

# gain4all

The quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies

Issue 12 Summer 2017  
£3.00 or FREE to Registered Users of GAIN Charity

## MARLIN'S MISSION

**IMPRACTICAL**

How sailing enthusiast & journalist **Dave Selby** became captain of his own destiny

### ALSO INSIDE

Parallel London 'GAINs' momentum  
Make every month GBS Awareness Month  
Don't gamble when you travel  
BBQ with confidence  
Ask the Experts  
Your stories  
Regional Round-up  
PLUS easy ways to support your favourite charity

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STUFF**  
Pages 5 & 15



Guillain-Barré syndrome is a rare autoimmune condition affecting the peripheral nervous system, in which the nerves in the arms and legs become inflamed and stop working



**Supporting people affected by GBS, CIDP & associated peripheral neuropathies**

In the UK each year, 1,200 people are diagnosed with GBS and a further 500 with CIDP



80% of those with GBS will make a good recovery, but between 5-10% of people will not survive and the other 10-15% may be left with severe mobility or dexterity issues



**GAIN is the only national organisation in the UK and Republic of Ireland dedicated to supporting people affected by these conditions**



Guillain-Barré & Associated Inflammatory Neuropathies (GAIN)

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

Registered charity no. 1154843 & SCO39900

# gain4all

Quarterly magazine of GAIN

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Front cover photograph  
courtesy of Dave Selby

Guillain-Barre & Associated  
Inflammatory Neuropathies  
Registered charity  
1154843 & SCO39900

## Message from the Editor

Welcome to Issue 12 of **gain4all**, the quarterly magazine of the Guillain-Barré & Associated Inflammatory Neuropathies charity. As we head into summer, some of us will be contemplating going on holiday, or maybe having a 'stay-cation' and getting out the BBQ. Either way, we have some advice on pages 8 & 9 for keeping safe and avoiding one or two seasonal pitfalls.

You may have noticed that the cover bears a promise of 'free stuff', and since there is no such thing as a free lunch, it will come as no surprise that in exchange, we would like you to do something for us! The month of May marked GBS awareness month in the USA, but here in the UK and Ireland we would like to raise the profile of the charity and the conditions all year round, and we need **your help** to do it. Why not pop over to page 5 to find out how easy it is to sign up and start spreading the word!

## Inside



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# Ringling the changes

**A recent review showed us just how much communication methods between GAIN and those affected by the conditions have been evolving over the years.**

An increase in the use of the internet and social media sees fewer people making phone calls in favour of text messaging and applications such as WhatsApp.

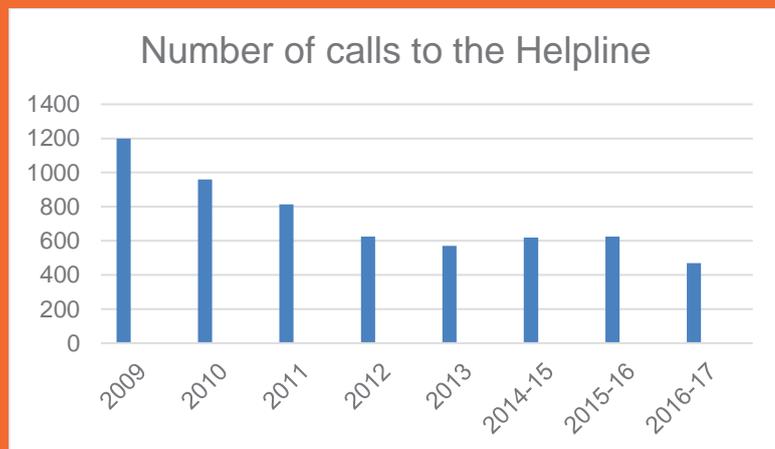
The charity has seen a dramatic increase in website traffic which has coincided with a decline in the number of calls being made to the Helpline. Consequently, our Helpline volunteers have at times felt frustrated at being available for a 24-hour period and then not receiving any calls.

We appreciate that our volunteers want to help newly diagnosed patients and feel our Helpline arrangements were no longer allowing them to fulfil their expectations.

**Overall there is a decline in people wanting one-to-one peer support as traditionally offered, favouring indirect contact through our website and social media platforms.**

The charity must respond to changing consumer habits and expectations and we regularly review our communication channels to make sure we continue to meet the needs of people looking for support. We hope that these changes will result in a better experience for everyone including our volunteers. We will be monitoring this arrangement to ensure that we continue to offer the best possible service.

**This diagram shows a significant decline in the numbers contacting the Helpline over the years, from 1,200 in 2009 to fewer than 500 in the past year**



## Arrangements from 1<sup>st</sup> June 2017

- The Helpline is answered by a member of staff during office hours (Monday-Friday, 9am-3pm)
- If the caller wishes to speak to someone with personal knowledge of the conditions, a volunteer with appropriate experience will call them back
- Outside office hours, the caller is invited to leave a message which will be responded to on the next working day
- The caller will also be signposted to the GAIN website where they can read and download further information
- The 'out of hours' message can be changed to reflect topical issues such as advice about flu vaccinations or the Zika virus

# Getting the word out



According to **Rare Disease UK**, a rare disease is defined by the European Union as one that affects fewer than 5 in 10,000 of the general population, or roughly 1 person in 2,000. There are between 6,000 and 8,000 known rare diseases and around 5 new rare diseases are described in medical literature each week.

**Guillain-Barré syndrome is a rare autoimmune condition affecting 1-2 people in 100,000, meaning up to around 1,300 people will be diagnosed with an acute form of GBS (also known as AIDP) in the UK each year. In addition, roughly 0.5-1 person per 100,000 is diagnosed with CIDP, a longer-lasting chronic variant, with a prevalence (the number of people living with the condition) of around 2,500 at any one time in the UK.**

The symptoms of GBS and the associated acute and chronic inflammatory neuropathies, of which there are several, may vary hugely from one patient to the next. Added to this, many of the symptoms are also present in other neurological conditions, making it potentially difficult to diagnose.

The GP to patient ratio varies considerably across the UK, with an average of around 1,800 (NHS Health Education England), and it is estimated that a GP may see as many as 30-40 patients each day, with around 10 minutes to spend on each appointment.

Taking these considerations into account, it is unsurprising that a General Practitioner, not having specialised in autoimmune inflammatory peripheral neuropathies, may not be able to positively identify and diagnose a rare condition such as Guillain-Barré syndrome or CIDP. In fact, given the variables, what may be more surprising is how often a GP does spot the syndrome and is able to refer a patient to hospital immediately.

Having said all that, however, here at GAIN we understand the frustration felt by patients and their families when GBS is not recognised and diagnosed at an early stage.

## What we're doing about it

We know that trying to raise awareness amongst the public has insignificant impact with a rare condition such as Guillain-Barré syndrome. There are too few cases, and most people tend to disregard or forget information unless they have a reason to retain it.

By reaching out to medical practitioners, however, we can raise the profile of the conditions, and at the same time improve signposting to the charity so that patients can access the information and support offered by GAIN **at the point of need**. We are currently putting together a campaign that will be targeted at neurology departments throughout the UK and Ireland. But we could also use your help.

## What you can do about it

**Become a Community Action Champion & help us make every month GBS Awareness Month!**

You can help get our information into local doctors' surgeries and other community organisations.

**Complete your details on the insert that came with your magazine** and we will send information packs directly to named doctors at your local surgery, or a supply of leaflets and posters for you to take to your surgery or other public access buildings such as a Citizen's Advice office or library.

**To say thank you, we will also send a bumper bag of free GAIN stuff to the first 30 gain4all readers to respond, so you can wear our name with pride and spread the word even further!**





# UNITED GRAND LODGE OF ENGLAND

Most people have heard of the Freemasons, but how much do you really know about them?

As GAIN is one of many hundreds of charities benefitting from the Freemasons Tercentenary celebrations this year, we thought it a good opportunity to find out a bit more.

## Freemasonry is one of the world's oldest and largest non-religious, non-political, fraternal and charitable organisations.

For many, its biggest draw is the fact that members from all walks of life meet as equals, whatever their race, religion or socio-economic position in society. Its values are based on integrity, kindness, honesty, fairness and tolerance.

The consensus amongst Masonic scholars as to the origins of Freemasonry is that it descends from the organisation of operative stone masons who built the great cathedrals and castles of the middle ages.

Throughout the 1600s, there is evidence of gentlemen becoming Masons of non-operative lodges, but it isn't until 24<sup>th</sup> June 1717 that four London Lodges came together at the Goose and Gridiron Tavern in St Paul's Churchyard, declared themselves a Grand Lodge and elected Anthony Sayer as their Grand Master. This was the first Grand Lodge in the world.

Further Grand Lodges were subsequently established, in Britain, Ireland and around the world.

There are currently 200,000 Freemasons under the United Grand Lodge of England, with a further 150,000 in Ireland and Scotland, and a total of approximately 6,000,000 Freemasons worldwide.

Find out more at [ugle.org.uk/about-freemasonry](http://ugle.org.uk/about-freemasonry)

## For Freemasons, for families, for everyone

Kindness has always been a core principle of Freemasonry. Individuals give time and money to help others, whether locally, nationally or globally. It may be realising a dream for a member's child, caring for older Freemasons, volunteering in a local community project, making donations to other UK charities or responding to an international disaster appeal.

**Raising over £33 million a year, the Freemasons are now one of the UK's top charities, and one of its main grant-giving bodies.**

## The five charities of the Freemasons



Improving the lives of our members, their families and the wider community through grant-giving

Caring for older Freemasons and their dependants for over 160 years, and operating 17 care homes, all able to offer specialist dementia care as required



Providing relief grants for individuals experiencing financial difficulty as well as donating millions of pounds to charitable projects

To relieve poverty and advance the education of the children of a Masonic family, and, when funds permit, support other children in need



Funded by Freemasons & their families to provide grants to people with a long wait for an identified health or care need & unable to fund it themselves

GAIN is fortunate enough to have benefitted from many Masonic charitable contributions over the years, and have received donations from four different Lodges so far in the last two months, totalling nearly £1,500! We would like to say a very warm 'Thank You' to all the members of the following Lodges for their kindness and generosity;



Warwickshire Masonic Charitable Association



Sandwich Masonic Hall Benevolent Trust



Duke of Connaught Lodge No. 1834



Province of Worcestershire Masonic Charity Organisation

# GAIN will not harass our donors, and we won't share your information with anyone else.

## That's a promise 😊

The reputation of charities and charitable donating has nosedived in the past two years, due largely to the revelations following the suicide of a poppy seller in May 2015. You may recall this person was generous with her time and money towards charities and ended up being bombarded with, per press reports, thousands of phone calls and letters from charities asking her for money.

Her death sparked a wave of complaints from other donors who were being similarly targeted. Subsequent enquiries found that some of our largest charities admitted to aggressive fundraising techniques targeted at elderly and vulnerable donors.

**Such techniques had never been used by GAIN or its predecessor GBS Support Group and at the time the board of trustees agreed that such techniques would not be used by GAIN.**

Just recently (April 2017) the charity received news that the Information Commissioners Office have fined 11 major charities for breaking the law when handling donor's personal information. The failures include –

- **Finding information about donors not provided by the donor**
- **Ranking donors by their wealth**
- **Sharing data about donors with other charities**

I would like to confirm that GAIN will not send follow up letters to donors asking for more money, sell donor details to any other person or persons nor do research into our donors' financial affairs.

As a small charity relying on our donors to fund our work, we are extremely grateful for all donations of any size. The only subsequent action after a donation is received is a letter of thanks to the donor. There will be no follow up begging letters.

**I trust that our past and potential donors will feel reassured by the ethical stance taken by GAIN.**

Chris Fuller  
Chair, GAIN Board of Trustees

### Charity fundraising enforcement action

In April 2017, 11 major charities were fined for failing to follow data protection rules by doing one or more of the following;

- ⊗ Finding information not provided by their donors
- ⊗ Ranking their donors by wealth
- ⊗ Sharing donors' data with other charities, no matter what the cause

**Great Ormond Street Hospital Children's Charity**  
(fined £11,000) ⊗ ⊗ ⊗

**Guide Dogs for the Blind Association**  
(fined £6,000) ⊗ ⊗

**Cancer Research UK**  
(fined £16,000) ⊗ ⊗

**Battersea Dogs' & Cats' Home** (fined £9,000) ⊗

**National Society for the Prevention of Cruelty to Children** (fined £12,000)  
⊗ ⊗

**International Fund for Animal Welfare**  
(fined £18,000) ⊗ ⊗ ⊗

**Royal British Legion**  
(fined £12,000) ⊗ ⊗

**Cancer Support UK**  
(fined £16,000) ⊗

**Macmillan Cancer Support** (fined £14,000)  
⊗ ⊗

**WWF-UK**  
(fined £9,000) ⊗ ⊗ ⊗

**Oxfam** (fined £6,000) ⊗

Further details available from [www.ico.org.uk](http://www.ico.org.uk)



# Don't gamble when you travel

If money and circumstance allows, summer sees many people packing up and shipping out for a week or two of relaxation and a bit of exploring. Most will take out holiday insurance, but some consider this to be an unnecessary extra expense that they don't really need.

**If you think you can't afford to get cover, think again. You can't afford not to.**

GAIN charity is contacted at least once or twice each year by people who have developed Guillain-Barré syndrome whilst on holiday abroad.

This is bad enough if you're fully covered by travel insurance, but becomes a potentially desperate situation if travelling without cover.

There is no viable alternative to travel insurance when it comes to covering the cost of hospitalisation, medical expenses, extended accommodation needs and repatriation.

**This is something we cannot help with.**

GAIN provides non-medical information and other assistance within the UK and Ireland. Our personal grant procedure has constitutional limitations and cannot be used to pay for medical fees, patient transportation, or goods or services that are available through other sources. Regrettably, this rules out financial assistance in lieu of adequate insurance cover.

## Travel insurance checklist

**Top of your list is Medical Emergencies**  
Your policy should cover;

- Treatment costs
- Getting back home
- Reasonable transport & accommodation expenses for family / friend staying with you
- Temporary emergency dental treatment
- Access to a 24-hour assistance helpline

**Remember, withholding details of your medical history may invalidate your policy!**

**Get the right policy for you**

- Consider whether single or multi-trip cover is best
- Are you travelling within Europe or further afield?
- Do you need additional cover for sports, etc.
- What is the total value of your luggage?
- Don't forget the extras!

**For more information and advice on travel insurance visit [www.gov.uk/foreign-travel-insurance](http://www.gov.uk/foreign-travel-insurance) #travelaware**

## Travel insurance with a pre-existing medical condition

You **MUST** disclose any pre-existing medical condition when buying travel insurance, as failure to do so could invalidate your policy. However, this isn't always much more expensive than regular travel insurance, and it is worth shopping around or using a comparison website to find the best deal.

**Remember**

- GBS is an acute condition. If you had it 2 years ago, you do not have it now, but should still disclose having had it, especially if your breathing was affected.
- CIDP is a chronic condition and should be included as a pre-existing condition.

# Know your food hygiene and

## BBQ SAFELY

Cases of food poisoning almost double during the summer, and research shows that the undercooking of raw meat and the contamination of bacteria onto the food we eat are among the main reasons.

Follow this simple advice from the Food Standards Agency to keep your family safe this summer.

**1. Pre-cook** - Cook all chicken in the oven prior to giving it a final 'finish' on your barbecue. Your friends and family will still experience that special barbecue 'scorched' taste, and you will know that you've cooked the chicken all the way through.

Sausages, burgers and kebabs can all be pre-cooked.

**2. Charred doesn't mean cooked** - Cook your barbecue food thoroughly until you are sure that your poultry, pork, burgers, sausages, and kebabs are steaming hot, with **no pink meat** inside. Turning meat regularly and moving it around the barbecue will help to cook it evenly. Cut open and check your burgers, sausages and chicken. If in doubt – keep cooking.

**3. Disposable BBQs** take longer to heat up and to cook food.

**4. Avoid cross-contamination** - Store raw meat separately before cooking, use different utensils, plates and chopping boards for raw and cooked food. Always wash your hands thoroughly with soap and hot water and dry them before handling your food for the barbecue and after handling raw foods including meat, fish, eggs and vegetables.

**5. Don't wash raw chicken** or other meat, it just splashes germs. Cooking will kill any bacteria present, including campylobacter, but washing chicken, or other meat, can spread dangerous bugs on to your hands, clothes, utensils and worktops by splashing.

**6. Keep plates and cutlery away from raw meat and fish.** Never serve your guests cooked food on a plate or surface that's had raw meat or fish on it, and don't use cutlery or marinades that have been in contact with raw meat.

### Facts about barbecue bugs

**Campylobacter** is the most common food poisoning bug in the UK. It's passed on to humans in undercooked poultry, and can lead to people being very ill indeed. Most people recover but not all. It is a common trigger for Guillain-Barre syndrome, sometimes resulting in permanent paralysis.

**E. coli** is often passed on through raw and undercooked meats and can lead to bloody diarrhoea, stomach pains, vomiting and occasionally fever.

**Listeria** can turn up in pates and salads. This bug is particularly dangerous for pregnant women as it can lead to a miscarriage, but the most at risk from all the barbecue bugs are children and older people.

**Salmonella** is another common bug found on raw meat and undercooked poultry. It leads to fever, vomiting and stomach pains and it can make you ill for weeks.

Visit the Food Standards Agency website for advice on all aspects of food safety and hygiene:  
[www.food.gov.uk](http://www.food.gov.uk)

“ as I surveyed my tiny curtained universe I realised my entire world was no larger than a Sailfish. I imagined the curtains were not drapes closing in my world, but a horizon of cotton-wool clouds and blue skies inviting me to a world beyond. All I needed was a course to steer, to take charge, to become captain of my destiny”



Dave Selby, keen sailor and Practical Boat Owner columnist, shares with us the inspiration behind Marlin's Mission

# *A man on a* **MISSION**

**As I turned right into the entrance of the Medway, the stiff wind and tide that had flushed me down the Thames like a crazy bob-sled went berserk.**

It was an explosive situation...literally. I was bearing down backwards – the howling, backing cross-wind and tide now both working against me – on the wreck of the munitions ship *Montgomery*, sunk in 1944 and still with 1,400 tonnes of extremely volatile TNT on board. There's an exclusion zone round this relic of war, and they say if she blows it'll blow out all the windows on the Isle of Sheppey and create a mini tsunami. Sails down, 4hp outboard motor thrashing away, when I throttled up *Marlin* slammed and crashed and the outboard was either half submerged or racing in thin air. When I eased the throttle back I was being sucked down on to the rusting superstructure jutting out of breaking seas the colour of rust.

In truth, there were any number of simple things I could have done to avoid the situation or get out of it, but the brain wasn't working. And in the end, it was the slackening ebb that gave me a break and allowed me to inch my way in to Queenborough and tie up for a rough, restless night. As I dozed fitfully *Marlin*, my beloved little 18ft Sailfish sailing boat that had done so much

for me, bashed and crashed against the pontoon. With each crunch I felt her hurt, and her hurt was mine, because *Marlin* and me we're one, a unit, not me and *Marlin* against the world, but me and *Marlin* a world entire. "*Marlin*," I pleaded: "I'm sorry, I've let you down, I've hurt you." For what kind of idiot was it who concocted *Marlin's Mission*? To sail a small boat 340 miles from Essex to the Southampton Boat Show to demonstrate that cost is no barrier to getting afloat, that the sea and sailing and all it has to give belongs to all of us no matter how modest our means. *Marlin* had given me all of that, but she'd given me more.

When I lay in hospital paralysed from the waist down my whole world was a bed, a bedside table, a glass of water, a pee bottle and a gantry of bleeping, green-glowing instruments, a shrinking universe closed in by a curtain. I don't know if it was the drugs, but I had nightmares too...of poodles! They appeared to me like those ferocious, slobbering lions you see engraved in those ancient leather-bound library tomes that showed a world once beyond imagining. As the lion-poodles leapt from the past and snapped at my dead toes there was nothing I could do; my useless legs couldn't kick them away. But where did they come from? The answer was in a distant past just days before.





Over the course of a week or so, during which I'd felt "fluey," I'd also been struggling with what I thought was an extremely bad back. And then I awoke one morning to find my legs wouldn't work at all. My girlfriend came round, called an ambulance, then a paramedic arrived and my girlfriend – Jules was her name – said she had to go and get her poodles groomed. The paramedic woman shot me a funny glance – knowingness, sympathy, compassion, or worse, pity perhaps – things I couldn't read or understand, because poodles have to be groomed, you know. That takes hours, and it took several hours too, for the ambulance to arrive, as the paramedic sat patiently by.

And that's how Marlin's Mission began, although I didn't know it at the time. For as I surveyed my tiny curtained universe I realised my entire world was no larger than a Sailfish. I imagined the curtains were not drapes closing in my world, but a horizon of cotton-wool clouds and blue skies inviting me to a world beyond. All around me I had everything I needed for life at hand, just as when sailing *Marlin*, for perhaps the biggest marvel sailing has to give is to tell us how little we need and how lucky we are. This was my mission: to helm this little ship. All I needed was a course to steer, to take charge, to become captain of my destiny.

To do that I had to take responsibility for myself, rather than hoping that a poor damaged poodle woman who was too hurt to cope with her own feelings could care for me and my emotions. It was too much to ask. A relationship ended and a new life began, and here it was all in tatters, a beaten-up boat and a broken-up man on the verge of giving up. What fool thought up Marlin's Mission?

In these situations, a hearty breakfast helps, but friends help even more. Sailing buddies Mark and David had heard of my plight and early that morning in Queenborough, as the wind howled through empty streets, they turned up after driving 150 miles to sort me out. "The wind's going down,

the tides are right," they cajoled. "Let's poke our nose out in to the Thames and give it a go?" We had the sail of our lives, 42 miles to Ramsgate in under seven hours, in a Sailfish, spectacular. We even made tea on passage, even more spectacular.

And then it came to me. This was what Marlin's Mission was all about. I imagined that when I set off last July from Maldon I'd be alone, doing it all solo, a man on a mission, but it wasn't my mission, it was something bigger, and people bought into that.

Along the south coast, I never once sailed alone, as people came out to join me and welcome me wherever I moored overnight. At the Southampton Boat Show, where *Marlin* was on display, I dressed her overall in bunting, bras and knickers, and flew GAIN banners, and each day gave a talk to demonstrate how anyone can get afloat, that cost and disability are no barriers, and also to raise money for GAIN. When people with personal experiences of GBS or CIDP, my particular variant, came up to talk to me I began to understand how important and wonderful it is to share experiences.

And just to think, what began in a very dark place, a low ebb, a failed relationship, has become Marlin's Mission, one of the very richest experiences of my life. And the mission continues. These days, when I give talks at sailing clubs who contribute generously to GAIN, I say that if someone could wave a magic wand that means I no longer need to spend three days in hospital every five-and-a-half weeks having IVlg treatment I'm not sure if I'd want that. Don't get me wrong, I don't want to be ill, although once I did, as I thought it might make the poodle woman show me she cared. It's just that through my illness the very most wonderful things in my life have happened. When, reluctantly perhaps, I took responsibility for myself I found that strangers became friends and all my good friends became better friends. I wouldn't change that. I'm a lucky guy.

**Marlin's Mission will never end. To date we've raised over £7,000 for GAIN. And the poodle nightmares aren't as bad as they once were.**



*You can read more from Dave Selby in his new book, **The imPractical Boat Owner**, published by Bloomsbury on 13<sup>th</sup> July 2017 priced £9.99*

# Ask the Experts

## Answers on the treatment of CIDP provided by Dr Jane Pritchard, Consultant Neurologist at Charing Cross Hospital and Chair of the GAIN Medical Advisory Board

**Question:** To your knowledge, is there any cure for CIDP?

**Answer:** It depends how you define 'cure' – but in CIDP literature this has been defined as 'remission of over 5 years off treatment', which has been reported at a rate of about ¼ of patients treated with steroids for less than one year. We would more usually use the term 'remission' in CIDP (i.e. stability without treatment). Shorter term remission is more common than 'cure': there is evidence from studies that up to 40% of patients with CIDP may be in remission after one year of treatment with either steroids or IVIg. It is for this reason that it is advised that the need for treatment is reviewed on an annual basis if patients are no longer showing any or little fluctuation in their clinical symptoms. They may subsequently relapse however, perhaps after another year.

**Question:** When treating a patient with CIDP, which treatments have a clinically proven efficacy, and on what would you base your decision when choosing one over another? What are your views on using an immunosuppressant corticosteroid rather than immunoglobulin for long term treatment, and will the Payment Reform, implemented on 1st April 2017, have an impact on what treatment is prescribed?

**Answer:** The treatments with clinically proven efficacy in CIDP are **immunoglobulin, steroids, and plasma exchange**, all of which have been shown to be superior to placebo in clinical trials. In other studies, they have been shown to be equivalent to one another in efficacy: between 50 and 80% of patients respond to each of the treatments. Failure to respond to one treatment does not mean that the other treatments won't work either (unless the diagnosis is wrong). 15% of patients do not respond to any of the three treatments.

The choice of treatment agents depends on the type of CIDP the patient is suffering, the personal situation of the patient and the patient's medical history. For example, it is felt that **motor dominant** types of CIDP respond better to IVIg than steroids. Some CIDP is very mild and requires no treatment. All three of these treatments have associated risks and different advantages and disadvantages.

Usually **intravenous immunoglobulin (IVIg)** is the first treatment of choice nowadays in CIDP. If it works we can see a response quickly in a matter of weeks, with improvement in strength and function. Some patients (15-30%) only need a single course. However, IVIg is contraindicated in patients with immunoglobulin A deficiency or in patients who have had an severe allergic reaction to IVIg. It is a blood product so some patients would choose not to have it on religious grounds, or because they are concerned about having a blood product from thousands of donors administered to them. IVIg is given in hospital and if it needs to be given long term by regular infusion typically every 6 weeks, has an impact on the patient's work which can be problematic, or if they are a main carer to other adults or children and cannot manage the time away from home, or if they wish to travel as their infusions need to be fitted around their plans. In some parts of the country it is possible to receive **subcutaneous immunoglobulin** (also known as SCIg or SubCut) at home which is more convenient for patients.

**Plasma exchange** involves having the patient attached to a machine to remove some of their blood and replace with another blood product (e.g. human albumin), over 5 days. It is only available in large hospitals and is felt to be the most invasive of the 3 treatments. There are problems with infections in the lines, blood clotting problems due to anticoagulation used on the machine, and the same concerns over administration of blood products. However, it can work very well for occasional patients.

**Steroids** are easy to administer either as daily or alternate daily treatments, or monthly oral or intravenous regimes. They can be very effective but are limited in their use by their side effects. In older patients, there are often competing medical conditions which mean that they need to be used with caution or avoided altogether, e.g. if a patient has poorly controlled diabetes or osteoporosis, or if they have recurrent chest infections and immunosuppression might put them at risk of overwhelming infection. A younger patient may have less comorbidities but would also potentially be facing longer term treatment.

Of these 3 treatments, I would only use plasma exchange if a patient had tried and failed on IVIg and steroids, yet still had significant disability. In a patient with sensorimotor (not pure motor) CIDP I would discuss the options with the patient, explaining the advantages and disadvantages of each. The majority of patients choose IVIg in my experience, but other young fit patients who do not want to spend time in hospital, and without major comorbidities, sometimes prefer steroids. Some patients try IVIg but if they need frequent IVIg infusions to remain strong then I consider adding in steroid or another immunosuppressant agent. If IVIg does not produce clear benefit I would then offer steroids next.

There is a difference in cost between the treatment options, with both IVIg and plasma exchange costing thousands per course whilst steroids do not. This cost is borne by the NHS at present and I know of no imminent plans for this to change. Since IVIg is a blood product, from blood donors, its supply is finite. IVIg is approved nationally (in England) for use in CIDP and there are clear NHS guidelines in place. So, whilst the long-term use of IVIg in CIDP is supported it is advised that the IVIg dose is titrated down to find the lowest possible dose/maximum possible frequency to maintain clinical improvement in each individual case.

**Question: Would discussing and implementing a patient-centred care plan or care pathway be an expected part of the long-term treatment of a chronic condition such as CIDP, and is there a mechanism for this care plan to continue during and after any transition, for example from paediatric to adult care provision?**

**Answer:** All care of CIDP is patient centred and individualised, as each patient's history, disease course, and response to treatment is specific to them. When moving from one consultant to another, whether from adult to adult or transition from paediatrics to adulthood then the treatment history would be reviewed carefully so as not to repeat treatments which were not effective or caused side effects, and to maintain continuity of care. The new treating neurologist would need to be comfortable that the risks of the current treatment continue to be justified, as they would now be taking on clinical responsibility for the management of the patient. It would be appropriate for the new neurologist to take the opportunity to review the diagnosis: it is all about getting the right treatment, to the right patient, at the right point in their illness.

## Guillain-Barré syndrome - relapse or recurrence?

GBS is monophasic in over 97% of cases. However, during the course of GBS there can be fluctuations in the initial phase, sometimes as the first IVIg dose wears off.

Other patients may respond to treatment initially but then start to decline later perhaps after 6 weeks or so; this is the group that might be first told they have GBS but subsequently be reclassified as CIDP as some CIDP patients present with a very acute onset akin to GBS. This is what would be termed a relapse in their GBS symptoms, and then they would be told they have CIDP.

A small minority of patients have a separate later recurrence of their GBS, sometimes having 100% recovered in between times. The majority have an acute onset illness evolving to its worst point within 4 weeks and then gradual recovery thereafter over many weeks and months.

What has often been described to GAIN by recovering or recovered patients sounds less like a relapse or recurrence and more a flare up in symptoms which never fully went away to start with. This is very common in neurological conditions and can relate to intercurrent illness, e.g. a cough or cold, sickness or diarrhoea, or when tired.

## Get involved and receive a free GAIN enamelled pin badge

A big thank you to everyone who responded to our 'Count me in!' appeal (*gain4all Issue 11*). Holding details of people interested in taking part in studies and trials helps us respond quickly when we get requests from researchers for participants. To say thank you, we are sending a free GAIN enamelled pin badge to everyone who has registered so far, and anyone else registering before 31<sup>st</sup> July 2017. If you would like to be counted in, please [email](mailto:office@gaincharity.org.uk) your details to [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk), subject line 'Count me in!'

Email: [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk)  
Subject line: Count me in!

### What we need to know about you:

Name  
Address  
Email (essential)  
Phone number(s)  
Date of birth  
Gender  
Diagnosis  
Date of diagnosis  
Details of current treatment (if any), stating type and frequency  
Whether you're interested in  
a) Trials  
b) Studies  
c) Both



## Liberating Research

Empowering patients and fundraising through research



### How does it work?

Liberating Research is the health research community that pays you for your opinion and allows you to give back to the charities and support groups that matter most to you and your health.

Most surveys average 20 minutes and pay around £30.

Select **GAIN** as your favourite charity and choose what percentage of your survey earnings you want to donate (minimum 10%). We transfer the money to the charity on your behalf and send the rest directly to you.

For more information, and to sign up and start raising money for Guillain-Barré & Associated Neuropathies, go to [www.liberatingresearch.com/charity/3213](http://www.liberatingresearch.com/charity/3213)

# We often say we would have done things differently with the benefit of hindsight.

When the **GAIN South West England** local branch got together in March, they decided to share the benefit of their hindsight with *gain4all* readers.

## Advice to **patients**

- Try to stay positive but realistic: most people will get better
- Find out as much as you can
- Make a list of questions and ask the doctors
- Care and need will vary at different stages. Short-term initially might be just getting through the night
- Be patient with yourself
- Keep a diary then you can look back on your progress
- Recognise you will have good and bad days
- Do the physio
- Say yes to hydrotherapy
- Say yes to occupational therapy
- Be prepared to say you can't do something. The carer will have to be patient – there will be things that can't be done for now (e.g. buttons) and some things won't get better
- For poor balance, restorative yoga may be helpful and could aid flexibility, posture, etc.
- Check out services provided by the voluntary sector (e.g. Age UK)

## Advice to **carers**

- Look after your own health and take help when offered
- Find out if there is a carers group in your area offering sitting services, transport, and general advice
- Keep ahead of potential future needs (e.g. wheelchair ramps)
- **Ask GAIN charity for help.** They will provide information, can put you in touch with a peer support volunteer for a visit or chat over the phone, and can often help with travel expenses while your loved one is in hospital

## Advice to **medical professionals**

- Despite the difficulties faced by the medical profession due to financial constraints and the relative rarity of GBS/CIDP, there is a need for a wider understanding to achieve prompt diagnosis and treatment
- GPs to recognise signs or refer to neuro consultants
- Greater awareness of consequences of immobility (e.g. stroke, pneumonia)
- Remember that GBS doesn't affect the brain or hearing. The patient, even if 'locked-in', can still hear and understand what is being discussed
- Understand that some patients experience hallucinations when in ICU, and try to reassure them if they seem distressed
- Multi-disciplinary teams to deliver care within neuro rehab including physiotherapy and podiatry specialists
- Consultants need to give information to patients, partners and carers
- Nurses need to be aware of physical difficulties (e.g. feeding)
- Need for wider availability of speaking tubes for patients with tracheostomy
- Greater access to and resourcing of hydrotherapy
- Consider alternative therapies (e.g. acupuncture, NSA care, chiropractic, yoga)
- Offer help for residual nerve problems

A diagnosis of GBS can be a frightening and isolating experience, but there are people who can help you get through it.

Contact us here at GAIN, and have a look at our 'Other Sources of Help' directory at the back of the magazine.



The GAIN Board of Trustees from left to right; Chris Fuller (Chairman), David Wada (Treasurer), Susan McAllister (Secretary), William Harmer (personal grant sub-committee Chairman), Adam Pownall (Vice Chair), Jenny Willison, Paul Swain, Robin Sheppard, Lee Raynor



## Bespoke Chairman and GAIN trustee, **Robin Sheppard** is one of several business champions recruited to help ‘lead a war on inaccessibility’

A new campaign to promote accessibility and inclusivity in UK shops and services has been launched recently by the government. Disability champions will be recruited for key sectors in business including retail, hospitality, sport, construction and manufacturing to promote the benefits of being inclusive to their own industries.

There are more than 11 million disabled people in the UK and the spending power of their households – ‘the purple pound’ – is £249 billion. The new champions will be recruited to demonstrate the business sense of making products and services available to a group of people who are regularly excluded from many shops, restaurants, bars and other public places.

Minister for Disabled People, Health and Work, Penny Mordaunt, said; ‘There are some great examples of inclusive businesses that are passionate about driving social change. That’s why I’m asking them to champion a war against inaccessibility, and encourage other businesses to benefit from the purple pound – the spending power of disabled people.’

Increasing accessibility is the right thing to do, but it also makes good business sense too.

Many businesses are already recognising the needs and the business potential of the disabled population. Sainsbury’s is already supporting the government in promoting the value of employing disabled people. Marks and Spencer has a clothing range especially designed for disabled children as well as accessible stores, and restaurants like Jamie’s and Pret A Manger are leading the way in making sure disabled customers get the same quality of service as everyone else. The new accessibility champions will help showcase the best examples and show other businesses the merit of making disabled customers a priority.

Expressions of interest to become business sector champions have been invited from successful business people with strong networks, who are self-motivated in leading social change for disabled people. The roles are voluntary, unpaid and initially for one year.

[www.gov.uk/government/organisations/office-for-disability-issues](http://www.gov.uk/government/organisations/office-for-disability-issues)

Hotelier and GAIN trustee **Robin Sheppard** founded **Bespoke Hotels** in 2000 and is currently the Chairman of the group which owns or manages an eclectic mix of more than 170 properties. Prior to that, Robin was awarded Egon Ronay ‘Hotel of the Year’, Egon Ronay Stars, RAC Blue Ribbons and Michelin Stars. He trained with British Transport Hotels at the Old Course in St Andrews, GM for Historic House Hotels, the Lygon Arms, and Hilton Hotels, opening the Royal Berkshire and winning Egon Ronay’s ‘Hotelier of the Year’.

He ran the Bath Spa Hotel and won two ‘Hotel of the Year’ awards thanks to Caterer and Hotelkeeper and the RAC; became operations director for the Forte before setting up Bespoke. Robin also created and ran Ty-Nant spring water, the prize-winning water company, with its distinct cobalt blue bottles.

Robin developed Guillain-Barré syndrome just before Christmas 2004, spending five weeks in intensive care before starting the long road to recovery. His book, *A Solitary Confinement* (Ecademy Press, 2007), invites us to share his Guillain-Barré journey, and is available from Amazon.



Back in March, Kate Edwards and her talented music students raised funds for GAIN to the tune of **£275.00** at their annual pupils' concert. A warm thank you to everyone involved!

# Would our fabulous fundraisers please take a bow...

*"I've come a long way since GBS took hold of me six years ago. I still have fatigue and mobility problems but that doesn't stop me joining in family fun whenever I can. My family has been very supportive, and I couldn't have managed without their help, plus that of my partner, Arthur (left)."*



Meg Molyneux's family & friends donated a generous **£100** to GAIN in lieu of birthday presents, as well as surprising Meg with an Archer's birthday cake!

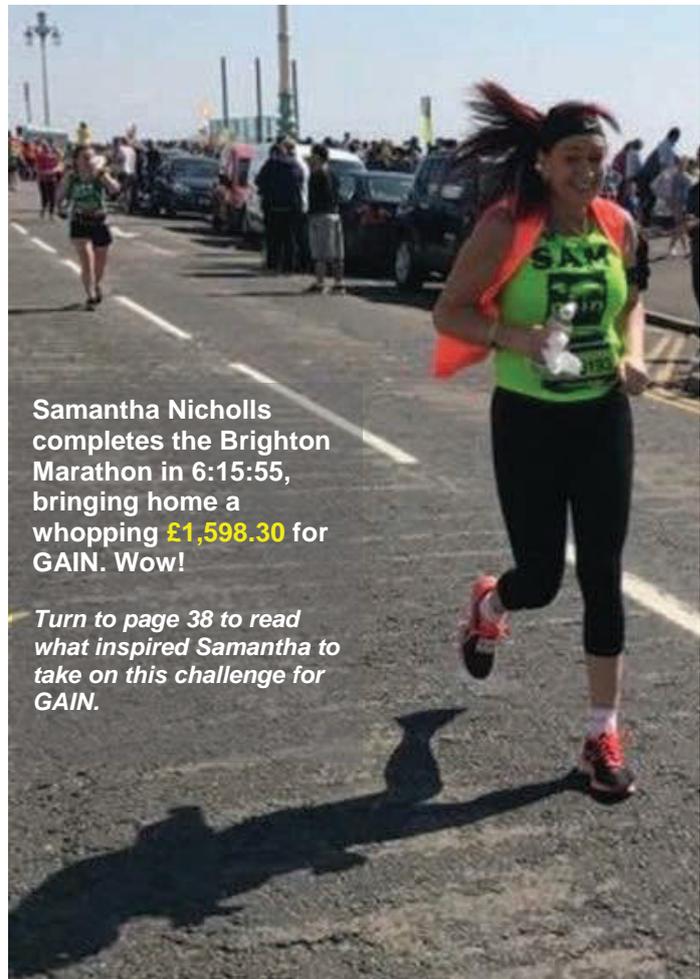


Tara Pountney smashes her PB and her target, raising an impressive **£500** at the Brighton Marathon in April

*"My dad was diagnosed with GBS in early July 2016. He is still currently recovering in hospital & has no movement in his hands. It has been a very stressful time for him & all the family, but he is getting better very slowly. None of my family had ever heard of this rare illness, so I decided to raise money & awareness for GAIN charity. Fingers crossed my dad will make a full recovery and be able to go home soon."*



A huge thank you to the staff & customers from Sir John Cockle Mansfield who raised over £600 for GAIN on their Charity Day, with live music, stalls and face-painting.



Samantha Nicholls completes the Brighton Marathon in 6:15:55, bringing home a whopping £1,598.30 for GAIN. Wow!

Turn to page 38 to read what inspired Samantha to take on this challenge for GAIN.

£ 24-HOUR-EVENT £ DRESS-DOWN-DAY £ BBQ £ CAR-WASH £ HEAD-SHAVE £ QUIZ-NIGHT £ OFFICE-SWEEPSTAKE £ EATING-COMPETITION £ CAR-BOOT-GARAGE-SALE £ BAKE-SALE £ GOLF-TOURNAMENT £ GOLF-CLUB-CHALLENGE £ SKY-DIVE £ OFFICE-LOTTERY £ FUN-RUN £ SPONSORED-SINGER £ BAKE-SHOW £ BAGS £ CHRISTMAS-GIFT-WRAPPING-SERVICE £ EASTER-EGG-HUNT £ BIKE-RIDE £ SWEET SALE £ FOOD-&WINE-TASTING £ DINNER-PARTY £ DOOR-TO-DOOR-COOKIE-SELLING £ SPORTS-DAY £ CHARITY-BOLE-NIGHT £ HUNDREDS-CALFENAP £ POOL-SALE £ GAD-DAILY £ 70S/80S-NIGHT £ FOOTBALL-TOURNAMENT £ KARAOKE-EVENING £ RECYCLING £ DONATE-YOUR-LUNCH-MONEY-&-BRING-A-PACK-UP £ STOP-SMOKING £ GIVE-UP-ALCOHOL/CHOCOLATE-FOR-A-MONTH £ DRESS-DAY £ BAD-HAIR-DAY £ NAME-THE-BEAR £ GOLF-TOURNAMENT £ SUMMER HOW-MANY-SWEETS/PENNIES/MARBLES-IN-A-JAR £ GUESS-THE-WEIGHT-OF-THE-C SWEAR-BOX £ COFFEE-MORNING £ DIAM-SALE £ ROLL-A-DOWN-NEAREST-THE-ROVER

**We're not all marathon runners.**  
**Some of us are good at making cake. Or jam.**  
**Do your own thing and make a difference.**



Lee Sharples completes the 2017 Greater Manchester Marathon, adding another £349 to last year's sponsorship, and bringing the total raised for GAIN to a massive £1,269. Cheers, Lee!



Thank you, Rosemary Clemas, for raising funds and awareness for GAIN at your local church's Christmas Tree Fair!



Charlie Sheppard (right) with friends, raising **£2,683.65** for GAIN in the Bath Half Marathon.

*“When I was 16 my old man (GAIN Trustee, Robin Sheppard) suffered from a life-changing attack of Guillain-Barré syndrome causing him almost total paralysis. GAIN charity supports people affected by GBS. This is an opportunity to do something to help other families who are affected by this illness.”*



A massive thank you goes to Simon Jacobs and his colleagues at Barclays Bank. Simon (whose mum was diagnosed with Guillain-Barré syndrome back in 2015) and his friends raised £400 doing a sponsored walk, which was match-funded by Barclays. They then went on to organise a dress-down Charity Day, raising a further £1,040 from donations and raffle, one of prizes being a very impressive GAIN logo cake! This amount was also match-funded by Barclays to the tune of £1,000, bringing the grand total to £2840.00! Well done, and thank you to everyone who contributed.

A special thank you also goes to Barclays Bank for their generosity in match-funding the donations from their staff.





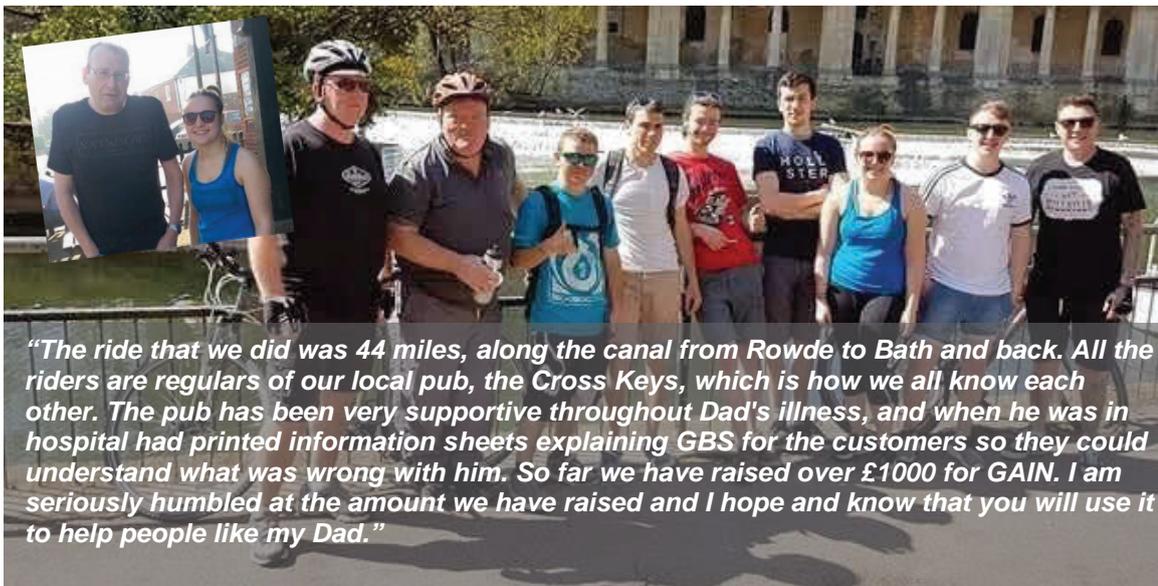
Peter Ayling (right) presents a cheque for **£2,100** to GAIN representative, Gordon Sturmeay.

The Travel Retail Consortium is a long-established UK based suppliers' club created to further the interests and development of the UK travel retail industry through its members.

They are also committed to raising funds for worthwhile charities, particularly those which are supported by the travel retail industry in general.

As Chairman of the TRC in 2015/16, Peter Ayling (pictured) had the chance to nominate a charity to benefit from fundraising activities over a two-year period. Over that period, three major events were held, raising funds totalling £2,100 through raffles and tombolas.

*Our thanks go to all the TRC members who contributed to this generous donation: Aeon, Accolade Wines, Aurora World, Coty Inc., Guinness, Heineken, Imperial Tobacco International, Invu, Mars, Morgan & Oates, Rémy Cointreau, Sekonda, Taittinger Champagne & Twinings.*



*"The ride that we did was 44 miles, along the canal from Rowde to Bath and back. All the riders are regulars of our local pub, the Cross Keys, which is how we all know each other. The pub has been very supportive throughout Dad's illness, and when he was in hospital had printed information sheets explaining GBS for the customers so they could understand what was wrong with him. So far we have raised over £1000 for GAIN. I am seriously humbled at the amount we have raised and I hope and know that you will use it to help people like my Dad."*

Half way, the team reaches Bath: L-R Kevin Whitbread, John Dalley, Dan Smith, Luke Smith, Shannon Kerfoot, Mark Pearce, Molly Dilling, Josh Scott, Luke Stonham  
Inset: Molly with her Dad, Shaun, outside the Cross Keys at Wadsworth





**Parallel London is a fully accessible fun run and a free family festival at Queen Elizabeth Olympic Park on Sunday 3 September.**

**There's a 10km, 5km, 1km, 100m and the Super Sensory 1km. All ages and abilities. No cut off times. Everybody running side by side.**

**Sign up today and raise money for a cause that matters to you.**



**PARALLEL  
LONDON**

[parallellondon.com](http://parallellondon.com)



Parallel London 2017  
Sunday, 3<sup>rd</sup> September

London Calling! Join **TeamGAIN**  
and be part of something fantastic!

Come along and meet the staff and trustees of your favourite charity as we **GAIN momentum** with Parallel London, the world's only fully inclusive mass participation event. Open to all ages and abilities, you can **choose your distance**, from 100m to 10km, and **do it your way**, and **at your own pace**, whether you walk, run, or roll. All mobility aids are permitted, and if you need someone to accompany you, buddies can enter free! If you really don't want to work up a sweat, come and join our gang of supporters to line the route and fly the flag for GAIN. We have a hospitality area, so everyone can get together before and after the race, and everyone signing up to take part **before 1<sup>st</sup> August** will receive a free limited-edition GAIN T-shirt.



**Sign up today and challenge yourself!**

### About Parallel London

Parallel London was created by **Andrew Douglass**, Chief Executive of live events agency *innovision*, who are behind some of London's largest public events over the past 18 years, recently including the Paralympic Marathon, the Olympic and Paralympic Torch Relay for Lloyds Banking Group, and the London 2012 Athlete's Parade. Parallel London's Patron is **Nick Ashley-Cooper**, 12<sup>th</sup> Earl of Shaftesbury, a spinal cord injury survivor who is passionate about building on the legacy of his social reformer ancestor, the 7<sup>th</sup> Earl of Shaftesbury. Andrew and Nick met through supporting the spinal cord research charity, *Wings for Life*. Parallel London is a not-for-profit initiative. All surplus funds generated from the event will be redistributed to nominated charities.

The long-term vision is for Parallel London to grow into a major annual fixture in the national event calendar that will:

- Encourage more active lifestyles and fitness regardless of ability
- Create significant new fundraising opportunities for charities of all sizes
- Positively change public attitudes towards disability and impairment
- Shine a light on accessibility in everyday life

### What does it cost?

Because we want as many people to join us as possible, being part of TeamGAIN only costs £10 per person, or £25 for a family of up to 2 adults and 3 children. We would love you to use the event to raise a bit (or a lot) of sponsorship, but there is no minimum requirement to do so. It's all about taking part.

### What do I get?

As well as being part of this fabulous, inclusive race and family fun day, you will also receive a GAIN goody bag and a colourful GAIN T-shirt to run in.

### What do I need to do?

You can purchase your entry place online at [www.gaincharity.org.uk/parallellondon](http://www.gaincharity.org.uk/parallellondon), or download an entry form and post it in with your payment to our Head Office address. If you would us to post you a form, give us a ring or send an email to [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk)

**So, what are you waiting for? 😊**

# Catching up with Hayley



"You might remember my story from issue 2 of gain4all magazine back in summer 2014. Three years on, I'd like to tell you how I'm doing now."

Hayley Watson



**On 26<sup>th</sup> April 2010 my life as I knew it changed forever. I was about to embark on a trip of a life time to help underprivileged children in Uganda, Africa.**

Through coaching soccer I could have given the children the chance to excel and learn new life experiences through playing football. I had to have the yellow fever vaccination to be able to enter the country. The next day I awoke with breathing difficulties and weakness in all four of my limbs. My friend persuaded me to go to A+E having no idea of what was about to follow.

Over the course of the next few days my weakness turned into paralysis and my breathing got worse so I was admitted into ICU with heart and lung failure. I was completely paralysed from the neck down. I had many tests and examinations and was then diagnosed with **Guillain-Barré syndrome**. I was treated with IVIG and intravenous steroids.

Things kind of stayed stable for some time – I wasn't getting any better but I wasn't deteriorating. I moved to a general ward and then onto a neuro rehab ward. Here I received vital therapy and slowly started to improve. Over the next 9-10 months I was starting to recover some movement. I did a walkathon to raise money for GAIN and I did 10 steps!! But then I had a relapse and was back to being confined to the wheelchair and hoist for transfers.

There was so much positivity coming from other people but inside me I felt empty and hopeless. I was suffering from depression and was on a downwards spiral. I had a psychiatrist come to see me and he wanted me admitted to his ward, so this is what happened. This was the lowest time of my life. Days turned into weeks, and I still felt so hopeless. I would spend all day in bed which is kind of ironic because when I wasn't able to get myself in and out of bed all I wanted to do was not be in bed.

After a huge fight on her hands from my mum I finally got the funding to move back to rehab. I went to rehab in Wales for 2 years and on the 3/3/16 I finally got

discharged and was able to move into my own house living completely independently after nearly 6 years of being in hospital. In November 2016 I managed to go to New York to help my nan celebrate her 80<sup>th</sup> birthday.

I am doing the colour run in Manchester on the 1st July. I saw this advertised in my first year in hospital and I said to myself I have to do that when I can walk again.

I still have a lot of pain especially in my back which limits my ability to walk; I have to walk with crutches. I am still on a lot of medication but, hey, I'll take all that seeing a few years ago I thought I would never walk again. I have set backs both physically and mentally but with the support of my amazing family and friends I get through them, and will continue to do so.

After living with GBS for nearly 7 years my life is now heading in a completely different path. I can no longer do sports, but who knows maybe in the future I'll be able to do it again. I currently volunteer at 2 children's charities who support kids with learning and physical disabilities and I also volunteer at a special school. I absolutely love it and couldn't think of a better way to spend my days. On my journey, I have met some incredible people who now play a vital role in my life. I would not have met these people or be on my altered path in life if it wasn't for GBS. So, I am grateful to GBS for that. It has made me into the person I am today.

I decided that on my GBS anniversary every year I am going to do one of the things on my bucket list. This year it is to use a pottery wheel to make something. But my main goal, within 5 years from now, is to go on the Inca Trail in Peru with my mum. We made this a deal when I was in my early days in hospital.

**We go through these challenges we face to remind us of how strong we really are. I've learnt that life is so very short and that things can change in an instant. So you need to get out and do the things you want to do and live your life to the fullest NOW, and ENJOY it.**

*Continued on page 27*



# Recycling

FOR GOOD CAUSES

**declutter**  
 di: 'klʌtə/  
 verb

1. Remove unnecessary items from (an untidy or overcrowded place)  
 "there's no better time to declutter your home"



### Easy Fundraising for Charities and Good Causes

Recycling for Good Causes offers a hassle free, cost free solution to fundraising for any non-profit organisation within the UK.

We offer our unique services to charities and good causes as well as individual donors wishing to recycle for their chosen charity.

It's really simple to do. By recycling donated unwanted items, we are able to convert them into much needed funds for your charity as well as help the environment.

- jewellery and watches (even if damaged) • gadgets •
- currency • stamps • cameras • mobile phones •



Have a clear out and support GAIN. Contact Recycling for Good Causes for your free sack

☎ 0800 633 5323 ✉ [info@recyclingforgoodcauses.org](mailto:info@recyclingforgoodcauses.org)

or to send just a few items of jewellery and currency (no stamps), post them in an envelope to;  
 Freepost RSXA-GJBY-ARRZ, GAIN, Unit 14, Amber Business Village, Amber Close, Tamworth, B77 4RP

Join us and help raise money when you shop online at no extra cost to you. With hundreds of retailers to choose from, you too could be givingabit!

Sign up today at [www.givingabit.com](http://www.givingabit.com)



# Catching up with Hayley *(continued from page 25)*

## Postscript

Whilst I was in hospital my weight more than doubled. This really affected my self-esteem and my confidence. I knew there wasn't much I could do whilst still in hospital, but from the day I got discharged I vowed to do something about it. Fast forward 1 year and I have lost 5 1/2 stone. It's the little things like being able to fit in clothes I couldn't, buying a smaller size, and my towel fitting around my body much better.

I have recently started my new chapter in life. I have got a job. My previous chapter I have been to hell and back but I have learnt so much from it, gained so much strength and if it wasn't for having had Guillain-Barré syndrome, I probably wouldn't have embarked on this new big adventure. #lifeaftergbs!



Throwing pots – something to tick off the bucket list!

Do you live in England and need more than 12 prescribed items each year?

Save money with a Prepaid Prescription Certificate.

If you know you'll have to pay for a lot of NHS prescriptions, it may be cheaper to buy a prescription prepayment certificate (PPC) – effectively a prescription "season ticket". A PPC covers all of your NHS prescriptions, including NHS dental prescriptions, no matter how many items you need.

There are two PPC options to choose from:

1. a three-month PPC costs £29.10 and will save you money if you need more than three prescribed items in three months
2. a 12-month PPC costs £104.00 (payable in 10 monthly instalments of £10.40) will save you money if you need more than 12 prescribed items in a year

Apply today and start saving money

- online at [apps.nhsbsa.nhs.uk/ppcwebsales](https://apps.nhsbsa.nhs.uk/ppcwebsales)
- by phone on the PPC order line 0300 330 1341
- download an order form from this link:  
[www.nhs.uk/NHSEngland/Healthcosts/Documents/FP95.pdf](https://www.nhs.uk/NHSEngland/Healthcosts/Documents/FP95.pdf)  
or pick one up from your GP surgery or pharmacy

For further information, visit NHS Choices  
[www.nhs.uk/NHSEngland/Healthcosts/Pages/PPC.aspx](https://www.nhs.uk/NHSEngland/Healthcosts/Pages/PPC.aspx)



# active<sup>®</sup> hands

## Frustrated by the limitations caused by weak grip or poor hand function?

Active Hands make gripping aids that gently yet firmly hold your hand into a gripping shape enabling you to hold tightly onto objects from hammers to garden tools, gym equipment to Wii controllers, ski-outriggers to boat tillers, adaptive bike handles to musical instruments, and many more. Our gripping aids are designed so that the user can put them on independently.

Our gripping aids are ideal for tetraplegic/quadruplegics, those with cerebral palsy, stroke recovery or any disability that affects hand function. Some of our products are also suitable for those with limb difference. Available in a range of sizes, our aids suit from small children to large-handed adults!

Active Hands can give you more freedom – take a look at our website to give you more ideas on how you can increase your independence using our gripping products.



Aids sold individually



General purpose gripping aid £49.95

To order and for further products and inspiration, visit our website:

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

# *The Secret Diary of Margaret Pearse Aged 82½*

**In October 2009 at the age of 82, I was on holiday in Sussex with my son, Clive, and daughter, Lulu, when I experienced very strong tingling in both hands, and the next morning when I got out of bed my left leg was completely numb and useless.**

I was taken by ambulance to St. Richard's Hospital, Chichester where at first it was thought I had had a mini stroke. Alas, I was admitted on a Thursday, so it was only on the following Monday (limited hospital staff at the weekends!) when I had a lumbar puncture that **Guillain-Barré syndrome** was diagnosed.

I was given immunoglobulin and sent to Southampton Hospital, to the neuro specialist unit. I was there for three weeks where I experienced a very frightening deterioration. I became totally paralyzed and doubly incontinent (therefore catheterized), and fed by a tube through my nose (don't know the medical term). I was luckily not put on a ventilator. The initial shock of all this was dreadful as I had never felt so puzzled and so ill ever before. My son and daughter had a very hard time as they really had no understanding of the illness – they, like most people, had never heard of it.

I subsequently transferred to Queen Mary's on 11<sup>th</sup> November 2009 where I began to make a slow recovery. I had been told by a neurologist at Southampton that I was in for a long, weary and frustrating journey ahead – maybe 4 to 6 months – and it was up to me to work hard. He explained how the illness could progress: an acute stage followed by a plateau and then, hopefully, the beginning of an upward move towards recovery. My son and daughter were particularly concerned about respiratory problems, as I have pulmonary fibrosis. I cope OK with that but get slightly out of breath and have a coughing fit now and then.

It was very hard to believe any cheerful thoughts of total recovery when it was impossible to move one's big toe but with fantastic nursing, wonderful physios, and the amazing, ever-strong support from family and friends I started on the road to recovery.

I was first taken ill on 1<sup>st</sup> October 2009 and left hospital on the 23<sup>rd</sup> February 2010. I am at home now walking with one or two sticks, depending how I feel. I am going to hydrotherapy classes every week with my daughter and find this is very helpful. I can't at the moment go out and about on my own but can go shopping using a trolley with a kind escort to carry my parcels and bring me home. The fear of falling and then returning injured to Kingston Hospital is a great concern to me.

Psychologically, I feel I have done well. It was so frightening at first that I really felt it would be a good thing if I didn't survive – after all I was 82 and how awful this was going to be for the family, etc. However, I somehow hung on to my sanity and decided to completely switch off and not allow any weeping or questioning of why this might happen to me. Luckily, I very much like people and enjoy hearing about their lives. Also, I do have a good sense of humour so as I got better life became easier with some wonderful nurses and physios, all of whom were very proud of what they called 'my splendid improvement'.

I certainly have a different approach to life and as I have just had my 83rd birthday I intend to enjoy every moment of the rest of my life and worry as little as possible about anything. I was fortunate to go into this illness in a fairly fit state of health – enjoying walking and being independent.

I think the relatives of people dealing with this illness need immediate reassurance and information so that they can provide encouragement and emotional support to the poor puzzled sufferer. MANY nurses in general hospitals seemingly have never heard of GBS. My daughter laminated fact sheets and gave them copies!

My son, Clive, lives in LA and my daughter, Lulu, a florist, is staying with me and is being truly wonderful with her support. Clive came over regularly when I was first ill and was equally splendid.

We went back to Sussex last week to celebrate my 83rd birthday. I am very lucky. I have a sister who stays from time to time to give Lulu a break, and lots of great friends. I look forward to improving my walking but am told to expect things to move slowly. I have occasionally very slight tingling in my hands and they are a little stiff in the mornings but since I couldn't use them at all for a long time, no complaints!

I would so like my recovery story to be told – when I was very ill the oldest 'good outcome' story we could find was of a 68-year-old man. At my age, I think my good progress can provide real hope to others. Perhaps I am one of the oldest survivors?

**Margaret Pearse, 25th April 2010**

*Postscript*

*Sadly, Margaret passed away in October 2012 following an unrelated illness, but had always felt it might be encouraging for newly diagnosed elderly patients to read of someone having a successful recovery at the age of 82. Margaret's son, Clive, has kindly shared her story with us, to mark what would have been his mum's 90th birthday in April of this year.*



*Happy Days!  
Margaret, celebrating  
her 83<sup>rd</sup> birthday  
with daughter, Lulu  
April 2010*

# Aaron's Story | Sam's Inspiration

*Written by Carl Nicholls*

**In 2009 our son Aaron was struck down with Guillain-Barré syndrome at the age of 19 being previously well and fit as youngsters are.**

Guillain-Barré (named after the French doctors who discovered it) is a relatively rare syndrome that anyone can get – approximately 1:100,000. Aaron had just got over a cold a couple of weeks before he started showing signs of weakness and tingling in his extremities – his hands and feet. He didn't really mention this for a few days until we noticed him trying to pull himself up the stairs, using the handrail as his calves were now too weak for him to walk up the stairs unaided. Aaron had been to the gym the day before and thought that it was just fatigue so we weren't overly concerned and laughed at the funny side of his efforts! Two days later Aaron could hardly walk and his arms were now feeling weaker – we called our GP and he told us to go to him straight away.

After a short examination our doctor told us that he thinks that Aaron has a nervous system issue and pulled down one of his medical books to show us about Guillain-Barré syndrome which he believed he had contracted. Guillain-Barré syndrome is an autoimmune disorder. Everybody has the same chance of contracting it. It would usually start within weeks of recovering from a cold, flu or any other virus that needs your white blood cells to fight off. It seems that when the white blood cells have dispatched the virus they continue fighting and attacking the peripheral nervous system. Imagine the peripheral nervous system as a bunch of cables surrounded by a sheath; the white blood cells attack the sheath making electrical messages from the brain more difficult to reach the extremities hence the tingling and numbness in his feet and hands. The longer it goes on the further up the body the numbness and weakness travels, until it reaches the lungs, which can potentially be fatal. Our doctor called the hospital and I took him directly to the ward where a registrar was waiting for us. After a quick examination the registrar told us that he certainly believed that this was Guillain-Barré syndrome and that 'he could well die!'

Obviously that news was shattering and the whole family descended on the hospital. It was a frightening time. After lots of tests, lumbar punctures, etc., Aaron was diagnosed and went to a high dependency unit. By now Aaron couldn't walk at all and had very limited strength in his arms. The hospital put him on a course of immunoglobulin which is derived from donors' white blood cells costing the NHS £100,000 for 1 week's course! This is thought to help stop the progression of the syndrome so recovery can start.

After a week in hospital Aaron was sent home to reduce the chance of him contracting any hospital borne infections. He was still very ill and had lost a lot of weight. He had to use a wheelchair and was walking with the use of a Zimmer frame and we had to take his bed downstairs. He remained like this for many months.

Aaron started to get sensation back and had to learn to walk again, having physiotherapy 3 times a week at Medway Hospital for 2 months. I remember Samantha in tears watching him trying to stand unaided so that he could finally be signed off! Aaron is lucky to have fully recovered with no ongoing issues whereas many people who contract Guillain-Barré aren't so fortunate. Some don't make it at all and others can have dramatic life changing issues including partial or total paralysis.

**GAIN is the UK's support and research charity for this devastating illness. The charity relies on fundraisers and donors, and receives no government funding. Samantha decided to run the Brighton Marathon in April 2017, raising £1,598.30 for GAIN, a charity which is close to our hearts.**



**Don't be left out! Join our 13 winners so far this year!**

**For a weekly chance to win up to £25,000, sign up to the Unity Lottery for only £1 per week and type **GAIN** in the 'select your charity' search box: [www.unitylottery.co.uk/charity](http://www.unitylottery.co.uk/charity).**



The **GAIN Unity Lottery** is undergoing an exciting change!

As of 1st July 2017, the Unity Lottery, through which we run the GAIN Unity Lottery, will be implementing a new prize for a 3-digit number match of 5 Prize Entries! This means that from July, the £5 cheque will be replaced with 5 Prize Entries into the next draw. So every time you get a 3-digit number match to your lottery number, you will automatically be entered for 5 Prize Entries into the following weekend's draw.

#### Why it's great for you

You get 5 more chances to win up to £25,000 in the next week's draw, and know that your charity is reaping the rewards too. 5 Prize Entries also means no more £5 cheques to take to the bank.

#### Why it's great for your charity

Your charity will receive at least 50% profit on the additional 5 entries won instead of a £5 prize – so every time you win against a 3-digit number match, your charity will earn an additional £2.50. This will make a huge difference to their profit week by week!

#### What happens now?

The change from the £5 cheque to 5 Prize Entries will be implemented as of 1st July 2017. There's nothing you need to do from your end, as this will be switched over automatically. From this date, every time you get a 3-digit number match, you will be entered for 5 Prize Entries into the next draw.

#### How will I know I've won?

As usual, you will receive a letter notifying you of your win. Instead of a £5 cheque at the bottom of the letter, you will be issued with 5 new lottery numbers which will be entered into the draw the following week, for that week only. If you're lucky enough to win against another 3-digit match, you will be sent a further 5 lottery numbers the following week and so on. And if you're even luckier to win against a 4, 5, or 6-digit number match, you'll be sent your winning cheque in the post!

#### Do I need to claim my prize?

All prizes will be issued automatically, so there is no need to claim.

#### Where can I find more information about the change?

You can find the updated Unity Rules on the website. You can also get in touch with the Unity team if you have any questions on 0370 050 9240, or email [info@unitylottery.co.uk](mailto:info@unitylottery.co.uk).

We hope that you will be as excited about this change as we are! Thank you for being a part of the GAIN Unity lottery. Your contribution to our lottery means that we can continue to raise essential funds and help support people affected by Guillain-Barré syndrome & the associated neuropathies.

# Your letters



*Jane Reid (nee Tempest-Roe), Jason Lloyd (GBS sufferer), Roland Price (Chairman, GBS Support Group), Glennys Sanders (Founder and President Emeritus), front Clive Lloyd CBE (former West Indies cricket captain) opening the Support Group's office April 1995.*

*Glennys Sanders, pictured left, shares her memories of Roland Price, former Chairman of the GBS Support Group, who sadly died earlier this year*

## **ROLAND PRICE**

**23 August 1924 – 11 February 2017**

**Local Contact/NEC member/Chairman of GBS Support Group 1989-2004**

In memory of a lovely gentleman and respected member of society who I was proud to call a friend. A caring husband, father and grandfather who was very proud of his family and their achievements.

Roland developed Guillain-Barré syndrome in 1984, spending some time in Intensive Care. I was asked to visit him during his stay in hospital to encourage him during his recovery. I kept in touch with Roland and he made a good recovery. In 1989, I finally persuaded him to become a Local Contact to visit patients currently suffering GBS in his area. He continued to provide support for many years.

He was a caring gentleman, with an empathy for people and a realistic understanding of GBS and its physical and emotional problems. He became Chairman of the GBS Support Group in 1991 and was committed and dedicated to the post.

During World War II, Roland worked on intelligence at Bletchley Park and spoke several languages fluently. He was an avid reader, loved the countryside and walking in the UK and Europe and was the co-founder of the Robin Hood Way Association, writing a comprehensive book on the route. Roland was very interested in music and was an active member of the Carlton and West Bridgford Male Voice Choirs, enjoying especially singing Gilbert & Sullivan. He loved sport, playing hockey (later becoming an umpire) and badminton, enjoyed cycling, and followed football, being a Nottingham Forest supporter. Roland will be missed by all who knew him.

*Glennys Sanders*

## A GBS Christmas Hangover...20 years on

Dear GAIN

At the end of last year, Chris found himself on a ventilator for the second time in 20 years.

Chris was admitted to A&E due to experiencing great difficulty in breathing. Whilst in A&E Chris did arrest and was transferred to Critical Care, where he was found to have very high carbon dioxide levels and low electrolytes. Chris was attached to a ventilator, and connected via various intravenous lines to correct his electrolytes. With the electrolytes corrected over the first day or so, Chris was extubated and the ventilator was removed, this after about 3 days. It took 3 weeks of intensive care, including attaching Chris to a 'big mask' or on invasive ventilation, for the carbon dioxide levels to reduce, and for Chris to recover enough to be transferred from Critical Care to the Respiratory Ward, where he made great progress, to be discharged home finally on 25<sup>th</sup> January.

The underlying cause, so we have been told, is that Chris, due to the effects of being ventilated for so long 20 years ago when he was in the throes of GBS, breathes mainly from the base of his lungs, leading to an eventual accumulation of carbon dioxide. Apparently this could have happened at any time, although Chris had no idea there was anything wrong. For the moment, or until his lungs are stronger, he has gone home with a NIPPY (non-invasive positive pressure ventilation), which is a machine working using pressurised air, not oxygen, at night via a small mask, which he is very happy with. The benefits are obvious to him, making him more awake and definitely giving him more energy. Chris has had his first follow up in Oxford, and is doing well, working, and driving himself once more.

We may celebrate Christmas later, but the main thing is that Chris is home, safe and well, thanks to the work and efforts of the team at Milton Keynes Hospital.

It would be interesting to know whether the medical team have come across this before with patients following severe GBS, or if anyone else has had a similar experience. Prior to the event, we had noticed that Chris was getting tired more easily, but we put this down to stress at work.

Best wishes,  
Tricia Swift

### *DVLA clarification*

*Thank you to **Gordon Sturme**y for sending us this extract from the DVLA regarding driving whilst enquiries are being made.*

*See also;  
[www.gov.uk/driving-medical-conditions/telling-dvla-about-a-medical-condition-or-disability](http://www.gov.uk/driving-medical-conditions/telling-dvla-about-a-medical-condition-or-disability)*

#### Can I drive while enquiries are being made

There is provision in law under Section 88 of the Road Traffic Act (RTA) 1988 that may allow you to drive while we process your application. To take advantage of this law you must meet the following criteria:

You must be confident that your application will not be refused due to your medical condition

You must have held a valid driving licence and only drive vehicles you are qualified to drive

You must meet any conditions specified on your previous licence

You sent your fully completed application to DVLA within the last 12 months

Your last licence must not have been revoked or refused for medical reasons

You must not be currently disqualified by a court

You must not have been disqualified as a high risk offender on or after 1 June 2013. A high risk offender is a driver convicted of a serious drink drive offence.

DVLA cannot tell you if this applies to you because we cannot confirm your fitness to drive until our investigations are complete. When our medical enquiries are finished you will receive a letter informing you of the decision.

If you require further information you can visit [www.gov.uk/driving-medical-conditions/what-happens-after-you-tell-dvla](http://www.gov.uk/driving-medical-conditions/what-happens-after-you-tell-dvla) or [www.gov.uk/government/publications/inf94-customer-service-guide-for-drivers-with-a-medical-condition](http://www.gov.uk/government/publications/inf94-customer-service-guide-for-drivers-with-a-medical-condition)

*The Law: Section 94(4)(5)(8) of the Road Traffic Act 1988*

*Rev Nov 16*



# Help out when you check out

Collect FREE donations for  
**Guillain-Barré & Associated  
Inflammatory Neuropathies**  
every time you shop online.



**Join, shop and raise here:**  
[easyfundraising.org.uk/causes/gaincharity](https://www.easyfundraising.org.uk/causes/gaincharity)

As featured in:



# Regional Round-up



*The South West England group, Saltford Golf Club*



*The Woolpack, Hothfield*

## KENT GET-TOGETHER 2017

Fifteen members answered our invitation to attend the now annual lunch organised by John Larkin and Ray Ponsford, both ex sufferers of GBS from the dim and distant past, but still with a tale to tell.

The Kent Group has met each year now for the past 4 or so years and hosted a post-Christmas meal at the Woolpack Beefeater restaurant where members have the opportunity to meet fellow sufferers, a lot of whom they may never have met, and compare their experiences in a relaxed and congenial atmosphere.

We met a little later this year than normal due to unforeseen circumstances, but the date chosen – 18th February – proved to be fine with the over indulgences of Christmas well and truly behind us.

All those that attended considered the get together beneficial and talked about other events we could stage during 2017 and include a possible change of venue for our get together in early 2018, as The Woolpack, although having served us well in the past, is not that central for Kent members coming from the west.

Everyone left having enjoyed the occasion and agreeing that it had been thoroughly worthwhile.

John Larkin - Kent Branch

## SOUTH WEST ENGLAND

### Get-Together March 2017

Sixteen people attended a meeting of the South West region at Saltford Golf Club on 18th March 2017. It was a very informal meeting where acquaintances were renewed, new members welcomed and we shared tales, some humorous, of illness and recovery.

From our collective experience as patients and carers we put together some advice which we hope others may find useful which we have submitted to Head Office (see page 16).

We rounded off the afternoon with tea and biscuits, and a raffle from which everyone went home with at least one prize! Our thanks go to Saltford Golf Club for once again providing us with a venue.

The next meeting in the South West region will take place on Saturday 14th October 2017 at the Phoenix Hall, Bovey Tracey, TQ13 9FF (south of Exeter not far from A38). We look forward to seeing you there.



*Saltford Golf Club*

Would you like to organise a get-together in your area?

Contact Sarah or Gill on 01529 469910 and we can help you get started.

# Regional Round-up

## LANCASHIRE & CUMBRIA

### June

The weather always seems to loom large in the quarterly meetings of the Lancs & Cumbria branch and June's meeting was no exception. With a heatwave outside we decided to keep cool with a talk on Dog Sledding in the Arctic. First, however, we paused for a minute's silence in memory of our dear friend and committee member, Ann Birchall, who had lost her battle with cancer since the previous meeting.

Our speaker for this meeting, Pat Ascroft, takes on challenges to raise money for Mencap and she certainly kept us spellbound and very amused, as she recounted her latest adventure, which took place in northern Sweden during February in temperatures of -25C. She started by telling us how at Heathrow her dozen fellow adventurers had redirected her to the adjacent check-in desk for the Saga holiday.

She then introduced us pictorially to the four dogs, which were her "children" and motive power for the week, while she spent seven hours a day standing at the back of her sled, dressed in uncountable layers of clothing. At the end of the day feeding her "children" was the priority, before collapsing exhausted on the floor of the yurt with nothing but the snores of her companions to mask the howling of wolves outside.

We were all full of admiration for Pat's courage and endurance, but couldn't match the final compliment paid to her by Daniella, the taciturn and monosyllabic Swedish leader of the expedition, whose parting shot was, "Good team", then turning to Pat, "I have never sled with such old lady"...and we doubt whether she ever will again!

### March

The June talk was a complete contrast to the more sombre tenor of the March meeting, when one of our members Fiona Wilson, described the research she had done to identify the people behind the 113 names on the First World War Memorial at St Anne's-on-Sea Parish Church. Fiona described and illustrated all the many research sources she had used, which ranged from those available on the internet to local newspapers and parish magazines available locally. Husband Gerald then described how they had set up a trail around the 40 WW1 memorial graves in the churchyard and how the church bell ringers were ringing commemorative quarter peals for each of the men who had died.

As usual at all our meetings we have our regular Sufferers' & Supporters' Forum, when we exchange experiences, questions, and tips on living with GBS & CIDP, before tucking into cakes and tea as we complete the draws for the 100 Club and raffle, and spend our final pennies on various stalls including plants, jewellery, jams and preserves.

### Looking forward

Future meetings, all at Bilborrow Village Hall on the A6 north of Preston, commencing at 2pm are as follows:

- 9th September 2017, when we have a speaker, Ruth Gibbs, talking about Eating Well, Feeling Good.
- 9th December 2017, which will be our Christmas party with the usual fun and games.
- 10th March 2018
- 16th June 2018
- 15th September 2018
- 8th December 2018



### **ANN – a few words from Sybil:**

*This is such a difficult piece to write, Ann leaves a void that cannot be filled. She was "the pulse and hub" of our branch; the lively fun-loving, thoughtful person who kept us all together with her concern and care for others. She was our P.A. – always in contact by phone, emails, Facebook, etc., with many members of the group – caring, concerned, supportive and helpful, I never knew her to be bad-tempered or down. Ann always saw the funny side of things and was irrepressible in her enthusiasm for life. Colin and Ann were perfect together, but even Colin had a job to "keep her down". Throughout her fight with cancer she was optimistic and fought it with every breath. Ann, you will be so greatly missed but will be in a corner of all our hearts forever.*

**On behalf of everyone at the branch, our heartfelt condolences and much love are sent to Colin and sons Andrew and Neil, their wives Jane and Siobhan and granddaughter Isabel.**

# Other sources of help

<b>Anxiety UK</b>	<a href="http://www.anxietyuk.org.uk/get-help-now/self-help-groups">www.anxietyuk.org.uk/get-help-now/self-help-groups</a>	Independent self-help groups across the UK
<b>Befriending Network</b>	<a href="http://www.befriending.co.uk/befriendingdirectory.php">www.befriending.co.uk/befriendingdirectory.php</a>	UK-wide directory of befriending services
<b>Age UK Befriending Services</b>	<a href="http://www.ageuk.org.uk/health-wellbeing/relationships-and-family/befriending-services-combating-loneliness">www.ageuk.org.uk/health-wellbeing/relationships-and-family/befriending-services-combating-loneliness</a>	Beat loneliness in later life with Age UK befriending services.
<b>Cruse</b>	<a href="http://www.cruse.org.uk">www.cruse.org.uk</a>	Here to support you after the death of someone close.
<b>Blue Badge</b>	<a href="http://www.gov.uk/blue-badge-scheme-information-council">www.gov.uk/blue-badge-scheme-information-council</a>	Apply for or renew your Blue Badge
<b>Disabled Facilities Grant</b>	<a href="http://www.gov.uk/disabled-facilities-grants/overview">www.gov.uk/disabled-facilities-grants/overview</a>	Grant for disabled people needing to make changes to their home.
<b>Independent Living</b>	<a href="http://www.independentliving.co.uk">www.independentliving.co.uk</a>	Products and services to help with mobility & independence
<b>Facial Palsy UK</b>	<a href="http://www.facialpalsy.org.uk">www.facialpalsy.org.uk</a>	Support and information for patients and their families.
<b>Contact a Family</b>	<a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>	Support for the families of disabled children
<b>NHS Choices Discharge from Hospital</b>	<a href="http://www.nhs.uk/conditions/social-care-and-support-guide/pages/hospital-discharge-care.aspx">www.nhs.uk/conditions/social-care-and-support-guide/pages/hospital-discharge-care.aspx</a>	Information about discharge from hospital
<b>Accessible Property Register</b>	<a href="http://accessible-property.org.uk/start.htm">accessible-property.org.uk/start.htm</a>	Accessible property to buy, rent or holiday lets
<b>ICU Steps</b>	<a href="http://www.icusteps.org">www.icusteps.org</a>	The intensive care patient support charity



# Leaving a Gift

Leaving a charitable donation in your will allows you to support the causes that were important to you during your lifetime

Many solicitors now offer a free will-writing service in exchange for a donation to a charity of your choice.

To find a solicitor who can help you with making your will, visit the Law Society's Find a Solicitor website, and use the quick search option 'Wills and probate'

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