

Guillain-Barré & Associated Inflammatory Neuropathies



Reaching out while you stay in

GAIN / coronavirus COVID-19 newsletter issue 1 27/03/2020

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. Read on for answers to some of the FAQs we've been receiving lately, along with a few ideas to keep everyone safe, healthy and in touch with each other during the coming weeks

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

What we know so far

Information has been changing daily for the last couple of weeks, and it isn't surprising that people feel uncertain and anxious. The latest message is quite clear though. As of this week, everyone must avoid or minimise contact with anyone outside of their own household through social-distancing. The most vulnerable amongst us, and also anyone with a high temperature and/or a new, persistent cough, **must** self-isolate to keep the risk of infection to an absolute minimum.

Thorough and regular hand-washing and sanitisation is vital, as is trapping coughs and sneezes in a tissue which is then disposed of safely.

Instructions for everyone in the UK, effective from 24th March until further notice

STAY AT HOME

- Only go outside for food, health reasons or essential work
- Stay 2 metres (6ft) away from other people
- Wash your hands as soon as you get home

Stay at home. Save Lives. Protect the NHS.

For more information visit;

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

#1 FAQ this week

Are people who have been affected by Guillain-Barré syndrome, CIDP or one of the associated inflammatory neuropathies more at risk from coronavirus COVID-19?

The following information is a general guideline only. If you have other factors to take into consideration, please seek medical advice.

GBS / acute variants

The advice for people who have had GBS is the same as for anyone else. A common misconception is that people who have had GBS have a weakened or damaged immune system – this isn't the case, and you are no more or less likely to contract the coronavirus or to be adversely affected by it.

CIDP / chronic variants

For those of you living with CIDP, or another of the chronic variants, you may have a suppressed immune system, depending on your treatment.

Having CIDP, or receiving immunoglobulin, either intravenously or subcutaneously, does not suppress your immune system, nor does plasmapheresis (aka plasma exchange or plex). However, if you take steroids, or other immunosuppressant drugs, then your immune system will be compromised and you are considered to be more vulnerable. If you are unsure, ask your GP or neurologist.

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

www.facebook.com/groups/727400487277814/

@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?

Q. I had GBS 10 years ago, and my immune system has never recovered. Should I self-isolate or am I ok as long as I keep to social distancing?

Having GBS doesn't damage your immune system, so unless there are other underlying factors, such as age or another medical condition that would make you more vulnerable, you just need to take the same precautions as everyone else.

Q. I have CIDP and get IVIG every 6 weeks. I've been told that people with chronic neuropathies are more at risk and should self-isolate, but the advice on your website says I'm not more at risk. I'm confused.

The advice from our Medical Advisory Board is that CIDP in itself does not weaken your immune system, nor does being treated with IVIG. If you are taking steroids or other immunosuppressant drugs, however, your immune system will be compromised. If your doctor has advised you to self-isolate, then you must take their advice.

Q. Who is classed as a vulnerable person?

The NHS has a complete list of people considered to be at greater risk of complications from coronavirus COVID-19. Visit their website for further information. <https://digital.nhs.uk/coronavirus/high-risk-vulnerable-patients-list>

Q. Does coronavirus trigger GBS?

Guillain-Barré syndrome is an autoimmune condition, which can be triggered by many viral and bacterial infections. We are not aware of any reported cases as yet, but as coronavirus COVID-19 is a viral infection, we would assume it has the potential to trigger GBS in a small number of people.

Q. Is coronavirus an autoimmune condition?

Coronavirus COVID-19 is not an autoimmune condition, but like many viruses, such as flu for example, it may have the potential to trigger an autoimmune response in some people.

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 Branch 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

#GAINmomentum indoors!

Have you heard about our exciting plans for GBS/CIDP awareness month this May? We want you all to get moving and get fit, and at the same time, raise awareness of the conditions and the charity. The plan hasn't changed, but the execution might need a bit of a tweak. We can't go and join a Saturday Park Run, or swim The English Channel one length at a time at our local swimming pool, but we can find fun ways to keep active in our own homes and gardens!

Visit the website to register, and then throughout the month of May, email us your photos and videos showing us what you get up to, and we'll share them on our #GAINmomentum gallery on the website! Prizes for the most imaginative, funny or bizarre!