

Information for Patients with Vascular Anomalies

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

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

Updated December, 2020

The World Health Organization (WHO) officially declared COVID-19, which is caused by the SARS-CoV-2 virus, 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. Social distancing, masks, and careful hygiene are a part of our lives for the foreseeable future. A countrywide surge in new cases is now being observed and many parts of the United States are observing strict 'stay-at-home' measures in an effort to contain spread and avoid overwhelming the already burdened health care system.

Please refer to guidance from local health care authorities for travel restrictions and shelter-at-home recommendations for your region.

The latest public health information from the Centers for Disease Control (CDC) can be accessed at <https://www.coronavirus.gov>. This addresses signs and symptoms of COVID and measures we all should take to prevent, diagnose and treat this disease.

Where does this leave the Vascular Anomalies Community? How do we rejoin the world? We cannot stay isolated forever. Current information does not suggest that vascular anomalies or its treatments put patients at any more or less risk than otherwise similar people in the general population. Speak to your doctor about other factors, **such as age over 65 years, diabetes mellitus, high blood pressure, obesity, or lung disease which may or may not be related to vascular anomalies which might put you at increased risk of getting COVID or getting sicker from COVID.**

The Vascular Anomalies Community endorses the **recommendations of the Centers for Disease Control and Prevention (CDC)**, which are updated regularly and can be accessed [here](#).

There is much we do not know about COVID-19 in patients with vascular anomalies. To learn more so that we can better guide our community, we have developed a 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 patient 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>

CDC RECOMMENDATIONS are summarized here:

In general, the measures to prevent transmission of COVID-19 are similar to those for other respiratory illnesses such as the flu but there are some differences that we are learning each day. The most important recommendations to prevent transmission of COVID-19 are:

- Avoid crowds, large group gatherings, or close contact with sick or even well people not in your immediate family.
- Practice **social distancing**. **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 home as much as possible but especially if you are ill.
- 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 and **proper handwashing** frequently.
- Wear cloth face coverings with at least 2 layers in public settings where other social distancing measures are difficult to maintain (food shopping, pharmacy)
- Wear cloth face coverings if you are ill
- N95 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.

FREQUENTLY ASKED QUESTIONS BY VASCULAR ANOMALIES PATIENTS

1. What is the status of the COVID 19 VACCINE?

- Scientists from multiple laboratories in collaboration with major pharmaceutical companies (Pfizer, Moderna, AstraZeneca) have developed vaccines to prevent infection with the SARS CoV2 virus. Early data from clinical trials using these vaccines have been released and show a high rate of efficacy in preventing infection from the SARS CoV2 virus. The data from research trials using these vaccines has been reviewed by the Federal Drug Agency (Food and Drug Administration) and the Advisory Committee on Immunization Practices (ACIP).
- On December 11th, 2020, the FDA issued an Emergency Use Authorization for the **Pfizer-BioNTech COVID-19 Vaccine** in individuals 16 years of age and older. The **Moderna Vaccine** was approved December 18, 2020 with similar administration guidelines. The CDC has recommended that initial supplies of the vaccine be administered to healthcare personnel and long-term care facility residents. Although the approved vaccines are considered safe, there are many questions regarding the safety and long-term monitoring of individuals who will receive the vaccine. Please refer to the CDC website (www.cdc.gov) for further details regarding a smartphone-based app (v-safe) for safety monitoring.

2. Is the COVID vaccine safe for patients with vascular anomalies and who should get it?

- Both the Pfizer and Moderna vaccines are 'non-live' vaccines **and can be safely given to immunocompromised individuals (including those on Rapamune®, Zortress®, Afinitor®, everolimus, sirolimus, Avastin®, vincristine, alpelisib, Mekenist®, thalidomide, etc.)** in the approved age

range. The immune response to the vaccine should be similar to other non-live vaccines in immunocompromised persons. Some non-live vaccine studies with Sirolimus monotherapy show an attenuated (diminished) response in some patients, but a normal response in others so there is not a good way to predict response. Immunocompromised individuals were excluded from the vaccine trials for the COVID vaccines. The CDC recommends continued vigilance, maintaining distance, wearing masks and hand washing during the ongoing pandemic, **even in individuals who have received the vaccine**. Each state will release detailed plans for distribution via advertising and social media. Check with your medical provider regarding the schedule of administration of the vaccine.

- Individuals who have been infected with the SARS-CoV-2 virus will develop natural immunity, but we do not know how long this protection lasts. The CDC recommends that **even individuals who have been previously infected receive the vaccine** in order to achieve longer duration of protection.

3. What should I do if I contract COVID-19 while on an immunosuppressant such as Rapamune®, Zortress®, Afinitor®, everolimus, sirolimus, Avastin®, vincristine, alpelisib, Mekenist®, thalidomide, etc.): Should I stop taking this drug?

- **Please discuss a plan with your health care provider.**
- **DO NOT stop any medication unless directed to by your health care provider.**
- 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.
- 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.
- Follow the precautions noted below (9, 10)

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

- 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 no underlying heart or pulmonary condition, beta-blockers do not put anyone at higher risk.
- If a patient has an airway hemangioma and has been exposed to COVID-19 or has symptoms your health care provider should be notified right away.

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

- **Discuss plans with your health care provider prior to you/your child having a positive exposure or symptoms.**
- Anti-seizure medications should be continued if you or your child has a positive exposure or symptoms unless advised otherwise by your prescriber.

- Fevers will lower a seizure threshold, so these medications are important.

6. 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.

7. 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.
- For VA patients who are taking anticoagulants (see #6) and for whom anti-inflammatory agents are recommended to help treat COVID 19, be sure your doctor is okay with your being on both types of medications.

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 are limiting surgical procedures to only the most critical cases or adjusting schedules according to local threat level. Please contact your surgeon for questions.
 - It is likely that patients will need COVID testing within 72 hours of scheduled surgeries.

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

- If you are hospitalized **make sure the COVID doctors 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. Your doctor may use anticoagulants (blood thinners) to prevent the development of blood clots if you are hospitalized with severe COVID 19 infection. These medications may be continued even after you are discharged to home.
 - It is very important to seek the advice of your medical provider.

10. Are there any other things patients with vascular anomalies should do during the pandemic?

- 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.

11. 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, phleboliths, coagulation abnormalities, large ectatic veins).
12. **If my child or I get ill with possible COVID symptoms where should we go to be seen? Should we go to the Emergency Room?**
- ***If you are experiencing any critical symptoms such as shortness of breath, severe chest pain, blue lips, or delirium, please call 911.***
 - Call your Primary Medical Provider if you or your child is ill and ask what the next steps will be.
 - If you do NOT have a Primary Medical Provider or a Vascular Anomalies Center, you can call ahead to the emergency department or urgent-care center, or local COVID HOTLINE and ask the next steps.
13. **Should my family members go to work and should my children go to school or take classes on-line?**
- 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, employers and institutions often have a protocol in place. If not, call the state or county health department to obtain specific information about extra social distancing precautions. If still not available, call your provider.
14. **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](#).) Given the current surge in infections around the country, please avoid nonemergency travel until the infection level has decreased – refer to the CDC guidelines.
15. **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.
 - It is very important for children and adults to get their vaccines per CDC recommended schedule – to avoid the resurgence of vaccine preventable disease and maintain herd immunity in the community.
 - Getting the Flu vaccine (seasonal influenza vaccine) is especially important during the ongoing pandemic, to decrease your chances of hospitalization from severe respiratory infection due to the influenza virus.
16. **Where can I find information about testing?**
- Check your local or state health department website for the latest local information.
 - If you have symptoms and want to get tested call your provider first.
 - If you have symptoms of COVID19 and do not get tested it is important to stay at home.

***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.

