



dhg

down's heart group

Newsletter Winter 2017

Issue 63



In this edition -

*Activity Weekend
Fundraising Events
Christmas Cards
And Lots More!*

New Data Protection Regulation (GDPR)



This comes into effect on May 25th 2018 and has major time and cost implications for DHG, so please help us achieve compliance as effectively as possible.

We are busy reviewing the data we hold for members, how and where it is held and the authority we are required to have from you with regard to us holding data.

Once this is clearly assessed, we will need to contact every member to advise them further and obtain the appropriate permissions to continue to hold this data (replacing the authorities we already hold from you). So it would be really helpful if we could communicate electronically with as many people as possible to keep costs down. If you have an email address, please help us by letting us have it - simply drop an email to info@dhg.org.uk with your name and postcode in the subject line and we will update our records from that.

We never share your information with anyone else without specific authority from you and our records are securely held, so you will not suddenly start receiving spam emails from DHG or anyone else. We will use your email to communicate with you regarding GDPR and your options regarding the information we hold about you and your family, which we only use to post or email newsletters or to find potential contact families (we always ask you first) and to look at statistics anonymously.

If you have any concerns or questions, please do contact us

0300 102 1644

info@dhg.org.uk

Contents

Thomas Morley (photo by Dawn Brown)	Front Cover
Data Protection	2
Member Stories	4
Activity Weekend	6
Fundraising Report	10
Easy Read	13
Christmas Cards	Back cover

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Chair's Report

Hi everyone,

I can't believe we're at Issue 63 of the newsletter!

Let's hope the mild Autumn hasn't produced too many viruses.

It is really important that you take notice of the information on data protection on page 2 and let us have your email address as soon as possible please.

I want to thank everyone who made our Jessica's Journey Activity Weekend such a success - an amazing achievement from Jessica's family and a fitting way to remember a life well lived.

Special thanks go to Dawn Brown, Dan's sister, for the phenomenal photos of the weekend. See pages 6 - 9 and to our volunteers Sam, Sian, Dan, Will and Rebecca, without them giving their time and talents the weekend would have been all the poorer.

Our AGM on 9th September took place at Mount Cook, alongside the Activity Weekend. I believe it was the best one yet. It was really useful with some great discussions.

I would love lots more of you to get involved!

Wishing you all the best for the festive season!

Best wishes
Helen Laverty



100 Miles
4 Smiles



Ben

Ben is fifteen years old and attends Oakfield High School in Wigan. He was born with an AVSD that was repaired before he was six months old. Since Ben's surgery his health has been great and his last check up revealed everything looks great for the foreseeable future!



From a slow start Ben has gone from strength to strength. He is enthusiastic about life, comical and independent. Ben plays for a local Down's Syndrome football team in Manchester called Moorside Rangers. He is actually a huge Liverpool Football fan.

Ben has been playing badminton for three years and was thrilled to receive two bronze medals at this year's Special Olympics National Games. He volunteers twice a week at a nursery for children with disabilities, this opportunity came about from his work experience; they were so impressed with him they asked him to stay on.

In short we are all amazed at Ben's zest for life and could not have imagined in those early days this guy's inner strength. We are just so proud of him.

Craig Fairhurst, Wigan

Tom Becomes Famous



We featured Tom's story in Issue 60 but he is so busy we are bringing you an update! This summer he represented his region at the Special Olympics National Games in tennis, winning a silver and a bronze medal. This resulted in him appearing in the Mid Devon Advertiser, being interviewed by ITV West Country News and riding an open topped bus for a victory parade.

Tom has also played at the National Learning Disability Tennis Event in Nottingham and taken part in the DHG Activity Weekend, where he met friends old and new.

Dante Piet Frank

I have a dream I wish to fulfil. I would like to build a village or centre which will cater for children with Down's Syndrome and heart conditions. This came to me whilst living in hospital for a month with my son, Dante, who was born with Tetralogy of Fallots in 2014.

Seeing other mothers in far worse situations than me was completely heart breaking - some were struggling to come to terms with diagnosis, some had family shun them, with husbands deserting them and friends denying them. They are struggling to survive, look after sick children and to travel to hospital for appointments. Seeing those sad faces made me want to make them smile and make a difference to their futures!



My dream would be purchasing a farm, ideally, or land. The setup would be nothing out of the box but a home environment: domes for the kids and their mothers, a hall for praise and worship, a hall for teaching mothers how to sustain themselves by learning how to sew, bake etc.

My wonderful Dante got through his surgery

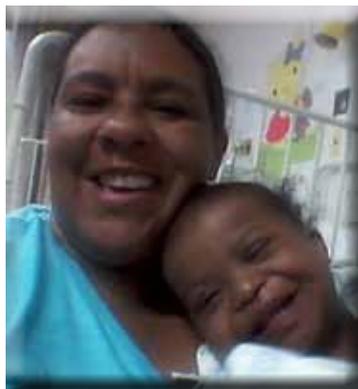
They could learn to farm crops and animals for feeding people that come to the centre. Sports would also be taught and groups of different denominations would come and learn about how it is to have a child with special needs. The list could go on I would love to call it Dante Piet's Rest Haven - it means everlasting rock.

I hope I will get my dream to become reality. In the meantime, my wonderful Dante got through his surgery and we have just come out of the hospital.

There has been some negligence to my baby's foot but I just got the excuse that this happens to babies with Down's Syndrome. There will be no compensation for his toes and no official apology. I am so hurt and want to start a campaign so everyone realises that a baby with Down's Syndrome should not be given second priority in healthcare.

Catarina Costopoulos, South Africa

Editor's note - if anyone has any ideas or knows of any funding sources to aid Catarina's fantastic plan please let DHG know and we can either put you in touch or pass the information on.





Eleven young adults with Down's Syndrome and a variety of heart defects spent the weekend of the 8th - 10th September together at Mount Cook Activity Centre in Derbyshire. They were accompanied by a parent or carer, but soon shook them off and went in search of fun and adventure independently. Most participants hadn't met each other before but by Friday evening were all getting on very well. Friendships were made that weekend which will last for many years.

The weekend was funded by Jessica's Journey - the fundraising events in memory of Jessica Ruppli. So it was fitting that her mum, Ghislaine and sister Rebecca attended the weekend and joined in with all the fun.

Activity Week

Sian, Dan and Sam helped by Rebecca and her boyfriend Will gave up their time and used lots of energy to help facilitate activities and to talk through any anxieties. - without them the weekend would not have been such a success. The weather was miserable but it didn't dampen anyone's spirits and anyone going on the water is bound to get wet!

Saturday's boating venue changed from the exposed Carsington Water to the tranquillity of the Cromford canal, or at least it was tranquil until the gang arrived!





After getting kitted out and listening to the instructors, the group split into three sets of kayaks and the competitive spirit began to creep in. They covered about five miles with a short break at the turning point. Teamwork was the key, although apparently some paddled more enthusiastically than others!

Weekend 2017

The minibuses returned the wet and cold adventurers in plenty of time for a hot shower and change before a hearty lunch. All the meals at Mount Cook were fantastic, as was the accommodation, staff and setting, being located at the top of an old quarry with fantastic views from every window.

Once everyone had eaten and socialised just a little more it was time to regroup and get ready for high ropes. This was next to the archery, where the parents became very competitive whilst having target practice with traditional bows. The instructor was very patient and managed to get all of the parent's group from absolutely awful to hitting the target with each arrow, some even scored bull's-eye!





Based at the foot of the old quarry, the high ropes pushed all participants to their limits. It was amazing to see how high up the frames they could go. The tyres and wooden poles were huge and awkward to negotiate but working as a team, each group made sure whoever was climbing was being held in place with the pulleys, taking up the slack and preventing falls.

The crate stack activity also took nerves of steel - just how many crates high could they go before they came crashing down? Some members were visibly shaking as they tried to step higher and higher but the sense of achievement afterwards made it all worth while. Everyone helped and encouraged everyone else, there was no negativity, no teasing, just care and enthusiasm.

It was an exhausted and very wet bunch that made their way back up the hill to the centre for a well earned warm drink and rest. It is amazing what a cup of tea can do to restore zest for life! Everyone was soon settled down to make bug houses in the art room whilst the "old ones" made rockets, ready for a launching competition after dinner. Again, there was a lot of competition amongst mainly the dads, with a little bit of subterfuge and possibly cheating along the way.

The rocket launch was very entertaining and went on until it was too dark to follow them. So it must now be time to relax? No, the youngsters wanted a disco!





Sunday morning was bush craft and all the youngsters disappeared into the woods to build dens, make fires and cook marshmallows. The older generation had free time to explore the area but most opted for the nearby geo trail, which was very interesting. It finished at a lovely cafe, which seemed the perfect end to a laughter filled morning.

After lunch it was time to say goodbye, swap email addresses and Facebook requests before setting off home. Everyone went away with new friendships as well as new skills and some fresh experiences in their minds and hearts.



All photos by Dawn Brown

Annual General Meeting

During the Weekend the Annual General Meeting took place and produced some good and frank discussions about the future for our young adults, the future of cardiac services and the future of DHG. This probably wouldn't have happened if such group of parents hadn't been thrown together for the weekend and it resulted in the most productive AGM for a while, reinforcing the need to work together as a support network.

Richard Mowberry and Alice Croot stepped down from the Committee and were given a vote of thanks. There were no new elections of Committee members, but several members expressed a wish to help DHG on an ad hoc basis, which was great to hear.

My Race

£5 per entry will be donated to DHG so dig out your trainers and get jogging!



DHG is the February charity for My Race, who organise virtual runs with a unique medal and goody bag for all participants. This “event” is a run you can do anywhere, anytime, alone or with friends or your dog. Simply upload evidence from a phone app or GPS watch to prove you have done it to the My Race website to receive your medal.

My Race will open the website page for the DHG run at the beginning of February. It will have its own link so participants can easily sign up. It costs £14 to enter and £5 from each entry is donated to DHG.

Please let all your running friends know about this run, as well as all your friends and family who could manage 5K, which is only 2.5 miles, with no time limit or blushes for coming last!

If you are interested please let us know at National Office and we will send you the link once it goes live. Alternatively, just keep checking in to

www.myrace.run

My Feral Heart

DHG gets £1 for each DVD of My Feral Heart sold by following the link below!



A sudden bereavement throws Luke, a fiercely independent young man with Down's Syndrome, into a new environment where he finds unexpected support from his streetwise carer and a heir dealing with his own demons. As friendships bloom and secrets are revealed, Luke verges dangerously close to disaster.

My Feral Heart is a beautifully understated film bolstered by strong performances, distinctive cinematography and an evocative score.

bit.ly/DownsHeartGroup

Running For Ebuka

In 2012 I met my class of five year olds just beginning school. It had been my ambition to teach infants with additional support needs and this was my first opportunity.

Amongst the children was a boy named Ebuka. On his first visit to the school the sparkle in his eye was clear to see and he left his mark quickly by filling our iPad with smiling selfies! Ebuka remained in my class for three years and it was a delight to see him develop. He found humour, joy and rhythm in every aspect of life and had the most infectious laugh. Everyone around benefitted from Ebuka's huge empathy, he had an innate understanding of how others were feeling and he would respond sensitively and accordingly. As much as he thrived on rough and tumble play, he could equally be found gently playing with his more fragile peers. He lived life to the full and made the most of every minute.



In August 2015, Ebuka moved up to a new class where he continued his learning journey with his usual positive spirit. In December 2016, we were devastated by the news that Ebuka had passed away at nine years old. He is so missed by all that knew him.

Having taken up running a couple of years ago, I signed up for the big personal challenge of a half marathon - The Great Aberdeen Run on the 27th of August 2017. I started my training in the gym and decided to contact Ebuka's parents to see if they would allow me the privilege of running it in the memory of their amazing boy. Believe it or not, I met the family in the car park while leaving the gym that day and the decision was made - it was definitely fate. The family told me they were keen for me to do the run in aid of Down's Heart Group due to support they had received when Ebuka was younger.

On the day itself, I was so nervous but the atmosphere in Aberdeen was electric. I managed to beat the time I wanted by ninety seconds too, which was a nice bonus! At the finish line I met family, friends and Ebuka's parents too.

I was truly overwhelmed by the support of family, friends and colleagues and was so pleased to raise £1454.50 in Ebuka's memory. This world certainly has less sparkle without Ebuka in it but I know that his memory will live on with those of us who were lucky enough to know him.

Jessica Stuart, Aberdeen



Fran's Fight



DHG member, Fran Sheppard, decided to give Pink Collar Boxing a go, in a bid to get fit and lose a bit of weight. She ended up having a boxing match and raised £500 for DHG!

The fight took place on 29th October at Pride Park in Derby, Fran went the three rounds but lost on points. Her opponent was thirty two years her junior and six inches taller but Fran said that didn't matter as she was fighting in memory of her daughter, Emily, who sadly died of endocarditis at six months old in 2000.



Fran's older daughter, Alex, was there to support her. Alex was four years old when Emily was born, she developed a strong bond with her baby sister and spent many hours at Glenfield Hospital whilst Emily was there.

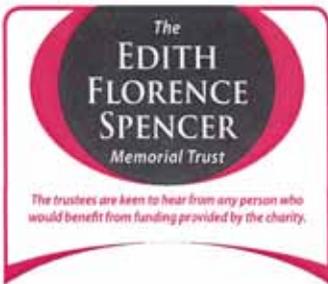
Alex has just graduated and is working as a Paediatric Nurse, which shows the influence her special sister had on her.

Fran says she isn't one for raising money but seems very good at it! Well done and thank you, Fran.

Generous Trust

The Edith Florence Spencer Memorial Trust recently presented Down's Heart Group with a donation towards our work. We are extremely grateful as we rely on donations and fund raising to keep going.

They requested we share their details as the Trust is open to individuals who have heart defects, heart disease, rheumatism or arthritis. If you or someone you know could benefit from receiving funds from this charity you should write, quoting reference MEV/EFSMT to



The Trustees of the Edith Florence Spencer Memorial Trust,
c/o Shacklocks Solicitors,
St. Peter's House,
Bridge Street,
Mansfield NG18 1AL

Hi,



There are lots of reasons why someone might need a blood test.

Blood tests can show if you have an illness.



Blood tests can be used to check if treatment is working.



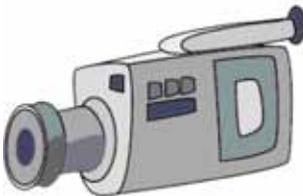
Some people are scared of needles.

They might need extra support or time to have a blood test.



The law says health services should put 'reasonable adjustments' in place.

This means they need to change their services so they are easier to use.



There is a report with easy-read information and films.

It shows how having a blood test can be a better experience.

This is the link tinyurl.com/blooddhg

Pods



Pods are themed inflatable play tents for use as play, sensory or learning spaces. They come in a handy backpack and are ready to use in forty seconds. The graphics can be changed very quickly and the internal sensory lighting is remote control. The Pods are made in the UK to high specification.

There are a range of themes and lighting to suit whatever mood your child might be in!

www.podsplay.com

hello@podsplay.com

03300 889620

Hearing Headbands



Malinka, a new company created by the mum of a little one with Down's Syndrome who has faced many challenges, makes beautiful headbands, sensory and teething toys.

The latest addition to the Malinka range are hearing headbands, designed to work with hearing bands and aids. They come in unisex fabric and are designed with comfort in mind.

www.malinka.me.uk

Ray James



Newly appointed as NHS England's National Learning Disability Director, Ray James was President of the Association of Directors of Adult Social Services and Executive Director of Health, Housing and Adult Social Care for Enfield. He has previously led a number of services to win awards for safeguarding, community involvement and independent living for disabled adults.

Mr James says *"I am looking forward to the challenges and opportunities over the next couple of years. We are committed to ensuring people with a learning disability get the right care and support using innovative services."*

Contact

National charity Contact a Family has rebranded to Contact, overhauling its identity both on and offline to reach more families with disabled children sooner.

contact

Contact still offers all the same advice, support and information but the website is easier to use and more accessible. As well as a national online and telephone service Contact also has local and regional offices with family workers and volunteer parent representatives, so help is always available.

The charity puts families in touch with each other, helping them to campaign, volunteer and fund raise to improve life for themselves and others. It also links families with resources and services that may be useful to them.

Contact has also published a brand new free resource, *“The Helpful Guide for Families with Disabled Children”*, packed with all the essential information the parent of a child with additional needs or a disability might need, helping them navigate a confusing system. To get a copy go to the website or call the free helpline.

www.contact.org.uk

0808 808 3555

Positive Outcome

In October Penny Green and Helen Laverty attended a network meeting of Down's Syndrome UK based support groups, the result of work by several parents who realised that together groups make a stronger voice for campaigning for things our offspring with Down's Syndrome are entitled to or should be able to access.



The meeting was a great success, already increasing communication between groups, revitalising the volunteers who strive to make things better within the Down's Syndrome community. There will hopefully be lots of projects and joined up campaigning to follow.

There has been so much negativity in the media over the past couple of years regarding termination, misinformation and lack of unbiased advice, the network decided to tackle this issue first. A new website *“Positive About Down Syndrome”* has just been launched and has already been very successful. It has been created by parents for parents, offering stories and experiences and is a place to ask questions without fear of being judged. The site gives the opportunity to see the reality of living with Down's Syndrome.

positiveaboutdownsyndrome.co.uk

Waving Not Drowning



Working Families is a UK work-life balance organisation, helping working parents, carers and their employers find a better balance between responsibilities at home and work. They can give basic advice on benefits that working parents can claim and employment rights including rights to time off in an emergency,

The charity has established that over half of parents of a disabled child are struggling to combine work with caring for their child. They want to hear from as many parents as possible to help with their campaigning work around flexibility in work and the right to 'adjustment leave'. If you have a child aged twenty five or under please complete the "Off Balance" survey at:

tinyurl.com/DHGwfoff

Working Families produces a newsletter called "Waving Not Drowning" which is for parents of disabled children and young people who struggle to combine work with caring or wish to work and need advice on employment and flexibility. They also have a new video highlighting how parents of disabled children might be able to stay in paid work using a number of their rights. Follow the link to watch it:

tinyurl.com/DHGwffilm

020 7017 0072

www.workingfamilies.org.uk

Without Tears



Interconnections book "Early Childhood Intervention without Tears" aims to help parents be less stressed and exhausted and draws on a current international project looking at mental, psychological and emotional health in families with a pre-school child with disabilities.

The author, Peter Limbrick, will be running seminars for parents and professionals to discuss some of the questions raised so far such as:

- When does prolonged parental stress and fatigue tip over into mental ill-health?
- How can we protect and nurture child and family's quality of life?

Delegates will receive a complimentary copy of the book in advance of the seminars which take place at Armada House in Bristol on 5th February, Cedar Court in Wakefield on 13th February and Quaker Meeting House, School Lane in Liverpool on 21st February. For more information and a booking form contact Interconnections:

01497 831550

peter.limbrick@teamaroundthechild.com

Baby Benefit Bar

Together for Short Lives has been leading a campaign involving families and parliamentarians from all parties to overturn an unintended anomaly in the benefits system, “the baby benefit bar”. As the law stands, seriously ill children under the age of three who depend on bulky medical equipment and who need specialist vehicles, are denied Mobility support from the government, despite these children’s needs already being recognised through the blue badge parking scheme.



Adapting a vehicle is a costly process, and some families can’t afford to buy one. This traps them at home or in a hospital bed and prevents them from doing things that other families take for granted. Awarding the higher rate mobility component to these children would cost just over £8.3 million per year, that’s just 28p for every UK taxpayer.

On 9th October, Work and Pensions Minister Penny Mordaunt MP announced that the Motability scheme will be extended to under threes. Referrals will be through the Family Fund, which will hopefully make the process easier on families.

tinyurl.com/yapzlm2

State Of Care

State of Care is the Care Quality Commission’s annual assessment of health and social care in England. The report looks at trends, highlights examples of good and outstanding care, and identifies factors that maintain high quality care.

This year’s report shows that the quality of care has been maintained despite some very real challenges. Most people are receiving good, safe care and many services previously rated inadequate have made the necessary changes and improved.

The fact that quality has been maintained in such a tough climate is testament to the hard work and dedication of staff. However, as the system continues to struggle with increasingly demand future quality is precarious.



www.cqc.org.uk/publications/major-report/state-care

Julia's Way



I'm Ella Cullen, Founder and Executive Director of Julia's Way, a non-profit organisation dedicated to reimagining life with Down's Syndrome. I have a fifteen month old daughter with Down's Syndrome and am a former labour and delivery nurse. I struggled to breastfeed my daughter and had a difficult time finding comprehensive information to guide me. I became discouraged and almost gave up on my breastfeeding relationship, despite a strong desire to provide this nourishment for my child.

After talking to many other women who have struggled or who were told that their baby would never breastfeed just because of a Down's Syndrome diagnosis, I became committed to advocacy, awareness, and education around this issue.

I am passionate about our current project, which focuses on supporting and empowering mothers who would like to breastfeed their babies. We are working to identify and overcome the challenges that our babies sometimes face when attempting to breastfeed. If you breastfed your baby or attempted to I would love to hear from you, especially if they had cardiac problems, too. It is extremely important that mothers of all ethnicities, races, economic backgrounds and medical situations are included in our new book *"Nursing Down Syndrome: A Comprehensive Guide for Mothers and Medical Professionals"* which is due out in mid 2018. If your story is chosen we will feature it in our book and our website. We would also love photos of you breastfeeding (or pumping) to include with your story.

There is already a brochure available as a prelude to our book, containing a breastfeeding guide for new mums and professionals. To order or download a copy please go to the website or to submit your story please email. We look forward to hearing from you!

www.juliasway.org

love@juliasway.org

Talking Mats



Talking Mats is a tool to help children to have their say about decisions affecting their lives as well as shaping the services that support them. It can be used to identify outcomes important to the child, review progress and form a person centred report.

Talking Mats is available as a digital app which will work on an iPad, Android or through a web browser on a computer. Mats and picture sets can also be purchased by contacting:

01786 479511

info@talkingmats.com

www.talkingmats.com

The Sequal Trust

The Sequal Trust is a small fundraising charity, founded in 1969, committed to bridging the communication gap for people of all ages across the UK with speech, movement or severe learning difficulties. It provide the means to “set lively minds free” by fundraising in an area where someone may require communication equipment.



Items provided range from a basic iPad to eye-operated systems with wheelchair mounts, including a variety of communication equipment available which also stimulates learning and independence and reduces the sense of isolation.

01691 624222

info@thesequaltrust.org.uk

thesequaltrust.org.uk

Kidz Events

Free exhibitions for 2018 - everything under one roof regarding disability. Simply register for tickets and enjoy an informative day out.

Kidz to Adultz

Middle 15th March at Ricoh Arena, Coventry

South 17th May at Farnborough International Conference & Exhibition Centre

Wales & West 5th July venue TBA

Scotland September - details announced soon



0161 607 8200

info@disabledliving.co.uk

www.disabledliving.co.uk

TomTag

Tom Tags are portable, easy to use plastic strips with holders for symbols providing a quick and easy way to make personalised picture schedules, timetables and checklists to help with daily life.



There is a huge range of pictures to choose from, with an “I can do it” range to help with living skills, routines and communication and an “I know what to expect” range to help take some of the anxiety out of situations like appointments or going to school.

www.orkidideas.com

Organisations Within the NHS Explained



Department
of Health

The Department of Health (DoH) creates national policies and legislation, providing long-term vision and ambition to meet future challenges. DoH supports the system by providing funding, assuring delivery and continuity of services and accounting to Parliament representing the best interests of the patient, public and taxpayer.

It is divided into fourteen departments including Health Education England, Health Research Authority, NHS Blood and Transplant and those below.



Leads the National Health Service in England, setting the priorities of the NHS and encourage debate to improve health and care. NHS England shares out more than £100 billion in funds and holds organisations to account for spending this money effectively.



Public Health

Is about helping people to stay healthy and protecting them from threats to their health. Sometimes public health activities involve helping individuals, or they involve dealing with wider factors that have an impact on the health of many people. Public Health contributes to reducing causes of ill-health and improves people's health and wellbeing.

healthwatch

The consumer champion for health and social care. They listen to people, especially the most vulnerable, to understand their experiences and what matters most to them. They Influence those who have the power to change services. Healthwatch empowers and informs people to get the most from their health and social care services.

NHS
National Institute for
Health Research

Funds health and care research and translates discoveries into practical products, treatments, devices and procedures, involving patients and the public in all of their work. They work with charities and the life sciences industry to help patients gain earlier access to breakthrough treatments and training.

NHS
choices

An extremely comprehensive website that provides information about a range of health conditions available on an A to Z basis.

*Edited from a piece by Deborah Morris, PRA, NWC CRN.
Project Lead NWC Research Community*

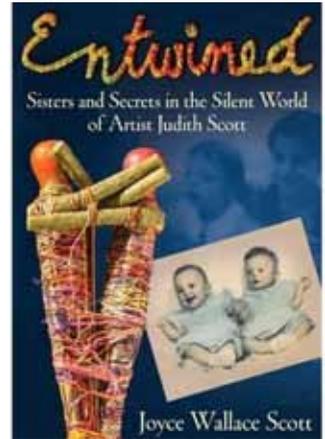
Entwined

Having met Joyce and become online friends whilst she was writing 'Entwined', I already knew the outline story of how she and twin sister Judith were separated and eventually re-united, but reading the book filled in the gaps and I couldn't put it down.

As you follow the journey of the twins in their early years and then the profound loss felt by Joyce when Judith was taken away to an institution, you cannot fail to be touched by the impact it had on Joyce and wonder how Judith must have felt. The description of the institution and how frightening it was to an eight year old child brought tears to my eyes. It paints a picture of both sadness and hope, but perhaps the most inspirational thing it illustrates is Judy's amazing character which shone through despite her lack of speech, something I had already seen in the preview of the documentary

"Outsider: The Life and Art of Judith Scott"

tinyurl.com/entwin



The story details Joyce's loving but infrequent visits with Judith until the 'epiphany' when she realised she could be Judy's legal guardian. The process was set in motion and eventually resulted in Judith travelling from Ohio to California. After thirty-five years institutionalised and never having flown before, she was due to be accompanied, but instead the institution put Judy on a plane alone. Yet as frightening as that must have been, this remarkable lady survived that ordeal to be joyfully reunited with her twin.

Joyce and her family found supported living for Judith and a placement at Creative Growth which resulted in the emergence of her amazing world renowned artwork. But perhaps more importantly *"Entwined"* details the final years of Judith's life surrounded by love and shared by her family, in stark contrast to those dark years in the institution.

Reading the book will make you sad, probably angry and you may need a tissue to wipe away the tears, but ultimately I found it an inspiring testimony to the strength of love that empowers us to make changes that not only impact on us but also future generations. An amazing account of the life of a lady who refused to be silenced despite her lack of verbal communication that perfectly illustrates the special bond between these twins.

judithandjoycescott.com/entwined.shtml



Penny Green, DHG Director

A Whole New World

A Whole New World of Aladdin is brilliant!



On the 29th August we went to see Aladdin at the Prince Edward Theatre in London's West End. This was an autism friendly performance which was organised by the National Autistic Society.

Just before the show started two actors who play the Genie and Jafar came on to introduce the show. They were really welcoming and explained the adjustments they made for people with autism, like the lighting.

We were also told that we could make as much noise as we liked, they were even encouraging us to make noise! They informed us that there were lots of staff to help us. We would really take this opportunity to thank the staff from Disney and Prince Edward Theatre. They took time to have conversations with us and get to know us.

We both highly recommend Disney's musical 'Aladdin'. It was superb, lots of fun and was full of energy from the start until the last note. The sets were amazing and so colourful. It really is a feel good show that leaves you singing the songs hours later.

About thirty minutes into the show the fire alarms started to go off. Someone came on the stage immediately and said that we all had to evacuate the theatre. The staff supported everyone out of the theatre in a calm, polite but direct manner. Within five minutes everyone was evacuated and everyone was safe. About ten minutes later someone told us that it was a false alarm and we could go back into the show. Considering that the majority of the audience either had autism and/or learning disabilities the staff should be proud of themselves for keeping us all calm.

It's very different from the animated film version but this show brought Aladdin back with a big bang. The Genie was both of our favourite character by a mile. Genie was played by actor Trevor Dion Nicholas, this was his West End debut but you would think he has been doing this for years. Genie is a genius! This is a love story between Aladdin and Jasmine. Both of the actors can truly sing and when they sang 'A whole new world' we are sure some people started crying around us.



This is an absolutely brilliant show that we recommend you go and see. It doesn't disappoint! So thank you for a great afternoon Aladdin and to everyone at National Autistic Society.

*Steve Hardy and James Dyer
Oxleas NHS Foundation Trust*

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



dhg

down's heart group

charity 1011413

Tel:
Email:
Write:

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

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