



The LAM Foundation COVID-19 Statement 03.11.2020

The LAM Foundation is closely monitoring the rapidly evolving developments regarding COVID-19. Although at this time the risk that a given individual will contract the illness is low, the infected number continues to rise, and it is likely to be some time before the spread of the virus is contained. The World Health Organization has now officially declared COVID-19 as a pandemic. In most cases, COVID-19 produces a mild respiratory infection, but in a minority of cases, the disease can be more severe and require hospitalization or even ICU care. The LAM Foundation endorses the recommendations of the Centers for Disease Control and Prevention (CDC), which are updated on a regular basis and can be accessed [here](#).

A slightly modified version is provided below.

RECOMMENDATIONS FOR THE GENERAL PUBLIC

In general, the measures to prevent transmission of COVID-19 are similar to other respiratory illnesses such as the flu and LAM patients should maintain the same degree of vigilance about infection control as they do in the typical flu season. The most important recommendations to prevent transmission of COVID-19 are:

- Avoid crowds, large group gatherings, or close contact with sick people.
- Stay home if you are sick or at high risk (see below).
- Clean and disinfect frequently touched objects and surfaces using a regular household cleaning spray or wipe.
- Use alcohol-based hand sanitizer or proper handwashing frequently:
<https://www.cdc.gov/handwashing/>
- Use facemasks only if you are sick
- Restrict international travel and non-essential domestic travel
- Check the CDC Travel Guidance prior to any trips:
<https://www.cdc.gov/coronavirus/2019-ncov/travelers/index.html>

ADDITIONAL RECOMMENDATIONS FOR THE ELDERLY AND THOSE WITH UNDERLYING CONDITIONS

The odds of developing COVID-19 increase with age, starting at age 60. It is especially dangerous for people over 80. Elderly patients and those with underlying chronic conditions such as diabetes, hypertension, heart or lung disease, are advised take precautions in addition to those above:

- Stock up on medications, household items and groceries to stay at home for a time until the outbreak begins to wane.
- Avoid all travel, if possible.
- Practice “social distancing” and try to maintain a six-foot distance between people.

SPECIAL RECOMMENDATIONS FOR PATIENTS WITH LAM

While having LAM doesn't put you at a higher risk for catching COVID-19, it is likely that COVID-19 poses greater risk to patients with significant underlying lung disease and/or those who are taking immunosuppressive medications, such as sirolimus. Although there are no disease-specific data, members of The LAM Foundation Scientific Advisory Board have developed tiered guidance recommendations that are stratified based on disease severity.

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.

Please keep in mind that although we have created these categories, the risk profile for individual patients may vary depending upon a number of other factors such as underlying health conditions, overall health status, significant impairment in their diffusion capacity, etc. Patients should exercise their best judgment and discuss with their healthcare providers when making decisions, rather than rely solely on these categories.

WHAT TO DO IF YOU SUSPECT YOU MIGHT HAVE COVID-19

The typical symptoms of COVID-19 are fever, cough and shortness of breath. Please contact your LAM physician if you have these symptoms, or if you need a note to stay away from your workplace.

ADVICE REGARDING SIROLIMUS CONTINUATION DURING THE COVID-19 OUTBREAK

Whether being on sirolimus 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 holding sirolimus should be made on an individual basis in close consultation with your healthcare provider.

ADVICE REGARDING LAM CLINIC VISITS DURING COVID-19 THE OUTBREAK

LAM patients who are doing well may want to have discussion with their LAM physician about postponing or remotely conducting routine LAM clinic and clinical trial visits until the outbreak passes.

NOTE ABOUT EVOLVING RECOMMENDATIONS

It is likely that COVID-19 recommendations for LAM patients will change through time. All LAM patients should pay close attention to the prevalence of COVID-19 in their local communities. In case of local spread, LAM patients in the moderate risk category are advised to adopt the same precautions as the high-risk category. 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. The incredible strength and spirit of the LAM community is that we all support each other, especially in times like

these. 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. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this paper.

ADDITIONAL RESOURCES

[Centers for Disease Control and Prevention](#)

[American Thoracic Society](#)

[Tuberous Sclerosis Alliance](#)