



**DOWN'S
HEART
GROUP**

NEWSLETTER

(Issue No 16)

SPRING 1997



Stepping in to Spring, Alexandra Bates - read her story inside

Contacts

National Office

National Administrator - Penny Green



Contact or Ansaphone always available (24hrs in emergency)

Founder - Linda Walsh

Chair - John Spall



Vice-Chair - Sheila Forsythe



Treasurer - Phil Thorn



Secretary - Shirley Glowocz



Legal Advisor - Brian Auld

Policy Advisors

Mary Goodwin
Dr Rob Martin
Dr Claus Newman
Dr Phil Rees

Benefits Information Contact - Mary Clayton

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

Representative for Inoperable Children and Young Adults - Wendy Tucker



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General enquiries should be addressed to the National Administrator. Requests for information about the work of the group from professionals, students etc. should enclose an s.a.e. 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: 00 3531 6769255

The Down's Syndrome Educational Trust
(formerly Portsmouth Down's Syndrome Trust)
The Sarah Duffen Centre
Belmont Street
SOUTHSEA
Hants.
PO5 1NA
Tel: 01705 824261

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

DHG WINS LOTTERY APPLICATION

It has long been an ambition of the Group to make a video about heart conditions which affect children with Down's Syndrome and their diagnosis and treatment, with the primary aim of informing and preparing parents.

We have been working on this seriously for the past two years, talking to parents and professionals and developing a script and locations. We were disappointed last year when our application for funding to Children in Need was unsuccessful, but undaunted then applied to the National Lotteries Charities Board under their Health, Disability and Care programme.

I am delighted to be able to announce that the Down's Heart Group is one of only a very small number from the 10,000 applications under this programme to have been successful. We have been awarded a grant of £15,000 (which is what we asked for) towards the total estimated cost of £25,000.

That sounds like a lot of money for a video - and it is! But we were determined, and advised, that we should aim for a "broadcast quality" product. Anything amateurish would not carry the authority nor do justice to the importance of the subject matter. We strongly believed this and in discussions with the Lotteries Board assessor this was clearly important in their treating our application seriously.

And quality is what we are going for. As our medical and nursing advisers we have Dr Rob Martin, Consultant Paediatric Cardiologist at Bristol and Mary Goodwin, Cardiac Liaison Sister at Great Ormond Street. We have been very fortunate in persuading Sarah Boston to direct the video. Many of you will know Sarah from her books, 'Will My Son' and 'Too Deep for Tears' about her son Will who had Down's Syndrome and had a heart condition. In addition to her 'Everyman' programme inspired by Will, Sarah has made many other documentaries for film and television. Sarah has brought in her long time collaborator - Rachel Trezise - a very experienced film and television producer, to oversee the whole production.

The Group will be committing some of its reserves to the project but this still leaves a considerable sum to be raised. To secure the Lottery money we must press ahead to make the video this year. We are therefore launching an appeal for the balance we require. We hope that members will contribute widely to this and thus help future parents and children.

We are also seeking contributions from commercial and other sources. If you have any useful "leads" for example either your employer or a trust please let either Penny or myself know and we will follow these up or if you wish provide you with material to do so. We find that a personal contact is worth a hundred begging letters!

If you would like to make a donation to the Video Fund a form is provided on page 21.

HEART/LUNG TRANSPLANTS

Many of you may remember the publicity last year about heart/lung transplants for people with Down's Syndrome, following the first such transplant to a woman - Sandra Jensen - in America. This gave rise to several articles in the press and a television programme.



The Executive Committee have been considering the Group's position on this issue particularly taking account of the views of families with children with inoperable conditions, and what appears to be the weight of medical opinion that people with Down's

Syndrome are not suitable for consideration for transplant. We question whether it is any longer tenable to cut off a whole group of people when one such person has had a successful operation. We believe that families are entitled to clear and objective information about the factors that are used to determine whether or not a person gets on to the national transplant register and we wish to produce a leaflet on the subject.

With the help of Dr Claus Newman, one of our policy advisers, we have prepared a paper along these lines which has been sent to all regional paediatric cardiac and transplant centres, area health authorities and other interested organisations seeking their comments and information.

If any member would like a copy I would be happy to supply them with one.

We will keep you informed of progress.

POLICY ADVISERS

We are delighted that we have recruited two further policy advisers Dr Rob Martin from Bristol and Dr Phil Rees Consultant Paediatric Cardiologist at Great Ormond Street. We are most grateful to them for their interest and commitment to DHG. I would stress that they, as our other advisers, Dr Newman and Mary Goodwin, are assisting us on issues of policy and general application. They cannot get involved in individual member's cases, second opinions, etc.

ANNUAL CONFERENCE - CARDIFF

The 1997 Annual Conference will soon be upon us - it seems no time at all since we were all in Bexhill last year. The Cardiff conference, being arranged by our South Wales Regional Co-ordinator, Chris Stringfellow, contains the successful mix of full sessions and small workshops on a whole range of interesting and relevant topics. We are looking for a good turnout of members from Wales and the West as well as members from other regions. This is a wonderful opportunity not only to hear high quality speakers but most importantly to meet and chat with other parents.

CHILDREN'S HEART WEEKEND

Another date for your diary is 18/19/20 July. The Children's Heart Federation, of which DHG is a member, is running a Children's Heart Weekend at Legoland, Windsor for members of all affiliated groups. Special rates for admission to Legoland and for nearby bed and breakfast accommodation in a college have been negotiated. For example, a package for a family of four for the entire weekend (excluding meals) will be about £150, while on the Saturday, which will include a party and barbecue at Legoland, a day ticket for four would be about £70. Further details will be available shortly from National Office.

I think this is the longest Chair's Report I have written for the Newsletter. It just shows how much is happening!

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

Nicola Desmond

Lindsay Wharam



East Midlands

Derby, Leics., Notts. & Northants.

Sarah Smith



Ireland

N. Ireland & Eire

Rosina Brierley



London Northern

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

We are currently reviewing this region due to its size and lack of contacts.

London Southern

Kent, Surrey, Sussex & S. London

Katie Spall



North East

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

Sally Hardman

Pat Studholme



North West

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

Mike Halpin



Scotland

Mainland & Islands

We are currently reviewing this region due to its size and lack of contacts.

South Wales

Dyfed, Glamorgan, Gwent & Powys

Chris Stringfellow



Wessex

Channel Islands, Dorset, Hants., Isle of Wight

(Hospital Visitor)
Vickie Richardson

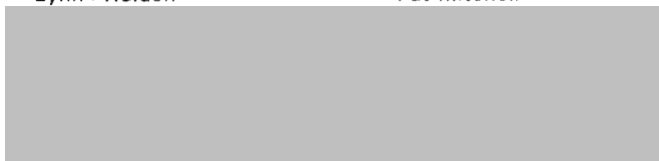


West Midlands

Hereford, Worcs., Salop, Staffs, Warwick & W. Midlands

(Hospital Visitor)
Lynne Holden

Pat Mitchell



Yorkshire & Humberside

Humberside & All Yorks.

Linda Watcham



In the first instance please get in contact with the regional Co-ordinator for your area, who may be able to put you in touch with someone more local.

1997 Annual Conference and AGM

The Down's Heart Group Annual Conference and AGM takes place on Saturday 26th April in Cardiff. Once again we have an interesting and varied programme for the day, and the meeting offers an ideal opportunity for families to socialise, and for professionals and parents to meet outside of the constraints of the hospital environment.

Main Sessions

Understanding Surgical Procedures and Techniques
Visual Problems in Children with Down's Syndrome

Workshop Sessions

Alternative Therapies and St. Briavels Centre for Child Development
Cranial Osteopathy
Independent Living for Older People with Down's Syndrome and discussion / information on Autism
Nursing Care

All members will receive an official invitation with this newsletter. Please return the registration form as soon as possible. There will be a crèche provided, but numbers are limited so it is important that you register early if you need to bring children with you, although we would appreciate you making other arrangements for them where possible in order to ensure that as many families as possible may have the opportunity to attend the conference.

Non-members and professionals are also welcome to attend, please contact National Office or the Honorary Secretary for more information and registration forms.

WE LOOK FORWARD TO SEEING YOU ON THE DAY!

Legoland Trip

We are still to be advised of the final details for the Children's Heart Federation trip to Legoland on 18th/19th/20th July, but as John has said in his report on page 3, the cost for the weekend for a family of four will be about £150 (including accommodation, party and barbecue on Saturday, but no other meals) or £70 for a day ticket for a family of four on Saturday (including the party and barbecue).

The Children's Heart Federation who are organising the day, are providing funding for the equivalent of two and a half families to attend the weekend. The Down's Heart Group Committee has agreed to supplement this to enable more members to take part in what promises to be an enjoyable event, and we hope that Saturday in particular will see a large gathering of members for the party and barbecue.

Free weekend for three families

**Contribution of £20 for a weekend visit
or £10 for the day visit for the first 50 members to apply.**

*If you are interested in attending please complete and return the form on page 21,
further information will then be sent to you when it is available.*

Alexandra's story.

Alexandra was born in the Maternity Unit at Bradford Royal Infirmary. She was three weeks premature. From examination by the doctors at the unit she did not appear to have any heart defect. A Consultant Paediatrician was called to see us. He would be taking care of her because of her Down's Syndrome. The referral to Killingbeck Hospital in Leeds was something he did automatically. It was explained that most children with the syndrome have some sort of heart defect and it is not always detectable at birth.

We received an appointment for Killingbeck approximately eight weeks later. She was seen by a Cardiologist, Dr Dickinson, who diagnosed her defect. We were told she had Atrio Ventricular Septal Defect. We were told it was a serious defect but it could be repaired with good results. He explained the nature of the defect to us and what they would do surgically to repair it. We were taken to another room where a staff nurse from the unit answered any questions we had. We were also told we could speak again with Dr Dickinson if we so wished. At that time it never crossed our minds not to have the surgery offered. It would mean her life would be prolonged and would be of a better quality.

Alexandra was then seen on a monthly basis. It would be expected that she would have the surgery between three and six months. They said that she was not very big and they would prefer her between 3 and 4Kg instead of between 2 and 3Kg. By Christmas it was clear that she was not going to grow as quickly as they thought. It was suggested that I stop breast feeding and give her formula milk with Polycal added to it. This we did.

By March she was still not growing very quickly and was beginning to struggle to feed. She began sweating and having trouble breathing when trying to suck at the bottle. She was prescribed a diuretic at this time. We had then been told she would probably have her surgery between 9 months and a year old. I took her off the bottle and started to give her a feeder cup and started to wean her onto solid foods in the hope that she would gain more weight. It was a slow steady process.

In the July she reached her goal weight although by this time I was beginning to feel despondent about the whole thing. I started to think that Killingbeck were putting off her surgery. I had heard some reports that a surgeon at Killingbeck would refuse to take children with Down's Syndrome onto his list because we had the medical know how to prevent these children being born in the first instance. I had also heard from someone who had had dealings with a lady who was a member of the local Down's Syndrome Association branch that Killingbeck

discriminated against children with the syndrome.

I am pleased to say that I found they do not discriminate and the surgeon who refuses to deal with children with Down's has been suspended. However, at the time it did not help me to hear all these comments.

Alexandra was put on the short list for early September. She was called on the 18th for surgery the following day. At this stage I had an awful feeling she would not survive. I was collecting my son from playgroup in our village hall to the rear of the doctors' surgery. Roger had received the news first and had asked if someone could get hold of me to let me know. One of the receptionists ran around to the playgroup to try and catch me before I left. I cannot describe how I felt. I was sat in my car just about to leave when she broke the news, a mixture of relief and foreboding came over me and I crumbled over the steering wheel in tears.



On arrival at Killingbeck everything fell into place. We were put at our ease and made welcome. The various tests were carried out without much resistance from Alexandra. I stayed with her until bedtime and then left her to sleep. Her surgery would take place at 8.30 am the next day.

She was in theatre for four and half hours. We sat on the ward and waited for the call from Intensive Care. At last we could go to her. We were met by one of the surgical team who explained what they had done. She had a large hole between the ventricles which has been patched. However, when they were able

to look more closely at the heart she did have a mitral valve but it was very poorly formed. An attempt to repair this valve with tissue had been carried out and the hole between the Atria was left open. They were pleased with what had been done. It was now a case of waiting.

Within twenty four hours they tried to take her off the ventilator, she struggled with this and appeared to fight it. This was not unusual with children with Down's. Twenty-four hours later the monitor registered that something was not right. The emergency medical team was summoned, she was sedated heavily and an echo cardiograph was taken. The consultant surgeon came to see us and explained that the repair to the valve had broken down. He said he would return her to theatre the following morning and try again but he felt that the tissue was too fragile and there was a possibility that it would not be possible. He gave it a 50/50 chance of success.

She returned to theatre the following day. Within two hours of her return to Intensive Care it had broken again. Another echo cardiograph was taken and shown to the

surgeon who was in theatre at the time. The medical staff thought that further surgery would not be advisable. The alternative did not sound very reassuring. Mr Watterson came to see us as soon as he was able. He explained they were faced with either trying to keep her condition stable and she would remain in hospital until she died. Her expected life-span would be from one day to perhaps 3 or 4 months, or they could return her to theatre where he would attempt to put in an artificial valve. If that was successful he would expect that she could get to her early teens without having to replace the valve.

On the down side she would have to take Warfarin for the rest of her life and we would have to protect her as much as possible from contracting bacterial infections. She would also have problems if she broke any bones because of the internal bleeding caused by such trauma and the difficulty with clotting caused by taking Warfarin. There was no choice for us we must let her have a chance at life. We were warned that he did not know how she would cope with another major operation in such a short space of time and this time he only gave her a 30% chance of even leaving the theatre alive. Apparently if the heart is stopped too many times in quick succession it eventually decides not to restart. We were advised to go and spend some time with her as this may be our last chance.

The next hour was heartbreaking. Although there was only one other child and its parents in the unit I felt our most precious moments with her were played in front of an audience. We had to say goodbye (just in case) without giving in and although she was sedated it was lifted a little so she could respond to us. She squeezed my finger and reached her arm up to cuddle me. The nurses took photographs of her. We went with her to the theatre doors.

She was in theatre three hours. When they returned her to Intensive Care Mr Watterson came to see us he felt the operation had been successful and her heart had started first time off the heart/lung machine but the next 48 hours would be critical. She made it and then removed herself from the ventilator!

She remained on Intensive Care for a further four days making ten in all. She was then transferred to a high dependency unit on the ward. She was very weak and had picked up an infection in her wound and a tummy bug and also an ear infection. Her peripheral veins were almost nonexistent and it was difficult obtaining blood from her. The surgeons and medical team wanted the arterial lines removed because of her susceptibility to infection. She remained on the diuretic and for five days was given antibiotics. She was then started on Warfarin. Warfarin and antibiotics do not mix.

We were discharged home after a total of four weeks in the hospital. She was still quite weak but there is only so much they can do in hospital. Post-operatively she still did not gain weight.

We visited Killingbeck last December when her heart was checked she was fine. The diuretic dose was halved with instructions to stop in February. When the diuretic was

stopped in February she began to gain weight quite rapidly. She is now 18 months old and progressing well. She is lively happy and gaining strength.

She has very mobile hips which were splinted in hospital this has delayed some progress here but we are confident she will walk one day. She rolls and crawls about quite quickly and is just starting to pull herself up onto her knees and climb on things. So far as we can tell she has no discomfort from her heart condition and at the moment it is not restricting her from anything. I am very conscious of taking her into areas where she may pick up bacterial infection i.e. playgroups, schools, crowded supermarkets and shopping centres. If we can get her to five years old without her suffering from a serious chest infection or similar then we have half the battle won.

She is susceptible to ear infections and over the winter these have caused some problems in that oral antibiotic cannot be used. It has been a long process getting her over these. Fortunately, we have not had to return to the hospital for a stay.

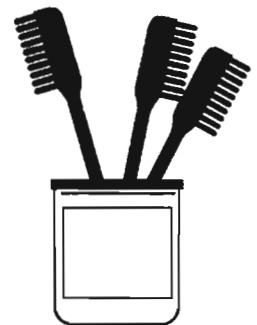
We are very pleased with the outcome of her heart surgery. We are looking forward to a happy future with our family. We will take whatever life throws at us because having a child like this makes us stronger and more determined to deal with it and carry on.

*Judith Bates
Bradford*

Tips

Superbrush - Triple Headed Toothbrush

Adult, Junior and Infant sizes.



This is a special toothbrush with three heads which allows teeth to be brushed on the inside, outside and chewing surface all at the same time.

This makes brushing both easier and more effective and assists in reaching difficult areas.

Particularly useful where children find having their teeth brushed, unpleasant, hateful or any other adjective you wish to use.

Contact manufacturer for local stockist details :

Dent O Care Oral Hygiene Products
7 Cygnus Business Centre
Dalmeyer Road
London
NW10 2XA
Tel : 0181 459 7550

Michael's Story

I arrived home one Friday from visiting my mother and flicked on the answering machine whilst unpacking the baby from the car. The messages ticked over, nothing unusual, I could return the calls later... then, suddenly, the last message stopped me in my tracks. "This is Dr....'s Secretary. Can you bring Michael to the hospital on Monday for his operation?"

I had to sit down as I suddenly felt faint and was shaking. My husband, Nick, and I had known since Michael was born that he would need cardiac surgery when he was between 6 and 10 months old to repair three holes in his heart (a VSD, ASD and a PDA.) Living with this knowledge was a terrible strain. In one way, we could not wait to get it over with but now the time had come, I was filled with dread. How would we cope with the stress? What if we lost him, or he suffered brain or kidney damage? The latter, we were informed, were rare but possible side effects of going on a heart-bypass machine. Yet we knew that without this surgery he would almost certainly die young and would suffer as his heart and lungs slowly failed. So we had no choice. In one respect, we were lucky to live near a Regional Children's Cardiac Unit which is one of the best in the country.

At 6 months old, Michael was still breast-feeding. He had thrived on it and escaped all of the winter colds and 'flu doing the rounds, so I wanted to keep my milk supply going whilst he was recovering in Intensive Care and then continue feeding him myself afterwards. Besides, he refused to take a bottle! A quick phone call to my breast-feeding counsellor, Deborah, resulted in the immediate delivery of an electric breast pump which enabled me to have a practise before we went in. Deborah was marvellous throughout and was on hand to give me advice over the phone in the initial stages when I got used to expressing. I would strongly recommend any breast-feeding mum to take her own pump in with her. Electric pumps were unavailable on the paediatric ward. To get one would have meant going to the SCBU/Maternity wards, a flight or two of stairs and umpteen corridors away, which would have been very tiring every four hours, especially at night.

On arrival at the hospital, we were fortunate enough to be given a room in the parents' accommodation directly above the ward. This had been built by the Trust for Sick Children in Wales, a charity we will definitely support from now on. After the hustle and bustle of the ward and the overpowering heat - I would advise packing summer clothes whatever the time of year! - it was like stepping into a cool and peaceful oasis. The rooms were equivalent to those in a luxurious hotel and there was a beautifully furnished communal lounge, a kitchen with microwaves,

cooker and fridges/freezers, and even a laundry room.

I was able to set my breast-pump up in my room and, once I got used to it, I actually found it quite relaxing. It meant that every four hours I could sit quietly on my own away from the stress of the ward. I even managed to read two novels: the first time I'd read anything since Michael's birth! To help with the letdown reflex, I used to look at some photographs of Michael, a trick which worked every time. I was determined to keep my milk going and so forced myself to eat and drink regularly - difficult to do when I was worrying so much, but necessary. Bananas and jam sandwiches proved excellent snack food. (Incidentally, when Michael began solids later on he loved bananas but I haven't tried him on jam sandwiches yet!)

Ward staff provided sterile collection bottles and stored my milk in the fridge or freezer so none was wasted. They fed the milk to Michael via a nasogastric tube whilst he was recovering.

Michael had his operation on the Wednesday. I was able to hold his hand and stroke his head whilst he was given the anaesthetic gas and I watched him to go sleep with a little smile on his face which didn't need to be covered with a frightening mask. We then had a very anxious four hours while we waited for the phone to ring and tell us he was out of theatre. Michael was then on the Intensive Care Unit until the Saturday.

Back on the Children's ward, Michael continued to be tube fed until the following Tuesday. I had tried to put him to the breast when I was holding him, but he seemed to have forgotten

what to do. I was really worried until one of the nurses explained that all of the drugs babies are on can make them feel "spaced-out". By Tuesday afternoon, the drugs must have worn off as Michael started feeding again. After that, his recovery was rapid. Now all the worry was over, the nurses urged us to make the most of their excellent baby-sitting service and go out for an evening meal together. We hadn't done this since Michael's birth, so we planned to go out on Friday - but after the Doctors' round on Thursday we were told Michael could go home on Friday! So much for our night out! But we didn't care. We were just delighted to have our son back with us and to have a future to look forward to with him.

Special thanks to : everyone at the hospital, Deborah James, all of our friends from my NCT Group for their support, cards, flowers and prayers, and to Chris Stringfellow from the Down's Heart Group in South Wales.

*Susan Davies
Cardiff*



Hannah's Story

One question people always ask me about Hannah - "Did you know? Did you have the test?" Given the time, I explain that no, I didn't have the test - to me, all life is precious, and having previously lost fourteen pregnancies I was not going to take any chances; but yes, I knew.

We don't have to be royal to have an annus horribilis, do we. Mine was 1990. In that year my marriage disintegrated; our home was flooded by a burst water main; I conceived an unplanned (and as far as my husband was concerned, unwanted) pregnancy; I turned 40; and, shortly after moving house, we survived a serious chimney fire. I just KNEW there was more to come!

Hannah was born three weeks prematurely, by elective epidural Caesarean section, and on medical advice and prior agreement, I also underwent tubal ligation. When they placed her in my arms I suspected all was not well, but said nothing.

She was born at 1.30 p.m. on 6th December, I did not see the Consultant Paediatrician until 5.30 p.m. on 8th December. In those 52 hours it had become obvious to me that Hannah had Down's syndrome, and although the midwives and other ward staff must have been aware of it they were not allowed to acknowledge it; how difficult it must have been for them, having to comfort and encourage me, without stating the obvious. When I



finally spoke to the paediatrician, I got the distinct impression that I knew more about the syndrome than she did. That initial handling of the testing and diagnosis was diabolical (but by no means unusual), and it made a traumatic event much worse.

I fell in love with Hannah instantly - in truth, I had been loving her since the moment of conception, and the extra chromosome merely increased my maternal instincts. However, those early days were a nightmare. Telling family and friends; abandoning breast-feeding as too stressful for us both; having to put on a brave face when inside I was screaming; and, of course, trying to recover from surgery! I can remember only two positive things from that time - firstly, I was asked if I wanted to see a social worker, whose successors later proved worth their weight in gold; and secondly, I remembered a boy in my son's playgroup had Down's Syndrome, and his mother responded immediately to a desperate note which just said "Help!".

During those two weeks in hospital I asked several times if Hannah's heart was O.K., and each time the doctor listened with a stethoscope and reassured me that everything was fine. How gullible I was then - I've got a lot wiser since and have learned two valuable lessons - 1) ALWAYS get a second opinion, even for a pimple on the nose! and 2) when people say "Don't worry, at least it can't get any worse", I know that it can get much, much worse!

On 27th December the Health Visitor made a routine home visit to introduce herself, and weigh the baby. When I undressed Hannah the Health Visitor said she thought she looked blue. "She's always like that" I replied; to which the Health Visitor suggested I get her heart checked. "I've had it checked", I said. "Get it checked again", she said - calmly, but firmly! The next day I took Hannah to our G.P., who thought she could hear a murmur, and referred

me to the local hospital's Consultant Paediatrician whom we saw on 1st January. He was unable to successfully listen to her heart or check her pulse - instilling me with a complete mistrust of anyone professional! - but he did manage to telephone Harefield Hospital to arrange for Hannah to be seen there on 3rd January - my son David's fourth birthday.

Following the Caesarean I was still unable to drive,

and enlisted the help of one willing soul to take us to Harefield and another to collect us later. Even at that young age Hannah was most uncooperative, and although the doctor was pretty sure it was AVSD, we were asked to return the following day to repeat the tests, if necessary under sedation. I remember having to return home and enter into David's birthday celebrations, entertaining visitors as though nothing was amiss.

The reality of it was brought suddenly home to me the next day, when the AVSD Complete diagnosis was confirmed and options explained. The operation had an 85% success rate, they proudly told me -but all I could think of was the 15% failure rate. The extra chromosome had until then seemed an enormous problem, but it paled into insignificance when I was faced with the prospect of losing my baby. The next five months were awful, my main memories are of the divorce proceedings, of David's problem behaviour as a result of the circumstances around him, and of my seemingly nonstop tears. In short, I didn't cope very well! At some point during these months Penny

Green came on the scene, I saw a cardiologist from another hospital who also recommended surgery, and although I still felt very pessimistic about it I decided that I had to give Hannah a chance. To complicate things even further, I had to arrange for David to stay with a foster family whilst I stayed in the hospital with Hannah, and it was at this time that the social worker really began to earn her keep!

The 'phone call came on Wednesday 5th June 1991; could I take Hannah in the next day, for surgery on 7th. I had to take David to the foster family and it was at this point that I fell to pieces and it was left to friends to pack our bags and I was so very grateful for one friend in particular - Dora - who stayed with me that night and remained with me all the next day, and came back to be with me from the time Hannah went into theatre at 10.30 am., until she was returned to SCBU at 5.30 p.m. My parents came from Lincolnshire to join the vigil, and the leaders of our church were also there. I later learned that the church had opened its town centre Citadel whilst Hannah was in theatre, so that well-wishers could go in and spend time in prayer for her. It worked!

I'd prepared well for the sight of all the tubes and the ventilator, but I was quite shocked to see how pink she was! After a brief word with Prof. Yacoub, I settled down in the chair by her cot - there was nothing I could do for the next day or two, and it was a great relief when the ventilator was removed on the Monday (substituted with a head box) and I was able to hold her, and give her a bottle feed. Whilst she was in Intensive Care I slept in one of the bedrooms at the hospital, but once she was back on the ward I was able to sleep on the floor beside her cot.

Throughout my stay at Harefield my friend Dora visited every day, and also did her best to co-ordinate my other visitors who always arrived at dinner-time and insisted on escorting me to the dining hall, ensuring that I ate at least one meal a day! When all the lines and monitors were removed the foster family brought David to visit, and he sobbed tears of relief to see his sister again. Hannah was a model patient, her only setback being anaemia, which a blood transfusion quickly put right. I had been told to expect her to be in hospital for four to six weeks, she was discharged after eleven days and hasn't looked back. Hannah is now a very healthy little girl, Harefield want to check on her just every other year and consider hers a very successful repair, even by Prof. Yacoub's standards. Not a day goes by without me thinking how lucky she is, and how lucky I am.

Those months, and the two weeks in Harefield, had a profound effect on me and I still have nightmares, waking and sleeping. With hindsight, perhaps I would have benefited from counselling. It helps to talk about it, even now. When I look back, I can't believe we actually endured and survived it. I'm sure it's made me a stronger person, and if nothing else it taught me that Hannah with Down's syndrome is better than no Hannah at all - a valuable lesson, as once it had sunk in that Hannah was no longer in grave danger from her heart condition, I then had to work through the process of accepting the learning disabilities; which, to be honest, is an on-going process!

Hannah's general development has been slow.

She was very small for her age, she was loathe to weight-bear and didn't walk alone until she was four. At the time of writing she still has no speech other than Mummy, Yes, No, Hello. But her level of understanding is very good, and she uses Makaton and Signalong to communicate. On the first day of term September 1995, she walked eagerly into mainstream school with a very proud big brother. I thought then that we were settled, but oh! no:- In December our lives underwent another major upheaval, when we moved from Hertfordshire to Kent to be with my new partner. I was concerned that I wouldn't find as good a school for her, but as it happens the move was most fortuitous as far as Hannah is concerned; the village Primary, although inexperienced with special needs and very cautious at first, have gone the "extra mile" to accommodate her; the Headteacher remains personally interested in her integration and welfare; all staff and pupils have had elementary instruction in Makaton; her Teacher has a very positive attitude towards her; she is very popular amongst the children; and her Classroom Assistant is BRILLIANT! Hannah is learning, not just academic skills such as counting and reading, but how to work and play alongside her peers, how to take her place in the community.

I too have learned a lot since that December day nearly six years ago. My attitudes have changed - for the better, I hope! I have a different outlook, different priorities. Life since Hannah has not been easy, her special needs and uncertain future have caused me many a sleepless night and tear-stained pillow. But I cannot imagine life without her - we all love her very much indeed, she enriches our family and our experiences, every day is a new adventure and a fresh challenge.

In my unbiased opinion, Hannah is a very pretty child, with a smile to charm your socks off! She has recently had a growth spurt and is no longer the smallest in the school. She is generally very happy; she is fiercely independent, with a stubbornness and determination that I'm told she owes more to her mother than to the chromosome! She is very interested in all that goes on around her, she is very quick to learn new things - the naughtier it is, the quicker she learns it. She loves books, painting, swimming, climbing, videos, Lego, and water play. I sometimes envy her, she gets so much out of life!

Even now, I look at other "normal" little girls of her age, and think enviously "I could have had a child like that". But it doesn't last long, and deep down I know I wouldn't swap her; she has a smile on her face before she even opens her eyes in the morning, and I am reminded of a quote: "We used to look " back with regret, and forward with fear; now we enjoy each day as it comes .

On 8th June 1996 Barry and I were married; and as I walked down the aisle with David on one side and Hannah on the other, there couldn't have been a happier, prouder woman.

*Joanna Simms
Rochester*

Christmas Card Competition



This may only be the Spring newsletter, but we need designs for our 1997 card NOW!

A prize of a £10 voucher and a £5 McDonalds voucher will go to the winner and the winning entry will be used on the 1997 Down's Heart Group Christmas cards.

(16,000 were printed and sold in 1996)

Five runners up will also receive £5 vouchers donated by McDonalds so get those pens and pencils busy!

COMPETITION RULES

Entries must have a Christmas theme and include the Down's Heart Group logo somewhere in the design. All entries should have the entrants name, address and age shown clearly on the back. The competition is open to all Down's Heart children and young adults, and their siblings. Entries should be sent to our National Office to arrive by the competition closing date May 31st 1997. **You may submit as many entries as you like.**

Downside Up - Update

Following mention of the Downside Up Charity Bike Ride in the last newsletter, Veronique Garrett has sent in the following articles. The first was written shortly after the bike ride, the other explains more about the organisation.



Recently fifty of us returned from Moscow having completed our first fund-raising event for Downside Up. We ranged from seven to fifty and came from as far afield as Hong Kong, Korea and even Australia. Our back up team included a cook, three masseurs (indispensable after seven hours on a bicycle), a bicycle repair man and three drivers.

Padded shorts were a must (Russian country roads are not the smoothest) and every evening after cycling hard during the day 'deep heat' was applied rigorously.

On our second evening, having had a glorious day in the saddle, we had the great pleasure of seeing Tania Jushkina (the Russian lady who came to London last February) at our hotel. Unfortunately she was unable to bring Jasmina, however we were able to catch up on all the news of how she was doing.

Our final stretch of cycling, under police escort, culminated in a steep climb to Red Square where we were greeted by happy faces and a welcome drink. We all completed the ride, be it on our bicycles as planned, or by foot as in the case of one cyclist whose bottom became rather sore after the first days exertions.

The following day, before leaving for London, I was shown around one of the orphanages in Moscow where I had the opportunity to meet several children and young adults with Down's Syndrome. It made me realise how important it is for these children to have a day care centre where the expertise and knowledge of professional can help them develop to their full potential.

Many factors prompted us to establish Downside Up. But the single most important was the birth in June 1993 of my daughter Florence who has Down's syndrome.

Since we returned from Hong Kong to Britain at the end of 1993, we have been staggered by the excellent support available here. I am thinking in particular of those organisations - the Down's Heart Group, the Down's Syndrome Association, the Sarah Duffen Centre, as well as local authority support such as portage - that we have had most contact with. Through this contact we have witnessed at first hand their invaluable contribution to smoothing the often rocky path that seems to stretch without end before parents of children with Down's Syndrome.

Another important factor was my brother's move in 1994 to Moscow. As Florence's uncle, he inevitably took a close interest in how Russia approached Down's Syndrome. It was clear that there was great scope for improving the quality of life of Russian children with Down's Syndrome. We were determined to do what we could. Four of us - my brother and I, and two friends - decided to set up

Downside Up, a British charity for Russian children with Down's Syndrome.

Our mission statement was the least of our problems. We were all clear what we wanted to do. Establish a day-care centre to provide the necessary support and early intervention, widely used in Britain, to enable parents to bring up children with Down's Syndrome in the community.

In Russia there is next to no provision for parents of children with Down's Syndrome, or for that matter of any child with special needs, to bring up their children at home. 98% are put into orphanages at birth. Of those nearly half die before their fifth birthday. Downside Up are initially targeting the 2% that have the courage to go against all professional and social advice and bring up their children at home.

With counselling for parents at birth, portage from an early age, physio, occupational and speech therapy, we hope the centre will help smooth the path of these brave parents and help their children reach their full potential.

Our objective decided, we had many bureaucratic hurdles to overcome. We are particularly fortunate that one of our trustees is a lawyer. He has helped us pick our way through the labyrinth of establishing charitable status here and in Russia, setting up bank accounts and dealing with countless other apparently impenetrable legal questions.

Having established Downside Up, our main focus now, as for most charities, is fund raising.

Our first event, the one which launched us, was a bike ride last summer in and around Moscow. Fifty-two participants left from a small town outside Moscow and rode for three days to finish in Red Square. Of course the event was not without its problems. Co-ordinating fifty two willing but pretty disorganised cyclists for three days in a country where things are done differently was a major challenge. But with the help of a crew of volunteers we all arrived back in one piece.

By February, with hard work, perseverance (as regards the Russian authorities) and a bit of luck, we hope to have our centre up and running. We have had many offers of help, from Russians and foreigners alike living in Moscow. We also have the brilliant Claire Lyons, our centre director, who manages the charity from Moscow.

In the meantime we have concentrated on a portage programme and other therapeutic services for thirty two children, translating educational material into Russian, and family support. Four of our children, the first of many we hope, have started in integrated kindergarten classes.

We have many plans for the future, but for the moment we hope to give Russian parents of children with Down's Syndrome an important freedom: the freedom to bring up their children in the community with the support they need to lead happy and fulfilled lives and to fulfil the potential we know they have.

Veronique Garrett
London

DHG Members with Inoperable Heart Conditions

I thought hard about the heading for this article having previously used the heading 'Children with inoperable heart conditions'. Of course many of our members are children but many others are teenagers and adults. Just about all the parents, like myself, having been told not to expect their infant to survive for more than a year or two. Many are living very full lives as we read in Peter's Story in the last newsletter, (Great photograph, what a handsome young man!) and the letter about Matthew included in this edition on page 18.

It isn't plain sailing towards adult hood for all our members and some begin to run into difficulties earlier becoming symptomatic with spells in and out of hospital, worrying parents sick and prompting further gloomy prognosis from medics. But still they continue to amaze everybody with their bravery, sheer tenacity and determination to fight back to health and get on with life. As Vincent's mum wrote, "He was crying to come home by 10pm! He amazes everyone' he is up and about and taking an interest in life again I am planning to take him to Disney, Paris for a 3 day break end of September which he is looking forward to."

Note : Vincent did go to EuroDisney in September. - Editor

Autism

Thank you for sending us your accounts of autistic tendencies. Copies have been forwarded to Dr. Jennifer Dennis, as she requested, in support of her research project. In her reply to us she says that she thinks that they may at last be getting somewhere towards investigating autistic like tendencies occurring in Down's Syndrome in a more coherent way. There are now three doctors showing an interest and she hopes to have some more news for us in due course. In the meantime if anyone else has experience of autistic tendencies Dr. Dennis would be very interested to receive more histories from us. Please continue to send them to me.

Why is it necessary for us to recognise autism?

Many of us have tendencies which may be regarded as slightly eccentric, a bit obsessive, fussy - insistent that things are done our way, over anxious - easily stressed, resistant to changes and sticking to routine, a lack of awareness towards other people, tendencies which may be included within the lists and charts identifying patterns of autistic behaviour. But when perhaps six or more tendencies exist in one person to a degree that inhibits their development and at times their happiness and relationships with other people, then it may be helpful to consider the possibility of autism. Of course, as with most conditions, there is a vast range of degree to which a person may be affected. When handicapped with Down's Syndrome there is a very real danger that autism will not be picked up by parents, or by professionals, as an additional handicap. Once autism has been recognised, as Steven's parents experienced, extra help can be available, "the whole attitude towards education has changed and become more considerate towards Steven's needs, hence the provision of One to One for 20 hours per week."

Steven was 14 years old before being assessed as autistic and qualifying for extra help and a change in the approach to his education. Not all children are so profoundly affected as Steven or my own son Alex. At the other end of the scale, children may be slow to learn and difficult to teach because they will choose to be interested in a very limited programme, from which they do not want to expand. They may be very "stubborn" about this and agitated if faced with sudden changes to their schedule or the school day. They may find communication difficult, have limited vocabulary and are perhaps not interested in rewards such as sweets or a desire to please, "clever boy / girl !"

Other children may be more profoundly affected by the condition, parents describe them as "different" and can be surprised to find that many other children are in fact very similar to their unique" child. A friend who teaches at a school for children with special needs tells me that several of their pupils with Down's Syndrome also have autistic tendencies. She has attended a number of training events to better understand the condition and meet pupils' needs more effectively.

National Autistic Society - 0181 451 1114

Help line - 0181 830 0999

Booklet : Could this be Autism?

Society for Autistic Handicapped - 01536 523274

Books : Autistic Children A Guide for Parents - by Lorna Wing
Published by Constable, London

The Other Side of Autism, a positive approach - by
Stella Carlton
Published by Self Publishing Association.

Wendy Tucker

Representative for Inoperable members



Vincent Lucy

Children's Heart Federation Trip to Lapland

On Saturday 14th December a hotel near Gatwick Airport was the venue for a gathering which seemed rather unusual amidst the surrounding pre-Christmas office party revellers. For the VIP's attending this meal where all under eighteen, and the entire group of some forty people had all retired to their rooms by 10.30pm. It wasn't that we were lacking in Christmas spirit, in fact quite the reverse, we were off to visit Santa himself the very next day, and had a very early start ahead of us.

The Down's Heart Group member lucky enough to be going on the trip was eleven year old Jennifer Godbold from Gosport, and I was selected to act as her escort. We met for the first time at the hotel, but were soon chatting away like old friends and eagerly looking forward to our adventure next day.

We were all up bright and early for the coach journey to the airport where we checked in, waved our goodbyes to Mums and Dads and then boarded the plane. The flight took three and a half hours during which time we were fed our second breakfast of the day, watched the in flight movie, and chatted to the other members of our party. This was Jenny's first experience of flying, but she was not at all concerned, and spent most of the flight getting to know Rosie, another little girl with Down's Syndrome who was in our group.

Our arrival in Lapland was breathtaking. The landscape was white as far as the eye could see, and as we got off the plane there was a steady fall of snow. It was as if we had entered another world, having left England on a dark, damp morning, and the faces of the children reflected the wonder that we all felt.

Our quest was to find the real Father Christmas, and having spent some considerable time getting ourselves into the snowsuits and boots provided, we didn't want to waste any more time. We had heard a rumour that he might be found at a reindeer farm some distance away, and decided to take advantage of a ride on a somewhat unusual mode of transport, sleighs pulled by skidoos.

As we sped along through the snow covered countryside, darkness began to fall and we remembered that this far North they have only a few hours of daylight at this time of year. Part way along our route we stopped at a tent (much like an Indian tepee) where there was a blazing fire and we had warm drinks, then we were on our way again, a long crocodile of sleighs disappearing into the distance before us.

We knew that we must be getting near the reindeer farm when we suddenly came across a number of elves dressed in highly decorative costumes. One of them asked if we were looking for Santa. The children shouted yes, and then he told us the sleigh in front was going the wrong way and pointed us in a different direction. We weren't sure what to do, but the children had been warned about 'Tricky Dicky' and decided this must be him, so we ignored his advice.

A few minutes more and we knew we'd been correct, for there in front of us lay the reindeer farm. A magical setting of log cabins and traditional buildings beside a frozen river. The whole area was crisscrossed by a

network of pathways flattened in the snow, and lit by nightlights contained in lanterns moulded from the snow.

We were free to explore at our leisure, and there was plenty to see and do. Down by the frozen river there was the opportunity to go ice-hole fishing, which is apparently a popular pastime in early Spring. There were rides on sleighs pulled by reindeer, husky driving and the opportunity to drive a skidoo - Jenny and I liked this one and went for a second go - as well as little igloos and snowholes built in the snow that you could go enter.

The staff were very helpful, and one encouraged Jenny and Rosie to try some snow shoes out. They had a practice run on the compacted snow of the footpath, and when they'd mastered it he sent them on to a large patch of soft snow. It looked so easy as they walked, and then ran along the top, and it was only when Jenny lost her shoe and I tried to help that I realised just how deep the snow was - I stepped across and sank up to my thigh. But help was at hand and the young man rescued Jenny and gave her a piggyback as he crawled across the snow on his hands and knees.

Lunch was a somewhat strange affair cooked on open fires in a large hut, and was eaten balanced on ones knee which was a bit tricky, but it was an ideal opportunity to warm up. And when we were sufficiently thawed out we decided to make our way over to a large log cabin where we had seen a lot of activity throughout the day.

Our patience was rewarded, for sure enough this was the place where Santa really was. Jenny and Rosie went in to see him together, and we adults were allowed to accompany them. It was wonderful. It was immediately obvious that this was indeed the real Father Christmas for he knew straight away who the girls were, and he sat them beside him at the fireside. I think they were slightly overawed to be meeting him in person, but he was very kind and friendly and gave them both a special present.

Soon afterwards it was time to board the coach for our return journey to the airport and the flight home. As we crossed the airport tarmac we waved goodbye to the elves who'd come to see us off, and as we climbed the steps onto the plane, we looked across the airfield and saw the Northern Lights - a fitting end to an incredible day.

A rather sleepy Jenny was met by her parents when we landed at Gatwick. It had been a very long day, 6.30am start and midnight before we got back to the hotel, but it was a memorable experience and I will never forget the look on Jenny's face when she saw Santa (I just wish my camera hadn't decided to play up in the cold then I would have had some photos).

Many thanks to everyone at the Children's Heart Federation, for what was a very well organised event, particularly Hugh who was our group leader for the day. I would also like to thank Jenny for allowing me to act as her escort, I had a great time and she behaved perfectly all day, it was a privilege to share the adventure with her.

Lastly a hello to Jenny and Rosie, and their families.

Penny Green

Research News

A few years ago, some of our members volunteered to give blood samples to assist in a research project being undertaken at St. Mary's Hospital in Paddington. The Director of the project, Dr Anna Kessling, has since moved to the Kennedy Galton Centre where the work continues. Although she has written directly to those families who actually took part in the study, she has also sent us the following progress report in order that all our members can be informed of developments.

Dear Members of the Down's Heart Group,

Sometime ago many of you very kindly allowed us to use blood samples from your family to help with our research into the reasons why some children with Down's Syndrome get problems with their heart development. When we collected the blood samples we promised that, once we had published the results of our study, we would send a copy of the scientific paper to each of the families who had helped in the study.

The paper is not the solution to the cause of congenital heart defects in Down's Syndrome, but it is a very important start on the road to the understanding of why these heart defects happen in some children and not in others. We looked at genes all over chromosome 21, using small differences in the genes, which are present in the general population, to tell apart the three chromosomes that a child with Down syndrome had received from their two parents.

We then compared the "versions" of the genes received by the children with and without heart defects to see if there were differences between them, and indeed there were. Perhaps unsurprisingly, the biggest difference was in a gene we might have expected to be involved in heart development, about which the paper is written. This is the gene for part of one of the collagen molecules. You may be familiar with collagens as being involved in the formation of skin and bones (and being in some cosmetics).

This is a different kind of collagen, which we know is present in the lining of the heart and is also known to be involved in the healing of wounds. So it's just the kind of gene you might expect to have something to do with the

joining together of parts of the heart, which happens during development, and which may be altered in Down's Syndrome.

Our work suggests that the "versions" of this gene from both parents may decide whether or not a child who has Down Syndrome also gets a heart problem. This work identifies this gene as being likely to influence heart development in Down's Syndrome. It is a very encouraging springboard for more research to discover how it works.

We are now studying the gene further, to tell us what the "fine print" differences are, which may cause the heart problems, and how they work.

Our work has influenced the views of scientists all over the world on how heart development may be influenced by genes in Down's Syndrome. Do not be discouraged if progress seems slow. The development of the heart is a very complex process and will not be solved very quickly. But it is only with the help of families like yours that we can continue this important research. Our best research efforts continue. Thank you again for your help.

Yours sincerely,

*Anna M. Kessling
Professor of Community Genetics
Director, Kennedy Galton Centre*

Children's Heart Federation Conference

This years conference of the Children's Heart Federation will take place from the 12th to 14th September in Newcastle.

The conference will focus on the theme of diagnosis. Further information will be available later in the year.

Make a note in your diary now as this will be of particular interest to many members.

PLEASE HELP US

by saving stamps, postcards, ring pulls and Greetings cards

We have volunteers collecting all the above to fund-raise on our behalf, but they need your help!

Please save used postage stamps (preferably on the envelope), postcards (used and unused), ring pulls from drink cans and old greetings cards (just the front picture) and send them to the following :

Stamps and postcards

Val Roberts

Greetings cards

Lynn Hemmings

Ring pulls

Chris Stringfellow

(See South Wales page 4)

6th World Congress On Down's Syndrome

PRESS RELEASE

From 23rd to 26th October next the 6th World Congress On Down's Syndrome is going to be held in Madrid's Palacio de Congresos.

Scientists, professionals, people with Down's Syndrome, their family members and associations have within their reach in Madrid the most important scientific and social event relating to Down's Syndrome that takes place every four years in one of the world's cities. The previous Congress was held in Orlando (USA) in 1993 and the next one will be in the year 2000 in Sydney (Australia).

The World Congress aims to take stock of advances made during that period of time in each of the disciplines relating to Down's Syndrome (genetics, medicine, psychology, pedagogy, etc...) at meetings to which the foremost world specialists have been invited as speakers.

In addition, there will be more than thirty optional workshops dealing with the specific applications of scientific discoveries for the prevention, health care, education and improved quality of life of people with Down's Syndrome, as well as the most encouraging personal testimonials and experiences and the most innovative and controversial intervention practices.

There will be a full schedule of parallel activities, with an interesting social and entertainment programme which

will include video rooms, film sessions, children's nursery, excursions and other social events.

Simultaneous translation from English into Spanish and vice versa is guaranteed at all meetings and workshops.

It is worth taking advantage of this unique occasion, which will probably not occur again for many years. It promises to be an event of real importance and of special interest to doctors, psychologists, educators, teachers, speech therapists, psychotherapists, psychomotor therapists, social workers and other professionals concerned with Down's Syndrome, as well as to parents, family members and to the people themselves with Down's Syndrome.

In order to receive the second call brochure on the Congress, which will include registration and booking forms, together with information on fees, hotel accommodation, travel, etc., the pre-registration form in the first call brochure should have been sent beforehand to the Official Agency of the Congress and this can be requested from:

VIAJES IBERIA CONGRESOS
c/ San Bernardo, 20-6° D. MADRID-28015-SPAIN
Tel.:34-1-532.81.37. Fax: 34-1-522.34.18.
E-mail: congresos-madrid@v-iberia.com

Jasmina back in UK

You may have read in the Sunday Telegraph of January 19th that Russian baby Jasmina and her mother Tania are back in this country. They were invited back by Martin and Patricia Smith from Haywards Heath, with whom they are currently staying.

The purpose of the visit was give Jasmina the opportunity to progress further with her development, and we are happy to report that her progress in this area is good. Sadly her health is still causing many problems, and since her return in November she has had several stays in hospital due to illness. They have now identified that she has a problem with her immune system and are giving her medication to assist her in fighting off infection.

She has attended Great Ormond Street Hospital for an outpatient clinic, and they have confirmed that the problems with her leaking valve remain and that surgery for valve replacement will be required in the future.



Fund-raising Update

On this page we feature some of the fund-raising events that have taken place since the last newsletter, as well as forthcoming events. We can't include all of them, but whether or not your event is mentioned, we do of course greatly value your support and would like to say a public 'THANK YOU' to you all.

Sponsored Trampoline

Many thanks to Tara Taylor, Louise Taylor and Gemma Baker of year 8 at Chaucer Technology School in Canterbury. Together they organised a sponsored trampoline event and raised £85-10p for the Group.

Sponsored Slim

Our Chairman John Spall is a shadow of his former self having lost 20lb in weight to raise funds for the Down's Heart Group. John, along with three fellow slimmers raised over £300 between them. Congratulations to you all on exercising such will power.

Sponsored Walk

Many thanks to everyone at HM Prison Whatton who sent in a donation of £90. The money was raised by a sponsored walk, and both prison officers and inmates were involved.

Christmas Raffle

Over the past few months we have had tremendous support from employees at Carlsberg-Tetley in Surrey. The latest donation was for £210.00 which was raised by a Christmas raffle and from donations given instead of buying Christmas cards for colleagues.

Moneyboxes

The little card moneyboxes continue to bring in funds for the Group. We still have supplies of these, so if yours is looking a bit worse for wear we will gladly send you a new one. If you know of somewhere that would have a proper collection box, we can also supply these on request.

Christmas Card Alternative

Employees at GE Pallas in the South West sent in £400 which included money raised by donations in lieu of sending each other Christmas cards. Their support of the Down's Heart Group results from parent member Meg Steeds who is one of the employees.

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

James Barker - Bedford (to the video fund)

Aisling Nelson - Streatham

Rosie Steeds - Bristol

Adam Watcham - Cleethorpes

1997 London Marathon



As in past years the Down's Heart Group is very grateful to have the support of several runners in this years London Marathon. They are :

Meg Peasley

Meg is 4ft 10ins, a teacher and mother of two teenagers. She lives in Dibden Purlieu on the edge of the New Forest, and has been running for eight years with the Hardley Runners. Meg is the youngest member of a family of seven, which includes sister Katie (our London Southern Co-ordinator), and is running in memory of her niece 'Bloomsie', the daughter of Katie and our Chairman John.

Tania Stanfield

Tania is a 25 year old mother of two who lives near Bristol and has been running with the Clevedon Club for about one year. Tania already had her place in the Marathon, but decided to run for the Down's Heart Group in memory of her friends little boy Alex Boulton who died recently aged seven months.

John Tyszkiewicz

John is a 35 year old father of three who lives in London and works as a broker in the City. This will be his fifth consecutive London Marathon, although his most recent run was the New York Marathon last November. Amongst his other talents, John numbers juggling and riding a uni-cycle and his next ambition is to swim The Channel.

Mike Dutton

Mike has very gallantly agreed to stand in at short notice after one of guaranteed place entrants was advised that his employer was sending him on a business trip which would mean he would be out of the country for the Marathon. Mike is 39, has four children and works as a Personnel Manager. He has been running since school and ran in the first London Marathon back in 1981, although this will be his first for five years. Like Meg Peasley, he also lives in Dibden Purlieu and is a member of Hardley Runners.

If you would like to sponsor one or all of our runners in the London Marathon, you will find a form for this purpose on page 21.

PLEASE SUPPORT OUR RUNNERS!

Letters to the Editor

Letters for publication should be sent to :
The Editor
Down's Heart Group

Thank You

I felt a need to write one or two things to you concerning the help and love shown to us when Daniel had his operation.

When Dan was young and we learnt of his 'Down's' and heart problem we were, of course, devastated, but the few days leading up to and during his operation was a very upsetting time - in fact a great ordeal.

We needed to talk to and be reassured not just by a person who had been in the situation of a similar heart operation, or a person who had a child with Down's Syndrome, but someone who knew and understood the two together and we were so relieved to hear about "you". We met Sheila from nearby Thornbury and she literally carried us through this new strange period of our lives (it seems like a dream now) and was there when we needed her most.

Dave and I felt such support. No matter how many friends a person may have, and we have many although no family, only a person who has a Down's Heart child is able to talk to and interact and indeed understand the child's needs in the way Sheila was able to befriend our Daniel.

We are eternally grateful for the help of the Down's Heart Group and will always be available to speak to or listen to other parents who need help.

*Pauline Bryan
Bristol*

Penpals Wanted

I am looking for penpals. My daughter is two years old and has had surgery three times. Lauren was tube fed for thirteen months.

Sharon Ferguson



The following letter was addressed to Wendy Tucker following her article in the last newsletter.

Children with inoperable heart conditions

In response to your request in the Down's Heart Group Newsletter I would like to tell you of my son Matthew.

Matthew is now aged 19, when he was born in 1977 things were very different, as Matthew had been placed for adoption and found to be a Down's baby with a hole in the heart, he was taken into care by the local authority. Decisions relative to surgery were taken by Social Services and the decision taken was that Matthew did not have any prospects for the future, as his life expectancy was very short it was decided that there should not be any corrective surgery. After some two years Matthew was advertised in a national newspaper, along with five other handicapped children, for foster care.

After some delay in the fostering process Matthew was three years old when he came to us as a foster child. He did not walk, or crawl but shuffled on his bottom. Advice from the medical experts at that time was that Matthew would never walk, would be doubly incontinent, probably never be able to speak and his life expectancy was very short, he would never be a teenager.

Matthew left school in July this year, he has started at the local S E C and is enjoying the change in his life style, which appears to agree with him. He is currently a fine young man who walks, cares for his own toilet needs and talks endlessly on the subjects of Star Trek, Elvis Presley, The Bill, X Files, WF Wrestling and Gateway Club.

In 1980 when Matthew was just starting to walk, along came a second Down's baby, Steven who was ten days old. Steven came as a short term foster child, intended to be a weekend placement, yet Steven and Matthew have both been adopted and are valuable members of our family.

There have been the ups and downs that you would expect, Matthew knows now that he cannot compete in sports events, he now regulates himself accordingly and has settled down to a steady pace. We must wait to see what the future brings!

Progress seems to have to be fought for. We have seen a programme on Channel 4, this last week, on the subject of Heart Lung Transplant and the selection process being against Down's people. I was told that the transplant would only give a 9 to 12 months relief, as the body would reject and the resulting complications would be terminal. I have discussed this with Matthew who says that he was born like it and does not want to have a transplant.

It is difficult to know what are the hard facts of the matter, if in fact there are any!!!

Hoping that this helps.

*Tony Morton
Spilsby*

Funny Stories Please.

I am currently working on a book about the times when we, as parents and carers, are faced with a difficult situation, and our children say or do something very amusing that diffuses the situation, and brings a smile to our face.

An example of this could be from a personal experience I have had with my eleven year old, Alexis, recently:

Alexis spent nearly six months with her leg and foot in plaster, following a bone graft operation. When the big day came to remove the plaster we arrived at a packed out Fracture Clinic, and nervously awaited the removal of the plaster cast. (Tom, my husband and I, were very worried that Alexis might not be able to walk, as the procedure had not gone entirely to plan.) Having duly waited our name was called and we found ourselves in a small cubicle, with the Surgeon, a couple of students, Ali's wheelchair, a physiotherapist with Tom and I trying to find a square inch to stand in. Ali was intrigued with all the new 'Routes' mapped around her foot and ankle, and she was holding up her leg and studying it hard. The surgeon asked her if he too might have a closer look, and Ali stared at him horrified for a moment; then replied. "No! You've broken it." Pointing out the scars she said "Look what you've done. You be careful next time!"

Fortunately she is now walking, and I often smile when I think of the expression on the Surgeon's face, when Alexis gave him a dressing down so publicly. Needless to say he also saw the amusing side of the situation.

I am sure that many stories like this are told to generations of families. I am publishing this collection to help everyone understand that there are lots of 'Ups with Downs' If you have any stories you would let me consider for publishing, please write them down and send them to me at the address below, or telephone between 18.00 and 20.00 hours. I look forward to hearing from you.

Vonnie Pearce



Vonnie has recently had a book of poems published entitled 'Circles of Love'. The book is available through the Down's Heart Group at a cost of £3.50p. For each book sold the Group will receive a donation of 50p. Orders via National Office please.

Can You Help?

Although we maintain a database of all our members which includes various details relating to their childrens health etc. sometimes we are approached by families for a contact with a more unusual problem, or one that does not show on our database. In these instances it often gets a result if we mention it in the newsletter. It may be that your child has the same problem or that you know someone through another group who child has.

If you can help with contact for any of the following, please get in touch with National Office.

Development Regression

Ruth is five years old and had surgery three years ago. Since her operation her health has improved dramatically but her cognitive and social development has regressed - she no longer talks and her behaviour is more like a one year old. Her Mum would like to hear if anyone else has had this experience. Autism and suspected Epilepsy have been ruled out by tests but the Neurology specialist thinks that the heart surgery was responsible for Ruth's regression although the cardiac team have always disagreed with this.

Irregular Heartbeat

Philip is thirteen years old. He had an AVSD repair two years ago and since then he has developed an irregular heartbeat which is being controlled with medication. His Mum would like to know if anyone else has had experience of this after surgery, although the cardiologist doesn't believe that the problem is related to his heart condition.

Translocation / Food Intolerance

Ashleigh is two and a half, she had successful heart surgery at four months. She is one of the small number of children who have Translocation Down's Syndrome, the particular form she has is a Robertsonian Translocation (21q;21q) which is apparently rare, she is also the first instance of this Translocation in her family as neither of her parents have this variation.

Since birth Ashleigh has had persistent vomiting and poor weight gain, initially this was attributed to her heart condition, but extensive testing has shown that she is sucrose intolerant and it is suspected that further investigation will identify other food intolerances.

Her parents would be very interested to find anyone whose child has the same problems as Ashleigh - preferably all of these problems, but as this seems unlikely, any of them.

Members Page

My name is Ailsa Lousie Pearcey I am 17 years old, when I was born I had heart problems (AVSD). My parents say I was always a fighter, even though I was very small 9lb 4oz at 14 months!!

I would like to share with other people what I feel I have achieved in the past year. I have always been at mainstream school, I have just taken my G.C.S.E.'s I passed English Language., English Literature (my favourite), Geography, Biology, Physics, Chemistry and Keyboard Applications. I failed Religious Studies (but I'm still a Christian) and Child Development.

I enjoy poetry, Sequin Art, Dancing and I go to town with my friends, to McDonalds, the Pictures, Swimming etc.& I am enclosing one of my poems, which was published in the paper (a published poet!!!)

I have recently started driving lessons! So clear the roads Ha ha' I am actually doing pretty well, I drive an automatic car. I start at Bolton Metropolitan College on 16th September, to do a secretarial course, NVQ 2 and hope to get a job after the course. I would like to set up a helpline for young people with disabilities, who need to talk to someone who has had experience of school! especially secondary, changing to college, and all the other things that sometimes you can feel a bit alone about.

I will be 18 in March and I am hoping to get a camcorder to make my own videos.

Being Down's can have its drawbacks, sometimes I wish I was normal and feel helpless, I know I cannot change things, and I am very lucky to be able to do so much it's not me so much, but sometimes other people make life a bit difficult, but I have good friends and family and on the whole a great life, I am hoping to start writing a book about the first 18 years soon, when I can get my head together.



The following letter was sent in by 10 year old Carli White, the winner of our 1996 Christmas Card Design Competition.

Dear Editor,

Thank you very much for the £10 voucher. Yes I am pleased with how the cards came out. I hope you sell all the cards.

I think I will treat Liam to a McDonalds with my vouchers, but Mum thinks I should take one of my friends. Thank you very much again.

Yours sincerely

*Carli White
Rushden*

Congratulations to Carli on her winning design which did indeed sell out. As well as receiving a voucher for £10, Carli's was also one of the first five entries received which each won a McDonalds voucher.

The winners of the other four McDonalds vouchers were Lee Hargreaves, Laura Watson, Joseph Coggin and Rebecca Andrews.

Many thanks to everyone who entered, and to McDonalds for donating the vouchers.

Ailsa also sent in the poem that follows.



A True Friendship From The Heart

Friendship doesn't come that easy
It needs to be worked upon
There is time, devotion and love involved
To make a friendship work.

A friend ship is a secret from the heart
There is time to work and play
Friendship means you are friends forever
If you have a true friend that friend will never go.

Friendship means a lot to me
Everybody needs a friend to share the laughter
and the tears
Sharing secrets with one another
And being there for each other.

Friendship is like a rose
Needs care and attention because without this
It would wither and die
A friend in need a friend in deed.

By Ailsa Lousie Pearcey



We would like to make the 'Members Page' a regular feature of the newsletter in future, a page which can include poems, stories, pictures, letters or anything else you want it to. The only stipulation is that it must be the work of our members with Down's Syndrome, so please send in your ideas, and lets make your page a really GREAT PAGE in forthcoming issues. - Ed.

