



dhg

down's heart group

Newsletter Winter 2014

Issue 52

INSIDE

Competition

Activity Weekend

Members Stories

News and more...!



Chair's Report

Welcome to our Winter 2014 newsletter.

In this issue you will see photos and a report of our activity weekend, which I hope gives you a flavour of what it was like. It was a brilliant success and great fun was had by all the young adults (and old ones too)! There were lots of new friendships made and all the parents and carers got on very well and thoroughly enjoyed their pampering sessions. I must congratulate Sarah, who organised it, and our mentors Paul, Ashley and Alice, without whom it could not have gone ahead. They did a splendid job of encouraging all of our young people to take part and the Manor Adventure staff worked well in supporting their efforts.

We hope to be able to run another weekend next year if we can secure funding.

On the back page you will see the Christmas cards that we have on sale, which means that yet another year has been and gone in the blink of an eye!

I wish you all good wishes for the festive season and hope that you all enjoy reading our latest newsletter.

Regards

Chris Stringfellow

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Christmas Cards

DHG are selling packs of Christmas cards for £1 which contain a minimum of 5 different designs from previous years. (see back page of this newsletter)



P & P 2nd class will be £1.25 for 1 or 2 packs, or £1.60 for 3 or 4 packs. Please email or call for other quantities.

Place an order by sending a cheque for the total to National Office together with details of your order and the delivery address. Alternatively, you can email or call with details of your order and pay over the phone with a card or via the website (we'll let you know how when you order). Cards will be despatched after payment has been received.

Please support DHG this Christmas time

*and check out the Competition on pages 9 & 10
for your chance to have your design featured on cards in 2015*

Information Update

Having recently moved our records to a new database with higher security, it is clear that some of the details we hold for members are out of date, which means that members may be missing out on invitations, news, information, support and other services.

The data we hold on members with Down's Syndrome and CHD helps us to understand issues facing families and the statistics we can draw from the database can be used to bid for funding or occasionally help with research. All data used in this way is used anonymously and we NEVER pass on personal information without your prior agreement.

If you receive a postal copy of the newsletter, it will include a form asking you to confirm that we hold your correct contact details. If you get email notifications, it will be part of that email. Once we have confirmed this information we will contact you in due course to check the accuracy of other data.

To save time and postage, if you have an email address it would be helpful if we could have this (you can email your response and we can get it that way), but we will not be sending you frequent emails and you will still get a printed copy of the newsletter unless you as us otherwise.

If you know anyone who is a member but doesn't receive any correspondence from us, please ask them to get in touch to update their details. Also, if you know anyone who isn't a member but has a reason to be, please encourage them to join DHG.

Bairbre

World Down Syndrome Day, 21st March, has been a special day in our family since 1979, when our daughter Bairbre was born, our first daughter after three boys. She was very “cyanosed” at birth but “pinked up” as the nurse described it, after being in an incubator for a while. World Down Syndrome Day came along many years later!

For Bairbre to get to 35 is a major achievement in itself

This year was Bairbre’s 35th birthday and for her to get to that age is a major achievement in itself. As in every year she has been talking about her next birthday almost as soon as one is over. She is not very demanding in what should be done on her birthday as long as lots of people know that it is a special day for her.

This year we had an afternoon snack in the Drumcliffe Tea Rooms just a few yards away from where our celebrated poet W.B. Yeats is buried. This is one of the places that Bairbre loves as she had a work experience placement there many years ago. That evening, two friends, Kenny and Edel, joined us for a celebration tea at home.

On Sunday the celebrations continued in the Clubhouse of the County Sligo Golf Club with a surprise organised by some of the lady golfers who had got a beautiful cake baked for her by Leanne, the chef there. Bairbre calls this Sunday morning group her fan club!

Bairbre takes golf very seriously and insists on practice when others would balk at the prospect of going out on the course. She can drive her own buggy to get round her local golf club in Rosses Point and when visiting other courses her wonderful Dad hires a buggy and drives her for her 9 hole competitions.

Bairbre is a golfer with Special Olympics Ireland and takes golf very seriously

Bairbre is a golfer with Special Olympics Ireland and this year attended the National Games in Limerick in June representing the Province of Connaught. She won the gold medal in her competition. The weather was good, she



Bairbre with one of her Special Olympic medals

played over three days, improving on her scores each day and played her best golf on the last day.

As a gold medal winner, she qualified for the Special Olympics World Summer Games in Los Angeles in July 2015 and was offered a place on the Irish Team, however, after attending an information session and thinking about the offer over a number of days, while initially excited about the prospect, Bairbre decided against accepting the place.

Bairbre's determination was very evident in late 1999 when she had a stroke which affected her right arm and leg and her first golf competition was just 3 weeks away. She recovered sufficiently to get to the course using a wheelchair and her scores at the golf skills competition helped the Provincial team to win the National Cup that year.

She had many months of exercising with weights to regain her full mobility. Others do not notice but I feel that she lost some of her capacity then to engage fully with people in conversations and in normal repartee, however, she has a pleasant social life both in and away from her training centre and she is generally content with her life.

Bairbre's complex heart condition has been stable for a number of years

Her heart condition, pulmonary vascular obstructive disease and Eisenmerger Complex with A/V canal defect has been stable for a number of years. She has fairly regular venesections and this has helped.

Bairbre can be a very surprising lady. As my Christmas present for 2012 which now has a prominent place in our kitchen, she gave me a large display collage of photos of family and herself and she wrote on it:

"To Mum thanks for having me its a great gift that I've grown up thanks this is for you to look at anytime. Happy Christmas from Bairbre Callagy."

She had worked on this by herself as I asked her three brothers and her sister later and no one had helped her with it.

As I said, a surprising lady!

*Mary Callagy,
Sligo*



Bairbre with niece, Niamh and sister, Ita

Jade



Jade at Disney, Orlando

Life changed for the better on the 1st of February 1989 when I gave birth to Jade. Later that day we were told she may have Down's Syndrome, this was confirmed soon after with a blood test. Just as we started to get our heads round this news we were told that she also had CHD.

At 6 months old Jade went into chronic heart failure, was diagnosed with an AVSD and eventually had surgery in November 1989. Things didn't go particularly smoothly, she spent 4 weeks in ITU due to pulmonary hypertension, it was an awful time. We were finally home at the end of December and after minor surgeries to clear an infection at the bottom of her scar Jade began to bloom.

Jade loved mainstream primary school and had lots of playmates. A move to the North East helped us find a lovely secondary school for children with mild to moderate learning difficulties that Jade attended for 6 years. Jade had many hobbies - horse riding, dancing, her beloved DVDs, of which there are now too many to count and was and still is permanently plugged into her iPod!

Jade has been in supported living for 4 years and is very happy

At 17, Jade was given the opportunity to attend Dilston college in Northumberland and she decided independently after a couple of visits that she wanted to go there. To my absolute horror it was term time boarding, I missed her so much, but we are so pleased we supported her decision, it was the absolute making of her. Her independence flourished and she progressed to living in a rented property with a couple of friends, which helped her decide to continue with supported living when she finished college.

Jade has been in supported living with her friend Rachel, who is also 25 and has Down's Syndrome, for 4 years and is very happy. She attends college 3 days a week, doing a course that will hopefully lead to a work placement in either catering or animal care. The girls have a support worker at home 24 hours a day but do all of their chores independently, although not always willingly! They also love the theatre, especially the West End, the cinema, discos, meals out and karaoke with friends at their local pub.

Jade never fails to amaze me in what she has and continues to achieve. I am extremely proud of the kind, sensitive, well rounded young woman she has become.

Nicola Hayes, South Shields

Amelia Rose

We were over the moon to find I was pregnant after only 3 attempts of AI. I never thought I would have children. Maggie had always wanted a girl and secretly, I did too. At the 12 week scan the nuchal fold measured slightly high but nothing to worry about, then at 20 weeks we learned we were having a girl but were referred to Leeds for a scan by a cardiologist as there was an irregularity with her heart. The following day at Leeds we discovered there was definitely a problem, possibly related to certain syndromes, and that our baby may only live for a few weeks.

If I'm being honest I never wanted a child with disabilities, thinking I wouldn't cope. We were in pieces and decided on an amnio which confirmed Down's Syndrome. We were pleased at this news and continued with the pregnancy. There were issues with my blood pressure and swelling and at 37 weeks after Maggie insisted on a scan which showed a lack of fluid around baby, they rushed us to Leicester with "blues n twos".

Amelia Rose was born by emergency section on 28th June 2011 weighing 4lb 9oz. PERFECTION! She had a 7 week stay in Glenfield Hospital. Her first surgery was in November, she recovered brilliantly and was home within 2 weeks.

We miss Amelia with all our hearts

She could charm the birds from the trees with her character, smile and all round beautifulness! Although she was tiny she was mighty and surprised everyone. She rolled everywhere, she loved Mr Tumble and could sign a few words. In August 2012 her little brother Max arrived and she loved, kissed and smacked him - all the big sister things.

In September 2013 Amelia had her second surgery which went well. She was back on the ward the next day but had chylothorax! Nothing worked to help this so it was decided to do the next stage of surgery. However, Amelia came out of theatre on ECMO, a machine to help the heart and lungs function.

Heartbreakingly, on 7th November 2013 after 10 weeks in hospital Amelia passed away as we held her. Her funeral was a beautiful day and we sent Amelia lots of lovely balloons to play with. We miss our Amelia with all our hearts. We have met some amazing people during this time; both professionals and families, who we are proud to call our friends.



Amelia at the park

Sally Jarvis, Doncaster

Christmas Card Design Competition



Enter your Christmas art into our competition.



If you win DHG will turn your picture into Christmas cards.

The cards will be sold to raise money for the charity.



Try to use the DHG heart logo in your picture if you can.



Send your Christmas Card Competition entries to:

Down's Heart Group
PO Box 4260
Dunstable
LU6 2ZT

Rules



If you have Down's Syndrome and a heart condition, it does not matter how old you are.

Brothers, sisters and cousins can enter if they are under 18 years.

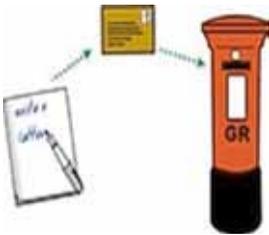


You can use paint, felt pen, crayon or pencil.

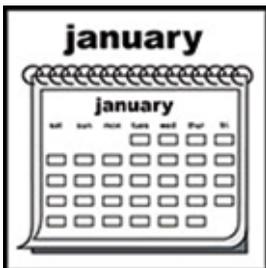
Please do not fold or crease artwork.

Put your name, age and address on the back of each picture.

You can send in as many pictures as you like.



You must send us the original picture, we can not use photocopies.



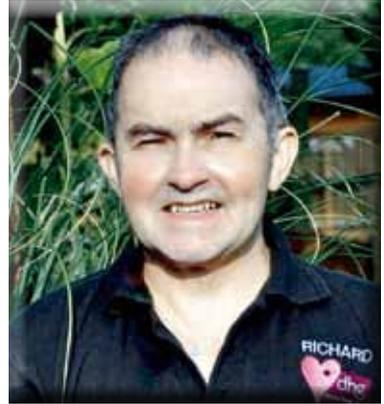
All artwork must be received at National Office by Wednesday 21st January 2015.

Richard Mowberry - Committee Member

Why did you get involved with DHG? I was asked by other Trustees to consider becoming involved with the DHG.

What made you volunteer to help? I am honoured to be the father of twin girls with Down's Syndrome, both have different heart conditions and both have had surgery.

What do you think you bring to the role? Experience of having been involved as a parent of a child with Down's Syndrome and heart condition times two!



Occupation? I am an Auxiliary nurse in Nottingham.

Hobbies? Playing guitar and photographing rock bands.

Family? I'm married to Shirley and have three daughters, Lauren, and twins Nicola and Claire.

Pets? We have a cat called Murphy and a goldfish called Surfboard.

Age? Over 21 (58 to be precise).

What do you see for the future of DHG? Continuing to provide information and support for parents with a child who has Down's Syndrome and a heart condition.

Favourite cake? Arctic Roll

Embarrassing moment? Falling into a boating lake while getting out of a motorised inflatable, one foot on the bank and the inflatable not tethered, I started to do the splits with only one way to go. There is a video somewhere after the event of me walking back to lodgings soaking wet.

Claim to fame? I am the photographer of the CD cover for a gentleman called Preston Reed the album called *"in here out there"*

I get a mention in the *"thanks to"* section.

<http://prestonreed.com/releases/inhereoutthere.html>

Nina Lawson - Secretary

Why did you get involved with DHG? Jon-Paul was diagnosed with Down's syndrome and a partial AVSD very early on in my pregnancy, it was a very worrying time as we had no idea how ill he would be. DHG were there for us every step of the way.

What made you volunteer to help? I felt I had learned a lot in a short space of time and wanted to offer support to other families.

What do you think you bring to the role? I have experience of the prenatal screening process and the subsequent cardiac care required throughout pregnancy. Jon-Paul has had successful open heart surgery, as well as closed heart surgery, two major abdominal surgeries and one minor abdominal surgery. He has spent time in hospital in heart failure, suffering from wound infections and was born premature. I think this has given me good all round experience of some of the challenges our children face.

Occupation? I'm a stay at home Mummy. I was a Housing Assistant for a local authority. I have good working knowledge of benefits, including DLA.

Hobbies? I like going to spin classes at the gym.

Family? I'm Mum to JP (4) and twins Corey & Dylan (20 months). I'm married to Andy.

Pets? I have a Staffordshire bull terrier called Enzo and a Patterdale terrier called Bella and about 20 tropical fish.

Age? I'm 30.

What do you see for the future of DHG? Growing and working closely with other organisations, so that families receive the best possible access to information.

Favourite cake? Coffee cake

Embarrassing moment? Probably losing Andy at a festival. I couldn't remember where he'd parked, there were 40,000 people there, it was very busy and I was very drunk! I walked around for two hours on my own looking as there was no mobile reception as we were on an airfield. The Police drove me around (with a riot van of people in the same position) until we found him. Kudos to the Police, good guys.

Claim to fame? My claim to fame is by way of my older brother. He used to play professional basketball in America and is a former male model.



Down's Heart Group were successful in securing funding for an activity weekend for a group of members together and let them experience some new activities to show them as they are careful. It was also an opportunity for them to socialise. Information Officer,



Chris climbing the wall

We had not embarked on a weekend like this before, so everyone was rather uncertain about how well it would work and if people would get on with each other. It was also quite different for the staff at Culmington Manor - Manor Adventure's Ludlow site, as they generally cater for large school parties, rather than our select group of adults!

On Friday 29th, nine of our adult members with varying heart conditions, one sibling and a mixture of parents and carers all met for the first time. Some were shy but all were fairly excited about the next couple of days. They had travelled from across the UK and were keen to find their rooms, dump their bags and get on with the fun.

DHG Activity Week

Three mentors also came along to offer a bit of support and inspiration.. All three worked extremely hard all weekend and played a vital part in making the weekend work.



Faye on the obstacle course

Paul Willgoss, a member of the Somerville Foundation, for grown ups with a congenital heart condition, has many cardiac issues but manages to walk, run and hike his way around Britain and is quite an action man. He was great at organising everyone and encouraging them to go to bed!

DHG Trustee Alice Croot, who works with young adults with disabilities when she isn't studying. She spent the weekend being called "*Alice In Wonderland*".

And Ashley Sykes, who has a heart condition and is a Mencap ambassador.

... of our adult members, something we have been planning for a while. The idea was to get (and their families and carers) that their heart conditions don't have to stop them as long Sarah Smith, reports on the event which took place at the end of August.

Nine activities had been chosen for the weekend, starting with Manor Olympics, an "ice breaker" involving everyone and soon teamwork and friendly rivalry were in full swing. Welly wanging and other silly games had everyone laughing and interacting very well in only a short time.

I didn't think I could ever do that!

The other activities were fencing, obstacle course, climbing, rifle shooting, abseiling, zip wire, kayaking and canoeing and it was fantastic to see everyone having a go at them all. There were nerves and scared faces at the beginning, but thanks to the brilliant staff and mentors all were encouraged to have a go. The smiles afterwards said it all really and all the gang achieved far more than they thought they were capable of.



Danny on the obstacle course

Weekend - August 2014

It rained on Saturday morning for all of ten minutes as the obstacle course got under way, but no-one really noticed as they were all too busy worrying about heights or underground spaces.

*I got stuck at the top
but the others helped me do it!*

The mentors reassured everyone that it was all OK and decided going first on the activities was the best way to encourage everyone else. This worked well until Paul demonstrated kayaking and promptly fell in! It did give everyone a good giggle, though!

This weekend was a great opportunity for the group to try many new activities. Fencing and rifle shooting were less high octane than the zip wire but proved almost as scary for some.



Tom climbing the wall



Andrew in his kayak

The evenings was spent drinking and socialising, with a little music and a few dance moves thrown in. Did someone mention nibbles?

*I was scared of the tunnel
but it wasn't too bad after all!*

Whilst the thrill seekers were enjoying themselves, the parents and carers followed a very different itinerary. A tour of Wood's brewery followed by a visit to the adjoining pub was a relaxing antedote to Friday's long journeys and overexcited youngsters. The tasters of beer were very generous and the tour was very interesting.

Thomas and I had a really good time!



Emily on the obstacle course

Free time in Ludlow in some fantastic sunshine was a pleasant way to spend Saturday morning and despite the mountain of food provided at Culmington Manor I think everyone still found room to sample coffee and cake in one of the many lovely shops.

The afternoon visit to the Teme Leisure Centre could have been the time to burn off extra calories. However, we had exclusive use of the spa facilities, so it was far more important to relax in the sauna or whirlpool!



Thomas on the ladder



Robbie ready to abseil



Paul going for a swim!



Elizabeth on the zip wire

The parents and carers' weekend was rounded off by a visit to the wonderful Estivals where everyone had either a massage, hot stone treatment or facial. The sun shone so we all sat out in the courtyard watching the wildlife and horses and had to tear ourselves away to get back to the others for Sunday dinner.

A fabulous weekend.

Very worthwhile for young people and parents/carers alike

We were all very tired at Sunday lunch and I think it took a few days for everyone to recover. After lunch, we finished packing and said some sad goodbyes. Firm friendships were made throughout the weekend and everyone wants to know when the next one is!



The gang left -right Emily, Andrew, Elizabeth, Ashley, Thomas, Paul, Alice, Isobel, Robbie, Faye, Tom, Chris and Danny

Down's Heart Group is currently working on an update to our website which we hope will go live by the end of the year. One section of the new site will have more ideas for fundraising, where our Alice, our volunteer fundraising officer will be adding lots of ideas and tips on how you can support DHG.



As well as ways that you can help that cost you nothing, such as using websites that make a donation for any purchases you make online (anything from booking train tickets and buying clothes to travel and car insurance) there will be ideas for fundraising events you can organise yourself - big or small. And of course there will be links to some of the more extreme events that some of our enthusiastic supporters sometimes embark on, such as marathons, treks and skydiving.

But if you just can't wait for the new website, here are a few links to wet your appetite. Go take a look and see how you can be part of ensuring that Down's Heart Group is able to continue to help both new families and existing members, when they need us and with a personal approach that fits their needs.



Raise money whilst shopping online at 100's of stores

www.giveasyoulive.com/join/dhg



Fancy trekking, cycling, dog-sledding or rafting perhaps

www.trekfest.org.uk



Need some ideas of ways you can raise funds

www.better-fundraising-ideas.com

And if you do see something that takes your fancy, let us know not only so that we can support your efforts with sponsor forms, literature etc. but we may also be able to help you get a discounted place or tell you of similar events that cost less or require less sponsorship to take part.

Email fundraising@dhg.org.uk

Rumbletums Presentation



Nicola Mowberry and Dr Lymm

University of Nottingham students were set a challenge to achieve 100% compliance in returning national student surveys. The Learning Disability Nurse students were first to reach the goal and received a charity donation of £300 which they decided to share between DHG and Rumbletums, a cafe in Kimberley, Nottinghamshire.

Rumbletums provides training opportunities for young adults with learning disabilities, where they can learn catering or child care, as there is also a playgroup running on the premises. Setup by a group of parents, who realised there wasn't much available in the area, the venture is now thriving, with several employees and up to 20 trainees.

On 2nd July, Dr Joanne Lymm, Director of Learning and Teaching for the School of Health Sciences at the University, presented a cheque for £100 to DHG member Nicola Mowberry, who is a trainee at Rumbletums and DHG's Information Officer Sarah Smith. The event was hosted by Rumbletums and attended by several trainees and LD Nursing students, who ate vast amounts of cake! Thank you to the students for their hard work and for nominating DHG.

Hole In The Heart

Artist and author, Henny Beaumont's daughter, Beth, has Down's Syndrome and a corrected heart defect. Henny decided to write about Beth's birth and early years in the form of a graphic novel called "*Hole In The Heart*", which was shortlisted for a Myriad Graphic Novel Award earlier this year.



an extract from the book

Henny is about to start lecturing to health workers who work with people with disabilities.

www.hennybeaumont.com

CHD Review Consultation

This is your opportunity to have your say on the new proposed standards and specifications for the congenital heart review. The consultation is open until Monday 8th December 2014.



NHS England, as the body responsible for commissioning specialised congenital heart services, is undertaking a national review of congenital heart services for children and adults. The review will consider the whole lifetime pathway and its aims are:

- Securing the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
- Tackling variations so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care.
- Improving patient experience, including how information is provided to patients and their families, and consideration of access and support for families when they have to be away from home.

Comment is welcome from patients, family members and professionals. A copy of the proposed standards and specifications and a reference pack can be found by following the link below. There is also an easy read version. The online version of the consultation is also available from this link.

<http://tinyurl.com/oa4ktr8>

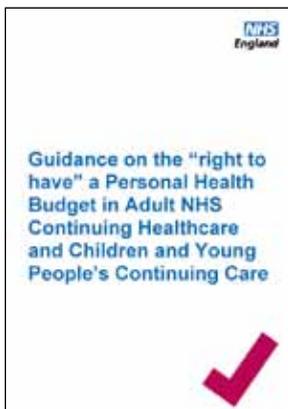
If you are unable to complete the online response and would like to respond to the consultation by post or email, complete a response form and send to Dialogue by Design at the address below.

Dialogue by Design are an independent organisation who are providing expert analysis of the responses to this consultation for NHS England. Email and postal responses should be sent directly to them and reach their office before Monday 8th December 2014.

CHDconsultation@dialoguebydesign.co.uk

Dialogue by Design
252B Gray's Inn Road
London
WC1X 8XG

Personal Health Budgets



From October people eligible for NHS Continuing Health Care or Continuing Care will have the right to have a personal health budget. This is an allowance to support identified health and wellbeing needs agreed between the individual, their representative, their families or carers and the local NHS team.

This booklet, containing a tool kit, practical advice and links to useful and important documents will help parents and carers get the best possible package

<http://tinyurl.com/kblw895>

Continuing Healthcare

The NHS and councils each have responsibility for different laws and policies and set rules about what they can spend money on. 'NHS Continuing Healthcare' (NHS CHC) is the name for one of the pots of money that has specific rules.



Foundation for People with Learning Disabilities has produced a booklet "*What do I need to know about NHS Continuing Healthcare?*" which provides information for families of people with learning disabilities about the scope and process of NHS continuing healthcare, together with possible implications and questions they may want to ask.

<http://tinyurl.com/fpldcontinuinghealthcare>

Care and Support Jargon Buster



Think Local Act Personal is a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support.

The Care and Support Jargon Buster is a plain English guide to the most commonly used social care words and phrases and what they mean. The definitions were developed and tested by a steering group including service users, carers, local authority representatives information providers and key stakeholders from across the social care sector.

<http://tinyurl.com/thinklocal-jargon-buster>

Kidz Exhibitions

Kidz exhibitions are aimed at parents, carers and healthcare professionals, with a focus on equipment, products and services for children and young adults with disabilities and special needs.

Each event has over 100 exhibition stands offering information on a wide range of equipment and services and Third Sector and Statutory Organisations also provide advice in areas such as specialist schools and colleges, transition, benefits, direct payments, personalised budgets and more.



Kidz up North	20/11/14	EventCity, Barton Dock Road, Manchester
Kidz in the Middle	19/03/15	Jaguar Exhibition Hall, Ricoh Arena, Coventry
Kidz South	04/06/15	Rivermead Leisure Complex, Reading
Kidz Scotland	17/09/15	Highland Hall, Royal Highland Exhibition Centre, Edinburgh

The events run from 9.30am to 4.30pm and are free entry, with lots of free parking and are fully accessible. Call or email for tickets in advance.

0161 607 8200

info@disabledliving.co.uk

www.disabledliving.co.uk

Netbuddy joins Scope



The online community Netbuddy has joined with Scope, so the old Netbuddy website is closing and a new online community is now accessed through the Scope website.

Scope
About disability

Many of the Netbuddy features, including the "tips" have been transferred and many improvements have been implemented. Groups for parents and carers and forums for discussing practical issues, such as equipment and technology or money, benefits and work are all available.

www.scope.org.uk/community

Council Tax Disregards



To be disregarded for paying full Council Tax as a Carer you must live in the same house as the person you are caring for and provide at least 35 hours care per week. You cannot be the partner of the person you care for or the parent if the person requiring care is less than 18 years old.

The person requiring care must be entitled to a qualifying benefit; Attendance Allowance or highest or middle rate of the care component of Disability Living Allowance.

If two carers are providing more than 35 hours of care each, your relative is disregarded because of their learning disability and there are only the 3 of you living in the property, there could be up to 50% discount. If only one carer lives with the person with a learning disability and provides more than 35 hours care there will be a 50% discount.

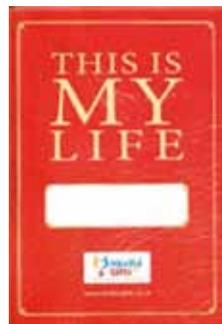
There are also criteria around disregards for a person with a learning disability. All local councils have a form to complete to request disregards.

This is My Life

This 34 page book is like a personal scrapbook, ideal for reminiscing as well as documenting wishes and helping people express their feelings, likes, dislikes and routines. There are separate sections for many topics including hobbies, food, friends and family.

"This Is My Life" is available for £4.99 but it's worth checking with your local Learning Disability team have something similar for free.

www.mindfulgifts.co.uk



New Guide To Services

contact a family
for families with disabled children

Contact A Family has updated their free guide *"Getting social care services when your child has additional needs"*

It includes information on how to get an assessment, services and equipment. It also has handy tips for meetings with social services and what to do if you are not happy with a service. It is free to download or call for free to order.

0808 808 3555

www.cafamily.org.uk

Hear My Voice



There are 1.4 million people with a learning disability in the UK. Their voices count, but they are often not heard.

With the General Election only months away, Mencap has launched a campaign called Hear My Voice, which will enable people to tell their local candidates what matters to them.

www.mencap.org.uk/hearmyvoice/action

Love Your Vote

Dimensions and the Parliamentary Outreach Service's campaign "*Love Your Vote*" is raising awareness of voting and the political process among people with learning disabilities, who can all register to vote regardless of capacity. People should discuss whether they want to vote or not and carers should ensure they have the opportunity to make an informed choice. A postal vote may be better for some.



Preparation and planning is key, ensuring enough support is given for registering, giving time to look at all the parties' leaflets and possibly doing mock elections with ballot papers so that the process becomes more familiar. Plan election day so enough support is given, either in understanding the process or enabling the person to get to the polling station and into the booth. It may be necessary to speak to the returning officers on the day for guidance about how best to make things work.

<http://tinyurl.com/loveyourvote>

How To Vote

Our friends at Mixit, the fantastic performing group of members with and without learning disabilities has produced a video called "*How To Vote*". It can be viewed on Mixit TV Youtube by following the link.

<http://tinyurl.com/lsayoqc>



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



down's heart group

charity 1011413

Tel:
Email:
Write:

0844 288 4800
info@dhg.org.uk
PO Box 4260
Dunstable, LU6 2ZT

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See page 3 for details of how to order