

Steering Committee Contacts

Brian Auld



*Charity Registration, Legal
Advisor*

Sue Bamber



Treasurer

Françoise Beattie



Publications

Euan Forsythe



Minutes Secretary

Denis Hopkins



Newsletter

**This space
vacant.**

Can you fill it ?

John King



Director

Wendy Tucker



Design

Linda Walsh



Founder

Editorial

Welcome to the third newsletter from the Down's Heart Group, and thank you all so much for the messages of encouragement that have been passed on to me. Please forgive me if I made the last newsletter a bit too harrowing - I know I could tell you to skip the sad bits, but if you are anything like I am, you'll not be able to, even though you know they are going to upset you ! It is turning out to be a most difficult task, achieving a balance between happy and poignant stories, the trouble is that I want to include every single one as it comes in, and I feel so guilty if I have to make some wait for a later issue. Those of you who needed to contact Sue Bamber, our treasurer, will no doubt have spotted that the telephone number I gave you was totally wrong. Thank goodness the number I did give turned out to be unobtainable ! Also, you will find the correct telephone number for Anna Danson in this issue. I didn't get off to a very good start, did I ? I would have liked to intersperse a few more photographs with the written word this time, but the photocopier at my husband's office can only reproduce very clearly defined colour photographs, or preferably black and white ones, so we are very short of material. Ideally, we'd like to run a **Rogues' Gallery** section, with mug-shots of everyone, but to do this we need you to send us the photographs. A regular feature from now on will be the **Letters** page. So many of you tell us things that don't quite fit any of the other sections, and this will be an ideal place to print them. The deadline for copy for our next newsletter is August 31st. I always end up in a self-inflicted last-minute rush when I have to chase articles, so please save me from myself !

Delia Gleave, Editor

Down's Heart Group

Welcome to our third Down's Heart Group Newsletter, and thank you for all the compliments and congratulations we've had on our previous issues.

Quite a lot has been going on since November when I wrote my last progress report for you. The first few weeks went by in a flurry of all sorts of Christmas-related activities. Firstly, there was the sale of Christmas cards, which went extremely well, considering how many people had stocked up before ours were available. Certainly we all but sold out, and have built up a good list of customers ready for next Christmas. Then there was the Christmas party, admirably organized by the Hojabri, Danson and King families, and well-attended despite weather and 'flu' epidemics! Next came the Oakham Christmas bazaar – what a wonderful sight! Over sixty people, under the leadership of Diane Cobain, were involved in this really enjoyable event which raised the magnificent sum of £1250 – the largest single sum ever paid into our bank account. Well done, Diane!

Once Christmas had been and gone, it was back to the real world and what better to bring us back to earth with a jolt than the thought of the paperwork involved in registering the Down's Heart Group with the Charities Commission. Words could not express our gratitude when one of our 'dads' turned out to be a solicitor willing to get to grips with the more-over's and hereuntofors of the constitution, so I'm delighted to say that we are well on the way to having a constitution, which is the first step along the road to Charity Registration. The next step, I believe, is to hold an Annual General Meeting at which a committee can be elected. We'll be in touch soon to invite you to that so that you can formally 'join' the Down's Heart Group and have a vote at the meeting. In the meantime if you have any experience of committee work or you feel you could help us to get through this difficult stage of formalizing the workings of the Group, then please do get in touch.

Yes, we are still asking for help! The mound of work seems to grow rather than shrink and we could use as many hands as are willing to help. I am particularly fortunate at the moment to have two wonderful volunteers working with me locally and we are desperately trying to keep the paperwork under control, but for the time being we are only just managing to keep our heads above the water. I just long for the day when we can start swimming...!

As soon as time permits, we have several projects in the pipeline which I know many of you are impatient to see come to fruition – not least are the handouts on **Feeding problems**, **Sleeping problems** and **Coping in Hospital**. The Fallot's Tetralogy booklet is now in the capable hands of Verity Ridgeman. There is a lot to be done and I know Verity still needs more accounts of families' experiences for inclusion. So, if your child has Fallot's and you haven't written up your story yet, please get in touch with Verity on 01-217-2475. More funding (about £700) is still needed for the Fallot's booklet, but I'm delighted to say that the AV Canal booklet now has funding and is undergoing its final updates before going to the printers.

Also high on our list of priorities is making contact with the cardiac units. We have now had meetings with several consultants in charge of paediatric cardiology units around the country and we have been delighted with the very positive reactions and offers of support received from most of them so far. Over the course of the next year we hope to work our way right round the country, working with the Regional Co-ordinators to build good relationships and to ensure that no new family leaves a cardiac unit without having seen one of our posters or being given one of our leaflets.

Regional progress is discussed in the next pages, but I must finish by saying how pleased I am that, while things still remain suspiciously quiet in the North-West, Yorkshire/Humberside and the East of England, they are positively buzzing now in the West Midlands which is in the process of setting up as our ninth Down's Heart Group Region. Who will be number ten ???

As you will read in John King's section, I shall be taking a back seat in the Group from now on and handing over to a much more competent team headed up by John as director and Penny Green as family support co-ordinator. Thanks for all the help you have given me in the past to get the Group off the ground – I know you will join me in pledging your support to John and Penny as they roll their sleeves up to take the Group on from here. Here's hoping that you enjoy reading our third newsletter, and that you will soon be taking us up on our invitation to become a voting member of the Down's Heart Group.

Linda Walsh Founder

Regional Co-ordinators

These are Group members who have volunteered to take over a region to try to develop local family support. They live in their designated region and liaise with the National office, hospitals and new and existing local members. Any information received by the National office is passed on to these co-ordinators who in turn will make contact with the people in their region who require that information. Also they will send out any information relating to the Down's Heart Group to local hospitals, clinics, information services and so on. However, as you will see, the regions covered are very large. We still need more regional co-ordinators, and also group 'contacts' to cover smaller areas within these regions, so if you think you could help in your area, please contact the National office.

Down's Heart Group (Wessex area)

(Dorset Hants Wilts)

c/o Pauline Proctor



Down's Heart Group (Kent)

c/o Peter Stephenson



Down's Heart Group (North East England)

(Cleveland Durham Northumberland Tyne & Wear and until further notice Cumbria)

c/o Sandra Welsh



Down's Heart Group (London & Northern Home Counties)

(Beds Berks Bucks Essex Herts and until further notice South Northants and Oxon)

c/o Denis Hopkins



Down's Heart Group (Northern Ireland and Eire)

c/o Rosina Brierley



Down's Heart Group (Bristol & South West)

(Avon Cornwall Devon Gloucs Herefordshire Somerset Worcs and South Wales)

Sheila Forsythe (DHG deputy director)



Down's Heart Group (Scotland)

c/o Lynn Gouck



Down's Heart Group (East Midlands)

(S. Derbys Leics Lincs Notts N. Northants)

c/o Gina Hojabri & Anna Danson



For all other areas please write to:

Penny Green



Stop Press ! Stop Press ! Stop Press !

As we prepare this newsletter for printing I would like to tell you about several movements which have occurred on the Steering Committee.

Linda Walsh, our founder, passes the position of director to John King, whose address will serve as the National Office. Linda is, of course, still very much involved with the Down's Heart Group; as well as being our founder, Linda will concentrate on research.

John King, as director, will be supported by Sheila Forsythe as deputy director, and, of course, the steering committee continues beavering away in the background - with positions vacant.

A new position created to cope with part of the mountain of work previously done by Linda is that of National Family Support Co-ordinator. This position is filled by the able and enthusiastic Penny Green (address on page 4). We welcome Penny to the steering committee.

Two positions we would like to fill are those of Fundraiser and Accountancy Advisor to the Group - if you have a few spare hours to assist us, please contact John (address on page 2).

CONGRATULATIONS

Luisa Marie Walsh

arrived at 1.00am on 22nd May 1990, weighing 8lb 13oz. Linda claims that this was actually a last-minute job she was doing on the 21st, rather than an out-of-character early one on the 22nd! We all send the whole family our love and best wishes.

A very big thank-you to

- ✧ Solutions Ltd, Long Lane, London, who donated a photocopier to the Group.
- ✧ Brian Auld and friends! Is Brian the fittest member of the committee? He's certainly the only one to run a half-marathon with proceeds to the Group.
- ✧ Pauline Shaylor of Castlethorpe, Milton Keynes for the extremely generous gift of paper, etc.
- ✧ The Guernsey Society for the Mentally Handicapped who donated £125 to the Group to cover the cost of an issue of our newsletter.
- ✧ The Leicester branch of MacDonalds who provided a drinks machine and a large amount of juice and cups for the Christmas party.
- ✧ Euan Forsythe for supplying the trifles for the party.

News from the regions

Ireland - Rosina Brierley is at last getting some feedback from all the writing she did at the start ! She has met with the Down's Syndrome Association of Ireland and has also met Cathleen and Willie Meagher, parents who visit the hospital in Dublin to give support to those whose children are undergoing surgery. Rosina has also heard from Gay Flynn of 'Heart Children'

Scotland - Lyn Gouck reports that she has made contact with three new families who live near each other and are interested in setting up a local group. She has also been in touch with the Scottish Society for the Mentally Handicapped and with the Scottish Down's Syndrome Association, both of whom have shown interest in the Down's Heart Group. The SDSA promised that they would give Lyn's name and address in their next newsletter. She would love to hear from someone with transport, however, who could deal with hospital visits, as she finds it very difficult to get around. The Group has been publicized so well that visitors to Glasgow from other parts of the country have contacted us, but Lyn does need help in other areas of Scotland.

North East - Sandra Welsh has recently had contact from families as far afield as Cumbria and Cheshire and is putting a lot of work into family support in her area. However, she would like to apologize for not arranging the promised 'social event' just yet. She's going through a worrying period with little Michael at the moment, and while she is more than pleased to talk to families and offer support she's having to take a back seat temporarily on the social side of things. Is there anyone up there in the North-East who might like to offer a hand in organizing a get-together or outing ? Please contact either Sandra or Linda if so.

West Midlands - A group of enthusiastic parents met for the first time in February this year. Watch this space for details of the West Midland region which they hope will soon be formed.

Wessex - Families from Portsmouth, Southampton and Petersfield have attended a family meeting. A meeting has also taken place with Dr Keeton, a paediatric cardiologist, who has pledged support for the Group.

East Midlands - Gina Hojabri and Anna Danson would like to thank everyone who contributed towards making the DHG Christmas party last year such a wonderful success, among them Gina's sister, Lisa, and her husband, Paul. Even though illness prevented a lot of people coming, there was still a large turn-out, including Santa himself who arrived with gifts for the children. They hope that everyone enjoyed it as much as they did, and that we'll be able to make it even bigger and better this year.

They would like to thank all those who sold raffle tickets when the Beaumont Leys Police Social Club held a fund-raising event for the DHG and the hearing-impaired in March. Gina, Anna and thirteen others attended the dance and draw. Winners included Linda Walsh's parents, Mr & Mrs Aplin, who very generously donated their prize, a microwave oven, to the DHG to be raffled or sold for Group funds. Proceeds from the raffle have not yet been received as the DHG is one of the Beaumont Leys police charities for 1990, and fund-raising will continue throughout the year with a presentation to be made towards Christmas.

Bristol and the South-West - The Group in this area has been doing a lot of fund-raising. They will have held their Barn Dance by the time you read this. Strong links have been established with hospitals - Sheila's is a familiar face to them now ! Local meetings are being planned in Cornwall and other areas. We are delighted to say that we now have two more active local contacts in this area. Judy Dart is our new DHG (Torbay) contact. She lives at 53 Woodville Road, Eliacombe, Torquay, Devon. Tel: 0803-298620. Our other new face, Elizabeth Miller, lives in Carmarthen, and I have given her a separate section so that anyone looking unsuccessfully (hint, hint !) through these pages for a mention of Wales might find her easily and perhaps be encouraged to join in !

Carmarthen - This is not a region as such, but I have given it prominence to encourage the rest of you in Wales to get together and sort something out! Elizabeth Miller is our new regional contact for Carmarthen and we hope to include parts of her wonderful, news-packed letters to Linda on our letters pages. Elizabeth makes me feel positively idle even though I am trying to cope with running three part-time jobs as well as my family! Elizabeth can be contacted at: Waunlwyd, Esgair, Cynwyl Elfed, Carmarthen, Dyfed, SA33 6UN. I hope that address is clear - new line after every comma.

London and Northern Home Counties - Strong links have been forged with the nursing team at the Brompton Hospital, and there has been a meeting with paediatric cardiologist Dr Shinebourne. Denis Hopkins has been invited to speak at various DSA meetings. We have had some very welcome help with the publication of the AV Canal booklet. Denis and Jenny Hopkins attended a Heartcare meeting in Northern Ireland in May on behalf of the Down's Heart Group.

Letters

For some unknown reason, the letters section seems to have slipped through the net for our last newsletter; my apologies - I was probably trying to get to grips with too many new things at once. We would like it to be a regular feature from now on, though, and are starting off with some heart-warming news. Here are some extracts from two letters written by the same person; one letter was to Linda Walsh, and the other was to all of us. The writer is an inmate of H.M. Prison, Bedford, and the first extract comes from his letter about his fund-raising efforts for the Down's Heart Group.

"We in the prison are putting together an auction - only all the items are donated from personalities! To make the whole project complete, we also required a good worthwhile cause for the proceeds to go to...and there you were, thinking that no-one cares!! Our intentions are honourable, I assure you, for we believe that we can still offer the community something

"As a fund-raiser not associated with any one group directly, I still give 100% commitment to my chosen cause, in this case the Down's Heart Group. When I read the letters of experience, some cheerful, some positive and some sad, that you, the readers, sent to Linda, I was very moved - moved enough to vote the Down's Heart Group as my cause. It was you, the readers, who put me in touch with Linda."

Mr Maksymiw explained in his letter to Linda how he became involved in raising money for charities.

"By nature I am deeply fond of children, but my admiration grew when the prison invited local (mainly handicapped, but does include children with Down's Syndrome) kids to exploit our gym facilities. It was working with these adorable, energetic little sods, week in, week out, that I truly saw the determination and sometimes unprecedented measures they took to achieve what the able-bodied could."

Mr Maksymiw approached the governor about fund-raising to buy these children a trampoline with the result that £1300 was raised by the inmates and staff holding a 24-hour sports marathon inside the jail! Because of Mr Maksymiw's success with this, the governor has consented to his present fund-raising event, the Celebrity Auction.

"One of our prison officers, who I understand is the grandfather of a child with Down's Syndrome, introduced me to your Group....."

We at Bedford Prison are in favour of your organization and are willing to donate all funds raised by my present project to your good work.....Let your readers know that people out there, and in here, do care."

Footnote

In conjunction with BBC Radio Bedford, a three-hour Celebrity Auction was held on Sunday, 22nd April, raising approximately £1200. This came live from inside Bedford Prison and was a credit to all who had put so much into the planning of the event. With a little persuasion from 'Maxi', donations from such as Kylie Minogue, Bob Hope and many more came flooding in. Well done all at Bedford Prison, and keep up the great work.

John King

Record up-date

With this newsletter you should all have received a questionnaire from Penny Green, who is updating and computerizing our records. Ideally we would like a separate form completed for each Child with DS in your family, so if you need extra (or replacement!) copies of the form, please contact Penny [redacted]

Heartcare Conference

22nd September 1990

For details, ring

Mrs Janet Rathburn [redacted]

NAWCH

We have some information, too, about the National Association for the Welfare of Children in Hospital. *NAWCH* is called after a Government report - 'The Welfare of Children in Hospital'. This report was produced twenty-six years ago and urged all hospitals to involve parents far more in the care of their sick children. A few hospitals were already proving that having parents to stay in the wards with free access to their children was beneficial for everyone. However most hospitals took no notice of the expert advice and so *NAWCH* was started by parents, doctors and nurses to persuade all hospitals to offer family-centred care. *NAWCH* has local branches around the country which provide information, friendship and practical help for families with a sick child.

For more information about *NAWCH*, please contact

The Director
29-31 Euston Road
London
NW1 2SD
Tel 01-833-2041

Teeshirts and Sweatshirts

Teeshirts and sweatshirts bearing the Down's Heart Group logo are now available.

Teeshirts

White with pink heart and black script

Adults'	S M L XL	£4.99
Children's	24" 28" 32"	£3.50

Sweatshirts

Sky blue, grey or white with pink heart and black script

Adults'	S M L XL	£9.99
Children's	24" 28" 32"	£6.99

These prices are inclusive of VAT and postage & packing. Cheque or postal order with order to:

Mara Young [redacted]

A 'phone call to Mara will ensure that she has your size and colour before you send payment. Only orders in writing accompanied by payment can be accepted.

Heartcare

are going to run a number of adventure week-ends for various age groups.

Details are available from

Steve McMillan. *Young at Heart*, [redacted]

Help wanted !

The Help offered 1 section is in danger of being squeezed off the page. Please help us to balance the act for the next newsletter !

D.S. / cerebral palsy / epilepsy - contact still needed with families with this or a similar combination, please. George & Carol Perrens, [redacted]

D.S. / Leukaemia - Gill Denne, the founder of C.A.L.L.: Childhood Cancer and Leukaemia Link, rang me to ask if we could find a contact for a family with a 4 year-old girl with D.S. who has recently been diagnosed as leukaemic. They would welcome contact with any other family in the same or a similar situation, they have problems with their daughter coping with treatment, etc. In the first instance, please contact Gill Denne, [redacted]

Bereavement project - Lynn Stallwood is working on this, you may already have received a questionnaire from her. If you have lost a child and could talk to Lynn about it or could cope with her questionnaire (I am filling in mine now, and she is dealing most sensitively with this extremely difficult subject), then please write to her or ring her. We can perhaps help her to provide for others what we perhaps couldn't find ourselves when we needed it. Lynn Stallwood, [redacted]

Fallot's Tetralogy booklet - more accounts are needed for inclusion in this. Please ring Verity Ridgeman [redacted] if you can help.

Heartcare - are going to print a booklet on admittance to hospital. If you have any ideas or suggestions for inclusion in this publication, please ring Fiona Benson [redacted]

Friendly accountant - the DHG books need auditing again ! Not an enormous task, and if you know someone who would do this for an economical fee, please ring Sue Bamber [redacted]

Printing - does anyone know of a low-cost source of printing for our leaflets, publications, newsletter, etc. ? Contact John King [redacted]

Christmas Card Competition

Prize : £15 Gift Voucher

We're looking for a design for this year's Down's Heart Group Christmas Card, and who better to ask than your children ? The card will be the same size as last year's, and can be printed in a maximum of two colours to make it an economical venture. Please get the pencils and paper out and send your ideas to Denis Hopkins. Make sure that the artist's name, address and age are written clearly on each entry. No limit to the number of entries from each person, and no age limits either.

Closing date for this is August 31st.

Atari 520 / 1040ST owners - if anyone out there could help me with the production of our newsletters, I would be undyingly grateful. At the moment I use 1st Word Plus and then import my documents into Timeworks DTP. Since the last newsletter, I have started teaching again, and no longer have enough hours in the day to key in as well as edit and set up pages - this is the reason why this newsletter hasn't appeared before now ! Please ring me to talk about my problem. If several people can offer help, then each of us will only have to deal with one or two sides of A4. Thank you. Delia Gleave [redacted]

Offers and requests from you - please use this section of the newsletter to "advertise", free of charge, obviously, if you need to know something or can share any useful information with us. Ring Denis [redacted]

Help offered !

Every one of us probably has some experience or skill which could be useful to others. This is the place to tell us

Miscarriage support - nothing official, but Delia Gleave [redacted] and Penny Green [redacted] have both been there twice since the deaths of their sons (one each) with D.S., so if you want to talk, we're here

Your experiences

Here is another selection of your experiences. We are extremely grateful to those of you who have managed to make the time to write your stories for us to print. In the last newsletter, we told you about Joanna Patenall, one of the three people featured on our general information leaflet. This time, as promised, we start with the other two children from the same leaflet, Vivienne Phipps and Matthew Weaver.

Vivienne's story

Vivienne was born on 8th September 1984 to parents in their mid-thirties who already had a daughter of eleven and a son of nine. After an initial hiccup about accepting Vivienne as what she was, we tried to settle down to try and give her as normal a life as possible. Six weeks later brought the first rumblings that all was not well with her heart. A murmur was detected and six months later we found out that she had a massive unrepairable hole. Her life expectancy was given as far as her early teens if nothing unexpected happened. Sadly something did happen and she died on 16th December 1987, aged three and a quarter.

During her short life we treated her as normally as possible. We took her everywhere, even flying off on holiday with her, although emergency plans were made should anything have happened whilst in a foreign country. While on this holiday, she decided to wander off on her own round the swimming-pool complex, and we found her inspecting the deep end of the pool. It had taken a lot of persuasion to get her into the shallow end!! We are also regular caravaners and took her all over the place with us. At one of our regular haunts she found a fascination for the toilets and once managed to shut herself in one. She was a happy little soul with a strong will. Small as she was, she loved to help with the dusting, laying the tea-table and loading the washing-machine, falling in on one occasion.

She went to handicapped play-school from an early age, but spent quite a bit of the winter at home due to ever-present colds and chest infections. At three, she joined a normal play-school and had a very happy couple of months where the other children treated her as a little dolly because she was small and blonde. Although she didn't talk much, she could make people understand and had a good comprehension of what was being asked of her.

Naturally we miss her, but having watched the pain and suffering she endured during her last month we feel that perhaps it was for the best. We took endless photographs during her life and will have these and lovely memories for ever.

Pat Phipps

Matthew's story

Matthew was born in 1981 - a much longed-for baby. We were told within twenty-four hours that he had Down's Syndrome. I breast-fed him and he was very demanding. He seemed not to be able to cope with the flow of milk and would scream with frustration. I should have suspected something. At his six-week check-up his heart-defect was discovered. It turned out to be very serious - the complete AV Canal defect. We were sent to the Brompton Hospital and were told that surgery was not recommended. Our GP said that Matthew's first infection would probably be his last. Our paediatrician advised us not to let him cry because it would put a strain on his heart which was stressed already. So began a year which was something of a nightmare. Matthew tried to cry a lot and I thought the carpet would be threadbare with the constant pushing up and down day and night. We never took Matthew into crowded places and friends and family kept away if anyone had a cold. My elder son suffers with cystic fibrosis and frequent serious chest infections - it was a most unfortunate combination. When Jeff was ill, we had to keep them apart, which made life even more difficult. We had more colds than ever before that winter, but Matthew never caught one. I have vivid memories of sitting feeding Matthew wearing a Dettol-soaked mask. Later he developed recurring bouts of very severe croup, which was very frightening. When he was cutting four teeth, he had tonsillitis followed by a chest infection and was admitted to hospital. They used postural drainage (physiotherapy) to clear his lungs and I watched him change from blue to pink. Mothers of most children with cystic fibrosis have to do this twice a day to keep the lungs clear, yet I have not heard of any other mums being shown how to do it for their children with Down's Syndrome who suffer with chest infections.

I can remember Matthew's first assessment being done at home. He took one look at the lady and screamed hysterically without stopping so that Jeff had to walk him round the garden so that we could hear ourselves speak. When the second Spring came round, we reached a momentous decision. Now that he was stronger, he had to be allowed to have a fuller life or life would not be very worthwhile for him.

anyway. He started at a pre-school playgroup. They worked very hard with him. He took a long time to get onto his legs. He went through a long casting stage. Anything that was put into his hand would instantly be put into orbit. This included spoons full of food and the wall took on the appearance of an edible collage. We were advised to try taping the spoon onto his hand so that he would get used to the feeling. His efforts to dislodge it were so violent that we gave up and fed him till it passed. Once I had thrown away all the books, refused portage or any work programmes and stopped feeling guilty about 'not doing anything with him' I felt much better. He walked when he was three, he started chewing when he was five. I would look with envy at babies and toddlers with Down's Syndrome tearing at bread rolls and munching crisps when Matthew could spot a whole pea in his dinner at ten yards without his glasses. Even now, we get really excited when he adds another food to his diet.

Matthew goes to an ESN(S) school now. He goes swimming and does PE and they just let him go at his own pace. Recently he has shown some decline in stamina. He has always had to walk slowly if we were going any distance and would ask for a carry if he got tired, but now he asks for a carry much sooner. I always use a major buggy for shopping. He goes a little bit blue when tired, and more so when he has an infection.

Matthew has a very happy and out-going nature. He is also very caring and is swift to respond when anyone is unwell, smothering them with love and concern. Sometimes he will be very difficult and if I get really cross and upset he will suddenly come and pat me soothingly and say "There, there, all right Mummy. Come on, a little smile now," and will beam in such an encouraging way that I just have to laugh. He rocks with laughter at this, too, and says "GOOD GIRL!" His heart may be faulty, but it is full of love.

Angela Weaver

Hannah's story

Hannah was born on 7th November 1978 at Foresterhill Hospital, Aberdeen; she was seven weeks premature. Labour had been stopped three weeks earlier and I was admitted into hospital for the duration of the pregnancy. She was born by Caesarian section due to a ruptured womb and placenta praevia. We were not told of any heart-defect for a few days and then it started with one hole in the heart and ended with the possibility of three

three. We were informed that her condition was serious and that her life was very much in the balance.

She came out of hospital weighing four pounds, which was two ounces under her birth-weight. I think she was allowed home because they could do no more for her in hospital. One week later, she was re-admitted in cardiac failure. At this time we were asked by the cardiologist if we wanted them to help her live. Then, I found this very difficult to come to terms with; now I understand the question. We were not given much hope for her long-term survival.

Hannah was seen by the cardiologist in Aberdeen at very regular intervals, I think once a fortnight at first. She was in and out of hospital many times with chest infections, cardiac failure and pneumonia. At this stage she was not seen by any other cardiologist. Information was given, gradually, although even that might only have been because I had some idea of the right questions to ask. They were very non-committal about the actual diagnosis, but came up with atrial and ventricular septal defects.

Hannah was a very weak baby, she was not allowed out for the first six months and was fed two-hourly; she had no sucking reflex for quite a while. At one year old she weighed eight pounds. After the first year she had fewer admissions into hospital. She was still frail and frequently ill. About this time I asked if she could see another consultant for a second opinion. It was arranged that she should see the cardiologist at Edinburgh Children's Hospital. When she was eighteen months old we went for the catheterization. They confirmed the diagnosis but said that she was not strong enough for an operation, which was possible, although because of the risks we would have the final decision. It was made clear that the operation could only be done if the pressures in the lungs were low. We were told to watch out for the reversal of shunt which would precipitate the lung-pressure rising; evidently this reversal meant the diagnosis would be Fallot's Tetralogy. When she was two years old, we went to live in Spain. She had continual illnesses, but was reasonably healthy until just before her third birthday when she showed signs of breathlessness and weakness and complained of pains in her chest. We contacted the Edinburgh consultant and decided to come home for an operation. Drugs before surgery included diuretics and antibiotics.

Before the operation we were told that they would patch the two large holes, close the Patent Ductus and remove the pulmonary stenosis (this had been

protecting her lungs from the pressure). We were told that the operation carried a high risk, but that without it she would probably not live to be more than five years old.

On the day of the operation she weighed fifteen pounds. We travelled to Edinburgh. I had left my other two children at home with my mother and the *au pair* whom I had brought back with me from Spain. My husband was only going to stay over the critical period, then travel back and forth. I had a bed in the mothers' unit, my husband could stay there over the critical period, then in Bed & Breakfast accomodation. When he brought the family to see Hannah, they could stay in a hotel. The operation took five and a half hours. The next days were traumatic; she was completely sedated and there were many problems. I had done nursing training, so the intensive care unit was not as shocking as I am sure it is to most parents. The operation was on a Wednesday and we did not manage to get her off the ventilator until the Sunday. She transferred back to the ward and her recovery was pitiful; she was like a little zombie. We went through a collapsed lung, oxygen tent and numerous problems. Also her throat had been bruised so badly by the ventilation that she could not make any sounds. They seemed happy with the operation, but would not commit themselves about the future.

After two weeks we travelled back to the hospital in Aberdeen for her convalescence. Again, her recovery was poor. She was on Digoxin and diuretics. When I brought her home she just lay in her pram and I pushed her around with me. I would say it took her about six weeks to recover. She was terrified of doctors, nurses and blood.

For the next eighteen months her health was not good; she developed asthma-like attacks, went into broncho-spasm and had a few goes at pneumonia. I kept telling the consultant that I was not happy with her health. A lot of the time she slept with us because of the breathing attacks during the night. Life was difficult. Again she was admitted to hospital many times. When she was about five years old her condition was not good and she was scanned. They said she was in cardiac failure because of the tricuspid valve failing. At this time she was on Digoxin all the time. We were told that an operation could be attempted. Without the operation she would gradually need more and more Digoxin until it would no longer work; she would probably have six months to live. We were given the choice of the operation. We were against having further surgery because of the heartbreak and pain it had caused before.

However, we agreed to go ahead, for how can you *not* do anything that might save your child's life?

There was a much better recovery from the second operation. The valve didn't cause problems, though the adhesions from the previous operation did. They also found another ventricular defect, but decided to leave that as it was small. Problems after the operation were that the wound refused to heal properly. It was decided that, because of faulty stitch material, they would have to open up the wound and re-stitch. Hannah was still terrified of the hospital and needed a lot of reassurance. I felt at this time that, no matter what, I did not want to set foot in the hospital again.

When Hannah came home she started to improve gradually and did not suffer the numerous admissions to hospital and poor health. She saw the cardiologists from Edinburgh and Aberdeen once a month and then once every three months. I have had open door at the Children's Hospital for a long time, and can see the cardiologist at any time.

Hannah is now eight years old, slim, has grown a lot and enjoys reasonable health. A few months ago, she started having attacks of what seemed to be cardiac failure. After scans and hospital tests they asked if she could go to the Edinburgh Hospital for tests as they thought the valve might be sticking. We asked what they could do if that was found; they said nothing. Evidently they have no better valve to replace it with; also, all the adhesions from previous surgery would make it impossible. I did not see any point in putting her through another admission. She was started on a Beta-blocker drug to combat the heart-racing which might have caused the valve to stick. This drug seemed to sedate her to the extent that she was like a sleepy lump. I reduced the dose but with no improvement. I decided I would rather care for her during the attacks than have her permanently sedated. The symptoms of her attacks were paleness, sweating, racing heart, breathlessness, blueness and heavy fluid loss. There is a very sudden onset - it has happened in the middle of a supermarket. Recovery can take anything from two to twenty-four hours. Up to now she has always recovered. I stopped taking her into hospital, I just got used to it.

Hannah can pace herself, knows when she is ill and can tell me. If she is tired, she lies down for a few minutes. She enjoys skipping, swimming, dancing, Brownies and trampolining. She seems to ignore the steady ticking of the valve which at times you can hear quite clearly from a few inches away. She does

tire on long walks, so we have a large buggy. She crawled at two years old, walked at two and a half, at four she had only a few incoherent words, but her vocabulary is now extensive and she can hold a very good conversation. She attends our local primary school. She loves writing and knows all her phonetics. She is a very out-going child, sociable but demanding of attention. I think that she is better behaved at school than at home.

Until Hannah was about six years old, every Christmas was spent nursing her, and many outings had to be cancelled because of her health. If it was damp or foggy, it was just not possible to go out. My eldest daughter (now fifteen) was disappointed so many times when things had to be cancelled.

Our life has been very difficult at times and we have had to take a lot of chances with Hannah's health to live a normal life. She gives so much to us all intentionally, but has taken such a toll unintentionally. As she gets older, we often wonder should we have let nature take its course. To lose her now is going to be even more devastating. Some people say they are better for having a child with Down's Syndrome in their lives. Yes, I think it has changed our values, but what a hell of a way to learn.

We no longer wonder every morning if she will be alive when we look into her room, we just accept that one day she might not. I really can't say that you ever accept that your child will die one day, I suppose, in the same way that we will all die one day. It's not quite the same, is it?

Hannah has so much spirit and fight in her that she completely exhausts us at times but life is difficult to imagine without her. She has certainly brought a lot of things to a lot of people; wherever she goes she gives a little of herself to somebody.

The 'Special Child', I once read in a poem. Oh yes, they are special, but you have to be strong to cope. You have to cope with frustration, heartbreak, hope and this wonderful child that just turns your heart upside down.

Advice to other parents? Just hang on in there and be sure that the decision you make is the right one for yourself and your family.

JeanLawrenson (Aberdeen)

Isabelle's story

Isabelle was born on 8th February 1986 at the Mile End Hospital, East London. There were no problems

at the birth and after six hours we were both allowed home, where we were greeted by my then husband (I have since divorced), Peter aged five and Georgina aged three. The children were delighted to meet their new sister.

The following day, our GP came to visit and check that everything was OK, which is routine practice. Upon examining her, he noticed that she had a cataract in her right eye and asked me to bring her along to the baby-clinic later in the week so he could give her a more detailed examination and arrange for her to see an eye-specialist.

At the baby-clinic Isabelle was examined and my GP explained to me that Isabelle also had a heart-murmur and he arranged for her to go to the paediatric clinic at Mile End the next day; at this stage I did not realise how serious Isabelle's heart-defect was, and was devastated the next day when, after being examined, she was admitted straight into the children's ward, given an ECG and blood-samples were taken. The consultant paediatric cardiologist came to examine Isabelle and said that he suspected that she had a heart-defect called Fallot's Tetralogy, but he didn't really explain anything to me.

The following day, Isabelle went to Guy's Hospital for an echocardiogram; it was confirmed that she had Fallot's Tetralogy, and the consultant from the hospital took time to sit and explain the defect and risks of surgery, which he felt wouldn't be needed until Isabelle was three or four years old. He also explained how Isabelle would fare without surgery.

On returning to Mile End Hospital, Isabelle went to see the eye consultant and I was told that she would need surgery to remove her cataract, but this would not be possible until she was much stronger. At this visit, there was a group of medical students and the consultant was explaining Isabelle's case to them. It was then that I heard him mention that Isabelle was being tested for Down's Syndrome; surprisingly, this did not shock me as only a couple of days before I can remember looking into Isabelle's face and thinking that she looked as if she had Down's Syndrome, but dismissing it as I felt that I would have been told. I later found out that the doctors were not certain themselves and had felt it best to wait until the results of the blood-tests, which the next day arrived and were positive.

Isabelle was allowed back home after two weeks in hospital and had to visit the cardiac unit every three months. At these visits she had chest X-rays and ECGs.

On 13th May 1987 she had her first cardiac catheterization, this went well and she was allowed home after two days. The doctors were pleased with the results and felt that surgery could be delayed for another year or two.

Because Isabelle was doing so well, she was able to go to Moorfields Eye Hospital and have her cataract operation in December 1987. The operation went well and four days later Isabelle was home again.

As the months progressed, I began to notice that Isabelle seemed to tire very easily. She would sleep through the night and then still need constant naps during the day. Her colour was also changing; her fingers and toes had always been bluish, but now her whole body seemed to have that bluish tint, she had a constant cold and her face was always red and her skin rough.

On 2nd January 1989 Isabelle went into Guy's Hospital where she had her second cardiac catheterization. This again went well, but the results were not so good; the consultants felt that Isabelle should have surgery within the next two months.

So on 15th March 1989 Isabelle was admitted into Guy's for Total Correction of Fallot's Tetralogy. The operation went very well and the results could be seen immediately - gone was all the blueness. Isabelle looked so pink and healthy.

After four days, Isabelle was out of intensive-care, and nine days after surgery she was allowed home. I couldn't believe how well she looked, even her constant runny nose had cleared up.

Isabelle had to take some medication after her surgery, but twelve weeks later that was stopped. She has had two visits to the clinic and the doctors are pleased with her and have said that she need not come again for a year.

Isabelle is so much more active now. She can climb furniture and in the last few days has taken her first steps, much to the delight of Peter and Georgina.

In January, it is hoped that Isabelle will start at the local mainstream nursery which is attached to the Junior School Peter and Georgina attend.

Dianne Frau

ATTENDANCE ALLOWANCE

Have you claimed yours yet?
How did you get on?
Were you turned down?

We are interested to know how people have got on with claiming attendance allowance, especially since its introduction for under twos, in April. Please write & tell us your experiences. Just a few lines will do, & you can send it in the same envelope as your questionnaire. To Penny Green, address on page 4

CALLING ALL ADOPTIVE & FOSTER PARENTS

In each newsletter, we include peoples own accounts of their experiences with their child. So far these have been from the natural parents, but we would love to hear from you, about your children, & the different problems that you perhaps encounter. (We will of course respect any requests for anonymity.) SO GET WRITING!



The Normal Heart

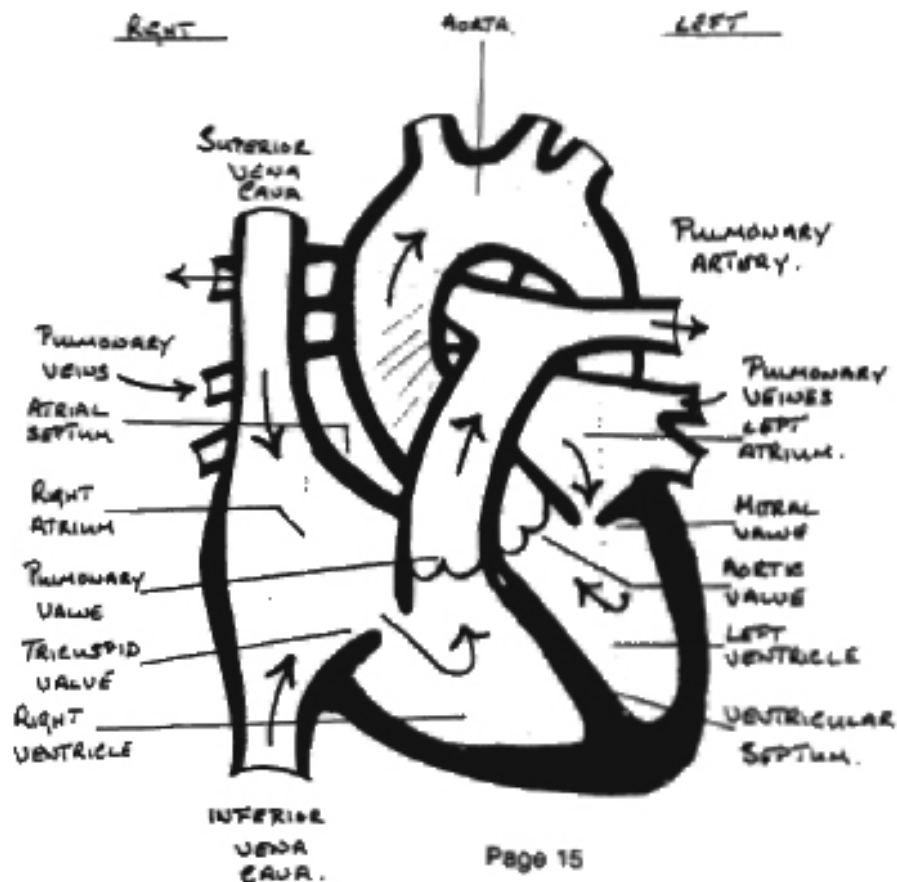
The heart is a pump with four chambers within it. Its purpose is to pump blood that has been to the body and given up its oxygen to the various organs through the lungs to pick up more oxygen, and then to pump the oxygenated blood into the body to supply the organs with oxygen and nutrition.

Blood returns from the body via the veins, and the veins join together to form two large veins, one from the top half of the body (the superior vena cava) and one from the bottom half of the body (the inferior vena cava), which run into the first chamber of the heart (the right atrium). This acts as a reservoir to fill the right ventricle, which it does through a flap-valve (the tricuspid valve). When the right ventricle contracts this flap-valve closes, the pressure in the pump chamber rises above that in the lung artery and the pulmonary valve opens. Blood is then pumped into both lungs and when the ventricle stops pumping and starts to relax, the lung (pulmonary) valve closes, which stops blood leaking back into the ventricle.

Within the lungs, the main arteries branch into very many small vessels which have thinner and thinner walls. They run very close to the end of the airway passages and at this point oxygen is taken up from the inhaled air and carbon dioxide is given off into the air passages. The blood then returns from the lungs via veins which join together and enter the receiving chamber on the left side of the heart (the left atrium). This acts as a reservoir to fill the left ventricle through another flap-valve (the mitral valve). This ventricle, when it contracts, closes the flap valve, the pressure rises, the aortic valve opens between the left ventricle and the aorta, and blood is pumped out into the aorta – the large vessel that divides into many arteries that supply the whole of the body. Following this the ventricle relaxes and the aortic valve closes. This process of contraction followed by relaxation occurs between 70 and 150 times per minute.

As the lungs are relatively small and have fewer and thinner blood vessels in comparison to those of the body, it is much easier for blood to be pumped through them. Therefore the pressures that need to be generated by the right side of the heart are much less, usually a quarter, than those required by the left side of the heart to pump blood all the way round the whole of the body. Thus, the left sided pressures are usually much higher than those on the right side. In the subsequent articles, we will discuss various heart defects, the effect they have on the circulation and how this affects their management.

Dr Philip Rees



Book reviews

Current approaches to Down's Syndrome

ed. David Lane and Brian Stratford

published by Holt, Rinehart and Wilson (1985), Price approx. £20

This book is a collection of twenty-one articles on the physical, social and educational aspects of Down's Syndrome. Each article is written by a different specialist.

Chapter 3 is *'The Heart'* and was written in 1983 by Dr K A Halliday-Smith, who was until recently the Consultant Paediatric Cardiologist at Hammersmith Hospital, London.

The chapter begins with a review of past research findings on the incidence of heart problems in our children and finds it likely that at least one in two will be born with a heart defect. It then reviews the type of defects which occur, their methods of diagnosis and their effect on the lungs. Much mention is made of the AV Canal Defect (AVSD) as this is the single most common problem in our children. The final sections deal with how parents react to the news that their child has a heart defect and the type of advice that can be given to them by their consultant.

The chapter is packed full of factual information and, as the book is aimed primarily at professionals, it is rather hard going in places. Nevertheless, most parents should find the effort involved in reading and re-reading certain sections well worthwhile.

It is one of the very few articles ever written specifically on the heart problems associated with Down's Syndrome, and is highly recommended reading.

Heart Children: a practical handbook for parents

published by HeartLine Association, Price £2.95 + 55p post & packing

At long last here is a book, written in language we can all understand, which deals with all the questions which haunt parents from the moment the possibility of a heart defect is mentioned.

The sixteen sections cover: reactions and coping with feelings; relationships; diagnosis and tests; what to tell your children; echocardiography and cardiac catheterisation; surgery; the main heart problems; everyday life with your 'heart' child; heart transplantation; bereavement; questions most often asked; benefits and welfare help; help and care organisations; reading list; glossary of medical terms; medicines and what they do.

Although it is written for *all* parents and does not cover the specific needs of those whose child's heart defect is linked with Down's Syndrome, it is nevertheless a most useful book which will really help you to understand what is happening to your child and your family.

The book is available from :

HeartLine 

Two-dimensional echo-cardiography

In our last newsletter we featured an article on Cardiac Catheterization. The following article is another in that series, written by Dr Philip Rees and published in the newsletter of the Heartline organisation.



The heart is protected from injury and prying doctors by the skin, by muscle, by the ribs and partly by the lungs. A test that enables one to see the structures of the heart and the great vessels safely, painlessly and without hazard to the patient or to the operator would clearly be of enormous help. The application of two-dimensional echo-cardiography, which fulfils the above requirements, has been an enormous advance in the management and understanding of children with heart problems over the last few years. In fact, it has had as much impact as did the arrival of cardiac catheterisation thirty-five years ago.

The test works on the sonar principle. Very high-frequency sound-waves are generated by passing a short-duration electric current through a crystal which resonates and produces a sound-wave beam. Either by having several crystals rotating, or crystals lined up and controlled electronically, one can produce a planar sound-wave rather like a fan. Jelly (often rather cold!) is used to make a good contact between the skin and the transducer which houses the crystal. As the sound-waves pass through the tissues of different density (an estimate of how solid they are) some of the waves are reflected back to the transducer and others pass onwards. The beam that is reflected (the echo) is received by the transducer and converted back into electrical energy and displayed on a television screen. This image can be recorded either by freezing the frame and taking a picture or, as the cardiac structures are moving, by recording the process onto videotape which is of more use to us. These tapes can then be of great help in assessing changes over many years.

We thus produce a picture of a slice through the heart and the vessels in the plane of the fan. By altering the angle of the transducer we can produce very many different planes and different images: by looking from different positions one is able to build up an overall three-dimensional picture of the heart from the many two-dimensional slices.

We routinely look at the heart from the following directions.

- (i) from below - just below the bottom of the breast-bone;
- (ii) from the lower left part of the chest;
- (iii) from the middle part of the chest to the left of the breast-bone;
- (iv) from above - either below both collar-bones or from the lower part of the neck.

We are very fortunate that children have thinner chest walls than adults, and that these are pliable and allow the sound-wave beams to penetrate much more easily. The quality of the image produced in children is therefore better than in adults. However, the children do tend to become rather bored and it may sometimes be necessary to give them a mild sedative.

This test is frequently done in the out-patients department and takes on average about fifteen to twenty minutes to perform. It is very good at picking up significant problems, but not as effective with the minor ones.

It is possible by using a combination of history and clinical examination, ECG and X-ray with echo-cardiography, to manage many children, even those with significant heart-disease, without further investigations such as cardiac catheterization. The treatment of others, where further tests are required, is made much easier and simpler by using the information from the echo-cardiogram.

It is still stimulating and amazing to be able to visualize structures within the moving heart, and I am sure that with improvements in the electronics of the machinery more information will become available from these images as the years go by.

