



DOWN'S
HEART
GROUP

NEWSLETTER

(Issue No 17)

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Star of the Down's Heart Group video - 6 year old Harry Dent

Contacts

National Office

National Administrator
Penny Green



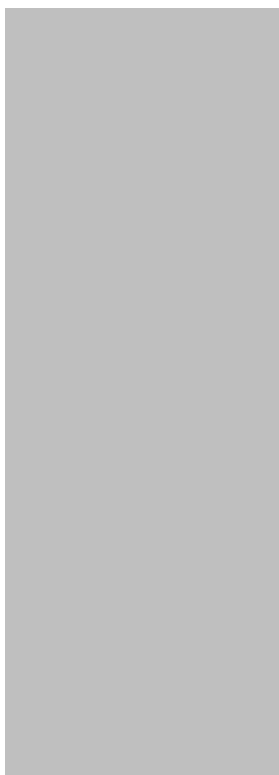
Contact or Ansaphone always available (24hrs in emergency)

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Chair

John Spall



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Patron

David Graveney

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Down's Syndrome Association
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Scottish Down's Syndrome Association
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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

Firstly I must apologise for the long gap since you last saw a Newsletter

I can assure you that this is not because we have been lolling about doing nothing - in fact, quite the reverse. 1997 was probably our busiest ever year and with a small team and so many tasks I'm afraid that something had to give and that was the Newsletter.

We have now rearranged our priorities and resources and we have every intention of producing four editions for you in 1998. I realise that the Newsletter is one of the main ways of our keeping in touch with our far flung membership and is also a medium through which you keep in touch with each other, through your stories and news. Our print run is now topping the 1,000 mark, of which some 250 go to professionals and other organisations, including many overseas. This means that in addition to writing the articles, editing and collating the contributions and arranging printing, we have a major logistical job in actually getting them posted out to you all.

Enough of the sob stuff you might say - what actually has DHG been doing?

Video

Well, perhaps the most important achievement of 1997 has been the completion of our first video "Heart Problems in Children with Down's Syndrome." With the boost of a grant of £15,000 from the Lottery Charities Board, and other grants and donations from the Constance Patterson Charitable Foundation, the Hospital Savings Association Charitable Trust, Angela & Nigel Barker in memory of James and many others plus a big contribution from our reserves we were able to go ahead and shooting took place in Bristol during August.

With Sarah Boston as our director and Rachel Trezise as our producer, both highly experienced documentary film makers, and a professional camera and sound crew, all problems were overcome and shooting in the Bristol Children's Hospital went far more smoothly than we, and I suspect the staff expected.

Not that we had a good start. We had sorted out for the first morning a wonderful location in a park with paddling pools, play equipment etc. in which to film a crowd of our children happily playing. The inevitable happened of course, clear skies at dawn, at two minutes to eleven (shooting due to start on the hour) the heavens opened and we all beat a hasty retreat to Sheila Forsythe's kitchen! That is where employing the best paid off as Sarah and her team calmly rearranged the schedule and coaxed some superb indoor performances from both parents and children.

The video lasts just under thirty minutes and provides explanations of the working of the heart and the more common conditions which children with Down's syndrome have, parents experiences and follows a family through the process of diagnosis and pre and post-operative care. The video will be launched in February and 1,000 copies have been printed. There will be an initial free distribution to the main paediatric units, child development centres and paediatric cardiology units in the UK and to other professionals and organisations. Copies will be made available free of charge on long term loan to new members. Further copies can be purchased for £5.00. There will also be extensive publicity to professional organisations and through professional journals.

This video would never have been made without the active participation of a large number of people and was a true co-operative effort. I would like to thank them all: - First my fellow members of the Steering Committee, Sheila Forsythe who did a superb job in organising the whole Bristol operation and Katie Spall who was responsible for the scripting. To all the families who took part Jo, Tony, Harry, Amelia and Alice Dent; Karen and Natalie Dance; Wendy, Mike, Oliver and Anna Hellowell; Sharon and Shanice Porter; Cilla, Jeremy, Joseph and Bryony Doyle; Lynn, Daniel and Thomas Ashman.

To all the staff of the Bristol Royal Hospital for Sick Children who took part and assisted us. To our professional advisers Rob Martin and Mary Goodwin. To Sarah and Rachel who were as committed and enthusiastic as we were and did a wonderful professional job for us.

What's more, unusually these days thanks to good accounting by Rachel and some discounts she was able to obtain, the whole project came in under budget!

Hospital Visitors

I have mentioned before that with heart operations taking place at younger and younger ages we have been aware of the need to provide support to families as soon as possible after diagnosis and during their hospital stay. Our aim is to provide a DHG visitor at each cardiac unit and we took a big step towards this when in September we ran a weekend course for current and new hospital visitors at Gatwick in Sussex.

This was a very intensive course and everyone worked very hard. I am sure we will see the results coming through in the coming months as we expect to have hospital visitors in place in at least two-thirds of the cardiology units. Our thanks to our two outside contributors to the course Mary Goodwin and Frank Kinch.

World Congress

Penny and I were the official DHG representatives at the 6th World Congress on Down's Syndrome in October and Katie also attended in a personal capacity. The three of us were at full stretch throughout the three days as we had a constant stream of visitors and enquirers at the DHG stand, particularly from developing countries and Eastern Europe, who were eager to obtain as much information as possible about heart defects.

A report on the Congress will appear in our next issue.

Children's Heart Federation

We have always valued our contacts with other children's heart organisations, particularly those based around cardiac units, where liaison and co-operation can help our families so much during their hospital stays. It was a particular pleasure therefore for some fifty of our members to join with families from other heart groups in the Federation for a wonderfully warm and sunny day out at Legoland, Windsor in July. We provided the largest contingent and by all accounts everyone I spoke to had had a very enjoyable, but tiring, day. Certainly we were all very happy to take the weight off our feet at the meal provided in the Legoland restaurant at the end of the day.

We were also able to send one family on the Federation's trip to Lapland to meet Father Christmas, the elves and the reindeers at Christmas.

Another example of this co-operation was the invitation which members in the Surrey/Berkshire area received from Heart Line to participate in their Steam Train day on a private miniature layout in one of their member's gardens.

You find members' stories of all these visits in this edition.

Topic Notes

We have been concerned for some time that some of our leaflets were looking a bit tired so with a co-operative effort by Penny and a number of co-ordinators we produced a completely new series of Topic Notes. These are A5 size cards, each of which deals in straight forward language with a particular subject of interest to members. These range through the common heart defects to such subjects as drugs, catheterisation, a book list, etc. The initial series has fourteen Notes and these will be added to during 1998. These were very popular at Madrid and we have received praise for them from as far away as Australia, and people have been particularly taken by the fact that the format means that a family need concentrate only on the topics of particular interest to them. When the reprint arrives we will be including a set with each video we distribute and supplies will be held by National Office, regional co-ordinators and hospital visitors.

Annual Conference

The wheel turns full circle as we return to Leicester for our 1998 Annual Conference, the area from which the Down's Heart Group grew initially and where the very first Annual Conference was held in November 1990. As usual this promises to be an informative and enjoyable day out for members and Sarah Smith our East Midlands Regional Co-ordinator has put together a series of main sessions and workshops which has something for everyone. See details below.

Patron

I am very pleased to be able to announce that David Graveney the Chairman of the England Cricket Selectors, has agreed to become the first patron of the Down's Heart Group. We are delighted that he is opening the batting for us. David has said that he does not want to be just a figurehead but is eager to make a contribution to the Group. 'Watch this space'.



1998 Annual Conference

Saturday 9th May, Burbage, Leicester

Keynote speakers on :

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

Workshops on :

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

Full details will be sent to all members in April. If you do receive details or are not a member please contact National Office for a Registration Form.

Registration payable on the day :
 DHG Members - £1.50p per adult
 DSA Members - £5.00p per adult
 Professionals - £10.00p per adult

Lunch is included in the Registration Fee. There will be limited Creche places available (with priority to DHG Members.)

Regional Contacts

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



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, Gtr. Manchester, Gwynedd, High Peak, Lancs. & Merseyside

Mike Haloin



Scotland

Mainland & Islands

(Glasgow Hospital Visitor)
Elaine Thomson



South Wales

Dyfed, Glamorgan, Gwent & Powys

Chris Stringfellow
17 Thornhill Road
Rhiwbina
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CF4 6PD
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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



Lindsav Allen



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

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

Ben's Story

Our wonderful son Ben Richard Marshall was born 3rd May 1997 at Castle Hill Maternity Hospital, Cottingham. I had a "normal" delivery which after having had a Caesarean for our daughter Laura was wonderful although a little painful!

Ben was three and half weeks early and weighed in at exactly the same as his big sister at 6 lbs 10 oz. Everything was initially wonderful and my husband Richard and I were over the moon as our family was now complete but then signs began to show that all was not well. Ben was very sleepy and particularly floppy and quite breathless and we were transferred to Special Care. The staff on the unit were brilliant but we could not help feeling that there was something being kept from us. We had noticed a single crease in the palm of one of Ben's hands but other than this he looked much like his big sister.

When after three days we were told they were testing for Down's Syndrome. We were devastated - it was a bolt from the blue. I was 28 when I fell pregnant and hadn't had any tests as I felt it unnecessary - our only coping

mechanism was denial. Two days later our worst fears were confirmed - Ben indeed did have Down's. Our initial fear was of losing him as I knew the commonness of heart defects, but once again we were reassured and Ben was seen by both paediatric consultants and had an ECG which they told us showed that he was healthy "as far as they could tell!"

Four weeks later Ben nevertheless went for his Echo to Killingbeck Hospital under the care of Dr. Dickinson where sadly it was confirmed that Ben had a large VSD that needed surgery sooner rather than later. Once again I felt sick with panic. We drove home not speaking and feeling as though our world had been turned upside down. Ben deteriorated in the following weeks as he became more breathless and didn't gain weight as he should have done.

Ben was admitted to Killingbeck Hospital Ward 7 on 23rd

July 1997 for surgery the following day. We will never forget the moment we said goodbye to Ben and handed him to the anaesthetic nurse - the next six hours were the longest of our lives. When we received the call to say that Ben had arrived on to the I.T.U. the emotions rushed through us - a mixture of fear and anxiety and excitement. I remember running the last few paces to the unit. Ben spent two days on I.T.U. and came home four days later.

His surgery has been a complete success and he is doing wonderfully. He babbles non stop, that is when he is not eating! The staff were very kind and supportive and the friends we made prior to and after surgery will be friends for life. No one knows the feelings you go through unless they too have been there.

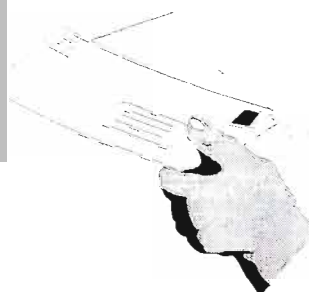
As a family we have come to terms with the Down's Syndrome, that's not to say that as a Mum I still don't feel sadness for all the hopes and expectations I feel we lost three days after Ben was born.

Ben is now nearly six months old and is one of the most precious things to myself and my family - the other being his big sister, Laura.



If possible could you print my name and address for anyone of a similar age with a child with the same condition as Ben who would like to write to me.

Carolyn Marshall



Thomas's Story

Thomas's heart problem was detected almost immediately, because he was born at home, our GP was called to check him over. Having elected not to have any of the available antenatal tests, we were very shocked to be told an hour after his birth that our son had Down's Syndrome. I suspect that his heart murmur was noticed too, but having just received one bomb shell I guess it was decided not to make matters worse at this time.

The special needs health visitor came to visit us that evening and an appointment was made for Thomas to see the paediatrician the next day, so that he could be properly assessed and have relevant blood tests. The support we received from everyone at that time was what kept us sane. Although feelings of fear, anger and loss of the "normal" child that we had expected were rushing through us, they all managed to convince us that it wasn't the end of the world. With all the help and support available these days he could quite possibly live a reasonably normal life.

After the paediatric assessment we were told that as far as they could tell his hearing, sight, etc. seemed normal. However they had detected a heart murmur which required further investigation. An appointment was made and fearing what the consultant might tell us, we were reassured when he said that from the echo it was clear that Thomas had a Ventricular Septal Defect, but they were 90% sure that surgery wouldn't be necessary.

Monthly appointments were made to monitor the situation and as far as I was aware all seemed OK although his breathing was a little fast. You can imagine my shock when at one appointment I was suddenly told they recommended that he have surgery within six weeks. I walked out of the clinic in a daze and could barely see to drive home, with all the tears streaming down my face.

When we arrived at Guy's Hospital, numerous tests were done, including a catheterisation which confirmed the need for surgery. Then at 8pm on the evening before his operation, I was told that it would have to be cancelled due to an emergency admission. I just sat on the bed and sobbed my heart out as I just wanted it all to be over and now I would have to face it all again. One of the nurses came and comforted me, assuming that I was worried about the surgery. When I told her it had been cancelled she was very angry as she had not been informed.

The next day we travelled home again having been told that the op would be rescheduled in a couple of weeks. Two weeks passed and we heard nothing. It was probably just my over anxious imagination at work, but to me Thomas's breathing seemed to be getting increasingly laboured. I wasn't prepared to wait any longer just in case, so I phoned Guy's and was told they couldn't do it for another couple of weeks. On hearing this I pointed out

how long I had been told it would be, and that this time had already elapsed. They said that they would ring me back. When they did they asked us to go in the following Friday, the operation to be on the Monday.

On arriving the second time I felt more at ease and knew my way around all the various departments. Someone said to me at one point, that you realise his surgery could be cancelled again, so the night before, I prayed harder than I ever have, not only that everything would be alright, but also that it would go ahead this time.

Nick arrived just before Thomas went down to theatre and we were told that the operation would last around three and a half hours. We decided it would be a good idea to go for a walk rather than sit worrying. After we had been in a couple of shops, we found a pub and calmed our nerves with a few drinks. When we got back to the ward the time had nearly passed but the staff said that there was no news.



From then on time dragged by and after four hours had passed, still with no word I started worrying that there must be a problem. Just as I was reaching panic mode we were given the welcome news that we could go and see him in Intensive Care. Although I had been shown around and had seen pictures of what to expect, nothing can ever prepare you for the sight of your child laying lifeless with tubes and wires everywhere.

The first day he did very well and was taken off the ventilator although he was very sedated. On the second night I had been allocated a room in Ronald McDonald house. At 3.00am I was woken with a start by the phone ringing. Thomas was having difficulties and they wanted me to be with him. I have never been so frightened as I was that night as I ran the short distance back to the ward.

When I arrived they said he had a buildup of fluid in his lungs, so he was put on diuretics and by the next day he was recovering. Since I had been expressing milk during his stay in ICU, it was a relief when he was able to feed again as none of the breast pumps worked very well.

He was discharged after seven days and remained on diuretics for another two months. Since the operation he has had chest problems on a couple of occasions, one which needed hospital treatment. He is now almost eighteen months old and is doing very well. You can really see the benefit from the surgery - before the operation he was very pale and skinny and puffed away like a steam train, now his breathing is normal, he is a healthy pink colour and is a lovely chubby little boy.

**Elaine Apps
Rye**

Reports from the 1997 Annual Conference

Our 1997 Annual Conference took place in Cardiff on 26th April. As usual this was an enjoyable event for all those attending, providing a valuable opportunity to meet and chat with other members as well as to listen to the invited speakers. The following are brief reports of the two morning sessions and the afternoon workshops, giving only an impression and example of the quality of the speakers, as it is always difficult to condense the amount of information given into a write-up suitable for the newsletter. For anyone interested in attending the 1998 AGM, please make a note in your diary for May 9th in Leicester, (full details will be sent to all members in April).

Understanding Surgical Procedures and Techniques

Mr. Ash Pawade, Consultant Paediatric Cardiac Surgeon, Bristol Royal Hospital for Sick Children

We were given the wonderful opportunity of having Ash Pawade as one of the main speakers at our Conference in Cardiff in April. He was able to provide us with some interesting information about past surgical techniques, current procedures and future developments, delivering this in a way which was comfortable and straight forward so that we could all follow, believing ourselves to be fellow cardiac specialists!

There were a number of really important points made by Ash, the first being that parents are the most important part of the team - he and his colleagues were enormously grateful that parents put their trust in the cardiac surgeon and his team, leaving their child, the most important person in their lives, in the team's hands and putting faith and trust in them. A number of us felt that not only was this a heart felt comment from a father whose own child had been through possibly more minor surgery, but was from a man with true consideration of the value of life in its fullest. He also stated that parents had an enormously important part to play in the pre and post operative period in the recovery of their child and were considered to be as important a part of the team as the others.

It appears that the last sixty years have been momentous in the cardiac surgical world. Since the 1970's cardiac surgical work has gone into the fast lane moving from palliative surgery, that is surgery which buys time to enable a full repair to occur at a later date, to foetal surgery for certain types of lesions, whilst fast approaching is the potential development of acceptance of the pig's heart for human transplant. All this has happened in my life time and I think I am young! What enormous developments can we hope for? Ash made the point that many of the conditions which in previous years would have been considered inoperable are now a possibility. He clearly was talking generally and not solely about our children.

Before 1981 there were forty-one centres undertaking cardiac surgery, these have been reduced to below twenty. The point that was being made was that it was necessary for areas of excellence to be established. The figures had shown that success rates were higher where surgeons were conducting complex operations very regularly and this was not possible with many smaller centres. Surgery is an art and needs constant practise and perfecting. Ash averages five surgical procedures in theatre each week which he felt ensures that he maintains and improves his technique. Much less than that is not adequate to ensure the high standard expected by all. There is concern with improved technology identifying foetal cardiac problems, this increases the likelihood of termination although in many cases successful surgery could occur. This may have some implication for our cardiac centres and the number of surgical processes undertaken by surgeons.

Another important point that was made was that our children should not be part of market forces and their heart should not be considered as a market commodity, but with the current regimes within Trusts, there was a growing likelihood of this occurring. Health of the patient was of the prime importance and other factors should not be taken into account.

Ash took us through various cardiac procedures with a video film and the session was finished by a number of very interesting questions from the floor. If the pertinent and appropriate questions were anything to go by it was very obvious that our members felt at ease with our speaker, who very ably and honestly explained individual situations with genuine feeling and interest in our children.

I was left with a strong feeling of hope for all those children who would come into the capable hands of Ash Pawade, and as he described a fellow colleague - I believe "He's a good human being".

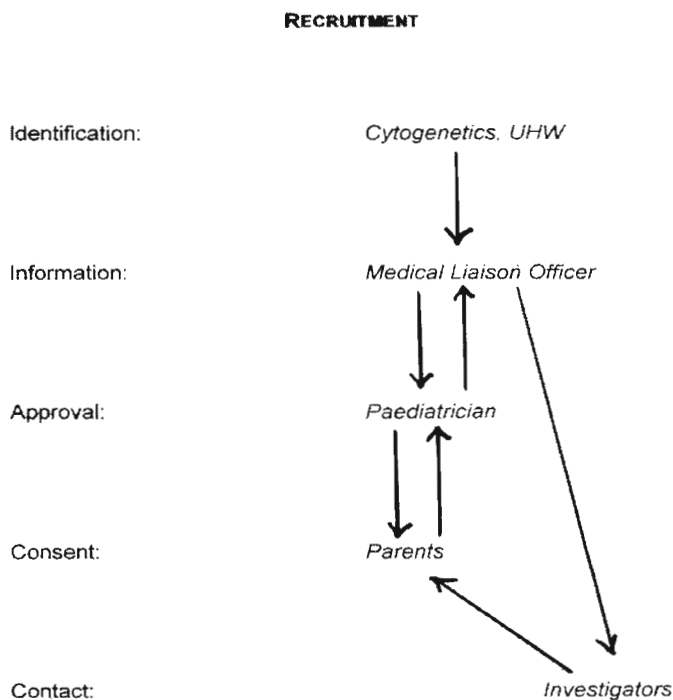
Katie Spall
London & South East Regional Co-ordinator

Visual and Cognitive Development in Young Children with Down's Syndrome

Dr. Margaret Woodhouse, Department of Optometry and Vision Sciences, University of Wales.

We were very fortunate to have Dr. Margaret Woodhouse to talk to us on a subject of such importance to all parents of children with Down's Syndrome, particularly those with young children and infants. It was a delight to listen to Dr. Woodhouse as she explained the data and the progress of her long term study with clarity and such enthusiasm, enabling us to understand the complexities of this work and the implications for the future care of our children. The following write up of the talk is by Dr. Woodhouse.

We are involved in a long term study of the way vision develops in young children with Down's Syndrome, and the association (if any) between visual and overall development of the children. We currently have seventy-two families throughout South and West Wales taking part in our study and we have had an overwhelmingly positive response from our families. We recruit the children in the manner shown in the diagram. Firstly the children are diagnosed by the chromosome analysis carried out by Cytogenetic department at the University Hospital Wales. The information about



the children is then passed on to our medical liaison officer, Dr. Sastry (who is a paediatric community medical officer). Dr. Sastry then contacts the child's paediatrician for his or her approval for a child to enter into the study. In the ideal situation the paediatrician will discuss the study with the parents and once the paediatrician lets the medical liaison officer know that the parents are willing to join the study we can then contact the parents directly.

We see each child for a visual assessment (which will be a normal eye examination) and a cognitive assessment (by Bayley scales, a standard developmental assessment technique). This is usually carried out on two separate occasions simply because we can't hope to hold the child's attention for long enough on one day! The assessments are all done as home visits, and therefore the research assistants carrying out the work (Mary Cregg, Helen Gunter, Margaret Parker and Val Pakeman) spend a great deal of their time travelling.

Refractive Error

Many children are born with refractive errors, that is they are long or short sighted. The usual course of events is

for children to out grow these baby errors so that by the time they are two or four years old very few children are long or short sighted enough to need spectacles. We find that among our children with Down's Syndrome, the eyes begin by having exactly the same range of refractive errors as ordinary children. However, our children with Down's Syndrome fail to grow out of their errors, and the older they get the more of the children have errors and need to wear spectacles. We don't yet understand how ordinary children grow out of their errors, so we are some way from understanding why the children in our study fail to do this.

This means that children with Down's Syndrome will need regular eye tests, and, since long / short sight appears to develop quite quickly, we would recommend yearly checks from the age of two.

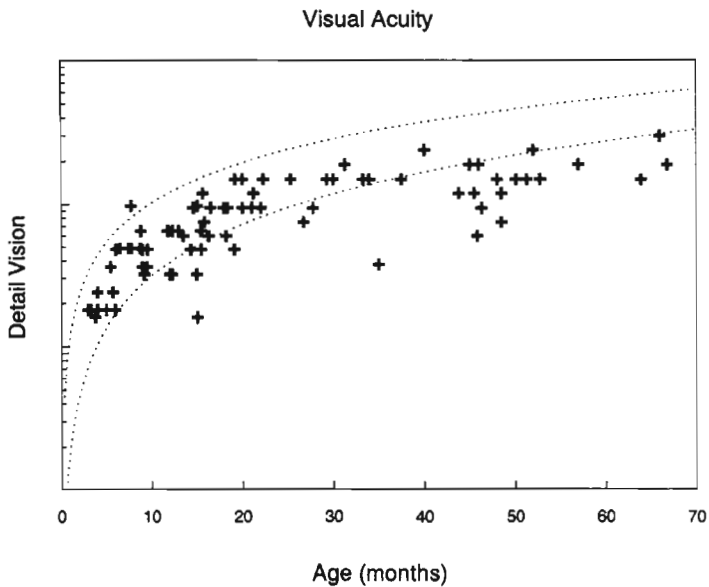
Accommodation

This is the ability to focus at near, and children usually have extremely good focusing - we all know that children can read on the end of their nose! We also know that as we get older we lose this ability so that by the time we get to middle age, most of us need to wear reading glasses. We have found that the majority of children with Down's Syndrome are not able to focus accurately close to them, even when they are very young. This means that any object close to them must be seen as blurred. This has obvious implications for school work for children with Down's Syndrome

which must be more difficult than for the average child. We don't yet know why the children cannot accommodate accurately, so we are not sure exactly how we should be treating it. However, **it is absolutely essential that any eye test for a child with Down's Syndrome includes a measurement of their ability to focus at near.**

Visual Acuity

This is the ability to discriminate fine detail, which in ordinary children develops fairly rapidly in the early months of life, and goes on to reach adult levels by the time the child is about four years of age. The diagram shows the normal range of visual acuity (dotted lines) for children, with the data for all of our children with Down's Syndrome as the crosses.



As the figure shows, the children with Down's Syndrome almost all have very good vision (that is within the range of ordinary children) when they are quite young. However, almost all of the older children, over the age of about two to three, have vision which is below normal. What appears to be happening is that the children's detail vision develops quite normally until they get to around two years and then they simply fail to make any further progress. By the time the children get to school their detail vision is, in almost all cases, below normal, by about a factor of two to three. That is, a child with Down's Syndrome needs an object to be two to three times larger to see the same amount of detail as an ordinary child. Although this deficit isn't enough to label the children as "visually impaired" it does mean that teachers ought to be aware that **children**

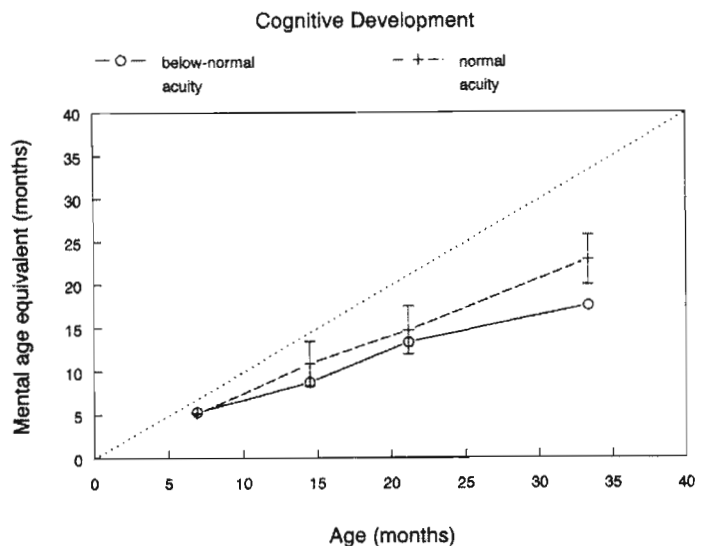
with Down's Syndrome don't have as precise detailed vision as their contemporaries.

Cognitive Development

We have found from the Bayley scores that the children's overall development is similar to their visual acuity development, that is they make fairly good progress until the age of around two when their rate of development slows down. Now that we have been following the children for some time we are to look at how individual children progress in both vision and general development. We are able to divide our children into those whose visual acuity is still good at our last visit and those whose visual acuity has fallen behind the norm at our last visit. The diagram shows the developmental scores for these children. The children whose visual acuity is poorer are also performing more poorly on cognitive tasks. We need to be fairly cautious in interpreting this but it seems to suggest that visual acuity is reflecting a global developmental stage of the child.

Conclusions

While the above data can at first glance seem to be quite depressing, in that it shows that the children start off developing very well and then fail to live up to expectations, in fact it does open up all sorts of possibilities. For the moment we can't suggest any programmes of intervention, but what is clear from our studies is that any intervention should be aimed at the crucial age of around two years. Finally I can't emphasize enough how important it is for children with Down's Syndrome to have regular eye sight checks. It is perfectly possible to measure spectacle prescriptions, detail vision and near vision in children no matter what their developmental level, and no matter whether they are able to talk and to read or not.



Discussion / Information on Autism

Malcolm Jones - Clinical Psychologist, Progress Care & Education Ltd.

Malcolm centred a lively presentation, peppered with questions and discussion, around teaching strategies and progress with an autistic young man of fourteen named Peter. Peter made splendid progress on the programme, he started without speech or any apparent understanding of speech - he was aphasic. He had no formal system of communication and became tense and threatening when adults spoke to him, calmed if they moved away and would attack if they persisted or asked him to do something. Peter was using the only "skills" he had learned to deter adult attention.

A Skill Teaching Strategy

It was vital to increase his range of skills, particularly communication skills. Initially coloured pictures were used, subsequently rebus symbols used in tandem with a reward system ensuring that Peter received the things he liked and desired. Peter learned quickly as the range of symbols grew and aggression became replaced by functional behaviour. Good behaviour rewarded, challenging behaviour no reward, and withdrawal of a treat. This was consistent and understood by Peter.

The concept of "running away" turned around and examined as "running towards"

Where was he heading? What did he want? Answer, the garden! Instead of punishment for absconding it became possible to use Peter's desire to run to the garden as part of the reward system giving him access to his interest and encouraging symbol use. Access withheld to reduce challenging behaviour.

Intervention points :-

- 1) Remove triggers of challenging behaviour.
- 2) Modify emotional responses evoking this behaviour.
- 3) Teach equivalent, socially valued skills to replace challenging behaviour.
- 4) Use Behaviour Modification to reduce challenging behaviour.

Wendy Tucker

Representative for Inoperable Children & Young Adults

Cranial Osteopathy

Chris Harris, Registered Osteopath, Natural Health Clinic, Cardiff

The birth of a baby is one of the most stressful events. During birth the baby is subjected to enormous forces, as the uterus pushes to expel the baby, against the natural resistance of the birth canal. The baby has to twist and turn through the bony pelvis on its short, highly stimulating and potentially stressful journey. The baby's head has a remarkable ability to absorb these stresses in a normal delivery. In order to reduce the size of the head, the soft bones overlap, bend and warp as the baby descends, and the baby tucks its chin onto its chest to reduce the presenting head diameter. Many babies are born with odd shaped heads as a result. In the first few days the un moulding process begins but is often incomplete, especially if the birth has been difficult. As a result the baby may have to live with some very uncomfortable stresses within its head and body.

Some babies cope well with even quite severe retained moulding and compression, and are contented and happy. For others this is not so and they can display a variety of problems.

Crying irritable baby who may need to be rocked to sleep and prefers being carried - This may be due to a feeling of constant pressure in the head, made worse by extra pressure when lying down.

Feeding Difficulties - Baby takes a long time to feed and one feed merges into the next, may also be 'windy'. Possibly due to mechanical stresses through head, face and throat or nerves to tongue irritated as they exit from the skull, making sucking difficult.

Sickness, Colic and regurgitation of milk between feeds - The nerve to stomach may be irritated as it exits the skull impairing digestion, or the diaphragm may be stressed or distorted thus having an effect on digestion and the stomach's ability to retain its contents.

Sleep disturbances - When baby sleeps (day and /or night) for short periods and awakes at slightest noise, may be due to tension in skull, which keeps nervous system permanently alert.

Infections - Retained moulding takes its toll on baby's reserves and depletes immune system. Frequent ear infections and loss of hearing due to 'glue ear' is as a result of birth compression around bones of ear which impede fluid drainage from ear, and also air passages with ENT system.

Sinus and Dental problems - Mouth breathers, and children with constantly blocked or runny nose, also dental overcrowding is due to impaired growth of bone of face and drainage of sinuses due to retained moulding compression.

Behavioural problems - Child fidgets constantly, is hyperactive and has poor concentration is caused by child being uncomfortable in one position for too long. Severe compression can modify normal patterns of learning in the brain.

Headaches and aches and pains (beginning at age 7 - 8) - Retained moulding may focus areas of pressure on the skull as the bony joints are forming a skull.

Asthma and Vulnerability to Chest Infections - Retained moulding can aggravate a tendency to asthma. General lowered immunity leads to more chest infections and chest remains tense and ribs do not return to full function aggravating an asthmatic tendency.

Osteopathic treatment is very gentle and safe. When specific palpations and pressure are applied to the head to effect the release of stresses, the patient may be quite unaware that anything is happening at all. The osteopath will have taken a detailed case history of the patient, to put together the 'story' of what the traumas have been and why present symptoms have developed. Children with Down's Syndrome can suffer from many of the above and it is recommended that four to six treatments are on average sufficient. It is advisable to treat as young as possible for best results, but it is still possible to achieve beneficial release of stresses throughout life.

Sheila Forsythe
Bristol and South West Co-ordinator

St. Briavels Centre for Child Development

Mike and Helen Downey, Clinical Psychologists, St. Briavels Centre, Monmouth

Helen and Mike gave an interesting and uplifting talk about the St. Briavels Centre which opened in 1979. When their son Adrian, was born twenty-seven years ago and diagnosed at thirteen months as being brain injured they had no where to turn to. Nobody could tell them what he would be like, what he was going to achieve and why he had these problems. For them he was a "bright kid behind a brick wall" but without help and advice they were unable to do anything for him. Eventually they found a centre that told them at what stage he was and where they could expect him to go. The centre told them what they had to do to help him achieve the goals and they went home and put it all into practice. The results were spectacular, he improved in almost every way.

After going to America to help other parents in similar circumstances they returned to England and the St. Briavels Centre was born.

Taking the best aspects of both conventional and of alternative therapy the Centre offers a programme tailor made for each child. They have five main principles that they apply :

1. In order to stimulate undamaged parts of the brain all children should go through the natural sequence of human development starting from an early age.
2. No miracles are promised but with love and hard work there can be improvement in a child's quality of life.
3. Every child is an individual and treated as such.
4. No single therapy will work, what is needed is a multi-disciplinary approach .
5. Parents make ideal therapists. They do not need to be passive carers but need help to enable their wishes and dreams for their children to come true.

From thirty-seven children in 1979 when they opened, to over two hundred and fifty now, the centre caters for children with all disabilities many of whom have Down's Syndrome. Many things are included in the programmes, however emphasis is placed on both diet and physical exercise. Each child is seen by a dietician and an individual nutritional plan is worked out. All the children are encouraged to do a lot of physical exercise as it is believed this has a significant effect on intellectual ability. From as early as six months children are taught to read. Using their eyes as well as their ears has helped the children's communication considerably leaving them less frustrated and better able to integrate. Mathematics is also introduced at an early age with some quite amazing results.

Children who attend the St. Briavels Centre make tremendous progress. With support and advice from a dedicated team of therapists and more importantly the determination of parents for their child to do better, great strides can be made and quality of life improved.

Veronique Garrett, Switzerland

Children's Heart Federation Trip to Lapland - Xmas 1997

Katie and I would like to say a great big thank you for nominating her to go to Lapland, it was the experience of a lifetime. When she found out that she was going she did not quite believe me, but once we were on our way her excitement just built up.

We were made so welcome at the Skylane Hotel, and had a wonderful evening with everyone who was going on the trip and those who were there to see us off. The children were given lots of lovely presents from Harrods and other companies.

Saturday morning we met bright and early in the hotel reception to board our coach. There were lots of excited children (not to mention parents) as we set off to Gatwick, with those who were staying behind, waving us off.

Katie had never flown before so she was a bit nervous. The cabin crew were great, they made us very welcome. The flight was good and everyone enjoyed themselves.

We arrived at Kittila, where it was minus seventeen degrees, in late afternoon. As we came off the plane it was so fresh and crisp that you did not really feel the cold. Then in to the airport where we collected our outdoor suits and boots before boarding the coach to take us to the Reindeer Farm, a drive of about twenty minutes during which our guide told us about the part of Finland we were in.

When we arrived, we were shown a nice warm cabin where we could leave our things. After which Katie wanted to go and visit Father Christmas, so off we went. It was soon Katie's turn to go in.

As we entered the room her eyes lit up. When he welcomed her by name she looked at me in total surprise - it was a moment I will never forget. She may be twelve, but I am so glad that she still believes in him.

They had a long chat and he read her letter, then gave her a lovely present and we had some photos taken.

Back outside we decided to go on a Husky dog sleigh ride. As we got on to the sleigh I slipped and landed on my bottom (ouch!). Katie thought this was really funny and couldn't stop laughing. The ride was great, rushing through the trees, with the lanterns glowing to show the way. Then we went on the Reindeer sleigh, and afterwards Katie stood for ages stroking them - what lovely animals.

Next we went and had some warm food and a drink before meeting up with Dr Eric (the doctor who came us). He took Katie on a Skidoo. She loved it and kept shouting for him to go faster. Then the Toboggan ride where we spent quite a long time as Katie loved coming down the slope on the sledge.

All too soon it was time to go. We got back on the coach, and Father Christmas came to wave goodbye. Back to the airport where we boarded our plane. Everyone was full of excitement but very tired. After having something to eat and drink, most of the children slept all the way home to Gatwick.

At the airport Katie's Daddy was waiting to meet us. She ran to him and it all started to tumble out about the wonderful

day she had had. All the way back to the Skylane Hotel and even after we finally got her into bed. What a lot of lovely memories she is going to have for ever.

Thank you seems such a small word to express our appreciation for putting Katie's name forward. She had the time of her life! I have tried to share our day with you, but to really do it justice I think it would take a book. Once again thank you so much.

Cathy Beech, Chelmsford



ARE YOU ABLE TO GIVE DHG AN HOUR A WEEK OF YOUR TIME AT HOME?

WE NEED TWO PEOPLE TO WRITE TO NAMED TRUSTS TO SEEK GRANTS FOR A DHG PROJECT

Previous fund-raising experience not essential, just enthusiasm and good writing and telephone skills.

**INTERESTED? - don't be shy
please give John Spall a no obligation call on [redacted] [redacted]**

Trip to Legoland Windsor - July 1997

In July the Children's Heart Federation arranged a trip to Legoland, Windsor for member families of Federation Groups, of which the Down's Heart Group is one. As well as free places for some families, there were special admission rates for all members, which encouraged a lot of people to come along and join in the fun.

Of all the groups attending, the Down's Heart Group actually had the largest contingent, but we were soon split up in the crowds of people, although throughout the day my family and I kept bumping into DHG members, some that I already knew, some I'd never met, and it was quite obvious that everyone was having a good time and thoroughly enjoying the rides and attractions on what was a brilliantly sunny day.

At the end of the afternoon we all met up in the Marche Restaurant and had a meal together. I think the sheer size of our party caught the staff off guard, but they managed to cope very well - even with those energetic children who had apparently forgotten 'that heart children are supposed to tire easily!'

After the meal, some families made tracks for home, but the more hardy amongst us (or do I mean the biggest kids?) took advantage of the shorter queues to go on more rides - several official representatives of the

Groups were to be found getting thoroughly soaked on the Log Flume! (sorry no photos).

At the end of the day there were a lot of weary families (mainly the parents), but despite having so many heart children all rushing around in the heat, and all the excitement, the only casualty of the day was our own Chris Stringfellow, whose son Richard was so reluctant to get of the Skychairs, that he managed to pull the safety bar back down on his mum's head and give her a mild concussion and a very severe headache.

Penny Green
National Administrator

The following letter was sent to the Children's Heart Federation.

Just a note to say thank you for the day at Legoland on July 18th. It was a lovely day for the whole family. We were quite impressed with the facilities and cleanliness of the venue. It made a change for our daughter Hannah to be able to go on all the rides, so a very good choice on your behalf. The meal in the Marche Restaurant was also enjoyable. Thank you again.

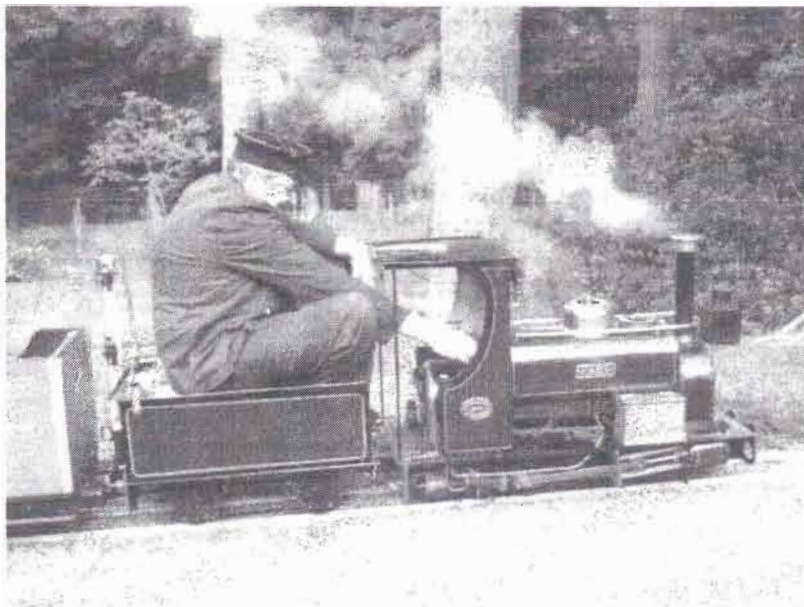
Joanna Simms & Barry Allen, Down's Heart Group

Steam Train Party - 'An afternoon to remember!'

Joshua and I were invited by the Children's Heart Federation to spend an afternoon in July at Runfold, the main attraction being model steam trains.

We set off from home in the very hot midday sunshine and arrived at Runfold with time to spare. We parked in the partially wooded grounds which gave us the opportunity to 'cool off' a little, before we went through to the gardens where we were greeted and welcomed by our host. Joshua was getting very excited.

As we walked further into the gardens a miniature steam train went by with a family on board. Joshua watched the trains in awe. Then we moved up to the lawns, Joshua saw the bouncy castle - he ran!! There were several children already bouncing on it, so he was



a 'happy chappy'.

We had numerous rides on the different trains which was very exciting. The track winding through the delightful gardens seemed endless, but the bonus for Joshua was the two tunnels. He loves to hear his voice echo.

Another surprise was afternoon tea, tables full of such varieties of food! It was lovely to meet

and relax with new friends, train drivers etc. and our host and his family.

A truly wonderful afternoon we had, one to remember for a very long time.

Sheila Saunders
Reading

Members with Chronic Cardiac Conditions

May 1997

We packed the caravan and set off to Cardiff, the main event to be the DHG Annual Conference, during which we agreed enthusiastically with fellow parents about the excellence of the speakers and workshops. Of particular interest to those whose sons and daughters have not had corrective surgery, were the confident assurances by Mr. Ash Pawade, that within the next eight to ten years we can routinely expect heart/lung transplants to be offered to people with Down's Syndrome, with the anticipation of improvement in post operative prognosis compared to what is possible at present. We have not tried to think through all the implications of this news for our family, there is time to see how things progress, and the Group will continue to monitor and report on developments in heart/lung transplant.

The care of pulmonary vascular disease and various approaches to this, feature regularly in conversations with parents. Often there is concern if other members are receiving the same advice and treatment and whether more can be done. There is interest in any experience of progress with **Vasodilators** such as the drug nifedipine, used to reduce high blood pressure and maintain an optimum haemoglobin level through widening the blood vessels. Recently I talked with a parent very pleased with the initial progress of her son since he started taking this drug - she has noticed improvement in his general well-being. Another parent has asked for feedback of experiences with these drugs and frequency of use within our membership.

There is continuing interest in the outcome of **Venesection**, carried out to reduce haemoglobin levels, with questions about possible dangers attached to this procedure. Over a four year period Alan, who is 28yrs old, had venesection every six weeks with no ill effect and it is thought, with benefit. Spencer, 23yrs, had venesection every eight weeks also over four years but this was stopped when shock to his system caused massive fluid retention. There is a certain amount of caution amongst cardiologists regarding this procedure. We would like to hear your experiences.

Keratoconus is an eye condition caused by an abnormal laying down of collagen and may include a number of complications. This can develop with age and is affecting one of our members whose family would very much like to have contact with any other members with this condition.

Lord Brian Rix wrote to a national newspaper just prior to the general election noting that no party had put clear policies for helping handicapped people before the electorate. The more I talk with parents from various parts of the country the clearer it becomes that the support available depends largely on where you live. There are inspiring accounts of successful inclusion and integration into mainstream education for our children. So why do I talk with parents who meet such barriers of rejection, lack of funding, resources and understanding, with such insensitivity towards the child and the family that they are left with feelings of guilt and of failing their child? Quality management of provision by government and local authorities should ensure that common standards are met across the country so that some families should not have to fight whilst others receive the provision for which all qualify. Comments please.

September 1997

I have spoken with the specialist cardiologist running a "Grown up Congenital Heart Clinic" set up recently at one of our major hospitals. She stressed the importance of people with congenital heart defects, as they become older and more symptomatic, being looked after by specialist clinics not by "generalists". Knowing how unsure parents of members over sixteen feel about transfer to adult clinics, I was becoming cautiously confident about the prospect of these clinics for our youngsters, with specialists who understand the long term effects of pulmonary hypertension and who value people with Down's Syndrome, treating them as individuals. She continued to talk about referral of people with Down's Syndrome, then added, "unless they are completely 'doolally' then what's the point anyway?" Well, I am the parent of one of the 'doolally' ones, something she wasn't considering while talking with such gusto! Thinking of Matthew, Nicola, Richard, Spencer and others who are definitely not 'doolally', and who could benefit from such a centre, I chose not to take up the issue with her, and am happy (but less than I was) to know that there are specialist centres where many young people will receive all possible help and relief from the symptoms of Eisenmengers.

So where does that leave our members with autistic tendencies? We need centres where there is informed understanding of autistic spectrum disorder and of the trauma, anxiety and fear felt by autistic people when hospitalized. My son is traumatised by the placing of a stethoscope on his chest, he kicks and screams in fear. His anxiety, caused partly by the unwelcome invasion of his space and total change to routine, spirals out of control, accompanied by increased heart failure. It is essential for the lives of our children that those entrusted with their care properly understand autism so that they can find ways to manage their treatment successfully. It may then be possible for young people with autistic tendencies to reach their third or even fourth decade of life, as can our other members.

Support and advice for parents in both understanding Autistic Spectrum Disorder in children with Down's Syndrome and in forging links with Education and Health Services may be possible with the help of Dr. Hillary Cass of Harper House Children's Service, Hertfordshire. She is co-ordinating a team with Dr. Gillie Baird from the Newcomen Centre, and Dr. Lorna Wing from the National Autistic Society with a view to providing a service of investigation, diagnosis, and treatment for such children. Dr. Cass is taking referrals through the usual route of G.P. or hospital consultant.

Spencer was rushed into hospital with multiple clots in one lung in August, but has thankfully made a good recovery. His father stressed to the consultant how loved and wanted Spencer is and that everything possible must be done for him. This point was made in the strongest terms and reinforced at intervals to ensure total understanding by all concerned. Along with the fear that our child might die, too often we fear this may be allowed to happen. I look forward to a time when parents need no longer doubt that all resources, technology and effort will be available for their child's treatment and we can trust they are in good hands.

Wendy Tucker

Representative for members with chronic cardiac conditions

The Story Of My Life

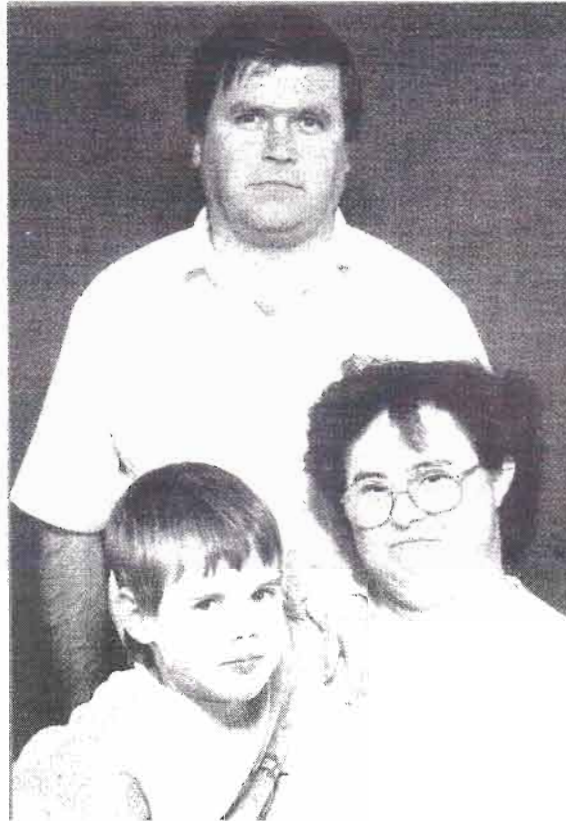
The following story was originally featured in the October 1997 newsletter of the Federation of Down Syndrome Associations of Spain. It was written by Ana Maria Brezigar who is the Director of the Prenatal Diagnostic Clinic of Postojna, Slovenia, on behalf of Renko, and has been kindly translated for us by Karin Fien. - Renko and her family were present at the 6th World Congress in Madrid in October.

My name is Renko Mojca, I was born on the 17th of June 1963. I live in the city of Litija, a small city in Slovenia and I've been working in a factory since I was seventeen years old. I have Downs Syndrome, a lot of people wonder how a person who is handicapped like myself is able to live an independent life. My husband is forty-three years old and works as a courier. We have a lovely healthy daughter, Urška who is six years old; she will begin primary school this fall.

I was born illegitimately, my mother explained to me that my father wanted to marry her but my grandparents opposed the marriage. Perhaps, they opposed the marriage because my father was a seasonal worker in Bosnia. My father immigrated to Germany before I was born, shortly after that my mother began to drink. My grandmother took care of me and I was raised by her.

I began walking at twenty-five months. My grandmother loved to sing, she sang to me all the time and I enjoyed her singing very much. She taught me to sing with her. Since I was delayed in speech she took me to language classes. My mother's family was very religious and we prayed before every meal. When I was seven years old I began attending a school for special needs children. I was quite fortunate and finished the eight year program at my school.

I started working at the factory and also attended cooking school in the evening for two years. I met my future husband



in the church choir we both belong to. He is nine years older than I am. My family was quite worried about our intention to marry. My grandmother attempted to change my mind but she was unable to succeed. I left home and we married. We own our home, which is not far from my husband's family. We have many friends at the church we attend and we consider our priest to be our dearest and most supportive friend.

We wanted to start a family. My gynaecologist was helpful whenever I needed support. He proposed we attend genetic counselling. We wanted to have a child who wasn't disabled and considered as such as I had been. We didn't want our child to suffer as we had by people's comments. I was told that our child would be at great risk of having Down's Syndrome and so I decided to have prenatal screening. My first pregnancy ended in miscarriage. Down's Syndrome was diagnosed in my second pregnancy. I requested a termination of the pregnancy. It was a difficult and painful decision.

My lovely daughter was the outcome of my third pregnancy. She was born a month prematurely and has filled our home with joy and happiness. A lot of persons ask how can we care for her properly. We love her very much. She is always well cared for and smartly dressed even though we

live modestly. She is a very happy child who loves to sing like her parents. I'm very proud of her. My husband always supports me when I need help. I love cooking, embroidery and knitting.

Recently, some sad events have occurred in my family, my mother has died. I have health problems because I am overweight. I intend slimming with the help of my doctors. I am currently trying to receive financial help to pay for my daughter's education. I consider my family fortunate and I happily accept the opportunity to share my life story.

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

James Barker - Bedford

Keith Iles - Calne (Grandfather to Gemma)

Scott Kennedy - West Malling

Mr Michelson

Aisling Nelson - Streatham

Mia Parsons - Carmarthen

Christopher Ross - Gloucester

Ernest Saunders - Reading

Rosie Steeds - Bristol

Jamie Totman - Surrey & USA

Katy Walsh - Rutland

Adam Watcham - Cleethorpes

Kathy Wells - Colchester

Fund-raising Update

London Marathon 1997

Let me talk you through the day: Went to bed at 01.45hrs on Sunday morning, finishing off a quick whisky and water, (the latter in the interest of rehydration therapy). Unfortunately middle son (Freddie - 5yrs) chose to have a bad night, and woke four times between 02.00 and 06.15 hrs, when I got up.

Scrambled egg on dry toast for breakfast, half a cup of black coffee and a pint of water to wash it down - then set off to Blackheath at 07.15hrs.

Changed into running gear - in this instance, shirt, tie, suit (single breasted to ensure ventilation) and black bowler hat deemed smart enough. Set off with massed start at 09.30hrs, and started to get pretty hot in ridiculous outfit by five mile mark, as well as fed up with the 'you late for the office, mate?' comments. Had to let running partner go ahead, and knuckled down to the task in hand - survival.

Saw cousin Anna in crowd, by chance, at around nine mile mark, who was supporting her runners - stopped for a chat (she works with BLISS - Baby Life Support Systems). Interviewed briefly by British Forces Broadcasting Service in Tooley Street, but not sure they understood a word I panted. Wife Bibi and children made the rendezvous in Cable Street (twelve miles), stopped for another chat, and, despite encouragement, warned them not to expect me to be challenging for the tape at twenty-six miles

Recognised by bunch of idiots in Indian Headdresses outside a pub in Docklands - apparently I ran most of the New York Marathon with them - promised to get together for a beer 'soon', ran on until cramp set in (possibly caused by having not gone on a run for the last five weeks?) and then took it easy around the depressing nine mile loop that is the Isle of Dogs and Canary Wharf.

Idiots in headdresses had clearly migrated to another pub, and had just bought a round and a bag of crisps as I limped past - had a quick glug of lager shandy, and a mouthful of cheese and onions, and shuffled on - bad idea as it turned out! - also didn't expect the arranged beer to be quite this 'soon' but there you go.... Tower of London - great feeling to be close to home, but depressingly close to the office, where I know I will be in nineteen hours or so. ..hopefully in a different suit! Embankment... a lot further to run than it looks. Luckily Bibi and the children had not got too bored of waiting, and were there to provide more much needed encouragement - just about enough to inspire me to gallop after one of the rhinos and an Utterly Butterly tub on legs. How the mighty fall!

Finish line in sight - just had to stop once again to photograph the timing gantry, which drew attention to my red face, just about visible beneath the Bowler hat, which had somehow expanded in the heat, and slipped down

around the ears. Suit still on, shirt still done up, tie straight, felt smart enough for the finish photograph, and skipped over the line in a pedestrian 4hrs 50mins - only 2hrs 40mins behind the leaders, but who had more fun??

Thank you for giving me the opportunity to run the London Marathon, and I hope that I did not disappoint!

John Tyszkiewicz, London

John was one of the five runners that represented the Down's Heart Group in the 1997 London Marathon. Between them they raised nearly £2000 for the Group for which we are extremely grateful, but perhaps even more worthy of mention is the fact that not one of them is actually a parent member of the Group, but all of them were prepared to put in such a huge effort to support our work. THANK YOU to Mike Dutton, Meg Peasley, Tania Stanfield, John Tyszkiewicz & Martin White and to all DHG members who sent in sponsorship for them.

We have a number of runners in the 1998 London Marathon, so if you want to get them some sponsorship or can come along to give your support, contact National Office for more information.

Chiltern Vehicle Preservation Group Bus Rally

The Down's Heart Group was nominated as the beneficiary charity for this annual event which takes place in Luton. As well as having the opportunity to have a stand and publicise our work at this well attended event, we were presented with a cheque for £250 from the proceeds, and it was nice to see a few of the local Group members who came along to give their support.

Penny Green, National Administrator

Bloomsie and Jasmina Cups

Two new sporting trophies were initiated in 1997 as part of a fund-raising Darts Competition on behalf of the Down's Heart Group, at The Plough in Crowhurst, East Sussex. The Bloomsie Cup (named after Elizabeth "Bloomsie" Spall) for the doubles and the Jasmina Cup (named after Jasmina Jushkina of course) for the singles.

The competitions were held over two evenings and were a considerable sporting and social success. In excess of sixty competitors fought out many close matches (I didn't get beyond the first round!) before the winners emerged, with local farmer Steve Blackford getting his name on both trophies.

£140 was raised for DHG. Many thanks to Mike and Lucy for hosting the event and to Chris Newton who organised it on behalf of DHG. We expect this to become an annual event and I hope I manage to do better next year.

John Spall, Chairperson

Well Done Newark

This is a tale of a lot of hard work and commitment by some very special people. It all began in September 1994 when Ruth was born with Down's Syndrome and a heart defect. Now she is a healthy, lively little girl with a younger sister Eve, to get into mischief with. Ruth and Eve's Grandad, Don, has also had heart surgery, so when the family decided to raise money for charity, the Down's Heart Group seemed a good choice. Read on to find out why we are so glad they chose us.

First, Don and many helpers organised a Golf Day on Sunday 6th July 1997 at Staythorpe Golf Club near Newark, where Don is the Captain. Teams of four golfers were asked to pay £30 per team, then had to have a team name some dafter than others. Tee off was 2pm, a "Texas Scramble" on a warm, sunny day and although it was a 'Fun Day' nobody wanted to come last! Whilst waiting to start, players could spend money on various games, including a tombola. We would like to say a special thank you to Joan Green for organising the games. Another big thank you to Joyce Johnson, Jan Scatchard and all the other ladies involved with Staythorpe Golf Club for a superb lunch and hospitality. Nothing was too much trouble. The whole event was very well organised, a marquee offered welcome shade, whilst the clubroom offered welcome beer.

Don had been so worried about intruders that he had slept in the clubhouse on the night prior to the Golf Day. It was nice to see him unwind and relax through the day as he could see his ideas and efforts come to fruition.



LEFT TO RIGHT : GRACE, SHEILA & EMILY SMITH, RUTH & DON

On the day Don presented me with a cheque for £350 with a promise of more to come. Don couldn't believe just how much more....

The Johnson family's next project was a race night at Balderton Cricket Club, where Don is a member. A wonderful man called Don Everett did most of the organising - thank you Don. We were unable to get to the Race Night which took place on Friday 19th September 1997, as I was in Durham on behalf of the DHG, and Chris was in Wales, apparently we missed a fantastic night.

Incidentally, cricket must run in the family. Don Johnson's son Paul, who is Ruth's Daddy, is Captain of Nottinghamshire County Cricket Team. I've seen his golf, so Paul, stick to the day job!

Throughout the fund-raising period Staythorpe Golf Club ran a raffle which I had the pleasure of drawing on the Presentation Night, Friday 3rd October 1997. Again a

tremendous amount of effort had gone into the raffle. Thanks to everyone for selling and buying tickets.

We now need to mention another very special person - Mr Billy Bamberger . Billy managed to raise £243.00 by running the Newark Half Marathon. Well done!

As you may have gathered from the tone of this article I was totally amazed at the amount of generosity in members of the golf club, the cricket club and the general public in the Newark and Balderton area. Don and Joyce Johnson gave so much time and energy to the fund-raising and Jackie and Paul Johnson also need congratulating on their involvement too.

Chris and I were invited along to the Presentation night to receive three cheques for the Down's Heart Group. As if that wasn't enough the people present decided to guess the birthday of a brilliant handknitted golfing doll, raising £54.61 in just an hour. During the journey from Leicester to Newark I felt quite relaxed about standing up in front of people and saying thank you on behalf of the DHG, but once I arrived and got an idea of just how much I was to say thank you for I started to feel very emotional and humbled.

By the time I stood up the DHG had a mumbling physical wreck as their ambassador. Everyone was very friendly and supportive and after a few laughs and a bit of barracking I just about managed to say a few words about the group and why we are so grateful for their fund-raising efforts.

Now you know how our friends in Newark raised us much needed funds, you ought to know how much....

Staythorpe Golf Club (Incl. Raffle)	£ 2521.00
Balderton Cricket Club	£ 512.65
Mr Billy Bamberger	£ 243.00
Guess The Birthday	£ 54.61
Chetwode Foundation	£250.00
Mr K & Mrs M King	£50.00
Raxel Storage Systems Ltd	£50.00

A Grand Total Of £3681 .26

But wait, Jackie tells me they haven't finished yet, as Paul has been selling his benefit year ties at £1 each, so there is still more money to follow.

THANK YOU TO EVERYONE INVOLVED!

Sarah Smith
East Midlands Regional 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.

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

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

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

Postcode:
Telephone :

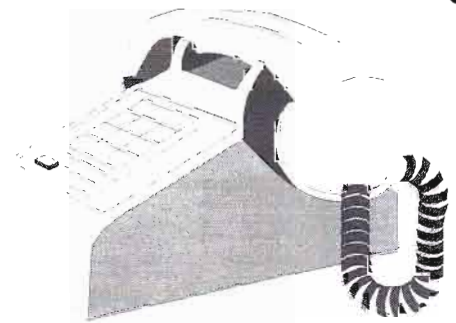
Send to: Down's Heart Group, [Redacted]



A recipe for mothers

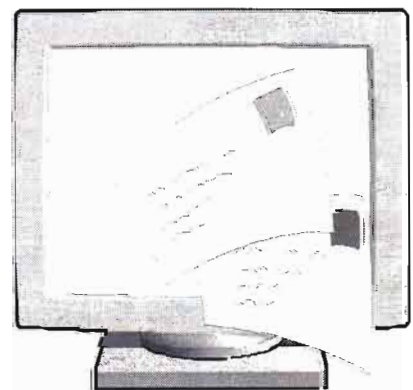
*Today I left some dishes dirty
The bed I made at 3.30
The nappies soaked a little longer
The odour grew a little stronger
The crumbs I spilt the day before
Are staring at me from the floor
The fingerprints there on the wall
will likely still be there next fall
The dirty streaks on the window panes
will still be there the next time it rains
"Shame on you old lazy bones" I say
"And just what have you done today?"
I nursed the baby till he slept
I held a toddler while he wept
I played a game of hide and seek
I squeezed a toy so it would squeak
I pulled a wagon, sang a song,
Taught a child right from wrong,
What did I do this whole day through?
Not much that shows, I guess it's true
Unless you think that what I've done
Might be important to someone
With bright blue eyes, and soft blonde hair
If that is true I've done my share.*

*Paula, mum of Joshua age 1
(from Australia)*



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.

