

DOWN'S
HEART
GROUP NEWSLETTER

(Issue No 13)

Spring 1995



Budding Artist Lucy Thomas.

Could she be the winner of our 1995 Christmas card design competition?

Contacts

National Office



Contact or Answerphone
always available
(24hrs in emergency)

Founder

Linda Walsh

Chair

John Spall



Vice-Chair

Sheila Forsythe



Treasurer

Phil Thorn



Secretary

Gill McLorinan



Legal Advisor

Brian Auld



National Administrator

Penny Green
contact National Office

Benefits Info Contact

Mary Clayton
Contact via National Office
or
your Regional Co-ordinator
(page 4)

General enquiries should be addressed to the National Administrator. Requests for information from professionals, students etc. should enclose an sae. for the reply.

Requests for support and information for families should be sent to the relevant Regional Co-ordinator as shown on page 4, or to the National Administrator.

Donations may be sent direct to the Treasurer.

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: 0181 682 4001

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

Down's Syndrome Association of Ireland
27 South William Street
DUBLIN 2
EIRE
Tel: 003531 6769255

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.

Christmas Card Design Competition 1995

Our 1994 Christmas Card from a design by 7 year old Jennifer Gouck from Glasgow proved to be very successful, selling over 15,000 cards.

Although it may seem very early to you, we are now looking for a design for this years card. Did you keep any of your children's Christmas artwork as suggested in the last newsletter? If not, could you get them to draw or paint something now?

Please send in anything you feel appropriate by June 21st. It could be a single colour drawing, a multi-coloured painting, potato print etc. The overall size is not really important as we can reduce or enlarge it, but it must have some connection with Christmas. In the past we have had Santa, reindeer, Christmas tree, robins, snowmen and an angel, so that should give you a few ideas, although it would be nice to have something different.

There will of course be a prize for the winning entry, plus a certain amount of 'celebrity' status for the designer, so get those entries flooding in to National Office straight away.

Chairperson's Report

I heard on the radio this morning that Grimsby is the "boom town of Britain", the town that has a greater proportion of successful businesses than any other in the UK.

Grimsby? unlikely you say, but you have forgotten an important fact. It's this year's venue for the Down's Heart Group's Annual Conference and General Meeting, so even more success is coming its way.

But Grimsby is in the middle of nowhere, how on earth could we possibly get there, will be your first reaction. Not so, Grimsby's success, particularly in food processing, is built on its good communications with the rest of the country. It is on the national motorway network, along the M180 only about thirty five minutes from the M1, and has direct rail links with London, Manchester, Sheffield and Doncaster. This makes it accessible on a day basis from many parts of the country.

You will find inside details of the very relevant programme of talks and workshops organised by Linda Watcham and the Yorkshire and Humberside region, which has something of interest for every member. Please do think seriously about attending. We can promise you an informative and enjoyable day and the opportunity of meeting other members. There is a crèche, but early booking is advisable.

Can I also draw your attention to two items where we are specifically seeking your help with our work.

The Committee is anxious to collect information, positive and negative, about how you and your child were dealt with by the "system" during that often painful journey through diagnosis to surgery (if appropriate). there are still suggestions that we and our children are not getting a fair crack of the whip and that prejudice against children with Down's Syndrome still remains in some parts of the National Health Service. If we are to campaign about this on behalf of current and future members, we need more than the limited anecdotal evidence we currently have. So please tell us your story. The more we have the better we are able to build up a picture of what is actually happening in different parts of the country.

Our other plea for help is nearer to home. That is for more input by members to the running of the Group and particularly for some new blood on the Committee. See page 6 for details. We will only flourish if each generation of parents play their part in putting their knowledge and enthusiasm into our work, during and shortly after those years when their children's heart condition is the dominant factor in their lives. As we say YOUR GROUP NEEDS YOU - please respond.

Are you sitting reading this newsletter with a mug of tea or coffee in your hand?

Then wouldn't it seem appropriate to be using a Down's Heart Group mug!

We now have a stock of white mugs with the Group's logo, available from National Office for only £4 (inc.p&p). They will be available at the Conference in May, or you can order by post.



Regional Contacts

If no name is shown, or you experience any difficulty contacting the co-ordinator for your region, please get in touch with our national office who will be able to help you.

Bristol & South West (Avon, Cornwall, Devon, Gloucs, Somerset & Wilts)

Sheila Forsythe

Gill McLorinan



East of England (Cambs, Lincs, Norfolk & Suffolk)

Lindsay Wharam

Nicola Desmond



East Midlands (Derby, Leics, Notts & Northants)

Sarah Smith



Ireland (N.Ireland & Eire)

Rosina Brierley



London Northern

(Berks & Oxon)

Morag Malvern



(Herts, Middx & London N postal codes)

Joanna Simms



London Southern (Kent, Surrey, Sussex & S. London)

Katie Spall

Linda Crozier



North East (Cleveland, Cumbria, Durham, I 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)

Southampton Hospital Contact
Vickie Richardson



West Midlands (Hereford & Worcs, Salop, Staffs, Warwick & W. Midlands)

Pat Mitchell

Noreen Hodekinson



Birmingham Hospital Contact
Lynne Holden



Yorkshire & Humberside (Humberside & All Yorks)

Mark and Linda Watcham



Annual Conference and General Meeting

Date: Saturday 6th May 1995

Venue: Humberside College of Health, Grimsby

(Situated in the main building of the District General Hospital)

As in past years, this promises to be an interesting, informative and enjoyable day not only for Down's Heart Group members, but for anyone with an interest in children with Downs' Syndrome, particularly those who have an associated heart defect. As we go to print our third workshop remains unconfirmed due to cancellation by the speaker arranged, but members will find more details on the official notification letter enclosed with this newsletter. Non-members and professionals are welcome to attend, please contact National office for registration forms.

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

- | | |
|------------------------|--|
| 'Dental Care' | - Elizabeth O'Sullivan
<i>Lecturer in paediatric dentistry Leeds Dental Institute</i> |
| 'Language Development' | - Irene Westerman
<i>Educational Psychologist Mencap HQ London</i> |

A buffet lunch follows during which there will be time to socialise, examine the various displays and purchase Down's Heart Group goods. In the afternoon there will be the opportunity to attend one of the three workshops run by:

- | | |
|---|--|
| 'Makaton' | - Peggy Ingham
<i>Special Needs teacher</i> |
| 'Creative strategies for living (coping with feelings)' | - Reverend Harold Ter Blanche
<i>Hospital Chaplain, District General Hospital Grimsby</i> |

Further workshop to be advised

There is a nominal registration fee of £1 per adult payable on the day.
A buffet lunch and refreshments will be provided.

We regret that due to the size of the conference room, we will not be able to admit babies or children who cannot sit quietly through the presentations. There will, however, be a crèche available, but places are limited, and must be pre-booked. If you need to bring children with you, please book early, places will be allocated on a first come first served basis, and you will be sent a crèche ticket for each child before the day.

Anyone wishing to arrange overnight accomodation can contact Yorkshire and Humberside Regional Co-ordinator, Linda Watcham [redacted] [redacted] for assistance.



Your Group Needs You

Yes, this is a recruiting campaign!

As with most voluntary organisations the burden of running things falls on a few willing hands - so it is with the Down's Heart Group.

For the past three years, the oversight of the Group has rested with only a few members of the Executive Committee, while the work in the regions has been developed by a small band of regional co-ordinators.

I believe we have come a long way in that time and have a healthy and thriving organisation which is well recognised as providing experienced support to our families and a national voice for our concerns.

If we are to develop our work and to take up more vigorously issues affecting us all, we need to strengthen our team. That means involving more members both to spread the load and to bring in

fresh ideas and impetus, to mix with the experience of the old hands.

We need to extend the range of skills on the Committee and particularly need someone with administrative skills and another with some experience of communications and the media - but also ordinary parents who can keep our feet on the ground!

The call on your time would not be excessive - there are usually four meetings a year plus the AGM, with some other work from home between times.

In the regions we need members to assist our regional co-ordinators in maintaining contact with families, hospitals and professionals. Our most urgent needs are in Scotland, Newcastle, Yorkshire and Essex, but help anywhere in the country would be welcome. Again, the demands would not be heavy.

I of course realise that many parents have more than a full time job coping with the daily demands of work and/or families. But the Group will only survive and grow if it attracts the active involvement of the members. So whether you are a parent, a bereaved parent, a grandparent or relative of one of our children, please do think about giving a little of your precious time, skills and experience to our work.

Out-of-pocket expenses are paid in all cases and we hope to run a training course later this year for new volunteers.

If you feel you can help, please do pick up the phone now and give me a call on 01424 830594.

John Spall
Chairman

T-shirts and Sweatshirts

Down's Heart Group t-shirts and sweatshirts are a great way of showing that you support the Group, and they are comfortable too! Sweatshirts are available in white, pale blue or grey, t-shirts in white only,

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

Adults t-shirts cost £7.00 sweatshirts £11.00
both available in S, M, L, XL and XXL

(Prices are inclusive of postage and packing)

Please order from **Phil Thorn**

Please telephone first to confirm availability of your choice : 0117 950 8162

Jodie's Story

On the 29th April 1992 I got a phone call from a Social worker to say she had a baby girl for a pre-adoption placement and being a Foster Carer I got very excited at the thought of a baby coming to stay for a few weeks. The Social worker told me to think very hard before I accepted her, as she had been born with Down's Syndrome and a slight heart murmur. I replied that she would need just as much love and care as all the other babies I've had and asked when could I see her.

Two days later I met Jodie, a tiny premature baby who was a week old. I thought she was beautiful. She was on the Special Care Baby Unit, very sleepy, very floppy and being tube fed as she was too tired to suck from a bottle. Her nurse told me she could be there for a month! I visited every day and as time went on she began to take her feeds and really enjoyed her cuddles. She was doing so well that at eighteen days old I was able to bring her home. She was feeding fine and showed no sign of the heart murmur, but she was like a little doll.

As the weeks passed Jodie started having breathing attacks. After a particularly bad one I rang the hospital and Jodie was seen the same day. I was told that the heart murmur was very definite and she would have to see a specialist urgently. Two weeks later Mr Wright from Blackpool saw Jodie and said he would refer her to Alder Hey for more tests. Within a month she was seen by Dr Arnold at Alder Hey and was diagnosed as having an AVSD.

Jodie was admitted three weeks later for cardiac catheter tests by which time she was five months old. The social worker came to collect us from hospital and I remember saying "I love this child so much. Why can't I adopt her?" I just knew how much I loved this very special child. When Jodie was eight months old the social worker told me they were taking Jodie off the adoption register and would process my application to adopt her.

Early in 1993 Jodie was admitted into hospital with a severe chest infection and slight heart failure. She was having great difficulty breathing and hated

being in the oxygen box. She bounced back, but only to go through the same four months later. I was never away from the GP's surgery so it was agreed Jodie go on a low dose of antibiotic daily.

In October 1993 on an Outpatient visit to Alder Hey it was decided that the time had come for Jodie's surgery and she would be admitted within eight weeks. This put my adoption application on hold until after her operation.

On January 5th 1994 Jodie was taken to theatre and five hours later she was in Intensive Care with tubes and wires everywhere. Twenty six hours later she was back on the ward with only her pacing wires. The staff on the Intensive Care Unit couldn't believe how well she was doing. The operation was a huge success, thanks to the care of the surgeons and staff at Alder Hey, and she was home a week later on no medication.

Jodie has gone from strength to strength. Six weeks after her operation she walked unaided at twenty-two months and she hasn't sat down since! At the end of February the adoption panel agreed to my applying to the Court to adopt Jodie, and on July 20th 1994 my dream came true when I was granted an Adoption Order.



Jodie never ceases to amaze me, she attends playgroup, goes to the Development Centre and has a Portage teacher. At her last check up at Alder Hey in July 1994, I received the wonderful news that they don't want to see her for one year.

I would just like to say a Great Big Thank You to the North West Regional Co-Ordinator Mike Halpin and his wife Lesley for all their support, advice and visits whilst we were at Alder Hey, and for putting me in touch with other parents who were willing to share their own experiences. As a result I now have a great network of friends, as well as my precious daughter Jodie-Louise whom I love dearly.

*Lynn Relph
Lancashire*

Barnaby's Story

Our fourth child was born in the early hours of Saturday April 9th 1994, at Derriford Hospital, Plymouth. His name is Barnaby, he has Down's Syndrome and he is now nine months old. He had a heart condition known as Tetralogy of Fallot, which is already corrected, having not been diagnosed until he was six months old. Let me tell you about it....

Earlier in my pregnancy I had been looking forward to a routine eighteen week scan, after a threatened miscarriage had settled down. Armed with a bottle of Lucozade and clutching the necessary coins to purchase an ultrasound image of the baby I was full of hopeful anticipation - even the nausea had subsided! After an unusually lengthy scan, with a bursting bladder and an idea lodged in my head that this baby at the very least was missing a limb, we were told there were indications of Down's Syndrome. My husband and I were told quite carefully and sympathetically, and with the proviso that they could make mistakes, but that there was a thickening at the back of the neck, and the femur measurement was short.

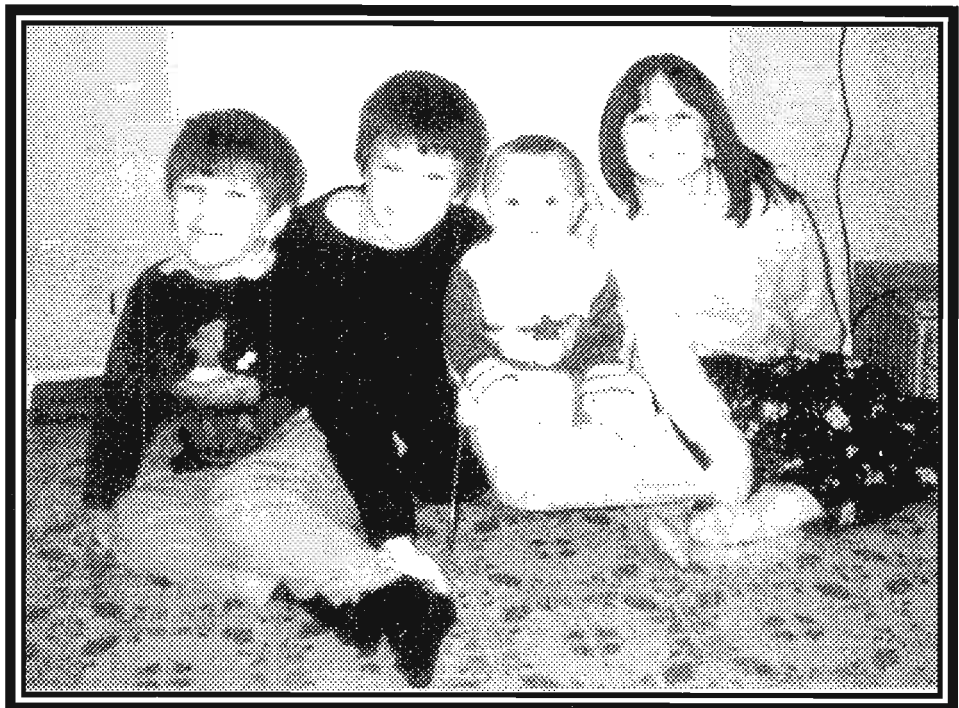
At my ante-natal appointment the previous week, the registrar had said that at thirty nine year I was running a 1 in 155 chance of having a baby with Down's Syndrome. In the dimness of that ultrasound room, as the words began to register, I felt as if I was in one of those BBC2 dramas, the compelling ones which are almost too real to be enjoyable. This feeling was compounded because I had to wait from that Friday until the Monday to see the obstetrician. Fortunately I was able to contact the Down's Syndrome Association on the Friday afternoon, and get hold of some useful and appropriate information.

Looking back I realise that the consultation with the obstetrician provided an old-fashioned and rather negative view of our future with this baby, though he himself thought he was giving me an honest and realistic picture. He told me that from the scan the baby was "almost certain" to have Down's Syndrome. A termination was offered with a week to consider this option; a further appointment was made to be kept if I chose to terminate, and a phone call to cancel that appointment if I chose to

continue with the pregnancy. That phone call must have seemed very trivial to the receptionist, but it was one of the most important I have ever made.

For the rest of the pregnancy we did some research into Down's Syndrome and what we might expect, and my immediate concern was that the baby might not survive the delivery, because I read that 40% of babies with Down's Syndrome have heart defects.

Barnaby's arrival was as joyful an occasion as the delivery of our other three children had been. He was the lightest of the four, at just under seven pounds, but I had a heightened sense of relief because he had survived, he seemed physically



Thomas, Edward, Barnaby and Joanna

well, and the Down's Syndrome was of no consequence at all in those early days. We actually felt it was easier for us because we had been prepared during the pregnancy, rather than having to deal with difficult information at that more vulnerable time immediately following the birth.

Barnaby seemed to feed well, he slept even better, going through the night (10pm to 5am) at about a week old, and our only worry was a slight blueness. Before being discharged from hospital his tests included a chest x-ray, an ECG and an ultrasound scan, and in view of a small hole being detected an appointment with a cardiologist was to be offered.

This came through for July, by which time the top hole had healed spontaneously, but he had one or two small leaks between the right and left ventricles.

We understood that these ventricular septal defects could heal between the ages of six months and five years. We were reassured that they would present no problems to Barnaby in the future apart from the need for prophylactic antibiotics in the event of any dental treatment. I asked the cardiologist about the blueness which came and went unpredictably and he suggested this had more to do with Down's Syndrome than the heart.

Barnaby's diagnosis was very optimistic and we both felt relieved. However, by September, coinciding with his getting more active and being awake for longer, we became concerned that the blue spells were coming with distressing frequency, and we became anxious enough to press for an extra appointment with the paediatrician.

On October 13th, following further x-rays, an ECG and ultrasound scans, a different cardiologist informed us that Barnaby had a major heart problem. I reeled from the shock of this news almost more than I had a year earlier when we were told about his Down's Syndrome, because this sounded life-threatening. I could hardly believe it when we were asked if we wanted nature to take its course. We hurriedly made it clear that we did not, and were reassured to find that surgery would have a 90% chance of success. That day I remained in our local hospital with Barnaby whilst he was stabilised with immediate medication (beta-blockers), and then tea-time at home became an ordeal of explanation to our three other children aged seven, six and three, making arrangements for school, playgroup, childminding and meals, and packing for our early departure to Southampton and the Paediatric Cardiology Ward the following morning.

Within hours of our admission I was informed of the exact nature of Barnaby's heart condition. He had a Tetralogy of Fallot, meaning a hole between the right and left ventricles, a narrowing between the right ventricle and the pulmonary artery, a thickening of the pulmonary valve and an overriding aorta.

He was given Propranolol, extra oxygen and sedated with morphine. This prevented him from having any further blue spells until he had had surgery. It was decided from a catheter test that he was suitable for full corrective surgery. On October 21st, exactly a week after our arrival, I took Barnaby to theatre at 8.15am, and he was in Intensive Care for me to see by 5.15pm. It was a very long day!

Having your child in Intensive Care is one of the hardest parts of it all, but I was well prepared beforehand regarding what to expect, how Barnaby would look, and what my reactions might be. The

nurses could not have been kinder or more informative and I was able to come and go as I pleased. Once I understood something of what all the wires, tubes and drugs were for, I was able to cope, and was amazed that I could do so. Barnaby did well to be back on the ward by Monday morning after just a week in Intensive Care. Initially he had been quite agitated, and getting the right balance of sedation seemed to be something of a challenge, but he had the tube to the ventilator out by Saturday morning, an achievement he had almost managed on his own during the previous night.

Barnaby made good progress, apart from developing a pleural effusion (fluid on the lungs), requiring a return to the operating theatre to have chest drains inserted. This delayed his recovery and our return home by about a week. It was a frustrating time because he was not able to support himself sufficiently to sit unaided, so he was confined to either lying in his cot or sitting on my lap. We had to wait for the left lung to stop producing a fatty substance, and to assist the process Barnaby was put on a fat-free diet. It was this particular week that he reached a developmental milestone in learning to roll over, but had to be restrained from doing so because of the tubes in his chest.

Barnaby and I were in Southampton General Hospital for nearly a month; he was discharged on November 9th, exactly nine months old. My husband and the other three children had remained at home in Plymouth, helped and supported by my mother-in-law who was able to stay for part of the time, and by friends and neighbours. Half-term coincided with the weekend of Barnaby's stay in Intensive Care, and it was helpful to Edward, Joanna and Thomas to see us both in hospital. Phone calls seemed unable to reassure as much as a visit could, and although I could not tell them how soon we would be home, they were understandably more settled and confident about the situation than they had been before seeing me. The distance between our home and the hospital (over one hundred and fifty miles) certainly compounded the stress of these circumstances, and for a family to stay together during such a time is probably the best option, but for us this was not realistic.

We were devastated by the seriousness of Barnaby's heart condition when it was fully explained, and it was as shock to think that it had been six months before we realised how dangerous those blue spells were. I recalled instances when I had by chance found him blue and distressed in his cot or his pram, and picked him up; how I had instinctively rather than knowingly held him in the correct position on those occasions. I felt guilty that

perhaps I had not acted strongly enough in his behalf, and upset for Barnaby that he now had a heart condition as well as Down's Syndrome with which to contend. In that first week prior to surgery I was churned up with mixed emotions.

The reactions of other people, including family and friends, were also unpredictable. Some did not like to wish him well in case he did not recover, others made me feel that I had exaggerated the whole thing and that there was nothing to worry about. Someone even wondered if we regretted not terminating the pregnancy.

There was no way I could deal with any of this at the time. I needed all my emotional energy for the crucial matter in hand - my child's recovery to health. I came to rely heavily on the doctors and nurses, on their experience, understanding and kindness. As parents on the ward we found ourselves amazed at what we could laugh at.

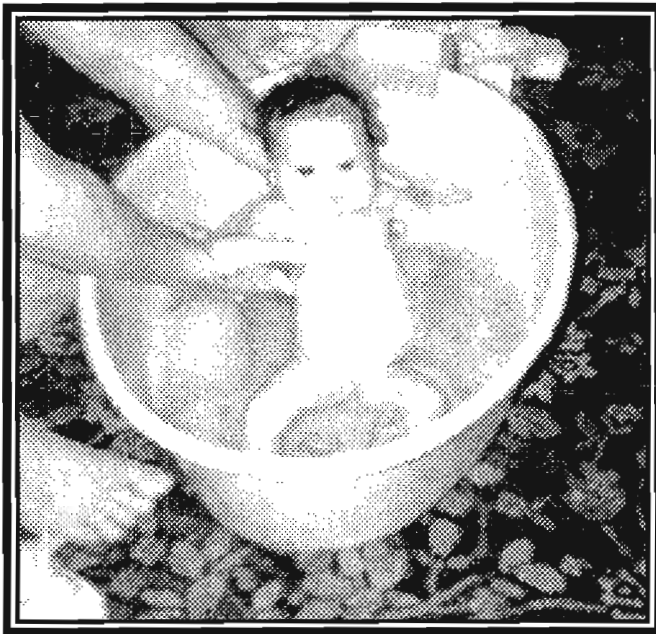
But I felt very vulnerable when the time came to return home; it was like coming home with a new

born baby. Barnaby was convalescing and continued on regular medication for two months. The other children made extra demands because I had been away, and I continued to have anxieties about Barnaby's health and future. There was quite a lot of adjustment for us all, but Barnaby made it easier. He is a survivor, a fighter, and an absolute delight to us and to all who know him. Just over two months after coming home, and within three months of surgery, the cardiologist took him off all his medication, and as all is well, made an appointment for a routine checkup six months ahead.

As a parent of a child with Down's Syndrome and a heart condition, it is possibly an understatement to say that this whole experience has changed my priorities in life, but perhaps overstating the case to say that it will continue to affect me profoundly in the future. Barnaby has given me - and given the whole family - strengths we never knew we had.

*Philippa Woods
Plymouth*

Kelsey's Story



I went into hospital on Thursday 30th July 1992, I was so anxious not only at the thought of having another baby but leaving my two other girls, Kelsey seven and Ashley four. I got settled into the ward then my doctor came to see me as I was having a caesarian section at my request as my first pregnancy was a mid cavity forceps and my second was a section. I was feeling a little bit frightened at the thought of the operation but he told me not to worry as everything was as it should be. The anaesthetist

came to see me and asked if I would prefer an epidural rather than a general anaesthetic, but being a bit of a coward I opted for the latter.

I went to theatre at 9am on the Friday, with Wullie waiting outside to be told as soon as the baby arrived. Kelsey was born at 9.21am, and I was taken down to the recovery room. I don't remember what time I came to, but I remember asking Wullie what did we have and being so happy when he told me as I really wanted another girl. Then the bombshell came, she had a heart problem.

Just at this point a young nurse came in to ask how I was going to feed Kelsey, I said by bottle. Then she said that heart conditions are quite common with Down's Babies. Wullie said "My daughter doesn't have Down's Syndrome", but at that moment the doctor came in to break the news to us. The nurse thought we already knew, but the doctor had been called away before he could tell us. I started to scream, then a nurse came to tell Wullie he could go and see Kelsey whilst I got cleaned up.

When Wullie came back he said she was so lovely with a mass of black hair. He brought some photographs with him, but I didn't want to see them or even see Kelsey. Then they told us they were taking her up to Yorkhill Hospital in Glasgow and asked if I wanted to go and see her before she went. Wullie took me down to the Baby Unit in a wheelchair.

All I could see was tiny babies lying in incubators then they told me "This little girl is yours."

When they took her out of her cot and put her in my arms, I experienced such a feeling of love, she was so beautiful. At that point I didn't care what was wrong with her, I knew I loved her and always would. I went back to the ward and Wullie went home to tell my mum and our other girls before going to Yorkhill to see the cardiologist.

I am so proud of the way Wullie coped with the whole thing not once did he ever say 'Why me? Why my baby?' He accepted it right from the start. Dr Dobbie came up to see me in the ward and he was so kind he tried to explain it all to me but I wasn't taking it all in. I asked about the test they do at sixteen weeks pregnant, he told me results showed that I was not in the high risk group and didn't warrant any further tests. It is just as well I didn't find out I don't think I could have done anything anyway. He then told me if Kelsey had been born naturally she would not have survived the birth.

The funny thing is before I went into hospital I bought some magazines but hadn't looked at them till late on that Friday night. The first article I read was all about a woman who had had a baby girl with Down's Syndrome and wouldn't accept her. The baby's father got in touch with a family whose ten year old son had Down's Syndrome. He went to see this lady, and when she saw how loving and kind he was she knew she had to look after her own baby. I think after I saw that I knew I had accepted Kelsey.

I was allowed to go up to Yorkhill Hospital on the Sunday to see her. When I went into the ward the nurses had dressed her up in a little white lacy dress and little booties; she was so beautiful with a mass of black hair. The cardiologist came to speak to us and told us about Kelsey's condition and that she would be between nine and twelve months before they could operate on her. I got to feed her for the first time. That day I was the proudest mum in the world.

When I went back to the maternity hospital that night I cried for hours knowing my baby was lying

in another hospital and I really wanted her to be with me. I was discharged on the Monday, went back to Yorkhill that evening and was told she was being sent back to our local hospital baby unit the next morning, I was so happy. On the Tuesday my own doctor came to see me at home, he is quite old now and he told me that Kelsey would always be ill and never out of the hospital even if she survived. I was so upset I got in the car and drove to the hospital myself to see Kelsey and find out what was going on. I spoke to the nurse who said she would get a doctor to see us. When Wullie and I saw him he said Kelsey was feeding OK and not on any medication so she could go home the next day. I can't describe how we felt, we were so excited at getting her home.

She came home the next day and only went back every four weeks for a checkup. At the first checkup she was put on Frusemide 6 mls a day, but apart from that she was okay. When she was eleven weeks old she was admitted to hospital with pneumonia, although she had been fine a week before at her checkup. After a few weeks in our local hospital there was no improvement in her so they transferred her to Yorkhill where she was taken to Intensive Care and put on a ventilator. Some days she would appear to get better then others she was worse. This went on for a few weeks.

Then one Thursday they phoned at tea time for us to go to the hospital although I had only been back a few hours. When we got there she was a lot worse. I phoned my minister and he came and baptized her Kelsey Charlotte Hillhouse Julyan. She died the following day, the 20th November 1992.

I had eleven lovely weeks with her at home and memories no one can take away. Like the first time she smiled at me, I will always remember that day! Sometimes I don't know how we will survive without her but I try to remember all the good times and think I was so very lucky to have had a very special baby and that others are not so lucky, they don't even get to take their babies home.

*Lynn and Wullie Julyan.
Ayrshire*

Memorial Donations

Since the last newsletter we are grateful to have received donations in memory of the following :

Angela Ackroyd - Nelson

Jake Blight - Bideford

Stephen Brown - Halifax

Philip Byers - Leighton Buzzard

Joel Ronayne - Jersey

Shelley Stewart - Bedford

Daniel Warwick - Ormskirk

Adam Watcham - Cleethorpes

Report on Children's Heart Federation trip to Lapland

During September 1994 I got together with a marketing company to launch an appeal to take thirty heart children and ten adults to see the real Father Christmas in Lapland. We were very lucky to have a Paediatric Cardiologist and four nurses from Paediatric Cardiology Units to accompany us. A representative from the marketing company, three committee members and myself made up the ten adults. All heart groups were asked to nominate two heart children to make the trip.

The morning of December 18th saw the party of us meeting up at Gatwick Airport at 6.30am. The children were surprised and delighted to be met by Postman Pat and Jess his cat. Mickey and Minnie Mouse were also sent by the Disney Company to meet the children and accompanied us on board the plane to say goodbye.

The flight was a great success with videos and a trip to the cockpit to meet the Captain. He took the children in groups of three and spent time with each group explaining the flight deck and controls.

When we landed at Ivalo the children were kitted out in thermal suits, moon boots etc., then we left for Father Christmas's village on sledges pulled by skidoos. We travelled over a mile and a half wide frozen lake then on through snow covered woodland to the village. It really was a Winter Wonderland. The locals had built an Ice castle for the children to play in and there were reindeer sledges, toboggans, ice hole fishing and many many other activities for them to pursue. The older children had great enjoyment on the motorised skidoos.

There were some unusual foods on offer such as reindeer stew, hot berry juice and local fish etc., which were all much appreciated by the children as they warmed themselves around huge log fires.

It was wonderful to see the children rolling around in the snow, playing snowballs etc., but the highlight of the day was being taken by reindeer sledge up to Father Christmas's log house. He really was the real Father Christmas. He greeted each child by name while holding the letter they had previously sent him. He spent time with each one and gave them each a very nice present. They were all photographed with him and these photographs will be sent direct from Finland.

We were an hour late leaving Ivalo due to having to de-ice the plane, which meant some anxious parents were left wondering what had happened to us at

Gatwick Airport. On arrival home the children were given a wonderful Disney stocking filled with presents donated by various Companies.

For many reasons this was a very important flight. Because medical back-up was available we could take children who had never flown before. We pushed back accepted barriers for heart children by taking them into such low temperatures inside the Arctic Circle. Although the Cardiologist went equipped for most eventualities, he was delighted not to be required to open his medical bag at all. And that is perhaps the most successful aspect of the whole trip.

*Yvonne Brandon-Beaumont
Children's Heart Federation*

From the members that went

This is just a quick line to say thank you for asking us to go on the Lapland trip to see Father Christmas. It was a very long day, but the sight of Sarah's face when she saw the Reindeer Sleigh and the joy of riding on it, and her face when we went into see Father Christmas helped to relieve some of the problems. We would both like to thank you for giving us the chance to go on this trip of a lifetime.

*Peter and Sarah John
Old Windsor*

Just a note to say a big thank you for allowing my son Jo the trip of a lifetime to visit Santa in Lapland. Jo has long term hearing problems which result in communication being very difficult, but he knew that he was going on an aeroplane to see Father Christmas. although I understand that he was a bit overcome by the snow and lack of daylight, but he came home laden with gifts, and I would like to thank Peter John for taking care of him on the trip.

*Jenny and Jo Hopkins
Milton Keynes*

The Down's Heart Group was saddened to hear of the recent death of Dennis Chandler from Stamford, a volunteer who was an invaluable help to our Founder, Linda Walsh in the early days of the Group. He will be fondly remembered for all his help and support.

Fundraising News

London Marathon - April 2nd 1995

By the time you receive this newsletter, the London Marathon will be imminent, possibly even over, but we can't let the event pass without mention of the fantastic support we have had this year.

We have been lucky in each of the last four years to have a runner in the London Marathon representing the Down's Heart Group, but this year sees our strongest ever representation with five runners out there pounding the streets of London raising funds for us. They are :

David Ashpole - Berkeley, Gloucs
 Dave Brown - Eaton Bray, Beds
 Mike Hambling - Essex
 Terry Turner - Stoke Hammond, Bucks
 Martin White - Winchester, Hants

None of the runners is actually a member, but each of them has committed themselves to a gruelling run and pledged their sponsorship to the Down's Heart Group. We wish them luck on the day.

Other Fundraising Events

Obviously the newsletter tends to focus on the larger fundraising events, but we are also extremely grateful to the many people who organise much smaller more localised events in support of our work. Sometimes the first we hear about it is when a donation arrives with an accompanying letter saying how the money was raised.

If you want to help the work of the Down's Heart Group to continue and grow, but you don't feel up to organising a major event, have a look at some of the examples below, they may give you some ideas.

West Midlands Region

- Pat Mitchell collected at her local Asda store

London Southern Region

- Sheila Saunders held a Coffee Morning
- Katie Spall had a stall at Crowhurst Village Fair
- George Beresford took his surplus home grown vegetables to his office and let colleagues help themselves and make a donation raising £8.50.

London Northern

- Angela Barker had two Tupperware parties and a stall at a car boot sale
- Billy Evans of Teddington is doing a parachute jump from 12,000 feet sometime during the summer. If you don't fancy the jump perhaps you could get him some sponsors! Forms available from National Office.

East Midlands Region

- Sarah Smith had a stall on her local market

North West Region

- The Saddleworth Branch of The Church of Jesus Christ of Latter-Day Saints held a Car Treasure Hunt around their local area, and sent the £25 proceeds to us.

If those haven't sparked your imagination there are still other ways to help.

Poetry Recital

How about helping your child to learn a poem or nursery rhyme by heart and getting friends and relatives to sponsor them for how many lines they manage to recite.

Deed of Covenant

If you could make an annual donation to the Group for each of the next four years, the tax on this can be reclaimed by us, thus increasing the value of your gift. All you need to do is fill in a simple 'Deed of Covenant' form and Standing Order for your bank or building society. Forms are available from National Office.

Money Boxes

If your little cardboard moneybox has fallen apart, you can't remember where you put it, or you never received one, we still have some left at National Office. For more vigorous use such as in an office, they may need a bit of sellotape to strengthen them, but they are an ideal way of collecting up odd change, and it's surprising how the money soon mounts up. Details of the bank account appear on the flaps of the top of the box, but it would be very helpful if you would then send the paying in counterfoil to Phil Thorn, our Treasurer, marking on it 'moneybox' for his records.

Give as You Earn

Many companies now run this scheme whereby employees can make a charitable donation from their wages before tax, often with a matching donation from their employer. If your firm doesn't already operate the scheme, perhaps they might be willing if you asked, it's an easy way to spread the cost of a donation to the Group, and it provides a very valuable regular income for us.

If you do any fundraising, please do write and let us know so that we can try to put it in the newsletter.

And thank you to everyone who has made a donation in whatever form.

Can You Help?

Down's babies miss out on heart surgery

by Lois Rogers
Medical Correspondent

Doctors and parents of babies born with Down's syndrome have alleged that hospitals advised against life-saving heart operations for the children. They claim the policy was designed to hasten death and save costs.

This weekend an eight-year-old boy is fighting for his life in a hospital in the south-east. His distraught parents have learned that had he received heart surgery in infancy he would be growing up as normally as other children with the condition, caused by a chromosome defect.

In a second case highlighted by the Down's Heart Group, representing 500 families, the parents of a seven-year-old face a similar plight. At least a dozen other families say they received the crucial heart operations only by going to more sympathetic hospitals.

Nearly half the 26,000 Down's syndrome children and adults in Britain are born

with heart abnormalities. Many need hole-in-the-heart surgery, now viewed as a relatively routine operation.

However, Dr Claus Newman, paediatric cardiologist at the Chelsea and Westminster hospital, said doctors were applying widely varying criteria to treating physical problems in mentally handicapped patients. "One doesn't have to look much further than the eugenics movement," he said.

Another leading paediatric cardiologist said: "If you have relatively limited resources who do you spend it on? People who are going to make the most contribution to the community or those that will always require assistance?"

Three families claimed this weekend they were advised against surgery by the Royal Brompton heart hospital in London. Another said the Yorkshire regional cardiothoracic centre in Killingbeck hospital, Leeds had adopted

the same stance. All four children were successfully operated on elsewhere.

Alayne Levy, 35, a teacher from West London, said her five-year-old daughter Hannah was eventually offered heart surgery at Great Ormond Street children's hospital. "At the Brompton, I felt they were giving their personal view of the value of her life. It was very upsetting." Lynn Gouck said her daughter Sarah was only strong enough to walk after an operation at Glasgow's Royal Hospital for Sick Children when she was five; it has increased her life expectancy from 15 years to 55. "The Brompton told us the operation was too risky," said Gouck.

Dr Michael Rigby, Brompton's director of paediatric cardiology, said Down's babies were treated the same as others. Killingbeck said its figures for operations on Down's babies were in line with other heart centres.

Reproduced from the Sunday Times of the 23rd October 1994

Over the last few months various media reports, parents comments etc. have heightened the Committee's interest in a number of areas. In order to attempt to clarify the position and what action, if any the Group should be taking, we urgently need to hear from families who have experience of any of the following areas.

Pre - Natal Diagnosis

Did you have any tests during your pregnancy, particularly blood tests, which are designed to indicate if the baby has Down's Syndrome?

Did the result incorrectly show that your risk was low?

Did a routine ultrasound scan pick up your baby's heart problem?

Were you given any counselling before agreeing to have tests carried out?

Were you put under any pressure to have a termination if your baby was found to have Down's Syndrome?

If you had any tests in pregnancy that showed that your baby had Down's Syndrome, and / or a heart problem, or you had tests that led you to believe that your baby definitely would not be born with Down's Syndrome, WE NEED TO HEAR FROM YOU.

Late Diagnosis of Heart Problem

After your baby had been diagnosed as having Down's Syndrome, how long was it before their heart problem was detected?

Were you told initially that their heart was 'fine', only to learn later that this was not so?

Did the hospital check for heart problems as a matter of routine because your baby had Down's Syndrome, or was it only when your baby had difficulties that the diagnosis was made?

If your baby's heart defect was not detected before a month old, or it was known that the child had a heart murmur, and full diagnosis was not made before three months, WE NEED TO HEAR FROM YOU.

Opinions

After seeing the cardiologist with your child and being given the diagnosis and any future treatment plan, were you satisfied, or did you go elsewhere for a second opinion?

Was the recommendation the same at both hospitals?

Was surgery recommended, and due to the length of waiting lists and / or cancellations by the time your child came to the top it was too late for surgery?

If you saw cardiologists from more than one hospital with your child, particularly if their recommendations about surgery were different, or your child missed out on planned surgery due to cancellations or the length of the waiting list WE NEED TO HEAR FROM YOU.

If you have experience of any of the above situations, either positive or negative, please let us know the details (even if you think we are already aware).

We urgently need information from as many families as possible, including those who are bereaved, so please get in touch as soon as you can, preferably in writing.

YOUR EXPERIENCES ARE OF VITAL IMPORTANCE.

1994 Annual Conference and AGM

The second of three reports on our 1994 Annual Conference, details the afternoon workshops. In the final part we hope to bring you a report on the slightly more technical aspects of the statistical findings of Dr Mark Jackson, our other main speaker last year.

The Role of the Cardiac Social Worker

Val Millington is one of two Cardiac Social Workers at Alder Hey Hospital and covers the whole of the northwest of England, North Wales, Lancs, Merseyside and Greater Manchester. She is paid by Liverpool Arts Council and has the same statutory rights as any Social Worker. She is based in the Cardiac Unit.

She prioritises her work and her first priority is bereavement or families who are about to be bereaved. She is there to support parents at the time of diagnosis when they are bound to be traumatised. She assesses the appropriate support needed and will offer home visits and referrals to bereavement support groups. She is available to give information to the families of newlyborn children and/or families attending a first visit to the Unit.

With respect to older patients she can support the family when making the decision about the risks of surgery. Her role is supporting the rights of the child.

She can offer information about Welfare Rights and education. We discussed the case for national automatic screening for heart defects of all children born with Down's Syndrome.

Val was an interesting and informative speaker who opened up the dialogue for some stimulating discussion.

*Lynne Holden
Birmingham Hospital Visitor*

Learning To Play

I spent a splendid hour in the learning to play workshop with two other parents where we were able to indulge ourselves in the opportunities of childhood fantasies.

Our two expert play leaders Julie Davenport and Norma Rimmer took us through various experiences with a child's eye and we were able to enjoy the simplicity and excitement of day to day objects that can be such fun when they become toys.

So we sophisticated adults sat on the floor with our eyes closed and one by one we took out of a basket an object and felt it, enjoying curves, smooth bits, rough bits, bits that made noises and long bits, short bits. Eventually we were allowed to open our eyes and find we were holding a piece of chain, a sponge, a kitchen whisk or a toy policeman.

Our second adventure was to join with little Jo Baxter aged eighteen months who very ably demonstrated what to do with a large plastic bowl of jelly! Imagination is important in this form of play and Jo had a lot of that. We were smothered in sticky red jelly and so was he. We all loved the sensation of jelly running through our fingers, the stickiness, the "splat" noise as our hands jumped out of the bowl filled with this lovely colourful, sweet smelling substance.

A further tactile experience was a moulding agent rather like Playdoh but edible and which we could make up in our own homes and keep in the fridge for a quick play on the kitchen floor when we and the kids are fed up with the housework. (The recipe for this homemade playdoh can be found at the bottom of the next page.) Did you know that waterthickened with cornflour with some colouring can make another lovely gooey mess that drips from your fingers? It feels good and it makes such a mess, but believe it or not it dries up reasonably quickly and can easily be brushed away.

Our last feely exercise was to place our hands in a large laundry basket full of shredded paper to find small toys or articles with which we could play. Oh the excitement and suspense and hoping to find something nice and also all that paper that could be thrown around the room.

The point that was very well made was that in and around our homes we have everyday things that can be made fun for our children that will hold their attention and give them an opportunity to experience different sensations which touching, feeling, smelling, tasting and all at very little cost, so don't spend time, energy and money in toy shops, just look in the cupboard and see what can appeal to your little one.

Katie Spall

London and South East Co-ordinator

Feeding Difficulties

This workshop was very ably lead by two Community Dieticians (a role I have not come across before), Jane Moss and Rachel Scott from Liverpool.

About a dozen parents gathered to learn something about what can be a very intractable and distressing problem both for them and their children.

Jane and Rachel asked us to think about our own feelings about food and eating, and how we could use this to help with making the experience more enjoyable for our children.

What did we think were the most enjoyable aspects of eating? As well as the obvious things such as taste and smell, the group identified the social enjoyment of eating and the rituals involved, such as sitting in the same place, using the same utensils, sitting at table etc. as being equally important. The things we didn't like were being pressurised and hurried when we eat, of having to eat when we were not really hungry and of being distracted.

We were asked to ponder whether with feeding, we always accentuated the positive and diminished the negative with our children.

Members of the group then came up with problems that they had or were experiencing with their own children's feeding. These included poor sucking, won't take a bottle (thicken the liquid), nasal gastric tubes (there is no experience of hunger), over and under weight (if over weight use semi skimmed milk from two plus and skimmed from five plus) and many other practical ideas too numerous to list in this short article.

The general advice of the dieticians was to recognise that young children use food and eating as part of their personal development and interaction with adults - for example it was their view that children could gag to order. They believed that it was possible to change a child's eating habits with firmness and persistence - inevitably it is a battle of wills and the parents are often the more distressed and the first to give in.

So in general - make eating an enjoyable experience; avoid distractions; establish patterns and rituals; do not become over anxious about short periods of non or lesser intake; be firm and consistent. It all sounds so easy!

John Spall

Chairman

The Down's Heart Group has it's own leaflet on Feeding Problems, and growth charts specifically related to babies with Down's Syndrome . Also useful handouts from the Feeding Difficulties workshop. If you would like any of these please contact National Office, (please send stamps to the value of 47pence for each growth chart).

Recipe for Homemade Playdough

- 1 cup plain flour
- 1 cup water (to which a few drops of food colouring have been added)
- ½ cup salt
- 1 tablespoon cooking oil
- 2 teaspoons cream of tartar

Put all ingredients into a saucepan over low heat and stir until it gels.

Letters to the Editor



Dear Editor,

Letters for publication should be sent to :

The Editor
Down's Heart Group
17, Cantilupe Close
Eaton Bray
Dunstable
Beds
LU6 2EA

As you can see this page has only two letters featured, that's because they were the only ones sent in for publication. We would really like to see more input for the newsletter from our members, and that includes the Down's Heart Children themselves and their siblings. Please send in your contributions, poems, pictures, drawings - in fact anything you feel other members might like to share - this is your newsletter!

I would like to make contact with any families who are bringing their child up on a vegetarian, cows milk free diet and who may also be using alternative holistic therapies. At the moment, Sam (eleven months old awaiting heart surgery to deal with his Tetralogy of Fallot), is back to being tube fed due to weight loss. Prior to this set-back, triggered by teething and a twenty four hour illness, he had had many healthy months of breast feeding and three solid meals a day, (but still poor weight gain).

I would like to hear from any families who could share experiences and ideas, especially if they did not follow the recommendations of the paediatrician and dietician. Please either write or ring

Gemma Judd



Dear Editor,

I thought other parents might like to read this extract from 'The Clowns of God' by Morris West, which was spoken at our daughters Christening.

You need a sign. What better one could I give than to make this little one whole and new? I could do it; but I will not. I am The Lord and not a conjurer.

I gave this mite a gift I denied to all of you - 'Eternal Innocence. To you she looks imperfect - but to me she is flawless, like the bud that dies unopened or the fledgling that falls from the nest to be devoured by the ants. She will never offend me, as all of you have done. She will never pervert or destroy the work of my Father's hand. She is necessary to you. She will evoke the kindness that will keep you human. Her infirmity will prompt you to gratitude for your own good fortune. More!

She will remind you every day that I am who I am, that my ways are not yours, and that the smallest dust mote whirled in darkest space does not fall out of my hand. I have chosen you. You have not chosen me. This little one is my sign to you. Treasure her....

Book Review

Those of you who have been members for some time, may remember our 1991 Christmas card which featured the three perky robins designed by Johnny Luntz of Torquay. Johnny derived a great deal of pleasure from his 'celebrity' status after winning the competition. Shortly after his death in January 1993, his mother Jill began writing down her thoughts and feelings. Last December these were published in a short paperback book which is reviewed below.

Johnny - A tribute to Love **by Jill Luntz**

Jill Luntz's moving biography of the birth, life and all too early death of her son Johnny who was born with Down's Syndrome.

Although Johnny also had a congenital heart defect it did not stop him from enjoying his life to the full, and his family should be so very proud of his achievements. Johnny's ability to draw love and understanding from strangers as well as friends and family was so beautifully narrated in this lovely tribute.

As I read the story, I shared in Jill's feelings of disbelief at the time of Johnny's birth, love and joy as he grew into a gentle, fun loving boy, and the ultimate feelings of sorrow and grief as Johnny lost his fight for life.

I felt privileged to share Jill's innermost thoughts and feelings as she described the effect that Johnny had on all their lives. Johnny's parents Jill and

Mike, and his sister Penny gained much comfort from their faith, and their courage could be a lesson for us all.

I would recommend this memorable book for all to read, especially those who are bereaved. I also feel it could benefit and offer insight to professionals.

"We cannot judge a biography by it's length or by the number of pages in it; we must judge by the richness of the contents.... sometimes the 'unfinished' are among the most beautiful symphonies."

Linda Watcham
Yorkshire and Humberside Regional Co-ordinator

The book is priced at £3-99, and copies can be obtained by sending a cheque or postal order to :
Jill Luntz



Change of Address?

It's very sad when we lose contact with a family because they forgot to tell us they were moving house. As we only produce a newsletter every four months, often the redirection of mail has finished before we send the next copy. 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 thefamily will be:

.....
.....
.....
.....
.....

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

Postcode:
Telephone:

Send to: Penny Green, Family Support Co-ordinator

