

gain4all

Issue 9

Quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies

SPRING 2016



GBS Project see page 10

www.gaincharity.org.uk



Our eBay for Charity donations have increased substantially since the last issue of *gain4all*. Thank you to everyone who has donated a percentage of their selling price to GAIN. We will keep a running total and let you know how much has been raised at the end of the year.

The 1-2-3 of selling for charity on eBay

Once you're ready to list your item, use the **Advanced Sell** form and as you're filling out the details, look out for the charity box just below where you set your price.

Select **Guillain-Barré & Associated Inflammatory Neuropathies GAIN** (if you just type in **guillain**, it will still find us) as your charity to support and then decide what percentage (10%-100%) of your final selling price you would like to donate. It is as easy as that.

It's seen by everyone

eBay for Charity listings are the same as any other eBay listing, except for the blue and yellow eBay for Charity ribbon  in search results and your chosen charity's mission statement and logo in your listing. This means your listing can be seen by everyone who searches through www.eBay.co.uk. It will also get extra visibility through the eBay for Charity pages.

What happens next?

Three weeks after your item sells, PayPal Giving Fund (eBay's partner charity) will automatically collect the donation from you and any fee credits will appear on your next invoice. Every time you list an item for charity, you'll get a fee credit on your basic insertion and final value fees equal to the percentage you donate. So if you donate 50% of your selling price to a charity, eBay will waive 50% of your fees.

You can manage your donations through the **My Donations** section of **My eBay**, under the **My Account** tab.

You can now list eBay for Charity items using the eBay Mobile App on iPhone and Android.



Please don't forget – Gift Aid is one of the easiest ways to make your donation tax effective. Using Gift Aid means that for every pound you give, the charity will receive an extra 25p from the government.

Simply tick the Gift Aid box when you first list an item for charity, provided you pay more in UK income or capital gains tax than you're asking charities to claim back in each tax year. PayPal Giving Fund will collect the Gift Aid from the government and pass it on to your chosen charity. You can also make a Gift Aid declaration in your eBay account.

about Guillain-Barré syndrome

Guillain-Barré syndrome (GBS) is an inflammatory disorder in which the body's immune system attacks the peripheral nerves.

Severe weakness and numbness in the legs and arms characterise GBS. Loss of feeling and movement (paralysis) may occur in the legs, arms, upper body and face. Severe cases may result in total paralysis and breathing difficulties, requiring long-term rehabilitation to regain normal independence, with as many as 15% experiencing lasting physical impairment.

In some cases, GBS can be fatal. Because the cause of GBS is unknown, there is no way to prevent the disease from occurring.

CIDP

Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) is a disorder related to GBS that follows a much longer course. Though rarely fatal, many patients seek an effective treatment that often proves elusive.

about gain

GAIN is a registered charity that supports those affected by GBS, CIDP and other related conditions in the UK and Ireland. Please contact us for further information or support.

The charity has three main aims:

The provision of information, non-medical advice and other assistance;

The promotion of research into the causes, prevention and treatment of Guillain-Barré syndrome and associated inflammatory neuropathies; and

Advancing the awareness of the public and of the medical professions concerning Guillain-Barré syndrome and associated inflammatory neuropathies, their causes, prevention and treatment.

How you can help

As long as people continue to be taken ill by GBS and CIDP, the Charity's work will never be complete. We can only continue to provide our service with the continuing help of our generous supporters. There are several ways in which you can help us and make that extra difference.

- Fundraising
- Make a financial donation
- Become a member
- Volunteer

CONTENTS

GAIN News	4
Meet the Medical Advisory Board	7
Guillain-Barré syndrome and research into the new food superbug	8
Guillain-Barré syndrome to take centre stage	10
Letter to the editor	11
Fundraising Reports	12
Getting out and about	16
News from around the regions	18
Hints and tips	20
Useful links	23



Guillain-Barré & Associated Inflammatory Neuropathies

Back cover picture FILMAR Photography www.filmar.co.uk

gain

Woodholme House
 Heckington Business Park
 Station Road
 Heckington
 Sleaford
 Lincolnshire NG34 9JH
 Tel: 01529 469910
 Fax: 01529 469915
 Email: office@gaincharity.org.uk
 Office Enquiries: 9.00am – 3.00pm

FREE HELPLINE:

0800 374 803 (UK)
 1800 806 152 (ROI)
 Registered Charity 1154843 & SCO39900



gain NEWS

gain2gether Glasgow,
Saturday 25 June 2016



Bookings must be received by Friday 10 June at the latest

If you have not already booked your place, please do so before it's too late

Some great reasons why you should join us:

- The venue - Glasgow University in the heart of the city's West End, with ample parking and easy access to public transport as well as fantastic green spaces, museums and galleries
- World class speakers
- Chance to meet up with others and chat over lunch and coffee
- To be part of the wider centenary celebration of the seminal work of Drs Guillain and Barré
- All of this for £30 per person

Booking couldn't be easier

Online at http://www.gaincharity.org.uk/shop/2016-gain2gether-glasgow/cat_34.html

Or you can pop a cheque in the post to the office at Heckington, don't forget to let us know if you wish to join the dinner party in the evening!

The programme

- 09:00** Registration and Coffee
- 09:50** Delegates seated. Welcome
- 10:00** David Cornblath - Readings from 1916 and overview
- 10:20** John Goodchild - History of GBS
- 10:45** Glennys Sanders - The setting up of the GBS support group in UK
- 10:50** Rob Hadden - Importance of patient groups
- 11:00** Ana Talbot - A patient perspective
- 11:20** Coffee (provided)
- 11:40** Hugh Willison - A career in research
- 11:50** Susan Halstead - Technical developments in anti-bodies
- 12:10** Govindsinh Chavada - IGOS
- 12:30** Greetings from around the globe
- 12:40** Lunch (provided)
- 14:00** Santo Garcia - Exercise for all
- 14:35** Lesley Murray - Challenges in delivering Immunoglobulin
- 15:00** Amy Davidson - Future Treatments
- 15:15** Tea (provided)
- 15:30** Angie Rupp - GBS in animals
- 15:40** Simon Rinaldi - GBS, the next 100 years
- 16:00** Close
- 16:15** AGM
- 19:00 for 19:30** Dinner, Hilton Garden Inn (additional cost) approx £25pp - details to follow

Golf Competition Sunday 26 June



For those who are making a weekend of it, Gordon Peebles (pictured) has kindly organised a fundraising golf competition in aid of GAIN to be held at Ferezeze Golf Club, Barrhead.

The competition will be a "Texas Scramble" team of four with 5 clubs each player, entry fee is £20.00 per team.

Rules for the competition

- 15% of combined handicap
- Fairway: Mark, lift and place
Rough: Mark, lift and drop only
- Four Tee shots each player, one of your counting Tee shots must be at a Par 3
- Two floating Tee shots

For more information or to book your place, please contact Gordon via email: gordon.peebles@hotmail.com

The donation of prizes for the competition would be greatly appreciated; if you are able to offer a prize or prizes, please let Gordon know.

Annual Prize Draw 2016

If you are able to sell raffle tickets for the Annual Prize Draw, please make sure that ticket stubs are returned to head office by 17 June 2016. Tickets are currently being distributed and we have plenty more should you need them. They will also be for sale at gain2gether Glasgow and via our website shop.



Trustee Vacancy

About the opportunity

GAIN is a UK registered charity founded in Lincolnshire in 1985. We are a small charity with a big mission: To support those affected by GBS, CIDP and associated inflammatory neuropathies.

General Responsibilities

1. Ensure that the charity complies with charity law and with the requirements of the Charity Commission as our regulator, and does not breach any requirements or rules set out in our governing documents.
2. Assist with providing strategic oversight and input into the operation of the charity.
3. To contribute specific professional skills and expertise as required.

What are we looking for?

Person Specification

The ideal candidate will have company/charity secretary or legal experience. We are particularly looking for individuals who will be motivated by supporting all aspects of our work.

All Trustees are expected to assist GAIN in securing a sustainable and diverse funding base for the organisation. An understanding of the voluntary sector and previous experience as a charity trustee are both desirable but not essential.

Essential

Commitment to GAIN's mission and values;

- Demonstrated ability to generate funds for GAIN, either through qualifications and/or experience in sales or marketing disciplines and/or previous charitable or corporate fundraising experience;
- Proactive, creative, enthusiastic and motivated to secure funds for GAIN;
- Commitment to attend meetings out-of-hours (evenings and weekends);
- Excellent written and spoken English communication skills.

Desirable

- Knowledge or a keen interest of the voluntary sector;
- Previous (or current) experience as a charity trustee;
- Senior management experience in the public, private or voluntary sector;
- Experience of working in small charities and able to understand and work towards overcoming its obstacles.

For more information and an application pack contact director@gaincharity.org.uk by 10 June 2016. Your cover letter should highlight your interest in GAIN and motivation for joining our Board. Please also detail your availability and relevant experience, ensuring this is in line with above job description and person specification.



The views expressed in this publication should not necessarily be taken as the Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) policy. Whilst every care is taken to provide accurate information, neither GAIN, the Trustee board, the editor nor the contributors undertake any liability for any errors or omission.



The next issue of the magazine will be published in July 2016 and the deadline for submissions is 30 June 2016. Please forward all articles to Lesley Dimmick fundraising@gaincharity.org.uk

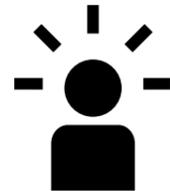
gain-in-numbers

Quarterly update 1 January – 31 March 2016



Volunteers

- 21 Helpline
- 128 Support
- 13 Applications being processed



New Users

72 registrations



Helpline Calls

188

Request for Peer Support

27

(includes phone call or visit)



Current users/ subscribers breakdown

Magazine subscription type:

Postal Magazine (UK)	755
Postal Magazine (Ire/Eur)	13
email Magazine	1380
No Magazine	38
Total	2186



Voting Members

285

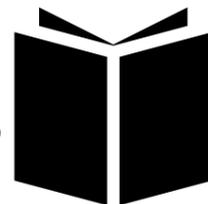


Direct Debit

85 Subscribers

Support Related Publications

Patient Information Packs	64	(excludes information requested and sent by email)
Communication Cards	4	(produced in house for hospital use)
Medical Information Packs	28	(plus extra booklets and Quick Guides for hospitals to pass on to patients)



Fundraising and Donations

DONATE



Donations Received	£9157.44
Fundraising Activity In Memory	£26156.57
Research	£2664.92
Little Box	£225.00
Gift Aid (Gross)	£141.50
Sale of Goods	£2814.31
Legacies	£55.10
	£100.00

Social Media



Facebook Group
GAIN Facebook Page
Twitter

1646 members
688 Likes
357 followers

GAIN Website

Total Sessions **7144**
(new sessions 75.5%, returning visitors 24.5%)
Users **5602**



Meet the Medical Advisory Board (MAB)

1. Who are you?

My name is Mike Cumberbatch. I am a neuroimmunology nurse specialist, but have previously worked as a research scientist in the pharmaceutical industry developing new medications for neurological conditions.

2. Where do you work?

I work in neurology at Addenbrooke's Hospital in Cambridge.

3. What is your role on the MAB?

As a specialist nurse I hope to be able to offer advice for patients and health care professionals on the management of GBS/CIDP and related peripheral neuropathies; and on the benefits and risks associated with various treatments.

4. What inspired you to join the MAB?

I work with many patients with GBS and CIDP, many of whom feel very isolated. GAIN offers very good advice for these patients and I wanted to provide as much support as I could.

5. Do you have a special interest in GBS/CIDP or one of the variants?

I am particularly interested in the long term treatment of CIDP and in home therapies. I think that subcutaneous immunoglobulins offer patients a flexible approach that enables them to continue to lead an active work and social life.

6. What current global research excites you?

I work with many patients who have a variety of autoimmune neurological conditions. Emerging research is showing that biological therapies (synthetic antibodies which can regulate the immune system) can be very effective at halting the disease and preventing relapse. I am keen to see more research on these therapies to treat patients with CIDP.

7. Finally do you see a time when GBS and CIDP are preventable?

I think that we will see a time when CIDP and other chronic autoimmune neurological conditions can be treated much more effectively. Part of this will involve earlier recognition and diagnosis, which will enable faster treatment and decreased probability of long term neurological deficits. However, I think that the biggest difference will be the development of new treatments to halt the disease process or even reverse some of the damage. Unfortunately, I think that this is still some years in the future. With such rare diseases it is difficult to generate the level of research required to drive the development of new therapies.

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Study

Thank you to everyone who has volunteered to take part in the study and returned their consent forms. There is still time to take part – you must have a diagnosis of CIDP and are currently or have recently been treated with immunoglobulin treatment or therapeutic plasma exchange. Interested call the office or email research@gaincharity.org.uk and we will send out the consent forms.

Guillain-Barré syndrome and research into the new food superbug

Joe Wanford¹, Christopher Bayliss¹ and Julian Ketley¹
¹Department of Genetics, University of Leicester, Leicester

Guillain-Barré syndrome (GBS) is a muscular condition caused by our immune system producing antibodies that attack our peripheral nervous system (a type of autoimmunity).

Damage initiated by these antibodies can quickly progress to a flaccid, full body paralysis. This condition often occurs following cases of gastroenteritis involving infection by any one of a number of microorganisms. The most common causative bug (implicated in roughly 30% of cases) is the bacterium, *Campylobacter jejuni* – the emerging food superbug. *Campylobacters* have emerged as wide-spread, disease-causing agents as a result of their intimate relationship with chickens and other poultry. These bacteria live in the guts of poultry without causing obvious signs of disease, but can cause gastroenteritis and subsequently GBS, if they make their way into the human gut. A common route is through ingestion of under-cooked chicken meat.

Actual cases of GBS following *Campylobacter* induced gastroenteritis are relatively low; fewer than 1 per every 5,000 gastroenteritis cases. Cases of GBS soon add up, however, as in excess of 700,000 people are infected with this bug every year. This case load is particularly worrisome when we consider that even with complete access to modern medicine, between 2-3% of these cases are fatal. Despite this staggering statistic, there are still many gaps in our knowledge of how *Campylobacters* cause gastroenteritis and ultimately how this disease progresses to GBS. In the Department of Genetics at the University of Leicester (UoL), we are interested in three main areas of *Campylobacter* research: how the bacteria can escape from the immune system, how they move towards nutrients in the gut,

and how they escape attack from small bacteria-specific viruses (a potential treatment strategy). We believe these areas of research are key aspects for understanding of *Campylobacter*-induced GBS and in the development of potential treatments.

The human immune system coordinates its attack on bacteria by recognising structures on their surface (termed antigens). Once these structures have been recognised, the immune system can produce specific antibodies, killing the bacteria before they have a chance to cause disease. Many bacteria, including *Campylobacters*, have evolved complex mechanisms to escape attack from our immune system enabling them to persist in the body for long periods of time. Each of the surface structures of *Campylobacters* are coded for by a piece of DNA (termed genes). Many of these genes are prone to mutation, at a far higher rate than other pieces of DNA in the bug (hypermutable sequences). Mutations in these hypermutable sequences cause the gene to be switched off, which in turn removes their cognate antigen from the surface. These mutations are reversible, meaning that the switch can be 'flicked' back on, returning the surface antigen to the cell. This process of frequent 'on and off' switching of genes, is known as phase variation. The result is that cells under attack from the immune system, can switch off some genes to escape attack prolonging their persistence in the body and increasing the potential for these bacteria to cause a disease such as GBS. Additionally, many of these surface structures are also required for the bacteria to stick to our cells and to survive killing by other parts of our immune system; generating diversity through phase variation is, therefore, *Campylobacter's* way of ensuring that at least one cell in a population will survive with potentially dire consequence for the infected individual.

Here at Leicester, we are aiming to better understand phase variation, what controls it, how it contributes to survival of these bacteria in the human and avian guts and whether it allows *Campylobacter* to resist phage infection. Answering these questions will enable us to improve treatment strategies for *Campylobacter* infection and ultimately to reduce the burden of GBS.

More recently, we have discovered that phase variation is directly important in the progression to GBS. One component of the bugs' surface is directly involved with initiating the autoimmune response, responsible for the onset of GBS, and this component is once again prone to phase variation. We are continuing to investigate why the bacteria switch between a state capable of causing GBS and a state on silence, and hope that this work will help with our wider understanding of the disease.

Answering these questions will enable us to improve treatment strategies for *Campylobacter* infection and ultimately to reduce the burden of GBS.

As already mentioned, *Campylobacters* are targets for small bacteria-specific viruses called bacteriophage. These 'phage' do not damage human cells but will continually infect and kill bacterial cells if they come into contact. 'Phage therapy' has been considered a potential treatment strategy for many bacterial infections, including *Campylobacter*. Much like antibiotics however, *Campylobacter* can become resistant to infection by phage and one culprit is phase variation. Phage require certain surface cells structures for sticking to and getting inside the bacteria. Many of these structures can be switched off by phase variation, rendering the bacteria resistant to some phages. If we are to use phage for treatment in the ever-looming, post-antibiotic era, we need to appreciate how the bacteria can become resistant to phage and whether phase variation will be a significant barrier to phage therapy.

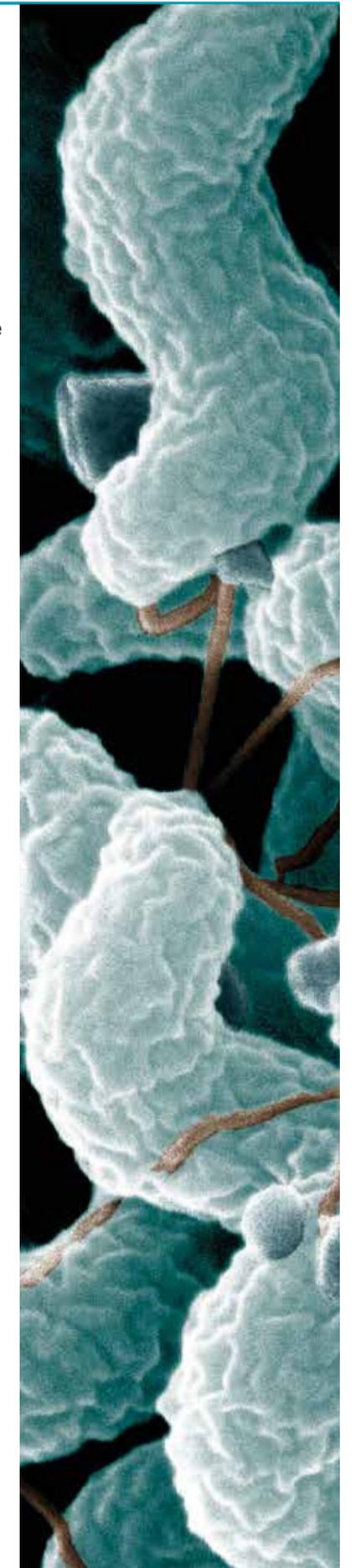
Phase variation is not the only way *Campylobacters* are cleverly adapted to cause disease. The gut can be a very harsh environment, and *Campylobacters* have become such effective bugs because they can move (a phenomenon we call motility) towards nutrients and away from things which may damage them. This so called 'chemotactic motility' is facilitated by the bacteria's flagella, a tail-like structure on the cell surface. Some of our current research is aimed at identifying factors which take external, chemical signals from the gut, and translate them into bacterial movement. A better understanding of the chemical signals involved in motility and how these signals are transduced can help us determine how the bacteria can live in both humans and poultry, and may even allow us to develop agricultural strategies to circumvent *Campylobacter* infection and subsequent GBS.

While work by clinicians and charities such as GAIN continue to reduce incidence and promote awareness of GBS, there is still much work to be done in academia to understand the fundamental biology of one of the most prominent causative bugs.

If you have any questions about our work at the University, contact us using the details below, or send us a message via Twitter. Alternatively, more information can be found on our 'Virtual Genetics Education Centre' (VGEC). This site features resources around *Campylobacter* biology and also GBS.

Joe Wanford jw643@leicester.ac.uk and
 Christopher Bayliss cdb12@le.ac.uk

Twitter: [@Leicester_Micro](https://twitter.com/Leicester_Micro)



Guillain-Barré syndrome to take centre stage



It is seven years since Adam Pownall was diagnosed with Guillain-Barré syndrome, then being 26 years old; he was a healthy, fit and active young man. Forging himself a career in the arts he was working hard as a performer, producer, project worker and dancer.

He recounts his story as "waking up one morning with what felt like a hangover, my feet were cold and they never warmed up".

It took three weeks for the symptoms to move through his body, resulting in him being ventilated due to full paralysis whilst in ICU at Queens Medical Centre, Nottingham under the care of their specialist Neurological Department. He spent a further six months in hospital care including rehabilitation in his home town of Mansfield.

It was over two years before he was deemed "fit" and could begin a phased return to work. Since then Adam has progressed his career in theatre now being the Artistic Director of Lincoln Drill Hall via Programming and Producer roles with Derby Theatre and Create Theatre, Mansfield.

In 2014 Adam was nominated for The Writer's Guild of Great Britain 'Olwen Wymark New Writing Encouragement Award'. Whilst collecting the award from then Chair, Nick Wood, Adam recounted his story with GBS to Nick and from then on they began to hatch a plan to tell this incredible story to help raise awareness of GBS and GAIN Charity.

In August 2015 with support from GAIN the 'GBS Project' was awarded funding from the Arts Council to research and develop the project. Adam as Creative Producer brought together a team of artists to help realise this story. They included regional, national and international artists such as choreographer Marc Brew, Director Tilly Branson with Nick Wood tasked to write the piece.

The project in its first stage was supported by Derby Theatre, Deda Derby and ARC Stockton and the whole team spent time working together in these

venues sharing the progress they had made with new audiences.

Director Tilly Branson said "The thing that really interested me about Adam's story and the idea to turn it into a piece of theatre is that though it's a personal story, there are some really universal human themes and questions. I hope that the piece gives the opportunity for the audience to consider how they might respond in those moments if we are not in complete control of what happens to our bodies

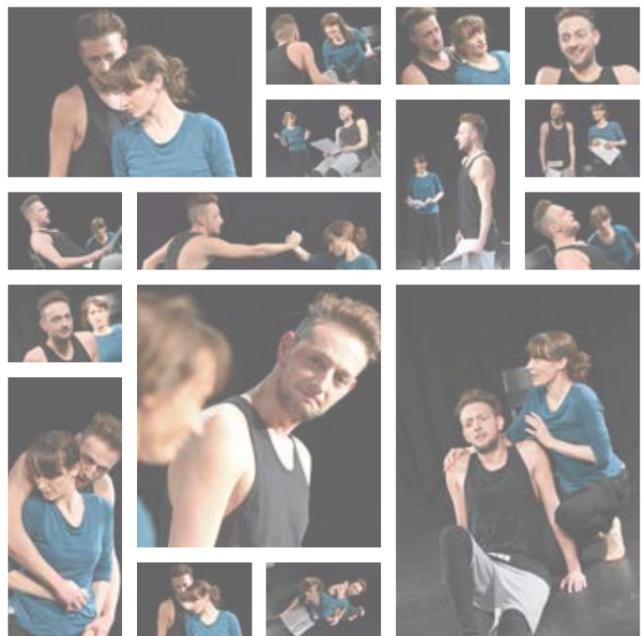
and our health; whether that's through illness, an accident or something completely unpredictable."

"Because our writer has interviewed Adam and some of his friends and family we have verbatim text that we use so we can tell the story from other people's points of view as well as Adam's. It's been really exciting using lots of forms and exploring how they can tell this story; because we are working with ideas and feelings that can't always be put into

words it's been really useful to consider how sound and dance can show an audience what it feels like to be in a battle with an illness."

Audiences have responded well to the early versions of the production and the company are now receiving support from the core Lincolnshire One Venues and Lincoln Drill Hall where the show will premier in the Autumn before a national tour dependant on further funding grants.

If you would like to keep up with development of the production and find our tour dates when they are released then you can find 'GBSproject' on Facebook and Twitter.



Letter to the editor

Friendship

A friend is someone you can trust,
On whom you can depend.
Someone compassionate and kind,
Whose friendship never ends.

For when they smile, it is sincere,
Not a polite disguise,
You see their smile is genuine,
Reflected in their eyes.

Some people toss you compliments -
'Confetti in the breeze'.
Which in the end will soon descend
Like old, autumnal leaves.

Friends do NOT over-compliment -
Their honesty shines through.
You really value what they say,
They value what you do.

When you converse there is no stress.
No fear or irritation.
You may agree to disagree
In friendly conversation.

How lovely to relax and speak
Of joys and troubles shared.
Friends will always understand
And show they really care.

A friend is someone special,
Like a single star at night.
You know that they are always there
Though sometimes out of sight.

True friendship stands the test of time,
Its firm strength never falters.
With age our beauty may well decline
But friendship never alters.

How precious friendship really is -
Good friends are often few.
How fortunate I am therefore
To have a friend like you!

Being a special centenary year for Guillain-Barré patients, Lynn, a GAIN member, kindly sent in two of her poems.

A Message from Porthminster Beach, St. Ives, Cornwall

What are you looking at?
The sleeping leviathan stirs in its bed,
Its fingers uncurling on sand.
The late summer breeze caresses some trees,
While dusk engulfs ocean and land.

Lights sparkle, as pinpricks in blackness,
Drawn curtains hide proud, Cornish homes.
In far distant cities commuters, still busy,
Head homewards, in crowds or alone.

What are you thinking of?
This world is a place filled with worry,
Ambition and often despair.
Its people, in different locations,
Living, loving, then dying somewhere.

Most people pass by us like shadows,
To us and to others unknown.
We use language and action to show our attraction,
Which often, like love, is unknown.

And therefore I ask you these questions
As waves interlace on the shore.
While I wait here alone, will you ever come home
And return to Porthminster once more?

A Little Princess

fundraising reports

Jasmine Dawood (age 6) suffered from GBS in November 2013 when she was 3 years old; it was the most frightening time of her life (and her Mum's). What started as a chest infection quickly developed into GBS and she lost all function of her legs and arms for almost three months. She then underwent a further few more months of physio and rehabilitation and thankfully, Jasmine has now made a full recovery. "It was like having a three year newborn again" said Jasmine's Mum Hayley, "even to this day she still has her tired days where she takes herself to bed for a little sleep. She has been so brave and strong".

In order to help others, Jasmine recently underwent a transformation and had all of her long red hair cut off (the hair was then donated to Little Princess Hair Donation Charity who make wigs for children cancer sufferers) and she has raised £364.00 for GAIN.

"I hope Jasmine's fundraising will go on to help other sufferers and their families. From my own personal experience taking part in this fundraising has helped both me and Jasmine finally find closure from this horrific experience. It is definitely something we will be doing again" said Hayley.



Local hair salon Lab Forte of Alcester Road, Moseley, very kindly cut Jasmine's hair for free



Valentine's Dinner

Ian and Anne Bennett held their 2016 Annual Valentine's Dinner on Saturday 13 February.

Again with the help of family and friends, the event was a great success and enjoyed by all, including other people who have had GBS - Jim Alderson and his wife Lynda and Susan Paterson with her husband Roy.



Happy Helpers - from left grandson Louie, Anne, daughter Debbie, Matthew and Amy

LATEST NEWS

Prudential RideLondon-Surrey 46 Sunday 31 July 2016

This new event will be held for the first time in 2016 as part of the Prudential RideLondon festival of cycling. The sportive (remember, it's not a race!) comprises a spectacular 46-mile route on traffic-free roads, beginning at Queen Elizabeth Olympic Park in east London and following the same route as the Prudential RideLondon-Surrey 100 for the first 27 miles before taking a new two-mile route, which then links up with the last 17 miles through London to the finish in The Mall.

The Prudential RideLondon-Surrey 46 has been created specifically for newer cyclists and also younger cyclists, who might find a 100-mile challenge intimidating or, in the case of 16-18 year olds, they are not eligible to enter. The Prudential RideLondon-Surrey 46 offers a great introduction to cycling on traffic-free roads and is a wonderful way to ride your first sportive.

Riders will depart in waves from Queen Elizabeth Olympic Park from 09:00-09:30, immediately after the last start wave of the Prudential RideLondon-Surrey 100. They will finish on The Mall and will have a spectacular unique medal designed for the occasion.

We have two places for this event so if you are interested in taking part please contact Lesley Dimmick by email: fundraising@gaincharity.org.uk

Bath Half Marathon 13 March



Charlie first left

I am proud to say that we managed to raise a massive £1,000. GAIN is very dear to my family and I feel immensely proud that with your help, I have been able to give back to it.

The run last month was so much fun. The sun was out and the whole of Bath appeared to be out to show their support to the runners. I somehow managed to run a time of 01:44:29 which I couldn't be happier about especially when my original goal was to run it in under two hours. So hopefully we all got our monies worth! Running that time was hard work.

Charlie Sheppard

Greater Manchester Marathon 10 April

I'm pleased to inform you that all went well and I completed the Manchester marathon - thanks for giving me this opportunity to raise money for GAIN.

Lee Sharples



Come Aboard *Marlin's* Mission

Practical Boat Owner columnist Dave Selby is gearing up for a 300-mile voyage in his 18ft Sailfish. The east coast sailor will be setting off from Maldon in June or July on "*Marlin's* Mission" to sail to the Southampton Boat Show in September, where *Marlin* will be on display to promote sailing to a new audience.

He'll be stopping off at marinas along the way and sharing tales of his adventures and all the preparations with a blog at www.pbo.co.uk along with regular updates in the monthly magazine and at www.ybw.com.

Once at the show *Marlin* will provide a stage to put across the message that small-boat sailing can provide 'holidays of a lifetime, for a life-time, for £2,000.' For existing boaters, Dave will be hosting practical demonstrations of boat maintenance, repair and restoration.



Dave with sailing companion Bart

Dave, who suffers from CIDP will also be raising money for GAIN and has set up a JustGiving page www.justgiving.com/Dave-Selby-Marlins-Mission. He added: "This is not a commercial enterprise, I simply want to share all that sailing has to give with others. There's a myth that boating is expensive. In fact, there's an ever-growing supply of cheap, small, affordable second-hand boats for less than half the price of one family holiday. Second-hand boats have never been more affordable, and they can open up a life-time of adventure. That's *Marlin's* Mission."

From his base in Maldon, on the river Blackwater in Essex, Dave, 56, will start preparations in April and aims to set off in July, in short hops around the coast as weather, health and time allow. Dave is appealing for the marine trades to get behind the project and would appreciate hearing from marinas and equipment suppliers who'd like to help the adventure on its way.

On his travels he hopes local sailors around the coast will sail in company with him and join him aboard *Marlin*. Contact Dave by email: dave@rollingassets.com or by phone: 01621 854978

PLEASE HELP!

GAIN would like to thank everyone who has found a home for one of our collection boxes. It is amazing how small change can soon mount up and our collection boxes play an important part in our overall fundraising. If you are in possession of one and no longer have a use for it, please return it to head office. We are running very low and they are expensive to replace.

Thank you



GAIN Lottery WINNER

Congratulations to our GAIN winner who won £1000 in a February draw. If you would like to be in with a chance of winning, join up today: <http://www.unitylottery.co.uk/charity/display/guillain-barre-associated-inflammatory-neuropathies>



Coming up...

If you are planning a fundraising event, please tell us. Here are some we already know about:

14 May Tough Mudder Half North

To support Taflyn visit: <https://www.justgiving.com/Taflyn-McLoughlin>

15 May Superhero 10k

<http://www.heroesrun.org.uk/content/enter-a-race>

To support Emily on her 10k run visit: <https://www.justgiving.com/Emily-Geere1/>

21 May Tough Mudder Midlands

To support James visit: <https://www.justgiving.com/James-Orsler1>

22 May Great Manchester Run 10k

<http://www.greatrun.org/great-manchester-run?gclid=Cj0KEQjwwpm3BRDuh5awn4qJpLwBEIQAATTAQSPtSajJQBHhCI8IHd5WzYoFMz2eSsPI8qySTs2ohAcaArs08P8HAQ>

To support Kayleigh visit: <https://www.justgiving.com/kayleigh-maughan/>

28 May London 2 Brighton (Walk)

<http://www.london2brightonchallenge.com/>

To support Steph visit: <https://www.justgiving.com/Stephanie-Urquhart/>

10 June Four Counties in Four Days Cycle

To support Chris and his team visit: <https://www.justgiving.com/fourcountries>

17 July Transalp 2016

To support Karla visit: <https://www.justgiving.com/Karla-Boddy/>

31 July RideLondon-Surrey 100

All places have now been filled - good luck to our riders Andrew, Gert, Tim, Geoff, Clare and Janey. Details for supporting team GAIN in this event will be available in the next issue.



20 August Coast2coast Cycle

Phil Wallace
<https://mydonate.bt.com/fundraisers/pr4gain>

Andrew Hook
<https://mydonate.bt.com/fundraisers/andrewhook2>

Owyn Wallace
<https://mydonate.bt.com/fundraisers/owynwallace>

10 September Thames Path Challenge

To support Ian visit: <https://www.justgiving.com/ian-favell1>

11 September Great North Run

All places have now been filled - good luck to our runners Steven, Chris, Mark, Iain and John. Details for supporting team GAIN in this event will be available in the next issue.



25 September Cheltenham Half Marathon

<http://www.cheltenhamhalf.co.uk/article/?recordID=1021>

28 September Cycle to Stamford Bridge

To support Lloyd on his personal cycling challenge visit: <https://www.justgiving.com/Lloyd-j-Austin/>

23 October Great South Run

To support Laura visit: <https://www.justgiving.com/Laura-Seddon2>



People with limited mobility and wheelchair users

Everyone should be able to enjoy the outdoors, no matter what their ability. However, if you have limited mobility, or are a wheelchair user, it's not always easy to access the countryside. We have highlighted some of the obstacles you might face, how you might overcome them and where to find support.

The problems you might face can vary greatly. If you are capable of walking long distances on flat paths you may still encounter problems with stiles, steps or overhanging trees. The impact could vary from a minor inconvenience, to something that could be overcome with the help of a companion, to an obstacle that could prevent you from enjoying an outing at all.

Users of both manual and powered wheelchairs can expect to encounter major problems on most country paths, particularly those with challenging surfaces, steps and obstructions. You are entitled to take a wheelchair anywhere that is open to walkers, but that does not mean the path will be practical for a wheelchair user.

There is an increasingly wide range of mobility scooters available and some are designed for use on more rugged routes. However these will still encounter problems with stiles, steps, and narrow or blocked paths.

If you have limited mobility you may also need other facilities such as regular rest stops; accessible toilets; extra wide parking spaces; or accessible public transport. So it is worth doing some research beforehand to decide if a particular route is within your ability.

It can be difficult to find reliable sources of information about accessibility in the outdoors, but the good news is that the situation is improving and more information is slowly becoming available. Some useful sources of information are identified on the next page.

There is also an increasing number of accessible trails. Some have special gates that can be unlocked with a RADAR key; some trails have signed diversions that avoid steps and other obstructions; and some country parks and other countryside sites have mobility scooters for loan, and may be able to arrange special assistance for visitors with disabilities.



www.ramblers.org.uk

Useful sources of information:

- Listings of Millennium Miles, photo trails and inclusive networks on the Fieldfare Trust website <http://www.fieldfare.org.uk/>
- Search on Ramblers Routes for Easy Access and Easy routes <http://www.ramblers.org.uk/go-walking/routes-and-places-to-walk/about-ramblers-routes.aspx>
- Search on the Group Walks Finder for Easy Access and Easy led walks <http://www.ramblers.org.uk/go-walking/about-group-walks.aspx>
- Managers of trails and green spaces such as National Parks and AONB offices, National Trail officers, the Forestry Commission, Woodland Trust, National Trust, Wildlife Trusts, and local councils
- Tourist information centres and libraries, for local information
- The following independent websites: Accessible Countryside for Everyone <http://accessiblecountryside.org.uk/> and Walks with Wheelchairs <http://www.walkswithwheelchairs.com/>
- Disabled Ramblers <http://disabledramblers.co.uk/>, who organise countryside visits using all-terrain scooters.

Euan's Guide

Euan's Guide is the disabled access review website and app where disabled people, their friends and families can write reviews about the accessibility of different places they have visited. It's a great way to discover local places with good disabled access and can be a helpful guide when planning holidays and adventures to someplace new.

The charity was created in 2013 by brother and sister Euan and Kiki MacDonald because they wanted to hear from other disabled people about their experiences of disabled access. Euan is a powerchair user, and knowing that he couldn't be the only one in search of this kind of disabled access information, he was keen to discover new places based on the recommendations of others. It's empowering, because people who use the guide know that they can confidently go somewhere if someone else with similar access requirements has been before them and loved it.

Now, Euan's Guide has thousands of places listed on site with reviews from people all over the country and beyond. There are reviews for everything from top tourist attractions and water adventure parks to everyday essentials such as post offices and corner shops.

Of course, no two reviews are the same and each will have a different emphasis. Where one person might pay attention to level access and accessible toilets, another reviewer might write about captioning and BSL tours; it all depends on whoever submitted the review!

You too can submit a review to Euan's Guide by visiting www.EuansGuide.com. If you've been somewhere that had friendly staff, was easy to access and you'd love to return, you can tell others about it! Chances are, they might like to check it out too, and Euan's Guide will always pass on your feedback to the venue you reviewed.

Now that Spring is in full swing, it's the perfect time to visit Euan's Guide and discover something new. There are lots of fun and unusual places to explore, including beach wheelchairs in North Berwick, accessible secret gardens in England, and Sailability centres around the coast to name just a few. You can even read reviews on the go with the Euan's Guide app if you feel like being spontaneous!

To find out more about Euan's Guide and to sign up to their newsletter, you can visit www.EuansGuide.com.

Rough Guide to Accessible Britain

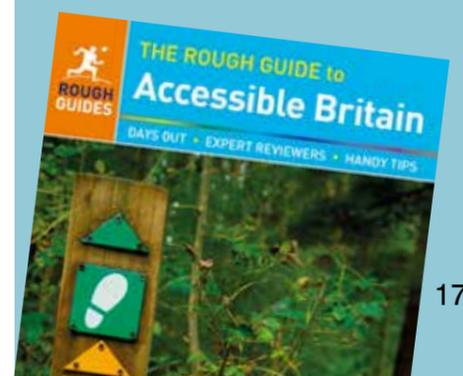
The brand new sixth edition of the Rough Guide to Accessible Britain is now available. It's packed with over 200 inspiring ideas for fantastic worry-free days out with reviews, hints and tips on some of the UK's best attractions written by and for disabled people.

To make planning your days out easier, entries are grouped into 10 regional chapters with everything from museums, parks and studio tours, to scenic drives and coastal towns.

Every review contains all the access information you need to enjoy your day including disabled parking, wheelchair access and more.

The guide is available to view for free:

<http://www.accessibleguide.co.uk/the-guide.html>



NEWS

from around the regions



Lancashire & Cumbria

After almost needing a boat to travel to December's meeting, it looked like skis would be required for the March meeting of the Lancashire and Cumbria Branch, but the day dawned bright and sunny with lovely views of the snow-capped Pennine foothills close by to our usual venue. Some twenty-six people attended for this the AGM, including national GAIN chairman, James Babington Smith.

Our Chair Sybil summarised the great year we have had with attendances typically between 30 and 35 people and 10 new members. She also thanked everyone for their help with running the Branch and especially with fundraising, which saw the accounts presented by our Treasurer, Joan, in good health. Rosie gave an update on "Rosie's Project" for the training of paediatric nurses treating children with GBS. Working with Caroline at Head Office, Rosie had made quite a lot of progress over the year and was pleased to announce that leadership of the academic side had now been taken on by a local person at the University of Cumbria in Lancaster. This was felt to be a major step forward. Rosie also thanked Jamie for the support from Head Office and members of the Branch for their support with fundraising.

Having completed our AGM, we then moved on to our regular Sufferers and Supporters Forum, when we exchange experiences, questions, and tips on living with GBS and CIDP. This time was slightly different as one of our members, Chantel Jones, gave a report on the GAIN Regional Day in York last October and used it to reflect on the psychological impact to herself of getting GBS, which almost overnight radically changed her own life and all her aspirations.

We finished the meeting with draws for the 100 Club and raffle; a sale of goods including Sybil's lovely preserves, tea and cakes, and lots of friendly chat. Future meetings are on 18 June (Plant Sale & Demonstration), 24 September and 3 December all at Bilsborrow Village Hall on the A6 north of Preston, commencing at 2pm.

Kent

The Kent Group held its usual Post Festive get together with lunch at the Woolpack in Ashford, Kent. Time just flew by and everyone had a good time - it was unfortunate that numbers were down due to ill health. Those coming for the first time were able to meet and discuss experiences with longer term sufferers.

Scotland

At the AGM, members agreed that they would organise their own social gatherings and fundraising events across the region and the branch would no longer be committee led. GAIN would like to thank everyone who has been involved with running the Branch over the years.

Yorkshire

The March meeting of the Yorkshire Branch was enjoyed by all and again gave everyone the opportunity to chat over a cup of tea. The next meeting will be on Sunday 16 October at the Betty Boothroyd Centre, Dewsbury Hospital commencing at 2.00pm

South West England

Members of the West country Branch met at Saltford Golf Club and enjoyed lunch and chat before the meeting. Once again Fran had an overflowing raffle table full of lovely goodies to tempt the members. It was good to meet some new members and catch up with those we had met before.

John Tuke recounted some of his tales from the past and his own story of GBS with those there raising some laughs and much head nodding and agreement with his recollections being similar to their own. Caroline Morrice gave an update on what was happening in the office, around the UK both in terms of GAIN and the wider neurological field. A quick update on the little pest spreading Zika raised a few questions, but top up the DEET containing insect repellent and steer clear of stagnant watering holes and you should be OK. There is always a small risk of getting GBS following a virus and an even smaller one of a recurrence so take precautions and enjoy your holiday. She also spoke of members getting involved in the CIDP study that was sent round by email and post and it was hoped we would be able to take part in other studies in the future. Finally a few questions were answered and the time was up.

The afternoon was rounded off with tea and biscuits and most people in the room won a raffle prize!

The next meeting will be on 15 October in Dorchester with guest speaker Lisa Shirley (physiotherapist).



Hints and Tips

Spring is here

Spring is the time to get out in the garden, to make the most of the weather and get set for the coming season.

It can be difficult to get motivated if you are not as able as you once were in the garden, and disheartening if you struggle to do jobs that were once easy for you to do. It may make it easier to plan the whole of your planned task through from start to finish before you begin. This way, you can anticipate which parts of the job may be difficult, and develop solutions to them. For example, it may be easier to use several small bags of compost than one big one, and it might make sense to gather all your tools and materials together before you make a start. Wheelbarrows are available with twin wheels and a single handle that make moving things around the garden much easier. For tasks that are currently beyond your ability you may have to plan for when someone is available to help you.

If you are affected by weakness, numbness, loss of mobility or grip, it may be worth looking at the different gardening tools that are available to make gardening more accessible. There is lots of information about these on the website <http://www.carryongardening.org.uk/>, including sources to buy them from. Peta have developed a range of easy to use gardening tools featuring pistol style vertical



grips with optional arm support cuffs <http://peta-uk.com/product-category/garden-tools/>. They also supply add-on grips to modify your existing tools.

Digging can be difficult and it may be worth considering a 'no-dig' approach, letting the worms do the digging, and applying a mulch to retain moisture, add nutrients and suppress weed growth. There are lightweight alternatives to traditional heavy forks and spades, and there is always the option of using long handled hand forks and trowels.

Using garden machinery may be more difficult than it once was. It may be necessary to use a more lightweight mower for example. Battery mowers are much more affordable than they used to be, and have advantages over both electric and petrol mowers.



There are a variety of lightweight battery powered secateurs, shears and trimmers that would make cutting tasks easier. When it comes to pruning, ratchet assisted tools may help, or it may be easier to use two handed loppers where the collective strength of two arms helps with the cut.

Where movement and mobility are affected, it may be necessary to have a seat to use or to alter your garden so that it is wheelchair accessible. Raised beds and containers may be options to consider that will 'lift' the garden up to a more reasonable working height.

Whatever adaptations you have to make to continue enjoying your garden, it is always possible to do so with the right help and support. If you would like any more advice you can contact Thrive on info@thrive.org.uk, or visit their main website at www.thrive.org.uk



Is it time to give your **finances** a spring clean?



It's now officially spring time, although it may not often feel like it. Sprucing up your finances is a great way to put a spring in your step. Here are the Money Advice Service's top financial tips for you to have a more flushed summer – and ways to get in contact if you wish to speak about your finances further.

1. Take a feather duster to your bank account

Look for any unusual payments that could be the result of overcharging. Audit your regular Direct Debits – are there any mistakes, or subscriptions you're paying for you don't really use? Finally, take a look to see if you're being charged a fee for your account. Extras such as travel insurance can often be bought cheaper elsewhere. We found only 60% of people check the items on their bank statements – but doing so could be the first step to managing your money.

Don't be afraid to switch your bank account if it's not right for you. You could get higher interest for doing so – or if you often go into overdraft, this could save you from higher fees.

2. Give your nest egg a boost

If you have an ISA, chances are you're not on the same interest rate you were on when you first opened your account. Spring time is the perfect time to take a look around and see whether you can find a better interest rate.

3. Get the real measure of your money

Do you know what interest rate you're paying on personal loans or credit cards? Sit down, make a list. Then you can see exactly which is costing you the most in terms of interest rates. Could you pay them off more efficiently, saving you money in the end?

4. Check all the nooks and crannies for the best deal for you

From utilities to your mobile phone, there are always opportunities to save. Make a list of all your providers and shop around – if you can save money by switching providers, challenge your provider to match the deal, or switch.

The Money Advice Service can help you with all aspects of your finances from savings to problems with debt. If you want personalised advice with your finances, you can contact us for free. Phone us on 0800 138 7777, or you can use our web-chat facilities, which are available through our website. If you wish to book a face-to-face appointment, our contact page will tell you more – the numbers differ with whether you are calling from England, Wales, Scotland or Northern Ireland - <https://www.moneyadvice.service.org.uk/en/static/contact-us>.

Useful links

Age UK

<http://www.ageuk.org.uk/>

Helpline 0800 169 6565

Information, advice and support for older people

Carers Trust

<http://www.carers.org/>

Tel: 0844 800 4361

Support and services for carers

Citizens Advice Bureau

<http://www.citizensadvice.org.uk/>

Tel. (Wales) 08444 77 20 20

Tel. (England) 08444 111 444

Free independent and confidential advice including fact sheets, sample letters and budget calculator

CAB self-help website

<http://www.adviceguide.org.uk/>

Cochrane Library

<http://thecochranelibrary.com/>

Independent high quality evidence for health care decision making

Department Health IVIg

<http://www.ivig.nhs.uk/>

A resource to healthcare providers to understand the Demand Management Programme for Immunoglobulin and access guidance and materials to ensure its effective implementation

Direct Gov

<https://www.gov.uk/>

Information on benefits, DVLA etc

Disabled Living Foundation

<http://www.dlf.org.uk>

Helpline 0300 999 0004

Impartial advice, information and training on daily living aids

Expert Patients Programme

<http://www.expertpatients.co.uk>

<http://www.wales.nhs.uk/sites3/home.cfm?orgid=537>

A self-management programme to help with learning for anyone over 18 with a long term health condition

Euan's Guide

<http://www.euansguide.com/about-us/>

Listings and review website to help disabled people find accessible venues

Listening Books

www.listening-books.org.uk

A service for those whose illness or disability makes it difficult or impossible to hold or concentrate on reading a book

Money Advice Service

<https://www.moneyadvice.service.org.uk/en/>

Not for profit government organisation created solely to help people with their finances

Neuro News

<http://www.neuro-news.co.uk>

Community hub for information on neurological conditions

Neurological Alliance

<http://www.neural.org.uk/>

The only collective voice for more than 70 national and regional organisations working together to make life better for 10 million children, young people and adults in England with a neurological condition

NHS Complaints Advocacy

<http://nhscomplaintsadvocacy.org>

The NHS Complaints Advocacy Service is a free and independent service that can help you make a complaint about a National Health Service (NHS).

Pubmed

<http://www.ncbi.nlm.nih.gov/pubmed/>

Citations for biomedical literature from MEDLINE, life science journals, and online books

Rare Disease UK

http://www.rare-disease.org.uk/documents/patient-experiences-2015.pdf?mc_cid=fe312c92e6&mc_eid=e173e4b5e2

The National Alliance for people with rare diseases & all who support them

Scope/DIAL

<http://www.scope.org.uk/dial>

Local disability information and advice

Turn2us

<http://www.turn2us.org.uk/>

Helping people to access welfare benefits, charitable grants and other financial help



The Charity receives no Government or Lottery funding and relies solely on charitable donations which can be made online through our website or forwarded to the office address.

Thank you



In memoriam

A donation to GAIN is a special way of remembering the life of a relative or friend.

www.gaincharity.org.uk