



dhg

down's heart group

# Newsletter Summer 2009

Issue 39



## Chair's Report

Welcome to the latest edition of our newsletter. As we are fast approaching our AGM, I would like to take this opportunity to appeal for more people to join our Executive Committee.

### *Committee*

Currently the Committee comprises of myself, a Treasurer, a Secretary, a Fundraising Co-ordinator and two other members. We meet about four times a year in the Leicester area (this is open to negotiation) and our Director, Penny Green and Information Officer, Sarah Smith, also attend.

All these people bring with them both a shared belief in the role of DHG, usually arising from involvement with someone with Down's Syndrome, as well as additional skills in areas such as health, law, accountancy, education, business, planning and development.

Ideally we would like to increase the size of the Committee and expand members areas of interest so that we can continue to develop and build our services in the present climate. If you can spare a few hours a month, could attend Committee meetings and would like to use your experiences and skills to help other families, we need to hear from you.

### *Future Plans*

Fundraising and reinforcing our name in the Cardiac Units are our main aims for the coming year. We recognise the need for contact with families at the beginning of their journey so they can get maximum benefit from our support and information as well as the important role the medical profession can play in this. We are certain that input from more members, regardless of their background, will help us achieve this.

### *AGM*

I look forward to your support and hope to meet as many of you as possible at the AGM on October 24th.

**Chris Stringfellow**  
**Chair**  
**email: [chris@dhg.org.uk](mailto:chris@dhg.org.uk)**

## Front Cover



We thought you might like these photos of our daughter Hannah with Sir Elton John!

Her dreams came true last July when we were his guests at one of his concerts in Doncaster. We had backstage passes and had the chance to meet him.

As you can imagine Hannah was over the moon; he kissed her hand and she's refused to wash it since!

During the concert he dedicated the song Tiny Dancer to "a special young lady named Hannah" which thrilled her of course.

As we had complimentary tickets to the concert we said we would make donations to the Down's Heart Group and Elton's Aids charity, so a cheque will be in the post soon.

**Barbara and Tony Cooper**  
**Melton Mowbray**

*Ed - Hannah searched the internet to find Elton's contact details and then wrote a letter to him herself. Her dad was so surprised when he got the phone call inviting them to a concert that at first he thought it was someone playing a joke!*

*Thank you to the Cooper family for their generous donation and of course to Sir Elton for giving Hannah such a wonderful experience.*

## New Telephone and Fax Numbers



To improve call efficiency, we have a new telephone number which provides a menu, allowing you to choose who you wish to speak to.

The number is low call rate from anywhere in the UK.

For anyone on a telephone package that provides free calls, we can provide alternative numbers if you prefer.

We also have a new fax number.

**Telephone:**

**08444 288 4800**

**Fax:**

**0844 288 4808**

*Please let us know if you have any problems or concerns with the new telephone system.*

## THANK YOU

On behalf of everyone at DHG, we would like to say a heartfelt thank you to all those members who responded to our appeal for funds sent out with the last newsletter. In the interests of economy we did not write to everyone individually, but do want you all to know that your donations, whatever the amount and frequency are greatly appreciated and will make a big difference to the organisation in these difficult financial times.



if you haven't already made a donation, it's not too late, but we appreciate that many members may be finding funds tight, so remember there are other ways to help us too!

- If you have email, please consider letting us contact you this way for things like notification of the AGM, it saves a lot of time and money. Just email [info@dhg.org.uk](mailto:info@dhg.org.uk) for further details.
- Do you need a printed copy of the newsletter or could you read it online? We don't want anyone to go without, but if you want to read it online and save printing and postage costs, just let us know by emailing [info@dhg.org.uk](mailto:info@dhg.org.uk).

There are various ways of supporting us by buying goods and services from selected companies who make a donation to DHG and we've been busy finding things which we feel offer good value and allow you to support DHG at the same time. The list is increasing all the time, so we've included details of some on page 8 of this issue.

These and others will shortly be available via our website at [www.dhg.org.uk](http://www.dhg.org.uk), so please visit regularly or contact us for written details if you prefer.

We are doing all we can to ensure that DHG funds are spent in the most efficient ways possible - PLEASE HELP US in any way that you can!

## AGM Notification

The Annual General Meeting is your opportunity to get involved and help shape the future of Down's Heart Group.

As it's not a Conference year this year, besides the usual items such as election of officers and presentation of accounts, there will be time to hear from members about what they value from DHG, service developments they would like to see and ideas for future growth.

Please come and join us if you can and let your voice be heard.

If you are interested in joining the Committee and contributing your skills, this meeting is for you, but please talk to our Chair or Director beforehand so that we can discuss your nomination.

# 2009

# AGM

10 am  
Saturday  
October 24th 2009

Friends' Meeting House  
16 Queens Road  
Leicester  
LE2 1WP

## Anya's story

Weighing 2.38kgs, Anya Sarah entered this world at 6.31pm on 15th February 2007, a month too early and screaming. Her bilirubin level shot up the next day and she had to have phototherapy in NICU where tests revealed that she had two holes in the heart. We were told these might heal on their own and since she was premature we were asked to take her for an echo when she was six weeks old. The paediatrician also asked us see a geneticist as soon as she was well enough to come out of hospital, we wondered why - nobody committed themselves to an opinion.

She finally came out of hospital when she was ten days old and we got an appointment with the geneticist for the following week when we were told what could be wrong with Anya, although they couldn't be sure till her blood results came back as Anya's physical appearance for Down's Syndrome was hardly noticeable. The wait was unbearable but three days later we got the results, Anya's blood report confirmed our worst fears, she was diagnosed with Down's Syndrome - our whole world came tumbling down.



The next day Anya was re-admitted to hospital for very high bilirubin. We were by her side for 48 hours until she came out of the danger zone and again we returned home. We had to repeat the blood test for bilirubin after three days but by then she was so yellow that we rushed to the hospital and Anya went back into the NICU for intense phototherapy.

At six weeks we took her to the cardiologist and were told that she required surgery as her heart was under pressure and the bigger hole showed no signs of closing. She was

put on medication and we were asked to return for a review in two weeks. It was so upsetting – here was this little helpless baby in my arms and all I could think about was whether she'd pull through the surgery and what would her future hold - it was a very scary and unanswerable thought. At the review we were informed that she was not improving and had hardly gained any weight, so surgery was scheduled for the 19th April 2007.

We left our elder daughter with my in-laws and took Anya to hospital on the 17th where she underwent a battery of tests, before surgery was fixed for 9am on the 19th. It took about three hours and when we met the surgeon afterwards, he told us the next 48 hours were crucial. When we were allowed to see her it nearly broke my heart to see my baby connected to so many machines and tubes.

Anya is a real little fighter, within 48 hours she was weaned off the ventilator and after eight days she was moved out of ICU, but the next day she was cranky, always crying and only wanted to be carried, which was unlike her. When the surgeons did their rounds I mentioned it to them but they felt it could be due to the withdrawal of painkillers and proceeded to discharge us the next day. On reaching home she was still cranky, so we all took turns in carrying her until she slept, hoping that the next day would bring her some comfort, but she only got worse. We all spent a very tense and sleepless night and by morning her wound was very red and had started oozing pus. We were told to take her to the ICU at the hospital, so we left in a hurry thinking we'd be back that night.

Anya was taken for an echo and then put on high dose antibiotics while they investigated what infection she had. They decided to operate that night, so Anya's chest was reopened and the infection removed, her sternum was a little damaged by the infection so it was retied and the wound closed. The surgery took about 1½ hours and when we met the surgeon after, he said that her heart looked fine, which was a good sign but she'd have to be on the ventilator for 5-6 days and again the next 72 hours were crucial. As we hadn't come prepared to stay,

we saw Anya moved into recovery and then headed home at midnight.

She was groggy for the next three days but her blood pressure had dropped, she was responding to the treatment and looked better. Her surgeon and cardiologist told us her heart was not infected which was a very good sign. Anya was in the ICU for over two weeks after being weaned off the ventilator. Her wound was cleaned daily and dressed by her surgeon. Her sutures were removed two days before we were discharged as they had put in much stronger ones this time. Finally it was time to go home and be with our family.

Anya's doing really well now, she rolled onto her tummy at three months and learned to roll back by six months. She learnt to sit at eleven months and says "Tata" and "lala", claps her hands, has learnt to wave, grabs hold of any objects that come into sight and bangs them all around. Her doctors are happy with her improvement and she goes for physiotherapy once a month. She has eyes for only her big sister and will watch what she's doing intensely. She's a happy baby, always smiling with a mischievous twinkle in her eyes. I thank God for every moment we have with her, each day is a new story and a new accomplishment.

What would our world be like with out her? I can't say, but the one thing I can say is that no matter what, she's brought us so much joy and just as much happiness. We are all so proud of her and we will fight for her every step of the way - just as she fought every step to be in this world.

For all you new parents out there who have just discovered that your baby has Down's Syndrome, don't feel bad, don't give up, they want to be treated just as any one else, so cuddle them and most of all love them. Your little baby needs you as much as you need him/her. With our help and support they can accomplish anything.

We have been blessed to have support from both our families and this helps us a lot, nobody wants pity or to hear someone say "I'm sorry".

***Seena Joseph  
Kerala, India***

## Richie's story

*I don't know if these circumstances are in any way similar to the two families you mentioned in a previous newsletter, but I hope this may be of some help or interest.*

Our son Richie is now 29, quite a remarkable achievement considering the prognosis given in 1980 when he was born. The risk associated with surgery was said to be high and the likelihood of a 'good' result without more than one operation was unlikely,

He has a complete AV septal defect with a common valve, consequently he now has Eisenmengers syndrome, a term which seems only recently to have been adopted by our cardiology consultant, who used it for the first time at our last annual visit, although I had come across it myself some time ago when I was looking for information on Pulmonary Hypertension on the internet.

It described ALL the symptoms Richie had developed, including coughing up blood (fortunately just one episode), bouts of tachycardia which were becoming increasingly common and the high haemoglobin levels and low platelet count. But, as I say the consultant (who I don't think has much interest in Richie really!) only 'coined' the term last year, and then just fleetingly.

### *New medication*

I was asking him about treatment with Bosentan and/or Sildenafil at the time, his idea on this is to reserve such treatments until a 'marked' deterioration occurs. I sometimes wonder what is recommended in other regions?

Anyway, Richie is now taking Verapamil three times a day, for the heart rate problem, (he'd previously taken a beta blocker Atenolol). The difference after stopping Atenolol and starting Verapamil was almost instantaneous! Richie 'brightened' up back to his 'normal' self and even his colour improved a little.

He's been taking Verapamil for about 9 months and has had 3-4 'blips' with his heart rate, but nothing like before

and not needing a trip to the hospital. When it starts he complains of a pain in his 'tummy' and looks very glum, sometimes he'll say there's a bumping feeling and then we see the telltale sign of his neck pulse, at an 'unusual' rate and rhythm. But, hopefully, for the moment it's fairly well controlled.

The most recent problem we've had was late on a Friday night when he complained of a pain in his foot (he often complains of pains here and there, so over the years we've come to think his pain threshold is a bit low). Anyway, having asked if it was cramp or pins and needles, which he gets now and again, I looked at his foot to find his right ankle was very swollen.



*Richie on his scoter*

Thinking that usually both ankles would be expected to be swollen if a 'bit of heart failure' was lurking, and as it wasn't red or hard or terribly painful (ie a DVT??) I thought maybe he'd traumatised the ankle because of his flat feet and awkward gate. I put a support bandage on and took him to see the doctor on the Monday.

Our GP was on holiday, and the Dr we saw felt it could be to do with his flat foot and didn't really give any advice, but the following week, as it was still swollen though not painful, we saw our own GP who said that sometimes fluid retention can be 'assymetrical' and gave him a low dose diuretic. Lo and behold after 2-3 days the swelling has gone and in fact Richie seemed a bit brighter again.

On the subject of sleep disturbance, he goes off to sleep OK, though

sometimes messes about beforehand, often though, we are awoken to his music on quite loudly, or we hear him chatting to himself or laughing. I don't know if that's because of a sleep disturbance or just that he wakes up and decides to amuse himself. He goes back off to sleep (I assume) after a 'stiff talk' from his dad, then doesn't want to wake up, so usually has a lie in until about 9am or so.

He has an oxygen concentrator and is supposed to use oxygen overnight, HOWEVER, this just doesn't happen. He'll laughingly put the nasal prongs in, but they're out after five minutes (unless he doesn't feel well, when I think the oxygen gives him a feeling of security), so we end up tying the tubing around his pillow and telling him to try to sleep with his nose next to the outlet prongs! Hardly an economic or efficient situation, but no one has come up with a more comfortable way of supplying oxygen overnight.

### *Enjoying himself fully*

I've intended to write a story about Richie for the magazine for some time, but his early life was very traumatic and I didn't think it was a 'good'

story for new parents to read about! However, here he is at 29, enjoying himself fully. He has a 'Shoprider' scooter, which I would advise anyone to get if they can, as it means we can get out for some decent 'walks' now and he loves to show off driving it about. I don't think the manufacturer would advocate driving their scooters over rough bumpy lanes and fields, but Richie does (we live in the Lake District so lots of opportunities for that!)

For anyone considering a purchase, I'd say don't go to the main dealers, we bought ours at quite a reduced price on the internet at MobilityBuggy and got excellent service.

**Christine Langdale  
Penrith**

DownsEd books  
available **FREE** online



“Down Syndrome Issues and Information” is an extensive series of comprehensive reference resources produced by DownsEd, examining issues for people with Down’s Syndrome from birth to adulthood.

They have recently added to the series which now covers:

- development overviews \*
- speech and language \*
- reading and writing \*
- number and maths \*
- motor skills \*
- social development \*
- memory skills
- education
- family issues
- employment
- society

\* These topics cover age ranges 0-5 years, 5-11 years and 11-16 years.



All the books are available to order in hardcopy, but many can already be accessed online for free, with the others due to be available soon.

*To find out more visit*

*[www.down-syndrome.org/information/index.aspx](http://www.down-syndrome.org/information/index.aspx)*

Easy Riders 20th anniversary

2008 saw the 20th anniversary of the Variety Club’s, Easy Riders Wheelchairs for Kids scheme. Working in unison with each child or teenager, they provide buggies, trikes, motorised and manual wheelchairs with lightweight frames that may be easier to use than standard wheelchairs



They want more children and young adults to apply for sports and non-sports wheelchairs to further empower disabled children throughout the UK.

*For more details  
telephone:020 7428 8100  
or email:wheelchairs@  
varietyclub.org. uk*

New DVD - Aspirations

Inclusive pop group, MiXiT, have released their first DVD which includes covers of some hits of the past few years as well as the band’s first original song ‘Aspirations’ which gives the DVD its title.

It’s a great mix of videos, interviews and the band just having fun!



*Get your copy online at  
[www.mixitmusic.co.uk](http://www.mixitmusic.co.uk)*

Help for Blue Badge holders



PIE Enterprises offer a variety of products aimed at making life easier for Blue Badge holders.

These include a concise UK Road Atlas which features the ‘on-street’ parking rules for every council in the UK, Petrol Stations & accessible toilets information on the National Road Atlas and Town centre plans with on-street parking rules, blue badge bays, accessible toilets and accessible car park information.

They also have a Blue Badge specific Sat Nav which can navigate directly to blue badge parking bays and easily find disabled accessible car parks.

*For more information call them on  
0844 847 0875 or order online at  
<http://shop.thepieguide.com>*



Directgov is promoting their online Blue Badge mapping service, which allows people to search by postcode or town/city name for designated Blue Badge parking bays, Red Route parking bays in London, accessible toilets and petrol stations, Shopmobility centres, railway stations and much more.

Blue Badge holders can also find out more about rules for street parking, in all local councils in the UK.

*Go to [www.direct.gov.uk](http://www.direct.gov.uk) and enter ‘Blue Badge’ in the search box.*

## Family Fund age limit increase



Recent changes mean that the Family Fund can now give grants for children up to 18. To qualify, children and young people must have additional complex needs, or have a serious or life threatening illness.

### **AND**

There must be evidence that those additional needs impact on the family's choices and their opportunity to enjoy ordinary life; and the degree of planning and support required to meet their needs is much greater than that usually required to meet the needs of children and young people.

### **AND**

They must need a high level of support in three or more of the following areas:

- The physical environment
- Education
- Communication
- Access to social activities
- Personal care, supervision and vigilance
- Specialist resources, including Information and Communications Technology, required
- Medical or therapeutic treatment and condition management

### **AND**

The condition must be long term (likely to last 12 months or more ) or life limiting.

### **AND**

Families must have a gross income of no more than £23,000 a year (£25,000 in Scotland, N. Ireland and Wales) and savings of £18,000 or less.

*For more information*

*Telephone: 01904 550037*

*or visit*

*[www.familyfund.org.uk](http://www.familyfund.org.uk)*

## Holiday Information Guide

Each year HFT's Family Carer Support Service produces a Holiday Information Guide with eight sections

- Before you Book,
- General Guides and Services,
- Tour operators
- Places to Stay UK,
- Places to Stay Abroad,
- Special Interest Holidays
- Insurance
- Benefits and Financial Help.



Although people with learning disabilities should have access to the same range of holidays as everyone else under Disability Discrimination legislation, it can still be helpful to know of holiday opportunities that people with learning disabilities and their families have already used.

The Guide is available free of charge by sending a stamped (76p) self-addressed A4 envelope to

**CSS Holiday Information**  
5/6 Brook Business Park  
Folly Brook Road  
Emersons Green  
Bristol  
BS16 7FL

or you can  
download it  
at

[www.hft.org.uk/  
Resources/  
Home  
Farm Trust/  
Family/  
Holiday  
Info 09  
HFT WEB.  
pdf](http://www.hft.org.uk/Resources/HomeFarmTrust/FamilyHolidayInfo09HFTWEB.pdf)

## Disability equipment advice

Disabled Living Foundation has launched an advice and information website on equipment for children and young people with disabilities.

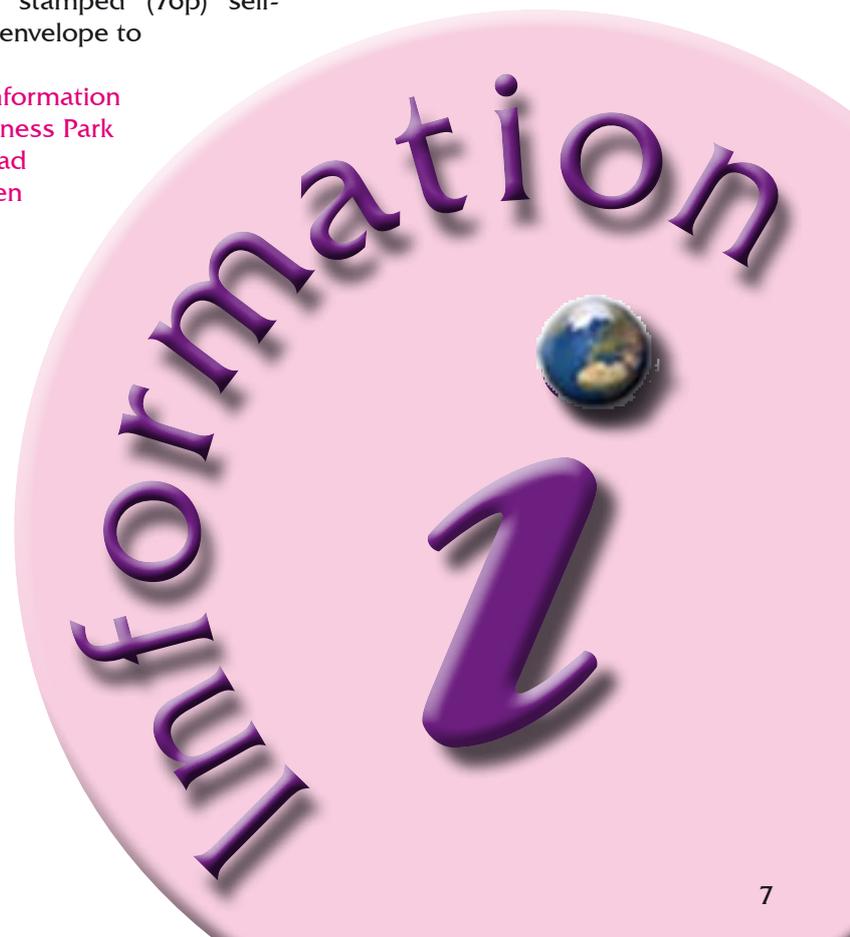


The site, Living Made Easy for Children, aims to bring together information on every product for children and young people with disabilities into one place. It includes a star rating system showing whether suppliers have provided prices for the product and whether they have signed up to industry Codes of Conduct.

Users can review products themselves, discuss with other parents or ask for specific advice from occupational therapists.

*For more information visit*

*[www.livingmadeeasy.org.uk/children](http://www.livingmadeeasy.org.uk/children)*



# Credit Crunch Fundraising

ways to help DHG that are FREE or provide a benefit for you

*We realize that in the current climate, it can be difficult for people to provide donations to charities, so we have come up with some ways to SAVE YOU money and PROVIDE SERVICES, whilst at the same time generating income for Down's Heart Group.*



We have signed a Community Fundraiser Agreement with Utility Warehouse which enables us to offer members access to the services of their discount club.

Recently they received a 5 star rating from "Which?" for their service levels and for value for money for their Energy and Telecoms/Broadband offerings. They also won the "Best Buy" Award for their telephone and internet service, receiving over 20% higher customer satisfaction levels than their nearest rivals.



Their Energy (gas and electric) comes with a triple guarantee, promising that:

- Gas prices are guaranteed to always be cheaper than British Gas, wherever a customer lives in the UK
- Electricity prices are guaranteed to always be cheaper than the prices charged by the regional electricity supplier for the area in which a customer lives
- For complete peace of mind, prices are guaranteed to always remain competitive compared with the cheapest standard tariffs available from the "Big 6" suppliers



For just £20 a month, their landline telephone and broadband package, provides you with:

- Line rental
- Free calls day and night (if gas and electric are also sourced)
- 24Mbs download speed and 40Gb capacity (subject to availability in your area)



For Mobile Phones, they provide some excellent packages and one of the cheapest pay as you go services available.

As they don't advertise their services, they pay commission to individuals and charities who introduce customers, so by signing up, not only could you save yourself up to £855 per year, but you could also provide up to £40 for DHG.

To take advantage of this offer, please visit <http://www.telecomplus.org.uk/B84554> or call 0800 1313000 today, quoting appeal number B84554 and talk to a Utility Warehouse advisor.

**Save yourself money and support DHG!!!**



### *Why make a Will?*

Many people don't have a Will. Never an ideal situation, but when you have a child with Down's Syndrome it can have serious consequences. Have you thought about how an inheritance might affect any means tested benefits your child will receive in the future?

Getting the right benefits can be a real struggle, but if you die without leaving a Will and your child inherits a reasonable sum, those benefits may be stopped. Then their inheritance will be used up until there is nothing left, so effectively they will not have gained from it and eventually benefits will need to be re-applied for but may not be awarded at the previous level.

By making a Disabled Trust/Discretionary Trust Will the money you leave your child will be better protected. Although it may be slightly more expensive, there will be

numerous benefits, including the fact that the money is left in Trust so it should not be considered when means tested benefits are being looked at.

When you make a Disabled Trust Will you need to appoint Trustees to decide how the money will be spent. It is important to choose carefully as these people will be looking after your child's money for them once you are gone, but it offers added protection, as it means that your child is less likely to find someone taking advantage of them for their money.

*Claire saw her solicitor, who advised that a Disabled Trust Will would be the most appropriate way to look after her daughter who had Down's Syndrome, when she was gone.*

*She chose not to do so as she did not want to do anything different just because her daughter had Down's Syndrome and as she was mentally capable, Claire did not think that there was any need to make a special Will.*

*Her daughter was on benefits and when Claire died all of these stopped. She used her inheritance to support herself until it ran out and then the benefit process had to start again.*

Some members have been charged extortionate sums for these Wills, so as well as making sure that you have the necessary information to ensure your child is looked after when you are gone, we wanted you to have at least one reasonable option to consider.

So we have teamed up with APS Legal. By choosing them you will be able to get a Disabled Trust Will drafted at a competitive cost and at the same time you will be helping Down's Heart Group as a percentage of what you pay will be donated to the charity.

We would be most appreciative if anyone chooses this option, but whoever you choose to draft your Will, **please do make one.**



If you do decide to obtain a Will through APS, please telephone 0845 430 4600 and mention DHG. They will arrange for a local representative to contact you.



### *Win a Fiat 500*

Tickets cost just £2 each and of that 95% (yes a fantastic £1.90) goes direct to DHG AND we haven't had to pay anything to sign up.

To get your tickets go to

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

click on the Fiat 500 and buy as many tickets as you want.

**Ticket sales close on August 21st.  
The draw is on 1st October.**

If you don't have internet access please call the DHG office for assistance.

**Please tell everyone you know about the draw and ask them to support DHG.**

***You could save yourself money and support DHG at the same time!***

## Greetings Card Company



We have recently joined The Greetings Card Company so that our supporters can buy cards and gifts whilst raising funds for DHG.

Between 7.5% and 20% commission is paid to your chosen charity for each purchase made from the website, which is easy to use.



There are some fantastic cards and gifts for all occasions, including Christmas, so why not start your shopping early

*Just go to the DHG's "shop" at*

*<http://www.charitycards.co.uk/charities/dhg>*

## Everyclick

Don't forget you can easily help DHG for FREE by using Everyclick as your internet search engine. Why not ask friends, family and work colleagues to join in too?



*So far we've raised over £850 through this simple FREE method. With your help it could be more!*

## London Marathon 2009

Another hot one for our runners but thankfully they all made it round relatively unscathed, although there were even more than the usual number of "never again" comments.



*Pictured left to right: Jack Pow, Bob Ayres, Leigh Woolnough and Paul Smith*

Our six runners did us proud as you can see by their finishing times:

Neil Carter - 3:28:25  
Paul Smith - 4:35:08  
Jack Pow - 4:44:59  
Bob Ayres - 5:03:53  
Jason Curtis - 5:13:46  
Leigh Woolnough - 6:19:06

It's always difficult getting everyone together for a photo after the race, so we missed getting Neil and Jason in this one, but we would like to say a huge **THANK YOU** to all of them.

***We have guaranteed places for 2010, please get in touch if you are interested.***

## Well done Sarah!



Here's DHG Info Officer Sarah Smith during her first ever half-marathon last October. Despite her comments we think she secretly enjoyed herself. - or was it just the thought of the £600 plus that she was raising for DHG?

## DHG - Charity of the Year



*Anderson, Anderson and Brown staff handing over the cheque*

In December 2008, Penny Green visited Aberdeen to collect a cheque for £6600 from local accountancy firm Anderson and Brown, who had undertaken all sorts of events throughout the year enabling them to present this wonderful final total.

DHG was nominated as their Charity of the Year by partner Graeme Allen whose daughter was born at the beginning of 2008.



*Pictured left to right: Graeme Allen, baby Zara and Penny Green.*

## Multi-coloured Sock Shop

Towards the end of last year Jonathan Pears of Loughborough needed to clear some surplus stock, so he very kindly donated a large quantity of socks to DHG.



There are all different types including bed socks, children's socks, character socks, boot socks, legwarmers, stockings and tights. Selling at £1 each sales have already raised over £300.

## Marathon des Sables

Back in March, 26 year old Mike Blamires set off to complete an ultra marathon in the Sahara Desert to fulfil a personal ambition and at the same time raise money for three charities of which DHG was one.



*Mike with his finishers medal*

Given the conditions, this is never a predictable race, but who would have thought the first day would be cancelled due to severe weather and flooding. After a frustrating wait, things finally got underway on day two.

On day three, to help make up the distance the organisers threw in a gruelling 91km (56 miles). There was lot of nail biting waiting for the results to be posted online that day, but finally it was confirmed that Mike had completed this very difficult stage in 16 hours 42 minutes and 6 seconds.

Day five was cancelled due to the weather, so that left just one more day to the finish, but by then 30 people had dropped out including one of the most experienced guys in the field. Mike was not going to give up at this stage though and ended the race 289th out of 770 finishers



*Here's Mike at the airport on his return, looking fresh as a daisy with only two small blisters.*

*Thank you for all your efforts Mike & Congratulations to you and Vickie on your engagement*

## BAE Systems are Go!

DHG has had yet more support from BAE Systems, thanks once again to member Alan Quinn who put our name forward.

This time it was from the Chadderton site who organised a full weekend of family fun back in September 2008 as a joint fundraiser for Dr Kershaw's Hospice in Oldham and DHG.

Commencing on Friday night, a small group of employees arranged a reunion of Chadderton site workers and over 300 past and present employees turned up and reminisced until the early hours.

On the Sunday afternoon, it was the turn of their families, as under marquee protection from the heavy showers, up to 400 people enjoyed the circus performers, face painting and many other activities arranged to keep spirits high despite the weather.



*Pictured left to right: Brian Kershaw (Dr Kershaw's Hospice), Barrie Giddens (BAE) Emily Smith (DHG) Steve Kilroy (BAE) and Sarah Smith (DHG)*

With an outdoor barbecue and plenty of ice cream the whole afternoon was a resounding success, including DHG's sock stall manned by Emily Smith, who raised a marvellous £46.

Thanks to the generosity at both events a massive £2,000 was raised, which was split equally between DHG and the hospice.

## Not up for a Marathon?



If you aren't up for something quite so demanding as a full or half marathon, how about a 5K Fun Run?

We've signed up with the Big Fun Run where races are open to all ages and abilities, so why not make it a fun family day out?

Join in at: Derby - 8th August  
Liverpool - 9th August  
Leicester - 22nd August  
Coventry - 23rd August  
Sheffield - 13th Sept  
Leeds - 13th September  
Cardiff - 26th September  
Milton Keynes - 27th Sept

Nominate DHG as your chosen charity and receive £2 discount on your entry fee.

*Go to [www.bigfunrun](http://www.bigfunrun) for online registration and more information. then contact us for your personalised sponsor forms*

Fundraising  
£



# dhg

down's heart group

PO Box 4260  
Dunstable  
LU6 2ZT

tel : 0844 288 4800  
email: info@dhg.org.uk  
website: www.dhg.org.uk

contact or answerphone always available (24 hours in emergency)

Charity 1011413

## GROUP CONTACTS

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penny@dhg.org.uk

**CHAIR**  
Chris Stringfellow  
chris@dhg.org.uk

**INFORMATION OFFICER**  
Sarah Smith  
sarah@dhg.org.uk

**You can contact any of  
the above by email or by  
calling 0844 288 4800 and  
selecting the appropriate  
option from the menu.**

## GROUP ADVISORS

**FOUNDER**  
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**LEGAL ADVISOR**  
Brian Auld

**POLICY ADVISORS**  
Dr. Rob Martin  
Dr. Phil Rees  
Dr. Graham Stuart  
Dr. Rob Tulloh

**PATRONS**  
Sarah Boston  
David Graveney

For further information about Down's Syndrome you might like to contact



Down's Syndrome Association  
Langdon Down Centre  
2A Langdon Park  
Teddington, TW11 9PS  
0845 230 0372

[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)



Down's Syndrome Scotland  
158 - 160 Balgreen Road  
Edinburgh, Lothian  
EH11 3AU  
0131 313 4225

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



Down Syndrome Education International  
The Sarah Duffen Centre  
Belmont Street  
Southsea, Hants, PO5 1NA  
0239 285 5330

[www.downsed.org](http://www.downsed.org)



Down Syndrome Ireland,  
Citylink Business Park,  
Old Naas Road,  
Dublin 12  
00 3531 426 6500

[www.downsyndrome.ie](http://www.downsyndrome.ie)

For general information on heart related issues you might like to contact



Children's Heart Federation  
Level One  
2-4 Great Eastern Street  
London, EC2A 3NW  
0808 808 5000

[www.childrens-heart-fed.org.uk](http://www.childrens-heart-fed.org.uk)



British Heart Foundation  
Greater London House  
180 Hampstead Road  
London, NW1 7AW  
0300 330 3311

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



GUCH Patients Association  
Saracen's House  
25 St Margaret's Green  
Ipswich, IP4 2BN  
0800 854 759

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

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