



# HeartLine

**Issue 63**

**Summer 2004**

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**1979**

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**2004**

**Luke - the boy's got style!**

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## From the Editor

Summer 2004

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At some point, with the luck of the gods and good medicine, your child will be old enough to start taking over responsibility for their health care.

It would not be wise to decide on 16th birthday that you should dig out the massive file of medical notes, and dump it on his or her bed. After all, it may have taken you, the parent, years to understand your child's condition,

how the surgeries have adapted the circulation, how to put it in language that your GP or Health visitor can understand.

Your child needs to know that he or she is not just a prop for a conversation between you and the doctor. So prepare for the consultation as you would for surgery, explain why it is happening

and what your child's role is, what they may like to ask, what they may want to talk about, and what you are going to ask.

Your child's condition doesn't belong to you – lay the foundation as early as possible for your son or daughter to exercise self-responsibility for it.

**Hazel Greig-Midlane**



# HeartLine

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I need your pictures and stories for  
Issue 64 Autumn 2004 by end of October:

**by email:**

hgmhla@btinternet.com

**by post:**

**by telephone:**

**contact details:**

HeartLine Office details appear on  
page 10.

**Front cover:**

Luke McCarthy

# SIMON'S STORY

Tricia Pope, founder member and ex Chair of HeartLine writes

This article was written at the editor's request to coincide with the 25th Anniversary of HeartLine. Unfortunately, due to other constraints on my time, it was not possible to get it written for the last publication.

## The beginning?

Because Simon's and our family's involvement with HeartLine began when the organisation started I am tempted to start there – at the beginning. However a friend I met through work, who has a young baby with a severe heart problem, said something to me the other day that set me thinking.

I was having a moan about Simon, as parents do. Was he spending too much money? The flat he and his girlfriend are living in is tiny – how do they expect to move to something bigger if they don't save? Why have they set their sights on a big wedding when the money could be better spent on buying a house? My friend's response was: "Do you realise how normal your moans are? If I thought that in 20 or even 25 years time I would be in a position to have the concerns you have now I would be ecstatic."

## Overcome and achieved

It has been 25 years (well nearly 27 actually, Simon was born in October 1977) and it has been a long haul. But, through our concerns about the way Simon chooses his priorities in life now, his father, Simon's sisters and I all share a deep thankfulness and pride at what he has overcome and what he has achieved. And that is where we are now.

## Milestones

The milestones of Simon's life come in two packages: the milestones that he has achieved through his life and the health milestones. The health milestones were:

- Born with Pulmonary Arteries with intact septum (ie no pulmonary valve and no way for the blood to access the pulmonary artery from the right ventricle.) Also small right ventricle which has never grown to normal size.
- Operation at 24 hours to clear the blockage to allow blood flow

through to pulmonary artery and thence to the lungs.

- Operation at 9 months to construct a flap where there should have been a pulmonary valve.
- Operation at 6 years to insert a homograft pulmonary valve.
- Operation at 19 years to replace homograft pulmonary valve.

It is probably worth noting that since all this took place there have been major breakthroughs in paediatric cardiac surgery and the course of treatment may now be different.

The early years were difficult – as they are. The nightmare of feeding a very poorly new baby every three hours with a toddler also needing attention. The traumas of surgery and the difficulties at school.

## Special needs

Simon was assessed with special needs as many heart children are. He had spatial perceptual and sequencing difficulties which severely affected his ability to read and write and to organise his work. These difficulties were part of his entire school career. Not helped I have to say, by a disinclination to apply himself to any subject that did not interest him – most academic subjects! He enjoyed English when it meant he could compose stories about SAS men doing amazing feats. He really learned to read in his teens when he became interested in the books of Andy McNab, Bravo Two Zero etc. If Harry Potter had been around then, who knows?

After a year in sixth form doing an NVQ in social sciences Simon attended the local community college to do a two year performing arts course. His main interest here was stage management and it was also during this time he underwent his last operation.

## Turning point

Looking back it seems that this op was the turning point – or maybe it was just that Simon grew up, or a combination of both. He had been interested for some time in weight training and keeping fit with regular work-outs at the gym. These tailed off in the year



*Normal concerns*

leading up to and following his operation but resumed once he had been given the all clear. I quietly wrung my hands to start with, but it became increasingly clear that there were benefits to the exercise – Simon developed more stamina and seemed well able to cope with work, including hauling equipment about and climbing ropes when he went through his stage construction phase.

## Did very well

Three and a half years ago Simon applied to the Beds and Herts Ambulance Service to become a Patient Transport driver. He loved the work which combined driving and working with people, both things he is good at. After eighteen months he successfully applied to join the Ambulance Technician's course. He did very well at the practical and verbal aspects of the course. After discussion with his tutor it was agreed that instead of taking a written exam he would undergo a verbal exam and spend a longer period on the road with a paramedic mentor before qualifying. This Simon did a year ago and now has his sights set on applying to the paramedic's course. As with everything he has decided to do, we will support him and wait and see what transpires.

In the meantime there is a wedding to help him and Laura save for, and encouraging noises to make about the benefits of key-worker housing as a first step on the property ladder!

## POWER KITING

*Debbie Ellis, mum to Charlie, writes:*

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Charlie started power kiting last year, when his dad and dad's friends got involved in kiting. He began on what is known as a 2 line Radsail kite and after nine months of kite flying in wind (and strong wind at times) Charlie was getting so good at flying his small 1 meter Radsail and trying to use a buggy (a buggy is pulled by kite). He was getting so frustrated each time it landed and someone had to launch it for him, that his Dad decided to get him a four-line PKD Buster 1.4 meter kite (the bottom two lines are brakes helping you to control the kite and also to land it). Being a four line kite, once the strings are unwound and kite opened up you can launch the kite yourself.

Charlie is very eager and keen to fly his kite, and likes it when the wind is strong enough to either pull him along the ground on his bum, or to lift him off the ground, or even pull him along in his dad's buggy. But plans are on the table for Charlie to have his own kite buggy.

We are lucky enough to have a field near us that a few of us can use to fly, but when we have time, which is not often, we go to the beach. It has also helped Charlie's tracking problem with his eyes as he has to keep them on the kite all the time.

*Debbie suggested that I take a look at some websites to see what a difficult thing power kiting is ... wow – very impressive. Well done Charlie! Let us know how you get on.*



*Charlie in his dad's buggy*



*Launching the kite*



*Charlie flying his kite*

## THE EMOTIONAL JOURNEY

Clare Woodcock of Lincoln writes: I would be interested to hear from other parents who have heart children about their personal emotional journeys following diagnosis

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Eve, our six year old daughter was born with a VSD. When she was five she had surgery to close the hole and repair a leaking aortic valve. Having to have surgery came as a huge shock but everyone who cared for her at Great Ormond Street, where the operation was done, was fantastic and made the experience as bearable as possible.

### Mental trauma

Eve recovered quickly but we had a lot of mental trauma to cope with. This has ranged from nightmares to lack of confidence at school. We recently learnt that her valve repair has not been successful and more surgery will follow in the future.

As a mum my hardest challenge has been to remain calm and to try not to be anxious, to keep life as normal as possible and to be open and honest when asked about the future operation. This isn't always easy and on a daily basis we have had to put up with temper tantrums and tears as she tries to make some sort of sense of her feelings too.

### How do you cope?

How have other parents in similar situations coped and what practical advice could they offer? Is there any

research published that has studied the effects of operations on children that might be helpful

*Clare has added more recently:*

### Update

A year and a half later and we can happily report that Eve is doing so well that we can postpone thoughts of another operation until further notice. This is great news and is a welcome relief from the anxiety that accompanies every six month check up.

### Laugh and smile

I know it helped Eve to be told this good news face-to-face by her consultant. In the past he and us have had to break bad news to her, and it was a joy to watch her laugh and smile. She came away from that visit a different person.

The plan is to wait and see how she copes with growth spurts in her teenage years. At some point we will have to face the prospect of another operation, but the relief at knowing that it won't be immediately or next year is enormous.

### Hard lesson

I have learnt to live in the present, a



*Eve*

hard lesson. I understand my daughter better, and maybe in hindsight, I may not have been so honest with her.

She still rages and storms with anger but it's tempered by my pride in her strength and maturity way beyond her seven years. For the time being I feel she is not being defined by her heart problems. A new school has helped her to start afresh and be positive about who she is too.

*Clare would welcome contact with other parents, via the HeartLine office.*

### Terms used

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

**Aortic valve:** The valve between the left ventricle and the aorta

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## MEDIC ALERT

Does your child need a Medic Alert symbol? This may be because he or she has fainting attacks, a family history of Hypertrophic Obstructive Cardiomyopathy, is on warfarin, has a pacemaker, or has an allergy for example.

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

Bracelets, neck chains and straps

come in a variety of designs suitable for children these days, and you may want to contact Medic Alert for a copy of their range: call Medic Alert during office hours, Monday to Friday, 9am-5pm: freephone: 0800 581420 or email: [info@medicalert.org.uk](mailto:info@medicalert.org.uk)

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## HOW TO GET ONTO THE MESSAGE BOARD

On the HeartLine website there are a huge number of messages from people talking about all aspects of their lives. For those of us who haven't been there yet, this is how to join in:

Open the internet – this is usually by clicking on the blue **e** on the screen, dialling and giving a password. Near the top left is the Address. Delete the address that is already there, and type in [www.heartline.org.uk](http://www.heartline.org.uk), then click on Go or press the enter/return key. On the HeartLine home page on the right hand side, click on the word Messageboard. Read the conditions that come up, and then go back up to the top of that screen. Click on Message Board on the right side of the screen. You can now go into the General chat area, the Conditions area, or look at some of the messages which were put up before March 2004.

# THE COLEMAN FAMILY AFFAIR

Linda Coleman from Birmingham writes:

I would like to write about my children and be available for contact

My first born, Mandie, died in November 1987 with a complex heart condition. Lee arrived prematurely in October 1988 with Pulmonary Valve Stenosis and various other problems, which were all put down to being premature.

## 22q11

Ben arrived in August 1992 with Fallot's Tetralogy, and in 1994 we were diagnosed with 22q11 deletion. Ben and Lee had various problems which in later years I learned were due to 22q11 deletion. Ben was also recently diagnosed with Asperger's traits, also because of 22q11.

Lee is 16 this October 2004 and by the age of 10 had outgrown his heart defects. Ben has had several operations for a shunt, repair, ballooning of the arteries. He has a leaking valve and the artery keeps on narrowing. I'm told that further surgery to repair the artery and put a valve in will be needed in the future.

## Limitations

Lee is 5'8" and fit and healthy, he goes to the gym, cycles a lot and copes really well. Ben is much more affected. He is small, frail looking, has low tolerance to exercise and the cold, and gets tired easily and exhausted after school. He has limitations and I've had various reports about his conditions: some put it down to Asperger's, some poor motor skills, some immaturity, some his heart, and some a mixture!

## Battle won

Ben has a swimming lesson once a week, a no-contact karate class once a week and he's just passed Grade 2 on

piano. Ben is 12 this August 04 so one of the youngest in his year, but he works hard at school and does well. I had a big battle to get him some extra help with statementing and transport to school when he moved from primary school up the road to secondary school, which I eventually won. He gets school transport and six hours a week.

## Asperger's

I'm now battling to get help on the Asperger's traits and have come to the conclusion that I will have to do it on my own the way it's looking. I'm now researching ways to help Ben, and setting up a programme. I'm also searching for software for autism eg social skills, empathy safety, road traffic, social interaction, personal hygiene etc. So if anyone out there has any info, get in touch. And for anyone who is in the same boat and wants info I can help.

## Tips

Over the weeks I've collected lots of interesting facts including food intolerance, vitamins, omega oils and tips and information. I had expected Ben to pick up and be stronger, have more energy and be more 'normal' and it's not the case, but I try to give him as normal a life as possible and help him pace himself.

We use relaxation and meditation and breathing exercises to help us cope and I am stronger for it. I'd love to write to other mums who have 22q11 child or Fallot's child in the 12 to 16 age groups, and will respond.



Ben in Judo kit

## Terms used:

**Pulmonary Valve Stenosis:** The valve between the right ventricle and the arteries that take blood to the lungs is narrow.

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

**22q11:** A syndrome caused when part of chromosome 22 is missing (deleted).

**Asperger's:** Asperger Syndrome is a mild form of autism – children affected have difficulties in three main areas: socialising, communication and behaviour.

Sometimes these problems are noticed soon after birth, but more often they become apparent after a year or two of apparently normal development.

**Statementing:** if a school cannot accommodate a child's special needs, a statement can be drawn up to provide the extra resources.



## STARTING A NEW MESSAGE ON THE MESSAGE BOARD

If you would like to start a new topic on the message board, decide whether it should come under General Chat, or Conditions and click on one or the other. Scroll down to the bottom of the page, fill in your name (can be any form of your name you like), the name of the new topic you are writing about, type in your message and then click on the Submit New Topic button at the bottom of the screen.

(See page 5.)

## GO ON THEN – GIVE US FIVE!

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*Often we mention the fundraising carried out by families, but there are some special relatives out there who never let us down. These are the ones who buy the last book of raffle tickets – “Go on then – give us another five!” – and who allow us to sponsor them as body parts are shaved, leaps are made from planes, mountains are climbed, cakes are baked.*

*Lisa Martin writes a tribute to her ‘special relative’, Roy Roy.*

At age 44 on the 5 February 2003 our Uncle Royston (Roy Roy to the family) collapsed and died immediately, after suffering a massive heart attack ... Roy had very few ill days in his life and had no underlying conditions! He was never married and had no children of his own. He lived at home with his mum Joan and one of his five brothers.

Roy was a very happy-go-lucky person with no enemies and many, many friends. He had many loves – his family, fishing, motorcycling and

listening to music being just a few of them.

### **Amazed**

Roy always supported HeartLine raffles and never needed any coaxing because of his great nephew Jordan's involvement. Since Jordan was born with Aortic Stenosis, HeartLine have been wonderful for us and this was all Roy needed to know.

A few years ago Roy brought £20.00 of raffle tickets to clear my batch of over 300 books, and was amazed to find that he had won the first prize of a holiday in a caravan anywhere in the country! Due to Joan being ill at the time Roy wouldn't go away, and gave the prize to Jordan and our family (this was much needed at the time) so we went away to Wales.

### **Helping others**

Roy knew that helping Jordan's charity meant helping others, and making more people aware of the fact that children have 'problem' hearts too, because before Jordan was born he had never given it a thought!



*Roy Roy*

A donation was given to HeartLine by one of the mourners rather than buying flowers, which I know Roy would have appreciated.

I love you and miss you very much Roy Roy.

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## TOUGH DAYS

*Hi, writes Mrs Tracey Allen, of Hayes, Middlesex, just a quick story about my son.*

Jack was born healthy, but we took him to Harefield for a scan as three of our other children were born with holes in their hearts.

It was found that Jack had a number of holes, but they were not life threatening. Then, last year 2003, when Jack fell ill, Dr Franklin found he had a problem with one of his valves, and also that he has congenital heart disease. He was referred to GOSH for a heart transplant.

He has been on the transplant list since September 2003 and in June

2004 we are still waiting. We can only hope he gets a transplant or we are faced with the fact we could lose our son. We have our days where we cope and days when we don't. Our four other children are the same.

Harefield Hospital and Dr Franklin are like friends over the last 10 years and now GOSH are fantastic. But these are tough days, just waiting.

Tracey would love to get in contact with other families - you can contact her via the HeartLine office.



*Jack and his brothers*



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## ADDING YOUR MESSAGE TO THE MESSAGE BOARD

Want to add your message to a topic being discussed? Scroll down to the latest message on that topic, type in your name, your message, and then the Submit Reply button.

*(See page 5.)*

## STATISTICS

Now I don't personally hold with statistics – I mean they are fine for working out how much food you will need to prepare for a party, but after that it's a little weird. To know that one of your children has a rare heart condition makes you feel picked on, and I think that my approach is much too subjective to be able to estimate how well or badly my child will do, given a 23% chance of this, or a 90% chance of that.

But for those of us interested, British Heart Federation has published a range of statistics about congenital heart defects – you can read the full report *Congenital Heart Statistics 2003* at [www.heartstats.org](http://www.heartstats.org). The main points are:.

- In the UK there are about 4,600 babies born with heart disorders each year – one in every 145 births.
- Treatment has improved enormously over the last 40 years, with the development of many new surgical and catheterisation techniques. The outlook for babies has improved dramatically: at least three-quarters are predicted to survive to adulthood, nearly 100% of those with simple conditions
- Around 3100 operations and 725 interventional catheterisations are performed each year on affected children.
- Deaths from operations have more than halved since the late 1970's.
- There are a number of medical complications - many people have a life-long risk of endocarditis even after repair. Those with more severe defects, particularly those who have cyanosis are at highest risk of serious complications such as kidney failure and blood disorders.
- There are about 150,000 people aged 16 and over living with congenital heart disorders. Of these around 11,500 have more complex forms, and they will need life-long care. The number of adults is estimated to grow by 25%, and the number with complex conditions by at least 50%, between 2000 and 2010. So over 1,600 extra adults each year will require specialist GUCH services. It is estimated that around 25% more cardiologists and surgeons specialising in congenital conditions are needed.
- Most people will have a similar quality of life to other adults, except physical functioning and general health perception where it is lower. But those who have cyanosis have a more severe and more generalised reduction in quality of life.

### Terms used:

**Congenital:** present at birth

### *Interventional catheterisations:*

using catheter tube to treat heart disorders – widening narrowing arteries, destroying dangerous electrical pathways and so on. Other forms of catheterisation are used to diagnose eg pressures

**Endocarditis:** inflammation of the lining of the heart

**Cyanosis:** unoxygenated blood is circulating around the body, resulting in a blue tinge to the skin, often noticeable on the lips, fingers and toes.

## LIAM

*In the spring magazine Donna Hackett told how her son Liam had spent several weeks in hospital as his prosthetic valve was replaced, and finally arrived home, only to have endless appointments to sort out anticoagulation ...*

On our arrival home I contacted Aston Villa to see if I could arrange a treat for Liam after all that he had been through and lo and behold they came up trumps! The manager's secretary Debbie rang me at home and enquired whether or not we were available on Thursday 8th April. We had been invited to go and watch the players train at their training ground and meet them afterwards.

We didn't let on to Liam and told him

that a player was visiting the hospital and that he was going to see him there. We set off and it wasn't until we started to leave the Birmingham area that Liam realised something was going on.....When we pulled up at the training ground his eyes lit up.

We were taken through the security barrier and right up to the facilities. We went inside and we were able to watch the players training. Afterwards the players changed and came through to where we were and Liam was able to meet his heroes and have his photo taken with them all.

Villa had done us proud, they even laid on refreshments as well and we were able to listen to Dion Dublin and Nolberto Solano play their



*Liam meets one of his heroes*

saxophone and trumpet together! It's a day Liam certainly won't forget in a hurry and neither will we. Thanks to AVFC!

# 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 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.

# UNDERSTANDING IS EVERYTHING

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"...at an antenatal appointment I met a distressed pregnant girl holding onto the side of the building, gasping with grief. The doctor had told her that her baby did not have a head. Really and truly, that is what she had understood when a medical student had been unable to find the head. No-one had said it to her, but of course there is a head!"

This anecdote is from 1976, and things have definitely improved since then. Either doctors are naturally more talkative these days, or training is already paying off. At Children's Heart Federation, it is less and less common for parents to complain on our helpline that their doctor is a bad communicator. Indeed they often comment on how helpful doctors are, what ingenious sketches of the heart they produce, and how tolerant they are of the emotionally pole-axed parent. Despite this it is often true that parents haven't understood what they have been told.

The main factors are lack of time and background. As parents of children with congenital heart disorders we are only too well aware that there is a clinic full of anxious families, that our question may not be the right one for this particular clinical expert, and what a valuable resource we may be wasting. The area of congenital heart disease is very complex. For many of us the circulation of blood is a complete mystery, and the implications of errors of our child's anatomy something that we come to understand only over a number of years.

At the same time, to exercise our parental responsibility we have to believe that we are at the best hospital and under the best surgical team, and that we can confidently consent to treatments that, of themselves, can be damaging and life threatening.

These are direct quotes from consultants to parents of children complex heart defects:

*"Take him home and enjoy him while he's here."*

*"I will have to do the surgery but it's never worked before."*

*"There's an 80% chance that she'll come through it."*

What are we to make of these statements? We need context in which to interpret them. We also have to take our child back into a community where heart conditions, particularly the more complex, are not understood, and

where we have to explain a pulseless left arm (due to a BT shunt) or low sats reading (perhaps due to hypoplastic right heart) to health visitors, clinics, and in our local a&e.

CHF have found that the best way to improve communications between doctor and parent is to prepare the parent. We provide the vocabulary that they may hear, suggest how to deal with emotional crises in consultations, and frame questions to deal with individual situations. We have published an information sheet Talking to your doctor giving the more frequent questions that parents have.

We suggest that this is a model that doctors can be trained to use themselves – good communication begins with preparing the patient for the consultation.

Learning what the patient needs in order to make the most of your services has to be a part of all effective communication training. For example, consultants have been known to complain that parents come through the door with a sheaf of website downloads. As a doctor you should know the best patient websites in your area of practice. How much better to advise patients on which ones are worth a look, than to criticise their efforts to become expert.

Support groups similarly are of disparate quality. By associating yourself with, and encouraging, the good ones you will know where your patients can be supported and become good quality supporters in turn. Training can show you how to do this effectively.

Learn to network. You may find that liaison nurses, advisers and advocates at tertiary, secondary and primary level are ready and eager to take on the work of preparing the patient.

In paediatric cardiology, understanding the diagnosis and treatment options are essential for the parent to exercise their responsibility to their child. As parents we appreciate and trust the efforts of doctors who understand our need to understand.

*Hazel Greig-Midlane works as Help Services Manager for the Children's Heart Federation, a federation of support groups for families with children with heart disorders.*

The preceding article first appeared in Hospital Doctor, 15 April 2005 p9.

## SURGERY POSTPONED

*Waiting for the date for an inevitable surgery is one of life's heavier burdens. Louise had had her son's second surgery for sub-aortic stenosis postponed twice when she wrote:*

We are still no nearer on as to when Luke will go in for his surgery after the last postponement. We were told if not this week we would go in on Monday, and wait until beds became available, but now I don't even think this is going to happen. It changes every time we speak to them.

They also said lists had been frozen till they got rid of the backlog of cancelled appointments and, when she phoned yesterday, she slipped up saying because the lists are going ahead next week she isn't sure when Luke will be fitted in.

I am feeling really down and so like I am being fobbed off. They phone me every day to tell me where they are up to or not up to. Today I was told at 1pm the surgeon was viewing the lists and in an hour they would have more information. At 4pm I was told "I will speak to you tomorrow. Still no news."

Even if they would just say a date at least I would have an idea but the waiting for the daily phone call is horrible. Then when they haven't

even got anything to tell us it makes it worse.

I know I probably sound selfish and I am glad in a way they do phone everyday because then at least I know they haven't forgotten us. But because they are contradicting each other I am starting to lose faith big time.

The kids are sick of me cause I am really snappy and this is suppose to be a nice time with Luke before surgery, not having an irate mother wondering if today's the day we will be going in.

Becca is two on Saturday and I can't even plan the party properly... it's "well, if I am here ...."

Sorry for moaning but feel a bit better for it. I know that everyone has been through it, and we went through it three times last time, but it is still driving me insane.

*Luke has since had his surgery and recovered. That, as they say, is the important thing. But there were casualties along the way...*

### Comment

Having your child's surgery postponed is a great way of taking control and power out of the parent's hands. First, you cannot fulfil domestic or work obligations, second you are unable to concentrate on the tasks that you may be able to perform within a non-existent schedule, third you have your fears for your child's health as the period of safety narrows, fourth you are anticipating needing your emotional strength for the period of the child's hospitalisation, fifth you have to keep other members of your family informed and optimistic, sixth you cannot leave your telephone, seventh you need to prepare the child, eighth other children suffer from your inability to make and keep to arrangements for their care, ninth you are permanently frightened that you are forgotten ... without exaggeration, life has the quality of a nightmare.

Oh, and like Louise, you feel guilty and selfish. Is this the platform from which parents can take informed decisions? From where we can be treated as partners in our child's care?

## THE STARS

*Clare Martin writes:*

I wrote for a previous magazine how I had gone into school and explained about HeartLine to the whole school assisted by helium heart-shaped balloons.

This unusual aid clinched it. The children voted for HeartLine and it was the school's chosen charity for 2002-03.

At the infant Christmas concert, the Junior Carol concert and Summer recital evening the retiring collection was for HeartLine.

A cheque for £1600 was presented to Anya Rowson, Chair of HeartLine, at the end of the academic year, making our local paper. The bulk of this money was raised by a sponsored silence in the school, infants completed two half-hour stints and

juniors managed two half-hour stints. This idea was suggested by two year 5 pupils. The total of £1600 from a one form entry school is very commendable.

The children watched their total increase in the school hall. Mrs Raps, the head teacher made a poster to which hearts were added for every £18 – the amount of one hospital pack.

In the infant nativity, Andrianna took a key role as the 'Big Star'. Her costume lit up – it is amazing what you can do with 4AA batteries and a string of mini fairy lights. Her father was concerned that to light up his 'Big Star' she would have to trail around with a car battery and any wet knickers incident (not our daughter of course) might short circuit the entire nativity



*Andrianna*

tableaux ..... oh the caution of an electrical engineer!!

## SILVER JUBILEE PARTY [close your eyes for this bit]

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*I gripped the knife firmly in my hand. In front of me a group of children stared wide-eyed. They seemed frozen to the spot. Before my eyes the dazzling white surface reflected back a score or more flames, the heat distorting the view of the grasslands beyond. I heard the sound of swift horse hooves, pounding closer and closer, and many voices raised in cries of protest .... and delight.*

*It had to be now. I plunged the knife into the glittering crust of the HeartLine Silver Jubilee cake, and we all had a piece.*

This was the climax (for cake-eaters) of our celebration of HeartLine's quarter century, held at Kempton Park Racecourse on Saturday 29 May.

The marquee – clear to see in the middle of the course – offered shelter to the many families who accepted the invitation to come. In fact the shelter was largely unneeded as, despite a pessimistic forecast, it didn't rain a drop.

Successful bets were seen to be

made, and it was an excellent opportunity to meet up with and talk to families only known to each other through the magazine or website. A game of football was in progress for the entire time, races were held, paces fainted (sorry, faces painted), and the wonderful Goldman Sachs once again made sure the whole affair was well organised and the children well entertained.

But back to the cake – once again a magnificent affair tasting divine. It



was made by Philip Wright, Head of Catering at SE Essex College, together with colleagues and students. The picture here is of Philip Wright putting the finishing touches to it. And not forgetting the stalwart Sharon Brookes who made sure it arrived unblemished for the occasion by sacrificing her seat in the family car to it.

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## ALL GOOD HOSPITALS

A report\* on success rates of surgery and catheterisation in all the children's heart centres was published in March. The authors analysed the data collected in 2000-2001 and reached the conclusion that there is little difference between the centres in terms of survival.

Parents have been hoping that there would be a guide to which hospital offered the best results for their child's condition. The findings of the audit are reassuring but:

- The data is from three to four years ago
- It only covers the more common and frequent type of heart defect
- It only relates to more common surgery and catheter treatments, not to deaths that occurred because, for example, of incorrect diagnosis or failure to offer treatment.
- It doesn't cover children who survived but with neurological or other problems

- It doesn't include how risky the surgery was for the individual child – because of other health problems for example

*\*John L Gibbs, James L Monroe, David Cunningham, and Anthony Rickards*  
**Survival after surgery or therapeutic catheterisation for congenital heart disease in children in the United Kingdom: analysis of the central cardiac audit database for 2000-1**  
BMJ 2004; 328: 611-0

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## SEND US YOUR STORIES ...

We want to know you – what is your story? And can you share one or two of the dozens of photographs you have of your children with us?

More than a thousand families read HeartLine, some of them new to our world. Every experience you share is going to be new to some of us, and of interest to most of us. Everyone has something to say: whether about

feeding, education, brothers and sisters, diagnosis, forms of treatment, genetics, employment, benefits, transport, appointments etc – and we want to print it.

People have sent copy to the magazine on tape, newspaper cuttings, by email, typed papers, and down the telephone – any way that you want.

See inside front cover for how to contact us.

By the way, if you send us pictures, we will try to return them, but cannot promise – they rarely get lost in the post or at the printers.

And pictures in the magazine go onto the HeartLine website, unless you ask that they shouldn't.

CHF is a federation of groups like HeartLine which are supporting families with children with heart disorders.

## **Conference – Parent Power!**

This year's conference will be held on 25 September in Liverpool and will be looking at how parents can, and have, made a difference to services provided.

The conference is free of charge and lunch and a crèche are provide.

Two workshops have been organised in the morning, one for new parents who have not attended a conference previously, and a workshop for parents to learn more about parent empowerment, barriers and how you can help facilitate change.

The afternoon session has two workshops, Talking to Doctors and Assertion Skills Workshop.

Call Claire Hennessey on 01934 863401 for further details

## **Information sheets**

CHF has published information sheets in a number of new areas. Copies are available by downloading from [www.childrens-heart-fed.org.uk/information/pubsmenu.htm](http://www.childrens-heart-fed.org.uk/information/pubsmenu.htm) or calling freephone 0808 808 5000. The new information sheets are:

**Pressures:** why pressures inside the heart matter

**Pre School Care and Education:** problems that parents might face and how to deal with them

**Immunisations:** which ones? And when?

**Heart Transplants:** preparation for some of the issues around a heart transplant.



**Genetics and Syndromes** – what does diagnosis of a genetic condition mean?

**Endocarditis:** what steps do you need to take to avoid endocarditis affecting your child?

**Your Child and Special Educational Needs:** how to deal with this most complicated of topics.

**Feeding Babies with Heart Problems and Feeding Children with Heart Disorders:** what parents have found helpful when faced with difficulty feeding.

**Talking to Doctors:** what you may want to ask.

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## ENDOCARDITIS

*Preventing endocarditis is a frequent worry for parents. The following is published by Children's Heart Federation and can be printed direct from their website – see page 13.*

Bacterial Endocarditis (BE) is a life-threatening infection of the endothelium. This is the smooth surface of the inside parts of the heart, including the heart valves.

Although any child can develop BE, it is very rare in those without heart problems. In those with heart disorders, the risks of becoming infected depend on whether the heart condition has caused rough patches on what should be a smooth surface in the heart.

The cause of BE is some types of bacteria that get into the blood stream in very large numbers. These

can then form strings which can stick to the rough patches of the heart. Once there, BE can spread within the heart.

A rush of bacteria getting into the bloodstream is called 'bacteraemia'. Cleaning your teeth and passing a motion cause bacteria to get into the blood stream, but in small numbers so the body's immune system can destroy them. A large number of the bacteria that cause BE can be found in infected mouths. So the easiest way for them to get into the bloodstream is if the gums are pierced - by a dental instrument, for example.

BE can only happen if there is a rough patch in the heart for the bacteria to attach to. Rough patches are likely to occur where the blood is turbulent. For example, blood passing through a VSD at high pressure could cause roughening to the lining of the

valves in the right ventricle. Rough patches can also occur when there is a procedure carried out inside the heart, such as a switch operation for transposition of the great arteries. Areas of scarring, usually from surgery, can also be colonised by bacteria.

### **What is your child's risk?**

Preventing BE means taking a large dose of antibiotics before, or soon after, the bacteraemia occurs. This is called prophylactic use – that is, to prevent disease rather than treat it. Since having too many antibiotics can be bad for your child, you will only want to use them if he or she:

- has rough patches on the lining of the heart , and
- has his or her skin pierced when there is a danger of infection.

The child's cardiologist is the best person to tell you if your child's heart is going to be more susceptible to BE than a child without a heart condition. Generally this will be if she or he:

- has had BE before
- has had a valve replacement
- has an artificial shunt or conduit in the heart
- was born with a heart defect, other than a VSD, ASD, or PDA which has been judged to have closed successfully at follow-up
- has hypertrophic cardiomyopathy
- has acquired valve damage.

Your child should not be at increased risk of BE because he or she:

- has a pacemaker or defibrillator
- has arrhythmia such as SVT
- has had acquired heart disease eg Kawasaki syndrome, which hasn't damaged the valves
- had a VSD, or ASD, or PDA that

was successfully closed more than six months ago.

### Symptoms

You should suspect BE if your child has had dental treatment, or an infection recently and:

- is generally unwell, tired, inactive
- has a temperature that has swung from high to normal over the last few days
- and has had shivering and sweating at night.

If your child is showing these symptoms you should contact your GP. You should remind the GP that your child is at risk of BE because of their heart condition and also ask for a blood test. If you feel the need for a diagnosis is urgent, contact the Cardiac Liaison Nurse (CLN) at your nearest Paediatric Cardiac Unit. The CLN should then arrange for a blood test to be taken, or arrange for you to see a cardiologist.

### Diagnosis

A blood test and echo will usually be enough to show if your child has BE or not.

### Treatment

Treatment is usually long-term antibiotics given straight into a vein, and other drugs to help support your child through the infection, such as warfarin to prevent clots.

### Avoiding BE

BE is a life-threatening disease. Children who survive it may have long-term effects such as valve replacement, brain damage, or even lost limbs, so it is very important to help your child avoid BE.

### Help to keep them free from other infections:

by making sure that teeth and gums are properly looked after. If this is difficult for you, talk to your dentist about ways of lowering the risk of infection. Make sure that your child's medical records show that he or she is susceptible to BE. Carry a BE card, from the hospital, HeartLine, or the British Heart Foundation. Remember to arrange for your child to have the antibiotics at the right time before the appointment for treatment

by avoiding body piercing: Piercing and tattooing carry high risk of infection, piercings on or around the mouth are very risky. Check with the cardiologist if ear piercing should be carried out with antibiotic cover.

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*Patron: Dr Philip Rees*

## HEARTLINE EXECUTIVE COMMITTEE

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

**Chair: Anya Rowson**

**Director of Operations: Anita Ford**

**Vice Chair: Clare Mason**

**Treasurer: Sharon Saunders**

Clinical Liaison: Adelaide Tunstill

## HEARTLINE COUNCIL

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

**Heart Children book: David Kinnear**

**Pre-Natal Support: Jan Kingsley**

**Clinical Support: Gill Thompson**

**Hospital Visitor: David Northeast**

Clinical support: Heather Hatter, Great Ormond Street, London WC1N 3JG 020 7829 8829