



Tuberous Sclerosis Alliance

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

Updated May 20, 2020

The Tuberous Sclerosis Alliance prepared these FAQs to address concerns from the TSC community and healthcare professionals regarding the novel coronavirus disease 2019 (COVID-19) outbreak. For more comprehensive and up-to-date information refer to the [Centers for Disease Control and Prevention](#) (CDC) website.

SYMPTOMS OF COVID-19

People with COVID-19 have had a wide range of symptoms reported – ranging from mild symptoms to severe illness. Symptoms may appear **2-14 days after exposure to the virus**. People with the following symptoms may have COVID-19:

- Cough
- Shortness of breath or difficulty breathing
- Fever
- Chills
- Muscle pain
- Sore throat
- New loss of taste or smell

This list is not all possible symptoms. Other less common symptoms have been reported, including gastrointestinal symptoms like nausea, vomiting, or diarrhea.

RISKS 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 a person 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.

- Use bar or liquid soap and water and wash for at least 20 seconds.



- If soap and water are not available, use an alcohol-based hand sanitizer with at least 60% alcohol.

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

- People aged 65 years and older
- People with a serious chronic medical condition such as:
 - Diabetes
 - Heart disease
 - Lung disease (e.g. lymphangiomyomatosis [LAM])
 - Hypertension
- Individuals on immunosuppressants (see below)

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

- 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.
- Put distance between yourself and other people outside of your home.
- Stay at least 6 feet (about 2 arms' length) from other people.
- Avoid touching your eyes, nose, and mouth with unwashed hands.
- Wash hands often with soap and water, especially after you have been in a public place, or after blowing your nose, cough, or sneezing.
- If an outbreak occurs in your community (e.g. workplace, school, church), stay home as much as possible and follow any specific recommendations made by local authorities.

**FDA DRUG SHORTAGES: The TS Alliance is not aware of any seizure medication shortages caused by COVID-19. Refer to the [FDA Drug Shortage](#) website for current information.*

4. Should I wear a facemask to prevent contracting COVID-19?

- Yes. The CDC recommends that everyone 2 years and older wear a **cloth face covering** that covers their nose and mouth when out in public. Wearing a mask is intended to PREVENT the spread of the virus if someone is infected but does not have symptoms.
- Anyone who has trouble breathing or unable to remove the face covering without assistance is exempt from this recommendation.

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

- Refer to COVID-19 updates from your local government websites for guidance. Continue to maintain physical distancing of at least 6 feet between yourself and other people, wear a facemask, and wash your hands often with soap and water. For reference see the CDC's guidance on [Returning to Work](#).
- The CDC has a [school decision-making tool](#) to help you assess your child's risk of returning to school.
- Contact your local school's administration to see what steps they may be taking to keep students healthy. For reference, see the CDC's Checklists for [In-Person Classes](#) and [Virtual or At-Home Learning](#).

6. Is it safe for me or my loved one to travel by car or airplane?

- The CDC recommends limiting non-essential travel as much as possible. In the absence of symptoms or recent exposures, it is safe for you and family members you live with to be in a car together. Be careful to maintain good hand hygiene and distancing at rest stops along the way and take care to avoid large crowds at restaurants or pit stops. Be particularly vigilant about hand hygiene before entering your vehicle. Try to limit public transportation such as airplanes, buses or trains to essential trips while following strict hand hygiene and social distancing. Please refer to the [CDC](#) and [Johns Hopkins](#) maps for the latest information on affected areas.

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

- Each institution/clinic has specific rules and recommendations regarding clinic visits. Many are conducting telehealth visits when possible to protect the clinic staff's and your health. If you have questions or concerns about an upcoming clinic appointment, we recommend contacting your TSC Clinic for further instructions.
- Please refer to the [CDC](#) and [Johns Hopkins](#) maps for the latest information on affected areas.

QUESTIONS ABOUT COVID-19 and TSC (May 12, 2020)

1. Does TSC put me at greater risk for COVID-19?

The sample size is limited. Based on a handful of reported infections in patients from a small number of large TSC Clinics in the United States and abroad, there isn't any evidence currently that having TSC puts one at greater risk for COVID-19. We continue to monitor for new reported cases and will update the TSC community should infection or complication rates change.

2. Does everolimus/sirolimus put me at greater risk for COVID-19?

There is no evidence yet. More studies needed to answer this question.

3. Should I keep taking everolimus/sirolimus for epilepsy or SEGA?

The current position from TSC care providers is to continue taking everolimus/sirolimus for seizures or SEGA. If you develop COVID-19, you would want to have a discussion with your doctor to decide if you should suspend your treatment for a period of time.

4. What happens if I develop COVID-19?

The presence of TSC will probably complicate the course of the illness because of potential involvement of other organs, TAND, and current medications you are taking. This will require a conversation with your primary care doctor and a TSC expert at a regional TSC center, if possible.

5. Can COVID-19 make my seizures worse?

Yes. If you have a high fever, are receiving antibiotics, or are unable to take your seizure medications, your seizures may worsen.

6. Will COVID-19 affect SEGA growth?

There is no evidence that COVID-19 infection will cause SEGA to start growing or to grow faster.

7. Will COVID-19 affect autism?

There is no data yet showing that COVID-19 infection will worsen autism or intellectual disability; however, those with an infection may develop a febrile or systemic illness, which can make some of those symptoms worse.

8. For those who are taking immunosuppressants should there be any concerns about taking the vaccine when it becomes available?

It depends on how the vaccine is generated, e.g., live attenuated, inactivated, or recombinant, or a combination antigen/antibody. There are different vaccine strategies – so we need to wait and see which one(s) will be deployed in the United States.

9. Should people who are on immunosuppressant drugs self-isolate even when stay-at-home orders are lifted?

We recommend people with TSC continue practicing safe social distancing when possible.

10. Do any of the treatments proposed for COVID-19 interact with antiepileptic medications or mTOR inhibitors?

There is a possibility that some anti-epileptic drugs (AEDs) such as phenytoin (Dilantin), carbamazepine (Tegretol), phenobarbital, and primidone may activate liver enzymes that metabolize certain drugs currently in trials to treat COVID-19 such as remdesivir and rotinivir. Thus, if you are taking any of these AEDs, the level of remdesivir in the body may be lower. Further studies will be needed to define pharmacological interactions between mTORi and COVID-19 anti-viral agents and mTOR inhibitor.

USE OF AN ORAL IMMUNOSUPPRESSANT DRUG

(e.g. Afinitor[®], Rapamune[®], Zortress[®], everolimus, sirolimus, Acthar Gel[®], steroids)

1. I have LAM, should I stop taking sirolimus (or other mTOR inhibitor drugs)?

Whether being on mTOR inhibitors, such as sirolimus or everolimus, increases the risk of complications from COVID-19 is not known. Given the potential for lung function decline of sirolimus, pulmonologists strongly recommend that people with LAM do not stop taking sirolimus as a precautionary measure during COVID-19. Certain circumstances, such as active infection with COVID-19, may necessitate a dose reduction or interruption in sirolimus use. In such circumstances, the decision to change dosing or hold sirolimus should

be made on an individual basis in close consultation with your LAM physician.

2. My child or I am taking Afinitor® (or other mTOR inhibitor drug). Do I stop it?

Based on current CDC statements and how recent influenza outbreaks like the H1N1 in 2009 were managed, it's recommended to stay on drug unless your child/you or an immediate family or close contact (e.g. schoolmate or work colleague) is diagnosed with COVID-19. Local school/community authorities who provide different recommendations specific to the community/region should also be followed. Consult with your doctor for further guidance.

3. My child is taking Acthar Gel®. Should I continue to administer?

If taking Acthar Gel or steroids for infantile spasms, do not discontinue without discussing with your healthcare provider.

RESOURCES AND REFERENCES

[American Thoracic Society Patient Information Sheet](#)

[The CDC: Coronavirus Disease 2019 \(COVID-19\)](#)

[Johns Hopkins COVID-19 Global Cases Map](#)

[Cystic Fibrosis Foundation](#)

[The LAM Foundation: COVID-19 Updates for the LAM Community](#)

MEDICAL REVIEW NOTE

These FAQs were reviewed and approved by Peter Crino, MD, PhD, University of Maryland School of Medicine; Darcy Krueger, MD, PhD, Cincinnati Children's Hospital Medical Center; and Mustafa Sahin, MD, PhD, Boston Children's Hospital.