



March 27, 2020

Re: **Familial Dysautonomia and Coronavirus**

Dear Families,

The Dysautonomia Center would like to provide the FD community with another update regarding the current outbreak of the novel coronavirus, COVID-19.

It has now been 2 weeks since The World Health Organization (WHO) announced the outbreak of COVID-19 was officially considered a global pandemic on March 11th, 2020. **The spread of this viral infection has become rampant throughout the United States.** The total number of *confirmed* cases in the U.S. is now 54,453, with 737 deaths associated with this infection. It is important to note that even this total number of cases is grossly lower than the real number of infected individuals due to low testing availability, and delay in the infection to manifest. All 50 states report the infection, along with the District of Columbia, Puerto Rico, Guam, and the US Virgin Islands. The numbers in New York City and around the country **continue to increase, and will continue to increase for an unknown period of time**, possibly months. Given this spread pattern, and the delay in the time it takes for the illness to manifest, you must **assume that all locations are at risk of having the virus** currently present in the community, despite lack of official announcements that it is present. Considering this, everyone should be prudent in their daily actions to prevent contracting or transmitting the virus to others.

Some newscasters and politicians have noted that the numbers of cases continue to increase despite efforts in isolation. And some are calling for a premature end to isolation efforts. We ask this community and others to **PLEASE** continue efforts in isolation, social distancing, and all other measures of hand hygiene and disinfecting commonly touched surfaces because **these efforts do work to protect individuals and reduce the spread of infection.** Due to the time it takes for the infection to manifest, we are still seeing a growing curve from the scant isolation practices common just 1 and 2 weeks ago. Our country's initiatives in communicating this threat to the public and calling for isolation were delayed. As a result, the efforts which were just started last week need more time to have an effect at "flattening the curve" of the number of total cases. In fact, the steeper the curve and the greater the number of total infected individuals, the more time it takes for the spread to slow. So please continue all efforts. Those who are calling for an end to isolation are short-sighted and dangerous. **We can do our part in the collective good, and be responsible to ourselves, our families and our community.**

Please continue to practice the following recommendations for measures of personal hygiene, social distancing, and isolation to combat the spread of COVID-19. They cannot be stressed enough, and are the most important measures of personal protection.

Recommendations for those at higher risk:

- Have enough essential medication, groceries, and respiratory supplies (if using) available at home to last at least 1 month if quarantined, or have a mail-delivery service available to replenish them.
- **Take everyday precautions**
 - Keep space between yourself and others (at least 2 meters or 6 feet).
 - Avoid close contact with people who are obviously sick.



o **Clean your hands** often:

- Wash your hands often with **soap and water** for at least 20 seconds, especially after blowing your nose, coughing, or sneezing, or having been in a public place.
- **Soap and water are the best option. If soap and water are not available, use a hand sanitizer** that contains at least 60% alcohol.
- To the extent possible, **avoid touching surfaces** in public places – elevator buttons, door handles, handrails, handshaking with people, etc. Use a tissue or your sleeve to cover your hand or finger if you must touch something.
- Wash your hands with soap and water after touching surfaces in public places.
- o **Do not touch your face, nose, or eyes** without making sure they are clean.
- o **Clean and disinfect** your home to remove germs: practice routine cleaning of **frequently touched surfaces** (for example: tables, doorknobs, light switches, handles, desks, toilets, faucets, sinks & **cell phones**).
- **Stay indoors and away from other people.**
- **If you must leave the house for an urgent doctor’s appointment or other urgent need (not a party or other social or religious gathering of any kind), avoid crowds**, especially in poorly ventilated spaces like elevators. If you use an elevator, choose one without others in it. Remember to space yourself at least 6 feet from other people. Avoid subways, buses, planes, and all other methods of public transportation.
- **Stay home as much as possible** to further reduce your risk of being exposed. If possible and allowed by your employer, work from home.
- **Avoid all non-essential travel** including plane trips, and especially avoid embarking on cruise ships. Also avoid non-essential activities such as volunteering, attending day-hab, visiting community centers etc.
- Please take 10 minutes to view this great video which illustrates how important hand hygiene is in preventing spread of infection to ourselves and others! <https://www.youtube.com/watch?v=I5-dI74zxPg>
(No endorsement of the company SkillShare that is being represented at the end of the video.)

Frequently disinfect commonly-used surfaces in the home! As the medical community has more time to study COVID-19, the following times have been found for how long the virus can stay alive and therefore infectious on various surfaces. COVID-19 can be found in the air after being aerosolized from medical procedures including nebulizer use for up to three hours, and can be found at four hours on copper, up to 24 hours on cardboard and up to two to three days on plastic and stainless steel! So, **items in the house should be disinfected frequently, and new items coming in from outside the home should be treated as possibly infectious and disinfected as well.**

Finally, it may ultimately be difficult or impossible to completely reduce spread of pathogens in our homes at all times, as there are so many entry points. But **the final step to infection is transmission to the person at risk.** The person at risk should be the most important focus. It is most important for them to not transmit these pathogens to entries to their body including commonly-touched areas on the face: eyes, nose, mouth. This practice of hand hygiene could keep them safe now and become a good habit into the future to prevent other infections.

We continue to not recommend the purchase and use of types of Personal Protective Equipment (PPE) at this time, especially in light of a national shortage. These items should be reserved for healthcare providers who are putting their lives at risk by caring for those with documented COVID-19, and not having enough PPE for their protection. If you are hoarding PPE, please consider donating it to your local hospital. However, we continue to receive questions on which types of masks offer protection against COVID-19, and how other types of Personal Protective Equipment (PPE) can be used most effectively to protect individuals and families. While we continue to stress that these measures are not recommended by the CDC, we would like to address their safe use. This is because we understand that if individuals and families already have these items and use them incorrectly, they could inadvertently place themselves at higher-risk by doing so. The use of PPE can give the user a false sense of security and can negate other simple yet crucial measures like hand hygiene. And if these items are not used appropriately, they can offer very little protection if any at all. There is training in medical and nursing school dedicated to their effective use. That illustrates how important effective use is compared to the item itself!

If you already have PPE at home and would like to make sure you are using it correctly, please follow these measures:

- **Gloves:** Hands must be washed before and after use. This is because if you pick up a pair of clean gloves with soiled hands, the gloves are then contaminated. Then, after discarding gloves, hands must be washed again. This is because when you remove contaminated gloves, germs can be accidentally spread back onto the hands. Hand hygiene is once again the best defense! Gloves are single-use.
- **Masks:** To begin, it is not necessary for the high-risk person to be wearing a mask while in isolation. But if another person in the household is sick, that person should wear a simple facemask to prevent spreading the virus to others who are at high risk. Two main mask types exist. The simple facemask (sometimes called a surgical mask), and a respirator (sometimes called an N95). Hands must be washed before and after use, for the same exact reasons as above.
 - **The facemask** offers barrier protection against large droplets from coughing or sneezing, by blocking these droplets from landing in or near your nose or mouth after someone coughs, sneezes, or spreads saliva while talking close by. The nose piece should be molded over the nose for a close-fit. But it is rather loose-fitting even with its best use, which may allow some infected droplets in from the sides, and it offers no eye protection.
 - Here are instructions from the WHO, on when and how to use face masks, including clear videos and graphic instructions: <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public/when-and-how-to-use-masks>
 - Also, here is a picture of correct, and incorrect use:



- **Respirators** offer protection against very small particles which may become airborne, as well as vapors and gases (it has been shown that COVID-19 could become airborne under “superspreading” events, such as in the hospital during procedures). But this high level of filtration could exacerbate pulmonary conditions, making it more difficult to breath. Any existing pulmonary health condition should suggest caution in their use. Healthcare workers are tested on their use of respirators to ensure they are not at risk while using a respirator, and are trained and tested on its effective use. Their effectiveness relies heavily on user practice. The nose piece should be molded over the nose for a tight-fit. The 2 straps should be looped around the base and top of the head to help create a tight-fit to the skin to not allow any air leaks. And many facial hair styles are disallowed, as they prevent a good seal.





- **Gowns/suits:** It seems that some families also have gowns and suits. If this is the case and you want to use them, please follow the steps on safe use in the following links.
- These links offer a review of how to wear all types of PPE and the best sequence on how to put them on and take them off. Again, they are not required. If you do not have them, you do not need to try to purchase them.
 - <https://www.cdc.gov/niosh/npptl/pdfs/PPE-Sequence-508.pdf>
 - <https://www.cdc.gov/coronavirus/2019-ncov/hcp/respirator-use-faq.html>

Hospitalization for COVID-19 infection, or any other illness

If you or your loved-one needs hospitalization due to COVID-19, other infections, or other medical conditions, please bring your own non-invasive ventilation machine (CPAP or BiPAP) if you have one with you to the hospital. Your local hospital may be running short on these as well as invasive ventilation machines, due to increased demand. Please also consider bringing a few days' worth of medications and any supplies you also need for continued usual care, in case the hospital is short on other items. This may be an extra precaution, but the situation is fluid, and we would rather have you arrive over-prepared than under-prepared.

As before, please note that our recommendations for emergency preparation, prevention, and supportive treatment for COVID-19 in patients with FD **do not differ** from those of the leading experts in infectious disease in the United States and worldwide including the Centers for Disease Control and Prevention (CDC), and the World Health Organization. These resources are openly available for all online, and provide comprehensive, organized, and factual information on steps you can take to stay safe.

Use of chloroquine or hydroxychloroquine

The use of chloroquine or hydroxychloroquine for COVID-19 is still experimental at this time. This is a drug that has been used to treat a parasitic infection called Malaria, and can also treat rheumatoid arthritis. COVID-19 is a virus, not a parasite. More studies are being done to find out how effective it is. However, in these dire circumstances, it is being given by some hospitals to some patients admitted for COVID-19. However, we want to make it clear that it is not recommended to prevent any infection, and is not recommended to treat people in the outpatient setting. Even with supervised use, this drug can have serious side effects, including death. This is especially risky in concoctions made at home. Please see the following article, which covers the tragic news of how an otherwise healthy man in Arizona died from ingesting just a teaspoon of this substance he had on hand in his home, <https://www.forbes.com/sites/tarahaelle/2020/03/23/man-dead-from-taking-chloroquine-after-trump-touts-drug-for-coronavirus/#625a113472e9>.

Symptom for COVID-19

According to the WHO, based on an analysis of over 55 thousand confirmed cases, symptoms of COVID-19 infection with associated prevalence can include: fever (87.9%), dry cough (67.7%), fatigue (38.1%), sputum (33.4%), shortness of breath (18.6%), headache (13.6%), muscle and joint aches (14.8%), chills (11.4%), nausea and vomiting (5%), nasal congestion (4.8%), diarrhea (3.7%), coughing blood (0.9%), eye redness and tearing (0.8%). There are also reports of sudden lost sense of smell and taste associated with the virus, which can be present even in the absence of other symptoms.

Emergency warning signs indicating the need to seek emergency help at your local Emergency Department include: difficulty breathing or shortness of breath, persistent chest pain or pressure, new confusion or inability to arouse, and bluish lips or face. But this is an incomplete list. **You are your own best advocate when at home and not with a health care provider. So please be prudent, and seek help for any serious departure from your normal health pattern with symptoms that are severe or concerning.**

There is more information available online at the following links:



Centers for Disease Control and Prevention links:

People at Risk for Serious Illness: <https://www.cdc.gov/coronavirus/2019-ncov/specific-groups/high-risk-complications.html>

Prevention and Treatment: https://www.cdc.gov/coronavirus/2019-ncov/about/prevention.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fabout%2Fprevention-treatment.html

Emergency Preparation: <https://www.cdc.gov/coronavirus/2019-ncov/community/home/index.html>

What To Do If You Are Sick: <https://www.cdc.gov/coronavirus/2019-ncov/about/steps-when-sick.html>

World Health Organization

The following links includes sources for information on how to protect yourself, frequently asked questions, travel advice, situation reports, and more. The second link contains a full report on what was currently known about COVID-19, including listed symptoms by prevalence.

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019>

[https://www.who.int/publications-detail/report-of-the-who-china-joint-mission-on-coronavirus-disease-2019-\(covid-19\)](https://www.who.int/publications-detail/report-of-the-who-china-joint-mission-on-coronavirus-disease-2019-(covid-19))

National Institutes of Health

<https://www.nih.gov/news-events/news-releases/new-coronavirus-stable-hours-surfaces>

Dysautonomia Center NYU

We have published and will continue to publish specific guidelines for FD patients on the following link:

<https://dysautonomiacenter.com/2020/02/28/familial-dysautonomia-and-coronavirus/>

If you have other questions or concerns that are not specifically addressed in this document or the ones preceding this one, please, contact the Dysautonomia Center.

We hope to have another document published soon for you all, on the best use of the many methods of pulmonary hygiene to optimize lung health!

Thank you. Please continue to stay safe and be well, and remember that your caution not only contributes to your safety, but to the safety of everyone! We know isolation is difficult. We sincerely thank you for your valiant efforts.