

# THE **MARFAN** FOUNDATION



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

The Professional Advisory Board of The Marfan Foundation continues to recommend that all eligible persons get vaccinated for COVID-19. This includes pregnant and lactating individuals. It also includes people who had and recovered from COVID-19 infection.

While there have been reports of rare side effects, including blood clots and myocarditis after the vaccine, a recent study found that the risk of such problems following a COVID-19 infection was much higher. The position of the Professional Advisory Board remains that the potential benefits of COVID-19 vaccination outweigh potential risks for individuals with Marfan syndrome and related conditions.

We will communicate any new recommendations as we await specific guidance for children younger than the age of 12 years.

### **Delta Variant and Connective Tissue Conditions**

Currently, there are no specific data about outcomes of the COVID-19 Delta variant in patients with connective tissue conditions. However, we do know the Delta variant is highly contagious – about twice that observed with previous variants. This variant **may** cause more severe illness than previous strains in **unvaccinated people**. Fully vaccinated people with a Delta variant breakthrough infection usually have a much less severe case of COVID-19. However, even fully vaccinated people carry extremely high loads of the Delta variant virus in their upper respiratory tract if they do become infected – even with a mild or asymptomatic illness. This makes it highly more likely that they will spread the virus to those around them – with potentially dire consequences for the unvaccinated, including young children.

There are people in our connective tissue community with health issues that may put them at [high risk for a bad outcome if they get COVID-19](#). Please discuss this with your physician.

### **Additional Doses of Vaccine**

The Professional Advisory Board recommends people with connective tissue conditions receive an additional dose of the vaccine when they become eligible. Immunocompromised individuals are eligible for an additional (3<sup>rd</sup>) dose of either the Pfizer or Moderna vaccine now. This includes people who have:

- Been receiving active cancer treatment for tumors or cancers of the blood
- Received an organ transplant and are taking medicine to suppress the immune system

- Received a stem cell transplant within the last 2 years or are taking medicine to suppress the immune system
- Moderate or severe primary immunodeficiency (such as DiGeorge syndrome, Wiskott-Aldrich syndrome)
- Advanced or untreated HIV infection
- Active treatment with high-dose corticosteroids or other drugs that may suppress the immune response

In immunocompromised people, technically the third dose is not considered a “booster” shot, but rather an additional dose of vaccine to attempt to achieve the level of immune response typical of individuals who are not immunocompromised. All immunocompromised individuals who become newly eligible for COVID-19 vaccination will be scheduled for a 3-dose regimen moving forward. Importantly, additional doses of vaccine are not yet available for immunocompromised individuals who received the Johnson & Johnson vaccine. We expect additional guidance in the near future.

The CDC recently announced that ALL individuals who received either the Pfizer or Moderna vaccine will be eligible for an additional (3<sup>rd</sup>) dose 8 months after having received their 2<sup>nd</sup> dose. This fits the traditional definition of a “booster” shot since it is meant to complement a normal initial immune response to the vaccine that is naturally waning over time. Individuals will be prioritized for this booster shot based on age, health status, and occupation, among other metrics, as was done during the rollout of the initial vaccination program. People should talk to their healthcare provider about their medical condition, and whether getting an additional dose is appropriate for them. The same logic of boosting a natural, but waning, immune response applies to people who have recovered from COVID-19 infection. It is the current recommendation of the CDC and the Professional Advisory Board of The Marfan Foundation that those that have recovered from COVID-19 receive a normal vaccination regimen. A brief delay might be warranted in those who received monoclonal antibodies directed against COVID-19 or those with a particularly severe infection. You should discuss this with your healthcare provider.

### **Mask Protection**

Current CDC guidelines suggest that ALL individuals (vaccinated or not) should wear a facemask in indoor or crowded settings if they are in a geographic area with high prevalence and transmission of the virus. Currently, this would apply to the vast majority of the country and the situation changes rapidly. In this light, the PAB of The Marfan Foundation recommends that all of our constituents wear a mask in crowded outdoor and all indoor settings to protect yourself and others. It is the specific advice of this Board that children in a school setting should wear masks if they are going to attend an in-person learning center. While these recommendations are subject to change and may not be strictly mandated in your locality at this time, we believe that current public health circumstances warrant this minimally burdensome measure to protect ourselves, our families and friends, our communities, healthcare providers, and the most vulnerable members of society at large.

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