

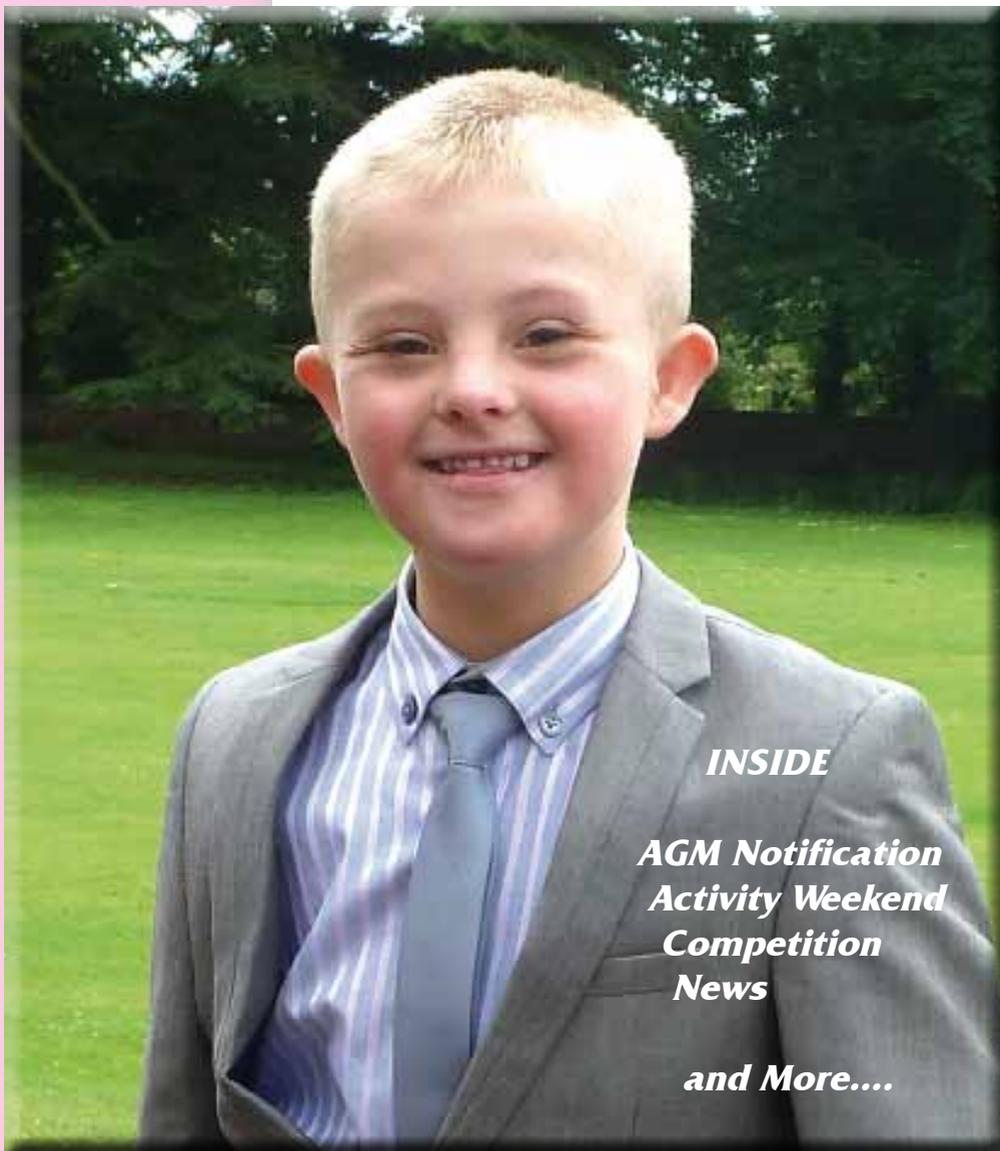


dhg

down's heart group

# Newsletter Summer 2014

Issue 50



***INSIDE***

***AGM Notification  
Activity Weekend  
Competition  
News***

***and More....***

## Chair's Report

Welcome to the Summer 2014 newsletter.

Our AGM takes place on the 17th May in Birmingham - details are on page 3. If you are unable to attend but would like to vote for a committee member then please remember that you need to access a voting paper via Penny at National Office. It is only a small room so numbers are limited, therefore, we request that you let us know beforehand that you will be attending. There will be no crèche facility available. I look forward to meeting everyone on the day.

Penny and I are currently attending the NHS new Congenital Heart Disease review meetings. If you are interested in following, then John Holden, Director of System Policy, has a blog that highlights progress to date, you can find all the posts here:

[www.england.nhs.uk/publications/blogs/john-holden](http://www.england.nhs.uk/publications/blogs/john-holden)

I trust that not too many of you have been affected by the weather and hope that we have a good summer.

Regards to all

*Chris Stringfellow*

## Contents

Matt Coppins	Front Cover
AGM notification	3
Members Stories	4
Fundraising Update	9
Future Events (including Christmas Card competition)	10
Easy Read Pages	12
Can you help	14
Information	16
Useful Links	23
World Down Syndrome Day	Back cover

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# Down's Heart Group Annual General Meeting

10am Saturday 17th May 2014

Holiday Inn Express  
Birchley Park, Oldbury  
Birmingham  
B69 2BD

You are invited to attend the AGM followed by a buffet lunch

If you would like to join us please register names of those attending by emailing [info@dhg.org.uk](mailto:info@dhg.org.uk) or calling 0844 288 4800 **as soon as possible**

- Your attendance and any dietary requirements will then be confirmed
- Due to room size anyone not pre-registered may be refused entry
- There are no crèche facilities available

If you are unable to attend but would like to exercise your right to vote, please request a proxy voting form from National Office. Completed forms must be returned to arrive at National Office no later than Thursday 15th May. Forms can be posted or emailed.

We currently have some vacancies on the Executive Committee and would welcome new Trustees, so if you can spare a little time and have enthusiasm for the work of DHG please consider joining us. For an informal chat to find out more about what is involved, please call 0844 288 4800 and choose to speak to our Chair or Director.

...supporting a better life 

## Matt's Story



*Matt at a water park*

Matt was born in June 2003. We didn't know he'd have Down's Syndrome before he was born, but the news didn't kill us, we knew if Matt was given all the opportunities he could have, he would succeed. He was the easiest, happiest and most loving toddler I've ever known.

Although he was born with an AVSD he was healthy. He had open heart surgery at 6 months old and was in and out of hospital within a week. His smiles returned pretty soon after.

We were spoilt as Matt met all his milestones at pretty much the 'right' age. I was the proudest mum and, sadly, probably the smuggest mum out there. My child was defying the odds.

I had a confident, out-going, happy and handsome boy who charmed all he met. His speech wasn't typical, but he had 30 words and on top of that he had around 200 signs to help him communicate. I felt so blessed, so full of hope for the future and joy for the present - I had no idea what was to come.

### *My child was defying the odds*

Things changed just before his 3rd birthday. We were at a toddler group, but instead of playing with the others, Matt had taken himself off to a corner alone. He was spinning a plate over and over and watching it as it clattered and stopped.

Over the next few weeks Matt stopped playing constructively and became fascinated with holes and instead of playing with cars, he became transfixed with just the wheels and watching them spin. At the same time, his signs diminished to 50 and he pretty much stopped speaking. I mentioned Autism to the paediatrician but she told me to stop being silly, that Matt was doing far too well.

Two months later, Matt was down to just 10 signs. He no longer initiated communication. He didn't want to play. He was anxious, unhappy and isolated. The only thing that made him happy was watching The Wiggles on TV. One month later he had no signs; no words; no play; no wish to communicate; no eye contact; no zest for life. Going out became hard as he was scared of new places. We asked another paediatrician to please assess him and on 14th February 2007, Matt was diagnosed with Autism.

Losing my child to Autism was the hardest thing I've even been through. I was left with a boy who's face was the same, but whose character was totally different. He was sad and lost and I felt exactly the same. He wasn't the boy I wanted. I did love him, but I was grieving my old Matt.

### *He was sad and lost and I felt exactly the same*

Matt started at mainstream school, where he did well. But between the ages of 8 and 9 he became very anxious and difficult and seemed to be permanently depressed. He stopped learning. He started to self-harm badly, punching himself over and over so he was covered in bruises. We asked for help from different professionals but got nothing useful. Matt was desperately unhappy and no-one understood why. Gradually his mood changed. He was happy and relaxed once more but he'd had another regression. He no longer knew his numbers or letters, and could barely even write his name.

Matt is now 10, he has re learnt about 20 signs, knows his numbers to 20 and is restarting work on addition. He knows some letters and can write his name with help. He has not spoken for 7 years, although did start to babble this year. His zest for life has returned and, on the whole, he is a very happy child.

He eats only 3 things, doesn't sleep well and needs a lot less sleep than I do. He can be funny, cheeky and very naughty. He is an awful escaper - last summer he escaped from a carer at Butlins. He was lost for over an hour and 3 police forces and the coastguards searched for him. Matt was found waist deep in the sea, fully clothed and shoes on!

### *His zest for life has returned*

Life with an autistic child is hard - escaping, physical violence, the house being smashed up, smearing, food being thrown, sleep deprivation and all the fights with the system. But I adore Matt and love him completely, he is worth it. Matt really does have the best smile and giggle there is.

When you see him jumping in puddles soaked to the skin with a huge grin and shining eyes it is amazing. When he throws a ball for our dog, gets him to drop it again then repeat the process it warms my heart so much. Once every few months he will spontaneously give me a hug and it's beautiful. He's not said 'Mummy' since he was 3 but I hope one day, his gruff manly voice will say 'Mum'.

*Helen Coppins  
Nottingham*



*The Coppins family and dog, Cody*

## Gwen's ambitions

Here is a photo of our Gwen who is now 15! She had a VSD repair when she was 8 months old and has gone from strength to strength.



*Gwen striking a pose!*

She is a very determined young lady, giving 110% to everything she enjoys! She loves to dance and act, and swims like a fish, coming home with yet another silver medal a few weeks ago.

She is great company and has a fantastic sense of humour.

Not only does she want to be an actress one day but she also wants to be a Youth Worker so that she can "help kids". I have no doubt that she will succeed at both!

*Julie Evans  
Fishguard*

## Sally's performances

Sally attends Derwen College and lives on campus with 4 other girls. She is studying Retail for half the week by working in the college farm shop.

The other half of the week she studies Creative Arts, with the performing art section being her favourite.

At the Christmas performance of Beauty and the Beast, Sally played the old crone who turns into the wicked fairy! She has a fantastic cackle of a laugh. We think she is being type cast though, as last year she played the Wicked Witch of the West!

Sally is also in the Makaton Choir which has performed at the World Skills exhibition at the NEC for the past 2 years. The choir interprets the songs and dances to them.

*Lauretta Edmondson  
Kenley*



*Sally in the Makaton Choir*

## Jamie's medals

Jamie was born in 2001 with a complex heart problem, but thanks to a brilliant surgeon, Victor Tsang and Dr Rees he has made a full recovery and his prognosis is excellent.



*Jamie in the competition*

Jamie attended mainstream primary school and left there last year. He now attends a special needs school who entered him in to the Jack Petchey Foundation awards. Although he isn't very keen on sports he did really well and came away with three medals which have pride of place in our living room.

We are so very proud of Jamie and all he has achieved in his 12 years.

*Jan Chatfield  
Long Ditton*

## Uncle Richard

This is Richard, he is 28 and lives in supported living about a mile from his parents in Cardiff. He enjoys getting out and about and leads a full and busy life.

He previously attended Derwen College as a residential student and when his course finished he decided he didn't want to go back to living with Mum and Dad as neither of his sisters had after finishing University.

Richard has had multiple surgeries for his heart and other issues but has pulled through each one extremely well. He recently became an uncle for the second time and adores his nieces almost as much as he loves his library of DVDs!

Richard is the son of our Chair, Chris and her inspiration for being involved with both Down's Heart Group and Children's Heart Federation.



*Richard with his sister's dog*

## The Patterson Family



*The youngest 4 siblings*

I first rang DHG 24 years ago to talk to Penny about a little baby we were adopting.

My baby girl had open heart surgery when she was 14 months old. I took her down to surgery, a beautiful happy healthy little girl, she had an ASD and a faulty mitral valve and we were told that it needed to be repaired ASAP or she would have irreversible lung damage. I remember taking her down as though it was yesterday. Six hours later I got to see her in ITU - a poorly, poorly little girl. I felt so guilty!

*I felt so guilty!*

We were discharged six days later with a very pink, energetic little bundle. She was amazing.

Alice is our 4th child and we went on to have another little girl, then promised ourselves that was it and we had now completed our family. But in October 2010 a friend told us about a little boy with Down's Syndrome, several holes in his heart, a PDA, pulmonary hypertension, chronic lung disease and was oxygen dependant. He was in foster care and they were struggling to find him a forever family.

He seemed to be so right for us, after a lot of talking and soul searching our family was made complete, when our little man came to live with us, with oxygen and all his medication. He fitted in as though he had always been there.

*It just goes to show how things have moved on for our children*

He had his PDA closed by cardiac catheter at Birmingham Children's Hospital. We had presumed he would need open heart surgery to fix his heart as it was so much more complex than Alice's had been all those years before. But no, he had his remaining holes closed by catheter also at Birmingham Children's. It was amazing! He was only down in theatre a couple of hours, (so different to Alice's 6 hours) and came bouncing back on the ward as though nothing had happened. He has gone from strength to strength since, he is amazing.

He is the icing on the cake for us and very definitely part of the family. It just goes to show how things have moved on for our children within the medical profession.

There's definitely no more children for us, much to the relief of my eldest two, as four siblings with Down's Syndrome is about as much as they can cope with! Ha ha

*Pam Patterson, Swadlincote*

## Holiday Time

*As the weather improves we tend to start planning a holiday or days out, but before YOU do, please consider signing up to Give As You Live first.*



Then whenever you book travel, accommodation or days out online, or even just buy some new garden furniture or a barbecue, DHG will receive a small commission each time you use a site that is in the scheme.

It is simple to do and as you enter a site to purchase anything, the "Give As You Live" box will pop open for you to use.

If you are going away, check out Just Travel Cover, a comparison site specialising in travel insurance for those with medical conditions. Once again, DHG will receive commission from any sales, whilst you get a good deal and peace of mind.



[www.justtravelcover.com/index.php?xyzid=76](http://www.justtravelcover.com/index.php?xyzid=76)

or call 0800 231 5532 quoting Down's Heart Group

## Save on Utility Bills

*With the rising cost of gas and electricity, it pays to compare deals from different suppliers and possibly save yourself some money.*



Why not try Ethical Switching, an impartial website comparing tariffs from all the energy companies, and you could be helping DHG too.

If you use the site, find a better deal and decide to change supplier using the simple process on their website, they will pay commission of £12 per utility to Down's Heart Group - so £24 if you change both your gas and electricity supplier.

Use this link and commission is automatically applied if you decide to change supplier.

[www.ethical-switching.co.uk/charity/1011413](http://www.ethical-switching.co.uk/charity/1011413)

## Christmas Card Competition

*It may only be the beginning of the summer but Down's Heart Group are launching their Christmas Card Competition for 2014!*

This year, entries are welcome from all young people, not just DHG members, so encourage schools, nurseries, Brownies and Cubs to enter, as well as siblings, cousins and friends.



### RULES

- Entries should be submitted on a sheet of A4 sized paper
- Name, age and contact address on the back in the top left-hand corner
- Please send entries unfolded in an A4 envelope marked 'Do Not Bend' and add some cardboard (cereal packet box will do) to prevent creasing
- More than one entry per child is acceptable
- Send entries to National Office (address on back cover)
- Closing date is 31st May 2014



Entries will be judged by the Executive Committee and the winner(s) - (two if there are two designs that work together) - will have their design(s) printed on DHG's 2014 Christmas cards. They will also receive a small prize.

*Good Luck!*

## Red Nightclub

*Red is a nightclub for people with learning disabilities and their friends, held every three months at Hull University..*



Red is at Armstrongs Bar, Hull University, Cottingham Road, Hull and the next event is on 20th June when the band Soul Patrol are playing. Events start at 7.30pm and finish at midnight. Tickets are £4 each, pay on the door. Over 18's only.

Red is a not for profit venture run by a dedicated team of volunteers.

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

## Activity Weekend

*Down's Heart Group will be sponsoring an activity weekend this summer for some of our members aged 16+. The date and location are still to be confirmed, but it will take place between June and October at an outdoor pursuits activity centre, with fully qualified staff.*

The weekend will be a great opportunity for youngsters to meet up with others with heart issues and we are planning to involve a number of young people who have heart problems but not Down's Syndrome, who will act as mentors.

They will all take part in a programme of activities geared to meet individual needs, all supervised by professionals with DHG trustees and volunteers providing extra support.

As well as the activities, there will be time for relaxation and to socialise with the other members of the group.

We appreciate that at least one parent/carer will need to accompany the members with Down's Syndrome to the venue, so we are arranging some separate activities for them too. They will spend the daytime away from their youngsters, during which time they will have the opportunity for respite, chat sessions, activities and possibly some pamper sessions or outdoor activities too, depending on availability.

In the evening, everyone will come together to share accounts of the day's activities and family members will share accommodation, which will be full board for 2 nights. (Friday/Saturday).

Places are limited and will be on a "first come, first served" basis, so to express an interest without commitment, please contact National Office as soon as possible.



The weekend promises to be great fun, where the youngsters can enjoy activities such as canoeing, archery and orienteering, whilst making new friends and gaining confidence.

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

**NOW!**



Swansea University  
Prifysgol Abertawe

My name is Angharad and I am a student

I would like to talk to people with learning disabilities who look after someone.

This is called mutual caring.

Mutual caring means when two people look after each other.

To help you decide if you want to help me, these are some of the things that mutual carers do:



Help with the shopping.



Help to get meals ready.

If you would like to help me with my research project .....



You can write to me at this address  
Miss Angharad Parr (PhD student)  
Room 114 Vivian Tower  
College of Human and Health Sciences  
Swansea University  
Singleton Park  
Swansea  
SA2 800



You can telephone me on this number  
01792 205678 x8699



You can email me at this address  
[522016@swansea.ac.uk](mailto:522016@swansea.ac.uk)



Thank you

## Transition To Adulthood

*How do parents make adjustments when they perceive that their child with a severe intellectual disability transitions into adulthood?*



The University of  
Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

My name is Sanchia Biswas and I am a Trainee Clinical Psychologist at the University of Nottingham. I am currently conducting a research project to understand how you view your son or daughter since they became an adult.

I also want to find out whether your lives changed when you saw your child become an adult, and if so, how you managed those changes. Gaining your views on this would hopefully provide valuable information to relevant services and other parents who may be going through similar experiences. This is an area that has received very little research so your views will be very important!

The study involves interviewing parents either face to face in Nottingham, Lincoln or West Yorkshire, via telephone or Skype for up to one hour to explore your views. All personal information will be kept confidential and anonymous.

The results of the study will be written up into a report that will be assessed by The University of Nottingham in November 2014 as part of the Trent Doctorate in Clinical Psychology. The results will also be presented to the department of Clinical Psychology at Institute of Work, Health and Organisations, University of Nottingham. The research will be submitted for publication in a journal.

If you choose to participate in this study, you will be entered into a prize draw for a chance to win one of three Amazon vouchers.

Please contact me to show your interest in the study. Your participation is voluntary and you are free to withdraw at any time, without giving any reason.

Work mobile number: 07702757250

Email address: [lwxsrbi@nottingham.ac.uk](mailto:lwxsrbi@nottingham.ac.uk)

Thank you

*Sanchia Biswas*

Can you help?

## Faints and Collapses

*A DHG Mum has recently contacted us about her teenager who is fainting or collapsing on a very regular basis. She is obviously extremely worried and is pushing really hard to get to the root of the problem as it is causing such distress.*

Several families have already responded to a request for anyone experiencing similar episodes, and whilst everyone's stories and symptoms are different, there are many similarities. The underlying theme is that everyone has been treated as if their youngster was the only person to go through this, whereas it does seem quite common. For our members the main worry is that these faints are cardiac related but it seems that very often whilst heart problems are ruled out, no actual cause is established.

We would like to hear from you if your young person has suffered from faints or collapses. There seems to be very little research into this, and families are feeling very isolated and frightened. Perhaps you would like to offer or receive support over this issue?

Please get in contact with Sarah at National Office [sarah@dhg.org.uk](mailto:sarah@dhg.org.uk)

## Mutual Caring

*Do you care for someone with a learning disability and does this person also care for you? Do you have a learning disability and care for your carer? If this is a situation you are in then I would like to involve you in my research.*

My name is Angharad Parr and I am doing some research at Swansea University. I would like to talk to two people who care for each other where at least one person has a learning disability and at least one person is above the age of 50. I want to know what it feels like to be a carer with a learning disability. I want to know what it is like to care for someone with a learning disability. I also want to know what it feels like to be cared for by someone else.



People are living longer so there may be more people caring than there used to be. It is important that we speak to carers to try and understand things that might be difficult for them and what we could do to make things better.

Please contact me if you would like to take part.

Email: [522016@swansea.ac.uk](mailto:522016@swansea.ac.uk) Tel: 01792 205678 extension 8699

## New Support Group



Cheshire has a fairly new support group for families with a member with Down's Syndrome. They are a really friendly bunch and the group has been growing steadily for the past year.

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

[admin@cdssgroup.org.uk](mailto:admin@cdssgroup.org.uk)

## Family Trust

*Having a valid Will in place is important because it is your expression of who gets your estate after you've gone. A Family Trust is a simple and straight forward way of protecting your money through future generations of your family.*



Placing your house and savings in a Family Trust means that, on your demise, your beneficiaries can borrow their inheritance out (in exchange for signing an IOU loan note) rather than have it outright. They can still spend it as you would expect, but on their deaths, the first thing their Will directs is to pay their debts back, which includes the loan note to the Family Trust. Their estate is therefore reduced so they are likely to pay less Inheritance Tax and the Trust is topped back up ready for the next line of beneficiaries to borrow.

The Family Trust has Trustees, typically yourself and two professionals, it is registered with HMRC and it will own your house and savings. Nothing can go wrong with the Trust and it can last your family up to 125 years.

A Trust does not incur probate costs or the waiting time that the probate procedure takes and will usually be self funding meaning the beneficiaries get more. The Trust will defer any distribution of assets, maintaining them 'in suspension', whereas Wills speak from the date of death, whatever the situation. This is useful if one of your children is going through divorce or bankruptcy, or is a disabled or dependent beneficiary.

*This article is reproduced from one written by Rob Abell of Will Planning Solutions ([www.willplanningsolutions.co.uk](http://www.willplanningsolutions.co.uk)) for information only. Down's Heart Group makes no recommendation as to the accuracy of the information and is not being paid any fee or commission.*

## Transition Help

The transition from childhood to adulthood is a crucial time for young people with learning disabilities. Securing the right support is key to making the process as painless as possible.



Netbuddy has a Transition Info pack full of useful resources, information and tips to help guide families through this important stage. It includes a step-by-step outline of the stages of transition, from age 11 to 14 through to adulthood. The Transition Info pack also includes a handy 'Transition Timeline' to download and print out; summarizing the main points families need to be aware of. There are also plenty of tips from other parents who are going through the process themselves.

[www.netbuddy.org.uk/info-packs/transition/](http://www.netbuddy.org.uk/info-packs/transition/)

## New Parent DVD

Downright Special is a charity supporting children with Down's Syndrome in Hull and the East Riding of Yorkshire. They have produced a fabulous DVD about coming to terms and understanding more about having a child with Down's Syndrome.

Clips on specific topics from the DVD which is called "*Great Expectations*", appear on the relevant pages on their website, it can be viewed on Vimeo at [vimeo.com/22816087](https://vimeo.com/22816087) or copies can be purchased for £5 from their website.

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



## Jointly App

Carers UK have launched a new mobile and online app designed by carers, for carers called Jointly. Key features include task lists, calendar and profile page.

Jointly is designed to make caring a little easier, less stressful and a lot more organised. Once you've invited others into your Jointly circle, co-ordinating tasks becomes as easy as sending a text message. Even if you don't share care you can use Jointly's care organisation tools to help you stay on top of things.



[tinyurl.com/jointly-app](http://tinyurl.com/jointly-app)

## Osteoporosis



A member contacted Down's Heart Group recently to discuss osteoporosis. Her daughter has just been diagnosed with the condition and her specialist suggested changing her diet and taking vitamin supplements. The young lady actually has a really good diet already and is also very active. She shows no obvious signs of having the condition and falls in the lower risk category for osteoporosis if lifestyle is considered.

This concerned mum would like to highlight the fact that people with Down's Syndrome are more likely than the general population to develop osteoporosis. This, coupled with the fact that due to thyroid issues and a tendency towards obesity, many of our young people are on fairly strict diets, means they may be missing out on the key foods that support bone density.

A recent article from Keogh Institute states: *"People with Down's Syndrome are more likely to develop osteoporosis, predisposing them to fractures. Women who are using contraception such as depoprovera for a long period of time are particularly at risk. As in the general population, weight bearing exercise and ensuring adequate calcium intake are useful for maintaining bone health."*

People with Down's Syndrome should also have their bone mineral density checked early in adulthood and women should have it checked again at menopause."

[tinyurl.com/DS-osteoporosis](http://tinyurl.com/DS-osteoporosis)

## National Patient Passport

After a lot of hard work by a dedicated team, Patient Passports are finally being presented to the Minister for Health. There has long been a need for a document that will accompany every person with a learning disability whenever they go for medical treatment, but whilst "passports" were being produced in parts of the UK, now after a huge effort, all the great ideas from each have been combined into one national document.

The Patient Passport holds all relevant information about the patient, from allergies to preferred name, which should make the whole experience of going into hospital less stressful for the patient, carers and medical staff.



## Own Fone



Own Fone sells a range of very simple mobile phones designed to meet customers needs. They have only a few buttons with either names or photos on, which you simply press to call and they can be personalised to make them as trendy as you like.

The phones are small so can be worn around the neck or popped in a pocket. And as they cannot be used to call any other numbers they are less attractive to thieves.

0800 669 6699

[info@myownfone.com](mailto:info@myownfone.com)

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

## Go Provence Supported Holidays

Go Provence is a British company providing supported holidays for children and adults with learning disabilities. Holidays include support during flights, full board in a country house and carefully planned activities for adults and children.

[ian@goprovence.co.uk](mailto:ian@goprovence.co.uk)

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



## Disability Grants



Disability Grants gives information on charities and trusts providing funding for a range of items and activities that can be used by a person with a disability.

The website is designed for you to search both local and national trusts and charities and explains what each one is likely to fund. Ipads, holidays, equipment or driving lessons are just a few examples.

[www.disability-grants.org](http://www.disability-grants.org)

## The Children and Families Act



*The Children and Families Bill became an Act and therefore law, on 14th March 2014. This Act has had more input from parents than any piece of law ever before. The reforms come into force in September. The SEN Code of Practice is the detail as to how the law is followed.*

By December 2017 all statements will have been changed and Learning Disability Assessments (LDAs) will have changed to Education, Health and Care Plans (EHCPs).

The Children and Families Act means Local Authorities will need to work closely with families to bring together a plan for future provision for education, health and care. They will need to establish strong partnerships across the three sectors to provide “*joint commissioning*” so that there are no gaps. They need to plan for providing information and independent support to families and determine which services could be provided through personal budgets. The suggested plan for a child will be called a “Local Offer” and should only be accepted by the family if they are completely happy with it.

Pilot schemes around the country have been promising but there is a lot of work to do between now and September to meet families needs. Local Parent Carer Forums or Parent Participation Groups may be able to give guidance.

[www.nnpcftemp/regions](http://www.nnpcftemp/regions)

## Housing and Support



*The Housing and Support Alliance runs a free, independent advice service for people with learning disabilities and families. They can advise on everything to do with housing, support and rights for people with learning disabilities.*

Topics they can offer advice on include:

supported living and supported housing  
family investment in housing  
funding for housing  
rights to housing and support  
tenancies and mental capacity

home ownership options,  
renting privately,  
support options  
welfare benefits  
extra care

[www.housingandsupport.org.uk](http://www.housingandsupport.org.uk)

0845 456 1497

## Hospital Hero

Congratulations to nurse Rowena Pearce, from the John Radcliffe Hospital who has dedicated most of her 30 years in the NHS to working with children with disabilities. She was the individual winner of the Oxfordshire Hospital Hero award having been nominated by three families, including DHG's Nina and Andy Lawson.



*Rowena with Andy and Nina Lawson  
(photo courtesy of Oxford Times)*

The award ceremony took place at Blenheim Palace and a very humble Rowena, said *"Nurses don't go around getting recognised. It's not something we aspire to."* She also explained how rewarding her job is and how inspiring she finds the families she works with. But if you were to ask the Lawson family, they would certainly say that Rowena is the inspiring one and an extremely helpful person to know.

## Member's Memoirs

DHG member, Uuganaa Ramsay from Scotland has launched her first book, *"Mongol"* which describes growing up in Mongolia before she came to the UK as a trainee teacher, the cultural differences she encountered and the birth of her third baby, Billy. Born with Down's Syndrome and heart problems, Billy only lived for 3 months. After his death in 2010, Uuganaa began a blog where she wrote to Billy about how she was feeling and this became the starting point for the book.



*Uuganaa reads from her book*

The book explores Uuganaa's early life, coming to the UK and her experiences surrounding Billy's birth, the difficulties in explaining his diagnosis to her parents and her reaction to learning of the alternative meanings of the word 'mongol' which she was only aware of as being a description of people who come from Mongolia. She now campaigns against the misuse of the term.

Uuganaa has had several articles published in different magazines, she was named the Creative Woman of the Year for Mongolians in Europe in 2012 and her book has won the Janetta Bowie Chalice Non-Fiction Book Award from the Scottish Association of Writers. The London launch of her book took place on March 25th and a special guest was actress Sarah Gordy.

# ZSL LONDON ZOO

Sat & Sun 17-18 May 2014

# ZSL WHIPSNADE ZOO

Sat 7 June 2014

## SPECIAL CHILDREN'S DAY

Special Children's Day is a unique event full of interactive and inclusive fun, with specialist facilities and staff on hand as well as discounted Zoo entry for the whole family!

ZSL Special Children's Day voted 'Best Education Project: Public and General Visitor' at BIAZA Annual Awards 2012.

*For more details please visit:  
[zsl.org/specialchildrensday](http://zsl.org/specialchildrensday)*



Children up to 18 years	£8.50 each
One Carer per family	FREE
Additional adults	£12.75 each
Children under 3 years	FREE

## Professor Ben Sacks



Professor Ben Sacks, former Chair in Developmental Psychiatry at the University of London and medical advisor to Down Syndrome Education, sadly passed away in February. He was an expert in health and development of children and adolescents with learning disabilities, especially those with Down's Syndrome and with autism spectrum disorders.

Ben had a very hands on approach to helping parents who were very grateful for the time he took at events such as the World Congress to meet with families and offer advice. He will be greatly missed.

Further information about Down's Syndrome is available from



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

0333 1212 300  
[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  
helping people realise their potential

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.thesf.org.uk](http://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](http://www.childrens-heart-fed.org.uk)



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

01709 761450  
[www.phassociation.uk.com](http://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



21st March saw the 9th anniversary of World Down Syndrome Day with events taking place across more than 50 countries to celebrate and raise awareness.

This year's theme was healthcare for all and as in previous years DSI released a reflective Global Video. *"Let Us In - I Want Access To Healthcare!"* it can be found at

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

The *"Positive Choices"* conference for Learning Disability Nurses took place on March 20/21 and all the delegates were asked to wear "Lots of Socks" for World Down Syndrome Day. DHG had a stand and as well as providing information, we were selling a range of goods, mainly cakes!



Penny Green also put together a montage to celebrate WDS Day, which can be found at

<http://ht.ly/uWdY>

*How did you celebrate and what plans do you have for 2015, the 10th Anniversary of World Down Syndrome Day? Why not let us know now.*

