



DOWN'S
HEART
GROUP

NEWSLETTER

AUTUMN 1991


Hello, my name is Joe!



Read about me on page 8


Committee Contacts

Brian Auld




Legal Advisor

Sue Bamber




Treasurer

Euan Forsythe




Chairman

Penny Green



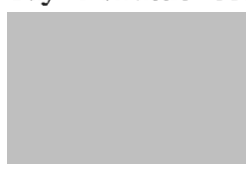
Family Support

Anna Price




Secretary

Jayne Shuttlewood



Committee Member

Linda Walsh



Founder

Can you help fill these spaces?

Editorial

Apologies to you all that it is almost six months since the last Newsletter, but during that time we have sadly lost the help of Gina Hojabri, Denis Hopkins, John King and Wendy Tucker who have all resigned from the Committee for personal reasons, which has left us rather short of helpers. We would like to thank them for all their past efforts for the Group and wish them well for the future. The loss of Denis has meant yet another change of Editor, so I have taken the job on temporarily, and I hope the Newsletter won't suffer too much as a result and that I can follow the marvellous example of my predecessors.

On a happier note, those of you with sharp eyes will have spotted a new name above in the role of Secretary. No not a new face on the Committee but a new name for Anna Danson following her marriage on 30th March. Congratulations and Best Wishes to her and husband Richard.

Penny Green

Regional Co-Ordinators

East of England

East Midlands

N. Ireland & Eire

John King & Anna Price

Rosina Brierley

London Northern

London Southern

North East England

Sandra Welsh &
Sally Hardman

North West England

Scotland

Bristol & South West

Mike Halpin

Lynn Gouck

Sheila Forsythe

Wessex

West Midlands

Yorks & Humberside

Pat Mitchell &
Noreen Hodgkinson

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

Penny Green

A Word from the Chairman

Welcome to the Autumn Newsletter of the Down's Heart Group. It has been edited, compiled and typed by Penny Green who also doubles as our National Family Support Co-ordinator. How she finds time to do this as well as look after newly arrived baby Michael I'll never know!

As you can see from the gaps in the Contact list, we have had a few people drop out for various reasons - they feel they need a rest or a change - but it looks as if John King will take over in East Midlands and will be helped by Anna Price (nee Danson). If you feel that you could contribute some time to the Down's Heart Group to help drive the Group forward, then either speak to me or better still, to Penny Green, especially if you have ever wanted to edit a Newsletter!

We are still working on a Constitution and Rules for the Down's Heart Group. Brian Auld has given a great deal of his time and advice but we have some major decisions to make before we can put the Constitution before the Group for approval and adoption.

Although the summer (what Summer?) is past its zenith, I would ask you to consider the Down's Heart Group Christmas Cards this year. They are a valuable source of revenue to the Group, plus they act as a publicity platform for our work. There were over 30 entries for the Christmas Card Competition this year, and the panel of judges chaired by Mr Paul Cross BA, chose a design by Jonathan Luntz aged 13 from Torquay in Devon. Jonathan has Down's Syndrome and he and his parents are members of the Down's Heart Group. Congratulations Jonathan on a super design, and many many thanks to all those children who sent in entries. Elsewhere within this newsletter you will find details of the cards and how to order them. They should be available from September.

The Down's Heart Group has been productive in other areas too; Penny and Malcolm Green have a new son Michael who was born on the 31st May, and Sue and Mervyn Bamber have another boy, Iain born on the 11th July. Congratulations and Best Wishes to you all, and anyone else I have missed who has had a happy event recently.

A lot of effort has gone into this Newsletter so I hope you enjoy reading it. I would welcome your comments on any matter relating to the content, layout and articles. There is even a 'Letters to the Editor' section so that you can have your say. I look forward to hearing from you.

Euan Forsythe
Chairman



A Message From The Founder

You will be reading elsewhere in this newsletter, I'm sure, about how the Down's Heart Group needs your support - we seem to have said that in every newsletter so far. But this time, more than ever, I would like to ask you to think very hard about the sort of help that a Group like this can give to families like yours when they are going through the difficult times.

If you don't believe that the Down's Heart Group has a valid job to do, then read no further. If on the other hand you believe that families and children like yours can be helped by the Group, then please consider getting involved.

At the time of the IGM last October, the active management of the Group was in the hands of a small group of eight committee members and what a busy lot they are....over the last year, those eight people have between them gone through - two adoptions, three pregnancies, one wedding, two divorces, a bereavement and two major job changes.

Even the good news events are bad news for the Group - when such important things are happening in your personal life it is very difficult to maintain voluntary commitments. The original eight active committee members are now reduced to four and of those four, three are trying to juggle Down's Heart Group commitments with vastly changed family/professional circumstances.

So, what does this mean for the Group? Well, fortunately, the depleted management committee still has a lot of enthusiasm and is supported by several Regional Co-ordinators and helpers around the country. The computer system is now in place and is making family contacts and administrative tasks much simpler now. While not bursting at the seams, the bank account has a healthy balance and the committee has established a Research Fund which will, in the long-term, be used to provide much needed research into Down's Heart problems, so long as the donations keep coming in. The Group has very sound foundations but is desperately in need of enthusiastic supporters to help it to move on and to grow. So long as the key people remain involved, the Group still has a future, albeit on a reduced level to that which we had planned in the early days.

Please ring Penny or drop her a line if you want to talk over the sort of help you might be able to offer - while planning and management skills are desperately needed at the moment, if all you have is enthusiasm and a bit of time then still pick up the phone - you are needed! Penny's number is [REDACTED]

Please remember that everything the Down's Heart Group does is done on a voluntary basis. No-one is paid for anything that they do - it is all done out of consideration for future families who may have to go through the pain, joy and anxiety that we have all faced. Any little that we can do to help these families, makes it all worth while and, even on occasions helps us to cope more easily with our own problems.

With just one or two more active committee members, real progress could be made.

Thanks for supporting the Group in whatever way you can.

Linda Walsh
Founder

Personal Profile

LYNN GOUCK (REGIONAL CO-ORDINATOR FOR SCOTLAND)

FAMILY DETAILS

I have been a single Mum for 4½ years now. I have three children, Jonathan who is 9, Sara who has Down's Syndrome is 6, and Jennifer who is 4.

DS CHILD

Sara was born on 12.10.84 in Sussex, with an AVSD. Doctors in London advised against surgery, but when we moved to Scotland, the doctors here thought differently, and Sara had successful heart surgery 1½ years ago.

OCCUPATION (Now/Prev)

I trained as a general nurse and then worked for 3 years in a hospital with adults with various handicaps. I gave up work when the children came along and now do just voluntary work.

WHY GET INVOLVED?

I became involved when I saw a letter from Linda Walsh in the DSA News, appealing for parents whose Down's children had heart defects to write to her. That was the beginning of the DOWN'S HEART GROUP.

WHY STAY INVOLVED?

I stay involved because I want to help parents who are going through the experiences I went through myself.

INTERESTS/HOBBIES etc

My hobbies are reading (anything and everything), playing the guitar and drawing. My ambitions are to live in the country, to write a book and of course to see that my children grow up happy.

GROUPS FUTURE

I hope to have more members for Scotland and I would like to see all parents who are contemplating heart surgery, to have access to as much information as possible.

COMMENTS

I would like to have more help in running the group for Scotland so that more could be achieved. So if there's any willing people out there, give me a ring!

(As well as being a single Mum with three children and acting as Regional Co-ordinator for Scotland, Lynn is also responsible for many of the lovely little cartoons that appear in the newsletters. Thanks Lynn, keep up the good work! - Editor)

Stop Press

Congratulations to David Jackson aged 8 of Oldham who raised £350 for the Down's Heart Group by going on a mile long sponsored walk on May 25th. David and his parents are members of the Group, and up until February this year David's heart condition was so severe that he had to be carried to the school bus. Yet his improvement following major heart surgery has been so dramatic, that just three months later he was able to face the challenge of a sponsored walk. We would like to thank him for the money, but more importantly to congratulate him on such a marvellous personal achievement. Well done David!

Georgina's Story

Georgina was born on the 9th of January 1987 at Newham General Hospital. I am a mum of four, and I was twenty four at the time. It was before we left hospital that they discovered that Georgina had a heart murmur. I was not too worried at this stage, as they said that some babies have this, but it can go within six to eight weeks.

Anyway, we went home, but Georgina didn't feed very well, slept a lot and seemed floppy. I told my health visitor, but she said that Georgina was a healthy, lovely baby and not to worry. I was not convinced. After calling out my GP several times, I had to take Georgina back to the Hospital for a check on the heart murmur. Still no-one would take me seriously, 'Oh she's small' they said, 'that's why she isn't eating much and sleeping so long.' By this time her chest was going in and out all the time.

I waited for my next appointment when Georgina was five months old. This time I demanded that somebody else saw her who could tell me what was wrong. A consultant, Dr Hammner, saw us and told me he thought she may have a hole in her heart, but still no mention of Down's Syndrome. Anyway, on the following Monday, Georgina went into heart failure. She was sent to Westminster Hospital for a heart scan. Imagine my horror when the doctor came back to say it was more serious than he first thought. Georgina's heart condition was worse than they had suspected, she had an AVSD; broken down into English, she had a large hole in the centre of her heart and a chamber that was merging.

A day later, he came back to tell me that Georgina had Down's Syndrome. I just couldn't grasp what was going on, I felt numb for days. All I knew was I couldn't just give up and let my baby down. Georgina went to Westminster again to have some tests that would see how bad things were. I received a letter saying that the Brompton would operate on her at Christmas of that year, when she would be a year old.

The decision to go ahead was really frightening, but none the less, I decided we must give Georgina every possible chance there was, so off we went to the Brompton. Everything was set, but come the day of the operation they refused to do it, saying they felt it was too late as she was already quite ill, and most children with Down's Syndrome didn't survive anyway. I was fuming, how dare they raise our hopes and then crush them so cruelly again.

I came straight home and contacted her consultant at Westminster who assured me he'd look to another hospital for help, and keep going until one agreed to operate, and so Great Ormond Street came to our rescue. They felt they could do the operation, but it

would have to be done fairly soon. So in October of that year, they called for us to come in. The surgery was to last five hours, the longest five hours of my life!

She came out of the theatre wired up so much that you could hardly see her. For days she just lay there; her kidneys failed, her lungs collapsed. She was very ill for weeks, at one point they told me that she would not make it because the operation had come too late. Well I prayed, and I remember sitting in a chair by the side of her reading 'Peter Pan'. Then, without any warning, she began to breathe for herself little by little, until she came off the ventilator. She'd made it, although there were still hiccups in her recovery. We spent eight weeks in hospital, and we had to go back a few times because she was ill.

Well this story is nearly at an end. Georgina still has leaks in her heart valves, a blockage in her respiratory system and she needs her eyes attending to, but she is the most happy, cheerful child I know. All through this she hardly ever complained and doesn't now. She is four years old, walks, chatters non stop, always smiles, and I think she really does love life. She is certainly a very brave and courageous child, and is very loving. I worry about her future, but for now she attends nursery twice a week, at the same place as my other children went, and although it is hard to get special teachers, they have been very good with Georgina.

I feel that all the heartache we've been through is worth it all, when you look at her cheeky smiling face and realise how close we came to losing her. But for her own grit and determination, our lives might not be as full as they are now. Having her has certainly changed me and my outlook on life.

So my story ends, but not before saying 'Thank You' to Linda Walsh & Pat, for all their kindness whilst Georgina was in hospital. They both helped me through, and for that I will be eternally grateful. Also 'Thank You' to Georgina for being who you are and for being so full of love.

*From a very proud Mum
Cindy Sharland
Stratford, London*

(In her account, Cindy refers to Pat Lucy, another Mum whom she was put in touch with through the Group. Pat lives fairly nearby and was able to take her little boy to see Cindy in the early days, and to give her hope and encouragement. The details that we ask for on our questionnaires enable us to make vital contacts for families such as Cindy's. That is why it is so important that we have all the information and that it is up to date - Editor)

Joseph's Story

Joseph was born at Southmead Hospital, Bristol, on 29th November 1989, weighing 7lb 2oz. From the moment he arrived there were obvious problems. I had had an elective caesarian and lay waiting for the first cry - but it never came. Instead, a very blue bundle was shown to me and whisked away to the Special Care Baby Unit (SCBU). John went with Joe whilst I was being stitched up and, sometime later, he returned with a doctor. As he walked through the door John shook his head, so my immediate thought was that Joe had died, but no, I was told that they thought Joe had Down's Syndrome and a complete AV canal. He had been ventilated and was a very sick little boy. I was told all this in a very concerned, caring manner, and it was a few weeks before John told me how he had been informed. The doctor who initially examined Joe, said his heart and lungs weren't working properly and when John asked if Joe was going to die, he replied "I haven't finished yet. It's a mongol." He hadn't even bothered to find out what sex the poor child was.

Some time later, I was taken to see Joe, and he was Baptised and Confirmed. Whilst I was with him, I thought his abdomen looked quite distended, but I didn't say anything as I didn't want to be told there was anything else wrong. The next morning, Dr Joffe came over from Bristol Children's Hospital (BCH) to explain exactly what was going on. He told us Joe had a complete AV canal, a patent ductus and that he was in very bad heart failure. Basically we had three options. The first was to keep Joe comfortable, but let him die. The second was to treat Joe's heart failure with drugs, in which case he would probably live till his early teens, but with progressive heart failure. The final option was to have surgery at about five months of age, which would mean Joe would have a good quality of life of normal span for someone with Down's Syndrome. There was, however, a one in three chance that Joe would not survive surgery. He answered all our questions and from what he said it was obvious he would do everything he possibly could for Joe. That was all we needed to hear.

By this time Joe's abdomen was becoming a problem, and another doctor was called from BCH. He wanted Joe transferred there, as he felt that he needed investigative surgery. This was during the ambulance drivers dispute, but they were great, providing transport for both of us. The ambulance for me arrived at about 5.00pm and it didn't take long for us to cross Bristol. Come 10.00pm, Joe still hadn't arrived and I was desperately worried. Eventually, at 11.45pm I was called down to SCBU. It turned out that Joe's bowels had decided to work during the journey and there had been a massive explosion covering the floor of the ambulance and the incubator! Joe had also managed to extubate

himself, so quite a lot had to be done before I was allowed to see him.

Joe was ventilated again, and the next few days were spent stabilising his heart failure. On the fifth day of his life he had surgery, a colostomy was formed as he had Hirschsprungs Disease. By this time I had gone home, as we felt it was important that our two other children felt secure in all that was going on. John and I spent every day doing a shift system of visiting so someone was with Joe most of the time. John is a teacher, and had been given sick leave for the remainder of the term. He was due to be start a Headship in North Yorkshire in January, but this was postponed for a term as no-one was sure if Joe was going to survive. Meanwhile he had a temporary job for the Spring term. Our two daughters had lots of contact with Joe and loved him from the moment they saw him. They wanted to be with him, and were made very welcome by all the staff on SCBU.

Just before Christmas we were told that there was a real difficulty controlling Joe's heart failure and he was a desperately sick child. Spirolactone was added to the Frusemide and Captopril Joe was already taking and this made a tremendous difference to him - so much so, that on January 14th he came home. We were tube feeding him, but he was our child for the first time since he had been born.

Ten days later, the day of the awful gales, we returned to BCH. Joe has a chest infection which rapidly turned to pneumonia and within days he was in ITU, ventilated again. After about a week the pneumonia was clearing, but it had thrown Joe into terrible heart failure. It was decided that he needed a cardiac catheter to find out exactly what was going on, and it was discovered that although the pressures in his heart were very high, he was 'borderline operable'. Meanwhile, Joe's poor little body was filling with fluid - he had ascites. Another diuretic was added - metellazone - but this had little effect. It was at this point that I began to question what we were doing. Should we keep trying to keep Joe alive when he was giving every indication that he needed to die?

A few days later we were told nothing else could be done for Joe with drugs, the only option was surgery - ligation of the Patent ductus and a band around the pulmonary artery to reduce the flow of blood to the lungs. Dr Joffe seemed very positive this should help, although as Joe was so sick, it was doubtful he would survive the anaesthetic. The very next morning, when we phoned to see how Joe had been overnight, we were told that he was having surgery that day - 21st February. We went straight to Bristol, having left the girls with friends, had a cuddle with Joe and he was taken to theatre. Four hours later we

returned to be met at the door of BCH by Dr Joffe, who told us Joe was back in ITU and so far all was well.

Gradually the fluid Joe was carrying disappeared and on March 1st, Joe was extubated. A few days later he left ITU and on March 13th he came home again. He was three and a half months old and weighed 7lb 2oz. Joe was still being tube fed, but he hated it, so I removed the tube and began feeding him with a syringe. It took a long time but it was the only way I could get him to take anything.

A week later Joe was recessing badly and was sweating a lot so our doctor sent us back to BCH where Joe was readmitted to the Baby unit. Dr Joffe did an echo that evening and his diagnosis was confirmed - Joe had a pericardial effusion (fluid around the heart), which meant his heart couldn't pump efficiently. Over the next three months Joe caught numerous infections and various drugs were used to try to clear the effusion. Nothing worked, so it was decided that it would be tapped. It was arranged for Joe to go to ITU immediately after this, to keep an eye on him. 45mls were drawn off and Joe seemed better immediately. The fluid gradually re-accumulated, and a fortnight later another 50mls were drawn off. Two days later, Joe was in big trouble! His left lung had collapsed and he was in ITU being prepared for a permanent drain to be inserted, when he arrested. Thank God there was an Anaesthetist there who promptly sorted Joe out. 128mls were drawn off and a drain was left in site. For the next few days fluid was drawn off daily, but after five days Joe pulled the drain out. Thankfully this time the fluid did not build up again, and on 11th June, Joe came home weighing 8lbs.

Over the next two months we had regular trips to BCH, and Joe very slowly began to grow and gain strength. In August he had his second catheterisation which initially seemed promising. The pressures in the heart were still on the high side but he was operable. During the catheter, however, Joe's left ventricle had been pumping very inefficiently and there was considerable concern over this. Joe was therefore called for another echo and we went to see the surgeon. We were given 50:50 odds for Joe surviving surgery, but he was being offered the chance of a good life. We never had any doubts over accepting - he had fought through so much and obviously had a tremendous will to live, so we couldn't deny him the chance he was being given.

By the time Joe was one year old he was rolling around, sitting up and coming on well developmentally. In December he was back in BCH to have his tear ducts probed, and then we had a good

Christmas. On 1st January '91 Joe started a rather nasty chest infection which took us back to BCH again. On 14th January we were called to Bristol Royal Infirmary for surgery on 16th, but couldn't go because of the infection. On 17th all surgery was stopped because of the Gulf War, and there followed an agonising fortnight as we waited for surgery to get going again. On 31st we were told that Joe's surgery was scheduled for 14th February - St Valentines Day.

The day before we were meant to be admitted, the surgeon rang to say he had an emergency case and therefore we shouldn't go in. On the morning of 13th we were called in and all the necessary tests were done very quickly. There were still doubts as to whether or not surgery would go ahead right up until the porter arrived to take us down to theatre, so we didn't have much time to worry. In fact, when we left Joe, the feeling was one of tremendous relief that things were actually going ahead.

John and I went home to spend the day with the girls. We phoned as instructed, at 2.00pm, at 3.00pm when we were told he was off bypass, and again at 4.30pm when we were told he was on the ward. It turned out that the anticipated problems of Joe's heart getting going again after bypass just hadn't happened, and Joe was back from theatre four hours earlier than expected. There were some initial problems, first with low blood pressure, and then with high left atrial pressures, but generally everyone was pleased with what was going on. After 13 days, Joe was off the ventilator and we were transferred to BCH ITU. Three weeks after surgery Joe was home.

Five weeks post surgery, Joe is doing all that he was pre surgery and making valiant attempts to do more. It is obviously early days yet, but we are told he has only minimal leakage of the mitral valve and there is no problem with the pulmonary artery. We still have his colostomy reversal to go through, and probably surgery for a convergent squint, but the future looks good. Our aims for Joe are that he should live life to the full and achieve all that he is capable of, eventually living independently, away from us.

The last fifteen months have taken their toll on all of us, particularly John, but the two girls have been tremendously strong, although the five year old is older and wiser than most children of her age, and the three year old is a lot less confident, socially, than her peers. However, they are delighted that Joe is now well and at home with us.

*Gill McLorinan,
Weston-Super-Mare*

(I met Joe and his Mum at the beginning of July, and what a super little chap he is and a picture of health! - Editor)

Jack's Story

We knew that the news would not be good when we heard the consultant outside the door say, "Is there a chair for the father to sit on?". Then he came into my private room (why had I been put in there?) with his solemn-looking cohorts and told us that our much-planned, long-awaited first baby, seven hours old, had Down's Syndrome.

For a split second, I felt outraged disbelief: I had worried long and hard about this very thing, therefore, it could not have happened. (In fact, I had not worried about it for some months, as I carefully tailored my worries to the stage of my pregnancy - up to 12 weeks: blighted ovum, miscarriage; up to 20 weeks: Down's Syndrome and miscellaneous; 20 weeks plus: incompetent cervix; and in the final stages: prematurity and foetal distress leading to brain damage.) Then the sheer horror of it washed over me; the worst thing that I could ever imagine happening to me was actually happening. I burst into tears, and Jack, who had been asleep in my arms, followed suit. I was encouraged to hand him over to a midwife, and did so with some relief.

After a rather remote and non-committal forecast by the consultant, I was asked if I wanted to hold him again. I felt that at that moment our entire future hung in the balance. (I had sworn to myself and everyone else throughout my pregnancy that if there were anything seriously wrong with the baby I certainly would not keep it.) More out of a feeling that I would shock everybody if I said, 'No, take him away, I never want to see him again,' than anything else, I said yes.

We talked for hours about our feelings for Jack and our fears for the future, only to have all our emotions and ideas thrown further into turmoil the following day, when Jack was diagnosed as having a serious heart defect. That afternoon saw us whisked off to Hammersmith Hospital. Jack was borne along the arctic corridors in a carry-cot by his father and a nurse. I shambled along in their wake, draped in dressing gown and overcoat, as we went from paediatric outpatients to X-ray - where they called out his name as if he were a proper person, not a fragile neonate of no fixed identity - to ECG and ultrasound. Yesterday we'd been wishing that Jack would die. Today now that it seemed as if he might,

we were still wishing he'd die, but hoping simultaneously and desperately that he wouldn't. When we got back to the maternity hospital, a young paediatrician whose directness and sympathy we had come to value took a couple of Polaroid photos of us with Jack, just in case...

In that first year Jack had two shunt operations (the second being an emergency operation when the shunt put in during the first operation suddenly closed up), to help him cope with his Fallot's Tetralogy by diverting extra blood through his lungs to compensate for the mixing. On top of that we had a false alarm of epilepsy; then, when he was ten months old, he had meningitis. He was in a coma for three days and not expected to live. But slowly, slowly, he came round, mercifully with all his senses intact.



By now we felt that we had learnt to just sit back and accept whatever fate had in store for us next. However, when we went into hospital for a third shunt, as he was beginning to outgrow the second, we assumed he would sail through it as easily as he had the first two. Not so. In an attempt to give him a shunt large enough to last him until he could have his total heart correction, the surgeons in fact made it too large, and he just could not cope with the volume of blood going through his lungs. It was pitiful to watch him lying in intensive care in an agitated state, pulsing all over. After a week

of this he was taken back to theatre to have his shunt banded. Having two operations for the price of one, as it were, had taken its toll on him, and he was on a ventilator for ten days. When he came off it, I was appalled: he stared at me without recognition, his arms twitched involuntarily, he whimpered the whole time, and he could no longer even hold his head up, let alone roll over or sit up. At eighteen months, after all our hard work with him, he was right back to square one. At the time I had no way of knowing that the effects of hypoxia, (lack of oxygen during the operation) would not be permanent. After a total of five weeks in hospital we brought him home. He remained deeply distressed for several weeks, waking every hour throughout the night.

Now that he is six, all this seems a very long time ago. Although we had always been told that Jack would

have his total heart correction at the age of five or six, the Big Op has now receded. His present consultant is keen for it to be left as late as possible, as Jack will require a replacement valve as well as the patching, and to do it too soon might mean that he would outgrow the valve and require yet another operation. After Jack's last shunt, I have no desire to rush into surgery, despite the benefits it might bring.

The strange thing is, most of the time I don't think of him as frail in any way. What he lacks in strength and stamina, he makes up for in wilfulness and sheer personality. He brawls with his brother, hectors his parents and certainly makes likes and dislikes known. He is great at clearing the table, loves dancing to records, pouring over books (chiefly the 'Alfie' books)

and listening to tapes. He is, though, hopeless at walking, as much because of his fear of becoming exhausted and breathless as anything else, but there's nothing that motivates him like the sight of our car. However pathetic and distressed he may be, once he spots it and realises he is on the home stretch, he produces a sudden burst of speed and bears down on it with cries of joy.

His latest achievement is one I would not have dreamed possible six years ago - he has just become the proud possessor of the Amateur Swimming Associations Puffin Badge for swimming five metres with armbands on!

Verity Ridgman

Items of Interest

Making the National Curriculum Work for Children with Severe Learning Difficulties

The British Institute of Mental Handicap is running the above workshop at Westhill College, Birmingham on September 28th 1991.

Further details from : BIMH
Kidderminster Road
Wolverhampton
Worcs.
DY10 3PP
Tel: 0562 850251

The Makaton Vocabulary

Makaton provides the non-speaking mentally handicapped with a means of communication, but it can also be used in conjunction with speech. It consists of a core vocabulary where each word is expressed by a sign or symbol, and the sign and the word are used with a suitable facial expression to enforce their meaning. Castle Priory College is running a course from 4th - 6th October 1991.

Further details from: Castle Priory College
Wallingford
Oxfordshire
OX10 0HE
Tel: 0491 37551/26350

Contact a Family Directory of Specific Conditions and Rare Syndromes

After 18 months of research, supported partially by the Department of Health along with others, Contact a Family are launching the above Directory on 4th November. It contains information on almost 200 specific conditions including medical descriptions, details of available Support Groups and Organisations, notes on pre-natal diagnosis and lists of Regional Genetic Centres and other useful organisations.

Available at £40 from: Contact a Family
16 Strutton Ground
London
SW1P 2HP
Tel: 071 222 2965

Down's Syndrome Blood Test

On May 14th, the Daily Mail reported that a new blood test to detect Down's Syndrome is being offered by St James' University Hospital, Leeds, and Leeds University, but it is not available on the NHS. The test which costs £88, claims to detect 80% of affected pregnancies. Apparently, anyone applying for the test will be offered counselling and be sent a kit to be taken to their GP who will take the blood sample.

Postural Drainage and Breathing Exercises for Children with a Chest Infection

(Please consult your physiotherapist before using the following procedures. - Editor)

Postural Drainage is defined as placing the child in various positions in order to drain secretions from the lungs by means of gravity. This can be further assisted by use of breathing exercises, and by clapping and shaking the chest wall. Once the secretions reach the large airways, they can be coughed up more easily.

The areas requiring drainage will vary from child to child and your doctor should be able to let you know which areas need draining most. The postural drainage can be done 2-3 times a day depending on the amount of secretions present.

Small babies can be treated on their parents' knee before feeds. As the child grows older, it will be easier to treat him on a bed over pillows or a foam wedge. It is often difficult to get toddlers to remain in one position for any length of time, but if they run or jump up and down in between short sessions of postural drainage, this often stimulates a cough. Often postural drainage in front of the television or someone reading a story to the child, is easier.

Postural drainage should not be given immediately following a meal because this may cause the child to vomit. Babies should be treated just before a feed. Babies and smaller children will swallow their sputum, but as soon as the child is old enough to understand he should be encouraged to expectorate into tissues.

Percussion is a type of clapping of the chest wall which is done with the hands cupped. It should never be painful and is best done over a layer of clothing. It is a rhythmical, relaxed movement from the wrist done over the rib cage area. Short periods of percussion combined with 3 or 4 expansion breathing exercises (see below) are done at intervals throughout the postural drainage treatment.

Chest Shaking or Compression is a coarse shaking of the rib cage during the relaxed breathing out phase of the expansion exercises.

Breathing Exercises can be taught from the age of about 3 years and have several different uses.

When the breathing IN phase is emphasised this helps to loosen secretions and keep good movement of the lower chest - expansion exercises. During these exercises breathing out is quiet and relaxed.

A breathing exercise where the breathing OUT phase is emphasised can be used to move the secretions along the airways so that they are easier to cough out.

Gentle breathing not trying to breathe in deeply or breathe out forcefully helps to overcome breathlessness and to prevent tightness in the chest - breathing control.

A programme of exercises while in any postural drainage position could be:

1. Breathing control: relaxation and gentle breathing with the lower chest.
2. 3 or 4 deep expansion breaths combined with percussion.
3. Breathing control.
4. Breathing exercise concentrating on the breathing OUT phase, which may help to produce a cough.
5. Breathing control.

As the secretions loosen and reach the upper airways a deep breath is followed by a cough to clear them. After coughing there should again be a pause for relaxation and breathing control. This series of exercises is repeated until the area being drained is as clear as possible. Drainage is then carried out in the other required positions in the same way.

With the children who are too young to co-operate with the breathing exercises, postural drainage is done in the various positions with percussion and shaking, leaving time for the child to relax after coughing.

Postural Drainage Positions

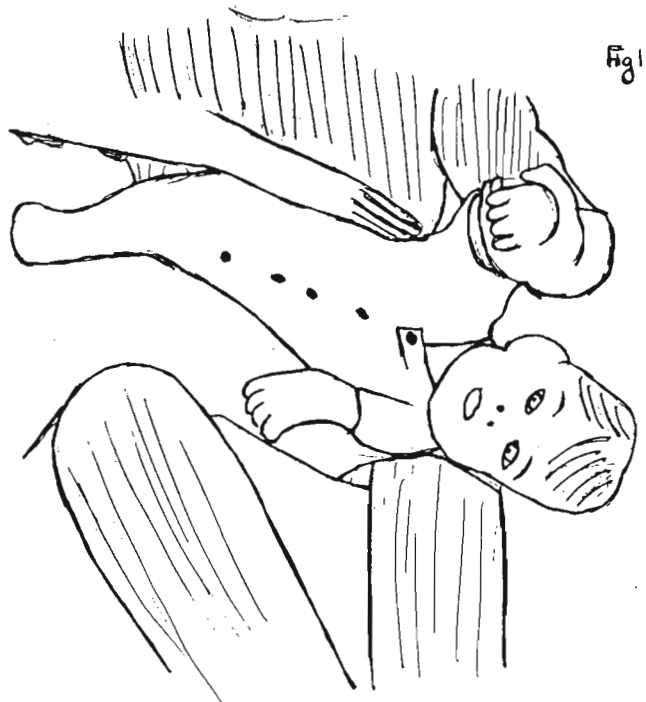
There are 4 main positions in which to carry out the above ideas, with a fifth one added for babies who can not yet sit up.

Tipped head down over a knee or a wedge:

1. On their tummy
2. On their left side (Fig. 1)
3. On their right side
4. On their back
5. Sitting upright (for babies who spend most of their time lying down, this position needs to be included to drain the upper lobes). (Fig. 2)

It is important to be aware of your child's ability to be laid flat or tipped up, as some children with breathing difficulties or heart problems will not be able to tolerate all the positions. If your child has a chest infection it is best to initially ask the advice of your physiotherapist and then on future occasions you will know what to do.

*Lindsay Caley
Senior Physiotherapist
Westgate House Children's Centre
Southmead Hospital, Bristol*



INFORMATION NEEDED

With this newsletter, many of you will have also received a separate request for more information for our records. Whilst we realise what a nuisance it can be filling in forms, we really do need to know.

We now have all family records on computer, and although it is difficult to envisage exactly what information would be required by anyone carrying out a detailed research project, we have tried to structure our records so that we have a good basis for helping any such project. We also ask other questions that are helpful when we are trying to cross reference families who have asked for contact with another family in similar circumstances.

With details of nearly four hundred children now on record, we should have a good database of information for the benefit of everyone, but it is vital that we fill the gaps that currently exist, some of them in quite basic details such as names and dates of birth.

PLEASE help by returning the documents you have received complete with the relevant details, AS SOON AS POSSIBLE.

Those of you who have decided against surgery, or whose child is inoperable, your information is just as important, so PLEASE complete the details accordingly.

Once this information is on computer, there should be no reason to trouble you further, unless some kind of research study is undertaken, when we might write to specific families for more details as necessary. Other than that, all we ask is that you notify us of any change in details, ie. address, phone number etc. and of course we will always be interested to hear about any surgery that your child has undergone,

SO PLEASE KEEP US INFORMED.

**OUR INFORMATION IS ONLY USEFUL FOR FAMILY
SUPPORT AND RESEARCH PURPOSES IF IT IS KEPT
UP TO DATE.**

(For anyone who is concerned, please be assured that we never give out personal details, phone number etc. without first contacting you to ask your permission, so there is no danger of you suddenly getting an unexpected call from another parent, you will always have the opportunity to say if it is inconvenient.)

Other Groups

Below are the details of some other organisations which you may find it useful to know about. This is only a small selection, but we do have information on many more, so if your child has a particular problem which is not common to children with Down's Syndrome, but you would like to know more about, please contact Penny Green who may be able to give you details of another group that you can contact.

IN TOUCH

This is a small but very helpful organisation which aims to put parents of special needs children in contact with others in a similar situation, no matter how rare the child's condition or combination of conditions may be.

A newsletter is published regularly and IN TOUCH holds occasional get-togethers (the next one will probably be in Manchester later this year). They keep a register of enquiries, including many from parents of children with Down's Syndrome plus another condition and they also have details of just about every support group that exists in this country, plus many others abroad. They publish three handbooks for parents and professionals:

Useful Addresses for Parents with a Handicapped Child	Price £4.75
Glossary of Mental Handicap & Associated Physical Disorders	Price £5.50
Coming to Terms with Mental Handicap	Price £7.50

Further details from:
Ann Worthington
In Touch
10 Norman Road
Sale
Cheshire
M33 3DF
Tel: 061 905 2440

NATIONAL ASSOCIATION FOR FAMILY BASED RESPITE CARE

This organisation brings together users and providers of those schemes offering respite care to

adults or children with severe handicaps and their families, across the country. These respite schemes offer parents and carers a well-earned break by using other host families or individuals to take over that care for short periods of time.

The Association held its first conference in Nottingham in July 1990 and it publishes a booklet 'Directory of Family Based Respite Care Schemes' listing some 200 respite care schemes throughout the UK.

Further information from:

Christopher Orlik
Research and Development Officer
Nat Ass for Family Based Respite Care Schemes
Norah Fry Research Centre
University of Bristol
32 Tyndall's Park Road
Bristol
BS8 1PY

BRITISH HEART FOUNDATION

The British Heart Foundation funds research and strives to improve the facilities for cardiac care, as well as offering an information service to members of the public and professionals alike. Although much of their work aims to educate the general public on how to reduce the risks of cardiac problems in later life, some of their publications are, in fact, of interest to those of us whose children are born with heart problems.

The following titles in their 'Heart Research Series' are of particular interest:

No.5	Congenital Heart Disease
No.6	Medicines for your heart
No.9	Pacemakers
No.11	The heart - technical terms explained
No.17	Cardiac Investigations & coronary angioplasty

These are pocket-sized pamphlets which are available free of charge from any regional office of the Foundation or from the new Head Office address:

14 Fitzharding Street
London
W1H 4DH
Tel: 071 935 0185

A range of publications and teaching aids, including posters and videos, are also available.



Can You Help?

Down's Syndrome and Cholesteatoma

As mentioned on the proceeding page, In Touch keeps a register of families with special needs and, no matter how rare the condition, they will do their utmost to find another family with a similar problem. At the moment they are seeking a contact for a family whose child has Down's Syndrome & cholesteatoma. If you can help at all, please contact them at the address shown on the previous page.

(THE FOLLOWING TWO ITEMS ARE REPRODUCED FROM THE IN TOUCH SUMMER '91 NEWSLETTER)

How Parents Learn About Their Diagnosis: Tell Us Your Story

"Was your child born after 1st January 1986? If so, we'd like to hear from you what your experience was like. Please tell us what you liked about the way you were told and also what could have been done better. Your recommendations will be very welcome. How old is your child now? When did you learn that he or she might have a disability - was this before the baby's birth, soon after the birth or some time after the birth? How did you feel about the way you learned the news? Were you satisfied or dissatisfied with the way you were told? What could have been done to make it easier for you? Any other comments or suggestions? There are a number of other points which we are looking at and we have prepared a leaflet that sets these out. We would be pleased to supply a leaflet to anyone who would like to find out more. Please send us your views and experiences. The working party was set up by the Regional Mental Handicap Advisory Group and its members include a social worker, a consultant paediatrician, a child psychiatrist, a midwife sister, a parent and a lecturer. We'd be glad to hear from you.

Please write to: Chris Gathercole



(If you do reply to this, could we ask you to make an extra copy of your story to send to the Down's Heart Group - if we recieved a few stories it would be interesting to compare them and perhaps summarise your feelings in a future newsletter. - Editor)

The Use of Complementary/Alternative Medicine by Disabled People

Andrew Vickers.

TEL: 011 607 6015

"I am working on a project concerned with the use of complementary/alternative medicine by or with disabled people. I am writing a book on the subject and am liasing with the Spastics Society on a directory of practitioners who have experience of disability work. My guiding aim is to allow disabled people, and those who care for them, to make informed decisions about complementary medicine and to enable them to obtain such healthcare, if they so choose. The best way of compiling the necessary information is to contact directly all disabled people or carers who have experienced techniques such as yoga or homeopathy. It is important that I hear as many reports as possible. I would appreciate anyone with appropriate experience contacting me at the address above."

(Once again, an extra copy of your experiences to the Down's Heart Group, please! - Editor)

**With Winter rapidly approaching,
don't forget to order your
DOWN'S HEART GROUP
sweatshirts now!
(They make great Xmas pressies!)**

SWEATSHIRTS

Sky blue, grey or white
with pink heart and black script.
Adults S M L XL £9.99
Children's 24" 28" 32" £6.99

TEESHIRTS

White with pink heart and black script.
Adults S M L XL £4.99
Children's 24" 28" 32" £3.50

Prices are inclusive of VAT,
postage and packing.

Please phone to confirm availability of size and colour, then send written order with cheque or postal order payable to 'Down's Heart Group' to:

Mara Young



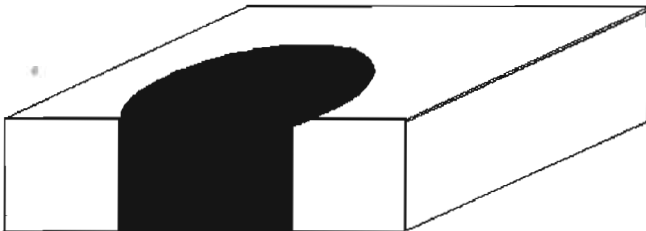
Ideas

Back in the first issue of the Down's Heart Group Newsletter, Tony Linde suggested that it might "be useful to pass on to each other experiences which had been helpful in bringing up our children: pieces of equipment that we'd found worked well, unusual toys or hints on overcoming any of the difficulties we'd been faced with. Sometimes the simplest item of equipment or idea can be a godsend." Maggie Linde went on to describe all sorts of useful but very simple (and inexpensive!) equipment which they had used with their daughter, Katie. One of the biggest successes was nothing more exotic than a bean bag which Katie loved to sit/lie on as a baby and used right up to the days when she was learning to walk - she was happy to take a step or two towards it, knowing that she would have a soft landing!

Despite this excellent start, I get the impression that we haven't exactly been inundated with response from readers eager to pass on their success stories. So, pens out please - just a few minutes of your time now to scribble a few notes for us, may make all the difference to a family that you have never met.

To start the ball rolling again, here is an idea that we found very useful for our little girl (another Katy). Although Katy was not particularly late in learning to sit up, there still seemed to be a long period of time when she couldn't really hold herself up for more than a few seconds at a time. And yet she was more than keen to enjoy the sort of 'hands free' play that you can only do once you are sitting quite steadily. 'Support your baby round the hips' say the books - well, yes, fair enough if you have the time to sit on the floor for hours on end, but what does baby do when you have other things to do?

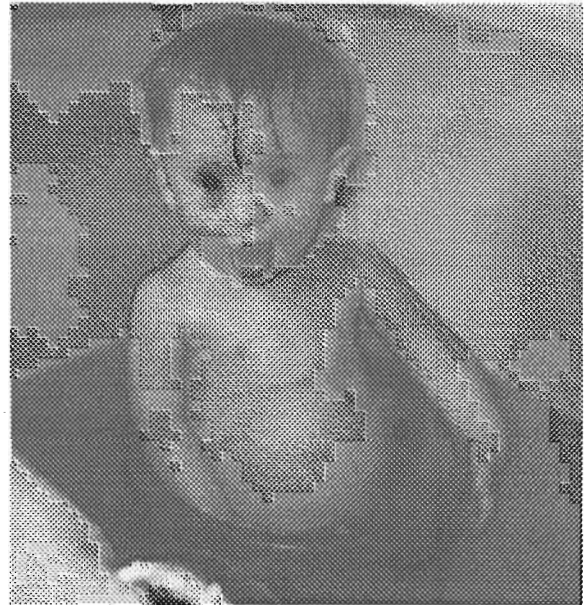
Just as we were coming to the end of this period, we discovered the 'bum-wedge' and although we only used it for a few weeks, we just knew that it had been an enormous help to Katy. It was simply a large, thick, square of foam rubber with a 'Capital D' shape



cut out of one edge so that the square fitted snugly round Katy's hips. This gave just enough soft support to stop her from wobbling over and it left her hands and arms free to get on with all the things she wanted to do. And as she was on the floor, she wasn't forever losing things, as so often happens even with the best-designed tables and trays.

To begin with, we used a double thickness of foam which supported her right up to waist/arm-pit level, but as her back grew stronger (and we're sure the wedge helped here) we were able to take away the top layer so that the foam only supported her round the hips and she had to work that little bit harder to stay upright.

Linda Walsh



As a baby, Edward disliked having a bath intensely. I don't think he was adverse to being clean, but just that he felt insecure being hoisted into the water on my arm and left precariously balanced against it whilst I doused him with soap and water.

At nine and a half months, my physio recommended I use a stability ring for him to sit in. She had suggested it for a child with Cerebral Palsy and it had worked well. Edward was by then sitting (if a little wobbly) so I thought it a good time to try it out.

Well there was no looking back. Edward took to it from the start. He would hold onto the rail to support himself initially and gradually learnt to lean forward and splash us all. He now adores the bath, screaming when I remove him. I stopped using the ring at about seventeen months, having continued until then as Edward has his bath with his twin sister and two older siblings, and needed a little protection from the 'rough and tumble'.

The ring has four legs which adhere to the bottom of the bath with suction pads. It is made by Tota and is available from large branches of John Lewis.

Debbie Scurter

Letters to the Editor



Haberman Feeder

Following the article in the last newsletter about the Haberman Feeder, I thought I would write to tell you of my experiences of using it.

When my son Jamie was born in January 1989, he was tube fed as he was too weak to suck. Along with the speech therapist, we tried continually to encourage him to suck from an ordinary teat, but it took about an hour for him to take 30ml of milk, and this left him exhausted and breathless.

After about a month, the speech therapist introduced us to the Haberman teat which allowed me to help Jamie by squeezing the chamber, so although he was sucking, I was doing the work for him. Within a week the feeding tube was removed and Jamie was able to take 80ml of milk in about 15 minutes, and because of this he was allowed to come home. As he grew stronger, he was able to take a full feed in 20 minutes.

The Haberman has also been useful on those occasions when Jamie has not wanted to feed, as I have been able to squeeze the milk into his mouth. This has been useful as recently as the last few months, as Jamie had corrective surgery in February this year, and I used it for a while afterwards when he was still recovering from the operation.

The Haberman worked very well for us, and apart from saving a lot of frustration with feeding, it certainly gave Jamie the chance to come home much sooner than if it had not been available.

On the negative side, it is only available through mail order and is expensive, although it is possible to get a grant from the DSS depending on your circumstances. Also, it should be mentioned that the teats do not fit all bottles, but I found that Boots and Maws were both compatible.

All in all, the advantages far outweigh the disadvantages, and I often wonder how I would have managed without it.

Debbie Barron
London

Musical Children?

I wonder if there are any parents who have a child who plays a musical instrument. If so, I would be very interested to hear from them & share their experiences. Please contact me at the address below:

Kay Morgan



'Heart News'

Dear Sir/Madam,

This is a plea on behalf of 'Heart News', which you should have received an information leaflet about at a recent Heart Care conference. We would really like you to help us by attracting 11+ readers to join our subscription list. If you have a newsletter/magazine for your group which you could place an advertisement in for 'Heart News', then it would really help.

Oliver Benson
Editor: Heart News



Oliver is the son of Fiona Benson of Heart Care, he has had heart surgery himself, and has set up a group for the the children themselves to join. If your child is 11 or over and you would like to know more, please write to Oliver



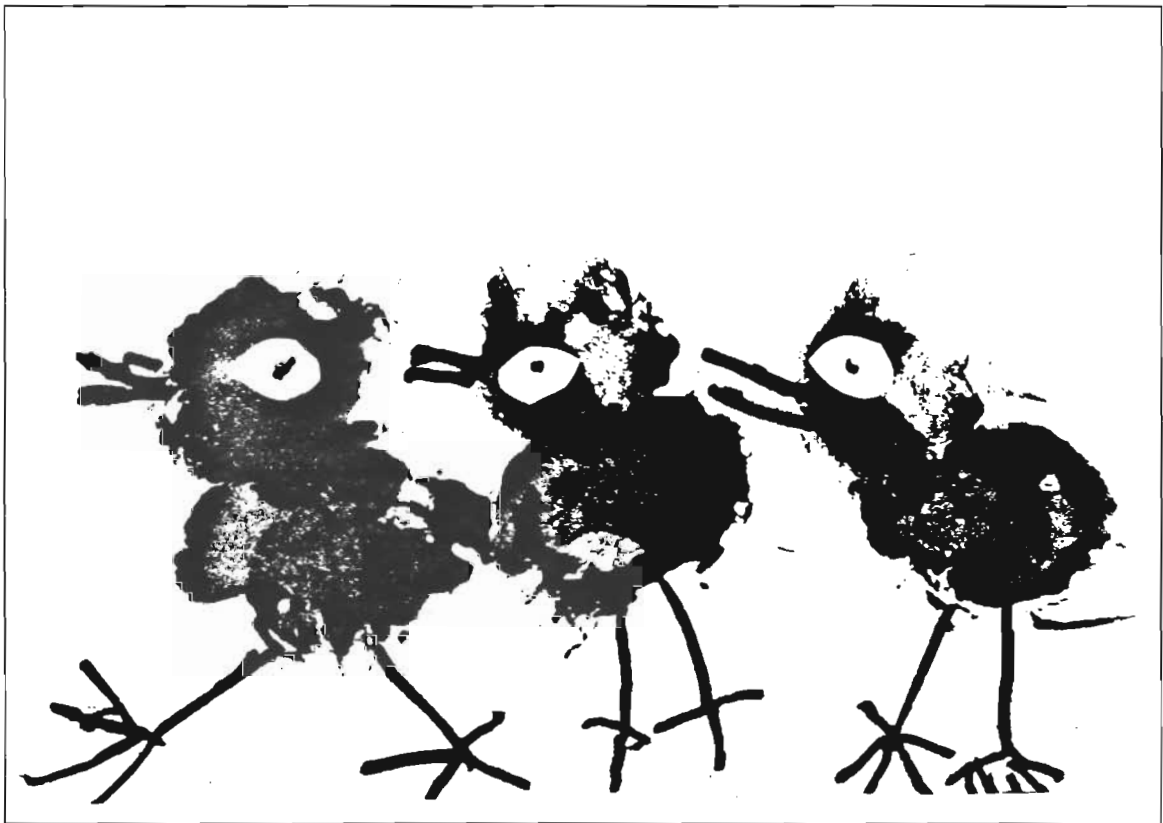
If you would like to have a letter published in the Down's Heart Group Newsletter, please write to:

**The Editor
Down's Heart Group**

DOWN'S HEART GROUP

1991 Christmas Cards

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*Cards will be available in packs of 10 for £1-30p
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