



your rheumatologist

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 **rheumatologist**.

what is a rheumatologist?

- A **rheumatologist** is a doctor who diagnoses and treats conditions that affect muscles, bones, and joints (like musculoskeletal pain disorders or osteoporosis)
- **Rheumatologists** also treat a group of immune system disorders, called *systemic autoimmune diseases* (diseases where the immune system attacks a person's own cells and organs)
 - Examples of systemic autoimmune diseases include rheumatoid arthritis, systemic juvenile idiopathic arthritis (SJIA), and systemic lupus erythematosus (SLE)

why might I see a rheumatologist?

In primary HLH, the immune system, which normally defends the body against invaders, does not work right. It attacks the person's own cells and organs, leading to inflammation.

- **Rheumatologists** specialize in seeing patients with inflammatory disorders like primary HLH
- Primary HLH can be difficult to diagnose and can be mistaken for other conditions
- **Rheumatologists** help to differentiate between primary HLH and other conditions with similar symptoms, such as SJIA and SLE

what will the rheumatologist do?



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



Do a physical exam to look for clues about the cause of the problem



Perform tests to rule out other possible conditions that may look like primary HLH



if the rheumatologist 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 **rheumatologist** may diagnose it

Order genetic tests



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

Ask a hematologist/oncologist for an opinion



Hematologists/oncologists are another kind of doctor. They also have experience diagnosing and treating primary HLH

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

Everyone's primary HLH journey is different. Sometimes a **rheumatologist** will continue to treat and care for a person after primary HLH is diagnosed. Other times, the hematologist/oncologist may do this. At times, the **rheumatologist** and hematologist/oncologist work together.

questions to consider asking your rheumatologist

- How did you diagnose primary HLH?
- What happens next?
- Will we continue to meet with you?
- What treatment do you think is needed?
- Since primary HLH is an inflammatory condition, what can be done about the inflammation?
- Should I also see a hematologist/oncologist?
