



dhg

down's heart group

# Newsletter Autumn 2012

Issue 45



## Chair's Report

Welcome to the autumn edition of the newsletter, I hope you've all had a good summer break. Although things have been quieter for DHG, we haven't been idle.

Our Director, Penny, was lucky enough to be selected as an Olympic Torchbearer and on 9th July many supporters turned out early in Dunstable to cheer her on. We had a very good morning with no rain and I would like to give my thanks to all those members and their families who came along for their involvement and enthusiasm.

We were unable to attend the World Down Syndrome Congress in South Africa in August as in the current financial climate we could not justify the expense, which is a shame as it is always a great platform for information and knowledge sharing. We hope that we may be better placed to attend the next one in India in 2015.

Finally I'm pleased to announce that plans are underway for our next Family Fun Weekend and Conference which will take place in Peterborough on 23rd and 24th March 2013 - *so put the dates in your diary!* The event promises to be informative and enjoyable, with speakers on various topics and a World Down Syndrome Day theme for the youngsters - look out for more details in this issue and contact National Office if you have any questions. Our AGM will take place on the Saturday morning, when new committee members are welcomed on board. Please let me know if you would like to join, as all offers of help are gratefully received!

*Chris Stringfellow*

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## Safe and Sustainable

*Safe, sustainable and world class. Not ordinary, OK or just good enough.  
Children and young people who need surgery must have excellent care.*

On 4th July the NHS announced the Safe and Sustainable Review decision relating to Children's Heart Services, which will see congenital heart networks structured around Specialist Surgical Centres in Bristol, Birmingham, Liverpool, Newcastle and Southampton whilst Great Ormond Street Hospital for Children and Evelina Children's Hospital will lead the congenital heart networks in London and the South East.



Whilst this decision will have no immediate effect on surgery and it will continue to be performed at the Royal Brompton, Leeds General Infirmary and Glenfield Hospital, by 2014, surgery will be transferred from these units to the seven designated surgical centres.

Information booklets for parents whose children are seen at these units and at Oxford are downloadable from the NHS website

[www.specialisedservices.nhs.uk/document/information-parents-with-a-child-who-has-congenital-heart-disease](http://www.specialisedservices.nhs.uk/document/information-parents-with-a-child-who-has-congenital-heart-disease)

On 1st August 2012 an independent review into children's congenital heart services in Northern Ireland reported its findings, which concluded the hospital in Belfast should cease carrying out children's heart surgery because of the small number of children treated there and proposed that the service becomes a Children's Cardiology Centre.

Although the review in Northern Ireland was not part of the review in England, the service was measured against the Safe and Sustainable national quality standards agreed by the relevant professional associations in the UK.

The report is available here

[www.hscboard.hscni.net/publications](http://www.hscboard.hscni.net/publications)

## Florence's Story

Florence Garrett, a 19 year old Down's Heart Group member, will be jetting off to Italy in November to compete for the Great British Down's Syndrome Swimming Team. The World Championships are held every two years and Florence will be part of a 23 person team.

Super fit Florence trains 5 or 6 times a week and regularly swims with Wandsworth Swimming Club and the Reading Cygnets. She holds the world record for the 25m Down's Syndrome backstroke.

Florence likes to keep busy by helping others out. She assists with the younger swimmers club, and volunteers at Battersea Arts Centre. She is also an ambassador for the charity Downside Up, which helps Russian youngsters with Down's Syndrome. Florence's mum, Veronique helped to found the charity several years ago after witnessing the plight of many youngsters with Down's Syndrome in Russia, where currently there is not as much support as here in the UK.

As a child, Florence had several heart and digestive system repairs. She could not walk until she was four and was not able to eat solids until she was five years old.



*Florence in action*

Mum Veronique Garrett said: "I am very proud, her four brothers and sisters are very keen and happy for her to go to the World Championships. We will go out to Italy to watch her."

If you know of a company that might sponsor Florence's training please contact [veronique.garrett@gmail.com](mailto:veronique.garrett@gmail.com)

## Taylor James's Story

We had our gorgeous little boy on December 3rd 2009. Taylor James having Down's Syndrome was a complete surprise and we were devastated, but we soon fell deeply in love with our smiley tiny bundle of joy.

T-J was born with several health problems including heart defects and feeding was a problem. He was born four weeks early but weighed a good 5lb 10oz. Taylor came home at five days old in good health but after a few weeks we were constantly in and out of hospital with breathing problems.

*It was a difficult winter and Taylor wasn't growing*

It was a difficult winter and Taylor wasn't growing. He developed further problems feeding which eventually resulted in him being fed by naso-gastric tube as his doctors wanted him to get to 9lb before his surgery.



*Taylor with big brother and mum*

But by twelve weeks old Taylor was a very poorly baby and he went into heart failure. We were rushed to Glenfield Hospital in Leicester, where T-J was put on a continuous drip feed to increase his weight whilst he recovered from an infection.

He finally had his heart operation at sixteen weeks old. It took nine hours of surgery for a full AVSD and PDA repair and he then spent five days on a ventilator and then a few days coming round in PICU.

*Then he was a totally different baby - alert, smiling and happy*

Once he was well enough he was moved on to the main children's ward and after just four more days he was well enough to come home. Taylor had never smiled until he came off the ventilator, but then he was a totally different baby - alert, smiling and happy.

We could never thank the staff at Glenfield enough for all the hard work, time and attention they gave. Taylor has to stay on medication as he has a leaky valve and will need more surgery in the future but for now at two years old he's happy and very active.

*Vikki Tranter*

## Ryan's Story

After difficult months with family and friends over this unexpected pregnancy, I was finally going to meet this precious child that had been forming inside me. Ryan Alexander was born on Tuesday 21st February 2006, weighing 7lb 5ozs and measuring 19.25 inches long. But there was something different about my son; I could see it from the second that I laid my eyes on him. He was not who I had expected.

After hours of uncertainty, the paediatrician delivered the news that our precious baby had Trisomy 21 with the possibility of having a major heart defect. My husband and I were heartbroken and could only find the strength to cry.

*We would not change who he is for any "normal" child*

After open-heart surgery at seven months, Ryan began overcoming hurdles that were incredible. Only eight days later, he was rolling over onto his belly and pursuing toys he had never had the energy or motivation to reach before. I remember hearing music, knowing it couldn't be played without pulling the butterfly dangling just beyond his grasp. To my delight I turned to see my once limp son standing, reaching to pull that butterfly, his face glowing with the sound of the music and the light display which accompanied it. He had just given me new hope, something I had wanted for him for a long time.



*Ryan receiving his baseball trophy*

One of the dreams we had for our little boy was to play sports - when Ryan was born, that dream dissipated. Yet at five years old, Ryan played on his first baseball team and received his first trophy. That season was a time of new dreams for our little boy.

He challenges himself and us, daily with new behaviours and tasks, and every day I see him growing up. He has unconditional love and forgiveness; his joyful smile lights up a room; he is perfect and comfortable in his own skin; he is care-free and enjoys life to its absolute fullest.

For my husband and me, he has been the motivation of our happiness in times of disappointment or discouragement. He has taught us how to love more fully, forgive more affectionately, and give mercy where it is undeserving. He is pure honesty. We would not change who he is for any "normal" child the world could give us. He is our little King, the Conqueror.

*Annah Hopkins, USA*

## Conference and Family Fun Weekend

*As mentioned in the Chair's Report on page 2, we have a confirmed location and dates for our 2013 Conference and Family Fun Weekend and we are looking forward to sharing it with as many of you as possible, so get the dates in your diary now!*

### *"Growing Up - Gaining Independence"*

*Saturday 23rd March 2013*

The conference will focus around ways of helping our youngsters work towards independence as they grow up at whatever level is right for them.

- ♥ Speakers to include a cardiac specialist
- ♥ Keynote addresses and workshops on topics relevant to all ages
- ♥ Information stalls and displays
- ♥ Crèche or youth club for all youngsters

### *Dinner and Disco*

*Saturday evening*

Themed around World Down Syndrome Day and providing the opportunity to enjoy a relaxed and inclusive atmosphere full of fun and dancing, particularly for the youngsters.

### *Fun Day*

*Sunday*

On Sunday we are looking to make arrangements to visit one of the nearby attractions (probably the Nene Valley Railway).

### *Venue*

**Marriott Hotel  
Peterborough  
(just off the A1)**

Hello again!  
Did you enjoy the Olympics?



What was your favourite?  
Mine was the diving!



This is my friend Craig. He was a student nurse at the University where I worked 10 years ago and still loves to dance! He was one of the NHS dancers in the opening ceremony!



And of course we can not forget Penny and her torch!



Only joking! We are very proud of you Penny.



So! Back to the summer!  
What have you been doing?



Swimming?



Riding horses?



Or learning a new skill?

Whatever you have done, will you send me some pictures to put in the next newsletter?



## Research

*Dr Andre Strydom from University College London is trying to find out if a new medicine can help the memory of people with Down's Syndrome.*

Do you have Down's Syndrome?  
Are you between 18 and 30 years old?



Would you like to help with medical research?



We are doing a clinical trial to find out if a new medicine can improve memory for people with Down Syndrome and if it has side-effects.



If you want to take part, you or your carer can call Dr Strydom at UCL on 02076799308 for more information



## Sleep Study

*The Department of Sleep Medicine at Edinburgh Royal Infirmary is carrying out a sleep survey to understand how well people with Down's Syndrome sleep.*



Sleep problems can be bad for your health and make you feel sleepy in the daytime. Being sleepy can make it harder for you to do well at things like school, college, work or hobbies.

People with Down's Syndrome (DS) have more chance of having sleep problems than people who don't. If we know more about sleep problems, we can help people with DS to get more out of life.

We want to know how well adults with DS sleep, so if you are 16+ we would like you to fill in a questionnaire. It doesn't matter if your sleep is good or bad, we would still like you to tell us about it!

Down's Heart Group have sent out questionnaires for us. Other groups like the Down's Syndrome Association and Down's Syndrome Scotland have sent out questionnaires too. So far, nearly 1000 people have already filled in a questionnaire, but we still need more.

If you have been sent a questionnaire, please fill it in and send it back! If you haven't had a questionnaire, you can get one from Down's Heart Group, or speak to the person running the study.

Her name is Lizzie Hill, her email address is [lizzie.hill@ed.ac.uk](mailto:lizzie.hill@ed.ac.uk) and her phone number is 0131 242 3879

Thank you for helping us with this important survey!

# DHG celebrating the Olympics

*Well it's been hard to miss the Olympics over the past months and it's been wonderful to see individuals with Down's Syndrome and Down's Heart Group members involved as Torchbearers and helpers at the Olympic Park. Here we tell you about what three of them got up to and how for them it all started many months ago.*

## Torchbearer on June 24th

What a day! Watching our daughter, Joanne, carrying the Olympic Torch in West Yorkshire on a sunny day in June it was difficult to remember back to the time shortly after she was born, when we were delivered the crushing news she had a major heart problem.

### *What a day!*

Joanne was diagnosed with Tetralogy of Fallot when she was three months old, and underwent surgery to fit a shunt at six months, followed by successful open heart surgery at six years old. This transformed the life of our blue and out of breath little girl. From being unable to walk any distance, she learnt to enjoy exercise and took up swimming lessons which then led on to swimming in competitions.

She now leads a full and varied life. She is ladies captain of the Great Britain Down's Syndrome swimming squad and has recently competed in Taiwan at the World Championships. Joanne gained a silver and two bronze medals in the ladies relay team. She will shortly be travelling to Italy for her next World Championship competition.

### *In her words she has an "awesome" life*

Joanne is an actor with the Dark Horse Theatre Company in Huddersfield and has appeared in local productions and also in an episode of the TV programme Shameless. She enjoys working as a volunteer with a local Special Needs Toddler Group and has a lovely boyfriend whom she met through swimming.

And so, it was with enormous pride that we watched our daughter carry the Olympic Torch in front of friends, family and supporters who have helped her throughout her 22 years. In her words she has an "awesome" life.



*Joanne Kempley*

## Games Maker at the Olympic Park

On hearing London would host the 2012 Olympic Games, our son Noah said, 'mum we have to be part of it' and we definitely were! Hannah, my husband Michael, our eldest son Ari and myself, were all accepted as Games Makers volunteers, with Noah as Hannah's support worker. During training everyone got to know Hannah and we discussed the sort of role that she would like, which enabled us to set up shifts that accommodated Hannah's needs. The staffing team were brilliant!

### *What an incredible experience*

The Opening Ceremony was such fun as we were assigned to the VIP lanes to scan spectator tickets as they entered the Park. Spying celebrities was very exciting! We attached the scanner to Hannah's wheelchair, Noah would then place the ticket in front of the scanner and Hannah pressed the button. Watching her perform her role really filled me with pride, I could see the smiles on peoples faces as Hannah offered 'high fives' and thumbs up, as they proceeded into the Olympic Park.

Hannah was able to perform numerous roles, such as pointing out directions using a huge pink finger, and handing out maps to visitors. The atmosphere was very uplifting with people generally happy and smiley, just like Hannah! Each shift we were put into different teams, however on many occasions other Games Makers asked to be in the same team as Hannah! They were genuinely so excited to be working alongside her.

### *The Olympics brought out the Hannah in everybody!*

On the final day we were told our job would be lining the route the athletes would take to the Closing Ceremony. Sensing something special, Hannah waved and cheered as they passed, but many athletes came over to hand her flags, pins, hats and of course pose for photos.

What an incredible experience. The Games brought out the best in people. They were happy, positive and friendly.....just like Hannah. The Olympics brought out the Hannah in everybody!



*Hannah and Dame Tanni*

## Torchbearer on July 9th

*DHG Director Penny Green was incredibly excited when she heard that she was to be a Torchbearer! She decided to try and use the opportunity to raise awareness and honour people with Down's Syndrome around the world.*



I hoped that people with Down's Syndrome could join me on my stage of the relay, but was told this was not possible. Disappointed, I looked for another way to include people and came up with the idea of names on t-shirts to be worn by supporters on the day. Helped by Jorge Arnoldson of Buddy Cruise, we came up with a logo for the event without using any of the Olympic logos or phrases that were not allowed and I asked for donations to add a name or logo to cover the cost of the t-shirts, with any money left over being divided between Down's Heart Group, Down Syndrome Nigeria Support and Down Syndrome International for their global outreach programme.

The response was amazing from all around the world! Lots of people wanted to be part of it and many wanted t-shirts to wear on the day, so what began as a simple idea turned into a huge logistic process as what started out as an order for 20 t-shirts ended up as an order for 360. In total 215 names of individuals and 34 organisations representing 35 different countries were included in 7 different designs on the backs of t-shirts. In addition there was one extra design for the names of some of those we have sadly lost, including our founders daughter Katy and my own son Daniel.

Finally the big day arrived and everything felt unreal. I'd felt sick with nerves in the preceding days but as I left for the briefing session at 5am, I actually felt amazingly calm, although our group were soon buzzing with excitement. Our local council media guys took me outside for some photos with a Torch and suddenly I was surrounded by people all wanting photos – and that was just the beginning. Soon we were on the bus and making our way to the start of the first stage, then waving madly at the crowd and cheering as each Torchbearer got off the bus to be met by the gathered audience.

As the last Torchbearer on our section, after seeing so many people in the town centre, I worried there would only be the people I knew for my stage, but when I got off the bus the road was lined both sides as far as I could see and some of my family were there waiting and cheering. The crowd were fantastic and lots of the kids had their photos taken with me whilst we waited for The Flame to arrive.



Then suddenly it was there! We did 'the kiss' to pass The Flame from one torch to another, I held it high (said a silent prayer to Daniel) and I was off, it was my 'Moment to Shine' and to honour many wonderful friends with Down's Syndrome.

*I was floating on all the adrenaline*

I didn't run, but apparently walked quite fast - I can't remember - I was floating on all the adrenaline. I remember seeing various people in the crowd and calling to them and waving and I'm pretty sure I was smiling the entire time, I was so proud.

It was all over too soon and we were back at the collection point being presented with our Torches and talking to the media. We had group photos taken with the Chair of the Council, who is a DHG member and friend of many years, then it was time to head off. Not home for me, but to my local pub who had kindly provided a Breakfast Reception for the DHG group, which was especially welcome for some who had left home in the early hours to travel long distances to be part of the day. When I arrived, everyone was busy eating but soon the youngsters were far more interested in holding The Torch and having their photos taken with it.



*It was a fantastic experience that I will remember for ever*



It was a fantastic day, an incredible experience that I will remember for ever and I would like to thank everyone that supported me and shared it with me in various ways, making it even more memorable and special. Thanks to Coca Cola I have my Torch to keep and I hope to continue to use it to help raise awareness and also to provide some fun and excitement for people with Down's Syndrome by letting them hold it and be photographed with it –

*after all they were the focus of my special day.*

## Rotary Club of Shepshed



£300 was presented to Sarah and Grace Smith on behalf of Down's Heart Group by Liz Marshall of The Rotary Club of Shepshed.

Rotary members had worked very hard on a fashion show in May and kindly donated half the proceeds to Down's Heart Group

## Everyclick and Give As You Live

*Support Down's Heart Group every time you search or shop online!*



With Everyclick.com you get great search results from Yahoo!, content from leading shopping providers and access to all eBay auctions. Every search you make creates a donation for Down's Heart Group. Just go to the website, start searching and follow the simple prompts to make this your default search facility.

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



Everyclick has also launched a new way to donate called "Give as you Live". With Give as you Live, thousands of brands including Play.com, John Lewis and Expedia have signed up to donate a percentage of every purchase you make online to DHG. All at no cost to you and at no cost to Down's Heart Group.

*Sign up by 31st December 2012 and Give as you Live will donate an additional £5 to DHG when you spend £10 or more.*

Make sure you sign up so you can track your giving - it updates every 3 minutes, you'll be amazed how quickly it adds up!

[www.giveasyoulive.com/join/dhg](http://www.giveasyoulive.com/join/dhg)

## Halloween Fancy Dress and Firework Party

In aid of Down's Heart Group, Leicestershire Down's Syndrome Group, Pancreatic Cancer Research Fund and STEPS of Shepshed

*Hinckley Golf Club, Leicester Road, Hinckley  
Saturday 3rd November 2012 7.30pm till late*

Tickets £20 - over 18's only

*Food, Fireworks, Live Band, Disco and a lot of fun!*

For more details and tickets contact Grace on

01455 888342 or email: [grace@dhg.org.uk](mailto:grace@dhg.org.uk)



## DHG Merchandise

*We now have quality products available for you to purchase to show your support for Down's Heart Group.*

All cloth items are machine embroidered and mugs are in dishwasher safe print. As all items are made to order, delivery may take up to 4 weeks. Pre-ordered goods can be collected at meetings or conferences to save on postal costs but we must receive sufficient notice.



*Please contact National Office for more details or to place an order.*

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



*As you are no doubt aware, benefit changes are taking place starting in April 2013 although not everyone will be affected straightaway.*

*Full details are not yet available and it will take 2 - 3 years to move everyone onto the new benefits, but we understand that the whole topic can be very confusing, so here we highlight some of the things you should know, together with where to go to find out more information as it becomes available.*

## Personal Independence Allowance (PIP)

This benefit will replace Disability Living Allowance for those aged 16-64 from April 2013 even if an indefinite or lifetime award is in place. There is no automatic transfer from DLA to PIP, The Department for Work and Pensions will write to individuals between 2013 and 2016 to let them know when they can claim Personal Independence Payment.

PIP is a non means-tested, tax-free payment that can be spent depending on the wishes and needs of the claimant. Entitlement isn't based on disability, but the level of help needed due to the condition or disability. Personal circumstances are taken into account and the impact the condition or disability has on an individual's ability to live independently. Information to determine PIP will be gathered from the individual, carers, healthcare workers and other professionals and most people will be asked to attend a meeting with an assessor as part of the process.

PIP will be made up of a Daily Living component and a Mobility component. Each component will have two rates – standard and enhanced. The length of time PIP is awarded for may vary from two years to indefinitely, with regular reviews as necessary. For more information go to

[www.dwp.gov.uk/pip](http://www.dwp.gov.uk/pip)

## Disability Living Allowance (DLA)

A child with extra needs is entitled to the care component of Disability Living Allowance from the age of three months and the mobility component from three years. There is no change from Disability Living Allowance to PIP for children up to 16 years of age, but all children entitled to DLA approaching 16 will be asked if they want to claim Personal Independence Payment. For more information go to

[www.dwp.gov.uk/docs/pip-briefing-young-people.pdf](http://www.dwp.gov.uk/docs/pip-briefing-young-people.pdf)

## Employment and Support Allowance (ESA)

ESA has replaced Incapacity Benefit and Income Support for new claimants and is paid to individuals of working age whose disability limits the amount of work they are able to undertake. Claimants are initially put on a basic rate whilst information is gathered regarding ability, which usually includes a visit to an assessment centre to be interviewed by a doctor or nurse (carers are allowed into the assessment to assist.) If the individual is severely disabled an assessment may not be necessary.

People eligible for ESA are put into one of two groups;

**Work Related Activity Group** - if it is decided that someone could possibly work in the future. Work focused interviews and work related activities are available for people in this group.

**Support Group** – if the individual is severely limited in what they can do regarding work, they will be placed in the Support Group and not expected to look for work but may take part in work focused interviews if they wish.

[www.dwp.gov.uk/employment-and-support](http://www.dwp.gov.uk/employment-and-support)

## Job Seekers Allowance (JSA)

JSA is for those who want to work or have worked in the past. Claimants must actively seek work and will need to attend work based activities and periods of work experience. People with learning disabilities get extra support in order to participate but will be expected to sign on like everyone else.

[www.jobseekers-allowance.org](http://www.jobseekers-allowance.org)

This is also a new benefit Universal Credit (UC) due to start in October 2013 which will replace many of the existing means-tested benefits and tax credits for people of working age who are not working or are in low paid employment. And from April 2013 there will be a benefits cap to limit the total benefits received by families where no-one is working.



*It is always a good idea to find out as much about the different benefits that may be available and to seek advice from more than one source on what to claim.*

[www.direct.gov.uk](http://www.direct.gov.uk)  
[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)  
[www.dwp.gov.uk](http://www.dwp.gov.uk)

## Banking Made Clear



Banking Made Clear is a new range of accessible resources developed by Barclays Bank and BILD (British Institute of Learning Disabilities) aiming to make managing money easier and improve understanding, skills and confidence where money is concerned.

The resources include an "easyread" and a "quick guide to banking, a teaching pack and a DVD with step by step instructions on various banking transactions and can be accessed by the visiting the 'Resource Centre' on the Barclays Money Skills website.

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

## Textile Grants

If you are a parent or carer who works or has previously worked in the UK fashion or textile industry, (including working in retail, manufacture, footwear, soft accessories and soft furnishings), have a child with special needs and are struggling to meet a need financially, you may be eligible for a grant from The Fashion and Textile Children's Trust. Grants start from £150.

Visit the website [www.ftct.org.uk](http://www.ftct.org.uk)

or contact Anna [020 7170 4117](tel:02071704117) or email: [anna@ftct.org.uk](mailto:anna@ftct.org.uk)

## Lagan's Foundation

Lagan's Foundation is the first UK national charity to offer "at home" support to families with babies and children under 5 with Congenital Heart Defects and/or complex feeding difficulties. The group has been working with Alder Hey Children's Hospital and is now recruiting Support Volunteers across the UK.



For more information [www.Lagans.org.uk](http://www.Lagans.org.uk) or call [01204 468300](tel:01204468300)

## Health Community



Down's Heart Group now has an online community with HealthUnlocked where people can share their experience of Down's Syndrome - especially related to heart issues.

We would love you to be a part of it and help us make it a success. It is very easy to join and get involved! All you need to do is register by going to

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

After you have registered, you can blog, post questions, review hospitals and suggest polls to both share your experiences related to Down's Syndrome and receive insights from people in the same situation as you!

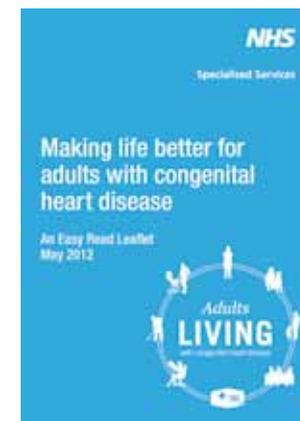
## Adult Congenital Heart Defect Review

Partly as a result of the review of paediatric heart services, the process to improve future NHS services for adults with congenital heart disease (ACHD) is now underway.

The NHS are working with ACHD patients, clinical staff and other relevant stakeholders as they review the services currently provided and develop standards for future provision. This process will eventually lead to centres being designated to provide ACHD care.

For more information and also an easy read version go to

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



## Upside Down's

Upside Down's is a new support group being set up in Harrow, for families in the surrounding area with loved ones who have Down's Syndrome.



The initial aim is to bring families together, for informal meets, coffee and chats. As the group grows so will the aims! If you are interested in getting involved please contact Julie Anslow on

[0751 4320 544](tel:07514320544) or email: [upside-downs@hotmail.com](mailto:upside-downs@hotmail.com)

## Personalised Christmas Gifts



*This year we've teamed up with My Child's Art to bring you a Christmas Fundraising project that's different.*

*You can have your youngsters Christmas design printed on Christmas cards as well as various other items that will make lovely personalised gifts and at the same time you'll be supporting Down's Heart Group.*

Simply contact National Office asking them to post or email you an artwork sheet, get your budding Picasso to create a Christmas picture on it following the clear guidelines, the return it to us by the 18th of October. We will then forward them to My Child's Art to be put on their web site.

My Child's Art will then send us unique log in codes and passwords which you will be notified of. You will be able to select your picture and then order as Christmas Cards, Wrapping paper, Gift tags, Mugs, Christmas Cracker kits, Grow pots, Seed packs etc.

You can personalise them online with greetings and messages, then simply enter your delivery address and pay online. Once all orders are submitted by a given cutoff date (approximately 10th November), they manufacture and dispatch the items to your chosen address.

The charity receives 10% commission from all sales.

*If you think it's too late for this year or you don't want to start Christmas too early, why not get a form for next year and send it back to us in the New Year and provided we are still running the scheme in 2013, we'll submit yours then!*



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



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

00 3531 426 6500  
[www.downsyndrome.ie](http://www.downsyndrome.ie)



Down Syndrome Education International  
6 Underley Business Centre  
Kirkby Lonsdale, Cumbria LA6 2DY

0300 330 0750  
[www.dseinternational.org](http://www.dseinternational.org)



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

0131 313 4225  
[www.dsscotland.org.uk](http://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](http://www.bhf.org.uk)



(formerly GUCH) The Somerville Foundation  
Saracen's House, 25 St Margaret's Green  
Ipswich IP4 2BN

0800 854 759  
[www.guch.org.uk](http://www.guch.org.uk)



Children's Heart Federation  
Level One, 2-4 Great Eastern Street  
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dhg

down's heart group

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# Win a Kia Picanto

with a £2 draw ticket (of which £1.84 goes to DHG)



*Last year the FSI Great Big Small Charity Car Draw car draw raised over £1000 for DHG. Let's see if we can beat that this time!*

The draw takes place on 19th February 2013 and tickets are available until 2nd January online via the DHG website or by going to

[www.smallcharitycardraw.co.uk/tickets.php?id=dhg](http://www.smallcharitycardraw.co.uk/tickets.php?id=dhg)

Or if you could sell tickets at a fete or Christmas party, you can get paper tickets by contacting National Office (details above)

*Please buy a ticket to support Down's Heart Group!*