



dhg

down's heart group

Newsletter Autumn 2016

Issue 59



In this edition -

***Twycross Zoo - what a fab meeting!
Jessica's Journey,
Member Stories and More!***

Outgoing Chair's Report

Hello everyone,

As many of you know I have stepped down as Chair. Thankfully, life is more settled now, so I can remain on the committee. Thank you for my beautiful bracelet, it will remind me of my nine years as Chair and many years involvement with DHG.

The AGM went well, it was lovely to meet new faces. Helen, our new Chair, has some great ideas and I'm sure the committee and members will give her the support and encouragement she needs to implement change and development.

I write this after reading the report on the latest review for paediatric cardiac services. Let's hope the new standards are implemented quickly to ease the anxiety of families and staff.

Have a great summer.

Regards

Chris Stringfellow

Cover Story

Sarah John and Dan Brown have spent their lives defying doctors and proving that you can have a good time despite having unrepaired heart conditions! They have become firm friends through attending various DHG events, Twycross Zoo being the latest.

Contents

Sarah and Dan	Front Cover
AGM and zoo report	4
Member's stories	6
Easy read pages	10
Fundraising	12
Information	14
Messages of support	Back cover

Letters and articles reproduced in this newsletter express the opinions of the authors and are not necessarily representative of the views of Down's Heart Group. Original material may be reproduced provided Down's Heart Group is credited. Permission for other items must be obtained from the original source.

Chair's Report



Hello, my name is Helen Laverty and I have the privilege of being the new Chairperson for Down's Heart Group.

I look forward to getting to know you all over the coming months.



It's all a bit scary because Chris has done such an amazing job!

And with your help I aim to do the same.



One of my plans is to recruit Chair's Ambassadors from across our membership who have Down's Syndrome.



We will then promote and encourage smaller fund-raising events to bring the communities together.



For now let's celebrate the marvellous achievement of Jessica's Journey.

With every good wish

Helen Laverty

AGM Report



The Annual General Meeting was held on Saturday 18th June in the Window on the Wild room at Twycross Zoo. The room was perfect with views across a pond which kept the little ones entertained, spotting the ducks. There were also activities to do to stop them getting bored whilst the adults got down to business.



Penny and Chris welcomed everyone and after a couple of technical hitches the meeting seemed to be over in a flash. It was great to see such a good turn out of delegates who were there to support DHG as well as getting to spend the day at the zoo.

Chris Stringfellow officially stepped down after nine years as Chair. We are very pleased that she is able to stay on the committee. Chris was presented with a Nomination bracelet with an opal heart charm as a thank you for her hard work and commitment over the years.

Helen Laverty was elected Chair. She spoke of the ideas she has for taking DHG forward; having a presence at local level, fundraising and working even more closely with other organisations and professionals.



Peter John remains Vice Chair, Phil Thorn stayed on as Treasurer and Mike Halpin as Secretary. Alice Croot is Fundraising Officer and Richard Mowberry and Roberta Nathan remain as committee members.

The Annual Report and accounts were presented, anyone wishing to view a copy should contact Penny. DHG is in a stable financial position but needs to work hard to sustain an income of funds.

Photos on page 4 and 5 by Catherine Clough

Twycross Zoo

The Down's Heart Group trip to Twycross zoo was a fantastic day out. It began straight after the AGM with everyone dashing off to find their favourite animals followed by finding their favourite food to bring to the lunchtime get together!

The weather was good and despite getting chilly it didn't stop Lily and Oliver having fun in the Wet and Wild area! They also enjoyed watching the elephants.

Olivia's sudden high temperature nearly brought an early end to her day but luckily she rallied after medicine and managed to see most of the animals, thanks to her poor mum carrying her most of the way!

The baby bonobos and chimps were very popular and far better behaved than their parents, who gave a fantastic, energetic, but violent display when the keeper was getting their tea ready. They did make us laugh with some of their tricks!

We were able to watch the penguins and their underwater antics through the glass wall and the giraffe enclosure has a viewing gallery which put us level with their heads and very long tongues.

The best experience of the day was the "walking with lemurs" enclosure where visitors can wander through the undergrowth with families of lemurs skipping and jumping around, getting within centimetres of anyone who stood still long enough. Emily didn't enjoy it quite as much as she was sure they would bite! It was also wonderful to watch the spider monkeys interacting with the children, running alongside the glass and playing peek-a-boo, making the kids squeal with delight.

It was lovely to meet so many families and put faces to names. Thank you all for coming along.

Where shall we go next?

Sarah Smith, Information Officer



Lily and Oly with elephants



Nilly



When I was pregnant I knew it was a girl, I had many dreams for my daughter, like her becoming a Kandyan dancer, but throughout my pregnancy, things did not feel the same as for our son. The moment I saw Nilshani's face, I knew that there was something wrong, but like any other mother, I just rejected the idea. I thought it can't happen to me. Eventually I had to face the truth and it was not easy, I had many sad times, I cried my heart out, but then I stood up strong to face the world with my daughter.

Nilshani, known as Nilly, had an ASD and also a cleft palate. When she was three months old, she developed a kind of fit called Myoclonic Jerks. At a year old we travelled to London for surgery on her cleft palate, followed immediately by heart surgery at Glenfield. After that, we saw a remarkable improvement in her growth.

Nilly faces her medical issues with courage

However, by the time Nilly was two and a half years old, her hips became unstable, she could dislocate them by herself. She was not able to walk properly so she had to be put in a plaster cast from her hip downwards. She was in braces until she was five, when at last her walking improved. Even now, she has a lot of medical issues, but she faces them with courage. She is a very cheerful girl otherwise we would have found it very difficult to put her through all these procedures.

Every time we took Nilly for her medical treatment, our son, Aiya, went with us. When I couldn't attend to our son, my husband helped out, we never missed a Parent's Day or a sports meet. Aiya became the Head Prefect in a private school in Colombo. He went to university in the USA, did his Bachelor's and Master's degrees, and is now working. He speaks to Nilly at least every couple of days. I thank God we have such an understanding son.

No school would take her

Finding a school for Nilly was extremely hard, there were no units for special needs children in private schools. No school was willing to take her, let alone accommodate her in a normal class. The then Bishop of Colombo helped us and finally the former Principal of Bishop's College decided to take her in.

I wanted Nilly to achieve what most people of our country thought a child with special needs could not. Some lessons were very hard for her, we had to teach her how to concentrate and even to answer. I knew she could do it, but maybe a little differently.

At sixteen, Nilly sat the Ordinary Level examination and passed all four subjects she sat, and even got an 'A' for English! This is rare for any student with Down's Syndrome, especially in Sri Lanka, and Nilly's story ended up in the national newspaper!

I learnt never to give up, to try and then try another way. It doesn't have to be what used to be.



I knew she could do it, but maybe a little differently

Nilly says: *"I love my family so much. Aiya is my hero, I'd like to go to university like Aiya and make my dreams come true. I miss my Aiya so much.*

My school is my second home. I like the interval; that's my best time as we get together and talk about songs, latest designs and TV shows. I learn a lot from my friends. We have lots of fun together and they are always around when I need them. We go to parties, spend the days together and have a good time.

Studying was easy because I want to be like Aiya and my friends. I find it difficult to read. I did lots of question papers. Aunty Shenenka, my speech therapist, taught me how to do the paper fast by tapping the pencil on the table.

I enjoy Guiding and Designing Club. I love to act and dance and I sing at the Soul Sounds Academy. I would like to become a fashion designer and to model clothes. I also love to cook.

I would like to become a fashion designer

I am waiting to go to the saree party of our batch and the Past Pupils Dance."

Nilmini De Silva, Sri Lanka



Tegan



My cousin Tegan, aged fourteen, has a passion for helping 'poorly people' and has taken part in many fundraising events. In 2012 our Nana Rita became ill with cancer and we would look after her by bringing her food, cooking meals, cleaning the dishes and towards the end, helping her wash and dress. A few days before she died she was admitted to St Anne's hospice where we visited her each morning and evening.

Tegan wanted to help with the other poorly people there so I explained that we could raise money and we got planning. Tegan suggested selling Christmas stockings and headbands with diamantes. We raised £500 for St David's and St Anne's hospice in memory of our Nana.

Last year Tegan saw an advertisement for 'Race for Life' on the TV and said *"My Nan had cancer I want to do that for money for poorly people!"* So Tegan, myself, her mum and our friend signed up. Tegan raised over £800, and including our sponsors we raised well over £1,000 all together!

Each Christmas Tegan uses her pocket money to buy warm clothes, food and toiletries to makes up boxes for homeless people. Again she saw this advertised on the TV and had to take part. This year she raised money for the Little Princess Trust after she saw a TV programme about a poorly little girl. She had her hair cut at the Celtic Manor and donated her hair to the Trust. She then arranged a sponsored walk with her cousins and raised £748 for the Little Princess Trust!



*Tegan with Chris Holder,
speedway star*

Tegan is a big fan of speedway. Last year a speedway rider called Darcy Ward had a very bad crash, leaving him disabled. The day before the Grand Prix, speedway riders and fans arranged a sponsored walk to raise money for Darcy. Tegan took part in the final two miles to the Principality Stadium in Cardiff.

*Tegan was born with pulmonary stenosis, AVSD
and Fallot's tetralogy*

She has been dancing since the age of three at Vanessa Clarke School of Dance and takes part in six charity dance shows and a pantomime every year. Tegan struggles sometimes and has to try harder than her friends to keep up with the choreography but she always pulls it off!

When she was four years old Tegan had open heart surgery, due to her being born with pulmonary stenosis, AVSD and Fallot's tetralogy and was in hospital for three weeks after this major surgery. Despite being really poorly she still managed to dance in her dancing show a month and a half later raising money for the British Heart Foundation and Bristol Children's Hospital!

Tegan became really ill again when she was nine years old, she developed micro plasma pneumonia. She was admitted to intensive care and her organs were shutting down but in true Tegan style she fought her way through it!

In June this year she was diagnosed with Bell's Palsy but as the weeks have gone on she is recovering and back to her normal self!

She is such a well thought of little girl with a lot of family and friends around her that love her!

*Vikki Wright (Tegan's cousin, side kick and partner in crime!)
Newport, Wales*

Sailing

DHG member, Alice, enjoys sailing at Lackford Lakes with WASH Sailability, a sailing group running under the national RYA Sailability national scheme at St Edmundsbury Sailing and Canoeing Association.

The sailboats have extra long sterns so are virtually impossible to capsize, but a safety boat and several volunteers are on standby, just in case! There is also a hoist to get wheelchair users on and out of the boats.

WASH sail every Tuesday and every other Saturday from April to September. The scheme has a Facebook page, WASH SAILABILITY or email

Washesailability@mail.com





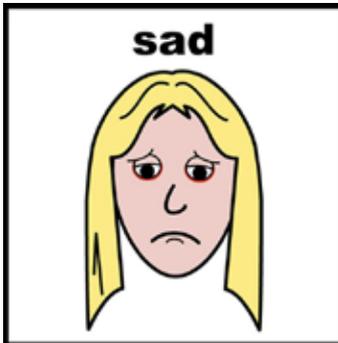
Department
of Health

The Department of Health is planning to stop having nurse advisors.



This includes our friend, Ben Thomas, who came to our conference.

He is the nurse advisor for people with learning disabilities.



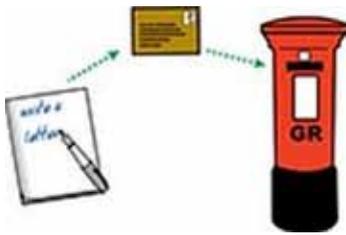
When things go wrong in services new reports are written.

Changes are made so that things do not go wrong again.



Nurse advisors are there to speak up for you.

They make sure the plans and changes are carried out.



Can you write a letter to your MP?

Can you ask them to stop these plans to scrap nurse advisors?



If you need help to write a letter ask someone you know to do this with you.

If you need more information then follow this link:

<http://bit.ly/1UyPSY2>



If you have an email address you can sign the petition here:

<http://bit.ly/28Sz0g7>



Please ask your friends and family to write a letter or sign the petition, too.

Give As You Switch



Raise up to £17 in donations for DHG when you get a great deal comparing or switching a range of policies via Give as you Switch

tinyurl.com/dhgswitch

London Marathon 2017

Down's Heart Group needs runners for next year's London Marathon.



If this is something you have always wanted to do please let us know. All runners will go onto the DHG list and places are allocated after the marathon ballot has taken place.

If you are allocated a DHG bond place you will need to raise a minimum of £1500 to cover costs, but if you get your own place there is no lower limit, we are grateful for any amount!

Why wait for London? There are many marathons around the UK or indeed, the world, so please consider fundraising for DHG when participating in any event. We provide sponsor forms and help with ideas to boost your totals.

0300 102 1644

info@dhg.org.uk

Cards For Causes



Raise up to 6% in free donations for Down's Heart Group whenever you buy or top up with Give as you Live's store cards for Starbucks, M&S, Cineworld, Argos and loads more!

Simply buy or top up a store card from the website to use in your favourite stores or online. It really is that easy!

tinyurl.com/cforcdhg

Jessica's Journey

Jessica's Journey took place from 6th to 13th August, starting from Dalmeny Hotel in St Annes-on-Sea and finishing at Ilkley Tennis Club, 100 miles away!

This fundraising walk was in memory of Jessica Ruppli, who sadly died at the age of 25. Her mum, Ghislaine, and younger sister, Rebecca, were joined by many along the way, either walking or showing their support. Another sponsored walk in Geneva in October 2016 will also raise funds for Down's Heart Group.

Jessica was born in Switzerland, but spent a lot of time in Ghislaine's home county of Yorkshire, visiting many of the places included in the walk. She spent happy holidays at the Dalmeny Hotel and was also a regular visitor to the Freedom of Spirit Trust for border collies near Bingley. She had her own sponsor dog, Tweed, who joined the walk at Eldwick for part of the journey.

Jessica had a passion for tennis and was a good player, due to the time and encouragement from former top ten player turned coach Jonas Svensson. So the family were delighted when Mats Wilander donated signed T-shirts and amazed when Roger Federer donated signed and authenticated items, including his winning kit from the Basel Swiss Indoors Open Championship! These valuable items will be lots in an auction due to take place after the October walk.

Prior to and during the walk many famous faces sent video messages of support, these can be viewed on the facebook page

[facebook.com/Jessica.100milesandmore](https://www.facebook.com/Jessica.100milesandmore)

To make a donation please visit

uk.virginmoneygiving.com/JessicasJourney100miles

Or send a cheque payable to Down's Heart Group (reference Jessica's Journey) to
PO Box 4260, Dunstable, Beds LU6 2ZT.

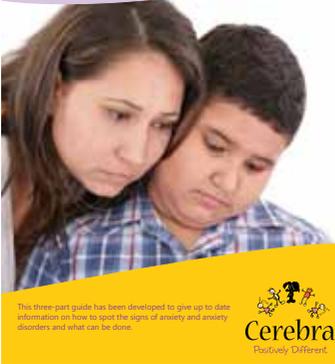
DHG Director, Penny, walked the last five miles in Yorkshire and will be participating in the Geneva event. Due to mobility issues this is some achievement! Penny has been involved with Jessica's family for many years and this could be her last sponsored event before she retires in 2018. To sponsor Penny go to

uk.virginmoneygiving.com/PennyGreenDHG



Anxiety Guide

Cerebra Anxiety Guide.
A Guide for Parents



Cerebra, a charity helping children with a wide range of neurodevelopmental disorders and conditions, has produced a booklet with up to date information on how to spot the signs of both anxiety and anxiety disorders.

It is a three part guide; part one describing common signs of anxiety, part two explains how professionals assess children with learning disabilities and part three gives guidance on helping your child reduce feelings of anxiety and gives some examples of specific disorders associated with it.

tinyurl.com/anxcerdhg

Bedside Communication



Widgit Healthcare has a range of free resources to help with communication whilst in hospital. The bedside message cards have 26 key phrases for patients supported by symbols. These can be used by the patient to express a range of emotions, needs and level of pain.

tinyurl.com/bedmesdhg

Patient Films



University College London Hospital and Camden Advocacy have produced several films explaining what patients can expect when visiting various departments and clinics.

These films will hopefully help lessen health inequalities due to poor communication and misunderstandings and make attending hospital a far better and less confusing experience for people with learning difficulties.

www.uclh.nhs.uk/ld

The Carter Report

Special Needs Jungle creates easy to understand resources, articles and information for parents and carers of children with special needs to better enable them to navigate the special needs system. They inform, educate and empower families to self-advocate confidently, so their children get the help they need.



One of Special Needs Jungle's latest articles is on "*The Carter Review of Initial Teacher Training*" and the fact that from now teaching children with special needs will be a core part of Initial Teacher Training.

The Carter report says that providers should ensure trainee teachers understand they are obliged to set high standards to inspire, motivate and challenge all pupils for whom they have responsibility, including pupils who might have special educational needs and disabilities.

The government has accepted the report's findings and the new guidelines will enable new teachers to be more effective and confident when supporting pupils with learning difficulties in the classroom.

www.specialneedsjungle.com

Cinnamon Trust

The Cinnamon Trust charity honours the special relationship between owner and pet. It enables the elderly or terminally ill to continue living with their companion until the very end. If an owner dies pets are rehomed or looked after by foster carers. The Trust also offers short term care whilst owners are in hospital.

15,000 volunteers help with all aspects of daily pet care, dog walking or helping to look after cats, rabbits and birds. This reduces owners' anxiety over their animals' welfare, leading to happy owners and happy pets.

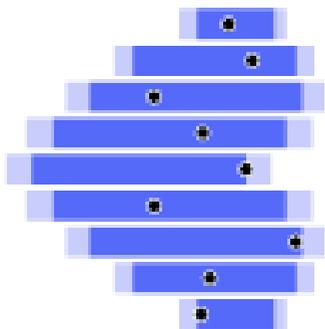


The Cinnamon Trust needs more volunteers, including those with a learning disability. Volunteers and dog walkers are allotted "*jobs*" that suit their circumstances and are given on-going appraisal and guidance. To get involved contact The Cinnamon Trust on:

01736 758707

www.cinnamon.org.uk

Understanding Children's Heart Surgery Outcomes



A new website has been launched to help reduce confusion about children's heart surgery statistics for the UK and Ireland.

It was developed by Christina Pagel from University College London and Sir David Spiegelhalter from the University of Cambridge, in collaboration with the charity Sense about Science and experimental psychologist Tim Rakow from King's College London. The website explains a risk adjustment method known as PRAiS (Partial Risk Adjustment in Surgery).

Each hospital performing children's heart surgery in the UK and Ireland has had its overall survival rates published by the National Congenital Heart Disease Audit (NCHDA) since 2013. The researchers used PRAiS to calculate a predicted range of survival for each specific hospital, taking into account the complexity of each individual child's medical condition and surgery.

childrensheart surgery.info

Changes For DLA In Hospital



Parents of children admitted to hospital for long periods will no longer have to struggle with the loss of their disability living allowance as well as dealing with illness. Previously, children who spent more than 28 days in hospital lost their entitlement to DLA. The DWP had argued that this was because the NHS, rather than the family, was providing attention and supervision for the child, however, the reality is very different, with families being expected to provide huge amounts of support.

The Mathieson family argued that the removal of their son's DLA was a breach of his human rights and took their case all the way to the supreme court, fighting on even after Cameron's death for the sake of other parents in the same position.

The supreme court upheld their claim in July 2015 and now the DWP has changed the law so that children admitted to hospital before their eighteenth birthday will continue to be eligible for DLA and will also not be obliged to make a claim for PIP instead whilst they remain in hospital.

tinyurl.com/newhospdla

Congenital Heart Services Review

The outcome of the Specialised Services Commissioning Committee (SSCC) review for CHD was announced at the beginning of July and has attracted a lot of media coverage and worry from concerned families. The SSCC reviewed the findings of a long consultation with all units, interested professional groups (ie Royal Colleges), patient groups, patient and parent representatives.



This review was not brought about as a cost cutting exercise but by demand from patient groups, including DHG, who had long worried about the failure to implement some of the most crucial recommendations that came out of the original Bristol Inquiry in 2001.

The new standards will ensure safety and equality for patients across the country. Units carrying out surgery must have teams of four surgeons and see at least 125 patients per year to ensure they maintain and improve their skills, provide secure on-call rotas, disseminate new techniques, and train the next generation of specialists. Outpatients and many other routine procedures will still take place at other hospitals, which will hopefully limit travel worries for parents.

There will be further consultation before any reorganisation or movement of services takes place but it is hoped this will not delay things further and we can look forward to an improved, safe service for all.

In addition to the big changes planned, there is a list of standards affecting communication with patients and families in all centres, such as making sure parents have the chance to discuss planned surgery, have access to a cardiac nurse specialist and be given a copy of all correspondence in plain language.



A practitioner psychologist experienced in the care of paediatric cardiac patients must be available to support families and young people at any stage of their care, families should be told about support groups and also how to claim travel expenses and how to access benefits. A list of these standards should be available shortly on the NHS website. They all have an implementation timescale between immediate and a year.

The full report can be seen at:

www.england.nhs.uk/2016/07/chd-future

The new standards can be viewed at:

tinyurl.com/chdstan

Special Facial Characteristics Voucher



Thanks to a two year campaign by Simon Berry, an Optometrist specialising in children's eye care, Special Facial Characteristics Vouchers towards the cost of glasses frames are now available for all children with Down's Syndrome, whether they attend hospital or local opticians, wherever they live in the UK.

Our children often have smaller noses or wear hearing aids as well as glasses making suitable frames more difficult to find and expensive. Specialist frames mean a better fit, fewer repairs and better vision.

William Dean with Simon Berry

Simon's campaign, backed by DHG, many other organisations and MPs, has persuaded the NHS to change the regulations on funding, giving parents wider access to financial help towards buying specially made glasses for their children.

<http://tinyurl.com/glassdhnew>

SeeAbility



SeeAbility and the Local Optical Committee Support Unit are calling for an overhaul of NHS England's sight testing and funding system. SeeAbility's report, 'Delivering an Equal Right to Sight', launched in July, found that one in ten of the learning disability population will be blind or partially sighted and six in ten will need glasses.

Recent studies indicate four in ten of the 100,000 children in special schools have never had a sight test and half of adults have not had one in the recommended period. Children with learning disabilities are 28 times more likely to have a sight problem.

Currently there is no NHS plan for eye care and new national learning disability strategies hardly mention the risk of sight problems or the need for checks. The current NHS contract fails to recognise that people are likely to need additional time or appointments to complete a sight test, as well as better support with glasses. SeeAbility highlights the need for awareness training in health and social care on sight problems in people with learning disabilities. Eye care services also need to provide accessible information and reasonable adjustments.

To sign the petition calling on NHS England to deliver a more inclusive system and offer free sight tests for all working age people with learning disabilities, please go to:

www.seeability.org

VISION 2020 UK

VISION 2020 UK is a registered charity uniting organisations with an interest in eye health across the country. It was established in 2002 as part of the VISION 2020 Global Initiative. There is a Learning Disability Group, with experts from the eye health, sight loss and healthcare sectors, which focuses on the specific needs of children and adults who have a learning disability.



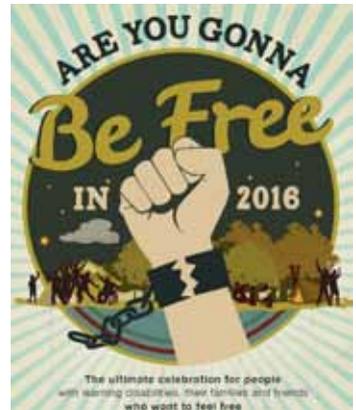
www.vision2020uk.org.uk

Festival Time

Paradigm is holding a festival for people with learning disabilities, their friends and family from 13th - 15th September 2016 in Chingford, London.

Camping and Glamping are available as well as a long list of activities including; Silent disco, pop-up cinema, DJ workshops, live bands, climbing wall, archery, zip wire, 3G swing, grass sledging, free fall jump, pamper zone, T-shirt making, art and drumming workshops and much, much more!

A full-festival pass is £185 + VAT and a Wednesday pass (main day) is £50 + VAT. For more details contact



020 8870 8643

loreb@paradigm-uk.org

tinyurl.com/befreeevent

Benefits and Work

Benefits and Work was formed in 2002 by barrister Holiday Whitehead and benefits writer and trainer Steve Donnison. It became a limited company in 2006 and is independently funded by member subscriptions.

Benefits and Work
Guides you can trust

They publish independent and accurate information on how to claim and keep benefits like ESA, DLA and PIP, offering information sheets and a website forum.

www.benefitsandwork.co.uk

Gwen Moulster OBE



Congratulations to Gwen Moulster, who as well as being awarded an OBE for services to nursing and people with a learning disability, was also named one of Nursing Times Inspirational Nurses of the Year and received the Royal College of Nursing award for learning disability nursing.

Gwen, a consultant learning disabilities nurse at South Staffordshire and Shropshire NHS Foundation Trust is celebrating 40 years in learning disability nursing. She was one of our conference speakers in 2015 when she spoke about the HEF (Health Equality Framework).

Gwen has worked with people of all ages and all levels of disability from mild to the most profound and complex. One of her most recent successes has been to help implement an intensive support team whose main purpose is to ensure people can be treated in their community, rather than going into hospital.

Gwen says, "I am so grateful to have found a career that offers so much fulfilment and I consider it a privilege to have been able to work with people with a learning disability. They are so honest, what you see is what you get, and I am proud to have spent time with such amazing people. Receiving an OBE is a huge honour but I have only been able to achieve what I have because of the people I have worked with; people with learning disabilities, their families and carers and my colleagues."

Workforce Development



The Foundation for People with Learning Disabilities is asking people with learning disabilities in Kent, Surrey and Sussex what they would like their workforce to know in order to support them.

The FPLD team will hold a series of workshops and one to one interviews with people over the age of sixteen across all three counties. They need to gather the views of family and support workers too.

The project finishes at the end of August 2016, so please get in touch as soon as possible if you are able to contribute. Participants will receive a voucher as a small token of appreciation for their time and expertise. To take part in either the workshops or completing the questionnaire contact Jill Davies at:

020 7803 1141
jdavies@fpld.org.uk

Together We Will

A new three month national campaign was launched in July to encourage and support disabled people, along with their friends and families, to become more active. The Together We Will campaign looks to address the low number of disabled people who regularly take part in sport as highlighted in the Sport England Active People Survey.

Results show that disabled people are half as likely to be active as non-disabled people. Research highlights often disabled people do not find opportunities accessible or appealing enough, or cannot find the right information.

Other insight shows that disabled people are keen to involve family and friends when being active and do not necessarily want to take part with just other disabled people. Fun is also highlighted as a key motivator for disabled people to be active.

Eight National Disability Sports Organisations, including Special Olympics Great Britain, are working together with the English Federation of Disability Sport to deliver the campaign which will help direct disabled people, their friends and family, to the recognised NDSOs for more guidance and information about being active.

specialolympicsgb.org.uk



Play Therapy Pods

Newlife Foundation for Disabled Children provides specialist equipment for children who have a disability or are terminally ill. They also loan out Play Therapy Pods which have been developed by the Newlife play specialists, each one contains over £400 worth of play equipment. There are two types of Pod, one for under and one for over fives and they offer targeted equipment for tactile, visual, interactive and auditory needs.



There are 130 Play Therapy Pods in circulation, each one being loaned free of charge to families for a period of twelve weeks. They are delivered directly to the families' homes and are accompanied by a guide on how to use the equipment as part of interactive play and developmental programmes. To find out more about the Play Therapy Pod Service, contact the Newlife Nurse Helpline on freephone

0800 902 0095
nurses@newlifecharity.co.uk

1,000 Families Study



Cerebra
Positively Different

The Cerebra Family Research Group at the University of Warwick, in collaboration with the charity Cerebra, are exploring the experiences of family members who live with a child with a learning disability aged four to eleven.

They are keen to survey at least one person per family to explore whether family members have similar or different experiences and capture the experience of the whole family.

This will be the largest study ever of families of children with learning disability in the UK. The 1,000 families study will further help to understand what it is like to raise a child with a learning disability and will help shape future information and support for families and children. To find out more about the study and to complete the online survey visit the website, or request a paper copy of the survey by emailing

familyresearch@warwick.ac.uk
w3.cerebra.org.uk

Learning Disability Alliance Update



Learning Disability England launched in June and is for people with learning disabilities, families, friends, providers, commissioners, self advocacy and carer groups, as well as development and training organisations. It aims to create a strong and authentic voice on national issues and a movement for change. They would like you to join and get involved.

In March an LDE consultation with over 900 responders revealed:

- 80% of people think Learning Disability England is a good idea or want to be involved.
- The biggest challenges facing people with learning disabilities are attitudes and the lack of opportunity and choice in their lives.
- The biggest challenge facing families is finding good support and services.
- The biggest challenge for organisations is money and funding.

The easy read results are now available at

tinyurl.com/jgcphmk
learningdisabilityengland.org.uk

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

0300 330 0750
www.dseinternational.org



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

00 3531 426 6500
www.downsyndrome.ie



helping people realise their potential

Down's Syndrome Scotland
4th Floor, Riverside House
502 Gorgie Road, Edinburgh EH11 3AF

0131 442 8840
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



Children's Heart Federation
Dragon Enterprise Centre, Cullen Mill,
Braintree Road, Witham, Essex CM8 2DD

0808 808 5000
www.chfed.org.uk



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

0800 854 759
www.guch.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:

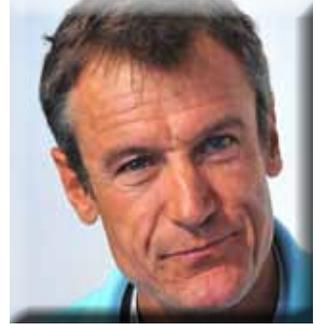
0300 102 1644
info@dhg.org.uk
PO Box 4260
Dunstable, LU6 2ZT



Gareth Southgate - England U21s football manager, says "Good luck!"



Sarah Gordy - actress, says "Best step forward!"



Mats Wilander - former tennis star, says "I hope you all support Jessica's Journey!"

Jessica's Journey - Support From The Stars!



Jonas Svensson - former tennis champion, says "Best of luck!"



Sally Phillips - actress, says "100 miles is so long!"



Chris Cohan - Notts Forest Captain, says "Hope the sun shines!"

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.