



Dear CDG Community,

The COVID-19 pandemic has made this a trying year for everyone. But there is good news to report.

A few effective and safe COVID-19 vaccines are now available, and additional COVID-19 vaccines will be coming soon. These vaccines have been tested under strict guidelines. Studies show that the first vaccines available in the USA, the Pfizer/BioNTech vaccine, and the Moderna vaccine, are 95% and 94.5% effective in preventing COVID-19.

While COVID-19 vaccines are effective in preventing COVID-19 in general, no one has tested the efficacy in CDG patients yet, and you should continue to follow other prevention protocols already in place:

- Wear a mask that covers your nose and mouth.
- Stay at least 6 feet apart from other people.
- Wash your hands with soap and water for 20 seconds or use hand sanitizer with at least 70% alcohol.

The unanimous recommendation on whether CDG adults > 17 years old should get the COVID-19 vaccine if it is offered or available is YES. Any adult eligible should get vaccinated and there is good research generally that patients with Inborn Errors of Metabolism (like CDG), need to optimize vaccinations since they get sicker and stay sick longer than other populations.

Generally, if an adult CDG patient is offered the vaccine and does not have contraindications (for example, a history of anaphylaxis to components of prior vaccines), then they should get it.

Our CDG medical professionals want to additionally ensure that patients/parents/caregivers are aware that as the currently available vaccines use the vaccinated individual's own cells to make the glycosylated spike protein and teach the immune system how to fight COVID, the effectiveness of the immune response could be less efficient in CDG patients than in healthy people. Therefore, we also encourage PARENTS and CAREGIVERS to get vaccinated to further protect our CDG patients.

In summary, while the general recommendation is that all CDG adults > 17 yrs old should be vaccinated if they do not have any contraindications, we do not know yet how effective the vaccination will be.

We hope that you find the above information useful in your decision making in the coming weeks and please do not hesitate to reach out to CDG CARE at info@cdgcare.com if you have any additional questions!

Warm regards,

CDG CARE and the FCDGC Team

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