

Histiocytic Disorder Follow-up Study

Histiocytic disorders are a rare group of blood diseases that can have diverse manifestations and can affect any organ system of the body.

Participate!

If you or your loved one have ever been diagnosed with a histiocytic disorder, you may be eligible for this study.

You may be eligible to earn up to \$25 for participating!

A Study for Patients with Histiocytic Disorders (Erdheim-Chester disease, Langerhans cell histiocytosis, Rosai-Dorfman disease, etc.)

Why are we doing this study?

This study is led by the University of Alabama at Birmingham (Dr. Gaurav Goyal). This study will help us better understand possible health problems that people with histiocytic disorders suffer from. This study will also identify people at risk for these complications in order to help personalize treatment in future. Findings from these studies will also help identify those that need to be followed more closely or those that need preventive measures to ensure a healthy life free of complications.

Who can join this study?

- Adults or parents/guardians of children with ECD, LCH, RDD, or JXG who are at least 2 years after diagnosis of histiocytic disorder.
- Family members of those who passed away
- The survey is currently offered in English and only medical records in English can be accepted at this time. The study hopes to expand to other languages in the future.
- *Individuals above the age of 18 years would need to complete the survey by themselves*

What happens if I join?

- You will be asked to complete a survey about your or your family member's health (45-60 minute)
- Will receive updates on key findings from the study as time progresses

How will it benefit me?

- You will contribute to our understanding of the healthcare needs of patients diagnosed with histiocytic disorders.
- You may have a chance to take part in studies designed to help survivors reduce the risk of complications.

Next Steps

If you are interested in participating or have any questions, contact our study staff to complete the survey at home, online, or via call:

Phone: 1-866-438-1640 **Email:** histio@uabmc.edu