



hepatologist/gastroenterologist

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 **hepatologist/gastroenterologist**.

what is a hepatologist/gastroenterologist?

- Hepatologists focus on liver disorders as well as the pancreas and gallbladder
- **Gastroenterologists** are doctors who diagnose and treat diseases of the digestive organs, including the liver, stomach, intestines, pancreas, and gallbladder
- Because of the overlap between these 2 fields, doctors are often trained in both areas

why might I see a hepatologist/gastroenterologist?

A swollen spleen and liver (hepatosplenomegaly), poor liver function, or yellow skin and eyes (jaundice) may be some of the first symptoms of primary HLH. A **hepatologist/gastroenterologist** may be brought in to see what is causing these symptoms.

- Primary HLH can be difficult to diagnose and can be mistaken for other conditions
- Hepatologists/gastroenterologists specialize in seeing patients with enlarged digestive organs, which often happens in primary HLH
- Hepatologists/gastroenterologists help to rule out digestive or liver conditions as the cause of illness



what will the hepatologist/gastroenterologist do?



Gather a complete medical history and ask questions about the health of family members



Do a physical exam of the abdomen and digestive tract to look for clues about the source of the symptoms



Perform endoscopic procedures (using a small camera to look inside the body) to rule out possible conditions and find the cause of liver problems

Once primary
HLH is diagnosed,
will I still see the
hepatologist/
gastroenterologist?

Once a **hepatologist/gastroenterologist** rules out digestive conditions, they are likely to send you or your child to another specialist to make the diagnosis. However, they may still check in with you during treatment since primary HLH can affect the spleen and liver.

questions to consider asking your hepatologist/gastroenterologist

• What does impaired liver function mean?	
• What is hepatosplenomegaly?	
• What is jaundice?	
 What can be done about the inflammation in the spleen/liver? 	
• What treatment do you think is needed?	