



dhg

down's heart group

Newsletter Winter 2016

Issue 60



In this edition:-

***2017 Activity Event
A Dinner Date
Member Stories
and More!***

Protecting Your Data

After recent media reports on the fund raising activities of some charities, Down's Heart Group would like to assure all our members and supporters that personal details are kept safely and are not shared with anyone.

We do not sell, names or addresses, send out unsolicited letters or undertake in any cold calling in order to generate income, nor authorise anyone else to do so on our behalf.



DHG sometimes receives requests from organisations and individuals conducting various studies and research, but participation is only considered if DHG has control of sending out correspondence, we are happy that it has appropriate ethical approval and it is clear that any information you may provide is being given outside of DHG.

Our database and statistics are kept securely for DHG's own use and funding bids and any information used has all personal details removed and is completely anonymous.

If you have any concerns about how your records are kept by DHG, please contact National Office on

0300 102 1644

info@dhg.org.uk

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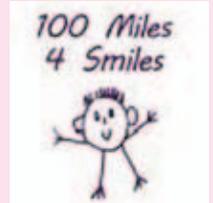
Chair's Report

Hi everyone

It seems that we've come round to newsletter time again. I'd like to thank Sarah for all the time she puts in to create such an informative newsletter for us.



The summer has been really exciting for us at DHG particularly with Jessica's Journey! I was able to join for the last bit of the UK leg, not to walk but wave and eat cake! Thank you so much to everyone who supported and sponsored the event, we look forward to hearing more about the second leg that took place in Geneva, in this newsletter.



I am keen for us to begin to think about how we can bring our community together and link in with others to raise awareness not only of Down's Syndrome but more importantly that our youngsters live with a heart condition. Any fundraising ideas you have or events where you'd like some support, then please let us know.



We will also be exploring other fundraising initiatives in the coming months, including planning a 'dining in night' for everyone to take part in. More details on page 10!



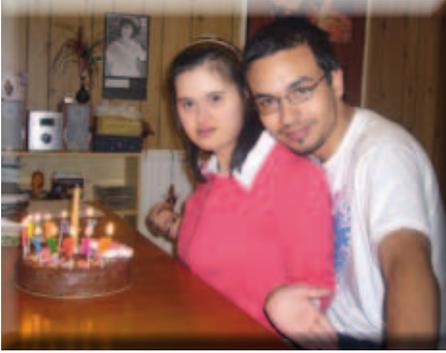
Look out for details coming soon on Down's Heart Group Champions and how you can get involved.

Keep safe on these misty mornings.
Regards
Helen



Helen Laverty

Elizabeth



Vivian wanted to share this beautiful poem about her daughter, Elizabeth, who sadly died in February 2016.

The poem's author, Graham Back, set up and runs a sports club for children with special needs. which Elizabeth attended every Wednesday for thirteen years.

Elizabeth with her twin brother Daniel

Her solemn face did not always show her thoughts
But just as a flower bursts into bloom
When something made her happy
Her smile, like sunshine, filled the room

When she first came she could not play badminton
But persisted and her skills advanced
Always looking forward at the end of the session
To listen to music, to get up and to dance

She was fond of her many bracelets
Displayed for all to see on both wrists
But I can't find the words to explain
Just how much she will be missed

When we had animals in, it was a pleasure
To see the joy upon her face
To know that in those sessions and others
She had found a safe place

I am not completely sure
If she was there since the sessions began
But what I do know for sure, is that
For me, she was the group's talisman

Graham Back

Down's Heart Group received a donation of £1050 in memory of Elizabeth and would like to thank her family and friends for their kindness.

Tom

Tom has three jobs at present, one he applied for through Project Search and Plus, one he saw advertised in the local parish magazine and one through the Down's Syndrome Association Workfit programme.

Tom works a four hour shift at a local pub on Monday and Tuesday, sweeping up, vacuuming and washing and drying dishes. He also works on a Friday for a couple of hours at a Christian retreat. The Workfit job is at the Veterinary and Environmental Agency Laboratories at Starcross. Tom catches a bus from home to Exeter and then the train to Starcross and is able to travel independently after some travel training. He's on three months probation working on Wednesday and Thursday mornings. He empties water sample bottles amongst other duties. Before he started at Starcross, Paul Harrison from Workfit gave staff training so that they knew the best ways of helping Tom at work and he also visited Tom at home to get to know him and then sent his CV to the employer.



On Wednesday and Thursday afternoons Tom goes to a leisure centre to participate in sport through RocActive. This includes gym, swimming, badminton, walking and football and he also has weekly swimming and tennis lessons at local clubs.

Tom did his own seven and a half mile sponsored walk

Tom enjoys going to church every week and loves *"singing his heart out"*. He is also a Sidesman and couldn't do either if the local churches closed down. On 10th September, Devon Historical Churches Day, Tom did his own seven and a half mile sponsored walk between the Bridford, Christow, Ashton and Doddiscombsleigh churches to raise money for the Devon Historic Churches Trust. The walk finished at The Nobody Inn, where Tom works and he was joined by some of his supporters for a celebratory drink.

It was also Tom's birthday in September and he asked for donations instead of presents. Altogether, Tom raised £810 to split between the Devon Trust and local churches. I did promise to make him a big birthday cake, though!

*Lyn Sewell,
Devon*



David

David was born in 1987 when attitudes towards people with Down's Syndrome were very different to what they are now - some hospitals or consultants refusing to operate on our children as they didn't feel they would achieve anything – my how times have changed! There was no Down's Heart Group and the only support regarding David's cardiac problems was from TACHD (The Association for Children with Heart Disorders). Other parents were experiencing this problem and with the efforts of Linda Walsh, Down's Heart Group was formed to provide specific information for us.

DHG has been there to support parents and babies from birth to post-operative recovery and then, in many cases, we lose contact with families as they move on to face the next challenge that life throws at them and DHG is placed on the backburner. Fast forward nearly 30 years and in some ways we and other families are now in the uncharted territory that Linda Walsh experienced as our children transition into adult services.

How has this been for you? Has it been a smooth transition or have you experienced difficulties and obstacles in getting treatment for your child?

Over the years many children have featured in our newsletters and were the stars of that issue, but what are they doing now? Let's have some updates, what are they doing now, what are their interests? How did the transition into adult services go? What difficulties did you face and how did you overcome them?



David was born with a partial AVSD which was repaired when he was three years old. Leading up to the operation he had appointments where he would be weighed and measured, ECG and Echocardiograph which he became quite used to. After surgery the time between appointments increased from three months to three years. During this time David fell out of the habit of having the ECG pads fixed to his chest so many appointments were carried out without the ECG as David refused to co-operate. He has been subject to blood tests...

How do you get your adult children to give a blood sample? What services are there for you to help? Is there a specialist nurse or learning disability team who can be contacted in advance? How do you manage with the dentist?

Can you let us know any areas of best practise in your region for managing these visits? This is your opportunity to provide information which may prove invaluable to those following behind to ensure any difficulties and barriers can be removed so that those that follow don't have to go through some of the things that you may have encountered. An opportunity to pass on your knowledge and experience.

David lives at home with mum and dad. He attends two day centres during the week (we call them college because when our other two children went to sixth form college David said he wanted to go too). He is now a fully qualified graduate of the University of Life!



Before he was twelve he required major surgery on his knees. Post-op meant moving his bed downstairs with a commode and baths were taken in a paddling pool in the kitchen (necessity really is the mother of invention).

This has resulted in David having much reduced mobility. He is able to move around the house without the wheelchair and can access the shower unaided but requires the wheelchair if we go out. David also has a tricycle provided by the wheelchair service, so if you are a wheelchair user ask if it would be beneficial for your child to have a trike.

A small trike was provided which he outgrew by the time we had moved to a bungalow - the bungalow made life a lot easier for all of us. Although still living within the same Local Authority we had moved to a different NHS Trust, so we were referred to the new Wheelchair services who told us that *"We don't provide bikes"*. So, although we still paid our rates to the same LA and we had a National Health Service, he couldn't have one! We immediately contacted our local MP to support us as it smacked of a "postcode lottery". Well, we were successful and a larger tricycle was provided, which David rides to the local station to watch the trains.

It smacked of a "postcode lottery"

Prior to his knee operations David enjoyed going to Riding for the Disabled. He was wearing callipers on both legs when he was able to return and on his first visit Ringo (David's horse the most gentle and patient horse you could meet) had walked no more than 560 metres when the horse unexpectedly collapsed. We managed to get David off safely but that was it for him and horse-riding! Ringo recovered but no-one could explain why it had happened.

David used to go sailing every week with the help of some local students after which the leader would take him for a spin in the motor boat with David driving! *"Go slow"* he said, that lasted about twenty seconds because when he re-appeared from behind an island he was a blur and his only concern was to look behind to study the wake, rather than ahead, its a good job someone was with him!

I used to take David to watch Everton, but he didn't like the noise and would keep his head down. I'd say *"Come on son watch the match like the rest of us have to - it's*

character building.” We never did see them win at Goodison Park! His brother Tom is an Arsenal fan (don’t ask) so David’s football allegiance depends upon who is winning, he has even changed his Everton shirt for a Liverpool shirt mid match because Liverpool were winning although he did apologise at the end and put his Everton shirt back on!

David’s interests are watching WWE wrestling and we went to Manchester recently to watch the live show. He is a whizz with the PlayStation and games. He likes watching YouTube where he finds the most amazing clips or Disney cartoons with an alternative dialogue, I don’t know where he finds them! He loves going to see the Chuckle Brothers.

He is an avid writer of notes to himself, we go through the little notepad blocks you keep by the phone like nobody’s business – all scattered around his desk.

This is a brief outline of what David’s life has been – we are now in uncharted waters like Linda Walsh was when she started – it is up to us to finish it, so come on let’s have the stories of the trials and tribulations of our children become adults.

*Mike Halpin, Liverpool
DHG Secretary*

Kaylie Lou



My baby girl had open heart surgery at three months to repair a complete AV canal heart defect. It was hard to see her struggle with eating before her repair. She wouldn’t fuss or fidget much either, because she didn’t have the strength to.

Two days after her surgery she started to cry and carried on for over an hour despite pain medication! The hospital staff were concerned about her distress and did what they could to make her more comfortable, but I was thrilled to see her so strong. She had never been able to cry for more than a few minutes before surgery and now that she was stronger, she wasn’t sure how to stop crying!

Our little Kaylie Lou Lou is two years old now with over fifteen words and personality coming out the roof. She is such a delight to us all.

*Susanna Driscoll,
Wisconsin, USA*

Adam

Vicky, Adam's mum, was one of the fantastic DHG London Marathon runners in 2016. Here she tells us both about her experience and about her eldest son, Adam.

Training was tough, I had began running in January 2015 on a C25k programme (couch to 5k), unable to run even 100m. I progressed well and ran four half marathons before starting the marathon training. To build up to running four times a week, though, was still a shock and I incurred a few injuries to set me back and force me to slow right down.

To finally run in the Virgin London Marathon, a bucket list venture, was amazing and the support you get from the crowd is like nothing else. Unfortunately, after twenty miles you really do hit the wall. I hurt all over and felt sick and I really had to grit my teeth. Would I do it again? Of course, despite all the pain and tears it is the best thing ever!

I would like to thank DHG for giving me this amazing opportunity. When Adam was born I didn't know he had Down's Syndrome but this was insignificant when he was diagnosed with an AVSD and the anxiety we experienced at this time was indescribable. To help other parents going through this means so much.



Down's Syndrome was insignificant when he was diagnosed with AVSD

We try to keep Adam active for obvious health reasons. He loves football and participates at a special needs club. He also participated in my training with his dad and younger brother by going to family fun runs. Adam is pictured here with some star wars characters he met at his last heart check up at Birmingham Children's Hospital.

*Vicky Ross,
Worcestershire*



A Dinner Date 4DHG



Would you like to raise money for DHG but don't like coffee mornings?

Well, we have the perfect solution!



To celebrate World Down Syndrome Day 2017 you could host a dinner date.



Cook a meal at home.

Invite guests and ask them to make a donation to us.

Ask them to Gift Aid, if they can.



All funds will be paid to DHG.

We will pass 15% to DSI for their Outreach Programme.



Another 25% of the money will be used to support DHG families to attend the World Down Syndrome Congress in Glasgow in 2018.

(Families must be UK based.)



Check the DHG website and Facebook for downloadable invitations, bunting and accessible menu ideas.

There may also be a few surprises!



So save the weekend of March 18th and 19th in your diary.

Tell your friends, colleagues, anyone you know who likes to entertain.



You could even have a St Patrick's Day theme!

Get your thinking cap on for menu ideas.

Send us photos of your dinner date, too!



Get all your friends and family involved.

Let's all have a dinner date 4 DHG!

Billy's Hilly Hike

One small group of friends, one steep and arduous walk and one grand total of £5081.25



DHG family member and long time supporter Billy Packman along with his friends Sam Kent, Tommy Lee, Raymond Smith and Ned Kelly decided to do a sponsored walk across the highest part of the Pennines. They set off from the Cumbrian village of Kirkham on 23rd July 2016 to follow a route of twelve miles.

The terrain was very hard going, with lots of climbs but took in some beautiful scenery and included Cross Fell and Great Dun Fell as well as some of the Pennine Way. The weather was good and all the team enjoyed it, although it may be a while before they volunteer again!



Billy and Lydia's grandson, Miles, sadly died of heart failure in 2007 whilst only a few months old. Such a little man obviously made a huge impression as, thanks to family and friends a massive £5081.25 was raised for Down's Heart Group.

This amount is amazing and proves what a bit of determination and friendly persuasion can achieve! Well done to Billy and all involved, DHG is extremely grateful.

Billy used Virgin Money Giving to raise awareness of the walk amongst people he knows, and as the money doesn't have to be collected in person he could target a far wider audience, irrelevant of where they lived.



Jessica's Journey In Geneva

In October I flew to Geneva to take part in the final stage of Jessica's Journey, a 10km circular walk from Joto Tennis, the club where Jessica played near her home.

It was a beautiful sunny Sunday afternoon as everyone gathered to show their support and love for Jessica's family, with her dad Urs, mum Ghislaine and sister Rebecca all there taking part. The tennis club wanted to be part of this celebration of Jess' life and were instrumental in arranging the Swiss part of this fundraising effort - former professional tennis player Jonas Svensson and his team were not only there but also also hope to be involved in the DHG activity weekend the money will be used to run in 2017.



Jonas presents Joto's pledge

After watching the video tribute that a family friend had made, we all set off on the walk in different little groups, chatting as we went in English and French and it was lovely to see two of Jessica's friends with learning disabilities taking part with determination to finish despite the fact that it was actually quite warm. When we got back to the tennis club there was cake and refreshments and time for a few photos before everyone left.

The final part of the fundraising was an online auction of the kit from Basel 2010 that Roger Federer had generously donated. I was in a DSMIG meeting as the auction came to a close, so it was difficult to concentrate as there was a final bidding war, which eventually brought the total to £1210.

Together with the money raised from the UK and Geneva walks, this brings the total amount raised in memory of Jessica to £9585.19 - a wonderful tribute to an amazing and inspiring young lady who never let her unoperated heart condition stop her from doing what she wanted.

We look forward to sharing that inspiration with some of our members at the activity weekend and hope that it will encourage more youngsters to try new things.



The pledge from Joto Tennis

*Penny Green
DHG Director*

Coin And Stamp Collection



Down's Heart Group is now collecting old and foreign coins as well as stamps. Any are accepted, so please consider sending them on to be put to good use. Perhaps you could ask schools, clubs or family and friends to hand over any they may have, too.

If you only have a few coins or stamps you can send them directly to National Office or we can arrange collection for larger quantities.

info@dhg.org.uk

0300 102 1644

Recycling For Good Causes



You can use this scheme to raise funds for DHG from unwanted items, such as jewellery and watches (any material, wearable or broken) and gadgets like mobile phones, cameras, game consoles, laptops and sat navs.

If your recyclables will fit in an A5 envelope simply send them to the freepost address below. For larger or multiple items order a sack by calling for free

**FREEPOST RSXA-GJBY-ARRZ, Down's Heart Group
Unit 14, Amber Business Village, Amber Close
Tamworth B77 4RP
0800 633 5323**

Just Travel



Compare travel insurance for pre-existing medical conditions, quickly and easily by using Just Travel Insurance. DHG receives a donation each time insurance is bought.

Follow the link or call and mention Down's Heart Group.

www.justtravelcover.com/index.php?xyzid=76
0800 231 5532

FADES Update

Feeding and Autoimmunity in Down's Syndrome Evaluation Study update, written by Dr Williams who has been leading the research;

We are thrilled to now have forty fantastic families enrolled in the FADES study and continue to get more every month. Three of our babies have recently celebrated their second birthday, one of whom is now a big sister!

Our families have been completing the questionnaires mostly online, providing us with a detailed picture of their experiences of feeding a new baby with Down's Syndrome. These have ranged from families who have exclusively breastfed their babies to those that have experienced difficulties with feeding and required intervention. We are also getting information on the medical problems that they face and the range of professionals involved in their care.



George Armour, taken by parents Gosia and George (Snr)

We have also had success in our sample collection, families have been collecting stool samples for gut microbiome and urine samples for c peptide at home using the kits that we provide. Blood samples have been coordinated with routine appointments where possible.

We are extending our recruitment period until March 2017!

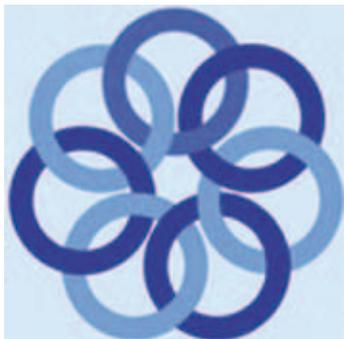
As well as the main cohort study we have been undertaking a qualitative study looking at the barriers and motivations for families with a young baby with Down's Syndrome to taking part in research as well as the feasibility of the FADES. We have interviewed charity support workers, community paediatricians, neonatologists and research nurses. The interviews are now being analysed and the results will help to inform this study and future research in babies with Down's Syndrome.

We want to take this opportunity to thank all our participants and their families, we couldn't do it without you! We are extending our recruitment period until March 2017. If you would like any further information about the FADES study or would like to take part, please do not hesitate to contact us at

fades-study@bristol.ac.uk

*Dr Georgina Williams
NIHR Bristol Nutrition Biomedical Research Unit*

Eye Tests Made Easy



Greater Manchester Primary Eyecare have launched a new service “*Eye Tests Made Easy*” to help people with learning disabilities get the right eye care. This service is for people over fourteen years old.

This free NHS funded service is for those who find it hard to have a standard eye test. It includes the option of domiciliary eye tests at home, school, college or day centre for those who can't get to an opticians.

The “*Eye Tests Made Easy*” service includes being able to visit the opticians before the eye test, having a longer appointment or a few short appointments and being treated by an optician who has additional training to communicate with people with additional needs. Easy read communication and feedback forms are also used.

www.gmpec.co.uk/ld-services.html

Personal Independence Payment



Contact A Family has a new guide, written by welfare rights experts, about Personal Independence Payment, the benefit that's replacing Disability Living Allowance for people aged 16-64.

It looks at what tests are used to decide if someone gets PIP, how the points system works, plus other benefits and rights entitlements when a child reaches sixteen years of age.

This is just one of several very useful booklets from Contact A Family. To download a free copy of the guide follow the link below, go to the website or contact CAF via the helpline

tinyurl.com/pipdgh
0808 808 3555

www.cafamily.org.uk
helpline@cafamily.org.uk

Think 20

Tiny Tickers, is a small national charity dedicated to improving the early detection and care of babies with serious heart conditions. Recent research shows a large proportion of parents-to-be don't fully understand what their 20 week scan is for so Tiny Tickers have launched a campaign to change that and make people associate the scan with hearts.



The campaign website includes a short and simple quiz so parents-to-be can find out more about the 20 week scan, an information pack including questions to ask the sonographer and Think Heart signs for newborns.

www.think20.org.uk

Trendy Bibs

Budz bandana bibs are a fashionable alternative for older children who find eating a messy adventure. They are available through the Firefly online shop and come in packs of four - blue/green or pink/orange with free delivery in the UK.

www.fireflyfriends.com/shop/uk/budz.html



YESS

YESS is a small Staffordshire charity offering emotional support to young people. They work with CAMHS and offer a range of services. YESS need people to become involved with forums and development groups. There are separate forums for young people and parents covering aspects that need to change within CAMHS, transition to adult services and referral systems.



The charity is young person centred and involves young people in their hiring process. These are usually paid opportunities, with support as needed. Please contact:

enquiries@yes-s.org.uk

01889567756

Going To School

Cornwall Down's Syndrome Support Group (CDSSG) has launched the second book in their *"Looking Up"* series and it has been very well received amongst families throughout the UK, Europe and now the USA. *"Going To School"* is a picture book for all children, taking them on a journey through a typical school day showing children having fun and learning alongside their peers.

The book uses photographs submitted by the families of the CDSSG and authors Angie Emrys-Jones, Sandy Lawrence and Vicky Bundy call it a celebration of diversity and inclusion.



Bonnie Langford with the book

CDSSG and Cornwall Council are providing a copy of *"Going to School"* to every rising school age child in Cornwall for the next four years. The families of CDSSG have funded this entire project by raising £5000 to produce the 30,000 copies required for the next four years - that's a lot of bag packing!

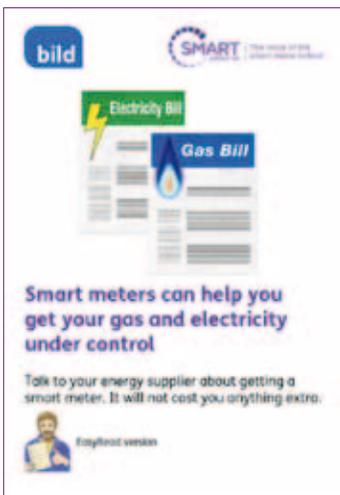
"Going To School" has been promoted by a host of celebrity selfies, including those by Sally Phillips, Miranda and the casts of Emmerdale and Eastenders. It costs £3.99 with free UK postage.

tinyurl.com/dhgbook

Smart Meter

A smart meter is a new type of meter which shows the amount of gas and electricity you're using and how much this is costing you on a handy portable screen. It also sends meter readings directly to the energy supplier. This means no need for estimated bills, waiting to have your meter read or sending in readings yourself.

As part of a national rollout smart meters will be fitted in 26 million homes by 2020. BILD has partnered with Smart Energy GB to make sure that the right information and support is available for people with learning disabilities. This information was developed with the support of self advocates from a number of advocacy organisations.



www.bild.org.uk/information/smartmeters

Infective Endocarditis

Infective endocarditis is an infection of the lining of the heart. It is a rare but very serious condition caused mainly by bacteria, which enter the blood from outside the body. This can be during ear piercing, tooth extractions and routine surgical procedures. It can affect people who have certain congenital heart problems, repaired or not and those who have a replacement valve.

NICE

National Institute for
Health and Care Excellence

The NICE guidelines on antibiotic prophylaxis against Infective Endocarditis were changed slightly in August 2016 recommending that care teams make decisions on an individual basis, rather than continuing to apply the originally recommended blanket guideline that antibiotic cover was not necessary.

Prior to any procedure, professionals involved - cardiologist, GP, dentist or hygienist, should explain about treatment and infective endocarditis. Parents, carers and the individual should be included in any decision regarding the use of antibiotic protection.

tinyurl.com/endodhg

Trisome Challenge

Rotary Friends, through The Sports Union For Athletes With Down Syndrome are organising *"The Trisome Challenge"* which will take place in November 2017 at the Xcel Centre in Coventry. (Exact date to be confirmed).

This will be a sporting event for people with Down's Syndrome, partnered with a buddy who hasn't got Down's Syndrome, across a range of sports. The buddy may be a brother, sister, parent or friend but pairs must have a male and female. They will need to think of a competition name like The Terrible Twins, Batman and Robin, The Two Ronnies or something more original!

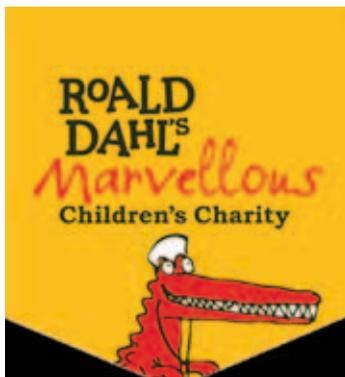
Together they will take part in a variety of sporting events including a swimming relay, table tennis doubles, boccia pairs, obstacle relay, indoor kurling and darts. There will be trophies for each sport and also other special awards.

The entry fee is yet to be decided but hopefully the event will take place on a Saturday early in November from 12pm to 6pm. For more information contact Geoff Smedley at



CEO@SU-DS.org

Marvellous Family Grants



Roald Dahl's Marvellous Children's Charity offers support grants of up to £500 for families in the UK with a child under twenty one who has either a long term health condition, receives medium or high rate care component of DLA or the enhanced rate for six of the twelve activities for PIP, or an equivalent level of need.

Applications are accepted through social workers, family workers, health visitors, occupational therapist, support organisations or someone working within the healthcare profession who knows your family and your history and can complete an application on your behalf.

The Marvellous Grants can be used for:

- play, art or music therapy sessions
- respite care or family days out
- peer group or counselling sessions
- travel expenses to and from hospital
- access to social communications technology
- beds, cots, bedding, or clothing
- car seats, walkers, bicycles, pushchairs and mobility chairs
- expenses to attend a family support event or conference
- equipment or expenses so children can join in activities with their friends
- payment of high heating bills as a direct result of applicant's health condition
- specialist furniture or household appliances required by the applicant's condition

tinyurl.com/dahldhg

Caldecotte Xperience



Caldecotte Xperience has a fantastic collection of bikes suitable for those with additional needs so the whole family can enjoy the countryside around this Milton Keynes activity centre. The bikes can be hired using cash, card or short break vouchers. Safety equipment and instruction on how to use the bikes is provided.

The centre also provides canoeing, sailing, climbing, archery, bush craft and fencing for children and adults with learning difficulties.

01908 232042

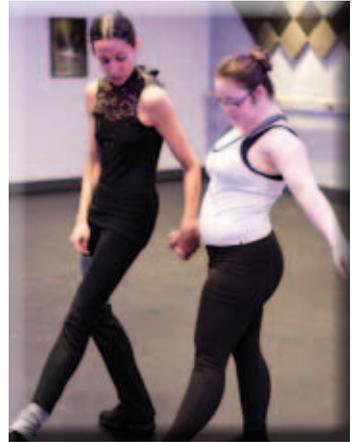
www.caldecottexperience.org.uk/additional-needs.html

Not Your Average....

Not Your Average Performers is an inclusive dance company led by professional dancer Tania Matos formerly of The Portuguese National and English National ballet. It has been running for several months but NYA's theatre arts sessions have been running since 2012. All sessions are accessible to adults with and without disabilities and mental ill health.

Not Your Average Performers is based in Hinckley, catering for the Leicestershire and Warwickshire region. It was founded by Bekki Maddox, whose daughter, Bethany, is in the photo practicing alongside Tania.

www.nyaperformers.org



Universal And Full Tax Credit

Universal Credits will be replacing tax credits and some other benefits like income related Employment Support Allowance and Housing Benefit. UC benefits will be transitionally protected so you do not lose any money when government start to move people to UC and full tax credits. UC will not replace DLA or PIP.

Turn2Us or Entitledto are websites where you can check your entitlement using a calculator, and also check if you are in an area that is already using Universal Credit.

www.universalcreditinfo.net

The logo for Universal Credit, featuring the letters 'UC' in a large, blue, sans-serif font, followed by the words 'Universal Credit' in a smaller, blue, sans-serif font. Below the text is a thick blue horizontal bar.

World Down Syndrome Congress

The next World Down Syndrome Congress will be in Glasgow from 24th to 27th July 2018. Dubai will host WDSC in 2020 and from then on there will be a congress every two years instead of the current three year cycle.

WDSC is the largest global conference for people with Down's Syndrome, their families and professionals working to improve the life chances for all with Down's Syndrome.

ds-int.org/wdsc-2018



Journey To Wellbeing



Sirona Care and Health is a Community Interest Company providing community healthcare and adult social care services in Bath and North East Somerset. It runs a variety of services including a day centre. The people using the day centre put together the following article about the Journey to Wellbeing “suitcase” they have been working on:

In 2015, the Bath locality Community Learning Disability Nurses, the Health Improvement Service and artists from Creativity Works asked our healthy living group at the day centre if they would like to help them to develop a toolkit around improving health. The aim was to create a toolkit to include a set of conversation starters and resources that could be used by professionals, family and friends to engage people with learning disabilities to think about their own health in a fun and enjoyable way.

Over twelve weekly sessions the artists helped us learn about different ways to paint and draw to make the toolkit look professional. All of us had at least one drawing included in the Journey to Wellbeing suitcase. The Journey to Wellbeing Toolkit is designed to be used either in a group setting or one to one. It is hoped that people will feel more comfortable when talking about their health. It then directs you to other easy read information to support each health topic.

www.sirona-cic.org.uk

Editor’s note - The Journey To Wellbeing project won an award at the Nursing Times Awards in October, so congratulations to all involved!

Professor Sue Buckley



Professor Sue Buckley OBE began her career proving children with Down’s Syndrome could learn to read. She is now Director of Science and Research at Down Syndrome Education International and has been presented with the National Down Syndrome Congress’ Education Award for *“improving the lives of children with Down’s Syndrome by developing innovative research-based education techniques.”*

DSE improves education for children in 170 countries and help 120,000 parents and professionals each year.

www.dseinternational.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 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



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

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



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

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0300 102 1644
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Dunstable, LU6 2ZT



Thanks to the fantastic fund raising efforts of all involved with Jessica's Journey, DHG will be able to host an activity weekend next summer - date and venue to be confirmed.



Activity Weekend 2017

Please put your names forward now by contacting National Office as places will be in great demand!

For the full activity sessions, participants must be 16 or over, but we also hope to run other sessions such as tennis and football for younger members, so, if you want to know more as soon as details are finalised, let us know as soon as possible.



All members must be accompanied by a parent or carer - 1 member and 1 parent/carer per will be funded by DHG, but other family members may come too (subject to availability and appropriate payment).



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.