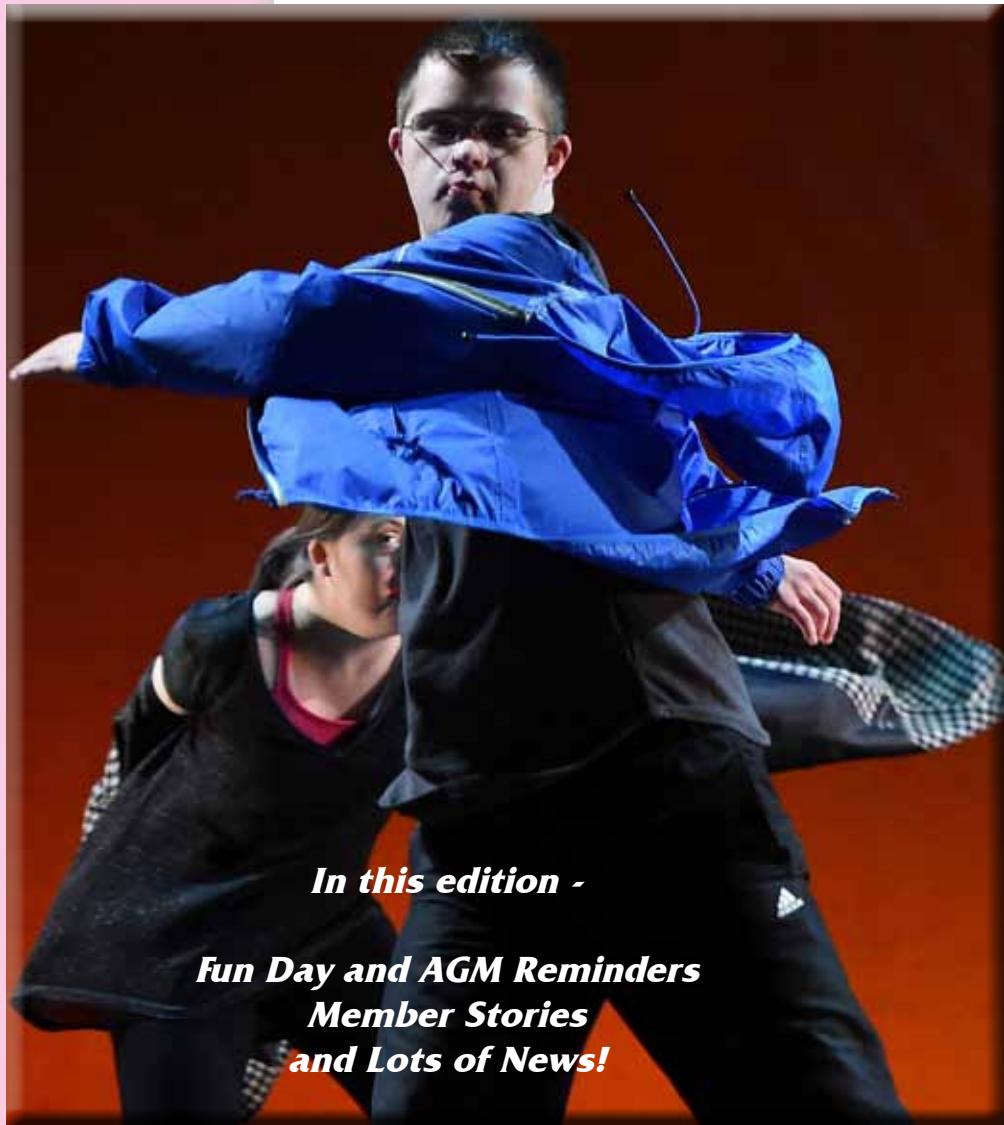




**dhg**  
down's heart group

# Newsletter Summer 2017

Issue 62



## Annual General Meeting

Down's Heart Group's AGM at Mount Cook, Derbyshire is on Saturday 9th September.  
Please let us know if you are able to attend.



DHG belongs to the members - the committee are guided by what the membership wants and needs, however, we cannot fulfil that if the members do not speak up! So please consider attending - you will not be asked to join the committee or commit to anything, we simply want to hear your views and meet more members face to face.

*A resolution to amend the Constitution will be tabled at the AGM which proposes changes to (a) allow the charity to use electronic banking and (b) to permit Trustee meetings to be held online as well as face to face. Full details of the proposed amendments are available on request.*

The Committee have undertaken a skills audit from which it is apparent that we are lacking in computer, technology and website knowledge. Are there any members who may be able to help us fill the gaps? If you could possibly offer a few hours per month please get in touch with us for an informal chat about what it may entail.

Together with the AGM, the Fun Day will be a lovely family day out for all (see back page for details) and the Activity Weekend participants and their parents or carers will be there with a wealth of knowledge that comes with having older offspring. The day will be a great "networking" opportunity - many new friendships have begun at DHG events!

## Contents

Andrew Laycock	Front Cover
AGM Reminder	2
Member Stories	4
Easy Read Pages	10
Fundraising	12
Information	14
Fun Day Information	Back cover

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

## Chair's Report

I can't believe it's the summer newsletter already!

Where has the year gone?



Sarah and Penny have been really busy getting ready for our AGM and activity weekend in September.



I really hope the sun shines and I get to meet lots of you in person.

Please get booked in as soon as possible.



Our Facebook has been really busy these last few months with lots of families of really small children getting in touch.

I hope all our Facebook community are full members of the group too in order for them to receive all our updates?



It has been lovely to watch how supportive everyone has been to each other, sharing stories, advice and generally building community.

It would be lovely to meet lots of you at our AGM.

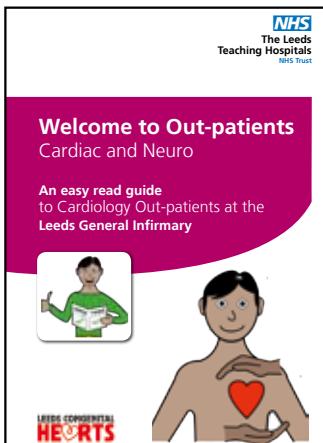


With every good wish,

*Helen Laverty*

# Members Stories

## Sarah's Starring Role



You may recognise Sarah John as she has attended many DHG events over the years. She is now 35 and has never been able to have heart surgery. Sarah maintains good health, with the odd bump in the road and copes very well with pulmonary hypertension, especially since a recent medication review.

Sarah has been helping Leeds General Infirmary with their new Easy Read leaflet on transition from children's to adult services. She spent time in the clinic posing for shots to tell the story of a typical outpatient visit.

The leaflet "*Welcome To Out-patients*" can be obtained from the Cardiac and Neuro Clinic and will soon be on the hospital website.

As a thank you, the cardiac clinic staff presented Sarah with a balloon and a teddy - Tedwin, which made her smile even more!

*Terry John, Yorkshire*

## Edith



Edith was born following an antenatal diagnosis, after my twelve week scan showed increased fluid at the back of the neck and consequently a consultant scanned me and found a significant heart issue linked to Down's Syndrome.

That was a heart-stopping moment as I had previously had a miscarriage and was now uncertain whether this baby was going to survive.

It was an agonising wait for the 16 week scan at Great Ormond Street Hospital, but we were then reassured that it was an AVSD and could be fixed with surgery. It was a huge relief. I had a further blood test (without miscarriage risks) so we could be ready and get support in place - the test came back with over 99% likelihood of Down's Syndrome.

I realised my knowledge was quite lacking. My advice is to use the Internet sparingly - there is a lot of rubbish out there! But it is helpful for finding organisations that give the right support, like Down's Heart Group. I found helpful, positive and informative guidance on the DHG website, and after falling in love with the gorgeous children pictured, I got excited about the birth of my baby!



When Edith was born in November 2016, it was love at first sight! She struggled with breathing, weight gain and had bronchiolitis. Despite our superb medical support, as surgery loomed I was extremely anxious. I did two things: firstly, I spoke with another DHG mum to get an idea of how things should be post operation. Secondly, I contacted Down's Heart Group, as I wanted more advice on how to cope emotionally before and during surgery. Penny rang me straightaway and immediately understood my concerns (better than I myself understood them). She gave me an idea of the general process, what to take with us, what to expect in terms of wires and machinery and advised me not to worry if there were hiccups during recovery, all of which was really positive.

### *I found helpful, positive and informative guidance on the DHG website*

Edith had successful surgery at four and a half months. She came off the ventilator that night. By the fourth day we were back on the ward - Edith had come round completely and was very active. We were home exactly a week after surgery!

A month after Edith's breathing was still settling but was miles better than prior to surgery. Two months on she still has her feeding tube but this should come out soon as she is now eating solids and gaining substantial weight. She is breathing easier, laughing, standing on me, getting on the move. It's a delight to see, and I couldn't have got through this extremely difficult time without the support we received. Thank you!

*Vanessa Lindsey, Suffolk*



## Cover Story - Andrew

*What are the chances of getting your daughter through heart surgery and then three years later having to go through it all again with your son?*



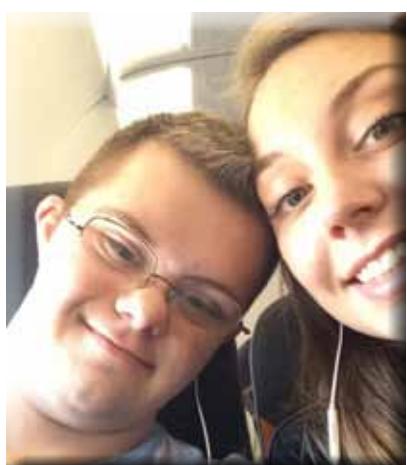
Well that is what happened to our family - and very stressful it was, too! Our daughter, Karen, had heart surgery as a baby at Yorkhill Hospital in Glasgow. Thankfully, she is now doing very well and has just graduated from university.

Andrew's AVSD was suspected at birth and confirmed shortly afterwards. As returning to Yorkhill was quite stressful for the whole family, coupled with the fact that Andrew's condition was much more complex than Karen's, we sought a second opinion.

After speaking with Dr De Giovanni for literally thirty seconds, our decision to travel down to Birmingham Children's Hospital had been made and eventually a referral for surgery was granted. Andrew had his operation there in April 1988.

Before surgery Andrew was very sleepy and didn't put weight on but only had one brief spell in hospital whilst starting medication. After the operation he was only in hospital for four days and stopped all medication three weeks post surgery.

Following a successful and enjoyable time at primary and secondary school Andrew, who is now nineteen, is now at Cardonald College in Glasgow studying Skills for Life and is doing well. His hobbies include swimming and regularly going to the cinema and he enjoys going out cycling our tandem. Andrew loves getting his hair cut and putting on his suit - he would go to the barber every week if we let him!



Andrew's main passion though, is for dancing. He attends dance classes twice a week through an organisation called Indepen-Dance who run regular dancing workshops and take part in dance festivals and shows. He takes it very seriously and rehearses hard but at the same time has a fantastic time.

The front cover shows Andrew in a show called Go Dance, which was an outstanding event.

[www.indepen-dance.org.uk](http://www.indepen-dance.org.uk)

*Martin Laycock, Glasgow*

## Gwen's A Winner!

Gwen Evans is eighteen and studying a level two vocational studies diploma at Pembrokeshire College. She has just won a gold medal in the inclusive Skills Competition Wales, which comprise a series of ICT challenges.

Gwen said she was confident going into the competition, having practised at college and being used to working on computers at home. She has been interested in ICT since her dad bought her a laptop two years ago. Gwen enjoys typing and writing love stories and plays, which she does in her spare time.



This competition, which included creating a document demonstrating different fonts and inserting images in just ninety minutes, was the first one Gwen has ever won! She thinks it has boosted her confidence and hopes it will help with her studies to train to be a child minder. She has also made her family very proud!

*Julie Evans, Pembrokeshire*

## Oliver's Meeting

Oliver Hellowell is becoming quite famous for his photography and through it is meeting some of his heroes. One hero he particularly did want to meet, was the wonderful surgeon who performed his heart surgery twenty one years ago. Mr Pawade was based at Bristol Children's Hospital when he first met a very tiny and very poorly Oliver, who without surgery would not have made it to today. Oliver's mum Wendy, wrote to Mr Pawade to ask to meet up to say thank you after all these years.



Mr Pawade said yes! and a camera crew asked if they could tag along and film the meeting. Oliver was quite nervous but soon the two were chatting like old friends. Ollie showed the surgeon some of his photos and gave him a signed copy of his book - Mr Pawade showed Oliver some pictures he has taken and some film clips of Tigers in India.

What a special day!

*Wendy O'Carroll, Somerset*



We found out that Ella had Down's Syndrome and would need heart surgery whilst I was pregnant. Our lifeline was Down's Heart Group, without the charity I'm not sure I would have got through it all. Penny Green, DHG Director, is amazing and would visit after Ella was born. She explained everything in layman's terms and supported me emotionally, even offering to come to appointments with us.

My friend Suzie from Leighton Buzzard has been so inspired by Ella she wanted to do something amazing, so when she said she wanted to run in the London Marathon I suggested DHG as her charity.

Suzie was so grateful for the help we had received from the charity she said yes straightaway and has been busy fundraising and training since! She is even getting Ella's face printed on her running vest! (See page 13 for marathon update)

*The two holes were closed using gauzes and she is flourishing*

Before Ella had her surgery we ended up in hospital several times due to breathing difficulties and choking on her bottle formula. She was blue lighted at two and a half months old which was the worst experience ever. On this particular day, Ella choked, but for some reason this time her breath didn't come back. Her eyes started bulging, her lips went blue and her skin went mottled. She was rushed to Luton and Dunstable Hospital, where she stayed for a few days to recover.



Luckily, at four and a half months, surgeons at Great Ormond Street closed up the two holes in her heart using gauzes and Ella is now flourishing. She attends school and is doing really well.

Ella was a ghost of a child. Her every breath used to be a marathon and now Suzie is running a marathon for us. I am so blessed that she's chosen Down's Heart Group!

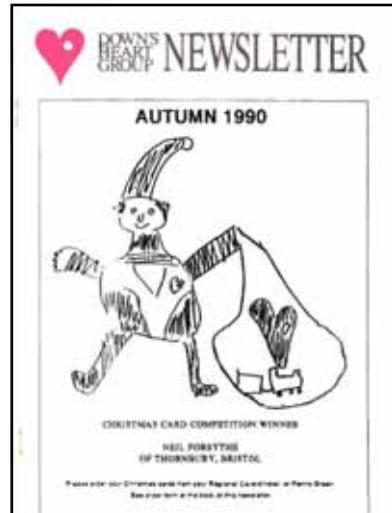
*Ann-Marie Turner, Bedfordshire*

## A Bit Of History

*Denis Hopkins, a former DHG newsletter editor, found a copy of Issue 4, which prompted him to write in. We are so glad he did!*

Dear Down's Heart Group,

Jenny had to battle through the belongings of her late mother and stepfather and she came across DHG newsletter for Autumn 1990. I would like to think that this was one of the first newsletters printed by DHG. There is a piece in it by Kevin; he and Trudy were Jo Hopkins' adopted grandparents. Jo was adopted by us when he was about ten months old. He was very poorly with a heart defect and had shunt surgery at a month old and more corrective surgery at about seven years old. He had been diagnosed with Tetralogy of Fallot with an AVSD.



We had contact with Linda Walsh after Jo had surgery and when possible attended meetings and get-togethers for DHG. We arranged a meeting for DHG families at Milton Keynes in the summer of 1990.

One of the speakers was my father in law, Kevin, who talked about religion - mainly about baptism and bereavement. It was very intense and brought home what a lot of parents were having to face up to.

Other speakers gave their time through the weekend and on the Saturday evening all the families went to a local pub for a meal. On the Sunday we had a bus tour of Milton Keynes and a great afternoon BBQ in our garden to finish off the weekend.

In 1994, Jo was lucky to get a place on the Lapland trip and Peter John, DHG's current vice chair, escorted him on this amazing journey. Planes had always been associated with sunny holidays not one with lots of snow and darkness! Jo came home laden with gifts.

Jo is now thirty five years old and his surgery has helped him get this far. His hearing and communication have been his biggest challenge over the years. He lives in a house with five other lads of a similar age and ability. He attends two day centres through the week and spends every third weekend at home with us.

I hope you enjoy this trip back in time and maybe can find other families who have kept an old copy that they featured in?

*Denis and Jenny Hopkins, Buckinghamshire*

# Easy Read Pages



Hello everyone,  
summer is here already!



Remember in the heat -  
SLIP on a cool shirt.



SLAP on a sun hat.



SLOP on lots of sun cream.



And drink lots of water.  
Then you will have a fabulous summer!



If you do something exciting please send us your stories and photos.



Are you coming to the Fun Day?

It is in Derbyshire on Saturday 9th September.



There will be lots to do -

drama, tennis, football, craft and games.



The Special Olympics is from 7th to 12th August.

It is in Sheffield.



Are any of you competing?

It is a great event to go and watch.

# Fundraising Report

## Coffee Morning



Hello, our names are Charlotte, Ruby, Bella, Caoilainn, Danika, Laura, Connor and Olivia.

We all go to Our Lady of Lincoln Church and as part of our 'giving back' we wanted to hold a coffee morning for a charity after Mass one Sunday. Helen Laverty suggested DHG.

We asked some grown ups to help us - Sheila and Peter made bacon and sausage cobs, Sue and Ray had a bric-a-brac stall with all sorts of treasures, Liz and Mary sold lots of yummy cakes and John and Pauline washed up!



We had a lot of fun. Laura read stories to people who wanted to think more about Down's Syndrome, "*The Prince Who Was Himself*" was the favourite. Connor and Charlotte held a raffle. Caoilainn, Bella and Nika showed our Will Beat bear and sold little bears whilst Ruby and Laura manned the DHG stand with Helen selling these lovely flower hearts Pam made for us and giving out newsletters.

We made £540 in two hours! xxx

*Junior members, Our Lady Of Lincoln Church*

## Cards For Causes



Raise up to 8% in funds for Down's Heart Group when you buy or top-up gift cards. Simply sign up to Give As You Live's "*Cards For Causes*" scheme to order cards to be spent by you or given as gifts. Choose from store cards and e-codes to use online or in-store.

With a wide range of reloadable gift cards for popular stores including Marks & Spencer, Tesco, Boots and Debenhams, you'll continue giving to Down's Heart Group at no extra cost whenever you shop in-store or online.

[cardsforcauses.giveasyoulive.com/charity/dhg](http://cardsforcauses.giveasyoulive.com/charity/dhg)



**Grand  
Total  
£7194.47**

*What an  
achievement!*

Yoel Levy 4:46:01, Noah Levy  
4:59:45 with sister Hannah



Rebecca Ruppli 5:57:05 with  
mum Ghislaine

The runners all did exceptionally well again this year, with no injuries and with all of them achieving good times. The weather was kind, perhaps a little on the warm side and drew even more crowds than normal, or so it seemed to those desperately trying to get good vantage points to encourage the runners on.

Suzie warmed up by running the Brighton marathon the week before and was hoping her twins would spot her out on course. Yoel and Noah were welcomed over the finish line by their sister, Hannah, who had fun waving the DHG flag for all to see. Talulla raised over £3000 in sponsorship whilst the three men got over £1000 each. Rebecca was supported by her mum, Ghislaine and after all their effort for Jessica's Journey it's a wonder they weren't totally worn out by fundraising!

*Thank you to everyone involved - we really do appreciate it!*



Talulla Barrow 4:59:35



Andrew Vine 4:24:56



Suzie Foster 4:31:08

# Information

## Pyjama Fairies

Pyjama Fairies 



Pyjama Fairies is a registered charity providing specially made gowns and pyjamas for children going into hospital for procedures or surgery. It was founded in 2015 and has given support to many young patients and their families in the UK.

The pyjamas and gowns are designed with front opening to make dressing easier and to allow ease of access for medical professionals. They are made in bright and fun fabrics and adhere to all UK safety legislation. The best news is that they are free!

The cost of making all garments is covered by either Pyjama Fairies members or donations. The charity is run by volunteers and is always looking for more seamstresses, experienced or not, to join the team. To offer your sewing skills or request pyjamas for a child who will be having a hospital stay contact:

[info@pyjamafairies.org](mailto:info@pyjamafairies.org)

[wrappyjamafairies.co.uk](http://wrappyjamafairies.co.uk)

## Clinical Procedures Study



Edge Hill  
University

*Has your child ever had a clinical procedure such as a blood test?*

My name is Greg Cigan and I am a learning disabilities nurse and PhD student from Edge Hill University. I am doing a study to find out about the experiences of families with a child or young person who has a mild to moderate learning disability and has undergone clinical procedures such as blood tests, scans and examinations in hospital and other places.

If you or your child (aged 6 to 15) live in North West England and would be willing to tell me about your experiences, then please contact me for further information by email, phone or text.

[Cigang@edgehill.ac.uk](mailto:Cigang@edgehill.ac.uk)

07932477830

01695 654313

## ACHD Patient Day

The Somerville Foundation is holding an Adult Congenital Heart Patient's Information Day in Norwich on Saturday 14th October 2017. The event will be held in conjunction with Norfolk and Norwich University Hospital at the Benjamin Gooch Lecture Theatre.



The event is free to attend, including refreshments. Places can be booked by contacting Toni Hardiman at Norfolk and Norwich University Hospital  
[nnu-tr.GUCH@nhs.net](mailto:nnu-tr.GUCH@nhs.net)

Grants are available in advance to help those struggling financially to attend. If you are living on benefits, working but on a low income, or have serious financial problems you could be eligible for a grant. Let Anna at Somerville Foundation know your circumstances by emailing in strictest confidence and she will do her best to help. Anna is also the contact for any special access needs, please contact Anna at Somerville Foundation on

01473 252007

[conference@thesf.org.uk](mailto:conference@thesf.org.uk)

## Standards Petition

*NHS England has just closed the national public consultation on how it will put in place new standards for hospitals providing congenital heart disease services in England.*

This follows the publication in 2015 of a new set of quality standards for all hospitals providing CHD services. The consultation has gathered as many views as possible from patients, families and clinical experts. NHS England will use this information to come to a final decision on how services should be provided by early 2018. Unfortunately, there have been many delays and legal battles, plus uncertainty about job security, resulting in services in some areas becoming unsatisfactory.



With that in mind, a group of patients in the North West have set up a petition asking that the Secretary of State for Health accelerates the decision making process to minimise the impact on patients welfare. As this decision affect the whole of England, you are invited to sign the petition by following the link

[tinyurl.com/DHGnwst](http://tinyurl.com/DHGnwst)

## Marie Curie Easy Read



Marie Curie, the charity that supports people through terminal illness, has produced an easy read version of eight of its information booklets. They cover topics like living with an illness you will probably die from, feelings, keeping well and who can help, as well as financial matters.

Each booklet is written in a simple style to be read independently or used as a tool for understanding. The range can be downloaded from the link, requested by email or by calling the support line.

[review@mariecurie.org.uk](mailto:review@mariecurie.org.uk)

**0800 090 2309**

[tinyurl.com/mceread](http://tinyurl.com/mceread)

## My Sister Lucy



The My Sister Lucy series is comprised of read-aloud eBooks with music and narration and are suitable for preschoolers and young readers. The main character, Lucy, has Down's Syndrome and goes on many adventures that all children can relate to, whilst promoting acceptance, inclusion and friendship.

The books, by American author and illustrator, Sue Workman, raise funds for US charities involved with World Down Syndrome Day.

[MySisterLucy.com](http://MySisterLucy.com)

## Period Protection



PantyProp produce a huge range of bikinis, pants and gym wear for use during menstruation. This is great news for those who love swimming and sport and who don't want or don't fully understand why they may have to take time out from what they enjoy.

[www.pantyprop.com](http://www.pantyprop.com)

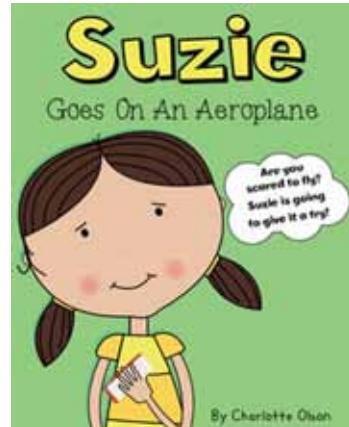
## Suzie Books

Parent and former Nursery Nurse and Teaching Assistant Charlotte Olson has written a range of books to help children cope with new situations. The child in the stories faces adventures most youngsters experience at some point. These simple and fun stories can be used as a learning and discussion aid for children who find new things challenging. Titles include: Going to the Hairdresser, Going to School, Toilet Time, Going to a Funeral, Going on an Aeroplane and Sammy's New Food Week.

All books are available on Amazon in pdf format and some are available for download to a Kindle. For a hard copy contact Suzie Books at

07971182991

[info@suziebooks.co.uk](mailto:info@suziebooks.co.uk)



[www.suziebooks.co.uk](http://www.suziebooks.co.uk)

## ELI Project

*The ELI Project holds Family Nights every fortnight from 5-7pm at Bryncoch Community Centre, Neath, providing a safe place for families to come together and interact.*

Parents chat over a cuppa, siblings play, and youngsters with special needs develop friendships. Parents benefit from sharing experiences and the children and teenagers form friendships and get involved with activities. Family nights are casual and low key meet ups.

The ELI (Every Life's Important) Project was formed when Todd and Stephanie Presley, who have four children including a son with Down's Syndrome and autism and live in Wales, met up with a couple who were already running something similar in the United States.



The plan is to expand across different countries and provide training to equip new groups so that more can use the service. It is a non profit organisation serving over 2000 families and hosting over 40 events each year across the two countries. In Georgia, USA, there is also a Women Connect group who meet regularly for dinner and a Men Connect who do all sorts of "man" activities! So far, in Wales the focus is on Family Nights but the more families get involved, the more the project can grow.

[eliproject.org](http://eliproject.org)

07487 643 205

## Continence Swimwear

Many families avoid going swimming because of the worry of "accidents" with continence whilst in the water or pool side. There are some very good products out there and although quite pricey, would probably be well worth investing in.



Pictured is a unisex "*swimwear undergarment brief*" for adults and teens which is worn under normal swimwear. It is very discreet and providing the correct size is worn can hold the equivalent of several cups of water as well as bowel containment. It is machine washable and latex free, available from Adaptawear, who also sell continence swimsuits and trunks.

0800 051 1931

[www.adaptawear.com](http://www.adaptawear.com)

ERIC, the children and teen continence charity, sells a range of swimwear in trendy colours and designs with added continence security, for all sizes.

0845 370 8008

[www.eric.org.uk](http://www.eric.org.uk)

## Sleep Assessment



Julie Sutton, LD Nurse and sleep expert, is hosting a seminar "*An introduction to sleep assessment with disabled children and teenagers.*" from 12:30 - 4pm on Monday 2nd October at Riversway Conference Centre, Shrewsbury. It is open to both families and professionals.

The afternoon will explore the principles of assessment, uncovering underlying causes of sleep problems and how to design the appropriate sleep interventions.

This introductory event will equip participants with a better understanding of sleep difficulties and build their confidence in sleep assessment which leads to effective sleep. It costs £45 per delegate or for a professional and parent coming together it will be a total of £60.

Julia will also be running a two day sleep course for professionals in November in London. For more details or for a booking form and to reserve your place contact:

[peter.limbrick@teamaroundthechild.com](mailto:peter.limbrick@teamaroundthechild.com)

## Dreams Come True

Dreams Come True is a national charity working to enrich the lives of those aged between two and twenty one with serious and life-limiting conditions. They have fulfilled the dreams of more than five thousand children and young people to meet their heroes, enjoy amazing experiences and visit special places. For some, a dream is simply to enjoy everyday activities so the charity can provide specialist items such as disability trikes, wheelchair swings, sensory equipment and technology.



Granting a dream helps a youngster to think beyond their illness or disability and focus on something positive, whilst creating lovely memories for the whole family. The friendly Dreams Come True team provide support every step of the way and the straightforward online application process makes it easy to nominate a child.

Anyone can nominate a child or young person for a dream; parents, extended family, medical professionals, social workers and friends. Dreams Come True simply ask that youngsters meet their criteria and do not have a similar application ongoing with another organisation and that they haven't been granted a wish by them previously.

01428 726330

[www.dreamscometrue.uk.com](http://www.dreamscometrue.uk.com)

## Caring Cutlery

Caring Cutlery produce a huge range of specially designed knives, forks and spoons for those with restricted grip or poor motor skills. Available in many shapes and styles with various coating and textures to suit a variety of needs, the cutlery suits left handed people, those with limited wrist movement or with tiny hands. Each piece will make eating a less frustrating and more enjoyable experience whilst encouraging independence.



They can be purchased from the Complete Care Shop which is a specialist retailer for other cutlery as well as an array of fantastic gadgets or items with special modifications, all there to make life just that little bit easier.

The Complete Care Shop offers advice and buying guides on the website and are also happy to help over the phone.

03330 160 000

[tinyurl.com/DHGspoon](http://tinyurl.com/DHGspoon)

## Help To Work



There are a number of different challenges people with learning difficulties might have in finding paid work. Mencap have long recognised this and have created four easy read guides covering finding a job or work experience, application forms and CVs, going to a job interview and starting work - all of which can be downloaded and printed off from the link.

[tinyurl.com/dhger](http://tinyurl.com/dhger)

## Wellbeing Service



### Providing Quality Care

The Wellbeing Service works in partnership with primary and secondary health care services and voluntary organisations to promote annual health checks for people in Hull who have learning disabilities. It is part of the City Health Care Partnership which is a social business, investing all profits back into services.

The service aims to address physical health inequalities, to raise awareness of these issues, reduce stigma and increase social inclusion. Although this is a Hull based service its online resources can be used by all and are really useful for explaining health issues, medication and pain levels.

[www.chpcic.org.uk/pages/wellbeing-service](http://www.chpcic.org.uk/pages/wellbeing-service)

## Disabled Holiday Information



D.H.I. is a charity almost entirely staffed by volunteers who either have a disability themselves or care for someone who does. It provides free information on fully accessible leisure pursuits, accommodation, attractions, activities and trails through a comprehensive website, for all with disabilities rather than just wheelchair users.

The service does not provide ratings /quality gradings for accommodation or activities, just honest and unbiased information based on experience and recommendations.

[info@disabledholidayinfo.org.uk](mailto:info@disabledholidayinfo.org.uk)

[www.disabledholidayinfo.org.uk](http://www.disabledholidayinfo.org.uk)

My name is Amanda Glennon and I am founder and trainer at Inclusive Teaching Matters (IT Matters), a Community Interest Company with a passion for improving outcomes of people with learning and communication difficulties. I help families and professionals to understand the strengths and challenges that Down's Syndrome presents by providing current and best practice strategies for communication, life skills and inclusion.



For the past few years IT Matters has been privileged to support the Down's Syndrome community across the UK and beyond! We have worked with many local groups on Makaton, using iPads and Special Apps for learning and life skills, Making Maths Count with Numicon and more. We have also provided services to Education and Healthcare and are currently providing training to several Universities. We were lucky to attend Positive Choices 2017 and took enormous pride in leaving there with over 100 Learning Disability Nurses being better equipped to communicate with Makaton users.

I haven't always done this – I used to be a Project Manager for a global corporation that make beans – so what inspired me to set up IT Matters? I had a life changing moment in 2005 when my twins Alice and Joe were 5 days old. That was the day my Alice was diagnosed with Down's Syndrome. I knew nothing about Down's Syndrome but soon developed a strong resolve to learn all I could, ensuring Alice would have the best possible outcomes in life.

When Alice came along eleven years ago there were few established local DS groups, in fact as there wasn't a group in my area I set one up along with three other parents – I am sure that will sound familiar to some readers! Fast forward to 2017 and there are groups across the country, a plethora of social media groups, blogs, forums and a fantastic parent led national network connecting lots of these together, ensuring we can share best practice and not all have to invent everything from scratch – GO Parent Power!

As Alice grew it became important to me to share my knowledge with a wider range of people. I thought about what matters to Alice - happiness and independence, and having access to the same choices and experiences as everyone else without a reliance on me. It was clear that we needed a further reach of understanding and tolerance of Down's Syndrome. That may include going to local clubs, football matches, theme parks and even an annual trip to Santa. I have worked very hard to ensure IT Matters covers as many of these areas as possible.

07500 016544 [amanda@itmatterscic.co.uk](mailto:amanda@itmatterscic.co.uk)

[www.inclusiveteachingmatters.com](http://www.inclusiveteachingmatters.com)



## Indepen-dance



*Indepen-dance is an inclusive dance company for people with disabilities and their carers, to enjoy, express, and fulfil their potential through dance.*

Based in Glasgow, with groups all across Scotland, Indepen-dance enables participation in high quality arts to improve health, quality of life and opportunities for people with disabilities. There are weekly social, therapeutic creative movement and dance classes and opportunities to work towards employment in dance.

Participants become lifelong members and join a thriving social network and the company nurtures people to experience improved health, well-being, confidence and communication skills. All activities are offered to people with and without disabilities, providing everyone with the opportunity to learn from each other and share creative experiences. Preparation for work in general and especially in dance and the arts is worked on, with some members going on to paid employment.

[admin@independance.org.uk](mailto:admin@independance.org.uk)

0141 559 4930

[independance.org.uk](http://independance.org.uk)

## My Health Guide



My Health Guide is an app commissioned and funded by NHS England and The Small Business Research Initiative for Healthcare. It enables users to capture video, audio, images and text in a single format allowing them to share selected information with carers, guardians and health professionals. The app was designed in collaboration with Humber NHS Foundation Trust, who signed a three-year contract to implement the Guide as part of its care delivery model for learning disabilities. The decision follows a twelve month initial trial and will hopefully be embedded in daily working practices.

People with learning disabilities are using My Health Guide to easily access their health and well-being information. All notes regarding medication and health information are kept in one place so that nothing gets lost or missed. This is leading to better communication between the app users and hospital staff and helps users be in control of their health issues, as well as being a tool for expressing how they are feeling.

[www.myhealthguideapp.com](http://www.myhealthguideapp.com)

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](http://www.downs-syndrome.org.uk)



Down Syndrome Ireland,  
Citylink Business Park,  
Old Naas Road, Dublin 12  
00 3531 426 6500  
[www.downsyndrome.ie](http://www.downsyndrome.ie)



Down Syndrome Education International  
6 Underley Business Centre  
Kirkby Lonsdale, Cumbria LA6 2DY  
0300 330 0750  
[www.dseinternational.org](http://www.dseinternational.org)



Down Syndrome Scotland  
4th Floor, Riverside House  
502 Gorgie Road, Edinburgh EH11 3AF  
0131 442 8840  
[www.dsscotland.org.uk](http://www.dsscotland.org.uk)

For other useful links and regional Down's Syndrome groups go to  
[www.dhg.org.uk/links.aspx](http://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](http://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](http://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](http://www.chfed.org.uk)



PHA UK  
Unit 2, Concept Court  
Manvers, Rotherham S63 5BD  
01709 761450  
[www.phassociation.uk.com](http://www.phassociation.uk.com)

Useful Links



charity 1011413

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



## Fun Day Saturday 9th September

Bookings must  
be received by  
Monday 14th  
August



£5 per person or  
£15 per family  
including lunch,  
activities and  
refreshments

**Mount Cook Activity Centre,  
Porter Lane,  
Middleton-by-Wirksworth,  
Matlock, Derbyshire  
DE4 4LS**



The Information Standard



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.