DOWN'S HEART GROUP NEWSLETTER

(Issue No 14)

Autumn / Winter 1995

Ashleigh Stafford

Registered charity Number 1011413

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National Administrator
Penny Green
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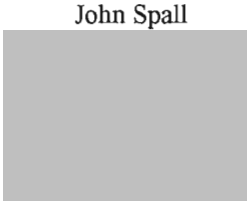
Contact or Answerphone always available (24hrs in emergency)

Chair
John Spall



Vice-Chair
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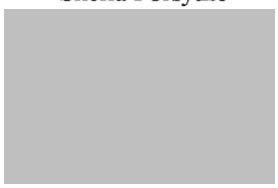

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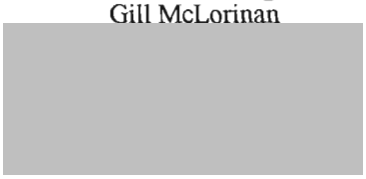
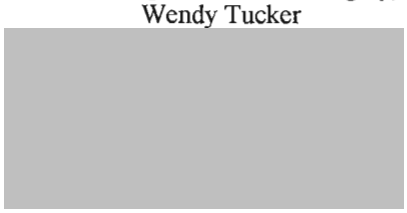


Representative for Inoperable Children
(Those who have not had and are not expected to have surgery)
Wendy Tucker



For details of your local area contact, please see page 4

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

Down's Syndrome Association
153-155 Mitcham Road
Tooting
LONDON
SW17 9PG
Tel: 0181 682 4001

Scottish Down's Syndrome Association
158/160 Balgreen Road
EDINBURGH
Lothian
EH11 3AU
Tel: 0131 313 4225

Down Syndrome Association of Ireland
27 South William Street
DUBLIN 2
EIRE
Tel: 003531 6769255

Chairperson's Report

In the last newsletter I promised all those attending the Annual Conference in May an informative and enjoyable day - and so it proved to be.

The facilities were first class, the speakers and workshop leaders excellent and it was good to see and hear the hubbub of parents exchanging ideas and experiences over lunch. For me always the most worthwhile part of the day.

My plea for some new blood on the Committee was also answered and I am delighted that Wendy Tucker from Nottinghamshire and Steve Brookes from Yorkshire have joined us.

You are in fact very lucky to get a full report of the two main presentations in this edition, in my excitement, I recorded the Rugby World Cup over the video tape of the Conference! Very red-faced and humble I was too in confessing all at the last Committee meeting. But, with the assistance of the speakers, all was not lost and we are able to bring you a summary of their talks.

Many congratulations to Linda and Mark Watcham and the Yorkshire and Humberside Region for a most successful event and thanks to everyone who assisted - in all some thirty people.

Penny and I are recently returned from Dublin where we attended the Third European Down Syndrome Conference with the theme of 'Towards an Inclusive Society'. This was an exciting and eye-opening event attended by over 500 delegates from 32 countries. It provided insights into the range of work being done in many countries and the huge strides being made by people with Down's Syndrome themselves in so many areas. Sadly, it also demonstrated that in many parts of the world the rights and potentials of people with Down's Syndrome are still not recognised and that a huge amount still needs to be done.

We will have a full report on the conference in the next edition.

And, although I am writing this on 31st August, as it is the final edition of the newsletter this year, it is the last chance I will get to wish you and your families a very Happy Christmas!

National Administrators Report

Many of you may be wondering why it has been so long since the last newsletter. Quite simply it is because the Group is becoming so well known that the workload at National Office is continually growing, and the day to day support and administration is taking up more and more of my time. Also the amount of Down's Heart Group equipment and stationery is starting to overrun my house, which doesn't make for the most efficient working enviroment.

I realise that members look forward to the newsletters, so please accept my apologies for the delay, various steps are being considered to help ease the problems, and I hope that you will find that the content of this issue compensates for your disappointment. I've tried to ensure that it has something of interest for everyone. If it doesn't, please tell me why, I welcome any comments - after all it's YOUR NEWSLETTER

As I say, it has been a busy time here, lots of enquiries for information from professionals, many new families contacting us for support, and a steady increase in membership. We have redesigned both our parents and general leaflets, and these came back from the printers just in time for us to take them to the European Down Syndrome Conference in Dublin at the end of August.

John has already mentioned what an interesting event this was, and I must agree. I personally found it an envigorating four days, and a wonderful opportunity to meet with other people who share a common interest. We spoke to many of the five hundred delegates (although it felt like all), over the four days, and there was a great deal of interest in what we are doing. Several of the Down's Syndrome Associations from other countries were impressed by the specialist nature of our Group, and have asked to receive copies of the newsletter so that information can be passed on to their members.

We had things to learn from them, and there was a tremendous sense of the mutual sharing of information and experience. It was really heartening to feel that we are all working towards the same goal, and that the best way of achieving this is by improving and maintaining communications between fellow organisations.

The Conference also saw a sudden rise in membership as there were several families who applied to join us whilst we were there. May I just take this opportunity to welcome them, they have helped take our membership to well over six hundred, a trend which I sincerely hope will continue.

Finally may I wish everyone the traditional Seasons Greetings for Christmas, and point out that National Office is of course manned throughout Christmas if you **need** to call.

Penny

Regional Contacts

If you experience any difficulty contacting the co-ordinator for your region, please get in touch with our national office who will be able to help you.

Bristol & South West (Avon, Cornwall, Devon, Gloucs, Somerset & Wilts)

Sheila Forsythe Gill McLorinan

East of England (Cambs, Lincs, Norfolk & Suffolk)

Lindsay Wharam Nicola Desmond

East Midlands (Derby, Leics, Notts & Northants)

Sarah Smith

Ireland (N.Ireland & Eire)

Rosina Brierley

Dublin Hospital Contact
Marion Delaney

London Northern (For Greater London letters refer to postcodes)

(Berks & Oxon)

Morag Malvern

(Beds, Bucks, W & NW)

Angela Barker
PLEASE CONTACT NATIONAL OFFICE UNTIL FURTHER NOTICE

(Herts, Middx & N)

Joanna Simms

(Essex & E)

PLEASE CONTACT NATIONAL OFFICE

London Southern (Kent, Surrey, Sussex & S. London)

Katie Spall

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

Sally Hardman Jane Wrighton

North West (Cheshire, Manchester, High Peak, Lancs, Mersey & N. Wales)

Mike Halpin

Scotland (Mainland & Islands)

Lynn Carlisle

South Wales (Dyfed, Glamorgan, Gwent & Powys)

Chris Stringfellow

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

Southampton Hospital Contact
Vickie Richardson

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

Pat Mitchell Noreen Hodgkinson

Birmingham Hospital Contact
Lynne Holden

Yorkshire & Humberside (Humberside & All Yorks)

Mark and Linda Watcham

Children with inoperable heart conditions

On receiving the news of this years AGM to be held on the 6th May at the District General Hospital in Grimsby, husband Mike and I decided that we really should attend. An added bonus would be a place for our ten year old son Alex in the crèche. We knew that he would aim for a whale of a time there and as it turned out, care and facilities exceeded all our expectations and he had a super day. Thanks to all involved.

Following the election of officers to the Executive Committee it was time to propose new members. I decided, just at that moment, that if there was a need for somebody on the committee with a particular concern for the futures of children and parents when heart conditions are recognised as inoperable, then I would very much like to join the committee.

I was very pleased to be elected, if surprised by my action!

Without early intervention, families live with the possibility of early bereavement or the onset of degenerative diseases, but at what age? Our children seem to be very able to "beat the odds" living, sometimes many years, beyond early prognosis. Medics can be consistently pessimistic with their estimates of life expectancy, (for Alex it was 1yr.,then 2yrs, then 5yrs,then definitely no more than 10yrs) However well intentioned, such predictions cause stress and make it very difficult to enjoy birthdays and seasonal celebrations. For our family, knowing a little boy four years older than Alex who was cheerfully defying the same prognosis kept us planning a future and thinking ahead as we had done for our other children. Otherwise, I think the enjoyment of planning for next year, or several years hence, could have been taken from us.

We would like to hear of your experiences.

The positive things that illustrate optimism and hope as well as the difficulties and traumas. We would like to know about the doubts or questions you may have. Maybe support would often be welcomed by parents from other parents who have been through similar experiences and generally from the Group in providing a focus for dissemination of information. It would be nice to know how older children and young adults are doing. What contributes to maintaining health and an active life? Generally, anything you would like to throw into the pot that will give a clearer view of the lives of young people who have not undergone corrective surgery and what this means to their families.

Secondary Conditions

For some children, Down's Syndromc and heart defects are not the end of their story, they have secondary conditions. For Alex it is autism.

For seven years I knew that my little boy was very different from the other children with Down's Syndrome that I met. I lost my original enthusiasm for support groups as other parents were not experiencing my difficulties. I really thought Alex was an "original,"one on his own. His paediatrician would write down my descriptions of his behaviour with interest and empathy, but little real comment. Then, during his seventh year, I watched a number of programmes on the television and read articles about autism. Alex was not alone! What a discovery. He was one of many, one of the gang! He belonged. I was over the moon, and took my "news" back to his paediatrician. Her concern for all of us was as unfailing as ever as she agreed that yes, Alex was autistic, but that he had so many problems she had not liked to worry us with yet more bad news.

Is this a familiar story?

How did you hear the news of your childs' secondary condition? What is the condition? Would you like to write about autism and your experience of this condition for the newsletter? Do you suspect that your child might be autistic and would you like more information?

Please share your experiences and concerns with us.

Wendy Tucker

(Editor - Wendy has taken on the role of representative of those families whose child has an inoperable heart condition. She would very much like to hear from anyone who has similar experiences, so please do get in touch.)

Donations

Since the last newsletter we are very grateful to have recieved amongst others, the following donations :

Jennifer Barber - Thornaby (in memoriam)

Bernadette and Stevie Chamberlain - Hong Kong (in memoriam of mother and daughter)

Cunnington and Goodwin families - Peterborough (donation raised by pushing the children in their buggies at the Great Eastern Fun Run)

Simon Fraser - grandfather of Santiago (in memoriam)

Heather Longden - Sheffield (after successful surgery)

Prince William Henry pub - London SE1 (donation raised by a tower of coins)

Ryan Ruddell - Ruislip (in memoriam donation raised by J&C Auto Supplies Ltd)

Grandfather of Alex Tucker (in memoriam)

Shelley Stewart - Bedford (in memoriam donation raised by her grandmother Mrs DM White from a bric a brac and craft stall)

A computer from Midland Bank PLC

Hannah Boniface - donation from grandmother

Godfrey Linnett - donation via Charities Aid Foundation

As well as those who make regular donations via Deed of Covenent and Give as You Earn etc. - THANK YOU ALL

East Midlands Update

The following item is by Sarah Smith, the Regional Co-ordinator for the East Midlands, but it reflects the type of work being undertaken in a lot of other areas too. Please remember that all the Co-ordinators etc. are volunteers, and give them your support in any way you can, they are working very hard to help families just like yours.

I thought, as I've been East Midlands Co-ordinator for two years now, I ought to let folk know what I've been up to. I've managed to contact all the families I know about by letter, and have managed to speak to over half by phone as well as meeting a few families. Sorry if I've not phoned you yet - I haven't forgotten. Please feel free to call me with any queries, problems, ideas or just for a chat.

I am hoping to do so much, there are vast areas in the East Midlands where the Down's Heart Group is virtually unheard of, and it worries me to think of the amount families who are missing out on the support we can offer. I would be extremely grateful to anyone who can tell me of any clinic, group, school or individual in their area which may benefit from knowing more about the Group. If you feel you can offer your services to the Group, in whatever capacity, or you feel you need more help or support from me, just let me know.

The group nationwide is going from strength to strength - lets make sure the East Midlands goes with it!

Glenfield Hospital

I live only nine miles away from Glenfield Hospital (formerly Groby Road Unit), so if anyone has a child coming to Leicester for surgery and would like a visit from someone who has been through a similar experience, please contact me.

Webb Ivory

These catalogues are an easy way to raise funds. 25% of the sale price goes to your charity and the customers get good value for money too.

Fundraising in the past two years

Thurlaston village carnival '94 bric-a-brac sale	£79.34
Sale of a wall unit	£40.00
Charity stall on Hinckley market for one day	£64.57
Donation from Thurlaston Carnival Committee	£50.00
Donation from Mr & Mrs Botterill	£20.00
Webb Ivory fundraising	£85.89
Elephant & Castle pub Thurlaston, tripe supper	£50.00
Coffee morning at our house	£25.00
Car boot sale at Croft	£35.41
Golf game at Thurlaston Carnival '95	£50.00
Donation from Preschool Playgroups Association	£50.00
Webb Ivory fundraising catalogues	£8.76
Total	£558.97

Thank you to everyone involved.

Thank you...

to Mrs Margaret Jones for knitting toys to sell
to Mr Jim Jones for donating his prize money back to us
to the regulars of the Elephant & Castle
to my Dad, Brian Wainwright for his donations and his help with the car boot sale
to my Dad's boss, Mrs Sylvia Yeo of Acclaim Driving Academy for the loan of a car and office and donation of diesel
and lastly to my husband, Chris for putting up with the chaos and for making and manning the golf game in the pouring rain.

"It'll be alright on the Night"

Emily, our eldest daughter who was five in April and has Down's Syndrome, has been attending ballet and tap at the village hall for nearly a year now. She passed her first exam in March (prejuvenile ballet) and has been rehearsing for her first show for several weeks. Now, as many of you will now, comprehension and speech for our kids are often long awaited, and although Emily says she's listening and understands what we say, we are never 100% sure.

So, the night before the show, Emily sat on my knee and was very excited that all the family were going to watch her dance. I was talking to her and explaining just how important it was that she did as she was told and remembered her steps when she burst in with "Aw Mum, don't you worry about my dancing.....it'll be all right on the night!"

Sarah Smith
Thurlaston

Solicitors Questionnaire

Many of you will already have recieved a questionnaire from a group of solicitors called Alexander Harris, which has been forwarded by ourselves. We would like to reassure you that no information has been disclosed directly to them.

They are researching current practice in surgical treatment of children with Down's Syndrome, and have asked for help from as many families as possible, hence our reason for contacting you.

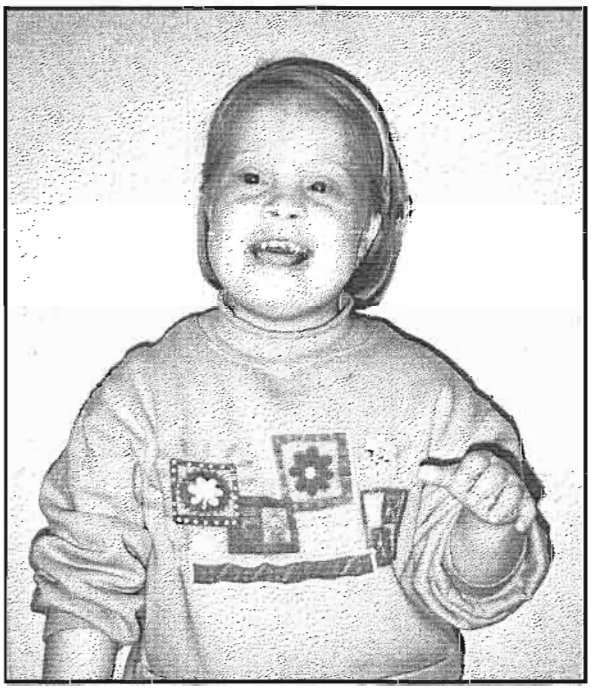
We have Alexander Harris' written assurance that any information they recieve from these questionnaires will be used for information purposes only, and that they would not contact any doctor or hospital mentioned by you without first obtaining your consent.

We hope this clarifies the situation, and that you will feel able to help them in their research.

Maria's Story

It was on August 30th 1994 that I first heard the cardiologist at the Kent and Canterbury Hospital say the dreaded words 'atrio ventricular canal defect' during an ultrasound heart scan of our daughter Maria, who has Down's Syndrome and was eight in March this year. On 17th November 1994 Maria had surgery to repair her AVSD and this, to our great relief, appears to have been very successful following weeks of anxiety and fears for her future. This is her story.

Maria was born in 1987 and discovering that she had Downs' Syndrome was a shock at first, but she has brought so much fun and love into our lives that it didn't take long for her to become a very precious member of the family. She is our sixth child: our oldest four have already left home to work or study, leaving our youngest son David (15) and Maria living at home with us in Ramsgate.



We were aware that Maria had a heart problem which we had been told was a small VSD and nothing to worry about: this had been diagnosed when she was two by an echocardiogram, which was repeated in each of the following two years and re-confirmed. But at her recent six monthly check-up with the paediatrician he had noticed a heart murmur and so arranged the August 1994 scan which revealed the major defect.

On this occasion the doctor told us that although serious, an AVSD was often successfully treated by surgery: uppermost in my mind was the shock of finding it so late, and whether this would make an operation too risky for Maria. This was the very reason for her first heart scan at two when we became aware of the high incidence of heart problems in children with Down's Syndrome often without symptoms. We had to battle with our paediatrician to arrange it since he had heard nothing unusual by stethoscope and ultimately we switched to a more sympathetic consultant.

From Canterbury we were referred to a paediatric cardiologist at a specialist London hospital, where on 5th October '94 the diagnosis was confirmed. We were also told to our dismay that Maria's condition was inoperable due to lung damage. This would progress so that she would not survive beyond her early twenties. Hearing this verdict was like living out a nightmare - we were devastated.

The shock of this news was to me far greater than the realisation, at Maria's birth, that she had Down's Syndrome. I asked myself how this could be since Maria had shown no symptoms such as breathlessness: she always had tended to tire easily but this I thought was due to the Down's Syndrome and a thyroid problem she has. In any case her first echo scan had shown only a small VSD.

In the days following I found myself looking at Maria and wondering why she was behaving so normally - going to school, singing, playing with her dolls and her imaginary friend Sarah - when she had such a major heart problem. We had to conceal our anxiety from her as she is very sensitive to our feelings - one of her favourite expressions to end any domestic arguments is "Just be happy!" At this stage I contacted Penny Green at the Down's Heart Group who gave me much encouragement, information and support over the phone.

We tried to accept what we had been told, not doubting the truth of it, but there were so many things we needed to know that we decided to seek a second opinion. We arranged a consultation with a specialist at Birmingham Children's Hospital who had been recommended to us by a good friend. On 27th October we travelled north where Maria was seen by a very caring and sympathetic consultant and given an ECG and an ultrasound scan. She finally had a cardiac catheter examination the following evening, which showed to our surprise and relief, that her lungs were reacting to the extent that heart surgery would definitely help her. To me this was a miracle! - an answer to our prayers and those of many friends.

We met the cardiac surgeon who was incredulous on hearing that her heart condition had not been found earlier. The Birmingham doctors gave us a 85-90% chance of success for Maria's surgery, and we had to weigh up the risk against the certainty of what would happen to her if the defect remained untreated. There was in fact no real choice. We wre so relieved that surgery was possible - she would have the operation.

The operation was scheduled for 17th November 1994 at the Priory Hospital in Birmingham. I felt strangely calm on the day, perhaps due to the kindness and confidence of both the cardiologist and surgeon which encouraged me to feel that all would be well. An Intensive Therapy Unit (ITU) nurse came to see us and explained what we should expect after the operation. Also the anaesthetist introduced herself and had a friendly chat with Maria. At 5pm we walked with Maria the short distance to the operating theatre. When we saw the anaesthetist in her blue theatre cap and gown Maria exclaimed "You look nice!" She got on the trolley chatting amiably causing the surgeon to remark that he could see who was in

charge! Maria probably thought this was yet another "look at her special heart" and seemed unconcerned. We stayed long enough to see her eyes close and walked quietly back to our room to wait and pray. The operation would take up to three hours we had been told.

After about two hours the surgeon came to tell us that all had gone well, he was very pleased with Maria's lung and heart function, and said that we would be able to see her in the ITU in about an hour. The relief that Maria had come through the operation safely was immense .... but we knew the next forty eight hours would be crucial. When we saw her in the ITU unconscious, surrounded by tubes, wires and monitors and looking so tiny on the large bed, we were overcome with emotion. She was taken off the ventilator the next morning and back on the ward after thirty six hours. From then on she made remarkable progress and was allowed home after six days. She had a follow-up appointment a month later, when her heart was found to be functioning well; the next check-up would be a year after that - a good sign!

Maria's heart condition was discovered very late; this late diagnosis and the events that followed raised a number of unanswered questions in our minds about the treatment of babies with Down's Syndrome and related heart problems. Why for example was Maria's diagnosis at two so inaccurate, and why is there so much apparent ignorance about the incidence of heart problems in children with Down's Syndrome? These questions of course are more likely to be answered if more first hand information can be shared, for instance by parents responding to the survey in the Spring 1995 Down's Heart Group newsletter.

I will always be grateful for the support I received from the Down's Heart Group at a time of great distress, and also for the kindness of the doctors and nurses who cared for Maria.

Mary Brennan
Ramsgate, April 1995

AA Members - Special Needs

The AA has recently introduced a service to members with special needs and their families. For no extra charge over your current level of membership, you are invited to complete a form giving details of your 'individual' circumstances which will remain confidential, but will enable the AA to respond with a service personalised to your specific needs in case of a breakdown. You do not need to have an orange badge or be registered disabled, and a note can be kept of the special needs of your immediate family.

It sounds as if this could be a very useful service for our members, please let us know if you have cause to use it.

Harriet's Story

Our daughter Harriet was born in the Simpson Memorial Maternity Pavilion, Edinburgh at 5.42am on the glorious morning of 3rd May 1993.

She is the second of twins, born at 29 weeks gestation, after a hair-raising ambulance journey of 75 miles from our home in rural Dumfries. She, like her sister, was ventilated and cared for using all the wonders of modern technology in the magnificent Special Care Baby Unit there.

Her Down's Syndrome was noticed by the staff within a few hours, but we were not told until they were certain, when she was 24 hours old. We were told with the utmost consideration by a tremendous Consultant, Dr Andrew Lyon, who came to the private room we'd been given - yes, both my husband and me! - and broke the news to us together.

Looking back- and even at the time - we realised how lucky we were to be together, our whole tiny and fragile family, at this time, when happiness and sadness roller-coasted one after another. Because of the distance we were from home, and the prematurity of both girls, the hospital authorities made a bedroom with private shower available to us for almost two weeks, until the girls were able to be transferred to our local hospital Special Care Unit. Although my husband went back to work after a few days, he came back to Edinburgh every evening, and so we were able to support each other, and to be supported by the nursing and medical staffs, We were made totally at home in the Special Care Unit at all times of the day and night, and we spent most of our time there, caring for our daughters from the first day. We fed them by naso-gastric tube, we changed and washed them, and - best of all - we not only cuddled them, but were encouraged to 'kangaroo' them. They were fed on my expressed breast milk, and this added to my feeling of being able to do something to care for my own daughters myself, while cared for and supported by my husband.

As we were still reeling from the shock of their early arrival, being so far from home and Harriet having Downs' Syndrome, we were confronted by news of Harriet's major heart defect. She was taken from the maternity hospital to the nearby Sick Children's Hospital for diagnosis on day three, where her condition - a complete AV Canal defect- was explained to us.

Then the heart-break reached its peak; we were confronted with the strong possibility of losing Harriet, if not within the next few hours, then within the next few weeks, months or whatever. That kind of threat certainly concentrated our minds, and the terrifying prospect of losing our daughter who was so precious already, and yet whose Down's Syndrome was still so awful, exacerbated our already difficult emotional state.

When Harriet and Hilary were transferred to Dumfries, we were delighted as it meant being able to live at home again, and we were ready to leave the hospital cocoon and face the world - well bits of it anyway!

Over the next few weeks, Hilary made good progress, and was soon out of her incubator, onto bottle feeds (still by E.B.M.) and eventually allowed home, but by this time it was clear that

Harriet was not at all well, and that she was in need of the specialist care that could only be provided at a centre of excellence again, and so, after two days with Hilary at home, we re-admitted her to Special Care (she was in need of a blood transfusion and also was in safe hands whilst Harriet was to be so far away again), and accompanied Harriet back to Edinburgh. After only a few hours, her heart failure was diagnosed as severe and she was ventilated and in Intensive Care.

The next week was pretty dire as we had our two girls in two different hospitals in two different towns some eighty miles apart. At first, Harriet seemed to be responding well, and we went home for two days to get Hilary out of Special Care. The staff there had done a wonderful job in stalling and keeping Hilary for us, but they could not go on forever, especially as she looked so well by now. So on Saturday 28th June Hilary came home at last. On Sunday we spent the whole day at home to try and get ourselves established in coping with one baby. We were in two hourly contact with Edinburgh, and as the day progressed, we realised that Harriet's condition was worsening and we were warned that emergency surgery was extremely likely.

On the Monday morning our early call to Edinburgh elicited the information that the surgery was definitely on, and that we should make every effort to get there in time to sign the necessary consent forms, and see her before she went to theatre.

By the time we got there with tiny Hilary in tow, we found Harriet already prepared for surgery, with all the lines in and heavily sedated. The surgeon, Professor Hamilton, explained to us very patiently what he planned to do, and that Harriets' chances were reasonable, although that came as no shock to us as the cardiologist had explained everything to us very carefully every step of the way.

Hilary and Harriet

The next three hours were the first of those unreal times when you find yourself in a kind of suspended animation, doing normal things, and realising every so often that your child is totally out of your control or reach, and that all you can do, quite literally, is pray. We've been there often since, but nothing prepares you for that first time.

Al last she emerged, and the wonderful surgeon explained to us - in the privacy of the corridor (conditions were mot so luxurious here!) - that although it had not all been plain sailing, they had not actually 'had their back to the wall at any time'. I still remember those words, and they seemed to explain it perfectly to us! Harriet had had a Pulmonary Artery Banding, which should enable her to live long enough to stand the definitive surgery, hopefully when she was about a year old.

Over the next week she made great strides, and was transferred back to our local Special Care Unit where she was something of a heroine. About two weeks later she was able to come home, and there was certainly dancing in the street that day.

The Autumn and Winter were reasonably uneventful, with only two spells in hospital, first for a week with pneumonia, and then for two weeks just before Christmas with bronchialitis. In between these, we moved house, and had a fabulous Baptism and celebration, albeit extremely belated, for the birth of our girls.

The Baptism was very special and important for us. Even when Harriet was extremely ill, we did not feel the need for her to be baptised at once, and our wonderful Rector supported us in our wishes. He visited us all in hospital before the PA Banding operation and asked a blessing for Harriet, and indeed for us all, but we firmly believe that that was for our frail human benefit - and that God didn't actually need reminding that we needed Him. The Baptism when it came was a glorious day of celebration, thanksgiving and dedication - and the sun shone too!

In January when the girls were some eight months old, Harriet went into hospital again for a cardiac catheterisation to ascertain when the definitive surgery should take place. This was set for February 16th, somewhat earlier than we had imagined.

The next few weeks were pretty awful, but we got ourselves into gear, and set off to Edinburgh again, having done all the reading and talking about the operation, and being as well prepared as possible. We were all to stay in the flat belonging to a friend, within walking distance of the hospital. However it was not to be.

The consultant cardiologist arrived to see Harriet after her admission. After numerous tests and bloods had been carried out, Harriet coughed, and I was able to admit that she had indeed developed that cough the night before. "Home" said the doctor, and we were devastated! Even though we realised that it was essential for her to be quite well, and that the danger of a virus attacking a girl undergoing such major surgery was extremely serious, we felt selfishly devastated that it was not to go ahead, and that we had to face a repeat performance a few weeks later. However, such thoughts only lasted a few hours, and soon we were home in our fools paradise again.

The cough did develop, and when she was eventually well again, in late March, it was only for the cardiologist and then the surgeon to be on annual leave. ********** and a few other expletives deleted!

On April 26th we tried again, and this time Harriet was a star. The surgery to deband the pulmonary artery and to repair the AV Canal was successful, and Harriet came through with flying colours. She was extubated within a week, and made a good recovery although her demand for oxygen continued for some time. The girls celebrated their first birthday in the Cardiac Unit - no candles though as she was still on oxygen. Two weeks post op Harriet was transferred back to our local hospital to convalesce and to be weaned off the oxygen.

By this time my husband and Hilary were at home, and my mother was in the same hospital having a hysterectomy. On Friday 13th May, I was the only one of the family standing as my husband, Hilary and my father had been stricken by a gastric bug collected as a parting gift from the Parents Unit at Edinburgh. Then surprise, surprise, Harriet caught the bug, and becoming ill again had to be transferred back to Edinburgh. After a week when she'd had a bank of tests and we'd been reassured that all was well, she came back to Dumfries, and then a week later back home.

We had three whole weeks at home!!!

Then Harriet again became unwell and was admitted to the local hospital with a suspected virus. She had become dehydrated and needed oxygen again. I was amazed at how quickly it had happened, and as usual, felt dreadfully guilty that we had not spotted it a day earlier. (The dilemma of being paranoid about her health yet not trying to over-react is a very real one, and not always helped by the medical professions apparent confidence that after major surgery all will be normal),

This time she did not respond well to oxygen and antibiotics, and after two weeks, when she was becoming steadily worse, she was - yes you've guessed - transferred back to Edinburgh again. Things were the worst they'd ever been, and she was ventilated within hours, her condition having deteriorated seriously over the previous night and during the journey. The wonderful doctor and nurse who'd accompanied us found it very difficult to leave us as the outcome was beginning to look rather uncertain.

The next six weeks were a nightmare. Harriet was in an extremely serious condition. She remained on a ventilator and also contracted at least two viruses. We had to face the prospect that although she desperately needed open heart surgery to repair the mitral valve whose regurgitation was severe, she was in no fit state to cope with the rigours of an operation.

We watched as at least a dozen heart patients had their surgery and walked out to go home, and also watched as some four others did not make it. The parents we got to know living side by side in the Parents Unit were simply disappearing overnight.

But Harriet is made of strong stuff. Despite all the medication (and they really had hauled out all the big guns!), Harriet's digestion never faltered, and she did at least make it to the second operation. The surgical and medical teams were superb, and the nursing staff of Intensive Care and the Cardiac Unit were our best friends - and Harriet's too. She came through the surgery very well, and was off the ventilator eight days later, and home - not even in an ambulance but delivered like a bouquet in her father's arms - three weeks after her second bypass surgery.

She was a new girl - a wonderful colour, and full of energy eating like a horse, and sleeping all night. Since then she's only had pneumonia once over Christmas and New Year.

During all this, we have tried to give Hilary and Harriet as normal, tranquil and routine a home life as possible, and I think that has been a saving grace for all of us.

Now we are at the stage of trying to get Harriet mobile, and we are delighted to see her sitting, reaching, rolling and turning round on her tummy. She will take weight on her legs, and sit both low and extended on her knees. We're incredibly proud of her, and I think that she is quite a remarkable little girl. Hilary treats her with total childish acceptance, and they smile, and steal, and talk, and vie with one another just as one would expect.

We're very lucky to have both our girls, and I don't think we could ever take them for granted - not even for a moment. Now we're beginning to face up to what will be our normal life - the balancing act of twins, one 'normal', one with Down's Syndrome, and all the joys and worries that go with that particular recipe.

Gina Davis
Dumfries

Children's Heart Federation Xmas trip to EuroDisney

Last year at Christmas, the Children's Heart Federation was able to take some heart children, including two Down's Heart Group members to Lapland to meet Santa. This year they will be taking children and their families in a fleet of white Rover cars to EuroDisney.

We do not have full details available yet, but understand that the Down's Heart Group will be allocated places for two children and their immediate families to go on the trip.

If you would like your childs name to go into our draw in order to select the two winning children, please advise National Office in writing as soon as possible, as details will have to be finalised well in advance in order to have the time to arrange insurance etc.

Chiara's Story

Chiara, a sister for our then two year old son, was born on August 5th 1990 in Bracciano Hospital, about 30kms north or Rome, at 5.20pm and almost immediately I notice her small fingers had the indicative bend (having worked with children with Down's Syndrome as a student teacher I knew this to be a 'sign'). I mentioned this to my husband Clive whilst Chiara was being cleaned and weighed and then whilst I was waiting to return to the ward, an English speaking doctor was found and my husband was told that they 'suspected' Chiara had Downs' Syndrome. Although we were shocked, during my pregnancy I had tested positive for toxoplasmosis, so there was always the possibility that our child would be handicapped, so mentally I felt somehow prepared.

After being left alone for half an hour the paediatrician came to talk to us and answer any questions we might have. She said Chiara was in good condition and as far as she could tell had no heart problem. Clive then had the difficult task of phoning our families in Britain. My parents were flying out the next day and set to raiding the local library and bookshops and phoning the DSA to find out as much information as they could. Friends in Italy were marvellous offering support and comfort at a very difficult time.

At six weeks Chiara was checked by a paediatrician at the Rome DSA, who suspected she had a 'whistle' (direct translation from the Italian!) and gave us the names of several doctors we could contact to have an ultrasound scan done. At this stage Chiara was growing slowly, always panting, listless and clammy to touch, but had never shown signs of blueness.

We made an appointment at the Gemelli Hospital ten days later where the doctors told us she had a complete AVSD and an open patent ductus arteriosus. She was given Lanoxin (Digoxin) and there followed weekly checks at the Gemelli, whilst an appointment was made with a paediatric cardiologist attached to the Bambino Gesu Hospital in Rome.

Our first meeting with him took place in November and much to our relief he spoke perfect English! He explained that Chiara required surgery as soon as possible. That the operation was fairly straightforward, had a 15% risk factor and that if we wanted to do it in Rome we could go privately and pay thirty five million lira (equivalent £17,000 sterling.) When we gulped and said we didn't have that sort of money he said 'no problem' and made us an appointment for March in the Apuana Hospital in Massa Carrara, Tuscany - where they operated every Monday (waiting lists in Rome are long as they cover the whole southern area.) We were told to go home and help Chiara put on as much weight as possible - at this stage she'd grown 100g since birth!

At no time did we ever feel that because we were 'foreigners' we were given inferior treatment - in fact quite the opposite, we felt we were treated as special cases and everyone tried as far as possible to make our experience an easier one. As March grew closer Chiara had grown very little - she would be 800g above her birth weight when operated on - and although clammy, panting and very immobile, her eyes were alive, always looking around, taking everything in, full of inquisitiveness. We arranged for my mother to come and take care of our son, Ben - who fully understood that Chiara had a poorly heart and that the doctors were going to fix it.

When we arrived in Massa on March 7th we were assigned a beautiful room with cot, bed, bathroom and a view of the Apuan mountains - where Micahelangelo got his marble from. Clive returned to Rome whilst Chiara spent four days having routine checks, x-rays etc. He returned on the Sunday.

The next morning, after a disinfectant bath and hair wash, Chiara was taken to surgery at 8am. We had decided to leave the hospital (after reading a booklet from Great Ormond Street) for the duration of the operation - we went to see the marble quarries.

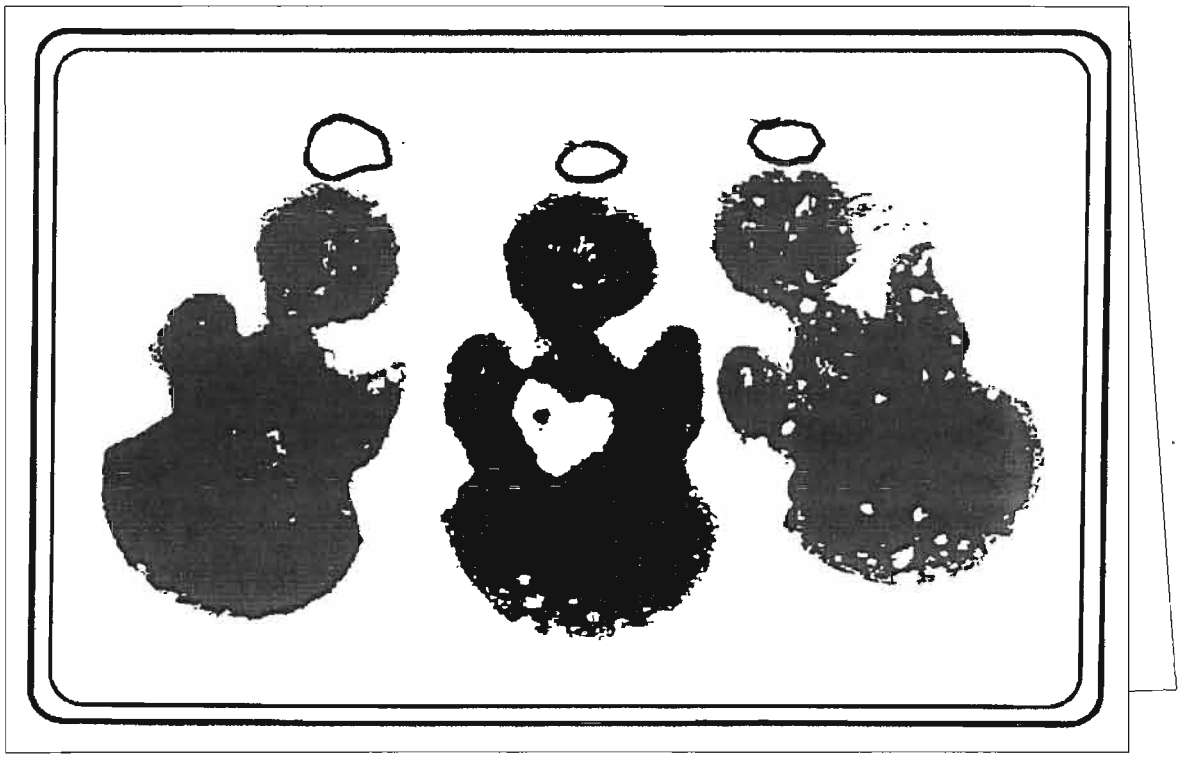
We returned at 3pm to find that Chiara was in Intensive Care being 'wired up' and we could visit her. This meant looking through a window at her. The nurse was trying to give her a dummy which she was spitting out, so we signed that she sucked her thumb. The nurse untied her wrist, which was restrained so she couldn't pull out the tubes etc. and we watched as she fell asleep.

Chiara remained in ICU until Wednesday midday when she returned to the ward a different child. No more sweatiness or panting, and although for three more days she was attached to tubes and pumps we could see the amazing changes taking place. Ten days later we were allowed home to a jubilant grandma, brother, friends - both English and Italian - who gave us such support during the first months of her life.

Chiara has gone from strength to strength. She is now an active, cheeky, happy, inquisitive, cheerful little girl. She stopped all medication in October 1991. We would like to thank ALL the doctors, nurses and assistants involved in Chiara's remarkable recovery.

Jan Norton
Rome

1995 Christmas Cards



This years Christmas card was designed by 7 year old Daniel Allen from North Yorkshire. It's hard to do justice to these cheeky little angels in the newsletter, so all members will be receiving a sample card. Please show it to family and friends and ask them to buy some and support our work.

There has had to be a price increase since last year, but we hope you agree that the cards still offer very good value for money, and as we organise production and distribution ourselves, all the proceeds go directly to the Down's Heart Group, unlike many other charity cards.

Cards are available in packs of 10 for £1 - 70p (plus £0 -35p p & p)
or packs of 50 for £7 - 50p (plus £1 -40p p & p)

Whilst you're ordering your Christmas cards, why not order one of our ceramic mugs or a hand-stitched cross-stitch keyring. They make ideal small gifts for family and friends. For a larger gift, try our t-shirts and sweatshirts.

Mugs		£3 - 25p (plus £0 - 75p p & p)
Keyrings		£1 - 50p (plus £0 - 25p p & p)
T-shirts	(children)	£3 - 50p (inc p & p)
	(adults)	£7 - 00p (inc p & p)
Sweatshirts	(children)	£5 - 50p (inc p & p)
	(adults)	£11 - 00p (inc p & p)

An order form for cards, mugs and keyrings is enclosed, for t-shirts and sweatshirts please ring first to check size and colour availabliity.

For cards, mugs and keyrings contact: Shirley Glowocz

For t-shirts and sweatshirts contact: Phil Thorn

Language Development in Children with Down's Syndrome

Irene Westerman, until recently an Educational Psychologist responsible for the Portage service in Leicestershire and now National Children's Officer of Mencap, gave an interesting and stimulating talk on the background and latest thinking on developing our children's language skills.

She began by explaining how children learn language, which is not just the spoken word but also signs, gestures, etc. It is a complex process and the pace varies widely between children.

Irene put forward four requirements for a child to learn to communicate:

SOMETHING TO SAY
A WAY OF SAYING IT
A REASON FOR SAYING IT
SOMEONE TO SAY IT TO

Remembering these simple rules at all times will enable you to take a constructive and positive role in your child's language development.

For many children with Down's Syndrome, language development is the area of greatest delay. Until recently this was seen as part of overall developmental delay. However, studies have shown that the picture is more complex. Language development is generally more delayed than other areas of cognitive skills in children with Down's Syndrome, and this gap is more pronounced than in 'normal' children.

There may be a number of reasons for this.

Hearing: Many babies with Down's Syndrome have hearing problems and even a slight loss can make it difficult to distinguish similar sounding words eg 'trees' and 'cheese'.

Memory: To understand speech a child must hear the sound very quickly, remember it long enough to be able to recall that sound from having heard it before and then put a meaning to it. This is quite a complex process, requiring both long and short term auditory memory, even for one word. When that word is part of a sentence the complexity is multiplied many times. There is some evidence that people with Down's Syndrome have better visual than auditory memory.

Motor Skills: Many children with Down's Syndrome have lowered muscle tone and this can, of course, equally affect the muscles involved in speech.

Processing Skills: By this, Irene means bringing together all these complex activities in working out what to say and how to say it. Evidence shows that children with Down's Syndrome are best at being stimulated visually and giving a motor response (eg being shown an attractive object and grasping it) and less sure when the stimulus is auditory and the response vocal (eg question and answer),

Helping Language Development

Remember at all times the rules for communication explained earlier. A loving, accepting family environment is the surest way of giving a child something to say, a reason for saying it and someone to say it to.

Accept all ways in which your child communicates, looking, touching, pointing, moving. Let them know from an early age that communicating is enjoyable and worthwhile.

Remember that visual ability is likely to be your child's strength; play to it. Use pictures, visual clues, video rather than audio tapes. Family photos and videos including the child will stimulate memory and the motivation to recall through speech.

Irene is strongly in favour of signing as another visual strength to supplement language. She has considerable personal experience of using Makaton with children from about one year and has found that it tends to be replaced by speech at about three or four and is no barrier to mainstream school placement.

As well as playing to strengths look to improve on the weaker areas. Extend auditory memory by using story books/rhymes which build up lists or by giving your child gradually more extended messages to deliver to other members of the family.

Don't underestimate your child's understanding of language by judging it by the standard at which s/he speaks - and don't let other people do so, particularly newcomers who don't know the child. A child's understanding is likely to be some way ahead of their articulation.

Many parents will be familiar with the concept of using reading at an early age to develop the language of a child with Down's Syndrome, through the work of Sue Buckley at the Sarah Duffen Centre. Irene is a strong advocate of this approach and explained the methods used, their success and the research being carried out to extend them further.

This is a short summary of a very stimulating, constructive and thought provoking session by Irene, which cannot do it justice. For parents who would like to know more, you can obtain a copy of the full text of Irene's handout from National Office.

At the recent European Down Syndrome Conference, Sue Buckley produced further research findings demonstrating that her approach is further closing the gap between chronological and actual reading ages of children with Down's Syndrome and improving their short term memory scores.

A full report will appear in the next edition of the newsletter, and Sue Buckley will be speaking at our Annual Conference in April 1996.

John Spall
Chairman

Dental Care for Children with Down's Syndrome.

Elizabeth O'Sullivan, a Lecturer in Paediatric Dentistry at the Leeds Dental Institute, gave an interesting and informative talk on the care of teeth for children with Down's Syndrome, and more particularly in relation to heart problems, and the precautions that should be taken if dental treatment is required. This report from Mike Halpin our North West Co-ordinator.

The development of the teeth and jaws of children with Down's Syndrome may be delayed and the first primary teeth may not erupt until the child is two years old, and not complete until four - five years of age. The child may still have primary teeth at fourteen years but this span is highly variable.

Of the children who have Down's Syndrome and a heart defect, 15 - 20% are severe and require surgery, the most common defects being Atria-ventricular canal defect and the Ventricular Septal Defect. The main problem after surgery regarding Dental care is the risk of Infective Endocarditis (IE). This is fatal in about 30% of those affected, even if it is treated, so avoidance is essential. IE is caused by the turbulence of blood and the presence of certain bacteria, often those found in the mouth, so it is important to prevent the bacteria from entering the blood stream.

Children at risk from IE should be given Antibiotic Cover before the following procedures are carried out:-

* Scale and Polish
* Gum Surgery
* Extractions
* Fillings that touch the gum margin.

They should also not have nerve treatment of baby teeth (root canal therapy), if the decay affects the nerve, then the tooth should be taken out.

Root canal treatment in permanent teeth is sometimes acceptable if carried out in a single visit under antibiotic cover. However, if there is any risk of infection, the tooth should be taken out.

There are no recorded instances of children being affected by IE when teeth become loose and fall out naturally.

Problems associated with Dental Treatment and Down's Syndrome

* The upper and middle face are often small, with the palate often high and narrow, the growth does not usually fully catch up, so the face always appears small in proportion to the rest of the body.
* Joint Laxity.
* Atlanto-Axial Instability of the neck, this occurs in 2 - 10% of children and may sometimes be detected by x-ray.
* Large Tongue/Small Mouth

Often the tongue appears to protrude from the mouth, this may be due to a larger tongue than usual or the mouth being smaller than usual. This may affect dental care in the following ways:-

* More difficult to clean teeth - the tongue may get in the way
* More difficult to treat teeth
* It can make general anaesthesia more difficult to administer.

Dental Problems in Down's Syndrome

* Decreased dental decay
* Increased gum disease
* Increased incidence of missing and pitted teeth
* Delayed eruption

What can you do ?

Prevention is much easier than treatment

* Regular dental " check-ups " from an early age.
* Fluoride
* Oral Hygiene
* Diet
* Fissure sealants

Fluoride is important to prevent dental decay. It can be given as toothpaste, tablets, drops, mouthrinse, gel or in the water. You may need to ask your dentist whether the water in your area is fluoridated. Make sure your child is able to rinse and spit before giving mouthrinse. It is better that the fluoride coats the surface of the teeth rather than tablets being swallowed whole and the fluoride getting to the teeth through the bloodstream.

Oral hygiene is important in preventing dental decay and gum disease , here are some useful hints:-

* Use a brush with a small head and a chunky handle, this enables the child to have greater control over the movement of the toothbrush.
* Brush your child's teeth from behind, whilst supporting the head, don't forget, the teeth have three surfaces to clean, the top, the front and the back.
* Brush the gums as well as the teeth
* Don't use too much toothpaste ! a ball the size of a pea is normally sufficient.

Diet is important in preventing dental decay, and to get the child into the habit of a healthy and balanced diet

* Reduce the amount of sugars in the diet.
* Reduce the frequency of sugary snacks.
* Encourage a healthy and balanced diet
* Introduce "safe snacks "

Try and avoid fizzy drinks, Cola's etc., even giving your child fruit cordial with naturally carbonated spa water may not be all it seems, as some of this natural water can be quite acidic in its make up, and can still damage the teeth.

Plastic coatings placed in the cracks of the molar teeth to help prevent decay in these teeth. If possible, this treatment should be carried out as soon as the permanent teeth erupt.

Dental treatment should be carried out under local anaesthesia, if not your child should be referred to a specialist centre for full mouth restorative treatment may be undertaken whilst under general anaesthetic.

Children with Learning difficulties may be unmanageable for dental care in the normal way, so careful planning is required when treatment is required. More time should be allowed in order that each procedure may be fully explained and showed before doing it (Tell-Show-Do). You may find some children will respond particularly well to "modelling" and to the use of "rewards"

Annual Report of The Executive Committee

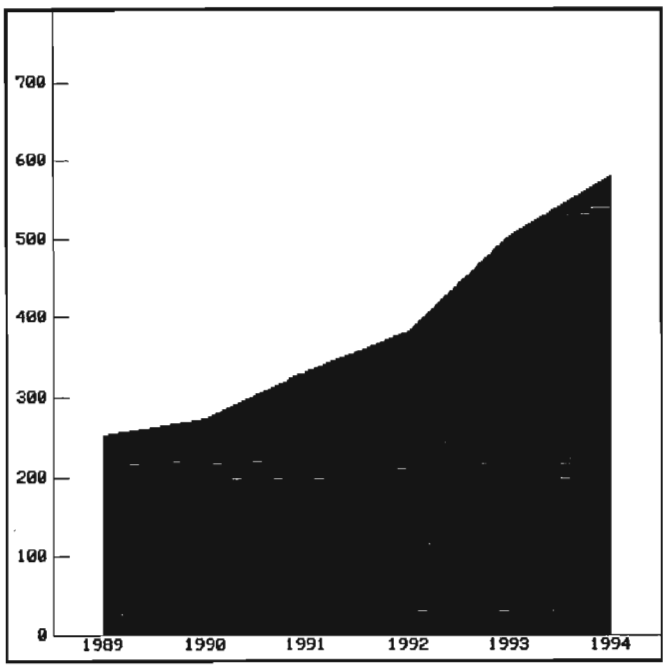
In our 1993 Report we said that we hoped 1994 would be a year of consolidation after the changes of the previous two years. While we have had rather more stability, the work has nevertheless continued to grow. The Group is becoming better known and National Office receives an ever increasing demand for our literature and advice from many sources.

This has been particularly noticeable from hospitals and other professionals, stemming from the setting up of Regional Information Services by many Health Authorities. Our record so far is that one maternity unit rang to request a parents pack and when asked how old was the baby the answer was three hours!

Along with this, regional co-ordinators are being asked to speak more and more about our work to groups of professionals, to training courses and parents groups and this is all helping to spread the word.

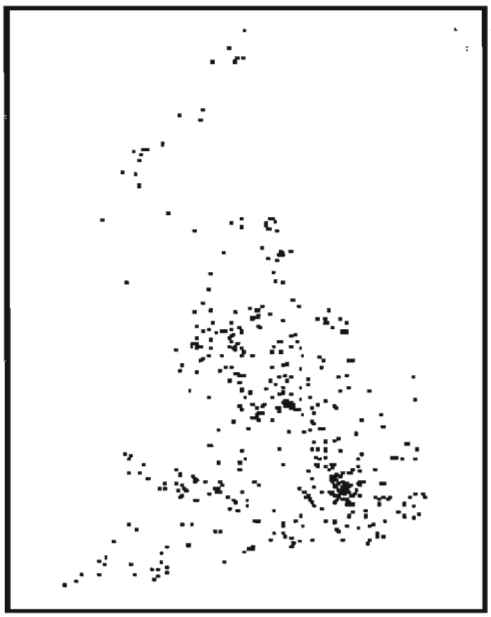
The whole issue of Down's Syndrome has been regularly in the public eye this year with the Brookside series featuring prominently a baby with Down's Syndrome, while there have been significant articles in the Times and the Daily Star about allegations that in provision of cardiac services, in some instances, the worth of children with Down's Syndrome is not always held in such high regard as "normal" babies. This is a matter of considerable concern to the Committee and we are currently asking members to document and supply their experiences to us on this and also foetal testing.

Membership of the Group has continued its steady rise as is shown by the graph below :



Year end membership figures

At the same time membership is now more evenly spread across the country as the map below illustrates:



Membership Distribution

Nevertheless it is still noticeable that clusters of members occur where there is an active regional co-ordinator, which indicates that there is still much to do before we can claim to be in touch with most families. We would like to thank all regional co-ordinators, hospital visitors and their helpers and supporters who have given their time and effort to maintaining and expanding the Group's activities at the local level. Also to those regional co-ordinators who regularly participate in the work of the Committee.

We have been active in supporting members in obtaining benefits to which they are entitled. Mary Clayton, our benefits contact has been successful in setting useful bench marks, particularly in the specialised area involving both Down's Syndrome and a heart condition. We have also been assisted in training and information through our membership of the Disability Alliance.

The Newsletter is an important medium for regular contact with members and between members, as most of the articles and stories are written by members themselves, providing heartening insights and information to other parents, often faced with similar difficulties and decisions themselves. The Newsletter also carries our name and message to related groups and professionals and our print run is ever increasing to meet these demands.

All this activity has to be managed, organised and administered. With the increasing workload of the past three years this has become a major task. By way of example the National Office in 1994 received and despatched over three thousand letters and nearly two thousand phone calls, as well as numerous other activities,

meetings, etc. This became quite impossible to manage on a voluntary basis and the Committee agreed that a part time paid position was required. We were able to achieve this with the assistance of a grant for two years from the British Heart Foundation and we are grateful for their support. This enabled us to appoint Penny Green as our first National Administrator. Both as our National Family Support Co-ordinator and now as the National Administrator, Penny is a tireless worker and organiser and has been a major influence in our current success.

We said in last years Report we had every expectation the Group would increase its income significantly in 1994 from the low point of £4,423 in 1993. This has currently been spectacularly realised with an income in 1994 of £14,389. As will be seen from the Annual Accounts this enabled us to meet all our expenditure and carry forward a surplus of £6,664 thus restoring our balances to a healthy level. This has been a tremendous effort by all concerned. Among some of the major fundraising events have been a football match against the Arsenal (not the first team!), bungey jumping, a medieval banquet, a bike ride over London bridges, head shaving and of course the London Marathon. Many individual donations from the members, relatives and friends have been much appreciated while the launch of our money-boxes, which we hope every member has in a prominent position in their homes, is beginning to pay dividends.

We are active in the Children's Heart Federation, a consortium of local and national groups concerned with the support of children with cardiac conditions. The CHF which provides a national focus and publicity for the work of all groups have developments planned in the coming year which should see the provision of a national helpline and increased fundraising resources and support for groups. Two of our children were among a party who, under the auspices of CHF, flew to Lapland at Christmas to meet Santa Claus.

The area where we have not been so successful is in persuading more members of the Group to become active in its work. As usual, the burden falls upon a small number of committed people, whom the membership are happy to allow to run matters. It is important for the health of the Group that more members with new ideas come forward to provide a regular injection into our work. We need more help at local level and fresh faces on the Committee if we are to build on our success to date.

Report of the Treasurer

It has been a marvellous year with record-breaking income in excess of £14,000. It will be seen that the income from events has increased more than five-fold. There have been many new and successful fundraising initiatives this year, organised both by the group and individual members, to whom we are particularly grateful. Donations have increased by more than fifty per cent and we are indebted to individual donors, particularly those making regular and significant contributions through the Give As You Earn scheme.

Expenditure in total is about twenty per cent higher than the previous year but this is consistent with the group increasing its activities. There is also now one part-time paid employee, the National Administrator , who runs the National Office. This was made possible by a grant from the British Heart Foundation.

The group's success financially this year needs to be maintained to enable us to improve the support for our families and to continue our other activities.

Income and Expenditure Account for the year ended 31st October 1994

	1994	1993
Income		
Donations	3,769	2,288
Events	8,012	1,368
Promotions	1,118	512
Interest receivable	127	240
Sundry income	697	15
Grants	666	-
Total income	14,389	4,423
Expenditure		
Family support	1,902	1,407
Overheads	5,823	5,021
Total expenditure	7,725	6,428
Surplus of income over expenditure/ (deficit of expenditure over income)	6,664	(2,005)
Transfer to family support fund	-	-
Transfer to research fund	-	-
Surplus/(deficit) for the year	6,664	(2,005)

Balance Sheet at 31st October 1994

	1994	1993
Accumulated Fund	**£**	**£**
Opening balance	7,536	9,541
Surplus/(deficit) for the year	6,664	(2,005)
	14,200	7,536
Family support fund	2,996	2,943
Research fund	1,088	1,051
	18,284	11,530
Employment of funds		
Cash at bank and in hand	17,578	12,056
Debtors	2,572	175
	20,150	12,231
Less current liabilities		
Creditors	1,866	701
Net current assets	18,284	11,530

These financial statements were approved by the executive committee on 8th April 1995 and were signed on its behalf by: John Spall (Chair) and Phil Thorn (Treasurer)

Speech Therapy for Natalie?

The following item is an extract from an article which appeared in The Guardian on March 28th this year.

Few parents are willing to battle as long and hard as Karen Dance to get their child speech therapy. Faced with East Sussex LEA's refusal to pay for what it says is "a health provision", she and her husband have finally taken their case to the Government's special needs tribunal, which has been available to parents since last September. "The authority has failed us and I feel very angy, " she says.

Her daughter Natalie, now aged five, has Down's Syndrome. A bright, happy child who is somehow holding her own in a mainstream primary school near Hastings, she understands everything, but is only able to use a few basic words. Most of her communication is by Makaton sign language.

Her mother believes she needs regular individual speech therapy, and that this should be at least one half-hour session a week with an appropriate therapist. Her claim is supported by a speech and language specialist at London's Royal Throat, Nose and Ear Hospital.

In December 1993 Natalie's needs were assessed for the first time. But it was not until this January that the LEA sent a final statement to her home. Her parents found it unacceptable, since it failed to mention Natalie's need for speech therapy, or that it would be provided.

Instead, the authority proposed that work on developing Natalie's speech and language should be undertaken by special needs and classroom teachers and ancillary staff, within a programme drawn up with the advice and support of the local therapy service. At a statutory meeting to discuss the statement, Natalie's parents, despite referring to the Lancashire Ruling, were told by the authority's special needs coordinator: "There was no procedure at present in East Sussex that would enable the education authority to pay for speech therapy."

Karen Dance has no quarrel with Natalie's school, Guestling Bradshaw Primary, which she says has been wonderful: some of the teachers, and even the dinner ladies, have gone on Makaton courses. But she is disturbed by the fact that between last July and this January Natalie had no speech therapy at all.

Natalie is now getting one session a month with a therapist, though she has to miss school to attend a centre. Yet this is outside any arrangements covered by the statement, and is only happening, Karen Dance believes, "because I made a fuss".

Peter Weston, East Sussex's special needs officer, says the authority is following the code of practice in stating that speech therapy is a health matter. He admits there can be a grey area where education and health authorities cannot agree, but says that in East Sussex the health authority has always accepted that speech therapy is their responsibilty. "What is needed is an integrated service under the direction of a therapist," he suggests. "Most children need a package which inhabits the whole of their week." He confirms that the authority will be opposing Natalie's parents' appeal.

Karen Dance is bitter about the authority's response. "I feel we've been lied to. Why don't they just say they haven't got enough money?" she says. "It would be easy not to fight, and avoid having sleepless nights. But I've got to try everything."

Since the article was published, the Dance family have been to the Tribunal, who found in favour of Natalie. East Sussex LEA has had to provide speech therapy resources in Natalie's school.

Written in memory of Joy Litster by her grandad

We would look in wonder
When things went all awry
You would only frown
Not once did we see you cry

You touched everyones heart
In your calm and courageous way
The way you fought on
Day after day after day

You tried so hard to stay with us
In each and every way
Yet through all your pain and suffering
A smile was never far away

You were with us in time for a moment
It seems like only a day
But you left us treasured memories
For these we would like to say

A joy it was to have known you
A joy you were to hold
What a joy it would have been
To have enjoyed you as we grow old

A joy it is to find you
In every lovely sunny day
A joy it is to see you
In everything that is warm and gay

A joy it is to remember
When we see the flowers in May
Of a very special person
Born to us on the third day

A joy it is to see a rose
Superstar is it's name
Grown with love in memory
Of a little girl who was the same
A SUPERSTAR

You are to us all forever OUR JOY. Thanks for the memories JOY

Letters to the Editor

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

Dear Editor,

When I took my daughter for her recent cardiac checkup, the consultant mentioned that I should never have her ears pierced for the same reasons that she'll need antibiotic cover for teeth extractions. I'd never heard of this before and thought it should be included in the newsletter to warn other parents.

Lynn Gouck
Glasgow

We contacted two cardiologists for the medical view on ear piercing, and thank them for their comments reproduced below:

From Dr KP Walsh, Consultant Paediatric Cardiologist at Alder Hey Children's Hospital, Liverpool

We generally advise that patients should not have their ears pierced due to the risk of bacteria getting into the blood stream as in dental procedures.

If a patient really did want to have their ears pierced then this procedure should be covered with prophylactic antibiotics.

From Dr JV de Giovanni, Consultant Paediatric Cardiologist at Birmingham Children's Hospital

You quite rightly mentioned that ear piercing, similar to that of extraction, poses a possibility of bacteraemia and therefore the possibility of bacterial endocarditis. It is important to put this in a reasonable context and such procedures are quite safe so long as they are performed under sterile conditions and so long as appropriate antibiotics are given to cover the procedures. The reality is that we do take teeth out if we have to and there is no reason why we should not pierce ears if this means a lot to the child. There are very occasional reported cases of endocarditis following such procedures but, with the appropriate precautions, I am quite sure that this can be almost completely abolished.

I would therefore advise the parents firstly, to go to a reputable place where sterility of instruments is guaranteed, secondly that topical antiseptics are used until the tunnel has healed and, thirdly, if there is any evidence of inflammation ie. redness or discharge, to go to their general practitioner for a course of antibiotics which should cover staphylococcal infections.

Dear Editor and Down's Heart Group Members,

I am writing to give you an update of my son Thomas's progress. For any of you who don't know of us, his name is Tom Pow, and he was born with Down's Syndrome and also a severe heart defect. As a baby he was always quite weak but he managed to cope with all the illnesses that he picked up. The doctors always gave us a bleak outlook, saying that Tom might only live until he was three years old.

From day one I did not find the consultant approachable, but as he was the specialist, I felt he was the better judge of Tom's outlook, which continued to be very bleak. **Inoperable** is the word he used that sticks in my mind.

In July 1994 I met some parents whose child had been given the same outlook, but who decided to seek a second opinion. Their child had surgery and is now fine.

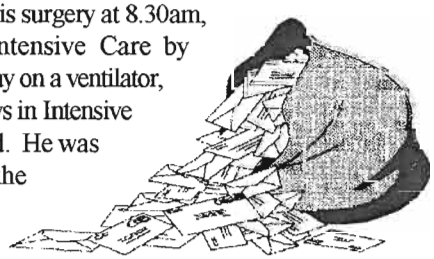
I knew that Tom's chances were fairly slim as he was by now eight years old, and his lung damage had become worse as he got older. However, I thought it was worth a shot. We therefore went to Harefield last September for a second opinion. I had prepared a long list of questions to ask the consultant, but did not need to ask any of them. He told me everything I needed to know, and gave me the first glimmer of hope in eight years.

Tom was offered an angiogram, which would give them an accurate recording of the pressures in his lungs, which would enable them to determine if an operation was possible. He had the angiogram in January 1995, and it was decided that he was a candidate for corrective surgery. Because of the high pressures the risks were higher, and he was given only a 50% chance of coming through surgery.

The hospital staff were wonderful. They have a team of family support workers, Tom's was called Tracy. She went through everything with me and told me to go home and think it through. I had already made my decision, but decided to go home and think some more. The one thing that kept coming into my head was that it was 100% certain that without the operation Tom would never grow up, but if I went for the surgery there was a 50% chance that he would.

On April 28th this year Tom went into Harefield for his surgery. The staff were just wonderful. The surgeon came to see me the night before, and explained the whole procedure to me. Nothing was too much trouble.

Tom went down for his surgery at 8.30am, and was back in Intensive Care by 1.45pm. He spent a day on a ventilator, and a further three days in Intensive Care to be monitored. He was then moved on to the ward, and came home a week later.



He has a slightly leaky valve, but they hope that this will correct itself in time.

My son is 'pink' for the first time in eight years, and I owe it all to Harefield, who see past the Down's Syndrome and realise that every child deserves a chance in life.

If any other members of the Down's Heart Group have been given a bleak outlook, I would advise them to seek a second opinion. You have nothing to lose, and an awful lot to gain. I know that things aren't going to be easy bringing Thomas up, but at last he has the chance that I and his brothers always believed he deserved.

Lorraine Pow
South Oxhey, Watford

(Sadly, for the majority of children with the AV Canal defect,by this age damage to the lungs would make surgery inadvisable , but as this letter and Maria's Story earlier shows, it is not always the case. - Editor)

Can You Help?

In our last issue we reproduced an article from the Sunday Times of October 23rd last year, reporting on babies with Down's Syndrome missing out on heart surgery. This and a number of other media items prompted the Committee to ask for members to write in with their experiences relating to three key areas. Those replies we recieved showed an interesting mix of experience across the country, but we would still like to hear from more of you.

Please do let us know if you have any experience, either positive **or** negative of:

Pre-natal Diagnosis

Late Diagnosis of your childs heart problem

Conflicting opinions regarding the decision for or against surgery, or referral too late for surgery

Your letters will of course be treated in the strictest confidence and there will be no communication of any content to a hospital or professional mentioned therein, unless it is with your prior permission or in such a way as to guarantee anonimity.

Change of Address?

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

Notification of Change of Address

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

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

Postcode: .....
Telephone: .....

Send to: Down's Heart Group,