

# eNewsletter

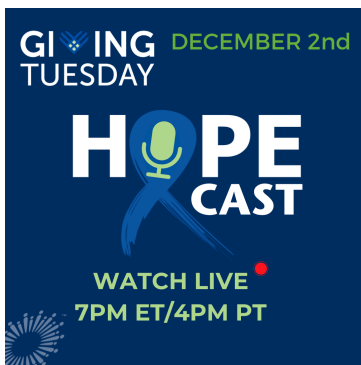
## HISTIOCYTOSIS ASSOCIATION

-- November 2025

In this month's newsletter, we're "capping off" November with a look at our new must-have eStore item, key registries for HLH and Langerhans-cell-based disorders, and exciting news about an amazing opportunity. Plus, don't miss our latest blog posts and podcast episode.

### Giving Tuesday - Board Match

After the meal, the thanks, and the parade, Giving Tuesday is coming to town - and with it, a powerful chance to bring hope to patients and families facing histiocytic disorders.



This year, we're celebrating with our 4th Annual **HopeCast** on Tuesday, December 2nd - streaming on Facebook, Instagram, [YouTube](#) and [LinkedIn](#). You'll hear inspiring stories from members of our Histo Community and a special appearance by Dr. Ken McClain - stories that remind us why we give and why this mission matters.

Giving Tuesday reminds us what generosity can do: fuel breakthroughs, create connection, and deliver hope where it's needed most. And thanks to our Board of Trustees, every gift will be **matched up to \$15,000**, doubling your impact.

Join us in kick-starting the season of giving - because hope grows when we give it together.

### DOUBLE YOUR IMPACT

### New in the eStore



Our brand-new trucker hats just dropped - and **they're more than a stylish accessory**. Every hat helps raise awareness *and* funds to support our mission. It's a statement, a conversation starter, and a way to make an impact - one wear at a time.



Even better? They make the perfect holiday gift - thoughtful, trendy, and a present that keeps on giving long after it's unwrapped.

Grab yours and show your support in style - and don't forget to check out the other great items in our eStore too!

## Get Our New Hat!

## Registries

Patient registries play a vital role in advancing care for histiocytic disorders. By sharing information, patients and families help researchers uncover patterns, answer pressing questions, and accelerate progress toward better treatments. This month, we're spotlighting two important registries that rely on, and benefit from - your participation.

### INTO-HLH Registry

As someone who has battled HLH, or is family member of someone who has, you know it can feel frustrating at times. That's why, as an HLH patient or caregiver, you should share your story as part of the INTO-HLH Registry.

The INTO-HLH Registry was created by Cincinnati Children's Hospital Medical Center, Texas Children's Hospital, and Sobi North America to help doctors to better diagnose and manage HLH and improve treatment outcomes for future patients.



The power is put back in your hands to advance the future of HLH care. To participate, email [intohlh@cchmc.org](mailto:intohlh@cchmc.org).

### Survivorship Study

The UAB Survivorship Study is still looking for pediatric patients to participate in sharing their histio journey. You can click below to learn more about the study and who runs it in this video by our very own Histo Ambassador, Brinda:



To participate, please email [hismo@uabmc.edu](mailto:hismo@uabmc.edu) or call 1-866-438-1640

## Further Reading

### Beyond the Diagnosis

**Episode 085**  
A Season for Gratitude  
w/ Kathy Wisniewski

**Now Available!**

It's that time of year where all thoughts shift to gratitude and we wanted to take a moment to express our thankfulness to our histio community for all you do throughout the year!

Join Kathy for this heartfelt message of thanksgiving and hope.

[Listen to Episode 85](#)

### The Histo Blog



**Celebrating Breakthroughs - Recap of Histo at NORD Breakthrough Summit**



**Giving Tuesday: A Day of Generosity, Hope, and Community**

This month, Ambassadors Hank and Tim shared their experiences at the NORD Breakthrough Summit. Jen followed with her reflections on the Summit and a rare disease think tank in Boston.

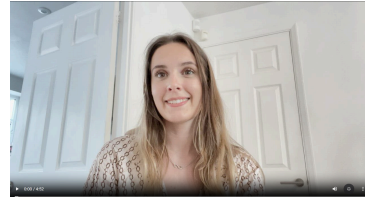
In the next blog post, Jen returned to share her experience of why Giving Tuesday matters.

[Read the Blog Here](#)

## Share Your Story

**Your voice has the power to inspire, support, and strengthen the community.**

Whether you're new to the histio community or have been part of it for years, your story matters.



Many people facing histiocytic disorders feel isolated - sharing your experiences can offer hope, connection, and reassurance that they are not alone.

If you'd like to share your story and inspire hope, there are a few easy ways to do it:

- [Record a video](#)
- [Submit your story](#) for our new community blog
- Or simply reply to this newsletter and tell us about your histio journey

Your story might even be featured on our social media or in a future newsletter!

FOLLOW US

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