Their fear is that patients will lose all of their cardiac care from their region. Many of them are unaware that the changes planned

will only make a difference for surgery and that the plan, if Commissioners choose the right option, will give children not only a better survival rate but a better chance of a good quality of life.

As you know Little Hearts Matter is working to ensure that the

pattern of cardiac units offering surgery will provide the high level of skill needed to treat and support the children, and their families, with the most complex of all cardiac disorders wherever they live in England and Wales.

To help MPs understand that the needs of children with complex

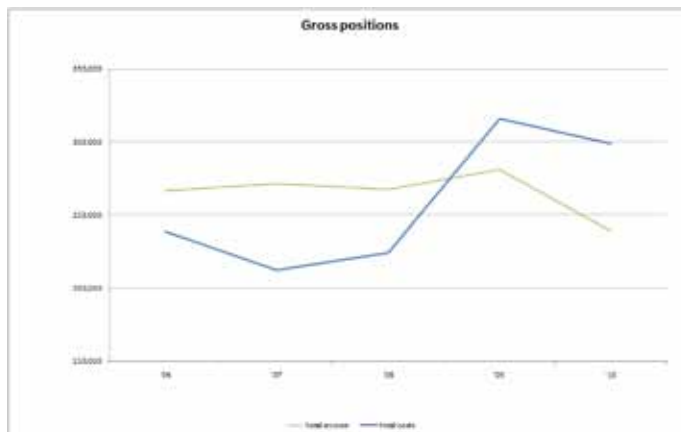


2010 Financial Update - £60,000 deficit

The draft abbreviated accounts were included in the pack for the invitation to the Annual General Meeting. The graph [to the right] shows how the income and costs of LHM have developed over the last five years.

As you can see the green line falls significantly in 2010 and this is our income, the majority of which is still raised by you. This fall in income has arisen from the cancellation of the Shugborough run and the loss of previously promised funds from our Corporate partner UK BPS.

The blue line which shows total costs has fallen slightly in 2010. This is due to the measures the office team and Board of Trustees took to make savings, but the loss of income occurred too late in the year to make a significant difference and the majority of costs LHM incur are fixed (75% of the total). These fixed costs include having the office with associated expenses and then also the staffing cost. It is this team who work so hard to give us all the information we need and are also always there to support us when we



need them. The variable costs are then for the support events and information production.

In order to run LHM we need to raise £250,000 a year, and to then expand our services and offer more events or support materials we need further funds. The office team, through Shelagh, are working very hard to obtain as much funding from Corporate partners as possible but we still need

your help. We as the Board of Trustees are confident about our current financial position as there is still £100,000 in the bank account, but we cannot rest as it is difficult to receive grants with our current financial statements and we must increase our income so that we show a slight surplus each year in our accounts.

David Baumber
LHM Treasurer

Glaxo SmithKline Impact Award

We are delighted to be able to announce that Little Hearts Matter has been awarded a Highly Commended award for our work with children and families especially at the time of diagnosis and our youth project work.

Glaxo Smith Kline, in partnership with the King's Fund, has created an award scheme to highlight innovation in supporting and informing people with medical conditions. The award brings not only much needed funds, LHM received £5,000 from GSK, but they also create a charity network and management training for the winning organisations. Suzie has attended the

first two days of training with three more to come in May.

"It was great to be in a room exploring the challenges that charities face with a group of innovative and like-minded people. So far we have explored Finance and Governance, I am delighted to say that although I picked up a number of useful tips, LHM's management structure is extremely sound. We looked at presentation techniques, you would have loved our Del Boy impersonations, network opportunities and staffing management style. We were even given a small video camera, and some training, with

which to film short excerpts for the website, video blogging. Some of the films are now up on the website, www.lhm.org.uk.

In May I will get the chance to link up again with my new charity friends and further explore fundraising, reserves and business planning. A great opportunity thank you GSK". Suzie Hutchinson

420 charities applied for the award with LHM getting through to the last 20 and then gaining a Highly Commended award. This is the first time that we have applied for the award so we are thrilled that our work has been recognised.

problems requires them to receive highly skilled surgery, LHM has written to every MP in England and Wales. We have not backed any one unit but are encouraging their recognition that the need for change is very overdue and needs to be decisive.

If you would like to join us in

our work to raise their awareness, you could also send them a copy of the letter. Enclosed is a copy of the letter with a space for you to add your local MP's name and then sign it from you.

Remember that LHM is not out to support any one unit, this is not an opportunity to campaign for

your own hospital, this is LHM's chance to balance some of the scaremongering information that MPs are receiving about the need for change.

You can find your local MP's details by visiting www.TheyWorkForYou.com



Medical

The article below looks at the emotional rollercoaster of future pregnancies after having gone through the diagnosis of having a child with a single ventricle heart condition.

Written by
Ruth Kirchmeier, Birmingham Women's Hospital
Sherrida Rollings, Guy's and St Thomas

If you have had a child affected by a complex heart problem, the thought of future pregnancies will inevitably be a scary prospect. Making the decision whether to try again is a complex one, coloured by the painful memories of what happened in the previous pregnancy or at birth when the diagnosis of a cardiac defect was made.

For those parents who chose to end the pregnancy or whose baby died after birth or whilst undergoing treatment, there can be a conflict between treasuring the memories of the baby who died and the hopes of having a healthy child.

Although we know from research and experience that if you have had a child with a congenital heart defect, there is a small increased risk in future pregnancies, by far the most likely outcome is that you will have a child with a normal heart.

Your own individual recurrence risk will be given to you by your medical team, but the range could be anything from 2-3% to 9-10%. The factors influencing this include the exact nature of the condition your previous child had

and your individual family background. However it may help to bear in mind that even if the recurrence risk is 10%, it means that you have a 90% chance of your baby's heart being normal next time, and even if there is a problem it would not necessarily be the same, or as severe, as your previous child.

Whilst statistics such as these are given to reassure you and help you make plans for the future, we know that when you have had a child with a congenital heart condition, it is hard to believe that it will not happen again.

Preconception Care

Most parents will want to know if there is anything they can do to reduce the risk of recurrence. Whilst as yet, the causes of single ventricle heart disease are not known there are a few simple things that parents can do to keep themselves healthy and therefore give their baby the best chance.

Eat a good balanced diet including foods rich in Folic Acid, e.g. fruits, green leafy vegetables, lentils, chickpeas, some cereals and bread.

Cut down on the intake of caffeine to reduce the risk of miscarriage.

Reduce and if possible stop smoking prior to conception. Smoking can affect the fertility of both men and women and may mean it takes longer to conceive.

Reduce and if possible stop drinking alcohol prior to conception. Alcohol too can affect both men's and women's fertility.

Take 400 micrograms of Folic Acid once a day ideally for three months prior to conception and for the first twelve weeks of the pregnancy. This is thought to reduce the risks of neural tube defects such as spina bifida.

Exercise regularly to maintain a reasonable level of fitness.

Facing the emotional impact of a further pregnancy

No one can take away the anxiety which the thought of a future pregnancy brings.

Sometimes it might be helpful for parents to see their obstetrician or GP prior to embarking on a pregnancy, to talk through some of the issues surrounding how a subsequent pregnancy would be managed and what support could be given. For some parents, making a decision to try again can be helped by talking to other parents who have had an affected child and who have had a further successful pregnancy. Little Hearts Matter can put parents in touch with one another and these contacts can be valuable sources of support both prior and during a pregnancy.

The booking scan

The booking scan, usually carried out by about 12 weeks of pregnancy, will hopefully be a positive affirmation that so far all is well and the first hurdle of early miscarriage is past. Seeing the baby on the screen can bring a mixture of emotions as hopes and aspirations for this new baby combine with memories of scans in the previous pregnancy.

Further routine screening tests will be offered to look for the risk of Down's

Our Story



Lynne and Carys

I had always wanted three children but after our second daughter, Carys, was born with a single ventricle condition, I started to think it would never happen. To start with, there was so much else to think and worry about.

I wanted to get her three operations over with before thinking about getting pregnant again. I did not want to be coping with a pregnancy at the same time as a big op. We were expecting the Fontan at about three years old but in the end she was nearly five before having it.

Then there was the risk of it happening again – it was hard to trust in my body's ability to nurture and grow a healthy baby (even though I had managed it once with Hannah). I had times when I was focused on the statistical risk (which was fairly small) but other times (often in the wee small hours) when I was terrified of the risk we might be taking with this as yet not

conceived new person.

Over the years we had had support from the medical team – we had visited the fetal medicine specialist to get an assessment of our risk factors when Carys was two or three and this had been a very useful session (although very uncomfortable being back in the unit where Carys' problems were first diagnosed).

It finally took us over seven years to make the decision to try for another baby. Once the blue line appeared we then entered an anxious nine months wait. The local obstetricians were very supportive – the doc who did our genetic testing in early pregnancy also threw in a quick nuchal translucency



syndrome and throughout pregnancy, the general size and growth of the baby will be assessed.

All parents of a child with a congenital heart condition should be given the opportunity to have a specialist fetal cardiology scan if they want one. This can be arranged as part of the booking process.

How early in pregnancy can heart abnormalities be detected?

Unfortunately congenital heart conditions can only be detected by detailed ultrasound scan and traditionally scanning in pregnancy for the detection of heart abnormalities has been around 20 weeks of pregnancy when the heart is the size of a walnut.

As scanning technology and expertise of those carrying out the scans has improved, it is now possible in some fetal medicine centres to offer an initial heart scan at around 14 weeks.

Clearly for parents who have had a previously affected child, any reassurance which can be given earlier in pregnancy is beneficial. Parents would need to talk to their obstetrician to find out whether early cardiac scans are available in their area.

What can be detected at this early scan?

The heart at 14 weeks is about the size of a pea and therefore it is not possible to visualise all the structures in the heart in sufficient detail to reassure parents that the heart is completely normal but it is possible to detect major abnormalities. The team will also look for other indications that the baby may have a problem for example, the nuchal translucency - fluid filled space at the back of the baby's neck (see below).

If all of the tests are normal it is likely that the heart will be normal although a further scan will be arranged around 20 weeks for added reassurance.

Why is a measurement of the nuchal translucency carried out?

It is known that there is an increased risk of the baby having a heart abnormality if the measurement of the nuchal translucency is larger than it should be for the number of weeks of pregnancy.

An increased nuchal translucency

scan (not offered at our unit at the time) which showed a low risk for heart defects. The same man did a very thorough abnormality scan at 21 weeks but still referred us to the foetal medicine unit in Birmingham (back in that room again!) for a further heart scan a few weeks later, just for our own peace of mind. Each time we were assured that nothing abnormal had been detected, but it was difficult to believe.

At 35 weeks pregnant a routine cardiac catheter appointment came up for Carys so off we went to Birmingham Children's for a two night stay (on those wonderful put you up beds!). A nuisance - but better to get it over with

measurement is also a marker of increased risk of chromosome abnormalities such as Down's syndrome. If this was found to be the case, the clinician would discuss with parents whether they would like further tests to check whether the baby's genetic make-up is normal.

What happens if an abnormality is found?

In the rare case that the fetal medical team detect or suspect that there is a problem with the structure or function of the heart they will organise for further scanning and other tests to be conducted.

Throughout the process expectant parents will be involved in discussions about the baby and any treatment path that is suggested for the baby and mother's care.

What other tests are offered in pregnancy?

If there are indications that there may be an abnormality in the heart, other organs, growth or development of the baby, further diagnostic tests will be offered to obtain additional information about the baby's genetic make up.

Chorionic Villus Sampling takes a sample from the developing placenta and is carried out at around 11 weeks. The procedure carries a risk of miscarriage of about 1 in 75 and the first part of the result (the PCR test) looking at the three more common chromosome differences which includes Down's syndrome initial results are usually available in 3 - 4 days. The full results are usually available within three weeks.

Amniocentesis takes a sample of amniotic fluid from around the baby and is carried out at around 15 - 16 weeks. The risk of miscarriage is about 1 in 100 - 150 and the first part of the result (the PCR test) looking at the three more common chromosome differences which includes Down's syndrome, is usually available in 3 - 4 days. The full results take 2 - 3 weeks.

It is very important that parents are given adequate opportunities to ask questions and voice their concerns with their doctors or midwives so that they ultimately feel comfortable with the decisions they make.

Whichever antenatal tests parents choose, waiting for the results will be

- I thought. However, a large blood clot found in her pulmonary artery during the catheter saw Carys waking up in the HDU with emergency open heart surgery planned for the next morning. Carys had another huge operation, time in ITU, HDU, on the ward, pacing wires, chest drains, drug pumps...the whole shebang. The cardiac nursing staff were starting to panic about just how big I could get before they would be called upon to step in as midwives. Everything I had been at such pains to avoid about the idea of being pregnant during an op all came to a pass in the end anyway.

Jacob was born a couple of weeks after Carys' eighth birthday and four

an anxious time. Many parents choose to wait until they have had the reassurance of a normal result before telling other people about the pregnancy and this can be quite a strain, particularly if they have opted for a later test.

It is important to remember that most future pregnancies will have no complications and most importantly that the new baby will be born without any problems.

The rest of the pregnancy

Most parents who have had previous problematic pregnancies, talk about the heightened sense of anxiety which remains throughout the pregnancy and how they worry more about other things going wrong, such as the baby not growing, not moving or being stillborn. This is a completely normal response to what has happened in the past and it is often helpful to talk to others who have had similar experiences as they will understand this mixture of fear and hope.

Midwives and doctors need to be aware of the increased anxieties that these parents will feel and allow time for them to voice their concerns.

The birth

Most parents with no previous problems view the birth with some sense of trepidation. For parents who have memories of their previous birth and what they had to face following it, the birth will be a further time of extreme anxiety and dread that something might go wrong even at this late stage. It is not until the baby is finally in their arms, having been checked over and pronounced healthy, that parents will gradually begin to relax and look towards the future. To embark on a future pregnancy is a courageous undertaking, but for most couples it is well worth the emotional rollercoaster ride it entails.



Jacob, aged five months

weeks post-op.

He was perfect (the paediatrician made sure to pay particular attention to his heart at his postnatal check). He is now six and loves coming to LHM events where he was impressed to have been lent a much loved book about the human body. He has been known to cover up half of the picture of the heart and ask "is that what Carys looks like inside?".



My story

Below Jenn, who is 33 years old and was born with Tricuspid Atresia very kindly agreed to let us publish some of her life story.

Written by
Jenn Costantino



while after my surgery. During High School though, I started feeling a fluttering in my chest and would get dizzy and nauseous. One time I blacked out. When this happened I had to be rushed to the hospital to be defibrillated, basically my heart was shocked back to its normal rhythm. This happened several times within a few years of each other, it was due to the extra scar tissue in my heart after my surgery. I was still very much able to live a normal life though.

After High School I went to Parsons School of Design in New York to study fashion design.

After Parsons, I began following the rest of my dreams, which were singing and acting. I was in an acting programme and studying Voice. Breaking into the industry was my main concern and nothing was going to go stop me!!

The summer of 2001, at 22 years old I decided to go on vacation. Firstly I was going to San Francisco to visit a friend and then to Las Vegas for a few days with some other close friends.

Well, it was probably my first trip as an adult by myself and I was so excited to really get out there on my own. I remember my mother gave me a note before I left, telling me how proud she was that I had gone through so much and am as strong as I was.

So I went to San Francisco, with not a care in the world. My second day there, I felt funny, and I thought maybe it's a palpitation. I was sure it was just the crazy hills there, they are exhausting!

The third day, my friend had to work so I was going to take the bus to the museum. On the bus there I kept thinking something doesn't feel right, and I was getting dizzy and nauseous. I knew I was in flutter, so now I'm on the other side of the country, what do I do? As soon as I got off the bus, I got back into a cab to my friends's place

and was terrified. I didn't have a cell phone yet, so I couldn't call him. I just prayed that I would make it back OK. I was alone and didn't know what could happen.

At his place I called my doctor who I have known since I was born. He said, OK my friend is at this hospital and she is going to take care of you.

I didn't call my mother because I knew she'd be on the next plane and all I have to do anyway is get shocked back to regular rhythm. It's like getting your nails done, quick and easy, right?

My name is Jenn. I am 33 years old and I was born with Tricuspid Atresia.

As a baby I did not have my tricuspid valve and not a sufficient amount of oxygen circulating. I was referred to as a 'blue baby'. My lips, toes, fingers, everything was blue.

At two and a half months old I had a BT shunt in order to increase my oxygen.

It was hard keeping up with other kids and I could rarely play outdoor games because I would always fall down and get tired easily. I spent most of my time drawing instead.

At eight years old I went into the hospital to have the Fontan procedure. It was the first of its kind and would help create a passageway for blood and oxygen around the heart and to my lungs. I don't remember much about it except for the fact that I was receiving a lot of presents from visitors whom I loved. I was home schooled during recovery and it seemed to go pretty smoothly.

I stayed in pretty good condition for a



So my friend stayed with me at the hospital and the next morning they shocked me back, this was also the day I was due to catch a plane for Vegas. I begged the nurses to let me go and promised I would stay calm and not do anything crazy, I just wanted to continue my vacation I had planned... so they let me go.

When I got to the airport I called my mother and told her, she was upset that I hadn't called her right away but I also never heard her sound so proud of me that I took care of it right away and was able to get through it alone.

As soon as I got on the plane the flutter started again, it just wasn't as bad. I managed to relax a lot in Vegas and made it back to New York safe without having to be admitted into a hospital.

Once I got back though I went to my doctor, the flutters wouldn't stop and he told me I needed to have a pacemaker. I was devastated, if I needed a pacemaker at 22, what was going to happen to me when I was 60? My grandmother has a pacemaker, not me!

I went in for a further evaluation and it turned out I needed a revised Fontan procedure. The doctors did tell me that I could live with the irregular rhythm for a while if I wanted to wait. But why wait? My life, my dreams, everything was just disrupted at this point; I might as well get it over with.

My surgery was scheduled for 13th September 2001, two days after 9/11, so it was moved to the following week. So, I went in and had my surgery. It was not like when I was eight, I liked it

when I was eight, my parents would have to hear everything that was going to be done to me and then tell me that everything was going to be OK. Not this time, I had to listen word for word to everything that was going to be done to me and I had to give the OK. It was the scariest time of my life, I thought I was done with surgeries.

While every other New Yorker was thinking about 9/11 and what would happen to New York, I thought about recovering and getting back to doing what I love in New York. Dealing with 9/11 and open heart surgery was not easy at all.

I got through it, and was out of hospital in eight days, back to acting classes within four weeks and spent the rest of the year



healing, auditioning and focusing on my voice.

This past summer I had to have a battery replacement for my pacemaker, I told the doctors though I had to finish recording my debut CD first. So two days after recording my last song 'Everywhere You Are' I went in for surgery, with every surgery there is fear, however I know that I will pull through because I want to be sure I can go back to living life and doing what I love, which is music!

And that's exactly what I did, only three weeks after my surgery I sang 'The National Anthem' at Keyspan Park in support of The American Heart Association. It was probably the most difficult song I ever had to sing, not because of the high notes (lol), but because of the strain that my body was going through.

I'm not telling my story for people to feel bad for me or to gain sympathy. We are all born with issues and for a reason. I want to get my story out there to inspire people. I'm finally at a point in my life, where I feel healthy enough to do just that.

Since my 2001 surgery I have been working in the fashion industry, done

background work in television and movies, performed at The Variety Children's Telethon, modeled on Project Runway to raise heart awareness. Most importantly though I have followed my dream of singing and recorded my debut CD 'The Best Part of Me' in which I wrote seven out of the ten songs.

Life is such a gift and if you don't treat it as the precious jewel that was given to you it will just go to waste.

I am 33 years old, with a pacemaker, but I also have talent, drive and people who love and support me. I must also mention that I am now in perfect health!! I can go out dancing, travel wherever I would like and feel free to try things I would have always been afraid of exposing myself to.

I'm not sure what my future has in store for me, but for now I will focus on my dreams and bringing inspiration to others whether it's through music, art or simply sharing this story with others.

I am living proof that miracles do happen! Never stop believing in yourself or your dreams, because I will never stop believing in mine.



Fundraising

Dear Members and Supporters,

I write to you a few days after attending my first Open Day and getting to meet many more of the families that LHM supports. It was wonderful to see the children of all ages enjoying themselves and the teenagers catching up with old friends.

Parents also caught up with friends they have made over the years and families who came for the first time wished they had come earlier and went away having made friendships that are likely to last for many years. They also gained a much deeper understanding of the breadth of services we offer for parents and children from diagnosis all the way through the family's journey.

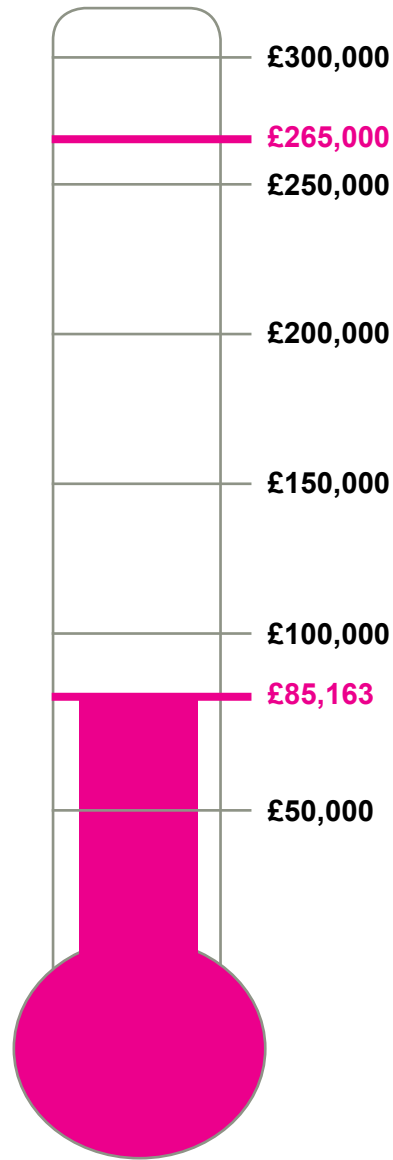
What I heard so many of our members say throughout the day was thank you, and it's something I would like to say to you, the members, as it is the fundraising that you have been involved in and the donations that you have sent that continue to enable the charity to offer the support and services it does for existing members and the many new people that are being made aware that we are here to help all families where a



single ventricle condition has been diagnosed.

Enjoy the summer and please keep us updated on all the fabulous fundraising you are doing. You can post on our Facebook page; we now have over 3,000 fans who view the posts on a regular basis.

Warm regards,
Shelagh.



Please continue to help us raise the vital funds we need to continue our work, we receive no government funding and rely solely on the donations from individuals, groups and companies. Everything you do makes a difference. Please try and support us in any way you can.

LEGACIES

We recently received a legacy from a long standing supporter, who, after he had taken care of his loved ones, chose to leave a legacy to us, for which we are extremely grateful. Following on from this I was talking to a member a few weeks ago and explaining the difference legacies make to charities generally and the fact that some charities rely on legacy income to fund up to 50% of their work.

It is a common myth that only the rich and famous leave money to charity when they die, this couldn't be any further from the truth. The reality is it is everyday people who when writing their will include a charity to benefit. The member was very knowledgeable about the workings of charities and was in complete agreement. She mentioned that she had indeed left a legacy and told me the charity she had chosen, I was quite surprised to hear her choice

but also very understanding that we all have our personal connections, when I asked her why she chose this charity, she said "because they asked me!... actually I didn't even think about LHM and come to think of it I've never heard the charity talk about or ask people to consider leaving a legacy for the work you will need to do in the future!" We looked at each other and smiled, both learning something from our conversation.

It can feel uncomfortable talking to people about wills and legacies, but having taken care of your family and friends, please do consider a lasting legacy to us if you can. You may also be interested to know that the Government is aiming to make legacy giving the norm and has introduced a reduction in inheritance tax rate for those leaving 10% or more to a charity.



10 ways you can help us to raise vital funds



MY FUNDRAISING PLEDGE TO LITTLE HEARTS MATTER

Fill up the flatpack donation box and return to us

Our flatpack donation box takes 30 seconds to put together and 10 seconds to put in a prominent place in the house. Then all that is required is encouragement so all the family help fill it, this could be by donating money given for completing household chores. Working family members can also donate the spare silver that jangles around at the end of the day. A full collection box holds on average around £25.

Ask your school, company, friends to do the same

Because the collection box is such an easy thing to do, we would also like you to encourage your friends, family, school, pub, in fact anyone you can think of to do the same as you.

Just call us on 0121 455 8982 or email us and we will send you as many as you need.

Recycle your ink cartridges and old phones

We get £1 for every cartridge and up to £30 per phone. All you need to do is pop them in the bag and then in the post. How about asking your colleagues to also donate their old phones and cartridges?

Ask your company if they have a charity of the year

Does your company have a charity of the year? If so would you nominate us? Or let us know if we need to apply. This is an area we really want to build on and have worked with both small and large organisations in the past.

Use Easyfundraising when ordering on-line

Why not raise funds for us whilst shopping on-line? After setting up an account you can choose from a large list of stores to shop on-line with and they will give a percentage of however much you spend, to us. It won't cost you a penny extra, and as many high street stores offer you a discount for shopping on-line it could even save you money.

Visit www.easyfundraising.org.uk

Sign up to our Lottery

For £1 a week you will be entered into the weekly lottery. There are over 160 prizes including a £1,000 cash prize every week.

45 pence of every pound comes directly to us to help fund our work.

Visit www.tlclottery.co.uk

Jump out of a plane or climb a mountain for us!

Imagine standing at the edge of an open door way in an aircraft flying at 10,000 feet - the noise of the engines and the wind ringing in your ears with only the outline of distant fields below, falling forward into the clouds, and free-falling at over 120mph! Or if conquering mountains is your game, why not climb Kilimanjaro, the tallest stand alone peak on the African continent...experience jungle and dramatic sunsets. A truly awe inspiring trek and life changing journey. All in aid of children born with half a heart.

Sign up to a monthly direct debit

Did you know that you can set up a direct debit and give a monthly contribution to Little Hearts Matter, this way of giving is simple and allows us to be able to plan ahead as we can forecast more accurately how much income we will receive a month. If this is something you would like to do, please complete the form (on page 25) and send back to us.

We are extremely grateful for donations from £1 to £1million per month!

Organise a summer BBQ in aid of LHM

The sun is coming out and the BBQ is out of the shed. Why not invite all your friends and family and have a charity BBQ in aid of LHM.

When writing your will consider leaving a legacy to us

If you are putting your affairs in order and would like to leave a legacy to a charity to enable them to continue their services in the future, please consider Little Hearts Matter.

THANK YOU



Spotlight On...

In every issue we feature articles where we talk about different aspects of education and cover ideas about possible sources of financial support to help you.

Written by
Isabel Baumber

Education

Parent Partnership Services

This article looks at the role of Parent Partnerships, who can be a great source of local support as you work to ensure your child's educational needs are met.

What are Parent Partnership Services?

Parent Partnership Services (PPS) are statutory services offering information, advice and support to parents and carers of children and young people with special educational needs (SEN).

PPS have a role in making sure that parents' views are heard and understood and that these views inform local policy and practice.

PPS are based with a voluntary organisation, with the Local Authority (LA) or Children's Trust.

As statutory services (ones that have to be provided by law) PPSs are all funded by their Local Authority. However they are all expected to be at 'arms length' of the LA and to provide impartial information, advice and support to parents. Some services are

based outside of the LA with local charities/organisations, some are based in LAs but in their own buildings, while others may share offices with other LA services such as schools, children's centres, support services, etc.

What services do Parent Partnership offer?

The services offered by individual PPS will vary but all will be able to provide information and advice about:

- How special educational needs are identified and assessed by schools and the local authority.
- Who parents can talk to in a school or LA about their concerns.
- The SEN Code of Practice, the statutory assessment process and statements.
- Parents'/carers' rights and responsibilities.
- Meetings and reviews about a child's needs.
- How progress is monitored and reviewed.
- What parents can do if they are not happy with a decision made about their child's SEN.

Please don't hesitate to contact the LHM office if you have any queries about any aspect of education. We have booklet available on 'Early Years and Infant School', 'Junior School' and 'Transition to Secondary School' which are available free of charge to members. We also have a more detailed pack for families who feel that their child may need additional support in school.

We also have a Benefits Booklet, which covers a whole range of ideas.

We'd be really pleased to hear about any other ideas members have.

How does Parent Partnership work?

PPS are free, impartial local services.

PPS work directly with parents and carers of children and young people with SEN.

PPS provide confidential information, advice and support.

PPS work in partnership with parents/carers, schools, the local authority and other agencies.

PPS support parents to inform and influence local policy and practice.

PPS enable parents and carers to make informed choices and decisions with confidence.

How can I find my local Parent Partnership?

The national website is www.parentpartnership.org.uk. Information for this article was taken from this website. On the home page, there is a map to link to your region and local contact details.

Please feel free to contact the office with any queries. We can also put you in touch with other families who may have experienced similar situations to you.

Benefits

Disability Living Allowance (DLA)

There are many changes being proposed to the benefits system, and at Little Hearts Matter, we will do our very best to keep you informed of changes, and influence those changes wherever possible.

We understand from our members that it is getting more difficult to successfully claim DLA at the moment, so would like to offer the following suggestions to help you.

Ask for the LHM pack to give you ideas of sample answers to adapt. Remember how important it is to stress what is different about your child's care needs when compared to a heart-healthy child of the same age.

Think carefully about the people you include to provide extra information about your child - it is very likely that the DWP will actually contact them for a report.

Ask for help e.g. from LHM, your health visitor, a local charity, Citizens Advice Bureau, etc. You can also ring the Benefit Enquiry Line (0800 88 22 00) for help with completing the form.

Ask for a second opinion before you send the application form in.

Keep repeating information if it is relevant to the question - don't worry about having already made the same point earlier in the form.

Get supporting letters from people such as LHM, health visitor, nursery, school, Cardiac Liaison Nurse, community nurse.

Make the most of the last page and paint a full picture of your child, their difficulties and how it impacts on the family.

Always keep a copy of your form when you send it in.

Remember that the person who reads your form is not a healthcare professional - they may not even have heard of your child's diagnosis before, so tell them everything about how the

condition impacts on everyday life.

If you are renewing your claim, you will only be sent one letter (six months before your award runs out) - there won't be any other reminders. Be prepared for the renewal process to take longer than it has in the past.

Don't give up! If you are not awarded the level you think is appropriate, or if you get a letter saying you are not eligible at all, the first thing you can do is phone to ask for a reconsideration, where someone different will look at your claim. You can also write to start an appeal. It is sensible to ask for an explanation of how the decision has been reached, and also for copies of all the information they have about your child, including medical reports.

Information about DLA can be found on the government website www.direct.gov.uk - look at the 'Disabled people' section, then see the 'Financial support' menu. You can also contact the Benefit Enquiry Line on 0800 88 22 00.



Ask the Experts

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

Suzie Hutchinson
Chief Executive
Little Hearts Matter



We are planning a holiday abroad and we are wondering where it would be safe to go?

It is always lovely to be able to plan a holiday abroad but it is also important to look at each destination, the travel to the country and the services that are available when you get there before booking anything especially when you have a child with a cardiac disability. Here are some tips to think about when planning your holiday.

1. Speak to your cardiologist

Firstly it is essential to check that your child is well enough to go abroad for a holiday. Speak to your cardiologist about holidays when you have a planned outpatient's appointment. If they are happy for your child to go abroad start looking for suitable destinations.

2. How far away is your destination?

Low level, short flights are possible from early on but many cardiologists prefer that long distance high altitude flights are not attempted until after the third (Fontan) stage of surgery.

3. Will you need oxygen on the flight?

Your cardiologist will tell you if you need to plan to take oxygen with you on the flight. All aircraft have a small bottle of oxygen on board but if there is an increased risk that your child may need oxygen during a flight they will expect you to supply your own. This may affect the cost of your holiday as you may need to book an extra seat to transport the oxygen and you will need to arrange to refill a bottle at your destination if you have used the supply on the flight.

4. Which are the safest destinations?

When planning where to go on holiday it is important to consider not only the beach, pool and/or sunshine, you also need to look at the medical care

provided locally and how your child would be transported to a hospital if they needed more extensive treatment. Island holidays may not be a good idea if transport to medical care on the mainland is not easy.

5. What sort of insurance do I need?

Whenever you travel abroad it is a good idea to ensure that you have full medical insurance, but it is essential when travelling with a child who has a disability. Insurance companies will expect a detailed letter from your cardiologist that states that your child is fit to travel. When planning your insurance make sure that there is provision for your child to be flown home if needed and that one parent can accompany them.

6. How hot is your destination?

Although children with heart problems like warm water to swim in and lovely sunshine, if it is too hot they can become dehydrated very quickly especially if they are on diuretics. Think about the heat at the time of year you are travelling. August holidays can be blisteringly hot. If your child is on Warfarin, dehydration can affect their INR levels. It is useful to take a Coagucheck machine with you on holiday to check dosage and clear instructions on changes in each daily dose if the INR level changes.

7. Medication

Many of the children's medications need to

be kept refrigerated so check to see if there is a fridge available in your room. Think about how much medication you wish to take with you and plan in advance your medication request from your doctor.

8. Local travel?

Think about how you are going to get around when you get to your holiday destination. Is the beach near your hotel or holiday home? Do you want to go exploring? Will you need a pushchair or a wheelchair to make sure that your disabled child can take part in everything whilst you are away?

9. Holiday type

If your holiday is an activity based one, will your disabled child be able to take part safely? How will you split activities if your heart-healthy children want to do something different?

Remember that the LHM team are available if you need any help with planning your holiday.



Grandparent's page

Chris Barrett shares a snapshot of life as a grandparent to Thomas and Joe.

Written by
Chris Barrett



Thomas is happy.

We are all conscious of the important role the Little Hearts charity plays in providing relevant information and support to new parents and those receiving the devastating diagnosis. This support can be a lifeline to families and we would encourage all parents to take their help and advice and never ever feel alone.

We have also supported the Fun Run over the years and if I can do it so can you!

Colin was able

August Bank Holiday 2003 is etched in my memory as the weekend I silently sobbed for our unborn grandson.

Sally and Spencer happily went to their local hospital for their 19 week scan and discovered that their much longed for second child had a heart problem and heard the devastating words of the obstetrician 'let's see if this pregnancy is viable'. A subsequent appointment with Dr Wright at the Birmingham Children's Hospital confirmed Hypoplastic Left Heart Syndrome, a very complicated and life threatening condition, whereupon details of the charity Little Hearts Matter became known to the family.

From that moment on our lives changed and like the famous story we were on a different journey. Not the journey planned for our family to the wonderful fun-filled places but the inevitable journey of hospital appointments, anxious times and an unknown future.

But not wanting to be ignorant of the facts and future we searched the website for information and found details of the Little Hearts Matter Open Day at The West Midlands Safari Park. This for me was a lifeline, once we stepped through those doors Sally and I were welcomed by the staff and introduced to families. We saw children running round, having fun, looking 'normal'. We listened intently to Mr Barron's words and the current success rate of the Fontan procedure. This gave us hope and encouragement and from that day on we continued to have hope, receive the encouragement and love every minute of Thomas's life.

Whilst Sally continued to remain positive after diagnosis and during her pregnancy we all naturally worried about the future and were concerned about Joe, aged 3, who was so looking forward to having a baby brother. It is

particularly hard for siblings being without their parents for weeks, if not months and this is where we were able to offer our support and love and care, providing as near normal a life as possible for Joe. Sleep didn't come easily and everyone was stretched to their limit but nothing compares to what Thomas was going through and with strength and prayers Thomas came home and life as a family of four began.

We are always on hand to offer our help and support and our first evening left alone to babysit was a total trust of faith. We will never forget the line up of drugs with labels and clear instructions, not sure who was the most nervous that evening.

After many operations at Birmingham Children's Hospital and the expert ongoing care, Thomas is enjoying a very happy life and gives daily joy to everyone around him. Thomas has introduced us to numerous holidays at Centre Parcs where he loves swimming, the play areas and arcades. His favourite holiday so far is Sol a Go Go Camp site in France where he scooted on his amazing micro scooter late at night and enjoyed the club nights till 11:00pm!

Every new experience provides us with great pleasure and the joy he has given us help compensate for the realisation that there is no cure for Hypoplastic Left Heart Syndrome but there is hope, continual research and



I joined Phoenix Trading because I was so impressed with the product. It is such a beautiful quality and value for money. I really appreciate it as an easy source of birthday cards, giftwrap and you cards at exceptionally good value.

I have been raising funds for LHM over the years and just by ordering through me at www.phoenixtrading.eu/chrisbarrett you can help.

Please ask for a brochure or order direct and a penny of the profit will go to LHM.





to offer advice on fundraising and served as a Trustee and has recently offered to be an ambassador for Little Hearts Matter in order to promote the charity to the corporate market and the local community, working with Ian Ash.

Sally took a career break as a Physiotherapist to care for Thomas in the early years but when he started school Sally was able to gradually increase her hours and we are more than happy to help in collecting Thomas from school and being able to care for the children in school holidays, etc.

Thomas loves school and he excels at mental arithmetic, has an incredibly enquiring mind and has a great knowledge of the mechanics of my car, brought about by his interest in reading the Renault manufacturer's manual on our way home! He is particularly popular with the girls in his class based on the number of party invitations he comes home with. Only last week I

was particularly proud to see Thomas being awarded a certificate in assembly for his 'Big writing' and an entry in the Golden Book.

Joe is extremely caring towards his brother and whilst they have a healthy competitive edge on the X Box Joe is currently teaching Thomas 'self defence'. Duvets and cushions are placed on the living room floor while they create a wrestling ring and Thomas is deftly developing his own wrestling moves. Joe is proud that Thomas is learning how to defend himself if necessary, while we look on with trepidation. I'm not sure Thomas actually enjoyed it initially but Joe was sure he needed the skills and Thomas

now gives as good as he gets.

Thomas is very conscious of healthy eating and one of his most significant achievements for us is being our mentor in successfully losing over 5 stone in weight between us. Being a huge fan of the Wii Thomas became worried and quite upset to discover I registered overweight and Colin obese when doing a body test. We were encouraged to do a daily body test and Thomas would note our progress and encourage us to have a healthier diet – it worked and now we daren't stray, having reached our

'ideal' goal.

Thomas is so proud of us but he will never know just how proud we are of him.

Calling all Grandparents



This page has been added to give our very important grandparents the chance to share their story, why they do things for LHM and what their involvement is.

Contributions can be as big or as small as you like, the most important thing is that we would love to hear from you. If you'd like to be a part of the newsletter just email Deb on deb@lhm.org.uk or give us a call - 0121 455 8982

We are really looking forward to hearing from you.

Phoenix Cards

so impressed
range, good
appreciate having
ap and thank

the last five
www.phoenix-

ct and every



Feature

On Saturday 12th March LHM held its Annual General Meeting and Open Day at the Bethel Convention Centre, Birmingham, below is an overview.

Written by
Tracey Baker and Joe Hollingworth

We attended our first Open Day in 2010 when Naomi was about seven weeks old, and she spent most of the day asleep in my sling, which was so lovely. Things were a little different this year, as we now have a toddler running about enjoying herself, and getting into everything, particularly when she saw Barnaby Bear sat on the welcome table.

This year's Open Day was held at Bethel Conference Centre, which was an excellent venue. The staff looked after us well, and it was very easy to get to. Naomi particularly enjoyed the huge lobby that was great for running around.

We were very eager to return to this year's Open Day. One of the best things about LHM is the relationships that are built, and the opportunities to talk to people who understand. Where else could you have a sensible conversation about what to do if your toddler won't co-operate for an echo?! Last year we had just been through the antenatal diagnosis, birth and stay in hospital and got great encouragement from attending the Open Day. It was so wonderful this year to catch up with friends we made last year, and find out how their little ones are doing, as well as make new friends, and

put faces to names from the LHM forum.

The main topic of discussion was the Safe and Sustainable review, which was the topic first session. It was quite eye opening to see how the quality of care differs across the hospitals, and how different each person's experiences have been. It really brings home the importance of making our voice heard in the Safe and Sustainable process. Suzie gave a clear explanation of the different options and a good discussion followed.

After the AGM we had reports from the quality of life study and the youth research which was very interesting and thought provoking, especially how the views of parents and children can differ! This cutting edge research could make a real difference to the care of our children in the future.

Over lunchtime Ian Ash, along with Emma and Shelagh, ran a session about the new ambassador scheme. The idea is to have LHM representatives across the country to help with the outward facing side of the charity. It was a really productive discussion, and made me feel really proud to be part of a charity that is so caring, and so well run. The ambassador scheme should hopefully really enhance the work of LHM.

In the afternoon we attended the session for parents of 0 - 5s, whilst everyone else went off to enjoy the session working with their children and discussing issues that come up with the different age groups. The 0 - 5 session was a great opportunity to share experiences, and get advice from friends who have been through similar issues.

The children's provision was excellent. Naomi had a super time in crèche, and the youth and children had a varied and exciting set of workshops. It is such an encouragement seeing the other children and teenagers at the Open Day. It gives us such hope for the future to see the teenagers doing so well. The youth produced an excellent

LHM Open D

puppet show at the end of the day which was enjoyed by all.

This year we booked a local hotel so



we could stay for the evening entertainment. The evening social was fantastic, one of the best bits, and chance to eat, chat and swap stories whilst the kids run around in a safe place. Naomi really enjoyed the magician (we were most amused by his brummie accent, pronouncing 'line' with an 'o' in it!).

We look forward to the next Open Day. Thank you to all the team for organising it.

See you next year!



*Relaxing with my mates,
grabbing a bite to eat,
having a laugh - a
normal Saturday, right?*



That's what I thought when my mate Sam asked me if I wanted to go to the 'Little Hearts Matter' Open Day in West Bromwich: a chance to meet new people and have some laid-back fun. I entered the doors to the awe-inspiring Bethel Convention Centre, not knowing that I would leave with orange hands and a piece of cardboard that looked like Harry Potter.

It's a long story.

talk about the problems they face with their heart conditions and how 'Little Hearts Matter' could help. My eyes were truly opened to the day-to-day problems of coping with activities I would find menial, such as exercise (light exercise anyway!), which became a struggle with a heart condition. But these difficulties were hugely outweighed by how supportive the group was with each problem, telling their previous experiences with the problems and how they themselves got through those situations.

While the younger members of the group prepared a puppet show to entertain trustees and parents, my age group formed the Youth Council to discuss what could be done to improve the charity. Within five minutes, the Youth Council had prepared a pitch to the Head Trustee, with their plans for the future and how to finance them. To see real decisions being made by people my age was incredible! Even the Head Trustee was blown away by how well thought out the pitch had been. My only contribution was a handshake to the Head Trustee - unfortunately this was when I realised my hands were still covered in butternut squash.

The Youth Council then met up with cardiologists and psychologists for a

revealing question and answer session. It was fantastic to see people my own age not only dealing with medical issues so seriously but also asking some thought provoking questions and taking in every word from the professionals' mouths. Astounding to think that kids as mature as medical experts were helping put on a puppet show five minutes later! Each age group presented an everyday issue in the form of puppet theatre, ranging from Punch and Judy at school to the cast of 'In The Night Garden' going to hospital for the first time. Anyone who missed the group of 15 -18 year olds' puppet production of 'Harry Potter and the Half Prince' truly missed out!

So a regular Saturday? Oh no, much better! The people I met at the Open Day had the biggest hearts in the world. I'm not going to forget them or how they helped each other out with warm advice and brilliant smiles, or how they knew exactly what they needed and how to give help to every child out there with a heart condition, or how they had joyous, friendly fun. And I'll never forget the sweet, sweet smell of butternut squash.

Day and AGM

To kick off the morning, we set up an ice-breaking session. I was expecting a circle of intimidating eyes staring down every person who was forced to stand up and nervously mutter, "H...h...hi my name is... and I'm f...f...from..."; instead we were separated into age groups and asked to reassemble a butternut squash. Yes, it's exactly what you heard. Through this, I met many new people in a fun way, even though my age group (the 15-18) lost to the youngest age group (10-12) who were mysteriously quick at repairing vegetables!

The groups were brought together to



Your fundraising

Thank you to everyone who has been fundraising for us, we love to hear about everything that you do, and we wish we could print everything. Here is a snapshot of some members, friends and supporters who have taken the time, persistence and in a lot of cases endurance to undertake a raft of amazing fundraising activities.



The Big Hearted Bake

We promoted our Big Hearted Bake in February and encouraged people to bake goodies and get all their colleagues, friends and family to get together and have a bake, donating the money to LHM. To date we have raised £7,000!

So thank you to everyone who got involved, there are some photos and thanks further on. We had hoped to raise £13,000 from this activity so there is still a long way to go, I know that many of you are planning on holding an event later on in the year and the

posters and information do not have a date on for that very reason, so please, it's not too late to organise your own, we have all the materials just contact us.

from their recent bake.

Katie Ratcliffe and friends at Newcastle under Lyme College in Staffordshire shared the love on Valentine's Day by selling homemade cakes to raise money for LHM and other heart charities.

They along with the rest of the college also sold handmade chocolate, raffled a big chocolate cake, named the bear and guess the amount of love hearts in the jar. Katie chose LHM as her family has been very involved with the charity since her little brother Marcus was born with HLHS nearly 12 years ago. Sadly he passed away at only a few days old but Katie's mum has been an important part of our bereavement team for many years.

Thank you to Katie and her friends for their support. (Pictured bottom left).

Thank you to the pupils and staff at St Cecilia's RC Technology College who went all out to raise over £500 including a Big Hearted Bake, a non-uniform day and selling Valentine's cards.

St Mary's Catholic Primary School, Ponders End also came up trumps by holding their own special bake, with all the children taking part and raising £550, thank you.

At the time of going to press special thanks to; St Mary's RC Primary School, Jennifer and Michael Pole, Mr and Mrs Batten, Birmingham Chamber of Commerce, Mr and Mrs Carroll, Christine Crawford, the Kish family and friends, Highworth Preschool, the Luntz family, the Palmers, Suzie, North Down's Primary School, Gill Cloke and family, Jean Wilson, Linda and Douglas Anderson, ISO Quality Services Ltd, Charlotte Sullivan, Ann Rousell and family, Mrs Widdicombe, Chadsgrove School, Lucy Allen, Rowley Hall Primary School, Andy Wignell, Jean Green, Mrs R A Bidwell, Dr W Crisp, Kingfisher Preschool, Royal College of Nursing.



Heather Guy at Nottingham College, who along with generous friends raised £527, five month old grandson, Jamie was Heather's inspiration behind holding the event. (Pictured above)

Thank you to everyone involved.

A huge thank you to Catarina Penalosa and the children of the under church, St Columbus-by-the-caste Episcopal Church in Edinburgh who kindly donated £110



Double match funding from Big Hearted Barclays

Barclays staff at Snow Hill, Birmingham (pictured right) held their BHB on Valentine's Day with Barclays kindly matching £ for £ the money raised. The event was organised by Joanne Hevey, she said " My friend's daughter Imogen suffered from HLHS but sadly passed away shortly after I planned this event. I hope to raise enough to make a

real difference to your charity." Thank you so much to Joanne and all at Barclays who raised over £400.

Also thank you to Lindsey Hooks for drawing Barclays staffs attention to us again and to Marsha Wolstencroft for helping to organise another successful bake.

Lindsey would like to say thank you to Jason Betteridge for your kind donation, Judy Piling for organising a shoe party and Thomas' cousins Taylor, Ellie Rose and Grace for their table top sale



Cousin Trey Uses Pedal Power

to raise £400

Ten year old Trey Campbell wanted to give something back to the charity that had helped his three year old cousin Sam's family from when he was diagnosed with Tricuspid Atresia. So he set himself the challenge of pedalling 20 miles from Bissoe to Portreath.

After weeks of collecting sponsorship and an appearance in the local paper, the day for his gruelling bike ride arrived. With grim weather forecast, Trey and his mum Rachel were up and out early to get a good head start. A small equipment error meant they were unable to drive to their starting point so they decided to cycle, adding another 10 miles onto their journey and some very big hills, but Trey's determination made him unstoppable.

From Bissoe to Portreath they enjoyed flatter tracks and beautiful scenery, and after a break and some well earned pasties they headed back. With the home stretch in sight Trey took the opportunity to ride through all the muddy puddles and finally made it home to Truro six hours later - tired, filthy but happy.

On completing the ride Trey said "I wanted to do something to help my cousin Sam, because I think he's great!"

Thank you Trey

Four Bikes And A Coconut Rat

Jon heard about the charity through Courtney's parents who have received support from us since seven year old Courtney was first diagnosed with HLHS. Inspired by his god daughter, Jon Allanson joined by friends Colin Platten, Mark Dobbs and Carl Holiday set themselves the task of cycling across Vietnam to raise money for LHM.

Jon says "None of us had rode a bike since our school days doing paper rounds so we all had to go out and buy one. Training started about six months before the event and was tough at first with short uphill sessions but slowly we got to cycling up to 40 miles."

Covering an average of 65km each

day, they travelled through hundreds of small villages where the children would cycle alongside them to practise their English. Their guide showed them lots of different points of interest along the way and introduced them to locals who were curious as to why they were cycling the long route when there was a truck following behind them! They also enjoyed two nights staying with local families where they tried delicacies such as elephant eared fish and coconut rat.

We'd like to say a huge thank you to Jon, Colin, Mark and Carl for their hard work in raising money for us. Thank you.



IN BRIEF

Thank you to the ongoing support of the East Midlands Public Authorities Football League who have supported LHM for many years raising an amazing £3,251 in memory of little Maddison Holland.

Big Thank you to Cora Banyard's Granddad and Nana who held a raffle at their

Freemason's Ladies Night raising nearly £600. Huge thank you to you both and Auntie Jude, Uncle Nigel and cousin Alexander.



Many thanks to all the Edinburgh Woollen Mill and Helen Kemp who organised a 'Guess the name of the bear' event raising £454 in memory of Tyler J Llewellyn Jones.

We would also like to send sincere thanks to all at Pelican Lodge, Plymouth and Philip Oke, who as Master of the Lodge nominated LHM to receive a donation of funds because a friend of his, Pete Breslan's granddaughter Imogen has received support from LHM.

Tough Guy With Big Heart

Ned Wheatley's grandad, John Austin and men and women from around the world descended upon Mr Mouse's farm to see if they have what it takes to become a 'Tough Guy'! On a cold January morning John proved just how tough he was whilst showing how big his heart is, raising money for his two chosen charities, Little Hearts Matter and Help the Heroes Sanctuary. Check out the challenge, it is incredible - www.toughguy.co.uk. We salute you John...thank you.



Horsing Around For LHM

A crazily dressed team of eight in Chippenham were braving the cold and wet weather to take part in the Badminton Horseless Trials. Abbie Robinson joined by friends and family, donned the essential gear such as trainers and LHM t-shirts (and the equally important pink tutus and plastic body parts) to run, climb, splash and shiver their way round the 5 mile course, which sees competitors running and climbing the course usually undertaken by horses. Abbie says, "We decided we wanted to raise money for LHM because of Malcolm's cousin, Adrian Robinson & his wife Rachel. Their four year old son Samuel was born with HLHS. Both Adrian and Rachel have spoken so highly of the charity." "Samuel is such an adorable boy and we just felt we wanted to say a big thank you on behalf of the extended Robinson family for all your work."

The team has already managed to raise an incredible £800. We'd like to say a huge thank you for all of the following, pictured from left to right above:

William Petty-Fitzmaurice, Geriant Williams, Scott Dunlop, Malcolm Robinson, Nicola Williams, Abbie Robinson, Rebecca Petty-Fitzmaurice. Also to final team member Hugh Lacey who isn't pictured.



Zipper Zone



Below Jon gives an update on the youth research that has been undertaken over the last two years.

Written by
Jon Brunskill
Youth Development Officer



We know that the physical, psychological and emotional development that an adolescent goes through during teenage years can create huge challenges. Add into this turmoil a complex heart condition and the anxiety and confusion is only compounded. Little Hearts Matter has worked closely with families affected by single ventricle heart defects (SVHDs) for over twenty years, but to date there is very little primary data that has been collected from the young people in which they are able to voice the physical and psychological effects of these non-correctable heart conditions.

Anecdotal evidence from parents and teenagers would suggest that there is a clear link between living with a SVHD and struggling with challenges above and beyond those of a normal adolescent. Often the support needed to ensure that these young people can reach their full potential is inconsistent or simply not existent. The aim of the 'How I Feel' Study was to provide quantified data supported by qualitative experience that would support the need for change within medical care, education services, career support and social services. We also hoped to identify challenges that may be incidental or occasional.

Over the last two years the LHM Research Team - consisting of Suzie Hutchinson, two parent trustees, two clinical psychologists, a youth worker and myself - have worked to create an accessible questionnaire targeting issues which have been identified as obstacles to young people developing towards an independent life. The questionnaire was broken down into the following sections:

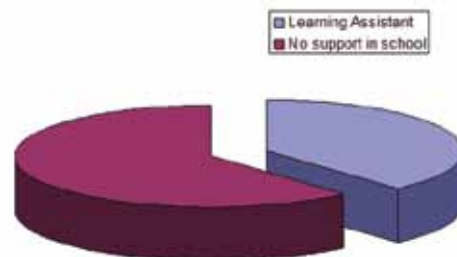
- Hospital and Medication
- Family and Friends
- School
- Feelings and...stuff
- Big Kids (for young people in Year 9 or over)
- Diet and Food
- Sports and Activities

31 young people, aged between 10 and 18, took part in this questionnaire. Young people treated at Southampton, Birmingham, GOSH (London), Evelina (London), Alder Hey (Liverpool), Glenfield (Leicester) and Freeman (Newcastle)

were represented. The participants had a range of SVHDs, including Hypoplastic Left Heart Syndrome, Pulmonary Atresia, Tricuspid Atresia and Univentricular Heart. Analysis of their response is currently underway, however initial results would suggest that the data supports anecdotal evidence.

For example, of the 31 participants, 26 attended a mainstream school, and of these 26 only 10 received learning support.

- 26/31 attend mainstream state schools
- 16 receive no support
- 10 receive support



This data will be supported by qualitative data collected through telephone interviews with young people with a SVHD. The aim is to illustrate the figures with powerful explanations from the young people directly affected by these conditions.

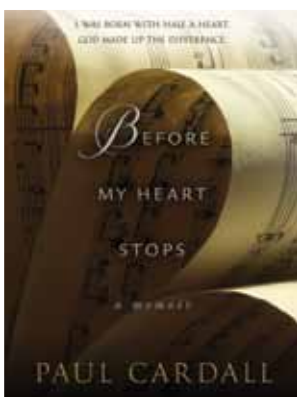
All young people aged 10 – 18 will be offered the opportunity to take part in this interview, and we hope to receive your support in our endeavour to produce a rigorous account of how it actually feels to live with a heart condition as an adolescent. The outcomes of this project will be more accurately targeted service provision from Little Hearts Matter, as well as an invaluable tool for the entire spectrum of care givers to these young people.



The review

Every issue we feature a review of a book, website or film that our members may find interesting. In this issue, Lindsey Hooks reviews 'Before My Heart Stops' written by Paul Cardall

Written by
Lindsey Hooks



Can be purchased from Amazon from around £9.98 - www.amazon.co.uk

www.paulcardall.com

and long periods where he was completely exhausted. If you have read his blog 'Living for Eden' (named after his daughter) you will already be familiar with the majority of the material, however, I only became aware of him on Facebook when his book was being released.

There is no doubt that Paul's story is one close to all our hearts, his positivity and attitude is very uplifting and is an inspiration to everyone, not just those touched by heart disease. The example he sets on how to approach each challenge is a lesson to us all and is humbling especially when you think of trivial issues which take our time and energy day to day.

It is very apparent that Paul is a deeply religious man and his resounding faith influences him and impacts everything he experiences. If you are religious I'm sure you will be able to relate to what he says, however, it is a very big part of the book and the constant references can be a little distracting. That said, there is no doubting his sincerity and it is apparent that his faith has helped him, and those close to him, cope with the difficulties they have had to go through.

Overall I enjoyed the book. It is always a pleasure to read about positive people with heart conditions like our children. I came away feeling that whatever is around the corner there is no harm in looking at the 'glass half full' and what can be done, rather than all the challenges and struggles we inevitably face. Personally I would

have liked less of a focus on the religious aspect however, you have to appreciate that this is who Paul is and it doesn't detract from what a positive and uplifting role model he and his family are.

I will finish with an extract I found while researching about Paul Cardell before I bought the book. Dr Angela Yetman and Dr Melanie Everitt are Paul's paediatric cardiologists. For me this sums up both Paul and his family's approach to life entirely and sends a positive message to all us heart parents.

"It's the most severe heart disease we see," explains Dr Angela Yetman. "He is alive and he's also done so well for himself." She said Cardall's "personality and temperament with an optimistic outlook have helped him survive, as have his parents, whose willingness to let him experience life rather than sheltering him for fear of the health consequences."

"They've made plans for the future," Everitt said. "Some kids and parents see this (disease) as a death sentence... We want to give them hope." Medicine and technology have advanced to the point, that such patients can look forward "not just an extension of life, but a full and active life." she said.

"I was born with half a heart. God made up the difference"

Paul Cardall was born in 1973 with Tricuspid Atresia, a single ventricle heart condition and was only given days to live. He defied medical expectations and endured a series of surgeries and childhood illnesses. While in High School tragedy struck and his best friend was killed in a car accident. After having quit playing the piano a decade earlier Paul took comfort in music and composed a musical tribute. He is now an award winning pianist and number 1 Billboard chart artist from Salt Lake City, Utah.

"The best way I know how to express the raw deep emotions I've experienced is through the piano music I create."

Paul is a dedicated Mormon from Salt Lake City, Utah where he lives with his wife and daughter, Eden. This book is essentially a diary of his day to day life from when he was put on the transplant list up to the point, 385 days later, when he received his new heart. Whilst waiting for his new heart Paul was in end-stage heart failure, he was on oxygen 24/7, took a daily cocktail of drugs, spent several nights in hospital



Medical

The article below looks at Protein Losing Enteropathy which is a complication that can occur following a Fontan procedure

Written by
David Simpson
Suzie Hutchinson



Can you make a difference to Protein Losing Enteropathy (PLE)?

I am David Simpson, a medical physicist by training, husband to Helen and father to Alasdair (10), Eleanor (5) and Catherine (2). Alasdair was born with Aortic Atresia and had three surgeries before the age of three to create a Fontan circulation. He recovered well and developed into a bright smiley boy who attended mainstream school.

Fast forward to 2007 and Alasdair, who had been in great health, was diagnosed with PLE. Helen and I found ourselves in another paediatric cardiologist's office having the 'breaking bad news' talk again.

Alasdair was put on a new regime of Prednisolone and Sildenafil and, though it was five long weeks before we left hospital, he went back to full-time school with the same energy he had before.

As a health professional with

research experience, I started looking at the scientific literature around this condition. I discovered that the use of Sildenafil had been reported in the literature for the first time only six months before Alasdair needed it. I also came across a small charity in Buffalo, USA, the Children's Heart Fund (CHF) which is committed to curing protein losing enteropathy. The charity was set up by the family of Colin Colson, a child who sadly died of PLE.

I had so many outstanding questions I decided I wanted to talk to the experts face to face and was lucky enough to be given a small travel grant by my professional association and support from my local hospital. I was very grateful to be able to talk to Suzie Hutchinson from Little Hearts Matter to confirm that I was talking to the right people.

Children's Hospital of Philadelphia

I met with Dr Jack Rychik who gave me two hours of his valuable time to talk about clinical care of children with PLE. He is setting up a single ventricle survivorship programme, a specialist clinic where Fontan children will be examined by Gastro Intestinal specialists as well as having their bone health assessed. This way, any signs of PLE can be spotted and treated early. He has had a good deal of success using Sildenafil in conjunction with Budesonide, a steroid used to treat Crohn's disease.

We talked about how best practice could be shared throughout the world of Paediatric Cardiology and what directions future research may take. Dr Rychik talked about how the support of the CHF had been important to him and that an International Symposium organised by CHF had helped co-ordinate research efforts. I was reminded how small the world of paediatric cardiology was when I met Dr Gil Wernovsky in the corridor, one of the experts Suzie had told me to look out for!

Sanford-Burnham Institute, La Jolla, San Diego

One coast to coast flight later I met up with Dr Hudson Freeze and his group. I saw the plaque he has on the lab wall acknowledging the support of the CHF and also the picture of my family he has on his group's notice-board! His group had cleared two hours to listen



to my questions and ideas about PLE as well as inviting other experts from the centre. We talked about the current state of research into the biology of PLE, the clinical trial of modified Heparin which they run and future directions which could be examined.

I was very grateful to have the opportunity to have world experts listen to my ideas. We talked about how best to look for a genetic factor for PLE, how best to co-ordinate research and whether there could be a role for novel inflammatory bowel disease treatments in PLE.

Dr Freeze was very grateful for the support the CHF had given his team. Financial support had put him in a position to bid for major grant funding. His contact with Jim Colson, CHF's scientific advisor and Colin Colson's Grandfather, was instrumental in getting him interested in the field.

Dr Freeze put me in contact with Simon Murch, a UK expert in PLE and also drove me around showing me the sights of San Diego!

Children's Heart Fund, Buffalo

I spent another day travelling back east before meeting the Colson family on the last day of my trip.

Tom Colson and I swapped 'heart dad' experiences whilst he took me to see Niagara Falls. We talked about how best to collaborate and how a charity can help research and clinical care.

This was more of a personal visit as my main focus was to thank the whole family. Alasdair's treatment was transformed by treatment only just reported in the research literature. Research doesn't just happen; it takes committed top-class researchers, passionate clinicians and money! Talking to Dr Freeze and Dr Rychik brought it home to me how much the Colson family had inspired them in their work and how much the financial support had meant in getting research off the ground. They made a difference for my son.

You can read more about my trip by visiting phizz-ple.blogspot.com

He's not really retiring!!

Some of you may know that Bill Brawn will be retiring from full-time work this year.

Don't worry all you Mr Brawn fans he will in fact be continuing at the hospital for four days a week for sometime to come.

Protein Losing Enteropathy (PLE)

Protein Losing Enteropathy means that protein is not being absorbed from food in the gut. We all need to absorb protein because it helps with the growth and repair of every part of our body. Children with heart conditions need protein to help them grow and to help them repair after treatments.

PLE can be a side effect of Fontan surgery. It happens in about 5% of patients and normally does not occur until some years after surgery.

The signs of PLE are fluid collection in the abdomen so an enlarged tummy but no weight gain anywhere else, fluid in the feet, increased breathlessness, loose bowel movements.

This complication happens because of a rise in blood pressure in the gut. Once the Fontan procedure has been done the body's one pump works to push oxygen filled blood out of the heart and around the body where all of the oxygen is used to make energy. The used blood then returns to the lungs, to pick up new oxygen, it flows there without its own pump. In some children, especially those that have slow movement of blood through the lungs, there is a congestion of blood around their gut. This congestion affects the take up, absorption, of protein.

The treatment of PLE is much discussed by cardiologists. A mixture of treatments are used as to date no one treatment is preferred.

In the article left, medication is discussed in some detail but there are also interventional treatments.

Opening up the lung blood vessels by ballooning them and then placing a metal mesh stent in place to keep them open creates a better blood flow through the lungs thus relieving the back pressure to the gut. These procedures can be done during a cardiac catheter so no need for surgery.

Another solution can be to re-open, stretch or create a fenestration between the Fontan into the heart. This can be done during a cardiac catheterisation. When the Fontan circulation is created blood returning to the lungs flows either through a tube, outside the heart, to the lungs or a wall is created within the heart to divert the blood from the lower body straight to the lungs. If the pressure rises in this tube it creates back pressure that affects the liver and the gut. If a hole, fenestration is created it acts as a pressure valve that allows some blood to re-enter the body circulation and divert from flowing to the lungs. This takes away from the lung circulation so relieving the back pressure.

If you have further questions about PLE and the range of treatments available, please talk to your cardiologist at your child's next appointment.



Mr William Brawn

Bill is a great friend of LHM. Not only did he pioneer the treatment of Hypoplastic Left Heart Syndrome in the UK but he also has been one LHM's Vice Presidents for many years, a role which has enabled him to raise the needs of LHM children and families in many areas.

We are currently collecting best wishes for a card.

If you would like a short, sticker size greeting to be added to his card please either give us a ring

on 0121 455 8982 or email us at info@lhm.org.uk



Feature

Last summer we sent out a questionnaire to all members to get your feedback on our current services. Below is a summary of your replies.

Written by
Isabel Baumber

Last summer, we sent out a questionnaire to all members to get your feedback on our current services and to help us plan for the future. We are extremely grateful to everyone who completed the questionnaire - your views and opinions are really important to us, for planning future work, and they also help us when we are seeking funding. Please contact the office if you'd like to find out more detail about the results of this questionnaire and how we are using them in our work.

We received 72 detailed replies, from members in different parts of the country, and from families with different age children. As well as the information we gained, we were lucky enough to receive many offers of help - people wanting to learn more about different volunteering roles within LHM.

Ideas for the future

We were particularly looking for feedback about the concept of the Journey to Independence, a way of linking different services with awareness and the need for fundraising.

The concept was well understood and well liked by members.

"[I] love the picture of [the] winding road, [it] describes life with a HLHS child perfectly. It is a journey, sometimes smooth, sometimes bumpy! Blind corners and new adventures, end point is unsure."

"There are journeys and journeys - hardly a stroll in the park on a summers' evening - more of a hike over the hills with the weather closing in behind you!"

We also asked for feedback about ideas for new services, which we are now looking to fund. "I think your ideas at all stages are appropriate to the children's and parents' needs".

The antenatal service expansion ideas were well received. "I like the ongoing follow up and support for whatever path has been chosen." Members asked us to make sure a realistic picture of life was given, balancing hope against living with constant worry.

The proposals for 0-2 year olds were for a feeding DVD and a pack to support

parents when going home from hospital with their baby for the first time. Both will meet a need which members readily identify with. "Getting home from hospital is very very daunting."

For 2-5 year olds, families want the opportunity to "bring them [the children] into the circle of understanding" giving the benefit of "preparation and information [...which] reduces stress and anxiety."

Responses about the plans for 10-14 year olds came from parents of children of all ages, including very young children. A huge amount of concern amongst parents of younger children was mentioned, for example "This is a period I'm very concerned about - that he will learn to be responsible for himself - resist typical teenage temptations, and more info can only help." and "I am terrified of the thought that [name] will start smoking, drinking, etc, so if she was part of a community where heart disease is not 'abnormal' then hopefully she will feel able to make better choices for her health and interact with some like-minded peers."

All the detailed comments made about proposed services will be included in our project plans.

Impact of our services

We were really delighted to hear your feedback about how much LHM had helped you at various stages of your lives, especially at the time of diagnosis and also when seeking information about your child's condition.

At diagnosis

"I had no ideas what HLHS was until I found the LHM website, it had drawings explaining what my son's heart looked like."

"Forums were so valuable and kept me going during the pregnancy."

"LHM had a huge impact on our lives. The packs that were sent to us had the answers we were looking for. Information was sent very quickly."

As you looked for information

"The LHM info is the clearest we could find."

"As LHM is specific to single ventricle, the information is tailored

and totally relevant."

As you learned about the challenges with feeding, development, schooling and social support

"I rang yourselves to ask if you had any advice about [name] feeding, and you sent me an amazing pack."

"I often use the message boards for advice about school, etc. Don't know what I would do without it."

"Everything I needed to know was on the website, I could email or phone LHM with any questions."

As they move through their teenage years

"I was pleased that [name] could finally meet other children with the same heart condition as him and had someone to talk to...", "Work with LHM has boosted [name]'s confidence. It has helped us to understand the limitations she faces and the future medical issues."

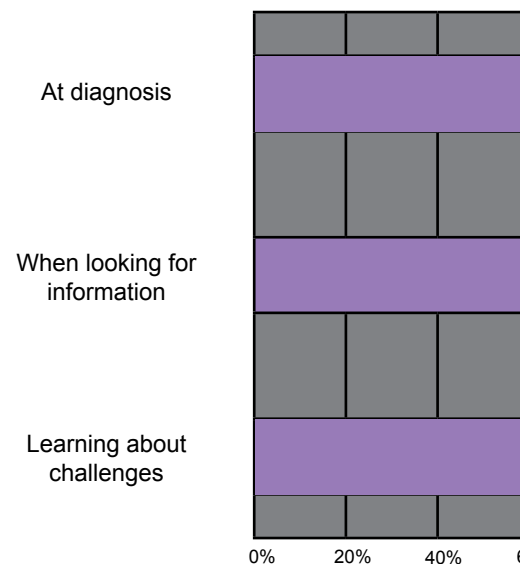
"You helped me feel normal, all the problems we have experienced have been 'normal' for a heart child."

"It is like my extended family. The friends have become good friends because they truly understand what it feels like to have one of these precious children."

"Friendships with other families in same situation and all office staff, trustees, etc, feeling like part of our journey."

Awareness

Here we presented a number of ideas for raising awareness of single ventricle heart conditions and of the work of LHM. These ideas including increasing the visibility of LHM in hospitals, LHM working as a voice for change, working to grow our profile, and seeking a celebrity to help us build awareness.



These ideas were almost universally endorsed. In the answers to these questions, your frustrations about lack of understanding came across, and also about living with a hidden condition. "Every person we come across [...] always assumes it's a hole in the heart - if only!"

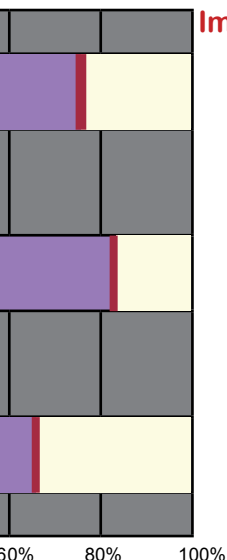
The question about whether you would be happy for us to use scars as a visual factor to explain the children's journey was received fairly positively, but there were some more mixed reactions. Three-quarters of the replies were positive. "Big emotional impact, and quite shocking to see on a child." "Every scar tells a different story and journey, and who better than the ones with the scars to tell you how it is!", "As cardiac children appear normal, I think it's important to show just how serious single ventricle heart conditions are."

Concerns included that it isn't specific to single ventricle conditions and it "suggest[s] a past event", Families were also concerned that the extent of the children's problems would not be communicated simply using the scar as a visualisation. "The children are much more than scars, which are the least of their problems. [...] The real problem is that their difficulties are usually not obvious, therefore can be forgotten." These concerns will be taken into account as we work to develop awareness plans.

What does this all mean to LHM?

We are so very grateful to you all for your replies and sharing your personal experiences. We will use this information as we develop our new project plans, and as we continue to seek funding for these projects. We have already used some of this information as part of our presentation to Glaxo SmithKline and the King's Fund, where we were shortlisted for an Impact Award in the autumn of 2010. The results were announced at the beginning of March this year, and we were delighted to have received a Highly Commended award. We could not have done this without your support - **thank you.**

Impact of our Services



Base 67, 70, 70



Direct Debit Form

If you would like to make a donation to Little Hearts Matter please fill out your details below and send to:

Little Hearts Matter, 11 Greenfield Crescent Edgbaston, Birmingham, B15 3AU

I enclose the sum of £ _____ cash/cheque made payable to 'Little Hearts Matter'; Date: ____/____/____

or:

I wish to make a regular donation of £ _____ per month from by Bank or Building Society account:

Bank Name and Address:

 _____ Postcode _____

Sort code: _____

Account no: _____

Date to start: _____

Name: _____

Signed: _____

Email: _____

Payee details:

Little Hearts Matter
 Barclays Bank Plc
 Colmore Row
 Birmingham
 20 - 07 - 71
 6304 6257

Thank you

We greatly value your support and would like to keep you informed through marketing literature by post or email about our work or events.

Please tick the box if you would prefer not to receive marketing literature.



Add 25% to the value of your gift simply by filling in your full name, address and postcode - we'll do the rest (please ensure you tick the relevant box):

I am a UK taxpayer - I want Little Hearts Matter to claim back the tax on this, my enclosed gift, from the Inland Revenue

I am a UK taxpayer - I want Little Hearts Matter to claim back the tax on this and all future donations until further notice.

Name: _____

Address: _____

Postcode: _____

Note: You must pay tax on your income at least equal to the amount Little Hearts Matter will reclaim.



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



- TOP LEFT: Akai Nounananou-Rodgers (5) celebrating her 5th birthday.
- TOP CENTRE: Grace Lee (5) and her brother Harry having fun at the beach.
- TOP RIGHT: Ellis Holtom (1) celebrating his first birthday, and looking like he really loves his zebra!
- MIDDLE RIGHT: Morgan Davies (3) just about to set out for his first morning at nursery school.
- MIDDLE CENTRE: Naomi Baker (1) celebrating her first birthday and concentrating on the task in hand - opening those birthday pressies!
- MIDDLE LEFT: Sarah Haselgrove (18) showing off her huge 18th birthday cake.
- LEFT: Samuel Robinson (4) enjoying his swimming lesson.



A Member's Tip

Free Carer's Entry to National Trust Properties

Lisa works for the National Trust and sent this in via our website message boards.

All National Trust (NT) properties allow free access to the carer of a disabled person. Additionally if you are sick of turning up and having to explain you are a carer (especially when your child doesn't look disabled) you can contact the central office of the NT for an 'Access for All Admit One Card' this is issued in the

name of the disabled person and so can be used by any carer accompanying that person, and just show it on entry (but you don't need to have one to gain free access).

Contact details for the Access for All Office are: - The National Trust, Heelis, Kemble Drive, Swindon, Wiltshire, SN2 2NA, telephone: 01793 817634, email: enquiries@nationaltrust.org.uk

There is a special NT handbook for Access for All, which details special facilities and access issues, this information is available on the NT website (www.nationaltrust.org.uk)

The NT for Scotland is a separate organisation, so Lisa couldn't comment on their policies, but it does cover England, Wales and Northern Ireland.

Barnaby's Big Adventure

Well, where hasn't Barnaby been in the last few months? His tux dry cleaning bill is through the roof and he even invested in a new pair of shades for all the sun he has soaked up - with t-shirt and teddy sunscreen of course - he's very sun safe.

His first big trip was with expectant grandparents Christine and John Highams who kindly offered to take him with them on their tour around Tonga, Australia, New Zealand and Hong Kong. Booked several years in advance, Christine's grandson Zac (HLHS) was due whilst they were away so she took Barnaby to spread the word about LHM and so she could show him the photos when he was older.

Barnaby had a fantastic six weeks. In Tonga he not only enjoyed the scenery but a boar ride and a bit of snorkeling; in Australia he took in the sights of Sydney Opera House, Bondi Beach, did a little surfing and went on an outback adventure meeting sloths, crocodiles and a koala (whose miniature cousin stowed away in Barnaby's backpack and is now living in our office - shh, don't tell anyone). Then in New Zealand and Hong Kong he enjoyed more sun, sea and sand before having to return very suddenly to the UK following news of baby Zac's birth.

Baby Zac Abram bravely battled with his condition and a further complication to his heart for six hours but sadly passed away the following day. Barnaby stayed with the family during this terrible time and, as he was looking for a middle name, decided to become Barnaby Zac in memory of such a special little boy and their family. Look out for his new name on his passport.

But with sand still fresh between his toes, Barnaby was restless again so he got suited and booted and headed off to meet Hollie Raffo, a little girl with HLHS in Staffordshire. She very kindly took him to her mum and dad's wedding where he got to drive the limousine and play with lots of children at the reception. He also met the Martins who wanted to take him with them and their Austin Sevens club to the Isle of Wight in September. It's in his diary! Pictured are Barnaby with the bride and groom Kirsty and James, and little Hollie.

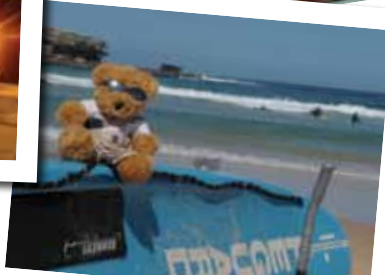
Before he had time to draw breath, he was off to yet another wedding in Wales with Auntie Heidi and Uncle Carl. Their niece Madeline Williams, who has Tricuspid Atresia, very kindly invited him along to join her as bridesmaid. Madeline almost out shone the bride in her bright pink dress and Barnaby was very jealous of Uncle Carl who looked very dashing in his uniform, having recently returned from a second tour of Afghanistan.

He enjoyed a quiet Christmas before whizzing up to Scotland to stay with Daniel Butler and family. The Butler family normally reside in Switzerland so, not only did Barnaby get to enjoy the sights of Edinburgh, they then took him home with them - two holidays in one!

Highlights included mooching around Edinburgh with Daniel and Auntie Phyllis, a trip to the beach (sunglasses weren't needed this time though) and then back to Switzerland for some skiing - his first time on the slopes.

From Barnaby and the LHM team we would like to say a huge thank you to the Highams, the Raffos, the Williams and family and the Butlers for taking such good care of him.

If you'd like to share your trip with Barnaby email info@lhm.org.uk with when and where you are going away and we'll see if he can make it.



In Tonga, Australia and New Zealand



Holly, Kirsty & Jim Raffo



Madeline Williams with Auntie Heidi and Uncle Carl



In Scotland and Switzerland with the Butler family



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Noticeboard

Big Fun Run

For the third successive year, Little Hearts Matter is proud to be part of the Big Fun Run, a series of charity run events held in towns and cities across the UK. All events are 5k and people take part to support a number of different good causes.

Last year we had over 50 people take part across various events raising over £2,000. This was a fantastic achievement and it would be fantastic if we could match or even beat it this year.

Sign up and meet up! Several of you told us how you found the Big Fun Run a great chance to meet up with other families local to you and in Glasgow a whole group met up to run together.

Once you register we can let you know if anyone else is running for LHM in the same event.

Fun Runs

Liverpool	Sat 6th Aug	Sefton Park
Sheffield	Sun 7th Aug	Rother Valley
Leeds	Sat 13th Aug	Roundhay
Manchester	Sun 14th Aug	Wythenshawe
Derby	Sat 20th Aug	Darley Park
Coventry	Sun 21st Aug	Memorial Park
Cardiff	Sat 27th Aug	Bute Park
Milton Keynes	Sun 28th Aug	Willen Lake
Dundee	Sat 17th Sep	Camperdown
Aberdeen	Sun 18th Sep	Hazelhead
London	Sun 2nd Oct	Victoria Park
Edinburgh	Sun 23rd Oct	Holyrood
Glasgow	Sat 29th Oct	Bellahouston



To find out more or register go to:

www.bigfunrun.com

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 Pack
- Preparation for Hospital Booklet
- Preparation for Hospital Pack - to borrow for a period of 3 weeks.
- Benefits - a guide for parents
- Feeding at Home - a guide for parents.
- Early Years and Infant School Education Booklet
- Junior School Education Booklet
- Transition to Secondary School Education Booklet
- Dental Care
- Fundraising Pack

DIARY DATES

On Your Marks For Little Hearts

Sunday 22nd May 2011
Worthing Sea Front

On Your Marks For Little Hearts

Sunday 25th September 2011
Shugborough Hall, Staffordshire

'LHM Lights of Love' Switch On

Sunday 11th December 2011
Staffordshire

Our Favourite Letter

"Dear Little Hearts Matter. My name is Grace Cunningham. I have raised £50. I hope that is enough money to help the poorly heart children. My fundraising was a big Christmas card and a big money box."
From Joy Cunningham's big sister, age 8 x

