

Concerns about the novel coronavirus COVID-19 and Neurofibromatosis

For now, the best advice from NF specialists is to follow guidance issued for everyone to minimize exposure to the virus. Persons with NF should contact their NF specialist if particular questions arise related to their condition.

For anyone who has had chemo or other cancer treatment, it's recommended to contact your PCP to find out whether you are immuno-suppressed. Many cancer treatments do not suppress the immune system, but some do.

Those with a history of breathing issues are at risk for more severe disease - this includes smokers, vapers, and persons with COPD or lung cancer. Anyone whose lung capacity is limited by an internal tumor or severe scoliosis would also risk severe disease. It's less clear whether asthma increases severity, but caution is recommended.

Others at risk for more severe disease are those 65 and older, diabetics, those with a serious heart condition, high blood pressure, obesity, liver disease or on kidney dialysis. People with auto-immune or auto-inflammatory conditions should consult their physicians about their level of risk.

Individuals with NF whose medical problems require frequent physician visits may be at increased risk of exposure to the virus by virtue of the added human contact.

So, in most individuals NF itself won't increase the risk from exposure to COVID-19, but secondary conditions may.

It is recommended at this time that individuals with NF should follow the guidelines issued by the CDC (www.coronavirus.gov) and NIH (www.nih.gov/coronavirus), which include:

Practice everyday preventive actions to help reduce your risk of getting sick and remind everyone in your home to do the same. These actions are especially important for older adults and people who have severe chronic medical conditions.

- Avoid nonessential travel, going to work, eating at bars and restaurants, or gathering in groups of more than 10. State guidelines may be stricter.
- Avoid close contact with people who are sick.
- Stay home when you are sick, except to get medical care.
- Cover your coughs and sneezes with a tissue and throw the tissue in the trash.
- Wash your hands often with soap and water for at least 20 seconds, especially after blowing your nose, coughing, or sneezing; going to the bathroom; and before eating or preparing food.
- If soap and water are not readily available, use an alcohol-based hand sanitizer with at least 60% alcohol. Always wash hands with soap and water if hands are visibly dirty.
- Clean and disinfect frequently touched surfaces and objects (e.g., tables, countertops, light switches, doorknobs, and cabinet handles).

- Limit close contact with others as much as possible (6 feet or greater is preferred).

As a community we know how to face uncertainty and how to adapt to the changing world around us. We tackle these uncertain times the same way everyone across the globe is doing right now — by drawing strength and inspiration from one another. Be #NFStrong!