



HeartLine

Issue 68

Autumn 2005



Abbie – taking her place in life

As HeartLine parents, something special, something more is asked of us. And many of you find the strength not only to deal with your own sadnesses, but to support others going through their own dark days. This multiplies the downside, but we can also enjoy the rewards of children coming out of hospital, cured, first days at school, jobs, and the many smaller miracles of eating, talking, sitting, walking So don't miss the stories of our children growing up on page 7 – the ordinary achievements of extraordinary people.

Hazel Greig-Midlane

I need your pictures and stories for Issue 69 Winter 2005/6 by the end of December. If you just want to write a few words about a particular problem, such as whether to go back to work, dealing with nursery, education, holidays, that is fine. Longer articles are also needed - don't worry if you are not comfortable writing it, we can always sort it out. Give me a call – evenings are best – on , and we can talk it through.

Send stories and pictures for the magazine:

by email
hgmhla@btinternet.com

by post

The HeartLine Office number is 01276 707636

Front cover:

Our cover star is Abbie Louise Stubbs. You can read more about Abbie on page 5.



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MY DAUGHTER SCARLETT - To The Day of Her Birth

David Ashford sent the story of his daughter Scarlett's life. 'I could not abbreviate my time with her any more than this,' he wrote, and because of its length, the remaining sections will appear in the next two editions of the magazine.

Close look

The 6th January 2003 had been a day my wife Katie and I had been eagerly awaiting.

We had an appointment at Kingston Hospital for the twenty two week scan of our second child. We already had a wonderful, happy, healthy eighteen month old boy called Felix and after a problem free twelve week scan we felt we could relax and enjoy the prospect of our first close look at the tiny features of this soon-to-be-family member.

All the way to the chocolate machine

Everything seemed well and we had that now familiar thrill of seeing her little heart beating and perfect limbs wriggling. The only slight inconvenience was that our baby was in a position that did not allow the echocardiologist an opportunity to get a reasonable view of the chambers of the heart. Katie was told that she should go and eat some chocolate and get baby moving around with the sugar rush. We were beaming all the way to the chocolate machine and could not stop looking at the printout of our perfect baby that I clutched proudly in my hand.

Should be two

The Aero seemed to do the trick and the baby had changed position but the echocardiologist had still not ticked off the last two boxes, and was continuing to search for something. We could all see the four chambers of the heart in that clover shape, surely this was all she needed to see? But her concern was not with the chambers but with the single fine line that came from the heart. There should be two of them, one the aorta the other the pulmonary artery. She could just about make out an aorta but there was no sign of the pulmonary artery.

Eat more chocolate?

We were ushered next door to let a more experienced operator have a look. After about five minutes poking and probing she confessed she could not locate it either. At this stage, although there was an escalating concern, we had no idea of the seriousness of the situation. Maybe she should go and eat more chocolate, maybe the machines are getting a little old or maybe we just need a more experienced pair of eyes.

The first of many, many tears

We were taken to a side room by a kindly midwife and told that it may be best if we go to see a fetal heart specialist. We imagined an unbearable delay of a week or so awaiting an appointment, but were told that we would be accommodated immediately. By her manner we could tell this was potentially very serious indeed and at this point Katie cried the first of what was to be the first of many, many tears.

As luck would have it, one of the country's top fetal cardiologists, Jalena Cavello, was at St George's Hospital in nearby Tooting that afternoon, so we could discover the extent of the problem, if any. As we speculated for, at least an hour, in the waiting room we still tried to be positive and assumed that she would merely confirm that the pulmonary artery was present and could be picked up by her advanced scanning equipment. Little did we know our true nightmare was just about to begin.

Amazing how ignorant

Dr Cavello silently set about her examination and we hung on every facial expression, which gave little away. After a short time Katie had to break the unbearable tension and ask if there were causes for concern. Dr. Cavello responded with a simple nod and said "Yes, but we can fix it."

What did this mean? Was this good news? It meant she was going to make it but what did "fix it" mean? I assumed at that moment she meant a brief operation within the womb and she would be OK. It is amazing how ignorant I was of the human heart and, as all parents of 'heart children' will know, it is a very rapid learning curve when your own child's heart comes into question.

She told us, understandably, that she preferred to continue her examination in silence until she had acquired all the facts she could, and then she would give us her full diagnosis. We stared intently at the amazing images of our baby's heart on the screen as if the swirls of red and blue that came and went meant anything to us, and after an eternity Dr Cavello turned to us with a sketch book to explain what she had found. It was worse than she had first thought. Our baby did not have a central pulmonary artery and had a large hole (VSD) between the chambers of the heart.



Waves of fear and sadness

I listened with horror, struggling to digest such essential information, as the fear and sadness came crashing in on me in waves. I listened as she told us about the operation our tiny baby would need soon after birth. I listened as we were told of the corrective surgery that would be required only a couple of years later and the follow up surgery that would continue throughout our child's complex life. I could just about hear her telling us of the complications and risks attached to each level of surgery. The risks of infections, bleeding...something about brain damage.

Then just as I thought that it would surely never come to this, she rounded off by saying "this is at best." At best! What could be the worse case scenario? But we knew the answer to that.

Then Dr Cavello asked us if we wanted to know the baby's sex. We had always felt very strongly about not wanting to know the sex of our baby until birth, but with these new circumstances we both felt we wanted to know everything we could about this little fetus that was going to need all our love and support, and to feel as attached as we possibly could to it.

A daughter

We were told we were going to have a girl. Amongst all the terrible news we had to take in on that never-to-be-forgotten day there was this one simple, magical fact. I was going to have a little daughter.

We went home from our routine scan still numb with shock. After the awful calls to family and closest friends, running over our newly acquired cardiac knowledge time and time again, we went to bed and talked and talked about this uncertain future, both unable to sleep. I even remember sitting at the computer that night on the internet looking up any information I could find on Ulrika

Jonsson's lovely daughter Bo, purely because this was the only baby with a heart problem I had ever heard of, and I wanted to know how she was, what her condition was and how well she was coping.

A positive sign of miracles

Then at about 3am something extraordinary occurred. I looked out of the window and from nowhere the entire street had been covered in a spectacular blanket of snow. London had had its biggest snowfall for seventeen years and we took it as a positive sign. Maybe miracles do happen and we were being reminded that something of such beauty can occur when you least expect it.

We had an immediate concern about something Dr Cavello had mentioned. There was a chance that our baby's condition was a chromosome defect, so another trip to St Georges was arranged where Katie had to give an amnio test and had further scans to see if the situation had improved (it hadn't). We had a long week waiting for the midwife to call and we feared the worst. Thankfully the test proved negative. This felt like the first good news we had had in a long time and we took it as a turning point in our fortunes.

Strong name

We had joined HeartLine and learned all we could about 'heart babies' and were feeling we could prepare ourselves to be the kind of parents that a child with our daughter's condition would need. We even gave her a name. Scarlett Elizabeth. We felt she needed a strong name and all the logos, websites, leaflets we were surrounded by were scattered with red hearts, so Scarlett seemed appropriate.

By thirty-two weeks we had another scan at St Georges. We had, again, tried to be positive and hoped and prayed that this scan would show some previously undetected lifeline, but sadly the scan only confirmed that things were 'no better, no worse' than previously thought.

Four weeks early and a bank holiday

On a hot bank holiday weekend in April we were given a reminder of how things cannot be planned to be as straightforward as one might hope. Katie started to get contractions that increased in both frequency and intensity, and we were convinced that these were more

than simple Braxton Hicks. We raced to Kingston Hospital and after a short period on the monitor it was confirmed by the midwife that the signs were that this did seem to be the start of labour.

Just practicing

The excitement that comes with that news was tempered by the fact that a) we were four weeks early and for a baby with Scarlett's condition every moment spent in the womb making her stronger would be beneficial and b) It was a bank holiday so would be more difficult than usual to track down the specialist staff at the various hospitals. On top of this the PICU at Kingston was full so there was a chance Scarlett could be moved as far as Brighton to find an available bed!

As it turned out this was all only Scarlett getting in a bit of practice but Kingston weren't taking any chances and Katie was kept in for three days which actually turned out to be an effective way to enforce her to take some much needed rest before the inevitable exertions to come.

Real thing

Two weeks later in the early hours of Saturday 3 May, Katie woke me to tell me she thought her waters had broken. She was getting regular contractions again and at first I assumed that this was once again the Braxton Hicks but after a few well directed screams my way it became clear that not only had labour started but Scarlett seemed to be in a hurry to get out. After a slow painful descent of the stairs, and an out-of-hours request for an emergency baby sitter for our son, we were racing as fast as my ever speed-limit-conscious wife would allow, along the A3 towards Kingston.

By the time we arrived in reception in maternity the decibels were rising and the nurses that ran to greet us had a greater than usual urgency about them. When the midwife examined Katie she found her to be 8cm dilated. I was hit by that wave of excitement that this time it was for real. I was about to meet my little girl!

A problem

The sense of excitement spread through the eight or so people in the room. All thoughts of a planned caesarian were now irrelevant and the midwife recommended that Katie should maybe try to have this baby naturally, seeing as she had gone this

far and was doing so well without any pain relief. Then I noticed the mood inside the room change dramatically. The warm, smiling faces of the nurses were now looking concerned and their jovial banter replaced by sharp hushed tones. "Was there a problem?" "Is Katie OK?" is our baby OK? No answer...more whispers...then finally the midwife tells me that there is a problem. My heart drops. It seems the baby's heart rates has dropped alarmingly "below 80."

Minutes

As they rush poor Katie, who is in such pain she is almost oblivious to what is going on, off towards theatre, I am told that this baby needs to be delivered right away. An anaesthetist appeared, bleary-eyed, running alongside the trolley and I overhear him ask the midwife how long he has got. She stabbed back "MINUTES!" The bed and its running entourage disappear into the theatre and I am told to wait outside.

Almost two years earlier I had stood on the same spot whilst my wife had an emergency caesarian for an undetected breech. Now the same suffocating feeling took hold of me. It made me almost unable to stand upright, think straight, breath. Katie and Scarlett needed the help of everyone available so I stood alone outside in a living nightmare listening to the terrified screams of my wife and the undecipherable dialogue of the medical staff.

PUSHHHHHHHH

I heard something about "natural birth," and "no time for a caesarian," then a kindly nurse appeared at the door, threw a set of theatre gowns at me and said "put these on quickly, they are going to do it naturally". I threw them on and rushed into the crowded theatre. I could just about see Katie's head through the maze of bodies. Above the general commotion came the voice of Fran the senior midwife, who was trying to get Katie to focus on breathing and pushing at the appropriate times. It was clear Scarlett needed to be out ASAP. "Come on Katie, we need her out next push," she demanded. "Come on, push Katie!!" we all screamed. Nothing. "Next push, one more push, it must be this push," said Fran. I found myself screaming Katie on like a Derby winner, squeezing her hand almost as hard as she was squeezing mine. "PUSH KATIE!!"

MY DAUGHTER SCARLETT cont.

Then a strange squelching sound, then a splash, then out of the corner of my eye Fran almost juggling a fast moving bloody mass. Scarlett was here. "Was she OK?" She looked OK, only silent.

My daughter crying

Huge relief was on the faces of the medical team, Fran smiled broadly, they smiled, Katie was smiling but how was Scarlett. She had sprung the team of three paediatric nurses, who had been waiting so patiently, into life and after a few whiffs of oxygen I heard that most beautiful sound that I feared I would never hear, my daughter crying.

Elated

I looked over to Katie, who was elated and crying. She had done it and she had done it all with barely any pain relief. Scarlett was brought over to us and I gave her the first of many kisses. She was held down to see her brave mummy and then taken away to the paediatric ward for tests.

You could sense the huge relief of the nurses and the anaesthetist confirmed to me that it was a very close call. After the

months of concern for Scarlett's weak heart, it turns out that these first problems were caused by something so simple. The chord had got entangled around her neck. The team were rightly pleased with a job well done but despite the relief of everyone I could not lose sight of the fact that Scarlett's real battle was just beginning.

Perfect baby girl

Katie and I spent a wonderful hour alone and she had a well earned bath. I could not stop looking at the door awaiting news of Scarlett. Then finally we were allowed to go and see her. She was lying in her little bed with a few small monitors stuck to her and a large clear Perspex box over her head with a supply of oxygen. It wasn't the maze of wires and tubes we had feared, and best of all she was gorgeous!

We spent a blissful half hour holding her tiny fingers and toes, stroking her lovely thick hair and smelling her flawless new skin. She didn't look at all blue and seemed very content. For those precious moments it was as if there was no heart

problem, just a perfect baby girl.

Part 2 of Scarlett's story will appear in the next edition of HeartLine.

Terms used

Aorta: main artery which carries blood from the heart to the body.

Pulmonary artery: the blood vessel that takes blood from the heart to the lungs

VSD: Ventricular Septal Defect, a hole between the two ventricles – the pumping chambers of the heart.

Chromosome defect: sometimes there is an extra copy of one of our chromosomes, or the chromosome is missing, or is located in the wrong order.

Amnio: a test of the amniotic fluid surrounding the baby in the womb

PICU: paediatric intensive care unit



ABBIE: LIGHT OF MY LIFE

Abbie Louise Stubbs lives in Scarborough with parents Ann Marie and Dave.

"She is a little miracle in all respects. I was told I would find it difficult if not impossible to conceive. We nearly lost her before her op, but just hours after the op they had to keep sedating her as she was wriggling around when she heard me and her daddy speak.

"To look at her you wouldn't know what she has been through. She is my mum and dad's first grandchild and is spoilt rotten – and as I am an only child she

may be the only chance they'll get.

"Her sister Chelsey (my partner's other child) is six and she absolutely adores her, and my in-laws-to-be are constantly on the phone asking about her.

"She is daddy's little princess through and through as soon as Dave walks in the door she laughs and wriggles until he picks her up. And me, well, I just feel blessed to have her.

"Abbie is the light of my life and her smile lights up any room she is in."



A Christmas present for HeartLine?

Your HeartLine needs more than £6000 a month to keep services going, and it is a struggle for Neville, our fundraiser, to get us noticed alongside all the other worthy causes.

HeartLine raffle tickets should be with you in November, and with Christmas on the horizon perhaps your workplace would like to send money saved on cards, or collected at parties?

The money we raise is spent on supporting families who in their turn offer support:

- ♥ We provide packs of information to

hospitals so that parents can be given support from the earliest possible moment (and a teddy for the heart child)

- ♥ We publish a comprehensive book Heart children in several languages
- ♥ Children who need Medic Alerts to keep them safe are provided with them free of charge
- ♥ We provide caravan-breaks for hard-pressed families
- ♥ Our volunteer parents keep in touch with families in more than 50 areas throughout Britain

- ♥ We send out our magazine regularly to more than 1000 families four times a year
- ♥ We provide sailing experiences for families including their heart child
- ♥ Parents offer literally hundreds of pieces of advice and support to each other every day on all aspects of caring for their heart child through our website message boards.
- ♥ The Office employs one full-time and three part-time staff, and our executive committee and area contacts are all volunteers.

Raising awareness

Next year, Children's Heart Week will be held from Sunday 12 February to Saturday 18 February – together with other groups in the Children's Heart Federation we are organising an event in the Houses of Parliament, and national publicity. What we hope to do is raise awareness in our local communities – schools, churches, scouts, guides, libraries, health clinics and with the local press. We are especially anxious that posters advertising our translated Heart Children books are sent out in your community.

There are three things that we need to do – reach out to those parents who do not have the support of HeartLine, because they don't know we exist, raise funds, and have fun!

We can provide material (for talks, quizzes, balloons) to take into schools, local press contacts, and try to help in other ways. Your area contact may be organising some activities, so check with her – numbers are on the back cover.

Awareness Day 05

This year many attempts to raise awareness and funds were thwarted because Tsunami relief work was desperately needed. Some successful activities were reported in the Spring issue of HeartLine.

Linda Hardy, Norfolk area contact, says:

"I had three of the HeartLine balloons filled with helium free of charge by my local card shop. Once they had read the Heartline leaflets they said that every card they sold in the week leading up to Valentine's Day, they would enclose a leaflet for us! They later told me they sold about 450 cards.

Your heart? It pumps your wee out of you!

My son's teachers allowed the children a wear red day; and I was invited in to give a short talk to the children on the day before.

I started by asking if they knew where their heart was, and what their heart looked like, and showed them a picture. Then I asked a few 'what does the heart do?'

Responses were everything from 'make you get in love', to 'it pumps your wee out of you'! Some answers amazed the teachers let alone myself!

By the end of the talk I think the children understood that your heart has to beat all day every day, and all night every night. If your heart isn't good at beating, your body gets into trouble!"

Wetherby News

The local paper of Annette Jackson, North Yorkshire area contact, ran an article headed Mum's work to repay charity's kindness, with lovely pictures of Tracey Wilson, Annette, and of course, two year

old daughter Katie with HeartLine balloons, and information for families about HeartLine's work.

Cake Stall

Roz Whittaker's three children raised £29 on a cake stall at school, and sent it to HeartLine.

Biddy had Fallot's Tetralogy 'and your charity was a great help to all the family' Roz writes. Biddy is now five and a half and is keen on sports, particularly riding and swimming!

Wear red

Edward's school, Longmoor, raised £119 for HeartLine – big thank you to his mother, Diane Jones, Area Contact for Nottinghamshire, and to the staff for arranging all the activities – they even obtained a heart monitor from their local hospital!

Next year even better ...

Mollie Hatcher's mother, Kate, has an offer of a 'Wear Red' day for Heartline next year at her older daughter's school – meanwhile Kate got a nicely written piece, with a mention of HeartLine, into her local paper, raised about £40 and distributed leaflets to her local community paediatric team.



Please make sure that families know about us, and help us to support each other

www.heartline.org.uk

admin@heartline.co.uk

01276 707636



Josh starts Junior School

Dear all, writes Anita, HeartLine Director of Operations and mother of Josh

Well here it is, the first day of a new term. Nothing new in that, no not really except for this – Joshua starts the juniors today – I don't know if I really believe this.

I remember writing and sending photos of his first day in reception. We were never sure if that day would come, and even when it did Josh started infants with his trachy still in. It was a battle to get him into the mainstream school we wanted, but we won and as I have said before – the school couldn't do enough to help.

But our safe infant school environment has evolved into a more mature junior one. Josh will cope – but will I? I can't imagine having a child in the juniors – it's such a different world. But then Josh is such a different child, to that small four year old in his 'you'll grow into it' school uniform, posing on the front lawn three years ago.

I suppose I should just say a little about him for those who don't know. Josh was born five weeks early on 25 December 1997. He had an ASD, VSD, large pulmonary arteries, double outlet right ventricle, absent pulmonary valve syndrome – corrective surgery led to the discovery of a gastric problem requiring a gastrostomy, also trachemalacia resulting in a tracheostomy (say a little about Josh? It just can't be done!)

Anyhow, Josh 's condition is not ongoing and he no longer has any serious problems. He is looking forward to starting a new school. Me, on the other hand, well I'm, so nervous you'd think it was my first day.

So there it is. I'm sure I'm not the first and I won't be the last.

But for any mum and dad whose heart child is having a 'first day' I say good luck, try not to cry (I bet I do) and the kids cope better than we expect.

*Best wishes to all from Anita Ford,
Director of Operations*

Will in the sixth form

Good to celebrate!

Debbie Lunniss is area contact for Somerset, and proud mother of Will. Thanks for this uplifting account of Will's triumphs, Debbie!

I am writing this for all those families whose lives are dominated by illness and hospital appointments and cannot imagine ever feeling relaxed about their 'heart child'. I also cannot resist an opportunity to boast a little, because of all my three children the achievements of my 'heart child' give me such overwhelming feelings of gratitude and pride and relief, and it is good to celebrate that with families who may feel encouraged by our experience.

Will had coarctation of the aorta (operated on at three weeks old on Christmas Eve) and a pulmonary band was put on at the same time. At two years old he had major surgery to correct his VSD and the band was taken off and his pulmonary artery was repaired.

Turning the corner

He had severe post operative infections and was ventilated for more than a month. He spent another five weeks fighting a yeast infection on his heart. There was talk of him needing a new patch (a further operation) because all the efforts to rid him of the infection were in vain. I believe it was a homeopathic remedy which helped him turn the corner, and I would encourage parents to seek such solutions in tandem with the conventional medical help which their child obviously needs.

I continued to have him treated homeopathically all through his childhood and found that I could often pre-empt that dreaded respiratory infection with a remedy. He was also diagnosed with bronchiectasis at about four years, attributed to infections and damage done to the lungs whilst ventilated. After a few years of seeing his homeopath, the doctors decided they must have misdiagnosed because the x-rays were clear and this does not happen with bronchiectasis! We battled through many illnesses with a GP who was sympathetic to alternative treatments and a homeopath who understood that I was not in a position to be purist and needed to keep my options open.

Bright and brilliant

Will missed a lot of school because he needed physiotherapy four times a day to keep his lungs clear. He had definite

dyslexic tendencies but because he was so bright the school never really addressed them. He was slow to talk but was brilliant at puzzles and making things.

Over the years his health improved, the chest infections tailed off, the visits to the surgery and the homeopath decreased, and check-ups at the hospital started to become annual! Every year we celebrated the date of his big surgery 30th April 1990, and Christmas Eve is always special to me when I remember how tiny he was when he had his first operation.

At seven we bought him a cello, thinking that he could learn to play that and have an interest which wasn't dependent on being in robust health. The GP didn't think he would have enough puff to play a wind instrument and Will didn't fancy the violin.

Multitalented

He is now 17! I wrote to HeartLine last year when he got his GCSE results. This year he has finished A/S levels and got three As and one B. He completed his Gold Duke of Edinburgh expedition (by Canadian canoe) with the Sea Scouts over the summer half term (when did he revise??), he has been on tour to Paris with the County Youth Orchestra (yes that cello was worth buying and my little son plays it too).

Proud of him? Definitely!

He spent the rest of the summer in Ecuador with his father who works there as an archaeologist. In fact Will was very nearly born there because I worked there too and only decided to come back to England for the birth at the very last moment. Of course I am so grateful that I did because we were five hours on a rickety bus from any medical help and it would have been disastrous for Will if I hadn't been here with access to the wonderful health services we have in the UK. (Yes I do mean it, people do not appreciate their good fortune enough!) He has a lovely girlfriend and plans to go to university after A levels next year. To say that I am proud of him is such an understatement.

If any one is interested in pursuing homeopathic treatment with their heart child, they are welcome to ring me (I am the area contact for Somerset) but I would suggest they discuss it with a GP, preferably one who is open to the idea. There is also plenty of information available on the Internet.

Good luck to all of you, and remember you may one day look back on the hard times from an easier perspective.

Terms used:

Coarctation of the aorta: narrowing of the aorta, the main artery carrying blood from the heart to the body

Pulmonary artery: the blood vessel carrying blood from the heart to the lungs

Pulmonary band: a band placed around the pulmonary artery to reduce the amount of blood it carries to the lungs

VSD: Ventricular Septal Defect, a hole between the ventricles, the pumping chambers of the heart

Bronchiectasis: an abnormal destruction and dilation (widening) of the large airways.

Dyslexic: having extreme difficulty in reading/and or writing and spelling despite at least average intelligence.

Helen gets married

It is always lovely to see children with heart disorders growing up, working, marrying – things we may not have expected for them. Mrs Susan Perkins of Gillingham sent a photograph of her daughter Helen with her husband Neil and wrote:



Helen and Neil were married on the 9 July this year, at Maidstone Registry Office, and had their reception at the Russell Hotel Maidstone.

Helen was born on the 13th September 1979 with a trachea oesophagus fistula and has had two shunts for her heart, and had open heart surgery when she was nine and eleven. She had one valve at the top of her heart doing the work of two valves, and no dividing wall in the middle of her heart.

Helen now works as a nursery nurse in Aylesford and hopes one day to run her own nursery, and Neil works in Strood. They live in Gillingham and their Wedding Day was a happy enjoyable day for all of us.

The meeting

Nicky Roper from Canvey Island in Essex writes:

My husband Tony and I have been avid supporters of HeartLine since our eldest child, Megan, was born with transposition of the great arteries on 25 August 1996. Like many others I would imagine, we found the stories of others a great comfort, especially in the early days. It meant that we were not the only ones that were going through it all.

Most stories we have read in HeartLine over the last nine years have tended to focus on the stories and experiences of younger children – I have (like most people, I suppose) been meaning to write down Megan's story and send it in ever since she was a gurgling, squidgy thing in nappies nearly a decade ago. But also, like most people, everyday life, after school clubs and two very active children, seem to have overtaken the urge to put pen to paper for years.

That is until now. Still, better late than never!

The phone rings

Sometime last year I received a phone call asking if our number could be passed on to another family who had a daughter with the same heart condition as Megan. "Of course," I said. "We haven't really spoken to many people with children with TGA. We would be delighted to hear from them. Please pass our number on."

Within the hour the phone rang. "Hello, my name is Bridget. My daughter Sophie has a heart condition, I heard you were expecting my call."

We chatted for a while, exchanging the usual email addresses and phone numbers, deciding that it might be a good idea if the two girls started to correspond as pen pals. From the beginning they got on famously as did I with Bridget, Sophie's mum. But it wasn't until after one year and many emails and photo-swappings that the two families met up for a trip to Whipsnade Animal Park

First things first

Firstly, let me introduce two girls with something very special in common.

My daughter Megan Roper (9) loves Avril Lavigne, Charlotte Church (in 'rock chick' mode), singing, drama, dancing and all things lilac (pink for us is SO last year).

Sophie Tanno (11) her penpal, also loves drama, Franz Ferdinand, sports and all things cool.

As I said before both girls have TGA, and

both had arterial switch operations at 10 days old, Megan at the Brompton, and Sophie in Australia where her family lived at the time. Both were totally excited at the prospect of finally meeting face to face (well, as excited as it is cool to be at their age!).

Sun 21 Aug 2005 – The Big Day Arrives

After giving Sophie and her brother Sam HeartLine wristbands as a present on arrival, the girls talked about anything and everything – it was like they had known each other for years.



They chatted as they watched the bird display, giggled as they tried to get soaked by the sea lions, and generally had a ball. The fact that the sun also shone all day (the first time for a few days!) was also the icing on the cake.

Our son Ewan (6) also found himself a friend in the shape of Sophie's older brother Sam (13). Having firmly grasped Sam's hand with his sticky little six-year-old fingers from the outset, neither of them left each other's side for the entire day and got on like a house on fire, playing on the bouncy slide, looking at the animals (including a rather sweet two week old baby rhino – a particular favourite of all of us) and eating ice-cream.

We finally left the zoo after hours of fun, happy but exhausted, although the day was far from over. Bridget and Stephen invited us back to their house. Once there, the children spent another couple of hours feeding the guinea pigs (Megan ever the adventurous type, even attempted to try one of the guinea pig's dandelion leaves herself, much to our amusement, and her embarrassment afterwards – she thought she had been handed an exotic new salad leaf to try herself), bouncing on a huge trampoline in the garden and eating pizza (though not at the same time I hasten to add) whilst Tony and I got to know Bridget and Stephen.

Although it was our first meeting 'in the flesh' so to speak, the conversation and the tea flowed freely in the warm August evening air. We all got on extremely well. It was good for the girls to meet and a good time was had by all. Hopefully it will be the first of many meetings. Our thanks to Bridget and co for such a fantastic day. Until next time ...

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

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

****Fundraising Officer: Neville Terry **Project Coordinator: Helen Baker **Administrator: Jo Kenny****

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 who live near you.
- ♥ Free on request are a wide selection of leaflets and fact sheets on dental care, feeding, respite care, so on.
- ♥ You can borrow a wide variety of books, – on pregnancy loss, consent and choosing for children, bereavement. And books for children – *Operation Fix-it* and *Rosie Goes Red, Violet Goes Blue*.
- ♥ Videos on Children and Heart Disease, Catheterisation, Surgery and Intensive Care, Warfarin, Ablation, Pacemakers, ASD closure by device, Bereavement.
- ♥ 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 quarterly magazine and lively message boards go to 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

For Sale

Pin badges	£1
Car stickers	£1
Wrist band	£1 child £2 adult
HeartLine teddy	£10
<i>Heart Children</i> book	£5 + £1 p&p

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 descriptionQuantity.....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.

THE RAG BAG

Forums

The HeartLine website forums have lots of super features: they offer an opportunity for members to meet each other online, discuss anything they choose and share pictures – go to www.heartline.org.uk/messageboard and click on Forums.

You can choose 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.

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

HeartLine Summer Party

The HeartLine Summer party was held on Saturday 16 July – within hours of getting home members were sending messages to the Forums:

... we would just like to say a big thank you to all concerned and involved in the Heartline party on Saturday. We had a fantastic day and it was well worth the journey from Bristol. ...

... have been back a couple of hours, and I'm exhausted but I had a really good day.

... a huge thank you to everyone involved in the organisation of today's party. It was absolutely fantastic to meet so many people, to put faces to the many names!! All the kids seemed to be having a wonderful time, I know one little girl who

arrived home, filthy dirty, exhausted but very happy!! She has now crashed out with a bottle!! (tempted to follow her example!!) ...

... thanks to the Goldman Sachs staff for everything they did, and to Pam and Jo for giving up a precious day off to come and help out, Emily for helping with the face painting, and Carol and her mum for scoubi-dooing all day ...

... I had such fun, it was so lovely to meet old friends and new!!

... have also arrived home exhausted but a very happy bunch of kids – they had a great day ...

... was great to meet some old, but also some new friends. I remember the first time I attended a Heartline party I knew nobody and was really nervous about going...and it feels good to know more and more people now Nia had a blast of a time as well, especially since she won a prize for her face painting (actually the face painter should have got a prize, but I guess Nia didn't care – at least she got a prize!).

Especially enjoyed the sack racing with Alison (and was very proud I did not land flat on my face) ;-)

... just got back – what a fab day! Already looking forward to the next one!

A huge THANK YOU to Anya, Pam, and the rest of the Heartline staff for a great day at a super location! My boys have already asked when we are going back there! (I think the 'experiment' area was a big hit with them!)

Thanks again everyone for a great day, roll on next year!

The activities were ideal, bearing in mind the wide age range of the children, and their lunches were super. A great location! I think the adult sack race should be compulsory for future parties!

Wonderful
Exciting
Totally
Lovely
And
Natureful
Day
Super



Fantastic day, fantastic venue, fantastic activities, fantastic company. Fantastic PARTY....

I asked Brenna today what her favourite bit had been and she said everything ... that just about sums it up...

Brighton Breeze

Rosie and Jim, parents of Sam, took part in The Brighton Breeze, a convoy of 750 VW's from Epsom to Brighton on 1 October this year.



Where did the summer go? JD in the sand'

Dear Heartline

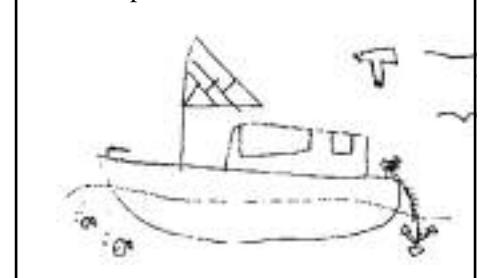
Thank you for letting us go on the boat ride on Saturday.

It was very good apart from one thing: I was nearly sick! We sailed round the needles and saw the castle a few times. When we came back we got nearly to the shore when we thought we might go swimming but we decided not to because the water was too cold.

Then it was only a few minutes before we got back to the shore.

From Matthew Squires

PS We would love to go next year if that would be possible



Lisa Williams lives on the Isle of Wight with husband Seth and children Cory, Jareth and Maisie. In the summer edition of HeartLine, Lisa described how Maisie was finally diagnosed with Tetralogy of Fallot, and the struggle to increase her weight. She kept a diary over the period of Maisie's surgery reproduced here.

Tuesday 25/09/01

Today is the day we been dreading and waiting for! We left our home on the Isle of Wight to travel to Southampton General. Maisie will have her surgery tomorrow to repair Tetralogy of Fallot. We know she has pulmonary stenosis and a muscle interfering with the blood flow to the lungs and a large VSD.

Her surgeon and Dr Joseph suspect that the pulmonary valve is two cusped rather than the three as it should be. They also feel that the obstructing muscle might actually be inside the pulmonary artery-if so they would repair it with a patch or homograft. They also think that the main coronary artery may lie across the front of the heart. This is a worry as surgery is needed underneath.

For these reasons a catheter is being done before the open heart surgery.

It was dreadful saying goodbye to Cory and Jareth, Jareth especially as he does not really understand.

When we got there, Maisie had an catheter and chest x-ray. Maisie also had to have bloods taken- this was so awful, her little veins are so tiny and it was distressing for us all, Maisie cried and cried and I felt helpless that I could not make it all go away!

They filled five tiny tubes, the blood will be tested for chromosome abnormalities and FISH to see if Maisie has any deletions on her chromosomes.

Maisie is very upset and would not be consoled. I had to persuade myself it was not a good idea to grab her and run!

Wednesday 26/09/01

Maisie had a good sleep – we didn't. They came at 8.30 for her to have her catheter, and I carried her down.

I thought I was calm and I was not even aware of crying, but my face got wetter and wetter as we got nearer. The nurse that came with us was pregnant and crying too, Seth had a set face and I know he was holding it together for me.

I took Maisie into the little room and the sleepy air sent her to sleep without upset.

We were told to wait in the hospital till Maisie's catheter was over, as Dr Joseph wanted to talk to us about his findings before he proceeded with Maisie's heart surgery. He told us it would take between 1-3 hours. It was three hours till he came back to talk but the news was good!

He told us the obstructing muscle could be removed without the use of patch or homograft. The main coronary artery was not lying across the heart, and the pulmonary valve was only two cusped but one cusp was large enough to be cut in two, so making a three cusped valve.

I was pleased things were not as complicated as previously thought!

Maisie went on to have her open heart surgery at 12 midday. We were told surgery would take between six to seven hours and to phone the ward at 5pm.

We had our mobile phones, so we left the hospital too worried to talk even. We walked and walked – concentrating on just putting one foot in front of the other. When my mobile rang at 3.05pm, I nearly lost the connection in my effort to answer it!

The ward said all had gone well! We hurried back to speak to Mr Munro.

Mr Munro said he was pleased with the surgery, Maisie was bleeding a great deal from the chest drain but this was common and would resolve soon. Then Dr Joseph came to talk to us. He said the pulmonary valve had been made into three cusps – still a little narrow but Maisie should cope with it like this. The VSD was patched. Maisie's pulmonary artery was kinked, which can cause breathing and feeding problems (and swallowing) but he was

not unduly concerned.

I was desperate to see Maisie and we had to wait for such a long time before we could go into PICU. We knew what to expect after seeing pictures of other heart children and speaking to other parents but it was still a shock! Maisie's ECG reading looked tidier somehow and her cheeks were pink. It was only at this point I realised just how poorly she had looked before.

Maisie was on the ventilator for three hours only- the intensive team nicknamed her 'amazing Maisie'!

Thursday 27/09/01

Today we are a bit concerned with Maisie's temperature – her legs were too cold and her upper body too warm, but this did resolve fairly quickly.

She was doing well. I was able to do all her feeds via a tube – it was not pleasant but I was pleased to be able to do something for Maisie and be involved. Also her mouth care. Her mouth was dry and nasty as her fluids were reduced because of the surgery, and so as to not make her newly repaired heart work too hard.

Maisie kept sucking the sponge dry where she was so thirsty (she normally hated water) and she was hungry as well – she'd only been allowed a tiny amount of infatrini every two hours.

At 4pm the powers that be decided that Maisie could come up to the 'high care' part of the ward. This was both wonderful and scary, as I was not convinced she was ready!

Maisie had started to drink infatrini via a bottle again which was good. She was a little puffy but again I was told it was normal. I was shown how to lift Maisie 'scooping hand under head and bottom' so no pressure on the healing chest wound. I was so frightened of hurting her when I had a cuddle and fed her.

Maisie was given a sedative and pain relief



MAISIE – Part 2 cont.

whilst arterial line and chest drain were removed – scary stuff again, but she was calm throughout.

I lost my voice even though I had no cold which was strange. I can only think it was because of stress.

Friday 28/09/01

Today Maisie seemed to take two steps backwards. She had to have some feed via tube, she seemed hot and puffy and her breathing seemed a little laboured.

Maisie was also seeming to passing less urine than the amount of liquid she was consuming. Dr Joseph was not too concerned, he put it down to morphine.

I realise this was true and Maisie, although very grumpy, smiled that evening!

I was in constant contact with home and both Jareth and Cory were ok. Jareth enjoying his 'everyday' present, an idea from HeartLine's Lisa C.

Saturday 29/09/01

There seems less and less time to write now as Maisie is very grumpy but is making progress. We said a complete goodbye to the tube today. She is not taking any more infatrini than before surgery but she is a lovely colour.

Today the cannula was removed YAY ... Maisie is happy as she can suck her thumb again!

Sunday 30/09/01

Maisie was getting cross as she could not lie on her tummy. Pacing wires were removed today which was distressing but necessary. Again it was another step forwards.

We came home on the Monday and I was so happy. I was so full of the future now we had a pink little girl – but more was to come.



Terms used

Tetralogy of Fallot: a ventricular septal defect (a hole between the two ventricles), pulmonary stenosis (a narrowing between the heart and the lungs), overriding aorta (the aorta sits over the hole so some blue blood mixes with the red and goes back to the body instead of the lungs) and poorly functioning right ventricle (the right ventricle is the part of the heart that pumps blood to the lungs).

pulmonary stenosis: a narrowing between the right ventricle and the lungs.

VSD: Ventricular Septal Defect, a hole between the two ventricles, the pumping chambers of the heart.

pulmonary valve: the valve between the heart and the lungs.

two cusped: two leaflets on the valve which open and close to control blood flow.

pulmonary artery: the blood vessel that carries blood from the heart to the lungs.

homograft: human tissue transplant

coronary artery: a blood vessel taking red blood to the heart itself.

(diagnostic) Catheter: a long tube threaded through blood vessels into the heart to diagnose problems.

FISH: a gene test – fluorescence in-situ hybridisation.

Pacing wires: in case surgery causes irregularity of the heart beat, wires are left in so an external pacemaker can be used to make the heart beat regularly.

Infatrini: a high calorie feed.

HeartLine Caravan Holiday Homes

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. Call the Office from 9 January on 01276 707636 for 2006 bookings. The picture is of the Oakdene caravan.



TODDLE IN WORTHING

Helen Woods writes

Last summer three Heartline members (Vashti, Penny and Helen) organised a sponsored walk and teddy bears picnic on Worthing sea front to raise money for Heart Transplant Families Together (HTFT) and HeartLine.

Stunning roller coaster

Like everyone else we have all found the journey you get thrust into when you have a heart baby to be a stunning roller-coaster, but we all feel we've been very lucky, partly because we got to know each other. We all live a short distance apart, and all three of our heart children (Lily, Lucy and Theo) have had surgery at the Royal Brompton.

I don't think you can ever say a big enough thank you for the care our children receive, but Vashti asked Penny and I to help organise a sponsored walk and teddy bears picnic, which felt like a good start. We had stacks of enthusiasm and absolutely no idea what we were doing!

How many firemen?

Between us we persuaded local companies



and our employers to donate raffle prizes and pay for an entertainer. Vashti especially uncovered hidden talents of persuasion, finding us a fantastic



beachfront venue and talking the local fire station into sending along a fire engine. The promise of lots of firemen soon got our friends offering to bring their children!

We roped in family and friends to lend us a bouncy castle, donate books to sell, bake a small mountain of cakes and run all the stalls on the day. Two of my older son's pre-school mums, one of whom had never even met Lily, Lucy or Theo, gave up their time and skill to paint faces and finger nails, and made the most amazing fairy castle cake. Although admittedly Penny and I might have ended up with more cakes to sell if our older boys hadn't got wise to being allowed to eat those they decorated badly enough.

Weather refuge

We had a last minute panic when the weather forecast promised to drench us all, but it gave me the chance to find out how many gazebos you can fit in an MX-5 (at least two, even with the roof up, which is more than can be said for children). In the event we did need them, but only as refuge from sunburn.

The stars of the show were all the children who walked and picnicked

on the day. Lucy and Theo got pushed on the walk by their big brothers (pictured bottom right), Lily (above right) needed no help from anyone, and dozens of their friends all got sponsorship and



joined us on the day. Scooby Doo (another of Vashti's hidden talents) led them all along the seafront, carrying HeartLine and HTFT balloons. The admiring looks they got from all the passersby brought a huge lump to everyone's throat.

So more families don't have to cope alone ..

Like everything else about being a heart parent, the day taught us a lot – in this case mainly that fund-raising is very hard work. But the day was fantastic; we had loads of fun and the kids loved every minute of it. We raised £2,004 – more money than we had dared hope – we know that means some more families don't have to cope on their own.

