



DOWN'S
HEART
GROUP

NEWSLETTER

(Issue No 15)

SUMMER 1996



Russian baby Jasmina Jushkina with her mother Tania

(photograph courtesy of The Sunday Telegraph)

Contacts

National Office

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

National Administrator - Penny Green
contact National Office as above

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

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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 pages 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

Information particularly relating to early education, development advice and research into speech and language development:

Portsmouth Down's Syndrome Trust
The Sarah Duffen Centre
Department of Psychology
University of Portsmouth
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

I'm sorry that it is so long since the last edition of the newsletter, but you will see from this edition that we have been very busy in the first half of 1996. As a small organisation we can only cope with one or two major issues at a time! We are very aware that the newsletter is our main point of contact with many members. We have said to ourselves 'must do better' and we will be making every effort to return to producing three editions each year.

Of course, we can only put an issue together if we have the material and that is where you all come in. We do have a regular flow of your stories about your children's heart operations and we are grateful for those. We would like more about their later achievements, whether it is at playgroup, school, youth organisation or within the family. These provide interest and ideas to other members and also make our wider readership of professionals and supporters more aware of what our children are capable of achieving. So please do think about giving us your news by writing to penny - anything from a full article to a few lines.

Can I say a special thank you to all the members who contributed to Jasmina and Tania's stays with us. Whether it was by making a donation, organising fund-raising or writing or visiting them. We and Tania are very grateful to you all. The response of the membership to the Jasmina Jushkina Appeal was tremendous and without it we could not have carried it through. Jasmina and Tania feature on our front cover and you can read the story on page 6. One of the highlights of this year's Annual Conference held in sweltering sunshine at Bexhill, was to have Tania and Jasmina there and for them to be able to meet many members. For those who couldn't make it, a full report will appear in the next issue.

Have you a budding Van Gogh or Picasso in the family? We need entries for the Christmas card competition and we need them now, so that we can put them into production early in September. So why not add drawing to the list of summer holiday activities. The only two stipulations are that the design must be on a Christmas theme and that the Down's Heart Group logo must appear somewhere in the design. Full details on page 5.



London Marathon 1997

The 1997 London Marathon takes place on Sunday 13th April. If you would like to run on behalf of the Down's Heart Group but are unable to obtain a place, please get in touch as soon as possible. We may be able to obtain a place for you provided that you can guarantee a minimum sponsorship of £250. We will supply official sponsor forms for all our runners.

Charitable Trusts

We are currently looking to fund a number of major projects and are approaching various charitable trusts for assistance. Many companies make charitable donations, but they are often more inclined to favour those charities with which their employees have a connection.

Do you know if your employer operates such a system?

Would you be prepared to find out and pass the information on to us?

Maybe a member of your family works for a company that might be prepared to help us?

Would you allow us to mention your name in any application we made?

We would be grateful for any contacts that you might suggest.

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 the setup in this region due to its size and lack of contacts.

London Southern

(Kent, Surrey, Sussex & S. London)

Katie Spall



North East

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

Sally Hardman



Jane Wrighton



North West

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

Mike Halpin



Scotland

(Mainland & Islands)

Lynn Carlisle



South Wales

(Dyfed, Glamorgan, Gwent & Powys)

Chris Stringfellow



Wessex

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

Vickie Richardson (*Hospital Visitor*)



West Midlands

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

Noreen Hodgkinson



Lynne Holden (*Hospital Visitor*)



Pat Mitchell



Yorkshire & Humberside

(Humberside & All Yorks.)

Linda Watcham



You may notice that we do not have contacts in all regions, and that most cover a very large area. We are currently looking to recruit area contacts who will work with the regional co-ordinators to offer a more comprehensive support service to families. If you would like to be considered for the role of area contact please let us know, there will be some training at a later date, and we do of course reimburse out of pocket expenses incurred.

Christmas Card Competition

**Well, it may be months away,
but we need your children's designs now!!!**

Get them busy in the holidays and see what they can achieve - don't worry if you don't think it's good enough, a lot can be done with a bit of imagination and a computer programme.

**There's a prize for the winning entry,
as well as having your design on 16,000
Christmas cards.**

We also have prizes of two free children's meal vouchers at **McDonalds** for the first five entries received at National Office - so get them in the post

NOW!!!

Designs must have a Christmas theme and include the Down's Heart Group logo somewhere. The competition is open to Down's Heart children and young adults and their siblings.

The Story of The Jasmina Jushkina Appeal

My name is Tania. I am Russian. I am thirty-three years old. I am a widow. I have a daughter. Her name is Jasmina. She is nine months old and I love her more than anything else in this life..... Doctors have diagnosed her as being Down's Syndrome..... I am afraid to lose my daughter because she has congenital heart defects, which need an operation. But in my country, doctors don't like to do operations for children with Down's Syndrome..... Because of this I am afraid to entrust my baby to these doctors and I do not have the means to go to another country. What can I do now?

It was this appeal which appeared in a letter in the Down's Syndrome Association's Newsletter in the Summer of 1995, from a Russian mother- Tania Jushkina - which touched so many hearts and which prompted the Down's Heart Group to launch an appeal to bring Tania and baby Jasmina to this country for the heart surgery for an AVSD, which she would be unable to have in Russia.

By happy coincidence one of our members - Veronique Garrett - had been thinking along similar lines, and as her husband Charles was fluent in Russian and her brother Jeremy was working in Moscow, her involvement at a stroke made the whole venture seem possible.

Copies of Jasmina's medical reports had already been forwarded to Dr. Taylor at Great Ormond Street Hospital by Veronique, and subsequent discussions with him indicated that subject to satisfactory test results there, surgery was a possibility at a cost of about £15,000. That set us back on our heels a bit - £15,000 plus travel etc. etc. was a very tall order for a small voluntary organisation with an income of about £10,000 a year!

We decided that the only possibility was to launch a public appeal and so The Jasmina Jushkina Appeal was born. We had no previous experience of running an appeal so had to play it by ear. Penny and Veronique sounded out contacts and we were very fortunate in getting Dominic Lawson and the Sunday Telegraph interested and willing to give us initial publicity. Penny wrote one of her sparkling press releases, the Sunday Telegraph commissioned photographs of Jasmina and Tania in Russia, and Victoria Macdonald the Health Correspondent wrote the first of many informative and sympathetic articles supporting the appeal. This appeared on 29th October 1995 and at the same time we wrote to all members.

I remember thinking at the time that to raise £15,000 would

take at least six months. Penny was on the phone on the Tuesday with the amazing news that £2,000 was sitting on her doormat that morning - and so it continued. With the help of another article in the Sunday Telegraph, various press and radio items and contributions from our British contacts in Russia, We had received £15,000 within three weeks. Then the contributions by members and fund-raising events large and small from throughout the country - playgroups, schools, clubs, coffee mornings, sponsored everythings took over and the total continued to rise. Within six weeks we had over £23,000 sitting in the Appeal bank account.

This all happened so unexpectedly quickly that we had to get our skates on to get everything organised. A sub-committee of Penny, Veronique, Sheila Forsythe and myself was set up to do this, and with Jeremy organising visas, travel etc. at the Russian end, arrangements were made for Jasmina to go into Great Ormond Street on 6th February, two days after her arrival here.

British offer hope to Russian Down's girl



The big day came. It started at 7am when Penny did a live interview on Radio 5 and ended much later that night when she and Veronique were at Heathrow to welcome Tania and Jasmina, along with two attendant television crews. Veronique and Charles had very kindly agreed that Tania could stay with

them whilst she was in London, but her initial stay was to be cut short as Jasmina's first night was very disturbed. After contacting Dr. Taylor it was decided to admit her to Great Ormond Street a day early as there was some concern about her condition. The four and a half hour drive from her home to the airport in Moscow, followed by the three hour flight to Heathrow had taken its toll, but thankfully she was soon stabilised and was well enough for the catheter to go ahead as planned on February 7th.

Results indicated that surgery was possible with a slight increase in risk due to Jasmina's age (by now 17 months), but Tania believed this was the best option in view of the problems in Russia, and the operation was undertaken on February 9th by Mr. Stark, who speaks some Russian and was able to reassure Tania in her mother tongue. Post operatively Jasmina's recovery was complicated by a hypertensive crisis while in Intensive Care, but this was overcome and her subsequent progress was good.

During her stay there was a regular stream of visitors to Great Ormond Street, both Down's Heart Group and Down's

Syndrome Association members and other donors and well-wishers, and their support and companionship was very important in sustaining Tania through this period. Jasmina's progress was uneventful after leaving Intensive Care and she was fit to be discharged on February 21st, staying with Charles and Veronique. She was then seen in outpatients by Dr. Rees on 4th March. He was pleased with her progress and pronounced her fit to return home to Russia.

The Down's Heart Group was able to host a small party at Great Ormond Street on 7th March to give us and Tania the opportunity to thank all the medical and nursing staff, Jasmina's regular visitors and others who had made the visit possible. And so Tania and Jasmina flew home on March 8th.

But that was not the happy ending to a fairytale story.

It had been clear to us that Jasmina, both because of her heart condition and the circumstances in Russia, had not been able to receive the sort of developmental stimulation and assessment that would be considered normal in the UK, there was therefore much ground to be made up. Also Tania was very determined to help other mothers in Yaroslavl, her home city, to keep their Down's babies and to have their own support group. We felt that we should give her support and some training in this, and as there was some money left in the appeal fund this was a possibility. We had discussed this with Tania and made preliminary plans for her and Jasmina to return to the UK so that she could have a checkup at Great Ormond Street, have full developmental assessments and programmes and meet and stay with some families. And so plans were made for a return visit in April and a two week programme organised. The idea was that they would stay with us in Sussex for a week, with visits to Great Ormond Street and the Sarah Duffen Centre, attend the Annual Conference and then spend a further week with Sheila Forsythe in Bristol visiting groups and families.

As April approached we telephoned Tania to make final arrangements, and learnt that Jasmina had not been too well and had been in hospital in Yaroslavl. In view of this we decided to take her straight to Great Ormond Street when they arrived. They were due to fly on April 18th, but after a

nightmare journey from Yaroslavl to Moscow, when their car broke down, they arrived a day later - all of us having spent an anxious few hours the day before wondering why they had missed the flight and waiting for news from them.

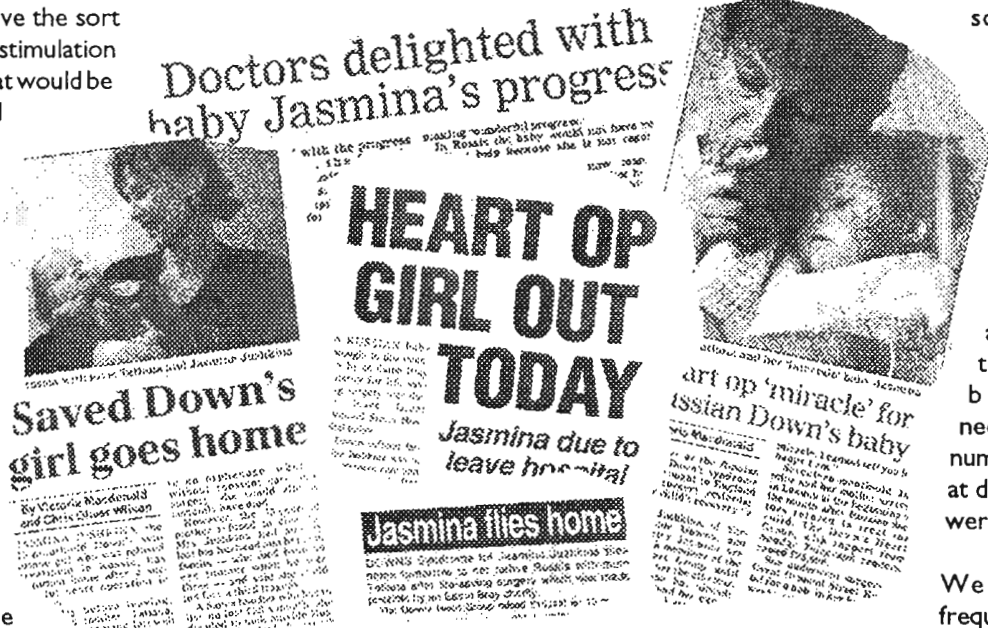
Investigation at Great Ormond Street revealed that Jasmina had fluid around her heart and one lung, was running a high temperature and was in general discomfort. What a blow to us all, particularly Tania as she faced yet another anxious period in hospital. Jasmina had made sufficient progress to be discharged by the following Thursday which meant that both of them were able to attend the Conference.

It was clear that Jasmina was still not right and I think it came as no surprise to us all, although deeply disappointing, when at an out patients appointment the following Monday, Jasmina had to be re-admitted as the infection had not been eradicated.

There then began a further period of great anxiety and concern as the source of the infection could not be located and Jasmina's condition deteriorated. Antibiotics seemed to be having no effect, a blood transfusion became necessary, and a number of attempts at draining the fluid were made.

We visited frequently and Tania came down to stay with us overnight on a number of occasions for a rest and some relief from the constant stress and anxiety. Martin and Patricia Smith also provided much support through frequent visits to the hospital, along with the telephone calls and visits from other friends.

Unable to stabilise Jasmina's condition satisfactorily, Great Ormond Street decided that a further catheterisation was needed, and this took place on 22nd May. This indicated a breakdown in the AV valve and this was now thought to be the source of the problem Jasmina had been experiencing. It was agreed that a further major operation would be necessary to repair or replace the valve, the former being the most desirable due to the possible follow up problems with an artificial valve in Russia. Mr. Elliott performed the operation on May 23rd, and was thankfully able to carry out the repair. The operation was successful and Jasmina made rapid progress through Intensive Care back to the ward and was then discharged on 5th June.



The change in her was so dramatic - as is very often the case - she was so much stronger physically (particularly her lungs!), more alert and attentive in every way and had changed from a baby to a young lady. Dr. Taylor was clearly very pleased with her progress when he saw her at outpatients and discharged her to return home.

So what had been expected to be one outpatients appointment ended up as forty three days in hospital with another major operation and two minor ones. This meant further heavy expense which exhausted the remaining funds and we had to go on the fund-raising trail again, with further publicity from the Sunday Telegraph. At a time when we had completely run out of funds and did not know which way to turn, we were very fortunate in securing the cost of the second operation from a charitable trust, which wishes to remain anonymous, and we are extremely grateful to them. Their Chairman was so touched by Jasmina's story that they decided to help despite their commitment to other projects, and a representative of the trust even went along to visit them in the hospital.

The strain of all this on Tania can hardly be imagined. Here she was on her own, in a foreign country, with a very ill baby, living in strange surroundings in hospital or other peoples homes. Almost everybody she met did not speak any Russian, so she had the additional strain of having to understand and converse about often complicated matters in a foreign language, although we did try to ensure that a Russian speaker was available at those times when decisions needed to be made to ensure that she fully understood what was said.

Inevitably, as with all mothers, her spirits went up and down with the condition of her baby, but underlying this was strength, fortitude and determination to face and overcome any difficulty and to always see as paramount Jasmina's welfare and future. This was coupled with great charm, intelligence, an impish sense of humour and very good (self taught) English, qualities which I know endeared her to everyone she met here.

The whole enterprise was a major undertaking for the Down's Heart Group and could not have been carried through to its successful conclusion without the help of a great many people, those who gave money, the doctors, nurses and other staff at Great Ormond Street, the Sunday Telegraph and all those who provided the publicity, those both here and in Russia who made the arrangements for the trip, those who visited and supported Tania and Jasmina and offered many small acts of kindness and friendship to them.

The Down's Heart Group, Tania and Jasmina thank you all most sincerely for your skill, humanity and kindness.

Our greatest reward is summed up in a quote from Dr. Taylor's final report "In terms of Jasmina's general care and response to illness she should now be treated as a normal child."

Many, many thanks to you all.

John Spall
Chairman

At our Annual Conference in April, Tania spoke to those attending. The following is a transcript of her speech.

Hello everybody. I am so glad that I can join you here at this conference. I want to tell you some small story what happened not long ago. It happened in the middle of March when me and Jasmina were in hospital in Russia after her operation. After we came from London, because she became very ill we go to hospital again.

And this was the day when Jasmina had had three nights sleep. I had some rest. I took with me in hospital all letters that you and other people send to us, and I took with me pictures of many, many, many, many children and I was looking at these pictures and some lady come to me. She look at the pictures I have. It seems to me that she never knew before about Down's Syndrome. I think so because it's very strange but may people in Russia don't know what is it Down's Syndrome.

She came to me and she look at pictures and she say "Oh they all look like Jasmina. Are they sisters and brothers?" I say "Yes." She look at me and she say "Are you joking? They are really sisters and brothers?" I say "Yes they are really sisters and brothers." And she look at me and I think she think that I am crazy.

But I am not! I really have a big family here. I have here, we have here, so many sisters and brothers and I am very proud that I live the same time and the same world with you. With beautiful kind people who have helped my 'little flower' to be alive.

I thank you so, so, so, so much and my especial thanks like always I do, it's for Katie Walsh who the reason for to start this Down's Heart Group. So I love you so much. Thank you.

Peter's Story

I thought you might like to publish the enclosed article. When Peter was born it was a major blow to be told he had Down's Syndrome. The heart problems seemed minor in comparison. Now our feelings are totally reversed. We have only become familiar with the scale of the problem for Down's people generally since we have been in receipt of the newsletter.

Following the article in the Autumn 1995 issue on children with inoperable heart conditions, I thought it might be interesting for parents of younger children to hear of our experiences.

Peter is now eighteen and has a degenerative heart condition. He was born in the early days of heart surgery where the complications he has were inoperable. We were always given pessimistic views on his life expectancy by the experts. I felt it was the surgeons preparing us for the worst case. This never discouraged my wife who taught Peter piano to Grade 5 (on the basis that this was an interesting pastime he could do sitting down).

Peter is still going strong despite experiencing some breathing

problems when he exerts himself physically. His condition is described as stable although we were warned at his last check-up that the time would occur when he would require specialist breathing apparatus at home to assist him. This still seems a couple of years away

We have never hidden anything from Peter. He has always listened to the heart specialist's comments on his health and we have never been quite sure how much he has taken in. However he has always had a morbid interest in graveyards and recently he has mentioned writing a will. Sometimes I think he does not understand what is going on around him. At other times I believe he understands only too well.



Peter driving a four wheel trike on Dartmoor last summer, his mum Chriss is his passenger

However in the meantime he gets on with life, has a tremendous appetite for food and listening to his hi-fi and likes to be involved with all the family activities. I am sure he will be able to cope when the time comes but I don't know how well I will.

Peter Davis, South Benfleet

Downside Up Charity Bike Ride

Having read the story about baby Jasmina and the lack of facilities in Russia, members might like to know of a new charity which has been setup by Charles and Veronique Garrett and her brother Jeremy Barnes, all of whom were involved in The Jasmina Jushkina Appeal.

Downside Up is a British based charity which aims to found a centre for Down's Syndrome in Moscow. The centre will provide day care and offer advice and information to assist families bringing up children with Down's Syndrome.

The charity has organised a five day bike round at the end of August which will travel through several historic towns around Moscow and finishing some 180km later in Red Square. They have about fifty riders taking part, each of whom is pledged to raise at least £1,500.

If you would like to make a contribution, cheques payable to **Downside Up** should be sent to :



Children's Heart Federation Conference 26th October 1996

This years Children's Heart Federation Conference will take place in London on 26th October. Speakers have yet to be confirmed, but are likely to be:

Mr. Victor Tsang - Consultant Cardiac Surgeon

Dr. Anthony Salmon - Consultant Paediatric Cardiologist

Dr. Elspeth Brown - Senior Research Registrar

all from the Wessex Regional Cardiothoracic Centre.

Workshops: Family Centred Care
Can Children Ride Bicycles in Heaven?
My Life as a Heart Child
Adolescents Care

The cost is yet to be advised, but the Down's Heart Group will assist the first five of its members who wish to attend. Please contact National Office if you are interested in attending or require further information.

Karl's Story

It all started on Sunday 7th July 1991 at 9.15pm when the doctors at Sunderland General Hospital decided to do a Caesarean Section on me. Karl was born at 9.20pm weighing in at 7lb 10oz. I didn't really know anything at this time because I was still under the anaesthetic.

Four hours after Karl was born the nurse told me that he would have to go to the Special Care Baby Unit because his colour and breathing weren't very good.

When my husband arrived back the next day at 10.00am, we went over to the neo-natal unit to see our beautiful baby boy.

When we arrived there I felt something was seriously wrong because Karl was wired up to a few machines, one of which was a heart monitor.

Iain and I sat looking at each other and wondering what was wrong, then half an hour later a doctor came over to us. He sat down and said "Karl has a heart problem which isn't too serious, and can possibly be treated with medicine. Also I am 99% sure that he has Down's Syndrome. We have taken blood tests and the results should be back within a couple of days."

Both Iain and I broke our hearts in the neo-natal unit because this was just the start of what we had to face, we felt devastated, but accepted it as Karl was our one and only child.

On Tuesday 9th July, Karl was taken to Freeman Hospital, Newcastle in an ambulance accompanied by Iain as I was still poorly and had to stay at Sunderland. There he saw a Dr. Bain who thoroughly examined Karl and said he had a hole in the heart which would possibly need surgery, but to wait and see.

After the examination Karl was brought back to Sunderland where he stayed for two weeks whilst he was on oxygen and the heart monitor.

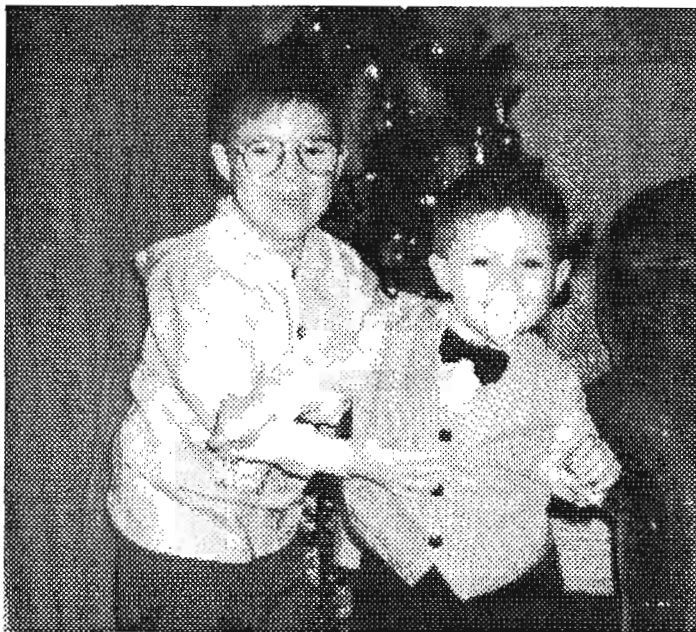
Every month Karl attended Freeman Hospital until he was four months when Dr. Bain decided that he would have to have him in to do a VSD repair.

On the 11th November 1991 Karl was admitted into Freeman Hospital weighing only 10lb. At 8.30am the next day Karl was taken down to theatre by Iain and I - it was a very distressing time for us!

The night before, the surgeon, Mr. Hamilton brought a model heart to show me and explained in great detail what he was going to do. I felt relieved but I knew I wouldn't feel 100% until Karl had the actual operation.

Karl was down in theatre for four and a half hours, and was then taken up to Intensive Care. Iain and I kept our tears back and knew we had to be strong to get Karl through this. Mr. Hamilton came and explained that the operation had been a success, and we shouldn't expect any further problems.

Karl remained in Intensive Care for four days and then he was taken back down on to the ward. In total he was in hospital eleven days, we then took him back for regular check-ups until he was discharged from Freeman Hospital in March 1993.



Karl with younger brother Lewis

After his surgery, instead of taking two hours to drink 2oz of milk, it took Karl fifteen minutes to drink 9oz. This was incredible and I had no more days of sitting feeding him all day long. Karl is now coming up to five years old and we have never looked back. His operation was a great success, he still sees a specialist doctor once a year when his heart is checked as well as his overall health.

Can I just say to parents who are undecided about allowing their children to have the operation, that if it had not been for Karl's operation he would not be alive today. Thank God he is still with us.

Alison Williamson, Seaham

McDonalds Child of Achievement Awards

Congratulations to eleven year old Kristian Adey, a Down's Heart Group member from Bradford. He received a McDonalds 'Child of Achievement' award for being one of the first children with Down's Syndrome to pass the London Guildhall School of Music and Drama examination in Speech and Drama. At the presentation of the awards, he met The Prime Minister and Mrs Major.

Kristian has an inoperable AVSD.



Children with inoperable heart conditions

As a result of the article in the last newsletter, under this heading, parents and carers are getting in touch to let us know about the progress of young people who for one reason or another are not to have corrective surgery.

For me, as the parent of an eleven year old, talking with carers of other children and adults has strengthened my confidence in our future. We shared common experiences, compared notes regarding different hospitals, advice and treatment offered and gleaned lot of really interesting 'tips' and useful information certainly adding lots of 'power to one's elbow.'

A worry all of us express and return to, is the one about time running out. It's the one that doesn't leave us, even when things are going well and health is relatively good, (now he's eleven, now she's twenty two....., you know the sort of thing.) It's the worry for which we all know we have to keep a sense of perspective, form philosophies and have beliefs strong enough to see us through low periods, when we try so hard not to feel unnecessarily depressed. But it only takes a set back for all the fear to come rushing back and self questioning of whether or not the fear is irrational, to start.

If I needed convincing, I am now totally convinced that talking with other parents and carers helps, it helps a lot. I have been left in no doubt that I have been talking with 'professionals' who's life is dedicated towards 'getting it right' for the person in their care. I have gained courage for myself through learning of the progress and treatments for Eisenmengers and polycythaemia of members of our group. So much is being offered by hospitals and so much quality life is being enjoyed by young adults concerned. Had I not spoken with Spencer's dad, Bill Tutty, a couple of weeks ago, I would be unaware of the programme recently on Sky TV regarding the successful treatment of a woman of forty five in America. Inspiring stuff!. I really must get out of the habit of thinking of Alex's age so

often and get on with investing in his future!

There are a number of things we would like to know more about, the main topics being:- Venesection, Psoriasis & skin care, controlling weight and diet, the wisdom of flying?, computer programmes for older people, experiences when having dental fillings/extractions etc.

Maybe you would like to give your experiences of these and other issues, perhaps, as an article for our next newsletter, or through contact with me.

Let me know also if you would like to be in touch with other carers. We have a lot to offer one another in support and in 'tips' and information regarding best practices within various hospitals. Comparing approaches can prove significant, particularly if we are unsure whether the best is being offered. My address and phone number are at the front of the newsletter.

AUTISM

Following the article in our last newsletter, I had a letter from Dr. Jennifer Dennis, Medical Adviser, Down's Syndrome Association. She writes that she is very interested indeed in the association between autism and Down's Syndrome, that there is a need to increase recognition of this and to try to develop appropriate advisory services.

Dr. Dennis would be very interested to have details of any children / adults within our group with autistic-like disorder to help her research which is at an early stage, it need be no more than one side of an A4 sheet. All contributions would prove extremely valuable and I will forward all information to her.

*Wendy Tucker, Representative for Inoperable Children
(Wendy's address is on page 2)*

MSB+

In view of a great deal of discussion recently regarding MSB+, we feel it is important that all members are aware of the current thinking regarding its use, and are therefore including the following item which is Reprinted from DSA News (GB) Spring 1996 Issue No. 79.

In the last months there has been debate in the newsletter and amongst members of the possible benefits of MSB+. (MSB+ is a complex multi-treatment containing vitamins, minerals, amino-acids, enzymes and a substance called Piracetam - see articles in DSA newsletter no.77). The officers, advisors and staff have been cautious in the advice given to parents. Over the past decades there have been claims made concerning a number of 'treatments' for Down's Syndrome. New parents are especially vulnerable to these claims and the hope they may offer. The claims made by some proponents of MSB+ need to be evaluated. Following the January meeting of the Scientific and Research Advisory Committee of the DSA, it has been decided that a researcher, unconnected with the Association should be asked to assess, evaluate and report on all the data from around the world on MSB+. A full report will be made and from this a judgement made by our scientific advisors and the trustees of the Association on the next steps.

In the meantime the DSA advice remains that we cannot recommend use of MSB+.

Children's Heart Federation Conference

I attended the Children's Heart Federation's Annual Conference in October 1995. This was a well organised event with a number of interesting speakers and workshops. Sadly, attendance was sparse. The Federation, of which the Down's Heart Group is a member, brings together the various voluntary groups concerned with children with cardiac problems. Most of the groups are geographically based and related to the regional cardiac centres, while others like ourselves, and for example the Hypertrophic Cardiomyopathy Association, operate nationally and are concerned with a particular condition or patient group.

The contribution of one of the speakers, Dr. Sheehan from Birmingham Children's Hospital was of particular interest to us. Dr. Sheehan spoke about an analysis which the hospital had completed of the last one hundred operations undertaken at Birmingham Children's Hospital for repair of AVSD. These covered the period from 1989 to 1994.

Of the 100 children involved, 78 had Down's Syndrome and 22 did not. 15 of the children had other associated defects. At the time of surgery:

The median age of the children was 4.2 months.

Their median weight was 4.2 kilos (approx. 9lb 4oz).

The mortality of those with 'simple' AVSD (this included most of those with Down's Syndrome) was 2.4% (about 1 in 40 operations).

The mortality of those with more complex AVSD (usually not Down's Syndrome) was 20% (1 in 5 operations).

Dr. Sheehan said that most children continued to have mild problems (e.g. chest and ear infections) after recovery from surgery.

His view was that there was a very strong case for surgery for all babies with Down's Syndrome and AVSD, which should be undertaken as early as possible. Failure to offer surgery should always be questioned and, if necessary, a second opinion sought.

He was also of the view that there is an overwhelming case for every baby diagnosed as having Down's Syndrome to have an echocardiogram as routine - this is Down's Heart Group policy. He made the telling point that it is not uncommon in the National Health Service to find screening of vulnerable groups where detection rates are only 1 in 50; in babies with Down's Syndrome the rate is under 1 in 3.

John Spall, Chairman

Does your child have Hirschsprung's Disease or another type of gut problem?

There is a newly formed group which offers telephone support to parents of children with a Gut Motility Disorder (GMD).

GMD's are conditions in which the regular, co-ordinated movements of the digestive tract are disrupted to such an extent that normal digestion and absorption of food/and or elimination of residue becomes difficult or even impossible.

Disorders fall into two main groups:

Neuropathic - in which the nerves of the gut wall are affected. Hirschsprung's Disease and Intestinal Neuronal Dysplasia are examples.

Myopathic - in which the muscles of the gut wall are affected.

Calls to the GMD Support Network are answered by Lesley Prior who can chat through the problems with a family, and if appropriate try and link them with one of a carefully selected group of volunteers.

The group also holds an annual conference at Great Ormond Street Hospital, in conjunction with a leading gastro-enterologist.

Lesley can be contacted on 01799 520580

The Family Fund Trust (formerly The Family Fund)

The Family Fund have changed their name to The Family Fund Trust, but their purpose is still to ease the stress on families caring for a severely disabled child under 16.

The Trust can help with holidays, washing machines, transport, special furniture needs and central heating, amongst others. There are a number of guidelines about eligibility, and special notes and guidelines on specific conditions including ones on Heart Conditions and Learning disabilities, as well as a booklet for parents explaining how the system works. All of these can be obtained from the Family Fund Trust Direct by sending a large s.a.e. to the address below.

There is a simple application form included in their leaflet, and you will be visited by someone from the Fund to discuss your application and to meet your child, but all personal information is treated in the strictest confidence. They aim to give a decision within six weeks of receiving the visitors report, and you can re-apply in the future although not normally within 12 months.

The Family Fund Trust
PO Box 50
York
YO1 2ZX
Tel: 01904 621115

The European Down Syndrome Conference - Towards an Inclusive Society 23 - 26 August 1995 Dublin

The Committee agreed that Penny and I should attend this conference as representatives of the Down's Heart Group and that we should have a stand to publicise our work. Mary Clayton also attended in a private capacity but gave us tremendous help on the stand, without which we probably wouldn't have coped.

This report is a distillation of about forty pages of notes which I took at the time and concentrates on the highlights which were most relevant to us. If anyone is interested in a particular topic which I haven't covered in detail I may have more information in my notes.

The conference was held at University College a modern, sprawling university campus on the outskirts of Dublin. The accommodation was very good, although the catering facilities closed too early (7 pm). The actual conference hall was very new, this being the first conference held there and naturally the facilities were first class.

We spent the first morning in becoming familiar with the site and putting up our stand. As we were there early we got the best spot, right opposite the main entrance to the conference hall. This was the stand's first outing and it looked very good. Penny had done a very professional job with the posters and leaflets. The whole thing very much enhanced our reputation and is certainly worth the money we spent on it.

The stand was a huge success and provided a focus for our presence. We were inundated from day one with requests for leaflets and information about our work. By day three, despite rationing, we had run out. We were able to establish contacts with many overseas associations and individuals. It emerged that we were the only organisation in any of the countries represented that dealt specifically with Down's Syndrome and heart conditions. There were many local parents at the conference who were very interested in the idea of a special group for heart children. Penny was busy in signing up new members and recruiting a hospital visitor for the Dublin cardiac unit.

During the conference we were approached by a number of parents who pointed out the letter from Tatiana Jushkina in the Down's Syndrome Association Newsletter and asked if we could do anything. This was particularly after the Russian delegate had given a harrowing account of the position of children with Down's Syndrome in Russia. I had also heard about this at first hand from my flatmate who was a music/dance therapist from Tallin, the capital of Estonia. (It was from these contacts that the

idea of the Jasmina Jushkina Appeal developed, which you can read more of on page 6 of this newsletter.)

In the afternoon we attended an International Meeting of Down Syndrome Associations. This was run by a steering group drawn from Australia, Spain, Canada, Mexico and USA charged with establishing an International Down Syndrome Association. Much of the meeting was spent explaining how this would work and when it might be functional (1996). The remainder was about the next international conference due to be held in Paris in 1996 (which has since been cancelled).

The official Opening Ceremony was in the evening performed by President Mary Robinson. She is clearly very popular in Ireland. She radiates charm and humour and has a complete lack of pomposity. She gave a short and well informed speech (she is patron of the Down Syndrome Association of Ireland) and used the conference theme 'Towards an Inclusive Society' to touch on wider themes in society as a whole and events north of the border.

Day two opened with a Keynote Address 'Towards an Inclusive Society' by Jean Kennedy-Smith, sister of President Kennedy and the American Ambassador to Ireland. This was a very general speech giving examples of the achievements of people with Down's Syndrome, the importance of education and changing attitudes in society.

The first major session was entitled 'Education at all Levels'. The first speaker was Seamus Dunne, Education Officer of the Down Syndrome Association of Ireland. He gave a hard hitting and controversial address based on the quotation "put not your trust in princes", if you are a parent seeking the best education for your child with Down's Syndrome. The princes were:

The European Commission - who spoke gobbledeygook, who made unrealistic plans in which funds ended up being used on segregationist, rather than integrationalist, projects and who "used language to hide meaning".

National Government - Concerned with what is 'feasible'. Not what should be done but what it is politically expedient to do.

The Bureaucratic Administration - do what is 'appropriate' i.e. what they think should be done - they keep parents in the dark and they misrepresent issues.

The Professionals - vested interests applied inconsistently,

The result is that parents views are rarely considered and they are sidelined. Hard hitting stuff!

Next was Mercedes Egan, Special Education Teacher Down's Syndrome Association of Ireland who focused on the special needs students. She said that about 50% of students in special needs schools in Ireland had Down's Syndrome. There were students with Down's Syndrome in mainstream schools but many without support. She was critical of the provision and the assessment of students with Down's Syndrome. She asked the questions:

How do we know their potential and ability?

How do we know this without trying to teach them?

How do we know they cannot read until we have tried every effort to teach them to do so?

She believed that each student should be assigned to a special school even if not attending one and thus have access to special school resources as and when they need them. She considered that special needs provision must be additional to, and not in substitution for, that provided for the generality of students.

Montserrat Trueta, President, Catalan Down Syndrome Foundation described the progress of integration in her region. She said that the education provision was complex, with many more private schools, and this had hampered progress. Legislation had been passed in 1982 and 1984 giving access to mainstream education, but with many provisos. A survey in 1994 showed that the proportion of children with Down's Syndrome in integrated education at various ages was:

- 2 years 98%
- 6 years 85%
- 12 years 65%
- 16 years 7%

Some of the reasons for this were that there were special centres for early intervention at the younger ages; there were many more special needs schools at secondary level in the private sector and their teachers could not transfer to the state sector so they resisted change. Most mainstream schools had a support teacher whose job was to develop individual programmes for each child. She believed that special schools should convert into resource centres supporting all mainstream teachers with special needs students.

Mary Lunny, Northern Ireland Branch of the Down's Syndrome Association, described the work she had been involved in to encourage integration. She said that Northern Ireland legislation tended to lag about 10 years behind the rest of UK. It was only in 1987 that responsibility for SLD schools passed from the Health to the Education Dept.

The Audit Commission had produced a report in 1992 showing the actual distribution of children with learning difficulties set against parental preferences:

	SLD	MLD	SP Units M'steam	M'steam
Actual %	46	25	7	20
Preference %	1	8	17	62
	(12% undecided)			

There were wide variations between the Education Boards in Northern Ireland.

The Down's Syndrome Association in Northern Ireland had pursued a policy of 'Educating the Educators'. Lectures, talks and training had been arranged for statementing professionals and others to show best practice in education for students with Down's Syndrome and the results of research and actual cases demonstrating the potential of children with Down's Syndrome. This had brought about some changes in attitude and approach but progress was slow and still patchy.

The afternoon session was on Speech and Language. The first speaker was Prof. Jean Rondal a Psycholinguist at the University of Leige. This was very much one for the professionals; I confess I did not understand much of it at the time and even less when I consulted my notes later! The general message seemed to be that speech was assisted not only by learning words but also through the techniques involved in conversation such as seeking information, generating topics, responding and something called 'conversational repair'. If the child was motivated in these areas speech would follow.

We were on more practical ground with our own Sue Buckley of the Portsmouth Down's Syndrome Trust, who gave a resume of her approach to language development through reading and updated us on her continuing study. She said that better and better results were being achieved year by year by children with Down's Syndrome,

where good teaching methods were being used. She quoted some recent results from three reading groups of children with Down's Syndrome:

No in Group	Ave. Chronological Age	Ave. Reading Age
8	6.2	5.5
9	8.3	6.2
5	9.5	7.2

Also two groups of seven children who had had similar 'scores' in 1992, since when one group had been through the reading programme and the other had not. While both groups still had a similar non-verbal reasoning score the reading group did much better on vocabulary and grammar and had improved their short term memory.

She went on to say, developing the short term memory point, that intelligibility goes down with longer sentences as it is difficult for children with Down's Syndrome to remember the opening part of the sentence by the time the end is reached. A sentence has to be held in the memory in its entirety to understand its meaning. It is more 'cost effective' to use a larger number of shorter sentences with children with Down's Syndrome. She was asked a question about developing language with a child with Down's Syndrome being brought up in a bi-lingual household. Sue's advice was to treat as one would a normal child in the situation.

She particularly recommended two books to parents who wanted to know more about speech and language. 'Teaching Children with Down's Syndrome to Read' by Patricia Odwein and 'Communication Skills in Children with Down Syndrome' by Libby Kumin.

In the evening we attended a State Reception (it sounds grand but was very informal and friendly) at the Royal College of Surgeons (how does the Republic of Ireland have a Royal College, I wonder?). This gave us an opportunity for further 'networking' among delegates, speakers and the organisers.

The first session on the following morning was 'Training and Employment' and was led off by JTH Stewart, Director of Employment, Industrial Relations and Social Affairs at the European Commission. It emerged that the EC had helped finance the conference. I have few notes on Mr. Stewart's talk. I am afraid that, for me, he confirmed Seamus Dunne's view of the EU.

This was followed by a panel discussion on the topic, comprising Gloria Canale and Roger Macade of the Aura Group in Barcelona, Dr. O'Reilly of the National Rehabilitation Board in Ireland and Brendan Sutton, Chief Executive of the Cheeverstown House, an 'inclusive employment project'. They all had a similar tale to tell and the Aura Group provides an example. This group is involved in the placement of people with Down's Syndrome in open employment. It had been operating for five years and currently had 35 workers with Down's Syndrome placed in local firms holding down a normal job. Most of these were long term workers but mainly in manual jobs such as kitchen assistant, laundry worker, cleaner and porter.

A key element of successful integration and job achievement was the allocation of a 'job coach' to each person placed, for their first six months at the firm. The 'job coach' was another employee doing similar work who was given time to train and assist the new worker not only in job skills but in all those other elements of employment such as pay, timekeeping, holidays, work discipline, health and safety, supervision, team working which make up the work culture and which can be difficult to understand and come to terms with for a person entering work for the first time.

Gloria and the other members of the panel emphasized that the education of people with Down's Syndrome must change and broaden if they are to take a full and independent place in society, of which many are capable.

Because of the emphasis a decade and more ago on the lack of basic skills such as numeracy and literacy of children with Down's Syndrome, the schools' focus had and continued to be on raising academic standards. This of course is welcome and not to be decried, but it did mean that people with Down's Syndrome coming out of school were often ill-equipped for employment, partly because they lacked work/social/survival/discipline skills necessary to fit in and succeed in the work place. Schools now needed to raise their sights and educational effort with the aim of equipping their pupils to take a more autonomous and independent place in the adult world.

Does this have a familiar ring? Sounds to me rather like employers in general who bemoan the quality and attitudes of the people the schools are sending them.

But these employment specialists are saying that we can see as much potential for the development of people with Down's Syndrome in the work place and the adult world generally as you educationalists have achieved in the schools. But you must share that vision too and

incorporate it in your work in the schools.

The second session was on the subject of Genetics. A pretty technical area and we were rather bombarded with statistics, graphs and survey data which it was difficult to absorb, let alone write down and understand later. Prof. Roberto Rasore-Quartino from Genoa, provided an interesting background and there were then contributions from the panel of Dr. Mulcahy, Stewarts Hospital, Dublin, Dr. Natalia Kovaleva. Researcher, St. Petersburg and Aine Buckley, Researcher, Dublin. I will quote at random some of the points that I found interesting.

The life expectancy of people with Down's Syndrome has increased five-fold in 60 years. In 1929 it averaged 9 years, it's now 53. In all probability Chromosome 21 is the cause of all Down's Syndrome features and this will be established in due course. The human geno project will tell us more. But it will not be found that 1 gene = 1 feature. There will be a concentration of research on Down's Syndrome because abnormalities is a good place to look for clues. The extra Chromosome originates from errors in formation of the egg (90%); the sperm (5%); the embryo (Mosaic) (5%). There is no evidence that radiation causes Down's Syndrome. A big study after Chernobyl found no link. Genetics as a form of treatment could contribute in the future to curing individual Down's Syndrome symptoms. Would/could Down's Syndrome be eradicated? A very cagey answer given to this one.

The last session of the day was entitled 'General Health, Nutrition and Fitness'. This included Prof. Hilary Hoey of Dublin, Dr. Jenny Dennis of the Down's Syndrome Association, Dr. Joseph Cumiskey Medical Adviser to the Olympic Council of Ireland and Michelle Hurley a Dietician from Dublin. I took several pages of notes but on re-reading them found that much of the information I, and I am sure most parents, already knew. I found this surprising as the session had seemed interesting at the time. Again a few snippets.

To get better medical services for Down's Syndrome we need to put pressure on the purchasers in the new NHS. While they are rather grey figures behind the scenes (the Area Health Authorities) it is they who set the standards and priorities which the providers (the hospitals, etc.) have broadly to follow. Provision across UK varies widely so it's usually possible to get examples of where things are done better than in your own locality and use these. Children with Down's Syndrome should be encouraged to become athletes, it has major physiological and psychological benefits, though there is a need for specialist coaching oversight and where there are complications, medical clearance. Benefits: better health, self-esteem, co-ordination, group activity and belonging,

competition, concentration and visualisation.

Tonight was Irish Night - plenty of eating, dancing and Guinness. I took no notes and even if I had they would have been unreadable in the morning!

Saturday opened with a session entitled 'Psychological Aspects of Integration'. The session was introduced by Dr. Chris Conliffe Clinical Psychologist from N. Ireland, followed by a panel of Dr. Juan Perera from the Balearic Islands, Ann Halliday a psychologist from Co. Clare and Dympna Walsh a psychologist from Dublin.

Dr. Conliffe said that many improvements had been brought about by the persistence of parents aided by a few sympathetic professionals. There was still a tendency in some quarters not to involve parents fully and to hold back information. There was insufficient recognition that for their child the parents are the best experts.

Dympna Walsh asked the question - "to integrate or not?" This must be an individual decision but the philosophy and research pointed in general to integration in education being the best course for most children. What was holding back progress was not theory or facts but lack of resources. All parents want the very best possible for their children. They want them to be happy, well adjusted, at ease with themselves and others, have friends and the material resources of life. These aims are more likely to be met for children with Down's Syndrome in an integrationalist society rather than one which seeks to categorise them as different and separate. She quoted a telling example. It is a myth that children with Down's Syndrome are friendly and so will have lots of friends. The reality is that children with Down's Syndrome are loving within the family but rarely have deep friendships outside it. There is still much for parents to fight for to achieve an inclusive society and they must always remember that what is provided for the generality of children should be the right of children with Down's Syndrome also.

Anne Halliday pursued this theme. She said that inclusion was a more fundamental concept than integration. It implied that every person in a society should have the full rights of citizenship within that society. She quoted Abraham Lincoln on the abolition of slavery that "it is not a scientific but a moral issue". Taking this theme further and from another continent she said that "separate development" of the disabled should be neither legally or morally acceptable. She questioned whether as a society we were ready to give people their full rights and said that some attitudes were similar to those of colonial rule, where we regarded the disabled as children not capable (or certainly not ready) to be full citizens and rule their own lives. As a post colonial society it was time we

started de-colonising the disabled.

Juan Perera pointed to research on the benefits of inclusion in adulthood, of which employment is a key element. He said that people are what they do. That is one of the early questions we ask when first meeting people and we start judging them by the answer to that question. Employment is not therefore just an economic activity but has deeper significance in how you regard yourself and how others see you. Research he is involved in on employment projects for adults with Down's Syndrome shows that with expert job analysis and design and tailored training and support a far broader range of work was possible. His research showed that adults with Down's Syndrome who had been working in the projects for some time showed a marked increase in self-esteem, a feeling of usefulness, greater ability to adapt, more personal autonomy, developed new skills quicker, were more assertive and had a greater awareness of their limitations. These improvements were as yet small but pointed to the significant place that employment can play in developing an inclusive society. The conclusions he draws from his studies are that it is never too late for those with Down's Syndrome to learn and develop further; that no intervention means deterioration; adults with Down's Syndrome are able to work in a wider range of jobs than we yet perceive; inclusive employment transforms life and is a springboard to fuller autonomous citizenship; it provides more economic and psychological security.

I haven't yet mentioned questions. These were invited at the end of each session and there were long queues at the microphones. The quality of the questions was high and very often provided practical examples of what was being propounded from the platform (and sometimes confounded them). Most questioners were parents speaking from practical experience, but also some professionals. Most impressive of all were contributions by young adults with Down's Syndrome who fluently (and sometimes at length!) told us of their own unique experiences and their demands of us for the future.

And this was the rationale and theme of the final session. A panel discussion - 'Young People with Learning Disabilities'. But this was not academics or workers or parents talking on the subject but the young people themselves. The panel was five young adults with Down's Syndrome drawn from four countries:

Chris Burke (USA); a young lady from Canada whose name I missed; Andy Trias (Spain); and Ciara McNeill and Emily Moore (Ireland).

Each gave a fluent and moving account of their own life

and their hopes for the future (Andy in English - his third language!). They were all working or studying in jobs ranging from actor to accounts clerk. Here was the theme of the conference in living colour! They challenged the perceptions and horizons of even this committed audience and they won from us a spontaneous five minute standing ovation.

So we left on a high. The conference had shown us what was being achieved across Europe and the potential for the future which could see developments over the next thirty years greater than those achieved since the sixties. It questioned and challenged us collectively and individually to have the vision to see what was possible and the determination and stamina to work for the achievement of an Inclusive Society.

For Down's Heart Group it provided a door to the wider world of Down's Syndrome beyond our shores, an insight into the future, many international contacts which will bear fruit in the exchange of information and ideas, some new members in Ireland, a hospital contact in Dublin, an application to join the European Down's Syndrome Association, the Jasmina Jushkina Appeal and a much enhanced profile as an organisation and the work we do.

I thought it was good value for money - I hope you do too.

John Spall, Chairman

PLEASE HELP US by saving stamps, postcards and ring pulls

Two members have volunteered to fund-raise on behalf of the Group, but they need your help!

We need all our members to save used postage stamps (preferably still on the envelope as certain postmarks can be worth a lot more), postcards (used and unused) and the ring pulls from drink cans. All of these can then be used to raise funds, so ask your friends, family and colleagues to help too.

Send your stamps and postcards to:
Val Roberts



And ring pulls to:
Chris Stringfellow (see page 4 - South Wales)

Fund-raising Update

It's not possible to mention everyone who supports our work by fund-raising, but here we have details of a few of them. Perhaps they might even give you an idea for an event you could organise - whilst we're always grateful for the money raised, these events have another important role, they help to raise public awareness of our children. So grateful thanks to everyone who's been involved in recent fund-raising on whatever scale, and if you do something please let us know, you may even feature in a forthcoming newsletter.

Sherry and Mince Pie Evening

Thanks to Nicola Tandy from Liverpool whose Sherry and Mince Pie Evening before Christmas raised £113. What a wonderful excuse to indulge yourself!!!

Parachute Jump

Last summer, brave member Billy Evans from Teddington did a parachute jump from 12,000 feet and raised £592 for the Down's Heart Group. Although he had jumped before, this was the highest Billy had ever been and he had to do a tandem jump with the instructor. His wife Mandy who was expecting a baby at the time stood on the ground watching, and was witness to a few scary seconds when the parachute failed to open and the emergency chute had to be deployed. Happily, Billy landed safely and baby Joseph wasn't shocked into an early arrival.

London Marathon

The London Marathon is becoming a major event for the Down's Heart Group. In 1995 we had five runners: David Ashpole, Dave Brown, Mike Hambling, Terry Turner and Martin White and together they raised over £2,000. In 1996 we had three runners: Jim Butler, Richard Stutchbury and Martin White (who despite having a place only decided to run a week before the race) and together they raised over £1,200. In addition we were delighted to receive a cheque from Stuart Davidson a Group member who also ran and raised money by running a 'Guess my finishing time' competition, which together with donation raised £202.

Recycled Toblerone

A giant Toblerone which was a prize in the Raffle at the 1995 Annual Conference was won by North West Regional Co-ordinator Mike Halpin. Rather than eat it, Mike raffled it again at Christmas. In all the giant bar helped to raise £160, and no-one from the Group was ill from eating all that chocolate!

Nanna's Wedding

When Nancy Glover of Doncaster got married in September last year, she and groom Clive Drury were finding it difficult to fit the contents of their existing two homes into one. They knew that people would want to give them wedding presents, but this would further add to the problem, so they came up with the idea of asking people to make a donation to charity instead.

In particular they wanted to donate to a charity that might help Nancy's six year old granddaughter Katie, so they asked her parents to nominate a beneficiary, and glad of the support they had received they named the Down's Heart Group.



Katie and her three year old sister Chelsea were bridesmaids along with their older cousin Jodie, and at the reception afterwards people were making donations all evening. At the end of the night Clive stood up and announced the total of £320 to cheers and a round of applause.

Many thanks to all our fund-raisers and benefactors for all the time and effort that they have put into these events, and also to all those whom we haven't room to mention here, and those who regularly make donations in other ways.

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

Kendal Batcheler - Dagenham
 Constance Brender - Essex (Great Grandmother of Amy Clark)
 Cameron Brown - London
 Gemma Iles - Chippenham
 Joel Ronayne - Jersey
 Rosie Steeds - Bristol
 Adam Watcham - Cleethorpes

Children's Heart Federation - EuroDisney Trip Christmas !995

In the last newsletter we asked members to put their child's name forward for the Children's Heart Federation Trip to EuroDisney. Here the two lucky winners describe their visit.

Rebecca Andrews - Ipswich

Thank you for recommending that our 12 year old daughter Rebecca should go on the trip to EuroDisney last December.

Rebecca had a wonderful time. We arrived at Oxford on the Monday night and stayed the night in a hotel before meeting the rest of the group at the Rover plant in Cowley. The planned photo shoot with sponsors and stars from Eastenders was curtailed by a snowstorm and everyone departed to the canteen for a welcome hot chocolate. Our fleet of forty white Rovers, loaned by the car company, left Cowley under police escort around eleven o'clock and made its way through every weather condition possible before arriving at the Channel Tunnel. Rebecca loved the journey through the Chunnel. We picked up an escort of gendarmes in Calais at seven o'clock, and it was another six hours before we arrived at Disneyland.

Not even cold weather could spoil our two days in the Park. We had lots of warm clothing, although some of our fellow travellers improvised by using the duvets off the hotel beds! Most of Rebecca's favourite rides were indoors, although the Christmas parade was worth a wait outside. Queuing was practically non-existent, mainly because the French rail strike stopped most people arriving.

We left on the Friday morning, again under police escort which finally gave up in the confusion of our trying to park in a pre-Christmas Calais supermarket whose population seemed to be 99% British. We had a minor scare when the tunnel was closed by strikers but it reopened (briefly as it turned out) in time for us to return to England. On arriving at Cowley, Rover staff were there to help us unload and scrape an inch of ice off our own car.

We'd like to thank you again - it was by far Rebecca's best Christmas present.

Richard Saunders - Gillingham

We were very excited to learn that we had been allocated a place through the Down's Heart Group and would be going to EuroDisney in Paris with the Children's Heart Federation. About forty families were going to make the trip. We all had to meet at Cowley, Oxford and spend the first night there as early the following morning we had to assemble at the Rover car plant for a celebrity launch.

Rover had loaned forty very luxurious all white cars for the

trip. Peter Dean the ex Eastenders star was there to see us off, along with representatives from the firms who were sponsoring the cars. The Police escorted our convoy to the M40 we went through red lights and the traffic was held back at roundabouts for us. I felt like giving a regal wave!

The weather had turned nasty, very cold with snow. We had one or two stops on the way down to the Channel Tunnel and were getting behind schedule, so we only had a quick dash round the Tunnel Exhibition Centre, where we were issued with our boarding passes. We had always said that we would never go on Le Shuttle, but I found it quite exciting. By chance we found ourselves next to the other family from the Downs Heart Group so passed away the time chatting to them.

When we reached Calais we were met by the French Police who escorted us all the way to Paris, and they didn't hang about! The combination of strange roads, speed, and driving

on the wrong side made a few of the convoy drivers a bit concerned and there was great relief when at about 1.15am the following morning we turned into the entrance to the hotel. Us parents might have been a bit fraught, but all the children still seemed happy and excited!



The hotel was enormous. The beds were very comfortable and our room was, thankfully, warm. Breakfast time each day was very enjoyable. Richard look forward to socializing with certain families that we had become particularly friendly with and Bob and I have become addicted to apricot jam since our continental breakfasts!

The two days in EuroDisney Park were spent doing what everybody does there while trying to keep warm at the same time. It was so bitterly cold. Richard got quite miserable the first day.

The second day we put on all the jumpers we had and were a lot warmer. Richard sorted out his favourite rides and we went on those time and time again. The parade was memorable and the Disney characters were tireless in their efforts to make the children happy. One or two of the characters visited our hotel and spent time with the children.

We had a Police escort again for the return journey to Calais. Not such a hair-raising experience this time, thank goodness! The convoy broke up at the Calais hypermarket! Most of us brought cheap wine etc. before heading back to Cowley. After a very welcome hot drink we transferred our luggage into our own car and set off for home.

A memorable holiday. We would like to say hello to the Andrews family from Ipswich and a special hello from Richard to Spencer, from Oxford, who was on the trip with his Mum and Dad. They have recently joined the Down's Heart Group.

Letters to the Editor



Dear Editor

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

Dear Editor,

I had a 'circular' letter from someone called Alexander Harris solicitors to do with children who have not been properly treated for their heart condition, but I want to tell you that I took exception to something on the form they sent, and wrote them an angry letter.

In two places it said something about 'date of death if appropriate' and that shocked me, although my child Thank God had wonderful surgery at Great Ormond Street, and is very healthy. I feel that the words 'death' and 'appropriate' should not be put side by side. Of course I realise they don't really mean consider a child's death appropriate, but I do feel that question could have been more sensitively phrased. I rather hope I am the only person who was upset by this.

Perhaps if there is going to be a report of bad practice in the Down's Heart Group newsletter or elsewhere, it would be good to publish the other side as well?

Our son Francis was born in University College Hospital London, and immediately checked for a heart condition when they saw he had Down's Syndrome. He had an AV Canal defect. We were kept fully informed, and sent to Great Ormond Street Hospital for the operation, which he had at thirteen months as planned. At that time, UCH said that for children with Down's Syndrome with his sort of defect, survival rate of the operation was 80%. At Great Ormond Street they said theirs was 90%, and I expect it has improved further by now. The success rate for Francis was a heart 98-99% perfect, and he can do everything, though in long distance effort like cross-country running he is slow. Great Ormond Street still check him, now at three yearly intervals (he is twelve), to establish long-term results. Most impressive I think. Without the operation his heart would now be failing.

I'm all in favour of research, and handing out 'brickbats' if necessary, but can I hand out two bouquets as well? for U.C.H. and G.O.S.H.

Caroline Kenny, Etchingham

(We would like to apologise to anyone who took offence at the solicitors questionnaire, but as you will read on page 22, the data provided was very useful. It was not the intention to hand out 'brickbats' to any unit, merely to establish a 'normal' pattern of treatment against which certain cases could be judged. - Editor)

I thought I would write and let you know about my pre-natal experience. I was 21 years old and 20 weeks pregnant when I had my first scan. I was told the baby was lying in an odd position and to come back the following week, the doctor didn't think there was anything to worry about but he had spent a lot of time looking at the babies chest. He was part of a team researching scanning techniques for non invasive Downs screening, and he assured me that baby showed no signs of any syndrome.

The following week I returned and was informed that he thought the baby had a cystic lung. To confirm this I was sent to see Professor Nicolaides at the Harris Birthright Centre, Kings College Hospital. Having sat on a long corridor full of parents awaiting a glimpse of hope about their expected babies for an hour, we (grandparents and myself) finally saw this top foetal expert and after being poked and prodded for an hour and a half, he informed us that the baby didn't have a cystic lung but had an AVSD, which meant the baby either had Downs, Edwards or Patau Syndrome, the later two being incompatible with life. And that at my age I should terminate and try again as I did not want such a burden on my life.

I was offered various diagnostic tests but declined. I tried to adjust myself to the thought of having a Downs baby but I have to admit to being terrified at the prospect. My doctor felt I would benefit from transferring my pre-natal care to Guys Hospital and I was referred to Dr. Sharland a foetal cardiologist, feeling as if my world was falling apart and cursing every happily pregnant woman. This all happened in the space of four days and every medical person could not believe I wanted to keep my baby.

We met Dr. Sharland on the Monday morning and she made everything seem bearable. She sketched a picture of the babies heart so we could understand what was wrong. All my nurse training had flown out the window. She informed us baby was a girl and asked if we had a name and from then on baby was Jemima, a real person not just a foetus with a heart problem. She gave us a photocopy of a page from the heart children book and she was always there to answer any questions I had.

I finally made it through what seemed like an endless pregnancy, having an urgent Caesarean at thirty five weeks as Jemima had stopped growing. On the 12th May 1995 my beautiful little Jemima arrived pink, screaming, weighing 3lbs 3½ozs and my first thought was "Thank God it's only Down's." Jemima is now six months old she had her surgery in August and after a month in intensive care with every complication possible we came home. She is reaching all her milestones and is the most perfect and delightful girl I could have wished for. Thank God I didn't have a termination.

I'm starting up a prenatal diagnosis support group called footsteps, it's for anyone who is expecting a child with a heart problem so if anyone who reads the magazine would like to be of help please contact me.

Natasha Whitney (0181 800 8368)

Dear Editor,

My daughter Karen, who has Down's Syndrome and an AV Septal heart defect, is now 16 years old and has lead quite a full and active life. However, more recently, walking any distance seems to tire her easily and her pace is very slow. I have been warned that pulmonary hypertension may start to develop. I would be interested to hear whether other teenagers with heart defects are experiencing similar problems.

In addition, three years ago, Karen had a brain haemorrhage and it was discovered that she had a rare disorder called Moya-Moya Syndrome, which affects the cerebral blood vessels. Karen recovered remarkably well but it has made her future uncertain, as doctors say she could have a further haemorrhage at anytime. I would like to hear from anyone who has faced this particular problem to find out what effect it has had on their child.

I hope am not describing a gloomy picture of Karen because as you can see from the photo, she is a super teenage daughter who continues to amaze me.

June Vine, Horsham



Can You Help?

Many of you will have read Lynne Davies letter in the latest issue of the Down's Syndrome Association newsletter, but for anyone who missed it we have reproduced it. The Down's Heart Group is aware of several members whose children have problems with their knees, including Lynne's son David, so if you share a similar experience, do get in touch with Lynne

Regular readers may recall my letter two years ago describing the 'habitual subluxation' - 'dislocation' or 'instability' of my son David's right knee cap. David is now nine years old and this problem started when he began 'grinding' his right knee as a baby. This progressed to a 'clicking' knee as a toddler and now, having worn the groove smooth, the knee cap glides from side to side increasingly causing problems as it 'gives way' without warning causing frequent falls etc.

Very little has changed for David in the past two years, however, he is now regularly reviewed by the Consultant Paediatric Orthopaedic Surgeon, and various appliances and therapies have been tried to no avail. Surgery has been mentioned "when he is older" - although information from the USA suggests this should be done at seven years old. This is not however always successful and can in fact worsen situations.

I was most surprised two years ago to receive numerous letters and 'phone calls from parents all over the country whose children or young adults with Down's Syndrome had this condition. I wonder would the response have been as great from those who have atlanto-axial instability?

Some information has been obtained from the USA, Canada and Australia, however, it has been suggested that the Scientific and Research Advisory Committee should be approached for further assistance. In order to access the present level of membership affected with or by this condition, I would be most grateful for the following information, IN WRITING, as soon as possible:

1. Name
2. Address including postcode and telephone number
3. Sex of child
4. Date of Birth of child
5. Age when problem(s) with knee started
6. Any treatments to date - surgery/appliances etc.
7. Consent to information being passed to Scientific and Research Advisory Committee for further research assistance.

It would seem that only by making others aware just how many of our children/young people are affected by this condition, can we hope to gain further information, advice and treatments.

Lynne Davies RGN, Ruthin
Chair, North Wales Branch DSA

Letters may be sent to the Down's Heart Group National Office for forwarding to Lynne.

The above article was reproduced from the DSA News (GB) Summer 1996.

Research News

Last year members will recall receiving a letter from a firm of solicitors, Messrs. Alexander Harris, asking them to complete a questionnaire about the nature and quality of treatment their child had received. This firm wished to carry out a survey in order to compare with the treatment received by a client of theirs. The Down's Heart Group agreed to address and forward these questionnaires to its members, in return the solicitors agreed to provide a statistical analysis of the data they received. The following is a breakdown of that information.

Greg Waldron of Alexander Harris writes: "Firstly 199 replies were received out of the 600 sent. This is an exceptional response and again please convey my thanks to all those who replied.

My analysis of the replies is general in nature due to the fact that the circumstances in each reply differed greatly and spanned a wide range of birth dates.

My findings were as follows:

In 48 replies surgery had not been performed.

This is further broken down that in 12 cases surgery was not required as the heart defect healed spontaneously.

In 8 cases the parents decided against surgery.

In 15 cases the parents were told that the condition was inoperable.

Reasons were not given in the remaining replies.

Therefore in 151 replies heart surgery was performed for the differing defects.

In 24 instances it was reported that surgery was unsuccessful, but in 12 of these cases the remaining problem was reported as a slight valve leak after a concurrent septal defect repair.

If you then consider that in 12 cases for various reasons surgery was unsuccessful, then as a percentage this is around a 8% general failure rate.

Out of the 199 replies in 20 cases the death of the child was unfortunately reported, but 6 of these were not apparently related to the untreated heart condition or heart surgery.

In 68 out of the total replies, parents spontaneously stated that they were very happy with all treatment and attention they had received and praised the practitioners and hospitals. Expressed as a percentage this is 34%.

23 of the total replies referred to poor attitudes and possibly discrimination to their child. Again expressed as a percentage this is 11%.

Finally, in the replies relating to babies born in 1994 and 1995 it was reported that 68% of the babies were diagnosed with a heart defect at birth.

Comparing this with figures from the replies for babies born in 1984 and 1985 then 44% were diagnosed with a heart defect at birth,

In around 20 replies delays in treatment due to problems with NHS resources were reported, but this did not affect the outcome.

There was no evidence of any child having been directly prevented from receiving treatment due to discrimination.

Book Review

Medical and Surgical Care for Children with Down Syndrome - A Guide for Parents

Edited by D.C. Van Dyke MD, Philip Mattheis MD, Susan Schoon Eberly MA and Janet Williams RN PhD Published 1995 by Woodbine House USA

This book gives parents an overview of specific medical conditions that are more common amongst children with Down's Syndrome, including eye, skin, ear, nose and sinus conditions, gastroenteric, neurological and orthopaedic conditions, dental concerns, reproductive issues and leukaemia.

The twenty-eight page chapter entitled 'Heart Disease and Children with Down Syndrome' includes basic information on how the heart functions, the causes of heart defects in children with Down's Syndrome, the symptoms of heart disease, associated disorders of the heart and circulatory

system, disease of the circulatory system of the lungs and diagnosis, medical and surgical treatment and their results.

All the information is carefully explained to give parents the ability to understand and ask more specific questions on their children's condition when in hospital or at Outpatients Clinic.

I consider it to be a useful handbook for parents.

*Sheila Forsythe,
Bristol and South West Co-ordinator*



Change of Address?

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



Notification of Change of Address

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

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

Child's Name :

Child's Date of Birth :/...../.....

Postcode :

Telephone :

Send to: Down's Heart Group, [redacted]



Dream Come True

*For eight long years for a baby I had tried
But each and every month my wish was just denied
Then finally the doctors gave the thumbs up sign
You're going to have a baby at Christmas time*

*It wasn't until the morning the doctor came to say
I am so very sorry to spoil your special day
Down's Syndrome suspected but please don't get depressed
We really can't be sure until we do some further tests*

*I gave birth to my daughter at 10 o'clock at night
I couldn't believe my luck she looked so alright
I laid awake for hours just gazing down at her
What a night that was, my mind was in a blur*

*It was three days after this the results came in
I went to see the doctor and I just stared at him
He tried to break it gently but confirmed my greatest fears
I ran out of the hospital in floods and floods of tears*

*But since that day I've learned to take this in my stride
Samantha's bright and happy, she fills me with such pride
My gorgeous little baby is so perfect now to see
And I thank God each single day for giving her to me*

Irene Booth, Elstree

