



**dhg**

down's heart group

# Newsletter Autumn 2013

Issue 48



***INSIDE***

***Fundraising  
Member Stories  
Useful Information***

***and more...***

## Chair's Report

Welcome to the Autumn newsletter!

On the back cover you will find details of our Down's Heart Group Christmas card. As we do not ask for a membership fee we rely heavily on fundraising to run the charity, so we hope these will appeal and you will support us by buying some.

As many of you know, my son, Richard has significant medical issues. We are off to Tunisia for a holiday at the beginning of October and having previously booked online, we have arranged this for the first time through a travel agent. We were very pleased with the level of service and we now have reserved seats and extra hand luggage to accommodate Richard's CPAP machine and his ileostomy supplies - normally we survive with just a bag for hubby and myself as hand luggage!

We booked through Thomas Cook so would award them a 10 for service. We arranged travel insurance with All Clear who are extremely good with medical issues, but also try Just Travel Insurance (see page 17) who can provide quotes from multiple companies for comparison of cost and cover.

I hope you all look forward to a happy Christmas and that we don't have too cold a winter.

*Chris Stringfellow*

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## Keeping In Touch



*Over the past few months, Down's Heart Group has been updating to a brand new database, which is no mean feat when you consider how many members we have and how many youngsters with such an array of heart problems!*

It has been the ideal opportunity to make sure we have members current contact details as well as obtaining up to date information on our members with Down's Syndrome. Many of you will already have had email requests for updates and we appreciate all the replies we have had so far.

For many members through, we don't have an email address or it's not current, which means we cannot email news, invitations and events out as they occur. And if you move house and forget to tell us, email is often an easier way of getting back in touch!

*So if you have an email address can you please make sure that we have it!*

*Email: [newsletter@dhg.org.uk](mailto:newsletter@dhg.org.uk)*

At the same would you consider getting the newsletter via email? Not only is there the cost of printing, but over the years postal costs have rocketed and we are currently posting out over 800 newsletters each issue. If you prefer a paper version that's fine (as long as we have your address of course), but if you are happy to receive an email notification and access the latest newsletter online at your convenience, thus helping us keep costs down, **please tell us.**

Whilst you are checking we have your up to date contact details, please take a couple of moments to update us on your family. We never give out any personal information but in order to secure grants and funding we often have to provide statistics, so the more we know about your youngster – their heart problems, medication, surgery, other problems, as well as your geographical area, the more proof we have of what we do and how many people we can potentially support.

We also always need articles and stories for the newsletter so please consider writing your story, or telling us about fund raising and general achievements and milestones.



## Kimberley's Story

Kimberley was diagnosed with complete AVSD at my 16 weeks ultrasound scan. She has no other medical problems.

She was born in February 2012, a healthy 8lb 8oz, but her early weeks were troubled with feeding difficulties. She failed to put on any weight and had to go on high calorie formula. Around three months old, still not gaining weight, she had a NG tube put in, which helped her get the calories she needed.

### *Troubled with feeding difficulties*

At nearly four months old Kimberley went to Evelina Children's hospital for her AVSD repair. Although the surgeon and nurses were very good and reassured us at every stage, it was a particularly anxious time, especially when the operation was in doubt as Kimberley was unwell the night before and running a temperature. But in the end it went ahead as planned.



*Kimberley in hospital*

We transferred to a local hospital after several days, to get help with feeding. Speech and language therapy helped Kimberley find the best teats and bottles and she started to get stronger. The NG tube stayed in for another seven weeks, until Kimberley figured out how to remove it herself!

*She is a lively, happy girl who is eating everything you can imagine!*

Since then, Kimberley has been drinking very well and a year on from successful surgery, she is a lively, happy girl who is eating everything you can imagine!

*Clare and Nick Vine*



*On her first birthday*

## Lily's Update

*Issue 46 featured Lily Humphrey with her story of several surgeries including a mechanical valve replacement. She was due to have a further mechanical valve replacement within the year, but Lily just didn't wait that long!*

In January 2013 Lily's mechanical valve was working OK, but her left ventricular outflow tract obstruction (LVOTO) had got significantly worse. Lily was permanently ill, had regular blue spells, Influenza A and MRSA and was retaining fluid. Before surgery, Lily had to be clear of MRSA. We spent a fortnight washing with special soap, I bleached every bit of the house and washed towels and bedding daily. Finally, Lily had 3 clear swabs and surgery could go ahead.

*Lily had to be clear of MRSA*

On World Down Syndrome Day Lily went for surgery at 2pm and was finally back on PICU at 9pm. The surgeon was pleased with how things went and said Lily would now have lots more energy. He wished me luck with that!



*Cheeky Lily!*

The next day, Lily had a portacath fitted to enable IV access as frequent blood tests have taken their toll on her veins and getting blood has been very difficult. Then Lily had a pneumothorax, so she had another chest drain inserted and was re-intubated for 2 days. She was on PICU for a week and the ward for 2 days, but this wasn't the end of the story! - A week later, Lily was very poorly.

*Now Lily has lots more energy and no blue spells!*

She was lethargic with a temperature and had a couple of blue spells. Our local Assessment Unit sent us home twice as Lily brightened whilst there! She was admitted on the third visit as her wound was also swollen and red and her portacath site had been bleeding back too. She was started on IV antibiotics and transferred to Glenfield Hospital in Leicester. She was treated for cellulitis with high dose antibiotics for another week and then Lily was showing signs of the extra energy I'd been promised!

Now Lily has lots more energy and no blue spells. The portacath has improved her quality of life enormously. Blood tests are now done at home or nursery - it no longer takes five adults to restrain her! Lily is just 4 and had her first trial day at school. Now that she has had her operation she is more than ready to put her new teachers through their paces!

*Jilly Humphrey*

## Charlotte Anne's Story



*Charlotte 5 days after surgery*

After trying for a baby for seven years and on what we had decided was our last shot at IVF we hit the jackpot!

At our 13 week scan the nuchal fold was measuring high so we decided on an amnio. I felt so guilty having the test but knew I needed to be prepared, or spend my pregnancy worrying and risking our health. At 17 weeks we had the call to confirm our baby had Down's Syndrome.

There were hysterical tears for the first half hour but nothing changed for us and we still loved our baby as much as we did before diagnosis.

We knew nothing about Down's Syndrome but had just been on a cruise where several passengers were adults with Down's, so we had just experienced how OK and "normal" life could be.

We were given options, discussed termination, with no pressure whatsoever and when we said termination wasn't an option the consultant was great. We immediately saw a paediatrician who explained the health risks and gave us information booklets from Down's Syndrome Scotland. It was probably a bit of information overload that day!

*We had just experienced how OK and "normal" life could be*

After what seemed like an eternity heart and bowel problems were ruled out at the 20 week scan. Finally I could start getting excited about things again. We got in touch with Down Syndrome Scotland and had a visit from the family support worker. All was good. Oh don't get me wrong - we still worried about stuff! At just under 40 weeks I was induced and on 29th March 2013, Charlotte Anne arrived weighing 8lb 7oz and breastfed almost immediately. What did we have to worry about, she was doing great!

We staying up all night watching her, texting, phoning and Facebooking everyone we knew. We lived that first day in sheer unadulterated pride and joy.

Charlotte had, we were told, a routine scan and ECG and as I sat in blissful joy staring at Charlotte, thinking how well she was doing, the paediatrician came in and very bluntly told me that Charlotte was in heart failure. She had two holes, two leaking valves and would probably need surgery within 3 weeks!

*The paediatrician very bluntly told me that Charlotte was in heart failure and would probably need surgery within 3 weeks!*

After a teary weekend we arrived at Yorkhill Hospital where Charlotte was checked over by consultants who confirmed she had an AVSD and VSD and would need surgery but certainly not in 3 weeks - we were told to take her home. We had no idea about the condition and some explanation at diagnosis would have been helpful! We tried to enjoy life but any slight failing in her health terrified me.

At 6 weeks Charlotte was struggling to feed. She just ran out of puff and physically couldn't suck anymore so had to be fitted with an NG tube. Another traumatic experience as we had to learn how to manage the tube and the reflux that came along with it! In June we got a call saying there was a cancellation and could we bring Charlotte in that night for pre-op checks. I felt initial panic but also a strange sense of relief that she was finally getting fixed.

The morning of the surgery was terrible. The surgeon spoke to us but all I could focus on was the size of his hands compared to my tiny girl. Thankfully Colin was there to talk through the procedure, risks, time frames, possible outcomes and to sign the consent form. The walk to theatre was one of the most awful experiences of our lives.

*Some explanation at diagnosis would have been helpful!*

Much of that day was spent in a daze, sniffing the night before's sleep suit. At 3.30pm we went to ICU. Everything had gone well. They had completed a full AVSD and left cleft valve repair.

Seeing our wee tottie lying motionless in that bed with tubes and wires was terrifying. She did remarkably well and was moved to HDU on day 2, the ward on day 3 and was off oxygen by day 5. For the first time Charlotte gave us a huge cheesy smile surely telling us how good she was now feeling. By day 6 we were discharged.

Charlotte had a couple of short stays in hospital for a nasty chest infection but in terms of her heart repair she is doing great. Feeding was still an issue but before 6 months we got rid of the NG tube and haven't looked back since.



*Charlotte a year after surgery*

Charlotte continues to flourish in every way and brings such love, pride, light and joy to our lives every day.

*Julie Telford*

## Introducing Heidi

*Thank you Heidi for sending in this lovely piece all about your life.*

### Who am I?

I am Heidi and I just left school. I am a Christian, I go to church every Sunday.

I have 2 brothers and 1 sister and 1 nephew. My brothers are called Tim who studies natural sciences at Jesus College in Cambridge. The other brother is called Dan and he has a very tough job of being a dad. My sister is called Suzie she just left for Ghana on the 12th July for 2 weeks working in an orphanage. My nephew called Josh will be 3 next January.

I also have very old parents. My mum called Liz who is 46 and my Dad called Steve who is 44.

I just recently turned 18 and I had a surprise birthday party at the Alan Higgs centre and it was definitely worth going to.

I had a prom on the 21st June at the Hilton hotel and it was awesome we had a 3 course meal Starter was Leek and potato soup and for the main course we had chicken in white wine source and for desert we had strawberries squashed to a pulp. It was delicious.



*Heidi ready for the prom*

### My Testimony

When I was a baby I had Leukaemia which is cancer for the blood and god healed me without any treatment. Then I got dedicated to the lord. Then I started going to church and I enjoyed going to church and seeing my friends. Then I found out about this youth group called 11up and I started going to 11up. Then when I was about 13 I got baptised and now I am a Christian.

### My 18th birthday Party

On Saturday 29th June 2013 I had my 18th birthday party we were going to go to Nando's and but it was closed so we went to Frankie and Benny's and it was delicious. Afterwards we went to see Despicable Me 2 it was hilarious and sometimes a bit emotional.

However when I got back my mum said that my friend Louise was coming round to pick me up for a surprise at 5:00pm and I kept on asking where we were going but she said you will find out when you get there. When I got to the Alan Higgs centre everything became clear. I ran in to see what all the commotion was about. There were banners everywhere they blew their hooters and I was gobsmacked I literally was quiet for a few seconds. We were going to have karaoke but the karaoke didn't work but the microphones did but that didn't stop me I sang along to the music that was playing and the music was inspired from my phone. It was awesome.

### My GCSES

At my school which I just left for good I had to do my GCSES which were French, RE and my favourite subject English. I found them quite easy but I found French the easiest because I was predicted the highest grade in foundation I was predicted a C in English I'm predicted a D and in RE I'm predicted a C.

### My BTECS

I also did some BTECS which were Science which I got a pass in. Home cooking skills another pass and wider key skills which was also a pass.

### My hairdressing course

I have just finished my hairdressing Diploma at CWT and now in September I start at Heart of England Training which is in town. I will be doing Introduction to the hair and beauty sector NVQ level 1.



*Practising her hairdressing*

### My Future

In the future I would like to be a successful full time hairdresser owning my own salon called Heidi's fabulous hairstyles. Also I would like to be a part time recording artist performing sell out tours. I would like to be married to a famous singer. Maybe even do a concert in Belfast. I would like to be a Christian part time singer.

*Heidi gained C in French, D in R.E. and E in English. Well Done!*

Do you do a sport or activity that helps to keep you fit?



Will you tell us about it?



Please send us some photos so we can put them in the newsletter.



Alissa is 21.



She loves skiing and has become very good at it.



Last year she helped the beginners on a trip to the French Alps.



Emily is 23.

She goes horse riding.



She won 3 medals, gold, silver and bronze at the Special Olympics this year.



Emily also competes in local dressage competitions and wins lots of rosettes.



Alissa and Emily both had heart operations when they were babies.



Their families didn't think they would grow up to be so active and healthy!



## Melissa's Half Marathon



Parent member, Melissa Harrison and her good friend, Becki Breen, braved hideous weather to take part in the Reading Half Marathon on March 17th. Despite getting extremely wet they both finished in a time of 2 hours 50 minutes.

Henry, Melissa's baby boy was there to cheer them on. Team "Henry" raised over £300 in individual sponsorship for DHG.

### *Plus additional corporate funding*

Their total was then increased by a donation of £100 from Zurich Insurance whom Melissa's brother-in-law, Nick, works for them. Like many companies they support causes that employees have links with and made the donation after Nick filled in a form telling them of his connection to DHG! Thanks Nick!

### *Does your employer support causes you nominate?*

Many firms have charity budgets to support causes close to the hearts of their employees, often making donations to support particular fundraising efforts of their staff and families. Others have separate grant giving trusts that may make sizeable donations to a charity if an application is supported by an employee.

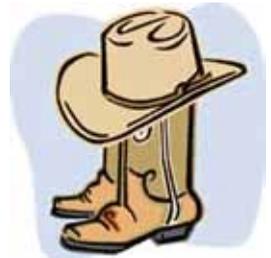
One of these is Autoglass. If you are a DHG member who works for them would you be willing to help us by supporting a grant application?



Do you know if your employer has one of these schemes? If they do, would you consider supporting DHG in approaching them for funding?

## Wing Barn Dance

Leighton Buzzard U3A Choir members, along with their small folk band, held a barn dance on 17th May at Wing Village Hall and chose to donate the money raised to DHG as two of those involved have links with the charity.



A great night was had by all who attended.

## London Marathon Update

*We would like to say a big THANK YOU to the six brilliant people who ran the London Marathon for us on April 21st, raising almost £8000 (with some still to come in).*



*Fi Barker - her first marathon*

Fiona Barker ran a time of 5:39:07

Phillip Box ran a time of 3:28:24

George Garrett ran a time of 4:20:07

Gary Ryan ran a time of 4:46:56

Kelly Stevens ran a time of 4:50:09

The sixth runner was parent member Philip Longster who was running his third marathon in 3 weeks!

He said *"I won't deny that it was tough but I am delighted that I managed to achieve something that is generally regarded by running experts as 'not recommended.'* "

Phil ran 5:10:58 in the Sussex Marathon on April 7th, 4:33:45 in the Brighton Marathon on April 14th and saved the best till last managing 4:42:08 in London. All his effort raised the massive total of £2459.



*The two Phil's - Phil Longster on the right looking remarkably fresh after his 3rd run.*



*Philip Box and George Garrett*

Phil probably speaks for all the runners when he says *"I wholeheartedly thank you for very kindly sponsoring and supporting me and the Down's Heart Group."*

## Fluffy Pink Pig Racing

Layla Batchelor organised a fundraiser for Down's Heart Group which took place on 23rd August and raised £747.45.

It was a family fun evening with the main event being fluffy pink pig racing, which was really good fun apparently. They also had a raffle, a buffet and disco and as it took place at a football centre, there was a pitch for the children to play on and even the rain didn't stop them. Layla said *"Everyone seemed to have a good time and we also made lots of money for the charity which was brilliant."*

## London To Paris Bike Ride



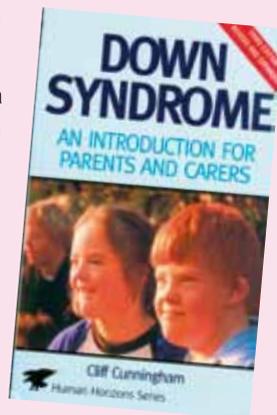
At the beginning of May, Rachel Welch successfully completed the London to Paris Bike Ride raising the fantastic total of £1768.75 for DHG. Well Done!

Huge thanks, go to Rachel who cycled in honour of her brother, Steve, who sadly died in October 2010.

## Cliff Cunningham

We were all saddened to hear of the death on May 17th of Cliff Cunningham, renowned writer and researcher on Down's Syndrome. No library is complete without at least one book with Cliff Cunningham's name on it and possibly his best know 'Down syndrome: An Introduction for Parents and Carers' is now in its third edition.

Professor Cunningham will be fondly remembered by many families and professionals for his contribution to improving the lives of those with Down's Syndrome.



## Merino Blanket



Merino wool blankets are recommended for anyone who really feels the cold and usually cost around £400. A DHG member has a brand new pure merino wool double overblanket and pillow case for sale for £200. Call Diane on

01803 873114



*Book Cover*

There are many books about families with learning disabilities but this one, subtitled 'Down's Syndrome: My Photographs, Their Stories', is unique in that it places Down's Syndrome out of the medical books and into an art book. It has been developed by documentary photographer Graham Miller and Down's Syndrome Scotland.

### *Heartbreaking and heartwarming*

Miller photographs families as he asks them to reflect on their life experiences. The result is both heartbreaking and heartwarming. These photographs are complemented with quotes from the interviews with families.

The whole book is in monochrome which really helps focus the eye on the many subtle details in the photographs. Words are used sparingly, just enough to set the scene and let the reader focus on the stories behind the pictures which are sometimes beautiful and always thought provoking.

This is a documentary of what it's like to share your life with someone with Down's Syndrome, it's not all sunshine and joy, there are words and pictures that touch on the often painful experiences of families. You feel the anxiety, the concern, the sense of loss from both the writing and the body language in the photos and yet overall there is a sense of warmth, acceptance and love that makes you realise that it's going to be okay.

All profits from the first 500 copies will go to Down's Syndrome Scotland and can be purchased for £29.95 from

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



*Eve - one of the photos from the book*

Photos on this page are  
© Graham Miller

## In memory of Sam



*Alice after a charity head shave*

I'm Alice Croot and I've signed up to run the New Forest Marathon on 22nd September for DHG. I have set up a Virgin Money Giving page

[uk.virginmoneygiving.com/AliceCroot](http://uk.virginmoneygiving.com/AliceCroot)

My parents, Becky and Tim were members of DHG when my brother Samuel was born but lost contact when we went to live in Germany, although they kept in touch with families met through DHG for many years.

I was 16 months old when Samuel was born and nearly 2 when he died. He had Down's Syndrome and problems with his heart and I know that the help, advice and support that this group gave my parents had value which cannot be overestimated.

Running a marathon for DHG is something I have thought about for the last two years, and I hope that you will sponsor me and help me genuinely help people in a way that large and general charities cannot.

*It's this level of personal interest and caring that makes DHG special.*

When I contacted DHG I received an email from Penny Green, who said she remembers my parents and Sam and thanked me for running. It's this level of personal interest and caring that makes DHG special. It means so much to people at a time that can be distressing and confusing, and a time when the care and support of people who have their years of experience are exactly what is needed.

I am running in the memory of my brother, but also on behalf of anyone with Down's Syndrome. I do care work with quite a few adults and to see them healthy and enjoying life is extremely gratifying, and that DHG plays a part in helping these people, is wonderful. Although it has been many years since we were involved in the group it has always been a part of our lives.

*Alice Croot*

## Travel Insurance for medical conditions

*Do you have trouble getting travel insurance for your family member with the heart condition?*



Down's Heart Group has just signed up with Just Travel who specialise in travel insurance for people with medical conditions.

Go online or give them a call, provide the required information and you will get quotes from several companies making it easy to compare price and cover. And if you take out a policy they will make a donation to DHG as well!

[www.justtravelcover.com/index.php?xyzid=76](http://www.justtravelcover.com/index.php?xyzid=76)

or call 0800 231 5532 and mention DHG

## Evelina and ECHO

Evelina London Children's Hospital which provides services from antenatal diagnosis through childhood, into adolescence and on into adult life has a new brand and name. The logo was created with help from young patients who took part in a finger painting session, with their fingerprints being used on the new logo.



Coinciding with this, ECHO, the Evelina Children's Heart Organisation is celebrating it's 30th anniversary and as part of their celebrations on Saturday 28th September they have organised a fund raising run in the grounds of Polesden Lacey, Surrey, providing a unique opportunity to run (and/or walk) through the beautiful grounds of this National Trust property on the edge of the North Downs.



There will be a 10K Challenge with additional 6k route and 2k kids' circuit and ECHO Patron Ulrika Jonsson will be starting the main race whilst Phil Gallagher from CBeebies "Mr Maker" will be doing the race and meeting the children afterwards!

Participants can choose to raise funds for Down's Heart Group. To register, please visit

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

or email [jowilson@echo-evelina.org.uk](mailto:jowilson@echo-evelina.org.uk)

## Recycle4charity



Down's Heart group have signed up for a new way to recycle mobile phones, ink cartridges, toner and laser cartridges whilst raising money at the same time.

Recycle 4 Charity provides a free, easy to use, custom branded, recycling programme. Just register, select DHG as your charity and you will receive freepost bags to send your items in. Larger items can be collected free of charge.

[www.recycle4charity.co.uk](http://www.recycle4charity.co.uk)

## Ethical Switching

See if there's a better deal on your gas and electricity? The Ethical Switching website allows you to independently and impartially compare your current gas and electricity supplier tariffs with the latest ones available and if there is a cheaper alternative, switch to that new supplier.



*Use our unique link to check and if you switch supplier, they will donate £12 to Down's Heart Group (£24 for dual) at no cost to you!*

Down's Heart Group will also be their charity of the month in March 2014 so we will receive donations from anyone who does not select a specific charity.

[www.ethical-switching.co.uk/charity/1011413](http://www.ethical-switching.co.uk/charity/1011413)

## World Down Syndrome Day Ball



Milton Keynes parent support group, Just The Way You Are MK will be celebrating World Down Syndrome Day 2014 with a "*Changing Perspectives*" ball at the Jurys Inn, Milton Keynes on 21st March at 7pm and invite you to join them.

The night will include a welcome drink, disco, live band, auction and raffle with proceeds being divided between their group, DSA and DHG. Tickets are £35 each and can be reserved with a £15 deposit by contacting:

Chloe on 07790134722 or Vicki on 07427149859

or email: [justthewayyouaremk@gmail.com](mailto:justthewayyouaremk@gmail.com)

## Give as you Live- and win what you want



*Hopefully by now you are aware that every time you shop online you could be supporting Down's Heart Group without it costing you anything.*

As Christmas approaches and online spending increases, there is potential for charities to benefit if buyers sign up to 'Give as you Live'. But did you know that currently every week whilst you're looking you could be in with a chance to **win** whatever item you want plus a donation equal to the cost for us?

Visit the Give as you Live website, make sure you're registered and supporting DHG, then find a product you'd like to win and hit the 'enter now' button. If you're chosen as that week's lucky winner, you'll not only receive your prize, but we'll receive a cash donation to the value of your item!

[www.giveasyoulive.com/wantit-winit](http://www.giveasyoulive.com/wantit-winit)

## Unique gifts with a personal touch!

Use your child's artwork to produce cards, wrapping paper, coasters, mugs and gifts for Christmas?

We'll send you an artwork sheet (which explains everything), send it back to us and you will be given a unique access code to logon to the My Child's Art website and order any of the products you like - and DHG gets commission on anything you order!



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

## DHG Merchandise

*Don't forget when you're looking for the perfect Christmas gift, you can show your support for Down's Heart Group at the same time by choosing from our range!*

We can supply polo shirts, sweatshirts and fleeces for all ages and ceramic mugs (all of which can be personalised), but if there's something else you want, please ask and we'll see if we can get it for you. All cloth items are machine embroidered and mugs are in dishwasher safe print.

Check out previous newsletters for details and an order form, or contact us for one.

## Relaxed Panto



The Hexagon in Reading will be hosting a special performance of their Christmas Pantomime 'Jack and the Beanstalk'. It will be a 'Relaxed Performance', specifically aimed at children and adults with special needs.

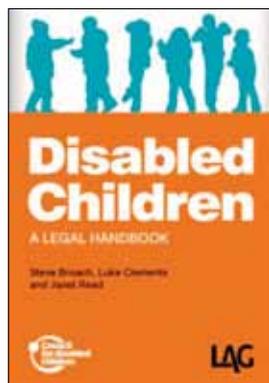
This performance will take place on Friday 3rd January 2014 at 10.30am and tickets are £10 plus booking fee. Contact the theatre on

0118 937201

## Disabled Children: A Legal Handbook

This accessible guide looks at the legal rights of disabled children and their families in England and Wales, explaining the difference between what public bodies must do to support disabled children and that which they may choose to do. The aim is to empower families by providing them with a greater understanding of their rights and entitlements.

Copies can be ordered from the Legal Action Group website which also has a link to download from the Council for Disabled Children's website.



[www.lag.org.uk/bookshop](http://www.lag.org.uk/bookshop)

## The Newman Trust



The Newman Trust provides holidays for disabled children for those who due to care needs or financial hardship, would not get one otherwise. Open to children aged 5-16, they provide a range of fun activities in a safe and supported environment, using a care ratio of one to one, which take place in various locations around the UK.

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

## What's On Netbuddy?



Learning disability charity Netbuddy has launched an online “what’s on” listing service for parents and carers with children, family or friends with special needs.

The listing provides details of inclusive club nights, autism-friendly film screenings, live music gigs for and by people with learning disabilities, special needs yoga groups and inclusive festivals. It also covers inclusive dance and drama, exhibitions by disabled artists, relaxed theatre performances and accessible sports.

[www.netbuddy.org.uk/events](http://www.netbuddy.org.uk/events)

## Free Advice

An updated version of Contact a Family’s guide “*Holidays, Play and Leisure*” is now available. Full of useful information to help you plan to keep the kids occupied, it covers suitable play and leisure facilities, help to pay for leisure, your child’s rights and short breaks for carers.

**contact a family**  
for families with disabled children

It is just one of a range of guides for parents and carers that can be downloaded from their website or requested by calling the helpline free Monday-Friday 9.30-5.00pm on

0808 808 3555 [www.cafamily.org.uk](http://www.cafamily.org.uk)

## Glasses E-petition

Children with Down’s Syndrome often find it difficult to get correctly fitting glasses unless they have special frames, but there is a discrepancy in the UK system for supplying glasses for children with ‘special facial characteristics’ which means that some people get help with getting these frames for their children and others don’t.



Simon Berry is an optometrist who wants to highlight this inequality and ask the government to make a equal service for all. His explanation of the current situation is on the ‘news’ page of his website along with a link to the e-petition he has setup to ask for changes. Please consider adding your vote.

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

## Charlotte's Tandems



Charlotte's Tandems is an organisation which loans out tandems to people with disabilities or special needs. Volunteers around the country retain tandems and trikes for local collection.

Often, people with extra needs find riding an ordinary bike very difficult – forward planning, balance, co-ordination and effort all need to come together at once. On a tandem the balance, direction and speed can be determined by the other rider, making bike riding possible.

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

## Support 4 Independent Living

Who will look after our young people, when we are no longer able to? Will their lives and livelihoods always be subjected to changes in Government policy & bureaucratic systems within Local Authorities?

Support 4 Independent Living has been developed by a parent of a young man with Down's Syndrome, who aspires to live as independently as possible, within his own home and community. It enables local young adults with learning difficulties to live a 'Life more Ordinary', as independently as possible, in a 'house share', as their own home, with personalised support. Here they can develop their independent living skills with the appropriate support, based on their individual needs, interests and aspirations.

The project is based in Hastings but the website offers a wealth of insight and information, wherever you wish to live.

[www.support4independentliving.org](http://www.support4independentliving.org)

## Personal Health Budgets

On 1st August 2013, the Direct Payment in Healthcare regulations came into force across England, which means that the NHS can now lawfully offer direct payments for healthcare. There is information on this and more detail on personal health budgets on the NHS England website.



[www.personalhealthbudgets.england.nhs.uk](http://www.personalhealthbudgets.england.nhs.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)



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

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



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

0808 808 5000  
[www.childrens-heart-fed.org.uk](http://www.childrens-heart-fed.org.uk)



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

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



dhg

down's heart group

Tel:  
Email:  
Write:

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

## Christmas Cards

Pack of 10 - **£3**



Show your support for Down's Heart Group this Christmas by sending these jolly cards which feature the charity logo in colour on the back.

Cards are 100mm x 152mm (4" x 6"), printed on good quality card and the wording inside reads *"Season's Greetings"*

*Postage and packing for one pack will be about £1.30  
(reducing per pack for a larger order)*

Please call or email by **30th September** to tell us how many packs you may order (no commitment) so we can gauge how many to order and prevent having a lot of stock leftover.