



# HeartLine

**Issue 78**

**Winter 2008/2009**

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**Live in  
Birmingham,  
Norfolk,  
Nottinghamshire  
or West Yorkshire?  
See page 15**

**Inside:  
Ben, Phoebe,  
Matthew, Ethan**



**Mia – chatty, happy, girly**

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

Every time that I write in the HeartLine magazine I am aware that we have a huge range of member interests: very new members with very new babies, skidding along the steep learning curve about their child's heart defect, to the hoary old members, concerned with the futures of their hospitals, involved with improving schools' attitudes to their children, framing advice hard won from successes and failures.

I am in the latter group – very concerned about the quality of research into children's medicines, and the long-term effects of treatments – but I hope that this magazine allows parents to raise any concerns and interests they have.

Recently a mother said that she would like to write about her child's heart defect but it was not as bad as most other children she had read about. Believe me – we all want to hear of children who completely recover from a heart condition just as much as to sympathise with the families whose children have uncertain futures. Whatever your story, your concerns, please send them!

Hazel Greig-Midlane

**We want your stories and pictures by end of April for the Spring edition of the magazine.**

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

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

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### **Our cover star:**

**Mia – Sarah's daughter is this issue's cover star.**

*Sarah writes:* Mia is four, and a very chatty little girl considering she had her tracheotomy until she was two years old! Until that time she couldn't speak and had to sign. She was fed by a gastrostomy (directly into the stomach) until last September, and had her 'button' removed in November. She lost weight to start with and is still tiny, wearing age two to three clothes, but we know she is growing now.

Mia's appointments are now yearly and the doctors are very pleased with her. Her chest looks like a patchwork quilt and she goes a little blue when too cold, but she is a happy little girl. The picture is of her with her twin Mikey and cousin, when she started school, which she loves – along with shopping and make up – a very girly girl.

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



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# SHARON'S BEN

*Benjamin was born on 19 of November 2007 by emergency caesarean weighing 6lb 9oz.*

## Something wasn't right

From the onset I could tell that something wasn't right with Ben as he appeared 'blue'. A few hours after the birth, Ben was moved to the neonatal unit due to poor glucose levels and because of his low temperature.

The next morning, we were told that Ben had had a settled night and that we could go and see him. It was at this point the Ben's heart defect was detected – I was enjoying a cuddle with my newborn, when the nurse in charge of Ben's care started to look worried. Ben's sats were dropping and his colour had changed. The doctors rushed over to Ben and we were ushered into the parents' room.

## Rare heart defect

Ben was then seen by a paediatric cardiologist from the Royal Manchester Children's Hospital and we were given the devastating news that our son had a rare heart defect called Pulmonary Atresia with Ventricular Septal Defect and that he would need an operation as soon as possible. They started Ben on a drug called Prostin to prevent his duct from closing. The next few days were spent at our local hospital, waiting for an available bed for Ben at Alder Hey for his operation. During the wait, I remained on the maternity ward (albeit in my own room) surrounded by new mums and their babies wondering to myself 'why us?'

## Transferred

We were transferred to Alder Hey on 22 November. When we arrived, the cardiologist once again scanned Ben's heart and confirmed the diagnosis as Pulmonary Atresia with Ventricular Septal Defect.

He explained Ben's defect by drawing a diagram and told us that Ben would need two operations, the first being a palliative measure until his heart was big enough to 'correct' the defects. For the first time since finding out about Ben's heart, we found the courage to ask the consultant about Ben's outlook and quality of life. We felt reassured and more positive when we were told that Ben should lead a 'normal' life after his operations.

## In shock

Ben's operation was cancelled three times due to bed shortages in PICU. Whilst we



*Ben*

waited for his operation, Ben received phototherapy for his jaundice. On 29 November 2007, when Ben was just ten days old, he had surgery to insert a modified right BT shunt. I don't remember exactly how long his operation lasted as a lot of my memory from that period is hazy (I think I was in shock with everything that happened). What I do know is that it felt like hours as we waited in our room at the Ronald McDonald

house for a phone call from K2 ward. After a few hours we received a call telling us that Ben was back on PICU.

We then made our way to see him, but before we could see Ben, the surgeon wanted to speak to us. To our relief, the surgeon told us that the operation had been a success and that Ben was already off the ventilator.



### Setbacks

Ben remained in PICU for just twenty-four hours before returning to K2 ward. It seemed that he was doing really well and would be home in no time, however he faced some setbacks on his road to recovery during the next few days.

An x-ray detected that one of Ben's lungs had partially collapsed when his chest drains were removed. Because of this Ben had to return to theatre to have the drain reinserted. The following day, we were informed that Ben had MRSA on his right eye and throat. The nurses had taken swabs from his eye as it was weeping after his operation. Because of this, Ben was moved into a side room and was given daily swabs (as were we) to make sure that the MRSA had not spread. He was given antibiotics and eye drops.

### Kidneys

Because of the MRSA, the doctors and nurses were concerned about Ben's wound, in case it became infected. On 6 December, Ben returned to theatre to have his wound closed. Whilst recovering from his operation, the doctors were also concerned about Ben's renal functions as his plasma creatinine levels appeared raised. Blood and urine samples were taken daily and a renal ultrasound was performed which found no structural abnormalities.

### Terms used

**Rare heart defect:** there are many different types of heart defect. (The incidence of Pulmonary Atresia with VSD is less than 2% all defects)

**Pulmonary Atresia with Ventricular Septal Defect:** there is no passage between the right ventricle and the pulmonary artery, so the heart cannot pump blood to the lungs by this route. There is a large hole (VSD) between the right and left ventricle

**Duct:** the ductus arteriosus is part of the fetal circulation and allows blood to travel from the left side of the heart into the pulmonary artery and so to the lungs

**Palliative measure:** a procedure which will improve the heart

**PICU:** Paediatric Intensive Care Unit

**Phototherapy:** light therapy

**Jaundice:** yellow colouring of the eyes and skin caused by inflammation of the liver (hepatitis)

**Modified right BT shunt:** a tube (shunt) is sewn in place to carry blood from the right subclavian artery to the right pulmonary artery

**Partially collapsed lung:** the whole of the lungs should inflate when we breathe in. A lung that does not inflate can quickly become diseased.

**Chest drains:** tubes inserted into the chest cavity to carry away excess fluid that may have gathered there as a result of the surgery

**MRSA:** Methicillin-Resistant Staphylococcus Aureus: a common bacteria that has become resistant to antibiotics

**Renal functions:** the work of the kidneys in filtering blood and producing urine

**Nephrology:** Specialising in kidneys

**Hypoxic ischaemic** – injury due to lack of oxygen and blood

Whilst I don't completely understand what was wrong with his renal function post operation, I have copies of letters which state that the Nephrology team at Alder Hey believed that Ben's renal dysfunction was attributed to a 'mild episode of hypoxic ischaemic acute kidney injury'. In

April 2008 after an outpatients appointment at the nephrology department at the Royal Manchester Children's hospital, we were told that Ben's kidney function had thankfully returned to normal. On the 8 December 2007, we were finally discharged from Alder Hey.

## OUR JOURNEY SO FAR

*Victoria, Phoebe's mother writes:*

Phoebe was born on 15 April 2006. It was Easter Saturday. I'd had a fairly trouble free pregnancy apart from some blood pressure issues the last few weeks. All our scans had gone well and I was so excited at the prospect of having my first baby. We did not know whether we were having a boy or a girl, but as everyone says, it didn't matter as long as it was a healthy baby.

### Perfect Pheobe Rose

After a traumatic labour ending in an emergency caesarean section, my baby was born at 3.23am, the midwife told me she was a girl and then quickly whisked her away. The next thing I heard was her shouting 'call the crash team' and another nurse said 'what's the number?' I was horrified. How could they not know the number? What was wrong with my baby? After a few minutes when I really did not know what was going on, she finally gave her to my husband to hold and show me

as I was too shaky from the anaesthetic to hold her myself. She was perfect. She was Phoebe Rose.

### Bottle

I spent the next three days in hospital. I tried to breastfeed her, but for some reason we just couldn't do it. The midwives put an awful amount of pressure on me to continue to try, but Phoebe just became dehydrated and lost quite a bit of weight. I finally insisted that they give me a bottle to feed her and although she did take this, it was just very small amounts.

She had all the newborn checks in the hospital and everything was okay, we were allowed home. I was absolutely over the



moon with her, she had lovely dark hair which was really long, and flawless skin: she was beautiful.

### Assured me she was fine

I took her to the baby clinics regularly for weight checks. At birth she was 7.5lbs, when we left hospital she was just under 7lbs, but it was okay, she was on the 50th

centile on the weight chart. She slowly gained weight over the first few weeks, and was taking okay amounts from the bottle. The one thing we noticed from the very start was how sweaty she was when feeding, sleeping and crying. I mentioned this to the health visitor, but she did not seem concerned. She also had little episodes of breathing really fast, again I mentioned this (and it is all written down in our red book) and again the health visitor assured me she was fine.

### Failing to thrive

It was at one of the baby clinics, after we had dropped below the 0.4th centile on the weight chart that one of the health visitors advised us to see the doctor regarding her poor weight gain. She also noticed that one of Phoebe's pupils was larger than the other. The doctor told us that Phoebe was 'failing to thrive' and referred us to paediatrics at our local hospital. That was the start of three monthly paediatric appointments.

We mentioned her pupil to the paediatrician and Phoebe was referred to an eye specialist. At this time we also noticed that she had started turning her right eye in towards her nose. The eye specialist claimed there was nothing wrong with her eyes, but the orthoptist thought otherwise.

### Duane's .. not better not worse

In fact, the problem was not with her right eye turning in at all, but with her left eye, which doesn't move laterally out towards the left, thus making it seem as though her right eye is turning in. This was diagnosed as Duane's Syndrome Type 1a. This was the start of three monthly orthoptist appointments. We were told the Duane's would never get better, but it would also never get worse and it was unlikely to affect her vision, but they wanted to keep a check on her.

The first winter after she was born Phoebe had regular bouts of sickness and diarrhoea beginning in October time and then having an episode approximately every four to five weeks thereafter. In January, she had such a bad bout of sickness that she became dehydrated and had to be admitted to hospital.

### Murmur

It was a relatively junior doctor that first heard her heart murmur. He told us not to worry as many children get heart murmurs when they were poorly, and it may just go away. Several other paediatric

doctors of varying experience came to listen to the murmur, each time saying not to worry, it was probably innocent, but all asking me if the way she was breathing was normal for her, which it was. At this point, I was a typical first time mum who had no idea about CHD, so accepted that it was nothing to worry about. They were going to do an ECG to check out the murmur and a chest x-ray to make sure she didn't have a chest infection. Phoebe's sickness got better whilst in the hospital, they decided not to do the chest x-ray and told us we could go home, but to wait until one of the paediatric consultants came to discharge us. We waited all day, we had bags packed and were just waiting for the discharge.

### Flashy doctor

At about 6.30pm a completely different doctor came to see us who we had not seen before. He was dressed in very expensive looking clothes and had the fanciest stethoscope I ever have seen. He was very grave looking and after listening to her heart and watching her breathing told us that Phoebe did in fact need her chest x-rayed. A nurse came with an x-ray card and off we went to the x-ray department. We were back on the ward at about 7.30pm.

My parents had come to the hospital, as they were concerned we had not telephoned them to say we were on our way home. The flashy doctor (I still to this day have no idea what his name was or who he was) returned to our room and sat us down. He asked my parents to leave the room. He then told us quite bluntly that Phoebe most probably had a heart defect. The x-ray had showed that her heart was too large for her age and size and the way she had been breathing was such that it had caused her ribs to flare out at the bottom. He said we would be taken to Alder Hey the following morning by emergency ambulance so she could have an echo as there was no-one at our local hospital who could do it. He then left.

### Entrance

I was so utterly, utterly gobsmacked. My parents came back into the room and I burst into tears. My husband, Nigel, was also in tears as we tried to tell Mum and Dad what the doctor had said. This was our entrance into the CHD world. The hospital would only allow one of us to stay with her, so my husband had to go home. I stayed up all night watching her sleeping, I was terrified, convinced that my beautiful baby girl was not going to



make it through the night! I had no idea about heart defects, like so many others I was blissfully ignorant to the fact that heart defects even existed.

### Not to worry

The following morning, the ward paediatrician came round and set us straight. He was such a lovely man, told us that the other doctor had no right to frighten us in that way, we would not be rushed to Alder Hey that day for an emergency echo and that Phoebe's heart, although slightly enlarged was not really too bad. He told us he would make us an appointment with the Alder Hey cardiologist when he next did his outreach clinic at our local hospital. We were to go home and not to worry...not much chance of that!

The appointment came through a couple of weeks later and Nigel and I took her to our local hospital to see Dr Peart from Alder Hey. He had a general look at Phoebe, listened to her heart and said the murmur was still there and quite loud. He told us to pop her onto the bed and he would take a look. The minute he put the ultrasound probe on her chest I saw the hole. It looked huge. He then pointed it out to us, told us that she had an Atrial Septal Defect (ASD). He looked at a few more things then told us to get her dressed.

### You'd choose ASD, but

He was lovely. He explained to us what an ASD was and told us that if you had to choose a heart defect for your child then this would be what you would choose as it is the simplest and most routine thing to fix. He went on to say that many people

live with ASDs and do not even know that they have them and that it should not affect Phoebe's childhood at all. He explained that the normal method of closure is by catheter, using a device that clamps onto the surrounding septum closing the hole without the need for surgery. It is a quick operation and a quick recovery time.

**BUT** (I knew there would be a but) Phoebe's ASD was quite large and its location was close to the wall of the heart with not enough septum for the device to clamp onto. It was also very close to her pulmonary vein and so if the device did dislodge and block her vein, she would die. He then proceeded to explain the method of closure via open heart surgery. Within the space of about ten minutes we had discovered that our child had a hole in her heart and that she would require open heart surgery to fix it. Again, the only word I can use to describe how I felt was gobsmacked. She was gorgeous...perfect (well apart from her eye defect) and she was my baby, my only baby, and she had to endure open heart surgery and the risks associated with it.

### **Gutted**

I was absolutely gutted. Not for me, but for her. Both Nigel and I were a bit too shocked to ask any questions, so were told to go to Alder Hey in three months where Dr Peart would have a proper look at her on his scanner which was far superior to the one at the local, and could also check the pressures in her lungs.

We got home from the hospital and the first thing I did was go on the internet and find out everything I could about ASDs. It was a minefield of medical terms and complicated-looking pictures. I found a website that was aimed at teenagers which had a really simple explanation and a little video that showed how the heart worked and what effect the ASD would have. Although she would probably have no real problems as a child, Phoebe's late 30's early 40's could be seriously affected by the ASD as oxygenated blood that is destined to travel around the body actually returns to her right atrial chamber via the hole resulting in more blood going through the lungs. This could cause pulmonary hypertension as the blood vessels in the lungs become permanently damaged by the increased blood flow.

We told our families and again, as most of them had little knowledge of heart defects and the prevalence of CHD in children, everything seemed doom and

gloom. Some of the family actually questioned the fact that she needed this hole repairing as she was generally so well and apart from her weight (which Dr Peart told us was probably nothing to do with her ASD) she was a healthy baby, developing normally.

### **Cotton wool**

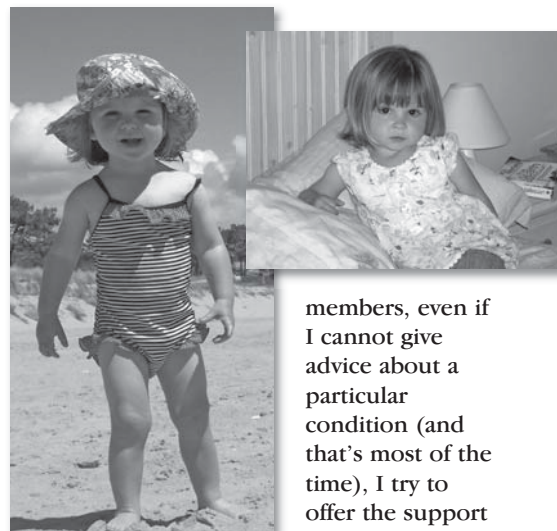
It was then that I started to wrap her up in cotton wool so to speak. Maybe I was going over the top, but I was not taking any chances. I went out of my way to keep her away from other people who are ill but then got the comments 'she'll never build up any resistance if she's not exposed to things' and 'it's only a bit of a cold, what harm could it do?' I'd take her to the doctors with the slightest sniffle or cough, I think they think I'm bonkers, but I don't care.

My husband, although he attended all her cardiac appointments with me, never really wanted to talk about it, he did not want to know the detail of what her defect was and what it meant, he did not want to talk about the 'what ifs' as he thinks that talking about these things is just tempting fate. I know though that he does think about it and that he worries about it just as much as I do, it's just his way of dealing with it.

### **Found HeartLine**

I'm completely the opposite. I need to talk about it and I need to know absolutely every little thing I possibly can about it. It was while looking for information that I found HeartLine. I have never really been comfortable with chat rooms and forums, never really known what to say, so for a few weeks I just read the posts by others. I realised that this was a little community with so much love and support between these parents of children with CHD. It also made me realise that this was not the end of our world...yes Phoebe had a heart defect, yes I was still absolutely scared stiff for her, but looking at this website really brought it home to me that we were actually very lucky indeed.

After a couple of weeks I finally plucked up my courage and registered with HeartLine and wrote my first post. Within minutes of posting, I had lots of replies, welcoming me to the boards and also bits of advice from some of the parents who had children with similar conditions to Phoebe. Since that day, I can honestly say that I have logged on every single day. I join in with all the threads from other



members, even if I cannot give advice about a particular condition (and that's most of the time), I try to offer the support that I am offered

every time I have concerns or worries. Even though I probably wouldn't recognise any of the other members if I met them in the street, I feel that each and every one of them is my friend. It breaks my heart when one of the other children is poorly, or in hospital having surgery, or in the very worst cases, loses their brave fight. HeartLine has become my lifeline.

### **Don't get your hopes up**

We attended regular cardiac appointments and every time we were told the same thing ... not enough septum to clamp a device onto, and at every appointment it seemed that the operation was put back ... when she's eighteen months old ... when she's two ... before she starts school ... until our appointment in August 2008. This time, when Phoebe had her echo, it looked as though there was a bit more septum, and when it was measured Dr Peart actually thought there might be a chance (albeit very slim) that he may be able to close her ASD by the catheter method, but not to get our hopes up ... but he had said there was a chance ... even a slim chance is better than no chance at all ... of course we got our hopes up!

We were told that our next appointment would be in six months, at Alder Hey, where he would do an echo and discuss it with the surgical team to determine the best method of closure. Either way, she would be having her ASD closed shortly after that appointment. That is when fear set in. We had gone from nicely plodding along attending clinic to the fact that surgery, whichever way it was to be done, was imminent.

We still have regular paediatric appointments, although they are now yearly, as are the orthoptist appointments.

## OUR JOURNEY SO FAR cont.

We are also attending children's orthopaedic clinic as Phoebe has developed a trigger thumb, which at some point will need surgery to fix. We have just been discharged from the cardiac clinic as the next step for us is surgery.

### Flimsy?

We attended the clinic at Alder Hey on 26 January 2009. I had it in my mind that we would go and by some miracle the septum would be sufficient all around the hole to easily clamp a device onto and it would be as simple as that. Not so. Dr Peart did the echo and had a look at her heart, which showed much the same as the last echo had in that there was a small amount of tissue, but he said it looked flimsy. He also pointed out the pulmonary vein and told us that if that got blocked by the device we certainly wouldn't be thanking him ... rather going after him with a knife! He then, for the first time ever, put the ultrasound probe on a different part of her chest and viewed her heart from another angle. I just could not believe what I was seeing, the hole was massive (measured 18mm) and it looked to my untrained eye that there was no surrounding tissue at all. My hopes were dashed. However, he still thought there maybe was a chance that he could do the closure with the device and told us he would have the discussion with the surgical team and see which method they thought was best for Phoebe and he would telephone me to let me know what they had decided.

### So much dread

So, this is where we are now, waiting for the telephone call. Part of me is hoping that he will phone and say bring her in

### Terms used

**Orthoptist:** a clinician involved in the diagnosis and treatment of sight-related problems, particularly those connected with abnormalities of eye movement and eye position

**Failing to thrive:** not growing at the usual rate

**Paediatrics:** specialising in children

**CHD:** Congenital Heart Disease, meaning heart condition present at birth

**ECG:** electrocardiography, measures the electrical impulses generated by the heart

**Echo:** echocardiography, scan of the heart using ultrasound (sound waves)

**Atrial Septal Defect (ASD):** a hole in

the wall between the atriums on the left and right sides of the heart

**Septum:** the wall between the left and right sides of the heart

**Pulmonary vein:** a blood vessel bringing oxygenated blood back from the lungs to the left atrium

**Pressures:** the force with which the heart is pumping into the aorta – to the body – and to the pulmonary artery – to the lungs

**Pulmonary hypertension:** high blood pressure in the lungs

**Trigger thumb:** locking of the thumb joint so that it does not bend normally

and they will close the hole with the catheter, but then I have a niggling doubt that because of the complexities with the flimsy septum, and the close proximity of the pulmonary vein that this is too risky an option and that open heart surgery, even with its own risks, is the better option. Then I think of the drive down to Alder Hey to take her in for the surgery and then handing her over to the surgeons for them to cut her chest, open her sternum, put her on bypass and stop her heart to close the hole and it fills me with so much dread I just cannot take it all in.

### So proud

I have spent the past few days on an emotional rollercoaster, fine if I'm with

someone else, but if I'm on my own, even for a few minutes in the shower, I'm heartbroken and cannot stop crying. My eyes fill with tears whenever I see my little girl playing and laughing. Poor love has absolutely no idea what is coming. What will she think of me for putting her through this, how will she react in the hospital and what will she think about having a scar the length of her chest. But I know I have no option, it is completely out of my hands and I can, at least, take some comfort from all the positive stories I read of other children on HeartLine, who never cease to amaze me how strong they are and how they fight so hard, and I am so proud that my daughter will be one of those children.



## TWINS START SCHOOL

Tracey's identical twin daughters are starting school: Olivia and Emma were three last November.

Both were born with serious heart defects and both were treated at Alder Hey Hospital, Liverpool.

Emma had interrupted aortic arch and aortopulmonary window which were repaired in November 05, and AVSD and PA widening in November 2007.

Olivia had a complete AVSD corrected in May 2006.

### Terms used:

**Interrupted aortic arch:** there is a complete break in the aortic arch, which carries oxygenated blood from the heart to the body.

**Aortopulmonary window** is a hole between the aorta and the pulmonary artery, allowing oxygenated blood to be pumped to the lungs.

**AVSD** is an atrioventricular defect – a hole between the atriums, a single valve across the middle of the heart (instead of the tricuspid and mitral valves) and a hole between the two ventricles.



# MATTHEW'S STORY

*Julie, Matthew's mother, writes:*

Complicated was the word that summed up my second pregnancy. With our first daughter Alice, everything had gone fine but we knew from the outset that this would be different.

## Twins!

At the first scan we were surprised to be told I was expecting twins. Matters then became further complicated when it was discovered that they were a rare and complicated type of identical twin. However, at the twenty two week scan things were about to get even more complicated.

The twins were unusual as instead of sharing an outside sac and having separate inner sacs, like most identical twins, they were completely together in the same sac with nothing separating them. So I was booked in for close monitoring and scans, lots of scans, at least every two weeks. Everything had been fine with the scans so far and there had been none of the twin complications we had been warned about.

## Blasé

I had almost got a bit blasé about having scans and so I told my husband there was no need to come to the 22 week scan. At this scan the sonographer tried for some time to get a good view of both their hearts. I had to go for a walk, jump up and down and drink more water and she tried again. She said because the boys were wriggling so much she was unable to get a clear view of the four heart chambers. I was then called into a 'nice room', always a bad sign I later realized, and told they had been on the phone to St. Thomas' Hospital and booked me in for a scan in their Fetal Cardiology Department the next day. I was already unnerved and thought they would have just called a consultant in to scan me if it had simply been a case of getting a good picture.

## Tears

As we waited to be called in, I grew more and more anxious. At last it was our turn. The twin they had not been able to scan properly the previous day was on the left and the heart specialist said the heart was normal; we breathed a sigh of relief. Then she scanned the baby on right and called in a colleague. I was then scanned again. Some whispered discussions at some length took place, with medical terms incomprehensible to us. It became apparent that the twins had swapped sides from the day before and they told us that one of the twins had a problem with their heart. They said they would fetch another colleague and then discuss it in detail with us. I looked at my husband in panic and as they left the room we both burst into tears.

After a short time we were ushered into the 'nice room' and told that one of the babies had complicated congenital heart disease. They explained that the echo scanning had proved incredibly difficult, as the twins kept swapping sides, the heart was on the wrong side (dextrocardia) and several veins took an unusual course. After a second scan we were told that it seemed as if that the heart condition was transposition of the great arteries and in addition the aorta was looking too narrow and there were several holes. Mortified, we tried to take in all information and ask questions whilst in floods of tears. The description of his heart just sounded so hopelessly wrong. None of the options sounded good, we were offered a termination but were warned that we would most likely lose both babies.

## Any chance still a chance

The consultant, Dr Miller, explained that the baby would require open heart surgery in the first few weeks of life to swap the arteries and may require an additional operation at four months to widen the aorta. The TGA swap operation was one of the more common ones they performed but the fact that the heart was on the wrong side and the baby was a twin, unlikely to make term, made it all the more complicated. We got home and our eighteen month old daughter Alice ran to us across grandma's garden and we knew then that any chance is still a chance.

## High risk to very high risk

It was decided that the twins should be delivered at St. Thomas' and that surgery would be performed once the baby was around 4kg in weight which could take up to 8 weeks. Dr Miller emphasized that the echo scanning in this case was incredibly difficult. This meant that the diagnosis was tentative, based on the information they could get at the time, but that there could be more things wrong or a slightly different diagnosis made once the baby was born. Not knowing entirely what we were facing made everything even more stressful. As the pregnancy had now gone from high risk to very high risk, I was assigned to an obstetrician, Mr Maxwell and the Thames team midwives and trips to London increased.

Meanwhile we tried to get on with things. Knowing about the heart condition that far in advance did make us worry but at least we knew we would be in the right place



with the heart experts. We tried to put a brave face on things whilst those around us tried to get us used to the idea we might only return with one baby. Talking about it made it seem real and made us panic and in a bizarre way we did not want to upset others around us. This is why the ECHO antenatal day was so good for us. We could openly discuss everything we were afraid of in a roomful of people in similar situations.

## Prematurity

The heart consultants wanted the delivery as near to term as possible so the heart baby would be as strong as he could be and not be hampered by problems of prematurity. Meanwhile the obstetrician was concerned over the high risk nature of this type of twin and the likelihood of the umbilical cords twisting and so losing both babies. After discussions it was agreed to deliver the twins by caesarian section at 31 weeks, the next week! We were very scared at the thought of a heart baby who was also very premature but we knew we had no option to avoid losing both babies. We were told the odds of survival for babies this premature were good and that we were in the best place. In the end the boys were born at thirty three weeks after a two week stay on the antenatal ward waiting for two beds to be free at the same time in SCBU. The consultant scheduled the c-section for a Saturday so the beds in SCBU would not disappear again.

## Helpless

The theatre was crowded with doctors, heart specialists, neonatal doctors and nurses and midwives and medical students. The boys, Edward and Matthew, were both born in the same minute, owing to a very quick surgeon, at 2.37kg and 2.11kg respectively. I had a brief glimpse of them before they were whisked away on incubator trolleys to SCBU. My husband went with them and came back relaying news as I still couldn't move after surgery. We felt so helpless not knowing if they would make it and not being able to do anything to help. Overnight both Matthew and Edward got put on ventilators. I forced myself into a wheelchair first thing so I could go and see them.

# MEMBERSHIP FORM

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

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

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

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

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

Address .....

.....

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

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

Name of Heart Condition .....

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

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

.....

## Other children in your family

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

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

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

- I 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,  
Surrey Heath House, PO Box 957, Camberley, Surrey, GU15 9FH*

# HEARTLINE OFFICE SERVICES

## GETTING IN TOUCH

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

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

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

Office Manager: Pamela Lawrence

\*\* Fundraising Officer: Neville Terry \*\* Project Coordinator: Helen Baker \*\* Administrator: Caroline Howcroft \*\*

## HOW WE CAN HELP

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

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

## WEB SERVICES

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

## FOR SALE

PIN BADGES	£1.50
Car stickers	£1.50
HeartLine teddy	£10
<i>Heart Children</i> book	£10 + £1.50 p&p

## 100 Club

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



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



Name .....

Address .....

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

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

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

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

Thank you.

In those first few days Edward seemed the weaker of the two and suffered air in the lung cavity (pneumothorax) twice and had to have chest drains inserted. Even after birth, Matthew was still proving difficult to scan and we got to meet most of the cardiology team and Matthew was a hot topic at their meetings. He was not blue in appearance as the holes in the heart were allowing the blood to mix and so looked pretty well. Matthew was off the ventilator quite quickly but was not allowed to start on milk until a course of action was decided about his heart surgery. Understandably he wasn't happy about this and screamed a lot. TPN gave him nutrients but didn't satisfy his hunger. He lost weight and fell below 2kg.

Obviously we knew in advance the twins were going to be in SCBU and so had bought them a small toy each, an Elephant for Edward and I had wanted a Monkey for Matthew but had been unable to find one and so got him a giraffe. Coincidentally they also received more elephant and giraffe toys from two other sets of friends. Matthew's giraffes stayed with him throughout all his moves round the hospital.

### Looked so well

On the Friday, after another echocardiogram, Dr Miller said that the aorta was narrowing too quickly and so they wouldn't be able to wait until he reached 4kg or even the usual surgery minimum of 2kg but would have to operate as soon as possible on Tuesday and earlier if he deteriorated over the weekend. Seeing him looking so healthy I had to fight an irrational urge to pull off all the tubes and run with him out of the hospital. Of course I did not, as I did realize how serious the heart condition was but he just looked so well and I did not want to have to put him through surgery. He was doing so well in fact that ironically over the weekend he was moved out of intensive care and into special care with other babies who were improving. I was also discharged from the postnatal ward and we were given a room (the Giraffe Room) at Ronald Macdonald house over by the Guy's hospital site. I was so scared at being further away and not being able to just pop across the corridor at any time. However, it was reassuring that from our room we could phone the ward directly at any time and it was only a short journey on the staff bus. Being so far away from home Ronald MacDonald house was brilliant in allowing us to be so near and accommodated and supported without ever being intrusive.

### Just want him to make it

Meanwhile Edward was thriving and the doctors said he was ready to be discharged if we were happy. We asked to wait until after Matthew's surgery on the Tuesday as we could not handle both things at once. The day before Matthew's surgery Dr Fox, the head of SCBU, came to talk to us about Matthew's recovery plan and possible problems post surgery. I was not registering the detail of what he was saying, I just kept thinking 'so he expects him to make it back'. I was feeling in a slightly more positive mood and then Dr Miller and the surgeon, Mr Austin, came to talk to us. They reiterated that they would not completely know what they were dealing with until they opened Matthew up and that they might not be able to fix all the problems in one go and that further operations may be necessary. We then got the risk percentages, they were not good, and added to this he was under 2kg, the usual weight minimum and with dextrocardia everything would be further complicated. I was in tears again. Mr Austin said 'I know they are not good odds but if we don't do it then it is 100% risk he will die'. I remember the last thing we said to Mr Austin was 'we just want him to make it'.

### Horrendous

On the eve of the operation, Matthew had to have his milk stopped again which we knew would make him scream again. We took both Matthew and Edward out of their cots and took a picture of them, the first one of them together and we hoped not the last. Unable to sleep, we arrived early the next morning at 7am and they were already getting Matthew ready. It was horrendous for us taking him down, with the nurse, to theatre and leaving him with the anaesthetist. We had already seen his personality emerging in the first ten days and I hated the feeling that I might not see him again. We were expecting the surgery to be over by 1pm. We tried to keep busy, looking after Edward on the ward with the usual cycle of feeding, expressing and nappy changing. News came back that it had taken two hours to get a line into Matthew for the general anaesthetic, as he was such a pin cushion from all the previous lines. 1pm came and went. One of the nurses said 'you look a bit stressed' (I think she thought I was having problems feeding Edward) when I explained about Matthew in surgery she said 'I take it back: you're looking calm considering'.

### Feared the worst

We paced about for a bit round the hospital grounds and stared over at the Houses of Parliament and said lots of prayers. By 4 pm we frantically asked every nurse, doctor and



consultant we could find what was happening. They disappeared but it seemed that no-one was coming back with any news. We feared the worst and thought they were just waiting for Dr Miller to break the bad news to us in person that Matthew hadn't made it. Then the SCBU consultant came in and ushered us into a 'nice room'. She said that in theatre they were trying to get Matthew off the heart-lung machine but that he was not coping on his own. We were distraught thinking that was it. I remember thinking at that point I can't imagine going home with only one baby. Then Dr Miller burst into the room with the latest news that Matthew had been off the heart-lung machine for 45 minutes and coping okay. Amazingly, they had managed to fix all of the heart problems in the one operation. We were so relieved. Dr Miller was still concerned however as it had been an incredibly long operation, over seven hours, and Matthew had been on the heart-lung machine for an immensely long time, far longer than normal, and that they were not sure what damage this may have caused (possible brain, liver, kidney damage etc). He said they had wanted him to leave theatre in pretty good shape and they felt he had but that he was still critical and that we would have to take it hour by hour. We made many hurried calls to family and friends who ten minutes previously had assumed he was essentially dead.

### Scariest thing

We raced over to PICU in Evelina to see him. It was Halloween and Matthew was the scariest thing we had ever seen. From the tiny premature baby we had left that morning he had ballooned up from the heart-lung machine and looked nothing like our son or even a baby. Owing to the swelling, they had been unable to close the chest cavity and so we could actually see his heart under the gauze dressing; quite a common occurrence we were told. He had more tubes and machines attached than we had ever seen and was unconscious from the morphine and ventilated again. We spent the night by his bedside worrying about blood loss, fluid levels and working out what all the extra monitors, lines and drugs were for. The nurse on that night was the most efficient and calm person I had ever met and still

## MATTHEW'S STORY cont.



found time to explain everything to us and get us tea. Mr Austin phoned us at 9pm to explain that he was very happy with the heart repair and phoned again at 3am to see how Matthew was doing.

Dr Miller and Mr Austin came round regularly checking on Matthew and called him their “star patient”. I think they were just as surprised as us that, against all the odds, they had successfully fixed his heart. All the echo scans were really good and showed a ‘normal’ heart.

### Healthy baby on PICU – interesting!

As the days progressed he improved and came round from the morphine. On the day he first opened his eyes, since the operation, the blanket the nurses had put on him was decorated with hearts, elephants and giraffes! His chest was closed on the Sunday and we were moved to a less high priority part of PICU. Edward was also discharged to us and spent his days sitting next to Matthew in his pram waking up to feed and then sleeping again, he was an easy baby luckily. The nurses seemed quite fascinated to see a healthy baby in PICU.

Matthew had various tests and was showing no signs of any damage from the heart-lung machine but was still being closely monitored. He was started on milk again but he did not tolerate it and so ended up back on TPN. A chest x-ray revealed that the nerve to the Matthew’s diaphragm had been damaged. Therefore his diaphragm was not working on the left side which was compromising his breathing. He managed to get off the ventilator but was dependent on an oxygen tube. Several more echoes were done and the cardiologists were amazed by the surgical repair. Matthew transferred briefly to Camel ward and then back to SCBU as his problems were now less about his heart and more about being an underweight premature baby.

### Skeletal

We took steps forwards and backwards on the road to recovery. After draining off the

excess fluid from the operation he was almost skeletal and I could see the bones in his bottom when I changed his nappy. It was a battle to get him back on milk feeds and for several weeks he could only tolerate 1 or 2 ml of milk. Eventually he started to tolerate it and finally got up to full milk feeds and even started breast feeding (amazing after so many weeks). He was dependent on the tiniest amount of oxygen but without it he deteriorated. He could only cope for so long before his breathing worsened and he ended up back in NICU on CPAP.

### Diaphragm operation

It was coming up to Christmas and we discussed with the consultants going back to our local hospital for Christmas and them eventually setting up home oxygen for us once Matthew was well enough to be discharged. The twelve week stay was taking its toll on us and we were missing our 21 month old daughter, Alice, terribly. Surprisingly instead, the decision was made that it would be better to operate on the diaphragm, essentially to pull it back down to try and resolve Matthew’s oxygen dependency. Mr Austin kindly said he would perform the operation. I knew this was minor in comparison to his open heart surgery but it scared me nonetheless. He had the operation on 19 December and on 20 December was off the ventilator, off oxygen and was saturation at 98-100% in air. The consultant then shocked us all by saying there was now no need to go to our local hospital and that Matthew could go home in the next couple of days. We were so surprised and overjoyed as we had given up all hope of being near home, let alone at home, for Christmas.

### Discharged

After lots of different checks at 5 pm on 23 December we were discharged. We got home relieved and slightly worried that it was all down to us now. The first three months were a bit of a blur of feeding and nappy changing and no sleep. I had to abandon breast feeding as Matthew tired so easily and I remembered the cardiac nurse saying he just had to put on weight no matter what. I got the comment a lot ‘oh are they twins but he’s so much smaller’. As we moved onto weaning him he would eat solid food but only if everything was mixed with either peach or mango and then one day he just got the hang of it and has loved food ever since.

### Second chance at life

Words cannot express our gratitude to all the medical staff at Evelina and St Thomas’ particularly Mr Austin and Dr Miller. Matthew is now just coming up to two

and it is hard for most people to tell the difference between him and his twin brother, Edward. They are both on the 98th percentile for weight and in age three to four clothes. Matthew is on no medication and just has to have check-ups (where they have been happy with his progress, although he still proves difficult to scan). Matthew has far more energy than Edward and on days out just refuses to have a nap. As one of my friends said ‘it’s like he knows he’s had a second chance at life and now he’s here he doesn’t want to miss a thing’. His favourite trick at the moment is to throw his hands up in the air and shout ‘Hooray!’ ... it’s like he knows!

### Terms used

#### *Transposition of the great arteries:*

(TGA) the aorta and pulmonary artery are plugged into the wrong sides of the heart – so the aorta takes blue blood from the right ventricle back round the body, and the pulmonary artery takes red oxygenated blood from the left ventricle back to the lungs.

**Aorta:** the major blood vessel which takes oxygenated blood from the heart to the body

**Septal holes:** defects in the wall between the two sides of the heart

**Open heart surgery:** an operation where the heart has to be cut open to repair it. Usually the heart will have to be stopped and a heart lung machine take over the oxygenation and pumping of the blood.

**Arteries:** vessels in which blood flows away from the heart. Veins are vessels with blood flowing towards the heart..

**ECHO antenatal day:** an antenatal day for families expecting babies with a heart defect, organised by the Evelina Children’s Heart Organisation

**SCBU:** Special Care Baby Unit

**PICU:** Paediatric Intensive Care Unit

**Evelina:** Evelina Children’s Hospital, on the same site as St Thomas’ Hospital

**NICU:** Neonatal Intensive Care Unit

**CPAP:** Continuous Positive Airway Pressure: a machine used to help breathing

# SPECIAL BABIES NEED SPECIAL FAMILIES

Our Saturday night was great, we'd been at a Halloween party and stopped over – little did we know that you had other ideas and wanted to join in! You were born at 03.40am on Sunday 28 October 2007 after a ninety minute labour! I was in shock but you were perfect! Quiet as a little mouse!

## Monitor

The next day we were going to be discharged when as a check they do on all newborns they put an oxygen saturation monitor on your feet (they do this to all newborns at UHND) with the theory that if the oxygen levels in your feet are ok, then your heart is pumping correctly. Ethan - your saturations were 72% out of a normal 100%. They tried three different monitors before they decided they needed to call a paediatrician. He came and took you away with the promise that they would either bring you back or come and get us.

## “Are you ok?”

The midwives kept coming in and patting my back going are you ok? I knew then there was a problem but no-one was saying anything. They kept doing it and the more they did it the more irritating it was. The more I worried.

Eventually, the consultant came back with the other paediatrician. Long faces: not good.

They explained that you had Transpositional Arteries, that the arteries going into the heart were the wrong way round and the blood with oxygen in from the lungs, instead of going round the body was just going back to your lungs. Eh? We could see you in ICU if we liked, I can honestly say I have never been so frightened in all my life. Daddy stayed with you, I couldn't stand seeing you like that I thought I was going to collapse in the heat.

They'd rang for the ICU Paediatric Transfer Team to come from Middlesbrough to take him to the Freeman Hospital in Newcastle ... the Freeman what?! where?

## Don't you know?

Daddy decided to drive – a decision I wasn't pleased with at the time but turned out good as we were able to concentrate

on other things. It was teatime, RUSH HOUR: GET OUT OF OUR WAY! don't you stupid people know we need to be with our little boy ... every blue light set me off crying wondering if it was you – had something happened on the way?

When we arrived they brought us to see you in the nursery. You were crowded by doctors ... doing what we now know as an echo ... they then took us to a private room and explained that there was no quick fix. You had three major defects, not just one.

## Over

Bang, all at once our perfect family was over.

The parents on the ward with their children were a big support that night, more than they know I think. They'd been there and were able to reassure us that you were in the best place. We left the hospital reluctantly at 10pm ... and got home to a house full of baby things. That wasn't right ... where was our baby? Ethan should be here. We cleared it all away, not really knowing exactly what the future held for us as a family.

## Get some sleep

We were woken at 1.45am with a telephone call from the ward, explaining that you had had a problem with your heart rhythm during the night and were being transferred to PICU. There was a chance that when we came in you could be ventilated as they had to give you a medicine to try to bring it under control. We were assured that you were ok and that there was nothing we could do and we should get some sleep ready for the next day. We tried. We got up and set off at 7am to make the one and a half hour journey back to the hospital through the rush hour. I think if I could've bought a pair of Dorothy's red shoes then I would have!

## Not a day goes by

Looking back, we have been thrown into this world, where the babies and children are wonderful angels on earth. Not a day goes by where I don't worry about you – are you bluer than normal, is your breathing ok ... and you just smile, laugh and get on with it.

The other mums and dad are amazing –



there's an understanding between us, You gain a huge amount of compassion and empathy. Every time one of us is dealt a blow we all feel it, every time we gain an angel a little piece of our heart is taken with them.

## Wouldn't change a thing

I think it was harder for us than it was for you, Ethan, My beautiful brave boy with his big smile. You don't know what the future holds. You have to carry on regardless. I can't believe you're going to be one soon! My big brave boy – my little hero. On our first night in hospital with you, a mum told me that special babies need special families. I guess that's us. And we wouldn't change a thing.



## Terms used

**Paediatrician:** a doctor specialising in children's health

**ICU:** Intensive Care Unit

**Echo:** Echocardiography, a scan of the heart using sound waves

**PICU:** Paediatric Intensive Care Unit

**Ventilated:** on a machine which gets air and oxygen into the lungs



# CHRISTMAS DRAW 2008

Thanks to your combined efforts, the draw has raised £3870.50. The money will help us to maintain and develop our core activities in 2009. We sincerely hope you will all benefit in some way. The prizes have been donated by many leading companies who have chosen to support HeartLine's valuable work. Without their patronage, we would have been unable to hold the draw. We wish to extend our sincere thanks to all of them. The names of the prize winners and sponsors are detailed in the table below.

TICKET	PRIZE WINNER	PRIZE	SPONSOR
2835	Carlo Milano	LCD Television 42AV505D Regza AV Series	Toshiba Electronics Europe Gmbh
5898	Barbara Laver	Radio Controlled 4-Tec All Wheel Drive Touring Car	Model Sport UK
18717	Julian Brierley	Wave Ceptor Watch and Calculator	Casio Electronics Company Ltd
28626	Stephen Edensor	IControl Watch	Timex Group UK
07951	Claire Pitts	Perfumes and Skin Care Products	Elizabeth Arden (UK) Ltd
40930	Sally Richardson	Goody Box	The Walt Disney Company Ltd
29222	Bradley Hunter	Introduction to Sailing Day	Private Donation
34395	Lorraine Jackson	CD Radio Cassette Player	Sony United Kingdom Ltd
36793	Sharon Ware	£50 Voucher	Selfridges & Co
37294	Anne Sidnell	Ultimate Bourne DVD Set and Calculator	Casio Electronics Company Ltd
28862	Linda Payne	Goody Box	The Walt Disney Company Ltd
09260	Angelina Fellowes	IControl Watch	Timex Group UK
21252	Steve Burgess	Gift Edition – Khaled Hosseini's Books	Bloomsbury Publishing PLC
06816	Michelle Campling	Mini Mutant Pack and Electronic Bouncer	Vivid Imaginations Ltd
48224	Julie Jacob	Goody Box	The Walt Disney Company Ltd
49660	Lisa Casey	£20 Voucher	Game Stores Group Ltd

*The children in the photo are Barbara Laver's grandchildren. Barbara won this radio controlled car donated by Model Sport UK. Mabel King is five and is a heart child, Charlie and Tommy King are three and are identical twins.*



## WHY FUNDRAISE FOR HEARTLINE?

It costs £6000 a month to keep our services going. Our office employs four people. Together with volunteers, they

- ♥ distribute packs to hospitals so that parents have a good chance of getting support and information as soon as a child is diagnosed with a heart condition
- ♥ keep the membership database up-to-date
- ♥ organise area contacts
- ♥ publish the comprehensive *Heart Children* book
- ♥ maintain a website of the *Heart Children* book in seven languages
- ♥ provide caravan breaks
- ♥ send children on trips and holidays
- ♥ help the more than 50 area contacts who are volunteers to support families throughout Britain
- ♥ maintain the HeartLine website, especially the Forums where hundreds of messages of support, information and just chat are sent every week
- ♥ support often distressed and confused people on the telephone

- ♥ provide information to hospitals, journalists, and researchers about congenital heart defects
- ♥ send out the magazine to more than 1500 families three times a year
- ♥ organise free Medic Alerts for children who need them
- ♥ print awareness material, run stalls and make information available for Children's Heart Week
- ♥ and they do ..... **fundraising!**

Thank you to the many who have fundraised for HeartLine

If you haven't got a fundraising idea, you can

- ♥ support others by going to the HeartLine website (<http://www.heartline.org.uk/>) and following the Fundraising for HeartLine link.
- ♥ join the HeartLine 100 club – a private lottery with two chances to win every month. For details see the website or call the office 01276 707636
- ♥ ask your school or employer to make HeartLine their charity.

**Good luck!**

# IN THE SWIM WITH HEARTLINE!

How many times has your heart child's trip to the swimming pool been ruined because he or she gets too cold to enjoy it? Even children who are not usually blue seem to suffer a sudden change of colour and a lot of shivery discomfort.

## Warm Belly Wetsuits Project

Now HeartLine has started the Warm Belly Wetsuits Project to give our heart children the opportunity to go swimming without getting too cold. The wetsuits fit children aged from 0 to 12 years, and are adjustable for long-term use. They are easy to put on and keep the child warm in water above 65° Fahrenheit (18° Centigrade).

Swimming has great health benefits, improving circulation and strengthening muscles, so we hope the project will bring these benefits to many of our children. We have started with a small experimental group of ten children, but hope to raise enough funds for two hundred children.

## Do you live in Birmingham, West Yorkshire, Norfolk or Nottinghamshire?

We have funding to buy wetsuits for children in these areas now, so if you would like your child to be considered for inclusion in the project, please write to Helen Baker at the HeartLine Office or email [Helen.Baker@heartline.org.uk](mailto:Helen.Baker@heartline.org.uk) with your name and address, your heart child's name, date of birth and size of wetsuit needed. The wetsuit is supplied free of charge, but in return, after six weeks we would need you to fill in a short questionnaire so that we can monitor and evaluate the project.

## Live somewhere else?

As funds become available we will allocate wet suits on a first come first served basis, so please contact Helen to register interest now.

The sizes available are as follows:

	X-Small	Small	Medium	Large	X-Large
Sizes	6 mos-2T	2T-4T	4T-(6X)7	7-10	10-12
Height	20-30 in 55-80cm	30-40 in 75-100 cm	40-50 in 101-127 cm	45-57 in 114-145 cm	53-62 in 134-158 cm
Weight	18-28 lbs 8-13 kg	25-40 lbs 11-18 kg	35-50 lbs 16-23 kg	50-70 lbs 23-32 kg	70-85 lbs 32-39 kg

*Rosie's son Samuel was one of the first children to receive a wetsuit from HeartLine's Warmbelly project - she wrote:*

Just a quick email to give you first impressions. Samuel swam in his suit on Monday - wow what an amazing difference. Although his teacher had her concerns about how cold he was getting I never really understood - he managed the whole time and has never shown too much blueness (We are used to his colour - its 'normal' to us.)

Well Monday was amazing - he managed not only the whole time but double the amount as he was so much faster and he smiled through the whole lesson - I am gobsmacked as to how well he was swimming!

Am really looking forward to lessons again next week!



*Fiona, Kate's mother, sent this picture (left) and wrote:*

I wanted to let parents know that having a heart condition doesn't always mean that there are restrictions on what your child can do. This picture is of Kate McGregor, aged 11, singing and acting with the chorus in the English National Opera's production of Pagliacci at The London Coliseum (Kate is the one in the white woolly hat!). Kate had surgery to repair Tetralogy of Fallots when she was a baby. Thanks to Dr Rigby and his team of doctors and nurses at The Brompton Hospital, Kate is living life to the full.

Lisa, Maisie's mother, sent this beautiful picture of her daughter. Longer term readers of the HeartLine magazine may remember Maisie's story and Lisa's struggle to get appropriate education for her daughter who was coping with a heart defect and losing her sight.



## CHF Federation Day September 08

Supporting Parents in Making Complaints  
*Jacqueline Swapp*

The Independent Complaints Advocacy Service is funded by the Department of Health. It is a free and confidential service which provides support to people who want to make a formal complaint against the National Health Service.

Jacqueline explained that there can be three stages to making a complaint: Local Resolution, Healthcare Commission, and Health Service Ombudsman. The first stage with some tips is set out here in the unlikely event that you will want to make a complaint:

- Complaints should be made within six months of an incident occurring or within six months of realising that you have something to complain about
- Complaints should be made to the Practice Manager of a GP Surgery or Dental Practice, or to the Chief Executive of Hospital Trusts or an Ambulance Service
- Complaints can be made verbally or in writing
- You should receive a response from a GP Surgery or Dental Practice within ten working days
- You should receive an acknowledgement letter within two working days and full written response within twenty-five working days from an NHS Trust
- If you are still unhappy with the response, you can either write back or request a local resolution meeting which will be chaired by either a practice manager or by a member of the Trust

When writing a letter of complaint it is best to be brief, but if you need to set out a long or complex account, attach it as a log sheet or diary or events, with details

Be clear and straightforward. Don't be afraid to say what has upset you, but try to avoid aggressive or accusing language: put your concerns politely but firmly

Explain why you are not satisfied. Use numbers or bullets so that you can refer clearly to each point and ask the questions you would like answers to in order of importance.

It is important that you say what you want to achieve, for example an explanation of what happened, an apology or action to remedy the problem you experienced, by a named person, by a set date.

### RSV and congenital heart disease

Dr Rob Tulloh, consultant paediatric cardiologist from Bristol, presented information on the need for prevention of bronchiolitis (RSV) in heart children.

Although RSV is a very common disease, children with CoHD are at particular risk of severe RSV infection, especially if they have impaired lung function and reduced ability to increase cardiac output.

Following infection, the child may be unable to compensate for the effects of the RSV as cardiac output and oxygen delivery may already be severely limited. In these cases the child may need hospitalisation and breathing support because of respiratory or heart failure.

In the most serious cases, RSV infection of an infant with CoHD can lead to death: death rates are more than three times higher than in previously healthy children at 3.4%.

CoHD children may have longer-term complications: RSV can increase the risk of Pulmonary Arterial Hypertension after recovery from the infection itself and correction of the heart defect.

So Dr Tulloh concluded that prevention of infection is an important goal in vulnerable children. Palivizumab prophylaxis is currently the only effective option available to protect against RSV infection. Research has shown that prophylaxis resulted in a

45% reduction in hospitalisation in vulnerable babies with CoHD. The British Congenital Cardiac Association has issued guidelines clarifying when and to whom prophylaxis should be given.

... and the most recent news:

### Government considers immunising children against RSV

In January 2009 it was announced that government advisors are considering a programme to immunise against RSV (respiratory syncytial virus) in vulnerable children after NHS research found that immunizing against RSV reduced the hospitalisation of children with congenital heart disease by 45%

Infants under six weeks old, those with chronic lung disease, congenital heart disease or immunodeficiency, and premature babies born before thirty five weeks are classified at the greatest risk of severe disease if infected with RSV.

### Ulrika Jonsson backs launch of heart defect website

Celebrity Big Brother winner, Ulrika Jonsson, who has a child with a heart defect, is backing Corience, a European web platform that provides information about congenital heart disease, launched in the UK on 30 January by Children's Heart Federation.

Ulrika said: Having a child with a heart defect puts everything else into perspective. As a parent, you are desperate for information that will help them get the best treatment and care, when they are born and as they grow. You look for ways of helping their brothers and sisters too. This is why I welcome the launch of Corience. It has information available in a clearly understandable way. I naturally know of the strengths of the British and Swedish health systems. To be able to see what works well right across Europe is a great benefit because sharing knowledge will help improve things for heart children in every country.

Corience is an independent European network dedicated to congenital heart defects (CoHD) sponsored by the European Union. Its aim is to provide accessible and authoritative information to patients, parents, doctors and scientists on good practice in the diagnosis treatment and support of people with CoHD. The UK version of the website will be followed in the autumn by versions in Spanish and German and later in Polish.

*Continued on page 17*



Anne Keatley-Clarke, Chief Executive of the Children's Heart Federation, commented: If you have CoHD in the UK you are likely to get very good medical treatment and follow-up. Being part of Corience has highlighted the work that remains in this country to ensure our psycho-social care is on a par with the best in Europe. Family support and emotional care is underdeveloped in the UK compared with other countries in Europe. Corience gives us an insight into what works well elsewhere and is also a powerful signposting tool, referring heart families to their local support organisations for advice, information and practical help.

The Corience website can be found at [www.corience.org](http://www.corience.org).

### More money for Special Educational Needs

In December 2008 the government announced £38 million funding to improve outcomes for children with Special Educational Needs (SEN).

The funding was announced as part of The Children's Plan One Year On, a review of what has been done since its launch. There will be £31 million allocated to support pilot programmes to improve outcomes for pupils with SEN. There will be a further £7 million for other measures including strengthening school leadership and improving online reporting for parents.

The report highlights additional developments of particular relevance to disabled children and their families, including:

- Parent Panels – these panels will provide direct advice to Ministers on a range of issues that affect parents in England and will include parents of disabled children.
- Children's health – the report confirms the Child Health Strategy 'Healthy Lives, Brighter Futures' will be published shortly, which is expected to confirm the level of funding available to PCTs for disabled children's services.
- Children's workforce – disabled children are identified as a vulnerable group needing support from the children's workforce. One of the key objectives will be ensuring that everyone receives appropriate training in meeting the needs of disabled

children and young people, and about their role in supporting children and young people with speech, language and communication needs.

If your child has or may have special educational needs, you may want to check who is on the parent panel advising ministers, and establish direct contact with him or her.

### Family Fund increases age limit to 17 in England

Many parents find themselves struggling to meet the additional costs relating to their child's condition. The Family Fund is a national charity which gives grants that relate to the additional needs of the disabled child and help relieve the stress of everyday life. They have recently increased the age limit of children they can help in England to include 17 year olds, as long as they get the application before the young person's 18th birthday.

This brings it in line with the eligibility criteria for Wales, but in Northern Ireland and Scotland the age limit is 16 years of age or under, providing the application is received before the 17th birthday.

As well as things like toys and holidays, the Fund helps with driving lessons, so the raising of the age limit could be very useful if your young person needs to be able to drive to work or college for example.

Contact the Family Fund by calling 0845 130 4542 for more information

### Help with disabled child care costs in London

The government recently announced a pilot scheme that will pay an increased level of working tax credit to low income parents of disabled children in London.

The maximum limits for all eligible low income families in London with a disabled child will be raised to £215 per week and for families with a severely disabled child even further to £300 per week. These limits will be further increased if childcare costs are claimed for more than one child.

And, by the way, childcare for a disabled child costs on average five times more than for a non-disabled child.

### Good advice – on pump feeding

*Abi sent a message: she just wondered if anyone who pump feeds their child, "where do you put your little ones to be fed?"*

"Logan is a bit of a problem at the moment – his feed runs for over an hour and twenty minutes but he doesn't want to sit still for all that long. He gets very agitated being strapped in his chair, tries to sit up and fall out. All the stress doesn't help with his vomiting! Last night he was so agitated I just couldn't keep him entertained and he ended up pulling his tube out mid feed & vomiting with all the stress!"

"Oh dear, remember this well," says Helen. "There were a few tactics that I used – Theo usually sat in his buggy, which I would then park in front of his favourite DVD for one feed, or in his highchair which was one that adjusted down to normal chair height - I'd put a little play table in front of him and I, or Isaac, would then sit with him and do jigsaws, play dough, scribbling, playing with Bob figures (it's really no wonder I never got much else done!). His last feed we would sit him in his bouncy chair where he would then doze off. We then didn't dare move him, so he stayed sat there asleep all evening till we went to bed ourselves - we'd carry the bouncy chair up the stairs with him in it, put it into the cot beside our bed, and he would stay in it till he was sick (inevitably every night!) and then I'd transfer him into his cot itself when I cleaned him up. We lined the bouncy chair with conti-pads (like Pampers care mats) to save on laundry a bit.

### New HeartLine dental leaflet

HeartLine is issuing a new leaflet Dental care for children with heart conditions. Contact the Office for your copy – see back cover.

Tooth decay is painful, and can damage your child's health – gum disease, throat infections, earache – these can often be traced back to bad teeth. And infection in the mouth could be a cause of endocarditis, a disease of the heart which can be fatal.

Endocarditis is rare, but children with heart defects are particularly vulnerable. Antibiotics before dental treatment don't protect against endocarditis we are told, so it is especially important that you protect your child from tooth decay, abscesses and gum disease.



### www.how2fundraise.org

When people are feeling the results of the economic downturn HeartLine needs members' help even more than usual.

Need a fundraising idea? Try

www.how2fundraise.org for inspiration – a wonderful site for those of us looking for a way to help the charity that helps us!

### A Breakthrough in Echocardiography training!

The HeartWorks system was devised and developed by a team of three anaesthetists from the Heart Hospital in London. Inspired to produce an accurate model of the heart to facilitate teaching of the practical skill of transoesophageal echocardiography during cardiac surgery, Doctors Sue Wright, Andrew Smith and Bruce Martin enlisted the help of a large number of eminent cardiac clinicians and morphologists to create an anatomical model of unsurpassed accuracy and realism.

The addition of custom designed ultrasound simulation software has resulted in freely interactive transoesophageal echocardiography image simulation with true to life control of the probe position. Work with Glassworks, a leading computer graphics company, has seen the model and echocardiography simulator evolve into a remarkable training instrument - which will revolutionise the teaching of echocardiography.

### HeartLine caravan holidays

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

Booking the caravans started on 2 January – the school holidays obviously get booked up very fast, but if you or other members of your family could do with a break in the low season, it is much cheaper. If anyone wants to book weekends or even just a few days during the low season they are

welcome: ring the office two weeks before you wish to go and we can let you know if the time is free.



We can only do weekends and short stays during the low season.

**Oakdene** high season £310, low season £135 a week. £30 a day low season only

**Mablethorpe** high season £290, low season £115 a week. £25 a day low season only

### Consenting to audit

The Central Cardiac Audit Database site has been set up to give the parents and carers of children with congenital heart disease information about every congenital heart disease centre in the UK, the number and range of procedures they carry out and survival rates for the most common types of treatment.

When they visit the hospitals to collect and check the information, the auditors need to review some medical records chosen at random. So when your child next goes into hospital for a procedure you (or your child if he or she is old enough) will be asked to give written consent for the medical record to be seen.

This is not the same as consenting to treatment. More information from your cardiac liaison nurse or cardiologist.

### Medic Alert

Does your child need a Medic Alert symbol? This may be because he or she has fainting attacks, a family history of Hypertrophic Obstructive Cardiomyopathy, is on warfarin, has a pacemaker, or has an allergy for example. Bracelets, neck chains and straps come in a variety of designs suitable for children these days,

HeartLine can cover the cost - just send your name, address and telephone number, the name of your child and the hospital he or she attends to Helen Baker at the HeartLine Office

### Helping with research: Genetics

A genetic research study at Oxford University is looking for samples from people with congenital heart conditions and their mothers for a database. You can help if you are the mother of a child born with a heart condition, or you yourself have a heart condition, and you or your child have been under the care of a consultant at one of these hospitals:

- Bristol Children's Hospital
- Great Ormond Street Hospital for Children
- Guy's and St Thomas's Hospitals
- John Radcliffe Hospital, Oxford
- Royal Brompton Hospital
- Royal Liverpool Children's Hospital, Alder Hey
- Southampton General Hospital

If you would like to get involved see the website at [www.well.ox.ac.uk/GOCHD](http://www.well.ox.ac.uk/GOCHD) or contact

Dr Jamie Bentham, Department of Cardiovascular Medicine, Wellcome Trust Centre for Human Genetics, University of Oxford OX3 7BN, Email: [GO-CHD@well.ox.ac.uk](mailto:GO-CHD@well.ox.ac.uk)

You will be sent an information leaflet, consent form, brief questionnaire and a blood bottle that can be filled by your GP practice nurse or a simple saliva kit you can use yourself.

### Heart Children book

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

To buy printed copies contact the office on 01276 707636.

## HeartLine's Forums

Our Forums have lots of super features: they offer an opportunity for Heartliners to meet each other online, discuss anything they choose and share pictures – go to the website and choose message boards. Once you have registered you can join in with **General Chat** for any topic under the sun, or you may want to go to **Conditions** to discuss children's congenital heart and related problems. There is a **Who's Who Forum** for profiles of members, **Bereavement Support Forum**, for those who have lost children and their friends, and **HeartLine Office**, for messages to and from the office. For those of you who haven't visited yet, please join in. It's a great way of giving support to other families, of getting help with your own problems – or just sharing a few minutes with friends.

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

Patrons: Dr Philip Rees  
Adelaide Tunstill

## HEARTLINE EXECUTIVE COMMITTEE

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

Chair: Anya Rowson

Trustee: Lisa Casey

Vice Chair: Alison Keen

Trustee: Linda Hardy

Treasurer: Kevin Ford, ~~Elizabeth Ford, Alison Keen, Anya Rowson, Lisa Casey~~

## HEARTLINE COUNCIL

*The HeartLine Council is made up of Area Contacts and other members who have specific responsibilities.*

Pre-Natal Support: Jan Kingsley

Clinical Support: Gill Thompson

Hospital Visitor: David Northeast

## SENIOR HEARTLINE MESSAGE BOARD MODERATORS

Sheran Taylor

Kerry M-S

Kate Hatcher

Val Thrubbron

## CORE SUPPORT GROUP

*The Core Support Group is being expanded to replace Area Contacts. Please contact any of these numbers for support.*

Hertfordshire	Sheryl Murphy	Stevenage
Norfolk	Tamasine Epps	Norwich
Surrey	Daphne Larner	Wallington
West Yorkshire	Joanna Howitt	Holmfirth

## SPECIAL SUPPORT

*These members offer support for the particular areas listed:*

Jewish families	Rochelle and Mark Goldwater
Grandparents	Jill Waring
Lone Parents	Hayley Woodbridge
Breast Feeding	Sarah Brown
Feeding	Liz Collins
	Annabel Blanch
Falot's Tetralogy	Sue Gearing
Falot's & Teenagers	Judith Smith
Hypoplastic Left Heart	Nicola Haselgrove
Fathers	Keith Collins

# WE HAD SNOW!



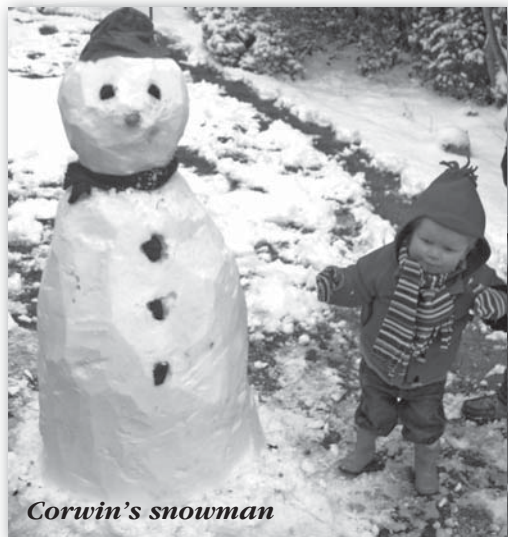
Alex



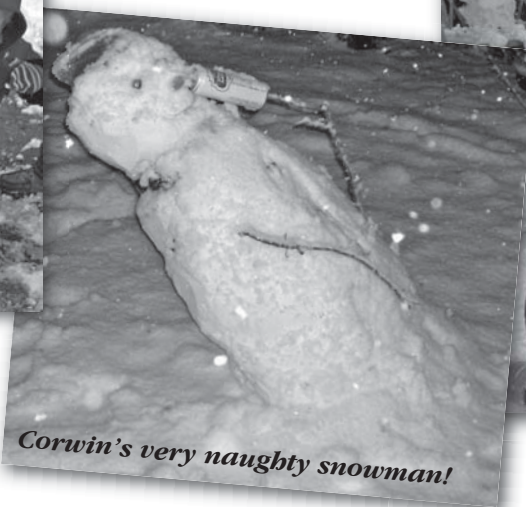
Charlie



Phoebe



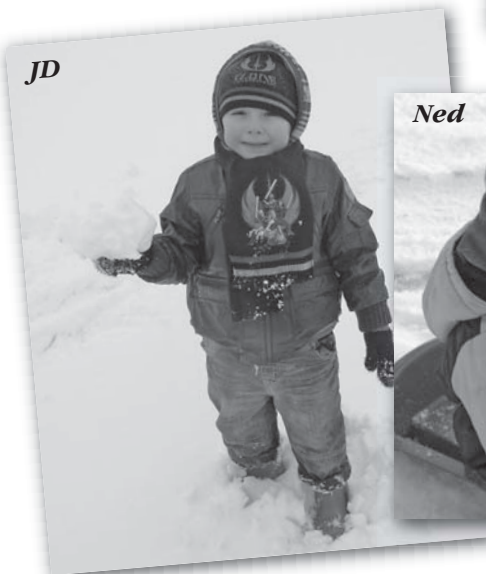
Corwin's snowman



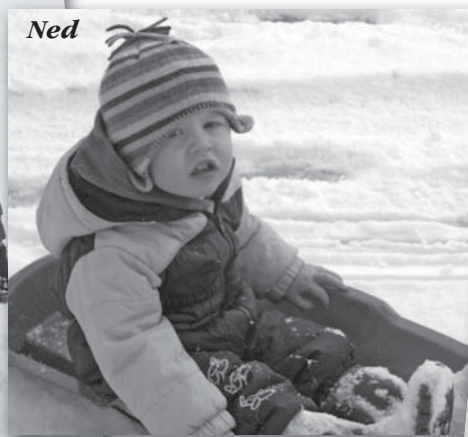
Corwin's very naughty snowman!



Scott



JD



Ned



Logan

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PO Box 957, Camberley, Surrey, GU15 9FH  
01276 707636  
[www.heartline.org.uk](http://www.heartline.org.uk)  
[admin@heartline.org.uk](mailto:admin@heartline.org.uk)