

Guillain-Barré & Associated Inflammatory Neuropathies



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With more than 18 million people vaccinated so far in the UK, the COVID vaccine rollout is going about as well as any of us could have hoped for. Even better news, is that there have been no serious side effects, with nothing more than a sore arm, short-term fever or feeling 'a bit fluey' for a day or two being reported under the Yellow Card Scheme (read more about this inside). Charities continue to be hit hard by the pandemic as most fundraising events are yet to restart, but we did have some good luck, in securing 25 places in the Virtual London Marathon this year! Most have been snapped up already, so if you would like to get your hands on one, pop over to the website shop before you do anything else!



Because we all care: unpaid carers

The Care Quality Commission (CQC) would like to hear from anyone who is caring for a loved one about their experiences.

"The changing priorities of our health and care services during the COVID-19 pandemic has had a significant impact on unpaid carers, and the last 10 months have been an extraordinary time for them. 81% are providing more care for their loved ones, often as a result of health and care systems temporarily reducing their services and relatives' care needs increasing.

"In many cases, unpaid carers have not got what they needed from these services, going for long periods without a break, not able to get the additional support they need, and in some cases reducing or giving up work altogether to care. Meanwhile some carers have been able to get the practical support they needed.

"We encourage carers to have their say on their experiences of health and social care services during the pandemic – good and bad - so that the right improvements can be made for all carers."

Helen Walker, Chief Executive of Carers UK

To join the conversation, go to;
<https://www.cqc.org.uk/help-advice/share-your-experience/because-we-all-care-unpaid-carers>

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



£150 MILLION RAISED FOR THE NHS CHARITIES COVID APPEAL

Public donated an additional £800m to charity during first lockdown

Donors gave £800m more than usual to charity during the UK's spring lockdown, but some charities have still lost out on hundreds of millions of pounds, according to new research from the Charities Aid Foundation.

Between January and June 2020, members of the public donated a total of £5.4bn to charity, according to CAF's *UK Giving: Covid-19 Special Report*.

The research demonstrates that despite the public feeling anxious about their household finances early in the pandemic, they did not give less to charity.

The organisation said the levels of household giving that took place during the first months of lockdown are normally reserved for the peak seasonal fundraising months of November and December.

Other key findings of the report included a large increase in the number of people donating to, or sponsoring, 'hospitals and hospices' during the height of the pandemic's first wave. One in five people reported donating to charities which support the NHS.

The number of people giving via a website or app increased significantly over the same period (from 13 to 24 per cent), while cash donations, normally the most popular way of giving, dropped off substantially between March (34 per cent) and April (13 per cent).

Positively for the sector, at the end of April, more people than usual reported that they intended to donate more in the next 12 months.

However, the report also found that some charities suffered unprecedented losses, as donors shifted their donations to charities supporting the NHS, and fundraising opportunities disappeared.

Medical research charities are among the hardest hit by this shift, losing out on an estimated £174m in the first six months of 2020.

Additional research by the Association of Medical Research Charities found many face cuts to their research investment of 41 per cent over the next year alone – a predicted £310m shortfall.

Other causes that are normally among the most popular also experienced large drops in donations, including animal charities, and those supporting children and young people.

Neil Heslop, chief executive of CAF, said: "There has never been a time in living memory when we have collectively been more aware of the value of charity in our lives and that is clearly borne out in this CAF report and in the generosity of the British people.

"It is also our sincere hope that these extraordinary levels of giving serve as inspiration and reminds us of what is possible when people come together to support the causes closest to their hearts."

There are lots of ways you can help us fill the gap in funding this year, even while we're still socially distancing. Join our brand new GAIN 200 Club, raise a donation by shopping online with EasyFundraising or Amazon Smile, collect empty crisp packets, or even take on a challenge and ask your friends and family to sponsor you! And don't forget to Gift Aid!

Yellow Card Making medicines safer

The Medicines and Healthcare products Regulatory Agency (MHRA) regulates medicines, medical devices and blood components for transfusion in the UK.

The Yellow Card scheme, run by the MHRA, is the UK system for collecting and monitoring information on safety concerns such as suspected side effects or adverse incidents involving medicines and medical devices. The scheme relies on voluntary reporting of suspected side effects or medical device incidents to be reported by health professionals and the public, including patients, carers and parents.

The purpose of the scheme is to provide an early warning that the safety of a medicine or a medical device may require further investigation. It is important for people to report problems experienced with medicines or medical devices as these are used to identify issues which might not have been previously known about. The MHRA will review the issue and if necessary, take action to minimise risk and maximise benefit to the patients.

Reports can be made for all medicines including vaccines, blood factors and immunoglobulins, herbal medicines and homeopathic remedies, all medical devices available on the UK market and reports of safety concerns associated with e-cigarette products. The MHRA is also able to investigate counterfeit or fake medicines or devices and if necessary, take action to protect public health.

All medicines can cause side effects (commonly referred to as adverse drug reactions or ADRs by healthcare professionals).

Side effects reported on Yellow Cards are evaluated, together with additional sources of information such as clinical trial data, medical literature or data from international medicines regulators, to identify previously unknown safety issues. These reports are assessed by a team of medicine safety experts made up of doctors, pharmacists and scientists who study the benefits and risks of medicines. If a new side effect is identified, the safety profile of the medicine in question is carefully looked at, as well as the side effects of other medicines used to treat the same condition. The MHRA assesses the balance of risks and benefits of all medicines at the time of initial licensing and throughout their use in clinical practice. Where appropriate, the MHRA seeks advice from the independent Commission on Human Medicines (CHM). The MHRA takes action, whenever necessary, to ensure that medicines are used in a way that minimises risk, while maximising patient benefit.

For further information and instructions on how to report a suspected side effect, visit;

<https://yellowcard.mhra.gov.uk/the-yellow-card-scheme/>



COVID-19 vaccines adverse reaction report

A national immunisation campaign has been underway since early December 2020. In clinical trials, the Pfizer/BioNTech and Oxford University/AstraZeneca COVID-19 vaccines have demonstrated very high levels of protection against symptomatic infection.

As part of its statutory functions, the MHRA is responsible for monitoring these vaccines on an ongoing basis to ensure their benefits continue to outweigh any risks. This is a requirement for all authorised medicines and vaccines in the UK.

All vaccines and medicines have some side effects. These side effects need to be continuously balanced against the expected benefits in preventing illness. Following widespread use of these vaccines across the UK, the vast majority of suspected adverse reaction reports so far confirm the safety profile seen in clinical trials.

Most reports relate to injection-site reactions (sore arm) and generalised symptoms such as a 'flu-like' illness, headache, chills, fatigue, nausea, fever, dizziness, weakness, aching muscles, and rapid heartbeat.

Generally, these reactions are not associated with more serious illness and likely reflect an expected, normal immune response to the vaccines. Following very substantial exposure across the UK population, no other new safety concerns have been identified from reports received to date, and for the cases of other medical conditions reported in temporal association with vaccination, the available evidence does not currently suggest that the vaccine caused the event.

Adverse reaction reports are updated weekly. For further information, go to;

<https://www.gov.uk/government/publications/coronavirus-covid-19-vaccine-adverse-reactions>

Ever feel like no one knows what you're going through? You're not alone.



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. From March, we're introducing 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



Join the GAIN 200 Club

Sign up before the end of March to take part!
The more people joining in, the bigger the prize fund, so spread the word to friends and family!

Taking part only costs £20 per number for the whole year, which is paid in advance. To join the 200 Club, or for further details, please visit the website or get in touch (contact details below).

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
-  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