



The LAM Foundation COVID-19 Statement

Revised on **05.15.2020** – Please read carefully.

The LAM Foundation is closely monitoring the rapidly evolving developments regarding the COVID-19 pandemic. As the United States and other countries around the world begin to take initial steps towards easing the stay-at-home restrictions, it is important to be aware of the continuing risk that COVID-19 poses to patients with chronic lung disease. LAM patients should continue to exercise caution and remain vigilant during this phase of responsible reopening. The LAM Foundation endorses the recommendations of the Centers for Disease Control and Prevention (CDC), which are updated on a regular basis [here](#), and also the Federal Guidelines for phased reopening [here](#).

A slightly modified version is provided below.

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: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/hand-hygiene.html>
- 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. Check the CDC website for information on the best practices of cloth face masks [here](#).
- Restrict international travel and non-essential domestic travel. Check the CDC website for travel guidance [here](#).

Frequent hand washing, avoiding touching your face, and social distancing remain the cornerstones for preventing the spread of COVID-19, and all LAM patients should strictly adhere to these principles until the threat of COVID-19 has passed or widespread effective vaccination of the community has been accomplished.

SPECIAL RECOMMENDATIONS FOR PATIENTS WITH LAM

While having LAM doesn't put you at a higher risk for 'catching' COVID-19, the presence of LAM might make you more susceptible to complications of COVID-19. Although there are no disease-specific data, the risk profile for LAM patients is likely directly related to the degree of lung function (FEV1, DLCO) impairment. Members of The LAM Foundation Scientific Advisory Board had previously put forth tiered guidance recommendations stratified based on disease severity. The same tiered system can be used as a guide by LAM patients to make decisions regarding going out in public again. Regardless of the risk category, LAM patients should continue to strictly adhere to frequent hand hygiene and social distancing in order to reduce their risk of catching COVID-19.

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	<ol style="list-style-type: none"> Lung function (FEV1 or DLCO) >70% and on sirolimus Lung function (FEV1 or DLCO) between 50-70%, on sirolimus or not 	Moderate	Await state/region to satisfy phase 2 criteria before participating in reopening operations.
Severe	<ol style="list-style-type: none"> Lung function (FEV1 or DLCO) <50% Patients requiring continuous supplemental oxygen regardless of lung function Patients undergoing transplant evaluation Post-transplant patients 	High	Await state/region to satisfy phase 3 criteria before participating in reopening operations.

Of course, individual risk does not fall so neatly into categories. In addition to FEV1 and DLCO, individual risk is also dependent upon other factors such as underlying health conditions, overall health status, impairment in diffusion capacity, etc. Patients should exercise their best judgment and seek guidance from their healthcare providers when making decisions.

Frequently Asked Questions

1. SYMPTOMS OF COVID-19

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.

How can I tell the difference between my normal LAM symptoms and symptoms from COVID-19?

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.

What should I do if I have symptoms suggestive of COVID-19?

Contact your LAM physician if you have symptoms suggestive of COVID-19. For the majority of the patients (probably >80%), COVID-19 causes a mild-moderate flu-like illness that does not require hospitalization.

Seek immediate medical attention if you have any of the following: worsening shortness of breath, persistent chest pain, bluish lips or face, confusion, or trouble arousing. Note that this list is not all-inclusive. If in doubt, err on the side of calling and talking with your healthcare provider.

2. TESTING FOR COVID-19

How do I get tested for COVID-19?

There are two types of testing for SARS-CoV2 (the virus that causes COVID-19) infection. The first is a test for the presence of viral RNA, or PCR testing, that is used to determine if active viral infection is present. At the present time, COVID-19 PCR testing is generally being limited to patients who have symptoms. The second type of test is an antibody serology test, to

determine if you have previously been infected with SARS-CoV2. That test is being refined to be more accurate and specific, and will soon be more generally available. The hope is that this test, and viral neutralization tests that will follow, will enable us to determine which patients are immune from future infection with SARS-CoV2.

Please contact your LAM physician if you think you might have COVID-19. Depending upon your degree of symptoms and the local / state policies and test availability, they can guide you towards the next steps.

To gain control of this outbreak, widespread PCR testing, contact tracing, quarantine of the exposed and isolation of the infected is necessary. In a lot of areas, PCR testing is currently being limited to patients with moderate-severe symptoms who might require hospitalization and patients with mild symptoms are being advised to stay at home and not undergo diagnostic confirmation. This situation is likely to change over time with improved access to testing capabilities and the development of novel testing platforms.

3. MEDICATIONS AND MEDICAL SUPPLIES

Does sirolimus put me at increased risk of complications from COVID-19?

Should I hold sirolimus until COVID-19 has passed?

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. 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.

Can sirolimus help prevent/treat COVID-19?

Should I take sirolimus to prevent/reduce my chances of catching COVID-19?

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/reduce my chances of catching 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 safe for me to continue to use a nebulizer at home?

A nebulizer can generate aerosols making it easier for the COVID-19 virus to spread. As long as you do not have symptoms of COVID-19, it is safe for you to continue to use your home nebulizer but be careful not to expose others who may be at risk for infection. Metered dose inhalers are not considered aerosol generating and are preferred. If you have symptoms suggestive of COVID-19, please talk to your LAM physician to discuss this question.

Is it unsafe for me to take painkillers such as ibuprofen?

Non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen or naproxen pose theoretical risks to those with COVID-19. Although there is no direct evidence to support this idea, we are avoiding their use in hospitalized patients with the disease. There is no evidence that taking NSAIDs increases the risk of catching COVID-19. Please do not alter your regimen or stop your medications before consulting with your healthcare provider.

Is it unsafe for me to take Angiotensin Converting Enzyme (ACE) inhibitors such as lisinopril?

Angiotensin Converting Enzyme (ACE) inhibitors such as lisinopril pose theoretical risks to those with COVID-19, but there is no direct evidence to support this idea. There is no evidence that taking 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.

4. HEALTHCARE VISITS

Is it safe to travel for my routine LAM clinic or other healthcare appointments?

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.

Should I postpone my routine bloodwork such as sirolimus/everolimus monitoring labs?

The decision to modify your bloodwork routine should be made in close consultation with your healthcare provider taking into account the local prevalence of COVID-19. For some patients who have been on a stable dose of sirolimus/everolimus for a while, it may be appropriate to reschedule routine monitoring for a later date. For patients who are newly starting sirolimus/everolimus or have had medication changes that are known to interact with sirolimus/everolimus, the benefits of monitoring may outweigh the risks. Please discuss the timing and frequency of individual bloodwork monitoring with your LAM physician.

Is it safe for me to perform pulmonary function tests (PFTs)?

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. Please discuss the timing and format (home spirometry vs. PFTs) of your upcoming PFT assessments with your LAM physician.

Should I continue going to pulmonary rehabilitation visits?

Many pulmonary rehabilitation programs remain closed at the time of this writing. Please discuss continued participation in a pulmonary rehabilitation program with your rehab team and your LAM physician. It may be possible to replace in-person pulmonary rehab with home-

based exercise regimens until safe reopening of rehab facilities is possible. Download an at home exercise program written and published by Dr. Mary Beth Brown, PT, PhD and Morgan Kelly, PT, DPT from the University of Washington [here](#).

Can I continue my clinical trial appointments as scheduled?

Safety of clinical trial participants takes precedence over maintaining a prespecified trial schedule. Please contact your study team to devise an individualized plan for your study activities, and to discuss alternatives such as remote/tele visits, home-based testing such as spirometry, utilizing local testing facilities in lieu of travel to study sites, and advice regarding continuation of study drug(s).

5. TRANSPLANT CONSIDERATIONS

I am a lung transplant recipient. What steps should I take to protect myself?

Lung transplant recipients may be at higher risk of complications from COVID-19. You should continue to stay sheltered and avoid unnecessary travel or contact. Stay in close communication with your transplant team regarding further guidance on your medication and disease monitoring.

I am on the lung transplant waiting list. What steps should I take?

Patients on the lung transplant waiting list belong in the high-risk category and should continue to stay at home as much as possible. Stay in close communication with your transplant team to obtain individualized guidance with regard to further testing and transplant evaluations. Depending upon the local spread of COVID-19 in your community and your disease severity, the timing of your transplant may be altered.

6. CONCERNS RELATED TO WORK

Is it safe for me to go to work?

Follow your state / local policies and above-mentioned tiered guidance when making this decision. In general, working remotely, if possible, is the safest strategy until the virus is under control in your community or a vaccine has been developed and implemented. The answer to this question is also dependent upon other factors such your lung function, your underlying

health conditions, and the ability to distance at work. Please discuss return to work strategies with your healthcare provider.

What if I can't work remotely?

Certain jobs may not be conducive to remote work. Please discuss with your employer to ensure adequate safety precautions are in place before going to work. Continue to follow hand hygiene, avoiding touching your face, and social distancing principles to prevent/reduce your chances of acquiring COVID-19. Contact your healthcare provider if you need a medical note to excuse you from work.

I work in a healthcare setting. What should I do?

Depending upon your profession, working in a healthcare setting may increase your chances of coming in contact with people who have COVID-19. Hospitals and other healthcare places have instituted rigorous cleaning and social distancing policies to limit the spread of the virus to healthcare personnel. Follow your institutional policies with regard to the appropriate use of personal protective equipment (PPE). Discuss your individual circumstances with your healthcare provider to make decisions regarding your ability to safely go back to work.

7. LIFESTYLE MODIFICATIONS

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. Check the CDC website for information on the best practices of cloth face masks [here](#). Special masks such as N95 and surgical masks are in short supply and should be reserved for use by medical professionals. Wearing a mask might worsen some LAM patients symptoms such as shortness of breath. This effect is likely effort dependent and more likely to happen with more vigorous activities such as exercise. Getting acclimated to mask use in the comfort of your home and slowly escalating the use outside your home might help overcome this for a subset of patients. For others, it may be ok to not wear a mask when outside in well-ventilated areas, for example while taking a walk outside. However, as much as possible, you should try and wear a mask in confined spaces such as grocery stores, or limit your excursions to such places. Slowing your pace at these places may also help. 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 as outlined above.

Should I stockpile on medicines and supplies?

LAM patients in the moderate-high risk category should have access to enough medicine and supplies that allows them to shelter in their homes for a few weeks, if needed. For all LAM patients, it is prudent to plan ahead and limit the overall number of trips to grocery stores or pharmacies. Follow the CDC guidelines to protect yourself while shopping [here](#). There is no shortage of sirolimus/everolimus, or for any of the commonly used inhalers by the LAM patients, at the current time. A list of the current drug shortages can be accessed [here](#).

Can I go outside during the pandemic?

It safe for LAM patients to go out on walks in well-ventilated areas. Follow social distancing guidelines when going on walks. Avoid touching surfaces such as playground equipment. Wash your hands after coming home.

Is it safe to order take-out and have groceries delivered?

Ordering food via take-out is safer than dining in a restaurant and delivering groceries to your home is safer than a trip to the grocery store. Follow social distancing guidance during these interactions. Paying by credit card in advance may limit physical interaction. Remember to wash your hands with soap and water after handling outside items such as food and grocery deliveries.

Should I wipe down everything in packages and deliveries?

Although the risk of transmission by handling packages and deliveries is very low, it is a good idea to wipe surfaces and outside objects with regular household cleaning sprays or wipes. The risk can be further reduced by leaving non-perishable items outside the home (such as in the garage) for 2-3 days before bringing them inside. Remember to wash your hands with soap and water after handling outside packages and deliveries.

Can I 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 and limit public transportation such as airplanes, buses or trains to essential trips while following strict hand hygiene and social distancing.

8. REAL LIFE EXPERIENCE IN LAM PATIENTS

What has been the 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](#). Please contact Jo Anne Nakagawa at jnakagawa@tsalliance.org or The LAM Foundation, if you have been diagnosed with COVID-19 and would like to contribute to this endeavor.

9. ANXIETY AND STRESS

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 that can be found [here](#). The LAM Foundation recently hosted two wellness webinars that can be accessed [here](#), and the staff is always available to lend a listening ear and think through potential stress-relieving strategies.

I'm worried the person I live with could get infected. What should I do?

Hand hygiene, social distancing, and following the preventative steps outlined above is the best strategy to reduce your chances of acquiring and spreading COVID-19. It is important to impress on all members of the household that their adherence to these principles protects everyone in the home. Some front-line workers have been spending the bulk of their time in a room that is separate from the rest of the family during periods when they are in direct patient contact, and for up to a week afterward. Others have been living apart. These more extreme measures are isolating and add to the stress of COVID-19 mitigation, and each family must make their own strategy that balances risk, mental health and quality of life. For caregivers, those who see an occasional COVID-19 patient with full personal protective equipment (PPE) under well controlled circumstances might adopt a more modest, 'strip and shower approach' upon

returning home, whereas those assigned to a large, overwhelmed COVID-19 unit might decide to stay in a hotel while on service. By analogy, for LAM patients, those with mild lung function impairment who are living with a COVID-19 caregiver with limited exposure might decide on the more liberal approach above, while those in the high risk category living with a healthcare provider who interacts with COVID-19 patients on a more regular basis might opt for the more extreme approach. The trade-off between risk and quality of life is a spectrum, and individual situations differ widely. The CDC offers guidance for those living with someone who has COVID-19 that can be found [here](#).

We have young children at our home. What steps can we take to protect them? How can we protect ourselves from getting infected?

Although serious illness has been reported in a few cases, the majority of the kids do not tend to become ill from COVID-19. However, children may spread the virus to other members of the household. Parents should become familiar with and educate their children about the principles of hand hygiene and social distancing, as well as other measures to prevent the spread of infection such as regular use of masks, frequent use of hand sanitizer, avoiding group activities which are not conducive to social distancing such as playdates, cafeteria, library, or gym visits. The CDC offers helpful guidance on talking with children about COVID-19 that can be found [here](#).

Depending upon the local prevalence and occurrence of outbreaks of COVID-19, schools may remain closed for an indefinite period. In the meantime, schools are providing opportunities for virtual and distance learning. As schools open, parents should emphasize the importance of hand hygiene and social distancing with their children. Teachers are busy devising learning strategies that are conducive to social distancing, such as staggered schedules, and avoiding crowded spaces like cafeterias, gyms, or libraries. Children should be encouraged to wear a cloth facemask as much as possible during school and should wash their hands immediately after returning from school. Clothes should be washed with the warmest appropriate temperature setting. Dryer heat (usually >120°F) is also very effective at killing the virus. Frequently touched surfaces in the home should be disinfected often. Social gatherings with other kids should be limited to essential school activities. Parents should reassure their children we are safe when we 'follow the rules', that the pandemic will have an end, and the life will return to normal.

10. IMMUNITY AND VACCINATION

What is herd immunity?

Herd immunity is the indirect protection from infection that occurs when the majority of the population is immune to a communicable disease. For example, if 80% of a population is immune to COVID-19, 4 out of 5 subjects who encounter an infected individual won't get sick and the disease is prevented from spreading in the exponential manner that occurred in this first wave. Current estimates suggest that at least 70% of the population will need to be immune in order to confer herd immunity against COVID-19. Development and widespread implementation of a vaccine is the safest way to establish herd immunity.

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.

11. LAM SUPPORT SYSTEM

What should I do if I haven't heard from my LAM physician regarding advice to protect myself from COVID-19?

Most pulmonologists, including LAM Clinic directors, have hundreds of patients under their care and are also assisting their respective institutions with responding to COVID-19. While it may not be possible for LAM physicians to contact every patient, given a little time to respond, most will be available to answer your questions and you should not hesitate to contact them. The LAM Foundation will periodically release COVID-19 guidance documents to try to address patient queries/concerns. The LAM Foundation is also planning to host informational webinars to disseminate key information pertaining to COVID-19 and its implications for the LAM community.

What steps are being taken by The LAM Foundation in response to COVID-19?

The LAM Foundation is committed to the safety and well-being of all LAM patients, and will continue to work tirelessly to advocate for the LAM community in these trying times. Resources provided by the Foundation include:

1. The LAM Foundation has created a monthly education series called LAMposium In Your Living Room. The first session was very successful with greater than 200 attendees. For more information on upcoming LAMposiums In Your Living Room click [here](#).
2. Staff at the Foundation are available for calls and inquiries.
3. Several COVID-related videos and guidance documents are posted [here](#).
4. The LAM Foundation has partnered with the Tuberous Sclerosis Alliance to produce webinars, meetings, and capture the natural history data in patients who are diagnosed with COVID-19.

NOTE ABOUT EVOLVING RECOMMENDATIONS

COVID-19 recommendations for LAM patients will change through time. Every decision in COVID times is based on probabilities, tolerance for risk and quality of life. The threshold for making another trip to the grocery store may be different in communities where the virus is prevalent than in communities in which it is not. We are going to have to learn to live with this virus for a while. By paying vigorous attention to the principles of hand hygiene, avoiding touching your face and social distancing, you can control your risk of getting infected.

We will closely monitor the outbreak and update this document as needed. The top priority of the Medical and Scientific Advisory Board of The LAM Foundation is the safety and well-being of our LAM patient community. Please feel free to contact your LAM physician or The LAM Foundation if you have any other questions or concerns.

DISCLAIMER

This content was created for general informational purposes only. The content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. These recommendations are based solely on expert opinion, and the advice of your personal physician takes precedence over them.

ADDITIONAL RESOURCES

[Centers for Disease Control and Prevention](#)

[Opening Up America Again – Phased Reopening](#)

[American Thoracic Society](#)

[Tuberous Sclerosis Alliance](#)

[American Lung Association](#)

[Cystic Fibrosis Foundation](#)