DOWN'S HEART GROUP NEWSLETTER

Katie Walsh, Christmas 1984

Who's who?

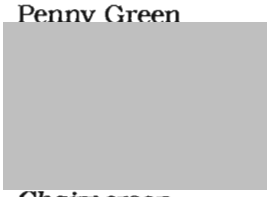
Brian Auld

Legal Advisor

Sheila Forsythe

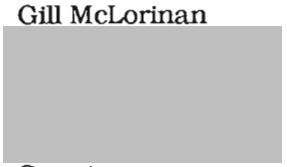
Vice-Chairperson

Penny Green



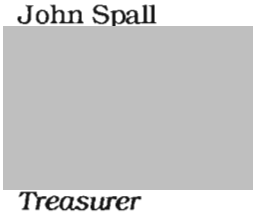
Chairperson
Family Support Co-ordinator
Newsletter Editor

Gill McLorinan



Secretary

John Spall

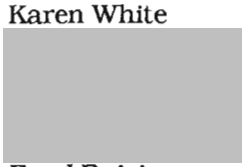


Treasurer

Lyn Stallwood

Bereavement Co-ordinator

Karen White



Fund Raising

Linda Walsh
Founder

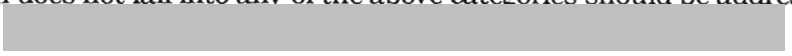
Who Do I Contact?

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 relevant 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 the above categories should be addressed to the main office: Down's Heart Group, 

Chairperson's Report

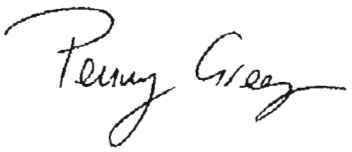
Well here we are with the Autumn/Winter edition of the newsletter! Doing three jobs for the group continues to keep me busy, along with looking after my own family, and I had an operation on a knee at the beginning of June which left me out of action for several weeks, so it's taken a while for me to catch up with everything. And all of this at a very busy and important time for the Down's Heart Group.

As most of you will be aware from the letter you received in May, we decided to apply for registration as a charity, and this meant that plans had to be made for an AGM on the 18th June, as well as all the paperwork involved with the application itself. Anyway, in the event all went well, our application was accepted within a fortnight, despite expectations that it would take much longer, and the AGM went well. I won't bore you with the all the details, as you can see from the previous page who was elected to which positions, but I would like to say thank you to all those who made the effort to attend, I hope you found the day was both informative and enjoyable. I was personally pleased to see faces both old and new, and would like to thank everyone for their support, especially all those involved in the organisation on the day, who did lots of running about and made me feel most inadequate hopping around on my crutches. I hope that next year we may see even more members in attendance.

As a result of our registration as a charity, it is now necessary for us to formally set up a membership list. Normally, this would be a simple task linked to a membership subscription whereby you were not a member unless you paid. We have decided, however, not to make such a charge, so we are asking everyone to confirm their wish to be members by signing and returning a simple form. Many of you have already done this using the form that was sent with the notification of the AGM, those people who have not done so, or whose forms have not reached us, will find another enclosed with this newsletter. PLEASE NOTE this is the last newsletter that will be sent to you unless you return the form by 31st October 1992. We will of course reinstate membership after that date, but this will only be upon your written request, so please do reply as soon as possible.

We are now looking to the future! As a registered charity new doors have opened to us, but we are limited in our exploitation of these by the lack of free time available to our already busy committee members. So once again can I remind you that we need your help, not only to fill vacant positions on the committee, but more importantly in supporting us in the groups aims. One way in which this can be done is by sending in stories and tips for the newsletter which can be shared with other members, also by spreading the word about our group to anyone who is likely to come into contact with families who could benefit from the support and information we can offer. We are still a small organisation, but comments from families confirm that there is a strong need for the specific type of help we can offer, and the committee is committed to taking the group forward and eventually reaching all families who have a child with Down's Syndrome and an associated heart condition. To do that we need the continued support of all our existing members, you all have very valuable information and understanding from your own experiences which can be shared with other families, especially those newly facing the problems, but in order to be able to operate an efficient system for family contacts and research ,we do need to have a certain amount of information about you on file, so please do keep us advised of major happenings in your child's life, not just those related to their heart either.

Finally, may I take this opportunity of wishing all of you a slightly premature 'Merry Christmas and Happy New Year' on behalf of everyone at the Down's Heart Group. I hope that next year may bring the opportunity to meet even more of you face to face, in the meantime please keep sending in the photos of your children which always make opening the post so worthwhile, and thank you for your valued support.

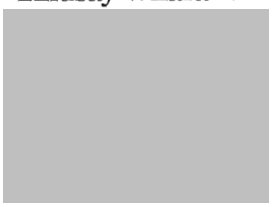


P.S. Don't forget this years Down's Heart Group Christmas cards are now available, please show your support by ordering some (see page 20 for details)

Regional Co-ordinators

East of England

Lindsay Wharam

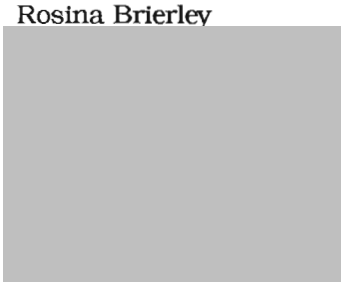


East Midlands

Anna Price

N. Ireland & Eire

Rosina Brierley



London Northern

Morag Malvern

London Southern

Katie Spall

North East England

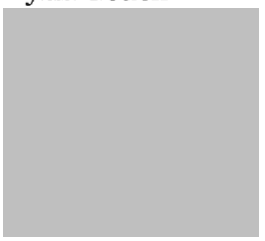
Sandra Welsh &
Sally Hardman

North West England

Mike Halpin

Scotland

Lynn Gouck



Bristol & South West

Sheila Forsythe

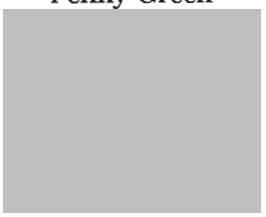
Wessex

West Midlands

Pat Mitchell &
Noreen Hodgkinson

Yorks & Humberside

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



Emily's Story

Our second child, Emily Jane was born, on 25th July 1990 at home. It was a planned home delivery, and looking back I am so pleased that she was born there; there was no taking her away from me or me feeling helpless. The midwife and GP left the room after her birth, ostensibly to give us time with the baby. I picked her up, I looked at her and shouted out to them "I think she's got Down's Syndrome", feeling as if I was commenting on her hair colour, (the shock didn't hit me until much later.) They came back and agreed, saying that they would get a Consultant Paediatrician round to see her. Unfortunately, I then bled so we had to be admitted to hospital, but Emily remained with me constantly. The paediatrician confirmed Down's Syndrome, but commented that he couldn't hear anything wrong with her heart, which was my main worry as the majority of my contact with children with Down's Syndrome as a paediatric nurse had been in relation to cardiac problems. By chance, the hospital had an echo machine on loan so said that they'd just check with that, but when they did, it was obvious even to my inexperienced eye that there was something very abnormal about her heart.

I sat there with little Emily asleep on my lap, tears flowing, as the doctors went off to discuss their findings. Hours before, I'd half hoped that they'd find something inoperable so that I could give her a wonderful life for a few years without the worry of her as an adult, but I felt very differently now. The compassionate paediatrician soon returned and explained with the aid of diagrams, what was wrong - a complete AV Canal defect. He also said that it was operable with pretty good results, and that he would refer her immediately. Emily didn't appear to have any obvious symptoms of a heart condition, and actually remained extremely well and asymptomatic until just a few weeks before she finally had her operation.

We attended Southampton General Hospital in October, a little later than we'd expected, and saw a paediatric cardiologist. Having done the usual x-rays, echocardiogram etc. he sat us down, explained again the diagnosis, and then gave us the options. Previously we assumed that one automatically had surgery, but in fact he spent most of the time putting the positive side of doing nothing, and the negative side of surgery. He also gave the distinct impression that he considered her life, as a "Down's child", of far less value than that of a "normal child". We came out in emotional turmoil, feeling that we were being forced into choosing a convenient euthanasia by default, that would dispose of Emily probably in her teens. By now we were both very much in love with our baby daughter and felt very distressed at this attitude.

We discussed it all with lots of people, including many medical friends, and there really seemed no choice but to give Emily the chance of a "normal" life. If we left her, her death was likely to be dreadful - heart failure, increasing breathlessness, and kidney failure, maybe taking months, and causing enormous distress to both Emily and our family. This scenario - put forward by our medical friends - had not been mentioned at our out-patients appointment, and one would have imagined that she would just die peacefully in her sleep one night! *(Obviously this was an extreme example that was put forward, for many children it is very peaceful - Editor).* We returned to see the cardiologist in December and were told resignedly that we would be sent for for cardiac catheterisation shortly.

At the beginning of January, on my thirtieth birthday, Emily was admitted to the children's cardiology ward and she went for a catheter the following day. This was fairly uneventful, and confirmed the diagnosis. The senior registrar who performed the catheter, saw us that evening and said that it was as expected, and that he would be referring us on to a cardiac surgeon who we would be hearing from. Interestingly, he did not appear to share his senior colleague's view of people with Down's Syndrome, commenting that they used to be treated differently, but that that view was now outdated and that they deserved as much of a chance as anyone else. We began to feel that we weren't being unreasonable after all.

At the end of January we went for an out-patients appointment with a very likeable cardiac surgeon who also had a positive attitude to the surgery. He seemed competent and very down to earth and we felt

very confident. He quoted the risk as one in ten deaths, but commented, very fairly, that if you are the "one" the risk is 100% for you. He also said that he would hope to do the surgery as soon as possible to avoid permanent lung damage and Eisenmengers Syndrome.

We returned home to await a date feeling sure that we were doing the right thing. Emily, meanwhile, was developing very well - her Portage teacher and Paediatrician were pleased with her. We rarely needed to see the GP, and she remained well apart from the odd cold. At the end of February we were given a date for surgery, but she seemed to be starting another cold, so we rang the ward and were told to stay at home as she had to be completely well for the operation. We felt frustrated but assumed that we would get another date.

By the end of February, Emily was sitting up unsupported for short periods of time. She was attending a local Opportunity Group weekly where she had physiotherapy and had the use of a hydrotherapy pool. She didn't enjoy the physiotherapy much and got rather sweaty with crying during it, but other than that she was still more or less asymptomatic. She did, however, have a very fast respiration rate and bad chest recession when she breathed in, but didn't appear to be bothered by it.

When the beginning of April arrived and we still hadn't heard from the hospital, I phoned the surgeon's secretary. She gave us a date a couple of weeks later. We duly prepared ourselves mentally, told all our friends and relations, had the church praying for us and got my mother over from the Isle of Wight to look after Jack, our four year old son. I drove to Southampton, anxious but delighted that at last there was the prospect of Emily's heart being "cured". We spent the day having the usual tests. The blood taking was extremely stressful and upsetting. The poor doctors tried about eight times before finally hitting a vein in the scalp. I hadn't realised how lucky we'd been when Emily had the catheter and the phleblotomist had popped the needle in effortlessly first time while chatting about her grandchildren!

Later on at about 4pm, we watched the surgeon slowly making his way round the ward checking on all his patients. When he reached us he said that he had some bad news - we had to be cancelled because of a lack of qualified paediatric staff in intensive care. The good news was apparently that it happened then rather than on the morning of the operation. Mother returned home and so did we, pleased that we only had to travel twelve miles to Winchester, not hundreds to Plymouth, but very disappointed having psyched ourselves up for it. We were to return the following week, but by then Emily had another cold.

A short while after this, I began to notice that she sounded more and more bubbly and had started to cough more. I was still breast-feeding her , and in the night particularly, I'd feed her, she'd have a coughing fit and the whole lot would come up again. I realised that her lungs were really starting to deteriorate, and I took her to the GP a couple of times, worried that she was in heart failure or needing antibiotics. They all felt that surgery was the only thing to make it better, but one of them did give me a course of Amoxil for her in case it helped, and it did.

During this time I had been ringing up the secretary, "nagging" every few days because I wanted the surgeon to know that Emily had deteriorated. Eventually, on Monday 13th May 1991, when she had coughed on and on and on without a breath, I phoned again feeling desperate. The secretary went of to see the surgeon and phoned me back two hours later with a bed the next day, for surgery on Thursday. Emily was just finishing the course of Amoxil, but was allowed in as she had started to deteriorate.

Yet again we went down to Southampton, this time a little more cynical. My mother waited to hear if we were being sent home before taking Jack off to the Isle of Wight. All the tests, including another stressful blood taking session, were repeated. During those two days, Emily appeared to have benefited from the Amoxil and seemed generally better, although she still had a bubbly cough. She seemed exceptionally happy and gorgeous, and I thoroughly enjoyed the time spent centred around her.

The morning before her operation, Andy and I played with her and at midday we bathed her in special cleansing solution, dressed her in a gown and she was then given her oral pre-medication to make her sleepy. I had last fed her at 10am, so she was quite happy. She fell contentedly asleep in my arms and we sat and cuddled her until we had to take her down to theatre an hour or so later. My stomach had been churning all morning, but the worst moment was when I laid her down in the cot to go through the doors to the anaesthetic room. She was asleep, and looked so small and vulnerable with all those masses of adults rushing around getting things ready for her. We both took deep breaths and left, briefly cracking as we got outside the door.

We had already decided to be positive and knew that she'd be at least four or five hours in theatre, so we went home, calling in to buy her an outfit for her first birthday on the way. We then tried, mainly without success, to keep occupied until we had been told to phone the ward. Things were obviously not right

The nurse couldn't or wouldn't tell me anything except that she would probably be another couple of hours. I couldn't bear being at home any longer, so we returned to the hospital to sit and wait. At about 8.30pm, the surgeon turned up in theatre gear. He explained that the anatomy of the valve (impossible to see on cardiac catheterisation) was unusual and extremely difficult to repair. He either had to make it more stenosed (tight) than he'd like or leave it too leaky. He chose the former, hoping that it might be OK until she was bigger and could have further surgery if necessary. He said that he was amazed that she had been so well and had even survived for this long.

The next two days were horrible. I sat for ages watching those machines, waking up at 5am, desperate to see her, but terrified of what I might find. It became clear that it wasn't going to work. The pressures which should have started going down were going up. That Saturday afternoon was horrendous. Andy had had to leave the hospital for a while and the doctors were obviously very worried. I felt totally distraught, certain that she would die and unable to do a thing about it. Several friends came down to give us moral support, which helped.

The following morning she had deteriorated further and was shutting down her peripheries in an attempt to keep her vital organs going. The original cardiologist was called in from his yacht to do an echocardiogram. Although he had not been our favourite person before, he was faultless now. There was no hint of "I told you so" which I half expected. Basically he said that the valve was too tight and if she didn't go back to theatre she had no chance. There was about a 50/50 chance of surgery working. The surgeon was called in from his Sunday lunch and we said goodbye to Emily in Intensive care. I had been to Communion in the hospital chapel that morning, and felt strangely peaceful considering that I understood during prayer that she was going to die. I knew I was saying goodbye to her for the last time.

Emily Jane died at 4pm when they tried to take her off the by-pass machine. The leakage through the mitral valve was incompatible with life. The surgeon came to tell us - it was of little surprise as we had been given bulletins during the operation. We felt numb and ridiculously calm. I remember thanking him for doing his best - as if he hadn't quite managed to cover up a scratch on a car rather than prevent my beloved daughter from dying. After a short while we were taken down to intensive Care where Emily lay, dressed in a white robe. They had taken little hand and footprints and we took some photos; I've never looked at them, but thought that I might want to sometime in the future, and this was our only chance. We cuddled her for a long time. When she was lying, head on my shoulder, it just felt as if she was deeply asleep. Finally I carried our precious little bundle of joy down to the mortuary.

Friends had packed our belongings and we got straight in the car and drove to the Isle of Wight to be with Jack. It was very hard in the morning when he came in and found us there and said "Where's Emily?" I was relieved that we had always been honest with him and he knew that Emily might die all along.

It is now eleven months since she died - longer than she was alive, but I am still very keenly aware of that yawning gap in our lives. She taught us so much, gave us so much joy, and touched the lives of so many people. Her smiling picture on the wall usually makes me smile back, and then sometimes cry. We now have another beautiful, healthy daughter, Olivia - concieved (accidently) two weeks before Emily went into hospital. She too is precious in her own right and I can't imagine how we would be feeling without her, but neither she, nor anyone else, will ever replace Emily.

We go round and round in circles wondering what else we could or should have done; gone to another hospital, refused surgery, even faith healing? However, we always return to the knowledge that we gave her the best chance we could. Her entire short life was very joyful, and there are no memories of a lingering, painful death. The last thing Emily knew in this life was falling happily asleep in my arms and we try to remember the positive happy times that we had with her, and enjoy these memories.

Sarah Coulbeck
Winchester

Marathon Effort

Congratulations to Chris Tovey, pictured above, for his run in the 1992 London Marathon. He is seen presenting a cheque for £1159 to Sheila Forsythe

Philip's Story

We have a daughter, Lauren, who at the time of my second pregnancy was just over eighteen months old. She is the apple of our eye, and I couldn't imagine ever loving another baby as much as I loved her and I would sometimes worry about that, as daft as it sounds!

We told Adam's father, Philip, as soon as we knew that I was pregnant. The year before he had had part of his lung removed due to cancer, and Adam was told then that it was only a matter of time before there was a reoccurrence, so we never delayed telling Philip anything, just in case. The week after we told him the news, the doctors suspected that he had a brain tumour; he died two weeks later. The day before, I spent a full afternoon with him, and we talked a great deal. He said how much he liked the thought of having a grandson, and we told him that if we had a boy we would call him Philip. He seemed to be pleased.

Adam was very close to his father and was devastated by his death, and as my Grandma had also died only a few weeks before, I had lost two people I loved close together. The emotions of pregnancy didn't help. We found it hard to comfort each other, and hard to talk, which all led to a miserable pregnancy, but we both looked forward to a happy Christmas with Adam's family and our new baby, a big, healthy, strapping boy to be called after his Grandpa.

Philip junior came into the world on Sunday 15th December 1991. My Mum was with Adam and I at the birth, which was a quick normal delivery. Philip was 7lb 11oz despite being two weeks early, and he looked just like Adam, even the nurse laughed as much as we did at the family resemblance. He had a broad neck just like his Daddy, and great big hands and feet.

We were all euphoric at having a boy; I was on cloud nine. I cried for Philip senior for a minute, thinking how lovely it would have been for him to see his new grandson. Adam was really proud that he had fathered a son, he told me that Philip would be a keen rugby player just like his Daddy, and we laughed at him making plans for his son at only a few minutes old. Mum and Adam went home an hour later, and I had a shower because I seemed to ne full of energy due to my happiness. I kept thinking "we've got a girl and a boy now so we don't need to have any more babies, we are a complete family", and also how lucky we were. Both of us said that after such a sad year, what a lovely end to it to have our son.

When my visitors came in the evening I was still the same, full of energy and happiness, brimming over with joy. I called Philip, E.T. because of the way he stretched his neck and looked around as though he'd been in this world before. My visitors seemed shocked that I had called my new baby E.T., but I think everyone thought the same but didn't like to say so. All babies looked funny when first born, I thought. Lauren looked like a Sumo wrestler, now she is beautiful, so it didn't bother me that Philip looked like that, I knew that in a few days he would alter and be just as beautiful. My visitors went home sharing my joy - as happy as I was it was bound to be infectious.

I tried to put Philip to the breast all afternoon and evening. He had difficulty latching on, would just seem to master it only to lose it after a minute. I persevered through the night and next morning, wanting to give him the best start in life, just like I did with Lauren. In the morning I was losing clots and was told I would have to stay in hospital another day to ensure I was O.K. I was terribly disappointed, all I wanted to do was get home and show Lauren our new baby. I rang Adam and Mum, and told them. Mum said it was for the best, and reminded me that I wouldn't get as much rest at home with Lauren as I would in the hospital. I knew she was right, so I went and had a bath, then had a cuddle with Philip whilst I waited for the Pediatrician to come and check him over ready for discharge the next day.

I put Philip back in his cot while the doctor checked his head, hips etc. I was laid on my bed watching her and she turned to me and said "He looks a bit funny doesn't he?". I looked at her and thought "you cheeky bitch", It was alright for me as Mum to think it, but not someone else. Then she added "Does he resemble the family?", I laughed then, and said yes he was the double of my husband. She asked me what the midwives thought and I said that they agreed, but I started to feel a bit uneasy. She said that she thought Philip resembled a Down's Syndrome baby across the eyes. I thought she was mad and answered that he was just like my husband, but I was frightened and also mad at what she was saying about my dear, darling little E.T.

She said that she would ask a Dr. Lewins to come and see us; then I realised that she was serious. She left me there on my bed all alone. I looked at the cot where my new baby son lay. I looked again and again trying to see what the doctor saw, but I couldn't. Then I broke down. I drew the curtains and picked Philip up, I just kept thinking "she's wrong". I just would not believe our new son had Down's Syndrome. I recalled my childhood and remembered seeing Down's kids, we used to call them "Mongols". They used to dress really old fashioned, crimplene trousers, shuffling rather than walking, dribbling at the mouth with their tongues hanging out. I was disgusted and terrified.

I thought that Dr Lewins, when he came, would know straight away that Philip was normal, that no way was he a "Mongol". Then Adam walked through the curtain. He was totally stunned at the state I was in. I broke down again and told him what the doctor had said. He too thought she was mad, and cuddled me and said not to worry, and that Dr Lewins would put our minds at rest and tell us without a doubt that Philip was normal, but I still felt uneasy.

About 10 minutes later, Dr Lewins came through the curtain and introduced himself. He said he understood that Philip had been born blue, (he had been born with the cord around his neck, but I had been assured at the time that he was O.K.) and asked us numerous questions like how was he feeding and did he resemble the family. He then looked at Philip's hands and feet, inside his mouth, his eyes, and then he looked at us and said he would like to do a blood test. We were shocked, knowing that he suspected there was something wrong with our son. I asked if he thought Philip had Down's Syndrome. He looked taken aback: I don't think he realised that the other doctor had voiced her suspicions. (I know that she was wrong to have done so, and I will never forgive her for the way she told me.) Dr Lewins said there was a high chance he had, and pointed out that although he had fully lined normal hands and feet, there were extra fleshy folds of skin around his eyes and neck which indicated the possibility of Down's Syndrome. At that precise moment my whole world caved in and I realised that our nightmare year was still continuing.

As soon as he went I broke down again. Adam couldn't say anything, he was even more shocked than I was, after all I'd had two extra hours in which to take it in. I cried and cried and looked at our new baby lying in his cot oblivious to what was going on around him. Adam went to my Mum's soon after, and as I found out later, he too broke down. I pottered around the hospital talking to other new mums, even telling a couple of them what had happened because I needed to talk. I could see the reaction straight away in their eyes and as they picked up their babies to cuddle them, thanking God that it wasn't them it

My visitors that evening were upset like I was, not wanting to believe it was true. Who does? It couldn't be happening to our family, they must be wrong. No-one on either side of the family had had a baby with any kind of handicap, so it was even harder to believe. When they had gone, I tried to cuddle Philip and feel love for him, but it was hard. Something seemed to be stopping me, I even thought fleetingly that it would be better if Philip died. (Dr Lewins had told us that a lot of babies with Down's Syndrome had heart defects, and I thought that if Philip had a heart problem then let him die now.)

Philip still wouldn't take to the breast and to be honest, because of the way I was feeling I didn't want to keep trying. He somehow disgusted me and I didn't want him feeding off me, especially if it involved a lot of effort on my part. I felt guilty because I certainly didn't feel like this yesterday, or did I? Was there something deep in my subconscious telling me he was different even then. Breast feeding is such a close bond between a mother and baby, and even then I hadn't exactly been thrilled about feeding him, I knew that he looked slightly different from other babies.

On Tuesday when Philip was three days old, Dr Lewins came to see us again. He said that he was 99% sure that Philip had Down's Syndrome, and Adam and I agreed with him. He told us that the blood sample would be sent to Leeds for a chromosome test that would confirm that Philip had Down's Syndrome if the extra chromosome was there. It would be about a fortnight before we got the result.

That afternoon a social worker came to see me. She was lovely, and it helped to have someone to talk to who new a lot about babies and children with Down's Syndrome. She totally wiped out my thoughts of "Mongol" kids, she assured me that in the last ten years at least, children with Down's Syndrome had led a near normal life. I was given a book with lovely photos of babies and children with Down's Syndrome. I started to look at Philip differently, I wasn't disgusted or repulsed, and I now know that that was just a shock reaction. After all, he was my baby and still carried my genes; he was Lauren's brother. In a way

would bring him up just like Lauren, to be bright, happy and lovely; he would be clever and dress fashionably. These thoughts got me through the next few days.

On the Wednesday Philip had to go under a lamp because he was jaundiced. I was really upset to see him laid out naked and to not be able to cuddle him. I think that was when I really began to love him properly, this poor defenceless, beautiful baby of mine. The social worker brought me some information on Down's Syndrome which I read greedily, I wanted to know everything about my son's condition, so I read everything in those few days in hospital. Everything sank in, I was amazed that I could remember it all. I felt different in myself, but I knew then that I had changed for the better.

Adam brought Lauren in to visit us. It was hard seeing her, I didn't want them to go and leave me there. Lauren looked so grown up and seemed so big. She loved Philip straight away, she cuddled him and kissed him; to her he was just a baby, her brother. Feeling that I didn't love him, being repulsed by him, disgusted by Down's Syndrome, were very early feelings and all due to shock, which disappeared within a few days. Although I still felt sad, I couldn't change things so I just got on with accepting Philip as he was and thinking he would have a wonderful life and a loving family.

By now he was bottle feeding, and though I was told that babies with Down's Syndrome were slower, by the Friday when we went home he was doing quite well. Looking back, it was better for us that he was bottle fed as I wouldn't have coped as well if I'd been breastfeeding and struggling with tiredness and the depression which set in when we got home. I kept saying "why me?", "why us?", I was convinced I had been paid back by God for some awful thing I had done in the past. I felt sorry for myself and listless, everything was such an effort. I would cuddle and kiss Philip all the time, thinking poor baby, poor little dear, he doesn't have a clue, bless him. The worst feeling of all was the grief. I realised at home that this was what I was feeling; the baby I had on Sunday was a big strapping lad, then on Monday he was taken away and I was given a baby with Down's Syndrome instead. It dragged me down and life seemed awful.

Adam seemed awful too, he wanted to go to the pub all the time which made things worse for me. He would go to work, then the pub and was letting me cope on my own, how could he do this to me? In the hospital he had been really strong, even saying to me one day "Julia, it could have been worse. he could have been born with ginger hair!". He put up a false front for a while I think to make it easier for me, but now I needed him more than ever, I needed his support and love and he just wasn't there for me. I realise now that he too was grieving for his 'big rugby playing son', and I found out later, that for a while he felt that Philip wasn't adequate to be called after his father whom he looked up to and loved so much. (I understand now, and it is hard to believe that we ever felt like that.)

Adam didn't want to talk and I did, this made it worse. He doesn't normally talk anyway, so I don't know why I thought he was going to be different. I imagined we would be brought closer together immediately, when it fact it was actually weeks later that we finally talked and sorted ourselves out; when the shock had subsided really. Adam eventually accepted that Philip had Down's Syndrome a while before I did, he sort of gets on with life and doesn't think much about anything, tending to block things out. Which is also how I've managed to cope.

Two weeks after leaving the hospital, Dr Lewins rang to confirm that Philip had Down's Syndrome. I had clung to the hope that maybe they were wrong until that phone call came. I broke down all over again, and it seemed worse because Adam was at the pub when I got the call. I felt so lonely, as though this was something I was coping with on my own.

A month later we saw a cardiologist who scanned Philip and confirmed he had a hole in the heart. We had previously seen Dr Lewins, who had told us that Philip had a heart murmur, but we had had so much bad luck, that we really thought we couldn't have a heart baby as well. Now we were being told that a hole in the heart like Philip's needed to be operated on, I couldn't believe it, I was totally devastated, my poor baby. Down's Syndrome seemed so insignificant now, that I could not believe that I had been so upset about it before.

About a fortnight later we went back to clinic to see Dr Lewins, and he talked us through Philip's heart defect. It was more serious than first thought. He has a full AV Canal or Endo Cardial Cushion Defect. I was, (and still am) terrified of losing this little boy I loved so deeply. I thought back to when I was pregnant, I imagined on the second day of his life that I might not love him, but now after holding him, loving him these past two months I could not imagine I had ever thought that. I love him so much, he has a lovely happy nature and is lovely to be with. The thought that he may be taken away from us is unbearable, so I block it out. It is the only way I can cope.

Philip is on heart medicine until he has his surgery towards the end of this year, at Killingbeck. This is

my nightmare, without the operation he will live until probably two at the most. We have to give Philip this chance but there are risks involved - 80% survival. Success rates cannot be given at the moment.

Adam and I are good together now, we enjoy Philip totally. Lauren adores him and plays wonderfully with him. We go to 'Kids' on a Thursday and Philip is so attentive and bright. I am so proud of him, he supports his head well, rolls over, tries to push himself up and uses many syllables when he 'talks' to me. At present he is only seven months old and weighs 15lb 9oz, a weight I thought he would never reach. We were told that he would be a poor feeder because of his heart condition, but in fact he is very good. Solid food is his best as he does tend to get a bit breathless with his bottles. He is a lovely, happy, laughing, smiling, cuddly baby who is adored by everybody who meets him.

Lauren, Philip and I go to church every Sunday, and I thank God for giving me two such beautiful children. I wish Philip did not have a heart condition, but as for Down's Syndrome, I really do not mind at all as I love him so much, and he is more special because he has Down's Syndrome. I realise that I, like my husband, have had to go natures course of grieving and disgust, of "why me?" and of feeling sorry for myself. Now with all the love everyone has for Philip, and considering he is such a big, strong boy, I feel quite confident that he will pull through his operation. We are very lucky that we have Philip, however long for, be it a year, five or ten. He is our big, strapping lad.

Julia Johnson
Barton-on-Humber

(Thank you to Julia for being so honest about her feelings, I'm sure a lot of people will be able to identify with those early emotions. - Editor)

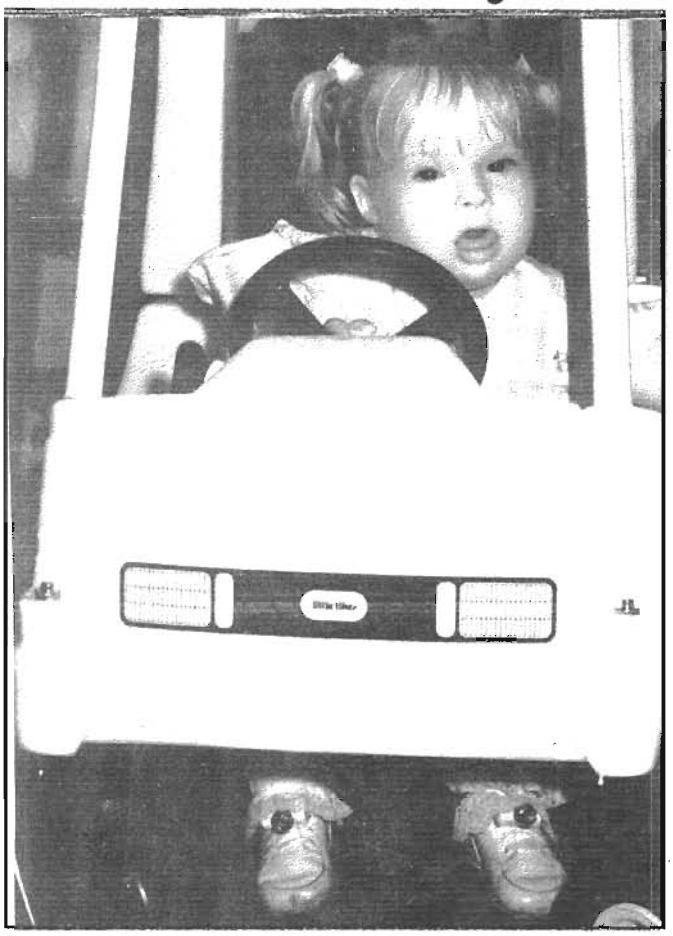
Contact Needed

A new family in the West Midlands would very much like to be put in touch with any parents whose child has an AV Canal (also known as AVSD or Atrio-ventricular Septal Defect) and Pulmonary Atresia. Please contact either Noreen Hodkinson in West Midlands region or Penny Green at the national office if you can help.

STOP PRESS

Congratulations to South West region for raising £435 at their cake stall on September 12th. Many thanks to everyone who helped.

Kelli-Jo's Story



Hi! My name is Kelli-Jo Anna Neill and I was born in Berwyn, Illinois in the United States of America on August 2nd 1989. I am very lucky because I have a birth mother, and I also have an adoptive mother and father with whom I live. The first thing that the doctor noticed about me after birth was that I have Down's Syndrome. The doctor that examined me before placement in my adoptive home at three weeks, said I was very healthy and marked no heart problems on my chart. My adoptive Mom and Dad took me to their doctor the day after placement and so begins my heart story.

Dr Collins told my parents she heard a murmur in my chest and referred us to a cardiologist at Christ Hospital in Oak Lawn, Illinois. She called to make the appointment for me right from her office. I saw Dr Arcilla, my cardiologist, the next day. Mom and Dad were very worried I could tell. The joy they had the day before was still there, but now they were watching me even closer. Mom kept counting my breaths and Dad just stood and watched over her. I think Mom realized this was a serious problem right away, it took Dad a little longer.

Dr Arcilla told us he thought I had a very large hole in the centre of my heart. He said he would need to do a few tests later on and surgery would be necessary

but he hoped I would live to eight or nine months at which time I could have the operation to save my life, in the meantime he would monitor me very closely and he started me on Lasix and Lanoxin. He told Mom to feed me every two hours, to watch my breathing and colour and to call him if she noted any changes. On the way home Mom started to cry. But for the rest of the time through surgery she kept saying "God wouldn't have given you to me if he wanted you back so soon!"

Three months went by and I could feel myself growing weaker and weaker. Mom and Dad kept on loving me, doing everything in their power to help. We went to the doctors every week, and I started an early intervention program when I was five weeks old, with one hour sessions of speech, educational, physical and occupational therapies weekly. These started to get shorter and shorter because I could not catch my breath. Mom said I was turning "dusky" and "blue" after feeding and therapy, and I didn't want to eat , I was so tired.

November 1989
I couldn't breath. Mom rushed in and found me, she rubbed my back harder than I'd ever felt before but still I couldn't breathe. Then I felt warm breath in my mouth and nose, my chest really hurt, Mom was pressing her fingers into it. Then I started coughing and coughing so hard. My chest felt better. Mom was holding me and looking into my eyes. She was talking on the phone, "Help! Baby is not breathing! Address is...", then there were strange men, loud noises, lots of people poking and prodding.

The next day Mom, Dad, Grandma and Grandpa were all in a strange room looking at me smiling. I knew I must be okay but what was all this stuff sticking out of me? The doctor was telling Mom that I did stop breathing, that my heart was worse than he thought and that I had a respiratory virus called R.S.V. I had to be well for two months before he could do my surgery. Mom grabbed my hand and stroked my cheek, "We'll make it won't we Kelli-Jo" she said smiling.

January 1990
I'd been fine. I went in for a catheterisation so that Dr Arcilla would have a good idea what he would need to do in surgery. I was a little sore and Dr Arcilla told Dad that I'd have to spend the night. He also said that I had an extremely large hole in my heart that involved all four chambers and that my mitral valve only had one flap and did not close. The blue and red blood were mixing together and I would have to have surgery at six months old. February 1990 was scheduled for my operation, if I made it that long.

February 1990
Mom was crying as they took me to theatre, and what was this... so was Dad. I was in the operating theatre over six hours, then in intensive care four weeks. Mom was there every time I woke, she kept stroking my cheek, and prayed every day. Then one night I went into a very deep sleep and frightened everyone, even Grandma and Grandpa were there when I woke. Finally some of the tubes came out, and they moved me to the next room but still with my oxygen.

Two weeks in a regular room and they said we could go home tomorrow. I couldn't remember what home looked like. Mom was so happy. But then I got a fever and was sick. Another test: result Roto virus, another two weeks in hospital. Oxygen, tubes, more blood and I was finally feeling better and we were going home the next day. As we left the doctor said that he used a Gortex patch in my heart and built up my valve with my own heart tissue. No artificial valve, perhaps no more surgery, time will tell.

April 1990
I felt great, I went back on my intervention program and had so much energy. No more going blue, I was gaining weight slowly and would be on medication for the next year seeing Dr Arcilla every month or two.

March 1992
A lot has happened since those early days. I've been diagnosed with several other chronic medical conditions. They are Asthma, Epilepsy, Spinal Biffida Occulta, vision and hearing problems. I'm currently off all medications. I also have glasses, and braces for my legs and tubes in my ears. Our days are filled with all the therapy sessions, but they are really paying off - Mom and Dad are so proud of me. I'm two and a half years old and am functioning overall like a twenty month old. Gross motor skills have been and still are my slowest area, I'm at twelve months.

I've just begun to walk, and I'm beginning to prepare for early childhood public education which will begin in September 1992. I have no heart problems at this point, and Dr Arcilla does not want to see me for a year. Pretty good considering what I've gone through, don't you think?

Deborah Neill (for Kelli-Jo)
U.S.A.

(I thought you might all like to share this story from one of our overseas members. News of the Down's Heart Group is obviously spreading - Editor)

Research News

Our last issue included details of the research project being carried out at St. Mary's Hospital Medical School by Dr Anna Kessling, who has since sent in the following article.

Why do so many children with Down's Syndrome have heart defects?

Our team a St. Mary's Hospital Medical School (in collaboration with the Hospital for Sick Children in Great Ormond Street, and funded by the British Heart Foundation), is trying to discover the answer to this question and a number of others.

Most children with Down's Syndrome have three copies of chromosome 21: what's different about the genes on the chromosome of the children who are born with heart problems? Do different heart defects have different causes?

What is the point of all this research?
If we knew exactly how the heart defects happen, it would help in diagnosis and treatment - it might help the cardiologists with their treatment, or even, in the long term, it might make it possible to prevent some heart defects by treating the mother, or the unborn child.

What has any of this to do with you?
We need blood samples from families with an affected child. If your family were to take part, we would normally come to your home at a time that suits you (yes, including evenings and weekends) to collect blood samples. Ideally, we need both parents, the affected child, and, if possible, one or more other children, or any grandparents...

We are experienced in taking blood from children with Down's Syndrome and difficult veins; we are friendly; we will be nice to you and your children... and it's only a small blood sample.

We will go just about anywhere for blood samples, but we do try to wait till we have a few families in the same sort of area (or an hour or two's drive from each other) before setting off to collect samples.

But you already have an affected child - how will this research help them?
To be honest, it won't. However, unless we study children with heart defects, we'll never understand how they happen or be able to think about treating them before they cause problems.

What sort of treatment would it be?
We can't tell yet - but think of all the things modern medicine can fix that were untreatable even 50years ago.

WITHOUT RESEARCH WE CAN'T IMPROVE OUR UNDERSTANDING.

WITHOUT YOUR HELP, WE CAN'T DO THE RESEARCH.

Would you like to help?

Do you think you might like to, but you'd prefer more details first?

PLEASE contact: Dr. Anna Kessling
Dept. of Biochemistry and
Molecular Genetics
St. Mary's Medical School
Norfolk Place
LONDON
W2 1PG
Telephone: 071 723 1252 ext 5479
(or leave a message on ext. 5476 or 5487)

Please give day or evening phone numbers if possible... and we'll get back to you as soon as we can.

Please try to help in this research

Dr Anna Kessling

P.S. A big THANK YOU to everyone who has already contacted us, especially those from whom we have already collected samples - those of you whose samples we haven't collected yet, please don't feel forgotten - we are waiting till we have someone else in your area so we can make a joint expedition!.

(Quite a few of our members have already given blood samples to help with this very worthwhile project, if you are not amongst them, perhaps because your child was unwell or not old enough (they like them to be three) when we first asked last year, please give it some thought. Although it is unlikely to benefit our children, it may help others in the future. - Editor)

Questions to ask upon finding out that your child has a heart defect

Miss Roxanne McKay, Consultant Paediatric Cardiologist at Alder Hey Hospital gave a talk to The Association of Children with Heart Disorders at which many interesting points were raised , one of them being assurances that children with Down's Syndrome would not be discriminated against when the hospital opts out and becomes a trust. Miss McKay also gave a variety of questions parents might like to ask, if their child is diagnosed as having a heart defect.
Here is a list of those frequently asked:

To a Referring Doctor
How certain are you of the problem ?

Which hospital will your child be sent to? Why ? How soon ? What is the urgency ?

How do we get to the hospital, public transport availability, assistance with finance ?

What are their facilities for parents ?

First Consultation or Admission
Ask who is talking to you: what is their input to diagnosis and treatment.

What tests need to be done? Why and what will they involve ?

Diagnosis
This is sometimes quick but may need many investigations.

What exactly is the problem? Get the doctor to explain it carefully and ensure that you understand the explanation.

Treatment
Be part of the decision to treat your child.

Firstly, is treatment possible, the answer is usually yes; some are low risk and some are high.

If you are told nothing, then question carefully and participate in the decision-making.

Also ask when and how the treatment is available.

Waiting Lists
Estimates are made on how many children are waiting for that treatment and a reasonable guess is made based on resources available at that time.

If it does not occur at the time stated, begin to ask questions; your G.P.; local paediatrician; consultant at your regional unit.

It may be necessary to put pressure on; ask how much damage has been done and is more damage occurring whilst waiting - in some cases waiting can cause increased risk for treatment or a less favourable outcome.

On the Ward
What are the rules and organisation of the ward where your child will be treated, this is usually governed by the hospital so speak to the ward sister, ie. visiting times, things to bring, which family members can visit?

Invasive Procedures
Most patients need some kind of invasive procedure or surgery.

What are the risks of the procedures, ask for chances or probability to be explained to you.

Ask what else can go wrong; who will be doing the catheter or operation.

Who will be around if something goes wrong?

Has your surgeon or cardiologist ever done this procedure before?

What else could be done? Are there alternative procedures? How do their risks and benefits compare?

When should it be done? When will it be done?

Who is involved in the operation?

Where does the blood come from?

Is there any possibility of a recurrence?

Will he/she be normal?

Will he/she require medication.

Will he/she require further surgery?

Why do heart valves/pace-makers need to be inserted; do they need replacing: will more medication be required?

Where will my child go after the operation? Can I see the Intensive Care Unit before they go there? How long will they be in there? Who will look after them? Who are all the different doctors and specialists and what are they doing?

What are all the different machines and procedures? If things are not going as expected ask why it is taking longer, has something gone wrong? Were there unexpected findings during the operation or catheter? If further investigations are proposed, discuss these carefully with the doctor; you should be communicated with all the time.

Who you should ask

First approach the nurse or sister, they should be able to give you a good idea. If you are still not happy, ask to see a doctor, and if you are still not satisfied ask to see a consultant.

Depending on the urgency it is best to go through the ward sister or consultant's secretary to make an appointment, then you will get individual attention at a mutually convenient time.

Returning Home

Although this is what you want, it can be very stressful.

Make sure you know what drugs your child needs and where to get them.

Does your G.P. know about them. A letter should go to your G.P. from the hospital. Check that junior medical staff have rung through to your G.P. and informed him/her of your child's discharge.

If there are any urgent concerns, ward staff are expert at giving any advice you may need on feeding. Check where your Out-patient appointment is, at the regional unit, or your home clinic. Which doctor will you see there?

If Your Child Dies

You will have many questions, but in such an emotional state it is difficult to take information in. You can come back after several weeks and speak to your consultant.

The most pressing question will be the necessity for a Post-Mortem and why, or if not, why not?

What do I do next and whom do I contact? The ward sister or social worker should help you with these questions.

Donations of organs is often a question parents ask; this is not usually possible with children with heart disorders, but do ask if it is an issue which worries you.

Was the treatment adequate?

What did you learn from our child? From the post-mortem? How will it help other children in the future?

Did anything " go wrong?" Was it expected? Could or should anything have been done differently?

Six to eight weeks is a good time to go back to see the consultant.

Second Opinions

Some conditions are so rare and uncommon that doctors may want further advice ie. transplantation.

You can ask for a second opinion if you are not happy, maybe the risks you have been given seem too high, you may be waiting too long, you may not be convinced of the diagnosis.

It does not cause problems and it will not affect your child's treatment.

The doctors would not hesitate to request it - nor should you.

This article is reproduced with the kind permission of Miss McKay, Consultant Paediatric Cardiologist at the Royal Liverpool Children's Hospital, Alder Hey.

(It has just recently been announced that Miss McKay will shortly be leaving the country to work in Canada. I'm sure she will be sadly missed in Liverpool, and we would all like to wish her well for the future. - Editor)

News from The Regions

West Midlands - Birmingham Children's Hospital Contact

We now have a group contact, Lynne Holden, visiting the hospital regularly. She writes:

If any parents are attending Birmingham Children's Hospital with their child, either for regular appointments or when their child is admitted for surgery, and they would like support from another parent who knows what they're going through, my home number is 0827 288641 (Answerphone if I'm not in) and my work numbers are 021 359 4481 Ext. 410, and 021 333 4640 (direct Line).

I think it is especially important to offer support to families who come to the Hospital from outside of the area. We all know how quickly you become involved in the routines of the hospital, and a friendly face from outside of that environment, who understands the things you are going through, can become a lifeline. Although there is accommodation available at the hospital, it is pretty drab and it can help to get away for an hour or two, especially in the company of someone who knows the area.

I work five or ten minutes away from the hospital, and it is my intention to visit the wards once or twice a week anyway, but if you are there and I miss you, please call me on one of the above numbers if you need support or would like someone to talk to.

Fathers need support too, even if they don't always show it. Often we enquire about the child and the mother and expect Dad to be strong, forgetting that his world is probably falling apart too - he can't fulfil his traditional role of looking after his family, as these circumstances are completely beyond his control - he's just as helpless as Mum. So we're here for Dad's too.

Perhaps it would help if you knew a little about us so that we don't seem quite so much like strangers.

I'm thirty seven, my husband Chris is forty and we live in Tamworth which is about half an hour from Birmingham where we both work; Chris is a printer and I'm Assistant Head of Music and Research at BRMB-FM and XTRA-AM, our local radio stations. We have two children, Lauren who is almost seven and Brittany who is almost three.

Brittany was born in April 1989 after an uneventful pregnancy. As you will probably know from your own experience, we thought our world had come to an end when we were told she had Down's Syndrome at four days old. After a couple of days we began to get on with our lives, little knowing that worse was to follow.

Brittany was the most perfect baby - she never cried, fed like a dream, slept twelve hours a night from birth, smiled at six weeks and was totally adorable. Everyone who met her was besotted with her. At eight weeks she had her check up, and the following day the doctor called to re-examine her, confirming that she had heard a slight murmur which she wanted the Consultant to hear. He did not seem unduly alarmed, leaving it up to me to decide if I wanted Brittany examined by the Heart Specialist that week or in a few months; thankfully I chose that week.

We arrived at the hospital on an extremely hot summer day, and just as we were called in Brittany threw up all down my dress. The Heart Specialist, the Consultant and half a dozen students then proceeded to examine Brittany and discuss her case as if I wasn't there. The Specialist then informed me that she had two holes in her heart that were very serious and that she would need surgery as soon as possible. He seemed amazed when I burst into tears; the students shuffled uncomfortably and I was ushered out as quickly as possible. I left the hospital, still sobbing, with Brittany and Lauren - nobody asked if I was alright or offered to help in any way - I drove home in tears.

The hospital phoned four days later at 8am for me to take Brittany in for her operation; it was Lauren's fourth birthday. Once again I flew into a weeping panic, packing and making arrangements and phone calls, and as I couldn't manage to drive, a neighbour had to take us. My reactions amaze me as I'm a strong person, usually well able to cope in stressful situations.

Brittany had her surgery on 13th July 1989 at eleven weeks old. She was out of Intensive Care within three days and home within seven. It appears to have been a total success. She suffers with numerous chest infections and a couple of other problems but is a very robust little girl. She has attended a Special Needs School full-time since twenty months, and is doing remarkably well even though she loses a lot of time through illness. She is completely adorable and thoroughly spoilt by family, friends and the staff at school.

Lynne Holden
Tamworth

(The staff on the wards have Lynne's telephone numbers, as does Susie Hutchinson the Cardiac Liaison Sister, so if she doesn't happen to visit whilst you are there, but you would like to talk to someone or you need any kind of help, please call her. Editor)

Can You Help?

Travel Costs for Visiting a Child in Hospital

Action for Sick Children is planning a parliamentary campaign to highlight the financial problems faced by families as a result of travel costs to visit a child in Hospital. The Down's Heart Group has already indicated its support for this campaign, and we are including this article showing some of the initial findings.

As all parents know, it is essential for the well-being of children to have a parent present while in hospital. The Department of Health has recognised this explicitly in its recent guidance, which says "This is not a luxury. It is now generally accepted that the care and comfort of parents for a child is fundamental to the care and treatment of children in hospital" (Department of Health, The Welfare of Children and Young People in hospital, HMSO 1991.)

Unfortunately, not all parents can be with their children as often as they wish because of the financial costs. Action for Sick Children has recently conducted research that shows that a significant number of families go into debt over visiting costs, and many more are unable to visit as often as they would like.

We found that the difficulties affect families at all levels of income. Families on Income Support often fail to receive the discretionary help that may be available from the Social Fund, either because their application is turned down or they find the application process too complicated and unhelpful. Families who are not dependent on Income Support have to 'make do' or rely on charities or friends. When a child is in hospital for some time or at a distance from home, they find themselves unable to pay essential bills or they get into debt. Some parents lose employment over a child's extended hospitalisation.

Overall we found that 18% of families could not afford visiting costs from their normal income. Armed with this research, Action for Sick Children plan to run a Parliamentary campaign in the Autumn this year, and to press the Government to provide on the spot assistance for families in difficulty. They will be calling on local people to write to their MPs supporting this campaign.

Please watch out for more details in our next newsletter, in the meantime, if you would like to share your experiences you can contact:

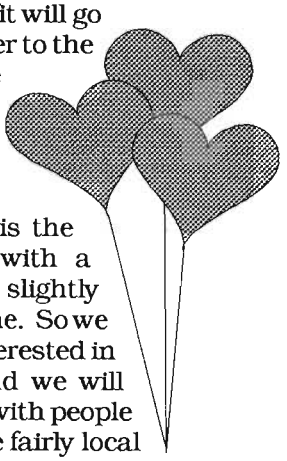
Pauline Shelley
Action for Sick Children
Argyle House
29-31 Euston Road
LONDON
NW1 2SD

(Or if you would rather contact the Down's Heart Group we can pass the information on, (withholding your name and address if you prefer). - Editor)

Valentine's Day Balloon Launch

Heartcare, the 'umbrella' group for heart support groups in the UK, is holding a Balloon Launch on Valentine's Day 1993 to promote awareness of the different organisations and raise funds at the same time.

The idea is to sell red, heart shaped balloons around 14th February for £1 each, and after the deduction of costs, a percentage of the profit will go to Heartcare and the remainder to the group whose members do the selling. They have asked for anyone willing to help, to set something up in their own area.



As the Down's Heart Group is the only member of Heartcare with a nationwide membership, it is slightly more difficult for this to be done. So we have agreed to ask anyone interested in helping to come forward, and we will then try to put them in touch with people from the other groups who are fairly local to them, whom they may be able to assist. We will then need to come to an arrangement as to what percentage of profit the Down's Heart Group receives.

If you would like to volunteer or to know a bit more about it all, please contact Penny Green on 0525 220379. PLEASE HELP IF YOU CAN.

Xmas Card Design Competition

We had a very disappointing response this year to requests for Christmas card designs from our members, so had to go to a non member artist. We thought that it would be a better idea if we asked now with Christmas approaching, for next years design.

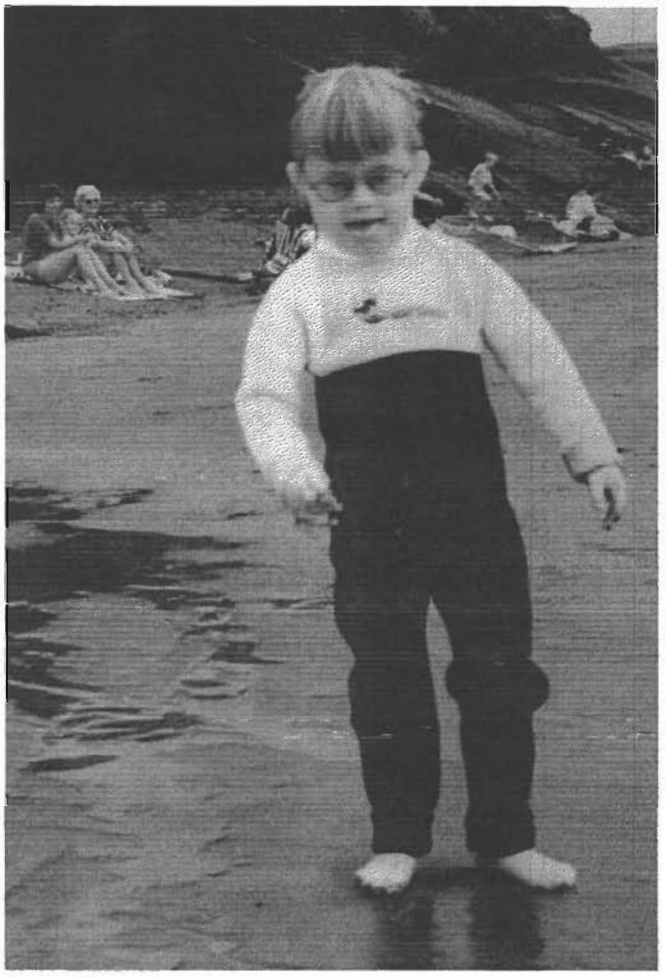
So when your children are busy painting, drawing etc. at Christmas, please think of us. Even if you feel your child's artwork has no potential as a card design, please put it forward for consideration, there are lots of ways in which even little 'stickmen' line drawings can be adapted and enhanced.

Apart from the £10 prize for the winning entry, the publicity it can arouse is very gratifying to a young artist, as Johnny Luntz, the designer of our 1991 card will tell you, he thoroughly enjoyed it all. Please submit all entries to our Secretary, Gill McLorinan (see page 2 for her address) to arrive no later than 28th February 1993.

The ones you missed

Many of you have said what a shame it was about the problems with the picture reproduction in our last issue, so I have included some of them again on these two pages. I hope you enjoy them. - Editor

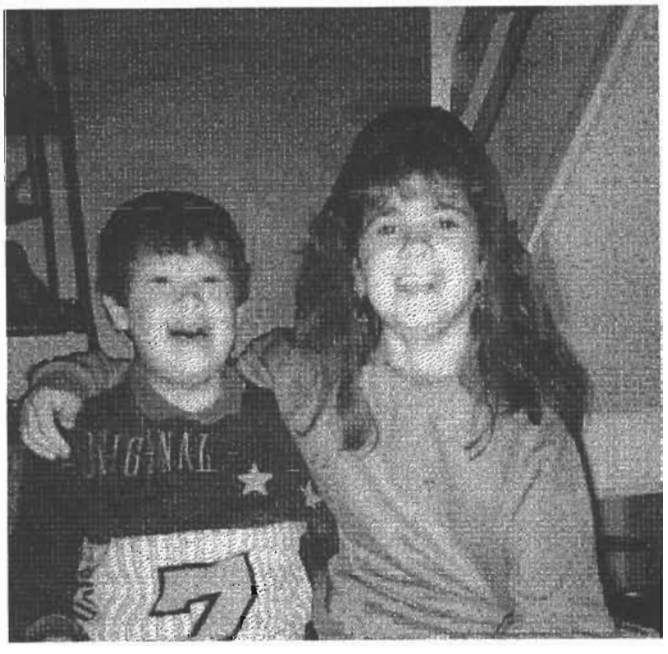
Andrew Forsythe meets Princess Diana (page 14)



Rebecca Payne in her wet suit (page 15)

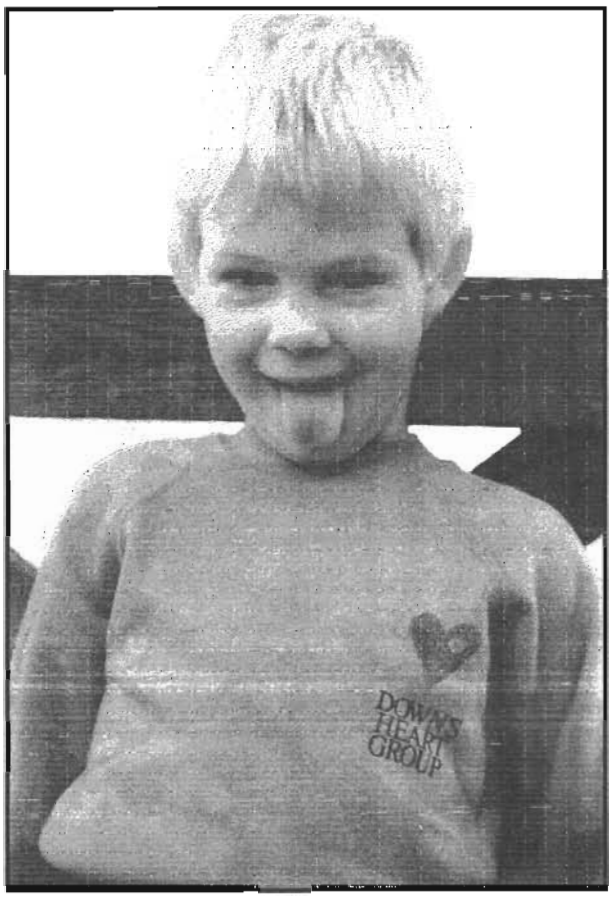
Noleen Hodgkinson (page 11)

Johnny Luntz with his Christmas card (front cover)



Johnny and sister Penny (page 7)

Right - Katie Maguire (page 8)



(Thanks to Founder, Linda Walsh for the photograph of her son Michael advertising our sweatshirts.)

'Nice sweatshirt, shame about the face!'

Don't forget when you're buying the Christmas presents this year, that Down's Heart Group t-shirts and sweatshirts can be obtained from our Fund-raising Co-ordinator, Karen White. (address on page 2).
Prices have been static since their introduction, but we need to place a new order which will certainly mean an increase. We will maintain the price on our existing stocks only until 1st December, so phone now to check availablity, and buy before the price goes up.

Sweatshirts

White, sky blue, or grey with pink and black logo

Adults S, M, L, XL	price £9.99
Childrens 24", 26", 28", 30", 32"	price £6.99

T Shirts

White with pink and black logo

Adults S, M, L, XL	price £4.99
Childrens 24", 26", 28", 30", 32"	price £3.50

Prices are inclusive of VAT and postage and packing, please give Karen a call on [redacted] to see that your requirements are in stock, then send a cheque or postal order with a written order to her address.

1992 Christmas Cards

Once again this year we are selling Down's Heart Group Christmas cards. These are not only a source of revenue to the group to enable us to continue with our work whilst maintaining the committee's commitment to the policy of no membership fee, but more importantly, they are a very valuable tool to increase public awareness of our children, their very specific needs and immense potential

Please help us to make 1992 another successful year for card sales by showing the enclosed sample to family and friends and asking them to place an order too.

We have been able to maintain last years price of :
10 cards for £1.30 (£1.64 inc. postage & packing)
50 cards for £5.50 (£6.85 inc. postage & packing)

There are also a few of the previous years designs still available, ring Karen White for details.

On the page opposite you will find an order form for your cards, but if you require some to be sent to a different address, or wish to place further orders, please use a sheet of paper and state clearly your order and the address it should be sent to. (A phone number also helps in case of query.)

(This is a computer generated representation which does not properly reflect the quality of the actual cards.)

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 about four monthly, 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: Down's Heart Group,

Christmas Card Order Form

Now you have seen a sample of the Christmas card, we hope that you will support the Down's Heart Group by ordering some using the order form below.

Please send :

..... packs of 10 cards at £1-65p = £ ... - ... p

..... packs of 50 cards at £6-85p = £ ... - ... p

Total = £ ... - ... p

N.B. Prices include postage & packing.

To: .....
.....
.....
.....
.....
.....

Send your completed order form, together with a cheque or postal order payable to 'Down's Heart Group', to: Karen White,