



Newsletter issue 17 / 30 July 2021

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 as restrictions are lifted.

England: www.gov.uk

Scotland: www.gov.scot

Wales: www.gov.wales

Northern Ireland: www.nidirect.gov.uk

Republic of Ireland: www.gov.ie

Reports of immunoglobulin shortages amidst increased global demand for plasma

Some of our members and supporters who have CIDP, or another of the chronic variants, and who are being treated with regular transfusions of immunoglobulin, may have been advised by their neurologist recently that the brand they have been receiving is not currently available, or is in short supply.

We are aware that there is a global shortage of plasma, due to a rise in demand, and to a reduction in numbers of plasma donors as a result of the pandemic. It appears that **Privigen**, which is manufactured in the USA, is the only brand of immunoglobulin to be affected so far here in the UK, but this could potentially have a knock-on effect as patients are switched to other brands.

We would expect many neurologists to take the opportunity to either reduce dosage and/or frequency, switch to another brand of immunoglobulin or to an alternative therapy such as corticosteroids, or remove treatment altogether for a time.

This is not a reason to panic, but is a perfectly normal part of the review process according to **NICE** guidelines (National Institute for Health and Care Excellence), which recommends an annual review in order to ensure that dosage levels remain appropriate, that treatment is still required, or to establish whether an alternative therapy may be more beneficial.

All medications carry a risk of unwanted side effects, so naturally, it is better to remove this risk if the condition being treated has gone into remission and treatment is no longer required. Regular reviews are therefore vital and are not undertaken without careful monitoring, but if you have any concerns, please make sure you talk to your neurologist, about **BRAN** (Benefits, Risks, Alternatives or Nothing) so you fully understand the reasoning and implications behind any decisions made.



GAIN 200 Club

Winning numbers for July;

111 49 7

New members wishing to join in time for the August draw, must phone the office, or register via the GAIN website before noon on Wednesday 11th August.

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/>

Could YOU be a plasma donor?

From April this year, people in the UK can donate plasma, and the plasma donated 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



Yes, we know it's still the middle of summer, but...

WINTER IS COMING

Biggest flu programme in history to roll out for winter 2021

Free seasonal flu vaccine to be made available for over 35 million people this year.

Last year saw the roll out of the biggest NHS influenza vaccination programme ever, with the aim of offering protection to as many eligible people as possible during the coronavirus (COVID-19) pandemic.

As a result of non-pharmaceutical interventions in place for COVID-19 (such as mask-wearing, physical and social distancing, and restricted international travel) influenza activity levels were extremely low globally in 2020/21. As a result, a lower level of population immunity against influenza is expected in 2021/22. If social mixing and social contact return towards pre-pandemic norms, it is expected that this coming winter, seasonal influenza virus (and other respiratory viruses) will co-circulate alongside COVID-19.

Seasonal influenza and COVID-19 viruses have the potential to add substantially to the winter pressures usually faced by the NHS, particularly if infection waves from both viruses coincide. The timing and magnitude of potential influenza and COVID-19 infection waves for winter 2021/22 are currently unknown, but mathematical modelling indicates the coming influenza season in the UK **could be up to 50% larger than typically seen** and it is also possible that it will begin earlier than usual.

From September 2021, providers will offer the flu vaccine to over 35 million people during the upcoming winter season, including all secondary school students up to year 11 for the first time. This builds on the success of last year's expanded flu programme, which saw a record number of people get their jab.

During the 2021 to 2022 season, which starts in September, the flu jab will be available to:

- all children aged 2 and 3 on 31 August 2021
- all children in primary school and all children in school years 7 to 11 in secondary school
- those aged 6 months to under 50 years in clinical risk groups
- pregnant women
- those aged 50 years and over
- unpaid carers
- close contacts of immunocompromised individuals
- frontline health and adult social care staff

Further info; <https://www.gov.uk/government/news/biggest-flu-programme-in-history-to-roll-out-for-winter-2021>

COVID-19 Vaccines



Take all recommended doses of your COVID-19 vaccine to get the maximum level of protection

Why?

The maximum protection is not reached until several weeks after full vaccination. If you have a two-dose vaccine, this means that you don't get full immunity until 2-4 weeks after the second dose.



Reports of Guillain-Barré syndrome following adenovirus vector COVID-19 vaccines

According to recent reports from the World Health Organisation (WHO) and the MHRA, there is a possibility that the Janssen (not available in the UK yet) and the AstraZeneca COVID-19 vaccines may be linked to a small number of cases of Guillain-Barré syndrome. Both are viral vector vaccines with an adenovirus platform. Pfizer and Moderna, which are both mRNA vaccines, have not been similarly linked.

It must be stressed that a definite causal link has not yet been established, and that the numbers are very low, representing a tiny percentage amongst the millions of people who have been vaccinated. Although it is likely that GBS will be added to the patient information leaflet as a possible but extremely rare adverse reaction, the conclusion overall is the potential benefits of both the Janssen and AstraZeneca COVID-19 vaccines continue to outweigh any potential risk of GBS, particularly given the increase in the more transmissible Delta variant.

We are concerned at reports of some doctors advising people not to get vaccinated if they have had GBS before, or not to get their second jab if they developed GBS shortly after the first one. Not having the second jab and subsequent boosters means any protection will quickly wane, leaving people exposed to the very real dangers posed by COVID and long COVID. GBS does not relapse, and only recurs extremely rarely. The chance of someone who has had GBS in the past getting it again is incredibly low, and we know of no one who has developed GBS for a second time after ANY vaccine. In England, the number of hospital beds taken up by COVID patients had increased from 1,500 on 30 June, to 5,182 on 28 July, and the people who are most seriously ill are the unvaccinated.

Please don't be one of them.

the Big Give

PLEDGES NEEDED NOW!

30 Nov – 7 Dec 2021

The Big Give Christmas Challenge

One donation, twice the impact.

The Big Give runs the UK's biggest match funding campaign, The Christmas Challenge.

For seven days from mid-day on Giving Tuesday, it offers supporters of participating charities the opportunity to have their donation doubled. Founded by entrepreneur and philanthropist Sir Alec Reed CBE, the Christmas Challenge has raised millions of pounds for thousands of charity projects since it launched on the Big Give in 2008.

How does the Christmas Challenge work?

The Christmas Challenge is a match funding campaign where donations to participating charities are doubled. The match funds come from two sources - charities secure some of these (pledges) over the summer. These funds are then boosted by funds from a Big Give Champion who contributes to the match fund. This collective pot is used to double donations from online supporters when the campaign is live.

This is the first year GAIN has taken part in the challenge, and we're delighted to report that our application has been approved and we can move on to the next stage.

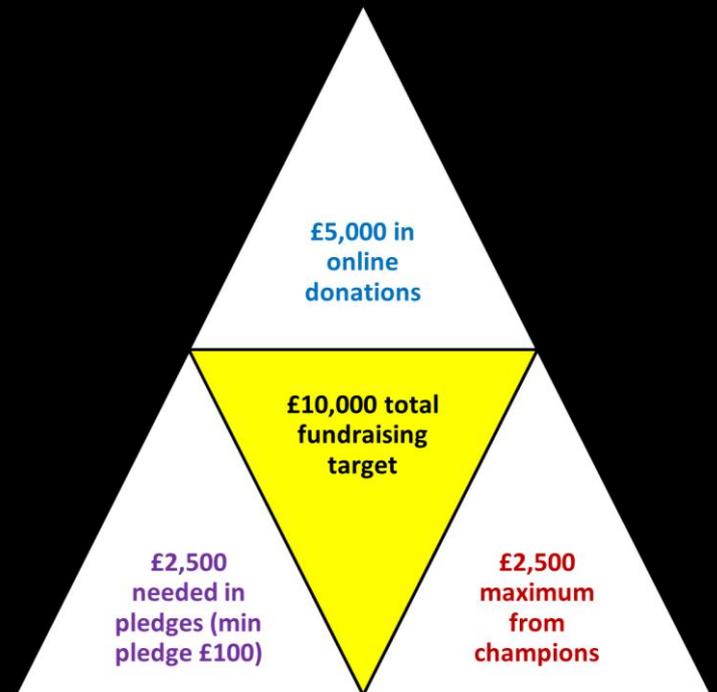
We have set ourselves a total fundraising target of £10,000, half of which we need to raise in online donations during the week when the campaign is active. Of the remaining £5,000, we are hoping that our campaign will attract support to the tune of £2,500 in Champion match funding, with the remaining £2,500 being raised in pledges from our own supporter-base.

Can you help us reach our pledge target?

If you, your employer, or other organisation that you are involved with, would like to support us in securing our pledge target and our place in this year's Big Give Christmas Campaign, and can pledge a minimum of £100, please complete a Pledge Form which can be accessed via this URL;

<https://www.thebiggive.org.uk/s/pledge?campaignId=a056900001xbYWNA2>

Pledgers can choose to remain anonymous, or be named and acclaimed on the GAIN website and social media platforms – it's up to you!



How do pledges work?

- ★ Pledges are part of the matching pot and are provided by supporters called Pledgers.
- ★ In order to take part in the campaign, and access the Champion fund, we must secure a minimum of £1,000 in pledges by 5pm on Friday 27th August 2021.
- ★ Pledges must not be paid until after the campaign has ended - they are conditional funding which we redeem according to how we perform in the campaign, and must be paid after midday on 7 December, and before the deadline of 5pm on 14 Jan 2022.

Don't worry if you aren't able to be a Pledger! During the campaign, we will be inviting **online donations from anyone who hasn't pledged, so as long as you can donate online, you can still take part and help us reach our total fundraising target!**



Please keep yourself safe and be considerate to other people by continuing to wear a face mask in enclosed spaces such as shops, especially if social distancing is difficult. This way, as restrictions are removed, we can all keep protecting each other from COVID, as well as other respiratory viruses such as flu.

An Amazon Smile

Some of you will have seen a story published by the BBC recently about **Malcolm Brown**, who developed food poisoning on holiday, and ended up in hospital with GBS on his return to the UK.

The article mentions that Malcolm's wife, **Janis**, had contacted GAIN to see if there was any voice-activated technology that they could buy, and that we had offered to provide them with an Amazon Echo Show. Although the family bought one themselves, the offer prompted Janis to do some



fundraising by running from Land's End to John o' Groats and back (virtually).

Imagine our surprise when, a couple of weeks later, we received a donation from Amazon, of £1,000!

Thanks to the generosity of Janis's friends and family, and also Amazon, the total donated to the GAIN Emergency Fund currently stands at over £3.5K including Gift Aid.



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

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](https://twitter.com/gaincharity)
-  [gaincharity](https://www.instagram.com/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