DOWN'S HEART GROUP NEWSLETTER

Issue No 22

SPRING 2000

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Rebecca's prestigious Baden-Powell Award

Philip's Special Achievement Award

AGM details

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Chair's Report

Brompton Inquiry

In the last Newsletter we wrote about the background to the Brompton Inquiry, set up to investigate claims by a "whistle blowe about alleged deficiencies in the paediatric cardiac services at the Royal Brompton Hospital, and the action that DHG had take to present evidence to it. We now bring the story up to date.

We, together with Penny and twelve members, had our day at the Brompton Inquiry on 8 March.

We had made three written submissions to the Inquiry prior to our meeting them. The first of these, as long ago as August 1999, was based on the results of a questionnaire we sent to over 100 members who had had contact with the Brompton over the years. The concerns expressed by DHG members were collated under six headings: second opinions; discrimination; emphasis on risk; delays in surgery; relationships; and follow up and after care. This went to the first stage of the Inquiry, which produced a report (the Hunter Report) in September, largely dealing with surgical outcomes and the staffing of PICU, which did not relate to most of our concerns. This report recommended a second stage to consider the concerns of individuals families and DHG and DSA.

DHG's second report commented on statistics produced by the Hunter Report, particularly in relation to the number of children with Down's Syndrome who had not had an operation at the Brompton, compared with other centres.

The third report was based on the personal experiences of our witnesses, all of whom we had individually interviewed and each had produced for the Inquiry. This report confirmed and amplified the concerns in our original report.

All of our members were magnificent in their testimony. We are very grateful to them all for being prepared to relive sometimes harrowing experiences, which must have been difficult and disturbing. Overall we believe that a powerful case was made to back up our concerns.

We are also grateful to the Inquiry Panel which, while being properly probing of our evidence, gave us a courteous, objective and sympathetic hearing. The members of the Panel are: Ruth Evans, former Director of hr National Consumer Council, Dr Nick Archer Consultant in Paediatric Cardiology, John Radcliffe Hospital, Norma Brier, Chief Executive Norwood Ravenswood, Dr Fleur Fisher, former Head of Ethics, BMA, Dr Barry Keeton, Consultant in Paediatric Cardiology, Southampton General Hospital, Sarah Leigh, Solicitor specialising in medical negligence.

We are due to give the Inquiry a further report on our views on best practice for the future, which should be with them by the time this Newsletter is published.

We have decided not to release any of our reports or statements until the Inquiry has reported, when we will look at this again. This is expected in July and we await their findings with great interest.

Transfer of Surgical Services

We report in this issue plans to transfer paediatric cardiac surgery services from three units to larger neighbours. This is part of a trend to concentrate surgery where there is sufficient "critical mass" of cases to provide work for at least two surgeons and the range of heart conditions to ensure that experience is gained and techniques kept up to date across the range. This should provide better outcomes and more effective peer review and are thus to be welcomed, and that has largely been the case where we have consulted parents. However there is a downside for families. They have further distances to travel, which is time consuming and expensive, is stressful in not being able to get home as often to see spouses and other children and more difficult for them, and other relatives, to visit. It is essential that these issues are tackled and resolved as part of the process of change and not as subsequent after thoughts. John made these points strongly at the Scottish meeting and he was impressed at the way Scotland was tackling these problems. We hope that the same care and attention will be demonstrated in the Welsh and English changes.

10th Anniversary Conference

2000 will see the tenth Annual Conference we have held (though we have been around for more than ten years!). This will be in Leeds and we are planning to make a weekend of it, with the conference proper on the Saturday and a visit and party on the Sunday. There will be a limited amount of overnight accommodation available at very little cost, for those travelling long distances but we also hope to see as many as possible of our northern members on both days. Make a note in your diary now. More details will be individually mailed to you shortly.

Pictured on the front cover with her Baden-Powell Award, is 16 year old Rebecca Andrews from Ipswich. Read more about her on page 15

Katie and John
Joint Chairs

Changes in Paediatric Cardiac Services in Scotland

In December last year, John Spall attended a meeting regarding the proposed national paediatric cardiac surgery service in Scotland. He was one of a number or patient group representatives asked to give their organisations views following the announcement of the decision to centralise the services currently in Edinburgh and Glasgow, at the Royal Hospital for Sick Children in Glasgow (Yorkhill). No start date for implementation was set, but the outline proposal for the new service was discussed in detail.

The major changes relate to surgery, so there is no proposal to make changes in other cardiology services, and out clinics will still be available for the majority of patient appointments. The exception being interventional cardiology i.e. cardiac catheterisation, where it is now generally accepted that this should only be undertaken on sites where paediatric cardiac surgery is available. Hence, catheters will have to take place at Yorkhill, and special provision will be made for cardiologists from Edinburgh who wish to treat their patients in the hospital where there is access to the Cath Labs and surgical back-up.

The question of pre-surgical clinics was discussed, the consensus of opinion being that these should take place at Yorkhill as it gave those not familiar with the hospital the opportunity to meet with the professionals who would be treating their child. In light of this, the question of funding for parents travel was raised, and this will be looked into. The problem of accommodation also arose, and it was confirmed that eight out of the twenty four ward spaces have a bed for a parent, and there is an expectation that more accommodation will shortly become available in the Ronald McDonald house.

There are no planned changes to the current pattern post-operatively, except where a child requires tertiary cardiac care for a longer period and this could be provided more locally by transfer to Edinburgh. Follow up will continue to be managed by the cardiologists at the satellite outreach clinics, and wherever possible care will be as close to home as possible.

The plan includes three surgeons based at Yorkhill, which will allow for less onerous rotas in the Scottish service. All three will also be involved in adult surgery. Other staffing in the paediatric cardiac unit will be increased on a pro-rata basis .

With respect to 'Grown Up Congenital Heart' patients, it was agreed that although these services fall outside the remit of the Implementation Group, there was urgent need for discussion regarding the impact the changes in Paediatrics would have on them. The topic of heart transplantation was also raised. Few paediatric transplants are needed annually in Scotland, and currently they are commissioned from two hospitals in England - Great Ormond Street in London and Freeman in Newcastle. It is not envisaged that this will change in the foreseeable future.

John was able to obtain an undertaking that there would be no change of policy about enabling parents to obtain a second opinion, even though this would of necessity be in England.

Annual Conference 2000

22nd & 23rd July in Leeds

This year the Down's Heart Group AGM and Annual Conference will take place on Saturday 22nd July at the Leeds Metropolitan University.

As this is both the Millennium Conference and the 10th Anniversary of the Down's Heart group, we will be offering overnight accommodation on Saturday within the University, and on Sunday morning we will be visiting a nearby attraction and finishing with a picnic lunch and games in the park (weather permitting).

Full details and registration forms will be sent out to all members in mid May, but make a note in your diary now for what promises to be an enjoyable and informative weekend for parents, and great fun for the kids. Places will be limited and on a first come first served basis.

The conference is also open to professionals and nonmembers - please contact National Office to be sent registration details and costs.

Paediatric Cardiology in South Wales

The paediatric cardiology unit in Cardiff has been without a surgeon for over eighteen months. The appointment of a replacement has been in doubt since the Royal College of Surgeons refused to endorse the appointment of a single surgeon, and the workload doesn't warrant two.

The current proposal is the retention of cardiology services with the addition of a third cardiologist, and agreement for surgery to be carried out in most cases at Bristol, but with provision for certain conditions to be operated on in Birmingham. The outcome is awaited.

Royal Brompton and Harefield

Following on from the merger between the Royal Brompton and Harefield Hospitals, the Kensington and Chelsea and Westminster Health Authority issued a Public Consultation Document in September last year, looking at the options for the future of the services currently provided on the Harefield Site.

These included transferring inpatient services from Harefield to a) The Brompton, b) another hospital local to either Harefield or the Brompton, or c) to another specialist service in London.

The outcome has not been announced yet.

Daniella's Story

Daniella was born on 2nd October 1991 weighing 5 lb. 8 oz., - she was five weeks early. She was blue, but a little oxygen soon sorted that out and everything seemed to be fine. We were both delighted, and being our first child thought she was perfect. Steve went off to work, and I went for breakfast, but a nurse fetched me and said," your baby's looking dusky, she might just be cold, but we've sent for the doctor". When she arrived and had a look at Daniella, she remarked that her eyes were a bit slanty, although lots of babies had slanty eyes, but she was definitely dusky, so they would take her to the Special Care Baby Unit. She said there was nothing to worry about and to get some rest.

I was woken by a nurse to speak with my husband on the phone. They had told him not to worry, but of course he did, and he came to the hospital as soon as he could, and we went down to SCBU to see Daniella. We were very shocked - she was in an incubator being given oxygen and light therapy as she was jaundiced, and she was linked up to machines that kept alarming. One of the doctors said that they thought that she might have Down's Syndrome, but that they would have to do tests to confirm it, and they still weren't sure why she needed the oxygen. The next day a consultant came to see us. and said that there was something wrong with her heart, but to find out for certain we would be going to the Royal Brompton.

When Daniella was two days old we made the journey to the Royal Brompton in Chelsea, taking with us oxygen, monitors and a glucose drip, as she had stopped tolerating milk. She was given an ECHO and the consultant Dr Shinebourne explained to us that she had a very large VSD (hole) and also a PDA (an open duct at the top of the heart which should have closed at birth), this meant that there was too much blood flowing through the lungs, which was why she was having such problems. He did say that her problem could be corrected, which was a great relief to us.

Daniella stayed in SCBU and was put on Frusemide, Spironolactone and Digoxin and gradually improved. At her next ECHO there was no change so they didn't want to see her for another six weeks. Although she was improving and being weaned off the oxygen she still wouldn't take a bottle so was being fed by nasal gastric tube. She was in SCBU for nearly seven weeks before she was well enough to come home, and although we'd overcome the feeding problem by using a special Haberman teat and a cup spoon, it still took up to one and a half hours for each feed.

Our next appointment with Dr Shinebourne was just before Christmas 1991. He told us nothing had changed, but that he was worried about her lungs, - this was the first we had heard about Pulmonary Hypertension although it had been present from very early on. He explained that she needed an operation to close both the hole and the duct to give her the chance of a normal life, but that there was a 20% chance that she wouldn't survive the operation. He also explained that without the operation her life expectancy would be cut by half and her quality of life would be poor. We were told to think about it over Christmas and to return at the beginning of January. We talked it over and found that there wasn't really a decision to make as we both felt that we had to give her the chance.

We returned to the Brompton in January and informed them of our decision, they put her on the urgent list, as both her feeding and breathing had got a lot worse. We went home thinking we would have about a two month wait, but the following week we received a phone call from the surgeon's secretary asking us to take Daniella in the next Wednesday for her operation on the Thursday. We made the journey to the Royal Brompton expecting to be there for about two weeks, and Steve managed to get a weeks holiday. It was a busy day with bloodtests, ECG, X-ray and ECHO, we also met one of the surgeons who explained what would happen and that she was first on the list at 8.00 am the next day, January 23rd.

Steve carried Daniella and took her into the operating room, then we left the hospital for a few hours, as suggested, and just wandered around, then sat waiting for a pub to open for a drink to calm us down. We plucked up the courage to go back to the ward about 1.30pm, then sat there dreading what they were going to say. It was a relief to hear that everything had gone alright and she had just arrived on PICU. We were told that the operation had gone well, but that she was having problems with her blood pressure, she also had to have a pacemaker attached as her heart kept going into the wrong rhythm.

The next few days were very difficult for us, sitting at the side of her cot unable to do anything. We had expected she would be in PICU for about four days, but after a week we were still there as she had a chest infection and her scar was leaking and bled when she moved. Steve couldn't take any more time off work, so he was commuting from Chelsea to Croydon. There was one set back after another, and it got to the stage where we just took each day as it came. She had a lot of problems with fluid around the lungs and it wasn't until they drained it away that we began to see some improvement in her and eventually she was taken off the ventilator. We had spent three weeks in PICU - it felt like three months.

We spent another week at the Brompton before Daniella could be sent to our local hospital at Croydon. She still needed oxygen and her diuretics and another drug called Captopril, for a small hole that remained. We spent another six weeks in hospital while she was gradually weaned off the oxygen. She still wouldn't feed properly and continued to be fed by nasal gastric tube, she also developed an intolerance to the milk and had to be given soya milk. Before we could take her home, both Steve and I had to learn how to pass the tube in to her stomach and check that it was in the right place, also how to use an oxygen cylinder if she went blue.

Maybe naively, we thought that once we got her home there would be no more hospitals except for check-ups, unfortunately this wasn't so. Within three weeks she was back in with a reflux, and a fortnight later still with a reflux and also heart failure. She was now back on diuretics that a couple of weeks earlier had stopped, and her oxygen saturations were dropping when asleep, sometimes dramatically.

In June 1994 Steve was made redundant and we decided to move up to Doncaster. The week before we were due to go, Daniella went into hospital over night to give us a chance to go out. While she was there they checked her saturation as she was looking a bit blue and found that it was very low. We couldn't take her home as her condition didn't really improve, although she was fine when she was awake, she required oxygen when she was asleep. It made it very difficult as we were due to move house, so in the end we had to go from Mayday Hospital to Doncaster Royal Infirmary the same day.

It was strange dealing with a new hospital who didn't know Daniella very well, but they were very good in listening to what Steve and I had to say. We got home oxygen sorted out to give her while she was asleep, and this allowed us to take her home, but we had to take her into hospital once a fortnight to have her oxygen checked. By the end of August things hadn't altered and we decided that we needed to know why things weren't changing and why she was needing more diuretics and was still looking swollen in the face and was getting breathless. Daniella's consultant Dr Keen decided to keep her in longer this time and arranged for her to go to Killingbeck Hospital in Leeds to see a cardiologist there and to have an ECHO.

I went to Killingbeck on my own with Daniella and saw Dr Dickinson who did all the usual tests. During the day, Daniella wasn't very well, and they were having problems giving her enough oxygen as her saturation was very low. Dr Dickinson came to see me and said that although the operation to close the hole had been a success she still had Pulmonary Hypertension and that there was nothing that they could do - this only happened in 1 in 100 cases. I was very shocked and Steve managed to make his way to Leeds to stay with us until we were sent back to Doncaster. We didn't sleep much that night trying to convince ourselves that even though there was nothing they could do, she could still live for years yet.

The next morning Dr Dickinson came to see us and Steve asked him what sort of life expectancy Daniella had. What he said stunned us both - in his opinion it was months and not years. We just sat there not saying anything for ages - it just didn't seem fair that after everything that we had gone through since Daniella had been born, we were still going to lose her. When we got back to Doncaster we decided that we wanted a second opinion and asked if an appointment could be made for us with Dr Shinebourne at the Brompton. They agreed and an appointment was made for the following week.

By the time we went down to the Brompton by ambulance Daniella was a lot better. Dr Shinebourne read all the reports and said that in his opinion she could live for another fifteen years, and that he would see her in a years time and expected to be saying the same thing then. It was such a relief to hear, and it made the journey back to Doncaster a lot more relaxed.

Daniella's breathing improved, but she developed a form of gastroenteritis which resulted in her losing 2 lb in weight over night - for someone only weighing 14 lb to start with it was drastic. Daniella was so dehydrated that she decided for the first time to drink a full bottle. This only lasted three or four days, but it proved that she could drink if she really wanted to. We were eventually allowed home the day before her first birthday - we had spent in total six months of Daniella's first year in hospital. Daniella seemed to be reasonably stable even though she still had to have oxygen when she was asleep and was taking a lot of diuretics, but even with all her problems she was doing really well, starting to communicate with us properly and learning something new all the time.

In March 1993 we had an out patient appointment with Dr Rigby, a consultant from the Brompton. He suggested trying to find out why the pressure was still high as he thought that the duct had reopened, and he would arrange for a catheter to be done, which we were pleased about as we felt that something was being done. The appointment arrived for the end of April, just as Daniella was getting over chicken pox. We checked with our G.P. who assured us that she was alright to have it done, but the evening after we arrived at the Brompton, after all the usual tests, a doctor came to tell us that there was a problem with Daniella's blood due to the chicken pox and she would be unable to have the catheter done.

Towards the end of June the next appointment arrived and off we went again. This time there wasn't a problem and the catheter went ahead as planned. Dr Rigby told us that they hadn't found anything major, there was another small hole, which we knew about, but that wasn't causing a problem. What they had found was that the pressure in her lungs was very severe and he gave her five years. Steve asked him if it was possible for her to have a transplant, as we had discussed this as the next step we could take to try and help our daughter. His response was shocking, he said," Daniella wouldn't even get on the list as she has Down's Syndrome and no mentally handicapped person would get on the list".

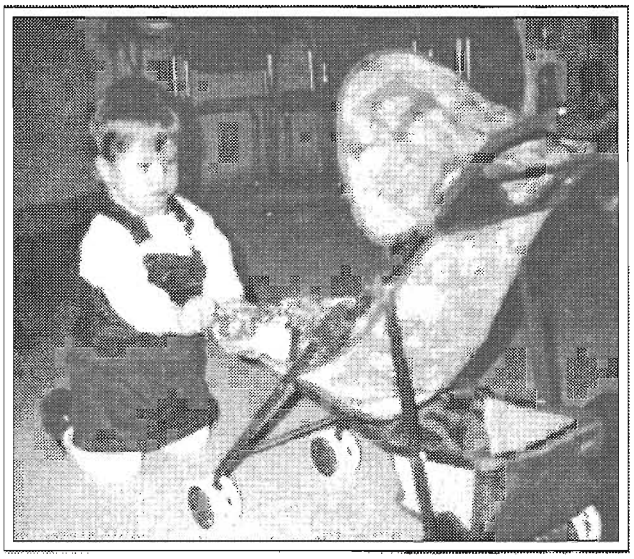
As Daniella was really well we decided to have a holiday visiting friends in France. We agreed that where ever possible we would treat Daniella the same as any health child and try to lead a normal life. We came to the conclusion that if anything was going to happen, it would not matter where we were and staying at home and wrapping Daniella in cotton wool wouldn't do any of us any good. The week before we were due to go, we had to take Daniella into hospital because she was breathless and had put on weight suddenly, which was the first sign that she was retaining fluid which needed to be sorted out before it got any worse. They increased her diuretics and decided there wasn't anything to be too concerned about and she was allowed to go home after four days.

We were at a friends house before going on holiday, when Daniella had what turned out to be a heart attack. The ambulance took her to the hospital, and after what seemed like hours, they came to tell us that she was breathing on her own and that they would be taking her to Intensive Care. When we saw her she was all wired up and heavily sedated, they wanted to keep her like this until the morning, then reduce the doses and see if there was any brain damage due to the length of time without oxygen We both thought that everything was going to be alright, and the big test would be the next day. We couldn't have been more wrong - just gone midnight on Friday 13th August Daniella died. She had another attack and there wasn't anything they could do. Although we knew it would happen one day, it didn't make it any easier to accept.

Daniella was a lively, happy little girl who always had a smile for everyone she met. We have no complaints about the medical treatment she received, all the medical and nursing staff were wonderful with her. We cherish the time we had with Daniella, although it will never be long enough, and some of the memories are still very painful. If we were given the time over again we wouldn't change a thing. In our opinion we did the best we could for Daniella and feel that our experiences have made us stronger people. The only slight regret that we have is that we didn't get the chance to fight for a transplant for her, and that she never met her three siblings.

Sue Allen
Doncaster

Megan's Story



Our little daughter Megan Caulfield was born 3 weeks-premature by Caesarean, as she did not put enough weight on. At that time the doctors did not know she had Down's Syndrome.

My husband was the first to see Megan and he knew there was something wrong. He asked the doctors but they would not tell him anything, they said that we would be contacted by a doctor when I had come round from the anaesthetic. He was then alone with the fear, and the first thing he said to me was "There is something wrong with our daughter." At that time I had not seen Megan, and I was upset that he could think like that.

We were taken into a room and a nurse came with Megan. She was laid in bed with me and I loved her more than anything. I could not find anything wrong with her. Her fingers were maybe a little bit short but in my eyes she was perfect. Then perhaps after half an hour the doctor came to tell us that Megan had Down's Syndrome. It was like a bad dream. I loved Megan and I hated her at the same time. My inside was chaos.

A week later the next shock came to us. Megan had an AVSD-commune heart defect. She was operated when she was 7 months old. Before the operation she was very tired and did not feed very well. Now after the operation everything is going very well. She could sit by her own when she was about 11 months old - crawl when she was about 1 year and walk about 22 months old.

She likes to dance - she talks on the telephone (we do not know what she is saying). She plays with her doll feeding her with a bottle and puts her to sleep in a pram. She understands what you tell her (both Danish and English). She lays the table when we are going to eat - and puts empty things in the dustbin. She knows some children's songs and can sing la - la - la. She likes watching TV - turns it on herself.

Megan was in kindergarten with other handicapped children. They worked hard on SIGN TO SPEAK and Megan was very quick to learn the signs. Then Megan moved to a kindergarten where the children are mixed handicapped and non handicapped.

Megan is by everyone called sunshine and she does make the sun shine on a cloudy day. I wrote a little story for the newsletter. Please excuse me if my English is not correct.

DEAR LITTLE SUNSHINE!

"Take her away, I don't want her! The words came from me - your mother. I had been looking forward to giving birth to you and now I don't want you. I throw you in to the arms of the doctor - "take her away." "It's not her fault." I hear your dads voice speaking from far away. Very carefully he takes you in his arms and cuddles you. Everything is chaos in my mind. I love you, no I hate you, I hate the doctor who has given dad and me the message - Your daughter is maybe not born as you wish her to be, but she can have a good life anyway. I know one thing - my life is ruined. Two hours before you had been taken by Caesarean section and I'm still confused by the medicine.

The doctor asks your dad if he would like to change your nappy, and of course he would love to. I can see your dad and you, whilst he is changing you with a smile on his lips. I'm jealous - you and me should have done this together, mum and daughter. Your little body is so thin with no clothes on - 2.045 gram and 45 cm. Oh my god I love you so much. You spread your fingers and I can see the line in your hand. They want to take a blood test from you, so they can maybe find an extra chromosome. It's not taken yet, but we all know that you have Down's Syndrome. Why you? Dad and I have been waiting seven years for you. Our baby is mentally retarded.

Next day you are checked by another doctor. He listens very intensely to your heart. 50% of all Down's children have a heart defect he tells us - yours is o.k .so we are happy. The night before you have been sleeping close to me and you have given me so much hope - and I love you more than anything. I don't know where my hate towards you came from. You are hungry but too tired too eat. You are crying a lot with digestive problems. I can see your nails are getting blue and around your mouth. I am screaming like mad and a lot of nurses come to look at you.

Next shock is given to us at the children's heart hospital. You have to go through a heart operation very soon. Dad and I cry a lot, and I have to leave you with dad and the doctor to scream my pain out alone. Oh god, it can't be true. Are we going to lose you now. That you have Down's Syndrome doesn't mean anything any more.

We have to wait 7 months for your operation. It's a hard time and we cry a lot. Every day we are waiting for a letter from the hospital. We know the day will come, but not prepared for the pain inside our hearts. The letter comes 14 days before the operation. The 3rd of December 1996 should be the big day or the sad day. We arrived at the hospital 2 days before the operation. They had to examine you and take some blood tests. The 3rd of December 8.15 in the morning me and dad followed you down to the operating theatre. We said "good night" to you. Crying and begging. Is it "good night" for ever or just a little while? - It was "good night" for about 6 long hours.

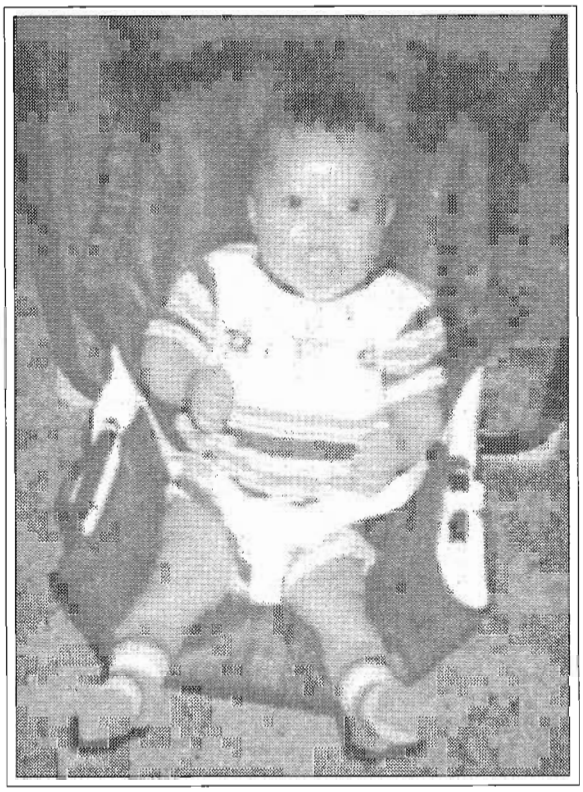
Your operation went very well, and after 10 days we where all home again. Your scar is getting pale on your chest. Dad and myself have got scars too. Maybe, as time goes by they will pale like yours.

Dear little sunshine you are a strong little girl. We are so happy that you are our child. Love you more than anything in this world.

Ulla Caulfield
Silkeborg, Denmark

Darrell's Story

My son Darrell was born on 29th December 1997, at King Georges Hospital, Goodmayes. He was born with AVSD which was detected at my 20 week scan. I was distressed because the midwife told me he had a defect and that Great Ormond Street Hospital (GOSH) will phone later for an appointment, with that she was gone.



After two very long weeks I went to GOSH to see Dr Sullivan the cardiologist. He explained everything in detail, gave a 95% success rate for surgery, and said it was the most common condition with Down's Syndrome. I was just relieved he didn't recommend a termination. Dr Sullivan said the baby would have the operation between three to six months. I never felt pushed into surgery, yet it was vital Darrell had his operation or he wouldn't be with us now.

Darrell began losing weight a little while after birth. GOSH put him on Frusemide and Captopril both three times a day, still losing weight GOSH made an appointment for the operation within two weeks. So at six weeks he went into GOSH and my nightmare began!

Darrell went down at 2.00pm and into Intensive Care at 8.30pm, I was allowed to see him at 9.30pm. I was told he was a very sick baby and it was at this point I realised how ill he was and had been. He then caught MRSA and septicemia. He was gravely ill, but with GOSH's loving staff and God he came through five operations and nine weeks on Intensive Care before going to DJW (high dependency ward) for three weeks. Although still ill my baby was doing well. He then spent 10 days at King Georges and finally home to me. Three and a half months later he was doing well, although still not eating or sleeping well, but he had gained weight.

Full details were given to me about the repair, but due to the severity of Darrell's illness the information didn't sink in. As Darrell was in GOSH for 12 weeks it was a great strain as I am a single parent and felt pulled in two. I was lucky I had good friends. I think we are fortunate Darrell is so young as he will have no memory of his stay in hospital. His surgery has been very successful and Darrell has now finished his medication, although recently he had a short course of diuretics due to a chest infection. I'm not sure if Darrell will ever need further surgery, he does not have a sternum as it was removed due to the infections he had after surgery, so he will have regular check ups and we will go from there.

Darrell is still a little behind others at his age, but this is due to spending so long in hospital and having Down's Syndrome. He only visits GOSH for check ups and they are pleased with him. My G.P. is very understanding and will see us anytime I'm worried. Darrell is a happy boy with no discomfort and we do all the usual family things.

I see Darrell having a bright future so long as his heart is OK. Yet in the back of my mind I will always wonder how long we have him for.

Sue Morris
Romford

Memorial Donations

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

Grace Colton - Burton Salmon
Reece Dunne - Basingstoke
Scott Kennedy - West Malling
Addie Power - Chelmsford
Frank Power - Cornwall
Joel Ronayne - Jersey
Chloe Sefton - Frome

New Guidelines for Organ Retention

Following on from recent media reports, new guidelines for the retention of tissues and organs at post-mortem examination were issued by The Royal College of Pathologists in March.

A copy is obtainable from :

The Royal College of Pathologists
2 Carlton House Terrace
London SW1Y 5AF
Tel : 020 7451 6700
Fax: 020 7451 6701
Email : info@rcpath.org

or it can be downloaded from their website at :
http://www.rcpath.org

If you have any concerns with regard to this issue that you would like to talk over, please contact National Office.

Annual Conference 1999

The following are reports on some of the sessions at last years Annual Conference. It is always difficult to convey in writing, all the information that is imparted by our speakers. Why not come along this year and see for yourself?

"Illness and Behavior" - Professor Ben Sacks

Professor Ben Sacks from the Sarah Duffen Centre, gave a very entertaining talk, full of anecdotes, but with plenty of food for thought. He began by looking at the effects on behavior of illness in general and later considered, more specifically, the effects on children with Down's Syndrome. "Illness" comes in all shapes and sizes, time and structure and can be acute or chronic, but many effects are common.

His first key point was demonstrated by giving us an American phrase "Tyrannical Child Syndrome". A child doing well before an illness can then become very dependent on others. Normally, what has the most influence on a child's behaviour is peer group. However, with a sick child it is the attitude of the parents which becomes paramount. With the onset of an illness, the dynamics between parent and child change, with parents doing more for the child. The new behaviours can become habitual, even after the cause (illness) has gone.

Obviously, parents need to understand the medical condition, but they should try to aim for "ordinariness", and not create a hospital environment at home. Love for a child should be to build up self image and self respect, not to incopacitate a child. To survive in a world of other people, the key is independence.

A second key point as a contributing factor to poor behaviour is often underachievement, which can have a medical origin and here Ben looked more specifically at children with Down's Syndrome. Poor hearing or vision, or hypothyroidism are all common in those with Down's Syndrome, and treated with relatively easy intervention, but left untreated can have a marked effect on a person's behaviour.

When a child misbehaves we must always look for the causes, either immediate causes such as pain (children with Down's Syndrome often have infections in many areas), or predisposing causes such as poor vision/hearing/thyroid function, or poor language skills resulting in frustration. If both the causes and symptoms of difficult behaviour are treated, then the improvements in behaviour are more than doubled.

After a very enjoyable and thought provoking talk, I shall never hear the name Ben Sacks without thinking back to his reference to the many hundreds of blood samples he has taken from children over the years without fuss or tears. I am sure that I am not alone in admitting that I wish he had been on hand at the battle scene when my son last had to give a blood sample. The practice isn't always as easy as the theory.

Sue Buckley's Workshop "How to teach reading"

I have attended several of Sue Buckley's presentations and each time I have been impressed and encouraged by her enthusiasm for the subject and always come away with something new. This was no exception.

In opening, Sue emphasised the need to start a child reading as early as possible, and showed how this can be achieved:

- To start when the child has a 40-50 word vocabulary and can select and match pictures.
- By using whole words and matching the words with pictures
- Making a personal picture book for the child, using simple sentences about the child's own world and within the child's comprehension.

In speaking about the 40-50 word vocabulary it was highlighted that *"Signing a word is the same as saying a word".*

The points covered in the workshop were:

Parents who ***teach*** their children, find their children do much better; read for meaning first; reading can be achieved ***without*** the letter sounds; sight reading first, and then phonics; children will learn faster without pictures; everyone ***reads by sight*** with sounds stored in the brain for those words not recognised; reading is a physiological linguistic guessing game; to hold a child's attention, find something that they enjoy; choose words the child is interested in, use key words linked together; grammar and syntax helps phonology; use speech sounds even if the child cannot say the word; children will copy lip patterns. Whether to continue to sign once a word is spoken, is still a matter of debate. Once children have reached a reading age of 7 to 8, they would have cracked phonics.

As usual there was a lot of audience participation with Sue more that willing to answer the questions as they arose.
A thoroughly worthwhile workshop.

Barry Allen
Rochester

Speech and Language Skills in Children with Down's Syndrome

Recent Research and implications for Approach - Professor Sue Buckley

A baby learning to talk has to realise that words have meanings. They have to learn what the meanings are and what words relate to, i.e. the word cat relates to a cat, in order to build up their vocabulary. Words = knowledge.

The progression of speech is the same for all children, regardless of disability, i.e.

- Communication skills - nonverbal skills such as eye contact turn taking, facial expressions and responding to speech.
- Learning that each word has a meaning — comprehension
- Vocalising
- Linking words together
- Grammar
- Clear Pronunciation

Children with Down's Syndrome generally have very good communication skills, but are not so good with grammar. Speaking clearly can also be a difficulty,

Most children with Down's Syndrome have up to a 30-40 decibel hearing loss when they are under 5. Although this is not considered to be a significant problem it is sufficient to affect the consonants at the beginning or ending of words, i.e. cat, mat, sat, could all sound the same to a child with a small degree of hearing loss. This is why signing can be useful and is recommended from when your child is 7/8 months old. A baby will also find signing more interesting. It is important to turn off the television, speak clearly and maintain eye contact when talking to your child and also sign clearly. It is vital to always talk with your child and encourage them to join in conversations, encourage babbling from an early age. A child that talks very little does not tend to be spoken to — creating a vicious circle. Practice is important to improve clarity and understanding.

The older child with Down's Syndrome will benefit from social experience in the community away from their parents. The tendency is to help your child speak in problem situations in order to avoid embarrassment; this gives the child no incentive, They should correct themselves and try to speak dearly. A predictable lifestyle also lessens the need for speech.

There is a huge variability of speech and language problems between children with Down's Syndrome. Some may have many problems, but most will have problems of differing degrees. Individual targeting by Speech and Language is therefore vital from an early age.

Donna Hoppe
Northolt

Christmas Cards

Last year we had two winning cards in our Christmas Card Design Competition, a nativity scene which was a joint effort from Hannah Boniface and Ana Copus, and another joint effort, a festive wreath from Vincent, Helen and Riyad Lucy. The children were all very excited at their success, and each received a voucher and personalised certificate.

On the left Vincent, Helen and Riyad Lucy with their winning card and certificates.

On the right Hannah Boniface

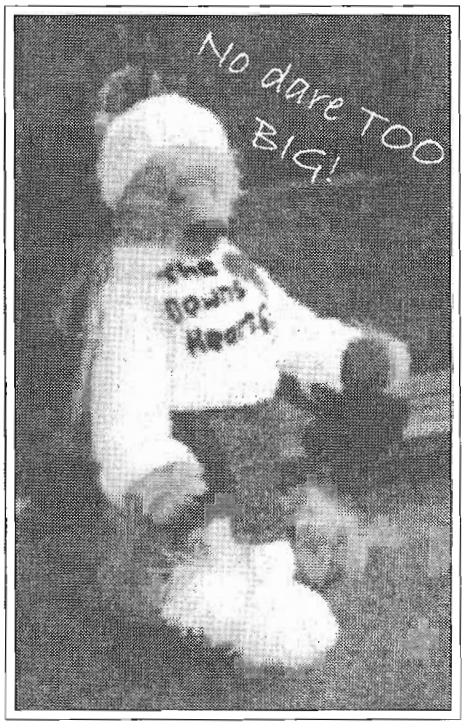
We would like to thank everyone who supported our Christmas fund-raising by buying and selling Down's Heart Group cards, and to all those who 'rounded up' their payments. We sold a total of 10,500 cards this year as well as receiving an extra £350 in donations added to payments, and the profit from the sale of stamps. Many thanks also to Mike Walshe and Westway Offset Ltd for their assistance with the printing.

This year we need to get cards printed earlier, so we are looking for designs now. Please send any festive designs to National Office by May 1st. A prize will be awarded to the child or children whose design is chosen.

Thank you also to those supporters who ran various schemes at work, where charity donations were given instead of sending cards to all your colleagues. The Down's Heart Group is very grateful for your efforts.

Dare Bear 2000

All money raised goes to the Down's Heart Group



My name is Dare Bear (aka Bobtail Oops-a-daisy). I was innocently watching the world go by in the shop where I live, when I was invited to a TeddyBears Picnic. They did **NOT** tell me I was going to do a parachute jump, until I was pushed!

Unfortunately, I still look terrified and decided I needed to conquer my fears by doing as many dares as I can from November 10th 1999 until December 31st 2000. I am hoping to be sponsored per dare, and I need your help.

Can you find a dare for me to do? I only weigh 620 grams, so I'm not too heavy to take on any event / activity. Or would you be willing to sponsor me?

Have passport, can travel

Bobtail oops-a-daisy

Can you help Dare Bear in his fund-raising efforts? He has already been for a flight in a Tornado, been scuba diving, visited Santa in Lapland before Christmas, had his passport autographed by Rod Stewart and he is running in the London Marathon with DHG member Quinton Hayter.

As well as the sponsorship from his dares, at the end of his adventures Dare Bear will be auctioned along with his photo album, wardrobe, passport etc. and the proceeds will also go to the Down's Heart Group. He is a limited edition designer bear.

If you have a dare for Dare Bear (the crazier the better) or you would like to sponsor him for his exploits, please contact National Office or Natasha on 01493 750707.

Halifax Masonic Lodge gives generously

Cliff Lake accepting a cheque on behalf of the Down's Heart Group from the Pennine Masonic Lodge, Halifax.

The Worshipful Master Derek Lowe of the Pennine Lodge, Halifax, nominated the Down's Heart Group as one of the beneficiaries of the lodges annual fund-raising. Derek's granddaughter is a member of the Group and has had successful heart surgery.

Committee member Cliff Lake went along to accept a cheque on behalf of the Down's Heart Group, and was presented with the sum of £508 which had been raised by various events. A while later he was surprised to receive a call from Derek saying that there was a further cheque for £300 on its way which his fellow masons had presented him with at the end of his term of office.

This brings their total donation to a magnificent £808, for which we would like to say a very big THANK YOU.

London Marathon - 16th April 2000

This newsletter should reach you just around the time of the London Marathon, so we have to mention the eight intrepid souls who will be out there pounding the streets of London raising money for the Down's Heart Group.

They are John Alcock, Andy Brierley, Quinton Hayter, Gary Lawless, Robert Paterson, Paul Smith, Charlotte Taylor and Peter White.

We would like to wish them all the best for the race, and thank them for supporting the Group by choosing to run for us.

If you would like to sponsor any or all of our runners, please send your donation to National Office clearly marking it London Marathon Sponsorship.

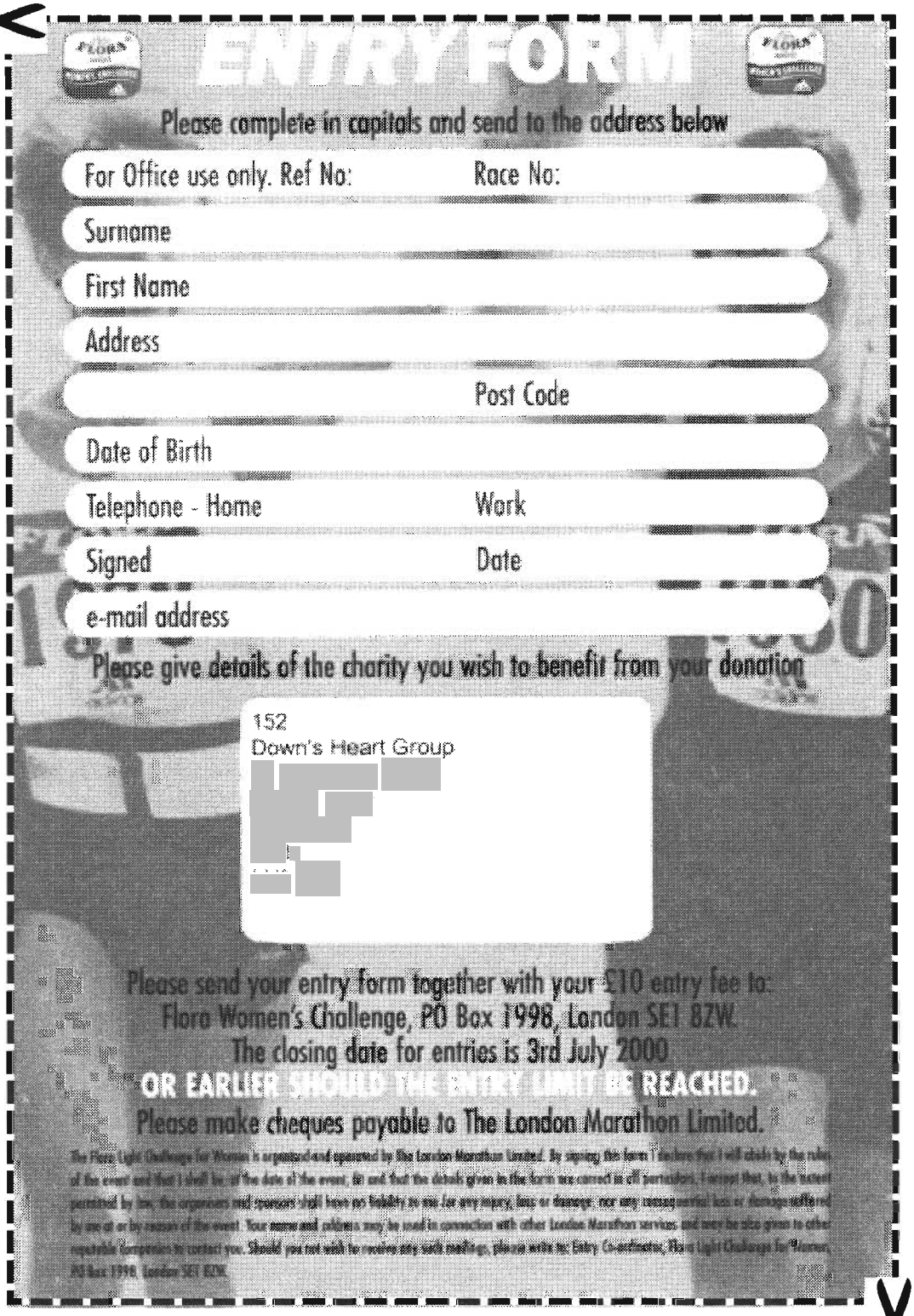
Flora Challenge For Women

Whatever your age, your fitness levels or running ability, signing up to take part in the Flora Light Challenge for Women is a great incentive to keep fit and feel healthier.

The Flora Light Challenge, in association with adidas®, is a three mile fun run... or walk... for women. It takes place in London's Hyde Park on Sunday 16th July 2000. It is an event for all women, of all ages, fit or not-so-fit.

Training and taking part in the Challenge may be even more fun if you team up with friends. You can walk, jog, run - it's your choice. The main thing is to have fun and enjoy your achievement.

And £5 from your £10 entry fee will be donated to the Down's Heart Group if you use the entry form below.



Once entered you will next hear from the organisers around 18th June when you will receive your running number and final instructions magazine.

Although they will not acknowledge receipt of entry, your cheque will be cashed within 14 days and your next bank statement will show that they have received your entry.

On the day every finisher will receive a goody-bag which will include an adidas® T-shirt.

To enter please complete the entry form and send it with the £10 entry fee to :

Flora Light Challenge for Women,
PO BOX 1998,
LONDON SE1 8ZW.

Cheques should be made payable to: The London Marathon Limited.

Closing date for entries is 3rd July 2000, or earlier if the entry limit is reached.

Photocopy forms are acceptable.

If you are entering on behalf of the Down's Heart Group, please let National Office know. We can let you have a sponsor form if you would like to raise a bit more money from your efforts, and it would be great to have a team get together.

Travelling abroad with your heart child

The following is based on the Children's Heart Federation Information Sheet published last year. It draws on parents' experiences and offers practical advice for travelling abroad.

Try to plan your trip abroad so that your anxieties can take a back seat for a while. Always check that your child is fit to travel with your GP (if your child is generally well) or with your paediatric cardiology centre (if your child is still frequently treated or monitored).

Where are you going?
Most of this information relates to the safety and comfort of your heart child, but when choosing a holiday destination, remember that an exhausted toddler seems to weigh three times as much if the temperature is over 28°C, it is near impossible to use a buggy on a sandy or pebbly shoreline, and that returning from the beach is always steeply uphill.

If you have any doubts about your child's fitness to travel, to fly, or to deal with high or low temperatures contact his or her consultant and ask for advice. Secure insurance *before* you buy the tickets.

Information from your doctor
You may need a letter from your GP or cardiologist saying that your child is fit to travel. This should state explicitly that your child is fit to fly, for example, and his or her health will not be jeopardised by visiting your destination. If your insurance company has to ask your doctor for this information, they may pass on the charge to you.

At an early date, visit your GP and ask about a supply of prescribed medicines. Remember that most antibiotics in liquid form will only keep a week In cool conditions, so ask your pharmacist how you can deal with this. Ask your pharmacist to recommend safe travel pills.

Make sure refrigeration is available if you need it for medication. One family were surprised that they were unable to arrange for a refrigerator in their hotel room when they reached the US.

Ask your cardiologist for the nearest paediatric cardiac centre to your destination.

If your child takes anticoagulants, arrange blood tests to fall two weeks or so before you leave . Then there is time to stabilise the dose and have another test if necessary. And this applies to any other regular check your child has - give yourself time.

Information from your travel agent
In some cases cardiologists advise that the child may need oxygen when flying. You may want your travel agent to sort this out with the airline. Check on local temperatures at the resort you are visiting, as these can vary considerably within a region. How long will it take you to get back to the airport? Where is the nearest English-speaking doctor? Is there refrigeration available? In the event of needing to use your insurance policy, will the travel operator be able to help?

Insurance
For most conditions you should have no problem in getting your child covered. You may want to make sure your insurance will cover the cost of bringing your child back to the home hospital, and of accommodating your family for extra time should you need to stay abroad with the child. You should also make sure that a parent is covered to stay and travel home with the child.

E111
If you are holidaying in Europe, make sure you have an E111 for all the family~ this means that you can get money back that you spent on treatment. Read all the notes carefully, as in some cases you have to take action while you are paying for medicine, or in a hospital, in order to get repayment. You can get an E111 from a post office or by calling 0800 555 777.

Medical screening line
The Insurer may ask you to speak to the Medical Screening Line. The call is supposed to take 4 - 5 minutes~ but write down the information you will need and have it to hand, to keep it short. Be prepared to answer questions on destination, how long you will be away, date of birth of the child, the name of the heart condition that has been diagnosed, and how stable the condition is.

Stability is a key question for insurers, so you may be asked what medication your child is on, the dosage, whether the dosage has recently changed, dates of admissions to hospital, dates when you have had any emergency call-outs to the child, or taken him or her to A&E. You will also need to describe what symptoms your child experiences. It may be a good idea to ask the cardiologist to say specifically that your child's condition is stable (if this is so).

At the airport
Call the airline you are travelling with if you would like transport to the plane, rather than having to walk to the departure gate, as this can be a long trip for a breathless, excited child. When you get to the airport, you may need to ask for the Special Needs Desk.

Pacemakers can cause alarms when going through security - carry the child's pacemaker card and show it before you go through. Your child will then be taken through separately.

Drugs
Carry two supplies of any absolutely essential drug, such as anticoagulants -one about your own person. Many travellers have problems with lost luggage, particularly when flying, so better keep all drugs in hand luggage. (Have a good story ready to explain the syringes, if you use them.)

Diet
If your child's diet is likely to change, try and do it slowly. Take a concentrated bottled fruit juice which is familiar to him or her, and make it up with bottled water rather than giving fizzy drinks. It is important for any child not to go short of drinks in hot weather, or when they are being active- but it is very important for some heart conditions.

Smaller children may need to eat little and often, and be very fussy about what they are given. Buying snack food in a foreign currency can be seriously expensive - carry a large supply of acceptable biscuits or a large supply of travellers cheques. On the bright side a number of parents have found that their child's appetite is improved when away, and they are likely to be tempted into eating food they will not touch at home.

Sun
Of course, you will not be allowing any children to stay out in sunlight for long periods - but remember that scar tissue is particularly prone to sunburn -so make sure your family expect to be smothered in high factor sun-protection lotions every time they go out.

Say it
Learn how to say that your child has a heart condition in the local language -write it down if you are uncertain about accent. (If you do not do this you could end up as one parent did, mystifying the doctor by using the section of the phrase book on car valves.)

Celebrating Holland - I'm Home

Many of you will at some time have read "Welcome to Holland" by Emily Perl Kingsley in which she likens the birth of a special child to going on holiday and arriving in a different country to that which you had planned. Here, Cathy Anthony, a parent, advocate and presently the executive director of the Family Support Institute in Vancouver offers her follow-up to the original.

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger - the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travellers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

I think that Holland is used to wayward travellers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its' tulips, windmills and Rembrandts.

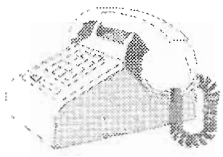
I have come to love Holland and call it Home.

I have become a world traveller and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

Cathy Anthony

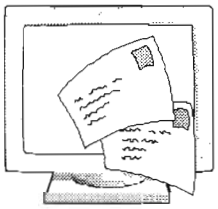
Please keep in touch!



It's always sad when we lose contact with a family because they forgot to tell us they were moving house. So often redirection of mail has finished before we send the next copy of the newsletter, and although we try to trace new addresses it's not always possible, so if you are moving, please do remember to tell the Down's Heart Group your new address.

Also, we love to hear how members have got on when they have had surgery, and of their achievements, so please do keep us informed.

If you are sending in a story, child's picture etc. please enclose a photograph of your child, and also state that you agree to the Down's Heart Group publishing it. We can return photographs if needed, but ideally we like to keep them - we have a lovely album of member children so you can be assured that they aren't being banished to the bottom of a filing cabinet!



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

Our members are very important to us!

Empowered Parents

As a parent, I have attended several DHG Annual Conferences and have found each one an invaluable source of information and encouragement.

I believe it was at the 1998 Conference that I learned that children with Down's Syndrome should have their thyroid function checked regularly — at least every two years. As my then 8-year-old child had never been offered this screening, I became somewhat concerned. I made enquiries with our G.P., who told me I would need to take Hannah to the Child Development Clinic at a local hospital.

When I took Hannah to the CDC in December 1998, I asked for Hannah's thyroid to be checked. The Consultant pooh-poohed the idea, stating that as Hannah was bright, active, and underweight-for-height, she would if anything have an OVER-active thyroid, and if that was the case, he would not want to treat her for it as she would then become lethargic and overweight. I found this attitude quite unacceptable, and made it clear that I wanted the screening to be done, and suggested we should discuss treatment according to the results. The Consultant asked me to wait until our next appointment, in six months, and he would then arrange the test. He then spent the rest of the consultation trying to persuade me to give up my claim for Speech Therapy in Hannah's mainstream school placement, giving me the benefit of his opinion that whilst mainstream education is ideal, this was not an ideal world, so why didn't I put Hannah in a Special School?

At our next visit, in June 1999, I reminded the Consultant that I wanted the Thyroid Screening done; he didn't have the bloodtest request forms available, and they were posted to me some weeks later.

Having got this far, I was then faced with the reality of having to subject my child to the blood test, and knowing that I wouldn't be able to adequately explain it to her and that she would not be a willing participant, I was plagued with doubts and didn't do any more until October. During half-term we took her to the hospital, three adults held her whilst the blood sample was taken from her arm. Not a pleasant experience, and whilst Hannah usually gets over things very quickly, she was very stressed by this and wasn't "herself' for the rest of the day.

Two weeks later I spoke to the Consultant over the phone — amazingly he took full credit for having instigated the test, and informed me that Hannah had Hypothyroidism — an UNDER active thyroid, quite the opposite of what he had suspected, and apparently a potentially serious condition if left untreated. When calculating the appropriate level of Thyroxine, I reminded him that Hannah had had an AVSD Repair — I believe that heart conditions are a relevant consideration when introducing Thyroxine.

I have subsequently broached the subject of Thyroid screening to other parents, and have been met with "my child is not symptomatic". Well, neither was Hannah. Thyroid malfunction is more common amongst people with Down's Syndrome and symptoms of Thyroid malfunction are often confused with "characteristics" of Down's Syndrome, which is why the BMA recommend routine screening.

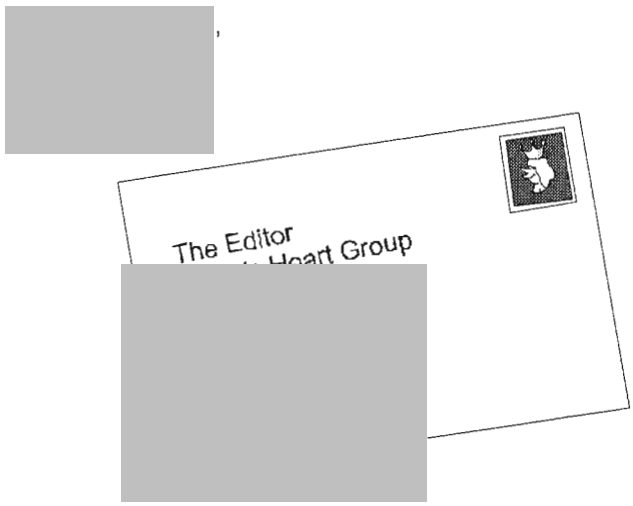
As a consequence of the diagnosis, Hannah is taking a low dose of Thyroxine daily —she willingly takes her pill at breakfast, and the effect on her has been quite amazing, within 48 hours she was a "new" person.

By attending the Conferences and reading all the literature available I have become what is known as an "empowered parent", and I have learned (sadly, perhaps) to not take so-called "professionals" too seriously — I will not hesitate to ask for a second opinion, particularly in matters of health and education. It was at the Conference in Portsmouth that Prof. Sacks urged us to become politically active, because if we as parents cannot fight for our children, who will?

I referred earlier to my battle to get Speech Therapy in mainstream school for Hannah, who has dyspraxia. Not only was the outcome of the SEN Tribunal Appeal in Hannah's favour, and quantified Specialist Therapy subsequently written into Hannah's Statement, but the LEA were found to be "unreasonable and irrational" in fighting the case and I got full costs, plus compensation for the cost of private Speech Therapy for the year's duration of the case. I had concurrently pursued a complaint via the Local Government Ombudsman re the delay in issuing Hannah's Statement, and was awarded further compensation. To other parents considering taking action, I think the most valuable advice I can offer is to take copies of all correspondence, log all telephone calls and ask for transcripts or written confirmation of any decisions made or given in telephone conversations, keep all receipts including postage, and make use of any national or local parent support/ action groups. Above all, if you have checked your facts and believe you have a valid case, don't allow the LEA to bully you into submission!

Joanna Simms
Cuxton

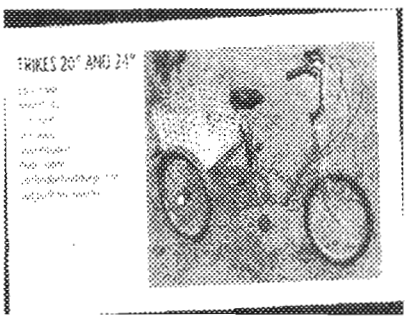
PS. At the time of writing I have provisionally arranged with the Art Department of Rochester Adult Education Centre to have a special exhibition during Down's Syndrome Awareness Week in June 2000. I envisage the exhibition incorporating paintings, photographs, sculptures, poems etc. about and/or by people with Down's Syndrome, to get across the message "this is me, I am happy with what I am". If anyone in the Kent / Medway area would like to contribute to or visit the exhibition, do please contact me now on 01634 710029. I wish to make a montage, and photographs (non-returnable) of people with Down's Syndrome at work, school, home, holiday etc. would be much appreciated and can be sent to me as soon as possible at



Tricycle Update

I wrote to you some time ago *(Summer 1999 newsletter)* asking for help in finding a tricycle for my 10 year old son. I received a lot of letters and would like to thank everyone who took the time to write.

I was originally going to have to pay £650 for a new tricycle for Colin, so after looking around a bit more I found a company called MISSION most bike shops would have heard of them they are charging £350 for a tricycle.



TRIKES 20" AND 24"
5 SPEED GEARS

PARKING BRAKE
STEEL FRAME
STEEL WHEELS
SHOPPING BASKET
PADDED SADDLE
COMFORTABLE
HANDLEBAR POSITION
MUDGUARDS AND
REFLECTORS

I have included a picture of the tricycle and I hope this will help someone else when trying to obtain one.

Isobel Turnbull
Stuartfield

Guiding Achievement

We are enclosing a photograph of our daughter Rebecca who was presented with the Baden-Powell award by the Girl Guides on 30th November 1999. This is the highest honour a Guide can receive.

We are very proud of her as she worked extremely hard to achieve the award. She had to learn and do everything the same as the other girls and received no dispensation. Her badges fill the back of her sash too.

Not only does Rebecca have Down's Syndrome but she is also registered blind, has diabetes, Eisenmenger's Complex and other medical problems. Rebecca is 16

Once a Guide achieves the Baden-Powell award she has to leave. Although Rebecca misses Guides she now goes riding instead. She has several pen friends, enjoys swimming and bowling, but loves music. Her favourite pop star is Ronan Keating. She loves trendy clothes and has a wicked sense of humour Good on you Rebecca!

Veronica & Iain Andrews
Sproughton

(Rebecca is shown on the front cover holding her award. WELL DONE Rebecca!!!)

Special Achievement Award

When Philip had major heart surgery at the age of eleven at Great Ormond Street Hospital, you were very supportive. He has grown into a bright active outgoing teenager, who enjoys Boys Brigade and the Church Youth fellowship and loves to go camping with them. He still has medication for a leaky valve and irregular heart beat, but usually this is not obvious, as they don't worry him over much.

Philip recently went on a residential week with the school 16 plus group, to the Special Needs College he hopes to go to at eighteen. It was for children from all the special schools around, and Philip got the award for exceptional performance

We are so proud of him, when he came to us at two weeks, the hospital paediatricians were talking about "if he lives until he is five"

Charmian Curran
Spalding

Sadly the copy of Philip's certificate we received wouldn't copy clearly for the newsletter, but we have included a photograph of the young man himself. WELL DONE Philip!

PLEASE SAVE STAMPS, POSTCARDS AND RING PULLS FOR US

We are collecting these to raise funds
but we need your help!

Please save used postage stamps (cut neatly from the envelope), postcards (used and unused) and ring pulls from drink cans.

If you live near to any of the Committee Contacts, you can pass these on to them to save postage, otherwise they should be sent to National Office.

Last year we raised over £300 from stamps alone. THANK YOU to everyone who has been saving them and sending them in.

National Contacts

National Office

[redacted]

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

Contact or Ansaphone always available (24hrs in emergency)

National Administrator	*Penny Green*
Founder	*Linda Walsh*
Joint Chairs	*John & Katie Spall* [redacted]
Vice-Chair	*Sheila Forsythe* [redacted]
Treasurer	*Phil Thorn* [redacted]
Secretary	*Donna Hoppe* [redacted]
Legal Advisor	*Brian Auld*
Policy Advisors	*Mary Goodwin* *Dr Rob Martin* *Dr Claus Newman* *Dr Phil Rees*
Benefits Information Contact Contact via National Office	*Mary Clayton*
Representative for those with	**Chronic Cardiac Conditions** *Jane Wrighton* [redacted]
Patrons	*Sarah Boston* *David Graveney*

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

The Down's Syndrome Educational Trust
The Sarah Duffen Centre
Belmont Street
SOUTHSEA
Hants.
PO5 1NA
01705 824261

Down's Syndrome Association
153-155 Mitcham Road
Tooting
LONDON
SW17 9PG
0181 682 4001
(Regional offices in Wales, Midlands and N. Ireland)

Scottish Down's Syndrome Association
158/160 Balgreen Road
EDINBURGH
Lothian
EH11 3AU

Down's Syndrome Assoc. of Ireland
5 Fitzwilliam Place
DUBLIN 2
EIRE
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