



**dhg**

down's heart group

# Newsletter Spring 2012

Issue 44

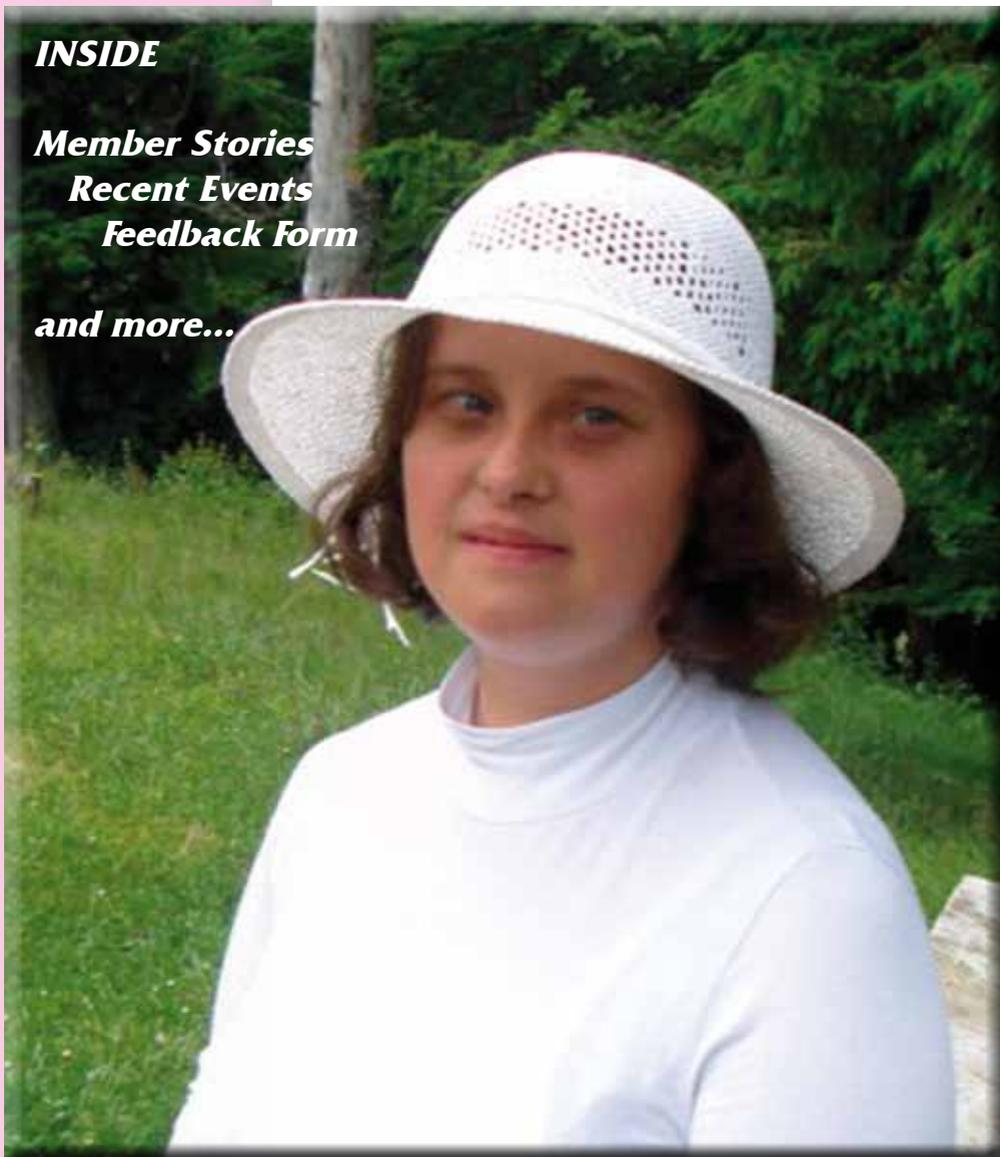
## ***INSIDE***

***Member Stories***

***Recent Events***

***Feedback Form***

***and more...***



## Chair's Report

Once again, welcome to our newsletter, we have been busy since the last issue. Our AGM took place in January with no major changes to the group, but it was lovely to see new faces attending, we really do appreciate your support and interest. DHG took part in several events through the week around March 21st to celebrate World Down Syndrome Day, which as you may be aware, was for the first time officially recognised by the United Nations, thanks in part to Penny, who in her spare time helps co-ordinate Down Syndrome International's social media pages.

Thanks to the suggestion of trustee, Nina Lawson, The Cornerstone Arts Centre in Didcot exhibited the Shifting Perspectives photographic display throughout March and DHG hosted a performance by MiXiT that I went to - they were great! On the Saturday night, several of the committee were at a jazz night organised by Grace Smith, our youngest trustee, which raised over £600 for the charity.

At the end of March, Penny, Helen and I attended the Positive Choices Learning Disabilities Nurses conference in Edinburgh, raising our profile amongst the attendees considerably - hopefully more families will learn about us through this and come forward for support. And then we've just had the London Marathon!

Regards to all

*Chris Stringfellow*

## Contents

Oana Bogdanescu	Front Cover
Olympic Torch Relay	3
Members Stories	4
Easy Read Pages	8
World Down Syndrome Day	10
Fundraising Report	12
Future Events	16
DHG Merchandise	17 and Back Cover
Fundraising Update	18
Information	20
Feedback Survey	21
Useful Links	23

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 original source.

## Olympic Torch Relay

*8,000 torchbearers will carry the Olympic Flame during its nationwide journey to the Olympic Stadium opening ceremony on July 27th. Amongst them will be two representatives from Down's Heart Group.*

On June 24th, DHG member Joanne Kempley will carry the torch through Brighouse, Yorkshire.

Before open heart surgery at the age of six, Joanne barely had the energy to walk upstairs. Now 22, not only is she a medal winner who has represented Great Britain at the Down's Syndrome World Swimming Championships, she also has several volunteering posts, is an accomplished actress, has achieved her Bronze Duke of Edinburgh Award and is working towards her Silver.

*Good luck, Joanne, enjoy your day!*



Then on July 9th, the Olympic torch will be carried through Dunstable by Down's Heart Group Director, Penny Green, who was chosen because of her charity work over the years and her tireless energy as an advocate for people with Down's Syndrome.

Penny is naturally thrilled to be a torchbearer. *"This is a terrific honour for me. I am proud to be able to represent so many wonderful friends from all over the world and to use this opportunity to raise awareness and advocate for inclusion."* she said.



Penny will wear the official gold and white track suit with matching gold trainers, whilst her supporters will wear t-shirts with a logo specially designed by Jorge Arnoldson from Buddy Cruise. The backs will carry names of individuals with Down's Syndrome and logos of Down's Syndrome organisations from around the world, so hopefully they will attract media interest.

To find out how to sponsor a name or logo on a t-shirt or to buy a t-shirt to wear on the day, please call Penny on **0844 288 4800** or email [penny@dhg.org.uk](mailto:penny@dhg.org.uk).

After covering the cost of t-shirts and printing, any money raised will be split equally between Down's Heart Group, Down Syndrome Nigeria Support and the DSi Global Outreach Programme.

## Daniel's Story

When Daniel was born he was blue, so I knew there was a cardiac problem.

At the age of three an echocardiogram showed three holes in his heart, Atrial Septal Defects. At six years of age, they decided to operate and close one of the holes, because oxygenated blood was mixing with de-oxygenated blood, causing Daniel to be short of breath and struggling with walking.

By the time Daniel was fourteen, he had started having blackouts. We were told by the cardiologist that he would develop angina and would need a pacemaker when he was older.

Daniel was at college during this time and I had to keep him at home for six weeks while they did a risk assessment!

He saw two epilepsy doctors and they confirmed it wasn't epilepsy after he had several EEGs done. It turned out Daniel had a pulse of 40 which was causing low blood pressure. This was discovered after several ECGs. Daniel was kept in hospital and surgery, followed by putting a heart monitor recorder in his chest for several months. This revealed vasovagal syncope, fainting brought on by a sudden drop in heart function.

The blackouts went on for eight years, during which time we were often told to call an ambulance. Sometimes Daniel would have as many as three episodes in one day.

I got angry because if Daniel had a blackout at college, they would ring me to collect him. I fought for eight years to get him a pacemaker. He eventually had one inserted three years ago. He also gets angina now, especially if he's not well. We had the pacemaker tweaked up this year because Daniel was still having vasovagal episodes, not as many as he used to have, and touch wood, no blackouts since.



So, if like me you want so badly for things to improve, fight for it! I did and it worked, eventually. Persistency is the key to better health for our youngsters!

*Katina Lifton*

## Kieran's Story

Kieran was born on the 28th September 2000. I didn't know that he had Down's Syndrome until shortly after his birth. Although I had the triple test, the results came back low risk and my midwife reassured me I would be OK as I was only 16 years old, so when I was told I was very shocked and confused.

I didn't know what it was and when I told the doctor she said *"basically your son is extremely mentally handicapped. It's very unusual for such a young mother to have a baby with Down's"* and with that she gave me some leaflets and told me she was deeply sorry for me, and I could scream, shout, cry if I needed to. The doctor also said Kieran had an AVSD and would be taken straight to Southampton hospital to prepare for surgery.



In the 12 days waiting for surgery I pushed the fact he had Down's to the back of my mind and him surviving the operation was my main focus. On the 10th October he had an eight hour heart operation. The surgeon told me he felt he'd corrected Kieran's heart defect to the best possible standard. He was right! Only 24 hours later Kieran was off the ventilator and ready to leave Intensive Care. Ten days later he was allowed home.

Kieran and I moved to Kettering, where I'd grown up and I had another son Liam, who's now nine. He and Kieran are very close. Having Liam helped me come to terms with Kieran's disability and helped me realise that there's no difference in the love and bond I have with my children. In the early years Kieran's health was a huge issue. He had many hospital stays - being treated for meningitis, infantile spasms, asthma attacks, swine flu and pneumonia. He also has an underactive thyroid, coeliac disease and has autistic tendencies. However, Kieran's heart has remained in great condition and he's been without cardiac medication since a few months after his operation.

Kieran is now 11 and ready for senior school. For the first time I feel able to let myself imagine his future and I'm excited at what it may hold for my young man! Finally I'm not consumed by sadness for the things he will never do. Instead I'm enjoying the many things he can do and that is a feeling I never thought I'd have. For many years I was stuck feeling the sadness and utter devastation and only saw Kieran's disability and many health issues and looking back it was a sad period of my life. I now see everything differently, Kieran is a boy who is funny and mischievous and is absolutely amazing, To even mention Kieran's name makes me smile - I am smiling as I write this.

*Amie Thubron*

## Rio's Story

Rio was born five weeks prematurely on 24th August 2011. Two days later he was diagnosed with Down's Syndrome and AVSD, I had no idea until then. But I wouldn't swap him for the world. He has a tough few months of life - hospital is our second home!

Rio was ventilated and sent to Sheffield Children's hospital in October for five days. It broke my heart seeing him like it. We returned to Grimsby hospital for two weeks and then went back to Sheffield to have an endoscopy. Rio had his larynx clipped, and then he went on the CPAP ventilator for three weeks.

Following this he had to have a bronchoscope and a bronchogram. He was diagnosed with an extensively floppy windpipe and branches. This means he changes colour to blue or purple when he cries. It is such a worry and I get very little sleep as I'm constantly fretting.



Rio spent his first Christmas and New Year in Grimsby hospital and is now at home but on oxygen 24/7. He has had a follow up appointment at Sheffield and he could be having a tracheostomy. I will find out in the near future.

So Rio-James is my fighting little soldier and I love him to bits.

*Nikki Hallett*

## Oana's Story

Oana was born with an AV canal heart defect in 1980 in Romania during the communist regime. At that time, persons with disabilities do not exist for them. The prognosis for Oana at birth was so bleak, because of her heart defect Oana couldn't walk till the age of four and the life expectancy we were given by the doctors was 18 years if she did not have a surgery.

The first eight years were very difficult because we were informed that any chest infection could be fatal and in those years she had a lot of infections, (not only chest infections) and our family struggled a lot for Oana to reach the age of eight. She was finally operated on at the age of eight, because till then she had very poor weight gain and also the lack of equipment to do this procedure in Romania was a problem. Whatever obstacle she encountered, medical personal and her family resolved it.

*Life can be challenging at times but it only make us stronger.*

The surgery resolved a lot of her problems and helped her to have almost a normal life. Even with all her health problems she went to kindergarten (taken in the arms by her family), she also went to a school for people with special needs, because this was the only possibility in the communist regime, where she learned to read and write.

Oana manage to beat her destiny.

Now she has gone from a child that couldn't walk to a young woman who has won medals in different sporting competitions. She likes to use the computer to talk with her friends on Facebook and to read. Her favourite book is Heidi by Johanna Spyri - she is impressed by the character Clara's desire to walk because she had the same problems.



This year Oana won a prize in the competition section HYH RISE Internet Awards 2011.

*"There is no greater challenge than challenge yourself".  
We look to the future with hope, happiness and gratitude!*

*Floreta Bogdanedscu*

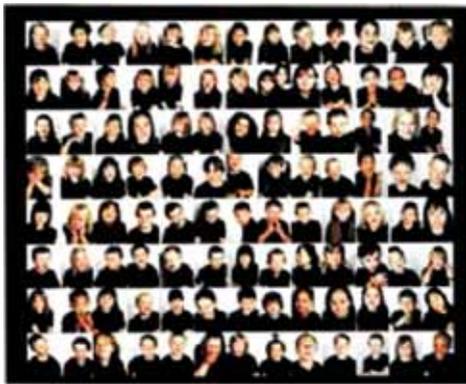
Lots of people have been doing lots of different things for



Chris, Penny and Nina were in Didcot with MiXiT



and the Shifting Perspectives exhibition



Grace organised a jazz night



in Hinckley

The band was called the lazy Alligators!



Sarah and Helen certainly had a lazy next day



after all that dancing!

Whatever you did, just enjoy being you! And maybe send us



some new pictures and stories about your adventures!

# World Down Syndrome Day

Formed in 1993 as a global umbrella organisation, Down Syndrome International has worked hard to bring the worldwide Down's Syndrome community together and improve the rights and life chances of people with Down's Syndrome. In Singapore in 2006 they launched World Down Syndrome Day, choosing the date of March 21st (21st day of 3rd month) to signify the uniqueness of Down syndrome in the triplication (trisomy) of the 21st chromosome and all Down's Syndrome related organisations and individuals worldwide are encouraged to come together by observing the day in some way.



2012 marked the 7th anniversary of World Down Syndrome Day, but following a formal resolution, for the first time it was officially recognised by the United Nations and a conference was held in New York, where the UN Secretary General spoke about the work being done across the world to improve the lives of those with Down's Syndrome.

Penny Robertson, Chair of DSI says, "It is estimated that there are 7 million people with Down's Syndrome worldwide and it is the most common and recognised form of learning disability in the world. But in most of the world's countries people with Down's Syndrome face a harsh reality of very low life expectancy, physical and psychological abuse, stigma and segregation, and very limited life opportunities as children and adults."



For the second year running, DSI produced a video for World Down Syndrome Day made in partnership with Down's Syndrome groups from 68 countries.

To watch the video "LET US IN – I WANT TO LEARN!" go to

[www.ds-int.org/let-us-in-i-want-to-learn](http://www.ds-int.org/let-us-in-i-want-to-learn)

Down's Heart Group members were also involved in events to mark the day including the Mixit performance at Didcot, a jazz evening in Leicestershire, walks and coffee mornings. Others produced items to sell including a music CD and jewellery, and many schools found inventive ways including football tournaments and odd sock days, of using the day not only to fundraise but also to raise awareness amongst pupils.

## All That Jazz!



The Lazy Alligators gave a wonderful performance to raise funds for DHG at a Jazz Night organised by trustee, Grace Smith.

The band played for a special charity rate, Hinckley Golf Club provided the venue at a reduced rate and Asda, Normanton Shooting Ground, The Dive School at Stoney Cove and Next all donated raffle prizes.

People were extremely generous and a total of £650 was raised. A great night out was had by all!

## MiXiT at Didcot

Cornerstone Arts Centre in Didcot hosted the Shifting Perspectives Exhibition throughout March and was the obvious venue for a World Down Syndrome Day performance by MiXiT, a group of mixed ability who got together due to their love of music and performing.

As usual they wowed the audience with everyone clapping along to the music and lots of youngsters joined them on stage for a final number.



## Odd Socks Rule!

The Hamlyn family got Weald Primary School involved in wearing odd socks to school to raise funds for Down's Heart Group and the Down's Syndrome Association.



It was a very colourful day, with some wonderful combinations of spots, stripes and crazy patterns as the pupils got behind the event. The response was fantastic and having set a target sum of £300, the family was delighted to learn that the final total was almost £1500.

Isaac's mum Sal said: "We feel so proud, grateful and humbled by all the support we've received."

# Fundraising Report

We go to print just after our biggest fundraising event of the year, The London Marathon and what a fantastic year this was! Eight people were running for DHG and one jointly for us and another charity and every one of them had a personal and inspirational reason to support Down's Heart Group.

Dad's Andrew Cox, Dan Hall, Andy Lawson and Tim Simpson were running for Roisin, Isla, Jon-Paul and Harvey whilst Mum Jo Yarnall was running for Hannah. The rest of the team comprised Jonathan Whitney running for niece Jemima, Tom Clague running for brother Ned and Jo Burnett running for Emily, daughter of her friend Sarah Smith who is DHG's Information Officer.

We started with bright sunshine and ended with torrential rain and there were a few struggles for some along the way, but everyone finished and we managed to see everyone at least once on the course or after they had finished. **Between them they have raised the fantastic sum of £17,000!**



Tim Simpson, Jo Yarnall and Dan Hall before the race



Tim Simpson still wearing his hat



Andrew Cox and his family



Jo Burnett sporting her medal



Tom Clague not beaten by injury



Andy Lawson with pink hair



A damp but beaming Jo Yarnall



Shaun Hunt and his family



Jonathan Whitney ran as a pirate

T  
H  
A  
N  
K  
  
Y  
O  
U

## Pack Your Bags and Run!



*Part of the industrious team*

Whilst you would probably find most students were in bed on the first day of the February half term, not so for Romero House of St Thomas Aquinas School in Birmingham.

One third of the pupils together with several members of staff, gave up the chance for a lie in and made their way to Morrisons Supermarket, where they took part in a charity bag pack for their Lenten charity this year, Down's Heart Group.

Overall, Romero House raised an amazing £1200 during the day and they were all very pleased.

Romero House students are aged between 11 and 18 years. They have been raising awareness and funds throughout the Lent period.

Their other large event was a Fancy Dress Fun Run, which took place on one of the warmest days so far this year!

We look forward to hearing how it went.

Thank you all very much!

## Women In Business

The Leicester North branch of Women In Business Network group chose Down's Heart Group as their charity of the year for 2011-12 after the charity received the most votes having been nominated by DHG member Amanda Phelps. She had to make a presentation about the charity and did such a fantastic job that DHG won.

The prize included a year's worth of subscription and meeting fees, which enabled DHG to attend monthly meetings and talk with local business representatives, raising the charity's profile within the Leicester area and leading to several fundraising initiatives.

We are grateful to Barbara Hodgson, WIBN franchisee for the opportunity and support and to all the members for help and ideas.

## Runners Support

Huncote Harriers have presented Down's Heart Group with a cheque for £300. Every August they hold a race called the Joy Cann in memory of one of their runners and the proceeds are donated to different charities nominated by their members.



London Marathon runner Jo Burnett and partner Nick Cox (who designed the updated DHG logo a few years ago), very kindly put Down's Heart Group forward.

## Summer Sings

Summer Logan is a young talented singer who has put together a CD of well known pop songs which is on sale to support DHG. Summer's voice is similar to Dido or Emili Sandé and the tracks include a real variety.

The album was launched for World Down Syndrome Day and Summer chose to support Down's Heart Group as her brother Mikey and their Mum received support from the charity. The CD costs £2.50, including postage (UK), with all proceeds coming to DHG.

Copies are available from National Office, for details email [info@dhg.org.uk](mailto:info@dhg.org.uk) or call 0844 288 4800



*Summer with brother Mikey*

## Thanks To . . .



Everyone else who has supported us in any way, including . . .

Our Lady of Lincoln Carollers Group, who donated £300 from their festive fundraising.

The Rotary Club of Shepshed who as well as donating £100 are organising a Fashion Show of which DHG will get half the proceeds.

Martha White's Grandad, Geoffrey Holland, who asked for donations instead of presents for his 85th birthday and raised over £200.

Val and Tony Roberts for their continued support in sorting and selling the used postage stamps you collect for us, a role they have been undertaking for many years.

## Upcoming Events

12th - 20th May	Children's Heart Week
1st June	Big Small Charity Car Draw begins
24th June	Olympic Flame in Yorkshire
9th July	Olympic Flame in Bedfordshire
15th - 17th August	World Down Syndrome Congress - South Africa

Please let us know of other events you think we should include here.



ZSL London Zoo is holding its annual Special Children's Day on Saturday May 19th when not only can you benefit from discounted tickets but there will also be special 'interactive events' laid on.

Tickets can be pre-booked online by selecting the 'Special Children's Day' link on [www.zsl.org/](http://www.zsl.org/) or you can just turn up on the day (you just need to show your child has special needs, which shouldn't be too hard for members)

## Children's Heart Week

This newsletter should arrive just in time for Children's Heart Week which takes place from 12th - 20th May.

The week will be full of awareness and fundraising events, starting with the Screening and Early Detection forum followed by a Parliamentary Reception at the Houses of Commons.

For more information about Children's Heart Week events, please go to the CHF website [www.childrens-heart-fed.org.uk](http://www.childrens-heart-fed.org.uk)



## DHG merchandise



Material items are machine embroidered as above

As illustrated on the back cover, we now have new quality products available for you to purchase to show your support for Down's Heart Group.

All items are made to order, so we've chosen a selection we thought you might like to give you an idea of prices, but please do ask for anything you don't see listed as we can probably source it for you. We would of course quote a price before you are committed to buying.

	Sizes	Cost	Colour
Polo Shirts	Kids	£12	White
	Adults	£15	Black or White
Sweatshirts	youth - hood and front pocket, adult - round neck	Youth £15 Adults £15	Black or White Black or White
	Fleeces	kids - zipped neck opening, adults - full length zip	Kids £12 Adults £20
Mugs		dishwasher safe	£6
Hooded Baby Towel		£12	White
Personalisation on any item		£1	
Postage and packing	1st item	£2.50	
	each additional item	£1.50	

As all items are made to order, delivery may take up to 4 weeks, so please allow sufficient time if goods are required by a specific date. Pre-ordered goods can be collected at meetings, conferences etc. to cut down on postal costs but we must receive sufficient notice.

Please contact National Office for more details or to place an order.  
Telephone 0844 288 4800 or email [info@dhg.org.uk](mailto:info@dhg.org.uk)

## Special Car insurance Scheme

We've recently signed up with Prestige Insurance, an insurance company who specialise in providing lower car insurance premiums for people who have a family member with a disability, as statistically they are better drivers.

So they view people linked to Down's Heart Group (including all your immediate family members) as more careful drivers meaning they can offer lower premiums! And DHG gets a donation for every policy sold!

**SPECIAL CAR INSURANCE SCHEME FOR MEMBERS OF DOWN'S HEART GROUP!**



We view people linked to Down's Heart Group as more careful drivers meaning we can offer lower premiums!



Please ring freephone 0800 3308057 when your car insurance is due and mention 'DOWN'S HEART GROUP' or email [prestige@taagl.com](mailto:prestige@taagl.com) with your renewal date & contact details and we will contact you at the time!

**PRESTIGE INSURANCE**  
[www.taagl.com](http://www.taagl.com)

Why not give them a call on **0800 3308057** or send them an email to [prestige@taagl.com](mailto:prestige@taagl.com) with your details and let them contact you to quote when your policy is due for renewal - you might get a pleasant surprise and be able to support DHG at the same time!

## Recycle your old Jewellery

We've also joined up with a jewellery recycling company to help boost funds, so we can turn old gold, silver or costume jewellery and watches into cash. Damaged, broken and incomplete items all help - so all those odd earrings and broken chains are a great start!

And it couldn't be easier to do - parcel up your unwanted jewellery and post free of charge to

**Down's Heart Group**  
**FREEPOST CENTRAL RECYCLING**

Or order FREEPOST envelopes (quoting Down's Heart Group) by calling Freephone 0800 633 5323, emailing [info@jewelleryrecycling.org](mailto:info@jewelleryrecycling.org) or online at [www.recyclingforgoodcauses.org](http://www.recyclingforgoodcauses.org)



## The Great Big Small Charity Car Draw



Great news! For 2012 they're extending the FSI Small Charity Car Draw so that it runs from June until the beginning of January, right through the Christmas period providing the opportunity to sell tickets at any Christmas events as well.

So we really need YOUR help! If you could have a DHG stall at a local event please contact us to discuss the idea.

email [info@dhg.org.uk](mailto:info@dhg.org.uk) or call **0844 288 4800**

## Small Charity Week's 'The Biggest Quiz'

The FSI is aiming to try to get as many quizzes (pub quizzes, school quizzes, community quizzes - every type is welcome) taking place across the UK in aid of this year's Small Charity Week! So why not hold a quiz during the week of the 11th - 15th of June!

They will support DHG by providing an essential toolkit to hold the best quiz, which we can pass on to you. It will have all you need, including quiz sheets and answers, guidance on how to run the best quiz, tips on how to secure prizes and how suggestions on how to promote/advertise your quiz successfully.

Get your pack by emailing [info@dhg.org.uk](mailto:info@dhg.org.uk) or calling **0844 288 4800**



## Down's Syndrome Visual Arts Exhibition

Suzie Moffat, mum to four year old Max who has Down's Syndrome, is organising an exhibition for artists with Down's Syndrome as she felt it was time to put these various works on a platform, to be appreciated without prejudice.

*'A unique visual arts exhibition that will touch the hearts and minds of all those that have a genuine love of art.'*

Funded by The Arts Council, Barnaby Arts Festival at the Heritage Centre in Macclesfield are hosting the pilot, from 21st to 24th June 2012, but Suzie hopes the exhibition will gain the necessary support and sponsorship to tour, commencing 2013.

She says *"this started as a small idea and seems to be quickly growing into something I'm going to be extremely proud of. As for Max, he's fantastic but I doubt he's painting work that will make the exhibition - yet!"*

You can contact Suzie on 07970 230 366 or [suziemoff@btinternet.com](mailto:suziemoff@btinternet.com)

## The Crafty Couple

We are a married couple with Down's Syndrome who make cards and craft items to sell to raise money for other people with Down's Syndrome. My name is Liam and my wife is Felicity.



Please have a look at:

[www.folksy.com/shops/theCraftyCouple](http://www.folksy.com/shops/theCraftyCouple)



## Please complete our Feedback Survey

*Your feedback is valuable to DHG as it helps us identify areas for development and improvement. It is also an extremely useful way to illustrate to potential funders, the benefits of some of our services, which can otherwise be hard to quantify.*

You can either complete this paper survey and post to the address on the back cover or if you prefer it can be completed online by visiting our website [www.dhg.org.uk](http://www.dhg.org.uk) (No personal information such as email addresses will be passed outside DHG.)

Please use the comments to give a more personal response, or continue on another sheet. **THANK YOU** for your time.

How did you hear about Down's Heart Group? (please tick all that apply)

Health visitor	<input type="checkbox"/>	Internet search	<input type="checkbox"/>	Friend	<input type="checkbox"/>
Doctor	<input type="checkbox"/>	Child Development Centre	<input type="checkbox"/>	Cardiac unit	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	Another organisation	<input type="checkbox"/>	Paediatrician	<input type="checkbox"/>
Family	<input type="checkbox"/>	Other (please specify)	.....		

When you first contacted Down's Heart Group or accessed our information, what were you looking for? (Please tick all that apply)

Contact with other parents	<input type="checkbox"/>	Information and support through surgery	<input type="checkbox"/>
Information about heart defects	<input type="checkbox"/>	Information about drugs and treatment	<input type="checkbox"/>
Bereavement support	<input type="checkbox"/>	To talk with someone who understood	<input type="checkbox"/>
Other (please specify)	.....		

Which of these DHG resources have you accessed and what did you think of them?

	Very helpful	Moderately helpful	Not at all helpful	Not used
Email support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parent to parent matching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Newsletter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone helpline	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Website	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conference / family weekend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Printed information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Would you like to make any other comment about any of our services?

.....

Would you recommend Down's Heart Group to other families or professionals?

Yes  No  Possibly  Please explain your answer



If you currently receive a printed newsletter in the post, would you consider getting it online to save us money on print and postage costs?

Yes - I'll have the newsletter online in future \*

I already get the newsletter online \*

No - please continue to send me a printed newsletter


\* Please confirm your email address at the end

We often receive information too late to include in newsletters, but could notify you by email. Please tell us what you would be happy to receive by email.

Yes No

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Sponsored events

Media requests

DHG events

Fundraising opportunities

Important information updates

Other events (with free/reduced rates)

Yes No

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Down's Heart Group is run by the members for the members, so we welcome any help that people can offer and always try to find ways to utilise help if we can.

If you can help, whether on odd occasions, for a few hours a month or by making a regular donation (no matter how small), please let us know - there is no obligation.

Talking to the media

Events management

PR experience

Grant applications

Graphic design skills

Supporting other families

Making a regular donation

Organising a fundraising event

Taking part in a sponsored event

Or anything else (please specify)

Writing business / strategic plans

Assisting at a national fundraising event

Running a stall at your local fete / carnival

Assisting at a local fundraising event

Packing and despatching merchandise

Researching potential sale merchandise

Info on FREE ways to raise funds online

Support fundraisers with info and advice

It would help to also have your name and email address, but you may leave these blank if you prefer. (This is for DHG only and will not be passed on to anyone else.)

Name

Email Address

.....

.....

Further information about Down's Syndrome is available from



Down's Syndrome Association  
Langdon Down Centre, 2a Langdon Park  
Teddington TW11 9PS

0845 230 0372  
www.downs-syndrome.org.uk



Down Syndrome Ireland,  
Citylink Business Park,  
Old Naas Road, Dublin 12

00 3531 426 6500  
www.downsyndrome.ie



Down Syndrome Education International  
The Sarah Duffen Centre, Belmont Street,  
Portsmouth PO5 1NA

0239 285 5330  
www.downsed.org



Down's Syndrome Scotland  
helping people realise their potential

Down's Syndrome Scotland  
158 - 160 Balgreen Road  
Edinburgh EH11 3AU

0131 313 4225  
www.dsscotland.org.uk

Further information about heart related issues is available from



British Heart Foundation  
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



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

0808 808 5000  
www.childrens-heart-fed.org.uk



PHA UK  
Unit 2, Concept Court  
Manvers, Rotherham S63 5BD

01709 761450  
www.phassociation.uk.com



**dhg**

down's heart group

charity 1011413

Tel:  
Email:  
Write:

0844 288 4800  
info@dhg.org.uk  
PO Box 4260  
Dunstable, LU6 2ZT

## DHG Merchandise

*NEW range of DHG products available for purchase*



*Fabric items are machine embroidered whilst mugs are dishwasher safe print*

**all items are made to order**

(for further information about ordering please see page 17)