



DOWN'S
HEART
GROUP

NEWSLETTER

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3




Rosie

Committee Contacts


Legal Advisor

Brian Auld




Vice-Chairperson

Sheila Forsythe



Chairperson, Newsletter & Family Support

Penny Green



Secretary

Gill McLorinan



Treasurer



Founder


Linda Walsh

Who Do I Contact?

Enquiries of a general nature not from families should be addressed to the Secretary. Requests for information about the work of the group from students etc. should be sent to the Secretary, enclosing an sae. for the reply.

Requests for support and information for families should be sent to the relevant Regional Co-ordinator as shown on pages 4 and 5, or to the Family Support Co-ordinator.

Donations may be sent direct to the Treasurer.

Correspondence which does not fall into any of these categories should be addressed to the main office: Down's Heart Group, 

For more general information about Down's Syndrome not related to heart defects, you might like to contact:

Down's Syndrome Association
153-155 Mitcham Road
Tooting
LONDON
SW17 9PG
Tel: 081 682 4001

Scottish Down's Syndrome
Association
158/160 Balgreen Road
EDINBURGH
Lothian
EH11 3AU
Tel: 031 313 4225

Down's Syndrome Association
of Ireland
27 South William Street
DUBLIN 2
EIRE
Tel: 010 353 1 6793322

Chairperson's Report

Well here we are with another newsletter, and an even greater distribution than last time due to an increase in membership. Many of you will have seen our article in the Down's Syndrome Association newsletter at the end of December, and I'm glad to be able to report that it had a good response. We have had many enquiries from families who read the item, and many have applied for membership of the Down's Heart Group, so welcome to all the newcomers. It is particularly nice to see several families with older children joining the group as the majority of our membership has previously been from families of children under ten.

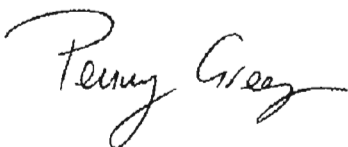
We need to continue to increase awareness of the Down's Heart Group so that more families know where to come for support and information, and every one of you can help other families by letting appropriate people you come into contact with, know about the Down's Heart Group. With this in mind, all members will find a leaflet enclosed with their newsletter. Please pass this on to someone who might benefit from knowing about us: Paediatrician, Health Visitor, Social Worker, Portage Teacher, GP, Special Care Baby Unit, local support group, etc. the list is endless. In this way we can increase awareness of the group and what it has to offer, and the more members we have the better the support we can provide and the more possibility of furthering research projects. PLEASE REMEMBER TO PASS THE LEAFLET ON.

Whilst on the subject of membership, you may recall that following our registration as a charity, it was necessary to ask everyone on the mailing list to confirm their wish to be a member of the Down's Heart Group. A reminder was sent out with the last newsletter, but 25% of families failed to reply. We had said that anyone not returning the form would be removed from our records, but as it was such a large number, and we didn't want to lose valuable members, we tried contacting a few families. From this it became clear that the vast majority were still very interested and the lack of response was due to oversight, hence, we have examined all the records, and where it appears that a family have previously been interested enough to supply a certain amount of information, we have assumed that they do still wish to be members, unless they notify us to the contrary.

As a result of all this, some of you will again have forms and questionnaires included with this newsletter. I'm sure you are probably fed up of receiving these, but we really do need this information. We now have quite a comprehensive database of information which is proving very valuable in establishing contacts for parents and has already been used to identify appropriate families for the research project being undertaken at St Mary's, Paddington. (If you were one of the families, we wrote to you about a year ago, asking for your help.) However, the value of the database is greatly diminished if there are lots of pieces of information missing relating to a particular child, such as their date of birth or when they had surgery. So PLEASE TAKE THE TIME TO FILL IN ANY FORMS you received with this newsletter, once we have the information we won't need to trouble you again.

On a different theme, have you still got your children's Christmas paintings? If so, please pop them in an envelope and send them to our Secretary, Gill McLorinan. They could be the winning entry in our Christmas Card Design Competition. (see page 16)

Finally, a note for your diary. This years AGM will be held on Saturday June 19th at Thornbury, 12 miles north of Bristol. Further details will be sent to all members nearer the time, but do make a note of the date now. I look forward to meeting many of you on the day.



Regional Contacts

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

Regional Co-ordinator
Lindsay Wharam

Deputy Regional Co-ordinator
Nicola Desmond



East Midlands (Derby, Leics, Notts & N.E. Northants)

Regional Co-ordinator
Sarah Smith



Ireland (N.Ireland & Eire)

Regional Co-ordinator
Rosina Brierley



London Northern (Beds, Berks, Bucks, Essex, Herts, Oxon, S.W. Northants & N. London)

Regional Co-ordinator
Morag Malvern



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

Regional Co-ordinator
Katie Spall

Deputy Regional Co-ordinator
Linda Crozier



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

Regional Co-ordinator
Sandra Welsh

Deputy Regional Co-ordinator
Sally Hardman



North West (Anglesey, Cheshire, Clwyd, Gtr Manchester, Gwynedd, High Peak, Lancs & Merseyside)

Regional Co-ordinator


Mike Halpin



Scotland (Mainland & Islands)

Regional Co-ordinator


Lynn Gouck



South West (Avon, Cornwall, Devon, Dyfed, Glam, Gloucs, Gwent, Powys, Somerset & N.W. Wilts)

Regional Co-ordinator


Sheila Forsythe



Wessex (Channel Islands, Dorset, Hants, Isle of Wight & S.E. Wilts)

Southampton Hospital Contact

Vickie Richardson



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

Regional Co-ordinator


Pat Mitchell

Deputy Regional Co-ordinator

Noreen Hodgkinson

Birmingham Hospital Contact

Lynne Holden



Yorkshire & Humberside (Humberside, N. Yorks, S. Yorks & W. Yorks)

Regional Co-ordinator

Linda Watcham



Wessex Region - Hospital Contact

Although we are still without a Co-ordinator for the Wessex region, we do now have a Mum who has become our contact for Southampton Hospital, and who is making regular visits. She volunteered after reading about Lynne Holden, our contact at Birmingham, in the last newsletter, and she has written the following item by way of an introduction to all those members in the area.

My name is Vickie Richardson, your contact for the Southampton area, if you need me, I can be reached on 0489 787805.

First a little bit about my family. My husband is Brian, and we have four sons (couldn't get the recipe changed), Rory who is 33, Dean 31, Peter 20 and Michael 18. Michael has Down's Syndrome with an ASD (atrial septal defect) which he is coping with quite well, although he has the usual respiratory related illnesses. He was also one of those who had severe sleep disorders including sleep apnea, which led to exciting nights of jumping in and out of bed when he 'forgot to breathe'. Still, he and we made it through the years, and today he is a very happy, much loved young man.

He is a typical teenager who enjoys his own space, and is lucky enough to have his own bedroom with his T.V., video, stereo etc. He loves drawing and painting - he is quite good too, having had pictures chosen for the cover of Mencap's newsletter amongst other things. He also likes drawing on his computer, nothing intricate, but the drawings are recognisable. He doesn't talk much but can make his needs known when it suits him! We think he could communicate more, if he wanted to - the monkey!

We don't live far from Southampton Hospital, and I have established contacts at the Paediatric Cardiology Unit, in conjunction with the Wessex Children's Heart Circle. We liaise with the caring staff and chat with the Mum's and Dad's of children undergoing heart operations. The ward sister, Jenny Evans, has my name and telephone number and will contact me should a family wish her to do so. Hopefully I can be of help to them - perhaps as someone to share their fears, knowing I understand their feelings on a more personal basis.

I visit on a regular basis and it is very encouraging to see how much support is offered to the family in hospital, I hope that I will be able to add to it. If your child is coming in to Southampton at any time, or you are there and miss my visits but would like a bit of support, please give me a ring, my number is at the top of the page.

*Vickie Richardson
Southampton*

(Many thanks are due to Angela Caxon of Wessex Children's Heart Circle, for introducing Vickie to many of the staff on the unit and for a great deal of help and encouragement. It's good to see support groups working together for the benefit of the families. - Editor)

Give as You Earn

The Down's Heart Group is now registered with the Give as You Earn campaign, after a request from someone wanting to make a regular donation.

Under the scheme, an employer deducts a nominated amount from an employee's gross monthly pay (before tax is calculated) and submits this sum to Give as You Earn. There is a 5% administration fee (minimum 25p, maximum £2) deducted from the employee's contribution, but many employers opt to pay this charge themselves, and some even opt to match their employee's donations.

If you or someone you know is interested in donating money in this way, it is worth asking your employer if they operate the Give as You Earn scheme. If not, there may be sufficient interest from colleagues to encourage the bosses to find out more. They can get further details by ringing Give as You Earn on 0892 512244.

For anyone wishing to donate to the Down's Heart Group, please quote our registered Give as You Earn number which is 000126740.

Jonathan - A Fathers View

As I write this article, I will first detail it's ending, as the ending has a significant effect upon the way in which I view the beginning and intermediate events, and so greatly colours my view of events that perhaps my descriptions will not make sense otherwise. I am the father of a two year old boy, a very energetic, happy, capable bundle of destruction and mayhem like most two year old boys. That I am the parent of this healthy, happy child is the happy ending to the story... this has not always been the case.

On the morning of 23rd December 1989, Jonathan Paul was born. He arrived following a very normal labour and delivery, and because of his large mop of almost ginger (at that time) hair looked just like my grandfather. We were both overjoyed and had no idea that there were any problems, and following the introductions and euphoria that comes with the birth of a new child, I went home to tell his grandparents and twenty-one month old sister all about him. When I returned to the maternity hospital in Cambridge that evening with my daughter and In-Laws I then got my first indication that something might be wrong - Rachel (my wife) was still in the delivery suite and wanted to see me alone first. Rachel had already been told by the paediatrician that Jonathan had Down's Syndrome, and she, in a devastated state, told me.

We had had no previous indication that this might be likely, Rachel was too young for the tests to detect this to have been carried out, and the pregnancy was quite normal. The paediatrician came to see us both then and explained that a blood test was to be carried out in the new year, and said that it was possible that Jonathan was normal and that everything was O.K. I suppose then that I clung to these words and refused to believe for a while that I had a handicapped son. It must be said that Rachel already knew that Jonathan was handicapped then, it took me a little longer. Rachel being a nurse was aware that heart defects are fairly common in Down's Syndrome Children and had already asked about the state of his heart and internal organs, and had received assurances that "He was fine".

On the morning of Christmas Eve, a little over twenty-four hours after the birth, Jonathan and Rachel were sent home. I suppose that my final acceptance of the child as mine to keep and cherish came early in the new year when we took him back to Cambridge for the blood test to confirm or deny his Down's Syndrome. The blood sample was taken by the doctor on the Special Care Baby Unit, it was my first real view of a ward full of frighteningly sick children, I was exceedingly happy to be simply taking my child home again with me - he was our son, and he was already an integral part of our family. Not

surprisingly a few days later our GP came to give us the news that Jonathan had indeed got Down's Syndrome. He also told us about a delightful little girl, now seven years old, also with Down's Syndrome who lives very close to us and with who's family we are now good friends.

I suppose that the next few weeks are a blur (as are the first few weeks of any new child). Jonathan did well at all of the normal things that all small babies do, feeding, sleeping, nappies etc... we got quite settled and started to find out about Down's Syndrome properly, reading all the books, and more importantly talking to other parents of Down's Syndrome children. This was particularly important as we quickly learnt that as with 'normal' children - no two Down's children are alike, and as with most parents - no two sets of parents with Down's children are alike, and therefore all advice, and statements about the progress of your special child should be treated with the same kind of care as any statements or advice are when directed towards any other child.

It came as an awful shock when the second bombshell dropped. Rachel had taken Jonathan for his six week routine ultrasound check at Cambridge, and they had detected an abnormality on an ultrasound scan of his heart. At that time the cardiologist could not really detect the extent of the damage, but thought that (as it turned out to be) the defect was serious. Jonathan was to see a visiting specialist from Great Ormond Street at some time in the near future. This was a real shock, we were at that time unable to make a good judgement of Jonathan's condition and many black thoughts went through our minds. Luckily Jonathan was able to take the appointment incorrectly sent to the young son of some friends of ours whose AVSD associated with his Down's had been repaired some months earlier - we were pretty quickly seen by a Cardiologist from GOS.

This was now one of the blackest periods of the run up to Jonathan's operation, he was a small baby and showing classic signs of a heart defect - very clammy on feeding, and prone to going quite blue at the extremities when bathed or cold. The cardiologist from GOS simply said that she thought that Jonathan's problems were indeed serious and that an appointment should be sent soon for us to actually go down to GOS to have a set of tests taken "on instruments that they knew and trusted". Our GP was also quite doubtful about Jonathan's ability to survive and tried to tell us that Jonathan might not survive to the operation. Above all we were being asked if we actually wanted to go through with what might be long and complicated surgery with Jonathan - "because, after all, he doesn't have the same potential as a normal child does he?". It was at this point that we decided that whatever it

took we would fight for any chance that could be given to our son.

The first consultation at Great Ormond Street Hospital was traumatic, many tests were carried out, the nature of the diagnostic ability of these tests we were not really familiar with at the time. We were asked again if we wished to continue with work to repair Jonathan's heart - we were able to give emphatically positive answers to this question by now. By the end of the day we had heard several conflicting diagnoses, summed up by a late interview with the Professor of Cardiology who thought that his condition was not as critical as originally thought and suggested that we should keep a close eye on his condition and review him frequently with a view to possibly operating at around six to eight months.

It was during the time that followed that we began to really investigate the implications of what was happening to our child. Things did not look too bright initially. We were in contact with the Down's Heart Group at about this time and were sent a few newsletters over a period. It was unfortunate that the literature from the Down's Heart Group was unhelpful to us at that time as most accounts of children who had heart surgery, had died. We began to get quite down - then we decided that it would perhaps be better to stop reading the literature from the Down's Heart Group - that helped a lot.

Jonathan went through the summer quite happily (as did the rest of us), he went through the autumn, he went into the winter..... It was about now that we began to notice a difference between what we were told would happen and what actually did. Jonathan had NO recurrent chest infections, he had only one generalised infection (but so bad as to require admission to hospital). He had colds and sniffles indeed, but we seldom bothered taking him to the GP, hence he had only one course of antibiotics during these months (for the infection) and consequently his own natural immune system was not being suppressed by antibiotics and seemed to be able to cope quite well with whatever was thrown at it. We were very fortunate in this. A cardiac catheter was performed, Jonathan's diagnosis was finally confirmed, that is,

a complete AVSD. Spring came.

Now the problems started to really show, his weight gain was poor, Jonathan's favourite recreation (being taken swimming) had to be restricted as he would turn blue very quickly in the water. Trips to Great Ormond Street became more frequent, however we were told that his heart seemed to be bearing up fairly well with it's simple support of diuretics, and that his condition was not seriously deteriorating, but they would like to get him in soon to fix the defect as he was not going to grow much more...



Eventually the decision was taken to admit Jonathan to GOS for surgery to correct his AVSD. Plans were laid, Grandparents booked time off work and replanned schedules to enable them to be around to look after our daughter. I suspended my work to enable me to have the time off to be at the hospital with Rachel and Jonathan and the day for admission came. We took Jonathan to GOS a couple of days before he was scheduled to be operated upon in order that they might do preliminary tests on him. The first day on the ward was our introduction to what was to become a great mystery and adventure to us during all of our dealings with GOS - the food trolley, many happy hours were spent trying

to 1) identify the contents of this trolley and 2) get Jonathan to eat it.

This first day was also to be Jonathan's introduction to the greatest horror and evil of all of his dealings with GOS - the blood sample. By the end of this first day Jonathan had a little snuffle, but no one seemed to be concerned by it so we took him (and ourselves) round the corner to the pizza restaurant to get some "real" food in both him and us! I came home, Rachel stayed in thoughtfully provided hospital accommodation - I got a good nights sleep and a cuddle from our daughter in the morning - Rachel got no sleep and no breakfast.

The second day was horrific, we were "prepared" for the operation to come. We had the introductory talk from the ward sister, we had the preparatory talk from the consultant, and we had the tour of Intensive Care which was the worst part of it, anyone who does not have to go through this is lucky. (In hindsight

however, this was not the worst bit of the final procedure by a long way). Then the Grandparents came in, bringing our daughter, and a very tearful goodbye and good luck was said. Last thing in the evening before everyone went to bed was the round of the anaesthetist, he came to check Jonathan over before prescribing the medication for the night and the following morning - he refused to allow the operation to proceed! Jonathan's snuffle was too bad to risk the anaesthetic! We were sent home!

The next few days were a blur, people rang to see how the operation had gone, were surprised when we answered the phone, were disbelieving when we told them what had happened. Rachel's parents went home and re-started work early, I went back and tried to figure out how I would hold my projects steady for another month until the next appointment came and then suspend them again...(my employer turned out in the end to be very, very, patient and sympathetic).

We got the appointment for Jonathan's next operation through, just after Easter was to be the date. On the morning of Good Friday we were to go to visit Rachel's parents, I had been feeling off colour for a while with a strange pain in my back which I attributed to lifting some heavy equipment at work. In the shower however, I noticed a strange rash starting at my navel and going round (clockwise) to my spine - I asked Rachel about it. The reaction was spectacular!! The GP confirmed shingles. Shingles is caused by the same virus as Chicken Pox and is infectious. The following Tuesday we rang and cancelled Jonathan's appointment. We then rang everyone else and told them that the operation was off again, everyone cancelled their plans again and for some reason I was not allowed to go into work for a fortnight.... the children never did get it.

We had the third appointment through. This time we did not tell so many people. The morning of Jonathan's admission came and all seemed well. Everything and everyone was loaded into the car and we set off for London. By the time we got to Great Ormond Street Jonathan was screaming and very, very hot. On the ward the Sister managed a record time for calling a Doctor, getting Calpol prescribed, finding a bottle, breaking the seal, and administering a very large dose to a very unhappy boy. It was some kind of throat and ear infection. We went home with some antibiotics. No one was surprised. We were told that the record was four cancellations we had to fail five times to beat it!

When the fourth appointment came through we took drastic measures, a week before the hospital admission was due we withdrew Hannah from play-school, I started to work from home and no one went out. We

ate most of the contents of the freezer and as little as possible contact with the outside world was undertaken. We arranged for Jonathan to be admitted on the day before his operation.

In July 1991 we went into Great Ormond Street for the last admission for Jonathan's AVSD repair. Tests showed Jonathan to be in good condition and the operation was confirmed for the following morning. The morning came and Jonathan was given a 'pre-med' When the time came for Jonathan to be taken to the operating theatre, I carried him down and handed him over to the anaesthetist. I suppose that it is difficult to say how we reacted during the period during Jonathan's operation, we had some breakfast and then went and sat quietly for a while and read some passages from our Bibles, quiet time and familiar strengthening words help a lot.

I suppose that it was soon time to return to the ward and check on the progress of the operation, we were told that his operation had been completed and that we could go down onto Intensive Care and see him. We have since discussed our first reactions and agree about the first impression, we didn't really see all of the wires and tubes at first, all we saw was a little foot sticking out from under the edge of a blanket. It was Jonathan's and it was PINK! Jonathan was attached to more wires and tubes than you can possibly imagine, though we had been prepared for all of the procedures that would be associated with intensive care, we were not prepared for the fact that he actually looked well for the first time in many months. Jonathan was pink all over.

In the period that immediately followed we learned from the surgical team that they were very pleased with the result of their work, in fact they were not prepared to say at that time, but I am sure that they suspected - they had achieved a 98% complete repair, Jonathan's heart was in good shape.

We now had nearly a week of Jonathan in Intensive Care, he was slow but steady for a couple of days in coming off of the ventilator. It was then that we had our first set-back, one of his lungs collapsed. Looking back now we were devastated, but from the reactions of the staff it was just one of those things which happens, they expected him to recover, but he just took a little longer to leave Intensive Care.

On leaving intensive care, Jonathan was sent to a high dependency ward for a few days. It was on this ward that he started eating again. We were feeding him down a Naso-Gastric tube up until then, but one morning he pulled the tube out, there was then much trauma in putting it back only for him to pull it out again. We tried a bottle and a spoon - it worked fine!

We were soon transferred back to the 'Normal' ward.

Within a very short time of Jonathan being transferred back to the normal ward, Jonathan developed a very nasty infection in the wound on his chest, eventually we made enough fuss to have a Doctor look at it. There followed a very nasty procedure where the top part of Jonathan's wound was reopened, the puss drained away and a sample taken. Jonathan was to spend several days with the wound being dressed frequently and packed with gauze to keep it open whilst it healed 'from the bottom up'.

A friend of ours turned up for a visit soon after this and we left Jonathan asleep in his cot whilst we went for a wander around the hospital and took our friend to see our accommodation in a Sick Children's Trust House. On returning to the ward we noticed a child partitioned off in a side ward - he looked a lot like Jonathan! He was Jonathan - a team of nurses descended upon us and bundled all three of us into the side ward. There we were bundled into plastic gowns, masks and gloves, swabs were taken from our noses and throats and we were told that Jonathan had a very serious infection and they were closing the unit.

There then followed the blackest period of our stay in GOS. Jonathan was given very high dose antibiotics through a line which had been inserted in his foot. The antibiotics caused almost continuous diarrhoea, whilst he continued to drink, Jonathan was obviously getting very dehydrated and for several days whilst we protested about his obviously deteriorating condition, he was left for us to continuously change nappies. Finally we managed to get doctors to look at him again and they confirmed that he was very dehydrated. We were told that Jonathan was going to need a further operation to put a 'Central line' in his neck so that he could be given fluids to correct his condition. It was at this point that I lost my temper, explaining as rationally as I could that the post operative care had resulted in both the infection and the dehydration and that I did not care for further intervention to be performed as I judged the risk of further complications due to post operative care to be far too great. With great self control we both explained that with suitable medical and nursing care, it should be possible to re-hydrate Jonathan using the line in his foot - it was, and we were treated with great respect by the medical and nursing teams after this.

Just over three weeks after his admission Jonathan was sent home. It was obvious to us that he was much improved, but we never dared to really face up to how much. Our first post-operative check showed Jonathan to be improving greatly, and it was suggested that we slowly cut down his diuretic support upon

which he had depended since two months old. The appointment also took all day! There were so many people to see....

At the second post operative check we really got the final indication of things to come. No tests, X-Rays or ECG's were taken, the Cardiologist simply looked at him, pronounced him to be in excellent condition, and a wonderful investment for the time and effort that it had taken to get him there. She suggested that we take him back next year for a check up, April 1992.

Post Script: Due to delays in sending this article to publication April 1992 is now long gone, as is 1992. The two year old boy described at the beginning of this article is now three and an expert at mayhem and destruction. He is extremely robust and extremely well, though he did have a bout of pneumonia earlier on in 1992. He came through smiling. The surgery seems to have left him with no discernable physical after effects whatsoever, he is very much into the physical stuff - climbing, running, playing with balls, rough and tumble.... It is time now to think about other things, like school!

*Paul Smith
Bishops Stortford*

Thank You

We don't normally include 'thank you's' in the newsletter as there would be so many, and it's very embarrassing if one is overlooked, but I'm sure you'll all agree that this gentleman deserves a mention.

In 1990, Martin Wehlan was asked to purchase some Down's Heart Group Christmas cards. Not only did he agree, but he also offered to take them to work and try to sell some - he sold 600. In 1991, he volunteered to do the same again, this time selling 1700.

Last year, Martin not only increased his sales to 2900, but also told his managers what he was doing, and they very generously donated £377 to match the sum raised from Martin's sales.

Grateful thanks go to James Capel & Co. Ltd. but more importantly to Martin for his wonderful support of our efforts, especially as he is not a group member and does not have a child with Down's Syndrome.

(Martin tells me that he hopes to be able to beat his sales record again next year. - Editor)

Martin's Story

Martin and his twin sister Caroline were born by Caesarian section at St Thomas' Hospital London on 27th February 1975, Martin is a minute younger than Caroline. Their elder brothers were eleven and five, and their sister nearly three at the time. Their father was a doctor working in Radiology then, and I was a part-time G.P. Martin was not thought to have a heart defect at birth, but by the time he was a week old one was suspected. This was because of his colour and 'grey' attacks.

I cannot remember what investigations were done, but I know that he was seen by a cardiologist. I did not want him to have any invasive investigations or surgery, but in retrospect I cannot remember why I was so adamant about this. I had worked at the Brompton Hospital for a while and seen quite a few babies after cardiac surgery, and it also seemed very important that I should be around to look after him, and I didn't want him to outlive me!

Martin could not suckle and stayed in hospital to be tube fed for three weeks. It was suggested that he should be fostered, but I did not think it would be very good for the other children's morale to think that you simply got rid of a child if it wasn't up to scratch. He was very ill with an infection when he first came home, and failed to thrive for months - he gained 2lbs in the first five months. He vomited persistently.

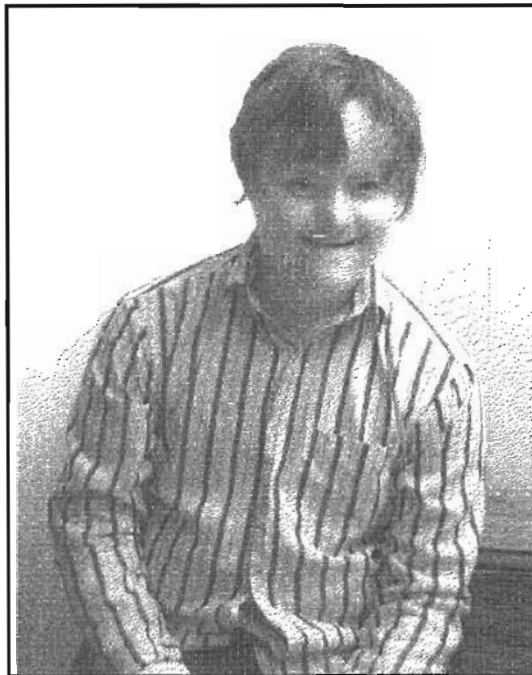
I think he went back to St Thomas' to see the cardiologist when he was about one. It was known by then that he had a VSD, but not if there were any other lesions like an AV Canal. I think he went to see a paediatrician on a couple of occasions, but we decided there was no point in going again. As far as I can remember, the only prognosis given was that Martin was unlikely to reach adult life.

Martin went to playgroup with his sister, then to a day-school for children with severe learning difficulties. When he was twelve he went to Bradstow which is a boarding school for the same group of children. He became increasingly deaf, so I took him to an ENT consultant about four years ago. Grommets were recommended but he was referred to Dr Shinebourne at the Brompton for an assessment of anaesthetic risk. This was estimated to be about 3% so I decided

against the operation.

He had an echo, ECG and chest x-ray at the Brompton which confirmed that he has a VSD and pulmonary hypertension. It also showed that he must have been born with pulmonary hypertension, so surgery would never have been possible anyway.

He now gets blue very easily, and we think he has had chest pain if he hurries for years (he stops and says "Tummy ache"). He has only ever spent one night in hospital apart from when he was born, and has had very few ordinary illnesses like chest infections and I have hardly ever given him antibiotics.



His present school have been very supportive, although I think that the staff there have found it quite difficult to accept that he is going to get worse, that he might die suddenly, and that there is not anything to be done about it. I have told them that I want him to be allowed to do anything he wants to do like swimming, but that they have to give him the benefit of the doubt if he feels he cannot manage something.

I do not know how much Martin understands about his condition. He knows he has a 'bad heart' and recently has started to say so if he doesn't want to do something! His favourite television programme is Casualty and he clearly thinks attending the hospital is some sort of extension of this. He is aware of death because his father and uncle have died, but I don't know what he thinks it is. I do not think he could understand any discussion about his own death, and I cannot see that it would benefit him. He lives very much in the present and his main and favourite occupation is watching videos.

He is due to leave school when he is nineteen in just over a year. I hope that he will be able to live near here in some form of sheltered accommodation or hostel. It is difficult having him so far away now (Bradstow is in Broadstairs, about eighty miles from London.)

*Penny Croft
London*

Harry's Story

Harry was born on the 28th January 1991 in Southmead Hospital, Bristol. Tony and I were delighted to have a baby brother for Alice and a son to follow in his fathers sporting footsteps. Almost immediately we noticed Harry's funny shaped eyes, and when the midwives left us, we discussed the possibility of Down's Syndrome. On the following morning we approached the paediatrician who confirmed this possibility. From that moment we knew.

I think Tony and I surprised ourselves by how easily we accepted the fact that Harry had Down's Syndrome. We counted our blessings that he didn't have any heart defects, not realising that some defects would not necessarily be identifiable until later. Harry looked healthy and pink.

It wasn't until Harry's six week checkup at the local GP's that a murmur was heard. We were expecting an appointment at the Children's Hospital for the heart scan at any time, but we still weren't particularly concerned. Three weeks later Harry had a cold and he became congested, his breathing became fast and laboured. We called a Doctor out, and he reassured us that it was only catarrh and that using steam would help to loosen it.

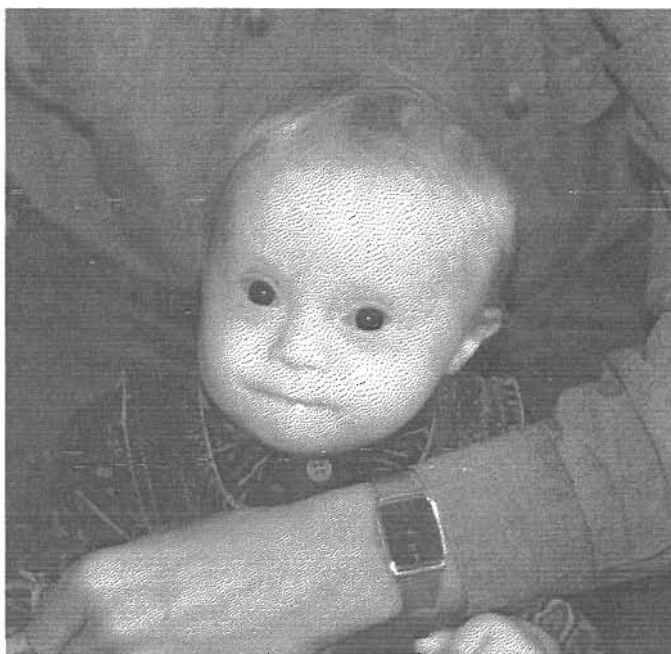
It was five days later on a routine visit to Frenchay Hospital that the first great concern was shown over Harry's heart. He was sent for immediate x-rays and an appointment for the heart scan was made for the following day. We were shown the x-rays, and Dr Roberts pointed out that the heart was enlarged, as was the liver, and that fluid was building up on Harry's lungs. He prescribed frusemide and warned us that Harry might have a hole in his heart.

At the Children's Hospital we met Dr Joffe, who, after the scan, confirmed that Harry had a VSD and a small ASD. He explained that Harry needed a cardiac catheter to give them more details which would help them decide what to do. This was carried out a few weeks later, and our worst fears were confirmed, Harry needed surgery to patch the VSD and to stitch the ASD.

On the 14th August we met Mr Wisheart, a surgeon

from Bristol Royal Infirmary, to discuss the operation. He drew diagrams to show the problem and explain why Harry needed surgery sooner rather than later if permanent damage was to be avoided. He was also very honest about the risks, but although Tony and I were given the choice of whether they should operate or not, there was no real choice for Harry's sake.

We were only given a few days notice before the operation. It was difficult trying to enjoy having Harry at home with us whilst dreading what lay ahead, but once we arrived at BRI it became a little easier. The doctors and nurses were all very reassuring and supportive.



Harry three months after surgery

On the morning of the operation, Harry awoke as usual at about 6am. He was very happy and cheerful, and I felt so guilty knowing what he was so soon to go through. Tony arrived at 7am to wait with me, and the porter came at 8.30am. Thankfully, Harry was asleep by then, and the nursery nurse carried him down to the operating theatre as neither Tony nor I felt we could.

We quickly left the hospital and headed for home, collecting an inflatable castle on the way. We had decided to hire it for the day of the operation and to invite friends and their children to come and

play with Alice. We wanted to have her there with us, but didn't know if we could cope with the demands of a lively two and a half year old when our thoughts were elsewhere. It may seem a little tasteless to some - having a 'party' whilst Harry was undergoing open heart surgery, but we needed something to keep us occupied.

Naturally it was a tremendously tense and stressful morning. Every time the phone rang our hearts missed a beat thinking it might be the hospital with bad news. We had been told to ring between 1.30pm and 2pm, but when the time arrived we hesitated, and it was about 1.50pm before we rang and heard that Harry had just come back on to the ward.

The relief at hearing those words was incredible; I burst into tears. It was as though a great weight had

been lifted from my shoulders, even though Harry still had a long way to go to make a full recovery.

On the way back to the hospital, Tony and I wondered how we would feel seeing Harry with so many tubes and wires attached to him. It was a frightening moment walking into the Intensive Care Unit, but we were so relieved to see Harry alive and be able to touch him, that we really didn't take much notice of anything else. In some ways it is worse now, looking back at the photos than when it was actually happening.

Harry made steady progress and was only in ITU for six days, although there was a slight set back on the fifth day when his temperature shot up, but with plenty of ice and paracetamol it soon came down and eventually stabilised. He was transferred back to the nursery and after another six days we brought him home. We could hardly believe that he had recovered

so quickly, it was incredible to think that it was all over.

It is now six months since Harry had his operation and he has recently stopped taking his diuretics. His breathing is very relaxed and he has put on weight. Harry has recovered completely from his ordeal - in fact I think he got over it sooner than we did. We owe a great deal to the Bristol Royal Infirmary, we will be eternally grateful to the staff there.

*Jo Dent
Bristol*

(This account was written about a year ago, but I'm happy to say that Harry has continued to make good progress. Jo reports that one of his favourite pastimes is emptying the kitchen cupboards, and he has just recently started to take his first few steps. - Editor)

Heart Defects in Children with Down's Syndrome

The AV Canal Defect

The first in a series of booklets we hope to publish about the heart defects commonly affecting our children, 'Heart Defects in Children with Down's Syndrome - The AV Canal Defect', is now ready.

The booklet includes a medical description of the condition written by Dr CGH Newman, Consultant Paediatric Cardiologist at Westminster Hospital, fifteen families relate their experiences with their child and extracts from other parents accounts which may help to answer many of the questions commonly asked by families.

The booklet does not aim to support or contradict the many arguments for and against surgery. As each child is an individual whose personality, physical make-up and heart defect cannot be directly compared, so each family has its own individual feelings about the right course of action to decide upon for their child. There are no easy answers to the questions we all face when making these decisions, and in the end the final answer must come from the family itself, but it does help to know that others have asked the same questions, and from reading their stories it can be seen that sooner or later they all found their own answers.

The booklet is being published on a computer based system in paperback, A4 comb bound form to keep costs down, and hence we are able to sell it at a price of only £1 (which will be used to offset postage, packing and production costs.)

If you would like to order a copy, please use the order form on page 19.

Basel and Johnny

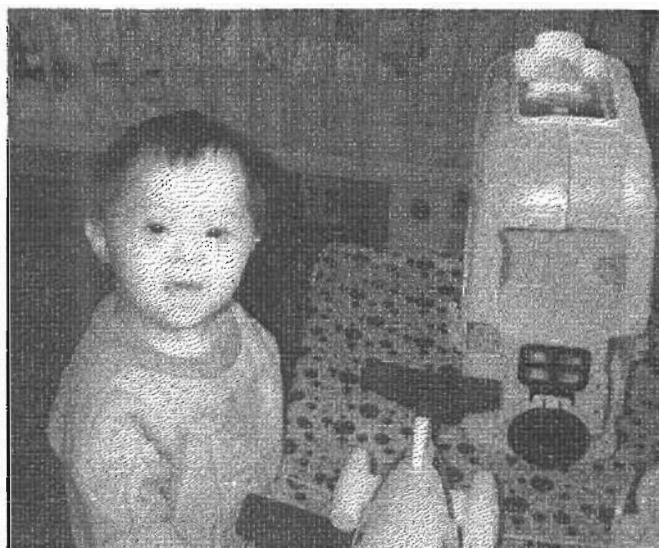
It is a difficult enough task to produce a newsletter that will interest our members, but harder still to keep the articles balanced. Whilst we have to face the fact that some families sadly lose their child, this has to be weighed against the greater number of children who survive. Many have undergone major surgery with all the attached risks, others have had no surgery but fight on long beyond the expectations of the specialists. So we try to include items for all members and hope that you will bear this in mind as you read the following pieces about two boys who died recently.

For Basel

*So short a time was Basel here,
Yet so much light did he give out;
So many lives have been brightened
By the pure hope that was his smile;
Always the radiance of his spirit
Will be a light within our hearts.*

*His nature knew not how to suffer,
Nor could it ever cause suffering;
We who have loved him
Have been blessed by his innocence;
He was but a visitor upon Earth,
And is at one with the Angels of Heaven.*

Peter Dignam



Basel appears in the DSA video 'One of Us' and features on the cover of one of their leaflets. This poem was written on 7th October 1992, two days after he died following open heart surgery. He was nearly three.



Taken from the Order of Service of Thanksgiving for the life of Johnny

"Jonathan" - the name that means "a gift from God" and oh! what a special gift we have been blessed with. The gift that came in an unexpected and different wrapping, but when accepted and opened, poured out the qualities of love, joy and radiant purity that was our Johnny.

We will forever thank him for what he has taught us, and for opening so many doors we would never have had the privilege to enter without him.

We give thanks to God our Heavenly Father for allowing us to have experienced the love of Jesus Christ our Lord first hand, through our precious son and brother, Johnny.

Mike, Jill and Penny Luntz

Many of you will remember Johnny's smiling face in our newsletter, holding up our 1991 Christmas card with the robins, which he designed. Sadly this Christmas was not so happy for Johnny, he developed a chest infection with added complications and died on 5th January. Johnny had not had surgery and was not expected to live beyond the age of two: he would have been fifteen in February and lived a full and active life.

Ideas & Helpful Hints

Overseas Travel

Visas for America

When taking your child with Down's Syndrome to the United States, you need to apply for a special visa from the U.S. Embassy in London. You will need to send your passport to have a special waiver stamped in it which entitles your child to entry into the U.S. The waiver is called a blanket waiver no - 212(d)(3)(A)(1), and if you don't have it you could be denied entry.

Medication

You would be well advised to take a good supply of medicines, antibiotics etc. with you when you travel abroad. Medication can be very expensive in other countries, for instance one bottle of Amoxil costs £50 in America. Most GPs will prescribe 'dry' antibiotics which, if needed, can be made up by adding a measured amount of cooled, boiled or distilled water.

Travel insurance

Some families have experienced problems getting travel insurance for trips. Members advice is to shop around, Pickfords are apparently very helpful and able to arrange insurance with no problem, there are probably others!

Vaccinations

If your child is due to go into hospital for a catheter or surgery, check with the hospital first about having any vaccinations that are due just before, and delay these if necessary. Otherwise you may find the hospital sending you home again, as many vaccines are considered 'live' and hospitals will not admit children who are 'carrying' them.

Help Lines for Bereaved Families

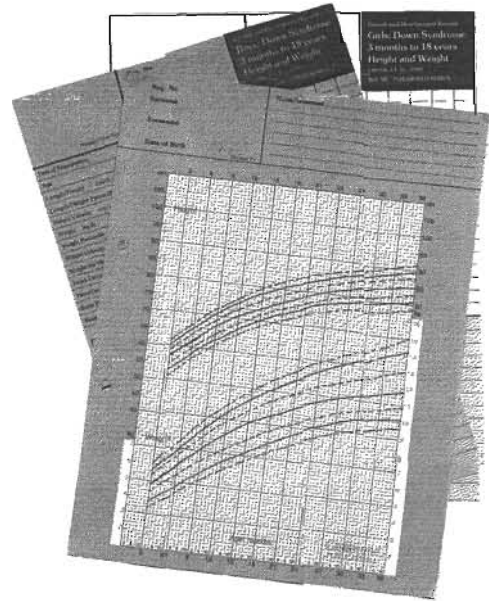
Bereaved families can of course always call the Down's Heart Group for support and someone to talk to, but you may like to know that there are also two telephone helplines which you can ring.

The Cruse Bereavement Line enables you to speak to a counsellor by dialling 081 221 7227, and is available weekdays from 9.30am to 5.00pm.

The Child Death Helpline enables you to speak to a volunteer who is also a bereaved parent, by dialling 071 829 8685, it is available on Mondays and Thursdays from 7.00pm to 10.00pm.

Both of these services are free apart from the cost of the phone call

Down's Syndrome Growth Charts



You will all have seen the growth charts used by hospitals, paediatricians, health visitors etc. to keep a check on your child's height and weight. Most of you will have found that particularly in the early days, your child doesn't even register on the accepted portion of the chart, and you may have spent many anxious hours wondering how to get your child to eat enough to make a significant weight gain.

Part of the reason why your child registers under the bottom centile (curve) on the chart, may be because the readings are being recorded on a standard growth chart. There are available, special charts for children with Down's Syndrome, which reflect their expected growth rates. They cover from age three months to eighteen years.

These are available to hospitals, paediatricians etc. and many are making good use of them, but if your child's growth is not being recorded on one of these charts, or you would like to have a copy for your own information and peace of mind, the Down's Heart Group now has these available.

If you would like a chart, please write your name and address on a sheet of paper, state whether you require the chart for a boy or girl, loosely attach stamps to the value of 28p (cost of the chart) and an 18p stamp (to cover postage), and send to the national office address. Please allow fourteen days for delivery.

Can You Help?

London Marathon 1993 Our runner needs sponsors!

April 18th will again see the Down's Heart Group benefiting from a hardy soul pounding around the streets of London. This is the third year we have had an entrant running in the London Marathon who is being sponsored on behalf of the group.

This year it is our Treasurer's son, Jon Spall, who in fact ran in 1991 but failed to gain entry last year. Not daunted, he applied for this year and was successful, and has once again promised his sponsorship money to the Down's Heart Group in memory of his little sister 'Bloomsie'.

What we now need is for as many members as possible to support Jon by getting sponsorship for his run. If you would like to help, even if you know you can only get a few sponsors, please contact the national office for an official sponsor form, and DO IT NOW, because the race is very soon.



Too Dear to Visit

2 DEAR VISIT

January 26th saw the official Parliamentary launch of a campaign to establish a fund for hospital visiting costs, organised by Action for Sick Children and Contact a Family.

Many of you will have experienced firsthand the hardships which can occur from frequent and prolonged hospitalisation of your child. Whilst help is supposedly available for those on Income Support, many eligible families are refused help or put off applying by the complicated procedures involved. Many other families have too high an income to receive any kind of help with hospital visiting costs, no matter how often their child may be in hospital or how long their stay might be.

This campaign urges the Government to establish a fund to reimburse parents for visiting costs according to new criteria. An Early Day Motion has been put down in the House of Commons, now they need as many MPs to sign it as possible.

If you would like to support the campaign, please contact your local MP, tell him your reasons and ask him to sign the Early Day Motion - *1241 Children in Hospital*. Either visit your MP at a locally run surgery, or write to him/her at the following address:

(Name of your MP)
The House of Commons
London
SW1A 0AA

Knitting Wool Oddments

One of our members, Nicola Desmond, has been very busy fund-raising for the group. She and her Mum have been knitting dolls, which have then been sold and raffled to raise money, mainly by Nicola's Dad who is in charge of selling the raffle tickets.

They intend to carry on with the knitting, but it does take a lot of wool, so if you have some oddments of double knitting wool you would like to donate, they would be very gratefully received. Please send your oddments (any colours), securely packed to :

Nicola Desmond
2a Fishtoft Road
BOSTON
Lincs
PE21 0AA

Benefits Who needs them?

Well most of us! This is a subject that is important to us all and we all have tales to tell about dealing with bureaucracies and the variances in advice from the different departments. There can be very different approaches from region to region depending on the interpretation of the legislation and policies of local authorities.

Many of us have the opportunity of seeking advice and advocacy from local Citizens Advice Bureau or Welfare Rights Centres, but these facilities are not necessarily available throughout the country.

It would be really helpful to have a good source of information on the main benefits available to our children, one that any one of our members could ring and gain factual information on what may be applicable to them, and speak to someone who uses every day language that they can understand instead of official jargon.

This would be possible if we could find someone that would be prepared to give some time and energy to providing this help to our members. Maybe someone that is retired or homebound who has an interest in delving into the vagaries of the benefit systems and could provide our members with up to date information,

Comments about the strength of baby's heartbeat during pregnancy

The other day I was talking to one of our members on the phone, when in to the conversation came the words "The ironic thing was that all through the pregnancy my GP kept saying what a strong heartbeat the baby had."

Not that strange you might think, but apart from the very same thing having happened to me, I've also lost count of the number of times it has come up in conversation with other members. So could this actually be an indication to doctors that the baby has a heart defect before birth?

Well it would be very interesting to look into further, so if you remember hearing similar comments from your GP during your pregnancy please let me know (even if you are one of the families I have already spoken to, because I didn't make a note of names).

Penny Green
Address and phone number on page 2

with the help of literature and data from national organisations, by writing a little for the newsletter and being available to speak to members over the telephone giving practical advice on how to go about making a claim, appeal rights, and points to stress to help make the case.

I can almost hear the groans of "Gosh, I couldn't do that", well that isn't necessarily the case. There are many non-experts who have developed knowledge and understanding of welfare benefits; the Down's Heart Group would be very willing to provide the opportunity of training and back-up of information from other organisations e.g. Child Poverty Action group, Disability Alliance etc.

The benefit system is meant to be used by the most disadvantaged people in our society, so we shouldn't feel intimidated into thinking that it can only be understood by professional experts - there must be someone out there who would be interested, or who would like to talk to someone about what this would mean in terms of time, expense and what they would have to do.

Please, please give some thought to this idea and then ring Katie Spall on 0424 830594 or Penny Green on 0525 220379 to find out more or just explore the idea with them. This is a role that could provide POUNDS weekly to some of our members who are not aware of their entitlements.

Competition Christmas Card Design

Have you sent in your child's Christmas paintings to enter our Christmas card design competition? If not, it's still not too late, we have decided to extend the deadline till the end of April, so get those entries in.

We want any drawings or paintings on a Christmas theme for use as our 1993 Christmas card. Don't worry if you can't see how a picture can be used, you'd be surprised what can be done with a little imagination.

So send them in now to our Secretary, Gill McLorinan (address on page 2), to arrive by 30th April.

We are giving a £10 voucher as first prize.

Letters to the Editor



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

Dear Editor,

We have a son with Down's Syndrome, called Peter. He is fifteen and has a hole in the heart and also the artery between his heart and lungs has not developed properly, leading to breathing problems, hence he cannot do sport at school etc.

We are interested in the possibility of surgery to correct Peter's problem, but as this would involve a heart and lung transplant it would be major. Peter has an annual checkup at Great Ormond Street who say he is "stable", but this problem severely limits Peter's life expectancy and there is no hint or prospect of surgery at present.

We would like to hear from people who are further along "the system" than ourselves. Some of our questions are:

1. What is the possibility of surgery in an underfunded NHS?
2. Are our children given equal priority with "normal" children suffering the same problem?
3. Do we wait until Peter is seriously suffering from breathing and associated problems before we start campaigning for an operation?
4. What are the chances of success as it is a very major operation?
5. As heart/lung transplants are fairly recent is this operation currently available in the U.K.?
6. What is the position on donors?
7. Is there any alternative regime or lesser treatment or operation that might extend life expectancy whilst still maintaining a reasonable quality of life?

Dear Editor,

When our daughter May, was born in 1978, the doctors told us she had a heart murmur. During her early years, apart from the usual childhood illnesses she had repeated chest infections, colds and stomach bugs usually during the winter months. She could not tolerate cold weather at all. On reaching her eighth birthday she became stronger and to date has been able to get through the winter with only the odd sniffle.

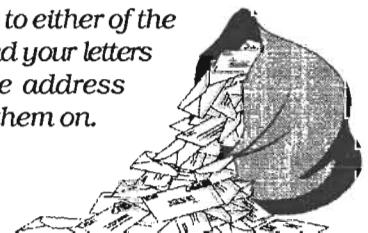


When the Down's Syndrome Association of Ireland began a screening clinic in Dublin, May had a thorough examination. This was in 1988, when it was discovered that she had an AV Canal defect. At present she is doing fine, and is monitored every two years, but we have been told her condition may present problems in the future which may require surgery.

I would be interested to hear from other parents with older children with AV Canal defect who have had surgery in their teens or later, or perhaps are at the same stage as we are.

*Sarah Cunningham
Co. Kildare*

If you would like to write to either of the above families, please send your letters care of the Editor at the address above, we will forward them on.



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 thefamily will be:

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

 Postcode:
 Telephone:

Send to: Penny Green, Family Support Co-ordinator



Order Form for

'Heart Defects in Children with Down's Syndrome - The AV Canal Defect'

Please send copy/copies of the booklet 'Heart Defects in Children with Down's Syndrome - The AV Canal Defect' to:

..... I enclose a cheque/postal order for £.....
 (no of copies x £1) made payable to
 'Down's Heart Group'.

 Postcode:
 Telephone:

Send to: Penny Green, Family Support Co-ordinator



