



HeartLine

Issue 66

Spring 2005

Inside:

**Emma Collins Raises
Awareness**

Piers' Story

**Starting at
Secondary School**

Can you please help?



Holly - ever so clever, ever so happy

Perhaps HeartLine's most important gift to families is the knowledge that, in the broad scope of things, we are 'normal', our problems have been experienced by others – there is always someone luckier than you, and someone dealt a nastier hand. Other parents know what you are talking about – they've been there and done that. Most are wonderfully supportive. The price of being supported is being a help and comfort to others, sometimes through bereavement. Other people's sufferings provide the experience and often the hope by which the rest of us live, and our own trials can provide the insight to help others.

In this magazine we report on how many of you have helped to reach parents who are not yet supported, by raising awareness of congenital heart disease and HeartLine.

Hazel Greig-Midlane



Christine Baker, photographer daughter of HeartLine Projects Manager Helen Baker, took this stunning picture of Jonathan Mason. When it appeared on the front of the Winter 2004/05 issue we failed to acknowledge Christie, and we are pleased to correct that now.

I need your pictures and stories for Issue 66 Spring 2005 by the middle of June:

by email:
hgmhla@btinternet.com

by post:

by telephone:

But for **HeartLine Office** ring
01276 707636.

Front cover:

Holly Mai Clark, daughter of area contact Tracey Dolby. An article on an ever so clever, ever so happy granddaughter appears in the Summer issue.



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PUBLICISING HEARTLINE

For 14 February this year HeartLine armed area contacts and our special advisers with information for schools and the press. Emma, whose parents give feeding support, gave her own talk:

My name is Emma Collins and I am nine years old. I have Tetralogy of Fallot and I attend Bute House School in Hammersmith. I have been a member of Heartline since I was born and I was operated on at the Royal Brompton Hospital.

For Congenital Heart Disease Awareness Day I gave a talk to my classmates about CHD awareness. In the process I publicised Heartline too.

I talked about what the heart is, and how it works. We measured everyone's pulse, and then we also did the jumping up and down to raise their pulse. But only two people did this because we jumped 30 times!

I told them about my problem and what they did to fix it and how my life is affected by ToF. And I gave everyone a Heartline balloon.

Having Tetralogy of Fallot has impacted on my daily school life a little too. I can't run or swim very well or fast, walk for very long distances, or run for long distances. I can't play action games very well or for a long time

But otherwise school does not do me the slightest bit of harm in any way. I only have to leave school when I have chest pain or mild fever which does not happen very often.

After my talk people had several different sorts of reactions. People were congratulating me and I feel glad that they understand. I feel very glad that I did this talk when I did, because now people understand what is wrong with me and can stop asking me annoying questions like, "Have you got a scar?" It can be frustrating sometimes.

Otherwise I don't think my life could be any better. The more I think about it the more I think that I have been very lucky that I don't have something else that could be a lot worse.

If any parents want to talk to me about living with ToF then you are welcome to do so.



ABOUT HEARTLINE

This is some of the information that was sent out for Awareness Day:

Whatever the kind of problem, the diagnosis of a heart defect is always extremely distressing, and the first thing most parents need is information so that they can understand the best way to deal with it. Most families are shocked to learn that a baby can have a heart condition and for many of us our understanding of the workings of the heart was limited to that needed to pass a GCSE. The learning curve is horribly steep.

Twenty-six years ago HeartLine was set up by staff and parents at Great Ormond Street Hospital, to provide information and support to children with heart disorders and their friends and families. Now HeartLine has a membership of 1500 throughout the UK and more than fifty area contacts. The only membership rule is that you are involved in some way with a heart child.

Support we give

As a registered charity, HeartLine is run mainly by parents and has an office in Surrey, where a small staff handle queries, arrange sailing trips, caravan holidays, and a summer event.

Packs of information are sent to the hospitals that treat heart children. These include a range of helpful information, a recent magazine with the stories and experiences of families and one HeartLine teddy. There is also an order form for the ever valuable Heart Children book, now published in the eight languages most commonly needed in the UK.

Keeping in touch

The website – www.heartline.org.uk – offers up-to-date information and a lively Message Board with nearly 3000 messages at any one time, where parents offer each other sympathy, comfort and advice during surgery, family, social and school problems.

We can arrange one-to-one contact for particular types of heart defects, for people whose babies won't feed, for grandparents and for those expecting a baby with a heart defect.

We have more than 50 volunteer contacts, parents themselves, who provide local support throughout Britain.

Please make sure that families know about us, and help us to support each other
www.heartline.org.uk

01276 707636

CAN YOU PLEASE HELP?

This year we asked our area contacts and others willing to give it a go, to distribute leaflets about HeartLine, around 14 February – CHD Awareness Day. We often hear of families with a heart child who have years alone before they get information about support from other parents. Anyone who can help us with raising awareness, please let us know. We can provide material for talks to schools, clubs and other groups or for you to pass on through libraries, health and community centres.

Many parents have contacted us to let us know that they were able to get an article in the local paper, ran a race or a 'wear red' day at school and you can read some of their stories on page 7. And of course Emma took it into her own hands and did her own thing at school.

As well as awareness we have to raise funds to pay for the many ways of helping and supporting HeartLine has. Fundraising has been very difficult recently because of the many other good causes that have been a call on your generosity. Despite this many of you have brought in funds and made generous donations which keep our work ticking

over. But there are other difficulties too.

Neville is HeartLine Association's fundraiser. He writes

First, why does HeartLine need the money? Well, we employ four staff, one full-time and three part-time, based in our Camberley office. Each month, we have to raise £5,685 to pay for our support centre and core activities. And of course we have to pay for this magazine to be produced and distributed.

In addition, we have to raise the money for our welfare projects: information books and sheets, the popular Baby Bear books, Antibiotic Cover cards, MedicAlert bracelets, Dental Packs, Hospital Packs, "Gentle Adventures" sailing days, two mobile homes for holidays and convalescent breaks, and a new project for supporting bereaved parents.

We currently have 1,375 families registered with us, but we also help hundreds of families who do not join, but are still able to get our support from the office or through the website messageboard for example.

Since I started fund-raising for HeartLine

in 1996, many companies have changed the way they give to good causes, mainly due to the increase in the number of charities looking for funding. Nowadays they tend to only offer support to charities which support their employees.

So this is where you can help us:

- ❖ If your company funds charities nominated by its employees, would you be prepared to nominate HeartLine? It doesn't have to be your company – it could be grandparents, aunts, cousins, or anyone else who knows about the support HeartLine can give.
- ❖ Call me at the Office with the name of your company if you would be prepared to let your name be used when I approach them, as a family who has been supported by HeartLine.
- ❖ If your company matches its employees' own fund-raising efforts, would you be prepared to raise money yourself?

If you can help, please telephone me on 01276 707636, or e-mail me on admin@heartline.org.uk

PIERS' STORY

Gemma Norman Walker writes:

Piers was born on Saturday 20 December 2003, a healthy 7lbs 12oz after a very short and fairly easy labour. I got to St Peter's hospital in Chertsey, Surrey at 5.30am and by 5.48am Piers was born!

No alarm bells

I remember the midwife saying that he was very blue from the waist down and unlike other babies his normal colour was not returning as quickly as I think they would have expected. Anyway this didn't really make any alarm bells ring in my head as they seemed to be quite happy with it, eventually his colour did come and he was just perfect.

We were allowed to go home on the Sunday afternoon as he seemed fine and only had slight jaundice, unlike my other son, Connor, who had to go under the lamps to draw the jaundice out.

Colic?

I can really only remember that he was very unsettled and we put it down to colic as Connor had had colic quite badly and the symptoms seemed to be the same. We'd

phoned our hospital to speak to the midwife about this and she agreed, yes it probably was colic but if we had any further concerns we should take him in.

Friday 9 January 2004 arrived and I'd just dropped Connor off to nursery when I walked in and took one look at Piers and thought, my God, what a strange colour! His face was literally green, a very light coloured green and he looked a bit startled. I took him straight to A & E and told them what had happened – his colour was normal by now.

They listened to his breathing and thought he 'panted like a dog', I was asked at this stage if this was how he had always breathed and to me, yes it was so. Therefore no further investigation took place, and we were sent home, being told his jaundice was probably showing in his face and this was the colour I had seen. We were referred back to St Peter's on Thursday 15 January to see the SHO on duty in the Paediatric ward just to check up on his condition.



Why didn't we just ask?

The SHO looked over Piers and everything seemed fine, he tried to find his femoral pulses in his groin area and was having problems trying to feel them, he took quite a bit of time on this and finally put it down to the fact that Piers was wriggling a lot and this was why he couldn't quite feel them. He told us if the colour change in his face happened again we should go back and they would do an ECG on his heart. Looking back now I really feel like kicking myself as this should have made me ask the question 'why are you thinking about the heart when he's here for jaundice',

something I'm sure a lot of parents have kicked themselves over; why didn't we just ask?

Not breathe AND eat

Anyway Friday 30 January arrives, the beginning of a long journey. I was trying to get Piers from breast milk onto a bottle and he just wasn't having it! Finally by lunchtime I really did start to think that something was not quite right – every time I tried to put the bottle in his mouth he just pulled away as if he couldn't breathe and eat at the same time. Finally after having a battle with my local doctors to get Piers seen, we finally saw our family doctor who once examined Piers told us we needed to get him down to A & E straight away as his chest and ribs were receding every time he took a breath. He wrote a letter for us to take with us.

Not routine

I arrived at A & E and Harry, my husband, went home and looked after Connor our eldest son. Piers was examined and it was only really now that it dawned on me that this wasn't just a routine thing – there really was something wrong with Piers, Doctors from the Children's ward came down, the registrar came down, everybody just seemed to be looking at this little baby in my arms talking things I really did not have a clue about. There was something wrong with the blood pressure in his upper body compared to the blood pressure in his lower body. By luck the Consultant Paediatrician, popped into A & E, she was on her way home and was asked if she could do an echo on Piers as they wanted to check his heart.

Pain

The echo was done, I heard the doctor say to the paediatrician we need to talk to the Mum. I was taken into a side room with the nurse from A & E and the doctor who had suggested the echo and they proceeded to tell me Piers had a heart condition, it was called Coarctation of the Aorta, a tight narrowing of the main artery (the aorta). They needed to find a bed for him in a paediatric intensive care unit and were phoning the Royal Brompton Hospital and another main children's hospital in London. Piers needed to be taken asap by ambulance, with blues and twos to the hospital where they would most probably perform heart surgery either that night or first thing in the morning. My heart sank and no words could express the pain I felt for my dear little angel.

Surgery

Harry was called and he followed the ambulance to the Brompton, everything seemed to happen in a flash and before we knew it we were standing in the PICU of

the Brompton looking at Piers. Lots of tests were done and we spoke to the assistant of the surgeon Mr Sethia who was going to perform correction of the coarctation in the morning.

On the 31st January 2004 Piers underwent emergency repair of aortic coarctation with end-to-end anastomosis performed by Mr B Sethia. This meant they cut out the narrowing area and joined the two ends together. The operation itself was difficult as the pressure gradient between the upper and lower part of the body rose to 30mmHg, which was not acceptable after they had corrected the coarctation, therefore he had to be re-opened.

I remember waiting downstairs with Harry just waiting to hear our phone ring to say he was out, but it seemed like eternity and both of us seemed to be in a world of our own. Eventually we heard that he was now out, after four hours and the surgery should have only lasted about two hours!

Relief, sadness, elation

Harry and I walked into the PICU and we both just took one look at Piers and just hugged each other, there were so many emotions going through us, relief, sadness, elation, it was a day I never want to go through again. There he was, our little angel, hooked up to about eleven machines including a ventilator to help him breathe as he couldn't do that by himself right now. We were both so, so proud of him and we sat and just watched him with admiration.

The next day Connor came to visit his brother Piers, we were both certain we wanted to keep Connor in the picture of things going on with Piers and I think he enjoyed the visit – the Children's play room helped his visit immensely!

Recovery

By Tuesday 3 February Piers was moved onto Rose Ward where he made a fantastic recovery and was eventually allowed to go home by that Friday.

Piers has had to have follow ups at the Brompton every six months and will continue to have them until they are happy to put it to yearly check ups. Looking at him now you would really not believe what he has gone through – he is a bright, healthy-looking little boy who is just adorable and has the temperament of a saint, he is just so laid back and happy with life, it is wonderful to see!

Manipulation

Life has been difficult since his operation, Connor found it hard having his Mummy and Daddy away from home so much, we have a wonderful family network though

and everybody rallied together. I really don't think we quite understood all the after effects there would be for Piers. He quite obviously was very uncomfortable for some time and in the end we took him to a Cranial Osteopath to see if that would help him. It was fantastic and Piers loved it. Instead of massage they call it manipulation and it totally relaxed him and made him a lot more comfortable and perhaps more able to cope with his pain.

What is important

I can only say that this whole episode in all our lives is one I never want to repeat or would wish on anyone but at the same time can honestly say it has made us think about what really is important in our lives.

We are so lucky to have such wonderful boys who have been equally as brave as each other.



Terms used

Jaundice: yellow tinge to the skin caused by hepatitis (inflammation of the liver) often seen in new borns

SHO: Senior House Officer, grade of doctor

Femoral: arteries carrying blood to the legs

ECG: short for electrocardiogram – for measuring the electrical activity of the heart

Echo: short for echocardiogram – an image of the heart created by using high frequency sound waves.

Coarctation of the Aorta: narrowing in the aorta – the artery taking blood from the heart to the body

Anastomosis: joining together

Cranial Osteopathy: stimulating the movement between the bones of the skull to relieve pressure of fluid build up.

TO CELEBRATE AND SAY FAREWELL

In the Winter HeartLine, Michael Spencer wrote of his daughter's last year of life. Here he tells us of the celebration of Chantelle's life:

We buried her on Friday 12th November in Brompton Cemetery. The service was lead by Noel Walter, the Senior Chaplain at GOSH, who had christened Chantalle on New Years Day 2003.

The 'Southbank Strings' – a group of the best violinists at Hana and Raffaello's school – volunteered to play, and they played three beautiful pieces of music. Hana, my eldest, played two pieces on her violin – one solo, and one with her teacher. She was amazing, not making any mistakes (she has been playing for about one year, and started one of the pieces on last Monday).

We were touched by the support from all our friends, family, school (and parents of other pupils) and my colleagues from work. I think there must have been about a hundred people at Chantalle's funeral. As the violinists played, the sun came out, and shone into the round chapel there – it had been grey and raining in the morning, and by 3pm, when everyone had gone, it turned grey again. The chapel was prepared beautifully by the florist Seiko often buys flowers at – the owner remembered Chantalle. There was a real sense that it was as much a celebration of Chantalle's life, as well as a farewell.

Nothing is lost

I finish with the address I stood up and made at her funeral – I felt as if she gave me the strength to get through it:

"We come together to celebrate this marvellous little girl's life, as well as to say farewell. Chantalle would have been three on Sunday. I would first of all like to share some memories of her with you, followed by some poetry.

Some of the things that we celebrate about Chantalle were what any normal child would do, but for her, they were real achievements. She was born with very weak muscle tone and major heart problems. It meant that she was in hospital for seven months of her first eighteen; had major heart surgery at three months old; about seven episodes of CPR as her heart almost stopped on two or three occasions; had a tracheostomy for three months; severe reflux, which meant she had real difficulty putting on weight and had to be fed via a tube ... I could go on and on. She really was an amazing little girl to have come through all this.

Despite all that she was a very cheerful little girl, with a real sense of humour.

She liked having her hair done; her nails painted (even her toes!), and took her little pink bag with her everywhere.

She was attending a special school twice a week, where she had just moved up a class because she was doing so well.

She could let us know what she wanted through sign and some words. For example, whether she wanted to be fed via her tube or to eat or drink herself. She was very persistent, and would not stop signing until she got what she wanted.

She loved Hana to play the violin, pretending to play at the same time, using a pencil as her bow. She liked to play on the piano too. She spent hours with Raffaello quietly playing with the train set or Lego. Her favourite video was the Wiggles singing and dancing, and she would try and dance along with it. She was even trying to jump, yet she had only recently started to walk.

Her latest 'thing' was sticking sellotape and stickers everywhere – including her nose!

As I used to go out the door, even just to get the post, she would insist on coming to the door to hug and kiss me good-bye. And when I walked in at night from work, she would come to the door, to be picked up, and then she would ask me for food, even if she had just had something.

She could be quite mischievous – pulling Raffaello's hair or pinching Hana. If I have ever seen a sign with expression, it was the 'sorry' that we asked her to say – she didn't mean it at all!

Seiko and I have so many fond memories, I could talk all day ... so I will move onto the poetry.

The first poem is a Japanese poem that Seiko read at her best friend's funeral in the summer. We both thought it apt. It is called "JIBUN NI HANA" – "One's Flower".

namonaikusa mo mi o tsukeru.
iinochi ippai ni jibun no hana o
sakasete.

Even the smallest plant can produce a beautiful flower or fruit. It appears simple, but the plant takes a lot of time and effort to produce this flower.

Chantalle came to this world with conditions and a purpose – she wanted to see how much she could do with this body of hers. How much strength she had inside her. Chantalle never gave up, and she fought for much of her life against many obstacles. She created her beautiful flower, and our memories of her will remain with us forever. Chantalle only lived three years, but her attitude to life is something we can all learn from.

Before I finish with the second piece of poetry, Seiko and I would like to thank everyone for coming today. We would also like to express our heartfelt gratitude for all your support – not only during the last ten days, but for the past three years.

This piece of poetry is taken from a card sent to us by some dear friends (and translated by them too). It is called 'Nichts geht verloren' and is by Rainer Maria Rilke:

An Autumn leaf parts easily from the tree.

A person that falls like a leaf off the family tree does not part easily.

We are mourning over her.
We miss her.

Unlike an autumn leaf,
she is irreplaceable.

... and still there is one who holds this falling in his hands with boundless tenderness

Nichts geht verloren – nothing is lost



WE RAISED AWARENESS

And if you didn't, most of those who were sent material for Congenital Heart Disease Awareness Day have some activity planned later this year or early next. Here is some indication of what went on –

Sally

Sally writes: Our son with CHD, has an older sister who is in her first year at junior school. She was very keen for us to do something on 14th February for Heartline so when the suggestion came for the 'wear red to school day' I had no choice but to have a go!

Having met with the headmaster at St. Stephen's Junior School he was very supportive and suggested that I came along to morning assembly and talked to the children about Congenital Heart Disease Awareness Day. Help! What had I let myself in for!

I'd managed to 'beg' a lovely Valentine bear from a local supermarket and arranged for the children to pay 50p which would allow them to wear red for the day and would also buy them a raffle ticket for the bear.

I need not have worried about assembly; the children were very well behaved and actually seemed keen to participate even when Mr Northgrave-Williams informed them that no football shirts, jeans or trainers would be allowed. I think the huge bear as a prize helped!

This is what I said:

"For those of you who do not know me, my name is Sally Twitchen and I am the local contact for a charity called Heartline. This is a charity that helps children who are born with heart problems.

"People are always surprised to learn that children can suffer with heart disorders and that it doesn't just happen to old people. Happily this is quite rare but for those who are life can be very hard and, sometimes frightening. Children with these problems get tired very quickly and have to take lots of medication and may miss a lot of school because of hospital visits. Sometimes, sadly they get teased by other children for being 'different'. That, I'm sure, doesn't happen here.

" I have two children, one of whom does have a heart condition. He has had two operations before the age of two and faces more as he grows older. I expect you can

all imagine how difficult this is for all our family so we were very grateful for the help and support we received from the Heartline charity.

"So, does anyone know what's special about Monday 14th February? Well, in my family it's extra special because it's Congenital Heart Defect Day which means it's the day where we try and help the charity as a way of saying thank you. This is where you come in.

"You see I've come to ask you all a favour and wear red to school on Friday 11th February. This is our way of letting people know about the charity and how it can help other families. For 50p you can wear red to school on that day and it also buys you a raffle ticket for this lovely bear. Now I know all you boys may not think this is much of a prize but just think how popular you'll be on Valentine's Day with your mum or girlfriend if you give him as a present. Of course if you do choose to give him to a girl everyone here will know about it! You have been warned!

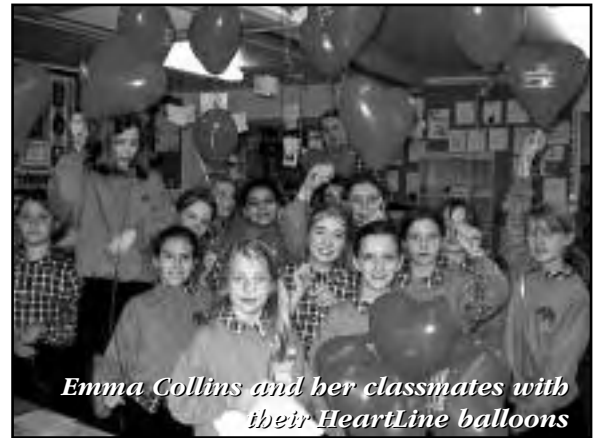
"Anyway, I just want to say thank you all for listening and thank you to the school for allowing me to come to talk to you. I do have some information hand outs which I will leave and I think you will all receive a letter to take home about the day."

The raffle, I understand will be drawn on the Friday in time for Valentine's Day!

Great success

On the day it was lovely to see so many children come to school dressed in red. The local media didn't respond but I managed to take some nice pictures. The total raised was £120, which meant that 240 children joined in on the day, which was really gratifying, and I felt that the day was a great success.

Libby is the second from the right, with Ben by her side.



Rachel

In mid-December, at the first suggestion of action for February, Rachel had telephoned her son's head teacher, and requested material to be sent. "She did mention that she receives loads of these kind of requests but as it is personal to me and my son she will look at it and she also asked if I could give her some written information on it.

Is there any way someone could send me some so I can show her?"

(Well, the information wasn't quite written at that point, but we got going and circulated it in the New Year, with balloons a little later.)

Mel, Diane, Fran, Val and Pam

Mel had already persuaded her three children's school to run an event for HeartLine once before, so could see no problem in running another event as soon as they were back.

Diane needed two packs of information as her daughters attend different schools. "Can I also say what a fantastic website HeartLine is" she added. " I wouldn't get through so many hard days without it."

Fran thought her son's school would be receptive to awareness raising: "as my son is one of two children in the same class who have CHD".

Val said that she would be on to the school as soon as her boys returned. "Not sure if they will be able to help but I will try my grovelling tactics!" she promised. Grovelling sounds like a perfectly good tactic!

Pam wrote that she was on to her child's

continued on page 8

school as soon as they returned from their half term, and she is planning other events over the year.

Katie and Karlie

Katie and Karlie did a sponsored walk because, as Katie said:

If it wasn't for HeartLine I think I would still be seeing those men in white coats!!

We managed to get into our local paper, they featured a whole page on us and a write up about HeartLine!

I gave most of my leaflets out on our walk, and have kept some for when we go to our local hospital. I am not sure how much we raised but I know I have over £150.00 pounds in sponsorship.

Nicky and Rosie

Nicky persuaded her daughter's school (Seabrook Primary School) to do the wear red day. "HeartLine balloons were used to decorate the entrance to the school and leaflets were handed out. The Deputy Headteacher explained to the children in their Assembly what it was all about. Although it is a small school, just over £70 was raised."

Rosie said that her son's school held a 'wear red day', and she was asked to give a small talk in assembly on the spur of the moment, so no preparation time was given! The school raised about £145

Debbie and Sandra

Debbie reported: I took the leaflets to various local surgeries and libraries, because the Awareness Day fell over half term so it was not possible to target local schools on that day. The balloons were very popular! We hope to do some fundraising later on this year.

Sandra said: I did contact my local school regarding Heartline and holding a 'wear something red day'. Although they originally agreed to this, it was later decided to hold a dress down day to raise money for a selection of nominated charities. They have agreed to add HeartLine to this list. I may not know until the end of the school year how much has been raised for each charity.

Jane

Jane wrote: "We had a good article in the Shrewsbury Chronicle about my daughter (half a page) which covered the

Coaguchek, CHF awareness and HeartLine". (Coaguchek is a machine that can be used at home for checking the clotting times of blood in children who are on warfarin.)

Vanessa

People whose children are not yet at school were also busy. Vanessa put HeartLine information material in the hospital, children's clinic and GP surgeries, and gave it to a local school and Homestart office. She took the opportunity to remind them that she is the area contact and to put people with heart children in touch, "It's amazing how many people still don't know about HeartLine", she writes. "I asked for our posters to be put up in the local GP surgeries and the hospital's children's clinic, and gave the balloons to a mom who was going to do a school talk. I have given info material to a local mom who has a heart child of 2½ and had never heard of HeartLine. She also happens to be a teacher and may do something for Awareness Day next year."

Mags

Local press stories weren't always as accurate as we hoped. "Article printed ... well ... bits of it!!!" wrote Frustrated of Lincs. "They did cut most of the important bits out ... and what they did leave in, got most of it wrong!!! No mention of HeartLine being for families of affected children ... or the Guess who I am? leaflet ... or any of the other info I sent! and ... they even mis-spelt my name and email address ..." She went on to say that although they managed to print the correct area telephone number and she had had two responses, they were both pensioners with angina. In fact, the newspaper had put HeartLine into the title, and that by itself is good publicity!

Kate

Because of Tsunami fundraising, Kate's older daughter's school was unable to participate in Awareness Day, but promised activity for next year. The local newspaper turned up at her heart child's toddlers group 'wear red' event, so Kate raised awareness with a nice pic of her and heart child and an article which ended with HeartLine's website address. And the toddlers group raised £40.

Elliott

Like Emma (see page 3) Elliott did his own thing. "My awareness assembly was a huge success with teachers saying I had put them to shame and that it was the best assembly the school had seen!" he wrote. "The response has been excellent and lots of teachers and pupils are planning different activities. Next term we are having a cake stall, own clothes day, disco and concert, all for Heartline. It is going to be excellent! To raise money and awareness to the public I managed to get an article published in the local paper. The response to the article has resulted in donations from members of the public, many to my father in his doctor's surgery from patients. One kind lady gave me £20 for the appeal! The disco will be held soon and it is fancy dress with lots of prizes, which should be fun. Some friends and I sold thirty-three handmade Valentines cards and Heartline bugs and managed to raise £51. That amount will be far more once we have finished all the planned activities."

Good ideas

While we were sending out material, several people had good ideas for other forms of fundraising, such as calendars and tea towels. Corinna wrote "Last year in nursery, my daughter already got quite a few Valentine cards – and I can imagine she will get even more in school. So how about doing some charity Valentine cards, but maybe also with a bit of info about CHD on the back where the charity bit goes?"

Any other good ideas we can print in the Summer magazine? It isn't too soon to be thinking of next year, or of other fundraising given the opportunity. Schools often vote for their year's nominated charity in September, so there may be a chance to get HeartLine in there!

Thanks

Thank you to the many not mentioned here who managed to talk to halls full of children, hand out leaflets, tackled their local press and raised awareness and /or funds, or started organising other activities. We can't manage without you!

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?

- Please pass my details to my local HeartLine Area Contact yes / no
- I would like contact with local families yes / no
- I would like contact with families and children with a similar condition yes / no
- I am willing to support other families yes / no
- *Please delete as appropriate*

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,
Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH*

HEARTLINE OFFICE SERVICES

The Camberley office is open Monday through Friday, between 10am and 4pm. Messages can be left outside of office hours, and will be dealt with as soon as possible on the following working day.

Tel: 01276 707636 Fax: 01276 707642

E-mail: heartline@easynet.co.uk

Web Site: <http://www.heartline.org.uk>

HeartLine Association, Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH

Administrator: Pamela Lawrence

Fundraising Officer: Neville Terry

LEAFLETS AVAILABLE

Dental Care for Children with Heart Problems

Feeding for Children with Heart Problems

Respite Care

FOR SALE

Pin Badges	£1.00
HeartLine 20th Birthday T-shirts Age 7-8	£5.00
New Updated 'Heart Children' Book	£5.00 plus £1.00 (p&p)

BOOKS TO BORROW

Pregnancy Loss • Choosing for Children • Parent's Consent • When a Baby Dies

Operation Fix-It • Rosie Goes Red, Violet Goes Blue

VIDEOS TO BORROW

Children and Heart Disease • Children and Catheterisation

Children in Surgery & Intensive Care • First Sight

Compilation from Children's Hospital, Ablation, Pacemaker, Closing ASD with Device

Living with Warfarin • When Our Baby Died

The Office also has a large number of leaflets about children in hospital, their rights, medicines, pain, feeding, education and information about a number of different kinds of heart defects.

ORDER FORM – please send to HeartLine Association, Community Link, Surrey Heath House, Knoll Road, Camberley, Surrey GU15 3HH

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.

MOVING UP TO SECONDARY SCHOOL

for children with special educational needs

This article is taken from Children's Heart Federation Information Sheet: Your child and special educational needs, 2004, which covers infant and junior school. You can download a copy from the CHF website – www.childrens-heart-fed.org.uk – or call the HeartLine office.

Reports of your child's special needs should be directly available to the secondary school from the Juniors.

But first you will want to find somewhere that is suitable and can be named on your child's statement, if he or she has one. Or you may want to consider a statement as your child changes school.

These are some of the reasons that children have needed a statement because of a heart defect:

- ❖ unable to walk upstairs
- ❖ unstable heart rhythm
- ❖ ngt (nasogastric tube) or gastrostomy
- ❖ breathlessness
- ❖ long hospitalisation

Your child might have other health problems.

Looking for a school

When looking for a school you may want to consider the following:

- ❖ How important is it for your child to stay with his or her friends?
- ❖ What is the school's SEN policy?
- ❖ What is access like? eg can you get a car near to the school
- ❖ What are the distances between classrooms?
- ❖ How many steps and stairs will your child need to tackle?
- ❖ Do children have to carry all books and equipment or do they have lockers?
- ❖ If you expect your child's condition to deteriorate, how will disability be dealt with as it arises?
- ❖ Where will your child's notes be kept?

Updating staff

You may find it more difficult to keep staff in a secondary school up-to-date with any concerns or problems. Usually secondary schools are bigger than junior schools, children are taught by several different people every day, and there is more emphasis on children looking out for themselves.

Problems

Try to steer a course between assertiveness and embarrassing your son or daughter. A difficulty some parents have is with children not wishing to draw attention to themselves, and struggling to be 'normal' in the eyes of their teacher and friends. Most young people would prefer not to have their Mum on the school trip with them, so look for alternatives to being the escort. Deal with problems as soon as they come up, by discussing them with your child and with the school, making a note of them.

Medic Alert

Many of us have found a Medic Alert bracelet useful for forewarning a teacher before our son or daughter is sent on a cross-country run, or inappropriately taught to box. This does not replace a full record of any existing medical condition, medications, GP and specialist contact address, and your daytime numbers which should be updated every term and left in the school office with a copy for the form tutor or teacher. In the event of an emergency a Medic Alert will bring any problems quickly to the attention of the staff (see page 14).

If your child has tachycardia (a fast heart beat), is on anticoagulant, or has a pacemaker, you may want to put this information on a Medic Alert so that they can get suitable care in an emergency.

BEST DRESSED PATIENTS

This is an article taken from AWSI, for younger readers:

Grandmas have been known to give kids dressing-gowns for hospital. Unless your dg is the coolest clothing you own, you probably won't need it.

And by cool, I mean NOT WARM.

Most hospitals keep temperatures at a level where you can be comfortably NUDE. So take clothes as if for summer holiday – probably not trunks or bikini – and opening down the front will make it easier for people to examine your chest.

Make sure you have warm clothes permanently to hand – they have a way of saying YOU CAN GO HOME this morning and you have to hang around for someone to bring your sweater and coat

before you can be out of the door if you haven't prepared.

Ask the hospital about where clothes are kept – and how they are to be washed.

At some point (don't take fright) you are likely to get FLUIDS on your clothes, so easy-clean stuff is the best idea.

Cool shorts and t-shirts or cotton nightshirts are good for night – easy to get on and off as you don't want to have to BEND ABOUT too much with scars on your chest. Any of the big clothing stores have the kind of thing in now colours and designs. And remember there may be a POSSLQ.

Can theatre gowns ever be cool?

It's amazing how great the theatre team

looks in TV hospital dramas – and how the patient never quite looks anything but a shambles, clotheswise.

Could be because you are lying ON YOUR BACK and clothes are made to hang down straight. And for the fellows, skirts are just not what we are used to. Prettying yourself up won't help: nail varnish will have disappeared long before and hair STYLES don't last through heart ops.

Our fashion advice for theatre? Just grit your teeth and go for the natural look.

Terms used:

AWSI: As We See It

POSSLQ: Person of Opposite Sex Sharing Living Quarters

LITTLE ROSS

Donna Neville writes:

This whole experience has opened my eyes to many things and as a result I have set up my own self-help group that has been called Understanding Differences and much of my time is spent on offering and gaining support through the msn group that I have set up, although I am still a member of Heartline, LHM and ECHO.

<http://groups.msn.com/UnderstandingDifferences/yourwebpage.msnw>

Being pre-judged

Already a single parent of two boys who do not see their dads I thought things could not get any worse for them... This may seem irrelevant coming from a story about HLHS, but for me this is quite a big issue, as many people out there are quick to pre-judge. From my own experiences I now know that things are not always the way that they may appear as I have to confess to previously being one of those pre-judgers!

Realising that I was pregnant with Ross came just after I had split with his dad too, then having Ross diagnosed with HLHS started another episode in our lives ...

Although having to deal with my own feelings and emotions of everything, I did still carry the opinions of others, including having another baby without a dad around and of the effects that HLHS would have on the other two boys.

Diagnosis

At a term of 26 weeks pregnant I then began to carry the worries of the risks, long term-life questions and trauma that HLHS brings.

My dad drove Ross' dad – lets call him A – and myself to the appointment at King's College where HLHS was confirmed. As you all know and I am sure will agree, this news was a real shock and rapidly put all the previous problems in life into perspective.

The initial reaction from A was "what is the point of putting a baby through all that pain?" It was this very negative reaction that instantly made my decision. I had already made the decision once to keep my baby and although having just experienced the worst shock I had ever had, I did not agree with A. After being

told that you are going to have a baby that may die after birth, it is a big decision to take on and is far from simple, but, for me I know that I would have lived the rest of my life having to deal with that experience and then the thoughts of never knowing.

A chance is better than no chance and never knowing if he would have survived, was my feeling and so I continued with the next 14ish weeks trying to prepare for every eventuality.

The birth

My decision was to have the baby alone. I did not want to carry anyone else's feelings. The birth was scheduled at Guy's (the induction had been booked) when Ross decided to come on his own by starting labour at around 6am. I visited East Surrey Hospital to be assessed and from there was transferred to Guy's in an ambulance – I am not a very good passenger at the best of times, but when you can't see where you are going, at the same time as trying to pretend that you are not really in pain or petrified of the events that lay ahead made this the worst journey of my life.

Ross was born naturally on 20th June 2002 at around 9pm after only having gas and air as pain relief, as I never thought that he would come so quickly going on the previous births! It wasn't too good at the time but I reaped the benefits after as I felt no side effects from different drugs/pain relief!

Special care

I already knew that soon after birth that Ross would be taken straight to the special care unit to be monitored. Seeing him for the first time was really emotional.

I had not prepared myself for the reality of not just being able to pick him up and give him a big cuddle, something that many out there take for granted. It was the tubes and wires that made it impossible. I did hold him but, had to be so careful not to hurt him anymore. He had needles in both hands (cannula) and his arm was taped and bandaged up to a board to keep his hand straight and keep the needles in. There were also lots of monitors, reading heartbeat etc, it all became very confusing.

I was given a bed in the maternity ward with all the other mums with their new



babies! Very inappropriate, but my need to be with Ross took over and I spent much of my time by his bedside in the ward where he was.

Surgery

Ross had his first surgery on the Monday at four days old. Till this point I still had not bought anything for him, and so during those terrible hours of waiting I wandered around the hospital and station like I was on another planet. I then brought him his first cuddly.

On the Wednesday I knew he was good to have his ventilator removed and I then was able to go shopping for his first set of clothes and blanket feeling a lot more positive and knowing that I would actually be taking him home with me.

I shielded everyone else at home from the knowledge of him even having surgery as it was easier for me to cope with things this way. They really had no idea and so the next time I rang, it was with good news.

Further surgery

Ross had his second operation at nine months and again returned home within

10 days. I realise how lucky we are. We now await his third stage operation.

Eating and being sick

The only real problem Ross experienced was to do with feeding! He is still very underweight and has food supplement milk drinks (fortini) and I have to fortify his foods, which was difficult to come to terms with at first. For example I have to put butter on his foods, fry it instead etc.

At first I breastfed Ross but due to the poor weight gain had the pressure to introduce a bottle. He never took to this, then the carton milk drinks were introduced – the straw was the answer! I found myself often holding him as the slightest cry and he would bring back any milk that he had consumed.

It was also an absolute nightmare to get him to eat food Ross has always been strong-willed knowing what he wants! It appeared that on the few occasions that he did eat that he would again start to cry and then bring it back up again. When I kept a diary I realised that although things seemed bad I was able to put things in proportion. (So if you are at this stage I recommend keeping a diary.) The pressure of knowing that he had to eat no matter what, otherwise he may not have enough energy, was very overpowering and I found myself constantly putting him back in the highchair to try something else. In the end my better judgement told me to take a step back and I started to leave him until the next mealtime.

Even now, he still has a tendency to be sick after the slightest amount of food or if he cries from the slightest little bump but, he is a lovely happy little boy, hence being called 'Little Ross'.

Emotional rollercoaster

Although this has and will continue to be one of the biggest emotional rollercoasters I have ever been through I do not ever regret having Ross and giving

him the chance of life. But, I will not lie about feeling guilty sometimes or that I live in fear of losing him, finding it hard to accept when people say to me "enjoy the time you have got".

When I was expecting him things were not as real as they are now that he is here. Ross has grown and is now a person, not just a baby that has no idea of what is happening. He is a little boy who will be fully aware of what is happening next time I take him to the hospital for his MRI scan and then his surgery. I will find this even harder to do than before and I am sure that he will hate me for ages after!

"Understanding Differences"

As I said at the beginning, this whole experience has opened my eyes to many things and as a result I have set up my own self-help group that has been called Understanding Differences. We have an internet site to communicate worldwide but also meet regularly with other families from a diverse background of problems, because HLHS is so rare the chance of meeting others with this condition locally is greatly reduced.

We are working hard to fundraise to offer some to the charities so that we continue to support them. The money that we keep is for supplying books to schools that cover the whole subject around going to hospital, emotions and those that raise awareness of conditions like *Rosie Goes Red*, *Violet Goes Blue* – a lovely book. Initially, my personal goal is to write our own series of early reader books that teach others about differences so that they gain a different insight into the subject of Knowledge and Understanding of the World, one of the National Curriculum topics that schools plan the children's learning around.

Not just heart

Additionally they will offer support to any families who may have a recent diagnosis they need to explain to their child. We



need to hear from anyone interested in supporting this idea to make it work. Not just from a background of CHD, things like diabetes are very difficult for children to come to terms with as with many other conditions and experiences.

On February 14 – CHD Awareness Day – we hope to raise much awareness and money to support these aims. CHF have donated some *Rosie Goes Red* books, Heartline have donated the *Growly Bill* stories and so we hope to be able to promote these charities as well as LHM and ECHO.

So watch this space ...

Terms used

HLHS: Hypoplastic Left Heart Syndrome – the structures on the left side of the heart are blocked, too small to function properly, or missing.

LHM: Little Heart Matters: support group for families whose child has one functioning ventricle (univentricular heart)

ECHO: Evelina Children's Heart Organisation: support group for families whose child is treated at Guy's Hospital.



Starting school

Samantha Foster writes:

I just wanted to let you know that my little baby (well, she isn't a baby anymore!) is starting school in twelve weeks! We went to view the school today and it is lovely, Jasmine really enjoyed herself. She is able to start from the day of her third birthday, which is the 13th June.

Because it is a special needs school, the classes only have seven children in and five staff, and there are physio and occupational therapists onsite, a full size swimming pool and hydro pool, sensory room etc.

I am so excited for her, as I think it will really help her develop. I thought that because she was in the nursery part, they will wear their own clothes, but they have a

little uniform! How cute will she look in it! This is the longest time Jasmine has been out of hospital, and she hasn't been able to mix with other children before, so she was really excited to see them all today.

Sorry for going on, but I wanted to tell someone!

Go on all you like, Samantha! Sounds like Jasmine is in for a very good time.

Ellis Aiden Ishan Ford, brother to Josh.

Dear HeartLine, *writes Anita Ford*, the last time I wrote I was awaiting the birth of our second child. We are very pleased to announce that Ellis Aiden Ishan Ford was born on 14 December 2004, a very healthy 7lb 5oz. Josh is very pleased to have a little brother, is a great help and loves being the big brother.

It's almost like having a child for the first time, like being a first time mum. Everything that most first time parents

take for granted didn't happen for us with Josh. We spent so much time in hospital with Josh (from 6 weeks old) that sometimes we feel we missed so much, even simple things like a baby gaining weight or taking a feed without being sick were things we didn't have with Josh. We have this with Ellis. Ellis is now 7 weeks old and weighs 10lb 8 ozs. Josh was 6 months old before he weighed this much!

Although we know Ellis is healthy and has no cardiac problems it doesn't stop me laying awake and listening to his breathing or worrying about taking him

out in the cold. I hope I get over this but it's hard not to compare Ellis to Josh and the 7 year age gap also contributes to this.

We are very lucky that Ellis is healthy because I don't know if I could have coped if he wasn't. We are just going to enjoy him and watch him make his milestones, and when he is older tell him all about Josh's epic stay in hospital and all about our friends at HeartLine who helped us through it. We are always grateful to HeartLine and are always willing to do what we can to help.

Named after Wayne

Tracey Kerridge sent an article from her local paper with a pic of her with son Rooney and his dad, Andrew. It told the story of how her son, named after footballer Wayne, was taken by air ambulance to Great Ormond Street at ten days old with serious heart defects.

"Now that Rooney is seven months old," writes Tracey, "he has been back to Great Ormond Street where they put a balloon inside a narrowed artery to try and help the narrowing which has come back.. We are now waiting for another op to try to sort out wonder boy Rooney Lee Kerridge. We would like to thank you all at HeartLine for helping us get through that hard time, and GOS for trying to mend Rooney's heart. I hope one day Rooney could fill Wayne's football boots and play football for England, as he is already a fighting star!"

More Message Boards

New boards have been added to the HeartLine website Message Boards. . There is now a board specifically for our bereaved families, and a board for correspondence with the HeartLine Office, which join the Conditions and General Chat boards : see www.heartline.org.uk/messageboard.

DIARY DATES

CHF Conference

The Children's Heart Federation Annual Conference will be held in Southampton over the weekend of 1-2 October this year.

HeartLine Summer Party

We hope to hold the AGM and Summer Party in May – details later.

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.

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.

Bracelets, neck chains and straps come in a variety of designs suitable for children these days, and you may want to contact Medic Alert for a copy of their range: call Medic Alert during office hours, Monday to Friday, 9am-5pm: freephone: 0800 581420 or email: info@medicalert.org.uk

Facts about heart defects

Are you a new reader of HeartLine? Even if you are a long-term member it may surprise you to know that:

- * Heart defects are the most common birth defect, and are the main cause of birth-defect related deaths.
- * 1 in every 145 babies is born with a heart disorder: most of us think of a heart condition as being something that the elderly suffer from, but 5000 children a year are born with a heart disorder – the most common kind of congenital defect.
- * Over 300 children a year are given pacemakers: even babies a few days old can be fitted with tiny life-saving pacemakers.
- * When the heart can't be corrected it can often be improved – an extra 1600 children a year are growing up with heart defects.