

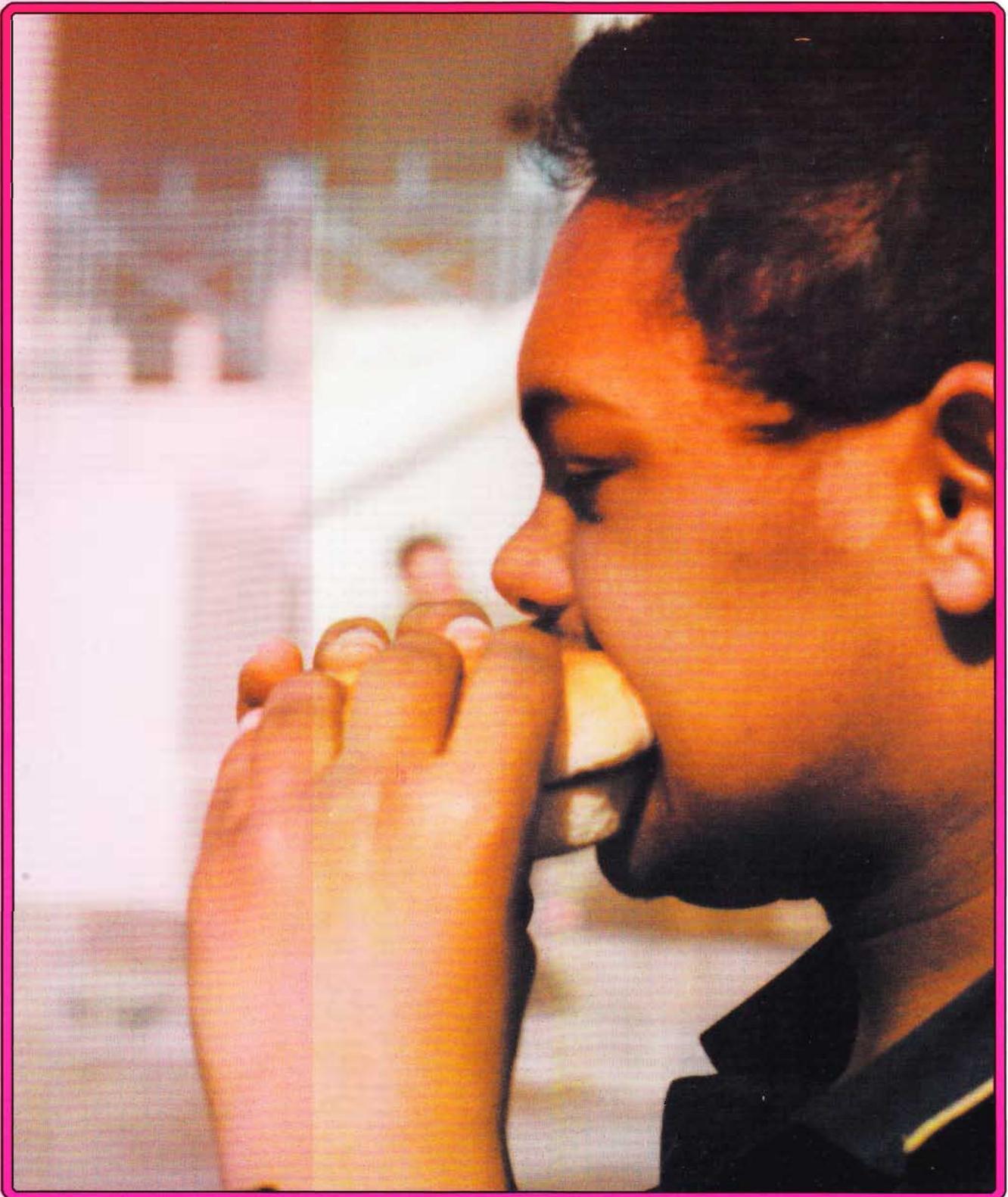


dhg

down's heart group

# NEWSLETTER

Summer 2005





### A note from the Director

Well here we are already heading up to the school holidays and if you are anything like me you are wondering where the first half of the year went.

To make things even scarier, here at National office we are already having to think about Christmas cards and prepare for the busy weeks despatching orders. And before that of course we have our AWARENESS WEEK in November, which I'm sure a lot of you are planning events for, so that will keep us on our toes even more.

Not that we've exactly had a quiet time the past few months. As you already know we have a new updated logo and style which is reflected in the format of these newsletters. But there has been a lot more going on behind the scenes which you will soon all be able to see.

The new website will be launched shortly and for that we have updated all the Topic Notes in the Information Pack and added lots of new ones on topics you regularly ask about. All of them will be available on the website as well as in printed form in a few weeks time.

We have also made it easier for families to contact us from the new website and we hope that although there will be a lot more written information readily available, that parents will still get in touch as we still believe that the 'personal touch' is one of the most valuable things we have to offer.

*Penny Green*

### LAST CHANCE TO NAME THIS NEWSLETTER

After the last newsletter we have had suggestions for a new name ranging from pretty good to rather strange!

We were so busy at our last meeting that we didn't get round to choosing a name.

If you have a good idea for a name please send it to us ASAP. We are fed up with calling it "newsletter"

Listed below are some of the suggestions so far, let us know your comments and suggestions;

- |                  |             |
|------------------|-------------|
| Bighearted       | The Pulse   |
| Upbeat           | On The Beat |
| Catch 21         | Blood Clot  |
| Download         | Pace Maker  |
| Heart Herald     | Zipper      |
| Personal 213     | Bypass      |
| 2 way flow       | C21         |
| The Pump Station | 21 Life     |
| Pump 21          | Echo 21     |
| Connect 21       |             |

### DADS RULE OK

Brazil's footballer Romario says that the birth of his sixth child with Down's syndrome had made him "a happier and more tolerant" person. "I see that some parents of children with Down's syndrome try to hide their children, they do not speak of that. I want to show that it's not abnormal,"

Danny Mardell has written a book about what it is to have a Down's syndrome child, and what it is to love them. Over time Danny has confronted his own bigotry and fallen in love with his boy, but in the book he acknowledges - with brutal honesty - what that involved.

### STAMPS

DHG are no longer able to get postage stamps at a discounted rate, as apparently charities do not qualify. Another fundraising door closes!

### SUCCESS!

On March 3 2005 Rebecca Robinson who is 22yrs old and works in the Bakery Dept of Holmfirth Coop went to St James Palace in London to meet His Royal Highness the Duke of Edinburgh and receive her Gold Duke of Edinburgh Award. Rebecca has worked over the last 7 yrs towards this goal.

She has learned to: -

- Horse ride
- Swim
- Dance
- Knit
- Mosaic Work
- Canoe on Lake Conniston and Lake Windermere
- Camping
- Environmental work for 12 months
- Voluntary work in small animal care
- Made Wood Bird Nesting Boxes
- Walked long distances in the Dordogne, France, Camped and swam in the lakes of the Dordogne, she also had to learn basic French and learn all about French culture and she also took part in a fashion show.
- Made hand made cards to sell for Bridgewood Trust.
- Learnt all about the British waterways canal system, skippered

a canal boat on the Leeds canal and also on the Aire & Calder canal. She also was taught how to work the boat through the locks. She has also spent many hours camping in the English Country side. Mainly the Lake District.

### CONGRATULATIONS REBECCA!



Rebecca Robinson outside St. James Palace with her gold certificate for the Duke of Edinburgh award scheme.

I have just read your Newsletter extra. My son who is 23 has oxygen over night and has done so for a number of years. The difference that it has made has been quite dramatic. He had got to the point where he was like a zombie in the morning, difficult to wake, a very bad colour and unable to function very well at all.

However it was a difficult and emotionally very stressful period for us when we first tried using oxygen. I started him with a mask and he HATED it. He is slightly autistic and always disliked having anything done to him - from hair washing to examinations of body or teeth. Having tried a mask myself I have huge sympathy for anyone using it in bed. Then the oxygen engineer called he talked to Matthew about a canula. We tried it for short periods once he had got used to putting this thing UP HIS NOSE for goodness sake!

Then it was weeks of sleeping in his room waiting for him to take it off as soon as he thought I wasn't looking, and even in his sleep. I was such a wreck from nights of not sleeping and knowing that it was very downhill if he didn't have it that in the end I just wept. That did it. He cannot bear to see me upset and he said 'Don't cry Mum, I will do it' and he did. I praised him to the skies every night and he has been using it ever since with enormous benefit. He puts his music on and sings in the morning! His health improved.

But even this is not without problems. Because of the hypertension in his lungs he has low platelets and very high haemoglobin. He bleeds easily and his blood doesn't clot. He has had dreadful nosebleeds. No one told me until quite recently that it is the oxygen going up his nose that is thinning the lining and drying it out that is probably causing the bleeds. We have to go to the hospital for cauterisation when it happens. So now I put a little vaseline up his nose each night to try to avoid the crusting that happens.

I hope that this can help someone else. A more acceptable method of delivery would be wonderful for those who have problems. Do not hesitate to contact me if you wish to do so.

Angela Weaver

"I'M GONNA GO FOR IT!"

Andrew Lloyd has become a local celebrity after starring in a new video about heart surgery. Andrew, 23, from Newport let the cameras follow his journey from being seen at Outpatients until after his recovery. Andrew required surgery for an Atrioventricular Septal Defect

The video was the idea of Sheena Vernon, a congenital heart defect nurse specialist based at Bristol Royal Infirmary and Eileen Danford, a community learning difficulties nurse, now working for Bath and North East Somerset Primary Care Trust. They realised that, despite the amount of young adults with congenital defects and learning difficulties, there was no information in a format to suit their age group.

A grant from the Down's Heart Group for £5,000 and a grant from the British Heart Foundation of £12,000 enabled the 25 minute video to be commissioned. It has been produced by Photosymbols.

The film, which will be mainly in DVD



Andrew with the film's directors

format was launched in Bristol on June 20th, with lots of interest both locally and nationally.

Eileen says "We are confident that "I'm Gonna Go For It!" will be a

really useful way of easing patients' and their families anxieties at such an important time in their lives."

When asked if he would go through the operation again, Andrew said "No way!" but he is glad that he had surgery and hopes the film will help others.

The DHG will have copies available shortly for distribution. We have been informed that they will be ready in about a month. Please contact National Office for more details.

Do you know about other videos or DVDs that may be useful for our families to see? Is there anything out there on operations, growing up, health, etc? Perhaps your local health service or charity has produced something that could be beneficial to a wider audience? If so, please let the Information Office have the relevant details.

Thanks.

## BEA LILLYWHITE'S STORY

17 May 1998 — the expected date of birth for our first child.

At 36wks I had a routine antenatal appointment at which they suggested that the baby might be breech. In order to find out I returned the next day for a scan and to monitor baby's heartbeat. The test didn't seem to go too well to me but I told myself there was nothing to worry about. I had done all the right things (no smoking, drinking, pate or soft cheese) so therefore nothing could be wrong.

The consultant said that the baby might be a little on the small side. "About 5 lbs" he said. He persuaded me that as it was my first baby it would be better to spend the rest of my pregnancy on the antenatal ward. I went home and packed my bag and felt apprehensive but also really excited. The next time I came home we would have our baby with us.

I was admitted to Poole hospital on a Tuesday afternoon. I was beginning to feel uneasy about things. However, that evening a heart trace was done on the baby and the result was 'fine'. Great, I thought, at least I can sleep easily tonight. By about 8.30 am the next morning I was in labour.

The heart monitor was strapped on again and the print out showed that the baby's heart was not coping with the contractions. I was bundled onto a trolley and rushed off - suddenly it was all systems go. The midwife needed to break my waters and then it was decided I needed an emergency caesarian. I was rushed into theatre. By now I was absolutely scared stiff.

Alan appeared, looking shaken by the suddenness of it all. After only a few minutes the baby was born. Nobody said whether it was a boy or a girl. Minutes passed which seemed like hours. From the haze of my shock I asked 'what is it?' A girl. I was so

happy. I finally had the baby girl which I had secretly hoped for.

More minutes passed. 'Is she alright' I asked. 'She's fine' said Alan, but looked very uneasy. The baby was given to Alan, all we could see was a little nose peeping out through the blankets. Everything seemed okay.

After a while we were wheeled into the recovery room where she was examined. The doctor said she needed to go to the Special Baby Care Unit to be checked over and looked after as she was tiny (41b 6oz) and blue. This seemed reasonable as she had just experienced a traumatic birth.

I was taken to the postnatal ward and Alan went off to phone everyone to tell them that Beatrix Mary Julia Lillywhite had been safely born. Some time passed. After all the trauma and high action of the morning everything seemed a little odd and flat.

In the late afternoon we went to see Bea in the SCBU. She looked very thin and weak and her skin looked papery thin, not at all how I imagined a 36wk gestation baby to look. That's when I started to cry.

The next day we asked why she was in an incubator. Eventually somebody mentioned that they were concerned that she might have a 'syndrome' but that 'syndrome' only meant a collection of identifiable features anyway. Well, the only 'syndrome' we had every heard of was Down's, so about 36 hours after her birth I said to Alan 'she's got Down's Syndrome hasn't she' and he replied 'yes, I think she has'. The enormity of this simple fact hit home and we wept and wept for the child we had 'lost' and also out of fear the future.

We were told a blood sample had been taken to confirm if she had Down's but it would take six days before the results came. The doctors felt unable

to confirm their diagnosis without the blood result so we spent a hellish six days preparing for the worst but hoping against hope this whole thing would be a bad dream. Five days after her birth I was discharged. We didn't have our baby with us. We returned the next day to be given the results of the blood test - Bea had Trisomy 21.

A couple of days later, a doctor explained the connection between Down's and cardiac problems, and the likelihood of Bea having a heart condition. This was just the icing on the cake. Hadn't we been through enough already? She went to Southampton Hospital for an echocardiogram to determine the situation.

We met the cardiologist who revealed Bea had Tetralogy of Fallot which included a complete Atrioventricular septal defect and some pulmonary stenosis. Again, we cried and cried. We asked if she was going to die. Dr Keeton explained it was repairable but she would need to be about 3 years old before any surgery was carried out. Bea stayed at Southampton for 10 days and then went back to Poole hospital for a further week.

By now she was 6 weeks old and we were desperate to take her home. Bea was able to take her bottles without an NG tube, although only 2 or 3 oz so she was discharged at last. Two weeks later we went to see our GP for her routine 6 week check-up and after examining her, he arranged to have her admitted to Southampton.

Bea needed palliative surgery urgently and a Blaylock shunt was performed by Mr. Munro. Before the operation we asked the chaplain to baptize her as how could such a small, poorly baby survive, however, she sailed through and was home 10 days later.

We now thought life would be easier and we could fall into a routine. Bea slept for great chunks of the day but

slowly began to develop. At 5 months she started at day nursery so I could return to work part time. I had made the decision not to return to work, but after the trauma of the past weeks, I felt completely exhausted and that a break away from everything for a couple of days a week (albeit at work) would be beneficial.

I was concerned about leaving her when she was so tiny and vulnerable but although it felt as though I had driven into a brick wall at 100 miles an hour, I felt things had to carry on as normal. When Bea was 8 months old she was hospitalised for 10 days with bronchiolitis and then had a chest infection every month over her first winter, so the going was tough. However, her first birthday came and things seemed to quieten down.

In May 1999 we took Bea aged 13 months to Southampton for a routine cardiac catheter. As the procedure would take 1½ hours they said it would be okay to go for a walk. When we returned Bea was not back, she had not woken from the anaesthetic very well, but now everything was fine. She returned to the ward asleep. After a couple of hours she began to stir, she did not look very well, she was blue and seemed to be gasping for breath.

After several nurses and doctors had looked at her, someone from paediatric intensive care appeared and Bea was rushed to ICU. She was very, very sick. The doctors thought that she was 'spelling' (muscle spasming around the pulmonary artery) and that they would need to perform the cardiac repair immediately as her only chance. I completely went to pieces and collapsed. Where was the justice in

spending a year coming to terms with everything and our emotions and now we were going to lose her.

After an hour Mr. Marcus Haw explained that Bea was suffering from Hib and pneumonia and that her lung had collapsed. The anaesthetic for the catheter had aggravated the bugs she was already harbouring. She was very sick indeed. Her chance of survival was 40%. Bea was now on a ventilator. That night we were called in to be with her in the small hours as she was so sick.



The following night we were again called in. The director of PICU, wanted to try an oscillating ventilator for Bea (one which inflates the lungs at several hundred times per minute) but said this was an extreme measure and might be the last thing they could try. It was a dreadful night. Her blood pressure, sats and other vital signs were all over the place. It was unbearable to watch and to see her dying before our eyes.

However, the skill and care of the doctors and nurses was so great that four days later she began to rally and within three weeks she was back on the ward. It was apparent that she needed her cardiac repair now rather than at age 3 but she needed

to recover before being subjected to open heart surgery.

A week later Bea had her repair. Mr Haw had only performed this operation twice before, and Bea's chances of survival were 75%. Bea recovered brilliantly, she only stayed in PICU for 1½ days and then on the ward for 10 days. Over 5½ weeks after going to Southampton for a cardiac catheter, we were going home. Bea was pink at last!!

I am finding hard to believe that all this happened so long ago as I can still remember every detail. Bea started to crawl at 18 months old, pulled herself to stand on New Year's Day 2000 and took her first step on 14<sup>th</sup> July 2000 (aged 2 years 2 months). Her cognitive development is good and she understands everything we say to her. Her speech and language development is delayed but she uses Makaton signs very effectively.

Bea works hard to achieve her goals and now has some serious competition in the form of her twin brothers, Isaac and Freddie, who were born when she was just 2. For ages we thought we would never have children - now we have 3!

Life with Bea has been very different from the life I had imagined. Yes, she is demanding. Yes, there is still a lot of heartache and yes, there are still a lot of hurdles for us all to cross. There are disappointments but there are triumphs. Bea is in a mainstream day nursery now for 3 days/week where she is coping excellently. She is a lively, inquisitive and very smart little person who had a very rough start. She deserves to succeed.

**Jackie Lillywhite**

**RYAN JAMES CROSSLEY**  
**(3 AUGUST 1994—28 MAY 2001)**

Ryan was born with Down's Syndrome and had a serious heart defect, repaired at four months. He was happy and well for most of his short life. We had always wanted him to go to a mainstream primary school and were so pleased when he was given a place at St. Peter's Primary School and we were full of hope for his future at the school.

Sadly Ryan became ill at the end of August and was diagnosed with leukaemia in September. He started what was planned to be three years of chemotherapy, with the hope of curing him (thirty years ago all children died from leukaemia, now 70% are cured). Ryan received excellent care and treatment at Southampton General Hospital and Royal Alexandra Hospital, Brighton.

Ryan enjoyed his time in hospital, watching his favourite television programmes and videos, eating the lovely hospital food! He was such a smiley, happy character; he became very popular with the doctors and nurses. Despite having few words he was able to communicate well with gestures, signs and his expressive face.

The prospect of getting him to his mainstream school kept us going and we were so delighted when he finally started school in November. We have nothing but praise for the teachers and all the other school staff who made Ryan so welcome, leukaemia and all. It was wonderful for us to know he was so happy at school and all of the children were so kind to him.

We had a happy Christmas with Ryan; we had our happy, smiley, boy back.

He started intensive chemotherapy in January 2001 but became very ill and this had to be stopped. At the end of February his chemotherapy started again but a blood test showed his leukaemia had returned.

We were all devastated to be told that Ryan could not be cured and would only live for a few more weeks; he

seemed so bright and full of life.

We were determined to make his last few weeks as enjoyable as possible, we "spoil" him as much as we could! He enjoyed a five-day holiday on Guernsey before a trip to Disneyland, Paris, arranged by "Round Table Children's Wish". We treasure special memories of hurtling round "Thunder Mountain" which Ryan loved so much that we did it twice! Ryan was a great dancer and we danced during the Disney Parade - more special memories.

After such excitement it was back to school and Ryan enjoyed two happy weeks with his school friends before the Easter holidays. We were able to

watching the other children. He also enjoyed an hour or so being pushed in a Swing Boat watching what was going on (once Ryan was on a swing he never wanted to come off!).

Ryan died in the morning on bank holiday Monday, when everyone was at home. We were all so sad but also glad that he was free from his leukaemia. We tried to have a "happy" funeral with hymns Ryan would have heard at school and some of his favourite pop music. All the children released balloons, when Ryan was buried, symbolising his spirit rising up to heaven.

We have always been very direct with John and Stephen; they knew



take him on three theatre trips, two cinema trips, more cafes, restaurants and Legoland, while he was still well enough to enjoy these visits.

Ryan had a quiet time at home in May. He became more sleepy and he no longer wanted to go to school. He enjoyed television and videos; we let him do what ever he wanted, which included waking up and watching "Tom and Jerry" through the night while poor mum tried to sleep!

John had so wanted Ryan to go to his school fair on 12th May. To our great surprise Ryan wanted to go on the Bouncy Castle with Stephen and he enjoyed sitting, being bounced,

Ryan was very ill and that he was going to die. We have told the boys that although Ryan's body is buried in Partridge Green, the smiley, happy part we loved is in Heaven with God and Jesus. The boys often say we have "invisible Ryan" with us when we go out.

We are very lucky that we have John and Stephen. We are so sad without Ryan but we can look forward to the future with the two boys and be glad that Ryan was part of our family for six happy years.

Thankyou for your support in the early days. We could not fault the Brompton, we were lucky that Ryan's

heart surgery kept him well for so long. We seem OK. We tell ourselves Ryan is happy – I hope he's not "at peace"; I want him whizzing and flying about!

**Liz, Mike, John and Stephen Crossley**

#### HAND MADE CARDS

Sharron Jordan makes hand made cards and has a website

[www.hand-madecards.org.uk](http://www.hand-madecards.org.uk)

If anyone wants to buy anything from her, instead of paying by Paypal, they can email Sharron with an order of what they want and send a cheque. Sharron will donate the saving on the Paypal charges to Down's Heart Group.

Thankyou Sharron!

### Saturday 1st October 2005 - The Heart Child's Journey

#### 10.00 Annual General Meeting

10.45 Conference opens

Review of Children's Services

Overview of paediatric cardiac services

Family's perspective

Panel discussion

12.45 Lunch

2.00 Workshops (choose 2 out 4)

- o Early years
- o At school
- o From teenager to adulthood
- o Influencing change

4.15 Feedback from workshop

4.45 Close

#### 2005 CHF Conference Booking Details

- o The conference is open to anyone who is interested in children's heart conditions.
- o Each member group is invited to send as many people as would like to attend.
- o There is no charge for attendance at the conference (lunch is provided).
- o A creche is available. Places are limited and will be allocated on first come first served basis.
- o If people other than Council Members would like to stay at hotel please contact Sharon Herzog on 020 7820 8517 for further details.

For a booking form please contact

Sharon Herzog, Children's Heart Federation 52 Kennington Oval, London, SE11 5SW

Tel: 020 7820 8517 Fax: 020 7735 8718 E-mail: [Sharonh@chfed.org.uk](mailto:Sharonh@chfed.org.uk)

#### SEA TO SEA - C2C CHALLENGE

This is a cycle ride from coast to coast across the North of England over 140 miles of fairly tough terrain. It begins on 19th August.

Three members of Co. deaf are attempting the ride in order to raise money for Co. deaf, Air Ambulance, Mountain Rescue and Down's Heart Group. Victoria Callaghan, Colin Donlop and Ian Stewart are currently in training for the gruelling journey and hope to have fun and raise money whilst doing it.

Victoria said "Your organisation has been selected because of a lovely friend, John Bowring. His daughter, Kimberley, has recently passed away. Since then, I wanted to do this 140 miles cycle challenge to raise some money for Down's Heart Group in memory of his daughter, for John and his family."

If you would like to sponsor the team, please contact National Office.

We wish them a safe and painfree journey.



#### The Heart Child's Journey

The 2005 CHF Conference  
Saturday 1<sup>st</sup> October 2005

at

The Holiday Inn  
Southampton

## Have you sponsored me yet?



I reckon if every member I've spoken too in the past 15 years sponsored me just £1 each, I'd raise at least £1000 for Down's Heart Group.

Even if only those who thought I'd helped them sponsored me, it still might be £15!

**So please, show your support and make a pledge.**

You can telephone, post or email me, or check out our new website which will be live soon, where you can enter your sponsorship online.

*Penny Green*

### CORNISH CENTRE

A new centre in Cornwall is to provide respite care for more than 20 adults, aged 18-35 with learning difficulties. The bungalow in Liskeard, owned by Caradon District Council, will offer day, evening and weekend activities. It is being run by the council, local social services, disability charity the Robert Owen Community, and the Learning Disability Partnership Board. It will offer activities such as daily living skills and kitchen skills, as well as leisure activities including visits to cinemas and other amenities.

### UK HOLIDAYS WITH EXTRA HELP

Sometimes holidays can be really hard work for everyone. Offspring expect that Mum will still wait on them hand and foot, whilst Mum often has this expectation that the family will turn into helpful, gentle, caring, happy people, desperate to help her relax. Dads, on the other hand can soon get "cabin fever" or turn into "action man" and drive everyone mad with his new found zest for life. Throw into the equation one child, teenager or young adult who needs a bit of extra supervision, but who really does not want to do

the family holiday thing and you might as well not unpack your suitcase.

One of the following websites may be just what your family needs. Many places now cater for activity holidays for the whole family, geared at each member, so that everyone is happy. Many centres and holiday cottages now cater for people with extra needs, and what is even better, a growing number of places encourage the person with extra needs to attend without the boring parents.

<http://www.vitalise.org.uk>

<http://www.badaguish.org/>

<http://www.bendrigg.org.uk>

<http://www.holidaycare.org.uk/>

<http://www.qe2activitiescentre.co.uk/>

<http://www.lowmill.com/>

<http://www.redridgecentre.co.uk/>

<http://www.dukesbarn.org/>

Mellwaters Barn, County Durham, [www.mellwatersbarn.com](http://www.mellwatersbarn.com) is one such place catering for people who might just want a bit of help. They offer self catering

cottages in great surrounding in a beautiful part of the world. The brochure makes it look great, but we can't recommend it first hand as we haven't actually been to any of the above. If you have had a super holiday with that extra bit of help would you like to tell us about it? Choosing a holiday can be a nightmare, but if it comes with some knowledge from a fellow holidaymaker at least you might know what to expect.

### TRAVEL INSURANCE

Make sure you read the small print very carefully. It is amazing what some companies will get out of because it could be passed off as "Down's related" and therefore a pre-existing condition.

### TOPIC NOTES AND INFORMATION

Thankyou to all the people who have been in touch with ideas and suggestions on problems such as feeding. Everything has been taken on board and you may recognise your comments on some of our new topic notes. As time goes by we are collecting information on a range of issues, so feel free to call and ask questions. If we don't already know the answers, we'll gladly try and find them for you.

## SKILLS VIA SOFTWARE

Computer software to teach people with learning disabilities the basic skills needed for everyday activities has been developed by researchers in Nottingham.

The package, designed by the University of Nottingham features shopping and road safety programmes. Users can navigate themselves round a supermarket and practice crossing roads in a number of scenarios. It also features a specially-designed joystick to help people with physical impairments be able to use it.

Professor Penny Standen, from the university, said: "For many of us activities like going to the shops or crossing the road are very simple tasks that we wouldn't think twice about. "However, for someone who has severe learning disabilities, which may include a limited use of language, and, in some cases, some form of physical impairment, it can be quite a daunting experience. "Our studies have shown that through the use of this new software, the skills and abilities of the people with learning disabilities who worked with us on this research did improve. "The software provides activities that are educational but also fun, therapeutic and stimulating."

## GENEPOOL

A new website has recently been launched through the National Electronic Library for Health called GenePool,

This library aims to provide a unique collection of clinically useful information on genetic conditions. GenePool is aimed primarily at healthcare professionals who are not genetics specialists, but is open to anyone from specialists to patients. The site should be easy to use and useful, but the [project team](#) always welcomes [constructive feedback](#).

See what you think on;  
<http://rms.nelh.nhs.uk/genepool/>

## PLEASE REMEMBER

Send your used stamps to DHG and recycle your toners etc. the bags we sent you last newsletter.  
Thanks.

## SPOTLIGHT ON SIBLINGS

This letter was emailed to the Information Office just in time for inclusion in this issue. Thanks to Sarah for sending it in. Hopefully it will be the first of many siblings letters.

Rachel Green was born on 23 August 1981, the second of four children to Kevin and Julie Green; I'm the youngest of the four at 17. Before I was born Rachel had a major heart operation, without which she would not have survived past her third birthday and I would never have met her. Which at times if I'm honest I don't feel too bothered by, because being a little drama Queen, I always wanted the attention!

But as I have grown up I have come to realise that my parents treat all four of us the same or as well as they can and I don't mind if they give Rachel a bit more attention because I know it doesn't mean they love her more or anything like that.

My response to Rachel has always been varied. Sometimes I find myself wishing she was "normal" (her autism causes her to ask questions over and over again and she will get agitated if anything ruins her daily routines) and other times I love her so much and I feel lucky having her as one of my big sisters.

Recently I have thought that more than ever due to this guy at my sixth form college who when I said about Rachel having autism said "Oh she had a great pick out of the gene pool" I thought this very rude but at the time I was too polite to say anything. He also accused me of being a "bad sister" which at the time I found very funny and still I never said anything because I didn't see the point as he would never know what it was like.

At times it can be very hard on the family, none harder than when in 2003 our mom was diagnosed with Breast Cancer. It was very hard explaining to Rachel why mom wasn't there to get her dressed or to give her a bath.

I wanted to write this because although Down's syndrome is quite common I have only ever met one person my age with a Down's sibling, but we were very different in the ways we cope mainly due to the severity of my sister's downs. Especially as she seems to go against all the normal traits of Downs Syndrome people, she is noisy and not particularly happy all the time and prefers her own

company. Rachel is affected quite severely and can't read or write, and it can be hard to understand all she says at times.

I know some people can feel worried about letting their friends come round to their house because of their Down's sibling, which is wrong. I have always willingly brought my friends to our house. Even though I knew Rachel would shout at them as she always does. But I always thought, well, this is my family - warts and all. Rachel is never a secret with me, never has been and never will be.

I feel my story may be more factual than anything partly due to the fact that I am the baby and everything is accepted by me as her various illness' had all ended by the time I arrived on the scene.

It was my birthday last week and I remembered the major part of any birthday in our household is Rachel singing 'Happy Birthday' and my friends who were round soon found out why I made such a big deal of her singing it.

I would like to take this moment to say to new parents to not worry and everyone deals with it in different ways.

## Sarah Green

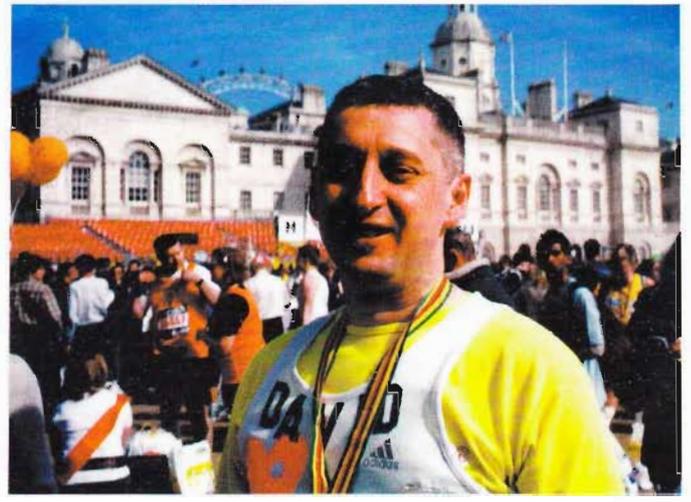
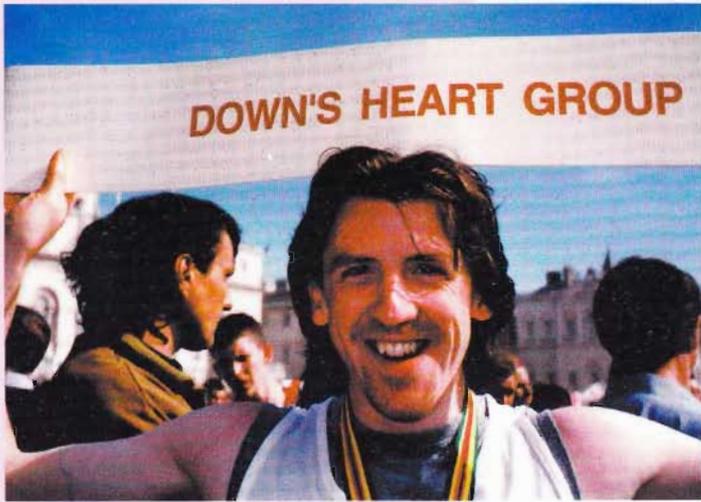
LOOK OUT FOR SARAH AND RACHEL'S BROTHER'S LETTER - this will appear in the next newsletter along with a picture of the four Green siblings together.

## SISTERS OF MERCY - NOT QUITE!

On September 4th Emily and Grace Smith will be doing the Hydro Active Women's Challenge in Birmingham.

Grace is quite fit and ready to go. She will be just 13 when she takes part in this 5km run. Emily will be 15 and a half. Her idea of running may be slightly different to ours! She did do well at primary school long distance when everyone cheered her on, but that is as far as her running experience goes. Her successful heart operation when she was a tot is the only reason she can take part and she is determined to finish the course. Mum, Sarah is also taking part, but will be running with the girls as support.

No doubt, if Emily and Grace got lots of sponsors from everyone out there, the 5km would just feel like a stroll in the park! Please sponsor them!

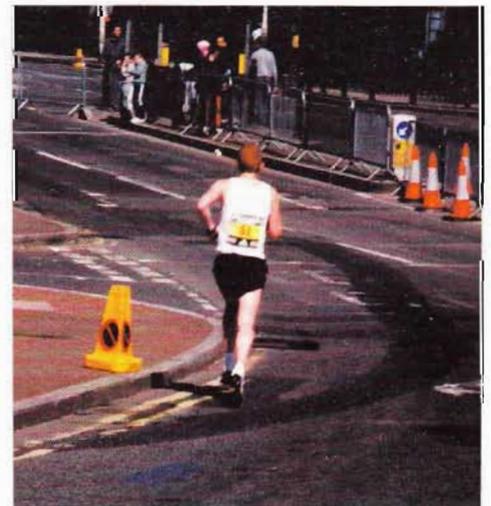


## MARATHON 2005

Thanks to Dave, Kev, Anthony, Chris, Graham and David the money is still being collected in, a grand total will be announced next issue



Thanks to Chris and Bob Stringfellow for the photos and for cheering our runners on



## SPOTLIGHT ON SIBLINGS

The following is a tribute from a sister of a man with Down's Syndrome who died in 2004 aged 55.

He was beautiful - my brother. Outside and in.

He was a beautiful baby. Not something I remember, being only eighteen months old when he arrived, but photographs show that he was, and the cutest toddler.

He was Houdini - my brother. Outside and in.

He could escape the most secure systems and set off to who knows where only to be searched for by us his panic stricken family or to be returned by an eagle eyed neighbour who had found him in their porch or a nearby telephone box. He even rose to the dizzy heights of being returned in a police car, sitting like royalty and grinning from ear to ear.

In the house he could make things disappear. The hated P.E. or swimming kit, laid ready the night before would mysteriously go missing just as his transport arrived.

He was a comedian - my brother.

Give him an audience and he was away! His mimicry of Tommy Cooper, Frank Spencer, Bruce Forsyth and others could rival the efforts of Rory Bremner, He was an enigma - my brother. He couldn't read but knew every record in his extensive collection and could find the programmes he loved in the T.V. Times. He was stubborn and exasperating - my brother. Once set on a particular path he was like Margaret Thatcher - "Not for turning". Sometimes his insistence could even lead the other person to believe that possibly they were the ones who were in the wrong. He was kind and loving - my brother. Everyone was a "Good man", a "Lovely person", a "Nice smiler", "My friend". His love for others was uninhibited and boundless. "He was beautiful" - my brother, and as we said our final goodbyes to him in September that was the music we played. Now as our first Christmas without him approaches, I feel more than ever the void he has left in my life. No one will ever again tell me I am "The most beautiful sister in the world", praise my mediocre cooking as if it was a cordon bleu offering or call me sister—mother. He was beautiful - my brother, outside and in, and I was lucky enough to be a part of his life.

Reproduces from Issue 24 of the Leicester Down's Group magazine.

## DOES YOUR SMALL HOUDINI ESCAPE FROM THEIR CARSEAT?

If so, there are pads you can buy which cover the child's chest and prevent them wriggling out. I wish they'd been around when my daughter was small, as we had several hairy moments when in the fast lane and an escapee appeared at our side. Thankfully, carseat designs have come a long way since then.

The pads, and other useful aids can be bought from

[www.safetyfirstsales.com](http://www.safetyfirstsales.com)

Any other tips would be gratefully received!

## ANGER OVER 'SPECIAL NEEDS' AUDIT

A campaigner for children with learning difficulties is angry that an official audit of educational provision will cover only a minority of children.

The Department for Education has confirmed that the audit will apply only to the most severe disabilities. Parent and special needs campaigner Julie Maynard says this amounts to a "cynical manipulation".

Many physical and learning difficulties will be excluded from the audit.

The audit will consider only the services available in England for a narrowly-defined set of "severe" needs, including "severe visual impairments" and the most severe cases of autism or behavioural problems.

Ms Maynard, who is a lay representative at special educational needs tribunals, says it means services for the majority of young people with statements of special need will not be covered.

The provision for children with the severest needs is not the problem area, she says. And she claims that the audit will allow the government to avoid the larger problems of children with less severe needs.

"It's a deliberate attempt to hide the fact that many parents cannot access appropriate provision for their children," she said.

The promise of an audit of the provision for pupils with special needs was written into Labour's education manifesto in April - as a way of establishing how services compared in different areas.

A spokesperson for the Department for Education and Skills said there were no plans to widen the audit to provide a more comprehensive picture of special needs provision.

The Shadow Education Secretary David Cameron attacked the limited scale of the audit and said "It is the schools looking after children with moderate learning difficulties that are being closed," Source: BBC News Online,



# dhg

down's heart group

## AWARENESS WEEK

As you may already be aware, the week of 31st October to 6th November is Down's Heart Group Awareness Week. This will coincide with the launch of our new image. Details of the launch have yet to be finalised, but we hope to invite the press and professionals to attend. Any members would be more than welcome to join us.

The DHG needs to raise its profile. For years the group has been working very hard to help families across the world. It has achieved huge success on a meagre budget of funds raised by the public. If it weren't for the enthusiasm of a small number of volunteers, the group would have folded long ago.

As more people realise what the DHG does, hopefully we can attract funding to maintain and increase the work currently undertaken.

Please use Awareness Week to talk to the local press about what the group means to you. Perhaps you can organise a coffee morning or something equally simple and enjoyable. The firework display last year raised awareness and funds - perhaps you know someone who could help organise a large scale function in your area?

Thanks to those of you who have already been in touch with suggestions. Remember, we are here to help you with events. Good Luck!

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DOWN'S HEART GROUP

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contact or answerphone always  
available (24 hrs in emergency)