

Information for Complicated Vascular Anomalies

Coronavirus Disease 2019 (COVID-19) Questions and Answers (FAQs)

These recommendations may be subject to change and will be updated as needed.

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The World Health Organization (WHO) officially declared COVID-19 a pandemic on March 11, 2020. The response globally has been to institute the best available means to slow the spread of the virus. Measures have included closing schools and non-essential businesses and ordering citizens to stay as close to home as possible. Social distancing and careful hygiene are a part of our lives for the foreseeable future.

As these measures achieve success, businesses are allowed to reopen. Schools are making plans to accommodate children and non-essential employees are getting back to work. Speak to your/your child's health care provider or Vascular anomalies provider before going back to work/school/daycare. The latest public health information from the Centers for Disease Control (CDC) can be accessed at <https://www.coronavirus.gov>.

Where does this leave the vascular anomalies community? How do we rejoin the world; we cannot stay isolated forever.

1. Check your local maps. County or regional health departments, state health departments will have data on outbreaks.
 - If there is an outbreak in your region you should isolate once again.
 - If your area is relatively free of outbreaks, carefully venture out but still utilize physical distancing. Make your trips out necessary ones.
 - Wear a mask when outside the home, take care not to touch your eyes, nose, or mouth with unwashed hands.
 - Wash hands often (with soap and water for 20 seconds) especially after you have been in a public place if not feasible use hand sanitizer (at least 60% alcohol) to disinfect your hands.
 - Avoid being in proximity to anyone not using personal protective gear (masks).
 - Speak to your health care provider about individualized risks and recommendations regarding return to school/work/daycare for your child and yourself.
2. In most cases, COVID-19 produces a mild respiratory infection, but in a minority of cases, the disease can be more severe and require hospitalization or even ICU care. Asymptomatic persons can carry this virus and cause infection thus **social distancing is essential**. The Vascular Anomaly Community endorses the recommendations of the Centers for Disease Control and Prevention (CDC), which are updated regularly and can be accessed [here](#).

3. SECURE-VA Registry – this is a voluntary secure reporting system designed to capture important information about pediatric and adult COVID-19 cases occurring worldwide in patients with Vascular Anomalies. Providers caring for these patients can report their cases to the Registry. The goal is to better understand the outcomes of COVID-19 cases in this population of patients. The registry can be accessed at <https://www.research.chop.edu/secure-va>

RECOMMENDATIONS FOR THE GENERAL PUBLIC

In general, the measures to prevent transmission of COVID-19 are similar to other respiratory illnesses such as the flu but there are some differences that we are learning each day. Complicated vascular anomaly patients should maintain the same degree of vigilance about infection control as they do in the typical flu season plus those noted below. The most important recommendations to prevent transmission of COVID-19 are:

- Avoid crowds, large group gatherings, or close contact with sick people.
- Stay home as much as possible but especially if you are ill.
- If you feel ill, stay home and call your medical provider.
- If your children are ill, keep them home and call their medical provider.
- If someone in your household tests positive, keep the entire household home. Call your medical provider to discuss further isolation recommendations.
- Clean and disinfect frequently touched objects and surfaces using a regular household cleaning spray or wipe.
- Use alcohol-based hands sanitizer or **proper handwashing** frequently.
- Wear cloth face coverings in public settings where other social distancing measures are difficult to maintain (food shopping, pharmacy)
- Wear cloth face coverings if you are ill
- Surgical masks and other medical masks **should be reserved for healthcare workers and first responders** as they are in the most need and supplies may be limited.
- Avoid international travel and non-essential domestic travel.
- Check the **CDC Travel Guidance** before any trips.
- Practice **social distancing** and try to maintain **a six-foot distance** between people. **Social distancing** means remaining out of congregate settings, avoiding mass gatherings, and maintaining distance (**approximately 6 feet or 2 meters**) from others when possible. **(This distance has been noted to be very important to prevent contamination from viral droplets.)**
- Stay at home as much as possible

FREQUENTLY ASKED QUESTIONS - GENERAL

1. What are the symptoms?

The following symptoms may occur within 2-14 days of exposure to the virus:

Most common:

- Cough
- Fever or chills
- Shortness of breath/difficulty breathing
- Muscle or body aches

Other symptoms:

- Stomachache
- Sore throat
- Headache
- Loss of sense of smell and taste
- Fatigue
- Congestion or runny nose
- Nausea or vomiting
- Diarrhea

2. How is the virus spread?

- According to the CDC, coronaviruses are thought to be spread from person-to-person through inhalation of respiratory droplets produced when an infected person coughs, sneezes, or talks. It can also be spread as aerosolized particles. (Particles that stay in the air after coughing or sneezing).
- A person may become ill by touching a surface or object that has the virus on it and then touching their own nose, eyes, or mouth. Wash your hands regularly and try not to touch your face unless you have just washed your hands.

FREQUENTLY ASKED QUESTIONS BY VASCULAR ANOMALIES PATIENTS

3. Who is at higher risk for serious illness from COVID-19 and how can this be related to complicated vascular anomalies (VA)?

- Older adults (greater than 60 years of age). Please note that even though the risks are higher with increased age, the disease and its significant effects can happen in younger people as well.

- People with serious chronic medical conditions such as:
 - Diabetes
 - Heart Conditions and specific issues related to VA: pericardial effusions, pulmonary hypertension and/or other cardiac dysfunction from a vascular anomaly
 - Lung Disease and specific issues related to VA: pleural effusion and/or pulmonary involvement or disease from a vascular anomaly, bone disease in the ribs, sternum, upper vertebrae, history of pulmonary embolism, history of multiple pulmonary infections, VA that affects the airway, or patients on medications that can worsen respiratory symptoms
 - Hypertension (high blood pressure)

4. For patients taking Rapamune®, Zortress®, Afinitor®, everolimus, sirolimus:

What should I do if I am on an immunosuppressant? Should I or my child stop taking this drug?

- Based on current CDC statements and how recent influenza outbreaks were managed, it is recommended to **stay on the drug** unless your child/you or immediate family member or a close contact is diagnosed with COVID-19.
- **Please discuss a plan with your health care provider.**
- If you or your child become ill, **include discussion about the immunosuppressant** with your health care provider along with other care instructions. Your health care provider knows you or your child best and will be able to make those decisions specifically related to the diagnosis, medication, amount of medication, and risk.
- **DO NOT stop any medication unless directed to by your health care provider.**
- Follow the precautions noted below (9,10)

5. What should my child or I do if we are on other medications or chemotherapy (steroids, Avastin®, vincristine, alpelisib, Mekenist®, thalidomide, etc.)?

- Based on current CDC statements and how recent influenza outbreaks were managed, it is recommended **to stay on the drug** unless your child/you is diagnosed with COVID-19.
- **Please discuss a plan with your health care provider.**
- If you or your child becomes ill, **include discussion about these agents** with your health care provider along with other care instructions. Your health care provider knows you or your child best and will be able to make those decisions specifically related to the diagnosis, medication, amount of medication, and risk.
- **DO NOT stop any medication unless directed to by your health care provider.**
- Follow the precautions noted (9,10).

6. Are patients who are currently taking a beta-blocker for infantile hemangioma (IH) at risk? If yes, what are the recommendations for the babies and/or caregivers who either present with symptoms or test positive for COVID-19?

- See comment on patients at higher risk in Q3.
- IF a patient has no underlying heart or pulmonary condition, beta-blockers do not put anyone at higher risk.
- Beta-blockers are not immunosuppressive agents BUT they can worsen the symptoms of a viral illness such as wheezing. IF an infant is ill with pulmonary symptoms their health care provider should be called right away to discuss the continuation of beta-blockers. **DO NOT stop the medication without your health care advisors' recommendation.**
- If a patient has an airway hemangioma and has been exposed to COVID-19 or has symptoms their health care provider should be notified right away.

7. What precautions, if any, are warranted for patients with Sturge Weber Syndrome (SWS) who are taking anti-seizure meds regarding COVID-19?

- Anti-seizure medications should be continued if you or your child has a positive exposure or symptoms unless advised otherwise by your health care provider.
- Fevers will lower a seizure threshold, so these medications are important.
- **Discuss with your health care provider prior to or if you/your child has a positive exposure or symptoms.**

8. Are there special precautions after surgery or with open wounds? Will surgeries be delayed?

- The same precautions for social distancing as noted above should be followed.
- A patient will need time to recover thus it is important to stay away from symptomatic people and as best as possible continue with good pulmonary exercises and an incentive spirometer to keep ones' lung function at its best.
- Standard wound policy should be continued.
- Many institutions will be limiting surgical procedures to only the most critical cases at this time. Please contact your surgeon for questions.

9. If my child or I get ill are there any other precautions to consider?

- It is very important to seek the advice of your medical provider.
- If you are hospitalized make sure the team discusses your specific case with your vascular anomaly specialist.
- COVID-19 has been associated with inflammation and a higher risk of blood clots, especially in hospitalized patients.
- Multisystem inflammatory syndrome in children (MIS-C) has been reported in associated with COVID-19. MIS-C is a condition where different body parts (heart, lungs, brain, skin, eyes, and gastrointestinal organs) can get inflamed. Please contact your child's health care provider immediately if any of the symptoms of MIS-C arise – fever, severe abdominal pain, vomiting, diarrhea, neck pain, skin rash, tiredness/fatigue, trouble breathing, or chest pain.

10. What precautions should people at higher risk of serious illness from COVID-19 do?

- The CDC recommends contacting your healthcare provider to make sure you have enough medication and supplies in case of an outbreak of COVID-19 in your community which may require you to stay home.
- Keep away from ill individuals.
- Avoid crowds.
- Wash your hand often (see above).
- Wear a cloth face covering
- Stay home as much as possible and follow all local health care agency recommendations.
- If you become ill contact your health care provider right away.
- If you or your child are not ambulatory, and you have a vascular anomaly that puts you at high risk for thrombosis (blood clots) please make sure your treating physicians are aware of this risk. (This applies if you have a history of blood clots, coagulation abnormalities, large ectatic veins).

11. If my child or I get ill where should we go to be seen? Should we go to the Emergency Room?

- Please call your Primary Medical Provider if you or your child are ill and ask what the next steps will be.
- If you do NOT have a Primary Medical Provider or a Vascular Anomaly Center, you can call the emergency department or emergent care center and ask the next steps.
- **If you are experiencing any critical symptoms such as shortness of breath, severe chest pain, blue lips, or delirium, please call an ambulance.**

12. Should my family members go to work?

- The CDC recommends **social distancing**. Take extra measures to distance yourself. Try to be **6 feet** away from others. Avoid personal contact (handshakes, hugs). Stay home as much as possible and avoid crowds or poorly ventilated places.
- Some family members have to go to work. If they are working in a setting with high interaction with COVID-19 patients or frequent social interaction, call your primary provider to obtain specific information about extra social distancing precautions.

13. Is it safe to travel?

- According to CDC's guidelines for individuals with high-risk factors, consideration should be given to rescheduling planned trips especially to areas affected by COVID-19. (See the [CDC Map of level 2 and 3 areas.](#))

14. Is it safe to go to clinic appointments?

- It is important to maintain regular clinical care.
- Many centers are providing virtual visits.
- Please contact your health care provider to discuss your options.

15. Do blood thinners (anticoagulants) increase my risk?

- We are not aware of any evidence that the use of a blood thinner increases your risk of acquiring COVID-19. If the reason for the blood thinner is heart or pulmonary related, or if there is pulmonary bleeding you should follow the CDC recommendations for high-risk persons.
- There are recommendations for the use of anticoagulants for those hospitalized. Please let the MDs know your particular medical history if you need to be hospitalized.

16. Is there a danger to using non-steroidal anti-inflammatory agents-NSAIDS (Motrin, Advil, Aleve) if my child/self is diagnosed with COVID-19?

- No current scientific data is establishing a direct link between NSAIDs and the worsening of COVID-19. The CDC, FDA, WHO, and the European Medicines Agency (EMA) are monitoring data on this subject and will any new information with the public as it becomes available. Individuals who rely on NSAIDs to treat chronic conditions should speak to their health care provider for individualized management recommendations.

17. Testing for COVID-19

- The CDC recommends testing for Viral nucleic acid (genetic material) to diagnose acute COVID-19 infection. Samples are obtained via nasal or nasopharyngeal swabs. Some test results may be available within an hour, other tests may take longer to report. Your health care provider will determine which test is best suited for your situation.
- The FDA has not authorized antibody testing for diagnostic purposes and the CDC does not currently recommend using antibody testing as the sole basis of a diagnosis of acute COVID-19 infection.
- Your health care team may perform other blood tests to determine the level of inflammation in your body. Xrays and ultrasound tests of your abdomen and heart may also be performed to assist the team with the treatment plan.

***This document prepared for people with complex vascular anomalies
by the following advocacy groups in cooperation with their medical directors:***

***K-T Support Group, CLOVES Syndrome Community, LDGA,
NOVA, VBF, Project FAVA***

DISCLAIMER

The vascular anomalies community advocates have jointly collaborated with our medical advisors to develop a FAQ information sheet for COVID-19 information as it relates to our population. Please remember this is for general information purposes only. It is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Specific situations might cause a variance in response, and if you are not sure, always seek the advice of your physician or other health care provider as they are the most familiar with your situation.

COVID-19 information is changing daily. Please consult the CDC pages referenced above for the most current information.

