

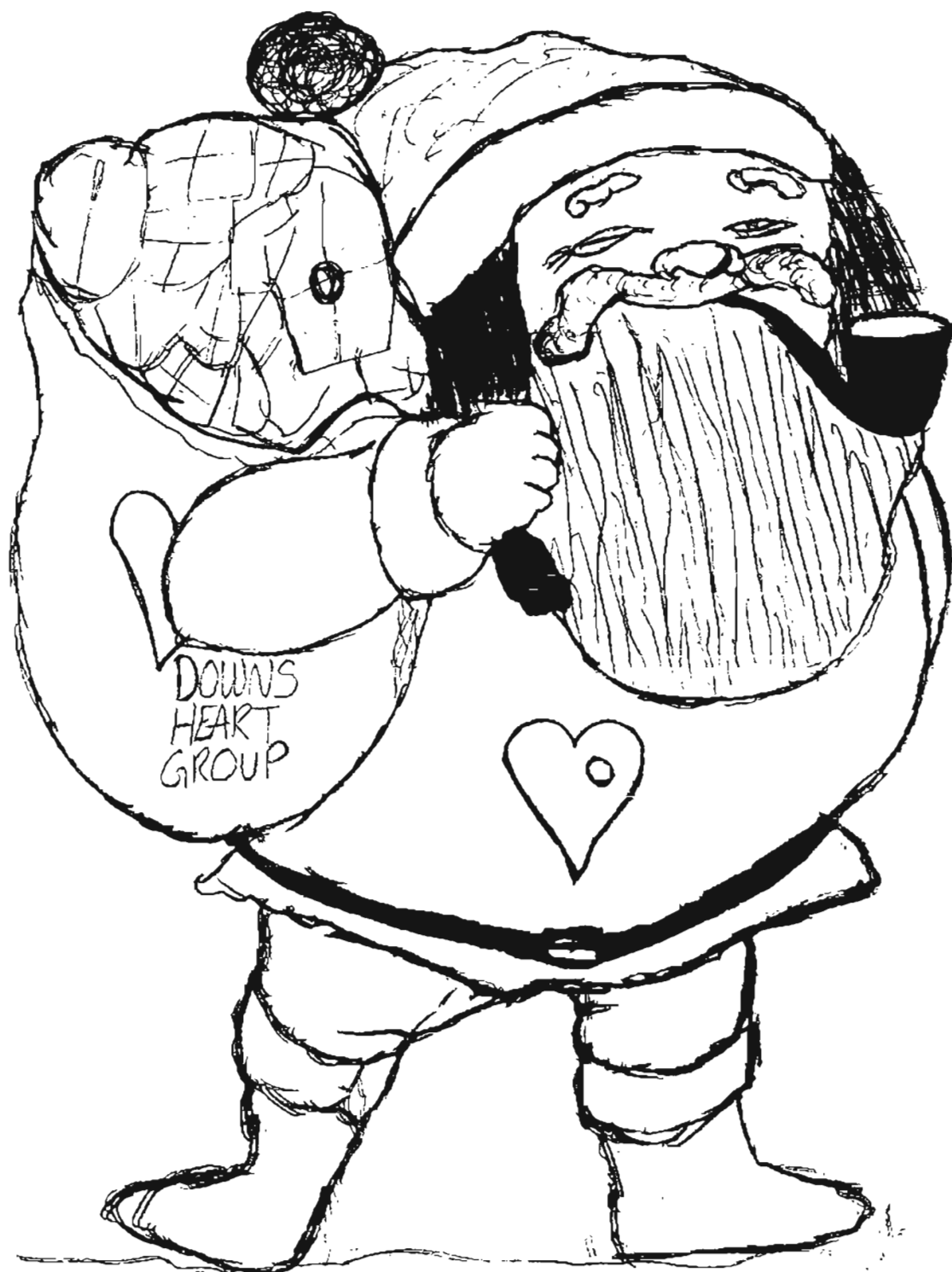


DOWN'S
HEART
GROUP

NEWSLETTER

(Issue No 12)

Autumn / Winter '94



Contacts

National Office

Contact or Ansaphone
always available
(24hrs in emergency)

Founder
Linda Walsh

Chair
John Spall

Vice-Chair
Sheila Forsythe

Treasurer
Phil Thorn

Secretary
Gill McLorinan

Legal Advisor
Brian Auld

National Administrator
Penny Green
contact National Office as
above

Benefits Info Contact
Mary Clayton
Contact via your Regional
Co-ordinator (page 4)

Front cover

From a design by Ben McGauley, one of the runners up in our Christmas card competition. The competition results were as follows

Winner	- Jennifer Gouck aged 7 from Glasgow
Runners up	- Jonathan Gouck aged 12 from Glasgow
	- Lee Hargreaves aged 7 from Buxton
	- Ben McGauley aged 18 from Colchester
	- Hannah Wrighton aged 8 from Hexham

For details of the winning design and how to order your cards, please see page 5.

Please keep your childrens Christmas artwork to enter for next years Christmas Card Design Competition, we are always pleased to have a wide variety to chose from.

General enquiries should be addressed to the National Administrator. Requests for information about the work of the group from professionals, students etc. should enclose an sae. for the reply.

Requests for support and information for families should be sent to the relevent Regional Co-ordinator as shown on pages 4, or to the National Administrator.

Donations may be sent direct to the Treasurer.

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: 0181 682 4001

Scottish Down's Syndrome Association

158/160 Balgreen Road
EDINBURGH
Lothian
EH11 3AU
Tel: 0131 313 4225

Down's Syndrome Association of Ireland

27 South William Street
DUBLIN 2
EIRE

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

First many thanks to all those members who, following my previous report, have taken out a covenant to pay each year to the Group the equivalent (or in some cases considerably more) of an annual subscription. Also to all of you who are using the money boxes. Money is beginning to come in from these and I have every hope that this will prove a regular (and relatively painless) source of income for us. If you would like further money boxes to give to relatives or friends or to put in your workplace please contact National Office.

You will see from page 10 the range of original fundraising events that have happened in the past months and we are very grateful to all those who have walked, run, played football, drunk coffee, sung, had their head shaved and taken part in many other unusual activities on behalf of the Group.

The Group continues to grow and the point has been reached where the work load at National Office can no longer be coped with on a volunteer basis. With the assistance of a generous grant from the British Heart Foundation the Executive Committee have been able to appoint Penny Green as our first National Administrator. This will enable us to continue to provide a high standard of service from the National Office to members and the many others who seek our help, advice and information. We are very appreciative of the British Heart Foundation's support in enabling us to take this important step.

I am sure that those members who managed to make it to Liverpool for the AGM this year would agree that it was a highly informative and stimulating day. We were privileged to have Dr Kevin Walsh to tell us about his work at Alder Hey while Dr Mark Jackson shared with us some of the results (at that time unpublished) of his research into survival rates of children with heart conditions, with and without surgery, particularly children with Down's Syndrome. These demonstrated very clearly the progress that has been made over the past ten years.

You will find the first of the two reports we will be running on all the sessions at the AGM on page 12

You will see from page 5 that we have another witty and attractive Christmas card this year, from a design by Jennifer Gouck, the daughter of our Regional Co-ordinator for Scotland. I get bombarded with sales pitches for charity Christmas cards every year. Having looked at them all I can honestly say that our cards represent the best value for money of any; that's why our sales keep rising. Despite their low price the cards still provide a good profit to the Group and of course they are a wonderful way of getting us better known. Do please put your orders in early as we sold out last year.

Which reminds me - a very happy Christmas to you all.

A word from the National Administrator

The National Office continues to keep me busy, with an ever increasing number of letters and phone calls to be dealt with, particularly from students etc. who need information for college projects. With only the one phone line (and of course one body to answer it), this inevitably means the line will sometimes be engaged when you call. Please do try again, perhaps in the evening (generally students imagine we have an office only manned during the day, so the evening is quieter), or else pop a letter in the post.

If you are lucky enough to get through on the phone, only to be greeted by the answerphone, I apologise, family commitments mean I'm in and out a fair bit, but do be brave enough to leave a message. I will get back to you, although it may be a few days later, as those who rang at the end of August will verify.

I did actually slope off then, on holiday with my family for a week, but despite being about one hundred and fifty miles from home, we still managed to go on to the beach and sit right next to a Down's Heart Group family who were also on holiday. My husband insisted I wasn't to 'talk shop', but he couldn't complain too much as he knows I have a particular affection for the little girl, who was in fact born the day after my own little boy Daniel. Seeing her gives me a wonderful insight in to how he might have been had he still been alive. We spent a very enjoyable few hours on the beach with them, for which I would like to thank them very much.

Regional Contacts

If no name is shown, or you experience any difficulty contacting the co-ordinator for your region, please get in touch with our national office who will be able to help you.

Bristol & South West (Avon, Cornwall, Devon, Gloucs, Somerset & Wilts)

Sheila Forsythe

Gill McLorinan



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

Lindsay Wharam

Nicola Desmond



East Midlands (Derby, Leics, Notts & Northants)

Sarah Smith



Ireland (N. Ireland & Eire)

Rosina Brierley



London Northern

(Berks & Oxon)

Morag Malvern



(Beds, Bucks & London W & NW postal codes)

Angela Barker



(Herts, Middx & London N postal codes)

Joanna Simms



(Essex & London E postal codes)

London Southern (Kent, Surrey, Sussex & S. London)

Katie Spall

Linda Crozier



North East (Cleveland, Cumbria, Durham & Tyne & Wear)

Sally Hardman

Jane Wrighton



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

Mike Halpin



Scotland (Mainland & Islands)

Lynn Gowk



South Wales (Dyfed, Glamorgan, Gwent & Powys)

Chris Stringfellow



Wessex (Channel Islands, Dorset, Hants, Isle of Wight)

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 & All Yorks)

Mark and Linda Watcham



Christmas Cards



This year the Down's Heart Group is again selling its own Christmas cards, to raise funds, and to increase public awareness of our organisation and the children it supports.

The cards are available in packs
or

10 for £1-50p (plus £0-35p p & p)
50 for £6-50p (plus £1-40p p & p)

To order your cards please complete the order form on the back page of this newsletter.

We believe the cards are very good value for money, and as we organise the production and distribution ourselves, all the proceeds from the sale of the cards goes directly to the Down's Heart Group, unlike many other charity cards.

We hope you like the card, and will support us by purchasing some. Perhaps your friends, neighbours and colleagues at work might like to buy some too!

For further orders or information, please contact the National Office (details on page 2)

Gareth's Story

Dear Editor, I read your newsletter with great interest and the stories about the Down's heart children are interesting to read. I wish I could have read some of the stories before Gareth had his operation, it would have helped me a lot to know about other children like Gareth. I have sent you my story about my son, I hope you find it interesting.

Gareth was born on November 15th 1976 with quite an easy birth. My two older children were over the moon with their new brother. My daughter Glynis was twelve and my son Adam was eight. I wasn't a young mum, I was thirty-six so I was glad of some help with a new baby. After two days I went home with Gareth and everything seemed to be fine. The weeks went by and Gareth was very cheery and didn't seem to be doing so well so I took him to the doctors. I knew something was wrong but the doctor didn't say what, he just asked me to take him along to the hospital for a blood test.

A day later the doctor called to see us and asked us both to go to the hospital with Gareth the next day. We didn't sleep that night for worrying about what could be wrong and arrived at the hospital early in the morning. We waited in an office until a doctor came in and sat down. My husband asked straight out "What is wrong with our son?" The doctor said "I'm sorry but your son has Down's Syndrome." We were both shocked as Gareth was four months old by this time and we weren't expecting anything like this. We went home, cuddling him all the way and crying at the same time.

Time passed and Gareth went for tests before he started school aged three. The doctor doing the tests found Gareth had a heart murmur which came as a great blow, I couldn't believe it! We were sent for further tests to Liverpool which showed that he had a small hole that might heal by itself. Every six months we went for a checkup, but things didn't seem to change, Gareth was cheery and always got colds in the winter and had a lot of time off school.

In the winter of 1991 Gareth was really sick and was rushed to hospital where he was found to have bronchial pneumonia. It left him very weak and it was three weeks before we took him home. The following June we were sent to see Dr Peart at the heart clinic, and a week later

we went to Liverpool for some tests. These showed that Gareth had a large hole in the heart and needed an operation.

We came home to talk about it and to decide what was best for Gareth. We knew he wasn't going to get any better, so we decided to have the operation. I went in to Alder Hey with Gareth on the Sunday to get him ready for Tuesday morning. I was really worried as Gareth was now fifteen, much older than most children with Down's Syndrome having a heart operation, but we couldn't turn back now.



Gareth went down at 8.30am on the Tuesday and came back at 2.30pm, two hours longer than they had said - I was so scared thinking something had gone wrong. Gareth spent three days in intensive care, then he was put on the ward with the other children. It took Gareth longer than the others to recover, he had chest problems so we had to stay in about two and a half weeks.

When we did go home it took Gareth a long time to get going, but I'm sure I did the right thing. Gareth has grown up and put on weight and in October last year he was

an Usher at his brother's wedding - I was very proud of him. He is back in full time school and will be eighteen in November, when he wants a party with all his pals.

Not forgetting the doctors and staff at Alder Hey - I have a lot to thank them for, they were fantastic to us all. We all love Gareth and we have lots of fun with him. He's hard work, but I give him all my love and time, he's just great.

*Phyllis Coleclough
Alvanley*

Joshua's Story

Joshua was born on 15th October 1993 after a pregnancy perhaps considered easier than we expected. Michelle and I were anxious due to her diabetes, and although she had several 'Hypos' as well as the usual sickness, we were reassured by the hospital that all was well, and this was supposedly verified by the regular ultrasound scans showing that the baby was progressing well with all functions 'normal' including the heart. Any anxieties were smoothed over with assurances and science.

Joshua is our first child, so the delivery room and its functions were alien to us, but in retrospect there seemed a lack of ebullience after his delivery - is this normal for the surgeons/nurses etc. or had they known immediately of Joshua's disability?

The first night was spent (as I'm sure most first nights are) by copious phone calls followed by several celebratory drinks (for me) and a well deserved early night (for Michelle).

The following day I arrived at the hospital with flowers, hangover and a ridiculous smile. My parents and Michelle's mother visited and all seemed perfect, the anxieties which Michelle felt pre-delivery seemed unfounded.

When Michelle and I were alone, two doctors and a nurse entered with Joshua. The doctor asked if we'd thought why he was underweight (he was 5lb 4oz but was initially expected to be large due to the diabetes), we naturally reiterated what we'd been told during similar questions we'd asked during the scans - that it was due to good diabetic control. "Had you considered it may be due to Down's Syndrome?" came the next question like a thunderbolt. Although I have some sympathy with the doctors job in having to tell us, surely this could have been handled with a degree more tact. However, the nurses and support staff were excellent, as were both of our families. I spent the second night phoning all from the first to inform them of the new circumstances, and that we still felt we had cause for celebration but we'd like a degree of privacy for a week or so.

This positive attitude (which, frankly we did not really feel at the time) began to impose itself on us, and helped by the mature attitude of those around us, we began to love Joshua for what he is - a delightful baby who is ours, indeed, perhaps we over compensated, his disability creating unity in the family and an outward gushing of emotional love both to him and us. We were told he had a 'slight murmur' of the heart, nothing to worry about, but that we should get it checked at the next cardiac clinic in two weeks.

We were allowed home.

By the clinic date we felt highly optimistic, surely if he had a bad heart we would not have been allowed home. The casual announcement during the echo that Joshua had a complete Atrio-Ventricular Septal Defect

was such a devastating shock that there are still insufficient words to describe our feelings. We had spent weeks growing to love him and being reassured by family and friends and now we genuinely felt we were going to lose him.

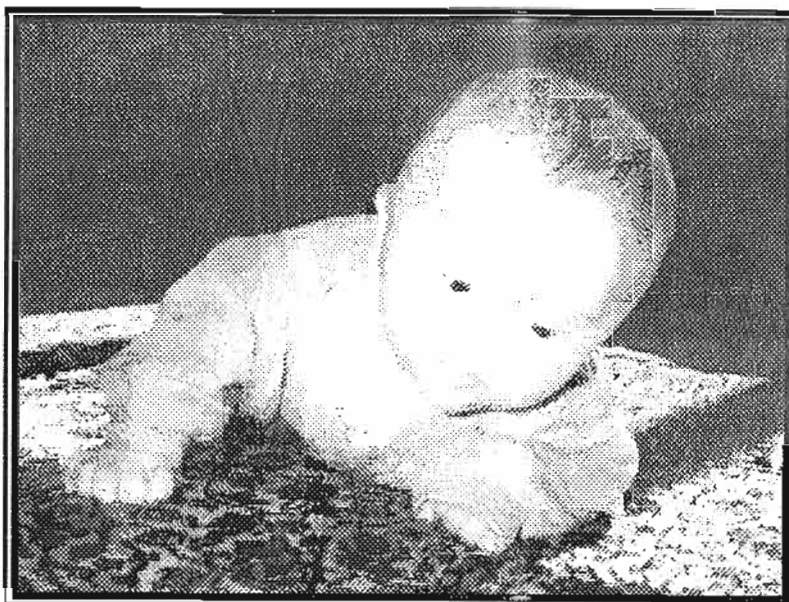
The surgeon informed us that if he did not have the operation he may survive for eighteen to twenty years or more, but would become highly dependent, and by definition, have a 'lesser quality of life'.

Much soul-searching ensued - is it selfish to risk the operation so he would not become a 'burden' to us and others in later years, or not to risk the operation so we could guarantee having him with us if only for a while? I felt we had to give Joshua the chance of as full and active life as possible, and Michelle, by now shell shocked, concurred. The fact that he looked well made the decision more difficult, though this was merely an illusion as scanning pre-operation photos proved.

There followed three months of pre-operation limbo, where tears were frequent and smiles sparse. It is impossible to appreciate any developmental landmark when uppermost in your thoughts is the possibility of loss. These feelings were also coupled with the belief that nobody really understood the physical and mental trauma.

The operation date came and we went to London's Royal Brompton Hospital. We were able to stay and conversing with other parents was invaluable and we found the surgeons, doctors and nurses as well as the ancillary staff, sympathetic informative and reassuringly experienced.

The day of the operation, following a sleepless night, we carried Joshua down to the operating theatre. Leaving Michelle inconsolable outside, I held Joshua while the anaesthetic was being administered. Whilst I did not need to do this, I did not want Joshua to be alone with strangers. Upon leaving the theatre, we were politely



instructed to leave the hospital and 'go shopping'. We ended up, as most do, at Harrods where I am sure the staff play 'spot the Brompton parent' as we wandered glassy eyed and zombie like through the departments.

Nothing could have prepared us for the sight of Joshua when we next saw him. Even though we'd been shown the Intensive Care Unit the previous day, the fact it was our son lying there was devastating, though we were grateful he was there at all as we'd feared the worst when the operation had reached five hours. Wires and tubes were everywhere, his chest had been left 'open' (covered by a plastic diaphragm) due to the swelling of his heart, he was attached to pace-maker, dialysis etc. etc. and we could barely see he was ours.

He'd also been deliberately paralysed so he could not hit his 'patch'. He had a further operation three days later to close the chest and from then on his progress was staggering. Within three days he'd been moved from Intensive Care to the High Dependency Unit, then three

days later back to the ward, and amazingly, four days after this we were allowed back home. Joshua still has check-ups, but touch wood, all seems well, and he is dearly loved as well as respected for his courage and fortitude (even the occasional sleepless night still seems pleasurable.)

It is the hardest decision a parent could make and what felt right for us is not necessarily right for everyone, but tensions and tears that were once everyday companions are slowly coming off our shoulders.

One thing for certain, in closing, is that an event such as this has allowed us to change our perspectives - once we realised we could lose Joshua, we had his preciousness to us underlined and in doing so, relegated his Down's Syndrome as a condition to cope with rather than the devastation it initially appeared.

*Stephen Turnbull
Canterbury*

As Christmas approaches don't forget that Down's Heart Group T shirts and sweatshirts make ideal presents.

They are good quality garments that wash well, both T shirts and sweatshirts bear the Down's Heart Group name and logo in a moderate size on the left side of the chest (as you wear it), and come in a range of sizes. T shirts are in white only, whilst sweatshirts are available in white, pale blue and grey.

Children's T shirts cost £3.50 and sweatshirts £5.50
both are available in sizes 24", 26", 28", 30" and 32"

Adult's T shirts cost £7.00 and sweatshirts £11.00
both available in S, M, L, XL and XXL

(Postage and packing are included in the price)

Would you like to buy one?

Then contact Penny Green at the National office for further details.

It's a worthwhile way to support the group and raise awareness at the same time, so why not order one for all the family including grandparents!



Where's Mine?

Yorshire and Humber side Co-ordinator helps launch hospital helpline

A helpline has been launched at Grimsby Hospital, for patients, relatives and staff. The twenty-four hour helpline provides support and information, and can also be used to obtain details of support groups both locally and nationally. The official launch was attended by about sixty five people, including health care staff, and one of the speakers was the Down's Heart Group Co-ordinator for the



Linda Watcham is pictured with Rev. Harold Ter Blanche the hospital chaplain and the trust chief executive Mr Peter Gray.

region, Linda Watcham. A write up of the launch appeared in 'Grapevine' the Grimsby Hospital magazine.

This is just one of the ways that Down's Heart Group volunteers are working in conjunction with other organisations to increase public awareness, and ensure that all families who might benefit from support are aware of the Groups existence and what it has to offer.

Donations

If you would like to make a financial contribution to the Down's Heart Group without organising a fundraising event, there are lots of other ways you can help.

Moneyboxes

With the last newsletter sent out in April, we included a small flat packed moneybox which can easily be made up and used to collect odd change, either at home or maybe in your workplace. We have already received several donations from moneyboxes, so please continue your support in this way. If you haven't received a moneybox, or you would like a further supply, please contact National Office.

Give as You Earn

This is a scheme adopted by many employers where you can make a contribution to charity directly from your salary prior to tax. Some employers match your donation, thus increasing the benefit to your chosen charity. If you would like to make donations in this way, ask your employer if they operate the Give As You Earn scheme, they may consider starting it if it's not already in place.

Covenants

With the April newsletter we also sent out covenant forms, this is a form of giving where you agree to making four annual payments to a charity, and the charity is then able to recover the tax on the sum you donate, thus increasing the value of your gift. Even a small donation made in this way is of great value to the group as it is guaranteed income for four years, and the reclaimed tax adds to the amount. If you would like to make a regular payment, Covenant forms (which are very easy to complete) can be obtained from National Office.

Postal Auction

Some time ago the Down's Heart Group was presented with an autographed copy of 'The Masters 1989', a book published by Augusta to mark the annual golfing event. 1989 was the year when Nick Faldo won the Masters and gave a percentage of his winnings to charity.

Whilst the Down's Heart Group was not selected to receive any of this money, it was presented with a copy of this book, autographed by Nick Faldo, who as the winner of the tournament was allowed to purchase a limited number of copies. The book is in mint condition, and we also have the original letter that was sent by Nick's agents, which verify it's authenticity.

We have made attempts to have the book auctioned at various golf clubs, but have been unable to have the book included as a lot. There has, however, been an offer made to purchase the book for £100, but in order to ensure that the Group receives the maximum financial benefit, we intend to auction it by post.

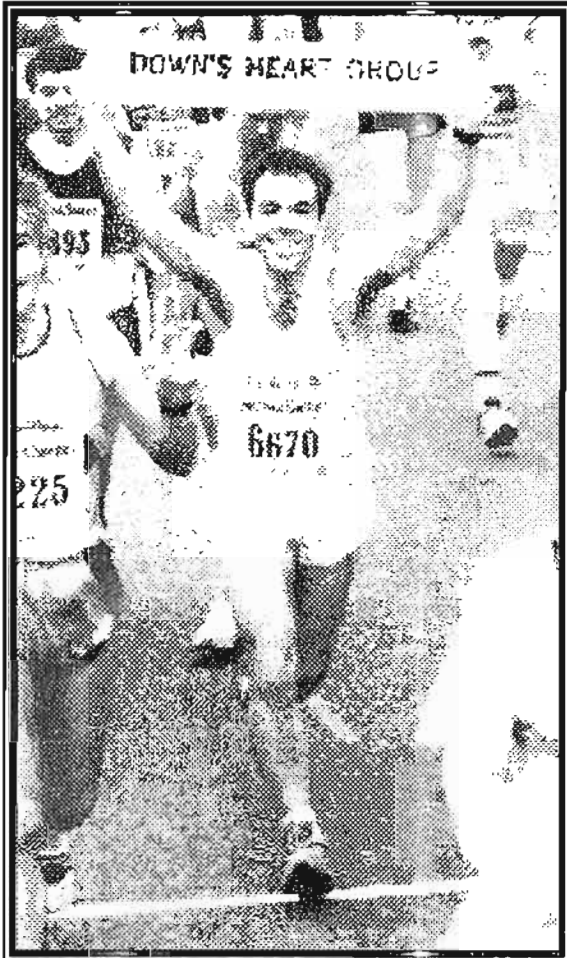
If you, or anyone you know, (particularly golfing enthusiasts), would like to make an offer for the book, we will accept postal bids addressed to the National Office, to arrive no later than November 30th. Bids should clearly state your name and address, and the amount you are willing to pay for the book.

We will then have time to despatch the book before Christmas, so it could make a great present for a golfing fan!

Fundraising Update

In our last issue we gave details of some of the fundraising events people had planned. We thought you would like to hear how well they went, and also about some of the many other events that have taken place. We would like to say a very big thank you to everyone who has made a contribution to funds, including those not mentioned here due to limited space, we couldn't carry on without your very valuable support.

London Marathon



Dave Brown crosses the line in the London Marathon

Dave Brown from Eaton Bray ran his first ever marathon in a very creditable three hours thirty two minutes and fifty one seconds. Our group administrator and her husband were there to cheer him on at the twenty five mile marker, and Dave was still in good enough shape to hold up a Down's Heart Group banner as he crossed the finish line. The next day he was witnessed to say that he'll do it all again next year. Dave's magnificent effort raised £1100. Congratulations and many thanks Dave and members of Ivinghoe Soaring Association for their tremendous support.

Book Party

Sue Packham of Sandhurst held a book party and raised £40. Thanks to everyone who supported it.

Thames Bridges Bike Ride

This was another fundraising event organised by non-members, when forty three riders of all ages and abilities turned out to complete a course over six of the Thames bridges, finishing with a triumphant dash over Tower Bridge. It was a great day out, and was thoroughly enjoyed by both riders and spectators. We were very pleased to have three Down's Heart Group families represented on the ride. A great event which raised £2315. Many thanks to Martin Wehlan and Peter Heyn the organisers, and all the riders.

Coffee Mornings

Member Helen Meakin of Sheffield organised a couple of coffee mornings helped by her mum. They had raffles and other activities taking place, and as well as having a very enjoyable time, they raised £660 which was divided between the local children's hospital and the Down's Heart Group. Well done Helen and her mum, what a lovely tribute to baby Bradley who died last Christmas.

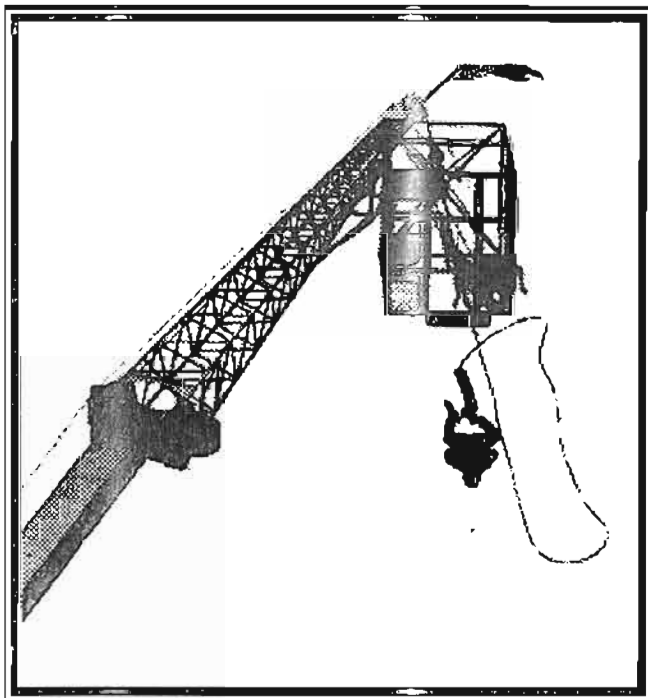
Medieval Banquet

This successful event organised by non-member, Maria Netherwood of Shipley, divided proceeds between the Annette Fox Leukaemia Research Fund and the Down's Heart Group who received a cheque for £260. Grateful thanks go to Maria and her helpers.

Charity Football Match

Our team of Down's Heart Group supporters, including a few dad's, tested their footballing skills against the Arsenal Ex-professional and Celebrity XI in June. The watching supporters saw some good football, and also had the opportunity to meet a few celebrities, including David Court (Ex Arsenal), Robbie Gee (Desmonds), Tony Hadley (Spandau Ballet), Rob Hudson ('Yorkie' from The Bill), Matt Mansfield (The Big Breakfast) and Terry Marsh (boxer). We also fielded a ladies five-a-side team which played against the Arsenal Gunnerettes, and although we didn't quite manage to win either game, both teams put in a very creditable effort, especially as most of the players had never even met before, let alone played a match together. The day was enjoyed by all those who came, and raised over £300. Thanks go to Charmian Lewis for the idea, and all the players and supporters for turning up on the day.

Bungee Jump



*A long distance shot of Stephen's jump
(all the crane wouldn't fit in!)*

Early in early August there was a special charity event at the Timber Batts Public House in Bodsham, near Ashford in Kent. The landlords had organised a two hundred foot crane for bungee jumping, and many people were taking part to raise money for different charities. Never one to miss an opportunity, Stephen Turnbull, son of the pub owners and a Down's Heart Group member (see Joshua's story on page 7) decided to jump in aid of the Group. His bravery raised a total of £500. But we suspect that he will not be repeating it, in his own words ..."NEVER AGAIN!" Well done to Stephen and thanks to everyone who sponsored him.

Cake Stall

This has been an annual event for several years, and the Bristol and South West region never ceases to amaze with the amount of money it makes on its cake stall at Blaise Fair in Bristol. This is not just a fundraising event, this is a real social gathering for many of the regions families, with members travelling from places as far afield as Bideford, Brixham and St Austell (over two hundred miles away), to help man the stall. This year they had to contend with heavy rain showers, but still managed to sell out, and also to raise the magnificent sum of £402.14. A big thank you to everyone who sent donations of money prior to the day or who helped in any way to make the event such a success.

Great North Run

As we go to print, we have just heard of the success of John Studholme and Derek Pentland, who ran this half-marathon on September 18th for the Down's Heart Group. They expect to have raised about £250.

Laura - a very special supporter

There is a very special supporter of the Down's Heart Group who lives in Washington Village, Tyne and Wear. Laura Cuthbertson knows one of our member families, and thinks so much of their little girl Rebecca, that she decided to raise some money to help other children like her. Together with a friend she raised £6 in May by raffling a large bar of chocolate. She then went on to hold two garden parties, (one which ended up as a house party due to rain), helped by her mum and younger sister Sarah. They sold home-made cakes, pop, sweets and toys, had raffles and played bingo. Laura thought of these ideas herself, and managed to raise £136.40, quite an achievement when you know that Laura is only nine. What a wonderful young lady you are, Laura, Thank you.

Head Shaving

The lovely summer weather ran out just at the wrong time for two brave chaps from Torrington who volunteered to have their heads shaved as a fundraising event for the Down's Heart Group. But Graham Price and Tony Wall weren't too unhappy, particularly when they raised the fantastic sum of £760, a wonderful tribute to the memory of baby Siobhan Price who died in January. A big thank you goes to Graham and his wife Carla, and their friends Tony and Zoe Wall.



*Graham and Carla present their cheque to
Down's Heart Group Treasurer Phil Thorn*

Annual Conference and AGM

The Down's Heart Group travelled to Liverpool on 23rd April to hold their Annual Conference and General Meeting. The day was well attended with over forty families travelling from as far away as Hastings, London, Bristol and even Grimsby.

The day started with the AGM which concluded fairly quickly, as most of the people holding positions in the group were willing to stand again and were duly re-elected. John Spall (Chairman) thanked everybody for all the hard work carried out by everyone over the last year, but reminded us that times are hard and that we need to generate more money over the coming year to be able to carry out the work we would like. I think this highlights the need for more people to become involved in the running of the organisation both financially and from spreading the work load amongst the committee (many hands make light work) instead of relying on the same old faces to do everything.

Anyway, to get down off my soap-box, the conference proper was started by Dr. Kevin Walsh Senior Paediatric Cardiologist (who will be known to the many of you who have attended Myrtle Street and Alder Hey Cardiac Units over the years). His talk was very informative and interesting as he explained the different type of problems encountered in children with Down's Syndrome, what associated difficulties one could expect and how to treat and overcome these problems.

Dr Walsh was followed onto the floor by Dr Mark Jackson (a research fellow of Liverpool University but based at the Institute of Child Health at Alder Hey) Dr Jackson has carried out research along with Miss Roxanne McKay whom many of you will remember from her days at Alder Hey as cardiac surgeon, by carrying out an epidemiological survey of the Merseyside area into the prevalence of Down's Syndrome and associated heart problems. Dr Jackson went on to compare results of surgery as opposed to pharmaceutical treatments. Lots of facts, figures and graphs to back up his talk and lots of information to absorb with Dr Walsh joining him towards the end in describing some of the processes involved, the treatment of some cases and how the statisticians can help the medical profession decide upon the success rate of certain operations.

After a break for lunch, when the girls from Faulkner Street Nursery and the rest of the creche helpers took a well earned breather from the 'marauding hordes' inhabiting the creche the afternoon session began with a choice of three workshops:

- 1) Val Millington (the Cardiac Social Worker from Alder Hey) held the largest audience captivated as she described her work and the role she has to play in the Hospital.
- 2) Jane Moss (a community Dietician at Abercromby Health Centre) described ways to overcome problem feeding in our children and to generally offer advice about diet and healthy eating.
- 3) Julie Davenport (Principle Officer at Pipkins Day Nursery in Southport) describing and demonstrating with help of Jo Baxter the joys of sloppy jelly and numerous other toys which can be made from ordinary household items which won't break the bank and are also very stimulating to our children. I think this workshop looked like a Blue Peter programme with lots of something which was prepared earlier but didn't take too much cleaning up at the end.

The day finished about 3.30pm when John Spall thanked everybody for their attendance, and wished everybody a safe journey home. Everybody left having gained something from the day, even if it was only how to get to Liverpool! I hope it is not too long before they have reason to return.

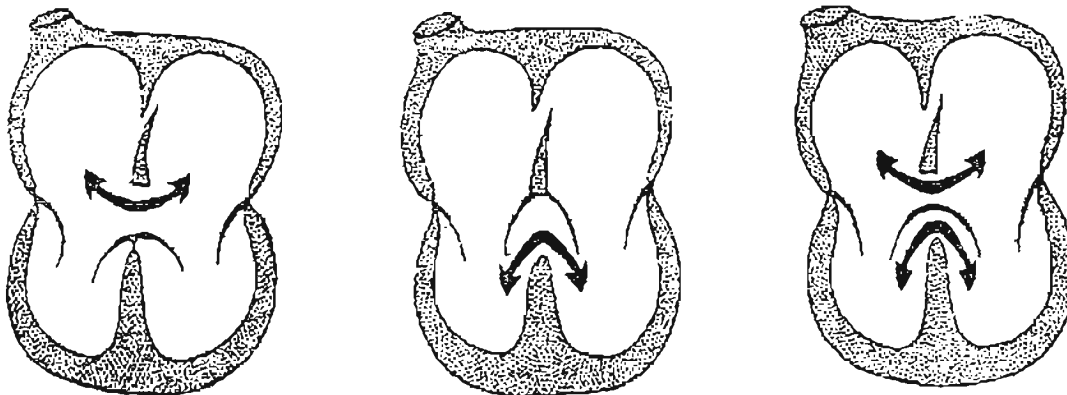
Many thanks to:

- Mrs Mackenzie (Head Teacher at Thornton County Primary)
- All the creche helpers without whom we couldn't hold our conferences
- All the volunteers on the day
- All the people who turned up because without you the whole day would be worthless

and Les (my missus) for being there and sorting out Life's little problems on the day, namely honourable son number one (David) and the buffet and the clearing up and the list goes on

*Mike Halpin
North West Regional Co-ordinator
Organiser of the Conference*

There are varying levels of shunting in the endocardial defects depending on the severity of the defect. These are shown below with arrows showing the direction of bloodflow across the heart.



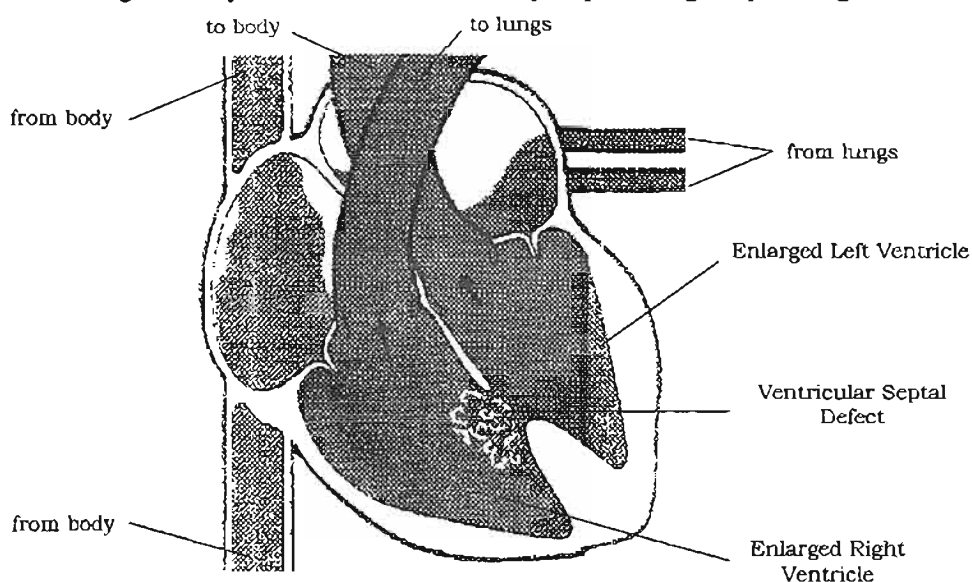
LEVELS of SHUNTING in ENDOCARDIAL CUSHION DEFECTS

Atrioventricular Septal Defect or Endocardial Cushion Defect (AVSD)

In the partial form, there is a hole between the two receiving chambers, (atria) and abnormal valve between the atria and the ventricles. In the complete form, this hole extends into the wall between the two ventricles and there is one single valve between the two atria and the two ventricles. This hole allows excess blood to pass from the left to the right side of the heart thus causing reduced flow to the body. For a child with a complete AVSD the symptoms would be of frequent breathlessness, difficulty in feeding and thus poor weight gain in the first months of life. The child would have an increased heart rate, pale and sweaty skin, reduced urine output and a swollen liver. Children with the partial form may be free from symptoms.

Ventricular Septal Defect (VSD)

In the Ventricular Septal Defect there is a hole between the two pumping chambers (Ventricles) which allows blood to pass from the left side to the right side and through to the lungs. The amount of abnormal blood flow depends on the size and site of the hole as well as the pressure difference between the two sides of the heart. If the hole is small, the child is well and there are no problems. If the hole is moderate, the increased blood flow to the lungs will make them heavy and congested. This may cause wheezing and breathlessness, the child may be slow to feed and have poor weight gain. The child generally fails to thrive. These complaints are more marked if the hole is large. VSD's may close spontaneously or become significantly smaller while others may require surgical patching.



In both the above conditions it is essential that an early diagnosis is made, if possible all Down's Syndrome babies should have an echocardiogram. The child is usually given medicines to reduce lung congestion (diuretics such as Frusemide),

There is a possibility that there will be a natural reduction in size or even closure of the hole but if it remains large it is essential to have an early surgical repair before there is irreversible lung damage.

The AVSD is the commonest form of heart defect found in children with Down's Syndrome.

Results of Surgery in VSD and AVSD

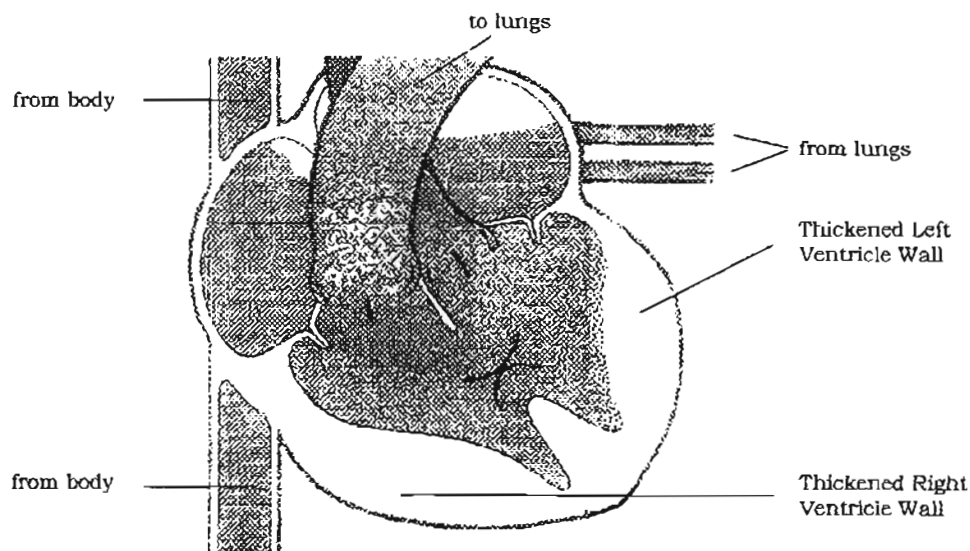
There is a low mortality figure of 10% or under but Down's children often spend longer on a ventilator post operatively. Occasionally it is necessary to re-operate for a residual hole. In the AVSD group, 10% will require further valve surgery either to re-suture a cleft or carry out valve replacement. There is occasional progression of pulmonary vascular disease but generally the majority of children are significantly improved as a result of their surgery,

Lung and Body Circulations

Cardiologists measure internal heart pressures in millimetres of mercury as in measuring blood pressure. The pulmonary resistance figure is the flow multiplied by the pressure. The effects of left to right shunts are to increase the lung artery pressure and cause a condition called pulmonary hypertension. In this condition there is increased muscle surrounding the lung arteries, less small lung arteries and therefore less lung flow. As the condition progresses there is less left to right shunting and eventually right to left shunting takes place. This condition is called Pulmonary Vascular Disease, and the child will have low oxygen levels and therefore be cyanosed and have increased blood haemoglobin concentration .

Eisenmengers Complex

This is when pulmonary vascular disease is almost too advanced for surgery.

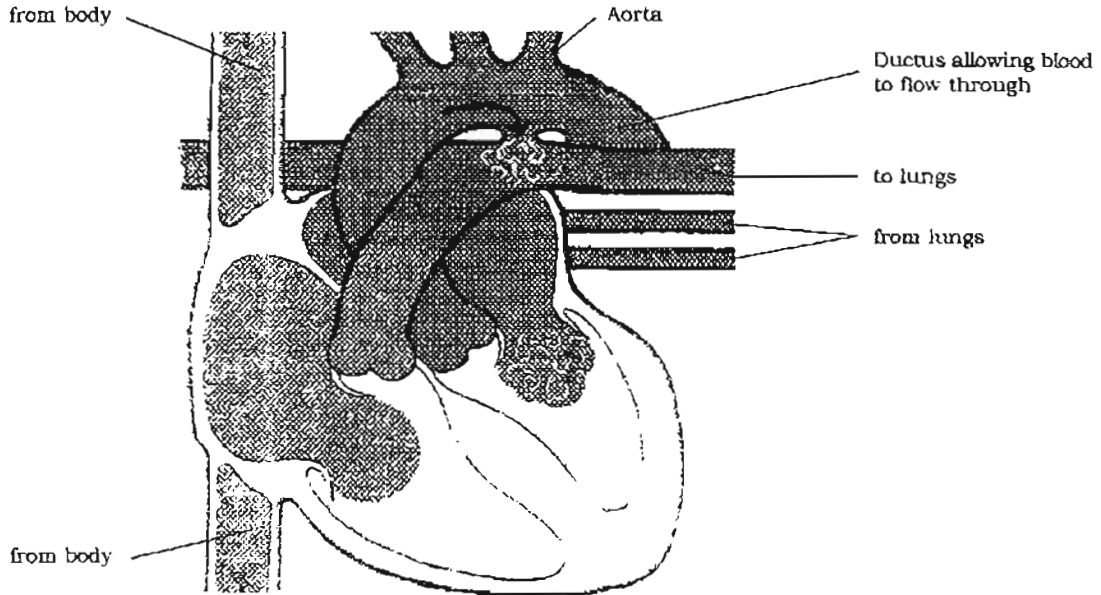


EISENMENGENS COMPLEX

Down's children have a propensity for pulmonary vascular disease because of the larger holes in the heart, the lesser numbers of small lung arteries and their smaller airways. The effects of low oxygen and pulmonary hypertension, Eisenmengers Complex, is that the child can experience blue spells, dizziness and faints, breathlessness and chest pain. They can be prone to having strokes or can cough up blood. Polycythaemia is another complication in Eisenmengers, and causes increased thickness of blood, headaches, chest, joint and muscle pain. It can also cause visual disturbance and thrombosis (clots of blood) and embolism (moving clots). The treatment for Eisenmengers Complex is to maintain an optimum haemoglobin level, by giving drugs called vasodilators which cause widening of the blood vessels and cause changes in blood flow therefore reducing blood pressure and aspirin, to act as an anticoagulant. Patients must avoid becoming dehydrated and they must be carefully monitored during any medical

Persistent Ductus Arteriosus(PDA) sometimes called Persistent Foetal Circulation

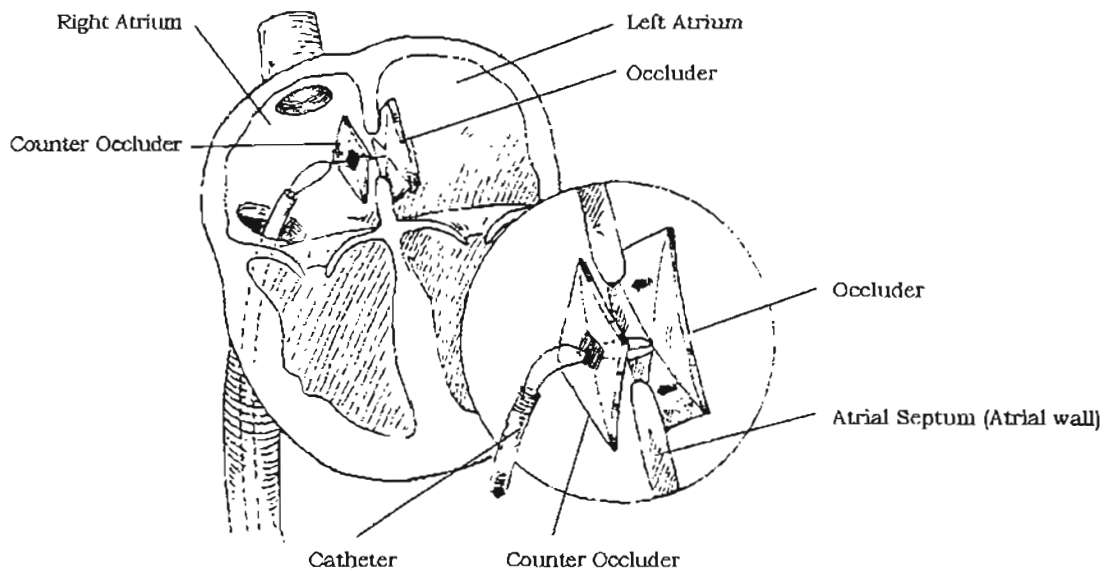
The heart and lungs are formed normally but the lung arteries remain narrow and constricted after the baby is born. This causes high pressure in the lung artery and de-oxygenated blood passes through the small vessel, the ductus, linked to the aorta which is the main artery to the body. This can be tied surgically if it is a large ductus in a small baby but otherwise it can be closed by transcatheter occlusion, when an occluder type device is placed in the duct by using a catheter and left there thus blocking the duct.



PERSISTENT DUCTUS ARTERIOSUS

Atrial Septal Defect (ASD)

There are different types of atrial septal defect depending on where the actual hole is on the heart wall. Surgical patching is necessary for the primum type defect. Surgery is also necessary for a large secundum defect with poor margins but transcatheter occlusion is available for smaller holes with good margins. This is done by putting an ultra sound probe into the gullet to give a clear image of the position of the occluder device on the end of the catheter. The occluder is then carefully placed into position in the hole and the counter occluder buttoned on to it, thus closing the hole.



General Advice to Parents

If the defect has been repaired or if it is an insignificant defect, there is no need to impose restrictions. However, strenuous exercise should be avoided when Eisenmengers Complex is present.

Antibiotics should be given prior to any dental or operative treatment to prevent endocarditis, an infection of the endocardium, which is the smooth lining of the heart. It is therefore very important to tell all Doctors and Dentists who are treating the child of the cardiac problems or repairs which have been carried out in the past.

The child should be given a healthy, well balanced diet.

It is important to follow a preventative dental health programme.

Dental Advice

Restrict sweets, sweetened drinks and bottles at bedtime. Teeth should be wiped or brushed after sugar-based medicine or if not possible, follow medicine with a drink of water.

It is important to brush teeth twice a day and floss teeth once a day. Use a toothpaste with added Fluoride. If there is insufficient Fluoride in the local water supply, Fluoride drops can be given. Check with your local Dentist before giving the drops as too much Fluoride can be harmful .

Make regular six-monthly dental check ups.

Can he fly?

Up to 22,500 feet the cabin is pressurised to sea level. Commercial jets fly at 30-40,000 feet and the cabins are pressurised to an equivalent altitude of between 6 and 8,000 feet.

Supplemental oxygen will be required if the patients Po2 is less than 50mmHg, but only a minority of patients would require it.

Contact the Airline Medical department in advance if in doubt.

In conclusion

50% of children with Down's Syndrome also have a heart defect.

Early detection by routine echo should allow early surgical repair.

Surgical repair prevents Eisenmengers Complex in the majority of children therefore.

ALL BABIES BORN WITH DOWN'S SYNDROME SHOULD HAVE AN ECHOCARDIOGRAM PERFORMED

Memorial Donations

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

Lee Carter - Leek

Erin Miller - Stranraer

Emily Coulbeck - Winchester

Siobhan Price - Torrington

Evan Davis - Norway

Edith Ridley - Great Aunt of Katie Eede, Uckfield

Louis Evans - Teddington

Mrs Robinson - Grandmother of David, Liverpool

Adam Keyser - Leicester

Rosie Steeds - Bristol

Joy Litster - Perth

Adam Watcham - Cleethorpes

Regional Co-ordinators Training Weekend

The Committee of the Down's Heart Group some time ago decided that there was a great need to bring together the field workers within the group, i.e. the Regional Co-ordinators who are spread throughout Great Britain and are the main contact with the membership.

These people have been prepared to put their time and effort on top of being parents, running homes and jobs etc. to helping others within a region of the country. As normal parents with various skills, experiences and anxieties they need help in being able to perform the duties expected of the role they have taken on.

To provide this support the Committee, for the second year running organised a training weekend. Last year it looked carefully at the role of the Regional Co-ordinator and this year covered one of the most important skills when dealing with parents/carers of our children - the skill of listening.

We were helped through this learning process by two trainers from the Samaritan organization who very ably, through the use of role play and individual exercises, were able to demonstrate the skills and provide us with the opportunity to experiment with those skills on each other. I believe all felt this to be a really useful learning experience but only the first step in a delicate and most important area.

The weekend also included an exercise on how to promote the Down's Heart Group to regional and local hospitals, other organizations, keeping in contact with our membership and making contact with potential new members as well as one thousand and one other duties to keep us occupied in our spare time! This was a brilliant exercise conducted by our Chairman, John Spall (I have to say that because he's my husband).

Following on from this we met with the Chaplain from Grimsby General Hospital, Harold Ter-Blanche who provided us with a superb account of the needs and concerns of ethnic minority groups and various religious beliefs. This was concentrated on being hospitalised, surgical treatment, maintaining their cultural behaviour when in hospital and helping us to recognize the need for sensitivity in dealing with their issues within their cultural background. Harold was a most delightful person who inspired us all and from whom we not only learnt a lot but gained a considerable amount of inspiration.

A hard act to follow but Mary Clayton, our Benefits Information Contact, ably did just that by providing us with the most up to date information on the major benefits our families should be receiving. Also tips on how to go about making claims and the importance of emphasising some of the most difficult characteristics of our children when making a claim. Mary has had a number of notable successes in achieving the highest rate of Disability Living Allowance at the appeal stage of the claim. Her help is available to all members via their Regional Co-ordinator in the first instance.

Our weekend finished with some really good suggestions of how to make money! Gill McLorinan, the Secretary of the Down's Heart Group, has had considerable experience of doing this very thing within the Bristol/Western Super Mare area for her son's playgroup. They actually

raised £225,000.00. (Some of Gill's suggestions were detailed in the last newsletter.) Yet another really good and useful session which left us feeling enthused and exhausted.

As with all training one of the by-products is the benefits of meeting other people in similar situations, the opportunity of exchanging ideas and experiences and having fun. We all did these three things and I believe the Down's Heart Group will benefit from all the effort and commitment of those involved.

Katie Spall

Regional Co-ordinator, London South and South East



From left to right, Back row: Linda and Mark Watcham, Mike Halpin, Penny Green, Linda Crozier, John Spall, Pat Mitchell, Mary Clayton. Middle row: Chris Stringfellow, Gill McLorinan, Nicola Desmond, Sarah Smith. Front row: Jane Wrighton, Katie Spall, Lynne Gouck, Sheila Forsythe, Lyn Holden

Non-Verbal Communication

Following our training weekend, I offered to write a short piece on non-verbal communication and how we should use it in our role of listener and supporter. So here goes.

Firstly, a conversation may continue on three levels, what is being said, what is being meant and what is not being said. How a conversation develops depends greatly on how the person doing the majority of the listening behaves. Body language is vital, for one must learn not to fidget, as this may give the impression of boredom. Showing an open, accessible posture is also important as it is hard to talk to someone who will not let you into

or distracted. Eyes and faces say so much. As a listener one must control ones facial expression - must remain accepting and unshockable. This guide-line brought up a recurring point from the whole weekend; we all should be non-judgemental.

Liz and Anna (from the Samaritans) also explained that while nods of agreement, ums and ahs were fairly natural interjections, we shouldn't be afraid of touching (if appropriate) or of letting silence fall. Saying the wrong

thing to fill a gap is far worse than a thought-gathering pause.

After listing the foolproof guide to listening correctly, I think it is important to add that to be so perfect is asking a lot and that if you care about what is being said and can just concentrate on the words you are off in the right direction.

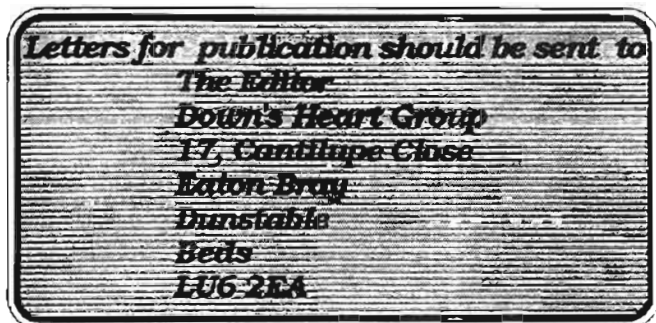
Sarah Smith, Regional Co-ordinator East Midlands

Time Flies

21st February 1994

I'd like to thank Penny, Sheila and Chris, For their kind support Is utter bliss.	But suddenly things They're going wrong, And you realise She hasn't long	To be so brave Is very hard, Live for today And put on a facade.	But first we must Just get things straight, After all they've done I ought to wait.
For nearly eighteen years I've been so bold, Right from the start When I was told	The doctor's so caring, While you sit and wait You know it's bad news But oh, how they're great.	Dawn is just breaking Here's another day, The birds they are singing So come on I say.	To see how things Go for one month, But still I will Fill in the bumf.
Her life will be short They don't know how long, With her Polycythaemia I need a prayer and a song	What a terrible job It must be for them, To give you such news They must first count to ten.	The squirrel's now running Across the lawn, There is no time To be forlorn.	Diuretics followed After the test, Now Venisect and Oxygen Seem to be best.
Well, she's fooled the doctors Past her early teens, But time's running out And we know what that means.	Bad news at the start Bad news at the end, A good doctor we know Is like a best friend.	Life is so precious For people like me, We appreciate What others can't see.	So if she's well For her eighteenth in May, She wants a BIG PARTY And <u>deserves</u> it I say!
Who needs a prayer When she's sung all this time Nursery, Camp-fire songs Pop music I just mime.	As the tiredness Is creeping on The days for me Are getting long.	No one can tell them For what it's worth, To have three faceless friends... Who are the salt of the earth.	My eyes are now burning As I slip off to bed, But I've finished my poem And can now rest my head.
She's a great organiser And so full of life, If she was my boss I'd now be on strike.	She sleeps much more And gets up late But when she's ready We're through that gate.	A voice on the phone From some caring folk Sparing my problems Gives me some hope.	Sweet dreams and God Bless you all! <i>Vicky Willatts Cwmbran</i>
I don't know where I get my energy from, But it seems to drive me On and on	"Come on Mum I'll miss my class Pottery first .. then Woodwork or Maths."	I still have a challenge I must now complete Her ambition of a lifetime .. Euro Disney's the treat.	<i>(Vicky's daughter Nicola celebrated her eighteenth birthday on 25th May, shortly after returning from Euro Disney where she had a wonderful time. Thanks to Vicky for sharing this poem about her experiences with us, and to the Children's Wish Foundation for making the trip possible - Editor)</i>
It's hard to be brave On times when you're low, When they're not so well It comes back with a blow.	But little thank God Does she realise, How quickly for her The time now flies.	Thanks to you Penny We might make it yet, But I'll not even hope Or take on a bet.	
But you do not think Of things to come. You live for today So come on Mum!	And as for me I cannot sleep, As the shock sinks in I wake and weep.	If we only go And just say 'Hello' To some of those characters, Her eyes they will glow.	
"I'd like a pub lunch. Let's got o the park... Can we go to Jackie's And see the new calf?"	A silent cry From deep inside, It breaks my heart But how I've tried.	And to see her expression It will all be worthwhile, To take in and see That laughter and smile.	

Letters to the Editor



Dear Editor,

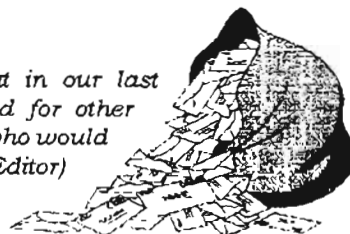
Just dropping you a line to say thank you for forwarding all the letters after my 'plea' in your newsletter. It's lovely that people take the time to put pen to paper! May I through your next newsletter thank all those who took the trouble to drop me a line. Could I also assure those who have yet to receive a reply, I promise I will be writing to everyone who took the trouble to write - I have not forgotten you!!

It was such a comfort knowing that you are not alone and that more importantly there are people out there that can actually say "I know exactly how it feels to be told you've had a child born with Down's Syndrome".

Thank you once again.

*Joanne Hayter
Macclesfield*

(You may remember that in our last newsletter, Joanne asked for other parents of a similar age who would like to exchange letters - Editor)



Dear Editor

I am trying to find a contact for a family whose child has diabetes. If anyone knows of a family with a child aged about ten who has not had heart surgery, please would they get in touch with me on 0151 928 4987.

*Mike Halpin,
North West Regional Co-ordinator*

Dates for Your Diary

Bereavement Conference

The National Association of Bereavement Services is holding a one day conference on Wednesday 9th November at the London Voluntary Sector Resource Centre, Holloway Road, London. The conference is aimed at parents and carers of people with learning difficulties. Cost £20 for parents, £30 for carers.

More details from:

Carole Lambert
National Association of Bereavement Services
20 Norton Folgate
London
E1 6DB
Telephone: 0171 247 0617

3rd European Down Syndrome Conference

This conference is being hosted by the Down's Syndrome association of Ireland in Dublin, from 23rd to 26th August 1995. There will be a wide-ranging social programme during the conference, as well as many subjects for discussion based around the theme 'Towards an Inclusive Society'.

Further details from:

Third European Down Syndrome Conference
10 Hagan Court
Lad Lane
Dublin 2
Ireland
Telephone: 010 353 1 6618904
Fax: 010 353 1 6785047

Contact A Family - Sharing Ideas Day

Skelmersdale, Monday 28th November. In a joint event organised by Contact a Family's North West Regional Office and the National Office, this day is for parents of children with special needs, those involved in support groups and also voluntary and statutory workers. It will provide an opportunity to share ideas and experiences, highlight areas of concern, develop parent support networks and find ways of working effectively together. No charge for parents, £10 for professionals/paid workers.

More details from :

NW Regional Office : 0161 727 2388
or Pauline Shelley
National Office (Mersey area) : 0171 383 3555

Annual Conference and AGM

The 1995 Down's Heart Group Annual Conference and AGM will be on Saturday May 6th at Grimsby Hospital, with a full programme, creche and lunch available. More details will be sent out to all members before the event, but make a note now to keep the date free.

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 thefamily will be:

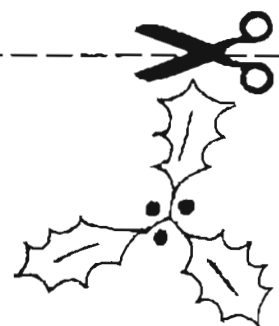
.....
.....
.....
.....
.....
Postcode:
Telephone:

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

Send to: Penny Green, National Administrator



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 £1-85p = £ ... - ... p
..... packs of 50 cards at £7-90p = £ ... - ... p
Total = £ ... - ... p

N.B. Prices include postage & packing

To help us when considering the purchase of other promotional goods, it would be help if you could spare the time to answer the following question.

What type of goods would you or your family and friends consider buying, (eg. pens, mugs, key rings, lapel badges) and what price range would you be prepared to pay?

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

to: Penny Green, [redacted] [redacted] [redacted] [redacted] [redacted] [redacted] [redacted] [redacted]

