

Guillain-Barré & Associated Inflammatory Neuropathies



Newsletter issue 16 / 25 June 2021

Welcome to issue 16 of the GAIN newsletter. June 21st came and went without a huge amount of change in terms of what we can and can't do. As the vaccine rollout continues, more and more of us are protecting ourselves and others, in the hope that one day soon, we can all enjoy a bit more normality. In the meantime, remain vigilant, and try to take advantage of the warmer weather if you can. Outdoors remains the safest place to be if you're gathering together with friends and family, so dig out the BBQ (cook your chicken thoroughly), get out the camping chairs and enjoy the heatwave that is just around the corner (well, maybe!).



Almost 200 memberships renewed, with donations totalling £2,500

A big THANK YOU to everyone who has already sent back their membership renewal form, and especially to those of you who were able to enclose a donation, or who donate to us monthly or annually via Direct Debit or Standing Order. Sending individual letters of thanks is costly, and as we're desperately trying to save every penny we can, please treat this message of thanks as a virtual group hug!

We need to ask you to renew each year, to comply with GDPR. If you haven't returned your form yet, you can post it back to GAIN, Glennys Sanders House, Pride Parkway, Sleaford, NG34 8GL not forgetting to attach a stamp, or leave off the stamp and send it to 'Freepost GAIN' (no other address details please, otherwise we get charged the Freepost fee PLUS standard postage!). Of course, if you prefer, you can email or phone us with your renewal confirmation.

However you do it, please let us know you'd like us to keep in touch by renewing your membership. It's free, and you will receive a regular newsletter (thank you to everyone providing us with an email address for this – you save us money every month!) plus the annual magazine.



GAIN 200 Club

Winning numbers for June;

78 15 83

New members wishing to join in time for the July draw, must register via the GAIN website before noon on Wednesday 14th July.

Open to residents of England, Scotland and Wales who are 16 or over. See the GAIN website for full terms and conditions;

<https://gaincharity.org.uk/product/gain-200-club/>

Well done to everyone who took part in GAINmomentum this year. The campaign raised £4,426.50 (£5,218 inc Gift Aid), and we sent out 33 awareness packs to surgeries and hospitals throughout the UK. Special congratulations go to Dawn Marie Todd, who was the winner of a £50 voucher in the GAINmomentum 2021 prize draw!

Did you know that immunoglobulin can now be made from plasma donations collected in the UK?

In April this year, NHS Blood and Transplant (NHSBT) announced that people in the UK will be able to donate their blood plasma for use in the manufacture of life-saving medicines called immunoglobulins. Immunoglobulins are antibodies that come from blood plasma and are used, amongst other things, to treat people who are affected by Guillain-Barré syndrome and CIDP.

The British Society for Immunology has previously worked on this issue with a coalition of partners in a group called UK Plasma Action. This will be the first time in 20 years that people in the UK have been able to donate their plasma for the manufacture of immunoglobulin therapies. This move to allow people in the UK to donate their plasma for this use represents a huge step forward as it will mean a more secure supply of these vital therapies for patients.

There is an increasing demand for plasma around the world amidst a worldwide shortage of donors. Plasma collected in England will be used to manufacture medicines to treat NHS patients.

To find out more, visit; blood.co.uk/plasma or call 0300 123 23 23



COVID-19 advice

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/coronavirus-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/>



Congratulations to Wales and England on reaching the final sixteen in Euro 2020!

If you're watching the match with friends, make sure you stay safe, and take nothing away with you other than the warm glow of victory (or the bitter sting of crushing defeat)



Wales
v
Denmark
26th June



England
v
Germany
29th June



Guidelines if you're watching in WALES

Pub garden / outside > up to 30 people
In the pub > up to 6 people from 6 households
Staying indoors with friends > exclusive bubble of up to 3 households

Guidelines if you're watching in ENGLAND

Pub garden / outside > up to 30 people
In the pub / staying indoors with friends
> up to 6 people from 6 households,
or 2 households of any size

Case reports describe 'unusual' Guillain-Barre variants following COVID-19 vaccination

Some of you may have read in the press this week about a small number of cases of Guillain-Barré syndrome occurring shortly after receiving the first dose of the AstraZeneca vaccine. This was taken from two studies reporting small clusters 'of an unusual variant of Guillain-Barre syndrome' following receipt of a COVID-19 vaccine.

The first report, originating from the department of neurology at Nottingham University Hospitals NHS Trust, included a 54 year old with no relevant medical history; a 20 year old with a medical history of ulcerative colitis; a 57 year old with a medical history of asthma and osteoarthritis, as well as bilateral knee replacements and regular use of steroid and salbutamol inhalers, loratadine, omeprazole and tamsulosin; and a 55 year old with a medical history of hypertension and regular use of amlodipine and lisinopril.

The second report, from the department of neurology at Aster Medcity in India, reviewed seven cases of severe Guillain-Barre syndrome that developed within 2 weeks of the first COVID-19 vaccine. All cases involved bilateral facial paresis, according to the authors, which generally develops in less than 20% of unselected cases. Other cranial neuropathies, including abducens palsy and trigeminal sensory nerve involvement, developed in four patients (57%), which are uncommon among reports of Guillain-Barre syndrome in India, as it occurs in less than 5% of cases, the researchers noted.

The report authors emphasized that a link between COVID-19 infection and GBS has not been determined, making an increase in the rate of Guillain-Barre syndrome following COVID-19 vaccination 'unlikely'. They also noted that the benefits of vaccination against COVID-19 'substantially outweigh the risk of this relatively rare outcome', according to the case report.

Further reading;

<https://www.healio.com/news/neurology/20210617/case-reports-describe-unusual-guillainbarre-variants-following-covid19-vaccination>

GAIN commentary

Very rarely, a person may react to a vaccination, causing an autoimmune response, and we are aware of reports of GBS (some diagnosed, and some assumed), occurring within a few days or weeks of a COVID vaccination. Many of these have presented relatively 'minor' neurological symptoms which may be mild GBS, but which appear less severe with a quicker recovery timescale (i.e days / weeks rather than months / years). Although there may be a causal link, this cannot be assumed, as GBS will occur naturally in both the vaccinated and unvaccinated population. There is an ongoing study looking at this in detail, so anyone receiving a diagnosis of GBS following a vaccination should ensure their consultant reports their case to the British Peripheral Nerve Society who are collating data pertaining to all hospitalised cases of GBS during the vaccine rollout, regardless of the suspected trigger.

It is vital that people are not discouraged from having their COVID vaccination as the advice remains that even considering possible links with serious but very rarely occurring side effects such as blood clots and GBS, the benefits still outweigh the risks.

GBS does not relapse, and only recurs extremely rarely, so the chance of a second episode would be almost zero for someone who has had GBS in the past. In the majority of cases of a patient experiencing more than one episode of GBS-like symptoms, CIDP (a chronic variant of the syndrome) should be considered.

All of the reports of GBS following the COVID vaccine have been a first episode rather than a recurrence, and all have been after the first, rather than the second dose. Without the second dose, immunity will wane in comparison to the fully vaccinated population leaving a person who isn't fully vaccinated exposed to infection and COVID, which brings with it a risk of death at +/- 1 per thousand. With this in mind, we would urge even those who have developed an autoimmune response such as GBS following their initial vaccination not to dismiss the idea of taking a second dose to fully protect themselves.

Over £1,000 donated while you shop! Easy-peasy, lemon-squeezy!

amazonsmile
You shop. Amazon gives.

Sign up via the AmazonSmile website or download the app and select GAIN as your chosen charity

Total raised to date

£471.22

Total raised to date

£578.99

 **easyfundraising**
feel good shopping

Select GAIN as your chosen charity on www.easyfundraising.co.uk and we get a donation every time you shop online!



Get connected – grab a cuppa and join a video chat!

Open forum	Lancashire & Cumbria	GBS / acute	CIDP / chronic
2 nd Tuesday of the month at 2pm	1 st Friday of the month at 2pm	3 rd Thursday of the month at 2pm	4 th Thursday of the month at 2pm

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

Not online?

You needn't feel left out.

Have you been left feeling disenfranchised or alienated as technology increasingly takes over so many areas of our lives? If so, you might be interested in getting involved in a new initiative from GAIN, aiming to put people in touch with one another without an app, website or smartphone in sight!

If you would like to be in contact with other members of the charity by putting pen to paper, please let us know.

We will collate basic information, such as name, address, diagnosis and date of diagnosis, and compile a list of people with something in common.

Anyone on the list can then get in touch with anyone else on the list by sending a card or writing a letter (exchanging phone numbers is a private arrangement).



- 13% of adults, and 51% of over-75s do not use the internet
- Two million UK households have no internet access
- Nearly 12 million people in the UK don't have the digital skills needed to communicate online, handle information and make online transactions

If you would like to connect with others, please get in touch to register your interest (contact details below).

A massive thank you to everyone who continues 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;
GAIN, Glennys Sanders House
Pride Parkway, Sleaford, NG34 8GL