

July 30th, 2020

MMS RESPONSE TO COVID19:

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 mitochondrial disease 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 mitochondrial disease who have had COVID-19 based on worldwide registries. While some of the few reported to have had COVID-19 may have had significant problems, 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 mitochondrial disease are at increased risk to MIS-C. However, children certainly are not "Immune" to COVID-19.

Immune deficiency is not a common feature of mitochondrial disease, and therefore most people with mitochondrial disease should not be at increased risk of contracting COVID-19. However, those people who have immune deficiency because of or in addition to mitochondrial disease are, like anyone with immune deficiency, at increased risk of infection. With respect to severity of illness, we do not at this time have any evidence that people with mitochondrial disorders are at increased risk for complications specific to COVID-19, but the lack of information leaves us with concern for that possibility. And we know many people with mitochondrial disorders have worsening symptoms of the mitochondrial disorder with any infection.

The Mitochondrial Medicine Society and Mitochondrial Care Network are 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, and as CDC recommends you may consider wearing a mask in the home (including masks for children if a child is old enough and can tolerate the mask). 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 mitochondrial disorder is a child or has children, 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 parent with mitochondrial disease: 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 mitochondrial disease can return to school, and whether person with mitochondrial disorder and family members can return to work and/or other outside activities.

Issues to consider when making your decision about return to school/work include:

- How severely affected is the person with mitochondrial disease? more severe disease (i.e. not able to walk, or having weakness or low tone) might increase severity of COVID19 complications
- Are CDC guidelines being implemented and followed in the school/work/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?

If our families have additional specific questions, we are advising them to speak with their pediatrician or primary care physician.

The COVID19 situation changes rapidly, based on community spread and local recommendations. Please obtain your information from scientific, trustworthy sources, such as those provided below.

Please see the newest COVID-19 updates:

UMDF website: <https://www.umdf.org/coronavirus/>

MitoAction website: <https://www.mitoaction.org/coronavirus/>.

CDC website: www.cdc.gov/coronavirus

<https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/checklist.html>

Additional Resources:

<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/talking-with-children.html>

The MMS and MCN Board

