



HeartLine

Issue 67

Summer 2005



**Special Heart, Special Kid
David shows off our wristbands**

While in Cambodia in June we had been shown terrible sights of the suffering of people of all ages – young babies were not spared torture by the old regime, and today poverty kills one in five children.

On return I was shocked to hear of the loss of so many children from our HeartLine family. In spite of all the advantages we have over the families of Indochina, still children are lost to congenital heart disease.

And now the tragedies in London have well and truly reinforced the lesson – to take comfort from what we had, and to appreciate and celebrate what we have.

Hazel Greig-Midlane

I need your pictures and stories for Issue 68 Autumn 2005.

This will be the last magazine before Christmas, so sort out last year's festive pictures and stories, and anything else you would like to share with other HeartLine members by the middle of September:

by email:
hgmhla@btinternet.com

by post:

by telephone:

But for HeartLine Office ring 01276 707636.

Front cover:

David Keen, son of Essex area contact Alison Keen. Details of the HeartLine wristbands he is wearing on page 4.



CONTENTS

My granddaughter Holly	3
Your Wristband	4
How I coped with Maisie	5
Notes – Forums, Christening and Medic Alert	6
Fundraising	7
Aiden's Story	8
Membership Form.....	9
Office Services	10
Bethany English	11
Warfarin and Chloe	12
Jamie's Hospital Diary.....	13

MY GRANDDAUGHTER HOLLY

This is a grandmother's story by Holly Mai Clark's Grandma. Holly is Area Contact Tracey Dolby's daughter.

The day Tracey told us she was pregnant we were all so excited. I knew this was Tracey's dream, to have a baby of her own to love.

Then came the dreadful news that the baby had something wrong with it. At first the doctors thought it was Down's Syndrome, but after tests we were told it wasn't Down's, but they thought there might be something wrong with the baby's heart.

Why them?

Melvin., Tracey's Dad, and I took Tracey and Noel to Great Ormond Street Hospital where she was seen by cardiologist Dr Rob Yates. This is where we found out how bad the baby's heart was. Tracey and Noel were so very brave and we were so proud of them, this should have been a happy time but instead there was real fear for the baby and we kept thinking why should this happen to them? What had they done to deserve this?

Afraid to be happy

Tracey found out the sex of her baby, so Holly now became a being, not just a baby.

All the way through the pregnancy Tracey was so afraid to be really happy, but we had great fun buying all the baby things. I have never seen so many baby clothes and equipment for an unborn baby before, but still Tracey tried not to get too excited.

Tracey was frightened that Holly wouldn't survive the pregnancy and then, as time for the birth got nearer, she said she didn't want Holly to be born because, while she was still inside her, she knew she was safe.

Perfect little baby

Holly was born on July 9th 2003. Noel rang me to tell me Holly had arrived and he had held her and everything! He said she was beautiful and when we saw her for the first time we knew exactly what he meant – she was perfect in every way. Surely there couldn't be anything wrong with this perfect little baby.

Holly was soon home from the maternity hospital and she was doing so well that, when we were told she was to have her first operation, we were all gutted. I don't know how Tracey and Noel got the strength to carry on with everyday things

the way they did. They made everyday special for their little star.

Hardest thing

When the day arrived for us all once again to travel down to GOSH we were all very quiet on the way there. Everyone was very kind but that didn't stop us being frightened and we didn't want to relay this to Holly. The hardest thing that we as grandparents have to do is leaving them all there, not knowing if Holly was going to make it through the operation or not. When Noel phoned to say they had just taken Holly down for the operation I could hear Tracey crying and felt so helpless, I wished I was there with them just to give a bit of support.

Fits

Noel phoned me to say Holly was out of surgery but everything had not gone as planned. Tracey said that Holly was now having fits and there was something wrong with her left leg as the nurse couldn't get a pulse. We were then told that Holly had had a stroke, as Tracy said "We took in a healthy, happy little girl and now look at her". Holly was put on medication for the fits and kept in for a week, by which time the fits seemed to be under control and she was allowed home. When she got home she was showered by so much love and input from her family she came on leaps and bounds. There is no sign now that she ever had fits, just shows what a fighter she is.

Next operation

I always with Tracey when Holly has her check-ups at the cardiac clinic at Addenbrooks Hospital with Doctor Wilf Kelsall. Every time they seemed so pleased with her that I began to think that maybe she wouldn't need anymore surgery because she was doing so well. But then came the terrible day when we were told she was ready for her next operation. This was arranged for 3 November 2003, with surgeon Professor De Leval, who is a lovely man and who explained everything he was going to do.

So helpless

This time I stayed in a hotel down the road from the hospital. On the morning of the operation Holly sat on her Mum's bed with a smile for everyone. It was so heartbreaking to see her so happy knowing what she was to go through before we were to see that smile again.



When Tracey and Noel took her down for the operation I just sat and cried, once again I felt so helpless. When they came back we went and had a stiff drink, we then had the long wait for the operation to be over. When we were paged to say she was out of surgery we were already waiting outside CICU so that Tracey and Noel her as soon as possible. Tracey and Noel went in to see her and then Noel came out and told me I could go in and see her.

Best and worst of places

CICU is one of the worst and best places I have ever been in, there seemed to be so many beds and you know that every one has a child in it. The nurses were amazing and I cannot praise them enough. Holly looked so small in the bed with tubes and wires coming from what looked like all over her little body. All I wanted to do was touch her. I didn't know if I was allowed, but then Tracey said it was OK.

Another op?

We were told that her operation had gone well but there was concern that her sats were not picking up – they were anywhere from 47 to 55 and they wanted them to get above 70. There was talk of her going back in for another operation but not go in through the chest but under the arm. Tracey didn't want this as it would mean another scar for Holly to cope with when she was older and she didn't want Holly to go through another operation – it was too much. Thankfully

MY GRANDDAUGHTER HOLLY cont.

her sats picked up and she didn't need that operation at that time.

I can't explain the feelings you have while you are going in to CICU – you are in a sort of limbo. One of us tried to be with Holly at all times in case she woke up and there was no-one she knew with her which must be scary for a child. Tracey was there with her nearly all day and all night, WHAT A MUM!

Bouncing back

Holly was in hospital for a fortnight, and I came home when she came out of CICU, but went down on the train every few days. Soon she was bouncing back to her old self, it amazes me what children can go through and still come bouncing back with smiles on their faces. Nothing seemed to hold Holly back once she was back home.

Christmas was magical with Holly having so many presents that I think they may have to move into a bigger house! Just when we were thinking that everything was going so well it was decided that because she was so well that it was a good time for her to have her next operation. This was to be 29th March 2004.

Once again we all went to GOSH and I stayed. Holly was first on the list so she went down early, I don't know why but I thought it would get easier after the first time but if anything it gets harder because I knew what she would be going through and how she would look when she came back from theatre. It was about 2.30pm when we were told that Tracey and Noel could go and see her. Those six hours seemed like 60 hours. Time just stands still with so many images going through your mind.

Chylothorax

We just wanted her well and home again. Holly came off the ventilator that evening at about 7pm which was very good for Holly and it looked as though things were going her way for a change. Then they decided to remove the drains (she had two) but the nurse spotted something in the drain and the doctor was called who told us that Holly had chylothorax so she had to have the drains left in.

On Friday 2nd April Holly was put on a low fat diet to help reduce the chyle and one drain was removed. She also had an ngt tube as she would not drink the monogen milk. This was very hard for a little girl who enjoyed her food very much. Sometimes the food they dished up to her was bright green and looked disgusting so I would make food up for her at home and take it in for her. It's amazing that some vegetables have some fat in them! Holly was giving the octreotide into her leg throughout each day to help reduce the chyle.

Holly was in hospital for nearly four weeks, then Tracey was shown how to give the octreotide and she was allowed home. What a great day that was!

Clever and happy

Holly is now 20 months old and is doing brilliantly. She is ever so clever and ever so happy and I know this has a lot to do with her home life which is the best that any child could have.

Last Christmas was fantastic – Tracey and Noel decided that Holly would open her own presents in her own time even if it took days.... wrong: Holly had everything open in a few hours! There was no stopping her.



Go through it for her

Holly will have to have more surgery and I know the next time will be even harder than before because now Holly can talk and walk and has a very strong personality, but I know that she will bounce back just as she always have. If I could go through it all for her I would, but as Tracey says, "It's Holly's heart that makes her who she is." And we wouldn't have it any other way.

Terms used

Cardiologist: a heart doctor.

GOSH: Great Ormond Street Hospital.

CICU: Cardiac Intensive Care Unit.

Sats: Saturation levels – the amount of oxygen that should have been absorbed by the blood – usually around 100%.

Chylothorax: a leakage of chyle from a duct into the pleural (lung) space. Chyle is a milky-looking fluid which carries fat around the body.

Ngt: short for a naso-gastric tube – for feeding the child through the nose directly into the stomach.

Octreotide: a medicine which slows absorption of fat from the stomach.

YOUR WRISTBANDS

Your HeartLine charity wristbands are now on sale!

Exclusive to HeartLine Association and available in two sizes, our red and blue wristbands are embossed SPECIAL HEARTS – SPECIAL KIDS.

They cost £2.00 for adults and £1.00 for kids,

You must include a stamped addressed envelope with your order. If you are ordering five or less wristbands, you need either a first or second class stamp. If you order more than five you need a 46p stamp for first class, or a 35p stamp for second class delivery.

Send your order with a cheque or postal order made out to HeartLine Association to HeartLine, Community Link, Surrey Heath House, Camberley GU15 3HH.



HOW I COPE WITH MAISIE

Lisa Williams, from the Isle of Wight, describes how she dealt with her daughter Maisie's heart problems before surgery.

After a very unhappy first marriage, which had produced my wonderful eldest daughter Cory, I met and married Seth. We had a little boy, Jareth, and our family was complete.

Sickly, nasty

When Jareth was just 10 months old I found out I was pregnant again despite taking oral contraception. To say I was devastated would be an understatement! I did not think I could cope with another baby as Jareth was such a demanding baby still. It was a sickly nasty pregnancy and although my other children had come into this world naturally I decided I wanted to be sterilised immediately after the birth, so opted for a c-section.

Maisie arrived 27th April 2001 and any negative feelings I had felt during the pregnancy vanished. I was completely besotted with her. She was a little smaller than my other children had been (a little under 6 lb) but my consultant always performed c-sections at 37 weeks so it was put down to that. However her apgar was 9 so all was well – or so we thought.

Struggled

I struggled at home with Maisie. I tried to breast feed but she couldn't seem to latch on. When she slept I could not wake her, but when awake she cried and cried and cried! I had an overwhelming feeling that something was wrong with Maisie and I repeatedly said this to my midwife and GP, but both just pooh-poohed my fears.

Deep fear

Then my GP said that Maisie had a heart murmur but again told me not to worry as it was common in babies. I have a heart murmur myself but I was not reassured. Everyone kept telling me I was depressed with the baby blues, including Seth, but I wasn't, I just could not shake off this deep fear that something was very wrong.

Alarm bells

There was a lady who lived over the road from me whose eldest child had been born with a hole in the heart or so I thought at the time. I engaged her in conversation and asked her what signs had indicated her son was poorly. She said her son had mottled skin and a cough. This made alarm bells go off as Maisie was the same. This lady's son had coarctation of the aorta but was, and is, doing really well. (She was of such special support to

me later – I think she will read this so thank you Carol.)

CHD? Ridiculous!

I rushed down to my GP and told him Maisie had congenital heart disease. He actually laughed and told me I was being ridiculous. I have to say I remind him of this often as it pleases me to do so. Finally he said a team from Southampton General had a monthly clinic at our local hospital. I could take Maisie and she could have a special scan of her heart that would put my mind at rest.

When the time came Seth said he would take Maisie. I have to say he had no patience with me as he too thought I was being silly. After a little while he phoned and said Maisie had a hole in her heart but it was a little more complicated – its full name was Tetralogy of Fallot. He also met our wonderful cardiac consultant – Dr Joseph.

Reaction

Seth had given up smoking for about three months, but he bought some cigarettes there and then. I was in complete shock and thought Maisie would die. I remember sitting in the garden (so Jareth wouldn't see me) rocking backwards and forwards with indescribable pain.

I was told Maisie would have 'blue spells' and when this happened I was to put Maisie in a special position with her knees drawn up, and I was to tell Dr Joseph immediately as it was a sign the heart problem was progressing. My family started calling me monkey mum as I carried Maisie around all the time like the monkeys do with their young in the jungle. Maisie never had a blue spell but I never let her cry. I would pick her up the instant she started. This created bad habits which I struggle with to this day.

Fatten her up

We saw Dr Joseph every month. We knew Maisie would have her repair surgery to her heart on September 26th. We were told to get her as big as we could before surgery and I remember thinking it was more like a Christmas turkey, the way the consultants talked about it!

Maisie was put on two diuretics, which helped her heart to cope better. The consultants were all lovely and I am so



grateful to them but I was getting tired of the drip drip effect with regard to how information on Maisie's Fallots was given to us. At one appointment, Dr Joseph put his hand on Maisie's tummy and said "good – the livers gone down" and I cried "when was it up?". I had so much to take on board and listen too. Seth attitude was if we needed to know we would be told. Mine was different. I wanted the 'full monty' as it were. To me, knowledge about Maisie's Fallots and information from Dr Joseph were empowering me to be able to cope! I still believe this is true.

Feeding in so many ways

After a huge row with the local hospital (oh, and to think I was such a quiet little person before I had Maisie!) I was given an ongoing prescription for Infatrini (a special ready made super duper fattening formula). Looking back now I must have acted like a robot – I became obsessed with how much formula Maisie took. She was completely uninterested in drinking. We tried every teat known to baby.

I vaguely remembered an SMA disposable teat being around when Cory was born some 12 years previously and I remember them being particularly soft. I contacted the local hospital but SMA was now providing a different teat for hospitals to use.

I then contacted SMA direct – they told me they had some of these teats somewhere. The next day three big boxes came through the post! So I tried everything: making one big hole, lots of tiny holes, x shaped valve..... I put sparkly hair bands round the feeding bottle and flicked them whilst feeding, I

HOW I COPE WITH MAISIE cont.

tried pulling faces. I tried making funny noises, I tried singing, I tried holding Maisie in my arms and feeding whilst walking along, I tried feeding al fresco, I tried feeding indoors. I tried feeding just underneath the light, I tried feeding in the dark. I tried Maisie feeding lying flat, sitting up, cuddling in bed!

In fact I did everything in my power. It got to the stage that we sometimes drew a small audience of children at baby clinic!

I was literally feeding all day and most of the night. Maisie frequently vomited up the entire feed and we would have to start all over again. When Maisie got nearer to

surgery I was syringing and spooning formula in. Solids were no better, although Maisie would take a few teaspoons of very mashed banana/double cream and sugar ... oh the shame!

Support

I joined every support group I could and it did and does help me enormously. Maisie was taking small amount of Infatrini a day and 9 mls of frusemide/spironolactone! Then Lisa H (from Heartline) suggested I ask for more concentrated type of the diuretics, which I did. This meant Maisie had these drugs in tiny amounts. This was a turning point and, although feeding was still a massive

issue it was a little easier.

Lisa kept a diary over the time of Maisie's heart surgery: we will print this in the next issue of HeartLine.

Terms used:

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

Tetralogy of Fallot: a ventricular septal defect (a hole between the two ventricles) and pulmonary stenosis – a narrowing between the right ventricle and the artery carrying blood to the lungs.

NOTES

Message boards become Forums

The HeartLine website message boards have become the Forums. With 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.

Christening

Vanessa writes: It was such a special day ... you wouldn't believe how much I cried (came out of the blue!) when we went into the church ... it made me realise how far Eden has actually come in the past fifteen months. I'm so proud of her!!!
Vanessa.



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



FUNDRAISING

School and work: who can help us?

Your HeartLine needs about £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.

Work places sometimes fund charities – could you find out if your work place (or your grandparents', uncles', friends') would consider making HeartLine their special cause? If a company may be able to help, call Neville on 01276 707636, or email to admin@heartline.co.uk

Schools often decide in September what charities they will support for the year. If you think HeartLine is in with a chance, could you put our charity forward?

If you would like help, ask the Office, but just to get you started:

- ♥ 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 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 work hard for our charity.

And we can provide leaflets about HeartLine, posters, balloons, car stickers to help persuade your school.

Linda's feeling jumpy

Linda, Aaron's mum, writes:

Well I am up to doing a tandem parachute jump for Heartline, but I need your back up. It costs about £350 to jump which usually comes out of the sponsor money.

Can you help Linda to help HeartLine?
Call the office if you can sponsor her:
01276 707636.

Emma slims backwards

Emma, Skye's mum, was doing a sponsored slim for HeartLine – and then discovered that Skye is due a brother or sister in about seven months. Never mind Emma – later?



*Skye –
"What
sock?"*



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

AIDEN'S STORY

I live with my boyfriend Jamie and two children, Antonia who is six and Aiden who is two and a half. I would like to contribute Aiden's story to the Heartline magazine, writes Trina from Angelsey, North Wales.

Aiden was born on 30 April 2002 weighing 7lb 1oz, and he was full term. I had a normal delivery, and everything was great. We were allowed home eight hours after the birth.

Hoarse? Blue? Must be holding his breath

But at home, after the first couple of days, we noticed Aiden was not feeding as well as his sister had. It seemed as if he needed feeding every hour ... and was only drinking 1½ oz at the most. At two weeks old his voice was kind of hoarse and he was going blue when he cried. We took him to our GP who was really not concerned about it. He said that Aiden would probably grow out of it – that some babies do hold their breath ...

Or asthma?

Over the next few weeks we were at the doc every week as Aiden became very chesty and was not drinking much at all. On one visit our GP asked if there was history of asthma in the family. I told him that there was: Aiden's dad Jamie has asthma. Another time we took him to a different doctor as our surgery was closed and he was given nasal drops.

A few days later he was very irritable and, at six weeks old, he was drinking nothing – only 1/2oz here and there- so we took him back to the surgery and the doctor said he was ok as long as he had some amount of fluids. But we were worried because he was existing on nothing. I told him that our health visitor was concerned too, as Aiden was still slow to gain weight, and the doctor said if I was still worried to bring him back in a few days.

A&E

The next day me and Jamie took Aiden to A&E in Bangor. We explained that he was not feeding well, his weight gain was slow and he was very chesty. They sent us straight for an x-ray and then on to the children's ward. The x-ray showed Aiden had an aspiration of the lung. We saw a doctor who explained what this was, and said he would like to keep him in. When we returned after a short visit home they had put Aiden on oxygen as his sats were low.

Bad news

The next day the doctor examining him heard a heart murmur. He was then seen by another doctor who gave him an echo.

All he said was that Aiden had heart trouble and needed to go to Alder Hey as soon as possible. I remember thinking, oh my god what is happening....? We rushed home, packed a few things in a bag and made sure Antonia was cared for (she stayed with my mum), then had a call from Bangor hospital telling us to get back as soon as possible because they wanted to take him soon...

Aiden was transferred to Alder Hey ward K2 where he was seen by Dr Kitchener and another doctor who explained that they were going to do a detailed scan of his heart. I remember me and Jamie standing there, not knowing anything about the heart. After they had finished they took us to a side room where they sat us both down – we knew it was bad news.

Transfer

They explained that Aiden had coarctation of the aorta and stenosis of the aortic valve, he was in heart failure and on top of that he had pneumonia. They wanted him to have surgery straight away, but the surgeon in Alder Hey was away so they had to see if he could manage a few more days, having fought hard for six weeks. Aiden was given a feeding tube, but we were told on the third day that he was in urgent need of the op and they were transferring us to Birmingham Children's Hospital – he would be going that day.

He was put in an incubator and we were taken to Birmingham – it was all happening very fast. We were seen by a specialist, and he was taken for bloods. Oh my heart bleeds to see him go through it. If I could have swapped places with him and the guilt, I thought I must have done something wrong.....

We were taken to stay in Edward House – a lovely place, very homely and the staff were stars. The next day was hard – the surgeon and anaesthetist came to see us and Jane, the cardiac liaison nurse took us to see ICU..... we cried so hard that day because we knew that tomorrow it will be Aiden lying there.

The day of the op

The longest day in our lives – we had been with him since the minute we got up, looking at him hoping everything will go well, my dad and sister, Jamie's mum and dad and sister all came up to give us



support. At 2pm they came for him. I carried him to theatre where me and Jamie gave him a big kiss and then we were led away ... we had a call at 7pm telling us that Aiden was out of theatre and in ICU. We all went to see him. It was sad, my poor little boy, all the tubes and wires... The surgeon Mr Brawn came to see me and Jamie and explained that the op had gone well. They had repaired the coarctation, but did not do anything to the valve as it seemed ok.

Getting better

Aiden's chest was left with his chest open for a few days and when they closed it, air got trapped in his lung so they had to put in another drain. He was in ICU for just over a week. The staff were so good – I felt helpless at first because we could do nothing, but gradually I was allowed to wash his mouth and change his nappy. He came off the ventilator and next day we were allowed to go to the ward. There they found that he had a stunned diaphragm and his sats were still low, so he was put on oxygen.

Slowly I was allowed to try him with a feed (he was on Infatrini) and slowly he was getting better. We were in Birmingham a total of three weeks before they sent us back to Alder Hey, Liverpool.

I was so glad to be there, closer to home. Antonia could come and stay with us now and my little soldier was getting better, we were only in Alder Hay a few days. They were happy with him and wanted my health visitor to weigh him every other day. We were given diuretics for him and with that we were allowed home.

Continued on page 11

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.

AIDEN'S STORY cont.

Home

We were on edge when we got home. Aiden had no voice when he cried – they said it could have been because of the ventilator and that it would come back. You could never tell when he was crying so he couldn't be left on his own. We got an apnoea monitor to put in his cot from the health visitor. Things were going well – we decided to have Aiden Christened. We got on with the preparations but a few weeks later his breathing became faster –

we contacted Alder Hey and the cardiac liaison nursed explained that he was in heart failure and needed a catheter procedure to widen his valve as soon as possible. We were given a date of 15 September, the day after his Christening.

Catheter

He was taken to ward K2 where they explained what was happening; the op went well and he was home again within a few days. They explained that Aiden

would need a new aortic valve eventually but when we don't know ... Aiden has had catheters a few times, but he is doing well at the moment. He has a lot of chest infections and has been hospitalised many times. His asthma gets bad sometimes, especially in winter. He has started nursery and is doing ok there.

I would love to hear from anyone who has a child with the same condition as Aiden. My email address is beil27@aol.com

Terms used

Aspiration of the lung: a pneumonia usually caused by stomach contents getting into the lung.

Sats: short for saturation levels (of oxygen in the blood).

Heart murmur: a murmur is a sound made by blood moving round the heart: sometimes but not always this could be caused by a heart defect.

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

Aortic Valve Stenosis: a narrowing which restricts red blood from moving from the left ventricle into the aorta

Heart failure: the heart cannot keep up with the demands that the body makes on it.

Feeding tube: a naso-gastric tube – for feeding the child through the nose directly into the stomach.

ICU: Intensive Care Unit

Chest open: the child's chest isn't closed for a while after surgery to allow swelling to go down

Apnoea monitor: a device to check if a child is breathing.

Cardiac catheter: a tube which is put into the heart via a vein. It is used to help diagnosis, by measuring pressures very accurately, or can treat a problem such as widening an artery, or closing a hole.

BETHANY ENGLISH

Sue Grau emailed this short account of Bethany English's funeral in March this year.

I know that we have all wept gallons over Bethy and I'm sure that there will be still more tears, but I thought that you might appreciate the highlights of yesterday and the bits that Bethy would have liked best.

Tracy was a star and kitted out those of us who didn't have the requisite number of ribbons. Posh new pink attire had been purchased and was worn with aplomb. People looked pretty and Bethy would have liked that. India's bright pink boots were a joy to behold, overtaken in the garish stakes by the stripy tights worn by Ms Unknown to Us. Bethy would have loved all of that.

A gaggle of pink and purple balloons wiggled merrily on their way skywards, waving their tails at the host of gorgeous flowers lining the route to Bethy's resting place. She would have liked that.

Dan was every inch the smart, proud father, dignified and self possessed. Jo was resplendent in a bright pink poncho, a



beautiful mother and mother to be. Parents any child would adore. Bethy loves them.

Then the photos; all of Bethy's stardom framed by a slide show. Bethy the sweetheart, Bethy the ham, Bethy the mischievous minx. Bethy's image captured in cyberspace. How fitting. She deserved that.

And then the little memento of Bethy's calling card with her own signature on it! What a giggle she must have had!

She was the brightest star. I see you, baby, shaking that ass ...

WARFARIN AND CHLOE

Emma Cornish writes:

I can't believe it's over three years since I last wrote about Chloe for Heartline magazine! I have just sat and read through what I wrote back then and it brought back so many memories – and not many of them good ones! Thankfully, since then, Chloe has gone from strength to strength and is sitting beside me now, a healthy, happy five year old.

What it's really like

My reason for updating on Chloe now is to write about our experience of living with a child on warfarin. Since Chloe was started on it at 18 months of age, I have spoken to many parents either dealing with it too or facing the prospect of it and found that the majority of the time, the advice we are given by doctors about it, however medically correct it may be, does not truly reflect what life with a child on warfarin is really like.

I should very briefly explain Chloe's story again for those who don't know us: she was born on 31st October 1999 with a complete AVSD and had her first open heart surgery at Southampton General when she was six weeks old to repair the huge hole and to separate her single AV valve into a mitral and a tricuspid. This was only partly successful, so in June 2001 when she was just 18 months old and after we came so dangerously close to losing her, Chloe underwent three more surgeries within three days, resulting in her own mitral valve being replaced with a 25mm 'On-X'.

This was the start of Chloe's journey with warfarin (or rat poison as the newspapers like to call it!) and the beginning of her new life as a 'healthy' child.

Bumps, bleeds and bruises

Warfarin is basically a drug which slows the blood's ability to clot. Contrary to popular beliefs, it does not 'thin' the blood – a misconception I have fallen for in the past too! It does have some side effects and limitations on what the children can do but the worst of those that I have experienced are the bruises and bleeding. We have to watch Chloe carefully if she bangs her head or stomach nastily as warfarin can cause internal bleeding in some cases. This can also sound worse than it is when described by doctors. Chloe has had her share of bumped heads and tummies – being the fearing-nothing, dare-devil she is – but

after quick trips to casualty and a couple of overnight stays, she's (touching all kinds of wood!!) been fine.

She has also looked like one giant walking bruise in the past too, as warfarin does make the children more prone to bruising. Bleeding takes longer to stop with Chloe, due to her blood's slow ability to clot but with a bit of firm pressure, all cuts, scrapes and nose bleeds stop bleeding eventually.

Green vegetables

Another thing we have learnt to consider on warfarin is Chloe's intake of foods high in vitamin K. This is found in high quantities in green vegetables amongst other foods, but that's not to say she can't have them (much to her disgust!) – just that we watch how much of them she has and make sure the quantity of them she has is consistent otherwise her INR ends up all over the place.

INR and blood tests

Which brings me to talk about INR and how we deal with that too. Patients on warfarin need their blood regularly checked to ensure their INR (blood clotting level) is within the levels the doctors want. We aim to keep Chloe's INR between 3 and 4 whereas a 'normal' persons INR would be a level of 1 and children on warfarin for reasons other than a valve replacement would have an INR range somewhere in the middle of the two.

When Chloe first started on warfarin, we had to take her to the local hospital for regular blood tests. These started off at weekly tests and gradually lengthened out to fortnightly, then monthly as her INR became more stable. To say Chloe disliked these blood tests would be a massive understatement. We had screams, nightmares, tears (her and me!) and a one point a HUGE haematoma on her hand where a nurse did not apply pressure



firmly enough after the test! This continued for several months until, with a little help from some friends (namely Hazel Greig-Midlane and the charity ACE – Anti-Coagulation Europe) Chloe had a Coagu-chek machine donated to her. (Coagu-chek is a machine for home testing INR – not dissimilar from one used for diabetics.)

Getting trained

I initially had problems with getting trained and started with my machine. Chloe's cardiac unit at Southampton General, for some unknown reason, had decided not to train anyone on its use that didn't live in Southampton. Since we live in Portsmouth that ruled us out. Our GP didn't agree with its use and the local hospital refused to help me with dosage etc if I insisted on home testing Chloe's blood.

We weren't defeated there though. In the end, a lovely rep from Roche, the makers of Coagu-chek, came out to train me, and Southampton eventually agreed to help me out with dosage according to INR if I home tested.

Excellent, accurate, simple

Our Coagu-chek machine is excellent!!! I have been using it on Chloe for over three years now and it's proved its accuracy more than once when Chloe has had bloods taken at the local hospital to collaborate

results. No more hospital screaming matches, bruised hands, collapsed veins etc etc. Just a quick needle prick and I have the result in less than two minutes. Simple!

Don't get me wrong though, it's not all been simple, I have had some very 'down' times through Chloe's treatments and they didn't stop after the replacement either, but I have now learnt to live with her condition as she does, and have long since come to the conclusion that the side effects and restrictions of warfarin are absolutely nothing compared to the life Chloe would have had (had she had one!) without her valve replacement.

The difference a valve makes

I can never stress enough the difference that having that valve replaced made! At her worst, coming up to the replacement, Chloe was unable to walk far, she was grumpy and tired, had a cough through CHF and the drug Captopril, and was getting more and more swollen from fluid due to CHF.

To bring you right up to date now though,

Chloe started school in September and LOVES it, she's very bright, extremely chatty(!) and is becoming a very keen dancer and swimmer. She doesn't let her condition rule her life in the slightest and nor do we! She lives life to the fullest and as yet I've not found anything I've had to stop her doing because of her condition or medications. She goes to parties, plays in the playground with her friends, does PE in school, everything the others do. Obviously as she gets older, there will be some limitations – piercings, tattoos, alcohol and certain contact sports, but for now we are celebrating her mechanical valve's fourth birthday(!) and Chloe is just enjoying life as any other five year old... the future will look after itself.

I have also just become Heartline's area contact for South Hampshire in an effort to give something back to Heartline in return for all the support myself and my family have received from them. If you live in this area, or any other, please feel free to contact me, whether it's for advice or just a chat with someone who's been there as well. My email address is emmacornish@btinternet.com.

Terms used:

Complete AVSD: Atrio-ventricular septal defect – the wall in the centre of the heart which separates the left and right sides, and the mitral and tricuspid valves, is missing.

AV valve: atrioventricular valve – a valve between the atrium and ventricle.

Mitral and tricuspid: in a normal heart the mitral valve is the left av valve, and the tricuspid is the right av valve.

Vitamin K: the vitamin that increases the clotting power of blood (often given to new-borns to reduce risk of haemorrhage).

INR: International Normalised Ratio

Haematoma: swollen bruise

Coagu-cheb: trade name of a machine for measuring the INR which can be used at home.

CHF: congestive heart failure – the heart is failing the body's needs and the organs, such as the heart itself and liver, become swollen (congested) with fluid.

JAMIE'S HOSPITAL DIARY

Tuesday 9th November 2004

Jamie was taken to his GP by Dawn because he had a wheeze. This had previously been diagnosed as a chest infection but had been getting progressively worse over the period of about two months. On this occasion Jamie was seen by Dr Mellish who said that he was unable to properly diagnose the problem and referred Jamie to the paediatric department at Ninewells in Dundee. Jamie was examined by the paediatric doctors and we were told that they detected a heart murmur and suspected a hole in the heart.

Wednesday 10th November 2004

Jamie attended a cardiac clinic today and was examined by Dr McLeod, a visiting cardiac consultant from Yorkhill hospital in Glasgow. At this clinic Jamie had a heart scan and it was confirmed that he had two holes in his heart and a leaky duct (we later learned that these were a Ventricular Septal Defect, an Atrial Septal Defect and a Persistent Arterial Duct). We were told that Jamie would need open heart surgery as soon as possible.

Thursday 11th November 2004

Jamie was transferred to Yorkhill and on arrival underwent a series of tests including

an ECG, a heart scan, a chest x-ray and blood tests.

Friday 12th November 2004

Jamie was discharged from Yorkhill and was given a date of Thursday 25th November for his surgery, we would have to come down on Tuesday 23rd November for further tests and preparation.

We returned home but Jamie was very sick during the night and ingested his vomit, this made him very wheezy again and he was rushed back to Ninewells. Jamie had a gastric infection which caused him to dehydrate due to his vomiting and lack of appetite. It was a constant struggle to get enough fluids into him but he was eventually discharged on Tuesday 16th November.

Tuesday 23rd November 2004

Jamie was admitted to Yorkhill for tests and preparation prior to his operation. Initial tests found that he had a temperature and after the anaesthetist was consulted Jamie's operation was postponed. Blood tests showed that Jamie had an infection but were inconclusive as to whether it was viral or bacterial. Jamie was referred to a dietician

who prescribed Duocal, an additive to be mixed with his feeds to help him gain weight. Before we left Yorkhill we were given a new date for Jamie's operation, this was Tuesday 30th November with Jamie being admitted on Sunday 28th November for tests and preparation.

Friday 26th November 2004

Dawn received a phone call from the assistant of Mr McArthur, the surgeon, saying that Jamie's operation was being put off for a while longer because he wanted to make sure Jamie had fully recovered from his virus. The new date for his operation is Monday 6th December being admitted on Friday 3rd December for tests and preparation.

Friday 3rd December 2004

Jamie is admitted again and this time all the tests are clear and the only problem looming on the horizon is that there are no free beds in the Intensive Care Unit, this situation changes daily as children are transferred back to the wards so we are keeping our fingers crossed. We spoke to the anaesthetist and he answered a lot of our questions, his answers put our minds at rest quite a bit.

JAMIE'S HOSPITAL DIARY cont.

Sunday 5th December 2004

Mr McArthur, the surgeon came up to speak to us and said they did not expect any complications. He would sew a patch on the VSD and the ASD and PDA are just a clip and a stitch on the way!

Monday 6th December 2004 – The day of the operation



We took Jamie down to the anaesthetic room and even while we were there we were still waiting for confirmation of the operation, eventually we got the news that it would go ahead. Jamie was taken to theatre at 9.30am to repair a Ventricular Septal Defect, an Atrial Septal Defect and a Persistent Arterial Duct. The operation went well and he was taken to Intensive Care at around 2.30pm. Lots of wires and tubes!!!! He is well sedated and stable.

Tuesday 7th December 2004 – Day 1 Post Operation



Although he is well sedated Jamie is fighting the sedation and trying to waken up. Today he had his chest drains removed and his wound dressing taken off to expose it to the air, this helps it heal better by allowing it to dry out. We were hoping the ventilator would be removed today but because he is fighting the sedation this will probably be left until tomorrow. He is on Morphine for pain relief.

Wednesday 8th December 2004 – Day 2 Post Operation

Jamie's sedation has been reduced dramatically and he is awake and off the ventilator, he has also had his arterial line, peripheral line, neck line and catheter



removed. He has been moved from the Intensive Care Unit to the high dependency area of Ward 5A and has been bottle fed today. He is still on Morphine for pain relief.

Thursday 9th December 2004 – Day 3 Post Operation



Jamie is recovering well and has been weaned off the morphine and oxygen. He is now getting Dihydrocodeine, Diclofenac and Paracetamol for pain relief.

Friday 10th December 2004 – Day 4 Post Operation



Jamie is still progressing well and has had his nasal gastric tube, oxygen tube, cannula and pacing wires removed. Pain relief has been reduced again and he is now on Paracetamol four hourly. The doctors think Jamie may be developing a cold so he has been moved to a side room to isolate him from the other children. Jamie saw a dietician again and she prescribed Infatrini, a ready mixed high calorie, high fat milk.

Saturday 11th December 2004 – Day 5 Post Operation

Jamie has had a bath and was dressed today!



The doctors have decided that Jamie does not have a cold and have said that we can take him out on a pass and he can stay with us tonight in Ronald McDonald House. He is now only on Paracetamol as and when required.

Sunday 12th December 2004 – Day 6 Post Operation

Jamie has been checked over by the doctors and he has been discharged. He even managed to fit in a wee visit from Santa before he left!



Terms used:

Ventricular Septal Defect: a hole between the two ventricles – the pumping chambers of the heart. This causes red blood to be pumped from the left side of the heart back round the lungs.

Atrial Septal Defect: a hole in the wall between the atrial chambers. This causes red blood to be pumped from the left side of the heart back round the lungs.

Persistent Ductus Arteriosus: a passage used for circulation before the baby is born remains open rather than closing shortly after birth. This causes red blood to return from the aorta back to the lungs.

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