



dhg

down's heart group

Newsletter Autumn 2010

Issue 41



Chair's Report

Welcome to Issue 41 of your newsletter. This edition includes details of the conference "Changes and Choices" that is being held on Saturday 13th November, 2010, at Wokefield Park near Reading.

Down's Heart Group hold conferences bi-annually, and hopefully this one will be bigger and better than ever. 2010 is the 20th Anniversary for DHG. We have come a long way since those early days!

The venue, Wokefield Park, is superb and offers facilities for all ages and abilities. The conference programme will cater for all, with keynote speakers in the morning and workshops after lunch. There will be a crèche and activities for the youngsters.

Saturday evening will be a Gala dinner and disco, with pink and purple as the colour theme. Sunday will be a day of fun and relaxation. We hope to see as many of you as possible. Bursaries may be available to help towards travel costs etc. Please get in touch as soon as possible to find out more.

As many of you already know, Penny Green, Director of DHG, dyed her hair pink to celebrate her 50th birthday and what would have been her son Daniel's 21st birthday. She has also raised over £1000. She will still be pink for the conference, so will be very easy to spot!!

Once again we are asking for members to step forward to join the committee. We are now able to run online committee meetings, which means they are accessible from anywhere in the UK. So, if you have never offered to join the DHG committee before due to travel worries there is nothing to stop you now! Please consider coming on board to help take Down's Heart Group forward for another 20 years.

I look forward to seeing you all at the conference and to seeing some new faces at our committee meetings.

Regards,
Chris Stringfellow

chris@dhg.org.uk

Cover Story - from Spain

Isabel Davies Atherton was born in September 2009. She was delivered at Torrevieja Hospital, Spain, by emergency Caesarean section, weighing just over six pounds (2.785kg). Isabel was diagnosed with a hole in the heart and was suspected of having Down's Syndrome. The paediatric cardiologist, Dr Izquierdo, told Alison and Blue, Isabel's parents, that there was a chance the hole might close by itself over time, and prescribed medication in the meantime to help regulate her blood pressure.

A further ECG in January revealed two further holes in Isabel's heart. This new development meant that she required open heart surgery in Valencia fairly urgently, and the procedure was booked to go ahead two weeks later.



Isabel and her "zip"

Alison writes:

"Hola amigos, it was all a bit stressful! The operation was booked really quickly (a good thing, but still a shock), then cancelled because Isabel's SIP card was not properly accredited, then finally went ahead as scheduled because the hospital accepted a guarantee of payment from our private insurer. This all happened in a period of five days. Phew!

I made sure that the cardiac team were aware prior to surgery that Isabel would be a donor if anything went wrong, as it would be a huge comfort to us to know that she had helped other children live if she didn't herself. They were very respectful and added

it to her notes, but I think they then realised how a routine procedure for them was a 'life or death' operation for Mum & Dad.

I would say to any parent about to go through the same thing to have faith in the surgical team, because these people are amazing. Everyone, from the surgeon to the orderly, was really kind and supportive.

Isabel was admitted to the Casa de Salud hospital in Valencia on 9 February, and underwent open heart surgery on 11 February. The operation lasted 2 hours, and they mended the three holes in her heart, plus a fault in her mitral valve, which was only discovered the day before her procedure during a final ECG. Phew!

She then spent four days in the paediatric intensive care unit, before returning to my care on 15 February with 25 staples in her chest plus stitches. Bless, she looked like she had been fitted with a zipper! They allowed us to go home early - on 17th February - as Isabel was making an excellent recovery, and Josh was over from the UK for a week to meet his little sister.

On 22nd February we went back to Torrevieja hospital, where a nurse removed all 25 staples and the stitches from where her chest drain had been. On 25th February we returned to hospital for a post-operative check. Isabel's paediatrician said that she is making excellent progress, and so he doesn't need to see her for another 3 months.

I can't tell you what a relief it is to have got through this with our gorgeous baby daughter still intact. There should be no stopping her now! Isabel has been a complete star throughout her ordeal, and it is quite amazing to see how her scar is healing, given that she was only operated on two weeks ago. She has been so brave, and we feel really lucky to have such a terrific little girl.

Thanks for all your support and best wishes, it has really meant a lot to us. I am so glad it is over!"

Alison Davies

“CHANGES AND CHOICES”

CONFERENCE WEEKEND PROGRAMME

DATES
Saturday 13th
November 2010
Conference
20th Anniversary Dinner and
Disco - Saturday evening
Family Fun - Saturday
and Sunday

**CONFERENCE
PRICES**

DHG member	£25
DSA member	£30
Professional	£35
Adult with Down's Syndrome	FREE

ROOMS
from £45 single, £65
double + £5 extra per
child (max 2 in a room)
disabled rooms and
interconnecting
rooms available

**CRÈCHE
and ACTIVITY
WORKSHOPS**
£12 per youngster

**DISCO
and DINNER**
Adult £15
Child £10
(under 12yrs)

9.30am
10.00a
10.30am
10.45am

11.30am
11.45am
1.00pm
2.00pm

2.45pm
3.00pm
3.45pm

FREE TIME

7.00pm

Saturday 13th November 2010

Arrival and coffee
Annual General Meeting
Welcome
Dr Jennifer Dennis - Down's Syndrome Medical
Interest Group and retired paediatrician
'Cardiac surgery for children with Down Syndrome:
Reflections by a paediatrician on the impact of
changing practice over the last 30 years'.
Coffee break
Changes and Choices - keynote speaker (TBC)
Lunch - please collect children from crèche
Workshops - choose two
1. Maths Extra - Vikki Horner
2. Music Therapy - Jenny Robson, Parity
3. Benefits or Open Forum - (TBC)
Coffee and changeover
2nd workshop choice
Summing Up, Thankyous and Raffle, please collect
your children for this part of the day.
Use the hotel's facilities or relax in the bar
Gala Dinner - pink and purple theme
Disco til late

Sunday 14th November 2010

freetime for breakfast and use of hotel facilities including;
swimming pool, sauna, gym, golf course, fishing, archery, rope
course, Nintendo lounge, 250 acres of beautiful grounds

Call National Office on **0844 288 4800** to book or to discuss your
requirements ASAP. A deposit will be required to secure your place. A full
programme, directions, crèche forms etc.
will be issued nearer the event.

This promises to be a great
conference and the
dinner and disco will be
a huge party as it is
the 20th Anniversary
of Down's Heart
Group.

Come along,
meet new
friends, get up
to the minute
information
and take the
opportunity
to relax for the
weekend.

Don't miss it!

2010

**Wokefield Park
Goodboys Lane
Reading
Berkshire
RG7 3AH**

5 minute drive from
junction 11 of M4

AGM

Child Maintenance

Since 12th April 2010, child maintenance payments are no longer treated as income when working out if you are entitled to means tested benefits such as income support, income based job seekers allowance or income related Employment and Support Allowance. These payments are already ignored as income for housing and council tax benefit and for tax credits.

If you receive child maintenance payments and were told in the past that your income was too high to receive a means tested benefit, you may find that these new rules allow you to qualify for the first time. Call Contact A Family on

0808 808 3555

Merlin Entertainments

Some of the UK's biggest theme parks and attractions are owned by the Merlin Group. These include Sealife Sanctuaries, Legoland, Chessington, Alton Towers and Warwick Castle.

Families with a child with a disability can apply for free tickets. The child must be under eighteen and the other tickets must be for immediate family. Help with petrol costs to get there is also given. Each child is only eligible for one set of tickets per year.

To take up this fantastic offer go to

www.merlinsmagicwand.org

and fill in the form. Leave at least six weeks for your application to be processed and the tickets to reach you.

Alternatively contact;

Merlin's Magic Wand Charity
Applications Manager
3 Market Close
Poole
Dorset
BH15 1NQ

Luke - Another Spanish Story

Luke and his English family live Murcia, Spain. At three months old, Luke was diagnosed with a VSD, a hole between the two lower chambers of his heart.

Although his Mummy, Kerry, speaks very good Spanish it was still really hard to understand what was going on and what help Luke needed.

Luke was premature which meant he was small for his age and he wasn't putting weight on due to his heart defect. A stronger milk formula was recommended and this was worth its weight in gold!

Luke was put on various medicines, and after a further ECG, where it was discovered that the hole was 7mm, his surgery was scheduled for as soon as possible, as he really wasn't coping well.

During this time, most of the family's money went on medicines, better milk and petrol to get to hospital. There is no financial help for English families living in Spain.

Luke had his operation on the 20th of January 2010, and although the operation was a success, he had severe breathing problems and could not come off life support as he couldn't breathe for himself.

On day two the hospital doctors said they would need to do a brain scan as they feared brain damage due to lack of oxygen. Everyone was really worried, but the initial tests came back OK.

On day three they started to bring Luke around and do another scan, and he was given the all clear although still could not breath on his own, but by day four he was breathing and fighting back.



Luke shortly after surgery



Luke at home after surgery

After eight days in intensive care, Luke was finally released onto a ward and gradually got better, day by day and was soon allowed home!

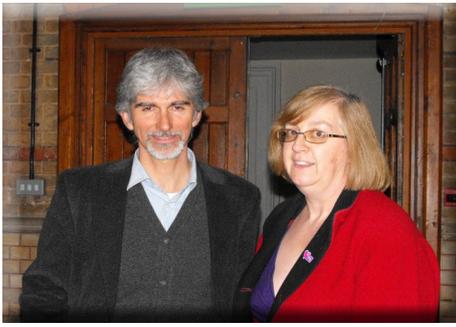
Luke is still on medicine, captropiril, as there is a very small hole (PVO) in one of his arteries that the surgeon couldn't fix at the same time. This should close eventually without further surgery, so fantastic news all round!

The surgeon (who spoke perfect English) and all the staff were fantastic throughout.

Kerry and Jason hope to be able to get on with running the Murcia Gazette now that things have settled down, but that will be up to Luke!

Luke's family and Isabel's family (from page 2) were put in touch with each other through National Office. Who knows, we may soon have a Spanish branch of Down's Heart Group!

This shows that no matter where you are in the world, there is no need to feel isolated - just call or email National Office and we'll try our best to put you in touch with a family nearby or a family whose child is a similar age or with similar heart problems.



Penny meets Damon Hill at last!

DSA 40th Anniversary

At the House of Lords for the Down's Syndrome Association's 40th Anniversary, Penny chatted with Damon Hill, former racing driver. She has always followed Formula One, so was quite excited about meeting him.

Penny also met Damon's son, Oliver, who was born just five months before Daniel.



The Duchess Of Wessex

Bangor

The Duchess of Wessex was guest of honour at a conference in Bangor. Penny was able to speak with her and explain what Down's Heart Group is all about.

Facebook

Follow Down's Heart Group and Penny on Facebook. She is constantly uploading interesting articles and has literally thousands of "friends" from all over the world.

Daniel Green Memorial Celebration

It has been an exceptionally busy few months for Down's Heart Group as a whole, so trying to fit in all the events Penny had intended to go along to has been impossible.

However, the Daniel Green Memorial Celebration has certainly raised awareness of the issues our families face and also helped to raise the profile of DHG.



No Caption Necessary!

Penny Goes Pink

Daniel lived for one hundred days so Penny decided to dye her hair Down's Heart Group pink for the same period of time twenty one years on.

Sarah, Penny's youngest, applied the shocking colour on Penny's 50th birthday, 3rd August, which would also have been Daniel's 21st birthday. Penny will remain pink until the conference which will make it one hundred days.

Penny refused to have her hair coloured until she had raised £1000 pounds in donations and would like to thank everyone for their support.



Start of the Severn Bridge Walk

Severn Bridge Walk

Local parents arranged a sponsored walk across the old Severn Bridge to celebrate World Down's Syndrome Day. Several of them decided to walk for Down's Heart Group and even dyed their hair pink or purple, too.

Penny took a lovely cake with the WSD logo on, which was used to entice some of the younger walkers down the home stretch!

Thankfully the weather was good for March and everyone finished in good spirits.



Chuks and the Desai Family

Down Syndrome International

Penny was a guest at the relaunch of the Down Syndrome International website on 23rd March. As well as meeting new faces she also met up with some old friends.

Suj Desai, a charming young man who plays seven different instruments and even taught himself to play trumpet gave a fantastic performance. He is a real ambassador for Down's Syndrome and plays all over the world.

Chuks Etuka from the Down Syndrome Association of Nigeria worked closely with Penny last year when she visited Lagos.

Carer's Allowance

Carer's Allowance earnings limit increased from April 2010. Carer's Allowance is the only state benefit specifically aimed at carers. However in order to get Carer's Allowance one of the rules is that your earnings must be no more than £100 per week.

How are my earnings calculated for Carer's Allowance?

In working out your weekly earnings certain deductions can be made from your gross wages. For instance any tax and national insurance you pay is deducted, alongside half of any pension contributions you make.

What about if I have to pay someone to look after my children while I am at work?

If because of your work you have to pay someone else to care for the person you look after, or to look after your children, you may also be able to deduct these costs from your earnings. However the maximum amount that you can deduct for alternative care costs is 50% of what would otherwise have been your earnings. No deduction is allowed if the person you pay is a close relative. These rules may allow some carers to qualify for Carer's Allowance even though they are earning slightly more than £100 per week.

What are the other Carers Allowance rules?

You must be at least 16 to claim and you can only get Carer's Allowance if the person you look after is in receipt of the care component of Disability Living Allowance at the middle or highest rate or Attendance Allowance (a benefit for elderly people). You cannot claim if you are a full time student involved in 21 hours or more supervised study.

If you are looking after a disabled adult then in certain circumstances an award of Carer's Allowance could lead to a reduction in that disabled person's benefits.

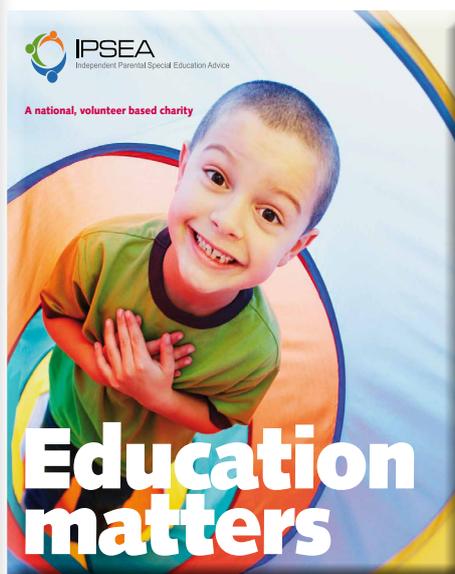
Parents with disabled children who are working and who want to know if the change in the earnings rule will help them claim Carer's Allowance should call Contact a Family's free Helpline on

0808 808 3555

IPSEA

IPSEA is a voice for children with special educational needs. It helps parents get the special education their children need. With IPSEA's help, thousands of children have maximised their potential by receiving the special education that they are entitled to.

IPSEA is an independent, volunteer based charity providing a unique service – free, expert, independent advice for every child – no matter what their SEN or disability.



Every year more than 50,000 people visit our website for:

- Model letters
- Support sheets
- Guidance on SEN Law
- SEN news

www.ipsea.org.uk

Our volunteers support parents with a wide range of issues, including:

- Improving the way that schools meet children's needs
- Requesting an assessment of a child's needs
- Planning for an annual review

IPSEA's advice line:

0800 018 4016.

IPSEA's tribunal helpline:

0845 602 9579

As well as giving advice, IPSEA seeks to improve SEN policy. Using the evidence gathered from parents' experience, we aim to benefit all children with SEN.

UTAG



UTAG is a company that produces a range of memory sticks which can be worn at all times. They store all necessary data and important medical details for a person and are easily accessible to anyone administering emergency treatment. The tags can be engraved with emergency numbers or allergies, in case of a wait to log into a computer.

UTAGs can be worn as a dog tag necklace or a sports bracelet. Alternatively the data can be stored on a credit card style piece of plastic which can be stored in a purse or wallet.

These products may appeal to parents of youngsters that run off at any given opportunity, teenagers desperate for more independence or anyone with an underlying medical condition.

Call **0845 872 3202**

or see www.utagice.com



Holiday Inn Offer

The Holiday Inn chain is offering a free room for a carer when a room for a disabled person is booked. Just ring the central booking line on

0845 124 9973

and request a room for a disabled person and an interconnecting room for their carer or support worker.

Also, if the person has a disabled person rail card you can get up to 35% off the cost of their room as well.



I too am a parent with a daughter with Down's Syndrome. I set up Maths Extra as a means of making the resources we have used so successfully available to other parents. We advocate two products.

The first one is to learn to tell the time, which I designed around Charlotte's learning profile. It was a fantastic success, she learnt to tell the time, both digital and analogue, in just over a year.

The other product is a wonderful system of hands-on wooden pieces

that have made a huge difference to Charlotte's maths. Maths was the most difficult subject for her, and for me!! The crucial element embedded in this system is the stimulation of cognition. Spatial awareness, memory and visual ability are all stimulated at the same time as the gathering of information about numbers.



I have worked hard to help with Charlotte's development, and everything that has worked for us I have tried to pass on to other parents. I have searched for and tried many resources. Finally I found these pieces of equipment geared to our kids' profile. I believe we should be playing with these materials as early as possible. Charlotte was thirteen when I found this equipment, after three years she passed entry level GCSE for maths.



Parents contact me because their child is not making progress in school and they, like me, want their son or daughter to be able to tell the time and use money. I'm glad to say that the Maths Extra resources are really helping families achieve this and this continues to be my main motivation for promoting the whole scheme.

www.mathsextra.com

Warm wishes, Vikki Horner
Maths Extra Limited

Book Review: Down's Syndrome – The Essential Guide

Providing information and sources of support, this book is essential reading for parents, carers, teachers and professionals working with children with Down's Syndrome. Published 1st June 2010, it covers all aspects, from diagnosis to adulthood, ensuring that parents receive all the guidance they need to support their child and family.

In straightforward terms, this book looks at what Down's Syndrome is, screening and diagnosis, coping with changes to family life, education and schooling, health conditions, finance, working with professionals and preparing for adulthood.

Authors Antonia Chitty and Victoria Dawson state;

'By reading this book, you can develop your understanding of the condition and, perhaps more importantly, find out about the help available and how to access it.'

Paperback price: £8.99
www.need2knowbooks.co.uk

Party Invitation!

Head on down to Southsea on 30 October for a freestyle funky solid dance Halloween evening with Jelly Jazz, Miss Funky Fox and friends in aid of Down Syndrome Education International and Rock Challenge. For more details see

www.downsed.org

Our research, advice and information improve education and transform the lives of children with Down's Syndrome.

Today, we are helping more than 100,000 people in over 180 countries.

See you at the party!

Frank Buckley
CEO

Down Syndrome
Education
International

Information

Find out what's happening now around the UK - come along to the DHG conference on Saturday 13th November 2010 at Wokefield Park near Reading. See page 3 for details.

WANTED - RUNNERS

WHEN; Sunday 17th April 2011
EVENT; Virgin London Marathon

WHO; Anyone who can commit to raising at least £1750 for DHG and run just over 26 miles.

HOW; Down's Heart Group hold Gold Bond places for those who haven't got their own place through the ballot.



Marco at the finish line

CONTACT;
National Office

director@dhg.org.uk

0844 288 4800

A.S.A.P!

London Marathon 2010

Down's Heart Group's five Marathon runners did incredibly well despite the hot weather, being held up for the first eight miles and a selection of injuries. The official finishing times were;

Tosh Evans	3:40:53
Marco van de Water	4:41:22
Emma Fuller	5:14:17
Ellena Talbot	6:28:21
Barrie Watson	6:30:14

Tosh said;
"Although my first marathon was fairly uneventful, it was still a fantastic experience and I'm grateful to the DHG for giving me the chance to take part. I was amazed by the sheer capacity and volume of the crowds, it was their support that kept me going for the 26 miles.

My training went well, despite a couple of injuries and a lot of snow! But I managed to get round in 3hrs 40mins which I was pleased with.

Thanks to the generosity of family, friends and colleagues I raise a total of £1,689."

The combined total from all the runners was **£10,000.**

Thankyou all so much

Rag Week

Bracknell and Wokingham College chose Down's Heart Group as their charity for 2010's Rag Week. Many crazy events were held to raise money, proving that helping others can be fun.

Our charity was chosen in memory



Penny and some of the Bracknell students at the cheque presentation

of Paul Clark, who sadly passed away earlier this year. Paul was a very popular student at the college and was also a Down's Heart Group member.

Paul's friends presented Penny Green with a cheque for **£1020.00.**

Help with Mortgage Interest

If you are receiving help with mortgage interest payments included in your income support, income-based jobseeker's allowance or income related employment and support allowance, the amount of help that you get may be reduced from October 2010.

This is because the average mortgage rate (currently 3.67%) as published by the Bank of England will be used to calculate mortgage interest instead of the standard fixed rate of 6.08% that has been used since January 2009.

Parents with disabled children who want to know how this change will affect them should call Contact a Family's free Helpline on

0808 808 3555

Lone Parents - Income Support

If you are a lone parent and your youngest child is aged 7 or over, you will no longer be able to make a new claim for income support as a lone parent from 25th October. This means that, unless you can claim income support on some other ground, you will have to claim jobseeker's allowance instead and show that you are looking for work.

If you are getting income support immediately before 25th October 2010 you may be able to continue to claim as a lone parent for a while after this date. The length of time that you can claim depends on the age of your youngest child.

If you are caring regularly for someone (including your child) who gets DLA middle or higher rate care or Attendance Allowance you can continue to claim income support as a carer.

Parents with a disabled child should contact the Contact a Family Helpline on

0808 808 3555

for further advice.

Unfair Airlines

The Mowberry family from Nottinghamshire were disgusted with their holiday company when they went on a recent holiday. They wrote to Disability Now for advice as they felt sure this type of treatment must be common for people with extra needs.

Shirley Mowberry wrote:

We booked five tickets for a flight with Thomson Airlines and wanted in-flight meals for only four of our party. The fifth member – our daughter – has severe medical needs and is fed entirely by gastrostomy, but Thomson's policy is that all members of a booking have to purchase meals.

Do we really have to buy an extra meal that won't be eaten? Is this

policy allowable under the Disability Discrimination Act or other legislation?

Andy Wright of Disability Now replied: I quite agree: it's a disgrace. Sadly, however, all airlines do this.

Airline computer systems are programmed to treat all people within a party in the same way: all with meals or all not; all seated together or all not.

I think it's unacceptable but until there are more challenges to these practices in the courts or DDA rules and regulations are tightened up (currently airlines do not have to comply with the DDA), this type of behaviour will continue.

Richard and Shirley wanted to make members aware of this discrimination and hope people can find a way around it or complain loudly until regulations are changed.



Claire and Nicola Mowberry

We Want You!

Down's Heart Group has always been run by members for members.

Our constitution states that the big decisions are always made by the committee on behalf of the members.

The best committees are made up from a real cross section of people, all with different ideas, backgrounds and skills.

DHG needs more committee members to survive and move forward.

Skills

Do you have any?

secretarial
accounting
admin
listening
fundraising
organising
presenting
advocating
grant finding
article writing
researching
parent friendly
web master
tea making

Could You

Attend the Annual General Meeting
Attend occasional meetings
Take on as much or as little as you like
Show an interest in the work of DHG
Have access to the internet and a phone to take part in online meetings every two months - they last a couple of hours and are really easy to do, no technological experience necessary!

Interested?

Please get in touch with either Chris, Penny or Sarah for chat to find out more.

0844 288 4800

or

chris@dhg.org.uk
penny@dhg.org.uk
sarah@dhg.org.uk

Are You

a parent
a sibling
a grandparent
an aunt or uncle
a professional working with people with Down's Syndrome and heart problems
a person with Down's Syndrome and heart issues

and a member of DHG

Ultra Run

On Weds 26th May, Gareth Robbins and his work colleague, Chris Welsby, attempted a 42.1 mile run from Cardiff to Swansea.

Unfortunately Chris was unable to complete the full distance but managed an amazing 28 miles. Gareth soldiered on alone and finished the total distance in 14hrs, slightly battered and bruised but overall extremely proud of his achievement.

Conduit, the company Gareth and Chris work for held several “dress down” days as well as supporting them with the run and a fantastic total of **£3000** was raised for Down’s Heart Group.

Thanks go to Chris and Gareth and all their work mates for their generosity.



Why Use Everyclick?

In August Everyclick made a payment of **£587.11** to Down’s Heart Group.

This money has been raised by users of Everyclick through Give as you Live, Online Donations and Fundraising Pages.

Thanks to all our supporters who use Everyclick as their search engine – every click really does add up!

To join go to

www.everyclick.com

and follow the instructions, choosing Down’s Heart Group as your charity.

Joley’s Crew Raise £2000

Hi there,
Just a wee bit of information on the recent charity events we held in Grangemouth.

Family and friends of our daughter Joley and the local community came together to sponsor me and a few friends to do a 5k and 10k run.

I was sponsored to grow my hair and beard and to wear a Celtic strip whilst running, being a Rangers fan this was no easy task. Ha ha! Likewise, my Celtic fan buddies were sponsored to run in the Rangers strip, just a wee bit more fun. Being Scottish as you can see from the photo kilts were also order of the day!

We then had a charity evening in our local Ship Inn pub including hair shaving, chest and leg waxing, which raised a great laugh with the females while the local lads endured pain for a good cause. We also held a prize raffle with live music and karaoke where you could bid for people NOT to sing, all in all a great night which raised **£2000** in aid of the Down’s Heart Group.

Annual Coffee Mornings

For the past few years, Mrs McLeod, DHG member Catherine Trussell’s Grandma, has run a coffee morning in Kirby Fleet. Each one has raised **£150**.

Thanks go to Mrs McLeod and her friends in Yorkshire for their continued support.

Maddison Primary School

Joley Moore’s school, Maddison Primary in Falkirk, has been very busy baking cakes to sell, raising **£100.31**.

The children in Joley’s class also made a beautiful card which they posted with the cheque inside, so DHG got two lovely surprises in one envelope!

Thanks go to the staff and children for all their effort.



Joley and her fundraisers

Joley, her big sister Carly and friends took part in supporting the cause by bellowing “Support the Down’s Heart Group” outside the local Supermarkets on a busy Saturday afternoon.

Joley is 5 years old. She has a complete AVSD with Tetralogy of Fallots and requires extensive cardiac surgery within the next month or so in an attempt to repair this. At this time it is unknown how successful this will be.

This fundraising was inspired following recent support from yourselves at a very difficult time.

THANK YOU.

Barry, Karen, Carly and Joley Moore.

Marathon des Sables

Mike Blamires is proud to announce that his mammoth effort to complete the gruelling Marathon des Sables raised **£592.34** for Down’s Heart Group.

Thanks again, Mike!



Joley baking to raise funds

Foreign Coins Wanted

DHG can make money by collecting foreign coins

So empty out your drawers of all those annoying little coins you are never going to spend, dust off the sand and ice cream, and post them to National Office. If you have a large amount please call so arrangements can be made.

0844 288 4800

Anyone able to act as a collection point volunteer please let us know.



Easyfundraising

Down's Heart Group have registered with a great website where you can raise funds simply by shopping and searching online.

You can shop online with over two thousand well known retailers at

www.easyfundraising.org.uk

Just use the links provided on the site whenever you make a purchase and up to 15% of the price will be donated to DHG - at no additional cost to you!

Just register and when you shop go to the easyfundraising site first and then to your chosen shop using their links.

Easyfundraising also features

www.easysearch.org.uk

a search engine with a difference. Search the Web with easysearch instead of any other search engine and you'll raise funds for DHG with every search you make. Make just 10 searches a day and you could raise around £20 a year - just by searching the web

Easyfundraising and Easysearch are both completely **FREE** to use and you can even choose to support more than one organisation if you like.

Spread the word to friends and family - imagine what a difference we can make to DHG funds if we all use easyfundraising and easysearch every time we shop and search online.



Gift To Charity

Get paid to shop and earn money for DHG - you can now earn free cashback for yourself and money for DHG every time you shop online at over 2,000 sites and in some high street stores by using the Gift to Charity website. Register, selecting DHG as your chosen charity, then when you shop online via their website or in store using a registered card, 50% cashback goes to you and 50% to DHG. To register simply go to:

www.gifttocharity.co.uk

and follow the simple procedure. If you do not have access to the internet, call Gift To Charity, free, on

0800 085 3399

YOU get £2.50 cashback just for registering. There are even 'No Spend Cashback' offers!

Gift Legal and Gift Insurance are other linked products to help you and DHG.

Ask your friends to sign up too, just by doing your shopping in a slightly different way you can help DHG generate funds that are vital to continue our work!



Christmas Is Coming!

Charity Choice are now open for Christmas 2010. Last year they raised more than £140,000 for more than 150 charities.

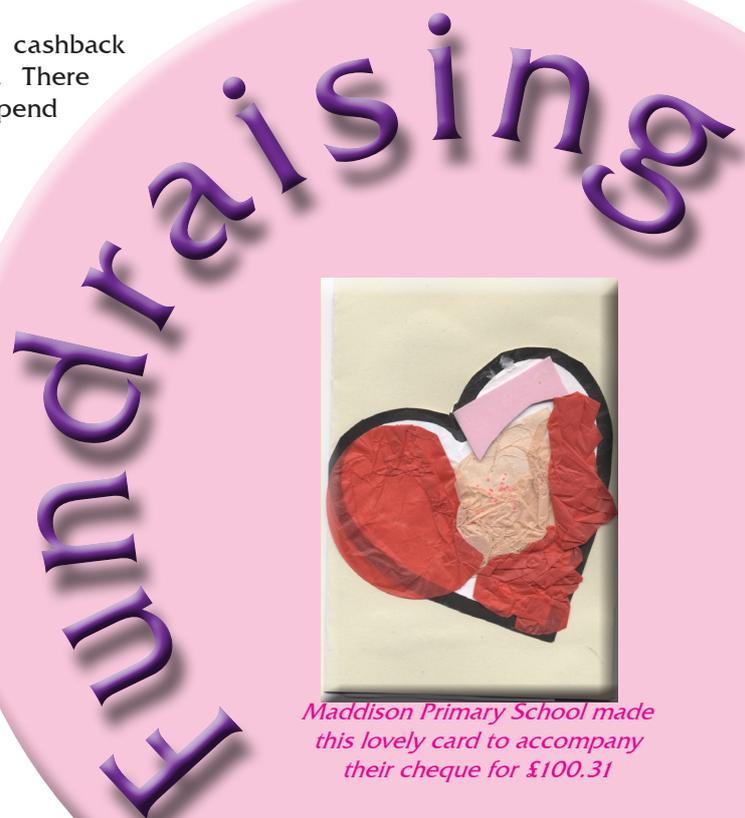
See the extensive range of charity Christmas cards at

www.charitychristmascards.com

Down's Heart Group could receive up to 50p for each card bought.

When it comes to ordering, purchase online to receive a £5 discount, or alternatively, send an order form by fax to

0845 0580 774



Maddison Primary School made this lovely card to accompany their cheque for £100.31



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

DIRECTOR
Penny Green
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.

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

Letters and articles reproduced in this newsletter express the opinions of the authors and are not necessarily representative of the views of 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.

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

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



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

www.downsed.org



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

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



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

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



PHA-UK
Unit 3A, Enterprise Court, Farfield
Park, Manvers, Rotherham,
South Yorkshire, S63 5DB
01709 761450

www.phassociation.uk.com