



# gain4all

Issue 4

Quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies

WINTER 2014



[www.colinvarndell.co.uk](http://www.colinvarndell.co.uk)

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



## Message from the Chairman

It is almost a year since we became Guillain-Barré & Associated Inflammatory Neuropathies (GAIN). It has been a very busy year, particularly for the office which has coped magnificently with an increased workload. We have raised our profile both in the media and with other charitable organisations. It is very satisfying to see more publicity in the media, often with reference to us as the main source of information for patients, families and friends. At the same time Caroline, as director, has become a member of a number of strategic groups, such as the Specialised Healthcare Alliance and the Neurological Alliance, which not only allows her to network with other similar charities but also to ensure that our particular requirements are considered at that level.

Last month I was privileged to attend the 75th anniversary reception of the Parliamentary and Scientific Committee hosted by Prince Philip at Buckingham Palace. We had recently been invited to join the committee which provides a forum for parliamentarians to meet and learn about a wide range of scientific topics. It has been very keen to involve patient groups and we are amongst a number of medical charities which have joined. I'm delighted to say that my name badge which read "Chairman GAIN" attracted quite a lot of interest and a significant number of people there said they would access our website to learn more about us. There were several comments about how "GAIN" was a catchy name, easy to remember.

As you will see from elsewhere in the magazine we are very keen to recruit new trustees. Under the new constitution we may now have up to 12 trustees so we have room for a few more. We are particularly interested in finding trustees with expertise in the fields of fundraising and the media. If you would like to know more about this role please ask Caroline to send you an information pack.

We continue to see a decline in the number of requests for visits, but a significant increase in the downloading of information from our website. We believe from feedback from patients that this has been a vital service for them and we will continue to work to improve the information provided. At the same time there is still a place for a local contact and we have no intention of losing that capability.

The cancellation of this year's conference was a disappointment for many of us. However, it was evident both from the poor take-up of places and from the feedback in the survey that a significant majority of our members are not interested in formal conferences. Part of the problem is the increasing cost of running a conference; a small charity like ourselves finds it difficult in this day and age to justify the expenditure. So in 2015 we will be running a number of day events in different areas which hopefully will provide a suitable forum for our members to meet, exchange information and ideas and learn about the latest developments. However, 2016 is the centenary of Guillain's and Barré's work and there is to be a major international conference to mark this in Glasgow. The charity is working with the organisers of this conference to plan our own event which will be able to draw on services of some of the world leaders in the treatment and research of this condition.

*With best wishes,*  
A handwritten signature in black ink, which appears to read "James Subington". The signature is written in a cursive style.

# about Guillain-Barré syndrome

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

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

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

## CIDP

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

# about gain

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

### The charity has three main aims:

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

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

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

### How you can help

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

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

# CONTENTS

News from the office	2
Caroline's adventures in Disney	4
Ask the symposium experts	5
Meet the Medical Advisory Board	6
Specialised Commissioning	7
Our Story	8
The stick is bigger than me	9
29 months and still getting a bit better	10
Books	13
Fundraising reports	14
Ken's Journey	22
Branch & Network News	26
Trustee Vacancy	28
Gifts in Wills	29

## gain

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### FREE HELPLINE:

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



## news from

*Seasons Greetings from all the trustees and staff of GAIN. We would like to thank our members and friends for all their help and support throughout 2014.*

*The 24hr helpline will operate throughout the Christmas and New Year period.*

*The office will be closed from 12.00pm Wednesday 24th December until 9.00am Monday 5th January 2015.*

*Emails will be monitored and urgent enquiries dealt with throughout.*

### Virgin London Marathon



Congratulations to Chris Walker who won our charity place for the 2015 event. If you would like to support Chris, please visit his VirginMoney Giving page:

<http://uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserPage.action?userUrl=Chris4gain&fald=511518&isTeam=false>

### Little box **BIG DIFFERENCE**



Thank you everyone who has already sent in the contents of their new money box. We have raised nearly £400.00 in a matter of weeks so please, keep putting that loose change in those money boxes – it really will make a big difference.



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 March 2015 and the deadline for submissions is 31st January 2015. Please forward all articles to Lesley Dimmick [fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk)

# the office

## gain2gether

The first regional one day event will be held on 21st March, 2015.

Full details will be sent out to all those living in SE England nearer the time.

If anyone has tombola items or raffle prizes that we can use, please send them in to the office or let us know what you have so that we can be prepared on the day.

## Prudential RideLondon-Surrey 100

Sunday 2nd August, 2015



We have been awarded a limited number of Golden Bond places for the 2015 event and are inviting all keen cyclists to apply. This is a spectacular event which was thoroughly enjoyed by our riders who took part this year. You must be 18 years or over, able to finish the course in nine hours or less and can ride safely within a large group of cyclists. There is a £45.00 registration fee and we are asking for a minimum sponsorship of £750.00 – all money raised from the event will go towards medical research. Please contact Lesley Dimmick for further information [fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk)

[http://www.prudentialridelondon.co.uk/The\\_Events/100.htm](http://www.prudentialridelondon.co.uk/The_Events/100.htm)

# Rotary

GAIN was invited to have a stall at the Rotary District 1070 Conference which was held in Scarborough on possibly the wettest weekend in September.

With around 1000 people attending it was great publicity for the charity.

We have been invited to attend again in 2015 and have also agreed to talk at Rotary Clubs in District 1070. We will happily travel to Rotary and Inner Wheel Clubs throughout the UK to attend club meetings or District events.



For more information contact Caroline on 01529 469910 or email: [director@gaincharity.org.uk](mailto:director@gaincharity.org.uk)

## Caroline's adventures in Disney!



I set out from Manchester Airport on a cold and damp October day arriving in Orlando some 9 hours later to a warm and sunny welcome. Why was I in Orlando? I had been invited to attend the GBS-CIDP Foundation biennial international symposium, which was being held at the Walt Disney Convention Centre with around 500 patients, support group representatives and medical professionals expected to attend this three day event. It was a great opportunity to catch up with colleagues and meet new people from around the world to share experiences and learn from each other.

The three day symposium offered attendees a wide range of speakers and workshops that would answer questions on almost everything you could think of! Each session offered the chance for attendees to ask questions of the speakers. The Ask the Experts sessions were very popular.

Dr Bart Jacobs, Associate Professor of Neurology and Immunology at Erasmus Rotterdam opened the symposium and gave an overview of the “alphabet soup of inflammatory neuropathies” and a copy of this can be found at <http://www.gbs-cidp.org/keynote-address-form-13th-international-symposium/>

On the Saturday morning we heard from the three potential recipients of the Benson Fellowship, a grant of up to \$150,000 per annum for up to three years. Presentations were made by Phillip Eftimov and Ruth Huizinga from the Netherlands and Rhona McGonigal from Scotland. An interesting selection of research projects, which were all deserving of the fellowship, however only one could be the recipient and this year's winner was announced as Dr. Ruth Huizinga, from Rotterdam. Ruth presented her project, “High innate responsiveness to microbial triggers predisposing to the Guillain-Barré syndrome: identification of genetic causal variants”. She was recommended by the Foundation's Medical Advisory Board and was unanimously selected by the Board of Directors for this award.

One of the most memorable sessions was chair aerobics – much fun and laughter could be heard. What a brilliant 30 minutes – hoping Santo Garcia, member of the GBS-CIDP Foundation Board of Directors is coming to Glasgow in 2016 for a repeat performance. Check it out on Youtube by searching Chairaerobics AFNP GBS CIDP 2014.

During the three days I had opportunities to hear many stories from around the globe and learn more about the variants of these diseases. Look out for more articles in future editions of *gain4all*.

# ask the symposium experts

Question	Answer
I had a flu jab 3 months ago and have just been diagnosed with GBS – is this connected?	If you are diagnosed with GBS more than 6 weeks after a vaccination it is not related. In the UK there is an eighteen fold risk of getting GBS after the flu as opposed to the vaccine.
Should GBS and CIDP patients get the flu jab?	<p>A report in the Lancet published in 2010 shows there had been no increase in the number of cases of GBS since 1978. UK data for period 1991 to 2001 shows one case of GBS following vaccination, fourteen following influenza and forty-five following other respiratory infection. Therefore it was concluded that the vaccine is relatively safe for GBS and CIDP patients.</p> <p>So, talk it through with your GP or consultant but consider the following:</p> <ul style="list-style-type: none"> <li>• Anyone who has a history of GBS and is in a high risk category should consider having the vaccine;</li> <li>• Anyone who was confirmed as having GBS as a result of a vaccine and is in a high risk category should consider having the vaccine;</li> <li>• Anyone diagnosed within less than 6 months previous could relapse but should consider it if they are in a high risk category.</li> </ul>
Has there been research on environmental factors causing GBS?	No! It was considered very unlikely that environmental factors would cause GBS.
Does reducing IVIG dose cause patient to suffer symptoms akin to relapse?	There are no side effects from lowering the dose, although a patient can have other symptoms including anxiety but should not cause a relapse.
Do I need to have EMG repeated?	No, you just need for one of us consultants to make a diagnosis.
Is childhood GBS and CIDP different?	Presentation, tests and serology are exactly the same. However AMAN is more common in children and they often present with Ataxia and around 15-20% require ventilation. In general, recovery in children is much better than in adults.
Is it OK to have an anaesthetic?	Yes it is safe to have anaesthetics, but surgeons need to consider nerve compression and breathing issues. You may need to check that any medication you are taking will need to be changed to help your body handle the stress of the surgery. However, during the acute stage surgery should only be carried out in dire emergency.

We hope to continue having an 'ask the experts' section in future issues of *gain4all* so if you have a question for our Medical Advisory Board, please email the office: [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk) or alternatively phone: 01529 469910. We will try to answer as many questions as we can.

## Meet the Medical Advisory Board (MAB)



### 1. Who are you?

*Dr Jane Pritchard, Consultant Neurologist. I qualified in 1993 from Oxford University Medical School and have worked in England (Oxford, Bath and London), Scotland (Edinburgh and Dundee) and New Zealand (Tauranga Hospital). I have been in London since 2000.*

### 2. Where do you work?

*Charing Cross Hospital, London (part of Imperial College Healthcare NHS trust) as a consultant since 2007.*

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

*I am the secretary of the MAB which means I receive a lot of the medical queries, requests for advice and information, and organise our annual MAB meeting and the attendance of MAB members at GAIN meetings.*

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

*I am interested in all aspects of GBS, CIDP and related inflammatory neuropathies (eg paraproteinaemia, vasculitis). I have a large and varied caseload of patients referred from West London and beyond. My PhD (from 2000-2004) involved visiting acute GBS patients across the South East to examine them and obtain their blood prior to starting treatment. We found that there was an acute reduction in regulatory T cells at the start of GBS but not in recovery. This is a common feature of many other autoimmune diseases.*

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

*I was asked to my first GBS conference by my then PhD supervisor Professor Richard Hughes and was voted onto the MAB. I enjoy interaction with my patients and the public.*

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

*I am excited by the prospect of more precise treatments for GBS and CIDP in future, as we understand more about what goes wrong with the immune response in each disorder.*

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

*No, because I think it is likely that the immune system will always have a tendency to make mistakes, in its attempts to help. But it would be nice to be able to correct the mistake more quickly and before more damage is done.*



# Specialised Commissioning

As a small charity we do not have the time or manpower to directly lobby organisations. That is better left to those that specialise in lobbying, such as the Neurological Alliance and the Specialised Health Care Alliance. However, Director GAIN does represent us on these bodies allowing our voice to be heard.

The Specialised Healthcare Alliance (SHCA) has a membership of patient groups and corporate members; it works on behalf of people with rare and complex conditions in need of specialised care. These services cover a wide range of conditions, including neurological conditions.

The majority of services in the NHS are commissioned at local level by the Clinical Commissioning Groups. Factors such as facilities, expertise and patient numbers are taken into account. This is a satisfactory system for conditions affecting a large number of people, for instance cardiovascular diseases. However, rare diseases also need significant funding and under the Health and Social Care Act 2012 the responsibility for commissioning services became the direct responsibility of NHS England. The actual work is undertaken by a number of Clinical Reference Groups which have worked to develop national policies with the aim of ensuring the provision of services will be of a similar standard across England.

NHS England has recently issued a paper on the future of specialised commissioning. This heralds a major change in policy; while certain highly specialised services would continue to be nationally commissioned, the majority would in future be "commissioned in partnership" with the Clinical Commissioning Groups. This would allow them more latitude in allocating money for specialised services. Of particular concern is that if a group could achieve an underspend in its specialised commissioning budget some or all of the savings would be passed directly to that commissioning group. This might provide the commissioning groups the opportunity to cut investment in specialised services.

The alliance wrote to the Director of Specialised Commissioning about these concerns. However the reply was not helpful and it was decided that we should write a letter to *The Times*. The following appeared in *The Times* on 7 November 2014. While it will take more than a letter in *The Times* to change the policy, it does highlight to NHS England that there is likely to be press interest in the future.

Why is this important? You may ask. Guillain-Barré and the associated inflammatory neuropathies are rare conditions and the treatments are expensive. We would not wish to return to the old position in the past where treatment was a question of the postcode lottery. We need to be certain that the needs of the patient are fully taken into account. Specialised commissioning, as originally established, aimed to do that. Everyone is agreed that, given the overspend in the past two years, the system both needs and can be reformed. However the proposed solution carries more pitfalls than benefits.

Letter in

## THE TIMES

7th November 2014

*Sir, The Health and Social Care Act 2012 has been much criticised. The decision to transfer responsibility for specialised services from local commissioners to NHS England was, however, recognised by all as a sensible step, providing certainty around standards and access to treatment where previously there had been little or none.*

*NHS England's subsequent experience has been less happy, involving a substantial overspend and cumbersome decision-making, all with damaging effects for patients. These problems are, however, fixable and do not challenge the fundamental sense of planning specialised services and sharing the associated financial risk across the country.*

*It is therefore of serious concern that NHS England is now proposing to co-commission specialised services with local clinical commissioning groups (CCGs).*

*It makes sense for the NHS to collaborate at national and local level, but muddying budgets and responsibility between NHS England and CCGs promises a return to the postcode lottery of the past.*

*We write as members of the Specialised Healthcare Alliance.*

*Signed by patient groups including GAIN as members of the Specialised Healthcare Alliance*

## Our Story

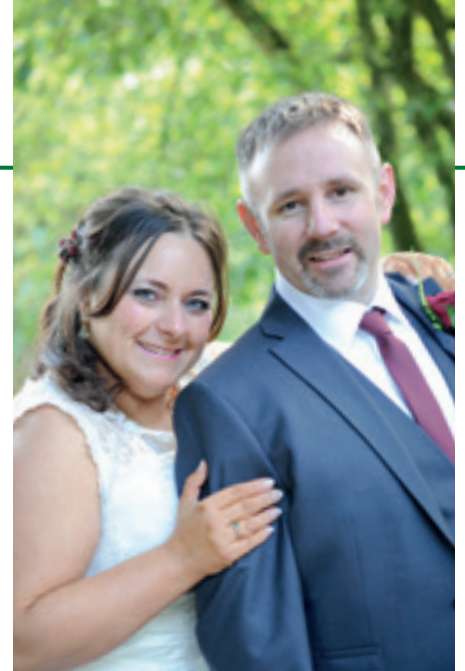
began in December when I'd finished a night shift as a nurse at The Christie Hospital in Manchester. I was relaxing looking at Facebook and it suggested I should be friends with a guy called Jez Smith because we had some mutual friends. His picture was him with a melon as a smile and I could see that our mutual friends were all people from Nazarene Theological College in Didsbury, Manchester. I clicked through to his page and saw the advert for his book *Faith through the storm* about when he was struck down with Guillain-Barré syndrome. Since I love reading and like to read about how God has helped people through adversity, especially illness, I decided to download the book on Amazon and over the next couple of days read Jez's book and got involved in his story. It touched me so much since his story struck a cord with events in my life of chronic illness: I had ME for six years and also went through a break up of a relationship.

I decided to message Jez to say how much I liked the book and how there were similarities in our story and that's when it all started. We messaged each other for a while, then chatted on the phone and two days later we met in a playcentre for coffee whilst Jez's kids (Lauren 6 and Luke 10) played.

The rest is history and our relationship has gone from strength to strength. In March we went to Leeds (where I went to Uni) for a weekend and Jez proposed to me. We got married on August the 23rd 2014 in Manchester and had a fantastic day, with Luke as a ring bearer and Lauren as a flower girl.

Over the summer, Jez with me on backing vocals have been recording an album of songs he wrote when he was ill in hospital. It is set to be released later this year and we are hoping to donate some of the proceeds and promote GAIN at the concerts we will be doing over the next year.

Susanna Smith



# The **STICK** is **bigger** than me

That's how I feel when I walk into a coffee shop using a walking stick. I'm so self-conscious of it, it feels as though it's massive, at least six foot tall and has a personality of its own that gets noticed more than me! Having the stick, however, means that I was lucky enough to have got a parking space close to the entrance. If that hadn't happened then I'd be in my wheelchair. At that point I become "invisible": I'm no longer Andie, I'm the disabled woman in a wheelchair. No matter how long I spent doing my makeup or how much my new top cost me, my identity is lost.

It's not all doom and gloom though. I am overall very happy, and appreciate being alive and well enough to even be out for a cuppa. It's more an adjustment period whilst I get used to my new life since getting ill with GBS in September 2013, as a result of catching a tummy bug from a colleague at work. A week after the bug I started feeling very unwell, with a severe headache, a racing heart and horrific back pain. A few days later when my legs became so weak that I couldn't stand up, I was admitted to hospital through A&E, where a doctor asked me if I "Had a habit of getting myself admitted to hospital when there was nothing wrong with me?" Three days later I was finally diagnosed with Guillain-Barré syndrome and taken more seriously.

I quickly deteriorated and became paralysed from chin to toe and spent three months ventilated in Neuro Intensive Care. I could only communicate via a letter board and couldn't move AT ALL, which was particularly scary at night, as I couldn't let the staff know if I needed anything, unless I made a clicking noise with my tongue on the roof of my mouth. I was incontinent, catheterised, fed through a tube and had so many needles in me that my veins are now "limp" and refuse to even allow me a routine blood test! I can hardly blame them!

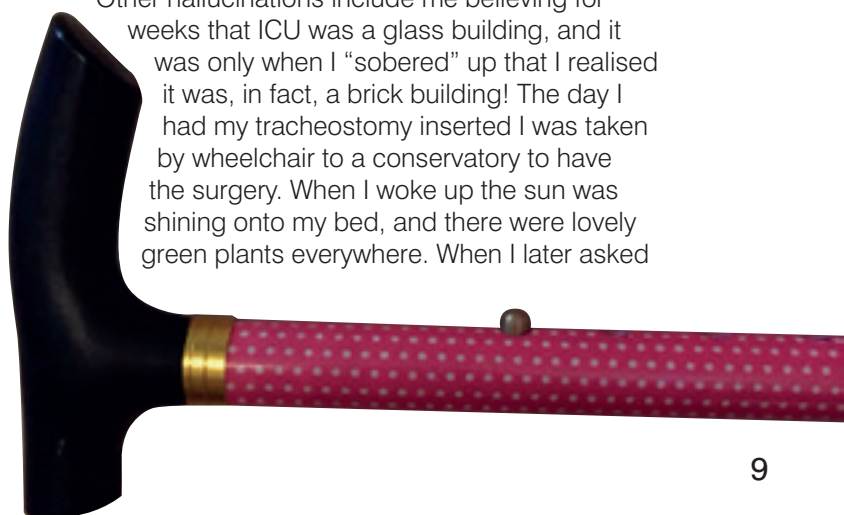
I was in ICU for three long months, where I suffered two bouts of pneumonia and several bizarre hallucinations, (which still play havoc with my brain)! The worse thing about hallucinations is that when you've suffered them, despite people telling you those things never happened, and you knowing they didn't, it's really hard to separate the fact from the fiction.

One hallucination, that will probably stick with me the longest, took place whilst I was moved from Neuro



intensive care to General intensive care for a few nights. One evening I was being given a bed bath by the nurses. I was on my side looking out of the window and there was a group of young men outside, one of them was wearing pink shorts, despite it being winter. They were laughing at me and one of them started filming me on their mobile phone. The man in the pink shorts then turned around and mooned at me. They were all laughing hysterically. I couldn't alert the nurses to this as I couldn't speak or move (I was a prisoner in my own body). I spent all night worrying I would end up on **YouTube** or **Facebook**. However, as you've probably guessed it never happened. I was on the first floor and there wasn't even a window!

Other hallucinations include me believing for weeks that ICU was a glass building, and it was only when I "sobered" up that I realised it was, in fact, a brick building! The day I had my tracheostomy inserted I was taken by wheelchair to a conservatory to have the surgery. When I woke up the sun was shining onto my bed, and there were lovely green plants everywhere. When I later asked



my parents where that conservatory was they told me I'd never even left my bed space! The curtains had been drawn, and the operation undertaken without me going anywhere! I also remember thinking how "nice" it was of ICU to put pictures of famous dead people on the ceiling. Why I actually thought that was nice is beyond me! The only things on that ceiling are tiles and lights, but I spent days looking at those pictures! I still, now, often lay in bed at night thinking about all the hallucinations. They are real memories to me, yet I know they didn't happen. It's very bizarre, and I hope they will fade over time.

I finally left ICU and had a short stay on a normal Neuro ward before progressing to the "Boot camp" that is Neuro Rehab! After lots of tears and tantrums I finally learned to stand up and take a few tentative steps. The staff on the rehab deserve a medal for being so kind and patient with me. The hydrotherapy pool also played a huge role in getting me up and about. The warmth and weightlessness I felt in the water was wonderful.

Six months after my admission to hospital I finally came home, and am now adjusting to my new life as a "Disabled person". I am 42 years old and a single mum to two beautiful girls. When I'm not busy getting sick with rare neurological disorders, I work for a High Street Bank. I have been on long term sick for 14 months and hope to be able to return to work next year. My consultant recently told me that he thinks this is "As good as it will get" and that I probably won't improve much more. At first I was really upset by this news but he then went on to inform me that some people who were as ill as me never get out of bed again, and from that point of view my recovery has been amazing. That has really motivated me to carry on recovering and prove him wrong!

Some very positive things have come out of this experience. I am now closer than ever to my family and friends, and I've got back in touch with several people who I'd drifted apart from over the years. I figured out who in my life was genuine and who wasn't. And most importantly I appreciate waking up every morning and living each day to the full, even if that is with a wheelchair and stick!

*Andie Phillips*



If you would like to follow Andie's blog, the link is:

[Pinklover72.wordpress.com](http://Pinklover72.wordpress.com)

**I wrote an article for GAIN in August 2013. My recovery has moved on since then so I am writing an update. Hopefully, it contains a few tips on how to get around some of the GBS restrictions and is an encouragement to those GBS sufferers on the slow track.**

To recap, I developed GBS in mid May 2012 when 63 years old. The onset was very rapid, from walking up the house stairs to no arm or leg strength within 16 hours. Fortunately, it did not go to my chest. I had no pain, and the sensory nerves seemed OK. I was quickly diagnosed and received immunoglobulin treatment. I had five weeks in hospital and nine and a half months in a rehabilitation unit. When I left in April 2013 I was using a power chair and could hardly stand. I had little strength in the legs or power in the arms to push myself up. I was given knee-ankle-foot orthotics, but they were very hard to get on and not very useful around the house. So I was using the power chair to get around indoors and reach the car. When out I used a self-propelled chair, but initially was not doing much of the propelling myself. I was walking in waist high water at the local pool, and using a rowing machine and recumbent cycle machine at a local gym.

October saw some changes. I was able to go to another gym where I could use more equipment, and slowly build up more strength in the arms and legs. But the great change was being given some ankle-foot-orthotics (afos). These were a lot easier to put on. I started with a zimmer frame, then carrying the zimmer frame in front for safety, walking sticks and finally walking sticks held up in front, again for safety and confidence. The carpet got a bit of a wear as I did up to 45 minutes at a time. By Christmas I was able to just about carry a bowl of cereal from kitchen to dining room with the support of the walls. I was also able to get to the car without the power chair, by placing a chair at the back door so that I did not have to step up or down. I used a computer chair rather than an ordinary dining chair since I could have the seat higher, which made getting to feet easier. It also enables me to move closer to the table without doing the shuffle of lifting the chair in. Chairs with arms are

# months a bit better

better. If I go out to eat where the chair has no arms, it's still hard work getting to a standing position.

My first outing without sitting in the wheelchair was to Ikea, indoors and a good distance to walk. My wife followed me around with the chair, but it was soon used as a trolley. Supermarket lunches and walks then became a weekly event. By January the physio sessions stopped once I could walk with the afos. At home I was not using the walking sticks, but outdoors I felt safer with them. I have been told by my daughter, who has experienced stilt walking, that the walking action is very similar.

We had our first weekend away in February in nearby Swansea. The hotel room had a wet room and was generally disabled friendly. The town centre was pedestrianised and had plenty of dropped kerbs. But afos do have their drawbacks. Since they keep the foot at right angles to the shin, walking on other than the flat is not easy. Uphill is just harder work, but downhill feels very unsafe as one has to lean forward on the walking sticks and I am only talking about slight changes in the gradient. One also has to continuously check on where one is stepping. I only fell on two occasions, the first when I had not noticed a slight depression in the pavement and the second a threshold in a doorway. My worst experience was on the enormous cobbles of Albert Dock in Liverpool. Check every step, authentic but terrible for the afo user.

Steps are still a big problem. Normal house steps are still a no go area. Shallow steps are possible if there is a good banister to supplement one walking stick. Street kerbs are now possible with two walking sticks. Without walking sticks the limit is about three inches. This is with afos. The drawback to afos is that they do not allow the shin to angle forward in the usual step climbing fashion. However, my thighs are still pretty weak, so it probably does not matter.

We try to go for walks where there is a nice long flat pedestrianized area. Roath Park lake and gardens in Cardiff where we live is ideal. Swansea Bay has a long sea front. Llanelly has a part of the coastal path. Hilly Lyme Regis was a no no!

In the garden I have had a busy spring, summer and autumn, emptying and refilling many of our 200 pots and baskets. We have done away with the heavier ones, and the rest I can lift with one hand at the rim and put them on a potting bench, where I can work comfortably. To work on the plants at ground level I have to use a small step stool, which has some small "arms" to enable me to stand up. I can then lower myself even further down onto the ground. Weeding a pot is just about possible from standing, but reaching the ground is very precarious.

In April I had a visit to both my orthotic and nerve specialists. I did raise the subject of whether I should wait for further improvement before organising a suitable car adaptation. They both thought I would not make much further progress. So I quickly organised a driving assessment in Cardiff which was on the same site as the rehabilitation unit where I spent nine months. I was expecting to need an automatic car with hand controls, since I had virtually no movement at the ankle joint. But after an initial assessment in the office the assessor pointed me to an automatic car and without using the afos. Success, after no driving for a year. We then tried a manual. But the clutch needs more pressure than the brake/accelerator. I tried again with an afo on the clutch leg. Success. The driving technique is a little different. The brake and clutch actions use the leg rather than the ankle muscles, and so are not quite so smooth, though getting better. So then it was a wait for DVLA approval.

Driving has given me a lot more freedom, though I am wary as to where I go on my own. Still I did most of the driving on a 1600 mile trip to Scotland in September.

I had been occasionally going to the local swimming pool for walking practice in waist high water. But on an occasion in August I was not able to walk at that



Afos



Footwear



Cut down stool

depth because of the number of users. So I stood in knee high water where the buoyancy effect is much less. By the end of 40 minutes I was beginning to walk a little. I did fall over at the end, but knee high water is sufficient to allow one to fall unharmed. Getting up away from the side wall though was impossible. With this confidence about walking a little without the afos in the pool, I started to try to walk at home with the walking sticks. Within two weeks I got to an hour with the walking sticks held off the ground. But then, when repeating the exercise with a shoe which had a small heel, compared with the flat shoes I had used till then, I fell down backwards. This seemed to stretch something in my knees, so even with the afos on I was losing some of the previous sense of balance. After our holiday in Scotland my knees seemed to be better and I have now started to walk progressively more at home without the afos. I even walk a bit without the

walking sticks knowing I can reach a wall or some furniture if I lose my balance. I now notice that my right foot exhibits some foot drop. However, I have also noticed some improvement in my left ankle movement, and so I am now actively trying to exercise both ankles. I use a wobble board while I sit in front of the television, and also try to initiate an ankle movement when the foot is dangling off the ground.

The leg strength is certainly getting better. I assume it's a combination of the nerves growing back and the gym exercise. I normally go twice a week, and this last two months have started using a leg press machine. However, I am only pushing 20kg from a right angle leg position when the normal older exercisers are pushing 70kg. I have been gradually upping the abductor and adductor weights and these are getting to 60kg and 45kg respectively. I suppose this enables me not to fall over when I walk along swaying from side to side.

The arm strength is still going up. This assists me when getting up from a chair since the thigh muscles are still pretty weak.

Miscellaneous tips for people with weak leg and arm muscles.

- If the hands are weak, especially the pinch grip due to weak finger tips, buy plastic electric plug pulls. They clip over the 3 pin plug and then can be pulled by hooking a finger or fingers through a loop. I bought "Plug Mates" from Amazon.
- For a step outside the front or back house door, use small paving slabs. They do not move and the height can be varied by the number of slabs. Mine did not need cementing.
- For temporary steps away from home I have two small plastic step stools. One of them I cut down, so I have 3 inch and 8 inch steps.
- If the seat to stand is difficult, a toilet riser is useful, and can be taken on travels.
- Ideally use a car with a higher seating position, as found in SUVs, and MPVs. You do not need a big expensive one. It makes it a lot easier to get in and out.
- If you use disabled toilets on your travels, always carry a RADAR key, since the toilet providers are inconsistent on whether a RADAR key is required.
- Practise walking in a swimming pool where you can vary the buoyancy effect of the water and falling over is usually safe. But you do need to ensure there is a non-slip surface to walk on.
- A small collapsible lightweight sack truck is useful for moving objects you cannot carry ( e.g. plant pots)
- If you use a manual chair, check on whether the arm position can be reversed so there is more space at the front side of the seat cushion. Mine does. It made it easier to move sideways off the chair while still using the arms to push up on.
- If your pinch grip for turning a key in a lock is bad, try using the grip between the first knuckle joints
- If you use afos and the thigh muscles are still weak, it will be almost impossible to get up if you fall. Fortunately on the two occasions I fell, I was adjacent to a seat on which I could pull up onto a seating position. So it would probably be advisable to have a carer with a wheelchair if you are doubtful.



- For my afos I find moccasin slippers are the best at home because they slip on very easily. I had only one pair of shoes with which the afos would fit at a squeeze, and so I normally use a pair of Asda trainers. They are wide, and the tongue and side give good access for my afos.

So in the last year (15-29 months since onset) I have gone from an electric wheelchair user at home, and a rather slow self-propelled chair user outside, to somebody who can get around the house easily, apart from the stairs, and with afos can get out in the car, and walk for a mile relatively easily (though it is slower than normal walking pace). I assume the progress is a combination of nerve growth and concentrated exercise. The latter gives me a sense of satisfaction that I am trying to improve my position. When I see the weights going up in the gym, I know I am doing my bit to get walking more normally. Perhaps the endorphins are kicking in as well. How far I get is hopefully the subject of another article.

*Richard Elms*



stool for working lower

# Books

## The Woman who Stole my Life

by Marian Keyes

Published by Penguin Books, Limited, 2014



Stella Sweeney is an ordinary woman living an ordinary life with her husband Ryan and their two teenage kids in Dublin. She works with – or really for – her terrifyingly ambitious sister Karen in their beauty salon. Nothing to get excited about here. Nothing to make her particularly unhappy. Or happy ... No-one would be interested in stealing her life. *But then things started to happen ...*

One day, Stella, attempting a good deed, causes a little car accident and faces down a bad tempered, handsome stranger. She hardly gave it much of a thought. But karma is hovering, and is about to swoop in and take over, changing Stella's life for ever. For better or worse.

*Suddenly, Stella has a life. A thrilling glamorous one.*

*A life that other people might start to covet...*



**her chaotic life is transformed when she develops Guillain-Barré syndrome, a rare disease that leaves her unable to move anything but her eyelids for months on end**





## Run Preston 10K

Karrie Houghton completed her first event for GAIN in 58 minutes which she was really happy with.

# fundrai REPORTS

## Tough Mudder

A bit battered and bruised but he did it! Daniel Josey completed the tough mudder challenge.



## Skydive

I am a Guillain-Barré syndrome survivor and I am so pleased to say that I raised £850 for GAIN charity (GBS changed my life for the better).

*Tannaz Khamea*



## Leicester Half Marathon

Stefan Brakes completed in 2 hours 9 minutes and his brother Jay, 2 hours 17 minutes.



# Derby Ramathon

sing



Michelle Sutcliffe ran the Derby Ramathon in honour of Ashton, a little boy in her class who is recovering from GBS (pictured with his sister Neveyah).

Michelle proudly wearing her medal



## 5km Walk

I was diagnosed with GBS last May after having my son. Although not back to how I was before, I was keen to push myself to raise money for GAIN and give myself a challenge. I still can't run, but managed to walk 5km with the help of my sister, Helen, and my son, Oli. So far we have raised £800.00

*Gayle Morgan*





# Yorkshire Three Peaks Challenge

I did the Yorkshire Three Peaks on Saturday 6th October. I began my walk in Horton-on-Ribblesdale at a very dark and dreary 06:00 in the morning. There were plenty of other walkers around at that time; however it was still so daunting. I travelled up to Yorkshire alone and planned to complete the walk alone too. However, I was very fortunate to make friends with a group of 6 people from Leeds at the top of the first peak (Pen-Y-Ghent). They were also completing the Three Peaks for charity (Macmillan) and were happy to take me under their wing! The walk was most definitely the toughest physical challenge I have ever undertaken; I have walked all of these peaks individually as a child and can safely say I underestimated the task because of this. The route was tough at various points with scrambles up and down all of the peaks. I completed the distance of just over 25 miles in 9 hours and 50 minutes, my goal was to complete it in 10 hours and the challenge is to do it in 12 or less so I was very pleased! I walked these peaks with my mum, and I'm so proud of myself to have done all three for her and GAIN. The walk was emotional at points!

*Charlotte Bray*

Charlotte raised over £1000 in memory of her mother who passed away in September 2013

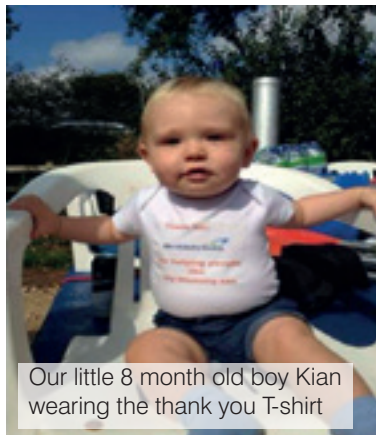
# NO PAIN no GAIN

On 7th September Warren Shipton, as a member of Team BG (British Gas), set off on the 2014 Monmouth raft Race – Warren’s wife Paula (pictured wearing her GAIN T-shirt) had been diagnosed with GBS earlier in the year.

“Our raft was more of a cruise ship, it wasn’t built for speed” said Warren “so I won’t tell you about where Team BG finished in the race! We printed T-shirts and on the back we had No Pain No GAIN and trust me rowing that raft was painful at times. I would like to mention the raft day was dedicated to my wife Paula, our close friend Diane Leigh and brother in law Tim Alexander. Having experienced the difficulties Gullian-Barré syndrome and neurological disorders can cause, I would like to say thank you to charities such as yours”.



**British gas were exceptional in helping the team support GAIN on their raft race day. The team raised £825.00**



Our little 8 month old boy Kian wearing the thank you T-shirt



## New Way of Fundraising



We are extremely grateful to Charles Valentine of Poulton, near Cirencester, for his kind donation of a *Windsor Power Bath* and a *Carony Autochair* – swivel car seat, which converts into a wheelchair – following the tragic death of his wife, Veronica, from MND. While being only a small fraction of their cost new, we have been able to sell these on ebay for a most welcome £500, which we have put towards our *Gain-a-million* Centenary Appeal.

If anyone else either has or knows of such equipment, or indeed other items which are looking for new homes that could be sold on ebay, it would be very much appreciated if they could contact Lesley at the office.

Tel: 01529 469910 Email: [fundraising@gaincharity.org.uk](mailto:fundraising@gaincharity.org.uk)

## Charity Gig raises funds for GAIN



Wearing silly hats

**Following the resounding success of our first charity fundraiser in February 2014, we decided to hold another one on 13th September. This time we chose a bigger venue and easily filled it when 180 music fans came to support my charity gig held at Amasal Social Club in Stafford.**

'The Good Cause Band' provided the musical entertainment for the evening performing classic rock covers from 'Pink Floyd' to 'Primal Scream' and they went down a storm! They are a local band that put on several charity gigs throughout the year and have raised thousands of pounds for various charities over the years.

I'm pleased to say we helped add to that total by raising an amazing £1,861 on the night itself!!! This totally exceeded our expectations once again and I would like to sincerely thank everyone that attended. We had an amazing evening of live music, lots of dancing, a fabulous raffle along with the infamous £1 whisky bottle game!

Of course I couldn't have done this without the support from my amazing family and friends who contributed in several ways and helped to make the night another raging success! Once again I feel privileged that I am able to help put these events on and am proud they are enthusiastically attended. A good proportion of which were GBS friends I have made through GAIN charity, so thank you to all who attended!

We also held a stall at our local fête in the Summer to raise funds and awareness for GAIN. We put on a 'Lucky Dip' stall which the kids absolutely loved. We raised £160 on the day, so when added together it makes a total of £2,021!

Watch this space for further events next year!

*Sally Haycock*



GBS survivors (left to right) Sally, Jill & Sue

# Stone Dominoes Ladies Football team Halloween Party

My two sisters and I organised the evening (Jules Kendrick, Sally Kendrick and Lisa Clarke).

Basically each year we pick a charity to raise for, and as my work colleague (Sally Haycock) was seriously ill last year with GBS, we decided to go with GAIN charity. Our venue was provided by a local sports club and lots of local businesses kindly donated prizes for our raffle.

We had a great night but most importantly raised £90.00 for the GAIN charity.

*Jules Kendrick*



# Cuckfield Village Charity Cake Sale

The cake sale was a great success thanks to all of those involved; we were overwhelmed by the number of family members, friends and locals that turned up on the day to show their support. We managed to raise a fantastic £2,151.00 on the day by selling both cakes and raffle tickets and hope to continue adding to this total between now and the raffle draw in January.

Sadly our dear friend lost her battle against GBS yesterday (13th November) but we are so pleased that we organised the charity cake sale in time for Lizzy Seward to know that so many people loved her and were behind her. I know that GAIN was a charity very close to Lizzy's heart and I hope that the funds raised will help others win the fight that she so bravely fought.

*Lindsey Deighton*





Roy Jones completed the run in 2 hours 37 minutes.



Kaye Liddle (pictured with her friend who also ran the race)

## Bupa **Great** North Run



Becca on the left

An amazing day and a great experience but at the same time quite emotional at some points. My brother, Christopher who is recovering from GBS, came with me and was really inspired (he may enter for next year).

The reason for me partaking in this event is to raise awareness of Guillain-Barré syndrome and help a worthy charity that has supported Ken, his wife Beverly and children Jaki (a fantastic friend of mine) and James – you can read Ken's Journey on page 22.

This was not a race to me, the time I finished does not matter. I cannot thank all involved with Ken and his family enough: this run to me was just a small part of appreciation and giving back the support they have received. I am looking for my next event to raise not only more money but more awareness to the condition.

*Becca Hepplewhite*



## 10K Rat Race

Lisa and Robert

“ The Stockton Rat Race was a huge success. The whole family went along to support Lisa Guppy and her partner Robert Horne in completing the 10K challenge for GAIN charity. ”

We are especially grateful to Lisa and Rob for taking on the challenge as until the day of the Rat Race they hadn't even met Ken (see Ken's Journey on page 22). Lisa is a Radiographer and a colleague of mine at The BMI Woodlands Hospital in Darlington where I work as an Administration Assistant in the MRI Unit.

Lisa and I work closely together and she has been a good friend and always willing to listen throughout Ken's illness. Her partner Rob is an Outdoor Activity Instructor and decided to take on the challenge with Lisa. We really cannot thank them enough for their effort and also for their continued support which means everything to us both.

*Bev Longstaff*

## Ken's Journey

by Bev Longstaff

We had only recently returned from a winter break in Tenerife and were looking forward to Christmas with the family. However, the events that unfolded on Saturday 22nd December 2012 were to change the life we once knew.

Ken had been out with friends the previous evening for a pre Christmas meal. That night he suffered with an upset stomach. The following day he went to work but returned at lunchtime stating that his tummy felt better but had lost vision in his left eye. By the time we arrived at A&E he had double vision and was very unsteady on his feet.

During the seven hours in A&E Ken had several tests but the doctors still didn't know what was wrong. It was decided to keep Ken in hospital overnight and the following morning a lumbar puncture was performed. As the day progressed he became more unwell until his breathing became impaired and he was transferred to Intensive Care.

Ken was now fighting for his life. He was fully ventilated and in a coma. For five days a diagnosis evaded all the doctors. On 27th December a Neuro Consultant came to see Ken from another hospital and after 30 minutes we had that diagnosis. He has Guillain-Barré syndrome.

He remained in Darlington Memorial Hospital until 31st December, when a bed became available at James Cook University Hospital. He remained in Intensive Care for eight weeks (Ken had a locked-in coma for seven of those frightening weeks). He was transferred to High Dependency where he remained for eight months. In that time he went to Queen's College Hospital in London for further tests which revealed a new diagnosis. Ken was originally diagnosed with GBS with Miller Fisher and Bickerstaff tendencies. Dr Mike Lunn – Peripheral Nerve Damage Specialist at Queen's – diagnosed him with an extremely severe form of GBS. Ken had been in hospital now for 6 months. Dr Lunn said that at this stage Ken was three months into a two year recovery. On his return to JCUH Hospital the emphasis was on weaning from the ventilator. This did happen but it wasn't easy and was very frightening for Ken. With perseverance he eventually became ventilator free and again he became trache free. In December 2013 Ken was transferred to a ward in James Cook for observation and in January 2014 he was transferred to The Neuro Rehabilitation ward. He has now been in hospital for almost two years. He is improving but the speed of his recovery is very slow. He has some movement in his arms and legs but with no function, ie., he still cannot walk or feed himself. He still needs assistance with every task.

This has been a traumatic journey for Ken. Throughout his illness he has shown true



Ken fully ventilated and paralyzed





From left to right: Jaki (our daughter), James (our son), Rob and Lisa (friends and fundraisers), Me (Bev) and Ken centre stage

strength and has that “I will get better attitude”. As his wife, this has been an extremely difficult and emotional time but I know he will get there. We have been blessed with such good family and friends who have helped when they are able. He is improving but as his consultant said GBS stands for “Get Better Slowly”. Doesn’t matter how long it takes as long as he makes a good recovery, whatever that may be. We are ever optimistic that his recovery will be good but only time will tell.

*continued over*

Barry Singh (left) and Ken Longstaff who both have GBS and shared a ward together in JCUH



The next stage in Ken's recovery is for him to return home. However, that is proving difficult as our family home needs to be adapted for Ken's needs. This again is another stressful phase in his recovery. But it has to be right to enable him to begin the next phase of his recovery and to regain some normality to both of our lives.

This journey is primarily about Ken but all too often the people who are supporting the loved one get forgotten. Please remember that they are equally as important. They are the ones that make things happen especially when your loved one is unable to communicate.

I am so proud of my husband and of what he has achieved so far. He will get there, I just know he will.

*Bev Longstaff*

## A Gathering of Friends



The founders: (from left to right) Bev Longstaff, Ken Longstaff, Barry Singh, Phil Graham, Janet Graham

**WHAT follows is not your typical GBS story.** Readers seeking to compare frightening and debilitating symptoms or to immerse in emotional journeys will find scant reference here. There are no war stories ahead. Instead, what we have is a tale of friendship; the bonding of three patients and their families. It's a tale of how three men, strangers at first and with varying degrees of GBS severity, became close friends. And then, how, through this friendship, their wives became friends too. It followed that the six would establish The James Cook Gathering of GAIN.



**My name is Phil Graham. I am 61 years old and, although I am the writer, I share this story in equal measure to Ken Longstaff (56) and Barry Singh (62). From here on in I shall write about us in third person perspective.**

Phil, Ken & Barry met in Middlesbrough's James Cook University Hospital in the latter weeks of 2013. At the time of writing (September 2014) Barry and Phil have been discharged for some weeks and Ken remains in hospital. As a measure of the varying degrees of severity it is worth pointing out that Barry was in hospital for five months and Phil for nine. Ken, however, is now at twenty-two months. Barry, although a little unsteady, manages to get around his home and community unaided and attends outpatient physio once a week. Phil is confined to a wheelchair and uses a walking frame for all transfers and is awaiting out-patient physio due to commence in a few weeks. Ken needs hoisting for all transfers in hospital and, although he has the use of a wheelchair, has only recently managed to gain some limited movement in his legs and his right arm. A most moving account of his GBS journey can also be found at: [www.thenorthernecho.co.uk/features/leader/11448881.Lockedin\\_by\\_a\\_rare\\_syndrome](http://www.thenorthernecho.co.uk/features/leader/11448881.Lockedin_by_a_rare_syndrome) with apologies for the lengthy URL.

There are four beds in Bay no.2 on Ward 26. When Phil was admitted Ken was already there. A third bed was occupied by fellow GBS sufferer, Tom O'Neill and the fourth became a transit bed with a number of head injury and stroke patients passing through at intervals. When Tom was discharged soon after, his bed was taken by Barry Singh. By that time Ken and Phil had developed a friendship based on a mutual understanding of each others' condition. They also found that each enjoyed the great outdoors and had, with their families, camped and climbed many hills in the UK. Importantly, both men shared and maintained a 'glass half full' attitude to their rapid disablement and slow progress towards recovery. Life stories were exchanged and Phil learned of Ken's job as an MOT tester in Darlington and of his wife, Bev, and their grown up children, Jaki and James. In return Phil related to Ken his sole trader business as a photographer and musician and that he was married to Janet with whom they, too, had grown up children, Daniel and Padraic. At the same time Bev and Janet found themselves swapping tales of mutual interest and concern. This, in turn, led the two women to becoming friends and supporting each other through the stress and worry of holding down jobs, running homes and generally holding things together whilst their husbands lay in hospital.



*left to right: Janet, Bal & Bev*



*left to right: Phil, Ken & Barry*

When Barry came to the ward it was obvious to the others that he was not of Ken and Phil's mindset. Although having lived in the UK most of their lives, Barry and his wife, Bal, are of Punjabi descent. Consequently, Bal in particular, the two are of differing customs and mannerisms. Barry was somewhat withdrawn, quiet and complex and initially chose not to involve himself in the general chit chat with those around him. How quickly that would change. It was in Ken and Phil that Barry saw their interactions as being more than mere male hyperbole. In them he recognised the discourse between the two, sometimes opinionated news swapping, sometimes slightly risqué stories raising a laugh, as pivotal to their mental and emotional wellbeing. After all, he thought, the physical side of GBS would take a long time from which to recover, with not much that one can do personally save for ward dispensed medication and physio, so why not help the time in hospital pass more amenably by striking out and joining in. And so he did, explaining to Ken and Phil that he was a bus driver based in Middlesbrough and that he was a father and grandfather. And, similarly, Barry had tales to tell and stories to swap and it wasn't many days before a firm trio of friendship was formed.

Bal, in turn, got to know Bev and Janet and before long the three women had begun sharing their own stories and experiences. Such was the developing closeness of the two triads, three GBS patients and three wives sharing similar concerns, that very soon a bond of friendship combining all six had been forged. Before long it had become a regular occurrence for hospital meals to be spurned as Bev, Janet and Bal took turns bringing in food from home for all to share. Tales and stories emanating loud, side splitting laughter was common among the six with patients in other bays often enquiring, "what's going on next door?" An additional characteristic of the friendship was the emotional help and support each gave the other. Shared experiences, both good and bad, were a recurrent theme.

Dr. Jenna Moffitt, neuro psychologist at James Cook University Hospital, had a professional interest in the health and wellbeing of the three men. So much so

that when Ken, Barry and Phil drew her attention to the paucity of GBS related information available on the ward, she listened intently. Such information as there was available – leaflets, notices, booklets etc. – had been sourced only as a result of Bev and Janet's tenacity through accessing the then GBS Support Group website. Dr. Moffitt listened too, to particular concerns that there was no recognition of the worry and stress endured by patients' loved ones and the valuable support they give.

Through Dr. Moffitt, a meeting was arranged in the ward day room for the six to meet with Gill Ellis, Support Officer from GAIN Charity in Sleaford, Lincolnshire. It was through meeting Gill that the first seeds were sown towards setting up a hospital based GBS support group. Gill outlined a number of options ranging from an 'association' requiring a committee and a bank account, through to an informal 'gathering'. A full and frank discussion ensued but no decision was reached following the meeting, the three families electing to first consider all of the issues before deciding what to do. A few days later, however, Ken, Phil & Barry were introduced to Paul Oxberry. Paul had been a GBS patient some three years earlier and Dr. Moffitt had suggested that it would be useful to hear Paul's experiences of life and work since leaving hospital. Paul related how GBS had impacted upon his family and that it had taken him a year to resume work as an engineer. His story was both graphic and moving. None more so than when he said he had competed in the Great North Run half marathon in September 2013. What made Paul's story more compelling was the fact that he had completed the entire 13.1 miles with limited feeling in both feet.

Paul's story was later relayed to Bev, Janet and Bal and, coupled with the now growing desire to 'do something', a further informal meeting took place where it was agreed to set up a focus group to support past, current and future GBS patients, to promote awareness of GBS and to raise funds for GAIN charity. Thus was born, with the help and facilitation of Dr. Moffitt, The James Cook Gathering of GAIN.

*Phil Graham*

## Branch & Network

If you would like to be kept informed of local meetings taking place in your area, email [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk) or phone us on 01529 469910 (Monday to Friday, 9.00am-3.00pm) with your name and address to make sure you are on the mailing list.

### Yorkshire

Sunday 19th October 2014, Boothroyd Centre, Dewsbury District Hospital

As usual, there was an excellent turnout, including several new members alongside the many regulars. As the Chair of the branch was standing down due to other commitments, founding member Doris Fryer welcomed everyone and said a few words in appreciation of Heather's previous involvement.

Gill Ellis, Support Officer at GAIN Head Office, had been invited along to the meeting and used the opportunity to talk about different branch structures that may be considered. Historically, the Yorkshire branch was set

up as an 'Association' requiring a formal committee structure, bank account and AGM. An alternative option would be to become a less formal 'Gathering', which only needs two or three people to keep things going who are prepared to take on a bit of the organising.

The last remaining committee member, Sue, along with a couple of other long-standing members and one or two more recent additions to the group all said that they would be willing to help out in this way. The overall feeling was that this would be a satisfactory way forward, ensuring that this long-established and well-supported local branch continues to thrive.

The date of the next meeting was set for Sunday 22nd March, same venue.

### South West England

Caroline attended the South West meeting hosted by Fiona Northcutt and Fran Harris at the Dorford Centre in Dorchester on 18th October. We had a fantastic afternoon, with plenty of members as well as cast members and crew from the Paranoid Dramatics production of *Alien*. The afternoon started with John Tuke telling us his GBS story and how he had been a member of the Medical Advisory Board and now volunteered to help the newly diagnosed. His entertaining story raised lots of laughs, several gasps and much agreement from the audience. He answered questions from the audience and encouraged sharing of information between those attending.



A cheque was presented to GAIN from Paranoid Dramatics to help with our work. This was raised through putting on a stage production of *Alien* initially in Dorset then at the Leicester Square Theatre in London. There is to be one final performance in 2015 and dates will be publicised. I can guarantee a most enjoyable evening!

# News

## Scotland

The Scottish Branch held their AGM at the Holiday Inn, Glasgow Airport on Saturday 4th October 2014.

The attendance was well down on the 2013 AGM, which of course resulted in less income for the branch.

Professor Willison updated the branch with latest advances in the research field and also mentioned preparations for the upcoming Centenary Conference in 2016 in Glasgow. Dr. Amy Davidson is in the midst of a trial using a drug with half of the patients and a placebo with the remainder. Initial responses are looking good but it is still very early days.

Thanks was given to Mr. & Mrs. Shaw from the Isle of Bute for donating the holiday for the Prize Draw, and the winners are as follows:

**1st Prize** – Mrs. A. Johnstone of Ayr,

**2nd Prize** – Mrs. D. Hislop and

**3rd Prize** – Mrs. E. Mabon.

The next Scottish Branch AGM will be held on the 3rd October 2015 at the Holiday Inn, Glasgow Airport.

## Kent

The Kent branch is once again organising a post Christmas get-together on Saturday 10th January (12.30 for 1.00pm) at The Woolpack Public House, Maidstone Road, Hothfield, Ashford, Kent TN26 1AP.

All members of the Kent branch of GAIN are welcome; if you would like to come along please contact Gill Ellis on 01529 469910 or email [support@gaincharity.org.uk](mailto:support@gaincharity.org.uk) as soon as possible.

## West Midlands

On 29th November 2014 members of the Branch met at the Skydome Arena, Coventry to watch recovered GBS patient Mike Egener play ice hockey for Coventry Blaze. A report will be published in the Spring issue.

## Lancashire & Cumbria

2015 Meetings to be held at Bilsborrow Village Hall, Bilsborrow at 2.00pm

14th March - AGM

6th June - Plant Stall

26th September - To be arranged

5th December - Christmas Party, Jacobs Join

## The James Cook Gathering, Teesside

The first meeting took place in the hospital's Academic Centre on the afternoon of Tuesday 1st July. Phil had agreed to be a point of contact for the group. A core feature on the agenda for meetings is an opportunity for all attendees to share their GBS experiences. Being the group's first meeting, topics for discussion were limited to introductions, explaining the background to the group and ideas for future events. In this, a number of social and fundraising initiatives were recorded along with a series of clinical support action points which were fed back via Dr. Moffitt. A second meeting was held in the same venue on Tuesday 26th August where, along with agenda items, feedback from the previous action points were received. The meeting was also attended by Lesley Connor from South Tees Hospitals NHS Trust Press Office who took statements and a photograph to accompany a Press Release supporting the group.

The latest meeting took place on Tuesday 21st October in the form of lunch in a bar/restaurant opposite the hospital followed by a general discussion around a loose agenda.

And whatever the future may hold for The James Cook Gathering of GAIN, wherever determination or frustration leads them, that bond of friendship, shared by the six founding members, Phil & Janet, Ken & Bev, Barry & Bal, shall forever remain strong.

*Phil Graham*

**The date of the next meeting is Thursday 29th January, 2015 at the Toby Carvery, Marton Road, Middlesbrough, TS4 3BS (opposite James Cook University Hospital). As agreed at the last meeting we shall meet for lunch at 1.00pm prompt. If you would like to join us please contact Gill Ellis on 01529 469910 or email [support@gaincharity.org.uk](mailto:support@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, 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.
4. To work closely with the Fundraising Team. Fundraising Responsibilities:
  - Actively participate as a key member of the Board.
  - Assist in securing additional funding and the diversification of funding sources.
  - Assist in setting the fundraising strategy of the organisation and in setting and monitoring performance fundraising targets.
  - Support specific fundraising activities with a particular focus on increasing unrestricted funding through public and corporate avenues.
  - Act as an ambassador for GAIN, representing the charity at key meetings and facilitating networking opportunities with potential donors, Corporations or other potential funding streams.

### What are we looking for?

#### Person Specification

The ideal candidate will have public and corporate fundraising expertise within the charity sector or will have consumer/retail sales and marketing 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 January 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.



# Gifts in wills

## What will your legacy be?

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

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

### How we use these gifts

These gifts come in all shapes and sizes. Big ones, small ones – £200, £3000, £20,000, £110,000, 20% or 100% of an estate or anything left over after the other gifts have been made.

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

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

“ these gifts come in all shapes and sizes

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

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

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

### How to leave a legacy for our work

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

Guillain-Barré & Associated Inflammatory Neuropathies  
Woodholme House, Heckington Business Park,  
Station Road, Heckington, Sleaford NG34 9JH

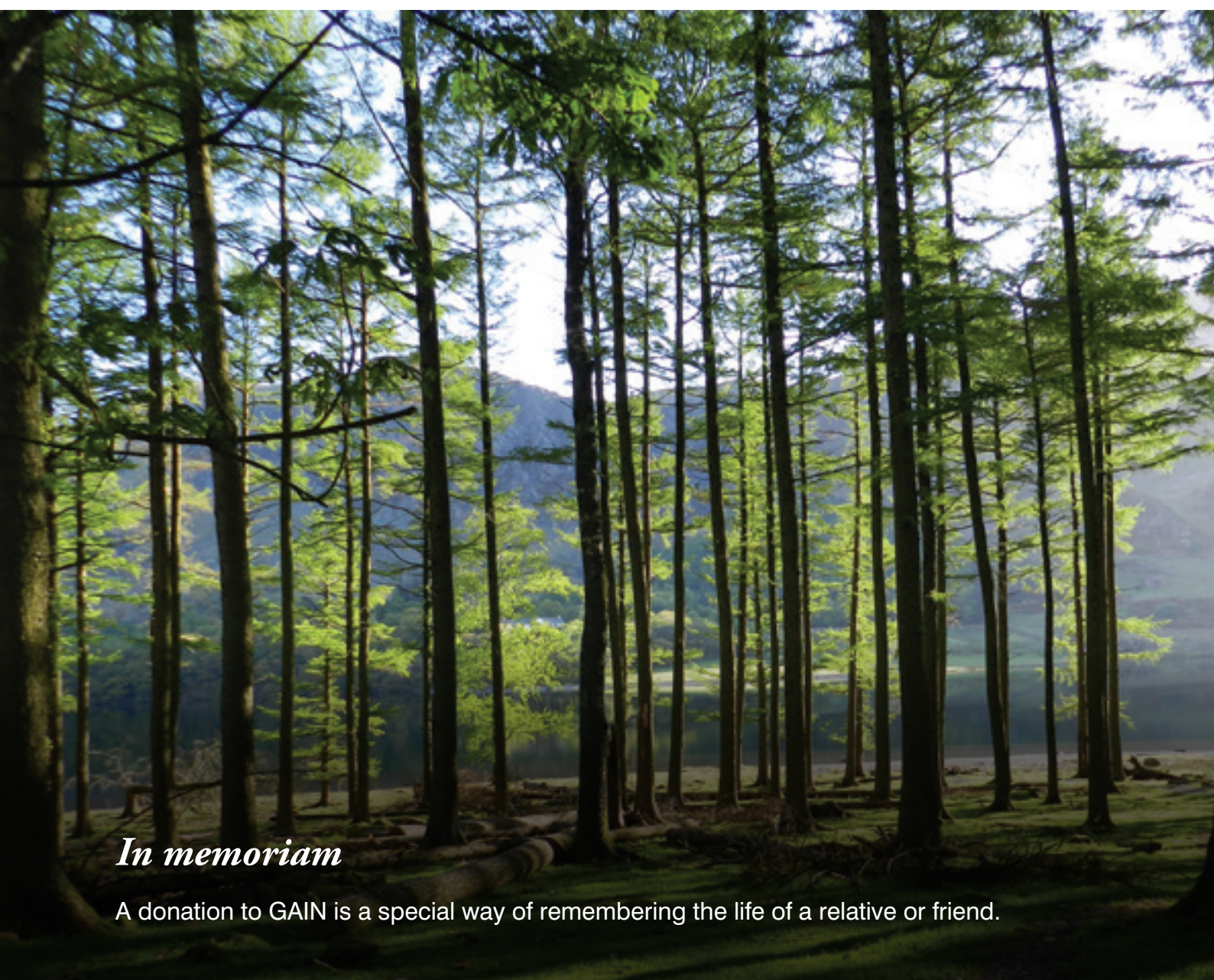
Registered Charity in England & Wales 1154843

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

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

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

*Thank you*



*In memoriam*

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

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

gain   
Guillain-Barré & Associated  
Inflammatory Neuropathies