

Guillain-Barré & Associated Inflammatory Neuropathies



Newsletter issue 11 / 3rd February 2021

We're now well into the COVID-19 vaccination programme, and with more than nine million people already vaccinated, the feedback we're hearing is very positive. Unfortunately, there are a few people who remain reluctant to take the vaccine, but they are thankfully, very much in the minority.

It's important of course that people remain vigilant, as we're not out of the woods yet. Until everyone has been fully vaccinated, we must all make sure we stick to the spirit as well as the letter of the law. The only way we're going to get this virus properly under control and return to normal life is for **all of us** to be part of the solution.

Keep going – we will get there!



Dr Fauci gets it wrong

As 2020 drew to a close, we were inundated with questions from concerned people following a statement by Dr A. S. Fauci, director of the National Institute of Allergy and Infectious Diseases in the USA. Dr Fauci, who is an advocate of vaccinations, and is highly regarded by medical professionals around the world, unfortunately got it very wrong when he advised people who have had Guillain-Barré syndrome not to have the COVID-19 vaccination in case it triggered a similar response.



His advice was immediately dismissed as unfounded in an open letter signed by members of the global neurological community specialising in these conditions, including our very own, Professors Michael Lunn, Hugh Willison and Richard Hughes; familiar names to many of you due to their longstanding connections with GAIN.

In the letter they point out that; *"To date, no cases of GBS have been associated with the COVID vaccines. However, the number of subjects in the clinical trials is too small to detect such a rare event, if it existed, and surveillance is ongoing. In the meantime, we would urge all to follow national and local guidelines about who should get the vaccine. At this time, there is no reason that those who had GBS in the past cannot get the current COVID vaccines."*

In a subsequent interview published on 15th January 2021 in *Neurology Today* Dr Fauci admitted that he had misspoken in December. He went on to say *"That [interview] was conducted at a time before the CDC came out with their clear recommendations. As soon as the CDC recommendations came out, I began advising people according to the recommendations. I do stand corrected."*

Further reading; <https://www.prnewswire.com/news-releases/guillain-barre-experts-clarify-covid-19-vaccine-confusion-with-open-letter-to-dr-as-fauci-301197070.html>

COVID-19 stay safe

Guidance on COVID-19 differs from country to country and is regularly reviewed and updated. Please check the current advice for where you live

England

<https://www.gov.uk/government/collections/coronavirus-covid-19-list-of-guidance>

Scotland

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

Wales

<https://gov.wales/coronavirus>

Northern Ireland

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

Republic of Ireland

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

Your questions, answered

As you can imagine, we get asked the same questions by different people on a daily basis. We don't mind, of course; it's what we're here for, and we're always happy to provide clarity where we can in these uncertain times. Here are the answers to some of the most frequently asked questions over the last few weeks.

Q. I had Guillain-Barré syndrome 5 years ago. Is it safe for me to have the COVID-19 vaccine?

A. Having had GBS puts you at no greater risk from vaccines than anyone else and does not prevent you from being vaccinated against COVID-19. This also applies to anyone recovering from or living with any of the variants, both acute and chronic.

Q. I have CIDP and receive intravenous immunoglobulin every 6 weeks. When should I have my vaccination?

A. Some doctors will advise you that the optimum timing is to leave between 7 and 14 days either side of an IVIg infusion. However, if you can't manage that, and are in a priority group, it is better to be vaccinated than not, so don't delay once you get the invitation as the vaccine will not interfere with the IVIg, and the IVIg will not have an adverse effect on the vaccine.

Q. I take corticosteroids for my CIDP. Does it matter which vaccine I get?

If your immune system is suppressed due to corticosteroids or other medication, then you should avoid any vaccine that is live attenuated. So far, none of the vaccines that have been rolled out in the UK are live attenuated, so any of them should be suitable for you to take.

Q. I was diagnosed with GBS 4 months ago, but am in a high priority group due to another health condition. Am I ok to get vaccinated, or should I wait?

A. Some doctors will advise you not to have a vaccination within 6-12 months of a diagnosis of GBS. However, this advice is purely precautionary, and not based on any scientific evidence that having a vaccination in the few months following diagnosis with GBS will cause any adverse effects. If you are in a priority group, it is better to be vaccinated as you are at far greater risk from COVID-19.

Q. I had GBS 10 years ago, when I was 44, but I haven't had an invitation to get vaccinated yet.

A. Having had GBS does not put you in a priority group, as you are no more at risk from COVID-19 than anyone else. You will receive an invitation to be vaccinated according to your age group, unless you have an underlying condition.

If you have a question, please phone us on 01529 469910 (9am-3pm, Monday to Friday), or email us at office@gaincharity.org.uk. If we don't know the answer, we will consult our Medical Advisory Board and get back to you.



Association
of
British
Neurologists

Guidance on Vaccination for COVID-19 and Neurological Conditions

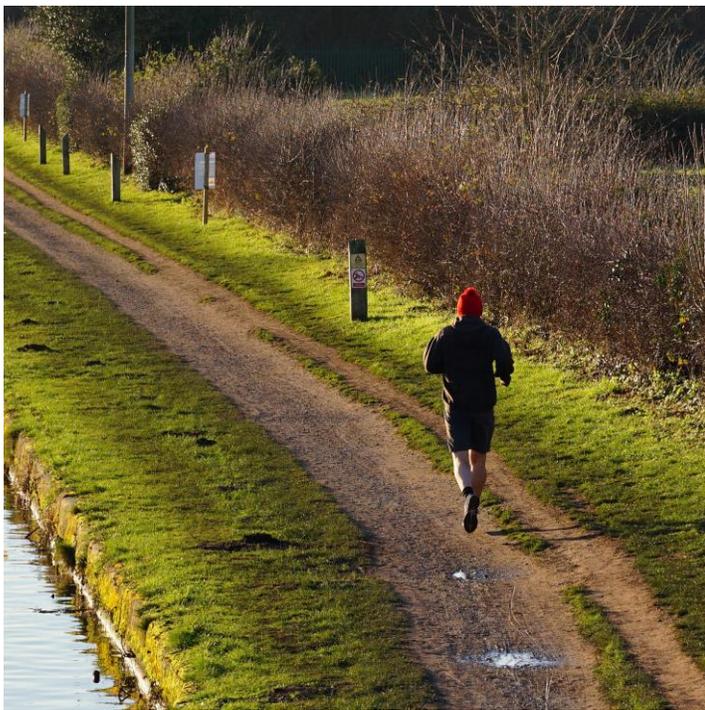
Many patients and their families are approaching neurologists to ask about vaccination against COVID-19. In general, other than for severely allergic people, there is no good reason to be worried about vaccination. In January, they released a document in an attempt to answer the questions that are commonly asked. People with more unusual medical problems should ask their GPs, who may refer you on to your neurologist. The government is rolling out vaccination and aiming to vaccinate those at greatest risk first.

Summary

- All COVID-19 vaccines are safe for neurology patients. The ABN recommends you take up whichever vaccination you are offered without delay regardless of your age, state of health or medication that you're receiving, unless you have a specific contraindication such as severe allergy. The vaccine protects individuals and society, and they are recommended for household contacts of immunocompromised adults.
- None of the COVID-19 vaccines are 'live' and therefore cannot cause infection.
- Because the vaccines have not been tested in pregnancy, they are not routinely recommended, however it is recognised that the potential benefits of vaccination are particularly important for some pregnant women who should take advice on the best course of action ([click here](#)).
- There is no information on the safety of COVID-19 vaccines in breastfeeding or on the breastfed infant. Despite this, COVID-19 vaccines are not thought to be a risk to the breastfeeding infant, and the benefits of breast-feeding are well known. Because of this, it is recommended that the vaccine can be received whilst breastfeeding.

Report published 9th January 2021

For further information, visit; <https://www.theabn.org/>



**Your race.
Your way.**

Would you like to get your hands on a London Marathon finisher's medal, but can't get a place?

We know that for most people, running a marathon is not something they could ever aspire to. However, for those of you who are able to take on such a challenge, GAIN has the opportunity to apply for places in the Virtual London Marathon, which takes place on Sunday 3rd October.

As long as you can complete the 26.2 miles within 24 hours on that day, you can run it wherever you like. Just track your progress on the official Virgin Money London Marathon app, and everyone who finishes will receive a much-coveted London Marathon medal and T-shirt.

Places cost £28 (£38 for anyone living outside of the UK) and we ask that you commit to raising at least £280 for GAIN. If you reach or exceed £500, we will send you a TeamGAIN running vest, customised with your name!

There's no time to waste! Places are limited to 25 in total, and they're going fast! If you're up for it, please pop over to the GAIN website right now to find out more and register for a place;

<https://gaincharity.org.uk/product/virtual-london-marathon-entry/>



The coronavirus (COVID-19) vaccine is safe and effective. It gives you the best protection against coronavirus.

Who can get the COVID-19 vaccine

The NHS is currently offering the COVID-19 vaccine to people most at risk from coronavirus. In England, the vaccine is being offered in some hospitals and pharmacies, at local vaccination centres run by GPs and at larger vaccination centres. More centres are opening all the time.

It's being given to:

- people aged 80 and over
- some people aged 70 and over
- some people who are clinically extremely vulnerable
- people who live or work in care homes
- health and social care workers

The order in which people will be offered the vaccine is based on advice from the Joint Committee on Vaccination and Immunisation (JCVI).

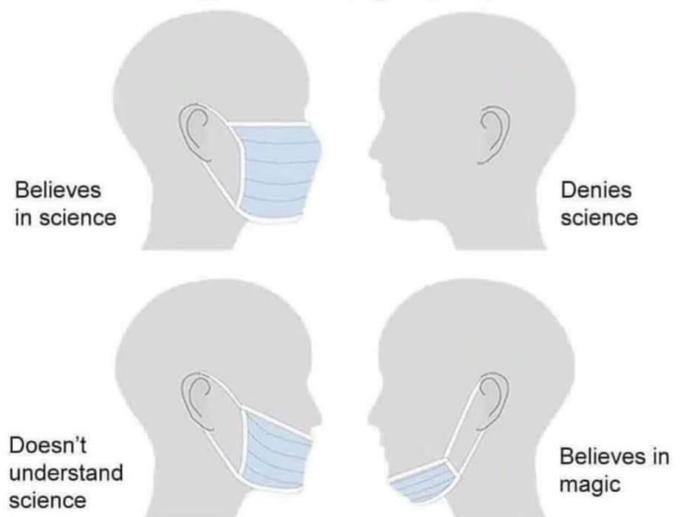
The NHS will let you know when it's your turn to have the vaccine.

It's important not to contact the NHS for a vaccination before then, so please be patient.

For further info, go to; <https://www.nhs.uk/>

The Four COVID Personality Types

(spotted at the local grocery store)



Get connected. Join the chat.



Joining a video chat is easy, and almost as good as having an actual face-to-face conversation.

Wherever you are and whatever device you are using, 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 on 01529 469910 to find out how.

General video chat	Lancashire & Cumbria	Midlands
2 nd Tuesday of the month at 2pm	1 st Friday of the month at 2pm	3 rd Thursday of the month at 2pm

For details of how to join a monthly chat visit www.gaincharity.org.uk



Join the GAIN 200 Club

Sign up before the end of March to take part! The more people joining in, the bigger the prize fund, so spread the word to friends and family!

Taking part only costs £20 per number for the whole year, which is paid in advance. To join the 200 Club, or for further details, please visit the website or get in touch (contact details below).

A massive thank you to everyone who has continued to support us during these difficult times. If you would like to make a donation, please visit the website and click on the donate button, or simply text GAIN to 70085 to donate £5

Keep in touch

Look us up on social media

-  office@gaincharity.org.uk
-  www.facebook.com/groups/727400487277814/
-  @gaincharity
-  gaincharity

Contact us during office hours
(Mon-Fri 9am-3pm)

Email: office@gaincharity.org.uk

Phone: 01529 469910

Helpline: 0800 374803 (UK) / 1800806152 (RoI)

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

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Pride Parkway, Sleaford, NG34 8GL