

Guillain-Barré & Associated Inflammatory Neuropathies



Newsletter issue 13 / 26th March 2021

As we come to the end of what has been a very tough financial year, we look ahead to the new challenges the coming months may bring. Last year, virtual events were hastily introduced in place of many of the cancelled marathons and other high profile fundraising challenges that charities rely on. An unexpected bonus was that this has opened up popular events such as the London Marathon to thousands of people who wouldn't ordinarily be able to get a place. We have also secured places in the Virtual Vitality London 10K, which ties in very neatly with this year's GAINmomentum challenge, which runs throughout May, for GBS/CIDP awareness month. Don't panic – you don't need to be athletic to take part! See inside for further details of how you can get involved.



Feeling lucky?

There's still time to join the
GAIN 200 Club!

Don't miss out! The first draw takes place on Wednesday, 14th April, so make sure you buy your number(s) no later than 13th April. The more club members, the bigger the prizes, so get your friends and family to join too!

You have to be in it to win it!

To enter, visit the shop at www.gaincharity.org.uk or email or phone us for an application form. Allocation of numbers will be randomised and sent out in the first week of April. Residents of England, Scotland and Wales only. Entrants must be 16 or over.

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/>

stay safe

Get ready for GAINmomentum 2021!



We all know the benefits of exercise, but few of us do enough of it. GAINmomentum is all about challenging yourself to get moving throughout the month of May to mark GBS/CIDP awareness month.

Raising awareness of a rare disease is never easy. Everyone knows someone affected by stroke, cancer or dementia, and we've all heard of the big charities that do fantastic work to help people with these conditions. But until someone you know is diagnosed with Guillain-Barré syndrome, CIDP, or one of the associated inflammatory neuropathies, chances are you've never heard of it before.

That's where GAIN comes in, providing information and support when it is needed most. It's really important that people know there is help available if they have been recently-diagnosed with GBS or CIDP. And that's where you come in.

What will YOUR challenge be?

Because May is GBS/CIDP awareness month, we want you to get active and spread the word. Run, walk, cycle, row, jump, stretch, roll, swim, dance or skip - it's your call! You might decide to climb a mountain one flight of stairs at a time, do the Couch to 5K challenge, or row the Channel using a rowing machine. Just set yourself a personal goal, making sure it's challenging but realistic, to avoid getting bored or disheartened.

If you like a bit of competition, or find that recording your daily activity using an app helps motivate you and keeps you focused, download **Strava** and join the GAINmomentum Club!

However you do it, and whatever your goal, count your steps, track your distance or keep a note of how many minutes you are active on each day throughout May, then sit back and bask in a sense of achievement.

Don't forget to tell everyone what you're doing and why. Set up your own fundraising page linked to the GAINmomentum 2021 campaign on JustGiving, and spread the word amongst family and friends. Their donations will help spur you on to reach your fitness challenge, at the same time supporting a cause that means so much to you.

Just go to <https://www.justgiving.com/> and type **GAINmomentum** in the search bar to find the campaign page, then click on the big orange Start Fundraising button towards the top right of the page. Once you've set your page up, you can go back and personalise it with your own words and images.

There are two options for registering to take part in GAINmomentum 2021.

If you would like a GAINmomentum T-shirt to wear, entry costs £10 per adult and £5 per child, but if you don't want a T-shirt, entry is FREE.

Just sign-up via the website shop, and towards the end of April, we'll send you an awareness pack, including a GAINmomentum button badge, and some information to take to your local surgery or hospital.

To sign up visit:
<https://gaincharity.org.uk/product/gainmomentum-2021/>
or email us at:
office@gaincharity.org.uk



#GAINmomentum

People vaccinated

First dose total 28,991,188
Second dose total 2,775,481

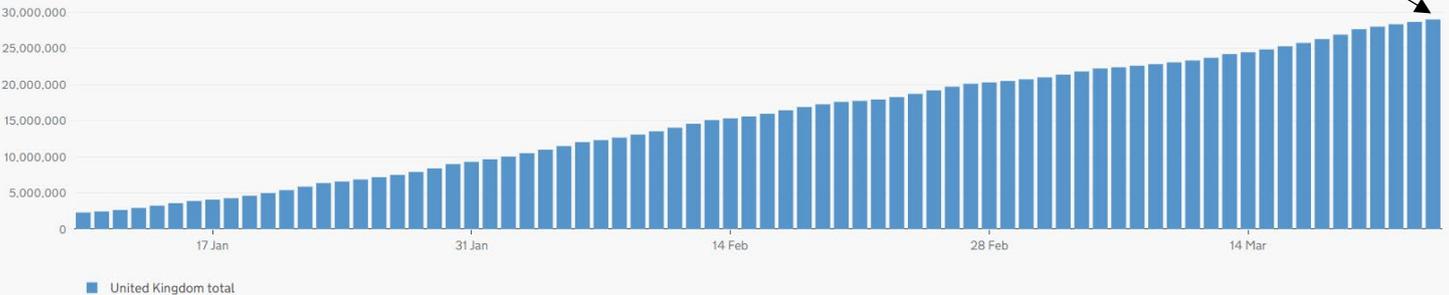
Vaccinating the nation

People who have received 1st dose vaccinations, by report date

UK total By nation

The number of people who have received a first dose COVID-19 vaccination, shown by date reported. Daily figures include all vaccines that were given up to and including the date shown, and that were entered on the relevant system at the time of extract.

Daily **Cumulative** Data About



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COVID-19 Vaccine AstraZeneca

An update on ongoing evaluation of blood clot cases

Last week, PRAC, the safety committee of the European Medicines Agency, concluded its preliminary review of cases of blood clots, including very rare cases of blood clots with unusual features such as low numbers of platelets, in people vaccinated with COVID-19 Vaccine AstraZeneca.

The committee confirmed that the vaccine is **not associated** with an increase in the overall risk of blood clots and that the benefits of the vaccine in combating the still widespread threat of COVID-19 continue to outweigh the risk of side effects. The committee recommended including more information and advice for healthcare professionals and the public in the vaccine's product information.

The amended product information and the associated direct healthcare professional communication are now available on the EMA website.

PRAC is continuing its assessment of the reported cases. In this context, EMA is convening an *ad hoc* expert group on 29 March to provide additional input into the assessment. External experts in haematology (thrombosis and haemostasis), cardiovascular medicine, infectious diseases, virology, neurology, immunology and epidemiology will meet to provide their views to PRAC on aspects such as any plausible mechanism of action, possible underlying risk factors and any additional data needed to gain a deeper understanding of the observed events and the potential risk. This expert group will also include two representatives from the public.

The outcome of the expert meeting, together with further analysis of the reported cases, will feed into PRAC's ongoing evaluation. The PRAC's updated recommendation on the issue is expected during its April plenary meeting (6–9 April).

For further information from the EMA, visit the website; <https://www.ema.europa.eu/en>



The Covid-19 vaccination programme has saved more than 6,000 lives, an analysis by Public Health England says.

Most would have been among the over-80s and some among people in their 70s, estimates up to the end of February suggest. It comes as people in England aged over 50 and in at-risk categories are being urged to book their Covid jabs before Monday, when slots are set to dry up. The NHS said appointments should be arranged by 29 March.

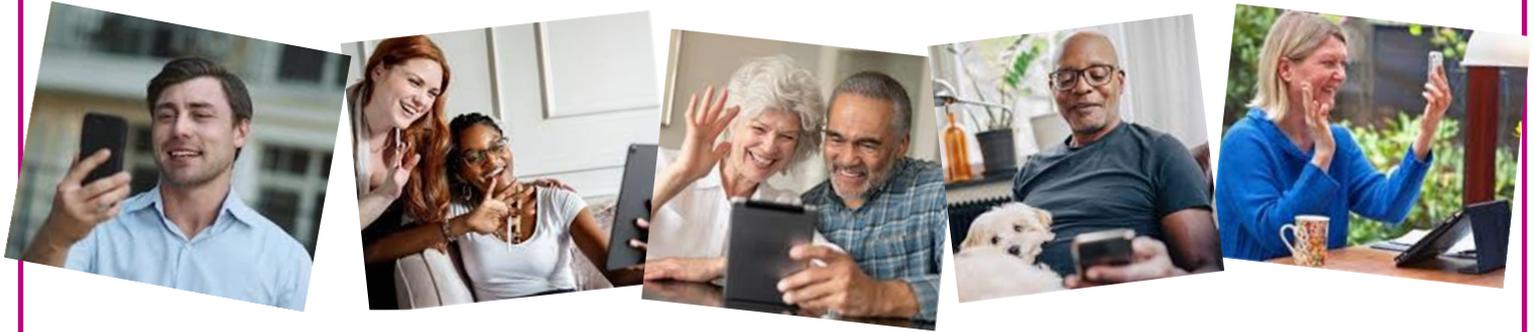
Four in five people in the first nine priority groups have now received at least one dose of a vaccine.

Immunisation head Dr Mary Ramsay said: "The vaccines have an excellent safety record - and I would encourage anyone who is offered a vaccine to take it as soon as possible."

NHS England medical director Prof Stephen Powis said: "It is a testament to the careful planning and sheer hard work of staff that the NHS vaccination programme is continuing to protect people against coronavirus at a record pace."

<https://www.bbc.co.uk/news/uk-56521415>

Want to talk to people who understand the issues you face? Join in with a video chat!



Joining a video chat is easy, and is a safe and accessible way to keep in touch and feel connected with other people who understand the issues you are facing. In March, we introduced a new, more tailored monthly chat for people who have been affected by GBS or an acute variant (AMAN, AMSAN, Miller Fisher), along with a separate session for those of you who are living with CIDP or a chronic variant (MADSAM, MMN/CB, PDN, POEMS, etc). We also know that it isn't only the person with the diagnosis whose life is turned upside down. If you live with someone diagnosed with one of these conditions, perhaps adapting to a new role as carer, or just struggling to come to terms with a very different and uncertain future, then let us know if you would be interested in talking to people in a similar situation by emailing simon.johnson@gaincharity.org.uk.

General video chat	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

Beat the scammers

Fraudsters are bombarding the UK public with scams, ruthlessly exploiting events like the pandemic to catch us off guard. People are falling victim to scams by email, text, phone calls and social media. Scammers are stealing £billions.

Free Which? Scam Alerts are regular email updates on the latest scams doing the rounds – and practical advice to keep you one step ahead of the scammers. Your friends and family can sign up too.

Go to: <https://campaigns.which.co.uk/scam-alert-service/>



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](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