DOWN'S HEART GROUP NEWSLETTER

AUTUMN 1990

CHRISTMAS CARD COMPETITION WINNER

NEIL PORSYTHE
OF THORNBURY, BRISTOL

Please order your Christmas cards from your Regional Co-ordinator, or Penny Green.
See order form at the back of this newsletter.

STEERING COMMITTEE CONTACTS

Brian Auld

Charity registration, Legal Advisor

Sue Bamber

Treasurer

Francois Beattie

Publications

Euan Forsythe

Minutes Secretary

Denis Hopkins

Newsletter

Simon Paul

Fundraising

John King

Director

Wendy Tucker

Design

Linda Walsh

Founder

Editorial

Autumn edition already! The DHG 4th edition and **yes** yet another new editor. As with all things that are purely self sufficient like the DHG we have to rely on word of mouth to get things done. When I first had contact with Delia about editing our newsletter I honestly didn't realise what a workhorse she was. I thought that here is another parent willing to give some help and expertise to our group. Well Delia took on the editing bit without another word and did a great job on two editions. Delia has been offered a full time post, teaching handicapped children within Bedfordshire, as well as keeping home, helping in any way possible with husband Richard's business, a young son, hoping for more children and playing in a Celidha band evenings and weekends. All this without what she doesn't tell us she does. She admits she can't continue the newsletter to such an extent, so I, Denis Hopkins, have volunteered to edit this edition with the help of Delia and steering committee members. Whether I continue to edit depends on how much of a mess this edition turns out. I would like to thank Delia for all her time and effort she put in on the DHG newsletters.

I am going to try to keep Tony Linde and Delia's format for the newsletter but I hope to introduce one or two new items. To keep the newsletter going we desperately need more stories, photos, letters, useful information, lots of good humour, jokes, cartoons etc., articles such as Doctors reports and hospital jargon, and of course stories and drawings by our children.

Good news this edition sees two new areas with regional co-ordinators. We welcome Pat Mitchell from West Midlands and Mike Halpin from North West England.

Denis Hopkins, Editor

DIRECTORS REPORT

Dear Friends

I hope you all have enjoyed the exceptional summer and fond memories of your holidays last for a few more months.

The pleasant surprise of receiving a DHG newsletter so quickly following the last issue is due largely to Denis Hopkins and Simon Paul giving so much of their valuable free time. If the newsletter gives the impression of the Committee and Co-ordinators of the Downs Heart Group being a large group of organised people then prepare to have your illusions shattered. The truth is we are a few dedicated parents scattered the length of the British Isles trying hard to achieve the aims recognised nearly two years ago at the birth of the DHG.

We need more help **NOW**. **YOU CAN HELP** in some way. We require help on the committee (meetings are only once approximately every 2 months) No skills are necessary - but a secretary would be useful. A bit of spare time and a lot of enthusiasm will be welcomed. Other needs are area Family Support Contacts, fund-raisers, or just articles for the newsletter. Please get in touch if you think you can help.

An ideal opportunity to come on board is our forthcoming Inaugural General Meeting on November 3rd - Details on separate sheet. We would really like to see you on the day of our I.G.M. even if you do not feel you can commit yourself to volunteering further. It will be an interesting day with a guest speaker, a display team consisting of children with Downs Syndrome - some of whom have heart conditions! And of course the business part of the day will take approximately 45 minutes. Please read the separate form regarding the I.G.M. and return it as soon as possible.

Since the last newsletter our major happening has been a bereavement counselling weekend organised to try to give us better skills to deal with bereaved families. The weekend, organised by Denis Hopkins & family, was a great success. We had area Co-ordinators from round the country gathered at Sherrington in Bucks with guest speakers. Also the opportunity to meet each other socially was a major plus. The weekend finished with a superb barbecue at the home of Jenny & Denis Hopkins where we were able to relax and also meet and thank the sponsors of the weekend.

Please keep in touch - Do write in to the newsletter - we need to hear from **you**. - I hope to meet many of you at the I.G.M.

John King

Regional Co-ordinators

WESSEX AREA

Pauline Procter

[redacted]

KENT AND LONDON SOUTH

Peter Stephenson

[redacted]

NORTH EAST ENGLAND

Sandra Welsh

[redacted]

LONDON & NORTHERN HOME COUNTIES

Denis Hopkins

[redacted]

NORTHERN IRELAND & EIRE

Rosina Brierly

[redacted]

BRISTOL & SOUTH WEST

Sheila Forsythe (DHG Deputy Director)

[redacted]

SCOTLAND

Lynn Gauck

[redacted]

EAST MIDLANDS

Gina Hojabri & Anna Danson

[redacted]

WEST MIDLANDS

Pat Mitchell

[redacted]

NORTH WEST ENGLAND

Mike Halpin

[redacted]

These are group members who have vlounteered to take over a region to try to develop local family support. They live in their designated area and liase 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 may require that information. However, as you will see, the regions covered are very largeand we still need more regional co-ordinators, and group contacts to cover smaller areas. If you think you can help in your area please contact the National office.

For all other areas please contact:

Penny Green

[redacted]

STOP PRESS ..... STOP PRESS ..... STOP PRESS

Fund Raising Events

Well done to Bristol Region for their great effort in raising £562.00 from their cake stall at the Blaise Castle Fair. This beat their total from last year and shows what can be achieved....keep up the good work Bristol!

Congratulations.....

to Gina & Ronnie Grech from Mid Glamorgan, Wales on the birth of a baby girl, Rosie on the 2nd September 1990. Rosie weighed 8lb 1oz at birth!

DOWNS HEART GROUP
CHRISTMAS PARTY

December 15th 1990

Please contact Gina Hojabri (East Midlands Regional Co-ordinator) at [redacted]

for more details.....

Thanks to the.....

HOLY NAME ROMAN CATHOLIC
JUNIOR & INFANT SCHOOL
Cross Lane
Great Barr
Birmingham
B43 6LN

for their kind and much appreciated donation of £550.00, a magnificent sum.

and thanks also to:

Peter Hardman [redacted]

for his kind and useful donation of printed posters....Thanks once again.

Thanks also must go to the many other people who donate all sorts of gifts and cash to help the group. We greatly appreciate all donations of any type of help since without this help the group could not continue. If anyone has any ideas for fundraising please contact Simon Paul, our Fundraiser, on [redacted]

News from the Regions

Bristol and Southwest

We have had quite a number of children having surgery in Bristol Royal Infirmary recently.

JOHN HINTON from Cornwall and HANNAH COX from Marlborough, Wilts both were doing well last time I was in contact with their parents. The most recent children to have surgery are SAM SOLLARS, Bristol and APRIL YARDLEY BLACKMORE from Hereford who both had AVSD and who both were on a ventilator for just over 5 weeks each. I'm pleased report that Sam managed to get home in time to celebrate his 1st birthday, much to Steve and Melinda's relief and is doing well. April is still in hospital but progressing and hopefully will be well enough to be discharged during the next few days.

ELLA ORAM-McCANCE did so well that she was trying to get off the ventilator the evening of her surgery and did so the following morning. She is doing very well and MARILYN, her mother was finding it strange being back home after 11 days having anticipated being in Bristol Royal Infirmary for most of the school holidays. As for our terrible two - JOE McLORINAN and SAM CROOT who between them have kept staff on intensive care and baby unit in Bristol Childrens Hospital busy. Joe is now doing very well after spending his first six months in Hospital apart from a 12 day spell at home, He is now 9 months old and counting.....

At the time of going to press Sam is still in intensive care unit.

We were shocked to learn that Timothy Davidson from Bridgend who fought through a difficult beginning to life, died suddenly, aged three while on holiday in France during the summer. Our thoughts and prayers are with Patricia, Stuart and Amy at this time.

The GRECH family new baby should be arriving at the beginning of September. GINA and RONNIE lost little JESSICA after surgery in October 1989.

FUNDRAISING.....During the summer, the group spent a day at a charity carnival at Canford, Bristol. Our stall consisted of a Down's Heart Group Balloon Competition for balloon travelling the furthest distance, and Elisabeth Miller and Graeme came with their badgemaking equipment. Our thanks to both and also to Derek and Marion Hill who coped very well with the crowds of people rushing to buy balloons. The prize for the balloon travelling furthest went to:-

STEPHEN CRANSWICK OF THORNBURY

whose balloon ended up in Drieburg, Germany. We had a nice letter from the finder, with a donation to the group enclosed, both of which we were delighted to receive.

We also had a successful BARN DANCE and at the time of going to press are busy baking for our cake stall at BLAISE FAIR, Bristol on 15th September hoping to beat the figure of £459 which we raised last year.

THANKS.....A big thank you to the pupils of CASTLE SCHOOL, Thornbury who have supported Phil Thorn, who is a teacher at the school by sponsoring him on his fund-raising, and by sharing the proceeds of a non-uniform day at the school between the school fund and the Down's Heart Group.

London & Northern Home Counties

Denis has made contact with three new families thanks to being asked to attend a D.S.A. meeting at Chelmsford.

He has made further distribution of leaflets and Posters etc. to the hospitals and clinics etc. within his area.

Denis would like to thank Pauline Shayler, Mr & Mrs G Miller, David Issacs and Simon Paul for all the help and support they have given him.

Denis is now editing the newsletter with the help of Simon Paul, so any news especially from London Northern Counties, he will be glad to hear from you.

Letters

The meaning of Baptism

From early childhood my mother and father taught me that I was made by god to know Him, love Him in this life and to be happy with Him forever in the next life after death. It was something to look forward to - I would have everything I needed or could ever want, I was a member of His family, entitled to share His happiness and joy forever.

Just as I could not become a member of my own family unless I had first been born, so I could not become a member of God's family unless I was born into it; and the sure sign of this new birth is the sacrament of baptism.

Now after fifty eight years I believe even more firmly that this is the truth; having seen so much pain, suffering and injustice in this world, there is a place where we find eternal rest and happiness, and that place is with the one who made us.

This is why it is so important to make sure that our children are baptised as it is the guarantee that they are made members of God's family with the right to all that Jesus Christ promised. When we are grown up we can make our own decision as to whether or not we wish to be a part of God's family, but a child is not in a position to do so, and depends very much on it's parents to do what is right for it.

Usually baptism is administered by a minister of religion, but because of it's importance the church allows anyone in an emergency to baptise - even a child or a non-christian can do it; all that is necessary is that they intend to baptise as Jesus taught his disciples, pouring water over the childs' head at the same time saying the words "I baptise thee in the name of the Father, and of the Son, and of the Holy Spirit."

It is so simple and yet the consequences are eternal, giving the child a guarantee of happiness and peace forever. Whatever our loss or pain we have hope for the future, because baptism transcends time and this material world and unites us together in the love of God. In him we belong to each other.

Kevin Pitt - Grandfather of one our children

A Letter from Jonathon's parents.

During a stay in Hospital with our son Jonathon we made many friends of the other patients and their parents, two boys in particular outshone the others. Neither of them were Downs Syndrome but they both had congenital heart defects. One of the boys, Andrew, was 13 years old and the other was Thomas, who was 14 years old.

Andrew had spent most of his life in and out of hospital and he had come to Harefield for his major corrective surgery. He was a very brave boy and understood exactly what his operation involved. On several occasions his operation had to be postponed because of unavoidable circumstance (which very often happens) and he became very disappointed. On one occasion I asked him what he was looking forward to after his operation and he said he just wanted to be a nice pink colour like all his friends and to play football at school. Thomas had come from Northern Ireland for a heart and lung transplant. He had been waiting for a donor for quite a while. I asked him after his operation how the news about a donor becoming available reached them. He said that he had been driving in the car with his dad and family just out shopping when a car came up behind them very fast flashing its lights and his father stopped and got out of the car the district nurse ran towards him to say a donor had become available and that they had to get to Harefield Hospital as quickly as possible. I asked Thomas how his father reacted to this news and he said that daddy just cried.

Both the boys left hospital after lengthy stays, they encouraged everybody with their carefree attitudes, we only wish that Jonathon could have told us of his feelings regarding his heart operation but as he has hearing difficulties his speech is very slow developing and he cannot say many words. He had his major corrective surgery and is now very well.

Name and address supplied

Record Update

Report from Penny Green

Firstly a gigTHANK YOU to all those of you who have taken the time to complete and return the questionnaires sent with the last newsletter. The more information we have the better family support we can offer & the greater the prospects for a research project. If you are one of those who have not yet replied, it's not too late, if you've lost the original give me a call for a replacement. I know it's a bit of a chore filling in forms, but we need to have the correct information, & it is very interesting to see some of the similarities between family details that are already emerging. These may prove vital for research.

Secondly to anyone whose name address etc. was incorrect, apologies, I've been suffering from word blindness after typing details of three hundred families, but if you let me know, I'll put it right. Also to everyone who has written to me, I'm sorry I haven't been able to reply to all of your letters, but each one has been read and all useful information noted. Many thanks also for the various cheques & stamps sent with questionnaires. I would like to write and thank you all personally, however, that really defeats the object, but your gifts are greatly appreciated & like all donations, will be put to good use.

We now have 341 families on record, & most of our regions have local contacts, but we are still in our infancy, & your Regional Co-ordinators could do with all the help you can offer them. We also need to ensure that as many people as possible know about us, so that new families especially, can be put in touch when they need us. So if you meet any other families, please mention the group to them, also Doctors, Social worker etc. we will be happy to send them some information.

Finally, please keep in contact, we need to know if you are moving house & we also like to know if your child has had surgery etc. to keep records up to date, but don't forget we are also here if you have a problem. We are all Mums & Dads like you, but we will do our best to help & we have details of lots of other organisations & groups who may be able to assist if we can't. One of the main aims of the group is to offer support and information, so please let us know what you the members want, within the limits of finance & resources, we will do our best to supply it.

Teeshirts and Sweatshirts

These are now available bearing the Down's Heart Group logo.

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 please to:

Mara Young

[redacted]

Please phone to confirm size and colour before sending order, complete with an order in writing and payment. Thanks.

There is a leaflet available called "Information for Teachers about children with heart conditions" which is packed full of useful information explaining some congenital heart disorders. The leaflet is published by:
HEART CARE

[redacted]

Help Wanted

D.S. / Cerebral Palsy / Epilepsy - contact still needed with families with this or 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 four year old girl with DS who has recently been diagnosed as Leukaemic. They would welcome contact with any other family in the same or similar situation; they have problems with their daughter coping with treatment etc. In the first instance please contact Gill Denne, [redacted]

Fallots Tetrology Booklet - More accounts are needed for inclusion in this publication. Please ring [redacted]

Contact a Family - Enid Church of Contact a Family is involved on a project with adoptive and fostering handicapped children and any information will be gratefully received. Enid Church C/o Contact a Family, 16 Strutton Ground, London SW1 2HP (Tel: 071 - 222 - 2695)

Help Offered

Miscarraige Support - Penny Green is offering advice on this particular problem - please contact her if you need to talk... Tel: 0525 - 220379

NEW ADDRESS FOR THE DOWNS SYNDROME ASSOCIATION

153/155 MITCHAM ROAD
TOOTING
LONDON
SW17 9PG

TEL: 081 - 682 - 4001

PERSONAL PROFILE JOHN KING

John is married to Marilyn & has four children, Martin 20, Paul 17, Sarah 15 and Thomas 18 months. Thomas is their adopted son and has been with the family for six months.

John is in the print trade as a print salesman and commutes to London from Leicester daily! He joined the DHG when Linda Walsh first founded it. He became involved because he had a little boy with DS and a heart defect. Their little boy died in hospital after being in intensive care after a number of operations. John gets great satisfaction from supporting other families (and receiving support) within the group. He gets great joy from meeting the children and is very proud of them all. He wants outsiders to realise our children's potential as individuals.

John has little time for any hobbies but spends as much time with his family as possible. His hopes for the group in the future are that can continue to build on the terrific base provided by Linda Walsh, the group's founder, and everyone else over the past two years. He hopes that the group will have contacts for all the Paediatric Cardiology Hospitals in the British Isles, and local contacts for all regions to ensure that help is never further than a phone call away. John's immediate priorities are to raise public awareness and to get some research on the move.

Editors word John is a great guy and is very dedicated to the Down's Heart Group.

YOUR EXPERIENCES

Danielle's Story

Is she still alive? That was what I meant and what my eyes were asking as we approached the nurses in the children's ward at Guys. But all I could ask was "any news of Danielle?". "No" came the reply. Definitely no news is good news. "She should be out of the theatre in half an hour or so and we'll take you down to Russell Brock ward (Intensive care).

Our story began in July 1980 when Dani was born at the Cambridge Military Hospital in Aldershot. Within hours of her birth we were told that she was Downs although I knew within half an hour as I overheard a telephone conversation about "telling the parents" and was thus forewarned and forearmed. The doctor was not too optimistic to say the least, but one particular Sister and a representative couple from the local D.S.A. were most helpful with positive photos, literature and information.

Danielle's hole in the heart was diagnosed within a few months, she had no outward symptoms although she was in and out of hospital with chest infections for her first couple of years. At about 9 months she went into heart failure whilst ill with diarrhoea and vomiting. This was countered with Digoxin twice daily, and was followed a few hours later by our first meeting with professor Tynen from Guys. (He was a rather unlikely looking heart specialist, overweight with nicotine stained fingers but as we were to find out he is an exceptionally skilled and qualified doctor, held in the highest esteem by all those that speak about him.)

Visits to see professor Tynen followed at approximately 6 month intervals. Gradually Danielle grew out of the Digoxin dose and it was stopped. She did not however begin to exhibit the expected symptoms of the hole in her heart. It was decided that she would go into Guys for a cardiac catheter to find out why. Our first visit to Guys went very well, we were all well looked after. Marie stayed at the hospital and I stayed at my Dad's in South London, and visited during the day. Danielle had a very heavy sedative so that she was just conscious enough to turn over when asked to by the surgeons. The catheter was to measure the pressure in the different chambers of the heart, and was inserted through the artery in her thigh. I'll never forget the "thumbs up" she gave when asked "OK"? as she came out of the theatre.

The investigation showed that she had a restriction in the artery between her heart and lungs which was providing a back pressure to lessen leakage through the hole and thus prevent symptoms at that time. No problem at the moment but it would be as she grew up. More visits to professor Tynen in the hospital in Aldershot followed. It was decided that she would have an operation to remove the restriction and close the hole if required. We were told that she would need the operation to remain healthy from her teens onwards and the risks were put at about 95% for operation survival.

About this time Guys ran out of money and all children's heart operations were cancelled for a few months. Then a benefactor put up sufficient cash to keep the operations going. We continued to wait for a "call in" for the operation. Finally I phoned Guys one Thursday in April '85, " didn't you get the letter, she's due in on Sunday!" PANIC. I arranged two weeks off work. Friday evening the phone rang "sorry all the beds are full, cancel". Later in April a letter came, into Guys on Sunday, operation on Tuesday. At the time Dani was just getting over an ear infection. Yes? No? The operation was finally cancelled 5 minutes before the pre-op jab. Come back next Sunday. On the following Sunday it seemed that her ear was better so back up to London. On Monday we were shown an empty Russell Brock with just a doll on the bed. That was bad enough I soon felt awful with the thought of our own darling on the bed festooned with tubes. The sister was not surprised and rapidly produced a stool and a cup of coffee. She was a bit worried as we were working a day on - day off system between the hospital and at my Dad's with Craig (Danielle's brother) and I was on the night after the operation. How would I react when Danielle was on the bed, if I felt like that with the doll?

We didn't get the OK from the lab about the ear infection until after Danielle had been given her pre-op! We went with her down to the anaesthetic room and Marie was allowed to stay with her until she went under. The hospital advised us to go out for the next few hours, so we spent a couple of hours wandering around Oxford and Regent Streets unable to concentrate on looking at anything. Then

back to a cafe near the hospital to leave untouched, a very nice omelette lunch. After the suggested five hours, it was back for the longest lift ride ever back up Guys Tower and down the ward for that fateful question.

We were both taken down the ITU to see Danielle, she looked awfully pale, on a ventilator, with three blood stained tubes from her chest, a massive stitched wound and a tube to catch and measure her urine. The effect was nothing like the doll. She needed us and we just got on with helping to look after her. After an hour or so Marie went home to take over Craig from my Mum and Dad. What amazed me most was how grateful the staff were that I stayed up all night, for an hour or so, moistening her lips, talking to her and holding her down when she struggled to escape the tubes and ventilator. The love and care displayed by the staff of Russell Brock was absolutely fantastic as Danielle received constant attention to her needs from up to three staff at on time.

Within hours of the operation we were told that removing the restriction was totally successful and the hole was now so small as to be insignificant so it was left alone. Danielle recovered quickly. She was back in the children's ward within 30 hours, out of bed within 60 and back to school 12 days after the operation. She was on antibiotics and a diuretic for a couple of weeks. Since the operation she has had no heart troubles at all. The visits to Professor Tynen have stretched from 6 weekly to 2 years now.

Danielle is now seven and a half, her only reminder of the operation is a fading white line over her breast bone, and Teddy Bear who's brothers and sisters are given to all the children who use a certain companies heart bypass equipment. She runs around (including round the block) from seven in the morning till eight at night. The only major problem now is a hearing defect which is an ongoing problem. She has recently had her twelfth hospital visit, but takes them all in her stride, she even claps and cheers when we drive up to the Cambridge Military Hospital. *To see her now you would never think that we had to ask "is she still alive?"*

Mr Atkins

(This letter is now a couple of years old - we hope all is well with Dani - perhaps the Atkins family could give us an update on Danielle's uplifting story. ***Ed.****)*

Michael's Story

Michael is four and a half and is always on the go from getting up to going to bed he can't sit still for a moment. We may be a little different to most of the families in the DHG as we knew all about Michael's condition because we adopted him at the age of five and a half months, and were able to read all his medical notes which told us of his Ventricular Septal defect.

We took Michael to see Dr. Hunter at Freeman's Newcastle shortly after we bought him home. He was given ECG tests, X-rays and a scan which Dr. Hunter was very pleased with. He told us that he thought the hole was a little smaller than the previous visit. He went into great detail explaining to us what was happening to Michael's heart and said he thought that surgery would not be necessary. We were over the moon. He used to visit the hospital half yearly but now only goes yearly.

When Michael was very small he was pale and quite sweaty when feeding but seems to have grown out of this and has no symptoms at all. He has never been in hospital to stay.

Michael often catches cold in the winter and I often take him down to have a check up at the doctors just for the peace of mind.

Michael takes no drugs at all for his heart condition but he has been given Amoxil twice this year for an ear infection. The doctors involved with Michael are very pleased with his progress.

Michael attends a special nursery class five days a week and loves it, joining in with all the activities from P.E. to swimming (which he loves!). We are never limited by Michael's condition as he has bags of energy.

Our hopes for Michael's future are for him to be happy and to enjoy every new step he takes in life and for him to keep progressing as he is now, and for him to know we will always be behind him to give love, encouragement and support.

Margaret Storey

(I'm sure we all wish to lend our support and best wishes to Michael and his family - it's nice to hear that the family are not limited as Michael has "bags of energy"! ***Ed.****)*

Russell's Story

Russell was born on the 9th February, 1978 at Torbay Hospital, Torquay.

After we were told that Russell had Downs Syndrome he had X-rays taken and an ECG. We were told that Russell had a heart murmur which he may or may not grow out of and that I should take him to hospital for a yearly check up to monitor his condition. So from then up until 1984 he had yearly check-ups at Torbay hospital and was seen by the Consultant Paediatrician. At the check up in 1984 the Consultant said that Russell's murmur had corrected itself and he felt that Russell could be discharged from attending hospital. I told him that Russell got out of breath quite easily. The consultant said that if I was worried then perhaps I would like a biannual check-up. I said yes.

In 1986 Russell had his next check-up. We saw a different Paediatrician. I mentioned to him that Russell still got out of breath after walking short distances etc. The doctor arranged, while we were still at the hospital for Russell to have an ECG. Afterward the doctor said that it appeared that Russell had a problem with the right hand side of his heart, but as he was not a specialist in heart complaints said he would arrange for Russell to see Dr. Joffe from Bristol when he next had a clinic at Torbay.

About a month later an appointment was sent for Russell to attend Dr. Joffe's clinic at which Russell had an X-ray taken and another ECG. Dr. Joffe said that Russell did appear to have a possible hole in his heart but at this stage could not diagnose the exact problem and Dr. Joffe said he would arrange for Russell to attend Bristol Children's Hospital for an ultrasonic scan.

Up until 1986 when we saw Dr. Joffe although we knew something was probably not right we had no indication as to how serious the problem would be. Russell's only sign of difficulty was his breathlessness after walking any distance or playing energetic games with his sister he tired easily. If it was cold he turned a little blue around his mouth and on his hands but we were told that Downs children tended to suffer from bad circulation; we did not fully associate this with his breathlessness.

In July 1986 Russell went to Bristol for the scan the result of which was not good and in the October he stayed in hospital in Bristol for two days so that he could have a catheter inserted to find out the full damage to his heart. We saw Dr. Joffe after this had been done who told us that the valve between the aorta and pulmonary arteries had a hole in it. Russell's heart had adjusted to compensate for this defect, but as he grew the hole would get bigger and eventually the heart would not be able to cope with it. We were told that any corrective surgery to sew up the hole would not be effective and would probably do more harm as Russell's heart would not be able to cope with the correction. The only possible remedy would be for Russell to have a heart/lung transplant and even if this was possible it would be very unlikely that Russell would survive the operation and/or anaesthetic. Russell had shown some distress under anaesthetic for the catheter and he was only out for approximately 20 minutes so he would be unlikely to survive a heart/lung transplant operation due to the length of time he would have to be anaesthetized let alone the trauma of the operation itself.

Dr. Joffe told us that it was unlikely that Russell would live beyond his teens but it was really difficult to say how long as it depended to an extent on how fast he grew which would in turn put more strain on his heart. We were told not to stop Russell doing anything he wanted to do - if he wanted to join in games, walk, run, PE at school etc., to let him do it and not try to protect him and to keep him as warm as possible in the winter months.

It was difficult to say how we felt - very upset naturally - cross I suppose that it had not been discovered earlier when perhaps something could have been done although Dr. Joffe did say that now they had the equipment to screen Downs syndrome children at birth for this type of problem. A bit lost to know what to do for the best. Probably subconsciously we had perhaps known there had been a problem from his being breathless after exerting himself so we were expecting to learn that he had a heart problem but assumed it would be correctable.

Russell is now twelve years old. The only symptoms he has is the breathlessness and he turns a nice shade of blue occasionally if he's got cold. He has not had to go to hospital again since he went to Bristol in 1986 for the tests.

In the winter months Russell sees the family doctor quite regularly as he suffers from catarrh which builds up and can't get rid of also tends to suffer from chest infections quite a lot. In the warmer months he fairs better although occasionally picks up a viral infection.

Russell now attends Torbay hospital for a once a year check-up at Dr. Joffe's clinic. An X-ray and ECG are taken and he is examined by Dr. Joffe. We understand from Dr. Joffe that there has been no noticeable deterioration over the last 2/3 years (presumably that means there is a slight deterioration each year as time passes) and told to continue as before letting Russell do what he is capable of and keeping him warm.

He takes no drugs for his heart condition. We have been told that Russell will suffer no pain from it. When he gets breathless he, presumably, probably gets a tightness in his chest (Russell calls it earache). Probably similar to someone running fast for a length of time and then stops, gasping/panting from the exertion.

Russell attends a local school for children with special needs. He joins in everything but the teachers keep an eye on him and let him rest if he finds it too much.

He joins in the PE class at school and does what he can and they go swimming once a week. At home he tends not to do much now. Whereas at one time when his sister Katie had her friends to play and they played energetic games he would try and join in whereas now he watches. We have got some land on which we have some sheep and in the summer we go out to help when required. Russell loves going out there but some days he will trudge round at his own pace quite happily other times he just finds himself a spot to sit and watch. It's the same at home, he will have his bike out and do a couple of laps round the path around the house or finds his football and kicks it around for a bit and then comes into the house for a rest or he will spend quite long periods just at the top of the garden watching the comings and goings of the neighbours.

I think at times he gets quite frustrated. On the other hand he seems to know when he needs a rest and doesn't push himself just plonks himself down for a few minutes and then he is ready for the off again.

We sometimes feel a bit limited to where we can go on family outings but on the whole provided we go somewhere where I can take his buggy we are okay.

Russell can some days seem to walk quite a distance, other days he has quite a difficulty. We use a major buggy which we can take with us everywhere and he's in and out of it like a yo-yo. If we are just sauntering along and stopping to look at different things (e.g. at the zoo) he's okay but if we are going from A to B for a specific reason and in a specific time then I push him in his buggy otherwise it would take all day to get to our destination. It's difficult to say how far he can walk - varies from one day to another. Katie's school is only 5 minutes normal walking distance from our home and he has a job to get that far without puffing and panting and to return is even more difficult as it is all uphill.

Russell did not start walking under his own steam until he was nearly three and crawling about 18 months plus. I think he only got going then because his sister Katie (16 months younger) started walking when she was just turned one year so he decided that to keep up with her he better start walking himself. Russell cannot run in the accepted sense, I liken his running to someone who does marathon walking events.

We do not think that Russell has any idea about the seriousness of his problem. His mental age is probably about 3/4 years now. On the other hand he does seem to know what he is capable of doing and what he is not and appears to be able to cope himself with his condition.

Russell does not speak fluently. Very stubborn. Very good at shutting himself off. We are convinced though that he understands most of what you ask him to do or would like him to do and can do most things if he puts his mind to it. He either says "I can do it myself" or "I can't do it" (when you know he can) depending on how co-operative he's feeling. According to Russell he does nothing whatsoever at school. You ask him what he's done on a particular day and he says "nothing". Or you perhaps know he's been on an outing and you ask did he see that, did he go there, etc. and he says "no". His classic is when he comes home from school on swimming days with damp towel and trunks and you ask if he's been swimming and he says "no"!! His speech is limited to either one word or very short phrases. So although being 12 years old and under normal circumstances old enough to be able to speak about his heart problem and to ask about it with his mental age he has no conception of the seriousness of his heart problem.

We just take each day as it comes. If Russell's feeling energetic he's energetic and if he doesn't, well, we don't push him and just keep an eye on him in case perhaps he's going down with some infection or may be just one of his off days.

We have to be a bit psychic too as sometimes he tries it on now and then saying he's got "earache" when

you know he's being lazy and trying to get you to carry him if it's down steps or such like where it would be impossible to use the buggy - on the other hand you have to size up the situation in case he is genuinely in need of assistance.

Jenny, David and Katie Diamond

Aaron's Story

Aaron was born on the 8th November 1982 at the West London Hospital in Hammersmith, London. He was not obviously a Downs Syndrome child to us, but the Hospital staff suspected. On the fifth day, we were told of the extra chromosome and possible heart murmur by the Consultant Paediatrician of Charing Cross Hospital. Downs Syndrome was confirmed the following week and we met the consultant again who was helpful, honest and supportive. He referred us to the Brompton Hospital for cardiology check.

This took place at seven weeks and I was devastated by the description - AV Canal defect plus pulmonary stenosis. The heart problems troubled me much more than Downs Syndrome because I feared he would die. No prognosis was offered. Risk of brain damage was never suggested and no surgery was offered.

Aaron attended regular clinics and his condition was described as asymptomatic. The pulmonary stenosis, which narrows the artery to the lungs, compensated for the AV Canal defect, so that additional blood was not being circulated through the lungs. We were always advised to look out for blueness or breathlessness but were never quite clear about what that meant. When he visited the clinic after his second birthday, he was doing well developmentally. He was nearly walking, feeding himself, beginning to use a potty, saying a few words and signing up to about 18 words in Makaton. Still there were no apparent symptoms of blueness or breathlessness. The cardiologist was pleased and advised us to come back in one year.

Three months later Aaron was irritable and looked a bit off colour. My instincts told me this was related to his heart but I wasn't sure what a blue spell was. The irritability was brief on the first day, but lasted longer the following day. When my GP came on the second day, she diagnosed an ear infection but said Aaron was not cyanosed (blue). Aaron continued to be irritable, but I assumed it was related to the ear infection. He didn't sleep much that night and was more irritable the next day. I was still assuming this was related to the ear infection but by late evening the third night, I noticed the pupils of his eyes were fully dilated and we telephoned the emergency doctor. Aaron was said to be unconscious and was rushed to Charing Cross Hospital. Endless tests were done during the night and when the Consultant saw him the next day, he told us that there were a few possible diagnoses, all of which were untreatable. He didn't think Aaron would survive the weekend. He then discussed these four conditions fully with us. Although Charing Cross had all of Aaron's medical records from birth including information about his heart defects from Brompton hospital, none of the possible diagnoses were related to Aaron's heart.

My husband and I are firm believers in God and we have interest and confidence in alternative medicine. When the Consultant told us that Aaron's condition was untreatable, I found that hopeful because I felt sure there were other avenues available. The Consultant, though sceptical, was open-minded enough to allow us to give homeopathic medicines to Aaron alongside the medical treatment.

In all honesty, I cannot say what worked, but Aaron began to improve. I feel we were allowed the best of all possibilities and I am grateful for that. He survived the weekend and eventually regained consciousness. At that point, although alive, he was in a terrible state and it gradually became clear that he had suffered brain damage which affected his muscle tone causing spasticity of all limbs. At this point, the diagnoses from Charing Cross Hospital's point of view was benign encephalitis. Aaron would recover but perhaps more slowly than normal because of the Downs Syndrome.

After two and a half weeks on the ward, Aaron was still in a dreadful state but at least most of the monitors and drips were off. Then one morning the original symptoms reappeared. My heart sank as I called the sister in, who then called the doctor, who the called the Registrar. The drips were back, the monitors and the oxygen. They talked about priests and rabbis! I hit rock bottom! I could not imagine what the future might hold. My husband, who was working away from London during this ordeal, was called home for the second time.

Charing Cross tried to find out how far they had to go to keep Aaron alive. They wanted a decision from

us about the use of life support machines. They kept referring to our "now doubly-handicapped child". Aaron seemed untouched by it. He stared quite attentively at the Registrar as if to say, "If you're talking about me, you've got the wrong child!". That gave me a thread of hope.

At this stage, Charing Cross finally realised that this whole crisis was related to Aaron's heart. I am sure that, from the start, I always mentioned "blueness" to each of the doctors I spoke to, but somehow their tests gave other indications which sent them off course.

The Consultant from the Brompton Hospital was then called in to examine Aaron. He explained quite simply what had happened and what needed to be done. The narrow artery from the heart to the lungs, the pulmonary stenosis, had gone into spasm and periodically cut off the blood supply to the lungs. The blood was not getting oxygen; and oxygen, therefore was not getting to the brain. A brain inflammation developed which caused the brain damage. They could perform a bypass operation (Blaylock Shunt) to ensure there would always be a supply of blood to the lungs. The operation was external heart surgery and carried a 3% risk. They would be prepared to do it on an emergency basis at the weekend, but would prefer to wait until the staffing was optimum.

I had always dreaded having to decide about surgery for Aaron, but when the time came, there was no decision to make. It was his only hope! We agreed, and Aaron was booked in for the following week. During the next 48 hours, Aaron had several further cyanotic episodes (blue spells). We learned how to deal with them immediately by getting oxygen to him at the first sign. Aaron was therefore transferred to The Brompton Hospital on Saturday, and the bypass operation was carried out on Sunday.

We were shown the Intensive Care Unit (PICU) before Aaron was there to prepare us for what to expect. It is overwhelming, but I was grateful for the advance visit. Aaron's recovery from surgery was rapid and without complication, and he was out of the PICU in under 48 hours. He was discharged back to Charing Cross on the Wednesday after his operation. The doctors were amazed!

Feeding was the next hurdle. Aaron was being tube fed and the challenge to get him to take sufficient solids and liquids by mouth, so that the tube could be removed. As Aaron's muscle tone was now spastic, this was incredibly difficult. However, after about 10 days, the tube was removed and we were then discharged home on Easter Sunday.

Aaron is now 6 years old. He is generally healthy and does not get many colds. He follows a vegan diet which helps reduce the catarrhal problems Downs children suffer from. Our GP has arranged for us to keep oxygen in the home in the event of further blue spells. To date we have not had to make use of it.

He attends a special school full time and enjoys it. The spasticity still restricts him completely, although he is very, very, very gradually getting some hand function back and some balance. He can sit up quite well independently, he can roll and uses a potty. He can say several words clearly and uses several Makaton signs. He is very alert, cheerful and happy. We love him very much and despite the developmental setback, I am thankful he lived through it.

Along with the usual paediatric and cardiology clinics, Aaron is seen quite regularly by a homeopathic doctor and a cranial osteopath. The bypass is a temporary solution and has a time limit of about 3-4 years. We now have to consider when it might be appropriate to do a second bypass. Only two can be done and no other corrective surgery is offered. We have been told that total repair of the AV Canal defect carries too high a risk and the hospital will not do it.

Mrs Silver

We hope you enjoy reading other members experiences, if you do, perhaps you would like to share your story with the other members of the DHG in the same way. Please write to:

Denis Hopkins (the Editor)

Bereavement

Reproduced from the Wolverhampton Adnews newspaper a very moving and thought provocing article written by DHG member Lyn Stallwood about the sad loss of her daughter Kate, and coping with peoples attitudes after the loss of a child.

Every year thousands of babies and children die. It goes against the natural order and it should not happen but it does. To lose a child is the most terrifying, upsetting and devastating loss. You expect to have your children for the rest of your life, not theirs. When a child dies a part of the parent dies alongside.

In November 1989 I gave birth to a beautiful baby girl who we named Kate. Three and a half weeks later Kate died. It was two days before Christmas.

From the moment she was planned, I had such dreams and hopes. Now they are shattered, as is my family. Our lives will truly never be the same again. I have experienced, first hand, just how badly society treats bereaved parents and I write this article in the hope that other bereaved parents may be spared much of the unnecessary hurt unconsciously inflicted by family and friends. People do not mean to be unkind, but insensitive questions and platitudes add hurt to an already intolerable level of pain.

So how can we begin to help bereaved families? The following is based purely on my own experience and I apologise to any bereaved parent whom I offend. However, after talking to other bereaved parents, it is clear that my experience of other peoples reactions to my loss and grief have been mirrored so many times.

Do not say: "You will get over it" and "Time will heal!"

People do not understand how long and deeply parents grieve for a child who has died. You do not "feel better" after the funeral, as I was so often told. You do not feel better the following weeks or months. Indeed the grief becomes worse as time goes by. It is often after the funeral that parents feel worse; the child is no longer there to be seen touched and held. Time does not heal; hopefully it simply makes the loss easier to bear.

"Pull yourself together". Our grief is not an emotion we choose to experience. No-one could or would choose to feel such an intense and overwhelming pain. It cannot and should not always be controlled.

"At least you have another child" and "You can always have another one." I have a little boy, Ben, who is two and a half years old, and he has been, and still is, my lifeline. Yes I am thankful that I have Ben, and he is very, very precious to me. Nevertheless the pain I felt for not having my daughter with me is still great, and to infer that Kate is missed less because of Ben is insensitive and inappropriate. Not only have we lost a much-loved daughter, but Ben has lost a sister. The question of "having another one": somehow it is assumed that once the dead child is "replaced" all will be well again. The child can never be replaced. However many children bereaved parents may have in the future, they will always remember and love the child who has died.

I find the question "will you have another one?" or "will you try again?" very upsetting and it also angers me. I was first asked this question less than a week after Kate had died. Very few people have failed to ask this question. We need time to mourn our children, and it hurts we bereaved "mums" dreadfully to be asked this.

"It's a blessing" and "it's a relief". Maybe some bereaved parents feel or know this to be so. It is up to the parents to know and comment; please do not try to find something "good" about the death in this way.

"I know how you feel". Have you lost a child? If you haven't, then you don't know, so please do not ever say it. I have experienced the loss of my father and other relatives, and know only too well that the grief experienced when a child dies is nothing like the grief you experience when someone else close to you dies.

For those of you still reading this, thank you for bearing with me. I have encountered all of the above, and expect I will meet others before too long. They are not said to hurt, but hurt they do. I suspect they are said because people do not know what else to say. Death is still a taboo subject and the death of a child doubly so.

Having listed the "don't", here are a number of positive things we can do to help the bereaved families.

Make contact: If you aren't sure whether the family will want phone calls or visits, then write. If you don't know what to say then be honest and say you don't know what to say. A letter expressing sympathy can mean so much to parents who are feeling very isolated and that no-one else cares because no-one has been in touch.

Keep open the channels of communication: if, having offered the usual "if there is anything I can do...", don't leave it at that. Bereaved parents often find it difficult or even impossible to phone someone even though they may desperately want to talk to someone. So follow it through, and phone, visit or write at regular intervals.

Be available: Many bereaved parents felt an overwhelming need to talk about their child and the child's death. It takes courage to listen, but we need an ear. If it upsets you you listen, then remember how much more upset we are feeling. We need other people to allow our grief to be worked through. Give us the opportunity to talk.

Acknowledge what has happened: If our grief is not acknowledged, then you are denying our feelings. To not mention what has happened gives no validity to our feelings. Do not be afraid to mention the child's name for fear of "reminding" us; be assured we have not forgotten. Do not be afraid to show your own emotions and cry - it often helps us to know someone cares.

Look beyond the smile and the brave face: When you see bereaved parents "carrying on as normal" stop and think a little about what their "normality" now is. It is always carrying some degree of hurt and sadness, so often forcibly hidden to spare others embarrassment and to spare themselves the further hurt should an approach or overture be rejected.

Be sensitive to the needs of the other children in the family: Children grieve too and this is manifested in many different ways. My own little boy is grieving deeply, and more than ever needs to feel loved and secure. Pay extra attention to the other children and be ready to care for them sometimes; the children perhaps need/want to be away from such a sad and unhappy environment at times (Julie where would we have been without you?), and the parents need a little time and space to grieve.

I leave my next point to the end because in some ways it is the most important, and some ways the least. My precious baby Kate was born handicapped, and I think it is partly this fact that has led to our loss being felt by others to be somehow easier. I think people assume that parents do not grieve for so long if the child is not "perfect". I do not, and pray that I never will, know what it is like to lose a "normal" child; I know only that to lose a handicapped child is devastating, and that the love I have for Kate will always be hers. So please, do not make the assumption that parents of handicapped children will grieve less. Nor, as I believe I may have encountered, assume that if the child is very young then the parents mourn less time - "Well you didn't have her for very long so...".

And Finally, don't simply be available for what you consider to be a "respectable" time after the child has died. Grief is no respecter of time, why should you be?

Thank you for reading this.

Lyn Stallwood

A Poem

Behind Closed Doors

Not many know, only a few can see,
the despair, the tears and the torment we feel.
Our lives have altered since losing our son.
We're left with deep scars and no where to run.
As time goes on, it is a fact,
we've learned how to smile and how to act.
Not all can be expected to share,
the pain and sadness we have to bear.
You're aware of those who can take your grief,
we're grateful to them, we get some relief.
We can talk with emotion, of the boy we have lost,
not holding back the tears, that would have to be at our cost.
Unfortunately with some, the mask must go on,
so we say we're fine, we're getting along.
They have not got time and don't want to know.
Their lives are so busy there's no open door.
We thank those dear friends, who gave us their time,
to us the bereaved, it is a life line.

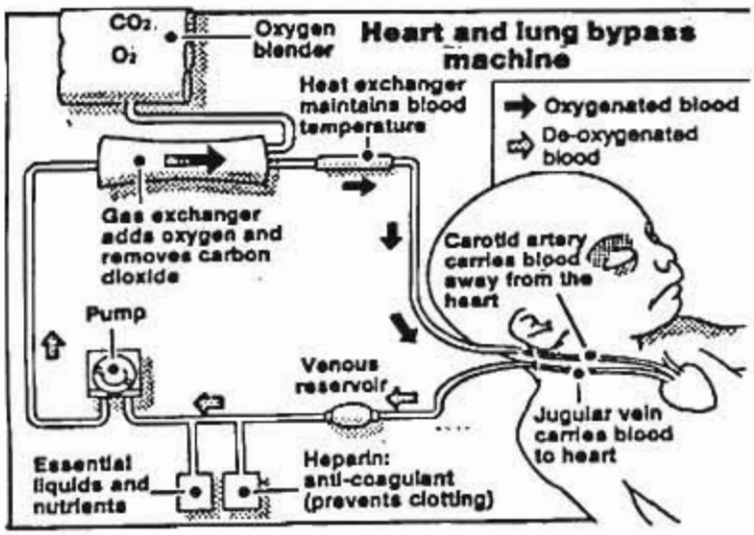
Mildred Flett

(Mildred and Ken lost their son Neil to Leukaemia at the age of 17.)

Small Miracles

A research project which has been launched in Leicester hospital offers new hope of saving babies suffering severe respiratory failure, the leading cause of death among newborns. The project involves a modified version of the heart lung bypass machine, a device which has already proven it's worth in thousands of transplants and open heart operations.

The modified equipment has helped to save the life of a baby girl, aged two days, who was born suffering from severe breathing problems. She had inhaled meconium, a sticky black substance discharged from her bowels, at around the time of her birth. The child had stopped breathing when she was admitted to the Groby Road Hospital, Leicester, in March of this year, and would have been declared brain dead within five minutes. She was transferred from a maternity unit in Peterborough to the hospital because it is developing the use of extracorporeal membrane oxygenation (ECMO) for such cases.

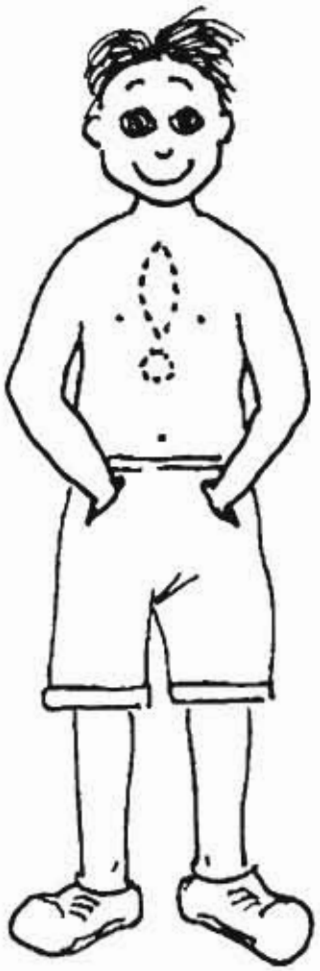


In this procedure, tubes connected to a heart-lung machine are placed in the carotid artery and jugular vein in the neck, through a small incision. The ECMO circuit withdraws blood from the vein and adds the anticoagulant heparin to prevent clotting, plus essential liquids and nutrients for the baby. The blood is pumped to a gas exchanger, which removes carbon dioxide and adds oxygen. The blood temperature is maintained at it's correct level by a heat exchanger, and the oxygenated blood is reintroduced into the carotid artery. The function of the failing heart and lungs is thereby supported. The baby was kept on the device for three days to allow her heart and lungs to develop. She is now breathing without assistance and has been allowed home.

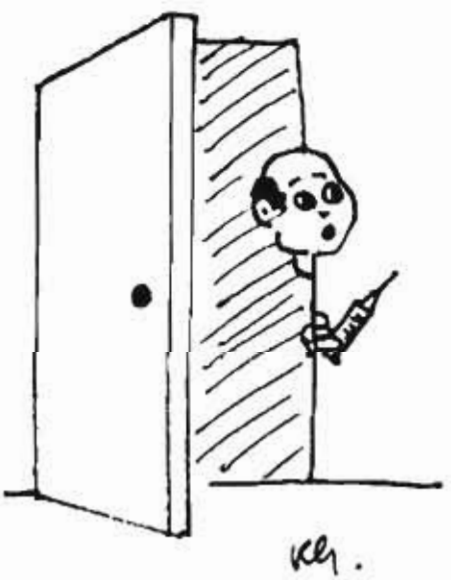
The technique is widely used in the emergency treatment of infants in the United States. More than 3000 babies have undergone the procedure, with a survival rate of more than 80%. It is now being introduced experimentally in Britain to evaluate it's potential. Dr. Andrew Fosnowski, a clinic research fellow at the hospital, who performed the operation said: "Despite significant advances in the care of infants with severe breathing problems, respiratory failure remains the most frequent cause of death among neonates (newborn babies). The Ecmo system has been proven to be beneficial in providing temporary life support for a patient with severe heart-lung failure, which cannot be treated by conventional therapy. We can consider them as candidates for this technique only if they have an estimated mortality risk of 80% or more, despite maximal ventilatory and medical support." The project, costing more than £100,000, is being funded by the Heart Link Children's Charity.

Mr Steve Bonser, senior chief perfusionist at the hospital, and research associate in charge of ECMO studies at Leicester University, said "In order to help more babies with respiratory failure, we need early consultation from the paediatric units concerned, to allow us to act quickly to reduce the chances of further lung damage."

One development considered by British and American researchers is a further modification in which the equipment could be connected to the umbilical vein of very premature babies, who cannot get adequate oxygen into their blood.



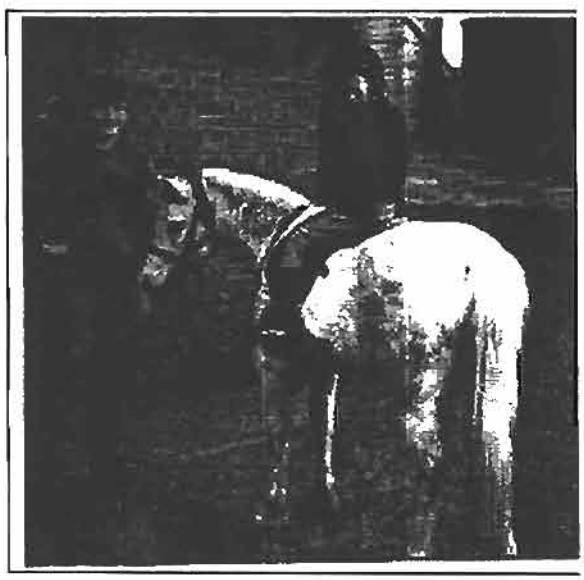
Embroidery
Courtesy of the
NHS



Cartoons Supplied by Lyn Gooch

Rogues Gallery

Members of the Bristol Fundraising Team



Nicola Beatty who was last years Christmas card designer

Andrew & Sheila Forsythe advertising the Downs Heart Group T-shirts & Sweatshirts