The magazine of Guillain-Barré
& Associated Inflammatory Neuropathies
Issue 13 September 2018 FREE

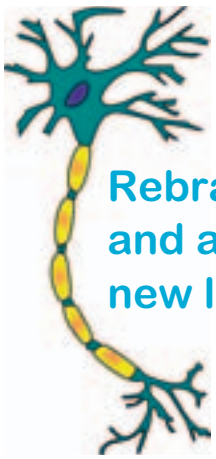
gain4all

Laying foundations for the future

Your Stories
From blurred vision to paralysis in 48 hours

Blindsided – a photographer's blog
From Kuala Lumpur to Queen Square and back again

A new home for GAIN and a date for your diary
Annual Report and AGM 2017
Regional round-up & letters



Rebrand and a new logo

Old friend, new image
Meet the new GAIN mascot

Dedicated to helping people affected by Guillain-Barré syndrome, CIDP & the Associated Inflammatory Neuropathies

About the conditions

Guillain-Barré syndrome, also known as AIDP, is an acute auto-immune condition affecting the peripheral nerves, in which the body's immune system attacks the myelin sheath (insulating coating of the nerves). This leads to the short-circuiting of the nerve signals which causes sudden weakness resulting in paralysis and a loss of sensation, often but not always with severe pain. The worst degree of weakness is usually reached within 4 weeks and always within 6 weeks. Recovery can take a few weeks or many months.

About 80% of those with GBS will make a good recovery, but sadly between 5-10% of people will not survive and the other 10-15% may experience long term residual effects ranging from limited mobility or dexterity, to life-long dependency on a wheelchair.

Some patients develop a similar but longer-lasting condition called CIDP. It is possible to recover from CIDP, but many will be affected for the rest of their lives and will require ongoing treatment, usually with steroids or immunoglobulin.

Every year in the UK, as many as 1,300 people are diagnosed with an acute form of the syndrome and a further 650 with a chronic variant such as CIDP. These conditions are neither hereditary nor contagious, nor are they age or gender-related.

About the charity

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

What we do:

- Help people understand and manage GBS, CIDP and the associated variants
- Promote and facilitate both clinical and non-clinical research
- Raise awareness of the charity and conditions

We provide information packs for patients and their families, awareness packs for use by health and social care professionals, hospital communication books, one-to-one peer support, personal grants and more.

We receive no government funding, relying on the generosity of the public to support our work. For every £1 we receive in donations, just over 85p goes directly to supporting our charitable objectives, with less than 15p paying for administrative overheads, such as premises and staffing.

For further information or to find out how you can support us in our work, visit our website:

www.gaincharity.org.uk

Guillain-Barré & Associated Inflammatory Neuropathies is a registered charity numbers 1154843 & SCO39900

Getting Better Slowly

Do you have a story you would like to share with our readers?
Email submissions for next issue before 31st October 2018 please to:

gain4all@gaincharity.org.uk

Preferred format: Word document
(text only - photographs to be emailed as separate files in jpeg or png format)

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www.gaincharity.org.uk

Find us on social media:

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https://www.facebook.com/groups/727400487277814/

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(https://www.instagram.com/gaincharity/)

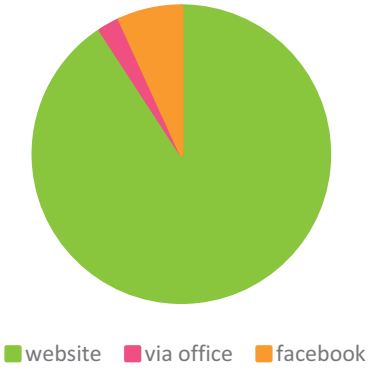
Guillain-Barré & Associated Inflammatory Neuropathies is a registered charity, numbers 154843 & SCO39900

A new home for GAIN and a date for your diary - see pages 8 & 9

Annual Report 2016-17 *some highlights*

Achievements, performance and plans for the future

We helped people



Support was provided to people in many different forms over the year. For those making direct contact with us in the **office**, we provided information and support over the phone, by post and by email, putting people in touch with our network of peer support volunteers as required.

The 20,000 visitors to the GAIN **website** were able to read and download information, and those seeking online peer support were able to find it through our **social media** channels, including our Facebook community with over 2,000 members.

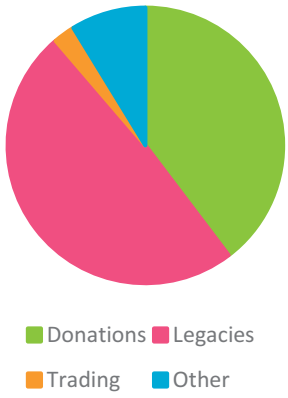
'The core objective of providing support was the primary reason the charity was founded and remains a primary objective. With the plethora of information and virtual support now available, our support services are in a continuous state of evolution.'

Trials and research

During the year we have recruited members for two different trials looking at how patients with CIDP manage their condition. These trials are ongoing and may take several years before the impact can be measured. The charity continues to support studies into both acute and chronic conditions. Members participating in these studies and trials provide a depth of knowledge to the pharmaceutical industry, which can assist in the development of new forms of treatment.

Raising funds

We saw an upturn in general donations and also in legacy donations over the year. The number of people donating directly and taking part in events to raise funds both increased, with more people opting to make regular donations via Direct Debit.



Raising awareness

One of the biggest awareness campaigns for 2016/17 was the play ***Getting Better Slowly***, the story of one of our trustee's struggle with GBS. The play toured around the Midlands to excellent critical reviews and audience feedback. It is planned that the show will tour again in Autumn 2018.

Working together

The Chief Executive meets regularly with the Specialised Healthcare Alliance (SHCA), Neurological Alliance, Rare Diseases UK and NICE, ensuring GAIN can represent the interests of patients within the NHS. GAIN has also been involved in the drafting of a new NICE guideline about Diagnosis of Neurological Conditions, which will be primarily for GP and A&E to help them identify the conditions early; this is due for publication 2018-19.

Annual General Meeting 2017

The Members' Annual General Meeting was held on 28 October 2017 with a small attendance, at Thorseby Hall Hotel near Ollerton, Nottinghamshire.

GAIN Chairman Chris Fuller welcomed everyone to the meeting. He spoke of the reality of our membership numbers falling and that most members now returned a postal vote rather than attending in person. It was felt we may attract more members next year when we have an event to coincide with the AGM. Chris also spoke about the way the charity is moving forward and the changes to the way we now operate.

The Treasurer, David Wada, explained that the trustees had agreed to using a larger firm of charity accountants this year. He outlined the new process and details of the company. David gave an overview of the years account and confirmed that they had been signed off. A few questions seeking clarification of the accounts were raised and answered by the Treasurer. The Treasurer confirmed that the accounts had been produced and examined by the accountants in accordance with SORP and were signed off in conjunction with the annual report following their adoption by the members.

There was a discussion on the new building and it was decided that the charity would like the office building to be called Glennys Sanders House, a lasting legacy to all she achieved in setting up the charity and seeing it flourish over 32 years. Glennys was very happy to have the building named in her honour and the charity will do something special when it is completed. We will post on updates on progress on our social media and website, so members can witness the transformation from building plot to purpose-built office.

Chris Fuller had received correspondence raising a number of concerns following the receipt of the annual report and accounts which may answer members questions on how the charity is moving forward.

Concern: The full accounts were not available in the proper format prior to the AGM – was this a concern to the Board?
Answer: The accountants were well aware of the AGM deadline and the Board was confident that they would be available for the meeting. The trustees meet quarterly, and the treasurer produces a quarterly statement of the charity's financial performance for the Board. So, at all times the trustees are aware of the charity's financial performance, plus of course the AGM gives the members an opportunity to see the financial position and raise any questions on the figures with the treasurer.

Concern: You are proposing to spend some of the accrued funds on purchasing a property. It means that the Charity will be rooted to one locality which future Boards might find inconvenient. It also means that we will lose the opportunity of spending more money on the objectives of GAIN.
Answer: The decision to purchase our own building was driven by a number of factors. These include the charity has outgrown its current premises in that the meeting room is too small for trustee meetings, our current lease ends in 2020 and we have had a number of legacies meaning cash distributed across a number of bank accounts earning interest below the rate of inflation thus slowly diminishing in value. The advice of our accountants was to invest into property which of course has the benefit of saving on year on year rental costs as well as giving more space to develop events for members or for our fund raisers. Such a move does of course firmly secure the long-term future of the charity and avoids the risk of having to rely on landlord goodwill in the face of rising office rental costs. What will become a fixed location is not seen a risk to the operational capability of the charity. It has since inception been located in the Sleaford area and as a national charity covering the UK and Ireland then, within reason, any site is as good as another. However, in Sleaford we have the key advantage of experienced staff and a move elsewhere would mean a loss of that expertise with damage to the charity's operations. As to your point about instead spending the money on the charity's objectives, I'll cover research in the next paragraph. In terms of our other aims, the report covers those but in summary we are increasing the assistance given to families of patients, researching other areas into which we could expand the range of that support, engaging consultants to improve the usability and content of our social media coverage as well as supporting the use of drama to increase the awareness of GBS.

Concern: In the abbreviated accounts there is no mention of expenditure on research. Obtaining funds for research into a rare disease such as GBS or CIDP has always been difficult and GAIN has in the past supported excellent research in Glasgow and elsewhere. Registers such as IGOS for GBS and the new registers for CIDP promise to make real advances in our understanding and treatment of them but need funding which is not readily available from government or generic charities. We may be on the cusp of discovering new treatments for GBS and related diseases with complement inhibitors which will make fundamental differences to people with GAIN conditions. It is only research which will lead to advances which will make a fundamental difference to the outlook for GAIN patients.
Answer: In terms of research, the report shows we are working with researchers to help them obtain feedback relevant to their research area from patients and ex patients. We are also in dialogue with the Medical Advisory Board (MAB) about the best way of funding a research student over a one to three-year period in an appropriate area of research. The charity has recently supported two research projects, one in Glasgow and one in UCL, where we are awaiting the final reports. We are about to support another study with patients several years post GBS.

Concern: The number of voting members is declining
Answer: In common with other charities, the number of members is indeed falling and has been doing so for the past five years. In the wider social context, we are finding that how people choose to engage with the charity is changing away from a more formal context than has been the case in the past increasingly towards the use of social media to obtain or share information. The number of people that we are helping, both directly and indirectly is increasing with around 4,000 people on our database. But we are not ignoring those who prefer a more traditional way of obtaining information. We are commencing to rewrite our information booklets in a clearer, more up to date format ensuring of course through MAB that the content is correct in terms of the medical content.

Concern: The tradition of holding an annual educational and supportive meeting for members has fallen into abeyance.
Answer: It was agreed through a membership survey that events would be held every two years. However, in 2014 we had to cancel an event because of insufficient attendees and in 2015 as well as 2016 we have struggled to get sufficient attendees at events to make a quorum, even at the Glasgow centenary event. No event was scheduled for 2017 and we are planning for an event in 2018 but the reality is, as said above, people are changing in the way that they choose to engage with the charity. I suspect that increasing family commitments as well as increasing costs are also a factor regarding national events.

The GAIN 2018 AGM will take place on Saturday 6th October 2018. See page 9 for details.

25 May 2018 saw the introduction of the new General Data Protection Regulation, which is tightening up how your data is handled. We spent several months working hard in the office to ensure we comply with the regulations, and need your help to keep everything up to date;

- **Please make sure that you complete the membership form sent out recently, giving your consent for how we contact you and what we contact you about. We don't want to lose touch, so please complete your form.**
- **Volunteers (past and present) must not retain information about people they have been in touch with previously. All information must be shredded or sent back to the office for destroying.**
- **Please make sure we are informed of any changes to your personal details (name, address, diagnosis, etc.) as soon as possible**

If we have no current permission on file, we may not be able to contact you – if you still want to hear about the charity please fill in the form or give us a ring.

Leaving a gift in your Will

Writing a Will may not be at the top of your bucket list, but it should have a place on it.

The consequences of **not** getting around to writing your Will could result in financial uncertainty for the people you leave behind.

If you are among the one in two adults in the UK who have not yet made a Will, there is no time like the present to do something about it.

Around 6% of the population of the UK use their Will to leave a gift to charity. It's not just for the wealthy, and every legacy donation, no matter how large or small, enables us to continue in our work, raising awareness, facilitating research, and helping people affected by GBS, CIDP & the associated conditions.

For every £1 we receive in donations, over 85p is spent on fulfilling our charitable objectives, with less than 15p paying for administrative costs such as premises and staffing.

Perhaps you could consider bequeathing just 1% of your estate to GAIN, leaving the remaining 99% to your family, or others close to you?

The cost of having a Will written by a solicitor starts at around £100, and some even offer a free Will-writing service in exchange for a donation to a charity of your choice. If you don't already have a solicitor, you can find one via the Law Society website;
http://solicitors.lawsociety.org.uk

Why not cross it off your bucket list today?

McClure SOLICITORS

Why do you need a Will?
You already know that every adult should have a Will. Without a Will the law decides who inherits. With a Will you decide. With no Will it will usually take longer and cost more to wind up your estate.

Why should you do it now?
No-one knows what is around the corner. If you leave it until you need it, it will be too late. So let's get it done.

Why should you use McClure?
We prepare thousands of Wills each year.
A standard Will only states who is to benefit when you die. Our Estate Planning Wills ensure that your estate finishes up where you want it - quite a difference.

At present we will prepare your Will free of charge for a voluntary donation for Charity. So now you can support the Charity and get a good deal.

What can McClure do for you?
- We make your Will free of charge
- You don't pay
- The Charity doesn't pay
- You consider a donation for Charity
- All of your donation goes to a Charity
  Simple as that

Why do we do it?
- Everyone benefits
- You get the Will you need
- We raise funds for Charity
- Over 50% of clients go on to use us for other services

We have branches across England, Scotland, and Wales. For further information and to find your nearest branch, visit the website:

www.mcclure-solicitors.co.uk/wills

Laying foundations

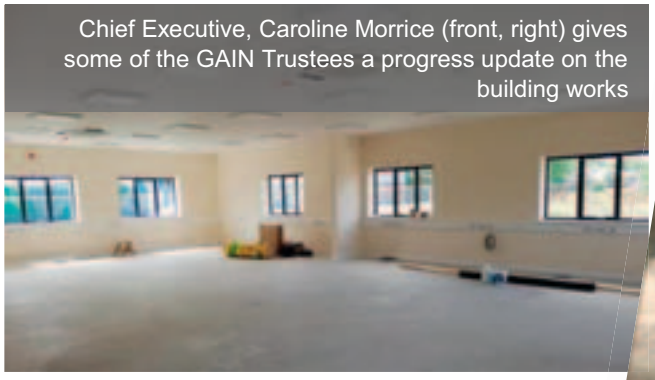
Later this year we will move into our own freehold office accommodation, Glennys Sanders House, which is named after the Charity's founder.

GAIN received a generous legacy in 2016, and with interest rates being so low, our accountants advised us to invest in property as this would offer the best return.

The new building will give us larger and more flexible office space to provide a platform with which to better engage with patients, their families and members of the Charity. We will look at ways of using that space for events and meetings as well as using our improving IT facilities for such developments as online conferencing, virtual branches plus closer engagement with volunteers as well as fundraisers.

It also allows us the opportunity for additional income from hiring part of the building to other organisations for their meetings and events.

for the future



Chief Executive, Caroline Morrice (front, right) gives some of the GAIN Trustees a progress update on the building works

AGM & Members' Meeting 2018

Although we had hoped that it would **coincide with** the 2018 Annual General Meeting, the grand opening of **Glennys Sanders House** has had to be put back due to ongoing building works onsite. Instead, the GAIN 2018 AGM and Members' Meeting will be held at the **Catholic Church Hall, Jermyn Street, Sleaford, NG34 7RF** on **Saturday 6th October.** Parking is available opposite the hall.

Everyone is welcome to join us for the AGM which will commence at **10.30am (arrivals and coffee from 10am)** and will be immediately followed by a Members' Meeting, to include a review of the year and our plans for the future. Tea and coffee will be available, and lunch will be served after the meeting. Attendance for the AGM is free, but if you are staying for the Members' Meeting and lunch, there is a charge of £5 towards costs. Please register if you would like to join us by sending a cheque (payable to GAIN) for £5 along with your name, address and telephone number to GAIN, Woodholme House, Heckington Business Park, Station Road, Heckington, NG34 9JH.

Enquiries to office@gaincharity.org.uk or by telephone on 01529 469910

Spreading the word…..

Thank You to everyone who responded to our ‘Spreading the Word’ Summer 2017 appeal

In terms of raising awareness of GBS and CIDP, putting up a poster in your local hospital may seem like a drop in the ocean. But, the sharing of information can have a ripple effect, often reaching further than we think. Consider for a moment how many people might see that poster, file the information away in the back of their mind, and then mention it to a recently diagnosed friend or neighbour?

We were blown away by your enthusiasm for taking our information to local surgeries, hospitals, and other publicly accessible places, with **over 70 packs** sent out containing leaflets, posters and information for health and social care professionals.

This means that in over 70 locations around the UK and Ireland, newly diagnosed patients and their families will have a better chance of being signposted to GAIN, so they can benefit from the information and support we offer. It also means that well over 70 health and social care providers have information at their fingertips that might help them recognise these rare and sometimes difficult to diagnose conditions.

Don’t stop there! If you have taken some information to your local hospital, please check every now and then to see if leaflet stocks need to be replenished or a poster replaced. We are always happy to provide display materials, so just let us know what is required and we will send it, either to you, or direct to the hospital or surgery.

Count me in!

So far, more than 370 of you have shown an interest in being invited to take part in studies and trials, should the opportunity arise.

This means that when we get a request for potential participants for a new study, we have a database of people we can contact.

If you are interested but haven’t yet added your name to the list, please let us know by **emailing**;

office@gaincharity.org.uk

with your name, date of birth, diagnosis and date of diagnosis

Meet Moxie!

This is Moxie, the new GAIN mascot

Why a tortoise?

A tortoise is a visual representation of recovery from GBS, which as well as being the abbreviation of Guillain-Barré syndrome, also stands for 'Getting Better Slowly'

…and this is the reason our mascot is called 'Moxie'

moxie

/ˈmɒksi/ *noun informal*

Meaning

force of character, determination, or nerve

Synonyms

courage, fortitude, grit, stamina, tenacity, toughness, perseverance

Moxie merchandise

Our new range of must-have Moxie merchandise is now available to buy online or by phoning the office on 01529 469910 (Mon-Fri 9am-3pm)

www.gaincharity.org.uk

L to R
Trolley token keyring £1.00
Thermal mug £8.95
T-shirt £7.95 (S,M,L,XL)
Hoodie £25 (S,M,L,XL)

FREE POSTAGE on all orders

Getting Better Slowly

Parallel London 2017 by Rebecca Ellis (aged 11¼)

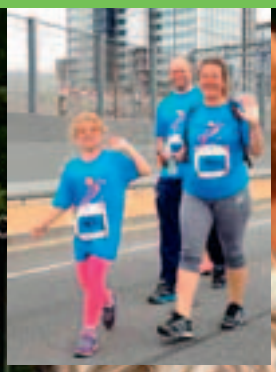
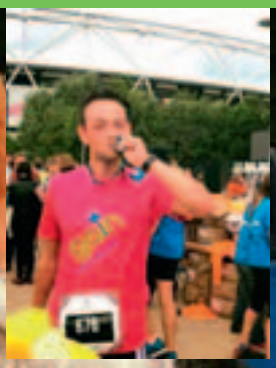
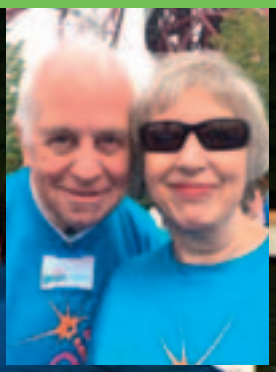
Me & my family went to London with GAIN. GAIN is a charity that supports people that have GBS (Guillain-Barré syndrome) and CIDP. It's a bad disease and it paralyses people. We did the 5K, but there was also a 1K, a 100metre run and even a 10K. I went all the way round with my dad and it was SO much fun! We walked, we jogged, we stretched our legs mid-way and got some water from the little stands. It was very refreshing. After the 5K we looked around for a while and we got some amazing noodles too. YUM!

In conclusion, you should go as it's so much fun. I may only be 11, but I loved every bit of it. Even the coach ride there and back.

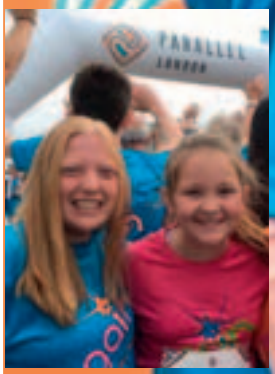
Parallel London 2017

GAIN on tour....

Parallel London 2017






We had a fabulous day at Parallel London 2017. The event is taking a break in 2018, but we are hoping it will be back in 2019. The exact date has yet to be confirmed at the time of printing, but we will publish details on our website as soon as we know more.

Parallel London is all about taking part. It is a fully inclusive, fun day that the whole family can enjoy, whatever your level of fitness and ability.

Watch this space and make sure you grab your chance to be part of something special!

PARALLEL LONDON

Start together, finish whenever

Although I mainly write about my photography, the last few weeks have been some I'll never forget, and it has nothing to do with cameras.

On Monday, 23rd March 2015, I was sitting at my desk worrying. Worrying about a series of symptoms that had steadily become worse since the previous Thursday. They were the kind of symptoms that would surely make you sound mad if you told a doctor about them. I was dealing with a numb tongue, and pins and needles in my toes along with the addition of pins and needles in my finger tips that morning. I had Googled it - of course I had - and had multiple sclerosis staring back at me. I decided to call the doctor and was squeezed into an appointment that afternoon.

The doctor was sympathetic and did basic observations before asking about my lifestyle - I don't smoke, I drink little, and I'm not a particularly stressed person. She did a series of strength tests with me to see if I had any weakness. I didn't. Finally, she took some blood to do a sweep of tests that would cover a whole range of areas - thyroid, cholesterol, sugars. I was relieved it wasn't just me and she was concerned enough to have it checked out. I made an appointment for a week later and tried to forget about it.

Tuesday, 24th March 2015

Like any other day, my son woke up around 6am and I headed to the bathroom before going to get him out of his cot. This time, as I washed my hands, I glanced into the mirror to notice only half my face making any movement. Jumping back into the bedroom in a panic, I told my wife who could see that half my face had drooped on one side and was making no movement. A drooped face says one thing; stroke. She called NHS24 who spoke her through various tests whilst sending an ambulance and I sat with our boy on the sofa like normal trying to stay calm for him. When the paramedics arrived, they did more tests before we were rushed across the City to Edinburgh Royal Infirmary with a suspected stroke. There I was assessed and taken for a CT scan before waiting for a while for the scan results to come back. They were fine, and I was diagnosed as having a transient ischaemic attack - a mini-stroke.

An hour later and we were making our way to another hospital across the city. There I saw a stroke specialist who began a series of tests on me to try and pin-point the effects this had had on me. Aside from a drooped face on one side, I had lost my ankle jerks and was wobbly on my feet, but I still had strength. He then asked me an important question, "what do you think when we talk about stroke?" It was a big question for me; until this point I had gone from the initial shock and then from pillar to post being tested, and suddenly a doctor was asking me how I felt about It. Two thoughts rushed into my mind "how is this going to affect our life?" and "why, at 34, am I dealing with a stroke?" I went with the latter. "That's the same question I have," he replied. I didn't expect to hear that. "I don't think we're dealing with a stroke here". He sent me for an MRI and an ultrasound of the arteries in my neck. All these came back clear and it was arranged that I would return the next day to the neurology department for further investigation.

It was good to get clear results back from the various tests that had been done. "Unremarkable" and "all fine" were the words of the day, but for me this just came back to the same question - what is it then? Is this something beyond the doctors' knowledge and most definitely outside my control?

Wednesday, 25th March 2015

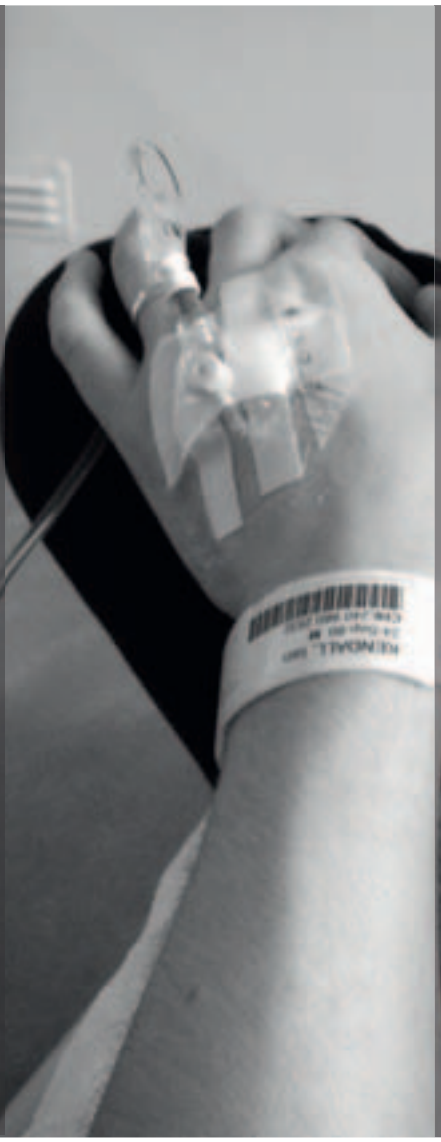
It was early, around 2am, and something was bothering me. The paralysis down the right side of my face affected everything, including closing my eye to sleep. I tried to close it by holding the lid shut but I could still see the street lights pouring in from outside our window. That didn't make sense. The only answer was that my left eye was open and that meant one thing: the left side of my face was now paralysed too. I woke up my wife who asked me to smile...nothing. Raise your eyebrows...nothing. I tried to remain calm this time as she called NHS24 again. "Make your way to A&E" - so we did.

A long wait in A&E followed before a neurologist, who I was meant to meet later that day, came to meet me. He carried out the tests on my arms and legs that I had become familiar with now. I walked precariously across the hospital floor, before he asked me to stand with my feet together and close my eyes...I nearly fell on him. He sat me down again and began to talk about what was wrong with me. After two terrifying days I finally had a name for what was plaguing me: Guillain-Barré syndrome. I was shocked that I had never heard of the condition and yet as he spoke I was aware this was going to become a big part of my life.

The best way to describe Guillain-Barré syndrome is as friendly fire from your immune system on your periphery nervous system. It's useful to think about your central nervous system as the mains of a house, and your arms, legs, respiratory system are all the appliances. My immune system had launched an attack on the cabling between them and was shutting them down. It can be treated but it is all about grabbing your immune system's attention and making it realise it is making a big mistake. Treatment is a five-day course of IVIg (Intravenous immunoglobulin) to boost the immune system and make it realise the fundamental error.

But the doctor warned me that it wasn't that simple. I was going to get worse first. I could lose the power to my legs and arms which were already showing signs of being affected. I could lose the power to breathe and swallow on my own. He warned that my mood would dip at some point and I would lose the will to fight it. I would then reach a plateau where nothing would change – I wasn't getting better, but I wasn't getting worse. Then, eventually, at last, came the recovery.

With this news I looked at my wife and our twenty-month old son – they would need to fend for themselves for a considerable amount of time. We had been a parenting team since he was born and now it would just be my wife to carry on, while still worrying about me. I find solutions and solve problems; now I was the problem and I couldn't sort it. I was in a hospital bed in A&E, wobbly on my feet and paralysed in my face but by the end of the week I would likely be on a ventilator in Intensive Care. I felt so out of control.

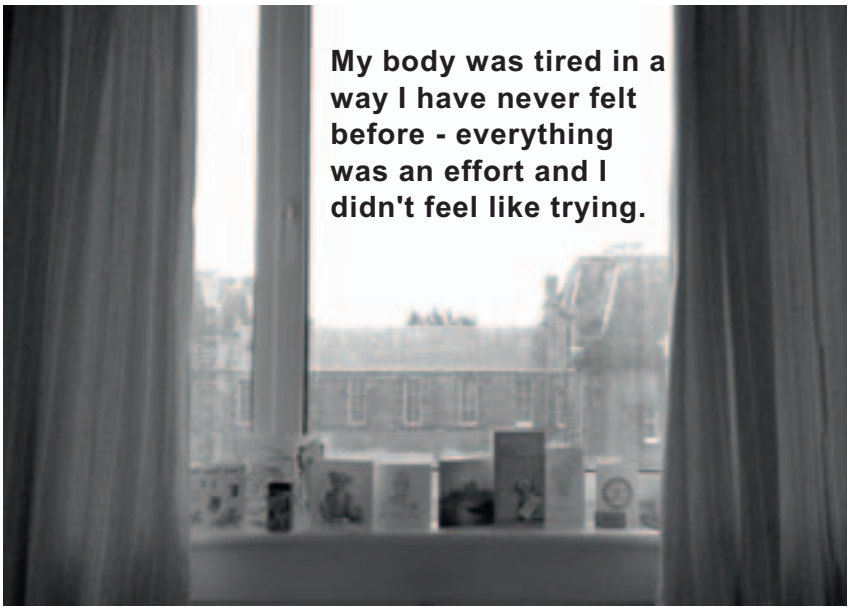


Once a bed was available, I was moved to Edinburgh's Western General Hospital to the Division for Clinical Neurology. While I was transported by ambulance, my wife collected things from home and ran a few errands for me. It was the first time I had been away from my best friend since this all began. I sat at the back of the ambulance where a nice paramedic chatted to me about his son, but all I could think about was when I would see mine again.

Treatment began almost immediately, and it took about two hours to complete the daily course. Each hour of each day became a countdown to when I had to sleep. Every day so far had brought an additional challenge to me each time I woke up and I already knew I was going to get worse – would it be my limbs, or my breathing failing today? Would anyone notice it was the latter in time? I stayed up late and had been awake for 22 hours by the time I did try to close my eyes.

The less time I spent asleep, the fewer debilitating changes would take place - in my mind anyway. I woke up around 6am and the pins and needles had moved up my arms and legs but everything else was okay. I did the same the next night and the night after that as though I was somehow cheating the system.

When the Sunday arrived, it was the last day of treatment and it was apparent that my immune system had realised its error. It was also our wedding anniversary and I spent a quiet day in my side room with my wife. My mood was low and there was nothing I could do to shake it. My body was tired in a way I have never felt before - everything was an effort and I didn't feel like trying. Aside from that, and despite the plateau, I still faced a long recovery and a large portion of that was going to be spent in hospital. I was done in, fed up and not equipped with the small talk other people needed from me.



The next day the consultants were back on the ward and I was reviewed to see how things were going. I was better than the day before in mood and I didn't appear to be getting any worse. I was told that they were happy with my progress, so I could head home. This was music to my ears. I could spend my recovery with my family which was all I wanted.

20th April 2015

I've been home for a few weeks and life is different now – I have to ask for my wife's help a lot more, especially when walking. I tire very quickly. I struggle to see for a lot of the day because of the gel on my eyes (I can't blink) and that brings about more dependence on my wife. Even this post about my condition, which would usually take a couple of hours, has taken a couple of weeks to complete. Eating and drinking has changed a lot too – I've had to rethink everything, and the straw has become my best friend with all drinks. Each night my eyes are taped shut to allow me some respite.

Talking is difficult and people struggle to understand me which is often hidden by text, email, and blog posts. Despite all that, I am very thankful - an early diagnosis and the particular subset of Guillain-Barré syndrome that I have means treatment started early and the condition was attacking my face first instead of my limbs as you would expect. I will also get better, albeit slowly. There are people fighting all kind of conditions every day, which won't get better. If this has made me realise one thing it's that you need to listen to your body when it's trying to tell you something. It was in the 1999 song "Everybody's Free (To Wear Sunscreen)" by Baz Luhrmann that I found the appropriate lines, ***"the real troubles in your life are apt to be things that never crossed your worried mind. The kind that blindside you at 4pm on some idle Tuesday."*** In my recent experience, this is definitely true.

A new beginning

27th June 2017

So here it is, the first post that follows the news I was going through a tricky time. In truth, I've been trying to formulate something to follow it since the month after it all happened but never found the words. It was a terrifying time, but an early diagnosis and treatment meant I was saved from progressing that far. That was two years ago and, when I wrote about it, never thought I would be still be referring to it all this time later. The good news is I've recovered well, with a couple of challenges that I am learning to live with...but I wouldn't necessarily change the hand I was dealt.

Guillain-Barré syndrome caused a lot of changes in my life. In a time when the future was thrown into the unknown, it became clear that I had taken a lot for granted, sat back and let others influence my decisions, and accepted the status quo. It was this difficulty that made me rethink all of that.

The effect GBS had on my photography was profound. Until that point, I made images of landscapes and cityscapes, but I suddenly I couldn't walk the length of the room, let alone climb a hill or pound the streets. Instead, I turned the camera on those around me - my friends and family. Over the next couple of years, this extended to family gatherings, days out and, eventually, weddings. The pull to this was strong and when I was there capturing these moments, all felt right in the world.

Last year I was invited to shoot my first wedding from start to finish and I jumped at the chance. The bride and groom (the lovely Matt and Catherine, a.k.a. my brother and sister-in-law) were the best at letting me know what they wanted but also letting me apply the style I was familiar with. I wanted to document their day as it happened and capture the wonderful couple they are. It was a fantastic experience and, at the end of the day and 18 hours on my feet, I knew I wanted to do more of it. Lots more.

The following months I continued to exercise my craft, but I also researched and took classes. Then, about two months ago, I sat down with my wife and told her I was going to make a go of it. She was so supportive. It was a moment of putting all that fear and uncertainty to one side and trusting my gut. That brings me to now - a new website and a new adventure.

To read more of Iain's blogs, and to view his photography, visit **http://iainkendallphoto.com/**

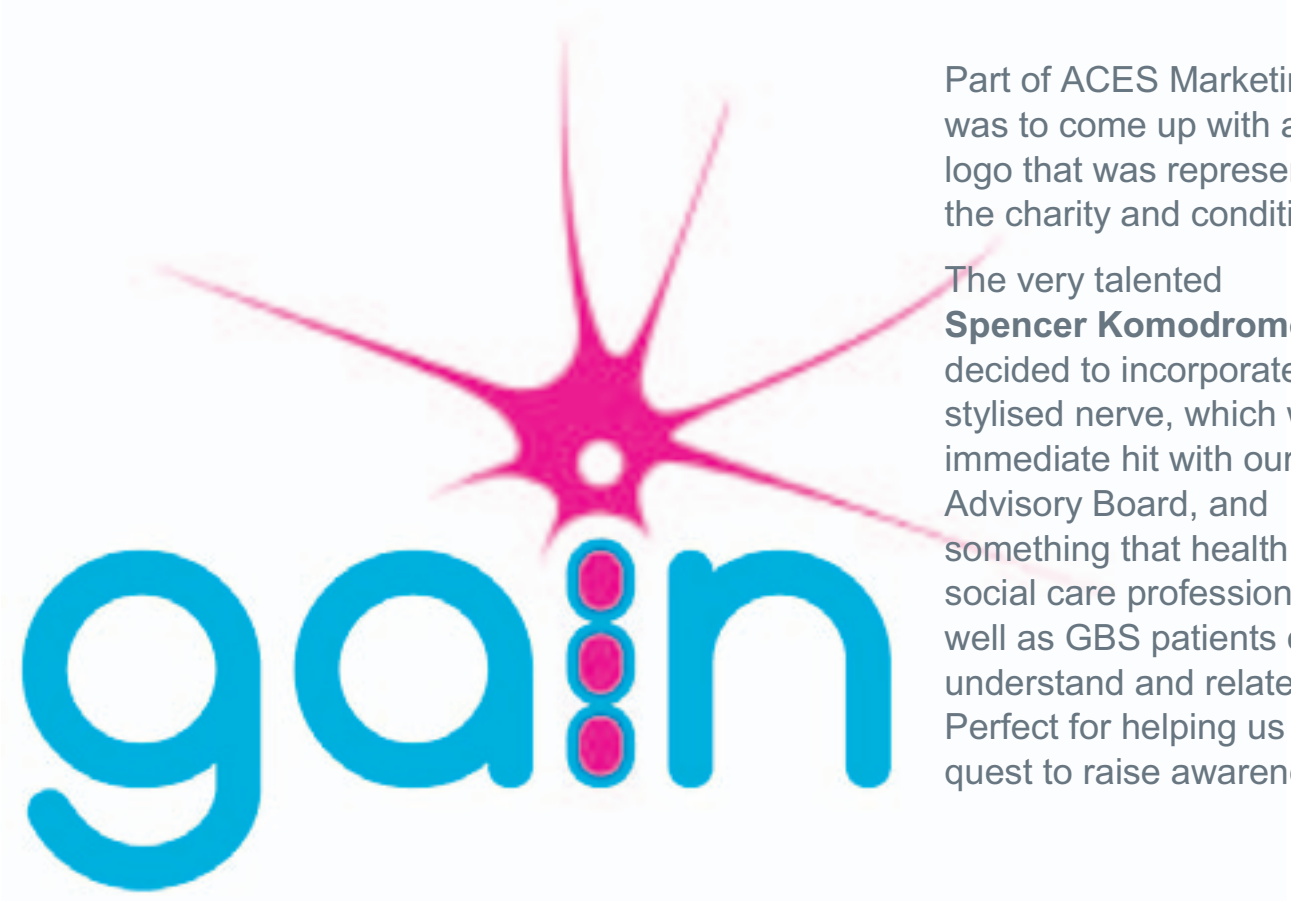
Website and brand refresh

GAIN recently attracted attention from Jersey-based company **Le Masurier**, with a view to helping us with a website and brand overhaul.

Le Masurier is one of Jersey's oldest and largest commercial property companies with property investments located in Jersey, the United Kingdom and throughout Continental Europe. The company first heard about GAIN in early 2017. As a rare and little-known disease, they recognised that GAIN is on a mission to raise awareness of Guillain-Barré syndrome with the medical professions and the public, aiming to improve outcomes by facilitating earlier diagnosis in sufferers.

Le Masurier are supporting GAIN in raising our profile by helping to fund a brand refresh and website transformation to give the charity a more professional image from the start.

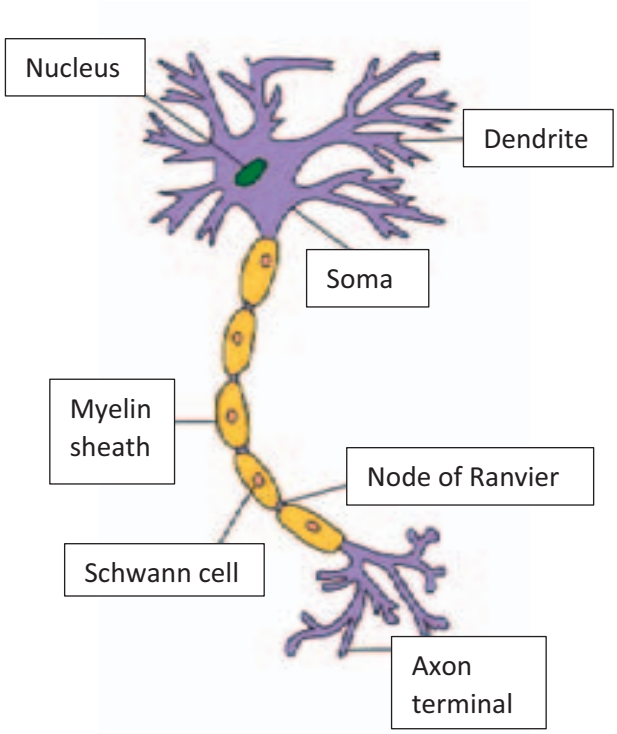
ACES Marketing worked with Le Masurier on our branding and website and are now working directly with GAIN on this project. It is particularly pertinent for them as one of the ACES directors has personal experience of Guillain-Barré syndrome, having seen a close family member suffer this debilitating illness in 2016.



Part of ACES Marketing brief was to come up with a new logo that was representative of the charity and conditions.

The very talented **Spencer Komodromou** decided to incorporate a stylised nerve, which was an immediate hit with our Medical Advisory Board, and something that health and social care professionals as well as GBS patients can understand and relate to. Perfect for helping us in our quest to raise awareness.

The letter ‘i’ in the new GAIN logo represents a neuron. The body of the ‘i’ is the axon, complete with myelin sheath and Schwann cells, some, or all of which may be damaged by Guillain-Barré syndrome (GBS) and the variant conditions. The ‘ink splodge’ represents the soma, dendrite, and nucleus. The new logo has been well-received by members, supporters, and medical professionals.



Although we loved the new logo, we were conscious that many of our members related to our old logo, which has for many years incorporated a tortoise, representing the ‘other’ meaning of GBS, that of ‘Getting Better Slowly’.

With this in mind, the tortoise itself has been given a new lease of life in the role of GAIN mascot. We have introduced a new range of tortoise-themed merchandise that is proving extremely popular and has captured the imagination of many of our long-standing members as well as grabbing the attention of supporters new to the charity.

The new logo and mascot (nicknamed ‘Moxie’, to represent the grit and determination shown by people recovering from or living with these conditions), have each attracted a great deal of positive feedback.

We are confident that these changes will help the charity move forward, enabling us to reach and appeal to a new audience as well as the many loyal supporters who have joined the charity and remained with us over the years.

To celebrate our new mascot, we have introduced a range of tortoise-related merchandise, including our very own plushie version of Moxie, which you can take home and look after for only £10.50 for the large one (28cm) or £8.50 for the smaller version (20cm).

Available to buy from the brand-new GAIN website or by phoning the office on 01529 469910 (Mon-Fri, 9am-3pm).

FREE POSTAGE on all orders

For our full range of merchandise, or to read and download information about the conditions, visit our sparkly new website

www.gaincharity.org.uk

Give as you Live®

Earn unlimited revenue for your favourite charity
Over 4,000 leading online retailers including Amazon, eBay, John Lewis and Expedia are waiting to donate a percentage of every penny you spend online with them, straight to GAIN.

www.giveasyoulive.com/join/gain-charity

GoRaise

GAIN has partnered up with GoRaise. It's now easier than ever before for our members and other supporters to join us in raising funds.

You can get free donations every time you shop online. It's simple, it's safe, and it doesn't cost a penny.

Once you've registered with GoRaise, every time you shop online at thousands of brilliant online retailers - including M&S, John Lewis, Argos, Ebay, Sports Direct, & Expedia - those retailers will donate a portion of what you spend to our cause, for free.

So, how do you get started?
Just go to our page at
www.goraise.co.uk/GAIN/
and register for free today.

Malcolm takes in Niagara Falls on a recent world tour

5 years on from Guillain-Barré syndrome

Malcolm Hanney OBE shares his GBS journey, taking us from Kuala Lumpur to Queen Square and back again

It was Christmas 2012 and I had just completed the first semester of a Masters' course in South East Asian Studies at the University of Malaya in Kuala Lumpur.

I was a somewhat aged student with most of my fellow and multinational students being less than half my age - but they treated me as just one of their group. Then on Christmas Eve, and after having had a bout of flu, I couldn't get up unaided from the table at a Christmas Eve buffet at a local hotel. My legs felt very weak and on the way back to my apartment I found I couldn't even climb a curb. All very strange and it got worse over the next 48 hours - hands and arms very weak as well - so off to Assunta Hospital I went in a taxi. The driver wouldn't even charge me - he said I looked so ill.

I then fainted in the Emergency department and that got me to the front of the queue! After a series of tests and lots of questions, the neurologist consultant told me I was off to Intensive Care and that I was to be treated for Guillain-Barré Syndrome (AMAN variant) - not that I could have spelt it let alone know what it was. A few hours later the 5 days of IVIG treatment began. I was so very fortunate that the diagnosis and treatment was so quick and I am sure that was a major factor in my avoiding a ventilator. My consultant - Datuk Dr. Raihanah Abdul Khalid - and the whole of her team were just wonderful. Both as her patient and as a former Chairman of an NHS Primary Care Trust for over 12 years before I left for Malaysia, I could only marvel at the control and input she had over all aspects of my care.

Three weeks later I was discharged and on a plane back to the UK accompanied by my sister and my very supportive estranged wife. There was no way I was in a position to stay in Malaysia and continue my studies and I had to go back to the UK to recuperate. I did walk out of the hospital but only just - and mainly to avoid fellow students having a Facebook photo opportunity of me with a Zimmer frame. I arrived back in England to the joys of winter snow the day before my 60th birthday. Not quite what I had in mind for a landmark birthday celebration.

Over the next few months I was very grateful for the support of what is now GAIN. I was provided lots of useful reading material; an introduction to a fellow sufferer (Jon Shelton) who gave me advice, inspiration and encouragement; and an invitation to a South West event, where I met a number of other GBS sufferers all with stories to tell and to learn from. I remember at that event I watched a woman sufferer get up out of her chair unaided and without holding on - and I wondered whether I would ever be able to do that again.

In March 2013, I had a week in the National Hospital for Neurology and Neurosurgery as my balance wasn't improving and my progress was slower than expected - despite a lot of hard work and physiotherapy. Lots more tests - including regular visits for my blood from 'Dr. Acula', an MRI scan, nerve tests, and a lumber puncture. After a review of all the tests results, the eminent consultant, Dr. Michael Lunn, confirmed the diagnosis of GBS (AMAN). His contact details (as a leading GBS specialist) had been given to me by GAIN. Strangely the confirmation of the original diagnosis made me very pleased - as I had begun to wonder if I might have something even worse. That is the trouble with excessive googling.

So I just got on with the 'Getting Better Slowly' process. I walked to the local village and back every day - about a mile - carrying a phone as I knew if I fell over there was no way I could get up again. And I went to the local gym five days a week doing various exercises designed to rebuild my core strength without which I knew my balance wouldn't improve.

I couldn't even climb on the treadmill the first few times but then I pulled myself up and started at 1km per hour pace and tried to improve a little each day. I also went on the bike machine and did various weight exercises - 2 each for arms, legs and trunk. Not too heavy on the weights - starting small and moving up gradually. Eventually I was able to climb a step unaided - that was fantastic as that meant that I no longer fell over going into any of the 4 pubs in my village! None of the pubs had been designed for a GBS customer.

Within a couple of months, I felt well enough to make a short trip to the University of Hamburg to attend a student conference. I had thought about giving up my studies but then decided that would be a cop-out.

In late May, 5 months after the GBS onset, I made a trip to Malaysia - to arrange fitting-out works to my new apartment in Penang, which I had purchased as my eventual retirement home. While in Malaysia, I went back to Assunta Hospital in Kuala Lumpur to say thank you to Dr. Raihanah and to let her, the nurses, the physiotherapists, and the cleaner know how I grateful I was for their care when I had been so ill. I also bought them the biggest box of chocolates I could find in Kuala Lumpur. Dr. Raihanah said the most important thing though was that I had gone back to say 'thank you' to them and that they could all see how I was recovering. She said the team don't often get the chance to see the really good results of their labours. I have gone back a few times since for that very reason.

In September 2013, my apartment was ready in Penang but I still had to complete my Masters' course. A few more courses to attend, a 2-month internship to arrange, and a thesis to write. So I was off again, with my satchel, to the University of Malaya and another group of young students who immediately thought I was one of the lecturers - not that they stood when I walked in the room.

I arranged an internship at the Myanmar Institute for Strategic and International Studies (MISIS) in Yangon for May-July 2014. I was MISIS' first ever intern - and probably one of the world's oldest interns as I was by then 61 years of age. I had a wonderful time in Myanmar and wrote various papers for them - Functional Cooperation in the South China Sea, Development of Financial and Capital Markets in Myanmar, and Health and Education in Myanmar. Two of the papers were published and they all got wide circulation within Myanmar Government departments. The months of July and August were spent writing my thesis 'Myanmar since 2011: Changing Priorities'. 1000 words per day was my target and achieved most days. I had already written the thesis in my head months previously but they wanted it down on paper, which was more of a challenge.

In late 2014, I learnt that I had been awarded a Masters degree (Dengan Cemerlang - with distinction). MISIS then asked me to work with them as a Senior Visiting Research Fellow, which I agreed to do on a pro-bono basis. It has been very exciting to be involved in Myanmar developments and activities as the country emerges from 50 years of military rule and economic isolation. The work has been interesting and is hopefully worthwhile. I have also made many friends in Myanmar and had the opportunity to travel through much of the country.

It was well over six months after the GBS onset before I had begun to walk confidently and the prospect of playing tennis again (my favourite sport) seemed a long way off. Indeed the first time I tried to play tennis - maybe 12 months after the GBS onset - I couldn't stay on my feet - still not enough sense of balance. That all seems a long time ago. I am now playing tennis twice a week, racketball twice a week and golf at least once a week. My tennis isn't quite as good as it once was. However, I get to play for the tennis group of the Penang Swimming Club in club matches and in the Penang International Invitational Tennis Tournament. In that tournament I played in the 120 Age Group Doubles category - each player having to be over 60.

When lying in intensive care in Assunta Hospital or in the ward in the National Hospital for Neurology and Neurosurgery, I realised how lucky I had been to go through almost 60 years of life without any serious illness or even a broken bone. You cannot help but notice people are dying near you in Intensive Care and that many people have really tough lives when living with serious illnesses.

I am very fortunate to have recovered as well as I have. Only three minor residuals - a crooked left little finger (I was told any operation will reduce my grip so net effect would be marginal at best); a bent right arm (I had botox injections to reduce spasticity and it is now almost straight - and I have an attractive right arm!); and I also told Dr. Raihanah that I find it more difficult to get up from sitting on the floor when previously I could spring up without holding on to anything - her response 'I suggest you don't go sitting on the floor'.

I remain so grateful to all those who gave me support when I most needed it - my friends, my family, and the professionals and others involved in my care and recovery. The quality of care and support and the generosity of spirit I experienced were so very special.

In 2016, I went on a 2½ month round the world trip - Hong Kong, San Francisco, and Chicago (where I visited old haunts and saw old friends from when I worked in these places). Then Toronto seeing a primary school friend and his family - I hadn't seen him for 27 years. After that a visit to Washington DC and 4 days of museums and a visit to Congress. I then had 3 weeks in the UK seeing my kids and other family and friends. My last stop was South Africa for two weeks visiting game reserves near Jo'burg and then enjoying beautiful Cape Town before coming home via Singapore.

Last year I also visited Thailand (Chiang Mai), Indonesia (Yogyakarta and Borobudur), Vietnam (Da Nang, Hue and Hoi An), Philippines (Manila, Cebu and Dumaguete), and (of course) Myanmar (Yangon). It is great to visit interesting places and I think I may now prefer the practical experiences of visiting South East Asian countries to any further formal academic study!

So, nearly 5 years on from the GBS onset, life is pretty good. It is perhaps a little odd but I do not regret that I had the experience. I now value every day of life and appreciate my good fortune even more than I did before.

Malcom on a trip to the Philippines in October 2016 and (right) enjoying a round of golf and taking part in Penang International Invitational Tennis Tournament 2017

Quiz Night in Penang

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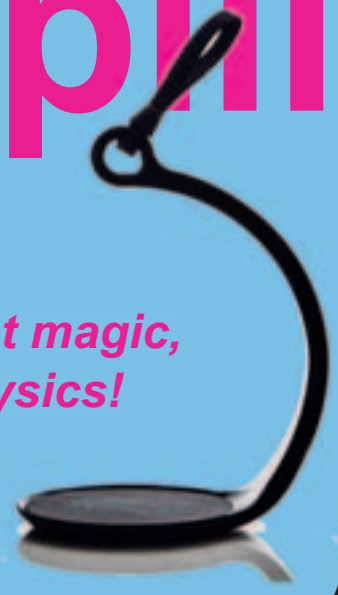
''This is such a genius invention. Three drinks plus biscuits one handed with my walking stick and not a drop spilt'' - Sonja

The incredible SpillNot



''It's not magic, it's physics!

May the Centripetal Force be With You! The SpillNot provides the ultimate solution for carrying cups of hot coffee and other beverages from room to room without ever having to worry about spilling them again.

With the SpillNot, the liquid in the cups does not spill or slosh in the cup, and the cup doesn't slide when carried or swung around.

- **Suitable for use by people with mobility or dexterity issues.**
- **Carry hot or cold drinks or soup**
- **Keep one hand free to hold onto a walking stick or bannister**

Available online from www.amazon.co.uk and eBay

The CEA Card is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA)

About the CEA Card

The CEA Card entitles a disabled person to receive a complimentary ticket for someone to accompany them when they visit a participating cinema.

The Card is also one way for cinemas to make sure they look after their disabled guests. If you require an adjustment to visit a cinema because of your disability, cinema staff should make them for you whether you have a CEA Card or not.

Approximately 90% of cinemas in the UK have signed up to the scheme, which was introduced in 2004 – check the website for a list of participating cinemas.

Who is eligible for a card?

Eligibility criteria may be updated from time to time; currently anyone who receives one of the following benefits is eligible:

- Disability Living Allowance (DLA);
- Attendance Allowance (AA);
- Blind Persons Registration;
- Personal Independence Payment (PIP); and
- Armed Forces Independence Payment (AFIP).

What does it cost?

The card is valid for one year, and costs £6.00, to cover associated costs (maintaining the website, processing applications and producing the card). With an average cinema ticket price coming in at around £7.49, you can be making savings from the very first time you use it!

How do I get one?

There are three ways to apply for a CEA Card:

Online

Visit www.ceacard.co.uk and upload a photograph and digital copy of your eligibility documents. You can pay online or by post

Part online – part postal

Complete the online form, print it off and post it along with your photograph and eligibility documents and payment (or pay online)

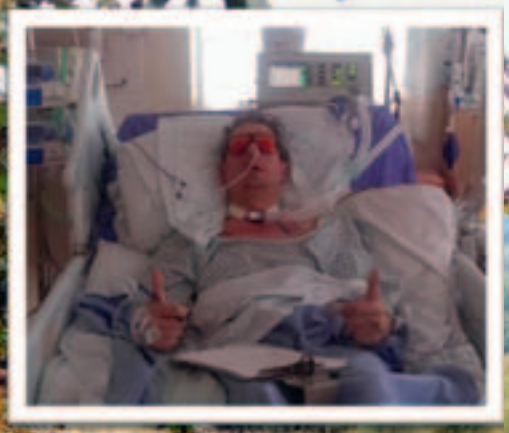
Postal application

Print the blank form from the website, complete it and post it with your photo, documents and payment

For full details and T&Cs visit

www.ceacard.co.uk

From blurred vision to paralysis in 48 hours



Phil Morgan tells us about his experience with a rare variant of GBS known as Miller Fisher

My mysterious illness began on June 14th, 2016. I started to notice my eyesight was becoming affected during the morning of that day. I found it difficult to focus and felt quite dizzy. I made a trip to see my optician late that morning as something was definitely not quite right. They detected nothing unusual but I went away a little unconvinced. Things got worse and I decided to get myself to see my GP later that day. Within hours I had severe double vision and felt very disorientated. The GP told me to go straight to A&E after a brief check with what looked like a bright torch into my eyes.

After a long wait to see a doctor at the hospital in A&E and some routine questions and checks, I was sent home around midnight that same day. I got a taxi but yet again I felt very concerned. Soon after getting home the A&E department had had second thoughts. I received a phone call and lucky for me was asked to return to undergo a CT scan. They suspected something but I was not sure what at this stage. I waited in a hospital bed for most of the night while the CT scan staff prepared the machine. The test eventually revealed nothing. I was taken to a bed in the stroke ward at Halifax and Calderdale Hospital where I was monitored for that following day.

The next day my condition was changing. I spent a number of hours in the hospital bed noticing a slow deterioration to my speech, lip movement and ability to swallow. I also begun to feel pins and needles in my hands. Jan, my partner had arrived by now and she went to discuss the symptoms with the staff nurse. At this time neither the doctor on call or staff nurse had a diagnosis other than the stroke consultant suggesting that it was stress, and I should go home as he could not help.

Jan and I knew there was something much more serious going on and asked for a second opinion. Lucky for me, Jan was previously a nurse and because of this she was determined to get a correct diagnosis as I lay in bed feeling quite anxious. My eyes had become very sensitive to light and I had already asked Jan to bring my sunglasses into hospital. My pupils had become fully dilated and my eyes were struggling to deal with daylight in the room. I also needed help to get up to the bathroom as my legs had become very weak and I had real difficulty moving without help. Within 24 hours I could not move my head and legs and my arms had become weak. I was in a state of 'undiagnosed limbo'.

After various visits from doctors, consultants and nurses at my bedside the next day I was taken for an MRI scan. The magnetic pulse 'bangs' all around my head, which was fitted inside a glass helmet were extremely discomforting to me under the circumstances. These tests are pretty awful even with all your faculties! Later on that day I found that the scan revealed nothing which was a good thing, but it did mean the undiagnosed limbo continued.

The evening of the second day in hospital, I was relieved to have a visit from a consultant neurologist and he carried out some basic reflex tests to my arms and feet. They didn't react at all, I had no reflexes and at this stage a diagnosis was made. I had Miller-Fisher syndrome which is a rare variant of Guillain-Barré syndrome. A blood test was taken before the decision to administer immunoglobulins (antibodies) was given to treat my condition. I had not heard of this illness at all before, Jan had heard of Guillain-Barré but not this rare form. We were both very worried and Jan knew as it turned out how long it can take to overcome this illness.

I could no longer support my head, my eyes were closed and wouldn't open, I couldn't talk, had no ability to move my head, had limited movement to my arms, no grip and my legs were heavy and

I was told that it was possible to make a full recovery. I tried to believe this and tried to stay positive

difficult to move. I had become almost paralysed within 48 hours. I later found out that Miller Fisher was a very rare syndrome which is only seen in 1 in 1,000,000. The neurologist had never seen this variation before, but had experience of Guillain-Barré, the more widely known syndrome, which, is a paralysis which starts in the limbs rather than the eyes (in my case). Both are similar and both can cause paralysis to the whole body. The big question at this time which I needed to know was, am I likely to get better?

I was told that it was possible to make a full recovery. I tried to believe this and tried to stay positive. By this time, I was very tired as I had not slept for 48 hours but was not likely to get any sleep that night either. My normal function to swallow wasn't naturally occurring. This simple function we all do much more often than we think was causing me some distress. The saliva built up in my mouth, had nowhere to go and I had to sit forward all night which was pretty gross! Jan requested a doctor to have another look at my condition and in the small hours of the night it was decided I had to agree to a tracheostomy. It was my worst nightmare as I really didn't want this, but had no choice. I was quickly put to sleep with an injection and woke in a brightly lit room. I seemed comfortable at first as I came out of the anaesthetic and slowly regained my memory of events.

I came around fully and felt like everything was hurting as I heard the assisted breathing machine pump on my left working away to assist my lungs. My diaphragm had become paralysed and the tracheostomy allowed me to breath. I had a feeding tube into my nose and a catheter downstairs, so was fully plumbed in. I wasn't going anywhere, even if I wanted to! My eyelids were fixed shut and I had no vision but fortunately I had slight movement in my arms but only a fraction of my previous strength. It was a real struggle to deal with the shock of this new situation and I felt as if the adrenaline was pumping. I used what movement I had in my right hand to communicate by writing/scrawling.

I was administered immunoglobulins over three days at a high dose. The doctor had decided this was necessary as my condition had got significantly worse in the first days. It is normally provided over a longer period and at a lesser dose. Immunoglobulins are given to counteract and stop the spread of the illness. The illness is a result of my immune system deciding that my peripheral nervous system should be attacked. The attack on my nervous system had eroded the myelin sheath cover which surrounds the nerves. Arrival of signals to my muscles and senses was no longer happening, so causing paralysis. The immunoglobulins seemed to stop my paralysis becoming total.

I was by now experiencing some pretty horrendous pain as you can imagine. My nervous system was under attack which meant I had a cocktail of painkillers at regular times throughout the day. In fact, I asked for pain relief every few hours, but was told I had received the maximum regularly throughout my stay in hospital. My tracheostomy was also a real challenge to maintain and initially the nurses had to assist with this maintenance. Without going into detail, it was a pretty disgusting piece of equipment but I couldn't do without it. Over the next few days while lying in bed I was regularly testing my movement. I could move my hands and had slight movement in my toes which ever so gradually improved. I managed somehow to make very slow improvements.

Visits from family, friends and work colleagues gave me a great deal of support and gradually I started to regain slightly more movement as this first week in intensive care passed. I did however take a turn for the worse as I contracted a chest infection and had to have a course of antibiotics which did make my health more perilous. I struggled through and progress was slow. The consultant neurologist, a Doctor Henderson decided that a new course of action was required. After making contact with other specialists in this field he prescribed plasmapheresis. He wanted my decline into Miller Fisher to be stopped as soon as possible.

After I had a central line fitted to a main artery at my shoulder blade, the dialysis nurse visited with the mobile equipment required to carry out the treatment. My blood was removed and spun in a centrifuge to remove the plasma and then new plasma was added in the process. This went on for what seemed like a couple of hours and made me very tired and so I usually slept for a good while afterwards. This was done over a period of two weeks. I had seven plasma exchanges over that two weeks which floored me completely. By now my blood was renewed and this did make an improvement on my condition and so began to make very slow improvements. Over the days following the treatment I began to get some movement back, and one of my eyes slowly started to open. The improvements occurred at a snail's pace as the covering to my nerves was regenerating. I had now been in the intensive care ward for around four weeks and I was convinced that I could get myself back to where I was before this nightmare started.

As the days rolled into weeks, I managed to sit up in bed more easily and had partial sight, if a little blurred in one eye. My sight was affected quite badly and even to date has not fully recovered. I had a daily physiotherapist who visited me and encouraged me to perform varying degrees of movement until I could eventually manage to take the weight of my head again with my neck muscles. This improvement was a big milestone in my recovery as not being able to do this caused me much discomfort. In time I began to sit in a bedside chair and eventually stand and then walk again!

During the whole ordeal, I was left with one ability which I never lost. I was lucky that I did manage to communicate by writing or should I say scribbling which formed my only means of communication. The struggle to get back to normal continued for the following months. I was now able to maintain my own tracheostomy which was good. Clearing 'the plumbing' as I called it was necessary. Over the next few weeks I slowly improved in the intensive care ward. I eventually took a shower and was able to sit in bed watching television (with partial sight). It was decided after two months that I was to be transferred to Huddersfield HRI. I stayed in my local hospital for three weeks and continued to make slight improvements. By the end of my stay there I could walk and exercise daily on my own. I was up and about getting to the bathroom and taking a shower on my own. I had my tracheostomy and feeding pipe removed, more steps towards my independent recovery. Breathing without the tube felt good and I managed to maintain my airway. Swallowing on the other hand was another story. The muscles in my throat and tongue were affected for some time and as there are numerous nerves in the face, it took a long time to get these working properly. As soon as I could swallow water and liquidized food I was

Phil with his wife, Janet, sporting their GAIN T-shirts

able to leave the hospital. The real recovery now began, without the support provided by the NHS. At home, I maintained my pain medication and continued with facial exercises to get my full movement back. I even started a regular full body yoga regime! My ability to eat and talk had been severely affected but over the months at home I made steady progress. Soup slowly tuned to solid food and chewing was now an option and the sensation of tasting food again felt like a miracle. In fact, the whole recovery seemed miraculous!

I eventually came back to work on phased return approximately six months on from contracting this illness. The recovery however, still continues. Facial spasms persisted for up to twelve months and now I can just about whistle again(!) and feel extremely lucky to have gained an almost full recovery. I still have the pins and needles in my hands and I have to wear spectacles full time as well.

I feel like my face doesn't quite work how it did but I am lucky, very lucky and living proof that it is possible to come from such a debilitating illness to almost full recovery! If you are recovering from Miller Fisher or you know someone who has this illness, it is one of the hardest journeys but never give up hope, you will get there!

Phil's Slei Gill and Booze Moor walk for GAIN

Walking 10 miles in the Yorkshire Dales for Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) because I can walk again!

Miller Fisher syndrome is a terrifying illness that required a couple of months in intensive care and many months recovering at home, struggling to regain the power to do normal everyday things. At my worst I was on life support, paralysed from my chest up with severe weakness in my limbs. My pupils were fixed and dilated so maximum light was entering my eyes for months on end.

Now it's time to give back and make something good out of a bad experience. I have chosen GAIN because they provide support and hope when you think there is none. I hope that I can make a contribution towards less suffering in the future for those affected.

gain2gether local

yorkshire

Autumn 2017

The Yorkshire Group meeting was held at its usual location, the **Boothroyd Centre, Healds Road, Dewsbury Hospital.** We started with some very sad news; the death of one of our members, Clive Hubert. His wife Shirley kindly brought a cheque for the amount of £385 for GAIN from the donations at his funeral. The speaker for this meeting was Mr Stephen Dunn of Jones Solicitors, Retford. He spoke on such matters as Power of Attorney for finance, and health and welfare. On care home fees with respect to such things as properties being sold or not! He also spoke about Grant of Probate and Grant of Letter of Administration. Stephen was an excellent speaker; everything was in plain language, and it was one of the most interactive meetings we have had for some time, although it was a pity our numbers were so low at this meeting. The photograph below is of Stephen Dunn and his son Isaac when we presented him with a book voucher, as a thank you for coming.

After Stephen's talk, we broke for refreshments and to allow our members to chat, and to buy the new merchandise and raffle tickets.

Spring 2018

The Dewsbury meeting was finally held on the 8th April after being cancelled originally due to SNOW!!!

We began with our financial report and decided to send a donation of £200 towards GAIN funds. There was a reasonable attendance to our social gathering; everyone brought food which gave us a lovely buffet, which went down well. We held our usual raffle and had cards and GAIN merchandise for sale.

Everyone enjoyed themselves and seemed loathe to part. The date for our next meeting will be 21st October 2018 at the Boothroyd Centre, Dewsbury Hospital.

L to R Isaac Dunn, Stephen Dunn and Susan Booth

south west england

A small group of members got together in October 2017 in Bovey Tracey, Devon. Our guest speaker was Ruth Wells CEO of MIND Exeter and East Devon. Ruth gave a very interesting talk explaining why severe illness resulting in profound life changes, pain, or physical impairment may increase the likelihood of mental health difficulties such as anxiety or depression. She identified some of the warning signs and gave advice on what one could do to improve mental health well-being. Her advice to anyone with concerns would be to contact their GP or charity mental health organisation. The national MIND office can tell you where your local branch is and you don't need to have a "mental health issue" to phone them for a chat. It is also good if one can talk to trusted family or friends. There are other local organisations that can help in Devon, and the Samaritans operate nationally. We are very grateful to Ruth for giving up her sunny Saturday afternoon to increase our awareness and understanding of these issues. As usual we rounded off the afternoon with tea and homemade cake, a raffle, and the sale of GAIN Christmas cards.

10th March 2018, Saltford Golf Club

On Saturday 10th March the South West branch met at Saltford Golf Club, and we were joined by William Harmer, one of the Trustees and a surprise visitor, Sir Ian Macfadyen, the charity's Patron. It was a real pleasure to welcome them both to our meeting. William began by outlining his GBS story and explained why his experience persuaded him to try to help others suffering from the same condition. He then updated the members with an outline of changes that are being made to the everyday running of the charity.

The new data protection act has big implications for all charities. Members must now give consent before being sent information, new policies have to be written, branch rules need amending and there are serious implications for volunteers who breach the new regulations.

A wonderful legacy has meant that the charity can now build a new office. It is to be named after Glennys Sanders, the founder, and hopefully will be opened on October 6th at the AGM. Construction is well underway in Sleaford.

There are several other innovations. The logo 'GAIN' now has a broken myelin sheath and a neuron, there is a splendid new mascot – Moxie the tortoise, a new website is coming and there are several new additions to the sales items. William brought some of these items with him and they were very well received.

New technology has changed the way people need support. At one time volunteers visited hospitals on a regular basis, but now there is ready access for information using a computer. People appear to need far less face-to-face support, although they still like to talk to the volunteers while not needing a visit. There are other things that volunteers can do to help so please ring the office for further information!

After William had outlined the above, Ian spoke to the group about his story. This prompted quite a lively discussion about symptoms and experiences. During tea and biscuits there was a raffle and an opportunity to buy some of the sales items that William had brought. It was a most enjoyable meeting where people met old friends and made new ones.

The next meeting is on Saturday October 27th 2018 at Nine Springs Natural Health Centre, Yeovil, BA20 1UR. Our guest speaker is to be Jane Robinson, an acupuncturist. The meeting will be between 2pm and 4pm and everyone is welcome to join us.

lancashire & cumbria

The Lancashire & Cumbria branch of GAIN get together four times each year to share support and information over a cup of coffee (and more often than not, a slice of homemade cake).

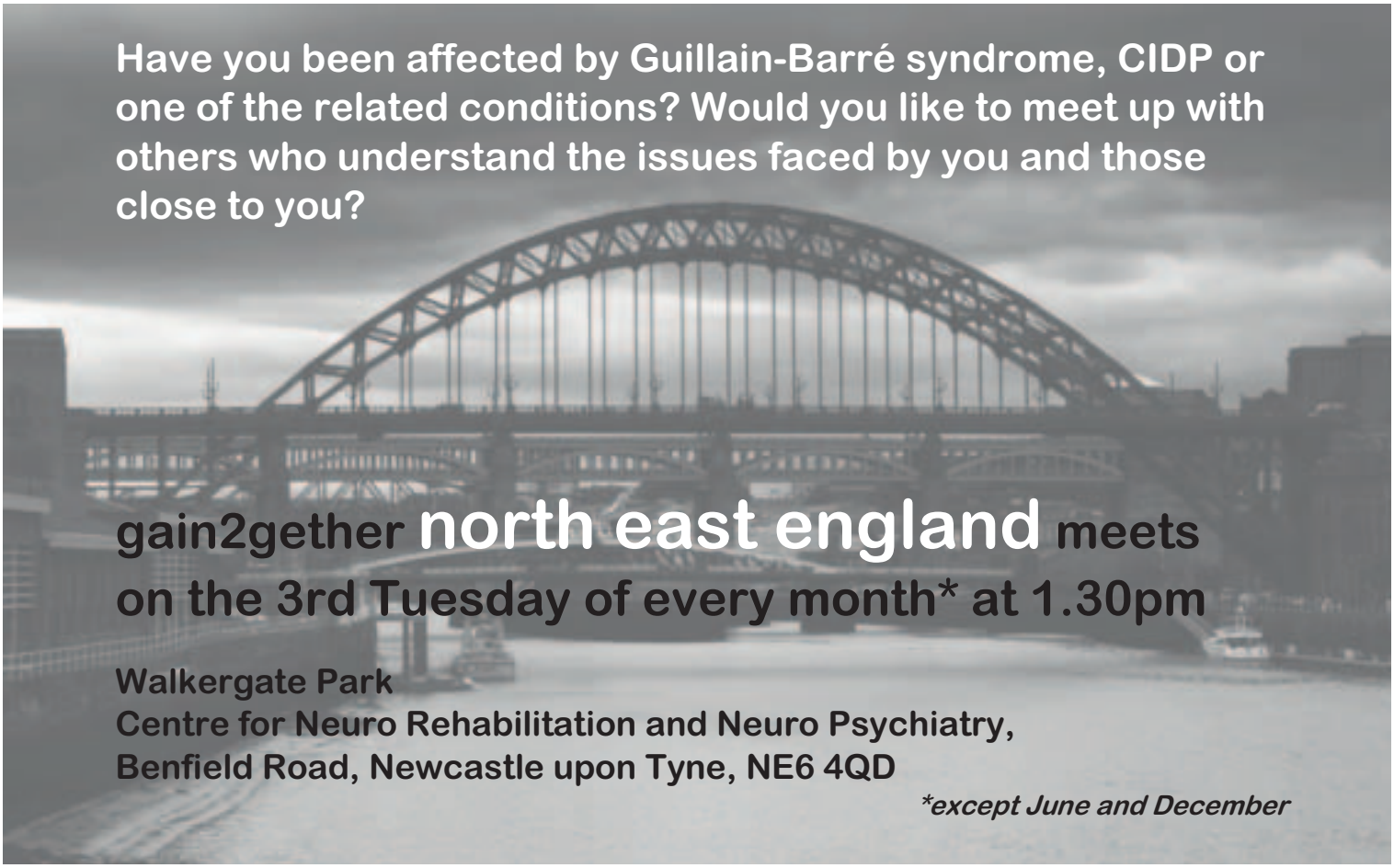
2018 diary dates

Saturday 15th September
Speaker

Saturday 8th December
Christmas Party with Tortoise Drive and Jacobs Join

Meetings take place from at 2-4pm at Bilsborrow Village Hall, just off the A6, north of Preston.

You can be sure of a warm welcome - come along and join us!



In memory of Alan Ross 1944-2017

Alan Ross, formerly treasurer of the Guillain-Barré Syndrome Support Group, died suddenly on 3 December 2017, aged 73, while on holiday in Cyprus with his wife Kay.

Alan was diagnosed with GBS in 2002 and was treated in the Western General Infirmary in Edinburgh. After recovery he became a local contact in the Lothians and Borders. In April 2002 he was elected treasurer of the Group, serving for four years. With his background in accountancy his election at the same time as Andy Leitch became chairman was fortuitous. The charity's finances were not in a good shape and he worked hard to ensure that they were put on a sound foundation. Alan's support for, and advice to, Andy was vital as he introduced the necessary governance measures to bring the charity into the 21st century. He was a pleasure to work with. He was never afraid to speak his own mind, but at the same time one was always conscious that here was a man of the utmost integrity.

Alan (centre), pictured with wife Kay, and Andy Leitch

Alan Ross was born and brought up in Renfrew, just west of Glasgow. On leaving school he became an apprentice accountant in Glasgow, qualifying in 1969 when he moved to Australia, joining an accountancy firm there. Alan had met his future wife, Kay, just before he started his apprenticeship, at an international church camp. Kay was Australian, and they corresponded while he completed his apprenticeship and got married after he moved to Australia. Their two children, Morag and Callum, were both born in Australia where he had become a partner in his firm. However, a call to the ministry meant a move back to Scotland to study theology at St Andrews. Following graduation, the family moved to Kenya where Alan was employed by a major accountancy practice specialising in dealing with clients handling foreign aid. He was very active in the life of the Presbyterian Church of East Africa and preached in a parish situated in an industrial area.

The family left Kenya in 1988, returning to Scotland where Alan was ordained and inducted into a parish church in Annan. He proved to be a visionary and innovative incumbent introducing new forms of worship, and his congregation multiplied. After the Chernobyl disaster he galvanised his congregation to organise and dispatch two lorry loads of supplies to help the victims. It was a measure of the respect in which he was still held by members of the congregation that a coachload of them came to his funeral.

Alan took early retirement in 1997, but his dedication to his vocation meant that he continued a part-time ministry undertaking the pastoral care of some small rural parishes near Lockerbie in Dumfriesshire. On retirement he and Kay moved to Ettrickbridge, a small village near Selkirk where they became pillars of the community. Amongst many other things he was treasurer of the community hall for 19 years. He had a wide range of interests and was never at a loss to reach out to others around him. While never afraid to defend his corner, he always tempered it with a gentle sense of humour.

Over 200 people from all over the Borders and further afield attended his funeral, with standing room only in the church and neighbouring school hall. Many messages of condolence also came from Australia and Kenya where he was still remembered with great affection.

Andy Leitch adds:

It was a profound shock when Jamie telephoned Maggie and me with the very sad news of Alan's untimely passing.

Having first met in a hotel at Liverpool Airport, I believe our first committee meeting was at a hotel at Glasgow Airport, not far from Renfrew where Alan grew up.

After Alan had studied the charity's financial situation, he realised that its expenditure was greater than its income and he introduced tough but necessary fiscal controls. Every year he would send me the draft financial return for the annual report and I had to learn how to understand the figures. As I was able to help him in my little way, he responded in spades by supporting my efforts to move the charity forward.

Maggie and I met Alan and Kay a couple of times after he retired from the charity. A few years ago, we spent two holidays in Scotland and arranged to meet up as we travelled back south. On the first occasion, we dined with them on a Saturday evening at a local hostelry and met up with them the following day at Ettrickbridge Kirk. The usual minister was away, and Alan took the service. The welcome and the atmosphere in that little church was wonderful and we think about it often. It was clearly obvious that both Alan and Kay were highly loved and respected by the community in which they lived. The second occasion on which we met, they would probably have preferred to forget for they both failed to turn up for dinner in a hotel that they had arranged! I believe they had retired to bed when they got our phone call and a little later they turned up somewhat embarrassed. Nevertheless, we had a wonderful evening and it is fitting that our last memories of Alan are ones that we will never forget. It had been Alan and Kay's intention to holiday here in Llandudno sometime in the future but alas this was never to be.

I am profoundly grateful for Alan's support and guidance. GAIN would not be the successful charity it is today but for Alan's financial acumen. We all owe him and Kay, whose support for Alan was total, a huge debt of gratitude.

Your letters

A success story

Dear Editor,

I was diagnosed with GBS on 26th April 2016, taken to Grantham Hospital for 2 days and to Queens Medical Centre, Nottingham for 14 weeks.

I went to critical care centre twice for a few days each time and had a tracheotomy because of my respiratory condition.

When the medical staff were satisfied, I was transferred to Ashby Ward, Lincoln Hospital for rehabilitation.

From the very first day I received excellent treatment both physio and occupational therapy. The food was good, and being a small ward, I received excellent care and encouragement. I left Lincoln after 9 weeks, being able to walk with a frame around my bungalow. I was told my recovery was very good and quicker than they expected. I have the highest regard for all the staff; I wrote to both hospitals and told them this and I received very full and grateful replies. I am now walking 1 or 2 miles each week, have started cycling again, done some gardening and am driving a car again after renewing my driving license.

The only weakness is in my hands, and smaller fingers not being very straight. I am so grateful and pleased with my outcome after a very negative prognosis while at Nottingham.

My medical details I assume will be recorded at the hospitals, but I thought you might like to hear of a positive outcome. I met Adam Pownall [Vice Chair, GAIN Board of Trustees] and saw his drama, 'Getting Better Slowly' – excellent.

Yours faithfully,

Jack O'Dell

Poetic contemplations

Yes, GBS may have left me infirm
But there's nowt I can do about that
'Cos today, instead, I feel quite in form
With the sun beating down on me hat.

But the vodka and tonic and tapas for two
Has worked wonders from inside me 'ead
My only annoyance as I sup down the glass
Is why won't it work on me legs?

Phil Graham

'on holiday and reflecting on how much my condition has improved, but with still some way to go'

Please email us at **gain4all@gaincharity.org.uk** or post your letters to;
GAIN, Woodholme House, Heckington Business Park, Station Rd, Heckington, Sleaford, Lincolnshire, NG34 9JH

Here at GAIN, we do our best to provide the information and support you need, even if that means signposting you elsewhere

These are a few suggestions for other organisations who may be able to help

www.carersuk.org

Helpline
0808 808 7777
10am–4pm Mon & Tue

Carers UK

www.carers.org

carerstrust
action · help · advice

money & benefits, support for young carers, health & wellbeing, working & learning, out & about, getting a break, legal & rights

Helpline open 7 days a week NHS

Carers Direct
Information, advice and support for carers

You can call the Carers Direct helpline on **0300 123 1053** if you need help with your caring role and want to talk to someone

Family Carers Ireland
Fairness for Carers

www.familycarers.ie

citizens advice

Benefits
Work
Money
Consumer
Family
Housing
Legal
Immigration
Health

www.citizensadvice.org.uk

Citizens Information
Phone Service
Mon-Fri 9am-8pm
0761 07 4000

Citizens Information

www.citizensinformation.ie

contact For families with disabled children

WE ARE CONTACT, THE CHARITY FOR FAMILIES WITH DISABLED CHILDREN

We support families with the best possible guidance and information. We bring families together to support each other. And we help families to campaign, volunteer and fundraise to improve life for themselves and others.

www.contact.org.uk

FacialPalsy UK
INFORM • SUPPORT • RESEARCH

Inform
Support
Research

www.facialpalsy.org.uk

Disability Rights UK

Advice / Information / Jobs / Volunteering
Projects / Programmes / Training

www.disabilityrightsuk.org

Cruse Bereavement Care
Somewhere to turn when someone dies

Helpline 0808 808 1677

www.cruse.org.uk

THE BRITISH PAIN SOCIETY

Links and information for people with pain

www.britishpainsociety.org/people-with-pain/

Chronic Pain Ireland

Information & support for people living with chronic pain

Self-management / Events & meetings
Support phone line / Online library

www.chronicpain.ie

Thinking about leaving GAIN a gift in your Will?

Don’t make it the last thing you do

Leaving a charitable donation in your Will allows you to support the causes that were important to you during your lifetime. So, don’t put it off, or leave it to your nearest and dearest to sort out after you’re gone.

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

Ask your solicitor about it, or to find a solicitor, visit the Law Society’s Find a Solicitor website and use the quick search option ‘Wills and probate’.

www.lawsociety.org.uk