

LAM and COVID-19

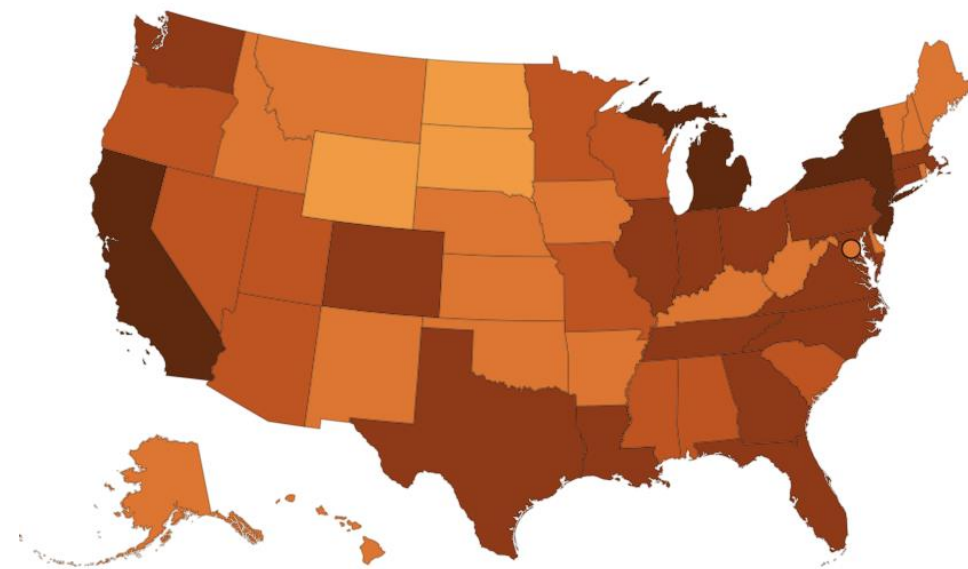
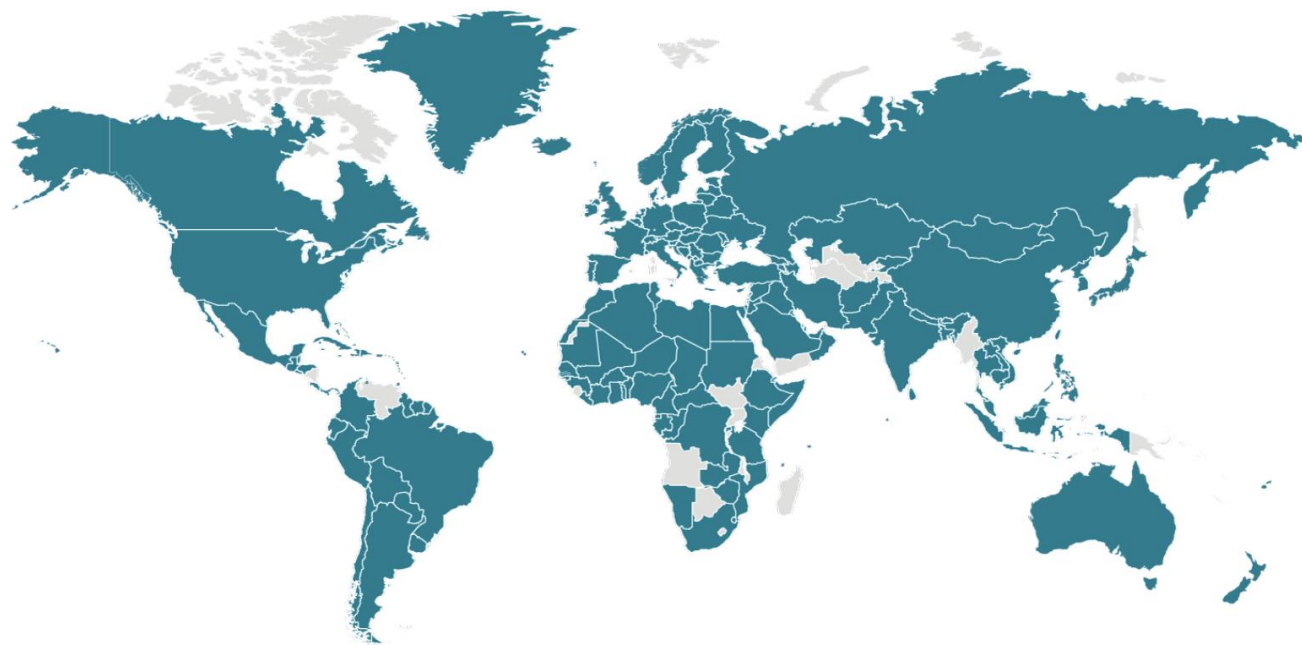
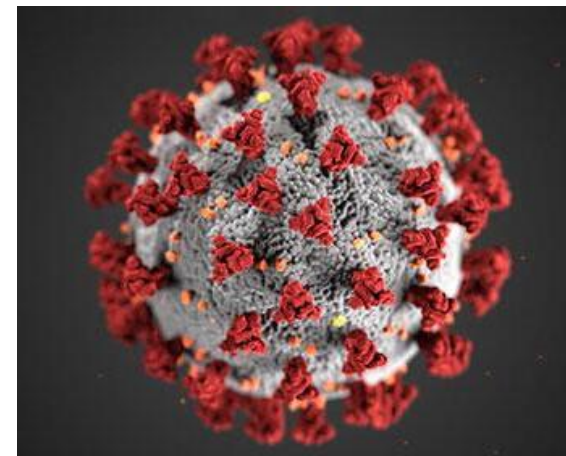
TSC Webinar

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No introduction needed



4 058 252

Confirmed cases

281 736

Confirmed deaths

215

Countries, areas or territories with cases

Last update: 11 May 2020, 20:00 GMT-4

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COVID-19 is caused the virus SAR-CoV-2 (aka 2019-nCoV)

- Coronavirus is a family of viruses is a common cause of respiratory infections, but the SARS-CoV-2 has mutations that make it more virulent
- In 80% or more of people, SARS-CoV2 infection is a mild flu-like illness
- About 20% of people are hospitalized, and 5% end up in the ICU
- Pneumonia, hyperinflammatory response to infection called 'cytokine storm' and increased coagulopathy appear to be the biggest threats from COVID-19
- It is likely the infection confers at least partial immunity, and that that subsequent infection will be less likely or severe

What are the typical symptoms of COVID-19?

- The typical symptoms of COVID-19 include fever, body aches, cough and shortness of breath
- Other symptoms of COVID-19 may include headache, fatigue, sore throat, and loss of taste or smell
- It may be difficult in some situations to distinguish your LAM-related symptoms such as shortness of breath from COVID-19 symptoms
- Some clues that might help include the presence of new symptoms such as body/muscle aches, fever, sore throat, headache, and loss of taste or smell
- Increased intensity of your chronic symptoms such as shortness of breath may suggest COVID-19
- If in doubt, contact your healthcare provider to discuss

I have LAM. How concerned should I be?

- Presence of LAM does not put you at a higher risk of catching COVID-19
- However, underlying lung function impairment due to LAM may put you at a higher risk of complications, if you were to get COVID-19
- The risk of complications is likely directly related to your underlying lung function (FEV1) – see next slide
- You should be concerned but you should not panic
- If you practice hand hygiene and social distancing, you can control the risk

Three tiered risk-assessment for LAM patients

Disease Category	Definition (any one of the listed criteria under the category)	Risk category	Recommendation
Mild	Lung function (FEV1) >70% and not on sirolimus	Low	Same as CDC general population recommendations .
Moderate	1. Lung function (FEV1) >70% on sirolimus 2. Lung function (FEV1) between 50-70%, on sirolimus or not	Moderate	Follow CDC general population recommendations unless widespread COVID-19 in your community, in which case you should follow CDC recommendations for underlying conditions.
Severe	1. Lung function (FEV1) <50% 2. Patients requiring supplemental oxygen regardless of lung function 3. Patients undergoing transplant evaluation 4. Post-transplant patients	High	Same as CDC recommendations for elderly and those with underlying conditions.

Three tiered risk-assessment for LAM patients

Disease Category	Definition (any one of the listed criteria under the category)	Risk category	Reopening recommendations
Mild	Lung function (FEV1) >70% and not on sirolimus	Low	Participate in reopening operations if state/region has satisfied Phase 1 criteria
Moderate	1. Lung function (FEV1) >70% on sirolimus 2. Lung function (FEV1) between 50-70%, on sirolimus or not	Moderate	Await state/region to satisfy phase 2 criteria before participating in reopening operations
Severe	1. Lung function (FEV1) <50% 2. Patients requiring continuous supplemental oxygen regardless of lung function 3. Patients undergoing transplant evaluation 4. Post-transplant patients	High	Await state/region to satisfy phase 3 criteria before participating in reopening operations

Recommendations for all LAM patients

- Pay attention to and adhere to the directions from your local and state authorities
- Wash your hands with soap and water or use alcohol-based hand sanitizer frequently
- Clean and disinfect frequently touched objects and surfaces using a regular household cleaning spray or wipe
- Avoid touching your nose, mouth, or eyes with unwashed hands
- Sneeze or cough into a tissue, or the inside of your elbow
- Stay at home if you are sick
- Continue to follow social distancing guidelines and try to maintain a six-foot distance between yourself and other people
- Avoid gatherings of more than 10 people
- Avoid eating or drinking at bars, restaurants, and food courts – use drive-thru, pickup, or delivery options
- Wear a mask when going out in public, especially in situations where distancing is difficult to maintain
- Restrict international travel and non-essential domestic travel

Sirolimus and COVID-19

- 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 off sirolimus, we strongly recommend that LAM patients do not stop taking sirolimus as a precautionary measure during the outbreak
- The role of sirolimus as a preventative or treatment agent in COVID-19 is not clear and is the subject of active investigation
- The decision to start sirolimus should be based on indications to treat LAM, and LAM patients should not start taking sirolimus solely for the purpose of preventing or reducing their chances of catching COVID-19

Should I take hydroxychloroquine to prevent COVID-19?

- The efficacy of hydroxychloroquine to prevent or treat COVID-19 is not clear and the drug has significant side effects
- Given the lack of proven efficacy and the prospect of potential adverse effects, multiple professional societies and The LAM Foundation recommend against the prophylactic use of hydroxychloroquine to prevent COVID-19 outside the setting of a clinical trial
- The same advice applies to the use of hydroxychloroquine as a treatment for COVID-19 — use outside of a clinical trial is not recommended

Is it unsafe for me to take common medications such as painkillers like ibuprofen or ACE inhibitors like lisinopril?

- Non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen, and ACE inhibitors like lisinopril pose theoretical risks to those with COVID-19
- There is no evidence that taking NSAIDs or ACE inhibitors increases the risk of catching COVID-19
- Please do not alter your regimen or stop your medications before consulting with your healthcare provider

Do I need to purchase a pulse oximeter?

- Pulse oximeters are used to monitor oxygen saturation and are most helpful in titrating the amount of oxygen in patients on supplemental oxygen
- There is no proven role of monitoring oxygen saturation by pulse oximeter as an indicator of contracting COVID-19, and because of inherent variability in the test, it is as likely to frighten as inform
- For LAM patients who have symptoms of COVID-19 and who have been advised to stay at home, periodic monitoring of oxygen saturations by a pulse oximeter may be useful to make decisions regarding the timing to seek immediate medical attention

Is it safe to travel for my routine LAM clinic visits?

- The risk of traveling for clinic visits is dependent upon the local spread of COVID-19 in your community
- In addition, each institution/clinic has specific rules and recommendations regarding clinic visits, and many are continuing to conduct visits remotely using Telehealth
- Please discuss the timing and format for upcoming appointments with your healthcare provider
- If your disease course appears stable, chances are that your clinic visit can be postponed or conducted remotely via Telehealth

What about pulmonary function testing (PFT) and pulmonary rehabilitation visits?

- Similar to clinic visits, most institution/clinics are following specific guidance with regards to reopening PFT laboratories for routine visits
- Those with the most urgent needs, such as preoperative patients or post-transplant patients, will be the first to be offered PFTs
- For patients who are due for a routine PFT but are doing well, it may be appropriate to postpone and reschedule to a later date
- Some patients may be able to use home spirometry to monitor their disease
- Many pulmonary rehabilitation programs remain closed at this time
- It may be possible to replace in-person pulmonary rehab with some home-based exercise regimens

Should I wear a mask in public?

- The current CDC guidance recommends masks when going out in public, especially when venturing into confined spaces where proximity to others may be difficult to avoid such as grocery stores and pharmacies.
- Cloth face masks are appropriate for this purpose (<https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/diy-cloth-face-coverings.html>)
- Special masks such as N95 and surgical masks are in short supply and should be reserved for use by medical professionals
- Please remember that the biggest utility of masks is to reduce the chances of spreading COVID-19 to others
- Wearing a mask is not a substitute for the preventative steps such as hand hygiene and social distancing

What is the real life experience of LAM patients with COVID-19?

- We are only aware of a few LAM patients who have been infected with COVID-19
- This low incidence is likely due to the overall rarity of LAM
- Overall, these patients have done well and recovered without requiring prolonged hospital stays
- The long-term effects of COVID-19 on lung function in patients with LAM are not clear. We are gathering information about LAM patients who get diagnosed with COVID-19 in collaboration with the Tuberous Sclerosis Alliance Natural History Database (<https://www.tsalliance.org/researchers/natural-history-database/>)
- Please contact The LAM Foundation or Jo Anne Nakagawa at the TS Alliance (jnakagawa@tsalliance.org), if you have been diagnosed with COVID-19 and would like to contribute to this endeavor

This pandemic has caused a lot of anxiety for my family and me. What can I do?

- The CDC has posted guidance to address the anxiety and stress that are common in many individuals due to the uncertainty and risk posed by COVID-19 (<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/index.html>)
- The LAM Foundation recently hosted two wellness webinars that can be accessed here: <https://vimeo.com/413208213>
- You have access to The LAM Foundation wellness portal: <https://thelamfoundation.org/wellness>
- The staff at The LAM Foundation and your respective Tuberous Sclerosis organizations (TS Alliance, eTSC, TSCi) is always available to lend a listening ear and think through potential stress-relieving strategies

When will a vaccine to prevent COVID-19 be ready?

- Multiple international efforts are underway to develop a vaccine against COVID-19
- However, candidate vaccines will need to be tested in humans before widespread implementation
- While the exact timelines are not clear, widespread availability of a COVID-19 vaccine is unlikely before the end of 2020.

Final Words

- Every decision in COVID times is based on probabilities, tolerance for risk and quality of life
- We are going to have to learn to live with this virus for a while
- With vigorous attention to the principles regarding hand hygiene, social distancing, and mask use, you are in control of your risk
- Understand that if you 'follow the rules' you will not get infected
- The best minds in the world are united against finding effective ways to treat and prevent COVID-19
- Some of the world's best advocacy organizations are working tirelessly on your behalf
- We will make it through this and come out stronger and better