

Little Hearts Matter Newsletter

Summer 2010



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On Your Marks For Little Hearts

Following a successful event at Mote Park we would love you to join us at Shugborough on 3rd October 2010.



We are very excited to be organising our 4th On Your Marks For Little Hearts running event at the beautiful Shugborough Hall in Staffordshire on 3rd October.

Last year we raised an amazing £22,274 and we are calling everyone who is free to join us and help raise £25,000 this year. We had over 200 runners raising a tremendous amount of money to fund the work we do.

Alongside the run we also held a wonderful sports day for the smaller

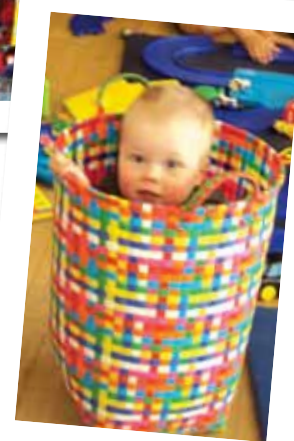
children (with and without heart conditions) who took part in egg and spoon, bean bag races and little runs. There was also a mini fun run for the older children.

This is a real family day out where you can meet up with old friends, and if you are new to LHM this is a great opportunity for you to meet other parents who also have children with a single ventricle heart condition and it's a great day for the children.

We are desperate for volunteers to help with registration, manning supporter stations and generally helping out. Please contact us if you are able to help. Finally, please see Will Goodenough's story on our website and in the latest copy of our youth newsletter, Big Hearts Matter - inspirational fundraising at its best... See you all at Shugborough.

News

Suzie's News



Other events are planned in other parts of the country so keep your eyes peeled for an event near you.

If you would like to get involved in organising an event in your area or you have ideas about what might work where you live give us a ring or email us your ideas. Sadly our network leaders often organise something but few families attend. We would love to know what you would like in your neck of the woods.

There has been a great deal of work on the Safe and Sustainable review of children's heart surgery service this month. We would like to say a huge thank you to Jeremy Glyde from the National Specialist Commissioning Group for travelling up to Burton to update the members who were able to attend the Open Day. I have written up his talk and added details about the next stages of the process on page three.

I have been delighted to be able to join many of you at your fundraising events over the past few months having taken on some of the fundraising activities that Kevin had started before he left us.

The Mote Park runners really gave their all and considering that we only had eight runners at the beginning of February it was wonderful to have 130 runners take part on the day. Their sponsorship money is still coming in and has helped with much needed funds.

I attended a great Dinner Dance organised by Sue Chesworth and her family in memory of her grandson Thomas. Thank you for making me feel so welcome.

I was bedazzled at a Hair, Nail and Body Art extravaganza at Salford College who had picked LHM to be one of their charities of the year

because Jordan Sharrock who is one of their students put us forward. Jordan's brother Joshua is one of our young members, he had to bravely stand up and have his life story told to the audience, almost as brave as heart surgery.

On the evening of Monday 10th May I had a wonderful time at the Amington Brass Band Concert. A mixture of classical, popular and film music had the audience tapping their feet. The band had chosen LHM as their charity as our very own Peter Groves, Deputy Chair and Deputy Treasurer of the charity plays in the band, as does his daughter Charlotte. Peter played the most beautiful solo as part of the evening's entertainment. The band and the audience raised £505 to go towards the work of the charity.



What an exciting year Little Hearts Matter is having. All areas of the charity's work are expanding with more and more members finding us to talk through issues with their children especially about issues at school and with Disability Living Allowance.

We will always try to help wherever we can.

Have you seen our new education books?

Pre-school and Infant School - looks at preparation for nursery and the first steps into mainstream school. It aims to help parents have confidence in letting their children make the move to school.

Junior School - looks at the next step of education and growing independence and begins to look at the step to senior school.

Transition to Secondary School - this is a book to help with the decision process when planning the move to the best secondary school and the things to think about telling the teachers at a new school to ensure that the children can make the most of their secondary school education.

All of these books are free to members, just give us a ring if you would like them. We have also developed an education pack which contains information on formalising the sort of support that can be available in school e.g. Individual Education Plans and Educational Statements.

The Midland Network Group had a summer event that revolved around bugs! It was a great day of sticking, painting, glittering and bug hunting. Thank you to Sally, Vanda and Clare for organising a great event.

Thank you to the band, their musical director Wes Kendrick and the band leader Bob Godfrey for a brilliant evening.

I have spoken at a number of Rotary groups who are looking to support our work so it has been a very busy few months.

I am delighted to pass the fundraising reins over to our new Head of Fundraising Shelagh Paterson.

Shelagh has come to us having worked within business and fundraising for many years. Her last position was that of Head of Corporate Fundraising with Age Concern so she has a wealth of knowledge working with companies of all shapes and sizes.

To succeed in meeting the income targets for this year she will need your help so have a look at her page in the newsletter where she will talk a little about her plans for fundraising for the remainder of the year.

My last piece is to say a big thank you to the team in the office and many of the Trustees. The beginning of the year has been really busy but losing Kevin has meant that all hands needed to be on deck to make sure that we could keep everything going. All of the team have helped out in one way or another. Thank you all very much.

I hope that you all have a chance to enjoy some very good weather over the summer, what with a poor rate of exchange with the Euro and the Dollar, ash clouds stopping flights and an economic crisis it would be great to have a really good summer at home.

Suzie Hutchinson
Chief Executive

Heartfelt Plea

Over the past couple of weeks I have been visiting the LHM website and message boards. We still have visitors to the boards but we have very few positive stories being shared. When new families find the site it can be really supportive if they receive messages from as many people as possible so that they get a broad view of what life with a child who has a heart problem can be like.

I am sure that you remember when you first heard that your child had only half a heart you were desperate to hear from other parents so that you felt less alone. Could I beg that when any of you go on-line to facebook your friends that you just quickly pop over to the LHM website and give us an update on how your children are. You can of course also leave messages on our facebook site but many new members find us at www.lhm.org.uk first so they miss out on positive news.



LHM In The Media



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

The year 2010 has proved no less busy for Little Hearts Matter and many of you have helped to raise awareness of the work we do to support others. I'd like to highlight just a few.

Tim York's fundraising efforts on behalf of his son Solomon featured in his regional media and we currently have a national news agency interested in his story.

David Simpson and his son Alasdair featured widely throughout the Kent media after meeting with children's author Harriet Goodwin at our Open Day in March. Alasdair has become a huge fan of her work and Harriet is keeping in touch with him.

Johnstone.

Many of you will be well aware of the developments around Safe and Sustainable Cardiac Services. During April we had to react quickly as news was released to the media. Little Hearts Matter was ready to react instantly with a press release. We secured some high profile national coverage which included the Daily Mail, Nursing Times, PA Community Newswire and HealthNews (both online national newswire services) and the Journal in Newcastle. The issues will continue to appear in the media and we are ready to respond quickly to ensure your voices are heard. We will keep you up-to-date as it progresses.



Alasdair Simpson (9) pictured left meeting book author Harriet Goodwin

Sadie and Ruby, alongside generations of the Arora family, took part in the Mote Park Run. Their story was picked up widely in the press.

Andrew Diamond is planning a sponsored bike ride later this year and we hope to highlight this alongside his family story shortly.

A BIG thank you to you all! Without your support we wouldn't have achieved this fantastic coverage.

As we go to press, our fundraising partnership with UKBPS is to be announced alongside pictures taken at the Open Day with Thomas Hooks, Matthew Baumber, Chloe Summers and her sister Leah

We are looking to recruit some high profile Celebrity Ambassadors and a Fundraising Patron to help raise our profile and support the charity. Please do let me know if you have any ideas on who might be appropriate and if you have any links.

Finally, Gwen is now working alongside me on promoting a number of your fundraising initiatives with news releases from the office. Please do keep us both in touch with your news so we can get the word out there about all the wonderful things you do for us.

Wishing you a happy and hot summer!

Feature

Below is an update of the review of surgical services and a list of dates of Parent Engagement Meetings.

Written by
Suzie Hutchinson

Over the past few months the LHM team has been working with other children's heart charities to ensure that the voice of the child and parent users of hospital services is heard as the review of surgical services is conducted. The Children's Heart Federation have taken that collective voice to the Specialist Commissioning team responsible for the review.

Getting parent priorities into the assessment process

The assessment panel led by Sir Ian Kennedy begins its review of each of the surgical units in May and June. CHF has argued strongly with the Safe and Sustainable organisers that the panel should include a parent with current first-hand experience of the children's heart surgery service. We want to ensure that the line of questioning at each unit digs beneath generalities to the specifics of what makes for an excellent experience for heart children and their families. Regrettably, the call for a current parent on the panel has not been met but the team has responded by giving an opportunity for a small group of parents to brief the panel before they start the review process.

CHF have drawn together a small group of parents whose children have a range of clinical and support needs and are treated at different units. They met with the assessment panel on 20th May. Louise Hall and Isabel Baumber represented Little Hearts Matter as they have a huge experience of working within the charity and have helped to build the support and information services that LHM provides. Their role will be to look at the national service provision for the surgical treatment of single ventricle heart disease. They will not be representing any one unit but the whole LHM membership.

Little Hearts Matter has submitted three main areas of concern to be put forward at the briefing meeting.

1. Highly Skilled Surgical Experience

The treatment of children with single ventricle disorders is complex and requires skilled and experienced surgery and post surgery management. With high learning curves associated with the treatment of conditions like Hypoplastic Left Heart Syndrome, how will the tertiary units ensure that future treatment for children with these life threatening conditions will be offered by the most skilled team in the country and avoid unnecessary mortality?

2. Antenatal Services

The antenatal diagnosis of single ventricle heart disease is the only initial diagnosis that offers parents an opportunity to make a truly informed

treatment decision.

How will the tertiary units ensure high levels of training for district general sonographers, clear referral paths for complex disorders from district general to specialist diagnostic services and then on to treatment teams?

How will the specialist diagnostic teams ensure that they remain up-to-date with current treatment outcomes and lifestyle issues for children enabling them to offer accurate, unbiased information and support to families and how will these teams ensure that the national treatment and termination rates are audited and analysed accurately?

How will the diagnostic team ensure that families can access unbiased support and information mechanisms other than those of the fetal team before their final treatment decisions are made?

How will the fetal medical team ensure that they are seen as an integral part of the regional cardiac service working with all congenital cardiac clinicians to ensure clear treatment pathways and consistent information and care plans?

3. Integrated Support

Children with non-correctable cardiac conditions whose whole life is affected by their heart disorder. The need for highly skilled surgery, although life saving, is only a small part of their world. Every day is filled with challenge, development is affected, mobility, education, the opportunity for an independent life.

How will medical teams ensure that families not only have access to world class surgery but support with medical care both in the tertiary centre, cardiology unit, local district hospital and the community?

How will the teams communicate added need within the home, throughout education, with mobility and social care? What plans do the team have for the role and expansion of the cardiac liaison sister service?

How will the team ensure that children and their families have access to support or information services that will help them cope with the emotional ride through life with congenital heart disease?

How will the team develop partnerships with organisations that can offer added care such as parent-to-parent support, patient and family condition and lifestyle information, youth support and information and parent-to-parent bereavement support?

The Children's Heart Federation are developing a DVD with short comments from parents about the current and proposed service that we can feed into the Safe and Sustainable process. The DVD is being filmed as this newsletter goes to print, and we really hope some of our LHM families have seen the information about it on the website and been able to participate.

Parent Engagement Events

The Safe and Sustainable team are holding a series of parent events where they will collect the views and concerns of parents and older users of the service.

Some of you have submitted your names to Jeremy Glyde following his presentation at the LHM Open Day in March. If you have not but would like to be considered for a meeting in your area contact Jeremy Glyde at www.eventsforce.net/specialisedcommissioningevents

Telephone: 0845 363 1478

The events are an opportunity for parents to communicate directly with the commissioners responsible for children's heart care services in their region. Through small group discussions and question and answer sessions, parents will have a chance to share their views on which features of the current heart care services work well and which aspects of care need to be improved in the children's heart care service of the future. The events will include a presentation on the proposed model of care outlined in the Safe and Sustainable 'Need for Change' document.

Members of the CHF team and Suzie from LHM will be present at the meetings.

Please take part and encourage other heart patients and parents to do so, this is a time when your views can influence service developments.

Dates for NHS Safe and Sustainable Parent Engagement Events

Leicester	Wed 9th June, 5 - 8pm	Glenfield Hospital
Birmingham	Mon 14th June, 6 - 9pm	Maple House
Oxford	Tues 15th June, 5-8pm	The Oxford Centre
Warrington	Wed 16th June, 6 - 9pm	Haliwell Jones Stadium
Leeds	Thurs 17th June, 5.30 - 8.30pm	Leeds Town Hall
Southampton	Mon 21st June, 6 - 9pm	Southampton General Hospital
Plymouth	Mon 28th June, 12 - 3pm	Plymouth Postgraduate Medical Centre
Bristol	Tues 29th June, 9 - 12pm	Cribbs Business Centre
Newcastle	Tues 1st July, 6-9pm	St James Park Stadium
London	Sat 3rd July, 10.30 - 2.30pm	Science Museum



Spotlight On...

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

Written by
Isabel Baumber

Please don't hesitate to contact the LHM office if you have any queries about any aspect of education. We have booklets 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.

Education

Individual Education Plans or IEPs

Some children with single ventricle heart conditions need support with their education, and this support may be documented through the use of an IEP. The IEP is a tool to help with planning, teaching and reviewing, and should be developed in partnership between the school, parents, any relevant professionals and the child themselves where appropriate. A small number of key targets should be agreed to help your child achieve overall educational progress. IEPs can help children achieve good progress in school without necessarily needing to lead on to statutory assessment and statementing. The different strategies in an IEP may give children all the help they need to achieve their potential.

The IEP should detail what the support is, how it is to be provided, and how often these additional or different activities are to take place. Ideally

IEPs should be reviewed every term.

It will help teaching staff to understand and meet your child's needs better, it will reassure you about what support is in place and what progress is being made, and it is vital to identify if different or additional support is needed in the future. Any request for statutory assessment

would usually need to include reference to progress against IEP targets, and support already provided through an IEP.

Formats vary, but the following might be included.

Name, class details, plan date, etc		
Targets	Action (resources, what, who, teaching strategies)	Outcomes at review
Target 1 explanation (including success criteria)		
Target 2 explanation		
Target 3 explanation		
Target 4 explanation		
Details of support to help reach targets (small group, 1:1, time, who will deliver support). Details of external professionals involved.		

Benefits

Carer's Allowance

Carer's Allowance is a benefit which isn't as well publicised as Disability Living Allowance (DLA), but can be quite helpful for some families.

If your child gets the personal care component of Disability Living Allowance at the middle or highest rate, and you spend at least 35 hours a week caring for them, you may be eligible for Carer's Allowance.

Unlike DLA which is not means tested, you cannot get Carer's Allowance if you earn more than £100 per week after certain deductions have been made. These deductions are known as 'allowable expenses' and are for things like:

- some National Insurance (NI) contributions
- Income Tax
- half of any money you pay towards personal or occupational pension schemes
- other expenses you have to pay because they are a necessary part of your job (this

is likely to be most relevant if you are self-employed)

After allowing for these things, you are allowed up to half the rest of the money you earn to help meet the cost of paying someone else but not a close relative) to look after a child or children while you are at work.

The weekly rate is currently £53.90. You may have to pay tax on the amount you receive. For each week you receive Carer's Allowance you will normally get a National Insurance (NI) contribution added to your NI record.

If you are not working or if you are employed in a job which clearly pays less than the £100 a week after deductions, it should be a straightforward process to apply for Carer's Allowance, provided your child has the DLA personal care component at the middle or highest rate. However, if you are self employed and your income varies, the application process involves lots of paperwork (for example, I had to fill in details of my income and expenses every month for a year).

Further information can be found on the

government website www.direct.gov.uk - look at the 'Caring for someone' section. You can also call the Benefit Enquiry Line on 0800 88 22 00.

Carer's Credit

Carer's Credit has been introduced from 6 April 2010. It is a National Insurance Credit which helps carers build up qualifying years for their pension.

You don't need to apply for this if you get Carer's Allowance or Child Benefit for a child under the age of 12 - you will already be getting these credits.

If you don't get Carer's Allowance and your child is 12 or over, you need to apply for Carer's Credit. Your child must receive the personal component of DLA at the middle or highest rate or you can get a healthcare professional to sign a document called a Care Certificate.

Visit the government website www.direct.gov.uk for links to the application form and further information.



Medical

The article below looks at the use of pacemakers for children with congenital heart conditions.

Written by
Catherine Renwick
Paediatric Electrophysiology Nurse Specialist
The Royal Brompton Hospital



Implantable pacemakers are commonly used now for children with congenital heart disease for a number of reasons that will be explored below.

The use of pacemakers dates back to 1899 initially with the first attempt to apply electrical impulses to a human heart to produce a ventricular contraction. By the 1960s these attempts to pace a human heart had evolved into the first implantable pacemaker that continues to be used to this day in a more technologically developed model.

What is an implantable pacemaker?

A pacemaker is a device that is capable of delivering an electrical impulse via specialised pacing wires connected to the pacemaker generator and the patient's heart to regulate the heart rate and rhythm. The pacing wires can be placed via a large vein in the chest into the heart or can be attached to the outer section of the heart. The pacemaker is battery driven and contained in a titanium shell. The

lead is also made of a metal alloy, but it is insulated by a polymer such as polyurethane. Only the metal tip of the lead is exposed to the lining of the heart. All the materials used are safe and are capable of lasting many years within the body.



The pacemaker usually is placed in the chest however in some children following cardiac surgery is placed in the stomach.

Why does a child need an implantable pacemaker?

The heart is a muscle divided into four chambers (left and right atria and ventricles). Blood is pumped from the heart to the lungs and to the body. In order to pump blood through the heart, specialised cells emit impulses which travel through the heart muscle like a wave, causing the heart to contract (squeeze). These specialised cells make up the conduction system which is responsible for this movement of electrical impulses and generating a heart beat.

The heart beat is initiated by the heart's natural pacemaker, the sino atrial node which sits high in the right atrium. The impulse is

Jamie's Story

I was enjoying my first pregnancy in the spring of 2001 when the routine five month scan revealed something which put all my plans on hold. The enlarged heart chamber spotted by a doctor was diagnosed by cardiology experts as Pulmonary Atresia, a condition in which the valve closes up, they told me immediate surgery after birth is required to open it.

I found myself in a whirl of weekly scans, tests and sleepless nights. I was warned that babies with heart defects are more likely to have Down's Syndrome, so I endured the agony of an amniocentesis, with its increased risk of miscarriage. I did learn that the baby was a boy so the enjoyment of that mystery was gone. I always thought I was having a boy but I

guessed he would be healthy without serious complications.

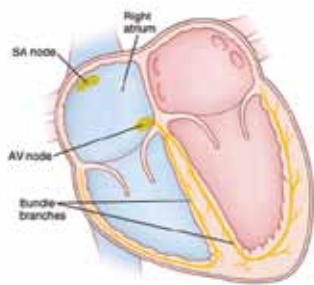
Almost six weeks after the initial diagnosis the doctors explained that the valve to his pulmonary artery was starting to close and that his heart circulation was failing. They told me they would have to perform a caesarean at 31 weeks as Jamie was at serious risk of not surviving, but it also meant that he would be more than two months premature, his lungs would not be well developed and he might be too weak to withstand an operation. They offered another option which would hopefully allow me to carry him for another month and enable him to grow and gain strength.



Jamie aged three months



synchronised through conduction tissue within the heart. As the impulse passes through the atria the atria contract and push blood down into the ventricles. The atria then relax and begin filling with blood again ready to start the process again. The atria and ventricles are usually electrically isolated from each other therefore the impulse can only proceed down to the ventricles via the atrio ventricular (AV) node. The impulse carries on down through the bundle of His to the right and left bundle branches (in the ventricular septum which separates the right and left side of the heart) and finally reaches the purkinje fibres which are spread throughout the ventricular muscle. This movement of impulses through the ventricles causes them to contract and push blood out of the ventricles to the lungs and body. The ventricles then rest and are ready to start this process again. This is called normal sinus rhythm.



Any interruption of these impulses can cause the heart to beat too quickly or too slowly. A permanent pacemaker is usually required when the heart beat is too slow.

In patients with congenital heart disease changes to the heart's rhythm can develop during and after surgery. The surgeons may be operating in very close proximity to the child's own conduction tissue which is not visible to the naked eye. Attempts are made to reduce the likelihood of damage to the conduction tissue but this is not always possible. In some cases the surgical incision

irreversibly damages the conduction tissue. Bruising and swelling during the surgery may temporarily cause damage that has the potential to recover however in some cases complete recovery may not occur.

Pacing the heart can be achieved through placing leads in or outside either the atria/ventricles (single chamber pacing) or both (dual chamber pacing). The position of the leads in the heart indicates which chambers are being paced.

The pacemaker takes over the work of the damaged or diseased conduction tissue to ensure a normal rhythm is maintained and the heartbeat remains at an appropriate rate for the child.

A common heart rhythm disturbance caused during surgery is third degree heart block. This involves damage to the AV node and prevents impulses passing from the atria to the ventricles and causes the heart to beat too slowly. The use of a pacemaker in this instance with the placement of a pacing wire in the ventricle is to ensure that the ventricles beat at the same rate as the atria to ensure a sufficient heart rate and adequate amount of blood is pushed out from the heart. This is known as ventricular pacing and requires only one lead to be placed in the heart.

Disease of the conduction system may also be seen in some patients with congenital heart disease and despite a good surgical outcome, deterioration in the heart rhythm may be noticed over time. Sinus node disease which causes progressive slowing of the heart rate and is seen in some patients requires implantation of a permanent pacemaker.

A pacemaker is usually implanted under general anaesthetic during the same admission for open heart surgery or as an isolated admission. The child should be able to go home the following day or once they are well recovered from cardiac surgery.

What can my child do once the pacemaker is fitted?

Those children living with a pacemaker generally can lead as normal a life as possible and should not be discriminated against because of the pacemaker. They should be encouraged and able to participate in physical exercise however should avoid contact sports which could damage the pacemaker or pacing leads. Damage to the pacemaker or leads may result in them requiring replacement and further admission to hospital.

Children with pacemakers need to avoid airport security devices and will be given an ID card when the pacemaker is fitted. You can show this at the airport to avoid walking through the device.

Magnets can be used in school however should be held at arms length and not held directly over the pacemaker as this affects the settings of the pacemaker. Mobile phones can be safely used however should be used on the opposite ear and carried in the opposite chest pocket to the pacemaker site.

For further information about suitable electrical equipment you should talk to your child's cardiologist or pacing department.

Follow up with a pacemaker

Follow up is usually in the pacing department approximately 4 - 6 weeks after initial implantation and this involves checking to ensure the pacemaker battery has plenty of life left (estimated in months-years), that the pacing wires are not damaged and working, to establish how much of the child's conduction system is working and how much is the work of the pacemaker. These checks are all carried out as an outpatient with regular follow-up with a cardiologist to oversee any problems which may arise. Follow-up will be life long and replacement of the pacemaker will be planned according to the findings at each pacing check.

This was pioneering surgery and had only been successfully done once before in Australia. They gave me a week to decide but I felt that if it allowed Jamie to grow stronger I had to do it. They explained that there were a lot of risks.

Thank heavens the operation was a success and Jamie was delivered on the 5th June, only five weeks early. He was taken straight to intensive care and another operation at 48 hours old. He spent a lot of time in hospital, he was on oxygen and spent several occasions on PICU with collapsed lungs and other problems. I remember our first Christmas at home, Jamie had just come out of hospital but was taken ill, we thought he would be ok but by Boxing Day he was in intensive care and in hospital for months. It was a very hard time for Jim and I, it's so hard to explain what it is like to spend so much time of yours and your baby's time in hospital.

When Jamie was 18 months old the doctors told us that his pulmonary valve was failing and that he needed surgery to replace it and take down the shunt that had been put in when he was born. We were upset that we had to go down this road but if it would make Jamie feel better and prevent him becoming so ill and weak we would have to go with it. When the day arrived I couldn't go down to the anaesthetic room so Jim went. I was too upset, I knew it was a big operation and couldn't face saying goodbye down there so I gave him a big kiss and said goodbye on the ward. The operation took about five hours. When I saw him on PICU I was shocked and upset, he had wires everywhere and big cut down his chest.

The Royal Brompton staff were amazing and put Jim and myself at ease, but within three hours Jamie went into heart failure. We were standing outside the room when suddenly the blue light went on and all the

medical team were in his room performing cardiac arrest procedures. I have to admit, I lost the plot. Jim managed to calm me down and in the end everything was ok. I will never forget the stress of seeing your child go through their first open heart surgery. Within a week Jamie was out of PICU and on the ward and a couple of days later he was discharged.

All went well for a while, Jamie was growing and Jim and myself were trying to lead as normal a life as we could. During this time I became pregnant with my second child. Then when Jamie was 2 years old we went for our check-up and they told us that Jamie's homograft had failed and he needed his valve replaced again and because his heart was enlarged on the right side he would need this reduced. The doctors told us he would need another open heart surgery. This time we were more prepared even though I was seven months pregnant during the whole ordeal.

Things went back to normal and I gave birth

Medical continued...

to Jack who was 100% fine with no heart complications. In 2006 Jamie's health started to fail and we had many occasions where I would rush him to our local hospital A & E with an irregular heart rhythm and being blue lighted to the Royal Brompton. He was put on drugs to try and regulate his heart rhythm.

We were told that his heart was failing and that we had two options, radical surgery and a pacemaker or a heart transplant. They wanted to consult with their colleagues at Great Ormond Street hospital to see which option they felt was best. Great Ormond Street agreed they should do the surgery. I have to say this period of waiting for a decision was possibly the worst time for Jim and myself, we could not sleep or concentrate



on anything. Once they had made the decision they called us in to talk through the procedure. As this had never been done before, he could not offer us any success rate. We trusted our surgeon so agreed to proceed. It is quite amazing how much trust you can put in one man, but we did and we knew if anyone could achieve a positive result it would be him. He said that he would cancel all his cases and it would take place in two days time. The Fontan procedure is normally carried out in two stages but due to Jamie's deteriorating condition doctors advised it should be done in one go. Also due to his rhythm problems he would need a pacemaker fitted to regulate the heart. He was going to have to attach the wires to the outside of the heart as he didn't have nerves to put the wires in. This was all pioneering and had not been done before. The day of the operation is etched on my memory. We were told surgery would take about six hours but it was more like eight. There was nothing we could do but wait. When the consultant finally called, he told us it had been a success, we were so relieved.

When we saw Jamie in PICU he looked ok and I thought gosh that went well. The

surgeon explained we needed to give him time to adjust to the surgery and the total change in his blood flow etc. We spent two months in PICU and there were times that Jamie almost didn't make it. One particular time he got septicaemia and was very, very unwell. You could also see the doctors were very worried and at one point I just broke down over Jamie, the doctor took my hand and gave it a big squeeze and I had to leave the room.

They decided to drain his lung, and within minutes he had gained colour and lots of stuff drained from his lungs. I think this was the turning point and he began to get stronger and better. He was put on Warfarin which became a bit of a nightmare as he had a massive phobia of needles and when they took blood to check the levels it was a very distressing time.

We spent Christmas day in hospital but all our lovely family came and spent the morning with us. His brother Jack came, he loved seeing his brother after two months. We were lucky that his grandmother had come to look after him, it must have been so hard for a

Charlie's Hearts



Our son, Charlie, was born in 2003 with HLHS, and we were really fortunate that he sailed through stages one and two.

However, after a routine pre-Fontan cardiac catheter he developed intermittent heart block, which meant that sometimes the electrical impulses in his heart didn't get all the way from the atrium to the ventricle, causing temporary bradycardia.

Although it didn't affect Charlie at all when his heart rate dipped, a fluctuating output is not good for a Fontan circulation, so it was decided that he would need a pacemaker. Charlie was rather pleased at the prospect, because he decided that once he had the pacemaker, it would be like he had two hearts – just like his hero Doctor Who!

So, Tardis suitcase in hand, Charlie arrived at Birmingham Children's Hospital for his Fontan and pacemaker insertion.

The Fontan went very smoothly, but there were issues with the pacemaker even before he came out of theatre, so when we saw him in ICU, he was being externally paced, and his new internal pacemaker was turned off. We were told this was fairly common post-op, and that it would be switched back on in a day or so.

Back on the ward less than 24 hours later, Charlie was recovering brilliantly, but when the Heart Investigations team turned his pacemaker back on, it still wasn't working correctly. It couldn't push enough electricity up the wires to make Charlie's heart pace properly, and even with the thresholds as high as possible, it still wouldn't work... and nobody knew why.

We are very used to Charlie's heart and how it works, but electrophysiology is not something we're familiar with, so we really didn't understand what was going on. This was quite difficult to deal with, because we're both the kind of people who like to know exactly what's what.

But it was even more frustrating to see the entire Heart Investigations team, doctors and the rep from the pacemaker manufacturer standing at Charlie's bedside, all totally baffled by his pacemaker's never-seen-before behaviour.

Nobody knew if there was a fault with the pacemaker, the wires, or the connections. We just knew there was a problem. We had spent years psyching ourselves up for the Fontan, and had thought of the pacemaker insertion as a minor added extra – yet here we were, Fontan working beautifully, and a little machine, barely the size of a



three year old to not see his mother, father and brother every day. We have amazing family and friends who helped us through such hard times and we love them all for being there.

Not surprisingly, after spending more than two months recovering in hospital, Jamie was held back a year at his primary school. His medical condition also means he receives added support at school and is limited to some sport activities. The teacher and all the children have been very understanding and we are thrilled that he can enjoy this element of a normal six year old life. He obviously isn't as strong as the rest of the children and does have to be careful but he has lots of friends who all look after him.

Jamie was in good health for two years and life seemed to go back to normal but in August 2008 I started to notice that Jamie's behaviour was not quite right. He was unable to calm himself down at some points in the day which was so out of character. I spoke to Jamie's cardiac liaison nurse and explained something was not right and she arranged for him to come down for an ECG. They identified that one of his leads from the pacemaker to his heart was broken and not working properly. They were concerned as due to his complex heart they had had to attach wires to his heart and they may need to do open heart surgery to replace this.

They told us they would discuss what to do next and would let us know within a week. During this time we had a dreadful experience. I was in Sainsbury's with Jamie and Jack, as I

was walking out of the supermarket I looked to my side and Jamie was not there, I looked down and Jamie was lying face down, not moving. I told him to get up but he did not move and then I knew something was very wrong. I managed to pick him up from the floor but he was covered in blood and completely lifeless. I tried to shake him but he did not move and then I started screaming for someone to get an ambulance. I did not know what had happened and I was not sure if he was dead as I could not bring him around. After what seemed to be a lifetime he came around and he realised he was covered in blood and began to cry in shock. Thankfully a lady took care of Jack my other son. The ambulance arrived and they took us to our local A&E who then sent us straight to the Royal Brompton.

Once there they were a bit baffled as to why Jamie had passed out as this did not fit the pattern of just one of his wires breaking. They discovered that he had had a Ventricular Tachycardia (VT) attack and this was a new problem that they needed to fix when replacing the wires. They told us they need to use a new pacemaker with a DF (Defibrillator) within it and this had never been done before on a child so young. Finally the surgery and pacing specialist came up with an option that was unique and would

solve the problem. He was to have a pacemaker and DF in his stomach with leads to his heart. Thankfully this was a success and he made a good recovery.

We have had a good couple of years and got back to normal and life. It makes you appreciate every day you have with Jamie and what an amazing and brave child he is. I cannot thank the whole hospital team enough, I just feel that without these amazing people Jamie would not be with us today. We have to thank all our family and friends too for their support during the hard times, without them we would not have been able to get through all of this. Lastly I would thank Jamie for being such a brave and amazing child after all he has been through and his little brother for always loving him.



Jamie (left) and brother Jack proudly showing off his Young Hero Award 2010

fifty pence piece, causing so much trouble!

Crunch time came, two weeks post-Fontan, when the pacemaker stopped working altogether, and there was nothing left but to take Charlie back to theatre. The surgeon would start by reopening the scar over Charlie's pacemaker, cleaning the connections and replacing the box. If this didn't work, he would have to reopen Charlie's sternotomy and start from scratch. Words can't express the relief we felt when the surgeon reappeared 40 minutes later, telling us that cleaned-up wires and a new box had done the trick.

At the time of writing, Charlie is eight weeks post-op, and he is like a new boy. The Fontan has massively improved his energy levels, so it is quite hard to say what impact the pacemaker has had in its own right.

But while we were at the hospital, we noticed that as soon as the new pacemaker was in, making Charlie haemodynamically stable, he improved very rapidly, and we home soon after. We had wondered what impact the pacemaker would have on Charlie's life, in terms of what he could and couldn't do, but we haven't come across many problems.

We were advised to avoid really strong 'Oidz'

magnets, but he can still play with his Magnetix toys, so long as he keeps them at least six inches from his pacemaker. He needs to avoid the scanners at airports, and has to walk quickly through the security alarm gates in shops.

He needs to be careful not to get his pacemaker knocked too hard, so contact sports are out, but they would have been anyway because Charlie is on warfarin.

We thought he wouldn't be able to go on dodgem cars any more, because they are powered by industrial strength magnets, but the Heart Investigations team assured him he can - so long as he doesn't climb up the pole on the back!

Although we had a slightly bumpy start on Charlie's journey with his pacemaker, we are so glad that he has it.

It means we don't need to worry about arrhythmias causing problems with his Fontan, and we can rely on the pacemaker to keep his extra-special heart working as well as it possibly can for many years to come.



Charlie back on the ward



Having fun at Center Parcs

Fundraising

Hello, I joined Little Hearts Matter in April and having had the pleasure of meeting and speaking to some families already I am completely bowled over by how committed you are to financially supporting the charity especially when your lives are already so incredibly busy. Your stories and effort have inspired me greatly. I have worked in the charity sector for many years and have never experienced the same level of passion and commitment from the people that benefit from the services and support. Little Hearts Matter staff and members really does feel like one, with a fabulous family feel to it with members really owning and embracing the charity.

Having read lots of the letters you have sent in I had intended to use most of this space to thank as many people individually as possible. However, Suzie and I are greatly concerned at the drop in fundraising income so far this year, and we are desperate to ensure this dip does not continue as we need to provide the same level of service and support as last year; to have to decide which services we can no longer run would be an awful position to be in as all the services and support are vital to different individuals and families.

Please do not feel that we are passing this pressure over to you, we are very aware that families are able to fundraise at different times, in different ways and different levels and we do sincerely appreciate all you do for us. I would obviously like you to continue and increase (if you can) the amount of fundraising you do, I also want us to look at getting the wider community involved, your workplace or a family member or friend's workplace is a great starting point. People who are not affected by a single ventricle heart condition are unlikely to be aware of the charity, and this is what we need to change because when people and companies are made aware of what we do and they gain greater awareness of the condition, they are extremely

motivated to support us. It can be a huge company or a small one, I am here to talk to companies, or if you would prefer we can provide the information for you to discuss with them... I

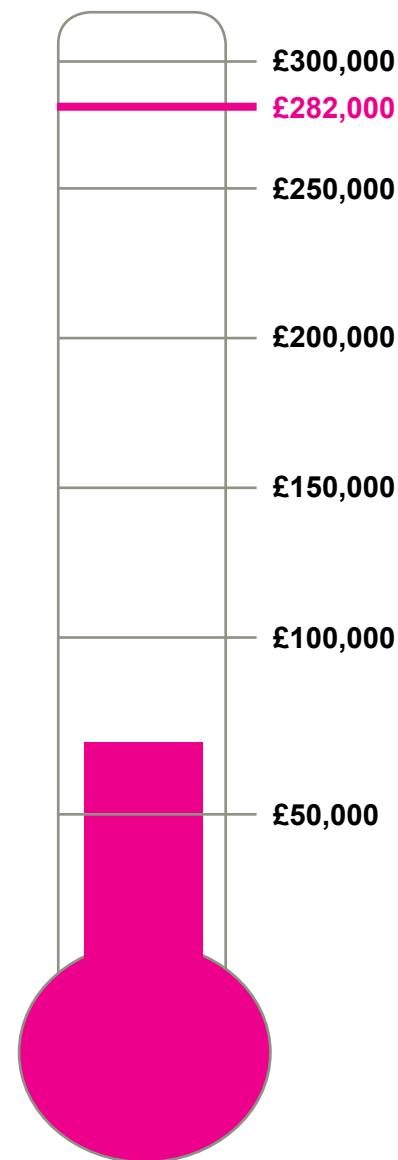


do believe if we start now we can reduce our fundraising shortfall this year. I thought it would help if everyone knew where we are at with the fundraising to date and our target to achieve for 2010. We can then look at our target (which will also be on our website so you can see monthly how we are doing) and in December we can all raise our glasses to each other reaching and indeed smashing this target.

Thank you and I look forward to getting to know more of you over the next few months. See you at Shugborough on the 3rd October. Please call me anytime on 0121 455 8982.

Best wishes and thank you to you all.

Shelagh



On Your Marks at Mote Park

Thank you to all the 100 plus people who donned their trainers and either ran or walked the 5 or 10km around Mote Park in Maidstone, the rain stayed off and it was great to see so many families turn up to enjoy the day. Unfortunately we do not have enough room to thank everyone individually, but your support is greatly appreciated, we would like to highlight three amazing young people, Andrew Kerry, Ruby Arora and Oonagh Lyons who all completed the 5km, what an

amazing challenge to conquer and in addition, between you and your families you raised a staggering £5,285. A huge THANK YOU to the Kerry, Arora and Lyons families.

Thank you also to Janet Rose, Holly Mason, Rebecca Wellard and proud dad to be, Jose who all ran on behalf of Gemma Wellard who is expecting her first baby and has been receiving help and information from LHM regarding baby's condition. Glad

you met up with other parents Gemma and Jose. Keep us updated on how things are progressing, we are always here if you need anything.



Generous Wedding Gift

Jake Gresty's auntie and uncle, Amy and Ben Chidgey were married in July last year. They were very keen to help their nephew and Little Hearts Matter and so invited wedding guests to make a donation to LHM instead of buying wedding presents. They have since emigrated to New Zealand but Jake and his mum and dad still keep them up-to-date with all the LHM news!.

A big thanks to you and congratulations from all at LHM.



Dress Up, Dress Down, Dress Silly

Massive thanks to Sarah Haselgrove from Hythe in Kent, who asked her school 'Pent Valley Technology College' to do a Dress Up/Down Day, raising over £500. Well done Sarah, and very much appreciated.

Have you thought about asking your school to take part in this, you can either dress up for the day, dress down or dress very, very silly having lots of fun and raising money for us as well, you could also have a prize for the silliest dressed person.

We have posters and leaflets that we can send, just call on 0121 455 8982.



Stuck for something to do this summer?

Sky Dives

Why not jump out of a plane and free fall at up to 120mph!

There are 20 skydiving centres across the UK, thank you to Nicola Johnson and Lianne Halford who are signed to jump in October and Jenna Sinclair who is booked to jump as we go to press. For more details contact us on 0121 455 8982.

Or if you prefer to keep your feet firmly on the ground - how about ...

A Summer BBQ

Dust off the BBQ, invite all your friends around and ask them to donate however much they felt they enjoyed the day, we have lots of balloons to help you decorate the garden.

What a way to celebrate turning 40!

Thank you Kerry, Chris and Scott for organising a 40th birthday party with a difference. They thought they would raise money for four charities whilst having a party. LHM was one of the chosen charities Kerry says "the charity has been a tremendous support to my sister and her husband Nick over the years". And how fantastic that your employer National Grid matched the amount you raised. A total of £700 was raised.

Thank you for choosing us.



IN BRIEF

Many thanks to Salford City College who raised over £1,000 to split between us and another charity with their Hair and Fashion show. Also big thank you's to the Sharrock family for putting us forward for this.

We would like to thank Ben & Jerry's in the Bullring, Birmingham for supporting us on their Free Cone Day for the third year running. In four hours they raised £586.89 and gave away 1461 free scoops of ice-cream. Thanks for inviting us down there guys and for continuing to support us. Visit www.ben&jerry.co.uk to find out more about Free Cone Day.



Cookie Bake

A huge thank you to class P3P at Eyemouth Primary School for raising funds for LHM. The class baked and sold cookies to all the pupils at playtime, raising £65. In addition a Slave Auction was held. Each child gave a list of slave jobs they would do to try

and encourage their mums and dads to bid for them. Colbie-Kate Ross promised to pick up all the dog poo in the garden, not argue with her sisters and brother and do all the housework - mum and dad thought this was too good an offer to turn down. Thank you to all the children who took part and the mums and dads for their generosity.



Hark...the Chepstow Choir sing... glory to the newborn king

Every year Chepstow Choral Society sing outside their local Tesco store and raise money in aid of charity. On December 15th a goodly number gathered to sing in aid of LHM. The choir sang many traditional favourites and the rousing chorus of 'Hark the Herald'

were greatly received by the Christmas shoppers

They raised a fantastic £175. A huge thank you to all the Choir members.



Little Hearts Matter would like to give a belated thank you to Tim York and friends for raising the incredible sum of £3693.23 when they walked Hadrian's Wall in March. Thank you Tim for all your support and well done.

We would like to thank Jackie O'Neill and her family for the very generous donation to LHM in memory of her father Joe Foves who sadly passed away in January this year. Joe, who was 89, was the proud grandfather of Kerri O'Neill and great grandfather to her triplets Alexander, James and Ava born in 2006. Little James sadly died of HLHS when he was eight months old having spent his short life at St Thomas'. Our thoughts are with you all.



Feature

This article is based on parental experience of looking at alternatives to help your child get around.

Written by
Isabel Baumber, Andrea Harris and Gill Cloke

Some members find that, as their child gets older, they become too big for a standard pushchair, but, because of their heart condition, they still need a pushchair to help them get around. This article is based on parental experience of looking at alternatives to help.

The NHS Wheelchair Service includes the supply of buggies. You will need a referral from your GP, and can find out more by phoning NHS Direct on 0845 4647 or, in Scotland, NHS 24 on 0845 424242. Their standard issue for a child who needs help with mobility, but who doesn't have any other special needs (e.g. support with posture), would be the Maclaren Major buggy. Once your GP has referred you to the Wheelchair Service, you and your child may need to go for an assessment. You can discuss your specific needs at the assessment appointment. Providing the Wheelchair Service agree that your child needs a larger buggy, they will provide one for you free of charge, and will probably deliver it to your home address. You may have to purchase accessories (including raincover) yourself.

The Maclaren Major is tested to 50kg, so will easily hold a child up to the age of 10. It folds flat, like an umbrella-fold buggy - but is a bit longer than normal. However, some parents find that it isn't very good for use in slightly rugged terrain, i.e. anything other than pavements.

If you do feel you need something other than the Maclaren Major, there are some alternatives. One product is the Axiom 2, suitable for 5-10 year olds, available from various specialist retailers such as Kidsense (www.kidsense.co.uk) - their website has a Special Needs section, and they are based in Leicestershire if you would like a demo before purchase, or the charity Fledglings (www.fledglings.org.uk, tel 0845 458 1124). Another product which has proved popular with our membership is the Ranger Mountain Buggy, available from Delichon (www.delichon.co.uk). Chariots all terrain pushchairs are a Devon based web stockist of the Baby Jogger

Advance Mobility range and Mountain Buggy range (www.specialneedspushchairs.co.uk - this website has a brilliant 'links' page or visit www.pushchairs.co.uk). The Advance Mobility Independence model is available under the wheelchair voucher scheme and is eligible for VAT relief. Both The Independence (3 fixed wheels) and Freedom (4 wheels, 2 of which swivel) models suit 5-10 year olds (to 45kg) and accessories are available for both to help your buggy grow with your child e.g. extended footwell, highback headrest or roll cushion to extend the seat depth. Once your child has outgrown these models it may be worth considering the Advance Mobility Freedom model for age 10 years+ (to 90kg).

If you do wish to pursue an alternative product, in England there is a wheelchair voucher scheme, which allows you to pay the difference between what is offered by the Wheelchair Service and what you think your child needs.

It is well worth looking into NHS funding (via wheelchair vouchers if available), or any other routes you have as these pushchairs are



expensive, typically costing over £500. Other tips for saving money are to look on Ebay or any other second hand places you know (you might even save some money on a raincover), and to remember that the product should be sold to you without VAT.

If you have more than one child needing a pushchair, and you need something bigger than a standard double buggy, the selection is more limited. The NHS Wheelchair Service may be able to help, but their help is likely to only be available when both children are older, and if they both have special needs. A specialist health visitor, paediatrician or physiotherapist may also

be able to offer advice.

If none of these routes are successful for two children, products I have found are as follows. Delichon will provide you with a 'unification bar' to join the Ranger Mountain Buggy to a standard Mountain Buggy. I think this would give the children a very comfortable ride, but the whole package would be very expensive and it is certainly too wide for some pavements and shops! A Maclaren Major Double exists, but has fairly limited retail availability. It folds well for its size (umbrella style), and can be purchased from www.lotsofbabies.com for around £600. Another option would be to contact the charity REMAP (www.remap.org.uk) who will adapt products for people with special needs if nothing is commercially available.

Please contact the office if you would like to discuss your child's needs in more detail, or if you'd like to chat to other families about their experiences. Good luck with finding something suitable for your family.



Ask the Experts

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

Mr David Barron
Consultant Cardiac Surgeon
Birmingham Children's Hospital



When is the best time to perform the Fontan operation?

There is no straightforward answer to this question - it is like asking when is the right time to upgrade your PC... the usual answer is that if your current model is working well then why change it!

There is no argument that the Fontan will improve your oxygen levels and generally improves exercise capacity, however, so long as you are well and thriving there is no great hurry. Usually, children who have had the Stage 2 operation start to become more breathless and more 'blue' (cyanosed) when they reach the age of four years - which usually corresponds to the age when they are getting more physically active and wanting to run around more. This is usually our trigger to plan for the Fontan operation. In Birmingham we typically do this around four and a half years of age.

Every child is different and some children

get more symptomatic earlier, in which case the Fontan would be offered earlier (not usually at younger than three years) - yet others manage very well for longer and may not need to have the Fontan until seven or eight years of age. It partly depends on the 'plumbing' of the circulation and there are some variants of heart condition where you naturally have a small extra source of blood supply to the lungs, which can allow children to last a little longer before becoming very blue.

In terms of the surgery itself, there are different types of Fontan operation, the commonest of which is the 'extra-cardiac' which means we use a plastic tube to divert the extra blood flow into the lungs. Obviously we would want the child to be big enough so that we can place a full sized tube at the time of surgery - so that there is not risk of 'out-growing' it. This can generally be done by the

time the child is around four years of age or 13-14kg in weight - so this is another important consideration in terms of the timing of surgery.

Hospitals and individual surgeons vary all over the world. Most commonly, centres would adopt the same policy I have described here - aiming for around four to five years of age. However, some centres, particularly in the USA favour earlier Fontan at two to three years of age or even earlier. These centres tend to use the 'lateral tunnel' type of fontan that does not use a plastic tube.

The most important thing to say is that there is no evidence to suggest that doing the Fontan at any particular age offers any benefit or better outcome. The results for the Fontan at all the different ages are the same - both in terms of the risks of the surgery itself and also in terms of how well the Fontan is working in the future.

Would you like to run for Little Hearts Matter and not have to travel too far to do it?

The Big Fun Run is a series of 24 runs staged across the UK where 1,000 plus runners will undertake a 5K run and support their chosen charity.

Each venue has been carefully selected. They all take place exclusively within scenic parks that are both safe and pleasant running environments. We are delighted to let you know that we have 41 runners

signed up so far.

A huge thank you to Nicola Owens, Sue Chesworth, Denise Smith, Lisa Jaconelli, William Lindsay, Tracy Maher, Jessica Maher, Karen Croft, Victoria Shepherd, Terence Small, Andrew Diamond, Keith Dowling, Eileen Scanlon, Stephen Leatherland, Nicola Brislee, Tracy Baker, Richard Baker, Nicola Harper, Neil Harper,

Step Webster, Hayley Crooks, Bernadette Barron, Eleanor Balfour, Mark McKeachie, Mark Cording, Sasha, Murray and Dylan Ratcliffe.

Please keep us updated on how you are getting on and do send us your photos.

Events are taking place in lots of places visit www.bigfunrun.com



Feature

On Saturday 13th March LHM held its Annual General Meeting and Open Day in Burton-upon-Trent, below is an overview from two of our members.

Written by
Joanne Morely and Andrew Kerry

This was the third Little Hearts Matter Open Day I have attended since my son was born in 2004 with Hypoplastic Left Heart Syndrome. I try to keep in touch with what's going on throughout the year on the LHM website but am glad to have the opportunity to meet families and professionals face-to-face.

I travelled up to the Bretby Conference Centre with my mum and son on the day of the Open Day sadly we weren't able to attend the social event in the evening, although I have heard they are well worth staying for.

The day started with coffee and a chance to meet up with some familiar faces and be introduced to some new faces. During this time I had an interesting conversation with Colin Smith who was going to be giving a presentation later in the day on Disability Living Allowance. He spoke about his role within the DWP and listened to me moan about the length of the application forms. He then told me that work was underway to reduce the reapplication form to just four pages - wow!

This year the young people were split into age groups with the youngest enjoying the creche, and the others enjoying a series of workshops in a variety of subjects.

The first workshop I decided to attend was on 'How to cope with medical conditions in primary school' facilitated by Isabel Baumber. It was an informative session with an opportunity to identify barriers faced by our children at school and for us to share our experiences in education and discuss ideas on how to overcome these barriers.

After a coffee break the AGM took place informing us all of the progress the charity is making. This was followed by the Youth Council, who showed off their acting skills with a variety of brilliant sketches which demonstrated how young people and their siblings feel about living with a heart condition.

We then learnt about the current consultation

that is taking place on the future of paediatric heart surgery sites in England, Jeremy Glyde spoke about what recommendations were being made and the aims and outcomes of the recommendations.

After a pleasant buffet lunch I attended a master class in Pacemakers given by someone who has reassured me continuously over the last six years, my son's cardiologist Dr DeGiovanni.

The talk was extremely informative of the ever amazing progression in medical science and was delivered with passion and wit.

It was time for us to leave Bretby and make our way home. My son had thoroughly enjoyed his day and had his signed copy of Harriet Goodwins book - The Boy Who Fell Down Exit 43 to read on the way home.

The Open Days seem to fly by and I would encourage any parent, carer or family member of a child with a heart condition who hasn't been before to try and attend next year. It is always good to share stories both good and bad and to get all the most up-to-date information on what's happening in the world of children with a heart condition.





Food, driving, school, footy, more food, jobs and even bridge building!

There were a variety of activities for the young and the old amongst us!!

After an early drive, we arrived at the Bretby Conference Centre where the day's activities would be held. To break the ice, we had a 'get to know you session' to tell everyone random facts about ourselves and also swap email addresses and phone numbers. The timetable for the day was packed with great workshops for us to attend. After the ice was broken and we had gotten to know people, the workshops began...

For the 14+'s amongst us, there was a workshop on driving which was led by BSM driving instructor Paul Kavanagh. He told us the basics about driving and helped us understand when we can start driving if we are part of the 'Higher Rate Disability Living Allowance' and also how to apply for a provisional licence via our local post offices and what evidence was needed to apply for one. He used a quiz and some videos to help us understand about hazards. All in all, the workshop was useful and gave us loads of info!

Next on the timetable was 'How to Cope with a Medical Condition at School' with Mary McCann and Karen. We talked about school and how we tell our friends about our condition. We also talked about our condition and whether we knew enough about our condition and medication to tell others about it in case something happened to us. The session was good because it let us hear about other people's experiences. Lunch followed this workshop. The buffet was great and everyone tucked in!!!

The session after lunch was a free choice and we chose football! (The group was made up of mostly boys!) We took rests every now and then

and we all enjoyed ourselves but, the game couldn't go on forever and we had to move on...

The final workshop was led by Gill Cook and Suzi from Connexions. They told us about jobs and steps that we have to go through before we can step into the world of work! They gave us lots of advice, tips and websites to help us with our choices.

us who did had more food! We also had an evening of karaoke and silly games. We eventually got to bed and woke up to a lovely breakfast in the morning.

The team who ran the event were great. They organised and ran the event very well, making sure that everyone had a smile on their face. It was a useful weekend and many friends were made by people! Soooo... thank you to Jon, Charlie, Rich and Alex for making the weekend so great!!



Sooooo... the activities were over. Or so we thought... LHM's very own Jon Brunskill is doing some research into life with half a heart. Some of us filled in an anonymous questionnaire to help him with this. It took about half an hour and was easy to fill out.

A few people went home after the activities but some stayed on. Those of



Zipper Zone



Jon gives an insight into an exciting new Mediabox Project which the young people are invited to take part in.

Written by
Jon Brunskill
Youth Development Officer



Zippers lead an exciting project for change

DURING THE EASTER HOLIDAYS six young people took part in a series of brainstorming sessions and creative workshops learning all about media skills.

The zippers who attended our first workshop week were trained in how to correctly light a scene, how to professionally record sound, how to use a proper film camera, and how to storyboard ideas.

It was all part of Little Hearts Matter's Mediabox Project called:

"I've only got half a heart... understand me?"

The **AIM** of this project is to film a documentary explaining what it is like getting through school with a heart condition.

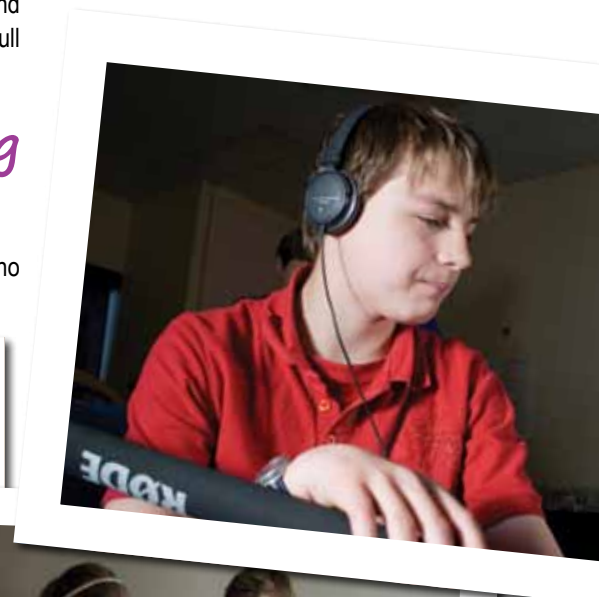
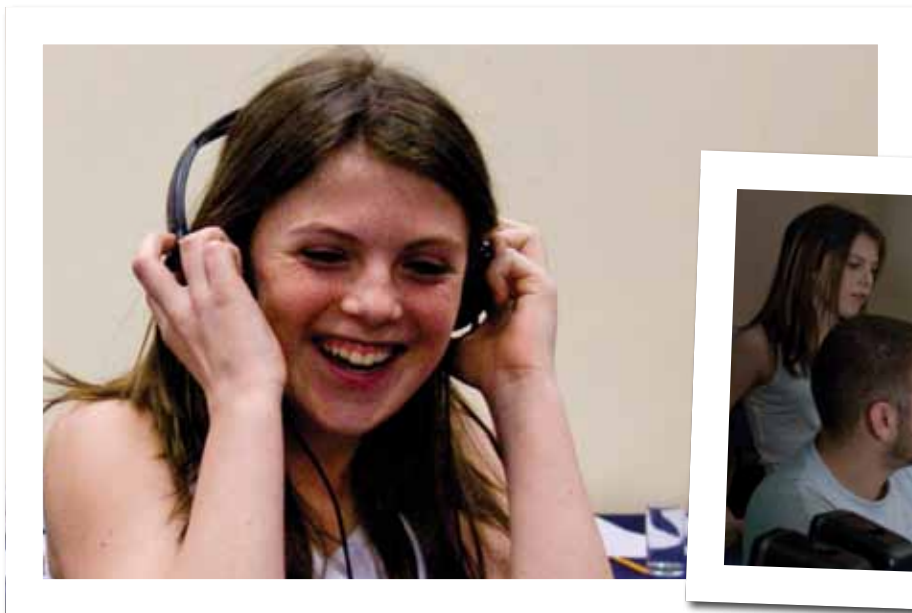
The DVD will be finished in August, and hundreds of copies will be sent out to young people with heart conditions. Once they have a copy of the DVD, it can be given to teachers to watch so that they can develop a better idea of what sorts of problems these young people face **and why**.

To discover more about what we did on the day, log on to www.zipperzone.org.uk and click on 'News' on the homepage for the full story.

Young people leading the way

It is really important that young people who

have a heart condition lead this project. This DVD is the chance for young people to have their say. Without their input, the DVD won't tackle the issues which really worry young people with long-term health conditions in schools. The Little Hearts Matter Youth Council identified life in school as being the most pertinent issue for young people with a single ventricle heart disorder, and we feel



that it is very important for the young people to continue to lead this project for change.

Here is what they believe

"If teachers became AWARE of the problems that we face, they will know how to avoid these problems and to help include us. Then everybody will be able to reach their full potential in school."

What evidence is there for this?

At LHM we are proud to have a direct influence from our youth membership into our service provision. This project was asked for by our youth representatives, and so we began work on making it happen.

It is not just our young members who are calling for more support in school.

This problem was also highlighted in parliament. Jim Cunningham MP - (who is pushing through the School Health Support Bill) - stated in the House of Commons in May last year.

"I want to underline, however that while many schools do provide excellent medical support for children with long-term conditions, that standard is not universally upheld. There is every reason

to change that."

We are delighted that our young members are taking such an active role in increasing awareness and creating a tool that can be used for positive change. The more young people who input to this project, the more

representative it will be, which is why we are urging all young members aged 11 upwards please get in touch to help out.

What Next?

This project has now started and the young people who attended have got some wonderful ideas for what they want to achieve to help other children with heart conditions in school.

They want young people's input into the rest of the DVD, so that it will be from a kid's point of view.

Please get in touch if you would like to get involved, and watch out for more workshop dates in the post!



Post GCSE Residential Workshops

When

June 29th - July 1st

Time

Drop off at 5pm on Tuesday 29th
Pick up at 6pm on Thursday 1st

Where

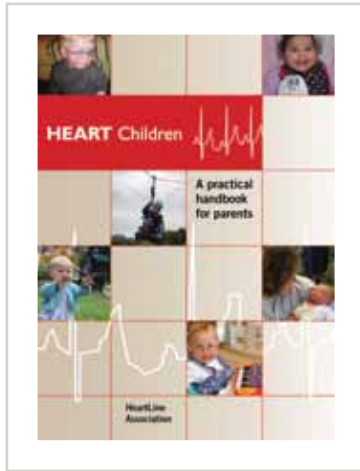
Stafford

If you would like to be involved and are interested in getting more details call Jon on

0121 455 8982



The Review



Every issue we feature a review of a book, website or film that our members may find interesting.

In this issue, Abi Meynell reviews the new Heartline book 'Heart Children'

Written by
Abi Meynell



I first came across this book when my son was admitted to hospital at five weeks old. I received a hospital bag full of goodies from the charity Heartlink at Glenfield Hospital, Leicester, at the bottom of which I found this book '**Heart Children - A practical handbook for parents**'. It is extremely useful to parents new to the world of CHD at a time when they have many unanswered questions and are in fear and shock. One aim of this book is to provide comfort in giving gentle explanations and sharing experiences.

It is very difficult to write an overview of this book given the wealth of information it contains! The main purpose of this book is to improve the parent's knowledge and understanding of their child's heart condition. It details life in hospital and outlines day to day challenges of looking after a heart child. At the back there is a list of resources, glossary of terms, even a useful template diagram of a heart for you to draw your child's unique heart on!

This book includes information on the main types of congenital heart defects. It includes a coloured diagram for each condition, explains the defects clearly, outlines any possible

surgeries and explains what the future may hold for your child.

The strength of this book is the incredible detail it goes into while avoiding difficult medical 'jargon'. A large chunk of this book details what to expect in hospital. This includes how to prepare your child for hospital and what may happen when your child is in hospital - including what to expect on the wards, the run up to surgery, intensive care unit and going home. There is a section listing and explaining the main medications and surgeries used in paediatric cardiology.

Other contents include: Understanding the heart, prenatal diagnosis, diagnosing your child, tests, echocardiography, cardiac catheterisation and the latest procedures explained, treatments available, what to tell your children, surgery and heart transplantation, everyday life with your 'heart' child, answers to questions most often asked, reactions, coping with feelings and relationships, bereavement, benefits and welfare help, a list of support organisations and a recommended reading list.

The book also looks to the future of your child and topics addressed in the book include

schooling, physical ability, suitable careers, holidays (flying and travel abroad), driving, insurance, genetic counselling, contraception, marriage, mortgages and a thousand and one situations which are hardly noticed by 'ordinary families'.

This book was invaluable to me when my son was lying in hospital at just five weeks old, but now he is nearly four, and I have acquired a wealth of knowledge about his condition, I still find myself turning to this book often for answers and reassurance. I have also found it useful to lend out to family and friends who want to know more. This book has recently been updated and I am very proud to see my son on the front cover! I would highly recommend it to all parents of a heart child, a must for your library.

Heart Children, published for Heartline Association, edited by Hazel Greig-Midlane.

It can be obtained from the Heartline office.
Tel: 01276 707636
Email: admin@heartline.org.uk

It costs £11.50 to purchase plus P&P (£1.50 in UK).

Walkaround UK

Dig out your walking boots and help raise funds for your charity and organise your own sponsored walk anywhere in the country when we all 'Walkaround UK'

Pick a route, a weekend, grab family, neighbours and friends and walk for Little Hearts Matter. Let's see how many families we can get walking this September? Please let us know and send us your pics too.

Remember facebook is a fabulous way to invite other members in your area. Contact LHM for more info or email info@lhm.org.uk. For easily accessible routes go to www.walkwithbuggies.com or www.walkwithwheelchairs.com



Noticeboard

The Next Junior Apprentice?

Jack Negus putting his heart and sole into his slipper venture



Photograph courtesy of the Bridgwater Mercury

Jack has always been a keen fundraiser for LHM, but his current ingenious idea has blown us all away. Jack is now running his own not-for-profit business to raise money for Little Hearts Matter - the charity which cared for him.

With help from his dad John, who used to work for shoe firm Clark's, Jack sells slippers of all shapes and sizes at craft fairs, and visits customers

at their home, care homes, or sheltered accommodation through his business, Hearts and Soles.

The self-confessed 'computer freak', who admits he isn't a slipper person, also runs his own website and is youth editor of village magazine, the Polden Post.

Jack recently said in a newspaper interview "The charity has supported me and my family all my life and I wanted to give something back so I thought this would be the perfect way, especially with my dad's knowledge of the trade, and I love it."

Jack, all of us at LHM were really touched by the depths of your efforts and your continuous support for the charity. Thank you so much and do keep us updated.

Inspirational Fundraiser

Your Newsletter

Thank you so much to everyone who has contributed to this newsletter - it has been wonderful to receive all your stories and photos and ideas.

The next issue is expected to be completed and will be distributed in September 2010.

If you would like to send your ideas and stories/photos for the next edition please send them to Deb - deb@lhm.org.uk by the beginning of August.

Also if there is something you would like to see in the newsletter do let us know.

We very much look forward to hearing from you.

LHM Publications

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

- Antenatal Information Booklet
- Preparation for Hospital Booklet
- Preparation for Hospital Pack - to borrow for a period of 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

facebook

Check out our facebook pages, they are being used more and more to share thoughts and ideas and just generally connecting with other members, there are nearly 2,000 fans signed up.

If you're not a fan, make June the official month of being an LHM facebook fan.

Login to 'facebook', type in '**Little Hearts Matter**' in search, click on '**Pages**' tab to the left hand side, our page is called '**Little Hearts Matter**' and we have over 1800 people who like it.

DIARY DATES

On Your Marks For Little Hearts

Sunday 3rd October 2010

Shugborough Hall, Staffordshire

'Lights of Love' Tree Switch On

Sunday 5th December 2010

West Midlands



Little Hearts Matter

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

Over To You



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

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



Barnaby's Big Adventure

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

Having returned from seeing all the major sights in London and Paris with the Chesworths and walking Hadrian's Wall along with Tim York and his friends we took Barnaby to our Open Day in Burton to meet lots more of our members.

Whilst there he worked his way into the hearts of the Lodge family who kindly agreed to take him on their upcoming holiday to Tenerife where he spent a week seeing the sights including a trip to Mount Teide and a day seeing the animals at Loro Park.

Pictured are Toby, Daniel and Barnaby at the crater of Mount Teide. Daniel took Barnaby all the way to the snowy top in a cable car - which was very, very high! At Loro Park he got up close and personal with some penguins and many more unusual animals too. Back at the airport he bumped into the giant Harrods bear before napping on the plane back home to Surrey.

His adventures didn't end there though! He helped Dad Graeme to give a thank you speech at the local church for their fundraising and then travelled courtesy of Royal Mail back to the LHM office. It wasn't as grand as travelling by aeroplane but it got him here safely.

He's now awaiting his next adventure, wherever that may be...

Many thanks to Sue Chesworth, Tim York and Debra, Graeme, Toby and Daniel for helping Barnaby to see the world. If you'd like to take him away with you and get your photos featured in the newsletter and website then please contact the office.



- TOP LEFT: Oliver Harrison (2) at 20 months, and 8 weeks post open heart surgery.
- TOP RIGHT: Corwin Meynell (3) and Pearl Wilson (2) meeting up and enjoying a day on the beach.
- BOTTOM LEFT: Caitlin McQuade (8) and her friend Heather enjoying the snow.
- BOTTOM RIGHT: Naomi Baker (4 months) born on 20 January 2010.

