



your hematologist/oncologist

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 **hematologist/oncologist**.

what is a hematologist/oncologist?

- A **hematologist/oncologist** is a doctor who focuses on the diagnosis and treatment of blood diseases and cancers
- This type of doctor has received special training in hematology—the study of blood—and oncology—the study of cancer
- A **hematologist/oncologist** may also have training in bone marrow transplants
 - This is a procedure where healthy blood stem cells from a donor are put into the body to replace damaged or diseased bone marrow

why might I see a hematologist/oncologist?

Primary HLH occurs when a person's immune system does not work properly. It can be difficult to diagnose. Symptoms can also be mistaken for other conditions, such as infection or cancer. These symptoms can include:

- Fever
- Rash
- Seizures
- Changes in mental state
- Muscle weakness
- Vision problems
- Swollen lymph nodes
- Vomiting and diarrhea

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

A **hematologist/oncologist** will partner with your care team to help figure out what is causing these symptoms.

what will the hematologist/oncologist do?

The **hematologist/oncologist** will do tests to rule out cancer or other conditions that could be causing symptoms. To help figure out what is making you or your child sick, the **hematologist/oncologist** may do the following:

- Ferritin level testing (a protein that stores iron)
- Bone marrow testing
- Blood and liver function testing

There may be more tests conducted.



if the hematologist/oncologist suspects primary HLH, they may:

Check for signs or symptoms



If someone has 5 or more of the symptoms used to check for primary HLH, the **hematologist/oncologist** may diagnose it

Order genetic tests



These tests check for mutations, or changes to DNA, known to cause primary HLH

Initiate treatment



Hematologist/oncologists have experience diagnosing and treating primary HLH. They may initiate treatment while running tests because of how serious the condition is

Once primary HLH is diagnosed, what is the hematologist/oncologist's role?

The **hematologist/oncologist** will oversee treatment, since they specialize in conditions like primary HLH. They will make a treatment plan and start treatment right away. The goal is to get symptoms under control in preparation for a bone marrow transplant. This is also known as a stem cell transplant. It is the only curative treatment for primary HLH.

Not everyone will need a transplant. The **hematologist/oncologist** will decide if you or your child does. If they decide that a transplant is right for you or your child, they will work with a transplant team to provide the care needed.

questions to consider asking your hematologist/oncologist

- How did you diagnose primary HLH?
- Can you review the test results with us?
- Are you taking the lead role in managing primary HLH?
- Who else is participating in the care team?
- What are your thoughts about a bone marrow transplant?
- Can you explain the transplant process?
- What treatment is needed prior to transplant?
- What will your role be in long-term care for primary HLH?
