



dhg

down's heart group

Newsletter Winter 2015

Issue 56



***In this edition - Members Stories
Fundraising Update, News
And More!***

Chair's Report

Welcome again to the winter newsletter, Issue 56.

Following the disclosure that data has been sold by some of the bigger charities I must reassure you that our data base is very secure. We do not give any information out to anybody without your express permission.

We have been involved with various research projects in the past but the letters that have been sent out from these have all come into the DHG office and are sent out by us, so no personal information is shared. Your information always remains with us.

Please remember to send in your stories and photos, as well as news from your area that we can share in a newsletter - we love to hear from you all!

I hope that you all have a good Christmas and New Year.

Regards
Chris

Chris Stringfellow

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Reviews, Articles, News

At the DHG office we are often asked about all sorts of things like where is good to go on holiday, which feeding bottles to use, activities that are OK to do if you have a CHD...

We don't have all the answers but we do know that the DHG membership has a great deal of knowledge on everything to do with raising youngsters with Down's Syndrome and heart problems, and what better place to share this knowledge than in this newsletter! So, if you have found the ideal holiday destination, as Penny did on page 9, please send us information and photos. This goes for anything you think would be useful for other families, whether it is a book or product review, a great idea that is happening in your area, or a way of getting a determined child to take their medication.

0300 102 1644

info@dhg.org.uk

...supporting a better life 

Transition

The National Institute for Health and Care Excellence is currently reviewing transition from children to adult services. The new guideline will cover both health and social care services and is due to be published in February 2016.

NICE

National Institute for
Health and Care Excellence

The consultation period for comment ended on 22nd October and hopefully comments from organisations such as Down's Heart Group will be taken on board. The new guideline covers principles and practice of good transition from children's to adults' services and aims to improve the planning, delivery and experience of care of young people in their transition period.

The new guideline states that every young person will have a named worker for a minimum of six months before and after transition. Any move from children's to adults services should happen when appropriate to the young person's development, maturity and individual circumstances, taking into account any long term conditions.

To view the consultation go to

tinyurl.com/transdhg

DHG would like to hear your experiences on transition and any tips or advice you would like to share, so please get in touch.

Jude



Jude on the beach



Jude and Beau enjoying the train

Jude was our beautiful Christmas present in 2009. We knew he had a heart problem prior to birth and that it was associated with Down's Syndrome but declined all tests.

Jude had total heart block

Jude was born in heart failure and quickly developed pneumonia, he was on oxygen and tube fed until his heart surgery at three months old to correct a complete atrioventricular septal defect. Just two days after surgery it was apparent Jude had total heart block so was taken back to theatre to have a permanent pacemaker implanted.

As you can imagine we were on a roller coaster of emotions fearing we would lose him at any time, but by some miracle and the amazing care he received at Leeds General Infirmary, Jude, our hero, made it.

Jude is almost 6 years old and has a brother Beau, a difficult decision to have another baby but hey ho, life's what you make it!

It was a difficult decision to have another baby, but hey ho!

Jude has attended mainstream nursery and reception, but in September he started at a special school as he is still non verbal so communication is our next milestone to achieve.

Jude's favourite things are going for a swing and playing catch, but mostly running away with the ball!



Jude playing catch

Karen Barron, Yorkshire

Gwen

Here is a photo of our sixteen year old daughter Gwen celebrating her success on passing six out of her seven GCSEs and her BTEC Science at her local Secondary School. It was a very emotional day as you can imagine. She started her college course in September and is so excited.



Gwen in centre, with school friends

In December 1999 (at eight months old) she underwent heart surgery and sailed through it. As you can see since then she has gone from strength to strength and has made all of her family very proud.

Julie and Richard Evans, Pembrokeshire

World Gymnasts

Hello, we are Grace and Alice. We were both born with holes in our hearts we are both members of Coalville Gymnastics Club. At a competition in June we were selected to represent Great Britain at the World Down's Syndrome Gymnastic Competition in Milan in November!



Grace and Alice

We are both very excited about it and looking forward to the experience, our coach Rachael has worked very hard with us. We are entering four disciplines - asymmetric bars, beam, vault and floor routine.

We are trying to raise the money for us to go, having just done a sponsored bounce and a car boot at the end of September. If anybody knows of any funding or has an employer who may like to help please, please let us know, as every penny will go towards our target of three thousand pounds that we need! Otherwise it will be "bank of poor mums and dads!" We will let you know how we get on.

Love

*Grace Hammond and Alice Patterson xxxxx
Derbyshire and Leicestershire*



Ava in hospital

Finding out we were expecting our third baby was a surprise but also exciting. At the 20 week scan we were told we had a 1 in 35 chance of having a baby with Down's Syndrome. After researching the tests we decided they were too risky as the results would not make any difference to us. We were happy being blessed with a third child.

At 36 weeks we went to hospital for a growth scan and were admitted for monitoring straight away as baby was not growing and there was a problem with the placenta. On the 16th January Ava was born by emergency C-section. She was so tiny, only 1.5kg and I could tell she had Down's Syndrome. She was taken into the next room to check she was OK and to do tests for trisomy 21. I was so relieved she was OK and was so beautiful.

From day one the medical problems started - low sugar level, low thyroid function, feeding problems (which led to her aspirating and having breathing problems), jaundice and we were told, a small hole in her heart *"not serious she could live with it the rest of her life."*

Every day was a struggle, so intense and worrying

At this point we thought we had hit rock bottom, It was so hard to stay strong and positive for our family and for Ava. As the weeks in hospital turned into months and thousands of tests, scans, drips and examinations, results showed Ava's little heart had two holes, an ASD and a VSD which were causing her huge problems and she wasn't thriving. Every day was a struggle, so intense and worrying, wondering if things were going to improve and if our baby was going to be OK.

Unfortunately, Ava was deteriorating daily and needed surgery soon. At about three months old Ava was transferred to GOSH for heart surgery. I could not even begin to explain the stress and worry that our family was going through. It was even harder trying to explain to my other two children why their *"Ava sister"* was not coming home yet.

Ava was deteriorating daily and needed surgery soon

Having to carry our Ava to theatre and hold her while they put her under is one of the hardest things I have ever done in my life. The hospital told us the surgery would take about four hours, it actually took six hours but felt like a lifetime! Later the surgeon appeared to say he was pleased that the surgery went as well as it could have. Seeing Ava for the first time after the surgery was heart breaking, I felt so helpless. But she is a little fighter and she pulled through.

She started to recover and eight days later she was discharged from GOSH and at four months she was discharged from Barnet Hospital. We took Ava home for the first time.

Today Ava is about seven months old. She still is on a lot of medicines and still being fed by NG tube but on the whole is doing great. We are very positive for her future although we know there is a long, long road ahead. The last cardiology appointment was good news, they are happy with the results of the surgery.



Ava with siblings, Isaac and Tahlia

Ava is an amazing little bundle of joy in our lives with the greatest smile and her brother and sister adore her.

I must mention that DHG's support and advice was amazing and helped me understand what was going on with Ava and what to expect and who to talk to to get the help needed.

Bennett Radomski, (grateful and proud Dad), London

Amy



Amy is seventeen and had an AVSD repaired in 2001 at the age of two.

She attended a mainstream primary and secondary school, and this summer gained a GSCE in Art and Design. In June this year she attended the school prom along with all her classmates. The excitement was unbearable....dress shopping, handbag, hair, nails!

Amy attends dance classes with Anjali Dance Company and also belongs to their Youth Dance Company. She has performed across the UK at top venues including the Southbank Centre and the Northern Ballet. This year she took part in the three day UDance Festival in Plymouth. She dreams of being a professional dancer.

She has just started a three year college course learning independence and life skills and is looking forward to the future, which mainly involves her boyfriend!

Jane Hanson, Oxfordshire

Daniel

Daniel has faced many health issues. He was born with a serious CHD, which required major surgery and as a child he spent a lot of time in hospital with heart failure. We always told his medical team that if they fought to repair his heart, he would fight to live.

When Daniel started school he was still unwell, he became withdrawn and lost his speech and was then diagnosed with autism. He also suffers from eczema and has had extensive surgery on his hearing. He found it very difficult to walk, especially up and down stairs, so was a wheelchair user for a number of years.

To build up Daniel's strength we eventually decided to use his Personal Budget to join a gym, to improve his fitness and get him involved in the community.



Daniel at the gym

Daniel soon began to shine. He lost weight, built up his cardiovascular system and immensely improved his health and socialisation. He yearned to do weight lifting, but we thought it would put too much strain on his heart. However, he eventually began weight lifting, and his consultant said, "Whatever you are doing with him, keep it up!"

Daniel has gone from strength to strength and has developed a major passion for weight lifting. He still has problems with his hearing and his concentration is very limited, so a great deal of his training is spent repeating the signals from the referees, the commands to lift, rack, and push, all of which are extremely important in his sport. One missed signal or command can make his lift a failure.

If they fought to repair his heart, he would fight to live.

Daniel now takes part in many competitions and his dedication makes him compete to the best of his ability. He gets maximum respect from all the other members of his gym, including world champions and he comes into his own when on the platform supported by the roar of the crowd. Above all he loves the white light which signals a good lift.

To date he has entered five power lifting competitions, and has won two golds and three silver medals. He is now looking towards the future and the opportunity to compete alongside able-bodied athletes at the Commonwealth Powerlifting and Benchpress Championships in Vancouver in December 2015. He will be the only lifter with special needs from Great Britain in the championships. Daniel is looking for sponsorship to help follow his dream so if you can help, please get in touch via DHG.

Peter McGauley, Colchester

Centre Algarve

Whilst on holiday in Portugal, Penny Green had the chance to visit Centre Algarve which is a holiday complex designed for people with special needs. She was very impressed!



The pool area

The complex is owned by a charitable trust, set up by a businessman who runs a fleet of taxis. After years of transporting people with special needs and disabilities he realised that they were faced with obstacles at every turn so even a relaxing holiday could be anything but!

Based within reach of several Algarve beaches, Centre Algarve provides a secure and safe area for all the family to enjoy. Rooms have fully accessible wet rooms, some have hoists and beds for bathing. The pool also has a hoist, so those who are less mobile can still enjoy a family swim.

There is a petting zoo, sensory room, soft play, sensory garden, swimming pool, splash pool, play area and classroom. There is a vegetable patch for children to get involved with and plenty of gardens to relax in. The centre has facilities for groups or school parties.



The sensory room

Only fourteen bedrooms means that the centre is not overwhelmingly large like many family friendly hotels and the team of volunteers and staff ensure everyone has a good time.

Centre Algarve caters for all age groups and offers everything an ordinary hotel offers but also includes so many features to make the holiday as relaxing and enjoyable for all as possible. The staff are very helpful and nothing is too much trouble.

For more information either contact Steve Saunders, view the website or contact Penny if you need to.

01279 661661

07468 533533

www.centrealgarve.org



Typical family bedroom

Hi, everyone!



Tell us what you have been doing and send photos so we can put you in the newsletter.



Have you moved to adult services for hospitals, colleges or social activities?

Tell us the good bits and the bad bits about the transition.



If you are an adult do doctors and nurses treat you like a grown up?

Does your social worker listen to what you want?



Contact us to share your experiences at

info@dhg.org.uk

Why did you get involved with DHG? Our eldest son, David had a partial AVSD, diagnosed as a heart murmur after his six week check-up. The only information for parents with children with Down's Syndrome and CHD was from The Association for Children with Heart Disorders so I contacted Linda Walsh, DHG founder, as soon as DHG began.

What made you volunteer to help? I helped set up, and was secretary of, the Merseyside and Cheshire DS group, so my association with DHG seemed a natural progression. I was the North West Co-ordinator for DHG for a few years and served on a committee to improve the hospital experience for parents and children at the Royal Liverpool Children's Hospital at Alder Hey. There was a lot of publicity then about hospitals refusing to operate on our children so it seemed the correct thing to do to ensure equal rights.

Occupation? I retired this year after 42 years working for British Telecom.

What do you think you bring to the role? Organisational skills, experience of life, parenthood and a sense of humour.

Hobbies? Cooking, baking, watching football, not necessarily in that order!

Family? Married to Lesley with three children David, Emma and Thomas.

Pets? David named our cat Dave after him! Also two rabbits, Peter and Pauline (after my in laws!).

Age? Nearly 61.

What do you see for the future of DHG? Campaigning, supporting and providing information for all in a format which is easy to understand. Also to instigate research when funds are available.

Favourite cake? As Jo Brand says – the one I have in my hand at the moment!

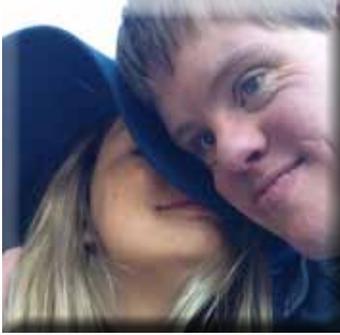
Embarrassing moment? Going to a retirement party and the organiser forgot to invite the guy who was retiring! Any excuse for another party!

Claim to fame? I am just me – one of a collection of individuals who work together to improve life and try to leave this world a better place than when we started.



Talulla and Barnaby

Talulla ran the Richmond half marathon in September and is training hard for the London marathon in April - both for Down's Heart Group.



Talulla says - My dearest brother Barnaby is 28 years old and was born with two large holes in his heart. From birth his lungs began to suffer and he acquired lung disease as a result. The doctors discovered this when he was six months old. Closing the holes was in those days very difficult and with the damage to his lungs the only course of action would have been a heart and lung transplant. That was something they did not do on children with Down's Syndrome.

They told my parents that they didn't think he would live past 15. Obviously B has beaten all odds!

Barnaby is a bit of a miracle in our eyes - doctors have put it down to good living. He truly is my favourite person and you couldn't find a happier and more affectionate chap, he's very gentle and kind. As you can see, I could keep writing about him for a while!

Please help me raise funds for DHG by going to

uk.virginmoneygiving.com/TalullaBarrow

Talulla Barrow, London

Amsterdam To Brussels



In July, school friends Wilfred Garratt, Harrison Taylor and Ralph Cornell set themselves the challenge of cycling from Amsterdam to Brussels. This was to raise money for four charities that have supported people close to them in the past, including Down's Heart Group. They covered 240km in a short space of time!

Wilfred chose for his share of the fundraising to come to DHG as his family are members. His sister, Florence, has featured in a previous newsletter sharing her swimming achievements.

Ironman Elliott

On Sunday 26th July, with the worst weather we have seen in months, Elliott Wood completed his first Iron Man event - The Outlaw Triathlon.

Elliott says - I really enjoyed the whole event. The weather was terrible throughout but it made it all the more memorable. I completed the whole thing in 11 hours 41 minutes which is a lot quicker than I was expecting, especially given the conditions. I was hoping for something between 12-13 hours on a dry day!

I followed a strict recovery plan so I actually felt great afterwards, a little achy but I had booked a family holiday to Majorca for the Tuesday after the event so I had a really good rest.

I am still receiving some sponsorship but I don't expect much more. I think I'm up to £2,600 so far including gift aid. Thanks for all your support and kind words.



Elliott Wood, Bristol

Please send us your fundraising stories and photos to share in the newsletter. We all love to hear what you have been up to for DHG

Robin Hood Half Marathon

Jenny Fleming is a Learning Disability Student Nurse from Nottinghamshire. She decided to take part in her first half Marathon, the Robin Hood Half, on 27th September.

Jenny says - Well, I did it! The hardest thing to date that I have ever done! I managed to finish in a time of 3hrs 50 mins.

I am so proud to have raised £300 for Downs Heart Group. I hope it will help in a small way and improve someone's life who has Down's Syndrome and their family.

Jenny Fleming, Notts



Savoo



Savoo is a search engine but it also lists vouchers codes from all sorts of shops and outlets. You can get money off anything from sending parcels to buying pet food!

More importantly, every time you use the site to link through to a deal or site Down's Heart Group will get a donation and between 1 - 30% commission. It costs you nothing and is simple to sign up to online:

www.savoo.co.uk/#downsheartgroup

Carer's Credit

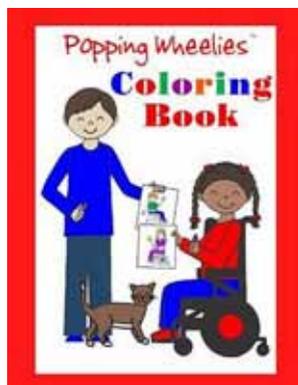


Whilst Carer's Allowance is available to those who care for 35 hours a week or more Carers (subject to availability) Carer's Credits is designed for those who are caring for others for 20 hours or more per week and do not qualify for Carer's Allowance.

If carers are not working full time, Carer's credits can fill the gaps in their National Insurance record and they could receive a boost to their State Pension, worth in excess of £200, by claiming. Application is straightforward.

www.gov.uk/carers-credit/overview

Popping Wheelies



Popping Wheelies colouring books and stickers are the inspiration of Sue Nuenke, who discovered there were no colouring books with pictures of children with disabilities. Volume 1 is now available through Amazon whilst other items can be ordered via Twitter or email.

WheeliesKids@gmail.com

Specialist Equipment

The Newlife Foundation supplies specialist paediatric equipment to families across the UK. They can provide equipment for loan or to keep and sometimes co-fund equipment with local statutory providers, charities or families. They are often able to provide items within 72 hours.

Newlife Foundation works in partnership with local health and social care professionals. It has a helpline which is manned by nurses and also has a toy loan facility.

Nurse helpline 0800 902 0095

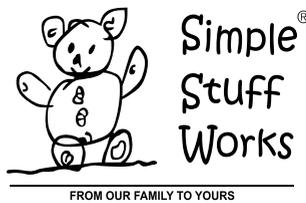


01543 462 777

www.newlifeable.co.uk

Simple Stuff Works

Postural Care is about protecting a person's body shape. People are at risk of developing changes in body shape if they find it difficult to move independently, spend lots of time in a limited number of positions or experience other difficulties such as hypermobility (they are very flexible at their joints) or have low muscle tone. Children are at greater risk than adults because they are growing so quickly.



Some people need postural care for a short period of time, when recovering after surgery for example. Others will need postural care for longer periods, perhaps their whole life, in order to be protected from the harmful effects of gravity.

Simple Stuff Works provides training, support and equipment for use in the lying position - believe it or not children spend over three times longer in bed than in school so this time is essential!

Please don't hesitate to get in touch if you think we might be able to help you. Take a look at our film - from our family to yours...

Sarah Clayton

www.youtube.com/watch?v=L7vmvTIG5zA

www.simplestuffworks.co.uk

01827 307870

The Prince Who was Just Himself

A book review by Laura Dillon (age 8).

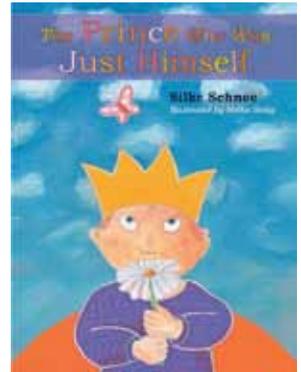


This story is about a little prince with Down's Syndrome. His family love him and think he is as good as anyone else but the people of the kingdom think that he is different and do not like him. An evil knight called Scarface threatens to destroy the kingdom but then prince Noah sees a tear trickle down Scarface's face and hops off his horse and hugs Scarface with his kind little hands.

My favourite part of the story was when Prince Noah made Scarface feel happy and then became a hero. Through Noah's kindness he prevented a war showing everyone has the ability to do great things. After that, Noah became the hero of the whole town and everybody finally respected him like he should of been at the beginning.

Laura Written by Silke Schnee this story is published by Plough Publishing and available through Amazon and other stockists.

www.plough.com



Christmas Countdown

Baxter's Books offer an alternative Christmas Advent countdown. Instead of the usual chocolate calendars, how about reading a different story each day? For £20 you receive 24 books wrapped in Christmas wrapping and ready to go on the 1st December!

Rochelle Baxter, mum of three book loving children, sells Usborne Books through her business, Baxter's Books. She is based near Scunthorpe and orders can be collected from there. If you aren't local, books can be posted, or Rochelle is open to other collection and delivery methods to suit.

The Christmas Advent must be ordered by Sunday 15th November in order to receive the books by 1st December. This is, however, subject to stock availability. To order this offer, or any other Usborne books, contact Rochelle via one of the methods below:



07799586262

rochelle.baxter@yahoo.co

Facebook: Baxter's Books

Show Me Where?

'Show me where?' can help people with communication difficulties show where they have a pain. It was designed by Irene Hammond, a retired special school nurse, and Jan Sharp of Cardiff University and is available as either a set of cards or as an App for iPad or Android gadgets.

"*Show Me Where*" depicts images of different body parts from which the person can select to show where the pain or discomfort is. For further information or to place an order contact Jan Sharp:



SharpJL@cardiff.ac.uk

029 2074 5335

www.cardiffandvaleuhb.wales.nhs.uk/show-me-where

Cook And Eat

Cook and Eat easy read cook books are adapted cookery books, written so that people with learning disabilities can make more meals with less help.

The range of books is available from South West Yorkshire Partnership NHS Foundation Trust and cost £10 each.

0800 587 2108

customer.servicesSWYT@nhs.net



Makaton

Makaton is used by over 100,000 children and adults. It is a language programme using signs and symbols, designed to support spoken language. Most people start using Makaton as children then naturally stop using the signs as they no longer need them. However, some people will need to use Makaton for their whole lives.



The Makaton Charity website has brilliant resources, some are free and some are available from the online shop. It offers everything you need to start learning Makaton or to develop your vocabulary as your child develops.

info@makaton.org

01276 606 760

www.makaton.org

Square Peg Foundation

Square Peg Foundation is a charitable organisation supporting disabled people. It produces and sells a range of clothing including hoodies with great slogans such as "Too many chromosomes? Nah, just too cute!"



Profits raised from the clothing along with fundraising has allowed Square Peg to buy a sensory bus, which will be operational and touring by Christmas. The bus will be visiting schools, shopping centres and events and will also be available for hire for childrens parties. The bus will begin its tour in the West Midlands and hopefully venture out across the country.

Square Peg now also own a wheelchair accessible static caravan on a family friendly site near to the fantastic beach in Borth, North Wales. It is on a flat site and offers a ramped access, wide hallway, sliding doors and wet room with a disability chair It is available to hire and priority is given to people with a disability, but as it needs to be rented throughout the holiday season, anyone can request a booking. Prices are kept really low so that families can afford to have a lovely week away.

lauren-porter-mp3p.squarespace.com

Park The Charges



Park The Charges is a current initiative by Carers UK and Julie Cooper MP, who are campaigning to introduce new legislation which would exempt carers claiming Carer's Allowance from NHS hospital car parking charges in England. They have an opportunity to raise this issue in Parliament through a Private Members' Bill which will be debated on 30th October 2015.

Hospital parking is a big issue for many carers. Visiting hospital with someone you care for is tough enough, without the stress of having to renew the parking ticket, the time it takes, and even just having the right change, not to mention the cost which can run into hundreds of pounds each year. Being exempt from charges would make a big difference to many carers.

To add your support to the Park The Charges campaign or find out more about it go to

www.carersuk.org/news-and-campaigns/campaigns/hospital-car-parking

Descriptive Praise

Descriptive praise is a phrase you may have encountered when trying to deal with behavioural issues. It is just one of the topics explained extremely well by Scope's online community of guest bloggers - professionals and parents ready to help and offer advice.



The main Scope website is vast and has sections for disabled people, families and professionals, covering all age ranges and disabilities. There are pages describing and listing the services it provides in each region of the country, which range from befriending, education, housing to short breaks and many more.

Scope provides free, independent and impartial information and support. There is a free helpline 9am - 5pm on weekdays.

0808 800 3333 helpline@scope.org.uk

www.scope.org.uk

IAPT Services

For many people with learning disabilities who experience anxiety or depression, accessing their Improving Access to Psychological Therapies (IAPT) services should be the first port of call.



Unfortunately, not many know about IAPT services or think that are suitable candidates for such a service, despite the fact that people with learning disabilities are 40% more likely to experience a mental health problem. The services should ensure that there is equal access but until recently this was not happening.

The Foundation for People with Learning Disabilities has just completed a project to develop better access to the services and published a Positive Practice Guide for practitioners. The guide recommends making reasonable adjustments so that people with learning disabilities can get the most out of talking therapies, including being given more time, easy read resources and being supported by a team or several services at once to ensure the best chance of getting better. Including family members in therapy and homework tasks has also proved very beneficial to those with anxiety or depression.

www.fpld.org.uk/our-work/iapt

Right Chair, Right Time, Right Now



The Wheelchair Leadership Alliance was formed in January 2015 under the leadership of Paralympic athlete, Baroness Tanni Grey-Thompson. This Alliance is a commitment group campaigning for a better deal for wheelchair users and aims to transform the quality and effectiveness of services across England.

Wheelchair Leadership Alliance is running a national campaign to raise awareness of issues in wheelchair services and show how people's lives can be transformed with the right chair. The campaign is targeting two key audiences, firstly the commissioners, providers and manufacturers who can make changes. Secondly those who can demand changes, wheelchair users and carers.

The campaign is underpinned by the Wheelchair Charter which outlines the crucial principles for the commissioning and delivery of high quality wheelchair services that will help people live their lives to their fullest potential. To pledge your support for the Right Chair, Right Time, Right Now campaign or to find out how you can contribute to the discussions go to

www.rightwheelchair.org.uk

Beach Wheelchairs

There is currently a small group campaigning for beach wheelchairs to be available for hire on Blyth South beach in Northumberland. Other schemes on Great Yarmouth, North Berwick, Brighton and Hove and at least ten Cornish beaches are really popular.



In September, people were welcomed to Blyth beach to test out a selection of wheelchairs from local manufacturer, Adventure Mobility. The day was very successful and for some it was the first time they had ever been able to be on a beach. The organisers were worried at one point that the chairs wouldn't be returned as families had so much fun!

For more information on the campaign and existing schemes go to:

beachwheelchairsforblythsouthbeach.wordpress.com

0191 3410187

New Help For Wales

New guides to help adults with a learning disability and their carers access health and social care services have been launched by Mencap Cymru in conjunction with Cardiff University's School of Law.



The toolkits will provide a one-stop-shop for information relating to health and social care services, including the duty and obligations of local authorities and health boards and the legal framework governing the challenging of decisions taken by these bodies.

tinyurl.com/dhgwales

Children In Focus

Children with learning disabilities are 28 times more likely to have a serious sight problem than other children, despite this there is no national plan to meet their eye care needs.

SeeAbility, a charity helping those with sight loss along with other disabilities, is currently campaigning for eye tests to be available in every special school in England.



Every child should have an equal right to sight so please sign the Children in Focus petition by going to

tinyurl.com/dhgcifp

www.seeability.org

Crime Prevention

A series of crime prevention booklets created by Christopher Langman, who has learning disabilities, have been launched in Stratford-upon-Avon. Christopher produced the booklets when he realised easy read was needed for people in the community.

Two of the new booklets on home security and hate crime have been published and are available to people in the Warwickshire and West Mercia police areas at police stations and support centres.



Charlie And The Chocolate Factory

The Theatre Royal on Drury Lane in London is presenting a relaxed performance of the musical Charlie And The Chocolate Factory at 6pm on Tuesday 19th January 2016.



Presented in association with Mousetrap Theatre Projects, the relaxed performance is aimed at families with a child with special needs. It is designed to provide an opportunity for people with autism, learning difficulties or other sensory and communication needs, who require a more relaxed environment, to enjoy the show. There will be adjustments to the sound and lighting, trained volunteers to help on the evening and free support resources for families to prepare for the performance. These resources are available from;

www.mousetrap.org.uk

Subsidised tickets for the relaxed performance will range from £2.50 to £20. These are available from:

www.CharlieandtheChocolateFactory.com

World Down Syndrome Day

Monday 21st March 2016 marks the 11th anniversary of World Down Syndrome Day. Each year the voice of people with Down's Syndrome, and those who live and work with them, grows louder.



This year's theme is *"My Friends, My Community"* and will focus on the benefits of inclusive environments, being treated equally and participating fully in the community. There will be several initiatives for WSDS 2016 as well as the Global Video Event and the WSDS Conference.

How will you celebrate World Down Syndrome Day? Will you be raising awareness at work, college or school? Will your local community celebrate with you?

DSi (Down Syndrome International) help Down's Syndrome groups and individuals across the globe, especially in poorer countries.

www.worlddownsyndromeday.org

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



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

00 3531 426 6500
www.downsyndrome.ie



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

0300 330 0750
www.dseinternational.org



Down's Syndrome Scotland
helping people realise their potential

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

0131 313 4225
www.dsscotland.org.uk

Further information about heart related issues is available from



British Heart Foundation
180 Hampstead Road
London NW1 7AW

0300 330 3311
www.bhf.org.uk



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

0800 854 759
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



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

01709 761450
www.phassociation.uk.com



dhg

down's heart group

Tel:
Email:
Write:

0300 102 1644
info@dhg.org.uk
PO Box 4260
Dunstable, LU6 2ZT

New Fundraising Initiative

Sainsbury's and Give As You Live have teamed up to offer DHG a fantastic new way of raising funds without it costing anyone anything!



The prepaid Everyday Shopping Card can be used in store for most purchases. You simply upload money onto the card before you shop via debit card or mobile phone. Every time you add money to your card DHG will get a donation of 4% (£2 for every £50 uploaded). You can still use your Sainsbury's reward card.

It is easy to keep track of money spent with the Everyday Shopping Card so it is ideal for students living away from home or someone who needs a little support.

Getting a card is easy, simply apply online, wait for your card to arrive in the post, activate it by following the instructions, upload money to it and enjoy shopping, knowing that you are supporting a good cause at the same time.

www.raisewithsainsburys.com/?cid=315

The Information Standard



Certified Member

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.