



dhg

down's heart group

Newsletter Summer 2013

Issue 47



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and more ...

Chair's Report

Welcome to Issue 47, the second edition of 2013. We had a very successful conference on 23rd March, despite several inches of snow! The speakers were very interesting and the afternoon workshops ran either side of a “*penalty shoot out*”, which thankfully we could hold indoors! Craig Armstrong from the Nottingham Forest Academy provided the fun and “coaching” and also sourced several fantastic raffle and auction prizes. Many thanks, Craig!

By the time this reaches you, the London Marathon will be over but hopefully our runners will have done well with no injuries and I sincerely hope the weather is warmer for them.

DHG continues to be part of the Information Standard, which means the accuracy and quality of our information can be relied upon, which is great to know. The Group also continues to work with many other charities and organisations to hopefully improve things for our youngsters and families.

Many thanks to all of you for your continued support and I hope that you had your brightly coloured non matching socks on for World Down Syndrome Day.

Regards

Chris Stringfellow

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World Down Syndrome Day



2013 was the 8th year that World Down Syndrome Day was marked on March 21st, the date having been chosen to represent the triplication of the 21st chromosome - 3/21. It was celebrated across the world in many ways, all with the aim of raising awareness.

For the second year running a conference took place at the United Nations Headquarters in New York. It was entitled “*Right To Work*” and highlighted the importance of early development and education, proper medical care and support for employment, independent living and community participation for all those with Down’s Syndrome.

Down Syndrome International’s, World Down Syndrome Day committee ran a ‘Lots of Socks’ campaign to spread the idea of acceptance and inclusion and the message travelled globally, with people across the world donning brightly coloured non matching socks to mark the day. Comments were welcomed as an opportunity to talk about Down’s Syndrome and raise awareness amongst local communities.



To mark the day, Down Syndrome International also produced another fantastic video featuring people from many countries at work. Titled “*I Want To Work*” it can be seen at www.ds-int.org/let-us-in-i-want-to-work

The WSDS Facebook group had a record number of members this year, all encouraged by DHG’s Penny Green, who also put together a montage of youngsters with Down’s Syndrome, some wearing their brightly coloured socks.

Daniel Bryan

Hi, my name is Daniel and my photograph has been in the Down's Heart Group newsletter a few times when I was younger.

I am now almost twenty four and want to tell you how I am doing after leaving Bristol's First Academy and doing work experience at Bristol Old Vic.

I am busy which makes me happy

I have been very fortunate and joined several drama groups in Bristol. Most days are filled with acting, dancing, writing, rehearsing and travelling to perform.

This means I am busy which makes me happy.

Drama is great if you have a disability and such fun. Our next big performance is "*The Breadhorse*" at Bristol Old Vic in March.

Thank you for your support for me and my family when I was younger.

Daniel Bryan



Daniel and girlfriend Jessica



Daniel outside Bristol Old Vic

Josh Stokes

Twenty one year old Josh has been working 35 hours per week as a studio assistant at a graphic design firm since November 2012 - he absolutely loves it and can't wait to get there each morning! He secured an interview through Remploy along with four other candidates with disabilities, some of whom could have done the job straight away but Operations Director, Adrian Wagemakers wanted someone who could grow into the role and who they could help develop as a person both in and out of the workplace.

He can't wait to get there each morning!

Adrian said "Trying to pick somebody wasn't as straightforward as it first seemed, simply due to the fact that we knew we were going to have to let four other people down. Josh was very attentive in the interview and we took him on a four week trial. From day one we saw enough to know that he could do the job. From my point of view, it was a business decision, ensuring that I got someone who could justify being paid a salary within the organisation."

Those four weeks went by quickly, and the whole team took to Josh instantly. From day one Josh has called one of the Directors 'Trouble', much to the amusement of everyone else! "Josh says it how it is and we like that."



Josh at work with Adrian

*Josh says it how it is
and we like that*

Josh's work entails many aspects. He is involved with a lot of packing and allocation, putting materials into units and sending them out across the World. He also helps out on print finishings, some of the laminating, assists with the mounting and does some of the cutting. "Josh works hard, and he's just a part of the team now. We do a lot of work here, and we can't do it as individuals. It's a team effort and Josh is very much part of that."

*Josh absolutely loves work
we have to persuade him to take annual leave!*

Helen, Josh's mum says "We're really impressed with the company's attitude and their willingness to look beyond Josh's disability and see who he is and what he's capable of. Remploy have also been excellent in the support they have provided. Josh absolutely loves work – we have to persuade him to take annual leave! We are extremely proud of him."

Rosie Bachofner



Rosie shortly after surgery

Our beautiful daughter, Rosie, was born in March 2011 with Down's Syndrome and a Complete Atrioventricular Septal Defect (AVSD). In September 2011 Rosie finally got her slot at Alder Hey to repair her tiny heart.

The risk was as low as 3–5% but nothing prepares you for the moment you meet the surgeon and they tell you there is a chance your baby may not survive. These facts have to be discussed and were spoken of in a very matter of fact manner which is just what was needed, I didn't need anything glossing over. Whilst the statistics were reassuringly low it didn't make signing the consent forms any easier.

Only one of us was allowed to take Rosie in for the anaesthetic and we decided it would be me. I was absolutely determined to 'man up' and be strong as I felt it was vital that Rosie saw me smiling when she went to sleep.

I came out to see Karen looking lost, we embraced for a moment with no idea of what to do next - we just hadn't thought about the waiting aspect at all. We ended up walking aimlessly, hand-in-hand, around the hospital grounds, then back to our accommodation, then to the canteen, then back to the room... this was going to be a long day!

Five and a half hours eventually passed. A further hour and a half passed, totalling seven hours in surgery. It was a very difficult period as we didn't know if it was taking longer because of complications. When the call eventually came we raced to see Rosie. I had never been in an intensive care unit before and really had no idea what to expect. I remember feeling like I'd stepped onto the set of some US hospital drama. I felt so in the way but was too scared to move – there was so much urgent activity, wires everywhere with machines beeping.

Lying peacefully amongst the mayhem was Rosie. We both sat and stared at her and I remember a sense of enormous pride in my daughter, so tiny, having come through the operation.

The nurse explained what each machine was doing and what the charts meant. I was so impressed with the work ethic on ICU – nurses were constantly busy, changing drugs, monitoring machines, liaising with doctors, filling out charts, even a toilet break required a detailed de-briefing for the nurse offering the five minutes cover.

The longer we stayed by Rosie's bedside the less daunting things seemed. I became engrossed in everything that was happening, I think it was my way of dealing with seeing all the tubes and scars on my baby girl.

Rosie was on ICU for three days, due to a 'pneumothorax' – a collapsed lung due to air being trapped between the lung and chest wall which prevents the lung from inflating fully. This was a little set back in terms of recovery time but we were assured it was very routine and no cause for major concern, although given our worn out state it didn't feel like that at the time!

On the fourth day Rosie was finally moved to the ward. Whilst she wasn't completely out of the woods, it was a huge step in the right direction and the feeling of relief and excitement was unforgettable. But once on the ward my feeling of relief quickly turned back to one of slight worry. I'd become too accustomed to the 24 hour monitoring on ICU, it gave a lot of comfort knowing someone was watching Rosie constantly. The vibe on the ward was completely different, far more laid back and whilst eventually I realised this was a good sign, it took some getting used to.

Rosie has made good progress since her surgery. She did spend the Christmas period of 2011 in hospital and has had several bouts of bronchiolitis. These were gruelling times hopefully behind us now. She has just celebrated her second birthday and is shuffling everywhere on her bottom.

Rosie has modelled for the kids boutique "*Ten Little Monkeys*" and has recently taken part in a photo shoot of child models with Down's Syndrome (see page 18). This was to raise awareness and show the ability and equality of people with Down's Syndrome. The shoot also allowed me to meet some truly inspiring people – many who, along with their families have been a great 'virtual' support to myself and Karen.

We are extremely pleased with how things are working out for Rosie. I write a blog

www.thefuturesrosie.com

which I began in the hope of giving other parents an honest view of life with a baby with Down's Syndrome.



Rosie in her birthday dress

London Marathon - Sunday 21st April



By the time you are reading this, the London Marathon will be over and we hope that our runners will have finished triumphantly and be feeling very proud of their achievement. Below they tell us briefly why they are running for DHG.



Fiona Barker - My brother, James, was born when Sarah, my sister, was five years old and I was three years old. He was diagnosed with Down's Syndrome and heart problems and spent most of his three year life in hospital.

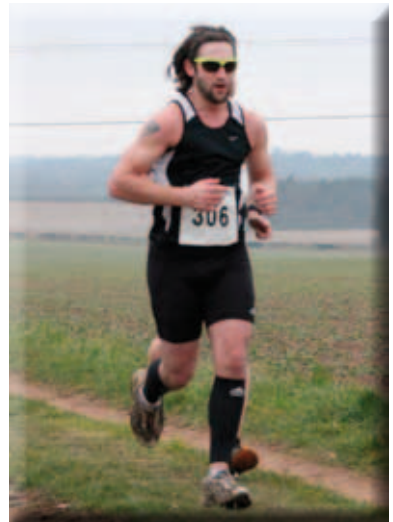
DHG was hugely supportive to my family, providing advice and guidance throughout his short life.

Kelly Stevens - I'm involved with "*Herts Inclusive Theatre*" and through them I heard about the good work of DHG. I am really looking forward to running and raising as much as I can to help out this fabulous cause.

I haven't decided what outfit to wear yet on Marathon day but I'm leaning towards dressing as a Baywatch gorilla, simply because I think the weather will be rather cold!

Phillip Box - I am running this marathon for a brilliant cause. I have a friend, Jo Yarnall, who is such an inspiration to a lot of people and has a daughter, Hannah, who has Down's Syndrome. Jo ran The London Marathon last year for DHG and also runs the local "*park run*" in Walsall whilst pushing Hannah in a pushchair.

I want to help raise awareness of Down's Syndrome and heart defects. Hopefully I can do that as well as raising a fair amount of money!





George Garrett - I am eighteen years old, so this is my first marathon and I am delighted to be running it for DHG. My nineteen year old sister Florence has Down's Syndrome and the whole family benefited greatly from DHG's support in the first few years when she had life threatening heart problems.

Florence is now a brilliant swimmer and appeared in the DHG newsletter a couple of issues ago.

Gary Ryan - I wanted to do something for a small but very important charity. I ran the Edinburgh Marathon last year and not running for a charity felt wrong, so I'm training even harder and am incredibly proud to know that for every hard fought mile I attempt to run, DHG will be receiving money from my sponsors!



Phil Longster - Our daughter Hope is now six and is generally in good health. In 2007 she had cardiac surgery followed by an emergency ileostomy. Thankfully, things have settled down now.

To make things a bit more interesting, I have also secured places in the Sussex Marathon on 7th April and Brighton Marathon on 14th April, meaning a marathon every weekend over three weeks!

If you would like to show your appreciation by increasing their final sponsorship total each has a page on Virgin Money Giving (just search for their name)

www.virginmoneygiving.com

Or you can make a donation to all of them using Charity Checkout

www.charitycheckout.co.uk/1011413/LondonMarathon

London To Paris Bike Ride



Rachel Welch is taking part in a London to Paris cycle challenge to raise funds for DHG.

The ride begins early on 8th May in London to avoid as much traffic as possible and it will take five gruelling days to reach the finish at the Eiffel Tower in Paris.

Rachel says *“This is one of my more crazy challenges and I hope to raise lots of money for a really great charity. I am cycling from London to Paris in honour of my brother Steve who died in October 2010. Any donation, large or small, will be very much appreciated. Thank you!”*

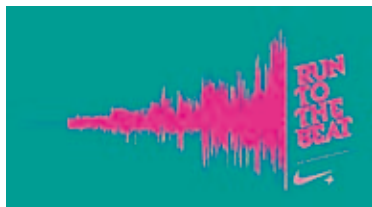
Rachel has a fund raising target of £1450. If you would like to sponsor her go to

www.doitforcharity.com/rwelch

Text to Donate

For a simple way to donate to DHG, simply text **DOWN44 £*** to **70070** replacing the * with the numerical amount of pounds you would like to give.

Run To The Beat



Down's Heart Group member, Andy Lawson, will be taking part in the Run to the Beat half marathon on September 8th in support of DHG. The event takes place in London, starting and finishing in Greenwich Park and as the name suggests, top DJ's will be playing live music will be played along the route.

Andy, who ran the London Marathon last year for DHG, is married to the charity's Secretary Nina and is Dad to Jon-Paul who had heart surgery at eight months old. The family recently welcomed the addition of twins, Corey and Dylan, so getting enough sleep and time to train may just be a problem for Andy!

To donate to Andy's fundraising, please go to

<http://uk.virginmoneygiving.com/AndrewLawson1>

Torch Fundraiser



On March 9th, Penny Green joined Caroline England of Herts Inclusive Theatre for a joint awareness and fundraising day in the Harlequin Shopping Centre in Watford.

Penny was an Olympic Torchbearer and Caroline a Paralympic Torchbearer so they went dressed in their uniforms and took their Torches which people were able to hold and have their photos taken with for a donation.

For part of the day they were also joined by two other Torchbearers, Holly Worthington and Kim Wilton-Woodhouse - it was a long but fun day which raised over £300.

Prestige Car Insurance

Families linked to DHG are perceived as more careful drivers and can benefit from lower premiums as well as supporting the charity who will receive a small donation for each policy taken out with Prestige.



Give them a call for a quotation on **0800 3308057** or **0333 4001580** for mobiles or visit their website for an online quotation - remember to mention DHG!

www.prestigekeepmoving.com

Charity Checkout



There is an easy online way to make a donation to DHG or even setup a monthly or annual payment.

*A single payment of £5 would provide a family with newsletters for a year
A £10 donation covers the cost of the initial support given to a new family*

Just click on the link on our website or visit

www.charitycheckout.co.uk/1011413/donate

The Bi-annual Down's Heart Group Conference and Family Weekend took place on 23rd and 24th March in Peterborough and despite heavy snowfall, only a few people cried off and a great time was had by all.



Hotel grounds in the snow

The day began with Annual General Meeting, an update of the year and the election of Trustees. The financial report showed a healthy balance given the current economic climate which reflects the hard work and commitment of our many supporters whom we would very much like to thank. Down's Heart Group relies on donations to continue its work and we are very grateful to everyone who has donated to funds in anyway throughout the year, every contribution, no matter the size is received with thanks.

We then heard from the first speaker, Professor Marcia Van Riper from the USA who delivered a very interesting presentation on how families adapt and deal with the birth of a child with Down's Syndrome. Marcia has a nursing background and is researching various factors that can affect a family's ability to cope with the birth of a child with Down's Syndrome in order to increase understanding amongst the medical profession. Part of her current research involves families from countries other than the USA, so if you would like to know more about helping with her project, email her at vanriper@email.unc.edu.

Our second presentation was given by DHG Chair Chris Stringfellow, who updated everyone on the current status of changes to congenital heart services in the UK. Many delegates had concerns over both the proposed changes and the delays in getting things implemented, so the questions session proved very useful in providing an opportunity for views to be expressed.

The final speaker of the morning was Paul Willgoss MBE, an adult with a congenital heart condition and Vice-chair of the Children's Heart Federation. He gave a very entertaining presentation on what it is like to grow up with a congenital heart defect and how the medics often underestimate the physical capabilities of this group of individuals. It certainly gave parents an insight into what their youngsters may actually be thinking!

Growing aining I



Prof. Marcia Van Riper

After lunch there were two lots of workshop sessions.

Barclays Bank held an informal discussion group with parents and young people about money skills and managing finances in general and gave out details of the scheme they have specifically for people with learning difficulties, which is proving to be very popular and extremely useful.



Workshop discussion

LD nurse Helen Laverty, led sessions exploring issues around puberty and relationships, a topic many families are concerned about. The discussions indicated that this is a subject that is relevant from an early age right through to adulthood and parents went away armed with tips and advice, from Helen and each other.

Up ndependence

The third workshop was with Professor Van Riper where the conversation focused on implications for the future, covering a wide range of topics introduced by the delegates including further education and supported living. Again, parents went away with ideas to help with a smooth transition to independence.



Busy being creative

Throughout the day the youngsters were looked after and entertained by a team of volunteers who worked very hard but seemed to thoroughly enjoy themselves too. As well as having DVDs, craft activities and toys, two volunteers from MiXiT worked with the youngsters to put together various song and action routines they presented at the end of the conference and during the evening meal. There were some very proud parents!



The end of conference presentation



Two hopeful goal scorers

The break between the afternoon workshops was extended to allow for a penalty shoot out with ex Nottingham Forest footballer and current Academy coach, Craig Armstrong. He had braved the weather to travel from Mansfield to Peterborough through several inches of snow, so was happy to find we'd moved the event inside!

Craig was wonderful with the youngsters and everyone had great fun trying to score goals against him - the competition could have gone on until the disco!



Craig with the winners of the Peterborough shirt and ball

As well as giving up his valuable time, Craig had also been busy obtaining several prizes for DHG including signed Peterborough, Stoke City and Chelsea shirts, a signed Peterborough ball, a pair of John Terry's football boots and a signed boxing glove owned by world champion Karl Froch - watch out for these being auctioned later in the year!

Craig and his family stayed for the entire afternoon and we would like to thank them for giving up part of their weekend to join us and adding to the fun for everyone.

The conference ended with the raffle draw, performance by the youngsters, thank you's for the crèche and activity workshop volunteers and 'goody bags' for all the youngsters. It was then time to say goodbye to those who weren't staying whilst for those that were, there was time for a quick swim or leisurely chat before the disco and evening meal.





The theme for dinner was "Around The World" to coincide with World Down Syndrome Day.

The room was decorated with silhouettes of famous landmarks and the tables held flags from various countries. During the evening there was a quiz based on identifying the flags, with some suspicion of cheating using mobile phones to find the answers!



Everyone had been asked to dress to represent a country and most dinner guests had embraced the idea. There were some fabulous outfits with whole families dressing as the same country as well as a few dubious interpretations - but the result was a very colourful array to celebrate people with Down's Syndrome across the world.



Dinner was a three course meal with fun options for the younger ones and the service was brilliant, as it had been all weekend. After dinner we were treated to another performance from the youngsters and then it was time for the disco with a great mix of music with all the party classics and of course the conga. Although there were many tired little people, everyone seemed to last until the end of the night and all had fun.



Due to the weather, most people decided to leave early on Sunday morning rather than staying longer to socialise and enjoy the hotel facilities, but even so it was a great event.



New Guidelines for Education



The UK All Party Parliamentary Group on Down's Syndrome (APPGDS) has published a new report presenting good practice guidelines for education for children and young people with Down's Syndrome from birth to 25 years.

The report was prepared by an Education Working Group including psychologists, speech and language therapists, teachers and representatives of the DSA, Symbol UK, NASEN, IPSEA, The Education Centre for Children with Down Syndrome, DSE and DHG. It was launched at a reception hosted by Virendra Sharma MP, Chair of the APPGDS, and attended by Edward Timpson MP Parliamentary Under Secretary of State (Children and Families) who is responsible for special educational needs and disability at the Department for Education.

The report calls on government to recognise the specific developmental and educational needs of children and young people with Down's Syndrome as a unique group. It goes on to summarise information about the specific learning needs of children with Down's Syndrome and sets out principles for effective education practice.

The APPGDS aims to raise awareness of issues affecting people with Down's Syndrome, and the prospects for improving life outcomes, and to campaign for changes to government policy to improve the lives of people with Down's Syndrome. The APPGDS steering group includes family members and representatives of IPSEA, the Down's Heart Group and Down Syndrome Education International.



Leela Baksi of Symbol, Virendra Sharma MP, Edward Timpson MP and Jane McConnell of IPSEA

Parliamentary Launch of INR Campaign



On 6th February I attended a Parliamentary reception to launch a campaign to provide INR self-monitoring machines on prescription to all that need them. Participants included patients, nurses, doctors, NHS staff, Members of Parliament and Peers and DHG members the Forsythe family.

Several national charities have formed The Anticoagulation Self-Monitoring Alliance (ACSMA), which is campaigning to get greater access via prescription to INR self-monitoring technology for patients receiving warfarin. The alliance is also seeking to raise awareness of the benefits of self-monitoring so that more families can gain access to the home testing equipment.

“There’s a finger-prick blood test that allows patients on anticoagulation therapy to self-monitor their blood clotting time. It’s effective, convenient, and in the end, cheaper for the NHS...”

David Cameron, December 2011

Many families currently make hospital visits each week to have INR checks. The expense of travel, disruption to parent’s work, disturbance to the child’s schooling and the long and sometimes difficult journeys could all be minimised or prevented by having an INR machine at home.

Children’s Heart Federation already provides machines free of charge to many families who require them but if this campaign is successful thousands more could be helped.



Sheila and Andrew Forsythe with Chris Stringfellow

To help ACSMA’s campaign calling on the Government to make self-monitoring devices available on NHS prescription, please email or write to your MP and ask them to sign

EDM 1047: ANTI-COAGULATION SELF-MONITORING ALLIANCE

*Chris Stringfellow,
Down’s Heart Group Chair*

Our own Super Models

Wanting to highlight that children with Down's Syndrome are breaking into modelling, journalist Kate Thompson invited several of them along for a photo shoot at the Normansfield Theatre at The Langdon Down Centre, once home of Dr John Langdon Down. Several of the children are DHG members and having helped get the group together, DHG Director Penny Green went along to meet them all.



Kosta, Seb, Rosie, Poppy, Thea, Harvey, Natty and Jack

Nine year old Kosta Gripari from Surrey, is on the books of the Stagecoach Agency and modelled for the National Theatre Awards last November - he underwent cardiac surgery as a youngster. Five year old Seb White from Bath was in the Marks and Spencer's 2011 Christmas campaign and has also modelled for Jojo Maman Bebe.

Two year old Rosie Bachofner, (read her story on page 6) has modelled for Ten Little Monkeys and lives in Cheshire, whilst Derbyshire cutie Poppy Dunham, aged five, has had on-going treatment for abnormalities in her heart, but it hasn't stopped her from modelling for Urban Angels.

Surrey stunner Thea Shiers, aged seven, was offered a photo shoot at Boden after her mum wrote to ask why children with Down's Syndrome weren't used as models. Another DHG member is eight year old Harvey Simpson, from Derbyshire who won a model competition for Next in 2009 and became their billboard star - his dad Tim also ran the London Marathon for DHG last year.

Natty Goleniowska age six from Cornwall, had heart surgery aged two and has worked for Jojo Maman Bebe, the Eden Project and Frugi, whilst cheeky six year old Jack Davies from Yorkshire has become the face of a council project and a children's museum.

The youngsters were fantastic - the article was in the Sun newspaper on February 27th.

Carers Together



Carers UK and Timebank have set up a 1-to-1 FREE online support service where you can chat online to a trained volunteer who also has experience of caring. For more information call Stephen Raybould or Halinka Wojtulewicz on:

0121 236 2531

www.timebank.org.uk/carers-together

Family Fund Travel Insurance



Families often struggle to get appropriate travel insurance for their disabled or seriously ill child when going on holiday. The Family Fund has negotiated an insurance package which is reasonably priced for families. For more information please call:

01273 748362

www.familyfund.org.uk/travelinsurance

Infant Heart Study



The Infant Heart Study is a national study looking at follow up care for babies with congenital heart disease in the UK which aims to improve the information and support available to families when they take their baby home after surgery. It has been funded by a grant from the National Institute of Health and will involve professionals from all the UK paediatric cardiac centres.

They want to hear from parents, siblings, relatives, friends and others with a range of experiences of caring for a child at home after heart surgery, but particularly from families whose baby had surgery before their first birthday. The results will be published and shared with professionals and a summary of the findings will be available on the Children's Heart Federation website.

If you would like to take part in the study through the Facebook discussion group, obtain more information or would like to talk to someone about the study you can find more details on the Children's Heart Federation website:

www.chfed.org.uk/ihs/



The experiences of *siblings* of children who have life-limiting conditions



Do you have a child with a life-limiting condition (e.g., Cystic Fibrosis, Muscular Dystrophy, Cancer, congenital conditions)? Do you have another child? We are a team of researchers in Bangor University interested in siblings of children with life-limiting conditions.

We would like to find out about:

- ❖ The experiences of the sibling
- ❖ Their life at home and in school.
- ❖ Their health and well-being.
- ❖ Their relationship with the brother or sister who is poorly.
- ❖ How you manage your daily lives.



There is little we know about how siblings adapt when they have a brother or sister who is poorly a lot of the time. This study may help to understand better siblings' and families' experiences.

What does taking part involve?

- ❖ If the sibling is aged **3 to 16 years**, we would love to hear from you! You will complete questionnaires about yourself (the caregiver), your child with a life-limiting condition, and the sibling.
- ❖ Siblings over 8 years old could also fill in a questionnaire about themselves.

How long will it take?

- ❖ The questionnaires take approximately 20 minutes to complete.

If you are interested in taking part, please contact:

Miss Joanne Fullerton
North Wales Clinical Psychology Programme
School of Psychology
Bangor University
43 College Road, Bangor
LL57 2DG

Tel.: 07957620608
Email: j.fullerton@bangor.ac.uk



Symbol UK



Symbol UK is a not-for-profit organisation whose aim is to provide good, targeted provision to families and also influence the quality of services provided by statutory bodies.

They can provide: speech and language therapy, training for professionals, new baby days, intensive assessment and intervention breaks for families, riding and performance arts camps, mini breaks for adults with Down's Syndrome, respite services for adults and children and finally work assessment breaks.

www.symboluk.co.uk/downs-syndrome-service

Discretionary Trusts and Wills

It is never too early to make provision for your child's long term future in case something happens to you, but when your child has a disability it's important that you seek specialist advice to ensure protection of any benefits they may be entitled to.



Mencap are running free seminars on wills and trusts for families and carers. The events will take place around the UK and will be led by legal professionals.

For dates and locations of events taking place in your area visit www.mencap.org.uk/pffe

Alternatively, contact Gina Collins on: **020 7696 6925**



Cerebra have a Wills and Trust Voucher scheme to help parents prepare for their disabled child's long-term future. To qualify, the child must be under 16 and receive DLA at either middle or high rate. Parents need to fill in an application form and Cerebra will then issue a voucher to the value of £350 towards the cost of having a solicitor prepare a will and discretionary trust to make provision for the child's future.

Once the voucher is received, the family need to find a solicitor to prepare the will and discretionary trust. When the will is drawn up the solicitor will complete the voucher and return it to Cerebra for payment.

To get an application form call Cerebra on: **0800 328 1159**

Sleep Study Update

Sleep study update from the Department of Sleep Medicine, Royal Infirmary of Edinburgh.



Sleep problems can be bad for your health and make you feel sleepy in the daytime. Being sleepy can make it harder for you to do well at things like school, college, work or hobbies. People with Down's syndrome (DS) have more chance of having sleep problems than people who don't. If we know more about sleep problems, we can help people with DS to get more out of life.

The Down's Heart Group sent out questionnaires for us last year. Other groups like the Down's Syndrome Association and Down's Syndrome Scotland sent out questionnaires too. So far over 1300 people have sent back a questionnaire. If you have been sent a questionnaire, please fill it in and send it back. If you haven't had a questionnaire, you can get one from the Down's Heart Group, or you can speak to the person running the study (details below).

**A big thank you to everyone who filled in a questionnaire!
We will soon be contacting everyone who sent one in.
It has taken us longer than we thought to do this,
and we are sorry you if have been waiting.**

Everyone who filled in the questionnaire will be invited to have a home sleep study – this is comfortable and easy to use in your own bed. If this test shows breathing problems during sleep, you will have the chance to take part in a trial of treatment. **The good news is that now anyone aged 16+ with DS can take part in the treatment study, whether they can give consent for themselves or not.** There are no drugs, needles or surgery!

If you would like to be involved or want more information, please contact Lizzie Hill, Research Fellow on **0131 242 3879** or **lizzie.hill@ed.ac.uk**.

Thank you very much for helping us with this important study!

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



(formerly GUCH) 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
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