



DOWN'S  
HEART  
GROUP

# NEWSLETTER

( Issue No 10 )

## Autumn / Winter 1993



*Some of the children enjoying themselves at the AGM*

---

---

# Committee Contacts


## Founder

Linda Walsh

---

## Chairperson


John Spall



---

## Vice-Chairperson

Sheila Forsythe



---

## Secretary


Gill McLorinan



---

## Treasurer


Phil Thorn



---

## Legal Advisor

Brian Auld



---

## Newsletter Editor & Family Support

Penny Green



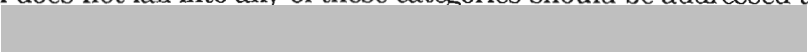
---

## Who Do I Contact?

General enquiries (other than those from families) should be addressed to the Secretary. Requests for information about the work of the group from professionals, students etc. should be sent to the Secretary, enclosing an sae. for the reply.

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

Donations may be sent direct to the Treasurer.

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

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

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

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

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

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

## Chairperson's Report

I am excited to be taking over at this point as Chair of the Down's Heart Group, at what I believe is the beginning of a further stage in the development of our work. I hope to play, along with others, a significant part in furthering that development.

I would as my first act wish to pay a public tribute to Penny Green, from whom I have taken over. Penny has been the driving force in keeping the Down's Heart Group on the rails and in business over the past two years, during some very difficult times. Being Chair was, as many of you will know, only one of the jobs that Penny has been doing for the Group. She is also National Family Support Co-ordinator, the National Administrator, Newsletter Editor and general long stop for everything that no-one else deals with. I am very grateful that she is continuing in all these other roles for the Group.

On top of all that, a new Green has arrived to take up what little spare time she has. Sarah, like all the Green offspring, arrived early (Penny is always in advance of herself!). Both mother and baby (and father) are doing well.

You may like a little information about the person who is now Chair. I spent most of my working life in the management of local government, but am now a director of a firm of financial consultants. I have been Treasurer of the Down's Heart Group for the past year, but have now handed that on to Phil Thorn, the Treasurer of the South-West region. My wife, Katie, is the Regional Co-ordinator for London Southern region, and is a Portage worker.

We had a baby with Down's Syndrome and an AVSD and persistent ductus in August 1988. Elizabeth, (known as Bloomsie), sadly died in Great Ormond Street in July 1989, but she became the inspiration for us to become involved in the Down's Heart Group through an appeal, made in the Newsletter a couple of years ago for more members to help run the Group.

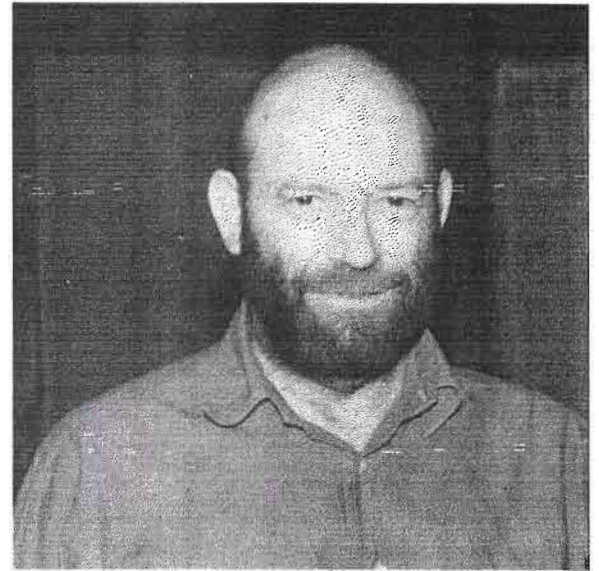
I was voted in as Chair at the recent AGM, organised by the South West region in Thornbury, Avon. Most people think of AGM's as dry, boring occasions but certainly this was not one. A very impressive array of speakers had been assembled, who were experts in their subject but at the same time had a clear understanding of individual problems and a practical approach to getting things done. You, the members who attended, were no less impressive. The quality of the questions, the standard and commitment of the discussions and the support and information members were giving each other showed the Down's Heart Group in action. It was also good to see so many members who had travelled long distances to be with us.

If you were unable to make it this year, do please try and come along in 1994. I promise you that the formal business is kept to the very minimum and that you will have an informative and enjoyable day.

The Down's Heart Group Committee now resumes its work after the summer break and commences its policy of holding meetings in each of the regions. This is to provide an opportunity for more people to attend and for the Committee to get a better understanding of the work being done in each region. We start off with the West Midlands region on Saturday, 16th October.

If you live in West Midlands, or anywhere else for that matter, and have an issue you would like discussed, or suggestions which could help the Group in its work, please do let me know.

*John Spall*



---

---

# Regional Contacts

## **Bristol & South West (Avon, Cornwall, Devon, Gloucs, Somerset & N.W. Wilts)**

Sheila Forsythe

Gill McLorinan



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

Lindsay Wharam

Nicola Desmond




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

Sarah Smith




## **Ireland (N.Ireland & Eire)**

Rosina Brierley



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


Morag Malvern



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

Katie Spall

Linda Crozier



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

Sally Hardman

Jane Wrighton



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

Mike Halpin



**Scotland (Mainland & Islands)**

Lynn Gouck



**South Wales (Dyfed, Glamorgan, Gwent & Powys)**

Chris Stringfellow



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

*Southampton Hospital Contact*  
Vickie Richardson



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

Pat Mitchell

Noreen Hodgkinson



*Birmingham Hospital Contact*  
Lynne Holden



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

Linda Watcham



If you have difficulty in contacting any of the above, please get in touch with Penny Green at our national office (details on page 2) who will be able to help you.

---

---

## Message from the National Office

Firstly may I apologise to anyone who has had to wait a while for answers to letters, requests for leaflets, etc. and of course for this newsletter. As you will have read from the Chairman's Report, there has been a new addition to my family which has rather slowed things down here. Realising that she would probably arrive a bit early like her three brothers, I had planned out my Down's Heart Group work to get as much done as possible before her due date of 20th September, but of course she decided (or perhaps it was our little angel, Daniel), that the day before Daniel's and my own birthday would be better. So she duly arrived on August 2nd, a full seven weeks early, and as a result I ended up with a nine day stay in hospital as opposed to the twenty four hours I had anticipated. As you can imagine, during this time the post and phone calls carried on as usual, and dear Malcolm, who was finding it hard enough to cope with our two lively boys, couldn't manage the Group correspondence as well, so hence the backlog.

Things are now improving, although young Sarah is still taking up a lot of time, so please bear with me, and if you do happen to ring up about something, please don't be put off by the answerphone. It's left switched on a lot of the time at present, but doesn't necessarily mean that no-one is at home, I may be feeding or changing the baby etc. If you leave a message I'll pick the phone up if I can, if not I'll definitely get back to you as soon as possible. May I also take this opportunity to thank everyone who has telephoned or sent cards of congratulations, it's wonderful to be involved with such an extended 'family' of friends, and to know that so many people appreciate just how emotional the birth of a new baby is, particularly when you have already lost your 'special' child.

On a less personal note, you will see from our Regional Contacts page that we are continuing to build up our network of group members who are prepared to act as a contact for the group. These people are putting in a lot of time and effort in trying to establish the framework for their regions, please give them all the support you can. They would all be grateful for a few families to come forward and offer assistance, perhaps by visiting a local hospital, contacting other support groups in the area or anything else which helps to make others aware of the existence of the Down's Heart Group.

Our membership is growing steadily, now totalling about 475 families, with about another 40 on the mailing list not yet having applied for membership. We are also in contact with many interested professionals who are supportive of our work and refer families to us, but there are still many families who might benefit from our help but are unaware that there is a group specifically for those families whose child has Down's Syndrome and an associated heart condition. Every one of us from time to time comes into contact with someone who would find it useful to know about the Down's Heart Group, please don't assume that they already know, tell them.

The more members we have on file, the more information we have available for research and family support, so getting new members is beneficial not only to them, but to the group as a whole. For this reason it is also important that the data we hold on all member families is as up to date and as complete as possible, so please do let us know if there are any major changes with your child, for example they have a catheter test or surgery, any other medical conditions develop, or any other major illnesses. Please do send back the questionnaires you receive, even if they've sat in a drawer for months it's never too late to return them. All the information we hold is a valuable resource for members and researchers so we need our records to be complete. Be assured that no information is divulged without first obtaining permission, unless of course it is of a very general nature without any means of indentifying those families it refers to.

Last but not least, please keep sending in your stories, photos, letters & articles for the newsletter, without your input it would not be possible to produce, and please don't assume that we necessarily know about local or even national announcements, research etc. if you see or read anything you find interesting and relevant to the Down's Heart Group, please let us have a copy, (and remember to tell us where it came from so that we can obtain the necessary permission to reproduce items).

*Penny Green*  
*National Family Support Co-ordinator & Newsletter Editor*

## Kimberley's Story



Back in May '92 I was flicking through the local newspaper when an advert hit me like a steamtrain, it read 'An adoptive family wanted for Catherine, she is a few months old and has Down's Syndrome'. We had been considering adopting an older child or young adult with Down's Syndrome, but as we already have three children of our own, a young baby would be ideal because she would be the youngest in the family and therefore grow up knowing our children as her brothers and sister, and my husband Kevin and myself as Mam and Dad.

We answered the advert straight away and we were soon underway with our assessment by the Fostering and Adoption officer, which was quite a stressful period. We seemed to be answering the same questions over and over, and as the Adoption Agency was anxious to get a permanent family as soon as possible, we sometimes had counselling sessions twice, sometimes three times a week. We were told very little about the baby, just the bare facts, and we were deeply into our assessment when we were told that she had a heart defect. We were then asked if we wanted to continue, but at that late stage although we had never met the baby, we felt we could not turn back, and in fact it made me even more determined to prove to the Adoption Agency that I could care for her.

Eventually the assessment was over and we were left to wait for the outcome of the Adoption Panels decision. Then one Friday evening Kevin came home and dropped the bombshell that he had lost his job. Within ten minutes the telephone was ringing; it was our Adoption Officer with the news that we had been successful and that Kimberley (we renamed her) would be placed with us soon, and that we could go and meet her for the first time. Kevin broke the news to her about his job and she told us that it could make

a difference to whether Kim would be placed with us. He promised her that he would get a job by Monday which was rather a brave statement. So with some frantic telephoning around, the break he was looking for came on the Sunday evening and he was offered a job to start the next morning. We were saved.

When we met the baby we were dumbstruck by this beautiful, dark, happy, contented baby girl; we fell in love with her immediately. She was just eight months old.

Kim had had a cardiac catheter test at six weeks old, which had revealed an AVSD. She suffers the usual symptoms of a heart defect, regular chest infections, breathlessness etc., and we have been told that she will need surgery, so we await the date like many others in our situation.

Kimmie has fitted in so well into our family, and as I mentioned we have three other children who absolutely adore their new sister, who is an inquisitive, cheeky sixteen month old with a happy life planned for her.

*Siân Castle  
Taffs Well, Nr Cardiff*

### Visas for America - Correction

In our Spring 1993 newsletter, we were prompted by a members letter to advise anyone travelling to America that they needed to obtain a special waiver for their child with Down's Syndrome. After some initial confusion, the American Embassy have now confirmed that this is no longer necessary. We would like to say sorry to anyone who was caused any anxiety by this item.

### Special Olympics Medal Winner

Congratulations to group member Emma Shuttlewood for her wonderful performance at this years Special Olympics in August. Eleven year old Emma from Leicester, a very keen and able gymnast, got bronze medals for both her vault and beam exercises, silver for her compulsory floor exercise and gold for her voluntary floor exercise. All the more outstanding and encouraging when you know that she had surgery for a VSD and patent ductus at the age of three.

CONGRATULATIONS EMMA, WE'RE PROUD OF YOU!

## Chanel's Story

I'd like to begin my story with something I wrote down when Chanel was six weeks old, hopefully to show how feelings change over a period of time. Perhaps to help new families cope with how they feel. It was written one evening after I'd cried for hours. I felt guilty and angry and couldn't sleep. IT HELPED!

- "It's late Friday evening, 21st December 1990. I've been meaning to write my feelings and thoughts down since the birth of my daughter thirty eight days ago. I can remember every detail from before the birth right up to now, it's etched on my mind like a nightmare that's never going to end. It began the 9th November. I'd been to the clinic for my usual anti-natal. The doctor wasn't too happy with the recent scan results and the baby wasn't growing well enough, I'd was asked to go into hospital for a few days to check on my weight and have a further scan on the Monday. The scan turned out to be fine, but the monitor on the heartbeat was too slow. The doctor said they'd induce the baby the following day,

Wednesday morning I was taken to the delivery suite where they put a drip in. The labour pains came rather quickly and within ten minutes Chanel was born. She was beautiful and so small. They placed her on my chest and I looked down a little hazy from the gas and air. She was so sweet, lots of black hair and the image of her sister, "She's not breathing", I held her out to the midwife. She assured me that everything was fine then took her outside. I had no idea what was going on, none of my others had been taken away. They brought her back in an incubator. My face must have asked the questions, but they said that she was fine, just a little cold because she was so small. We were both wheeled up to a new ward full of mums and babies. My Mum and my sister came to visit in the evening. I wrote in my diary that evening "14th November 1990 - baby is fine, wonderful, beautiful 5lb 5oz. Her name is Chanel".

The following day I wanted to bathe the grime from her hair, the nurse helped. Chanel had a little bobble of skin by her ear and I can remember asking what it was. The nurse assured me it was fine, but something in her manner worried me. When I asked whether we could go home, as being my fourth child I didn't have to stay in, I was told the doctor would need to check her over. During lunch the nurse came in to say the doctor was with Chanel. "Save my pudding, I'll be back" I told the other mums, they all laughed.

I sat up on the bed watching the doctor, the usual checks went on and on. "Is there something wrong?" He looked at me, then asked the nurse for an instrument. He held Chanel's hands out straight and looked at them for a while. Then he asked if she looked like any other member of the family. I told him

that she was very much like her sister, even the eyes were the same with extra skin at the edge. "What's wrong?" His reply seemed cold and harsh. "She's Down's" was all he said then he walked away.

The nurse came up and explained what Down's Syndrome was. I began to cry. The baby was crying too so I picked her up. As I held her a horrible feeling went through me, this baby wasn't mine, that bond you feel when they're born wasn't there. My baby had gone and this baby was here in her place. My world had fallen apart. All the plans you have while you're carrying suddenly disappear and new ones that you don't like take over. I phoned my family who came up, as I tried to explain we all began to cry. The other mothers were wonderful, they all left the ward to give us time to come to terms with it. My ex-husband couldn't understand and I got very annoyed trying to tell him we'd had a retarded child. I was angry with him and myself wondering who's fault it was. Obviously it's no-ones, but it takes a long time to stop blaming someone. The doctor came back in to explain in detail what his diagnosis was. Chanel had the characteristic features of Down's Syndrome, but there were no extra lines on her hands. There was a test they'd do which took a week to ten days for the results.

That evening a nurse came over to me. I'd been crying most of the day and she wanted to reassure me. Another baby with Down's Syndrome had been born five days earlier and she felt they may have been hasty in their diagnosis. She felt sure Chanel was normal and I began to agree. I went home on the Sunday, staying at my Mum's for a while. Within days Chanel became ill with a cold and her breathing was very shallow. I called my doctor, then the midwife turned up for a routine check and sat with me while we waited for him to arrive. He phoned back to ask if I minded seeing a different doctor, and at the same time said that the test results were positive. I wasn't expecting it and was very upset. The pressure of her being ill as well didn't help. Chanel spent the next few days in hospital. When I took her in, I was very frightened to leave her there in case I didn't want to go back for her. By the time she was well enough to come home, I had been told that there was something wrong with her heart.

Whilst she was away I had a visit from the mum of a thirteen year old who was in mainstream school and doing very well. She gave me information and contacts for places like Koala's, a group in Swindon for special needs children, and a meeting place for families. A social worker also came to see me, giving me options and general information on what help I could get.

The bond I have with her now at six weeks old is not the same or as strong as I'd like it to be. I love her and



feel very protective, but something is not quite right, like a block perhaps to protect myself from what's to come. She is now part of my family, but life is not the same and I don't feel the same any more." -

Now as I look back over the last two and a half years my feelings have changed drastically. I went to Koala's just to see other children with Down's Syndrome doing something, Chanel was two months old and still like a new born. My family and friends left the decision to me, if I couldn't cope they'd understand. I already had a broken marriage and three very individual children that needed so much. Cheri-Lea my eldest was ten, David was eight and Kye was just over two. I had an evening job that I loved, and I had just bought myself a home that needed everything doing to it. I was determined to keep Chanel, and looked on it as if it was meant to happen and that I would cope and enjoy her for as long as possible.

In February we went to the hospital for checks, Chanel's heart defect was quite severe and she was put on Frusemide. I had a job giving it to her and often didn't get it down, but her deterioration was very fast so I'd force it down her with a lot of upset to both of us. About this time our weekly visits from a Portage nurse began, and I used to look forward to seeing her. She seemed to enjoy her work with children like Chanel. We started a programme of aims and objectives, some of the work we did was fun and some hard work, but when Chanel followed a toy with her eyes it was such an achievement.

She now weighed 9½lbs. Her first smile was at ten weeks. I was still feeding her myself with no problems, but she wouldn't take a bottle which made working very awkward. We had appointments all over the place, physio etc. Her muscle tone seemed good to me and I had great expectations believing she'd be the best ever. It didn't turn out like that, and by the summer of '91 her aims were as little as lifting her head and keeping it straight. In September Chanel caught a nasty cold and got a chest infection. She was in hospital for a fortnight and an appointment was made with Bristol Children's Hospital where she spent a day having a catheter.

In October I asked my vicar to christen Chanel as I didn't think she would survive the operation, she had a hole in the middle of her heart and only one valve instead of two. Deciding about the operation didn't seem a choice, without it her life would be so poor that it was worth the risk. My ex-husband came with me to the hospital, and on the 22nd of October we carried Chanel into the anaesthetic room, kissed her goodbye and left her, as I thought for the last time.

During the operation we walked into town. I remember

buying the other three children an outfit each, but I couldn't buy Chanel anything, I felt I'd already lost her. When we eventually went back to the hospital, a nurse took us into a small room and asked us to wait for the surgeon. He had a foreign accent which made it hard to understand. He said the operation hadn't gone as well as hoped, but they had patched the hole and done the best they could with the valves. Another ten minutes and we were allowed to see her. The tubes all over her body were shocking, but we'd been prepared for it when we were shown around earlier in the week.

I spent hours at her bedside, travelling from Swindon at 9.30am and leaving again at 2.30pm in time for the other children. Chanel's Intensive Care took a little longer than we'd expected or had been told. Eleven days on the ventilator and then just over a week in the nursery before coming home on the 14th November, her first birthday and the beginning of a new easier life. We had to bring three different medicines home, Frusemide three times a day, Spirolactone once a day and Digoxin twice a day. It was still hard to spoon feed these down. I'd given up work by now, I couldn't leave her with anyone to start with.

Our Christmas was happier than the year before, and within three months Chanel was as healthy as anyone else in the family. Things began to change, and from being like a motionless rag doll, Chanel became full of energy with the will-power to overcome every hurdle. She had an assessment at fifteen months and the physios report was promising although they said she was functioning at a level of six to eight months.

Chanel is now two and a half, it's April 1993 and she's been walking since the age of two. She goes to school full-time, the bus comes for her and she likes to carry her own bag even though it's heavy. We haven't had any illnesses since surgery, only colds more often than the others, but she copes. Her appointments are now very few and she seems happy. She has her own personality and a temper that sometimes needs sorting. She likes to empty cupboards out all over the floor and won't eat much unless she can feed herself as well as the chair, floor, her clothes and hair.

Chanel is very happy as far as I can tell. She loves her brothers and sister, and me I hope. As far as the future goes, my attitude is as long as she's happy and nothings wrong I don't worry. As the saying goes "Que Sera Sera - Whatever will be will be"

We are happy now, let's hope we always feel this way.....

*Lisa Macieszonek  
Swindon*

## Andrew's Story

Andrew was born by Caesarian section on 14th May 1990, and the fact that he had Down's Syndrome did not altogether shock my husband and I, as I was forty-seven and he forty-eight so we knew that there was an increased risk. My pregnancy was mistaken for the menopause and was not diagnosed until twenty-three weeks at which point the gynaecologist felt it was too late for an amniocentesis test. In many ways this made things easier for us as neither of us would have been in favour of abortion and to have been faced with a decision would have been very difficult.

When he was two days old, Andrew was showing signs of gong blue when feeding and a scan showed that he had a fair sized hole in his heart. This news was much harder to accept than the diagnosis of Down's Syndrome, but of course we had to come to terms with it. We were told that Andrew may require an emergency operation at only a few weeks old as he could go into heart failure. When we took him home from hospital he was under the care of the Special Care team and was monitored closely. However, although he tended to sweat a lot when feeding he did gain weight slowly and didn't seem to be too badly affected.

The cardiologist from Killingbeck Hospital, Leeds, performed a cardiac catheter test when he was about seven months old and explained that Andrew had increased pressure in his lungs and would need surgery before the age of two. He could develop irreversible lung damage, and if this happened an operation would be pointless. He would then gradually become an invalid and would spend the latter years of his life in a wheelchair. He could survive to his early twenties, give or take a few years and should have a reasonable childhood. On the other hand there was a fifteen to twenty per cent risk that Andrew would not survive an operation and the decision was left entirely to us. After much soul searching we decided that we wanted to give him the chance of a better quality of life.

We were seen by the surgeon at Killingbeck in January 1991, but we were shocked when his first words were "Do you realise that if Andrew survives an operation

he will probably outlive you?" We said that we hoped he would, only to be told that "after our death Andrew would probably end up in an institution and some parents would prefer their child to die before them." We certainly did not agree with him and said that we had given it a lot of thought and definitely wanted Andrew to have surgery. He then agreed to put Andrew on the waiting list, which at that time was two years, but a second surgeon was expected to start work within three or four months.

As time went by it became less and less likely that Andrew would reach the top of the waiting list before he reached two years old, but he would not be treated as an emergency. We wrote to our MP complaining about the length of the waiting list but to no avail. In August 1991 when Andrew was fifteen months old, the cardiologist agreed to 'shop around' for a hospital with a shorter waiting list.



Andrew was referred to the University Hospital of Wales in Cardiff, where a new paediatric cardiac unit had opened earlier in 1991. The surgeon accepted Andrew without actually seeing him, subject to him having another cardiac catheter test in Leeds to confirm that his lungs were still alright. This was done in September 1991 and the result sent to Cardiff. All was well and a few weeks later we received a

telephone call to say the operation was arranged for 6th November and we should travel to Cardiff on 4th November. Accommodation would be provided for my husband and I and we could expect to be there for two to three weeks. Andrew was then almost eighteen months old and still needed support when sitting and could not pull himself from lying to sitting.

The team in Cardiff were wonderful and we shall be eternally grateful to them. Andrew was the first child with Down's Syndrome to have surgery in their unit and we were all delighted when the operation was successful. Andrew did have a few complications and remained on a ventilator for almost a week and in Intensive Care for ten days, however, he fought through it and one week after leaving Intensive Care

he was allowed home to be followed up in Leeds. Last month we took him for his check up with the cardiologist and were told that everything is fine and Andrew does not need to be seen again for three years.

We have nothing but praise and admiration for the care Andrew received in Wales and never felt there was any discrimination. Andrew was treated as a child and not a child with a mental handicap which did seem to be the case in Leeds. Having said that, we are also very grateful to the cardiologist in Leeds who sympathised with us and did all he could to get surgery for Andrew.

Since the operation Andrew has made steady progress and walked when he was two and a half. He is a lively, bright and happy little boy who enjoys life to the full. He attends a special school nursery on three mornings each week and the nursery at the hospital where I

work on the other two weekday mornings.

Although we had many anxious times in the earlier months, these have been outweighed by the joy and pleasure Andrew has brought us. We have been supported throughout by our two daughters now aged twenty-four and twenty-six who both love Andrew very much.

We feel that Andrew can now look forward to a full life and hope he will have every opportunity to reach his potential.

We would say to any parents in a similar situation to keep on fighting for their rights, our children are very precious and deserve a fair deal.

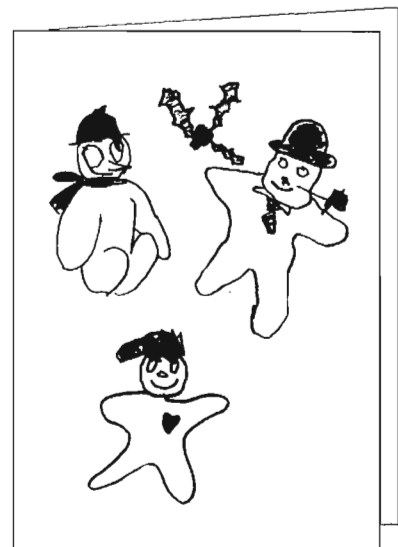
*Jean Jackson  
Otley*

## Christmas Cards

Shown opposite is this years Christmas Card designed by eight year old member Grant Brookes from Hastings, who had surgery for Fallot's Tetralogy in 1988. Grant's picture of the jolly snowmen was the winning entry in our competition to design a Christmas card, so congratulations to him, and a big thank you to all the other entrants, better luck next year.

Enclosed with this newsletter is a sample card, please show it to friends, neighbours etc. and ask them to support our work by buying some. All of the proceeds from the sale of the cards comes directly to the Down's Heart Group. As well as being a valuable source of income for us, the cards also serve the purpose of raising public awareness of our children, so please help if you can.

Cards are in packs :   10 for £1-30 or  
                                  50 for £5-50 (both plus postage and packing).  
Please use the order form on the back page of this newsletter.



## AV Canal Booklet

Our booklet 'Heart Problems in Children with Down's Syndrome - The AV Canal Defect' has now been available for just over four months, and has been very well received. As well as giving details of the condition, it relates fifteen families accounts of their experiences with their child, and extracts from other parents which help to answer some of the many questions we all try to find answers for.

If you would like to order a copy, please send a cheque or postal order for £1, payable to 'The Down's Heart Group' to the national office (address on page 2) together with your name, address and the name of the book.

**Please allow 28 days for delivery.**

# Report on the AGM

## Election of Committee Members

At the AGM on 19th June, the following were elected to serve on the Executive Committee for the next year:

Chair	John Spall
Vice-Chair	Sheila Forsythe (re-elected)
Secretary	Gill McLorinan (re-elected)
Treasurer	Phil Thorn
National Family Support	Penny Green (re-elected)

Following the formal business of the day, the meeting progressed with talks from the Head Teacher of a Special School and a Speech and Language Therapist, and with a workshop session in the afternoon. Lunch was a buffet meal which gave everyone the opportunity to chat informally whilst they sampled the delicious spread organised by Marion Hill and Meg Steeds. During the break there was also the opportunity to buy Down's Heart Group sweatshirts and t-shirts, and examine the display of leaflets and literature on show. Throughout the day there was a fully supervised creche for the children, who had the opportunity to play with much of the special equipment at the school. When I visited them, they were certainly all having a great time, children and helpers alike.

*Penny Green*  
National Family Support Co-ordinator

## Speech and Language Therapy by Christine Jenkins

We were very fortunate in having Christine Jenkins to talk to us on this very important subject of Speech and Language at our AGM in June. Particularly as Christine has researched and made her subject for her M.Sc. - Down's Syndrome Children, Speech and Language.

Christine is a Speech and Language therapist in Swindon. She was able to take us through the history and progress of the views and philosophy of communication with special needs children, and the current methods of looking at pre-verbal skills as the important first stage of developing a rapport with our child. Many of the methods we may find we are already using naturally, like talking to our babies, making sounds, repeating babies sounds back to them, gestures and listening.

Christine's research has shown that children with Down's Syndrome, on the whole are very good at getting their message over by gestures, pointing and facial expressions etc., but they are more inclined to have difficulties in the areas of joining words together and in their level of comprehension. Children with Down's Syndrome have the ability to understand better what they see rather than what they hear, and the curve of their learning level peaks earlier than many other children with special needs.

Christine was very keen that Makaton should be used as a method of early communication. She stressed its importance in helping a child's development of language, which it was clear is slower in our children than many others. All children with Down's Syndrome should have speech therapy sessions to help them in their early years. This may be a big problem in many parts of the country with cutbacks in provision for special needs services. It would seem, from Christine's experience, research and knowledge, that this service is so important for all our children, that it is yet another area that you may need to make protests about if you are not receiving sufficient support.

It was really delightful to come across a practitioner who has such a depth of knowledge and interest in children with Down's Syndrome, and whose enthusiasm and zest was passed on to us all at the AGM. This could be judged by the quality and quantity of questions from the audience, and the number of parents who were keen to join her workshop in the afternoon session.

Thank you Christine, I am now a wiser person for your talk, and hopefully I can pass that on to other Mums and Dads.

*Katie Spall*  
London Southern Co-ordinator

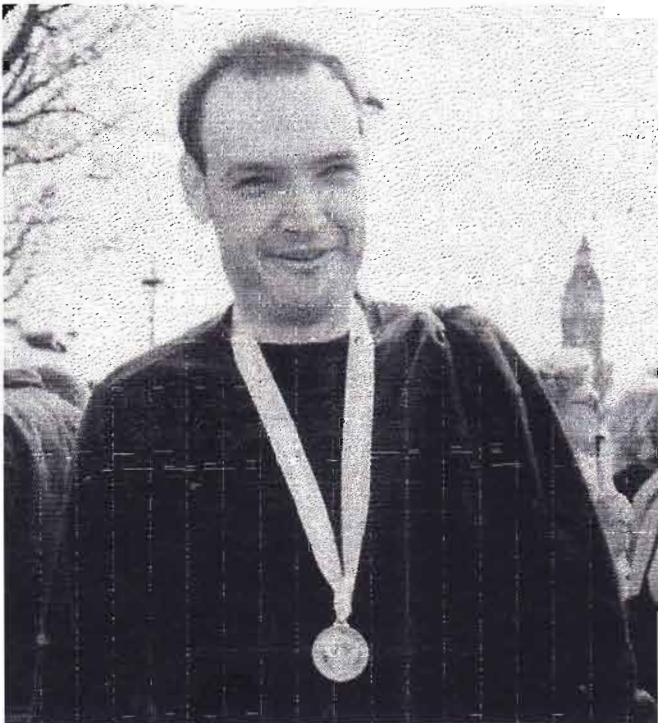
# Fundraising News

## Karate Marathon

On May 8th, three Karate clubs organised a twelve hour Karate Marathon in aid of the Down's Heart Group. During the day, about one hundred members took part in continuous demonstrations and practice routines, under the watchful eyes of the three instructors.

By the end of the twelve hours many were willing to confess to being totally exhausted, and there were certainly a few sore feet in evidence, but everyone felt that it had been worth all the hard work. Particularly when all the sponsor money was collected in, and they were able to present a cheque for £800 to five year old Kirsty Glowocz, who accepted it on behalf of the Group.

## London Marathon



In April, we were represented for the third time in the London Marathon, and for the second time by Jon Spall, son of our new Chairman. Jon's foot-pounding of our Capital's streets raised in excess of £250 for the Group. He is pictured here with the medal he was given for successfully completing the event.

## Pub Support

Back in January, group member Daniel Waterhouse aged seven, accepted a cheque for £100 from the manageress of the Bass House, Halifax. The Down's Heart Group was one of the charities who benefited from various fund raising activities at the pub, having been nominated by the ex-mayor after Daniel's mother wrote to him to tell him about the work we do.

## Memorial Donations

During the last year, the Group has received donations in memory of :

David Burton  
Joel Day  
Phylis Kislingbury (great grandmother of Harry Dent)  
Jonathan Luntz  
Callum O'Reilly  
Mia Parsons  
Rosie Steeds  
Adam Watcham

*These items relate just some of the ways in which the Down's Heart Group has been funded over the last few months. Other donations have come from members holding table top sales, coffee mornings, cake stalls, even brothers and sisters getting involved in fund-raising at school.*

*Obviously it is not possible to mention them all, but every donation from the very smallest amount is gratefully received and put to good use. Thank you to*

### **Heartbeat in Pregnancy**

In the last issue, I mentioned that in conversation with a number of mums, the subject of the baby's heart beat at ante-natal check ups had often arisen. Many were told that the baby had a 'good strong heartbeat', which they found quite ironic later when the baby was born and the heart condition diagnosed.

Many of you wrote or phoned to say that this had happened to you, but I'm sure that there are still some members who have not. Please think back if you can, and if you recall being told something along these lines during pregnancy, do let me know as it may be important for future research.

Penny Green, [redacted] or address on page 2

# Down's Syndrome - Recent Studies

## A members report of a Sue Buckley Study Day

On 24th April, Salisbury Portage Service in association with the Down's Syndrome Association, organised a study day entitled "Down's Syndrome - Recent Studies". Sue Buckley, the Director of the Portsmouth Down's Syndrome Trust was the speaker. She spoke on:

- 1) Recent developments in understanding Down's Syndrome
- 2) Language development
- 3) Preparing for school

The day was very well attended by a variety of people including parents (a creche was available for the children), speech therapists, portage workers and special school teachers.

In the first part of the morning we were given a brief insight into Sue Buckley's background and the roots of her interest (or perhaps sheer enthusiasm would be a better way of describing it!). The formation of the Portsmouth Down's Syndrome Trust and its aims for the future were also explained. The Sarah Duffen Centre, within the University of Portsmouth, is the focal point of the Portsmouth Down's Syndrome Trust and is working towards "enhancing the lives of children with Down's Syndrome and their families". It believes "now that we know more about the reasons for their delayed progress we are able to develop effective early education programmes to enhance their progress by building on strengths and overcoming weaknesses."

Sue Buckley then went on to describe the recent developments in understanding Down's Syndrome based on research carried out within Britain and from as far afield as the United States and Australia. Two of the topics covered were :

- i) A study of sleep disorders and behaviour problems - possibly related to breathing difficulties.
- ii) Variability in all children - just because a child has Down's Syndrome it does not mean that they will learn at a specific rate, as with all children every child with Down's Syndrome is different.

Each area of research raised questions and heightened our awareness of the complexities of the Syndrome, demonstrating a vital need for more research specifically aimed at this rather than mental handicap in general.

After a coffee break which gave us some time to try to digest all the new ideas, Sue turned our attention to language development, which is obviously one of her major concerns. We were taken on an interesting journey of enlightenment which described the "normal" root of language acquisition. This journey was then travelled in the footsteps of a child with Down's Syndrome who encounters such obstacles as a short term memory, increased sensitivity to failure, the difficulty of expressing orally the things that he/she can understand and wants to verbalise, frustration, possible physical problems, and language processing difficulties.

One point that Sue strongly emphasised about the Sarah Duffen Centre, was the fact that rather than concentrating on stating the problems, the prime concern should be to find practical ways of counteracting the difficulties. So naturally, she then went on to suggest the implications of these investigations.

The importance of signing was stressed, not only as a tool to use at the onset of communication, but also to compliment oral language throughout the development of more complex structures - something to stem the frustration that can build up. Once a child has become frustrated it is important that the parents and other involved adults are understanding of this sense of failure. They must learn to encourage oral language by using clues to attempt to understand what the child is trying to say, rather than unintentionally adding to this frustration by admitting non-comprehension, or by merely repeating the words back to the child. We should all be encouraged to allow more opportunities for the child to initiate communication instead of always being the responsive partner.

Two other ways of helping language development, which are being researched at Portsmouth, were explained:

- a) To investigate whether, with specific teaching methods, children with Down's Syndrome can improve their short term memory skills and in so doing improve their attempts at remembering information. Two programmes have been devised to teach the memory skills:- rehearsal and organisation. The rehearsal programme is basically to get the child to repeat a list of items (using easily made equipment), adding to this when he/she is successful. It has been shown that the children find this "fun and are highly motivated." The organisation programme teaches categorisation and grouping as a way to remember things - something which does not come naturally to most of these children.
- b) To investigate early reading development and its effect on speech. Sue pointed out that using written language systems can have a variety of benefits:
  - Symbols and words can prompt production and be used to greatly increase productive practise.
  - They may also help to overcome the auditory memory problems even at the stage of first word learning.
  - Later they can be used to prompt and help the child to practise longer sentences.

Sue emphasised that print is a very powerful tool for language teaching as the child can be taught to read, understand and practise grammatically and syntactically correct utterances.

One member of the audience was very sceptical about the importance of written language at such an early stage, but Sue Buckley produced examples and statistics to support her theories.

The final part of the day was devoted to turning our attention to schooling. It quickly became obvious that Sue was completely in favour of children with Down's Syndrome being educated within the normal state education system. She maintained that a child surrounded by peers who had similar language difficulties would not gain so much as those mixing with children who had no such problems. Also she believes that the atmosphere in special schools is not conducive to language development and socialisation. This was not a criticism of the teachers themselves, but rather stressing the limitations of collecting children with these problems together. They should be given the chance to socialise with, and learn from "normal" children. This, however, would mean extra funding for the schools to provide the class teacher with supplementary help - something that many authorities do not feel they can afford. Sue's answer would be to close the special schools and use the money saved to finance this integration.

A few members of the audience took exception to this, especially special school teachers, but it was a point that Sue would not be swayed on. Again she quoted examples to support her beliefs. It was interesting to hear the other side of the argument, although I must admit that I was convinced by Sue's theories.

In conclusion I would like to say how impressed most people seemed to be with Sue Buckley. She was easy to listen to and maintained our attention throughout each session. Her ability to quote all kinds of research into Down's Syndrome, the findings and implications as well as the relevant names and dates was commendable. The arguments to support her theories were well thought out and substantiated, and no doubt convinced the majority of us there.

One question that was raised amongst some of the parents was why we had not been informed about the existence of the Sarah Duffen Centre before. Obviously we all want what is best for our children, and this centre appears to be concentrating on exactly that. We came away wanting to find out more and knowing that an increasing amount is being understood about Down's Syndrome.

To anyone who gets the chance, I would strongly recommend they attend a Sue Buckley Study Day.

*Jo Dent  
Frampton Cotterell, Bristol*

## Can You Help?

### Unnecessary surgery

We have recently had contact from a Mum whose little girl was diagnosed as having an Atrial Septal Defect (ASD) and advised in favour of surgery. After making the agonising decision to go ahead, it came as a great shock to the family to be told after the child had come back from the operating theatre, that no defect had been found and the operation was completely unnecessary.

If any member knows of another family who have had a similar experience, please would you ask them to contact our national office on 0525 220379, as the family would very much like contact with another family to whom this has happened.

*(If your child is awaiting surgery, this item will obviously be quite alarming. Please be assured that this is an extremely rare, if not unique case, and we as a group are not aware of any other family to whom this has happened. - Editor)*

### Hearts and Minds

#### **A publishers request for poems and short stories from handicapped people**

Disabled people are rarely given the opportunity to speak for themselves or to express their creativity. Two publishers, Poetry Now and New Fiction are joining forces to enable a combined voice of the disabled to highlight their experiences. Poetry Now and New Fiction want to provide a forum where ideas and talent from novice and experienced writers can be shared.

Submissions are invited in the form of poetry of no more than thirty lines and stories of less than one thousand words. All submissions should be addressed to:

Veronica Hannon  
Hearts and Minds  
Poetry Now  
1-2 Wainman Road  
Woodston  
Peterborough  
PE2 7BU

The closing date for submissions is the 16th November 1993. Those stories and poems accepted will be published in March 1994. All unused work will be returned to the writer; and appropriate s.a.e. should be enclosed for this purpose. Receipt of manuscripts will not be acknowledged unless a stamped postcard is enclosed for this purpose.

### King's College Department of Health Funded Study

#### **Needs of families caring for children with life-threatening/life-limiting disorders**

We are working on a national study funded by the Department of Health which is looking at the needs of families caring for children with life-threatening/life-limiting disorder. We would like to talk to families, particularly those living in the South West Thames, South Western, East Anglia or Trent Regions, who are caring for such children, so that their views and ideas may be used to improve the support available.

Participation in the project would involve an interview which will cover the degree of your child's dependence on you, your child's educational needs, use of and need for health and social services, any additional costs you have incurred and any support services you would find helpful. The interview will last about one hour and will be arranged at a time and place convenient to you.

You may stop the interview at anytime and it will not prejudice the care or treatment of you or your child in any way. Indeed you are not obliged to participate in this study, and your participation will not affect the support or care you receive from any source. Your confidentiality will be strictly guaranteed.

If you would like any further information, or would like to be involved in the study, please write to/ telephone Christine Citrone who will be happy to discuss the study in more detail with you. She can be contacted at:

Department of Nursing Studies  
King's College London  
Cornwall House Annexe  
Waterloo Road  
London  
SE1 8TX  
Telephone: 071 872 3028

### Bristol Royal Infirmary Video

Families whose children are awaiting surgery in Bristol Royal Infirmary, will be interested to know that Bristol and South West Children's Heart Circle have produced a video to introduce the cardiac unit, particularly the staff who will be involved with the surgery and care of your child. The video has been very well received by the families who have had the opportunity to see it before admission. Sheila Forsythe (0454 413237) has a copy which can be borrowed if you are interested.



## Research News

### Why don't all children with Down's Syndrome get heart defects? What causes the heart defects in affected children?

These two questions are the motivation for a big research effort by our team at St. Mary's Hospital Medical School in London. Many families from the Down's Heart group have already parted with blood to help our research (and those who volunteered but haven't yet been contacted need not worry! We'll get to you as soon as we can!) After three years hard work, we have some promising results... and the British Heart Foundation has given us money to carry on for three more years (watch this space...).

What have we found? As most children with Down's Syndrome have three copies of chromosome 21, we are studying the genetic material in that chromosome. There is a gene near the end of chromosome 21 which is responsible for one of the body's scaffold proteins, collagen.. There are lots of different types of collagen, and only one has anything to do with chromosome 21 (so far as we know), however, this one is found in the heart.

As this particular collagen is found in the heart, and as the gene is on chromosome 21, it's a good place to start looking for differences between children with Down's Syndrome, with and without heart defects.

Most people are familiar with the idea that there are different blood groups, A, B, AB and O. These differences arise because a blood group gene exists in different forms in different people; all the forms work as well as each other. We are able to identify such "forms" - different versions in different people - of most genes. We do this by studying the genetic material, the DNA. We have done this for many genes on chromosome 21, including the collagen gene. While it's early days in our research (these things move slowly), our initial results suggest that there is something about the different forms of the collagen gene which, while they are quite normal, may have an effect on the type of heart defect (especially in atrioventricular septal defect - AV Canal) in a child with Down's Syndrome. We are working hard to find out exactly what is going on. While these results are very exciting to us, they are only a very first step in unravelling what is sure to be a very complicated process... This is not the complete story, and it may still take years to sort out how heart defects happen and what controls them, but it is an important (we think) first step.

We could not do any of this without your help. THANK YOU!

Dr Anna Kessling  
St. Mary's Hospital Medical School, Paddington

*Many of you will remember our request in a newsletter a year ago, for families who would be prepared to help in the St. Mary's research project. At that time they were looking for children with an AV Canal defect aged three or over, now they would like children with Down's Syndrome who have any type of heart condition aged eighteen months or over. They need a blood sample from the child and both parents, and ideally also from at least one sibling or possibly grandparents, although the child and parents alone are also useful.*

*If you would like to know more, please write to Dr Kessling at the address below giving your family details, address and day-time and evening phone numbers. It would also be useful for the team if you could include a note of times or days that are always good or bad in your household, to help them arrange the best time to visit to take the samples. It may be some time before they can actually come to collect samples as they try to visit several families in one area together to save costs, but they do need as many samples as possible, so they will get to you eventually.*

Dr Anna Kessling  
Department of Biochemistry & Molecular Genetics  
St. Mary's Medical School  
Norfolk Place  
LONDON  
W2 1PG

## Letters to the Editor

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

15th July 1993

Dear Editor,

We have a daughter Daniella, who is nearly two years old. At two days old she was diagnosed as having Down's Syndrome and a heart defect, which was found to be a very large VSD and a PDA (persistent ductus arteriosus), associated with this she was found to have Pulmonary Hypertension (high pressure in the lungs).

She had corrective surgery at the Brompton Hospital at three and a half months old, which successfully closed the VSD and PDA. This should have resulted in the reduction of the pressure in the lungs, but unfortunately we have since found out that it is still very high, and that there is nothing else that they can do to reduce it.

At our last cardiac appointment we were told that Daniella's life expectancy was approximately five years. We casually asked about the possibility of a transplant in the future, but were told that she would not get on the list because she has Down's Syndrome. This both angered and upset us.

We would like to hear from any family who's child has a similar condition, or has had a similar response regarding a transplant.

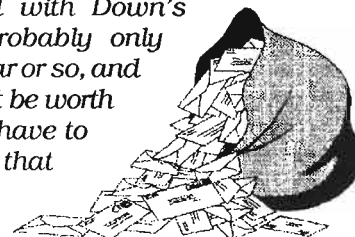
*Sue & Steve Allen  
Doncaster*

*(Please write to Sue and Steve care of the national office address.*

*The question of transplants arises quite often in connection with our children, and as far as we are aware the response has always been the same - that the child would not get a transplant because they have Down's Syndrome. One cardiologist did however, go on to explain to a family some of the reasons why.*

*After transplantation it is necessary to keep the patient on immuno-suppressant drugs to prevent the body rejecting the new organs. This would be very inadvisable for someone with Down's Syndrome who already has an increased susceptibility to infection and needs all the help their immune system can give to fight infection.*

*He felt that if a transplant were to be carried out on a child with Down's Syndrome, it would probably only prolong their life by a year or so, and in his opinion it would not be worth all that the child would have to be subjected to to gain that time. - Editor)*



3rd April 1993

Dear Editor,

I would like to thank you very much for the mention in the Spring issue of the Down's Heart Group Newsletter, which I received today.

I really am glad to work with any of the support groups, whether they be regional or national, and having Vickie Richardson come along on Unit visits was a real delight, she is a very warm, compassionate and lovely lady. Our last visit together however, was only confined to the Cardiac Ward, next time I hope we will be able to go into Cardiothoracic Intensive Care, so that the staff there can also get to know her.

Just one point, I wondered if your members were aware of the national federation group, Heart Care, of which both the Down's Heart Group and the Wessex Children's Heart Circle are members. This group is a great place for the sharing of ideas, information and concerns for any of the member groups, of which there are some twelve or more.

Through Heart Care I have met some wonderful people who have helped me, which in turn has benefited our Circle. Our liaison with them will continue once my Chairmanship comes to an end this May, through the elected representative on our own Committee, his specific job is to attend and report back to us about the Heart Care meetings and activities.

Once again may I thank you for your kind words and I look forward to working very closely with Vickie in the future.

*Angela Coxon  
Chairman, Wessex Children's Heart Circle*

# Change of Address?

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



## Notification of Change of Address

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

..... Child's Name.....  
 ..... Child's Date of Birth.....  
 .....  
 .....  
 .....  
 .....  
 Postcode: .....  
 Telephone: .....

Send to: Penny Green, Family Support Co-ordinator



## Order Form for Christmas Cards



*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: To: .....  
 ..... packs of 10 cards at £1-65p= £ ... - ... p .....  
 ..... packs of 50 cards at £6-85p= £ ... - ... p .....  
 Total = £ ... - ... p .....

N.B. Prices include postage & packing  
.....  
.....

Send your completed order form with a cheque or postal order payable to 'Down's Heart Group',  
to: Shirley Glowocz

