



HeartLine

Issue 62

Spring 2004

**HeartLine is
25 years old!**

**Growing
Up
With
HeartLine**



Elise – a joy to behold

From the Editor

Spring 2004

For 25 years now, families have benefited from the support of HeartLine Association. As one of the parents who has had 21 of those years, I know the difference that HeartLine can make. My son wasn't diagnosed until he was 18 months old, and we were sent home to grow him to a reasonable size for surgery. Pregnant with my third child, who sported a vsd before birth, a HeartLine poster caught my eye in the

antenatal waiting room. As Luke's care and treatment became more complicated, so the information available to me through HeartLine improved. I have made friends I expect to keep for life – a few have had the ultimate tragedy of losing their heart child, many have had the joy of seeing their children grow through all the usual and often trying stages of adolescence to adulthood, and some have tottered from crisis to

crisis, never quite sure what the future may hold. The effort we have to make to keep in touch is now so much less – and once again it is HeartLine that has played a leading part in making internet contact an easy option. The HeartLine website Message Board has created a new community for parents and opportunities to renew old friendships.
Hazel Greig-Midlane



HeartLine

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I need your pictures and stories for
Issue 63 Summer 2004 by end of July:

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HeartLine Office details appear on
page 10.

Front cover:

Elise Woodbridge-Colella

HAPPY BIRTHDAY HEARTLINE!

Margaret Horstead is HeartLine's Lincolnshire Area Contact. She writes:

Wow!!! I can't believe that HeartLine has been going for 25 years!

HeartLine has been an important part of my life for almost 18 years now. Although saddened by how many families congenital heart disease affects, I'm thrilled to see how HeartLine continues to grow and develop. HeartLine does a wonderful job supporting families up and down the country and is a valuable source of information to those who suddenly find themselves plunged into a strange new world of cardiac care and all that goes with it.

I can still vividly remember the feelings of isolation and helplessness my husband and I felt when our daughter was first diagnosed way back in the '80s

Stephanie was born on July 5th 1984. She weighed in at a healthy 8lbs, and like my son who was born four years earlier, she had arrived two weeks late and even then she had to be induced!

Fit

After a very long and painful labour, (remember .. this is back in the "olden days" when child birth was "natural" and the best you got was gas and air, if you were lucky!), Steph was eventually born very quickly. We were told that being delivered with such speed had caused her to be slightly "shocked" and accounted for the low body temperature and bluey tinge to her skin. But after six hours in SCBU under a heat lamp, she was brought back down the ward and pronounced fighting fit! We were delighted. Our family was complete!

Persevere

I had breast fed my son until he was nine months old without a problem. Steph however was a totally different story! She was obviously hungry and wanted to feed but seemed unable to latch on for any length of time and quickly became frustrated and very, very cross. After a very short feed she would fall asleep exhausted by all the effort, only to wake up an hour or so later starving hungry again! I found this all very confusing, but the staff insisted some babies took longer to get use to the idea of breast feeding

and encouraged me to persevere.

After three or four days, things were still no better and the staff suggested trying a nipple shield. This did help her a little to stay fixed on, but although very fretful, Steph would still be quickly satisfied, fall asleep, and be ready for another feed an hour or so later.

I wasn't at all happy about her feeding and asked the Sister on the ward for her advice. She said that she would arrange for the Doctor to have a look at her next time he was on the ward, just to put my mind at rest.

Neurotic mother

When the Doctor arrived, they took Stephanie into the treatment and I had to wait outside, the "norm" in those days! A few minutes later, he brought her back to me and told me that she was absolutely fine. He put her feeding down to the fact that she had a "dainty mouth" and told me I was being a neurotic mother and was behaving like a first time mum! He said we were to go home and get into a routine and that he would see us in Out Patients in two weeks time.

Suitably chastised, we went home and struggled on with the hourly feeds. Even though I had loads of milk, feeding Steph was really hard work, but we persevered and I kept telling myself that I had just been very lucky having such an easy baby first time round.

Discharged

The day for the Out Patients appointment arrived and we were sent for a chest XRay before seeing the Doctor. Steph still hadn't regained her birth weight and this was put down to the fact that she had a small mouth which was why she was having feeding difficulties. The Doctor confirmed that all was well and that there was no need for us to see him anymore. We were discharged!

Try not to get too attached

At my six week post natal appointment with my GP, I told him how exhausted I felt and explained about the problems I



Steph and friend Prue

was having feeding Steph. He listened to me closely and then said he would have a look at Stephanie first. He sounded her chest carefully and I could see the concern on his face. He told me he could hear a noise in her chest and that she had a very loud heart murmur. He telephoned the children's hospital about 80 miles away, and arranged for us to be admitted straight away. As I left his office he put his arm around me and told me "Try not to get too attached to her. Keep her at arms length!" How those words have stuck with me over the years!

This was my first taste of the world of CHD and I didn't like it at all. I was distraught and in a complete blur. I had no idea how I managed to drive home, but I did. I rang my husband, then organised my parents to stay with our son. It was all so unreal ... like a nightmare.

Fallot's

The next morning Stephanie had a catheter and we were told that she had Fallot's Tetralogy. We were told that she would have an operation to close the hole in her heart when she was about six months old. They suggested that I express milk and feed it to her from a bottle, as this wouldn't require so much effort for Stephanie sucking. We were sent home with a photocopied page on ToF and an appointment to return in two months' time.

Exhausting

Once at home, I contacted La Leche who gave me lots of advice and even lent me an electronic breast pump to express milk. Expressing and feeding was almost

a constant job, but by making the hole in the teat much bigger with a hot needle, I developed a knack of almost pouring the milk down Steph's throat! She would often then throw the whole lot back and we would have to start all over again. With an active four year old to cope with as well, it was exhausting but at least the weight finally started to creep up slowly.

Postponement

Despite repeated chest infections and several stays in our local hospital, at six months we were told she was doing so well, they would like to leave her until she was nine months old as she would be bigger then and the operation would be easier. At nine months they said wait till she's a year old. Then at a year old, she had just started walking and again they put the operation off until she was 18 months old. At 18 months they said two years. We just couldn't believe it. Each time we were gearing up for the dreaded operation. It was such a strain.

Second opinion

It was about this time that our GP retired and we met his replacement. I explained how concerned we were that the operation which we had been told would save her life, kept being put back. He suggested that we take a second opinion and arranged for us to be seen at Great Ormond Street Hospital.

No pulmonary artery

Once in GOSH, a full catheter was performed which showed that Stephanie had no Pulmonary Artery at all, and her Aorta was positioned over a large VSD. Her lungs were being supplied with a mixture of blood from all the extra collateral arteries which had formed from her Aorta. They explained that there was no operation to correct her condition and a heart and lung transplant would be her only option. The hole in her heart was actually keeping her alive. We were told that nature had her fairly well balanced,

as she was growing and developing at an almost normal rate and that they would like to wait and see how she went on.

Other health issues

As she grew up, Stephanie had other health issues, repeated chest infections, problems with her teeth, ears, eyes, migraines etc, and the childhood illnesses always made her very poorly, but thank goodness we came through them all. She attended main stream school with the help of a full time 1:1 and although restricted in what she could physically do, managed most things at her own pace.

Scoliosis

Stephanie hit puberty at 12 and shot up in height. It was about this time that she developed scoliosis and at 14 had surgery on her back to stabilise her spine with a metal rod. This was a very worrying time indeed. It was a major operation for a "normal" child, never mind one with complex heart issues. But thanks to the wonderful skill of the teams at GOSH, she came through and was back at school (part time) to sit her GCSEs three months later.

22q11.2

Steph had had chromosome tests before that had always proved negative, but when she was 18, she had a blood test which came back positive. It was confirmed that she had a chromosome abnormality called 22q11.2 or DiGeorge Syndrome. Both myself and my husband tested negative and it was explained that it was "just one of those things" which sometimes happens.

On reading up about the syndrome, I found that quite a few of the 180+ characteristics associated with it fitted Stephanie, but having said that, I'm really pleased I didn't read up about it when she was tiny, as it would have frightened me to death wondering what was in store for her! The degree to which this deletion affects the individual is very, very varied indeed.

Together

When Stephanie was about two years old, I read a story in our local press about another family who had a "heart child" and how alone they felt. They were asking if there was anyone locally who was in a similar position to get in touch. I telephoned them the same evening and we arranged to meet up the following week, along with about four other families.

Not alone

While being somewhat amazed and also saddened to find others with very sick children living in the same locality, I so well remember how wonderful it was to know that we were not alone. There were others facing similar issues and having to learn this whole new "language" and how helpful it was to exchange ideas and information. The world of CHD was so complicated and confusing, it was so good to speak to others who actually understood what we were talking about and so the Lincolnshire area of HeartLine was born!

Hope and encouragement

Stephanie will be 20 in July. She stands 5 feet 6 inches tall, weighs about 9 and a half stone, and has the most amazing long legs! I really hope that reading Stephanie's story will give some hope and encouragement to parents of newly diagnosed children. I'm not saying it's all been plain sailing, because it hasn't. We've had our fair share of ups and downs, but equally it's not been as desperate as we first thought.

Thank goodness things have moved on dramatically since Stephanie was a baby. Medics now realise how important it is for parents to be well informed and actively involved with their child's care. The expertise of the dedicated cardiac specialists who are rapidly developing new skills and techniques brings hope that, one day, all heart babies will live a good quality of life.



BLESSED NOT CURSED

Wise words from Zena, Nathan's mother:

When our precious second son was diagnosed with dilated cardiomyopathy in July 2003 our world fell apart. We kept asking ourselves the same 'old' question "why us??" I had followed the rule book ...Had a clean healthy pregnancy, didn't smoke, didn't drink, didn't fly. We fed him well and cared and nurtured him, what did we do wrong? I racked my brains looking for clues.

Then one day it dawned on me.....cursed? Not at all – we are Blessed. So very often you hear of tragic stories of children or teenagers suddenly losing their lives to DCM, may be playing football or doing normal every day activities, their parent totally unaware of their condition.

Changed us forever

We have been made aware of Nathan's condition before it could have been too late for us – although we didn't realise it at the time: the night we were told it's 50/50 whether he will make it, changed us forever.

We accept now that we will probably never know if Nathan was born with DCM or whether a nasty virus attacked his heart, and we also accept that each day

with him and his special brother Ewan is a true pleasure.

Life's direction is still uncertain for us at the moment but maybe life is more important than direction?

Different

We led a 'normal' life for 14 months prior to Nathan's diagnosis: nearly one year on from then and Nathan's second birthday is rapidly approaching, are we different?....YES

We love life and openly express it to each other.

We understand who are our true friends.

Those who really care are always there.

There is no price for life.

Needless to say my husband and I worry about Nathan and of course Ewan like any 'heart' parents do, but I know I certainly worry less about menial things, ironing, money, time and so on.

Look at the good things

So if you feel low, try to step back and feel blessed for a life that you have or have shared.



It's not easy to always be positive but I try to look at the good things in life as much as possible.

Term used:

Dilated cardiomyopathy (DCM): a condition in which the heart becomes enlarged and weak, sometimes because of a virus

ELLIS

Sharon Brooks has worked actively with HeartLine helping families since Ellis was small. She writes

As parents we often worry about the things that our heart child will be able to do as they grow older.

We worry about feeding, friends, and of course school as well as what the consultant will say at our next visit.

My daughter Ellis had corrective surgery for pulmonary atresia four years ago and had stents put in last year. Now, at the age of nine, she is doing as many things as other children of her age. She has just started netball at school. She has swimming lessons each Saturday and she also enjoys rhythmic gymnastics.

Ellis enjoys life to the full and we try to give her the same opportunities as her older sister. Ellis will be competing in her second rhythmic gymnastics competition in Northampton in November. Not bad for a little girl that could hardly ride her bike a couple of years ago!

I would like to say a big thank you to Verity Adams, Ellis' coach at South Essex Gymnastics Club, who also has a son who was born with TGA, for supporting Ellis with her gymnastics.

Terms used:

Pulmonary Atresia: the pulmonary artery, which should take blood to the lungs, is blocked or missing

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



JOSEPH HAWKINS ELLIS

Joe's mother Karen Hawkins writes:

As the day approached for my planned caesarean I was a total mess. After going through the trauma of having a full term stillbirth the previous year I was extremely nervous. Early on in my pregnancy I was diagnosed with diabetes and was advised to have my baby delivered by caesarean at 38 weeks.

Big boy

He was delivered at 37.5 weeks and after the words "he is a big boy and does not want to come out" I finally got to meet my baby boy weighing 8lb 6.5 oz. I only saw him for a few seconds as he was whisked off to SCBU for monitoring as I was a diabetic and they needed to check his sugar levels. I could not believe that he was alive and was totally overwhelmed, he was so beautiful. We named him Joseph.

Something wrong

I was taken to the ward and my partner Trevor went off to see our son. When he came back to see me I knew something was wrong but he did not say anything only that they had sent him away from SCBU and that there was a lot of fuss around Joseph. I then heard the doctor looking for me and he came and delivered news to me that absolutely devastated me. I was told what the doctor thought was wrong with Joseph and that they were going to transfer him to Leeds General Infirmary which was 80 miles away from where we live in Grimsby. The doctor said that Trevor should follow them. I could not go and had to wait until the next day.

Vital organ

I felt total despair, I thought this is it, he is going to die and was inconsolable. I did not want to go the Leeds, I was terrified of seeing him, I don't know what I expected but I was really afraid. I knew nothing about the heart – to me it was a vital organ and that meant trouble.

I was transferred to LGI maternity unit and Joseph was way over in the brand new paediatric cardiac unit with Trevor. Oh, and to make matters worse I had been involved in a minor car crash on the way to Leeds.

Total despair

Trevor came to see me in the maternity wing and said that he was bringing Joseph to see me but I was dreading seeing him. I felt like I did not want to get to know him in case anything happened to him, I could not bear the thought of losing another

child. Trevor persuaded me to see him and he looked so normal and so beautiful that I just burst into tears and I don't think I stopped crying for the two weeks he was in there. I felt like every time anyone saw me I was crying but I could not stop, I felt total despair, I can't describe it any other way.

I was 38 when Joseph was born and other than my previous stillbirth had not had any pregnancies and had waited until I found the right man. I did not drink, smoke or do anything I should not during my pregnancies, how could this be happening to me?

Discharged

The consultant told us that Joseph had TGA and multiple VSD's and he had a balloon septostomy and a pulmonary artery banding during his first two weeks of life. He recovered well and we were discharged and we went back to Grimsby.

Shunt

Suddenly we were alone with a baby that was not hooked up to monitors with nurses and doctors close by and found it very difficult to cope, we used to stay up all night to make sure he was breathing. Apart from the usual feeding problems Joseph was OK, although I was completely neurotic, checking him every few seconds not daring to believe that he would be alright. After several check ups it was decided further surgery was needed and he had a cavo pulmonary shunt when he was two years old. The surgery went very well and he recovered quickly. He needs further surgery, probably in the next couple of years.

Joseph is now doing really well. He started school in September and although he has had a few chest infections, colds, etc. is enjoying himself. He is very bright and eager to learn and amazes me every time I look at him and talk to him, he seems to have amassed a tremendous amount of knowledge. He really is a very happy boy.

Strain

Having a child with CHD has put myself and my partner under a lot of strain and sometimes I thought that we would not be able to cope, I get very depressed sometimes and know I am difficult to live with but my partner is very understanding and we are still together and still happy.



Luckiest person

I don't know what the future holds for Joseph and sometimes I don't want to know but I have a very supportive partner, who has always been there for me and a beautiful son. Having Joseph has changed my life forever and every morning I see him wake up I feel like the luckiest person in the world.

Sometimes I think that the NHS gets a lot of criticism but I am eternally grateful to the paediatric cardiac team at LGI: they gave me that chance to be with my son and that is the best thing anyone could have given me.

Terms used:

SCBU: Special Care Baby Unit

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

Multiple VSD's: several Ventricular Septal Defects (VSDs) – holes – between the two ventricles – the pumping chambers of the heart.

Septostomy: creating a hole between the two sides of the heart to allow oxygenated and unoxygenated blood to mix or to reduce pressure on one side of the heart.

Pulmonary artery banding: restricting the flow of blood into the pulmonary artery so that high pressure won't damage the lungs

Cavo pulmonary shunt: connecting blood returning from the body directly to the pulmonary arteries, bypassing the right side of the heart.

CHD: Congenital Heart Disease

UPDATE: OUR BEST MAN

Michelle Wilkes writes:

I just wanted to give you an update on my son James for the magazine. James was born on 24 March 1999 with TGA at 32 weeks. He had two temporary measures installed before being switched in October 1999.

Playschool

James started playschool in September 2001 and came on in leaps and bounds. We think it was starting to mix with other children that brought his confidence out.

I found out I was pregnant again in January 2002 around the same time that James was diagnosed with pneumonia. The Freeman decided that the pneumonia wasn't affecting his heart so they let our local hospital deal with it, which they did and after a three day course of azithromycin he was as large as life again.

A she

I had the usual 20 week scan at Newcastle as they wanted to do a detailed heart scan to see if this baby was to also have a heart defect. It's hard to describe how it feels not knowing if the nightmare is going to start again or if you could cope a second time around. The scan revealed that the fetus was perfect with absolutely no heart defect, and it was going to be a she (wow! a little girl). We had to change all the boys' names we had picked. My due date was 9 October, but I was told I wouldn't go to term so we decided the baby would probably arrive on 11 September, and as I am patriotic, I decided to call her Liberty Manhattan if she was born that day, much to everyone's shock and disbelief (you can't call her that! is what most said).

James started nursery on 10 September and the feelings of dread filled my mind. What if he couldn't cope? What if he didn't like it? Well, all the worry was enough to start the labour.

Full of smiles

He came out of nursery beaming with pride and full of smiles after thoroughly enjoying himself and I was filled with pride and also fear as I was 35 weeks and six days pregnant.

I went to hospital at 3pm that afternoon and by 3.40 my waters had broken. I kept telling my husband Wayne that I was going to have her at a minute past midnight, to make the date September 11, but I couldn't wait that long. Kate Bethany Wilkes decided to put in an appearance at 5.47pm, weighing in at 6lb 8oz, which was a good weight for just short of 36 weeks.

The first thing James said as he walked in was "Oh look, Grandma, Mammy's found a baby." I was taken to a postnatal ward and then we were discharged home the following day, with both myself and husband commenting on how easy and relaxing the whole thing had been compared to James, who was rushed away minutes after birth.

James started again on New Year's Eve with a really nasty chest infection and was given azithromycin again, so our local hospital ran tests to try to find out the cause but to no avail. It must just be that he is prone to winter chest infections.

School

James started school on 14 September 2003 and I along with all the other mothers tried hard not to shed a tear. He looked so small in his uniform, with his lunch box by his side. He went running in full of excitement, and came out much the same. I was worried about other children teasing him because of his scar, but I needn't have because a little girl in his class has a scar from a kidney op, and a little boy in the class has haemophilia – so the teacher is more than prepared for any bullying. Also James and the other two children are treated the same by parents and teachers, if maybe they are

a little more special.

James is five in 13 days and he's a proper little boy, full of cheek and mischief. He thoroughly enjoys school and would go on a weekend if it were open. The past five years have been a rollercoaster of emotions and I can't believe how far forward we have come.

Positive

He goes to the Freeman every Christmas for his check up, and they are quite happy. He has a small leak from one of the valves but it doesn't require medication. I treat James exactly the same as my daughters, Laura and Kate, and we have a very positive attitude towards things. James is a normal five year old who had a difficult traumatic first year of life but nowadays it's easier to put it to the back of our minds until the Freeman Christmas visit, because I couldn't spend all day everyday thinking "what ifs". Also if anyone out there is thinking about having another child after having a child with a defect please remember that no two pregnancies are the same and lightning doesn't always strike twice.

I married my long-term partner Wayne three weeks ago after being together for 11 years and our daughters were bridesmaids as Laura is 10 and Kate has learnt to walk and is 18 months old. James was Best Man and Ring Bearer, and wore matching suits with his Dad. We were busting with pride

Terms used:

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

Azithromycin: an antibiotic

Haemophilia: a condition where the blood does not clot properly

Liam was born on the 11 September 1988, and weighed in at 7lbs 14ozs. He was very slow to feed and what you did manage to get down him soon ended up everywhere else! He just failed to thrive and was floppy even at six months. He was in and out of the local hospital due to his 'feeding problems' right up to his first Christmas, which he spent on the ward. He finally came home on soya milk and semi-solids to try and put some weight on him.

Fussy parents

Finally after much forwards and backwards and branding us 'over fussy parents' the paediatrician detected a heart murmur...."nothing to worry about" he said. Our baby was referred to the Birmingham Children's Hospital's cardiac unit. After that things moved very quickly....

Dr Eric Silove sent him for an ECG and ECHO which seemed to take forever. Finally there was just us and the cleaner left in the heart unit as everyone else had gone home...

Dr Silove pulled no punches and said 'Liam has a rare abnormality in his heart only usually found in adults who have had rheumatic fever – he has Mitral Stenosis. He went on to tell us that if nothing was done within the next six to eight weeks Liam's life would be in great danger.

Strike

Finally we arrived into the world of the cardiac unit on a bleak August day. We met with the surgeon Mr Sethia who gave us a 65 per cent chance of Liam pulling through. As it was Mr Sethia didn't get to perform his operation as after Liam was starved all day, it was postponed due to an 'unofficial strike' in theatre.

This proved to be a good thing for Liam in the end because we were then transferred to another surgeon Mr Bill Brawn. He gave Liam's chances of 95% (so confident) Finally Liam went for his first operation (Mitral Valvotomy) just before his first birthday on the 7th September....all seemed to go well.

Failure

Liam then started to vomit and showed signs of heart failure, he had an x-ray and echo which confirmed fluid around his heart. He was kept in hospital to try and stabilise his weight, and on 18 October went back down to theatre for the second time to try and stretch the valve cusps (Valvotomy). He came back to ITU in a critical state and we were told that the

staff were on stand by, as he would have to return to theatre again next morning. Liam was packed in ice over night, the surgeon called throughout the night.

Prosthetic valve

Next morning Liam returned to theatre for the third time and was finally fitted with a prosthetic valve – a St Jude valve. Mr Brawn was able to insert a size 21mm as Liam's heart had become so enlarged. Liam spent a week in the intensive care unit and finally after nine and a half weeks we returned back home....

Booklet

Our life with warfarin had begun ... levels too high, levels too low ... be careful, clinic every other day. There was no information anywhere for us to look at ... So we contacted universities, pharmacists, and the British Heart Foundation and between us all produced an information booklet about looking after children who are on warfarin. These are available from the BHF.

Can do

Apart from not being able to take part in contact sports due to this medication, Liam has led an active life with things he can do. Throughout his time in primary school he had a nursery nurse who kept an eye on him within the classroom and at playtimes and dinnertimes. He has a medical statement even now he is in year 10 at secondary school, the care obviously changes as they get older as they take on the responsibility themselves more.

Larger one

Apart from chest infections and a bout of pneumonia when he was five, and a catheter when he was nine, Liam has had out patients check ups each year. In July 2003 Dr Oliver Stumper decided it was time to plan for Liam to go in to BCH for his valve to be changed for a larger one....

We arrived on Ward 12 at 11.45 am on 14 March (just in time for dinner), pressed the buzzer to enter the ward and heard a voice say."I'm not letting you in here". It was the voice of the sister, Debbie Withey, who nursed Liam when he was in the old hospital for nine and a half weeks. After catching up on what we had all been up to, Liam had his echo, ECG, blood tests etc, and we settled in. Mr Barron the surgeon came to speak to us all to explain what would happen, and told us Liam was first on the list next morning.....

Walk around the shops

Next morning dressed in a flattering

gown, Liam walked round to the operating suite, and we stayed with him while he was given the anaesthetic, gave him a kiss and walked off trying hard to keep the tears from falling, not very successfully ... Graham and I had a walk around the shops for a couple of hours and then returned to wait in the hospital.

Liam was in theatre for six hours. We finally got called to see him in intensive care. Liam looked so huge compared to the other patients, he just about fit on the bed ... Liam was kept paralysed so his body could rest and also because his gases were not right, so they had to get that right before they began to wake him ... eventually at about 2.30 in the morning they reduced the sedation and Liam's breathing tube was removed.

Paralysed

Before this Liam had been asking by writing letters on our hands how things had gone, and later when he could talk said while he was paralysed he could hear us talking to him, but couldn't move, even though he was trying. At about 1.00pm the next day Liam was transferred to the High Dependency Unit up on Ward 12. This unit had only opened the day before so it was all brand new! Liam made steady progress and on the Friday went to a room on the ward (still attached to the heparin). he seemed quite well and in good spirits and had visitors over the weekend which included his best friend Rob.

Pain

Monday night after our good friends Ann and Trevor had been, I got the camp bed set up at the side of Liam's bed, and we both settled down for the night. Liam tossed and turned, and eventually at about 3.00 am said he had a pain in his neck, (you take notice if Liam says he has a pain because he never complains) so I went to tell the nurse who came and looked at him, and tried to alter his pillows in case it was that.

After 15 minutes Liam said his chest hurt. Off I went again to fetch the nurse, she gave him some codeine and paracetamol, Liam then said he felt sick so we got the sick bowl, then he wanted the toilet, so I unplugged his heparin and got him there where he was promptly sick. We got Liam settled back in bed and the nurse by this time had gone to bleep the doctor ... who took ages to arrive, by which time Sister Withey was on the case and things moved

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

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

Tel: 01276 707636 Fax: 01276 707642

E-mail: heartline@easynet.co.uk

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

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

Administrator: Pamela Lawrence

Fundraising Officer: Neville Terry

LEAFLETS AVAILABLE

Dental Care for Children with Heart Problems

Feeding for Children with Heart Problems

Respite Care

FOR SALE

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

BOOKS TO BORROW

Pregnancy Loss • Choosing for Children • Parent's Consent • When a Baby Dies
Operation Fix-It • Rosie Goes Red, Violet Goes Blue

VIDEOS TO BORROW

Children and Heart Disease • Children and Catheterisation
Children in Surgery & Intensive Care • First Sight
Compilation from Children's Hospital, Ablation, Pacemaker, Closing ASD with Device
Living with Warfarin • When Our Baby Died

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

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

Name

Address

Postcode..... Daytime Tel. No.

Item or description Quantity..... Price

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

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

Thank you.

Continued from Page 8

fast ... monitors were bought in, an ECG was done, cannulas were attached and Liam was moved back to HDU.

Clot

The surgical team arrived, and an echo was done which showed Liam's heart was being squashed by fluid, and he had a very large clot in his right atrium. Things moved extremely quickly. Graham first of all burst into tears, then he pulled himself together and it was my turn.

Liam was given morphine to dull the pain and he settled a bit more. Dr Andrew Clarke who was part of the surgical team came and explained what they were going to do and that they were getting ready to take Liam straight into theatre. While we waited consultants, registrars, cardiologists all came to look at Liam. It was so scary.

We helped to push Liam's drip stand down to the operating suite. Liam didn't go into the anaesthetic room – he went straight into theatre so we had to leave him at the door, and all he was saying was "hurry up, I want this pain to go".

Pink not grey

Liam was gone for just over two hours. Dr Clarke came to see us and told us he had done an evacuation of tamponade and removed a very large clot from his right atrium...we couldn't thank him and the team enough. We were told by so many if Liam had not been in the hospital when this happened he would not be here now ... Liam did not have to go back to ITU and instead we went to collect him and he went back on HDU. Straight away you could see the difference – his colour was pink instead of the grey he was before.

Scared

Liam was not the same boy he was before, he wouldn't be left alone, one of us had to stay with him. I could understand why he

felt like that it had scared us as well. Liam had a chest drain in for two days and then the echo showed that it was okay for it to be removed. Liam said it was like a hose pipe! So did the nurses... Liam was very apprehensive though about having his neck line out as he linked this with what happened before. (He had the neck line out last of all before the chest pain started).

Victor who was a happy doctor reassured Liam that he would do echo's to show that things were okay, which thankfully they were. All the doctors and nurses were wonderful with Liam and laughed and joked with him, especially about his team Aston Villa..

Home

Finally on the 27 March we were off home! At last a proper bed to sleep in (for me that is!) We had to return to the ward next day as his INR was still not right. We arrived next morning and Nurse Jenice did Liam's test which was 2.5 again – this meant that Liam had to have an injection of Kexlan (I think that's how you spell it) in his leg again (he'd had one the day before as well). Finally after another three hours of waiting around for haematologists to make a decision on dosage and intervention of Dr Oliver Stumper (Liam's cardiologist) we were off again.

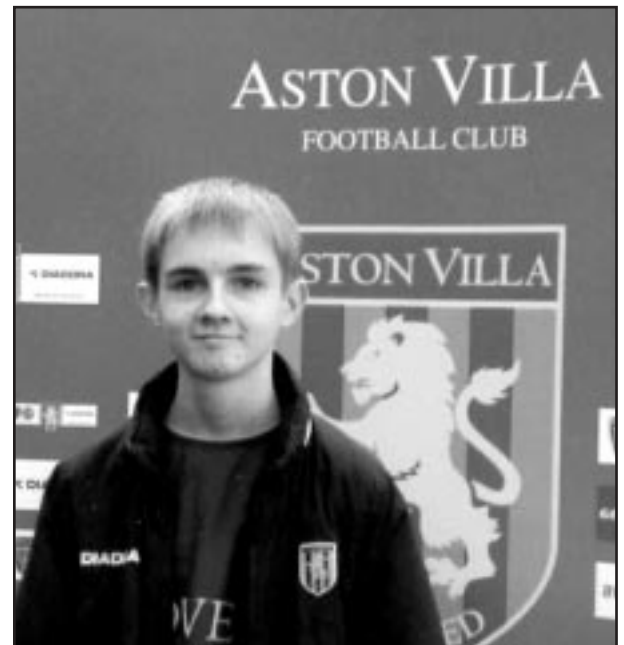
Liam has had to go to the hospital near home for his INR checks and to the doctors to have his dressings changed on his chest where his drains were as they have taken a while to heal.

A stars

Liam will return to BCH to see Dr Stumper on the 13th



May, until then he will receive home tuition for his schooling. Liam is doing very well at school, and recently three principal's distinctions were forwarded to him at home for Mathematics, Science and German. He recently got A* and A's in his mock exams. We are so very proud of him for all he has achieved so far in his life and hope it continues as he strives to become a vet in the future.



Terms used:

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

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

Mitral stenosis: the Mitral Valve in the heart opens to let oxygenated blood pass into the left ventricle, and then closes as it is pumped into the aorta and so around the body. Stenosis means that it is narrow, and therefore not allowing enough blood through, and causing a backflow to the lungs.

ITU: Intensive Therapy Unit

Heparin: a drug given directly into a vein which thins the blood when there is a danger of clotting (an anticoagulant)

INR: International Normalisation Ratio, a test of how fast blood clots – 1 equals normal clotting, so an INR of 2.5 means that blood is taking 2.5 times as long to clot as normal.

DANIEL MCINTYRE – Continued

“Back in 1997 we sent in Daniel’s story – A Normal Life,” writes Daniel’s Mum. “This is just an update on how he is progressing”.

In brief, Daniel was born in November ‘94 at Southend Hospital, weighing 7lbs 11ozs, was diagnosed with Tetralogy of Fallot when he was two months old, had a BT shunt when he was four months old at the Royal Brompton Hospital, and had his corrective surgery when he was two and a half. This was a success to our great relief, apart from a slightly leaky valve which is not uncommon in this type of operation.

Active

Daniel is now nine years old, all skin and bones (just like his dad used to be at that age). He is doing well at school, in the top group for English and Maths, and is involved with all aspects of school life. Outside school he is extremely active, having swimming lessons and has just joined a local football team.

To look at him, there is nothing obvious to show what he has been through when he was younger – until he takes his top off and you see his battle wounds. Physically he is very fit and can keep up with his friends up to a certain point, then he starts to get breathless, but it’s not enough to hold him back. Mentally he is very clever – a lot brighter than his dad!

Squint, migraines and tantrums

There seems to be nothing bothering regarding his condition, though he has been through a lot. At three old years he had an EEG due to his laying-on-the-floor episodes at nursery, unaware where he was. From 18 months old he has been under the opticians, being checked for an eye squint and migraines. He is taking daily migraine medicine for these, due to their frequency and severity. He also had speech therapy. He is now seeing a psychotherapist regarding his behaviour towards his younger brother Scott, and his tantrums.

The long term outlook is that he will require a valve replacement when his in his late twenties (it keeps being put back each time he sees Dr Rigby). Obviously he will start to get more breathless as he gets older until he has his operation or catheter in twenty years time! In the

meantime he might get the odd comment about his scars, but knowing Daniel he will take it in his stride.

Brothers

Daniel now has two brothers both with their own problems. Sadly in 1998 we lost a baby we were expecting. Scott was born in October 1999, eight weeks early, weighing only 980 grams (about 2lbs). He was transferred to Great Ormond Street Hospital at four days old and underwent hernia operations at eight days old. Scott stayed in hospital for about seven weeks. He was in and out of hospital for different problems before being put on a milk free diet at 11 months old until he was three. Scott had a hernia repair at four months old. He is still small and wears pants sized 18-24 months! He is very lively, loves riding a bike and going to playschool.

Aidan was born in May 2002 weighing 7lbs 5ozs. Because of previous problems he was kept more of an eye on during pregnancy and had about 13 scans. Everything seemed to be okay until about 30 weeks when a problem was noticed with his kidney. His left kidney is in his pelvis and had to be checked by catheter at four months old. His kidney appears alright and we just have to be aware that he may have to be careful as he gets older and has to avoid some contact sports.

As a precaution Aidan was also put on a milk free diet for the first year of his life. Aidan is the biggest out of his brothers and loves his food which is nice (after being on the special diet with Scott, and Daniel has to be careful due to his migraines). Aidan has brown curly hair (often gets mistaken for a girl being so pretty) and Daniel and Scott have very blonde straight hair. He also loves riding Scott’s bike.



Daniel (in the hat) collecting £221.58 + £60.00 donated from a parent at the school’s harvest festival back in October 2001, and (below) a recent picture of Daniel and his two brothers.



Terms used:

Tetralogy of Fallot: a Ventricular Septal Defect (hole between the two ventricles) and Pulmonary Stenosis – a narrowing between the right ventricle and the artery carrying blood to the lungs.

BT shunt: taking blood from an arm artery to the lungs

EEG: mercifully short for Electroencephalogram

NITS

(I know, I know! There will be a large percentage of you who surreptitiously start scratching as soon as you see the title!)

Clare Mason, *HeartLine Vice Chair*, writes: "here's a piece about Jonathan and his adventure when he played James in the film *Nits* recently".

Jonathan is mad keen on sport, particularly rugby, and had longed to play in the under eights' team like his brother Thomas. I'd always been really worried about this as apart from having his heart condition, he's really slight and delicate and catches a cold at the drop of a hat. So, as a compromise, we enrolled him in our local drama school, Stage 84.

Lacked confidence

He began with ballet lessons at three years old and did brilliantly well attaining 'highly commended' in his exams, but was teased at school and so decided to quit when he was six. He continued at Stage 84 with his other lessons, drama workshop, performing arts, speech and drama and singing, and although my husband Michael and I knew he had talent, he lacked confidence and rarely volunteered for parts or solos.

His brother successfully auditioned for several parts and appeared in *An Inspector Calls* at the Alhambra Theatre, Bradford, *Heartbeat* on YTV, and *Emmerdale* on YTV, amongst others. Jonathan had always watched with envy wishing he could do the same, but he wasn't often sent for auditions as he'd be really shy and nervous when he got there.

Audition

In October last year though, the school's principal Valerie said it was about time Jonathan had another go and so, along with Thomas, was sent for an audition with lots of other boys for a part in a film called *Nits*.

Each child was given a script to read and very quickly memorise. At this point, I thought that Jonathan had no chance, as in the summer last year we'd notice his eyesight start to deteriorate, and at the time of the audition he was undergoing tests to diagnose his problem.

Fortunately, my Mum went through Jonathan's script with him and we crossed our fingers and hoped for the best.

Short-listed

As with most auditions, the boys all came out and we got ready to leave. It's rare that we are told anything there and then, more often than not; you only find anything out if they are actually successful. On this occasion though, all the other boys were sent away and Thomas and Jonathan were asked to stay. They had been 'short listed'. The director of the film thought they were both great, although Jonathan was very young and might not be able to cope (He's

a very young seven year old). The director also didn't know that they were brothers.

They stayed for another few minutes and then we were told we could go. We usually try and forget about it after that, as you lose more than you win with auditions and the director had lots more children to see.

The one

The day after, we were telephoned by Mrs Jackson who said that Jonathan had been recalled for another audition. It was there that we were told they were 99.9% sure he had the part and the next day, we were asked to take him for a rehearsal as yes, he was the one!!

Harry Wootliff, the director, worked one-to-one with Jonathan for a few hours over the weekend. She would read him each line and ask him to say it one way or another until she was happy with it. She told me later that they walked up and down the street outside practising, and that people looked at them as if they were mad. I was amazed at how good she was with Jonathan, overcoming his sight problem without even mentioning it.

Learnt the script

On the Sunday of that weekend, she told me how grateful she was to me and Michael for helping Jonathan to learn his script as he knew it word for word. I was astonished as we'd been so busy, I'd not had time to look at it let alone learn it with him. To this day, I'll never know how he did it.

Filming began on the film the following Monday in Chapel Allerton, Leeds. Michael chaperoned Jonathan when I was working and then I would do it on my days off.

It's an experience we'll never forget, really intense, very hard work but so exciting. The whole cast and crew made us feel welcome and never once did we feel as if we were in the way.

Jonathan worked with Nicola Stephenson of *Holby City* and *Brookside*, Ben Crompton of *Clocking Off* and *102 Dalmatians*, Rita May of *Children's Ward* and many others. Many of the cast and crew were working for free as the camera man, Brian Tufano, (*Bladerunner*, *Quadrophenia*, *East is East etc*) is such an expert, they just wanted the chance to work with him.

Best week

Filming took a whole week which is a long time for a 10 minute film and so far, has been the best week of Jonathan's life. When it ended, the assistant director shouted 'It's a Wrap!' and everyone cheered for Jonathan who had worked really hard and he was presented with an Arsenal shirt and the



clapperboard from the film which had previously been used on the Harry Potter films. Jonathan was overwhelmed and the director Harry cried as she carried him to the car afterwards.

Nomination

We didn't hear anything for a while afterwards and we were really quite impatient to see the finished product, but didn't realise how long it takes to put a film together. It was only by chance in January when looking on the internet that Michael saw it had been nominated for a BAFTA in the short films category.

We were given another great treat in December when Jack Shepherd who plays David Platt in *Coronation Street* (a friend of Jonathan's) gave us the money he earned from switching on the Christmas lights in Leeds so that we could have a luxury family break in London. We stayed in a four star hotel in Oxford Street and went to see *The Lion King* at the Lyceum Theatre. We had a fantastic time and were able to see Jonathan's film at the same time which made it even more brilliant.

Always remember this

We were invited to London to the Sony Cinema in Golden Square to see a screening of the film, everyone was shaking Jonathan's hand and saying how wonderful he was, even the other actors and famous people, it was quite surreal. Seeing our son on a large screen was really emotional, after everything he's been through, it was wonderful to see him make such an achievement. If he never gets another part again, he'll always remember this.

The film didn't win a BAFTA but it was still wonderful to be nominated and we're keeping our fingers crossed for its success at the Bradford Film Festival and all the others it is being entered for.

We would like to thank Valerie Jackson at Stage 84 for putting Jonathan forward for the audition and supporting us throughout, and Harry Wootliff the director for having faith in him. Also, Jack Shepherd and his Mum Janet for being so kind and paying for us to go to London and starting Jonathan's obsession with *The Lion King*!!!

NEVER STOPPED ME!

My name is Fiona Vause and I am 16 years old. When I was five weeks old I was taken to the doctor by my mum and dad as I wasn't growing or feeding so well. The same day I was sent to the Huddersfield Royal Infirmary (HRI) so they could do some tests on me. While I was there I had a chest X-ray done and this is when they discovered I could possibly have Scimitar Syndrome. Because I wasn't gaining much weight either, my mum and dad were told that it might be better to feed me through an NG tube, and they agreed.

Confirmed

Two weeks later (when I was seven weeks old) I was sent to Killingbeck Hospital for some more tests. Here I was given an ultrasound and this is when they confirmed I had Scimitar syndrome, a hole in the heart and PDA.

In November 1987 when I was four months old the surgeons decided that they could do my first operation. This involved cutting and tying abnormal veins and arteries I had which were attached to my right lung. After the operation I was kept in Killingbeck for three weeks then taken back to the HRI. Even though it was about one month after the operation I still wasn't progressing and was still on medication for heart failure.

Home at last

In January 1988 I was once again taken back to Killingbeck and had my second operation done. This involved closing up my PDA. Two weeks after the operation I was sent home at last. By this time I was almost seven months old and on the waiting list for the third operation which I needed (hole in the heart needed repairing).

As I approached two years and three months old my mum and dad received a letter confirming that the operation could go ahead.

Theatre again

Once again I was taken to Killingbeck and taken in to theatre. Seven hours later the surgeons had finished my operation and found that instead of having the one hole (a large VSD) I also had a small ASD.

I came out of Killingbeck after two weeks, still on medication and still being fed through the tube. I eventually got rid of the tube and the medication by the time I was three years old, but still not eating very well. Now I eat almost everything.

Reaching those valves ...

When I was nine years old I came home from school one day and said to my mum "I want to play a trumpet" but decided eventually that a cornet would be better because my fingers were too little to reach the valves on a trumpet. Seven and a half years later I am still playing my cornet and in three brass bands.

During this period I have done several contests with the bands I am in, played in London and toured Paris with the wind band I was in a few years ago.

Small but ...

Even though I went through a lot when I was younger and I am still only four feet eight inches and only weigh five stones, it has never stopped me doing the things I want to do, and hopefully it never will. As well as doing all these things I also had dancing lessons from the age of 12 up to being 14 years old.

The reason I am telling you my story is to let parents know, who may have children with similar problems as I did, to never give up hope that your child could lead a normal healthy lifestyle.



This is Me at the Brighouse Lions Marching contest in July 2003



This is me at approximately 5 months old



This is me at 1 year & 8 months old

Terms used:

Scimitar Syndrome: some veins that carry oxygenated blood from the lungs drain into the blood vessel bringing unoxygenated blood back to the heart from the lower body. On x-ray this defect shows as a scimitar shape

PDA: Patent or persistent ductus arteriosus - a passage used for circulation before the baby is born remains open, instead of closing shortly after birth. This causes red blood to return from the aorta back to the lungs.

NG tube: a naso-gastric tube - for feeding the child through the nose directly into the stomach

Cover Star

Our cover star is four year old Elise Woodbridge-Colella. Hayley Woodbridge, Elise's mum, writes: I hope you will agree that she is gorgeous!! (Definitely! – Ed).

Her conditions are Shones Complex/Left ventricular obstructions, coarctation, aortic stenosis, sub aortic stenosis, mitral valve stenosis and regurgitation, hypoplastic aortic arch, VSD.

We are currently awaiting her next check-up in June, for an up-to-date status.

Caravan holidays for HeartLine families

Heart Line has two Holiday Caravans:

❖ Golden Sands, Mablethorpe, Lincolnshire. Heated, sleeps eight and is very near the beach. Plenty to do on the site for children and adults.

Price £85.00 Low Season and £200.00 Peak Season. Plenty of available weeks in the summer.

❖ Oakdene Caravan Park, Ringwood, New Forest. Heated, sleeps six. It's a bit quieter than Mablethorpe, but plenty to do on site for both adults and children and is 10 miles from Bournemouth.

Price £200.00 all year. Plenty of availability up to 24th July and after 28th August.

For more information get in touch with



HeartLine Office – see page 10.

The picture is of the Oakdene caravan, complete with resplendent ramp for easy access.

Frazer and snow

Helen and Tim Hart parents of Frazer write:

Thank you for the HeartLine magazine which I have just received and which provides excellent reading. I am enclosing a picture of our very precious heart baby Frazer on his second birthday. He had his first experience of snow which was very exciting. We are so thrilled that he has made it so far and thank you all at HeartLine for your continued support. We are sure that the caravan facilities at both Ringwood and Mablethorpe have contributed to his fairly healthy glow.



Medic Alert

Does your child need a Medic Alert bracelet? 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 see page 10.

Share!

Whatever you would like to say about your child's treatment is likely to be of interest to other parents. We are likely to be equally fascinated by tales of claiming DLA, statementing, diet, holidays, feeding, genetics, schools, transport and any other aspect of life with a child with a heart condition.

And as every day babies are born with parents who have only just learnt of heart defects, you don't have to be original. Everything you write will be new to someone. See inside front cover.

Articles that appear here are put onto the HeartLine website. If you would

rather they didn't, just let us know and we'll limit its publication to the magazine. And if your article isn't in this magazine, that's because it is likely to be in the next one!

Hush money!

Sarah Miller and Jessica Prior of All Saints C of E Primary School had the idea of holding a sponsored silence to raise money. Here they are presenting a cheque for £1600 to Anya, HLA Chair.



Children's Heart Federation

Feeding, education, genes, medicines, endocarditis, immunisation, transplants, talking to doctors, DLA – some of the new and updated information sheets that can be printed from the CHF website www.childrens-heart-fed.org.uk, or free from freephone 0808 808 5000.

HeartLine Message Board

Due to demand, HeartLine has split our message board between General Chat and Conditions. General Chat topics being discussed are: Kempton races, DLA, and coping with being small. Aortic stenosis, chicken pox and palpitations are currently top of the Medical Conditions list.

Join in – go to www.heartline.org.uk/messageboard

