

Histio Town Hall: COVID-19 and Our Community Hosted by the Histiocytosis Association and Histiocyte Society

Frequently Asked Questions (FAQ)

General Questions

- **Do Histiocytosis patients have any special risk for severe COVID-19 infection?**
 - Risk in adults:
 - Should be noted that there is a wide spectrum in the ways that the disease or treatment could affect the body and immune system
 - Need to consider your individual condition and treatment that you have had or are having
 - Risk in pediatrics:
 - This is not known for sure yet
 - If your child comes down with a fever, you should call your physician as you would in any instance, however, take into consideration the added risk of COVID-19 when discussing symptoms with your physician
- **Should a PLCH patient be concerned about increased risks?**
 - Due to the possible severity of lung disfunction that could be present in Pulmonary LCH, and any lung disease, it is recommended to take additional precautions and remain in communication with your physician specific to your condition
- **Should immune-compromised individuals be concerned about increased risk of contracting coronavirus?**
 - There is not much data to indicate that there is an increased risk, however it is best to be cautious and follow the proper social distancing and hygiene protocols outlined by the CDC and WHO

Treatment Related Questions:

- **Should I stay on my treatment?**
 - To date, no specific treatment is known to be problematic for coronavirus – talk to your physician and take your medicine
 - General guidance from various entities, including the American Society Clinical Oncology, is that non-infected individuals should continue the cancer treatment they are on
 - For patients with targeted treatment where immune system is not impacted greatly, this guidance is largely applicable
 - There are of course many considerations that may impact decisions around this, therefore you should always consult your physician
 - Take consideration for minimizing trips outside of the home, and consult your physician about your specific condition and treatment – your physician knows best for you
- **Should I start treatment or alter my treatment?**
 - Very case specific, however there are some principles you can consider, including:

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- How pressing is it to begin treatment?
 - Are you treating a modest case of disease or something very severe?
 - Could it wait a few weeks?
 - Is it a treatment that will affect your immune system?
 - Should the treatment be delayed because it will require a lot of doctor and lab visits that could be minimized at this time?
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- **What if I was treated in the past/am in remission now?**
 - While not certain, there are some chemotherapies may have a lasting effect on the immune system, therefore it is always best to follow the proper social distancing and hygiene guidelines outlined by the CDC and WHO

Additional Questions:

- **Is it possible that COVID-19 would cause Histiocytosis disease relapse?**
 - There is no evidence of COVID-19 specifically triggering histiocytic disorders
 - It is true that infections can on occasion trigger HLH, however, there is no reason known at this time that COVID-19 is any more likely than other infections to trigger HLH
- **Does COVID-19 cause cytokine storm/HLH?**
 - Cytokine Storm is an umbrella term that covers a wide variety of syndromes
 - There are cytokine storms that are caused by genetics, infections, rheumatologic diseases, and malignancies
 - Based on early data and research, COVID-19 cytokine storm is a virus associated cytokine storm, however, appears different from other cytokine storms and therefore the overall picture currently is that the COVID-19 cytokine storm is *different* from an HLH cytokine storm. Literature that mentions HLH may be pointing to the fact that these cytokine storms share similar features
- **Are we going to be able to tell, for children with Histiocytic disorders, if there is a higher risk of need to be hospitalized?**
 - There is a nationwide registry that was launched recently to capture all pediatric populations with COVID; this registry has menus that allow for different patients to be “binned” into a variety of categories (including those that don’t have any prior medical history, but also those with a variety of reasons to be on immunosuppressive medications). It is our hope that by having a robust pipeline for capturing of all children, that we can look at the rates of hospitalization for each subgroup and then pull data retrospectively to track their outcomes and any changes that became necessary for their disease

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- **Is there a plan to conduct a research study to address COVID-19 risks on Histiocytosis patients?**
 - The NIH and others are collecting genomic data (DNA sequencing) to sort out whether certain gene variants may be predisposing to more severe outcomes, even in previously healthy people