



COVID-19 Guidance for CDG Patients and Families

During these unprecedented times, patients and families have many questions about the potential risks of Coronavirus, especially as communities consider reopening workplaces, schools, and other activities. There is much still uncertain about risks for all people and it is not known if people with CDG are at a higher risk either of contracting COVID-19 or having severe outcomes if infected. At this time, there are very few reported children and adults with CDG who have had COVID-19 based on worldwide registries. We do not have any evidence to believe or suspect that the frequency of poor outcome is out of proportion to that in the general population.

Much remains uncertain, and the current understanding is that children in general have a milder disease course, even when they have underlying complex disease. Some children without known underlying medical issues have been reported to have an inflammatory syndrome, MIS-C, similar to Kawasaki's disease. It is unclear whether children with CDG are at increased risk to MIS-C. However, children certainly are not "Immune" to COVID-19. Immune deficiency can be part of CDG, and therefore these individuals are at increased risk of contracting COVID-19 disease. With respect to severity of illness, we do not at this time have any evidence that people with CDG are at increased risk for complications specific to COVID-19, but the lack of information leaves us with concern for that possibility.

The FCDGC is advising our patients to follow the Center for Disease Control (CDC)'s COVID-19 recommendations to help reduce the risk of exposure, including CDC's recommendations about when it is safe to return to school and activities. We advocate that you all wear masks outside your home. We also advocate that you practice social distancing, hand washing, avoid touching the face, and choose your interactions with others carefully. If the person with CDG is a child, we recommend that as much as possible, you choose childcare providers that you trust, have them wash hands & remove shoes when entering your home if providing home care, have them wear a mask when possible and sit as far away as possible when not providing hands-on-care. With respect to children returning to school, for the child who has or has a sibling with CDG: Reports suggest that the likelihood for a young child being infected with Coronavirus in a school setting is low, but not zero; this must be weighed against any benefits resulting from the return to school.

Every family needs to make an individual decision about whether an affected child, or the child or sibling of a person with CDG can return to school, and whether person with CDG and family members can return to other outside activities.

Issues to consider when making your decision about return to school or other activities include:

- While there is little evidence about how people with CDG are affected by coronavirus versus the typical population, the National Institutes of Health (NIH) and Center for Disease Control (CDC) have categorized certain groups of people as "high risk" in terms of how coronavirus can negatively affect their health: 1) Older adults 2) People who have serious chronic medical conditions like: heart disease, diabetes, obesity, and/or respiratory difficulties.
- How severely affected is the person with CDG? More severe disease (i.e. not able to walk, or having weakness or low tone) might increase severity of COVID19 complications
- Is the individual frequently ill and has a history of infections which last longer than usual, before COVID times. Discuss with your doctor what the risks of in person school are for your child in a typical year and how the risk is different for this year.
- Are CDC guidelines being implemented and followed in the school/activity setting?
- Is the affected person missing out on therapies that they typically receive while at school? Are there any other options to receive these therapies (virtual, outpatient) if staying out of school?
- Has there been any regression since being out of school due to lack of therapies, education, or socialization?
- Is on line schooling available as an alternative (even if it is just for a few hours of the school day)?

The COVID19 situation changes rapidly, based on community spread and local recommendations.

The Frontiers of CDG Consortium members

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