



Little Hearts Matter Needs You!

Over the last few years the charity team have been working hard to build services that meet requests from you, the members.

Over the next year we hope to provide many more of your service requests - education information packs to help you plan for your child's education needs, Fontan surgery information and a pack of ideas around the MCT diet. We hope to have a number of regional events and an activity weekend for families of children over the age of ten.

The telephone service team is building its availability and its service provision so that you can ring every evening and talk to another parent. And we hope to provide new information sheets for your filofax.

But we need you to help us do it all!

YOUR EXPERIENCE

Each and every one of you has a unique experience that may help another family. We could tell your story in the newsletter or link a family to you who has a similar story.

Some of you might like to be one of our service experts, for example, have you had personal experience of education statementing or the planning needed before going on a trip abroad?

Personal experience helps us to provide parent - to - parent support.

WHERE YOU LIVE

We would like to be able to link families who are close to each other. Let us know if you are happy to be linked to other families close to home. Little Hearts Matter would like to create a national network of linked families.

We can also tell your story and raise

awareness of Little Hearts Matter's work in your local press. Any fundraising ideas interest local papers so tell us what you are doing for Little Hearts Matter.

Could a local group of parents run a fundraising event together?

YOUR IDEAS

We need your ideas for new services at each stage of your child's life. If lots of parents ask for the same information or support we will work hard to try and provide it. One of the jobs will be to find funds to support it.

We need your ideas for fundraising. What has worked for you?

YOUR CONTACTS

Anne-Marie Bostock used to work for Tesco. She thought that they might be able to help us and so she suggested Little Hearts Matter as a charity that they might be able to help. And they did! They undertook lots of small projects.

Lisa Morgan used her contact within a school to encourage children to pick Little Hearts Matter as their charity. They even took part in the Shugborough Run.

Who do you know?

If we try to approach a company that know nothing about us we will not make an impact but if you know someone, it might just work. We can do all of the work!

Every time we look at the press we see

YOUR CHARITY NEEDS



headlines about the credit crunch. The next few years are going to be a challenge for Little Hearts Matter but we are all good at challenges especially you, the membership.

Together we can beat the recession. We can work together to find every source of financial support.

Together we can continue to ensure that every family that contact us can find the support that they are looking for.

We need you to help us face the 2009 Challenge.

Give us a ring on 0121 455 8982 if you can help.

Suzie Hutchinson
Chief Executive

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Little Hearts Matter's Voice

Little Hearts Matter has a voice.
Your voice!

A large part of the charity's work is taking the needs of children and their families to as many different audiences as possible. Every time a member family tells us about a concern that they have about their diagnosis, medical treatment, schooling, DLA application, their child's lifestyle or their fears for the future we start to work to make change. Firstly we try and help each individual family and then we start to research where change can be made - within medicine, education, social care or government.

At the moment we are working:-

With the Department of Health to

- raise awareness of the diagnosis and the need to increase antenatal choice.
- highlight the need for a high minimum standard of surgery in experienced specialist units.
- encourage community and hospital services to work in partnership to ensure that all carers have an up-to-date understanding of care needs.
- work on transplantation and the need to raise awareness of the need for donation.

Within Education to

- raise the needs of individual children in their schools.

With Social Services to

- aid individual families with their DLA

Suzie's News...



Suzie Hutchinson
LHM
Chief Executive

applications.

With the General Public to

- raise awareness of the risks of congenital heart disease.
- raise awareness of the treatments and lifestyle needs of children and their families with single ventricle heart disease.
- raise awareness of the work of the charity.
- to raise awareness of the need for funds to support the charity.

This is only the beginning. We have so much more that we hope to do over the next few years.

We are currently researching the educational and social service needs of our membership children. We hope to take their needs to the Minister for Children, the Right Honourable Beverley Hughes. We would like all services to work together looking at the whole child's needs not just their medical treatment and care.

In May 2009 there will be a great opportunity for Little Hearts Matter to raise their voice as the week from the 11th to the 17th of May 2009 will be a newly established Heart Week.

For part of the week Little Hearts Matter will work with other children's cardiac charities to raise the need for improved national care as part of the Children's Heart Federation led work on maximising the opportunity for care.

Little Hearts Matter will be organising some of their own initiatives so watch this space and you will learn more soon.

Kevin is initiating a great fundraising opportunity that everyone can get involved with - look at his fundraising pages on pages 8 and 9 for more details.

Your Voice is the voice that leads us. We need to hear from you about both your successes and your frustrations so let us know your thoughts either through the new website, by phone or by letter and of course you can always pass on your thoughts at any of our events.

We look forward to hearing from you.

It's been a busy few months for LHM. I'm pleased to say that we're keeping the momentum going by kicking off the year 2009 with lots of activity which will help promote our work.

The Shugborough Run in October proved to be a real success and we received some excellent media coverage in newspapers across the country. The Staffordshire media were very supportive and we secured a double-page spread in the glossy magazine Staffordshire Life - many thanks to the Metcalfe family for taking part. I hope it has encouraged many of you to join us again at the Leeds Castle run taking place in March. Thank you to all those that took part in media work and photographs.

LHM in the News...



with
Emma Pelling

emma@pellingpr.co.uk
0207 624 7533

It was lovely to meet so many of you at the Open Day in early November. I really enjoyed our media training session with the young people. I hope we can continue to work with our young members to ensure that their voices are heard. If you are one

of our young members and would like to get more involved in media work then do get in touch. We hope to run more media training sessions for those interested later in the year.

February is always a busy month for us with Congenital Heart Disease Day and the Cookie Bake. You'll see an example press release in your Cookie Bake packs so do please use that if you are planning an event and would like to let your local media know.

The month of May will see the first Heart Week. This is a great opportunity for us to raise awareness of the needs of our children and the work of Little Hearts Matter. We hope to secure some positive media coverage around this period and, as always, are looking for families and young people willing to speak to the media. Do let me know if you would like to get involved.

I'm sure Kevin will be encouraging you to take part in the various fundraising events taking place and I'd like to echo that by urging you to think about how you can publicise your fundraising activity. I'm always happy to help with news releases and advice.



Medical Research Update

Better diagnosis of complex congenital heart disease at birth

Many of you may have read about a study that has just been reported by a Swedish research team that the taking of oxygen saturations just after birth can give an indication as to whether a child has complex heart problems. If the baby's saturation levels are low then they are offered an automatic cardiac scan to determine whether they have a heart problem or something like a chest infection. This piece of research has some very positive results.

Little Hearts Matter is currently part of a medical team in the West Midlands that is working to prove the same thing.

The aim of this research is to prove that it would be beneficial for all maternity units to be offering oxygen saturation testing after birth. If the study is successful, and like the Swedish research it looks like it will be, this would mean that:-

- babies with cyanosis (who go blue) will be diagnosed before they are sent home from hospital;
- babies could be treated more quickly and prevent the collapse that many babies have before a diagnosis is made.

We will report the results of this study in the next newsletter.



Trustee News

Below are some updates from the Trustees of Little Hearts Matter.



Pete Turner
Chairman, Little Hearts Matter

As Chairman of the Board of Trustees, it is with great pride that I lead the charity into 2009. We have a lot of things already planned and I hope to catch up with as many of you as possible during the year.

We are always seeking new members of the Board of Trustees - particularly from among our membership. The Trustees are a group who meet at least four times during the year and agree the strategy, budget and operation of the charity to ensure that the fantastic amount of money you raise for Little Hearts Matter is used to give the most benefit to our membership, as well as raising the profile among medical professionals, government and corporate business.

I would like to ask our membership whether they would be interested in helping shape the

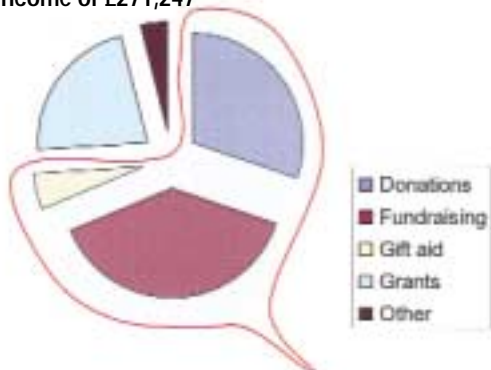
work of the charity and would consider becoming a Trustee for Little Hearts Matter. Whilst we have a number of specific areas of responsibility we are looking to cover at present, including a legal and human resources representative to help advise the Trustees and staff as appropriate, we are always looking at enhancing the most important aspect of our board - input from the membership.

Currently, two thirds of our Board are members of the charity, and our governing document states this as a minimum requirement. If you are interested in talking to me about working with our Trustees, or are able to help out in any other way with the running of the charity, please contact me through the office team on **0121 455 8982** or **info@lhm.org.uk**.

Pete Turner

The financial year for the charity from April 2007 to March 2008 saw income levels of £271,000. Of this amount, a staggering £200,000 came from you all in the form of fundraising, donations and gift aid so I would like to say a big thank you for all of your hard work and generosity. The remaining income came from grants and a one-off sum of £40,000 from the Industrial Agents' Society. I bring particular attention to this amount as the original contact formed with the society came from a member, which shows how members and the office team can work together to do excellent fundraising work.

Total income of £271,247



£200,000 from YOU

But where does this money all go? The accounts show that we spent nearly a quarter of a million pounds! A very detailed analysis of this spend is included in the Annual Report, which was sent to all members last September.

• **£173,000** has been spent on services in the form of the website, having people in the office on the end of the telephone and arranging events, producing the information we all use and



David Baumber
Treasurer, Little Hearts Matter

many other areas which all contribute to being able to give members the support they need.

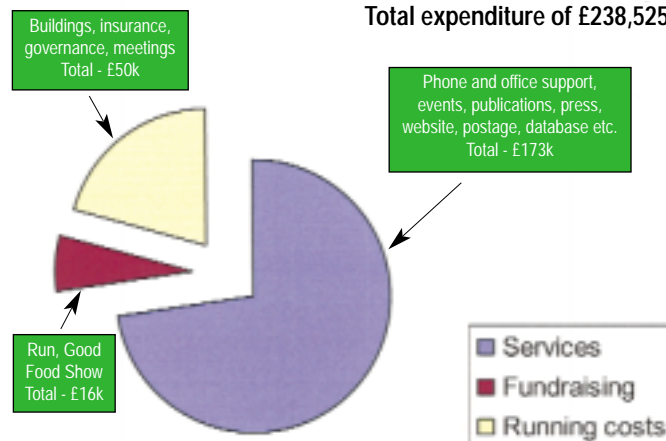
- **£16,000** on the costs directly associated with fundraising events (eg organising our highly successful run at Shugborough).
- **£50,000** on other required costs such as building costs, insurance, and governance without which the charity cannot operate.

A lot of the costs of the charity are fixed and we cannot sustain the levels of service without all of our continued efforts to raise funds. We

have on average five new member families a month joining our growing charity and we are also trying to extend our services as more children enter their teenage years and need support to gain independent living skills. As we enter into this period of recession your continued support and fundraising efforts remain crucial so can I take this opportunity to thank you all on behalf of both the Trustees and the office team.

David Baumber

Total expenditure of £238,525





Medical

Here we look at possible treatments following a Fontan and why some children are unable to have the Fontan procedure.

For many families, the fact that the Fontan procedure is the last surgery available for a child with a single ventricle heart condition leaves them feeling uncertain as to what the future will hold for their child if they become sick. The article below has been written by Dr Oliver Stümper, a paediatric cardiologist who has worked for many years with children facing the challenges of living with a Fontan circulation. Here he explores a variety of treatments that may be available to aid the circulation and ensure that transplantation remains the last treatment necessary many years after the Fontan operation.

The Fontan operation is the last step in the cardiac surgical treatment of patients with a single working ventricle. After this operation all blue (deoxygenated) blood returning from the body is routed straight to the lung arteries to pick up oxygen and to remove carbon dioxide. There is no effective pumping chamber to push the blue blood forward which means that the pressure of the blood in the venous (returning blood) system is rather high. This creates a higher back pressure within all of the organs lower than the heart such as the liver and the gut, muscles and skin.

Most children undergoing the Fontan operation will dramatically improve after the procedure. This is despite the fact that a great number of children take a rather long time to get

used to the new circulation, with fluid building up in the chest and swellings. After the operation there is almost twice as much blue blood going through the lungs to pick up oxygen. This in turn allows most children to do much more exercise before becoming tired and breathless.

Many years after the Fontan operation patients may suffer from a reduction in exercise tolerance, fluid collections (oedema) in the feet or the tummy, increasingly cold hands and feet, etc. Most of these problems are related to the long-term effects of having only one pumping chamber (ventricle) and the rise in back pressure within the veins. If such problems occur, doctors should be made aware of them, as there are treatments to improve the situation.

Detailed investigations such as scans, blood tests and possibly cardiac catheterisation will confirm that all the parts of the Fontan circulation have grown adequately over time. Frequently, there will be a degree of narrowing of the lung arteries, which in turn creates a higher pressure in the veins to force blood beyond the obstacle of the narrowing. This is particularly common in patients with Hypoplastic Left Heart Syndrome, who had a Norwood operation shortly after birth. The narrowing found in these patients is most commonly due to compression of the left lung artery by the new aorta created during the Norwood surgery. This can be treated by a catheter procedure during which a metal mesh work (stent)

is positioned within the area of narrowing, so as to keep the vessel open. Narrowings can also develop anywhere else in the Fontan pathways and have to be ruled out in every patient who develops increasing symptoms late after the original Fontan operation.

A less common problem is the onset of increasing cyanosis (blue skin) late after the Fontan operation. In the majority of such patients, the blue blood from the body will have found a short cut to the collecting chamber (atrium) of the heart, avoiding passing through the lungs first. Such communications are called fistulas and again can be treated very effectively with a catheter procedure.

As there is no pumping chamber (ventricle) propelling the blood into the lung arteries, there is a continuous slow flow of blood rather than the normal pulsating blood flow seen in people with two pumping chambers. This has an effect on the blood vessels themselves, which become stiffer and in part lose the ability to relax during exercise. This in turn further increases the back pressure in the veins. Over the last couple of years doctors have used new drugs, which decrease the stiffness of the lung arteries, with very good effect in a number of patients with a Fontan circulation. At present these drugs are experimental and are very expensive. Also they have significant potential side effects and the body may get used to them, so that they are no longer effective after a couple of years unless the

My Story

by
Andrew James

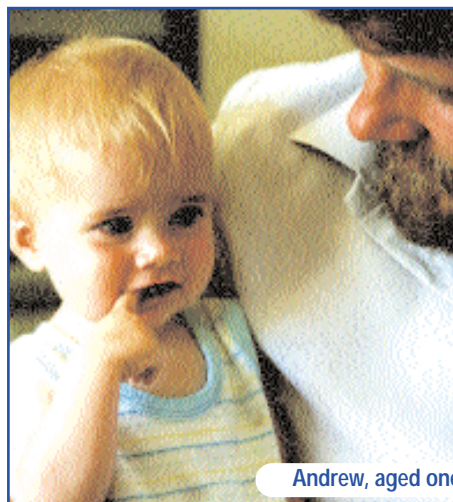
"I have been lucky enough to have known Andrew, and his parents, since shortly after he was born as I was liaison sister whilst I was at Birmingham Children's Hospital.

Andrew's story has been one of ups and downs. He and his parents, Pat and Stuart, have had to weather many a storm and yet Andrew is still one of the most upbeat young men that I know.

In his story he describes how some of the treatments explained in Oliver Stümper's piece above have been used to solve the problems that he has faced since his Fontan procedure. He also describes how he found the experience of transferring from a child centred unit to an adult unit.

Not everything in Andrew's story is positive but I think that his positive ending explains why he is happy to keep battling with every new challenge."

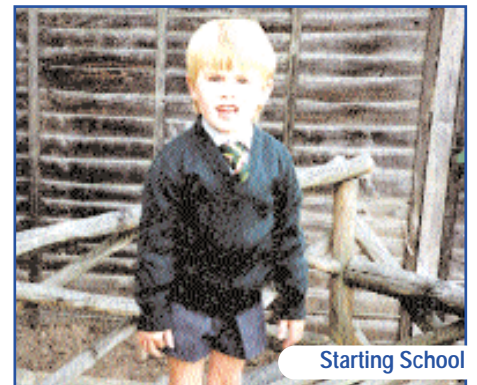
Suzie



Andrew, aged one

I was born on 26th November 1986. Within 24 hours my parents were told that I had a Univentricular heart and Left Pulmonary Stenosis. The first seven years of my life were taken up with innumerable hospital visits and operations, modified Blalock-Taussig Shunt, Left Pulmonary reconstruction (twice), Glenn Shunt and more cardiac catheters than I can remember. I was blue (sats in the middle 60s to low 70s) and under size.

In 1993 my consultant, Dr John Wright, decided that I needed the full Fontan procedure. This was carried out on the 5th January 1994. About two weeks later Dr Wright noticed that blood was leaking into my pulmonary artery and carried out a cardiac catheter during which he inserted a double umbrella device into the artery close to the heart, which I was told was a first for Dr Wright and his team. This was a ten week stay in hospital.



Starting School

The next four years were probably the best I have ever been. My sats went up to the low 90s and I was able to partake more fully in school life.



dose is steadily increased (which is likely to also increase the side effects). Nonetheless, these are very important developments and in years to come there will be widespread use of the next generation of these drugs (known as pulmonary vasodilators) in patients with a Fontan circulation.

In some patients with long-standing high pressure in the veins, the liver function may suffer which results in an increased likelihood of developing small blood clots in the veins, which may flow to the lungs and clog up the very tiny blood vessels (capillaries) of the lung. If that happens, then the back pressure will increase further. This is why some centres, looking after patients with a Fontan circulation, recommend the routine long-term use of Warfarin or at least Aspirin. However, as so often in medicine, there have never been large studies, involving thousands of patients, undertaken, to provide a definitive answer as to whether the long-term use of such drugs is of clear benefit.

High pressures in the veins can also affect the gut, the way food is absorbed and what food is excreted and not used by the body. In some patients, a large amount of protein may be lost into the gut, which in turn leads to a decrease of the amount of albumin (protein) in the bloodstream. If the albumin is low, then a higher degree of water seeps out into the surrounding tissues (oedema). Protein is also an essential part for the body to make immunoglobulins, which help fighting infections. The whole complex of these problems is termed "protein losing enteropathy". This develops in some 5% of all Fontan patients at some stage after the operation. If the diagnosis is made, various treatments can be initiated, including the prescription of a high protein diet, heparin and steroids. However, reducing the pressure in the venous system appears to be the most promising approach. Using a catheter procedure to create a blow-off valve (fenestration) to allow some of the blue blood to enter the filling chamber (atrium) without having to first go through the lungs, together with medicines that decrease the stiffness of the

blood vessels in the lungs has had very promising early and medium-term results.

To ease the blood flow through the lungs, the function of the one pumping ventricle is of crucial importance for the long-term well-being of patients after the Fontan operation. A large number of patients will receive long-term medication (ACE inhibitors such as Captopril or Enalapril) to make it easier for the pumping chamber to pump the blood to the body. However, in the longer term the body may get used to these drugs, and in turn they may become less effective. A whole new generation of heart failure drugs are currently being introduced into adult practice and some more are being developed - these newer anti-failure drugs will find their way into the treatment of patients with a Fontan circulation in due course.

It remains debatable as to whether stem cell therapy in patients with a Fontan circulation will be of any benefit, as the cause of poor ventricular function is rather the underlying architecture of the right ventricle (in patients with Hypoplastic Left Heart Syndrome) and/or the presence of fibrosis (hardening) or scarring. What will, however, become a reality, probably during the next decade, is the implantation of miniaturised impeller (rotating) pumps in the Fontan circuit, which will be able to contribute significantly to the overall cardiac pumping, reduce the pressure within the veins and support the pumping chamber.

As you can see, there are a range of new techniques and management approaches to help deal with problems after the Fontan operation. These should significantly contribute to maintain the well-being of patients after the Fontan operation.

Ask your cardiologist if you'd like to understand more about these possible treatment options for your child now and in the future.

Dr Oliver Stümper

Consultant Paediatric Cardiologist
Birmingham Children's Hospital

But all good things come to an end and Protein Losing Enteropathy (PLE) raised its ugly head.

This involved me in overnight stays in hospital while I was given transfusions of human albumin. I now understand that PLE can be a problem with some post-operative Fontan patients. PLE has become a large part of my life. I came to dread the fortnightly blood tests for albumin levels, as a result of 21 or lower meant an overnight stay, whereas over 21 was freedom till

the next test. I also developed needle phobia because of all the cannulas I've had. My veins are small and collapse easily so it is very difficult to get a cannula into me.

PLE also indicated that the pressures around my heart were getting out of balance and Dr Wright decided that my Fontan needed to be fenestrated to reduce the pressure differences. He carried out this procedure during a cardiac catheter. This caused my sats to go down into the high 80s and once again life was good, if a little slower than before.

In 2005 Dr Wright had to finally let me go and transfer me to the Queen Elizabeth Hospital. This was a little scary for me as I was leaving the doctors and nurses that I had grown up with and come to look on as friends. The transition, for me, was a terrible time. The first time I attended an adult hospital I was very frightened because my mother was not allowed to come with me as it was not visiting time (unlike the Children's Hospital). This upset me a lot as I needed my mom to support me because of my needle phobia. I spent two (long) hours without her while they were taking blood and sticking needles in me. A clash of personalities with a doctor did nothing to alleviate the problem.

Continued over...



Andrew at 17, the proud uncle

Why Can't My Child Have A Fontan?

Recently we have had a few messages posted on the website asking why it is not always possible to perform the Fontan Procedure, Stage Three and if it is not possible when will you know?

The first thing to be aware of is that it is rare for a child not to be able to undergo the Fontan operation. Over the years, the surgery done in a child's early life and the regular tests performed in outpatients and during a cardiac catheter mean that doctors have a clear picture of the heart and the support that it needs.

The Fontan operation relies on these things:

1. Low blood pressure in the lung blood vessels so that blood can flow there without resistance.
2. A well functioning heart muscle on the side of the heart that is working.
3. Good clear passage of blood through the one atrium/collecting chamber and one ventricle/pumping chamber.

Most children with single ventricle heart problems have leaking valves and a strain on the heart muscle of the one working ventricle/pumping chamber but as long as the doctors are happy that the Fontan surgery will help this there is no reason to delay or cancel the third stage of surgery.

Some children need medications to reduce the pressure of blood in the lungs, Sildenafil, for example. Most of the children have medication to open up blood vessels so that blood can flow through them with less effort, for example, Captopril.

Doctors work to manage the heart before Stage Three to ensure that as many children as possible can have the surgery.

There may be some children that still are unable to have Stage Three because of the one side of their heart that is working is not strong enough or because the blood pressure in their lungs is too high to allow blood to flow there without a pump (this is the circulation that Stage Three creates).

So how will the children cope without the Fontan?

To start with they will be no different. The doctors will manage their heart problems as they always have with medication and possibly some simple supportive surgery. This can help a child for many, many years.

Gradually their hearts will fail to do their job adequately and the only treatment may be a heart transplant.

Suzie Hutchinson



Andrew's Story Continued ...

However, I am now under Dr Sarah Thorne who is a worthy successor to Dr Wright.

Over the next couple of years I spent many weeks in and out of hospital with PLE and fluid retention. I spent several months in a wheelchair unable to walk due to the severity of the PLE. On one occasion I lost 34 kilos of fluid in a few weeks! This was a particularly bad period (last year, 2007) when, for the first time, I had doubts about my life. Then I was put on a new drug regime, Co-Amilofruse, Bendroflumethiazide and Sildenafil which seems to have done the trick and I am now once again on the straight and narrow. In fact I am so well that Dr Thorne gave the go ahead for the holiday of a lifetime. In September this year my parents and I went away for two weeks to America.

My life after the Fontan has not been all that I



Andrew at 21 in New York

hoped it would be. I could not run as my school friends did, I will never play football. I have to guard against chest infections and colds, especially during the winter. There are a lot of restrictions in my life, I will probably never be able to get a job because I tire easily. My ambition is to be an historian working in a museum, but there are a number of hurdles to

overcome first. I do voluntary work one day a week in the IT department of a local charity but feel pooped when I get home (I am driven there and back by my mom). I don't go out on my own too often - public transport and diuretic drugs don't mix well.

Despite all the restrictions on me I enjoy my life. I spend a lot of time reading, listening to music and watching films and TV and I enjoy being with my family and friends. I would like to thank all of them, particularly my parents, for all the love and support they give me.

Finally, I'd like to quote Abraham Lincoln (16th President of the USA) **"In this sad world of ours, sorrow comes to all; and, to the young, it comes with bitterest agony, because it takes them unawares."**

But a positive attitude and outlook can make all the difference to not only make you, but all those around you, feel that you are going to make it and be fine.

Bryan's Story

Bryan Rothlein was born in 1977 in Tulsa, Oklahoma, USA. Today he is a successful veterinary surgeon.

That is an achievement in itself... but even more amazing when you consider that Bryan was born with eight major cardiac defects - including hypoplastic left ventricle.

Bryan, 30, explains: "My heart problems were quite complicated. I had HLHS, transposition of the great vessels, mitral atresia, PDA, ASD and VSD.

"Back then they did not have the three-step surgery procedures they have now. The day I was born I had a Blalock-Taussig shunt, then when I was two I had another BT shunt.

"When I was seven (in 1985) I had the Fontan procedure at the Mayo Clinic in Rochester, Minnesota. I was one of the first 100 Fontan procedures in the US."

Thirty years ago, the doctors did not think Bryan would survive, and told his parents Jerry and Lesley that the prognosis was very poor.

"We were told he would never eat, never walk, never go to school," says Lesley. "I always said that I thought Bryan heard that, and he said 'just you watch me!'"

Bryan adds: "They said I wouldn't live for very long, and if I did, I wouldn't be able to go to school, and would basically be a vegetable. I proved them wrong.

"I went to high school, and college, and veterinary school, which is four years past undergraduate degree."

Before Bryan's Fontan, he was so weak that his mother often still carried around. For a boy who loved sports, it was difficult to hear that he could not join in with everyone else.

"I wanted to play baseball, but my doctors worried about my scar getting hurt because I have wires holding my chest together," remembers Bryan.

However, his friends found a way for him to



join in. After his Fontan, when Bryan was in the second grade, he was able to play T-ball (similar to baseball, but where the ball is hit from a tee, rather than thrown by a pitcher).

"Bryan would hit the ball and his friends would run for him," explains Lesley. "It got them all involved and was good for all the kids."

Since playing competitive sports was out of the question, Bryan showed his true grit with academics.

Lesley continues: "When he was little, we always told him he could use his brain instead of his body. He spent much of high school in bed, but he still ended up graduating with honours, and went on to veterinary school. And veterinary school is tough. Bryan struggled with it because he was tired, but he did it.

"We are just so proud of him and he is such a wonderful human being, so kind, compassionate, and he really loves life."

As Bryan was one of the first children to undergo the Fontan, there were no older children for his parents to look to for inspiration, and no other parents to share experiences with.

"We didn't have anyone to talk to who had been through what we were going through," explains Lesley. "If we had only known of someone when Bryan was born who was 30 years old, it would have made all the difference in the world to us. That's why I am so happy that seeing Bryan can give other parents hope for the future.

"That is one thing I tell parents... NEVER GIVE UP HOPE. We have had the door shut in our faces so many times, so we just go find another door with another answer. There is ALWAYS hope."

Life has not been plain sailing for Bryan - his early years were a real struggle, and even post-Fontan there has been the occasional bump in the road.

"I take eight different medications every day, and have been pretty healthy since my Fontan," says Bryan. "I did have one setback in 2006 though, when my heart rate went up to 250. I have had arrhythmia problems because the old way of doing the Fontan leaves the patients susceptible to severe arrhythmias, although this is much less common with the new-style Fontan.

"The doctors talked about converting my Fontan to the new way, but in 2006, I had an ablation. It took 11 hours, but it worked and I have not had such severe arrhythmias since."

Bryan's father Jerry says: "We fought every day for his life, and when I see what he has accomplished, it is just a remarkable achievement. We never thought that we would see his 30th birthday."

One of Bryan's goals is to help raise awareness about children with heart disease and he volunteers with various US support groups which are helping families with children born with the same or similar conditions to himself. Bryan is keen to let people know that life with a single ventricle condition can be good, in spite of the difficulties.

"For some reason, I was supposed to make it," he says. "I believe I've made it because of divine intervention, great family support and medical technology. I'm very thankful for all three of those things

"I'm glad that my story can bring hope to other people in the same situation.

"There are others of us out here who are adults. We do make it, and we do well in life."





The Feature

An overview of LHM's Annual General Meeting and Open Day 2008



Francesca posing for the camera



Coffee and chat

Hello again from your correspondents on the Open Day front, reporting back on developments from November's event, for those of you that didn't manage to come along - though also inviting comments from those of you who did.

For a start, this is the first time in the last few years it's been in the same place more than once, and we certainly appreciated the continuity. We felt that this was good, just knowing the way there, and the way around when we got there, and what to expect. And we like Bretby Conference Centre as a venue - friendly staff, good food, comfortable surroundings, nice accommodation (for those of us who stay). What do other folk who attended think? Do you like the venue and what's on offer, does the location work for you? Do let us know - the office is always considering alternatives, and would love to know how this one strikes the users. In fact, the March Open Day will also be held in the same venue, and the office team are looking at whether coaches from different parts of the country would help more members to get there.

And the different spaces available came into their own on the very first night, when in a wonderful new innovation, the teenagers had their own social event - a disco and karaoke

"It was like coming home, I felt really comfortable and welcome. I loved all the sessions especially the Fontan talk but my favourite bit was the Saturday night social - I no longer feel alone."

Hannah Willis
(on her first attendance at an LHM event)

night, in their very own (suitably darkened) party room - this was a great contribution laid on by Churchgate: a property development company that has picked LHM as their charity of the year! This was a strong addition to the very full youth programme for the weekend - the young people also got to do football, drama and interview training, with camera work, besides some serious encounters with adults with heart conditions and helping out with a Quality of Life Study. The youth programme is really going places these days, under the wonderful, and non-stop Jon Brunskill (took over last year from Kassie, remember). Fair play to them -we were only mildly envious at not being allowed into their music sesh...! But anyway, we were too busy in the main children's party and get-together - which was just as good as last year, and a wonderfully affirming time.

The Quality of Life Study also came up in a fascinating presentation for the main programme, presented by Dr Jo Wray - this is a big survey happening in conjunction with big American institutions, and we were mesmerised by her account of the difference between the perceptions of doctors, parents, and heart children, over the children's own quality of life - and how we need to act on those differences. There was a great talk from Tim Rakow on Communicating with the Medics - I know, don't even go there, eh! And please, don't write to us, send comments (via the office) to him - he's looking for volunteers for his study...! But he had some very timely things to say on the difficulties of framing a picture with only partial information, and says one of his desired results is to help doctors communicate more effectively with lay-people - someone give this man a GRANT!!! Prof David Wilson talked to us on genetics, in a way that was fascinating and entertaining! No - truly! We very nearly understood it... There was then a choice of workshops on topics such as dental care, feeding and the Fontan operation, so you could choose according to your particular needs, or could go to the 'coffee and chat' room and catch up with old and new friends. It was a great day all round, full of priceless information.

And all of this, as ever, while our children were being looked after for us, oh joy... On which subject, we wanted to include some comments this year from our other consumers!

"I call it the Heart Hotel, because they run the place just for us heart people when we come. I like the Heart Hotel, I want to go again. I

like the activities and games they do. I did like the disco and the drama - but there was a bit too many teenagers. But I liked our party and the games. And we got to go to bed really late! Because Mum and Dad kept talking, and talking, and talking. They kept saying we have to get you to bed, then they'd start talking to the other mums and dads again and we stayed up even later! I loved the soft-play in the creche. And I liked seeing my friends again. I'd love to go next year, even though it's a bit far away. We can always take a break."

Olivia, aged 7

(Easy to see who doesn't do the driving! - Olivia's Mum.)

Gill Cloke

Sam Hall, aged 15 says "We all had great fun at the Open Day; we did all sorts such as football, mock interviews and other fun games. We started off by doing a game called fruit bowl to break the ice where you basically just run around like a mad person. We then played some football which was great as everyone had good fun. We also had a talk by Suzie about what we should eat which was very educational, and tasty as it included lunch. We had some mock interviews about LHM which I found really odd, but strangely calm, because I've never done something like that before.

We were then meant to do some drama but we couldn't because we didn't have the time, which was a shame.

A big thanks to Jon and Olly for making it such a cool day. I think everyone really enjoyed it."



Thomas & Archie playing Scalectrix



Charlie had fun drawing

Note from the office - for Olivia and any other 5 to 10 year olds reading this - we hope you'll enjoy it even more in March, as we're planning a special programme for your age group with craft, drama, mini-football and a film session.

Looking forward to seeing you...





Fundraising

Some of your fundraising exploits and ideas.

Having taken down the decorations and packed the baubles and lights away until next December, the house looks empty and the excitement of Christmas is but a memory! So my mind turned to New Year resolutions!

AND THAT'S WHY I sent you the all new Fundraising Pack as a Happy New Year gift packed full of ideas, stories and information which I hope you will enjoy reading. Of course I really hope that you, like many others, will be inspired to organise your own fundraiser or take part in one of the events advertised such as Dress Up, or one of the run/walk events.

It can be great fun organising your own event and we are at hand to help out with posters, balloons, advice, etc, just pick up the phone.

So how about your resolution for 2009 being **"We will organise one Fundraiser in 2009"**. Do you know that if every membership family raised £250 this year, we would be able to beat the credit crunch and fund all of our family focused activities for 12 months.

Will you take up the challenge and make that resolution? Go on, get reading and have a go -



Kev Bazeley
Fundraising Manager
kevin@lhm.org.uk

you will be surprised how much fun it is and the glow of achieving and helping others just like you is amazing.

Now to 2009, there are some new ideas this year as well as some old favourites making a return. Across these pages you can read about ideas for next Christmas along with more details about Valentine's, Leeds Castle, the Cookie Bake (which I have had a go at!), LHM's first sale, as well as a new and very simple idea inspired by Danetre School in Northamptonshire for all levels of your family to take part in during the May awareness period.

Before I go a special mention of **VALENTINE'S**. Why not get romantic this

Valentine's, treat your loved one and support LHM at the same time!!!

From the 2nd of February until Valentine's Day, Tesco will be helping us to help you by selling Taittinger Champagne with a donation of £1 per bottle sold coming to us. As if that were not enough LHM Valentine cards will also be on sale with a 30p donation from each card. **So come on, get romantic for LHM.**

Please enjoy reading the Pack. Call me if you make the "Resolution" or have an idea you would like to share or talk through, I would love to hear from you. Please remember the support of you, the membership, and your wider families is, and always will, be the backbone of all our fundraising activities; you are a vital part of all that we achieve. Thank you!

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. We will try and feature as many of you as possible next time.

Best wishes for 2009.

Your Fundraising Stories

BIG HEARTED BREWERS!!

Last year I met another wonderful family at the children's hospital in Birmingham. Murray and Sasha Ratcliffe had travelled down from the north of Scotland to stay in Brum for 10 days as their little boy Dylan underwent his third operation.

This wonderful and typical LHM family told me all about Dylan and the support they had received with his condition. They were very aware that the services provided by LHM are funded by our own activities and that we receive no government money to pay for our service provision.

Murray and his work mates from Belhaven Pubs, desperate to help, took the bull by the horns and organised a Hill Walk which took



place in the autumn of 2008 on the Isle of Arran.

A massive effort from almost 30 walkers supported by collections in a number of Murray's Pubs has raised over **TEN THOUSAND POUNDS!!!!**

So thank you to Dylan, his Mum and Dad and the many supporters from Belhaven Pubs, you are all just brilliant.

IN MEMORY OF DANIEL MILLER

Pat, Tony and Aidan Hughes work mates and fantastic friends of Emma and Phil Miller took the plunge at Devil's Gorge in Cheshire and abseiled 3 times and raised over £800 for LHM in memory of Emma and Phil's little boy Daniel.

Pat tells us that Emma and Phil were so grateful to LHM and its membership when Daniel was born that it inspired her family to do something and make a contribution to our ongoing work. To the Hughes family and all their supporters a **HUGE** thank you, we are so grateful.



EDINBURGH MARATHON

Another runner took up the training challenge last year and ran the Edinburgh Marathon in support of LHM.

Steven Lloyd from the North East put in the time and effort to raise funds that he knows are vital to us continuing our support work to all the membership.

Thanks Steve and well done on your total of just under £1,000. Brilliant.

JAMES STRIDES OUT FOR PEARL

Jenni Wilson's brother James strode out for us in support of his little niece Pearl and took part in the Bristol Half Marathon and raised a massive foot blistering £750. Having heard about James and not to be left out the local church coffee mornings sent us an additional £200. Thank you.



If you would like to run in support of Little Hearts Matter but have never run - call me, I can talk you through the processes and supply you with run programmes that will get you in top shape for YOUR run event.



LHM Events & Ideas

Lights of Love and Cards

Yes I know, just finished cleaning up the pine needles and got the house straight and someone is talking about Christmas already, well if the supermarkets are already selling Easter eggs - I didn't want to be left behind!!

So, two new ideas for Christmas 2009...

Firstly, to be ready for next Christmas and for me the loveliest new idea for 2009 will start with the planting this Spring of our first **Lights of Love**

Tree. The idea behind the tree is to give us all collectively, a charity focal point for celebration, remembrance, happiness, joy or any other emotion that you wish.

Every year and starting right now you will be invited to purchase at a cost of £5 a **Light of Love** to shine on our tree throughout the Christmas Celebrations. Your **Light or Lights of Love** will be switched on at dusk on the first Sunday in December each year and will shine right through until the 12th day of Christmas.

So if you would like to remember or to celebrate an anniversary, birthday, achievement at school or for any reason you like, do join those of us who have already purchased their very own 2009 **Light of Love**.

The second new idea - if you are fed up with writing all those cards to everyone you see every day at work and spending a bomb in the process every year, why not order some of our alternative Christmas Cards?

Ready for September 2009 and designed for the office wall or the classroom these A3 Christmas posters will invite people to write their Christmas greetings on the card and pay a fee for doing so - you set the fee as you see fit - simple idea, you raise funds for LHM and everyone saves time and loads of effort.

A simple, easy no effort way to help!

Leeds Castle Run



Thank you to all of you who joined us in October at Shugborough Hall to take part in the annual Run and Walk. 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.

Aware that it is difficult for everyone to get to Staffordshire, Leeds Castle in Kent is the latest walk/run venue. As you will have seen from the Fundraising Pack, this is a truly stunning location.

So come on all of you fellow southerners, join me and the team at Leeds on the 29th March 2009 and run, walk or crawl around the estate, but please don't come alone; bring all your family, friends, workmates, neighbours in fact anyone you like. The more the merrier.

Income from this sponsored event will be used to enhance our growing networking provision. It's a scheme that you all asked for and one that we are of course happy to manage, but like most things your help in achieving the aims would be appreciated and is indeed vital.

So, dig out the trainers or walking boots and come and enjoy.

For those Shugborough lovers - you can of course come to Leeds if you wish but feel free to use the joint entry form to enter for Shugborough as early as you wish, now if you like!

Dress Up, Dress Down, Dress Silly

You will be aware that throughout May we along with others will be trying our hardest to bring the work of your charity, LHM, and the involvement of our families to the attention of the general public in a month long awareness campaign.

One way to do this whilst combining it with the NEED to raise our own funds is to hold a nationwide fun activity that you all, young and old, at school, work or in retirement can get involved with.

So why not make this your resolution and organise a Dress Up, Dress Down or Dress Silly day at your school, at work, at the play group or your club.

Not a new idea I know, but so simple to organise and so simple to raise funds with, as the pupils of Danetre School in Northamptonshire did last year when they raised over £2,000 by holding two dress down days at their school.

So why not join me, the most serious bloke in the world and the rest of the team in Birmingham and just like the hares every year, be silly this May and Dress Up, Dress Down or Dress Silly - just take your pick.



Cookie Bake

As if we did not eat enough in our house over Christmas I promised Suzie I would have a bash at baking cookies for this year's event. Based around Valentine's (but not exclusively) you can of course take part whenever you can fit it in.

Well I had a go with flour, eggs and all sorts of stuff and I think the pictures say it all! Good fun though and you can join in too - details of the annual bake are in your Fundraising Pack so why not join hundreds of others and get baking.

But don't keep it all within the family - why not take the idea to work as Lindsey Hooks is doing at her Barclays Bank offices - they match fund £ for £ too which is brilliant for us.

Or how about schools, Brownies, Cubs, Scouts or Guides and of course lets not forget the WI or Inner Wheel, the list of clubs you could get involved is endless - could this be your New Year's resolution idea!!!

If you want more leaflets or recipe ideas - please call for your pack - and enjoy the baking.

PS - Lads this not a girly thing, you too can get involved!!

Merchandise Sale

Well if M&S and Next can do, it so can we.

Looking out for a gift for Valentine's, a birthday or a new rucksack for the school books?

Look no further, check out our sale items on the merchandise sheet enclosed with this newsletter.





Zipper Zone



Hello Eveybody!

Five months in the job now, and I'm all nicely settled in. Some of the projects are beginning to take shape, which is very exciting. As always I'm only an email away, and I love being able to talk to parents and children alike, so if you have anything that you'd like to ask me, or you just fancy a natter, please do feel free to either drop me a line at the office, or send me an email to the usual address:

jon@lhm.org.uk

So what's news in the Youth Department of LHM?

The Youth Newsletter is being printed and posted

to our teenagers every month, which gives all of the older members some information on issues which affect them, and also a few fun activities and reviews. **BUT** I'm still not getting anywhere near as much as I'd like from the young members to stick in the newsletter. So **please, please, please** send in those photos, pictures, stories, achievements, grumbles, reviews...**ANYTHING!** It will make it more exciting for everyone and you never know, you might just brighten someone's day, or encourage them to do something that they might have always have wanted to try.

From February onwards we will begin to collect data for LHM's research project. This project is to investigate how having a single ventricle heart condition has an impact on the day-to-day life of adolescents. Together with a team of experts, we have devised a questionnaire which we will be asking any of our members aged 10-18 to complete. This is going to be hugely important, as it will help raise awareness of the importance of service provision. It will also help heart charities secure government and corporate grants and funding, which can be used to help the thousands of children in the UK. Please contact me if you are interested in taking part, we really need as much help as we can get with this, as the more people who take part, the more credible the research can be.

I'm very proud by the way. I can now officially announce that Little Hearts Matter now has a Youth Council! This Council will become the voice of the

children and teenagers within the charity, and will ensure that Little Hearts provides services that the young people want and need. The councillors are:

Carys Allen	Evie Fairman
Will Goodenough	Sophie Green
Ben Hall	Sam Hall
Sarah Haselgrove	Hannah Palmer

They are already drawing up a Constitution, and planning their first annual meeting, and I'm sure it won't be long before some serious plans and projects are off the ground and massive achievements are being made. Watch this space!

Last but not least, I wanted to say thank you to everyone I met at the Open Day in November. It was fantastic to meet so many parents and I was so pleased that so many of you took such an active interest in the work that I'm doing. I take the role incredibly seriously, and believe that what we've done together in the last five months shows just how much we can achieve if we all work together. I'm really looking forward to the next Open Day in March, where I'm hoping to meet plenty more of you. If you see me please grab me for a chat, it really is one of my favourite parts of the job, and I relish any feedback or ideas.

As I said before, please do contact me if you have any worries, woes, questions or queries. Or nice things. Nice things are fine too.

Best wishes
Jon Brunskill, Youth Guy

Month	Service/Project	What can parents do to help
January	<p>Youth Council</p> <p>If your child is a Youth Councillor, encourage them to be as active as possible. If your child isn't a Councillor remind them that the Councillors are there to represent the young people of LHM, so if they want something doing, get in touch with the Councillors.</p> <p>Youth Newsletter</p> <p>This is really one of those 'the more you put into it, the more you get out of it' projects. I need loads of reviews, stories, photos and achievements from the young members to keep this as interesting as possible. Encourage them to put pen to paper or flick me an email (at least) once a month please!</p>	
February	<p>Youth Website</p> <p>We really need to get this right first time. There will be a two week period where we need as many young people as possible to test the site and tell us what's great and what's rubbish.</p>	
March	<p>Open Day</p> <p>Come along and join in! We've got a great itinerary this year, with a good balance of fun activities, and useful heart information sessions.</p>	
April	<p>Big Questions Bible</p> <p>This is going to be a publication giving some lifestyle information to our teenage members on all of the normal important adolescent issues, but in the context of their heart condition. If there are any nagging worries that you would like candid, medically verified answers to, please contact me with them - the chances are everyone else is just as worried about it.</p>	
May	<p>Activity Weekend</p> <p>This year the idyllic Cornwall countryside will play host to LHM's chilled weekend, which allows families to chat, relax and enjoy all sorts of fun family activities! We'll be in touch.</p>	





Noticeboard



BOOK REVIEW

Walk on Water

The Miracle of Saving Children's Lives

by Michael Ruhlman

Published by Penguin Books, available from Amazon for around £10



This book is amazing, but I'm not sure whether to recommend it or not. I've read it twice now, and I'm still not sure whether I'm delighted that it's been published (as it raises awareness of what our children go through) or whether I'm disappointed about the sensationalist nature of it, having been written by a journalist.

The author spent a year observing Dr Roger Mee, one of the pioneers of paediatric heart surgery, at work in the Cleveland Clinic, USA. Dr Mee's specialism is correcting TGA (transposition of the great arteries), but he also does many other complex procedures including operations on babies and children with single ventricle hearts, in a world where "disaster is never more than a breath away".

I found the history of heart surgery interesting, starting with the first closed heart operations, followed by the use of another person as a 'bypass machine', then the cooling of babies in ice to allow surgery on newborns. The book devotes a chapter to the Norwood procedure - the personalities involved, the early results and the families' experiences.

Another key theme in the book is the difference in success rates between hospitals. Obviously the US healthcare system is different to the UK, but some of the principles relating to specialist procedures and volume / outcome must be the same, which makes this a bit disturbing. Roger Mee is clearly an expert in his field, but parents in general don't know, so they take their children wherever they are recommended to go.

The book is packed full of family stories, some of which are easy to relate to, especially the section which talks about how children cope very differently with surgery. One family whose child does well who are in hospital at the same time as another whose son of the same age dies a few days later - the book portrays the different emotional wrenches for both families very well. One

of the stories which makes a particularly difficult read is where one child gets a heart originally intended for another child, who is too sick to be on the transplant list when the donor heart becomes available.

In some ways, the book is reassuring - seeing in print the world we live in and the feelings we experience was strangely comforting to me. We hear how each child's heart is unique and there is no way to predict the outcome of procedures for individuals. There is also a lovely section towards the end of the book about how families are united by the child's condition and their experiences, and how most parents the author approached agreed to share their story in the hope that they could help other families.

In other ways I found it a grim reminder of the realities we sometimes try to put to the back of our minds. As the book looks at children's heart surgery in general, we are reminded that on the continuum of congenital heart disease, single ventricle conditions and especially HLHS are among the most severe. HLHS is described as "one of the last riddles of congenital heart disease". The book also mentions failing Fontans in particularly negative terms.

I think I'd conclude by saying that I wouldn't recommend the book to parents whose baby or child has surgery coming up soon. However, as a parent who hopes not to be facing open-heart surgery in the foreseeable future, there were times when I found it to give an interesting insight into the 'hidden' part of our children's care. If you go into the book focusing on the subtitle (*The Miracle of Saving Children's Lives*), knowing that you'll need some tissues, and being very aware that it's not a support book, you should be OK!

Isabel Baumber

Dates For Your Diary

Saturday 14th March 2009

Family social at Bretby Conference Centre

Sunday 15th March 2009

LHM AGM and Open Day - Bretby Conference Centre, Burton upon Trent

Sunday 29th March 2009

5km/10km Run or Walk
Leeds Castle, Kent

Friday 8th - Monday 11th May 2009

Activity Weekend for children aged 10 and over

Sunday 11th October 2009

5km/10km Run or Walk
Shugborough Hall, Staffordshire

Meningitis leaflet

In this issue of the Newsletter we have enclosed a copy of the Meningitis information card. Many parents worry about what to look for if they suspect that their child has Meningitis. The card explains all of the signs and symptoms that you would find in a baby and explains the glass test when looking at any rashes that your child may have. The information on the card can also be used for older children as the signs are the same.

Please remember that this card is no substitute for speaking to a doctor. If you have any worries about your child's health, you should always seek the advice of someone with medical experience.

Little Hearts Matter's Publications

- LHM Filofax
- A Guide to Benefits
- Preparation for Hospital Pack
- Antenatal Diagnosis
- Feeding Booklet

If you would like a copy of any of the above please contact the office on 0121 455 8982.

The next issue of the LHM newsletter will be out in May 2009.



Over to you...



Little Hearts Matter,

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

Michael's Stage Three, and Post-Fontan Life

Michael had his long-awaited Stage Three at Birmingham this summer. (Summer? What summer?? We left the last week of term, and it was raining; we got back for the first week of term - and it was raining...!) Have to say we were dreading this and desperate to get it over. We did loads of hospital play - thanks to the office for lending us the toys! But Michael was totally uninterested, every time we got out the toy doctor kit and said 'let's play hospitals!' he'd say, 'no, want to play Robin Hood', trot off to fetch his sword. Sigh. We persisted as much as we could, but even when we got to our pre-admission play therapy session (HIGHLY recommended may I say), he still blanked the poor play therapist as she did her doctor-speak, and was totally unresponsive. Until she got out the butterfly cannula - at which point he nearly fell backwards off his seat in his hurry to get away, clutching his hands to his chest and saying, 'No I don't want it...!' OK, we thought, he does remember...

Still, he was positively saintly on admission (with a little help from his Big Sis Olivia) - and all went well with the op itself. While one never really gets used to it, we were in fact pleasantly surprised how well and quickly things went this time; the operation took 6 hours, and he was through it and in ICU just when they said he would be; almost unbelievably to us, the oxygen tube came out the same night - something it took us weeks to achieve previously! - and he went back up to the ward the next day, with a starry progress report from consultants. After that, things slowed down again in the way we're more used to..! It's an art getting rid of all the wires and tubing after the Fontan, and we weren't particularly speedy - his chest drains kept draining so they knew the pressures weren't right, and had to go back in and 'tweak' twice more - he's now the proud possessor of a fenestrated Fontan with LPA stent (for those who like the techno-speak!) - and all in all we were in for five weeks.



Loads of you know what this is like, the mixture of boredom and stress... Constant checking of his pain control, and medicines, and what scans he had and when, having wounds dressed, having cannulas flushed, and medicines down them, trying to get him to walk, and sit, and do helpful games thought up by the play therapists (like 'blowing' games to open out the lungs), trying to think of anything we could interest him in while flat in bed, or even something he hadn't watched on his bedside TV 15 times already... And trying to think of different things to do with Olivia and anywhere we could go that wasn't too distant, or who could take her out this weekend (when everything

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: Charlie Turner's (5) first day at school.
- LEFT: Oliver Bevan (9), and his mum and brother Joseph climbing Snowdon.
- TOP LEFT: Thomas Evans' (5) first day at school, 7 weeks post surgery!

remotely interesting in hospital was closed, including the Play Centre), and worrying how she was coping with it...

And it could have been longer than 5 weeks, so we're just grateful to be back; and now in fact can say cautiously but with increasing sense of wonderment that after Stage Three life can be actually, rather good - in fact it looks like it might be rather wonderful, if it carries on like this! He's so much more bouncy, and chatty, and just so happy, seemingly. He keeps saying 'I'm better now' - and I'm beginning to think he's not just repeating what he's heard others saying, but is feeling it. He has much better energy and can keep going longer; whether bouncing on the sofa, chasing the cat, or walking or scooting to school nursery - OK, this is all of 2 streets away! But we always bugged it before.

We also feel he's just making more sense - he can follow conversations better, he's more cheeky and inclined to back-chat, and is positively impudent

with his big Sis - poor soul, after she's spent the summer being told 'be nice to him!' Last word should in fact go to Olivia - who besides camping, theme parks and outings, was taken THREE times to Cadbury World - the acme of 7-year-old cool. So the night before we left, Olivia said most indignantly 'I don't want to go home! I like it here, it's not fair!'

Someone liked our summer, then...

Gill Smith

Hospital by Olivia

