



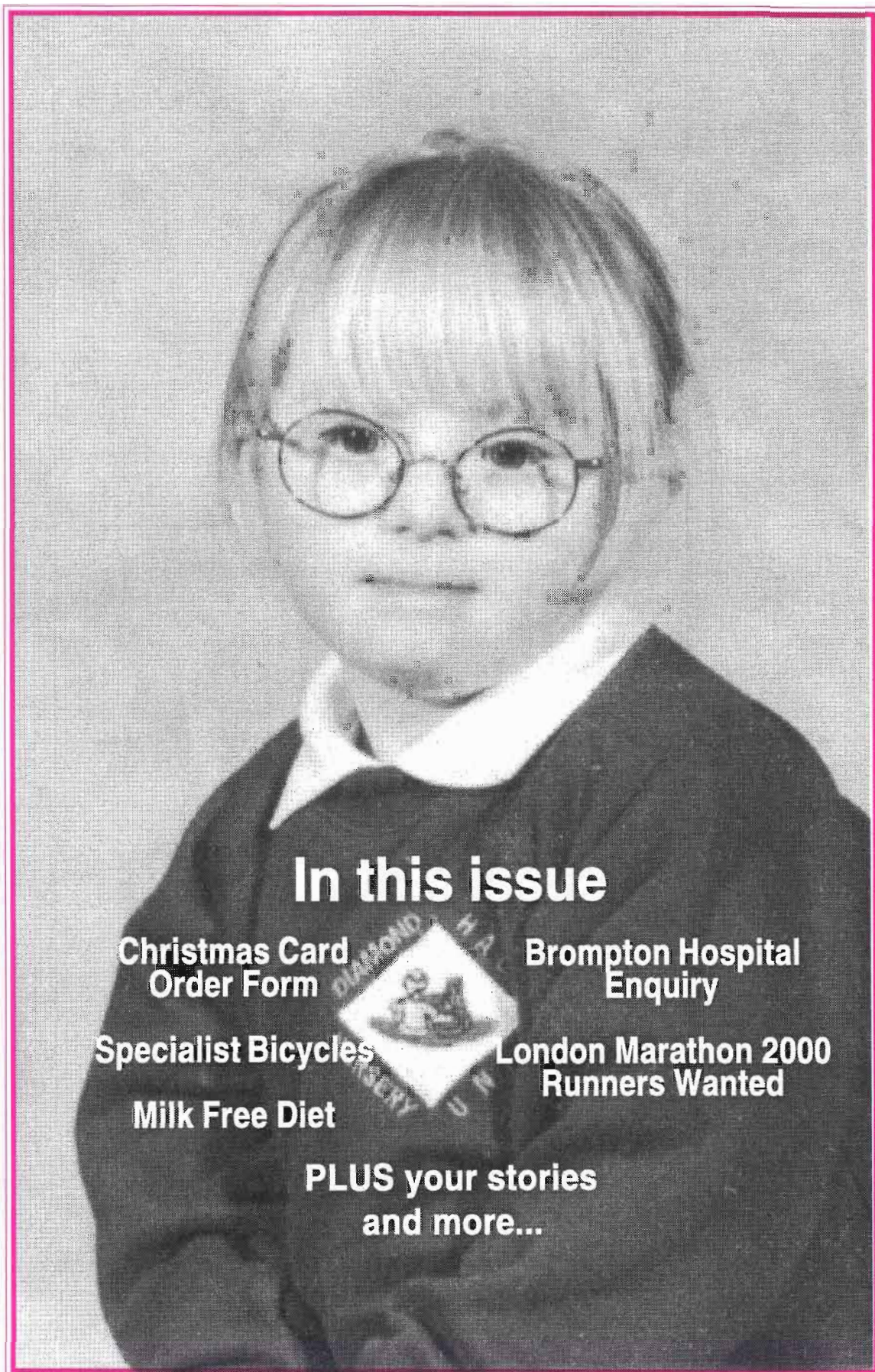
**DOWN'S
HEART
GROUP**

NEWSLETTER

Issue No 21

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**PLUS your stories
and more...**

Chairs' Report

Please note the change of apostrophe from before the 's' to after it which puts into correct English the fact that, following the AGM, we are now joint chairs of the Down's Heart Group. They say that a problem shared is a problem halved - we have yet to see evidence of that - but it does give us something to talk about over breakfast!

Brompton Inquiry

This independent review was announced in early August to examine anonymous allegations made by a "whistle blower" about the paediatric cardiac surgery services at the Royal Brompton Hospital. These primarily related to surgical outcomes, medical staffing and attitudes to patients with Down's Syndrome.

Following on the announcement we wrote to the 100+ of our members who had had contact with Brompton over the years, asking them to complete a structured questionnaire about their experiences. Given that this was in the high holiday season, we were gratified to receive nearly a 50% response in the two weeks we had to prepare a report to the enquiry.

As a result we were able to make a sixty five page, detailed submission to the review drawing conclusions from the experiences of some 35 of our members who had had contact with the Brompton, together with comparative statistics, drawn from the membership as a whole, particularly about the number of unoperated children with Down's Syndrome and AVSD at the various paediatric units across the country.

The independent review produced its report on September 8th. Its broad conclusions are that Brompton's surgical results are similar to those elsewhere; that it could find no evidence that medical staff had consistently given misleading information about outcomes; that the current medical staffing of the PICU had been acceptable; and that it could find no evidence that children with Down's Syndrome had suffered institutional or individual discrimination which impeded their appropriate management and treatment.

We were pleased to learn that Brompton's surgical outcomes stood up to those at centres elsewhere, and that can provide some reassurance to parents. However, this was not the main concern of parents, which were much more concentrated on the failure to offer surgery and general attitudes at the hospital. We were disappointed that these matters had not, in our view, been adequately dealt with and this is reflected in the press release we issued at the time, which is reproduced on the following page.

However, the review did recommend that the independent panel should be reconstituted, under the chairmanship of a lay person to consider the complaints and concerns of individual families and those submitted by the Down's Heart Group and the Down's Syndrome Association. This would also have the aim of assisting in producing guidelines for the management of Down's Syndrome with congenital heart disease. The review also recommended that there should be improvements in data collection and analysis of surgical outcomes, and in communication with families and support groups.

We are clear that the important issues we have raised on behalf of members should not be lost sight of and we will be pressing them on the new panel, the constitution and procedures of which we are yet to have news. At the same time, given the terms of reference, the panel will also be looking to the future to propose better arrangements.

This is the opportunity for the Down's Heart Group to contribute to this review. It has a unique experience in this area over the past ten years, not only through the experiences of its members, but also the detailed knowledge of many of the seventeen paediatric cardiac units nationwide through its network of regional co-ordinators and hospital visitors. The Down's Heart Group can thus make an important and informed contribution to the panels development of guidelines, procedures, structures and staffing to ensure best practice for children with Down's Syndrome and a congenital heart condition, and their families.

We have written to the original 100+ members who have had dealings with the Brompton asking them for their views about improvements which are needed. We now invite all members who would like to make a contribution to write to Penny at National Office. Particularly we would like to hear of your good experiences / arrangements / procedures / facilities / staffing, which might be applied elsewhere, and bad experiences with positive suggestions about how these could be avoided for parents in the future.

We need these contributions urgently so that we can present a further report to the panel giving a considered view about what should constitute best practice.

Volunteers

Thank you to those members who volunteered to help the Group following the appeal in the last newsletter. We still need more hospital visitors, so if you feel you could give something back to the Group in this way, do telephone us. Full training is given and expenses paid.

Conferences

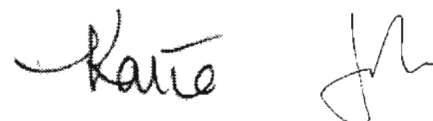
We are sorry that, because of the pressure of events, we are not able to bring you reports in this issue on the Annual Conference

and the Chronic Cardiac Conditions Conference, both of which were highly successful events which will be of interest to the wider membership. We hope to include these in the next issue.

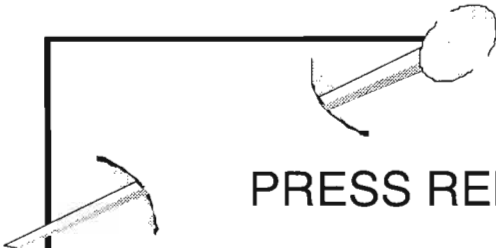
DHG Christmas Card

This year has flown by and here we are again with the DHG Christmas card - in fact two cards as we are producing two different designs this year. This is an important source of revenue for the Group so please buy lots, sell them to your friends and send them as widely as you can. In this way you not only help our funds but get DHG more widely know.

And while we are on the subject -a very Happy Christmas to you all from us, the Committee and Penny and all our volunteers.



Katie and John Spall
Joint Chairs



PRESS RELEASE - 9th September 1999

INDEPENDENT REVIEW OF PAEDIATRIC CARDIAC SURGERY AT THE ROYAL BROMPTON HOSPITAL

While it will be a welcome relief to parents to know that surgical success rates and management of the Paediatric Intensive Care Unit has been found to be satisfactory, the Down's Heart Group is disappointed that the Independent Review considered only the narrow allegations made by the anonymous "whistleblower" and not the wider issues raised in the evidence which we presented.

In particular, it did not deal with the question of the number of children with Down's Syndrome who were not offered surgery at the Brompton (which appear to be higher than other units), many of whom went on to have successful surgery elsewhere; delays in offering surgery to children with Down's Syndrome; and the follow up and after care of inoperable children with Down's Syndrome.

We are not clear whether these matters will come within the terms of reference of the new panel, which appears to be restricted to drawing up new guidelines for the future.

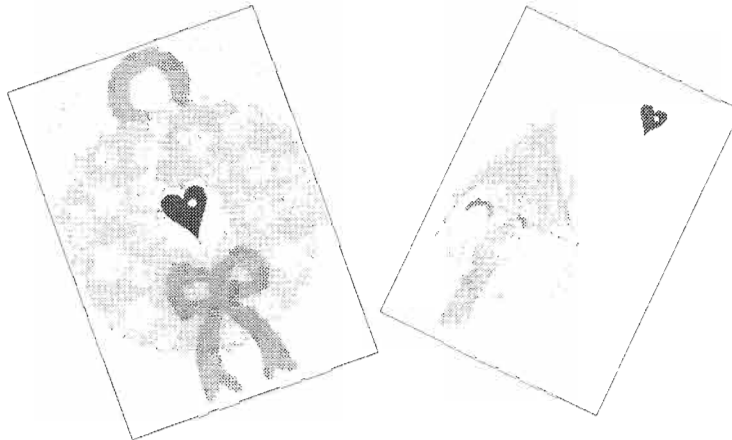
We are concerned that these important matters should not be lost sight of in the transition from one panel to another.

We are pleased to see that the new panel will be chaired by Ruth Evans and that it will have lay members. We will be seeking early clarification from her on these matters.

We will be pleased to present evidence to the new panel and to assist them in their work, which we consider of considerable importance and overdue.

The Down's Heart Group does not intend to make further statement on this matter until it has presented its evidence to the new panel.

Christmas Cards



This year we have two cards which we are selling in mixed packs of both designs. We hope that you like our festive wreath and nativity scene and will help support the Down's Heart Group by buying and sending some of our cards this year. And why not see if your family and friends would like a pack too!

Cards are available in packs of
10 at £2.15p or 50 at £9.50p
(including p&p)

Please contact us if you would like a sample card and one is not enclosed

We are also able to supply you with books of stamps with your order with the profit coming to the Down's Heart Group

Prices for overprinting cards with your own message are available on request

Order Form

PLEASE COMPLETE USING BLOCK CAPITALS and post to National Office address

Please send :

To :

..... packs of 10 cards @ £2.15p = £ - p

.....

..... packs of 50 cards @ £9.50p = £ - p

.....

..... books of 10 2nd class stamps @ £1.90p = £ - p

.....

..... books of 10 1st class stamps @ £2.60p = £ - p

.....

..... ceramic mugs @ £4.00p = £ - p

I would also like to make a donation of = £ - p

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

TOTAL of cheque or postal order enclosed = £ - p **N.B. Postage and packing are included.**
Payable to **"Down's Heart Group"**

PLEASE ALLOW 14 DAYS FOR DELIVERY

Charlotte's Story

After a rather strange start to my pregnancy (it took three tests before my G.P. would confirm I was pregnant!) everything went well until I developed pre-eclampsia again, I had also had it when expecting my first daughter Carrie. A close eye was kept on me and the baby until it was decided that I would be induced at 36 weeks. I was admitted to hospital and the following day was taken to the labour ward at around 4.00pm. By 8.30pm I had a beautiful baby girl, she was handed to me for a quick cuddle before being whisked away to the SCBU.

I remember commenting on how "squashed" her face looked, it never crossed my mind she might have Down's Syndrome. About an hour later a midwife popped her head around the door and told us the paediatrician was on his way to see us - I knew something was wrong. In came this young man who simply blurted it out - "Your daughter has Down's Syndrome", it came as a great shock, I was only 24 years old.

At two weeks old Charlotte was diagnosed with two holes in her heart (an ASD and a VSD). We were referred to Newcastle's Freeman Hospital for an appointment with Dr Bain. He was great, explaining everything in plain English! He said Charlotte would need to be put on some weight before surgery as she was only 5lb 2oz. This was easier said than done as she was being tube fed. At four months old, on 8th December 1994, she went to theatre.

Almost six and a half hours later we were allowed to see her. They had lots of problems trying to get her onto the heart lung bypass machine as she was still so small, only 5lb 15oz. She was so tiny and helpless, we stood at the side of the cot in ITU and told her how brave she had been. She turned and smiled, it was as if she was letting us know she was OK. A week later we were allowed home.

Everything went well until 1st July 1996. She had a terrible summer cold and was still asleep at 8 o'clock so I let her have a lie in. By 9 o'clock she was still asleep so I went to wake her, but couldn't. I could see that she was still breathing, so I couldn't understand why she wouldn't wake, she was floppy and wouldn't respond. I called an ambulance and then our local G.P. as I knew he would arrive quicker.

As soon as he came in through the door he ran back out to his car for an oxygen mask. After about 10 minutes she started to come round. The ambulance arrived and we were taken to Carlisle Hospital. When we arrived we were put in a room and the nurse came to take details. She said the paediatrician would see us shortly. Four hours later and with no help from anyone, the diagnosis was that she had low blood sugar levels, although no blood tests had been taken!

Off we went home, told to give her a sugary drink should it happen again. Four weeks to the day it did, so we took the advice, to no avail, called out the Doctor again, who again gave oxygen and she slowly came round, and was fine the rest of the day. After four weeks it happened a third time. I waited to see if she would slowly come round on her own as our G.P. had instructed and she did and again was OK. At our next visit to our G.P. he asked what the hospital had said at the follow up

appointment - what follow up? None had been made, he telephoned there and then, and we went the following week.

It was suggested to us that she may have been coming round from an epileptic fit when we were finding her drowsy in the morning, so tests were done. These proved negative, nothing more was done and she had no more "funny turns".

In March 1997 we had a routine appointment with the cardiologist Dr Bain, he asked how she had been and I explained about the "funny turns", he seemed to know what it was and asked us to go and see a colleague in Newcastle. Charlotte would need to stay overnight for a sleep study, this was arranged for the following Tuesday. She wasn't too keen on all the wires and monitors, but finally went to sleep.

The next morning Dr Spencer arrived to give us the news, Charlotte had Obstructive Sleep Apnoea, and would need to sleep on a C.P.A.P. ventilator. I was devastated, she had been through so much, it just wasn't fair, I cried, not knowing how she could cope with this. That night the nurse brought in the

C.P.A.P. and showed me how to use it, Charlotte was already asleep when we put it on, she amazed us all at how well she managed to cope, and two days later we were allowed home. She goes once every six months for a sleep study to see if things are improving, but is still on the C.P.A.P. at night.

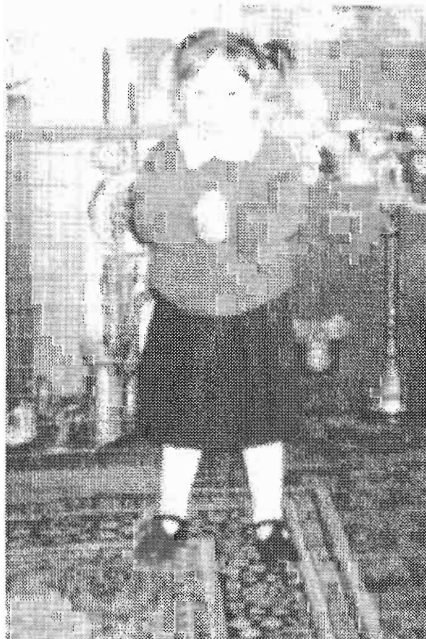
In September this year Charlotte joined her big sister Carrie attending our local mainstream Primary School. I was so proud of her, she has come through so much, but is always smiling and loves a cuddle she really is a very special little girl.

Thank you all for such a wonderful Newsletter and just for being there when we need you.

A very proud mum,

Michelle Gray
Appleby, Cumbria

P.S. If there are any readers who also have a child with Obstructive Sleep Apnoea I would love to hear from them. Please write care of National Office.



PLEASE HELP US

by saving stamps, postcards and ring pulls

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

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

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

THANK YOU

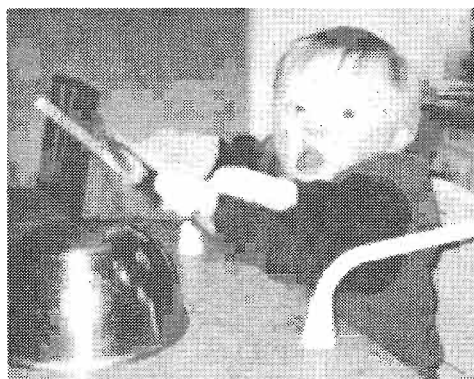
Matthew's Story

Matthew John was pulled into this world by three people having got stuck by his shoulders. I was not aware of the drama going on as I was floating up on the ceiling with the gas and air, but eventually I was handed my little boy. He was a bit of a stranger to me, but it took me a day or two to get used to the sight of my other two. He wasn't interested in the breast and he seemed very quiet, but he was lovely.

When his head had crowned they realised he had been in distress as it was green, hence the number of staff in the delivery room. They decided to take him away to warm him up as he seemed to be a bit cold. We had the required cup of tea and talked of how well the acupuncture had seemed to help the second stage of labour – my partner John was the acupuncturist. The plan had originally been that I would have the needles during the first stage as well but it hadn't worked out that way.

I had been in labour for the best part of a week with nothing constructive happening, and I was very fed up and tired of pain. I was seven days overdue, so finally in despair I took myself in to find out if the baby was alright as I hadn't felt him move for a while. I was monitored and the baby was fine though quiet, and I wasn't in labour. The nurse suggested that I have a nice hot bath as that sometimes gets things going, to stay in for the night and she would give me a sleeping pill so I could get some rest.

Needless to say the pill didn't work and the pains got stronger. The hospital was very low on staff and the ward I was due to go into had been closed! The nurse on night duty was very busy, but eventually she decided to monitor me again. The contractions had changed and I was six centimetres dilated. I was promptly put in a wheelchair and whisked over to delivery. John had gone home several hours earlier, so he was contacted and all I had to do was hold on until he got there! Hence there was no acupuncture during the first stage of labour.



After the birth I was taken to a separate room off the closed ward, which gradually filled up with new babies and mums. Matthew had been born at 3.10am and at 7.00 am a paediatrician and a nurse came and asked for my permission to allow Matthew to be taken to the Royal Brompton for tests as he needed a lot of oxygen, and they wanted to check out his heart. I was wheeled over to see him in SCBU, where he was ready to go in his mobile incubator. I spoke to him and he responded to my touch.

At about 12.00pm I heard that he was on his way back to Maidstone, and at 2.30pm I was taken over to see him again. He was still well wrapped up in his incubator, but he was due to come out of the head box which was good news. Things seemed to be looking up. I assumed that as he hadn't been at the Brompton for very long, that everything was OK.

John had gone to do a lecture, so I had been alone for most of the day, recovering and very glad that my body was no longer pregnant! A while later I was told that the consultant paediatrician wanted to see me and my partner at 6.00pm, and it was important that he see us both. I contacted John and told him to get to the hospital on time. He already knew that Matthew had been to the Brompton for tests, he also knew, but didn't tell me, that if you went to the Brompton it was serious.

During the day I found out that they thought that Matthew's shoulders had been broken when he was pulled out, and also they were worried that he had ingested meconium and also blood as the cord had broken during delivery. It transpired that apart from a broken right collarbone, he was fine. He had a sign on his cot "handle me gently I have sore shoulders".

At 6.00pm we were taken into a comfy room with the doctor and a nurse and told the complete opposite from what we were expecting. We couldn't take it in at first, so we didn't have much of a reaction. Not only did Matthew have a severe and complicated heart condition, they thought he also had Down's Syndrome – a blood test would confirm it. We were told that his heart condition was operable, and we would be referred to the Royal Brompton for further tests in another month.

When we went back to my room after seeing Matthew, the full extent of what we had been told began to sink in, and we went through all the emotions everyone in the same situation does. But like most people, over time you get used to it, learn to adore your child for who he or she is, and get on with it.

After a couple of days Matthew was out of the incubator and managing to feed from the breast. When I first started to feed him, the nurse vaguely mentioned that he might have trouble, but ignorance is bliss – I didn't know that babies with Down's Syndrome and heart babies can have trouble sucking – we persevered and he latched on and did really well from then on.

Matthew had his shunt operation at the age of five months, and I can honestly say that it's the most traumatic thing I've had to deal with. But the operation was a success and his blood saturation levels have improved slightly. He has Tetralogy of Fallot and AVSD, so further surgery is needed, but we have every faith in the wonderful heart surgeons at the Brompton.

As I have mentioned before, my partner John is an acupuncturist and also a Chinese herbalist. I do Reiki and Metamorphic Technique, my mother is a healer and reflexologist, and we have several friends who are healers and complementary therapists. So needless to say, we have taken this route with regard to Matthew's care at home.

Every day Matthew has a concoction of western and Chinese herbs to help strengthen his heart and immune system. He has cranial osteopathic treatment every six weeks, which again keeps him physically fit and helps keep the excess mucus at bay. He has regular Metamorphic treatments to help his mental development and he is on a healing list.

Matthew responds well to all this help and is very well despite his problems - we hardly ever see the doctor. The complementary therapies give us the power to help our child where the doctors don't seem to be able to. If anyone would like to talk to us about the therapies we use, please do not hesitate to contact us.

**Karen Gavin
Nettlestead**

Sarah and Gavin's Story - Our Experiences!

When we adopted Sarah at 10 months old we knew she had a heart condition, but little did we know what it involved. Our first visit to the cardiologist in Aberdeen was very worrying as we were going in "blind" as it were. We came out of there having been told "we'll send you to Edinburgh for catheterisation". Edinburgh? Catheterisation? Our minds were in turmoil.

The appointment arrived and we set off on the 180 mile trip not knowing what to expect. We were shown to the ward and Sarah was given a bed. I was told that unfortunately there wasn't a bed for me so I ended up on a camp bed in the playroom!! Sarah was hysterical and when they took her away in the ambulance to the other hospital she was beside herself.

My husband and I wandered for miles waiting for her coming back, then came the news that "it would be too dangerous an operation for her to go through". We just accepted it, but in hindsight I wish we'd insisted that they operate.

Six months after this we adopted Gavin who also had a heart condition - Aberdeen clinic - Edinburgh - Catheterisation, here we go again!!! After tests it was decided to operate as Gavin would not have lived. They wanted to go ahead right away, but Gavin and I took flu and had to go home.

A month later we were back in the same ward only this time I got a bed in the Mothers's Unit!! It was a lonely time - I was nearly 200 miles from home, on my own in a strange place (which I may say was not the cheeriest place I've been in), but

it's amazing how many friends you make and there is always someone worse off than you.

I'll always remember the morning of Gavin's operation - it was a lovely bright spring morning. I kissed him goodbye knowing that he only had a 50/50 chance of coming through the operation. That was the longest day of my life. I had been told not to come to ITU until 4pm and when I got there the surgeon took me into a wee room, and of course I thought the worse. However, he gave me a big cuddle and said everything had been a great success. I howled!

Gavin spent two weeks in ITU as he developed severe croup, but he was a wee fighter and got back to the ward and had his first "solid" meal - mince and tatties!!

A week later he was home and despite recurrent bouts of croup he hasn't looked back. He plays football, does gymnastics and is generally a typical boy.



Sarah has, until now, enjoyed good health although she is at present on diuretics as there has been a build up of fluid. She has also been on Thyroxine since she was three, but her levels have remained steady.

We don't know what the future holds for Sarah, or for Gavin, but we just take each day as it comes and just treat them as "normal" children.

Allan & Morag Doak

Abigail's Story

Abigail was born on 17th June 1998 at 4.35am, weighing 7lb. After what appeared to be a very healthy pregnancy and labour, I recall feeling quite depressed and cried a lot, but I put this down to Abbi being our second child and people around me were not so excited, or so I thought. Abbi came home from hospital the same day and to me she seemed a model baby. She slept all night, breast fed on demand and appeared content. Joshua, Abbi's 20 month old brother bonded immediately and quickly learned her name, gave her his toys and frequently kissed her.

Abbi's early weeks of life were okay. I expressed a few concerns about her skin being dry and her hands and feet being very cold, and the health visitor questioned her poor weight gain and took urine samples. I was assured everything was fine; told to moisten the dry skin, and that her hands and feet would be okay, just that in the early days the blood supply feeds the vital organs first. The urine test was negative. More concern was expressed about my own emotional well-being; suggestions made that I may be depressed.

In retrospect I feel I was responding to others reserved approach to Abbi, including Abbi's dad Paul. I clung to a strong relationship with my mam who is always there for me. As time went on Abbi attended the clinic fortnightly, had all her vaccinations and health checks, at all of which I was told she was doing well and progressing normally. Although I felt in my own mind Abbi was not developing as quickly as her brother, I thought she must be under-stimulated due to sharing time with Josh.

I returned to full time work after 18 weeks maternity leave leaving the children with my mam and dad. At Abbi's hip check on the 12th November 1998, I expressed my concern that Abbi was not holding her head as well as I would expect. I was told she was developing normally and doing everything expected. The following day Abbi sounded a little chesty so I asked my mam to take her to the GP. I received a phone call that afternoon to say Abbi had a virus which did not need treatment just to push fluids and that the doctor could hear a heart murmur for which he would refer her to the Freeman Hospital

consultants for investigation.

Over that weekend we watched, but would not accept Abbi's condition was worsening. On the Monday I went to work leaving the children as always with my mam. I rang the doctor from work who informed me that nothing could be given for a virus and he would refer Abbi to a cardiologist. That night I went home and within an hour I saw our baby deteriorate drastically. We rushed her to the emergency doctor who said she had pneumonia and was critical. She had to get to hospital immediately. X-rays and swabs were taken. Abbi had the virus bronchiolitis and pneumonia. She was put onto oxygen and received intravenous antibiotics immediately.

The following morning the doctors did their rounds. As they discussed Abbi I sat alone on the bed. Although I did not know what they were talking about I knew it was more than what she had been admitted for. The doctor turned and asked me if Abbi's dad was oriental I said "no why?" The doctor replied "I think your daughter has Down's Syndrome". At that I went into a state of shock and disbelief.



My mam was sent for and my sister, brother-in-law and Josh came with her. My sister said she had had an inkling, but because the professionals did not pick up signs she thought she must be wrong. This at the time I could not handle and became physically and emotionally out of control. The ward sister managed to locate Paul. When he arrived at the hospital I told him their suggestions. He was obviously in a state of shock, but at the same time something changed in his approach to Abbi. Tests were taken and we had to wait until the Friday (four days) for confirmation.

When it came, although we thought we had prepared ourselves we had not. The physical pain I felt was indescribable and I had to get away from everyone in the room (family, doctors, nurses and Abbi) and be alone with Paul. During the devastation Paul was able to acknowledge that he had been frightened of Abbi, that it was as if he knew there was something wrong, but now he had no fear. We went back into the ward and I picked Abbi up and have her a cuddle, then Paul changed her nappy. She was five and a half months old and this was the first time Paul had done this, which was quite the opposite to the way he was with Josh as a baby.

The next devastating news came the following Tuesday 24th November when after an echo it was confirmed Abbi had a VSD which needed surgical closure as soon as possible, but

due to the bronchiolitis virus it would have to wait six weeks.

The same questions rolled over and over in my head:

**WHY US?
WHAT WILL THE FUTURE BE?
WILL ABBI DIE?**

All questions that have no definite answer. We felt angry towards people who had lots of "perfect" children and did not appear to us to care and dote on them as we feel we do on our children. People tried to comfort us by saying daft things like "special children are only born to special parents". What a load of rubbish. This sweeping statement still infuriates me. However, we have learned quickly that people just do not know what to say, and why should they. Abbi is not theirs, she is ours, only those closest have any idea of the pain and the loss.

Abbi had her VSD closure on the 14th January 1999. The operation went fine, but concerns were expressed over a leaking valve, which would be checked regularly. Abbi went home six days later. Sadly Abbi's follow up appointment to see the surgeon was brought forward as her breathing changed to a pant. Mr Hamilton (the surgeon) confirmed his concerns that the valve was leaking more and proposed hospital admission for Abbi to commence heart medication "Captopril", and he was not ruling out further surgery in the next six to 12 months to repair the valve.

I am sitting in the hospital February 13th 1999 writing this account with many emotions flooding through me, but I only want to share the positives as I have been angry for so long for myself.

- 1) I am so proud and at times jealous of the obvious bond Paul and Abbi now have.
- 2) Everyone, who means anything to us, adores Abbi for who she is and are not shy in saying this.
- 3) Both our kids are put on equal pedestals by all our family and friends.
- 4) Josh expresses his love for Abbi daily and she is now responding to him endearingly.
- 5) Relative strangers, stop and ask genuinely how the kids are.

We wish to express a special thanks to hospital staff, family and friends who have and will always be there to help, support and comfort us since November.

I would especially thank Anchor Trust and the people I work directly with. I do not believe there could be another employer that could be more understanding and supportive.

**Alison Fryer
Whitley Bay**

Memorial Donations

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

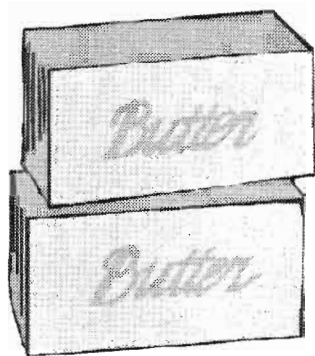


Jack Jelfs - (grandfather of Hannah Jones)

Nasal Congestion and a Milk Free Diet - One Parents Story

After attending the Down's Heart Group AGM in Leicester last year, and taking part in the medical workshop, we brought home with us some literature on Nasal Congestion in children with Down's Syndrome written by Dr Jennifer Dennis. When I eventually found time to read it, I had to agree with the statement that "we have been too accepting of the problem of catarrh in our children, regarding it as an inevitable part of the syndrome."

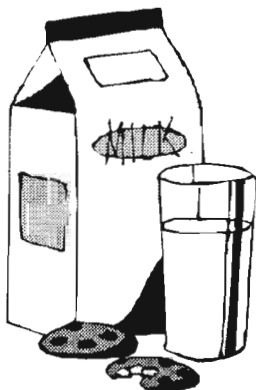
Like many, our son Jacob now nearly 7, did have a permanently snotty nose, (for want of a better word), which required constant wiping through the day and inevitably got worse when he was ill, which for minor illness was frequently. As a mum, the worst part of the snotty nose ritual was the decrusting in the morning. Painful for Jacob and a chore for me. How many mornings have you found yourself sitting on your child, with a supply of warm soapy water trying to wipe away the thick crust that has formed round the nose and attached itself to their eyelashes?



So from Dr Dennis's five possible solutions in tackling the problem, we chose to go with the Milk Free Diet, but we decided to do this properly as to me milk with its calcium and vitamin content seemed like a vital part of anyone's diet. And for Jacob it was, as his meals consisted of a Yoghurt for breakfast and milk chocolate or ice-cream as his puddings, not to mention the amount of butter he liked on his bread.

The first thing I did was to contact my health visitor who promptly brought round some recipe books for Soya meals and told me to go to our G.P. and ask her for a referral to a dietician, which I did. And as we have an excellent G.P., she immediately referred us to a dietician for which we waited about a month to receive an appointment. Strange how talking to all these professionals, they were all aware that milk can increase the production of catarrh.

The dietician gave me lots of ideas of replacement foods for Jacob and I decided to put him on a three week trial of completely cutting out ALL milk products and milk by-products from his diet. Fortunately although milk chocolate was out, plain chocolate was in - no it had never crossed my mind either that their was no milk in dark chocolate. Luckily it was July, so I had complete control of Jacob's diet and didn't have the worry of inconveniencing school.



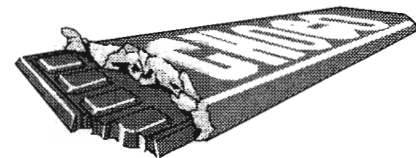
So off we went reading all the labels as we went round the superstore buying our weekly shopping. However after a while you find you get very good at shopping for a specialised diet and your always on to a winner if you buy fresh food and avoid pre-packed and frozen foods. Also I must congratulate the larger stores these days as Soya products are readily available on the shelves, such as milk, butter, yoghurt and ice-cream.

Biscuits are the biggest problem as most have some form of milk product, but I have found the cheaper the brand the more successful I've been, and did you know Jaffa Cakes are made with dark chocolate??

After the first week there wasn't much change in Jacob, but the second week, although still snotty, I could see a vast improvement in his complexion, his skin seemed to tighten up around his face and didn't seem as grey and sallow looking. After three weeks I've got to be honest, the change was noticeable in him and he actually had a clear nose. The dietician even commented on how much quieter his breathing was. But to test the theory we were to go back to his old diet to see if there was any deterioration. Although there wasn't an immediate reaction, a couple of days of milk product build up in his system brought back the snotty nose. It took three weeks to clear Jacob's system of milk products but only two days for the catarrh to return. Which was enough to convince me that a milk free diet was the way to go in the future.

So with the dietician's backing his school now provide Jacob with suitable meals and I try to keep things strict at home. This means that when we are out and about or at parties the odd deviation from his diet is acceptable and doesn't cause too many problems. However, Christmas did prove to be difficult.

Jacob has been on this diet for 6 months now and the notable benefits have been his beautiful snott and crust free face, there's no longer any battle in the morning when it comes to getting washed. He tends to breath a lot more through his nose, which means his mouth is closed a lot more which has in turn stopped the dribbling completely.



Considering the time of year now, he hasn't been ill any more than his younger brother. His teachers at school are extremely impressed with his progress over the last term, he now joins in with the class, he attempts every task he is given, and he has even started to participate in his language group and makes an effort at copying speech, his concentration levels have increased, his attention span is greater, and I believe his hearing has improved. But then wouldn't you feel better in yourself if your permanent head cold had gone away and your airways were now clear???

From our own experience I would definitely recommend a Milk Free Diet to anybody and say after a couple of months, its just as easy to cater for as any so called normal diet.

**Amanda Phelps
Earl Shilton**

This article by a Down's Heart Group member, was reproduced from the newsletter of the DSA Leicester Group in which it appeared earlier this year.

Fund-raising Update

WANTED Runners for London Marathon 2000



**Do you know someone who wants a place
and would be willing to run for us?**

The Down's Heart Group has its own guaranteed entries for the London Marathon in 2000. We are looking for runners who need a place and have missed out on the ballot entries (although we'd welcome anyone with their own place too).

- x** We aren't asking for a minimum amount of sponsorship to get a place, but we do need to cover the cost of the entries and of course make some money for the Group at the same time.
- x** We aren't giving away lots of fancy goodies to our runners, just a promise that all the money raised will go towards our work. (Like all charities we have admin. costs - but we believe these are minimal for an organisation of our size).
- ✓** We can supply sponsor forms and information to help with fund-raising.
- ✓** We can guarantee that your efforts will be greatly appreciated by the Down's Heart Group membership.

If you or anyone you know is interested, please contact Penny Green on 01525 220379 to find out more.



Fund-raising Update

Welsh Charity Walk



On 5th June, I successfully completed a seven mile walk along with family and friends, to fund-raise. Our daughter Gwen Siân was born on December 1st 1998, and the help, support and advice that we have received from you has made me realise that we are not alone. I wanted to show some appreciation with a fund-raising event during Down's Syndrome Awareness Week to ensure that your good work can continue in helping families like ours.

I was overwhelmed by peoples generosity, and we managed to raise £1,437 in sponsorship and donations. I decided to share the money as follows:

DSA Welsh Regional Office	£700
DSA National Office	£315
Down's Heart Group	£422

Gwen had heart surgery on August 4th at Bristol and I am pleased to say that we have had no problems with her care in the medical field. I appreciate that some of the money will be spent in a bid to end medical discrimination against people with Down's Syndrome and do recognise the benefit of this project.

I am also sending a photograph of those who took part in the walk. - Gwen came along too!!

Julie Evans
Fishguard

A few words from National Office

Over the last few months the workload at National Office has increased significantly. Due to our limited staffing (one person), this has meant delays in responding to some requests, so apologies to anyone who has had to wait longer than usual for replies to letters etc.

We are taking steps to improve this situation, one of which is the recruitment of a volunteer to help out on a regular basis. So if you ring in during the week and get a different voice on the phone, please be don't be surprised.

This would probably also be a good time to explain about the availability of the office telephone line. Generally the phone is manned between 9.30am and 12.30pm, (but I'm usually around up until about 3.00pm), every weekday. Outside of these times you may get through to the ansaphone, but if you leave a message we will get back to you as soon as possible, particularly if your call is urgent.

As we have two telephone lines into the office, there may be times when your call cannot be answered as I am already on the other line. In that case, please do leave a message on the ansaphone, even if it's just to say you will call later - there is nothing worse than wondering if you have just missed a call from a distraught new parent!

At weekends and during annual leave, the telephone line is redirected to nominated volunteers. They do not have access to membership records etc. so may have to take messages to pass on to National Office. They will try to help you in any way they can, but particularly at weekends their main role is that of emergency support to families.

We realise that 'office hours' are not always convenient for you to make your call, in the same way that our volunteers cannot be available at all times to answer it. If you need to contact us and your call is unanswered, please make use of the ansaphone or you can of course always write to us or send us an e-mail.

Front Cover Picture

For any of you wondering about the photograph on the front cover, the young lady featured is Ashleigh Owens from Sunderland. Her Aunty lives near National Office so Ashleigh's family visited us a couple of times when she was younger.

We recently received the photograph along with a cryptic covering note, part of which is reproduced below.

Hello, remember me? I bet you can guess who I am. I am five years old, I have a big sister who is six years old and a little sister who is two years old. I have had my complete AVSD repaired twice in a week. I spent 15 days in Intensive Care at

the Freeman Hospital Children's Heart Unit.

I was tube fed long term and never bottle fed. I have acid reflux and digestive and bowel problems i.e. enzyme deficiencies and food intolerances.

I have a Robertsonian translocation (21:21) which was new in me. By now you will have guessed who I am ...

It is lovely to see that despite her problems, Ashleigh is doing so well.

Information / Can you Help?

Vincent is now fourteen and has an unoperated complete atrioventricular septal defect and pulmonary hypertension. He is currently using an oxygen concentrator eight to ten hours a night and an oxygen cylinder during the day when needed. He has hypertensive crises which are very worrying, but up to now he always recovered within two to three days.

He has a high haemoglobin count of about 24+ I believe. He has had venesection, but this caused him great distress and gave very little benefit, so it will not be considered in the future. The Eisenmengers Complex gives him severe headaches, visual disturbance, blood shot eyes, joint pains and rashes all over his body among other things. He has a variety of medications including frusemide, spironolactone, aspirin, antibiotics, morphine and valium (when in crisis or fitting).

My problem now is the severe pain that he is getting in his right leg. It has become more frequent since April, now weekly. It is impossible for him to put any weight on the leg.



Vincent and Helen on Red Nose Day

We have been to our local hospital who know Vincent well and are excellent with him, but they can't come up with a positive reason, even though he has been x-rayed, seen the physio etc. The thing that seems to work is to increase his aspirin from one to three a day until the leg is easier, but this seems to be the cause of him coming out in biggish purple blotches on his body - they disappear when the aspirin is reduced.

I wonder if any other parents of a child / young person at Vincent's stage in his problems have had a similar experience with the legs? It seems to be from his knee, but I'm not sure. As a baby / small child he did have an awful knack of clicking his knees almost out of joint - you could see the knee joint moving out sideways. When I first heard the noise I thought he was banging something on his cot! Could this be the cause? I would be very interested to hear from anyone who has any similar experience.

Secondly, and totally unconnected with Vincent's health, I am after a touch screen for his computer. He finds the mouse very difficult to manage, but a touch screen is very expensive. I wondered if anyone knows if such items are available second hand or cheaper!

By the way, Vincent still has a full life. He manages to enjoy every day, depending of course on how his health is. When he is feeling well, his greatest pleasure in life is making whoever he can, as wet as possible with his water pistols, his water game Hydrostrike, or just splashing you. He also loves cooking - he makes lovely scones and fairy cakes (with a little help otherwise the egg shells go in too!). He enjoys his videos and books.

He likes shopping but only certain shops: Early Learning Centre, WH Smiths, Woolworths, Disney Store, HMV and Virgin Megastore, anything else does not hold any interest. The staff in all these shops know him well and miss him when he has not been in for a while. He also gets on well with his

younger sister Helen, who also has Down's Syndrome.

All in all we have a good life, although he has to rely on a wheelchair nowadays when outside. I suppose the problem of the painful right leg could eventually make him immobile in the home as well, so I'd like to try to find the cause. I look forward to hearing from anyone who can help with my queries.

**Pat Lucy
Wembley**

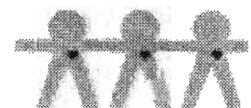
If you would like to contact Pat, please send your letters C/O National Office.

Children's Heart Federation

The Children's Heart Federation has moved offices and also launched a new free phone helpline.

The address is :
Children's Heart Federation
52 Kennington Oval
London
SE11 5SW

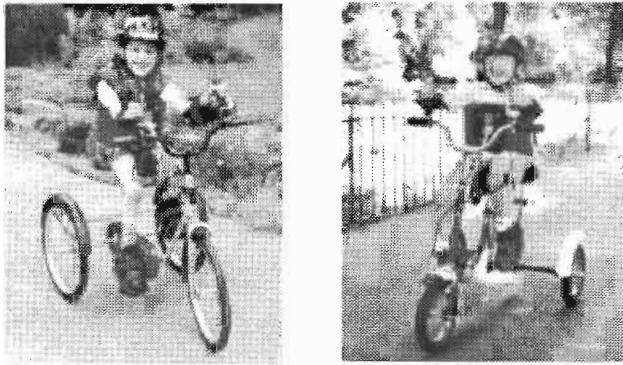
Helpline : 0808 808 5000
Telephone : 020 7820 8517
Fax : 020 7735 8718
Email : chf@dircon.co.uk



Information / Can you Help?

Special Needs Cycles

Following the request in our last newsletter about a tricycle for an older child, one of our members called to tell us about her very positive experiences with a company called Pashley Cycles.



Pashley are a specialist company who make hand built bikes, and have introduced a range of bicycles for children and adults with special needs, which even include a wheelchair tandem with a fully detachable wheelchair which goes in front of a specialist bike.

They have a range of tricycles suitable for small and larger

children, many of which feature a low gear fixed wheel to reduce speed and allow reversing, wide axles for increased stability and a parking brake for ease getting on and of the tricycle. There are also a number of optional extras available which include vertical hand grips, moulded saddles for pelvic stability, heel cups to maintain foot position and a push/pull bar to assist in parental control.

The company offer a free assessment service anywhere in the U.K. mainland, where they are happy to show you some of their products and advise on what would be most suitable for your child. Whilst these bikes are not cheap, they may represent the perfect solution for many children, and there are a number of organisations which can be approached for assistance with funding the purchase.

To find out more, contact Malcolm Jones or Becky at :

Pashley Cycles
Masons Road
Stratford-upon-Avon
Warwickshire
CV37 9NL

Tel : 01789 292263
Fax : 01789 414201

or visit their website at www.pashley.co.uk

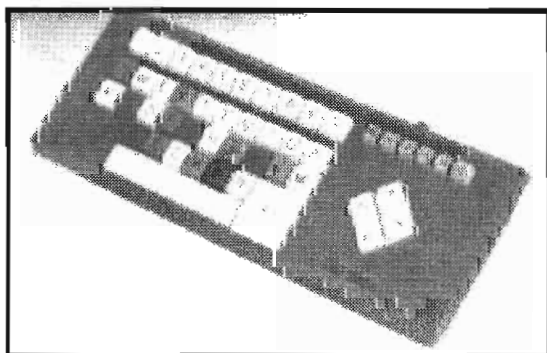
Computer Accessories

Down's Heart Group member Alayne Levy, was kind enough to come along to our AGM in April and bring with her a range of books and computer accessories that she has found useful for her daughter Hannah aged 10.

Alayne has found that instead of buying expensive specialist software marketed for children with special needs, that there are many good programmes available that are easily adapted for our children. As the mum of five, the eldest of whom has Down's Syndrome, Alayne has good insight into children's usage of computers, and the different needs of children with Down's Syndrome.

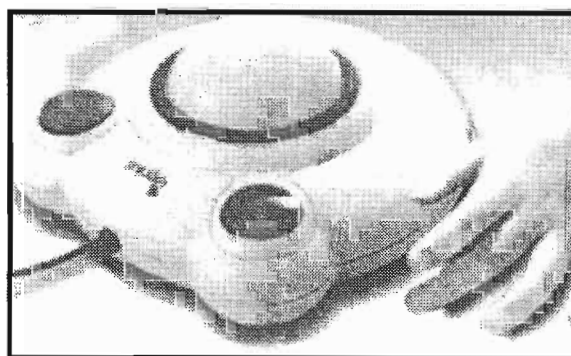
She has also witnessed some of the difficulties children experience in using computers, and has found a number of products which can help overcome some of these.

The BigKeys Plus keyboard is an uncluttered keyboard with brightly coloured keys, one-inch square in size, making them



easy to see, find, read and press. No setup software is required and it is compatible with all PCs.

The KidsBall is a large track-ball which can be used on a desktop or in your lap. It has a bright fun shape which will appeal to children, and it supports all software that operates



in Windows 3.x/95/98. It comes with easy install software and can coexist with your normal mouse.

For more information about either of these products, to place orders, or to discuss the suitability of software for your child, you can contact Alayne at :

Interactive Kids
on
020 8 891 1644

Members Page

We recently received a letter from Natasha Grange of Romford, enclosing copies of two accounts she had written to go in her portfolio at college. Thank you to Natasha for taking the time to send them in, and we are glad that you enjoyed the Conference.

Sadly, as they were copies, they would not scan very well for the newsletter, so we have retyped them here, but we must congratulate Natasha on her lovely handwriting and perfect spelling. The following are typed exactly as written (I hope so or no doubt Natasha will be in touch to tell me off - Ed).

I went to Portsmouth to the Downs Heart Group Conference with my mum and dad. I had to get up very early (for me) as we left home at 7.00 in the morning but I slept in the car for most of the journey. We had our breakfast - a picnic - in the car.

When we arrived, we had coffee and mum and dad stayed for the talks and I went to help with the little children. We drew stencils and coloured them in, and talked to the other helpers. Some of the children watched television - cartoons. Then we had some lunch, it was wonderful. After that I went to help with the babies and cuddled them which I liked.

I won a prize in the raffle which I gave to my dad, it was a bottle of whisky. Then I did some more talking to different people and had more refreshments. After that it was time to say goodbye and thank you very much.

NATASHA GRANGE



THANK YOU to Natasha for telling us something about what she has been doing in the past months.

Would **YOU** like to share some of your favourite things with us?

PLEASE send us your drawings, stories and letters, or maybe a photograph of you doing something you enjoy.

And tell us if you have won a prize for being good at something like riding.

I go riding with the Pony Riding for the Disabled Trust. Last month it was the yearly competition. I came first in the Handy Pony Class which is all about control of the pony. I had to go in and out of poles, trot over poles, put a plastic cup from one side to the other, and other things. Also I came first in the Best Turned Out Rider, I received a silver cup and a big red rosette. After that we had a lovely barbeque.

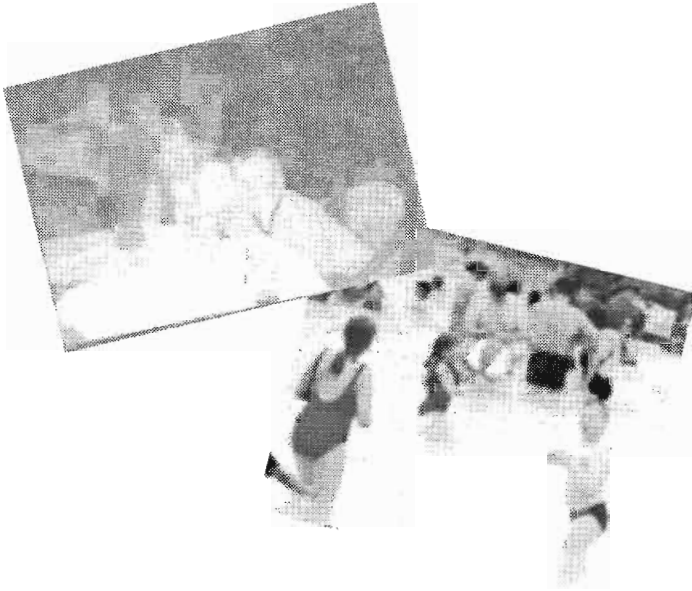
On Wednesday 26th May, I went with the PRDT to the Horse Races at Great Yarmouth. We had our own marquee with lunch and refreshments provided. I enjoyed it but I did not win any money. The PRDT received a cheque from the races presented by a jockey.

NATASHA GRANGE

Letters to the Editor

Centre Parcs Holiday

A short note to say thank you very much for the holiday at Centre Parcs, it was fantastic. All my family had a great time.



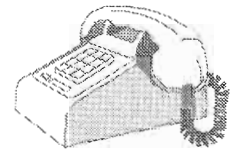
I have sent a few photos of Colin in the swimming pool, we were there every day, after tea as well, the kids just loved it. We were visited at our living room window in the morning by a swan waiting for some bread, also squirrels and lots of cats. In the evening when we walked home from the pool we had to be careful while pushing Colin in the wheelchair as the roads were covered in baby frogs, there were hundreds of them.

One again thank you.

Isabel Turnbull
Stuartfield, Aberdeen

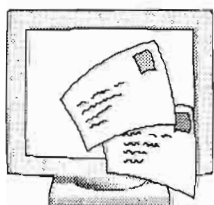
The Turnbull family were the lucky members who were chosen at random to go on a Centre Parcs Break funded by the Children's Heart Federation.

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.

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!



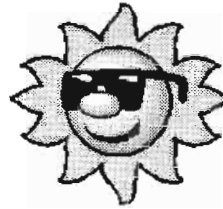
So do keep us informed of new addresses, telephone numbers, e-mail addresses and any interesting news about your child.

Our members are very important to us!

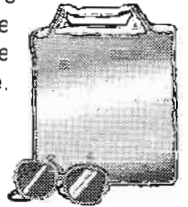


Respite Care Funding

To Penny & Committee,



We can't thank you enough for helping us raise the money for our holiday. We had a lovely time and the weather was OK. Luke really enjoyed having his ice creams and eating chips. We visited the Zoo and quite a lot of places round Bude. We stayed in a B and B recommended through the DSA and found the accommodation very nice and clean. We would recommend it to anyone.



John, Noelle and Luke Ensor
Rotherham

The Ensor family received a grant from the Children's Heart Federation Respite Care Fund as featured in the last newsletter.



National Contacts

National Office



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

Contact or Ansaphone always available (24hrs in emergency)

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

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

The Down's Syndrome Educational Trust
The Sarah Duffen Centre
Belmont Street
SOUTHSEA
Hants.
PO5 1NA
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
00 353 1 6769255

Regional Contacts

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

Sheila Forsythe
Wendy Hellowell



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

Nicola Desmond
Lindsay Wharam



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

Sarah Smith
Linda Wainwright (Glenfield Hospital)



Ireland - N. Ireland & Eire

Rosina Brierley
Marion Delaney (Dublin Hospital)



London Northern - Beds, Berks, Bucks, Essex, Herts., Middx., Oxon. & N. London

Sheila Boniface (GOS Hospital)
Joanna Simms (Harefield Hospital)



London Southern - Kent, Surrey, Sussex & S. London

Katie Spall



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

Sally Hardman



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

Mike Halpin



Scotland - Mainland & Islands

Elaine Thomson (Glasgow Hospital)



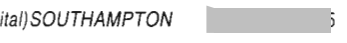
South Wales - Dyfed, Glamorgan, Gwent & Powys

Chris Stringfellow



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

Vickie Richardson (Southampton Hospital) SOUTHAMPTON



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

Lynne Holden



Yorkshire & Humberside - Humberside & All Yorks.

Lindsay Allen
Carolyn Marshall (Leeds Hospital)



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