

# Guillain-Barré & Associated Inflammatory Neuropathies



## Newsletter issue 19 / 24 September 2021

As we head into autumn, we are receiving lots of enquiries regarding the seasonal flu jab as well as the COVID-19 booster rollout. Our advice is to go and get yours when it's offered. A sobering reminder of the consequences of not being vaccinated can be seen on page 2. Elsewhere in this issue, we launch a dedicated video chat for carers and family members of those diagnosed with the conditions, and invite you to take part in an exciting new study being conducted by the UCL Queen Square Institute of Neurology and MRC Neuromuscular Centre in London. We also have a couple of opportunities coming up for you to come along and say hello, with our members' meeting and AGM in October, and an open day in November. See you soon?

### New video chat dedicated to carers and family members



Early in the pandemic, when it became clear our local branches would be unable to continue meeting face to face, we introduced regular video chats to reach out and help people keep in touch who might be feeling particularly isolated. Regardless of where you live, these monthly group chats provide an easily accessible way to get together with others who understand some of the issues you are facing.

We initially held a general chat, which anyone could join, then added a session for people recovering from GBS or an acute variant, and another for those living with CIDP or a chronic variant.

As the months passed, we realised that carers and family members who are coping with the stress of having a loved one in hospital or living with a disability, perhaps coupled with financial worries or holding together a family and a job, sometimes felt guilty talking openly about the impact of their loved one's condition on their own lives. So, we decided to introduce a dedicated session just for them.

The general chat has now been replaced with a video chat for the carers, family and friends of people diagnosed with any of the conditions, both acute and chronic.

The slot has also changed, moving from the 2<sup>nd</sup> Tuesday of the month, to the **2<sup>nd</sup> Thursday of the month at 2pm**, to bring it in line with the acute and chronic video chats, which take place on the 3<sup>rd</sup> and 4<sup>th</sup> Thursdays respectively.

To find out how to join, visit the GAIN website and click on the Video Chat tab at the top of the page (desktop) or drop-down menu (smart phone).

**The passing of the Autumn Equinox on 22<sup>nd</sup> September means the nights are drawing in...**



**...so it must be time to stock up on GAIN Christmas cards and stocking fillers!**

We have sold over £470 worth of Christmas cards so far and it's still only September! Help us to raise awareness as well as funds by heading over to the GAIN website to grab yours now.

While you're there, have a look at our new range of sterling silver tortoise-themed jewellery – the perfect gift for a special someone who is Getting Better Slowly, or is living with a GBS/CIDP warrior.

**[www.gaincharity.org.uk](http://www.gaincharity.org.uk)**



LONDON  
MARATHON  
2021

## Good luck to all our runners in the London Marathon!

As well as one person who managed to get a public ballot place, we have a further 21 runners taking part in the virtual marathon this year. The total raised so far by the 22 members of Team GAIN is a magnificent £12,418.90 plus Gift Aid, which is a phenomenal achievement!

Team GAIN members are Paul, Henry, Michael, Mark, Richard, Millie, Lucy, Sam, Simon, Ed, Michael, Dougie, Shaun, Jess, Amy, Saara, Ikra, Rachael, Abbie, Nyree, James and Sally

Good luck everyone!



## GAIN 200 Club

Winning numbers September

78   19   116

New members wishing to join in time for the October draw, must register via the GAIN website or by phoning the office before noon on Wednesday 13<sup>th</sup> October (contact details on back page). Open to residents of England, Scotland and Wales who are 16 or over. See website for full terms and conditions;

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

I know we keep banging on about getting vaccinated, but it really is important that we all protect ourselves from the very real and present danger from COVID and flu. Please take up your offer of a booster jab, as well as the seasonal flu vaccine. GBS doesn't relapse, and we know of no one who has had a second episode following a vaccination.

Deaths involving COVID-19 by vaccination status 2 January to 2 July 2021

640 deaths amongst the fully vaccinated

11,677 deaths after first dose only

38,694 deaths amongst the unvaccinated

# University College London launches new study into the causes of inflammatory neuropathies

The UCL Queen Square Institute of Neurology and MRC Neuromuscular Centre in London is conducting a study into the risk factors in CIDP and chronic inflammatory neuropathies in order to better understand the causes and further develop effective treatments.

They are collecting saliva by post into a small tube (with full ethical approval) from patients with CIDP and associated chronic inflammatory neuropathies and also from people who have ever received a diagnosis of GBS or an associated acute neuropathy. They will be looking at important genetic pathways and are keen to involve as many patients as possible around the UK.



*The UCL Queen Square Institute of Neurology is a global leader in neuroscience. Part of the Faculty of Brain Sciences, they are at the forefront of the mission to translate neuroscience discovery into diagnostics and treatments for patients with neurological diseases.*

If you are interested in getting involved with this exciting new study, please email Caroline Morrice at [takepart@gaincharity.org.uk](mailto:takepart@gaincharity.org.uk) with a few details, including your full name, address, date of birth, diagnosis and date of diagnosis.

## GAIN members' meeting and AGM 2021

Saturday 16<sup>th</sup> October 2021  
at 10am

Glennys Sanders House,  
Sleaford, NG34 8GL

also streamed via Zoom

To join Zoom meeting:

<https://us02web.zoom.us/j/81715047927?pwd=aWRLZHZYdmlyQ0hyNm9nS2RkbEcxZz09>

Meeting ID: 817 1504 7927

Passcode: 465255

### Agenda

09:30	Arrive / coffee
10:00	Opening remarks
10:15	New clinical guidelines for diagnosis and treatment of GBS and CIDP (MAB*)
10.45	Research and the new(ish) antibodies (MAB*)
11.15	COVID and vaccines (MAB*)
1145	Review of the year
1200	AGM
	Close

Please submit questions and let us know if you are attending in person NO LATER than Thursday, 14<sup>th</sup> October. Non-voting members are welcome to stay for the AGM but cannot vote.

\*updates from the GAIN Medical Advisory Board

## Come on over to our place!

If you're within easy reach of Sleaford, or just fancy a trip to Lincolnshire, why not join us for our Autumn Open Day pop-in? You can come along any time that suits you, between 10am and 3pm on **Friday, 12<sup>th</sup> November** at Glennys Sanders House, Pride Parkway, Sleaford, NG34 8GL.

As well as a warm welcome, you will have access to as much tea, coffee, and cake as you can manage (in exchange for a modest donation, if you feel so inclined). You will also be able to peruse the 2021 GAIN Christmas card and gift-wrap collection and pick up a few stocking fillers from our gifts and merchandise range, including some lovely new tortoise-themed sterling silver jewellery. See you there!



## Coronavirus (COVID-19)

Coronavirus remains a serious health risk. You should stay cautious to help protect yourself and others.

- Let fresh air in if you meet indoors. Meeting outdoors is safer
- Wear a face covering in crowded and enclosed spaces where you come into contact with people you do not normally meet
- Get tested and self-isolate if required. If you have no symptoms, get regular lateral flow tests. If you have symptoms, get a PCR test and stay at home
- If you haven't already, get vaccinated

Make sure you have the latest advice and information for where you live

If you are in England, Northern Ireland, Scotland, or Wales you can find recent and upcoming changes to COVID guidelines by visiting the gov.uk website and selecting your location:

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

If you live in the Republic of Ireland, you can find the latest public health updates here:

<https://www.gov.ie/en/publication/3361b-public-health-updates/>

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



Carers, family & friends	GBS / acute	CIDP / chronic	Lancashire & Cumbria
2 <sup>nd</sup> Thursday of the month at 2pm	3 <sup>rd</sup> Thursday of the month at 2pm	4 <sup>th</sup> Thursday of the month at 2pm	1 <sup>st</sup> Friday of the month at 2pm

For details of how to join a video chat, visit [www.gaincharity.org.uk](http://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

Don't forget, you can also support us when you shop online! Look us up on AmazonSmile, EasyFundraising, Give As You Live and GoRaise

## 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](mailto: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