



dhg

down's heart group

Newsletter Spring 2017

Issue 61

In this edition-

Activity Weekend

Fun Day,

AGM,

Member Stories,

News

And More!



Annual General Meeting



Down's Heart Group AGM will take place at 10am on Saturday 9th September 2017 at Mount Cook Activity Centre, Matlock, Derbyshire.

We welcome new Trustees, so if you feel you could spare a few hours and help take DHG forward please get in touch for a chat about what it would entail.

All members are welcome to attend but please notify National Office beforehand for catering purposes.

Forms are available for the nomination of Trustees and Proxy Voting Forms for those unable to attend - please contact us if you require either. Completed forms must be returned to arrive in the office no later than 10am on 7th September.

There will be lunch afterwards should you wish to stay and socialise - £5 per person or £15 for a family, with under 3's free.

Why not enrol younger children in the Fun Day activities and make a day of it? Or combine the AGM with some sight seeing or walking as Mount Cook is set in beautiful Peak District countryside with trails leading from the doorstep.

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Chair's Report

Hello everyone,

I hope you've all had a healthy and happy Winter, and are now enjoying Spring! Our London Marathon runners trained very hard and I was certainly cheering them on (via the TV). I look forward to reading their amazing stories in our next newsletter.



The last few weeks have been very busy with plotting and planning for our AGM and also the activity weekend supported through 'Jessica's Journey'. As you read the newsletter there is lots of info on how to join us at Mount Cook.



I'd love for as many of you as are able to join us for the Annual General Meeting. This is an important time for us, and as well as exploring with you what we've achieved we want the AGM to be an opportunity for you to tell us what you want from your membership.



We want to be able to support you and new members in the most effective way so the AGM is a chance for you to have your say; and of course meet old friends and make new.



I look forward to seeing you in September.

Please think about contributing to our next newsletter. We always have space for words no matter how many! Stories, tips and just plain fun! I bet there are some budding young jokers out there who will send in a joke or riddle or two to make us chuckle.



With every good wish,

Helen Laverty

Thomas



I was around back in the early days of Down's Heart Group - I was East Midlands Coordinator along with a lady called Gina. We had a vast area to cover as volunteers and it was all before the internet and Facebook, so everything was done by phone, meeting or letter and information was very scarce!

Thomas was born in 1987 with an AVSD but back then his chances of surviving surgery were poor. He has spent almost thirty years with an unoperated condition!

The initial diagnosis was that Thomas wouldn't get to his fifth birthday. It was a sad time thinking that there was such a short time limit on his life. We lived in fear, which, looking back tarnished some of the good times.

There have been ups and downs throughout, but mostly ups

As you can appreciate there have been lots of ups and downs throughout, but mostly ups I'm pleased to say! I'm extremely proud of Thomas and he has managed to stay really healthy. He faces everything with a smile and we fight everything that comes our way. Just recently he was taken in to hospital as they thought he had sepsis but he defied that, too!

Love your life and live it to the full!



Thomas has a fabulous personality and I thank God for every single second I have him in my life. His speech has never been particularly good but he gets by. He developed Eisenmengers a few years ago and could suffer a stroke at any given time.

My fabulous son just proves that you should never listen to the negativity and to go with your gut instinct. We take every day as it comes and reckon you should love your life and live it to the full!

*Anna Slater,
Leicestershire*

Kate and Her Book

Kate was born in July 1994. I needed help for her to be delivered and she was bruised on her face with slight swelling where the forceps had encouraged her exit. She fought her way into this world.

She had serious cardiac issues

The day I was leaving hospital, my room was filled with doctors as they gave me the news that Kate had Down's Syndrome. Two days later we were rushed back into hospital when Kate had suffered an apnoea attack. It was also discovered that she had serious cardiac issues and needed to have open heart surgery.



I fought to get her weight up enough so that they could operate, tube feeding her every three to four hours. We had many trips to Bristol and London hospitals but after eight months she had her successful open heart surgery.

Speech and communication is a battle for Kate, she dislikes large groups of people and finds new things stressful. She has met many challenges so far, but with support, love, and a strong belief in herself she has succeeded. She lives by our motto *"If you don't try you will never know."* Last year Kate decided to run or walk the 5K Pretty Muddy challenge to raise money for cancer research. She hates getting wet and muddy but completed this with determination and a little help from her friends and although they came last she succeeded.

"If you don't try you will never know."

Kate has a passion for art, dance, drama, theatre, acting and singing. She has written and illustrated a book *"The Girl Trapped in the Musical"* with support from Alice, her personal assistant, who continually helps to inspire Kate.

The story centres around a girl who enjoys escaping into a world of musicals, away from the real world, only to find herself trapped amongst good and bad characters from various musicals. The book, along with some of the props and images used to illustrate it, were shown as part of APEX Arts in the Inland Art Festival, a contemporary art festival based in Redruth, Cornwall. Kate has raised enough money to have fifty copies printed and has applied to Waterstones to do a book launch.

*Angie Perry,
Cornwall*

Mia



Mia - courtesy of Tiny Angels

My name is Mia and since my third birthday I've gone from taking steps with a walker to walking up and down aisles in big shops trying to get away from my parents and brothers, Ethan and Austin. I'm getting very fast!

Not only that, my vocabulary has soared and my signing has taken off. I went to see Singing Hands recently and sneaked on stage but luckily the ladies didn't mind too much. I love going to nursery and I've become fiercely independent and quite the explorer, trying to climb in, on and up things! I must be making up for all those times things were a bit of a struggle.

I've even managed to land a modelling contract with the agency Tiny Angels. No castings yet but fingers crossed! With being so cute I'm sure it is only a matter of time.

So let me tell you a little bit about my heart story. After I was born, the doctor found I had a small VSD and that my PDA was making my heart whoosh, but they were so small, they told my mum and dad it wasn't anything to worry about. Things changed though when I started scooting around and bumshuffling at speed. Another small VSD was discovered and later the cardiologist found a mitral valve leak which was termed severe.

I climb in, on and up things!

So on the last day of May I left my big brothers at home trying not to worry and I checked in to Alderhey Children's hospital to have my holes closed and the PDA sorted. The surgeons were surprised when they looked at my mitral valve as it had tried to self repair and built up quite a lot of tissue which they had to trim down.



I went into theatre shortly after 9am and Mum and Dad didn't get to see me until 6pm. What a long day for them! My leaky valve could only be repaired from a severe to a moderate leak.

My mitral valve had tried to self repair

When the doctor said my parents could see me Mum nearly ran into PICU as she had missed me so much! The next morning, after a sleepy night I woke up from sedation and saw my Dad sitting there and said "Daddy". There were lots of wet eyes that morning but I didn't know what all the fuss was about!

I got upright and eating pretty quick with mum managing to breastfeed me too, and we were home by Sunday. Everyone was very pleased as we had only checked in on Monday.

I take Lisinopril daily which I take like a pro and a month after surgery my leak turned into a mild one and still is, so fingers crossed I wont need any more operations!

Since my heart surgery I've just crashed through milestones left, right and centre and it doesn't look like I'm going to be stopping anytime soon. I had a great birthday with all my nursery friends. I now have a special Waldorf doll that looks like me and has a heart beat like I do now! Mum's even knitting me a jumper to match.

Today is World Down Syndrome Day and Mum is dressing me up all week in blue and yellow. She's made WSD awareness ribbons for all the nursery workers and nursery has even done lots of socks activities!

So from me to you (with help from Mummy as I haven't learned to write yet!) Love and Hugs, Mia xxx

*Mia and Joanne Zahler,
North Yorkshire*



Rocking odd socks, Mia with dad and brothers

Dan

For the second year, Weston Favell shopping centre has celebrated World Down Syndrome Day, thanks to Dan and his mum, Eileen, asking them to get involved. They had a display, balloons and yellow and blue lighting.

Dan goes to the centre at least twice a week and is well known by all the staff. You may remember Dan from past newsletters as despite his unoperated heart condition he is always busy living life to the max!

He is pictured here with some of the shopping centre team showing off their lots of socks.



Activity Weekend



Thanks to funding from Jessica's Journey, Down's Heart Group is pleased to offer free places on our activity weekend at Mount Cook Activity Centre, Porter Lane, Middleton-by-Wirksworth, Matlock, Derbyshire, DE4 4LS.

Participants must be over sixteen with Down's Syndrome and a heart condition, (corrected or not) and be able to be present for the whole weekend, from 4pm Friday 8th September until 2pm Sunday 10th September.

They must be accompanied by a parent or carer, who will also be free of charge, but a refundable £100 deposit will be required to secure places. All food, accommodation and activities are included.

We welcome extra family members and siblings with prices starting from £67 for an extra person not joining in with the activities to £137 for siblings wanting to join in. Whilst all are welcome to apply for a place, priority will be given to those who did not go on the previous activity weekend.

Accommodation is in rooms sleeping four with two sets of adult sized bunk beds. The bunk ladders are also designed for adults! There are two fully accessible bedrooms which sleep three as a maximum, with a double sized bottom bunk with single over. Several other rooms are wheelchair friendly. Rooms will be allocated to best suit the participants. Sharing with other families will not be necessary as we all value our privacy!

The centre has ample free parking, including disabled spaces, and is near rail and coach links. The whole site is accessible for wheelchairs or those who struggle to walk too far.

Activities will include archery, high ropes and climbing, all fully supervised by trained staff and mentors and will be taken at a pace that suits everyone. The aim of the weekend is that everyone has fun, gains new skills and a bit of independence. Parents and carers will follow a separate, relaxing programme designed to help you unwind a little and get some "me" time, whilst still being nearby if needed.

We will need to know of any health problems and you must disclose any behaviour that may require extra supervision so the weekend runs as smoothly as possible. All the necessary forms will be sent out once the refundable deposit has been received. We recommend you book places ASAP as they will go fast! Please contact National Office as soon as possible to secure your places;

0300 102 1644

info@dhg.org.uk

Fun Day

Down's Heart Group are pleased to announce a Fun Day for members with children under the age of sixteen. This will be on Saturday 9th September at Mount Cook Activity Centre, Porter Lane, Middleton-by-Wirksworth, Matlock, Derbyshire, DE4 4LS.

There will be ball skills sessions - a mix of tennis and football, drama sessions and general fun activities to keep youngsters engaged and entertained. Children will be split into appropriate age and ability groups so that the sessions cater for their needs and sporting and artistic flare. Siblings are very welcome to join in so why not make it a day out for the whole family?



There will be a team of drama coaches, sports coaches and enthusiasts and crèche workers to lead the activities, giving parents a chance to chat and relax a little. However, parents will be required to remain on site throughout. We will also require you to notify us of any medical needs or behaviours that may require extra attention, so that we can get the right balance of children to helpers.

Free refreshments will be available throughout the day, but lunches at £5 per person or £15 for a family, with under threes free, must be paid for when booking places for the Fun Day.



We look forward to welcoming parents to the short AGM in the morning whilst children get stuck in to fun and games. This is a great opportunity to see what DHG has been up to over the past year and to get to know other members, "*friends*" on Facebook and DHG Trustees.

Mount Cook is set in the Peak District with trails and paths from it's doorstep whilst being easy to get to by road or rail. It provides en suite bed and breakfast in rooms to sleep a maximum of four in two sets of bunk beds. Families will not need to share with other families. There are also many hotels and guest houses in the area.

Please contact National Office as soon as possible to book places. Bookings must be made by Monday 14th August. Please make sure you let us know how many of you are coming even if you do not require lunch.

Please don't hesitate to get in touch for more information.

0300 102 1644

info@dhg.org.uk



Hi, everyone!



Changes are happening at some heart hospitals.

Find out more by looking at the easy read leaflet here tinyurl.com/dhgeasy

Or watch a video here [youngpeoplechd.co.uk](https://www.youngpeoplechd.co.uk)

And tell the NHS what you think.



What are you doing on the weekend of 8th - 10th September?

Are you an adult or over 16 years old?

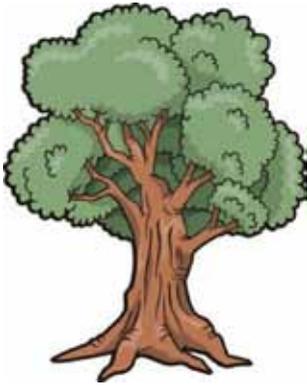
Are you coming to the Activity Weekend?

Come and have an adventure like Tom in the photo!



Are you coming to the Fun Day instead?

Come and make new friends!



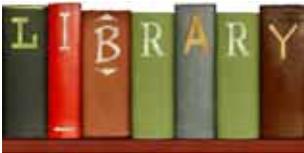
Can you tell me about your favourite books or bedtime stories?

Mine was always the Magic Far Away Tree.



As a grown up I love Harry Potter!

All of the books are brilliant.



Listening to stories and learning to read words, symbols or pictures is so important.

Let's have a library corner section for our next newsletter.



Send us a book review about your favourite book.

The best one will Win a £10 Amazon voucher!

Christmas Day Swim



Carolyn Schofield took part in the annual Weymouth Harbour Christmas Day Swim and raised £250.50 for DHG. She decided to do it for her godson, Liam Tolton, who has Down's Syndrome - and had never done anything like it before.

The Christmas Day swim was started just after the Second World War by two local publicans. It is now run by Weymouth and Portland Lions Club. Perhaps we could have a DHG team there next year?

More than 300 swimmers, most in fancy dress, and thousands of spectators attended the event. The atmosphere was great, despite the rain. The swimmers set off in stages and Carolyn had to swim from one side of the harbour to the other, where warm clothes were waiting.

Well done, Carolyn, and thank you.

Otley Beer Festival



Peter, left, receiving cheque

Terry John was approached by a committee member of the Otley Beer Festival after the local press had covered Jessica's Journey. She and husband Peter, DHG Vice Chair, were able to explain what DHG does, which resulted in a £200 donation.

The Otley Beer Festival started about twenty years ago to help raise funds for the local church roof. Over the years it has grown considerably and has been able to help charities, both local and national, as well as the church.

Cheers, Otley Beer Festival Committee!

Surgery Collection

Pictured are some of the members of the Preseli GP Practice team based at Newport Surgery in Pembrokeshire. They are proudly holding their certificate, donation box and stamp collection box. Staff decided to donate money to Down's Heart Group instead of sending Christmas cards last year and £70.00 was raised.



They will continue to collect used postage stamps at the Practice for DHG, who send a big thank you to staff and patients for their kind donations.

Julie Evans, Practice Manager, has personal experience of the *“wonderful help and support available from DHG and will always be thankful.”* Her daughter Gwen underwent heart surgery in 1999 and is now a healthy eighteen year old attending college.

It's great that such a simple idea can raise funds whilst not wasting paper and cash, not to mention the time it takes to write the cards out!

London Marathon

By the time you read this newsletter the 2017 Virgin London Marathon will be over and the six DHG runners will hopefully be recovered from the gruelling ordeal. Perhaps they are already applying for next year's ballot?



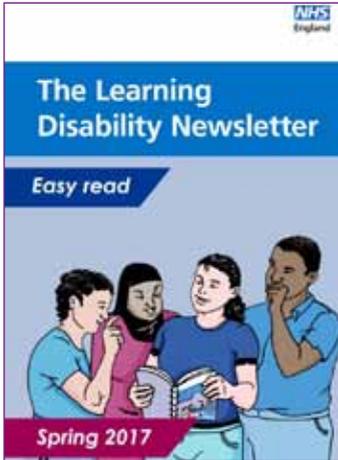
Cheeky monkeys! Ella was Suzie's inspiration to run

This year's Marathon had a *“siblings”* theme to it with five of the runners being brother or sister to our fabulous members. The only non sibling was Suzie Foster who ran to say thank you for the support her friend Anne-Marie Turner received when daughter Ella was small.

Noah and Yoel Levy are brothers to Hannah, who was a Games Maker at the London Olympics. Talulla Barrow ran for her brother, Barnaby, who featured in the newsletter a year or so ago and Andrew Vine's sister, Karen, has an unoperated AVSD and his family have been members since the beginning. Rebecca Ruppli ran in memory of her sister Jessica, following on from the wonderful success of *“Jessica's Journey”* last summer.

There will be a full report of their experiences and fundraising in the next edition, when we will be saying a huge thank you once again.

Learning Disability Update



NHS England publish three easy read newsletters for people with a learning disability each year. They are available to read online and the recent topics include personal health budgets, transforming care partnerships and health screening.

To subscribe to receive the Learning Disability Update via email, or to give NHS England feedback on these newsletters, email

LDEngage@nhs.net

GHP Awards



Down's Heart Group has been crowned "*best Down Syndrome Not For Profit Organisation 2017*" for the UK at the Global Health and Pharma awards.

This was a very pleasant surprise and made us feel quite proud!

111 Video



**when it's less
urgent than 999**

111 is a phone number you can call for advice if you feel unwell but it is not an emergency. Many people, especially those with a learning disability, do not know much about it, so NHS England has made a video called 'Inclusive NHS 111' which explains what the 111 service is and when and how to use it.

To find "*NHS 111 An Inclusive Service*" on YouTube follow the link:

tinyurl.com/gl6kw88

CHD Consultation

There is a new consultation open until 5th June 2017 for people to find out more and have their say on the latest Proposals for Congenital Heart Disease Services.

In July 2016, NHS England published a set of proposals regarding the future commissioning of congenital heart disease (CHD) services for children and adults. They describe the actions which the NHS wish to take in order to ensure a consistent standard of care for CHD patients across the country, for now and for the future.



The NHS propose to do this by implementing national service standards at every hospital that provides CHD services. The effect of these proposals, if implemented, will be that some hospitals will carry out more CHD surgery and catheter procedures, while others, which do not meet the relevant standards, will stop doing this work.

The public consultation for Proposals for Congenital Heart Disease Services aims to provide information about the proposals, and the potential impact they may have, if implemented, on the delivery of services, and to seek your views about these plans. During the consultation period there will be several face to face events around the country and a series of webinars. There is now an easy read survey and a website aimed at children and those with learning disabilities, so that they can get involved, too. See our Easy Read article on page 10 for details.

To read more about the consultation, to fill in a survey or to register for the events, go to

www.engage.england.nhs.uk/consultation/chd

My Therapy App

MyTherapy app is a new smartphone and iPad app that reminds patients and their carers when to take medication. It can also be used to track health by monitoring blood pressure, weight and even symptoms.

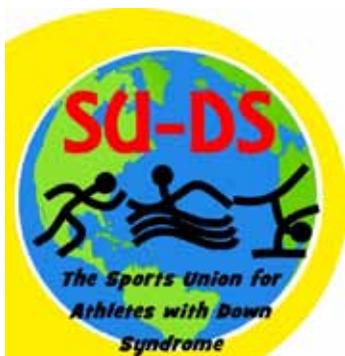
Data can be printed off to share with healthcare providers to help with any ongoing conditions. Statistics indicate that 89% of people using the app now take their medications correctly and 78% of doctors are finding it a great tool. MyTherapy app is available for free from



www.mytherapyapp.com

Trisome Challenge

The date has now been set for Saturday 11th November for this year's Trisome Challenge. It will be held at the Xcel Centre, Coventry, CV4 8DY.



The Trisome Challenge is supported by the Charity "English Disabled Sports Team Championships". It is a sporting event where teams compete together in a swimming relay, darts, table tennis, bocchia, indoor kurling and an obstacle relay. There will be many prizes and items for taking part.

The event is open to anyone with Down's Syndrome and their "buddy", who can be a parent, sibling or friend (without disability). Teams of two must comprise of one male and one female and it costs £30 per pair.

Entry forms, which should be returned by 1st July, are available from

CEO@SU-DS.org

www.SU-DS.org

Special Zoo Days



Special Children's Days are annual events at ZSL Whipsnade Zoo and London Zoo, welcoming children with special needs and their families and friends. With increased specialist facilities and number of staff, as well as interactive events and discounted entry, Special Children's Days are exciting and exceptional events.

The days include a dedicated entrance with staff, animal-costumed characters and volunteers on hand to greet guests, free day planners, Singing Hands, wildlife gardening, sensory storytelling, talks and an art zone. Meet some of the fantastic animals and keepers, get close up and hands on in the 'Touch Paddock', or play in the splash zone, secret garden and tunnels. If all that gets too much, there is a chill out room, too.

Special Children's Days at London are 6th and 7th May and at Whipsnade on 17th June. As this is short notice for the London dates if special tickets are sold out, standard admission tickets can be bought but once inside all activities are free for all visitors.

0344 225 1826

info@zsl.org

www.zsl.org/zsl-london-zoo/whats-on/special-childrens-day
www.zsl.org/zsl-whipsnade-zoo/whats-on/special-childrens-day

Green Light Trust

Green Light Trust is based near Bury St Edmunds and has been working in communities across the East of England and beyond since 1989. It runs a programme where participants can enjoy working outside in a woodland environment. They learn about the flora and fauna, woodland conservation, how to use tools safely, to cook over an open fire and make green wood items like garden furniture.



Each participant has their own set of targets to ensure progression including written and oral skills as well as ABC qualifications. Green Light Trust can offer a free taster day for prospective participants and up to five friends and family to join in to see if the programme is right for them. The day will run from 10:30am to 3pm and include a walk in the woods and an introduction to general conservation work and bush craft activities.

01284 830829

info@greenlighttrust.org

www.greenlighttrust.org

Pony Axe S

Pony Axe S makes the countryside inclusive at last! It takes people who use wheelchairs to all the places where wheelchairs can't take them. With inbuilt ramp and easy loading there is no need to transfer to all terrain or beach wheelchairs and no need to leave the wheelchair behind. Pony Axe S takes the person, in their wheelchair, anywhere - across beaches, along rough tracks, through mud or long grass. All those places they never thought they would get to are all possible.



Simon, the buggy's inventor, says *"Pony Axe S is about access. We take people into the countryside for a picnic, or to watch the birds, study butterflies, strange rock formations or walk their dogs. We can park you in your wheelchair to paint, or photograph or snooze, chat, drink or whatever. Liking ponies is a bonus but this is not a pony based activity."*

Simon and his ponies are based in the South West but he is trying to get the buggies out across the UK and beyond.

simon@ponyaxes.com

ponyaxes.com

Harvey Hext Trust



The “*Harvey Hext Trust - A Sibling’s Wish*” is a charity supporting children grieving a sibling’s death. Harvey was a lovely young man with Down’s Syndrome who sadly died in 2015 from cancer. His twin brother, Spencer, and big sister, Olivia, were given a cardboard memory box, but their Mum, Sarah, felt this was not durable or special enough to keep such treasured memories in. Instead, she worked with Olivia and Spencer to design a personalised, wooden memory box to keep all their important mementoes of Harvey in.

This gave her the inspiration to set up the charity. It works to help bereaved children design bespoke memory boxes using their own choice of images, special drawings and themes. The design is then printed and heat wrapped onto an A4 sized wooden memory box, creating a beautiful place for them to keep their important keepsakes. The children are also given a ‘Harvey bear’, which has a concealed pouch to keep their favourite item from their sibling in, so they can keep it with them at all times.

Sarah believes the memory boxes are an important part of therapy to encourage children to show emotions and to talk about their bereavement. The boxes are a simple but effective way of helping a sibling remember their brother or sister and the box is their own to keep forever. The charity does not charge families for the service.

www.asiblingswish.com

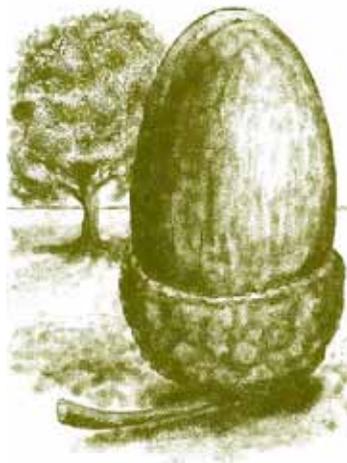
Positive Choices

Hull, “*City Of Culture 2017*”, was the venue for Positive Choices in April. Hundreds of Learning Disability Student Nurses attended the two day conference which, as always, was full of learning, inspiration and fun.

DHG had a stand and took part in the “*Whirlwind Cafe*” and managed to talk to almost everyone! It was exhausting but worth it to spread awareness of DHG.

We were able to meet up with representatives from Cheshire and Rotherham Down’s Syndrome support groups as well as Downright Special, who are local to Hull and the Cornwall group with their fabulous “*Pick n Mix*” dancers, who stole the show!

We are looking forward to PC18 in Dublin already!



All Ability Bikes

Edinburgh All-ability Bike centre has a large range of bikes to suit all abilities with tandems, side-by-side, trikes and two wheeler bikes. Their aim is to help people to get involved in cycling in a safe way.

The centre offers lessons for people of all ages and abilities on either a group or individual basis. All sessions are free to attend and you are welcome to stay as long or as short as you wish.



tinyurl.com/dhgbike

What? Why?

What? Why? Children in Hospital is a registered Scottish charity that by working with hospital staff and families has been able to develop and share video clips with age and ability appropriate information to show hospital procedures and reduce anxiety for children and parents.



The videos include ambulatory ECG, Xray, exercise stress test, CT scan, cardio pulmonary exercise test, preparing for hospital, MRI, breathing test, ecg, echo and sleep study and are an excellent way to prepare for hospital visits.

tinyurl.com/mq6v2rt

GoTo Shop Trolley

The standard and disability trolleys available in most supermarkets are unsuitable for many disabled children, which limits the opportunities for families to shop where and when they want. The "GoTo Shop" trolley is designed for children with special needs, providing extra postural and head support and a secure five-point harness. It is comfortable, wipe clean and cool.

To help the GoTo Shop Trolley Campaign install an adapted trolley in every supermarket download a flyer from the Firefly website and give it to your local shop.



community.fireflyfriends.com/campaigns/gotoshop

Toy Like Me



There are 150 million disabled children worldwide yet until recently toy companies have portrayed disabled people in an unimaginative way. Wheelchair characters were usually just in hospital sets and disabilities like deafness were completely ignored.

ToyLikeMe was established in 2015 by journalist, Rebecca Atkinson, who is partially deaf and partially sighted. She was joined by parents fed up of being unable to find positive representation of disabilities in toys. The group started to makeover toys to give them different disabilities, and then share on social media. This resulted in over 40,000 followers in 45 countries, including many celebrities. ToyLikeMe was inspiring change.

Playmobil became the first global brand to back ToyLikeMe and have produced a line of characters that positively represent disability. Now many other brands are following, making dolls with Down's Syndrome, figures with hearing aids, glasses, safety helmets, walkers, feeding tubes and there are even dolls undergoing chemotherapy.

Recent research by Sian Jones at Goldsmith University's Psychology Department has found that non-disabled children are more open to forming friendships with disabled classmates after playing with such toys, so the faster they reach all toy boxes the better!

www.toylikeme.org

Kidz Events

This year's dates for the "Kidz to Adultz" events are:

- 8th June - Rivermead Leisure Complex, Reading.
- 14th September - Highland Hall, Royal Highland Centre, Edinburgh.
- 16th November - EventCity, Manchester.

All events are free but you must register to get your entrance ticket. Check the website for the latest information on exhibitors or contact Disabled Living.

info@disabledliving.co.uk 0161 607 8200
www.kidzexhibitions.co.uk

Transition Standard

The National Institute for Health and Care Excellence has published the quality standard for 'Transition from Children's to Adults' Services'. It sets out five quality statements aiming for high quality care for young people transitioning to adult health or social care services:

NICE

National Institute for
Health and Care Excellence

1. Young people start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
2. Young people have an annual meeting to review transition planning.
3. Young people have a named worker to coordinate care and support before, during and after their transition.
4. Young people meet a practitioner from each adult service they will move to before they transfer.
5. Young people who have moved from children's to adult services but do not attend their first meeting or appointment are contacted by adult services and given further opportunities to engage.

www.nice.org.uk/guidance/qs140

Disabled Living

Disabled Living is celebrating 120 years of delivering services. It started as a small Manchester based charity called the Band of Kindness, formed to teach children to be kind to animals and in turn citizens. It provided Christmas hampers for disabled children, organised an annual motor ride to take disabled children on an outing and began a loan service for special chairs and carriages.

In 1913 the organisation built a nursing home which it ran until the home was taken over by the NHS to become the Children's Orthopaedic Hospital in Marple.

Now Disabled Living offer the Kidz to Adultz events, Bladder and Bowel UK, impartial and free advice on equipment and assistive technology and training for professionals.



0161 607 8200
info@disabledliving.co.uk

New Appointment

Dr Jean O'Hara has been appointed new National Clinical Director for Learning Disability. She is a consultant psychiatrist in intellectual disabilities.

Dr O'Hara's work has focussed on ethnicity and diversity, parents with learning disabilities, inequalities in healthcare and health outcomes for disadvantaged and vulnerable populations, particularly those with learning disabilities and mental illness.

Bowel And Bladder

Some children and teenagers with a learning disability remain incontinent of the bowel and bladder. This has a serious impact on their self-esteem and on social and play activities. For parents there are added time pressures, increased physical demands and very significant costs.

Charmaine Champ is the Continence Consultant and Trainer at Interconnections - a support network for those involved with children and adults with additional needs. She has recently produced two books to help young people, parents and professionals.

"The Bowel And Bladder Assessment Pack" is a guide to help carers support youngsters with toileting. Along with ideas and advice it includes assessment forms and monitoring charts so that all aspects of a child's continence needs can be considered and addressed.

"Bobby Can Use The Toilet" is a social story to help children learn to use the toilet. It has clear text and illustrations to help parents and carers teach the toileting routine. It can be used with children at home or school and the pages are wipe-able for use in bathroom areas.

The Assessment pack is £18.00 and the Bobby story is £12. Both are available from Amazon or directly from Interconnections (plus £2.50 postage/packing for UK)

To find out more or place an order, contact:

peter.limbick@teamaroundthechild.com



Bowel & Bladder Assessment Pack

Charmaine Champ



A guide for carers and professionals helping children and young people with a learning disability, physical disability, autism or complex needs to be successful with toileting

Includes Assessment Forms and Monitoring Charts to copy for use with individual children

interconnections

Charmaine Champ



BOBBY CAN USE THE TOILET

Including a PULL-OUT SUMMARY CHART

interconnections

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 Syndrome Scotland
4th Floor, Riverside House
502 Gorgie Road, Edinburgh EH11 3AF
0131 442 8840
www.dsscotland.org.uk

For other useful links and regional Down's Syndrome groups go to
www.dhg.org.uk/links.aspx

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
Dragon Enterprise Centre, Cullen Mill,
Braintree Road, Witham, Essex CM8 2DD
0808 808 5000
www.chfed.org.uk



PHA UK
Unit 2, Concept Court
Manvers, Rotherham S63 5BD
01709 761450
www.phassociation.uk.com



charity 1011413

dhg

down's heart group

Tel:

0300 102 1644

Email:

info@dhg.org.uk

Write:

PO Box 4260

Dunstable, LU6 2ZT

Activity Weekend 8th - 10th September

*For members with Down's Syndrome over 16
and siblings over 14*

Funding from Jessica's Journey will pay for 1 member with Down's Syndrome and 1 carer on a first come first served basis, so book **NOW!**



See pages 8 & 9 for more information

Fun Day Saturday 9th September

*For members under 16, siblings and older
members not involved in the activity weekend*

Tennis and football ball skills sessions with professionals as well as other fun activities.
£15 per family or £5 per person (to cover lunch and refreshments) Please book places **ASAP**



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.