

SUMMER 2015

# gain4all

Issue 6

Quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies



**gain** Guillain-Barré & Associated Inflammatory Neuropathies

In June 2010, GBS had a profound impact on our family.

GBS is an acute disease of the peripheral nervous system, in which nerves are damaged by the body's auto-immune system and cease to function; causing sudden weakness and numbness and can lead to paralysis requiring long-term rehabilitation. GBS affects about 1200 people in the UK a year.

While the majority recover, 10-15% are left permanently disabled whilst 5-8% die.

GAIN exists to provide support and information to patients and their families, to raise awareness of the conditions and to attract funds for research.

We have made a contribution to this worthwhile charity, that is close to our hearts and we hope you approve of our choice of favour.

*Phil & Sharon*

Here's a Favour  
from  
Phil and Sharon

"We have made a contribution to this worthwhile charity, that is close to our hearts and we hope you approve of our choice of favour".

See page 8 for details

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

# Trustee Vacancy

## About the opportunity

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

## General Responsibilities

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

## What are we looking for?

### Person Specification

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

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

### **Essential**

#### **Commitment to GAIN's mission and values;**

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

### **Desirable**

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

For more information and an application pack contact [director@gaincharity.org.uk](mailto:director@gaincharity.org.uk) by 31st August 2015. Your cover letter should highlight your interest in GAIN and motivation for joining our Board. Please also detail your availability and relevant experience, ensuring this is in line with above job description and person specification.

# 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

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Office Enquiries: 9.00am – 3.00pm

### FREE HELPLINE:

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

## AGM report

The Vice Chairman, Chris Fuller, welcomed everyone to the GAIN Annual General Meeting as the Chairman, James Babington Smith, was unable to do so due to ill health. The Director, Caroline Morrice, read out and answered questions regarding the Chairman's report.

We had received a number of postal votes which were counted by an independent body and the results were opened and included on the day. Approximately 25% of the voting membership responded and all the motions were accepted. Of particular note were the **changes to the membership and full details are on the renewal form enclosed with this magazine.**

Membership is now free to all, with options to buy a magazine subscription, make regular donations and to be a voting member.

During the next few months the Director along with the Trustees will be looking at the foundation Model of the constitution and will provide updates to allow members to make an informed decision about the future of the charity.



# NEWS

## Notes of the

**Caroline Morrice** welcomed everyone to the Regional Event and gave a short update on the aims and objectives of the charity. She went on to explain how the charity was now involved in working with other charities including rare diseases and pan-neurologically which was now giving us a voice in national and local debates which we could not achieve on our own.

Increasing the use of social media to raise awareness is being embraced by the office and its use during meetings is very common to share comments and thoughts as they are said is a routine occurrence! Look out in future editions of *gain4all* as we bring you our guides to social media and how to use them to best effect.

**Adam and Nick** gave an enthusiastic introduction to themselves and how they are collaborating on a show to highlight GBS using Adam's own experiences. Nick, a seasoned playwright, was working with Adam to create the show which we all will be queuing up to see in 2016.

The project involves developing a GBS awareness show for touring the country – mix of acting and dance. Using Adam's story and his black humour to give the audience a vision of GBS, it is hoped

that people will recognise how lives are affected by this disease. The current working title is GBS although may change to Limp in the future – and you will have to go and see the show to get the full picture of why!



Adam Pownall



Nick Wood

GAIN is supporting the production as this is a major awareness project and we are all waiting for the outcome of the Arts Council Grant Application so the work can really start. *To read more about Adam and the project, see page 18.*



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 October 2015 and the deadline for submissions is 15 August 2015. Please forward all articles to Lesley Dimmick [fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk)

# from the office

## GAIN Regional Event 20 June 2015



**Claire White** gave an update on the 3 year research project, funded by GAIN, which involves evaluating the effect of exercise, post recovery, in GBS and CIDP. The results are expected in December 2015.

58 people have gone through the 12 week project (most recruited through GAIN network), with 40 people in the final 12 month follow up. There has also been an online survey which basically highlighted an active bunch of people who could walk short distances with or without assistance.

Future research may look at people attending clinics and those not undertaking exercise.

Results and feedback will be through GAIN.

**Dr John Winer** recently announced his retirement and stepped down as Chairman of the MAB and handed the role on to Dr Jane Pritchard. Having joined the MAB at the birth of the charity John has supported us for the past 30 years. He gave a history of his time with the charity from becoming involved in 1985 as a young naïve research fellow in London, working with Richard Hughes. The first meeting was in Guys Tower in London attended by an enthusiastic bunch of around 60 people. Over the years he has seen many changes in the charity making it the professional organisation it is today. He felt that the name change has been very positive in making more people aware of the charity. John spoke of the importance of GAIN supporting research; original work focussed on infections triggering GBS, last 10 – 15 years more learned about how the damage is being caused, next 30 years something better than intravenous immunoglobulin and more research on nerve repair.

John was presented with a claret jug and bottle of claret purchased using money collected from the Medical Advisory Board, Trustees, Staff and Members.

### Why claret?



Guillain and Barré were medical students together at the Salpêtrière in Paris at the turn of the twentieth century and specialised in neurology. During the First World War, they were both serving as doctors in the French Army. They noted the cases of two soldiers who had become partially paralysed. One 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.



## Ask the experts



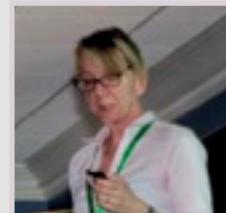
John Winer



Anne Fowlie



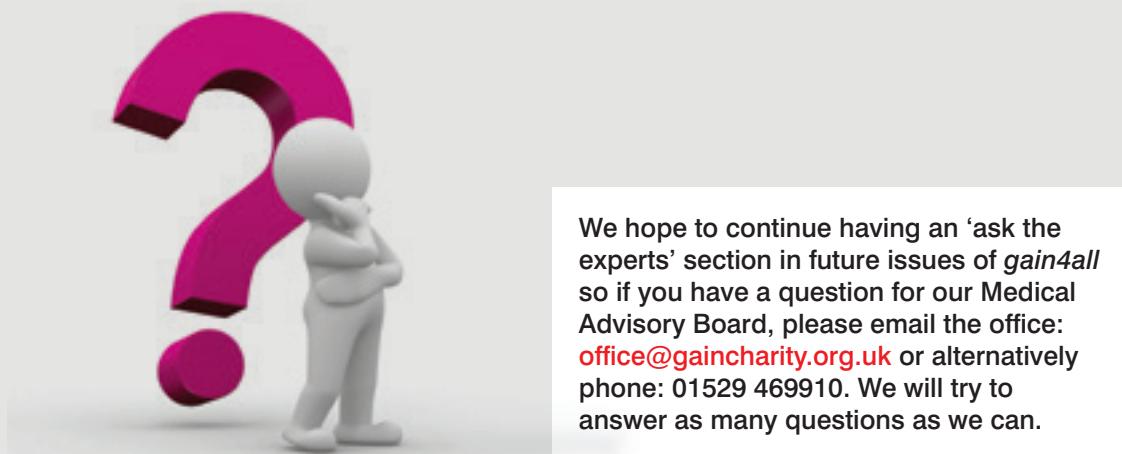
Jane Pritchard



Claire White

<b>Can GBS come back again (93 year old) – tingling in legs etc.?</b>	<p>Chances not – particularly at that age.</p> <p>GBS only rarely recurs (quoted at 3%) so at the age of 93 you would need to check there wasn't a new problem developing which is more likely</p> <p>ie would need to be re-assessed properly.</p>
<b>When is nerve damage seen as irreversible?</b>	<p>Time gets longer as we get more experience. Sensory changes can improve for years. Motor problems generally reach a plateau at 2 years but a little more improvement can still occur in some individuals.</p> <p>Nerves go on recovering for at least the 2 years quoted in the books, and in real life for significantly longer. Sometimes nerves can seem not be working due to block of the signals rather than damage to the nerve: on electrical tests these cannot be separated.</p>
<b>15 years living with CIDP, now problems with vision. Is it connected to CIDP?</b>	<p>Could be – check with an ophthalmologist. There are a number of visual problems which could be due to GBS or CIDP, including double vision, cataracts and rare cases of optic nerve problems. In all these cases a thorough ophthalmology check would be needed to sort out the cause of the visual problems, and only then would it be possible to decide whether it was anything to do with the CIDP.</p>
<b>Fit active 80 year old, had GBS 6 years ago – result of swine flu jab. Had flu jab recently, now tingling etc. Is the GBS back?</b>	<p>Not necessarily, the flu jab may have caused the tingling. If it continues ask for a re-assessment. In our survey of patients who had vaccines after GBS or CIDP only a handful reported some recurrence of symptoms, and these were not severe. Best to be checked out though in case symptoms are returning.</p>
<b>From Facebook there seems to be an increase in the numbers getting the illnesses and is this linked to more people getting the flu vaccine?</b>	<p>Don't believe everything you read on <i>Facebook!</i> There is no known increase in the incident rate of GBS and CIDP. You are at greater risk of getting GBS following a severe bout of flu than from having the vaccination.</p>
<b>Something on a Facebook post – comment re fatigue associated with GBS. Is it tired nerves or muscles?</b>	<p>Nerves and muscles are very linked – effort being put into exercise to be considered.</p>
<b>Is there an indication when the treatment for CIDP should stop?</b>	<p>CIDP burns itself out in time – difficult to predict the length of time. Need to gauge it between the doctor and the patient.</p>

<b>Is physiotherapy aimed merely at strengthening muscles and has nothing to do with nerve repair?</b>	Is evidence in animals that rehab and exercise can improve recovery. Nothing for humans.
<b>GBS 2 years ago, in hospital 6 months. Now undertaking lots of exercise and gym. Still have muscle spasms in legs and hands are claw like which is a nuisance. Occurs with or without exercise. What is it?</b>	Not sure but could be some residual damage. It is not unusual for GBS to leave residual fatigue and many patients complain of cramps. Spasms however are often associated with central nervous system (brain and spinal cord) disease, rather than GBS.
<b>Risks of intravenous immunoglobulin?</b>	Blood thicker so rare stroke and heart attack, occasionally kidney damage, allergic skin problems, theoretical risk of infection.  Immediate risk of allergy, high blood pressure, headache, rash. Theoretical risks of more strokes/heart attacks as it makes the blood more viscous, and the risk of transmission of infectious agents since it is from blood.
<b>Any innovations in pain control for CIDP?</b>	Pain medicine in general is a huge area of research. Lots of international trials because of the huge numbers of patients with diabetic painful neuropathy, CIDP and other neuropathies borrow the drugs designed for these patients.
<b>Can you have CIDP then GBS?</b>	No. CIDP then GBS doesn't happen, but some people start with what looks like GBS and then turns into CIDP.
<b>Trigger points for GBS?</b>	Trauma – evidence not good; infections – evidence good; viruses – evidence good, vaccines – occasionally.
<b>Is stress linked to the cause of GBS?</b>	Likely to get autoimmune disease however difficult to prove, no evidence. The mind to body link is complicated.
<b>Re link between GBS research and MS research?</b>	Similar pathological processes but different part of nervous system.  Both are autoimmune diseases but MS continues for life where in GBS the immune system corrects itself after those first few weeks, hence not giving ongoing immune treatments in GBS.
<b>Daughter had GBS 4 years ago, still having tingling in legs etc. Can anything be done?</b>	Physio, pain relief.  Drugs to help with symptoms e.g. gabapentin, pregabalin.





## Meet the Medical Advisory Board (MAB)

### 1. Who are you?

*Dr Simon Rinaldi.*

### 2. Where do you work?

*I am an Academic Clinical Lecturer in Neurology, in the Nuffield Department of Clinical Neurosciences, University of Oxford, based in the John Radcliffe Hospital.*

### 3. What is your role on the MAB?

*I am (currently) the most junior member of the MAB, but my role is similar to the other members. We are primarily involved in providing specialist medical advice and support to GAIN. We review literature for the website, answer medical questions posed to the charity, assist with the preparation and content of advice leaflets for patients and professionals, and from the “ask the experts” panels at GAIN meetings.*

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

*I have a particular interest in the antibodies associated with all of the inflammatory neuropathies, and continue to be involved in research studying how the immune system damages nerves in these conditions.*

### 5. What inspired you to join the MAB?

*I was approached by an inspirational senior consultant! (now retired) I also have the utmost respect for the other members of the board, who were known to me previously, and had been impressed by the information booklets and support offered by GAIN, so it was a simple decision to accept the offer.*

### 6. What current global research excites you?

*The International GBS Outcome Study (IGOS, [www.gbsstudies.org](http://www.gbsstudies.org)), set up by Dr Bart Jacobs in Rotterdam, but involving doctors and scientists around the world, is a hugely impressive undertaking. Already, over 1000 patients have been entered. For each of these, detailed clinical information is recorded in a database and blood samples are collected. This resource will be invaluable in addressing many of the as yet unanswered questions in GBS.*

*The work of Professor Hugh Willison in Glasgow also remains extremely impressive. Hugh was my PhD supervisor, and he remains a supportive mentor and collaborator, but I don't think I am biased (or alone) in holding this view. The recent work of his group has offered a paradigm shifting insight into why current blood tests are often not helpful in diagnosing GBS and shed new light on reasons how and why specific nerves may be damaged in this condition. Alongside this, he is also running the first clinical trial of a new drug (eculizumab) for GBS in over 20 years.*

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

*While I think that GBS and CIDP will be more quickly diagnosed and have better treatments and outcomes over the next few years, I don't think preventing them completely is likely to be possible in the foreseeable future. There are a few reasons for this. They don't seem to be caused by one genetic factor, or one infection, or indeed one disease process, so I don't think one intervention or treatment will eradicate them. They are also rare enough that screening or treating whole populations is unlikely to be safe, effective or practicable enough to undertake.*

*Having said that, we should perhaps take heart from New Zealand, where a government scheme to treat campylobacter in poultry appears to have had the knock on effect of reducing the number of GBS cases.*

## Guillain & Barré 100 Years

2016 is the centenary of Guillain's and Barré's work and to mark this there will be a major international conference in Glasgow in June. GAIN will hold an event to coincide with this so that we can draw on services of some of the world leaders in the treatment and research of GBS & associated inflammatory neuropathies.

It will be held on Saturday 25th June in Glasgow (further details will be issued in the next issue of *gain4all*, on our website and through the usual social media channels).

**GBS 100 Golf Day** - Sunday 26th June  
Fereneze Golf Club, Barrhead (please contact the office for further details).

## Dates for the diary



**Regional Meeting** The next meeting will take place on Saturday 10th October 2015, in York. Full details of the event will be published on the website, through social media and everyone living within a 50 mile radius of the venue will be notified by post or email.



**Our thanks to everyone who signed up to our Lottery. As a result, we have already received cheques to the value of £78.50**

You can still join online at: <http://www.unitylottery.co.uk/charity/display/guillain-barre-associated-inflammatory-neuropathies>



From 1 July 2015, you will be able to phone our 0800 number free from a mobile. This is great news for those affected by the illness and will only cost the charity a few pence more than calls from land lines.

## Annual Prize Draw 2015

The Results of the 2015 prize draw are:

**1st prize** ticket number 00694

**2nd prize** ticket number 17884

**3rd prize** ticket number 06926

**4th prize** ticket number 13993

**5th prize** ticket number 10804

**6th prize** ticket number 17651

**7th prize** ticket number 15159

*Thank you to everyone who supported it.*

# Favours for GAIN

In April this year, Sharon and I finally tied the knot; we had been engaged for far too many years. There is not too much that we haven't been through in our time together but nothing had prepared us for the impact that GBS inflicted upon our family five years ago.

In 2010, I was healthy and actively travelling the country for work during the week and at weekends, was running around everywhere with our young family. On 1st June 2010, having cycled only a few hundred metres with my son, it was obvious that something was wrong with my legs. Two days later I was flat out in bed with Campylobacter food poisoning, rapidly losing all strength and beginning to get pains in the peripheral parts of my body. It took three and a half weeks and several visits from my GP before GBS was suspected and when I was admitted to hospital, a lumber puncture confirmed this. My GP was amazing and followed my progress and gave so much more advice than any of the hospital staff and consultants. Mainly because she had come across something new and had the desire to learn. The alarming thing was how little the staff in hospital looking after me, actually knew about the condition!

At this stage, I had no idea what GBS was nor what to expect.

I was lucky. My breathing problems stabilised and I was sent home just over a week later to recover back at home, which although the surroundings were nicer than the hospital, it was ill equipped for my recovery.

After seven long months of being totally dependent upon my family to go anywhere, the first milestone was reached and the wheelchair was finally no longer needed! After eleven months, I undertook my first, very emotional bike ride with my son again and for me, at that moment, it was what all the rehabilitation had been for (although I should probably say that it was so I could walk back down the aisle with my bride!) My family were amazing with the time and help they gave and were instrumental in helping with the mental recovery needed to overcome GBS.



When it came to our wedding, we decided not to put the traditional wedding favours on the guests' tables. Instead, the money we would have spent was donated to GAIN and a small card left on the table to inform our friends that we had done so. On the day, more money was raised by my youngest son, who had his own initiative to sell pocket sized packs of tissues to the guests that were left over props from the Best Man's speech.

When I first returned home from hospital, I was left for a while, on the sofa with a laptop. I thought I could Google to find the solution for a quick recovery to an illness I had no idea about, other than the name "Guillain-Barré syndrome". Every search I made brought up websites full of worst case scenarios. After a short time, the laptop nearly went through the window and it was a long time before I used the internet again. It was probably this experience that influenced the idea of the charity donations instead of wedding favours and having discovered that a well publicised heart charity did a similar thing, we decided to do the same for a GBS related charity. This was how I discovered the GAIN website. Probably too late for my own experience but very important to know that there is a charity out there who can help others who are faced with the same uncertainties that we faced.



## DIAMOND WEDDING CELEBRATIONS

Our thanks to Mr Denys and Mrs Barbara Le Fevre who recently celebrated their 60th Wedding Anniversary and raised almost £400.00 by kindly requesting donations for GAIN in lieu of gifts.



The future? Well, although GBS still likes to remind me that I have done too much every so often, I am probably physically and mentally better than I ever dreamt I would be. I am back working, I have probably learnt the true value of

friends and family and above all, finally got around to marrying my soul-mate who helped me through the worst times. And by the time this makes the newsletter, I have hopefully completed the 50 mile Liverpool, Chester, Liverpool cycle ride with friends and my son, who was one of the key motivators to keep pushing on. This is a small part of my training towards next year's goal – to cycle up the Stelvio Pass in Italy which has been on my bucket list since I was about 14.

Keep up the great work and ensure that awareness is spread throughout professionals as well as the general public!

*Phil Wallace*



# fundraising



## Milton Keynes Running Festival 2015

On the anniversary of contracting GBS, Jenny Bone completed the Milton Keynes 5k run in 51 minutes, 6 seconds raising £315.00 for GAIN. 'It was an amazing experience' said Jenny.

## Great Manchester

I was supposed to run the Manchester 10k in May 2014 but was still in a wheelchair and just out of hospital after 3 months, having suffered from Guillain-Barré syndrome.

A year later, along with my husband, brother and Dad, I did it. It was tough but a great feeling to cross that finish line just a year later than I had intended. Between us we have raised over £3500 for GAIN and hope the money will make a difference.

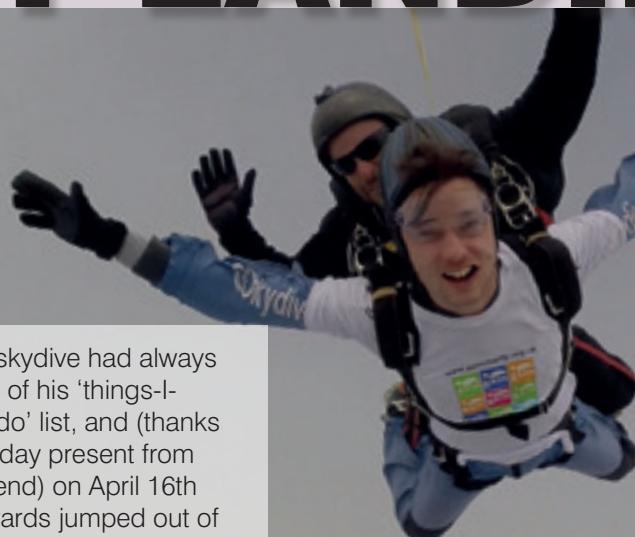
Ruth Curry



## HAPPY LANDING



Doing a skydive had always been top of his 'things-I-need-to-do' list, and (thanks to a birthday present from his girlfriend) on April 16th Ben Edwards jumped out of a plane at 15,000ft.



“

I wanted to take the chance to increase awareness and hopefully raise a few quid for the charity which is close to me and my family said Ben.

# reports

## Run

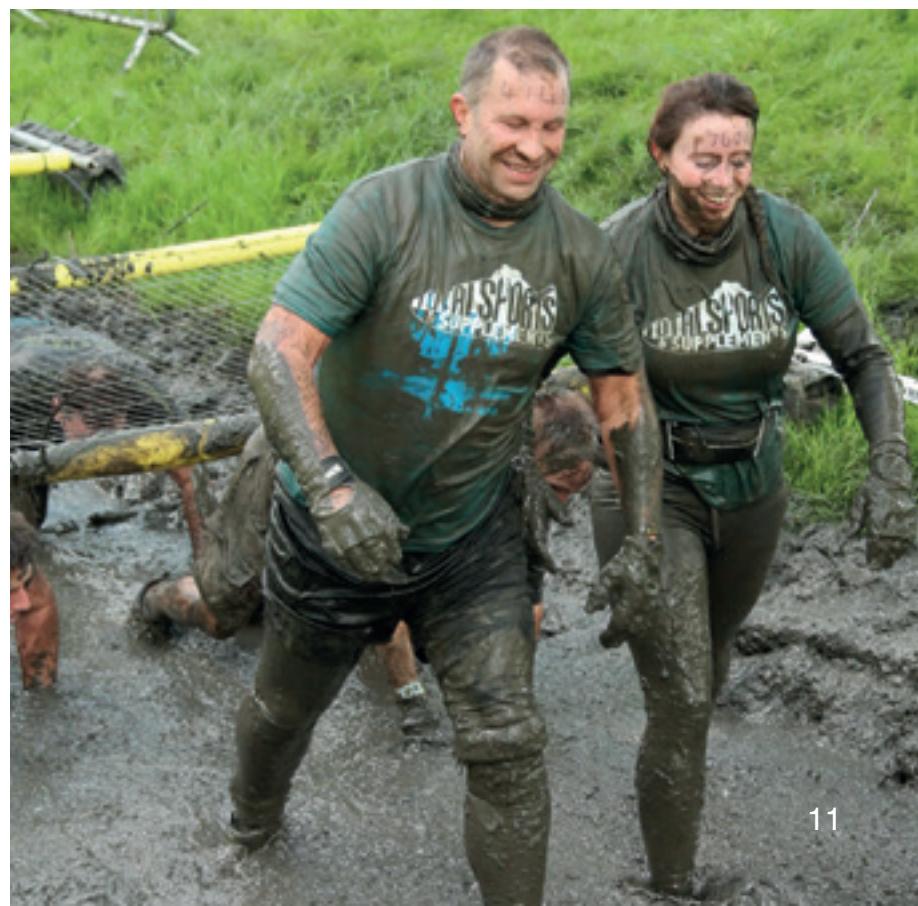


Hayley and her partner Dave at the finish line

## Dirty Weekend at Burghley

I sadly lost my dad last year to Guillain-Barré syndrome and have witnessed first hand the devastating consequences of this illness. I miss my dad dearly every single day. I completed a 13 mile obstacle Rat Race in his memory and in doing so, I hoped to raise awareness and funds for GAIN. I am pleased to say I achieved this goal raising a total of £658.34 (including giftaid). I would like to take this opportunity to say a massive thank you to all those who donated, everybody's generosity and support has been overwhelming.

Hayley Rose





## Year Long Series of Fundraising Events

My name is Karrie and I'm a 22 year old Mental Health Nursing student and in November 2013 I started to develop symptoms of GBS. I was admitted to hospital and became paralysed from the chest downwards. I had to have an NG tube fitted and also a pacemaker to control my heart rate.

Eventually I began to improve with amazing support from my family and the hospital staff. I received intensive physiotherapy and was encouraged to write a list of short and long-term goals. My early targets were: getting into a wheelchair and going home for a few hours on Christmas day. Whilst my long-term goals were: getting back to ice skating; running a 10km race and getting back to my degree.

Before GBS I was a very fit and active person; I loved running and I particularly enjoyed figure skating, so I was so determined to get back to these activities. I was discharged in January 2014 and I spent the next few months doing daily exercises to slowly building up my strength.

In July 2014 I finally had the pacemaker I was fitted with removed and this made me feel like my ordeal with GBS was finally over. I do still get some residual nerve pain but for the most part I am fully recovered. I decided at this point to do a year long series of sporting events to raise money for GAIN and also the MS Society. GAIN provided my family and me with a lot of support whilst I was in hospital so I really wanted to help fund them to continue helping others. Also, I wanted to see how far I could push my body to prove to myself that GBS won't ever prevent me from attempting anything in my life.

So far I've done: the Preston 10km run; a Boxing Day 10km run (which was very cold!); the Great Manchester Run; I've walked up Ben Nevis and

“ It was devastating at the time and as I'd never heard of this condition, I wanted to raise awareness and give some hope to others”  
Helen Baker  
(Karrie's Aunt who has also raised £172.00)

”



I'm now training for the Great North Run in September. Walking up Ben Nevis was a really difficult challenge but I was so lucky that my Mum, Auntie and boyfriend all joined me for that climb. I think the Great North Run (which is a half marathon) is really going to test my fitness but I'm really anticipating the challenge. I've raised over £400 so far and have a target of £600. I really want to give people newly diagnosed with this terrible disease some hope that things can get better with time, patience and of course heaps of support.

Finally, I've recently been giving talks at my university to trainee nurses on how it feels to be a patient in an acute hospital. My aim is to increase awareness of GBS and also to explain to these students how it feels to be so dependent on others. I'm hoping that I can inspire them to become caring and compassionate nurses in the future because I know that the amazing nursing care I received contributed so much to my recovery.

Karrie Houghton

Left to right: Mum, my boyfriend, me and my Aunt



# Prudential RideLondon – Surrey 100

The Prudential RideLondon-Surrey 100 is now the biggest and best celebration of cycling in the UK. The weekend brings together more than 70,000 cyclists including the world's top professionals. It starts in Queen Elizabeth Olympic Park, then follows a 100-mile route on closed roads through the capital and into Surrey's stunning countryside. With leg-testing climbs and a route made famous by the world's best cyclists at the London 2012 Olympics, it's a truly spectacular event for all involved. It finishes on The Mall in central London and highlights will be shown on the BBC.

The 2015 Prudential RideLondon-Surrey 100 takes place on Sunday 2nd August and this year, we are very lucky to have four cyclists – Jess Nicholson, Robert Foden, Ben Dawbarn and Ross Clarke – who are all taking part in support of GAIN. We would like to thank our cyclists and wish them the very best for training and the actual event itself. If you can sponsor Jessica, Robert, Ben or Ross then please visit their online pages or contact the office. All money raised from the event will go towards much needed medical research. Thank you

## Meet the Team...



**Jessica**

Last October, Jessica's 3.5 year old niece Libby became ill and at a visit to the Sydney Children's Hospital, her condition was diagnosed as Guillain-Barré syndrome.

Libby was admitted to hospital and was bed-ridden for about 2 weeks, but with two intravenous immunoglobulin infusions, physio and occupational therapy, she started to walk again – disjointedly but made steady progress over the weeks. She's a real little fighter and is almost back to 100%

Being based in the UK, Jessica called GAIN for guidance and support. "It's challenging being so far away from family during hard times. I'd never heard of it before and having read up, found out that it strikes at random with no cause or cure yet identified. I want to do my bit to raise awareness and funds for the Charity in the UK".

To support Jess, please visit her JustGiving page <https://www.justgiving.com/JessdoesPru100>

### Robert, Ben and Ross



Robert, Ben and Ross will all be cycling the RideLondon having just completed a 5 Peak Charity Challenge. Over the course of 7 days their team are going to be climbing the highest 4 mountains in England, Ireland, Scotland and Wales. They then fly over to climb the highest mountain in Europe, Mont Blanc, before flying back to London to take part in the RideLondon bike ride. They are doing this monstrous challenge for 3 charities very close to their hearts, St Rocco's Hospice, the Royal Brompton and Harefield Hospitals Charity and GAIN – all proceeds will be split equally between the three charities.

Robert's niece Candice died 5 years ago on her 26th Birthday. "No warning, flu symptoms then gone in less than a month! Wow. The effects of this still haunt the family and her parents still cannot come to terms with the loss of such a normal fun loving beautiful girl. The charity funds research to find out WHY".

Robert, Ben and Ross appreciate your well wishes, support and donations and ask you to please donate whatever you can as every penny really does matter.

<http://uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserPage.action?userUrl=ecoshred5peakchallenge&ald=556063&isTeam=true>

Ross Clark



Robert Foden



Ben Dawbarn



## Virgin London Marathon 2015

**A big thank you to all of our London Marathon runners including Chris Walker, who won our 2015 GAIN Charity place and raised over £3500**



Back in October 2014 I received the phone call I was waiting for – I had been pulled out of the GAIN ballot for the 2015 London Marathon in 6 months' time. When I received the call I was driving back from the hospital in Leeds having had scans on my neck due to a rugby injury and as I wasn't able to play rugby at the time, it was the best news I could have wished for. So that night it was time to get the trainers on, slowly start building up and get plenty of training under my belt.

The first few weeks were OK starting with 6-7 miles after work, then I had to step it up again and after Christmas it was time to start getting some 10 milers under my belt and really put some hard work in. Sadly I seemed to be doing too much and injured my foot so I had to rest up for a few weeks (just my luck).

My online total hit over £1,000 and I was really worried I was going to have to pull out but there was no chance. I was not going to let myself down or all the people around the world suffering from GBS, because I seem to have been very lucky in my recovery.

Six weeks before the run I went to see my doctor and had a pain killing injection under the ball of my foot which wasn't very nice at all. Two weeks before the run I had a very steady 2 mile jog and it felt OK but I didn't want to push it too much. My target when I was training was to do the marathon in under 5 hours but that target didn't seem possible anymore. The day of the marathon was getting closer, I had my vest ready

“ If you have suffered from GBS and have the odd bad day which I did in late 2012, don't ever give up, this one is for you guys. ”



for it and the total on my online page was flying over £2,000.

Now there was just the small matter of our best friend's wedding which was the day before in West Yorkshire. Not the best preparation for a marathon having no training and a wedding the day before but I really wanted to get this huge achievement under my belt. It got to 9.00pm on the night of the wedding and it was time to drive to Potters Bar to our hotel where we arrived at 12.40am, jumped into bed and were up again at 6:00am and set off for the trains and underground. We got off the last train and as I was heading to the start line, I realised I had no breakfast; it had been such a crazy 24 hours. Luckily there was a Sainsburys where I got some flapjack and yoghurt; talk about bad preparation for the biggest marathon in the world. I checked my phone for the last time where I had a ridiculous amount of messages of support from family, friends and sponsors. I said goodbye to the family that came down to support me and now it was just me and 26.2 mile of tarmac in London.

The buzz at the start was crazy and we got off on time to a big cheer from the runners and the crowd. The first few miles were going really well and after about 8 miles I was flying and feeling really good. I got a message from my family saying they would be at the 12 mile mark so when I was almost there, I pulled my music out and gave them a wave – it was 'brill' to see them, music back in and that was that.

After doing two half marathons in 2013 & 2014, I was now entering unknown territory. I first started feeling the pain at 18 miles and wasn't sure if I could go on much longer, but I just kept plodding along but I was ready to pack it in at 22 miles as I wasn't sure how I was going to finish it. I have never felt as much pain in my life and couldn't feel my feet, the last 4 miles were the longest 50 minutes of my life but then I turned the last bend and there was Buckingham Palace and the home straight. I took my music out and just soaked the last couple of minutes up and

crossed the line. I was greeted with my medal and had a photo taken before sitting down for a couple of minutes, just sorting myself out. Then I had a very slow walk to see everyone who came down to watch me – Natalie (my girlfriend), Mum, Dad, Kelly (sister) and Michael (her boyfriend). After a couple of photos and a chat, we made our way back to the tube station when Kelly told me my time from the Internet, 5hrs 44secs, I was so pleased.

I then sat down and checked my phone, I had so many 'well done's' and when I checked my Virgin money page, it had smashed £3,000, so it wasn't a bad day in all. After a few tube trains and a 3 hour drive home, I hobbled through the door and was greeted by the dog. I then jumped in an ice cold bath and just had a look at my feet, I had blistered on top of blisters and three of my nails had gone black, but hey I just ran the 2015 London marathon for such a fantastic cause.

I wouldn't have done it if it wasn't for all the support from everyone at GAIN, also the Facebook page that the girls down there run and my family and friends.

If you have suffered from GBS and have the odd bad day which I did in late 2012, don't ever give up, this one is for you guys.

*Chris Walker*

Anyone wishing to support Chris can still donate by going online at [www.virginmoneygiving.com/chris4gain](http://www.virginmoneygiving.com/chris4gain)

**If you are lucky enough to  
get a place for the 2016  
London Marathon and will be  
supporting GAIN, please let us  
know:  
[fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk)**



Ben

# The Ward Friends Challenge 2015

Over a 16 month period 2012-2013 as a family we walked (or were carried) the length of the Capital Ring Walk which is a route around London covering 78 miles which passes near our home. We knew we wanted to do something which all of the family could be involved in, including our children, Lucy who was then 2 years old and Ben, who was four and has walking problems (a residual from GBS).

We did this because our son Ben suffered from Guillain-Barré syndrome when he was 2 years old, affecting his lower limbs. Although he recovered, he was left with damage to the nerves that control his calf and foot muscles.

Ben is now 7 and currently in school Year 2. He has had a few operations in the past few years as well as Botox injection as of course regular physiotherapy. He has been making great progress and his mobility issues don't hold him back at all and are only really noticeable when running or playing football. He has an amazing capacity for reading and learning and will tell you everything about his latest favourite subject if given a chance. Like every 7 year old boy he loves Minecraft, which is a computer game a bit like Lego if

you are lucky enough not to know it already. He also enjoys swimming and Tae Kwon Do, which allows him to concentrate and work hard in order to pass his gradings and achieve his colour belts. Ben is also one of the children featured in the gain a million logo.

This year I wanted to do something again to help raise money for the gain a million appeal. Not being very original I have ended up walking the Capital Ring again, only this time with friends instead of the family. Now with much bigger, heavier and busier children we knew that it would need to be without them this time. One other difference is that instead of completing the walk over many weekends over 16 months, I decided that we were going to complete the 78 miles over 3 days.

Intoxicated by a few beers and inspired by my companion having already completed a 100km challenge walk the plan was set. My friends Nick and Matt would accompany me every step of the way and many others would join us for a day or so.

Along the way I started to hear dark mutterings about blisters and began to hear the word 'Compeed' but I was still blissfully ignorant of the realities of such a long walk.

## Day 1

We set off from Highgate just about on time full of good spirits. We finally stopped walking 12 hours later, 32 miles further along the route in South East London.



16 Nick, Al and Matt with their reward (beers not shown)

On the way we enjoyed passing the Olympic stadium and park, crossing the Woolwich foot tunnel under the Thames. By the evening the expected rain came, fortunately we were fairly well protected being in Oxleas Woods, but the last few miles were a real challenge and every sign we saw seemed to tell us that we were still 2 miles from the end. Eventually we stumbled through the twilight, just about able to make out ponies along the path and finally emerged at the train station.

We were somewhat disappointed to find that we had reached our target point an hour and a half later than planned and that somehow we had travelled 4 miles over the expected distance. This was going to be longer than anticipated!

## Day 2

After a bath and some sleep we reconvened at 10am the next day, compared blisters and were off again. Although some new friends joined us for the day, we found it hard to keep up with their fresh legs and decided that to be able to complete the weekend we would need to cut out some of the (ever increasing) distance. So we gave our tired legs a break and finished at 17 miles for the day, having reached Earlsfield 10 miles from our intended destination but knowing that this would give us a chance to complete the final day as planned.

## Day 3

The final day got underway at Osterley Lock, following the Grand Union Canal as we head out of London, passing through some surprisingly large and wild parks and meadows, through Harrow, Hendon, Hampstead and Highgate (as well as some places that don't start with 'H'). By now, we felt the distance travelled with every step and I must have looked a little out of place as we walked past the junction of the North Circular Road and the A1, complete with walking poles and knee supports. Finally we made it to Highgate Woods, where we were met by friends and family including Ben and were able to walk the last few yards to the pub for a well-deserved beer and fish and chips.

Along the way we've passed through 20 London Boroughs, crossed over and under the Thames, the A40, A1, North Circular, South Circular, and all our favourite motorways. We've seen some beautiful sights, also many abandoned shopping trolleys,

And so we've done it! The walk has raised £1700 with hopefully some more to come and not forgetting and we need to go back in a week to complete the walk!

You can see more information about our walk and donate at:

[www.justgiving.co.uk/wardfamilychallenge](http://www.justgiving.co.uk/wardfamilychallenge)

*Alastair Ward*



left to right: Joff Bukht, Alastair Ward, Nick Bennett, Matt Howard and Richard Adderley

# The GBS Project

**A**dam Pownall is a Theatre Programmer and Producer for a leading regional theatre in the UK, Derby Theatre. In 2014 he won the Olwen Wymark Award for supporting New Writing within Theatre for the Writer's Guild for his work in opening and running Create Theatre, a state of the art studio theatre in Mansfield. He specialises in support of emerging companies, artist development and new writing and is a proud advocate for regional theatre in the East Midlands. Adam had a brief career as a performer, theatre maker and director and is currently about to be producing his own work again to raise awareness of Guillain-Barré syndrome, a condition he was diagnosed with in 2009. The piece will bring together his passion for dance, new-writing, verbatim theatre with a focus on working with disabled artists.

## Adam's Story

You go to bed a fit, active, healthy young man. You wake up the next morning and your feet are cold. Three weeks later you're lying in bed in ICU unable to move, unable to speak, unable to blink your eyes, staring up at a circle of faces who are telling you everything's going to be alright. You have Guillain-Barré syndrome. It'll be two years before you're back to anything that feels like normal.

## The Aim

Adam wants to raise awareness of the disease, but that objective alone isn't enough to make a play the right format.



Adam's story is compelling not only because it takes us to a place most of us are only likely to visit in nightmares, but because it is a journey from helplessness to a new strength. As you listen to him talk about his experience you watch relationships develop, laugh at the indignities and humiliations that accompany helplessness, meet siblings, parents, friends, nurses, doctors, taxi drivers, a world of people who revealed themselves as they dealt with how they faced Adam's illness, and learn what to do when the tube from your catheter gets wound round the axle of your wheelchair as you free wheel down the slope to the pub. It's moving and inspiring, but in the way that Adam has found a narrative stance for his story, it's also very funny.

It'll be a one man play, but not a lecture. The central relationship is between Adam and the GBS but the story is full of rich characters. It will be very physical. Use dance, movement, music, sound to help us get as close as we can to the experience.

# Meals on Wheels

*(not just for the elderly)*



## Everyone has heard of them, but do you know where it all started?

During the Blitz in World War II, the Women's Volunteer Service for Civil Defence (now Royal Voluntary Service) provided food for servicemen and for people whose homes had been bombed, leaving them without the facilities to cook for themselves. The concept of delivering meals to those unable to prepare their own food evolved into the practice we all recognise today as 'Meals on Wheels', but more properly known as Community Meals Service.

Lately, the Community Meals Service has been under threat, with some local authorities reducing or withdrawing the service altogether. Increasingly, the provision is moving towards a commercially led service rather than the traditional voluntary or council led service that we perhaps associate with the term 'Meals on Wheels'.

However, many elderly or disabled people remain entitled to a subsidised Community Meals Service through their local authority. To find out if you may be able to get subsidised community meals, go to [www.gov.uk/meals-home](http://www.gov.uk/meals-home) and enter your postcode to link to your local authority website (England and Wales only), or phone your council and ask to speak with someone in the adult social care department about your local community meals service.

There are now hundreds of commercial community meals providers across the UK, some operating purely at a local level and others via a series of nationwide franchises. Some deliver hot meals daily, while others deliver frozen meals once a week, to put in your freezer and reheat in your oven or

microwave as required. Many offer great flexibility, allowing people to order as few or as many meals as they wish, with no contract or obligation, sometimes ordering as late as the day before the meal is required or even the same day!

Companies such as Apetito and their sister company Wiltshire Farm Foods, who have a franchise network across the UK, offer a choice of portion sizes for different appetites, as well as catering for special nutritional requirements and religious or cultural preferences.

Community Meals can offer a perfect solution for people coming out of hospital, with short or long term disabilities, or for anyone who needs a bit of help in getting a nutritionally balanced meal prepared.

With the growth and expansion in commercial provision of hot and cold meals, you no longer need to have an assessment or referral in order to have meals delivered to your door. With prices from as little as £2.95 for a main course, many people choose to use this service even without subsidy.

## Other sources of information

### Royal Voluntary Service

Telephone 0845 608 0122

Monday to Friday: 8am - 6pm

Website [www.royalvoluntaryservice.org.uk](http://www.royalvoluntaryservice.org.uk)

### Apetitos (Hot meal service)

Call free on 0808 163 7421

Website <http://www.mealsonwheels.info/hot-meal-service>

Wiltshire Farm Foods (Frozen meal service)

24 hour customer helpline 0800 773 773

Website <http://www.wiltshirefarmfoods.com/>

### Oakhouse Foods (Frozen meal service)

Call 0845 643 2009

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



# My experiences of Guillain-Barré syndrome



On awaking on 31st October 2012, getting out of bed I said to my wife, 'there is something wrong with my fingers.' They felt heavy. Pam (my wife) called 111, an ambulance car with paramedics, who examined me but could find nothing wrong, so they left. I had a job to walk downstairs because my left leg started to drag so we decided to call the doctor. He examined me and by this time my arms felt like lead, and were beginning to drop. He took me to hospital in his car, and that's the last I

remember until I woke up in ITU on a life support machine.

On awaking, I could not move or speak which made life very difficult. I was diagnosed with relatively unheard of Guillain-Barré syndrome and after a month, was moved to the high dependency ward. I was back and forth from different wards as I had pneumonia twice. I was due to go for rehabilitation but on the morning I woke with a chest pain and it turned out I had pneumonia again. So, instead of going to rehabilitation, I had to go to a chest ward for about 3 months, before moving to rehab where I started to get limited physio. I did manage to stand up in parallel bars and I went on the bike for a very limited time. Then I was discharged home in June 2013, still virtually paralysed from the shoulders down.

From there, I had limited physio. I had one hour a week, where the physio's were brilliant as they got me standing and walking with a frame.

I was admitted to an intensive neurological rehabilitation centre in March 2015, where I have had intensive physio and occupational therapy to get where I am now. I can walk very well and they are working on my arms because I still cannot feed myself. Had I been admitted earlier on in my recovery, I think I might have been in an even better position than I am now. I should be being discharged at the beginning of June, with a better outlook on life.

Thanks to everyone for their help and putting up with a miserable sod like me.

*Tony Wyatt*

# Branch

## West Midlands

Would anyone like to organise the next get-together in the West Midlands? We've had a wide variety of excursions over the last few years, and this group always seems up for a new adventure! If you have an idea for a venue, event or just getting together over a coffee, please get in touch with Head Office and we can help get the word out.

## Yorkshire

The next meeting of the GAIN Yorkshire branch will be held at the Betty Boothroyd Centre, Dewsbury and District Hospital, Dewsbury on Sunday 18th October from 2pm until 4pm. All welcome for an opportunity to meet up for a coffee and a chat with others affected by GBS, CIDP and related illnesses.

## North East England

If anyone is interested in picking up the reigns in the Durham & Teesside area (James Cook Gathering), or getting something off the ground elsewhere in the North East of England, we would be delighted to hear from you. There is no committee or accounts to worry about, we just need one or two people who are able and willing to organise a couple of get-togethers each year. It could be nothing more complicated than meeting up for a coffee (or a pint!), or something a little more involved, depending on what you and the other group members want out of it. If you're interested, please give us a ring at Head Office on 01529 469910 or send an email to [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk)

# & Network News



## Kent

The Cream Tea held on Saturday 27th June was again, a huge success making £610.00 – people were all very generous both with donations and raffle prizes.

It was a beautiful day and everyone enjoyed themselves in the sunshine. There were GAIN logo items, plants, cards and of course, cakes for sale and the extra strawberries to go with the cream teas, were very popular.

## Lancashire & Cumbria

It was another hectic meeting with 35 attendees and several new faces at the quarterly Lancashire & Cumbria Branch meeting on June 6th. After an introduction by Sybil our Chairman we had an interesting and informative talk on Acupuncture during which several members volunteered to have their Chi lifted and their Ying & Yang put back in balance by the application of acupuncture needles to face, feet, ankles and arms. We then got on to our regular Sufferers & Supporters Forum when we exchange experiences, questions, and tips on living with GBS & CIDP including discussion of the use of Botox for facial palsy, steroid side effects, prickly tongues and flakey feet before finishing off with draws for the 100 Club and raffle, a sale of plants and Sybil's lovely preserves, and tea and cakes. Future meetings are on 26 Sept (Hearing Dogs for the Deaf) and 5 Dec (Christmas Party) all at Bilsborrow Village Hall on the A6 north of Preston, commencing at 2pm.



## Scotland

The Scottish branch of GAIN will be holding their AGM and Annual Conference at the Holiday Inn, Glasgow Airport on Saturday, 3rd October from 11am until 4.30pm.

The AGM will start at 12.15pm, followed by lunch at approximately 12.45pm. Cost is £8.00 per head which includes all refreshments during the day (tea, coffee, biscuits and light lunch). Members of the Scottish branch will receive invitations to attend nearer the time. Enquiries from interested non-members should be directed to Head Office. All welcome.

## South West England

The next meeting of the South West of England branch of GAIN will be taking place in Saltash Wesley Methodist Church, Saltash, Cornwall on Saturday, 24th October from 2pm. All are welcome, and further information will be available nearer the time.

**Here's a couple of easy ways to raise money for GAIN that does not involve parting with extra cash**



**Everyclick.com has launched a new way to donate – it's been christened "Give as you Live". It means you can search the web, shop online from your favourite retailers, trade on eBay and raise money for GAIN.**

You get great search results from Yahoo!, content from leading shopping providers and access to all eBay auctions. Every search you make creates a donation for charity.

Our special address is <http://www.everyclick.com/guillain-barre-syndrome-support-group/93918/498807>, all searches, shopping and eBay activity made from here will raise money for us. Make sure you sign up so you can track your giving – it updates every 3 minutes, you'll be amazed how quickly it adds up!



**Did you know that if you shop online, you can raise money for GAIN at no extra cost to you!**

We are registered with [www.givingabit.com](http://www.givingabit.com) who have partnered with over 1,200 shops that will pay us a donation every time a purchase is made. It will not cost you a penny more and it is free to sign up. In fact you could even save money as there are thousands of discount codes too! You still buy directly from your favourite shops, including Amazon, Sainsbury's, John Lewis, Joules, and many more – you just visit them through the givingabit.com website to create a donation for us!

How can they do this? It is entirely funded by the retailers that are on givingabit.com. They're happy to make a donation, as it is their way of thanking you for making a purchase from their online shop when you visit them from givingabit.com

On average, 3% of whatever you spend is given to us as a donation, but remember, this is at no extra cost to you. Also, they are partnered with many home & car insurers, as well as mobile phone companies and holiday specialists, which could create up to a £50 donation for GAIN at no extra cost to you!

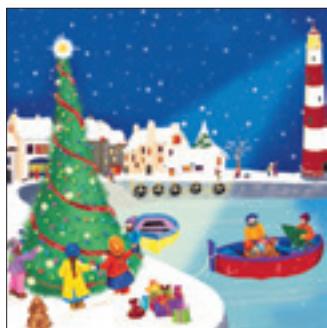
All you need to do is go to [www.givingabit.com](http://www.givingabit.com) and sign up. Once you have signed up, click on 'Find a Charity or Community' from your Quick links box, and choose Guillain-Barré & Associated Inflammatory Neuropathies. It's a free way of donating to us!

Thank you for your continued support! Oh, and happy shopping!

# 2015 Christmas cards



**1. Santa's New Hat** (with foil)  
 81 x 200mm  
 £4.25 for 10 cards



**2. Home in Time for Christmas**

121 x 121mm  
 £3.75 for 10 cards



**3. Church View Robin**

126 x 126mm  
 £3.75 for 10 cards



**4. Frosty Tree**

(with flitter)  
 81 x 200mm  
 £4.25 for 10 cards



**6. Floral Wreath** (with silver foil)

121 x 121mm  
 £3.75 for 10 cards



**7. Christmas Baubles**

126 x 126mm  
 £3.75 for 10 cards



**5. Three Ships**  
 126 x 126mm  
 £3.75 for 10 cards



**9. Christmas Fun**

126 x 126mm  
 £3.75 for 10 cards



**10. Bobbing Robins** (with red foil)

200 x 81mm  
 £4.25 for 10 cards



**8. Decorative Partridge**  
 140 x 140mm  
 £4.25 for 10 cards

A variety  
 of 20 cards  
 from the 2015  
 selection

**12. Variety Pack**

Various sizes  
 £7.45 for 20 cards



**11. Skating Santa**

140 x 140mm  
 £4.25 for 10 cards

The Greeting inside these cards reads:

*With all good wishes  
 For Christmas and the New Year*

# 2015 Christmas Card Order Form

Please detach this order form and send together with payment to:  
GAIN, Woodholme House, Station Road, Heckington, Sleaford, Lincolnshire NG34 9JH



**OR order ONLINE through our website: [www.gaincharity.org.uk](http://www.gaincharity.org.uk)** and click on the **SHOP** link

Card Ref.	Title	Qty per pack	Price per pack	No. of packs	Total Price per line £
1	Santa's New Hat (with foil)	10	£4.25		
2	Home in Time for Christmas	10	£3.75		
3	Church View Robin	10	£3.75		
4	Frosty Tree (with flitter)	10	£4.25		
5	Three Ships	10	£3.75		
6	Floral Wreath (with silver foil)	10	£3.75		
7	Christmas Baubles	10	£3.75		
8	Decorative Partridge	10	£4.25		
9	Christmas Fun	10	£3.75		
10	Bobbing Robins (with red foil)	10	£4.25		
11	Skating Santa	10	£4.25		
12	Variety Pack	20	£7.45		

Subtotal

Post & Packaging

Donation – thank you

**TOTAL price** £

<b>Postage and Packaging Costs</b>		
UK	Europe	Rest of the World
£3.50	£5.75	£9.90

We hold a large stock of cards, but some designs sell out early. Should this occur, please select box and tick below to advise what should be done with balance of money.

Send alternative cards, similarly priced  Donation to us  Refund

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008

Print name

Signature

Date

## Payment by cheque

Cheque enclosed for £   (Sterling only) payable to: **GAIN**

## DELIVERY DETAILS

Name

Address

Postcode

Telephone



# GAIN

## Personal Grants Funds

This Fund was originally created to help pay the travelling expenses for those visiting their loved ones in hospital. Since then, the Charity has considered and made grants for other goods or services that were not available elsewhere. Requests for a personal grant will only be considered if the hardship is due to, or has been aggravated by GBS, CIDP or an associated inflammatory neuropathy. The total grant we award is £1000, which could cover several different applications.

### Some examples of grants:

- medical or other equipment (possibly on loan)
- adaptations to homes
- payment of travelling expenses including parking charges for visiting patients in hospital

Since January 2014 we have made 26 awards to help people, mainly with travel but we have also provided other items including a folding bed which meant a patient could return home to continue their recovery (the standard hospital bed would not fit in their room), a mobility scooter to give access to local facilities and shops, a rise and recline chair and a key safe.

Sadly we have also had to decline some applications where the help was available through other sources or the request was to cover recurring household bills or debts. People who are in debt or have difficulty meeting everyday expenses should seek help from your local Social Services, Citizens' Advice Bureau, Citizens' Advice Scotland, Citizens' Information Republic of Ireland, the consumer Credit Counselling Service or the National Debtline.

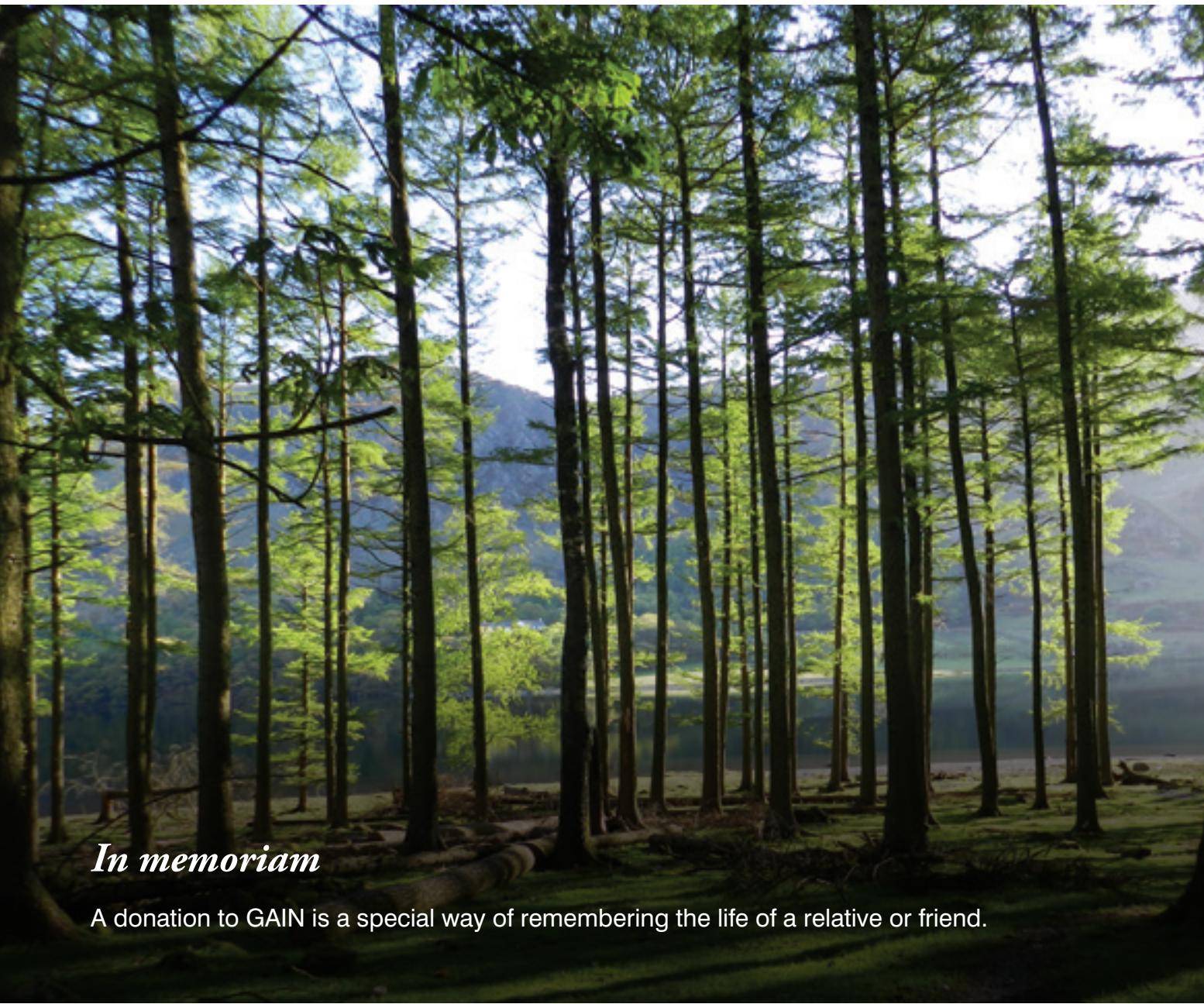
If you were a member of the Armed Forces you could also try the Royal British Legion or other service charity. There are also a number of charities and benevolent funds associated with other occupations that may help.

We will always try and help, even if we can only signpost you to another source of help or support. Once approved we will arrange for the payment to be made as soon as possible. That may be a cheque or bank transfer for a travel claim or direct to a company for goods and services. Wherever possible the charity will arrange payment direct with the suppliers to take advantage of discounts and to speed up the delivery process.



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)

**gain**   
Guillain-Barré & Associated  
Inflammatory Neuropathies