

COVID-19 Vaccines and the GBS|CIDP Community

Posted on [December 17, 2020](#)

*The GBS|CIDP Foundation is committed to sharing the most accurate information from the world's leading experts, many from our Global Medical Advisory Board. The COVID-19 situation changes daily and we will continue to share updates that are vetted by the experts in GBS. In addition, we are in regular contact with the FDA representing the patient voice in the top-level decision-making. We understand that there are many opinions creating confusion so please consider the source of your information before drawing conclusions. As always, all decisions should be made with your personal physician based on your own health. **Please continue to check our website for updated COVID-19 information.***

An Open Letter to Dr. A.S. Fauci, Director NIAID, NIH

20 December 2020

(Please see the following open letter statement authored by members of the GBS|CIDP Foundation International medical community as referenced.)

As clinician/scientists who have spent careers studying GBS, we are concerned that your statement on the “New Normal” television show about GBS and the COVID vaccine will have unintended consequences. Your statement is already all over the internet with many believing it to be true and acting accordingly.

On the television show, you stated that people who had GBS in the past should avoid the COVID vaccines as they may cause another episode of GBS. GBS was associated with the 1976/1977 swine flu vaccine at a rate of about 1 case/100,000 vaccinees. Since then, the only vaccine associated with GBS has been the flu vaccine at a rate of 1 extra case of GBS/1,000,000 vaccinees, that is, 21 cases when 20 are expected (Salmon et al. Guillain-Barré Syndrome Following Influenza Vaccines Affords Opportunity to Improve Vaccine Confidence. *The Journal of Infectious Diseases*, jiaa544, <https://doi.org/10.1093/infdis/jiaa544>). In a survey conducted in the Netherlands, people who had GBS in the past were queried about whether they had another GBS episode following seasonal flu vaccine, and the answer was an unequivocal ‘No’ in over 100 recovered GBS persons, many of whom received multiple flu vaccines over many years (Kuitwaard et al. Recurrences, vaccinations and long-term symptoms in GBS and CIDP. *JPNS* 2009;14:310–315). This study and the published literature does not support the idea that people who had GBS in the past should avoid vaccines in the future (Principi and Esposito. Vaccine-preventable diseases, vaccines and Guillain-Barre’ syndrome. *Vaccine* 2019;37:5544- 5550 and Hawken et al. Simulation Study of the Effect of Influenza and Influenza Vaccination on Risk of Acquiring Guillain-Barré Syndrome. *Emerg Infect Dis* 2015;21:224–231). In fact, the CDC recommends that everyone get the flu vaccine as the

benefits of the vaccine outweigh the risks of GBS (<https://www.cdc.gov/vaccinesafety/concerns/guillain-barre-syndrome.html>). Any risk of GBS or that people with past GBS should avoid either the Pfizer-BioNTech COVID-19 Vaccine or the Moderna COVID-19 Vaccine is not listed in the FDA authorized package insert for either product.

To date, no cases of GBS have been associated with the COVID vaccines. However, the number of subjects in the clinical trials is too small to detect such a rare event, if it existed, and surveillance is ongoing. In the meantime, we would urge all to follow national and local guidelines about who should get the vaccine. At this time, there is no reason that those who had GBS in the past cannot get the current COVID vaccines. If they have concerns, they should speak to their local health care professionals.

Sincerely yours,

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FDA approved package insert for Pfizer-Biontech COVID-19 vaccine, no mention of GBS as risk

This information is a public document and has been forwarded to the Foundations by our key opinion leaders in the GBS medical community. Of note, there is no mention of GBS in the vaccine insert, not as a risk nor as a vaccine to avoid for those who have had GBS or CIDP or are getting treated for CIDP.

Please see insert for more details. [Download](#)

Statement from Professor Lunn in Reference to Newest Research on COVID-19, GBS, and Vaccines

Posted on [December 15, 2020](#)

In reaction to recent research published in *Brain* ([click here to read more](#)), Professor Lunn has offered this guidance in regards to our community:

One vaccine is not the same as another. The only reason that one advises against flu vaccine in someone with GBS is if they actually had GBS in the 6 week window after a flu vaccine and then only out of an abundance of caution which is not based on any real science.

The rate of GBS after flu vaccine in all assessed years after 1976 has been about 1 per million and no study has linked vaccination to recurrence of GBS or CIDP.

COVID vaccine is nothing like flu vaccine.

COVID doesn't cause GBS in any significant number if at all and there is no reason to suspect the vaccine would cause it.

Statement attributed to:

Professor Michael Lunn MA MBBS FRCP PhD

Consultant Neurologist and Professor of Clinical Neurology

National Hospital for Neurology and Neurosurgery

Queen Square, London

New Study Reveals No Association Between COVID-19 and Guillain-Barré Syndrome

Posted on [December 14, 2020](#)

A UK based epidemiological study, linked below, has found no causal association between COVID-19 infection and Guillain-Barré syndrome. This means that GBS developing at the same time or close to that of COVID-19 is most likely coincidental. A number of peripheral nerve world leading experts have also written a separate commentary, linked below, in light of this study to explain there is no reason for the COVID-19 vaccine to cause GBS, and that any cases that do occur around the time of vaccination are again most likely coincidental (as cases occur at around 1 per 100,000 people per year). They stress the importance of recognising this fact, and therefore not interrupting the COVID-19 vaccination programme when sporadic cases of GBS occur which will be inevitable.

Read full articles

Epidemiological and cohort study finds no association between COVID-19 and Guillain-Barré syndrome

No association between COVID-19 and Guillain-Barré syndrome

A statement from the GBS|CIDP Foundation International Global Medical Advisory Board, November 2020

Posted on [December 4, 2020](#)

The GBS|CIDP Foundation has received many questions about COVID-19 and its relationship to Guillain-Barré syndrome and CIDP. It is important to emphasize that presently we have no information on potential cause and effect. One must keep in mind that COVID-19 became known to most of us in March of this year and it is now November. We have limited data to draw a relationship between the virus and neurologic illness based on 8 months of observation. So far, there does not appear to be a high increase in GBS or CIDP following COVID infections. Even if there were a higher incidence, management would be preventative using frequent handwashing, physical distancing, and quarantining in the appropriate situation. If a patient developed GBS or CIDP after a COVID infection (or vaccine), the treatment would be the same as a patient who was not infected by the COVID virus (or vaccine).

There is no data so far to support that patients with prior GBS or CIDP are more prone to develop an infection with COVID.

In the past few weeks, 3 pharmaceutical companies have announced preliminary data on the protective effect of Covid vaccines. The protective effect of all of the vaccines is greater than 90% which is impressive for a viral vaccine. The data is preliminary. It has not been fully reviewed by experts in the field of vaccine epidemiology or the FDA. The vaccines, if protective, will not be available for widespread use until late spring 2021. There are 4 more pharmaceutical companies working a vaccines for Covid 19 prevention.

The GBS|CIDP Foundation has also received questions about the safety of these COVID vaccines but this needs to be further investigated. It would be appropriate at this time to summarize the stance of the GBS|CIDP Foundation regarding the seasonal flu vaccination.

Studies on the safety of flu vaccinations showed that for every 1,000,000 people who receive a flu vaccine, there is 1 (one) additional case of GBS. Normally in 1,000,000 people, there would be 20 cases of GBS (2/100,000) but if they all receive the flu vaccine, there would be 21. Who is the one person who got their GBS from the vaccine versus the 20 who would have gotten GBS anyway is not known. Thus, the GBS|CIDP Foundation

advocates for receiving the yearly seasonal flu vaccination in the fall of each year. We can easily quantitate the benefits of 1,000,000 people getting the flu vaccine in terms of deaths/hospitalizations/days off work. Those benefits far outweigh the very small risk of GBS in patients who receive the flu vaccine (again 1 extra case for every 1,000,000 people vaccinated).

For more information on GBS and vaccination please see the [CDC statement](https://www.cdc.gov/vaccinesafety/concerns/guillain-barre-syndrome.html) here: <https://www.cdc.gov/vaccinesafety/concerns/guillain-barre-syndrome.html>

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