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PFF Coronavirus FAQs

To members of the pulmonary fibrosis community,

The Pulmonary Fibrosis Foundation has been closely monitoring the impact of coronavirus (COVID-19) and its spread throughout the United States. People who have chronic medical issues may be at higher risk for serious illness from COVID-19, including those with pulmonary fibrosis. Public health officials recommend patients in the higher risk category should reduce the risk of being exposed to COVID-19.

To limit or prevent the spread of COVID-19, the Centers for Disease Control (CDC) has provided recommendations including:

1. **Get a COVID-19 vaccine.** If you have not been vaccinated, find a vaccine near you.

2. **If you have been fully vaccinated, you can:**
   a. Resume activities you participated in prior to the pandemic.
   b. Choose not to wear a mask or physically distance from others, except as required by local regulations and guidelines. If you have questions about whether you are safe without a mask, ask your doctor.
   c. **Travel in the U.S.** without testing or self-quarantine.

   ✦ **Important:** Those who are immunosuppressed, either from medications or from medical conditions that cause immunodeficiency should continue more stringent precautions against exposure to COVID-19. In these individuals, vaccine response may be much less protective than in the general
If you are immunosuppressed, speak with your doctor about the need for continuing personal protective measures.

3. If you have NOT yet been fully vaccinated, you should:
   a. Wear a mask that fully covers your nose and mouth whenever you are with people who don’t live with you. N95 respirators should be reserved for health care professionals.
   b. Avoid crowds and poorly ventilated indoor spaces.
   c. Physically distance by staying six-feet apart from others who don’t live with you.
   d. Wash your hands often and with soap and water for at least 20 seconds. Use an alcohol-based hand sanitizer if soap and water are not available.

Common Questions

What are the symptoms of COVID-19 infection?

While symptoms may vary from few or no symptoms to severe breathing difficulty, more common symptoms include:

- Fever (Temperature over 100.4° F)
- Muscle pain or body aches
- Worsening cough
- Increased shortness of breath
- Chills
- Repeated shaking with chills
- Headache
- Sore throat
- New loss of taste or smell
- Congestion or runny nose
- Nausea or vomiting
- Diarrhea

What should I do if I think I have been infected with COVID-19?

If you get sick, stay home and call your pulmonologist. If he/she is not available, contact your primary care physician. Let your doctor know about your symptoms and that you may have COVID-19. Get medical attention immediately if you have:
- More difficulty breathing or shortness of breath
- Persistent pain or pressure in the chest
- New confusion or inability to arouse
- Bluish lips or face
- Increased oxygen requirement

**How does COVID-19 impact patients with interstitial lung disease (ILD)?**

Emerging studies indicate that ILD patients who are hospitalized with COVID-19 have worse outcomes than matched COVID-19 patients without ILD. (Source: [https://www.atljournals.org/doi/pdf/10.1164/rccm.202007-2794OC](https://www.atljournals.org/doi/pdf/10.1164/rccm.202007-2794OC)). It is important to note that more research is needed to gain a better understanding of the impact of COVID-19 on patients with ILD.

**Should I get vaccinated for COVID-19?**

Yes, you should get vaccinated as soon as possible. In accordance with [Recommendations issued by the Centers for Disease Control and Prevention](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations.html), the PFF strongly encourages vaccination for COVID-19, as the benefits far outweigh the risks. The authorized vaccines have been demonstrated to be safe and extremely effective in preventing COVID-19 and/or limiting the development of severe COVID-19. Following vaccination, individuals should continue to adhere to safe practices, including the use of face coverings, hand washing, and physical distancing until the prevalence of the SARS-CoV-2 virus in the community is significantly reduced. To ensure that you are not part of the limited population for whom vaccination is not recommended at this time, we encourage you to reach out to your primary care physician and pulmonologist for more information.

COVID-19 variants have recently emerged around the world and in the U.S., and some of these strains of the virus are known to spread more easily. This may mean that for those who are exposed to these variants, immunity from a previous COVID-19 infection or from a COVID-19 vaccination may not be as effective at preventing infection, though more research needs to be done to fully understand the impact of the new COVID-19 variants.

People who are eligible to receive the COVID-19 vaccine should proceed with vaccination, as the currently authorized vaccines are highly effective in reducing the severity and spread of disease. Strategies that are known to reduce the spread of infection, such as wearing a mask, social distancing, and frequent hand washing,
remain crucial in limiting the spread of COVID-19, especially as new variants of the disease are discovered.

**Is it safe to travel for routine clinic visits and take pulmonary function tests (PFTs)? Should I continue traveling to my pulmonary rehabilitation appointments?**

If you have been fully vaccinated, it is considered safe to resume your normal activities including clinic visits and routine testing. For those who have not yet been vaccinated, the risk of traveling for clinic appointments is dependent upon the spread of COVID-19 in your area and the clinic in which you are seen. If you have concerns about traveling for a clinic appointment, you should discuss your specific situation and risks with your care center. There have been expansions in telemedicine during the COVID-19 pandemic, so you should talk to your doctor to determine if telehealth visits are an option. Home exercise programs may be developed in discussion with your pulmonary rehab center and physician during the COVID-19 pandemic. Several online resources are available to assist patients with exercise training. Discussing the use of these tools with your physician is recommended prior to initiating a home program.

**How can I prevent the virus from entering my portable oxygen concentrator (POC)?**

The filters in POCs are not designed to filter viruses. Oxygen equipment should be cleaned, and filters replaced as specified by the manufacturer for routine maintenance. It is now more important than ever to clean and disinfect frequently touched objects, including POCs. Also, wash your hands frequently and adhere to social distancing guidelines.

**Should I wear a mask with an exhalation valve or vent?**

It is important to wear a face covering when in public to help reduce the spread of COVID-19. Wearing a face covering can prevent the wearer’s respiratory droplets from reaching other people. In addition, face coverings offer some protection to the wearer, but they are not a substitute for physical distancing. Face coverings should be worn in addition to maintaining a six-foot distance from others.

Note that masks with one-way valves or vents allowing the wearer to exhale through the valve can result in the wearer’s respiratory droplets reaching others. This type of mask is not recommended by the CDC, as it does not prevent the person wearing the mask from transmitting COVID-19 to others.
I am enrolled in a clinical trial. Should I continue going to study appointments?

The FDA has issued guidelines for clinical trial investigators in response to the COVID-19 outbreak. In addition, the FDA has developed information for patients who are enrolled in a clinical trial. If you are enrolled in a current trial, contact your trial center for information about any changes in visits.

How can I get involved in a clinical trial related to COVID-19?

The PFF Clinical Trial Finder has been updated to include clinical trials related to COVID-19, in addition to PF-related clinical trials. Typing “COVID-19” in the “Keyword” filter of the PFF Clinical Trial Finder will show studies related to COVID-19. If you are interested in participating in any of these trials, you should contact the listed site coordinator for the trial via phone or email. You can also find clinical trials investigating COVID-19 on the website of the National Institutes of Health at https://clinicaltrials.gov.

I am a lung transplant recipient. How can I protect myself from infection?

Lung transplant recipients should use an abundance of caution as they may have a lower immune response to the COVID-19 vaccine according to a recent study by Johns Hopkins University. The study suggests that a substantial proportion of transplant recipients likely remain at risk for COVID-19 after 2 doses of mRNA vaccine. Future studies should address interventions to improve vaccine responses in this population, including additional booster doses or immunosuppression modulation.

Vaccination is still recommended for post-transplant individuals, but they may not be as protected as the general population. Therefore, transplant recipients and their loved ones should get vaccinated and continue to take precautions to prevent infection from COVID-19. Monitoring viral rates in your community to help individuals judge their activities based on the exposure.

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

Patients on the waiting list for a lung transplant should maintain contact with their transplant center. According to the American Society of Transplantation, the risk of acquiring COVID-19 from an organ donor is low. However, transplant surgery may be delayed due to the threat of exposure in the hospital and the current strain on medical personnel and resources.
Can COVID-19 lead to pulmonary fibrosis?

The impact of SARS-CoV-2 infection on the development of chronic and progressive lung disease is under study, and much remains unknown.

Pulmonary fibrosis (PF) or interstitial lung disease (ILD) has been reported in some patients following COVID-19 infection, however the rates of development of PF after severe, moderate, mild, or asymptomatic COVID-19 infection are undefined. Severe COVID-19 pneumonia with Acute Respiratory Distress Syndrome (ARDS) appears to present the highest risk for subsequent PF.

While COVID-19 patients are being followed after infection, data does not yet exist to understand whether post-COVID-19 abnormalities in lung function or chest imaging will improve, stay stable, or progress over time. The medical community is working to determine how to best care for patients who have lung abnormalities following COVID-19 infection.

Post-acute sequelae of SARS-CoV-2 (PASC) is a term to describe a prolonged constellation of symptoms, including breathlessness and cough, that some individuals experience after COVID-19 illness. Treatment of PASC is being studied, and currently involves supportive care, symptom management, and treatment of serious complications.

What should I do if I had COVID-19 and have been diagnosed with pulmonary fibrosis?

Discuss with your doctor how he or she plans to follow your disease course. If your doctor is not affiliated with a post-COVID center, consider going to one in order to access to the most current care, treatments, and opportunities to participate in research. The PFF has released a statement about lung fibrosis resulting from COVID-19. The PFF also provides educational resources on supportive care including supplemental oxygen, pulmonary rehabilitation, pulmonary function tests and the PFF Care Center Network.

Will my anti-fibrotic treatment help prevent me from contracting COVID-19? Is the medication being used as a treatment for COVID-19?

While a tremendous amount of research and clinical trials for coronavirus treatments are underway, there is currently no clinical evidence that anti-fibrotic therapies approved to treat forms of pulmonary fibrosis are safe or effective in preventing and/or
treated patients infected with coronavirus. Several studies are investigating the use of anti-fibrotics approved for various forms of PF to treat patients who have developed lung fibrosis as a result of COVID-19. If you’re interested in learning more, the PFF’s Drug Development Pipeline now includes therapeutic agents and devices that are in clinical trials to treat COVID-19. You can also visit clinicaltrials.gov for a complete list of COVID-19 studies worldwide.

**What is known about immunity to COVID-19 in those who were previously infected?**

The latest research on COVID-19 indicates that people can continue to test positive for up to three months after diagnosis and not be infectious to others. However, if you had COVID-19, you should be vaccinated as soon as possible after quarantining. You will not have enough immunity to skip the vaccine. In addition to getting vaccinated, those who have recovered from COVID-19 should continue to follow everyday preventive actions.

The Pulmonary Fibrosis Foundation is monitoring the dynamic situation with COVID-19 and will address additional questions and future plans for PFF events and programs depending on the evolving situation throughout the United States.