

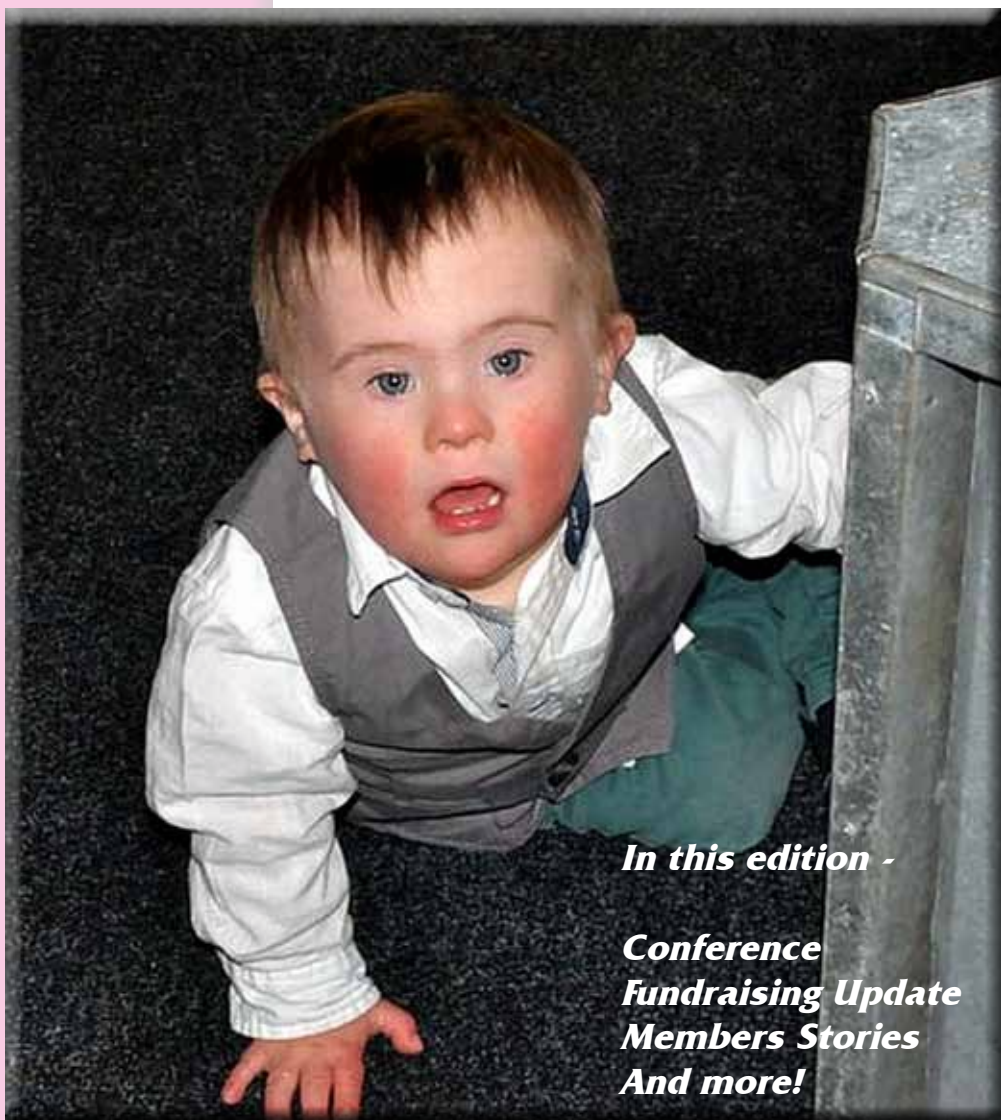


dhg

down's heart group

Newsletter Autumn 2015

Issue 55



In this edition -

*Conference
Fundraising Update
Members Stories
And more!*

Chair's Report

Welcome to this 55th edition of our newsletter.

Our conference was held in May and despite poor attendance an excellent time was had by all! Our thanks go to those who made it possible, especially the volunteers who ran the crèche and activity workshop for the youngsters. Thanks also to Cornwall Down's Syndrome Support Group who had a stall showcasing their newly launched book "*Looking Up*". It has featured on our Facebook page and is well worth a look at. (See page 10 for more info)

As you will see from the report of the AGM I will be resigning as chair next year, so to ensure a smooth handover we have a chair elect, Helen Laverty, who has been a Committee Member and Trustee since November 2011. She is a lecturer teaching Learning Disability Nurses and brings with her a wealth of experience of Down's Syndrome as well as being a great advocate for young people with learning disabilities. Helen has already helped DHG network with many professionals and other organisations.

I hope you all have a good summer.

Regards

Chris Stringfellow

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New Phone Number

Down's Heart Group has a new telephone and fax number.



This change should reduce the cost for some callers as calls to 03 numbers cost no more than a national rate call to an 01 or 02 number and must count towards any inclusive minutes in the same way as 01 and 02 calls.

These rules apply to calls from any type of line including mobile, BT, other fixed line or payphone.

Phone: 0300 102 1644

Fax: 0300 102 1645

Annual General Meeting



The Down's Heart Group AGM was held at Combe House Hotel in Somerset on Saturday 16th May 2015.

Chris Stringfellow and Roberta Nathan stood down as their three year term was up, but were both re-elected. Chris announced that she intends to step down as Chair in 2016 so it was agreed that Helen Laverty be appointed Chair-Elect, ready for a smooth hand over next year.

Nina Lawson resigned as secretary and thanks must go to her for the great job she has done over the past few years.

Down's Heart Group's board of trustees now comprises:

Chair	Chris Stringfellow
Vice Chair	Peter John
Chair Elect	Helen Laverty
Treasurer	Phil Thorn
Secretary	position vacant
Trustee	Alice Croot
Trustee	Richard Mowberry
Trustee	Roberta Nathan

The accounts were presented and it was noted that whilst they remain stable the charity must continue working on ways of increasing income to enable DHG to best meet the needs of its members.

Samantha



Sam with Stephanie and Steve

On 30th June 1994 Samantha Jayne Roulet was born, two weeks early and by emergency caesarean, a much wanted second daughter. I looked at her and said *"That's a Down's baby"*.

The midwife took my husband away to weigh Samantha and no doubt to check her over to confirm my suspicions. I hoped I was wrong, however, as Steve came back with red teary eyes and said *"I'm so sorry"* my whole world just crumpled. I screamed and sobbed.

I couldn't look at Samantha and felt rigid. Ann, the midwife, pleaded with me to look at her, telling me she was beautiful, so after a few minutes I did look at her, but there was no feeling as I was still in shock. I lay awake all night trying to put things into perspective. We would love our little girl, do all we could to give her a good life. If any friends or family didn't accept Sam they would no longer be friends.

The next day I went out on the ward and made a point of telling everyone that Samantha had Down's Syndrome. My baby was just as good and beautiful, if not more so, as any other baby and I wanted everyone to see that.

My baby was just as good and beautiful as any other baby

I was ignorant and had old fashioned images of people with Down's Syndrome flashing through my mind. I spent the next weeks learning all I could. The need to know everything is how I deal with trauma. However, when I look back, I was not on this planet for a while!

Whilst in hospital with a chest infection a hole in Sam's heart was detected. They said it was small and should close by a year old and we were to go to Great Ormond Street Hospital in December. Once there we were in for a bombshell! Sam had a large hole which needed repair before any damage was done to her lungs. Without surgery she may not live beyond ten years old. Tests were booked for two weeks time, during which I wondered if it were best that she died, but then she would smile at me and my heart would break all over again.

The tests revealed two holes - one to be patched and one to be stitched. We spent Christmas happy in the knowledge that Sam would have a chance - she was booked in for surgery on 2nd January. Everything went to plan

and one week later we returned home. Samantha continued to make good progress, at sixteen months she was very vocal with the usual dada, mama, and has continued to be very vocal! She commando crawled and bottom shuffled and was walking by the age of two.

Everything went to plan and one week later we returned home

At infant school, one of her teachers wrote *"Samantha can take you to the highest of highs and the lowest of lows"* this was not a negative comment but a true reflection of her character as she was, and still is, a very strong willed person!

Getting Samantha into the most suitable senior school was a huge battle, causing lots of stress and worry. But it was worth it and the next five years went quickly. We discovered Samantha had Coeliac disease which she copes with very well. When she broke her ankle, needing a metal plate and pins with no weight bearing for six weeks she was an absolute star and the cast was removed in time for her leaving prom!

Sam then moved on to mainstream college with special needs provision and she spent three years there travelling daily. Then in 2013 she started at our local college and this course will end July 2015. We are now looking at what to do next and trying to secure the funding for it.

During her nearly 21 years Samantha has had regular checks for eyes, ears, heart and blood tests. She wears glasses and has an underactive thyroid and she takes her own medication in the morning. Last year she went to the London Hospital for her heart check up and has now been discharged.

Sam has been to concerts, theatres, zoos, theme parks, away with schools and college. We have had holidays in Italy, Greece, Disneyland Paris, France and Wales. She loves eating out, and uses any excuse not to have my cooking! She is also partial to a cider!

Sam wants to move out eventually because she does not want to follow rules, wants to drink alcohol when she wants to and order takeaways all the time! I do point out that this would not work! She wanted to learn to drive but although she can physically drive a car (she has driven off road with an automatic at Mercedes Benz World), I have explained that the roads are too dangerous, also she cannot drink cider and drive, so she has chosen cider!



Prom night



Sam is almost 21!

Samantha has an iPad and mobile phone and often texts me from upstairs to see what's for lunch! Why she cannot come down the stairs and ask is beyond me! She also writes me notes asking for things she wants to buy, she will go online, see what she wants and write it down. Every time I get a note I smile because to me it's an achievement.

In fact, she never ceases to amaze us with the things she does or says when we are least expecting them - even when she has used bad language!!!! After all, Samantha will say, "I am nearly 21 and my sister does it". I have no answer to that!

Samantha enjoys her life, don't get me wrong she has down days when she tells me she hates her life, hates her parents, as any other teenager would do, we argue and stop and then I get a note saying sorry or I say sorry, depending who is at fault! All of which is normal, whatever "normal" is! I look at Samantha and see a beautiful person; someone who is honest and true and would not knowingly hurt you, just wants to please.

All of which is normal, whatever normal is!

My eldest daughter has been a great influence on Samantha and even though they argue like sisters do, they are there for each other. I am full of pride for both of my girls and although life has not always been easy I think we have done okay. Nearly 21 years ago my world was shattered and my heart broken because of ignorance and the unknown. Today my world is different with different views and a different outlook and my heart; well that was well and truly mended many, many years ago!

*Sue Roulet
Hampshire*

Member Stories

Everyone loves reading about DHG members, whether it's a happy or sad tale, straight forward or very complicated, regarding babies, children, adults or those no longer with us.

Please send your stories and photos to share in the newsletter. You don't need to use perfect grammar and spelling, just forward the story in your own words and style to

info@dhg.org.uk

Ollie

Ollie was diagnosed antenatally with Down's syndrome and a VSD, however, once he was born scans showed that his VSD had closed but he had a small ASD. I was told that this would most likely close by itself or at worst case scenario he would need a catheter repair. Ollie grew well and had no major health issues.

At six months old a check up showed the ASD had grown but he was still doing well. Things changed at ten months old when he was scanned by a new consultant who thought that he had a partial AVSD requiring open heart surgery. This was a big shock as he was still developing well. I was told not to worry too much as they wouldn't operate for two to three years unless he started to deteriorate.

Over the next six months Ollie began to show signs of deterioration. He stopped gaining weight, started to develop chest recession and to turn blue if he got cold or upset. When he was eighteen months old he started on diuretics as he was showing signs of heart failure. The consultants discussed the need for surgery in the near future.

Between November and January we were given dates but then cancelled five times due to emergencies and lack of beds. On one occasion Ollie was in his gown and all ready to go to theatre when it was cancelled! This was very stressful although I did understand why it happened. Finally, Ollie had his surgery in January 2015, a month before his second birthday. He was the size of an average nine month old.

Surgery went well and Ollie was on PICU within four hours. We received the great news that there was nothing wrong with Ollie's valves, just a very large ASD. Ollie was not a good patient on PICU, he didn't like the tubes and drains and over the first few hour managed to pull them out, including his chest drain. The nurse looking after him said she had never know anyone be able to do that! The staff soon decided Ollie could return to the ward and I'm sure they were relieved when he went!

Ollie recovered fairly quickly but continued to need chest suction. After eight days we returned home. He is now nearly two and a half, he grew 5cm in the three months post surgery and gained weight steadily. His mobility has improved and he is developing well. He loves racing around the house on a ride on car and has a wicked sense of mischief.

*Jilly,
Leicester*



Post surgery paint and play

Conference and Family Fun Weekend

Down's Heart Group welcomed families and professionals to a wonderful venue, Combe House Hotel in Somerset, for our bi-annual conference. The speakers were excellent, the weather was very kind and the atmosphere all weekend was great!

The weekend began for many with the Friday evening meal offering the chance to unwind after long and difficult journeys, due to the closure of the main road enroute to the hotel following a serious accident. The restaurant was soon full of the sound of laughter.



Dr Ben Thomas

Following the AGM, the conference programme began on Saturday with Dr Ben Thomas, Advisor to the Department of Health for Learning Disabilities, who spoke about the “*Strengthening Rights for People With Learning Disabilities*” green paper and the improvements this should provide to those using NHS services once it becomes law at the end of summer.

The “*No voice unheard, no right ignored*” consultation gathered comment from people with Learning Disabilities and their families about the green paper’s proposals and there has been a promise that all comments will be taken into account before the white paper is finalised.

Dr Thomas talked about the changes within the NHS over his career and how people with extra needs are now supported and listened to in a far better way within the NHS. There are obviously many improvements still to be made but he is quietly confident that things will continue to get better, especially for those who may require treatment traditionally offered in a unit often many miles from home.

Gwen Moulster, Clinical Director of South Staffs NHS Trust shared a wealth of information on the Health Equalities Framework (HEF), explaining what a useful tool it is to parents, carers and health professionals to measure and monitor, very simply, the health of anyone with a learning disability.

She played a video demonstrating how the life of one young man was dramatically improved by using a HEF plan, which also showed how families felt more in control and enabled to make sure health issues weren’t overlooked or that the “*syndrome*” was blamed for either ongoing or new health issues.



Gwen Moulster

The HEF App has just been created and Gwen was excited to give delegates the first chance to view it! It will be formally launched very soon and will be integrated with

Lincus. HEF is already available to download free of charge and the HEF App will also be free.

tinyurl.com/healthequal

Professor Rob Tulloh from Bristol Children's Hospital gave a talk on the importance of continued and joined up health care, which is still very important even after a successful cardiac repair. They should still have regular cardiac check ups, preferably every two years with either a paediatric or adult congenital heart specialist.

In his role as Consultant Congenital Cardiologist, Rob specialises in pulmonary hypertension, prompting many questions from the floor in best practice and treatment. He was keen to point out that every patient should be treated individually, as what works well for one may not be the best route for another.

Before dashing back to work, Professor Tulloh presented Penny Green (DHG Director) with a beautiful glass bowl in recognition of her twenty five years involvement with the charity. No one had ever seen Penny stuck for words until this, she was quite overwhelmed!

Lawraine and John Hails are Directors at MiXiT, the performing arts group made up of young people with and without learning disabilities. Their daughter has Down's Syndrome and they talked about the struggles they've had trying to get her the financial and social care she is entitled to. Lawraine campaigns for clear and easy access to PIP, Direct Payments and other allowances available to help people live the lives they want.

All parents in the room found this presentation very interesting and enlightening DHG will be looking to feature Lawraine's tips and advice in a future newsletter!

Those at the conference were left with the feeling that with such advocates as Ben and Lawraine, the voices of those with Learning Disabilities are going to be heard! The whole day was very inspiring, giving us all confidence in the future - thanks to all the speakers for giving up their valuable time at the weekend.



Dr Rob Tulloh presenting gift to Penny Green



Lawraine and John Hails



Activity workshop in the sunshine

Conference Continued



Whilst the adults were busy listening to the presentations, all the youngsters, no matter what age, were having a fabulous time, making new friendships and learning new skills. The volunteers who looked after them deserved a well earned rest on Sunday!

At the end of the conference all the youngsters gave a performance of a song they had been rehearsing during the afternoon. They had worked hard and showed great team work. It was wonderful to see them all making sure everyone was included and had a turn to hold the microphone.

The weekend was taken up by having fun!



On Saturday evening, after the conference, there was just time to grab a quick rest and shower before the dinner and disco. The room was beautiful and the food extremely good. It wasn't long before the dance floor was full and the dinner seemed to give everyone lots of energy!

Even the littlest people stayed awake long into the night and no doubt slept the whole way home on Sunday!

Looking Up



At the DHG conference, Cornwall Down's Syndrome Support Group showcased their wonderful book 'Looking Up', a series of pictorial stories following the early years of 28 children with Down's Syndrome. It is a wonderful gift for any new parent and the group deliver a copy together with a present and card to all new babies born in their local hospital.

CDSSG are looking to spread the use of this book countrywide. It can be ordered in bulk by contacting the group or single orders can be purchased by following this link:

Positive Choices

Every year DHG attends the Positive Choices conference. It's a free to attend conference for student nurses who are studying a course to exclusively work with and for people who have a learning disability. This year we were in Cardiff.

It's a huge two day event ensuring student nurses, movers and shakers in the LD service world, people with a learning disability and those who love them can get together to talk about things that are impacting on the world at the moment.

There were many speakers including Mia and Natty Goleniowska from Downs Side Up. Mia is the author of the best seller *"I love you Natty!"*

MixiT also put on a performance and wowed the audience as usual.

Next year the Positive Choices conference will be in Nottingham and with DHG members Helen Laverty and Emily Smith as part of the organising group it promises to be bigger and better than ever!

www.positive-choices.com



The DHG stall



Mia and Natty

Being Included

Down's Heart Group was represented at a conference at Nottingham's Queens Medical Centre in June by member Emily Smith who gave a presentation on *"Being Included"* to learning disability student nurses. Then in the afternoon, there was a speed date style workshop, where the students rotated round the tables where they met and spoke with the day's speakers.

Emily was nervous to begin with but told the audience she was the one who knew most about Down's Syndrome so that gave her confidence!





The DHG conference was great fun.

The girls thought the disco was the best bit!



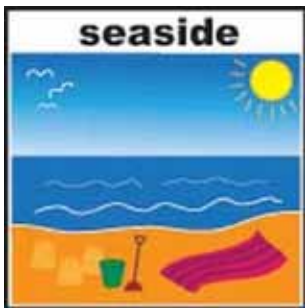
Have you been anywhere exciting?

Tell us about it and send photos for us to share.



Monkey has been taking photos.

Have you met him yet?



Summer is for holidays on the beach.
Where did you go?

We hope you met some new friends.



Some people like going to the mountains or the forest for a holiday.



Whatever you did this summer, we hope you had fun!



It is good to eat outside in the summer.

BBQs and picnics are both really good.



Some of you will be going to new schools or colleges soon.

How exciting!

We hope you have everything ready for the first day.

Phil Thorn - Treasurer

Why did you get involved with DHG? Mary and I had a son, Richard, who had Down's Syndrome and a heart problem.

What made you volunteer to help? We were pleased with the support we received from Down's Heart Group and the treasurer's job was my sort of job and available.

Occupation? Retired Mathematics teacher, Head of Year and Lead Mentor.

What do you think you bring to the role? Number skills.

Hobbies? I enjoy playing and watching cricket, golf, walking, crosswords, bridge, numbers, beer, spoonerisms and puzzles.



Family? I have 3 daughters and 2 grandchildren, Dylan who is 3 and Molly who is 1.

Pets? Only balls.

Age? 21 three times.

What do you see for the future of DHG? To keep supporting families where necessary.

Favourite cake? Chocolate

Embarrassing moment? Plenty of those! I went on cricket tour a week too early! I once reversed into a lamp-post that wasn't there a few seconds earlier!

Claim to fame? I played county cricket for Gloucestershire and whilst playing for Wiltshire played at Lords for Marylebone Cricket Club, the top club. I took all 10 wickets in one game.

I produce "*Thorny Solutions.*" - A Level Maths solutions for my old school. Teachers and students use them as they are easier to follow than the Mark Schemes.

Chris Stringfellow - Chair

Why did you get involved with DHG? I met Sheila Forsythe, who was the DHG Hospital Co-ordinator for the South West region, at a presentation that she gave to a group of Health Visitors in Cardiff in about 1995! So I have been involved with DHG for 20 years.



What made you volunteer to help? I felt that parents of children with Down's Syndrome and cardiac issues did not have enough information from within the NHS. I subsequently became the South Wales co-ordinator. I joined as I felt that the ideas put forward by the group were very valid and there was very little information available to us, as parents, regarding the conditions.

Occupation? I have recently retired as a Health Visitor and as yet my feet have not touched the ground!

What do you think you bring to the role? My association with the NHS and young families. I have been Chair since 2007 and will be resigning from that position in 2016 but hope to remain part of the committee. During my time with the group we have assembled information about most of the cardiac conditions and associated conditions that are seen by others in the world of Down Syndrome as invaluable.

Hobbies? Reading, swimming, Sudoku and now internet Mah-jong.

Family? A long suffering husband, Bob, and 3 children Louise, Helen, and Richard. Richard is 29 and has Down's Syndrome. Also 2 granddaughters Catrin 6 years and Seren 1 year. We have another granddaughter due in November!

Age? Beyond retirement!

What do you see for the future of DHG? To keep up to date with the changes within the NHS. Keep producing info and to support families with both children and adults

Favourite cake? Anything except chocolate.

Embarrassing moment? Falling up some stairs in Paddington station and 999 being dialled. The fall resulted in a head injury and a broken knee cap!

Claim to fame? Being Richards mum

Fundraising Report

London Marathon 2015

This year's runners have raised in excess of £13,000! Thank you all.

Josephine Williams says - I'd highly recommend running a marathon for DHG! It's an incredible and amazing experience - I wish I could do it all over again! A very special thank you to my family and friends, especially my niece, Mali, who sent me the best good luck video. Also, to St Anne's Church, Malpas, and my school Our Lady of the Rosary and Avonmouth, for being so generous.



Rose Jenkins says - the marathon was a truly fantastic experience. I knew I'd set myself a huge challenge but the months of training paid off and I made sure that I enjoyed the unique atmosphere. As well as raising money I've spread awareness amongst friends and family of the important work that DHG carries out. I think I have caught the marathon bug now!



Ellen Robertson and Suzanne Adams say - we were really pleased by the amount of fundraising we were able to do. The whole experience was fantastic.



Luisa Walsh says - it was great to run for an organisation that means so much to our family.

Gary King says - thanks to all at DHG for their support and the opportunity to run for this great charity. All the training was well worth it and this is certainly an experience I will never forget, especially the last 6 miles! I hope you have some committed runners next year and DHG and fundraising goes from strength to strength.



Photos from top - Josephine, Rose, Ellen and Suzanne, Luisa and Gary with DHG Chair Chris Stringfellow

London Marathon 2016



Would you like to run the London Marathon in 2016?

It is not too late to add your name to our waiting list. When the ballot results are out in October DHG can then allocate places, hopefully increasing the amount of DHG runners! Please contact

0300 102 1644

info@dhg.org.uk

Silverstone Half Marathon

The 2016 Adidas Silverstone Half Marathon takes place on Sunday 13th March 2016 and starts at 12pm. Entries are now open for your chance to run on the iconic Silverstone race track whilst raising money for DHG.



www.adidashalfmarathon.com/how-enter/online-entry

eBay

Do you use eBay? Do you know there are easy ways to support DHG whilst doing so?



Make DHG one of your favourite charities by logging in as usual and then going to tinyurl.com/dhgebay. Add DHG to “my favourite” from the list on the right, then each time you buy something and go to the checkout you will have the option to round up your payment to include a small donation to DHG.

Whenever you sell on eBay, consider donating a percentage of the proceeds to DHG. Under “Raise money for your favourite charity” in the listing form, choose DHG as your preferred charity, select the percentage of your final sale price that you would like to donate from the drop-down list, then complete the rest of the listing.

Once your listing is live, the charity icon will appear next to your listing’s title in eBay search and on the item page, making it more attractive to some buyers. Information about the charity you have selected and the amount you are donating will also show up.

If you are a tax payer you can increase the value of your donation with Gift Aid by completing the Gift Aid form and Paypal Giving will do the rest.

Somerville Foundation Annual Conference

The Somerville Foundation Annual Conference is being held in Bristol on Saturday 10th October 2015. The conference is free of charge for patients, friends and relatives and for professionals with an interest in Grown Up Congenital Heart medicine.



The speakers are all experts in GUCH medicine and will be giving informative and interesting presentations around living with a congenital heart condition and managing health. Delegates can choose which talks to attend and a chill out room will be available for those who want to spend time relaxing. There is also an optional informal dinner in the evening.

Anyone aged 16-24 has the option of joining in with the conference in the morning and then attending a social afternoon to meet up with other young people born with a heart condition.

Please let Helen at Somerville Foundation know if you have any special access needs. There are grants available to help with travel costs if required. To register your interest email, call or book online:

conference@thesf.org.uk

01473 252007

tinyurl.com/sforgconference

Childrens Heart Federation Family Day

Join the CHF Summer Family Day at the Chatsworth Estate, Derbyshire on Saturday 22nd August 2015.



The day includes:

- Bush-craft skills
- Adventure playground
- Access to the Chatsworth House and Gardens
- Chatsworth farmyard with goats, lambs, horses and cows.
- A sumptuous lunch in the sun (or under cover!) provided by Edensor Tea Cottage.

To find out more or to register interest, go to:

tinyurl.com/chfchatsworth

Winter Wonderland

Childrens Heart Federation are running their Winter Wonderland weekend from Friday 11th - Monday 14th December 2015. It is a Christmas themed weekend at Butlins in Bognor Regis. The weekend includes food, accommodation, a Christmas party, access to the water park, rides, meeting Santa, panto and any other basic activities available at Butlins.



Families are asked to pay a deposit to secure their place which is returnable after the weekend. This fabulous weekend will be advertised at the end of September, so keep an eye on the CHF website for details of how to apply.

www.chfed.org.uk

Kidz

Kidz events are the largest free exhibitions totally dedicated to children with disabilities and special needs, their parents, carers and professionals who work with them.



Kidz Scotland is Thursday, 17th September 2015 at Royal Highland Centre, Edinburgh EH28 8NB

Kidz to Adultz is on Thursday 19th November 2015 at EventCity, Barton Dock Road, Manchester, M17 8AS

Kidz in the Middle is on Thursday 10th March 2016 at Ricoh Arena, Coventry CV6 6GE

www.disabledliving.co.uk/Kidz

Lagan's Foundation

Lagan's Foundation's Educational Information Open Day is on Saturday 19th September from 11am until 4pm at Unit 1, Boundary Industrial Estate, Millfield Road, Bolton, BL2 6QY. The event is free and includes lunch. There will be many expert speakers and stalls. To book, go to:

tinyurl.com/lagan-info
01204 468300



Stepping Up



This guide aims to help young people and their families have a positive experience of making a good transition to adult services.

With young people at its centre, it provides a framework for all services and agencies to work together to support young people during their whole transition journey, preparing for adulthood, moving on to adult services and settling into adult services.

The focus of Stepping Up is to enable young people to have choice and control over their lives. Free copies are available from Together For Short Lives or can be downloaded from:

www.togetherforshortlives.org/steppingup

Tooth Decay

Foundation for People with Learning Disabilities and Easyhealth have a booklet called "*Tooth Decay*" which is all about caring for teeth. It is in easy read format and is one of several guides on key medical issues that can affect people with learning disabilities:



It can be downloaded at:

tinyurl.com/easytooth

Petite Shoes

Many of our young adults are blessed with very tiny feet, which are cute but almost impossible to fit nice, fashionable shoes to. Several websites offer smaller sizes and are reasonably priced:



www.pretty-small-shoes.com
www.shoetastic.co.uk
www.petite.shoes

Fink Cards



Hayley Goleniowska of Downs Side Up has developed a range of questions for *“Talking About Down’s Syndrome: Conversations for New Parents”* which form a new Fink pack of portable cards. Each brightly coloured card contains a carefully written question designed to get parents talking about the bewildering array of emotions, facts and myths that bombard them in the early days of their child’s life.

Fink cards were first developed by Lisa Warner and now cover a wide range of topics. New families can use the cards with extended family or at medical appointments and they can also be used by support groups, health visitors, portage workers and midwives and They also make an ideal training tool for medical professionals, allowing them to reassess the way they view Down’s Syndrome. The packs are available for £14.99 from

finkcards.com/products/downs-syndrome-new-parents

Disability Equipment Service

The charity, Social Information on Disability (SID) has been closed but the Disability Equipment Service and AskSID for Advisers have been taken over by two members of the SID staff. They hope to continue and improve the services. Disability Equipment Service (DES) provides a free listing service for items for sale or donation and AskSID for Advisors, which is an online database is now iDis (Information for Disability)



www.disabilityequipmentservice.co.uk

www.idis.org.uk

Family Carer Support Service



The Family Carer Support Service (FCSS) has a Freephone service, including from mobiles, for family carers of people with learning disabilities. The service is run by Hft between 8.30am and 4.30pm on weekdays.

Support provided includes helping family carers know their rights, understand the law, navigate health and social care systems and challenge decisions.

www.hft.org.uk/familycarersupport
0808 801 0448

Families In Focus



Families In Focus is running information and support sessions throughout the year for families with a member with a learning disability.

The courses aim to help with understanding and managing difficult behaviours and anger, education issues, siblings, wider family, handling stress and sharing feelings. Parents' concerns and experiences will help to form part of the two hour sessions being offered across the county. For more information contact:

Lesley 01442 219 720

Francine 0786 751 0027

info@familiesinfocus.co.uk

www.familiesinfocus.co.uk

Facing The Future

"Facing the Future: Together for Child Health" is a new set of standards developed by the Royal College of Paediatrics and Child Health, the Royal College of General Practitioners and the Royal College of Nursing.

These standards will improve healthcare services for children and young people with life-limiting conditions when they are unwell, and ensure that specialist child health expertise and support are available to them when they need it.

The standards apply to urgent care services, from out-of-hours GPs to emergency departments, and aim to reduce unnecessary hospital admissions by providing care closer to home.

tinyurl.com/facefuture



Useful Resources

Have you found a useful resource that others might benefit from knowing about?

Please let us know so we can consider including it in a future issue or on our website

info@dhg.org.uk or 0300 102 1644

Further information about Down's Syndrome is available from



Down's Syndrome Association
Langdon Down Centre, 2a Langdon Park
Teddington TW11 9PS

0845 230 0372
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's Syndrome Scotland
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



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
Unit 3.37, Whitechapel Technology Centre
75 Whitechapel Rd, London E1 1DU

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

Tel:
Email:
Write:

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

Do you have a new baby with Down's Syndrome?

Would you be willing to assist in a study to help understand why children with Down's syndrome are more likely to experience problems with their hormones and their gut, help reduce this risk and lead to the development of new treatments to help with feeding.

This study group is looking for new parents willing to complete a questionnaire about their child's feeding and health as a young baby and at six and twelve months. They will also ask about the child's health yearly after this until the age of five years old.



You would not need any additional hospital attendances and they will provide pre-paid packaging so that all samples and questionnaires can be sent back to them.

To register an interest or download a more detailed information sheet about the study visit www.bristolnutritionbru.org.uk and click on the tab titled 'FADES Study' or contact Dr Georgina Williams at the Bristol Biomedical Research Unit in Nutrition on the details below.

Email: fades-study@bristol.ac.uk

Tel: 0117 342 1756



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.