



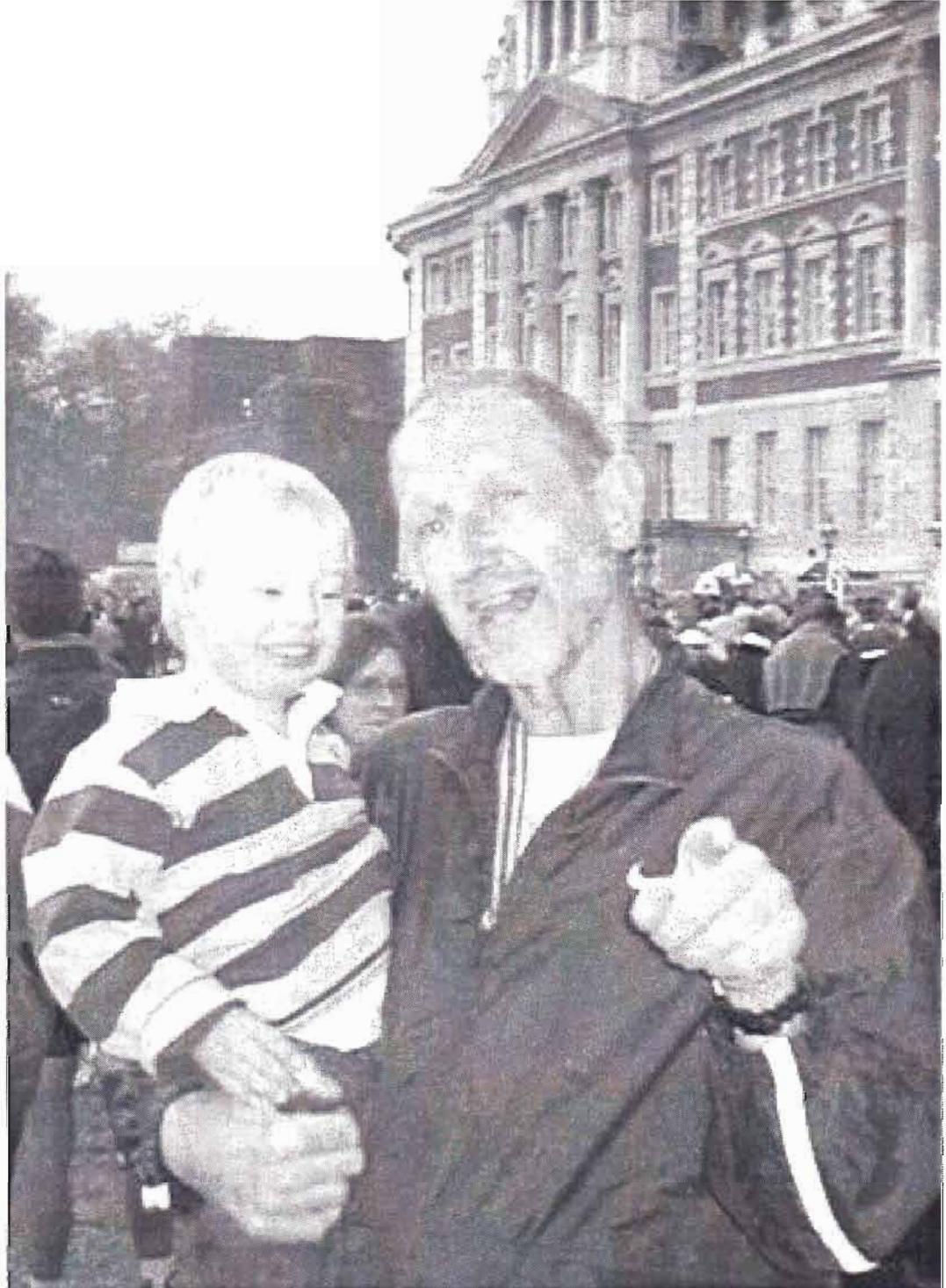
**DOWN'S
HEART
GROUP**

NEWSLETTER

Issue No 24

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PLUS much more ...

Chair's Report

Dear Members

I hope you enjoy reading this issue of the newsletter with its mixture of news and information as much as I have.

I've been chairman of the DHG now for 2 years and have told you little of the plans we have for the regeneration of your charity. In September last year we held the AGM in the comfort of my dining room in Yorkshire. We had a nearly full compliment of the executive committee and as the cricket season had just finished, Phil Thorn our treasurer managed to attend. A postal ballot of members votes had been gathered by Penny and the result, including resignations from certain committee members, was a reduced committee and team to manage your charity. We need more volunteers for the committee please - contact Penny at National Office.

The reason for this comparatively small gathering around my dining table was that the 2001 conference had been cancelled due to poor support. It seemed only a few people wanted to travel to a London venue in July for a conference. Having migrated from London to York a few years earlier I can hardly blame you. So immediately following the AGM we decided to hold a business development meeting to help plan the future of the DHG. I had captive a team who had no choice but to get working, and get working they did. The group were unanimous in their decision that the DHG had to change. We need to re-invent ourselves and perform differently to position ourselves strategically to address the needs of our members now, in the 21st century.

Not to change **what** we do, but to change **how** we do, what it is we do.

Our first significant step towards this initiative is the annual conference. You will see on page 3 the announcement of our very first medical symposium 2002, 'From birth towards Independence'. Penny and Lynda have been working exceedingly hard to make sure this is a great success for everyone. It's a new format, a faster pace, more content and asks for greater participation from the delegates. I can guarantee there will be something of interest for all; members, carers and professionals.

I also intend to take the opportunity of meeting many of you personally, and discussing with you your own family's needs from the Down's Heart Group. I know I can rely on you for your support and look forward to seeing many members in Dunstable on 21st September.

Finally, I would like to extend my grateful thanks on behalf of the Group, to all our friends and supporters who have contributed so generously to our cause to enable the Down's Heart Group to remain efficient and effective. Our fund raising performance this year is the best ever, with donations ranging from a few pence added to round up payments, right up to four figure sums from sponsored events. No slacking, keep up the good work - no matter how small the amount, we need your donation to ensure the survival of **your** Down's Heart Group.



Note from the Editor

Firstly my apologies for my part in the long delay since the last newsletter, which resulted from an illness that slowed me down considerably, and stopped me putting in the extended hours that the DHG often requires. I'm not looking for sympathy, but I would like to tell you a little about my illness, because I believe that it may act as an important reminder for some of our members.

I had been having palpitations occasionally for several months and I nearly passed out whilst visiting a child in ITU, but I didn't think it was anything. I finally went to the doctor when I got tremors in my hands and was constantly hot. Initially he diagnosed stress, but a week later I went back to see him at the insistence of my mum who thought I might have an overactive thyroid.

The doctor thought this highly unlikely as my blood had been fine nine months earlier and my weight hadn't changed, but he took blood and told me it was 'probably my age'. Two days later he was on the phone telling me there was an urgent prescription waiting for me at the surgery. Suffice it to say that my thyroid levels were so high that the path lab had given them straight to the consultant endocrinologist who had immediately phoned my GP. I needed betablockers to help control my tachycardia whilst the drug to reduce my thyroid levels took effect, and then of course it went too low, so I had all the problems of an underactive thyroid.

The main point being that I didn't have the weight fluctuations that doctors always seem to look for, but I can tell you I felt terrible. When it was overactive I had no energy and got out of breath very easily. I was constantly hot, couldn't sleep properly and had these attacks of feeling as if I was going to faint. When it went underactive I felt tired and ready to go to sleep by mid afternoon, although I had difficulty sleeping at night, and it affected my memory and I felt constantly 'woolly headed'.

So please do ensure that you get the recommended thyroid tests for your children, they may not be able to tell you exactly how they feel, and there may not be any obvious signs, but I can tell you that the wrong level of thyroxin in your body, as well as having medical implications, can also make you feel really awful.



Front Cover

Richard Dale holding William Lake, pictured shortly after completing the 2002 London Marathon,

Announcing the 2002 AGM and DHG Symposium

From birth towards Independence

Saturday 21st September 2002

Queensbury School, Dunstable, Beds.
9.30am - 4.30pm

From 'bump' to teens

from prenatal diagnosis through to teens

The transfer to adult services

making the change medically and in education

Beyond education towards independence

steps towards employment and independent living

DHG Members £7.50 adults £5 children
DSA Members £12.50 Professionals £25
The cost includes a buffet lunch and refreshments

Please call [REDACTED] for more information or to obtain a registration form

NOTES

There will be a limited number of crèche places available with priority being given to DHG members.

The venue has full wheelchair access.

Transport links are very good - the venue is approximately 7 miles from each of the following :

The M1 motorway

Luton Airport Parkway station (Kings Cross - Bedford line)

Leighton Buzzard station (Euston - Milton Keynes line)

Luton Airport (cheap flights available from Aberdeen, Belfast, Edinburgh, Glasgow & Inverness).

Esther's Story



Mike was born in 1953 in Limerick, Ireland, and is a Chef in a Secure Unit in Leeds. Andrea was born in 1960 in the Black Forest, Germany, and is now mainly a housewife, although as a registered nurse she works one night in a nursing home in Leeds. We met and married in Germany and had the two children in Bad - Homburg, Frankfurt in Germany. Lydia was born in September 1992, she loves swimming, reading and pony riding. Esther was born in June 1994 with Down's Syndrome, complete AV Canal and Fallot's Tetralogy

Esther's prognosis at birth was very poor. We were told two weeks of life without surgery. She was admitted 50 km away into a University hospital in Giessen. We were allowed to take her home for one week, but then Esther became very breathless, sweaty and pale, and emergency surgery had to be carried out to insert a Central Aorta Pulmonary shunt.

After surgery Esther had a cardiac arrest, and her chest had to be reopened. She developed Chylothorax (draining of lymphatic fluid into the chest cavity), which meant she had to have a special bottle fitted and changed every day or two due to the sticky fluid. This caused Esther tremendous pain. She was fed via a central line as she was not allowed anything orally until the lymphatic leakage ceased, which was four - five months.

She also developed a pneumothorax, pneumonia, stomach ulcers and a pressure sore because she could only be moved with great difficulty due to all the tubes and drains. She was in constant pain, and we were unable to hold, cuddle or carry her.

Eventually the lymphatic fluid couldn't be drained any more due to all the adhesions, so surgical intervention became necessary, and at last the lymphatic leakage stopped. At this point Esther gave us her first smile, seemingly relieved to be able to breathe better. We will never forget that moment, (even the care staff were so moved).

Back on the ward. Esther became very ill again! Her central line had become infected causing Septicaemia. Thankfully she recovered, and was discharged before anything else could happen.

On discharge, Esther was very limp, and had a nasal gastric

tube. She was being fed every hour with 20 ml of a special feed, which she usually vomited up, becoming very cyanosed during the process. She cried throughout the night, had to be carried around every hour due to breathlessness and had to be taught how to swallow. She had lost a lot of weight and strength, and was very frightened of people, hospitals and doctors.

Esther had to go for a heart catheter in June 1995 to plan future surgery. It was discovered that the pressure in her lungs had increased due to the excessive blood flow in to them. Corrective surgery was discussed, but we were told that surgery was not possible as the mortality risk was too high - her prognosis was still quite negative. We went for different consultations with a wide range of opinions which varied from eighteen months to fourteen years life expectancy.

At eighteen months, Esther still couldn't sit, roll over or hold her head firmly. She suffered many viral and bacterial infections, so treatment with antibiotics, steam therapy and postural drainage became part of daily living. We went for physiotherapy which was very difficult, as Esther still didn't allow anyone near her. Her crying always caused severe cyanosis and exhaustion. An occupational therapist visited us once a week for stimulation, advice and support. One trained lady would come for one hour a week, so that I could go shopping or take Lydia to the playground alone. Again, she had great difficulty keeping Esther from getting distressed.

We decided to take Esther to Ireland, to introduce her to our Irish family, as we were doomed by such poor prognosis. There at the coast, she developed an appetite and we were able to throw the nasal gastric tube away! She was even able to sleep for longer intervals, which made us think, that the climate must have a positive effect on her.

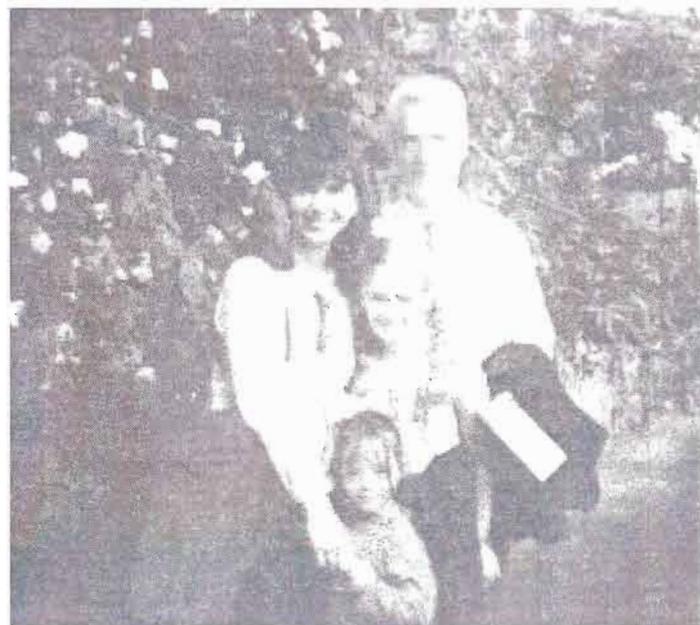
Eventually in July 1997 we moved to Yorkshire to be near to our friends and family. We were pleased to hear that the local doctors had a more long standing experience with children with Down's Syndrome who had heart defects - even Esther's surgeon had trained at Leeds. Lydia was four years old, just ready to start school, and Esther had just turned three, when we crossed the ocean. She was not able to sit unsupported and there was little hope of her ever walking due to suspected damage during her cardiac arrest.

Straight away, Esther had a mostly undisturbed sleep, which helped us tremendously to recover and settle in England. Her medication was changed and Digoxin was discontinued. Different diuretics such as Spironolactone and Chlorothiazide were started due to congestion of her lungs, and she continued on aspirin to keep the shunt open.

As her strength increased, Esther became quite an expert at shuffling along the floor, and gradually, she lost her fear of people and it became quite a pleasure to attend hospital appointments without the terrible screams. She started to attend a little play group, although she still wouldn't allow me to be out of her sight. We received speech therapy at home, and we were advised to only speak English with Esther. We communicated through Makaton signing and her speech improved and she found it rewarding being able to express herself.

In September 1998 when she was four, we were offered and accepted a place at a handicapped school with an integrated nursery, where she received physiotherapy, speech and occupational therapy. After many sessions in a standing frame, Esther started to use her legs, and at age five she went on to a walking frame. Just before going to school she was able to walk unaided! We were so pleased!

In September 2000 Esther started to attend Lydia's primary school with a special help assigned to her. She needed hearing aids, due to glue ears, but tolerated them very well and again her language was much improved. In September 2001 Esther



repeated reception to enable her to catch up a bit more. She has started to run, has better coordination, enjoys reading, singing and socialising. She thoroughly enjoys school and has lost all fear of strangers.

She has become more robust, gets less infections and has less time off school. She is vaccinated for flu every winter, and we have been advised by a dietician about keeping to a healthy anti-candida diet which became necessary after so much antibiotic intake.

The latest investigation in January 2002 at the cardiology clinic, showed that Esther's heart is still enlarged and working too hard. Therefore, we were considering together with the team, if surgery could help at this stage. Again the high risk of not surviving was pointed out to us.

Esther is enjoying life so much, after such a struggle, she just loves everything, shows such great interest in learning and has developed such an endearing character. Lydia loves playing with her and was very worried about this possible operation. We are grateful that surgery was offered to us, but feel at this stage, we cannot consent to this difficult operation with such little hope of a successful outcome.

Andrea & Michael Coleman
Leeds

Jamie's Story

On Friday the 30th of November 2001 our son Jamie was born at 5.13am and weighing 6lb 4oz. Of course we were both very happy and over the moon. The Paediatrician was called because Jamie was a bit floppy, but when he came and checked Jamie all over, he passed him A1. However, by mid morning Jamie was having trouble with his second feed, so the Paediatrician came back and took him away for some tests.

It was two and a half hours later when a Dr Winrow came and told to us that Jamie had some sort of heart problem so he was in ICU until they could make arrangements to get him to Great Ormond Street Hospital. By 11.00pm Jamie was on his way.

Early next morning we knew what was wrong with him because they had done an echo scan on Jamie's heart. He had two holes through his heart, an extra piece on his left side and a narrowing of an artery restricting blood flow to his lungs. The Registrar, Orla Franklin, told us they would be operating within days.

Ten days after Jamie was born they operated on him for the shunt, before the shunt Jamie had deepened to purple in colour and had rapid breathing. After the operation he was totally different, a very good colour and his breathing was a lot slower and much less of a strain for him.

When Jamie was admitted to Great Ormond Street they also did a chromosome test because his heart problems were linked with Down's Syndrome. We had to wait ten days for the results and as we both thought, they came back positive. We did have an idea that it could be because of our ages 41 and 47, but whatever the outcome his would still be our son. Despite Jan having all the scans while carrying Jamie, and a couple of extra ones, none

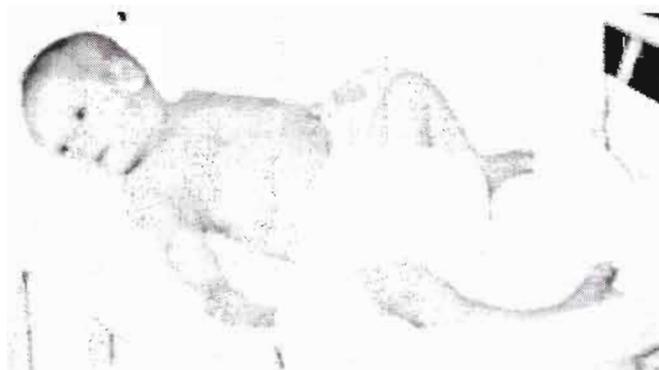
of them showed up any problems with Jamie's heart.

As to how we coped - Jan being a Mum took the heart problems as very bad news as did I, but with the help of everybody at Great Ormond Street, (who are wonderful), and by consoling each other and talking it over we are getting through it.

Jamie is a happy baby always smiling, playing and feeding very well. We are both very happy with him - until his next operation!

Ian and Jan Chatfield
Tolworth, Surrey

PS: Jamie had a check up on 6 March 2002 and has been sent home for four months until his next check up. Great news!!!



Gwen's Story

Gwen Siân was born on 1st December 1998 and I knew as soon as she was placed in my arms that she had Down's Syndrome. From that day, my husband Richard and I had to come to terms with her condition (which we knew nothing about), and take care of our other daughters, Ruth 5 and Beth 2. I was desperate to get home, so after various tests (which later confirmed the extra chromosome), we brought Gwen home the next day. We were so relieved that her heart was OK (as far as the hospital could tell), and she was placed on the waiting list for a heart scan.

Gwen was a happy, healthy baby, who breast-fed beautifully and slept all night. I bonded with her from day one. Richard and I felt many different emotions during the first few months, but we coped well as a family. She continued to be well, although her weight increased very slowly. When she was 5½ months old, she had her heart scan and we were told she had a large hole (VSD) which needed surgery. I was shocked because there were no obvious signs of a heart problem. We turned to the Down's Heart Group - we had already been in touch with the Down's Syndrome Association who pointed us in this direction. Within a few days, we received an information pack and video, and our minds were put to rest. We were still worried, but not so much.

On 4th August 1999, Gwen had successful surgery at Bristol Hospital for Sick Children (150 miles from home!) Leaving Ruth and Beth was difficult, knowing the distance would prevent them from visiting. Richard was travelling back and forth to make sure we were supported at Bristol but also caring about Ruth and Beth back in Wales. The care that Gwen received in Bristol was marvellous. The doctors, Intensive Care nurses and ward nurses, made a smashing team. After three nights on Intensive Care, she was back on the ward, doing very well. She'd been through so much, bless her, I wasn't happy until she smiled (on the 6th day after surgery!) - then I was so relieved I cried.

On 10th August we were on our way home and it was as if we hadn't been away. Gwen continues to thrive and only needs annual checkups on her heart. She is now 21 months old, feeding herself, crawling into everything, pushing to stand, babbling non stop, sitting on the potty every day, causing havoc with her two sisters and cuddles with such love.

If anyone had told me 21 months ago, that I would feel like I do today, I would not have believed them. We are fortunate to have the support of family and friends and the advice of the Down's support groups - it all helps. I have a lot to be thankful for as this photograph shows. Thanks for being there when it mattered.



P.S. Can I say thanks to Richard for being a tower of strength through what has been a difficult time for him too.

Julie Evans
Fishguard, Pembrokeshire

My Duke of Edinburgh Award

On the 13th March I woke up very early as I was going to St James's Palace to get my Duke of Edinburgh Award. My Mum and my sister in law went with me. We got the 10am train to London. I was very excited, as I had been doing my award for six years. First my Bronze, then my Silver, then 'Gold'. It was hard work but fun.

When we got to London we went to a posh Italian restaurant for lunch. Then it was on to St James's Palace. We had to wait outside for one and a half hours. It was very cold. I was very nervous. Then the big moment came. The Duke of Edinburgh came up to our group. I was at the front of the group and he asked me where I had come from. I said Doncaster. I was happy then. Then I was given my award by a lady who has sailed around the world. I could have looked round St James's Palace, but I was very tired so we got a taxi to Kings Cross and came home. It was the very best day of my life.

Suzy Brown
Doncaster



My Son Chris by Siegfried M. Pueschel

Many of you will have read some of Dr Pueschel's professional work relating to Down's Syndrome, but in this article he writes personally about the life and loss of his son Chris.

The article is reprinted from the December 1999 issue of 'News & Views', DSA Malta.

It was on a warm, beautiful Sunday afternoon in July 1965 when the telephone rang. The call came from the maternity hospital where my wife had been admitted in labour the night before. A somewhat subdued voice at the other end of the line let me know that my wife had given birth to a baby boy.

When I came to the hospital, I was asked to have a look at our new arrival. The initial joy and happiness was soon overshadowed by my recognizing that Chris had facial characteristics usually seen in infants with Down Syndrome. Although the first reaction was shock, disbelief, and despair, that which followed was even more disturbing since we were asked to place Chris into an institution for persons with mental retardation.

We were told that Chris would never become a real human being, he would never be able to relate to us, and never accomplish anything in his life. Moreover, we were informed that he would destroy our family and would be a menace to society.

Fortunately, my wife and I did not believe those words and did not follow the physicians advice of institutionalization, because we felt that Chris belonged to our family, that we have brought him into this world, and that we would take care of him to the best of our abilities. Initially, my wife wanted to take Chris and go away and also I had similar thoughts in order not to burden my spouse. However, we soon felt that it would be the best to work together to help Chris and provide him with the love, affection, and care any child needs. Although we always had been a close-knit family, Chris brought us closer together.

Chris was born with congenital heart disease, which initially interfered with regular food intake, his developmental progress, and his general health. During the first year of life, he had a few close calls when he suffered severe respiratory infections developing into pneumonia on several occasions. We were told not to worry because "he soon would die anyhow."

Yet, Chris proved all doctors to be wrong. I am sure it was my wife's extraordinary care which she provided for Chris in the ensuing years and her love and devotion that resulted in Chris making continuous progress and he started thriving and blossoming. Thus, the fundamental encounter of the initial sorrow which usually is experienced by parents who have a child with Down Syndrome, was soon transformed into a joy and happiness which Chris brought into our lives. Jeanette, our youngest daughter, put it so well when she said, "He became the sunshine of our family."

What kind of person was Chris? He was the most friendly and happy individual you could ever meet. Chris liked to have fun - and lots of fun. He could make people laugh and his endearing smile was truly contagious. He loved to dance and probably did not miss even one dance party at the Trudeau Memorial Center where he worked.

Chris had a good sense of humour. One evening I asked him what he would like to drink - orange juice, milk, or something else. He answered "May I have some whiskey please? He loved Hula girls since he had seen them in Hawaii during one of our

visits there. When we were ready to leave the Hawaiian islands he asked May I take a few of the Hula girls along home? He must have studied these girls very carefully because he was able to draw them with all the "appropriate anatomy".

Chris also loved to go to parties. One time Chris and I were invited to a Rhode Island Association for Retarded Citizens Award banquet. Chris and I were seated at the head table and Chris was sitting beside Senator Chafee. When dinner was served, Chris was looking around the table for some ketchup since he just could not eat a meal without ketchup. When he could not find any ketchup, he gently elbowed Senator Chafee saying, Senator Chafee, do you have any ketchup with you? Of course, the Senator could not but get him some ketchup right away.

Chris was a permanent member of the Rhode Island Special Olympics medical team. He always accompanied me when I volunteered as physician during the state Special Olympics games. He liked to drive a golf cart when I had to go from venue to examine sick or injured athletes. His involvement in Special Olympics was recently featured on a local TV station and he was so proud of that.

Chris enjoyed martial arts and both of us attended martial arts classes almost every evening. He was well accepted in the community of martial arts. In spite of his limitations, he progressed well in Tae Kwon Do martial arts and was awarded Yellow Stripes. Chris also enjoyed bowling and there was never a Saturday when he missed the bowling event. He was so proud when he received a bowling trophy this year.

Chris also liked painting and drawing. Under the guidance of Janice Conners, he became quite an artist and with some more training he would have given Picasso some competition! Chris loved music; Star Wars' music, German folk songs, and classical music were his favourites. He really became alive when listening to German folk music often happily playing the conductor. Chris probably had the largest video Star Wars collection in the world. Not too long ago I asked him what he would like for his birthday; his answer was "May I have some Star Wars tapes? Of course, I bought him a few tapes, which he enjoyed wholeheartedly.

Chris loved his co-workers and the staff at the Trudeau Memorial Center and he had many friends there. He was particularly affectionate towards his girlfriend, Marian. I often heard him saying, "You are my sweetie." Although he did not know any of his family's birthdays, he never forgot his girlfriend's birthday and made plans for this day many months before it occurred. Not too long ago, he told me "I would like to give Marian a ring for her birthday." Chris also liked Martha Canning, a good friend of his, very much. When he was permitted to stay with the Cannings for a few days, which he enjoyed so much, he tried to help to care for Martha whenever he could.

In general, Chris was a very caring person and had a unique ability to relate so well to people. Once I visited the Trudeau Memorial Center and what I experienced there was just unique. I observed Chris helping a blind person. Chris guided him to the rest room, took him to lunch break, and brought him safely back to the workstation. Although for most of the time they did not talk to each other very much, yet there was marvellous communication evolving between them. The kindness, care, and sensitivity exhibited by Chris, the complete trust displayed by the blind person, and the warm interaction between them, all this was just overwhelming. Chris showed a quality of humanness that is rarely seen. He displayed the same caring attitude, kindness, and gentleness towards his family members and many other people whose hearts he touched.

Although Chris was significantly mentally retarded, he had many special skills. For example, when Chris was about 12 years of age, he was still riding a bicycle with training wheels. I felt he was probably ready to ride a 2-wheeler and thus I took off the training wheels from his bike. I had real difficulties getting them off; but how surprised I was on the next day when Chris had mounted them again on the bike, demonstrating his mechanical skills. This talent also became apparent when he was employed at Day One, a company that manufactured bird feeders. On one of my visits there, I observed that Chris was not only skilful in assembling the bird feeders but also showed his mechanical know how in the operation of the various machines used in the production process of the bird feeders.

One day when he was about 16 years old, Chris demonstrated another of his talents. We were ready to go out shopping as we usually did on weekends. When I attempted to start my car, it would not start. As my frustration grew, Chris with a wink in his eyes said, "Why don't you put the gear into neutral?" Of course, once I did this, the car started. I then asked "Chris, would you like to drive the car?" He wasn't quite sure what to say, but then uttered "Yes, let me try." So we changed seats and although nobody in our family ever taught him how to operate a car, Chris was able to start the car, put the shift in drive, and then slowly drove off. He knew exactly with which foot to press the gas pedal and the brake and how to steer the car. He had been so observant over the years and had visually absorbed and memorized the different steps of driving a car. This observation and similar ones showed that Chris was visually so alert and that his visual learning skills were markedly advanced compared with his other abilities.

Unfortunately, there were times when Chris could not use his skills and talents. While he was working in a sheltered workshop Chris was often involved in monotonous and boring jobs. Yet, he was an excellent worker, and in spite of an interfering tremor of his hands, he was very accurate and precise in his work. When special tasks needed to be carried out, Chris was often the one who was asked to do them. He was extremely reliable, dependable, and was liked very much by his co-workers and supervisors.

Chris interacted well and was very close to his older brother, Siggie, and his sisters, Pamela and Jeanette. They grew up together so harmoniously, teaching each other the important things of life. His brother and sisters helped Chris in developmental tasks, in language acquisition, and in learning self-help skills. In turn, Chris taught his siblings to be more tolerant of everyone and to accept and respect the difference in all human beings and much more. Thinking back to the early childhood years, our children had lots of fun playing together and enjoying life to their fullest.

Chris often called his brother Siggie when his television or VCR needed to be fixed. He called him affectionately "Sigily". Chris was also very fond of his younger sister Jeanette whom he baptized "Jackson". He also loved his "Pamie" very much and was frequently worried about her when she was pregnant and asked "is Pamie alright?" He loved his siblings dearly.

Sometime ago, Siggie, Pamela, and Jeanette wrote a little booklet with the title "CHRIS..... OUR BROTHER" which portrays so vividly his siblings' genuine feelings of affection and love towards their special brother. This booklet speaks volumes about their warm interaction and beautiful relationship. Also, a home movie made of our children depicts their joyous life during the early childhood years.

Chris had a very special relationship with his mother, She indeed

was a most caring person who gave all her love and much more to Chris who loved to be cuddled and hugged by his mother and in turn loved to "mush" her. They had a marvellous time together. One day when Chris was sitting with his mother in the car, she asked "Chris, can you drive the car?" Although he was able to do so, he replied "I can't, my feet are too short," indicating that he could not reach the gas and brake pedals with his feet. From then on, the term "short feet" took on a special meaning. When he affectionately said to his mother "You are my short feet" that meant I love you so much - more than anyone in the world.

Some ten years ago on Mother's Day Chris gave his mother a drawing with a bright shining sun and a beautiful flower and wrote beneath "To Mum: You are as pretty as a flower on a sunny day!" And he was so right. After my wife passed away a few years ago, Chris often came to me crying "I miss my mother so much" and then we used to hug and weep. Sometimes Chris awoke in the morning saying "I was dreaming about my mother, I saw her in the kitchen and gave her many kisses". He adored her and he loved her so much more than one will ever be able to express in words.

I would also like to mention briefly what Chris meant to me. Although I had been involved in research activities relating to Down Syndrome when Chris was born, undoubtedly, Chris gave direction to my professional career and to my life in general, and since my wife's death, Chris actually was my life.

Chris was a brilliant teacher. He taught me that individuals with Down Syndrome are persons in their own right in spite of their limited capacity for academic achievement. He taught me that an IQ score is a demeaning measure of human potential and human qualities. Furthermore, he taught me that persons with mental retardation have an intrinsic value of humanity and that they can contribute to society and perform tasks which previously were never expected of them. Chris let me know that using "quality" as a measure of relationship brings a dimension that "quantity" just cannot match. Chris taught me tolerance and patience, and he taught me many more things I never learned in medical school. He also taught me that beyond intelligence and material accomplishments we so highly value in our culture, that there are more important human qualities we can strive for. He taught me that service to humanity must rank higher than personal gratification and private enterprise.

Chris so well exemplified that there is a goodness, humanity, and magic in our children with Down Syndrome that must be protected and never be betrayed. I am so grateful to Chris because he has given me more than a father ever could have asked for. I am so proud of my Chris.

Chris and I enjoyed life together in our new house. We took care of the daily chores together, we enjoyed our meals together, we liked to go shopping, we travelled together all over the country and beyond, we went for walks together, we admired the beauty of a rainbow and listened to the chirping of a bird together, we liked to listen to music together - we had such a good time together and were so close.

When Chris passed away, I was holding him in my arms and could not stop hugging him - and there was an endless stream of tears - and now his mother is holding him closely and she always will hold him in her arms. And then I had to say Good-bye my Chris, Farewell my son. We always will love you, and you will always be in our hearts.

In Memorium

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

Anne Allchin - Bristol (aunt to Joshua Turnbull)

Jack Aplin - Rutland (father of founder Linda Walsh)

Reece Dunne - Basingstoke

Maisie Farrington - Ambleside (a little girl who was in ITU with Ben Priestley)

Frank Hulbert - Chippenham (Grandfather of Gemma Iles)

Amanda Hunter - Grangemouth

Gemma Iles - Calne

Joan Jeans - Sandhurst (neighbour of the Packham family)

Jasmina Jushkina - Yaroslav, Russia

Nathaniel Miller - Carmarthen

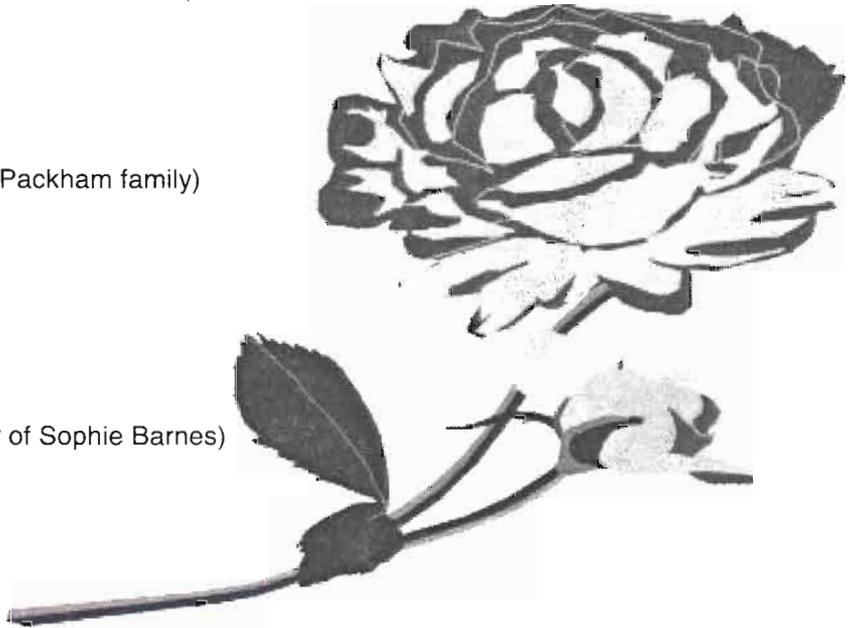
Tom Pow - South Oxhey

Margaret Preater - Leicester (grandmother of Sophie Barnes)

David Smith - Kirbymoorside

Connie Watson - Leighton Buzzard

Alice Beth Wood - Doncaster



Jasmina Jushkina

It is with sadness that we tell you of the death of the little Russian girl Jasmina Jushkina.

Those of you who have been members for several years will no doubt remember how the DHG assisted in making it possible for her mother Tania to bring Jasmina to the UK for the heart surgery that she so desperately needed, but was denied in Russia because she had Down's Syndrome. Some of you will remember meeting them at our 1996 conference in Bexhill.

Jasmina had her first surgery in February 1996 when she was 17 months old, and then needed further surgery on a return visit in May of that year. After her return to Russia she made good progress as a result of the work of her family, but it was always difficult given the lack of facilities available to them over there. When she sadly began to have further problems with her heart it became obvious that more surgery was needed.

She returned to the UK in January 2001, thanks again to a generous benefactor, and underwent another operation. Initially it seemed successful, but within a few days it was apparent that she was in difficulty, and after a long struggle, she died peacefully on February 22nd.

Jasmina

I don't want to say that you had been
Because you are, and you will be
I don't want to say that you had gone
Because you are here and you will be
I don't want to say that you had died
Because you are living and you will be
I don't want to say final farewell
Because I believe that our future meeting will be

Your loving Mum
Tatiana



Fund-raising Update

As it has been so long since the last newsletter, we don't have room here to personally thank everyone who has been involved in raising funds for the Group. This is just a small selection to let you know the sort of things that have been happening, and maybe to encourage you to get involved.

We do appreciate every donation we receive, no matter the amount, and would like to say a public **Thank You** to everyone who has supported our work in any way at all.

Coffee morning in Byfleet

I held a coffee morning for my grandson Sean Reeves who had a successful heart operation at the Brompton hospital in May 2000, and enclose a cheque for £25.

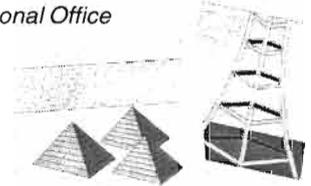


You can see from the photograph, how well and happy Sean is.

Georgia Harris
Byfleet, Surrey

Postage Stamps still arriving

Stamps continue to arrive at National Office from members and supporters nationwide.



Among those collecting for the DHG, are members, various clubs, offices, retirement flats and a residents association.

Perhaps the most unexpected are a group in Ethiopia - the pen-friend of a member, having heard about our stamp collecting to raise funds, has organised a collection for us out there.

When the stamps get to National Office, they are all put together, and about twice a year we get a visit from the Roberts family, when we usually hand over several A4 boxes full. Tony, Val and Michelle then devote a great deal of time and patience to sorting the stamps to obtain the best profit for the DHG. Over the past few years they have raised a considerable amount of money for the group in this way, for which we are extremely grateful.

So please, keep collecting those stamps. British and foreign, cut around them carefully leaving a small border of envelope, and when you have a packet, pop them in the post to National Office.

We want those stamps!!!

Mountain Bike Bonanza

I decided to raise some money for a worthy cause after the passing of my Nephew and godson James following complications from heart surgery. My sister (James' mum) decided on the Down's Heart Group as beneficiary - my challenge was to think of a fund-raising idea. I didn't have to think for long as I was keen to do a couple of "Enduro" style mountain bike events, having last year done the Shwinn 100k race.

I set off with the task of finding out what was out there, and quickly found that they were all sorts of different types from straight 100km races with fields of over 1500 riders to monster epic challenges with only 100 riders. My list came down to: Karimore Enduro 6 - 4th May, Wight Diamond Challenge 1st/4th June, Iron Lemming 15/16th June, Kona 100k 7th July, Summer Polaris 20/21st July and the Shimano Sleepless in the Saddle 24 hour - 14/15th Sept. These might not sound much to the non mountain biker but some are serious undertakings and some are great challenges racing against world champions and Olympic riders.

I started off with the Karimore Enduro, a 6 hour race on an 8 mile course where you do as many laps as you can. Unfortunately I had a bit of a cold so didn't perform as well as hoped but came 17 out of 38 in the category completing 9 laps. Olympic rider Nick Craig did an incredibly 13 laps one more than anyone else including the pairs category !!!

I worked on my fitness leading up to Isle of Wight where I raced in a Polaris style orienteering event with my riding partner Mark. We really enjoyed the 12 hours of riding (7 on Saturday and 5 on

Sunday) to finish 12th in our category out of 32 teams and 49th overall out of 159 teams. We were well pleased with a better performance. On the Monday the King of the Hill challenge brought out the fun side to the event with all 5 of the Island hills to ride in any order you chose. Well 56 km later and I finished in 8th place out of 16 in my category...which was the beer category having had to consume 5 or more pints to be eligible !!!

Then my training took on a greater dimension as I was off to Wales for the next challenge - branded as the "Toughest mountain Bike event in the UK". I'd read the article and seen all the event details but in the pub on the pre event check in I was looking over the map with some friends and was quite amazed by the route of day one. If any of you have been to the Brecon Beacons you will understand the distance and terrain to be covered.

The route starts in Talybont on Usk, then traverses the Brecon Beacons National Park 4 times in the day with the final traverse going over the Black Mountain...Black is an apt name cos there was nothing up there. To finish the day there was another 40km to get riders to the overnight stop. Well at the 5th out of 6 check points with two legs to complete, the planned dinner time at our overnight stop had passed and riders were starting to get very tired...me included. I stopped for a bit of aptly named trail mix which picked me up and I completed day one in 12 hours and 2 minutes which was less than an hour behind the leaders.

So camp was made, dinner was had, darkness was falling and last orders were calling, the event organisers came in and we

overheard that there were 41 riders (out of 100 starters) that were still out on the ride. The organisers had got their measurements wrong and in fact the route had taken us over 9000 foot of climbing and over 80 miles of Welsh's best riding terrain. I had a grin on my face but not all did !!!

Day two started with the same dull dampness that had lingered over the hills and only 17 riders turned out for the 7.30 start. Off we went venturing into the unknown hills of mid Wales finding some amazing riding and still managing to enjoy it !! Another 55 miles was ridden with 5000 foot of climbing. I dug deep to complete the challenge and be one of only 38 to complete the whole course, gaining a respectable 17th place in 19 hours and 15 minutes.

Onto my next race the Kona 100k in mid Wales on some of the same ground as the Iron Lemming. Over 1700 riders had entered giving a fantastic feel to the race. I started well and kept up the pace throughout the race despite all the mud...me and my bike were unrecognisable at the finish line. I wanted to do better than last years race (Schwinn 100k) where I got a top 200 finish out of 750 riders, but this was not going to be easy with so many more riders. The course was tougher than last year and but my previous form came through and I finished in just under 6 hours in 55th place in my category and 161st overall.

I was so pleased and was incredibly emotional towards the finish as I felt that I had broken the back of this challenge and the money had been flowing in steadily. To date I have raised £800 but there are still several people to return forms including work, where I have asked colleagues to donate instead of giving me a leaving present, as I have got a new job.

4 down and 2 to go. Feeling really fit now and up for the last two challenges which I am sure I will complete. I hope you find this article informative and interesting please contact me on 01522 534811 if you feel you want to support me in my challenge. It's certainly been a life enhancing experience and one which will make a lasting impression on me and most fitting to commemorate James short life.

**Bruce Dinsmore
Lincoln**



Want to support the DHG but stuck for ideas?

Here are a few suggestions to get you started. Remember the amount you raise is only part of it, you will also be raising awareness, and we will be grateful for any donation.

**£1 provides an Information Pack for a new family
£5 covers the cost of loaning a video to a family**

Ask local venues if they will have a collecting box.

Pub / shop / hairdressers / works canteen

Do a sponsored event.

Slim / swim / parachute jump / bike ride / walk / silence / head shave / beard removal / skip / marathon / run

Hold a hostess party and ask for the commission in cash.

Tupperware / Chocaholics / jewellery / make-up / clothes / ceramics / books / Ann Summers

Ask your employer if they operate a giving scheme

There are several schemes in operation where donations are deducted from salary before tax, and some employers match the employees donations. If your company doesn't operate such a scheme, ask them to start one.

Invite some friends round

Have a coffee morning / a lunch get together / a night in with a drink and a good video / a pampering session / a tea party / a barbecue - and get them all to pay

Have a car boot sale, a garage sale or a stall at a fete

Sell nearly new books / children's clothes / craft items / garden equipment / toys / marmalade, jam & cakes / Christmas cards

Ask playgroup / school / college / work to help

Ask to hold a collection at the school play.
Have a non-uniform or a dress down day and charge for it.
Have a raffle.
Hold a promise or favours auction.
Ask them to buy or sell DHG Christmas cards.

AND DON'T FORGET

- If you are doing something that needs our official authorisation, let us know well in advance.
- Sponsored events need DHG official sponsor forms.
- Always ask sponsors / donors if we may reclaim the tax on their payment. All we need is their name, address, authority and verification that they are a UK taxpayer whose annual tax payment is more than the amount we will be reclaiming, we will do the rest, **and it doesn't cost them a penny.**
- If you are making a donation to the DHG, no matter the amount, please consider giving us authority to reclaim the tax. (There is a form on page 15 which you can use, either when you make a donation, or to cover all future donations.)

London Marathon 2001

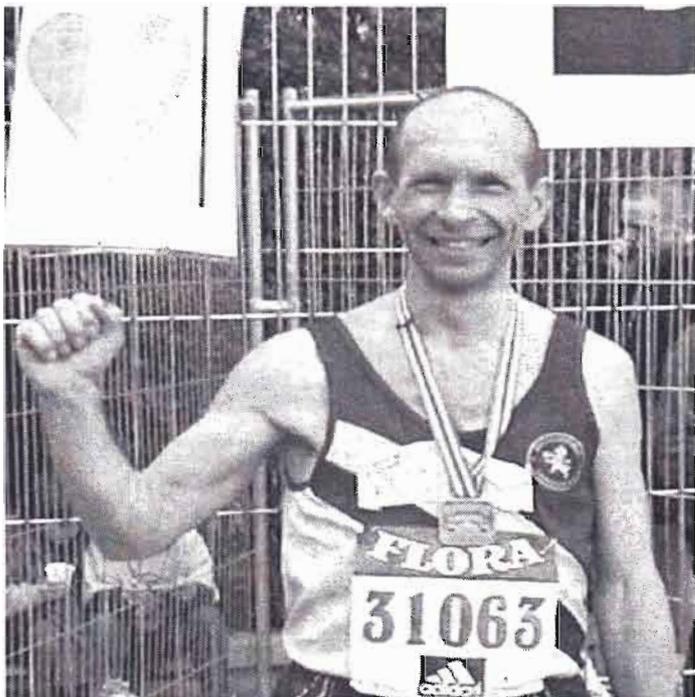
2001 was not a good year for DHG as far as the London Marathon went. We originally had six entrants for our Gold Bond places and two runners with their own places, but after some serious early injury problems, we lost a few entrants. Then last minute injuries and a nasty bug eliminated even more.

In the end we were very fortunate that we found a last minute replacement in Melanie Gray, from Leeds. She, along with Lee Pinchback from Southend and veteran supporter Martin White from Winchester, who were both running on their own entries, managed to raise a very much appreciated £1745.



London Marathon 2002

2002 was a much better year. At first the prospect of filling ten places seemed daunting (as five of our runners were invalidated out in 2001, their places carried over to 2002), but once again Melanie Gray helped us, this time by pointing several members of her running club in our direction, who together with DHG members and supporters made up the number. We were also lucky enough again to have extra runners who had obtained their own places, (including our chairman's postman!), which brought this year's team up to thirteen.



2002 entrant Richard Gay from Leeds



2002 entrants Quinton Hayter and John Taylor

So Sunday April 14th saw the DHG being represented by these wonderful people :

Alison Cullen - Twickenham
Richard Dale - Tockwith
Laurence Freeman - Sutton at Hone
Sue Gamblen - Leeds
Richard Gay - Macclesfield
Jonathan Harrison - Leeds
Quinton Hayter - Macclesfield
Joe Noya - Stevenage
Gareth Robinson - Leeds
Elliott Scripps - St Albans
Paul Smith - Watford
John Taylor - Leeds
Margaret Taylor - Leeds

Two of them were nursing injuries only a few days before, but they all made the distance, many in pretty impressive times, and we would like to thank all of them for their fantastic support. There is still some money to come in, but the expected total is in excess of £12,000.

**Thank you to all those who have supported
our work in many different ways.**

London Marathon 2003

The 2003 race will take place on Sunday April 13th. The DHG will again have guaranteed Gold Bond entries available, and would also welcome runners who have their own allocated place.

For more information please contact Penny Green at National Office, telephone 01525 220379.

Down Syndrome is Contagious

Down syndrome is a genetic disorder characterized by a triplication of the genetic material on the 21st chromosome. This trisomy occurs with the first division of the developing zygote, as a result there is extra genetic material present in every cell of the individual. Recently, science has discovered that this cellular abnormality is highly contagious. As result, family members (and even friends) of individuals with Down syndrome often find themselves exhibiting dramatic changes due to this "something extra" permeating their bodies at the cellular level. These changes manifest themselves in a number of ways.

Something extra in the visual cortex results in parents who view the world differently. In addition to seeing things in an entirely new light, these parents also report having an increased ability to focus on what is important. Spontaneous appearance of tears of joy have also been confirmed.

The section of the brain used in logical thought undergoes dramatic changes. Parents suddenly find themselves able to comprehend and discuss complex medical procedures. The ability to decipher long strings of acronyms appears almost immediately and it is not uncommon for affected parents of newborns to be able to differentiate between ASD, VSD and PDA. Familiarity with G-tubes, Pic lines and the NICU is another side effect.

Over time, the entire nervous system is transformed, enabling parents to perform tasks previously thought impossible. These changes result in individuals finding the nerve to advocate before large crowds, speak to classrooms of medical students and educate the population about issues they are passionate about.

These changes are closely tied in to dysfunctions in the verbal abilities, which makes it virtually impossible for parents to bite their tongue. Often, individuals who previously considered themselves reserved will find themselves outspoken and effective communicators.

The pulmonary system is altered to a dramatic extent. Parents report having their breath taken away at the slightest prompting. The cardiovascular system develops similar vulnerabilities and reports of hearts pounding loudly and swelling unexpectedly are not uncommon. One mother reported that her heart skipped a beat when her son smiled at her for the first time.

The extremities are also altered. Arms reach out to strangers for support, and in turn, hands comfort and nurture those in need. Legs strengthen and balance improves, allowing parents to stand firm in their convictions and walk without faltering, even when shouldering a heavy load. Scientists are baffled by the widespread scope of these symptoms. Equally perplexing is the response of those afflicted. Parents readily acknowledge fundamental changes in their being, however, almost universally declare a preference for their new, altered level of functioning. "I wouldn't change a thing" is a common refrain. Apparently, the presence of a little "something extra" enhances the lives of individuals fortunate enough to be infected.

Wendy Holden, Ellensburg, WA
Kittitas County Parent to Parent coordinator

My cousin Timmy

My cousin Timmy died on March 3. He was 53. He had Down's Syndrome. I want to write about him here because I think of him every day when I read of the battles you guys are fighting over statements and speech therapists and classroom assistants and DLA's and God knows what else. Nobody fought for Timmy, and the state didn't care. This happened in America; presumably, for people of Timmy's generation, it often happened here, too.

He was my father's brother's son. The beginning of his story was a common one in those days, probably unknown now that we live with sophisticated fertility treatments: for years his parents had hoped in vain for a child. Finally, they adopted a girl, Trinkie. Almost immediately, Aunt Dickie got pregnant — another girl, Anne. Then another pregnancy: Timmy.

I was told of his birth (I was 15). I remember sharply being told six weeks later that something was terribly wrong, that he was being "sent away", that he would probably die soon. After that, a long, long silence. I asked my father once, towards the end of his life. He didn't know what had happened to Timmy.

Aunt Dickie died when her daughters were young teens, and Uncle Larry when they were 17 and 19. Uncle Larry had been a high-flyer at the height of his career, but later fell on hard times. He left his daughters nothing, and some tough years followed for them. They knew their brother had survived infancy, they knew where he was living. They were terrified to get in touch, for fear they would find themselves financially responsible for him.

Years passed. Elements of the family which had been remote, came back together; Anne and Trinkie asked my sister, a doctor, to help them get in touch with Timmy. She was able to reassure them about financial responsibility, and it took her no more than a few phone calls to do the rest.

It was wonderful for the family to be in touch, and to learn at last that nothing more "terrible" was wrong with Timmy than trisomy 21. It was wonderful for the devoted careworkers at Timmy's institutional home, to have long-lost relatives turn up. It doesn't often happen, and Trinkie, in particular, became an energetic supporter and fund-raiser. She was there for Timmy during his last days in hospital. He died of pneumonia.

We learned that Timmy had been in a private nursing home until Uncle Larry's finances declined. Then, aged about ten, he became the responsibility of the State of Connecticut, and by a stroke of good luck, was sent to the excellent institution where he was cared for sensitively and affectionately for the rest of his life.

But his sisters' appearance on the scene came far too late to do Timmy any real good — he had no speech (although his carers suspected he was "one of the bright ones"), no skills, none of the pleasures therefore which underpin life for most of us, DS and NDA alike: semi-independence, a sense of usefulness, of pride in his achievements, friends and family to talk to. All the things you are working every day to secure for your children, Timmy lacked.

I hope and believe that no children with Down's Syndrome are condemned to a life like Timmy's in Britain or America now. It must, quite recently, have happened to many. Remember Timmy, the next time you're feeling particularly low and frustrated, and give your lucky child an extra hug.

Jean Miles, Edinburgh

I saw Jean's item on an internet mailing list and asked her permission to reproduce it. In her reply she told me of the death of her grandson Oliver at 6½ weeks. Oliver had a heart defect and Down's Syndrome.

Your Letters

DHG Video and prenatal diagnosis

I hang my head in shame at the length of time it has taken us to return the enclosed video. You kindly sent it to us about 20 months ago following the heart/Downs diagnosis of our unborn son. Whilst I have lent it to family and friends, I just could not bring myself to watch it until last night - I don't know what I expected - something depressing I think - the truth could not have been more different. It is an excellent, positive, inspiring video, full of hope, and I just wish I'd watched it the day it arrived, that black day of 2000!

Reality is very different now. Our gorgeous son, Isaac, sailed through major heart surgery at 4 months, and he is now a 20 month old bottom shuffler of whom I am so proud.

In July of 2000 we discovered during an antenatal scan that Isaac had a complete AVSD, shortly followed by the DS diagnosis. The rest of the pregnancy was spent in tears, and I was filled with fear and dread, and ignorance. I thought life would never be the same. I thought we would never do anything "normal" ever again. I worried that life for our 3 year old son, Joshua, would be ruined by the arrival of a "disabled" brother. And I felt such guilt too.

These thoughts and fears are a year away now, and mostly could not have been more inaccurate. Isaac has enriched our lives; his older brother adores him, and, to us, life IS normal now - it is just that our concept of "normal" has changed - it is not a better normal, or a worse normal, but it is normal nonetheless!

I have filled in the questionnaire you sent (ages ago!) and hope that in the future we may be able to help others in similar situations to ours, perhaps particularly people who find out during pregnancy that their unborn child has Downs Syndrome.

To us termination was never an option, but that certainly does not mean we found continuing the pregnancy easy. I was afraid I wouldn't be able to love our son when he was born. To be honest I don't feel I did bond with him totally until after his heart surgery. I was so afraid we would lose him, that I almost couldn't bear to love him completely - it was almost a form of self-protection. Now I wouldn't be without him - he has changed me, he has changed our lives, and all for the better.

Sal Hamlyn
Sevenoaks

Bicycle Fun

I have just received my newsletter that I always read with great interest. Not long ago one mum wrote in to ask if anyone knew where to get a three wheel bike. I wrote to her with some ideas.



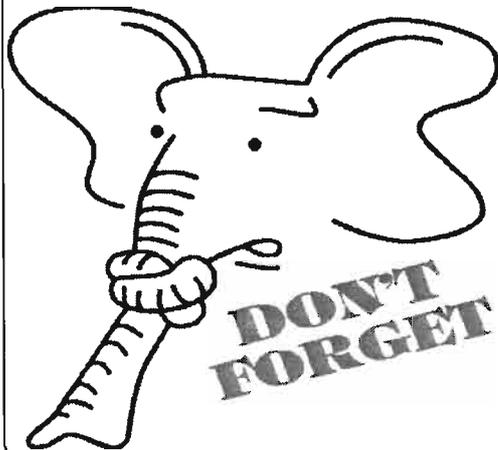
My son Gareth who is 24, has had a good time on his bike this year. I thought I would send you a photo of Gareth in the nearby woods where we live. My two little granddaughters are always trying to get on the back for a ride. They love him to bits and like being with him. He has so much enjoyment with his bike, it gets him in the fresh air. He cannot walk far, so the bike is one way of getting him outside (when the weather is nice). I hope other young people with Down's Syndrome have as much fun as Gareth.

Phyllis Coleclough
Frodsham, Cheshire

This letter was written in 2000, but we hope Gareth is still enjoying his bike, when the weather allows.



Let us have your contact details



We quite often get offers of discounted or free tickets to places and events, but we need to contact members very quickly.

For instance earlier this year we were offered tickets for Legoland Windsor at £5 a ticket. We were able to send email notification to about 90 members very quickly, and as a result secure tickets for 22 families to have a lovely day out.

On another occasion, the Children's Heart Federation were offered the cost of sending a child on their annual Lapland Trip. The company paying wanted a child from their area and needed an answer within the hour. One of our members lived in the right place and we had mum's mobile on record - so one quick call and they were off to see Father Christmas.

If you want the chance to be included in events like these, please ensure that we have up to date contact details for you.

TELEPHONE - MOBILE - EMAIL & of course ADDRESS

Developments affecting Paediatric and Congenital Cardiology

Whilst it has been a long time since our last newsletter, the Group has not been idle in that time. As well as the normal day to day administration and support of families, members of the Executive Committee, Group Contacts and several members have been involved in meetings and consultations which are set to change the future of paediatric cardiology in the UK.

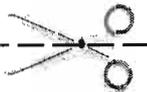
There has been the publishing of the report of the Brompton Inquiry which made numerous recommendations, many of which were influenced in some part by the evidence and reports of the DHG and its members. The Inquiry also included in its recommendations, "Guidance for the avoidance of discrimination in the care and treatment of children with Down's Syndrome", based largely upon a document written and presented to them by the DHG. The Brompton Hospital trust accepted all of the reports recommendations, promising to action all those relating directly to itself and to speak to the Department of Health with regard to those relating to national policies.

Following the publishing of the report, the Down's Heart Group and the Down's Syndrome Association were amongst those invited to join the Parent's Liaison Group set up by the Brompton Hospital, to look at the implementation of the recommendations. Meetings are ongoing, and have afforded the represented parent groups the opportunity to put forward ideas which will effect future policy and procedures at the Brompton.

Some of the recommendations have also been taken up by the Department of Health Review of Paediatric and Congenital Cardiac Services which was set up following the long awaited report of the Bristol Inquiry. There has been consultation with patients and staff at all the paediatric cardiac units in the UK, the Children's Heart Federation, and all the related support groups both local and national were given the opportunity to attend meetings and express their views and concerns. A report and recommendations have been presented to ministers in the Department of Health, and the report is expected shortly. There will then be a two or three month consultation period to look at the standards proposed for the care of heart children and the proposals for the future of paediatric cardiac units, which will be an opportunity to comment on their proposals.

Drawing on the experience of its member groups including the DHG, the Children's Heart Federation has published a booklet entitled "Children's Heart Services - a guide to care standards" which is aimed at providing parents with information about the standards of care which their paediatric cardiac centre should be providing, and managers and those responsible for paediatric cardiac services with an opportunity to reassess their unit against these guidelines and to seek to overcome any shortfalls. This booklet was prepared in collaboration with representatives of Constructive Dialogue for Clinical Accountability, British Paediatric Cardiac Association and Paediatric Cardiac Nurses Association, and produces much needed guidelines. It also underlines the acceptance in the National Health Service of the need for change in Paediatric and Congenital Cardiac Services, and the realisation that this change centres around the partnership with patients and their families.

So as you can see, there are likely to be many changes taking place in Paediatric and Congenital Cardiac Services in the near future, and you can be assured that the Down's Heart Group will be doing everything in its power to ensure that the needs and views of our members are represented, both individually and through our membership of and association with other organisations. We would like to thank all of those members who have given their time to attend meetings, fill in questionnaires and talk to us. Without your vital information, it would have not been possible to provide such detailed comment upon the precise issues affecting our members.



Gift Aid Declaration for Down's Heart Group

if you would like us to reclaim the tax on any donation you make to the Group, either now or in the future, please complete the form below and forward it to the National Office address as shown on page 16

Name
Address

Date / /

I confirm that I wish the Down's Heart Group (charity 1011413) to reclaim tax on :

- the donation of £..... - which I made on / /
- all donations I make from the date of this declaration until I notify you otherwise.

Signed : _____

Notes (please read)

You must pay enough overall tax to cover the tax we reclaim, which is currently 28p for every pound you give. Total tax includes payment under PAYE and tax deducted on bank interest.

If your circumstances change in the future and you no longer pay sufficient tax, please notify us and we will cancel your declaration.

You have the right to cancel this Gift Aid declaration at any time, and may do so by writing to us or telephoning. If you do so, we will reclaim tax on donations you have already made, but not on any future donations.

If you are not a taxpayer you cannot make a Gift Aid declaration.

National Contacts



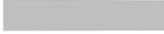
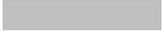
Regional Contacts

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.**

We are currently undertaking a review of our regional setup, which makes it inappropriate to include contact details in this issue. For your information details of 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
The Sarah Duffen Centre
Belmont Street
SOUTHSEA
Hants.
PO5 1NA
02392 824261

Down's Syndrome Association
155 Mitcham Road
Tooting
LONDON
SW17 9PG
02086 824001

(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