

# Q&A series

## Coronavirus (COVID-19) Questions and Answers for Individuals Affected by Rare Neuroimmune Disorders

### Part I with Dr. Benjamin Greenberg



Dr. Benjamin Greenberg, Associate Professor at UT Southwestern Medical Center, Director at the Perot Foundation Neurosciences Translational Research Center, Vice Chair of Translational Research and Strategic Initiatives, Director of the Transverse Myelitis, Neuromyelitis Optica Programs and Director of the Pediatric Demyelinating Disease Program, answers some of our community's most frequently asked questions surrounding the COVID-19 pandemic in the context of rare neuroimmune disorders.

#### How can I prevent becoming infected?

Wash your hands – wash often, use soap and water, and for at least 20 seconds. Wash your hands after being in public, coughing, sneezing, blowing your nose, tending to children, handling packages, etc. If you can't wash your hands, use hand sanitizer that contains at least 60% alcohol. Use enough to cover the entire surface of your hands and rub them together until they are dry. Avoid touching your face – your eyes, nose, mouth, and especially so with unwashed hands.

Stay home if you are able to do so (or if your state/community has issued governance to do so). Stay away from others who may be sick. Use "social distancing" and maintain at least 6 feet distance if you must go out into the community.

Frequently touched surfaces should be cleaned and disinfected daily. These are items such as your phones, doorknobs, countertops, faucets, sinks, toilets, desks, etc. - anything you or your household members may be touching on a frequent basis). Disinfect with EPA-registered household disinfectants that are appropriate for the surface. CDC offers additional guidance for [Cleaning and Disinfection for Households](#).

#### Should I be wearing a mask?

According to CDC, "CDC recommends wearing cloth face coverings in public settings where other social distancing measures are difficult to maintain (e.g., grocery stores and

pharmacies) especially in areas of significant community-based transmission. It is critical to emphasize that maintaining 6-foot social distancing remains important to slowing the spread of the virus. CDC is additionally advising the use of simple cloth face coverings to slow the spread of the virus and help people who may have the virus and do not know it from transmitting it to others. Cloth face coverings fashioned from household items or made at home from common materials at low cost can be used as an additional, voluntary public health measure."

#### Do I need to stay home? Because I have TM can I be around other people? Or around babies?

If your state or local government has issued a "stay at home", "shelter in place", or other similar order; yes, stay home except for essential needs. CDC has also issued a Domestic Travel Advisory for New York, New Jersey, and Connecticut.

If your state/community hasn't issued an executive order or guidance, consider if COVID-19 has been spreading in your community, where you will be going, and who you will be with – remember that someone may have the disease and can spread it without knowing it. That includes you to those you live with and love and are in close contact on a daily basis.

If you must go out, try to limit it for essential needs such as groceries, medications from the pharmacy, and essential medical appointments. While you are out, practice the "social distancing" method of maintaining at least 6 feet between you and other people.



Having TM in and of itself doesn't automatically make you more susceptible. You must consider the other risk factors that may be a result (secondary conditions) of your having TM (i.e. recent diagnosis & have received immunosuppressant therapies or are on steroids, a level of injury that complicates respiration, requires a use of ventilation or other breathing assistance, etc.) as well as the risk factors associated with COVID-19; are you a person 65 or older? Do you have any other underlying health concerns such as asthma, heart conditions, severe obesity, diabetes, etc.?

Babies are not one of the higher risk categories for COVID-19 however, they may still contract, carry, and spread the virus. They may or may not show symptoms of the disease. If you are not the primary caregiver, and as you would aside from a pandemic and handling babies, wash your hands frequently, avoid touching their face or getting your face too close to theirs, and if you or they are sick, keep your distance.

**If a person suspects they have COVID-19 but cannot get tested, how long are they infectious? How long after I start feeling ill should I remain in isolation? If I can't be tested to confirm because of lack of tests available?**

According to CDC, a person who has been in isolation and will not be tested to determine if they are still contagious, may stop home isolation after these three things have happened:

1. You have had no fever for at least 72 hours (that is three full days of no fever without the use medicine that reduces fevers) **and**
2. other symptoms have improved (for example, when your cough or shortness of breath have improved) **and**
3. at least 7 days have passed since your symptoms first appeared

**I have self-isolated myself and my children for the past 8 days and will continue to do so. My question is my husband is doing the shopping when needed, should we be concerned about the products coming into the household from outside the home having the virus on the packaging, plastic bags, etc.?**

The virus is primarily transmitted person-to-person and most often by respiratory droplets. According to WHO FAQ, studies suggest the virus may last on surfaces for a few hours to several days depending on the type of surface, environment, temperature, etc. On 3/17/20, an NIH News Release noted the

virus was detectable on cardboard up to 24 ours and up to 2-3 days on plastic. Although, there isn't definitive guidance on handling product that comes into your home from CDC, as a precaution, you may follow typical cleaning guidelines with a household spray or wipe. When bringing in groceries, for instance, you could place your bags on the floor and wipe down surfaces of the products with a disinfectant wipe or warm, soapy water before placing them on the countertop or putting them away. If an item can stay outside of the home (e.g. in a garage, in the hallway, on a porch) for a few hours or a day, let it be. After bringing them in too, your husband should follow the usual prevention methods of washing hands for at least 20 seconds, and you could also wipe down countertop surfaces, and doorknobs, etc. NIH also offers Cleaning And Disinfecting Your Home guidance: <https://www.nih.gov/health-information/coronavirus>

**I am 71 and wonder if I can walk the dog outside since this would be exercise for both of us?**

If you can go outside for a walk to exercise, it would be great for the both of you! Movement, fresh air, and hopefully, sunshine! 71 is within the higher risk category but being able to move, get fresh air, and be outside helps all of us far more than just physically! Things to keep in mind are 1) Maintain social distancing and keep at least 6 feet apart from other people – if you walk down the sidewalk and another walker is there, give each other space, move off the sidewalk, or cross the road but remember it's not the time to let someone come close and pet your dog!; 2) if you can go with just you and your dog or a member of your household you've been isolating with, refrain from inviting the neighbors or a friend to go along; 3) avoid public parks or other areas that may be more crowded with people; 4) wash your hands when you return home. Referring back to the guidelines of keeping yourself protected (handwashing, social distancing, cleaning & disinfecting your space) pertain when getting back from a stroll outside. A safe, socially distanced, breath of fresh air will do so much for us all right now!

**I live in a nursing facility. I wear masks all day and wash my hands often. What else should I do to prevent infection?**

Those are great precautions. Also ensure that people coming into your room use alcohol-based hand cleansers or wash their hands.



**As a nurse with TM working on an Infectious Disease unit where I will be working with patients who are positive for the COVID-19, do you think I should reconsider my position?**

Your TM does not increase your risks beyond other individuals. Unless you are over 65, have reduced lung function or are immunosuppressed then there are not guidelines to change positions. We are grateful for the work you do.

**If we do start feeling ill or have a fever, do we treat this like we would the influenza? Keeping fevers down with Tylenol and Motrin, or do we follow a different protocol for this? This would be, if we do not feel bad enough to seek medical attention.**

Follow the guidelines from CDC on [What To Do if You Are Sick](#) and [Caring for Yourself at Home](#). The “protocol” is the same if you were to have influenza – call your doctor to let them know you may be infected and your symptoms - stay home, rest, reduce a fever, aches, pains with OTC medications as directed by your physician, hydrate, and monitor your symptoms. If they worsen, call your Dr. before going to their office or urgent care. CDC notes, if you develop emergency warning signs for COVID-19 get medical attention immediately. Emergency warning signs include: Trouble breathing, persistent pain or pressure in the chest, new confusion or inability to arouse, or bluish lips or face. This list is not all inclusive. Please consult your medical provider for any other symptoms that are severe or concerning. If these symptoms develop, call 911.

**How do I prevent getting infected by home care workers coming into my home? Are there any situations in-home nursing or home care workers shouldn't be allowed in? What questions should I be asking of them or their agencies about their preventative measures? Can I require them to wear masks & gowns before coming into my home?**

Home care worker visits should be limited as much as possible. No one with symptoms of fever or cough should be present. No one with known coronavirus exposures should come. Finally, they should pursue frequent hand washing. CDC recently recommended wearing masks in situations when social distancing is not possible, which is likely the case for home care workers.

**In the event that we are infected with COVID-19, how can we help guide a medical professional unfamiliar with our condition on how to care for us?**

There are no specific guidelines for our patient population, so management will be based on medications being used, other medical conditions, and symptoms.

**How does the advice for MS differ from the advice for TM and other demyelinating diseases regarding Coronavirus and why?**

TM patients are not usually on immunosuppressive therapies, while other patients may be on medications. This leads to differences in recommendations.

**Can the coronavirus enter the body through the urethra or rectum as I insert a catheter or gloved index finger in the rectum respectively?**

We do not think so – this is a virus spread by the respiratory route.

**If I have TM and will not get a flu or pneumonia shot, what are the implications of getting a vaccination for coronavirus when it is developed?**

While we do not know the specific safety related to such a vaccine, in general vaccines are considered safe in our patient population. We routinely recommend the flu and pneumonia shots.

**Will titer testing be available to know if we had been infected and either had no symptoms or very mild symptoms?**

At some point yes, but the timeframe is unknown.

**What is the difference between enteroviruses and coronaviruses? If this coronavirus is a respiratory virus like EV-D68, and can this cause AFM, too?**

There have not been any known reported cases of spinal cord involvement from coronavirus

**My child recovered well after AFM, although did have respiratory issues in the beginning but is otherwise “healthy”. Could he still be impacted more drastically by coronavirus because of his AFM?**

In general, young individuals are faring better with COVID-19, but if there are ongoing pulmonary issues that does increase risk for complications. Precautions to prevent infections should be pursued.



**Are there special precautions for caring for one at home who is ventilator dependent?**

Limiting individuals coming into the home, screening for infections (cough/fever), screening for sick contacts and frequent hand washing is critical.

**School is closed for the next two weeks to stop the spread. My son with TM, even with the typical viruses that go around school, is always hit harder and longer than the average child, even his siblings. I'm concerned two weeks isn't going to be long enough to protect him. If I keep him home to protect him, should I keep his siblings home, too?**

In general, if practicing social distancing to protect one member of the household, then the entire household should pursue the same strategy or be separated.

**Compared to influenza in the immune suppressed/immune compromised, is this virus now considered to be more deadly?**

The fatality rate with COVID 19 does indeed appear to be significantly higher than influenza in the general population.

**Is this virus more contagious and more concerning than enteroviruses that can cause respiratory issues and paralyze kids?**

This virus is more concerning based on its higher fatality rate and complication rate than enteroviruses.

**If I get COVID-19 should I consider or ask for the experimental antivirals and treatments some are being given?**

It would require conversations with the treating physicians.

**Are there any recommended vitamins or supplements that we can take to give an extra boost to our immune system?**

None that are known to be as protective as social distancing and hand washing.

**I use an anti-inflammatory medication (ibuprofen) for pain. Should I discontinue using it?**

That is not known to be a specific issue with the virus, despite the various conversations. We recommend discussing with your treating physician.

**Should I take high dose Vitamin C? Can this exacerbate existing lesions?**

A normal multivitamin should be adequate.

**Is it advisable to take extra Vitamin D and what dose?**

Not in general, specifics should be discussed with your treating physician.

**Would my doctor's office have suggestions for mail-order pharmacies I could get so I don't have to go to the pharmacy? Is it easy to convert my current prescriptions to mail-order ones?**

Yes, most offices are converting to mail order easily, just ask them and it should work out.

---

Visit [wearesrna.org/covid-19](https://wearesrna.org/covid-19) for the latest information on COVID-19 and rare neuroimmune disorders.

---

