



**dhg**

down's heart group

# Newsletter Spring 2008

Issue 37

## **In this Issue**

**Conference 2008**

**Everyclick Challenge**

**Stories**

**Latest News**

**... and more**



## Front Cover - Santiago Fraser

Dad, Angus writes; "Santi was born in 1994 with a VSD and ASD and was operated on in the Royal Brompton Hospital when he was four months old. The operation was a great success and apart from some relatively minor operations he has been incredibly healthy since then.

We have moved around the world quite a bit and Santi has already been to 10 different schools and lived in 5 countries; England, Venezuela, Colombia, Argentina and France. He has always been in regular school. At school he enjoys languages and speaks English and Spanish and is now doing well in French.

Santiago loves watching films, playing video games and playing football with his younger sister Mariana (11) and brother Andrew (8) - pictured with him on the front cover. Santi is the lovable big brother!"

Parents, Angus and Andrea are preparing to run the Paris Marathon on 6th April 2008 and have decided to support Down's Heart Group.

**"This is the first time we will be running for a cause and it has certainly added to the excitement!"**

If you would like to sponsor either of them please contact National Office to pledge your much needed support or go to the website [www.dhg.org.uk](http://www.dhg.org.uk) and make a donation online.



*Santi at the foot of a mountain - is he our most cosmopolitan member?*

## Chair's Report



Welcome to Issue 37 of the newsletter.

This is my first edition since taking over as Chair of the Group, although I have been Vice Chair for the past seven years or so and have been a member of the committee since about 1995. I have three children - Louise who is 26yrs old and married, Helen, 24yrs, who is now our Secretary, and Richard who is 22yrs and has Down's Syndrome. I also have a long suffering husband by the name of Bob who is very supportive.

The Down's Heart Group has come a long way in the past few years and we need to build on our success. We hold a fairly unique position here in the U.K. and worldwide as we address the needs of children and adults with Down's Syndrome and a cardiac issue.

We have developed our information leaflets and have added to them over the years. These have been vetted by the professionals involved in the care of our children and adults and we need to say a "THANK YOU" to all concerned. Our information packs are a valuable resource for parents and professionals alike. The pack for the professionals contains all the topic notes but parents receive specific information relating to their child's condition.

Penny Green is our Director and will be well known to the majority of you. She has been involved with the Group since 1989 and is the most valuable resource that we have. She has a

great depth of knowledge gained over these years and has come to know most of the doctors involved in our children's care. She runs our office and will be first point of contact for most people.

We have various new projects that we would like to start and one of these involves visiting all cardiac units in the country and putting up information boards in these units.

We would also like to know if there is anything that the membership thinks that we should be addressing, so please feel free to email and write to us about any ideas that you have.

We have had suggestions of a sibling group, and also of involving our members with Down's Syndrome who would like to be part of the committee or even to have their own subsidiary group.

In order to achieve our aims, the Group needs to keep its focus on fundraising and it is only due to you, the members, that we survive. We are very grateful to you all and look forward to many more fundraising activities by everyone.

One of our biggest recent projects was to update the website to bring it into the 21st century, which background work continues on. This has been extremely successful and we have hits on the website from around the world - in the last 5 months of 2007 we had visitors from 118 different countries. It is also possible to download much of our information from our website [www.dhg.org.uk](http://www.dhg.org.uk).

Last year we also worked with the British Heart Foundation on a DVD for young adults with learning disabilities who need cardiac surgery and this DVD has been very well received by all groups.

I hope to hear from you in the future with any comments that you have and I wish you all a Happy New Year.

**Regards,  
Chris Stringfellow**

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



# From Cradle to Independence

## Down's Heart Group Conference and Family Weekend

**8th and 9th November 2008  
Holiday Inn Bristol Filton**



**Conference Programme to include items for all ages and abilities  
with disco on Saturday evening and time to enjoy the leisure facilities before Sunday lunch**



Following the success of our last conference, places are likely to be taken fast. Don't miss out – reserve your places now by contacting National Office.

Final cost is likely to be in the region of £150 for a family of four, so we are asking for a deposit of £25 per room. (Deposits will be refundable providing cancellation is made at least four weeks in advance of the event)



### Everyclick Challenge

Down's Heart Group has the chance to win a free national poster campaign on over 1,500 sites across the UK, as a result of entering the Everyclick Charity Challenge.

**DHG will receive funds even if we don't win!**

Everyclick.com will keep a tally of how much is being raised for each charity entrant throughout the three month challenge period. The average amount raised by each supporter will then be calculated and the panel will judge the entrants on the money raised and the innovative and imaginative ways they have encouraged their supporters to use Everyclick.

Each search raises money for DHG and you can increase this by also shopping online via Everyclick. Many retailers such as Tesco and Amazon, give a set amount or percentage of your purchases to charity, just ensure you are a registered DHG supporter on Everyclick, use their shopping search to find your online stores and DHG will get the donation.

**Please help us by encouraging friends, family and work colleagues to switch their search engine to [Everyclick.com](http://Everyclick.com)**

**Let us know of any innovative ways you can think of to attract more supporters.**

**Just think of how many people DHG could reach if we won!**



**The Challenge runs from  
14th January to 14th April**

**Use Everyclick every time you search**

**Using Everyclick raises funds for DHG**

**Online shopping can raise funds too**

**Everyclick is free**

**It's easy to register**

## Oliver

Oliver is a bright, articulate and devastatingly handsome young man.....not that I'm biased at all you understand! He continues to amaze me with his speech, which was so delayed at one time I feared he would never talk properly or with any clarity.

Oliver's favourite pastimes are playing and watching, snooker, golf and skateboarding. He can read every snooker player's name and gets me to video all the competitions. It is the same with golf.



He loves watching skateboarding videos and DVDs, so I have to boldly walk into skateboard shops and ask scary looking guys with lots of piercings if they can recommend any

## Gage

My son was born on October 2nd. I had no idea he had Down's Syndrome and knew nothing of his heart condition!

The hospital where I had him was awful, they told me NOTHING good from the time he arrived. They said he wouldn't ever do anything and he'd never amount to anything! They wouldn't feed him at the hospital and when I asked why he wasn't eating the nurse's reply to me was he won't be of any good to you, just let him go! I had to sneak formula into the hospital to feed him and they were mad at me when they found out! Gage had jaundice and with them not feeding him, he lost weight.

After being in the hospital for four days

good skateboard videos. (Without too much swearing in them!!) If Oliver is with me they always treat him really well and show an interest in him.

Oliver is progressing well at mainstream school, although handwriting is definitely his greatest difficulty. I think it is something he will never really master, so he'll have to be a young man with a laptop in his briefcase I think!

From a health point of view, Oliver is absolutely fine. His heart operation to repair an ASD, VSD and PDA at three and a half months old was completely successful and he now only has a checkup every two years. He had his tonsils and adenoids removed several years ago so bouts of the dreaded green runny nose have been drastically reduced and I can't remember the last time he needed antibiotics.

Despite being told when he was 18 months old that he had quite severe hypotonia he is now a very physically able young man, as can be seen by the skateboarding.



Oliver can be challenging behaviourally sometimes, and does tend to wake unspeakably early in the mornings. However, when a delicious blonde haired blue eyed boy climbs into your bed at 5am and whispers "Mum! Mum! It's me!...Oliver!" and then goes on to tell you that "Mum, you are my most scrumptious lady in the whole wide world, and I love you as high as....ummm.....mount Kilimanjaro" - it really is quite impossible to be cross!!

**Wendy Hellowell**

# Your L

I finally had enough and told them I was leaving and so was my son. They went nuts, telling me he couldn't leave - he still had jaundice and his heart couldn't take it. In fact they told me anything they could come up with to keep Gage there! He was over the legal birth weight to leave and I knew in my heart that he needed his family and the strength of prayer at home! So that day with a huge fight from social workers, doctors and nurses, my son and I went home to HEAL!

Since then we have had doctors' appointments and lots of praying about his heart! I still have no clue what to do and I am just as confused but at least now I know he's going to live. I also know he's going to do lots of things they said he wouldn't!



I have never been so proud in all my life! He's an Angel from God!

**Dawn Price, Richmond, USA**

## Theo

This is our gorgeous son Theo.



When he was born in November 2006 and quickly diagnosed with both Down's Syndrome and a Complete AVSD we were shocked and very afraid of what the future might hold for our longed for child. If we had been able to see beyond the surgery we might not have been so very frightened beforehand!

Whilst trusting the expertise and reputation of Alder Hey Hospital, we were understandably, very worried. Trying to keep him as well as possible before surgery and then having the courage to hand him over for the life threatening operation you know has been approaching

since the day he was born. Anticipation is the worst thing and had we been able to see how well things would go and how fantastically quickly Theo would start to recover we would have saved ourselves more than a few tears and sleepless nights.

Theo was tube fed at birth, for 3 weeks, whilst we tried, but failed, to establish breast feeding. My health visitor puts Theo's great health and ability to feed down to my having expressed breast milk for 5 months for him. My personal belief is that it was down to his receiving practically continuous Reiki throughout his life to date!

Reiki is a Japanese word (pronounced Ray – Kee) which means 'universal life force energy'. It is a non-intrusive hands-on healing technique. Reiki energy works holistically by healing body, mind and spirit so can be used to great effect to alleviate both physical and emotional issues.

Whilst, in general, the medical profession don't recognise the value of complementary therapies I have hard evidence of the benefit Reiki

has given, not just to Theo, but many other people. It may be that during your trips to cardiac clinics you will never hear about complementary medicine, therefore I really want to share Theo's Story. He came home just 5 days post op and his recovery and developmental success since, have all been astonishing.

The prognosis at Theo's birth was so bleak and the stories we heard so worrying that I hope by sharing our story other families might find hope or want to discover more about Reiki and how it could help them as well.



We are now so hopeful for Theo's future, having found it very difficult to see beyond his operation before hand. Now every day feels like a gift and we are enjoying every moment with Theo, the things that parents with healthy children take for granted. We look to the future with hope, happiness and gratitude.

***Helen Avraam***

If anyone would like to contact me about Reiki or our experience please email me at [helensavraam@aol.com](mailto:helensavraam@aol.com) or see [www.reikifed.co.uk](http://www.reikifed.co.uk)

# ettters

## Letter From Romania

I work in a Daycare Centre for children with special needs, where some children with Down's Syndrome are our clients. My job is not to work directly with the kids, but in the office in social development services, however, I am also social assistant when needed!

In this centre we have an ergo therapeutic room, where the children can improve their ability to do different kinds of activities. I'm happy because a few days ago, when I was in this room, I was singing and dancing with the children. They are so lovely and so lovable! It was a great day! Andrea has a great smile and Maria also. They both hug me with so much love; I feel

I could cry with happiness.

They are indeed in an inner world (sometimes I wonder what kind of fantastic world that is). They are teaching us so much about care, love and affection and we should appreciate properly their presence in our life.

I just wanted to share this feeling with you. You are doing a great job, good luck in the future and thanks for your site, help and support.

***Mioara Suciu, Galati, Romania***



Our Trustees and staff would like to say a sincere **THANK YOU** to everyone who has sent in donations of any kind recently.

Due to postage costs, letters of thanks are only sent if requested, but we appreciate every single act of support, whether financial or otherwise. Sadly we can't include them all in the newsletter.

As well as those involved with events, many people bought our Christmas Cards and rounded up their payment, others made donations instead of sending cards. Those people who send in used stamps also help create a modest but steady income.

Gift Aid  
increases your donation

On top of this, we now hold Gift Aid declarations from many supporters allowing us to increase their donation by reclaiming the tax from the Inland Revenue.

We are incredibly grateful to **ALL** our supporters and as the saying goes – every little helps, but we need your continued support please if we are to continue and develop our work and reach more families.

So how can **YOU** help?

Budding fundraisers don't have to stick to events highlighted in our newsletters. Any event that takes your fancy and can raise some much needed cash for DHG is more than acceptable!

Contact National Office with details of your proposed event and DHG will do what it can to support your efforts. We can supply personalised Sponsor Forms etc. and can list information about your fundraising event on our website and in our newsletter.

## London Marathon

On Sunday 13th April, these six generous souls will be running through the streets of London on our behalf.

Jason Curtis – Bridgend  
Sue Gardner – Leicester  
Anthony Jones – Caerphilly  
Phillip Longster – South Croydon  
John Tyszkiewicz – Saffron Waldon  
Eifiona Williams – Cardiff

We wish them well in their efforts and thank them for supporting DHG.

To show your thanks for their hard work by sponsoring them, contact National Office on 0845 166 8061 or visit [www.dhg.org.uk](http://www.dhg.org.uk)



online entry only  
from 2009

The format for entering the London Marathon is changing. From midday on race day this year, runners will be able to register online for a place in the 2009 Marathon - this will be the only entry method.

The entry system will remain open until Friday 5th September 2008 or until 120,000 applicants have signed up for a place, whichever is the sooner. Applicants will not be guaranteed a place but they will know if they have been successful on October 1st, giving unsuccessful applicants an extra two months to find charity places.

Gold Bond places

*Down's Heart Group have Gold Bond places available but we operate a waiting list, so please call to register your interest as soon as you decide to run - 0845 166 8061.*

## Other Events

Motor sports fans may like to take part in the Silverstone Track Half marathon on Sunday 9th March 2008.



The track temperature will be just perfect, and there is no need to worry about choosing wet or dry tyres. Just don't expect scantily clad women to follow you around the start lane holding an umbrella to protect you from the rain!

You've probably heard of the BUPA Great North Run, but did you know they also arrange a lot of other events?

These include :

BUPA Great Edinburgh Run  
Sunday 4th May, 2008.

BUPA Great Manchester Run  
Sunday 18th May, 2008.

BUPA LONDON 10000  
Monday, 26th May 2008



This is a new event covering 10k run around Central London, incorporating much of the 2012 Olympics marathon course.

GREAT IRELAND RUN  
Dublin - Sunday 6th April, 2008

BUPA Great Women's Run 2008  
Sunderland - Sunday 15th June, 2008

BUPA GREAT SOUTH RUN  
Portsmouth - October 26th, 2008

For details of these or the other Great Run events, please visit [www.greatrun.org](http://www.greatrun.org)

## Blenheim Palace Triathlon

Sian Harrison, Colin Beardsley and John Hill - Team Pathway Care, took part in this event on Saturday 2nd June 2007 and would like to thank everyone who contributed to the £587 they raised for DHG.

On a very hot day, Sian swam 750 metres in the lake, Colin raced his bike for 20 kilometres and John brought the team home with a 5 kilometre run.

Sian said "The Triathlon was great, we had a fab day for it and really enjoyed ourselves. Out of 121 teams we came in 16th so I'm really chuffed with that. The water was so incredibly cold that I nearly jumped back out, but I managed to keep going. Colin and John suffered a bit more with the heat but it was well worth it."



*John, Sian and Colin dressed for success*

If you're interested, this year's event is on the 7th and 8th June 2008.

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



## British London 10k Run

This year the five mile run around London's landmarks begins at 9.35 on Sunday 6th July. If you live not too far from London please consider taking part, it is a fantastic morning with a wonderful atmosphere. Why not persuade work colleagues to join in and make a fun day of it?

Please register through Down's Heart Group by calling National Office on 0845 166 8061. DHG are holding places for a lucky few on a first come first served basis.

## ALL NEW **national** EVENT

DHG is joining with the Down's Syndrome Association and Down's groups throughout the UK for a national event in 2008.

During Down's Syndrome Awareness week, Saturday 31st May to Sunday 8th June 2008, individuals and groups are being encouraged to arrange or participate in local walks of around 3km.

There is a £5 registration fee payable to the DSA, to cover the cost of providing T-shirts, badges and marshalling equipment. Apart from that funds raised will go to the organising group of each walk.

DHG is not organising our own walk, but you are free to do so if you wish. Otherwise we hope that our members will be able to attend a local event and that we can come to an agreement with the organisers with regard to the distribution of sponsorship raised. The main focus is on raising

awareness and giving an upbeat message about Down's Syndrome and the achievements of our youngsters, so we hope that many of you will want to get involved.

To arrange a walk or to register to take part in a walk, please contact

DHG (NOT DSA) on  
0845 166 8061

We will take your details and liaise with DSA, either to get you an organising pack sent out or to find details of your local walks.

Registration fees will be payable to Down's Heart Group but will be passed on to the DSA who will forward your T-shirt.

Down's Heart Group will liaise with groups organising the walks our members are taking part in and will supply you with appropriate sponsor forms.



# THE BIG STEP FORWARD

Fundraising  
10k



## Annual General Meeting 2007

Our 2007 AGM took place on Saturday October 27th. The meeting was well attended with everyone full of enthusiasm for the future of the Group. Now we just need to maintain that enthusiasm and momentum to keep the charity moving forwards.

There were several changes on the Committee which now comprises

Chair	Chris Stringfellow
Vice Chair	Peter John
Treasurer	Linda Stokes
Secretary	Helen Stringfellow

Other members	Lindsay Allen
	Maggie Linde
	Roberta Nathan
	Gareth Hammond

### Can you help?

In order to support two member families, we would very much like to hear from anyone who has contact with a person with Down's Syndrome who

**Has an unoperated heart condition and has been prescribed Ramopril**

or

**Who has Eisenmengers and experiences sleep disturbance**

If you can help please contact National Office as soon as possible.

## Goodbye to Lynda

Lynda Hale has worked at National Office for the past few years as Admin Assistant and prior to that as a volunteer. She seemed to cram twelve hours work into a six hour role and really made a difference to the running of the office.

Lynda left DHG at Christmas, destined for bigger and better things, so we would like to say **THANK YOU** for all her hard work and good luck with her new ventures.

## Important Information about changes to Independent Living Funds (ILF) rules from 1 April 2008

This letter was sent out on Behalf of the Trustees of the ILF.

Each year the ILF is given an amount of money from the Department for Work and Pensions and the Trustees of the ILF are responsible for making sure that they do not spend more than this amount of money. Over the next three years from April 2008, ILF will be given a fixed amount of money and because of a higher number of applications being made it means that some of ILF's rules need to change.

Trustees want to make sure that ILF can continue to support you, whilst also continuing to enable new users who will benefit most from applying to ILF. The most important thing to tell you is that if you already get money from the ILF, you will continue to get your current award, as long as the rules in ILF's user guide leaflets continue to be met. All valid applications and requests for an increase in funding received by the ILF before 1 April 2008 will be dealt with under the old rules.

**The 2 main changes detailed below will apply to ILF Users living in England, Scotland and Wales from 1 April 2008.**

Where the ILF receives a new application or a request for an increase from a Group 2 user (former 1993 Fund Users or users who applied on or after 1 October 2007) both changes below will apply.

If you are a Group 1 user (former Extension Fund users) requesting an increase, only the second change will apply:

1. Change to the amount needed from your Local Authority (LA) towards your support (Group 2 Users only) For all new applications received by ILF the minimum contribution required from the LA will be £16,640 per year or £320 per week. This means that the ILF will not be able to start making payments to any new applicant who has less than this amount provided by their LA.
2. For existing ILF Users, if the cost of the care that you already receive goes up, the LA will not have to increase its contribution in order for ILF to consider paying you more money. If the amount of care you need changes, we will still consider paying you more money up to our maximum of £455 per week but will only be able to do this when the amount you get from your LA is at least £320 per week. When your LA is meeting the £320 per week contribution, ILF will be able consider any increase in funding up to £455 without having to ask your LA to increase their contribution further. This means we no longer have to operate a complicated policy which we called our £ for £ policy. You may want to contact your LA directly for more information about their current contribution towards your support.

The ILF will only be able to pay you a new or revised award from the date that the Agreement Form is received at the ILF offices, unless we receive evidence of the care costs from an earlier date.

We expect to have to apply the 2 main changes outlined above for the whole of the 2008/09 Year but we will continue to monitor the situation throughout the year.

These changes affect information provided in the ILF user guide leaflets 1, 8, 13 and 17. New versions of these leaflets will be sent soon to replace the ones you have. All other ILF rules will continue to be in place. If you need more information, or have any questions, please contact your caseworker.





POPS have launched their new intermediate range of books - the Blue Elephant Series - which will widen the scope and appeal of the programme to more children experiencing difficulties learning to read. The POPS programme is now used in over 1000 schools supporting pupils with autism, communication difficulties, Down's syndrome and pupils on Reading Recovery programmes.

The Blue Elephant Series builds on the success of the Red Elephant Series, providing entertaining stories whilst moving the Reader forward in small easy steps. Over 85% of the words introduced in the Red Series are reused in differing contexts to revise key vocabulary and consolidate progress made. Feedback from many teachers and parents has directly influenced the design and features of the Blue Elephant Series.

### Independent Evaluation

Jane Beadman, an Educational Psychologist with the UK Education Consortium carried out a study over 8 months with schools she recruited in Devon and Dorset. The POPS resources were used with children of differing ages and abilities. This is a summary of her conclusions:

- The scheme was flexible enough to use for each pupil whatever their level of reading ability.
- All pupils were reported to have made progress using POPS after being unsuccessful on other reading schemes.
- Pupil enjoyment is high.
- The scheme plays to strengths of visual/kinesthetic learners.
- The content is appropriate to children's experiences.
- Success in reading POPS provided a knock on effect for improved behaviour, self-esteem and attitude to learning.
- POPS makes pupils keen to read, and is viewed as something that is fun and special and is something that they can achieve.
- The scheme provides quality resources – 'chunky', laminated cards so teacher/TA time is not wasted refining resources.
- Words learned in books are retained and used in another context by pupils.

### Games

The game element in the Red Elephant Series proved very popular with many people requesting more games in the new series.

The Blue Elephant Series books have 6 pages of games in each book. The popular Lotto game is joined by a 'Find the Word Game', a game to complete simple sentences using key words from the story and a 'Word and Picture Match Game' to develop and assess comprehension skills.

### Blue Elephant Word Cards

Word Cards support key vocabulary in every book. Also included is a Sentence Building Set with starter words, joining words and grammatical markers carefully chosen so that a child can easily build simple sentences relating to each book.

### Social stories

These will help with issues such as behaviour.

POPS have included story lines on issues commonly experienced by children with additional support needs, such as Kal's frustration at not getting a turn to talk and his best behaviour when it is Mrs Pearce, his special helper's birthday.

### Speech Therapy

In response to requests from parents and teachers for a structured and fun way to develop a child's language, POPS have included a Speech Therapist script in each book.

The script is a guide to using the book to develop a child's communication skills. Also included is a comprehensive new section in the Free Teaching Manual on how to use the programme to improve a child's communication skills.

**"Most of our sales come from word of mouth recommendations, which we feel is the best measure of success."**

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

## Bercow Review

### Children, young people and speech, language and communication

The Bercow Review is an independent review supported by officials from the Department for Children, Schools and Families and the Department of Health.

Ed. Balls, Secretary of State for Children, Schools and Families, said about the review "It's critically important that young people with language disabilities get specialist intervention as early as possible so that they can play an active and fulfilled role in society throughout their entire lives."

### opportunity to bolster support for vulnerable children and young people

MP John Bercow, who is leading this review said "It is the first major review in seven years for people with speech, language and communication needs and it provides an excellent opportunity to bolster support for vulnerable children and young people."

"I am determined, with the help of expert advisors, to see and hear for myself what the present situation is and how we can improve the support available. I have been visiting speech, language and communication services across the country to learn what works, what the problems are and what people think should be done to facilitate effective early intervention."

### interim report due in March

The review's call for evidence ran for three months between 18 October 2007 and 18 January 2008 and is now closed, but they will be seeking views on the interim report once it is finalised in March. Details of how you can contribute will appear on their website.

The final report will be published in July 2008.

More details can be found at [www.dcsf.gov.uk/bercowreview/index](http://www.dcsf.gov.uk/bercowreview/index)

Take this chance to have your say on any issue regarding speech, language and communication, whatever your child's age.

## Out Of Pocket

A depressing report from Carers UK has highlighted the plight of many carers across Great Britain.

New statistics show that Carers lost out on an average of £11,050 in earnings in 2006 due to giving up work, cutting their hours or taking a more junior position. Those caring for the highest number of hours lost out on the most money. 13% of carers surveyed cared for a disabled child and 15% were caring for an adult son or daughter with disabilities.

The report recommendations include:

- Introducing new legislation to make it illegal to discriminate against carers in the same way that it is for disabled people.
- Undertaking a full review of carers' benefits and explore tax breaks, tax credits and other methods of financial support.
- Carers should be supported to undertake paid work if they are able, but those who are not able

to work should be given enough money to avoid living in poverty.

- The UK Government should extend the right to request flexible working to all employees. Requests should be allowed from day one of employment and there should be a continued focus on awareness raising and managerial training.

**CARERS UK**  
the voice of carers

Carers UK is an organisation with branches in the UK, Scotland Wales and Northern Ireland.

Website: [www.carersuk.org](http://www.carersuk.org)

Carers UK Tel: 0207 490 8818

Carers Scotland Tel: 0141 221 9141

Carers Wales Tel: 0292 081 1370

Carers N. I. Tel: 0289 043 9843

### To A Child With Love

Daily we learn from each other,  
Together we prosper and grow.  
Sharing in sunshine and laughter  
Caring in troubles and woe.

We taught you about birds and flowers.  
You taught us that when things go wrong,  
It's important to hope and have courage  
Facing each day as it comes along.  
People told us you would not achieve much,  
They told us "She's different you know."  
And they said that because of your syndrome  
Your learning would always be slow.

We did not listen to experts.  
You opened our hearts with your smile,  
And we are so proud of achievements you've made  
And the courage you show all the while.  
We will always be here when you need us  
To help when the going gets tough;  
Just give us one of your cuddles,  
And that will be payment enough.  
Always believe you are special,  
For when all is said and done  
Loving you is a pleasure,  
And we are the privileged ones.

© Vonnice Pearce.



## A new way to **SAVE** money and help DHG

The Utility Warehouse provides gas, electricity, telephone, mobile and broadband at very competitive rates for consumers, by purchasing large bundles of capacity from the main utilities suppliers at a bulk discount and passing a proportion of this discount on.

**If you register via DHG they will pay us a commission at no extra cost to you!**

It's simple to do! Just have your current bills handy, then call Utility Warehouse on

**0800 131 3000**

quote **84554** and say that you want to switch to Utility Warehouse as suppliers of gas, electricity, internet, phone or mobile.

The sales person will talk you through everything and ensure that you are happy with the procedure. (There is the statutory 'cooling off period') at any time.

### What is it worth to Down's Heart Group?

DHG will receive up to 5.8% of your bill on a monthly basis as well as a monthly commission for introducing customers. So if 6 members each introduced another 10 people to the scheme through DHG, we could make between £120 and £180 per month.

**Make a switch - save money AND help DHG**



For gas, they guarantee prices will always be cheaper than British Gas, wherever you live in the UK.

For electricity, they guarantee prices will always be cheaper than those charged by the regional electricity supplier for your area.

For your complete peace of mind, they guarantee prices will always remain competitive compared with the cheapest tariffs available from the "Big 6" suppliers. (The six major companies who currently supply over 98% of UK households)

- It's easy to switch.
- No minimum term contract.



Standard residential line rental just £9.99 per month, **saving you up to £30 a year compared to BT.**

They also offer a range of great value calling features on all phone lines at just £1 each per month - **a saving of up to 42% compared with BT!**

#### Compare their prices

##### Local/National (peak)

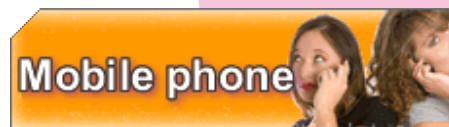
BT	Home Phone	You save
3.25p	2.5p	23%

##### 75 minute call (off-peak)

BT	Home Phone	You save
53.25p	3.5p	93%

##### Max duration for "free" or "fixed price" calls

BT	Home Phone	You save
60 mins	75 mins	£££'s



Talk to the sales team to find out if Utility Warehouse can save you money on your current mobile bills



- No minimum contract term.
- Free connection.
- Free USB modem on Standard service or wireless router and USB adapter on Max service.
- A fixed monthly price no matter how long you stay online.
- High speed - up to 140 times faster than dial-up.
- Complete piece of mind with "MyDataSafe", secure online backup service.
- Up to 10 email accounts with FREE anti-spam and anti-virus.
- 150 MB web space.



**Rated best broadband and phone calls combination in the UK's leading consumer magazine, October 2007**

#### BroadCall gives you:

- up to 8 Mbps broadband
- 40 GB data transfer per month
- free email anti-spam
- free email anti-virus
- no BT line rental charge on your phone
- Unlimited free UK weekend calls
- free connection
- free USB modem
- no minimum contract term
- savings of up to 93% on international calls

#### BroadCall Plus gives all that plus:

- Unlimited data transfer per month
- free wireless router & USB adaptor

**Research suggests an average consumer can save over £500 a year by switching to Utility Warehouse**



# dhg

down's heart group

Charity 1011413

PO Box 4260  
Dunstable  
LU6 2ZT

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

contact or answerphone  
always available (24 hours in emergency)

## GROUP CONTACTS

### DIRECTOR

Penny Green  
penny@dhg.org.uk

### CHAIR

Chris Stringfellow  
chris@dhg.org.uk

### VICE CHAIR

Peter John  
peter@dhg.org.uk

### INFORMATION OFFICER

Sarah Smith  
sarah@dhg.org.uk

### FOUNDER

Linda Walsh

### 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)

**the down syndrome  
educational trust**

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

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

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

**Down's Syndrome**

**SCOTLAND** helping people realise their potential

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 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  
14 Fitzhardinge Street  
London  
W1H 6DH  
0845 070 8070

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



Grown Up Congenital Heart Patients Assoc.  
Room 5, Saracens Business Centre  
25 St. Margarets Green  
Ipswich, IP4 2BN  
0800 854 759

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

**The letters and articles reproduced in this newsletter express the opinions of the authors and are not necessarily representative of the views of the Down's Heart Group.**

**Original material may be reproduced provided Down's Heart Group is credited. Permission for other items must be obtained from the source.**