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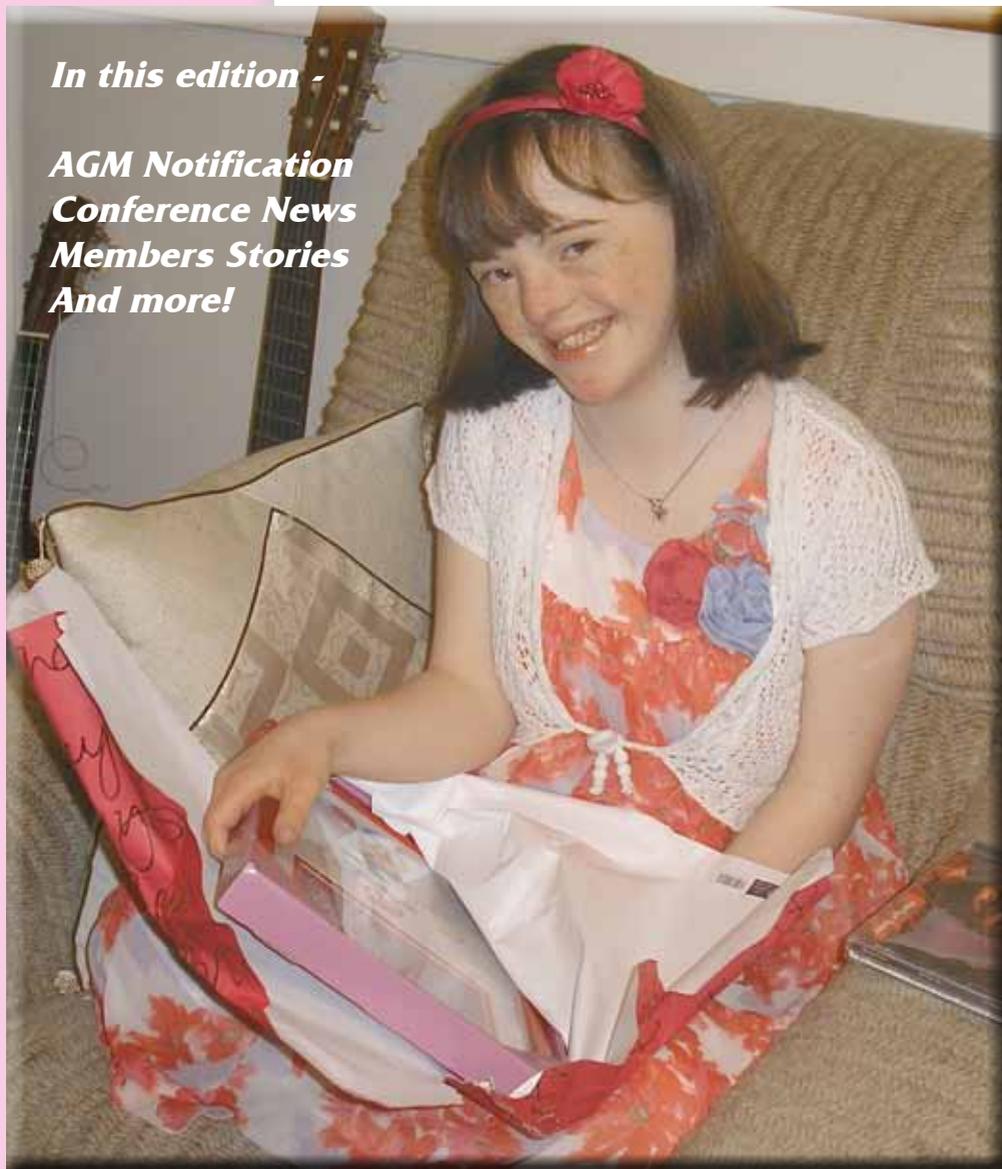
down's heart group

# Newsletter Summer 2015

Issue 54

*In this edition -*

***AGM Notification  
Conference News  
Members Stories  
And more!***



## Chair's Report

This is our summer edition of the newsletter and includes details of our AGM and conference that is taking place in Somerset in May. These weekends always turn out to be a lot of fun for both adults and children alike. We always have a disco and even those with wheelchairs end up on the dance floor!

I'm hoping that we will see a lot of new faces at the conference and that some will also consider becoming new faces on our committee. It would be great to have more representation from some parents of our younger members, especially as Nina Lawson will be stepping down as Secretary this year. The Trustees/Committee only meet about four times a year and a lot of our communication is now via email.

I plan to step down next year but we do have a chair elect for then, Helen Laverty, who will be standing for chair in 2016. She is Professional Lead for Learning Disability Nursing at the University of Nottingham, bringing with her a wealth of experience in the learning disability field and an ability for us to see those who are actually looking after our children, young adults and adults in the real world. See page 7 for more about Helen.

I am really looking forward to seeing as many people as possible at the conference weekend so please try to come along.

*Chris Stringfellow*

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## Annual General Meeting 2015

Down's Heart Group's AGM for 2015 will take place at the start of our conference

10am on Saturday 16th May at  
Combe House Hotel, Holford, Bridgwater, Somerset TA5 1RZ

All members are welcome to attend but must notify National Office beforehand.

Forms are available for nominations for the election of Trustees. These must be returned and arrive in the office by 10am on 14th May.

If you would like to stand as a Trustee please call for an informal chat about what the role entails. We look forward to welcoming you!



## Donations For Membership



Given the ever rising cost of postage, after a lot of debate and consideration the Trustees have agreed to ask members to help reduce the financial strain printing and posting the newsletter places on the charity in one of two ways.

For those who have access to the internet, each issue is available to read online or download. When you register for online newsletters we send you an email each time a new issue is published with a direct link for you to access it.

Anyone who does not have internet access or prefers to continue to receive the newsletter in paper format is asked to consider making an annual donation to help towards the cost. Currently newsletter printing and postage costs the charity about £6,000 annually, so we are suggesting a donation of £10, which if you are a UK tax payer can be Gift Aided to increase it's value.

Your support in one of these ways will help ensure that our services continue to be available to everyone who requires them, whatever and whenever their need.

Please contact us, either to transfer to online newsletters or for details of how to make an annual donation and Gift Aid it.

*THANK YOU*

## Esther



Esther was born with multiple congenital heart conditions and Down's Syndrome and could not receive corrective heart surgery. She lived every moment to the full and managed to reach eighteen years and four months, when her heart eventually stopped whilst she was dancing in her princess dress in front of the mirror.

We resuscitated Esther and she lived on for four days in Intensive Care, which gave us and all her family and friends time to say good bye, before she went into the loving arms of our Lord Jesus.

Esther had understood that her life would be shortened due to her poorly heart, but she was not frightened to die. Her faith in God was so strong. Over the years, she built a real love for Jesus, which gave her such joy. She was able to comprehend the wonderful idea that she could live with Him for ever in heaven. This is such a comfort for all of us, as we dearly miss her.

We are now so glad and thankful for all the people that enriched her life. The fantastic high school she attended, where she had endeared so many teachers and students with her loving, stubborn and mischievous ways. Her memorial service was full of very funny stories, so that we were laughing and crying at the same time.

We have a dear friend who is a Nutritional Consultant, who gave us wonderful advice about how to built up her weak immune system, to prevent getting pneumonia to which she was prone. This improved her quality of life.

Esther was presented to the obstetric students and made quite an impact on them, convincing them that her life was worth living.

We are so grateful for the eighteen years we were allowed to enjoy our precious Esther.

*Mike, Andrea and Lydia Coleman,  
Leeds*



## Danny



Danny was born on 1st May 1969, before cardiac surgery was routine for children. He has a complete AVSD and Eisenmenger Complex and has been on Sildenafil for two years. This medication has enhanced the quality of his life but won't prolong it.

Danny loves life and lives it to the max! He could swim before he could walk aged two and still goes swimming every week. He also goes ten pin bowling weekly and plays a good game of pool. Dan's darts team won the league, but he can no longer play as the pub doesn't have a team anymore. He loves all sports, including horse riding but his passion is Liverpool FC.

*Sildenafil has enhanced the quality of his life*

Danny manages to do all these things despite his Eisenmenger's. The consultant calls him a "walking miracle" and often asks Dan if medical students can meet him. Danny has had lots of admissions to hospital with chest infections but, thankfully, keeps bouncing back!

At the local shopping centre everyone knows Danny and he takes ages chatting with everyone. On Wednesdays he goes to Jenny's restaurant, where he sits and sorts the cutlery and napkins for a short time. The staff adore him and when Danny was in hospital they all came to visit him every night.

*The consultant calls him a "walking miracle"*

Over the years Danny has created himself a role at Tesco and now helps out whilst his mum does the weekly shop. Due to his health limitations he could never have a job and whether he is at Jenny's or Tesco everyone knows to call an ambulance and then his mum, who is only ever a few minutes away if he starts to go blue or have a funny turn. But for Dan this "work" gives him a lot of satisfaction.

Danny has attended the Caring and Sharing Trust for 19 years. They put on shows for a variety of people from MP's to OAP's and Danny is usually the star! He is an inspiration to all that know him.



*Danny with Liverpool's Brendan Rodgers*

*Eileen Brown, Northampton*

## Peter John - Vice Chair

**Why did you get involved with DHG?** After my daughter Sarah was born in 1982 with an inoperable complete AVSD, we contacted DHG and found a fantastic source of information about support and medical matters, feeding problems and how to improve her quality of life.

**What made you volunteer to help?** I wanted to put something back, as our family had received so much help and support over the years.

**Occupation?** I work for a large supermarket chain, having previously worked in the film industry for over 35 years.

**What do you think you bring to the role?** A parent's viewpoint and experience of an inoperable condition over 30 years.



**Hobbies?** Walking our dog, photography, following rugby (although I no longer play), following sports, taking Sarah to the theatre and cinema when possible.

**Family?** Married to Terry for almost 40 years, two daughters - Sarah (32) and Katherine (30).

**Pets?** A mad Welsh Springer Spaniel dog called Owen and a cat called Ivy.

**Age?** 63

**What do you see for the future of DHG?** Working closely with other organisations so our families receive the best support and access to information.

**Favourite cake?** I'm afraid I'm not a lover of cake, preferring a good portion of cheese instead!

**Embarrassing Moment?** After breaking my leg in several places playing rugby, when laying in hospital in agony waiting for specialist to assess damage, a doctor appeared and examined my leg. I told him to "go away" in no uncertain terms. He then explained he was the specialist hoping to re-set my leg!

**Claim to fame?** Being at Wembley Stadium in 1966 World Cup at the England v. Argentina quarter final game, being behind the goal taking films from Press Cameramen to the Press Box. England won the game one-nil.

## Helen Lavery - Committee Member

**Why did you get involved with DHG?** As a nurse I have worked with and for people who have a LD for over 30 years and thought I might have some skills that could be useful.

**What made you volunteer to help?** I made a throw away comment to Penny and Sarah that if they needed any help to just call! However, I was very honoured to be asked to be a trustee for DHG.

**Occupation?** I'm the Professional Lead for Learning Disability Nursing at the University of Nottingham.

**What do you think you bring to the role?** A strong professional drive to ensure people with a learning disability get what most of us take for granted. I don't have a child with Down's Syndrome but that doesn't stop me campaigning to ensure you and your family get a real fair chance in life. I try to make sure all nurses know about the rights of people with a LD and will always advocate on your behalf.



**Hobbies?** I love to read, shop and spend giddy times with friends and family.

**Family?** I have been married to John for nearly 30 years. We have one amazing daughter, Annie, who is 21 and a student at the Royal Central School of Speech and Drama in London. Some of you will have met her in Peterborough at our conference when she led the performance workshop.

**Pets?** Two cats - Belle and Haribo. John keeps bees, too, but they are all called Buzz!

**Age?** My birth certificate says 53 but mostly I think 25!

**What do you see for the future of DHG?** Well I tell everyone we're the littlest charity with the biggest heart and believe that together we are better!

**Favourite cake?** Mmm... Christmas, cheese, chocolate, currant!

**Embarrassing moment?** Well Annie would tell you I was an embarrassment! How about goosing a complete stranger I thought was my husband from behind? Or sleep walking in a hotel in Ireland and waking up on the landing with a little nightie on? Take your pick!

**Claim to fame?** How about having loved Donny Osmond since 1972?

*Helen will be standing as Chair Elect at the AGM so that she can begin to work with existing Chair, Chris Stringfellow to ensure a smooth handover in 2016.*

## London Marathon

Good luck to Suzanne Adams, Chris Deas, Rose Jenkins, Gary King, Ellen Robertson, Luisa Walsh and Josephine Williams who are all running in the London Marathon on Sunday 26th April in support of Down's Heart Group.



Please support them if you can by donating through the DHG website or even by going to London and cheering them on. Let's hope the weather is kind and that they all get safely round the course.

*All seven runners get a huge thank you from all at DHG*

## Children's Heart Week



Children's Heart Federation are celebrating Children's Heart Week from 11th to 17th May.

Any family with a child with CHD is welcome to join in with the activities, which were still being finalised when this newsletter went to print. See the CHF website for details

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

## Pop Factor



Pop Factor concerts are happening across the country until the end of May, featuring all the latest hits from the biggest groups.

Designed for younger audiences and those with special needs, the atmosphere is friendly and audience participation is encouraged. Professional performers are joined on stage by local dance troupes to give an exciting and memorable evening.

Prices vary but are around £12 per ticket, but DHG have been offered a discount, so contact Sarah before you book. Dates and venues are on the Pop Factor website, as well as a booking facility.

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

## Conference And Fun Weekend



*The agenda is now set for the Down's Heart Group conference and family fun weekend taking place on 16th and 17th May 2015 at Combe House Hotel, Holford, Bridgwater, Somerset.*

There will be a welcome supper available for those who wish to arrive on Friday evening. Saturday will begin with the AGM and will be followed by the morning sessions:

**Continuing projects and health opportunities for our youngsters.**

Dr Ben Thomas - professional advisor on LD to Department of Health

**Unlocking learning potential through more practical and visual means.**

Suzanne Hodgkiss – education specialist from the Fortune Centre of Riding Therapy

**The Health Equalities Framework and how it will impact/help our families.**

Gwen Moulster – Clinical Director, South Staffs NHS Trust. Lead on HEF

**The importance of continued and joined up health care, even after corrective surgery.**

Prof Rob Tulloh - Consultant Paediatric and Adult Congenital Cardiologist, Bristol

Lunch - time to collect youngsters from the crèche and activity workshop

Delegates will choose two afternoon workshops from the following:

**Personal budgets/direct payments – how they should work.**

Lawraine Hails – director at MiXit and campaigner for living again

**Engaging reluctant learners.**

Suzanne Hodgkiss - education specialist from the Fortune Centre of Riding Therapy

**Completing HEF action plans**

Gwen Moulster - Clinical Director, South Staffs NHS Trust. Lead on HEF

There will then be a presentation by the youngsters from the activity workshop followed by thanks and goodbyes to those not staying for the evening.

Saturday night is time for the dinner and disco and Sunday will be time for either relaxing in the hotel, chatting with new friends or getting involved with a trip or activity.

*Please email or call national Office for more details or to book a place.*

## Click and Collect



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

**easyfundraising**  
.org.uk

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

*Use Easyfundraising or Give as you Live and support Down's Heart Group!*

DHG encourages people to sign up to one of the online fundraising sites to support us without costing you a penny, but did you realise many of the websites that do 'Click and Collect' are also part of these schemes?

If you decide to check local availability and reserve the item before you go, then using online fundraising still donates to the charity when you pay in store!

## Share Options

Do you, family or friends, have a small number of shares that you don't know what to do with or that would cost too much to sell? Would you consider donating them to help DHG receive a grant?

Sharegift is a share donation charity who take shares as a donation and keep them until they get enough to sell. Dividends received until then are added to the pool of funds.

When you donate shares you name a charity you would like to receive a grant. Sharegift only take appeals for funds from donors and they try to support every charity suggested to them. Grants are based on the value of shares donated to them and the number of suggestions they receive for any particular charity.

Those odd shares are doing nothing where they are but collectively they may do a great deal. Down's Heart Group cannot guarantee that they will get anything out of it but without donations of shares we will never get a grant. So it might just be time to check your old paperwork and see if there are any old share certificates lurking about!



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

## Company Donations



*Down's Heart Group runs on donations and can only continue to exist as long as those donations come in. We make appeals to charitable trusts for funding but whilst doing some research we have realised there are a lot of trusts that we are unable to approach – but maybe you can on our behalf?*

Many companies have a charitable trust set up that is only open to appeals from employees. The charities range from those set up by specific companies to those set up by career bodies, for example, pharmacists. Your company may simply match any donations you make – you might just need to ask them. It doesn't matter how small the donation is as it all helps DHG keep going!

If you have any ideas for charities or companies to approach please email Frances at DHG. She has documents that explain who we are and give facts and figures about the charity. She will also be happy to research whether your company has a charitable trust to approach. The appeal will have to be in the name of the employee or person in that employment but we are happy to prepare much, if not all of the paperwork if we can.

We miss out on many grants because Down's Heart Group exists to provide advice, guidance and help to those that need it. We do not have fancy buildings and we do not need specialist equipment. Many charitable trusts are more than happy to buy a specialist scanner, for example, but they will not pay core running costs, which are what we need to continue to provide our specialist personal service.

[t&cfundraising@dhg.org.uk](mailto:t&cfundraising@dhg.org.uk)

## Body Shop Party

*How would you like to hold a Body Shop At Home fundraiser for DHG?*

You could hold a Pamper evening either at home or a local venue and invite as many guests as you like. A Body Shop representative would come along and do makeup demonstrations, mini facials, foot spas etc. All the products are on display for guests to try. People then place an order and DHG would receive 15% cash back on top of any entrance fees, refreshments and raffles.



Tracey Jones covers Cheshire, but can help put you in touch with someone local to you. Contact Tracey via Penny at DHG and enjoy your pamper evening!

[penny@dhg.org.uk](mailto:penny@dhg.org.uk)



Did you wear crazy socks for World Down Syndrome Day?



Send us your photos to put in this newsletter.

Tell us about your hobbies and activities.



How are you going to spend the summer?

Do you have a new sport to tell us about?



Are you coming to the Down's Heart Group fun weekend in May?



Brave Monkey can help us when we go to hospital.

Look out for him in the newsletters.

## Brittany Meets Nigel



Brittany got to meet one of her favourite actors Nigel Harman when she was visiting her mum, Lynne Holden, at work at the BBC in Birmingham. She has liked Nigel since he starred in Eastenders, playing the character of Dennis Rickman, the son of 'Dirty' Den Watts.

Brittany featured in a recent DHG newsletter, when she moved into supported living with some friends. Apparently, she now only goes to see her parents if food is involved and is thoroughly enjoying her independence.

She is certainly giving other young adults something to aspire to!

## Maggie Woodhouse OBE

*Dr Maggie Woodhouse from the School of Optometry and Vision Sciences at the University of Cardiff was awarded an OBE for services in Optometry and for people with disabilities in the Queen's Birthday Honours List.*

Maggie has been running a study of visual development in youngsters with Down's Syndrome for over 22 years. Her research is supported by a study group of over 250 youngsters and has resulted in new techniques for assessing vision in patients with limited communication, together with recommendations and changes to eye care practice that have been adopted across the UK and beyond. Maggie is especially interested in how visual and learning disabilities impact on education.

Maggie says:

*"I was over the moon to be recognised in this way, totally bowled over. The work I've been involved with has been far from a solo effort. I've been lucky enough to work with enthusiastic, committed and brilliant people. And lucky enough to meet such wonderful children and parents along the way. The award is for them, really"*



## Listening Books



Listening Books is a charity that provides a postal and internet based audio book service for those that may struggle to read a printed book. There are over 8000 titles in the library, including all the latest releases and top authors.

Annual subscription starts from £20 and members can have CDs delivered or can listen online.

[info@listening-books.org.uk](mailto:info@listening-books.org.uk)

0207 407 9417

## Books Beyond Words



Books Beyond Words, for adults who can't read can be used as communication tools to help people explore their lives and, just as importantly, their emotions. They have been specially created to tell stories in pictures to help with the understanding of such situations as going to the doctor, feeling cross, making friends, falling in love and speaking up.

Currently, they are creating eBook versions of their back catalogue. All titles are available online and ebooks can also be purchased through the website.

[www.booksbeyondwords.co.uk/bookshop](http://www.booksbeyondwords.co.uk/bookshop)

## Danshell Easy Read



Danshell have produced a range of easy read resources about key issues for people with learning disabilities, all of which are available on their website. Topics covered include making decisions, bullying, feelings, advocates and having your say for both adults and children.

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

## Living Paintings



Alison Oldland MBE formed Living Paintings after working with people with visual impairments. Her idea was to make art more accessible by providing extras like braille and audio to bring paintings to life. Alison has since developed “Touch To See” books which contain raised tactile images accompanied by atmospheric audio guides, making books easier to navigate and fun.

There are books for all age ranges, covering many topics. All books can be borrowed, free of charge, from the Living Paintings library, which operates throughout the UK.

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

01635 299771

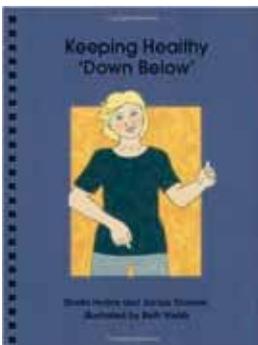
[info@livingpaintings.org](mailto:info@livingpaintings.org)

## Cervical Screening



Cervical screening checks for cancer of the cervix and all women over 25 are invited to go for a smear test. Research suggests that women who have never been sexually active do not get cervical cancer.

Some women who have had bowel problems or surgery can find the test very awkward and uncomfortable. Women in these categories can opt out of the screening programme but it is best to discuss with medical professionals first.



Jo's Cervical Cancer Trust and Public Health England have produced a short information film to explain all about smear tests (cervical screening) to women with learning difficulties. It is designed and produced by women who have learning difficulties and aims to give women and their carers information about smear tests and hopefully reduce any fears they may have over the procedure.

The film is available on the Jo's Trust website or can be purchased for £3. There is also a pictorial book called Keeping Healthy Down Below, produced by Books Beyond Words for £10 from

[www.jostrust.org.uk/videos/smear-test-film](http://www.jostrust.org.uk/videos/smear-test-film)

[www.booksbeyondwords.co.uk/bookshop](http://www.booksbeyondwords.co.uk/bookshop)

## Sleep Disordered Breathing



*Lizzie Hill BSc(Hons) RPSGT is a final-year PhD Research Student at The University of Edinburgh. She has been studying sleep-disordered breathing and has kindly shared a preliminary report.*

Sleep-disordered breathing (SDB) is the commonest medical cause of sleepiness. Muscle relaxation during sleep leads to a partial or complete collapse of the airway, resulting in a repeated cycle of pauses in breathing. These breathing pauses disrupt sleep, leading to daytime sleepiness. A clinically-significant number of breathing pauses during sleep is known as obstructive sleep apnoea (OSA). Snoring can occur due to vibration of the narrowed airway.

Children and adults with Down's syndrome are predisposed to SDB because some of the common features of Down's syndrome overlap with the risk factors for SDB. These include a tendency to be overweight, generalised hypotonia, short midface, thick neck, large tonsils/adenoids and a relatively large tongue.

*Early results suggest that around 20% of adults with Down's Syndrome have Obstructive Sleep Apnoea*

SDB is common in the general population, affecting around 10% of children and 20% of adults. Approximately 2-4% of adults and 2% of children have OSA. We think that around 55% of children with Down's syndrome have SDB. Two small studies found sleep apnoea in over 80% of adults with Down's syndrome, but these included only 22 people in total (Resta 2003; Trois 2009). Here in Edinburgh, we have been running a research study to work out the prevalence of SDB in adults with Down's syndrome. Early results from our survey of over 1000 people (including many DHG members – thank you!) suggest that around 20% of adults with Down's syndrome may have OSA, with over three-quarters of responders reporting snoring and over a quarter reporting breathing pauses.



Night-time symptoms of OSA include snoring, breathing pauses, gasping/choking, restlessness, frequent awakenings, sweating and frequent trips to the toilet or, sometimes, bedwetting. Children with Down's syndrome often sleep in unusual positions, such as sitting up, flopped over or with the neck extended. In the daytime, OSA can result in excessive sleepiness, irritability, hyperactivity, behaviour problems, morning headaches, dry mouth, poor concentration/memory and mood disturbances.

Unfortunately, many of the daytime symptoms of OSA may be overlooked and dismissed as “*just part of their condition*” - despite the increased risk of OSA in people with Down’s syndrome, only 7% of people in our study had been diagnosed with OSA, and only 5% were currently receiving treatment.

However, untreated OSA can have serious consequences. Impaired daytime function can result in problems with learning and memory, and is likely to worsen cognitive impairment already present in some people with Down’s syndrome - one study estimates that untreated SDB in children can lead to a 10-point reduction in IQ (Kohler, 2009). Sleepiness can lead to a generally reduced quality of life for the individual and their family. Repeated pauses in breathing cause surges in blood pressure, putting extra strain on the heart, and there is a high risk of developing pulmonary hypertension in children with OSA and Down’s syndrome, especially if they already have co-existing heart problems.



### *Untreated OSA can have serious consequences*

National guidelines from the Royal College of Paediatrics and Child Health (RCPCH) state that all children with Down’s syndrome should be screened for OSA at age 6-9 months using a test called oximetry, which measures blood oxygen levels using a finger-clip. If the oximetry result is normal, screening should be repeated annually until the age of 3-5 years. If the oximetry is abnormal, a detailed sleep study at home or in hospital is recommended, recording information on breathing, oxygen levels, body position, snoring and sleep stages. The Down’s Syndrome Association’s “*Health Book for Adults*” includes sleep as one of the areas which should be reviewed annually by a GP.

### *Children should be screened at 6-9 months using the oximetry test*

The first-line treatment for OSA in children is removal of the tonsils and adenoids (T&A). This is a relatively straightforward procedure carried out under general anaesthetic, and cures OSA in the majority of cases. Treatment for OSA in adults, or in children who still have OSA after T&A, is continuous positive airway pressure (CPAP). This involves wearing a mask over the nose and/or mouth, blowing pressurised air in to hold the airway open from the inside. This is a simple, non-invasive and generally effective treatment. However, it is a therapy rather than a cure and so has to be used every night to feel the benefit.



## *Sleep study continued...*



One study showed improvement in sleepiness, behaviour and quality of life in 10 children with neurodevelopmental disability (including Down's syndrome) when using CPAP (Marcus 2012). In Edinburgh, we looked at 28 adults with Down's syndrome and OSA to see how they got on with CPAP. Of the 28 people in the study, 20 were still using CPAP after 12 months. Overall, using CPAP leads to significant improvements in sleepiness, general health, cognitive function and behavioural/emotional outcomes. The full results of this study will be available soon.

## *CPAP leads to significant improvements*

In summary, children and adults with Down's syndrome are at an increased risk of SDB/OSA which, left untreated, can have a negative impact on health and wellbeing. However, effective treatment is available and should be offered to all children and adults who need it, whether they have Down's syndrome or not. If you suspect someone you know has SDB, please visit your GP in the first instance.

## **TAC Bulletin**



*This online bulletin comes to you twice a month and is free. It aims to share information, help build the knowledge base and support teamwork around disabled babies, children, young people and adults. Just send Peter Limbrick an email if you want to receive the next TAC bulletin.*

Team Around the Child (TAC) is a joined-up approach suitable for children, adults and elderly people who need support simultaneously or in close succession from a group of services or agencies. TAC brings the various elements of support together as a whole approach for the whole person. It brings the key practitioners together, regardless of agency boundaries, into regular face-to-face meetings to share views, discuss what each other is doing and agree a single joined-up plan of action. This plan is then modified and added to at successive TAC meetings.

In the TAC approach there is a very strong element of empowerment. TAC requires that parents of infants are fully involved in each TAC meeting, as, of course, are older children and adults in the TAC meetings about planning support for them.

## Challenging Behaviour Foundation



EHC Plans replaced statements of Special Educational Needs (SENs) in September 2014. The Challenging Behaviour Foundation has produced a new information sheet to cover everything that family carers need to know about the changes.

As part of the new Act, children and young adults up to 25 years old should receive an EHC Plan instead of a SEN. This change is happening so that your child's education, health and care provision will be more joined

up and everyone involved in your child's care can have a clear idea of what your child needs and what everyone should be doing. The new system also gives children and their families more say in the process.

The new information sheet on getting an EHC plan covers:

- How to get an Education, Health and Care assessment
- What the assessment will involve
- What the new EHC Plans should include
- What family carers need to think about in relation to challenging behaviour

[tinyurl.com/nccbbbs](https://tinyurl.com/nccbbbs)

## Update On CHD Service Review



The independent report 'Consultation on draft standards and service specifications for the congenital heart disease service' has been published, following the consultation that ended in December.

459 responses were received in response to the consultation, all views have been considered and this report sets out what has been drawn from the consultation. The next part of the review will focus on developing the standards and specifications to improve patient experience for people with congenital heart disease.

To follow the progress of the review go to:

[tinyurl.com/CHDconsult](https://tinyurl.com/CHDconsult)

## Monkey Wellbeing

Hi I'm Helen, Monkey's Mummy. I am an Early Years teacher and Nursery Nurse.



Monkey was born when our daughter was facing major surgery at 18 months old. As parents, we felt out of control, worried and afraid. But with determination, imagination, a toy Monkey and a homemade storybook our little girl was able to face her hospital stay with more confidence. The idea was simple, a toy monkey was the patient and he was photographed in the actual hospital rooms that Josephine would visit, with the equipment that she would see all around her. It paid off, Josephine was relaxed and positive, recognising the machines and people that Monkey had introduced her to. Her positive spirit throughout her stay helped to relieve everyone's worry – and boost her recovery.

The hospital requested more books as the surgeons and nursing team felt that the book had directly impacted Josephine's swift recovery because she was so well prepared. Daniel and a friend walked 100 miles to raise money for the first print run of 10,000 books and my handmade book, featuring a monkey's visit to hospital, was transformed into an essential resource for all families faced with the hospital experience.

We now have a series of books covering all sorts of titles from asthma to starting school, visiting the Emergency Department to having an injection. With 66 titles requested! Monkey's NHS Explorer resource pack went to over 19,000 Primary and Special Schools in England introducing NHS emergency and urgent care pathways to children. I was also delighted to be invited to the NHS England Steering group as a patient and parent representative for the Children's Survey. We have developed a Friends and Family test for children and their families. Monkey has been a flu fighting superhero, has an asthma plan, a head injury leaflet and all sorts!

We are currently visiting Brighton and Hove's primary and special schools as part of the Great Choices Make Heroes campaign with Zoe Ball. We are putting together an emotional health and wellbeing pack and Monkey has also recently been to the Dentist. He has CT and MRI scans coming up, too.

I am completely passionate that children understand health information at their level of development and that their voices are heard loudly!



[monkeywellbeing.com](http://monkeywellbeing.com)

## Money Matters

**contact a family**  
for families with disabled children

Contact a Family have put together a range of FREE resources to help you check that you're claiming everything you're entitled to. Some of the titles are:

*"Our Money Matters"* - lists financial help available to families with a child with additional needs in England, Wales and Scotland.

*"Help with Fuel Bills and Keeping Warm."* - advice on keeping bills low and information on money saving schemes you may be entitled to.

*"Claiming Disability Living Allowance for Children"* - tips on claiming DLA for the first time or getting more help if your child's needs have changed. Getting DLA can help you qualify for extra amounts of other means-tested benefits and tax credits.

### Other resources include:

Help with Council Tax Bills, The Tax Credits Guide, Personal Independence Payment and Other Benefits at 16, and Disability Living Allowance - *"claiming the higher rate mobility component for children with learning disabilities and autism spectrum disorders"*.

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

0808 808 3555

## Which Appliance?



Rica is a UK consumer research charity which provides tips and practical information on travel, vehicles, household appliances and aids to make life a little easier. They have an easy to navigate website showcasing items that are easy to operate and handle. Many items are aimed at those with visual impairments, older people or those with physical disabilities, it is also a great source of information for those of us supporting someone with a learning difficulty or fine motor skill problems.

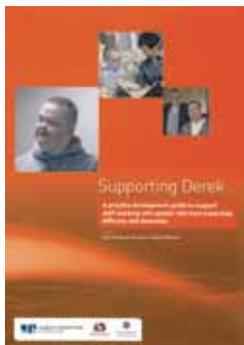
By purchasing goods that are easy to use and simple to understand, such as cookers with simple dials and easy to hold knobs or kettles that are easy to pick up can make life a lot safer and simpler for someone trying to be as independent as possible.

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

020 7427 2460

## Down's Syndrome and Dementia

*Chris Stringfellow recently attended a conference organised by the DSA in Bristol on Down's Syndrome and dementia. Chris found the day very informative.*



The course facilitator, Diana Kerr, is now a freelance consultant on dementia having worked with some of the most renowned studies into dementia over the past few years. She is also an advisor to service providers and planners in health and social care and the author of several publications on learning disabilities and dementia, and on the night time care of these people.

Diana presented an extremely interesting day that provided a lot of food for thought. It was presented from the point of view of the person with dementia and gave ways to deal with the problems that arise because of the cognitive decline.

A DVD called *"Supporting Derek"* was shown, highlighting practical examples of helping our adults and their carers cope with day to day problems. This DVD is part of a resource pack of the same name from the Joseph Rowntree Foundation.

[www.jrf.org.uk/publications/supporting-derek](http://www.jrf.org.uk/publications/supporting-derek)

Chris said *"The whole day was both very good and heartbreaking but has given us an awareness of how we need to deal with dementia. If you are in the position of caring for someone with dementia then the DSA produces a very good range of booklets."*

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

## Short Breaks Legal Resource

A new short breaks legal resource for parents and carers has been launched by Every Disabled Child Matters (EDCM). It contains information on local authorities' statutory duties to provide breaks and consult with families of disabled children.



The resource aims to help families by explaining what short breaks provision families with disabled children should expect to be available in their area, explaining the legal framework relating to short break services, providing template letters to help challenge decisions by local authorities and signposting families to sources of legal support.

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

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

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Email:  
Write:

0844 288 4800  
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PO Box 4260  
Dunstable, LU6 2ZT



## Why not join us at our 2015 Conference and Family Fun Weekend on 16th and 17th May in Somerset?

Expert speakers, interactive workshops, information stands, lovely venue, crèche, activity workshops, dinner and disco



Come for the whole weekend, just the day, or even just the disco!

Just look what fun we had last time!

*See page 9 for details*



Down's Heart Group are certified members of Information Standard, ensuring all our information is accurate and current. The standard applies to any articles within this newsletter which contain treatment or diagnosis information.