

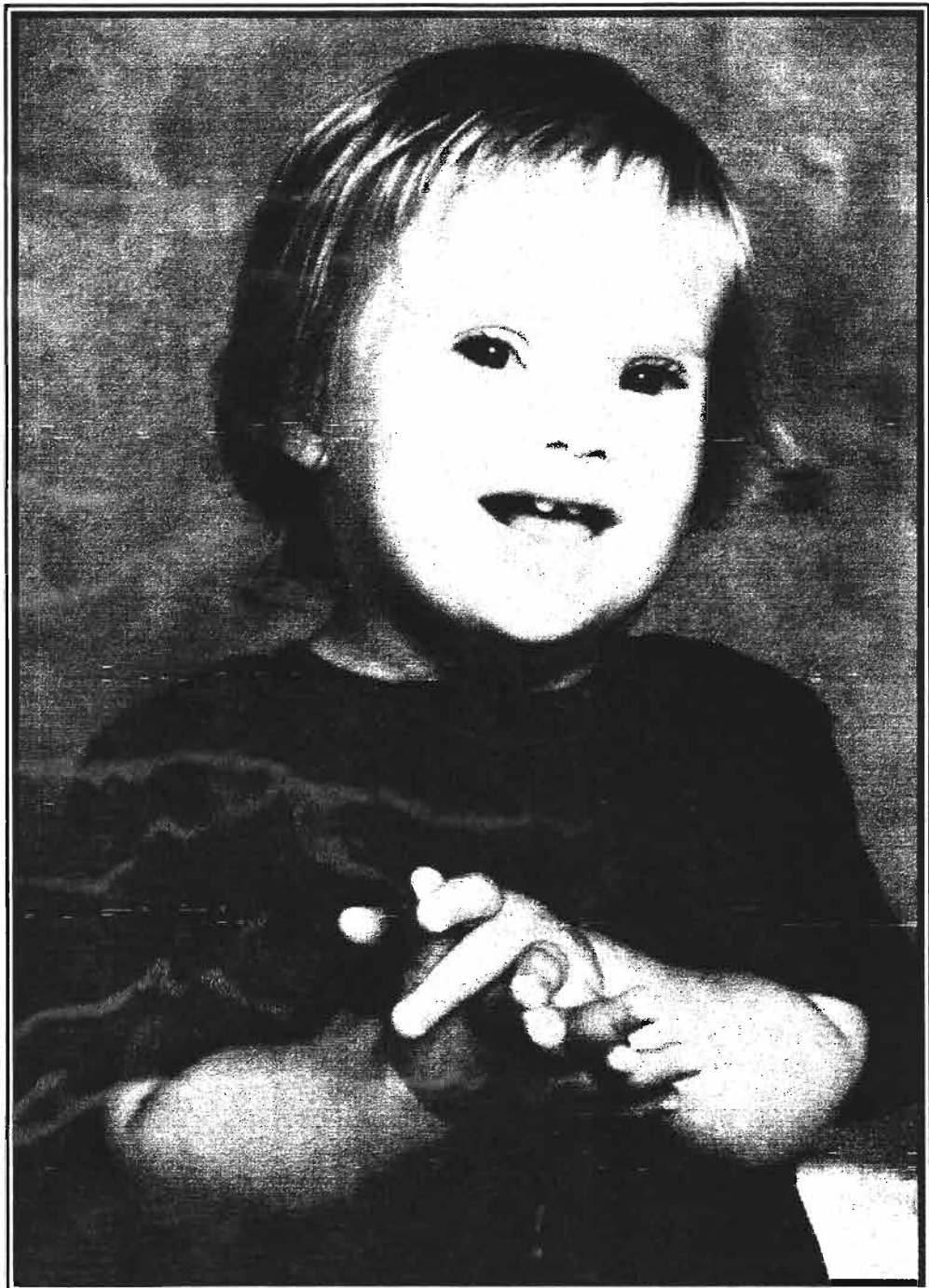


DOWN'S  
HEART  
GROUP

# NEWSLETTER

(Issue No 11)

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# Committee Contacts

**Founder**

Linda Walsh

**Chairperson**

John Spall

**Vice Chairperson**

Sheila Forsythe

**Secretary**

Gill McLorinan

**Treasurer**

Phil Thorn

**Legal Advisor**

Brian Auld

**Newsletter Editor & Family Support**

Penny Green

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## Who Do I Contact?

General enquiries (other than those from families) should be addressed to the Secretary. Requests for information about the work of the group from professionals, students etc. should be sent to the Secretary, enclosing an sae.

Requests for support and information for families should be sent to the relevant Regional Co-ordinator as shown on pages 4 and 5, or to the Family Support Co-ordinator as above.

Donations may be sent direct to the Treasurer.

Correspondence which does not fall into any of these categories should be addressed to the main office:

Down's Heart Group

For more general information about Down's Syndrome not related to heart defects, you might like to contact:

Down's Syndrome Association  
153-155 Mitcham Road  
Tooting  
LONDON  
SW17 9PG  
Tel: 081 682 4001

Scottish Down's Syndrome  
Association  
158/160 Balgreen Road  
EDINBURGH  
Lothian  
EH11 3AU  
Tel: 031 313 4225

Down's Syndrome Association  
of Ireland  
27 South William Street  
DUBLIN 2  
EIRE  
Tel: 010 353 1 6793322

**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.**

## Chairperson's Report

I see that it was only in the previous edition of the newsletter that I was telling you about the Group's successful AGM in 1993. And here I am writing about this year's! This is not just that time has flown by (which it has) but because we are bringing the meeting forward from June to April. As our financial year ends on 31st October, we thought that waiting eight months for the AGM was a bit much.

I have felt for some time that the description "Annual General Meeting" is something of a misnomer for what is a full day of speakers, workshops, socialising, etc., with the formal business restricted to about half an hour. The Committee has agreed to retitle the day as the Annual Conference and General Meeting (a good compromise!) to reflect this.


We are moving our furthest north this year with Merseyside region playing hosts, under the able guiding hand of Mike Halpin. This is the one occasion in the year when we can all get together and I hope to meet many of our northern members at what will be an interesting, informative and enjoyable day. Full details are on page 5, and all members will also find their official notification letters enclosed with this newsletter. If you would like to come but are concerned about the journey or any other aspect of the day, do please talk to your regional co-ordinator.

The Down's Heart Group is launching a fund raising drive. As you know, the Down's Heart Group is a charity run entirely by its volunteer members. This means it gives tremendous value for money, but this cannot be done without some costs. To enable us to provide coverage across the country, to train our volunteers and to give a better service to you, the members, we need to increase our annual income.

We quite deliberately do not have a membership subscription as we believe the Down's Heart Group should be open to all eligible families without restriction. This does, however, mean that we have no assured income year to year, and must start each year from scratch to raise what we need.

We cannot do this without your help. If you feel you could manage a donation each year in lieu of a membership subscription we would be most grateful. Better still if you could make this a commitment for four years by a covenant, as we can then reclaim the income tax on this without further cost to yourself. A Covenant form is enclosed with this newsletter should you wish to use it.

To make giving as painless as possible, we are introducing a money box scheme. This will enable you, your family and friends to give the odd amount of small change, payment for a small service etc. to the Down's Heart Group, by popping it in your money box. You will find one box enclosed, extra boxes for family and friends can be obtained from our national office if required. We believe this idea has considerable potential, so please get folding at once, and put your box on prominent display. If you have any queries about using the boxes, or paying in the money, please contact the Treasurer (details on page 2).



*John Spall*

### DATA PROTECTION

*Due to recent concern from a family considering membership of the Down's Heart Group, we would like to clarify the situation with regard to information held about member families.*

The Down's Heart Group is registered under the Data Protection Act and members may apply to the national office for a copy of the data we hold relating to their family. Information is stored on two computers used by the national office and the secretary, and from these, reports are printed for the relevant Regional Co-ordinator. Neither computer is linked to the telephone system, so data cannot be accessed by anyone outside of the group.

The information we hold is to assist us in giving the best possible support and information to member families, but we also hope that some of it may be useful for future research. If at any time we identify your family as a suitable contact for another member, or for a research project, we will always contact you first to ask permission before giving out your address and/or phone number, and you are always quite at liberty to refuse.

If you still have any concerns, do get in touch, but please be assured that all Down's Heart Group volunteers follow a strict code of confidentiality.

# Regional Contacts

## **Bristol & South West**

(Avon, Cornwall, Devon, Gloucs, Somerset & Wilts)

Sheila Forsythe Gill McLorinan



## **East of England**

(Cambs, Lincs, Norfolk & Suffolk)

Lindsav Wharam Nicola Desmond



## **East Midlands**

(Derby, Leics, Northants & Notts)

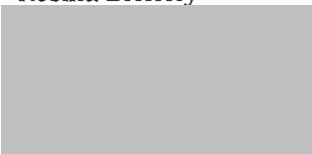
Sarah Smith



## **Ireland**

(N.Ireland & Eire)

Rosina Brierley



## **London Northern**

(Beds, Berks, Bucks, Essex, Herts, Oxon & N. London)

There is no Co-ordinator at present,  
please contact National office for assistance.

## **London Southern**

(Kent, Surrey, E. Sussex, W. Sussex & S. London)

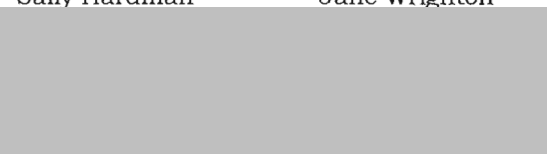
Katie Spall Linda Crozier



## **North East**

(Cleveland, Cumbria, Durham, Isle of Man, Tyne & Wear)

Sally Hardman Jane Wrighton



## **North West**

(Anglesey, Cheshire, Clwyd, Gtr Manchester, Gwynedd,  
High Peak, Lancs & Merseyside)

Mike Halpin



## **Scotland**

(Mainland & Islands)

Lynn Gouck



## **South Wales**

(Dyfed, Glamorgan, Gwent & Powys)

Chris Stringfellow



## **Wessex**

(Channel Islands, Dorset, Hants & Isle of Wight)

Vickie Richardson (*Southampton Hospital Contact*)



## **West Midlands**

(Hereford & Wores, Salop, Staffs, Warwick & W. Midlands)

Pat Mitchell Noreen Hodgkinson



Lynne Holden (*Birmingham Hospital Contact*)



## **Yorkshire & Humberside**

(Humberside, N. Yorks, S. Yorks & W. Yorks)

Linda Watcham



**If you have difficulty in contacting any of the above, please contact our national office (details on page 2) who will be able to help you.**

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# Annual Conference and General Meeting

Date: **Saturday 23rd April 1994**

Venue: **Thornton County Primary School, Thornton, Liverpool**  
(Approximately two miles from the end of the M57 and M58, seven miles from the city centre.)

As in the past, this promises to be an interesting and enjoyable day not only for Down's Heart Group members, but also for anyone interested in the care of children with Down's Syndrome who have an associated heart condition. As we go to print, a few arrangements remain to be confirmed, but members will find more details on the official notification letter enclosed with this newsletter. Non-members wishing to attend, please contact the Secretary (see page 2) for further details.

The agenda for the day includes the formal part of the Annual General Meeting, followed by two sessions with our guest speakers:

**Dr Kevin Walsh** - senior cardiologist at Royal Liverpool  
Children's Hospital, Alder Hey

**Dr Mark Jackson** - currently collaborating in the research programme  
funded by the Down's Syndrome Association

This will be followed by lunch during which there will be time to socialise, purchase sweatshirts and t shirts and examine the various displays. After lunch there will then be the opportunity to attend one of three workshops run by:

**Val Millington** - cardiac social worker at Alder Hey  
cardiac surgery here and overseas

**Julie Davenport** - officer in charge of Pipkins Day Nursery  
videos on 'how to play' and ideas on making toys to stimulate

**A Dietician** -  
(to be advised) suggestions on how to get a child with feeding problems to eat

A buffet lunch and refreshments will be provided.

A creche is available, but places are limited, and must be pre-booked to ensure we have adequate supervision for the children. They will be allocated on a first come first served basis, so please book early if you need to bring children with you.

There is a nominal registration fee of £1 per adult, payable on the day.

## Harry's Story

Harry Oliver was born on 3rd June 1992 at Farnborough Hospital, Kent. He weighed 7lb 3oz, and was our first child. He emerged into the world rather abruptly, speeded by Ventouse extraction. I remember asking "Is the baby alright?", and being told "He's Fine."

Two days after, Harry's paediatrician, Dr Hobbins, broke the news that he had Down's Syndrome. Still reeling from this shock, she told us that she wanted to do an ultrasound scan of his heart, as Down's children often had heart problems. We wheeled Harry down to the deserted shadows of the Ante Natal Clinic on Saturday morning, where he had the scan. Back on the post natal ward, Dr Hobbins again had to break the news to us that she thought there was something wrong with Harry's heart. She made an appointment for Harry with Dr Baker of the Department of Paediatric Cardiology at Guy's Hospital for 12th June. She told us that she knew that they were operating much earlier on cases like Harry's, and thought that they may operate when he was around three months old.

Meanwhile, on the post natal ward, Harry failed to wake for feeds, and would often fall asleep whilst feeding. He lost weight and was jaundiced. Eventually, it was decided that he should have his feeds by naso-gastric tube. Slowly his feeding problems lessened and we were allowed to take him home on 9th June. The time at home passed as normally as it can for any family with a new baby!

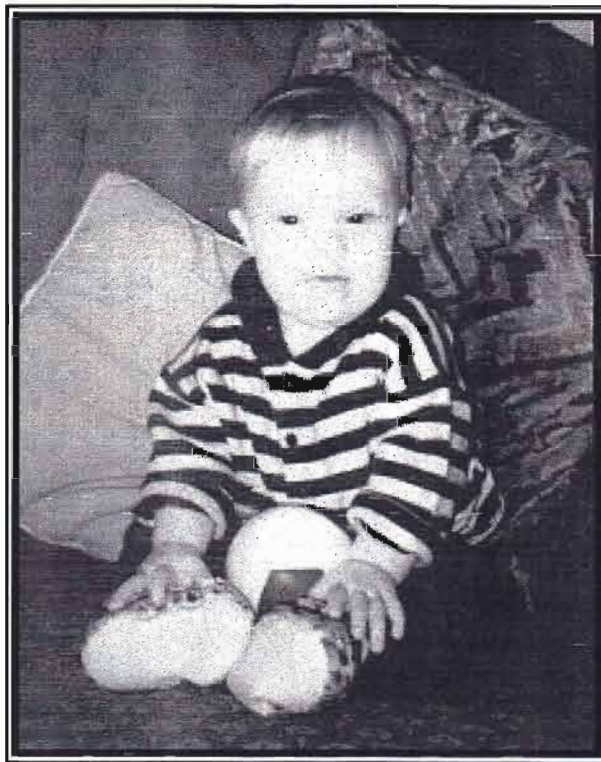
At Guy's, Harry had an echocardiogram, and we were told that he had an AVSD. Diagrams were drawn to explain this to us, and surgery was advised "sooner rather than later" to avoid any permanent damage to his heart and lungs.

Three days later we had an appointment with Dr Hobbins at Farnborough Hospital Out Patients for a check up. We were asked if Harry had shown any signs of heart problems, such as sweating and clamminess on feeding, and turning blue. Thankfully, he had not. On our return home, Harry vomited his entire feed, and continued to be sick after every feed that day. Horrified by the amount and manner of this sickness, I telephoned our GP. She said she thought it might be pyloric stenosis, which is common in first born male babies, and she arranged for Harry to be admitted to the children's ward at Farnborough Hospital.

Harry was given Gaviscon and various other remedies to prevent sickness, and was once more fed by naso-gastric

tube. A scan of his stomach showed that he had no problems there. After we had been at Farnborough for about six days, Harry started to be sweaty and blue after feeding, and Dr Hobbins thought that he should go directly to Guy's. Harry and I were transferred by ambulance, with Eamonn following behind in our car.

At Guy's, Harry had another echo, a chest x-ray and an ECG. Also because he was still jaundiced he had an ultrasound of his liver, which thankfully proved normal - I really don't think we could have coped with anything else at this stage. Harry was given Frusemide and Spirolactone. He was on a ward with four other babies, and they all had breathing monitors. Throughout the day these monitors would go off as a distracted mother picked up her baby before switching it off. Reassuringly, nurses would appear from nowhere, and thankfully were not annoyed at the 'false alarms'.



On 29th June, just over three weeks after Harry was born, Mr Anderson the surgeon, operated to repair Harry's AVSD. The days before had been very hurried. Mr Anderson explained what would happen if Harry did not have surgery - he would not live until his fifth birthday. We were also told of the ten percent chance that Harry would not survive the operation, but for Harry's sake he had to have it, there was no real choice for us.

We had decided that he should be christened before his surgery. We had a beautiful little service in the Chapel at Guy's. My mother came to stay at our house to look after the cats, and Eamonn and I

moved into Ronald McDonald House, a house where parents of children having treatment at Guy's can stay, which aims to be a home from home, with laundry and cooking facilities, it is just a few minutes away from the hospital.

We also had a visit to ITU, and met 'Frankie', a life-size baby doll which is wired up to all the machines, drips and monitors, so that parents know what to expect. We were reassured by the one to one ratio of nurses to patients, and the quiet kindness of the staff.

Eamonn and I bathed Harry on the morning of his operation, and took him down to the anaesthetic room. We stayed with him until he was under the anaesthetic, and then went back to the ward to begin the long wait. We sat on the ward, not able to do anything. Finally, at about noon, the Sister phoned down to the operating theatre to see what was happening. She came back to tell us that

Harry was off by-pass. Some time later, she told us that Harry was out of theatre and 'everything was alright'. We could go and see him in ITU.

The relief of seeing him again was indescribable, and I cried yet again. I knew we were not at the end of the tunnel yet, but we were on our way.

Incredibly, Harry was taken off the ventilator later that evening, and the next day the pace-maker was disconnected. I held him for the first time since the operation, and a few days later I gave him a bottle which he sucked until it was finished with great gusto! He had never finished a bottle so quickly before. Our little fighter had no complications while he was on ITU, and three days after surgery, when he was just a month old, he was back on the ward. He slowly began to gain weight and was discharged one week after the operation.

It was such a joy to have him home again. He was taking diuretics until September, and has a yearly check up with the cardiologist, but is doing very well. He now has a very slight heart murmur.

Harry is now very nearly sixteen months old, and is a lovely child. His health is excellent - he has a few colds but that's all. He is sitting and commando crawling extremely quickly, and goes swimming once a week, which he loves.

We can't thank Dr Hobbins and the staff at Farnborough, and Dr Anderson and the staff of Rothschild and Paediatric Russell Brock wards at Guy's, enough for their kindness, and we are so grateful for what they did.

*Jo Wall  
Bromley*

## Lucy's Story

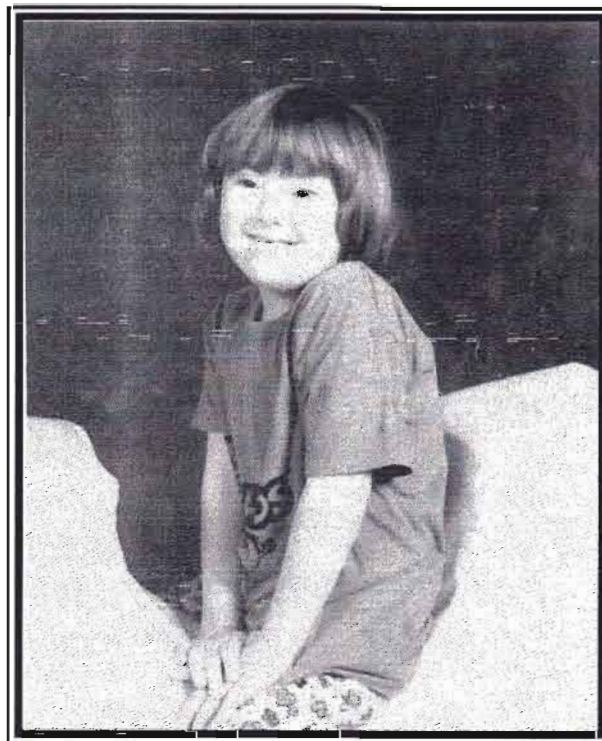
Lucy was born on 1st January 1986. We were thrilled with our third child, another girl - so what - as long as she was well, what a wonderful start to the New Year!

On day three I was taken to a side ward where a doctor was waiting. "I have bad news", he said, "your baby is a mongol". I felt my face drain, but with relief I said "I can cope with Down's Syndrome, I thought you were going to say a heart condition". "Yes", said the doctor, "that as well, she will probably have heart failure in three weeks" All I could do was to look into the cot and apologise to Lucy. Also how could I tell my family?

The next day Lucy was taken to Freeman Hospital where my husband was told that she had got a major heart problem but they would do their best for her. It was explained she had Fallot's Tetralogy and complete AVSD.

She was fine for two years, then began taking occasional spells and was put on medication which prevented these attacks until she was five years old, when they began again. We had been told that no surgeon was prepared to operate, but after a catheter test at six and a half, we were informed that Lucy's condition was deteriorating and surgery was necessary very soon. A

new surgeon at Freeman agreed to operate, but said the risk was very high indeed. If she survived the surgery her recovery in ITU would be up and down for ten to fourteen days.



Lucy's operation was on Monday 14th September 1992. She went to the theatre at 8.15am. At 3pm the surgeon came out to tell us it was all over and at 5pm we were allowed to see her. Although she was on a ventilator and had about a dozen drips and tubes entering various parts of her little body, she was pink! Pink finger and toe nails - previously mauve.

After only twenty six hours Lucy came off the ventilator. She wanted ice cream! After thirty six hours she was out of ITU, and after forty eight hours she was riding a trike down the ward! All the staff, including the surgeon were amazed at her recovery. One week after the operation we went home.

We will always be indebted to all those who prayed for Lucy's recovery, we sensed their support and Lucy has proved their prayers, and ours, were answered.

*Doreen Bridson, Stockton*

## Philip's Story - Continued

Our beautiful, brave little boy, Philip, died on the 23rd December 1992.

We had the phone call we'd been dreading, on Thursday 10th December. He was to have his operation on Monday 14th December, the day before his first birthday. We had to take him to Killingbeck on Friday morning. We expected short notice, but as Philip's birthday was on Tuesday and Christmas was looming, we really didn't expect to get the call until after the New Year. I was devastated.

I'd wanted to give Philip a birthday party before his operation, I was so terrified that he was going to die that I at least wanted his party so that I could capture it all on video. I'd arranged to borrow a camcorder for Tuesday, and I'd bought his cake, a lovely bright coloured clown that day. His birthday outfit was hanging in the wardrobe, and the Disney paper plates etc. were all ready.

Our social worker, Margaret, had just walked through the door as we got the call. I'm so glad she was there because I was crying and shaking from head to toe. She calmed me down, reminding me that this was what we had been waiting for. A chance for a better quality of life. "But what if he dies? I'm terrified he's going to die." The thought kept going through my mind, I was terrified of losing my beloved son.

Adam, my husband, was quite calm about

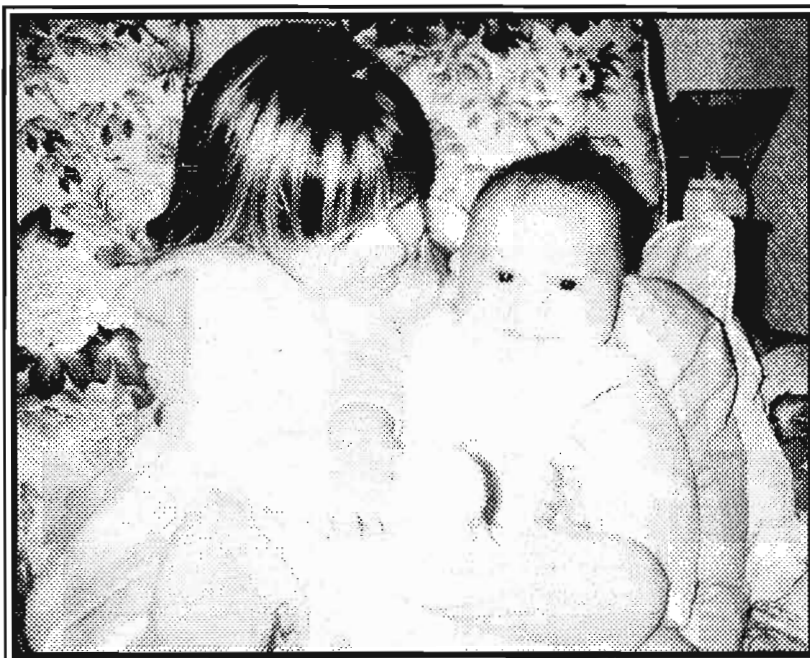
it, he was positive like my Mum, that Philip would be alright, the operation would be successful and we would bring our son home. But there are no guarantees in life and nobody could eradicate the deep fear inside of me. After what we had been through in the past year we couldn't possibly lose him now, surely? There would be no point in it would there? Once over the shock, we had accepted that Philip had Down's Syndrome quite easily, but the heart condition was different, it threatened his precious life and that was unacceptable.

By the time Margaret left us on our own I'd calmed down and was acting as normally as I could. My Mum and Dad came across to see us and to give Philip a big hug before we took him to Killingbeck in the morning, and our friend Sheila came and wrapped all the Christmas presents that we'd already brought, while I bathed Philip, cuddled him, played with him, loved him. We took photos of him laid on the carpet laughing, and I asked Adam to take one of

Philip asleep in my arms. I prolonged bedtime because I wanted to make the most of his last night at home before his surgery. I can't recall how I slept that night, but I don't think it was fitfully.

Our daughter, Lauren went to stay with our friends John and Lynne whom she adores. She understood that Philip had a poorly heart and Down's Syndrome, we didn't hide anything from her. I'd even discussed death with her, just in case, so we didn't have to worry about her.

We arrived at Killingbeck just after 11am, they did some routine checks and pronounced him fit for surgery. I wanted them to say he'd got a cold or a bug, just so that I could take him home again. I wanted the operation, but I didn't. Philip woke for a bottle in the night, and as I'd asked, they came and got me to feed him rather than the nurse. Once he settled, I went back to bed, but not really to sleep, the dread of the operation dragging me down.



Philip with Lauren

Over the weekend we were as normal as possible with Philip, acquiring a baby walker and toys similar to his own to make the hospital as much like home as possible, and only leaving him when he slept. Lauren came to see us on Saturday with Auntie Jane, and was inquisitive about all that was going on around her. Sunday passed pretty much the same, always with the dread of what was to come the next day.

On Monday morning we were up early as Philip had to go to

theatre at 8.40am. We cuddled, loved and played with him, but when I put his gown on he got grumpy, he seemed to sense that something was going to happen. I couldn't walk him down to theatre, so we kissed him goodbye on the ward, and a nurse carried him off. His head was resting on her shoulder, and I watched him all the way down the ward, his little face looking in our direction, until he disappeared round the corner. I cried. We walked. We had breakfast at a superstore across the way to pass time. We had a least four hours, maybe six to wait - it was hell. I kept thinking "As long as he's alright the worry is worth it. He'll be alright, he will."

After six hours a sister in charge came to speak to us. The news wasn't good, it wasn't even hopeful, they couldn't get Philip off the by-pass machine. My worst fear was of him dying all alone in theatre, if it had to happen I wanted it to be in my arms. I showed the sister our photos, rambling on about how he couldn't die he was too lovely.



After an agonising hour the surgeon came in to say that they'd got Philip's heart going and he was being settled in Intensive Care where we would see him soon. I was so relieved that I put my arms round him and kissed him.

We saw Philip a little under an hour later. He had pink lips and looked beautiful. Considering what he had just gone through he looked well, and the tubes, wires, ventilator etc. didn't worry us, they were all there to make our boy well again. We went back and forth to PICU all evening, checking that Philip was stable. On Tuesday Mum and Dad visited, relieved to see their precious grandson looking quite well.

On Wednesday he came off the ventilator and I rang everyone to let them know how well he was doing - we didn't think about set-backs at this stage, although we'd been warned it was possible, we thought we'd had our set-backs on Monday in the theatre, and didn't chose to think about it.

On Thursday a set-back occurred. Philip had a chest infection which was getting progressively worse. I panicked. Lauren was with us, we had planned for her to stay the night, but we decided I should go home with her whilst Adam stayed with Philip. I rang when I got home, he was stable. I rang before I went to bed, he was stable. The next day I went back to Killingbeck with Lauren, Philip was still stable. Mum and Dad came to visit and took Lauren home with them.

On Saturday x-rays showed no improvement, but Philip looked well and was stable. Friends came to visit and Adam's Mum came, bringing our Christmas pressies. Everyone was relieved at how well Philip looked and we were sure he would make an improvement soon.

On Sunday Adam decided to go to work, but while he was gone Philip declined. We nearly lost him, all the monitors went haywire, his pressures dropped - it was terrifying.

On Monday they stabilised Philip, but told me that he had a virus on top of his chest infection. Things looked grim, but there was still hope. They sent for a drug which might help, anything was worth a try.

By Tuesday there was no improvement. The x-rays showed that his lungs were worse, he couldn't feed, he had blood in his tummy and lungs. Our hope was floundering but the doctors said not to give up, they weren't. He seemed to stabilise that evening, by which time we had moved, with Lauren, to a bungalow on the premises to be near to our boy. We wanted to be as normal as possible, and Lauren helped, she was never shocked by seeing Philip. She accepted the tubes, the ventilator, everything, though she wouldn't kiss his face, only his hands.

On Wednesday morning I took Lauren across to PICU to see Philip. The surgeon took me aside and said things were grim, he didn't hold out much hope now. I didn't want to believe it. Adam came across and didn't really react to what the surgeon had said. He was very worried,

but didn't talk to me about it so as not to add to my fears. I suggested going out for lunch with Lauren, but Adam was adamant that we just go to the hospital canteen that day.

We'd just had lunch when a nurse came to ask us to go straight to PICU. She took Lauren to the playroom whilst we rushed across to the unit. The surgeon told us that Philip was dying, he had minutes to live. His heart couldn't cope with the strain, his lungs had stopped working. We walked into the side room and over to our boy, sobbing. I picked him up and cuddled him - I'd been asking to for a week, but only now he was dying was I allowed. We sobbed and cuddled and kissed him, then after a while a nurse asked if we would go to the quiet room whilst they removed all the drips and things.

The staff were lovely, they carried him through in the duvet he'd had over him that day. He looked peaceful but poorly. I bathed him and put him in my favourite babygro, then we took lots of photos. Lauren came to see him, she sang him a song and kissed him goodbye. She didn't really seem upset, she thought Philip was asleep and had got better and was coming home. I explained as best I could, but she couldn't understand she was just three years old.

We will never get over losing him, we will just learn to live with his death. How can you ever get over losing your child? Parents die, then children, in a normal world. I will have my boy back one day. God is looking after you darling, until I have you in my arms again.

*Julia Johnson  
Barton on Humber*

*(The first part of Philip's Story featured in our Autumn/Winter '92 newsletter. We were very sorry to hear it's sad ending, but would like to congratulate Julia, Adam and Lauren on the recent arrival of baby Jack, who is helping to fill the emptiness left by the loss of Philip - Editor)*

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## Memorial Donations

Since the last newsletter, we are grateful to have recieved donations in memory of the following children:

Bradley Meakin - Sheffield  
Siobhan Price - Torrington  
Hilary Williams - Maldon

## James's Story

James was born on the 11th August 1991 at 4.35am weighing 6lb 9oz. It was a difficult birth but very rewarding, especially with James being our first child. James was first passed to me and I immediately fell in love with him, then he was passed to his dad. After a few minutes he began to turn grey so the nurses took him away and gave him oxygen, but he was soon back with us and it wasn't long before we were on the ward. Being totally shattered I was left to sleep while James was cared for in the nursery.

At 9am I awoke and within fifteen minutes had James by my side - it felt wonderful. Not long after, the doctors came round to examine him and detected what they thought to be a heart murmur, but to be sure James was to have several tests, x-rays etc. (Apparently after they had examined James they knew he had Down's Syndrome, this was a surprise, but not and has never been a disappointment, I didn't care as long as I had James.) I then phoned my husband who was also shattered having been with me all night during the birth. When he arrived the consultant came to see us both, and talked about our feelings regarding Down's Syndrome and discussed James's future as to whether we wanted to consider putting him up for adoption. James was a long awaited child, and no matter what arose in the future, he was ours and we would deal with any problems that we faced as a family.

The consultant was very helpful explaining as much as he could about Down's Syndrome and the problems children with Down's Syndrome tend to have, and once all the test results were through to clarify the heart problems, we were allowed home. Within three months we were referred to a heart specialist, Dr Peart, who after examining James, telephoned Alder Hey hospital to book him in for a catheter test.

Within three days we were in the hospital once again meeting the specialist as he was to carry out the catheter the following day. This confirmed that James had an A.V.S.D. which was operable, but would need surgery before he was nine months old. We left the hospital feeling frightened that we would lose him.

On 26th December James became very ill and was taken to our local hospital with Bronchiolitis which made it very hard for him to breathe. He was given oxygen and medication and thankfully was well enough to go home within a few days. Almost immediately we received a letter stating the date for James to go back to Alder Hey for his heart surgery on 11th January 1992.

This was the most frightening time of our lives, not knowing what would happen and that it was totally out of our hands, but the staff and other parents were very supportive, and Mr Franks, the surgeon who was to do the operation made sure we were fully informed about what would happen.

The day of the operation finally came and both my husband and I were allowed to go with James to have his anaesthetic - it was a very emotional time. James was in theatre for about six hours and was then taken to Intensive Care. The surgeon came to see us and explained that they had had a few problems whilst in theatre and that the pressure in James's lungs had not reduced as expected, the next thirty minutes were critical. They kept us informed of what was happening, and after half an hour we were allowed to see James, although we were told that the next forty eight hours were very important as James was still critical.



James was in Intensive Care for five days during which he gradually came off the ventilator and drugs, before finally going back to the ward which was such a relief. Although the surgeon had a very busy schedule, he still kept a watchful eye on James's progress, but there were no more problems and after another seven days we were able to take our lovely son home once again.

James had regular check-ups for a while, and as each month passed we saw a dramatic change in his health. He ate and drank better than before, his awareness and activity improved, he went from being a very poorly boy to a very happy and active child who is deeply loved by all our family and friends who think he is a very brave little boy.

Although he still has a leaky valve and is prone to infections and colds, he fights on and always has a smile for us. He is now two years three months old, walking unaided, has a vocabulary of about twenty five words, is potty training well, attends nursery school, absolutely idolises 'Fireman Sam' and generally likes to live life to the full.

We are very proud of James and what he has overcome, and each day we thank God for the great gift he has given us, and for the joy James brings to us in everything he does. We love him very much.

*Yvonne Walton  
Prestatyn*

## Christina's Story

When Christina was born her heart condition was not diagnosed, but at six weeks old I took her to our doctor as she had a cold. She listened to her heart and said "You do realize she has a heart murmur don't you." It came as a great shock. Our hospital was informed and a subsequent echocardiograph showed a large hole in Christina's heart.

She was difficult to feed during the first nine months prior to her operation, only taking two to three ounces of milk per feed. I fed her seven times a day but she used to be very sick, her 6.00am feed especially used to all come back. She weighed 11 lb when she had her operation.

The hole in her heart had been the size of an old five pence piece we were told, and that she would be in Intensive Care for four days, but in fact she was out in two. She had absolutely no problems at all, in fact the nurses called her 'little Miss Remarkable'. We all came home exactly a week after her operation, and she was so well that that evening we took her to a barbecue with us.

We feel that the prayers of so many people helped the operation to go so well and her subsequent recovery to be trouble free. We praise God for the skill of Mr Duncan Walker and the loving and expert care of the nurses. The children's ward has such a happy caring atmosphere.

This photograph of Christina was taken in April 1993. She is a bubbly, very energetic bundle of fun, who goes to a special school nursery for two days a week and a mainstream nursery for the other three mornings.



*Pam Hands  
Habrough*

## What is Makaton?

I had heard of Makaton but I didn't know much about it. Why should I, my daughter would start speaking soon. To be honest, I didn't want anything to do with it. Natalie, my daughter, has Down's Syndrome and wasn't speaking by the age of two. I was getting , more and , more anxious but kept thinking it would happen soon and to be patient. I thought Makaton would hinder her and delay further any speech. I tend to assess Natalie's progress myself by comparing her to my son who is eighteen months older. (It is not a fair way but it gives me a rough guide.) Luke, my son, was speaking before his first birthday and certainly holding basic conversations at eighteen months, when Natalie was born. So Natalie was now two and not speaking. I was getting worried. She understood what was said to her and would carry out instructions when asked.

Nobody pressured me at all to learn Makaton. When I look back I realise now my attitude was one of failure. I didn't want Makaton. I didn't want to admit to failure. We'd passed so many hurdles together and I didn't want to admit defeat. She'd speak soon, but she didn't, she hasn't. It was only when Natalie started getting frustrated I realised what a mistake I'd made. After all, she could understand me and I her, to an extent, but she could not communicate. She couldn't ask for a drink, or let me know if she was hungry, or any of her basic needs. Frustration became her way of letting me know that all was not right. So I asked, can I learn Makaton? I asked Jenny, my Portage Worker, who immediately showed me some signs and how to do them. Suddenly Natalie was signing that she was thirsty and names. She learnt Luke's name first. It was great. She was communicating to US for the first time.

I asked Sarah, our Speech Therapist, for help and went with my husband to her Makaton workshop. While we were learning, it felt strange to start with. I was a little self-conscious, especially when out and people would stare at us but I don't even think about it now. We all use Makaton as part of our daily lives. My son even uses it at school and doesn't understand why nobody else knows sign language. The speed that Natalie picks up signs amazes me still. It's like the missing piece in a jigsaw puzzle. Makaton is one of the best things that has happened to us. I just wish I'd given Natalie the opportunity to use it earlier. She'll be three at Christmas and hungry for more words to sign and I won't be stopping her any more. She is a very happy, loving, cheeky rascal but, without Makaton, I think she would have become very frustrated.

*Karen Dance  
East Sussex*

## The Disability Living Allowance and problems with applications for children with Down's Syndrome

The Disablement Income Group's (DIG) Advisory service has, since April '92 received an ever increasing number of enquiries relating to applications for the Disability Living Allowance (DLA) in respect of children with Down's Syndrome. Application for DLA and decisions on outstanding Attendance Allowance (AA) claims were being refused or awarded at a low rate. The enquiries began with the introduction of the DLA system for children and adults under the age of sixty five.

DIG found that there were two main causes for this. The first is the new, lengthy self-assessment application form. Parents have had great difficulty filling them in. This is not surprising, as they are not designed to elicit information about a child's needs. The problem is compounded by the fact that children have additional criteria to satisfy.

Under the old AA system, applications were made on a short and straightforward form. A visit was then carried out by a DSS medical practitioner who followed very brief guidance which basically assumed that an award should be made.

The second problem is that this guidance was not carried over to the new DLA system. The decision on whether or not an application is successful is now made by a non-medical adjudication officer using guidance contained in a new 'Disability Handbook'. There is a massive departure from the previous concise advice for AA. Instead, guidance on children with Down's Syndrome is scattered across three chapters. As a result the impact of the condition is diluted and consequently it is much harder to establish entitlement to DLA. There is no clear case made for an award for a child with Down's Syndrome, whereas before this was almost automatic.

This adjudication problem, however, concerns applications for children over two, as the earlier guidance covered only this age group. The decision to award the allowance to babies and children under two was a relatively recent development. The Government was convinced that only in certain cases should an award be made, ie. very sick or severely disabled babies who demanded a very high level of care and attention. Consequently it is difficult to secure entitlement for a very young baby, ie. three months plus, unless there are other conditions which give rise to high care needs.

While the adjudication problem concerns mainly the over twos, the difficult application pack is common to all ages. The following guidance is to help all parents and others make a successful application, it is not just for the over twos.

*N.B. The following information concentrates on what your child is unable to do, how much looking after they need and constant comparison of your child's development against that of a child or brother or sister without Down's Syndrome. It is a very negative exercise.*

### CRITERIA:

An adjudication officer must bear in mind the criteria and decide whether or not in each case these are met. (The following is a brief guide, the full criteria are available from DIG, together with the current official guidance.)

Your child must need, because of his/her disability:

- care for a significant part of the day (either for a set time or, say, at the beginning and end of the day). This is for the new lower rate of £11.95 per week.

OR

- a lot of care throughout the day; or continual supervision throughout the day. Satisfy either or both for the middle rate, payable at £30.00 per week.

OR

- at night, prolonged or repeated attention/care, or needs someone to be awake for a prolonged period or frequent intervals to watch over them. Satisfy either or both and the middle rate is payable.

To receive the higher rate of care component of £44.90 per week your child must satisfy at least one of the day conditions AND at least one of the night-time conditions.

### EXTRA TEST FOR CHILDREN:

Children must also meet one of the following:

- he/she has attention or supervision needs "substantially in excess of the normal requirements of a person of his/her age."

OR

- he/she has substantial attention or supervision needs "which a younger person in normal physical and mental health may also have but which persons of his/her age and in normal physical or mental health would not have."

### STEPS TO TAKE:

- 1) Study and try to get to grips with the qualifying criteria (above).
- 2) Write out a daily schedule of care needs, including even the smallest of tasks. Remember to cover as much of the day as possible. For night-time care concentrate on how often you need to see your child at night.

### CHECK-LIST OF EXTRA CARE NEEDS:

- Stimulation/physio/portage/speech therapy/massages (point out if this is for short bursts throughout the day). Try and expand this as much as possible, stress what has been achieved and what stage you are working on.
- Feeding often takes longer and this needs to be pointed out. For older babies and children slower to feed themselves, poor grip, teeth slower to develop.

- With dry skin, you may spend extra time applying creams.
- Medication can increase the number of nappy changes and necessitate extra attention in washing and changing. There are often difficulties in taking medication.
- Constant colds and chest complaints need attention, particularly at night, this often means frequent checking and clearing air passages.
- Constant supervision for older children.

*Look back over your schedule and see if there are any gaps in the daily pattern of needs as this can lead to a lower rate being awarded.*

This list is not complete. You the parent and other experts will be able to add to it. The idea is to give a complete picture of your child's needs.

Use your schedule to supplement your application, support your request for a review, or build up your case for appeal.

#### SOLUTIONS:

DIG has already approached the Department of Social Security with regard to a children's claim pack. The response from the Department has so far been negative.

Parents should let the DSS/DLA Unit know how difficult the forms are to complete when returning them. With regard to adjudication, our ultimate aim is to campaign for improved guidance for better decision making. Parents can help by sending us details of their problems claiming DLA. We will present this to the Disability Living Allowance Advisory Board. In the meantime compiling a check-list may act as a partway solution as adjudication officers begin to recognise the special needs of children with Down's Syndrome.

Please send details of your problems claiming DLA to:  
The Advisory Officer  
The Disablement Income Group (DIG)  
Unit 5  
Archway Business Centre  
19-23 Wedmore Street  
London  
N19 4RZ  
Telephone: 071 263 3981

*Article by Margaret Lavery of The Disablement Income Group, reprinted from DSA News (GB) Spring 1993.*

*(If you are experiencing problems in claiming any benefits, it may be helpful to have a word with your regional co-ordinator who can contact Mary Clayton on your behalf. Mary is a Down's Heart Group member who has kindly agreed to try and offer help and advice re benefit claims, following our appeal for someone last year. - Editor)*

## COMMUNITY CARE CERTIFICATE

PRESENTED TO

DOWN'S HEART GROUP

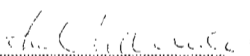
BY THE

LORD MAYOR OF BRISTOL

COUNCILLOR JOHN CHANNON

*in recognition of their valued work in  
support of the special needs  
community and as public testimony  
to their practical evidence of caring*

DATE 28TH OCTOBER 1993

SIGNED   
LORD MAYOR OF BRISTOL

PRESENTATION EVENT SPONSORED BY  
WELCH LTD BRISTOL

At the end of October, Phil Thorn our Treasurer, was proud to be presented with a Community Care Certificate from the Lord Mayor of Bristol, in recognition of the work of the Down's Heart Group in support of the special needs community.

It is very gratifying to have our work recognised, and this award reflects the strong support network that has developed, particularly in the Bristol and South West region, largely due to the efforts of Sheila Forsythe and her team.

As the group continues to grow, we hope that this level of support will be available throughout the country, and from publicity such as this we can both raise public awareness of our special children, and also reach new families in need of our help.

# T Shirts and Sweatshirts

Did you know that the Down's Heart Group has T shirts and sweatshirts for sale?

Want to know more?

They are good quality garments that wash well, both T shirts and sweatshirts bear the Down's Heart Group name and logo in a moderate size on the left side of the chest (as you wear it), and come in a range of sizes. T shirts are in white only, whilst sweatshirts are available in white, pale blue and grey.

Children's T shirts cost £3.50 and sweatshirts £5.50  
both are available in sizes 24", 26", 28", 30" and 32"

Adult's T shirts cost £7.00 and sweatshirts £11.00  
both available in S, M, L, XL and XXL

(Postage and packing are included in the price)

Would you like to buy one?

Just follow these three easy steps :

- 1) Telephone Matthew and Siobhan Holland on 0272 683426 to confirm availability of the sizes and colours you require.
- 2) Forward a cheque or postal order, payable to 'The Down's Heart Group' along with a written order to :



- 3) Await delivery of your goods.



Where's Mine?

*It's a terrific way to support the group and raise awareness at the same time, so why not order one for all the family, grandparents as well !*

## Cycling with dad

When our son Robert was born we were devastated. He had Down's Syndrome, and in addition serious heart defects. We soon got over feeling sorry for ourselves, and realised we had been given a job to do. As Robert grew, he had many problems, suffering in particular from breathlessness, and turning very blue with the least bit of exercise. However, at the age of eight he had a shunt operation at Killingbeck Hospital in Leeds to by-pass a narrowing tube to his heart. This made an enormous difference to Robert: he was able to walk much further before becoming breathless and he became a very active child, although still very limited when compared with normal children.

My wife, Wendy, and I had cycled for many years. We had done a fair amount of touring, club runs with the Whitby and Scarborough clubs, and I had done a considerable amount of time-trialling. However, our dearest wish was

that one day we might be able to get Robert involved. After much searching we purchased a second-hand Jack Taylor tandem at the CTC York Rally in 1989. We tried Robert on it at the end of that summer - but it was a disaster. He was petrified, perhaps sensing that I was not yet very confident on the front. We decided not to try again until the following year.

At Easter the next year we were camped on a farm near Helmsley in the North Yorks Moors National Park. On the quiet flat lane by the farm we made another attempt. Robert was again shaking like a leaf and I stopped immediately. However, I was now a fairly competent tandem rider, so we tried again - with Wendy running alongside holding Robert's saddle for the first hundred yards. This was much more successful and we managed two miles. In the evening, Robert asked for another ride, so we went two miles in the opposite direction.

The following day dawned cold and windy again but we decided to try the five miles each way to Helmsley, including a couple of hills. We made it without too much trouble, including a welcome café stop in Helmsley. Robert's cycling career was well and truly under way.

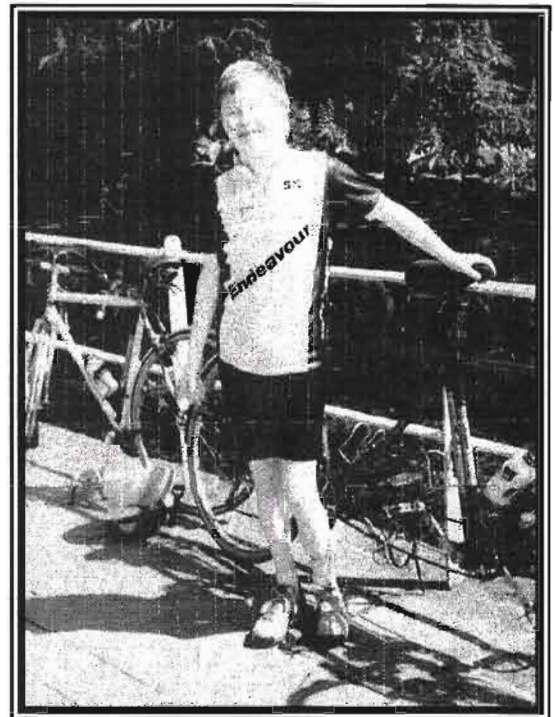
For the remainder of that year Robert cycled regularly during his holidays from the Pennine Community College at Wakefield, the highlights being the CTC Birthday Rides near Northampton and Tandem '90 at Corbridge in Northumberland. At the Birthday Rides we averaged forty two miles a day for the week, while at Corbridge we had a long weekend with similar mileages, including a very hilly fifty mile ride, Robert's longest at that time.

1991 saw Robert cycling regularly during holidays. Again we spent a week at the Birthday Rides, this time at Hereford. Robert is now quite well known at the Rides, where he takes great delight in overtaking other riders and particularly enjoys what he calls the 'tea breaks'.

We take part in many of the CTC standard rides in Yorkshire, starting from Malton or York. In 1991 Robert completed a thirty two mile rough-stuff event, a fifty in five hill ride, and the sixty five mile GHS ride from York, in honour of the former CTC Secretary and President. These rides qualified him for a North Yorkshire DA bronze medal, presented to him at the awards evening the next winter. Summer 1992 saw us at Ayr for yet another Birthday Rides.

At the outset, the most we had dared hope for was rides of perhaps ten miles over flat terrain but there seems to be no limit to what Robert can do. He still tires when walking, but on the tandem he can pace himself and ease off when he feels it necessary, while I take on more of the work. Although now twenty-one years old, Robert looks much younger and has a mental age of perhaps four, but he is full of fun and thoroughly enjoys his cycling.

He has bought himself a helmet along with quite a wardrobe of brightly-coloured cycling tops and shorts. Having finished at the college in July 1992, Robert now lives at home while attending Dalewood House, a centre for the mentally handicapped in



Whitby. This gives him the opportunity for more cycling and it is wonderful that we can now all go together.

In February 1993, at the annual dinner of the North Yorkshire District Association of the Cycle Touring Club, Robert was awarded the John Hesse Memorial Trophy, which is presented to the rider under the age of twenty five who has made the most outstanding contribution to the District in the preceding year. The citation read "This rider hasn't, indeed couldn't, organise an event, he doesn't hold an official position in the Club, but he always has a smile on his face, and he brings a lot of pleasure to a lot of people".

We realise that degrees of handicap - and hence cycling potential - vary immensely and that not everybody may do as well as Robert but we hope that this short account of Robert's activities may encourage other parents to consider tandem riding as a means of enabling their offspring to participate in a healthy sport and pastime along with other members of the family.

*Mike Fielding, Whitby*  
(This article was originally published in the March 1993 edition of *Cycle Touring and Campaigning*. We would like to thank them for publishing such a positive article about Robert's achievements - Editor)

# Fundraising - Ideas & Events

## Ideas for raising funds

As the Down's Heart Group grows, so our efforts at fundraising are going to become more and more important. We regularly report on sponsored events that our members have been involved in, but how about you doing something. Fund raising can be tremendous fun as well as beneficial to everyone in the Down's Heart Group.

My son regularly attends Springboard Opportunity Group, a pre-school group for children with special needs and their families. In April last year we opened a brand new, purpose built centre. It is a wonderful place, but what makes it particularly special is that the money for it, £225,000 was raised by the parents. Yes, we had a magnificent grant of £85,000 from Children in Need, and we applied for various grants from local and district councils and other organisations, but we raised a large proportion it through events both large and small.

*Here are a few ideas to get you started.*

The inevitable Spring/Easter/Autumn/Christmas Fayre can raise a useful sum without too much effort. Rope some friends in, have a couple of planning evenings (a few bottles of wine help the ideas flow!) and see what happens. If you choose a good venue and get your publicity right it's amazing how many people will come looking for a bargain.

Car Boot Sales require no organisation. Just collect your goodies from around the house, get up early to get a decent pitch, and in a few hours you can make a very easy £50. Be prepared to haggle, though, as few people are prepared to pay the marked price.

Coffee mornings with a 'bring and buy' and/or a raffle are a good way to meet other Down's Heart Group and Down's Syndrome Association members in your area, and again, £20 can be raised with little effort.

To get the children involved, how about a sponsored bike/trike ride? We turned this event into a 'fun day' for all the children, but aimed it at the brothers and sisters. We asked a local school if we could borrow their school field and the children were sponsored for each lap they managed. We encouraged a local entertainer to come along (free of charge) and all the families brought a contribution towards an enormous party lunch.

We have had sponsored treasure hunts, pub crawls, diets - you name it, we've sponsored it! Careful on this one though - Granny and your next door neighbour will get a bit fed up if you keep asking them to sponsor you for sitting in a bath of baked beans! Sponsorship fatigue sets in if you ask too often!

If you feel ambitious you can organise a barn dance or a sixties night. This requires a lot of preparation and plenty of good will from bands and musicians if you are going to make much money, but can be good fun.

If you have any television personalities living near you who might feel like adding their name or presence to an event, a 'name' will always attract more people.

There are endless ways to raise money and every amount counts; Beetle Drives, Quiz Nights, get friends to collect petrol tokens and use them to get gifts suitable for a raffle. We have two members of the group who knit toys and sell them in aid of the Down's Heart Group, who have raised a lot of money over the past years. Another Mum regularly goes to Table Top sales and sends the proceeds to the group. So, if you feel you would like to have a go, any amount will be gratefully received. It all helps us to reach out to more families!

*Gill McLorinan  
Secretary*

## Forthcoming Events

### London Marathon - April 17th

Yet again this year, we are fortunate to have representation in the London Marathon. Dave Brown, a friend of my husband, applied for a place in the event, and said if he was successful he would like to raise funds for the Down's Heart Group as he knows we are involved on the committee. He was lucky enough to be allocated a place, and so far he has sponsorship pledged for over £500, but if any members would like to add to this, either personally or by getting Dave some additional sponsors, please contact me on 0525 220379 for an official Sponsor Form.

*Penny Green  
Editor*

### Thames Bridges Bike Ride - May

Another event in the pipeline is a sponsored bike ride from Parliament Square to Tower Hill crossing six of the bridges over the Thames on the way. Details have yet to be finalised, but the two fellows who thought up the idea, (and are not even members of the group), have had such a good response that it looks as if there will be quite a few bodies pedalling the route, including at least one Down's Heart Group Dad.

If you would like to join them, are willing to get them some sponsorship, or perhaps know a celebrity who could start the ride, please contact the national office on 0525 220379.



## Medieval Banquet - June 4th

June 4th is another date for your diary. Maria Netherwood is organising a Medieval Banquet at her farm in Shipley, West Yorkshire, proceeds to go to the Annette Fox Leukaemia Research Fund and the Down's Heart Group.

Maria, yet another fund raiser who is not a group member, has put a lot of work into organising the event which promises to be a great evening out. Let's show our encouragement by publicising the event as much as possible, or some of you may even be able to attend.

More details can be obtained by telephoning Maria on 0274 586025.

## Charity Football Match - June 12th

Vale Farm Sports Centre in Wembley is the venue for a football match between Arsenal Celebrity team and a team playing for the Down's Heart Group. Apart from the match, the event will feature Bungy Pulling, Gladiator Jousting, a Bouncy Castle and Disco amongst others.

Proceeds from the day are being donated to the Down's Heart Group, so please publicise the match, which is being organised by a lady who is not a group member, and if you can, go along to support on the day.

Some players are still needed for the Down's Heart Group team, so if you're over twenty five and interested in playing, or you want more details about the event, please contact Charmione Lewis on 081 795 3652.

# Can You Help?

## Fax machine needed

The national office would definitely benefit from the use of a fax machine, but in view of Group funds, it cannot be considered a priority for purchase. As well as receiving information from outside sources, it could also be used both to speed up and cut the cost of much of the communication between committee members, as many of the Group's key personnel have access to the use of a fax. So does anyone know of a kind benefactor who may be able to help? Perhaps your firm is updating their equipment and getting rid of their old fax machine, we would be very grateful to take it off their hands.

Any offers, please contact Penny Green at the national office on 0525 220379.

## Dislocating Kneecaps

Does your child have problems with their knees? Mike Halpin, Regional Co-ordinator for the North West, would like to hear from anyone else whose child has had a similar experience to his six year old David, who has very loose kneecaps which frequently dislocate. A number of contacts have already been made, and it appears that this may be a far more common occurrence than realised.

If your child also has knee trouble, please get in touch with Mike on 051 928 4987, or write to him at the address on page 4.

## Christmas Card Design Competition

Following the tremendous success of our 1993 Christmas card, which sold out, we are now looking for a design for Christmas 1994, with a £10 voucher going to the child whose entry is chosen.

Entries can be of any design and size, but should be on white paper, and either incorporate the Down's Heart

Group logo, or have scope for its inclusion. There is no limit to the number of entries from each child, but please ensure their name, age and address is shown on the back of each entry. Entries should be sent to the secretary (address on page 2), to arrive no later than 31st May.

## Photographs Needed

We are planning to help raise awareness of the Down's Heart Group and our children, by applying to the various television networks for broadcasting time on their 'announcement spots' used by charities and support groups.

Our idea is to show photographs of some of the children, with a voice-over explaining what the group has to offer, and asking families to get in touch, but we need your help.

If you have any appropriate photographs that you are willing for us to use, please send them to the national office as soon as possible, clearly marking your child's name on the back. We will hopefully have enough to be able to choose half a dozen or so at the next committee meeting at the beginning of May.

Photos should be clear, with good contrast, but other than that they may be of anything you like. We hope to portray the positive side of children with Down's Syndrome, but also to highlight the additional problems they can be born with, so proud displays of scars from cardiac surgery, will be just as acceptable as happy snaps of family life with siblings.

*(It's always nice to have photos of the children on file, in fact I hope to make an office display of them all sometime soon, but if you would prefer to have your photos back, please make sure this is clearly stated when you send them in. Thank you - Editor)*

# Letters to the Editor



**Letters for publication should be sent to  
The Editor**

Our daughter Beth was born on 5th July 1980, with Down's Syndrome and a severe heart defect. I have had to fight every inch of the way for what I have wanted for her, and breast feeding was the start. I was told babies with Down's Syndrome do not suck, cannot feed etc. I just would not accept that until I could try and see for myself.

Beth was in an incubator and had a tube down her nose for feeding. I pointed out that if she could be fed in this way with bottle milk she could just as easily have my milk. As it turned out I had enough to feed the whole nursery and it was no problem filling the little bottles. This carried on for three days, during which time it was plain that Beth was making sucking motions with her mouth, yet I was still denied the opportunity of attempting breast feeding. I felt that a battle of wills had developed.

At last I was given permission to try, but I was told not to expect too much and not to be too disappointed if she did not suck. I felt this was done to humour me more than anything else. Right from the start Beth latched on to the breast like a leech, and I had to ask the nurse to help prize her off!!! From then on I never had any difficulty. She fed three hourly and gained weight.

Looking back, it would have been so easy to just accept what seemed to be the general rule, and I wonder how many other mothers are deprived of the joy of breast feeding because our children are expected to go by the rule book.

After having Beth at home for a while I had to stop breast feeding due to my health, and Beth was put on a Playtex feeding bottle. This was suggested by my health visitor as being the nearest thing to a human nipple. The teat was short and stubby, and with the added bonus of the disposable polythene "bottles" there was less risk of any contamination. Beth had no problems with the change over and continued to do well.

*Kathleen Johnston  
Inverurie*

*(This letter was actually written three years ago, but after some recent feed-back from new Mums, I thought it would be useful to include it now. Some babies do have problems sucking, and sometimes a baby is too ill to suck, or uses up too much energy in soing so, but if the circumstances permit, mothers should be encouraged to breast feed if they want. The natural immunity in breast milk can be particularly beneficial to babies with a heart condition. - Editor)*

Dear Editor,

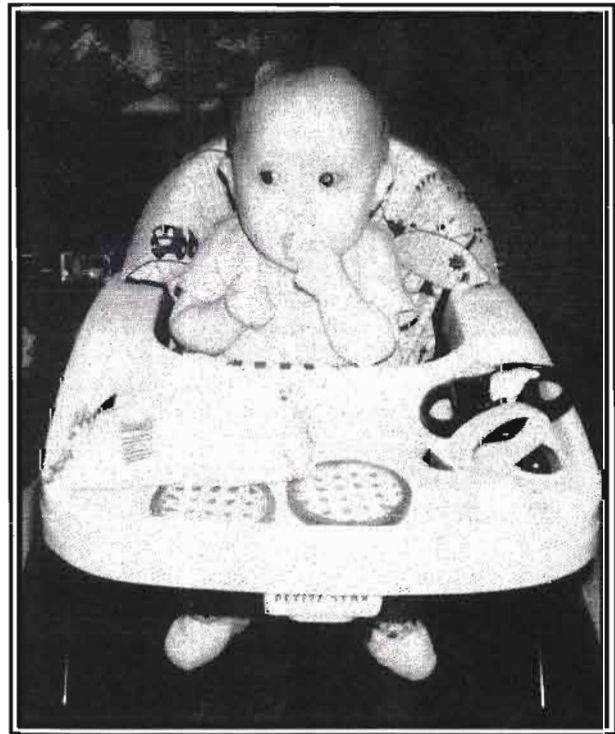
Five months ago I gave birth to a beautiful baby boy whom we named Jordan. An hour later we were told that our much wanted first child had Down's Syndrome. The shock was enormous, we just could not believe it, especially as both of us are young (I am 27 and my husband is 25).

Well five months on and Jordan is the light of our lives - lively, alert, with no serious problem except a small hole in his heart which the specialist says will close in time.

I am writing because I would like to get in contact with other parents. I have given up work and spend most of my time at home with Jordan, so I feel it would be nice if I could perhaps write to other parents like myself and my husband, especially couples of similar ages to ourselves.

*Joanne Hayter  
Macclesfield*

*(If you would like to write to Joanne, please send your letters, clearly marked, to the above address for forwarding on - Editor)*



Dear Editor,

This is Amanda, she was only 4lb 10oz when she was born, but weighed 14lb on her first birthday 31st October 1993. Amanda is the best thing that could have happened to me, she is my life, I love her so much. Could you put her picture in the next newsletter to wish her Happy 1st Birthday love mummy and daddy, because if it wasn't for the operation she had she might not be here.

*Louise Bromet, Bristol*

A Work of Art

A child is born, we all rejoice and shout hooray, hooray,  
 But as he grows a silence falls as we hear someone say...  
 There's something wrong, he isn't 'right', whatever can it be?  
 He appears to be quite 'normal', but he isn't like you or me.  
 Why can't we call him 'normal', what other word is apt  
 To describe this little person, of course... he's handicapped!  
 He won't see life the way we do and he'll never understand,  
 He'll need us all to be there to lend a helping hand.  
 He'll bring such joy and happiness to people near and far,  
 He'll make us question why we're here and who we really are.  
 He'll give us everything he's got with trusting open arms  
 And all he'll ever ask of us is that we shield him from life's harms.  
 So if you see a child like this, don't turn and walk away,  
 Stop and have a chat with him, he'll brighten up your day.  
 For who are we to take this child and set him far apart,  
 He may not be like the rest of us, but he's a work of art...

*Dany Sherlock*  
 1988

**From the National Office**

I would just like to say 'Thank you' to everyone who sent the Down's Heart Group a Christmas card.

As my home is the group's national office, I'm fortunate enough to benefit from receiving cards and 'thank you's' from members, but I do take them along to committee members to pass on your messages, so they do get to see them too.

It's always nice to know when someone has been helped by the Down's Heart Group, and somehow, notes like that seem to arrive just when I need a boost. Sometimes being a mum to three young children, organising their social lives, and running the national office all gets a bit much, but just when I feel like throwing the towel in, someone comes along and says how much contact with the group has helped them, and my energy is renewed.

So although I can't reply to all your notes personally, I know I speak for all our volunteers, when I say that they are greatly appreciated, THANK YOU.

*Penny Green*  
 National Family Support Co-ordinator

# Change of Address?

*It's sad when we lose touch with a family because they forget to tell us they are moving, and often the redirection of mail has finished before we send the next newsletter, so if you are moving, please cut out the slip below and use it as a reminder to tell the Down's Heart Group your new address.*



## Notification of Change of Address

Please note that with effect from ...../...../.....  
 the new address for the .....family will be:

.....  
 .....  
 .....  
 .....  
 .....  
 Postcode: .....  
 Telephone: .....

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

Send to:  
 Penny Green, Family Support Co-ordinator,



