



Coronavirus (COVID-19) Precautions for FOP Patients & Families December 30, 2020

The Coronavirus (COVID-19) pandemic continues to pose a significant risk to the population worldwide particularly with the ongoing surge of cases. The ICC recommends that people living with FOP to continue to follow strict precautionary measures to **prevent infection from SARS-CoV-2, the virus that causes the COVID-19 illness**. The ICC is providing this update to the prior statement of July 9, 2020.

People living with FOP are at high risk of severe illness with COVID-19.

The key recommendations are changing rapidly and are country specific:

- **Please follow the advice of your local health authority for patients in the high risk group (similar to immunocompromised).**
- **Preventing the spread of SARS-CoV-2 (the virus that causes COVID-19) is critical.**
- **New! At this time, COVID vaccines are not recommended for patients with FOP due to the lack of safety and efficacy data. No COVID vaccines to date have been tested in children.**
- **New! Although vaccines are now becoming available, there are still many unknowns: the vaccines have not been tested in children, it is unknown if the vaccines will be safe or effective in patients with FOP, it is unknown if the current vaccines work when given subcutaneously, and availability of a vaccine will be limited. If a patient with FOP decides to take a COVID vaccine, please contact your FOP physician for guidance.**
- **New! Family members should get a COVID vaccine when it is available to them.**
- **New! Even if someone gets the vaccine, it is still important to follow the standard precautions with masks, hand washing, and physical distancing measures.**
- **New! Patients with FOP and everyone around them should follow the standard precautions by adhering to masks, hand washing/sanitizing, and physical distancing measures, regardless of whether they have had a vaccine or not.**
- **World Health Organization (WHO) information: click [here](#)**
- **Centers for Disease Control (CDC) information: click [here](#)**

SARS-CoV-2 is a new type of coronavirus that can cause the COVID-19 disease. COVID-19 can affect your lungs and airways. The most common symptoms of COVID-19 are fever, dry cough and tiredness. Some patients may have shortness of breath, aches and pains, loss of taste and smell, nasal congestion, runny nose, sore throat or diarrhea. In some, the disease can be severe and life threatening. **The best way to prevent illness is to avoid exposure to this virus.**

New! How does the development of a vaccine change things?

- Recent developments of a vaccine provide long term hope. However, the impact of the vaccine on the pandemic will take quite some time to manifest. Many types of vaccines are being tested and so this is a rapidly changing field.
- **Vaccines to date have not been tested in children or with subcutaneous delivery.**
- Some of the vaccines (Moderna, Pfizer) use mRNA injected into skeletal muscle to induce immunity. These vaccines were developed for injection into skeletal muscle (intramuscular/IM delivery) to work. **It is unknown if subcutaneous injection will provide immunity or what level of immunity.**
- Other vaccines including those from China use different methods to induce immunity. The Sinovac and Sinopharm vaccines are inactivated virus vaccines. The Johnson & Johnson vaccine uses an adenovirus-based system to express components of SARS-CoV-2 to induce immunity. Whether these will be safe for patients with FOP, or can be used subcutaneously in patients with FOP, remain unknown
- The duration of immunity conferred by the vaccines is unknown
- At this time, the ICC does **not recommend vaccination for children** due to the lack of safety and efficacy data.
- The ICC does **not recommend intramuscular vaccination** for patients with FOP, as this route is high risk to induce significant flare-up activity.
- The ICC **currently recommends holding off on subcutaneous injection of COVID vaccines because of the lack of safety or efficacy data.** However, the risks and potential benefits should be considered carefully with your physician. **If you do decide to get the COVID vaccine, contact your FOP physician for guidance.**
- The ICC recommends that **FOP family members and caregivers get vaccinated for COVID-19** if safely available for them.
- Vaccinations can take 4+ weeks to show any efficacy, so there is no protection immediately after vaccination. In addition, vaccines do not confer absolute immunity to the SARS-CoV-2 virus, and may not have activity against all forms of the SARS-CoV-2 virus. **Anyone who receives a vaccine should still continue with masking, hand hygiene, and physical distancing.**
- This information is rapidly evolving. Please discuss with your local care providers regarding benefits and risk of any locally approved vaccines.
- It's very important to maintain social distancing and wearing a mask when around members outside your household
- Additional updates will be shared as new information becomes available.

How is SARS-CoV-2 spread?

- People can catch the SARS-CoV-2 virus from others who have the virus. SARS-CoV-2 is highly contagious. The disease can spread from person to person through small droplets from the nose or mouth which are spread when a person infected with SARS-CoV-2 (even if asymptomatic) coughs, sneezes, or is talking. Data also suggest that the virus can be air-borne. Transmission is highest in indoor settings.

- It is possible for a person infected with SARS-CoV-2 to be **asymptomatic or have minimal symptoms, but can still spread the virus.**

How can I decrease my risk of exposure to the SARS-CoV2 virus that causes COVID-19?

- **FOP patients, their families and caregivers should avoid getting exposed to the virus**
- Stay at home. No outside visitors unless absolutely necessary
- If it is necessary to leave the house or have an outside visitor, we recommend protecting yourself by wearing a face mask, gloves, and goggles or a face shield.
- If you are in a clinical trial, please communicate with your site for specific recommendations.
- Everyone should wear a mask – three layers of high quality cotton, or a surgical face mask. This includes patients with FOP and their caregivers.
- Regularly wash your hands with soap and water **for at least 20 seconds.**
- Have personal aides or caretakers wash their hands with soap and water **for at least 20 seconds** before assisting you.
- The concern with NSAIDs (non-steroidal anti-inflammatory drugs), ACEi (angiotensin-converting enzyme inhibitor) and ARB (angiotensin receptor blocker) increasing risk of COVID-19 infection and severity of illness is unclear; please contact your healthcare provider before stopping or starting medications.
- In the event of a fever, consider taking acetaminophen (Paracetamol or Tylenol) instead of Ibuprofen for fever, but the most important thing is to **prevent infection and self-isolate.**
- Dexamethasone (glucocorticoid similar to prednisone) seems to help hospitalized patients with severe COVID-19 respiratory illness in the later stages of the disease. Don't take prednisone without consulting with your healthcare provider. We don't know if prednisone intake early in the disease can further increase risk of complication with the virus or not.

General recommendations:

- Avoid touching your eyes, nose, or mouth.
- Avoid high-touch surfaces in public places – elevator buttons, handles, handrails, handshaking, etc. Use a tissue or your sleeve to cover your hand or fingers if you must touch something.
- Wash your hands after touching surfaces in public places.
- Cover your cough or sneeze with a tissue, then throw the tissue in the trash.
- Stay in touch with others by phone or email. You may need to ask for help from friends, family, neighbors, community health workers, etc. if you become sick.
- Clean and disinfect frequently touched objects and surfaces (including iPads, phones, laptops) using a regular household cleaner or wipe.
- Rest, stay well hydrated, and self-isolate.

Take steps to prepare for possible infection:

- Contact your healthcare provider to ask about getting an extra supply of your regular prescription medicines to have on hand if there is an outbreak of COVID-19 in the community and you need to stay home for a long period of time.
- Be sure you have over-the-counter medicines and supplies (tissues, etc.) to treat fever and other symptoms. Most people will be able to recover from COVID-19 at home.
- Have enough household items and groceries on hand so that you will be prepared to stay at home for an extended period of time.

- For respiratory concern or airway management questions please contact your closest FOP expertise center (See the ICC website for a list of current centers). You may also contact:

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What should I do if I think I have been exposed to SARS-CoV-2?

- If you have symptoms that resemble COVID-19, you should immediately self-isolate.
- Contact your primary care doctor immediately for guidance. Where available, you should be tested for both the influenza virus and the SARS-CoV-2 virus.
- Follow established local guidelines for positive and negative results

Should you get tested for COVID-19?

- Please contact your local healthcare provider if you are having any symptoms suggestive of COVID-19 to discuss testing
- We do recommend that you and your care-givers get COVID-19 testing if symptomatic
- As far as we are aware, no FOP patients have developed a flare-up after carefully taken nasal swab for COVID-19 testing

Should I return to work/school?

- We recommend that you reach-out to your local healthcare providers and employers/schools to discuss when and if it would be safe for you to return to work. Several factors need to be taken into consideration (your current health status and current medications, local COVID-19 cases, work and school environment, transportation considerations).
- You will need to continue to maintain social distancing, wear a mask, and use frequent hand hygiene. Also recommended is that you avoid large gatherings and indoor events.