

COVID-19 Vaccine Roll-Out Recommendations for People with Down Syndrome

Dear Families,

Ten months ago, our world was turned upside down as the novel Coronavirus spread across the United States. Our lives fundamentally changed as businesses closed, in-person activities stopped, prevention measures were enacted to keep our community healthy and we lost friends and family to the virus. At the beginning, we did not know much about this virus and how it would affect our loved ones with Down syndrome. We know a lot more today, thanks to new research data, but many more questions remain (see www.dsmig-usa.org/covid19).

We know that many people with Down syndrome are at risk of experiencing severe illness from COVID-19. Like the general population, not everyone with Down syndrome who contracts the virus will have bad symptoms, but the likelihood of severe illness is higher. Because of this increased risk, the Centers for Disease Control and Prevention (CDC) added Down syndrome to the list of medical conditions that make a person at increased risk for severe illness from COVID-19 (see www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html#downsyndrome). Increased risk means that a person is more likely to be hospitalized, placed in the ICU, put on a ventilator or die because of COVID-19.

In the last few months, the U.S. Government has approved and begun distribution of two vaccines – one manufactured by Pfizer and the other by Moderna. Both of these vaccines are shown to have over 90% efficacy protecting individuals from becoming sick from COVID-19. Both vaccines use the same technology – mRNA. This technology is similar to an instruction manual telling your body what to do if it comes into contact with the virus and how to fight it if you do get COVID-19. It does not contain the virus and will not give you the illness. Right now, the Moderna vaccine can be given to people 18 years and older while the Pfizer vaccine is approved for people 16 years and older. Three additional vaccines are still being studied, so more may become available in the coming months. Both vaccines require two doses, and it is very important that you receive both doses to ensure optimal protection.

Decisions about the distribution of the vaccine are being made at a state level, county level and in some instances, at the physician level. While the federal government has made recommendations about who should be vaccinated when, there is flexibility in prioritizing vaccine eligibility. When a person with Down syndrome will be able to receive the vaccine depends on where they live. Based on the federal recommendations, at a minimum, everyone with Down syndrome should receive a vaccine when your community is vaccinating people who are considered “high risk”, or phase 1c. In some states, people with Down syndrome will be able to receive the vaccine earlier if their state is prioritizing people with intellectual disabilities. It is important to understand the plans for your state and your county and to have a personal plan for how to access the vaccine once eligible.

After consultation with experts in public health, NDSS recommends the following:

1. Follow your State Public Health Department and/or County Health Department on social media and sign up to receive their emails. These agencies will be keeping the public up to date on who is currently eligible for a vaccine and how to get one. If they have an email newsletter, we recommend signing up for it. Some Health Departments may require a prescription from your doctor in order to get a vaccine. Check with your local health department if this is required and make sure you have one if needed.
2. Call your physician. The ideal place to receive the vaccine is from a physician who is most familiar with the medical needs of your loved one with Down syndrome. Soon, individual medical offices will be able to distribute the vaccine, and it is important that you know if your physician will be participating. They will also be able to exercise their professional medical judgement about how they will distribute the vaccine among all their patients. We recommend calling your physician and asking if they will be administering the vaccine. If they are, ask how they will be notifying patients when they are eligible to receive the vaccine, and make sure that you keep up to date with their plans.
3. Reach out to the local health department's call center. They will have staff who can help you understand when you can receive the vaccine and where to receive it if your physician is not offering it. Because every health department has their own approach, it is important that you stay up to date with the plan for your area.
4. If your area is offering the vaccine to people age 75+ before they offer the vaccine to people with high risk conditions and the person with Down syndrome that you care for is over the age of 40, we recommend that you reach out to your physician and/or local health department to share with them the results of the recent T21RS CCOVID-19 study (see t21rs.org/results-from-covid-19-and-down-syndrome-survey). It shows that individuals with Down syndrome over the age of 40 have the same risks as individuals without Down syndrome over the age of 80. We cannot promise that your loved one will be able to get the vaccine at this time, but it is an opportunity to advocate for them using this information.
5. If your loved one with Down syndrome is not old enough to get the vaccine, the best way for their caregivers and people within their daily lives to protect them is to be vaccinated as soon as they are eligible. Caretakers should stay up to date on when they are eligible for the vaccine so they can receive the shot, thereby reducing possible exposure for their family member with Down Syndrome.

NDSS will continue to monitor the vaccination roll-out and provide information on how your loved one with Down syndrome can receive the vaccine. We highly recommend that you stay up to date with the plans in your local area. Please check our website for more information, including an upcoming link that will provide detailed allocation plans for your state and local area. If you have specific questions about the vaccine regarding someone with Down syndrome, please reach out to your physician.

Regards,



Kandi Pickard

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