



DOWN'S
HEART
GROUP

NEWSLETTER

Issue No 26

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Food can be fun!

We invite you to share your feeding tips - see page 3



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Share your experiences

AND MORE ...

Chair's Report

Dear Members

I hope you find this issue of our newsletter with its mixture of stories and information as enjoyable as I have.

We've struggled to bring you this issue as National Office has become a very busy place fielding many calls from members and responding to requests for support and information. We have resolved to bring you four newsletters each year and over the past two and half years you have only seen three. We are currently in the process of correcting this issue by increasing our staff by one person and will soon be advertising for a part time 'Information Officer'. If anyone is interested please contact me directly and I will be happy to provide a job specification and application form.

Recently we have undertaken a review of Down's Heart Group services and in addition to the new Information Officer post we have agreed to several projects for the coming year. These include updating the current video, the production of a new video aimed at people living with Down's Syndrome and a heart condition, re-launching the website for which we are in receipt of a £5,000 grant from Children's Heart Federation, and a redesign of the Down's Heart Group image & reprinting of information sheets, flyers, posters etc. We also intend to produce a fund-raising pack for Down's Heart Group awareness week - 1st to 5th November.

Last year we launched an affiliate programme and many independent groups are currently reaping the benefits of membership. If you would like to know more about this programme contact Penny at National Office.

Our Bristol conference was a great success, in spite of some of us having property stolen from the hotel the evening before. I had all my presentation material stolen so I had to busk it the best I could!

We presented two papers at this years 8th World Down Syndrome Congress in Singapore. Many people with Down's syndrome participated in the event which was attended by 700 people from over 130 countries. Watch out for our report which will be distributed within the next couple of months.

Finally I would like to extend my thanks to all our friends who have contributed to this issue of the newsletter and those who give up their time attending meetings or fundraising to support our cause. We need your contributions and participation in order to provide the support and information our members need.



Note from the Editor

Well if things go according to plan this will be the last newsletter I edit as I will be handing the job over to our Information Officer when they are in post. After twenty-one issues it will seem strange not to be responsible for putting the newsletter together, but with the increased workload at National Office it will be nice to free up some time to address some of the other tasks that need my attention.

I would like to take this opportunity to thank everyone who has contributed to the newsletter over the years, in particular those families who have taken the time to write their story. Whilst it has not been possible to publish all of them, I can assure you that they have all been read and they have provided valuable knowledge and insight which is used to help other families.

Finally, thank you to everyone who has sent me cards and good wishes since my mishap at the beginning of June. My foot is improving slowly and I hope to be off the crutches and 'running around' before too long, at which time 'normal service' in the office will resume, in the meantime thanks for your patience.



Front Cover

Christina Sorensen demonstrates just how much fun food can be when you are left to get on with it yourself!

Invitation to Affiliate with DHG

The Down's Heart Group has recently put together an affiliate membership package for interested organisations.



The Group was established in 1989 to provide support and information for families who have a member with Down's Syndrome and an associated cardiac condition. This is the scope of our work; we leave all other Down's Syndrome related issues to the Down's Syndrome Association.

Over the years the Group has grown to over 1000 members and has a seriously committed team to manage its day-to-day affairs and a team of eminent professionals who support us on clinically related matters and the accuracy of our information.

We now extend an invitation to all interested groups to become affiliated to the Down's Heart Group and reap the benefits that it brings for your members who may not already be aware of our existence.

If you would like to find out how to affiliate with the DHG for free, and consider in more detail the benefits, please contact us.

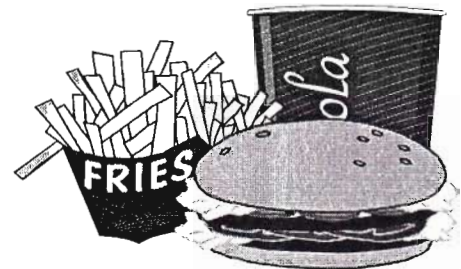
We look forward to welcoming your group on-board soon

Many thanks to everyone who supported our work last year by buying their Christmas Cards and stamps from us. Thanks to your combined efforts we sold 8600 cards, 39 mugs, 1476 first class stamps and 5148 second class stamps, which resulted in a profit of £2300.

- Our treasurer Phil Thorn once again beat all the other Committee members with sales of 1000 cards, 300 first class and 600 second class stamps.
- And member John Carter was once again our most successful salesman with sales of 860 cards and 200 first class stamps.

We are especially grateful to all those people who rounded up their payments to include a donation. Including the tax we can reclaim from those who Gift Aided their donations, these amounted to £1129.

Don't forget your DHG cards this coming Christmas!



Food Glorious Food

As our cover photo demonstrates, food can be fun for our children, but as many parents know it can also be a cause of much concern and anxiety.

From trying to get babies to feed, toddlers to accept lumps or drink from a cup, right through to watching the weight of our young adults, few families can have escaped the troubles of food! We would like to invite you all to share your tips and tricks for the benefit of other parents.

Shortly we will be starting work on updates and additions to our Information Pack. Feeding Problems will be one of the new inclusions, so if you have gems of wisdom to share, we NEED to hear from you.

Also, if you have suggestions for any other topics that you think we should consider putting in the Info Pack, do let us know. Particularly those subjects that you had difficulty finding information on or where help was available but you felt the need for specific advice in relation to your child having Down's Syndrome. And of course any advice you have relating to these.

So please do get in touch and help us to provide relevant, helpful information for families based on the experience of other parents.

YOUR HELP NEEDED!

Claire's Story

On the morning of 23rd January 1986, my wife, being "with child", felt as though "Baby" was making its presence felt. The upshot was that she was taken into hospital for various tests. At two minutes past five that afternoon, Claire was born after a 20 minute labour, weighing in at 6lbs 6oz. At 8 o'clock that evening, Dr Holland the paediatrician came to tell us that Claire had Down's Syndrome. Tests were done the next day, and it transpired that Claire had three holes in her heart.

The next few months were a daze as we went in and out of hospital by bus, changing down town Oxford, eating at Macdonalds late at night (the enthusiasm for Macdonalds food soon disappears in these circumstances!), to get into see Claire in Special Care, and later in Ward 4B. She was really underweight, had no instinct to suck on a bottle, and even when we got her home, we would spend all night just trying to get some nourishment down her.

At a year old, she was taken into hospital as she was so underweight, and later on as they thought she had a collapsed lung, but that was proved wrong. We only found out much later that, around this time, the hospital staff contacted social services as they thought we were incapable of looking after Claire, but social services decided that they would probably do more harm than good.

She started part time at school when she was two and a half years old, and would be so shattered on coming home, that we couldn't wake her before 8:30pm, and then the battle to get some nourishment down her began. I used to measure out her medication before leaving for work into little syringes, two lots of diuretics and one lot of Digoxin for her heart. During term time, this would have to find its way into school.

Because my wife and I both worked, myself on regular hours and she on shifts we were lucky enough to find a good childminder. Apart from having loads of experience with her own kids, she seemed to have an instinct for Claire's needs. Again, we didn't know at the time, but the Health Visitor called on her to discuss Claire and said that she would never walk. So she promptly encouraged her to walk. The word "can't" didn't exist in our childminder's vocabulary.

In due course, she started to flourish and do well at school. The chance of her going on a school holiday was mooted: my wife was reluctant, but I was keen to encourage this as Claire was ready for the experience, and we needed the time to ourselves as well. Mind you, I had to get the headmistress around to persuade my wife! Claire had a really good time.

When she was seven, it was discovered that two of the three holes had healed, and an operation would be necessary for the third. The famous Stephen Westaby did the operation. He was obviously a very talented surgeon, and I think we were lucky to

have him. When he set eyes on Claire, he said, "Oh, what a lovely child." Of course, it was quite a traumatic time. My wife couldn't face taking her down for the anaesthetic so I went, and when I got back to the ward, I broke down.

She was sedated for a week afterwards, and one of the most touching things I experienced in that time was the Catholic chaplain at the local prison where I play the organ, who was due to have surgery to remove cancer from his stomach a short while later, came in and gave her a blessing. On the following Monday, after they had allowed her to come round at the weekend, I took her for an X-Ray, and we found ourselves afterwards at Mass in the hospital chapel, and Claire was the centre of attention; she was beaming and feeling quite happy.

After the operation, she gained weight, got a lot stronger, and now is a lot stronger than her Dad! She is now well overweight instead of underweight. That year, just a few months after her operation, I took her to Walsingham, to the New Dawn conference which is a week long event for charismatic Catholics, which she thoroughly enjoyed. The problems of keeping tabs on her at

times were a nightmare, as she had no sense of danger, but could quite easily wander off. Mind you, with help and support, she is a lot more sensible now.

We still go to the New Dawn every year now, and have been camping for the last few years. Claire can now find her way independently to the Youth events, but still need some guidance around meal times. Through the years, people have got to know her and watch out for her. Thanks to her, I have made some

good friends there, one of whom especially, has been a good friend through some difficult times, and if I'm feeling a bit low, she just has that touch to encourage. Mind you, Claire does a pretty good job herself. She knows when her Dad is feeling down, and just gives him a cuddle. At other times, she just beams at people, and they feel lots better!

She is now in her second year at Derwen Residential College, and loving it. Her first year was great, but I think she's feeling a bit sorry for herself this year, probably because her boyfriend has left! Apart from giving 100% at "work", she also goes out partying at nights!, trips out, and gets to church most Sundays. We turned up at the church one Sunday, and, after Communion, she went and laid down by the altar. When I told her afterwards that I wasn't too happy about it, she said, "But Daddy, I was saying my prayers!"

The proudest moment at college so far was when we went to see her take part in a fashion show. She took the part of an alien, came down the catwalk, saw me, and shouted Daddy!

**Tim Charles
Bicester**



Vision in children with Down's syndrome



Because children with Down's syndrome often have particular difficulties with language, educationalists describe the children as 'visual learners' and recommend the use of visual aids in the classroom. It is therefore especially important that the children's vision is as good as it possibly can be and that the children are given every opportunity to access visual stimuli. Unfortunately, children with Down's syndrome are at much greater risk of eye and vision disorders than are typically developing children. They therefore need regular eye examinations, are more likely to need glasses than typical children, and may need compensation in the classroom / learning environment for visual deficits. Classroom and advisory teachers as well as parents need to be aware of the visual difficulties that the children may experience.

At the Down's Syndrome Vision Research Unit, we have been studying visual development in children with Down's syndrome since 1992. We have a large group of enthusiastic and highly committed families taking part in our studies, many of whom have been with us since the beginning, and we see over 100 children regularly. Our most significant findings are described below.

Refractive Errors

Long-sight, short-sight and astigmatism are much more common in children with Down's syndrome than in typical children, and many more will need to wear glasses. Ordinary children are often long or short-sighted in early infancy, but grow out of these errors over the first few years of life. Children with Down's syndrome start out with a similar range of errors as do ordinary children, but are much less likely to outgrow the errors and much more likely to become more long or short-sighted.

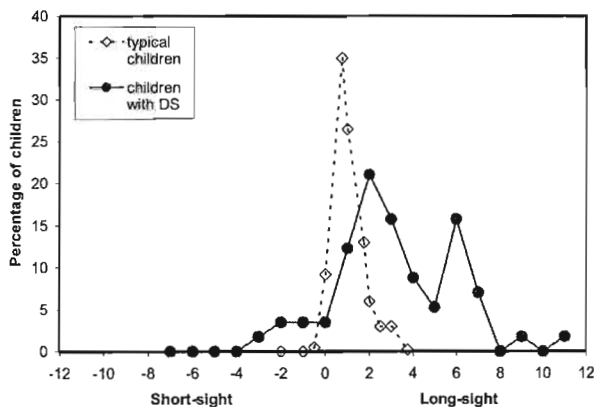


Figure 1. Long and short sight amongst 6 year olds

It is important (as for any child in the classroom) that the teacher understands when a child will need his/her glasses, and what level of vision he/she will have both with and without glasses. Long-sight of low to moderate degree can be overcome in typical children by accommodation (active focusing) and not all children who are long-sighted need glasses. However, children with Down's syndrome, because they have difficulty in focusing (see later), will be much more dependent on their glasses for clear comfortable vision than will typical children. Children who are short-sighted, on the other hand, may be better off without glasses for close work.

Squint

Children with Down's syndrome are at much greater risk of developing a squint (eye-turn) than are typical children. A child with a squint is likely to have a poorer level of binocular vision especially depth perception. Tasks requiring fine depth discrimination, such as threading beads, will be more difficult.

Accommodation (focusing at near)

Children's interests are mostly close at hand, and most of children's learning takes place at near. And it is at near that we find the greatest differences between vision in children with Down's syndrome and typical children.

Usually, children focus very easily and very accurately on near targets and it is only as we approach middle age that we expect to experience difficulty in focusing at near. We find, however, that most (over 70%) children with Down's syndrome focus very poorly at near – they tend to under-accommodate by quite a large amount. This is consistent for any individual child, and persists even when the children wear their glasses to correct long sight. This means that near work, especially in school, must be more difficult for the children because it is out of focus.

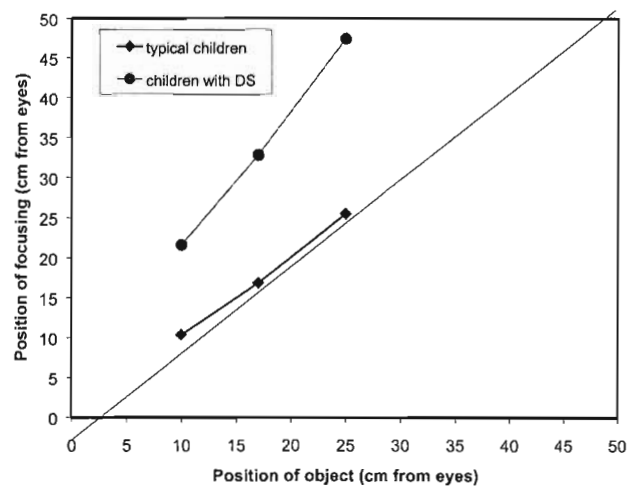


Figure 2. Near focusing in children

We don't yet know the reason for the poor focusing and we have studies underway to examine various possibilities. However, we do now know that the children's focusing improves dramatically with bifocal spectacles. In a controlled trial, we supplied bifocals to a group of 17 primary school children with Down's syndrome, and conventional spectacles to a second group (the control group). The two groups were matched for all of the factors that might influence spectacle use or near work, such as age, cognitive ability, school placement etc. Over a 20-

week trial, the children in the bifocal group consistently focused more accurately on near work than did the children in the control group.

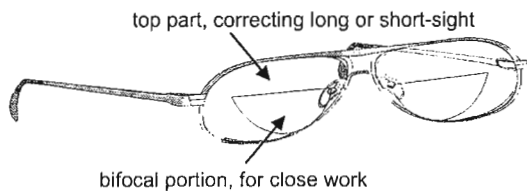
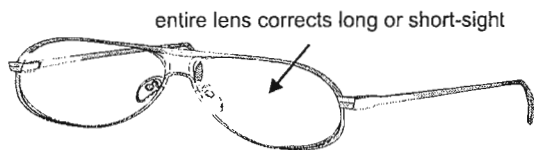


Figure 3 Bifocal lenses



Conventional (single vision) lenses

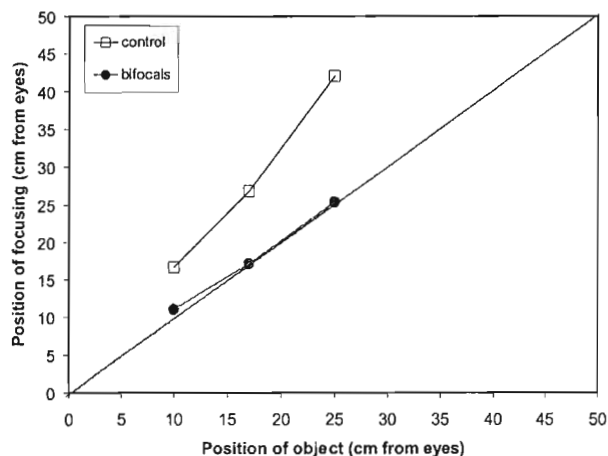


Figure 4. Measures of accommodation (near focusing) in children with Down's syndrome wearing bifocals and children wearing conventional spectacles (control)

In the trial, and now that we prescribe bifocals clinically, we find that children with Down's syndrome wear bifocals very successfully. None, so far, have encountered any problems, and several of the children prefer to wear their bifocals all of the time rather than keep them for school use. Two children were very reluctant to wear glasses when they had conventional ones, but now wear bifocals very happily. In some cases teachers and classroom assistants have reported improvement in concentration and quality of work when the children wear bifocals. We are now, therefore, recommending that all children with Down's syndrome who show poor focusing are prescribed bifocals.

The positioning of the bifocal is very important. The top of the bifocal should lie across the child's pupil (this is a much higher position than usual for bifocals) so that the child can look down through the bifocal without effort. We provide an information leaflet that parents may take along to their child's eye examination; this specifies the correct position for the bifocal.

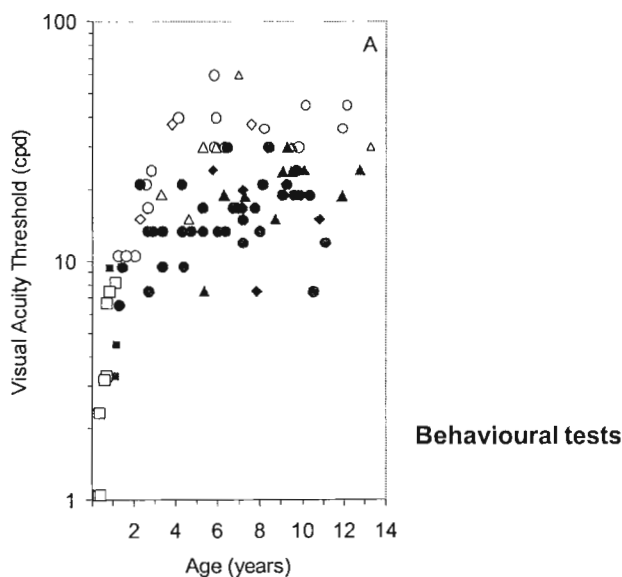
Visual Acuity (detail vision)

Detail vision is usually measured in adults with the familiar letter chart. For children (and people of any age with learning disabilities) there are lots of alternatives that don't need reading skills. These include picture naming, matching or signing and the preferential looking tests that only require the child to look towards a picture or target. It is, therefore, possible to measure how well someone can see whatever the age and ability.

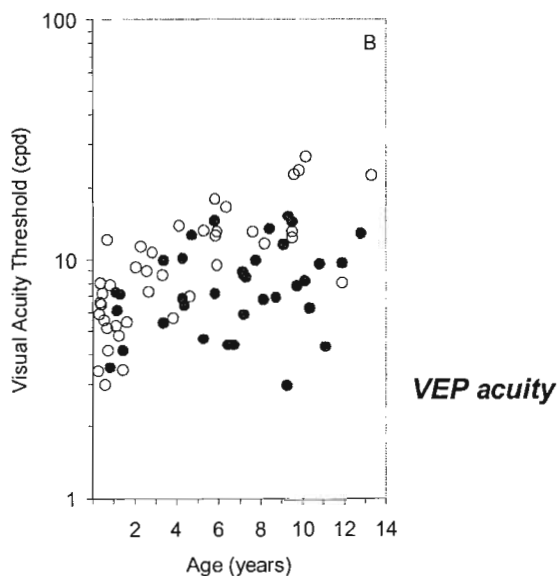


At birth, detail vision is quite poor for all children, and rapidly develops over the first two to three years. Acuity in children with Down's syndrome also improves in childhood, but it lags behind typical visual development at all but the youngest ages. The difference is the equivalent of perhaps two or three lines on a conventional letter chart at both distance and near, and is there even when children are wearing glasses that correct any long or short sight.

The clinical ways of measuring acuity such as described above, using letters or pictures, are known as 'behavioural' tests because they measure aspects of a child's behaviour or performance as well as vision. One reason why we record a poorer visual acuity for children with Down's syndrome is that the children might under-perform on the test, not trying as hard when a test becomes difficult. In one of our latest studies we have measured acuity objectively using EEG techniques to record the brain's responses to visual targets (EEG's measured this way are known as visual evoked potentials or VEP's). Our data show that even with this technique, visual acuity is poorer in all children with Down's syndrome than it is in typical children.



Children with Down's syndrome, filled markers; control children, open markers



**Children with Down's syndrome, filled markers;
control children, open markers**

Our results show that acuity deficits are genuine and represent a (mild) visual impairment. It is important that teachers acknowledge that, even if children wear bifocals successfully, or if they focus accurately without spectacles, their visual acuity will still be below normal. Thus reading materials, for example, do NOT look the same to a child with Down's syndrome as they do to his/her classroom peers. The material does not appear to have the same level of detail. Enlarging the print may help the child to access print more easily, but does NOT restore a 'normal' appearance to the material.



In similar studies, we have also shown that children with Down's syndrome are poorer at discriminating low contrasts and at detecting when a scene is out of focus. All of this may indicate that the children have a poorer ability in all visual discriminations than typical children. *Visual tasks are therefore more difficult for children with Down's syndrome for reasons over and above any learning disability that they have.*

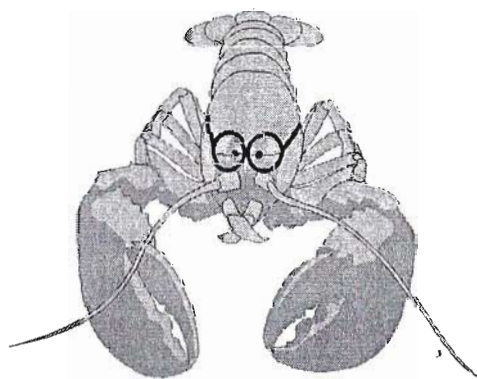
For this reason, we recommend that children with Down's syndrome are registered with their local education authority's visual impairment support service. A support teacher can advise the classroom teacher on whether materials are adequate.

Additional problems

Blepharitis is an inflammation of the eye lash follicles that causes debris to collect along the margins of the eyelids and can cause irritation of the eyes. Children with Down's syndrome are particularly prone to this condition, which although not usually sight threatening, can be a source of discomfort and itching, and can result in scarring of the follicles and in-growing

eyelashes. Blepharitis responds very well to simple treatment and parents should be encouraged to take their child to a local optometrist for advice.

Children with Down's syndrome sometimes have problems finding glasses that fit well. In general, the children have smaller noses and a shorter distance from ears to face than typical children, and so glasses have a tendency to slip down. This is not only irritating for the child, but means that he or she isn't looking through the correct part of the lens. It is almost always possible (although time-consuming) for an optometrist/optician to adjust a frame, replace pads, shorten sides etc. so that glasses fit properly. *Children with Down's syndrome have as much right as other children to expect glasses that fit properly and comfortably without slipping.*



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In Memoriam

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

Samuel Asquith - Leeds

Meghan Batrouni - Newport

Eve Brice - Retford

Katie Lawton-Livingstone - Colchester

Albert Phipps - grandfather of Vivien

Tom Pow - South Oxhey



Our Button - Jack's Story

Where do I start to tell our story? The past year just seems like one big blur with many highs and some very low low's, so forgive me if I am a bit foggy!

My husband Dean (33) and I (28) tried for a baby for about eight months, and although I had always considered that we might not be able to have children I had never considered that our baby may not be the full picture of health. I was only a matter of weeks pregnant when I found out, and was a little disappointed not to get the excited response I expected from my husband and family.

Just before the twelve week scan the hospital sent me some information and a tick sheet for me to complete which asked if we wanted to know if there were any problems found during the scan. I don't think that Dean and I actually even thought much about it. When our health visitor called around before the scan I asked her what it was all about and she simply said "well it doesn't harm to know" so we ticked the box.

The day came for us to see our little button! The sonographer asked why we had ticked the box and we replied that we would like to know to be able to prepare if things are not right. She was quite strong in her manner "well why, if you would not have a termination, do you need to know?" We were sent away for a cup of tea to see if the baby would move about a bit, and on our return we were seen by another lady.

Once she had put all the measurements etc. into the computer she found that the chances of our baby having Down's Syndrome had changed from about 1 in 750 to 1 in 134. After a brief chat about the types of tests that could be done she left the room to find out if St George's had an appointment for our bump to have a heart scan. We had decided that an amniocentesis was out of the question as we would not want any chance of miscarriage. We were shown into a sitting room and the details of the appointment given to us. I don't think we even discussed the amnio between ourselves, it was just taken as read.

On the way home we went to see my mum and dad - until then I don't think that either of us had shed a tear, but when I had to tell my mum then they just came out. My mum was beside her self - I was born ten weeks early and had all sorts of complications so she did not want me to have to go through any of the pains that she had to. My dad was more practical and said that although there was a 1 in 134 chance we may not be the one.

We went home and met with Dean's sister, we had a very long chat with her about the possibilities, she said one of the nicest things that anyone has ever said to me, that she could think of no better people than us to give this baby a loving home and all the encouragement he needs to grow.

We struggled through the next two weeks until we went to St George's for the heart scan, unfortunately we were given the wrong date and had missed it! Another sonographer carried out the scan, she confirmed that certain parts of the heart were OK but asked us to come back one week later to see the cardiac sonographer. When we returned they found that our baby had an AVSD and said that were the one - the heart defect was another soft marker for Down's Syndrome. The cardiac sonographer conducting the scan was very thorough and very direct, she took time to draw diagrams and gave explanations to us. We were also asked to think very carefully about having an amniocentesis. We were taken to another room for a cup of tea and a chance to digest what we were faced with. The lady supporting us was a midwife and we were the first family she had to help in this situation, she was great! She gave us information as we needed it and explained that she was there to help as much as she

could, would be at each appointment we had and was at the end of the phone if we needed her. We went back into the cardiac sonographer and had the chance to ask any further questions. We were given another appointment for two weeks time for another scan and possible amnio.

The tears came and kept on coming, all I could think about was this little life inside me, by this time I had already changed so much mentally and physically and I guess I already had a strong bond with the life that we had created. We had also been given a Heart Children book with a diagram of the AVSD, this book also contained very real photographs of a child immediately after surgery in intensive care, I could not get these pictures out of my head. Was it fair to have a baby then put it through this? The other vision that I could not remove from memory was of a girl having a termination on a hospital drama on television. How could I just lie there and let that happen to the life inside me?

I started ringing all the numbers of help lines I could. At 8am on a Saturday morning I rang the Down's Heart Group (the only people that did not have an answer phone on!) explanations were given again, alternatives given and some positive stories told. I was also offered to meet another family with a toddler that has Down's Syndrome and had been through the same heart surgery. I just wanted someone to tell me that all is going to be OK and that I would have a perfect baby, that this was all going to go away. Of course no one could do that. I just kept on going round and round in circles in my head.

By mid morning I had worked myself up so much that I was being sick and could not calm down. I decided to ring the doctor. I don't know what I expected (drugs and lots of them I think!). Ringing him was probably the best thing I could have done. I explained our problems to him and he simply said, "you just told me that you would not terminate a pregnancy purely because of Down's Syndrome and the heart surgery has a 95% success rate - what is the problem?"

During this time I was told that my parents next-door neighbours had had a baby boy with Down's Syndrome many years ago and that they would speak to me if I wanted. I went and had a very hard afternoon with this lady. Her little boy had died at about 18 months of leukaemia, and by all accounts she had had a very heart wrenching time and did not want me to go through the same thing. She wanted me to base my decision on fact and have the amnio. She and her husband both had tests to find out about their genetics and found that she was carrying the extra chromosome. They had fallen pregnant time after time and terminated every pregnancy that the test showed positive for Down's Syndrome, until she felt she had a 'perfect' baby. I guess what they went through 30 years ago was very different, although emotions don't change attitudes do (most of the time!)

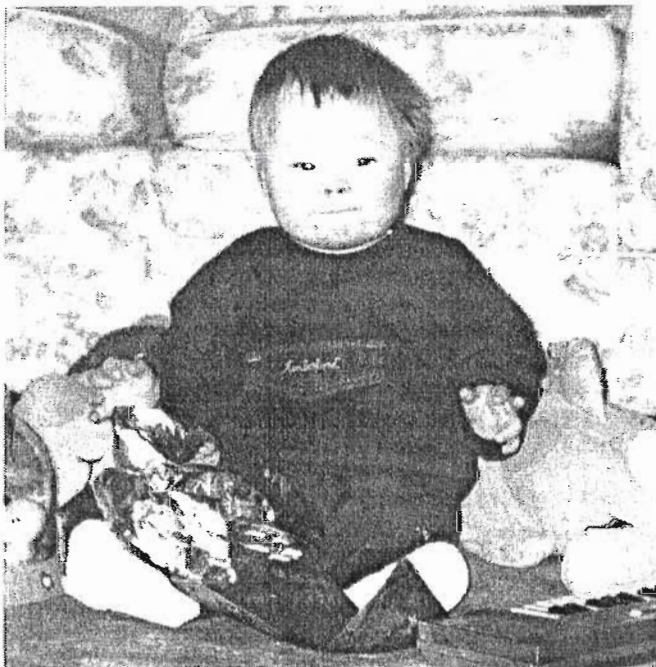
The afternoon was exhausting but it did make me realise that I did have a choice. I think this was the first time that this had even really dawned on me. Dean and I discussed this and we seemed quite calm for about an hour! I could not do this, I could not have the tests. I felt like I was betraying our baby by even having the conversation. How could I consider not having him when we had been trying for a baby for eight months I felt that if he wanted to live he would fight and I would do all I could to help.

We went back to St George's and explained our research and our decision not to have the amnio. Scans continued with other soft markers coming into vision.

I started seeing our local hospital to keep them in the picture. On arriving I was shown into an office so that I was not left waiting

with other mum's. I guess that others in my situation may not feel comfortable with other 'normal' mum's but I did not want to be treated differently. During the appointment the midwife explained that they did not have any information leaflets about Down's Syndrome or heart conditions and asked me if I had any numbers of organisations that could help me. At that I wrote some numbers down for her! We talked about antenatal classes - there seemed to be a slight problem with me joining other groups. I guess that they just wanted to shelter me. I did not want to be sheltered I was a pregnant mum and proud of it too. I was offered counselling which I accepted - I did not go back! The consultant asked if I would Like to meet another mum that had had a baby with Down's Syndrome but nothing more was said. Later in the pregnancy I was scanned at the local hospital, the sonographer would not talk me through the scan or explain what she was seeing, after the scan the consultant told me that the baby's kidneys were worse but could not tell me any more just saying that they are not the experts, well why scan me then!

We decided to get a referral to deliver at St George's as we felt that the relationship was stronger and they had all the facts, history, knowledge and facilities that would benefit our boy.



Brompton visit

Dean and I visited the Brompton hospital where Jack's heart surgery was going to take place and met with the Cardiologist and Surgeon that were to look after him. They were both very nice gentlemen and spent as much time as we needed with them. The Surgeon actually said "how about I tell you what I can and if I have not answered all of your questions you can ask me at the end". My husband jokes even now that he must set himself targets to cover every possible question in his opening! We were shown around the ward and the intensive care unit, which was an invaluable experience for us.

I still cannot believe the support and love that people have shown to my husband and myself during the past year. I have always been in my box and don't like people coming inside, I have changed - I have come close to being more hugged than my

baby! Most of the hugs that I received if not prompted by tears ended in tears just for the fact that so many people care so much. Jack had his Christening in May 2003, many of the guests I had never met, just spoken to for hours on the phone! My faith in human nature has been restored ten fold!

There were also attitudes that hurt me beyond belief such as one of my brothers who's initial reaction was "well you should not have told anyone you were pregnant until you knew that all was well". He is usually so good with children and we used to be quite close, I don't think that he knows too much about Down's Syndrome and does not know quite what to say to me. He has visited but you can tell that he looks uneasy! Even now I try to call (without pushing) so that he can't just walk away, Jack has so much to offer him.

Faith

I can remember walking down to the church, I have not been a church goer but just wanted someone to talk to, sometimes you cannot believe that you can be so alone in such a busy world, how can the world still go round when you are in so much pain. I spent time with the reverend and he prayed and talked as much as I needed. Later when I had Jack I spoke to the Curate to arrange his christening, he turned out to be such a wonderful man and made a point of coming to visit us from time to time and even came to visit Jack at the Brompton after his operation, you could see the tears in his eyes. It was after his surgery and recovery that the Curate christened him and you could see the joy on his face. From time to time Jack and I go down to the church for the Sunday service in a way just to let them know we have not deserted them now our prayers have been answered.

Jack's Arrival

Jack was breech so we went to St George's for him to be turned, but he decided that he did not fancy this so we were packed off home to go back for a Caesarean section in two weeks time. After a curry for dinner I decided that I must have wind - a few hours later I could not sit still for a second and started bleeding, I was insistent that nothing was wrong but my husband made me ring the hospital, I was told to come straight in and be checked over. OK I was in labour - the time had come!

Jack was born by Caesarean section on 20th December 2002 at five thirty in the morning weighing in at four and a half pounds. When he was shown to me I said his name and he responded so quickly to me. They took him off to intensive care to be checked over and hooked up to a heart monitor and to be scanned. When I was returned to the labour ward I was given two pictures of Jack and I looked at them and said to the sister "he has Down's doesn't he" there was no need to answer, he was the most perfect beautiful baby in the world to me. He was wheeled into me for a very short time but I was unable to hold him until I was able to walk down from the maternity ward to see him myself.

Before Surgery

We were transferred to our local hospital on Christmas Eve. We met some truly wonderful people there, staff and other parents the stories are endless and all so heart breaking. I practically lived there, if I was unable to spend the night I would go in early and come home late, I could not understand how other parents who hardly spent any time there at all could be taking their babies home so soon. I did not know how long we would have Jack, I did not want the only life he had to be in a hospital world, there was so much I wanted him to see and experience and to cuddle him when I wanted without anyone else there. Jack's heart and kidney problems were as we expected, after monitoring and scanning things started to stabilise, our main battle was his

feeding and weight gain. Weighing in days were quite an emotional time for me - Sundays and Wednesdays! The day that his weight had gone up and we were discharged the nurses actually weighed him at about six in the morning before I got up, just in case I had lots of tears again! We spent about five weeks all in all at hospital until the day they said that we could go home. It was wonderful we had dreamt of this for so long and had talked about what would be the first thing we would do when we got in.

Weight gain became the aim of our lives I was part breast feeding and expressing and using a bottle for the rest. We had to get him as big as we could for his operation to help him the only way we could. One night Jack decided that he wanted more and more milk then he turned a shade of blue and started to choke - that is desperation! I don't know who cried more me or him!

We did end up back at the local hospital for a night or two about a week later as Jack went into heart failure and had to start on his diuretics to help his heart pump the liquid out of his lungs. One day when the nurse came to visit we had to have the nasal gastric tube back down as his feeding was so poor, this brought a new set of challenges!! One night we could not aspirate his tube at all so we ended up at the hospital at about midnight just to check that it was still in place!

His feeding went down and down so one morning we called the nurse out. She said that we had to go back into the hospital again. On the way we called the Surgeons secretary to ask how long the waiting list was. To our amazement we were told that if we could get up to the Brompton that afternoon they would operate on Jack the following morning. I can't explain how I felt. Looking back now I am just so glad that we did not have a date set and have to prepare for that - we got an ambulance transfer from St Peters - it was a whirl wind. His operation was a complete success! We returned home about ten days later with our wonderful bundle of joy.

During these first weeks I can remember everyone wanting to come a see this little button that had caused so much heartache, I did not want anyone else to meet him just yet I wanted him to myself and apart from anything else I felt that every new person he met could be a possible risk of a cold or tummy bug that could cause so much damage to our tiny little boy. He is not so tiny now and he loves cuddles from everyone (especially ladies!).

Back home and return to the weight battle, for a week or two we carried on with the nasal gastric tube, bottle and breast and extra calories in the form of powder to be mixed into his milk and within days the tube came out and the weight started to stick!

Jack has always been such a lively nosey little chap, even at St Peters they used to put him in a pram on reception so that he could check out what was happening, and when it was time for sleep put the hood up and put him in a corner! When we got home he used to give us such a fright when on his play gym all hell would be breaking loose with his toys then all of a sudden it would go quiet as he crashed into sleep mid action!

New Friends

We have met and continue to meet such wonderful people. We met a family without whose help we may not have got this far. They have a little boy with Down's who was about one when we met them, he also had the same heart condition as Jack.

In turn we were asked to talk to a lady who was pregnant with a baby with Down's and again the same heart condition as Jack. She was making her decision whether to continue with the

pregnancy, she did and she also has a beautiful healthy baby boy who's surgery was a complete success.

Whilst waiting in the reception area of the Brompton I got talking to another pregnant lady that was also waiting to see the same people. Her baby had a hole in his heart and would also need surgery, needless to say we became good friends during the following months, (Little Oliver is doing well now!).

We continue to meet and make new friends at a place called White Lodge, which is a day respite care centre, which we attend for a play group and Hydrotherapy. Our health visitor has been and continues to be a tremendous support through the whole experience.

Now

Now we have the most beautiful baby boy, who is growing more inquisitive by the day that any parent could want. He is Jack! We are preparing for his first birthday and first Christmas at home I wish I could say that I was not going to spoil him but...

Attitudes Now

Even recently Dean was met with a drunken acquaintance saying "I admire you and your missus for bringing up a Mongol!" After the initial anger I guess that you can't be angry with someone who knows no better, he probably went home with a glow for showing his support! Saying that, I get stopped quite frequently by people saying that he is such a happy boy and they want to have a cuddle!

People used to say during my pregnancy that you are only given as much as you can take, I didn't want to take it and I felt how much more could we be given. I did understand that this was meant in a kind way but it used to drive me mad!

My dad said (at some stage during my pregnancy) that although "Jack may not be the worlds best athlete he may be the worlds best snooker player!" and why not.

The Future

The future looks very bright! Jack is doing so well and is such a bright button in our lives, with any luck we will be able to provide him with a brother or sister to terrorise soon!

We continue with an active schedule of portage, physio, speech therapy and hydrotherapy to make sure we give him as much as we possibly can and he is doing so well, I guess that the hardest thing is to listen to comparisons in months to normal children, what is normal? Jack is a healthy, happy baby that has the same tantrums as any other child, he embraces life and does not want to miss a second! If there is a person in the room he craves their attention and to hell with anything else - this proves interesting during portage sessions and could prove fun at assessments!

I would not be telling the truth if I was to say that I don't have down moments about Jack's future but when look rationally at my concerns are they that different to other parents?

I am glad that Jack chose us.

**Elaine Archer
Addlestone**

DOWN'S 'CURE' BREAKTHROUGH

New 'Cure' - the real story

Many of you will have read articles similar to the one above which appeared in the Sun newspaper last October reporting that it would soon be possible to reverse the learning and memory defects associated with Down's Syndrome.

These articles stated that the gene responsible for these specific problems had been identified and very much implied that a treatment would soon be available for the neuronal damage that caused them. Several members contacted us for more information and to find out how they could involve their children in any research that might be going on in this respect.

To get the facts we contacted Dr William Mobley the director of the Down Syndrome Centre for Research and Treatment at Stanford University. He very kindly reported that "the work is very encouraging, but no way near being ready to translate to people. Having said this, we are very committed to finding ways to improve cognition and will work very hard at this."

So as you can see there is positive news regarding the future potential treatment of these specific problems, but the press have overemphasised the progress and we will have to wait a little longer before this is developed into a safe treatment to give to humans.

Rosie goes red, Violet goes blue



This wonderful book written by Fran Davies and published by the Children's Heart Federation tells the story of sisters Rosie and Violet. Using simple dialogue and illustrations it explains that Violet's heart condition sometimes makes her go blue, but then she has surgery and comes back pink.

The book is ideal for young children and may be suitable for explaining to some of our older members too. Single copies can be ordered from **0808 808 5000** or it can be downloaded from www.childrens-heart.org.uk with copyright waived for those who would like to print it out.



Personal Experiences of Health and Illness

This growing website provides personal experiences of various conditions in video, audio and written format.

A few months ago they added a module for Parents of Children with Congenital Heart Disease which as well as the personal accounts also includes information, resources and a Questions and Answers section. They are now starting work on a module covering prenatal diagnosis.

Visit the website at www.dipex.org and click on modules which will show a drop down menu.

Inclusion Skating at the National Ice Centre



We have been made aware that the National Ice Centre in Nottingham frequently hold special inclusion sessions for disabled people. They can access the ice either on skates if they have sufficient co-ordination or in single person sledges (both provided by the NIC) or directly in their wheelchair.

The price is £3.50 per skater (carers/parents skate for free) and able-bodied siblings and friends are welcome at the same price. By all accounts the staff are very welcoming and the children love the speed, music and atmosphere at the NIC. There is also designated disabled parking adjacent to the Centre.

If you would like to know more please contact the National Ice Centre on **0115 853 3000** and ask to be added to their disabled database for notification of future sessions.



Annual Conference - Parent Power!

Liverpool - Saturday 25th September 2004 - **FREE TO ALL**

During the morning session the conference will be looking at how 'Parent Power' can be used to influence services and how parents can and have made a difference to services provided. The afternoon is split into workshops entitled 'Talking to Doctors' and one on Assertion Skills - getting your point across effectively. And then a report of a survey looking at families who check their child's INR at home.

This event which is free, is always well attended with particular call on the creche places which are allocated on a first come first served basis. So if you are interested in attending please call Claire Hennessey on 01934 863401 for more details and a booking form, as soon as possible.

No Time for Us

Relationships between Parents who have a Disabled Child

A survey of over 2,000 parents in the UK

Contact a Family asked parents of disabled children what effect they thought having a disabled child had had on their relationship. The views of over 2,000 parents with disabled children were collected through a postal survey, a web-based survey, conference and workshop during 2003.

Respondents

84% female, 12% male, 4% no answer
85% white, 3% Asian, 2% Black African, 1 % Black Caribbean,
5% other, 4% not given

Families

67% of children were being brought up by both parents
17% by a single parent
10% in a stepfamily
3% in another situation
3% no response

Census figures suggest that there is an overall rate of 23% of children being brought up in single parent families, 65% live with both parents and 10% in step families

Current relationships

43% of parents described their relationship as very good
16% as quite good
17% as variable
6% as not very good
Less than 0.5% said it was very poor
14% had little or no contact with their child's other parent
4% no response

The effect of having a disabled child on a relationship

23% thought that it had brought them closer together
19% thought it had little effect
31% felt that it had caused some problems
13% felt that it had caused major problems
9% felt that having a disabled child had led to separation
5% no response

Experience of counselling

24% had experienced professional relationship counselling. Of the remaining 76%, 38% would have liked to have had counselling. 70% of those who had experienced relationship counselling had found it very or quite helpful.

Problems experienced since having a disabled child

76% stress or depression
72% tiredness / lack of sleep
51% financial difficulties
32% problem~ at work
22% housing problems
10% domestic violence
8% drug or alcohol problems
8% none of the above
4% no response

% of those linking it to having a disabled child

88%
84%
66%
71%
69%
55%
67%

What helps relationships?

Ranked for importance

- 1) Time away from the child to be with their partner
- 2) Ability to communicate openly
- 3) Sharing the care of the child between the parents
- 4) Support of family and friends
- 5) Local and national support groups
- 6) Lack of money worries
- 7) Support from professionals (e.g. GP, therapist)
- 8) Work, either staying in or giving up work
- 9) Having other, non-disabled children
- 10) Child going to full time school

What could have helped?

Ranked for importance

- 1) A break or more breaks, or more flexible breaks
- 2) Emotional support/counselling
- 3) Support and information around diagnosis
- 4) Fewer financial worries
- 5) Help and support from family and friends
- 6) Professional support
- 7) Support for the father
- 8) Recognition of the needs of the whole family
- 9) Practical help at home
- 10) Information about services and entitlements

*This is an Executive Summary, the full report, priced £5, is available from Contact a Family 209-211 City Road London EC1V 1JN
Tel 020 7608 8700 Fax 020 7608 8701
e-mail info@cafamily.org.uk Web www.cafamily.org.uk
Helpline 0808 808 3555 or Textphone 0808 808 3556
Freephone for parents and families*

Your Letters

Dear Editor

I am a solicitor specialising in clinical negligence who has acted on behalf of a number of young people who were born with Down's Syndrome and an atrioventricular septal defect (AVSD). Most of my clients came to me a number of years ago and were born in the 1980s when the attitudes towards babies and adults with Down's Syndrome were very much different than they are today.

In the cases that I have dealt with and continue to deal with, the children were born with an AVSD but either their parents were not advised that surgery was available, they were not advised that surgery should take place within a certain time limit or their child was left at the bottom of a waiting list for surgery rather than being marked as an urgent case.

As a result of a failure to receive the operation the longevity and quality of these children's lives was completely compromised.

In the case of a client called Adam the Defendant Health Authority admitted that he had not been put on an appropriate waiting list marked urgent and we settled his case. Sadly Adam died before the litigation was concluded at only 12 years of age.

We could not succeed at trial in Kristian's case as the Judge refused to believe his parent's evidence that all they were told following his birth was that they should "take him home and enjoy him while they had him". Kristian's prognosis is guarded and he becomes very blue and tired upon exertion. His life expectancy is almost half of what it would otherwise have been.

Jo and her parents have only come to see me recently. However their tale is similar to and as distressing as those that I have heard before. Even now they have had to fight the system to ensure that Jo will receive a heart and lung transplant when her condition deteriorates. Jo's parents have had to use immense media pressure in order to achieve this promise which otherwise would not have been forthcoming.

It was therefore with great delight that I read the stories in the Down's Heart Group Newsletter for Summer 2003. We received a copy of the Newsletter at our office and it was passed to me due to my interest in Down's Syndrome heart defect cases.

I can see that medical science has developed significantly in the last 10-20 years meaning that AVSD can be detected on fetal cardiac scans and an AVSD repair is now considered to have a 95% chance of success rather than the 70% chance quoted in the 1980s.

I am delighted to read in Duncan's story that his parents received lots of information as early on as possible not only with regards to Duncan's possible Down's Syndrome but also his heart defect and duodenal atresia. This enabled them and their friends and family to prepare as much as possible for all that they had to face in terms of Duncan's treatment after he was born.

I see that Allira had her heart defect operated on at two months of age i.e. prompt and effective surgery bringing about a better chance of success. It is wonderful to hear that Allira has thrived since her operation and does not require any further surgery.

Alfie's parents say that they have not come across any form of discrimination in any way at all over their son's Down's Syndrome.



I have been tainted by the cases I have dealt with. It was a joy to read the DHG Newsletter. Thank goodness that that part of the medical profession which were willing to discriminate against babies with Down's Syndrome no longer seem to exist.

Lesley Herbertson
Head of Clinical Negligence
Alexander Harris

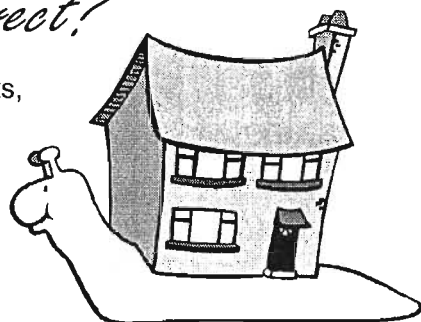
Sometimes with all the emotion that surrounds diagnosis, treatment and surgery, it can be difficult as parents to know if we are over-reacting to things that may happen in hospital. Families often 'put-up' with things that they are not happy with because they are frightened to 'rock the boat' and possibly jeopardise their child's treatment. Hospitals are usually more than willing to listen to your comments and address any issues you have, but if you have concerns and would prefer to discuss them with the Down's Heart Group first, we will of course be glad to talk through your options with you.

Are your contact details correct?

We sometimes get offers of DISCOUNTED or FREE tickets for events, but to take advantage we need to contact members very quickly.

If you want the opportunity to be considered for events like these, please make sure that we have your up to date contact details.

TELEPHONE - MOBILE - EMAIL & of course ADDRESS



Fund-raising Update

Well we did it!

We managed to spend the whole night in one of Derby's most haunted buildings. We saw orbs (little balls of light) we heard footsteps (even though we knew there was no-one else in the building) we also smelled nice sweet smells and horrible ones. It was a night to remember that's for sure it was spent between sitting in a very dark cell and sitting on a very hard wooden bench - it was a long night as this photo the next morning shows!



When my son Adam was born I wanted to do something really special to say thank you for the support which you gave my family. Adam was born with an AV Septal Defect, which was successfully operated on and we have been told that hopefully no further surgery will be needed! YEA!

You were also there for us when we had to fight our Disability Living Allowance claim, very long story but we were turned down three times but with your help we won in the end!

I hope the £736.50 we raised will go a little way in helping other families, like you were there to help us! THANK YOU!

Julie Murfin, Derby

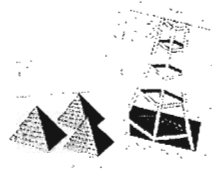
*Recycle your Printer Cartridges
and earn funds for DHG*



Thank you to everyone who contacted us about cartridge recycling after the last newsletter. Unfortunately we encountered a problem with the company we were going to use. We are now dealing with another company, who as well as supplying boxes for collection can supply Freepost envelopes for the return of small inkjet cartridges.

We will be sending out envelopes or flyers in the next couple of months, but if you can't wait that long we'll gladly send you details **NOW** of how you can support the DHG in this way. Just give us a call on [redacted]

*Thank you for the stamps - but
we still want even
more !!!*



Thank you to everyone who has sent in their postage stamps - especially those of you who didn't include a name and address. Christmas is a time when people get lots of letters, and this obviously prompted many of you to send them off to us as we received a steady flow of packets in the following weeks.

On April 5th there were 9 packets of stamps which filled the postman's bag - thank you to the Grant family from Cleveland.

We have several groups and companies collecting as well as individuals so we are getting a good supply, but we could always use more! Why not ask your friends and neighbours to collect for us? Or what about your work or local school!

When you have a reasonable number, pop them in an envelope and post them off to National Office. (NB It's usually cheaper to split them up into smaller lots which can be sent 2nd class post, rather than one big packet which tends to cost more).

Marathon Darts players hit their target

Darts players Paul Finch, Dave Horan and Dean Archer were right on target for the DHG when they took part in a darts marathon. They had to get as many bullseyes and outer bulls as they could in twelve hours at the Ladas pub in Epsom. Not only did they amass 220,000 points beating the previous record by 70,000 but at the same time they raised a fantastic £2,292 for DHG.



FLORA

Flora London Marathon



Once again this year the Down's Heart Group had the support of several runners who put in time and effort to compete in the London Marathon and raise much needed funds on our behalf. Most of the

money has now been collected and the current grand total stands at £6925. **Well done to you all.**

We would like to say thanks to all our runners, particularly John and Margaret Taylor who have run on our behalf for three years and raised a considerable amount of money.

The 25th Anniversary London Marathon will take place on Sunday 17th April 2005 and we will once again be looking for committed individuals to run on our behalf. We will have our usual Gold Bond places available to anyone who is unsuccessful in the ballot, but of course would welcome other runners who have their own places.

If you'd like to run in 2005 you need to enter using the official entry form that is within the official event magazine called Marathon News which will be available in all good sports shops in August. If you have applied to run or have run the event in the last five years a copy will be sent to you automatically.

JUST KIDS - New Edition

Due to popular demand and having already sold nearly 10,000 copies they have recently had a reprint of the 'Just Kids' book, and are now starting to think about bringing out a new book.



If you would like your child to be featured in the next book, please start putting together a potted history of their lives with amusing anecdotes and success stories. This should only be 6 lines of A4 – and you should also include an up to date photo, preferably some sort of 'action' shot i.e. your child at play, riding a bike, at school with other class mates, swimming etc. If you prefer to e-mail a digital photo, this can be sent to Mary at:

All posted photos will be returned once the book has been put together.

They are very interested in hearing from parents of older people with Down's Syndrome or indeed from young adults themselves with information on achievements and skills they have learned like driving a car, passing GCSE's, going onto Higher Education, jobs they are in, marriage, having a child themselves etc.

Please send information to

Mary Schultz

Or telephone 01245 259742 (evenings) for further information.
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Useful Organisations

Netmums

A national network of websites offering information on a wide range of topics for mums :

www.netmums.com

Rathbone Special Education Advice Line (S.E.A.L.)

Offers a freephone advice line for 10am to 4pm Monday to Friday in English, Urdu, Punjabi, Gujarati, Bengali and Hindi.

Tel : 0800 917 6790 or 0800 085 4528
or email : advice@rathbonetraining.co.uk

TES Extra for Special Needs

A monthly newsletter for everyone involved in helping with learning difficulties or disabilities in mainstream and special schools. Free samples are available from their website :

www.tes.co.uk

In Car Safety Centre

Have a range of car seats for children with special needs (some up to 11 years) and can offer advice to meet your needs.

Tel : 01908 220909 or Fax : 01908 317536

NED

*A concert of prayer rises heavenward
Each hour round the world night and day,
On behalf of our Ned, who's so precious,
Whose heart needed mending some way.*

*The Doctors did all of the fixing,
Now the Nurses look after each need;
His Mum and his Dad never leave him
Alone, by his side intercede.*

*Perhaps he was playing with angels
As they watched o'er the bed where he lay;
His little blond head sweet and tousled,
Asleep, while the days slipped away.*

*He has tubes coming out from all over,
He's stuck in a cot that has sides,
He's thirsty but can't drink anything
While still even one tube resides.*

*But now he is waking and watching;
He's wondering why he is there;
He smiled a big smile for Hannah,
He's signing to all those aware.*

*And Jesus is there right beside him,
Ned's small hand in His safely held,
He's helping Ned's heart to get better,
As we join hands in prayer round the world.*

For Ned with love from Auntie Paul

National Contacts



Regional Contacts

National Office



Website : <http://www.dhg.org.uk>

Contact or Ansaphone always available (24hrs in emergency)

National Administrator	<i>Penny Green</i>
Admin. Assistant	<i>Lynda Hale</i>
Founder	<i>Linda Walsh</i>
Chair	<i>Cliff Lake</i>
Vice-Chair	<i>Chris Stringfellow</i>
Treasurer	<i>Phil Thorn</i>
Secretary	<i>Position Vacant</i>
Legal Advisor	<i>Brian Auld</i>
Policy Advisors	<i>Sister Mary Goodwin</i>
	<i>Dr. Rob Martin</i>
	<i>Dr. Claus Newman</i>
	<i>Dr. Phil Rees</i>
Patrons	<i>Sarah Boston</i>
	<i>David Graveney</i>

LETTERS AND ARTICLES REPRODUCED IN THIS NEWSLETTER EXPRESS THE OPINIONS OF THE AUTHORS, AND ARE NOT NECESSARILY REPRESENTATIVE OF THE VIEWS OF THE DOWN'S HEART GROUP.

For your information details of our regions are given below.

Bristol & South West

Avon, Cornwall, Devon, Gloucs, Somerset & Wilts

East of England

Cambs, Lincs, Norfolk & Suffolk

East Midlands

Derby, Leics, Notts & Northants

Ireland

N. Ireland & Eire

North East

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

North West

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

Oxford

Berks & Oxon

Scotland

Mainland & Islands

South East

Beds, Bucks, Essex, Herts, Kent, Middx, Surrey, Sussex & London

South Wales

Dyfed, Glamorgan, Gwent & Powys

Wessex

Channel Islands, Dorset, Hants., Isle of Wight

West Midlands

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

Yorkshire & Humberside

Humberside & All Yorkshire

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

The Down's Syndrome Educational Trust	Down's Syndrome Association
The Sarah Duffen Centre	Langdon Down Centre
Belmont Street	2A Langdon Park
SOUTHSEA	TEDDINGTON
Hants.	TW11 9PS
PO5 1NA	0845 230 037
02392 824261	(Regional offices in Wales, Midlands and N. Ireland)

Down's Syndrome Scotland
158 - 160 Balgreen Road
EDINBURGH
Lothian
EH11 3AU
0131 3134225

Down's Syndrome Ireland
41 Lower Dominick Street
DUBLIN 1
EIRE
00 353 1 873 0999