

What is the INTO-HLH Registry?

An electronic database designed to collect information about HLH and its treatments. Information is collected from participants' medical records and routine clinical care.

The registry aims to advance what is known about HLH. The insights obtained from this registry might help doctors to better manage HLH in the future.



The INTO-HLH Registry is a collaboration between Cincinnati Children's Hospital Medical Center, Texas Children's Hospital, and Sobi Inc, the industry sponsor.



What are the objectives of the INTO-HLH Registry?



Understand more about how HLH progresses over time, including its symptoms and impact on patients' quality of life



Investigate how patients respond to treatment and what are the outcomes



Learn more about the long-term complications of patients with HLH and the general well-being of patients and caregivers

Questions?

If you have any questions about the INTO-HLH Registry, patient recruitment, or educational opportunities, a member of the INTO-HLH Registry Team (IHRT) at intohlh@cchmc.org would be happy to carry on the conversation.

For additional questions, please contact Dr. Michael Jordan, the Principal Investigator for the INTO-HLH Registry (email: Michael.Jordan@cchmc.org).



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• COMMUNITY OF HOPE •

Insight into the Natural History and Treatment Outcomes of Hemophagocytic Lymphohistiocytosis (HLH)

A PATIENT REGISTRY FOR PEOPLE WITH HLH

hlhregistry.org | intohlh@cchmc.org



Despite over 20 years of research, we do not know how effective standard HLH therapies are, how often they fail or need to be adjusted, and what complications are seen in patients with HLH

For the most part, we only have the experience of expert physicians, but we need more data to make progress

What will taking part in the INTO-HLH Registry involve?

- The INTO-HLH Registry will collect data (also called “medical information”) from the participants’ medical records and their routine clinical care, over a period of 5 years
- This information will include the progression of the condition, its symptoms and treatments, and the outcome of the treatment
- The registry will also collect information on how HLH impacts patients’ daily life and long-term outcomes

How can you or your loved ones participate?

Volunteer profile

- Pediatric and adult patients of all ages in North America
- Patients with clinically confirmed or suspected HLH
- Both surviving and deceased patients are eligible

01 Visit the registry’s website at hlhregistry.org and read the information about the registry



02 Answer some questions to check if the registry is right for them or their loved one



03 Participants will have to provide consent and agree to release their medical records for data analysis at CCHMC

How will participants’ personal/medical information be protected?

- HIPAA or PHIPA (depending on the country) and GCP guidelines will be followed to ensure all data privacy requirements are met
- Participant data will be anonymized and protected with a unique coded number, called a Global Unique Identifier (GUID)
- Access to participants’ protected health information will be limited to selected and qualified members of the registry team

When will the results be available?

- First analysis of the registry will be available in June 2024, with more to follow
- Details on the registry will also be posted on clinicaltrials.gov

Your or Your Loved Ones Participation Could Make a Difference

By sharing your or your loved one’s data, you will be contributing towards advancing what is known about HLH

Insights generated by the registry may help to identify unmet needs in HLH and treatment outcomes for future patients

