



# dhg

down's heart group

## Newsletter extra May 2005

### WELCOME TO OUR FIRST "EXTRA" BULLETIN

We would like future newsletters and bulletins to be as interactive as possible, so please get in touch with your views and ideas, as well as news and stories.



*Penny Green, Director says:*

As you can see progress is well underway with the launch of our new DHG image and we hope you like the changes.

A lot of time and effort has gone into updating and adding to our literature ready for printing of the new Information Pack and the launch of the new look website. I would personally like to thank everyone who has been involved in this process, especially our advisors who have given of their own time to check the accuracy of all the documents and given helpful suggestions along the way.

This is just the beginning implementation of our ambitious business plan which we have set to ensure the future growth and development of DHG.

I hope that you will all know firsthand the benefits of membership of DHG and that we can rely on your continued support over the coming months.

### FUNDRAISING GUIDE

Rather than just targeting regular fundraisers, our new "Fundraising Ideas" leaflet has been enclosed with every copy of this newsletter, in the hope it will inspire those members who want to organise an event but have not got round to doing anything yet.

Some members will find themselves far too busy to think about raising money, and that is fine. Maybe someone you know wants an excuse to do something whacky and just needs a worthwhile cause to raise funds for?

The guide is by no means exhaustive and any alternative ideas would be gratefully received.

The most important aspect of the leaflet is to show that raising funds is supposed to be fun and that any help needed with organising or literature can be given by the staff or committee of the Group.



### PHOTO LIBRARY

Do you have any good photos of our members with Down's doing something exciting, or just enjoying themselves? If so we would love to have a copy at National Office where we want to update our photo library to use for publicity and on the website.

No photos will be used without permission from the family, so we will need to send you out a form to sign, or you can contact us for one before you send in your photos.

We want our website pictures to show the more positive side to having Down's and a heart defect by portraying our kids as the gorgeous, mischievous and well rounded individuals they are. So we hope to be able to change them on a regular basis.

Many of our young adults have hobbies and interests that can be demonstrated by a snapshot. Let them show off their achievements!

### NAME THE NEWSLETTER COMPETITION

We are looking for a new, modern name for the DHG newsletter and this 'extra' addition to reflect our update image. We intend publishing them alternately with at least three of each coming out in a year.

So what should we call them? Ideally the names should have some link to each other, (however tenuous) and to Down's Syndrome, heart defects and news.

We have had a few suggestions already, ranging from boring to completely mad but we felt that YOU the members should decide, so get thinking.

There will be a prize for the best name, so phone, write, fax or email your suggestions to National Office before 18th June.

## **RUN, RUN, RUN** **Great North Run**

Thanks and congratulations go to Paul Critchlow for taking part in last year's Great North Run. He has raised £400 for the Down's Heart Group.

In a letter accompanying the donation Paul says "I would like to dedicate this donation to the memory of Yasmin Brookes and Emily Dawson, two little girls who are greatly missed by their family and friends. Though their lives were

very short, Yasmin and Emily brought about lasting friendships, simply by being born with Down's Syndrome.

Their parents, Steve and Gloria Brookes and Nigel and Kerrie Dawson are members of Rotherham Organisation for Down's Syndrome and despite their loss, their work for R.O.D.S. continues unabated and they are an inspiration to all."

## **London Marathon 2005**

## **Hydro Active Women's Challenge** **Sunday, 4th September 2005**

Following the success of the past few years, September 4th sees the 2005 Challenge taking place in three locations - Hyde Park, London; City Centre, Birmingham and Sefton Park, Liverpool. The fun begins at 11am when everyone runs, jogs or walks the 5km (3 miles) and hopefully raises some sponsorship money for their chosen charity.

Please support us by joining our team in Birmingham or by getting together a team for London or Liverpool. The entry fee is £15, £5 of which goes to your designated charity and every finisher gets a goody bag with a t shirt and a medal. You can register online at <http://www.womenschallenge.co.uk> or contact DHG national office for an entry form. DON'T FORGET to nominate Down's Heart Group as your charity!

## **Or Sponsor Penny**



For those who don't feel up to taking part themselves, how about sponsoring Penny Green, DHG's Director, who has pledged to take part.

As many of you know, Penny fractured her foot last year which is still causing problems. Penny said "I have always wanted to do the London Marathon for the charity (walking I admit) but that is now completely out of the question! I thought I could manage a 3 mile walk instead, although, much to my horror I now realise I will have to go into "training" for it, or be in a lot of pain."

If you would like to sponsor Penny, please give her a call at National Office on 0845 166 8061 (I know she needs the encouragement) or better still sign up for one of the events—(Please come to Birmingham, Penny needs all the support she can get including a possible piggyback!)

### **NEW INVENTION**

Does a member of your family need oxygen at night? Do they hate using a mask or cannula? Does their face get sore?

Would you be willing to write a letter in to National Office supporting development of a delivery system which would overcome this?

The Down's Heart Group has been approached by someone who has a brilliant idea, already being tested by two children, with exceptional results. However, to get selected for funding, he needs letters backing up the need for new, nicer to use equipment.

Can you help him to help you?

Our Marathon runners all got over the line safely and may be looking forward to applying for a place in 2006. The London Marathon is perhaps the largest fundraiser for the Down's Heart Group, with each runner raising at least £1000.

A huge thank you to all who took part. A full update will be in the next newsletter.

Their times were;

Dave Jones	3:55:31
Kevin Clarke	4:01:20
Anthony Shortall	4:55:48
Chris Ford	4:59:05
Graham Merrick	5:21:27
David Bray	5:24:40

## **NEW VIDEO**

United Bristol Healthcare, with funding from British Heart Foundation have just made a film following a 20 year old man with Down's Syndrome through diagnosis, heart surgery and aftercare.

The film will be available shortly in DVD format initially. The Down's Heart Group will be able to provide copies, which should be useful for families, patients and support groups.

More details in the next newsletter.

## **CARAVAN CORRECTION**

In the last newsletter, Bristol Children's Heart Circle advertised their caravan in Somerset. It is fully booked through August.

## **NEW CONTACT DETAILS ARE;**

Glynis and Tony Collins on  
0117 3735204

# **OFFICIAL NOTICE of ANNUAL GENERAL MEETING**

**TO BE HELD ON SATURDAY 18TH JUNE 2005**  
**AT THE EDUCATION CENTRE, LEICESTERSHIRE ANIMAL AID ASSOCIATION**  
**FOREST ROAD, HUNCOTE, LEICESTERSHIRE. LE9 3LE**  
**AT 10.30 AM**

This year's AGM does not incorporate a conference, as conferences are now every two years.

AGM AGENDA: (draft)

1. Welcome
2. Adoption of 2004's AGM minutes
3. Annual Report
4. Election of Officers - there are vacancies for the posts of Secretary and Treasurer.
5. Proposed resolution to change the constitution to allow a maximum of 25% of the elected officers to be non members. This would allow DHG to use skills offered to us by non members, without changing the balance for voting and opinion. Currently members do not seem to be coming forward for active committee roles, whereas offers are coming in from outside the Group.
6. Annual accounts and adoption of accounts
7. Any Other Business
8. Close

This notice is instead of the individual letters normally sent.

If you would like to nominate someone for a position on the Committee, or would like to put yourself forward, please contact National Office on 0845 1668061.

If you want to attend but don't want to join the committee, we still need to know that you are coming so that catering arrangements can be made.

We look forward to welcoming you on Saturday 18th June. The venue is a five minute drive from J21 of the M1 and M69. Directions will be sent on confirmation of attendance. The AGM should be concluded by lunchtime. A committee meeting will follow lunch.

Copies of the Annual Report, the Annual Accounts and the Change in Constitution will be available on request from National Office for those not attending.

New committee members or simply fresh enthusiasm and ideas always receive a friendly welcome.

The future of the group depends on the membership. Please try to attend.

## LETTERS TO MPs

In January, members of the Down's Heart Group were urged to write to Dr Stephen Ladyman and their local MPs regarding the Paediatric and Congenital Services Review Group recommendations which still have not been funded and implemented.

The recommendations, published in November 2002, drew upon findings from the Kennedy Report at Bristol Royal Infirmary and also the Inquiries at Royal Brompton, Harefield and Alderhey. The Review Group were to "make recommendations to Department of

Health Ministers to ensure high quality, patient focused effective, efficient, accessible and safe services for children, adolescents and adults with congenital heart disease and their families."

Two years later, Stephen Ladyman said "There is no part of our population that's more important than our children. And nothing more important than the quality of care that we provide for our children. That is why services for children and

improving the health of children have been given such prominence by the Government."

Those who wrote to Dr Stephen Ladyman received a standard reply, whereas local MPs have been more sympathetic.

It is not too late to write to MPs to ask them to act quickly to see that the recommendations of the PCCR are implemented without further delay.

...supporting a better life 



**dhg**  
down's heart group

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tel: 0845 1668061  
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website: [www.dhg.org.uk](http://www.dhg.org.uk)

Contact or answerphone always available  
(24 hrs in emergency)

## GROWN UP CONGENITAL HEARTS REVIEW

Standards are being drawn up for the NHS to follow regarding transition to adult services, and services for those young adults who have a congenital heart problem. A section on patients with special needs is to be included, and will cover consent and understanding.

Patients with congenital defects have different problems to those adults who develop heart disease, and therefore require the expertise of the paediatric teams, who generally have more experience in congenital problems. It is not appropriate to treat young adults on children's wards, but if the patient has a learning difficulty, adult wards can be very intimidating.

This review is all about getting the balance right, whilst maintaining the highest possible care.

The DHG will be researching families' experiences to determine where current problems lie, and will present the findings to the review committee for inclusion and, hopefully, action.

We will let you know of any developments.

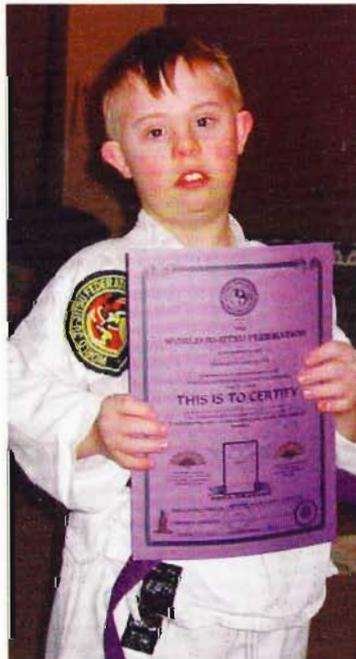
## TONER RECYCLING

Please use the enclosed recycling bag to raise funds for the DHG.

**ARTICLES REPRODUCED IN THIS BULLETIN EXPRESS THE OPINIONS OF THE AUTHORS, AND ARE NOT NECESSARILY REPRESENTATIVE OF THE VIEWS OF THE DOWN'S HEART GROUP**

## CONGRATULATIONS

Jacob Phelps (13) has achieved his purple belt at Ju Jitsu, which means he has now passed 7 gradings. Wow!



## SIBLINGS ON SHOW

After the report by Charlotte Riddick in the last newsletter about siblings and their feelings, it has become apparent that siblings have plenty to say about what growing up in a Down's Heart Group family is like.

The next newsletter will have a "Spotlight on Siblings" slot, which will hopefully become a regular feature. This will obviously depend on how many siblings write in or email.

It will be interesting to see how different children view their lives and families, and hopefully will be reassuring to see that most siblings develop into decent people, despite their parents' worries that they neglected them when other family members were far more demanding of their time!

## NOT TO BE OUTDONE

Another new feature is to focus on our members who have Down's Syndrome. What are their views on life, families, having Down's? Are there any bits of artwork to show, photographs of doing something special, certificates or awards to show off to the world?

Please email or post articles in to share with a very interested audience.

## DOWN'S HEART GROUP AWARENESS WEEK 31ST OCTOBER—6TH NOVEMBER 2005

Last year's Awareness Week was very low key, but this year with more time to plan, the DHG hopes to really get noticed. People cannot use the Group if they do not know it exists. As well as an ongoing campaign aimed at professionals in the Health Service, we need to "spread the word" across the UK and beyond.

Press releases and local interest stories will hit the media. Awareness and fundraising events will be taking place. Get involved by hosting an event, or by persuading an organised firework display to do it on the DHG's behalf.

The Balloon Launch that was such a success last year will be happening again. It would be fantastic to have several launches around the UK to mark Down's Heart Group Awareness Week—and even better if it all resulted in families like those already members of DHG finding out about our support group.