



dhg

down's heart group

Newsletter Spring 2013

Issue 46

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Chair's Report

Happy New Year! Welcome to Issue 46 of Down's Heart Group Newsletter. This edition contains details of our bi-annual conference. The theme this time is "Growing Up – Gaining Independence" and we have an exciting weekend planned. I do hope you will come along and join in. We are meeting in Peterborough as we have not held a conference in this part of the country before.

World Down Syndrome Day is 21/3 as always, so the DHG conference ties in with this celebration, being held at the end of that week on Saturday 23rd March 2013. Please look through the conference details and if you are interested in finding out more, contact Penny at National Office.

Our trustees would like to thank all our supporters and fundraisers, without whom Down's Heart Group would not exist. We really do appreciate the hard work and effort that goes into raising money to keep our services running.

We would also like to thank members for letting us know what they are up to, please send in your articles and stories for inclusion in the newsletters.

I wish you all a happy and healthy New Year and hope to see as many of you as possible at the conference.

Chris Stringfellow

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Please Help Keep DHG's Heart Beating

*UK Giving 2012, Britain's biggest annual survey of charitable giving, has recently revealed that donations to charity fell by 20% in real terms during 2011/12 - for Down's Heart Group that is cause for grave concern. We are doing all that we can to raise funds and keep costs down so that we can maintain our services, but we need **YOUR** help, too.*



Did you know it costs Down's Heart Group:

- £5 printing and postage to send a family four newsletters a year
- £10 to support a family when they initially contact us
- £50 per month for phone and internet which are vital for our helpline

Every year we have wonderful people undertaking all sorts of events to raise money for us and we are incredibly grateful, but not everyone has the time and energy to take on such a commitment. There are lots of other ways you can support us that don't even cost you money, especially if you ever shop online, for example (see our website).

However, there is now another way to help DHG sustain its services - a simple way to make regular donations.



Down's Heart Group now has a new online giving page where you can easily set up a regular donation - monthly, quarterly or annually. The minimum amount is £3 (due to the system we are using) but other than that you can decide the amount and frequency of your donation. It only takes a few minutes to set up and then there is nothing else to do but be happy in the knowledge you are helping DHG make a difference.

The new page goes live on January 14th and can be reached via our website or direct at

www.charitycheckout.co.uk//1011413/donate

If you are able to support us with a regular donation, whatever the amount, it will not only help us to continue our work but also assist in our financial planning.

Lily Humphrey

Lily had to have corrective surgery for complete AVSD at just six weeks old, I was told afterwards that she still had a leaking valve but was unlikely to need further surgery until her teens. So you can imagine my shock five months later when I was told that Lily needed valve surgery as soon as possible!

I got lots of information from the Cardiac Liaison Nurses and I naively thought after the valve repair everything would be fine. Eventually, after a cancellation, surgery took place when Lily was ten months old. Lily's surgery lasted over seven hours, after five I was going stir crazy. A surgeon came to tell me that Lily's valve had disintegrated during surgery and they had no option but to put in a mechanical valve.

No-one knew of a child as young as Lily who had Down's Syndrome and a valve replacement



Lily 5 days after surgery

Over the next few days I had a very steep learning curve. I found out about valves, warfarin, INR, blood tests, repeat surgery, blood clots and so on. I contacted various groups including DHG, but no-one knew of a child as young as Lily who had Down's Syndrome and a valve replacement.

After surgery she progressed in leaps and bounds, managed to get rid of the NG feeding tube she'd had since birth and the overnight oxygen that she hated! She was definitely happier without things stuck to her face and her eating improved rapidly.

Due to Lily's valve replacement she needs to take warfarin to thin her blood. To check how thin blood is, doctors test something called INR. At first Lily's blood was tested in hospital, later we were given a machine to test her blood at home, reducing trips to hospital. So I learned another new skill – blood testing a wriggly toddler by myself!

Lily's INR is unfortunately very unstable. We've had frequent admissions to hospital; if her INR is too low she has to have intravenous medicine and then blood tests every four hours. If the INR is too high vitamin K is given to reduce it. As a result Lily has become very tactile defensive and will not let anyone touch her hands. She's developed a fantastic head butt and bite reflex that she aims with great accuracy at the doctors doing the tests! The first time Lily was given vitamin K she had an extreme reaction, resulting in a longer stay in hospital than for the open heart surgery and valve replacement!

Eventually Lily's blood became fairly stable and things began to settle down, however, this wasn't to last. Lily was admitted to the high dependency unit with a severe respiratory infection and a very low platelet count of 8, when it should be 200-400.

She was at major risk of internal bleeds. Lily had intravenous medication for five days which increased her platelet count enough for us to go home, but before the week was out it had dropped rapidly again and we were readmitted.

Between October and December 2010 we were in hospital virtually every other week. Lily was given steroids, immunoglobulins, platelet transfusions, plasma transfusions and more besides. She had a bone marrow aspiration which thankfully was negative for leukaemia. Lily was diagnosed as having ITP (immunothrombocytopenic purpura) and I was told that it was nothing to do with Down's Syndrome or her heart, she was just unlucky. .



Lily on holiday

Lily's ITP has improved and her platelet count is no longer at a dangerous level but she has dips. Thankfully it is manageable and does not affect her significantly most of the time. Lily's home INR machine is not accurate enough so this means we have to go to hospital for blood tests at least once a week, or when she is very unstable, every day! Lily has got better at having blood tests as long as they are done in her feet.

Recently we managed six months with no hospital stays! We go on holiday (arranging for blood tests at a local hospital) and do normal activities for a three year old. Lily wears a helmet if she is doing anything really physical, but that is the only outward sign of her medical issues. If you met Lily you would never know what she goes through.

She is a happy, sociable and wonderful little girl

I am very proud of Lily and the way in which she takes everything in her stride. She is due to have her valve replaced in the next year and I am hopeful that she will cope with it as well as she has coped with everything else.

Jilly Humphrey



Lily and Jilly - photo by Terry Harris, from his project DS The Big Picture

Hannah and Sam Wilkinson

When I became pregnant with Hannah, our 8th child, we promised she would be our last, however complications began at about 20 weeks pregnant and we discovered that Hannah was unlikely to survive. We also discovered she had Trisomy 21. At 28 weeks I had an induced birth but Hannah was born sleeping, having passed away shortly before.

Days after Hannah's burial, our daughter Rebekah, aged 8, asked if we could adopt a baby. We were rather surprised by this request but promised to think about it. Our hearts were still raw, but I felt very strongly that we were meant to parent another child. Months later Glenn finally agreed to speak with an adoption counsellor. We spoke with our children about adopting a baby with Down's Syndrome or another disability and our son, Jake, told us that having Down's Syndrome wasn't a disability but an ability to teach us how to be better people. From that moment on, there was no doubt whatsoever.

The wait began. We had no due date to mark off, no growing belly to remind us that a baby was going to join our family. Jake, just 12 years old, said we should grow our new baby in our hearts instead. We only ever thought we would be offered a girl, so we chose girls names and settled down to enjoy Christmas. In the New Year our adoption worker phoned to offer us a baby boy with Down's Syndrome. I emailed Glenn with a single line -

Congratulations my Love, we have a four day old baby boy



Sam and Hart

Samuel had an AVSD and a PDA which several hospitals thought were too severe to repair, but luckily Toronto Hospital for Sick Children agreed to operate. The surgery was a success although he was left with a mild leak in his mitral valve which is checked every two years. Sam is now eleven, he reads very well, loves to watch movies and play with his games. He is in the Honour Roll at school every term. Sam wears hearing aids and uses a hearing service dog called Hart. There is not a day that there is not a smile on his face.

Sam is not a replacement for Hannah, in fact, the only peace I ever felt about Hannah's death was from something Rebekah said when Sam was only weeks old. She said she knew why Hannah had left our family when she did, it was because Hannah knew that Sam needed our family more than she did right then.

The Wilkinson Family - Glenn, Joanne, Jesse, Meghann, Jake, Emma, Rebekah, Rachael, Sarah, Sam and our Angel Hannah

Sydney Warren

Sydney Elliott Warren was born on August 15th, 2005 in Fayetteville, Arkansas to Kim and Bill Warren. We were very excited for the birth of our second daughter, but to our surprise, Sydney was born with Down's Syndrome.



Sydney's smile

Most likely as a result of her genetic condition, she was also born with three holes in her heart. She had a Patent Ductus Arteriosus (PDA), a small Ventricular Septal Defect (VSD) and a large Atrial Septal Defect (ASD).

We were sent home with a newborn not knowing when (or if) she would need surgery. Each cardiologist had their own opinion. Within several months, Sydney's PDA and VSD had closed on their own.

*To our surprise,
Sydney was born with
Down's Syndrome*

The cardiologists at Arkansas Children's Hospital tried to wait until Sydney reached the weight and age at which they could close her ASD via catheter, but unfortunately, her ASD contributed to other health issues and slowed down the progress of her therapies, so eventually the cardiologists decided to close the hole via open heart surgery on August 8th, 2007.

After a five day stay in the hospital, including a possible infection, Sydney came home and has been thriving ever since. She began to crawl a couple of months after her surgery and then started walking a couple of weeks after that! She shows no signs of slowing down!

Sydney has been thriving ever since

She is a great joy in our lives and touches the lives of everyone she meets. Though we wish she had never had to have it in the first place, we are very thankful she was able to have the surgery.

Kim Warren

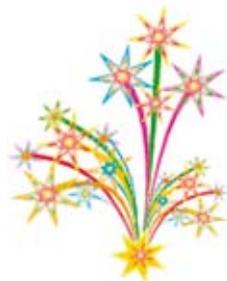


Sydney and her big sister

There have been some spooky goings on at Halloween



And I know the Down's Heart Group have been well supported with fireworks from Hinckley Golf Club. What did you do?



Our family fun weekend will take place in March 2013 are you going?



There will be chances to catch up with old friends and make new ones!



Whilst the parents talk about serious stuff!



We've got plenty of activities planned for all ages!



Hope to see you there

DHG Merchandise

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

Below is a selection to give you an idea of prices, but please ask for anything you don't see listed as we can probably source it for you. You will be quoted a price before you order.

All cloth items are machine embroidered and mugs are in dishwasher safe print.



	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. 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

The Torch's Travel



A lot of members have been asking about my adventures since the Olympic Torch Relay, so I've been asked to do a short update for you all.

I was fortunate that Coca-Cola bought my Torch for me, so I've been able to use it in various ways to raise awareness and some funds. I've talked to a number of schools and scout groups and particularly enjoyed a visit to a local special school where many of the pupils were very excited to have their photos taken holding the Torch.

I also attended other events including the Chair of Central Bedfordshire Council's Civic Reception and the Nigerian Entertainment and Lifestyle Awards, where the adults (including an actor from Holby City) were even more keen to get a photo holding it!

At the end of August I was asked to an event at The Disability Resource Centre in Dunstable where one of the Paralympic Flames was visiting in the run up to their Games. For three hours there was a queue of people waiting for photos with the Torch and the Lantern! A few days later I watched the Stepping Stones DS team as they acted as Torchbearers for the Paralympic Flame – it was particularly emotional to watch DHG member Nicole Williams as she carried her Torch with such pride.



In October I was honoured to be asked to cut the ribbon for the official opening of Upside Down's, the new group set up by Julie Anslow and Ang Whyte in Harrow, before flying to Nigeria to support our friends at the Down Syndrome Foundation there for their Awareness Week, for the third time. Of course, they wanted me to take the Torch, so having obtained confirmation from LOCOG that it didn't present a safety risk, I managed to persuade the airline to let me take it onboard as hand luggage and the Torch and I headed to Africa.



I spent a busy week in Nigeria - it was wonderful to see everyone again after two years and they all had a great time taking photos with the Torch.

It's reassuring to see the Foundation in Nigeria gaining strength, funding and recognition for the work it does as there is a lot to be done in raising awareness and promoting acceptance and inclusion. Medical services are also a huge issue,



especially for those with heart defects due, to lack of facilities in Nigeria Those that are lucky enough to get funding for surgery have to travel to India, which must be a terrifying time for the one parent that accompanies each child, far from home and family.

It was especially emotional for me to see Honour, my Nigerian goddaughter, again and how well she is progressing. When I last visited she was in desperate need of heart surgery, which she had in India a few months later, now approaching her third birthday she is walking and talking and her future looks brighter.

Then just when things started to quieten down a little, along with other Torchbearers and Games Makers from our region, I was invited to attend the BBC East Regional Sports Awards at the beginning of December. It was a fantastic evening, with many sports personalities in the audience and there was a great sense of community spirit all evening. At the end we got to chat and take photos with some of them - amongst others I met Olympic Gold Medallists Greg Rutherford and Etienne Stott and Paralympic Gold Medallist Jonnie Peacock and even I got to hold Etienne's Gold Medal!

I am sure that there will still be plenty of opportunities for people to share and enjoy the Torch in the future. In fact, I'm already working with a friend who carried the Paralympic Torch on arranging an event in a shopping centre next year, where we hope to use the opportunity to raise awareness of our two organisations and also raise some funds. So if you have an event that's supporting people with learning disabilities and think a Torch would add value in some way, do let me know and I'll see what I can do – if I can't come personally, I am in contact with a number of other Torchbearers who may be available instead.



It has been a truly wonderful year. I have really enjoyed meeting so many people - the inspirational ones, the ones who were just desperate for a photo with an Olympic Torch and all those who wanted to learn a little more about Down's Syndrome and Down's Heart Group. It has been great to be able to represent the global Down's Syndrome community and some of the organisations that strive to make a difference.

I must admit, though, it has been a bit too busy at times and it will be good to get back down to earth!

Penny Green, Director

Run For Russ

Laurence Gale writes about his late nephew, Russell Diamond who was the inspiration for family and friends to complete a half marathon in October.



Vicky, Rachel, Kate, Lynsey, Laurence and Manny

How can we put into words what we managed to achieve during our 'Race for Russ'? Not only did we bring together a group of family and friends to take part in the Run The Beat, but it was a fantastic experience for my daughters and I as it was the first time we have run together in a Half Marathon.

Russell was a wonderful person who died in 2007, aged 29. He is sorely missed by us all, but has left us all with plenty of fond memories and was the inspiration for us to compete and achieve personal bests for the half marathon.

I'd like to thank Vicky and Lynsey's friends (Manny, Stuart, Rachel, Nick, Kate and Charlie) who also took part, spurring us on and making it a day to remember. And thank you to everybody who sponsored us (friends, family and work colleagues) bringing our total to over £750 for a worthy charity.

We will continue to 'Run for Russ' in the coming years, there's even talk of us all doing a triathlon!

Laurence Gale

Grants

DHG has been busy applying for grants to help boost the charity's finances, securing several small grants which will help us maintain and deliver our services and plan ahead. However, we still rely heavily on donations and fundraising so please keep up the good work and let us know if you hear of any fundraising opportunities we can get involved in.

Halloween Party

DHG benefitted from a spooky night in Leicestershire, where party goers in fancy dress really got into the 'spirit' of things in support of four charities.

Stuart Purt is dad to toddler George, who has Down's Syndrome but luckily no cardiac issues. It was after George was born that the family decided to start fundraising to support various charities and this year, Stuart and a few friends got together to organise their second Halloween party at Hinckley Golf Club in Leicester. The party was to raise funds for four charities - DHG, Leicestershire Down's Syndrome Group, Pancreatic Cancer Research Fund and STEPS.



The party was a fantastic night, with almost everyone arriving in fancy dress. A local party and balloon shop, Balloonatics, provided some spectacular balloon displays including a huge three metre spider on the ceiling. There was a disco and brilliant live music by Fool's Gold resulting in not an inch to spare on the dance floor all night.



A hog roast and BBQ tempted people outside and then a wonderful firework display rounded off the evening.

Down's Heart Group members Lucy Thomas and Emily Smith, dressed as a witch and a cat, danced most of the evening and were great ambassadors for DHG. They certainly changed more than a few people's perceptions of Down's Syndrome through the evening!

A total of over £3000 was raised on the night, with a quarter coming to Down's Heart Group.

Thanks to everyone involved for their hard work and for putting on such a great event.



My Child's Art

Did you have trouble knowing what to give as presents at Christmas? Then why not use this year's festive artwork for next Christmas' cards, wrapping paper, mugs and gifts!



Contact National Office for an artwork order sheet, add the artwork, return to DHG and we'll look after it till it's time to forward it to My Child's Art in October. Then they'll put it on their web site and send you a unique login code and password you can use to place an order.

As well as getting unique and personalised items ready for next Christmas, your order will be raising money for Down's Heart Group, 10% commission from all sales.

Reading Half Marathon

DHG member Melissa Harrison and her friend Becki are running in the Reading Half Marathon on Sunday 17th March 2013. They are raising funds for Down's Heart Group and their inspiration for running is Melissa's gorgeous son Henry.

If you would like to sponsor Melissa and Becki please get in touch with National Office.

0844 288 4800 info@dhg.org.uk



London Marathon 2013



Yet again Down's Heart Group has several runners raising funds by taking part in the gruelling London Marathon which takes place on Sunday 21st April. At the time of going to print, runners names had not been finalised, so please check our website for details on who is running and why they chose to run for DHG.

Please show your support by sponsoring them via the DHG website or their individual pages on Virgin Money Giving. We hope their training goes well and that they all have a fabulous day! Why not come along and join the DHG supporters to cheer them on!

Got a burning desire to run in the London Marathon? DHG has guaranteed Gold Bond places every year, but get your name down early as our waiting list is always full.

World Down Syndrome Day

*The DSi World Down Syndrome Day Committee has announced the theme for World Down Syndrome Day 2013 - **Odd Socks Day**.*

The idea is easy, costs nothing, can be done anywhere by anyone, include any number of people and can be incorporated into any other larger events happening on the day. It also carries a message - a pair of socks may be different (different colour, different design etc) but they are both socks and can quite happily be worn together if people accept the difference.



The idea is to encourage people to wear odd socks on March 21st and pay £1 to do so. By getting schools, youth groups, local pubs and offices involved opportunities to raise awareness about Down's Syndrome are endless.

Get your school, office or college to join in

Most events on WDS Day will be raising money for either local or national organisations, but if 25-50% of any money collected was given to Down Syndrome International for the Global Outreach Programme many more people throughout the world with Down's Syndrome could benefit. DSi say "We believe '**Reach Out**' can make a real difference to the life opportunities for people with Down's Syndrome and we now have the structure in place to conduct programmes quickly and efficiently while leaving a sustainable and lasting legacy. We are working to raise funds to commence these programmes as soon as possible."

This would truly reflect the essence of World Down Syndrome Day, when we all come together around the world to unite in celebration of the gift that people with Down's Syndrome bring to our lives, our communities, our world!



DHG's conference and Family Fun weekend is on 23rd March. Join us to celebrate World Down Syndrome Day at our dinner and disco.

Contact National Office for details.

Odd Socks Montage

In line with the 'Odd Socks Day' theme for WSD 2013, Penny Green is putting together a photo montage of people with Down's Syndrome wearing odd socks, which will be launched on the run up to World Down Syndrome Day and will be on Youtube and various other sites as part of the awareness campaign.

Penny needs good quality photos of youngsters with Down's Syndrome doing almost anything as long as they are wearing odd socks. Due to the volume of photos anticipated, no acknowledgement receipt can be given but if you send a read receipt request with your email you will get notification of its arrival.

If you would like your photos to be considered for inclusion please email **no more than two photos** to WSD2013@dhg.org.uk giving the name of the person in the photo, the country they are from and also include the following statement in your email:



"I give permission for you to use these photos in your video montage which will be shown on Youtube and other websites. I own the copyright of these photos or have obtained permission from the copyright holder for you to use them and I have the right to give permission for this persons photograph to be used."

DS – The Big Picture

Terry Harris, whose daughter Lucy has Down's Syndrome decided to do something totally different to raise awareness. He has managed to draw together many organisations offering support by gathering photos of group logos. He has combined these with hundreds of photos of people with Down's Syndrome and many famous faces holding a picture of Lucy.

The result is a huge exhibition which will take place around World Down Syndrome Day (21st March). The exhibition will also have an associated website with videos and pictures with an interactive gallery so that visitors from around the world can view and leave messages, as well as click links to all the logos and organisations involved.

www.dsthebigpicture.com



Down's Heart Group Conference

Down's Heart Group's bi-annual conference and family fun weekend will take place on the weekend of 23rd and 24th March 2013 at the Marriott Hotel in Peterborough.

The weekend will follow the usual format, with the conference on Saturday, a meal and disco on Saturday evening and a family day Sunday, either using the hotel's pool and leisure facilities or a trip out to a local attraction.

"Growing Up – Gaining Independence" is the theme of Saturday's conference. There will be speakers and workshops on cardiac issues, general issues around Down's Syndrome, and a focus on helping people with Down's Syndrome, no matter what their age, to reach their potential and become as independent as possible. There will be something for everyone – parent or professional.



A crèche for younger ones and activities for older children and young adults will be provided. As the conference ties in with World Down Syndrome Day, music and art activities will no doubt have an international odd sock theme!

Saturday evening is "Dinner and Disco", a family orientated affair with lots of cheesy tunes and bad dancing but thankfully the bar will also be open!

Sunday is family day with an optional trip out. Alternatively, relax with coffee and chat with new friends or enjoy the leisure facilities at the hotel.

Several families will be at the hotel on the Friday evening too, whereas others may just attend either the conference or the dinner - it's up to you. DHG has agreed preferential rates for anyone staying overnight and we may be able to assist families on limited income (please ask in confidence).

Please contact National Office for full details

info@dhg.org.uk 0844 288 4800

We look forward to seeing you in March!

NHS Continuing Care



NHS continuing healthcare is a package of care provided outside hospital, arranged and funded solely by the NHS, for people with ongoing healthcare needs.

NHS continuing healthcare can be received in any setting. At home the NHS will pay for healthcare, such as services from a community nurse or specialist therapist, and personal care, such as help with bathing, dressing and laundry. In a care home the NHS will also pay for care home fees, including board and accommodation.

NHS continuing healthcare is free

To be eligible the main or primary need for care must relate to health, people are likely to have a complex medical condition that requires a lot of care and support or need highly specialised nursing support. Someone nearing the end of their life is also likely to be eligible if they have a condition that is rapidly getting worse and may be terminal.

Eligibility for NHS continuing healthcare does not depend on a specific health condition, illness or diagnosis, who provides the care or where the care is provided. Assessment of care needs is undertaken by a health or social care professional and will need to be reviewed periodically.

To get a booklet all about NHS continuing health care follow the link for a free download or contact Foundation For People With Learning Disabilities.

www.learningdisabilities.org.uk/publications/continuing-healthcare

Foundation For People With Learning Disabilities
1st Floor, Colechurch House
1 London Bridge Walk
London SE1 2SX

Tel: 020 7803 1100

The Foundation For People With Learning Disabilities have a huge range of literature covering many aspects of learning disability, so their website is well worth a visit.



Learning Disabilities Hospital Support

DHG members Maralyn and Alvin Adey formed a new nationwide advice group called Learning Disabilities Hospital Support after their 27 year old son Kristian, who has Down's Syndrome, heart and lung problems, spent eight weeks in hospital with a brain abscess.



Maralyn, Kristian and Alvin

This latest hospital experience made them realise how difficult it is to maintain adequate communication between consultants, nursing staff and family members.

Lack of information passed on to ward nurses was a real worry and because Kristian is an adult, gaining knowledge of his condition and care was an uphill battle for his parents.

Maralyn has created LDHS as a way of helping people in the same situation know their rights and to campaign for improvements. She has already worked with Leeds Teaching Hospitals Trust to create a Patients Passport. This passport travels round with the patient and contains vital care and needs information. Maralyn has also helped develop a training DVD with the Trust for its staff. Currently the group only has a few volunteers and is looking to recruit many more to roll the initiative out across the UK.

www.ldhs.org
info@ldhs.org.uk 07770 882 404

Carers Week

Carers Week will take place from 10th to 16th June 2013. This annual UK-wide awareness raising campaign aims to improve the lives of carers and the people they care for and it also provides an opportunity to:



- Raise the profile of caring and help the public identify themselves as carers and access support, advice and information.
- Celebrate and recognise the contribution the UK's 6.4 million carers make to the people they care for and their communities.
- Highlight the challenges of caring and campaign for sustainable funding for services and support for carers and the people they care for.

www.carersweek.org

Special Children of 2002



Was your child with a disability born in 2002?

Do you live in England?

Will you tell your story?

This could help the Prime Minister see what 'ordinary' families go through and hopefully lead to improvements all round. Sadly, David and Samantha Cameron lost their disabled son, Ivan, when he was only six years old, due to a rare condition.

Peter Limbrick from Interconnections is collecting stories about other disabled children born the same year to highlight some common themes and difficulties for families struggling to access the NHS, education and social services. He then intends to persuade the Camerons and Government to read these stories in the hope that better understanding of what life can be like for these families can be gained.

Stories should be no more than 1500 words and photos can be included. Peter promises not to share your contact details and false names can be used.

peter.limbrick@teamaroundthechild.com 01497 831550

The True Colours Trust

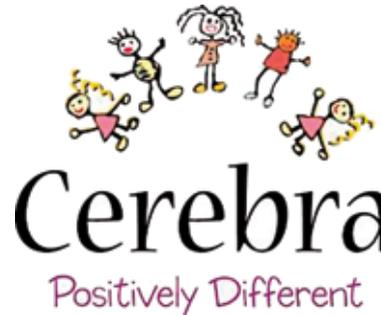
The True Colours Trust has a small grants programme for young people between the ages of 18 to 26 who have a disability or complex health care needs. Support will also be considered for families who care for a young person.

Applications can be for household items, play & exercise equipment, music equipment, computing and games equipment, mobile phone, leisure activities, hospital visits, driving lessons, sensory items, jet baths, holiday, removal costs and funeral expenses. Other items recommended by a medical professional or social care worker, may be considered at the Trustees' discretion.

Each applicant must be referred by a medical professional or social care worker. The referrer must specifically endorse the items requested. Any professional assessments, supporting statements or letters or quotations are welcome. The application must be signed by the applicant (or parent/carer on their behalf) and the referring person.

www.truecolourstrust.org.uk

Wills and Trusts



Cerebra are offering £350 vouchers to get help from a solicitor to draw up a will and a discretionary trust for families.

There is a simple application process which must include a copy of a letter confirming your child's condition and a copy of DLA award of middle or high care rate.

www.cerebra.org.uk

West Coast Down's Syndrome Support

West Coast Down's Syndrome Support Group is a new charity in Cumbria. It is open to all parents, carers and siblings as well, of course, as to those with Down's Syndrome.

The group is planning lots of activities and meets on the third Wednesday of each month at Wellington Bistro Café in Whitehaven and also at Monkey Madhouse in Workington on the first Monday of each month.

Contact Emma Southward on 01946 61947

Cinema Offer

The Cinema Exhibitors Association Card scheme allows one free cinema ticket for a person requiring assistance. To be eligible for a card, applicants need to be in receipt of Disability Living Allowance or Attendance Allowance at any rate, or be registered blind.

The CEA Card will be in the name of the person requiring assistance. They will still pay for their ticket but the accompanying person, who can be their carer, friend or relative, will go in for free.



Cinema Exhibitors Association Cards are accepted in 90% of cinemas in the UK including all of the national chains and a lot of the local independents. Application forms are downloadable from the website.

www.ceacard.co.uk

Cheaper Water



Water Boards in England, Wales and Scotland can offer capped water bills to those with a disability or who are on certain benefits. If your family's benefits include Tax Credits or Disability Living Allowance and there are three or more children under 19, or you or someone in your household has a medical condition that means they use a lot of extra water (incontinence or in nappies etc) you may qualify.

A water meter needs to be fitted before you apply. If accepted, water costs will be capped to the average household bill, regardless of how much you use. The company will then check each year to see if your situation remains the same. Contact your local water supplier for further information.

Family Grants

Buttle Small Grants programme can provide essential items for children and young people whose development, health and well-being are at risk.

Individual grants provide a fast response to families who lack basic items such as bedding, a cooker or a washing machine.

The programme runs across the UK and is part of the BBC Children In Need emergency essentials programme. For more information contact;

info@buddleuk.org

020 7828 7311



World Down Syndrome Congress



The World Down Syndrome Congress took place in South Africa in August 2012. Down's Heart Group were not able to attend due to costs so we are unable to bring you a personal report of the event.

However, by following the link below and then clicking on "News" you will be able to view the presentations and some video footage.

www.wdsc2012.org.za/home.php

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
6 Underley Business Centre
Kirkby Lonsdale, Cumbria LA6 2DY

0300 330 0750
www.dseinternational.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



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

0800 854 759
www.thesf.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

Tel:

0844 288 4800

Email:

info@dhg.org.uk

Write:

PO Box 4260

Dunstable, LU6 2ZT



AGM & Conference Invitation

If you received this newsletter through the post or via email you should also have received official notification of Down's Heart Group's AGM and conference.

"GrowingUp-Gaining Independence"

*Saturday 23rd March 2013
at the Marriott Hotel, Peterborough.*



If you require further information or did not get a notification, please see page 17 then contact National Office. The conference is open to anyone interested in attending although priority for the crèche and activity group will be given to DHG members.

*Crèche and activity group during the conference
family dinner and disco Saturday evening*



Down's Heart Group has a board of Trustees whose combined skills and experience guide the charity. We are always keen to expand the number of Trustees to bring new attributes to the Group. If you would like to get more involved please contact our Chair - Chris Stringfellow or Director - Penny Green on 0844 288 4800 and select the appropriate option from the automated switchboard.

See page 17 inside for more details.