

Rett Clinic Boston

Dr. Lieberman, MD, PhD



Hi Rett families,

Boston Children's Hospital is continually re-assessing the situation and providing updates. What I gather is that children are generally at lower risk of becoming infected or sick from the virus than adults. Older adults are at greater risk and those with compromised immune systems are at greater risk. Girls and women with Rett syndrome are not generally immunocompromised, but some do have more frequent pulmonary infections, especially those who are not ambulatory, so those individuals would be at slightly higher risk. Your primary care provider is a good source of information in your area and should be the one to help get with appropriate testing if COVID19 is suspected.

There is more information regarding COVID19 and Rett syndrome and here:
<https://www.rettsyndrome.org/covid19/>

You can also read the views of Dr Walter Kaufmann and Dr. Santosh and their views on Rett and coronavirus here:
<https://www.reverserett.org.uk/coronavirus-concerns/>

Other links are here:

CDC: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>

FAQs regarding prevention and treatment:

<https://www.cdc.gov/coronavirus/2019-ncov/about/prevention-treatment.html>

Signs and symptoms of illness:

<https://www.cdc.gov/coronavirus/2019-ncov/about/steps-when-sick.html>

General suggestions:

1. Wash your hands and your child's hands several times daily
2. Do not touch your face
3. Caregivers should reduce or eliminate contact and self-isolate per CDC guidelines
4. Wash surfaces, toys, devices and other items that are in contact with the child's hands with disinfecting wipes several times daily
5. Caregivers that touch items and surfaces that are in contact with child's hands should wash hands immediately before and after touching these surfaces; this includes wheelchairs

I've had Kedna, who helps schedule our Rett patients, call families of children that have upcoming appointments (next week) in Rett Clinic to see if they would still like to be seen in clinic, postpone their clinic visit, or choose a telemedicine option (Virtual Visit) if approved by their insurance. Anyone can feel free leave a message for Kedna about their child's upcoming appointment at (617) 355-2063. I'm in clinic at Boston Children's as long as Boston Children's wants me to see patients in clinic.

Feel free to send me an e-mail: David.Lieberman@childrens.harvard.edu if there's a question you think I can answer. I'll get back to you as soon as I can. You would still go to the ER for medical emergencies like status epilepticus. Call the primary care provider regarding testing for COVID19 or symptoms related to a possible infection.

Stay Well

Keep Calm and Carry On

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