DOWN'S HEART GROUP NEWSLETTER

Photograph reproduced courtesy of the Herald Express, Torquay

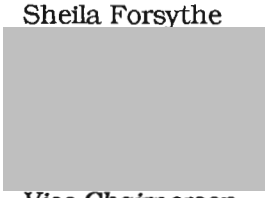
Johnny Luntz with his Christmas card

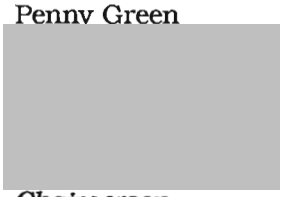
Read his story on page 7

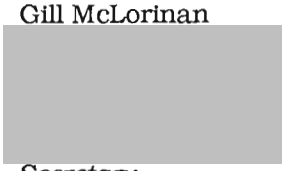
Committee Contacts

Brian Auld

Legal Advisor

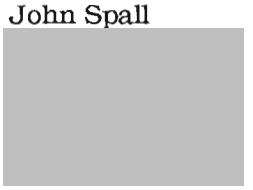
Sheila Forsythe

Vice-Chairperson

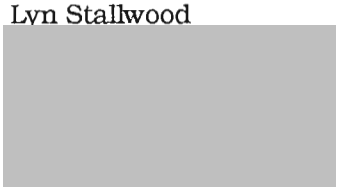
Penny Green

Chairperson
Family Support
Newsletter Editor

Gill McLorinan

Secretary

Jayne Shuttlewood

Committee Member

John Spall

Treasurer

Lyn Stallwood

Bereavement

Karen White

Fund Raising

Linda Walsh
Founder

Who Do I Contact?

Enquiries of a general nature or for information about the work of the group should be sent to the Secretary.

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

Advice and suggestions about the organisation of fund raising events can be sought from the Fund Raising 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,

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

Report on Group Progress

Well here at last is the seventh issue of the Down's Heart Group newsletter, once again delayed due to reliance on the generosity of others for help with its production, a factor which I hope will soon be rectified so that in future we will be able to meet set deadlines.

Anyway, if you have read the previous page already you will have noticed that once again there have been a few changes on the committee. Our Secretary, Anna Price had to resign due to the then impending arrival of her new baby, and her place has now been filled by Gill McLorinan who's son Joe featured on the front cover of our last newsletter. Our Treasurer, Sue Bamber, felt that having held the role since the group's beginnings, (despite being the only committee member who was not a parent of a child with Down's Syndrome), it was time for her to move on to other things and asked if a replacement could be found. Fortunately this coincided with an offer of help from a family in East Sussex and John Spall duly became our new Treasurer.

We have not, however, been as fortunate in finding a successor for our Chairman, Euan Forsythe, who felt unable to continue in the role after his initial period in office, due to increasing pressures at work. Since his resignation it has been left to the other committee members to direct the group, which was far from an ideal situation. So at the last committee meeting, Sheila Forsythe was elected Vice-Chairperson whilst still maintaining the role of Regional Co-ordinator for the South West region, and I take on the added role of Chairperson.

Thus it falls to me to offer our thanks to the retiring committee members for all they have done for the group in the past, and to welcome the new faces who I am sure will play a great part in the next step of the Down's Heart Groups progress.

In addition to those already mentioned, those sharp eyed amongst you will have seen that we now have a Fund Raising Co-ordinator, Karen White. She came into the role after organising a disco to raise money for the group, and is keen to expand her knowledge and experience by helping any of you who would also like to organise any kind of event on our behalf, so please give her a call. We look forward to some interesting events under Karen's direction and hope you will give her your support.

Talking of events, I musn't forget to mention that the the committee has continued in it's productive manner (as mentioned in the last newsletter), with the arrival of Anna Price's baby, Amy in October, Jayne Shuttlewood's baby, Jack in December and Lyn Stallwood's baby, Alice in February. Congratulations to all three of them and the respective proud fathers.

Well Christmas is well and truly out of the way, but as this is our first newsletter since then, it is the first chance to say a very big THANK YOU to everyone who purchased our Christmas cards, and especially to those people who made a very great effort in selling them on our behalf to friends, family and work-mates. As a result we boosted group funds, but more importantly we increased public awareness of our children and their special needs. In all we sold 25,150 cards, about 25% more than in 1990.

And finally, a date for your diary. The Annual General Meeting of the Down's Heart Group will be held on Saturday 20th June at the Enderby Leisure Centre, Enderby, Leicestershire, from 10-30am to 4-00pm. We are still finalising details for the day, but speakers should include Miss Roxanne McKay who is a surgeon in Paediatric Cardiology at Alder Hey Hospital, Liverpool. All members will be notified of full details nearer to the time.

Penny Green
Chairperson

Regional Co-ordinators

East of England

Lindsay Wharam

East Midlands

Anna Price

N. Ireland & Eire

Rosina Brierley

London Northern

Morag Malvern

London Southern

North East England

Sandra Welsh &
Sally Hardman

North West England

Mike Halpin

Scotland

Lynn Gouck

Bristol & South West

Sheila Forsythe

Wessex

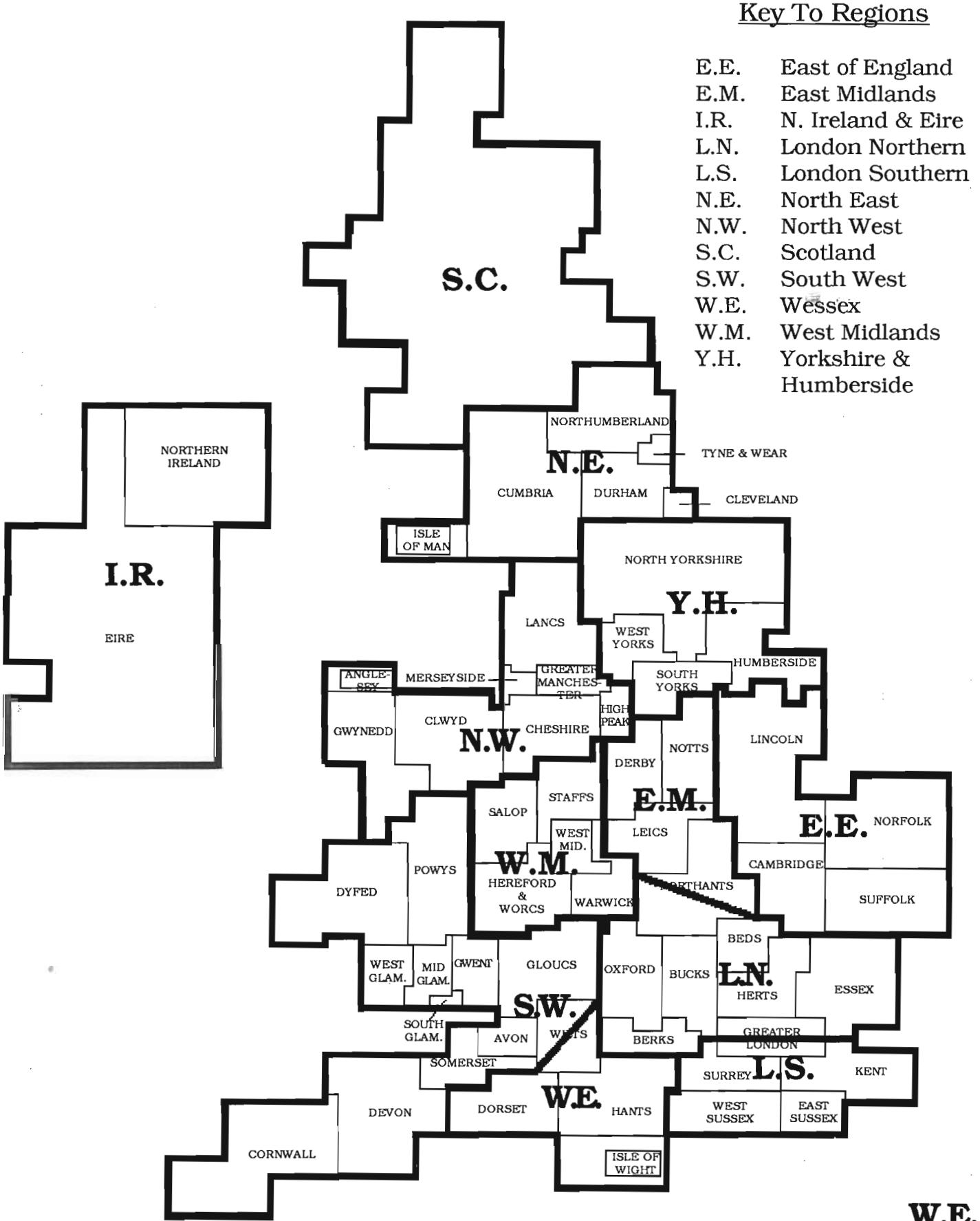
West Midlands

Pat Mitchell &
Noreen Hodgkinson

Yorks & Humberside

For those regions where no name is shown above, please contact:
Penny Green

Map of the Down's Heart Group Regions



Personal Profile

SHEILA FORSYTHE

(VICE-CHAIRPERSON & REGIONAL CO-ORDINATOR FOR BRISTOL & SOUTH WEST)

I was born in Dumfries, Scotland, trained at Queen's College, Glasgow and worked in Health Service Catering Management until moving to Thornbury, near Bristol in 1979.

I am married to Euan, and we have two sons, Neil aged 8 and Andrew aged 6, who has Down's Syndrome.

Andrew was born on 12.10.85 in Bristol with an AVSD. He had corrective surgery at Bristol Royal Infirmary in November 1986.

I was introduced to the Down's Heart Group by Phil and Mary Thorn over 5 years ago, prior to Andrew's surgery, and have been the Regional Co-ordinator for Bristol and South West area since 1988.

My overriding interest is the DHG, but other 'hobbies' include being a Beaver Scout Leader (with 20 years service in the Scouting movement), gardening and flower arrangement and walking our three West Highland Terriers, Paddy, Sporran and Tobermory.

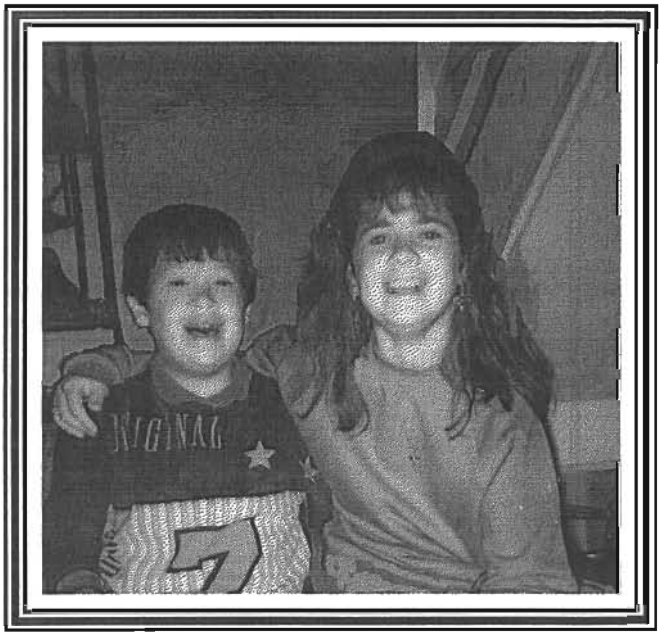
I also give voluntary help at both boy's schools and am on the Bristol Children's Heart Circle committee and the 'Friends' committee of Andrew's Special School.

In my spare time (what spare time? - Editor) I provide a family taxi service to horse-riding, swimming lessons, mini rugby and cub scouts, and enjoy watching rugby, especially at Murrayfield!!!

(Sheila spends a lot of time visiting families in the two hospitals in Bristol, although how she fits it in I'll never know. She is also a very good cook, and usually manages to provide at least one batch of delicious homemade biscuits at committee meetings, which is a great inentive to attend. - Editor)

Sheila and Andrew Forsythe

Jonathan's Story



Jonathan with sister Penny

Jonathan was born on February 27th 1978, a much wanted second child for Mike and me, and a welcome brother for Penelope who was then fifteen months old. Having begun our family much later than the majority, (I was thirty-five having Penny - as she likes to be known - and thirty-six having Johnny- as he prefers to be called), I was aware of the greater risks, and in fact had a sort of inner premonition that I was carrying a Down's child when pregnant with Johnny. As the moment of birth and my first glimpse of him conformed my thoughts and fears, I was overcome with grief and self pity. I was not informed by the consultant until twenty-four hours after his birth, but I knew in my heart without a doubt that he was a Down's baby as I had half expected it. I'll not dwell on the fact that I felt only pity and no love for him in the first week of his life, because now I know that it was only a shock reaction.

Although weighing in at a healthy 8lb 4ozs, he was a 'blue' baby at birth and was immediately given oxygen, and then put into an incubator for forty eight hours. At five weeks he was admitted to hospital with pneumonia, and the doctors suspected a heart defect which was not obvious at birth. At ten weeks he was readmitted with severe bronchitis and was transferred to the Children's Hospital in Bristol, where after catheterisation it was diagnosed he had a congenital heart defect of the most complicated and serious kind, causing pulmonary hypertension so that surgery was out of the question. However, he has proved the doctors theory wrong when it was predicted he would be unlikely to survive beyond, at the very most, two years, but he had to have another catheter at three years after suffering almost continual chest infections, dehydration and heart failure during his short life so far. Yet, although he easily picks up infections, we have been able, with the support of our GP, to he help him with antibiotics, other medication, tender loving care and trust in God.

Johnny is a sturdy though small boy for his age, with amazing reserves of energy, and he is able to take part in everyday activities both at school and at home. We do notice he gets breathless more quickly these days, and he cannot cope with long walks or excessive physical activity. He does, however, go to school like all children, attends Sea Scouts, goes horse riding, has swimming lessons, and is involved with Explorers groups at Church, to name but a few of his pastimes.

We are told by his consultant whom we see annually, that he is surprised Johnny is as well as he is, and that his condition hasn't continued to deteriorate. We are thankful of course (it goes without saying), but are nevertheless realistic about the serious nature of his problems.

We take each day at a time, and make sure his experiences are those to give as much fun and happiness as possible. He is still making excellent progress at his Special School - he had partial integration during his Primary School years - and we are so proud of his achievements. His general knowledge is superb and his articulation is improving but is still his weakest point, which is such a shame as he has so much to say!

We love and adore him each and every day, and thank God for the extra precious gift we have been given, and for what Johnny has taught us about the true values in this life.

I hope that what I have been able to tell will be encouraging to other families in a similar situation.

Jill Luntz
Torquay

(Jonathan's design was chosen for the 1991 Christmas card, after which Jill wrote to say : "He is over the moon that his design for this years Christmas card was chosen, and he is lapping up all the attention and congratulations this has brought his way." This story shows that even for those children for whom surgery is impossible, the future is not always as black as it sometimes seems. - Editor)

Katie's Story

Katie was born on 22nd July 1989, (the hottest weekend of that year!!!), and we were informed immediately that she had Down's Syndrome. The consultant paediatrician thought that her heart was fine at that time. At our six week check-up he detected a small murmur and we were referred to the Brompton Hospital. Katie had all the tests done and we were informed she had an AV Canal defect. The advice they offered was not to operate as the operation was high risk and that she would probably live until she was approximately twenty-one years old. Those few words I will never forget. We were also informed that if we did wish to go ahead with the operation we should let them know in six weeks time at our next appointment. We were devastated - I just couldn't stop crying - how could this be happening to us? It all seemed so unfair.

A few days passed and I began to think straight again. I decided to have a second opinion. As we live very near to Harefield Hospital it was a natural choice. All the red tape and paperwork were rushed through and we saw a Dr Weintraub. He told us before we started worrying whether Katie should or should not have the operation, the first thing was for her to have a catheter to check if her lung pressure was such that she could have the operation.

This went without any problems and the outcome was that Katie was suitable to have the operation. Dr Weintraub is an Australian who was on a years educational visit, (learning about transplants) at Harefield. He was a marvellous support to us as he informed us that in Australia they actively encourage this operation and that it is very successful. He was surprised at the response we had received from the Brompton. He had worked with an English surgeon in Australia - a Mr Brawn - who was now working in the Birmingham Children's Hospital, and he thought it would be wise for us to go to him if we decided on the operation.

After reading the Down's Heart Group booklet many times - having to stop quite frequently for a good cry - we really felt we had to give our little darling every chance in life and to go ahead with the operation.

Katie was very pale, thin and frail - she sweated quite a lot and often had a mottled look to her skin. Fortunately she never went blue and never really suffered with any chest problems.

Katie had her operation on 1st December 1989. The staff at the hospital were absolutely fantastic and we managed to get accommodation there (very basic). Mr Brawn came to see us immediately afterwards (still in his surgical gown), and told us everything had gone very well. Such a relief!

Katie was then in intensive care for approximately ten days. I remember giving her what looked like a lolly but had a small sponge on the end of a stick which we could dip into water and give her a few drops. After coming off the various life support machines she eventually came out into the ward for about eleven days. There were various hiccups through her recovery. She caught a virus which caused diarrhoea and a very high temperature. Also, she was very anaemic for a while and they thought they might have to re-operate to correct this - but fortunately it sorted itself out. She was so thin - bless her - but she was hungry and they started her on a special milk and fat diet which we continued when we came home.

We brought Katie home Christmas week. We had to take care that she did not get a chill and be vigilant in her medicines and food subsidies.

We have always had immediate access to our local hospital at anytime just in case we were worried about her. We've had our aftercare transferred to Harefield now. Katie had to go in for a weekend a few months after the operation as she had collected some fluid around the heart and this needed to be drained off.

Our last visit to Harefield was 6th June 1991, where she had the usual checks ie. X-ray, Ultrasound, ECG. The consultant up there - a Dr Radley-Smith - told us that Katie was doing fantastically, she couldn't get over how she had grown. She asked us to continue with our yearly check-ups, but did not foresee any problems in the future and no need for

further surgery, She also told me that they now do this operation at Harefield, (preferably when the child is very young - three months or so), she asked me to inform the Down's Heart Group of this as I told her about the response we had at the Brompton.

The Dr Weintraub that I mentioned earlier has now left Harefield but we keep in touch with him by letter - he is currently in America studying and says he misses Harefield. We asked him once why he seemed to have taken a special interest in Katie, he informed us that he had a sister with Down's Syndrome who also had an AV Canal defect and that he wished the operation had existed when she was born.

I just hope that this story can give 'heart' to another parent who is perhaps going through the same agonising choice for their child and that they have the great success that we have had with our darling little Katie.

Juliet Maguire
Croxley Green

David's Story

David was born after forty-one weeks of pregnancy and nine hours of labour, and because I'd been friendly with the midwife through the pregnancy, I wasn't too worried when she said they were just taking the baby away for some oxygen. I was only too pleased to see the reward for all my effort.

They brought him back after about five minutes and said he was a healthy 6lb 4oz and that a midwife was going to feed him. I wondered why they hadn't asked me, but thought it might be to give me a rest or something. Then I got my cuddle. he had this orange fuzz on his head and all I could think was, well at least he's not bald.

Richard, my husband, who'd been on the phone, came back in the middle of what seemed like a load of fuss, closely followed by a doctor who "uhm'd and ah'd" at the bottom of the bed. He finally said, "It appears the baby could be a mongol". I looked at David for ages because I didn't know how this guy wanted me to react, and then he left. I thought 'well if somebody tells me what a mongol is, then we'll be well sorted'.

This information came in the form of a social worker and a health visitor who asked me how I felt about the baby, and what my plans were. I said "How can I make plans? I've just had a baby". With which they left.

When we left the hospital David had a heart murmur, so they referred us to Pendlebury Hospital. By the time he was four months old they had diagnosed him as having Fallots Tetralogy, and explained about possible 'blue spells' in the future.

I'd noticed from birth, that when he cried his feet turned blue, but the very next day whilst visiting a friend who had a new baby, I had David draped across my knee when suddenly his snoring stopped. I picked him up, his eyes where turning skyward and he was navy blue. In panic I jerked him and he took a deep breath. He was fine then, but he spent a few days in Pendlebury, and on the day I went to collect him I found him wired up to monitors. He'd done it again. they started him on beta blockers, and when he was settled I brought him home.

The blue attacks eventually came back, and at twenty months he had his first shunt. He bounced back, and seven weeks after the operation he took his first steps. I phoned everybody I could think of, I was so excited until I realised that everybody else's babies had walked about twelve months earlier. That was when it finally hit home, David was different. I felt strange about getting excited over everything he did, because I realised then that it didn't mean as much to everybody else as it did to me.

David had been going to a special nursery since he was three months old, and they had an informal parents group every Monday morning. I started going and before long I found that my feelings were not unusual. Every one of the parents had had to 'bite their tongue' at one time or another so as not to sound over enthusiastic about their child's achievements. A few said that they thought they might have imagined things their child had done, and I felt great because I'd done that loads of times! That group was a life saver because over the next few years, David was in and out of hospital, and I had somewhere to sound off how I felt about everything.

David had an infection in his bloodstream about eighteen months after his first operation. This blocked his shunt completely, so exactly two years and a day after that had been done, he had a second shunt operation. The doctors discharged him after five days because he kept running off and visiting a ward at the other end of the corridor.

Soon after this operation he started at a 'normal' playgroup and he got on really well, the other children seemed to get through his stubbornness. After that he went to ordinary nursery and eventually mainstream school split with a special school. Although he got on well, he was let out of a lot of activities because after doing so much (or so little), he

would squat down and get in everybody's way.

The blue attacks gradually returned, until it got so that if he got excited or if he ran, he would pass out after crying with pain. Obviously, I tried to restrict him, but this didn't always work as he wanted to play with other children. I realised that I wasn't being fair, so I let him out and watched from a distance.

In 1990, David went for balloon dilation at Pendlebury to try to stretch the artery that was causing him the problem. It worked for a short time only, and then they said that it was time to push for corrective surgery at Alder Hey. We waited for a while and then out of the blue in January '91, a letter came to say that he was to be admitted in three weeks time. I couldn't believe that this was the letter.

As the time grew nearer, I wondered if we were doing the right thing, but then I knew he had to have a chance. Richard had to stay at home to look after our five year old twins, and I did not look forward to being alone to face it all, but once there in Liverpool, there was a calmness about it all.

The surgeon came and spoke to me, and I felt confident about the whole thing. She was there to meet us on the morning of surgery, and I held David's hand as he went to sleep. 5 hours later she came to see me on the ward and said that I could see him once they had him settled in intensive care, (I had been shown round the evening before, so knew what to expect). She said that the operation had gone really well, there had been quite a lot of work to do but the repair to the heart was good.

David looked like an angel! I almost walked past him because his colour was so different, he no longer looked like the baby I once had. I even took some photos to show the twins and their Dad as they were all curious. Within a few hours David was off the ventilator, two days later he was back on the ward, and nine days later he was home.

About a fortnight later we went into town and I asked David to walk down some steps as he was too heavy in the buggy. After that he would not get back in. In May we thought that we might as well put this new found energy to good use. A low key sponsored walk was what I had in mind, so I phoned Linda Walsh to tell her I thought the Down's Heart Group should benefit.

She gave me some advice, and the next thing I knew, there were photographers, reporters and parents from all over the country phoning us. It was a bit mind blowing, but good to know that there was so much support. Linda also rang Philip Schofield's agent, as he was due to be at the event we planned to walk to.

The day came, and the mile was spent by family and friends all chasing to keep up with David. Philip Schofield was really nice and posed for some photographs with David, and even donated £5. I don't know who was the most exhausted that day, but it certainly wasn't David!

Christine Jackson
Oldham

(David still has a leaky valve, but he has gone from being a little boy who had to be carried to the school bus each day, to one who went on holiday for a week without taking a buggy. His speech is progressing well, and every day he learns something new. His Mum says that her biggest anxiety now, is what he will get up to next. - Editor)

Research News

Trisomy 21 Research at Addenbrooke's Hospital

Some time ago, we circulated an appeal by Dr Richards of the University of Cambridge Clinical School for families who had another member with a heart problem, in addition to a child with Down's Syndrome and a heart defect. Several of our families volunteered to take part in this research, which "focuses on the consequences of Trisomy 21 on the development of the brain as well as the heart, for it is these two tissues that are most severely affected in Trisomy 21, Down's Syndrome individuals."

Dr Richards recently wrote to keep us up to date on her progress.

"Our research on heart development is also progressing well and we are about to publish data on a new protein that we have discovered is present in heart tissue during septation. We still have quite a bit more work to undertake on the characterisation and function of this protein (which we have named {FHP1} Foetal Heart Protein 1), however, at this point in our investigation it appears to be important in regulating cell division. In the next few weeks we should have completed the family analyses ie determining whether the gene is abnormally transmitted from parent to Down's Syndrome child in the families you put us in touch with. These families are extremely valuable to our research so please continue to spread the word."

If you would like to know more about how you may be able to help Dr Richards with her research, please contact her at the address below. Participation in the research involves taking a blood sample from the family member(s) involved, but it may be possible for this to be done by your family GP or even on the next occasion when a sample is needed for other purposes. While families with two or more members with heart problems are of particular interest, we believe that Dr Richards would also be pleased to hear from any family whose child has an atrioventricular septal heart defect, otherwise known as AVSD/AV Canal/Endocardial Cushion Defect.

For further information please contact:
Dr Sarah-Jane Richards
Dept of Medicine
University of Cambridge Clinical School
Level 5
Addenbrooke's Hospital
Hill's Road
Cambridge CB2 2QQ
Tel: 0223 336947

Study on the causes of heart defects in Downs' Syndrome

Back in October we asked some families if they would be interested in helping with a study being carried out by St. Mary's Hospital Medical School. The project is being funded by the British Heart Foundation to look into the causes of congenital heart defects. It involves a team of doctors from St. Mary's and Great Ormond Street Hospitals, and they are starting by looking at children with Down's Syndrome because such a high percentage are born with these problems.

Ideally they want samples of blood from affected children over three, and where possible from an older sibling as well as Mum and Dad, although the child's blood alone is of value to their study, so adopted and fostered children are not ruled out.

We have been able to pass on the names of 15 families who are willing to assist, which has apparently been a great help as they were previously limited to patients of Great Ormond Street.

For more information please write to :
Dr Anna Kessling
Department of Biochemistry and Molecular Genetics
St. Mary's Hospital Medical School
Norfolk Place
London
W2 1PG

Thank you to the family and friends of Noleen Hodgkinson (pictured above), for the donations recieved in her memory after her death last year. We have been asked to put the money towards research.

Physiotherapy for the child with congenital heart disease

Many babies with heart disease need physiotherapy for their chest, whether or not they have had operations. All babies/children having surgery will need chest physiotherapy, some need very little treatment, others need much more; but some babies who do not have operations will also require physiotherapy treatment.

Chest physiotherapy really means clearing secretions (or phlegm) from the child's lungs. If excessive secretions are allowed to collect inside the lungs they will make breathing more difficult, and in some cases part of a lung may collapse. A chest infection could also develop. There are several reasons why secretions build up in the lungs. It is perfectly normal for some to be present but when they can be heard or felt it usually indicates a problem. However, all children at some stage, whether or not they have heart disease, will have coughs and colds.

Some children with certain heart conditions, eg. those with a "hole in the heart", are very prone to chest infections and these, especially babies, very often need treatment whether or not they are having surgery.

The babies/children that are having an operation do need treatment because the anaesthetic tends to cause an increase in secretions, and also the pattern of breathing is affected by the anaesthetic and other drugs used (eg. for sedation, pain killers), so even if there are not many secretions, the child may not be using the lungs properly and needs to 'expand' them.

The operation itself may lead to 'inhibition' of breathing and moving about normally, largely caused by fear and pain; both factors which can be dealt with easily. It is perfectly routine therefore, for all children admitted to hospital for surgery to heart or lungs to have physiotherapy treatment. It is vitally important that the lungs are cleared of excess secretions and that the lungs are well expanded.

The physiotherapist will see the child prior to the operation to make sure the chest is clear, by listening to the chest with a stethoscope, looking at the chest x-rays and examining the child as well as talking to the parents. An explanation as to why the treatment is needed (as discussed above) is given to the parents, plus any details about the operation they may wish to know; (Doctors and Nurses also advise on this explanation).

Obviously, babies cannot co-operate and their treatment is passive, but older children and even some toddlers can perform simple breathing exercises, so for those that are able, blowing exercises and coughing are taught. By 'breathing exercises' we really mean deep breathing. Normally, everyone takes a deep breath every so often, usually subconsciously; or you may yawn, sigh or exercise (for example, even going up the stairs makes you breathe harder). In other words, the rate and depth of breathing changes frequently, but after an operation the breathing is reduced (sedation, fear and pain all contribute) and if all areas of lung are not expanded properly for any length of time (a few hours is often all it takes) they 'go down' or collapse. Then, even if secretions have not been a problem, they tend to collect in the ares of lung not moving properly and so further problems may develop.

To prevent all these terrible things happening - the solution is to take deep breaths and cough!

Children respond better to blowing games, if they blow hard they have to take a deep breath - so bubbles, whistles and the like are all invaluable. If your child is of an age to do these things it is a tremendous help to the physiotherapist if you can teach them to blow and cough before they ever come into hospital. Even babies help themselves because crying can actually be good for them. When crying they take deep breaths.

The deep breathing has two functions; not only does it expand the lungs, it also helps to loosen any secretions; the baby will often cough spontaneously after crying, as will toddlers. Older children will usually cough to command - some swallow the phlegm but all should be encouraged to spit it out into tissues. This is not as nasty as it appears - the type of secretions coughed up (colour etc.) can be useful to the staff in detecting infection, for example.

The physiotherapy treatment 'proper' begins after the operation (or, in the case of the child not having surgery, whenever indicated). The sooner treatment begins the better, as it is easier to prevent problems than to deal with them later. This usually means the day after the operation (sooner in some cases) and treatment is given as often as is necessary, which may be once a day but more often is twice, three or four times a day.

Frequency of treatment is very variable and depends on the child and the nature of the operation. The child will be on the 'Intensive Care Unit' and therefore will have various attachments, and may well be on a ventilator which is doing the work of breathing for them.

Physiotherapy chest treatment involves positioning the child so that any secretions are loosened and drained with the help of gravity, thus the child is often laid flat on the bed and first turned onto one side and then the opposite side. Sometimes the chest is patted with a cupped hand (or fingers in a small baby) - the noise this makes is caused by air being trapped by the hand and it is not painful when carried out properly - it is done to dislodge the phlegm. Then the chest is vibrated or shaken on the breath out - again to move the secretions on and make them loose. If the child can cough they are encouraged to do so but very often in the early stages they are too sleepy, or if on a ventilator, or very young, eg. babies, they are unable to cough to command.

If secretions are there and the child cannot cough it is then necessary to use suction to remove them. Suction can be very disturbing for parents to watch if they do not know what is happening. Some parents prefer not to watch at all, and this is fine (in fact it is worse to observe than to carry out the procedure!). If the child is on a ventilator then the suction catheter (which is a small fine tube) is simply inserted into the main airway to the lungs through the tube already in the airway, which is connecting the child to the machine. If they are not on a ventilator then the suction catheter is put into the main airway to the lungs, usually by going through the nasal passages or occasionally through the mouth. This stimulates a cough reflex and secretions can be removed by applying the suction, or negative pressure, from the suction apparatus (often connected to the wall by the bed).

As the child progresses, treatment may be needed less often, or suction may be stopped, but treatment will continue until the chest is clear and the lungs are well expanded - this may be two days in some cases, two weeks in others. Some children need treatment when they go home and parents are then taught how to do this themselves. This may well involve using postural drainage (*see item in Autumn 1991 newsletter*), in which, to further help the drainage of secretions (which tend to collect at the bottom of the lungs), the child is tipped over pillows so that the hips are higher than the head and shoulders, lying first on one side and then the other; chest patting and shaking is done in each position (combined with the child doing blowing and coughing if they are able to co-operate).

The parents can be invaluable help to the physiotherapist and her treatment whilst the child is in hospital. especially by encouraging the child to do their breathing exercises and coughing between visits from the physiotherapist - a 'little and often' is by far the best method. In addition, just generally supporting the physiotherapist and not (very often inadvertently) discouraging the child from co-operating by careless comments, eg. "Oh no! she's come to make you cough again.", etc. - these may well frighten a child and any progress previously made will be lost. Remember, if all else fails - crying does make them breathe deeply!

It is obviously a very worrying time for parents with sick children in hospital. Knowing what is being done, and why, can help to some extent - never be afraid to ask questions. A feeling of involvement, as for example by helping to do breathing exercises and encouraging coughing, is often therapeutic for parents and children - not to mention the physiotherapist.

The chest care is obviously a very important factor in the overall recovery of any child, especially in the first few days, but other things are also important, eg. posture correction - some children develop the most appalling posture following operations, which may become habitual unless dealt with early. Also, the child must be encouraged to move stiff arms and neck etc. - here again parents can help by encouraging them to carry out regularly the exercises shown by the physiotherapist. Some babies may need arms/ legs/ fingers moved for them if they become stiff. The physiotherapist would show the parents how to do this if necessary.

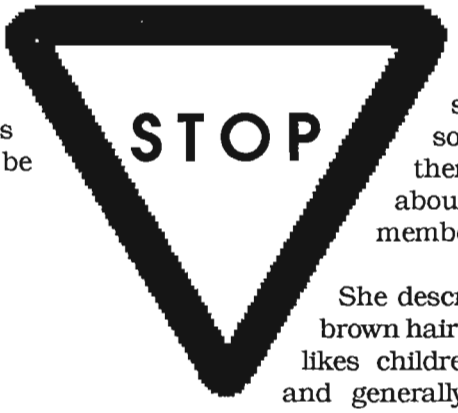
An important fact to remember is that <u>everyone</u> is working to the same end - and that is to make the child fit and well again in the best way possible, and that <u>nothing</u> is done without good reason. This is sometimes difficult for parents to understand - but nearly always this can be resolved by a simple explanation - so if none is forthcoming- ASK!

Lynne Kendall
Superintendent Physiotherapist
Killingbeck Regional Cardiothoracic Unit
Leeds

Can You Help?

Feeding Problems

A letter from one of our overseas members asks:
If it were possible, I should like contact with some parents who have managed to get their children chewing and eating solids at a later age. Alex is now five and will not eat hand held foods, only food that has been well mashed or pureed. He eats on his own with a spoon, but we seem to be stuck there. Any suggestions?



Elizabeth Osborn de Jacas

[redacted]

Items for fete stall

One of our members has been given a variety of things which she hopes to sell at a fete in Moseley, Birmingham in June, to raise money for the group. If you have any handicraft or bric-a-brac items that you would like to donate for the stall, or if you are in the area and might be able to lend a hand on the day, please contact :
Katie Spall

[redacted]

Work with Down's Heart Children

At Christmas we received a card from a young lady Lyndsay Coathup, who has a little adopted brother Matthew, who has Down's Syndrome and a heart defect.

Lyndsay wanted to wish all our members a Happy New Year, and said that she would very much like some of our Mums or older members themselves to write and tell her more about the Down's Heart Group, and its members.

She describes herself as 5' 5" with shortish brown hair and tanned skin, and says that she likes children, cooking, reading, horse-riding and generally keeping fit. After working away for a time as a nanny, she would now like to concentrate on a career involving children with special needs, and wonders if anyone knows of any opportunities available in the Leicestershire area.

If you know of any vacancies, or would just like to write to Lyndsay, she can be contacted at :

[redacted]

Andrew meets the Princess

Last summer, the Princess of Wales visited Bristol, to open the new Music Room at Castle School, Thornbury, and one of our members, six year old Andrew Forsythe was in the crowd to greet her. As you can see from the photo opposite, not only did he get to see her, but she also stopped to speak to him and accept a posy of flowers.

(Have any more of our members got memorable moments that they would like to share with us? Please send them in for inclusion in the newsletter! - Editor)

Ideas

Continuing from our last issue, thank you for the following ideas that we have recieved, please keep them coming, a really simple or silly thing that's worked for you may be just what another family is looking for!

I thought this little gadget looked very useful, particularly as it can be used to allow a baby to lie on it's tummy and look around.

I've never seen them on sale in this country, but they seem to be available in most large supermarkets in France - cost about £7. (Their main intended use is to keep baby's head out of the water in the bath!)

Newsletter readers may know if they're available in the UK, or may volunteer to collect and post to other families if they are off to France on their holidays.

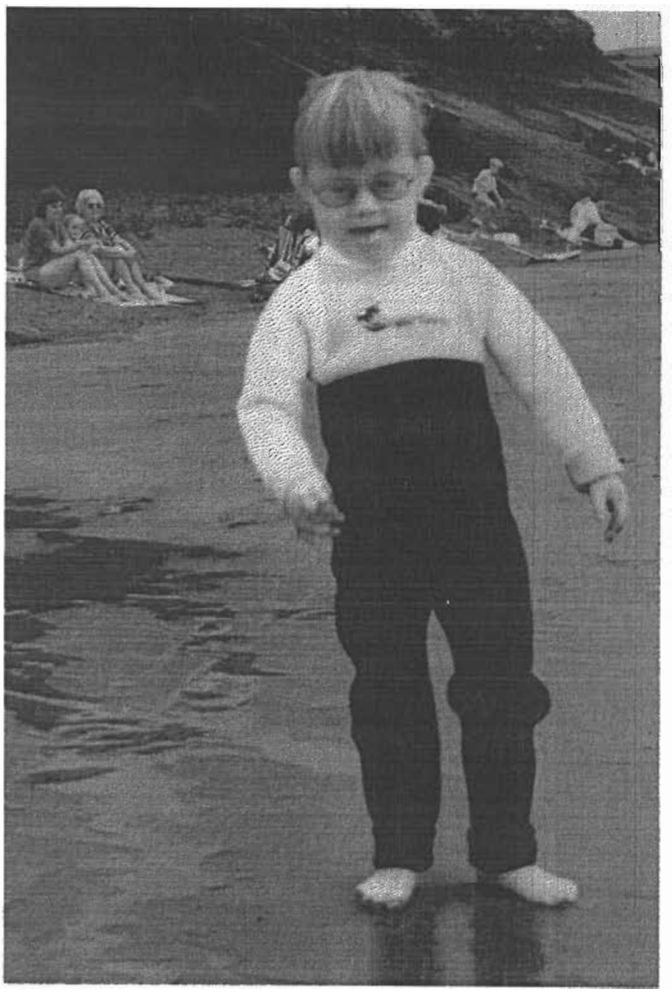
Linda Walsh
Founder

(Has anyone seen them for sale over here? Or are you going to France and might be prepared to collect for another family? Please let us know - Editor)

Like many children, Rebecca who is 6, loves being on the beach and playing in the water. But because of her poor circulation she spent more of her time wrapped in a blanket trying to get pink and warm again, than actually playing. Last summer saw a breakthrough as we bought her a wet-suit, (the sort worn by windsurfers), which kept her beautifully warm for quite long spells. It also protected her from sunburn, on the rare occasions that that was a risk!

We had to hunt quite hard to find one small enough, and it was fairly expensive (nearly £50), but well worth it.

Julie Payne
Southwell



Letters to the Editor

If you would like to have a letter published in the Down's Heart Group Newsletter, please write to:
The Editor
Down's Heart Group

Slimming by Mark

No-one at this table has got cherry pie
That's funny
It looks like a nice cherry pie
But I've got this yoghurt

I like cherry pie
In fact, it's my favourite
It does look nice
But I've got this yoghurt

I would like a little bit,
Just a little bit
With no custard
But I've got this yoghurt

My trousers are getting looser
So that's a good thing
When they fall down
I can have pudding

But today I had some chips,
so,
I've got this *** yoghurt

(Overheard by one of the ladies at Mark's school whilst he sat muttering at the dinner table)

Heartcare Conference

Heartcare, the umbrella organisation for heart support groups, is holding its annual conference on April 11th at the University of Birmingham Guild of Students. Workshops will include Insurance, Statementing and the Childrens Act.
Further details can be obtained from:
Janet Rathburn

South West Region

I've just read through my copy of the newsletter and found it informative and inspiring.

As a counsellor and family support I try to help families remain positive, and reading of Georgina, Joe and Jack has made it much easier for me to say to parents, 'Don't ever give up hope'.

If any of your families are from the South West region, I would be only too pleased to hear from them, and offer whatever support I can, either in this hospital or in the community.

They can get in touch with me on 0272 215411, Bleep 2229 or ext. 5706, by writing to me at the address below, or through their health visitor or GP.

Can I also endorse the view of many parents I meet, who have found the Down's Heart group to be a real 'friend' during their child's stay in hospital, and later back home.

Helen Vegoda
Counsellor in Paediatric Cardiology
Bristol Royal Hospital for Sick Children
St Michael's Hill
Bristol
BS2 8BJ

(Cardiac surgery for the region is carried out at Bristol Royal Infirmary. If at anytime parents are worried about their child's admission to Ward 5, or their operation, they can also contact Helen Stratton, the Cardiac Liason Sister, by telephoning 0272 2230000 and asking for Bleep 2776. Helen is always happy to arrange a pre surgery visit to the unit, when families will meet her and other staff who will be caring for their child. She has an office on the ward near the Nursery, so is available to discuss any aspect of the child's care during their stay in hospital. - Editor)

Would you like to help?

Have you ever thought that you would like to help the Down's Heart Group in a practical way, but not known who to talk to or what sort of help you could offer? Then read on, here is your opportunity!

Over the last few years, we have had many offers of help from people who cannot spare a great deal of time, or are unable to commit themselves on a regular basis, but who would like to feel that they were helping the group in some way. Often when the offer is made, there is nothing that immediately comes to mind that could easily be passed on to another person, so their name is kept in mind for the future. Then when certain jobs and projects arise that could be passed on to other members, it is reliant on the committee to remember who has offered what type of help in the past.

This is obviously far from an ideal situation, especially in view of the increasing number of families that we now have as members, and the considerable committee changes that occur. So, now that we are using a computer to manage our information, it seems an ideal opportunity to make a list of people that may be able to help us from time to time with various tasks. So, if you have offered in the past, or would like to offer help now, please would you fill in the form below, indicating what type of skills you have or help you would like to give and some idea of the amount of time you might have available.

It is unlikely that you will be contacted immediately, but as and when opportunities arise, we will then have a selection of names available from which we will be able to identify those who have appropriate skills for that particular task, and be able to approach them for assistance. This will of course place you under no obligation as we are well aware that family circumstances etc. can change very quickly.

If you would like to help, but think you can't do anything that the group would find useful, or that the amount of time you have free is too little to be of value, please do let us know, there are all sorts of ways that we can use extra help. In fact, the responses that you come up with as a result of this item, may even give us all some new ideas for ways to improve the support and information available for families.

I would like my name to be included in the list of those who want to offer help to the Down's Heart Group. Please contact me if there is something I can do.

Name:.....
Address:.....
.....
.....
.....
Postcode.....
Telephone:.....

Please indicate the type of skills and amount of time you have available.

Typing.....	Other handicrafts.....	Available time (approx)
Wordprocessing.....	Childcare.....	.....hour/s per
Proof-reading.....	Fund raising.....	day/week/month.
Sewing.....	Hospital visiting.....	(delete as necessary)
Catering.....	Visiting new parents.....	

Other(please state).....

Send to: Penny Green, Family Support Co-ordinator, Down's Heart Group,

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:

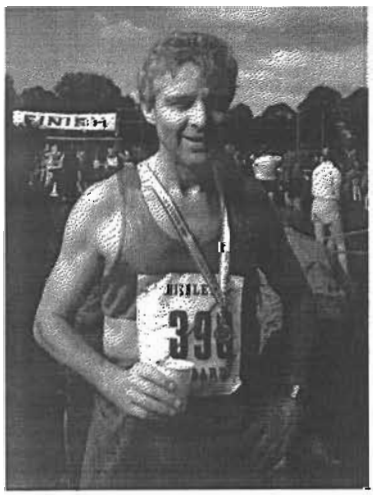
.....
.....
.....
.....
.....
.....
Telephone: .....

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

Send to: Penny Green, Family Support Co-ordinator

London Marathon 1991 & 1992

In 1991, Jon Spall ran the London Marathon to raise funds for us, in memory of his little sister 'Bloomsie'. Apparently, after 4hours 4minutes and 56 seconds, he managed to finish in 13,450th place looking fresh and relaxed, and having enjoyed it so much that he applied for a place this year but has, unfortunately been unlucky. We would like to thank Jon very much for his wonderful effort in raising funds for the group.



Don't worry though, the Down's Heart Group will still be represented on April 12th. This year, Chris Tovey from Thornbury, Bristol will be running for us and hoping to raise lots more money.He last ran the London Marathon in 1990, and expects to be in good shape for it this year. As a friend of Sheila and Euan Forsythe, he knows young Andrew well, and can see the benefit of our group, so felt that he would like to help.

If you are watching the race, look out for him. He is 5ft 8ins tall, has silver hair and will be running in the colours of Thornbury Running Club - sky blue vest with red hoop, red shorts and a red long sleeved t-shirt under the vest. He is number 25310, and expects to finish around 3hours 25minutes.

Please show your support for his efforts by getting as many names as possible on the sponsor form that you will find on the back page of this newsletter. Let us know that you have pledges from people and how much. We will relay the information to Chris to spur him on, and after the race we will send you an official letter confirming how he got on, which you can show to people as you collect their money.

Please let our Fund Raising Co-ordinator, Karen White (whose address and phone number you will find on page 2), know how much money you have had pledged on your sponsor form by Friday 10th April at the latest, so that we can let Chris know before the race.