

Scientific & Medical Advisory Board

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Re: COVID-19 and Barth syndrome affected individuals

To whom it may concern:

We write with the latest advice regarding Coronavirus for patients with Barth Syndrome and their families. The following link provides updated resources: <https://www.barthsyndrome.org/barthsyndrome/familyresources/toolbox/health-advisories.html>

Given the immunocompromised state, cardiomyopathy and cardiovascular issues in Barth syndrome, we recommend that those with Barth syndrome and their caregivers are strictly adherent to social distancing practices including cessation of in-person school and work, and avoidance of social gatherings.

We do not have guidance on length of time this social distancing is required, as advice is changing rapidly, for the most up to date guidance please consult <https://www.cdc.gov/coronavirus/2019-ncov/prepare/prevention.html> and <https://www.cdc.gov/coronavirus/2019-ncov/community/index.html> regarding physical and social distancing to avoid spreading and catching coronavirus.

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