



# dhg

down's heart group

## Newsletter Extra Autumn 2005

Welcome again to our updated newsletter. I hope that the new format is easier on the eye and a pleasure to read.

Down's Heart Group Awareness Week is at the beginning of November and we hope that you will support us by broadcasting our details to your friends, families and any business that you have contact with.

DHG relies on fundraising and is trying to become more recognisable to the general population. Any fundraising or awareness initiative is really helpful, no matter how small. Please contact National Office with your ideas, or for advice on events, whether it is a sponsored silence or a freefall.

My son Richard is at Derwen College in Oswestry and is thoroughly enjoying himself. If anyone is thinking of colleges for their teenager they need to be applying for places from about 14yrs old. The best website for a list of specialist colleges is -

[www.natspec.org.uk](http://www.natspec.org.uk).

See next newsletter for more info.

Enjoy the newsletter and good luck to anyone organising any coffee mornings or cake sales to raise awareness.

### Chris Stringfellow - Vice Chair

Richard on the train to college



### HYDRO-ACTIVE WOMEN'S CHALLENGE

Birmingham team - back row; Sarah Smith, Emma Tonkinson, Jo Tolley, Linda Wain, Tina Dixon, front row; Emily Smith, Lianne Wainwright, Grace Smith



Runners, power walkers and walkers pounded the city streets on September 4th to raise funds for Down's Heart Group.

The London team consisted of Joan Brunnick Ryan, Debbie Dicketts and Linda Dicketts. Pat Lucy was determined to participate, but daughter, Helen, didn't have a pusher for her wheelchair.

As Penny Green had pneumonia, she and Sarah missed the trip to Birmingham. They are planning to do the 5k challenge around their village once Penny is completely better.

It was extremely hot in Birmingham city centre, with the sun reflecting off the concrete surfaces. About 3000 women were there. Tina and Emma were interviewed by BRMB radio and the official photographers were everywhere. The whole event was

very well run and there were plenty of spectators to encourage us. However, next year Jo is determined to bring her own DHG supporters to help us along.

Our youngest runner Grace Smith completed the 3 miles in 32 minutes. 15 year old Emily got back in 70 minutes. The heat made her clammy and dizzy, so she had a few rests - the offers of help were amazing. Emily would not give in and crossed the line with many wellwishers cheering her on.

Everyone who took part had a great time and it was good to meet other group members. The medals, T-shirts and huge goody bags made it all worthwhile!

At a guess, the combined total of sponsorship will be over £1500. Not bad for a morning out!

### SILVER WEDDING DONATION

Elizabeth and Geoff Holland from Trowbridge recently celebrated their silver wedding anniversary. They chose not to receive gifts but wanted any donations to go to the Down's Heart Group. This kind gesture raised £200.

Elizabeth and Geoff also organise whist drives which have raised a further £250 for the group.

Granddaughter Martha, who is now 6, had successful cardiac surgery when she was 2 at Great Ormond Street Hospital.

The family and Martha's mum Julia, in particular, were very grateful for the support they received from DHG, especially through pregnancy.

Martha with Elizabeth and Geoff



**£8517.50**  
is the total  
amount  
raised from  
the London  
Marathon  
2005. Thanks  
again to  
everyone who  
took part.

Thanks to Waitrose for their £1000 donation to employee David Bray



Martha and sister Alice

### CHARITY KEYRINGS

Down's Heart Group have on offer at a fantastic price, some gorgeous keyrings. Available in several wonderful designs - please phone for details on keyrings not pictured below.

Never be without a pound coin for your supermarket trolley or gym locker again. These specially produced keyrings are made for the job and are pretty too!

What great stocking fillers!

The keyrings cost just £1.50 each.

Postage and packing on 1 -3 keyrings is 25p and on 4-6 keyrings it is 40p.

Contact National Office on

**0845 166 8061**

to place your order, now, while stocks last!



### HARRY'S HORNETS £358.61 STING

Sunday 11th September was a busy day for Safira Djerboua's family and friends. They staged a 5 - a - side football tournament at Berkhamsted Sports Centre. 6 teams battled it out for supremacy and after all teams had played each other Harry's Hornets were victorious.

Safira with Granddad and the winners.



The competition was organised by Safira's parents, Kelly and Adel, along with grandparents Fran and Harry Magee.

Kelly and Fran made themselves busy persuading people to part with their money, which is probably as exhausting as playing football! £358.61 was raised on the day and thanks go to all involved.

Dad wasn't in the winning team but it didn't seem to matter to a certain little lady!



### WARNING - PETROLEUM JELLY

Oxygen via a mask or canular can cause the user to have a dry nose and nosebleeds. To combat this, many use petroleum jelly based cream, however research has shown that the petroleum reacts with the oxygen and actually makes the condition much worse. All oxygen users are advised to use a water based cream to protect the nasal lining.

It is very important that people using oxygen therapy also have a humidifier to make life far more comfortable.

## CYCLING FROM COAST TO COAST FOR DHG



Victoria, Colin and Ian set off on 19th August on the C2C challenge. These are some of Victoria's diary extracts:

C2C Challenge was certainly a challenge - especially during the first day. I really did not think I would make it. Ten minutes after setting off from Workington, Colin's back wheel spoke snapped, causing a 2 hour delay!



I loved zooming down the steep hill near Keswick, so bumpy yet so thrilling! The scenery was breathtaking.

Second day = sunburnt, a very hot day. It was tough getting to the summit.



Third day = a fail!!! Duh! Due to a very narrow track and a large stone!

Fourth day = we made it!

Arrived on the East Coast at 5pm.

My sore bottom and last year's car injuries forgotten from day 2, when I began to feel fitter and more motivated by the thought of raising money for DHG!

Let you know the total soon.  
Victoria

## BOB-A-JOB GENEVA STYLE!

Rebecca Ruppli and five of her friends in Class 6 at Geneva English School raised a wonderful £50 for Down's Heart Group. They did small jobs around the home to raise the money, proving that the simple ideas are just as worthy as the more involved ones. Thankyou girls! Are you available for a trip to the UK? I have hundreds of little jobs that just don't seem to get done!



Rebecca and her helpful friends.

[WWW.EVERYCLICK.COM](http://WWW.EVERYCLICK.COM)

## CHRISTMAS CARDS

Enclosed with this newsletter is a flyer about 2005's Christmas cards. The designs are as beautiful as ever and the prices are as competitive as we can make them. Compared to most charity cards DHG's are really good value, with all profits being ploughed straight back into the Group. Please order from National Office, on  
**0845 166 8061**

We run a Christmas Card Design Competition every year. When your youngsters produce their Christmas artwork, think about sending it in to us. Designs should be original (no Mickey Mouse or Power Rangers) and have some connection with the festive season. Winners receive a prize as well as having their design on thousands of Christmas cards.

## FOOTBALL FAVOURITES

Everton midfielder, Kevin Kilbane has been really positive in his comments about having a daughter with Down's. He is really proud of little Elsie, and not afraid to show it!

Chelsea player Frank Lampard and his mate Steve Terry (brother of Chelsea player John) helped David Bray, one of this year's DHG Marathon runners achieve his £3325.00 fundraising by sponsoring him for £250. Thankyou!



Everyclick is a search engine, like Google (and quite good in comparison). What makes Everyclick better for us all to use is the fact that each time Everyclick is accessed it donates money to charity.

Down's Heart Group is one of Everyclick's registered charities. It costs nothing to use, either for DHG or anyone out there who goes onto the site and chooses DHG as their charity.

Each time you click onto Everyclick to look for anything on the internet, DHG gets a few pence to add to the coffers. On average, each person using Everyclick will raise £12 per year for DHG. That is very easy fundraising!

It only takes a minute to set up, simply go to

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

and follow the instructions on screen. You then receive an email from Everyclick confirming your details and chosen charity.

Make Everyclick your home page and it becomes even easier to use.

Ask colleagues, friends and family to use Everyclick to donate to Down's Heart Group. They can all support DHG without having to pay out a penny.

Just think of all those £12s adding up through the year without selling raffle tickets or dodgy cakes cooked by the kids. Better still, it gets you out of having to shave your head or have a waxing session on sensitive parts!



# dhg

down's heart group

PO Box 4260  
Dunstable  
LU6 2ZT

tel; 0845 166 8061  
email; info@dhg.org.uk  
website: www.dhg.org.uk

contact or answerphone (24 hours in emergency)  
always available

### MOUSE WITH DOWN'S SYNDROME DELIGHTS SCIENTISTS

Professor Elizabeth Fisher of University College London and Victor Tybulewicz of the National Institute for Medical Research have produced the first mouse with a near copy of the human version of Down's.

These mice, called Tc1, have memory and learning difficulties and also heart defects. Until now it has been difficult to work with the mice's genes. The genes found in human chromosome 21 are dispersed through several chromosomes in mice.

This development will provide scientists with the best tool yet to study and hopefully understand Down's Syndrome. They are not looking for a cure, but want to discover why people with Down's are more susceptible to problems such as leukaemia, auto-immune disorders and Alzheimers. Once they have the answer to that, they hope to improve therapies to help people with such health issues.

The Tc1 mice should have a huge impact on Down's Syndrome research. Hopefully the work will improve understanding of other chromosomal disorders, too, such as Edwards and Patau.

Edwards Syndrome is caused by 3 copies of chromosome 18, whilst Patau Syndrome is caused by 3 copies of chromosome 13. Both of these syndromes can be life limiting, but as they are less common than Down's, it is Down's Syndrome that seems to be more frequently studied.

The research results were published on 23rd September 2005 in the journal "Science". The story was taken up initially by Mark Henderson of The Times.

What are you doing about it?

Coffee Morning, Cake Sale, Auction of Promises, Wine Tasting, Dinner Party, Whist Drive, Pampering Party, Bonfire Party, Golf Competition, 5-a-side, Sponsored Anything, Raffle, Tombola, Pink and Purple Office Day, Balloon Race, Duck Race, Race Night?

Could you tell

your doctor, paediatrician, dentist, speech therapist, playgroup, cardiac team, school, college, work, radio, newspaper, Scouts, village journal, Round Table, Masons, WI, anybody

about the Down's Heart Group?

Let's get noticed! Let's get listened to!

Let's reach everyone who could benefit from knowing about us!

Let's use this week to highlight

**Down's Heart Group!**



Sunday 2nd July 2006 is  
the British 10K London Run  
DHG needs runners to take part  
please contact  
National Office 0845 166 8061  
to register your interest



### WEBSITE

The long awaited new website is now ready! We are still working to get the banking side of it complete, however everything else is good to go!

Log on to

[www.dhg.org.uk](http://www.dhg.org.uk)

and see what you think. We would appreciate any feedback, good or bad. We have worked hard to make the site as user friendly and as simple as possible. The photos represent different ages of our members and we hope to change them fairly regularly. Please send us any good quality photos you may have of your child busy doing something.

As time goes by we hope to add more topic notes and information. The news and events page should become quite busy, and hopefully back issues of newsletters will be available to download. Current issues will be available in pdf form, so you can download a copy instead of having one posted if you prefer, which cuts our costs a little.