

# gain4all

Issue 8

Quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies

WINTER 2016



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



Especially at this time of year, we all find ourselves with unwanted items that we don't really want, may never use and are taking up valuable space. Why not have a good clear out, raise some funds and donate a percentage of the selling price to GAIN?

### 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](http://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

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### gain

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

### FREE HELPLINE:

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



# Message from the Chairman



As you may have heard I am to stand down as chairman at the next AGM. I have enjoyed my time as chairman, but the time has come for someone else to take on the role. The charity is undertaking a search to identify a suitable successor. In order to accomplish this, we will be advertising the post as widely as possible and will consider both members of the charity and external applicants.

The next few years will see the charity having to adapt both to the decline in subscribed

membership and the increased numbers of requests for support. We will have to meet the changing needs of those affected while continuing to offer a range of support to assist all those who need our help. At the same time, we must do all we can to increase our support for research at a time when so many traditional funding routes are beginning to dry up.

The change of name has been very successful in attracting more interest. The number of people asking for help has increased very significantly, while we have been featured far more often in the media. We must build on this to ensure that the charity grows and becomes even more effective in this ever-changing world.

Some of you may have read the Alzheimer's Society has been warned by the charity commission about its means of communication and protection of data. This is obviously a warning shot to all charities and we will review our procedures. Inevitably this will mean tighter regulation to ensure data held by the office and volunteers are properly secured and that our communications cannot be hacked. The penalties of not meeting the correct standards are severe, including very large fines. None of us would wish to have our funds hit in that way.

# gain NEWS

## Call for a Chairman

**Guillain-Barré & Associated Inflammatory Neuropathies is the only charity in the UK supporting those affected by these rare peripheral neuropathies. As James Babington Smith, Chairman of the Board of Trustees, is stepping down later in 2016, the charity now seeks an exceptional and inspirational individual to take up the baton and guide the charity through the coming period of challenge and development.**

### THE POSITION

- Lead and motivate the Board, manage and support the Director and staff team to excel at delivering GAIN's mission and strategic plan, while ensuring top class governance and performance in a tough, cash-starved operating environment.
- Act as a key figurehead for the charity, representing it as needed with key stakeholders. Assure a positive public image for the charity as the 'go-to' source of national expertise on these conditions.

- Develop and grow effective partnerships and alliances with existing and potential partners, supporters, opinion-formers and funders. Ensure clarity of vision, energy and an ever growing reputation for matchless expertise in the sector.

### THE CANDIDATE

- Seasoned and wise leader with a proven record of taking forward effective and high-performing Boards at times of strategic challenge. Able to motivate dedicated staff, set realistic yet ambitious goals and targets and see that these are achieved.
- Excellent, clear-thinking communicator with developed interpersonal and diplomatic skills allied to strength of purpose and determination.
- Ideally experienced in the charity or social enterprise space. Commercially acute and accomplished networker who instinctively seeks partnerships to optimise shared interests.
- Calm, irrepressible and resilient with genuine commitment to GAIN's mission, ethos and values.

**Further information and application pack can be obtained from the Director. Contact Caroline Morrice on [director@gaincharity.org.uk](mailto:director@gaincharity.org.uk)**



## gain2gether 2016 Programme

Planning is well underway for our day in Glasgow on Saturday, 25 June 2016. The event will be held in a hall in the John McIntyre building, located next to the main gate of Glasgow University and opposite Bute Hall and the Hunterian Museum.

The morning session will start with some readings from the seminal 1916 paper and a history of Guillain-Barré. Further contributions will come from leading neurologists and some of our former recipients of research money. Subjects covered will include current and future research as well as current and future therapies.

Each attendee will be given a packed lunch. This is to allow you to be flexible; you may wish to remain in the hall and talk to your friends or explore the campus and the Hunterian Museum or visit the Kelvingrove Park.

The session after lunch will be rather more light-hearted and will include contributions from a patient perspective, greetings from overseas charities attending the day, some physiotherapy and finally a look ahead over the next hundred years.

In the evening there will be a social function held in a local restaurant.

For those who wish to make a weekend of it there will be a golf competition run by Gordon Peebles, a Scottish member, in aid of GAIN.

We believe there will be something for everyone in the program and we look forward to seeing you on the day in Glasgow. If you would like to join us, online registration will be available through our website from 1 March.



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 April 2016 and the deadline for submissions is 18 March 2016. Please forward all articles to Lesley Dimmick [fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk)



## Meet the Medical Advisory Board (MAB)



**1. Who are you?**  
Dr Shakti Agrawal – Consultant Paediatric Neurologist

**2. Where do you work?**  
At Birmingham Children's Hospital and up until recently, I was head of the department.

**3. What is your role on the MAB?**  
I am on the MAB for paediatric GBS.

**4. What inspired you to join the MAB?**  
I was introduced by my adult neurology colleague and friend, John Winer, who encouraged me to join the MAB due to my special interest and publication of a review article on paediatric GBS.

**5. Do you have a special interest in GBS/CIDP or one of the variants?**  
As you know CIDP is not so common in paediatric patients (although some GBS do end up being like CIDP), so one does not see enough cases of CIDP to develop expertise in CIDP.

**6. What current global research excites you?**  
The role of specific monoclonal antibodies in acute treatment of GBS is something that needs exploring further.

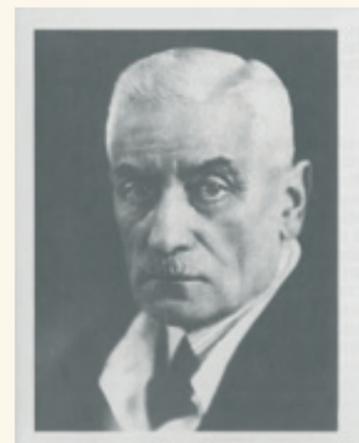
**7. Finally do you see a time when GBS and CIDP are preventable?**  
As you are aware it is very difficult to prevent GBS as it is very difficult to identify susceptible candidates. However, sinister organisms, like Campylobacter jejuni, if identified in a diarrhoeal illness one could be more cautious and perform specific anti GQ1B antibodies perhaps to predict the chances of developing GBS. Again an area that has not been looked at so closely in the paediatric population.

# Celebrating 100 years

Having been medical students together in Paris and both specialising in neurology, Guillain and Barré worked together during the First World War serving as doctors in the neurological unit of the French army. They noted the cases of two soldiers who had become partially paralysed. One, in particular, had fallen over when he had put his pack on and had been unable to get up. Both the soldiers quickly recovered, possibly assisted by treatment with pork chops and claret!

2016 marks the centenary of their seminal work on the disease studying these French soldiers who had contracted GBS whilst serving on the Western Front.

### Georges Charles Guillain



Born March 3, 1876 in Rouen; died June 29, 1961 in Paris.

After customary schooling he commenced the study of medicine in his native town, but after two years moved to Paris, where he received his clinical education at several hospitals and became interested in neurology. He received his medical doctorate at Paris in 1902 and became chef de clinique for nervous diseases and was

habilitated in 1910; habilitation is the highest academic award in France gained after post-doctoral research. After the war he served at the Hôpital Charité until his career was crowned with the professorship of neurology at the famous Hôpital de la Salpêtrière in Paris in 1923. He held this position until his retirement in 1947. Guillain was a prolific writer and received many honours. He was a member of French, American, and Japanese academies of science. In 1949 he was appointed commander of the Legion of Honour.

### Jean Alexander Barré



Born May 25, 1880 in Nantes; died April 26, 1967 in Strasbourg.

Barré received his medical education in his native town and after graduation moved to Paris. Barré was appointed professor of neurology in

Strasbourg in 1919. Like Guillain, he too was a prolific writer, publishing more than 800 scientific papers. His particular interest was in vestibular function and disease, and he founded the Revue d'oto-neuro-ophtalmologie. Many of the neurologists from France and other countries who trained with him became professors.

# Acute bulbar palsy variant of Guillain-Barré syndrome found

By Lucy Piper, Senior medwireNews Reporter

Researchers have identified a new variant form of Guillain-Barré syndrome (GBS) that is characterised by prominent acute bulbar palsy without neck or limb weakness.

The fact that acute bulbar palsy was the most prominent clinical symptom across the disease course in the 11 patients studied differentiates this clinical syndrome from the Miller Fisher syndrome (MFS) and pharyngeal-cervical-brachial (PCB) variants of GBS, says the team.

Indeed, according to a recently proposed classification system, "none of the cases satisfied the criteria for the MFS or PCB variant", they add.

The patients were identified from 184 enrolled in the Korean Inflammatory Neuropathy Consortium over a 2-year period. All of the patients showed the general features of GBS, including acute monophasic event and recovery, less than 4 weeks of clinical nadir and no accompanying upper motor neuron signs.

The most common initial symptom was slurred speech, followed by gait disturbance, diplopia, dizziness and tingling limbs.

All the patients had accompanying neurological symptoms. Ten patients had below normal or absent reflexes, while ophthalmoplegia and gait ataxia were each seen in nine patients, sensory abnormality in eight and unilateral facial palsy or diplegia in six patients.

Researcher Jong Seok Bae (Hallym University, Seoul, Korea) and colleagues propose that GBS presenting acute bulbar palsy without limb weakness could be classified into "acute bulbar palsy plus" if patients present with accompanying neurological symptoms – as in the case of the 11

study participants – and "isolated acute bulbar palsy" in the absence of such symptoms.

They add that all 11 patients had accompanying ophthalmoplegia, sensory ataxia or both, which are components of the MFS and PCB variants, and so acute bulbar palsy plus without limb weakness could be considered as a transitional spectrum between the two syndromes, appearing to be closer to PCB than MFS.

The study participants also shared positivity for immunoglobulin (Ig)G anti-GT1a antiganglioside antibodies, which have been associated with other kinds of GBS with bulbar palsy including the PCB variant, with all 11 patients testing positive, while just six tested positive for IgG anti-GQ1b antibodies.

“Therefore, IgG anti-GT1a antibodies appear to be involved with the pathogenesis of this syndrome and so can be used as a marker of this variant

*the team writes in Neurology.*

Nine patients were treated with a 5-day course of intravenous Ig infusions and the response was good with symptoms resolving within 3 months. Only one patient had symptoms that persisted for more than 6 months.

## medwireNews

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## Information for travellers to areas with circulation of Zika virus disease

A new mosquito-borne virus is fast spreading across the Americas and the Caribbean, with cases reported among travellers returning home.

Zika virus outbreaks are proliferating across multiple countries and territories in the region, such as Puerto Rico, Mexico, Brazil, Panama and Venezuela. They have been associated with increased reports of birth defects, including babies with very small heads, and of paralysis in adults.

There is no vaccine or specific drug to treat the virus.

### How is Zika transmitted?

The virus is transmitted by the bite of *Aedes aegypti* mosquitos, which are found in all countries in the Americas, including the U.S., but not Canada and mainland Chile.

Reports that the disease can be transmitted by sex are unconfirmed by the World Health Organization. It is unclear if the virus can be transmitted through human blood.

*Aedes* mosquitos also spread the more-common dengue fever and chikungunya. Zika symptoms are typically similar to these viruses, but milder, including fever and skin rash, usually accompanied by conjunctivitis and muscle or joint pain.

### Birth defects, paralysis?

The outbreak has led to reports of increased numbers of women in Brazil giving birth to babies with microcephaly, a rare condition that causes the brain to develop abnormally in the womb and results in a very small head.

In addition, there are reports of adult Zika sufferers subsequently developing Guillain-Barré syndrome, another rare but serious nervous system disorder that can cause muscle weakness, poor coordination and paralysis.

No direct links between Zika and Guillain-Barré syndrome have yet

been established. It is unclear if the virus can be transmitted from mother to child during pregnancy or birth, although this is can occur with both dengue and chikungunya.

### How the outbreak started

Zika was little known outside of Africa until Chile reported an outbreak on its remote Easter Islands in 2014. The first cases on mainland South America were reported in May 2015 and since then the virus has spread across countries, as far north as Mexico and to the Caribbean.

Guyana, Barbados, Suriname and Haiti have confirmed cases and in most other countries in the Caribbean there is a high chance of an outbreak, the Caribbean Public Health Agency said on Tuesday. The virus's novelty to the region means that "almost everybody" is susceptible, the body said.

### Prevention

People living in or visiting tropical areas with *Aedes* mosquitoes are advised to use insect repellent, wear long-sleeved, light-colored clothes and use insect screens or mosquito nets while inside.

Some affected countries have called on women to delay pregnancy because of the possible link to microcephaly. El Salvador has suggested that women wait until 2018, while Colombia, Ecuador and Jamaica (where the virus's presence is unconfirmed) have called for shorter delays, according to media reports.

### Places with reported zika cases so far:

Barbados; Bolivia; Brazil; Cape Verde; Colombia; Dominican Republic; Ecuador; El Salvador; French Guiana; Guatemala; Guadeloupe; Guyana; Haiti; Honduras; Martinique; Mexico; Panama; Paraguay; Puerto Rico; Saint Martin; Samoa; Suriname; Venezuela.

## Letter to the editor

Dear Sirs,

*This is not really a question as such, but I would like to share my experience and maybe help others in some way. I was diagnosed with GBS in 2008 and spent five weeks in hospital. At the start of my recovery I found I was suffering from what I can only call painless cramps up my right shin and left ankle. As time progressed these cramps became painful and more and more unbearable keeping me up and walking around for nights on end. I found these were worst if I had pushed myself and over done things, such as standing for too long, walking too far or going up and down stairs.*

*Six months ago, I was put on simvastatin for my cholesterol, and within days these cramps had gone completely. I still get, what I would call normal cramp, but no longer the extreme agony of before. I can even over do things and have no dreaded after effect. Now this might be a known fact, or it might just be a fluke, but just in case it might help someone else I thought I'd write and share my experience.*

*I hope I have not wasted your time, and thank you for your section in the magazine, it is a great help.*

*Yours faithfully*

*Alison Riley*

# NHS non-emergency numbers

**This service is for people who urgently need medical help or advice but it's not a life-threatening situation. Call this service if**

- You need medical help fast but it's not a 999 emergency
- You think you need to go to A&E or need another NHS urgent care service
- You don't know who to call or you don't have a GP to call
- You need health information or reassurance about what to do next

For less urgent health needs, contact your GP or local pharmacist in the usual way.

If a health professional has given you a specific number to call when you are concerned about your condition continue to use that number

## England – Call 111

The NHS 111 service is staffed by a team of fully trained advisers, supported by experienced nurses and paramedics. They will ask you questions to assess your symptoms, then give you the healthcare advice you need or direct you to the local service that can help you best. That could be A&E, an out of hours doctor, an urgent care centre or a walk-in centre, a community nurse, an emergency dentist or a late-opening chemist.

Where possible the NHS 111 team will book you an appointment or transfer you directly to the people you need to speak to.

If the NHS 111 advisers think you need an ambulance they will immediately arrange for one to be sent to you.

Alternatively, you can look at the NHS Choices website <http://www.nhs.uk/pages/home.aspx>

## Scotland NHS24 – Call 111

NHS24 and NHS Inform are health services that have been tailored specifically for people living in Scotland. The helpline is open 24 hours a day, 7 days a week.

### When to phone

You should only phone the NHS 24 helpline:

- if you or someone you know is unwell
- when your doctor's surgery is closed and you feel it can't wait until it re-opens.

If you're well, but have a question about your health or local NHS services, please contact <http://www.nhsinform.co.uk/>

## Wales NHS Direct – Call 0845 46 47

NHS Direct Wales is a phone service giving health information and nurse advice. You should call you GP surgery first as they may offer an out of hours service. Alternatively use the NHS Wales Direct website <http://www.nhsdirect.wales.nhs.uk/>

Since 2004, GPs have been able to choose whether to provide 24-hour care for their patients or to transfer responsibility for out-of-hours services to Health Boards. Health Boards are responsible for providing a high quality service for the local population. Some Health Boards provide care themselves. Others provide care through external organisations. This may be for out-of-hours treatment, or when surgeries are closed for another reason. This means different areas can have slightly different services. Further details can be found on the website <http://www.nhsdirect.wales.nhs.uk/localservices/localhealthboards/>

### Types of out-of-hours care

Out-of-hours cover may include some or all of the services below:

- GPs working in A&E departments, or minor injuries units (MIUs).
- Teams of healthcare professionals working in primary care centres, A&E departments or MIUs.
- Healthcare professionals (other than doctors) making home visits, following a detailed clinical assessment.
- Ambulance services moving patients to places where they can be seen by a doctor or nurse, to reduce the need for home visits

## Northern Ireland Out of hours Service Call – 0282566350

For out of hours treatment and advice call the Dalriada Care service for urgent conditions which cannot wait until your own doctor's surgery is open.

### Why is it important to phone first?

Please do not come to the centre without phoning first. This is because:

Many problems can be sorted out over the phone

- Patients often come to the centre when they need to go to casualty instead
- Patients who 'drop in' may have to wait longer. Those who have been asked to come to the centre will usually be seen first.
- All the centres are not staffed all the time which can result in unnecessary delays for patients

### What will happen when I phone?

Your details will be taken by an experienced member of staff. A nurse or doctor will call you back. Depending on your query you may be given advice over the phone, be asked to attend a centre, or a home visit will be arranged.

You should attend your nearest A&E Unit if you have had a serious accident.

If the condition is potentially life threatening (e.g. suspected heart attack) phone 999 [www.dalriadacare.org](http://www.dalriadacare.org)



The NHS non-emergency number

**Please note that these services record all calls and the records are maintained securely, and will only be shared with others directly involved with your care**

## Book launch

### *I'm Going Nowhere!*

The launch of Phil Graham's book *I'm Going Nowhere* took place on Saturday 21 November and was well attended by over one hundred guests including esteemed guest speakers Caroline Morrice (Director GAIN) and Dr.

Neil Archibald (Consultant Neurologist – James Cook University Hospital). The event was kindly hosted by the Park Head Country Hotel. Seventy-nine books were sold on the day and further orders have been received – one from as far as South Africa! "The event exceeded our wildest dreams and we are delighted to be able to help raise awareness and further funds for GAIN" said Phil.

"Our Dad has brought to the fore what it is like to be struck down with GBS. This book vividly captures his physical and emotional journey through the illness. A journey which we and our Mum shared with him. What we have witnessed has left a lasting impression on us. From initial paralysis to his long road to recovery our Dad has shown his strength of character and his ability to focus and remain positive through some terrifying times. As a family we have always been close – we are even closer now"

*Daniel & Padraic Graham*

*"Just finished your book and thoroughly enjoyed it from start to finish. In some parts I didn't know whether to laugh or cry! I actually laughed out loud in places."*

*"Can't put your book down! Feel as though you are telling me what happened face-to-face"*

All profit from sales will be donated to GAIN and books can be ordered by contacting Phil either by email: [phil@filmar.co.uk](mailto:phil@filmar.co.uk) or by phone: 01388 602479.

Cost £9.99 plus £2.00 (UK p&p)

*Pictures courtesy of John May Photography*

# fundraising reports

## One step at a time

At the end of September, Les Colley together with his supporters walked from Bromsgrove Hospital to Worcester Royal Hospital in five and a half hours raising over £200.00 for GAIN.

“The day was amazing and I really wanted to raise the profile of this amazing charity” said Les. “They helped me and my family so much through the illness. I wanted to do whatever I could for them and hopefully, this will raise lots of money for the charity. I want to thank everyone that walked with me too.”



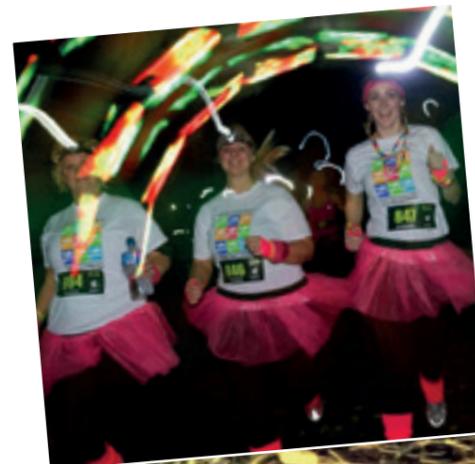
## Birthday Celebrations

In June last year, Allan Reid (left in photo) and Ronald Stalker celebrated their 40th birthdays with a joint party. Guests very kindly made donations enabling Allan to forward a cheque to GAIN for the generous amount of £1100.00

## GLOWING in the Park

Sarah, Katie and Alice took part in the Glow in the Park fun run on 30 October in Manchester raising £560.00 for GAIN. They also plan to climb Mount Snowdon in April.

“My dad passed away from GBS suddenly in 1987. I hope that the money we've been able to raise can help provide families and sufferers with the much needed support that we didn't have”  
*said Sarah (Bossos)*



## Coming up...

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

### Dry January

If you can help Rita through a non-alcohol January, please visit her JustGiving page: <https://www.justgiving.com/Rita-Woloszczuk>

### 6 March Anglesey Half Marathon

<http://angleseyhalfmarathon.com/>

### 10 April Manchester Marathon

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

If you can support Lee please visit his JustGiving page: <https://www.justgiving.com/Lee-Sharples/>

### 24 April London Marathon

If you have a place through the public ballot and will be supporting GAIN, we would like to hear from you.

### 2 May Belfast Marathon

<http://www.belfastcitymarathon.com/about>

### 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-Geere1/31-July-Prudential>

### 31 July Prudential RideLondon-Surrey 100



*The best celebration of cycling in the UK*

The 2016 Prudential RideLondon-Surrey 100 will be on Sunday 31 July and we still have a small number of Charity places. There is a registration fee of £45.00 with

minimum sponsorship of £750.00 and again, all money raised at this event will go to much needed medical research.

If you would like to take part and support GAIN, please contact Lesley Dimmick, tel: 01529 469912 or email: [fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk) for an application form.

### 11 September Great North Run



We have just heard that GAIN has been allocated five Charity places for the 2016 event which, having been on the waiting list for so long, is fantastic news. There is a registration fee of £45.00 with minimum sponsorship of £375.00

If you would like to take part and support GAIN, please contact Lesley Dimmick, tel: 01529 469912 or email: [fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk) for an application form.

### 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 his JustGiving page: <https://www.justgiving.com/Lloyd-j-Austin/>

## Struggling with your weight and need some help?



### Your GP can help you to achieve a healthy weight, and enjoy the health benefits that it will bring.

Being overweight can seriously affect your health. If you're overweight, you're more likely to develop health problems such as heart disease, a stroke and type 2 diabetes. Most overweight people are overweight because they consume more energy than they use through physical activity. This means that the best way to lose weight is to make achievable, long-lasting changes to your eating and physical activity habits. If you've tried changing your diet and physical activity habits but are finding it difficult to lose weight, a trip to your GP could help. This is what you should expect.

### Assessing your weight

First, your GP or practice nurse will want to assess whether your current weight is healthy or not. This means measuring your weight and height to calculate your body mass index (BMI).

Your BMI indicates whether you are a healthy weight for someone of your height. A healthy BMI for adults is between 18.5 and 24.9. A BMI of 25 or above means that you're overweight.

### Measuring your waist

Your GP or practice nurse may measure your waist.

Your waist circumference can indicate whether your weight is putting you at risk of health problems, such as type 2 diabetes and heart disease.

### Other tests

Your GP may take your blood pressure and carry out other tests, such as a blood test, to check for any health conditions that may be related to your weight.

### Achieving a healthy weight

If you're overweight, changes to your diet and physical activity levels are the first step to helping you lose weight.

Your GP can help you to assess your current diet and levels of physical activity, and set goals for change.

### Your diet

Nottingham GP Dr Ian Campbell, from charity Weight Concern, says that the best way to assess your diet is by keeping a food diary – a written record of everything you eat – for one week. This can help you and your GP identify habits, such as adding sugar to your tea, that you can change.

### Exercise

Your physical activity levels can be measured with an activity diary.

Your GP may also suggest that you wear a pedometer for a week. A pedometer measures the number of steps you take and gives an indication of your daily activity levels.

### Setting goals

Once your GP has a clearer picture of your diet and level of physical activity, they can help you identify simple lifestyle changes.

"It's important that the patient decides what changes they're going to make," says Dr Campbell. "That way, they're more likely to stick to them. I usually get them to agree to three reasonable goals."

This could be cutting down on alcohol, eating a healthy breakfast and incorporating physical activity into your daily routine.

Your GP should offer you regular follow-up appointments, usually every two weeks to a month, to monitor your progress.

### Other weight loss services

Your GP may refer you to other services, such as local weight loss groups. These could be provided by the NHS, or may be commercial services that you pay for.

"Having support from other people in your situation can really motivate you to lose weight," says Dr Campbell.

If it's appropriate, your GP may recommend exercise on prescription, where you are referred to a local active health team for a number of sessions, under the supervision of a qualified trainer. Depending on where you live, the exercise programme may be free or at a reduced cost. There may also be other physical activity opportunities that your GP could point you to.

For more information visit <http://www.nhs.uk/Livewell/loseweight/Pages/WhataGPcando.aspx>  
NHS Choices

**What is winter tiredness?**

If you find yourself longing for your warm, cozy bed more than usual during winter, blame the lack of sunlight. As the days become shorter, your sleep and waking cycles become disrupted, leading to fatigue. Less sunlight means that your brain produces more of a hormone called melatonin, which makes you sleepy. Because the release of this sleep hormone is linked to light and dark, when the sun sets earlier your body also wants to go to bed earlier – hence you may feel sleepy in the early evening.

While it's normal for all of us to slow down generally over winter, sometimes lethargy can be a sign of more serious winter depression. This health condition, known medically as seasonal affective disorder, affects around one in 15 of us but can be treated. If your tiredness is severe and year-round, you could have chronic fatigue syndrome.

# Winter Tiredness

*(or Seasonal Affected Disorder)*



**10 tips from The Sleep Council to get a more restful night**

- 1. Keep regular hours**  
Going to bed and getting up at roughly the same time every day will programme your body to sleep better.
- 2. Create a restful sleeping environment**  
Your bedroom should be kept for rest and sleep. Temperature, lighting and noise should be controlled to help you to fall (and stay) asleep.
- 3. Make sure that your bed is comfortable**  
It's difficult to get restful sleep on a mattress that's too soft or too hard, or a bed that's too small or old.
- 4. Exercise regularly**  
Moderate exercise on a regular basis can help relieve some of the tension built up over the day. Make sure that you don't do vigorous exercise too close to bedtime, however, as it may keep you awake.
- 5. Less caffeine**  
Cut down on stimulants such as caffeine in tea or coffee, especially in the evening.
- 6. Don't over-indulge**  
Too much food or alcohol, especially late at night, can interrupt your sleep patterns. Alcohol may help you to fall asleep initially, but it will disrupt your sleep later on in the night.
- 7. Don't smoke**  
It's bad for sleep.
- 8. Try to relax before going to bed**  
Try to relax both the mind and body.
- 9. Write away your worries**  
Set aside time before bedtime to review the day and make plans for tomorrow – make a list. The goal is to avoid doing these things when you're in bed, trying to sleep.
- 10. Don't worry in bed**  
If you can't sleep, don't lie there worrying about it. Get up and do something relaxing until you feel sleepy again, then return to bed.

For more information, visit their website at <http://www.sleepcouncil.org.uk/>

**Try these tactics to boost your vitality during the winter months**

**Sunlight is good for winter tiredness**

Open your blinds or curtains as soon as you get up to let more sunlight into your home. And get outdoors in natural daylight as much as possible, even a brief lunchtime walk can be beneficial. Make your work and home environment as light and airy as possible.

**Fight fatigue with vitamin D**

The wane in sunshine over the winter months can mean you don't get enough vitamin D, and that can make you feel tired. The main source of vitamin D is sunlight, but here in the UK we can't make any vitamin D from winter daylight between November and March so it's especially important to get vitamin D from your diet. Good food sources of vitamin D are oily fish (for example salmon, mackerel and sardines), eggs and meat. Vitamin D is also added to all margarine, and

to some breakfast cereals, soya products, dairy products and low-fat spreads. Even with a healthy, balanced diet it's possible to become vitamin D deficient. The latest National Diet and Nutrition Survey found evidence of vitamin D deficiency in all ages especially toddlers, 11-18 year old girls and men and women over the age of 65. The government recommends that people at risk of



vitamin D deficiency – including everyone 65 or over – should take a daily supplement.

**Get a good night's sleep**

When winter hits it's tempting to go into hibernation mode, but that sleepy feeling you get in winter doesn't mean you should snooze for longer. In fact if you do, chances are you'll feel even more sluggish during the day.

We don't technically need any more sleep in winter than in summer. Aim for about eight hours of shuteye a night and try to stick to a reliable sleep schedule. Go to bed and get up at the same time every day. And make sure your bedroom is conducive to sleep – clear the clutter, have comfortable and warm bedlinen and turn off the TV.

NHS Choices <http://www.nhs.uk/Livewell/tiredness-and-fatigue/Pages/winter-tiredness.aspx>



### Lancashire & Cumbria

*Storm Desmond* was an uninvited guest to the Christmas meeting of the Lancashire & Cumbria branch on Saturday 5 December, but this was not enough to deter those who had already come through GBS and similar, though boats on the canal may have been a more appropriate way of getting to the meeting. Even Father Christmas managed to arrive and in total we had twenty-seven including a couple of new people.

As is our tradition at the Christmas meeting, we had a Tortoise Drive (think Beetle!) with winners and losers moving round the room, so everyone got to meet. Then after a very amusing recitation from our chairman, Sybil, we were serious for a minute or two with our Sufferers & Supporters Q&A Forum, which is such an important part of our meetings when we share experience, advice and support, especially for those still facing great difficulties to themselves or their families through GBS and similar. Then on to the raffle and our Jacob's Join tea and lots of friendly chat, finally launching off onto our journeys home which for several members meant arriving home to a night without power.

We hope for better weather for our spring meeting on 5 March as usual commencing 2.00pm at Bilsborrow Village Hall on the A6 between Preston & Garstang. Further meetings: 18 June, 24 September and 3 December.

Regular members Doris Stewart and best friend Jacqui Hughes have been coming to the branch meetings since 2010. When Doris became ill with Guillain-Barré syndrome Jacqui was not only her friend, she became her carer. It was suggested Jacqui put pen to paper and she came up with writing something a little different, **Guillain-Barré – syndrome from a carer's point of view**, with a twist. After Jacqui had finished her piece, she said she hadn't realised the impact reliving the events would have. Carers of loved ones are on an emotional journey too, and Jacqui has put together that journey superbly. Our thanks to Jacqui Hughes for sharing her story.

# NEWS from around the regions



Jacqui (on the left) with Doris

### A journey through the eyes of a carer

by Jacqui Hughes

My name is Jacqui and I have been asked to share my experience of supporting my best friend through the journey from diagnosis to recovery from Guillain-Barré syndrome. Before you begin to read this account, two things need to be made crystal clear. Firstly, I am 'as mad as a hatter', a born optimist and always see life as 'a glass half full'. Secondly, I love music and always associate events and moments in time with lines from famous songs. So, I challenge you to identify all the songs referred to in this reminiscence!

"Where do I begin to tell the story?" Well 7 years ago my life was quite normal (normal for me any way!). I had a job that required me to create 26 hours in every day – but they were "Happy Days". I loved my job and I really loved my social life with my best friend Doris. Doris had unlimited energy and she did everything at double speed. I frequently found myself 'Power Walking' – well "Keep on Running, Running From Now On" just to keep up with her!

In fact I nicknamed her as Speedy Gonzales! The winter of 2009 was colder than normal, but Doris and I still faced "Stormy Weather" to take my Boxer dogs on long walks past "Mountain High and River Deep". The truth was that my dogs followed 'Auntie Doris' like the Pied Piper – I just trailed behind! I was constantly in awe of Doris's energy and the way she "Talked with the Animals" (the truth is she prefers dogs, cats, degus, and parrots etc. to humans – she often says 'animals give love that is unconditional'). All the indications were that it was going to be a "White, White Christmas". Little did I know it was going to be a "Blue, Blue, Blue Christmas" before very long.

As usual, her daughter and granddaughters came up from Dorset for Christmas and we all had a great time, including time with her other daughter, son-in-law and grown up grandsons. I did, however, notice that Doris was very tired and frequently began to complain about feeling ill and having tingling in her mouth and feet. After the family had all gone home, the symptoms became worse and on 31 December she finally agreed to ring the doctors. Well what a waste of time. She could not get an appointment and even worse the receptionist decided to advise 'It is just a chill – take paracetamol and keep warm'. When Doris pointed out she has an allergic reaction to paracetamol and they make her sick, the receptionist replied 'Well never mind – you will just have to be sick'. (Needless to say, when Doris ultimately ended up in hospital, I started the "Battle of Jericho" and the "Walls Came Tumbling Down". I loudly and publicly tore a strip off the receptionist, practice manager and senior doctor at the practice and Doris eventually received an unconditional apology and assurances that new protocol would be put in place to prevent receptionists giving medical advice). Over the next few days her symptoms got worse. After

the asinine response from the Surgery, she refused to contact the practice again. Eventually, during the following weekend, I dragged her to the Emergency Doctors and she saw a recently qualified doctor who examined her and commented 'If it wasn't so rare, I would suspect you could have Guillain-Barré syndrome. If the symptoms persist or get worse you must go to Accident and Emergency'. Less than 48 hours later the symptoms were significantly worse and I ended up taking her to A&E. After 6 hours in A&E they decided she had a Renal Infection, sent her home with medication and told her to contact her GP for an appointment within the next 2 days.

The next day I went off to work and rang Doris every couple of hours to check how she was and whether she had got an appointment at the doctors. She had managed to get an appointment, but not for 2 days. I visited that evening and became very concerned; she looked really poorly and was very unsteady on her feet. Against my better judgement, I went to work the next morning and just hoped she was going to be OK until I could take her to the doctors. Oh boy! Did I have a day to remember!! Around 3.00pm I got a phone call from Doris's doctor who was actually at Doris's house, her legs had lost all feeling and the doctor had found her crawling to answer the door when she arrived! The doctor had arranged admission to hospital but it was going to be up to 3 hours before an ambulance could attend. The doctor asked if I could come home and take her to the hospital as it would be quicker than waiting for the ambulance. I picked up my briefcase and was "Homeward Bound" within 5 minutes. I got to Doris's house and the doctor helped me get Doris into the car – I set off and the doctor rang the hospital to confirm we were on our way. We were met at A&E and Doris was quickly transferred into the Observation Ward. After 4 hours I was told she was settled on the ward and I should go home and ring in the morning. It was now 9.00pm, so I went home and contacted Doris's eldest daughter (who lives 8 miles away) and agreed we would ring the hospital the next morning then meet at visiting time the next evening. The next morning I rang and was told she had 'a comfortable night' and they would have carried out tests to identify what was going on by visiting time that evening. Little did I know that was "Castles in the Sky".

At around 11.00am that morning I received a phone call from Doris's daughter asking me to get to the hospital as quick as possible. Doris had deteriorated rapidly and they were going to perform a tracheotomy. However, Doris being Doris, she had refused to let them perform the procedure till she had spoken to us both. I picked up my car keys and flew! It is true to say I was driving close to the legal speed limits but was clearly "Flying without Wings". Her daughter and I arrived within minutes of each other to discover she was paralysed up to her mouth, but refused intubation until she had seen us both. Listening to my best friend (and partner in crime) trying to tell us both "Time to say Goodbye" was heart-breaking – but I needed to be strong for her daughter. Once that ordeal was completed, Doris was taken into Theatre and we sat and waited for news. Following the operation, the surgeon came to talk to us and told us it was definitely Guillain-Barré syndrome and that because of Doris's age (66) and a history of COPD, recovery was going to be very slow and it was unlikely she would ever live independently again. Realistic as this may have been – they underestimated the "I Get knocked Down and I Get Up Again" attitude that is Doris.

I had previously seen people in Intensive Care so warned Doris's daughter to expect her mum to look 'rough' – OMG! I was not prepared for the scene before me – the lighting in the side room was dimmed and there were numerous tubes and machines attached to Doris. It was a cross between "Ground Control to Major Tom" and "I'm an Alien, I'm a Legal Alien". Having recovered from the initial shock, her daughter and I settled into a pattern that would carry on when we visited over the next 7 days. Doris drifted in and out of consciousness and we sat and shared funny stories about the person we both knew was the real Doris. There were serious concerns about Doris's lung function and the complication of a chest infection. The ward staff were really good. They constantly monitored the tracheotomy and cleared blockages, cared for her with compassion and reassured us both she was going to improve soon. They were right – within 7 days she had improved enough to move to the Intensive Care Ward and was much more alert. In fact, she started trying to talk and this presented a situation that verged on a comedy routine. Her mouth didn't move properly and the tracheotomy meant there was no sound! Doris got really cross with us because we could not understand her – the solution was akin to a game of 'Charades'. All I could hear in my head was "Give Me a Sign. Hit Me Babe One More Time".

During the next couple of weeks the chest infection was improving, but did cause repeated blockages in the tracheotomy, which caused Doris considerable distress and fear (she still couldn't speak and therefore became terrified she could not let them know when it got blocked). To address this, staff made a makeshift rattle, using a small sample bottle and bits of plastic, and fastened it to Doris's wrist. All she had to do was shake the rattle if she needed help. Well – it was a roaring success and whenever she rattled, it was reminiscent of the Dowager at Downtown Abbey! At this point, two significant things happened. Firstly, following a period of gradual independent breathing, the tracheotomy was finally removed and secondly, they found Doris had contacted MRSA. The treatment was a regular application of a body wash – the only problem was that she had an allergic reaction and her skin went bright red. She looked sunburnt and all I could think was "Last Year We Went to Sunny Spain". However, she was now off tube feeding and eating real food. The only problem was that the liquidised food served at mealtimes was 'gross' – I decided the best answer was to make rice puddings, soups and liquidised stews at home and bring them in each day in a food thermos.

The skin reaction subsided and the next 2 weeks of the physiotherapy sessions finally gave Doris the strength to start walking. I would like to say it was "Wheels on Fire" but initially it was more "Only 24hrs from Tulsa" – but it was independent mobility! Within a week or so she finally transferred to the High Dependency Unit where she continued to make slow but steady progress and very quickly moved to the Rehabilitation Ward. She had turned a corner and it was a case of "I Can See the Green, Green, Grass of Home". It was now the end of April and it was all systems go for a weekend 'pass', prior to planning discharge. There was a suspicion she had picked up an e-coli infection, but the hospital decided it was clear and Doris came to stay with me for her first weekend out of hospital in over 4 months. Well, 24 hours later she was running a fever and I had to take her back. I was gutted – but these setbacks are to be expected. I went home and was asleep before my head hit the pillow. Some hours later the phone rang and I "Woke up One Morning Half Asleep. With All My Blankets In A Heap". It was 3.00am and Doris wanted me to take her an electric blanket because she was freezing. I thought she was 'off her trolley' but the nurse came on the phone and said it was OK, the e-coli infection was causing the shivers and gave me instructions on how to get through the hospital to the ward. To fully understand this fiasco you need to know two things. Firstly I am

terrified of the dark and secondly, to get to the ward out of hours, you have to go via the morgue! With electric blanket and Imodium in hand it was like "The Monster Mash" but I completed my mission!

The infection cleared and two weeks later Doris was discharged to my care (much to the horror of Doris's daughter – she believed I was too irresponsible to care for her, but I have a bungalow, so it was a 'no brainer'). Doris stayed with me for the next 3 months while she recovered her strength. There were times she became very upset that she was not making the progress. But she still fought and "The Higher You Build Your Barriers, The Taller I Become" reflects her determination. Between hospital appointments and clinics she began to make rapid progress and had a phased return to her own house. When I finally moved her back home I knew it was important to let her have her space and independence but couldn't help saying "You Just Call Out My Name and I'll be There". It was so hard to walk away – but it was the right time. The first time she got behind the wheel of her car and actually drove again, I knew she had won the battle.

## South West England

On Saturday 24 October the West of England branch met at Saltash in Cornwall. We were delighted to welcome James Carter, senior orthotist at Plymouth Community Healthcare, who talked to us about muscles and what happens to them after periods of paralysis. He demonstrated how the stronger limb muscles can take over, for example the stronger calf muscles are responsible for raising the whole body weight off the ground and the smaller muscles at the front of the leg only need to lift the weight of the foot up to 90 degrees. These smaller muscles are the ones most likely to suffer wastage. James explained how orthotists use special braces to try to maintain a full range of motion in the arms and legs. However this can cause other problems as a full brace is very controlling and the patients might feel very vulnerable.

James explained how it is very difficult to maintain the full range of muscle strength so physiotherapy is an essential factor in stretching muscles and keeping them supple. As patients recover they may regain enough energy to do their own exercises, but learning to use muscles again, through all the phases connected with walking, can be very difficult and challenging. If the nerves have been

Over the last 6 years, she has gone from strength to strength. As expected, there have been many frustrations and hard times but throughout she "Ate It Up and Spat It Out". She still has some weakness in her legs (she sometimes wobbles when walking and often refers to it as doing the 'Viennese Waltz') but I have my best friend back. Her wicked humour and mission to control my 'sweet tooth' is as sharp as ever – and I couldn't be happier. I am no longer the Carer – now I just care deeply. I watch her take off in Kermit (her new yellow Nissan Juke) and I feel so proud of how far she has come.

I hope this article is helpful for those Carers who have "Only Just Begun" the journey and those who are still on the "Long and Winding Road" to seeing their loved one beat Guillain-Barré syndrome. For me it has been a privilege to take that journey with Doris. My thanks go to all the members of Lancashire and Cumbria Branch at Bilsborrow, their friendship has been invaluable.

badly damaged and no longer send messages to the muscles, they will fade away. Weak muscles tire quickly and the patients will experience peaks and troughs, like athletes, and as such may benefit from managing their activity levels accordingly. Residual problems can often be helped. For example, relatively simple devices can help with foot drop and wrists can have splints to hold them in a neutral and functional position.

The talk ended with a very useful question and answer session. Of particular note was the advice about shoes that can help people with poor balance or no feeling in their toes. The shoes should bend at the joint line, be firm and tight at the back to hold the heel in the vertical position, and with a wide heel for better balance. It is also sensible to wear socks without seams and without elastic in the ankle, such as those recommended for diabetics.

The West of England branch is very grateful to James for coming to talk to us. It was a most useful session and completely fascinating! The meeting ended with tea and cakes and an opportunity to discuss individual problems with James.

The date of our next meeting is Saturday 19 March at Saltford Golf Club at 2.00pm

**Yorkshire**

The October meeting of the Yorkshire Branch was well attended and our thanks to guest speaker Maureen Connor from 'Carers Count' of Kirklees. We were also presented with a cheque for £500.00 from the Association of Yorkshire Golf Club Stewards presented by Mr Eric Snowden and the sister-in-law of one of our members, Clive Hubert, asked for money instead of birthday presents that she split between two charities. One of them was GAIN and raised £300.00

**Our next meeting will be on the 20 March 2016 at the Betty Boothroyd Centre, Dewsbury Hospital.**



**IN MEMORY**  
*Ken Sawyer*

The Yorkshire Group recently lost Ken Sawyer who passed away peacefully at the end of November.

In the late 1990's an attempt was made to form a Yorkshire branch of GBSSG. This move failed but some months later Ken appeared and with his determination and sense of direction our Yorkshire group emerged.

Ken was a regular at Annual Conference and worked hard to raise the profile of CIDP within the national organisation.

*Peter Kirbyson and Doris Fryer*



Susan Booth receiving cheques



**Gifts in wills**

What will your legacy be?



A gift to Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) in your will is an extra way of looking after the people you care about who have been affected by GBS, CIDP and associated inflammatory neuropathies: your own family, friends or even people you'll never know. People you will want to help because you know how hard it can be when families are affected by these rare and often devastating conditions.

Your gift will help make sure we can be there for all of them if they ever need us, whether that's 10, 20 or 30 years from now.

**How we use these gifts**

These gifts come in all shapes and sizes. Big ones, small ones – £200, £3,000, £20,000, £110,000, 20% or 100% of an estate or anything left over after the other gifts have been made.

We use these gifts to give support to people affected by the conditions when they most need it:

- a recovered patient will listen and help using their own experiences;
- up to date literature to inform the patient and their loved ones;
- medical information packs for hospitals and GP surgeries;
- research into the conditions to try and find a future where no one has to suffer.

“ these gifts come in all shapes and sizes

We understand that when making a will your family must come first but even a small gift will help us give every person affected by GBS, CIDP and associated inflammatory neuropathies, and their loved ones, the best possible support in their hour of need.

For more information email: [fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk)

or look at our website: [http://www.gaincharity.org.uk/wills-and-legacies/info\\_55.html](http://www.gaincharity.org.uk/wills-and-legacies/info_55.html)

**How to leave a legacy for our work**

Please ensure your will includes our full name, registered office address and registered charity number.

Guillain-Barré & Associated Inflammatory Neuropathies  
Woodholme House, Heckington Business Park,  
Station Road, Heckington, Sleaford NG34 9JH  
Registered Charity in England & Wales 1154843

**If you have already left a legacy for the GBS Support Group**

Following the change in status and transfer of all assets and liabilities to the new Charitable Incorporated Organisation (GAIN), the GBS Support Group has been registered on the Charity Commission's Register of Mergers which means that a legacy left to the GBS Support Group will be treated as if it had been made to Guillain-Barré & Associated Inflammatory Neuropathies.

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](http://www.gaincharity.org.uk)