



Reaching out while you stay in

GAIN / coronavirus COVID-19 newsletter issue 2 03/04/2020

We're all having to do our bit and stay home just now, and that includes the staff here at GAIN. We might not be in the office, but we're still here for you, offering support and information from our kitchen or dining table. The first edition of the newsletter seems to have gone down well, so we've decided to make it a weekly event, updating information as it becomes available and keeping you informed of anything we think may be of interest.

Visit our website for updates www.gaincharity.org.uk

The latest Government advice

After a slightly confusing start, with guidelines that seemed to change daily, there is now a very clear message.

Stay at home

- Only go outside for food, health reasons or work (but only if you cannot work from home)
- If you go out, stay 2 metres (6ft) away from other people at all times
- Wash your hands as soon as you get home
- Do not meet others, even friends or family

You can spread the virus even if you don't have symptoms.

For more information and ongoing updates visit;

<https://www.gov.uk/coronavirus>

As we mentioned in the last newsletter, **having had GBS (or another acute variant) or living with CIDP (or another chronic variant) does not in itself damage or weaken your immune system.** However, there may be other factors to be considered, such as age, or taking steroids or other immunosuppressant medication, that could make you more vulnerable than other people.

The most vulnerable amongst us, and also anyone with a high temperature and/or a new, persistent cough, should self-isolate to keep the risk of infection to an absolute minimum.

This link (apologies for the length of it!) specifies those groups considered most vulnerable, along with guidance on shielding and protecting the vulnerable.

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

Keep in touch

Post is being picked up from the office regularly, and emails and social media are monitored during office hours

@ office@gaincharity.org.uk

f www.facebook.com/groups/727400487277814/

t @gaincharity

gaincharity

If you need to phone any of us, please use the mobile numbers below (Mon-Fri 9am-3pm)

Caroline	07719 280965
Gill	07877 982651
Simon	07878 090965

And if you want to drop us a line, you can write to us at the usual address;

GAIN, Glennys Sanders House
Pride Parkway, Sleaford, NG34 8GL

Any Questions?

The following questions and answers come from Dr Gareth Parry (ONZM, MB, ChB, FRACP) Dr Parry is an internationally renowned neurologist with a career long interest in neuromuscular diseases, particularly GBS and CIDP. He lives and works in New Zealand and in 2009 was awarded the NZ Order of Merit for Services to Neurology

Can COVID-19 cause GBS?

There have been no cases of GBS reported following infection with COVID-19. Given the number of cases reported world-wide (greater than 200,000 so far) it is highly likely that if the virus had a predilection for triggering GBS we would know by now.

If I have had GBS could COVID-19 trigger a recurrence?

GBS is almost always a disease that occurs only once and the likelihood of COVID-19 triggering a recurrence is immeasurably small.

If I have had GBS or currently have CIDP am I at greater risk of getting COVID-19 infection?

No, there is no increased risk of contracting COVID-19 infection.

If I am on treatment for CIDP will the treatments make me more susceptible to getting COVID-19 infection?

The two commonest treatments for CIDP are IVIg or steroid medications like prednisone. Steroids, along with all other immunosuppressive drugs that are sometimes used to treat CIDP [e.g., azathioprine (Imuran), cyclophosphamide (Cytoxan), rituximab (Rituxan) and others] compromise the effectiveness of the immune system leading to a greater susceptibility to any infection, including COVID-19, and a reduced ability to fight infection if it does develop. IVIg does not affect immune surveillance and there is no increased risk of getting COVID-19 infection or the ability to fight it.

I have been told that it is particularly important to get the flu jab this year. Could that trigger a relapse in my GBS or CIDP?

The flu jab will not protect you against COVID-19. However, it will protect you against getting the flu and if you were to get both the flu and COVID-19 infection the outcome would be extremely serious. It is therefore doubly important to get the flu jab this year; the risk of it triggering a recurrence is dwarfed by the risk of getting the infection. The one possible exception is if the original GBS was clearly triggered by a flu jab, i.e., the GBS occurred within 2 weeks of getting vaccinated. Even in that situation, the benefit of vaccination might outweigh the risk of complications, especially if you are a smoker or have another chronic disease such as chronic bronchitis or asthma, diabetes or heart failure. Discuss this with your doctor.

Join the conversation

Not being able to mix with friends and family outside your own household is difficult, and especially so for anyone living alone or with health issues. If you have access to a smart phone, or if you have a tablet, laptop or computer equipped with a camera and microphone, you can join in with our **virtual gaintogether** meetings, taking place every Tuesday at 2pm.

When?

Every Tuesday
at 2pm

Where?

From the comfort of
your own home!

Visit our website for details of how to join in
www.gaincharity.org.uk



Do you have CIDP or a chronic variant?

Do you attend hospital for regular IVIg infusions?

We have learned this week of a cancellation of an appointment for IVIg infusion due to the ongoing COVID-19 pandemic.

Although this is the first cancellation we've heard about, we expect it will become more common as things progress and more people are hospitalised with the COVID-19 virus. The cancellation was not due to a shortage of IVIg – as far as we know, there is no shortage, nor is any expected.

Our Medical Advisory Board have told us this decision will come down to individual trusts and their capacity. It is unlikely to be the neurologist's decision, as they obviously wouldn't want their patients to deteriorate in the short term. However, if your treatment is cancelled, and you experience a decline as a result, this would not be expected to be a permanent decline, improving again once treatment recommences.

Under normal circumstances, any long-term treatment is reviewed regularly in accordance with NICE guidelines, to assess whether it is still needed. We know that in some cases, there is no decline following withdrawal of IVIg as the CIDP is no longer active, so there is a chance that even if treatment is cancelled there may be only slight deterioration or none at all.

Yet another consideration in the current climate is that a hospital is now a potentially high-risk environment, so the benefits associated with receiving IVIg must be balanced against the risk of being infected with COVID-19 as a result of attending hospital.

In any case, the advice is to keep in touch with your neurology team so they can put the case to the wider hospital management who will be deciding which beds are used for which purpose.

Great news! GAIN trustee Adam Pownall's *Getting Better Slowly* is to be streamed for charity.

Getting Better Slowly is the inspiring true story of one man's two-and-half-year journey to recovery after Guillain-Barré syndrome paralysed him. The show is free to view and donations to support the work of GAIN are invited.

Go to <https://gaincharity.org.uk/getting-better-slowly-online/> grab a coffee or glass of something cold and watch the performance in full from your favourite spot on the sofa.

Available from Friday 3rd April.



Moving House?

If you are in the process of moving house, and wondering whether it can still go ahead, visit the Zoopla website for latest Government guidance and up to date information on how COVID-19 is impacting the property market.

<https://www.zoopla.co.uk/discover/property-news/coronavirus-latest-property-news-information-and-advice/>



Eat Crisps for Charity

Thank you to everyone who continues to support our crisp packet recycling programme. Some of you have collected several kilos as a group, and we would ask you to please hang on to them until the COVID-19 crisis is over, so we're not asking courier drivers to make unnecessary journeys.

Stay in, work out #GAINmomentum indoors!

What's that saying about the best laid plans of mice and men go oft awry? Never a truer word!

All over the world, people are having to cancel or postpone events, with casualties including the Olympics, UEFA 2020 and closer to home, the London Marathon, Wimbledon and the Edinburgh Festival to name but a few.

Well, our plans for celebrating GBS/CIDP awareness month might have changed a bit, but we want you to know that it's still full steam ahead this May!

As we've seen on the news and across social media channels this week, all it takes is a bit of imagination, and we can all find new and fun ways to keep fit and active. Some of you might already be tuning in to Joe Wicks or the Green Goddess, Diana Moran for a daily workout. But there are lots of other things you could try.

Here are a few ideas to get you started on your 31-day challenge.

Climb a mountain, one flight of stairs at a time.

Ben Nevis – 8,810 steps – 678 flights

Snowdon – 7,120 steps – 548 flights

Kilimanjaro – 38,680 steps – 2,975 flights (group challenge!)

Run a marathon in laps of your back garden

If we're still allowed out, set yourself a target of walking or running 5-10,000 steps each day (keeping to social distancing rules)

Mow the lawn or have a daily 'weeding workout'!

If you have access to a treadmill, rowing machine, or exercise bike, set yourself a target and go for it. Row across Lough Neagh (24km) or cycle from John o'Groats to Land's End (1.407km, or just over 45km per day)

Visit the website to register, and then throughout the month of May, share on social media and email us your photos and videos, and we'll include them in our #GAINmomentum gallery on the website! Prizes for the most imaginative, funny or bizarre!