Novel Coronavirus Precautions For Barth Syndrome Individuals Thursday, March 13th, 2020



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Human coronaviruses are a large family of viruses[i] which were first characterized in the 1960s[ii]. They are responsible for a substantial proportion of upper respiratory tract infections in children[iii]. The novel coronavirus has been named Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) and the disease it causes has been named "coronavirus disease 2019" (COVID-19). This is a new virus in the coronavirus family. The virus that causes COVID-19 and the one that causes Severe Acute Respiratory Syndrome (SARS) are different from one another.

Symptoms

There are many similarities between COVID-19 and the flu[iv]. Both cause fever, cough, body aches and fatigue. Gastrointestinal symptoms (vomiting and diarrhea) has been <u>reported</u> in at least one child with COVID-19. The symptoms can be mild or severe. These viruses can result in pneumonia. Fatalities have occurred with both viruses.

Transmission

COVID-19 can be spread through **person-to-person** contact with large droplets from an infected person when they cough, sneeze, talk, and exhale. Studies suggest that COVID-19 may persist on surfaces for a few hours or up to several days. It can be spread through droplets that land on objects and surfaces. Generally, this is within a distance of 3 feet/ 1 meter. The flu and COVID-19 can be spread by an infected person **before symptoms appear**.

Studies are underway to determine if COVID-19 can be transmitted through smaller particle droplets that spread over distances greater than 3 feet/1 meter from an infected person coughing, sneezing or talking. This is known as airborne transmission.

Prevention and Treatment

Both the flu and COVID-19 may be prevented by frequent, thorough hand washing, coughing into the crook of your elbow, staying home when sick and limiting contact with others who are or may be infected.

A vaccine is available and effective in preventing or reducing the severity of most dangerous flu types. There is no vaccine available at this time for COVID-19, though it is in the process of being developed

Neither the flu nor COVID-19 are treatable with antibiotics, which only work on bacterial infections. Antiviral medications can address symptoms of the flu and can sometime shorten the

duration of the illness. Antiviral medications are currently being tested to see if they can address COVID-19.

People with cardiovascular conditions such as Barth syndrome are at high risk of disease severity with any respiratory illness. The American College of Cardiology has released <u>COVID-19 Clinical</u> <u>Guidance For the Cardiovascular Care Team.</u>

Individuals with Barth syndrome are at risk of experiencing <u>cardiac arrhythmia</u>. Therefore, it is important not to take over-the-counter decongestants and multi-system cold remedies that contain decongestants before first consulting with the doctor.

Antibiotics are effective for bacterial infections that can occur as a result of viral infections. If the doctor thinks respiratory symptoms could be helped by antibiotics, **avoid taking fluoroquinolones**. Use of these drugs should be avoided in people with conditions that are associated with serious cardiac <u>arrhythmias</u>. The antibiotics in this class are: Avelox, Cipro, Factive, Levaquin, and Ofloxacin.

Barth Syndrome Specific Concerns

There are precautions for your loved one who has Barth syndrome during the <u>COVID-19</u> outbreak or anytime. Start by familiarizing yourself with standard Neutropenia precautions which exceed WHO and CDC precautions.

Neutropenia Precautions

- When traveling be prepared by having an N-95 mask available to use when exposed to someone who is visibly sick (coughing or sneezing). N95 mask is rated to filter very small particles to protect the wearer from dust, mold, and some bacteria and viruses. Protective face masks do not prevent you from getting a respiratory infection as air comes in around the mask. They do however help prevent the person who is sick from spreading the virus to people around them. If you are sick, sneezing or coughing, you should stay home.
- Have gloves on hand to use when needed
- Avoid crowded places
- Avoid interaction with people who are sick or have been recently sick
- Avoid person-to-person contact with others (6 feet/2 meters)
- Don't share food, drink cups, utensils or other personal items, such as toothbrushes
- Wash raw fruits and vegetables
- Avoid touching surfaces that may have or would have been touched by someone in community or classroom or
 - <u>disinfect</u> surfaces before touching (e.g., tables, desktops, doorknobs, light switches, handles, toilets, faucets, etc.)
- Avoid touching mouth and nose
- Wash your hands frequently for at least 20 seconds

- Keep personal <u>hand sanitizer</u> available that is at least 65% alcohol
 - If you plan to make your own see WHO-recommended Handrub Formulations under additional resources below
- Wrap infants in two blankets, carry several clean blankets to change outer blanket when needed
 - inner blanket/clean blanket
 - o outer blanket/barrier blanket
- Bathe when you get home
- Call the doctor with a fever of 100.4°F/38° or higher
- Call the doctor for advice with symptoms of illness
- Stay home when sick

Recommendations for Mitochondrial Patients: United Mitochondrial Disease Foundation (UMDF)

Barth Syndrome is not classified as a primary mitochondrial myopathy. However, the defective biosynthesis of cardiolipin in Barth syndrome patients does result in mitochondrial dysfunction. Therefore, mitochondrial precautions should be observed with patients who have Barth syndrome. Below are additional recommendations provided by the Scientific and Medical Advisory Board of the <u>UMDF</u>.

Respiratory viruses may lead to bacterial infections including ear, eye and sinus infections or even a secondary bacterial pneumonia. In some cases, respiratory viruses can be dangerous, and result in respiratory distress and the need for immediate medical attention. The risk of dehydration and subsequent organ failure has been noted in early reports, and as with other viral illnesses in mitochondrial patients, early administration of oral and intravenous fluids to prevent dehydration may be a very important part of effective treatment.

Be aware that relatively few children have been identified with COVID-19 disease, and so the impact on children with mitochondrial disease is unclear. If there are other family members attending school or attending a workplace in close proximity to other workers, keeping your child with a mitochondrial disease home from school may be giving you a false sense of security unless you practice effective hand washing and keep your other children away from the child with a mitochondrial disease. Although strict quarantine may be protective, this seldom occurs in homes.

If there are signs of illness (fever, cough, runny nose, achiness) then:

- A young infant with a mitochondrial disease and a fever should always be seen by a doctor, even if it seems like they just have a cold, as it may be COVID-19 disease, or influenza, which needs to be treated with the same degree of concern as would COVID-19.
- Until we know more, it makes sense to see a medical provider if the illness causes a high fever, or a fever that goes away and then comes back. These can be signs of a bacterial infection including pneumonia, ear infections, and sinus infections.

- Any sign of difficult breathing, unusual noises with breathing, not being able to drink liquids, severe coughing, extreme tiredness or constant fussiness in an infant or child is serious and requires urgent medical evaluation. Again, this is true for the mitochondrial patient regardless of a coronavirus pandemic.
- A parent or caregiver who is uncomfortable with the condition should be taken seriously and be encouraged to seek medical care.

Precautions for Heart Transplant Recipients

Power2Save provides a list of <u>Frequently Asked Questions about COVID-19</u>. The website does state that it is not necessary for the transplanted individual to wear an N-95 mask. However, neutropenia is an additional risk for the person individual with Barth syndrome who has received a transplant. The <u>SCNIR</u> recommends that someone with neutropenia have an N-95 face mask available for use when the person with neutropenia is traveling and may be exposed to someone who is coughing or sneezing.

Other COVID-19 Precautions

- Seek medical advice if you have been in contact with someone who has COVID-19
- Seek medical advice if you develop COVID-19 symptoms
- Call doctor if you or someone in your home has traveled from an area with <u>widespread</u> or ongoing community spread of COVID-19
- Contact the school to inquire about available resources for a child who would be at high risk if exposed to COVID-19 (e.g. Hospital/medical homebound program)

Additional Resources

- <u>Situation Reports WHO</u>
- Situation Summary CDC
- COVID-19 Situation Map WHO
- COVID-19 Travel Guidance CDC
- Tourism and Coronavirus Disease (COVID-19) UNWTO
- Get your Household Ready for COVID-19 CDC
- Monitor your health CDC
- Rolling updates on COVID-19 WHO
- WHO-recommended Handrub Formulation
- About the COVID-19 NETEC
- American Society for Microbiology Coronavirus Updates
- Symptom Similarity Chart (AAFA)
 - o COVID-19, Seasonal Allergies, Cold, Flu
- <u>Position Statement of the ESC Council on Hypertension on ACE-Inhibitors and Angiotensin</u> <u>Receptor Blockers</u>

Videos

- When and how to use a Facemask WHO
- COVID 19 WHO
- What is Coronavirus (COVID-19) WHO
- How to Protect Yourself Against COVID-19 WHO

References

- [i] Novel coronavirus (2019-nCoV) Video World Health Organization
- [ii] Tyrrell DA, Bynoe ML. Cultivation of viruses from a high proportion of patients with colds. Lancet. 1966;1:76–77
- [iii] Kahn JS, McIntosh K. <u>History and Recent Advances in Coronavirus Discovery</u>. *Pediatr Infect Dis J.* 2005 Nov;24(11 Suppl):S223-7, discussion S226.
- [iv] Maragakis LL. Coronavirus Disease 2019 vs. the Flu. Johns Hopkins Medicine Health, Infectious Diseases