

Guillain-Barré & Associated Inflammatory Neuropathies

Reaching out while you stay in

GAIN / coronavirus COVID-19 newsletter issue 8 15/05/2020

Welcome to issue 8 of GAIN's lockdown newsletter

After this week, we are planning on moving to a monthly rather than weekly newsletter. This is partly to free up resources and keep costs down, but also because eight weeks in, there is very little to say that is relevant specifically to people affected by Guillain-Barré syndrome, CIDP or the variants. We are all briefed daily in the news on any changes and developments that are taking place, and if anything crops up that requires sharing or comment from us, then we will reach out via our website and social media platforms. We're still here though, so if you have a question or concern, by all means get in touch!



Stay alert. Work from home if you can. Save lives.

Last Sunday, Boris Johnson addressed the nation, with a set of relaxed lockdown restrictions applying to people living in England, and changing the now-familiar message of 'stay home' to 'stay alert'. This has caused some confusion as neither Scotland, Wales nor Northern Ireland have relaxed their guidelines in the same way, with the 'stay at home' message remaining very firmly in place. As some of the changes have given rise to more questions than answers, here is a brief overview of the current rules depending on where you are.

In its exit plan published this week, the **Northern Ireland** Executive announced that restrictions will remain in place until at least 28th May, and schools will remain closed until the summer holidays. Face coverings should be worn on public transport and in shops.

<https://www.nidirect.gov.uk/campaigns/coronavirus-covid-19>

The message in the **Republic of Ireland** remains to 'stay at home', except essential workers not able to work from home, or anyone going out to buy food, medical supplies or to attend medical appointments. People may visit to care for a vulnerable person, including a relative, but not for social visits. Travel for exercise limited to 5km from your home.

<https://www.gov.ie/en/campaigns/c36c85-covid-19-coronavirus/>

Wales is keeping to tighter restrictions, with people still being urged to 'stay home'. Mark Drakeford, First Minister of Wales, has told people not to travel into Wales from other parts of the UK, with a warning that they may face a fine if this instruction is ignored.

<https://gov.wales/coronavirus>

The message in **Scotland** is still to 'stay home'. Workers who cannot work from home are not returning to work, as businesses have been told to stay closed unless they are essential to fighting the virus or for societal wellbeing. Face coverings should be worn on public transport and in shops.

<https://www.gov.scot/coronavirus-covid-19/>

Only in **England** has the message changed from 'stay home' to 'stay alert'. Workers are now urged to go back to work if they are unable to work from home, providing safety measures are in place. Face coverings should be worn on public transport and in shops or other indoor public spaces. Exercising outdoors is no longer limited to once a day, and people are permitted to travel anywhere (within England) for purposes of exercise and wellbeing. Some outdoor sports are allowed, but restrictions still apply. Garden centres are reopening. One person can now meet up with one other person from a different household in an outdoor public place, and people can now sit in a park or on a beach to relax or sunbathe. Reception, Year 1 and Year 6 children are expected return to school on 1st June.

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



Any Questions?

We were asked by one of our members this week why we don't include specific coronavirus guidance for people who have had GBS or are living with CIDP. For the majority, the advice is the same as for anyone else, so there aren't special guidelines for people affected by these conditions. In the first few issues of the newsletter, we answered lots of GBS/CIDP related questions that were asked in the early days of the pandemic. Most of the answers haven't changed over the weeks, but here is a recap.

Q. 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 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.

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.

This is a general guideline only. If you have other factors to take into consideration, please seek medical advice and if you are advised to shield then you should do so.

Q. I had GBS 10 years ago, and my immune system has never recovered. Should I shield or am I ok with 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. 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.

Q. Does coronavirus or COVID-19 cause GBS?

Guillain-Barré syndrome is an autoimmune condition, which can be triggered by many viral and bacterial infections. **There have now been several reported cases of Guillain-Barré syndrome being triggered by COVID-19, but it is too early to know how significant these numbers may be, and currently numbers are relatively low.** (updated 15/05/2020)

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

GBS is almost always a condition that occurs only once and the likelihood of COVID-19 triggering a recurrence is immeasurably small. **To our knowledge, none of the people so far who have developed GBS following COVID19 have had the syndrome before.** (updated 15/05/2020)

EMERGENCY APPEAL UPDATE

Thank you again to all of you who have so generously donated to GAIN over the last few weeks, and also to everyone taking part in challenges and fundraising campaigns to help raise money to meet the projected shortfall in income this year.

We know that this is an extremely challenging time financially for many families, that there are even more of you who would love to help, but who just can't. We have to ask, but we understand that not everyone is in a position to make a donation or to fundraise.

You can still help by spreading the word and sharing links on social media. We know this works because we have been receiving donations from people we've never heard from before.

General donations £6,878

The 2.6 Challenge £5,084

GAINmomentum £4,488

Total (so far) £16,450



THANK
YOU

<https://gaincharity.org.uk/donate>

Other sources of help

If you come to us for help, we will provide you with whatever support we can. But we can only do so within the confines of our charity remit, which is to;

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

Unfortunately, we can't help people with financial hardship caused by loss of income, etc, but there is often support available if you know where to look. If we can't help, we will try to signpost you to someone who can.

For general hardship, whether caused by the coronavirus pandemic or otherwise, contact your local council as they will be able to tell you about accessing your local food bank or community larder and may be able to help via a hardship fund.

UNITED KINGDOM

Find your local council

<https://www.gov.uk/find-local-council>

Trussell food banks (nationwide network)

<https://www.trusselltrust.org/get-help/find-a-foodbank/>

Carers UK - <https://www.carersuk.org/>

Age UK - <https://www.ageuk.org.uk/>

Salvation Army Emergency Assistance

<https://www.salvationarmy.org.uk/emergency-assistance>

ENGLAND

Citizens Advice

<https://www.citizensadvice.org.uk/>

Mental health support

<https://www.mind.org.uk/>

SCOTLAND

Citizens Advice

<https://www.citizensadvice.org.uk/scotland/>

Mental health support

<https://breathingspace.scot/>

WALES

Citizens Advice

<https://www.citizensadvice.org.uk/wales/>

Mental health support

<https://www.mind.org.uk/>

NORTHERN IRELAND

Find your local council

<https://www.nidirect.gov.uk/articles/find-your-local-council>

Citizens Advice

<https://www.citizensadvice.org.uk/about-us/northern-ireland/>

Advice NI

<https://www.adviceni.net/>

Mental health support

<https://www.mindingyourhead.info/>

REPUBLIC OF IRELAND

Contact your local coronavirus community support team; <https://www2.hse.ie/services/community-support-coronavirus/>

Community food services

https://crosscare.ie/services_category/community-food-services/

Citizens Information

<https://www.citizensinformation.ie/en/>

Services for older people in Ireland

<https://www.hse.ie/eng/services/list/4/olderpeople/>

Mental Health Ireland

<https://www.mentalhealthireland.ie/>

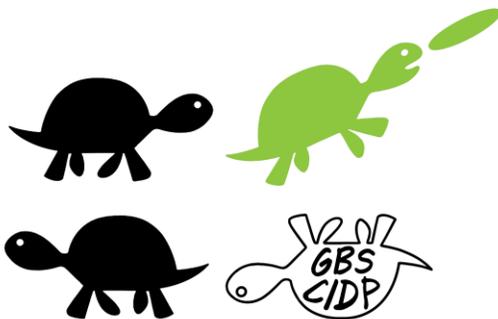
Join our weekly get-together

Video calling is as easy as having an actual face-to-face conversation and is almost like being in the same room. WhatsApp, Facetime, Skype and Zoom may be familiar names, but we'd like to introduce you to Starleaf, the app GAIN uses for our **weekly chat**. Wherever you are and whatever device you are on, the StarLeaf app lets you chat to anyone, anywhere. Download Starleaf from your app store, or online via www.starleaf.com/products/portfolio/the-starleaf-app/

No smartphone or computer? Don't worry! You can't video chat using a landline, but you can still join the conversation using your ordinary phone. Call us to find out how.

Join the weekly chat every Tuesday at 2pm and connect with other people who understand what it means to be affected by GBS, CIDP and the variants.

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



#GAINmomentum

Can you believe we're already half-way through the GAINmomentum month-long challenge?

Whether or not you have registered for the campaign, we hope everyone is getting more active and spreading the word during GBS/CIDP awareness month.

Don't forget to keep sharing your photos and videos on our social media platforms!

For loads of inspiration and instructions for exercises you can do at home, visit the NHS website;

<https://www.nhs.uk/live-well/exercise/gym-free-exercises/>

<https://www.nhs.uk/live-well/exercise/gym-free-workouts/>

<https://www.justgiving.com/campaign/GAINmomentum2020>

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