



**dhg**

down's heart group

# Newsletter Autumn 2014

Issue 51

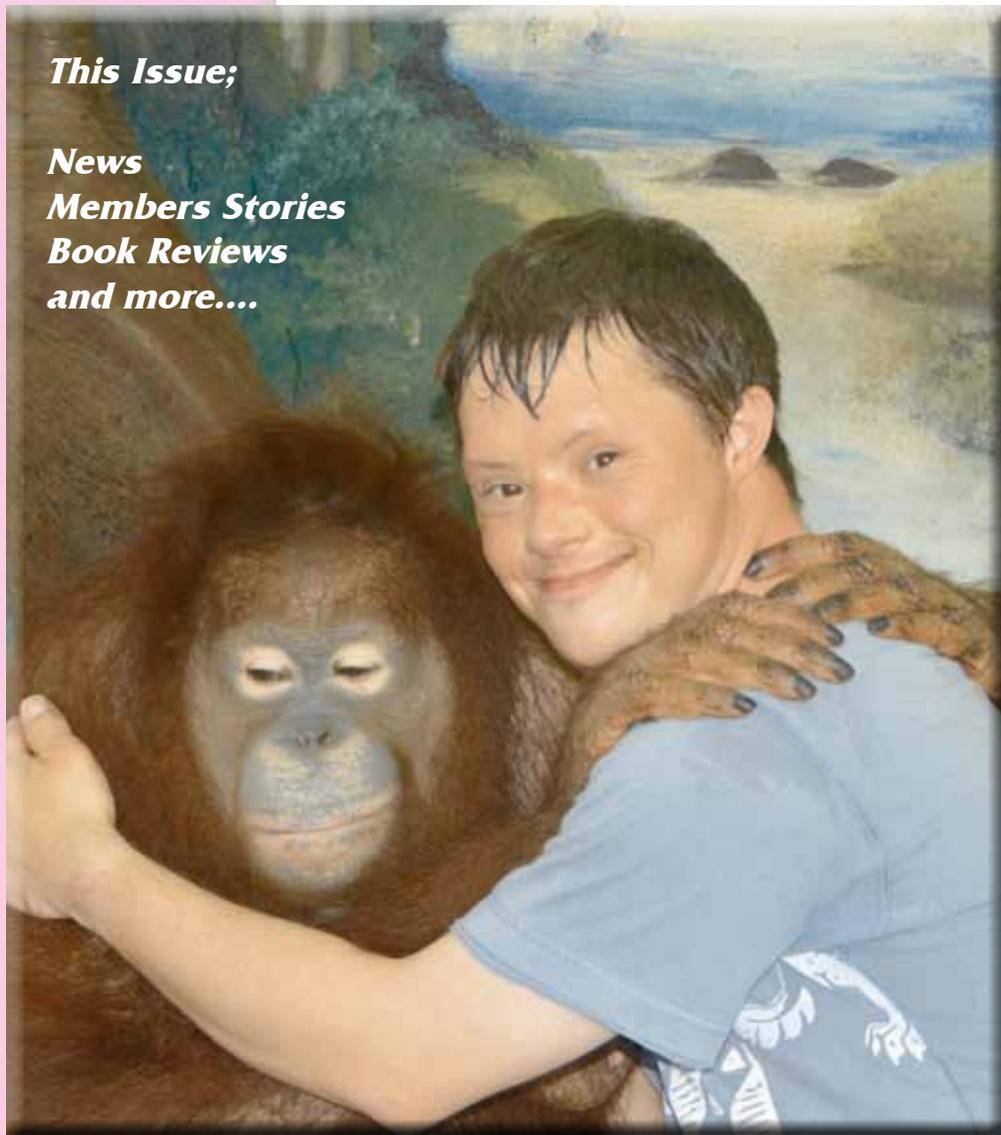
***This Issue;***

***News***

***Members Stories***

***Book Reviews***

***and more....***



## Chair's Report

Welcome again to our newsletter.

In April our London Marathon runners were successful in getting good times and raising lots of money for DHG although unfortunately one had to drop out before the race due to and another pulled out at 15 miles under medical advice, but we are very relieved to see that they have both recovered well.

You will have seen from our Facebook page, emails and previous newsletter, we are sponsoring an adventure weekend in August at an activity centre in Ludlow. We have been lucky enough to secure funding to put on this weekend so please keep your fingers crossed for suitable weather for our young people.

As reported on page 3, our AGM did not see many changes to our committee so we continue as before and in this and following newsletters you will see a biopic of committee members and our two members of staff, which will help you to put a face to the names.

My best wishes and regards to all of you and hope that we have a summer to remember. This hopefully includes good weather!

Regards

*Chris Stringfellow*

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'I Love You Natty'	Back cover

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## Annual General Meeting

The Down's Heart Group Annual General Meeting was held on Saturday 17th May in Birmingham. Very few people attended, which was a shame as it is a great opportunity to have your say and help shape the future of the charity.

The majority of the committee stays the same, with just Grace Smith stepping down from a three year term and Alice Croot being formally elected as fundraising officer.

Chair -	Chris Stringfellow	chris@dhg.org.uk
Vice Chair -	Peter John	peter@dhg.org.uk
Secretary -	Nina Lawson	nina@dhg.org.uk
Treasurer -	Phil Thorn	phil@dhg.org.uk
Fundraising Officer -	Alice Croot	alice@dhg.org.uk
General Committee -	Helen Laverty Richard Mowberry Roberta Nathan	

Finances are in good order but fund raising and grant applications need to be worked hard on so that we can maintain the level of service.

*Next year's AGM will take place at the Conference and Family Fun Weekend on 16th May in the Somerset area. Date and venue to be confirmed.*

The Trustees work hard to keep Down's Heart Group going from strength to strength. To evolve and change with the times needs fresh ideas so we always welcome any feedback or advice from the membership. After all it is your group!

Over the next few newsletters we will running question and answer pages introducing all the DHG staff and trustees. This will hopefully give readers a bit of background information on those involved in the charity.

If reading about our team inspires you to come forward to offer any time or skills please get in touch on any of the email addresses above or

[info@dhg.org.uk](mailto:info@dhg.org.uk)  
0844 288 4800

## Lucy

*I'd like to thank everyone at National Office, especially Penny, for all the years of support and help. I can remember the days when Penny ran the office from under her stairs!*



*Lucy with an early riding certificate*

Lucy was born in 1991 and her birth family decided that it was best for all if she was to be adopted - I first saw her when she was less than a day old. Lucy had an ASD and VSD, problems with her kidneys, reflux, hypomobility and capillary fragility. I can still hear the paediatrician saying *"she may not go 12 days"*. My reply was "every baby deserves to die with the love of a family around them" and on that understanding I brought her home four days later. I walked her around and told her she could think on if she thought she was dying on my watch!

Our first consultation found the VSD had healed on its own and over time the ASD has become so small that Lucy has not required surgery. Likewise, after three years on antibiotics Lucy's kidney problem was resolved and one of the positive outcomes from being on them was that Lucy didn't have the usual coughs and colds. I also believe the knock-on effect was that her speech has been much clearer than some of her friends with Down's Syndrome.

*The prognosis was poor, but Lucy was and is a fighter, she also has a very positive (some would say bossy) nature.*

Lucy's reflux problem hasn't given her much trouble and as she got older she has learnt what she can eat and what to avoid.

One of Lucy's mystery conditions started at 5 months old when she would scream for up to six hours for no apparent reason and a day or two after a screaming bout she would pass black sticky stools. Tests revealed that Lucy was bleeding internally but it was never established where from. As Lucy wasn't overly anaemic it was a joint decision to wait and see rather than operate. The bleeds lasted until she was four and a half years old, when they simply stopped and haven't reoccurred since.

Lucy has been horse riding from an early age - her first clear word was *"stirrup"* at three years. Within a couple of months she had a vocabulary of

200 words and short sentences. I remember her first two word sentence, "Mum now!". She is still saying it on occasion but I don't jump to obey any more! It has been a hard lesson for both of us to learn!

When Lucy hit puberty she had some problems, so because of her childhood bleeds she started having the contraceptive injection to stop her menstruating, this worked well for a number of years. However, during this time she had a fall from her horse, resulting in a hip fracture which healed after ten weeks. She only had one X-ray and very little follow up, but to be honest Lucy appeared fit and healthy and assured everyone she was fine.

Around this time a Haematology consultant told us Lucy had a collagen condition; either Ehlers - Danlos Syndrome or PXE. Lucy then saw a Consultant Geneticist who was unable to do conclusive tests due to lack of family medical history (due to the adoption). We agreed with his professional decision as Lucy was fit, active and well.

### *Lucy was given the diagnosis of Osteoporosis*

Lucy became a student at The Fortune Centre of Riding Therapy on a 3 year residential course. Midway through I queried the length of time Lucy had been receiving the injections, but as Lucy showed no signs of any medical worries and was reluctant to change to a contraceptive implant she continued with the injection.

During Lucy's last year at Fortune she became reluctant to ride. This was attributed to her wanting to be in control of her life and a little hesitancy after a couple of minor falls. At this time Lucy was also on a controlled diet, dropping from a size 16 to a size 8. This was a major achievement for Lucy which she is rightly very proud of.

After Fortune, Lucy moved to the Minstead Training Project as a resident. The new GP referred her for a bone density scan as she had received the injections for 11 years, they were stopped and Lucy was changed to the implant.

Current NHS guidelines say that people under 60 years of age do not receive bone density scans without first being seen by a Consultant Rheumatologist. But in Lucy's case, to save time, she had her scan while awaiting her Consultant appointment.

Lucy was given the diagnosis of Osteoporosis. Blood tests showed that Lucy had extremely low levels (12) of Vitamin D in her system and was prescribed high dosage Vitamin D.



*St James' Palace for the Duke of Edinburgh awards*

## Lucy continued



*Lucy dancing with her Dad*

After 6 weeks of treatment Lucy's levels had risen to 100, and she is now on life long daily medication to maintain these levels. She will also undergo annual Bone Scans and Consultant appointments.

*My question is how many people with Down's Syndrome might be suffering from undiagnosed Osteoporosis?*

Lucy is now 23 and is a hardworking, active young lady who loves working outside and dancing. By looking at Lucy no one can tell that she has Osteoporosis, therefore it is important that any fall or accident is recorded and that she is seen by a Doctor, to confirm that she has no fractures. Lucy is also at risk of spontaneous fractures of her vertebrae. Lucy understands that she can no longer ride and has to be sensible in her actions.

*Gwen Thomas  
Hampshire*

## Anthony Jacoby

Anthony Jacoby, "AJ" is only 5 months old and has gone through 3 rounds of GI surgery and has two holes in his heart – which are expected to heal naturally.

Throughout his journey in life he has still been able to reach infant milestones like any other child.

His biggest achievement is being able to sit up independently for short periods of time, and also being introduced to eating baby cereal.

He loves to smile and laugh. He's very ticklish and loves bath-time.



*Jessica Witherspoon, Indiana USA*

## Amber



*Amber wearing her new hat*

Amber is now 8 years old. She was born 3 weeks early and had, amongst other things, an AV septal defect. She had many heart scans over her first few months and when she was 7 months old we were told the great news that the hole had almost fixed itself, leaving her with a heart murmur that would have to be monitored but that no surgery would be needed.

Amber attends a mainstream school and is doing very well. She joins in with the lessons, loves books and is brilliant at reading, and is accepted and included by everyone.

In year 2 she was nominated and elected by her classmates as a school councillor to represent them and their views at school council meetings, where she came up with the great idea of having a cake stall at the school fair to raise money.

### *Amber is accepted and included by everyone*

Amber works very hard at school, and this was rewarded recently when she received a special award from the headmistress for ongoing effort and attainment in all areas. It was presented to her in a whole school assembly, which my partner, myself and Amber's Grandad were privileged to attend. She had to go up in front of over 300 children plus the staff to collect her certificate from the headmistress.

She was very nervous but held her head high and made us very proud. Two of her classmates read out a list of things that Amber is known and loved for, which included always looking after them when they are upset or hurt, making them laugh, working hard and her amazing knowledge of and love for animals. The applause rang through the school.

### *The applause rang through the school*

Every day Amber makes us so proud and glad that we are her parents. She has the power to change people's attitudes and lives just by being herself, and what a gift that is.



*Amber with her award*

## Tom's Holiday



Tom has sent us some photos of his holiday.



Tom went to Thailand to see his twin brother, Ben.



He met lots of exciting animals.



Tom learned a new dance.

Here is Tom's letter. We think his writing is great!

I WENT TO THAILAND WITH MY MUM, TO SEE  
MY twin BROTHER BEN.  
I HAD EXCELLENT HOLIDAY I DO A LOT OF THINGS  
I WENT TO THE ZOO I HAD A CROCODILE, MONKEY, TIGER  
CALLED LUCY, ORANGUTAN CALLED MITO.  
I WENT TO THE BUTTERFLY FARM AND ONE ELEPHANT  
TRICKING.  
I SLEPT IN THE TREE HOUSE IN THE JUNGLE.  
I WENT TO A SPEEDBOAT TO KHAI NOK ISLAND AND I SWAM WITH  
THE FISH IN THE ENJOY SEA, I HAD A LOVELY TIME.  
I WENT TO SEA FANTASY SEA SHOW AND I SAW DANCING ELEPHANTS  
ON THE STAGE. I HAD A LOT OF LOVELY FOOD I ATE FISH  
AND FISHCAKE, PRAWN, FROGS LEGS.  
I SAW A ELEPHANT ON A MAIN ROAD.  
I LOVE THE WARM WEATHER IT IS SO GOOD I LOVE PHUKET.

Can you tell us all about you? We would love to put your photos on this page.

## Alice Croot - Fundraising Officer

**Why did you get involved with DHG?** My brother had Down's Syndrome and CHD but sadly died when only six months old. DHG were a great comfort to my parents and although not old enough to remember Sam, I have memories of people we met through DHG and stayed in touch with as I grew up.

**What made you volunteer to help?** I ran a marathon last year for DHG. Penny remembered my family and this along with the support throughout the training made me want to do more. It's fantastic to be involved in a charity that does such great work, knowing that you really can make a difference.

**What do you think you bring to the role?** I'm still very new to it! I am enthusiastic and have raised money before, including running a 'Santa Fun Run' (very good fun!) and shaving my head (not quite as fun). I bring personal knowledge of how DHG can help, motivating people to collect that little bit extra in donations, hopefully.

**Occupation?** I'm a support worker, working with some people with Down's Syndrome. I am also studying for a post graduate degree in eighteenth century history and culture.

**Hobbies?** I love books and read at a ferocious rate! I like seeing my friends and visiting my parents. I enjoy films, walks and the occasional run. I have made a few wedding cakes in the last year.

**Family?** Dad, Tim, works with the army and mum, Becky, worked as a nurse. They live in Germany. My younger brother, George, is a butcher but is joining the army as an engineer. Sam would be 24 now - he is still very dear to us all.

**Pets?** My parents have a border collie called Pepe, after the French skunk in the cartoons. She has one brown eye and one blue.



**Age?** I'm 25

**What do you see for the future of DHG?** Support for even more families and further links with other groups supporting those with Down's Syndrome.

**Favourite cake?** I'm very fond of carrot cake with dates and walnuts!

**Embarrassing moment?** Too many to say!

**Claim to fame?** I sang at the Royal Albert Hall with the Hampshire Youth Choir.

## Penny Green - Director



**Why did you get involved with DHG?** In August 1989 on my 29th birthday I gave birth to our second child Daniel. On day 4 we were transferred to Great Ormond Street Hospital as he had heart and bowel defects. He spent the next fourteen weeks either at GOSH or our local hospital before he sadly died in the November.

**What made you volunteer to help?** I was supported by the group, so it felt natural to want to give something back although I never imagined back then where it would lead!

**What do you think you bring to the role?** A little bit of personal experience, acquired knowledge and a passion for supporting and informing parents and carers.

**Occupation?** In the dim and distance past I worked in a bank, but for the past 24 years I've been with DHG and Director for the past 10.

**Hobbies?** Family history, travel when I can.

**Family?** Malcolm, long suffering hubby of 34 years without whose support I'd never have been able to get so involved with DHG. Andrew 26, Michael 23 and Sarah, almost 21. Andrew is older than Daniel but sadly cannot remember him. All three of them have always been outspoken advocates for people with learning disabilities.

**Pets?** A German Short Haired Pointer called Fidget (who sometimes tries to sit on my lap in the office!) and a Siberian Husky call Kiera.

**Age?** I would say "no comment", but for anyone that can remember me having pink hair in 2010 to celebrate my 50th and Daniel's 21st, it's not exactly difficult to work out that I'll be 54 in August.

**What do you see for the future of DHG?** Hopefully many more years of supporting families, providing information and advocating on their behalf. Ideally some new blood to come in and pick up the reins from old folks like me and to continue to evolve the role of DHG according to the needs of it's members, whilst maintaining the vision that our Founder Linda Walsh had when she started it all.

**Favourite cake?** One without any calories.

**Embarrassing moment?** Too many! And I'd sooner forget them than go public!

**Claim to fame?** Probably the pink hair.

## London Marathon 2014

DHG had 5 runners this year and they worked extremely hard to raise funds for us.  
Thank you all so much!

### Laura Stevens and Chris Deas

My dream was to run the Marathon and I ran in memory of Tom Pow and my Grandad Pop, two heroes in heaven who were with me every mile! I had horrendous knee problems and was told not to run. Thankfully, a new physio gave me the right exercises and the confidence to go for it.

I was due to run with Paul Smith, but he had to pull out a few weeks before. I was also running with Chris Deas, a close friend. Chris trained so hard! He changed his whole lifestyle and raised an amazing £1,641.00! He was so nervous on race day but really kept our spirits up. We started off together and after about a mile we split as he had a time he wanted to beat.

Unfortunately at the half way mark I caught up with Chris and he was so poorly. He was taken into an ambulance where I waited with him for about an hour, but he could not continue as he had a really high temperature and had collapsed twice,

After leaving Chris at the half way mark, I met a women called Donna. We walked and ran the last stretch together both struggling with our knee pain, and then finally running up the last 200 metres together!

What an amazing day. The London Marathon 2014 was an experiance to say the least, I cannot thank my family and friends and the crowd enough for their amazing encouragement. It was hard but I did it and I will never forget what an emotional roller-coaster it was. I am so proud to have taken part and have raised £1500.



*Laura*

*Laura with Paul and Chris*

## Layla and Richard Batchelor

*Husband and wife team, Richard and Layla ran the full 26 miles together. Here Layla explains why:*

I ran the London Marathon because I wanted to set myself a challenge. Richard did it to support me and to help me achieve my goal.

We chose to raise money for DHG because I did a post graduate course with Chris Stringfellow, the Chair's daughter, Helen. I also lived with her for a little while. I have helped out in the crèche at an AGM and have therefore seen what a worthwhile charity it is.

*Layla and Richard*



*Richard and Layla*

## Paul Smith

I was really disappointed not to have been able to run due to illness, but it was the right decision. We had a great day watching Laura and Chris. They did brilliantly and we are very proud and grateful to them for attempting such a massive task, especially Laura who then had to run on her own after Chris had to drop out.

My incentive to run is in memory of my nephew Tom Pow. He was a very lovable and mischievous boy who even though he had corrective surgery died of complications 18 months later unexpectedly at the age of 15 in 2002.

I have now run 6 marathons in his memory and all funds raised went to DHG. DHG supported my sister in law Lorraine, Tom and his twin brothers Jamie and Jack through his surgery.

Tom's family have supported the DHG with numerous charity golf days since he died which have been well supported by friends and family. It is a great charity and we will continue to do as much as we can to raise awareness and money.

*Paul*



*Paul with Tom Pow*

## Activity Weekend

We still have a few spaces left on the Down's Heart Group Activity Weekend

29th - 31st August 2014

Manor Adventure, Ludlow, Shropshire.



This is a free event for over 16's plus a carer. Other family members may be able to attend, depending on availability, but may have to make a financial contribution.

There will be professionally organised activities during the day for the youngsters, whilst parents/carers have a chance to relax and enjoy themselves knowing they are not too far away.

Families are for their own travel costs, but DHG may be able to assist if this is an issue.

Places are going fast so please contact us as soon as possible for more details and to book a place.

[sarah@dhg.org.uk](mailto:sarah@dhg.org.uk)  
0844 288 4800

### Pulse Oximetry Success



Public Health England is extending Pulse Oximetry screening on newborns to all hospitals as soon as possible. This quick, painless and cheap test measures oxygen levels in blood and can detect over 90% of life threatening heart defects at birth.

For more information on the Children's Heart Federation's Pulse Oximetry campaign visit

[www.chfed.org.uk/pulseox](http://www.chfed.org.uk/pulseox)

## Family Fun Day

The Disability Strand Group of Families First are holding a family fun day from 11am to 3pm on Friday 15th August 2014 at Palmerston Community Learning Centre, Cadoc Crescent, Barry, CF63 2NT for all families who have children with special and particular needs. The aim is for children and young people to have fun and for parents and siblings to find out what services and activities are available. There will be sports activities, play, dance, music, sensory equipment and much more. Families will also be able to sign up to the Disability Index.

01446 704736

[www.valeofglamorgan.gov.uk](http://www.valeofglamorgan.gov.uk)



## NICE National Institute for Health and Care Excellence

### *Adjustable pulmonary artery banding for reducing pulmonary hypertension in infants with congenital heart defects*

NICE is looking at a very specific type of procedure called 'Adjustable pulmonary artery banding for reducing pulmonary hypertension in infants with congenital heart defects'. Adjustable pulmonary artery banding is used in young children who are born with heart problems. In this procedure a metal band is clipped around the blood vessel which carries blood from the heart to the lungs in order to restrict the blood flow and reduce the high pressure in this vessel. The tightness of the band can be adjusted at any time using a remote control, without the need for further surgery.

NICE welcomes comments from the parents or carers of patients who have experience of this procedure, but also from any patient or carer who would like to comment on the guidance in general.

If you would like to be sent a link to the consultation document or would like to submit any comments please contact Heidi Livingstone in the Public Involvement Programme.

[Heidi.Livingstone@nice.org.uk](mailto:Heidi.Livingstone@nice.org.uk)  
020 7045 2183

## Play and Leisure: Your Rights

*Adapted, with permission, from an article written by Polly Sweeney of Irwin Mitchell Solicitors, which appeared in the Spring/Summer 2014 edition of Contact a Family's newsletter, 'Connected'. For information on local play and leisure, look out for their "Holidays, Play and Leisure Guide" due out soon.*

There is a duty under section 25 of the Children and Young Person Act 2008 for local authorities to provide *"breaks from caring to assist parents and others who provide care for disabled children to continue to do so."* These "short breaks" should form part of a child's care package, either directly commissioned or provided as a direct payment.

The Breaks for Carers Of Disabled Children Regulations states that local authorities must provide a range of short breaks in their area, including daytime care in or outside the child's home and educational and leisure services.

In addition, play and leisure opportunities are available under the Chronically Sick and Disabled Persons Act 1970 and under the Childrens Act 1989. These might include: provision of leisure facilities, occupational, social, cultural or recreational activities, assistance to enable your child and family to have a holiday and travel assistance.

Article 31 of the United Nations Convention on the Rights of the Child also states that children have a right to relax and play and to join in a wide range of cultural, artistic and other recreational activities.

The Equality Act 2010 places a legal duty on organisations to make reasonable adjustments to their policies and premises and to provide auxiliary aids and services to avoid discrimination. Disabled children cannot be forced to meet any additional costs for these reasonable adjustments.

You can request a copy of the local authority's *"short break service statement"*, which sets out details of services provided, eligibility criteria, etc.

You should request an assessment of your child's needs and also an assessment of your needs as a carer. The time frame for assessment is a maximum of 45 days from referral. The care assessment should then include a *"plan of action"* stating which services are going to be provided and by whom.

## Embody Dance

Embody was formed in June 2009 by Community Dance Artist Emma Breeze. Based in Coventry, Emma runs dance classes all over the West Midlands and caters for all levels and ages.



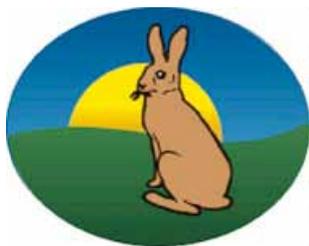
The Tiger Feet programme for people with disabilities has had fantastic results and encouraged many people to give dancing a go.

07533 916231

[embodydance@hotmail.com](mailto:embodydance@hotmail.com)

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

## Thomley Activity Centre



Thomley Activity Centre is a Buckinghamshire based recreational and educational facility for disabled children and teenagers, and their families.

It is situated in 7 acres of beautiful countryside. All facilities are fully accessible and securely enclosed, and include a soft play area, music room, sensory room, cycle track, art room and much more!

01844 338380

[enquiries@thomleyactivitycentre.org](mailto:enquiries@thomleyactivitycentre.org)

[www.thomleyactivitycentre.org](http://www.thomleyactivitycentre.org)

## KIDS

KIDS is an organisation supporting disabled children and young people to develop their skills and abilities. They provide a wide range of services to disabled children, young people and their families.

The website is full of really useful information on personal budgets, short breaks, availability of schemes and advice on getting the best for your child.

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



## Little Eden



*Dawn and Glenn Harvey have transformed their garden in Sutton, Surrey, into a magical place for families with a member with special needs.*

They throw their gates open every Monday and Friday afternoon from 2pm to 6pm so that youngsters of all abilities have somewhere stimulating but safe to play. Parents get to relax, chat and build up a really useful network.

Tate Harvey was born in 2007, seven weeks early, with Down's Syndrome, a VSD, bowel problems and talipes, which means he still doesn't walk. He is the inspiration behind his parents desire to spend all their savings and years of work developing the ordinary back garden into a centre with heated pool, a tree house, sensory equipment and fun apparatus, as well as quiet areas. Dawn and Glenn tend the beautiful gardens, which is hard work but extremely rewarding.

*Dawn says "We provide soft drinks, sandwiches and snacks for the children throughout the afternoon. The kettle is on all day for parents and carers and one of our mums always brings along homemade cakes or biscuits!"*

Little Eden took six years to develop and opened in 2010. Since then the Harvey's have done a huge amount of fundraising to ensure the equipment and pool can be maintained and that new toys and activities can be provided. Indoor space has also been created, just in case the weather is bad.



Little Eden is free, but there is a charity box in which every penny goes towards the upkeep of the garden, and for food and drinks for the next session. It is not compulsory to put in, but every little helps!

Needless to say Little Eden is very popular and families need to contact Dawn for a session slot on

020 8644 4567

dawn@littleeden.me.uk

## Communication Project

*How effective is Makaton sign language in supporting the transition between non-verbal to verbal communication in children with Down's Syndrome?*

Jessica Phillips is developing an academic research basis to support the use of Makaton and communication in children with Down's Syndrome. She is looking for families to help.

Children will be tested using the Kaufman Assessment Battery for Children. It contains 4 play based tasks assessing auditory and visual communication skills. Families will then be interviewed on their perspectives of communication development.



Involvement is anonymous and confidential and you can withdraw from the study at any time. Please contact:

07527505354  
phillipsjl@cardiff.ac.uk

There is also a Facebook page relating to the study:

[www.facebook.com/downssyndromecommunicationproject?ref=bookmarks](http://www.facebook.com/downssyndromecommunicationproject?ref=bookmarks)

## Carer's Allowance Online Service

# DWP

Introduced in October last year, the new Carer's Allowance Online Service allows carers to make a claim for Carer's Allowance using the internet. As well as making new claims, claimants in receipt of Carer's Allowance can also now use the service to notify the Department of Work and Pensions of a change of circumstances.

Carers have been able to make claims online for some time, however, this revised service is quicker and easier to use. So far, over 15,000 carers have made a claim using the new service with very few problems reported.

The service is available 24 hours a day, seven days a week and once a claim has been completed and sent online, it is received immediately by the Carer's Allowance Unit helping ensure that a decision is made as quickly as possible.

The service can be accessed from smart phones and tablets as well as computer and lap tops.

[www.gov.uk/apply-carers-allowance](http://www.gov.uk/apply-carers-allowance)

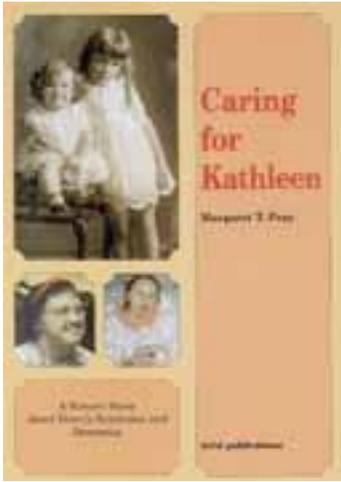
## Margaret (Peggy) Fray

Author Margaret Fray, known as Peggy, passed away earlier this year at the age of 90.

Her book *“Caring For Kathleen - A Sister’s Story”* is about Peggy’s life caring for her younger sister, Kathleen, who had Down’s Syndrome and developed dementia, but lived a good life, reaching the age of 70. It reflects the changing shape of services over the past 70 years and the huge gap in provision for people with a learning disability who develop dementia

After the launch of the book in 2000, Peggy became a Trustee for the Down’s Syndrome Association and campaigned for automatic access to specialist dementia care for those that needed it. Peggy worked hard giving sound advice and was a fierce advocate for many.

Published by BILD, available from them or from Amazon  
ISBN 978-1-902519-19-7

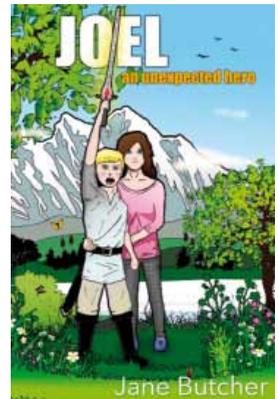


## Joel - An Unexpected Hero

Jane Butcher comes from a family of authors but steered clear of the profession by becoming a teacher until she adopted her son Ben, who has Down’s Syndrome, when he was 4 months old. Ben is now 23 and was the inspiration for Jane’s book.

Joel - An Unexpected Hero is the tale of a brother and sister. Rebecca loves her younger brother Joel, but sometimes she finds it hard to look after him – Joel has Down’s Syndrome.

One day, when Rebecca and Joel discover a ring of toadstools used by elves, they find themselves transported into a magical world in which Joel is the hero. Soon Rebecca discovers that her brother possesses very special qualities that she hadn’t noticed before...



Published by Onwards and Upwards, available from Amazon  
ISBN 978-1907509742

## Inclusive Films



'A Real Home A Real Life' is a film about people getting closer to the lives they want.

This is a UK film showing eight people with learning disabilities and the different ways they have moved into a home of their own, showing the different support they receive and how they are getting closer to the lives they want to live.

This and other films are available free of charge on DVD or can be viewed on the website.

0121 455 0485 [www.inclusivefilms.org](http://www.inclusivefilms.org)

## My Future Choices

My Future Choices is a free magazine for disabled young people, their families and people who support them.

It is produced by Transition Information Network (TIN), an organisation working to improve the experience of disabled young people's transition to adulthood. Their aim is to provide information about the transition process that is useful for all involved.

Visit the website for more information or to read the latest issue of the magazine.

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



## Safety Harness



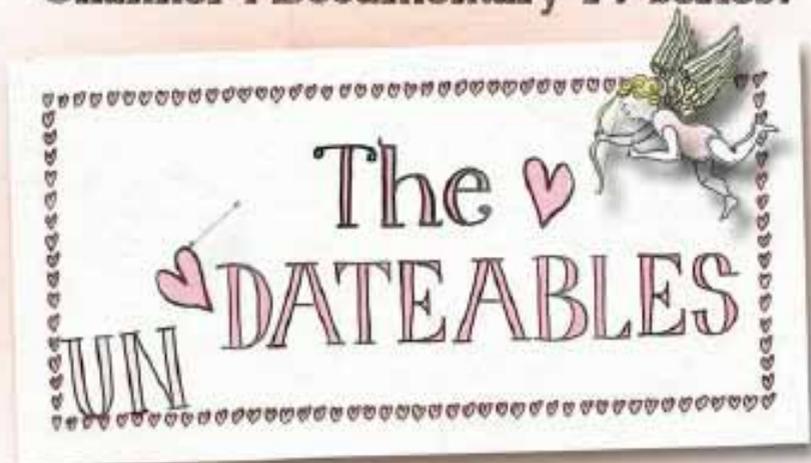
Many of our children are extremely good at escaping their car seats or running off when out and about. They can undo regular buckles and clasps and hypomobility allows them to wriggle out of almost anything!

Crelling Harnesses provide a range of safety belts and harnesses for use in the car, out walking or on a plane. The restraints come in all sizes up to adults.

01253 852298 [info@crelling.com](mailto:info@crelling.com)  
[www.crelling.com](http://www.crelling.com)

# Are you looking for love?

Are you interested in taking part in a  
**Channel 4 Documentary TV Series?**



**A Documentary series  
about love and disability**

betty is making a **fourth** series of the romantic and insightful  
documentary series **♥The UN DATEABLES♥**  
for Channel 4

**We will be following disabled people and those with a variety  
of conditions through the highs and lows of finding love.**

**If you are single and looking for love please get in touch on**

**0207 290 0223** or email

**[undateables@betty.co.uk](mailto:undateables@betty.co.uk)**

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



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

00 3531 426 6500  
[www.downsyndrome.ie](http://www.downsyndrome.ie)



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

0300 330 0750  
[www.dseinternational.org](http://www.dseinternational.org)



Down'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](http://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](http://www.bhf.org.uk)



(formerly GUCH) The Somerville Foundation  
Saracen's House, 25 St Margaret's Green  
Ipswich IP4 2BN

0800 854 759  
[www.thesf.org.uk](http://www.thesf.org.uk)



Children's Heart Federation  
Level One, 2-4 Great Eastern Street  
London EC2A 3NW

0808 808 5000  
[www.chfed.org.uk](http://www.chfed.org.uk)



PHA UK  
Unit 2, Concept Court  
Manvers, Rotherham S63 5BD

01709 761450  
[www.phassociation.uk.com](http://www.phassociation.uk.com)



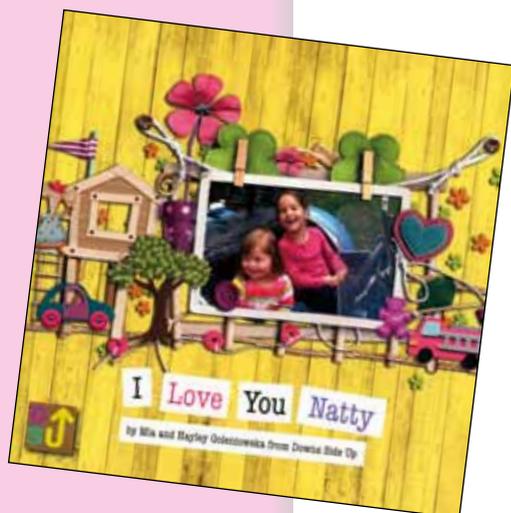
down's heart group

charity 1011413

Tel:  
Email:  
Write:

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

## I Love You Natty



Written by big sister Mia with help from her mum, well known writer Hayley Goleniowska, 'I Love You Natty' is a wonderful uplifting introduction to Down's Syndrome from a sibling's perspective.

With simple text and colourful graphics incorporating some beautiful photographs, it talks about Natty having a heart problem and needing to stay in hospital for a while.

The book touches on the emotions of Mum and Dad and mentions some of the extra support Natty needs. But the overall message throughout is that having a little sister is fun, that the girls share wonderful adventures together and love each other unconditionally and that for Mia, that extra chromosome makes absolutely no difference!

The book is available from Amazon at £5.99 plus postage or can be ordered into any Waterstones store without the postage cost. ISBN 978-0-9929251-0-9

And you can follow the family's journey on their award winning blog

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