Update on COVID-19 and Vaccine Information for People with Marfan, VEDS, Loeys Dietz and Related Genetic Aortic and Vascular Conditions

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The Professional Advisory Board of the Marfan Foundation agrees with the new CDC recommendations and recommends that all eligible persons get a new updated vaccine (Moderna or Pfizer) for COVID-19. The updated vaccines should work well against currently circulating variants of COVID-19 and continue to be the best way to protect yourself against severe disease. The main reason to get vaccinated against COVID-19 is to protect yourself against severe illness, hospitalization, and even death. COVID-19 vaccines also reduce the chance of having long COVID. This vaccine is expected to provide better protection against variants that are currently making people sick.
The updated COVID-19 vaccines are similar to earlier COVID-19 vaccines that were safely administered to hundreds of millions of Americans during the pandemic.

This recommendation includes pregnant and lactating individuals. It also includes people who had and recovered from a recent COVID-19 infection.

Children who were previously vaccinated (ages 6 months through 4 years) should get just one dose of either updated vaccine. Those 5 through 11 are eligible to receive a single dose of the updated vaccine at least 2 months after their last dose of any COVID-19 vaccine regardless of previous vaccination.

As with the previous vaccines, the most common reactions following COVID-19 updated vaccines are pain, redness, and swelling where the shot was given, and headache, fever, muscle aches, chills, or fatigue. Anaphylaxis (severe allergic reaction to the vaccine) has been rarely observed following COVID-19 vaccines. These types of allergic reactions can rarely occur with any kind of vaccine or medical product.

While the possibility of myocarditis after vaccination exists, the risk of such problems following a COVID-19 infection is much higher. Myocarditis cases occurring after mRNA COVID-19 vaccination have generally been less severe than myocarditis caused by viral infection. The position of the Professional Advisory Board remains that the potential benefits of COVID-19 vaccination outweigh potential risks for individuals with Marfan syndrome, Loeys-Dietz Syndrome (LDS), Vascular Ehlers-Danlos syndrome (VEDS) or related conditions.

The Professional Advisory Board has defined who in our population may indeed be more susceptible because not all people with Marfan, VEDS, and LDS are at equal risk due to individual variability. The Foundation's Professional Advisory Board asserts the following:

Higher Risk

People with genetic aortic conditions who also have significant lung disease should consider themselves at high risk and employ the highest protective strategies to try to prevent infection. This group includes individuals with any of the following lung diagnoses:

- Restrictive lung disease
- Emphysema
- Significant asthma (requiring chronic medications or hospitalization)
- Chronic obstructive pulmonary disease (COPD)
- Respiratory insufficiency
- Recurrent pneumothoraces

People with genetic aortic conditions at higher risk, as explained above, are advised to get flu (influenza) and pneumonia (pneumococcal polysaccharide vaccine, PPSV, also known as known as Pneumovax 23, PPV-23) vaccines.

People with genetic aortic conditions are also at higher risk with COVID-19 if they have any of the following cardiovascular diagnoses:

- Significant valve regurgitation (causing symptoms or requiring medications)
- Heart failure
- Cardiac (ventricular) dysfunction (causing symptoms or requiring frequent monitoring or medications)
- Hypertension
- Among ACTA2 patients, the only group that is at a higher risk are children and young adults with ACTA2 alterations that disrupt arginine 179, referred to as smooth muscle dysfunction syndrome

Selected patients with vascular connective tissue disorders can have additional associated conditions that could impose higher risk with COVID-19. These include:

- Chronic malnutrition
- Inflammatory bowel disease requiring use of immunosuppressants
- Other diseases requiring chronic use of steroids or other immunosuppressive drugs
- We suspect that any person with VEDS who has experienced coughing up blood due to lung hemorrhage is at higher risk of pulmonary complications if infected with COVID-19. Additionally, even in the absence of lung hemorrhage, infection by COVID-19 is known to cause shortness of breath, significant cough, and difficulty breathing, although in some cases, the infected patient is asymptomatic. We do not have COVID-19 specific data specific to VEDS patients.

You should discuss any of your personal chronic conditions with your primary care doctor to determine if they might increase the risks associated with COVID-19.

Not at Higher Risk

People with genetic aortic conditions with none of the previously mentioned conditions whose cardiovascular features are an isolated aortic root dilation or aneurysm are not considered at higher risk than the general population.

- People who have had open heart surgery to replace their aortic root (with either valve-sparing, mechanical graft, or porcine valves) should be at a similar risk as the general population, as long as there is no significant valve regurgitation, no significant cardiac dysfunction, and it has been at least six months since the surgery, and they have fully recovered.
- People with chronic but stable dissections (greater than one year) without organ dysfunction (liver, kidney, heart), should also be at a similar risk as the general population. Those with recent chronic dissections should consider themselves in the high-risk category.

You should discuss any other chronic conditions with your primary care doctor to determine if they might increase the risks associated with COVID-19.

Protective Strategies

People with genetic aortic conditions at higher risk, as explained above, are advised to get flu (influenza), RSV, and pneumonia (pneumococcal polysaccharide vaccine, PPSV, also known as known as Pneumovax 23, PPV-23) vaccines. Please discuss this with your physician.

Cost of the Vaccination

The updated COVID-19 vaccines will be available for everyone who wants them. Individuals will be able to find this vaccine almost anywhere they normally would go to get their vaccines, like a healthcare provider's office or local pharmacy.

Under the Affordable Care Act, all insurance companies are required to cover vaccines that are recommended by the Advisory Committee on Immunization Practices (ACIP), including the updated COVID-19 vaccines. All children without insurance can get their COVID-19 vaccine under the Vaccines for Children Program. Uninsured or underinsured adults can get their COVID-19 vaccine for free under the Bridge Access Program through the end of 2024 from participating providers, HRSA-supported health centers, and pharmacies. Uninsured or underinsured adults can go to www.vaccines.gov to find COVID-19 vaccines at no cost to them. The COVID-19 vaccines available at no cost through the Bridge Access Program will become available across the United States at the same time as these vaccines become available through regular insurance and standard mechanisms.

COVID-19 At-home Tests

The FDA has extended expiration dates for a number of at home tests. If you have unused COVID-19 tests with expired dates, please check this website, as the expiration date for the test might be extended for up to a year.