



International Rare Histiocytic Disorders Registry (IRHDR):
Introduction Letter

Dear Patient/ Family Caregiver,

The Division of Haematology and Oncology at the Hospital for Sick Children is conducting a research study. This research study is being done to build up a registry of patients with rare histiocytic disorders in order to learn more about these disorders and what types of treatments are being used. You are being given this letter because you / your child, have been identified by your doctor as potentially having one of these disorders.

This study has two parts. The Registry is the main part of the study and its goal is to collect information about patients with rare histiocytic disorders (RHD,) to learn more about the diseases, how they present and to understand their unique features.

The second part of the study is an optional Biobank sub-study. The goal of the Biobank is to collect, store, and distribute samples obtained from registry participants for use in future research to further understand why people get RHD and how it can be treated.

This study does not involve any additional tests and it will not impact your/your child's current treatment. We would like to use the leftover part of the sample of the tissue that was taken from you / your child as part of the diagnosis of RHD. We would also like to collect information from your / your child's health records.

Participation in this research study is voluntary. If you / your child would like to participate or have any questions, please email us at irhdr.registry@sickkids.ca

Once you contact us, a member of the study team from SickKids will get in touch with you to tell you more about the study. It is important to know, you / your child do not have to participate in this research study if you/your child does not want to. You / your child's decision will not affect the care you/your child receives.

Sincerely,
Dr. Oussama Abla
The Hospital for Sick Children
Staff Haematologist/Oncologist
International Rare Histiocytic Disorders Registry