

Coronavirus Disease 2019 (COVID-19) Questions and Answers (FAQs)

March 13, 2020 Due to quickly evolving information, recommendations are subject to change and will be updated as needed.

The [FamilieSCN2A Foundation](#) recognizes that this is a very concerning time for everyone around the world, especially those with loved ones suffering from chronic conditions. We have recently participated in training on how to help our community and have developed the guidelines below. Most importantly, we want to emphasize that we are listening to you and that your concerns are validated. Our goal is to help in any way we can.

Thank you to our friends at the [Lennox-Gastaut Syndrome Foundation](#) (LGSF) and the [Tuberous Sclerosis Alliance](#) for pulling together much of the information regarding the COVID-19 outbreak. For more comprehensive and up-to-date information refer to the [Centers for Disease Control and Prevention](#) (CDC) website.

FACTS

1. The US, along with many other countries, is past the attempted containment phase (steps taken to stop the spread) and are now in the mitigation phase of this pandemic. **This means that the focus needs to be on measures at the population level that slow the rate at which people get infected and prevent the healthcare system from being overwhelmed.**

YOU can make a difference here by taking part in **community mitigation:** social distancing, schools closing, cancelling of events, working from home.

The Goal: Spread out cases (flattening the curve) to prevent overwhelming the healthcare system.

COVID-19 will get worse before it gets better and many of us will get sick (the severity of illness will be different for everybody based on risk factors).

1. This will affect you and impact your daily life and schedule. Make a plan for what you will do and account for all of the “what ifs.”
2. Based on evidence from countries that are past the peak, children are not nearly as affected as older adults. This does not mean they will not become infected, however the majority of children have mild symptoms.

SYMPTOMS OF COVID-19

The following symptoms may appear 2-14 days* after exposure to the virus:

- Cough
- Fever
- Shortness of breath

Most of our children are non-verbal and can't express how they feel. If you feel concerned, do not hesitate to call your child's doctor. Do not just take them to an urgent care or ER - always call first to develop a plan to keep everyone safe.

*Based on the previous incubation period associated with the Middle East respiratory syndrome (MERS)-related coronavirus.

RISK OF ILLNESS

1. Can I get sick by touching a surface or object that has the virus on it?

- According to the CDC, coronaviruses are generally thought to be spread from person-to-person through inhalation of respiratory droplets produced when an infected person coughs or sneezes.
- It may be possible for people to become ill by touching a surface or object that has the virus on it and then touching their own mouth, nose or eyes. Wash your hands often and try not to touch your face unless you have just washed your hands.

2. Who is at higher risk for serious illness from COVID-19?

- Older adults
- People with a serious chronic medical conditions such as: Diabetes; Heart disease; Lung disease; Hypertension
- Individuals on immunosuppressants (including ACTH and other steroids)

3. What should people at higher risk of serious illness from COVID-19 do?

- Make a plan and stay informed
 - The CDC recommends contacting your healthcare provider to ask about obtaining extra necessary medications** and supplies in case of an outbreak of COVID-19 in your local community, which may require you to stay home for a prolonged period. You may want to consider a mail-order vendor if you cannot obtain extra medication.
 - Keep away from others who are sick. Do not be shy about asking people if they have symptoms.
 - Avoid crowds of more than 10 people.
 - Wash hands often and correctly - for at least 20 seconds.
 - Stay home as much as possible and follow any specific recommendations made by local authorities.

- o **FDA DRUG SHORTAGES**: The FamilieSCN2A Foundation is not aware of any current seizure medication shortages caused by COVID-19. Refer to the FDA Drug Shortage website for current information.

5. Is it safe for me or my loved one to go to work or school?

- If COVID-19 is spreading in your community, the CDC recommends “social distancing” or taking extra measures to put distance between yourself and other people. This may include staying home as much as possible and avoiding crowds, especially in poorly ventilated places.
- Contact your local school's administration or your employer to see what steps they may be taking to keep students and/or staff healthy. For reference, see the CDC's [school and childcare guidance](#).

7. Is it safe for me or my loved one to continue going to clinic appointments?

- We recommend maintaining regular clinical care for all critical appointments however, call ahead and see if telemedicine is an option.
- If you are able to postpone regular f/u appointments for non critical care - do so.

8. How can I explain this to my child with Autism/Intellectual Disability and their siblings?

- Your child will likely be out of school for a lengthy period of time. Work with their teachers to create a routine that keeps them engaged and learning at home.
- Create social stories for children and people with Autism.
https://theautismeducator.ie/2020/03/11/corona-virus-social-story/?fbclid=IwAR2aFwyRevP-64K5gZcVG162OJEoDC3x_ZxE0F3RxexgTVtKak6E0dH6Jzw

RESOURCES AND REFERENCES

- [American Epilepsy Society Statement on COVID-19](#)
- [Johns Hopkins COVID-19 Global Cases Map](#)
- [Centers for Disease Control – Updates and How You Can Help](#)
- [World Health Organization – Advice for the Public on How to Protect Yourself](#)
- [Interactive Comic about COVID-19 – Understanding Coronavirus for the Public](#)
- <https://nationalhealthcouncil.org/issue/covid-19/>

Sincerely,

The FamilieSCN2A Foundation Board and Executive Director

Leah Schust Myers, Carla Forbes, Jennifer Burke, Michelle Lewis, Will Hutson, Maura Bragg, Catalina Betancur, Emily Park, Amy Kozsuch, Michael Vasey & Mery Oman

*Copyright © 2018 * FamilieSCN2A Foundation * All rights reserved.*

www.scn2a.org

Our mailing address is:

P.O. Box 82

East Longmeadow, MA 01028

Want to change how you receive these emails?

You can update your preferences or unsubscribe from this list.