



# HeartLine

Issue 79

Spring 2009

**Remember!**  
**Wetlands on 4 July**  
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**Our Core Supporters**

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**Jamie - our little big man**

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**HeartLine Association supports children with  
heart disorders and their families**

This edition of the HeartLine magazine is a bit different from the usual. The structure of the support HeartLine Association offers has changed, and the details of the new core support group are now on the back cover.

Want to know who they are? On pages 4 and 5 you will find out a little more about these folk – the belly dancer, the grandparent, the parent with experience of Fallots Tetralogy, those with children with syndromes, the Dad willing to share with other fathers, and children treated in hospitals from Glasgow to London.

To complete the pictures, you can meet our trustees and staff on pages 7 and 8.

But the most important change is that I have crammed in as many pictures of children eating as I possibly can. After years of handling calls and articles about the problems so many of us experience, I thought it was time for an eat treat!

Hazel Greig-Midlane

**We want your stories and pictures by the end of September for the Autumn edition of the magazine. We'll be especially pleased to see holiday pictures – email articles and pix to [hgmhla@btinternet.com](mailto:hgmhla@btinternet.com), or write to the Editor at 32 Little Heath, London, SE7 8HU.**

**HeartLine magazine is published three times a year and sent free of charge to our members.**

**Shortly afterwards it can be seen on our website: [www.heartline.org.uk](http://www.heartline.org.uk)**

**Send stories and pictures for the magazine:**

**by email: [hgmhla@btinternet.com](mailto:hgmhla@btinternet.com)**

**by post:**

**32 Little Heath, London SE7 8HU**

**Contact for HeartLine Office:**

**Email: [admin@heartline.org.uk](mailto:admin@heartline.org.uk)**

**Tel: 01276 707636**

**Our cover star:**

**Jamie**

At the time she sent her son's picture in, mother Kerry wrote: "People always seem to be surprised when we say how old he is (4), he's still on the smaller side but has such a big boy outlook on life, we couldn't be more proud!"

**Back issues** available from HeartLine Office or from [www.heartline.org.uk](http://www.heartline.org.uk); go to What's New and scroll to the bottom of the page.



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# NANA CHRISTINE

*Christine's thoughts on her role as mother to Kirsty and grandmother to Abbie and Ryan.*

I am Abbie's nana Christine. I joined HeartLine over six years ago.

Kristy my daughter was told at her eighteen week scan her baby had a hole in her heart and needed another scan. By the time she was twenty weeks Kristy had had two heart scans and was asked to go to Cardiff for a more detailed scan.

## Results

After the scan Kristy called me in with them while the doctor gave her and Ian the results. He was very good and told us that the baby would be born with a hole in her heart but that she had other things wrong. He said that she had Pulmonary Atresia and Hypoplastic Right Ventricle. These were definite and she could have lots of other problems some with her heart, her tummy could be the wrong way around, her bowel and spleen might also be affected as well, but it would not be known until she was born.

He told us about the operations she would need and her chances for each one.

## Remember his hands

I will always remember the doctor drawing diagrams of how her heart would look and how a normal heart looks. I remember his hands, but nothing else about him, not even his name. Then being led to a private room. David my husband was there, Kristy and Ian and I.

I think we were all in shock I remember the quietness of the room and David saying we would cope. We were given the HeartLine book before we left and a few days later we joined HeartLine.

## A need in me

I want to do as much as I can to help and support my children – it is a need in me as a mother. I do know how Kristy must feel sometimes as her brother had septicemia at seventeen days old. I was a new mum and if my sister-in-law had not visited that day we might have lost him.

I would also like to give my grandchildren something my children didn't have – grandparents who are part of their lives.

## Tell me to back off

I have taken Abbie to more appointments than her dad. Some times it has just been because he can't get time off work but sometimes it has been because I feel a need to know what is going on and how things are – I've even been with them when Ian is able to take them.



*Abbie*

I do tend to try too hard to help, and do too much – I have had to tell Kristy several times that if I get too much, just tell me to back off.

## Operation days

Though on operation days I do back off. I sit by the phone, which is terrible. I feel I should be there, giving Kristy a hug, taking the pressure off of her, but I know that that's Ian's job now, and it is so hard. It does not stop the feelings of

helplessness though. I have tried going to work on operation days but cannot concentrate, keep stopping to check my mobile. I also feel that I may be needed and want to be able to dash at a moment's notice, even though I know things are going to be fine.

## Enough

Abbie's second BT shunt was an emergency, and even though I knew it had gone well and she was fine, I finished



work at 7.30pm, rushed home, showered and changed then dashed to Bristol. We only had ten minutes with Kristy and Abbie as it was so late, but it was enough to settle me.

I stayed overnight once so Kristy could spend time with her son Ryan – he misses her so much. Abbie was still in PICU. The feeling of helplessness that there was nothing you could do to make her better (she did not like cuddles) and all I wanted to do was cuddle her, to make her better. It's a mummy thing.

### Sharing your time

I look after Ryan while Abbie is in hospital in the daytime, taking him to and picking him up from school. I think it keeps me from running off to see how Abbie is doing, as I have to be there to collect him. I have had to promise Ryan that if he wants to see mummy or Abbie I will take

### Terms used

**Pulmonary atresia:** the pulmonary valve is blocked or missing

**Hypoplastic right ventricle:** the ventricle that pumps blood to the lungs is underdeveloped

**BT sbunt:** Blalock-Taussig shunt – an operation to join an artery to the

pulmonary artery to take more blood to the lungs.

**HeartLine book :** Heart Children: a practical handbook for parents. See page x if you want to order a copy of this book

**Septicaemia:** blood poisoning – an acute infection throughout the body

him if possible.

It's hard to know that you are sharing your time between both grandchildren, not just when Abbie is unwell and recovering. Ryan enjoys our company as he enjoys the quiet life, which is hard at home as Abbie is loud and busy. Abbie also likes the one to one and independence she gets with me.

### Same room

On Abbie's last appointment in Cardiff we were in the same room that we were told of Abbie's heart defects. It felt weird, almost creepy. We were keeping Abbie occupied but my mind kept going back to that day. When we left the room we both said together how weird it was.

Now we are awaiting her next operation that could be anytime.



## MEET THE CORE SUPPORTERS

*Anya Rowson, Chair of Trustees writes:*

At HeartLine's Annual General Meeting this year we voted to change our system of Area Contacts, Council and Core Supporters. Over the years since I became involved in HeartLine the way our members use our services has changed greatly and we found that Area Contacts were being underutilised. Changes in the law requiring us to have all our Area Contacts CRB checked also meant that having 50+ Contacts was going to be expensive.

Our new system will mean that we have four 'ranks' of people working for HeartLine.

There will of course be the staff working in the Camberley office for HeartLine, legally the Charity has to have five trustees, and these have the roles of Chairperson, Vice Chair, Treasurer and two trustees without portfolio. Due to the extremely popular nature of the boards we also have four senior moderators and now we have a newly formed Core Support Group. To start off the new system we have fifteen Core Supporters, although this number is likely to change. Each has a term of office for a year (exactly the same as the trustees) and at the end of the year they can choose to reapply for another year or to run

screaming for the hills. We will also invite members to apply for one of these positions at that point.

Our Core Support members are volunteer parents who are here to help other parents, whether you want to pick their brains on a particular matter or just need a friendly listening ear from someone who understands what it's like to care for a child with a heart defect. They have kindly agreed to have their telephone numbers printed in the magazine so that you can call them for any advice and support you may need. Please remember to call within social times! They will try to help to the best of their ability, but may end up referring you to another Core Supporter or indeed back to the office. These Core Supporters will hold NO information about members, so it will be up to you as to what information you give them, and whether or not you would like them to have your details in order to call you back at a later date. The biggest change for this group is that they are not arranged in geographical area but rather have particular interests or areas of expertise listed to help you choose who best to call – these are set out on the back page together with their telephone numbers.



### Val

I live in Peterborough, Cambs and am a stay-at-home Mum with two boys age nine and thirteen. Alex, nine, is my heart-child: he has the

condition Pulmonary Atresia with Intact Septum. He had open heart surgery at GOSH the day after he was born, followed by two further open heart surgeries at eleven months and at three and a half years. He is now doing very well with no more surgery planned.

I have been a member of HeartLine for five to six years now, and am a Moderator on the HeartLine message forums. I have given a lot of support to others going through diagnosis/surgery and general support via the boards over the last five to six years, and have learned a lot from others there.

I can be contacted at home most of the day (apart from school-run times), and am around some of the time at weekends.

### Debbie

The area I live in is Bedfordshire and am a mum to a heart child with Transposition of the Great Arteries with Ventricular Septal Defect, who is now fourteen years old.



I have been a member of

## MEET THE CORE SUPPORTERS CONT.

HeartLine for getting on for thirteen years and an area contact for the past four years. I am general core support so no specialised area really, but I have a lot of experience of TGA, learning support and migraines. but on paper I am general support for HeartLine.

My interests are my family of course (I have two sons), my pets, belly dancing, the gym, boxing, steam engines, swimming, cross stitch, quilting and toddler group.



### **Elaine**

My name is Elaine Murray-Bell and I'm a mum of two. My second child, Jack was born in July 1997 and we very quickly discovered he had congenital heart disease (Double Outlet Right Ventricle, Pulmonary Stenosis and VSD).

Jack was born with CHARGE Syndrome which also meant he had multiple problems to deal with. He is registered blind and was fed via gastrostomy up until he was ten years old so I have many years experience of visual impairment and feeding issues.

I live in Dumfries which is in South West Scotland and Jack attends Yorkhill in Glasgow.



### **Jan**

I have four daughters, the youngest one is my heart child. I have been involved with HeartLine for nearly sixteen years and in the past I have

done fundraising and held parties for Heart families.

My special interest is the Brompton Hospital as we have been attending there since July 1993.



### **Liz and Keith**

Our daughter, Emma, was born in London in 1995 with Tetralogy of Fallot and has her care at the Brompton Hospital. We also lived in Boston, USA,

where Emma went to Boston Children's Hospital.

We have been members of HeartLine for more than fourteen years, having been supported and providing support to families facing the shock of cardiac disorders. Having had a nightmare with feeding, both of us are prepared to help others with the issues they face. Dads also need different support and Keith speaks to

fathers about the challenges they face with managing all the issues.

Emma is currently at boarding school and also supports families who want to speak to a child who has 'come through all this'. She loves doing this as it gives her a chance to demonstrate that you can live a very full life despite the inconvenience of heart problems.



### **Margaret**

I live in Lincolnshire and have been involved with HeartLine for many years.

My daughter Steph was born in 1984 with complex CHD. She was a very poorly baby and initially the outlook for her was bleak to say the least ... but she will soon be celebrating her twenty-fifth birthday!!

Despite being constantly in and out of various hospitals, Steph was two years old before I heard about HeartLine. Even after all these years, I still remember how desperately lonely and isolated we felt. Family and friends would sympathise as best they could, but no one really understood or could help with all the technical terms of this new "Heart language" we suddenly had to learn ... this was long before the Internet was about remember. It was such an amazing relief being able to actually talk to other mums and dads who truly understood ... and this is why I think HeartLine is so very important.

Steph has Pulmonary Atresia and a VSD, along with DiGeorge Syndrome and Scoliosis and these are all areas I have a particular interest in.

I work from home so I'm usually about through the day as well as most evenings too. I'm always up for a chat so please feel free to give me a ring anytime



### **Sarah Batt**

I have lived in Milton Keynes since 1993 and work at The Open University. I have two children: Amir and Adam. Amir was born

prematurely in 1990 with congenital heart disease and stayed in the SCBU at the local hospital for several weeks. He had his first surgery when he was three months old at The Royal Brompton & Harefield NHS Trust and remained in ITU at the Brompton from December 1990 to August 1991. He was tube fed for several months after he left hospital.

In 1993, when Adam was four weeks old, Amir had a stroke which left him with left sided hemiplegia, atrial fibrillation, epilepsy etc, etc, and was in hospital at The John Radcliffe for five weeks.

Amir has proved a fighter, despite the odds. Over the years I have gained a lot of experience in dealing with the medical profession, the education system and the local council on his behalf. Amir is now in transition to adult services which fortunately is going well.



### **Shelly**

I live in the Chatham area of Kent and work at Medway Maritime Hospital in Gillingham. I am Grandmother to Tyler and Joshua, both of whom

have complicated heart defects.

Tyler was born on 5th October 2005 : his diagnosis is Double Outlet Right Ventricle, Pulmonary Stenosis, large VSD and straddling mitral valve. Despite his problems he is very well, a healthy weight and attends nursery school five days a week.

Joshua was born on 26 April 2008 with Pulmonary Atresia with MACPAs, severe Tetralogy of Fallot, VSD and a very rare left circumflex to pulmonary artery fistula. He also has 22q11 (DiGeorge syndrome), severe failure to thrive, gross reflux, impaired immune system, three hernias and joint problems. He is currently waiting for a gastrostomy and at thirteen months still weighs only 13lb 5oz.

I have been heavily involved with both boys, attending most outpatient and inpatient hospital visits alongside Hannah their mother, her partner Mark and the boy's paternal grandmother - Karina. We are a strong team and remain very positive despite the difficult year we've had and numerous hospital admissions. I have taken an active interest in paediatric heart conditions and joined HeartLine in early 2008, finding the boards an enormous support and getting to know some amazing people. My hope is that I can use the experience I have gained to help and support others going through similar experiences.



### **Sue**

My daughter, Imogen, has Tetralogy of Fallot and had a full correction performed at Great Ormond Street in July 1998. I have worked with

HeartLine since 1999 providing telephone

## MEET THE CORE SUPPORTERS cont.

support to parents with children who have the same condition as Imogen. I live with my husband, Imogen and her younger brother Stephen in West Sussex and being a working mum spend most of my time running late!

I welcome calls from parents wanting/ needing a chat at any time. Imogen's voice is on our answer machine; if I am at work or away for a weekend or longer I will always ring back as soon as I am able. At the time of writing Imogen is performing a main role in her school musical and will be moving into Year 7 in September therefore we now have some eleven years of 'post op' experiences covering Imogen's time at nursery (which she started three months post op), infant

school and junior school.



### Rosie

Hi! I live in Halifax, West Yorkshire with my hubby and four gorgeous children. Rebecca is fifteen, and drop dead gorgeous, David is thirteen and almost six feet tall. Jonathan is ten and a super brain box, Katie is six and my gorgeous little chicken.

David is my heart child. He was diagnosed at two days old with Tetralogy of Fallot: as he grew complications set in and he was diagnosed with a few other issues, heart and respiratory. I'm pleased to say that after two open heart surgeries and three

caths, plus bronchs, MRIs and aortiopexy, he's doing amazing.

David attends Newcastle Freeman Hospital for all his cardiac and respiratory outpatient appointments.

I've been a member of HeartLine for almost thirteen years, and actively involved for almost twelve. For the majority of that time I have been area contact for Yorkshire. I have arranged parties, get-togethers, and put my hand to a bit of fundraising. I've also been a warm friendly listening and supportive ear at the end of a telephone.

I'm available most evenings from 4pm til late and throughout the weekend.

### Terms used

#### **Pulmonary Atresia with Intact**

**Septum:** the pulmonary artery – the blood vessel carrying blood to the lungs, is blocked or missing. If the wall (septum) between the two sides of the heart has no hole, there may be no way for deoxygenated blood to reach the lungs.

**VSD:** ventricular septal defect – a hole between the ventricles, the pumping chambers of the heart.

#### **Transposition of the Great Arteries**

**(TGA):** the big arteries, which should be taking blue blood from the heart to the lungs, and red blood from the heart to the body, are round the wrong way. This means that deoxygenated blood goes back to the body, and oxygenated blood from the lungs is directed back into the lungs.

**Double Outlet Right Ventricle:** the aorta arises from the right ventricle instead of the left.

**Pulmonary Stenosis:** narrowing of the pulmonary valve, the valve between the right ventricle and pulmonary artery.

**Gastrostomy:** a surgical procedure for inserting a tube through the abdomen wall and into the stomach

**CHD – congenital heart disease:** a heart condition present at birth

**DiGeorge Syndrome:** a number of health problems, including a heart defect, caused by a part of a gene that is missing on chromosome 22.

**Scoliosis:** curve in the spine

**SCBU:** Special Care Baby Unit

**Hemiplegia:** paralysis on one side of the body

**Atrial fibrillation:** abnormal irregular heart rhythm caused by electrical signals in the atrial chambers

**Epilepsy:** seizures (periods of unconsciousness) caused by irregular bursts of electrical activity in brain cells

**Straddling mitral valve:** the mitral valve, which should be on the left side of the heart is partially situated to the right through a hole in the wall between the

two sides.

**MAPCAs:** Major aorto-pulmonary collateral arteries: where the pulmonary artery is blocked or missing, the heart often grows extra blood vessels between the pulmonary artery and the aorta.

**Tetralogy of Fallot:** (sometimes called ToF or Fallots, pronounced fallows): a ventricular septal defect (hole between the two ventricles) and pulmonary stenosis – a narrowing between the right ventricle and the artery carrying blood to the lungs. The aorta, which should only carry red blood around the body, is positioned over the VSD, so that blue blood is pumped into it as well.

**Circumflex to pulmonary artery fistula:** a passage between the circumflex branch of the left coronary artery and the pulmonary artery, causing deoxygenated blood to be pumped to the heart muscle.

**22q11:** a syndrome which often includes a heart defect, caused by a part of a gene missing on chromosome 22.



## HeartLine's Forums

Our Forums have lots of super features: they offer an opportunity for HeartLinners to meet each other online, discuss anything they choose and share pictures – go to the website and choose message boards. Once you have registered you can join in with **General Chat** for any topic under the sun, or you may want to go to **Conditions** to discuss children's congenital heart and related problems. There is a **Who's Who Forum** for profiles of members, **Bereavement Support Forum**, for those who have lost children and their friends, and **HeartLine Office**, for messages to and from the office.

For those of you who haven't visited yet, please join in. It's a great way of giving support to other families, of getting help with your own problems – or just sharing a few minutes with friends.

[www.heartline.org.uk/forums.html](http://www.heartline.org.uk/forums.html)

# MEET THE TRUSTEES

## Chair of Trustees Anya Rowson



I'm Anya, and have been living in this roller-coaster world of CHD for nearly 16 years, since my lovely boy Tom was born with complex cyanotic CHD. As I write this the spectre of hospitals is hanging over us all once more as Tom is zooming towards the top of the waiting list, in that time-warp fashion that always occurs when you are waiting for any procedure in the cardiac unit.

Of course I wish that I had never heard of HeartLine, and that Tom was a healthy stropky teenager refusing to study for his GCSEs instead of just a stropky teenager refusing to study for his GCSEs, but HeartLine is such a large part of my life, that I can hardly remember what life was like without it!

I have been a trustee for 14 years and the Chair for the last 12. I still maintain, that if I had inflicted some nasty injury on Hugh B-D (former Chair) when he suggested I took over from him, I would be out on a good behaviour bond by now! I spend a good part of each year trying unsuccessfully to persuade members that it really is time I stood down and let others take over, and the rest helping to write strategic plans, interviewing magicians for the party or staying with a bunch of teenagers at a PGL weekend! Any spare time I have left after that is spent working out how to get out of giving Hazel a photograph of myself to accompany this article!



## Treasurer Kevin Ford

I am married to Anita, a former Committee member herself and we have two sons, Joshua, 11,

and Ellis four and a half. Joshua was born with a relatively rare collection of five disorders, called Variant of Tetralogy of Fallots. Apart from a routine replacement valve, his corrective cardiac surgery is complete, but unfortunately, Joshua needs treatment for scoliosis, which will result in his spine being fused this summer.

We have been members of HeartLine for around 10 years now and I have been the Treasurer for three years now. The most time consuming element of the role of is to review the year to date accounts as they are issued, and of course I have to sign the odd cheque or four!

I would also like to take this opportunity to say a big "thank you" to Pam and her team at the Office for all their hard work and of course to the other trustees whose collective contributions ensure that we make the right decisions for HeartLine and its members.



## Alison Keen

I have been involved with HeartLine for 12 years and was Area Contact for Essex before becoming a Trustee.

Last year I helped run the PGL heart children weekend in Weymouth and look forward to doing it again this year. My long suffering husband is Andrew and our children are Laura twenty, Emily, 17, and David, 12. David was diagnosed with Tetralogy of Fallots, Velocardiofacial Syndrome (22.q.11) and verbal dyspraxia. Our next big hurdle is the transition to secondary school in September 2009 and the quest to find trousers with a small enough waist and long enough legs!



## Lisa Casey

I live in Cardiff and teach fulltime. I am married to

Jonathan and have three children; two girls ages 12 and 10 and a boy aged eight. Iwan was born with a large VSD, ASD, Mitral and Tricuspid valve leaks; he had surgery at five months at Birmingham Children's hospital and is doing well at the moment.

I have been involved with HeartLine since joining the message board six years ago and found myself with my arm firmly pinned behind my back by Anya a couple of years ago, shortly after which I readily agreed to become a HeartLine trustee. I have been a great supporter of the University of Cardiff Hospital for several years and am in regular contact with staff on the cardiac unit there. Although I am very relieved that Iwan is doing so well, I will never forget the difficult times that we endured when he was ill, nor the impact that his illness has had on us, his parents or his two sisters. For that reason, I can be found most summers up to my armpits in mud on the HeartLine PGL siblings weekend.



## Linda

I am Linda. I am married to Ken and mum to Calum, 11, and Aaron, seven.

Aaron is treated at Great Ormond Street

Children's Hospital. He was diagnosed prenatally with DORV, PA, VSD. He had a full repair at eighteen months and now has a leaking pulmonary valve that will eventually need replacing.

I have been a member of HeartLine since soon after Aaron's birth. I was an area contact and arranged many outings for the Norfolk area, and now I am the newest of all the Trustees, with just two years in post.

I am a full time childminder and am currently studying for a BA (HONS) in Early Childhood Studies.

## LOW SEASON CARAVAN HOLIDAYS

HeartLine has two caravan holiday homes for members to use. The caravan in Mablethorpe, Lincolnshire, accommodates eight people and the other, in Oakdene, Ringwood, New Forest, accommodates six.

Booking the caravans starts early in January each year – the school holidays were obviously booked up very fast, but if you or other members of your family could do with a break in the low season, it is much

cheaper. If anyone wants to book weekends or even just a few days during the low season you are welcome: ring the office two weeks before you wish to go and we can let you know if the time is free. We can only do weekends and short stays during the low season.

Oakdene low season £135 a week/£30 a day.  
Mablethorpe low season £115 a week/£25 a day.



## MEET THE STAFF



On 11th May we welcomed **Lorna Russell** into the office as an Assistant Office Manager to help Pam in the day to day running of the Charity and also

to help us raise the profile of HeartLine in the Cardiac Units across the country. I have also charged Lorna with the job of membership fundraising, and she is buzzing with ideas, so be prepared!! Lorna joins us from another charity called BEN. We welcome her to the Charity and look forward to a long and happy partnership with her.

Sadly the creation of this role meant that the post of Office Administrator had to be made redundant and it was with heavy hearts that we said goodbye to Caroline Howcroft at the end of March 2009. Caroline had been with HeartLine since July 2007 and the Trustees would like to thank her for the hard work that she did

for HeartLine and her support of Pam. We wish Caroline a happy summer with her son Morgan and all the best in any new position that she finds once Morgan starts school in September.



**Pam Lawrence** is HeartLine's Office Manager and has been running the office in Camberley since 1995. She has a certificate in Managing Voluntary and Community Organisations from the University of Sussex.

Pam was brought up in Kenya and has lived in the UK since 1972. Her hobbies include camping in her motor home, hunting for mushrooms and growing vegetables. She loves cooking and entertaining.

Also working in the office at Camberley are Fundraising Officer Neville Terry and

Project Coordinator Helen Baker.

Last and definitely least, magazine editor since May 1997 edition number 36, and occasional odd jobber **Hazel Greig-Midlane:**



I am self-employed – in theory part-time – mainly reviewing research and writing leaflets for public bodies – and I am a representative on the Medicines for Children Research Network, where I pursue the right to free oral syringes whenever I can.

I have three children, the middle one, now in his late twenties, born with AVSD and subsequently had a mitral valve replacement, several pacemakers for complete heart block, surgery for subaortic stenosis, and has atrial fibrillation – so a long association with structural defects, arrhythmias and anticoagulants then!



## FUNDRAISING – WE NEED YOU!

Contact Lorna in the office with fundraising ideas or if you can help. You can call her on 01276 707636, or email [lorna.russell@heartline.org.uk](mailto:lorna.russell@heartline.org.uk)

### Start fundraising Online for HeartLine

It's very simple, we would like to encourage you our members, your friends, family, and colleagues, to support HeartLine when going online. This can be done in a number of ways from one easy to use website, [www.everyclick.com](http://www.everyclick.com).

#### What is it?

Everyclick.com is a one stop shop that enables individuals, companies, schools and colleges access to a number of ways to give online i.e. searching, shopping, donation and sponsorship. Everyclick will ensure that funds are distributed to HeartLine via Charities Trust.

#### How Does It Work?

Searching the web with Everyclick – Instead of using Google to search the internet you can support HeartLine by searching [www.everyclick.com](http://www.everyclick.com). With every search, money will be donated to HeartLine. The idea is to get some of your friends, family

and colleagues to sign up too – the more the merrier.

**Shopping with Everyclick** – You can shop online with leading retailers (including M&S, eBay, John Lewis, Boots, Carphone Warehouse and many more) and buy your favourite products from hundreds of online retailers. You can get a single online basket and do one checkout payment even if you buy items from different retailers. It is totally secure. Half of the revenue from the shop goes to HeartLine.

**Sponsorship with Everyclick** – If you plan to do a fundraising or challenge event for HeartLine then Everyclick has now launched a sponsorship service which enables you to build your own page and collect sponsorship for your fundraising. You will be able to see who's giving, track progress and invite donations.

**Local with Everyclick** – You can search and post online classified ads, some of which are free.

**Donations with Everyclick** – Make an online donation to HeartLine – it's any easy way to facilitate online giving. Everyclick provides simple cut and paste Donate Now buttons that can be easily added into any

webpage, blog or social networking page.

So, what are you waiting for? I will keep you posted on how we are doing in the next issue of HeartLine magazine. In the meantime, if you have any questions then call me on 01276 707639 or send an email to [lorna.russell@heartline.org.uk](mailto:lorna.russell@heartline.org.uk).

### Running the marathon

In early October the results for the next London Marathon entries ballot will be out. HeartLine would love to be in touch with people who have places and would be happy to fundraise for us.

So if your mother, brother, great-aunt, work colleague or indeed you have a place, Lorna in the HeartLine Office will be able to help set up a sponsorship page and publicity, provide a becoming HeartLine running vest, and general support on the big day!

### School charity?

Next term is often the time that schools nominate a charity to benefit from fundraising events. Contact Lorna for material to support your bid for HeartLine to be Charity of the Year. She can provide information about HeartLine and help with talks and events.

# MEMBERSHIP FORM

We welcome all friends and families with children with heart disorders, and professionals with an interest, into HeartLine Association. You need to return this form to the Office Address to become a member, or update your or your child's details - such as changes of address or your child undergoing treatment.

Your details will be kept on a database used by the Office.

Your details will not be given to anyone without your permission.

**Please describe your relationship to the child, e.g. parent, grandparent, etc.** .....

Name ..... Partner's Name .....

Address .....

.....

Telephone Number ..... Email Address .....

Heart Child's Name ..... Date of Birth .....

Name of Heart Condition .....

If the child has other health problems, please give broad details .....

If the child has been treated for the Heart Condition, please give the name of the hospital and details .....

.....

## Other children in your family

..... Date of Birth .....

..... Date of Birth .....

How did you hear about HeartLine? .....

● I am willing to support other families yes / no (Please delete as appropriate)

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**HeartLine does not charge a membership fee but relies heavily on voluntary donations for services to families. We are grateful for any support you can give us.**

*"I would like to help HeartLine. Please find enclosed donation of ....."*

If you are a tax payer and agree to HeartLine reclaiming the tax please complete and sign the following:

I want HeartLine Association to reclaim tax on:

- The enclosed donation of £.....
- The donation of £..... which I made on ..... (date)
- All donations I make from the date of this declaration until I notify you otherwise.

*(Delete as applicable)*

I understand that I must pay an amount of income tax or capital gains at least equal to the tax HeartLine reclaims on my donation in the relevant year.

Signed ..... Dated.....

Please return completed form to: **HeartLine Association,  
Surrey Heath House, PO Box 957, Camberley, Surrey, GU15 9FH**

# HEARTLINE OFFICE SERVICES

## GETTING IN TOUCH

Our Office is in Camberley, Surrey, and is open from 10 to 4 Mondays to Fridays. Messages can be left outside of these times and we will deal with them as soon as possible - usually the next working day.

**TEL: 01276 707636 FAX: 01276 707642**

**EMAIL: ADMIN@HEARTLINE.ORG.UK**

Office Manager: Pamela Lawrence

Assistant Office Manager: Lorna Russell

\*\* Fundraising Officer: Neville Terry \*\* Project Coordinator: Helen Baker \*\*

## HOW WE CAN HELP

As a member of HeartLine you are entitled to our help to find information.

- ♥ We can put you in touch with other member families who have similar problems, or live near you.
- ♥ Free request leaflets and fact sheets on feeding and dental care.
- ♥ Ask if you need help on any subject - we can probably find it for you.

## WEB SERVICES

- ♥ For up-to-date information, back copies of the magazine and lively message boards go to [www.heartline.org.uk](http://www.heartline.org.uk)
- ♥ Translations of the *Heart Children* book into: Arabic, Hindi, Urdu, Gujarati, Punjabi, Bengali and Italian are published at [www.heartlinetranslations.co.uk](http://www.heartlinetranslations.co.uk)

## FOR SALE

PIN BADGES	£1.50
Car stickers	£1.50
HeartLine teddy	£10
HeartLine linen bag	£2.50
P+P	£0.50
<i>Heart Children</i> book	£10 + £1.50 p&p

## 100 Club

**Just £2 (or £4, £6, £8 or as much as you like) and a chance to win every month! Call the Office for details.**

## Everyclick.com

Search – search the web

Shop – buy direct from the best retailers

Donate – make a donation

Sponsorship – build a fundraising page



**ORDER FORM** – please send to HeartLine Association, Surrey Heath House, PO Box 957, Camberley, Surrey, GU15 9FH



Name .....

Address .....

Postcode ..... Daytime Tel. No. ....

Item or description ..... Quantity ..... Price .....

I enclose a total payment of £ ..... plus a donation of £ .....

A contribution towards postage would be much appreciated, and would help us to help more families.

Thank you.

## JOY OF EATING

Here's a special treat – all those children who have gorged every day for months on 5mls of milk and a chocolate button, driving their families to distraction, and then one day ...

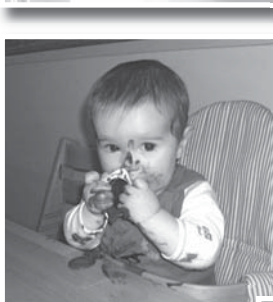
“Eating is still a battle but there are these moments of the joy of eating, hence it's a photo opportunity.”

“It's probably the only pictures I really take of Aaron as it's our biggest achievement that he eats now and I'm so proud of him. We still have good and bad days but the attached pictures were obviously taken on a good one!”

“... here is my beautiful boy stuffing his face on a buckwheat and blue cheese pancake ...”

“You have my full permission to use it how you see fit. Personally, I would like to blow it up to house size and fly it like a flag above Reading!”

“We never thought we'd see this day, it took 5 years but he made it in the end.”



# HARRY – THE HARDEST THING

*My name is Amanda Tweed and I am a member of HeartLine and also post on the website forums as Paul & Amanda. Here is my story of my son Harry, who has Pulmonary Atresia with VSD.*

I was pregnant with my third baby when at twenty nine weeks my waters broke. I was kept in hospital for forty eight hours and given steroids in case I went into labour early. After that, I had to go to the hospital twice a week for scans and have blood taken to check for any infection.

## Not right

On 31 March I went into labour five weeks early, and Harry was born. He weighed 4 pound 2 ounces. I had a quick cuddle then he was taken to the special care baby unit and put in an incubator and on CPAP. It was not until the next day that we found out that something was not right. They thought Harry might have a problem with his heart and wanted to send him to the Freeman Hospital for an echo. He was started on a drug called prostaglandin to keep the ductus open. He also had an x-ray that showed he had an abnormally formed spine. But the main priority was his heart so he was taken to the Freeman by ambulance.

## Risks were higher

We had to follow in the car. The nurse showed us to a parents' room and after he had an echo and doctors had examined Harry, they came and told us he had a heart defect called Pulmonary Atresia with VSD, and that he would need a series of surgeries as he grows, the first being a BT shunt. As Harry was very small the risks were higher. We could not believe what was happening. Nothing was picked up while I was pregnant and my other two children were fine.

## The hardest thing

Then at four days old Harry went in for his surgery: we went up to the theatre and gave him a big kiss and they took him in. It was the hardest thing we have ever had to do. It took around five hours, which felt much longer. We went to see him in PICU and the surgeon said it had gone well – the next twenty four hours were critical.

The following day we got a call to say that Harry had a bad turn when they tried to take him off the ventilator. He had to be put back on and may have needed to go back into theatre, as they thought the shunt might be too big: but they did not want to put a smaller shunt in as there

was more risk of it becoming blocked.

## Rest

The surgeon came in and said they would wait and see how Harry goes overnight as he looked to be improving. He told us to go home and rest – he said he believed in being optimistic and he was right. The next day Harry was doing much better so it was decided he did not need to go back to theatre. They would let Harry rest for a few days. He was a little jaundiced and needed a blood transfusion so he was put on a blanket like a sun bed. They made a second attempt to take the vent off and this time he came off no problem.

## Genetics

While Harry was still in PICU we were seen by a genetics doctor from the Centre for Life. Not only did Harry have a heart defect and a spine problem, but we also found out he only has one kidney. The doctor thought he might have a syndrome with these problems he has – he thinks the most likely is Vater syndrome. Currently Harry is being seen every few months at the Centre for Life.

It was then not long before Harry was moved from PICU to the ward, and after a few days we was transferred back to the special care baby unit in our local hospital to get him to gain weight. He was supposed to come home tube fed, but surprised us all and took his bottles no problem so he was allowed home after two weeks there.

In December 2007 Harry was looking quite blue at times, and after seeing the doctors at the Freeman they said the time had come for more surgery for Harry as he was outgrowing the shunt. He then had a cardiac catheter and they said as Harry was still very small a decision was made for him to have another shunt – a bigger one to let him grow before he has the repair.

## Different

In April 2008 he had his second shunt. This time it was very different: he was bigger and much stronger. The day after his surgery he came off the ventilator no problem and after four hours was back on the ward. He was home within a week

He still faces more operations as he grows but he is doing well and we can't thank



*Harry and his big brothers*

the staff at the Freeman enough – they all do such a good job

It's Harry's second birthday on 31 March. I can't believe it – time has flown over your mammy and daddy's brave little man and we all love you loads x x x

## Terms used:

**Pulmonary atresia with VSD:** the pulmonary valve and artery are blocked or missing, and there is a hole between the left and right ventricle.

**CPAP:** stands for continuous positive airway pressure – a way of getting more air into the lungs.

**Echo:** short for echocardiogram – a scan using sound waves to get a picture of the heart.

**Ductus:** a blood vessel which usually closes shortly after birth – by keeping it open blood can get to the lungs.

**BT shunt:** an artery is moved so that it directs blood into the lungs

**PICU:** paediatric intensive care unit

**Ventilator:** a machine that helps you breathe

**Jaundiced:** yellow colouring of the skin and eyes caused when the liver is not fully coping

**Tube fed:** feeding through a tube which runs from the nose to the stomach – a nasogastric tube

**Vater (or VACTERL) syndrome:** A collection of abnormalities affecting some of the following areas: Vertebrae (spine), Anus, Cardiac (heart), Trachea, Esophagus, Renal (kidneys), Limbs,

# LIBBY'S STORY SO FAR

by her parents Cheryl and John

Libby was born on the 8th October 2007 by Caesarean Section weighing 5lb 12oz.

## Perfect

After having a relatively smooth pregnancy, apart from early bleeding and high blood sugar throughout, with Libby, I was excited and apprehensive about meeting my little girl. I had lots of anxieties in pregnancy about becoming a mummy, but all those worries melted away the moment I set eyes on my little princess.

Libby was perfect, I had no preconceptions of what she would look like while I was pregnant, other than what I had to go off with the scan pictures. We used to joke that from the side profile on scan, Libby looked exactly like her Daddy, and guess what..... she does look exactly like John.

## Jaundice and breastfeeding: our problems commenced

We were discharged from hospital, and all was satisfactory on Libby's baby checks that are performed and entered into the little red book prior to discharge, so that was a relief. As in pregnancy I had convinced myself I was never going to meet Libby, but after talking to other mums, I found out this is quite common with your first child. It was probably another fear/anxiety that I was having.

We brought Libby home on day four, my milk had just come in, and I was breastfeeding every few hours. With no previous experience of breastfeeding, I was just going with the flow and offering Libby feeds on demand, she did not seem to feed for long at first and I was encouraged to undress Libby to stimulate her. This looking back was totally the wrong thing to do, as she was probably breathless and cold, and her little heart was working overtime anyway, without being naked and not having the strength to feed.

At around day six the midwife came and said Libby looked jaundiced. Over the next two weeks Libby became more and more yellow as the days progressed. We were back and forth to our local hospital for Libby to have blood checks for the jaundice levels. Within these two weeks we must have seen over six different doctors who all thoroughly examined her, and when listening to her chest completely failed to detect that there was anything wrong with Libby's heart.

At three weeks old we were admitted to hospital after a phone call at home to say

Libby's bilirubin levels had gone above the treatment level, and she would require some phototherapy. Libby had the phototherapy over night and we both stayed with her, John stayed awake all night while I tried my best to get some sleep; I remember thinking that this was the worse point... how naïve was I!

## The Bad News

On the morning after the phototherapy, one of the consultants came on the ward round, to review Libby to see how she had progressed overnight. He set to work examining her in the incubator. John had gone home to shower and change and I was waiting for us to be given the all clear and sent home.

When the consultant had examined Libby, he turned to me and asked me "did you realise/know that Libby had a heart murmur?". Obviously I said no, completely shocked and dumbfounded. How could it have just become apparent, it was not there last week, and no other doctor had said anything? The point was her murmur had been missed up to this point.

We were discharged from the hospital that morning and we had an appointment made for the outpatient clinic where we would see Dr Gibbs in two weeks time at our local hospital, as he was one of the heart specialists from Leeds who would come to see children in our area with heart problems.

We never made the appointment, as we were admitted for poor feeding the next night and one of the consultants arranged for us to go to Leeds the following day.

## Worried but relative calm

I was worried about going to Leeds, but not over concerned. I think I had convinced myself that Libby looked ok, so there could be nothing wrong. We were taken by taxi, on our own, no nurse escort. The taxi was driven by a complete maniac, who had no consideration for our safety.

Apart from the hair-raising taxi ride we had been given reassuring advice by the nurses at our local hospital that it may just be a murmur that heals itself (now I know ie ASD), or she may just need a bit of keyhole surgery: which still seemed daunting to me, but I had no other ideas of what was to come and of the bigger picture. As I said, we were very naïve at this point!



Libby, 2 days old

## The scan 1 November 2007

By the time we arrived at Leeds, Libby was hungry and not a happy little bunny. We went and found the ward. When we arrived we were sent straight for the scan, even though Libby was getting hungrier and more agitated.

We sat in a treatment room while the lady registrar scanned a very upset Libby. There were three doctors in the room, and I had to give Libby some syrup on a dummy to settle her. Looking back now I would have requested to feed her prior to the scan, but being new to this game, we did as we were told. The three doctors were talking in hushed voices with lots of medical jargon; we could not make out what was being said, even though we were only inches away from them.

## Not what we wanted to hear

When the scan was complete, I was allowed to pick Libby up. The registrar turned to us and said, "We have found something wrong with your baby's heart". I will never forget those words, and they will be etched in my memory forever more.

I was in shock; I just felt my stomach twist with fear and worry. John and I were numb, shell-shocked, this was not what we expected at all, even though we had come to have her heart scanned, I think we still thought it was going to be nothing to worry about. I could feel my own heart start to beat so fast, this was not good, and the registrar's face said more to me than her words did.

We were told to go and feed Libby as she was now beside herself with hunger and we were sent to the feeding room at the bottom of ward 10, which I am sure many of you will know who visit LGI and ward 10.

I was worried sick, I knew as her expression and tone were not good. I used to be a paediatric nurse so had some experience of hospitals, but not on this level, and certainly minimal experience with heart children, and when its your

own child, all that knowledge goes out of the window anyway. John, my husband, was trying to stay as positive as ever, and saying Libby may just need a little op or bit of medication. As I was the pessimist, as usual, I was thinking the worse.

### **My worst fears ignited**

We finished feeding Libby, which had taken three quarters of an hour. I was beside myself, and worried sick, still having the registrar's words rattling around my head. We still did not know what was wrong with our beautiful little girl.

We were led into a side room and the registrar asked one of the nurses to take Libby from me so we could talk properly. At this point, I knew things were on a slippery slope to extremely bad news coming our way. I would not part with Libby, I just felt so protective of her and felt like my worse fears in pregnancy were starting to come true. Nobody was going to take her from me; I needed her in my arms whatever the news was, and coupled with the hormones raging round my body, I must have been so abrupt and rude.

We sat down in the little room and the registrar started to tell us about Libby's heart and that she had a heart defect called a complete AVSD, and was drawing pictures on the paper to demonstrate what was wrong. John and I were trying to take it all in, but it was hard to believe what was being said to us. I remember saying, "but she is ok, look at her". The registrar then went on to tell us that Libby would require surgery at around three months old to repair the two holes and faulty valve, but the surgery all depended on how well Libby was, and she may require it sooner depending on her condition, but that they liked to wait for the heart to grow more. Then she went on to describe the risks involved in the surgery, and that Libby could have a stroke or die, as this was open heart surgery.

John broke down, I just sat there looking at John and then at Libby and then back at the registrar. I was completely shocked and devastated, I was still trying to not believe her words, I could not cry, I just felt angry and frustrated. Why? Why had this happened to our little baby?

We just wanted to get out of there, out of that room, I felt claustrophobic and like I was going to hyperventilate. I wanted to run as far away from that place as I could, I would never let them touch Libby, my

baby that I had wanted for so long, they had to have made a mistake. Libby looked, apart from the jaundice, completely fine – she is our baby, how can this be happening?!

### **The daunting reality**

We traveled back to our local hospital, in complete silence. John sat in the front with the crazy taxi driver and me in the back with Libby in her car seat. I just kept touching Libby's head and looking at her in disbelief that anything was wrong.

I felt so angry I wanted to scream, Why us? This is not fair, with a few choice words in between, but I could not stop thinking about the registrar's words, open heart surgery, death, a stroke, three months old. John kept turning round and whispering it's ok, we will get through this, and I just could not look at him, I wanted to blame someone at that moment in time and unfortunately he was the closest person to me. You do irrational things when you have just been given the worst news of your life. We both kept reading the same part over and over in the file they had given us to take home, about the heart defect information.

We got back to the hospital and walked up to the ward. I remember it was quiet and the nurse saying "we were just about to send out the search party". I could not look at them, and walked straight into our room.

None of the nurses knew what to say and the one who was supposed to be looking after us did not even come to console us or offer advice, so all we had was our LGI ward 10 manual, that we read more than fifty times just looking for answers to why and why it had happened to us. I was searching for answers that did not exist.

### **Next day**

We stayed in hospital that night; I think now looking back we were too scared to go home; we waited for the doctors to see us on the ward round the next morning. They explained about keeping away from infection and that Libby would need to have injections to try and prevent her catching the flu as the winter was fast approaching, and heart children were more at risk. Overnight we had been thrown into a category, our child was not just Libby Grace, she was Libby Grace, heart child. It was hard to understand.

For three more weeks we cocooned ourselves at home with our precious little



*Libby – aged 3 months*

girl, and all the cards, flowers and well wishes for the future from her birth. We did not even now know what the future held for Libby and us as a family. We were completely devastated. Words can never explain how much of a rollercoaster of emotions we felt, and how completely shattered our world had become overnight. I felt despair, I felt like we were completely alone. I decided I had to keep going for Libby's sake and that she needed me so much, and I would be there for her always, and I threw myself into becoming a mummy, and continued breastfeeding, to everyone's amazement, because of the stress and worry, but I was just determined to give Libby the best start in life, and to concentrate on the here and now.

### **Back to Leeds December 07**

When we returned to Leeds for our check-up appointment, we had prayed for a miracle to happen, and I was still in disbelief thinking they had got it wrong, as Libby was showing no signs of cardiac failure: we had been having weekly check-ups at the local hospital prior to coming back to Leeds.

We met Elaine one of the liaison nurses for the first time, who is fantastic, so lovely and calming.

In the same treatment room Libby was scanned again, this time asleep and not hungry. She was scanned by Dr Blackburn, our consultant now and it was the first time we had met him. After the scan, he turned to us and gave us some hope that we really needed. The VSD part of the defect had closed considerably, which was rare. This meant that as Libby was not in cardiac failure, they would not be looking at surgery at this point in time. To say we were relieved was an understatement. We

## LIBBY'S STORY cont.

could not believe our ears, but it was not all plain sailing. Libby would still need open heart surgery, but they could afford to wait until her heart becomes stronger as she grows. I was so pleased we had been given more time. We were to be reviewed in three months.

### Our little Libby Grace

So here we are. Libby is now seventeen months old and is beautiful, bright as a button, so funny and symptom free, you would not even look at her and think anything was wrong with her heart. She has no idea what is to come. We are just waiting like so many others for her surgery, which we have been told will be around three years old. We try not to think about it too much as we believe that it would not be beneficial for Libby if John and I were down all the time. Don't get me wrong, we have our days when something will happen and it gets us thinking and then we are both in floods of tears, but that's usually when Libby has no idea and she is tucked up in bed on a night.

I feel guilty for what Libby has to face, about the surgery risks, the scar, and what I will tell her. I feel like Phoebe's mum (Issue 78), Victoria, when she said "will Phoebe blame her for letting her have it done". I feel the same, Victoria; you are not alone. I was choked when I read your story, and it could have been me saying the same words. I also think "how will I sign the consent forms and let them do this to her", even though I know long term it is our only option. We as a family have never had such hard decisions to make.

I have so many times taken myself back through my pregnancy thinking did I cause this, may be it was when I slipped

down a curb, or ate that Mr Whippy ice-cream, and did not realise I should not have, or too much photocopying at work! I blame myself, after all I carried her for nine months, and I am always looking for answers, but sometimes there are none.

But I would not change a single thing; Libby is fantastic, and the best thing that ever happened to us. We love her so much and I am so proud of who she is. We go for six monthly check-ups to Leeds, and so far Libby's heart has not changed in terms of causing her to need surgery at anytime soon.

### HeartLine

I would just like to say lastly, that when we had our devastation after finding out about Libby's heart we needed some support, and even though our families were fantastic, they had never been through this, so had no idea how to help. That's when we found HeartLine and discovered a new world out there of children and families that were going through or had been through what we had, and worse. We felt comforted and no longer alone, and we started to look at the forums and realized there was so much love and compassion out there from complete strangers, with the only connection of having children like Libby.

It was a saviour for us, and even though we have not used the forums we would like to say thank you to all the children and families out there for sharing their stories. Reading about you and your families makes us smile and mostly cry, and we feel like we are part of a special little group who totally understand each other, there is nothing else like it to comfort you in a situation like we have had to face, and with the challenges that the future holds for our family.



Libby – 1 year old



Libby – now, aged 17 months

### Terms used

**Bilirubin:** a yellow waste product normally dealt with by the liver – in new babies this can take a while to establish and the build up of yellow colouring in skin and eyes is called jaundice.

**Phototherapy:** treatment using light to cure jaundice

**Registrar:** senior doctor

**Keyhole surgery:** surgery which does not need a major incision.

**ASD:** atrial septal defect, a hole between the two chambers of the heart which collect blood

**Scan:** echocardiogram – uses ultrasound – sound waves – to get a picture of the heart and its structures

**LGI:** Leeds General Infirmary

**AVSD:** atrioventricular septal defect: a hole between the atriums, a hole between the ventricles, and a single valve in place of the tricuspid and mitral valves.

**Liaison nurse:** cardiac liaison nurses are

appointed to help families both in paediatric units and when families are at home.

**VSD:** ventricular septal defect: a hole between the ventricles

**Issue 78:** the Winter 2008/09 issue of HeartLine magazine – this can be seen on the website [www.heartline.org.uk](http://www.heartline.org.uk) at the end of the What's new? page

**Forums:** HeartLine message board can be found on our website [www.heartline.org.uk](http://www.heartline.org.uk)



## Last call

If you and your family would enjoy a great day out for free, contact the office urgently: 01276 707636  
email [admin@heartline.org.uk](mailto:admin@heartline.org.uk)

There may just be time for you to get to HeartLine party Wetlands, South West London, on 4 July

## NOTES

### Medic Alert

Does your child need a Medic Alert symbol? This may be because he or she has fainting attacks, a family history of Hypertrophic Obstructive Cardiomyopathy, is on warfarin, has a pacemaker, or has an allergy for example.

Bracelets, neck chains and straps come in a variety of designs suitable for children these days, HeartLine can cover the cost - just send your name, address and telephone number, the name of your child and the hospital he or she attends to Helen Baker at the HeartLine Office

### What do you think of SEN?

Tell the government what you think of the special educational needs process.

Earlier this year, the Government set up the Lamb Inquiry, under the chairmanship of

Brian Lamb, the Chair of the Special Educational Consortium, to advise the Secretary of State on the most effective ways of increasing parents' confidence in the special educational needs (SEN) assessment process. At the end of April, Brian Lamb submitted the report, 'Lamb Inquiry Review of SEN and Disability Information' outlining his recommendations and identifying further issues from the evidence so far. Now the Inquiry is very keen to get your views of the SEN system and is inviting everyone – parents, children and staff in schools and children's services – to answer their online questionnaires. To tell the government your views and experiences, visit: [www.dcsf.gov.uk/lambinquiry/evidence.shtml](http://www.dcsf.gov.uk/lambinquiry/evidence.shtml)

### Parents rate disabled children's services

The Office of National Statistics today published an overall satisfaction score of parents of disabled children of fifty nine out of a hundred for delivery of the

government's 'core offer' for disabled children. The 'core offer' was introduced in the Aiming High for Disabled Children programme as the commitment from local authorities and PCTs to disabled children and their parents on how they will be informed and involved as their needs are assessed and necessary services are delivered. David Congdon, Head of Policy and Campaigns at Mencap, and Every Disabled Child Matters comments "We are encouraged that this information on parental satisfaction with services for disabled children and the core offer has been collected, creating a baseline for England. However, the information we have at this stage lacks the detail we need to really understand how well local services for disabled children are performing. We look forward to June when a more detailed national and local breakdown will be available."

## CHF SPORTS AND EXERCISE CAMPAIGN

In the last issue of HeartLine magazine we included a questionnaire from Children's Heart Federation. Survey of Experiences of Sport and Exercise for Children and Young People aged up to 19 with Congenital Heart Disease.

Around a third of the parents who responded felt that the school did not offer enough of the right type of sports or alternative activities for their child. In addition, there were several reports of children being left on the sidelines, both in PE lessons and school trips.

### Some quotes from parents:

"He cannot do swimming but has not been offered an alternative activity. He just

has to sit out and watch other children swim"

"She was excluded from the playground – considered 'fragile' according to the head Teacher"

"Cardiologist said not to limit her – that she'd know when she needed to rest"

"Written advice would be helpful both as a reminder for my son and to give to the school. He sits inside and plays board games."

Thank you to the many who completed and returned this at short notice – your efforts contributed enormously to the

campaign run by CHF launched in May.

### What can be done?

Every school will have at least one child with congenital heart disease (CoHD).

These children may have surgery several times during childhood and their condition and treatment often leaves them with some physical restrictions, but the main reason behind this exclusion from sports and activities seems to be a lack of knowledge and confidence amongst teachers about what is safe and appropriate for children with heart conditions.

A heart child with obvious physical restrictions should be given an individual

# A VISIT TO ST THOMAS'S

by *Chloe McCollum*

*Chloe has written about how she has braved a full heart check-up, and gives us some insight into how frightening these can be.*

I had a great time with Joyce when we went to St Thomas's for a heart check-up. It was good getting there. The bus ride took us right to the door. The hospital was very big and busy and we saw lots of people there. Before I was a bit frightened of the doctors, the machines, having sticky things on me, and that horrible cold jelly. I especially didn't like the machine that squeezed my arm.

I'm now 26, and I had my operation – open heart surgery – when I was 11 months old. When I was little I had check-ups at Guys Hospital and mostly didn't mind it. But as I got older it seemed more scary, and I haven't liked it for years. As I've been in good health and my colour is good then doctors would say from the little reading they could get things were ok, and come back in two years. But my mum thought I should have a proper check-up. She tried bribing me and even had a photograph album made to show me what would take place. I always say I'll be ok, but when I get there it's all too horrid. We don't go to Guys anymore and I'm too old to go to the Evelina which looks amazing, so off I go with the other grown-ups.

This time I've taken my mum, but also my best supporter Joyce with me ... and I really tried to be on my best behaviour. Everyone was very patient, and after creating a bit, I let my blood pressure be checked. When we went in for the ECG

and ECHO, I was a little bit more relaxed. The jelly was warm, and the lovely technician let me move the tester along, and Joyce lied down next to me. It took a long time, but the doctor could get a good picture of my heart. It looked like a video of ET's heart light pumping. We saw the consultant who said I was doing well and "it was a really good repair". And come back in two years. I now know the machines don't hurt me, and I hope I won't be scared again, but I really hope Joyce joins me next time as well.

## PS: Mum's comments

Chloe was born in 1982 in Guy's Hospital in London. Shortly after her birth it was discovered that she had Down's Syndrome. Dr Joseph suggested she have an ECG and an echocardiogram because of her colour and inability to feed well. It was then discovered that she had an AVSD (atrioventricular septal defect – called an AV canal defect in those days!) and after monitoring and a catheter examination it was decided an operation was necessary and quite possible. Mr Deverell performed the operation which went exceedingly well. Chloe never looked back. From being a very poor eater and quite a floppy little one, she immediately became a good eater and physically very strong.

Although her appetite still amazes us, she isn't overweight because she is an extremely active young woman. She swims, dances, goes bowling and to the gym; and also enjoys long walks. She has left college now, and works one day a week in a city farm, enjoys adult education courses; and sometimes



*Chloe in party mood*

performs at the Albany in Deptford with Heart and Soul.

We've been talking about sharing her story for ages, and finally because she is really proud of managing her last appointment she agreed to writing it. Taking along someone (other than a parent) who really understands and communicates well with a person with learning difficulties seems such an important thing to do to help that person understand and cope with check-ups. I only wish I had thought of it earlier. We are really pleased and thankful that her repair went so well and know it will continually need monitoring, and hope the next appointment goes as smoothly.

*Zelda McCollum*

plan for sports and resources to enable them to be included in activities so that they can take part and feel normal

Children's Heart Federation has launched a campaign called **Let's Get Moving for Heart Children's Health** to ensure that:

- Parents of children with CoHD and young people with CoHD know their rights in relation to access to sport and exercise at school and in the community;
- Individual Education Plans (IEP) for children with CoHD cover sports and exercise;
- Teachers feel confident about including children with CoHD in sport and school

trips because they have received appropriate training and information;

- Healthcare professionals and voluntary sector information services provide accurate and accessible information about sport and CoHD;
- Providers of sport and active leisure in the community know how to encourage the involvement of people with CoHD.

To join the campaign sign up on the Let's Get Moving page at [www.chfed.org.uk](http://www.chfed.org.uk), or call 020 7422 0630, or write to

Let's Get Moving, CHF,  
2-4 Great Eastern Street,  
London EC2A 3NW



*11 year old Harrison gave a quite brilliant speech on his frustrations and hopes at a reception at the House of Commons on 19 May.*



## My Sister Makes Me Smile

This book started out originally as a one off project to produce a valuable resource for children, families, health professionals, teachers and anyone

involved in the care of a heart child to get an insight into what it actually feels like to be a 'heart child', 'sibling', or carer. The project has now led to the development of an independent, non profit making publishing company ginnymoo publications which will support the printing and publishing of books to raise wider awareness and understanding about long term health conditions.

### Pivotal support role of siblings

The book was inspired by the story of Eliyas who is now eight years old and has a complex heart condition. His story, emphasises the very powerful and pivotal support role that siblings have in the lives of children with long term conditions. It was, in fact, his sister who made him smile again when he had really lost hope in hospital after his surgery.

We felt this project was really important to give hope and inspiration to other

families who have children whose future is uncertain.

The book has been beautifully illustrated by children and an artist, Suzanne Stobbs who is the parent of a child with a long term lung condition (cystic fibrosis) who is himself very inspiring. You may have seen his story on TV, 'A Boy called Alex' on Channel 4.

### Valuable to all children

We think this book will also be valuable to all children who want to read something inspiring, satirical, humorous or just get some tips about keeping your heart healthy.

The stories in the book are from many families and children affected by heart conditions. Many of these families responded to a request for stories made by HeartLine, a while ago.

Books are available at a suggested donation of £5.99 to ginnymoo publications who can be contacted at [ginnymoo@googlemail.com](mailto:ginnymoo@googlemail.com). The book has been recommended by an independent Head Teacher and The Royal and Brompton NHS Hospitals Trust.

Thank you to all the HeartLine families who have contributed to this project.

### Looking back

*Jenny Brown was a founder HeartLine member. She writes:*

A few weeks ago I decided it was time to think about spring cleaning. The best place to begin seemed to be at the top – in the loft.

While sorting through the boxes, I came across back copies of HeartLine. In fact, they were the first magazines which had been published. Michael and I were founder members of HeartLine along with other parents who welcomed the support which HeartLine offered.

Our son Phillip was born with coarctation (narrowing) of the aorta in 1978. He was under the care of Mr de Leval, Dr Taylor and Dr Rees until 1996: we will always be grateful for all the help they have given us.

When the HeartLine organisation was set up, I became Area Contact and met many parents who were in a similar situation to ourselves. Travelling to and staying in London, worries about health care and schooling were problems which we faced together. Phillip now attends the local hospital where he has annual check-ups; he leads a full and active life.

I am still a member of HeartLine and hope you will continue to support families in the future.

### Child Trust Fund accounts for children getting DLA

The Government will contribute £100 every year to the Child Trust Fund accounts of all disabled children, and £200 to children getting the highest rate care component of DLA, receiving £200 per year.

If your child was getting DLA in the 2009-2010 financial year he or she will get a payment starting in the 2010-2011 financial year.

### Grants and childcare – from Peace of Mind Care

Peace of Mind Care is a new UK-wide charity, set up by the parent of three children with disabilities. Their aim is to make life a little better for terminally ill or severely disabled children and their families, by providing respite for the main carers, days out for the children and their families and providing items of need or a bit of fun for children.

They fundraise to pay for these services for families and will consider anyone who

needs help, regardless of income. Parents can contact them directly.

Peace of Mind Recruitment agency is their childcare agency and can find childcare for families with disabled children, placing nannies, babysitters, nursery staff. There are one-off fees attached to this service, which go towards the grants.

They have various fundraising activities. To get involved, or for more information and to apply for their grants schemes, tel: 01189812823 or 01189841777 (Mon-Fri, 9am-4pm) or see their website at [www.peaceofmindcare.co.uk](http://www.peaceofmindcare.co.uk)

### Folic acid can reduce risk of heart defects

Researchers in Canada have found that adding folic acid to food can significantly reduce the likelihood of congenital heart disease in babies. Since December 1998, all grain products sold in Canada have been fortified with folic acid. Thanks to provincial databases the researchers were able to show that over this time, folic acid has decreased the incidence of congenital heart disease by over 6%. Despite the success of this initiative, Raluca Lonescu-Ittu, one of the researchers, advises that efforts to encourage future mothers to take folic acid supplements should continue, saying: "This level is still not quite sufficient for women planning a pregnancy, who should start taking folic acid supplements at least three months before becoming pregnant."

### Short films from Contact a Family

Contact a Family have produced three new short films featuring families talking about their experiences of raising a child with a disability and the best sources of support they have found. The first families focuses on the support provided by Contact a Family and how parents have benefited from this. The second one features families talking about the importance of sharing experiences with other parents and gaining support from each other to reduce isolation. And finally, the third film – Meet the Fathers – features two dads talking about their experiences and some of the issues they have come across as dads of disabled children. Tune in to You Tube to watch the films – <http://www.youtube.com/user/cafamily>

### Heart Children book

As well as English, we publish Heart Children in seven of the languages: Arabic, Hindi, Urdu, Gujarati, Punjabi, Bengali and Italian on the internet at our dedicated website: [www.heartlinetranslations.co.uk](http://www.heartlinetranslations.co.uk). To buy printed copies contact the office on 01276 707636.

*Patrons: Dr Philip Rees  
Adelaide Tunstill*

## **HEARTLINE EXECUTIVE COMMITTEE**

*The Trustees who form the Executive Committee are elected at the Annual General Meeting*

**Chair Anya Rowson**

**Vice Chair Alison Keen**

**Treasurer Kevin Ford**

**Trustee Lisa Casey**

**Trustee Linda Hardy**

### **Senior HeartLine Message Board Moderators**

The Moderators safeguard the message board on the HeartLine website and ensure that the rules are adhered to. The message boards can be found at [www.heartline.org.uk](http://www.heartline.org.uk)

**Sheran Taylor**

**Kerry M-S**

**Kate Hatcher**

**Val Thrubbron**

### **Nurse Advisors**

As HeartLine is unable to give medical advice one of the nurse advisors may be able to help you

**Gill Thompson**

**Adelaid Tunstill**

## HEARTLINE'S CORE SUPPORTERS

If you would like support for something that is not listed,  
please telephone the HeartLine office on 01276 707642.

### **Sarah Batt**

Sarah is willing to offer support for families of children who:

- have a tracheotomy
- need strategies (for tube feeding)
- need speech and language support
- take warfarin
- have had a stroke and/or hemiplegia
- are approaching the transition to adult services

### **Annabel Blanch**

Annabel is willing to offer support for families of children who:

- need feeding strategies particularly if your child has projectile vomiting
- have behaviour problems
- have problems with speech & language

Annabel is a SENCO and can give general advice

### **Liz and Keith Collins**

Keith is willing to offer support to other dads and Liz is willing to offer support for families of children who:

- have Tetralogy of Fallots
- need feeding strategies (not tube fed)
- are teenagers living with CHD

### **Shelly Coombs**

Shelly is willing to offer support to other Grandparents

### **Rosie Freeman**

Rosie is willing to offer support for families of children who:

- attend the Freeman Hospital
- have Tetralogy of Fallots

### **Sue Gearing**

Sue is willing to offer support for Families of children with Tetralogy of Fallots.

### **Kate Hatcher**

Kate is willing to offer bereaved parents her support.

### **Margaret Horstead**

Margaret is willing to offer support for families of children who:

- are new members
- have DiGeorge Syndrome

### **Annette Jackson**

Annette is willing to offer support for families of children who:

- attend Leeds General Infirmary
- need strategies for helping with reflux
- are under the care of a Dietician
- need help with an application for DLA or Carers Allowance
- need help with an application for Blue Badges
- attend Evelina Hospital

### **Jan Kingsley**

Jan is willing to offer expectant parents pre-natal support.

### **Jan Lyons**

Jan is willing to offer support for families attending the Brompton Hospital.

### **Elaine Murray-Bell**

Elaine is willing to offer support for families of children who:

- need feeding strategies for pump fed children
- have CHARGE syndrome
- need help with an application for Disability Living Allowance

### **Val Thubbron**

Val is willing to offer support for families of children who:

- want to use the HeartLine Message Boards
- attend Great Ormond Street Hospital

### **Debbie Ware**

Debbie is willing to offer new parents general support, particularly how to make the most of being a member of HeartLine.

*Meet the core supporters – see page 4*

## **HeartLine Association**

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