



Coronavirus (COVID-19) Precautions for FOP Families March 27, 2020

In light of the continued and rapid spread of Coronavirus (COVID-19), the ICC has updated some of the information and recommendations for people living with FOP, their families and caregivers. People living with FOP are at high risk of severe illness with COVID-19. Therefore, it is paramount to **prevent infection from COVID-19 and self-isolate**. Prednisone and other immunosuppression medications can further increase that risk.

The recommendations are changing rapidly and are country specific:

- **Please follow the advice of your local health authority**
- **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, nasal congestion, runny nose, sore throat or diarrhea. In some, the disease can be severe and life threatening. We are still learning about this new virus.

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 or exhales.

It is possible for a person with COVID-19 to be **asymptomatic or have minimal symptoms but can still spread the disease**.

COVID-19 droplets land **on objects and surfaces and can last for several days on hard surfaces**. Other people then catch COVID-19 by touching these objects or surfaces, then touching their eyes, nose or mouth.

The following guidelines are especially important for FOP patients and families:

- **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. See link demonstrating appropriate hand washing technique <https://twitter.com/SinghLions/status/1240686550939136003>
- 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 still evolving and 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**.

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.

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:

Zvi Grunwald, M.D.

The James D. Wentzler Professor and Chairman Emeritus

Department of Anesthesiology

Thomas Jefferson University

Philadelphia, PA. USA

Tel: 215-955-6161

Cell: 215-206-7362

Fax: 215-923-5507

Email: zvi.grunwald@jefferson.edu

The recommendations are evolving rapidly; we will do our best to update you on a regular basis.