

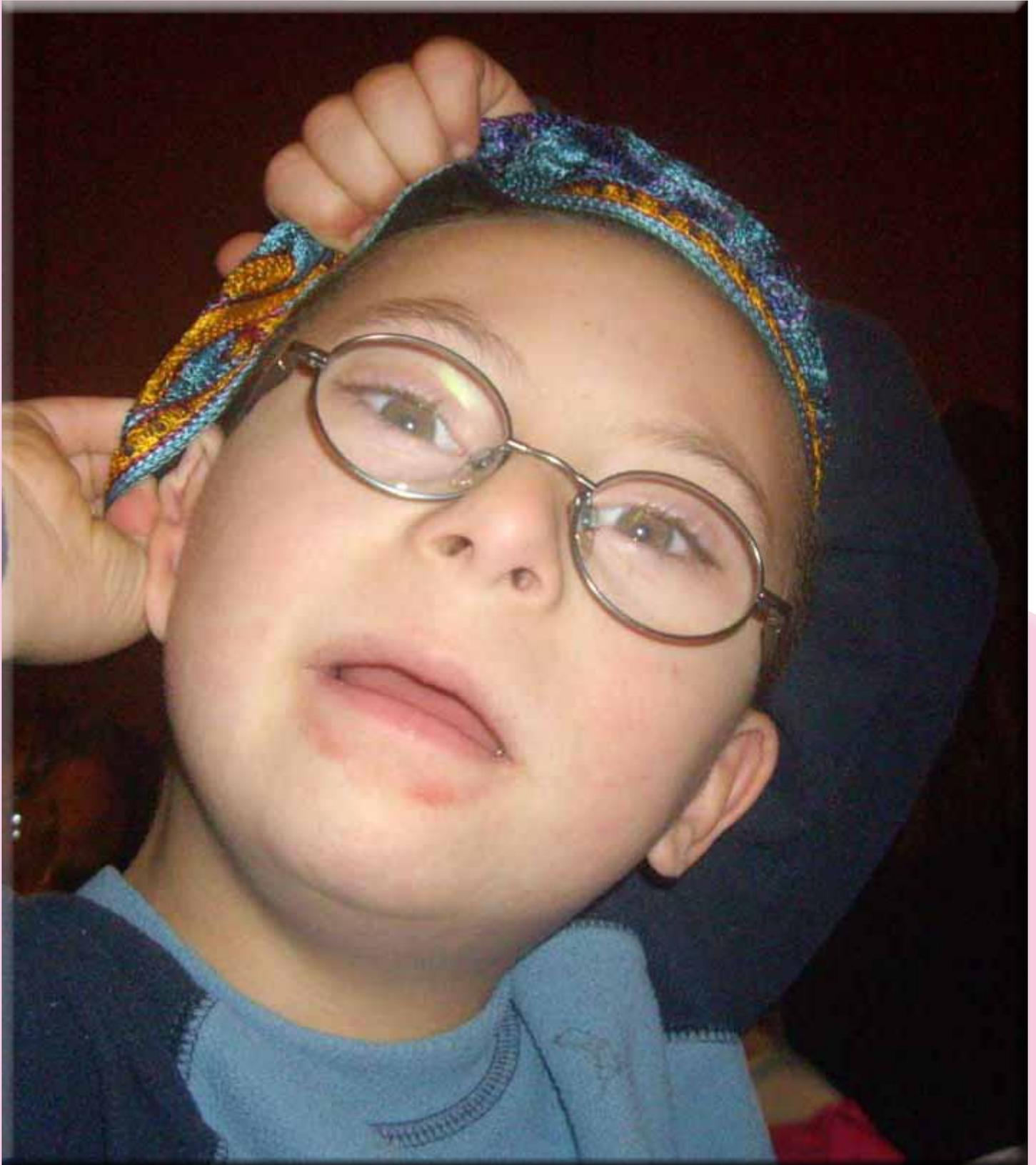


dhg

down's heart group

# Newsletter Spring 2011

Issue 42



## Chair's Report

Welcome to the latest newsletter. I would like to congratulate all our London Marathon runners for their brilliant effort on Sunday 17th April. The weather was very warm for running but hopefully everyone will recover quickly. It is not too late to donate to their targets so please support them if you can.

As you may know, consultation has started for the Safe and Sustainable campaign to decide the future of the Paediatric Cardiac Surgical Units. This should mean an improvement to local cardiac outpatient services, but also a reduction in centres performing surgery. This is to concentrate the expertise of surgeons, improve safety rates, and provide better staffing levels. We won't know which units will stay or go until the end of the process which should be around July.

We are hoping that the Government will take on board the extra travel costs to families whose children need surgery. This issue has been raised at all meetings and many are campaigning for the government to intervene and award some money towards extra costs.

DHG desperately needs to raise funds. If anyone can do any fundraising, a coffee morning or something more extreme, we would be very grateful. Funding in today's climate is a big issue and many charities have not survived this recession. Thanks to everyone for all of your efforts over the past few years to keep Down's Heart Group going.

If there is anything that you as members think we could be doing better please let us know. We are here for the benefit of you and your families.

Penny and Sarah have been occupied with the Information Standard process which will give our literature accreditation. It has been a gruelling time for them and I extend my grateful thanks for the work that they have done.

Let's look forward to a lovely summer. Regards,

Chris Stringfellow



## CONFERENCE AND

### Our Survey Said....

92.9% of attendees would come again.

For the conference:

**Value for money** - 46% said excellent, 23% said above average.

**Networking** - 64% said excellent, 21% said above average.

**Location and venue** - 50% said excellent, 36% above average.

**Agenda** - 42% said excellent, 42% said above average.

**Creche** - 36% said excellent, 36% said above average.

The majority of delegates thought the speakers and workshops were either excellent or above average.

For the dinner and disco:

91% of guests thought the dinner and disco was brilliant, with both value for money and networking opportunities scoring 91%.

The accommodation and facilities were rated as excellent or above average by 90% of attendees that stayed overnight.



"The best bit was meeting everyone! Parents found it really helpful to meet and talk to other parents. Also it was fun."



All Down's Heart Group events are greatly subsidised by the charity - keeping cost as low as possible for those wishing to attend. DHG never makes a profit from delegates and generally runs conferences at a financial loss to the group.



"Opportunity to meet with other families, to hear current cardiac issues, have a relaxing weekend away."

# FAMILY FUN WEEKEND

"It gave us a chance to meet other parents and children which we found very valuable."



Bursaries for attendance to future conferences may be available for those on the tightest budgets. Please don't let money matters prevent you attending.



# 2010

## Committee

- Chairperson - Chris Stringfellow  
0844 288 4800 option 7  
or [chris@dhg.org.uk](mailto:chris@dhg.org.uk)
- Vice Chair - Peter John  
[peter@dhg.org.uk](mailto:peter@dhg.org.uk)  
or via National Office
- Secretary - Nina Lawson  
[nina@dhg.org.uk](mailto:nina@dhg.org.uk)  
or via National Office
- Treasurer - Phil Thorn  
Roberta Nathan  
Richard Mowberry  
Helen Laverty  
Grace Smith

all via National Office 0844 288 4800



# ACGM

## Introducing Nina Lawson

My name is Nina and my husband and I received a prenatal diagnosis of Down's syndrome and congenital heart disease for our son Jon-Paul very early on in my pregnancy. Jon-Paul was born naturally at 36 weeks (he has always been a very busy boy and clearly 40 weeks gestation was too long for him, he had people to meet and things to do!)



*Nina and Jon-Paul*

We knew when we received Jon-Paul's cardiac diagnosis during pregnancy that he would need to undergo surgery. Jon-Paul had closed and open heart surgery at eight months old.

During this difficult time we received invaluable advice and support from the Down's Heart Group. It really helped us to be able to talk through our fears and concerns with someone who had already been through the experience. It also helped to prepare us mentally so that we felt strong and able to support Jon-Paul.

After the surgery I felt I would really like to give something back to the charity. I am now DHG secretary and hope to help families as we were helped ourselves.



*People Magazine ran an article on Nina, Andrew and Jon-Paul in February 2011. Nina was pleased to raise awareness for DHG*

## Accessibility

Down's Heart Group is for people with Down's Syndrome, as well as their families, carers and professionals. With this in mind, the committee thought that the newsletter, or at least part of it, should be written with Change symbols so that the whole membership can enjoy each issue.

We would value feedback from all our readership on what you think of these "taster" articles. Concepts for the newsletter, its format, regularity

and content are evolving constantly. Unfortunately we are confined to the limits of a tight budget but we would like to check that we are covering all our reader groups.

Please let us know your views on how we could improve the newsletter and communication in general.

All pictures used

[www.changepeople.co.uk](http://www.changepeople.co.uk)

## Introducing Helen Laverty



Hello, my name is Helen Laverty I had the pleasure of meeting some of you in Reading last year, and promise to improve my Conga skills for



next time!

I consider it to be a huge honour to be asked to join the trustee's board of the DHG, and whilst I am not a parent of a person with Down's Syndrome, I am a



mummy

and have worked with and for people who have a learning



disability for the past 33 years in lots of different settings. I currently work for the University of Nottingham, as a health lecturer. I teach nurses about how to work with people who have a learning disability, and will always be happy to express your views to them.

I believe strongly in four things:-

- ❖ **There's no such thing as a wasted opportunity**
- ❖ **People with a learning disability should never be measured by what they can't do – always by what they can do**
- ❖ **You can't be empowered and have a voice some of the time – you have to be empowered and have a voice all of the time!**
- ❖ **Don't tell someone to only reach for the stars when there's footprints on the moon**

I look forward to meeting lots more people in the coming months, and being given the opportunity to use my time and talents within the DHG



## Mum Of The Year

Congratulations to Dianne Preston from Lancashire for winning the Tesco magazine "Caring Mum of the Year award" for 2010.

Dianne and husband David have

devoted the past 28 years to fostering over 60 babies, nearly all of whom had health issues or trauma. She and husband, David, also adopted Sophie, who is now a beautiful teenager, and have three sons as well.



**Hello Everyone!**

We are trying something new at the DHG



We want to think

about how we share information with you



Large print

could be best;



or photos . We might want a meeting



We also want to give you your say

Maybe you could write



and tell us what you've been doing?



### Christmas Card Competition

The Down's Heart Group Christmas Card Competition is back due to popular demand! This time it is even bigger and better than ever!

The winning artist will receive a personalised DHG teddy and have their design printed on official Down's Heart Group Christmas cards for sale Christmas 2011.

There are four categories for entrants;

Child with Down's Syndrome, Adult with Down's Syndrome, Child, Adult.  
(Children classed as aged 16 or under)

Get your entries in to National Office by 1st August 2011 to ensure inclusion in the shortlisting process.

So, search out those wonderful hand made cards you did last winter, or get creative through the summer.

Send your entries to;

**PO Box 4260  
Dunstable  
LU6 2ZT**

before 1st August 2011!

**GOOD LUCK EVERYONE**

Orders for packs of cards can be made from 1st September 2011, prices to be confirmed.

**All proceeds to Down's Heart Group.**

### Cover Story

This Issue's front cover shows Micah Samuel. He doesn't have a heart condition but came along with his parents to the DHG conference in November 2010 in Reading.

Micah seemed to have a fabulous weekend and wowed everyone he met! He made friends in the creche and enjoyed dancing at the disco.



*Sam the photographer*

The photograph was taken by Sam Fawkes - a young man who does have a heart condition. Sam also took many of the photos on the conference spread on page 4.

Sam certainly enjoyed himself and when he wasn't taking fantastic photos he was off like a whirlwind in all directions to chat and party!

## Safe And Sustainable Survey

The NHS is currently looking at the best way to provide surgery for children with congenital heart disease and is keen to receive feedback on the proposals. Full details of the Safe and Sustainable Review of Children's Congenital Cardiac Services in England can be found at;

[www.specialisedservices.nhs.uk/safeandsustainable](http://www.specialisedservices.nhs.uk/safeandsustainable).

As part of this consultation, health care professionals and parents of young people with congenital heart disease are being asked to complete a questionnaire. This can be done either online or DHG can send out a paper version. All responses will be taken into account along with a wide range of other information such as the views of clinicians working in children's congenital cardiac services, Royal Colleges and professionals' groups and NHS managers working in this field.

Ipsos MORI will undertake the analysis of the response forms and the findings will help the NHS in its final decision. As part of this review, there will also be a number of consultation events across England and Wales.

Please return the completed questionnaires by 1 July 2011.

<http://surveys.ipsosinteractive.com/wix/p904445602.aspx>

The above link will take you to the survey. Alternatively phone National Office on 0844 288 4800 to request a paper copy.

## Carers Week

This year, Carers Week is June 13th to 19th. Carers UK offer support, information and advice and are currently campaigning hard against cutbacks liable to affect carers and disabled people. The advice line is open on Wednesdays and Thursdays;

**0808 808 7777**

or write to;

**20 Great Dover St  
London  
SE1 4LX**

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

## Safe and Sustainable Review Of Children's Congenital Cardiac Services In England

The remit of 'Safe and Sustainable' is to build on the fantastic service we already have and to look to the future and how we can ensure that the service not only survives but also improves. We have to take what was learnt from the Bristol and Brompton Inquiries and recent issues surrounding Oxford and do everything that we can to ensure that these mistakes cannot happen again. We have to be looking to develop and improve in line with the progress constantly happening in the field of congenital heart disease.

The Brompton Inquiry was over ten years ago. Down's Heart Group was heavily involved with the presentation of parent's evidence and in the group set up at the hospital to assist in implementing the 119 recommendations that came out of the Inquiry. DHG has been involved in much of the consultation process of the Safe and Sustainable review so far and has attended all the general meetings.

The point of this review is not a cost cutting exercise and it is not something that has been Government led. It came about due to parent groups asking why a few of the recommendations of the 'Bristol Inquiry' had still not been addressed, particularly in relation to ensuring the best clinical outcomes for children undergoing heart surgery.

One of the facts that had been established from research was that there is a correlation between the success rates (both mortality and morbidity) and the number of procedures a surgeon is involved in. In some units there is not the capacity for an agreed minimum number of operations to take place in a year, so these surgeons are not getting the opportunity to fulfill the criteria and maintain their skill levels.

Units with only one surgeon encountered problems with covering holiday and sickness periods as well as with training and progression. With a team of three or more surgeons in one unit, it is possible to have one very experienced surgeon who mentors other colleagues and then there is continual progression as the more senior ones retire. There is a real lack

of paediatric cardiac surgeons here in the UK and a few of the really excellent ones have recently or will soon retire.

The consultants and cardiac teams recognise all of this and whilst naturally none of them wants their own unit to close, they have pretty much all been on-board with the rationale behind 'Safe and Sustainable' since the beginning.

In an ideal world the Commissioners would agree how many units were needed, what facilities they needed and how to distribute them geographically and we would build six or seven brand new hospitals to meet that need. This is not feasible, so a great deal of work has gone into looking at all the possible different options and finally four options for further consultation have been presented.

Some units will stop providing surgery, but they will continue to do everything else they do already and there are also plans to increase knowledge locally with designated paediatricians with cardiac specialist training.

Many aspects have been considered, including;

- \* Number of procedures
- \* Access to other services as many youngsters have other medical issues, too
- \* Retrieval times for sick children
- \* National specialist services such as transplantation and ECMO and whether these could be relocated
- \* Population density

If you want to read more check out;

Safe and Sustainable website;  
<http://www.specialisedservices.nhs.uk/safeandsustainable>

Children's Heart Federation website;  
[http://www.childrens-heart-fed.org.uk/news/safe\\_and\\_sustainable\\_childrens\\_heart\\_surgery\\_services](http://www.childrens-heart-fed.org.uk/news/safe_and_sustainable_childrens_heart_surgery_services)

Central Cardiac Audit Database;  
<http://www.ccad.org.uk/congenital>

A final decision is expected by the end of the summer, 2011.

## Pulmonary Hypertension

Down's Heart Group is working alongside GUCH (Grown Up Congenital Hearts) and PHA-UK (Pulmonary Hypertension Association) to gather up to date information from patients and carers.

Improvements in drugs and therapies mean that youngsters with Eisenmengers or PAH can have a better quality of life. Research on use of medication, availability of services and general health matters will hopefully ensure all patients are offered the best possible combination of resources.

Please help us by filling in any questionnaires sent out and by updating your family's records for the confidential DHG database.

## Newlife

Newlife run a Nurse and Equipment Grants Service, which since inception has made equipment grants worth over £5 million, ranging from £50 to £17,000. These grants are for purchasing items including mobility, care equipment, communication aids, comfort and therapy equipment.

Every grant begins with a call to the Nurse Helpline to ask about eligibility, but essentially equipment is funded relevant to the child's need. The child will be aged eighteen or under, have a significant disability and be a permanent resident in the UK. Newlife do not means test and can make same day equipment grants in emergencies.

Newlife is aware that the cutbacks are already affecting many families and so has increased the number of nurses, the hours of the service, the way people can contact Newlife nurses and made further funds available to fund urgent equipment grants.

All services are manned by qualified and experienced nurses. All Newlife services are free and confidential. The freephone nurse number is;

0800 902 0095

[www.newlifecharity.co.uk](http://www.newlifecharity.co.uk)

Grant application forms can also be downloaded from this website.

## Benefit Changes

In these confusing times of reviews and shake-ups to the welfare and benefits system it is good to know that you can turn to Contact A Family for up to date information and advice.

DLA, LHA, PIP? What is your family entitled to? Call Contact a Family's free helpline on

0808 808 3555

or go to

[www.cafamily.org.uk/cashcounts](http://www.cafamily.org.uk/cashcounts)

**Down Syndrome South Africa**  
**11th World Down Syndrome Congress**  
**15th - 18th August 2012 Cape Town**

THE "BIG FIVE" REASONS WHY TO COME TO SOUTH AFRICA!

RIGHTS  
EDUCATION  
EMPLOYMENT  
HEALTH  
SOCIAL

Come and join us for what promises to be a congress to remember at the Cape Town International Convention Centre, where there will be something for everyone, including a one day pre-congress Synod for young adults with Down syndrome on the 14<sup>th</sup> August and post congress workshops. Come and meet the experts, get the latest information as well as visiting a top destination.

For more information email: [dssa.odo@icon.co.za](mailto:dssa.odo@icon.co.za)  
[www.wdsc2012.org.za](http://www.wdsc2012.org.za)  
or [www.downsyndrome.org.za](http://www.downsyndrome.org.za)

Tel: +2711-484-8890/1  
Fax +2711-2525323

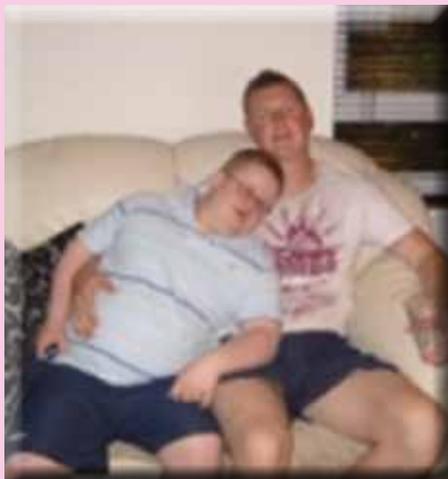


# Information

Celebrating WDS 2011

For World Down Syndrome Day (21/3/11) Penny Green, DHG Director and Down Syndrome International member, put together a wonderful montage of pictures and music which can be seen on You Tube.

All the children with heart problems have a Down's Heart Group logo on their photo. The montage has made popular viewing and has hopefully raised our profile. To watch go to [www.youtube.com](http://www.youtube.com) and search "Celebrating World Down Syndrome Day 2011 by Penny Green"



Tom and David

### Tom Byrne

This is Tom's first marathon but he has participated previously in sponsored events like sky-diving. His motivation to support DHG comes from brother-in-law, David Udall, who is a Down's Heart Group member.

### Ben Coak

It's also Ben's first marathon although he has previously run half-marathons, plays rugby union and Australian Rules football. Ben has been running curry nights and dress down days to help boost his fundraising efforts.



Ben



## London Marathon 2011

A huge THANKYOU goes to all our marathon runners for this year's London Marathon. We really do appreciate all the effort that goes into preparing physically and mentally for such an event, not to mention the struggle to raise funds in the process.

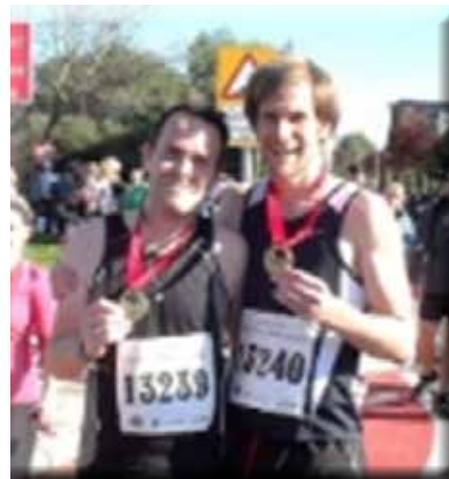
There were five runners in the 2011 race for Down's Heart Group. Dan Hall was due to run but sadly withdrew on medical advice. He is being looked after by his lovely daughter, Isla, his inspiration to support DHG. Dan should be fit to take his rollover place in 2012.

### The London Marathon is Down's Heart Group's biggest fundraiser each year.

Anyone wanting to donate money can do so through National Office or by accessing the runners' Virgin Money Giving pages on the internet. These pages are kept open after the event as not everyone gives their money beforehand. As you will be aware, National Office accepts money at any time of the year!

So it is not too late to show your appreciation and admiration for the DHG marathon runners by giving what you can towards their totals. Every penny raised is put to good use supporting families around the UK.

Thankyou Tracey, Ben, Tom, Ben and Tosh and all your supporters. Well done!



Tosh and Ben

### Tosh Evans and Ben James

Tom 'Tosh' Evans is running the London Marathon for DHG for the second time and this year is joined by his friend Ben. Ben says neither of them are particularly athletic but watching Tosh succeed last year has made Ben want to do something for a worthwhile cause, too.

### Tracey McIntyre

Nurse Tracey is our only female runner. She had several injuries during training but won a place on the celebrity "green" start line through a Virgin Money Giving competition. This should hopefully give DHG some much needed coverage!



Tracey

## Official Finishing Times

Tosh Evans	03:56:01	Fantastic results from five fantastic people!
Tom Byrne	04:00:01	Wishing you all a swift recovery and a well earned rest.
Ben Coak	04:35:11	
Tracey McIntyre	05:03:44	
Ben James	05:34:32	

## Matthew's Story

Matthew was born in 1981 and has a complete A/V canal heart defect (AVSD) which we were told was inoperable. The early years were very difficult indeed and we were informed that any chest infection could be fatal. He would be very unlikely to live beyond his early teens.

Matthew suffered very few chest infections although he had dreadful croup every winter until he was about eleven. He was very blue with any exertion and was struggling more and more when another parent, to whom I will be eternally grateful, told me about oxygen and with the use of that at night Matthew's colour and exercise tolerance noticeably improved.

Matthew has Eisenmengers complex which is pulmonary hypertension and this causes a cluster of other problems including very low blood platelets. This in turn causes him to bleed a lot. He suffered horrendous nose bleeds for years which required him to go to hospital.

Nobody told us that the oxygen delivered by nasal canula was aggravating the problem by thinning the skin inside his nose.

In 2005 Matthew suffered pneumonia and heart failure and survival was touch and go. He was in hospital for a month, which was awful, and was on oxygen round the clock delivered by mask. Matthew also has mild autism which makes life a bit more difficult but has occasional advantages as once a pattern is established it will continue.



*Matthew's underskin bleeding*



*Matthew*

Amazingly he survived and came home using the mask and since then the nose bleeds have been far fewer.

Matthew's legs have developed bleeding under the skin which looks like bluish brown bruising. Recently this suddenly got worse and the blood under the skin was fluid. He had also developed regular swelling of his left lower leg by the end of the day. The GP gave him a tubifix bandage and it has helped him a lot controlling much of the swelling and bleeding.

**Angela would like to hear from any other families whose youngster has similar problems with bleeding under the skin. Please contact National Office if you would like to get in touch.**

Matthew enjoys life very much within his limits and now has Direct Payments for assistants to take him out for bowling, special clubs etc.

Pretty amazing for someone who was not expected to survive beyond his early teens at the very most!

Matthew is such a gentle and caring individual that he touches the hearts of everyone who knows him well.

Angela Weaver

## Isabel's Campaign

Isabel Davies Atherton, who was on the cover of Issue 41, has been in the Spanish newspapers again recently. Her parents, Alison and Blue, are campaigning for local facilities for children with Special Needs. They have lots of local backing and promises of funding, so hopefully can achieve their goal.

## Lucy Bridson

Our daughter Lucy was born 1st January 1986 with Fallots Tetralogy, complete AVSD and pulmonary stenosis. We were told that no surgery was available and just enjoy our time with her.

Lucy being the fighter she is, battled on for six years before Mr. Hamilton, cardio-thoracic surgeon, appeared on the scene at Freeman Hospital and offered Lucy surgery. We were warned how serious a risk we were taking, but Mr. Hamilton encouraged us to accept surgery. Lucy was home in just one week. We were informed that Lucy would probably need some further repair possibly after her eighteenth birthday.



*Lucy with her medals from Blyth gala*

Eighteen year later and aged 24, Lucy competes for the Northern Region Special Olympic swimming team and has won a box full of medals. She enjoys drama, dance, keep fit and music.

Lucy has now developed two leaks in the mitral and pulmonary valves, which we are told may need surgery in the future. As her energy level is so high, these new problems are proving to be of no trouble to her as yet.

Doreen Bridson

## Donated Jewellery

Michelle Boggis makes very pretty jewellery. She kindly donated a box full of various pieces to Down's Heart Group to sell on.

Nina Lawson held a jewellery party just before Christmas and the committee have also bought items resulting in a total so far of £140.50. The remainder of the jewellery is ready for another party shortly where hopefully the amount will be doubled, especially if the guests are given plenty of wine first!

Many thanks to Michelle and Nina.

## Footprints Day Nursery

£350 was raised by the children at Footprints Day Nursery in Ashford, Kent, when they took part in a fundraising week.

The "Babay Room" did a sponsored walk, the "Toddler Room" did an assault course and the "Preschoolers" had a car race. They all had a fabulous time.

There was also a cake stall, a "guess how many sweets" and "name the bear" competition.

Thanks to the staff and parents at Footprints for all their hard work.

## Joley Moore

We bring the terribly sad news that Joley, who featured in issue 41, passed away at Yorkhill Children's Hospital on New Year's Day.

Joley had a complete AVSD with Tetralogy of Fallots. She was in Yorkhill undergoing tests to see if surgery could be attempted when things took a turn for the worse.

The family describe Joley as the "wee gift" that they just could not keep.



*Joley Moore*

## DHG Merchandise

Down's Heart Group are launching a brand new range of clothing. Excellent quality garments with embroidered logos at competitive prices.

Prices start at £14 for a polo shirt (black or white). Black fleeces start from £17 and black or white hoodies from £19.



Teddies are also on sale, £15 for a medium and £17 for a large one. They are absolutely gorgeous and extremely cuddly!

Mugs are available, as are other items such as baseball caps.

Personalisation on any product is £1.50 and postage and packaging will be charged.

Please contact national Office to place an order or for further information

0844 288 4800  
[penny@dhg.org.uk](mailto:penny@dhg.org.uk)

## Name The Teddy

The lovely new Down's Heart Group teddy needs a name!

Can you help?

Enter the Name The Teddy Competition and you could win your very own personalised bear.

Entries cost £1 per suggestion.

So get thinking about which name suits teddy as the Down's Heart Group mascot.

Competition closes on 1st July 2011.

Please send entries to;

PO Box 4260  
Dunstable  
LU6 2ZT

How about Donald Henry George? Daphne Harriet Gloria? No? Something simple?

The more entries we get the better chance poor teddy has of being given a decent name!



## Big Small Charity Car Raffle

FSI are running a charity draw and the prize is a Fiat 500, 1.2Pop. Tickets cost £2 each and £1.90 comes to Down's Heart Group. To buy tickets use the link below or contact DHG office.

<http://www.smallcharitycardraw.co.uk/tickets.php?id=dhg>

Tickets are on sale until 16th September 2011. Good luck!





2nd July, 2011 marks the fourth FSI Challenge and it will be bigger and better than ever before!

Runners and walkers can take part in either a 4km or 10km route at Thornbridge Hall in one of the loveliest parts of the Peak District. There will be two action-packed days of fun to make the trip worthwhile.

The run is a great day out as well as a great way to raise funds for Down's Heart Group. The course can be walked or run by participants of almost any ability – so you don't need to be an accomplished athlete to take part.

The FSI Challenge is part of a whole weekend of activities and entertainment on Saturday 2nd and Sunday 3rd of July. You can bring a picnic and drinks for relaxing after the race and you can camp overnight in the grounds of Thornbridge Hall. There will be a garden party on Sunday.

If you are interested in taking part in the Challenge get in touch by emailing [sophie@thefsi.org](mailto:sophie@thefsi.org) to register your interest and receive your registration details.

### Get Paid To Park!

Gift To Charity is now partners with NCP car parks. Use your Gift To Charity debit or credit card and earn 3% cash back every time you park your car.

If you have yet to register, click on: <http://www.gifttocashback.co.uk/offlinecashback>, and complete the easy registration process, which enjoys the same level of security as online banking.

This is just one just one of thousands of cash back incentives, special offers and discounts to be had by shopping online and in store with a Gift To Charity registered card!

### Land's End To John O'Groat's

Martin Laycock has set himself an amazing challenge. Over the last two weeks in June he will be cycling the length of Britain to raise money for two charities close to his heart.

Martin says "I am fundraising as a personal challenge. My challenge is cycling from Land's end To John O'Groats over 15 days in June. I am raising money for two charities, the Down's Heart Group and the Pancreatic Cancer Research Fund.



*Martin and Andrew Laycock*

The Down's Heart Group helped support my family when my son, Andrew, was born. Soon after his birth we discovered he had Down's Syndrome and also needed heart surgery. It was a lot to deal with and was a very difficult time for us. The DHG were invaluable in offering help and advice and they continue to support other families in the same situation.

While planning this trip my Dad was diagnosed with Pancreatic Cancer so I have decided to try and raise some money for the Pancreatic Cancer Research Fund.

My Dad will be undergoing some treatment while I am doing my Land's End to John O'Groat's cycle trip.

Donations can be made on my Virgin Giving Page or through DHG office or website.

### Woodhall Spa Triathlon

Two student nurses will be raising funds for Down's Heart Group when they undertake the Woodhall Spa Triathlon on 29th May.



*Julia Ibbitson*

Julia Ibbitson and Sam Nutter both have Virgin Money Giving pages or alternatively, donations can be sent to DHG National Office.



*Sam Nutter*

## Thankyou Everyone!



### Could You Use...

- Easyfundraising
- Everyclick
- Utilities Warehouse
- Gift To Charity
- Easysearch
- Ebay

APS Legal and Associates?  
You could save lots of money and help DHG raise funds at the same time.

Check out [www.dhg.org.uk](http://www.dhg.org.uk) for more information or contact National Office on 0844 288 4800



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down's heart group

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email: info@dhg.org.uk  
website: www.dhg.org.uk

contact or answerphone always available (24 hours in emergency)

Charity 1011413

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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)



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

[www.phassociation.uk.com](http://www.phassociation.uk.com)