

gain4all

For people affected by GBS, CIDP & the associated variants

Guillain-Barré & Associated
Inflammatory Neuropathies
gain4all issue 15
Winter 2019/2020 FREE



Introducing new
GAIN Ambassador

Lee Clark

YOUR STORIES

Dylan's story – a parent's worst nightmare
Mike Ralls - CIDP & me
David Stonehouse - recovering from GBS
Peter Woolsey – diagnosis debate

FUNDRAISING HEROES

From cakes to kayaking, you've been busy!

ALSO INSIDE

Updates from University of Lincoln
& our Medical Advisory Board
Hospital discharge
Applying for PIP
Mythbuster – flu vaccination
Recycle for charity!
Accessible breaks & scooter hire



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



Supporting you every step of the way
www.gaincharity.org.uk

Guillain-Barré syndrome is a rare autoimmune condition affecting the peripheral nervous system which causes rapid, ascending paralysis. Around 80% of people with **GBS** will make a good recovery, usually over many months, but between 5-10% of people will not survive, and another 10-15% may be left with severe disability.

Chronic variants such as **CIDP** are similar but tend to progress more gradually and require ongoing treatment, sometimes for life.

Approximately 1-2 people per 100,000 are diagnosed with GBS each year, and a further 1-2 per 200,000 with CIDP.

Getting a diagnosis of Guillain-Barré syndrome, CIDP or one of the variants can be an isolating experience, but it doesn't have to be. Get in touch and find out how we can help.

Visit our website or contact us:

Office **01529 469910** (Mon-Fri 9am-3pm)
Helpline **0800 374803** (UK)
 1800 806152 (RoI)
Email **office@gaincharity.org.uk**

Find us on social media   

GAIN is a registered charity, number 1154843 & SCO39900



Getting Better Slowly

Do you have a story you would like to share with our readers? Please email submissions for the next issue before **15th March 2020** to:

gill.ellis@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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Guillain-Barré & Associated Inflammatory Neuropathies is a registered charity, numbers 1154843 (England and Wales) & SCO39900 (Scotland)

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Get Involved

From Ironman to Best Man, we have a great bunch of people out there helping to raise funds and awareness for GAIN. We have stories throughout the magazine all about our **Fundraising Heroes**, so if you want to help but don't know where to start, we're sure you'll find some inspiration!

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Cover story – see centre pages plus p.20
Cover photograph:

Lee Clark with brother Michael, sister Kerry, and members of the GAIN team

2018-19 Annual Report

Highlights

For our AGM this year, we were delighted to welcome the full board of Trustees, plus several of our members, both in the room and remotely, via our new video-conferencing facilities. We were joined for the Members' Meeting by Chair of the GAIN Medical Advisory Board (MAB), Dr Jane Pritchard, and Professor Niro Siriwardena of the University of Lincoln. MAB members Dr Rob Hadden and Professor Hugh Willison also joined the Members' Meeting via video link.

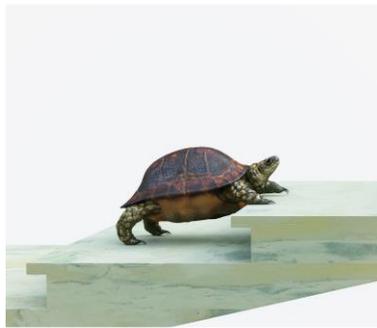
Key Highlights

- Investing in a purpose-built office
- Improved patient engagement

- More patient involvement in trials and studies
- Enhanced social media



GAIN Chief Executive, Caroline Morrice kicked off proceedings with an overview of the year, looking at what we've been doing to meet our three charitable objectives



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

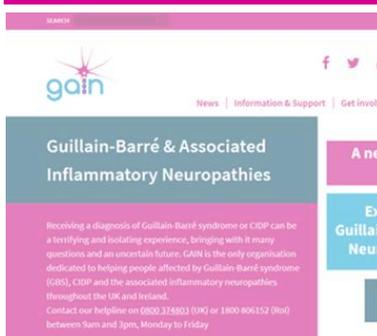
How did we help?

- We responded to 302 direct requests for support, putting 77 people in touch with a peer support volunteer
- 30,000 people visited the new website
- 2,000 people used the Facebook group
- We made 42 personal grants (£27,167)
- GAIN initiated a project to produce a series of exercise videos for patients

GAIN involvement in research

- Members have taken part in studies and trials for several different projects
- Funding offered for projects including HINT and EAN Global Guidelines
- Study commissioned with University of Lincoln to help determine future strategy for the charity
- Assisted pharma in pre-trial stage of several projects

2. Promotion of research into the causes, prevention and treatment of GBS, CIDP and the associated conditions



3. Advancing awareness of the charity and conditions

How did we do that?

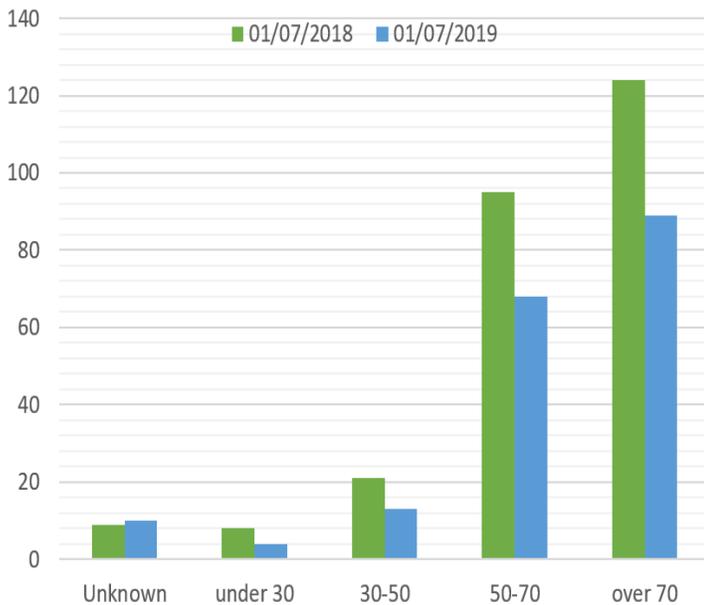
- New and improved website
- Direct contact with hospitals providing information packs for staff and patients
- Greater engagement through Facebook, Twitter and Instagram
- Welcoming Lee Clark as GAIN Ambassador
- Patient stories published in magazines, newspapers and on the website

What else is going on?

- GAIN Chief Executive regularly engages with
 - Specialized Healthcare Alliance
 - Neurological Alliance (as Trustee)
 - NHS
 - Rare Disease UK
 - NICE (National Institute for Health & Care Excellence)
- We have secured a Silver Bond London Marathon place
- GAIN has a free Will-writing partnership with McClure Solicitors



Age profile of voting members



A few challenges

- Increasing age profile of voting members
- Decreasing number of voting members, year on year
- Fewer people wanting to join Local Branches

Possible solutions

- Revisit the constitution type - is it still fit for purpose?
- Set up virtual branches using **Starleaf** and **WhatsApp** so that people can access meetings from their own home using a smartphone, tablet, desktop computer or laptop

Medical update from the MAB

Dr Jane Pritchard

Dr Jane Pritchard is a highly respected Consultant Neurologist with special interest in peripheral neuropathies and has been Chair of the GAIN Medical Advisory Board since 2015. Dr Pritchard generously gave up her Saturday to attend our Members' Meeting in October and present us with a medical update including new summary guidelines for diagnosis and treatment of Guillain-Barré syndrome, first results from IGOS (International GBS Outcome Study), IVIg commissioning in England, and the identification of CIDP clinical sub-types. Some of the content is shown here and overleaf, and the full set of slides is available on our website www.gaincharity.org.uk.

New variants of CIDP with pathogenic (i.e. disease-causing) antibodies

- A subset of CIDP patients have antibodies directed against the nodes of Ranvier and paranodal regions
- NF155 (neurofascin 155) antibodies associated with tremor, ataxia and IVIG response
- Anti contactin 1 ab associated with CIDP + nephrotic syndrome
- Acute onset CIDP can be associated with these antibodies
- Querol & Illa 2017 NF155 4.6% CIDP patients, contactin 1 in 6.2% of 65 CIDP patients
- These patients may respond to rituximab

Diagnosis

1 When to suspect GBS

- Rapidly progressive bilateral limb weakness and/or sensory deficits
- Hypo/areflexia
- Facial or bulbar palsy
- Ophthalmoplegia and ataxia

2 How to diagnose GBS

- Check diagnostic criteria
- Exclude other causes
- Consider:
 - Routine laboratory tests
 - CSF examination
 - Electrophysiological studies

Acute care

3 When to admit to ICU

- One or more:
- Rapid progression of weakness
 - Severe autonomic or swallowing dysfunction
 - Evolving respiratory distress
 - EGRIS >4

5 Treatment options

- Intravenous immunoglobulin (0.4g/kg daily for 5 days)
- Plasma exchange (200–250ml/kg for 5 sessions)

7 Early complications

- Choking
- Cardiac arrhythmias
- Infections
- Deep vein thrombosis
- Pain
- Delirium
- Depression
- Urinary retention
- Constipation
- Corneal ulceration
- Dietary deficiency
- Hyponatraemia
- Pressure ulcers
- Compression neuropathy
- Limb contractures

4 When to start treatment

- One or more:
- Inability to walk >10m independently
 - Rapid progression of weakness
 - Severe autonomic or swallowing dysfunction
 - Respiratory insufficiency

6 Monitoring

- Regularly assess:*
- Muscle strength
 - Respiratory function
 - Swallowing function
 - Autonomic function
 - Blood pressure
 - Heart rate/rhythm
 - Bladder/bowel control

8 Clinical progression

- Treatment-related fluctuation:
- Repeat same treatment
- No initial response or incomplete recovery:
- No evidence for repeating treatment

Long-term care

9 Predicting outcome

- Calculate mEGOS on admission
- Recovery can continue >3 years after onset
- Recurrence is rare (2–5%)

10 Rehabilitation

- Start rehabilitation programme early
- Manage long-term complaints: fatigue, pain and psychological distress
- Contact GBS patient organizations

Summary consensus statement

- Diagnosis and management of GBS in 10 steps
- Nature Reviews Neurology (2019) Sept 20th
- Expert authors from around the globe, including Royal Aberdeen Children's Hospital, Professor Hugh Willison and Dr Bart C Jacobs
- Designed as a globally applicable guideline

Key points

- Most patients reach their nadir in 2 weeks
- 20% develop respiratory failure
- 60-80% can walk independently at 6 months
- Recovery can continue for up to 5 years
- Recurrence remains rare (2-5%)

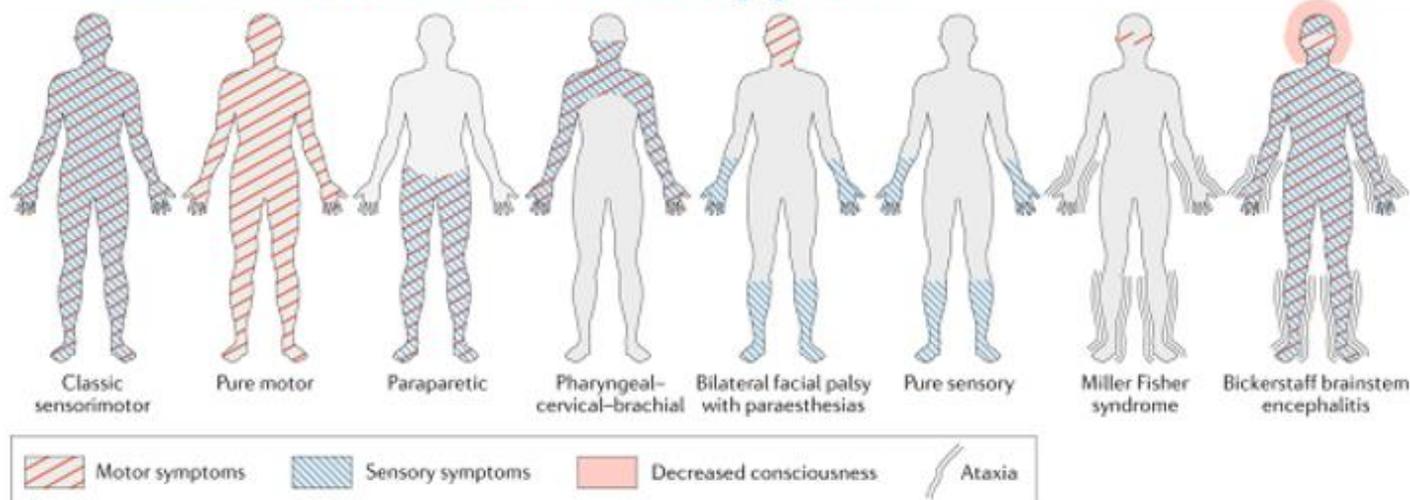
Starting treatment

- Inability to walk 10m unaided
- Rapid progression in weakness
- Severe swallowing or autonomic dysfunction
- Respiratory insufficiency - EGRIS score
- Predicts likelihood of the need for ventilation at one week based on weakness, speed of onset, and presence or absence of facial or bulbar weakness. Choice between IVIg 0.4g/kg/d for 5 days or 5 sessions of 200-250ml plasma exchanges

Treatment

- Evidence base is for IVIg in first 2 weeks
- Evidence base is for Plasma Exchange (PE) in first 4 weeks
- PE followed by IVIg is no better than either PE or IVIg alone
- Where patients have not responded to first treatment there is no evidence to support further courses being given

GBS clinical subtypes



University of Lincoln update

Professor Niro Siriwardena



UNIVERSITY OF
LINCOLN

Professor Niro Siriwardena is Foundation Professor of Primary & Pre-Hospital Health Care in the School of Health and Social Care, University of Lincoln. His research focuses on quality improvement and implementation science using a range of methods (systematic reviews, observational and qualitative studies, experimental methods and clinical trials) to identify important gaps in primary and prehospital (ambulance) healthcare provision, address these and make a difference to care and outcomes. He kindly attended our Members' Meeting to provide an update on progress on the research project his department is currently conducting on behalf of GAIN. An overview of some of the methodology is provided here, and the full presentation is available on the GAIN website www.gaincharity.org.uk

Team

- Community and Health Research Unit: Dr Joseph Akanuwe, Despina Laparidou, Dr Zahid Asghar, Prof Niro Siriwardena
- Lincoln International Business School: Dr Jennifer Jackson
- School of Psychology: Prof Tim Hodgson
- Lincoln Institute for Health: Dr Ffion Curtis

Introduction

- Systematic review and qualitative meta-synthesis
- Qualitative interview study
- Online self-administered questionnaire survey

Systematic review & meta-synthesis

- Review question: What are patients' experiences and perceptions of GBS and CIDP and its care at diagnosis, discharge and during recovery?
- We followed ENTREQ guidelines for enhancing transparency in reporting the synthesis of qualitative research (Tong et al., 2012).
- Review protocol was registered with the PROSPERO International prospective register of systematic reviews

Survey results

Characteristic		N	(%)
Sex	Female	130	(44.7)
	Male	140	(48.1)
Age	<18	2	(0.7)
	19-39	40	(13.7)
	40-59	96	(33.0)
	60-79	123	(42.3)
	80+	9	(3.1)
Ethnicity	White	264	(90.7)
	BAME	5	(1.7)
Marital	Single	5	(19.6)
	Married	168	(57.7)
	Other	45	(15.4)

Data synthesis

- We used thematic synthesis, following the Thomas and Harden (2008) approach.
- Six themes were identified:
 1. From uncertainty to hope
 2. Feeling lost in a changing life situation
 3. Fractured care
 4. Positivity towards recovery
 5. Adjustment
 6. Towards a new self

Qualitative interview study

- Interviews and data analysis completed
- Six key themes identified:
 1. Importance of early diagnosis
 2. Experience of inpatient care
 3. Active support for recovery
 4. Communication
 5. Awareness, knowledge and information provision
 6. Redefining recovery

Online self-administered questionnaire survey

No	Theme	Subtheme	Quotes
1	Importance of early diagnosis	Early detection/delayed diagnosis	"We went down to the doctors. He examined me and that was when he recommended I go straight to hospital; which I did and was admitted; and from day 1 they thought it was GBS." (P5:M). "They didn't find the GBS until I had the nerve conduction study. That was two months after the holiday." (P3: M).
		Misattributing symptoms	"First they thought it was meningitis or MS" (P2: F).
2	Experience of inpatient care	Delayed treatment	"...I think if I had had that treatment earlier, it would have been better" (P5:M).
		Positive/negative experience of care	"In the intensive care unit, there was a wonderful nurse. She was absolutely fantastic because I have got long hair, she would help me wash my hair; she would braid my hair to stop in getting tangled because I can just move my head a little bit: the back of my hair was getting tangled. She would wash and braid my hair. She would spend the most time with me to try and lip read me and spend time with me; but some of the other nurses where not as nice at all; very unpleasant." (P1: F).

Dylan was only three years old when he started to complain that his legs hurt. His mum knew it wasn't just growing pains, but it took a few days of fear and uncertainty before Guillain-Barré syndrome was confirmed.

A parent's worst nightmare

by Carina Whitehouse

Dylan's symptoms started with him kicking his legs around all night crying in pain, but we couldn't really understand the exact problem. He was only three and had nightmares, so we weren't sure if it was a really bad night or that something was wrong.

He woke up from a little bit of sleep and seemed fine but tired the next morning. He said his legs hurt but was happy enough and went to nursery.

When I collected him, he was as white as a ghost and said his head and legs hurt. The teachers said it had started in the last 10 minutes, but he'd been fine until then. I took him straight to the doctors who said it was growing pains. I wasn't convinced but took him home and the same happened all night.

Something wasn't right, it couldn't just be growing pains. Dylan stopped wanting to stand and became unable to weight-bear in his legs and so I took him to A&E.

They were convinced it was irritable hip, but they needed to rule out septic hip. After blood tests, x-rays, an ultrasound and an MRI where he had to be put under general anaesthetic, septic hip was ruled out. Dylan was getting progressively worse with time which ruled out irritable hip altogether.

The morning of Dylan's diagnosis, he stopped being able to pick up his apple slices with his finger tips and was pawing at them with his whole hand. He was now virtually horizontal in bed and having to be carried to move anywhere. He couldn't hold a drink and was in agony to be touched at all.

The Orthopaedic team handed him over to Neurology and Guillain-Barré syndrome was the suggested diagnosis. This was a week on from the first signs.

Dylan was moved to a room in front of the nurse's desk and we were warned that he may need to be ventilated if he got any worse. Dylan had nerve conduction tests which almost conclusively diagnosed GBS and ruled out the need for another MRI and lumbar puncture. Dylan started on Intravenous Immunoglobulin that evening through a cannular in his foot. His heart was monitored throughout the night.

It was the most horrific night, but he was so brave. The next day, there were signs of improvement. He had his second round that evening, a day off and

then the physio came to meet him. Hollie was amazing and Dylan bonded with her straight away along with the Occupational Therapist, Bronagh.

Over the following weeks Dylan had to learn to do a lot again - firstly just sitting upright. He couldn't sit on his bottom without being in complete agony. He had to learn to hold his fork, drinks and food again, to go to the toilet and later to walk again. He started by rolling, then 'army' crawling, crawling on all fours and then after 20 days, he took his first wobbly steps!

It took a lot of play to get him back to his full self, but you'd never know this had happened to him now. He never talks or asks about it, he just got on with it all as if it was just one of those things.

He has been signed off by the Neurologist as being recovered and hopefully it will never return. It's a parent's worst nightmare to see your child in so much pain and feeling so helpless to do anything to take it away. The thought of it returning is a worry but at least the signs will be more obvious. Dylan's strength throughout was so inspiring. Hopefully his story will help other parents going through a similar experience right now.

It took a lot of play to get him back to his full self, but you'd never know this had happened to him now. He never talks or asks about it, he just got on with it all as if it was just one of those things.



If your child has been diagnosed with Guillain-Barré syndrome, or one of the variants, GAIN can provide information and support, and put you in touch with other parents who understand the issues you and your family are facing.

You can phone during office hours on 01529 469910 or email us any time at office@gaincharity.org.uk



Children aged 2 or 3, pregnant women, people with long-term health conditions and those aged 65 or older should get their free flu vaccine

**HELP US
HELP YOU**
STAY WELL THIS WINTER



Richard Pile, GP

It's flu season again!

Protect yourself & STAY WELL THIS WINTER

For most people, flu is an inconvenience, requiring a few days off work, and they probably do not need to be vaccinated. However, for those in a high-risk group, such as over 65s or people with quite serious and ongoing health issues, including chronic neurological conditions, flu can be extremely dangerous and even fatal, and the NHS recommends these groups protect themselves against flu by having the seasonal flu vaccination. Although there is a very small chance of a vaccination triggering an autoimmune response, such as GBS, it is important to understand this small risk weighed against the potential consequences of not having a vaccination.

According to the Medicines & Healthcare products Regulatory Agency (MHRA);

'The balance of epidemiological evidence is not sufficient to confirm that currently used influenza vaccines are causally associated with the development of GBS. As GBS also occurs naturally in the vaccinated population, and particularly because flu-like illness is a known risk factor for GBS, a number of cases are reported each year in temporal association with vaccination. This does not mean the vaccine was the cause.'

Recent data supports the findings made in previous studies that an influenza vaccination may trigger GBS in fewer than 1 in 1,000,000 people vaccinated.

There were approximately 13,000,000 people vaccinated in the UK during 2017/18 and there were 10 reports submitted through the yellow card scheme for the same period.

'These may be true side-effects, may be due to concurrent diagnosed or undiagnosed illness, or they may be purely co-incidental events that would have occurred anyway in the absence of therapy. Based on current evidence, the MHRA findings are that these reports do not indicate a causal relationship between influenza vaccine and GBS.'

This is supported by independent research showing colds and **flu-like illnesses** to be relatively common triggers for GBS, with approximately 1 case of GBS triggered in 60,000 cases of flu. The **seasonal flu vaccination** by comparison is a very low risk trigger, with approximately 1 case of GBS triggered per 1,000,000 vaccinations, as stated above.

Vaccines stimulate the immune system, so theoretically this might lead to the appearance of an autoimmune disease. It is not currently possible to identify those for whom a vaccine might act as a trigger, or why, but what we do know, is that people most at risk from flu are better off protecting themselves from flu, and the best way to do this is to have a flu vaccination.

Seasonal flu vaccinations

Mythbuster

When am I most at risk from flu?

Flu circulates every winter and generally peaks in December and January. This means many people get ill around the same time. But it's impossible to predict how many cases of flu there will be each year or exactly when it'll peak.

Does everyone need a flu vaccine?

No, just people who are at particular risk of problems if they catch flu.

Ask a GP about having an NHS flu vaccination if:

- you're aged 65 or over
- you're pregnant
- you have a serious medical condition
- you live in a residential or nursing home
- you're the main carer for an elderly or disabled person whose welfare may be at risk if you fall ill
- your child is in an at-risk group and is aged 6 months or over

Why are certain groups targeted for the flu vaccine?

Complications such as **bronchitis** and **pneumonia** are more common in people with other conditions, especially if they're also older. In long-stay residential homes, vaccination helps prevent the rapid spread of flu among residents.

Is my child entitled to the flu vaccine?

Children eligible for the free nasal spray flu vaccine include:

- children aged 2 and 3 on 31 August 2019
- children in primary school
- children with a health condition that puts them at greater risk from flu

How long will the flu vaccine protect me for?

The flu vaccine will provide protection for you for the upcoming flu season. People eligible for flu vaccination should have the vaccine each year.

What type of flu vaccine will I be offered?

There are several types of flu vaccine. You'll be offered one that's most effective for you, depending on your age

Can I have the flu vaccine while I'm taking antibiotics?

Yes, it's fine to have the flu vaccine while you're taking a course of antibiotics, provided you're not ill with a high temperature.

How long does the flu vaccine take to become effective?

It takes between 10 and 14 days for your immune system to respond fully after you have had the flu vaccine.

If I had the flu vaccine last year, do I need it again now?

Yes. The viruses that cause flu can change every year, which means the flu (and the vaccine) this winter may be different from last winter.

Can the flu vaccine cause flu?

No. The vaccine does not contain any live viruses, so it cannot cause flu.

You may get a slight temperature and aching muscles for a couple of days afterwards, and your arm may feel a bit sore where you had the injection. Other reactions are rare, and flu vaccines have a good safety record.

For children, the nasal spray vaccine cannot cause flu because the viruses in it have been weakened to prevent this happening.

When is the best time to get my flu vaccine?

The best time to have a flu vaccine is in the autumn, from the beginning of October to the end of November.

If you have missed this time, you can have the flu vaccine later in the winter, although it's best to get it earlier.

Is there anyone who cannot have a flu vaccine?

Yes. You should not have the flu vaccine if you have ever had an allergic reaction to a flu vaccine or one of its ingredients. This happens very rarely. You also need to take precautions if you have an egg allergy.

Can I get the flu vaccine privately?

Adults who are not eligible for a flu vaccine on the NHS can pay for a flu vaccination privately. The flu vaccine may be available from pharmacies or in supermarkets. The vaccine costs up to £20.

Can I have a flu vaccine if I'm breastfeeding?

Yes. The vaccine poses no risk to a breastfeeding mother or her baby, or to pregnant women.

Is it OK to have the flu vaccine during pregnancy?

Yes. In fact it's important to get the flu vaccine if you're pregnant. It's safe to have at any stage of pregnancy, including in the first trimester and right up to the expected due date. It helps protect the mother-to-be and her newborn baby from catching flu.

For further advice on the seasonal flu vaccination, please visit;

<https://www.nhs.uk/conditions/vaccinations/flu-vaccine-questions-answers/>

Life after GBS Hospital Discharge



A diagnosis of Guillain-Barré syndrome can turn your life upside down. As an acute condition, the syndrome is only active for a maximum of six weeks, and sometimes less than this. Recovery however takes much, much longer, and people sometimes find themselves in hospital for many months before being able to return home. So what happens next? The NHS website has some useful information on what to expect during the hospital discharge process.

Being discharged from hospital

Each hospital has its own **discharge policy**. You should be able to get a copy from the ward manager or the hospital's Patient Advice and Liaison Service (PALS).

Once you're admitted to hospital, your treatment plan, including details for discharge or transfer, will be developed and discussed with you.

A discharge assessment will determine whether you need more care after you leave hospital. You should be fully involved in the assessment process. With your permission, family or carers will also be kept informed and given the opportunity to contribute.

What's meant by minimal or complex discharge?

If the discharge assessment shows you'll need little or no care, it's called a **minimal discharge**.

If you need more specialised care after leaving hospital, your discharge or transfer procedure is referred to as a complex discharge.

If you need this type of care, you'll receive a care plan detailing your health and social care needs.

You should be fully involved in this process.

A care plan should include details of:

- the treatment and support you'll get when discharged
- who will be responsible for providing support and how to contact them
- when and how often support will be provided
- how the support will be monitored and reviewed
- the name of the person co-ordinating the care plan
- who to contact if there's an emergency or things do not work as they should
- information about any charges that will need to be paid (if applicable)

You'll also be given a letter for your GP, providing information about your treatment and future care needs. Give this letter to your GP as soon as possible.

Medication

If you're given any medication to take home, you'll usually be given enough for the following 7 days. The letter to your GP will include information about your medication.

If you need to keep taking your medication, make sure you arrange to get a repeat prescription from your GP before your hospital supply runs out. Some surgeries require up to 2 working days (48 hours) notice for repeat prescriptions. If you're registered for patient online services with your GP, you could order your repeat prescription through the NHS website.

Your local pharmacy can help you get on top of your new medicines. Simply arrange a chat and ask for the New Medicine Service (NMS).

Medical devices

If you're sent home with a medical device, make sure you know how to set it up and have been taught how to use it.

Also, make sure you know where to get any supplies you need to use the device and who to call if you need help.

Organising transport

If you're being discharged, arrange for a relative or friend to collect you, or let the staff know if they need to make other transport arrangements for you.

Returning home

If you're returning home, make sure you have everything you need for your recovery. It may be helpful to ask a friend or relative to stay with you or visit regularly. If this is not possible, make sure you have plenty of food, drink and other essentials at home.

Sick notes

You may need a sick note or information for insurance companies or your employer. Speak to the nurse in charge of your ward if you need a form to be completed.

<https://www.nhs.uk/using-the-nhs/nhs-services/hospitals/being-discharged-from-hospital/>

Living with a long-term condition

Personal Independence Payment

Most people with GBS make a good recovery, and even many with a chronic variant such as CIDP manage the condition successfully and continue with their normal lives. For some, however, life does not get back to normal, and they may need to consider applying for a long-term illness or disability benefit such as PIP.

Citizens Advice can help you through the process.



If you need extra help because of an illness, disability or mental health condition you could get Personal Independence Payment (PIP). You don't need to have worked or paid National Insurance to qualify for PIP, and it doesn't matter what your income is, if you have any savings or you're working.

The main eligibility rules

To be eligible for PIP you must be aged between 16 and your State Pension age.

You must also:

- find it hard to do everyday tasks or get around because of a physical or mental condition - you can make a claim whether you get help from another person or not
- have found these things hard for 3 months and expect it to continue for another 9 months
- usually be living in England, Scotland or Wales when you apply
- have lived in England, Scotland or Wales for at least 2 years - unless you're a refugee or an immediate family member of a refugee

There are exceptions to these rules if you're terminally ill or in the armed forces.

Your illness, disability or mental health condition

PIP is not based on the condition you have or the medication you take. It is based on the level of help you need because of how your condition affects you.

You're assessed on the level of help you need with specific activities. It's hard to say if the level of help you need will qualify you for PIP. But, if you get or need help with any of the following because of your condition, you should consider applying:

- preparing and cooking food
- eating and drinking
- managing your treatments
- washing and bathing
- managing toilet needs or incontinence
- dressing and undressing
- communicating with other people
- reading and understanding written information
- mixing with others
- making decisions about money
- planning a journey or following a route
- moving around

The help you get may be from a person, an aid (such as a walking stick or guide dog) or an adaptation to your home or car.

If you're in a hospital or care home

You can claim PIP while in hospital or a care or nursing home, however it can affect when your payments start. If you're in hospital, payments start when you leave (unless you're a private patient). If your care home costs are met privately (for example, by you, a friend or family member) payments can start while you're in the home. Otherwise only the mobility component of PIP can be paid while you're in the home.

If you already get PIP, stays in hospital or a care home can affect your PIP payments.

You may be eligible for PIP if you're **under State Pension age (and over 16)** and need help with daily living activities or getting around, or both. If you're awarded PIP before you're of State Pension age, you'll continue to receive it after too. You can still make a claim if you're working.

- PIP isn't based on your National Insurance contributions and isn't means-tested, which means it doesn't matter how much income or savings you have.
- If you've reached State Pension age and have care needs, you should claim **Attendance Allowance** instead.

For more information or to find your local office, visit the Citizens Advice website;
<https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/PIP/>

Sally Haycock

Ironman Staffordshire 70.3

Thank you!

Sarah Ross

Great North Swim 2019



Having been diagnosed with Guillain-Barré syndrome in 2013, resulting in paralysis and hospitalisation for 3 months, I was fortunate enough to overcome this debilitating illness. On discharge from hospital I spent the next 3 months in a wheelchair and then over the next year I learned to walk again, first with the aid of crutches and then onto walking sticks.

I started running in 2010 and was determined to get back to it and with a lot of hard work, persistence and sheer bloody-mindedness I completed my first half marathon post GBS in 2015. Having successfully completed 2 marathons and other long-distance events in the last few years I was looking for a new challenge.

Last year I had to have some time off from running having been diagnosed with Plantar Fasciitis. It turned out to be a long 10 months, so I needed to look at another activity to maintain some fitness. I decided swimming could be an option but unfortunately, I hadn't swam since school days! So off I went to the leisure centre and I taught myself to swim. Once I became proficient, I went open water swimming and loved it! This then set a seed! Having watched the Brownlee brothers on TV over the last few years they inspired me to try a triathlon. Deciding to head straight for the deep end (excuse the pun!) I entered Ironman 70.3 Staffordshire. Why not? I can swim now; I can ride a bike and finally my plantar fasciitis is manageable. I have trained hard and respect the challenge I have set myself. Let's do this!! I am passionate about GAIN as they helped me and my family through some tough times, providing support when necessary. They also continue to raise awareness and support research into these conditions. Thank you for your support.

Postscript

Just wanted to say a massive thank you to everyone who has donated to this great charity on my completion of Ironman Staffordshire 70.3. This means so much to me as this charity helped myself and family out when we needed them most. In total with cash donations we have raised **£1520**. This far exceeded my hopes and wishes so thank you once again. By the way I loved every minute of Ironman and cannot wait until next year's event!!! Bring it on!!!! x

In September 2018 my sister, Kayleigh, went from a fit and healthy woman in her early thirties to being hospitalised and paralysed from the neck down plus facial paralysis on the left side of her face. This all happened and progressed in just a few scary days. This was a terrifying experience for her and her worried family and friends.

After numerous scans and tests Kayleigh was diagnosed with Guillain-Barré syndrome (GBS). None of us had heard of this condition before as it is it was rare, so when we found out what it was and that it could be fatal and life changing, it was obviously a massive worry and shock to all involved.

Luckily, she received great NHS care and the Neuro-Doctors were very quick in their testing and diagnosing this condition. Kayleigh started IVIG as soon as they could and started to slowly show signs of recovery. After many physically and mentally draining weeks in hospital, and 24 hours in critical care the treatment and physio started to help. Kayleigh started to feel a bit more herself, eventually came out of hospital and could walk and move around again but was still very tired with not all muscles working effectively. We are now 9 months down the line and Kayleigh still has residual symptoms which she could have for life. She still suffers with fatigue, and the left-hand side of her face which suffered paralysis is still slowly returning. Kayleigh is having facial physiotherapy and manages her fatigue with plenty of rest, vitamin B supplements and a very supportive family and friends network. She is doing amazingly well and still Getting Better Slowly.

Kayleigh normally likes to take part in endurance events to raise money for charity, as this wasn't possible for her this year I decided to raise money for GAIN by doing the 1 mile Great North Swim 2019. The swim was touch and go with a lot of weather warnings on the run up to the event with the water temperature dramatically dropping due to heavy rainfall. This made my nerves pretty bad but I knew I had to push them aside and crack on with the event, as I was doing this for my sister and GAIN. The day came and the vibe at the event was positive and cheerful, the water temperature at 13 degrees shocked me a bit but I completed the swim in a good time and thoroughly enjoyed taking part for such an amazing cause.

Hopefully Kayleigh will be back to full strength soon and can herself take part in events to raise money for this worthy charity.



Sarah (left and right) and with her sister, Kayleigh (centre)

Thank you!

*Dan & Carla on their
wedding day with
Dan's parents*



WeddingAid!

My dad, Steve Pickford had GBS in 1996 and we have valued the work of the charity ever since. He was so pleased when we chose to fundraise for GAIN at our wedding. He even included touching words about GBS in his speech. Carla and I both work for charities, but we knew GAIN was the charity for us because of the way that they changed things for our family for the better.

Guests donated on the day (including donations for song requests from our DJ!). We raised over £1,100 through cash donations, online to our JustGiving page and Gift Aid! We encourage readers to make giving to GAIN a part of any special occasion!

CIDP

and me

by Mike (Lou) Ralls



Guillain-Barré syndrome...

...Chronic Inflammatory Demyelinating Polyneuropathy...

...two conditions that I had never heard of until 25th June 2018

The week before this date, everything was normal. I was doing Spin classes at my local leisure centre and was over half-way through my training for my run in the Great South Run and pleased with myself as I had managed ten miles! Visiting a couple of National Trust properties, along with my part time working hours in the Prison Service, everything was a normal type week.

On the weekend before 25th, I went to work as per normal, but started to feel pain in my right leg which caused me to limp. I managed the 55-mile journey home and put it down to a sport injury ...maybe those ten miles were just a little too much! I got up on 24th June and headed back into work, but still had a slight limp...the pain felt just the same. I managed the 55-mile drive back into work, but as the day progressed the pain increased, and my mobility started to rapidly deteriorate. So much so, that my colleagues were stepping in, to help out with some of my duties. The pain was now increasing, and the limp was very pronounced to the point that I was dragging my right foot. Somehow, I managed to get to my car and set off for home.

I made it home, I don't know how.

Throughout the night, there was no relief from the pain, but it did not increase further. Mental note to self...ring the doctor in the morning.

On a Monday morning, trying to get an appointment with the GP is extremely difficult and I got turned down initially. However, my wife decided that I was going to see one! and she did "make it so" even though it was a sit and wait appointment.

This turned out to be the best piece of luck for me....as I had to see a locum. After a 40-minute wait, in I went40 minutes later, she had rung the hospital to admit me, with suspected GBS. She asked us to go straight to Queen Alexandra Hospital Portsmouth. Unbelievably, she had been recently studying GBS...what are the chances? However not understanding the severity of this condition, we went home for a cup of tea first!

I was to report to the Acute Medical unit in the first instance. I was expecting to have a quick examination and then be sent on my way.... I was soon made aware that I was going nowhere and that I was to have several tests. At this stage, the pain was quite intense in my right leg and mobility poor, but now my left leg was becoming immobile, although not too painful. At this stage I was issued with a walking frame.

Several general consultants performed reflex tests, pin prick tests, the normal pulse/temp's tests, and eventually I saw my assigned Neurologist.

I was treated with IVIG and after a short while I started to feel better and my mobility improved. I was sent home after a week.

I felt like I was improving at home, but after 5 days the pain started to come back and the tingling and numbness started to gain in my right leg again.

A call to the doctor, and they sent a nurse practitioner out to my home. She was there within 10 minutes and called for an ambulance to return me back to QA hospital.

I was re-admitted and this time things started to speed up...the pain was increasing further and my mobility was decreasing very rapidly. It had now started to move further up my body. Tests now included a lumbar puncture, Electromyography, bloods, and chest x-rays. A further 5-day treatment of Intravenous immunoglobulin and again, I started to improve slightly but 3 days after the treatment had finished, I went into full relapse. At this point, QA Hospital decided to move me to the main Neuro hospital down on the south coast...Southampton University Hospital.

Admitted to Southampton 14th July and by now, I could no longer walk, even with a frame. And so was provided with a wheelchair as long as I had chaperone nurses!

It was at this time that the tests increased greatly...bloods were taken regularly, lumbar punctures, more EMG's, CT scans, MRI's, no expense was spared, I had everything that they could throw at me. By now, my legs and torso and arms had become paralyzed. Spirometry tests were conducted every two hours, obviously now the concern was that it was now debilitating my breathing and affecting my lungs.

I am now at the stage that I cannot move on or off the bed and am now unable to feed myself or control my general body functions. At this stage I am not allowed to be moved from my bed and had to be turned every two hours to prevent bed sores. I am catheterized as I am unable to urinate. I am beginning to become a conundrum to the doctors as they could not understand why the IVIG would work for a matter of days and then I would relapse, yet again, and deteriorate further. They decided that the next course of action would be blood plasma exchange (plasmapheresis). This did not work either.



I started to improve slightly but 3 days after the treatment had finished, I went into full relapse

Again, I relapsed further. I was lucky, in as much as I could still breath unaided, but the numbness was starting to get deeper within my chest area. Up until this point, I had tried to be as positive as possible, which certainly helped, however now I felt like I was actually dying and asked the registrar if that was the case. By the way, I had built up a great relationship with this particular registrar and we could be brutally honest with each other, as that was what I asked for. Later he did tell me that at one point they were going to call the family in.

But I digress, and for now will condense my treatment, instead of giving a daily / weekly account...I was given in total 6 IVlg courses, each course was 5 days. I was given 3 lots of blood plasma exchanges. The question was asked...what next? What more could be done? It was then that they decided to throw everything at me...and for two weeks I was on an intravenous anti biotic (the strong kind), then blood plasma again and IVlg...topped off with 60mg of steroids on a daily basis.

Bloods were now being sent off to Porton Down. Throughout this, they informed me it was unlikely I would walk unaided again.... but I had news for them!!!

After this course of treatment...finally I started to improve without the usual relapsing. My Neuro Consultant told me that my condition was chronic and not acute and therefore CIDP and not GBS. Due to my constant relapsing.

From here onwards, I made gradual improvements with the help of the most fantastic neuro physios. They put my feet in casts to help prevent foot drop, they used hoists, wheelchairs and even at the earlier stage with them, used to wheel my bed outside the main entrance for fresh air--- it was really very hot last summer! I could write a book regarding what those incredible people done for me, but for now, I will just say that I had the best help that I could possibly have wished for.

I will say this, I am positive by nature but there were dark periods. I am human and they were intense but did not last long. I remember thinking that I was not going to survive this at one stage, and then on another occasion think...I will beat this, if it's the last thing I do!

So.... after nearly 4 months in hospital and after learning to eat and feed myself again, get around using a wheelchair initially and then crutches, learning how to do simple things with my hands, I am delivered into the capable hands of the Neuro Physio unit back at QA hospital for two sessions in the Neuro gym on a rehabilitation program. What these people do is incredible.

After twice a week hourly session for nine months, I have finally been discharged from Neuro physio. I am on a reduction plan with regards my steroids and have decreased my gabapentin down to next to none, from a total daily dose of 1200mg. Now that's the hospital part of my story. Of course, I could go on forever about all the things that happened in there. What I have not yet mentioned is the support I received from my family and friends, and what they went through too, but I will say this, I was lucky (if you can say that) and that was because one of my old working acquaintances was a recovering GBS patient and he found out that I had it too.



*They informed me it was unlikely
I would walk unaided again
....but I had news for them!!!*

By sharing his story with me and seeing how well he looked I could see that you do get through it and that things will get back to near normal, eventually (hopefully). I was made aware that it was going to be a very long process though.

I still get pain at times, I get tired, am clumsy and forgetful but I push myself through all of this....and now, can declare that I am running, (albeit not as good as I was 18 months ago) and have just increased my running distance to 6 miles.... in preparation for the Great South Run....and hopefully raise some much-needed funds for GAIN. (I did not put CIDP on my story as not many know of the chronic version.... including DVLA!)

At present, I find climbing stairs difficult and that is very odd, but my nerves in that area have probably been damaged. A nuisance really when I have to go up and down them on regular basis at work!

I have not been discharged from my two neuro consultants ...they are being extremely cautious with me, as we are not sure when my next relapse may happen. It could be months, or a year and it could be significant or not, that's the unpredictable side of this illness.

Before I finish, I just want to mention that I did assist with a research at Leicester University and that I will always go and speak to anyone in the local hospitals if asked to.... the scary part of GBS /CIDP is ...no one has ever heard of it, let alone know what it does, how it happens etc...what I do know though, is that it really does help to spread the word about it, to inform as many people as you can...and to let those who contract it, know that there really can be light at the end of the tunnel.



On the 9th of February this year, my incredible mother was admitted to Salisbury Hospital having begun to lose sensation in her feet. Later that day she was diagnosed with Guillain-Barré syndrome (GBS).

It is a terrifying condition, involving progressive paralysis of the body until treatment hopefully prevents further deterioration and the patient begins to steadily regain movement and feeling.

After being moved to Southampton Hospital's specialist Neuro ward, Mum began to receive treatment. It was successful and the paralysis plateaued before it was able to reach her chest and respiratory system. She spent just under two weeks there before returning to Salisbury Hospital to continue her recovery.

At first her recovery was focused on rest, allowing her immune system to recover, anyone who knows my mother will realise this was the toughest time for her as she hates to sit still! Soon, with the incredible support of medical staff at the hospital, she was able to start physio. Mum threw herself into every challenge she faced from improving her dexterity to her first steps, every time I visited, she couldn't wait to show me what she could now do. Her attitude was incredible to see and has been a fantastic inspiration for me, not just for this marathon.

After just under 2 months in Salisbury Mum moved to a carehome in Bramshott for 2 weeks before finally getting back home, 3 months after leaving. At home she kept on breaking down the barriers facing her, constantly pushing herself to get better and not settling one bit. She's now cycling to the shops on her own!!

On the 6th of October it is Mum's birthday and we are all going up to Scotland to celebrate this, along with her incredible recovery from GBS and me successfully completing the Loch Ness marathon that day. She still a way to go in her recovery before she's back doing park runs but there is no doubt she'll get there soon. Anyone who knows my mother, knows she is incredibly determined in everything she does and brave beyond belief, the past months have shown that to be more than true.

Mum and I chose GAIN as the charity to support as due to the rarity of the disease there is relatively little out there in the way of understanding and support. Our hope is that through this tough time for Mum and the family we might be able to bring some good out of it.

Our congratulations and thanks go to Jamie, who successfully completed the Loch Ness Marathon, raising donations totalling £4,312.20 plus Gift Aid for GAIN!



Jamie with Mum, Jenny

Anyone for tea?

Back in May, we invited people to help us mark GBS/CIDP Awareness month by hosting tea parties and bake sales. The lure of cream scones and cake seems to have done the trick, with lots of you getting on board with the idea, both during May and beyond!

Lee Clark with Matt Bloomfield who is still recovering from having had GBS in 2017



Here in the office, our brand-new GAIN Ambassador, Lee Clark joined us for a cream tea, along with siblings Michael and Kerry and around 50 other guests. A table load of scones and cakes were enthusiastically demolished, bringing in donations totaling £500.

Above; Lee (centre), Michael and Kerry with members of the GAIN team, Simon, Caroline, Gill and Chris



Afternoon tea with a difference! by Jill Rushton

With my mother in law's wishes fulfilled, donating her body to medical science at Keele University and requesting 'no fuss' upon her death, we, as a family, decided that we could not let her go without some way marking her incredible 90 years! As she very much enjoyed regular visits to our local hidden gem, Elford Hall Restored Garden, we decided to hold an informal



gathering in the form of 'Afternoon Tea' on Sunday, 1st September 2019. With over 100 family members and friends from all over the country and beyond, coming along, we shared memories, photographs and her infamous homemade cake recipes! Fine bone china tea sets and crisp white damask tablecloths with freshly cut flowers adorning the tables - it really did look amazing. An afternoon of friendship, love and laughter - we think she would have approved!

Always having a keen interest in GAIN and my role as a volunteer contact, along with my husband, we decided to make GAIN one of the suggested charities for donations to be made. Leaflets were displayed and questions asked - we spread the word too! To date, and to our knowledge, £260 was raised on the day which was Gift Aided with further donations being made online.

Her quiet, unassuming gift has not only helped with the training of doctors, nurses, paramedics, physiotherapists - indeed every aspect of the medical profession, but has encouraged others to support smaller, less known charities such as GAIN too!



Sarah Ross held a bake sale at work to raise funds and awareness for GAIN as well as swimming a mile in a very chilly Lake Windermere!

Sarah tells us why on p.14



Sophie Blackwell & her sister-in-law Beth (pictured) held a tea party and raised £200 in memory of Beth's 'Bamp', who sadly died after having GBS twice

Cupcakes complete with Moxie toppers!

Thank you!

BAKE!

Feeling inspired? Why not have a go yourself and start planning your own bake sale, tea party or picnic to raise funds and spread awareness!

May is GBS/CIDP awareness month, but you can throw your own event any time you like. Get in touch and we can supply you with a GAIN collection box, Moxie edible cake toppers and a Moxie tortoise-shaped cookie cutter to get you started!

Email your details to office@gaincharity.org.uk or give us a ring on 01529 469910 during office hours (9am-5pm Monday-Friday)



Sarah Clements of ACES Marketing in Effingham, Surrey threw a garden party in the summer, complete with tortoise-shaped biscuits made using our Moxie cookie cutter!

They obviously went down well with her guests, because GAIN received £160 in donations!



Barbara Mair's good friend Nikki became very poorly with Guillain-Barré syndrome in 2018, so throughout 2019, Barbara undertook not one, but FOUR Kiltwalks to raise funds and awareness for GAIN! Starting with Glasgow in April, Barbara then went on to tackle Aberdeen and Dundee, finishing with Edinburgh in September.

By walking 100 miles, Barbara raised £700 (£770 including Gift Aid) in donations from friends and family, which is increased by 40% (£280) due to the support of The Hunter Foundation.

This brings the grand total to a pure dead brilliant £1,050!



The Kiltwalk is the lowest cost platform to raise funds for what you care about. Thanks to the support of The Hunter Foundation, all of your fundraising will be topped up by 40%, so you can raise funds for the charity of your choice and **140%** of what you raise goes where it is needed most.

Find out more at www.kiltwalk.co.uk



GAIN Chief Executive, Caroline Morrice, also happens to be very involved with Inner Wheel, an organisation which supports many charitable projects, both here in the UK and internationally.

When Caroline spoke at their annual assembly in Cardiff, she happened to mention our 'little' crisp packet recycling scheme, suggesting that members might like to start **collecting crisp packets** on our behalf, and a collection point was set up in Cardiff with great results.

The ladies of Inner Wheel have embraced the challenge with enthusiasm, and now, Caroline comes away from every local and regional meeting with a car boot filled with boxes and bags exuding the aroma of salt and vinegar or cheese and onion!

A massive GAIN Thank You to all Inner Wheel members, along with their friends and families, who are collecting crisp packets to help people affected by GBS and CIDP. It really is very much appreciated!



Mrs Joan Fatchett, pictured above with Simon Johnson of GAIN, and SEVEN boxes of crisp packets collected by **Lincoln Inner Wheel Club**. Joan and her husband have since dropped off another load of crisp packets and are even getting other local organisations on board!

Eat crisps for charity *update*

Thank you all for your enthusiastic crisp packet collecting!

So far, we have sent in (from the office) **182.74 kilos** of crisp packets, earning the charity **£365.48!** In addition to this, crisp packets have been sent direct to Terracycle from schools, colleges and workplaces around the UK, proceeds for which will be paid direct to our bank account at the end of the year.

We are now rolling out a scheme to make it easier (and free) for people to send in their crisp packets.

If you can collect at least 6 kilos of crisp packets, we can email you a **FREE** courier shipping label. You then pack up your crisp packets in a box, print off and attach the label, and either drop the parcel off at your local UPS collection point, or go to the UPS website and arrange a free collection.

We know it sounds like a lot of crisps to get through (!) but if you can bring on board friends, family and neighbours, or maybe put a collection box in your workplace or local pub/café, etc, you might be surprised at how quickly they mount up.

As far as we are aware, this scheme is ongoing for the foreseeable future, so there isn't any timescale involved, provided you have room under your bed or in the garage for a small mountain of crisp packets to accumulate!

Please contact us for a label when you are ready to send your parcel as each label requested must be used within 15 days of our requesting it from Terracycle.

Thank you again and keep eating crisps responsibly!

This is a recycling programme run by Terracycle with support from Walkers



RECYCLE YOUR CRISP PACKETS!

Every year countless pieces of crisp packets end up in landfill sites across the UK. We are working with TerraCycle® to put an end to this enormous loss of resources.

The Crisp Packet Recycling Scheme allows us to recycle your crisp packets and prevent them from ending up in landfill.

Not only are you helping the environment, but the waste you recycle with us also helps to fund schools or organisations.



Drop off your waste at...



Your collection leader is...



The more you recycle, the more money we raise!

YES PLEASE 😊

Packets from any brand of potato crisps & related products (including outer wrap from multibags)

NO THANK YOU 😞

Crisp tubes and bags from non-potato crisps such as popcorn, pretzels, meat snacks, dried fruit, etc

Other recycling schemes you can get involved with

GAIN has joined four more Terracycle recycling schemes and we need your help!



Ella's Kitchen

Ella's Kitchen baby food pouches and snack packets

- Join programme; <https://www.terracycle.com/en-GB/brigades/ellacycle>
- Name GAIN as your charity
- Spread the word** to family & friends that you're collecting pouches, caps & packets
- When you have **at least 5 kilos**, pack them into a box, request a FREE shipping label and have your parcel collected or drop it off



The Pringles Can Recycling Programme

All sizes of Pringles tube plus seals and lids

- Spread the word** to family & friends that you're collecting Pringles crisp tubes (plus the seals and lids) for GAIN
- When you have at least 1 kilo (approx. 20 large tubes), email GAIN and we will send you a FREE shipping label
- Pack your tubes in a box and have it collected or drop it off at your nearest UPS location



The Ring Carrier Recycling Programme

All flexible plastic ring carriers used to hold cans

- Join programme; <https://www.terracycle.com/en-GB/brigades/ringcarrier>
- Name GAIN as your charity
- Spread the word** to family, friends (& local pubs, etc) that you're collecting ring carriers from drinks cans
- When you have around a kilo, pack them up and request a FREE shipping label



The RB Hygiene Home Recycling Programme

Dishwashing, cleaning and fragrance flexible packaging

- Join programme; <https://www.terracycle.com/en-GB/brigades/rb>
- Name GAIN as your charity
- Spread the word** to family & friends that you're collecting
- When you have around a kilo, pack them into a box, request a FREE shipping label and have your parcel collected or drop it off at your nearest UPS location

A portrait of Lee Clark, a middle-aged man with short grey hair, wearing a dark sweater over a white collared shirt. He is looking directly at the camera with a neutral expression.

GAIN ambassador

LEE CLARK

talks about the loss of his father to Guillain-Barré syndrome

Lee Clark, professional football manager and former Premier League player, tells us about his family's experience with Guillain-Barré syndrome.

Lee starts by recounting the beginning of his father's illness, and how it progressed.

Well it was December 2017 and my father had been diagnosed with cancer and one of the options of him surviving and getting through that was to get his voice box removed. He spent the Christmas period in hospital having the operation and was doing well going to see his pigeons as he was a pigeon racer. All of a sudden, he started feeling ill and aching, so he was taken back to the hospital.

What did the doctors think might be causing his symptoms?

They thought it was a brain tumour, brain cancer because obviously he recovered from bowel cancer and was doing exceptionally well recovering from throat cancer, they thought it might have spread to the brain. They also thought it might have been a severe heart attack or a severe stroke. After tests, these ideas were dismissed, and it was an emotional rollercoaster. When they did eventually find it was Guillain-Barré, we thought what's that and what is it doing to our father?

How long did it take for your father's illness to be diagnosed?

'It took two and a half to three weeks.'

How did you feel before your father's condition was diagnosed?

The worst part was not knowing rather than the diagnosis, the not knowing 100 percent what it was was the worst part.

Did he receive IVIG treatment?

He did, and initially there was an improvement so that gave us hope, but then he went back to where he was.

Did the medical team tell you what to expect?

I was in on a daily basis and didn't see lots of improvement, the doctors couldn't give us a timescale for the recovery.

How did the illness affect your father?

He was head of the family and a very hard-working man, he was a grandad and great-grandfather and helped the children out, he was very active. I got the feeling he was embarrassed and lost a little bit of self-confidence, a man that had done everything for his family was just lying in bed because he was so ill.

Was your father able to be taken off the ventilator?

Through the physiotherapy, they were trying to take him off the ventilator for certain periods of the day, he got up to three hours off twice a day, but he then started to have problems, so they had to reduce that. We were told that him having to rely on the ventilator wasn't such a good scenario to be in. When he decided to come off the ventilator and come home, we knew it wouldn't be a long time before he passed.

Would it have helped to get an earlier diagnosis?

Without being an expert, it would have helped the family 100 percent if we got an earlier diagnosis.

How would you like to help GAIN?

If I can help in any small way, put my story out there to raise awareness of Guillain-Barré syndrome.

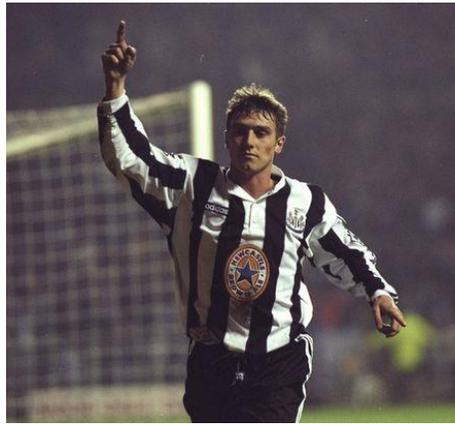
What have you learnt from your experience with Guillain-Barré syndrome?

Be positive about it, around the person who has been diagnosed and to not think of the worst-case scenario which unfortunately happened to my family.

How did you feel when GAIN asked you to be an ambassador for GAIN charity?

More than delighted, I was very proud.

To watch a video of Lee's interview, please visit: <https://gaincharity.org.uk/raising-awareness-of-guillain-barre-syndrome/>



Lee Clark

**Professional football manager
and former Premier League and
England under 21 player**

Lee Clark was born on 27th October 1972 and played professional football for Newcastle United, Sunderland and Fulham, as well as playing for England.

He is currently Blyth Spartans manager after having spells managing Huddersfield Town, Birmingham City, Blackpool, Kilmarnock and Bury.

Lee was born in Wallsend, Northumberland, and started his football career at his boyhood club, Newcastle United. He came up through their youth ranks and went onto play first team football, helping Newcastle get promoted to the Premier League. He was part of the side that was beaten to the title by Manchester United in 1996, helping them come second two seasons in a row. After making nearly 200 appearances and scoring 23 goals, Lee moved to Sunderland in the First Division in 1997.



After playing a part in Sunderland getting to the Playoff Final in which they lost on penalties, Lee helped them get promoted to the Premier League with a then First Division record of 105 points the following season.

Lee moved onto Fulham, where he played 149 league games and scored 20 goals. He earned another Division One title medal in 2001 and scored at Old Trafford in 2003 when Fulham famously beat Manchester United 3-1.

When Clark's contract expired, the Fulham club captain moved back to Newcastle United in the summer of 2005, where he played and coached. Overall, he played 265 times for Newcastle and scored 28 goals.

Whilst playing for Newcastle in his first spell, Lee played for England Under 21s making 11 appearances between 1992-1993, and in 1997 was a member of England's squad for Le Tournoi de France.

Following his player career, Lee moved into coaching, originally as First Team coach and Reserve Team manager under Glenn Roeder at Newcastle before following him to Norwich in The Championship where he became assistant manager.

His managerial career began at Huddersfield Town, who he took charge of in December 2008. He helped the club to a ninth-place finish in League One, having lost only two home games with him in charge. In his second season, Huddersfield secured a playoff spot.

Lee became the first manager to win three Manager of the Month awards in a single season since Roberto Martinez in 2007/08. Huddersfield were unfortunately beaten by Millwall in the Playoff Semi Final.

The following season, Clark's Huddersfield went on a club record 25-game unbeaten run in the league and secured a play-off spot, but went on to lose to Peterborough in the final at Old Trafford.

After leaving Huddersfield, Lee took the Birmingham City job in June 2012 and kept them in The Championship in the final game of the 2013/14 season. His next management role was at Blackpool, which was then followed by a spell at Kilmarnock who he kept in The Scottish Premier League.

After a stay at Bury, Clark took charge of Blyth Spartans in The National League North for the start of the 2019/20 season.

Fabulous footballing friends!



Matthew Bloomfield pictured above with the two teams taking part and below, with GAIN Trustee Adam Pownall

Continuing with a football theme, **Steve Davis** arranged a Charity Football Match in July, to help his friend, Matthew Bloomfield and to raise funds for GAIN.

'In 2017 Matty developed a life changing and potentially life-threatening disorder called Guillain-Barré syndrome which is a rare but very serious condition which has seen a fit and healthy young lad having to learn to do everyday things again, such as walking.'

Thanks to the generosity of friends and family, not only were funds raised to help Matt, but a very impressive **£1,165 was raised for GAIN**, to help others who have been affected by these conditions.



Thank you!

Matthew Kerr

Matthew Kerr is an Adventurous Training (AT) Instructor at the Joint Service Mountain Training Centre (JSMTC) in North Wales, delivering different aspects to tri service, Army, RAF & Navy. In August, Matty, along with a couple of colleagues undertook a charity event in support of two members of the organisation who have been diagnosed with life-changing diseases.

Their challenge consisted of sea kayaking for 11km, mountain biking for 19.5km (elevation of 340m), mountaineering 31.6 km (summitting each of the 5 peaks in Snowdonia that are over 1000m) and finishing off on the bike again for another 20.8km. They completed the challenge in 21 hours, starting at 1900hrs on Tuesday 27 August, pushing on through the night and finishing at 1600hrs on the Wednesday.

The total raised was split 50/50 between GAIN and Cancer Research, with GAIN receiving a whopping £1,040.50!



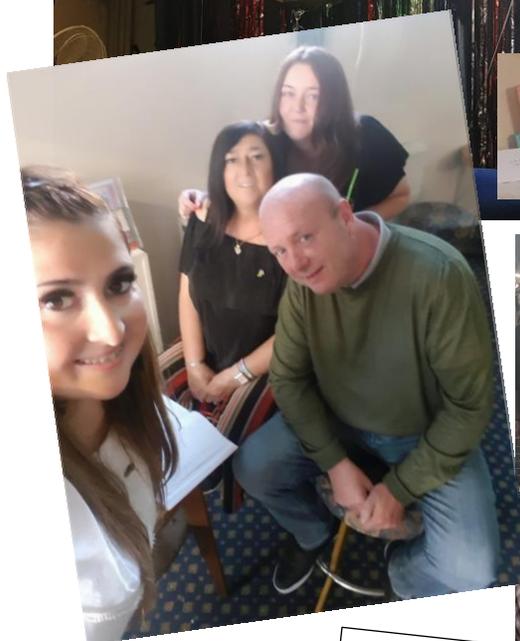
Matthew, pictured (right) with his colleague Michael Plumb, who is recovering from GBS, and Pat Lloyd Borland from GAIN

Charity RACE NIGHT



Danielle McGuinness had Guillain-Barré syndrome in January 2019 and is now on a mission to raise funds and awareness so that other people can find support and information when they need it.

With the help of family and friends, Danielle's Race Night raised **£721** plus Gift Aid!



Thank you!

There are all sorts of ways you can help us to support people affected by Guillain-Barré syndrome, CIPD and the associated variants.

By holding fundraising events, you also raise the profile of the conditions and the charity, and if fundraising isn't your thing, you can still help by taking along information to your local GP surgery, hospital, library or Citizens Advice office.

Let us know what you're up to and see if we can help you to help us!

*Tel 01529 469910 (weekdays 9-3)
Email office@gaincharity.org.uk*



Creative thinking

Our wonderful supporters find all sorts of creative ways to raise funds and awareness for us. **Pearl Budge** put her artistic talents to good use, generously donating proceeds from the sale of her artwork to GAIN!

Amy Pierce tells us why her friend Zoë Ogden decided to run the Manchester 10K for GAIN.

'John, my Dad, was struck down with Guillain-Barré syndrome in November 2010. He was 65, living life to the full looking forward to retirement with his wife, my Mum.'

But after having the swine flu vaccine at work he became weak and began losing feeling in his hands and feet.

Within the next 48 hours he was rushed into hospital and placed into a coma as he was very frightened, his body began to lose any control and feeling, unable to breath on his own. This is when Guillain-Barré was first mentioned. He was in the coma for a month where he was placed on life support with a tracheotomy, he almost died on numerous occasions but kept fighting.

We had never ever heard to Guillain-Barré syndrome. We managed to get the vaccine script that was provided with his flu vaccine and Guillain-Barré was listed as a rare side effect.

Once he was woken the effects of his illness became a real living nightmare, like 'locked in' syndrome Dad couldn't speak or move, all he could do was move his eyes.

We tried hopelessly to understand what was happening to him, the doctors didn't really know either. So many questions, no one could answer, so we googled GBS and found GAIN.

We contacted GAIN, they helped put us in touch with other people who had had GBS and answered lots of questions including contact with a GBS specialist, we attended a conference and were able to ask lots of questions.

He was kept in this state for 9 months in his local intensive care, his movement didn't return, he was frightened and very scared. We fought to get him moved to a specialist hospital as we felt he needed a specialist Neurological unit rather than a local hospital who had tried numerous times to get him off the ventilator but each time he lapsed backwards again!

Calling an emergency meeting with his Consultant, Doctors and Nurses we finally managed to get him moved to Salford Royal, once there the ICU team remarkably managed to get him off the ventilator and breathing on his own and tasting a bit of yogurt within 48 hours! It was a miracle!

He then spent the next 4 months in the specialist hospital before moving into a rehab hospital for almost 12 months.



Zoë Ogden
Manchester 10k

All in all Dad spent nearly 2 years in hospital. During this time Dad didn't get to see his grandchildren very much, as they were not allowed into see him in ICU, but in 2012 Dad returned home not sure what the future would bring. He is still paralysed from the neck down, has to have full care with visits from 2 carers, 4 times a day, John and his wife are now 74. His brain function is 100% but his body just doesn't move.

Thank you so much to Zoë for running the Manchester 10K to raise funds for GAIN and hopefully one day find a cure.'

Well done Zoë for completing the Manchester 10K & raising £698.75 including Gift Aid for GAIN!

Tesni Foster and Joe Sims 3 Peaks Challenge

Joe Sims and his sister, Tesni Foster successfully took on the 3 Peaks Challenge in October to raise money for GAIN. This entailed starting early in the morning and climbing Ben Nevis in Scotland, then driving to the Lake District and climbing Scafell Pike (at night with a head torch) and lastly onto Snowdon in Wales. This is approximately a marathon of climbing, and all in 24 hours!

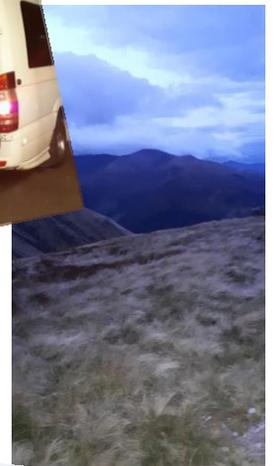
Joe tells us why.

'GAIN is now a charity close to our hearts due to what has happened to my dad turning all our lives upside down. My dad was in Thailand when he got Guillain-Barré syndrome. He was completely fine one day and the next it started to paralyse him completely starting from his feet all the way up to his eyes! It happened within 48 hours and it paralysed his breathing leaving him on a ventilator for 3 weeks and blind for 4 days. When he was out of a critical condition he was flown home by air ambulance to St Thomas Hospital in London where he has been for over 2 months recovering and learning to walk again.'

I'm sure most people are not aware of this awful condition as we were not either. Anyone, at any age or health can get it. We feel the awareness for the syndrome is quite frankly not good enough and we would like to help GAIN raise awareness and help them support other people who get GBS and their families. So if it means climbing mountains and shouting from the top of them to achieve this then so be it!

Tesni and Joe completed the challenge, raising £3,199.13 including Gift Aid

Thank you!



Most of us could do with a bit more exercise in our lives, and it's all too easy to find excuses...too busy...not enough energy... can't afford it....whatever your level of fitness and whatever your budget, **NHS Live Well** can provide you with lots of ideas and inspiration to get active

GET FIT for free



Images and text reproduced with permission of www.nhs.uk

Build activity into your day

To improve your health, try to put some time aside to do activities that improve your heart health and your muscle strength. The government recommends doing at least 150 minutes of activity a week, as well as strength exercises on 2 or more days a week (see page 30).

But do not worry about hitting these targets straight away: every little helps. What's more important is choosing an activity you enjoy. The easiest way to increase your activity levels is to build activity into the things you do every day, like going to work, shopping and seeing friends.

Tips to build activity into your day

- Walk or ride part of your journey to work or the shops
- Get off a bus or tube stop before your destination
- If you drive, park further away from your office and walk or ride the rest of the way
- Go for a walk or a bike ride with your friend rather than meeting for coffee
- Exercise before or after work, or during your lunch break
- Lots of gardening can provide a good workout
- Exercise in front of the TV
- Try an online video workout

Walking is simple, free and one of the easiest ways to get more active, lose weight and become healthier!

Sometimes overlooked as a form of exercise, walking briskly can help you build stamina, burn excess calories and make your heart healthier. You do not have to walk for hours. A brisk 10-minute daily walk has lots of health benefits and counts towards your recommended 150 minutes of weekly exercise.

What if I'm not very active?

If you're not very active but are able to walk, increase your walking distance gradually. If walking any distance is difficult, check whether your local swimming pool holds exercise classes. The water helps to support you while you move and can help you strengthen your muscles.

If you're not active because of a medical condition, get advice on exercising with a disability;

www.nhs.uk/live-well/exercise/get-active-with-a-disability/

If you can't leave the house, why not see if one of the free NHS exercise videos can help;

www.nhs.uk/conditions/nhs-fitness-studio/

Keep motivated!

- Make it a habit (a weekly walk with friends, walk to the shops, walk during your lunch break, etc)
- Listen to music and step up to the rhythm
- Use the free Active10 app to track your minutes
www.nhs.uk/oneyou/active10/home
- Mix it up! Variety keeps it interesting. Inspiration can be found online
<https://walk4life.info/>
www.walkswithwheelchairs.com/
www.ramblers.org.uk/walksfinder
- Join a walking group
Walking in a group is a great way to make new friends and stay motivated.
See what's happening in your area;
www.walkingforhealth.org.uk/

For advice on eating well, maintaining a healthy weight, exercise, sleep and tiredness, sexual health, alcohol support, quitting smoking, healthy body and mental wellbeing, visit www.nhs.uk/live-well/

What activities strengthen muscles?

To get health benefits from strength exercises, you should do them to the point where you need a short rest before repeating the activity. There are many ways you can strengthen your muscles, whether you're at home or in a gym.

NHS Live Well tells you how.

Examples of muscle-strengthening activities:

- carrying heavy shopping bags •
- yoga • pilates • tai chi • lifting weights •
- working with resistance bands •
- exercises that use your own body weight, such as push-ups & sit-ups •
- heavy gardening, such as digging and shovelling •
- wheeling a wheelchair • lifting and carrying children •



What is yoga?

Yoga is an ancient form of exercise that focuses on strength, flexibility and breathing to boost physical and mental wellbeing. The main components of yoga are postures (a series of movements designed to increase strength and flexibility) and breathing.

What are the health benefits of yoga?

Dozens of scientific trials of varying quality have been published on yoga.

While there's scope for more rigorous studies on its health benefits, most studies suggest yoga is a safe and effective way to increase physical activity, especially strength, flexibility and balance.

There's some evidence that regular yoga practice is beneficial for people with high blood pressure, heart disease, aches and pains – including lower back pain – depression and stress.

Does yoga count towards my 150 minutes of activity?

Most forms of yoga are not strenuous enough to count towards your 150 minutes of moderate activity, as set out by government guidelines.

However, yoga does count as a strengthening exercise, and at least 2 sessions a week will help you meet the guidelines on muscle-strengthening activities.

Activities such as yoga and tai chi are also recommended for older adults at risk of falls, to help improve balance and co-ordination.

Try our yoga workout videos in our Fitness Studio;
www.nhs.uk/conditions/nhs-fitness-studio/yoga-with-lj

What is tai chi?

Tai chi, also called tai chi chuan, combines deep breathing and relaxation with flowing movements. Originally developed as a martial art in 13th-century China, tai chi is now practised around the world as a health-promoting exercise.

What are the health benefits of tai chi?

While there's scope for more rigorous research on tai chi's health benefits, studies have shown that it can help people aged 65 and over to reduce stress, improve posture, balance and general mobility, and increase muscle strength in the legs.

Can tai chi help to prevent falls?

Some research suggests tai chi can reduce the risk of falls among older adults who are at increased risk. However, more research is needed.

Don't I need to be fit to do tai chi?

No, tai chi is for everyone. It is ideal for inactive older people wanting to raise their activity levels gently and gradually. Also, many of the tai chi movements can be adapted to people with a disability, including wheelchair users.

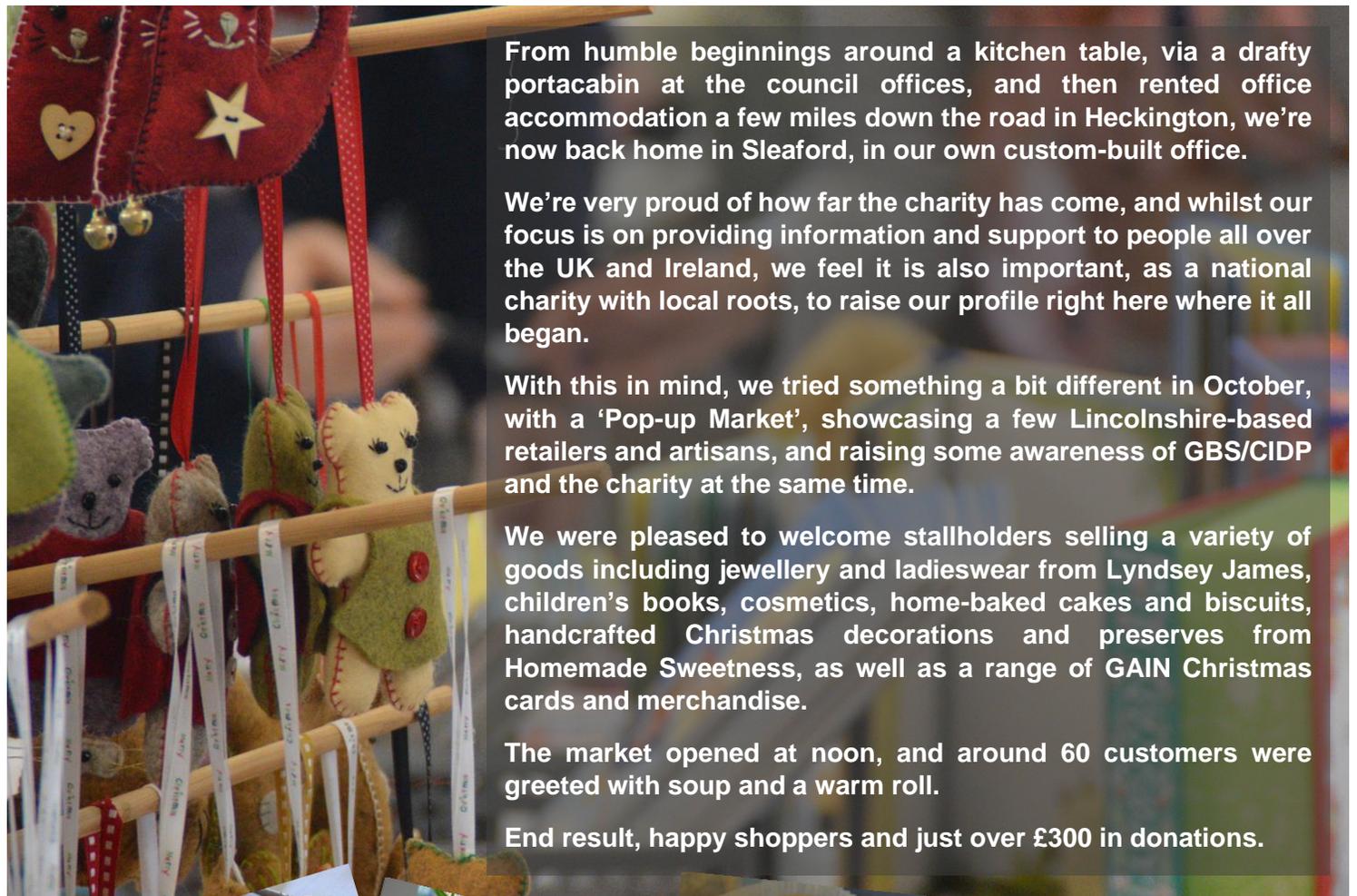
Can I injure myself doing tai chi?

Tai chi is essentially a gentle activity that is unlikely to cause injury if done correctly. The exercises involve lots of flowing, easy movements that don't stress the joints or muscles.

You can search online for tai chi classes in your area or find one using the Tai Chi Union for Great Britain website; <http://www.taichiunion.com/>



Pop-up Market & SOUP KITCHEN



From humble beginnings around a kitchen table, via a drafty portacabin at the council offices, and then rented office accommodation a few miles down the road in Heckington, we're now back home in Sleaford, in our own custom-built office.

We're very proud of how far the charity has come, and whilst our focus is on providing information and support to people all over the UK and Ireland, we feel it is also important, as a national charity with local roots, to raise our profile right here where it all began.

With this in mind, we tried something a bit different in October, with a 'Pop-up Market', showcasing a few Lincolnshire-based retailers and artisans, and raising some awareness of GBS/CIDP and the charity at the same time.

We were pleased to welcome stallholders selling a variety of goods including jewellery and ladieswear from Lyndsey James, children's books, cosmetics, home-baked cakes and biscuits, handcrafted Christmas decorations and preserves from Homemade Sweetness, as well as a range of GAIN Christmas cards and merchandise.

The market opened at noon, and around 60 customers were greeted with soup and a warm roll.

End result, happy shoppers and just over £300 in donations.

Photographs by Rebecca Ellis



About this free will-writing service then...

GAIN Chief Executive Caroline Morrice reports back on the free will-writing service brought to you in partnership with McClure Solicitors.

I thought, why not give this a go, my husband and I had made a will when we got married so maybe 23 years on it could do with a bit of an update. GAIN employees, like Trustees and members can use the free will service, because **it really is free** to everyone including the charity.

So, the first challenge - Sleaford is nowhere near a McClure office. Not to be phased by this I thought we could go to a branch near where we were on holiday! Unfortunately, there were no appointments, so a McClure solicitor called us on my mobile. This worked well, and we sorted out everything in around an hour (some of which involved my husband and the Solicitor reminiscing about their time in the Royal Navy).

All good so far. Then the new wills turned up in the post and an appointment was made for a solicitor to meet us at home to go through the detail and sign them off. This all went well, and our lovely neighbour was roped in as a witness.



McClure solicitor with Caroline's husband, Graeme

So if you are thinking you need to have a new will drawn up, do consider McClure. If the free one doesn't meet your needs, they have a range of options at a fair price. You don't need to live near their offices, just a phone call and a visit!

To arrange your consultation, call McClure Solicitors on Freephone 0800 852 1999. Please mention GAIN.

As we rely entirely on voluntary donations, legacies are vital to us. Thank you

Did you know that some goods and services for disabled people and people aged 60 or over are eligible for zero or reduced rate VAT?

Reliefs from VAT for disabled and older people

When can goods and services be zero-rated?

Supplies of goods and services are only zero-rated when all of the following conditions are met, the:

- customer is eligible to buy supplies at the zero rate
- goods are for the personal or domestic use of the customer
- goods and services are eligible to be supplied at the zero rate

Who should decide whether goods or services qualify for zero rating?

The supplier is responsible for making sure that their customer meets all the conditions for zero rating.

Who can buy zero-rated goods and services?

VAT reliefs for disabled people are not means-tested. They are not dependent on the benefits a disabled person may or may not get and a person does not have to be registered disabled in order to qualify.

Which goods and services are covered?

- adaptation of goods
- adapted motor vehicles
- boats
- **building works:** ramps, widening doorways and passages, bathrooms, washrooms and lavatories, lifts, preparatory, restoration and making goods, goods supplied in connection with these construction services, grant-funded building work
- **emergency alarm call systems**
- **hydrotherapy pools**
- **installation of goods**
- **low vision aids**
- **medical and surgical appliances**
- **mobility scooters**
- **other equipment and appliances designed solely for use by disabled people**
- **parts and accessories**
- **repair and maintenance of goods – paragraph 5.2**
- **specialist adjustable beds, chair lifts, hoists and sanitary devices**
- **specialist computer devices**

For further guidance, visit the gov.uk website; <https://www.gov.uk/guidance/reliefs-from-vat-for-disabled-and-older-people-notice-7017>

Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) is a big name for a small charity. We help people all over the UK and Ireland who are affected by a rare condition that most people only hear of for the first time when they get a diagnosis of something unpronounceable. But that doesn't stop us from having some of the most generous, creative and inspirational supporters that any charity could wish for!

Did you ever wonder just how much of your donation directly helps others?

Here at GAIN, we have three objectives;

1. To help people affected by Guillain-Barré syndrome and the associated neuropathies, by providing information, assistance with travel costs whilst visiting relatives in hospital, and contact with others who understand from personal experience the issues they are facing
2. To promote and help fund research into the causes and treatment of these conditions, hopefully getting ever closer to prevention or cure
3. To raise awareness of the conditions amongst health professionals and the public so that people are more likely to receive an early diagnosis and be signposted to the charity for support

This is an expensive commitment and we rely solely on voluntary donations, people organising and taking part in events to raise funds, and income from legacies.

For every £1 we receive, over 91p is spent on fulfilling our charitable objectives.

There is a long way to go, but thanks to people like you, we can keep heading in the right direction.

DID YOU KNOW?

Dear Members and Supporters

Did you know that 'Freepost' is free to the sender, but not the recipient - the cost is picked up by the organisation associated with the Freepost address.

You are welcome to use our Freepost address to return a membership form or Personal Grant Application, etc, but please don't add anything else! Writing a postal address after the words 'Freepost GAIN' cancels the Freepost element, meaning we then pay Royal Mail an unpaid postage surcharge.

- A. Full postal address – attach a stamp
- B. Freepost GAIN – no stamp required

Thank you, The GAIN Team

P.S. Thank you to everyone who attached a stamp this year when returning their membership forms. You saved the charity around £400!

If you write 'Freepost GAIN' followed by our postal address, and you do not attach a stamp, Royal Mail charges the charity a £2.00 'no postage paid' fee, so PLEASE DO NOT DO THIS!

NO
STAMP
REQUIRED

Freepost GAIN ✓

~~Glennys Sanders House~~ ✗

~~Pride Parkway~~ ✗

~~Sleaford~~ ✗

~~NG34 8GL~~ ✗

Free post Gain
Glenny Sanders House
Pride Parkway
Sleaford
Lincolnshire
NG34 8GL

paid
No postage paid
£2.00



David Stonehouse shares his story of Guillain-Barré syndrome from diagnosis to recovery.

Down to me

‘He tapped my knees with his hammer, but they were totally dead - he would have got more response from a tree trunk. I had various tests carried out, the last one being a lumbar puncture which confirmed that I had Guillain-Barré syndrome, and within one day I was paralysed from the neck down.’

I have just arrived home from driving to my daughter's home in the Midlands with my wife Dee. We have been abroad twice of late and my life is slowly returning to some form of normality. This is my story, and is especially for people like myself, who take a little longer to recover from Guillain-Barré syndrome.

We went on holiday for a second time to Goa, India. It was the 26th January 2015, my birthday. We had lunch at a beach shack café, where we had eaten before, the previous year. The food was ok, I had the kingfish. Later that day I started to feel unwell and that evening I was violently ill with sickness and diarrhoea. I didn't recover, so after three days we had the doctor out who checked me over and gave me vitamin tablets.

After a few more days I was having problems with my eyesight with slight double vision, also difficulty with swallowing. I lost my appetite and the weight fell off me. I felt very weak I hadn't the strength to climb the few steps out of the swimming pool. We were flying home on 13th February, and the evening before we flew home, we had dinner at the hotel garden restaurant. I hadn't the strength in my hands to eat my tea and I couldn't fasten my belt. I was really struggling to do the smallest task and on leaving the restaurant my legs had turned to jelly and I collapsed on the stairs. Two security staff had to carry me over to the reception area.

I was taken to hospital where I had an ECG, and I was eventually treated for dehydration. The next day was Saturday and the doctor was going to discharge me. I told him that I couldn't walk as I had no strength in my legs. He said show me and I did. He then tapped my knees with his hammer, but they were totally dead - he would have got more response from a tree trunk. I had various tests carried out, the last one being a lumbar puncture which confirmed that I had acute Guillain-Barré syndrome, and within one day I was paralysed from the neck down. Luckily it did not affect my breathing. I underwent the treatment to stop the paralysis spreading any further and I knew that I was facing the biggest fight of my life. I spent a further twenty days in hospital. The doctors and nurses were great - they really looked after me well.

On 4th March, two doctors accompanied me on my flight back home to Manchester from Goa via Germany. I was stretchered for the whole journey. I spent two weeks in Scarborough hospital and a further five weeks in Bridlington hospital. I eventually got back home on 29th April. My wife is a retired nurse and looked after me 24/7. She had to feed me toilet and wash me - what a mess I was in! It took me a long time to accept that I was quadruple disabled.



Because I was expected to make a full recovery, we had to fund the full cost of the ramp put in place to the front door for the wheelchair.

My wife made contact with the charity Dial A Ride and we used their buses to go to Scarborough and surrounding area. They were brilliant for people like me in a wheelchair. While at home a community physio came to me twice a week. She later told me the first time she saw me she assessed my ability at 5%. She told me she would be coming to the house for approximately three years and her target was to get me walking and to be able to go up and down the stairs.

I was very fortunate to be in contact with a lady called Ann who had recovered from GBS some 15 years ago. She was brilliant, giving me encouragement and hope, and lifting me out of the black holes I would slip into.

In September 2015, eight months after this all started, I had an appointment with the neuro consultant at York Hospital. I was feeling good with the small amount of recovery I had got back in my arms and legs, only to be told there was a possibility I would never walk again. I was devastated by these few words and my world collapsed around me, but I wasn't giving up and on 4th January the next year I stood up from my bed for the very first time.

My body felt so heavy I honestly thought I would never be able to walk again, but in May 2016, I took my first few wobbly steps in a gutter frame. I progressed very slowly to a walking frame, and later that year I was given the opportunity to go to the hospital gym. This felt like real progress - I was so excited!

But I had a problem with sit to stand - to enable me to use the gym I had to be able to stand up from my wheelchair. I couldn't do that, so we compromised, and the physio took the wheelchair arm and side off and I was able to transfer to an adjustable bed, job done. I was able to stand up and walk from one end of the gym to the other in my frame. It was extremely difficult, but I did it. I was good enough to go once a week- another brick wall knocked down!

My hands were beginning to claw, and the occupational therapist came to measure my hands for splints. She asked me what I hoped to achieve, and I replied that I wanted to walk out of the house and drive my car. She replied, 'How will you ever drive a car again with hands like that?' Wow, who needs people like her! And guess what, I'm still waiting for the splints - never did get them.

I was advised by my physio to go to the gym at Plaxton Court, Scarborough, to build up my strength and stamina. Gill is the instructor there who specialises in people with disabilities, but I forgot to tell her at the induction that I was unable to stand from my wheelchair. It wasn't an issue however, and after a few weeks I was able to achieve this.

I've been going two years now and the wheelchair's gone. I'm able to walk with a stick and use a crutch. I'm able to use most of the equipment at the gym. But above all, me and my wife Dee, who stood by me through thick and thin, have got our lives back. Ray, a very good friend of ours, gave me the opportunity to see if I could drive his car. After I had mastered the art of getting in and out of the car, I drove around a large car park quite well. DVLA sent me for a medical, and now I'm back driving again. Absolutely fantastic!



Last year, 2018, saw the most improvement. I'm able to climb the stairs and do most things around the house. I've achieved what I wanted to achieve. The ramp's gone and the wheelchair's gone. I walk down the house steps and drive my car. My physio discharged me on 10th September 2018. She and I achieved what she wanted to achieve, and she told me it's down to me now. But you know what? It's always been down to me. So, my story is for the GBS people like myself, who take a little longer. Keep positive. Keep smiling.



*Above: Back in the driving seat
Right: David and Dee stepping out again*



Without the support and help from the physio team the gym staff, etc. and Ann who's always been there to give me encouragement, I wouldn't be where I am today.

So many thanks to all of you, and above all, to my wife Dee for sticking with me - that was a big ask.

Back in 1990, Helen Young's sister died within two weeks from a syndrome she'd never heard of, Guillain-Barré. She was only 18, Helen was 21. Helen decided to raise funds to help other people affected by this devastating illness.

In 1992 I ran the London Marathon to raise funds for GAIN and if I'm honest it was to do something positive after such a tragedy.

Despite Guillain-Barré syndrome only affecting 1,300 people in the UK each year, I know three other people who have had it, one of whom is still recovering as I write and is receiving support from a local GAIN peer support volunteer. Coupled with the fact I reached a birthday milestone this year it seemed timely that I should do something else to raise awareness and funds. I opted for the September London to Brighton Bike Ride, 56 miles.



What an epic day!

I'm not sporting by any stretch of the imagination, so this was no mean challenge. I was more used to pootling around my local area on my bike, 3 miles max!

I booked my place back in January and then promptly partially damaged my achilles and another tendon trying to get fit for my birthday!! The recovery was slow and I only got back on my bike mid-July (the organisers suggest a three month training programme). I started training earnestly with one month to go in August and thanks to mad biking friends who think cycling 50 miles is a mere jaunt, managed to cycle up Box Hill on three separate occasions prior to the ride (part of the London 2012 Olympic route, although Olympiads cycle up it 9 times in one day!!).

I set off to the ride with mixed feelings - nervousness definitely, as I had no idea what to expect and everyone had warned me about the worst hill of all, Ditchling Beacon, which rises out of the landscape like Mount Doom in Mordor. It rises from 90 metres above sea level to the summit at 248 metres in just over one mile. That's an average 9% incline with it hitting 16% at one point!!

I was cycling on my own, so my methodology was slow and steady, no heroics, I just wanted to do it.

In fact, I only stopped for the water break after 17 miles and lunch stop at 30 miles. Everyone taking part was very friendly and supportive.

One man joked he was naming me 'relentless' as I just kept going at the same speed, (he kept overtaking me and then stopping and I would overtake him ad infinitum).

I have to say I thoroughly enjoyed the day - the weather was perfect, dry and sunny. I started at 7am and finished five and a quarter hours later. I cycled every hill even Ditchling Beacon, although that was painful! At the top I had wobbly legs but that was soon fixed with water and jelly babies - a must on a long bike ride.

The scenery at 248 metres up was awesome and the descent down to Brighton was a delight. The feeling of accomplishment was immense.

I crossed the finish line at Brighton Marina with great joy. It was an epic day and one I will never forget. Friends couldn't believe an un-sporty person was doing this and so were very generous at sponsoring me. I'm delighted to say they have helped me raise just over **£2,000** for GAIN which is my proudest achievement of all. If I can do it at fifty then anyone can do it!!

Thank you!

Winter is the perfect time for planning next year's Big Getaway. But if you are living with disabilities, the idea of going on holiday can be daunting. There are lots of companies out there offering accessible travel and accommodation solutions, who might be able to help. Disabled Holidays and Virgin Holidays are just two examples worth having a look at.



We understand both the difficulties that a disabled holiday maker can face and the worry that this causes. Our job is to take away that worry by providing you with all the support you need at every step including choosing, booking, preparing to go, travelling, holidaying and coming home.

We count it a privilege to be trusted with arranging your holiday so please do give us the chance to impress you by calling us on 0161 804 9898.



Donna, Sales and Training Manager
Favourite part of your job?
Matching the customer to their perfect holiday, listening and taking on board their individual needs and making them feel they are valued.

The UK team know where the best places are, when to go and where to stay: from accessible hotels and home-from-home guest houses to cosy log cabins and secluded cottages.



Frankie, Team Leader
Favourite part of your job?
I enjoy sharing my customers' excitement and hearing the stories about where they've travelled to and what they've LOVED!

The overseas team are experts in the hottest destinations, the warmest welcomes, the coolest resorts and the coldest drinks! How to get there, what to see and where to go – the overseas team have all the answers!



Natalie, Team Leader
Favourite part of your job?
To be part of helping to create special memories for our customers. Often, we can find places and accommodation and offer assistance that our customers simply didn't imagine was possible.

For more information, visit
www.disabledholidays.com/



Unleash your inner adventurer with accessible holidays

No one should miss out on the adventure of a lifetime, regardless of ability. Disabled holidays abroad can sometimes be a challenge, but we're here to make sure you can have the holiday you want. From wheelchair-friendly hotels to specially adapted car hire, whatever you need to make your holiday perfect – we'll do everything we can to make it happen.

Our Virgin Holidays' special assistance team are here to support you, your friends and family, or specialist carers so you all have a great time, no matter where in the world you travel to or what you want to do.

Our special assistance holiday experts work with you from the moment you book accessible holidays and then through every point of your adventure to make sure you've got everything you need you're treated with dignity, respect, and courtesy. So, if you need a wheelchair-friendly hotel, adapted transfers or car hire or even assistance regarding medical equipment, we'll do our best to find you the best solution.

If you rely on a carer to help you with everyday activities, let us know. We can make sure all the details are taken care of, such as suggesting resorts that are suitable for both of you, that you travel together, and that accommodation is available for both travelling companions.

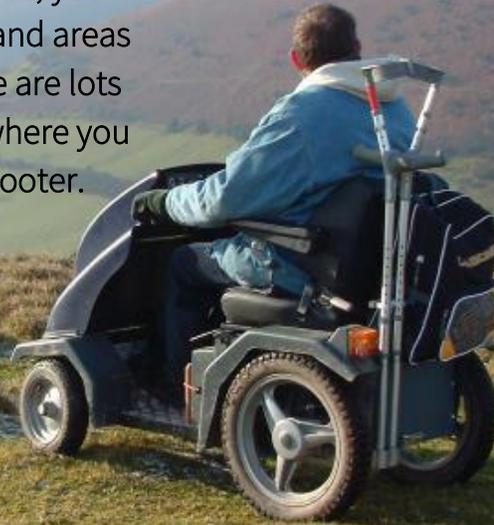
If you need to speak to someone about your requirements, the Virgin Holidays special assistance team will be more than happy to help.

Give them a call Monday–Friday (9am–5.30pm) on 0344 557 3998 or email at any time on special.assistance@virginholidays.com.

For more information, visit
www.virginholidays.co.uk/important/special-assistance/overview

Wish you were here?

If you are a wheelchair-user or are going on holiday with someone who is reliant on a wheelchair, you don't have to be restricted to visiting lowland areas or locations with level tarmac paths. There are lots of places throughout the UK and Ireland where you can hire an all-terrain Trampler mobility scooter.



Trampers are renowned for their reliability, long battery life, and ability to go uphill and down dale. For a list of public sites, stately homes and parks where Trampler Buggies can be hired, visit the Trampler website and go to:

www.tramper.co.uk/Press/561247bea00324f026e278d3

Marie Houlden and her family live in the beautiful county of Dorset. While walking in the Peak District in May 2007, she became increasingly frustrated with the lack of freely available information on walks suitable for those with access challenges, and so created,

walks with wheelchairs

Walks with Wheelchairs will allow you to:

- Read reviews of the routes before trying any walks
- Download walk directions and detailed OS maps **free of charge**
- Share your own routes for walking with a wheelchair or buggy
- Add your own comments for other users



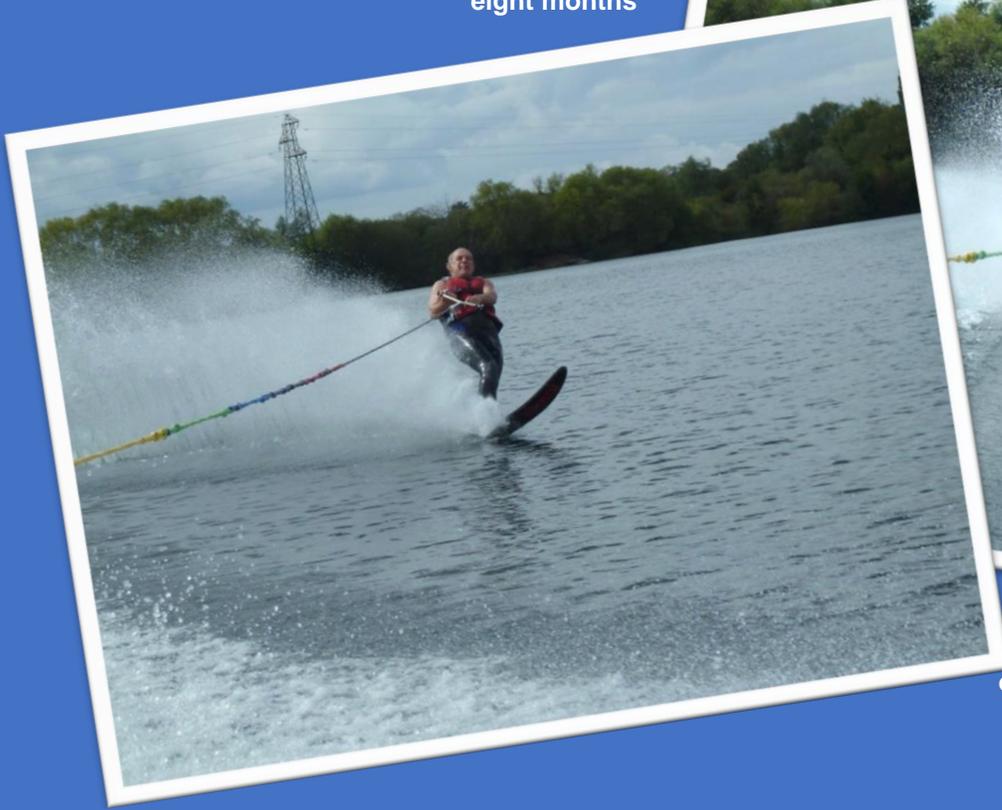
For information and inspiration, visit
www.walkswithwheelchairs.com

Diagnosis debate

Although in his late 70s, Peter Woolsey was a fit and active entrepreneur who enjoyed regular trips abroad both for pleasure and business. This unexpectedly ground to a halt in December 2018, when he started to experience the first signs of Guillain-Barré syndrome. Despite his own GP making an accurate diagnosis however, things didn't progress quite as expected, and he found he had to argue his case.

DECEMBER 2018		JANUARY 2019	
<i>Friday</i> <i>14th</i>	Attended conference in the West End of London, travelling by train and tube.	I managed to walk to and from a set of stairs and then climb the stairs - unaided - and walk back to my bed on the afternoon of January 3 rd . Leave hospital, walking with one stick, return home and being exercising daily. My local physiotherapist and I design a simple programme of exercises.	
<i>Friday</i> <i>21st</i>	Been feeling tired since last Friday, with numbness in my feet and legs. Legs finally gave way today. My GP diagnosed Guillain-Barré syndrome within ten minutes of seeing me and called A&E to tell them what was required. His diagnosis was over-ruled by a senior doctor (Spanish) who told her junior doctor (also Spanish, in Spanish), to ignore the diagnosis, saying that I only had shingles and I was a nuisance. Having lived in South America, my wife speaks Spanish fluently. She understood exactly what the senior doctor said and told me, so that I could challenge her. I had to threaten to sue the senior doctor (in Spanish, via my wife), to force her to arrange a lumbar puncture. This was delayed until the next day.	Symptoms seem to reappear, but a doctor at Townlands in Henley (the first knowledgeable doctor to talk to me about GBS) reassures me.	
<i>Saturday</i> <i>22nd</i>	After arguing for a lumbar puncture (and threatening legal action), I had two failed attempts by a young registrar. I then insisted on an experienced anaesthetist who successfully obtains a sample of my spinal fluid.	MARCH 2019	
<i>Sunday</i> <i>23rd</i>	Consultant neurologist confirms I have GBS and insists that, owing to my age, I must assure him I'll take rehabilitation seriously before he will prescribe IVIG! Treatment eventually commences this evening, two days after my own GP diagnosed GBS.	Able to do most things by March, including business visits to Norway and Scotland. Able to cycle again.	
<i>Monday</i> <i>24th</i>	Assigned to a Renal Ward, no one knows why I'm there and no one knows about GBS. Five days of agony, terror nightmares.	APR - JUN 2019	
<i>Saturday</i> <i>29th</i>	I read up about GBS online and start exercising every 2 hours, day and night, am told to stay in bed by daytime staff!	Business trips to Estonia, Scotland, Manchester, Ukraine. Able to function normally, although feel tired occasionally. Relearned how to swim.	
		AUGUST 2019	
		Drive to Spain via France and manage to water ski on two skis on a cable system, not ideal but realise I'm much stronger.	
		SEPTEMBER 2019	
		ISIS Aqua-Ski Club, Playhatch, near Reading. Manage to Water-Ski on a single Mono-ski for ten minutes. I now have full mobility and more than 80% of my previous strength.	

Back on the water - from a paralysed GBS patient to a 78-year-old mono-skier in just eight months



If you would like to share your experience of diagnosis and treatment (whether good or bad) please email your story and photographs to office@gaincharity.org.uk, subject line: gain4all stories

The cost of getting to hospital

The **GAIN Personal Grant Scheme** was established in part to help families with the cost of visiting a loved one in hospital for the many weeks and months it can take to recover from Guillain-Barré syndrome. The unexpected expense of daily journeys, whether by public transport, or by car, soon mounts up, and with your support, we help many families every year. In 2018/19, for example, we approved **42 grants** totaling almost **£30,000!**

But what about outpatient visits once you have been discharged, or people needing regular treatment for a chronic condition such as CIDP or Multifocal Motor Neuropathy? Although GAIN can't help with these, there may be help available elsewhere, through non-emergency patient transport services (PTS) and through the Healthcare Travel Costs Scheme (HTCS).

Non-emergency patient transport services

Some people are eligible for non-emergency patient transport services (PTS). These services provide free transport to and from hospital for:

- people whose condition means they need additional medical support during their journey
- people who find it difficult to walk
- parents or guardians of children who are being transported

PTS may not be available in all areas. To find out if you are eligible for PTS and how to access it, you will need to speak to your GP or the healthcare professional who referred you to hospital.

Refunds of hospital transport costs

You may be able to claim a refund for the cost of your transport to hospital through the Healthcare Travel Costs Scheme (HTCS) if you:

- are not eligible for PTS
- cannot afford the cost of travelling to hospital
- cannot get a friend or relative to take you

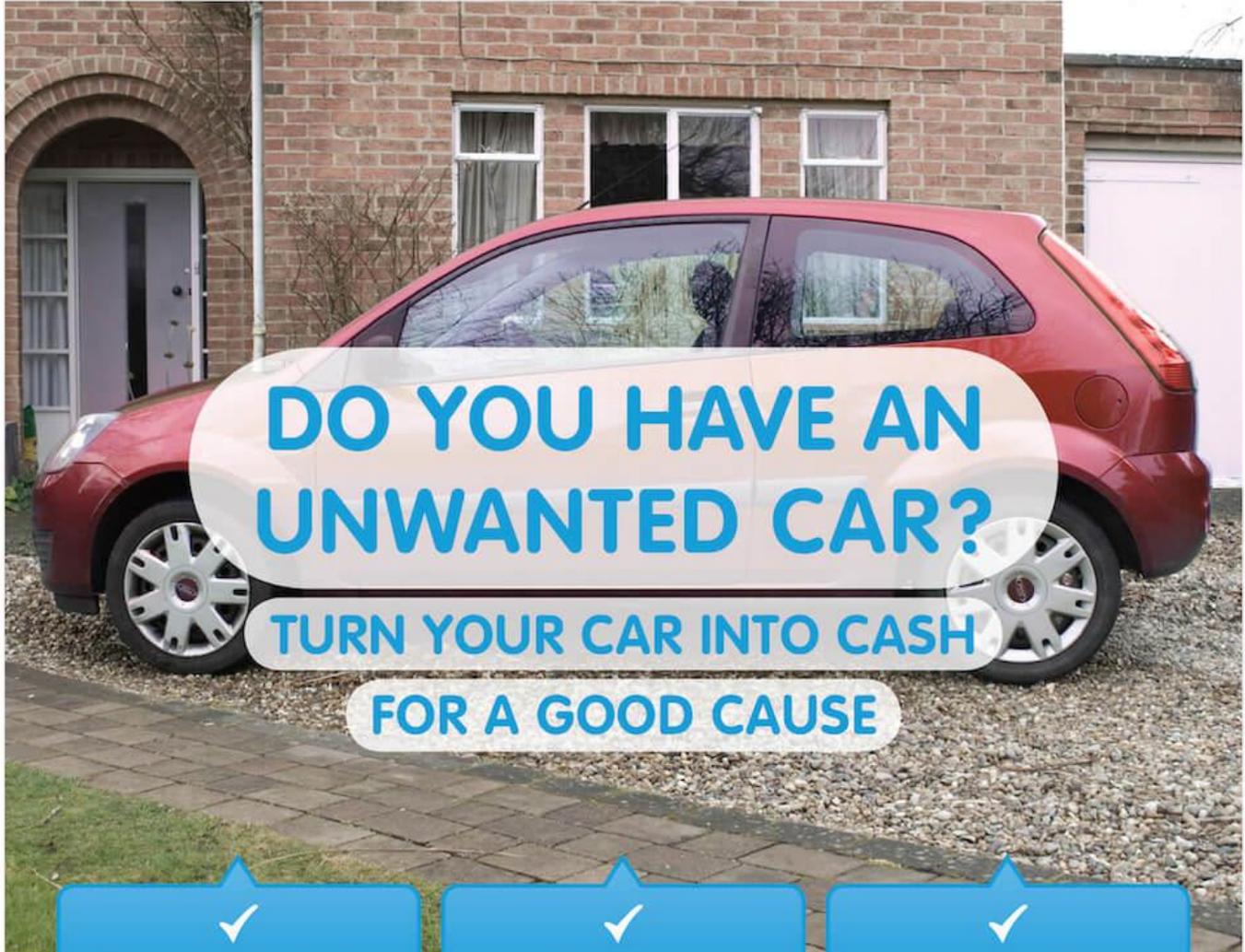
More information about Healthcare Travel Costs Scheme (HTCS), such as who is eligible, what the conditions are and how you can access the scheme is available on the NHS website;

<https://www.nhs.uk/using-the-nhs/help-with-health-costs/healthcare-travel-costs-scheme-htcs/>



If you would like to donate an unwanted car to support GAIN, visit the GIVEACAR website;

<https://giveacar.co.uk/charities/guillain-barre-associated-inflammatory-neuropathies-gain/>



✓
Free collection

✓
Any car

✓
Nationwide

To find out more, call us on **0207 736 4242** or visit www.giveacar.co.uk



‘ making a difference one car at a time ’

Giveacar is a non-profit social enterprise supporting over 1,600 charities.
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Lancashire & Cumbria

NEWS

The AGM in June saw Sybil Loxam stand down as Chair of the Lancashire & Cumbria branch of GAIN, after more than 20 years on the committee.

Heartfelt thanks for all her contributions and support over the years were paid by all present. The team at Head Office would like to add their thanks and appreciation to Sybil for her many years of service, and to wish Rosie Hyslop well as she takes over as Interim Chair.

The Lancashire & Cumbria branch of GAIN produces a bi-annual newsletter which is posted out to all branch members and is also published on the GAIN website and on social media. If you would like to become a branch member and receive a copy, please let us know at Head Office.

Dates for your diary 2020

2pm Saturday 7th March

Speaker: Pat Ascroft

2pm Saturday 20th June

AGM & Plant Sale

2pm Saturday 12th September

Speaker: Dogs for Good

2pm Saturday 12th December

Christmas Party & Jacobs Join

All welcome!

Please join us at **Bilsborrow Village Hall**,
just north of Preston



GAIN offers free information and support to anyone affected by Guillain-Barré syndrome, CIDP or any of the associated variant conditions, including, if required, one to one peer support from a GAIN volunteer. This might be in the form of a phone call, a video chat or even a hospital visit.

However, sometimes there is a need for more regular contact, especially for older people, who may be on their own, and for whom a diagnosis of CIDP, or a long, slow recovery from GBS could result in them feeling lonely and isolated.

Independent Age offers a friendship service to older people who could benefit from contact with another person, with regular phone calls or visits.

If you are an older person feeling a bit isolated, or if you know someone who would benefit from a referral to **Independent Age**, why not look them up? Further details can be found on their website or by phoning their free helpline number (right).



advice and support for older age

**Independent
Age**



Regular phone calls or visits

Many of us lose touch with friends and family over the years, and it is great to have someone to catch up with for a chat. Our friendly volunteers will call regularly on the telephone or, in some cases, visit in person.

Call our Helpline on **0800 319 6789** or visit the website for further information

www.independentage.org/get-support



Introducing StarLeaf, GAIN's brand-new video-conferencing facility

'StarLeaf enables seamless collaboration through intelligently engineered, reliable meeting room systems, superior video conferencing, and secure messaging. Designed and engineered by StarLeaf, the experience is intuitive and feature-rich, allowing total interoperability across all devices.'

StarLeaf is our excellent new video conferencing system GAIN had installed at the end of September, which will help link us to patients, volunteers and medical professionals. The system involves a camera linked to several speakers, ensuring sound is captured from around the room. This is linked to a 62" television on the wall and can be controlled by a touch screen remote, as well as being controlled from a computer and tablet.

Members of GAIN can download the StarLeaf portal on their computer, smartphone, or other device and join in with the conversation using a log-in which we will provide. This was tested during the Annual General Meeting in October, when members of the charity who could not attend, along with members of the Medical Advisory Board, joined the meeting using a variety of devices from their own homes. The system allows the user to either video call or voice call, whichever each individual is most comfortable with.

With StarLeaf, GAIN has opened up the possibility of operating digital branches, allowing fellow GBS and CIDP sufferers to get together and share their experiences in a safe environment, and from the comfort of their favourite armchair.

Although we want you to lead the conversation, we will be here in the office to help facilitate, and to answer any questions that arise. There could be group chats specifically for parents of children diagnosed with GBS or CIDP, or people diagnosed with a variant such as Miller Fisher or Multifocal Motor Neuropathy, for example.

The new video conferencing system could also help the charity offer a more tailored and accessible approach to peer support. StarLeaf provides a platform to talk to patients in hospital or recovering at home, and can include other family members, even if they live elsewhere, if they wish to join the conversation. With StarLeaf, we can arrange face to face peer support even if the most suitable volunteer lives at the other end of the country!

Ultimately, we hope this new communication facility will help us reach out and bring together people from all over the UK and Ireland, and in so doing, alleviate feelings of isolation that so many people experience.

If you have access to a smartphone, tablet, laptop or PC, and think you might like to take part in a group audio or video chat, please register your interest by emailing office@gaincharity.org.uk with your name and any particular area of interest.

gain2gether *local*



Dedicated to helping people affected by Guillain-Barré syndrome, CIDP & the Associated Inflammatory Neuropathies
www.gaincharity.org.uk

If you have been affected by **Guillain-Barré syndrome**, **CIDP** or one of the related conditions, come along and meet up with others who understand the issues faced by you and those close to you.

gain2gether North East England meets at 1.30pm on the 3rd Tuesday of every month*

Walkergate Park
Centre for Neuro Rehabilitation and Neuro Psychiatry,
Benfield Road, Newcastle upon Tyne, NE6 4QD

**except June and December*



If you live within easy reach of Dewsbury in Yorkshire, why not come along and meet up with other people who have been affected by GBS or CIDP?

gain2gether Yorkshire meet up twice a year at the **Boothroyd Centre, Dewsbury & District Hospital.**

Meetings in the South West of England take place twice a year, in the spring and the autumn, in a variety of locations around the South West region.

Next meeting to be held at 2pm on Saturday 21st March 2020 at Salford Golf Club, Keynsham.

Guest speaker is neurologist

Dr James Stevens of Southmead Hospital. Bristol.

Everyone welcome!

(bar lunches available to purchase in club house prior to meeting if required)



William Harmer, GAIN Trustee and longstanding member of the South West of England local branch, has sent us a photograph of his stack of Moxies!

If you would like to start your own Moxie family, we have small (20cm) and large (28cm) versions available on the website priced from only £8.50.

Visit www.gaincharity.org.uk to get yours!

gain2gether local events are volunteer led. If you would like to start a group in your area, please contact us for further information.

Phone 01529 469910
or email office@gaincharity.org.uk

Your letters

Dear GAIN

On the 20th July 2019 my niece Kimberley Foden married her partner Alexander Giovedi. Although I was very much involved in their wedding I was unaware that they had asked for donations for GAIN in memory of her cousin Candice Marie Roberts to be given in lieu of wedding presents: it was not until I saw the GAIN Thank You note I was informed.

As always, the effects of Guillain-Barré syndrome upon ourselves and family is a constant, and so every opportunity that lends itself we will use to raise funds and awareness; and as a consequence, Candice is with us.

I know you appreciate all your donations and the stories behind them thus I just wanted to send you some pictures of the couple and their special day and make you aware of their modest generosity.

Karen Roberts



Main picture: Kimberley & Alexander
Top right: Candice's niece and nephews, Katie, William and Harry
Bottom right: Candice's cousins, Kimberley and her sister Bridi

Footnote: Karen's daughter, Candice died in 2010 aged just 26, following a diagnosis of Guillain-Barré syndrome. Her family continue to help others by raising funds and awareness in her memory.

Reminiscing

July 2019, the 10th anniversary since I was diagnosed with Guillain-Barré syndrome, I looked back at everything I have 'gained' in those 10 years. Strength to bring me, and my family, through this debilitating illness, friendships reinforced, and many new ones made, along with two lovely new grandchildren!

As volunteer Local Contacts for GAIN, my husband and I hope that we have made a difference to all we have met or spoken to - there is nothing better than seeing or speaking to someone who has been through the same, or a similar experience.

Fundraising, taking part in research questionnaires and spreading the word has been, and continues to be, an important part of our lives - hopefully one day more will be known about this illness.

We have met many lovely people along the way, one of which actually met and fell in love with the son of her nurse in Intensive Care! It really is good to talk!

Jill Rushton

Jill and her husband have spoken with and visited many patients and their families over the years, offering support and advice from the perspective of having 'been there'. If you can spare an hour or two every few months and would like to help other people come to terms with a diagnosis of GBS or CIDP, please contact us here at GAIN Head Office and we'll send you an application form to become a Peer Support Volunteer



One small step for some, a major milestone for others. Jill successfully navigates steppingstones following her recovery from GBS

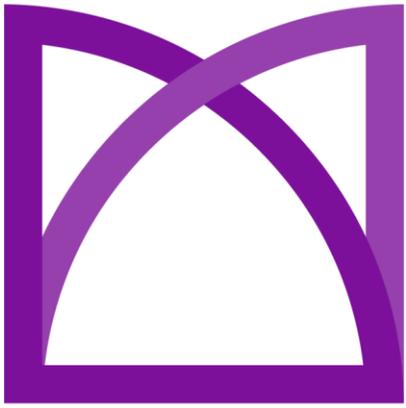


Here at GAIN, we do our best to provide the information and support you need, even if that means signposting you elsewhere

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

<p>www.carersuk.org Helpline 0808 808 7777 10am–4pm Mon & Tue</p> 	<p>www.carers.org  carerstrust action · help · advice</p> <p>money & benefits, support for young carers, health & wellbeing, working & learning, out & about, getting a break, legal & rights</p>	<p>OPEN 7 DAYS PER WEEK </p> <p>Carers Direct Information, advice and support for carers</p> <p>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</p>
 <p>www.familycarers.ie</p>	 <p>Benefits Work Money Consumer Family Housing Legal Immigration Health</p> <p>www.citizensadvice.org.uk</p>	<p>Citizens Information Phone Service Mon-Fri 9am-8pm 0761 07 4000</p>  <p>Citizens Information</p> <p>www.citizensinformation.ie</p>
<p>contact <i>For families with disabled children</i></p> <p>WE ARE CONTACT, THE CHARITY FOR FAMILIES WITH DISABLED CHILDREN</p> <p>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.</p> <p>www.contact.org.uk</p>	<p>FacialPalsy^{UK} INFORM • SUPPORT • RESEARCH</p>  <p>Inform Support Research</p> <p>www.facialpalsy.org.uk</p>	 <p>Disability Rights UK</p> <p>Advice / Information / Jobs / Volunteering Projects / Programmes / Training</p> <p>www.disabilityrightsuk.org</p>
 <p><i>Somewhere to turn when someone dies</i></p> <p>Helpline 0808 808 1677 www.cruse.org.uk</p>	 <p>Links and information for people with pain</p> <p>www.britishpainsociety.org/people-with-pain/</p>	 <p>Chronic Pain Ireland</p> <p>Information & support for people living with chronic pain</p> <p>Self-management / Events & meetings Support phone line / Online library</p> <p>www.chronicpain.ie</p>

If you know of any useful organisations not listed here, please let us know about them



McClure
SOLICITORS

GAIN has partnered with McClure Solicitors to provide a free Will-writing service for our members, friends, volunteers and staff who want to write, update or review their Will. This service is FREE both to you and to GAIN and carries no obligation.



Why do you need a Will?

You already know that every adult should have a Will. Without a Will the law decides who inherits, but with a Will, you decide.

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.

There is no obligation to make a donation or leave a legacy to GAIN, but we would be very grateful if you consider it. A gift in a Will, no matter how small, would help us to provide the practical, emotional and financial help that people affected by GBS, CIDP and the associated inflammatory neuropathies rely on.

McClure has offices throughout the UK, but if there isn't one in your area, they can come to you. It really couldn't be easier, so why not arrange a free consultation today!

Tel 0800 852 1999



<https://www.mcclure-solicitors.co.uk/wills>