

Little Hearts Matter Newsletter

Summer 2009



Children are Special



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Ask The Experts



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Over to You



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Children's Heart Week

Drama, dance and a whole load of dens... it can only be the Little Hearts Matter Activity Weekend.



Wow what a week, well nine days actually! This was an opportunity for LHM to really raise the profile of the work of the charity in lots of different arenas.

Our week began at the **2009 Activity Weekend**. This was an opportunity for over twenty member families with older children to

spend a weekend away together exploring lots of new activities and making new friends. See the pictures of den building, cooking, drama and dance, fishing, golf, fun and games. The photos missing are the very eggy ones from the egg chuck! A game of skill and lack of fear where eggs are thrown between partners!

At this year's event we floated 133 boats with little candles, 132 white ones and one red, to represent the number of children born each year with a congenital heart defect. It was really moving. This was the beginning of Children's Heart Week.

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News

Suzie's News



Life at Little Hearts Matter is a real whirlwind at the moment.

Lots of great events for members, lots of new information and lots of awareness within the general public.

We have also been working to raise awareness of the new 'Antenatal Information Pack' by placing medical articles in lots of different magazines and medical journals.

We will be using the new packs for expectant families soon.

We had a marvellous time in Cornwall on what was our fifth activity weekend. (See the other articles in the newsletter).

We had 22 families altogether. The only reason that we could organise this event this year was because of a very thoughtful donation by one of our past Trustees - Carol Shanahan.

She donated virtually the whole cost of the event in memory of her brother Michael.

We held a volunteer training day in April. A huge thanks to all of the current and potential volunteers who attended. What a great day. Lots of fun but also lots of thoughtful work as we plan to expand parent-to-parent services.

Thank you so much for your time.

Our next training weekend will be held in October so anyone who is interested in joining the team or exploring what volunteering is all about give us a ring on 0121 455 8982 any time.

The next few months are going to be very

busy. We are trying to hold as many network events as possible. Watch this space. I hope to see you as I travel out and about.

I need to end on a more serious note. Please, please read Kevin's section on fundraising further into the newsletter.

Our fundraising income is down. We all knew that it was going to happen but we have to find as many new ways as possible to raise funds, wherever they are.

I hope that you know that we are all working really hard to build lots of new support and information services and at the same time raise much needed awareness. We really want to continue to grow as we know that you would like so many more services.

We are not asking you to give yourselves, not that we would turn any gifts away, what we need is your help to get our fundraising voice heard wherever you work, within your local community, with your friends and your children's friends. WI's, Round Table, the school playground may be looking for a charity to support. Help us become their charity of the year.

If they don't know that we are there how can they support us?

Have a good summer.

With thanks from Suzie.

Suzie Hutchinson
Chief Executive

News Flash...

Education Booklets

We currently have education booklets published on 'Early Years and Infant School' and 'Junior School', which are available free of charge to members. If you would like a copy please call the office on 0121 455 8982 or email the office at info@lhm.org.uk

Further publications on education are currently being written.

Oxygen Saturation Study

We hope to be able to publish the results of this study in the Autumn when they become available.

LHM In The Media

with

Emma Pelling

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Firstly I'd like to say that I'm delighted to be back with Little Hearts Matter after three months maternity leave with my new baby boy Theo - the sleepless nights are beginning to subside! In my absence, some of you may have been in touch with Caroline who has done a fantastic job at promoting the work of the charity.

It's been a busy few months with the Leeds Castle run in March and the launch of our new Antenatal DVD and Children's Heart Week during May. Many thanks to all the families that helped with media work by talking about their experiences - we secured some particularly positive coverage around Children's Heart Week in the health media and regional newspapers.

Our next big event is 'On Your Marks for Little Hearts' later in the year at Shugborough. I look forward to hearing your stories and promoting the event which proved to be a huge success last year.

Please do keep in touch and send me your stories. I'm always happy to be contacted by you with any ideas you might have about how we can continue to promote the work of the charity.

Wishing you a happy summer!

Emma



The Haselgrove family after completing the Leeds Castle Run!



Children's Heart Week

(continued from front page)

"We all thoroughly enjoyed ourselves and the happy memories will be treasured for years to come"

Many thanks go to Carol Shanahan, a past Trustee, who sponsored the weekend in memory of her baby brother who died of a congenital heart defect many years ago.

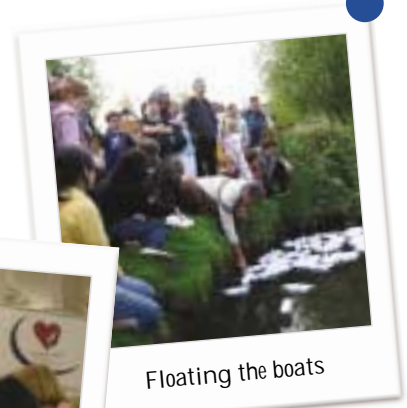
Awareness of the new **Antenatal Information Pack** was Little Hearts Matter's push for the whole week with articles about the pack being placed in medical and nursing magazines.

The aim of the new pack is to provide antenatally diagnosed parents with a written and DVD information resource that they can use to support the discussions that they have with the diagnosing medical team. This pack is in its final stages of edit but will be available fully by the end of June.

Everyone present signed a petition to forward sport opportunities.

The week culminated with a **Sports Event** at Weston Park. Lots of Little Hearts Matter members came to the event and took part in the many different sports on offer. There was tag rugby, football, run by our very own Jon Brunskill, circus skills, egg and spoon races and much more including lots of trips on a train and great games in the wonderful adventure playground. The weather was very changeable with rain, wind that blew a marquee away and lovely sunshine.

Over the week Emma worked hard to try and place as many stories about the charity in as many magazines, national and local papers as possible. Hopefully you will see a story close to home.



Hospital Awareness - Guy's and St Thomas' Central Hall provided a great venue for lots of children's heart charities to raise awareness of their work. A big thank you goes to Jo Wilson from Echo (the local support group) who arranged this awareness event.

Access to sport and activity for children with congenital heart disease has been the Children's Heart Federation's awareness aim over this week. They started their campaign at the **House of Commons** where the Minister of Sport, Gerry Sutcliffe, presented his ideas on how to make sport more inclusive for heart disabled children.

Dear Suzie

I am writing on behalf of our entire family to thank you all for such a wonderful weekend. We all thoroughly enjoyed ourselves at Hengar Manor and the happy memories will be treasured for years to come.

The event was so well planned and wonderfully executed. What really made the weekend were the team of people involved, great personalities one and all. Yourself, for your resilience, spirit, great sense of humour and passion for what you do, Jon for his engaging personality, discretion and positive nature (a rarity in someone so young), Kat for her ability to engage with the youngsters and Olivia for her death scream!!!

Thanks must also go to those outside of your organisation who helped make the weekend what it was; all the staff at Hengar Manor, (Paul for his energy and fun, Roger for his patience with us all at the fishing lakes) and Phil from the Eden Project (what a top bloke!!), last but not least Dr Oliver (Action Man) Stümper for scaring us all to death with his tree climbing antics that had many holding their breaths, and for making me cry with laughter at his proposed sabotage technique when we were racing to get the barbecues lit.

Matthew really enjoyed himself and embraced the weekend fully. His comment to me after the water polo was that "it seemed strange seeing lots of other children with chest scars like his" it was quite a watershed moment for him he now says he feels less "different".

Our children came away from the weekend exhausted but very, very happy. We all made a lot of genuine good friends over the four days and the quality time spent together and information exchanged was priceless. We came away shattered mainly from chasing after Sophie!!

My final thanks must go to Carol, without her generosity and selflessness none of this would have been possible, her tribute to her brother on the final night left a lump in my throat. It's wonderful that there are people like her in the world.

Once again, many thanks to you all,

Lots of love
Ian, Claire, Matthew, Lucy, Katie and Sophie Flavell



Medical

A parent's most difficult but vital task is to find the right balance for the particular child between pushing them to achieve and accepting them as they are.

Written by
Dr Stephen Williams
Consultant Paediatrician

Children Are Special

Of course all children are special. Special to their parents, special to their families, yes, even special and valued by society. Children with heart problems may have special needs caused by that problem or in some way related to it. For some parents of children with heart problems they are in the middle of the storm of sorting out immediate issues of the heart's working, the lungs working and gaining weight. Others will have reached smoother waters and be thinking of their child's development. But there is so much for children to learn! Movement and mobility, emotional security, communication: understanding others and being understood, enjoying social interaction, solving puzzles and complex manipulations. It is impossible to make an exhaustive list and that's before considering teenagers! This article considers what development is, what problems children can have, what parents and professionals can do to help and most importantly what to aim for.

❖ Development

There is an approximate order of events that help us make sense of what is happening as children develop and we often simplify these into 'milestones'. These are the particular ages that our child achieves different abilities. The first year is mostly about learning movement skills so that by just over a year, half of children are walking and most are getting about efficiently one way or another so that they can explore and examine things with their hands. During that year they have just enough social and communication skills to keep us adoring them to soak up the emotional warmth that we can give them. In the second year they start to share the pleasure of looking at things by pointing and rapidly learn more words to tell us their wants and show us things. As their second year moves into their third, their ability to copy behaviour has turned into imagination, pretending that one thing is another. By the end of their third year they'll most likely be able to draw a neat circle. Speech will be in many word phrases or sentences. Most likely they'll be out of nappies and busy learning self-care skills. Socially they will be co-operating in play in their fourth year and learning some of the most important lessons in life of give and take, listen and speak, run and sit still.

❖ How can I find out how well my child is doing?

Books can be great. Pictures and text in popular books can illustrate the many recognised

milestones that this article is too short to highlight. There are some screening tests that your health visitor may use. One of the most straightforward is the Denver test whose simplicity seems to bring health professionals' admiration and disapproval in equal measure. I'm a great fan as it manages to give all the key information on a great spread of developmental achievements on just one side of A4. The key, as always, is in appropriate interpretation and often the things that matter most are not what a child can do but how the child does it. A problem of brain control of movement (cerebral palsy) may show most clearly in the way the child grasps the brick and struggles to let go rather than whether or not the tower is two or three bricks and similarly it may be far more important what a child intends to communicate rather than the clarity or length of what they say. In fact, if they can mime how they fell and where it hurt that'll do perfectly well.

❖ What problems should I look out for?

I am tempted to reply, "none at all!"

For the vast amount of developmental problems that children have, the evidence that early or intensive intervention has lasting value is poor and what is usually most important is that children and parents enjoy interacting with each other without the anxiety of having to perform. I do accept that this is an unfashionable thing to say and you will easily find many people with excellent motives 'to do something' who will say the opposite. There are many who will claim that their therapy is wonderful if started early enough but the evidence is usually short-term, anecdotal ("there was this child that was cured ..." etc.), apocryphal ("it's well known that ...") or a statement of faith ("this will help ..."). Parents reading this should find it reassuring that there is no imperative to seek out the latest and best intensive 'head start in education' programme.

All children benefit from lots of attention, being spoken to and listening to conversations. They learn from exploring their environments and fun-filled interaction with everything they can come across. Most parents find that young children are far more interested in 'real' things than toys but everything has value, not least children's books. Helpful advice on playing with and stimulating children can be obtained from other parents, health visitors, children's centres, speech therapists, physiotherapists, psychologists, 'Positive Parenting Programmes', Portage teams and play therapists.



Health visitors are the usual first access point for these but many Local Authorities also have a children's information service. The government's 'Sure Start' schemes are gradually being turned into children's centres - hopefully there will be one near you. They often have speech therapists and psychologists as mild problems with speech and behaviour are so common and simple advice can be so valuable.

While I continue to say that parents shouldn't need to worry about their child's development, there are exceptions. One important one is that early intervention to help children who have severe nerve deafness has long term profound value; especially if treatment can be started by six months old. This has led to a neonatal hearing screening programme and continuing vigilance to pick up deafness as soon as possible. Another would be for children with stiffness due to cerebral palsy or other neuromuscular conditions where starting effective physiotherapy to ensure that joints remain supple as soon as appropriate is likely to have long-term value.

My last exception is for children entering Local Authority (LA) nursery or school where the child has significant developmental problems. Teachers rise to the amazing challenge of meeting the educational needs of a huge variety of abilities and children's prior experience often with only one helper in a large class. If a child is going to need a lot of help to understand what is going on in mainstream school, if they will need a significantly individualised learning plan or help to move about, they are best having these needs carefully assessed by the LA well before starting at nursery or school. The process of assessing a child normally takes at least six months and needs to be complete before the September when the child is three years old.

In some areas of the country it can be a big disadvantage to children with special needs which aren't recognised in time for the LA to do this assessment before they go into nursery at three years old. Once they've enrolled and started attending an LA nursery then the nursery will be expected to pay for the child's assessment from its



own budget. That's fine if the nursery only has one child with special needs that academic year but they can struggle if there are more, so that one child will have to be prioritised over another for educational psychologist time and often affected children are only allowed to attend for shorter periods of the week.

This last point is really just an administrative issue. Children with special needs may even benefit from more time at home gaining emotional security as a firm base to approach the wider world at a more gradual pace.

❖ What problems can children have?

Not for the squeamish this section, but I think some parents might like to know a bit about the broad areas of developmental problems and patterns.

Children with congenital heart problems and complex cardiac surgery are prone to have minor problems of concentration, clumsiness, speech delay and specific educational difficulties. These sorts of problems are likely to be impossible to tell apart from the sorts of problems that lots of children have. They often won't show until children are in school and often not until after seven or eight years old when children are expected to become much more independent in their learning. Diagnostic labels may be given to the problems children may show if they are particularly severe. These might be attention deficit disorder (ADHD), dyspraxia or dyslexia but many children have their own particular pattern of strengths and weaknesses that make labels pretty useless.

Very occasionally children with heart problems who have been very sick can have damage to the part of the brain that controls movement and this can show itself as stiffness and difficulties with letting go, separating the function of fingers, walking, posture and maintaining balance. The difficulties will depend on which part of the brain was affected. This is cerebral palsy. How it shows itself changes in each individual until they stop growing so helping them is a long term but very rewarding project.

Sometimes children's heart problems are just part of a child's problem and a good example of this would be children with a chromosomal disorder like Down's syndrome. These children might not have as many connections in their brains so they pick things up more slowly. This delay affects all areas of development to a similar degree so that large movements, manipulation, speech, social interaction and puzzle solving are all affected. This is often called 'global learning difficulties'.

It is not unusual for children to have combinations of the problems above.

Children with heart problems are not at any special risk of two further categories of developmental problems: autism and metabolic disorders. Autistic spectrum disorders show themselves by problems with communication, social interaction and something we don't have a word for in English; 'rigidity of thought'. This means that along with reduced communicative interaction and social diffidence, children may show less imaginative pretend play, they might play repetitively and react badly to change. Metabolic disorders are rare and very variable but can show a deterioration of function over time, e.g. Duchenne's Muscular Dystrophy.

❖ How do I get the right help for my child?

Talk to experienced family members, play group, nursery and school staff to understand how your

child is getting on.

See a community paediatrician to rule out medical causes of developmental problems, make sure no medical treatments would be valuable and ensure you are getting support and therapy from all the right health sources, from speech therapists to orthopaedic surgeons. For children under four or five years old often community paediatricians will carry out developmental tests. Normally, referral to a paediatrician would be carried out by your GP but many health visitors can also do this.

If your child has significant problems with development or learning then the Local Authority (LA) can provide 'Portage workers' in some areas to give you ideas how to stimulate your pre-nursery age child's development at home. They can provide assessment by an educational psychologist of your child's learning needs by observing how your child learns over a period of time rather than just what they can do on a particular day (a particular weakness of developmental tests). The LA can provide money for support staff to help your child engage with lessons at mainstream school or they can fund placement at a special school either for specialist teaching skills or so that your child can be close to specialist therapists.

The route to the extra money that LAs can provide has been through something you may have heard of as 'statementing'. Essentially schools have three levels of intervention for children with special needs. Level one, 'School Action', involves the school or nursery providing extra lessons or support within their own resources. Level two is 'School Action Plus' and involves the school seeking extra advice and help from specialists outside the school but paying for it out of the money that comes to the school with every child. Level three used to be through a 'statement of special educational needs' which involves a bureaucratic but thorough assessment of all aspects of the child's strengths and weaknesses, including parents' and professionals' advice. The LA was then meant to provide the money to allow those needs to be met. In practice, in many areas of Britain the LA is giving the money they used to hold back for statements directly to schools so that they don't need to use resources on the lengthy and costly process of producing the 'statement'. This is good where the child's needs are clear and the child does receive the right amount of help. My advice to parents would be to get the best possible out of their school by talking frequently to the SENCO and gently, but persistently, encouraging them to prioritise their child. Similarly to get the best out of the LA find out if they run a parent liaison service aimed at helping parents through the system. Use it and they may represent your child's needs more clearly to the special needs department. If you are not confident with your school's approach, moving schools is a risk because educational assessments are done over a period of time and this may mean a further period of trial and observation. Once your child has a defined extra level of input this will usually be carried on if you move to another school, for example if you move to another area. Certainly it will be if your child has one of the increasingly elusive educational statements.

❖ What should I be aiming for if my child has a special developmental need?

This is absolutely the fundamental question to get right.

I think the answer is to aim for the child's maximum self-esteem.

Almost never with developmental problems can we aim for cure. Similarly it is very rare that we can offer ameliorative treatment but that shouldn't be discounted and for the right child, stimulant treatment for ADHD can transform SAT test results from struggling for 1s to achieving 3s. We are increasingly using drug treatments to help unusual forms of cerebral palsy so a doctor's involvement can be helpful. Unfortunately miracle cures promised on the internet and in foreign countries are rarely helpful in a measurable way.

Most often the paediatrician's assessment will lead to neither cure nor treatment and the baton of responsibility will pass on to education, physiotherapy and speech therapy to help the child achieve their fullest potential. This is where a parent's most difficult but vital task is to find the right balance for the particular child between pushing them to achieve and accepting them as they are. Push the child too hard and the child will feel they are a failure and self-esteem will plummet. Back off too much and the child will be aware that they are not achieving as well as they could and again their self-esteem suffers. Get it right and their self-esteem soars.

GLOSSARY

Communication - everything we use to understand one another's meaning and express ourselves including gesture, words, intonation, listening and speaking.

Portage - a system of teaching pre-nursery age children the next stage of development through play and exercises. First tried in the city of Portage, USA.

Educational Psychologist - someone who works for the Local Authority usually who can assess a child's learning needs and advise teachers on how best to help a particular child.

Attention Deficit Hyperactivity Disorder (ADHD) - A problem where children find it difficult to concentrate for as long as other children at their age. Usually children with this will be impulsive, disorganised and tend to always be on the go. For a recognised diagnosis this needs to be the child's approach in all circumstances.

Dyslexia - *Dys* - difficulty with, *lexos* - words. A problem where children are not as good at reading, writing or spelling as you would expect from how good they are in other areas such as maths, memory, concentration, motor co-ordination, etc. If a child does have problems in those other areas as well then they should be recognised separately. Although they are often associated with dyslexia they should not be confused with it.

Dyspraxia - *Dys* - difficulty with, *praxos* - control of movements.

Global learning difficulties - difficulty in all of the main areas of development: speech, social interaction, manipulation, large movements and puzzle solving.

Community Paediatrician - children's doctor with expertise in assessing children's development.

Special Education Needs Co-ordinator (SENCO) - person responsible for the setting's/school's special educational needs policies and children.



Medical continued...

John's Story

by Anne-Marie Hennessy

Having just packed John off to school, wearing his trendy blazer, tie, hair gel and cool dude sunglasses (yes, it's March and totally unnecessary but he insisted), it's hard now to cast my mind back seven years and remember what it was like then when life was one huge round of hospital and clinic appointments, with a lot of Early Intervention...

John is my second child, born in 2001, diagnosed antenatally as having a Hypoplastic Left Heart and operated on at Guy's by David Anderson. The first surgery went quite well and we were home in four weeks, after an extra week in the local hospital. A few months later we were back in again when John needed a catheter and emergency ballooning to his aorta. It was then that the junior paediatrician on the ward noticed something wrong with John's eyes. They did all the tests they could and announced he was, at that time, blind, also with Nystagmus, a condition that makes the eye move uncontrollably and is associated with very poor vision. It seemed John might have had a stroke during the first surgery and had sustained some cortical impairment (scarring in the brain) which had damaged the area associated with movement and co-ordination and the visual cortex. His blindness was from the brain damage and I was told to expect him to remain blind and that he would need to learn Braille. It seemed just as I was getting my head round having a baby with a serious heart condition, I now had another issue to find out about and deal with.

At home, the Greenwich Visual Impairment support team kicked in and we had home visits

from a lovely lady who brought a range of visually stimulating toys for John. It seemed that the brain can learn to see again and the more we stimulated John's sight, the more chance there was that he would be motivated to look and that his brain might re-route the messaging and form a new pathway to allow him to see better. Amazingly, it began to work. Just as I had got my head around looking for nurseries for the blind, his sight seemed to improve. At first he could only see toys directly in front of him, then perhaps a metre away, but gradually that distance improved and we realised he could see, albeit poorly, and could use his sight to get by. It felt like a miracle. His sight continued to improve over the years and now you would not know he is visually impaired; although his sight remains poor and cannot be corrected with glasses. He sometimes goes off to the loo in a restaurant and sits with the wrong family when he comes back, or goes up to another mum in a shop thinking it's me, but otherwise runs round like a mad thing, like all small boys. The input from consultant ophthalmologists and low-vision aid clinics continues, and someone now goes into school to ensure they have the best (James Bond!) gadgets to help his vision: Magnifiers, a special mouse to increase the size of text, etc, etc. I found it hard at first to think that he may never be able to drive, it seemed so unfair when he can't walk far either, but as he continues to surprise us, I believe he may do so again.

Around the time we found out John was blind, he was rushed back into hospital very ill indeed. They were convinced it was a virus and did not want to move him to Guy's. Eventually I had to beg Guy's to take him into the cardiac ward, phoning my cardiac liaison sister there as I was convinced it was his heart. We were blue-light transferred there in the middle of the night and luckily a scan picked up that John's aorta was almost blocked again. This time he needed surgery to the aorta so we did Stage 2 at the same time. Another three weeks in hospital and then we were home again.

I became pushier than I ever thought I could be. As John grew it became apparent that he only crawled using one side and probably as a result of the early stroke, had hemiplegia of his left side (restricted movement due to poor messaging from the brain). We added physiotherapy to our list of appointments. As he grew, he developed walking skills slowly, first walking at two and with an



unusual gait. There was talk of splints and we were fitted for special supportive boots and insoles. We added Orthotics to our list of appointments. At the routine Paediatric appointments, someone mentioned stamenting and I decided to go for it. I felt extra help could only be of benefit to John.

At this stage, his eating was poor, his weight gain dismal, as he was sick multiple times a day. We were always off the bottom of the growth chart, so had intervention from the Speech and Language team for eating, appointments at feeding clinics and special high calorie milks, Thick and Easy calorie supplements, and more appointments. In the end John got used to Soya milk, which helped the sickness a bit and we struggled on with the poor feeding, narrowly avoiding a gastrostomy as opinion was divided about whether he needed it. He grew out of the vomiting and poor eating and I am happy to say now has school dinners with his friends, eating stuff I wouldn't touch! But it seemed a long time coming. Little and often was needed for years and I had to persuade nursery and school to allow extra snacks, but he did gain weight and he did learn to eat fairly normally, so if you are still back there in the dark days of feeding problems, please take heart, it does get better!

As John grew, I kept trying to get him a proper statement and perhaps because he had the visual impairment as well as the hemiplegia and heart condition, I was lucky enough to have a statement for him by the time he went to nursery. He also attended a fantastic place called the Early Intervention Centre, where children with a range of complex and profound needs go. Many therapies and interventions are co-ordinated there and John had music therapy, physiotherapy, speech therapy for food intolerance, all under one roof. It was hard to send him off there with the other children in a specially converted ambulance, as I so wanted him to be playing and learning out of a



was on nil-by-mouth. His blood pressure crashed and he became quite unstable under anaesthetic when they tried to insert the line. Luckily Suzie was visiting that day and was supportive as we tried to believe things could get better again. John made it back onto the ward and went a few days on the line. Then disaster struck



medical context and see him playing like healthy children, but they were my prejudices and I soon changed my mind. The children at the Early Intervention Centre may have had a lot of needs more complex than John's but it was a great place for him to be and the support and care for the children was amazing. Because of the upsets in hospital, John was very anxious about strangers and would be sick every time I left him, but the staff took it in their stride! I was a wreck every time I left, but it was good for me too.

By the time he was three, John was able to attend a mainstream pre-school, though I did make sure they knew about John's condition. There were still some sad moments like Sports Day, when John was very upset that he couldn't join in races, but on the whole he flourished there and made excellent progress. We discovered John had some partial hearing loss, usually in the winter, and so were referred to audiology clinics. Glue Ear was diagnosed, a normal childhood problem, but as they were concerned about the anaesthetic being risky for a heart child, we were referred to St Thomas' for grommets. More appointments established a few minor surgeries were needed, but they decided to wait as before I knew it, it was time for Stage Three.

John was now nearly four and despite being small for his age and a bit underweight, doing very well. However, he was becoming very breathless on exercise though (he couldn't cross the road without needing to be carried) and stairs were a real barrier for him. The Fontan was scheduled and was carried out shortly before John's fourth birthday at Guy's. It went quite well. Afterwards, however, was when we ran into a series of complications that spiralled downhill and had me very worried again. The chest drains couldn't come out as John's body kept producing fluids, a condition called chylothorax. Without the drains out, mobilising was painful and infections more likely. John had a collapsed lung and multiple infections. He was in such pain from the drains that he regressed to using baby noises and whimpering. It was really distressing for everyone and a new plan needed to be in place. After many setbacks we did get him more stable but John had had an uncomfortable few weeks and was not doing well. We realised the fluids were not lessening and another plan was needed.

The first way to treat chylothorax is by a low or non-fat diet. If that doesn't work, plan B is the child is put on nil-by-mouth and fed through a hickman line (nutritional liquids fed directly into the venous system). There was to be no cake on John's fourth birthday! After a few weeks of chylothorax and no progress, the hickman line was inserted and John

- the line got infected and John got massive infections again. We were back to intensive care to have the lines urgently removed, the drains re-sited and there was no plan C. After his problems with anaesthetic previously, this time we asked for a specialist to advise and they found a paediatric cardio-anaesthetist who recommended Ketamine. The drains were re-sited, the infected hickman line removed, but a plan C was still needed. We had talked about trying another treatment, the use of Otricide, a strong substance used in chemotherapy, which had helped with chylothorax in a few cases. It was a long shot but high doses were tried on John for a few days and to our delight, the fluids began to lessen, the drains coming out and mobilisation could begin. Just a few days later we were home.

As John got slowly better, it was time to apply for reception. At home, I had read to him at every opportunity and he developed a love of books that stood him in good stead. He learnt to read early, although the book was one inch from his nose and the TV the same! He'd been in the nursery attached to the local school, where his sister attends. So my assumption was that he would go there too. This was not to be so straightforward. Perhaps worried by his recent stay in hospital, or fearful about a condition they didn't understand, the school turned John down. I was very upset as it was my nearest school, his sister was there and I could see no reason why he would be better anywhere else. The school claimed he would not be able to 'access the curriculum' there. I appealed and John spent the next half-term back in nursery while the appeal process chugged along and we waited to see where he would be offered a place. Luckily, we won the appeal and a term later than planned, John started mainstream school. Hooray!

Without sounding trite, I do think it's been a lesson in counting your blessings and looking for the silver lining. Next week we are going to see England play in a World Cup qualifying match and as John has the DLA for mobility and visual

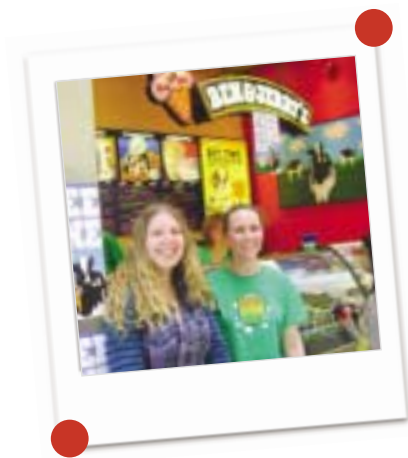
impairment, we got tickets in the disabled section long after the match had sold out! Now there's a bonus! John has turned out to be a bright, chatty little boy who enjoys life and is learning well; he drives his sister and me mad at times which is exactly how it should be and he brings a smile to the face of people who meet him. I think the rounds of appointments and clinics we did early on to get him the treatment and support he needed undoubtedly helped him to get on as well as he has and I wish you every luck with finding opportunities to ask for what your child needs, whether it's physiotherapy, vision aids, feeding support, emotional support or learning support. The help is out there, though it may take persistent parents to get it! John has written about his heart at school and seems to be interested in knowing more.

My hope is that as he gets older he will decide to study medicine and become a doctor! My other hope is that the developments in medicine continue to expand and progress to allow our fantastic children to lead a long and active life. My best wishes to all families reading this. It wasn't all plain sailing. At times John's behaviour is poor and concentration limited. He was referred to CAMHS for emotional support and can still get frustrated and upset quite easily. John gets 25 hours of support, because of his physical conditions, (he has no learning disability) - but at times it hasn't been easy to get the school to understand how his condition impacts on him. I have had a fight to get them to allow him extra calories; they don't always plan ahead how they will include him on school trips that involve a lot of walking. He has a Maclaren Major buggy from the local physiotherapy department, but John doesn't like to use it. My latest battle is to get the school to give John a buddy to help him carry his bag upstairs, as it is hard for him to manage stairs and heavy bags. The battle continues!

But since the Fontan, I have to say, he has gone from strength to strength. He is less breathless, eats better, hasn't been ill over winter, and loves school. He did need two rounds of grommets and our clinic list still includes physiotherapy, ophthalmology, orthotics, audiology, cardiology, low vision-aids but we are no longer under Speech and Language! He doesn't stop talking and is on the school gifted and talented list for maths and reading. We have found the use of certain aids at school helps him a lot. Easy grip handwriting pens, a writing slope, a sloping cushion to improve his posture, a computer with a special large font; of course each child is different but speak to your school's SENCO if you think something similar might help your child. The early years were a struggle, undoubtedly, but now when I see him run around in the school playground, he is enjoying his life so much and is doing so well, that I can only thank my lucky stars that he has come this far and continues to amaze us.



Fundraising



As I write, summer has arrived with a vengeance and Gwen and I have spent the afternoon at Ben & Jerry's in the Bullring here in Birmingham taking part in their annual 'Ice cream for a donation' fundraiser. And to enter into the spirit of the day we had to have a huge ice cream each!!! It can be a horrible job sometimes. So thank you Shelle and the team at Ben & Jerry's for your support, see you at Shugborough in October.

Motivation...

Someone asked me this week what it was that motivated me to keep pushing the fundraising snowball uphill.

You can see that motivation throughout this and every edition of the newsletter. Every day I speak to or hear from members and their families who have joined with me to help raise the income that we need to keep going and more importantly to respond to your needs and expand our services where needed. So thank

Kev's News



you to everyone for your support and thank you for the two ladies who wrote to me today, your letters moved me very much.

The Website...

Many of you have emailed to say how much you like the new website which outlines many of our Fundraising activities for 2009. We are now also able to advertise events that you may be doing that others can be involved with, so come on, let's have your ideas.

Leeds Castle...

A huge thank you for those of you who came and supported our first outdoor event at Leeds Castle in Kent. The setting is stunning and the day went very well, lots of tears but lots of fun

too. With the support of all the South East families this event has the potential to become something special.

And so to Shugborough...

Entries are now open on-line for the 11th of October 'On Your Marks for Little Hearts' walk or run being held again at Shugborough Hall in Staffordshire. Last year was a fabulous day so why not come and join us this year and run, walk or crawl 5 or 10km and help raise those vital and much needed funds.

Christmas...

It's never too early to think about Christmas. The 'Alternative Christmas' cards are just about to go to print and I will send you all some with the August/September Newsheet. Lights of Love can now be purchased by going to www.justgiving.com/lhmlightsoflove

It's a lovely way to say congratulations, to remember, to say well done or for whatever reason you like.

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

Kev Bazeley
Fundraising Manager
kevin@lhm.org.uk

PS - 'Dress Up, Dress Down or Dress Silly'

Lots of you have said that you were unable to put together a Dress up day for the May Awareness week - don't worry, you can do it at any time, go on have a go and do let us see the pictures.

A Wonderful Mum and Nanny

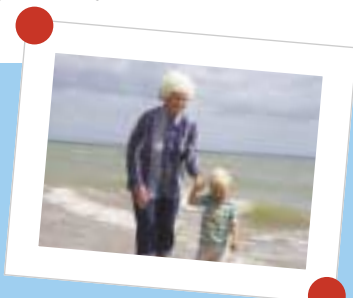
For Nanny

- I've searched as widely as I can but no-one's had a better Nan.
- She'd talk to me for hours on end she was my Nan and my good friend.
- I always thought it marvellous with Nanny looking after us.
- On special days she'd come to stay always there on Christmas Day.
- She was, since I was very small the nicest present of them all.

There is no-one in life like Mum is there and when we lose them a hole is created that can only be filled with wonderful life long memories.

Can I thank Anne-Marie who recently lost her Mum, Eileen (John and Liliana's Nanny) for the very generous donation to LHM in memory of her special mum.

She was a huge part of John's life and John who is seven years old wrote and read this poem at her funeral.



A Christening - What a Happy Day

Little Lara Jones was christened in February and she and all her family obviously had a fabulous day.

Lara's mum Jane wanted LHM to benefit from the day and asked for donations instead of gifts for Lara.

So a huge thank you to all and to Lara especially for the wonderful gift to others of over £700.





Team Cora Put Their Best Feet Forward

Inspired by her little one, Cora, Deb Banyard from Reading along with Cora's Aunties Jude and Helen, Cousins Kieran (11) and Alex (17) and friends Jo and Kirsty made the long journey to Maidstone to take on the more difficult 10km course at Leeds Castle.

other day but we were not prepared for the hills and mud on the course!!! Who would have thought that a castle would be in a field at the top of a hill!!

But they all completed the course and raised an incredible £2,500.

Thank you 'Team Cora' and thank you for travelling so far to support the services that will benefit from your efforts.

If you want to run for LHM, why not visit our website where you can find more than a dozen events organised for 2009.

Deb says "not having exercised for about five years, training started gently. We did lots, going out in all weathers every



Colbie-Kate Ross and her pals from class P2D at Eyemouth Primary School in Scotland have cooked up a real treat again this year when they turned their hands to baking for Little Hearts Matter.

Thank you children.

Can I also thank all the children up and down the land for their brilliant cookie bake gifts to us, you have all been great. Don't forget you can bake at any time of the year. It's great fun, a good way to raise funds to help others and very importantly it's SOOOOO YUMMY!!

The Kids Keep On Baking...

How Old!!!

We can't believe that Simon Rose has reached the ripe old age of 40 already! He doesn't look a day over 39. Thanks to everyone who bought raffle tickets at his birthday party and thanks to Polly and Arlo for the gift of £96. What an easy way to fundraise and a great idea too, thanks all.



Table Top Sales and Raffle

A massive thanks to Grandmother of Evan Greenlees, Kathleen Duthie and her friends at Our Lady of Good Council Parishioners in Sleaford, Lincolnshire who raised an incredible £855 at a recent table top sale and raffle.

Kathleen is a long time supporter of Little Hearts Matter and has to date raised over £6,000.

Thank you Kathleen and I know that you would like a huge thank you to go also to all your friends and your church. **Thank you** all.



2009 Paris Marathon

The Jones family friend Sebastien Mallet returned home to France to take part in this year's Paris Marathon to raise funds for us and in support of Lara Jones.

Sebastien says "I wanted to help LHM raise awareness of the children and the work that LHM do in support of the children and their families. Thank you to all who supported me and helped raise over £1500, I hope it helps".

Yes Seb it does help and thank you so much for your support.

Irish Eyes are Smiling - On Us!!!

Mum, Jo Wright wrote to us recently to tell us about her cousin Chris who lives in Ireland.

Inspired by Monty, Jo's son, Chris recently organised a charity football match and quiz night in his local pub and then sent us an amazing 700 Euros!

Jo tells me how well supported she is by Chris and his mum who helps so much with her son.

Chris, thank you so much not only from Jo and her family but from all of our families. A huge thank you to you all over the water.

A Wonderful Lady

I recently heard from Edward Hyde from North Glasgow who told me about one of his students, Miss Alice Atkins who was studying the art of stained glass production at the age of 84.

His letter really moved me when he told me of Alice's very sad death earlier this year.

Her part finished work was completed by the other students who then auctioned the glass and sent us a lovely donation of over £400 in memory of Alice.

Thank you all, she must have been a very special lady.

Big Hearted Cousin Strides Out For LHM

Lorcan Mullan's cousin Eoghan Totten took part in a recent sponsored run at St Patrick's School in Downpatrick County Down and raised a fantastic £77.30 - well done Eoghan and thanks to all who sponsored him. I bet Lorcan is really chuffed with his cousin.

Feature

An overview of the Little Hearts Matter Annual General Meeting and Open Day held in March 2009 at Bretby Conference Centre.

Written by
Gill Smith

Good lord - another AGM and Open Day - already?? It doesn't feel like a year since the last one!

Well no - that's because it **wasn't** a year. In fact it was less than six months - it's all right, you didn't fall asleep and miss half the year. There had to be another AGM because of Little Hearts Matter's accounting date moving. But anyway it was **GREAT** to have an excuse to have another one this soon! I mean, a get-together with like-minded folks, tons of information and a built-in day-long party for the kids - who can resist?

We always stay over, for the fab knees-up and social the night before the meeting day - and I know I've said it before, but I'll say it again, the accommodation is great, and the staff at the Bretby venue are **lovely** - and it has to be the best lasagne in 15 counties AND the chef buys our raffle tickets! For those of you who haven't tried staying, it is recommended - the kids have a ball, while the grown-ups eat, drink, chill and swap medical stories - the perfect social occasion really...!

The talks this time were extremely varied - so much stuff going on that my other half and I couldn't even cover

them all between us!

The big presentations in the morning were Suzie's update and the latest on the government green and white papers looking at the future of cardiac services in the UK; Kev Bazeley (fresh from suborning Bretby staff to buy raffle tickets) talked about what's going on in fundraising, accompanied by a kind of slow strip-tease - honest... no really, you really had to be there! (So make sure you are, next time!). And as a highlight: Bill Brawn on congenital heart disease and the NHS, a fascinating speech, a lovely man, and, yes, a **great** surgeon - as he went out, a Mum near me murmured 'God has left the building...'

The afternoon was where it got complicated, with three sets of break-out groups running at each time slot - two education and one medical. On the education side, we were offered sessions on Key Stage 2 by Barbara Hunter, Director of Outreach and Inclusion; on Nursery and



Key Stage 1 by Helen Phillips, of Specialist Inclusion Support Services, with Isabel Baumber from our own Trustee Board; and Transition from Junior to Senior School, by Helen Phillips and Suzie. Or you

could go to Paula Banda from GUCH on Medical Transition and GUCH Services, followed by Oliver Stümper from Birmingham Children's Hospital on 'what treatments are available before a transplant is needed'. I'm exhausted just listing them! It was a great programme and a tribute to our office team.

Yes, there was a youth programme again - and, this time's innovation and a highlight for our family - this time there was a programme specially for the 'tweenies' - the (roughly) 5 - 10 year old kids, too old for the crèche and not old enough to join Jumping Jon Brunskill and his Teen Terrors. So in the sports hall there was a non-stop programme of activities, games, drama, craft, wheelie things and whizzy things, food, talks and general mayhem - this was an absolute HIT with our 5 and 7 year olds. Hope it happens again!

All this **and** they made us dress up in silly clothes for a photoshoot! You may have received the results by now - the publicity for 'Dress Up, Dress Down, Dress Silly' was done while all the rest of this was going on - we had flamenco dancers at the breakfast table, kilted blokes at the coffee-break, and super-heroes in the kids clubs. (Told you Kev B was a persuasive sort). Not that I want to put anyone off coming next time...!

Open Days go from strength to strength - we're on a roll now. They are seriously great weekends (particularly if you dress to impress...!)



Ask the Experts

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

Dr Robert Tulloh, BM BCh MA DM (Oxon) FRCP FRCPCH
Consultant Paediatric Cardiologist
Bristol Royal Hospital for Children



How much energy should my child have after the Fontan?

Little is known about the long-term future after the Fontan operation. Most children who undergo this procedure have limited exercise ability before the Fontan. This is due to a variety of reasons, such as limited lung blood flow down the Glenn/Hemi-Fontan/Cavo-Pulmonary Connection, when the SVC (Superior Vena Cava, bringing blood from the upper body) has been connected to deliver blood to the lungs.

The aim of the Fontan procedure is to increase the amount of blood delivered to the lungs. When the IVC (Inferior Vena Cava, bringing blood up from the lower body) is connected into the circuit, the blue blood will go straight to the lungs to pick up oxygen. This means that your child is much pinker.

The increased oxygen levels lead to a reduced feeling of breathlessness during exertion, a feeling of well being and that they can run or exercise much more than before the operation. No formal study has been undertaken to determine how much exercise a child should take, but we all agree that regular exercise is good for hearts of all ages. The sort of exercise that is encouraged is *isotonic exercise* where there is no straining but light repetitive movements, such as swimming or aerobics. The exercise that is discouraged is *isometric exercise* where your child is straining against a heavy object, such as in weightlifting. It is not recommended that there should be exhaustion afterwards, but a feeling of mild tiredness. Those who have abnormal heart rhythm on exercise should probably take it easy.

I tend to say that the children can exercise as much as they wish to, provided that:-

- they are not pushed beyond their ability by others.

- they are sensible and know when to stop, to prevent exhaustion.
- they undertake sensible types of exercise as above. Running or swimming are good for you, whereas straining against heavy objects is not. Some children find that they can run for quite a long way, whereas others tend to tire more easily.
- high octane fairground rides are not usually advised.
- children taking Warfarin are usually advised to avoid contact sports.

It also may depend on the type of heart problem. A child who has two reasonably good ventricles, but for technical reasons, has had to undergo a Fontan operation, is likely to cope better than someone with one right ventricle which is not working so well, and has a leaky valve. It is likely that competitive sport is not possible, but that they will be able to kick a ball around a playground or join in with team sports in a defensive position where less running around is required.

Some children still have a significant amount of blueness (cyanosis) after the Fontan. This might be due to a hole left open deliberately (fenestration), to allow the pressure to be low. Sometimes it is due to some blue blood escaping to the left side of the circulation. This can make the child quite breathless after the operation. Usually it does not need further intervention, but sometimes it is necessary to close the leak to improve the exercise tolerance. Discuss this with your cardiologist if you are not sure.

Often children take a little while to recover from a major heart operation but it is usual to be fully recovered by six months. If a child has had

the Fontan, has been previously well, but whose exercise capacity is decreasing, then medical review is needed. It will be important to check that there is not some new development such as a leaky valve, heart rhythm problem or even an airway problem. It is worth remembering that children who have heart problems may also happen to have asthma in addition. Of course, the cardiologist would want to be certain that there was not a heart cause for the breathlessness before treating any asthma!

The exact amount of exercise is different from child to child and depends on underlying heart anatomy, function, oxygen levels (sats), medication, etc. Some children have been known to run long distances after the Fontan where others are content to undergo gentle swimming and take up a more sedentary life. The aim is to improve the quality of life, not to turn everyone into competitors for the 2012 Olympics!

As always, it is sensible to ask your cardiologist for their view on recommended exercise after the Fontan operation, everyone has a slightly different way of putting it!

CLOTHING BINS

We have four of the new LHM clothing bins in place in the Birmingham area and Bedfordshire with more planned for the future.

YOU CAN HELP. If you know of a location anywhere on the UK mainland that will allow us to place a bin please let me know and I will follow up your lead. The more the merrier, not only to raise funds but also as a great notice board for the charity.

Please visit www.lhm.org.uk and click on **Fundraising & Merchandise** for more details.



Feature

Many of you will now be aware that we have a new website. It is important to us that everyone is able to access the site so below is a step-by-step guide to registering.

Written by
Gwen Webb



gwen@lhm.org.uk

Since the launch of the new website in February I have received lots of feedback about the new site. I'd like to say thank you to everyone who has taken the time to send me comments and suggestions. I love hearing from you so please do keep them coming. Quite a few of you have emailed me about registering on the new site and the two login

procedures. We realise that this is slightly confusing (and we are looking at how to improve this) so below we have provided step-by-step instructions on how to register.

If at any time you have problems getting onto our website then please, please give me a call or send me an email and I'll be more than happy to answer your questions or talk you through it.

HOW TO REGISTER

1. Go to www.lhm.org.uk
2. Click on 'Register' in the top right hand corner.
3. Fill in the registration form. If you would like to become a 'Full Member' of the charity, please tick the box and wait for the full form to show.
4. Once you have completed the form click 'Register'.
5. If you have completed all parts of the form you will receive a notification on screen to tell you that a confirmation email has been sent.



REGISTERING ON THE MESSAGE BOARDS

1. After completing 'how to register', click on 'Your Stories and Message Boards' in the side menu.
2. You can then click on 'Message Boards' in the next side menu.
3. Click on the underlined text where it says 'Click here to visit our message boards'.
4. A new window will open with the Message Board front page.
5. Click on 'Register' which is at the top left hand side of the page under the logo.
6. The next page will show you our general terms of use. You will need to scroll down the page to read all of them.
7. If you agree to these terms, click on the 'I agree to these terms' button (If you don't agree you will not be able to register on the message boards).
8. Enter a Username, your email address, choose a password, select your language and choose your time zone. You should be able to choose the same username and password that you chose for your registration on the main site.
9. At the bottom of the page you will see a verification code. Type the letters and numbers that you will see in the picture into the box below it.
10. Click 'Submit'.

You are now registered on the message boards.

Had problems with any of these steps? See the **HELP!** section below

HELP!

This section explains some common problems you may encounter when registering. If these don't solve your problem then please call or email me and I'll be more than happy to help.

Registering

I can't view the form correctly or I can't type in the boxes.

This is probably to do with your browser. Please get in touch and let us know what browser and version you are using (or just call and say "help!") and we can look into this for you.

I haven't got an email confirming my registration details.

This may be because you did not enter your email address correctly or it has been blocked by your email account junk filter. Check your

junk mail folder and settings.

I've clicked 'Register' but it takes me back to the registration form.

This means that you have not filled in all the required information. A red star will appear by the boxes that you need to edit. Try entering more information.

I've entered the same Username on the message boards as I did on the main site but it's saying it's already in use. Why?

Someone else must have already registered with that Username on the message boards. Although most people choose the same username for both, not everyone does, so it is possible that you could register your username for the one but someone else has already registered it for the other. You will need to choose a different username for the message

boards.

Logging In

I'm entering my details but it's telling me they're incorrect. Why?

Firstly check your registration confirmation email to make sure you're using the correct details. Next check whether you included different case letters as this will make a difference. Finally, if you chose a different username on the main site to the boards, check that you are using the correct set of login details.

I've forgotten my login details and I'm not getting your automated emails. What can I do?

Send an email to gwen@lhm.org.uk and I will be able to advise you further.

Got a problem that isn't answered here? Email Gwen or call me on 0121 455 8982.





Zipper Zone

Hello parents!

I am very happy that I managed to meet so many of you at the Little Hearts Matter Activity Weekend 2009.

On the Friday morning I was both nervous and excited in equal measures, I'm sure that a lot of you felt the same. Any anxiety was put at ease as soon as all of the amazing families arrived though, and it was a joy to see children and parents alike throw themselves in to the weird and wonderful activities that were available.

I know that many of you relished the opportunity to kick back, relax and chat to other families who know exactly what living with a child with a single ventricle heart defect means. I felt privileged to be a part of the team that was able to facilitate this, and hope that you enjoyed yourself as much as I did! When Suzie and I began planning the Activity Weekend last year, I was more than a little daunted. I had been lucky enough to be involved in three previous activity weekends, and so had an insight into the level of organisation and hard work involved. In terms of

precedent, the bar was high; anybody who has attended an LHM Activity Weekend knows just how successful they are. Gulp!

Back to basics, I thought. For starters, why does Little Hearts Matter offer the opportunity for families to go away and spend a weekend together? What should the families get out of the weekend? What exactly did we want to **achieve**?

Suzie has always had immense pride in how Little Hearts Matter is able to provide information to hundreds of families, whilst maintaining a very personal touch. We like to really get to know our families, so that we can help you every step of the way. We also acknowledge, however, that there are certain times when you might need to talk to somebody who has been, or is going through, a similar journey to you. It's always nice to know that you're not alone.

We know that living with a serious heart condition, or living with somebody



who has a serious heart condition, can be very tough. Life can be stressful and difficult. Little Hearts Matter aims to relieve as much pressure as possible. To this end, I feel that the Activity Weekend is hugely important as it brings the heart children from the minority into the majority, and allows families to share problems and solutions, trials and tribulations, and obstacles and achievements.

During the Activity Weekend, everyone present witnessed something very special. Carol Shanahan funded this event in memory of her brother, who died at just a few hours old. In her report, one paragraph resonated with me and filled me with a particular sense of achievement. "The big story, however, was how just over 100 people went from a nervous and slightly apprehensive meeting of semi-strangers on a Friday afternoon through an amazing experience to a Sunday evening celebration of each other, and the family they had created. It was a weekend where something magical happened and I was delighted to have been a part of it."

I hope to meet many, many more of you as soon as possible. If you have any comments, suggestions or queries, please get in touch: jon@lhm.org.uk or 07590 531153.



Hi everyone, Kat here, that crazy friend of Jon's that gate crashed this year awesome activity camp, acting as a helper so I could join the P-A-R-T-Y! Woo!



warm and lovable characters. It was an absolute pleasure and honour to have met you and your families and to have shared in all the fun you kids create! You lot really are a remarkable bunch and I hope to see you again soon, as well as meet more members and families of LHM. Thank you so much for including me in such a special and memorable weekend!



The Review



Every issue we feature a review of a book or website or film that our members may find interesting. In this issue, Tim York, one of our members has reviewed the new LHM website.

Written by
Tim York



In 2007, after I found out about our unborn son, Solomon's heart condition (Tricuspid Atresia), I turned to the internet to look into the condition; the surgical procedures involved; and the general lifestyle changes our family would need to adapt to. During this research I, like many of you, had my first interaction with Little Hearts Matter through its website where I found lots and lots of useful information and also the message boards.

Since finding LHM's website in 2007 it has been totally replaced (in 2009) with a much more professional, colourful, user-friendly, and secure website. If you haven't logged on to the new website and message boards yet then I really recommend that you take the time to do so!

So what has changed?

Loads of stuff to download!

I think that a really useful feature of the new website is that a lot of the publications and resources that get sent out by post for the LHM Filofax can all now be downloaded from the site in the 'Publications & DVDs' section. It is also easy to download past copies of the newsletter (this is handy when you want to pass on the current LHM news to family and friends by email!) and loads of other resources that are not available in paper format.

The 'Heart and Lifestyle' section remains relatively unchanged (I think) but is still an excellent place to get a good idea about the various conditions, surgical procedures and lifestyle issues that our children face. I've found that it is also a very good section to point people to when trying to raise awareness and share knowledge and understanding of these conditions.

News

I like the new News section of the site as the LHM team appear to be on the ball with keeping it regularly updated - it is really good to be able to see in more detail and more regularly the latest things the team have been up to on our behalf.

Fundraising

One of the great improvements to the website is the new Fundraising section as it is now much easier to see what official fundraising events LHM have got scheduled but it is also good because us parents can advertise what events we are going to be taking part in too! It seems a lot better organised than before and there is loads of information and ideas about how you can organise your own events and get involved with raising cash for Little Hearts Matter.

The Message Boards (Forum)

For me one of the most important parts of the LHM website has always been the message boards (forum). This is just a really useful place where parents can ask either the LHM team or other parents about pretty much anything or share their own experiences with others. This means you can talk about your child's condition; the hospitals and facilities; any milestones they have achieved; advice on DLA and benefits... absolutely anything! There's now even a section for Grandparents to share their experiences! I'd say that the new message boards, if you are not so technologically confident, can seem a little daunting at first as there are a lot more features available than the old site. However, I've found that you can keep things as simple as you like and you'll soon get used to it.

For those of us who like to add a bit of colour, you can now add coloured text, mini-pictures, 'smilies' and a personalised signature to your messages (I'm easily pleased!) Don't be put off - there is usually someone from the LHM team or even other parents that are to hand to answer any questions on these new features (or anything else) - I don't think any question is considered too daft!

If anything, I'd say the current forum seems a little less used than the older version but hopefully that'll change in the coming months as and when people get used to them (and realise that they are not that complicated after all). I certainly think that the new forums (and website in general) are a lot more secure than before too and that can only be a good thing.

Security

As already mentioned the new website is a lot more secure than the older site. The 'Family Stories' and 'In Memory' sections are now only accessible to members who have signed up via the website. Also the 'Message Boards' are doubly secure as you have to register and log in to use the Message Boards too. Although this can seem like an unnecessary process it actually prevents any of the (often private) parents comments from being accessible by Google and other search engines. So don't be afraid to post!

All in all I think the new website and forums are a fantastic resource for the families and friends of our heart children to use. I'm sure if anyone has any ideas as to what could be added/improved your ideas would be most welcome. I hope you take the time to check out the new site and find it as useful as I do!



Noticeboard



Registration is now open for those of you who want to walk or run the 5 or 10km course around picturesque Shugborough Hall, Stafford.

Last October the sun shone, the children loved every moment, as did I and lots of families walked or ran the course to raise funds in support of the services provided to everyone. Money is still coming in which is wonderful, please can you pass on our thanks to your sponsors for their generosity.

REMEMBER - you do not have to run!!!

So come on everybody, join me and the team at Shugborough on the 11th October for a 10.30 start and run, walk or crawl around the estate and please don't come alone, bring all your family, friends, workmates, in fact anyone you like, the more the merrier.

Income from this sponsored event will be used to maintain the charity's parent support services - your help in achieving the aims would be appreciated and is indeed vital.

For those of you who just cannot get to the Midlands but still want to run or walk for us why not go to www.bigfunrun.com where we are an official charity.

Walkaround UK

Join with me and organise your own walk anywhere in the country when we all 'Walkaround UK'. Just pick a route, a weekend, grab family, friends and walk for Little Hearts Matter.

Ian Ash, one of our Trustees has a team walking in Cornwall in the summer so let's follow his example and see how many families we can get walking this September!

If you would like more information please contact us on 0121 455 8982 or email info@lhm.org.uk

If you can't take part but would like to help why not sponsor ME - throughout September I will be walking 100 miles to raise funds for Little Hearts Matter, if you would like to sponsor me please go to www.justgiving.com/walkarounduk.

For easily accessible routes go to www.walkwithwheelchairs.com or www.walkwithbuggies.com

LHM Publications

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

- Antenatal Information Booklet
- Preparation for Hospital Booklet
- Preparation for Hospital Pack - for loan 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
- Dental Care
- Fundraising Pack

Please Tell Us

Lots of you are having a go at at Dress Up, Dress Down or Dress Silly, Walkaround UK and many other things, please do let us know what you are up to, especially if you are taking part in one of the fundraising initiatives either from the website or from the Fundraising Pack you received earlier in the year.

I would love to get involved in all that you are doing.

If you are planning a fundraiser you think may be of interest to others or would like others to get involved, let me know and we will publicise it on the website.

Thanks as always,
Kev

DIARY DATES

On Your Marks For Little Hearts

Sunday 11th October 2009
Shugborough Hall, Staffordshire

Alternative Christmas Card

1st December 2009
Don't forget to use your alternative Xmas Card

Lights of Love - Switch On

Sunday 6th December 2009
The Rookery, Stafford

CONGRATULATIONS

Everyone at Little Hearts Matter would like to pass on our best wishes to Louise and Duncan Hall on the birth of their son Alfred, and to Sam, Ben (and Freddy) on the birth of their brother.

Louise has been a Trustee of Little Hearts Matter for over ten years.



Over To You

Children's Heart Federation - Christmas Trip to Alton Towers

This year the CHF asked all their charities to nominate a family to attend a lovely family Christmas trip to Alton Towers - as always we did it fairly by picking a name out of the bag, and this year the Lilley family were absolutely delighted to be picked. Below is a letter sharing their experience.

Dear Little Hearts Matter

I am writing to you just to say a big 'Thank You' for giving me, Jon, Hannah, Heidi and Helena (HLHS) the chance to spend time together as a family during our stay at the Alton Towers Resort.

The girls were really excited and couldn't wait to arrive there. We had a great time, there was so much to keep them entertained and we especially enjoyed going to visit Santa Claus in his log cabin.

The hotel was brilliant, we stayed in a nice big room, the girls thought it was great as they had the chance to sleep in bunk beds! Helena however ended up in our bed - she thought it was wonderful - a nice big bed to share!

The lady from the Children's Heart Federation was so nice (think her name was Sam), she made us feel very welcome and answered any questions we had.

We as a family have got a tough year ahead because Helena is due to have her third stage possibly in the summer time. Family time is precious, so a big THANK YOU again for letting us experience the magical Alton Towers at Christmas time, we had a lovely time.

Love and best wishes from
 the Lilley Family



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



- ABOVE: Samuel Robinson's (2 years, 10 months) first day at playgroup.
- ABOVE LEFT: Michael Smith (5) at his first dance show.
- LEFT: Oliver Harrison (1) off to a Pudsey Bear Party at his nursery.
- BELOW: Matthew Luck celebrating his 18th Birthday.

