

INTO-HLH REGISTRY NEWSLETTER

WELCOME TO THE THIRD ISSUE OF THE INTO-HLH REGISTRY'S NEWSLETTER



Dear HLH warriors and family,

This edition of the INTO-HLH Registry newsletter showcases the Registry team's dedication to the fight against HLH; through rigorous data collection, quality improvements, and collaborations with experts around the world.

Our original goal of 200 participants on the Registry has been reached and exceeded! Although this goal has been met, the study team strives to expand outreach strategies to increase participation across North America. Be on the lookout for our increased social media presence across multiple platforms.

In this issue, we've included some descriptive preliminary data, what you need to know about our database transition, and an excerpt from Dr. Adi Zoref-Lorenz to share some insight into Malignancy-Associated HLH.

Thank you for your participation and support. You are helping Build a Community of Hope; grounded in science, collaboration, and care.

To infinity and beyond,
The INTO-HLH Registry Team

ENROLL HERE



GET INVOLVED

Your Story Matters — Share It!

One of the most meaningful ways you can support others affected by HLH is by sharing your story. Reach out to intohlh@cchmc.org to submit you or your family members story and photos for the INTO-HLH Registry website. Don't underestimate the power of your experience — share it today and inspire someone else on their HLH journey!

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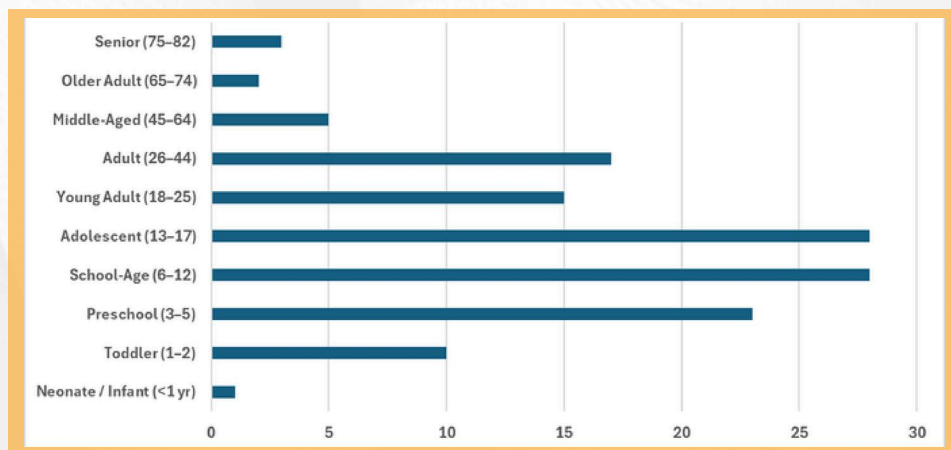
A Look Inside the Data

Past Goal:
200 Participants

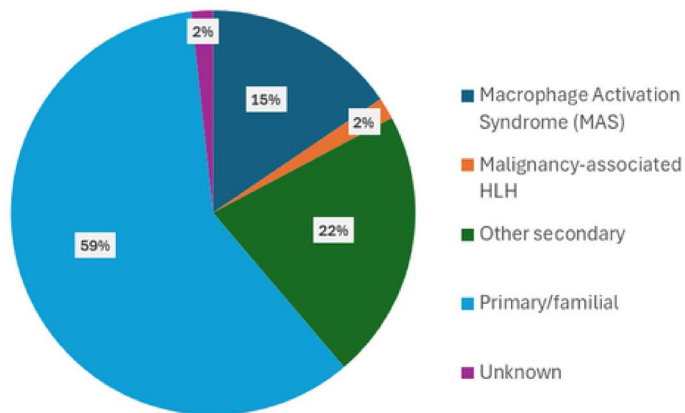
New Goal:
300
Participants

Current Standing: 210
Participants

Age of Participants at Enrollment (Not Diagnosis)



Final Diagnosis



Top 7 Treatment Institutions

CCHMC	86
Children's Hospital of Philadelphia	9
Texas Children's Hospital	7
NIH	6
Boston Children's Hospital	5
Children's Healthcare of Atlanta	5
Phoenix Children's Hospital	5

CALL TO ACTION

The INTO-HLH Registry is currently primarily composed of participants with Familial HLH. If you or your loved one have secondary HLH, MAS, Cytokine Release Syndrome, or other forms of HLH, please visit our [website](#) to learn more about joining the Registry and how your story can help drive progress.

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Quality Improvements: A Database Transition To REDCap



Later this year as part of ongoing improvements to the INTO-HLH Registry, we will transition all future data capture from Zelta to REDCap. REDCap is a HIPAA compliant and widely used research data webform application. Please visit [the REDCap website](#) if you would like to learn more about the platform.

What this means for participants

If you agreed to receive Patient Reported Outcomes (PRO) questionnaire, you will complete the surveys through REDCap instead of Zelta. Once the transition is complete later this year, you will simply receive your REDCap survey invitation through email as usual, along with reminder messages near the due date to fill out your next scheduled questionnaire. The study team will contact participants who consented to ePROs to further explain the changes once the transition is finalized.

This transition will also affect the eConsent process. The link on the INTO-HLH Registry's webpage will bring you to the REDCap website where the process will be completed in a similar manner.

A Message from Adi Zoref-Lorenz, MD Malignancy-Associated HLH



Malignancy-associated HLH is one of the most serious forms of HLH. It is most often linked to blood cancers, especially lymphomas and leukemias. In some patients, HLH is already present when the cancer is first diagnosed. In others, it can develop later, including during chemotherapy or after newer immune-based cancer treatments. Because this syndrome can progress quickly and cause severe inflammation, organ damage, and life-threatening illness, early recognition is critical.

Awareness of malignancy-associated HLH has increased greatly in recent years. Doctors and researchers now better recognize that some patients with cancer develop a dangerous inflammatory “storm,” in which the immune system becomes overactive and causes harm. This growing awareness has led to important efforts to improve diagnosis, identify warning signs earlier, and better understand which treatment approaches may help.

An important international effort led by the Adult HLH Working Group of the Histiocyte Society has helped advance this field. In a large analysis of 225 patients with malignancy-associated HLH, one of the main findings was that first calming the dangerous inflammation before starting cancer-directed treatment was associated with improved survival. However, no single HLH-directed therapy was found to be clearly superior for all patients. These findings highlight both the progress that has been made and the many unanswered questions that remain.

This is why the INTO-HLH Registry is so important. By collecting real-world data from patients with malignancy-associated HLH, the registry can help doctors and researchers better understand how this syndrome presents, how it is treated across centers, and which strategies are linked to better outcomes. The more we learn from patients and families, the closer we come to identifying the treatment approaches that can truly improve care.