dhg
down's heart group

Newsletter Spring 2018

Issue 64

DHG is changing, please read the IMPORTANT UPDATE inside

NOTICE of EXTRAORDINARY GENERAL MEETING

Saturday 12th May 2018
11am - 2.30pm

at Holiday Inn Express Birmingham
Birchley Island, Oldbury, West Midlands B69 2BD

(Please notify National Office by May 3rd if you will attending as we need to provide numbers to the hotel for refreshments)

Proxy voting forms can be obtained from National Office for anyone unable to attend but wishing to vote or give their proxy to someone who is attending. To be valid, forms must be returned to National Office to arrive no later than Thursday May 10th

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The Future of Down's Heart Group

After a great deal of consideration looking at all aspects of the work of Down's Heart Group, taking into account the level of usage of services and the related costs, the Trustee Board has made the unanimous decision to refocus future service provision.

We would like to reassure everyone that the DHG is not closing, just moving forward in a new way which we feel reflects the changes in families needs, largely due to the increased usage of the Internet and social media. In future we will not be providing a helpline manned by paid staff, nor sending out quarterly printed newsletters and as a result DHG will no longer require paid employees to service these functions, so both staff members are being made redundant.

In the future we are looking to communicate electronically with members and to provide support by the Trustees on a voluntary basis and therefore be able to direct a much larger percentage of our income to directly supporting families. We are also using this opportunity to review the membership data we currently hold to ensure that we are compliant with the new General Data Protection Regulation (GDPR) which comes into force on May 25th.

There will be an Extraordinary General Meeting held on May 12th in Birmingham, (details on page 2 opposite) when we propose making changes to The Constitution that will remove the election of Trustees from being decided by the membership and instead making it an election from within the existing Trustees. The reason this is being put forward is due to the fact that it has become increasingly difficult over many years to have enough attendees at the AGM to be quorate and therefore able to conduct the business of the meeting.

Composition of the Trustee Board will remain the same and the only other changes to The Constitution will be to reflect the change to Board elections. If you would like a detailed copy of the proposal, please contact National Office.

There is more detailed **IMPORTANT** information about the changes and **How to Renew your Membership** on pages 6 and 7, but for the foreseeable future, our contact details will not change, so please get in touch if you have any questions.

We know that you will wish to join us in thanking Penny and Sarah for all their hard work in the past and wishing them all the best for the future and we hope that you will all renew your membership and be part of DHG's future too.

DHG Trustees

30 years – where have they gone?

Our son David was born 30 years ago but where has that time gone? It only seems like yesterday that the midwife was handing over a 4lb 15oz bundle of joy to us – we still have the bundle of joy living with us but he is somewhat bigger now. David was originally diagnosed with a heart defect when he went for his six week check-up and the doctor found a murmur, so referred us to the paediatrician. Then we were referred to Myrtle Street Hospital in Liverpool where he was seen by the cardiologist who identified that Davis had a partial AVSD, but he felt that David should be OK to wait until he was bigger and stronger before a repair could be made.

It was at this time we were searching for information regarding children with heart defects, but the only support group available at the time were the Association of Children with Heart Disorders (TACHD) who we able to talk to at the time but they had no experience of the Down's Syndrome aspect. There was little or no information available from the DSA but we heard on the grapevine that Linda Walsh was trying to set up a support group for parents such as ourselves to provide as much information and shared experience as possible to enable parents to make themselves aware of their situation and that was the beginnings of the Down's Heart Group.

David progressed to Alder Hey Children's Hospital where regular bouts of weighing ECG's and Echocardiograms were carried out and when he was three he was deemed big and strong enough for a repair to be carried out. The operation was successfully carried out by Miss Roxanne Mackay who later emigrated to Canada - their gain was our loss.

After a successful transition from Children's services to Adult services David now visits Liverpool Heart and Chest Hospital on an 18 month basis for a check-up. The cardiologists from Alder Hey hold regular clinics there to provide the necessary support for those children who were born with a congenital heart defects as they approach adulthood. On each of these visits we have been informed that the repair is still good, although there is small amount of leakage, it is nothing to be concerned about and the original repair has not deteriorated.

David has limited mobility due to having reconstructive surgery to correct problems with both knee joints in 1999. He is able to get around the house unaided but requires a wheelchair when we venture out anywhere and he enjoys life to the full - PlayStation, YouTube, WWE wrestling and riding his bike.

Shortly after being referred to Alder Hey, stories were coming out in the press about hospitals in England refusing to operate on children with Down's Syndrome, some saying *"well they have a major heart defect - there's nothing that can be done- it's inoperable"*. This would appear to been the case in several cardiac units at the time - but my, how things have changed! We like to think that the Down's Heart Group and its members played some part in changing these attitudes, so we have the situation whereby many of the operations deemed inoperable at the time are now run of the mill surgeries.

Now 30 years later as our children (we still call them children although many are now fully grown adults) are meeting different challenges, the situation in some ways is not too dissimilar to the situation Linda Walsh found herself back in the 1980's – facing the unknown. We still rely on parents supporting one another by sharing common experiences, but things have changed, we now have our own website with lots of information on it, we have worked to provide information to enable parents and professionals to make informed decisions and we have an important voice within the Health Services.

David with brother Tom and sister Emma

As an organisation we have been able to provide support up to and immediately post surgery, after which many families move away from DHG to face other challenges, which leaves us in the situation where several of our Trustees have served for many years and all their children are adults, but we have failed to attract representation from families with younger children.

The help and support we have been able to provide and receive is immeasurable and to those other parents at the time we thank you for sharing your experiences with us. It's now time for DHG to respond to changes in the way families interact with the charity particularly reflecting the advances in technology and social media, in order that we can continue to use past knowledge to support families in the future.

Mike Halpin
DHG Secretary
Liverpool

Extraordinary General Meeting

At the Extraordinary General Meeting (EGM) to be held on May 12th the Trustees propose amendments to The Constitution that will change the way that Trustees are elected, (see page 2 for details of time and location).

Currently Trustees are elected by the membership at the Annual General Meeting, but The Constitution calls for a minimum of 20 votes for the meeting to be quorate, a requirement which has caused increasing difficulty over the past few years. Despite the introduction of proxy voting, numbers have remained minimal which continues to be a concern every year, so in future the Trustees propose that the election / re-election of Trustees is down to the Trustees in office at the Annual General Meeting. This will of course be open to members to attend should they so wish (with prior notification to ensure the chosen location can accommodate numbers).

The only other proposed changes to The Constitution directly relate to this change in the election of the Trustees and the change in member voting rights.

If you would like a detailed copy of the proposed changes, to raise any query or to attend the EGM, please contact National Office.

Proxy voting forms can be obtained from National Office for anyone unable to attend but wishing to vote or give their proxy to someone who is attending. To be valid, forms must be returned to National Office to arrive no later than Thursday May 10th.

Forms for nomination of Trustees are also available from National Office and once duly completed by the proposer and nominee, must be lodged with National Office at least 48 hours before the EGM.

How DHG Uses Your Data

*There will be clear information about our data usage with the new online membership form **ALL** members need to complete, but here is clarification of how DHG has always dealt with your information.*

- We have never shared your personal data with anyone without your explicit permission
- When writing to ask people to take part in outside research projects, we have always added contact information (ie address labels) in house
- We have never sold mailing list data to any other organisation
- Data is password protected and access limited to personnel with a need to know
- All data is removed from records if you cancel your membership
- We use data to support you (by knowing basic information about your child you have already told us), to put families in contact (with approval of both), to monitor trends in treatments etc. and to contact specific families for research

Future Changes at DHG

*Hopefully by now you will have read the message from the Trustees on page 3 and know that there are changes taking place at DHG that affect **ALL** members. These are listed below, along with details of how they may impact you and any **ACTION** that you may need to take.*

- To ensure we comply with the new General Data Protection Regulation (GDPR) which comes into force on May 25th, you will need to **CONFIRM** your membership of DHG by completing a **NEW** online membership application form which will be available shortly on our website.

- Membership will still be available to individuals who prefer not to use electronic communication (please call to request a printed application form), but in future all DHG updates etc. will be made electronically.

- Both members and non-members will still be able to access support and information by letter or telephone, but this will no longer be staffed, so it may be necessary to leave a message on the answerphone for one of the volunteers to call back.

- Due to the time and cost of compiling, printing and posting the Newsletter, we will no longer be producing a regular Newsletter.

- We will send out an occasional email Newssheet containing items such as changes in benefits, opportunities to participate in research, free or reduced cost events etc. and AGM information. (this will be a membership opt in option to comply with GDPR)

- Items of interest and updates will also be posted on our website and social media pages.

- We are looking at developing a grant funding programme to offer some financial support to families experiencing exceptional difficulties whilst their youngsters are in hospital.

If you would like clarification on how any of this may affect you, please do contact us.

We value your membership and we very much hope that you will confirm your membership under these new legal requirements and continue to be part of the Down's Heart Group for many years to come.

Katy

Katy is twenty one and had a heart transplant just over a year ago.

Katy had slight heart failure as a result of chemotherapy treatment for Acute Myeloid Leukaemia in 1998 when she was only two. This was controlled well with medication until she developed a chest infection in September 2016. This progressed into congestive heart failure with a reduction in her heart's performance.

There were many hospital stays and visits between West Cumberland Hospital in Whitehaven and the Freeman Hospital in Newcastle from September until her blue light transfer on 9th December to Ward 24 at the Freeman.

On 13th December Katy had some tests including a right heart catheter to gauge the condition of her heart. The medical team discussed her that Friday and came to the conclusion she needed a heart transplant so Katy was placed on the active transplant list, classed as urgent. She required *"support"* drugs at this point and we were told that we would have to stay in hospital until a suitable heart was found.

Katy was placed on the active transplant list, classed as urgent

Obviously the prospect of Christmas in hospital didn't go down well with Katy but as it turned out, this was irrelevant. On Christmas Eve she deteriorated and was moved to ICU and put on dialysis and further *"support"* drugs. She was sedated at this point and more or less missed Christmas Day itself. On Boxing Day she opened a couple of presents but wasn't really interested so we decided to totally postpone the rest of the celebrations until we returned home - whenever that was to be!

Katy's organs were starting to fail

Katy was completely bed-bound in ICU for the next two weeks. The *"Mrs Brown's Boys"* DVDs were our lifesavers. They kept her mind off things. On Wednesday 4th January the consultant took my mum and I into a side room to explain that Katy's organs were starting to fail. He asked if her daddy could get there that day and not the Friday as planned. That was a shock for us and an indicator that we didn't have much time left as once the organs have failed, a transplant cannot usually take place.

On the Friday (6th) her daddy and I met with the palliative care team to make plans for the coming days. At 6am the following day, I was sleeping on a camp bed next to Katy when a nurse shook me awake. All I heard was *"her heart"* - assuming we had lost her I jumped up. The nurse said "No, we think we've found her a heart!" I remember running out of ICU down the corridor to the relatives room to give her daddy the good news.

The heart was a match!

The heart was a match! At approximately 11.30am I dressed in theatre greens and went into theatre with Katy as she was very nervous, and I stayed with her until she was asleep. The remainder of the day until she returned from theatre at about 7.30pm passed in a blur.

At about 7pm we heard she would be back from theatre soon and the operation had been successful. We then phoned both grandmas and our sisters and brothers to tell them that Katy had had her transplant and would be back in her room soon.

Since her operation, Katy has gone from strength to strength. She's visited London twice for a wedding, two shows and a Harry Potter themed week. She has had a holiday in Plymouth with family. Then she competed in the transplant games in North Lanarkshire and finished the year by visiting the Edinburgh Christmas markets.

Katy has gone from strength to strength

Katy has returned to the Hensingham Day Centre for four and a half days a week and attends Cardio Rehab Gym on a Friday afternoon. She's back at her dance class with Inspire Dance Group and attends St Bees Church regularly.

Apart from the week before Christmas when Katy developed pneumonia (and had to reside on CCU at West Cumberland Hospital under the care of some amazing staff for a week) she hasn't experienced any health issues and her health has continued to improve.

We are ever grateful and thankful to her donor

We are ever grateful and thankful to her donor and their family AND the fact that they had the conversation about organ donation. Without this gift, Katy quite simply would not be here nor to be able to celebrate Christmas and New Year at home with her family.

Emma-Jane Taylor, Cumbria

Graciella

Proud Dad, Garcia, shares his thoughts from Angola.

I have got a special child with Down's Syndrome. Graciella will be four years old on 30th April. She is my first daughter but now has got younger twin brothers. She plays well with them and is always trying to teach them that she is the oldest!

It was quite complicated to understand

In the beginning it was quite complicated to understand why our daughter had Down's Syndrome and why this had happened to us. Unfortunately, in our country, Angola, we don't have a hospital where it could have been picked up while my wife was pregnant. After Graciella was born the medical team did not even realise that she was a special child. So it took us a long time to get the information we needed to help Graciella and us as new parents.

Today, I can say that we learn with her, Graciella has such skills which people sometimes don't believe, she is very clever and beautiful. She plays, jumps and climbs the same as other children and fights and takes leadership over her brothers. Graciella learns slowly but is very dedicated. She is amazing.

Graciella learns slowly but is very dedicated

Graciella was recently in clinic for her routine check up and thankfully everything is good with her. The only problem we are facing is just social exclusion, people think Down's Syndrome is some kind of witchcraft! We are starting our fight against this out in the streets.

My recommendation is "keep loving you kids and remember, we have a lot to learn with them, too"

Graciella is something else!

Garcia K. Antonio, Angola

Easy Read Page

Bill of Rights

for people with Learning Disabilities

inspired by the 'Can you understand it?' team, Bexley Mencap, Bexley Advocacy for All and ResearchNet

- Respect me and respect each other
- Speak slowly, clearly and politely
- Speak to me in a way I understand
- Please check I have understood what you are saying
- Speak to me first, then my carer
- Find out how I communicate
- Find out if I need a family member or advocate to speak for me
- Help me to make my own choices
- Ask me if I have a black book or hospital passport
- Make signs easy to understand in hospitals

London Marathon

As we go to print, April 22nd is fast approaching, when five amazing DHG supporters will be joining the thousands taking part in the 2018 London Marathon.

Our runners this year are parent Graham Street and two of his work colleagues, Dennis Mobley and James Farthing, all from Nomura, where fundraising activities have included the sale of flapjacks in the office.

Dennis says - *"I was initially invited to run and participate in the charity for DHG by a colleague at work. The charity is of particular interest to me because I had a cousin (Jimmy) with Down syndrome, and my colleague's daughter also has Down Syndrome. Since signing up to run I have learned about the cardiovascular and other complications that are more common in Down Syndrome people. This has motivated me to run for the charity and do my absolute best."*

We are also happy to have the support of Dr David Charnock, an Assistant Professor in learning Disability at Nottingham University whose interest in supporting DHG is on a professional level.

And last but not least, our only lady runner this year is Olivia Dueser who was supposed to be running with her friend Talulla who ran for DHG last year. Sadly Talulla has had to withdraw due to injury, but she has promised to be there cheering Olivia on.

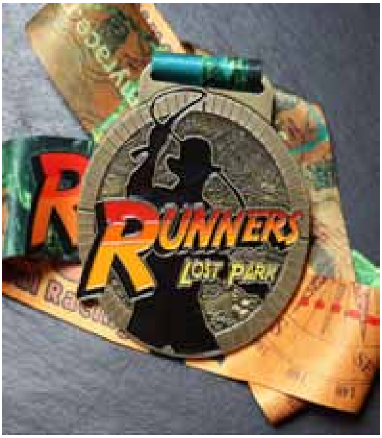
Olivia says -*"I wanted to run for DHG as I am amazed with the incredible work they do, providing the personal and individual support both before birth and thereafter, that families need when they are given the heart-breaking news that not only their baby has Down's Syndrome but also a heart defect. I have seen and heard from Talulla about how much of a vital role DHG has played in helping their family and I couldn't be happier or more proud to run for such a charity."*

We want to thank all our runners for their efforts on behalf of Down's Heart Group and hope they have a wonderful day, taking in the atmosphere and the amazing support provided by the crowds.

If you, or someone you know would like to run the London Marathon on behalf of DHG and raise funds to help support more families, please contact National Office. We do have annual waiting list for places, so it's never too soon to get your name down!

My Race Virtual Racing

If you are not up for a long distance or taking part in an organised event, but you'd like to undertake your own 5km run for DHG, here's your opportunity.



A virtual race can be completed at any location or time, meaning you do not have to physically turn up to a race start line. You could complete your virtual race in your lunch break, before work, after dropping the kids off for school, on a treadmill at the gym or you could walk it at the weekend or with the dog and the kids It doesn't matter where or when you do it!

Enter online - it costs £15 of which £5 goes to DHG, run your race and upload a photo of your achievement, get your race goodie bag with your fabulous bespoke medal.

www.myrace.run/race/runners-lost-park/

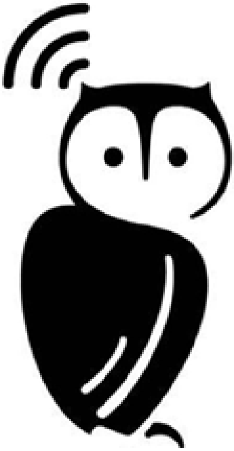
A Close Shave

Baby Ruby Pearson has worked her charms on Tony Rickett, a close friend of her dad Mark since they were around seven years old, growing up in the same small village. Tony decided (or was coerced into) having his hair and beard shaved for DHG.

Before and after the shave

The *"Close Shave"* happened on 27th October at The Hop and Barley pub in Lincoln and raised just over £400 for Down's Heart Group. Thanks go to Tony's friends and family, the pub for hosting the event and their regulars. Tony's transformation was quite amazing and the "after" photo shows Ruby checking out the new face.

Listening Books



Listening Books is a national charity that provides a postal and online audiobook library service to children and adults who struggle to read or hold printed books due to an illness, disability, mental health or learning difficulty.

There are thousands of books to listen to including authors like JK Rowling and Roald Dahl. Titles are available to download and stream through the website or app, or as MP3 CDs sent through the post, with free postage. Members can choose from a range of options to find the service that best suits their needs and membership starts from £20 per year.

www.listening-books.org.uk

info@listening-books.org.uk 020 7407 9417

Angry Birds

The Home Teacher is an American mum who blogs about her life and ideas on teaching at home in a fun way. She has a host of resources to share for free with parents.

The Angry Birds range gives helpful coping strategies for children and parents on emotional and anger management. Consisting of posters and a workbook for children to use with an adult Angry Birds will help children explore, understand and manage their anger.

All are available for free download at

tinyurl.com/angrydhg

Family Factors Research

Family Factors and Quality of Life in Children and Adolescents with Down's Syndrome

My name is Anna Lee. I am a nursing doctoral student at the University of North Carolina at Chapel Hill and I'm working with Dr. Marcia Van Riper, a nursing professor here. You may recognise her name, as Dr Van Riper has been involved with DHG before on a previous study. She is active in research on families of children with Down's Syndrome globally and has a programme of research concerning adaptation and resilience in families.

THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

We are inviting you to take part in a research project that we are conducting with parents of children with Down's Syndrome. The purpose of this study is to learn about how parents view family functioning and quality of life of children with Down's Syndrome.

Who can participate?

If you are a parent of a child with Down's Syndrome aged between four and twenty one and live in the same household as the child, you are invited to participate. Also, you must understand English, be at least 18 years old, have an email account, and have access to the Internet.

What will we ask you to do?

We will ask you to complete online questionnaires. You will be given an individualized electronic link for online survey (Qualtrics), which includes the consent form and all the questionnaires: general family information, family demand, family appraisal, family resources, family coping, and children's quality of life. It will take approximately 30-40 minutes. Once you complete them, the link will become inactive.

This project has been reviewed by the institutional review board for human subjects research at the University of North Carolina at Chapel Hill. If you agree to take part, all information you give will be confidential. No one except the research team will have access to your information.

If you wish to be involved in this research, please email me, Anna Lee, to register at

annalee@email.unc.edu

Many thanks for your kind consideration.

Anna Lee, RN, PhD(c) and Marcia Van Riper, PhD, RN, FAAN
Professor & Chair, Family Health Division
University of North Carolina at Chapel Hill

SEND

The government has announced a two year trial of a single route of redress for children and young people aged up to twenty five with education, health and care plans will begin in England in March. Currently, the first-tier SEND tribunal can only make judgements on the education elements of Education, Health and Care (EHC) plans but from March the tribunal will be able to make non-binding recommendations on the health and social care aspects too.

By April 2018, all local authorities in England were expected to have transferred all children and young people with statements of special educational needs to the new SEND system following a 'transfer review'. Unfortunately, a Freedom of Information request by Special Needs Jungle has shown that many will miss the deadline.

Local authorities should continue to comply with the previous SEN system during the transition period so that children continue to get the support they need. It is hoped that transfers will not be rushed to meet the deadline as each EHC should give bespoke and carefully considered support to each individual.

tinyurl.com/senddhg

Sibs Talk

Sibs was set up in 2001 by the current Chief Executive Monica McCaffrey in response to demand from parents and professionals for information on how to support siblings of disabled children. It is the only UK charity representing the needs of over half a million young siblings and over one and a half million adult siblings.

The charity is running a pilot project called Sibs Talk, which is free for a limited number of primary schools. It is a one-to-one support intervention for school staff to use with siblings in Key Stage 2. Its purpose is to improve siblings' wellbeing and their engagement with learning.

Sibs Talk is an activity booklet where each page is a short session for the sibling to work through with a member of staff. There are ten sessions that can be spread out over a term. If you think your child could benefit from the scheme ask their school to contact Sibs for more information.

www.sibs.org.uk

Carer's Credit

Carer's Credit is a credit that helps with gaps in your National Insurance record, which is what your State Pension is based on. If you care for someone for at least twenty hours per week and are over sixteen years old but below state pension age you could be eligible.

Your income, savings or investments won't affect eligibility for Carer's Credit. Carers who do not qualify for Carer's Allowance may qualify for Carer's Credit.

Department for Work & Pensions

The person you are looking after must get one of the following:

- Disability Living Allowance care component at the middle or highest rate
- Attendance Allowance
- Constant Attendance Allowance
- Personal Independence Payment - daily living component, (standard/enhanced)
- Armed Forces Independence Payment

You do not need to apply for Carer's Credit if you get Carer's Allowance or Child Benefit for a child under the age of twelve as you will automatically get credits. If you are a foster carer you can apply for National Insurance credits instead.

The application form includes a Care Certificate, which you should ask a health or social care professional to sign. The forms are available from the Carer's Allowance Unit.

0345 608 4321 www.gov.uk/carers-credit

Tell Us Once

In the past, a grieving relative may have had to spend hours on the phone repeating the same information to many different organisations. The *"Tell Us Once"* service means that information only needs to be given once as the service will notify most local and central government departments. This includes the Department for Work and Pensions to cancel benefits, the Passport Office and the local council to cancel housing benefit or a blue badge.

Tell Us Once doesn't operate in all areas but the registrar, when registering the death, will give the options available. The service can be accessed by meeting with a local authority bereavement advisor, by phone or online with details given by the registrar.

tinyurl.com/dhgonce

YHA Breaks

The Youth Hostel Association (YHA) believes every young person should have the opportunity to travel to a new place, learn vital life skills and discover new environments.

Recognising the challenges caring for a child with CHD brings and the impact ill health can have on them and their siblings, they offer free family breaks for children and young people who are experiencing especially challenging life and health situations.

The child must be between the ages of two and eighteen (in crisis situations applications for babies under two may be considered) and meet at least two of the following criteria.

- Is disabled or has a life limiting or threatening condition.
- Experienced homelessness or are living in temporary accommodation.
- Witnessed or experienced domestic violence.
- Have experienced bereavement (either the loss of a parent or sibling).
- Is a young carer.
- Is a sibling of a disabled child / child who has a life limiting/threatening condition.
- Lives in an area of deprivation.
- Has an annual household income below £25,000.

breaks@yha.org.uk 01629 592 723

www.tinyurl.com/yha-breaks

CitizenCard UK

CitizenCards are national proof of age documents and display the PASS hologram endorsed by the Home Office, ideal for those who do not have a driving licence but may need ID.

Application is online and takes around twenty one days. A standard application costs £15 or if you require a card within a few days the fast track route that costs £30.

If your youngster is at school or college check with them first as CitizenCard provides free cards through working closely with education and large charities.

www.citizencard.com contact@citizencard.com

Locking Cooker Valve

Cadent Gas can fit a locking cooker valve to the pipework of a cooker or hob in vulnerable people's homes. This service is free of charge and performed by trained engineers. If Cadent do not cover your area their website has links to other gas suppliers providing this service.

This simple safety device will help a person retain their independence whilst providing reassurance to family and carers. The valve can easily be locked and unlocked by the person retaining the key. When locked the gas supply is isolated which means if the cooker is unintentionally turned on or left on there is no risk of gas escaping.

Either fill in the form by following the link or call Cadent Gas directly for more information.

tinyurl.com/dhgcooker 0345 835 1111

Hotels With Hoists

The Ceiling Hoist Users Club (CHuC) was formed to promote the needs of disabled people who need to use hoists and ceiling track hoists. The CHuC website brings together accommodation providers, hoist suppliers and hoist users to discuss the lack of ceiling track hoists in hotels, guest houses and self-catering accommodation which severely limits choice for people wanting to get away for leisure, business, or important social events.

The CHuC website lists suitable accommodation and campaigns for better planning of new buildings and adequate renovation of older properties to make them fully accessible for all.

A recent report by Trailblazers, part of Muscular Dystrophy UK, discovered just how few fully adapted rooms are available across the country. They are now calling on the government to amend building regulations and create an *"access renovation fund"* to ensure businesses can afford to make rooms accessible. The report also asks the tourism industry to provide mobile hoists and staff training to ensure disabled people have the equipment they need for a safe stay. To go to the Ceiling Hoist Users Club or to read the Trailblazers report follow the links below.

chuc.org.uk tinyurl.com/dhghotel

Blue Badge Scheme

There have been recent changes and proposed changes to the Blue Badge scheme in some parts of the country , so it may be worth checking if you are eligible.

(Ed - listed qualifying criteria are those which might commonly apply to our members, there are others we have not included)

You qualify automatically for a Blue Badge if you are aged two or over and one of the following applies:

- You get the higher rate mobility component of disability living allowance (DLA).
- You live in Scotland and previously got an indefinite or lifetime award of the higher rate mobility component of DLA, which has been terminated following a PIP re-assessment.
- You live in England or Northern Ireland and have been awarded 8 points or more in the ‘moving around’ activity of personal independence payment (PIP).
- You live in Scotland or Wales and have been awarded 8 points or more in the ‘moving around’ activity or 12 points in the ‘planning and following journeys activity’ of PIP.
- You live in Scotland and previously got a fixed-term award of the higher rate mobility component of DLA, have not been awarded the appropriate points at a PIP re-assessment (as in the above bullet) and have asked for a mandatory reconsideration of the decision within the last year.
- You live in Wales and have a mental disorder which means you are unable to follow the route of a familiar journey without the assistance of another person.

There are also special rules if you have a child under the age of three. You can get a Blue Badge if your child has a specific medical condition which means they:

- must always be accompanied by bulky medical equipment which cannot be carried around with the child without great difficulty; and/or
- need to be kept near a motor vehicle at all times so that they can, if necessary, be treated in the vehicle or quickly driven to a place where they can be treated.

In Scotland, a Blue Badge can also be issued to carers and relatives of people who pose a risk to themselves or others in traffic.

Applications are processed by local authorities, or the Blue Badge Unit in Northern Ireland (0300 200 7818). In England, you may be charged a statutory maximum fee of £10; in Scotland, up to £20; in Northern Ireland the fee is £10; in Wales it is free of charge. The badge lasts up to three years.

You can apply online at www.gov.uk/apply-blue-badge if you live in England or Wales, or www.mygov.scot/apply-blue-badge/ if you live in Scotland.

Information about the blue badge scheme in Northern Ireland is available at the NI Direct website at http://tinyurl.com/jgat854

ILF Transitions Fund

Independent Living Fund (ILF) Scotland have just opened a Transition Fund, through which young people aged between 16 and 21 who have lived in Scotland for at least 6 months can apply for a grant towards an opportunity that will facilitate their participation and inclusion within their communities. You can apply for up to £7,500 for things like art or music lessons, a device or piece of technology to help you, to join a class and/or club, travel training or training courses.

www.tinyurl.com/ilf-apply

National Congenital Heart Disease Patient Experience Survey

The NHS has launched a national Congenital Heart Disease Patient Experience Survey in all specialist surgical (Level 1) centres in England, to enable the views of patients and their families to be heard in a consistent way across all centres.

There are separate surveys for outpatients and inpatients and for different age groups:

- A parent/carers survey aimed primarily at parents of babies and young children;
- A child patient survey;
- An adult patient survey aimed at older children, young people and adults.

If you have any questions about the survey please contact: info@msbconsultancy.com

www.chdpatientsurvey.co.uk

Down’s Syndrome: Grandparents Chat UK

We asked the lady behind a new Facebook group specifically for UK grandparents to tell us a little about how the group came about.

Please introduce yourself

My name is Birdy I live in Cornwall with my husband John and we have eight Grandchildren; one of them, Ted, just happens to have Down's Syndrome.

Why did you start the group?

Sometime ago when my daughter mentioned the idea of a book for grandparents of children with Down’s Syndrome, we looked around and found very little apart from a Facebook group in the USA which I joined. As nice as it was, it was a bit too culturally different for me to relate too, so we said that we should start our own group just for UK grandparents. As it often does - 'life' got in the way and the idea was shelved, but when the Cornwall Down’s Syndrome Support Group were given funding for the book, 'Tea At Grandmas', the idea came up again and still finding nothing we thought 'lets just go for it' and we set one up.

Was the idea a success?

Within 18 hours we had 102 members and more are being added all the time. It's become a wonderful group of lovely grandparents all sharing their experiences, their proud moments, their challenges and their encouragements. From experience, it can sometimes feel like you are on the outside looking in and that grandparents are overlooked when support is offered. I think the popularity of the group and the hive of activity shows just how much grandparents want to chat with others on a similar road to themselves.

What are your hopes for the group?

Hopefully it will continue to grow and flourish as the comfortable corner of the internet for grandparents old and new that we want it to be!

Who can join?

As long as you are a grandparent to a child with Down's Syndrome in the UK or have a grandchild with Down’s Syndrome in the UK, then you are very warmly welcomed to join us.

What are your aims going forward?

To build up our Facebook community and nurture the friendships that we are making in the group so we can all help one another as we travel this journey together.

Birdy and Ted cooking

www.tinyurl.com/DS-Grandparents-UK

Further information about Down's Syndrome is available from

Down's Syndrome Association
Langdon Down Centre, 2a Langdon Park
Teddington TW11 9PS
0333 1212 300
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 Syndrome Scotland
4th Floor, Riverside House
502 Gorgie Road, Edinburgh EH11 3AF
0131 442 8840
www.dsscotland.org.uk

For other useful links and regional Down's Syndrome groups go to
www.dhg.org.uk/links.aspx

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
Dragon Enterprise Centre, Cullen Mill,
Braintree Road, Witham, Essex CM8 2DD
0808 808 5000
www.chfed.org.uk

PHA UK
Unit 2, Concept Court
Manvers, Rotherham S63 5BD
01709 761450
www.phassociation.uk.com

dhg
down's heart group

charity 1011413

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

Our newsletter has changed over the years to reflect our members needs - now we are changing again

IMPORTANT INFO INSIDE