



**DOWN'S  
HEART  
GROUP**

# NEWSLETTER

Issue No 23

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# Chairs' Report

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This should more accurately be entitled ex-Chairs' Report as we both stood down as chairs of the Down's Heart Group at the recent Annual Conference. Katie after one year and John after seven years, preceded by a year as Treasurer.

Those years have seen tremendous changes in the Group, which has grown in services, support, strength and stature. Among the highlights we would pick out are

- the Group's video "Heart Problems in Children with Down's Syndrome" and the Lottery Grant which made it possible
- the topic notes which have been so well received for their readability and clarity for parents
- our "globalisation" through our overseas membership and our presence at international events - we remain the only group in the world, as far as we know, dealing exclusively with children with Down's Syndrome and a heart condition
- the development of our hospital visitor service which brings support to families just at the time when they are often under most stress
- the Group's appearance before the Brompton Inquiry and the magnificent performance of our witnesses as they related their often distressing experiences
- the quadrupling of our membership and professional contacts.

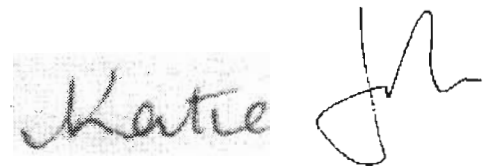
None of this would have been possible without a dedicated team of volunteers and committee members with whom we have worked over the years. We would like to thank them all for their support and friendship. In particular, we would like to pay a special tribute to Sheila Forsythe who has served as Vice-Chair during the whole period and who is retiring with us. Sheila has always been a source of wise counsel drawn from her considerable experience and contacts as Regional Co-ordinator for Bristol and the South West, and she has been ever ready to step into the breach when required.

Also, of course, our thanks to Penny, who runs such an efficient and productive National Office in, as we know well, cramped and far from ideal conditions. She is the centre of the Down's Heart Group operations and without her dedication and skills the Group would have folded long ago.

It is important that any organisation renews itself from time to time as it provides an opportunity to review and keep the best from the past but also to bring in fresh people and ideas. We wish the new team of Cliff Lake and Chris Stringfellow every success in taking Down's Heart Group forward.

Not that you have entirely got rid of us as we have agreed to take on the running of the enlarged South East region, John as Regional Co-ordinator and Katie as Co-ordinator of Hospital Visiting for the three London paediatric cardiac units.

We have made many friends and had many fun times amongst all the serious issues and hard work and that is what volunteering should be all about. We hope to continue in the same vein!



**Katie & John Spall**

## *A message from our new Chairman*

Ever since the Downs Heart Group was launched back in 1990 we have been committed to providing support for families who have a member with Downs Syndrome and congenital heart defects.

This year we held our 10<sup>th</sup> Birthday celebrations in Leeds where we had a fantastic turnout. Everyone enjoyed the disco, Tropical World and the picnic in the park.

Reaching the ten-year milestone is a magnificent achievement and is a great reflection on the hard work everyone has put in over the last decade of the 20<sup>th</sup> century. John & Katie have over the last year done a tremendous job in chairing our charity to this millennium crescendo. John in particular has given so much of himself over the past eight years and encouraged so many of you to dedicate yourselves in providing the necessary time, effort and money in keeping the Down's Heart Group an effective and efficient organisation. Following Penny's successful effort in talking me onto the committee, John convinced me that I couldn't escape without some time in the 'Hot Seat' and I am delighted to accept the job as Chairman. I believe that with the support of Penny together with the Committee I will be able to justify John's faith in my ability to sustain the growth of our charity far into the new millennium.

I hope I can count on your support and encouragement over the coming time and I look forward to meeting many of you personally.



**Cliff Lake**



# Christmas Cards & Stamps



**Christmas Pudding**  
 Designed by 9 year old Nia Llewelyn-Sudale  
 (on a pale blue background)



**Angel**  
 Designed by 7 year old Alicia Skelton  
 (on a pale yellow background)

Cards are available in packs of **10** cards (5 of each design)  
 at an all inclusive price of **£2.75**

As in previous years **stamps** are also available.

Please consider buying all your Christmas stamps from us as we make a profit on all sales. As long as you order at least one pack of cards we will gladly supply any number of stamps.

*(Samples available on request)*

## ORDER FORM - PLEASE SEND TO NATIONAL OFFICE

Please send :

..... pack(s) of 10 cards @ £2.75p      £ ..... - ..... p

..... book(s) of 10 2nd class stamps @ £1.90p      £ ..... - ..... p

..... book(s) of 10 1st class stamps @ £2.70p      £ ..... - ..... p

..... ceramic mugs @ £4.00p      £ ..... - ..... p

I would also like to make a donation of      £ ..... - ..... p  
 (a few pence to round up your payment means a lot to us)

You may if you wish deduct £1 from total  
 if ordering five or more packs of cards      LESS £ ..... - ..... p

To (name & address) :

.....  
 .....  
 .....

Telephone No : .....  
 (useful if we need to contact you )

TOTAL of cheque or postal order enclosed      £ ..... - ..... p  
 Payable to "**Down's Heart Group**"

N.B. Postage and packing charges are included.

## Down's Heart Group Nurses Prize

The Down's Heart Group Committee has decided to award an annual prize in the field of nursing related to children with Down's Syndrome and cardiac problems, and the Paediatric Cardiac Nurses Association have kindly agreed to assist with the judging from a professional point of view.

Basic details are given below, so if anyone (members particularly) is aware of nursing staff who they consider have shown innovation in the care of a child with Down's Syndrome and a heart defect, please make sure they know about this prize.

<b>Purpose</b>	to promote innovation and best practice in the nursing care of children with Down's Syndrome and a heart condition .
<b>Amount</b>	£250.00 to be provided by Down's Heart Group to be spent as the winner wishes.
<b>Format</b>	Nurses to submit a report of up to 500 words outlining an innovation in the nursing care or best practice of children with Down's Syndrome and a heart condition.
<b>Timing</b>	Entries to be submitted to the Paediatric Cardiac Nurses Association between 1st September and 31st December each year. The winner to be announced by 1st March in the following year.
<b>Judging</b>	Will be by a panel comprising two members from the Down's Heart Group and two members from the Paediatric Cardiac Nurses Association.
<b>Obligations of the prize-winner</b>	To provide an article, based on the winning report, to be published in the Down's Heart Group Newsletter. To present the report to a Paediatric Cardiac Nurses Association study day.

## Urgent - Your child's SEN provision at risk

*This letter was recently received from IPSEA (Independent Panel for Special Education Advice), by a member who asked that it be drawn to everyone's attention in view of the possible implications for our children.*

Dear parent/carer,

For over 17 years now the law has required LEAs to 'specify' a child's special education provision in their Statement, in order to 'protect' it. Despite this, many LEAs refuse to say clearly how much help a child should receive. What does it mean if your child's Statement uses phrases like "access to support" and "regular help"? (Christmas is regular!)

Previous Governments have been reluctant to enforce this law. Now the present Government are proposing to change it and the Special Educational Needs Code of Practice, to weaken LEAs' duties to be specific in Statements. If they get away with it, all Statements will be woolly and all special needs children will lose their guarantee to the provision they need.

IPSEA is campaigning against the Government's proposal to weaken Statements, arguing instead that there is a pressing need to strengthen the law, by:

First, making it legally binding on professionals to state in their reports on children their opinion not just on the type of provision a child needs, but also on the amount of provision. Then you, as a parent or carer, would have a clear idea of the professionals' views on how much help your child needs.

Second, making it legally binding on an LEA, when writing a Statement, not only to specify the type of provision, but also to quantify the amount of provision to be arranged. Then you, as a parent or carer, would know exactly what provision your child was entitled to under their statement.

It is vital that as many parents as possible support these changes: politicians will listen to you more carefully than to an organisation such as IPSEA. Also, 'numbers' can be as important to politicians as arguments! Please write to your MP and, if possible, go and see him or her. Try to get a promise that they will write to the Secretary of State opposing the weakening of Statements, and that they will vote for IPSEA's changes when the time comes.

Also, write to the Secretary of State, David Blunkett MP, at the House of Commons, London SW1. Let him know what you think of his Department's proposals. Explain why you think Statements should be strengthened, not weakened!

IPSEA believes that this is an argument which parents/carers of special needs children can win, if we all do our bit! In particular, remind your MP that there is an election coming ...

# Rosemary's Story

Rosemary was born on 5th March 99, at the Royal Victoria Infirmary, Newcastle-Upon-Tyne. My labour had commenced prematurely earlier in the week on a Tuesday night. The doctors and nurses at the hospital had managed to stop the contractions using Ritoprin, and an injection of steroid to open my baby's airways and then I was transferred to the ward. It was established that the baby was a good size and that I would be given a further injection of this same steroid so that the baby's lungs would function more efficiently. I was 32 weeks pregnant.

On the Friday I was discharged and the staff informed me that I would not be given any further treatment to inhibit labour (whenever it commenced). They told me that naturally the baby's lungs would be prepared to function around 34-35 weeks gestation, and that they didn't know when labour would commence but that they did not expect me to go full term. I was very unsure and uncomfortable, I did not know what to expect, and with three children at home of ten, eight and six years of age, I was very concerned to see them and reassure them that I was all right and that I was still expecting a baby. Having suffered a miscarriage the year before that they were aware of, I knew that they would worry what the outcome of this pregnancy would be.

I was only home a few hours when contractions suddenly began at 5.00PM, my waters broke simultaneously, and the ambulance arrived very quickly. I arrived at the hospital at 5.30PM and was told that my baby was about to be born. By 6.09PM I had delivered a baby girl. There were some tricky moments when the midwife seemed very anxious that I should not delay. It seemed that there was some concern for the baby, but I knew in my mind that the best thing I could do was to get this baby born as smoothly and quickly as possible. When she was born she was a little blue, I lay there not wanting to hear any bad news, but after a minute of receiving oxygen they gave her to me, wrapped up in a blanket.

That first view of her sent triggers off in my brain, she was so precious, so tiny and she just looked different. When the paediatrician had been looking at her and giving her the oxygen I had looked over to see my little girl, I saw this hand, broad, short fingers, I couldn't help thinking about them anxiously as I lay there. When I looked into her eyes I felt something puzzling, she just looked different, but then I guessed that I would probably look odd if I had just gone through the hurried entry into the world that she had.

However, that didn't seem the answer, and I asked the nurse if she was all right. In a way that nurses have of trying to reassure you, she said that the paediatrician would be in to see me soon and she brought me a cup of tea. I lay there with the strangeness of the moment, the timelessness of it all, drinking tea and wondering.

Eventually the paediatrician came in and apart from reassuring me that Rosemary was doing well enough in the Special Care Unit, he asked me what I thought of her. I said that she looked different, and that her hands seemed to be broad with short fingers - I jokingly said that it was alright, they would be good for wicket keeping, (Rosemary's dad plays cricket.) When he had listened to my observations he said that they too had also

noticed this, that they thought she might have Downs Syndrome as she had several characteristics that suggested it.

I was in a moment of shock I suppose, I had just given birth rapidly and to a premature baby girl, and now she was so very "Special". I don't know if what I thought was what other mothers thought or felt when they have this news, but I began to worry. Would I be good enough to be her mum? I imagined her as a child, as a grown up and somehow I thought of my own age at the time, 38, and wondered too if I would always be there for her.

In that short while, lying there on the bed she had arrived into the world upon, I realised that life would never be the same again, and I realised that she was so very precious and that I was so lucky to have her. There were tests that would be carried out to confirm the Down's Syndrome, but I knew already that they would be positive.



Rosemary was only a few days old and Dr Milligan of the Special Care Unit came to talk to her father and me. There was also an echocardiogram test that had been performed which suggested that Rosemary had a heart defect. When we had the blood test results confirming that Rosemary had Trisomy 21 Down's Syndrome, Dr Milligan came and spoke to us. He told us of the physical characteristics that we might find in a person with Down's Syndrome, he told us of the medical problems that they were known to have. He told us that he wanted Rosemary to go to the Freeman Hospital to see a consultant, Dr Christopher Wren, who would be able to assess Rosemary's heart condition.

I think that he was very calm and reassuring, he let us ask whatever we wanted and he helped us to begin to understand, but we just felt so stunned. Now we had a baby girl, who not only had Down's Syndrome but also had a heart condition. It was so unreal, so unfamiliar; we had no idea of the future. I didn't want to lose her. I found myself telling myself that I had to be strong, that I had to show everyone that our little girl, despite all our fears for her future, was something to be glad of.

I felt as though I had let her down. I felt as if it was my fault

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that she was not strong. I remembered that Dr Milligan had explained that the heart condition was more common in children born with Down's Syndrome, and so that in some way it began to seem a less separate issue, and more just part of Rosemary's special nature.

When Rosemary was six days old she was transferred to North Tyneside General Hospital. She was then in the S.C.B.U. under the watchful eyes of the nurses, in particular Sister Sylvia Bauer. Rosemary had a cubicle room of her own; it was a special time to get closer to her, to feel more like her mum. It meant that her brother and sisters, and her dad could come more easily to visit her and it meant that I could feel nearer to her because she was only a three minute taxi ride away, day or night. It was so hard to go home from the hospital each day leaving my little girl behind. When she was about six weeks old she was allowed to come home.

She had been to see Dr Christopher Wren at the Freeman Hospital in Newcastle when she was about ten days old. I remember coming back in the ambulance beside her heated incubator, looking at her frail little form, unable to say the feelings that I had welling up inside me. Seeing her tiny heart on the echocardiogram, seeing the movement, and even from my untrained eye noticing that it didn't look right, and then trying to take in what was said when Dr Christopher Wren explained that she had an Atrio Ventricular Septal defect.

Rosemary was only home for a week when she began to get cyanosed and she spent a week in hospital returning on Captopril, Spironolactone Chlorothiazide and with a nasal gastric tube. Then we got used to the new regime, part oral feed, part nasal gastric, but within the following two weeks she drank less and less orally, and more and more via the tube.

I had one awful night and in the morning the only thing to do was to phone the hospital. Mercifully the cardiac liaison nurse, Sister Paddy Walsh answered the phone. She asked me how many respirations Rosemary was having per 15 seconds, I counted them and she told me to bring her in.

When we got there it was soon discovered that Rosemary's sodium level was low and she was put on continual tube feeding at low flow and was given sodium supplements for several days until they were satisfied with her. Rosemary was then gradually reintroduced to bolus feeds and she was also on a calorie booster supplement with her milk. The plan was to fatten her up ready for her surgery. It was possible that she would have her surgery soon, we felt that there was going to be some chance of it in June.

Initially we were given a date, but the evening before, it was cancelled because of shortage of bed space. A week later Rosemary was re-scheduled to have her surgery, The surgeon, Mr Assif Assan, had come to see us and explained the procedure. We felt really glad that she would have it, but we were so scared too. When we brought her to the theatre early on the Monday morning 28th June 1999, we were in a weird trance, time seemed to stand still. Everyone was very kind and sensitive, to us and so gentle as they received Rosemary from her father's arms, but I felt so bereft as we walked away from the theatre.

We went into Newcastle to spend some time, we did not have any real shopping, but we just went into various gadget shops and things that seemed unrelated to babies. I couldn't look into Mothercare as we went past. I couldn't talk much, but

Rosemary's dad chatted most of the time. Eventually we went back to the hospital, we went to have lunch, not that we had any appetite, but it used up more time. We went to the parent's room and waited to be called. The moment finally came when we were called to go and wait in the parent's room in the children's intensive care unit. I could not talk still, a hundred thoughts seemed to be chasing around my head and I felt tense.

Then Mr Assif Assan came in. He told us what we needed to hear and he said he would send a nurse in to bring us through. When we finally saw her I could not believe it, she was all wired up and had the various lines, and she was lying so deeply asleep, because of the sedatives of course. Her dad stood closely to look at her, the staff and even Dr Christopher Wren were explaining it all. I just couldn't talk, and I JUST STARED AT HER. I wanted to hug her, to cry, to let all my love out for her, I wanted to check every inch of her to make her mine, but as I sat looking at her I realised that the nurses and the doctors were taking such great care of her.

She was very fragile and she had several problems during the following days, eventually when eleven days post operative, she was capable of doing all her own breathing. We were so glad when she was removed from the intensive care unit. We thought that it would not be too long before she would be able to go home, but a week after the return to the ward there was a sound noticed from her, it was called Stridor. A Bronchoscopy was performed and it was discovered that she had a Subglottic Stenosis. This was due to the scar tissue that had formed as a result of prolonged intubation. Rosemary was given low flow oxygen therapy; she was also given steroids to reduce the inflammation that had occurred when the Bronchoscopy was done.

Rosemary was again having more problems; it began to feel that she would never get home. We had started to feel really desperate. All we wanted was to be together again. Rosemary was transferred to North Tyneside General Hospital, she was given oxygen therapy and we were equipped with an oxygen concentrator in our house. Then we were able to bring her home. It was somewhat unceremonial when we finally sat with her in our home. We had had so many journeys with her, physical and emotional, all we really wanted was to be still.

Rosemary has just had her first birthday and we are so proud of her, she can now sit by herself, she says "mum", "dad", "hi-ya" and "Ted-d-Bear". We feel that she has so much character, we see only Rosemary, not her Down's Syndrome. I can still feel the strain of all that happened in her first year as I think about it, and sometimes I just look into her eyes and hold her close wanting to chase the bad memories away.

I guess it is the same for all parents of children with heart problems. I hope that our story will be of help to other parents. It was comforting to know that the Down's Heart Group existed, and reading other parents letters in the days before, during and after Rosemary's surgery gave us something to identify with. Thank you to those people who contribute to the Newsletters.

**Alison Parrack  
Whitley Bay**

# Caroline's Story

We were quite young when Caroline, our first child, was born in East Dulwich hospital in London. Initially we were told her heart was fine. Then at one month old she became ill with a chest infection, it was discovered she had a 'murmur'. During her first year, she was in hospital several times with chest infections and heart failure and each time surprised the medical staff by 'pulling through'. She attended outpatients regularly at Charing Cross Hospital under the care of the late Dr. Hugh Jolly paediatrician and Dr. Alan Harris Cardiologist.



When she was thirty months old Dr Harris recommended a catheter test which revealed the true complexities of her heart

condition. We were told there was no surgery suitable for her. We were devastated by this news and have since felt resentful that the diagnosis was not made earlier when surgery could have been an option. We believe discrimination played a part at this time.

Except for one serious illness at seven, Caroline thrived and enjoyed reasonably good health. We moved to Surrey when she was ten and her cardiac care was transferred to St. Helier Hospital and Dr Redwood. Here she had venesections occasionally and her blood count monitored three monthly.

We returned to our native Northern Ireland in 1992 when Caroline was twenty. Since then she is under the care of Dr Norman Campbell at the Royal Victoria Hospital in Belfast. Caroline continued to do well until last January when she suddenly collapsed and had to be rushed into hospital. Now her mobility is very limited and she needs oxygen at nights.

Dr Campbell said he would not recommend heart and lung transplant for Caroline, as he believes people with Downs Syndrome have a higher rate of infection and rejection. He is currently investigating a new treatment for pulmonary hypertension, that he says, may be of benefit to her.

It is heartbreaking to know Caroline will no longer be able to use her wonderful dancing talents. She is aware of her own limitations and avoids situations and locations where she knows she may be physically challenged. She is in good spirits and is a fun-loving, happy and extremely popular person who really enjoys life.

**Sheila Artt**  
**Magherafelt, Co. Derry**

## Portage comes to Latvia

*The following extracts are taken from a letter to Katie Spall from fellow Portage worker Rosemary Gardner who has been involved in setting up a Portage Service in Latvia.*

"I had to write to you about Portage progress in Latvia. The Down's videos and the printed materials have been most useful to them...

We went again last February to 'accredit' the portage visitors we trained in the summer. There are now 52 visitors actually working with both certificates and 10 more soon due. Those 62 people visit 72 children at present. This is in addition to their day jobs as speech therapists, teachers, doctors and psychologists, and overcoming tremendous difficulties to provide the service.

One lady has a half hour bus ride and twenty minute walk to the home of the child she visits with cerebral palsy. One paediatrician was back visiting six weeks after her caesarian section - breast feeding her own baby and working full time...

I visited a one year old called Matiss. Like many of the mothers I met, his Mum was told not to 'waste her love' on him. She thanked me for bringing Portage, which had to her been 'so marvellous'. her young son is sitting, standing almost up on hands and knees and vocalising nonstop...

Our tremendous news is that Ineta has been awarded an MA

in Special Needs Education by Riga University. (She says she has been re-educating dinosaurs), and now there are three full time and one part time worker being employed by Riga City Council to provide a Portage Home Visiting Service.

Thank you for your help. That Valdis and Ineta have not yet contacted you themselves is due to their own great involvement - they ARE Latvian Portage - cajoling the Ministry of education councillors etc. and applying for training grants and funds for toys.

Their son had a bad time over Christmas and New Year. They do not know what their future will be, but have thrown themselves into Portage. Their son is now receiving Portage visits! and as well as developing his own idiosyncratic signing, uses the Makaton I have taught them, reads and counts and is a wonderful strong person.



Ineta & Valdis with their son



# Preserving hearts - protecting children

Robert Anderson is President of the British Paediatric Cardiac Association and Joseph Levy Professor of Paediatric Cardiac Morphology at the Institute of Child Health

If a heart malformation has caused the death of a child, that heart has a unique importance for surgeons and cardiologists, because it is a problem that had proved to be beyond their skill.

## One in five to one in a hundred

It is a tragedy if any child dies due to a heart defect, and all of us working in the field are committed to performing at the best of our abilities to ensure that this does not happen. At the time at which I started my work, in 1970, probably one child in every five who had symptoms in the first days of life would not survive the attempted surgical correction. Nowadays this number has dropped to no more than one or two babies dying in each hundred requiring treatment.

There are many reasons for these spectacular advances: the instruments and materials used have improved markedly, and intensive care facilities are now superb. But a large part of the improvement stems from our superior knowledge of the structures of the malformations requiring correction. This has been made possible because of the opportunity to study the hearts that were retained before and during this period.

## Modifying the approach

Let me give a specific example: the first heart I was asked to examine came from a child who died after surgery in Liverpool. After the surgical procedure, it was discovered that the heart was not beating correctly. This was because the impulse which should have stimulated the ventricles to beat was not conducted from the atrial chambers. This condition is known as complete heart block. It was well recognised that it could be caused inadvertently during the surgery by placing a stitch through the tiny muscular bundle which, in the normal heart, is responsible for conduction. By taking tissues from the heart, and by preparing it for microscopic examination, I was able to show that such a stitch had been incorrectly placed. With this information, the surgeon was able to modify his approach so that the complication would not be repeated.

I was then asked to examine other malformations in which it was known that heart block was a recognised surgical risk. We found abnormal patterns in several malformations that made surgical correction safer not only in Liverpool but also, by publishing in international literature, throughout the rest of the world. This was only made possible by the foresight of those specialists who had preserved malformed hearts in the hope that they would provide the answers to help us avoid future deaths.

On the basis of this experience I was funded by the British Heart Foundation to continue my work. I have gathered together hearts with malformations, notably at Royal Brompton and Great Ormond Street Hospitals. These have provided a foundation for research, extensive publication, and more importantly, annual courses for the continuing education and training of all those involved with the diagnosis and treatment of children with heart conditions. All of these efforts have contributed to the advances made in treatment. They need to be continued if we are to achieve our goal, namely to save all the children thus afflicted.

## Bristol Inquiry

I was working in a research environment and relied upon the cooperation of pathologists who performed the autopsy, but permission for the autopsy was the responsibility of the clinical team. It had always been my presumption, and that of the pathologist, that the need for the autopsy had been explained to the parents, together with a request that the heart should be preserved.

Following on the evidence I gave to the Bristol Royal Infirmary Inquiry, I was amazed when I read of the outrage of so many parents - I was unaware that they had been kept in ignorance of the fact that their children's hearts had been kept for further study and examination.

Whilst excuses cannot in any way salve the hurt which has been done, we acted out of ignorance, not malice.

## The future

With publicity given to the large number of hearts that have been kept, parents may think we no longer need to add to them. But, in fact, no two congenitally malformed hearts are exactly the same. We know there are limited patterns of malformation, but the variations may not have been recognised, and could be crucial in determining treatment.

Happily, because of the advances there are far fewer deaths - all the more important that we establish, by performing a full autopsy, that the treatment offered was itself satisfactory and correctly performed. The autopsy is the gold standard for audit and we can derive considerable benefit from examining organs even if parents agree to an autopsy but want the organs returned to the body.

I can assure parents that we treat organs with proper respect and due reverence. In future, if parents grant permission for organs to be retained, they will be told where they are to be stored and can reclaim them should their wishes change. Hearts given to us in this way will be used for research and for education of the young doctors. Ideally this should mean that future parents will not have to suffer the anguish of those presently being asked permission to perform an autopsy and to retain the organs.

## The bottom line

All of those working in Great Britain and Ireland to diagnose and treat children with congenitally malformed hearts are committed totally to ensuring that the events which took place in Bristol cannot recur within any of our centres. If we are to retain our standards of excellence, which are now as high here as anywhere else in the world, we need to preserve malformed hearts for the purposes of continuing research and education.

Within the British Paediatric Cardiac Association, we have established the mechanisms to ensure this continuance of excellence. But we are also well aware that, in the aftermath of Bristol and its Inquiry, we have lost some of the support from parents which we had come to expect as automatic. As an Association, we are committed to regaining all this trust and respect. We accept fully that we need to demonstrate that, as a whole, we are worthy of its receipt.



## Dialogue with parents

As the current President of the Association, I have been charged with establishing suitable dialogue with parents and guardians so as to ensure that we regenerate this mutual respect. To do this, we need to be transparent in all our actions. Nowhere is this more true than in the matter of the retention of hearts. None of us condones the widespread removal of organs such as occurred in Alder Hey Children's Hospital. To the best of my knowledge, this was a special case that had little to do with the preservation of hearts. And, of course, we would not have condoned the retention of hearts anywhere within the United Kingdom and Ireland had we known that they had been obtained without proper permission.

The retention of the hearts has provided much good in terms of education and research, but for the future we must make sure that this is undertaken only when the child's parents are fully informed and when they have generously consented to enable this work to go ahead.

*This article was originally published in the August 2000 Update of the Children's Heart Federation.*

## PLEASE HELP US

by saving stamps, postcards and ring pulls

*We have volunteers who are collecting all of these to fund-raise for the Group, but they need your help!*

### **Please save :**

Postage stamps (cut neatly from the envelope)  
Postcards (used and unused)  
Ring pulls from drink cans.

**They are worth money to us!**

Details of where to send them can be obtained from National Office.

**THANK YOU**

## DownsEd launches new Internet services



The Down Syndrome Educational Trust which very kindly hosts our website (amongst others), has recently launched a range of new Internet services to update and replace it's successful *DownsNet* site.

The Trust is a world renowned authority on research into the cognitive development and education of children with Down's Syndrome, and has long been a source of information and practical guidance for families and professionals concerned with the care and development of people with Down's Syndrome.

As part of their update to the website, they have launched the new *Down Syndrome Information Network* with books, articles, discussion lists and specialist search services. This includes over 150 articles and two complete books, totalling nearly 2,000 pages. They are also working on translations into other languages for the vast number of overseas visitors to the site.

There is also a new *DownsEd* Site with information about the Trust and its services.

To find out more about the work of DownsEd, why not visit their site:

*Down Syndrome Information Network* - <http://www.down-syndrome.net/>

*Specialist Search Services* - <http://www.search.down-syndrome.net/>

*DownsEd* - <http://www.downsed.org/>

*Discussion Lists* - <http://www.down-syndrome.net/discuss/>

## Do you ever buy on-line from retailers such as Amazon, WH Smith, HMV, Vauxhall, MadAboutWine and others?

Next time, why not consider going to their site from the DownsEd site. You can access the Down Syndrome Educational Trust's 'on-line high street' at <http://www.free2give.co.uk/shops/downs/down.htm>. It costs you nothing, but by ordering via this site the Trust will receive between 1.5% and 7.5% commission on your purchase.

# Fund-raising Update

## The Flora London Marathon 2000

Once again this year we were grateful for the support of so many people in the London Marathon. Sadly one of our entrants was taken ill the day before the race and was unfit to run, but the other seven did us proud and between them raised over £4,000 for Group funds.

Below are their names and official finishing times in hours, minutes and seconds :

John Alcock	6:10:30
Andy Brierley	3:55:41
Quinton Hayter	4:58:12
Robert Paterson	4:45:06
Paul Smith	4:02:09
Charlotte Taylor	3:29:25
Peter White	6:07:55

Many of these wonderful people seem to be very camera shy and never send in photos for the newsletter, but here is a photo of Quinton complete with his running partner Dare Bear and his support crew, wife Joanne and son Jordan. Quinton helped Dare Bear to add running the London Marathon to his growing list of activities, and as you can see they both completed the course and are proudly sporting their medals.



**THANK YOU & WELL DONE to all our runners and the families and friends who helped with the training and fund-raising.**

## London Marathon 2001

If you or someone you know would like to run in the 2001 London Marathon on Sunday April 22nd, we would greatly value your support. Entry forms for the ballot are now available with entry closing on October 20th, contact the London Marathon office on 020 7902 0189 for details of stockists countrywide.

If you can get your own entry this way, the Down's Heart Group will get the benefit of all your sponsorship money, but for anyone who is unlucky in the ballot, we do have a small number of guaranteed places available (which do cost us money). Please get in touch with National Office if you would like to know more.

## Fundraising Catalogue

If you get snowed under with catalogues from other organisations, **DON'T WORRY**, we are not about to send you another one!



But if you are one of the few who don't get asked, or you would like to support the Down's Heart Group instead, we can supply you with a catalogue from Fundraising Direct.

It's really simple:

- You place the order yourself.
- Pay by cheque, postal order, Switch, Visa, Delta or Mastercard.
- It's delivered direct to you.

And as long as you remember to quote our unique Fundraiser Source code with your order, the Down's Heart Group will receive 25% of your order value.

**If you would like a catalogue, please contact National Office.**

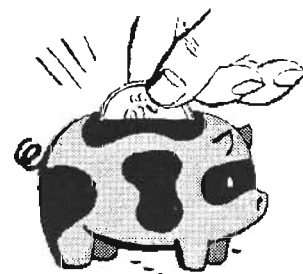
## The Flora *Light* Challenge for Women

In the last newsletter we included an entry form for the Flora Light Challenge which took place on July 16th. Several of you took up the challenge, roping in friends and relatives, and on the day the Down's Heart Group was represented by about twenty people.

The money has only just started to come in, but by all accounts everyone had a good time and the event looks to have raised somewhere between £1500 and £2000 for the Group.

**Well done to all you ladies.** If any of you have photos we would love to see them in the next newsletter.

*Apologies to everyone that I was unable to join you. As many of you know I had an accident in March which resulted amongst other things in a badly sprained ankle which was still giving me trouble. As our Annual Conference was the following weekend, in the end I didn't dare risk it - but you seem to have managed quite well without me!!! - Penny Green*



# Did You know?

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The following piece originally appeared in two parts in the January/February and March/April 1999 issues of "CHS Heart Talk" the newsletter of the Children's Heart Society in Canada. Although they may seem obvious to most of us, I wonder how often we've seen them done, or perhaps even done them ourselves?

## Caring for kids: Guidelines for parents and professionals when interacting with children

### What Works:

- **Get Down at the Child's Eye Level**  
*How would you feel if someone four times your size loomed over you at a time when you were scared anyway?*
- **Speak directly to the Child or Adolescent**  
*The youngster is an individual. Talk to him or her, not just the parents.*
- **Be Honest**  
*Hiding the truth from children, even with the best of intentions, results in the child's losing trust in hospital personnel or his/her parents.*
- **Identify, Allow, and Respect Normal Expressions of Emotion**  
*Crying is okay and so is anger. A youngster will feel and cope better if they can let their emotions out.*
- **Give the Child Choices**  
*But only real choices! If the child can choose juice or water to drink with medication, great! But he has no choice about taking medication, so don't offer one.*
- **Talk to the Child or Adolescent About Things of Interest to Him or Her**  
*All kids have school, friends, pets, and hobbies and would love to share that part of themselves with you.*
- **Support the Relationship Between Child and Parents**  
*All youngsters, even teens, need their parents, and parents are the experts on their own children.*
- **Maintain Your Own Self-Control**  
*If you find yourself "losing it," get someone else to work with the child.*
- **Respect the Youngster's Right for Privacy**  
*Everyone needs his or her own space, both physically and emotionally. Adolescents, in particular, are sensitive to violations of this basic human right.*

### What Doesn't Work:

- **Avoid Comparing the Child to Others**  
*Nothing makes children madder than "you should be able to do this. Johnny is younger than you, and he can do it."*
- **Be Careful When You Touch Children Other Than for Medical Reasons**  
*Touch children only when they indicate readiness to receive physical comfort. Children aren't pets!*
- **Don't Pity**  
*People need supportive caring, not pushy sympathy.*
- **Refrain from Infantilizing the Older Child**  
*Treat kids appropriately for their age. Just because the youngster is under 21, doesn't mean your voice needs to go up three octaves.*
- **Try Not to Say, "Be a Big Boy"**  
*Children will do the best they can. Added pressure or embarrassment doesn't help, and it's harmful if the child learns to feel negatively about himself.*
- **All Children Are Not Raised the Same**  
*Don't expect other people to use the same child discipline or child rearing techniques that you use with your own children.*
- **Stop Yourself before You Threaten**  
*Saying, "If you're not good mommy will have to leave," may result in temporary good behaviour because the child is frozen with fear. But there may be serious psychological consequences later.*
- **Don't Be A Grouch**  
*Humour is especially effective with children and adolescents*

# Christmas Card Competition



## We need your Christmas Designs!

Yes, here we are only just publicising this years cards and already thinking about next years, but sadly we have to agree designs and arrange printing six months in advance of the event, and as most children don't feel much like producing Christmas designs in May, now is the ideal time to set our competition.

What we need is drawings, painting, collages etc. with a Christmas theme, that incorporate the Down's Heart Group logo somewhere in the design. There will be a small prize for the winner or winners, and their design will be printed on the Down's Heart Group 2001 Christmas cards.

So as they get busy over the festive season, remember to save your children's best designs and submit them to the competition.

### COMPETITION RULES

- ♥ Entries should be on an A4 sheet of white paper
- ♥ The Down's Heart Group logo must appear somewhere in the design
- ♥ The entrant's name, age and address should be on the back in the top left hand corner.
- ♥ Entry is open to all Down's Heart Group member children and young adults and their siblings.
- ♥ Closing date for receipt of entries at National Office is February 28th 2001.
- ♥ Winners will be notified in writing.



### Regional Changes

**If you live in the South East part of the country, these changes affect you.**

We have made some administrative changes to our regional structure in the South East. The counties of Oxfordshire and Berkshire now form the Oxford Region, and all of London, Bedfordshire, Buckinghamshire, Essex, Hertfordshire, Kent, Middlesex, Surrey and East and West Sussex form the South East region.

The new Regional Co-ordinator for the South East region is John Spall, and Katie Spall will be co-ordinating the hospital visiting at the cardiac units in the region - Royal Brompton, Great Ormond Street and Guy's. John and Katie's address can be found on the back page of the newsletter.

There are currently no contacts for the Oxford area, either regionally or for the John Radcliffe Hospital. If you might be in a position to help in the Oxford area, please contact us for a no obligation chat.

### Memorial Donations

Since the last newsletter, we are grateful to have received donations in memory of :

**Alan Clarkson** - Brough

**Joy Litster** - Perth

**Ryan Paul** - Aberlour

**Louis Perrigo-Sanders** - London

**Emily Sheppard** - Derby

**David Williams** - Macclesfield





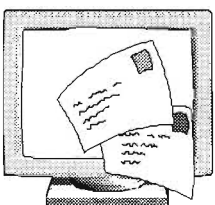
*The Creed of Babies with Down's Syndrome*

*My face may be different  
But my feelings the same  
I laugh and I cry  
And I take pride in my gains  
I was sent here among you  
To teach you to love  
As God in the heavens  
Looks down from above  
To Him I'm no different  
His love knows no bounds  
It's those here among you  
In cities and towns  
That judge me by standards  
That man has imparted  
But this family I've chosen  
Will help me get started  
For I'm one of the children  
So special and few  
That came here to learn  
The same lessons as you  
That love is acceptance  
It must come from the heart  
We all have the same purpose  
Though not the same start  
The Lord gave me life  
To live and embrace  
And I'll do it as you do  
But at my own pace*

*Author unknown*

*Thinking of moving? - Please keep in touch!*

We don't like losing members who forget to tell us their moving, so please remember to let us know your new address. Apart from anything else it prevents us wasting precious resources on printing and postage, so please help us.



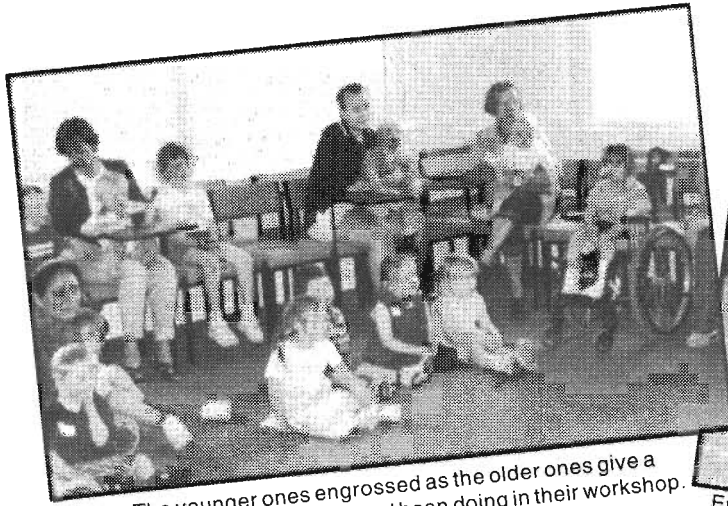
Keep us informed of new addresses, telephone numbers, e-mail addresses and any interesting news about your child.

**You, our members are very important to us!**

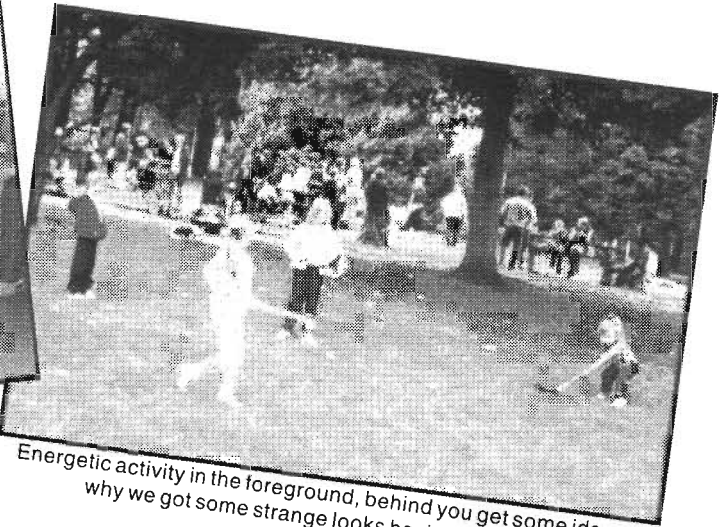


# 10th Annual Conference - Leeds 22nd/23rd July

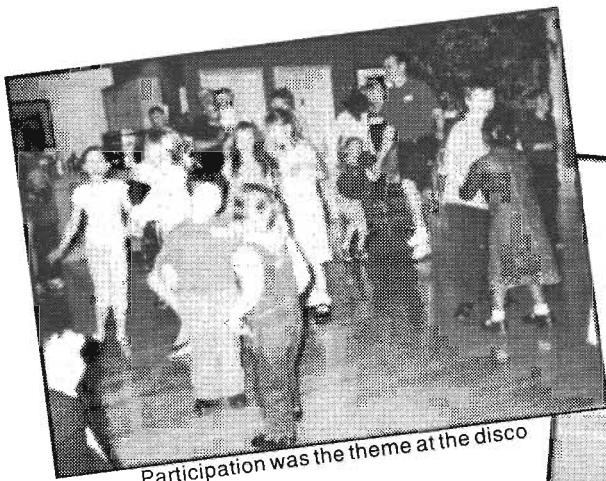
For those of you who missed it, there will be some write ups in the next issue, but here are a few photographs to give you some idea of what we got up to! Everyone seems to have enjoyed themselves despite a few problems with the city signposting in Leeds, and it was lovely to see faces both old and new.



The younger ones engrossed as the older ones give a presentation of what they had been doing in their workshop.



Energetic activity in the foreground, behind you get some idea of why we got some strange looks having our picnic.



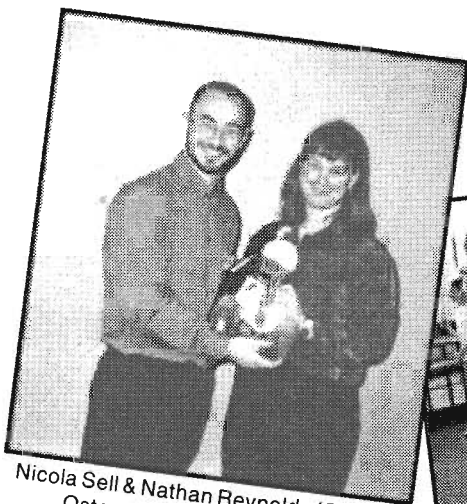
Participation was the theme at the disco



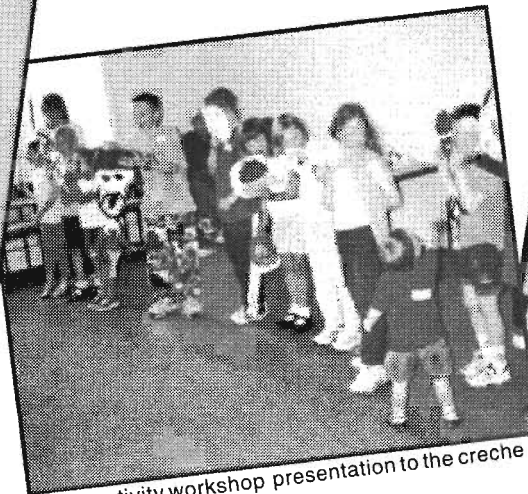
Michael Gray is thanked for his workshop on P.E.



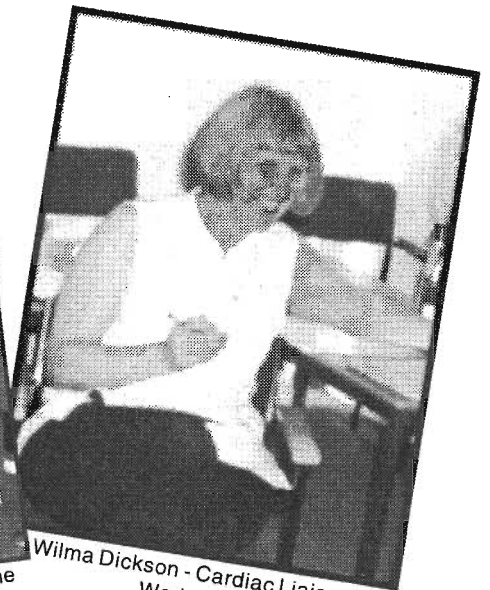
Cliff Lake thanks Dr Gerald Mason



Nicola Sell & Nathan Reynolds (Cranial Osteopathy) with Dare Bear.



The activity workshop presentation to the creche



Wilma Dickson - Cardiac Liaison Workshop

# Letters to the Editor

My daughter Michelle was born on the 28th May 1991. She had Down's Syndrome and congenital heart disease. In March 1993 she had open heart surgery. From that point in time we rarely worried about her heart though she was left with a leaky valve, which meant having regular heart check ups. But as time went on so these visits became less frequent, so much so that at our last consultation we were informed that we would not receive another appointment for two years.

Of course we were aware of all the problems, that someone with a heart defect faced particularly concerning those of tooth extraction, minor operations, bacterial infections etc., and every time that Michelle had an attack of tonsillitis, an ear infection or a throat infection, there was always the worry that this might lead to something else, namely endocarditis. From the age of four never a winter seemed to go by without her being bugged by one or the other of these illnesses, which once they seemed to get a hold, recurred regularly through the winter.

Then there was the frustration of making a doctors appointment, getting through to the receptionist the urgency of the situation and the need to see the doctor of our choosing. The doctor that we knew would be sympathetic towards Michelle, thoroughly examining her and find out what was exactly wrong.

Then last year something new occurred. After several throat infections in the late spring and after finding out Michelle had an under-active thyroid gland, she started to get ill, all silly little insignificant things. Things you wouldn't necessarily go to the doctors with.

First she hurt her foot at school (though the school didn't know how the injury occurred) and she couldn't walk for a couple of days. Then during the school summer holiday she started to get occasional car sickness; she went off of her food; became more tired than usual. She developed a rash, which the doctor said was a heat rash, developed a cough, which seemed to get better then recur. She even had bouts of very loose stools.

All this came to a head when she had another period of not being able to walk. This time we couldn't think of anything that she had done, though she had been complaining that her foot hurt a few days previously. We took her to the Doctor who despite being told about all her other complaints put in down to a twisted ankle, told us to administer cold compresses and if it wasn't better by the next day go to the A & E department of the local hospital.

The next day her foot was still the same, so we went to the hospital's A & E department. They x-rayed her foot, couldn't find anything wrong, sent us away and made an appointment to come back in three days time, which we did. In between time Michelle's big toe had swollen double the size of her toe on the other foot, she had also developed blood spots on that foot and ankle. It was those spots that alerted the next doctor to the fact that she had something different to a twisted ankle, though the heart was still not suspected.

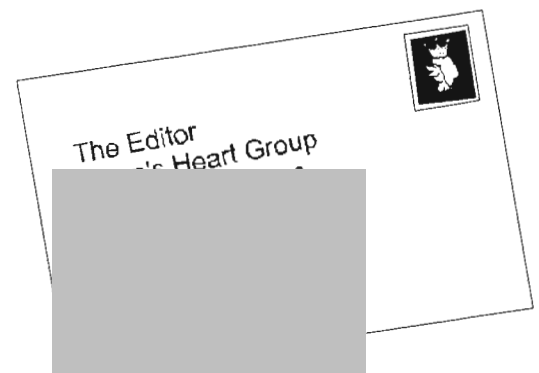
To cut a long story short, after having several more tests, two weeks later Michelle ended up in hospital with suspected endocarditis. She had a four week intensive course of intravenous antibiotic treatment. I was told the illness was caused by a slow growing bug and that it had to be killed slowly. Over that four weeks, though I have nothing but admiration for the staff at Bedford South Wing hospital, for the

concern, kindness and care they showed us, Michelle was poked and prodded about, at times her skin looked like a pin cushion.

At times I wonder if I had been more virulent; less worried about having to make an appointment with the doctor and having to go through the fearsome doctors receptionist; more insistent about seeing the doctor I wanted to see; less guilty at going to the doctors to get another course of antibiotics (partly the fault of the media), then perhaps my child wouldn't have had to go through this. She was lucky they caught the disease in time and it hadn't done any damage to her heart. It frightens me what might have been if we had met up with another insensitive doctor.

Michelle is back to her normal self, a happy sensitive little girl, though she still has to attend endless hospital appointments both here and in London. You might ask why I am writing this, well with all the coverage concerning antibiotics, I feel it is just another hassle why we shouldn't go to the doctors for things that to others are insignificant. But for our children if we do not go for these minor things and I am talking about throat infection, tonsillitis etc. even though the child might recover from the disease independently of antibiotics, the infection might lead to other things that are not so easy to cure. And remember a child might have a throat infection and not complain about a sore throat. My child did, she just seemed unwell.

**Pat Senior  
Flitwick**



## *And from the Editor - A Request*

Many of you, especially new parents, comment how helpful and informative you find the newsletter, and how you particularly enjoy reading other families stories.

We can't print every one we receive because we try to get a balance in each issue of both happy and sad stories, older and younger children etc. But in order to do that we need a good supply of stories, so PLEASE DO SEND us your story, and include a photograph, where possible.

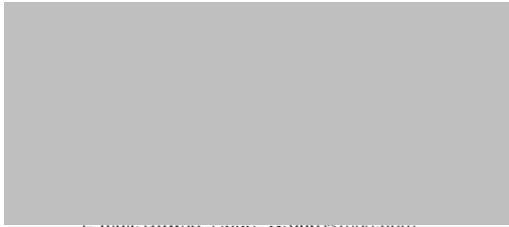
We also want to include details of members accomplishments, so if your child (or young adult) has received an award, or they would like to write a piece for the newsletter, please send it in.

This is YOUR newsletter, please help the Group to reflect the true potential of our youngsters, by sending in items relating to their everyday life.

And send in your fundraising photos too!!!

## National Contacts

### National Office



Website: <http://www.downs-heart.downsnet.org/>

Contact or Ansaphone always available (24hrs in emergency)

<b>National Administrator</b>	<i>Penny Green</i>
<b>Founder</b>	<i>Linda Walsh</i>
<b>Chair</b>	<i>Cliff Lake</i>
<b>Vice-Chair</b>	<i>Chris Stringfellow</i>
<b>Treasurer</b>	<i>Phil Thorn</i>
<b>Secretary</b>	<i>Donna Hoppe</i>
<b>Legal Advisor</b>	<i>Brian Auld</i>
<b>Policy Advisors</b>	<i>Mary Goodwin Dr. Rob Martin Dr. Claus Newman Dr. Phil Rees</i>
<b>Benefits Information Contact</b> Contact via National Office	<i>Mary Clayton</i>
<b>Representative for those with</b> <b>Chronic Cardiac Conditions</b>	<i>Jane Wrighton</i>
<b>Patrons</b>	<i>Sarah Boston David Graveney</i>

For general information about Down's Syndrome, you might like to contact:

The Down's Syndrome Educational Trust The Sarah Duffen Centre Belmont Street SOUTHSEA Hants. PO5 1NA 02392 824261	Down's Syndrome Association 153-155 Mitcham Road Tooting LONDON SW17 9PG 02086 824001 <i>(Regional offices in Wales, Midlands and N. Ireland)</i>
Scottish Down's Syndrome Association 158/160 Balgreen Road EDINBURGH Lothian EH11 3AU 0131 313 4225	Down's Syndrome Assoc. of Ireland 5 Fitzwilliam Place DUBLIN 2 EIRE 00 353 1 6769255

## Regional Contacts

### Bristol & South West - Avon, Cornwall, Devon, Gloucs, Somerset & Wilts

Sheila Forsythe  
Mike & Wendy Hellowell

### East of England - Cambs., Lincs., Norfolk & Suffolk

Nicola Desmond  
Lindsay Wharam

### East Midlands - Derby, Leics., Notts. & Northants.

Sarah Smith  
Linda Wainwright (*Glenfield Hospital*)

### Ireland - N. Ireland & Eire

Rosina Brierley  
Marion Delaney (*Dublin Hospital*)

### North East - Cleveland, Cumbria, Durham, Isle of Man & Tyne & Wear

Sally Hardman

### North West - Anglesey, Cheshire, Clwyd, Gr. Manchester, Gwynedd, High Peak, Lancs. & Merseyside

Mike Halpin

**Oxford - Berks & Oxon**  
Please contact National Office

### Scotland - Mainland & Islands

Elaine Thomson (*Glasgow Hospital*)

### South East - Beds, Bucks, Essex, Herts, Kent, Middx, Surrey, Sussex & London

Sheila Boniface (*GOS Hospital*)  
Nicki Cranmer (*GOS Hospital*)  
Stephen & Debbie Silver (*Brompton*)  
Joanna Simms (*Harefield Hospital*)  
John & Katie Spall  
Victoria Stevenson (*Brompton*)

### South Wales - Dyfed, Glamorgan, Gwent & Powys

Chris Stringfellow

### Wessex - Channel Islands, Dorset, Hants., Isle of Wight

Vickie Richardson (*Southampton Hospital*):

### West Midlands - Hereford, Worcs., Salop, Staffs, Warwick & W. Midlands

Lynne Holden

### Yorkshire & Humberside - Humberside & All Yorks.

Lindsay Allen  
Carolyn Marshall (*Leeds Hospital*)

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