NMOSD and COVID-19 FAQs

Dear Friends,

We hope everyone is well as the world moves beyond the COVID-19 pandemic. The pandemic was a difficult experience—yet much was learned about COVID-19 and NMOSD. Below are answers to some FAQs from the community to aid in your navigation going forward. While the Foundation does not provide clinical care policies or recommendations, we hope these 10 frequently asked questions assist all NMOSD patients to make informed decisions with their doctors.

- 1. What is the difference between SARS-CoV-2 and COVID-19? SARS-CoV-2 is the name of the strain of coronavirus that caused the pandemic. COVID-19 is the name of the disease caused by this virus. The acronym COVID-19 is derived from: CO = corona + VI = virus + D = disease + 19 = emerged in 2019.
- 2. <u>Does NMOSD increase my risk of SARS-CoV-2 infection</u>? There is little to no evidence at the present time to suggest that having NMOSD directly increases the risk of being infected by the virus itself. Avoiding exposure is key (see below). Certain medications used to treat NMOSD can reduce the ability of the immune system B cells to generate antibodies in response to certain preventive measures such as vaccines. However, vaccines induce good T cell responses even on the most effective NMOSD therapies. Appropriate vaccination remains the best practice to reduce the risks of severe or long COVID-19, or death due to COVID-19. Likewise, vaccination against other preventable infections can also safely and effectively reduce risks. Consult your NMOSD specialist or healthcare team to discuss the best plan for you to mitigate the risks of SARS-CoV-2 infection or other preventable infections.

- 3. <u>Does COVID-19 increase my risk of having an NMOSD relapse</u>? While there is no established proof that infection causes relapses in NMOSD, some data suggest inflammatory events such as infection might raise the risk of having a relapse. Importantly, some evidence suggests that appropriate vaccination may actually reduce the risk of relapse, by reducing the risk of infection or serious outcomes of infection. To minimize relapse risk, observe best practices to avoid infection. These practices include maintaining appropriate immunization, minimizing exposure to individuals who have COVID-19 or other transmissible infections, and practicing good hygiene and healthy lifestyle practices.
- 4. <u>Does COVID-19 increase my risks of a secondary infection</u>? Experience over 5 years since the onset of the pandemic has shown secondary respiratory infections are increased in some patients who experience COVID-19 disease. Likewise, in other viral infections such as influenza, up to 65% of individuals experience secondary infections caused by bacteria or fungi. These risks may be greater in patients on immune suppressing therapy. Again, the best way to lower risks of secondary infection is to prevent primary infection due to the SARS-CoV-2 virus or other preventable infections through appropriate vaccination and exposure control practices.
- 5. Should I continue NMOSD therapy if I am diagnosed with COVID-19? The U.S. Centers for Disease Control & Prevention (CDC) has offered guidance on this point. The CDC encourage patients to decide with their doctors regarding the best treatment plan, weighing all factors. Generally, the CDC suggests there is no evidence for patients to change their normal treatment regimen & schedule. Stopping treatment may increase risks of relapse and necessitate clinical care in settings that may increase risks of exposures to the SARS-CoV-2 virus or other germs. Please note that the CDC guidance may be subject to change. Consult your NMOSD neurologist with any special concerns.

- 6. What should I do if I have symptoms of an infection ? If you have a persistent fever, cough, sore throat, runny nose, swollen lymph nodes, eye redness or any other symptoms of respiratory or other infection, please contact your NMOSD neurologist right away. You may be tested for other respiratory infections (e.g. influenza, respiratory syncytial virus [RSV], etc.), which may be treatable in early stages. In any infection, early detection and treatment affords best outcomes.
- 7. What should I do if I experience symptoms of a relapse ? If you experience new onset signs or symptoms of an NMOSD relapse (e.g. vision change, numbness or weakness in limbs, bowel or bladder dysfunction, etc.) please contact your NMOSD neurologist right away. Early and accurate diagnosis of true relapses allows best care—and is essential for best long-term outcomes.

8. What can I do to help stay healthy and minimize risks of infection?

Safe Lifestyle:

Practice hygiene, social distancing and CDC measures to minimize risk of infection.

Immunize Wisely. Appropriate vaccination is safe and effective in most patients and can prevent infection and reduce risks of relapse. Practices to minimize any remote risk of vaccine-related relapse are available and involve a short, low-dose oral steroid taper a few days before vaccination and an oral anti-histamine dose on the day of vaccination. Please consult your healthcare team to develop an immunization plan that is right for you.

Healthy Diet:

Eat a nutritious diet, wash fruits and vegetables and avoid any raw meats or eggs.

Sleep Restful:

Restorative sleep occurs late during the sleep cycle, which takes 6 or more hours.

Stop Smoking:

Respiratory infections target lung disease. Stop smoking for your health & others.

Be Resilient:

The ability to adapt was a lesson from COVID-19. Resilience is a superpower.

Stay Positive:

The COVID-19 is history. Outbreaks of infection will come and go, but optimism & best personal and public health practices are lasting ways to stay healthy.

- 9. <u>Can I learn more about NMOSD & enhancing quality of life</u>? The GJCF website offers many resources for patients, caregivers, families and healthcare providers to consider in choosing how to improve quality of life.
- 10. <u>Does GJCF have any healthcare recommendations</u>? The Foundation does not offer clinical or healthcare recommendations. We hope this FAQ sheet helps you & your doctor decide best healthcare practices for you.