

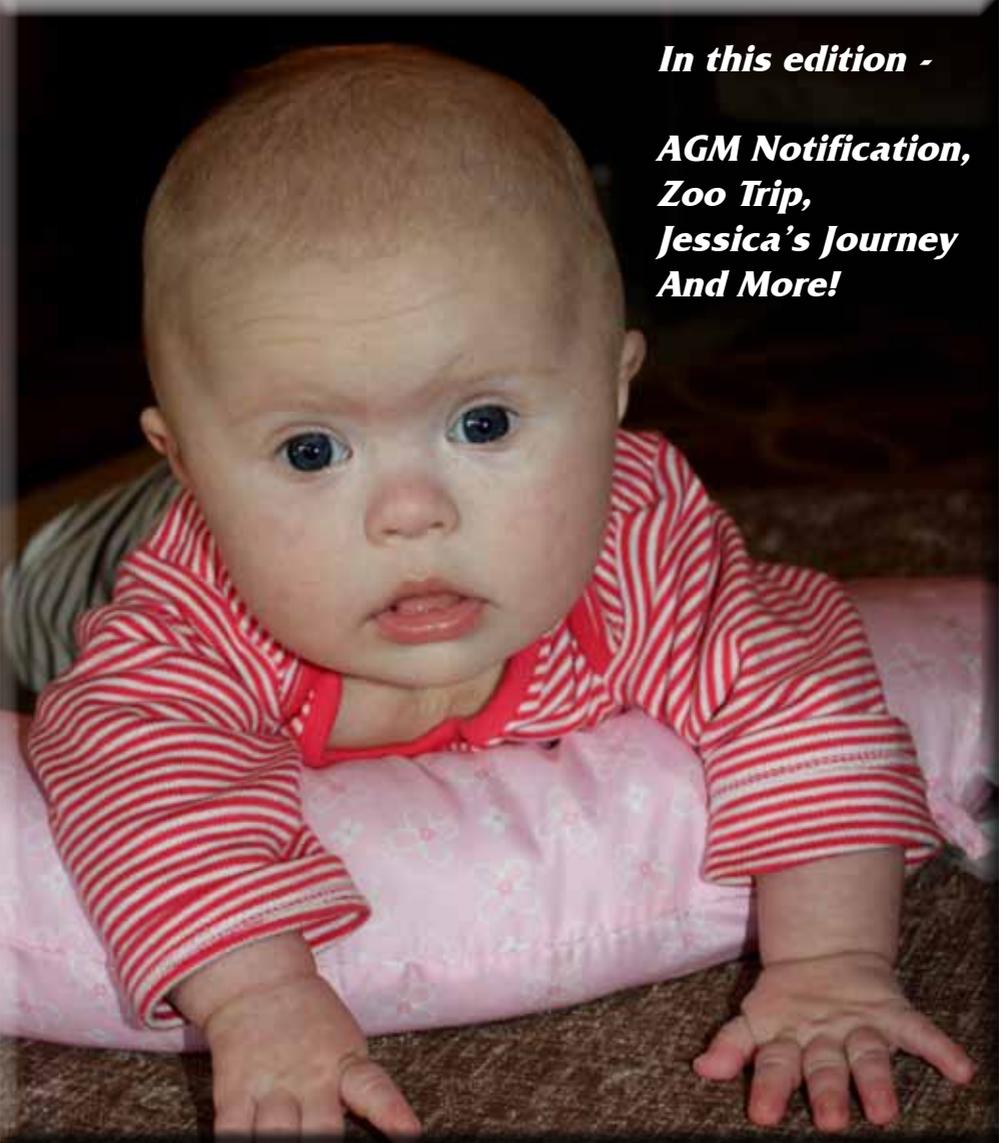


dhg

down's heart group

Newsletter Summer 2016

Issue 58



In this edition -

***AGM Notification,
Zoo Trip,
Jessica's Journey
And More!***

Chair's Report

In an ideal world this would be Chris Stringfellow's last report as Chair, but as we all know, things don't always go according to plan!

A number of weeks ago Chris' husband, Bob, unfortunately suffered a stroke. At the time of writing, although he is doing very well, he is still in hospital, so Chris' life is a little hectic at the minute, as you can imagine.

Although Chris will be standing down as Chair at our AGM on Saturday 18th June at Twycross Zoo, she will be remaining as a Trustee, so perhaps we can persuade her to write a final "*outgoing Chair*" report in the next newsletter.

I'm sure you will all join me in sending them both our best wishes and for Bob to make a full and speedy recovery.

Regards
Penny

Penny Green, Director

Contents

Elodie (story on page 8)	Front Cover
AGM notification	3
Members stories	6
Jessica's Journey	13
Easy read pages	14
Information	16
Twycross Zoo invitation	Back cover

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Annual General Meeting And Family Fun Day



Down's Heart Group's AGM will take place at the start of the Family Fun Day, which anyone is welcome to attend. You must pre-register and only members are eligible to vote at the AGM.

10 am on Saturday 18th June 2016 at Windows on The Wild, Twycross Zoo, Burton Rd, Atherstone, Warwickshire CV9 3PX

There is separate parking for Windows on The Wild and the room has its own access from the car park. For those wishing to travel by train, Atherstone is the nearest station. There will not be a separate crèche, so you may wish to bring something along to occupy your youngsters during the meeting which will finish by midday.

If you would like to stand as a Trustee or feel that you have a skill that you could offer, please call or email for an informal chat with no pressure about what it would entail. Forms are available from National Office for nominations of Trustees, these must be returned and arrive in the office no later than Thursday 16th June.

info@dhg.org.uk

0300 102 1644

After the AGM delegates will have access to Twycross Zoo for the Family Fun Day and benefit from the

reduced ticket rate of just £8 (with under 2's and carers of a paying visitor going FREE!)

Tickets will be issued at the AGM, must be booked and paid for in advance. They are available from the DHG website, where they can be paid for securely through Paypal, or call National Office to make alternative arrangements. All payments must be received by 10am on 15th June to guarantee discounted tickets.

Once in the zoo, you can do your own thing. There are several food outlets within the zoo grounds, but we will announce a meeting place for those that wish to get together for a picnic lunch if you prefer to bring your own. There are open spaces for running off excess energy and indoor places if the weather is bad.

To book tickets go to;

www.dhg.org.uk/conference.aspx

We look forward to welcoming you!

26 Years On By Penny Green

It seems incredible to think, but by the time you are reading this I will have just celebrated 26 years of working with Down's Heart Group in various voluntary and paid roles. The few of you who were at my first official event in Wolverhampton will know that it's easy for me to remember the date as it was my eldest, Andrew's 2nd birthday and he was thoroughly spoilt by everyone there.



Newsletters - how they have changed!

I attended the DHG Inaugural General Meeting in Leicester in 1990, all 23 AGMs since and 103 out of 105 meetings of the Executive Committee. As well as all 18 DHG conferences, I've been to numerous other events including four World Down Syndrome Congresses, Down Syndrome Medical Interest Group meetings, Children's Heart Federation Conferences and many, many more.

I've spoken with and met countless people with Down's Syndrome and their families, sadly far too many to remember all the names, but there are always families that stick in my mind for various reasons and a quick jog of the memory is all it takes.

Recently I've had a few of those moments, which come as a shocking reminder of how long I have been doing this. At the flashmob in Bayswater (which will form part of a BBC 1 documentary about Down's Syndrome screening) I met a DHG member I've 'known' since 1998 and her daughter Katie, who at 18 is no longer the little girl I remember. Then on Facebook a member was posting some reassurance to a mum whose little one is due to have heart surgery and said her daughter Kim is 4 – oops only seems like yesterday I visited them prior to Kim having heart surgery!

Being part of this amazing community has been such an incredible experience and has kept me so busy all these years, that I sometimes wonder what I will do when I retire because I know that I will miss it dreadfully, but I can't keep on forever and it's time that some of us who have been involved with running DHG for many years handed things over to some members with fresh new ideas and energy. So if, like me, you believe that DHG offers a unique and individual type of support to families, not only when they first get the diagnosis and are feeling isolated and alone, but also later on when sometimes something unexpected makes them reach out for further support and information, then I'd like to ask YOU to consider if you could join our Board of Trustees and help move the charity forward for another 25 years?

If you'd like to have a chat and find out more, do get in touch or better still, why not come along to our AGM on Saturday 18th June at Twycross Zoo? As well as an opportunity to chat and meet some of the Board in person, we've organised a special discount entry for all the family, so you can see what DHG is about, ask questions, have some refreshments and then spend from noon onwards in the zoo. Our Trustees bring many different skills to the group, but the most important is their understanding of the issues our members face and the desire to make each family's journey that little bit easier.

And finally, whilst your putting that date in your diary, remember to add 24th – 27th July 2018 for the 13th World Down Syndrome Congress which will be in Glasgow. This is likely to be the only time it comes to the UK for many years, so make sure you are there - it's a great time for all, information and socialising for families and a wonderful social event for people with Down's Syndrome. DHG will be there and it's likely to be my retirement party too, so it would be wonderful to see lots of our members there.



DHG displays through the years

Neo



At birth, Neo (nickname Piping) was suspected of have Down's Syndrome, purely through his physical appearance. He needs to undergo chromosomal analysis to prove it but since that's not available here in Gensan, only in Manila, our family agreed to let Piping just be himself and not make any judgement about his condition. I have often been reprimanded by my mother for being too emotional and paranoid.

Our family chose to be positive, giving Piping the love and care and continue praying that he will grow as normal as any child can do.

Our family chose to be positive

In February, Piping had a 2d echo and the result was very heartbreaking. The cardiologist concluded that he has congenital heart disease - AVSD and PDA, problems common to a child with Down's Syndrome. He must undergo a heart operation two months from now to avoid any complications.

We don't know what to do! In March we will try to visit another government hospital in Davao City, a four hour ride from Gensan, to seek a second opinion. Lots of challenges are in our way, especially emotional and financial worries.

Let him just be himself and not make any judgement

The good thing is, we get moral support from our local Down's Syndrome Facebook group and somehow we are guided in our way to conquer those challenges.



As a young parent it is indeed hurtful seeing my son with this condition, my wife is getting weak every time we speak about the operation. As of now the only thing that keeps me going is the love for my wife and my son.

*Fiel Arreza,
Philippines*

Lola

Our twins (the little people) were born in April 2011 to Daddy Del and I. We didn't know that Lola had Down's Syndrome until after she was born, nor that she had a heart defect.

When Lola was a week old Hirshsprungs Disease, a bowel disorder, was detected and required surgery. Lola's heart was checked to make sure she was strong enough to withstand the anaesthetic and surgery. They found she had a VSD but her heart was strong enough to allow surgery and it was thought that the VSD would close by itself. This was not the case and disappointingly the VSD increased in size.



In May 2012, Lola had open heart surgery at Glenfield Hospital, Leicester. This was a success and amazingly only five days later, Lola was allowed home, but six weeks post-op when her heart medications were stopped, Lola developed a persistent hoarse cough. After several trips to the GP and hospital and due to the fact Lola always seemed well in herself, the cause was still undiagnosed and, frustratingly, kept being put down to the fact that Lola had Down's Syndrome. This went on for months.

Mummy knows best, I didn't accept this and set about doing my own research. Having hit a brick wall I contacted Down's Heart Group to seek advice. It was so lovely and refreshing to speak to someone who had experienced similar issues and that showed empathy with our situation. Above all they listened!

DHG asked the Down's Syndrome Medical Interest Group to review and further advise. It was this advice that finally led to Lola being diagnosed with a collapsed lung and receiving the treatment she required. Worryingly, Lola had been unnecessarily suffering for eighteen months!

Following treatment, Lola's health and development have gone from strength to strength and she is just like her cheeky brother. They both attend the most incredible nursery they both attend weekly swimming classes. Had it not been for the Down's Heart Group this may not have been the case.

By the time you read this I will have run in the London marathon 2016 to raise funds for DHG and will probably still be recovering, but it will be worth it!

*Lorraine Kent,
Northamptonshire*



Elodie

When Elodie was born we learned she had Down's Syndrome and there was a 50% chance she would have heart problems, which was an incredibly scary thing to hear.



The next day the consultant carried out a scan of her heart and said that apart from a valve which should have closed after birth but had not and was causing a slight murmur, there were no other issues. He said in most cases the valve closes within the first 48 hours.

Elodie was on oxygen at this point but there did not seem to be any particular concern. After four days she came off the oxygen and, although the murmur remained, was released from hospital after twelve days. We were told she was to have a follow up appointment with a heart specialist from Bristol Children's Hospital to check everything was okay.

When she turned two months we saw the specialist who informed us the valve had not closed and Elodie would need an operation. The condition is called patent ductus arteriosus (PDA). The blood vessel connects the two arteries of the heart. Before the baby is born it is open to allow blood into their lungs, but after birth when the lungs fill with air it needs to close otherwise too much blood goes into them. They can do keyhole surgery where a catheter is inserted into a vein at the top of the leg and once it is in the heart a plug is fed through and put in the hole. The biggest risk with keyhole is the plug may move and if this happens an operation would be needed both to remove it and then to fix the hole.

The valve had not closed and Elodie would need an operation

The consultant wanted to try keyhole surgery, but the hole may be too big for the biggest plug and if that's the case she would need open heart surgery. I came home that night pretty shaken. The appointment came through quite quickly and was set for four weeks later. My husband and I travelled the four hours to Bristol Children's Hospital for the pre-op admission day and were given a lot of information, which both put my mind at rest about many things, but was also scary as the reality of it hit me.

I came home that night pretty shaken

Four days later Elodie and I made the journey back for the operation while my husband stayed at home with our other daughter. I thought I was pretty strong and it would be okay, but as I arrived the nerves kicked in. The nurse who was looking after Elodie was amazing though, she stayed with me quite a lot and made sure I was okay.

Elodie was second on the operating list, scheduled for 10.30am, but after a very anxious wait finally went down at noon. I got to carry her and gave her lots of kisses. The moment she drifted off to sleep from the anaesthetic and I was asked to kiss her and say goodbye was one of the hardest things. I wasn't expecting it to be easy, but I was not prepared for how upset I was. I found it hard to catch my breath but the nurse stayed with me and gave me a big hug.

I could not believe Elodie was so alert

I went for a walk to try and take my mind off it, but just an hour and a half later (I was told it was likely to be two or three hours) the hospital called me to say Elodie was out of surgery and hungry! I rushed back and could not believe Elodie was so alert. She fed really well, was cooing and smiling. At 6.30pm she needed some calpol, then had a feed and went to sleep. She slept well, as usual, not even waking when the nurses carried out their checks.

The next day Elodie had an x-ray and ultrasound to check the surgery worked, which it had - if the plug stays put for the first 24 hours, it is unlikely to ever move, it will just get swallowed up by heart muscle. Elodie was still really happy and her skin looked pinker and brighter too.

Elodie's skin was pinker and brighter

We were discharged at midday. I was elated. I had kept in touch with my husband, but the call to say we were on our way home was lovely. Three days later however I woke feeling emotional and short tempered. I couldn't put my finger on what was wrong at first, but I think it was the come down after all the stress and worry. It took me at least another week to start feeling better.

As for Elodie, she is excelling - there is no scar, she is happy and full of energy. The heart specialist said the surgery had worked and everything looks good. She doesn't need a check up for another six months.

*Ginette Davies,
Cornwall*



Olivia



Olivia was born in October 2012. She was diagnosed with Down's Syndrome and an AVSD. She would need open heart surgery at six months and put on medication until then. We were so scared and devastated our baby would have to go through such a procedure but quickly accepted it had to be done.

At Olivia's next scan we were told it still looked the same so the surgery was put back until she was one. At age one we were told they would operate when she was stronger and about five. But, at just over a year old, Olivia had croup and kept getting really bad colds and infections. We saw her paediatrician who found the valve was deteriorating quite quickly so surgery was brought forward to August 2014.

Surgery day was the scariest, most worrying day of our family's lives. However, the nurses and staff of Bristol hospital were fantastic and looked after Olivia and us. After six very stressful hours we met with the surgeon who told us the repair to the valve was unsuccessful. It was very badly damaged so she will have to have another surgery when she is older.

The valve was deteriorating quite quickly

Nothing can prepare you for seeing your child lying with bandages, wires and machines all around, it was very distressing, but Olivia was very well cared for by the staff of Bristol children's PICU. She pulled out her pacer wire so took her a little longer to stabilise but two days later she was in high dependency and doing really well. She was drinking, responding and wanted to get out of the cot! Four days after surgery Olivia was standing up in the cot! We couldn't believe how strong she was, it was fantastic!

When we were on the ward we had a visit from the ENT team to ask us if we knew that Olivia had a restricted airway. We didn't, so they sent her for some tests and, yes she did, so will need to have her tonsils and adenoids removed!

Without heart surgery the other things would have been left undiagnosed

Before leaving hospital we noticed her stomach was very big. She had been diagnosed before with distended tummy but was always given laxatives. A lovely nurse I mentioned it to asked us if we would like to meet a specialist and we agreed. We met with two great doctors who asked us if we ever heard of Hirshsprungs disease. We said no, and they told us it probably isn't that as Hirshsprungs is usually diagnosed at birth.

After a biopsy Hirshprungs was confirmed and bowel surgery was needed. Due to just having cardiac surgery and the risk of infection she had to wait until December. In December, what was supposed to be key hole surgery unfortunately ended up as open surgery due to the blockage being so big. But just like the little trooper that she is she, was up and about two days later. If it wasn't for the heart surgery the other things they found would have been left undiagnosed.

Olivia has a very bright future ahead of her

We don't know when Olivia's surgery for a complete new valve will be. She has regular scans and there seems to be no change. The hole she had is repaired nicely. She has been through so much in her short life so far but we know she's a very strong, determined little girl. The way she dealt with everything thrown at her is wonderful, she never complains but is always laughing and smiling. She doesn't realise her strength helped me get through breast cancer chemo and radiotherapy as my focus was on her the whole time.

Olivia is now nearing her third birthday and has just starting to learn to walk and say a few words. She makes everyone smile when they meet her and has the cheekiest grin. Her brother, sisters, daddy and myself are all very protective of our Olivia but we know she will face any obstacle in her way. Olivia has a very bright future ahead of her.

I'd like to say thank you to all the staff at Bristol hospital and St Michael's who were so supportive throughout my pregnancy and Olivia's two very busy years.

*Donna Cowan,
Somerset*



Stories

The newsletter relies on members writing their stories and sending in photos so please consider doing yours if you haven't already. Don't worry how much or how little you write or about grammar and spelling as everything is carefully edited before being printed.

It is important, though, that any photos are high resolution, preferably 1Mb and taken on a good camera, iPad or phone. Send items to

sarah@dhg.org.uk

Sing4Fun Again!



In March, Sing4Fun, the South Wigston Community Choir, held another concert to raise funds for charity. Helen Laverty went along to represent DHG and thoroughly enjoyed it, as did the rest of the audience.

The evening raised £500 to be split equally between DHG and another deserving cause. However, a lovely, kind man, who remains anonymous to us, decided he would match that figure, bumping the total to £1000!

Thanks must go to this gentleman, the Sing4Fun choir and its organisers and DHG member Judy Warner for putting DHG forward as a beneficiary.

London Marathon

We are pleased to announce that the DHG runners all completed the marathon on 24th April. What an achievement!

A report on how they all did, along with amounts raised, will be in the next newsletter. The London Marathon is our biggest fundraiser, so thanks to all who donated. It's not too late for those who haven't!

Awareness T-Shirts



The wonderful Sarah Gordy, an actress with Down's Syndrome, kindly modelled one of the DHG awareness tops at a recent function. She certainly wears it well!

There were plenty of the t-shirts being worn at the recent Positive Choices, Learning Disability Nurses conference in Nottingham.

In total we sold 69 t-shirts, (grey being the most popular colour choice) and raised £482.83.

Does anyone have design ideas for next year?

Jessica's Journey 100 Miles and More....



'You are braver than you think, stronger than you seem and smarter than you believe' - Powerful words which Jessica believed with a passion, and would be telling those supporting the long distance walk "Jessica's Journey." A charity walk of determination, strength, courage, smiles, inspiration, happiness and love - all of which Jessica had in abundance, but was so sadly cut short in December 2015 when she lost her battle with meningitis.

Jessica was born in August 1990 in Geneva, Switzerland, with Down's Syndrome and a complete AVSD, starting her family's association with Down's Heart Group. Despite not having surgery, Jessica's health thankfully remained stable. There were times when she came perilously close to the edge but her determination and strength pulled her through. Jessica was truly an inspiration and achieved a great deal, all of which were deemed not possible from the start - but she had other ideas!

DHG were always on hand in the background, to give help and advice, and it is the very same Penny Green, who answered a frantic call from a very worried new mum from Yorkshire in a foreign country and gave her support, who is there at the end of the phone today. It is Jessica's mum, Ghislaine, who will carry the torch for her brave daughter, who will walk this journey '100 miles and more' along with Jessica's sister, Rebecca, to raise funds towards providing a weekend of 'fun and experiences' for other young members of DHG, so that they might enjoy doing something they never thought they were brave enough to do.

So, Down's Heart Group supporters, we need you.....to support us in any way you can to make this a success, from donating, to joining us at the start and finish line. The walk will start on 6th August from Lytham St Annes on the Lancashire coast and finish in Ilkley, Yorkshire, on 13th August, taking in many of the places Jessica loved to visit in Yorkshire and Lancashire, with a few surprises along the way!



Help us pay it forward and give the legacy of Jessica's inspiration the support she gave to others all her life, which would have been her pleasure. Further details are on a dedicated Facebook page, where it will be possible to follow and support the walk and donate toward this wonderful cause. Alternatively, contact DHG.

www.facebook.com/Jessica.100milesandmore

Save the date 6th - 13th August 2016

Please join and support us and
LET'S MAKE THIS HAPPEN



Do you want to come to the zoo and meet the baby monkeys?

We can meet up for a picnic.

You could make some new friends.



Jacob won an award for doing so well in Jujitsu.

He is a black belt and won *“Enabled Martial Arts Man of the Year”*



Katie has a new job.

She is working at a Community Centre.

Here she is baking a cake for the customers.



Dan is a huge Liverpool fan and was very lucky to meet Robbie Fowler.

He was very excited about it!



Heidi went to London to give a speech.

She was brilliant!

Heidi met Lord Shinkwin and lots of families.

Remember to send us your news!



If you like to play sports you could join Special Olympics!

You'll have fun, get some exercise and make new friends!

There are lots of clubs and lots of sports.



In 2017 there will be a National Special Olympic Games in Sheffield.

This will be a very exciting week of competitions and fun.



You can contact your local club or look at the website

specialolympicsgb.org.uk

The Expert by Experience!

There are lots of great partnerships, Cannon and Ball, French and Saunders, Hinge and Bracket, but over the last three years I have had the absolute pleasure of being in an exciting partnership with the amazing Emily Smith.

My 'day job' is professional lead for learning disability nursing at the University of Nottingham; essentially I make sure that students who want to work with and for people who have a learning disability get the best education we are able to provide them with. My job also entails making sure that the other fields of nursing and midwifery don't forget about people with a learning disability and their families, too.



I teach policy and practice and support students in placements in environments where people live, learn and have fun. But it is most important that the whole concept of what it's like to live with a learning disability comes to life for them, if they are then to be able to provide life-style opportunities that promote independence and inclusion for people and most importantly make sure no one gets left behind.

Enter the expert by experience! I cannot begin to tell you how important Emily is now in our team and to our students. (Not just for her hot chocolate, navigating skills and sense of humour – but that's telling tales out of school!)

Emily not only facilitates sessions that are three hours long to up to thirty students at a time, where she generously shares her story, answers questions, and gently guides the students to think in a more joined up way, she also acts as expert co-facilitator to students who are using a creative narrative option for their BSc. (hons.) degree dissertation option. Emily is a safe pair of hands in the classroom; she commands respect and leaves her audience spellbound with her stories and insights into living with a learning disability in the 21st Century.

Thanks, Em, for all you share, do and have taught me (Oh! And I'll remember not to listen to you when you guide me the scenic way in the dark!! – mind you, we've never got lost!)

Helen Laverty



Somerville Foundation Events

[The SF Social Weekend](#) will be at the Stirling Court Hotel, Stirling, from 8th - 10th July 2016. The weekend is open to all GUCHs (Grown Up Congenital Heart patients) and their families, and is an opportunity to meet others with heart conditions in a fun, relaxed and safe way.



Stirling Court Hotel is in the centre of Stirling, a short walk from The National Wallace Monument, and 2 miles from Stirling Castle. The weekend, Friday evening to Sunday morning costs £240 for a single and £300 for a double or twin room. This rate includes dinner on Friday and Saturday evenings and breakfast on Saturday and Sunday morning.

admin@thesf.org.uk

[The SF Annual Conference](#) is in Leicester on Saturday 17th September 2016. Enjoy an interesting, informative and empowering day of presentations around living with a congenital heart condition and managing your health. The speakers are all experts in GUCH medicine at Glenfield Hospital, Leicester. The Conference is free of charge.

tinyurl.com/tsfleic

If you have any special access needs or are struggling financially Somerville Foundation have grants available to help with travel or hotel costs. For further details contact Helen at Somerville Foundation on:

01473 252007

conference@thesf.org.uk

Learning Disability England

People First England will soon become Learning Disability England, a new organisation bringing together self-advocates, families, friends and organisations to create a strong voice on national issues.

Surveys were carried out in March asking the opinions of those with learning disabilities and those that care for and support them on how they would the organisation to develop and what issues they would like it to focus on. The information is being collated and Learning Disability England will be launched in June, to coincide with Learning Disabilities week. To find out more or to join, go to:



peoplefirstengland.org.uk

Snoring and Early Years Learning



Dr Anna Joyce from Coventry University's Centre for Research in Psychology, Behaviour and Achievement is conducting a new study exploring the effect that disruptive sleep has on early years learning.

Heavy snoring or gasping for air may be signs of obstructive sleep apnoea syndrome (OSAS), which is where the airway becomes blocked. Due to low muscle tone and narrow airways, OSAS is particularly common in people with Down's Syndrome, however, there is barely any research on this, hence Dr Joyce's project.

We need good sleep to be at our best and those with sleep problems find it more difficult to learn, pay attention and remember things, so will struggle in the classroom. Dr Joyce is determined to get the message across that all children should be screened and treated for sleep problems so they have the best chance to be healthy and happy.

The study is for children aged two to four years. Those interested in participating will attend a session lasting 90 minutes at either Coventry University or the UCL Institute of Education in London (whichever is most convenient) where the children will play games that will test their motor, visual and language skills.

Parents will also be shown how to use equipment to monitor their child's breathing during sleep, which they will then take home. After recording a night of sleep, the equipment will be returned to assess whether breathing difficulties are apparent. Volunteers will be given a £40 shopping voucher for taking part in the study. Please contact Dr Joyce at

024 7765 9509

email anna.joyce@coventry.ac.uk

Travel Chair



The TravelChair fits into a standard airline seat giving postural support for children. It is suitable for ages three to eleven, depending on size and weight. It has an adjustable headrest, footrest and body harness. The chair weighs 6kg and can fold to fit into an overhead compartment.

Virgin and Monarch airlines offer the use of a TravelChair for free, parents just need to request it when booking. The TravelChair can be bought for £3000 from Meru, who sell aids and gadgets for children with disabilities.

www.meru.co.uk

See And Learn

See and Learn Speech is designed to help parents and teachers support children with Down's Syndrome to develop clearer speech.



It is one of the programmes offered by DSE (Down Syndrome Education International), whose expertise, developed over many years, is used across the world. See and Learn Speech teaches young children to hear and produce speech sounds, to hear the differences between sounds and to develop their speech sound system, all of which lead to clear speech. It can also help children to identify sounds in words which is important for reading.

See and Learn Speech offers a structured approach to support speech development, working in small steps towards clearer speech production and practising skills including:

- becoming familiar with speech sounds - storing sounds in the memory system
- discriminating between speech sounds - hearing the differences between sounds
- producing speech sounds - individual sounds and simple combinations
- saying words - saying words that begin with a particular sound
- saying more complex words - saying words that have one, two, three and four syllables and putting words together

www.dseinternational.org

Anyone For Tennis

Everyball Enabled Tennis has been established for five years and is recognized by the Tennis Foundation. They run disability tennis sessions all year round at Halton Tennis Centre in Buckinghamshire. Their main aim is to inspire anyone with a disability to play tennis, regardless of their background or ability, and of course to have plenty of fun.



They have a tennis session for youngsters with Down's Syndrome on a Saturday, between 1 – 2pm on either our indoor or outdoor tennis courts. All sessions are delivered by a LTA Level 3 tennis coach. If you are interested please contact Alex or Laura:

07582159583
07585955872

alex@everyball.net
laura@everyball.net

www.haltontennis.co.uk/tennis/disability

What do you think about your local care services?

The **Care Quality Commission (CQC)** is the independent regulator of all health and care services in England. We register, monitor and inspect services to make sure they provide safe, effective, compassionate, high-quality care, and we encourage them to improve.

We are inspecting The Royal Brompton & Harefield NHS Foundation Trust



We will shortly be inspecting services provided by The Royal Brompton & Harefield NHS Foundation Trust starting on the **14th June 2016**.

The Royal Brompton & Harefield NHS Foundation Trust specialises in treatment for heart and lung disease and includes the following hospitals:

- Royal Brompton Hospital
- Harefield Hospital

Your experiences of services help us to understand what is good and bad at these hospitals, so please get in touch using the contact details below.

www.cqc.org.uk/sye
tellus@cqc.org.uk
03000 616161

Paddy Walsh

Down's Heart Group would like to wish Patricia "Paddy" Walsh a very happy retirement. Paddy has worked on the Freeman Hospital Children's Heart Unit for 38 years, since it opened in 1978.

Paddy is retiring from her role as cardiac liaison nurse. She has played a huge part in so many families' lives and will be fondly remembered for her friendly and professional nature.



General Anaesthetic

The Royal College of Anaesthetists has written a leaflet entitled: 'Your Child's General Anaesthetic'.

If your child will soon be having an operation or procedure and you would like to find out more about their general anaesthetic, you can download the booklet in a variety of accessible formats.

tinyurl.com/rcadhg



Tap2Tag

Tap2Tag is a simple device, either a rubber wristband, key fob or card which contains a near field communication (NFC) chip. Important personal and medical information can be uploaded to a secure website and accessed through the device in an emergency. When necessary, the chip can be 'tapped' with an NFC enabled phone or through the website to allow the data to be accessed by the person responding in the emergency. It can also send messages to carers to alert them of an incident.



East Kent Hospitals University NHS Trust is currently running a trial of Tap2Tag along with My Healthcare passports to see if these devices can really help those with learning disabilities and health issues get faster and relevant treatment when it matters most. If the study is successful Tap2Tag could be rolled out across the NHS.

Positive Choices



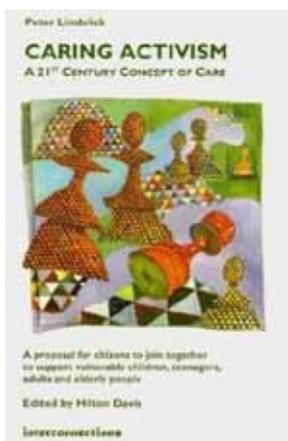
Linda raising funds

Nottingham University hosted the Positive Choices Learning Disability Nurse Students' conference on 31st March - 1st April. It was, as ever, very well attended and everyone was buzzing with enthusiasm for the future.

DHG member, Linda Phillips, worked hard on our stand, promoting our work both from the perspective of being an LD nurse and a DHG parent. Many students had already heard of us, largely thanks to Helen Laverty.

There were many thought provoking speakers and performances, including a tear inducing piece from the wonderful MiXiT. DHG's Emily Smith flitted between the DHG and Special Olympics stand on Thursday, as well as opening Friday's conference and doing introductions and thankyou's all day with Prof. David Charnock.

Caring Activism



A Caring Activist Team is just three or four people supporting a vulnerable person who would otherwise struggle to get the care and services they require. The vulnerable person is in the team and will be the lead, unless this is not possible at the time. There is no formal qualification for being in a team and permission is not required from any agency.

Caring Activism is done on a local level, with the activists being present in a helping relationship with the person. Teams work independently of local authorities but will form working partnerships with public, voluntary and private organisations when that brings added benefit to vulnerable people. Team members may provide immediate relevant practical support or spend time with the person as an antidote to loneliness.

Caring Activism does not come with a rigid set of rules. It must be made to fit each individual situation to the benefit of a particular vulnerable person. For more information you can read Peter Limbrick's new book on the subject or go to the website (where details of how to purchase the book are also available).

www.caringactivism.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



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

0300 330 0750
www.dseinternational.org



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

00 3531 426 6500
www.downsyndrome.ie



helping people realise their potential
Down's Syndrome Scotland
158 - 160 Balgreen Road
Edinburgh EH11 3AU

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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AGM and Family fun day at Twycross Zoo

10am Saturday 18th June 2016

**Reduced rate tickets only £8 (one carer goes free) but
they must be prebooked through DHG.**

See page 3 for details

Twycross Zoo is home to rare snow leopards, a baby Bonobo, a dancing gorilla, the famous chimps and a huge range of other fantastic animals.

This promises to be a great day out with free parking, disabled access, picnic areas, cafes and lots of indoor space if the weather is typically English!

www.twycrosszoo.org



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.