

Guillain-Barré & Associated Inflammatory Neuropathies



Reaching out while you stay in

GAIN / coronavirus COVID-19 newsletter issue 5 24/04/2020

What's new?

Not much, really. There is no quick fix for this global crisis. The best thing we can do in the absence of a vaccine is carry on with social isolating for the time being and continue to protect the most vulnerable. In the meantime, we will try to keep you informed, while we all do what we can to help and support one another.

Stay at home. Save lives.

We know that for many people, the problems caused by the current lockdown go way beyond the inconvenience of social distancing and staying at home.

Whether your worries are related to your health, family or finance, we are here for you, and if we can't help, we will try to signpost you to someone who can. But we also want to be here in another 12 months, when all of this is behind us. We are expecting a shortfall of at least £50,000, and potentially as much as £100,000 in lost fundraising income this year. And we need help if we're going to survive. If you can't help, don't worry, but if you can, we would be very grateful for anything you can afford, no matter how small. Thank you.

3,500 members x
£2.60 = £9100
£5 = £17,500
£10 = £35,000
£26 = £91,000

**IT'S ALL
IN THE NUMBERS**



**WE NEED
YOU!**

SUPPORTED BY **LE MASURIER**

Emergency Appeal – thank you to everyone who has contributed so far!

For the **coming week only**, we are inviting you all to take part in a very special campaign called **The 2.6 Challenge**. Organised by the mass participation events industry of the UK, it takes place from 26th April, the day on which the 40th London Marathon (26.2 miles) should have been happening. The mission is to help save the UK's charities, which are being hit hard by the cancellation of events in this, the busiest fundraising season of the year. To join in, you can make a donation, or do a bit of fundraising yourself - think up a challenge around the numbers 26 or 2.6 and ask friends and family to chip in a couple of quid to sponsor you!

Visit the website for further information and to start fundraising or make a donation.

<https://gaincharity.org.uk/gain-2-6-challenge/>



CORONAVIRUS / COVID-19 VACCINE DEVELOPMENTS

Coronavirus is spreading around the world, but there are still no vaccines to offer protection against the disease it causes, COVID-19.

Medical researchers are working hard to change that, and here in the UK, human testing began this week.

Why is a coronavirus vaccine important?

The virus spreads easily and most of the world's population is still vulnerable to it. A vaccine would provide some protection by training people's immune systems to fight the virus so they should not become sick. This would allow lockdowns to be lifted more safely, and social distancing to be relaxed.

When will we have a coronavirus vaccine?

A vaccine would normally take years, if not decades, to develop. Researchers hope to achieve the same amount of work in only a few months. Most experts think a vaccine is likely to become available by mid-2021, about 12-18 months after the new virus, known officially as Sars-CoV-2, first emerged. That would be a huge scientific feat and there are no guarantees it will work. Four coronaviruses already circulate in human beings. They cause common cold symptoms and we don't have vaccines for any of them.

How do you create a vaccine?

Vaccines harmlessly show viruses or bacteria (or even small parts of them) to the immune system. The body's defences recognise them as an invader and learn how to fight them. Then if the body is ever exposed for real, it already knows what to do. The main method of vaccination for decades has been to use the original virus. The measles, mumps and rubella (MMR) vaccine is made by using weakened viruses that cannot cause a full-blown infection. The seasonal flu jab takes the main strains of flu doing the rounds and disables them.

'I've had GBS. Does this mean I won't be able to have the new vaccination?'

Vaccines work by protecting people from the risk of contracting a range of conditions. Some of these, such as seasonal flu for example, as well as being potentially dangerous to the most vulnerable, can also trigger Guillain-Barré syndrome.

We have received several enquiries asking whether someone who has had GBS will be able to have the new coronavirus vaccine when it becomes available.

To be honest, it is far too early for anything other than speculation, but based on what we know about other vaccines, there is no reason currently to think people who have had GBS should not have this new vaccine.

We will tell you more when more is known.

COVID-19 and GBS – more follow-up

By Dr Gareth Parry (ONZM, MB, ChB, FRACP)

This “rapidly evolving field”, to quote my previous communication, has indeed rapidly evolved. In this week's New England Journal of Medicine, the top-rated clinical medical journal in the world, there is a report of five patients who developed GBS associated with COVID-19 infection.

This report is much more persuasive than the prior one I wrote about. I have reviewed the clinical reports and there is no doubt that they did have GBS and the interval between the infection and the onset of GBS was 5-10 days, typical of the interval for other infections.

Also, the number of cases seen from a relatively small population in Northern Italy suggest that the association was not coincidental. These five GBS cases occurred among about 1200 COVID-19 patients admitted to the same hospitals but, of course, there were many other cases admitted to other hospitals and occurring in the community but not admitted to a hospital.

Nonetheless, this report does suggest that COVID-19 may be a GBS trigger for some susceptible individuals. Whether this is just a nonspecific viral trigger or will represent an increased susceptibility with COVID-19, resembles that seen with the EB virus (that causes glandular fever) and Zika virus remains to be seen.

I have requested that my neurological colleagues around NZ test all GBS patients for COVID-19 and to communicate the result to Dr Taylor or to me. It will be interesting to see if there is a spike in GBS cases during this epidemic. The link to the article for those wishing to read about the cases:

<https://www.nejm.org/doi/full/10.1056/NEJMc2009191?query=RP>

IN THE NEWS

Domestic abuse victims 'have no escape' during lockdown

Charities fear domestic abuse is likely to increase during lockdown, and that victims feel unable to seek the help they need because they are trapped at home with their abuser.

There is support available, so if you are being abused, please reach out and ask for help.

Refuge (for women and children)

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

Respect (for male victims of abuse)

<https://mensadviceline.org.uk/>

Childline (for children)

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

Ramadan and Coronavirus/COVID-19

The Muslim holy month of Ramadan is a special time for nearly two billion Muslims all over the world. In any normal year, it is a time of communal prayer, of daytime fasting, night-time feasting, extensive socialising and acts of profound generosity and charity as Muslims reaffirm their faith in God.

This year, those observing Ramadan will be praying and breaking fast at home instead of gathering together. In addition, in accordance with advice from the British Islamic Medical Association, some key workers may decide not to fast this year, because having to wear PPE makes you much hotter and more dehydrated than usual.

Children, the elderly, women who are pregnant, breast-feeding or menstruating, and those with certain health conditions are already exempt from fasting, so many of those who are currently self-isolating will not be required to fast.

Ramadan this year starts on 23rd April and finishes with Eid al-Ftir (Festival of Breaking the Fast) on the evening of 23rd May.

www.bbc.co.uk/news/uk-52369828

<https://britishima.org/ramadan-rapid-review/>



Beat the isolation and join the conversation!

You may have seen **Dame Judi Dench** on the BBC this week, talking about using video chat to keep in touch with her friends and family during lockdown. If you have never considered using technology to communicate, now is the perfect time to start (but preferably not in the bath!)

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 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



When?

Every Tuesday
at 2pm

Where?

From the
comfort of your
own home!



Driver & Vehicle Licensing Agency

<https://www.gov.uk/guidance/dvla-coronavirus-covid-19-update>

The DVLA has a very limited number of staff working on site and are prioritising applications from key workers. Please use their online services only and do not send in any paper applications until further notice. Check DVLA website for updates.

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)

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

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