



DOWN'S
HEART
GROUP

NEWSLETTER

(Issue No 18)

Spring / Summer 1998



Daniel Bryan's first school photo - read his story inside

Contacts

National Office

National Administrator
Penny Green



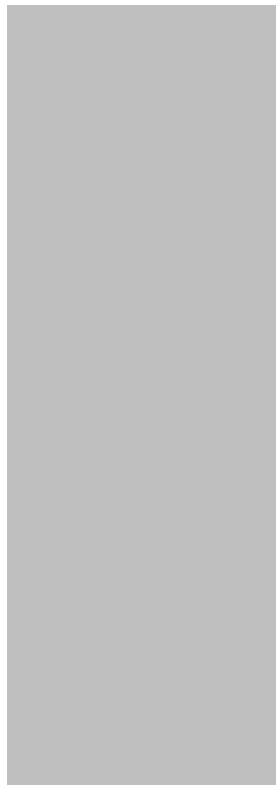
Contact or Ansaphone always available (24hrs in emergency)

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Linda Walsh

Chair

John Spall



Vice-Chair

Sheila Forsythe

Treasurer

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Patron

David Graveney

In this Issue

Chairman's Report	page 3
Annual Conference	page 4
Sophie's Story	page 6
Daniel's Story	page 7
Kathy's Story - a tribute	page 8
Information Page	page 9
World Congress Report	page 10
Fund-raising Update	page 14
Competition	page 16
Poem - "Hope"	page 17

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

The Down's Syndrome Educational Trust
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SOUTHSEA
Hants.
PO5 1NA
Tel: 01705 824261

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

Scottish Down's Syndrome Association
158/160 Balgreen Road
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EH11 3AU
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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.

Chairman's Report

I was told off by Penny for a lengthy Chair's report in the previous edition of the Newsletter, which extended on to a second page and upset her carefully planned layout. I have promised to do better this time and obey her injunction to "keep it short".

World Congress

As promised a report on the Sixth World Congress appears in this edition. An extremely hectic, tiring but rewarding experience. As requested by the organisers, we have printed in full, the text of the Official Conclusions of the conference, which represent a challenging rallying cry to everyone involved with Down's Syndrome to re-double our efforts in the future. Some aspects, which go to the core of the nature and potential prevention of Down's Syndrome, may be controversial, but overall they represent a massive agenda for change, probably even greater than that which has occurred over the last ten years.

Down's Heart Group embraces this programme for action and in its own very small way will work to bring it about. In particular it is pleased to see emphasis on practical solutions to health care, preventative medical programmes, access to organ transplant programmes, specialised needs, the role of the family and of course the effective integration of people with Down's Syndrome in all aspects of community living.

Effective Action

In particular, DHG is reviewing all its services to members and its own internal workings. Out of this already has come the proposals for our hospital visiting service, responding to the changing patterns of surgery; overhaul of our information services with the production of the video and the Topic Notes series; and the provision of a new computer and publishing facilities at National Office.

We have also for the first time for 1997/98 adopted a specific "Business Plan" detailing what we hope to achieve during the year, together with the budget required to achieve this. This is very much in line with recommendation 14 from the World Congress and the requirements of the Charity Commission.

Chronic Cardiac Conditions

One of our targets for this year is to review and improve our services to families with older children and adults who, for whatever reason, have not had a heart repair. We realise that within this group there will be a range of conditions, circumstances and needs, and that indeed in some cases no particular requirements at all, as families are coping quite adequately and do not see themselves as having a particular problem.

We will shortly be writing to all families in this group to seek their views about DHG services and gauging reaction to the possibility of DHG holding one or two meetings in the autumn, specifically for such families.

We very much hope that if you receive our letter and questionnaire you will take a few minutes to complete and return it, as even if you do not feel that you have any special needs, this of itself will help our planning.

I hope all this comes in at under one page, or I will be in trouble again!

PS If you live in the East Midlands don't forget the Annual Conference in Leicester.



*Since the last newsletter we are very grateful to have received many donations. Some are mentioned below, but we would also like to take this opportunity to express our thanks to **everyone** who has helped the Down's Heart Group in any way. Your support is greatly valued.*

Anpak Ltd, Essex
Barclays Bank, Hounslow
Carlsberg Tetley
Sock Shop

*(bubble post packs for video distribution)
(proceeds from sale of recipe books)
(several fund raising events)
(socks)*

Donations in memory of :

Keith Iles - Calne (Grandfather to Gemma)
Courtney Saunders - Hull

DHG 1998 Annual Conference

takes place on
Saturday 9th May in Burbage, Leicester

With Keynote speakers on :

- ◆ Surgery / Anaesthesia
- ◆ The new Green Paper on education
- ◆ Young people growing up with Down's Syndrome

and Workshops on :

- ◆ Medical problems
- ◆ Statementing
- ◆ Integration - the teachers perspective

Full details and registration forms will be sent to all registered members at the beginning of April. The Conference is open to non-members and professionals, please contact National Office for a Registration Form.

Registration payable on the day :	DHG Members	- £1.50p per adult
(Lunch is included in Registration Fee)	DSA Members	- £5.00p per adult
	Professionals	- £10.00p per adult

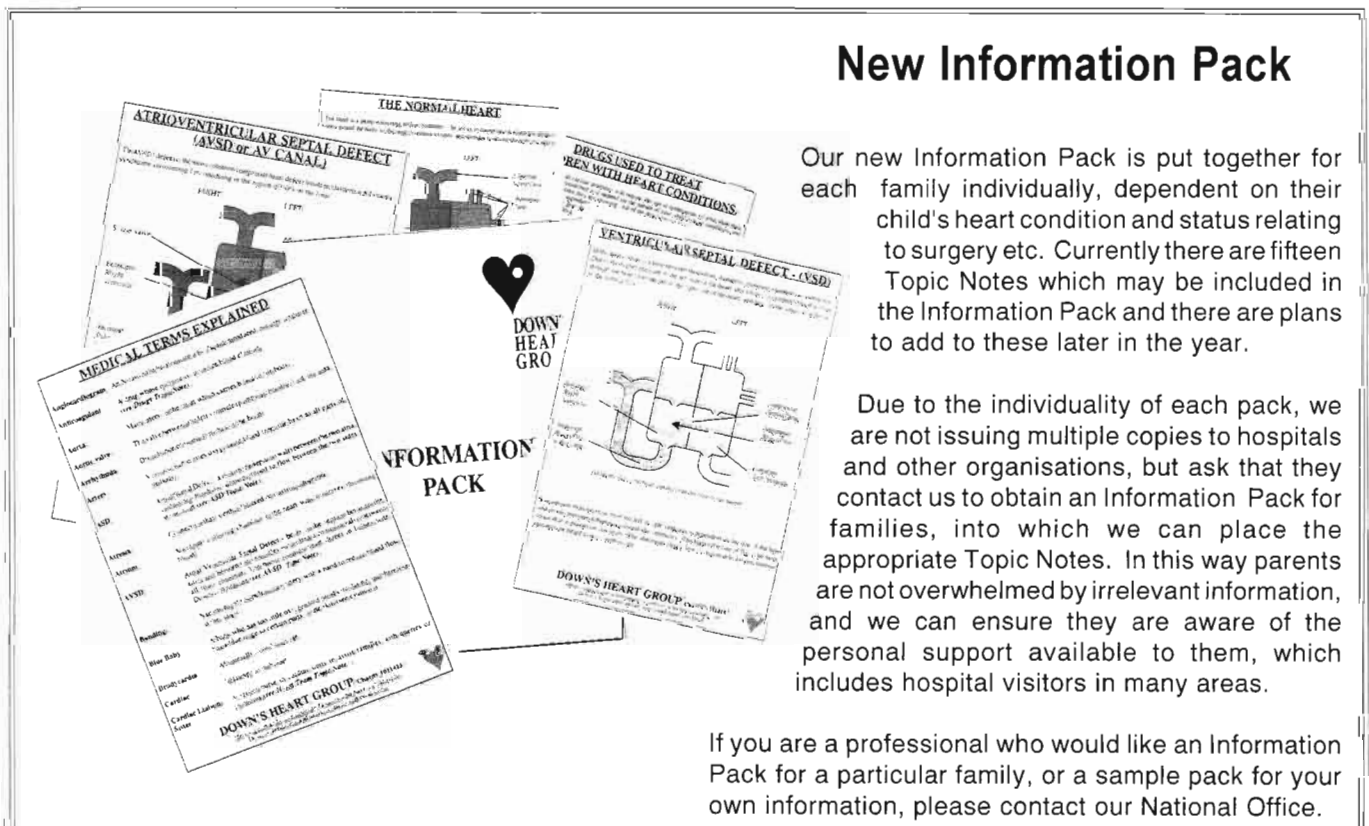
There will be limited Creche places available (with priority to DHG Members.)

New Information Pack

Our new Information Pack is put together for each family individually, dependent on their child's heart condition and status relating to surgery etc. Currently there are fifteen Topic Notes which may be included in the Information Pack and there are plans to add to these later in the year.

Due to the individuality of each pack, we are not issuing multiple copies to hospitals and other organisations, but ask that they contact us to obtain an Information Pack for families, into which we can place the appropriate Topic Notes. In this way parents are not overwhelmed by irrelevant information, and we can ensure they are aware of the personal support available to them, which includes hospital visitors in many areas.

If you are a professional who would like an Information Pack for a particular family, or a sample pack for your own information, please contact our National Office.



Regional Contacts

If you experience any difficulty in contacting someone locally, please get in touch with our National Office who will be able to help you.

Overseas members please contact National Office in all instances. (details on page 2)

Bristol & South West
Avon, Cornwall, Devon, Gloucs., Somerset & Wilts

Sheila Forsythe

Wendy Hellowell

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

Nicola Desmond

Lindsay Wharam

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

Sarah Smith

Ireland
N. Ireland & Eire

Rosina Brierley

(Dublin Hospital Visitor)
 Marion Delaney

(Dublin Hospital Visitor)
 Julie Keating

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

(GOS Hospital Visitor)
 Sheila Boniface

(Harefield Hospital Visitor)
 Joanna Simms

London Southern
Kent, Surrey, Sussex & S. London

Katie Spall

(Guys Hospital Visitor)
 Sharon Porter

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

Sally Hardman

(Freeman Hospital Visitor)
 Pat Studholme

North West
Anglesey, Cheshire, Clwyd, Gr. Manchester, Gwynedd, High Peak, Lancs. & Merseyside

Mike Halpin

Scotland
Mainland & Islands

(Glasgow Hospital Visitor)
 Elaine Thomson

South Wales
Dyfed, Glamorgan, Gwent & Powys

Chris Stringfellow

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

(Southampton Hospital Visitor)
 Vickie Richardson

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

Pat Mitchell

Lynne Holden

Yorkshire & Humberside
Humberside & All Yorks.

Linda Watcham

Lindsay Allen

Sophie's Story

To start Sophie's story I must explain that David and I are foster parents. We have three sons of our own and we have fostered pre-adoption babies for fourteen years, apart from a break in 1989, when I did my nurse training. I worked as a Staff Nurse on the paediatric unit "between babies" on a part time basis.

In 1996 we were fostering a pre-adoption baby who the midwife was visiting routinely, when she told me about a premature baby, born at thirty weeks, weighing 1lb 13oz who had Down's Syndrome and a heart defect and whose parents, very sadly, felt that they couldn't take home. The midwife asked what would happen to her if she was placed for adoption and I said half-jokingly, "Oh she'll probably come here"

Surprise surprise, a week later we were asked by Social Services if we would consider fostering Sophie, as she is now called. The pre-adoption baby we had was due to go to her new mum and dad so I jumped at the chance to go and visit Sophie on neo-natal intensive care. I'm afraid it was love at first sight. She looked so vulnerable lying there hooked up to all that equipment. She really needed someone to love her and I ached to pick her up and cuddle her.

For the next month I visited Sophie every day and fed and bathed her. David came in to meet her and was as keen as I was to foster her as long as it took to see her through the cardiac surgery that we knew was round the corner. When Sophie was ten weeks old and weighed 4lbs, she was referred to Alder Hey Children's Hospital and discharged home to us on back-up oxygen.

Two weeks later we set off for Alder Hey, where Sophie underwent ECG, chest x-ray, echocardiogram and blood tests. The cardiologist very carefully explained the nature of Sophie's complete atrioventricular septal defect. He drew some diagrams and the cardiac surgeon also explained that in order to prevent Sophie's lungs from becoming damaged by the extra blood pressure. They would need to put some bands on the pulmonary artery and they would like to operate in five days time! This was a bit of a shock and Sophie's birth mum had to be contacted in order to sign the consent forms. The emotional trauma had only just begun for everyone involved.

We returned to Alder Hey and I took Sophie to the anaesthetic room and returned to our room in floods of

tears, suddenly realising the depth of my feelings for this tiny baby. Sophie amazed us all. She spent one night on ICU, and in five days we were home. We spent the next twelve months trying to encourage her to feed, even going back to tube feeding for a period of four months. Her three monthly trips to Alder Hey were always good news and she remained bright and alert, very responsive, but was a very poor feeder, weighing 12 lbs on her 1st birthday

In January 1997 Sophie had a cardiac catheterisation to gain more exact information and we were told that they would repair the hole in her heart and reconstruct three of the valves when her weight reached 13lbs. We

approached this weight with fear and trepidation but on April 10th 1997 Sophie was admitted for her repair. Sophie's birth mum had attended pre-admission clinic with us and had signed the consent forms.

On Monday morning Sophie went to theatre at 10.00am. This was the longest day of our lives. The ward staff were wonderful and kept us informed throughout of Sophie's progress. At 17.00pm. we finally got to see Sophie on ICU, including her birth mum who wanted to be there. Again it was very emotional for all of us.

Sophie was on ICU for seven days. She had a few complications, cardiac arrhythmia's and chylothorax requiring a chest drain. She remained in Alder Hey for one month and I stayed with her all the time. David stayed for four days after her surgery and came to stay every weekend. Birth mum didn't visit again but we kept in close contact with her.

Sophie finally came home on May 13th. Her surgery was fairly successful although she will need her mitral valve replacing with an artificial one at some point in the

future, but not for a few years yet. Sophie's sternum has not knitted together and she is waiting to have this repaired. Sophie's only medication now is iron and vitamins. She is now two and is a picture of health. She's full of energy, crawling, shouting and laughing.

Our proudest moment was when we went to court on December 15th 1997 to adopt Sophie. We are all delighted to welcome her into our family. She's an absolute delight to be with and we just couldn't imagine life without her.

**Dianne Preston
Barnoldswick**



Daniel's Story

Daniel Alexander Bryan arrived on the 21st April 1989 after an uneventful labour. He is the fourth out of five children and we had been trying for four years for a baby.

When Daniel was born we immediately noticed his thick chunky hands and fingers, flat nose and the gap between his toes, but upon questioning were reassured by the hospital. During the next few days, seeds of doubt were sown as I compared his weak cry and lethargic way with that of other babies around me. No one else noticed, so when discharge time came I felt I simply had to mention something. I commented that he had a strange shaped face, but still nothing was said.

So we brought Dan home, a healthy normal baby, and I forgot about my doubts. Then at five weeks he began having apnoeic attacks. I lay awake at night listening to his erratic breathing, waiting for the next breath. I was terrified but no-one took me seriously as he was breast feeding normally, and seemed fine although his skin was very dry and flaky.

Then he had a serious apnoeic attack, he turned blue and stopped breathing. My nextdoor neighbour brought him around and we rushed to hospital, but nothing was found and we were again discharged. The following week the same thing happened, but by chance there was an Australian doctor visiting the hospital, and he suspected Daniel's condition. He told me that he was going to do some blood tests, and when I asked why he muttered something about chromosomes. Immediately it all came back to me, and I asked if he suspected that Daniel had Down's Syndrome. He said yes, and his suspicions were confirmed; at five and a half weeks Daniel was finally diagnosed. He also had a slight heart murmur which we were told was very common.

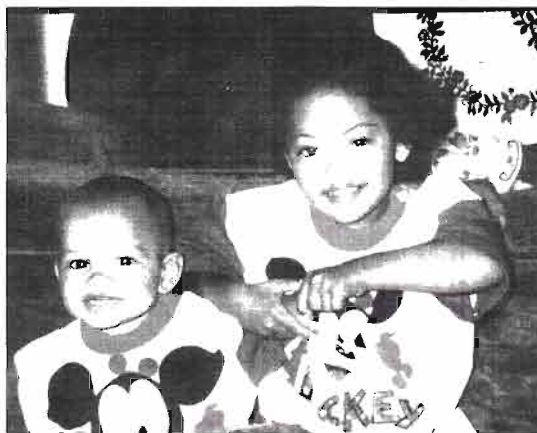
We were given an appointment to see the Paediatrician who gave us a poor prognosis of Daniel's well being, health and mental state, and we left in a daze. Over the next few weeks our health visitor vanished, and people like our GP and midwife admitted they "don't see too much of this problem", and we were left alone. We looked around for support and were given a community nurse (our lifeline for the following years) and also joined the local Opportunity Playgroup which was inadvertently the most important decision we made.

Daniel's heart was checked six monthly. His murmur was mentioned to us whenever he had any routine checks, though we were never told exactly what the problem was. Dan made good progress. He had Portage, went horse riding and swimming, and I began to teach him to read. His breathing remained erratic and we had little sleep for the first three years, although no more serious attacks.

Eventually at one of his six monthly checks we were told that he had a Patent Ductus Arteriosus. We were told that he actually had two holes which had not closed at birth and were allowing blood to flow from his heart to his lungs which gave the heart extra work to do. He showed no

external signs of this at all and we were told 'one day' it will need to be fixed. With Dan's erratic breathing we were happy to leave it at that.

Dan was soon to start at our local primary school, and late in 1994 we were told he would need his heart operation soon. We did wonder why it had been left so long - if his having Down's Syndrome gave him less priority - but we were never given any answers. However, once we were referred to our local Children's Hospital we were given more understanding of his condition and shown that it was important to put it right soon to prevent chest infections and problems as he grew bigger. We agreed that it would be done in 1995.



We were shocked when a letter arrived for us in January 1995, we had much later in the year in mind!!! The operation was set for the 26th. We were extremely nervous and needed support; we had so many questions. That is when we were given information about the Down's Heart Group - another lifeline. We didn't have to go anywhere, you came to visit us at home and gently answered our questions and calmed our fears. We were loaned a film on catheterisation and were able

to talk through all the details with someone who themselves had faced the terrible worry - so important to talk to people who've lived it too!

We were told by the hospital that Daniel's incision would be in his groin, and an umbrella like device would be guided up to the area where the leakage was occurring. Then the umbrella would be opened and secured in place to cover the hole. We were amazed and also very fearful, more so of the anaesthetic. Daniel was admitted the day before his operation for tests. I had to leave him that night as I was still feeding his baby brother Tim, but his father stayed with him. We both agree that this time was much worse than when we were given the diagnosis of Down's Syndrome, we were so frightened of losing him.

I went back early next morning with Tim. Dan had his premed at 9am and went to theatre at 10.30am. I took him into the anaesthetic room and left with him singing (wobbly but singing) a song. I was numb. The operation lasted two hours. Dave and I sat in the parents room and didn't speak. I'm sure many mums and dads will know exactly how we felt. We were very nervous to go back and the time seemed to stand still.

When eventually we dared to go back, we were walking along the corridor not speaking, when who came along beaming but Sheila Forsythe from the Down's Heart Group. "He's back" said Sheila - that is why I wrote to thank you.

Dan is now fine. He needs no special care, treatment or check-ups again.

**Pauline Bryan
Bristol**

Kathy's Story - tribute to a young lady who is sadly missed

Kathy was born on 23rd July 1965 at Colchester Maternity Home our second child. I was thirty eight years old. Nigel, our son, had been born there three years earlier and I had had a very quick birth so with this pregnancy my doctor had said I would have to get in at twenty minutes otherwise it would be too late. I knew I was nowhere near giving birth but obediently went in at twenty minutes only to hang around another forty eight hours until she was born -so much for the second child being quicker than the first.

It was an easy enough birth, and she weighed 4lbs 15 oz. The midwife called another nurse saying "Sue got something to show you" but nothing was said to me at the time. Kathy was brought to me for a cuddle the next morning and I noticed her face went inky blue in a line straight across. I took her into bed with me, and she was frozen. I rang the bell, and a nurse whipped her away, and afterwards I was told to feed her in the nursery, as she was too small to bring out. They kept me in eleven days and wanted me to stay longer to learn how to cope with her, as she was shocking at feeding. They also said they wanted me to have a good rest, but I had already missed my sons third birthday on 25th July and was very anxious to get home.

The day after I came home my Doctor called and told me "I had a suspect mongol" but that it would be confirmed in a month by the paediatrician at the hospital. This was confirmed then and the doctor also said she had a heart murmur. We attended his clinic for years and the only trouble was at sixteen months she had bronchial pneumonia and went into hospital for nine days. She came out looking fit and well although it was then they told me she had a hole in the heart.

She didn't seem to have any obvious heart trouble, although she was very difficult to feed and didn't walk until she was five and a half years old. I assumed this was normal for her condition. When she was seven years old the paediatrician told me she was perfect and had no more heart trouble and he didn't want to see her any more. I was surprised but assumed that the hole must have closed.

I had had a nervous break down when she was three and had been advised to put her into care as it was too much of a strain for me. She was taken into the local special school at three (the usual age then was seven). She finally went into care in a hostel a couple of miles away from us when she was nine. From there she went daily to school and came home to us every third weekend and all school holidays.

When she was fifteen I had her home for the weekend and we missed her pick up coach. I went home and phoned the school to say sorry we were going to be late but that I would get a taxi. The secretary said what time is your appointment? It turned out that she was due to attend a heart clinic held at the school at 2.30pm.

Two doctors I didn't know were there and they weren't too pleased to see me, they said "You've never been here before" and I told them I had no idea she was attending a clinic. They said (still annoyed) "well she's inoperable, incurable, and will be dead in ten years time, and quicker if she has anything else wrong with her". How I got home

that day I don't know.

From then on we noticed her gradually getting worse, blue hands feet eyes and mouth but she certainly didn't look desperately ill, and was able to keep up with activities at school, and later at sixteen at an adult hostel and the training centre. Once she had left school she no longer attended a clinic. I was told her G.P. would see to her.

It was in 1991 when I was told she had Eisenmengers Complex and in 1995 when I was told she wouldn't live beyond thirty. Now she is thirty and has been in a wheelchair two and a half years. She has three to four angina attacks a day and gets a lot of pain in her arms and ears due to circulation problems. Once out of pain she reverts to being a happy, loving girl who loves life and enjoys being taken out and about.

She has left the training centre as she can no longer cope but still goes horse riding, to the cinema and theatre, aromatherapy, relaxation, disco dancing etc. She is now in the community with twenty four hour staffing and has blossomed. At Christmas they took her to Olympia to see the horse show which she loved. I also took her to our local Pantomime which she thoroughly enjoyed.

I can't believe what will happen to her. One thing I don't think she knows she is ill. She can speak but can't hold a conversation with you. But never have I seen her worried or fearful, she simply seems to take what comes, which is marvellous.

**Joy Wells
Colchester**

Joy wrote the above account in January 1996. Kathy continued to lead a happy and active life within her limitations until she died early in October 1997. There was an abundance of floral tributes at Kathy's funeral, as well as numerous donations in lieu of flowers for the Down's Heart Group.

PLEASE HELP US
by saving stamps, postcards, ring
pulls and Greetings cards

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

Please save used postage stamps (cut neatly from the envelope), postcards (used and unused), ring pulls from drink cans and old greetings cards (just the front picture).

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

THANK YOU

Information Page

Call For Hirschsprung Disease Study Participants

Dr. Aravinda Chakravarti and his research group in the USA are currently in the seventh year of a study to determine how Hirschsprung disease is inherited. The primary goal of their study is to identify the genes involved in the development of this disease. The fact that children with Down's Syndrome have Hirschsprung disease more frequently than other children leads them to believe that there may be a gene for Hirschsprung disease on chromosome 21. They wish to conduct detailed genetic studies to enable them to understand the relationship between these two diseases, and hopefully facilitate better treatment.

Families interested in participating or learning more about the study can contact Penny Green at our National Office, who will pass on their details to the research group in America.

Sleepy Time Bunny Clock



This clock is cleverly designed with an animated face to help children understand the difference between bedtime and getting up time. At night the alarm is set and the bunny goes to sleep, in the morning at the preset time the bunny awakes, with or without an audible alarm, and lets children know it is morning.

The clock is currently available at a special offer price of £15.95 with postage and packing cost of £3.50.

For further details or to place an order contact :
Beckett Karlson



Does your child have special needs?

Are you having **problems** with their **education?**

Then ring **IPSEA** for **free advice** on **01394 382814**



IPSEA
Independent Panel for Special Education Advice
4 Ancient House Mews, Woodbridge, Suffolk IP12 1DH
IPSEAS Advice Line provided in support of the National Lottery and NASEN
Registered Charity No. 327891



NATIONAL LOTTERY CHARITIES BOARD

FREE independent advice
FREE representation at the Special Needs Tribunal
FREE second professional opinions



Are you Bilingual? Could you translate to and from another language to English?

The Down's Heart Group has many connections around the world, and receives several newsletters and articles each year in other languages. Could you spare a little time now and again to read some of these, and translate articles of interest for inclusion in our newsletter?

There are also occasions such as the World Congress, where we would like to translate some of our literature into other languages.

If you can help with **any** language, please contact Penny Green at National Office for more details.

cruse – bereavement care

From March 14th this year, Cruse have a new service for young people and children coping with a bereavement.

The "Youth Line" is available on Fridays between 5pm and 9pm and on Saturdays between 11am and 6pm by calling :

0181 940 3131

6th World Congress on Down's Syndrome

This congress was BIG. To quote a few statistics:

- ♥ There were approaching 3,000 delegates from sixty countries, the majority of whom could be accommodated in the main conference hall at one time.
- ♥ There were 9 plenary sessions with 17 eminent world experts.
- ♥ There were 33 workshop sessions involving the presentation of 285 individual papers.
- ♥ There was an exhibition of 133 individually designed posters from organisations and centres worldwide.

This was at times quite overwhelming and made us reflect fondly on the homely, intimate European Conference in Dublin in 1995, with its mere 500 delegates!

It made us realise what a tiny cog the Down's Heart Group is in a very large global movement. Our popular stand was one of the very few manned by a support group. We also did a presentation to the cardiac workshop, and we launched our new video and topic notes. There were no other heart groups, so we can still say we are the only one in the world.

It was quite impossible to attend more than a fraction of what was available, particularly as we had to staff the stand continuously. What follows, therefore, are some quotes and extracts from presentations which caught my eye and which you may find of interest. Of course these are taken out of context so in no way reflect the complete presentation by their authors.

Genetic Research

One of the important themes of the conference. My impression was that we're at the point where "specialist shall speak unto specialist" particularly in the workshops e.g. "MNB encodes a serine/ghreoline protein kinase with an essential role in *Drosophila* postembryonic neurogenesis". Eh! well beyond the lay parent at this stage but with significant implications for the future.

Prof. Charles Epstein from San Francisco in a plenary session did some crystal ball gazing about where genetic research, combined with similar progress in the biological and psychological sciences, might lead in the 21st century. He was guardedly optimistic, particularly as Down's Syndrome was attracting considerable genetic research interest because of its range of associated abnormalities.

- ♥ Chromosome 21 will be completely mapped and sequenced, the genes identified and their functions defined.
- ♥ The gene or genes responsible for many of the components of Down's Syndrome (e.g. congenital heart disease, Alzheimer's disease) will be identified.
- ♥ Some genes which are responsible for the cognitive elements of Down's Syndrome will be discovered.
- ♥ There is a reasonable likelihood of developing drugs and other therapies that will ameliorate or even prevent some components. Also possible approaches to improving cognitive functioning can be devised.

"There is at the present time, a sense of excitement and anticipation among research workers interested in Down's Syndrome"
San Francisco, USA

The Parents

"A number of reports and research studies have recommended guide lines for this practice (of breaking the news of Down's Syndrome). Important aspects of these recommendations are:

1. *breaking the news as early as possible*
2. *with both parents together*
3. *with the child present*
4. *giving early opportunity for follow up interviews*
5. *providing sufficient information in clear nontechnical terms*
6. *handling the interview in a sympathetic and honest manner."*

Padua, Italy

"We enter a new world where we are asked to become an educator, a speech therapist, an occupational therapist, etc. We have to go through many emotions that other parents will never feel. We have to learn a new vocabulary and have contacts with many professionals, who on many occasions will tell us what to do without asking us what we want..... All of this new information leaves us (parents) quite vulnerable. We feel guilty because we gave birth to a child with Down's Syndrome, we feel guilty if we do not invest all of our time on the development of our child and we feel guilty if we do not try every new therapy. Enough!"

Quebec, Canada

"Mothers in our study met the challenges of the birth of a child with Down's Syndrome by modifying expectations of the child, adjusting their behaviours and making use of the family and community support.... after initial negative feelings mothers develop strategies to foster contentment with their children."

Madison, USA

Madrid 23rd - 26th October 1997

Early Intervention

"This study has assessed the speech and language skills of a group of children with Down's Syndrome who have had consistent and structured early intervention from birth to five years and compared them with a group matched closely for sex, age and social class. The control group has had a wide variety of experiences in terms of instruction help or remediation, more typical of early intervention in the UK. The results indicate no significant differences in outcome between the two groups, but with individual variation with both groups."

Portsmouth, UK

Inclusive Education

"We now enjoy a new generation of young adults with Down's Syndrome most of whom have grown up with their families, attended their neighbourhood schools, making friends, while fully expecting to participate and contribute as young adults. New possibilities have been created by a generation of families who have pursued their dreams even further than they had previously thought possible."

Calgary, Canada

"The educational capabilities of students who have Down's Syndrome are often poorly understood and nearly always underestimated..... The educational achievements of students who have Down's Syndrome are far more substantial and individualistic than is commonly believed."

Minnesota, USA

"Both of the students (with Down's Syndrome) learned to calculate algebraic expressions with parenthesis, with positive and negative numbers and even with powers. The boy was able to do the algebraic sum of monomials. The girl performed expressions with fractions."

Padova, Italy

"All children with Down's Syndrome can learn to read and write!..... Teaching Down's Syndrome children to read and write as a part of their empowerment for everyday life in a literate society is a top priority!"

Koblenz, Germany

"That children with Down's Syndrome could maybe learn to read and write became generally known in the field at the end of the eighties. However the dogma "They will never learn maths" remains alive until the present day. In the literature, there is very little description about the process of learning maths for our children..... Teaching maths was conducted simultaneously with teaching reading at a very early age and made effective use of the emerging reading proficiency."

The Netherlands

"Two years after the initial assessment there was still no significant difference between the reading scores of the children with Down's Syndrome and the reading age control group, indicating similar rates of progress in the two groups, despite the children with Down's Syndrome being significantly delayed on all other measures."

Portsmouth, UK

Work

"The work role is a main factor towards the individual with Down's Syndrome achieving adult identity, as well as being an exceptional source of learning and the necessary condition for real social inclusion."

Genoa, Italy

Sexuality and Down Syndrome

"Individuals with Down Syndrome increasingly find themselves dealing with social interactions, higher visibility in the community and improved opportunities of employment. As this occurs sexuality, in all its complexity, becomes an issue of increased importance. Friendships, relationships and sexuality are normal parts of adult human development. For some individuals this may mean friendship; for others, physical closeness; and for some, it may mean marriage and children "

Iowa USA

Alzheimer's Disease

"This finding indicated that, contrary to other published reports, while adults with Down's Syndrome are affected by Alzheimer's dementia, reported dementia among adults with other aetiologies for intellectual disability is more prevalent."

New York, USA

People with Down's Syndrome

"I have always wished to give my heart to God and to people; I don't want to be happy on my own. The Down's Syndrome, although sometimes it was a burden to me, in my opinion it was neither a malediction nor a blessing; maybe it was a test to see if, in spite of everything, I could live a complete life, a life like everyone else. I am convinced that it was an incentive to myself, to prove that I was like everybody else, a sort of challenge, after all. A challenge that I accepted and that still spurs me on to give my best and to deeply commit myself to obtain the things that my heart needs."

Cosio Valtellino, Italy

"Timothy is a healthy young man ... His parents were determined to give him a normal (even demanding) upbringing, including schooling. They ignored traditional stigmas and taboos... were committed to his independent future... at school there were positive and understanding teachers. His enrolment at the vocational training centre for a painting and decorating course was facilitated by an officer from the local Rehabilitation Centre. Timothy is a person with high ability and a positive environment that ignores stigmas."

Gabarone, Botswana

"I know I have Down's Syndrome, I know that it means I have an extra chromosome. I don't really understand what that means except that I look a little different and that I am supposed to be slow. My mum says I have never been slow in my life but she is my mum and she loves me. I know I look like my dad and it's important to me to have my own identity because I am an individual."

New South Wales, Australia

"There are so many prejudices. Everyone interferes and acts as if he/she knows things better than Peetjie and her family. Whenever she makes a mistake, it is always considered as being caused by her having Down's Syndrome. As a person with a handicap you have to be perfect!"

Schinnen, The Netherlands

John Spall

The DHG Display Stand

Remembering the popularity of our information in Dublin in 1995, we made sure that we took with us an extensive supply of the Topic Notes and videos, and somehow managed to avoid any excess baggage charge on the flight. The first priority upon arrival was preparing our stand, which we did amongst a lot of friendly banter as all the 'associations' were together in one area, and busy with the same task. There was a lot of chatter as old acquaintanceships were renewed.

After much discussion, John, Katie and I agreed on a layout and we set about putting up posters, setting out Topic Notes, newsletters and leaflets, and making a display of empty video boxes which we hoped wouldn't get knocked over. Finally we were happy with the result, and that was the way the stand stayed apart from a few minor alterations later when we reorganised slightly to enable Sam Campbell to display information from the Scottish DSA.

Throughout the Conference there was a fairly constant stream of delegates at our stand. The busiest time was during the breaks, although even during the sessions and workshops, there were always a number of delegates wandering around in search of information. As in Dublin, there was a great deal of interest in our work and available information, and a large quantity of our literature was given out. The Topic Notes were particularly well received, and we had many requests for permission to translate them into other languages. There was also a good response to the video, and thirty four copies were sold.

Answering questions kept the three of us very busy throughout the Conference. There was a wide diversity of subjects covered ranging from parents asking individual questions specific to their own experience, through others representing organisations who wanted general information that could be passed on to members, to professionals looking for broader insight in to the problems their clients might experience. Inevitably with delegates attending from so many different countries there were occasional language problems, but these were mainly overcome, and having our parents leaflet available in Spanish assisted on numerous occasions.

Workshop Presentation

The workshop in which the DHG was involved, took place in the first session, so consequently none of the panel of speakers had had the opportunity to preview the setup. There were a few initial problems with the simultaneous translation, but Professor Conor Ward, the panel Chairman, coped admirably with the technical difficulties which were soon resolved, and we were able to get on with addressing our sizable audience..

Our workshop began with a presentation from a cardiologist, Dr J Casaldáliga, followed by one from a surgeon, Mr JM Brito, both of whom were Spanish. It was quite a strange experience to view the slides and be vaguely aware of the speakers voices, and then after a short delay to hear the English translation through your headphones, but none the less, they were very interesting presentations, and very much in line with those that I have attended in the UK.

Finally it was time for John and I to deliver our item on the work of the Down's Heart Group. We spoke about the Topic Notes and the video, and how these had been written by parents in order to make them easily understood by families, and how this personal level of support and understanding is complimentary to the work of the medical profession. We talked about the changes in the age at which children are generally now having surgery, and the steps we are taking to respond to these, and we talked about those young adults for whom surgery had not be available, and the different support requirements they and their families have.

Judging by the questions asked at the end, our audience had been attentive and interested in all the presentations.

Penny Green

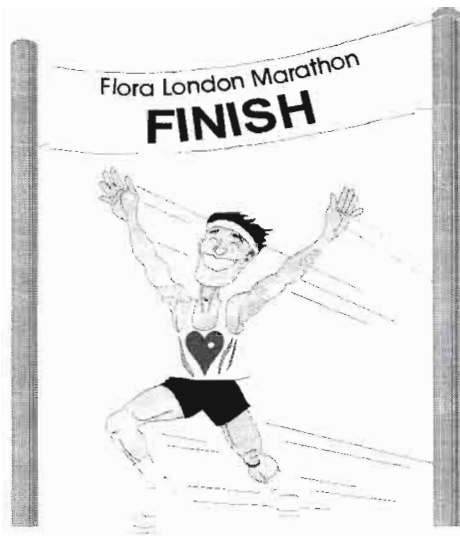
Official Conclusions of The 6th World Congress on Down's Syndrome

The aim of the 6th CONGRESS was to give an answer to the challenges facing persons with Down's Syndrome as the 21st century approaches, formulating the following proposals and conclusions:

1. The promotion of genetic investigation in order to probe deeper into knowledge of chromosome 21's identity (especially finding out what each gene lodged inside it is responsible for and how they interact), as well as to probe into knowledge of mechanisms intervening in the non-disjunction to prevent the appearance of the syndrome.
2. The study of the specificity in Down's Syndrome, trying to isolate typical characteristics of Down's Syndrome so that it is possible from specialisation to design more efficient instruments of a medical and psychopaedological nature for the rehabilitation and education of persons with Down's Syndrome.
3. The search for practical solutions (strategies, programmes, methods, etc...) which, taking into account findings of recent scientific research, provide concrete solutions applicable to the health care, early attention, education, social and labour integration of persons with Down's Syndrome.
4. To specify the quality of life model proposed for persons with Down's Syndrome in three aspects: a) that their needs and expectations are met, b) that they develop all their potentialities and c) that they enjoy all their rights.
5. In the area of health: an endeavour must be made to spread and establish preventive medical programmes for Down's Syndrome everywhere in the world and also to maintain a critical attitude towards therapies not confirmed scientifically. By applying the principle "the same cases require the same treatment", organ transplants for persons with Down's Syndrome who require them should be encouraged.
6. Becoming aware of the important role of the family as the Down's Syndrome person's first natural nucleus of integration will encourage actions to be taken that are addressed towards effective training and the involvement of parents in the attention, education and social insertion of their children.
7. Specialised attention must preferentially reach those persons with Down's Syndrome who have other additional serious limitations or needs which prevent their effective integration. Attention could be given to them in specialised centres, with the support of the family, attaining the level of normalisation that is possible in each case.
8. In the field of education the Congress decisively supported three criteria: a) inclusion, with the proper supports, in an ordinary school, b) specific programmes and curriculum adaptations and c) the application of new technologies in the classroom as a particularly useful strategy.
9. The Congress called attention to the importance that the adult life of persons with Downs Syndrome has at the present time, including self advocacy, in such a way that the services provided are adapted to their rights, needs and demands, guaranteeing a positive quality of life.
10. All the means at our disposal must be used to encourage effective integration of persons with Down's Syndrome in school, work, culture and social life, with the understanding that non-discrimination means equal opportunities. Likewise, the change towards a better social image and participation of persons with Down's Syndrome in public life must be pursued.
11. Training and employment of Down's Syndrome persons in ordinary firms must be a priority as a source of personal realisation and autonomy and full participation in the life of the community.
12. Encouragement must be given to the worldwide creation of specific associations for Down's Syndrome, independent from the associations which attend to persons with mental retardation in general. These associations should claim representation and financial support from governmental departments.
13. The Down's Syndrome associations must ensure that parents, professionals and persons with Down's Syndrome are integrated in their organisation and management and they must be guided and reorganised by democratic principles.
14. The services - to create them whenever necessary - have to respond to criteria of quality, efficiency and social economy and in so far as possible they have to be rendered and integrated in the normal services of the community.
15. The training of specialists in University and in post-graduate courses is fundamental if persons with Down's Syndrome are to receive global and specialised attention in accordance with their needs.

Mr S. AL MALAQ (Saudi Arabia), Prof F. ASTUDILLO (Spain), Prof M. BEEGLY (USA), Prof R.I. BROWN (Australia), Prof S. BUCKLEY (UK), Prof C. EPSTEIN (USA), Prof A. FORTUNY (Spain), Prof C. GARCIA-PASTOR (Spain), Prof M.J. GURALNICK (USA), Prof R. HODAPP (USA), Mrs M. MADNICK (USA), M^a M.N. MENDONÇA (Brazil), Mrs J. MILLS (Canada), Prof E. MOMOTANI (Japan), Prof E. MONTOBIO (Italy), Prof L. NADEL (USA), Prof R.R. OLBRISCH (Germany), Prof J. PERERA (Spain), Prof S. PUESCHEL (USA), Prof A. RASORE-QUARTINO (Italy), Mrs P. ROBERTSON (Indonesia), Prof J.A. RONDAL (Belgium), Prof J. RYNDERS (USA), Prof B. SACKS (UK), Mrs M. SCHOEMAN (South Africa), Prof W. SILVERMAN (USA), Prof P.M. SINET (France), Mrs R. SNEH (Israel), Prof D.C. VAN DYKE (USA), Prof J.E. WANN (Sweden), Prof H.A. WISNIEWSKI (USA), Prof K. WISNIEWSKI (USA).

Fund-raising Update



Flora London Marathon

Sunday April 26th is the date of the London Marathon. This year the Down's Heart Group will be represented by twelve individual runners and a team of three who are running jointly on behalf of the Down's Syndrome Association and the Down's Heart Group. All of the runners have their own reasons for taking part, but interestingly not one of them is a member of the Group. Below is a little information on each of them; if having read it you would like to sponsor any of them, please send your donation to National Office.

Dave Brown

This will be 31 year old Dave's third London Marathon, the other two having also been in support of the Down's Heart Group. A Cash Management Officer for First Chicago Bank in London, Dave is a friend of National Administrator Penny Green and her husband. Apart from the sense of achievement at completing the marathon, he is a keen supporter of the Group and has also encouraged some of his colleagues at First Chicago Bank to run. Dave also enjoys flying model gliders, climbing and walking.

Martin Christmas

40 year old Martin is a father of three, and Manager of a building company. Amongst his numerous hobbies he includes, flying model gliders, climbing, running and biking, often along with his friend Dave Brown. He decided to run in the marathon to get fit, and hopes to complete the race in 4½ hours.

Christian Collett

26 year old Christian is a Market Analyst for First Chicago Bank in London. He hopes to finish in 3 hours and 45 minutes. Amongst his hobbies he lists sailing and skiing. This will be his first marathon, and his reasons for taking part are that he is "always up for a challenge" and that he wants to help a good cause.

Norman Cottrell

Norman is 54 and a Director for GPT telecommunications company. He ran in the London Marathon for the first time

last year, and hopes to improve on his time this year and run it in 4 hours. His hobbies are golf and running. Norman's daughter Tania Stanfield also ran in the London Marathon last year, on behalf of the Down's Heart Group.

Dave Deacon

47 year old Dave is a Claims Investigator for the National House Building Council. Dave says he was no good at sports at school, was always the last to be picked for the football team, and he was a bit of a 'fatty'. He took up running ten years ago to lose weight, and this will be his first marathon. He hopes to finish in 5½ hours.

Wendy Durrant

Wendy is the 29 year old part-time Bookkeeper/Secretary to Martin Christmas, and has a fifteen month old daughter. Her hobbies are aerobics, and running which she took up to lose weight - she says it's worked. She hopes to complete the marathon in 4½ hours.

Stewart Newnham

28 year old Stewart is an International Economist for First Chicago Bank. His hobbies are all forms of keeping fit, skiing etc, so running is just another one to try. This will be his first marathon, one of the things on his 'to do in life' list. His target time is 4 hours 20 minutes.

Andy Powell

Banker Andy also works for First Chicago Bank in London. He is 27 years old and runs for 'the sheer hell of it'. He has run two marathons before, the second without training which he doesn't recommend. He's also embarrassed because his Mum will be there watching him on the day. When he's not training he likes to play golf, but his pace will have to be a bit quicker for the marathon to achieve his estimated finishing time of 3 hours and 20 minutes.

Amy Robens

The second of our lady runners, Amy is also our youngest entrant at 25. She is a journalist for Marketeers and enjoys running, skiing, netball and socialising. Amy lists her reasons for running as to support the Down's Heart Group, to get fit and to achieve a goal for 1998. Amy's target time is 4½ hours.

Brian Shipton

At 56 Brian is the most senior of our runners, but one of the most experienced having completed six marathons in London and five in Berlin. Another employee of First Chicago Bank, he works in telecommunications and lists his hobbies as making home-made wine and beer. He is very involved with charity support, and each year organises a London to Brighton charity walk for the American banks. Brian is looking to finish in 3 hours 50 minutes.

Lionel Trigalou

Frenchman Lionel has been living in the UK for 4½ years, and works as a Credit Analyst at First Chicago. He enjoys sailing, skiing and going to the movies and the theatre. Having competed in the London Marathon last year, he was unhappy with his time and sees this as an opportunity to improve on last year and help a charity at the same time. He hopes to finish in 3 hours and 45 minutes.

Martin White

Martin is a 35 year old Management Consultant for Coopers and Lybrand. A keen runner, he has taken part in numerous off road races of marathon length, as well as three previous London Marathons in which he supported the Down's Heart Group. He was recently in New York on business, and kept to his training schedule by running in Central Park, all part of his determination to complete the race this year in under 3 hours. Apart from running, he is also keen on mountaineering and skiing and more recently spending time with his six month old daughter. Martin says he is running for his neighbours, DHG members Andrew and Sarah Coulbeck who sadly lost their daughter Emily in 1991.

Team from Metropolitan Police

Shortly before going to print National Office was advised that a team of three officers from the Metropolitan Police will be running in the Marathon on behalf of the Down's Syndrome Association and the Down's Heart Group jointly. Due to time constraints it has not been possible to obtain information on these three runners, apart from their names :

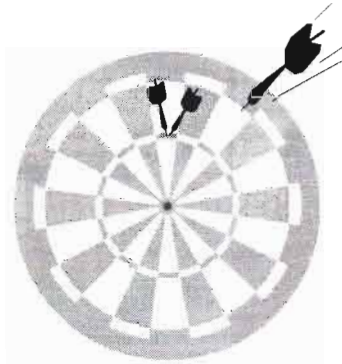
Mark Butler

David Clark

Paul Wakefield

All three are from five area TSG one unit.

We wish all the runners every success, and thank them for their support of the Down's Heart Group.



The Bloomsie and Jasmina Cups

The second year's darts competition for the Bloomsie (doubles) and Jasmina (singles) Cups, presented by the Down's Heart Group, was held recently at the Plough, Crowhurst, East Sussex spread over two evenings. As usual there was fierce but friendly competition among the regulars and both trophies changed hands this year. The winner of the singles, and holder of the Jasmina Cup for the coming year is Paul Baker, while Chris Newton and Kevin Dale triumphed in the doubles, and hold the Bloomsie Cup until next year.

Special thanks to Chris Newton, who again organised the competitions for us and arranged for the engraving of the cups, to Mike and Lucy for their hospitality and collections and to everyone for their generosity.

The two evenings raised the magnificent total of £194.30 for the Down's Heart Group - a great result all round.

John Spall
Chairman

The Larondina Dance Company and Alessendre Dance School

The Larondina Dance Company and pupils of the Alessendre Special Needs Dance School entertained a full house at the Royal Academy of Dancing, in November, to an enchanting and varied programme of items.

The company of eight very young dancers and sixteen in their 'teens and beyond, the majority of whom had Down's Syndrome, moved easily from expressive pieces to music such as Pie Jesu and the theme from Schindler's List to outright fast and furious comedy numbers such as John Denver's I Like to Deal with the Ladies and the Boys' Comedy Number. Throw in some rock and roll, some twenties flappers and this was a hugely enjoyable evening which had the audience stamping and clapping for more.

The level of concentration and serious endeavour with which these young performers approached their work and their obvious joy in performance illuminated the evening and earned them respect as well as applause.

The evening ended with a number danced to John Denver's Higher Ground, the lyrics of which sum up the philosophy of this company and its individual dancers:

*Maybe it's just a dream in me
maybe it's just my style
Maybe it's just the freedom that I've found
But given the possibility
of living unto the dream in me
You know that I'll be reaching for higher ground*

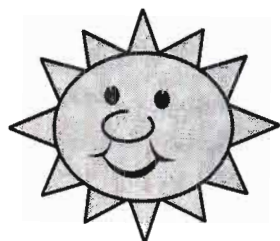
Certainly this company is individually and collectively reaching for their own higher ground and Artistic Director Angelina Alessendre is to be congratulated on the personal and artistic growth she is achieving with her dancers.

If you live in London and you get a chance to see this company I can promise you an enjoyable and uplifting experience. I understand that there are plans to launch a new branch of the school in the Croydon area.

While it would be invidious to pick out individual dancers I must just mention our pleasure that Down's Heart Group member David Beard is a member of the company, and lead one of the numbers.

John Spall
Chairman

Announcing our Annual



Christmas Card Design Competition

with **NEW** Calendar Design category

As in past years we are running a competition to design the
Down's Heart Group Christmas Card for 1998

This year, in addition to the card we would also like to produce a Calendar
featuring members drawings and paintings.



**So please get busy with your paints and crayons,
and enter our Competition.**



Prizes will be awarded in both entry categories.

RULES

- ♥ The competition is open to all Down's Heart children and young adults and their siblings.
- ♥ All entries should be on an A4 sheet of paper, with the entrants name, address and age on the back in the top lefthand corner.
- ♥ Entries will be judged in two categories - Christmas Card and Calendar, and those not selected in the Christmas Card category will be included for consideration in the Calendar category.
- ♥ There is no limit to the number of entries from one person.
- ♥ Entries should be forwarded to the Down's Heart Group National Office address (see page 2)

GUIDELINES

- ♥ Entries may be in colour or black and white, using felt pens, crayons, pencils or paint and the use of stencils, printing and collage is not prohibited.
- ♥ Entries for the Christmas Card category should have a 'Christmas theme' and should include the Down's Heart Group logo somewhere within the design.
- ♥ There are no restrictions on the Calendar category, although items with a 'seasonal theme' would be appreciated.

CLOSING DATE FOR ENTRIES IS MAY 31ST 1998

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.

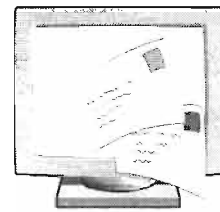
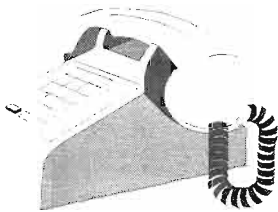
Please note that with effect from/...../.....the new address for thefamily will be:
.....

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

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

Postcode:
Telephone :

Send to: Down's Heart Group, 



Have you changed your phone number - perhaps to cable?

Please let us have your new number just in case we need to contact you,

Do you have e-mail?

Then please make a note of our e-mail address on page 2, and perhaps you'd like to let us know your e-mail address too.

Hope

I'd like to make a wish for people everywhere
I'd wish for understanding and friends that truly care

Our minds are full of fears, we wonder if we'll cope
The only thing that helps us is knowing that there's hope

Some days are up hill battles and the road is really rough
The months stretch out before us and we know we must be tough

One day there'll come a morning when we'll see a ray of sun
And know that all the fighting has been worth the days we've won

We realise we'll beat this because we'll fight it all the way
And with hope and understanding we know there'll be a better day

Debbie Chapman

