



your infectious disease specialist

A PARTNER IN YOUR PRIMARY HLH TREATMENT JOURNEY

Many professionals will provide support to you and your family during your primary hemophagocytic lymphohistiocytosis (HLH) journey. Here you will find specific information about an important member of your care team—the **infectious disease (ID) specialist**.

what is an ID specialist?

- A doctor who is an expert in diseases caused by bacteria, viruses, fungi, and parasites
- **ID specialists** diagnose and treat infections that may be serious
- They work alongside other doctors, like pediatricians, to help diagnose and treat illnesses

why might I see an ID specialist?

Primary HLH can be difficult to diagnose. It can be mistaken for other conditions, such as viral infection or sepsis (a life-threatening condition where organs can shut down because of infection). Symptoms that may seem related to infection include:



High fever that lasts a long time



Rash



Seizure or neck stiffness



Confusion



Swollen lymph nodes



Enlarged spleen



Coughing and difficulty breathing



Vomiting or diarrhea

There may be more signs and symptoms than the ones listed above.

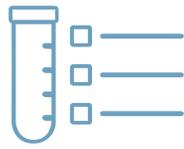
An **ID specialist** may partner with the care team to rule out infections or other conditions that could be causing the symptoms of primary HLH.



what will the ID specialist do?



Review symptoms and physical exam results



Perform lab tests using a sample of blood, urine, or other fluids or tissues to see if infection is present



Once the **ID specialist** rules out infection as a cause of illness, he or she will refer the patient to other doctors to rule out other possibilities



If the **ID specialist** suspects primary HLH, he or she may refer the patient to a hematologist/oncologist

Once primary HLH is diagnosed, will I still see the ID specialist?

The **ID specialist** may continue to help in managing inflammatory signs and symptoms (like fever, rashes, stomach problems, and spleen enlargement).

People with primary HLH will have weakened immune systems during treatment. This makes them more susceptible to infection. Because of this, the **ID specialist** will likely play an ongoing role in treating and preventing infection for primary HLH patients.

— They may manage antibiotics used to treat infections, how they are given, for how long, and any side effects that could occur

questions to consider asking your ID specialist

- Do you think that my child or I have an infection?
- What can be done to treat these symptoms?
- Are you recommending antibiotics? Which ones? For how long?
- What are the side effects of the antibiotics you are prescribing?
- What other treatment do you recommend?
- Will you be involved in the ongoing care for primary HLH?
- How will you help prevent or manage any infections that happen during treatment for primary HLH?
