



Coronavirus (COVID-19) Precautions for FOP Families

July 17, 2020

Coronavirus (COVID-19) pandemic continues to pose a significant risk to the population worldwide. Although some of the restrictions might be lifted in certain parts of the world, ICC recommends that people living with FOP to continue to follow strict precautionary measures to **prevent infection from COVID-19**.

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

The 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)**
- **World Health Organization (WHO) click [here](#)**
- **Centers for Disease Control (CDC) click [here](#)**

What is COVID-19?

- COVID-19 is a **new** type of coronavirus that 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. **There is currently no vaccine to prevent coronavirus disease 2019 (COVID-19). The best way to prevent illness is to avoid being exposed to this virus.**

Should you get tested for COVID-19?

- Please contact your local healthcare providers 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 developed a flare up after nasal swab for COVID-19 testing

Should you 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 and transportation considerations)
- You will need to continue to maintain social distancing, wear a mask and frequent hand hygiene. Also recommend that you avoid large gatherings and indoor events.

How is it spread?

- People can catch COVID-19 from others who have the virus. COVID-19 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 with COVID-19 coughs, sneezes or talks. With data to suggest that it is air borne.
- It is possible for a person with COVID-19 to be **asymptomatic or have minimal symptoms but can still spread the disease.**

How to prevent getting COVID-19?

- **FOP patients and their families and caregivers should avoid getting exposed to the virus**
- Stay at home. No outside visitors unless absolutely necessary
- If necessary to leave the house or have an outside visitor, we recommend protecting yourself by wearing a face mask, gloves and glasses.
- If you are in a clinical trial, there will be communication from your site for local recommendations.
- Wash your hands often 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. Consider taking Acetaminophen/Paracetamol 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.

General recommendations:

- Avoid touching your eyes, nose, and 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 cleaning spray or wipe,
- Rest, stay well hydrated and self-isolate.

What is the purpose of wearing masks?

- Cloth or surgical masks are effective at preventing spread of COVID-19 but **does not** necessarily protect you from getting the infection. Thus, when a person wears a mask, they are protecting other people around them. It is important to continue to maintain social distancing and ensure that others around you are wearing masks.

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:

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