



dhg

down's heart group

# Newsletter Spring 2015

Issue 53



***DHG Founder's  
daughter Luisa runs  
London Marathon in  
memory of the sister  
she never knew***

## Chair's Report

Welcome to this spring edition of the newsletter.

I have now retired from work and am looking forward to some free time, so far this has not happened! I hope that you all had a good Christmas and that the New Year is a good one for everyone.

Our conference will be held at Combe House Hotel in Holford, near Bridgwater, Somerset on Saturday 16th May 2015 as part of our Family Fun Weekend on 16th and 17th May. **Please see the announcement on Back Cover.**

The theme is "*Lifelong Learning*", with something for everyone, so I'm really hoping for a good turn out. Those who have attended in the past had good things to say about our conferences, so I look forward to seeing new faces, as well as old friends. Some of us will be looking to stand down in the next couple of years, so any "new blood" on the committee would be really appreciated.

Regards to all,

*Chris Stringfellow*

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## Congenital Heart Disease Review

*The NHS England consultation on Congenital Heart Disease closed on December 8th, it ran over three months and over 500 responses were received.*



These are now being analysed and the information will be used in conjunction with the other work that the CHD review has undertaken to report to the various (and numerous) departments and boards of the NHS that need to comment and sign off on the proposals before the final agreed configuration can move towards implementation.

Due to fitting with meeting schedules of the various bodies and the restrictions imposed by the General Election it is likely that the final decision will not be announced until the summer. This does not, however, mean that DHG's work inputting into the process has finished, as work continues in several areas around the proposed new standards.

This includes such things as looking at patient feedback, discussing ways to ensure that all views are collected and that monitoring is independent of individual units. There has also been discussion about the information currently available to patients and their families/carers, primarily via the NICOR/CCAD website. Ease of use of the site will be looked at as well as the option of presenting additional or alternative data that may be more help to parents.



As always it remains important that we hear feedback from families about their experiences at all stages of their journey in order to inform our input into the various processes. So if you feel there is anything you would like to bring to our attention (either good or bad) please get in touch.

You can call, write or email - all comments will remain confidential unless we ask for your permission to use them. We may, however, refer to them in relation to service provision provided it is possible to do so whilst maintaining your anonymity.

### AGM NOTIFICATION

The DHG 2015 AGM will take place at 10am on Saturday May 16th at the Conference (venue details on back cover.) Any nominations for the election of Trustees should be received on the official forms at National Office no later than 10am on May 14th. (Forms are available from National Office)

## Rebecca

*The following article was written by Rebecca. She is a very busy young woman and hopes to inspire a few of our readers!*

My name is Rebecca, I have a VSD, I am 32 and I live with my Mum. My Dad died six years ago. I have done lots of things.

I used to live in Holmfirth but now live in Bradford. I like to swim. I have been a Brownie, then a Guide and then I did my Duke of Edinburgh and got my gold.

I love canal boats and did a lot of Duke of Edinburgh work on the canal and in France for my gold award. I went to high school and later when we came to Bradford I went to Shipley College.



*We are proving them wrong!*

I love to dance and go to the Jewels cheer leading and I go to Unique Voices and we are doing a show called Bugsey Malone. I am a very busy person because I also belong to the choir called Sing from the Heart.

The doctors told my mum when I was born I would never do anything so take me home and love me, but, yes guys, we are proving them wrong!

I help at an allotment two hours a week and also work at the Co-op and get paid for three hours a week. Right, my big love is horses and I have ridden for 19 years. At the moment I am at Caring for Life in Leeds on a Monday and we have lots of horses there including some retired Police horses.

I do have a VSD. I have two holes and I am looked after by Dr Ballard at Leeds and Dr Sainsbury at Bradford. I am also visually impaired and have an under active thyroid but I have lots of fun with my mum and my brother and family live two doors away. My little dog is called Tilly.

My Mum says give it a go and you can do it if you try.

*Rebecca Robinson, Yorkshire*

## Alice

Alice is now 22 and I really do not know where those years have gone. She is our second daughter, born by emergency Caesarean at 38 weeks. Alice came home after five days, she was a sleepy baby and fed well.

A week later Alice had a scan to check her kidneys had developed properly. The doctor looked her over and sent her for an ECG. I wasn't too worried as my mother and brother have small murmurs on their hearts.

Dr Scott came in with a nurse. First they told us Alice had a heart condition and needed an echo. I was in tears. Then they asked if I had heard of Down's Syndrome, which I had, and said they would do a blood test as they thought Alice also had this condition. What a shock that was! I was 24 and had never met anyone with Down's Syndrome. We had to wait another five days for the positive result.

At five weeks old, Alice spent New Year's Day in hospital as she was going in to heart failure. We saw the team from Guys in February 1993 who said Alice needed surgery as soon as possible as she had an AVSD. Alice had her open heart surgery in March. She was extremely slow to recover and was in intensive care for nine weeks. It was touch and go a couple of times. I never thought she would come home with us again.

*It was touch and go a couple of times!*

I stayed in the nearby Ronald McDonald House and Tim was able to bring our other daughter to London at the weekends as he had to return to work after two weeks.

Eventually Alice was helped off the respirator by way of a negative pressure ventilator lent to Guys by King's College Hospital. At last we were able to take Alice home at the beginning of June.

Alice is very mentally and physically disabled. She has other medical conditions which are diabetes type 1, hypothyroidism, coeliac disease and scoliosis, she has spinal rods fitted.

We are now preparing for Alice to go and live with three friends, who she attends day care with. They will have an adapted bungalow with full time care. We will miss her so much at home but it will be good to know that she has a lovely place to live. We won't be too far away and Alice will still come home for visits.

Alice is a happy girl who loves people and cuddles!

*Rachel Kent, Suffolk*



## Teddy

I discovered our boy was on his way on Christmas Eve 2013. I didn't really get excited, as I had already lost six babies in the first trimester. We had our 12 week scan, NT test and bloods, followed days later by a call telling us we had a 1-10 chance of Edward's Syndrome and 1-5 chance of Down's Syndrome.



*Teddy and Daddy*

We had further testing at Addenbrookes Hospital and saw Teddy in 3D on the scan. We were quite pleased when only Down's Syndrome was confirmed and said again we would be continuing the pregnancy. That week I was asked no less than 11 times by medical professionals about termination!

### *We were expected to lose our baby*

At our 20 week scan we discovered Teddy had an absent Ductus Venosus, which restricts blood flow to the baby, He also had cardiomyopathy, and pericardial effusion. These problems in unborn babies are rare but survival is virtually unheard of. They also discovered his duodenal atresia, which is where the stomach isn't joined, him having this also gave me polyhydramnios, which is excess amniotic fluid, This eventually put me in a wheelchair.

We were expected to lose our baby. I went into premature labour at 24 and 28 weeks, and had to have medication to stop it. We went for a scan with the heart consultant and another specialist, and they were astounded! They measured, re measured and measured again! Teddy's heart had sorted itself out! It was normal size! No fluid! I spent two months before Teddy arrived in Addenbrookes due to the risk of early labour, my previous history and the polyhydramnios. My waters were increasing and I couldn't walk or even turn in bed due to Symphysis Pubis Dysfunction and a twisted spine.

At 35 weeks I hadn't felt Teddy move quite as much. Teddy was in trouble, the placenta was not working. I needed to be induced that day or he would die! I phoned Stuart, who did an amazing job organising the kids and getting to the hospital so fast. I wouldn't let them begin as I didn't want him to miss the birth. I was also very scared. Teddy was born and whisked into the incubator for help with his breathing. I managed a quick cuddle before he was rushed off to NICU to have tubes and canulas put in.

### *Teddy came home for six days and then things went wrong again!*

Teddy had a heart scan and it showed a PDA and a large ASD. He had his first surgery to fix his duodenal atresia at four days old, then made his way through NICU and eventually was transferred to Ipswich SCBU, He was there nine days whilst we worked hard to get feeding established as he only started oral feeds at 21 days old.

Teddy came home for six days and then things went wrong again! He stopped feeding and a twisted bowel was suspected so he was transferred to Addenbrookes that night, the idea was to starve him for 48 hours as this can rectify the problem. Stuart and I were sent home only to be called at 2.30 am as Teddy needed help with his breathing and had been moved next door - we had no idea that next door was PICU and the help he needed was a ventilator! At 6.30 am we had another call asking permission to operate as Teddy's bowel had ruptured.

Teddy was too poorly for the whole procedure to be done and had a stoma fitted. Exactly a week later the wound totally collapsed and his insides fell out whilst I was with him. He was rushed into surgery for the third time on life support.



*Teddy and friend*

*Our boy is a pure fighter!*

Teddy's scar was repaired and his stoma moved. A few weeks later we started to get excited as he was allowed off the ward for a short while and I was able to give him his first ever bath. There was talk of getting a plan together to get him home.

The next morning Teddy went into respiratory arrest, he was back on life support, his airway had closed up. We were told he would probably need more surgery, a cricoid split, or even worse a tracheostomy. I felt a part of me die, such sadness for this poor little boy, who's done nothing but fight for life since conception, when was he going to get a break? But again, our "Super Ted" managed to sort himself out and no surgery was needed.



*The Farr family*

After weeks in Ipswich hospital and only a few days at home, Teddy is getting stronger. He is due to have his stoma reversed after Christmas, as bronchiolitis and croup have delayed things.

We have had so much to learn but believe me, if you ever have the privilege of meeting our Super Ted, you'll understand why we love him so much, why we have fought for him, and why we're so proud of him. Our boy is a pure fighter!

*Penny Farr, Ipswich*

## James

James is now 14. When he was born we were told that we would have to go to Harefield Hospital for a check of his heart, the appointment was booked for six weeks. In those next six weeks we took James to our local accident and emergency department numerous times as he kept stopping breathing at different times.



*Aged 5 on the trampoline*

At the check they found high pressure in his heart and booked an appointment for early January to have further tests to see what was going on. On Boxing Day James had another episode of not breathing, we took him to our local A and E department. This time they checked his blood before putting him on oxygen and found his blood was blue, that was the problem, not enough oxygen.

When he had his check at Harefield, I had to put my two month old baby on a full size operating table and walk out, leaving him with these people, it was awful. The nurses told me that sometimes babies have a bleed out after having a large needle put in their small veins. James bled out after leaving theatre and was rushed into another room, where all the children were recovering from open heart surgery, and given a blood transfusion.

### *They didn't expect him to last a year*

This was the day we were told he had Pulmonary Valve Stenosis, they couldn't operate and there was no point giving him medication. We were sent home with oxygen for life!

Amazingly after six months of oxygen, James came off it and we had no more incidents. We still visit hospital because James has asthma. He also goes for his regular check ups and appointments with the paediatrician etc,

Friends and family didn't expect him to last a year, yet here we are now 14 years down the line, not a easy ride! Although it's worth being woken at 2.45am in the morning to be told *"It's my birthday, I'm a man!"*

*Caroline Hoy, Cambridgeshire*



*James, aged 10 on skates*



Happy New Year!  
We hope you all had lots of fun at  
Christmas.



Conference and Family Weekend  
DHG is meeting on 16th May.  
There will be fun activities.



In the evening there is a disco.  
There is also a meal.  
Would you like to come?  
[See back page for more information.](#)



Portraits  
Do you have a good photo of you?  
Would you like it to be in a big display?  
[See page 17 for what to do.](#)

## Coastal Cycle Ride



*Paige, Daisy and Glen*

I accompanied my daughter Daisy and her friend Paige Harbottle, both 15 years old, when they cycled 110 miles to raise £368.00. They originally heard of DHG through a friend of a friend and decided to give the money to donate to them after researching the website and thinking it was a worthwhile charity.

The cycle ride started in Whitley Bay, Tyne and Wear, on the 27th October 2014 and followed the coastal route north up to Seahouses in Northumberland, approximately 55 miles away.

We stayed over night in Seahouses and returned the same route the next day. The weather over the two days was very windy with day two raining for the last 30 miles. Having said that we all enjoyed the challenge over two days.

*Glen Mason, Tyne and Wear*

## Christmas Cards

Thank you to everyone who supported DHG by buying some of our Christmas Cards and to those who rounded their payment up to include donations of various sizes.



The design competition results will be in the next newsletter, so we look forward to offering a brand new design for Christmas 2015.

## £500 Donation from Wayfair



At the end of the year, member Rachel Evans got an email telling her she had won the Wayfair Christmas Competition and her nominated charity (DHG) would receive £500. She thought it might be a scam and contacted us to check and we were delighted to confirm we had also had an email saying DHG was the lucky winner.

Thanks Rachel, what a great way to start 2015!

## Raffle

Alan Wilcox, along with Jude and Karen of Knighton and Clarendon Park Conservative Club in Leicester, held a midweek raffle and raised £145. Alan is grandad to Down's Heart Group members Katie and Tom Warner so they decided to donate the proceeds to DHG.



## Elliott's Triathlon

My name is Elliott Wood, I am 29 years old and I am a Primary School Teacher at a school in Bath. I have a wonderfully understanding wife and a beautiful baby boy called William.

I got involved with Down's Heart Group as they have been supporting some good friends of mine who have recently had a beautiful girl with Down's Syndrome. I think you'll agree that DHG is a wonderful charity and because of this, I have set myself a sponsorship challenge to aid their supportive endeavours.



*Elliott and William*

I have entered my first ever Ironman distance triathlon, The Outlaw Triathlon, which takes place in Nottingham on Sunday 26th July, 2015 and involves a 2.6 mile open water swim, 112 mile cycle ride and a 26.2 mile run.

I am hoping to raise £10,000 to share between DHG and my school and I have made a good start towards achieving this figure. I have the full support of my family, friends and colleagues and they have been providing me with lots of useful tips, but if anyone has any others please get in contact with me via DHG.

My training is going well and I am increasing my running distance. I have also been spending a lot more time in the water as the cold weather has affected the frequency of my cycling. I think my wife is very appreciative of this! The break over Christmas has really helped me focus on the challenge I face over the coming months.

Thank you very much for your support and if you feel that you would like to help with my sponsorship effort, please visit my Virgin Money Giving page. Any contribution is appreciated!

[virginmoneygiving.com/ewood101](http://virginmoneygiving.com/ewood101)

*Elliott Wood, Bath*

## London Marathon 2015

*DHG has seven runners in the London Marathon on Sunday 26th April. You can show your support for their efforts by making a donation via the DHG website either individually or as a team - any amount is greatly appreciated.*

*We wish them well in their training and will be cheering them on in April.*

### Luisa Walsh

My Mum Linda, with me in the photo, is the founder of DHG, so I have always had a close interest in the charity and its work. I'm running in memory of my sister Katy (pictured on front cover)

I have run for DHG before in the Cardiff Half Marathon and it's great to hear there are a few of us running for the charity as we can hopefully support each other.



### Josephine Williams

I am running the London Marathon for the Down's Heart Group as my lovely 6 month old niece, Mali, was born with a VSD. She is growing beautifully and enjoying solids thanks to the hard work and persistence of her mother!

My brother and sister-in-law have found the DHG website to be a fantastic source of information.

### Gary King

I will hopefully complete an ambition that has been itching away at me for over 15 years! I have worked and participated in sports, mainly football, judo and badminton. Various injuries and the thought of running 26.2 miles has always put me off a marathon but training with friends recently has spurred me on.

My friend Louise has a brother called Richard who has Down's Syndrome and it is a pleasure and an honour to be running for DHG.





### Rose Jenkins

I am currently studying medicine at Nottingham University. I am an avid runner and so far enjoying the challenge of training for a marathon! I have previously taken part in a 'Tough Mudder' event and was keen to support another charity for this next effort.

I chose DHG after hearing about it's important work from Penny Green at a conference run by the Down Syndrome Medical Interest Group back in June. I feel very privileged to represent and support a charity that so clearly has a very significant impact upon individuals' lives.

### Chris Deas

Chris ran for DHG last year and had put so much effort into his training that he was devastated when he had to pull out at about 15 miles as he was taken ill, so he really wants to achieve his goal this year. He'll be running again in memory of Tom Pow and looking forward to crossing the finish line and celebrating with members of Tom's family who have been supporters of the charity for many years.

### Suzanne Adams

By four months old, my middle child, Jamie, had been through two major heart operations. The first two years of Jamie's life presented a huge challenge for us.

Down's Heart Group enabled us to join a family weekend where we met other families just like us. DHG helped us to see the light at the end of the tunnel.

Now Jamie is like a different child. He has two yearly heart checkups, he is strong, able and a very happy little boy. He still has severe communication difficulties, but with support from DHG we can look to the future with confidence.

### Ellen Robertson

I jumped at the chance of running for DHG because I know it's a charity close to Suzanne's heart. I sometimes get to work with Jamie in school and he likes to play with my daughter Isla. It's great to see him doing so well now.

We have had a cake sale to raise money and have a couple of big fundraising events coming up very soon. We have been asking local businesses for sponsorship and raffle prizes, too.



*Suzanne and Ellen*

## Sarah Smith - Information Officer

**Why did you get involved with DHG?** Our eldest, Emily, had an AVSD repaired at 16 months. I attended the first DHG AGM and decided to “*give something back*”. That was 23 years ago!



**What made you volunteer to help?** DHG were there for us, even though we were a bit shy about using them. I was at home with Emily and felt I had a little spare time to offer.

**Occupation?** I have been DHG's Information Officer for 10 years now, working 18hrs per week.

**What do you think you bring to the role?** Hopefully I'm a friendly voice at the end of the phone.

**Hobbies?** Horse riding and I compete in dressage. Both girls usually beat me! I teach RDA and volunteer for Special Olympics East Midlands Equine team.

**Family?** Chris and I celebrated our 25th wedding anniversary this year. We have 2 daughters, Emily, who will be 25 in April and Grace, who is 22. Both Grace and my Mum, Linda, have been on the DHG committee in the past.

**Pets?** 3 naughty horses, 1 very energetic mongrel, 1 possessed rescue cat, 5 friendly rescue chickens and about 20 tropical fish.

**Age?** I spent the last year believing I was 47, when in fact I'm only 46!

**What do you see for the future of DHG?** I'd love for DHG to have enough funds to implement all the great ideas the committee have had and for us to reach every family who we could help.

**Favourite cake?** Absolutely any! But pavlova is probably the best.

**Embarrassing moment?** Too many! Thankfully, I don't take myself too seriously. Being on tv with ink leaking all down my skirt, standing in the ring at Windsor Show whilst the horse I was holding chewed through his reins so I had to run out to find some more - just hope the Queen wasn't watching!

**Claim to fame?** I was once on “*Stopwatch*” with our school hovercraft with Peter Purves and Daley Thompson.

## Roberta Nathan - Committee Member

**Why did you get involved with DHG?** In 1993 we had Elana who had a rare and complex heart condition and a range of health issues. Despite being extremely fragile, we were fortunate to have her for nearly three years until she passed away in October 1996. During this time DHG offered support that was invaluable to us as a family, especially an opportunity to talk to Penny, who as a bereaved parent was particularly honest and supportive.

**What made you volunteer to help?** I always wanted to be more involved so when our son left for University in 2008 it was the right time and I felt genuinely welcomed onto DHG's committee.

**Occupation?** I am a quality assurance and continuous improvement specialist at The Open University.

**What do you think you bring to the role?** Business experience - working with committees, audit/quality assurance, research and management experience.



**Hobbies?** Any spare time will find me curled up with the latest Joanna Trollope or Scandinavian novel. I enjoy cooking and fair weather gardening only.

**Family?** We're a close knit bunch with family across the world and so we'll often be found Skyping/texting to keep up on the latest family happenings,

**Pets?** Sadly our aged and sobby King Charles Spaniel Daisy is with us no longer. After having her for nearly 13 years we've not felt able to replace her.

**Age?** I'm not age sensitive although I hope I'm a young 53.

**What do you see for the future of DHG?** I'd like to see the charity extend its range of support and expertise over time, we are a small but well-formed team at the moment with very committed board members but we are always open to suggestions and offers!

**Favourite cake?** I've food intolerances which mean I'm a cake free zone.

**Embarrassing moment?** I'd rather not say! No I haven't one I can draw on really... haven't we all done something silly at one time or another?

**Claim to fame?** Not sure I have one of those either, I'm a closet sketcher/poet, always wanted to be a writer and had some success with poetry being locally published when I was a teenager, I tend to sketch/jot away if time allows when on holiday – one for retirement... I keep promising myself.

## Introduction To Autism Spectrum Conditions



Learning Disability Wales  
Anabledd Dysgu Cymru

This Learning Disability Wales workshop will help participants recognise the main characteristics of behaviour for children and young people on the autism spectrum, understand the range of the spectrum and the need to backup spoken language.

Practical and theoretical principles will be explored with opportunities for discussion and questions.

It takes place on Thursday 12th February 2015 in Swansea and is open to parents and practitioners. The course fee is £51 for parents.

Book online or for more information contact Inacia Rodrigues

[tinyurl.com/ldwcourse](http://tinyurl.com/ldwcourse)

0292 068 1174

## World Down Syndrome Day

March 21st marks the 10th anniversary of World Down Syndrome Day, providing the opportunity to raise awareness across the globe.



Preliminary plans include the 4th World Down Syndrome Day Conference 'My Opportunities, My Choices' – Enjoying Full and Equal Rights and the Role of Families to be held at the United Nations Headquarters on Friday 20 March 2015.



DSi is again asking people to support the 'Lots of Socks' campaign and they have merchandise for sale featuring the new logo.

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

Everyone is invited to hold an event to raise funds and awareness and split the proceeds between DHG, local groups and DSI. There is also a World Down Syndrome Day Facebook group fundraiser in support of the DSI Outreach Programme, which aims to raise awareness and equality across the world regarding Down's Syndrome.

Find out more here [tinyurl.com/WSDonFB](http://tinyurl.com/WSDonFB)

Let us know how you celebrate WSD 2015 and send us your photos.

## Big Picture 2015

### PORTRAIT21

In 2015, DS the BIG Picture will be creating 21 portraits that will be released, three each day for seven days, to raise awareness of Down's Syndrome by creating a message that people want to see and understand,

The style and content of the portraits will remain a secret for now, but the organisers are asking for nominations of people with Down' Syndrome for the campaign. Send an email including name, age, likes, inspirational person (sports, actor, relative or super hero), country, county, postcode and of course the photo to:

[portrait21@dsthebigpicture.com](mailto:portrait21@dsthebigpicture.com)

## The Gauntlet Games

*Would you and perhaps a team of friends like to experience a game show type obstacle course whilst raising funds for Down's Heart Group?*

The Gauntlet Games at Woodhall Park, situated between Hertford and Stevenage, takes place in 2015 on two Saturdays, the 18th April and 5th September.

It is called a race, but the emphasis is on having fun and catching your breath whilst waiting your turn on the Gladiator style events, where you may be challenged by a gladiator wielding an inflatable weapon. Other obstacles include muddy bogs, dodging paint balls, giant slides or balancing on beams.



Achievable for most fitness levels with 5km or 10km options, entry fees start at £29.

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

## 12th World Down Syndrome Congress



WDSC 2015 takes place 19th - 21st August in Chennai, India, with the theme "5 Truths" - Social Awareness and Self Determination, Health, Education and Employment, Support Systems and Rights and the Law..

For those unable to attend in person, web seminars will be accessible and papers will be available from the website.

[www.ds-int.org/wdsc-2015](http://www.ds-int.org/wdsc-2015)

## Finding Work



Richmond Works is a free service to help adults with special needs find and stay in work. Clients will get help with building confidence, writing CVs, training and skills, applying for jobs, practice for interviews and support in the workplace.

In this project Remploy is working with Twining Enterprise and Richmond Council and the service is aimed at those living in the Richmond area, but Remploy run similar schemes across the country.

0300 456 8102  
[www.remploy.co.uk](http://www.remploy.co.uk)

## IPSEA

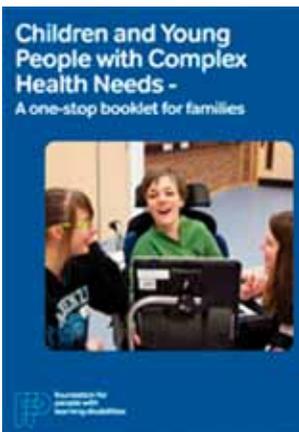
Independent Parental Special Education Advice - IPSEA offers free and independent legally based information, advice and support to help get the right education for children and young people with special educational needs.

Resources to empower parents and carers are available, free of charge, on the IPSEA website.



[www.ipsea.org.uk](http://www.ipsea.org.uk) 0800 018 4016

## Complex Health Needs



Children and Young People with Complex Health Needs - A one-stop booklet for families. This is one of many publications available from the FPLD. It gives information to help improve the lives of children and young people who have complex health needs.

This booklet explains what is available to make the home more comfortable and how it can be adapted to a child's needs as they grow up. There is also information on planning for transitions in a child's life and parents rights.

[tinyurl.com/fpldcomplexhealth](http://tinyurl.com/fpldcomplexhealth)

## Learning Disability Alliance



Learning  
Disability  
Alliance  
England

The Campaign for a Fair Society together with National Forum for People with Learning Disabilities, Association for Real Change, National Valuing Family Forum and Housing & Support Alliance, has a new initiative called Learning Disability Alliance (LDA).

It is a membership organisation for individuals, groups and organisations who want to ensure people with learning disabilities are heard and aims to make social care and support for disabled people high on everyone's agenda. Information on joining is here:

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

0114 321 6166

## Out And About

The Foundation For People With Learning Disabilities has produced a really useful new booklet on staying safe whilst out. It is easy to read and has many tips for confidence and safety for both people with learning disabilities and those who help them stay out of danger.

FPLD produce a wide range of literature and booklets on various topics pertinent to our young people. They are all written in an easy read format. Staying Safe can be downloaded for free from the FPLD website

[www.fpld.org.uk/publications/safeoutandabout](http://www.fpld.org.uk/publications/safeoutandabout)



## Duty of Candour



Duty Of Candour is a new law that came into force on 27th November 2014 which places a legal duty on hospital, community and mental health trusts to inform and apologise to patients if there have been mistakes in their care that have led to significant harm.

This new law aims to improve patient safety and provide more transparency within the NHS. It forms part of a wider package of measures following on from the Francis Report into the Mid Staffordshire NHS Trust.

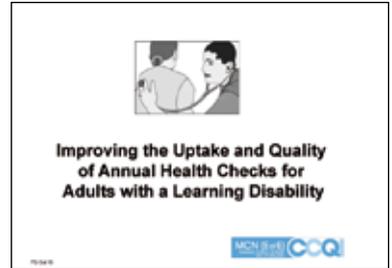
[tinyurl.com/nhsnewsafecandour](http://tinyurl.com/nhsnewsafecandour)

## Annual Health Check Study

*A recent study published in the Lancet shows the annual health check scheme for people with learning disabilities makes a difference and could help reduce health inequalities.*

GPs signed up to the scheme are more likely to offer patients with learning disabilities basic health assessments such as blood pressure, weight, hearing and vision checks, medication reviews and blood tests and are also more likely to pick up previously undiagnosed problems such as thyroid disturbances and obesity.

However, almost 40% of individuals with Down's Syndrome were not offered the checks even if their GP practice is part of the scheme because they are not on the learning disability register, which simply means they have the wrong code allocated to their notes. If someone you know has not had an annual health check, you could contact their GP practice to ensure they have the correct details on record.



[tinyurl.com/GPhealthcheck](http://tinyurl.com/GPhealthcheck)

## Sibling Study

*Are you over 18?*

*Have you grown up with a sibling with Down's Syndrome?*

*Would you be interested in sharing your experiences as part of a research study?*



*The Brown siblings*

The role and perspective of siblings is often overlooked in research and it is therefore important to find out more about your experiences. As part of my third year undergraduate Psychology degree dissertation, I am interested in learning more about what it is like to have a sibling with Down's Syndrome.

The study will involve an interview lasting around an hour in which you will be asked to share your own experiences of having a sibling with Down's Syndrome.

If you are interested in taking part or would like more information please get in touch at

[m013795b@student.staffs.ac.uk](mailto:m013795b@student.staffs.ac.uk)

Thanks, I look forward to hearing from you.

*Kizzy Moss*

## National Family Carer Network



By linking organisations supporting carers or developing best practice guidelines, The National Family Carer Network (NFCN) helps family carers of adults with learning disabilities be heard and voice their opinions.

NFCN also produce newsletters, giving information on national developments and offers regular events to enable individual family carers and groups to get together to discuss ideas and policy issues.

[info@familycarers.org.uk](mailto:info@familycarers.org.uk) 07747 460727

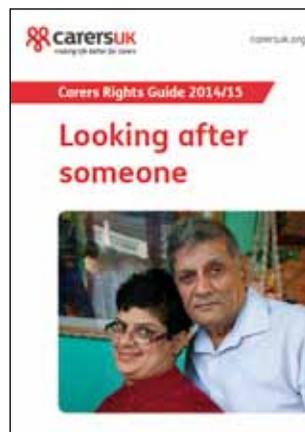
## Carers Rights Guide

Each year Carers UK produce the Carers Rights Guide outlining carers' essential rights and signposting what financial and practical help is available. There are four versions available for England, Wales, Scotland and Northern Ireland.

Each guide covers benefits, technology, workplace rights and financial, practical and other help. The version for England also includes a section on the Care Act 2014, and what it means for carers.

You can order a printed copy or download a free version by visiting the website or calling the shop.

[www.shopcarersuk.org](http://www.shopcarersuk.org) 01933 221 781



## Please Press 1



Please Press 1 is a website designed to help you save time and money on phone calls to call centres and lines with menu options. Using Please Press 1 could save you on average 3.5 minutes per call and at 10p per minute, the savings soon add up!

Simply enter the phone number you will be using into the website's search and it will tell you how to get the department you need directly. Then when you dial the required number you can press ahead as each menu starts.

[www.pleasepress1.com/uk](http://www.pleasepress1.com/uk)

## Tom's Tennis

*DHG member Tom has weekly group tennis lessons at his local tennis club. His coach suggested he might like to attend the Lawn Tennis Association (LTA) training camps. Tom attended two regional learning disability development camps in 2014 and the 11th National Learning Disability event in Nottingham.*



The LTA subsidises the coaching and there are training camps and clubs around the country. In 2015 there will be six regional development camps in Leeds, Swindon, Glasgow, Coventry, Wrexham and Neath and five regional series tournaments. The link below will take you to the learning disability training camp section of the LTA.

<http://tinyurl.com/LDtennis>

This is what Tom has to say about this exciting sport:

It is great fun to play tennis, singles and doubles; it's good for teamwork. Also you can communicate with people with learning difficulties.

You get put in groups and you get on well with the other people in the group. You listen to the instructors and pay attention and concentrate properly; for example they ask you to do warm up activities, ball games like pass the ball between your legs and over your head. The other game we do, we have lots of cones in the middle and baseline, put the ball on the cone and run back, and put the ball in the middle and go again.

You get very enthusiastic about tennis. They've got a running ladder, they show you how to do different steps, for example, two feet apart, then middle again.

They provide lunch and a drink and a hotel near the tennis centre; you pay for dinner. The tennis lasts a couple of days.

We practised serving. Tennis is about concentrating well as a team and not making mistakes for example making double faults. I like to do tennis because it's good fun to play.

*Tom Sewell, Devon*



*Tom with Lesley Whitehead,  
Tournament Director/coach*

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  
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)



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  
Unit 3.37, Whitechapel Technology Centre  
75 Whitechapel Rd, London E1 1DU

0808 808 5000  
[www.chfed.org.uk](http://www.chfed.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

## ***'Lifelong Learning' Conference and Family Weekend***



**16th and 17th May 2015**

Combe House Hotel, Holford, Bridgwater, Somerset

Join us at this wonderful old hotel in beautiful surroundings. Come for all or just part of the weekend, but don't miss out on the fun, put the dates in your diary now!



**Conference and AGM on Saturday  
with crèche and activity workshops for the  
youngsters**

**Dinner and disco on Saturday evening**

**Family day on Sunday**

**Register your interest with no obligation - email or call us NOW!  
we will then forward further information including the programme and costs**