

# Little Hearts Matter Newsletter

Registered Charity Number: 1058735

Issue 3

Winter 2007/2008

## On Your Marks for Little Hearts

The first Little Hearts Matter run was held on Sunday 14th of October at Shugborough Hall, Staffordshire.

It was dark, damp and cold when the LHM team arrived at 7.30am to set up the event. However, that didn't dampen anyone's spirits and by 9am runners began to arrive to the sound of upbeat music and the smell of freshly cooked sausage and bacon wafting through the air. By 10am over 200 runners gathered around the walk village area and many proud parents prepared their children - many in fabulous fancy dress - for the 'Fun Run' at 10.30am. All the children ran or toddled through the finish to the applause from the crowd and a well deserved medal and prize.

No time to waste, as volunteer members from the 22 Signal Regiment called runners to the stage for a warm up - some would argue it was more like a work out! By 11am the race was ready to begin and they were away.

Freddy Hutchinson was the first winner through the line for the 5km run with a fantastic 27.5 mins followed by Ben Radbourne at 45.6



Thomas Hooks, aged 2 dressed up as a spider



Little Hearts Matter organised its first run in October in the beautiful surroundings of Shugborough Hall

• ABOVE: On Your Marks Set Go

mins for the 10km and Chris Hall with a gallant 73.46 mins for the 15km run. Runners received a well earned energy drink and banana, kindly donated by local companies as well as their own medal to remember the day.

Both spectators and runners had the opportunity to enjoy the really spectacular scenery of Shugborough via a free hot air balloon flight courtesy of Wickers World. There was also ice-cream, plenty of hot and cold food, an LHM Balloon Release, soft play and creche for the kids and much more. We are delighted the weather stayed dry and everyone seemed to enjoy the day. We would like to thank the Stafford Knot Rotary and the 22 Signal Regiment for the huge amount of support they gave, by providing invaluable volunteers



Family Success - The Manley Family at the finish line

before, during and after the event. We are really pleased to announce that thanks to the fabulous support and effort of all the runners and their kind donators, we hope to have raised a total of £20,000!

With such a fantastic response, we have booked Shugborough Hall for next year. So grab your running shoes, start training now and we look forward to welcoming you at the second 'On Your Marks for Little Hearts' sponsored run on Sunday 12th October 2008.



A well earned treat for the Durber family

INSIDE THIS ISSUE...



Winter Warmers

Pages 4



A Guide To Benefits

Pages 8,9,10,11



Over To You

Page 16

Here we are at the start of a bright new year. May I start by saying that I hope that it will be a year filled with positive things.

Little Hearts Matter hopes that it will be able to build all the membership support and information services throughout 2008.

Many of you will have taken part in the questionnaire created by the Information team. The results of this will help to form part of the charity teams' evaluation of the services that you as the members want.

Where the funds are available we always work to provide support and information solutions that help the charity's membership.

Before we look too far into the future let us review last year.

September, October, November and December were extremely busy

It began with a new venture for the charity the "On your Marks for Little Hearts" run.

This Fundraising event had been created because we had become frustrated with the lack of marathon places. As LHM is only a small charity we couldn't compete with the likes of Cancer Research UK or the British Heart Foundation for places in the big races.

Well who says that you need to be big to create a wonderful event? Not only did over 200 runners take part in the big race, their supporters had a great time taking balloon rides, eating bacon sandwiches and playing fundraising games. They also cheered all the brave runners on. See the front page report.

The next event was the Open Day. We really hope that those of you who were able to join us found this education day helpful. We hope to produce a DVD of all the educational tips

## Suzie's News...



Suzie  
Hutchinson  
LHM  
Chief Executive

discussed but we are also working on education information packs. See Open Day report.

My next commitment was as a delegate at the British Congenital Cardiac Association meeting in Leeds. This was a fantastic opportunity for me to keep up to date with the issues that cardiologists and cardiac surgeons think are important as they build their care and treatment services. The Fontan procedure and the future for the children, and adults, who have undergone this surgery formed a big part of the discussion over the two day meeting. The overall view, you will be pleased to know, is that the Fontan is more successful than originally envisaged but that there is still a great deal of work to be done to maximise the good effects of the surgery and reduce the complications.

The LHM team then moved swiftly on to the next new adventure: The Good Food Show.

What has that got to do with LHM? I hear you ask.

We were there for all five days of the show to promote our healthy eating 2008 Cookie Bake. We think we managed to speak to some 15,000 visitors as we gave away some 15,000 chip and bean cookies.

Olive Catering, an organisation that specialise in creating healthy eating experiences for children, came up with a series of cookies that all contain vegetables. The Chip and bean one has Soya beans in them. Not baked beans, as one young visitor to the stand suggested as his guess at the mystery ingredient.

These new recipes have been created to ensure that the schools and clubs that didn't take part in the bake last year because they said it didn't promote healthy eating have no excuse in February. Please remember to tell all your friends and family about the bake.

Those of us who manned the stand all requested new feet from Father Christmas. Believe me it was very hard work but the most amazing way to raise the profile of the work that we do and, importantly, the needs of the children and their families living with only half of their heart.

Amidst all of this we have tried to make sure that every caller has received support, every email has been answered and all information that has been requested has been sent.

My final words have to be a big thank you to all the staff, Trustees and our many member volunteers who have given up so much time and hard work to help the charity grow over the last year. Let us hope that 2008 is just as successful.

Over the last few months I've been busy raising the profile of Little Hearts Matter through a number of national events. I've also continued to keep in touch with journalists about our news and developments.

On 14 October we held our first charity run at the beautiful Shugborough Hall in Staffordshire. In the months leading up to the run I worked with the media to encourage runners to take part. An advertisement appeared in the leading running magazine Runners World as well as on their website which is regularly visited by runners looking for events and news. I also made links with the regional media and worked with them throughout to ensure as much coverage as possible. Many stories appeared on runners taking part. I was delighted to send a final news release to say that over £20,000 had been raised for Little Hearts Matter - what a success!

It was lovely to meet many of you at the Open Day on 11 November. I spent the day working alongside a photographer to secure a new range of images for the charity to use. A big thank you to all of you that took part in the photo sessions.

One of the highlights of the day for me was seeing Ben Hall receive the prestigious Diana Award from Trustee Ian Ash. The glossy magazine Cheshire Life included a piece on Ben's award in their December issue. Many congratulations again to Ben!

### LHM in the News...



with  
Emma  
Pelling

[epelling@aol.com](mailto:epelling@aol.com)  
0207 624 7533

Little Hearts Matter took a Stand at the BBC Good Food Show in Birmingham (28 November-2 December). This was a great opportunity for us to promote the Cookie Bake and the work of Little Hearts Matter. Information was handed out to thousands of people. TV Chef Lesley Waters kindly took time out of her busy schedule to visit our Stand on the weekend of the show. She had fun decorating cookies with Charlie Ramsey, Thomas Hooks, Matthew

Baumber and Rachel Baumber. Lesley has been a huge support to Little Hearts Matter and we're so grateful for all her support.

I'm looking forward to 2008. February will be busy with the Cookie Bake and I'd like to encourage you all to take part. I'll also be working with Tesco on the Valentine's Cards initiative. The cards will be in Tesco stores towards end of January so look out for them!

As always, please do let me know your news.



Charlie Ramsey, Lesley Waters and Thomas Hooks  
decorating cookies at the Good Food Show

### INCORPORATION UPDATE

We are delighted to report that the proposed change of legal status for the charity, from an unincorporated association to a charitable company, was approved unanimously by the membership at the AGM in Burton-upon-Trent on 11th November.

The Trustee and office team will be working hard over the next few months to make sure this can become effective from 1st April 2008. As we have explained before, there will be no changes to what the charity does and why it exists.

We hope that this change in status will help us to attract corporate funding, and to continue to find people with the skills and experience we need to run the charity well. It will also help to better control any potential risk to individual Trustees and members, through everyone holding a defined limited liability of £1 (the minimum level possible) - a notional guarantee which enables members to have a vote at General Meetings.

There will be a new charity number, and we also now have a company number. Instead of a Constitution, we now have a Memorandum and Articles of Association as our governing document. This is available for any member to view.

Please do not hesitate to contact the office if you would like to discuss this process in further detail.

Isabel Baumber



# A Time To Remember

**Below is a report on the Remembrance Afternoon, this is a lovely account of the afternoon, as we hear from our members who have lost their precious babies and children.**

On Sunday 29 September a bereavement afternoon was held at the Moat House Hotel, Acton Trusell, Staffordshire.

This was the first time in quite a few years that an event specifically for bereaved parents, siblings and families had been arranged.

Fifteen families attended the event from various parts of the UK. The main aim of the day was to provide families with the opportunity to meet and to offer support and reassurance to each other. It can be comforting to know that feelings they may be experiencing are totally normal, that they are not alone in dealing with their own tragedies. For some families, that attended, the death of their child had been a matter of days earlier, for others it had been some fourteen years ago, however, although circumstances were different the compassion between parents was ever present.

Parents could share pictures of their children along with their own personal stories on a display stand. It was lovely to see the photos and to show off our babies, this is something that can be hard to do with other people who can be frightened of seeing pictures of a baby who is no longer alive.

For all of us it was a great comfort to know that everyone in the room, even though individual experiences differ vastly, would understand why it is important to celebrate a life no matter how short. It is not always possible to do this in a public way as many people often seem uncomfortable celebrating the life of a baby who is no longer with us physically.

Each of us were encouraged to get to know each other over a cup of tea. Before long, experiences and treasured photographs were being shared. The overwhelming feeling was that this was a unique experience, with everyone fully understanding how each was feeling and no pretence to protect the feelings of others was required. It was good to be able to talk openly without fearing you were upsetting the other person. It also provided each of us with an insight into how others have coped or are learning to cope with their tragedy. For those of us where the condition was not diagnosed until after the birth and where no surgery had taken place it was an opportunity to talk with families who had experienced the various stages of treatment

and gave us all the chance to both reflect and celebrate our children's lives. It was lovely to meet others who 'understood', no long explanations to meet others who 'understood', no long explanations being needed and no excuses needed for tears. Hopefully friendships were formed that will help in the months to come.

Some of us met up again at the 'On Your Marks for Little Hearts' run at Shugborough a couple of weeks later. This was a great occasion where families could support the charity irrelevant of their own personal circumstances. It was lovely to see some runners with pictures and messages proudly displayed for all to see chatting with other runners whose children were participating at the event.

The event will be held next year (2008) at about the same time of year. It would be great to see you all again and if you have any suggestions or questions please contact LHM.

I think that everyone who attended would agree that the afternoon was a great success

Peter & Judy Groves

and gave us all the chance to both reflect and celebrate our children's lives. It was lovely to meet others who 'understood', no long explanations to meet others who 'understood', no long explanations being needed and no excuses needed for tears. Hopefully friendships were formed that will help in the months to come.

The event will be held next year (2008) at about the same time of year. It would be great to see you all again and if you have any suggestions or questions please contact LHM.

I think that everyone who attended would agree that the afternoon was a great success

Peter & Judy Groves

## Jessica

My baby sleeps in a field of dreams,  
a promise of life, now broken.

My baby sleeps in a field of dreams,  
never to be woken.

My baby sleeps in a field of dreams,  
innocent, untouched, unknowing.

My baby sleeps in a field of dreams,  
gold light surrounds her, glowing.

My baby sleeps in a field of dreams,  
but now our dreams are shattered.

My baby sleeps in a field of dreams,  
but she was real, she mattered.

My baby sleeps in a field of dreams,  
through wind and rain, unaffected.

My baby sleeps in a field of dreams,  
an angel now, protected.

I've held an angel in my arms.

Lord, how blessed am I ?

To hold this angel in my arms,  
my baby had to die.

Sweet Dreams, Little Kitten

Dedicated to our daughter, Jessica Thayne Lunn

02/09/06 - 04/09/06



# Feature

Here we take a look at why it is essential to keep your child warm and includes some tips from other parents.

When the cold weather is upon us, it's time to think about ways to keep the children warm.

Poor circulation (movement of blood around the body) and an inability to exercise to keep warm is a problem for many children with a single ventricle heart condition. Often their feet and hands feel like ice and their lips go blue very quickly when the weather is cold.

In these days of centrally heated houses many of us don't think of the simple ways to keep warm so here are some ideas of how to keep those noses from catching frostbite.

• **Pile on the clothes.** Lots of thinner layers are better than one thick one, as they trap, and warm, air. Go back to buying vests; lots of shops have good thermal ones for children. Put tights on under trousers and put socks on top. Yes even on the boys. Batman wears tights! Find a hat with earflaps and nice thermal gloves. Try the local ski shop, they have gear especially designed for very cold weather.

Gill Cloke says *"Michael hates wearing gloves! I had to resort to the old remedy of long string/ribbon attached to each & through the coat sleeves; this helps with losing them but doesn't solve the problem of how much he hates wearing them in the first place. The problem is he can't keep hold of Brum/Thomas/Lightning Macqueen when he's got his mitts on...! The only way round it we found was to either get Thomas gloves (and we promptly lost one); or to make a a character - I did try making a very basic puppet on a green pair - a few felt triangles up the back and a couple of eyes - and he quite likes his dragons. Though I suspect he would always prefer to be without, basically (and his hands do go black...)"*

*"So the other remedy is a buggy-bag with a big front pocket - in which you can put both hands AND Brum! We were very lucky and given a lovely fleecy buggy-bag with a big pocket, but it would be relatively easy to sew a flap on the front I would imagine. I am better at persuading Michael that Brum/Thomas is cold and needs to stay warm in the pocket than at persuading him to keep his gloves on..."*

• **Warm up from the inside.** Have hot cereal for breakfast; warm the morning drink of milk. Make hot chocolate or tea for snack time. Have soup with a sandwich for lunch and plan warm snacks throughout the day. Remember that your children need little and often so you'll be helping their diet and keeping them warm.

*"Our family are quite big porridge eaters*



Michael Smith wrapped up and ready to play in the snow

*anyway, which made it quite funny when Matthew's nursery class were doing Goldilocks and the Three Bears. They all had a taste of porridge, which didn't go down too well with most of the little ones, but, in true Goldilocks style, Matthew ate it all up because it was 'just right!'."*

Isabel Baumber

## Idea

Sprinkles on porridge!

Gill says "one of our first really successful 'lumpies' was pink and purple porridge, with coloured sprinkles - encourage them to eat the first layer, then sprinkle again!"

• **Cover those noses.** Remember scarves or a balaclava can help keep those noses warm.

• **Snug in bed.** All in one nightclothes with extra socks can help when the duvet slips, many catalogues have all in one suits for older

children. If it's really cold, how about using a sleeping bag.

*"My personal 'obsession' is keeping Matthew warm in bed. Ever since he was a baby, he has gone extremely cold when he is deeply asleep at night. When he was a baby, I made some sleeping bags (Grobag style) from fleecy fabric with long sleeves and gloves on. Now he's bigger, we have bought a goose down duvet (his duvet was probably more expensive than all the rest of the family's bedding put together!), and I have put fabric flaps on all his duvet covers so they tuck in".*

Isabel Baumber

• **Sore lips.** Prevent sore lips by using lip balm or simple Vaseline.

• **Runny noses.** If a runny nose persists, seek advice from your health visitor or the G.P. It might develop into an infection.

If you have any other ideas let us know.

Suzie Hutchinson

## And some useful products:

Duvet grippers £6.99 from Great Little Trading Co (to keep the duvet tucked in) <http://www.gltc.co.uk/fcp/product/-/bedroom%20essentials/Duvet-Grippers/879>

A charity called Fledglings has lots of products for children with special needs, including some all-in-one sleeping suits for older children. They can be contacted by phone 0845 458 1124 or email [enquiries@fledglings.org.uk](mailto:enquiries@fledglings.org.uk).

Polartec trousers, can be worn over regular

trousers or by themselves. They can be bought from JoJo Maman Bebe either online at [www.jojomamanbebe.co.uk](http://www.jojomamanbebe.co.uk) or call 0870 241 0560 and cost £12.

Wrist cosies are a good alternative to gloves. These can be bought from Muddy Puddles at [www.muddypuddles.com](http://www.muddypuddles.com) for £5 or you can call them on 0844 557 4950.

Long sleeved vests are a good idea and can be purchased from most retailers.



Below is an overview of the Little Hearts Matter AGM and Open Day held on Sunday 11th November 2007.

# Open Day



The Open Day was at Staffordshire this year, in the very friendly Bretby Conference Centre in Burton-upon-Trent, with accommodation, which was great for us - much easier to schlep around between talks and forgotten items in the room! Not only that, but it made a very easy and welcoming venue for the traditional social do on the evening before, which is always so appreciated by those of us who've come longer distances to get there - this do alone justifies the accommodation cost!

If you live close by and may not have chosen to come to the social the night before, we strongly recommend it, it's a great chance to relax and do some catching up with folk you only see at these events, and spend time marvelling over the kids (yet again) - particularly as they were having a ball with organised games and activities laid on by those wonderful folk at the office and their ace youthwork teams... We could just sit, and watch, and wonder. This is the (for us) great unmissable draw of these events - not just the chance to get more crucial information, but the opportunity to chat with parents who are 'walking alongside', and let the kids play with others like them, where all of you can share some common understandings.

The Open Day itself was the usual mix of serious business and serious socialising - of talks, presentations, charity business meeting, a welter of positively head-spinning information (often coming at you at high speed and frequency), mingled with more mixing and nattering; and we want to say a big thank-you to the organisation, because this is made so much easier by the provision of a Creche facility and supervised activities for the older kids - so great to know our wee ones are well looked after while we got some serious time to concentrate on thinking about them but without being distracted by the little darlings!

The theme of the meeting this year was



Ian Ash addressing LHM members during the AGM

Education, covered by a variety of professionals and standpoints. A range of professionals were present during the day, including the Deputy Head of the Education and Disability Department of Levenes Solicitors, two Early Years Inclusion Officers, a Disability Adviser working for a national charity, a Parental Supporter from a local Parent Partnership Service and a Personal Adviser from Connexions Staffordshire. These offered advice on a huge range of topics through age-group related workshops (from Pre-school and Infant School, Junior School, and Senior School and beyond) and covered issues such as childcare and starting school, settling into junior school and preparing for senior school, finding the right school, special needs and statementing, inclusion and disability rights, 'Early Support' and other forms of family support, how to manage school as a working parent, legal rights for working parents, how to address problems with staff and access appropriate extra support - even, rather dauntingly, how to take your Local Education Authority (LEA) to a tribunal (not recommended, but just in case of need...!)

As will be clear from that shopping list, a huge amount was covered, more than we can



Sophie Green & Carys Allen talking about their school experiences in the video

possibly report on here - more information on the exact content of the talks and workshops will shortly be available from the office or via the website. It was absolutely non-stop, and totally fascinating; exhausting, that goes without saying, but so worthwhile. Several days needed afterwards to absorb everything - and little off-shoots are still springing up from things we learned there that we're now trying to pursue, in our case with nursery and primary age children.

Two highlights in particular. First was the presentation of a Diana Award - for showing personal courage and "demonstrating outstanding qualities in overcoming adversity" - to Ben Hall. He was put up for this aged ten for a number of reasons - his own courage with coping with HLHS, the way he helps other children regardless of their needs, how he has spoken to parents about managing his heart condition, and his wonderful support of his family in their bereavement following the death of his young brother; he's the youngest person ever to get one, and a hugely worthy winner. We also particularly were struck by the 'Video Corner' session with Kassie (LHM's youth worker), where the older kids get the chance to discuss their issues with school - so there really is something here for the young people as well, and footage from some of these were shown in the Open Day and made a big impact. (...And OH how we look forward to being parents of teenagers!!)

Gill Cloke & Lindsey Hooks



Some of our little members enjoying the day





# Henry's Story

Our story as told by  
Robert Bromberg

At last I feel able to write of our experiences over the past year. Henry was born as the result of a hard won pregnancy and two previous miscarriages. This pregnancy was proceeding like clockwork until the twenty week scan. I should have been suspicious like my wife Laura when the sonographer couldn't see part of the heart and asked the specialist to have a look. She said that Henry was probably lying awkwardly and asked if we would like to go to Bristol where their scanning equipment was better. I naively suspected nothing although my wife as a natural pessimist knew for sure that there were problems and she was right. We saw the paediatric heart consultant in Bristol and during the scan the atmosphere got quieter and more sinister. "Have you got any major congenital heart disease on either side of your family?" she asked, and I knew that our world was about to collapse.

She explained what a univentricular heart was (which I had never heard of) and what Hypoplastic Left Heart Syndrome and an unbalanced AVSD meant with diagrams on the back of an envelope. We were 'counselled' with termination recommended as the best option. A palliative care procedure was explained, but all the awful consequences were made clear to us and it wasn't recommended. I went into shock and was led blindly around the hospital unable to speak by Laura. The hospital did not suggest any organisation or support group that we could access. Fortunately, the shock had passed for me by the next day and when the worst effects had hit Laura I felt able to research the internet and a telephone enquiry to the British Heart Foundation elicited a recommendation to LHM. Thank goodness because Suzie Hutchinson (who I am profoundly grateful too) spent two hours on the phone with me, and confirmed in my mind that we would keep him, a decision that Laura had long since come too. To my shame I was so angry with our unborn boy that I refused to talk and sing to the 'bump' or 'Little Junior' as he was known before birth. I would mutter to him, "you only had to grow properly and you failed in that". I am very upset that I ever did such a thing. Of course it wasn't his fault and I resumed singing and talking to him, but the experience of pregnancy for both me and in particular for Laura was ruined. We had the experience of going to the NHS birth preparation class where we were all told to look forward to our new healthy, bouncing baby. The women leading the class even knew about our plight and rightly looked embarrassed!!

Henry was born in Bristol on 15th September 2006 (he was 'too risky' to be born locally). He was transferred to Birmingham at 3 days old, since his condition is not dealt with at Bristol.



The experience of having a baby whose chance of death without surgery at six days old is 100%, and whose chance of death with surgery is 30% is an unbelievably heart wrenching and emotional experience. Carrying him down to his first operation felt like an appointment with an executioner. Fortunately the man who met us at the doors of the theatre looked like an even more genial relation of Santa and treated Henry like the most precious person he had ever met. Henry survived thank goodness after an awful six hour wait! With what we came to understand as the normal ups and downs in ITU he had some scares but Henry came through. He stayed in Birmingham for three weeks and then returned to Gloucester for eight weeks to learn to eat, but he never did and returned home on a naso-gastric tube, several medicines, and a feeding pump. The challenge then really began for us without any nurses, left alone to care for this very vulnerable little boy. We were doing well until the December check-up just before Christmas.

Another consultation, another consultant and another quiet, sinister moment we had come to dread. Although Henry still appeared well to everyone, there were no femoral pulses detectable by feel and the scan showed only the most flaccid of heart movements. It was severely impaired and failing rapidly. Henry was hours from death. The wonderful Dr Wright that evening, December 22nd stayed on to catheterise his heart and balloon out the scar tissue that had built up in the Aorta. I had the second experience of carrying Henry to surgery, bursting into tears and enduring the wait for news. I will always remember Dr Wright coming up the corridor with his thumbs up in the air. Henry remained in hospital for only a week, rather than the month that was first anticipated ... served me right for teasing my wife all year about the possibilities of eating turkey in a hospital canteen for Christmas. Henry returned home on the penultimate day of the year and on New Year's Eve, with our precious boy at home, we finally had Christmas Day with our family.

In January another catheterisation proved that Henry's heart had very impaired function, but was now slowly mending. Apart from on-going feeding difficulties and poor sleeping (this continues to this day) it was lovely having Henry at home. True, Laura's maternity leave where she should be enjoying bonding with her little boy was marred by the punishing medicine and feeding regime, multiple and continuous appointments and the need to avoid bugs, and therefore other parents, children and babies. However, he was alive and mega-cute. Henry has always been a big communicator and with his cheeky smile and love of people every trip to the supermarket brought and still brings a string of new admirers.



Having 'bounced back' with determination, our little fighter once again ran into trouble in March. Though due for his second stage operation, he couldn't wait the few weeks for planned surgery. Our community nurse came out and saw him have a grey-blue fit and advised us to call an ambulance. In Gloucester Children's Centre which is normally a calm, friendly hospital unit Henry's oxygen saturations were in the low 30's and dropping. Someone had clearly hit a panic button and suddenly people were running from everywhere. I have never seen so many registrars, consultants, crash team, sisters and nurses in one spot. They saved Henry and later that night he had yet another 90 mph+ blue-lighted ambulance ride to Birmingham. Next day I carried him once more to his operation with yet another gut rending wait to see if it had been successful. He left Birmingham in only four days and went back to Gloucester to recuperate which he did for another five weeks. By May he decided to give up eating altogether and became nil-by-mouth by elect. He joined our local nursery for special children to learn to eat.



It is a wonderful place staffed with dedicated and wonderful people. It was soon apparent that the emphasis for all the very young children was to have fun, fun and more fun.

There were interesting toys and exciting multi-sensory experiences. Henry was particularly partial to paint, which he liberally covered himself with, and everything around him. The children get to experiment with a wide range of textures and substances. Food is part of that rich experience. Touch it, play with it, roll it around, sniff it look at it, sing about it and make a great mess with it without any pressure to taste it or eat it. Henry just loved the whole thing - as long as he did not have to touch the jelly!

The breakthrough came in August 2007 when extra sessions of 'food camp' were held. One day when singing about currant buns, Henry picked his cake up and began demolishing it and then demolished another one belonging to the child sitting with him. He was away ... and hasn't looked back since. He began to experiment with Wotsits, Skips, Custard Creams and a variety of fruit. By November he would try anything and out came the naso-gastric tube.

This has changed our life. In toddler group he looks and acts no differently to any other child. He is always happy and content, which he has been since birth unless he is ill and is a joy to all.

During the year Henry has become a little celebrity.

In October 2006 he became the symbol of the Gloucester Hospital campaign to ban smoking in their grounds and he made first page in the local paper 'The Citizen'. His heart condition touched all.

In August 2007 he became the mascot for heart valve donation at Birmingham Children's Hospital and appears on their website.

On the day of the launch in between catnaps in his buggy and tasting very small quantities of food he was determined to communicate and smile with everybody there, as he clearly thought they had all turned up to see him. This included nurses, surgeons, representatives of charities, employees of the heart valve bank and visiting dignitaries.



Despite some of the harrowing and emotional experiences over the past year we have still been incredibly fortunate. We still have Henry, and he is the most adorable and engaging little boy. Each day I wake I am thankful that he still remains with us.

We have been able to surround him with love especially with the help of Laura's parents who are both young enough to have the energy and have the time as they are retired. They have given up hours and hours to support the three of us both at home and in our frequent visits to hospital

Henry has developed a character of his own. He is obsessed with Thomas the Tank Engine and seems to love everything about him, the other engines, the toys and the TV programmes. We have already visited him at the Gloucestershire Warwickshire Railway our local steam venue and he is booked on the Santa Express.

He loves painting, books, people, and other children riding around on the garden tractor with his Dad, going out for lunch, the computer and every one of Dad's many gadgets. Henry has a very happy and fulfilled life. He is having a ball!

We so easily could have chosen to have a termination and I understand fully why others in wrestling with their conscience come to a different decision. It is certainly no easy ride to bring a child with a disability into the world. I have not mentioned our profound and grateful thanks to all at Birmingham Children's Hospital and Gloucester Children's Centre. Nor have I mentioned the fight with the system to get everything to which Henry is entitled. For example the application for Disability benefit is made as difficult as humanly possible, and local services are a challenge to obtain with the notable and grateful exception of the James Hopkins Trust and Acorns Hospice who provide various respite care and support.

However, Henry is good company and a little boy who we are very proud of and love. He has brought joy to all of us. I am reminded of the LHM motto. "Half a heart, not half a life" and this certainly applies in every way to Henry.





# A Guide To B

There can be many extra expenses involved when you are looking after a child with a single ventricle heart condition, for example, with possible financial support, we have researched this topic further, and are in the process of developing an information leaflet with more details. We hope that this information will help to point you in the right direction of some of the sources of funding which may be available to help in certain circumstances.

If you are aware of any other grants, or of any regional/country differences in the information included here, please contact the LHM office at The government website [www.direct.gov.uk](http://www.direct.gov.uk) and the Citizens Advice Bureau website [www.adviceguide.org.uk](http://www.adviceguide.org.uk) are two useful starting points.

## General Living

Benefit or Item	Main Criteria	Means Tested	From What Age	To Find Out More
Disability Living Allowance (DLA) Personal Care Component	If baby or child needs more care than a non-disabled child of their age	No	3 months	<a href="http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10011731">http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10011731</a> Benefits Enquiry Line 0800 88 22 00 The LHM office has a DLA information pack.
<ul style="list-style-type: none"> <li>• DLA consists of two components - personal care and mobility. See below for information regarding the DLA mobility component.</li> <li>• Extremely long application form to demonstrate that baby or child needs care over and above a child of that age without the condition.</li> <li>• Awarded at different levels depending on care needed during the day and night.</li> <li>• Timings - phone to request form even if you then subsequently complete an electronic version, as your request date is the earliest the claim could be backdated to.</li> <li>• Paid every four weeks.</li> <li>• Use a computer if you can, as it will save time on future applications.</li> </ul>				
Carer's Allowance	DLA personal care component at middle or highest rate. Earnings below £95 per week after certain deductions have been made (rate correct in 2007)	Yes	As DLA	Tel: 01253 85 61 23 <a href="http://www.direct.gov.uk/carers">www.direct.gov.uk/carers</a>
A person who is looking after a disabled person may be able to get Carer's Allowance and claim income related benefit.				
Extra Child Tax Credit	DLA	Yes	As DLA	Helpline phone number 08.00 - 20.00 for England, Scotland & Wales 0845 300 3900
An extra amount is added to your CTC calculation for each child who is on DLA. If your child gets the highest rate of DLA care component, a further amount is added. Based on your joint annual taxable income.				

## Hospital Costs

Benefit or Item	Main Criteria	Means Tested	From What Age	To Find Out More
Visiting costs such as travel, parking.	Varies according to potential source of funding	Family Fund and Social Fund are means tested.		<a href="http://www.familyfund.org.uk/">www.familyfund.org.uk/</a> <a href="http://www.dwp.gov.uk/advisers/sb16/community.asp#pressure">http://www.dwp.gov.uk/advisers/sb16/community.asp#pressure</a> Cardiac Liaison Nurse or hospital social worker.
<ul style="list-style-type: none"> <li>• See Holidays/Days Out for description of Family Fund. Hospital visiting costs have been funded.</li> <li>• Local charities to the hospital may have emergency funds.</li> <li>• Community Care Grants from the Social Fund may be available for people on a low income who are under 'exceptional pressure'.</li> <li>• Travel costs to and from hospital for treatment may be funded for people on a low income - the hospital benefit office will advise.</li> </ul>				



# Benefits

Below are some ideas of possible financial support you may be able to receive.

feeding, warm clothes for winter and frequent hospital trips. Following our previous newsletter article where we suggested some ideas of retail.

you. We can't guarantee that you'll be eligible for everything listed here, so please contact the relevant organisation directly to explain your

to let us know of your experiences. Thank you.

(the CAB site has separate sections for England, Wales, Scotland and Northern Ireland).

## Out and About

Benefit or Item	Main Criteria	Means Tested	From What Age	To Find Out More
Disability Living Allowance (DLA) Mobility component	If child is unable or virtually unable to walk from age three If your child needs guidance or supervision when walking out of doors from age five.	No	If your child is 3 you can only get Mobility allowance if he or she is entitled to the higher rate. From age 5, two rates are available.	<a href="http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10011731">http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10011731</a>
There are two different levels of financial support available, depending on your child's mobility needs. The higher rate is the only possibility from age 3 to 5. As with the DLA personal care component, the application form is long and time consuming.				
Motability	DLA mobility component at higher rate.	No	3	<a href="http://www.motability.co.uk">www.motability.co.uk</a> Tel: 0845 456 4566
If your child receives higher rate mobility allowance, you can get a car through a purchase scheme to help disabled people to hire or buy a car - you need to have at least 12 months award remaining.				
Road Tax Exemption	DLA mobility component at higher rate. Need exemption certificate from benefits agency.	No	3	<a href="http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/Yourvehicleandlicence/DG_10028003">http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/Yourvehicleandlicence/DG_10028003</a> Ask for form DLA 404 from DLA Unit Tel: 0845 712 3456
Road Tax Exemption - if your child receives higher rate DLA mobility allowance, you can apply to not pay for road tax, provided that car is used only for the benefit of the child concerned.				
Blue Badge	DLA mobility component at higher rate.	No	Easiest to apply for from age 3 with DLA higher rate, but is possible earlier if necessary	<a href="http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/DG_4001061">http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/DG_4001061</a> Contact your local authority.
Blue Badge - parking concessions (places and sometimes prices) - easy to apply for with higher rate mobility component of DLA. Please see individual websites (links available from main direct .gov site) for information about how the scheme applies in Wales, Scotland and Northern Ireland.				
Disabled Person's Railcard	DLA mobility either lower or higher rate Or DLA personal care middle or highest rate.	No	Children only pay for train travel from age 5	<a href="http://www.disabledpersons-railcard.co.uk/">http://www.disabledpersons-railcard.co.uk/</a>
Disabled person's railcard costs £18 per year and gives 1/3 off most fares for the person plus accompanying adult. Also local schemes to provide cheap transport for people with mobility problems.				
Pushchair	Individual assessment if child has difficulty walking	No	3 (possibly 2½)	Referral from your GP or physiotherapist. Phone NHS direct on 0845 4647 or, in Scotland, NHS 24 on 0845 4242424
NHS Wheelchair Service will provide Maclaren Major Buggy or may provide voucher to that value towards a different pushchair. Accessories are not included, but you may find charities which will fund them.				



# A Guide To Benefits - Continued

## Holidays / Days Out

Benefit or Item	Main Criteria	Means Tested	From What Age	To Find Out More
Family Fund	Income related (gross income less than £23,000 and savings of £18,000 or less).	Yes	Any time	0845 130 4542 <a href="http://www.familyfund.org.uk/">www.familyfund.org.uk/</a>
<p>The <b>Family Fund</b> provides timely grants to families with severely disabled or seriously ill children, based on families' views and needs (you can ask for whatever you need most). Government funded, based on the effects of the disability on the family. Holidays or family breaks have been successfully applied for. Can apply to Fund more than once.</p>				
Free Swimming	Swimming forms a part of their therapy.	No		Contact your local leisure centre or pool.
Some pools will offer free entry to disabled people.				
Free/Reduced Entry Fees	DLA award letter or letter from your GP giving proof of disability.	No		Contact the attraction you plan to visit, or look on their website.
<p>Free or reduced price entry to certain attractions for either your child or yourself as their carer. Some examples are Twycross Zoo - reduced price for child and free carer, Space Centre - free carer, Warwick Castle - 50% for child and carer, Cadbury World - free carer, Legoland - free carer. Obviously LHM cannot guarantee any of these prices - they are based on genuine personal experience but should be checked by yourself.</p>				
One - off special holidays	Varies by charity	Unlikely	Most charities have age limits, so please check.	Contact a Family (charity for families with disabled children, especially rare conditions) has a list of these organisations on their website. <a href="http://www.cafamily.org.uk/holidays.html#wishes">http://www.cafamily.org.uk/holidays.html#wishes</a>
<p>There are a number of charities, such as the Make A Wish Foundation, which offer special treats or holidays for children who are very ill or are living with severe disabilities. They cover the whole of the UK but have different eligibility criteria so you will need to check with the individual charity directly for further information.</p>				
The Cinema Exhibitors' Association Card	Be in receipt of DLA	No		<a href="http://www.ceacard.co.uk">www.ceacard.co.uk</a> Tel: 0845 123 1292
<p>This is a national card that verifies that the holder is entitled to one free ticket for a person accompanying them to the cinema. A processing fee of £5.50 is charged per card and it is valid for three years. For more information or to download a form you can visit their website, it also lists all the participating cinemas.</p>				

## Household Costs

Benefit or Item	Main Criteria	Means Tested	From What Age	To Find Out More
Washing machine or extra bedding	Varies according to potential source of funding.	Yes		<a href="http://www.familyfund.org.uk">www.familyfund.org.uk</a> <a href="http://www.dwp.gov.uk/advisers/sb16/community.asp#pressure">http://www.dwp.gov.uk/advisers/sb16/community.asp#pressure</a>
<ul style="list-style-type: none"> <li>• See Holidays/Days out for description of Family Fund. Washing Machines have been funded where a child is on diuretics.</li> <li>• Community Care Grants from the Social Fund may be available for people on a low income who are under 'exceptional pressure'.</li> </ul>				
Disabled Facilities Grant	Essential adaptations required to your home.	Not means tested if for child		<a href="http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/DG_4000642">http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/DG_4000642</a>
<ul style="list-style-type: none"> <li>• A Disabled Facilities Grant is a local council grant to help towards the cost of essential adaptations to your home to enable you to continue to live there.</li> <li>• Available in England, Wales and Northern Ireland.</li> <li>• Can be a very long process, so get in touch with Social Services as soon as you know that you might need to adapt your home.</li> </ul>				
Free Nappies	If child still needs nappies due to their disability.	No	Age 3 or above	Your health visitor or school nurse should be able to put you in touch with the Continence Service.
<p>NHS Continence Service can fund and deliver nappies if your child needs them due to their disability.</p>				



## Utilities / Household Bills

Benefit or Item	Main Criteria	Means Tested	From What Age	To Find Out More
Warm Front	Warm Front grants - qualify through DLA entitlement. England only.	No	As DLA	Freephone 0800 316 6011 <a href="http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/On_a_low_income/DG_10018661">http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/On_a_low_income/DG_10018661</a>
Cold weather payments	Cold weather payments - Income support with a disabled child premium or Child Tax Credit with disabled child element.	Yes		JobCentre Plus <a href="http://www.direct.gov.uk/en/Over50s/Benefits/ConcessionsAndOtherHelp/DG_10018668">http://www.direct.gov.uk/en/Over50s/Benefits/ConcessionsAndOtherHelp/DG_10018668</a>
<p>Warm Front is the Government's main grant-funded programme for tackling fuel poverty. If you need help paying for heating and insulation improvements in your privately owned or rented home, you may be able to get money from the government's Warm Front grants scheme if you're receiving income or disability - related benefits.</p> <p>If you're on a low income, you may be eligible for a Cold Weather Payment to help you with extra heating costs during very cold weather in your area.</p>				
Council Tax Benefit	Room in your house specifically required by a disabled person.	Yes		<a href="http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_064481">http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_064481</a> Contact your local authority or local council to find out if you are eligible.
<p>The disabled band reduction scheme aims to ensure that disabled people do not pay more Council Tax because they live in a larger property than they would have needed if they were not disabled eg a second bathroom or kitchen needed by that person. Having a disability does not automatically entitle you to a reduction.</p> <p>These are called Rent and Rate Rebates in Northern Ireland. Contact Northern Ireland Housing Executive or Rate Collection Agency.</p>				
Specific bills	Extra water use due to a disability.	No		0845 9200 888
<p>Thames Water offer help with water bills if customers are high water users due to a disability within the family which requires the use of extra water eg having to wash large quantities of clothes and bedding regularly such as due to diuretics.</p> <p>It might be worth contacting other utility providers to see if they can offer any discounts if there is a specific need for additional spending on your part due to your child's disability.</p>				

Andrea Harris & Isabel Baumber

### Disability Living Allowance

#### Aids to understanding the application process

Disability Living Allowance has been created to help severely disabled people with some of the costs incurred due to the effects of their disability. The allowance is paid to the disabled person. This may be via a carer in a child under the age of 16 years.

The allowance is tax free and application is not affected by any savings or the income of the family.

To apply the disabled person has to have lived in the UK for at least 13 weeks out of 52.

If it is an application for a child they have to be over three months old. The only exception to this rule is if the child has a life threatening disorder from birth and then an application can be made by a health or social service professional under special rules.

All applicants have to be under the age of 65.

#### There are two application forms

1. From birth to the end of their 15th year.
2. 16 years old and above.

#### DLA is made up of two components.

1. To relate to the care needs of the applicant
2. To relate to their mobility needs.

The allowance is not awarded to anyone because of their diagnosis, it is purely the care or mobility needs that are considered and those have to be considerably greater than a peer of the same age group.

### Care Component

#### Lowest Rate - £17.10

The applicant needs help with personal care for part of the day.

They need attention or supervision for at least one hour each day.

#### For Example

- Do they need to be watched for a deterioration in their condition?
- Do they need help with eating?
- If they are over 16 can they prepare a full cooked meal independently.

#### Middle Rate - £43.15

If the applicant needs help with personal care frequently through the day, or Someone who needs help with care just through the night.

#### For Example

- Someone who needs nasogastric feeding
- Someone who needs supervision because they do not know when their condition deteriorates.
- Someone who needs overnight oxygen therapy.

#### Highest Rate - £64.50

This would be available to someone who needs help with personal care throughout both the day and the night.

#### For Example

- This could mean that they need supervision at night.

- Care must be for 20 minutes or more on each occasion

*At night means after the last person in the house has gone to bed.*

### Mobility Component

#### Lower Rate - £17.10

Is only awarded in the five years and upward group to someone who cannot walk outside on unfamiliar routes without someone to guide them.

#### Higher Rate - £45

This is awarded to someone who is virtually unable to walk because of a physical disability. The exercise can lead to the onset of discomfort. When completing the form it is useful to state if the applicant has to sit down, how fast they can walk and what their balance is like.

Only having received the higher rate mobility allowance can someone apply for motability, this is aid for buying a car.

Young people at the age of 16 can learn to drive if they are recognised as disabled. Support for driving lessons can be sought from the Independent Living Fund.

Blue badges are awarded through the higher rate mobility component but can also be accessed through the blue badge scheme for a child over the age of two if a child needs bulky medical equipment which cannot be carried around without great difficulty.

Suzie Hutchinson





# Fundraising

Some of your fundraising exploits

Welcome to the fundraising pages where we feature some of the fabulous fundraising you have been doing in support of Little Hearts Matter.

Please continue to send your photos and stories of your fundraising events to [paula@lhm.org.uk](mailto:paula@lhm.org.uk). We can't promise they will be published



**Paula Hancox**  
Fundraising Officer

in the newsletter but we all enjoy reading about what you have been up to and looking at the photos. If you would like to get involved with fundraising and need ideas or information to support your event, please don't hesitate to contact me at the office or by email. I look forward to hearing from you.

## DOUBLING YOUR MONEY!

Over the years we have given ideas about this in our newsletters, so I thought that I would tell you about how I managed to pull various things together to more than double some fundraising. I ran in the LHM run at Shugborough Hall this year and with a team we turned £3,700 into £7,700 at no extra cost to our sponsors. We managed to raise this by:

- using Justgiving - we were able to send an email out to 300 potential sponsors (we also used paper forms)
- company matched funding - I persuaded 5 colleagues to join me and E.ON UK matched £3,000 of our sponsorship
- gift-aiding as much as possible raised a further £1,000.

We don't expect everyone to raise these levels but by just exploring around the edges, it might be possible to increase the amounts we raise.

David Baumber

## BIG HEARTED BUSINESSMEN

We are really pleased to announce that the Elite Chapter of BNI, who meet in Sutton Coldfield each week, has adopted LHM as its nominated charity for the year.



Pictured with Suzie Hutchinson is BNI member Chris Williams who recently ran in the Amsterdam Marathon and raised £600. The BNI also presented LHM with a further £320.

## ANYONE FOR A GLASS OF WINE?

Ellie and Richard Steadman raised £1,400 by holding a wine tasting and BBQ in memory of their daughter Emma Jane. Ellie said "Emma would've been two years old in September so it was great to have a party and raise money for the charity".

People paid to taste the wine and there was also a raffle as well as Pogo Sweepstake. Richard said "I wanted to do something silly so decided to get the guests to bid for how

long they thought I could pogo for. To make it more fun I did it in a tuxedo.

"Everyone had a great time and it was a really positive way of remembering our beautiful baby Emma".

## AND SOME MORE THANK YOUs

In June this year Corwin Meynell's Gran opened her garden and held a coffee morning to help raise funds for LHM. They were lucky, with one of the few sunnier days in June and managed to raise £500! Wendy put on a bring and buy stall, name the teddy game as well as live music!



"Thank you Granny for raising £500 at your coffee morning"

Pictured below is 11 year old John Hands dressed as Harry Potter at his mum's recent fancy dress, 40th birthday party in aid of LHM. The Hands family and friends presented us with £223 which was funds raised through a raffle at the birthday party and a raffle at Amanda Hands dad's golf club and a donation from Ragdoll Productions.



Mrs Lucy Allan and her friends have been fundraising in support of Little Hearts Matter for their daughter, 4-year-old Evangeline who has HLHS, pictured above right. Lucy has been

holding coffee mornings and has had Little Hearts Matter merchandise and collection tins so that people can donate. She presented us with a cheque for £94.60 and continues to fundraise for us. We are truly grateful to Lucy for her ongoing support.



Joe Kilty very bravely ran the Great North Run for Little Hearts Matter and raised a smashing £1,500! He managed to do the gruelling 13.1 miles in 2 hours and 1 minute. Joe commented "The one minute really hurt!". Our thanks goes to Joe and hope he has now fully recovered.

Sarah Green and Ann Haigh gallantly ran in this year's London Marathon which was the hottest on record and raised £1,248.40! Putting on a brave smile for the camera, they are pictured below, shortly after they had finished. Well done and congratulations to them both



## NATIONAL COOKIE BAKE 2007



Gill, Michael and Olivia

Our son Michael has HLHS; for the last three years we've done the cookie bake through my older daughter's nursery, who've been terrific, sold cookies for a solid week each time and raised hundreds of pounds. This year however, my daughter started school, so it all seemed more difficult to organise. However, I did raise the subject of selling cookies at school with Mrs Blackadder, the teacher of P1B - my daughter's class - expecting a flat 'no'. Greatly to my surprise, however she adopted the idea with enthusiasm - and asked if they could do it as P1B Enterprise for this year.

I'd never heard of 'Enterprise' in primary school - I don't know if all of you know about it, but it turns out to be a project that every Primary class has to do, every year - it can be about all sorts of things besides fundraising - but the basis of it is (I think!) that the kids have to have a topic, find out the facts for themselves, think up an activity and carry it out, and write up the results - there may be other aspects, but I'm still hazy on the details. But the LHM Cookie Bake fitted the bill perfectly, seemingly - and I was just amazed at the results.

First-off they took information gathering very seriously. They got me in to talk about Michael, and the condition and the charity first; and I have to tell you, even though I'm used to talking to people about Michael and telling folk the basics - I had some sleepless nights about this!... If you've never addressed a whole classroom of 5-year-olds before - and on such a difficult topic - you'll know what I mean! How was I going to convey the seriousness, to 5-year-olds?? I kept the story basic but with a few real 'sticking points' to remember - Michael's helicopter ride (from Scotland down to Birmingham), his 'zipper' scar (blood and guts always wow with this age-group), and how Olivia got to visit the Chocolate factory while he was in hospital... Olivia also helped me make the presentation; we started off with a 'guessing game' about where the heart was and what it did (I wish I could have recorded this - it was a hoot!), then Olivia confidently filled them in on the realities - and I may say that this (and the Cadbury's visit) raised her street-cred no



P1B's storyboard

## Bells and Hearts

Fiona and Ian Lunn tied the knot on Monday 25th June 2007 almost one year after losing their beautiful daughter, Jessica.

"We had always talked about getting married, but had always said that we would wait a few years and include our kids. When a friend found out about Little Hearts Matter, I became determined to somehow raise money for them, through some kind of fundraiser. Eventually, we decided to combine our wedding and Jessica's fundraiser, so that she was still being included in our big day and so that all our family and friends could do something to help heal the hurt of her loss. We decided that the wedding reception would be the fundraiser, that we would ask everyone for donations instead of wedding gifts and we even asked our suppliers if they would take something off their final charge and we would donate it to LHM, in their name".

"At the reception, we were able to announce to everyone that they had helped to raise £1,197.05, over £300 of which was donations from our suppliers. I told everyone that our wee girl would be so very proud of them all".

We are very grateful to Fiona and Ian for thinking of us during this happy, yet emotional day in their lives. Pictured above, are Fiona and



Ian on their wedding day and a picture of Fiona with her bouquet, quietly remembering Jess.

Philip and Julie Thomas (pictured below left) also celebrated their wedding earlier this year and decided to ask their guests to offer donations to Little Hearts Matter in lieu of wedding gifts for themselves. They are friends of Alison and Pete Turner whose son Charlie has HLHS and they wanted to do this for them. Thanks to the generosity of their friends and family, we were presented with a fantastic £1,000.

There have been a few people choosing to use their own special occasions to support Little Hearts Matter including grandfather to 1½ year old Joseph Webb, Mr McLean at his 70th birthday who raised over £600.

We are really pleased and honoured to receive donations in lieu of gifts and our thanks go to you all for your kind support.

end! And after that P1B took over, under Mrs Blackadder's guidance - and for the next two weeks did wonders. They looked up stuff on the web, they read 'easy' books about hearts and blood, they drew heart cards and LHM slogans and illustrated the whole story on a 'story-board' wall (and I was amazed by the amount of technical detail they had in their grasp), they made a presentation in Assembly; then they set a date to sell cookies, designed posters advertising their cookie-baking and made invites to send out to all the parents.

Then we got down to making cookies. We ended up with hundreds of cookies - enough for each child to take home several, and dozens over to sell in school. The mums and dads duly turned up on the Friday morning to see the photos, posters, write-ups, pictures and presentation - and pay for their cookies! From them, and selling in school, P1B made £120 - and I kid you not just about every 5-year-old child in that class now knows about veins, arteries and how the heart works!

It's really well worth asking in your local schools if they'd consider adopting this as an Enterprise topic - schools like having a really worthwhile project, particularly if they can mention you in doing it, since a personal connection always helps motivate the kids and parents. And you may find you enjoyed it and are as inspired by it as we were - honestly!

was reduced to tears when I saw their presentation wall. One wee boy had designed a card with the slogan 'Little Hearts Matter to me...' I well up even now...

Gill Cloke



Olivia & Mrs Blackadder decorating cookies

We are proud to announce that the 2007 Cookie Bake raised £14,000 with many schools, clubs and groups all baking in support of LHM.

We hope 2008 will be bigger and better as this year we have had two healthy cookie recipes developed especially for LHM so now you can bake both healthy and sweet cookies and raise money at the same time!

The new recipes are the chip 'n' bean cookie and the orange squash shortie, both with great tasting ingredients including a mystery vegetable in each.

If you would like to take part in next year's Cookie Bake you can register now at [info@lhm.org.uk](mailto:info@lhm.org.uk)





# Zipper Zone

Hello to all young people, I hope you all had a brilliant Christmas and got everything you wished for!

The time has come for me to write another piece for the youth section of the newsletter, (Parents if you are reading this, please can you pass it on to your son or daughter so they can have a read). We have had a further successful few months with our youth project work; the Education pack is coming along and it is nearly written, the DVD to accompany it has been filmed and the editing is taking place.

The Open Day in November at Bretby Conference Centre was a great success, everyone had a terrific time doing the activities and taking part in the puppet show. The focus was on Education and we had some of you share your school experiences on camera, which we were very grateful for. If anyone else would be happy to write to me and tell me how

supportive or unsupportive your school has been and if your heart condition affects your progress, then I would be really interested to hear your stories. My email address is [kassie@lhm.org.uk](mailto:kassie@lhm.org.uk).

The On your Marks for Little Hearts Race in Staffordshire last November raised a lot of money for the charity which was very much appreciated. Thank you to all of you who took part, especially those of you in fancy dress - the outfits were very funny.

In the Summer we will be running another Activity Weekend and I am starting to plan activities for it, so if there is anything in particular you would like to do, drop me an email and I will see what I can organise!!

Look forward to seeing you all soon,

Kassie.



Carys Allen (11) proudly showing her medal for running the fun run for 'On Your Marks for Little Hearts'.

From Left to Right: Daniel Smith (11), Matthew Luck (16), Bailey Smith (9) and James Metcalfe (11) at the LHM Open Day.

## Ben and the Diana Award



Following the sad death of Princess Diana a special award scheme was created to reward children who have demonstrated special qualities of caring. It might be work in eradicating bullying, support for charities or working with someone in need.

Our very own Ben Hall has just been presented with the Diana Award.

Whenever Ben is with younger children who have, like himself, been born with single ventricle heart disease he immediately offers his caring support. The younger children look up to him as a happy, caring, and full of life young man.

Ben also helped his family and friends through the devastating loss of his younger brother Freddy.

Ben is the youngest recipient of this special award. Normally only children over the age of 12 are eligible but the Award committee were so taken by Ben's thoughtfulness that they honoured him at the age of ten.

Well Done Ben.

## Competition



As we are currently in the beginning stages of designing our new **Youth Website** we are looking for you to draw some pieces for our **Graffiti Wall**. Between now and the end of February the design team and I would like you to email me ([kassie@lhm.org.uk](mailto:kassie@lhm.org.uk)) as many graffiti pieces as you like that are relevant in some way to Little Hearts Matter.

(You can use the programme 'Paint' on your computer and email me your design as an attachment or if you are a tech head and know of any other software you can use to produce your Graffiti, feel free to use that.)

The winning design will be the first piece of Graffiti to go on the wall once the youth website goes live and the winner has the option to either receive a **£20 Gift Voucher for HMV** or if you have a particular interest in web design or photography, and considered it as a career, then I can arrange for you to spend **a day with our SGUD design team as work experience**.





# Noticeboard



2008

## Volunteer Appeal

Little Hearts Matter would not be able to offer the support services that it has created if the charity didn't have a large number of volunteers.

They man the support line out of office hours. They run the regional networks. They help to write all of the information that the charity produces and they help initiate many fundraising activities. It is also important to remember that all of the charity's Trustees are volunteers and they give huge amounts of time to the work of the charity.

Volunteering is hard work but the LHM team, as well as getting involved with organisation and support, also have an opportunity to meet up with other LHM members and have gained a huge amount of support from each other.

### We are looking for new Volunteers.

- Could you answer the telephone to a distressed parent?
- Could you support someone through the decision making needed with an antenatal diagnosis?
- Are you an organiser who would like to become involved in arranging regional network events?

We have organised a weekend where you could find out if you have what it takes to be a volunteer.  
1st & 2nd March 2008

If you are interested in exploring becoming more involved just give us a ring and we will book you into the weekend's activities. All your expenses will be paid by the charity.

If you would like an opportunity to chat the role of a volunteer through with the team just give us a ring on 0121 455 8982.

## Cinema Exhibitors Association Card - Application Form

We have enclosed with this copy of the newsletter an application form for the above card. This is a national card that verifies that the holder is entitled to one free ticket for a person accompanying them to the cinema. A processing fee of £5.50 is charged per card and it is valid for three years. For more information or to download a form you can visit their website, it also lists all the participating cinemas.

## Bethan - A year in the life of the baby with half a heart.

Bryan and Mandy Edwards, one of LHM's families have written a book about their daughter Beth's first year. If anyone is interested in seeing a copy you can visit her website [www.bethan.org.uk](http://www.bethan.org.uk). Part of the proceeds will be donated to Birmingham Children's Hospital and Edward's Trust or alternatively you can choose Little Hearts Matter in the optional instructions box.

## Something the Lord Made -

Starring Alan Rickman and Mos Def  
Reviewed by Paul Hooks



When my father-in-law found this film I thought he had found a documentary on the history of the BT shunt however, it is in fact a film drama. That said, it does try and be true to the history even if the focus is very much on the relationship between Vivian Thomas and Alfred Blalock.

This does mean that Helen Taussig's role, (the 'T' in BT Shunt) gets somewhat overlooked and the film focus leaves you feeling that the shunt should have been named after Blalock and Thomas rather than Taussig. My research suggests Taussig came up with the idea, Blalock thought and planned the actual procedure and Thomas was heavily involved in the animal experiments.

### Anyway onto the film....

It starts in the 1930s with Vivian Thomas losing his job in Nashville. Although he is a carpenter he has a high school diploma and is working so he can pay his way through college. He gets himself a job as a janitor at Vanderbilt University Hospital which is where he meets Dr Blalock. Blalock soon recognises his talents and starts using him as a research assistant where they work on the nature and treatment of hemorrhagic and traumatic shock. At this point the only controversial element of the story is that the research is carried out on dogs although this is not mentioned as an issue during the film. One of the experiments they conducted was where the left subclavian artery was joined to the left pulmonary artery. This failed, however, years later Blalock was to return to the idea. In 1941 they successfully proved that the shock was caused by the loss of blood and other fluids, this was a big breakthrough and resulted in Blalock being offered the post of Surgeon in chief and professor and director of the department.

At this point Blalock and Thomas have a very close working relationship and Blalock takes Thomas with him and you start to see the racial issues unfold. They had segregated buses; Thomas was not even allowed to enter through the front doors of the hospital.

At St John Hopkins Hospital Blalock was introduced to Dr Taussig who has been working with Blue Babies for a number of years. Taussig suggested

the construction of a 'patent ductus' (open tube) may be the solution and they agreed to work on this. It appears from the film that Thomas was the one who finally managed to replicate the condition and then they adapted the idea they had linking the left subclavian artery to the left pulmonary artery.

On November 29th 1944 a small frail child was wheeled into an operating room at Hopkins for the first attempt to treat Tetralogy of Fallot. It was the first blue baby operation and came to be known as the Blalock-Taussig Shunt. Unfortunately he died several months later after a second operation however, two additional surgeries and the resulting physical changes proved it was a viable way to save lives and in years afterward, as we all know, it has helped thousands of children.

The outrageous element to this is it took 25 years for Thomas to be credited publicly for his role in devising the blue baby surgery. In 1976 he was awarded an honorary doctorate and his portrait hangs in the lobby of the Blalock Building at The John Hopkins Hospital across from the image of Alfred Blalock.

Something the Lord Made (film) via Amazon £3.50 plus P&P

Also available:

Partners of the Heart \$29.98 ([www.pbs.org](http://www.pbs.org))

Amazon.com \$25 (narrated by Morgan Freeman)

Partners of the Heart book £10.50



# Over to you...



Little Hearts Matter,

11 Greenfield Crescent, Edgbaston, Birmingham, B15 3AU, telephone: 0121 455 8982; email: [info@lhm.org.uk](mailto:info@lhm.org.uk); [www.lhm.org.uk](http://www.lhm.org.uk)

## ELLA WOODCOCK

Dawn, Ella's mummy understandably couldn't choose which special photo to use for the newsletter, and neither could we, so we thought we'd feature a few of Ella's achievements.



Ella with big sister Chloe at home for her first Christmas, after coming home for the first time after her stage 2 surgery, two days before Christmas.



"Ella's first sports day at School, she was able to take part in all the races, with a staff member alongside her and at her own pace".

"Ella decided she would dress up for Halloween this year, just like her sister, so she chose this lovely outfit and even did a short stint 'trick or treating'".



"To see Ella smile and play in the rivers, climb on the rocks during our summer holiday this year in the Yorkshire Dales was a real achievement".



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](mailto:info@lhm.org.uk)



- ABOVE: Olivia Rhodes (3) and Michael Smith (3) meet up earlier in the year.
- LEFT & BELOW: Charlie Turner as Joseph in his school nativity and celebrating his 4th birthday dressed as 'Donkey' from 'Shrek'



## World's Easiest Cheese Sauce Recipe!!!

NO LUMPS (guaranteed).

1. Melt a knob of butter in the pan.
2. Add a couple of large spoonfuls of Philadelphia or other soft cream cheese (full fat version), stir it until it starts to melt;
3. Add a little milk and it'll just smooth right out into a sauce Then add your cheese, to taste.

You can also add ketchup to this, to make 'pink sauce' - always a hit in my family!  
Particularly good with tuna, and sweetcorn - and also good as a way to sneakily get a few finely chopped veg down...!

Gill Cloke

