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.

What happens if I join?
• You will be asked to complete a survey about your or your family member’s health (45-60 minute)
• You will become a member of the largest study of its kind ever conducted

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.

What else should I know?
• If you sign up and change your mind later, you can stop being in the study at any time.
• If the participant is 18 years or older at the time of study entry, they would need to enroll themselves.

Next Steps
If you are interested in participating or have any questions, contact our study staff:

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