

Little Hearts Matter Newsletter

Autumn 2011



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Want to join us on an adventure?



Having already blasted ourselves into the 21st Century with Facebook and Twitter we are now venturing into email updates and newsletters, and we would like you to join us!

- Would you like to be the first to know about upcoming events and important news?
- Would you like to be informed about any studies you may be able to take part in?
- Would you like to be able to read mini e-newsletters online as well as receiving the main newsletter in the post?

If yes then please get in touch and tell us your email address. You can do this in several ways:

**Email us at info@lhm.org.uk
Register on our website www.lhm.org.uk
Existing members - login to the website and edit your account details.**

We won't bombard you with emails, you can opt out at any time and we certainly won't share your details with anyone else.

We may also contact you on a one-to-one basis because your experience/

Did you know?

It costs us:
28p to send a letter
12p to make a phone call
0p to send an email!
And it's good for the planet too!

location is similar to a family in want of other family support, but you can easily decline.

Don't forget we are always available to answer questions and offer support by email, just contact info@lhm.org.uk or call 0121 455 8982.

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News



Suzie's News

It is difficult to believe that we are now in the last quarter of the year! Hopefully many of you have had a chance to find some sunshine over the summer. The LHM team have juggled annual leave with running the charity, tidying the office and planning the workload for the end of the year. In years gone by we had quiet Augusts but this year we have been very busy. Many more newly diagnosed families are being referred to us for information as they learn more about their baby's heart problems and we are also being asked to be involved with lots of new research as well as providing an expert voice whenever the needs of children with single ventricle heart problems are being discussed.

It is very important that LHM has every opportunity to provide a voice for the children and their families so please let us know where your challenges are so that we can make sure that anyone in arenas for change is able to understand what is most important for families. Although we will not know what the final shape of congenital cardiac surgery is going to be until December we are remaining involved with the process as much as possible, we are working to ensure that the needs of children with the most complex heart conditions are high on the priority list for the Safe and Sustainable team as they plan the

implementation of the new service. For an update on work that has been done over the summer look at page 13.

We know that many of our families have been very upset by the Safe and Sustainable process and their worries for the future care of their children. It is a time of uncertainty. First and foremost Little Hearts Matter is here to support you through it whatever the final decision may be. We are not supporting any one unit but we are working to ensure that at the end of the process the highest quality service, the only service that will really be able to offer the best care into the future is available for every child and that the needs of their family remain a priority. Ring, email or message us with any concerns, fears or confusions.

The autumn is the beginning of a new year for many with lots of the children starting school for the first time, others will be moving up a year. Their lives are moving on just as they should, just like other children. You, as their parents will have concerns about their ability to cope with the challenges of the year ahead, remember that we are here if we can help and we also have information books that may help with information for new teachers, just give us a ring on 0121 455 8982. We also have lots of parents who would be happy to chat about their experiences either on our out of hours parent-to-parent phonenumber, website message pages or the LHM Facebook site.

Disability Living Allowance has also been a big part of our work over the last few months. It is clear that the Department for Work and Pensions is trying to make the process of application as difficult as possible. Although we understand their need to ensure that they are awarding the allowance to people who really need added care it is also clear that the stress-filled process of applying is causing families a great deal of worry. We will be doing some more work in this area over the next few months, there are DLA packs available to help you when you are completing the forms just give us a ring if you need any help on 0121 455 8982.

Over the last few months we have been pulling together project grants and funding bids. This is the way that we

work to bring in much needed funds so that we can offer you a new service. We need your help in three ways.

What are the support and information services that you want to see next?

What LHM services have made the greatest difference to your family's life and how? We need to know what impact our work has as many funders ask us for proof that our services help our members.

Do you work for a company that might sponsor an existing service, like the newsletter or who might like to support a service in the future?

If you can help with any of these areas, either give us a ring, email me, **suzie@lhm.org.uk** or send a message through our website or Facebook page.

Finally we are delighted to be able to announce that the Fontan book that we have been working on over the last year is finally ready for you. The aim of this new pack is to help prepare parents and children for what a Fontan procedure is all about. Written especially for our members, the new booklet explains why a Fontan operation is necessary, what the surgery is all about and what care a child will need after the operation. It will go hand in hand with a booklet all about the MCT diet, a special diet that some children need for a short time after surgery and a leaflet on anticoagulation therapy. Many of our families have been asking for more information on the Fontan procedure for a long time so we hope that this new resource will answer all of their questions. It is of course free to all our members, if you would like a copy just give us a ring or go to our website where you can download the information.

Finally I urge as many of you as possible to get your friends, families, local school or colleagues at work to hold a Christmas bake for us. Being big hearted in the festive season is what it is all about so hopefully we can all raise much needed funds to secure the charity as we plan to move into 2012. Ring Shelagh or Gwen to ask for more details or look on our website.

Finally best wishes for all the end of year festivities.



Facebook / Twitter

If, like us, you are embracing technology and getting your head around social networking then why not follow us?



www.facebook.com/
Littleheartsmatter



LHM_UK

You'll get our daily updates plus the chance to ask those questions that only other heart families can answer.

But don't forget...

Facebook is a great place to make friends but we understand that some things are just too personal to share in such a public place. That is why we have our secure website message boards to allow families to share their experiences, questions and best wishes in a private place. If you have not visited them yet or have not done so in a while we really hope you'll be able to stop by soon. Families new to us find reading the past questions and answers a great resource, as well as asking questions themselves.

Who's online?

The message boards are available to anyone but they have to go through a quick registration process on our website and then activate their message board account to be able to read and post. This means that they are very secure and not easy for anyone to find. This is important to us to ensure that sensitive messages,

particularly on our antenatal and bereavement message boards, cannot be found by just anyone.

How do I login?

If you have any problems logging in please email info@lhm.org.uk or call on 0121 455 8982 and speak to Gwen.

First time?

Go to www.lhm.org.uk.

Click 'Register'.

Complete the form.

Make sure you make a note of your username and password.

Click through the links to access the message boards.

Next step

On the message board front page click on 'Register'.

Enter the same username and password you chose on the website.

Complete the very short form.

Your account will be active immediately.

Login with your chosen details.

What will I find?

Here are just some of the different topics covered on the message boards:

- Antenatal
- Benefits and DLA
- Bereavement support
- Education
- Feeding
- Grandparents page
- Good news
- Hospitals
- Travel

Not got anything on your mind?

Please still pop by to see if you can answer questions, share your experiences - good or bad, and just generally offer support to families who need it.

Not online?

Don't worry! We will continue to offer the same support via post and telephone that we have always done. If you need us please don't hesitate to give us a call or write us a letter.

Did you know?

Most families find our website and message boards before they find us on social networks.

They really enjoy being able to read past questions and answers to know they are not alone, which isn't so easy on Facebook.

LHM in the Media



with
Emma Pelling

I hope you all had an enjoyable summer. As I write this we are enjoying a burst of summer weather which feels well deserved!

As reported in the last newsletter, the main focus of our media work this year has been around the Safe and Sustainable review. This is such an important piece of work for Little Hearts Matter and it is vital that we represent the needs of our families

and get our voice heard.

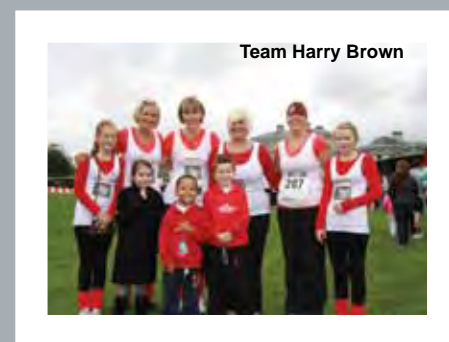
Throughout the past months we have sent out statements to the press and liaised with journalists showing our support for the highest quality service that this country can offer. Thank you again to all the families who have fed back their thoughts to us – your views are essential. Over the coming months we will continue to work with the media and ensure that we are at the forefront of the discussions. The announcement on how the service will look is due towards the end of year so we will keep the pressure on.

Other high profile media work took place during August with Little Hearts Matter showing its support for the pulse oximetry test. We urged government to introduce this simple test as part of routine screening for all newborn babies. We worked alongside the BBC and Isabel Baumber did a series of BBC radio interviews showing our support for this test.

Fundraising awareness was

heightened around our charity runs at Worthing and Shugborough this year. We received consistent coverage in the lead-up to the Shugborough run in newspapers and radio networks across the region. It certainly seemed to encourage runners on the day with over 150 taking part.

I look forward to being touch with many of you soon.



emma@pellingpr.co.uk
0207 624 7533



Medical

This article looks at what the children should be eating after their Fontan procedure.

Written by
Suzie Hutchinson
Verified by

Jo Bartleman, Paediatric Dietician, Birmingham Children's Hospital

From the time that children with a serious heart problem are born everyone is worried about them getting enough calories to allow them to grow because running an inefficient heart takes a great deal of energy. Many of the children have added calories mixed into their milk and when they are weaned every spoonful must be full of calories so that every mouthful is full of energy.

As the children move through surgery they gain more energy from their changing circulation but they will still require more calories than other children of their age. It becomes important to find a balance between a

healthy diet and making sure that they still have enough energy to grow.

Many parents ask if they should be putting their children on low fat, low salt and low sugar diets because of all of the information out there about keeping your heart healthy and protecting teeth from decay. It is often difficult to understand how to find the balance having been told that full fat food and lots of snacks are what their child needs in their early years.

After the last planned operation, the Fontan Procedure, and once the children have recovered from their surgery they will have more energy

than they have ever had before. More oxygen-filled blood will be circulating around their body and they will feel more positive about running about, climbing the stairs and generally taking part in physical activity. This new activity often makes them hungrier than they have been for a while. So how can you find the balance of helping to keep them healthy and yet giving them the energy that they need?

High calorie diets do not have to be high in fat unless a child is having problems eating enough food and their dietician suggests a high fat content.

Normal amounts of butter, cheese and cream mixed in with a balanced diet will be fine. Excessive fat can increase the risk of acquiring heart disease like furring up arteries, something that happens as we age. Children with only half a heart have a heart problem already so it is important that they have a balanced diet with



Ten Top Tips

1. Plan snacks and meals

Even following the Fontan Procedure children will still prefer to have lots of small meals rather than three big meals a day because they are easier to digest. It is therefore important to plan snacks spread between meals. Six meals and snacks spread evenly through the day is perfect.

2. Every plate of food should be balanced

One third of the plate should be protein - meat, fish, eggs, cheese, nuts or beans. One third should be carbohydrate - bread, potatoes, rice or pasta. One third should be vegetables - peas, sweetcorn carrots and tomatoes for example. If you want to add some extra calories put, a little butter on the potatoes or a bit of cheese on the vegetables. Everyone needs a bit of fat in their diet but adding it in moderation is always the best way.

3. Puddings are allowed

Find a balance between nice filling puddings like pies

and crumbles with fruit, yoghurt and ice-cream. If added calories are needed add some cream to the fruit. A little sugar is ok but remember that teeth must be cleaned regularly to prevent decay.

4. Snacks can be filling and fun

A snack at break time, mid-afternoon and just before bed (before teeth are cleaned) are a really good way of catching up with calories. Have you thought about peanut butter sandwiches, fingers of cheese, pizza slices, unsalted nuts (once the children are over five) as a good balance with the occasional bag of crisps and biscuits.

5. Adding flavour but not salt

Look in the spice rack for things like paprika, curry flavours or Mexican spices to add to food instead of salt. Potato wedges made with paprika taste great. Make a big pot of chilli with added beans for a great protein and flavour filled meal especially when served with jacket potatoes or rice.

6. Packed lunches or picnics

Some children don't like school lunches or they have problems eating all of their food before getting out to play. Fill their lunch boxes with lots of small pieces of calorie filled food. Peanut butter and cucumber sandwiches cut into small pieces, chunks of cheese, slices of apple, pear





a little bit of everything not a lot of just one thing.

It is also important to balance the salt intake, everyone needs a little bit of salt but adding lots of salty things into the diet is not good for the heart. This is made difficult because often children with heart conditions want highly flavoured food. This is probably because the medications that they have to take for their heart condition have made their taste buds less

sensitive than other children of their age. This makes them want the sort of flavours that adults like, for example, curries, blue cheese, pâté and strongly flavoured fish.

So in answer to parents questions, below are some top tips to help you find a balance.

Many children are challenging to feed, they all have different likes and dislikes and sometimes it seems easier to let them have what they

will eat especially if you are worried that they are not getting enough calories. In the long run it is better for their health, growth and heart function if you can work through the fads and fancies and help the children find a balance between a normal diet and the occasional treat.

This helps not only children with a heart problem but everyone else in the family as well.

or banana, a flapjack and some low salt crisps.

7. What to drink

The main problem with lots of soft drinks or fruit juices is that they are full of sugar which means that they are bad for your teeth. Always add water to squash or fruit juice and make sure that if children choose this as their drink of choice that they are careful when they brush their teeth.

Milk is a good drink as there are good calories in milk. If your medical team are happy about your child's calorie intake then semi-skimmed milk is fine for children over the age of five. Cups of tea are fine but be careful about the amount of sugar that you add.

8. Five a day

Making sure that we all eat at least three helpings of vegetables and two of fruit helps us all keep fit and healthy. Encouraging any child to eat vegetables can be a challenge. Mixing peas and sweetcorn into mashed potatoes or serving vegetable soup all helps to get children to eat vegetables. Chopping fruit up small and mixing lots of different types together makes for a fruit salad that is easy to eat.

9. Winter eating

During the cold winter months we all like a nice hot meal

to help warm us up. It can be a real challenge for children with only half a working heart to eat a big hot meal. A bowl of hot soup with added pasta and cheese, macaroni cheese with added ham and vegetables, egg fried rice or a jacket potato with the middle mixed with sweetcorn, ham, cheese, butter and milk can all be warming and filled with calories and goodness.

10. Treats

Everyone deserves treats, even ones which are not that healthy. The occasional McDonald's or Kentucky Fried Chicken is a fun treat especially good on a day that has been full of difficult challenges.

Sweets, crisps and fizzy drinks are also a treat that can be included in an otherwise healthy diet. It is important though that they are a small snack and that they do not take the place of a meal.

Think about replacing sweets with chocolate as chocolate contains good calories as well as sugar. Nuts are a healthier option than crisps and flapjack and oat based biscuits are a tasty and healthier option than ordinary cakes and biscuits. It is important to remember that they all contain sugar and teeth must be brushed after they have been eaten.



Personal story

Marie-Claire O'Hara shares how she prepared her daughter Nora for her Fontan operation last year.

Written by
Marie - Claire O'Hara

My name is Marie-Claire and my 'heart child' is Nora. She turned four years old in January this year. It was a significant milestone because, perhaps in common with many of the parents reading this newsletter, we were told before she was born that with her single ventricle heart condition and other heart complications she had a fifty-fifty chance of reaching her fourth birthday. Ever since we received Nora's diagnosis, I have viewed life with Nora in terms of milestones or, perhaps more accurately, hurdles. It's not the 110m hurdle sprint, though, more like a long steeplechase with a few water jumps thrown in for good measure. Don't get me wrong though, these last few years have been the best of my life - and the scariest, the most joyous and the most rewarding.

Nora's heart condition

Nora's a complicated little lady - at least where her heart is concerned (but maybe in other respects too!). She was born with Tricuspid Atresia which means the tricuspid valve of her heart never formed with the consequence that her right ventricle is also severely hypoplastic. She also has pulmonary atresia as her right pulmonary artery was absent and, instead, her right lung was being fed blood from an additional aortic arch. She also has double outlet right ventricle which means the greater vessels all arise from her hypoplastic right ventricle so, in her case, it is good news that she also has a rather large VSD opening her left ventricle into her right ventricle. Her heart is also located in the wrong part of her chest and is pointing in the wrong direction. I do wonder sometimes how on earth all this happened but that's a question that will probably remain unanswered

- and, for Nora and her family, the answer doesn't really matter. It's what we can do about it that matters.

Surgeries

Well, we were lucky, because after Nora was born and after some discussion, it was decided she could be put forward for surgery - the BT shunt and construction of a new right pulmonary artery. Nora had her first open heart surgery at the grand old age of eight days and, at a cherubic eight months, she had her stage 2 procedure and a repair of her pulmonary artery reconstruction. Both surgeries were successful although she did have serious complications afterwards due to various infections and her stays in hospital were fairly lengthy. However, after we put stage 2 behind us, we were able to breathe a big sigh of relief and enjoy a couple of years of relative normality.

The Fontan

Then the sadly rather familiar 'merry-go-round' started up again when she turned three last year in 2010 and she went for a MRI scan and we started the long slow count down to the stage 3 Fontan completion surgery. I should add that thankfully, Nora was considered a suitable candidate for the Fontan because there was always a niggling issue about her reconstructed pulmonary artery.

Attending hospital for the pre-surgical MRI scan was when I really started to think about how we were going to prepare Nora for hospital and that, really, is why I decided to write this article. Many parents are probably wondering the same - having a three or four year old child in hospital is a whole different kettle of fish to having an infant in hospital. I would say having



a slightly older child going through surgery is harder in some ways and easier in others - but it's all challenging whatever way you look at it! By this time, we also had another child to consider - Nora was our first child so when she was born we were fortunate not to have to worry about looking after siblings. This time round was different.

Waiting

The trouble with the waiting for Nora's surgery was the fact that we did seem to wait such a long time and I found it very hard not to talk about it because it really did start to consume my thoughts a lot. Little kids see and hear so much, so I knew I couldn't really keep it from her. It was hard to make plans because we didn't have a date but we had a rough idea it would be the summer or autumn of 2010. And, of course, physically, Nora's condition was getting worse - with more blue spells, more breathlessness and tiredness, and less ability to walk far or climb stairs. I felt she needed to know that it would get better and that was why she was going to have an operation.

Preparation for surgery

In the end, we started to talk to Nora about surgery in general terms even before we had a date. We didn't get a date until October 2010 and Nora's surgery took place on 15 November 2010, some time later than we had first



thought. Therefore, we probably started to discuss it about four months in advance.

In the beginning our discussions were the odd, general and matter-of-fact comment along the lines of "after your operation, you'll be able to ride your bike" (when, for example, Nora was getting upset because she couldn't manage to ride her bike) or "after your operation, you won't get all breathless any more" (when she was sitting on a wall in the play park having some time out from playing with the other kids).

As time went on, we would sometimes get out the toy medical kit and play with her teddy bears, listening to their hearts with the stethoscope and bandaging their paws. I always kept anything I said as positive as possible and never ever betrayed (knowingly anyway) any anxiety I might have felt.

At that time, in the summer of last year, we went to meet another little girl just turning three years of age - the gorgeous, bright little Pearl (pictured below) - and her mum Jenni. Pearl also has Tricuspid Atresia and was also going to be having her stage 3 shortly. That was a lovely opportunity for the two girls to meet, splash in the paddling pool together and see each other's surgical scars. I also hoped it meant that the girls might not feel they're alone as they were going through the same surgery at a similar age.

Pearl's mum and I discussed what we were doing to prepare our girls for

surgery and I got some good ideas from Jenni. Jenni had the book 'Rosie is Red, Violet is Blue' and she explained the purpose of the surgery to Pearl was to help her 'get her puff back' because Pearl was often 'puffed out' from exercise. Jenni explained to Pearl that the doctors could do this by opening Pearl up and putting 'the puff back in but that it would take a little while for the puff to start working. This seemed to match perfectly Pearl's understanding for her age. I remember Jenni telling me after Pearl's Fontan operation that the nurses remarked on how well Pearl was coping with hospital.

Children as young as three or four don't have any real concept of time - everything in the past is 'yesterday' and everything in the future is 'tomorrow' and Nora can certainly tie me up in knots asking me "is it tomorrow today?!" Therefore, with no date for surgery, and given Nora's understanding of time, I left any discussions at a 'high level'. There were times when Nora was keen to talk about it and times when she wasn't so I tended to be led by her and didn't push the subject.

At this stage I got a Topsy and Tim book about going into hospital and would sometimes read that at bedtime and that would be a springboard for a wider discussion about hospital.

When we got the date for surgery and had about a month's notice, our discussions about hospital became more specific. Often Nora would ask me questions herself - such as where

would she be sleeping in hospital and would I be there with her. I would tell her all I could remember from before and try to give her as much detail as possible as I find children of her age often do like little details - like what sort of lunch might she be eating, where she would eat it - the idea of eating it in bed was quite exciting! We would discuss what pyjamas, books, DVDs and teddies she would like to take with her. We also looked over old photos of her in hospital for her previous two surgeries and that gave me an opportunity to point out some of the machines, tubes, etc.

We also did some role play with me usually pretending to be the patient (as Nora liked to be the doctor or nurse). Jenni, Pearl's mum also adopted this approach. As a 'patient' we were able to ask leading questions like "my tubes are hurting, can I take them out?" or "can I have more medicine because I'm hurting". I also used it as a prompt to get Nora to pretend to put 'magic cream' on my hands and then put a line in, and I might pretend to cry a little but then be surprised at how quickly the line went in because I managed to stay still!

I firmly believe in total honesty with your child - and this is of course recommended by LHM in its guidance for preparing children for hospital - and that means telling them that there will be times when it will hurt. It does take a certain amount of courage to be honest with your child in this respect especially when you probably haven't been through a tenth of what they have had to go through in their little lives already (well, I certainly haven't anyway). One's instinct is to protect them from the truth because it might frighten them. But I fought my instinct by putting my 'thinking head' on and seeing things from Nora's perspective. Knowledge really is power and the better understanding Nora had of what her surgery and her hospital stay afterwards would entail (taking account of her age and ability to grasp the situation), then the less fearful, confusing and unpredictable the whole episode would hopefully be. I also thought that if I did not help her understand what to expect that she may not trust me or her dad again and I did not want to damage our relationship.



Personal story cont...

The surgery and hospital stay

I had once read on the LHM website message board a post from a parent about how she wrapped up little presents for her child while he was in hospital to help him through. I decided to adopt that idea and in the final week or so before surgery I started gathering and wrapping little presents, and one big one (for Nora's little brother to bring to her in hospital on his first visit to her after her surgery) - anything from crayons, colouring books, reading books, snap cards, sweeties. I would take one out every time she did something very brave or helpful (in the sense of being co-operative with the nurses and with her mum, dad and grandparents).

The day of the surgery itself felt very familiar, having been through it twice before, plus other minor occasions when Nora had to have a general anaesthesia. As we set off from home, waving goodbye to my mum and our little son, I didn't cry but inside I was fearful that this might be the last time we'd have our little girl at home with us. I knew the risks were low, but even so, as much as my head said it should be ok, my heart was very afraid. The thing I remember most about setting off to hospital was how Nora seemed so calm and unafraid, unlike us grown-ups who were quaking inside!



We took Nora down to surgery where she fell asleep really quickly sitting on her dad's lap with her favourite teddy bear while I held her hand and stroked her hair. Just under five hours later we were in ICU watching as this amazing team of nurses and doctors worked on getting her comfortable immediately after surgery. She was experiencing tachycardiac episodes when her heart was racing which meant there was lots of staff around her bedside monitoring her. It settled down quickly and within a few hours Nora was taken off the ventilator successfully as she was increasingly more alert (albeit for short periods before she would drop off to sleep again). Her oxygen sats were climbing (and even though it was a 'fenestrated' Fontan which reduces the sat levels, they were still fairly high) and her finger nails were looking pinker than I

ever remember seeing them.

Another heart parent had also told me about the likely strict fluid-restriction in the 24-48 hours after surgery which can be difficult as your child can be extremely thirsty and upset because they cannot quench their thirst. I was glad I found out about this and I took ice-pops with me and stored them in the ICU freezer. They were a good way of delivering fluid in a slow way which was more satisfying for thirst than 10mls of water gone in one small gulp. This certainly made the day or two after surgery more comfortable for Nora and it was also a good transition to go from liquids to solids (given Nora's previous history of gut and bowel problems post-surgery).

Thereafter, like all children who have the Fontan, the main issue was getting the chest drains out. Part of getting better was encouraging Nora, with the help of physiotherapists, to climb out of bed and at first sit up in a chair for a little while, and then take a little walk. Nora's chest drains were placed into a little toy shopping trolley so that she could lean on the trolley and her drains could be safely transported whilst we



walked to the toilet, or to the nearby playroom or off to the fish tank at the end of the long corridor. We made sure of course, that her pain relief was appropriate although it did not take away all of the pain and discomfort of moving. It was very hard for Nora at first and she cried, but I am glad we were quite firm with her in encouraging her to get up when she was fighting against it because I think it speeded up her recovery by helping her body get rid of any excess fluids building up.

There was plenty to do around her bedside thanks to the play specialist and to the teachers from the lovely little hospital nursery and school. And with all our own books and DVDs, plus visitors, chatting to the little girl across the ward who was also having her Fontan operation, plus mealtimes and physiotherapy, each day seemed surprisingly busy and short. Nora was discharged in record time - eight days after surgery. I could hardly believe it, given the fact that after stages 1 and 2, complications had crept in just when we had thought it was home time, and then



her hospital stays had been extended quite considerably. This time, having 'psyched' myself up for a long haul stay in hospital of at least a month, we were home just over a week later!

The difference the Fontan has made

Of course it has taken some time for Nora to recover. However, the most dramatic difference at first was in Nora's sats which went from high 60s/low 70s pre-surgery to the 90s!

Now, six months on, Nora is almost a different child, our whole lives have improved, She can manage nursery well - she can even walk there. We never use the buggy any more for her and she can walk around the supermarket now by my side instead of squeezed into a supermarket trolley seat (and Nora is tall for her age) with her big long legs dangling down and people looking at us in a slightly odd way (as if to say 'what's that big kid

doing in the trolley seat?' Little did they know).

We can manage the airport better now which makes our short trips over to Ireland to see her grandparents much easier as it usually involves quite a bit of walking or me having to manage a big Phil and Ted's double buggy for Nora and her baby brother (which in Stansted airport, means carrying the buggy down two flights of stairs to the foot of the plane, plus kids and bags!!!).

When I ask Nora about her hospital stay now, all she seems to remember are the best bits - like the play specialist called Claire, the hospital nursery, the presents, the visitors and the playroom. She remembers the drains too but almost in a matter of fact way rather than as a dreadful memory that she would rather not talk about. And she loves showing off her surgery scar to everyone!

Whilst Nora's special heart makes her special, she is also just a normal little girl and normality is what we aim to achieve for her now as much as possible. The next thing on Nora's 'to do' list, having crossed through three open heart surgeries, is the rather exciting one of starting school in September and I think she'll be off to a flying start now that she has had her Fontan surgery.



LHM Publications

Little Hearts Matter is hoping to launch its new booklet about the Fontan Operation in the next few weeks.

Don't forget the following publications and packs are available free of charge to members - to get your copy just call the office on 0121 455 8982 or email info@lhm.org.uk or visit

www.lhm.org.uk.

- Antenatal Information Pack
- Preparation for Hospital Booklet
- Preparation for Hospital Pack - to borrow for a period of 3 weeks.
- Benefits - a guide for parents
- Feeding at Home - a guide for

parents.

- Early Years and Infant School Education Booklet
- Junior School Education Booklet
- Transition to Secondary School Education Booklet
- Dental Care
- Fundraising Pack



Fundraising

Dear Members and Supporters

Summer has well and truly finished, the faint smell of firework gunpowder is in the air and at LHM we are on the countdown to Christmas, with the focus from me being very much on supporting our members fundraising over the next few months.

This year we needed to raise £273,500 and we believe with a final push from our existing fundraisers and encouraging some new member fundraisers we will reach the target amount we need to provide all the services we have planned.

Studies show that a much higher percentage of people think about fundraising at this time of year, so we have included a varied list that will appeal to existing fundraisers and new fundraisers. If you haven't considered fundraising before but would like to give it a go, please check out the list, we have included the ever popular Christmas big hearted bake, or if your time is limited, then please just send us your unwanted mobile phones or cartridges, or if fundraising just isn't your thing, why not consider setting up a regular monthly

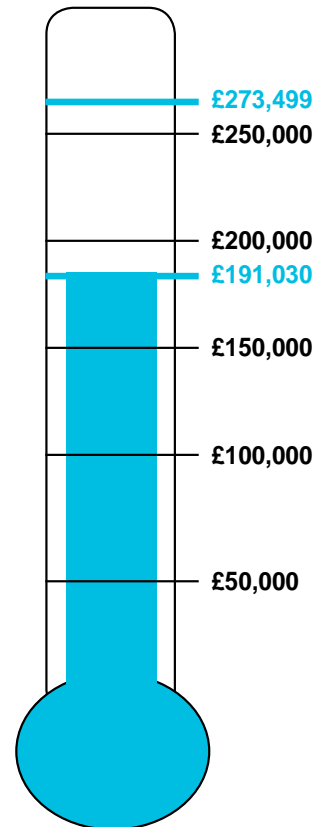


donation to the charity to help fund its current and future services. If everyone was able to do something, no matter how small, this will enable the charity to continue and grow the services we offer our parents and our children as they grow ever more independent.

As this is the last printed newsletter before Christmas, I would like to wish you all an extremely happy and magical Christmas with your loved ones and a fabulous New Year, and thank you for all the support you give us.

Shelagh Paterson

Please help us reach our target by texting a donation. Type HELP 22 and £donation amount to 700 700.

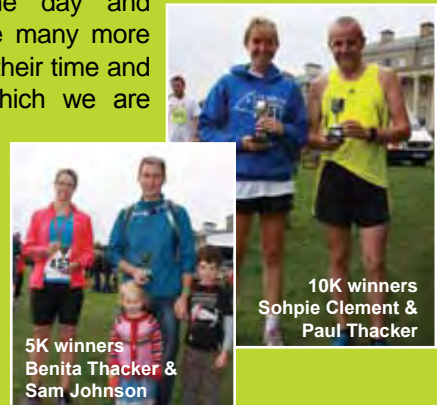


Striding ahead with their support

We have held two runs this year, one in May in Worthing and our annual Shugborough Run in September, and as always we remain indebted to all the volunteers who give us so much of their time to ensure the runs are successful, this year we would like to thank Suzie's husband Rod, her parents, sisters Fiona and Vicky, brothers-in-law Gareth and Glen and nieces and nephews, local members, the Morrell and Pakianathan family and Worthing Council. Thanks to the Walker family for offering to help next year.

Stafford Knott Rotary came up trumps again, giving us so much support in so many ways from promoting the event

locally, marshalling on the day, along with erecting and dismantling the event village and Peter from the Rotary kindly lending us his marquee. David Morton from DFM Radio & Electronics, a business which specialises in Sound Re-inforcement and Public Address provided all the PA systems. Stan Robinson kindly delivered a flat bed lorry for our stage and our staff also pulled family and friends in to volunteer on the day. Special thanks go to Ray Crowther of Stafford FM who did a brilliant job highlighting the run and coming down on the day and compering. There are many more people who also gave their time and equipment for free which we are indebted to. One final thanks – to all the runners who came along and participated and raised vital funds for us. Please visit our website and have a look at the hundreds of photos of the events.



10 easy ways you and your friends can help us fund the services we provide

Call us on 0121 455 8982 or email info@lhm.org.uk for your fundraising materials

Please choose whatever appeals to you and imagine... if everyone filled a collection box and chose just three of these we would be on our way to raising the £85,000 we so desperately need to continue the level of service we provide to the children and their families.



1 Big Hearted Christmas Bake

Get your friends, your family, your classmates and your cat! (but not your goldfish), dust off your wooden spoon, get your bowl out, have some fun, maybe get a bit messy and sell your

baked Christmas goods to all your friends, family, classmates and colleagues to munch on - and show just how big hearted your community are by donating the money to LHM.

3 Buy and promote our Christmas cards

Choose from our 5 different designs and take the Christmas catalogue enclosed to work and ask your colleagues to also buy them. We can send you a poster to put up in the office to advertise them, just call us.

Why not add a link on to your Facebook pages encouraging your wider friends to also purchase their cards from us.

5 Hold your own pre-Christmas charity dinner

Why not hold your own pre-Christmas charity lunch or dinner. Invite your family and friends and ask them to donate to LHM whatever they thought the meal was worth. Whether you cook like Gordon Ramsey, Nigella Lawson or Wendy Craig a good time will be had by all.

7 Sign up to a monthly direct debit

Did you know you can set up a direct debit and give a monthly contribution to Little Hearts Matter? This way of giving is simple and allows us to be able to plan ahead as we can forecast how much income we will receive each month. If this is something you would set up, please contact us and we will send you a form.

9 Add your message to our Lights of Love tree

The aim of 'Lights of Love' is to fill a tree with bright white lights every Christmas time. Your lights can represent remembrance, love, celebration, anything you wish. If you would like to dedicate a light, either fill in the Christmas catalogue form enclosed or visit the justgiving website.

A fabulous activity to promote on your Facebook page. The switch on date is Sunday 11th December in Stafford. Please contact the office for the full address. It will begin at 4.30pm and everyone is welcome to come and enjoy a mince pie, sing some carols and chat with friends.

2 Recycle your old phones

Will Santa bring you a new phone? If he does, please send us your old one, or your used ink cartridges. We get £1 for every cartridge and up to £30 per phone. All you need to do is pop them in the bag and then in the post. How about asking your colleagues and friends to also donate their old phones and cartridges?

4 Get your child's school to use our Alternative Christmas Card

We have enclosed two copies of our Alternative Christmas Card in the hope that you will use it in your workplace or at school, it's a simple request - instead of everyone sending each other individual cards, the children or your colleagues can add a message or a handprint and donate £1 to Little Hearts Matter. Just think how popular you will be - no-one having to write over 30 Christmas cards. If you need more just call us.

6 Easy fundraising means easy money for LHM

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

8 New Year's Life Changing Challenge - are you up to it

Jump out of a plane or climb a mountain for us - imagine standing at the edge of an open doorway in an aircraft flying at 10,000 feet and then falling forwards and free falling at over 120mph! Or if conquering mountains is your game, why not try climbing Kilimanjaro, experience jungle life and dramatic sunsets. A truly awe inspiring trek and a life changing journey.

10 Ask your company if they have a Charity of the Year

Does your company have a charity of the year? If so would you nominate us or let us know and we will talk to them direct. We have worked with many companies and offer great support along with the fact that the money raised will make a huge impact.



Personal story

Graeme Healey describes their journey so far with Millie from being diagnosed antenatally to having her first operation.

Written by
Graeme Healey

Initially we were diagnosed at the 20 week scan as having a girl (our first together) with suspected Hypoplastic left Heart Syndrome. We went through the rollercoaster of emotions along the way, from fear, anger, frustration, guarded joy when she was born by induction at St Michael's in Bristol, to abject despair and grief, through determination, fear again and finally being totally ecstatic and overjoyed.

Originally Millie, or 'Mills' as we call her, was born weighing 4lb 15oz, and because of that the team in Bristol were unable to pursue a surgical route as they just didn't have the experience in carrying out such a complex procedure on such a small baby.

Evelina's in London was approached as they DID have the experience, and so at five days old, still on her Prostin, she was moved to a lovely PICU just across Westminster Bridge from Parliament. There they fought over the weekend to stabilise her as she'd taken a turn for the worse early Sunday morning, and at one point there were serious concerns on her even making it through the night. But she did, and two days later she was taken for a CT scan. It was then that the true nature of her heart defects became apparent, and they discovered no less than six defects, congenitally corrected transposition of the great arteries, partial anomalous pulmonary venous drainage, double inlet, outlet left ventricle, hypoplastic and tortuous aortic arch, hypoplastic right ventricle and tricuspid valve atresia.

We'd already put a DNR (Do Not Resuscitate) order in place after her first bounce back. Simply because she'd already stated to us that she was a fighter so if she went it would be

because she'd had enough and was telling us she wanted to call it a day. But it came with conditions; if she was deteriorating and it could be sorted out with a little tweak of her current infusions then go ahead and do it. If however she had a full blown crash then they were not to attempt resuscitation. We didn't want someone banging away and shocking her etc when she'd already clearly made her mind up. We carried her DNR on until her first surgery in Birmingham where we lifted it simply for the reason that no self respecting surgical team in the world is going to go into open heart surgery with a DNR in place. The DNR is a very personal thing but for us, seeing our little girl hooked up to all those machines keeping her alive, it was perhaps the one thing we felt we

could do for her that perhaps gave her back some control over her own destiny, whether it be real or perceived.

There came that dreadful moment when we were taken to a private room off PICU and as soon as that happens you know it's bad news. For Mills, combined with her low birth weight it was the worst possible news. After a lot of explanation of her problems, normal procedures for corrective surgery, possible outcomes if surgery were pursued, it came down to the one simple fact that they didn't feel there was anything they could realistically do for Mills and that they felt the kindest course of action for her would be to make her comfortable and offer palliative care. One of the phrases used by her consultant in that meeting was "sometimes the hardest thing to do is the kindest." It takes a moment for your brain to catch up when you're told something like that and when it does it's the worst possible feeling in the world. We became so lost in the depths of despair and we examined her options from every conceivable angle, and at one point we even





the fact that they would either work or they wouldn't. That may sound a bit cold but it was how we dealt with it, our defence mechanism if you will. Of course we were terrified, and both times they were the longest hours of our lives to date, and that was despite sleeping through them. We didn't have the money to go gallivanting around Birmingham, and there wasn't a great deal else we really could do, plus we were dog tired from the late nights and early

intervention, but if there was then my hat is off to 'the man'.

Mills still requires more surgery in the future but for now we're just all enjoying finally having her home after literally bouncing back from death's door.

In order to help others try and make some sense out of things when they receive a diagnosis as devastating as being told your child has a congenital heart defect, or series of them, I've started work on both an online blog and also a video diary on You Tube of her journey, and if they help even one parent to understand and keep strong for their child, then they will have served their purpose.

instructed them to 'withdraw treatment'. That was when we were reminded that we were entitled to a second opinion and we leapt on that out of sheer desperation.

Mills' notes were couriered to Birmingham Children's Hospital and apparently, off the record, their first response upon viewing her CT scan was "Oh." My wife and I joked as to whether that was an "Oh ****", or an "Oh, we can do something with that."

BCH felt that they had a small window of opportunity and so Mills was blue lighted there from the centre of London in rush hour traffic by an incredible retrieval team and she had her first surgery the following evening and hasn't looked back.

First surgery on 10th June was an atrial balloon septostomy and bi-lateral pulmonary artery banding, which were done in an effort to stabilise her circulation and improve haemodynamics enough to give her a chance to gain enough weight for her Norwood-type op. Up to the point where she had her Norwood plus (I call it a Norwood plus because of the variants), she remained on her Prostin, in all for a total of almost two months, that was despite understanding that they generally didn't like to keep babies on it for much more than a week. It wasn't until she hit 2.5kg that she started showing the first signs of destabilising; steadily lowering sats and bp, increased heart rate, visibly working harder to take breaths. Blood gases were being done and her lactate was showing elevation, meaning that she was starting to work harder. So the decision was made to proceed with her Norwood plus.

From our point of view on her surgeries we just resigned ourselves to

mornings with Mills. I guess our bodies knew what we needed better than we did ourselves.

And the joy at receiving the phone call to say Mills had pulled through surgery and was now in recovery is beyond description.

One of the other ways I dealt with it was by, in a way, finding God. I'm not a born again Christian by any means, but we did a LOT of praying, and in the end I don't know if there was any divine

They can be found at <http://maxrayne.wordpress.com/2011/06/29/millies-story/> for her blog and on YouTube at <http://www.youtube.com/user/Milliehealey?feature=mhee>



News

Safe and Sustainable Ipsos Mori Independent Report of the Consultation Process

The next stage of the Safe and Sustainable process is complete.

On the 24th August we saw the publication of the Ipsos Mori report of the Safe and Sustainable public consultation process. The NHS have only rarely received such a huge response to a consultation process with over 75,000 service users, professionals and related organisations responding to their survey on the future of Congenital Heart Services.

The Little Hearts Matter team commends the Ipsos Mori team for producing an unbiased, clearly referenced report of the written and texted consultation response. The LHM team is delighted that there has been overwhelming support for the need for change and a whole hearted recognition that the new National Quality Standards are essential to support the need to develop a world class service.

Many areas highlighted in the Little Hearts Matter consultation response have been seen as a priority for the majority of consultation respondents with a majority of professionals and other charitable and service organisations mirroring the areas raised by LHM as a priority within the future service need.

The full report can be found on our website, we encourage members to read it themselves but in summary:-

- There has been overwhelming

support for the new National Quality Standards which will provide a benchmark for the treatment and care of children with complex heart conditions.

- There has been high praise given to ensuring excellent care, with huge support for improved monitoring, training and team working within cardiac networks.
- High levels of support have been given to ensuring that the child should be at the centre of care although some individual respondents put the needs of the family first.
- The national response was dominated by users of the service most likely to be affected by a change in designation for example 49% of individuals who responded came from the East Midlands even though they are only 9% of the population.
- A majority of individual written responses expressed a preference for Option A as the most suitable option - dominated by a 49% individual response from the East Midlands.
- Health professionals, related organisations and individuals outside the East Midlands group showed a preference for Option B.
- Options C and D received the least support.

- The texted responses placed Option B as the highest priority followed by Option A with little support for Option C or D.
- The need for a 24 hour, seven day a week service was seen as a priority for 83% of both individual, professional and organisational respondents.

LHM urges the JCPCT team to prioritise the need for a high quality service provision as they discuss the final configuration of congenital cardiac surgical services ensuring that every unit that makes its way into the configuration pattern had the greatest opportunity to success as a super centre following the high expectations of services set out in the new National Quality Standards document.

The next step

The JCPCT (Joint Committee of Primary Care Trusts) is expected to make a final decision by the end of 2011. Implementation of any changes to children's congenital heart services is expected to start in 2013.

A detailed implementation plan will be developed once a decision has been made.

As always if the Ipsos Mori report has raised anything that you would like to discuss further please feel free to give the LHM team a ring on **0121 455 8982** or email us on **info@lhm.org.uk**

Your Opportunity To Help Shape The Future direction of LHM

Would you like to have a say on how Little Hearts Matter is run and how the charity moves forward?

We are looking for new Trustees to join our board, and your skills and experience may be exactly what we need!

Our Board of Trustees is made up of volunteers - some members, some non-members, who agree to help out for a period of three years.

The role of a Trustee is to help manage the charity's finances and to

work out the future direction we need to take while ensuring we continue to offer the things our members need and remaining within agreed budgets. Trustees normally attend four meetings each year.

We would love to hear from anyone - whether a member or not - who might be interested in becoming a Trustee. We are also seeking to gain

new skills within the Trustee Board - particularly from the legal, corporate and fundraising areas.

If you are interested in joining the board and sharing your views on the way forward, please contact me through the team in the office on 0121 455 8982.

Pete Turner
Chair, LHM Trustee Board



Spotlight on...

Every issue we feature articles where we talk about different aspects of education and / or ideas about possible sources of financial support to help you, this time we will be looking at help for bullying.

Written by
Isabel Baumber

Bullying

As the new school year gets underway the LHM team have been contacted by a number of parents concerned that their child is being bullied at school. Sadly bullying is a problem in all schools but it can be made worse if a child has a disability because other children see it as a difference or a weakness.

If you think your child is being bullied the first thing that you need to do is sit down and talk to your child about it and in a safe and comfortable environment, giving them a chance to tell you their side of the story. If your fears about bullying are confirmed then you need to approach the school so that they can investigate the problem and work with you and your child to find a solution to the bullying.

The following information is from the Kidscape website www.kidscape.org.uk, which is packed with useful advice and tips. They also have a helpline for parents, **08451 205 204**, and offer courses for parents "Teaching parents and carers skills to protect children from bullying".

Bullying can take different forms, such as physical, verbal or emotional - or a combination. Children who are vulnerable in any way are often the subject of bullying.

Useful tips for parents

- ✓ If you are worried that your child is being bullied ask him/her directly.
- ✓ Be aware of the signs and symptoms of bullying.
- ✓ Take bullying seriously and find out the facts when told about an incident of bullying.
- ✓ Don't agree to keep the bullying a secret.
- ✓ Talk with a teacher or headteacher,

if it is school bullying. Many schools have a bullying protocol.

- ✓ Help children practise strategies such as shouting no, walking with confidence and running away.
- ✓ Give your child a chance to vent his/her feelings about being bullied.
- ✓ Get other parents together and discuss ways to stop the bullying.
- ✓ Talk to the parent governors at your school and suggest a school policy on bullying.
- ✓ Arrange to meet your child, if the bullying is happening on the way to or from school.
- ✓ Ask that the bullies be kept at school until everyone has had a chance to get home.
- ✓ Check that your child is not inviting the bullying by some obnoxious habit, such as spitting, picking nose, etc.
- ✓ Keep a written diary of all incidents.
- ✓ Invite children over to help your child make friends.

Remember that you do not have to cope with this alone, seek the support and help of others.

Useful tips for children/young people

There is also a section of the website specifically for children and young people, which includes the following suggestions.

Tell a friend what is happening.

Ask him or her to help you. It will be harder for the bully to pick on you if you have a friend with you for support.

Try to ignore the bullying or say 'No' really firmly, then turn and walk away.

Don't worry if people think you are running away. Remember, it is very hard for the bully to go on bullying someone who won't stand still to listen.

Try not to show that you are upset or angry.

Bullies love to get a reaction - it's 'fun'. If

you can keep calm and hide your emotions, they might get bored and leave you alone. As one teenager said to us, 'they can't bully you if you don't care'.

Don't fight back if you can help it.

Most bullies are bigger or stronger than you. If you fight back you could make the situation worse, get hurt or be blamed for starting the trouble.

It's not worth getting hurt to keep possessions or money.

If you feel threatened, give the bullies what they want. Property can be replaced, you can't.

Try to think up funny or clever replies in advance.

Make a joke of it. Replies don't have to be wonderfully brilliant or clever but it helps to have an answer ready. Practise saying them in the mirror at home. Using prepared replies works best if the bully is not too threatening and just needs to be put off. The bully might just decide that you are too clever to pick on.

Try to avoid being alone in the places where you know the bully is likely to pick on you.

This might mean changing your route to school, avoiding parts of the playground, or only using common rooms or lavatories when other people are there. It's not fair that you have to do this, but it might put the bully off.

Sometimes asking the bully to repeat what they said can put them off.

Often bullies are not brave enough to repeat the remark exactly so they tone it down. If they repeat it, you will have made them do something they hadn't planned on and this gives you some control of the situation.

Keep a diary of what is happening.

Write down the details of the incidents and your feelings. When you do decide to tell someone, a written record of the bullying makes it easier to prove what has been going on.

It is always important to take any concerns that your child has about the way they are treated when they are away from home seriously. Sometimes a simple explanation can be found to a problem or skills to cope can be taught, on other occasions a careful plan of action to solve the issue must be found.

Remember that the Little Hearts Matter support team is always here if you would like to talk.



Your fundraising

Shelagh's amazing 67 mile marathon raising over £3,715



Super fit Shelagh Miller has undertaken a gruelling adventure marathon in Donegal raising an amazing amount of money for LHM. Pictured is Shelagh and her best friend's daughter, Caitlin, who has HLHS and has recently celebrated her 10th birthday.

Natwest Salisbury swap calculators for cycling shorts

On the 2nd and 3rd September staff at Natwest, Salisbury undertook a 24 hour charity bikeathon. Led by Chris Ashton, Natwest's local CEO, all the Natwest branches in the area took part in the challenge in aid of us and local children's hospices Naomi House and Jack's Place, raising a whopping £4500.

Pictured (left to right), Eve-Marie Moore, Alex, Martha Henry, Lucy Pearson (one of our young members), Helen, Chris Ashton, and Charlotte.



What an amazing summer, and I don't mean the scorching hazy days we were looking forward to, I mean the fabulous fundraising that so many of our supporters have embarked on, below are a few of the amazing people who have undertaken some truly astounding activities to help raise money to enable us to continue providing the services we do, on behalf of all the families we support - THANK YOU.

Could our logo bring luck to this rising team?

When dad Jeremy Nield, reserve team manager of Ashton Town AFC in Wigan contacted us with an idea, we must admit we got rather excited. When General Manager Darryl Picton told us more about what they would like to do for us, we were over the moon! In a first for both us and Ashton Town AFC we now have our charity logo on their football strip. And doesn't it look great? Jez has a 14 year old son with a heart condition and so suggested us as a charity



they could partner with. But that's not all, the club has kindly decided that they would like form a long-term partnership with us, holding several fundraising events and raising crucial awareness for us. Thank you so much.



Sophii sings her heart out

Clarks village in Somerset played host for a charity

music event in aid of Little Hearts Matter. Launching her new single 'We Will Never Be' was local singer/songwriter, Sophii Negus.

Sophii kindly chose to dedicate her song to the charity as her brother Jack has HLHS. Jack is one of the oldest members of the charity with HLHS and he and his family have been involved for many years, in fact Jack also fundraises for us via his business, The Slipper Shop. Sophii would especially like to thank, David Titchener for taking the cover shots, Gordon Morris who kindly lent the sound system. Studio 9 of Glastonbury for recording the song and the brilliant shops, staff

and security team who helped host this great event. For more information about Sophii visit her website - www.sophiinegus.com

Special thanks to

Dan Walker, family and friends who have undertaken many fundraising activities including a 30 mile coast to coast run in Menorca, raising £10,000.





Amelia matters...

Lisa Hine set up Amelia Matters charity following the birth of Amelia who will be six in April.

Lisa has fundraised tirelessly for the charity with much of the money being donated to Little Hearts Matter, along with so many of you, we are amazed at how Lisa managed to juggle her life and fundraise so successfully. Thank you Lisa for all your support. Pictured is gorgeous Amelia.

Hop, leap and a jump for Kayleigh



After helping her aunt Angela at her Little Hearts Matter fundraising event, Kayleigh Quinn decided that she too wanted to do something to support the charity that had supported her cousin Stephen who has HLHS. But instead of holding a cake sale, shaking a collection bucket or doing a run, she decided to go to extreme lengths, and do an extreme sport by jumping 160ft attached to a glorified elastic band.



Graham Holder who has raised over £33,500 in memory of his son Rocky, cycling 300

miles from London to Paris and organising street collections.

Jenny Owen who has raised £200 from the sale of her chicken eggs (pictured with Kerry Gavin, her son Charlie and Sam Skelton.



We're Waitrose Winners

Thank you so much to the person who nominated us and to all the shoppers who gave their green token to us for the Community Matters scheme at the Enfield branch of Waitrose, we were very grateful to receive a cheque for £424 - a huge thanks also to the Ward family for collecting the cheque on our behalf.

Please nominate us at your local Waitrose.



The power of four



Take four slightly mad people, dress them up as cowboys and given them four hours to give away as much free Ben & Jerry's ice-cream as possible. Add to that one slightly less authentic LHM team member with a collection bucket and what do you get? A fantastic £419.28!

For the fourth year running Ben & Jerry's in the Bullring have allowed us to collect money at their Free Cone Day, in return for their free delicious ice-cream people are encouraged to give donations to LHM.

Thank you so much to all the team for their continuing support.



Free Media Expert - what a prize

We were very excited to meet Suzanne Bridges in January this year, she owns the successful Creative Media agency in Birmingham. She wanted to offer us free PR support to increase the awareness of the charity and help secure funds.

Whilst Emma Pelling focused on the national press, we were incredibly lucky to have Suzanne and her team focus on the West Midlands region.

We have secured more coverage in this region than we could ever have imagined and we are extremely grateful for her time and support.

On behalf of all our families - a huge THANK YOU.



Mark Forrester who recently completed the Liverpool Half Marathon in aid of LHM raising a splendid £250.50.

Paul Rawson and John Houghton cycled from Holyhead to Chester over three days in aid of LHM. They were inspired to raise money by the support given by LHM to Paul's brother-in-law and his wife, whose son has HLHS. He is now eight months old and doing very well. Paul and John managed to raise an incredible £1020.77 from their efforts.



Personal story

Anna Thomas shares her family's difficult journey and heart rendering decision-making for their daughter Phoebe.

Written by
Anna Thomas



Our "Phoebe journey" began on 23rd December last year at the 20 week anomaly scan. The sonographer said she was having difficulties seeing the heart and asked me to take a walk around to get baby to move. I didn't think twice about it. We'd just been told we were having a girl and I was thinking about how it would have been nice to have a boy (we have twin girls) but, as they always say, "as long as they're healthy"...

On returning to the scan the sonographer said she was still having difficulties seeing the heart and went to get the doctor. Still, I wasn't too concerned, it just didn't occur to me that anything could be wrong. The doctor then has a look and told us almost immediately "your baby has a serious heart condition, it looks like Hypoplastic Left Heart but you'll need to have a cardiac specialist confirm the diagnosis". At that point our world came crashing down... surely not, not

our baby, not our little girl.

The following day, Christmas Eve, we went to the Brompton Hospital and had the diagnosis confirmed - Hypoplastic Left Heart, but with additional complications, including an 'intact atrial septum' (IAS). The three stage operation was discussed, but only briefly and as something that probably wouldn't be available to us as our baby's heart was in such a bad state and the expectation was that she would probably live for just a few minutes, possibly hours.

We were given the option of an abortion, which we quickly turned down. So we began the process of coming to terms with the fact that I would carry our little girl to term but that she would not survive. We sought to bond with her more as we knew time was short but we also began to grieve and say good-bye. We named her Phoebe Anna. Phoebe meaning 'bright' or 'radiant' as, whilst we knew we

would see great sadness with Phoebe, we also knew that she would always be a shining light to us. Anna is my name and we gave it to Phoebe as her middle name in recognition of the fact that she was part of us, part of me, and we loved and valued her as our daughter.

Our cardiologist from the Brompton encouraged us to get a second opinion at St Thomas's and, whilst we didn't particularly feel the need, we thought that would be a good thing to do. So some weeks after the original diagnosis we went to St Thomas' and, not surprisingly, had the diagnosis of HLH confirmed. However, the cardiologist there, whilst recognising the added complication of IAS, was more optimistic and suggested that the three stage operation was still a possibility.

Great news, so everyone said, there was now hope. But to be honest we primarily felt confused and uncertain. The three stage operation wouldn't fix Phoebe, she would always only have half a heart. What would her quality of life be like, how long might she live? Would she even survive the first operation... or the second? There were all sorts of secondary, but still valid concerns - how would it impact our marriage and our other daughters Sophie and Kate? And so began the process of making the hardest decision of our lives - to operate or not?

We had many further meetings with cardiologists, the surgeon and various



other medical practitioners, all of whom very kindly answered our many questions, as much as they could, and in a very understanding manner.

We watched the DVD and read all the information provided by Little Hearts Matter, for which we were very grateful. However, so much was unknown. So much was dependent on Phoebe herself, what, if any, damage had already been done to her lungs (which was unknown) and how would her heart and lungs respond to being out of the womb?

For us, unlike the question of an abortion, there was no clear-cut answer of whether or not to operate on Phoebe. This is why the decision was so difficult.

After much discussion, thought, tears and prayer we decided not to operate on Phoebe.

Phoebe was born at St Thomas' Hospital at 38 weeks by caesarean on Monday 18th April 2011. She spent just over 24 hours in the NICU being ventilated, on morphine, on a drug to keep a heart valve open and with an intravenous drip giving her nutrients. On the afternoon of Tuesday 19th all these tubes and needles were taken away. Initially she struggled to breathe, she went blue and we said very emotional goodbyes to her, convinced that this was the end. But eventually, defying expectations, Phoebe began breathing for herself!

Much to our surprise and to the enormous credit of the NICU doctors at St Thomas' the next day saw us discharged and returning home with Phoebe. We had invaluable support from CHASE Hospice, a charity providing palliative care to terminally ill children.



We had seven precious, wonderful days at home with our beautiful daughter, which will remain in our memories for the rest of our lives. True to Phoebe's name, the sun shone unseasonably brightly and warmly throughout her life. Other than getting short of breath at times, Phoebe seemed like a healthy baby. We did normal baby things, took her on walks and gave her lots and lots of cuddles. She met family and friends, in person and via Skype video. Phoebe was even baptised at our church on Easter Sunday. On Tuesday 26th April the sun disappeared behind the clouds and Phoebe began slipping away, passing away in the early hours of the morning on Wednesday 27th April.

Not for one moment have we ever regretted continuing with the pregnancy. As for our decision not to operate... perhaps there will always be a small doubt as to what may have been, but primarily we are extremely grateful for the nine treasured days that we had with Phoebe. We miss her, at times with a physical ache, but we also feel at peace about our decision and it is our sure hope that we will one day be reunited with her in heaven.

To anyone facing the diagnosis of Hypoplastic Left Heart we would emphasise that there is no right or wrong decision when considering whether to operate or not. We heard many stories of children who were doing really well following surgery and of others still in a wheelchair at five having spent much of their life in hospital. It is a personal and deeply agonising decision to be made by the parents, considering their context and the information they have about their baby's condition.

It is our hope for everyone placed in this extremely difficult position, whatever their decision, that they will receive as much care and support from medical professionals, LHM, family and friends as we did and that they will be blessed with at least a little time with their precious baby.

Financial help for buying household items

Our office support team have had a few calls recently asking about financial assistance. Below are some of the possible sources of help we are aware of - please look at them carefully regarding your own individual circumstances, and contact the organisation directly to see whether they can help. If members are aware of other organisations, please do let us know.

The Family Fund

This fund gives grants to low-income families to meet the additional needs of caring for a disabled child. There is no entitlement to a grant from the Family Fund, all grants are discretionary. Please contact them or check their website for eligibility criteria, www.familyfund.org.uk or 0845 130 45 42.

Community Care Grants

The Social Fund gives various types of payments designed to help people on a low income with specific costs. Community Care Grants may be applicable for families with disabled children.

For more information visit www.direct.gov.uk/carers then choose 'Guide to financial support for carers' found under 'Money matters' or you can contact your local Jobcentre Plus.

Newlife Foundation

A children's charity which helps disabled and terminally ill children. They offer equipment grants for specific items needed by a family to help care for their child.

Contact the BDF Newlife Nurses on 0800 902 0095 or visit the website www.newlifecharity.co.uk.

Family Action

This charity provides services and support to disadvantaged families. Applications for grants must be made by a social worker or health visitor on your behalf. Small welfare grants are available for medical treatment, disability aids and household needs for families who have a low income.

For further information, contact 020 7254 6251 or visit the website www.family-action.org.uk

Chest, Heart and Stroke Scotland

This charity offers Personal Support Grants e.g. for holidays, hospital visiting, equipment, white goods. They support families living in Scotland and applications must be made by a sponsor (e.g. health visitor) on your behalf.

Visit www.chss.org.uk or telephone 0131 225 6963 for more information.



Grandparents page

Rosemary Baker, Grandma to Cory Lovell one of our young members shares her experience of being a grandparent to a child born with half a working heart.

Written by
Rosemary Baker

Our grandson was born on the 28th November 1999. We planned to go down and see him the following day but the next day I had a phone call from Jo in tears saying they were being transferred to Bristol Children's Hospital because Cory had turned blue and that they thought he had something wrong with his heart, all I could get out of Jo was "they kill babies up there". I tried to tell her that that was a long time ago and things were better now.

That afternoon Jo, Dave and Cory arrived by ambulance where Grandad and I met them. He was rushed into the intensive care unit and we all waited in the parent's waiting room. After what seemed like hours a doctor came in to see us. Not one of us was prepared for the devastating news he was about to give us.

He explained that Cory has only one half of his heart and this was called Hypoplastic Left Heart Syndrome. He told us about the condition and said that babies as small as Cory very rarely made it and there was very little chance of him surviving. There was nothing they could do for him except make him

comfortable, but he would die within a few days. I will never forget the look on our faces! Then the doctor came back and said there was the slight chance that a surgeon in Birmingham may be able to operate on Cory, but this operation had not been performed on a baby so small. We left Jo and Dave to make the decision but as we walked out they followed us saying there was only one decision to take, if there was a small chance it had to be taken.

We all arrived in Birmingham later that night. The nursing staff on the intensive care unit were brilliant. The next morning we met Mr Brawn the surgeon who explained he could not be sure that Cory would come through the operation. It was the longest day of our lives.

We got the call that he was back in the intensive care unit and were all allowed around his cot. We spoke to Mr Brawn and thanked him, he told us he had done 10%, the rest was up to Cory. It was so difficult to see this tiny person lying there with a plaster on his chest saying 'chest open', but Grandad and I managed to keep strong for Jo and Dave. It was difficult for Grandad who had never seen anything so small with so many tubes and lines coming out of him, that every time we talked about Cory to family and friends you could see the tears in his eyes (and to this day he is still like it).

We stayed with Jo and Dave for almost a week before we felt we could leave. A week later I returned to be with Jo as her husband had to come home. Cory was making progress every day. He had a little bell attached to his toe and every time he heard our voices he would move his toe and ring the bell. The joy of that ringing we will never forget. We stayed reading and talking to Cory and after several weeks they said they were going



to try and take him off the oxygen. Jo and I held our own breath as they did it but after a few seconds he began to breathe on his own, after that he seemed to get stronger.

We met Suzie from LHM while we were there, she was there to answer any questions we had, and there were lots. We were given a pack that explained about the heart and telephone numbers that we could ring if we needed help understanding anything or just support.

Cory was transferred to a ward where he was put on a nasal feeding tube as he would not take a bottle, he was beginning to take notice of his surroundings and even at his age and with an illness he began to get a little temper on him. If he could not get his own way he would hold his breath when crying which would get everyone running to him, Grandma included but I'm sure I could see a little smile sometimes!

On Christmas day Grandad and I went up to Birmingham to stay with Cory so that Jo could have a break. We stayed for five days and in that time Grandad and Cory got to know each other really well. Grandad has a beard and when he had Cory on his lap, Cory would put up his little hand and touch Grandad's



beard. It was the start of a beautiful friendship that remains to this day.



As time went on Cory was still very tiny, so Jo went to see another consultant who said that he had Aligilles 20 Syndrome. This means that he is not going to grow very quickly.

Cory's Fontan operation was not done until he was eight years old due to the fact that he is still very tiny for his age. Jo and I went up to Birmingham as we were told it could be 8 / 9 weeks before he would be well enough to go home. He had the operation and was soon up and pushing his little shopping trolley around with his drainage bag in. Jo and I took it in turns staying with Cory at night, but he was no problem and has the nurses eating out of his hand as he only has to smile and he is waited on by most people. Grandma and mother were used to it and were not taken in by it!

After about three weeks Cory had made such good progress that they were thinking about sending him home. We spoke to Dr Stümper about Cory and he could not believe how well Cory had been after the third stage. He did tell us that they had put off doing the Fontan as they were not sure how Cory would be and thought it would take him a long time to get over it. Cory was in hospital for three and a half weeks and then sent home.

Over the years we have had Cory for holidays, at first it was to give Jo a rest but now he's come to expect his holidays with Grandma and Grandad. Cory lives in Cornwall and we live in Bristol so we would meet up at Cullompton services and as a treat he always had a McDonalds!

He goes into work sometimes for half a day with Grandad and comes home with his pockets full of sweets or money. Sometimes they go to watch or ride the

trains.

We take him and his friend to the pictures, and they both run to get the back seats, but we have to buy the sweets before we go as he says they're too expensive to buy at the cinema. If there is something on at the Hippodrome like a musical then I take Cory to the matinee, he loves music and a good musical.

Every year we go on holiday abroad, we have been to Spain,

Portugal and Grand Canaria and he has never had a problem flying. This year we are taking him to Florida, and everyone has been so helpful. So hopefully Cory will have a wonderful time and he tells everyone he is going to swim with dolphins.

Everyone loves him, I take him to stay with his uncle and cousins in Yorkshire and he does everything they do and has never played on his illness to the extent that he cannot do anything.

Cory has given Grandad and Grandma so much joy and love since he was born that we cannot imagine what our life was like before he came along. I have to phone him most days and when he goes to his father's for a weekend if I don't phone him I get a telling off the next time I speak to him!

I know that this will never change and that we will have Cory on holiday and weekends for as long as he wants to come which I know will be forever!



Announcements

Heady for Hearts to a whopping £100,000



We are thrilled to announce that MSA (Britain) part of the global safety and gas detection company are to support the charity over the next five years aiming to donate a staggering £100,000. As part of their support they are donating 5p for every hard hat they sell in the UK.

Staff at the head office in Lanarkshire are raring to go and have already started fundraising. Sales Director, Michael Burdon says "We are a very passionate team and are all very excited about supporting this amazing charity and the inspirational children that suffer with this condition. Around nine months ago I was completely unaware that this condition existed. I am proud to lead my team into this fantastic partnership. This fits our company profile also as we say in MSA, because every life matters."

LHM Christmas Cards

We have five fabulous designs this year, two of which were designed by children; winners are pictured below with their certificates.

You can order by completing the enclosed order for, or visiting www.lhm.org.uk.

Why not take advantage of this year's special offer, save £3 when you buy four packs.



Zipper Zone



In this edition of the LHM newsletter we hear from Hannah Palmer, one of our young members and a member of the LHM Youth Council.

Written by
Hannah Palmer



facebook

So, I'm sure most of you have Facebook, or a mobile phone. Technology is becoming one of the best ways to communicate with everybody.

That is why Little Hearts Matter has made their own Facebook page. So that all of you can talk to other young people with the same conditions as you, about how you feel, any questions you might have or if you just want a chat!

To become a member of this group all you need to do is add Jon Brunskill

as a friend and then you will be able to write in the group! This is a great way for all of us to keep in touch and also for Jon and the rest of the team to know what we want from Little Hearts Matter.

Also, The Little Hearts team are thinking of setting up a text message service. Any of you young members could send a text about anything you want, and this text would get through to another teenager, like me, with a heart condition. If any of these questions were medical, they would be forwarded on to the right people so that you can get your answers. I think this is a great idea because it gives all of you and me, the chance to communicate with people who

understand our conditions and how we might feel about things.

So there you have it, another two ways Little Hearts Matter wants to help us to lead as easy lives as possible. If you have any questions about any of these ideas please email Jon on jon@lhm.org.uk or you can email me at hannahkp@ntlworld.com.

Hope you're all having a great time at school, and remember, LHM are always there if you need any help ☺



My Road to Independence

Finally! After nearly a year of driving lessons, theory tests and practical tests, I, Hannah Palmer can DRIVE!! And I've only been 17 for a month! This was only possible through the help of Motability, a company that allows teenagers who are on the higher rate mobility component of the Disability Living Allowance to have driving lessons from BSM at age 16.

I first heard about the grants that Motability offer at the Little Hearts Matter AGM Last Year from BSM. After the conference, I contacted Motability about the grants that they offered and they approved my

application, which included 40 hours of driving lessons with BSM. All I had to pay for was my provisional licence, and my practical and theory tests, which was amazing (even though I had to do 2 theory tests) and a few extra driving lessons to make sure I was up to standard.

So here I am, 8 months, £176 and a driving licence later, I've got a very nice Ford Fiesta through Motability, that I drive everywhere, literally everywhere! Now I can drive, I feel a lot more independent, I can do a lot more, which is important to me because, being 17, I want to be able to go out when I want and do what I want to do. It's a lot easier for my parents as well, as they don't get calls at all hours of the night saying 'Can you pick me up now?' or 'What time can I stay out till?'. In fact, I now get calls asking me to take them

everywhere!! And my friends love me even more!

I love being more independent because I feel more adult and it gives me more freedom.

I would highly recommend anyone coming up to the age of 16 who is on the Higher mobility rate of the DLA to contact Motability and complete your own Road to Independence!

Hannah's dad adds "When we first found out Hannah had a single ventricle heart we didn't dare think past the next few months - it's hard to believe that 17 years later Hannah has passed such an important milestone. Thanks to Little Hearts Matter, Hannah not only found out about Motability - she has the confidence to face life head on! Thank you Little Hearts Matter!"



Noticeboard

Little Hearts Matter 2012 Open day

3rd March 2012
Bethel Convention Centre
West Bromwich

We would like to invite all of our members and any other families who have a child with a single ventricle heart disorder to join us at the 2012 Open Day.

Next year's event will be a little special.

The shape of your child's cardiac care in the future

Following all the discussions and concerns raised during the Safe and Sustainable cardiac review and consultation process the most important thing for families to know now is that their child will receive the best treatment and care possible in the future and that they will be kept safe at all times.

By March 2012 we will know what the shape of the future service will look like and have an idea of the process of change from the old system of care through to the new one.

The 2012 Open Day will concentrate on the shape of the new service for children with single ventricle heart problems allowing the children and their families to explore what the changes might mean for them and looking for ways to make sure that the new pathways of care are of the highest quality providing the best care but also the least disruption possible for families.

So if you would like to explore more about future care, gain support from each other and make sure that the Little Hearts Matter voice reflects the view, concerns and hopes of the majority of members put the date in your diary.

Barnaby Update

Barnaby has been so busy recently we couldn't fit all his exploits into this edition - he will let you know about his adventures in the next edition - **do remember to ask us if he can go with you on holiday as he does love meeting you all and seeing new places.**

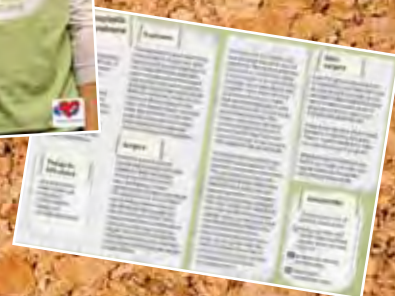


New Information for Teenagers

Little Hearts Matter has been working with the British Heart Federation to produce some information leaflets written to help explain congenital heart conditions to teenagers. The BHF produce lots of these leaflets but we have worked with them on three.

Hypoplastic Left Heart Syndrome, Tricuspid Atresia and Pulmonary Atresia with an intact ventricular septum. The copies are bright and cheerful and we hope appealing and informative.

If you would like a copy we have a number of leaflets in the office or you can go to the BHF website and look for them in their teenage information section.



Flu Jab

Just a quick note to remind you all to get your children down to the doctors or nurses clinic to receive their Flu jab. I know that having any sort of injection is not much fun but when you have a heart problem flu can really make you ill. The jab helps to protect you from most of the flu bugs around and really can help to make the winter more infection free.

Unless you have been told by your cardiologist not to have the vaccination it will be recommended so book your appointment soon.



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



UPPER TOP LEFT: Morgan Davies (3 years 11 months) taking part in his first school sports day!

• UPPER TOP RIGHT: Alasdair Simpson (11 years) in his last sports day at primary school.

• TOP LEFT: Tilly Docx (1 year 6 months) and her big sister Abi enjoying the sunshine in Norway.

• TOP CENTRE: Luke Jenkins (6 years 10 months) on a Make A Wish Disney Cruise.

• TOP RIGHT: Michael Smith (7 years 7 months) racing ahead at his school sports day.

• MIDDLE LEFT: Jake Gresty (5 years 10 months) on the beach at Callela.

• MIDDLE RIGHT: Ella Woodcock (7 years 4 months) playing in the river in the Yorkshire Dales with big sister Chloe.

• BOTTOM LEFT: Mason Williams (1 year 6 months) celebrating his first birthday.

• BOTTOM RIGHT: Thomas Rousell (11 years 5 months) starting secondary school.

