



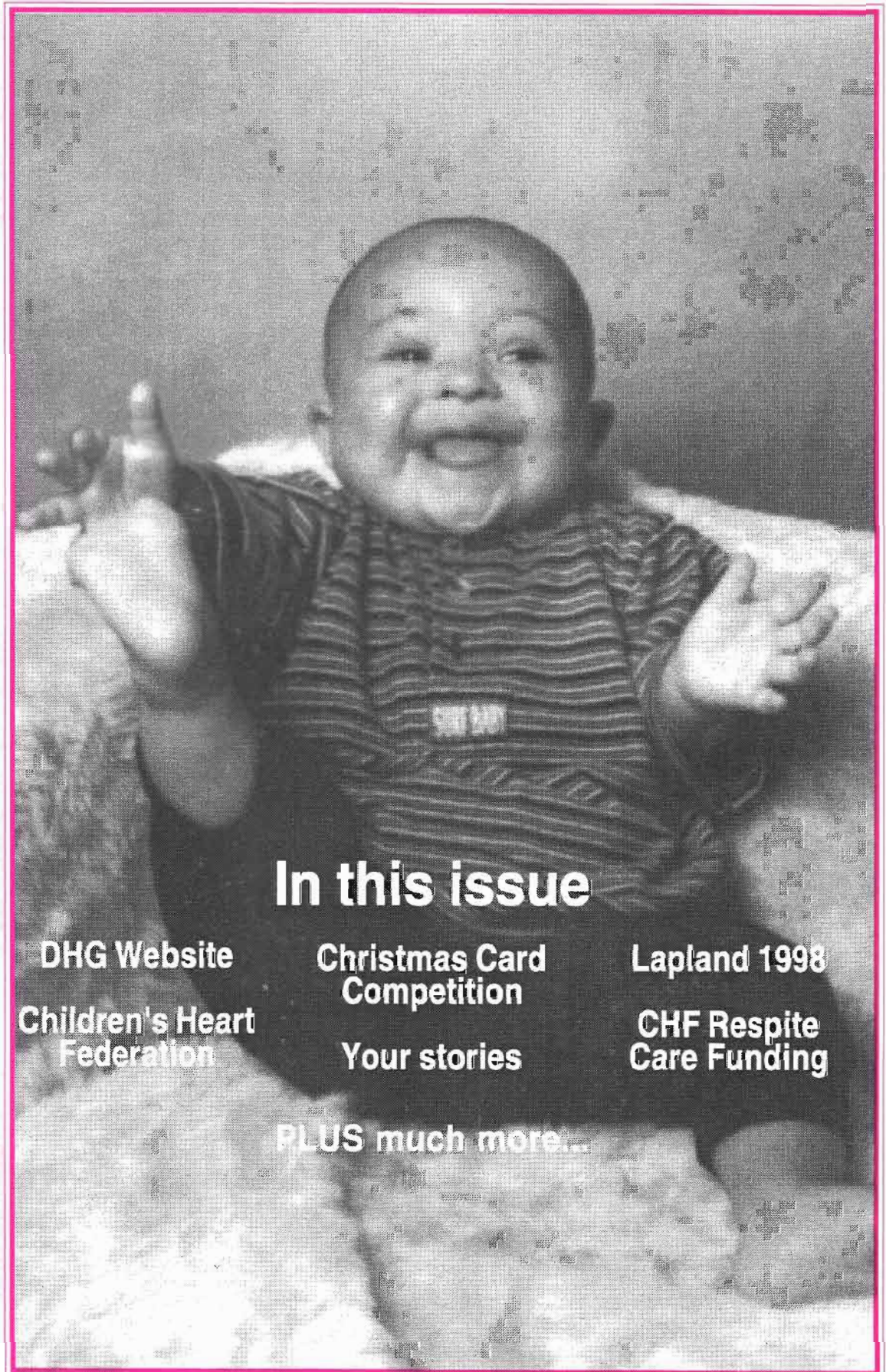
**DOWN'S  
HEART  
GROUP**

# NEWSLETTER

Issue No 20

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# Chair's Report

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## Hospital Visitors

Another successful hospital visitors course was held in the delightful surroundings of Ashdown Forest in Sussex. This means that we have now reached our goal of all current hospital visitors having been on the training course.

Hospital visitors are an important part of giving information and support to families before and during heart surgery. This is the crucial time when parents need to have solid, objective and understandable information about their child's heart condition, the process leading up to and through surgery, the medical terms and the staff they will be dealing with.

Much of this is supplied through our many Topic Notes and our video and these have had a big impact and success with parents and professionals. Nonetheless the hospital experience can still be bewildering and sometimes lonely, particularly for families having to travel long distances to a centre, often having to leave other children at home. This is where our visitors can make a difference offering a befriending, experienced, listening presence to help parents with practical tasks, and the shared experience and reassurance of another parent.

At the moment our hospital visitors are a small band. Some centres are not covered at all; at others we need more visitors to enable us to provide a regular service and to spread the load. So we need additional help at each of the seventeen paediatric cardiac centres. This is not everyone's cup of tea. Visitors need to be objective, good at listening and communicating, able to put their own problems to one side to help others, have a reasonable lay knowledge of the various heart conditions, be diplomatic, supportive and realistic.

If you feel that your family has benefited from the Down's Heart Group why not consider putting something back for the next generation of parents? Full training will be given and expenses met. If you are interested, and without commitment, why not talk to our trainer Katie Spall, herself a hospital visitor, on 01424 830594, to find out more.

## Committee Members

Most of the current committee, and certainly the office holders, have been toiling away for some years now and they are getting tired and need a break!

We are in urgent need of new people joining the committee NOW. We would particularly like some new blood with business or management skills so that we can avoid a succession crisis in a year or two - it's called planning ahead! The duties are not onerous - there are four committee meetings a year plus the Annual General Meeting - all expenses are met. If you have some appropriate skills and experience and would consider helping us, please give me a call, without commitment, on 01424 830594 to learn more.

## Chronic Cardiac Conditions

Wendy Tucker, our Co-ordinator for families with a child with a chronic cardiac condition decided to stand down because of the need for her to concentrate more on the care of Alex, her son. Wendy has done a tremendous job, in difficult circumstances, in raising the profile and representing this group of our members. We are very grateful for her contribution to our work and we wish her, Mike and Alex well for the future.

A fitting finale to Wendy's contribution was the special day conference on coping with chronic cardiac conditions held in London on 19 June 1999 - see write up in next edition.

I am pleased to say that Jane Wrighton, who lives in Hexham and was formerly one of our contacts in the North East, and who has a daughter Hannah, has agreed to take over from Wendy. We are delighted that the momentum will be maintained.

## The Future

These notes so far may sound a bit down beat (sorry about the pun!) - not so - the Down's Heart group continues to thrive. We had a record number of new members last year and our finances returned firmly into the black after the heavy expenditure in the previous year on the video - which incidentally, in now beginning through sales and copyrights, to recoup some of its costs.

So we continue to be a healthy, developing charity with lots of new ideas to improve our services - just that to cope with and expand upon that success we need a bigger crew - so come aboard.

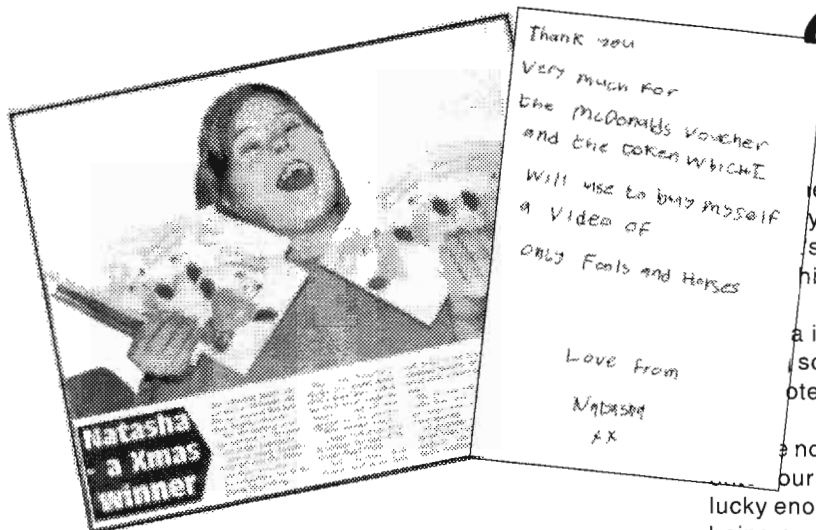
### **New Telephone Number**

If you have our Vice-Chair and Bristol and South East Regional Co-ordinator, **Sheila Forsythe** listed in your telephone / address book, please note that Sheila now has a new telephone number which is :



**John Spall, Chair**

## Christmas Card Competition



Winner of our 1998 Christmas Card Design Competition, 7-year-old Natasha Grange from Romford, Essex. Her cuddly teddy bear was printed on 17,000 Christmas cards which were sold in aid of the Down's Heart Group.

Natasha is shown as she appeared in her local newspaper, along with some of her cards. Also shown is the thank you note she wrote to the Down's Heart Group.

We are now looking for designs for our 1999 card, so why not enter our competition and you could be the person who is lucky enough to see their design printed on Christmas cards being sent around the world this year.

### COMPETITION RULES

- ♥ Entries should be on an A4 sheet of paper.
- ♥ The Down's Heart Group logo must appear somewhere in the design.
- ♥ The entrant's name, age and address should be on the back of the entry.
- ♥ Entries should be sent to the National Office address shown on the back cover to arrive by August 13th.
- ♥ Entry is open to all DHG member children and siblings.
- ♥ There is no limit to the number of entries you can make.

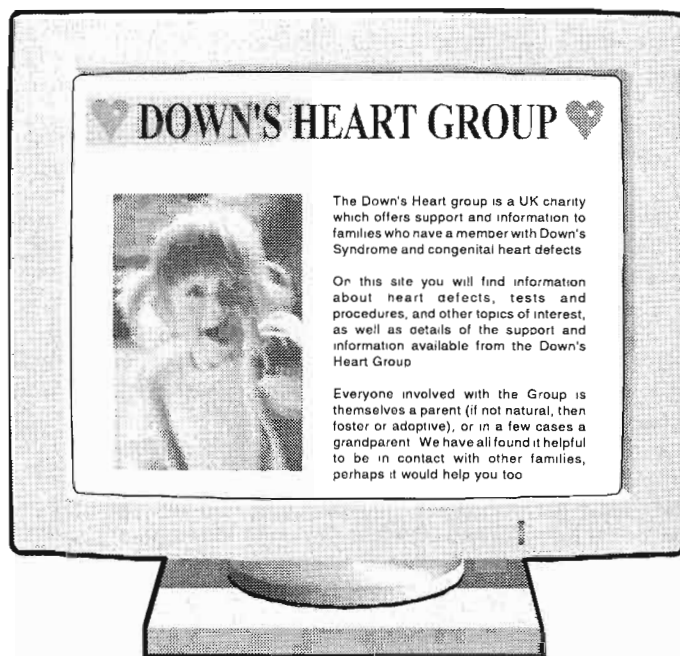
## Website

Information about the Down's Heart Group is now available worldwide to anyone with access to the Internet.

The website currently gives details about the support and information available to families, and readers can access all our current Topic Notes on-line. All pages are cross-referenced so that it is possible to jump quickly from one page to another by clicking on the highlighted links within the text.

Future plans include putting the newsletter on-line, an on-line Application Form for membership of the Down's Heart Group and links to other useful sites.

Some of the site is still under construction, and there are a few problems to be ironed out when using certain browsers, but if you have computer access, please visit the site and let us know what you think - there is a visitors book you can 'sign' to do so. Early comments have been very favourable, but we would value your thoughts too.



<http://www.downs-heart.downsnet.org/>

# Trey's Story

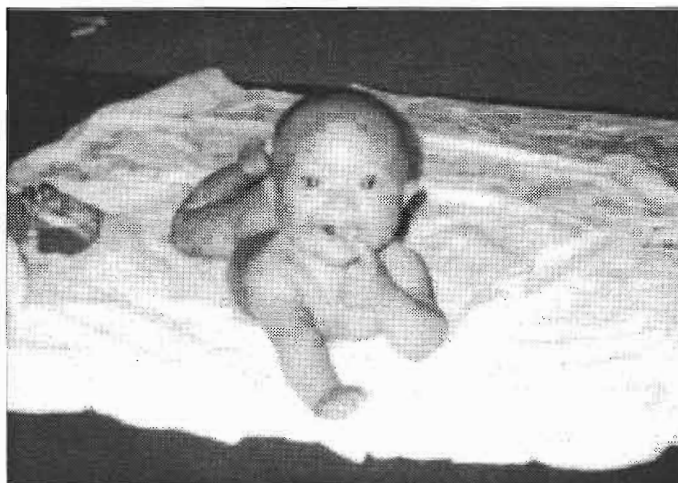
When Trey's story starts, I was living out in America with my husband Joe. I was pregnant with my first baby and had a blood test at four and a half months, which is done routinely in the States. The test came back positive and I was sent for an amniocentesis, which would take three weeks for the results to come back. Those were three very long weeks!

I had been told that I was carrying a boy, and we had named him Trey. When the results came back, they confirmed that he did have Down's Syndrome, and I broke down. It felt like the perfect little baby I was going to have had died, and I was left with something I knew nothing about.

Two days later I went for an echocardiogram on Trey's heart, only to be told that he would need major heart surgery within his first year of life. I was devastated, and can't remember how I drove home through the blur of tears.

The next day the hospital called me in for a counselling session. They needed to know what I had decided to do about the pregnancy, as there is a two-week waiting list for terminations in America. As I was five and a half months pregnant by now, I had to make an immediate decision. I had fifteen minutes to choose. I could feel my little boy kicking and moving; I knew I could never forgive myself if I killed him; I had to give him a chance.

I went through a lot of different stages in the following three months. First I went into shock, I felt nothing. No love, no fear, just no emotion at all. Then realisation set in and I couldn't stop crying. I thought I was selfish for bringing him into the world. I didn't know if I'd made the right decision or whether I could cope. I think more than anything I was scared I would let Trey down. I was scared that he would be ugly and deformed and that I wouldn't be able to love him - at the same time I hated myself for feeling that way.



I then went into denial. I almost convinced myself that the doctors had made a mistake and my baby was fine. My relationship with Joe was breaking up, and with no family in America, I was alone.

Trey was due on Christmas Day, but two days earlier when I went for my check-up, the nurse couldn't find a heartbeat when she listened. Suddenly I was being rushed in for an emergency Caesarean. Doctors surrounded me, my waters were broken, and it was then that I realised that I loved Trey no matter how he looked. Then I was left alone with two doctors who explained that the panic was over, Trey had been lying on the umbilical cord, but in all the commotion he had moved, and I no longer needed the Caesarean. Eight and a half hours later I gave birth to a 6lb 13oz son - he was perfect, but he had to spend five days in Intensive Care before we could go home.

When Trey was two months old, we flew home to England, leaving Joe behind. My family supported Trey, and I don't know what I would have done without them.

At four and a half months, Trey had his heart surgery. It was the worst day of my life, one I'll never forget. I still cry now when I

watch 'Children's Hospital' and know what the parents are going through. I carried Trey down to the theatre. He was smiling so innocently, not knowing what was happening. I kissed him and ran. I didn't care what people thought of me sobbing my heart out in the hospital.

My mum and I had a four and a half hour wait while Trey had two holes closed and a leaky valve fixed. I could have hugged Mr Haw when he told me Trey was out of surgery and it had gone well. I didn't care what Trey looked like in Intensive Care, I was just glad that he was alive and I sat by his side every day talking to him.

But after three weeks he had become very ill and weak, and he was sent for a cardiac catheter, and then straight back into theatre because more holes had been found. He was strong for me and again came out of surgery well.

After four and a half weeks, Trey was woken up. It was the first time I'd seen him open his eyes, smile and move, in a month - it was amazing.

Since then Trey has gone from strength to strength. He's almost a year old. He was sitting up at ten months and almost crawling. He's a beautiful baby always full of big smiles - everyone he comes into contact with loves him.

I made the right decision in having Trey. I work hard with him each day to help his development. He has already made me proud by earning his first swimming certificate and badge - I know whatever he achieves in life, I'll be a very proud mum.

I was very lucky to have caring and supportive doctors and nurses at Southampton General Hospital. They helped me through so much, I'll be forever grateful to them.

Sally Newman  
Bournemouth

**Together with another mum, Sally has setup a Down's Syndrome Preschool Parent Support Group which meets at Poole Hospital. For more information contact Sally on 01202 248107 or Sharon on 01202 388174.**

## PLEASE HELP US

by saving stamps, postcards and ring pulls

*We have volunteers who are collecting all of these to fund-raise for the Group, but they need your help!*

Please save used postage stamps (cut neatly from the envelope), postcards (used and unused) and ring pulls from drink cans.

Details of where to send them can be obtained from National Office.

**THANK YOU**

# Christopher's Story

Our son came to us at twenty-two months old, a real poor little scrap of a fellow. His main problem at that time was his heart and hearing – he had an atrioventricular septal defect plus pulmonary hypertension. He spent the first five years of his life in and out of the Brompton Hospital as well as our local hospital in Braintree. He had lots of investigations, lots of chest infections, and spent lots of time in an oxygen tent. He did not attend school until he was nearly six years old – still a very poor scrap.

He was only sixteen pounds at two years old, unable to even sit up. I spent hours swimming with him plus taking him to physio. I used to take him out most days to the park or to mix with other children, and he was soon able to talk and walk – this all happened within a few months after taking him on. He developed so well that he was able to start at a school for children with only slight learning problems.

At seven years old he went for surgery yet again. He collapsed and was taken to London where he underwent quite a minor operation for his tonsils, which turned into major surgery. He was in theatre some ten hours, lost seven pints of blood and came out on a life support machine with a ten per cent chance of pulling through. It was a week of touch and go when Chris was just not expected to make it. We were devastated and never left his side for five days, sleeping on Intensive Care.

He did pull through, but for the next five years he was a changed child, sleeping only three or four hours a night, very violent and unmanageable.

He had further surgery on his ears to improve his hearing, which is still ongoing. Christopher then developed bad breath, which went on for a whole year despite visits to the dentist etc. It was finally found on x-ray, that he had a bone stuck in his nasal canal that had grown in and had to be removed. Yet again more surgery.

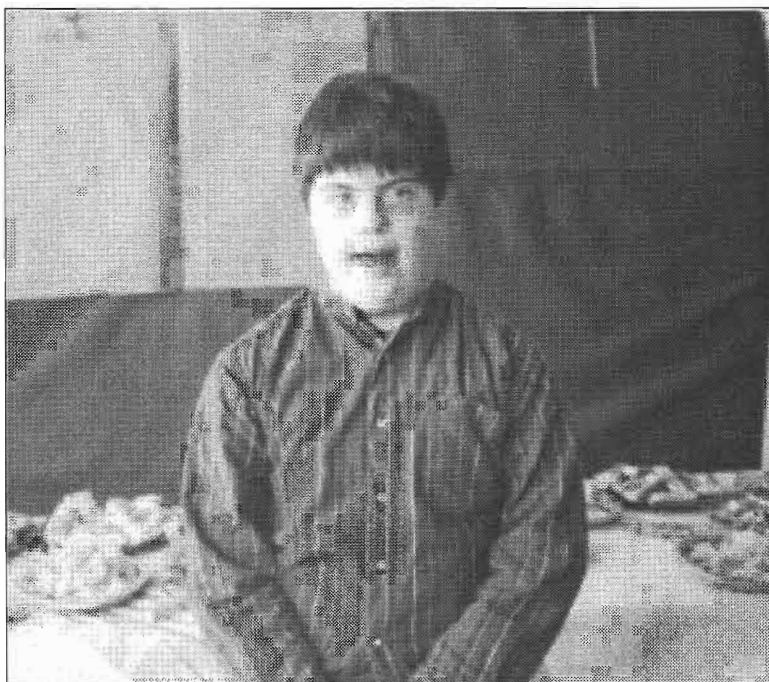
Within a year a new problem arrived. When bathing Chris I noticed that his testicles were very enlarged and was advised by the doctor to take him to the hospital. There it was found that he had an undescended testicle, and this had to be removed to prevent cancer – so more surgery. However, by then infection had set in, so Chris was on antibiotics for the next three months.

At about this time we moved to Clacton in the hope that the sea air would help Chris, which it seemed to do for a while. At last we were really beginning to feel that things had settled down, when Chris started to walk into things and find it difficult to see. I took him to the opticians who referred me to the local hospital. There we were told that he has developed Keratoconus on both eyes, which is too bad even for contact lenses, and

although he had glasses, these didn't seem to help. He does manage very well, although he does of course get very cross when he can't do a lot. Currently he is waiting for cornea operations on both eyes – more surgery.

I wouldn't want anyone to think we ever had any regrets about taking Chris on, we love him with all our hearts. My husband dotes on him and would never contemplate the idea of him going into a residential home, although he does go to respite care. Today as I look at him four weeks off his seventeenth birthday, I can't believe how far he has come. We were told he would make his teens – he has done far more than most people I meet! I don't want people to think it has been all bad – through Chris we have met many people, he is well liked and has travelled all over Europe, America and England. He rides a horse, and is currently acting on the stage.

It has, however taken it's toll on my health, but when I came out of hospital after surgery for cancer, Chris was my angel, and looked after me. He carried the shopping, and was such a comfort to me, fetching and carrying, and hanging out the washing.



We didn't give birth to him, but we both know he was meant for us. He is the spitting image of me – people think he is our birth son as he is so much like us. Never a day goes by when he doesn't throw his arms around us and say, "I love you". I dread the day when he closes his eyes for the last time, but I know that the world and I have been better for having Christopher.

Just to finish off, he now weighs in at twelve and a half stone, not bad for a little scrap who came to us at sixteen pounds. He is under eight specialists who have all been

excellent. I think we have been very lucky, as I do hear of some terrible tales of other people's problems. I do hope any other parents reading this will be encouraged to keep going, there is always light at the end of the tunnel.

**Lynne Philpot  
Clacton-on-Sea**

P.S.

Chris has just recovered from a broken leg remarkably well, but it has left him with a bad limp which may need further surgery, we don't know yet!

*Sadly, Christopher is one of our members who did not have surgery as a baby, but his Mum's story shows just how much our youngsters can achieve, even when everything seems to be stacked against them.*

**WELL DONE Chris!**

# Fionn's Story

Fionn is eight months old and an absolute joy! During the traumatic period following his birth, I could never have imagined how much pleasure he was to bring us all. At the time we wondered how we would be able to cope with him; now we wonder how we would cope without him.

Fionn was born, by Caesarean section, on 24<sup>th</sup> August 1998. We were delighted with him though I did feel concerned about his eyes and his inability to grip. Doubts crept in and weren't dispelled by repeated assurances that everything was fine. The following day the paediatrician told us that he did, indeed, have Down's Syndrome. He said his heart sounded alright but he performed an echocardiogram to eliminate the possibility of any silent heart problems. Unfortunately, it confirmed their presence. He informed us that there was a serious heart defect, which may not be operable, though he did arrange for us to see a cardiologist in Leeds for a special opinion the following day.

Our shock about the Down's Syndrome suddenly seemed irrelevant as we confronted a much bigger fear. Not only had we "lost" the child we'd been expecting, but we also seemed in danger of losing the child we'd been given. Still reeling from the shock, I returned to the maternity ward only to be greeted with the news that my father, who was being treated on a neighbouring ward, had died suddenly that morning. It felt as if a bomb had gone off in our life. This was supposed to be a happy time, what had gone wrong?

Fortunately, the visit to Leeds resulted in our first lot of good news. We were told that Fionn had a complete AVSD and that, though serious, it was operable. The relief was indescribable. There were no guarantees but at least there was hope.

Initially, Fionn looked so well it was easy to slip into a comfortable denial. But this didn't last long. By the time he was three weeks old he was showing signs of heart failure. He became breathless when feeding and didn't gain weight. He was prescribed diuretics but continued to deteriorate, vomiting copiously at every feed and looking increasingly pale and exhausted. A week later he was admitted to hospital and commenced on Captopril and naso-gastric feeds. This helped enormously, and after two weeks, he was well enough to come home. For the next few weeks he kept reasonably well and we made the most of every minute.

His heart condition was closely monitored, and generally, we were told to keep "growing" him ready for surgery. However, at his December check-up we were told we couldn't afford to wait any longer as the valve was leaking badly and his lungs were being affected. We were anxiously waiting to be called to Leeds when fate struck again and Fionn became very ill with

bronchiolitis. Back into our local hospital and an incubator, which Fionn absolutely hated! He recovered so slowly we thought we'd be spending Christmas in hospital, but he was allowed home the day before Christmas Eve. We rushed out to buy a tree and to try to drum up some festive spirit. We knew it was his first Christmas and also it could be his last.

Despite continuing chest problems, Fionn was admitted for surgery in the New Year. The risks were made clear to us, but it was also made clear that we had no choice. We had to go ahead, but handing him over at the theatre doors was the hardest thing I've ever had to do.

The operation lasted five hours and went well. As expected, there were some respiratory complications (excessive secretions, collapsed lungs etc.), and Fionn was in Intensive Care for a week before he could manage without the ventilator.

It was a terribly worrying time, but the staff were wonderfully calm and reassuring. We never doubted that Fionn was in good hands and found the experience more bearable than we'd expected.

After two weeks he was allowed home – a wonderful day! I had dreaded the thought of going home with an empty car seat and felt so grateful as we bundled him in. I cried all the way home.

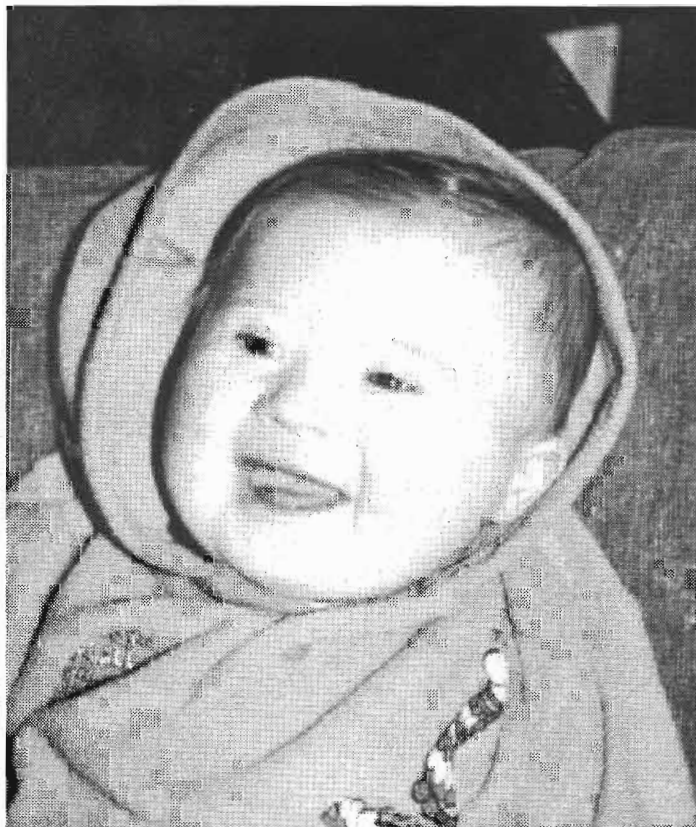
Considering how ill he was when they operated, Fionn made an astonishingly fast recovery (we were told most babies do!). Just two weeks after surgery he started sucking from a bottle again, the breathlessness and vomiting stopped and he started to develop what have now become wonderfully chubby, rosy cheeks. He's gaining weight and is full of energy and big, wonky smiles. He does have a minor problem with his trachea as a

result of a difficult intubation, but this will hopefully resolve itself as he grows. As far as his heart is concerned, things couldn't be better.

It's been a difficult journey but we have much to be grateful for. Family and friends have been wonderful and Fionn has had excellent medical care, both here in Scunthorpe and in Leeds.

And most of all, we are lucky to have Fionn who has lived up to his name and been a courageous little fighter. He has made such a difference to our lives. He is a delightful little character and we no longer think of him as a Down's Syndrome baby or a Heart baby, but as Fionn, our "Bestest" baby, and we can't imagine life without him.

**Shirley Tierney (proud mother)**  
**Scunthorpe**



# Why Ruth deserves her Teletubbie!

Our eldest daughter Ruth was thirteen on August 31st last year - she wanted a Teletubbie! This may not seem the most obvious present for a girl about to become a teenager, but as she has just had her AVSD successfully repaired without any complaint (apart from wanting to go home), we felt she deserved what ever she wanted.

Ruth's heart problem was detected when she was born, and we saw a doctor from Great Ormond Street at our local hospital every six months, then every year and then every two years, and although we always knew that there was a possibility of surgery we never really thought about it, especially as Ruth was always so well and never had any problems or had to take any medication. Ruth had her first echo in January 1998, and it was then that we were told that the best option for Ruth's future was to have the surgery. We went home to consider the options. We were told that the operation had over a 95% success rate, but we still found that all we could think of was the other 5% and we already know, as all parents of children with Down's Syndrome know, what it feels like to be in that small percent. We also found it difficult to decide to put her through everything and take the risk when she was so well.

After contacting the Down's Heart Group and being put in touch with others who had been through the same thing, talking to friends and family, we decided to go ahead, as we felt we had to give Ruth every chance of a longer and happier life, and we felt that it would be wrong to turn down the chance of that, knowing that for some they don't have that option. We were told that the operation would be before the end of year, but we were surprised when the letter came with the date set for July 20th, we expected later in the year, but at least it meant a shorter time to wait!

We received a lot of support from our family, friends, and our local Down's group, and we were very grateful for all the help and information given to us by the Heart Group. We tried to just carry on as normal and not to think of it too much until the time came, which was of course very difficult and there were times when we wondered if we were doing the right thing, but mostly we just tried to forget it! We took the children camping, (we have a son of eleven, James, and another daughter Poppy who is eight). We had a tea party for the Down's Association, and we all entered our local village fun run when Ruth was sponsored for the Down's Heart Group. Many people were very surprised that Ruth had any heart problems.

We did not tell Ruth about the operation until nearer the time, and it was hard to tell how much she understood, but at least she was not worried, and was more concerned about who was going to look after Poppy and James while we were away!

We arrived at GOSH on Sunday 19th and Ruth settled in well after having chest X-ray, echo, ecg, and blood tests. She finally settled to sleep at about 10pm cuddling her new Grommit beanie, and we went off to try to get some sleep. She was second on the list and she went to theatre at 1pm. As only one parent was allowed into the anaesthetic room Kevin took her as I did not think I could cope with that, and I'm not ashamed to say that I shed a few tears whilst I waited for him to come back. We were then shown into ICU, and met the nurse who would be caring for Ruth. It was very hard to think that Ruth would there in a few hours time.

We had been told to expect Ruth back at 3pm, so we decided to go for a walk, it was very hot and so we bought a lolly and I thought how much Ruth would have loved to be having one too. I could not help but wonder how many other parents had done that same walk. We went back to the hospital at the given time, Ruth actually came back at 3.30pm, and we were told every thing had gone very well. Due to problems with another child in ICU no parents were allowed in and it was 5.45pm before we could see her, although her nurse had been to reassure us that all was well.

It was very distressing to see her in ICU with tubes etc everywhere, but we were very impressed with the care she was receiving and we were told about everything they did which helped to ease that. We saw the surgeon Mr Tsang later in the evening who told us that he was very pleased with how Ruth's operation had gone and that she was doing very well.

Ruth remained in ICU for three days, on the Thursday evening we returned to the ward, she was still very sleepy and although she got up and sat in a chair on Friday she did not eat or seem interested in anything until the Saturday afternoon, but on

Sunday she had a bath and was eating roast pork for lunch, we of course felt such relief then and for the first time in a week could start eating and sleeping better.

Kevin returned home on the Monday ready to return with the car to fetch us home when they said we could go, that evening was the only time Ruth got upset, she wanted to go home too.

The only problem we did have was that whilst Ruth was in ICU, she had her eyes open, although she was asleep, and due to this her eyes became very sore, so we could not come home until they were happy that they were improving, but we were allowed home on Wednesday 29th July.

Ruth was so pleased when Kevin and the children arrived to take us home, but I must say I did not enjoy the car journey through London one bit, coming from a very small village it was quite a

shock to us! Everyone was very surprised to see Ruth so well after having such a major operation only the week before, but she is a big disappointment to them as she does not like showing off her scar!

We have nothing but praise for the staff of GOSH. They made sure we were aware of every thing that was happening to Ruth and that we understood everything. Ruth enjoyed the meals, painting in the playroom, the visit from the clowns, and reading lots of the books. We were given a lovely room whilst Ruth was in ICU, and Kevin was given a room whilst I slept by Ruth's bed when she was back on the ward, which was very nice as neither of us wanted to be there on our own. It was nice to have the visit from Katie from the Heart Group, it is so good of her to give up her time to support people like ourselves.

Although those few months were dreadful for us all we are sure we did the right thing and we are so glad that it is behind us and we can now get back to normal. We send a big thank you to all at the Heart Group and our best wishes to every one who has been through or will be going through a similar experience

**Julie, Kevin, Ruth, James and Poppy Maxfield  
Dunsby**



# The Children's Heart Federation

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The Children's Heart Federation is a national charity which brings together most of the heart groups associated with particular paediatric cardiac centres in the UK and Ireland and specialist national groups such as the Cardiomyopathy Association and the Down's Heart Group, which provide support for particular conditions or patient groups.

The Down's Heart Group is an active supporter of CHF as it believes that we are all stronger through having a national voice to represent us and to provide services and facilities that we might find it difficult to provide alone. It also provides the opportunity for co-operation between the various groups. I am currently the Chair of CHF as well as Joint-Chair of DHG, so am heavily involved in both. This article is to give you some idea of the services which CHF provides.

## **National Helpline**

This is staffed for twelve hours each weekday between 9 am and 9 pm. During the evenings it operates from volunteers homes, who are parents from the various groups of which a number are DHG members. The helpline provides assistance to parents and professionals with information about the range of heart conditions and problems which parents face. In about 70% of calls parents are referred on to the local or specialist group for follow up support.

## **Holidays**

You will have probably seen articles in our Newsletter from lucky families who have been on holidays with CHF. The Federation always provides a trip to Lapland at Christmas to meet Father Christmas and one family is selected by each group to make the trip. Another trip is organised in the summer on a similar basis. Previous trips have been to Legoland in Windsor and Legoland in Denmark. This summer each group is being given a chalet at Sherwood Centre Parc in Nottinghamshire, for a long midweek break.

## **Respite Care**

CHF provides grants to groups to enable them to fund respite care for their members when this is an appropriate form of support - see the accompanying article on the next page for more details.

## **Computers in Hospitals**

CHF works to provide better educational and recreational facilities for all heart children while they are in hospital. One current project is aimed at providing computers in paediatric cardiac wards, loaded with educational and recreational software and group details, which will eventually be connected with the hospital school and through appropriate security "firewalls" to the Internet and thus patients own school, home and friends. Four pilot projects have proved successful and a further six centres are being equipped this year.

## **National Conference**

A conference is held each year in different parts of the country providing an opportunity for members of different groups to come together, hear first class speakers and swap information, ideas and problems and hopefully learn from each other. This year's conference will be in Leicester in September.

## **Publications**

CHF produces a range of publications on heart topics of general interest. You may have seen favourable press comment on its latest " Travelling abroad with your heart child" which provides detailed and practical steps to take to try and ensure a trouble free holiday.

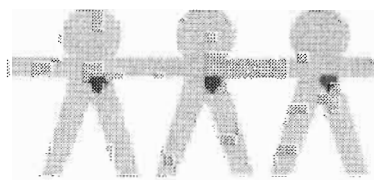
## **The Future**

In the coming year CHF is looking to establish a Welfare Fund, to finance trials in the use of INR machines for taking blood samples which heart children and their parents can use at home, thus avoiding regular and expensive and time consuming trips to hospital for tests, and running training courses in relevant subjects for members of groups.

The CHF Helpline number is below should you wish to contact them.

*John Spall*

**children's heart**  
FEDERATION



**Helpline: 0990 14 34 04**



# How members of chf groups can receive Respite Care Funding

Everyone knows how difficult it is to get a baby-sitter who is just willing to look after a child who has had heart surgery, let alone prepared to deal with an arrhythmia attack in a three year old. When the whole family does get out together, the heart child can need more attention than other children. This is why the Respite Care Fund will pay for care for your child in your home, staying at a residential centre, or on holiday with the family.

## **We never get out...**

Liz and Andrew haven't been out together since Josh was born four years ago. Although Josh is quite well, he is prone to sudden high temperatures and chest infections. He is expected to have heart surgery in the next year or so. Liz's sister invites them to a wedding with an evening reception. Liz and Andrew contact their local nursing agency and work out a price for the care Josh will need for the two half days and one night they are away. Their support group agree that this meets the criteria for respite funds and apply to chf.

The rules for getting respite care are straightforward: you need to apply to your Group. Your application will need to say when you need respite, what activity you will be undertaking at the time (in broad terms), and how much the respite will cost. It must involve special care for your heart child and a break from his or her care.

## **Questions and Answers**

How can I find someone to look after my child?

*Ask the hospital about reputable nursing agencies, or a list of care homes is available from chf.*

What about travel to and from a residential care home?

*This can be included in the cost of the respite care.*

## **I can't get sorted out**

Laura's 18 month old daughter heart child Kaylee is difficult to feed, and doesn't sleep much. Laura has recently moved, and needs to redecorate the bedrooms. The nursing agency nearest to her doesn't have anyone who has been cleared to work with children. She finds another agency in yellow pages and finds out the cost of 16 hours care for Kaylee, which her Group agree to cover from their allocation of Respite Care Funds.

Can I have funding for a holiday without my heart child?

*No, only for the cost of looking after your child while you are away.*

Can I have funding for a holiday with my heart child?

*Yes, the whole holiday can be paid for if there is provision for your heart child to get care relevant to his or her needs.*

I need to hire a car to go on holiday with my heart child - can I get funding?

*Only if there is provision on the holiday for your heart child to get care relevant to his or her needs.*

Can we go abroad with our whole family?

*Yes, if you can do so within the funding*

## **We want to be on holiday together ....**

Liam, 6, is a twin with heart and other problems. It makes holidays very difficult for Ben and Clara, who have three children. Liam needs constant attention. He is not safe near water; or among crowds as he tends to wander. Ben and Clara could use respite care funding for Liam to receive care in a residential home. But they do not want to separate the family so either they could take a carer with them on holiday with respite funds, or they could holiday at a special centre which will entertain and care for Liam while they spend time with their other children.

We have been invited to a two-day works do. What will respite care pay for?

*Respite care funding can be paid for the children to be looked after as long as you are getting special help for your heart child.*

Who do I apply to?

*Contact your Group - either their office or someone on the committee.*

## **Who will look after Hannah ...**

Hannah has had a lot of surgery, and at thirteen she is a very difficult and demanding young woman. Her parents want to take a weekend away at a theme park to celebrate their son's birthday, but they know that Hannah will cause problems. Respite care will pay for a carer to go with them, someone will be there to calm Hannah down and look after her while the family are free to enjoy their time out.

Can we have money in advance for booking?

*Yes.*

Can I add my own money to chf funding?

*Yes.*

*Reprinted from the Children's Heart Federation  
Update February 1999.*

## **Memorial Donations**

Since the last newsletter, we have received donations in memory of :

**Jamie Foskett** - Kings Lynn (9 months)  
**Christian Fox** - Northampton (5½ years)  
**Owen Jackson** - Halifax  
**Morgan Jones** - Wrexham (4 months)  
**Joy Litster** - Perth (9 months)

**Monica Sellis**  
**Maya Staines** - London (14 years)  
**Anne Steedman** - Middlesbrough (16 years)  
**Scott Thomson** - Unst (18½ years)



# Review

## INFORMATION PACK ABOUT HEART PROBLEMS FROM THE DOWN'S HEART GROUP

The incidence of congenital cardiac disorders in people with Down's Syndrome is rather high and the fraction of those that are amenable to cardiac surgery and other forms of treatment is now very much higher than it used to be. The relatively recent changes in attitude towards providing these treatments has resulted in increasing numbers of children with Down's Syndrome undergoing cardiac surgery.

The Down's Heart Group is an organisation which was established to help the parents of children with Down's Syndrome and a heart condition. Their aim is to supply information about the heart conditions found in people with Down's Syndrome in a straightforward and easily understood form.

The Group has published an Information Pack containing fifteen A5 sized cards each covering a separate topic and a video tape. The cards describe virtually all of the cardiovascular conditions which occur in people with Down's Syndrome as well as topics such as The Heart Team, Medical Terminology, drugs used in cardiology and cardiac catheterisation.

The topics are covered in a straightforward, factual and easily understood style while maintaining a supportive tone. Concerned parents will be able to find information about almost all the general questions they are likely to ask in this pack. The companion video-tape graphically illustrates some of the same topics as well as demonstrating some of the concerns that parents expressed during group discussions. These materials are highly recommended.



*Review by Professor Ben Sacks, Consultant Developmental psychiatrist and Medical Advisor to The Down Syndrome Educational Trust.*

**Reprinted from Down Syndrome News and Update, Volume 1 No.1, with the kind permission of The Down Syndrome Educational Trust.**

## Fund-raising Update

Since our last newsletter, we have had donations from many people. It is not possible to mention all of them, but we do appreciate all the support we receive, no matter the amount. As we rely on donations to fund our work, we are grateful for every sum given, and a small unsolicited gift to say thank you for a hospital visit or an enjoyable conference, means just as much to the Down's Heart Group as some of the bigger gifts from companies etc.

We still get credits to our bank account in respect of the change collected in our little cardboard moneyboxes, many of them anonymously, so **Thank You** if you are collecting small change for us. We do have a number of moneyboxes left in anyone wants to put one on their desk at work.

Fund-raising event over the past few months have included :

A sponsored walk by Dave Deacon, who was to have run in the 1998 London Marathon for us, but was sadly unable to take part due to injury. Dave raised over £300.

A sponsored swim by member Barbara Dunne of Basingstoke, who swam one hundred lengths of her local swimming pool and raised nearly £500 in memory of her son Reece.

£1000 donated by Channels Golf Club Chelmsford, from their charity fund-raising for the year. The Captain for the year was Bob Wren who is the great uncle of DHG member Amy Clark.

Over £200 from the Timber Batts Ashford, whose proprietors are Ken and Maureen Turnbull, grandparents of Joshua.

A production of 'Hansel and Gretel' by the Dehaviland Dance and Drama Studio St Leonards on Sea, from which the proceeds went to the DHG.



**THANK YOU to those mentioned above, and to all our other benefactors whom space prevents us from mentioning.**

# Lapland Trip - Christmas 1998

The Children's Heart Federation, Lapland Trip has become a regular annual event. Each member group gets to nominate one child, accompanied by a parent or helper, to join the party for the one day trip to visit Santa at his home in Lapland.

In 1998, the Down's Heart Group was lucky enough to have two children go, as not only did we have our normal nomination, but a company in Tamworth also put up the funds for a local child to go. They urgently wanted a child nominated, and as one of the few national groups in the Children's Heart Federation, the Down's Heart Group was approached to see if we had anyone in the locality who might be interested in going. Lynne Holden and her daughter Brittany jumped at the chance, and as you can see from their letter below, they had a thoroughly good time.

The other lucky DHG member was Ben Mohsen from Feltham.



Dear Down's Heart Group,

This is to say a big **Thank You** for putting Brittany's name forward for the trip to Lapland. It was **magical**. I don't know what I expected but it was far, far better than anything I could have imagined.

The organisation was first class, right from when we arrived at the Hotel until we left. I must say I was rather worried about bringing Brittany on my own as it usually takes two or more adults to look after her, because, as you know, she is rather lively and tends to run off frequently. However, there was so much to keep her occupied in Lapland that it wasn't a problem.

She particularly enjoyed cuddling the huskies and the reindeer and being pulled around on a sled by Mom! I fell in love with the reindeer too but for me, the best part was meeting Santa! I am convinced that he was indeed the **real** Santa. He even said he remembered me when I was a little girl! Brittany received a lovely gift from Santa and also many gifts the previous evening at the celebration dinner. It was very kind of all involved.

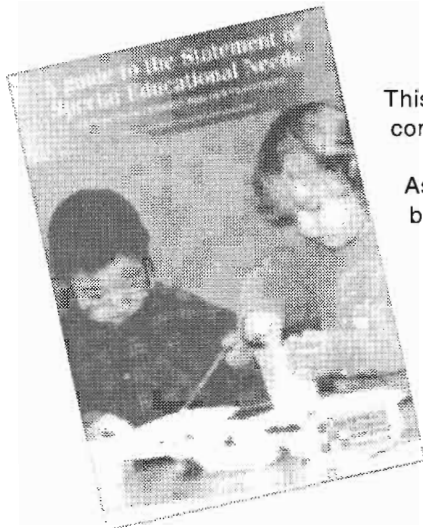
The reason for the trip was brought home to us on the aeroplane on the return trip. We were sitting next to a little girl from Leicester who had had to walk for a little while before getting onto the aeroplane. She was ashen and breathless. Her eyes were red, her fingers, lips and tongue were blue. Her heart condition was obviously very severe. There was no mistaking the sparkle in her eyes though. Despite her obvious discomfort, she had enjoyed a truly wondrous day. We are very fortunate that Brittany's two holes in her heart were repaired when she was eleven weeks old and, as far as her heart is concerned, she has remained well.

Once again, thank you for providing us with the trip of a lifetime (although I think we may save hard so that we can return with the rest of the family in the future!).

*Lynne Holden and Brittany*

**Lynne Holden (and Brittany)**  
Tamworth

# Information / Can you Help?



## A guide to the Statement of Special Educational Needs

This very useful booklet, produced by the Down's Syndrome Association, answers the many common questions asked by parents of young children with Down's Syndrome.

As well as explaining what a Statement is, how it comes into existence and when it should be made, it also looks at the complete Statementing process under the headings :

- The assessment process
- The Proposed Statement
- Common problems with the Proposed Statement
- The Named School
- Negotiating at the Proposed Statement stage
- The Final Statement
- Arranging the Provision

Also listed are other Sources of Information and Help.

The booklet normally costs £2.50p, but is free to families of children with Down's Syndrome, and is available from the Down's Syndrome Association National Office (details on page 16).

## Mosaic Down's Syndrome

*The following is an extract of a letter from Tracey Stokes, who has written to the Group in the hope of contacting families whose child has the Mosaic form of Down's Syndrome.*

At the moment, we do not know for sure what causes mosaicism or when it occurs, although it is thought to be a mechanical problem during the cell division of the embryo, not a genetic one. Until we know this for sure, we cannot predict a couples' chances of having other children with this problem. In my case, I had a clear amniocentesis result as well - as none of the antenatal tests are accurate for mosaicism.

In early September 1998, Professor Anna Kessling (Professor of Community Genetics and Head, Academic Unit of Medical and Community Genetics at Imperial College), kindly agreed to see me to discuss Down's mosaicism. She is one of a handful of people currently researching Down's Syndrome in the UK and has advised the DSA in the past.

She was extremely interesting to talk to and showed me some of her team's research so far. They are asking why and how Down's syndrome occurs and why it appears to manifest itself so widely amongst those who have it - ie. why don't all people with the syndrome all have heart defects? Or the same heart defects?

However, only people with full trisomy 21 (and their families) are participating in the study group. She confirmed that, as far as she was aware, little research has been done anywhere (not just in the UK) into Down's mosaicism, but that with a group of at least 50 families (she would need a certain critical mass), she would be interested in conducting some research into it, subject to research funding. Such research ought to tell us when mosaicism occurs, and perhaps what causes it, if due to genetic reasons.

*Please contact National Office for a copy of Tracey's complete letter and contact details, if you would be prepared for your family to participate in such a study.*

# Tamba

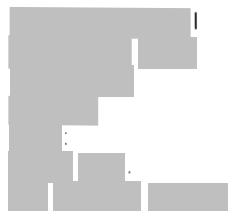
TWINS & MULTIPLE BIRTHS ASSOCIATION

Many of you will have heard of the Twins and Multiple Births Association (Tamba), but did you know they also have a Special Needs Group?

This group has both parent and professional members who are closely involved with twins, triplets or more, where one (or sometimes more), of the multiple children has special needs of varying complexities.

The group offers three newsletters a year, contact for mutual support, family days out and a comprehensive resource and information service.

For further information about the group, you can contact Margot Eastwell, who is their Special Needs Resource and Information Co-ordinator :



*You are sure to get a helpful and understanding response from Margot as she is also a member of the Down's Heart Group, in her capacity as mum to seven year old twins Benjamin and Thomas (who has Down's Syndrome).*

# Information / Can you Help?

## 'Just Kids' booklet reprint - photos needed

Some of you will be familiar with a booklet called 'Just Kids' originally produced some years ago but now sadly out of print. The booklet was originally produced by Mary Hynes who's grandson, Ben, appears on the front cover and was intended as a positive statement for new parents, carers and even professionals to show that children with Down's Syndrome are just that, 'children'. Over the years we have come across many parents who have received great hope and encouragement from the booklet and have taken the decision, in co-operation with Mary Hynes, to oversee the updating and reprinting of 'Just Kids'.

We would like to receive photos of children for possible inclusion in the booklet and would like to ask you to consider sending us a photograph of your child. The pictures need not be formal (although it's fine if they are and professionally taken shots would be very welcome) but can be casual shots of your child at play or work and can feature other children or parents so long as the child with Down's Syndrome is the focus of the picture. Each picture will need to be accompanied by a brief statement with a few facts or interesting anecdotes about the child; their birth date/age, milestones achieved and when, problems they've had and how they coped, hobbies, skills, how they've affected your lives and other peoples; in fact anything of possible interest to other parents of children with Down's Syndrome.

Please do give serious consideration to submitting a photograph of your child. We believe that 'Just Kids' was a wonderful booklet which offered a little positive light in the face of the inevitable barrage of negative thoughts and emotions which can hit new parents. We will keep you informed on the progress of the booklet and, should we be able to include your child, we will let you have a proof copy of your child's entry for your approval prior to printing.

All photographs together with information about your child should be sent to my attention as soon as possible. We hope to get the information together by the end of July 1999.

I look forward to hearing from you soon.

Regards

Mary Schultz.

*Photographs for consideration should be sent direct to Mary at:*

92 Longstombs Avenue  
Chelmsford  
Essex  
CM2 9LB

*Please also send a note stating that you enclose a photograph for possible inclusion in the 'Just Kids' booklet. And add your name, address, child's name and date of birth and a few interesting facts or anecdotes about your child.*

## About One Hundred Hours

One Hundred Hours is a registered charity which has been working since 1992 in the north of England to give support to families who have a baby with serious and multiple disabilities and complex health problems.

It is a free service offering support to parents during the first couple of years with weekly home visits. We provide emotional support and information, and help parents to get the best available services for their child.



The One Hundred Hours  
**SOFTY SURVEY**  
Support Over First Two Years

The SOFTY Survey is a UK postal survey to find out what support systems are available to parents to meet their own needs during the first two years after disclosure of their child's actual or suspected multiple and complex disabilities.

*We are enclosing a copy of the SOFTY SURVEY with newsletters going to members whose children are under five. Please ignore the date shown on the front of the survey, and return your questionnaire by the 31st July 1999.*

## Insert for 'Personal Child Health Record' book for babies born with Down's Syndrome

The Down's Syndrome Medical Interest Group has produced a fourteen page insert for the parent held records books. This contains additional information for both parents and professionals which will help them to maintain the health and wellbeing of their child with Down's Syndrome.

Areas covered are:

- ♥ General information
- ♥ Expected developmental progress
- ♥ Possible health problems
- ♥ Suggested schedule of health checks
- ♥ Advice about immunisations, feeding and growth
- ♥ Down's Syndrome specific growth charts
- ♥ Sources of additional help and advice

The insert costs £1.50 (including postage and packing), but thanks to sponsorship from Marks and Spencer, it is currently available free of charge to families with preschool children.

**All enquiries to:**

Down's Syndrome Medical Information Services  
Children's Centre  
City Hospital Campus  
Nottingham  
NG5 1PB

Tel : 01159 627659 Ext. 45667

# Members with Chronic Cardiac Conditions

Dear Members,

I offered my resignation from the Executive Committee of the Down's Heart Group, to the Committee meeting of the 27th February 1999. I also wished to confirm that I remain a supportive member of the Down's Heart Group, and of continuing work on behalf of people with Chronic Cardiac Conditions and for those with Autistic tendencies.

From our point, I hope that changes will just affect representation of your thoughts, ideas and recommendations to the Committee and into the Newsletter - there will be somebody else now with that responsibility. I look forward, as always, to our personal contact, sharing news and views, our phone chats, letters, all the nice things that happen through knowing you, with the confidence that gives us as Alex's parents.

With Best Wishes

*Wendy Tucker.*

## Services, Training and Products Catalogue

The Down Syndrome Educational Trust have just produced a new catalogue detailing their services. It contains details and dates of the training they can offer until the end of next year (2000), as well as their expanded range of books and educational software selected specifically for our children.

They will be working hard to get copies of the catalogue to all Child Development Services, Education and Social Services, in order to reach the maximum number of professionals with up-to-date information through training and periodicals. If you would like a copy for yourself, or for a professional involved with your child, these can be obtained from :

DownsEd  
The Sarah Duffen Centre  
Belmont Street  
Southsea  
Portsmouth  
Hants.  
PO5 1NA



**They would no doubt be grateful for the enclosure of stamps to cover postage (64p second class, 80p first class).**

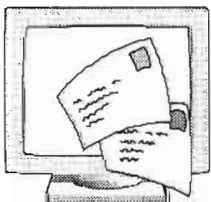
## Please keep in touch!



It's always sad when we lose contact with a family because they forgot to tell us they were moving house. So often redirection of mail has finished before we send the next copy of the newsletter, and although we try to trace new addresses it's not always possible, so if you are moving, please do remember to tell the Down's Heart Group your new address.

Also, we love to hear how members have got on when they have had surgery, and of their achievements, so please do keep us informed.

If you are sending in a story, child's picture etc. please enclose a photograph of your child, and also state that you agree to the Down's Heart Group publishing it. We can return photographs if needed, but ideally we like to keep them - we have a lovely album of member children so you can be assured that they aren't being banished to the bottom of a filing cabinet!



So do keep us informed of new addresses, telephone numbers, e-mail addresses and any interesting news about your child.

**Our members are very important to us!**



# Letters to the Editor

## Tricycle Needed



Colin is nine years old and loves his bike, but we now have a problem. We have had to move Colin's seat of his bike up as he has grown so much lately. This is making him a little top heavy, so every time he turns his bike he tips over.

We are looking for a second-hand tricycle or some ideas as to what to do with Colin's bike to stop him tipping over.

**Isobel Turnbull**



## Thank You

Thank you for being there throughout Jamie's short life. As promised we are donating a token sum of money in memory of our beautiful little boy, who brought us and everyone around him, so much joy in such a small amount of time. My sister has also enclosed a cheque, we will continue to do so. Please keep us in touch with the good work you do.



**Rachel, Martin & Jade Foskett  
Kings Lynn**

P.S. I've also enclosed a copy of something my sister read out at Jamie's "Goodbye Service".

### A Few Words for Jamie

When I think of Jamie, I see his amazing smile that seemed to stretch from one ear to the other, his deep blue eyes that shone brighter than a million of the brightest stars, and hair that was touched by the warm glow of the sun.

A little boy who had more strength, courage and spirit than anyone I've ever known.

He loved to love, and was so good at it.

I will never be able to forget him because he's the sun on a misty dawn, the wind through an Autumn tree, and the rainbow on the rainiest of days.

I am so grateful that, through the love and courage of Rachel and Martin, I had the chance to be touched by a true angel.

I love you Jamie Lawrence Foskett .....

**Love from Nennie**

xx

## Feeding Problems?

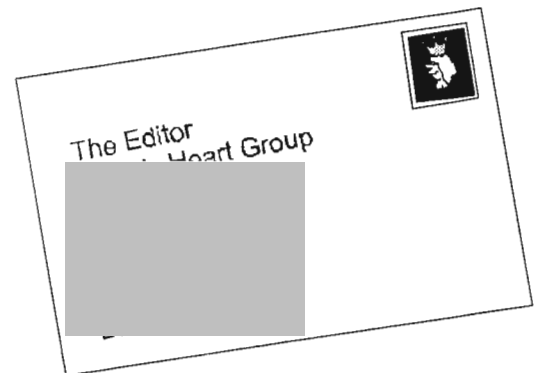
Isobel, our dear little daughter, was born on 23rd September 1998 two weeks early, and seemed to do very well for about six weeks. She then failed to thrive and got a stomach bug and a very bad cold. She was operated on at Harefield Hospital on 16th December. She was an absolute star and sailed through the recovery with flying colours. She was discharged with a naso-gastric tube on the 23rd December in time for Christmas.

She has resumed breast-feeding much to my delight, and we've begun to feed her solids too. Her weight gain has been nonexistent which is a worry and I'd be interested to hear from any other parents who have experienced a similar problem.

Her operation was successful, so the weight gain (or lack of it) is nothing to do with heart failure. We have got the dietician at Harefield Hospital and our own community dietician looking into the problem.

Isobel is a delight. She is all smiles and coos. She is fascinated with her hands and feet but is still fairly floppy. We have begun portage with her, which seems quite fun but time-consuming, and I feel my toddler is missing out, but I'm sure I'll work out a balance somehow.

**Victoria Stevenson**



## HOLIDAY BUNGALOW IN DEVON



Holiday Bungalow in garden setting situated in picturesque holiday park in Fishcombe Cove, Brixham, Devon. Two bedrooms, sleeps 4-6; well-equipped kitchen with microwave; Colour TV; 250 yards from beach; ten minutes

walk from Brixham Harbour. Heated indoor swimming pool, bar, restaurant, shop.

Available for holiday lettings from Easter through October, details: Brett & Sheila Boniface, [redacted].

## National Contacts

### National Office

Website : <http://www.downs-heart.downsnet.org/>

Contact or Ansaphone always available (24hrs in emergency)

<b>National Administrator</b>	<i>Penny Green</i>
<b>Founder</b>	<i>Linda Walsh</i>
<b>Joint Chairs</b>	<i>John &amp; Katie Spall</i>
<b>Vice-Chair</b>	<i>Sheila Forsythe</i>
<b>Treasurer</b>	<i>Phil Thorn</i>
<b>Secretary</b>	<i>Donna Hoppe</i>
<b>Legal Advisor</b>	<i>Brian Auld</i>
<b>Policy Advisors</b>	<i>Mary Goodwin Dr. Rob Martin Dr. Claus Newman Dr. Phil Rees</i>
<b>Benefits Information Contact</b> Contact via National Office	<i>Mary Clayton</i>
<b>Representative for those with</b>	<b>Chronic Cardiac Conditions</b>
	<i>Jane Wrighton</i>
<b>Patrons</b>	<i>Sarah Boston David Graveney</i>

For general information about Down's Syndrome, you might like to contact:

The Down's Syndrome Educational Trust  
The Sarah Duffen Centre  
Belmont Street  
SOUTHSEA  
Hants.  
PO5 1NA  
01705 824261

Down's Syndrome Association  
153-155 Mitcham Road  
Tooting  
LONDON  
SW17 9PG  
0181 682 4001  
(Regional offices in Wales, Midlands  
and N. Ireland)

Scottish Down's Syndrome Association  
158/160 Balgreen Road  
EDINBURGH  
Lothian  
EH11 3AU  
0131 313 4225

Down's Syndrome Assoc. of Ireland  
5 Fitzwilliam Place  
DUBLIN 2  
EIRE  
00 353 1 6769255

## Regional Contacts

**Bristol & South West** - Avon, Cornwall, Devon, Gloucs, Somerset & Wilts

Sheila Forsythe  
Wendy Hellowell

**East of England** - Cambs., Lincs., Norfolk & Suffolk

Nicola Desmond  
Lindsay Wharam

**East Midlands** - Derby, Leics., Notts. & Northants.

Sarah Smith  
Linda Wainwright (Glenfield Hospital)

**Ireland** - N. Ireland & Eire

Rosina Brierley  
Marion Delaney (Dublin Hospital)

**London Northern** - Beds, Berks, Bucks, Essex, Herts., Middx., Oxon. & N. London

Sheila Boniface (GOS Hospital)  
Joanna Simms (Harefield Hospital)

**London Southern** - Kent, Surrey, Sussex & S. London

Katie Spall

**North East** - Cleveland, Cumbria, Durham, Isle of Man & Tyne & Wear

Sally Hardman

**North West** - Anglesey, Cheshire, Clwyd, Gtr. Manchester, Gwynedd, High Peak, Lancs. & Merseyside

Mike Halpin

**Scotland** - Mainland & Islands

Elaine Thomson (Glasgow Hospital)

**South Wales** - Dyfed, Glamorgan, Gwent & Powys

Chris Stringfellow

**Wessex** - Channel Islands, Dorset, Hants., Isle of Wight

Vickie Richardson (Southampton Hospital)

**West Midlands** - Hereford, Worcs., Salop, Staffs, Warwick & W. Midlands

Lynne Holden

**Yorkshire & Humberside** - Humberside & All Yorks.

Lindsay Allen  
Carolyn Marshall (Leeds Hospital)

LETTERS AND ARTICLES REPRODUCED IN  
THIS NEWSLETTER EXPRESS  
THE OPINIONS OF THE AUTHORS.  
THEY ARE NOT NECESSARILY  
REPRESENTATIVE OF THE VIEWS OF THE  
DOWN'S HEART GROUP.