

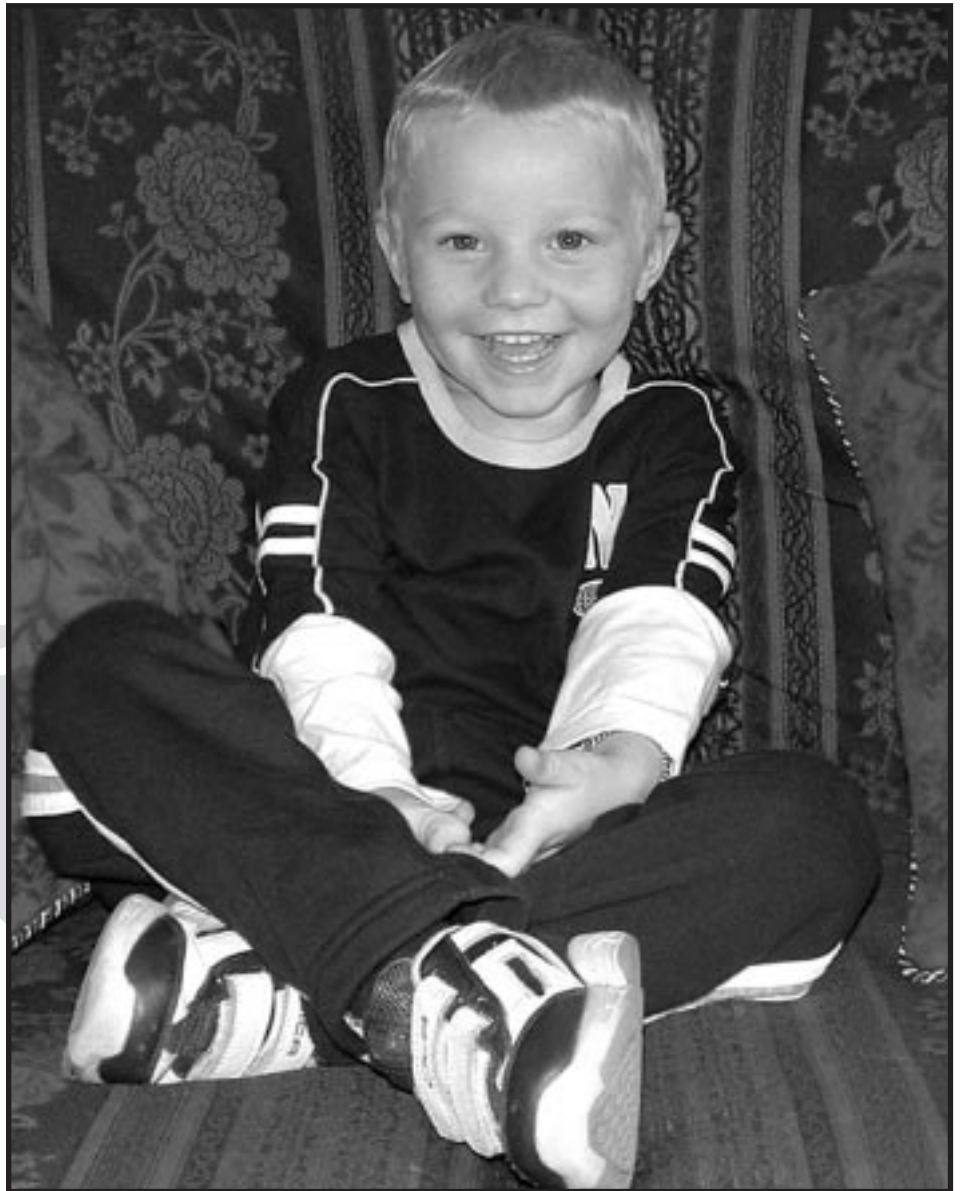


# HeartLine

Issue 61

Winter 2003/2004

---



## Lewis lights up

---

*Free membership – see page 9*

HeartLine Association is a Registered Charity No. 295803

## From the Editor

Winter 2003/2004

---

Feeding – we have permission to print an article about feeding problems and some clinical discussion. Although most of us may be able to crack feeding problems with a lot of patience, a few children have long term inability to take food through their mouths. Over the years I have seen several of my friends' children progress via nasogastric

tubes to gastrostomies – feeding directly into the stomach. Is progress the right word you may wonder? This requires surgery, and it may look like the most artificial of options. But for families it seems to work. No more passing of tubes, your child is not wearing their health problem on their face, and he or she is free to put delightful-tasting things into their

mouths if they choose. I know of one young person who, tempted by cropped tops, gave up her gastrostomy, so that she can flash her slender midriff for all to see!

So if it comes to it, a gastrostomy can be yet another gift from the clinicians to our families to help us lead the 'normal' lives we all crave!

**Hazel Greig-Midlane**



# HeartLine

## CONTENTS

Full of Surprises	3
Rhianna	6
Hayley's Story	7
Catching up with Imogen	8
Membership form	9
HeartLine Office Services	10
About Aaron	12
Feeding – one hospital's approach	14
Christmas Draw – the winners	15
To Those Who Don't Know	15
Committee and Area Contacts	16

Please send your pictures and stories for Issue 62 Spring 2004

**by email:**

[hgmhla@btinternet.com](mailto:hgmhla@btinternet.com)

**contact details:**

HeartLine Office details appear on page 10.

**Front cover:**

Lewis Osten

## FULL OF SURPRISES

*Anne Toogood of Deal in Kent says: Hello, I thought I'd write and share our story with you. The rollercoaster ride may not be over yet, but here's how it's been so far...*

---

### First surprise

Our first daughter Lauren was born in May 1999. It was a normal pregnancy, birth and development. Our second, Joanne, was born in January 2001. It was a normal pregnancy, birth and then our first surprise happened.

Being born in January, I didn't think anything of Joanne's slightly mottled hands and feet, which the Health Visitor commented on. I just put it down to the cold time of year. At the six to eight week check, the doctor detected a heart murmur and requested an appointment at the local hospital to investigate further. At the hospital they did an ECG, I think a chest x-ray too. They told me that there were problems with her heart and wanted to send us to London.

### Guessing

Maybe because we were going from a local hospital to a London hospital the next day, I perceived there being a sense of urgency about it. I was later informed that there was a clinic at the Royal Brompton in Chelsea which just happened to be held the next day. I asked questions about what they had found but of course without the equipment and specialist diagnosis at this stage, they would only be guessing as to exactly what might be wrong. A lady from the chaplaincy team was in the local hospital that day. Was there anything she could pray for – oh yes please. And I shared the story so far.

### Spell

A friend looked after Lauren whilst her husband drove me, Joanne and my husband Mark up to the Royal Brompton. Joanne was diagnosed with Tetralogy of Fallot (TOF). We were told that, depending on how she fared, she'd either need one or two operations to correct it, the first operation being a stop gap before needing the second. We couldn't believe the news. What a complete surprise. We were given a sheet of paper describing what TOF is, and on our way out from the appointment, picked up information about HeartLine. We were told that Joanne might spell when she's older (a spell is where she'd temporarily go blue and pass out due to the restriction between the heart and lungs cutting off blood supply to the brain). Surgery would be brought forward if this occurred.

### Different kind of cry

At six months old, the spells began. I noticed it first in the different kind of cry that she had. Because of the age that she was, the fact that she slept a lot and having to run around after Lauren (now a

toddler), I wasn't always in the room at the same time to see whether she was turning blue and going limp at the same time. Then she'd start spelling when I was holding her so I rang the Royal Brompton and described the symptoms. They prescribed Propranolol (a beta blocker to relax and regulate the heart). An appointment was made for us to go and see Dr Rigby, our Consultant at the Brompton. Just Joanne and I went up.

### Can you stay in?

It was my 30th birthday that day and the news was that they'd need to operate soon. The spells indicated that intervention was required sooner rather than later. Could we stay in today? I was numb and a bit shaky. There's Lauren to consider and arrangements made as to who was going to look after her. Mark would want to be with me and Joanne in hospital too. We agreed Joanne would be admitted the next day and surgery went ahead as planned the day after. She was in theatre about two hours during which time a BT left shunt was performed and all had gone well. They'd performed a shunt rather than corrective procedure at this stage since she was a bit on the small size, weightwise. They felt it better to wait until she was older for corrective surgery, such major surgery.

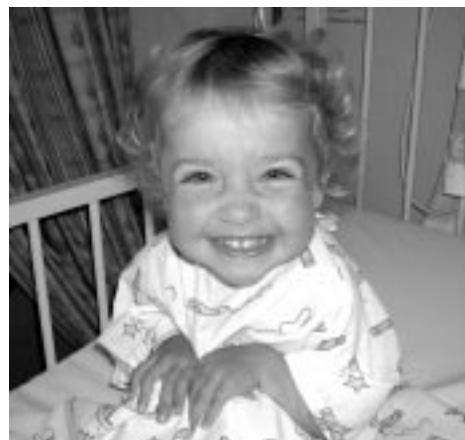
She'd need to be on aspirin to keep her blood thin and flowing freely through the shunt before the second operation when she's about two to three years old – health dependent. A BT left shunt is the insertion of a small additional vein (I'm not sure whether it was real or synthetic) through which blood from the heart to the arm could divert allowing a freer flow of blood around the body rather than squeezing itself through the restricted area in the heart.

### Tubes and lines

We began monitor watching virtually as soon as we arrived in PICU and I didn't stop asking questions about the various tubes and lines/medicines everywhere. We didn't feel too overwhelmed at seeing her in this condition since we'd been for a visit to PICU the day before to give us an idea of what to expect. The evening of surgery I was able to cuddle her – complete with wires and it felt so good just to hold her again. I used 'daisy' the milking machine to express some milk – what a weird experience that is!! And so she was still able to feed via the NG tube they had temporarily inserted.

### Feeding and weight gain difficulties

We were told that some heart children can



have feeding and weight gain difficulties and Joanne was in this category. Lauren was quite a sickly baby and I remember constantly wearing an old towel over my shoulder after feeds – waiting for the inevitable so I wasn't surprised that Joanne was like this too. Both Lauren and Joanne also seemed to suffer a lot of wind and they were regularly in a baby carrier being jiggled around the house. Night-time always seemed the worse. The day could go quite well and then as soon as Mark came back from work, the crying would start off and on through to about 10-11 pm. Looking back on it now, I think that for Joanne it was not only wind problems but the strain of getting enough oxygen too.

Weight gain was regularly monitored but was poor and the sickness continued so we spent various days at our local hospital whilst they did some tests including a sweat test for Cystic Fibrosis. She also had a barium meal and gastric reflux was diagnosed. Joanne drank normally but didn't seem to tolerate any lumps in her food. I knew Joanne couldn't help being sick but it didn't stop me feeling frustrated that it kept happening. Thank goodness for washing machines!!

I think it was around this time that we began to see the hospital dietician and Joanne was put on a very high calorie diet – olive oil or butter in savoury foods and cream or honey in puddings. She was also put on a high calorie milk.

### Sickness

February 2002 – We were back at the Brompton for Joanne to have a catheter procedure to formalise the information needed for corrective surgery at a later date. As time progressed, when she cried there would be a blue tinge to her lips and nose. Joanne was otherwise meeting development milestones and keeping Lauren in check at times!! I'm grateful for the fact that Lauren was very amenable and seemed to take in her stride various

'holidays' with grandparents or day visits with close friends whilst Joanne was in hospital. Whilst at the Brompton in February, they prescribed Domperidone and Ranitidine and also suggested Gaviscon to try and reduce the sickness. Not only was the sickness at mealtimes but sometimes also 1-2 hours later. It would only take for her to fall over after a meal, start crying and then she'd be sick.

### **Rescheduling**

Between February and November 2002, we led a pretty normal life between weigh-ins, dietician appointments etc and then Joanne seemed to begin breathing noisily. I can't remember now if it was a gradual thing or if it started suddenly but Mark and I both put it down to being short of breath, since the time was drawing close to when corrective surgery would be performed. We had an appointment arranged for surgery in December 2002. We anticipated being there up to two weeks, which meant that we'd be home for Christmas. On the day of surgery we were informed that it had to be cancelled. The surgeon was up into the early hours of the morning operating on another patient. We were naturally disappointed and emotionally prepared for it to go ahead but I'd rather it be cancelled than a tired surgeon operating on her. There were other patients who'd also been cancelled once or twice, so there was a possibility of being squeezed into the operating schedule in a couple of days. We expressed our desire to come back in the New Year instead – not wanting to sound ungrateful at the efforts being made to reschedule but we'd rather a more definite appointment.

### **The wait**

Early New Year 2003 – We got another appointment through for corrective surgery. Here we go again.... We made preparations for the care of Lauren as well as emotional and physical preparations ourselves. Surgery (including time to anaesthetise and bring round) was expected to take three to four hours. We browsed aimlessly round nearby shops whiling away the time but as the fourth hour approached both of us were becoming more and more anxious for news. I could stand the wait no longer so hung around outside the security doors to the surgery area waiting to grab any surgical team member, whether involved with Joanne or not, to try and find out some news. A moment or two later a chap appeared and I asked him if he could find out about Joanne.

### **Relief and joy**

He informed me that she was in PICU so I dashed down to get Mark from the hospital foyer and together we waited outside the PICU area until lines and tubes were in place ready for us to see her. What a relief it was. Even as I write this, the sense of relief and joy washes over me again. Surgery had gone well and her recovery was very good. Within a day or so she was eating ice cream. It was so lovely to see the sparkle back in her eyes again. The doctors and consultants were curious to still hear her noisy breathing and tried a course of steroids to see whether incubation had caused her throat to swell. A week later, still no difference.

### **Larynx and vocal chords**

Mr Busche performed a bronchoscopy and said that the aorta (which in Joanne curves round to the right rather than the left) was pushing slightly on her airway and there was some other possible obstruction. Contact was made with a Mr Harcourt who holds a clinic at the Chelsea and Westminster Hospital. We were transferred to Chelsea and Westminster for them to perform a microlaryngoscopy (MLB) and found that she had a floppy larynx and her left vocal chord was also paralysed. They were hopeful of it correcting itself in the course of time and that the laryngomalacia would also disappear when she weighed about 20 kg (she was 10 kg at that stage so it would be two to three years yet). They wanted to be kept informed of her progress and so requested that we see an ENT Consultant locally. After two years of regularly being sick, stomach acid might also have played a part in causing some damage.

Did I tell you that we were in the process of moving house too?!! We were going through the legal formalities etc whilst Joanne was in hospital. You'd have thought we were a glutton for stress or something!! Thankfully our time in hospital did not delay anything and we moved in February 2003.

### **Lump**

Food wise, Joanne was still having things pureed, but fine at drinking milk through a beaker. The vomiting seemed to get worse rather than better. Our local doctor suggested Omeprazole rather than Ranitidine. Weight gain was extremely slow despite filling her with umpteen calories. Early February 2003, Joanne fell onto her chest in the driveway. No doubt it was sore so soon after surgery but a day or two later, we were washing her in the bath and noticed an egg shaped lump between her nipples. We called the

Brompton and described what it looked like, how she seemed in herself etc. They suggested taking her to the local hospital to get it checked out. Was this rollercoaster ride ever going to end?

Lauren was very upset about Mummy and Joanne having to go to hospital yet again. She wanted to come with us but it was her bedtime and I really didn't know how long we were going to be there for. At the local hospital, they examined her and took an x-ray. They spoke to the Brompton and were informed that the sternum (broken to repair the heart) sometimes doesn't heal straight. She was quite skinny looking too which made it seem even more prominent. Not only would she have various op and drainage tube scars, now she'd have a third boob too. We felt so sorry for her.

### **More tests**

Between February and April 2003, Joanne was looking skinnier and skinnier and the sickness showed no real signs of improving. Various health professionals were looking after Joanne and because she'd had a dip in weight before, none seemed overly concerned suggesting that this is 'normal' for her. We felt like we were banging our heads on a brick wall. What weight would she have to drop to before they started getting concerned? As a last means of diagnosis suggested by the Speech and Language Therapist (S & LT), a videofluoroscopy was performed, similar to a barium meal but concentrates more on the throat and oesophagus – her swallowing action and following the food/liquid to the top of her tummy. Joanne was better with lumps and milk but with yoghurts especially, the food would sort of yoyo a bit before going down properly. The S & LT suggested allowing more time for her to swallow in between mouthfuls of food, giving more textured foods, elevating her mattress and allowing 45 minutes to one hour after meals before letting her have a nap or go to sleep for the night.

When the S & LT came to the house and gave me all this new advice, I felt at my wits end and questioned whether this was going to be the way forward to stop the sickness. I felt embarrassed for Joanne's sake in doing this but virtually stripped her naked for the S & LT to see how awful she looked in the flesh. The S & LT looked quite shocked and called the local hospital doctor from our house.

### **NGT**

Over Easter Joanne was admitted, and she and I spent a week there whilst a nasogastric tube was inserted to allow a

special feed to be pumped into her stomach at night. The feed flow rate was started really slowly but even then she was still being sick. Understandably she's not a fan of being in hospital and particularly if she's disturbed at night-time for observations, she just gets upset and is sick again. She began to put on weight, albeit still slowly. The local hospital doctor preferred that the NG tube only stayed in for approximately eight weeks so we knew that around June/July time she'd have a Gastrostomy (tube inserted directly into the stomach). He hoped that this would only be needed about six to twelve months until she was eating sufficient amounts of food not to need it anymore.

### Noisy breathing

The stridor (noisy breathing) was still present and could be heard through the floorboards of our house! It was a bit of a head turner around the shops too – people thought it sounded like croup. On the few occasions when it would stop (ie when she was concentrating on colouring/playing) it would cause me to turn my head and see if she was ok. It became a strangely comforting noise. So much so, even Lauren could sleep through it in the same bedroom!

In June Joanne began spelling – similar to the spells that she'd had before heart surgery. She'd go floppy, her eyes would roll and she'd pass out in my arms. I felt so helpless. I just used to cuddle her and keep calling out her name to try and bring her round. It was triggered by crying so we did our best to keep her calm – resorting to virtually a dummy in her mouth the whole time. Of course you can't prevent all falls and children playing/hurting each other so the spells occurred once or twice a day. I rang the local hospital explaining the situation and went in to be seen. Joanne has open-access to the hospital because of her heart condition. Our usual doctor was not working that weekend and, although I gave a history of what she'd already had and been through, the doctor was none the wiser as to what could be the cause.

What if it keeps happening I asked? Can I take oxygen home for her? I came away feeling not entirely happy and Mark said I should have been more forward in my unease about the situation. I rang the hospital a day or so later and was able to speak to our usual doctor and he said he would speak to the Ear Nose and Throat Department and get back to me. He phoned back saying that he'd arranged an appointment for us to go to Guy's Hospital in London for them to

investigate, early the next week. Phone calls around the family enabled us to sort childcare out for Lauren. Here we go again.....

Phone calls about soon-to-be appointments like these, always send my heart racing. In one sense I'm relieved that something's happening and in another dreading what will happen. Joanne has regularly surprised us in one way or another and my thoughts were of any other surprises in store.

### Vocal chords

We saw a Consultant – Mr Blaney who explained that they'd do an MLB to see what was happening. The plan was for a PEG to be inserted as well whilst she was under anaesthetic – two birds with one stone as it were. We signed the consent forms and were advised to be on the ward whilst the procedure was being performed, then we were on hand to hear what had been found. We just had time to eat lunch before the phone call came asking us to go down to theatre. Our hearts were racing – we were curious and nervous at the same time. We were shown a video of her throat and vocal chords and what we saw made us marvel at her ability to still be alive. Not only was one vocal chord paralysed, but the other one was too and when she cried, they were coming together, cutting off the air supply hence the blue spells. To think that she had had an NG tube passing through such an already narrow gap. She really was a walking miracle.

### Stunned

Vocal chord paralysis doesn't mean that she can't talk since the chords still vibrate but they don't move apart with the windpipe as she breathed, instead they stayed in a fixed position. The only sensible course of action was to have a tracheotomy inserted, creating a safe airway through which she could breathe. We were both stunned. It was a bolt out of the blue and we'd not anticipated anything like this at all. The educated guesses so far had been some kind of internal growth or worsening of the laryngomalacia but not this. Medical staff around us kept saying how sorry they were. When Joanne was admitted, there was another child on the ward with a trachy and so we'd seen some of the care involved, never realising that this would be the same for us.

### Desperately trying to talk

The PEG was inserted whilst she was still under anaesthetic and it was another one to two hours before we were able to see her in PICU. When we caught sight of her,

she clambered to cuddle me, despite wires and all the other attachments. With just a Swedish nose on (small barrel shaped object pushed onto the end of the trachy to moisturise her airway) she was trying desperately to talk to me and I had to lip read to try and understand what she was saying. It cut me to the heart. Would I never hear her voice again, is this how she would always be? It upset us both a lot to see her like this. After a night in PICU she was transferred back to one of the children's wards. Over the next few days we were to find out that a four to six week stay was needed so that we could be trained in how to care for Joanne ourselves at home.

### Overwhelmed at responsibility

Joanne coped so well with her new bodily attachments (PEG and trachy) she seemed totally unfazed by them and that gave us a boost of encouragement. During our time in hospital we learnt how to suction out her natural secretions which I likened to having a runny nose. We changed her neck tapes or necklaces as we called them and then changed the trachy tube itself. All this was naturally very daunting when it's done for the first few times. You can't help but be conscious of where the tube is and the responsibility it carries. We were told that the trachy tube could block off at any time so we'd always need to have a portable suction pump and emergency medical supplies to hand, even if we were just popping next door or even to the local corner shop. That really sunk in for me and I felt very overwhelmed at the responsibility.

### Voice heard

The S & LT at Guys gave Joanne a very basic speaking valve to try and it took a day or so for her to get used to it. She then progressed onto a valve called a Passey Muir which stayed on better and was a very fetching purple colour! There was no looking back then and her voice could be heard properly once again.

From a health point of view, Joanne was well after about a week after surgery. It was learning to care for her that was to keep us in hospital for the next few weeks. Trachy tubes are changed twice a week in hospital, only once a week at home, and we needed to be observed changing them for both us and the staff to feel confident in what we were doing. We knew quite early on that we were going to be there for a while, so we had a good stream of visitors which helped relieve the boredom of being in hospital. We were restricted to being on the ward though because of our lack of experience so by

the end of the third week I was desperate to get home and return to some resemblance of normality. Mark had spent a couple of days back at work – although not fun, at least it was a break.

### Respite

We transferred to our local hospital just for a night and because they don't often see trachy children, nursing staff were being taught how to look after her whilst we were there. Equipment that we'd need to have at home began arriving and it was then it began to sink in again that all this was for real. It was easy to feel cocooned and safe with people to hand who knew what they were doing. Now it was our job. Joanne can need suctioning anytime – day or night – so to relieve the burden of twenty four hour monitoring, respite care was arranged and we had some carers assigned to us for three nights and twelve daytime hours during the week.

There are very few limitations – playing with sand and water is not advised, swimming is a definite no-no. In the safety of our own home and heavily supervised, we chose to let Joanne play in a paddling pool. Having a trachy and PEG do mean that she's prone to infection more often and it means that we've regular visits to the chemist for antibiotics as well as other regular medication.

### Hoping

The prognosis long term is that three to four monthly MLB's will be carried out under anaesthetic in London to laser away growths that naturally occur inside and to see whether the vocal chords have corrected themselves. If they don't, the worst case scenario will be for the vocal chords to be lasered away bit by bit to

create an airway wide enough for her to breathe through, which will be at the expense of her voice. We try to remain on the positive side and are hopeful that vocal chord lasering will not be required. We're hoping she'll have a CT or MRI scan to look at whether there might be a growth or something else on the nerves of the vocal chords as a reason why both of them paralysed.

Now that breathing is not so laboured and calories are not burnt off so quickly, she has put weight on very well and her third boob hardly notices at all. Would you believe she put on 1 1/2 kg during our three week stay in hospital!

Joanne's is a bit of an unusual story which is partly why I thought I'd send it in. She's a real star and it has been a joy and encouragement to us as parents and to other family, friends and medical staff to see her living and coping so well. We are grateful that Lauren was born first and is normal so that Joanne is not cocooned or mollycoddled too much which could be the case if she were an only child. Lauren has had to go through a lot too. And she has fared well and could be a nurse in the making – you never know!! If an outsider weren't able to physically see Joanne's trachy, they'd think of her as no different to any other child her age. She's mentally alert and keeping pace with Lauren in her play and social skills.

### Follow up comments

One thing we have learnt through our experiences is to follow up comments made about procedures that doctors or consultants hope to conduct whilst admitted. They are busy people and it's easy for them to unintentionally forget

about things. The welfare of your child does not carry the same emotional weight or high-priority place in the mind of the health professional as it does in the mind of a parent, so we encourage you to be proactive.

What a rollercoaster ride it's been. It may not be over but we'll deal with the stomach churning times as they go. Although family don't live nearby, they try to do all that is practically possible. We have good church prayer support and emotional support too.

### Terms used:

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

**Tetralogy of Fallot:** Fallot's Tetralogy: a ventricular septal defect (hole between the two ventricles), pulmonary stenosis (narrowing between the right ventricle and the artery carrying blood to the lungs), hypoplastic right ventricle (thick, poorly working right pumping chamber), and overriding aorta (the aorta sits over the vsd and takes some deoxygenated blood back to the body)

**BT left shunt:** rerouting blood from the left arm to the lungs

**Tracheostomy/tracheotomy:** an operation to cut a hole through the neck into the trachea (windpipe) to help breathing. The hole is referred to as a tracheotomy/

**PEG:** Percutaneous Endoscopic Gastrostomy A surgical procedure to place a tube into the stomach for direct feeding.

## RHIANNA

*Susan Ingrey from Thames Ditton Surrey wrote concerning the article about Isolda Kate in the Summer 2003 magazine.*

I went through exactly the same when my daughter Rhianna was born prematurely at 33 weeks by emergency caesarean with the same condition. Weighing only 3lb 12ozs Rhianna was diagnosed with coarctation of the aorta and vsd when she was 12 days old at the Brompton and had surgery that evening as an emergency. Twelve weeks later it reoccurred and she was admitted for balloon dilatation, successfully this time.

As I write she is a well, lively and happy, precious two year old! I was devastated by the news and the pain and anxiety at the

time was indescribable. When Isolda's mother described the experience and feelings she had I found her words so comforting, knowing that someone also knew how I felt at that time.

It has taken me two years to come to terms with Rhianna having this condition. I love and enjoy her as each day progresses to a promising future in a way I never thought I would see at the time. I wish Isolda Kate and her family love health and happiness for the future.

*Susan would like to be in touch with other families with the same condition – please let the HeartLine Office know if you would like to contact her.*



### Terms used:

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

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

# HAYLEY'S STORY

Hayley Robbins wrote:

My name is Hayley Robbins and I'm 12 years old. In July 2001, my Mum, her partner, Dave, my brother, Joe, my stepbrother, Russell and I moved into a new house in Blackwater, Surrey. For seven years, I was treated for Asthma by my old doctor. Since we've moved house, my new doctor, Dr Hinton, has been concerned about my weight. Apparently a girl of 12 is not supposed to weigh 3 stone when her twin brother weighs six. So Dr Hinton referred me to a paediatrician, Dr Maltby in Frimley Children's Hospital. I was given a diet sheet to fill in and follow, which I did and all was going fine.

## Heart condition? What heart condition?

Up until one day I got a cold, went to see the doctor and was thought to have pneumonia. I then got referred to Frimley Park Hospital, under Colonel Moorthy. I attended my appointment with him to have an echo scan, when he asked my Mum, 'How long has Hayley had the heart condition?'

We couldn't believe it. Once we had got over the shock (my Mum and I for not knowing, and Colonel Moorthy for thinking that we knew) it was then explained to us that I had a hole in my heart. Between the left and right atrium.

So we had gone to the hospital thinking I had pneumonia and gone home thinking that it was a hole in the heart.

## Tests

Colonel Moorthy was also a doctor at Southampton Hospital, which is where I was referred to next. Colonel Moorthy also wrote to Dr Hinton explaining everything. And so I found myself entering the cardiac ward at Southampton Hospital on 27 September 2002 and there I stayed for thirty six hours. I had all kinds of tests done, experiencing having a catheter test and a TOE after the doctor had finished examining my heart, she told my Mum

that it was a lot more complicated than just a hole in my heart – it was Partial Anomalous Pulmonary Venous Connection with an underdeveloped lung, called Scimitar Syndrome. Mum then told me.

On the 9 October 2002, which happened to be my birthday, I was in Southampton again, and on the 10th I had open-heart surgery. All went well.

## Kicked out

After my operation, I was in PICU for two days, until they got sick of me making so much noise, so I was taken into high care, where I stayed for another forty-eight hours. When I'd got kicked out of there, I was in the normal ward again.

A few days after that, I had my dressing taken off, nobody could believe how neat my scar was) and my pacing wires taken out. I was then allowed out of the ward, so my Mum and I went downstairs and bought a bag of roast-chicken flavoured crisps – my favourite!

## Wesley – too many legs for a visitor?

My Nanny, Granddad and Uncle Adam had been coming to visit me with my brother, Joe, but this time I was really excited because Dave was bringing my puppy down to see me. His name is Wesley. At home, my Mum said that he wouldn't settle down because he knew somebody was missing, but when he was at the hospital, he was really pleased to see me. I was very pleased to see him too! I was also surprised when Chloe, my best friend, came to visit me. She gave me a get well soon card and some presents. When it was time to leave the hospital, I was really sad – I had had a really good time there. Everything and everyone were really nice there, and I had made friends with nearly all the doctors and nurses.

## Presents

Before I went home, I went downstairs and bought Sally, Kelly and Sara (who were the nurses which looked after me

# 'My puppy, Wesley, came to see me'

the most) Usha and Irene (who are two of the doctors) Annie (a nurse in intensive care) and Mr Haw (my wonderful lifesaving surgeon) a present each and said goodbye to everybody. I went into hospital again on Tuesday 15 April 2003. Everything was fine, although I still have to have aspirin every day to stop the blood clotting where they did the surgery. I was allowed to do PE at school and I don't get as breathless as I used to.

I have recently had another check-up and I don't need aspirin any more and I don't need to go back to the hospital for another two years.

Thank you to everybody at Southampton hospital and everybody who helped!

## Terms used:

**Partial Anomalous Pulmonary Venous Connection:** some of the veins bringing blood from the lungs don't drain into the left atrium.

**Scimitar Syndrome:** the vein from the right lung drains to the inferior vena cava – the big vein carrying deoxygenated blood to the heart from the lower part of the body. The vein is shaped like a scimitar sword. The right lung is usually underdeveloped.

**PICU:** Paediatric Intensive Care Unit

**TOE:** Transoesophageal Echo – an echo that is carried out from inside the oesophagus.

## The message board

Have you had a chance to read the HeartLine message board yet? There is usually something of interest being discussed for all of us. As we go to print:

Alayne writes: "If anyone can offer any advice on what to do on the day of the op, all suggestions welcome. I feel sick thinking about when he gets taken into theatre ..." Answers range from sleeping to shopping.

"We have a home care nursing team who visit fortnightly to check him and a doctor who will see

him any time during surgery hours. My enquiry is whether these services are unique to my area or is this standard across the counties?" asks Paul, who is about to move to a different part of the country. So far replies suggest people find their local services are available and helpful – let's hope Paul finds this is the case in the family's new location.

"I know this has probably been discussed several hundred times before" says Jo, opening the thorny subject of endocarditis again, 'but wondered if anyone could give some guidance on when I need to be careful with my son Oliver, aside from the usual precautions with the dentist. Eg, if he falls

and his mouth bleeds should I be concerned? If he falls and cuts his leg?..." Lots of response on this bewildering and frightening subject.

"We were sent home not knowing what (if anything) could be done. I have never shed so many tears. I have been unable to sleep or eat and I am terrified that my beautiful son is going to die and I am unable to stop these negative thoughts. I feel I am going insane with grief..." This mother received several messages of support and some practical suggestions as to how she could find out more about her son's condition.

You can join in the discussions at [www.heartline.org.uk/messageboard](http://www.heartline.org.uk/messageboard).

## CATCHING UP WITH IMOGEN

*Sue Gearing has been HeartLine's contact for parents with children with Tetralogy of Fallot. She writes:*

A number of years have now passed since I wrote the last article for Heartline concerning my daughter, Imogen. In the intervening period I have spoken to many mothers (and fathers) whose children have just been diagnosed, are about to undergo surgery or have undergone surgery, in relation to Fallot's Tetralogy. Imogen's Fallots was corrected in July 1998 at Great Ormond Street and now that she has started school, it felt right to pen an update on how she is getting on.

Imogen is now full time at school, in her second year, and loving every moment of it. So far she has not been restricted in anything that she can do, either physically or mentally, and is a happy, smiley six year old.

### **Needn't have bothered!**

The school Imogen went to has been particularly good in keeping an extra eye out for her and, at the same time, ensuring that she doesn't feel that she is different. Indeed, in many ways I needn't have bothered asking them to keep an extra eye on her as she powers around and gets involved in everything in exactly the same way as all her classmates.

Looking back, I still find it amazing that, at a little over eight months, she underwent open-heart surgery and yet, here I have a healthy pain of a six year old with far too much energy.

### **Dancing**

Her energy levels have been such that she has now taken up tap dancing on Saturday mornings and also modern dance on Tuesdays (which is a sight to behold!). She has been at dance classes now for over a year and loves it.

Whilst going through the trauma of the diagnosis and the surgery, it is very difficult to imagine that you will ever emerge from the other side. Thankfully, we have and, as you can see from the pictures, so has Imogen.

### **Spoiled rotten**

Being a realist, I fully appreciate that she may need some further surgery in the future and very few days pass without me looking at her, wondering whether this will or will not be the case. I still feel guilty when I tell her off or send her to her bedroom and she is still spoiled

rotten by all my family and friends.

Imogen now has a baby brother, Stephen. He was born on 12 April 2002. During my pregnancy I had a number of extra scans to try to ascertain whether or not Stephen had Fallots. He did not, for which I was very grateful. However, at the time of these scans, looking at how well Imogen has done, I remember saying to the Consultant that it wouldn't seem like the end of the world if he did have Fallots. One of the wonderful things about this heart condition is that it is fixable. Imogen and Stephen adore each other, although I am waiting for the inevitable sibling rivalry.

Interestingly, as Imogen has grown up she has always been aware of the fact that she has had a problem with her heart. She is very proud to inform people that when she was born her heart was broken but that Doctor Phil (her name for Phil Rees at GOSH) took her to London and fixed it. She will then proudly show her scars on her chest and then tell everybody that they need to give money to the hospital in London so that Doctor Phil can fix other children!!!

### **Hunt the Hoola Hoops**

As she gets older she has become more interested in exactly how her heart was fixed and how her chest was 'unzipped', but as we have always been very open with her about it, so far she has been completely accepting and happy about everything.. In September 2003, at her last check up at Great Ormond Street, we took a packet of Hoola Hoops and when Doctor Phil was doing the scan, we tried to hunt the Hoola Hoops whilst she was eating them. She informs everybody that Doctor Phil is very good at hunting Hoola Hoops! She is also very fond of the sticky stickers that she has when undergoing an ECG. We started this at here previous check-up and it has worked well to take away any fear she may have had.

### **Coped**

When we last saw "Doctor Phil", he decided he did not need to see Imogen until Christmas 2005 and therefore Imogen will not see him for two years. It is interesting that she complained to us that she was not going up to London to see Doctor Phil and that she was worried that he would forget her and not want to



play with the Hoola Hoops. I am sure that Imogen has so far coped well with her experiences because we have tried very hard to support her in a fun way. This has not always been easy for me to achieve but the results in Imogen are there to see. I am hopeful this will continue as she grows older and, inevitably, becomes more inquisitive about the exact details of what went on. The real test of course will be how she reacts if she does need further surgery.

When Stephen was born Imogen told the midwives all about her heart then asked them if they wanted help to fix Stephen's. We explained his was already fixed to which she said 'Poor Stephen, that's not fair, never mind I'll share Doctor Phil with him anyway....'.

### **Starve themselves**

Feeding, well there's an issue! Probably in retrospect the most stressful part of my relationship with Imogen. I have just read the article in Issue 60 by Liz Collins and it is spot on. I particularly love the part where a paediatrician told them that no child will deliberately starve themselves. The number of medical practitioners friends and relatives who have told me that.....believe me Imogen can!

We managed to avoid the tube, but the lengths I went to and still go to to ensure Imogen intakes food are quite amazing. Whilst she was a baby she would only take

*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](mailto: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 3-4, 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.

one to two mls max from a tiny Maws bottle, but only if lying down in her cot at night. So for over 12 months I fed her hourly like that through the night. Gradually during the day things progressed. However a good meal would be two teaspoons of solids and one ml of milk.

### Ways and means of feeding

Distraction was always the key to getting a bit of food into Imogen during daylight hours.

At the age of three, a milky button used to make her thirsty enough to drink her milk from her cup – one mouthful that is! We've operated bribery charts, penalty charts, eat whatever you like whenever you like, no nibbling between meals, cook your own, go to a restaurant, surprise new cartoon plates, mugs, cups etc etc etc etc etc etc.

Imogen has been known to hide food in the cupboards in the kitchen and then pretend she's finished. I find it two weeks later as it walks out the cupboard!

School lunches are one piece of ham (small!), three grapes, some cold pasta (about 10 small shells), a cup of water and one mini cookie. If the box is empty when she comes home then we're on a good day!

### The Imogen Centile

Until the age of two I used to keep a food diary solely for my own benefit so that at the end of the day (or night) I knew exactly what had gone in. She is at six just over two stone – small but perfectly packaged. We have the Imogen centile which runs parallel to the bottom line on

the graph. We've never made it onto the graph. The comforting thing looking back is that she has over the six years, with a few small dips, been consistent on her line. Her general consultant Doctor Mark (Mark Evans) weighs and measures her every six months and as long as she remains consistent from a velocity of growth point of view leaves us to it. Seeing Mark regularly has eased the pressure enormously.

Imogen now eats very well compared to a few years ago but in comparison to her friends eats very little. However her friends think she is very lucky as when I'm asked by Imogen if she can have a biscuit or snack or anything that's edible, where their mums often say no, I jump up and down with delight shouting YES YES YES.!

### Communicate

Finally, there is one thing I would like to say to all parents of heart children and this is something which has come up time and time again from the calls that I have had with parents over the last three to four years. At some stage in every call every parent has commented that they haven't felt comfortable in ringing up the hospital, either before or even after operations, to ask the Consultant about something which is concerning them in relation to their child. For whatever reason – being a nuisance, being silly, wasting people's time etc etc.

You are that child's parents and you have a right to fully understand what is happening in relation to your child. It is an exceptionally stressful time and there is a lot of information which you have to assimilate and understand. Much of this

information is technical and very few of us parents will have done a medical degree. For goodness sake, PICK UP THE PHONE. You are not a bother, you are not silly, you are not stupid – you are a parent who is concerned about their child. You are the one that will have to look after that child in the years to come and the child's well-being is therefore very dependent upon the parents 'remaining in one piece'. Therefore communicate, and if you have a medical practitioner who fails to communicate with you, or you find difficult to understand, then do not give up but approach the person constructively and respectfully and ask them to communicate more fully with you or to explain whatever you haven't understood.

### Call me

The jobs that the medical practitioners do are extremely stressful, but that in itself is no excuse for a failure to communicate effectively with parents of a sick child. To use time more effectively, it is a good idea to start a notebook and every time something comes into your mind, write a note in the book to remind you about what it is. This will mean that you can use your time face-to-face with the Consultant more effectively. As always, any Fallots parents who want to call are very welcome.

Be warned, however – Imogen hears the phone before I do and, if she is in the house, tends to get to it first. She can talk the hind legs off a donkey and therefore it may take half an hour before I manage to wrestle the phone from her grasp!

### Terms used:

**Tetralogy of Fallot:** Fallot's Tetralogy: a ventricular septal defect (hole between the two ventricles), pulmonary stenosis (narrowing between the right ventricle

and the artery carrying blood to the lungs), hypoplastic right ventricle (thick, poorly working right pumping chamber), and overriding aorta (the aorta sits over the vsd and takes some deoxygenated

blood back to the body)

**...avoid the tube:** Didn't use a nasogastric tube, through which food passes into the stomach.

## PAIGE

Jaqueline Hedges from Wickford, Essex, writes: My daughter Paige went Trick-or-Treating in our road and collected money for HeartLine. I have enclosed a cheque for the proceeds and this photo of how she looked on the day. Paige is 6, and had an ASD but had open heart surgery when she was two and a half to mend the hole, and is very fit and well now.

### Term used:

**ASD:** an Atrial Septal Defect – a hole in the wall between the atria.



*Miss Mackenzie is Headteacher of Park Wood Infant School in Gillingham Kent. She wrote to Anita Ford:*

'Please find enclosed a cheque for HeartLine from park Wood Infant School for £120.

All our children enjoyed raising this money and we look forward to hearing further news of the HeartLine campaign.'

Thank you! to the teachers and children who helped Josh with raising this money.

# ABOUT AARON

*Linda Hardy writes ...*

At my routine nineteen week scan the radiographer could not see the valves in the baby's heart. She also pointed out she could see three cysts on the brain. I was asked to come back the following week, in order for it to be viewed by a consultant. This I did. The consultant could see the problems in the heart and the three cysts on the brain were still there. In came the possibility of the baby having Edwards Syndrome, which would prove to be fatal. The only way this could be proven one way or the other was to have an amniocentesis. This I was totally against.

I was then referred to Great Ormond Street Hospital where they did a much more detailed scan, and told us exactly what was wrong with the baby's heart. It was not good. On a scale of 0 to 10, 0 being nothing wrong and 10 being too bad to do anything with, we asked where it would be. Eight pushing 9 was the answer. Edwards Syndrome was also spoken about here too. If it was, then they could not operate, as the Syndrome would overpower the operation and the baby would die.

I was told I could wait and have the baby's blood checked when it was born, which could mean the baby dies before they have the chance to operate, or have an amniocentesis test so they could plan the operation and all the other detail. I really had no option. I had the amniocentesis done. The following few days were the longest days of my life.

Finally the phone call came. Good news said the consultant. It is clear of Edwards Syndrome, but it has indicated Klinefelter's (47XXY). I was so relieved. The phone then went down. I then sat wondering what on earth is this Klinefelter's? The phone rang again. It was the consultant again, to briefly explain Klinefelter's.

Aaron's heart problems have been diagnosed as double outlet right ventricle, pulmonary atresia (Fallot's type) and ventricular septal defect. He had his first operation at twenty-eight hours when a right sided shunt was fitted. This shunt collapsed at ten months old and he nearly died. Many people taking their part saved him.

Knowing he has the syndrome helps us, as we know what might lie ahead of him. We already know he may need extra help with his education. We already know that he will know treatment for it in the form of testosterone injections, as this he lacks. Other than that we know little of how it will affect him as, like many of these syndromes, it affects everyone differently.

## Aaron – your story

A date arrived for your cardiac catheterisation – it was 11 June. We had to be at GOSH for 10am the day before. Daddy and Calum travelled down with us and went home later leaving us alone, after the usual tests in which you were very good.

### Broken

You were booked for a 1.30pm operation. I signed the paper work and waited. We played most of the morning. You were not allowed food for six hours before and no water for three hours before. I got you all ready and we watched the little girl go down before us and I was getting slightly nervous. Then the bad news, the machine had broken. They could not do it. I gave you your lunch and packed to go home.

We were booked in to come back on Monday 16 June for it to be done the next day. We returned at 4pm on the sixteenth as you had had all the pre op test done. This time you were first on the list at 8.30am. The evening went quickly and you slept through to 7.30am. It was not long before you were collected and taken down. I waited on the ward. Two and a half hours later you returned. You recovered so quickly that at 3pm you were allowed home.

On 14 August we went up again to GOSH for a pre admission clinic. The operation we had been waiting for was booked in for 13 October and you would be admitted on 12 October, the day before.

### Delay

Then on Friday 5 September Nicky at GOSH rang to say unfortunately the date had to be changed to admission on 2 November for the operation on the 3rd. It could have been the weekend before, but it would have been over Calum's birthday and I said no. We were absolutely devastated that we would now face an even longer wait. There was nothing we could do except pray. I wanted the operation sooner and only God could make this happen.

### Implications

It was still totally unexpected though when at 5.20pm on Tuesday 9 September the telephone rang and it was Nicky from GOSH. I automatically said OK, so when in December is it going to be now! To my total surprise she said, "We have a cancellation so can you come in tomorrow. His operation will be on Thursday." I jumped at the chance and realised the implications soon afterwards. Nothing however was going to change it. I telephoned every one. Nanny was sorted out to care for Calum. I went to get the train tickets and Daddy went to collect Calum from After School



Club. Calum was very upset. He helped pack our bags.

### Wednesday

Mummy still looked after Sasha and Megan up to 12 noon. They were picked up and Granddad came to collect us for the station. We were hoping to get the 1pm train. But we got there in time to get the 12.40pm train. You slept the whole journey. We went to GOSH by taxi and arrived at 3pm. There we sat around and waited. Your bed was eventually ready and we unpacked some things.

Calum and Nanny left at about 5.30pm. They caught the 7pm train home. The anaesthetist came round to see you and also the surgeon. Daddy was found somewhere to sleep the night and was so tired he was going over to bed at 8pm. But as Daddy was about to leave you decided to be sick! Not good for someone about to undergo a major operation. It was in front of two doctors as well. Should you have been sick again the operation could not go ahead. You slept well most of the night. Mainly in bed with me. I prayed hard that you would not be sick again.

### Thursday

The operation was due to start at 8.30am. You were not allowed any milk or food from 2.30am, or water after 5.30am. You were very good. You woke up at about 6am. Daddy came back about 6.30am. We played with you as much as we could and then gave you your pre-operation bath. We were told you were going to have a pre-med at about 7.30am, but they had to ring from theatre to say give it. 8.30am came and went, no call. We thought the operation would be starting late. By this time you were getting hungry and difficult to entertain.

Then they called up for you. Sister Heather came and told us they were ready. We took you down. Mummy carried you all the way. The anaesthetist was lovely. You sat on my

lap and made no fuss at all. They started you off with strawberry scented gas, then, as they called it, the smelly socks.

### **Six to eight hours**

You were fast asleep. Mummy and Daddy gave you a last kiss and left you in the care of the team. We were told it would be 6-8 hours. We returned to Ladybird ward collected our things. We were given a bleep that would go off should we be needed at all or when the operation would be over. Then we went off to parent accommodation to get our room. We were over in 3 Powis Place 3rd floor, room 9. Daddy found it hard with all the stairs. We sorted out our things and then decided to go out for breakfast. We then went for a nice long walk and also a trip to Sainsbury's.

### **Waiting**

We returned to the room and sat and waited. It was a long wait. Six hours passed, it got close to seven. Seven hours passed, then finally after seven and a quarter hours the bleep went off. We returned to Ladybird ward. You were out of theatres and in intensive care. We went down, we sat outside waiting to be called in. Mary Goodwin came to see us. She said it would be about 10 minutes or so. Well it ended up being nearly an hour as you had pulled out the ventilator and they had to sort you all out again. You did not react to the sedation enough – you kept waking up too much on it so in the end they had to give you a paralysing drug.

### **Survived**

It was great to see you. You had survived the operation. The only way now was up. The surgeon came over to see us. They managed to do a better operation than they planned. They did not have to put in a valve. Your pulmonary artery was long enough to do the operation without it. This was better, though you may have to have one put in once you are a lot older. You continued to do well, though you had bruised your windpipe when you pulled your vent out.

During the night you really came on well, so well that they thought you were ready to have your vent out. They tried at 4am. Unfortunately because of the damage you had done to your windpipe you could not manage alone. They had to quickly put it back again. This caused you more bruising.

### **Friday and Saturday**

They decided then you needed some steroids to help take the swelling down and also lots of rest. They would try again on Saturday or maybe during the night if you showed signs of being better. You spent the rest of the day just as you were. On Saturday

your temperature went up to 39.9 and your heart rate was far too fast and they really did not know why. They could not take out your vent with you like this. They managed to get your temperature down but they had to find out a reason why.

### **More surgery**

They sent off samples to be tested, and you also had another echo scan. We had returned to our room. When we came over to see you again we were told the echo showed a small hole in the patch they had put over your hole in the heart. We were told you would need more surgery. We were devastated. After a great deal of discussion they decided the best thing would be to do another cardiac catheter. This would show them exactly what was wrong, and was planned for early Sunday morning. They kept you asleep and on the paralysing drug so you would not have to wake up and then be put through it all again. We signed the consent forms.

We left you again – you looked so peaceful and we knew there was nothing else we could do. We got on the phone and told as many people we could.

### **Sunday**

We returned to you early as we thought you were going down at about 9.30am. In the end they had two other emergencies and you did not go down till 1pm. Again we left you in their care. We went to Covent Garden, sat in the sun and ate lunch and bought some tea. We were in a shop when Dr Graham Derrick called us on Daddy's mobile. They had completed, and you would not face any more surgery. The catheter did not show any hole at all. We knew God had healed you. The whole of King's Community Church plus many others had been praying for you. We were over the moon. We made our way back to see you. They instantly stopped the paralysing drug and slowly downed your ventilation. You coped very well.

### **Monday**

They spent the day preparing you to come off the ventilator. They tried at 3pm but you did not cope on being bagged alone so they could not risk it. They said it could be down to the large amount of sedation you had had. We went out for a drink and when we returned they were in the process of taking it out. It came out at 5.15pm. I was at last allowed to give you a hug. I did not want to let go of you. You were very sleepy due to all the drugs they had given and were still giving you. But you were doing great. They weaned you off all the drugs over night. You also had loads of diarrhoea. This they put down to the antibiotic's you were still on.

### **Tuesday**

We came over early again to see you. You were so well they were prepared to get you upstairs to DJW, the high dependency ward. They were full – no room. They decided that, OK, you were now well enough to go up to Ladybird ward.

Once this was finalised we returned to our room and packed all our things up as Daddy would have to go home and Mummy would sleep on the ward with you. We then decided to go out for lunch to celebrate it all. We went to Pizza Hut.

We returned at about 1.30pm. You were fast asleep in Ladybird ward. We started to unpack your things. Daddy went home. They then decided, as you had had so much diarrhoea, to save it being passed to everyone else, you needed to be in a side room alone. This was great. I could watch what I wanted, listen to the radio etc etc. It was a bit restrictive, as I could not take you out anywhere. You were still too sleepy anyway.

### **Wednesday**

After a good night you were sick. It went everywhere. When the doctors came round you were put on clear fluids only. You still slept most of the day and by the night they decided you had not had enough to drink, and so a drip was started up. This was started at 10pm. You slept well. At 2am when they checked you all was well. At about 3am you woke up and needed a changed bum. The cot was soaking wet. The cannula had come partly out of your arm. I think you must have pulled it out. They decided to leave it and sort it in the morning.

### **Thursday**

You were a lot livelier. The doctors came round and said you looked over-saturated and were glad the drip stopped when it did. They said all being well you should go home tomorrow. You were allowed to go out and about again. I took you to the park and then down to Holborn High Street in the morning and later on to Covent Garden for a while. You were eating well by now as well.

### **Friday**

You had your stitches out at 10am and soon after that the doctors came round and said you could go home. We were on the 11.30am train out of Liverpool Street. Whilst on the train we noticed that your t-shirt was getting wet. Pus was coming from one of your stitches, so we took you straight to the local doctors, who put a dry dressing over them and gave you another course of antibiotics. But at least we were home.

### Terms used

**Edwards Syndrome** is the result of a child having three, instead of two, copies of chromosome 18.

**Klinefelter Syndrome**: instead of inheriting either chromosomes XX (for a

girl) or XY (for a boy), a child inherits two X and a Y chromosomes. This happens in about one in every 1000 male live births.

**Double Outlet Right Ventricle**: the right ventricle pumps to the lungs and to the aorta.

**Pulmonary Atresia (Fallot's type)**: the pulmonary artery is blocked or missing. In Fallot's Tetralogy the pulmonary artery is narrow (pulmonary stenosis).

**Ventricular Septal Defect**: a hole between the right and left pumping chambers – the ventricles.

## FEEDING – one hospital's approach

*Linda Griffiths is Practice Development Nurse at Alder Hey – Royal Liverpool Children's Hospital*

Feeding difficulties are extremely common amongst children with congenital heart defects and nutritional support is a very important part of their treatment. Adequate growth has many advantages. Not only does it allow them to grow at the same rate as their peers (particularly important as they approach their teenage years) but it also adds to their general feeling of well being.

### Less risk of surgery

It is recognised that adequate growth also adds to the likelihood of a successful outcome from surgery, and has a positive influence on post op morbidity. If the child is bigger when they undergo surgery then this means that the surgeon can use larger prosthetic material and therefore reduce the risk of re-operation.

### Need calories and protein

Children in congestive cardiac failure have higher energy expenditures than healthy children and therefore require a greater calorific intake to ensure normal growth. It has also become apparent over recent years that not only do they require extra calories to gain weight but they also require extra protein in order to grow in length as well. This is rarely achieved against a background of cyanosis and congestive cardiac failure. Breathlessness, exhaustion and food intolerance are common and frequently these children require naso-gastric supplementation.

Traditionally these children have been managed with long-term naso-gastric tube feeding, calorie dense feeds and more recently, combined with protein dense feeds as well. This has not always proved successful as it is felt that the naso-gastric tube may contribute to gastro-oesophageal reflux and oesophagitis. The tube also interferes with the development of feeding skills and ultimately with the development of speech and language. Many children who have had long term naso-gastric tubes develop aversive feeding behaviours to the point where they would not tolerate anything near their mouth at all let alone putting food in.

### Early PEG

The benefits of early insertion of a percutaneous endoscopic gastrostomy (PEG) were being investigated on the unit at Alder Hey Children's Hospital. A retrospective study was undertaken by Dr Ciotti, which reviewed the nutritional status of children with congenital heart disease who had a PEG to deliver nutritional support, compared with a matched group of children who had received standard nutritional support. The results of the study were compelling and as a result, the team at Alder Hey have concluded that early insertion of a PEG was to be recommended as opposed to long term nasogastric feeding to support nutrition.

As a unit we had always been aware of the challenge of looking after these children. We were also aware that more and more children were being admitted for PEG insertion with ever increasingly complicated feeding routines that parents would have to manage at home. In addition, the cardiac liaison nurses were reporting many families were looking after their children at home with long-term nasogastric tubes with very little co-ordinated support.

### Survey

We started to look at these issues as a multidisciplinary team, including a gastroenterologist, cardiologist, cardiac liaison nurse, speech therapist, dietician and the practice development nurse from the ward. In the first instance we met together to look at future service provision and decided that one of the first projects to be undertaken would be a patient satisfaction survey. It was felt that it would be interesting to gather the views and opinions of families of the existing service. This also meant that any improvements that were implemented could be measured from a quality point of view.

It was decided to carry out a postal survey. Seventy five families were targeted as having a child with a feeding problem. 45% were returned – of these many were comprehensively filled in with add-on sheets attached. Again the results were quite

compelling. As a multidisciplinary team we were exploring the idea of a cardiac feeding clinic and the survey backed this up – 65% of those surveyed described the idea of a cardiac feeding clinic as an excellent idea. It was also apparent that most families had access to all the services they needed, but they were delivered in quite an ad hoc manner.

### Clinic

Finally in April 2001, at no extra cost to the Trust, the first exclusively combined cardiac feeding clinic was set up. It planned to see five families with a half-hour clinic appointment each. This ensured that families would experience a systematic, co-ordinated approach to their child's feeding problem that is closely linked to their cardiac review. The advice that they receive is always consistent as they meet the whole team together in one room.

The feeding clinic has been invaluable as a learning experience for staff and it is hoped that staff from outside of the Trust would feel free to visit. They would always be made welcome as the opportunity to teach other staff is seen as invaluable. The team have recently won the "Innovative Team of the Year" award 2003 at Alder Hey which has been an honour and those involved feel very proud to be a part of something that has made such a difference.

The future is full of potential for further development including ideas to develop specific feeding leaflets to cover various conditions written in a jargon free manner to back up verbal information that they are given in the clinic. The audit seemed to suggest that a support group would be helpful to many families. Also the clinic is to be used as a base for a pilot study entitled 'Pilot study of neurodevelopment status and cardiac outcomes following nutritional interventions in children with heart disease and feeding difficulties'.

*Ed – This article has been provided by Children's Heart Federation. For more information please contact CHF on freephone 0808 808 5000.*

# CHRISTMAS DRAW 2003

Thanks to your combined efforts, the draw has raised £3,188.25. The money will help us to maintain and develop our core activities in 2004. Therefore, 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. Therefore, we would like to extend our sincere thanks to all of them.

The names of the winners and sponsors are:

Ticket No.	Prizewinner	Prize	Sponsor
2131	Diane King	2 Return Tickets to New York	Virgin Atlantic Airways
8761	Karen Frew	Message-Cam	Casio Electronics Co. Ltd.
23923	Jolene Thompson	DVD Player SD230E	Toshiba Information Systems (UK) Ltd.
6925	Melissa Needham	Printer MPC400	Canon (UK) Ltd.
18210	Karen Bartlet	Combi-Oven	Samsung Electronics Research Inst.
1007	Ian Gaskell	Compact Discs	Universal Music
3950	Ashleigh Hacker	Compact Discs	Universal Music
18230	Arthur Cooper	Compact Discs	Universal Music
5944	Sandra Lees	Compact Discs	Universal Music

## TO THOSE WHO DON'T KNOW ...

*You might have all guessed by my most recent postings, writes a mother on the email list, that I've been feeling pretty down over everything lately. Tonight – I've sat and written this, I hope it doesn't upset anybody – but I just thought I'd share. It's aimed at a certain insensitive friend (who incidentally will never get to read it!).*

**When your child ...**

Says 'Mummy' at three and a half you barely notice; you never think 'Oh wow – he can still say it'.

**When your child ...**

Spikes a fever, you never think he's in heart failure and check his ankles.

**When your child ...**

Spikes a fever a week after a fall – you never think 'he may have bacterial endocarditis'.

**When your child ...**

Cut's his lip, you don't spend five hours in casualty waiting for emergency prophylactic antibiotics.

**When your child ...**

Goes to school, you don't think, "I hope his poor speech is accepted by the other kids and he gets friends".

**When your child ...**

Goes swimming, you don't have to ignore the people looking at your child's chest scars and explain to others why he's so blue when he's in the water.

**When your child ...**

Tells his teacher something, you never have to worry that he was misunderstood – and really he said something else and just goes along with her for the 'easy option'.

**When your child ...**

Is asked to take a baby photo into school, you don't have to panic and hunt endlessly beyond the ones in the PICU looking for one that won't 'offend' anyone in the class.

**When your child ...**

Undresses in class for PE, you don't worry that other kids will tease him.

**When your child ...**

Sees snow for the first time – you are overjoyed, not filled with dread over how his body will cope.

**When your child ...**

Starts school you imagine his bright future – not worry endlessly that he may die from his 'heart problems' before he finishes his education.

**When your child ...**

Comes first in sports day, you are filled with pride that he won – not filled with pride that he's alive to try.

**When your child ...**

Has a cold and high fever, you wrap him up warm and give him cuddles and calpol, you never silently worry that his heart may not cope with the strain.

**When your child ...**

Comes home from school, it's the end of another day – not the beginning of

one more evening together.

**When your child ...**

Goes to bed – you 'chill out' – not pop up and down stairs every half hour to check he's still breathing.

**When your child ...**

Brings home his school photo – you think 'how cute!' Not marvel over how lucky he was to make it that far.

**When your child ...**

Goes to school in the winter, you wrap him up to keep him warm – not to prevent him from going blue.

**When your child ...**

Goes for a school medical – it's no big deal – you don't worry the whole week before over what 'else' they may find.

**When your child ...**

Plays outdoors in the windy autumn evenings, he comes in cold and red with a runny nose – not blue, breathless and coughing like an old man.

**When a brown envelope ...**

Drops on your doormat – your heart sinks over an unpaid bill – not yet another hospital appointment.

**And finally ...**

I'm willing to bet you've never sat browsing the Internet at night, crying your heart out for a stranger – reading the story of their child, who just lost their life to the same condition that your child has.