



March 12, 2020

Re: **Familial Dysautonomia and Coronavirus**

Dear Families,

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

The World Health Organization (WHO) announced yesterday (March 11, 2020) that the outbreak of COVID-19 is officially considered a **global pandemic**. This means that this contagious illness is present globally, with sustained transmission throughout the world. 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.

We have been contacted multiple times from concerned families asking about what additional measures they can take to protect themselves during the current outbreak of COVID-19.

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. A summary of these recommendations is below, followed by a list of resources for your convenience.

According to the CDC, people at increased risk for serious illness from COVID-19 include **older adults (>60 years old) and anyone with a serious chronic medical condition such as heart disease, diabetes, and lung disease. Patients with FD are included in the group of patients with a serious chronic medical condition**, given their high frequency of respiratory infections and chronic respiratory disease.

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.
 - **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.
- **Do not touch your face, nose, or eyes** without making sure they are clean.
- **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**).
- **Avoid crowds**, especially in poorly ventilated spaces like elevators, subways, other methods of public transportation. But also **avoid large gatherings** including parties, bat mitzvah celebrations, etc.
- **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.
- During a COVID-19 outbreak in your community, **stay home as much as possible** to further reduce your risk of being exposed. If possible and allowed by your employer, consider working from home.

As far as we know, symptoms of COVID-19 infection include: fever, cough, and shortness of breath. 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.

Answers to Commonly Asked Questions, From Those with FD and Their Families:

Should I cancel my planned trip or cruise? YES. Please cancel all non-essential trips and outings. If you need a note stating you should cancel the trip for medical reasons, we can provide this.

Furthermore, we understand the planning that goes into preparing for your annual evaluation at the Center, but we also want to consider the safety of our patients as a top priority. If you are traveling to NYC from outside of New York State or from outside of the United States, we recommend that you cancel your appointment and reschedule for another time in the coming months. We will make additional slots available for families needing to reschedule. Of course, we will remain in contact with you and will review the situation in the coming weeks to provide updates and further guidance.

Should I take my child out of school? Schools are closing temporarily when outbreaks are known to be in communities. Schools everywhere are preparing for such measures. Until then, you should discuss your options with your child's school to find out options which may be available for completing studies and assignments from home. This is ultimately a personal decision to remove your child from school, but it may be advisable if your child is already having current lung infections and pulmonary issues. If you need a note stating your child should complete studies from home temporarily during the outbreak, we can provide this.

Is the use of antibiotics, oral or topical preparations such as mupirocin or bacitracin, any use to prevent the infection? No. Antibiotics have properties that either destroy bacterial cell walls or prevent them from multiplying. They are specific for different kinds of bacteria. They are not effective against viruses or COVID-19 which is a virus.



Are there any other recommendations for medications, vitamins or supplements (e.g., zinc) that are effective to boost the immune system or prevent contracting COVID-19? None are known at this time. Being a new virus, there are no supplements, medications, or vaccines to either prevent or treat COVID-19 infection at this time. Some pharmaceutical companies are currently developing vaccines, which may be ready in several months or a year or more to the public, depending on the results of clinical trials.

Is there anything else that can help prevent serious outcomes from COVID-19 infection? Yes. Those with FD are at higher risk of serious outcomes due to impaired lung function. This is why it is more important than ever to **maintain optimum lung health**. Continue to use methods of pulmonary hygiene you have been instructed on which may include: being as active and mobile as possible, deep breathing, coughing, using nebulizer treatments as prescribed, chest vest, cough assist, huff-cough after treatment, and any other interventions as instructed by your pulmonologist.

Do those with FD have immunodeficiency? No. The immune system in FD is not much different from the general population. The total white blood cell count and all the different immune cells should be the same. However, the immune system can be weaker while battling other chronic infections. Once again, this is why it is important to optimize lung health.

Should I ask my home health nurses to wear special suits or protective gear while caring for my child at home? Everyone in the family, not just visiting nurses, should use the same protective measures to reduce the risk of bringing pathogens including COVID-19 into the house. Infectious disease officials stress common-sense precautions for everyone to take that can significantly reduce the risk of transmission. These measures were outlined above. But in addition to these, if clothing or objects like purses and back-packs are touching surfaces in the community, they too can become vectors (carriers) for germs including COVID-19. When entering your house from outside, measures to reduce this risk include taking off your shoes at the door, leaving items like bags at the door or at least not placing them on the kitchen countertop or other areas frequently used, changing your clothes for use around the house after coming inside, and... wash, wash, wash! - your hands, commonly used surfaces, while preparing food, etc.

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.

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 link includes sources for information on how to protect yourself, frequently asked questions, travel advice, situation reports, and more.

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

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, please, contact the FD center.