

# eNewsletter

## HISTIOCYTOSIS ASSOCIATION

-- Awareness Month Recap 2025

In this edition, we're recapping all the highlights from Awareness Month - and celebrating the incredible community that made it all happen. From exciting awareness events hosted by community volunteers at Wendy's and the Houston Astros game, to two major fundraising milestones, September was packed with powerful moments and meaningful impact.

## 2025 Patient and Family Summit

### A Powerful Ending to Awareness Month: Patient and Family Summit Recap

To close out Awareness Month, we had the privilege of hosting the Histo Patient & Family Summit in Seattle, Washington - a truly unforgettable weekend that brought our community together in powerful ways.

The summit brought together more than **100 attendees**, both in-person and virtually, including **patients and families who traveled from across the U.S. and the U.K.** Over the course of two impactful days, we heard from **24 speakers**, including **more than 20 doctors** specializing in various forms of histiocytosis. These experts generously volunteered their time - just days before their own international medical meeting - to educate and connect with families affected by these rare disorders.

What made the event so special wasn't just the access to world-renowned histio experts - it was the connections formed among attendees. We watched as friendships blossomed, stories were shared, and a true sense of community took root. It was incredible to provide this unique opportunity for families not only to learn, but also to feel seen, supported, and empowered.

The summit culminated in an unforgettable evening at a **Seattle Mariners game**, where we raised awareness in style - waving our custom "**Beat Histo**" foam fingers and sparking curiosity among fans. We're proud to say people asked about the message behind them, giving us one more opportunity to spread awareness for histiocytosis in a big-league setting.

Following the summit, our team remained in Seattle to support our partners at the **Histiocyte Society Annual Meeting**, where **196 doctors from 31 countries** came together to discuss the latest in histiocytosis research. We're especially grateful to many of those doctors who, before diving into their own scientific sessions, chose to spend time with our community at the summit.

Thank you to everyone who joined us and made this event a success - whether you were learning, sharing, supporting, or simply showing up. The strength of this community continues to inspire us every day.



## Fundraising Events

### Blue Ribbon Run

Another amazing year is in the books for the **Histio Blue Ribbon Run**! 2025 marked the **4th consecutive year** of this powerful movement, and the impact keeps growing.

Here's what the community accomplished this year:



- 🏃 4 teams
- 👣 49 participants
- 🌍 16 U.S. states
- 🌐 5 countries
- 💰 Over **\$7,405 raised** for histiocytosis awareness and research!



Whether you ran, walked, donated, or simply spread the word, you helped shine a powerful light on this rare disease. Thank you for being part of this movement and making September one to remember.

To the left is a picture of the Blue Ribbon Run/Walk we did in Seattle during our Patient and Family Summit. Part of our path went along Pike's Place, so we stopped and took a picture with one of the fish artisans.

**There's still time to help us reach our goal!**

If you haven't had a chance yet and would like to support our mission, you can [donate here](#). Every dollar gets us one step closer to a world without histiocytosis.

## ***Mighty Miles' Lemonade Stand***



They did it again! For the second year in a row, Miles and his incredible family hosted a lemonade stand to raise funds (almost \$3,000) and awareness for histio — and what a day it was!

We caught up with Miles' mom, Nicole, who shared some highlights:

“We had three types of lemonade: regular, strawberry, and cherry. Plus, we offered a variety of lemon-flavored snacks and sweets. For the kids, we set up our bounce house and had tons of lawn games. There was even a table for making superhero masks and capes, rock painting, and fake tattoos! My older son, Jackson, wowed everyone with a little magic show. And Miles worked so hard serving drinks and collecting donations — he was amazing!”

It was a day filled with fun, laughter, and community spirit — all in support of a great cause.

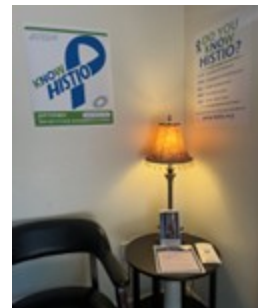
## Community Awareness

Throughout Awareness Month, our incredible community took action to educate others about histiocytic disorders in creative and impactful ways. From adding custom awareness frames to their social media profiles, to wearing blue every Wednesday in September, hanging flags and posters in their neighborhoods, requesting proclamations, and hosting awareness events of all sizes - the dedication was inspiring.

Below are just a few snapshots of the awareness efforts led by members of our community:



**Andrea**, a Histo mom and ambassador, brought awareness to her local **Wendy's in Tennessee**, sharing information with customers and staff alike.



Placeholder

In **Waxahachie, TX**, a devoted Histo grandmom created an awareness corner in the lobby of her massage office - which she shares with a local hair salon - helping spread the word to everyone who walked through the door.



For the second year, the Histiocytosis Association was able to participate in the childhood cancer awareness night at the Houston Astros stadium. Fundraising event coordinator, Allie McFadden, along with her daughter (*and youth histio ambassador*) Avalon, set up an awareness booth to educate fans on histiocytic disorders. It was a great night of making connections with other local organizations and sharing all about histio.

These are just a couple of the many meaningful ways our community helped shine a light on histiocytosis this September. We are so grateful to each of you who participated and helped raise awareness in your own unique way.

## Upcoming Events

While September may be over, raising awareness for histio is a year-round mission - and members of our community are continuing to carry it forward!


Two of our dedicated histio ambassadors are continuing our mission, both hosting fundraising and awareness events in their local communities - helping to keep histio in the spotlight and supporting ongoing efforts to fund research and provide resources for families.


We're so grateful for their passion and commitment - and for everyone who continues to raise awareness beyond Awareness Month.



## Breathe and Believe: Histo Wellness Event

Join Dena for Her First-Ever Histo Community Event!

 Glendale, CA

 October 11th

Dena, an inspiring adult LCH warrior and proud ambassador for the Histo Association, is hosting her very first community event — and you're invited!

If you're in the Glendale area and would like to support Dena while connecting with others in the histio community, grab your yoga mat and come out for a day of wellness, connection, and fun.

### Not into yoga? No problem!

You're still welcome to join the celebration and enjoy the other activities Dena has planned — including a **small raffle** and more surprises.

Let's rally around Dena and make this a memorable day of support and solidarity.

To register or donate in support of Dena's event, [click here](#)



## Histo Ty-Fighters 5K

Join the Ty-Fighters for the 9th Annual 5K – A Star Wars-Inspired Fundraiser!

Just one week later, another dedicated member of the histio community is preparing for an incredible event. Histo Mom (and ambassador) Michelle, and her son, Ty - a brave JXG warrior, are excited to host the 9th Annual Histo Ty-Fighters 5K on **Sunday, October 19th** at **Burke Lake Park in Fairfax County, Virginia!**

This fun, family-friendly, *Star Wars*-themed 5K brings together the community for a morning of exercise, laughter, and most importantly, awareness for histiocytosis.

So grab your lightsabers, lace up your running shoes, and don your stormtrooper masks—it's time to unite for a great cause!

#### Event Details:

- 📅 **Date:** Sunday, October 19th
- 📍 **Location:** Burke Lake Park, Fairfax County, VA
- 🌐 **Can't attend in person?** Join virtually from anywhere in the galaxy!

All proceeds benefit the **Histiocytosis Association**. [Register here](#).

## Further Reading



**Episode 083**  
**Meet the Team: Staff Highlight Series with Our New Executive Director, Jen Silvers**  
**Now Available!**

### Beyond the Diagnosis

In this episode we're introducing you to the Histiocytosis Association's brand-new Executive Director, Jen Silvers, as we continue on in our staff highlight series! Listen in as we learn about Jen's hobbies, background and what led her to this role. You might find yourself surprised!

## Listen to Episode 83

FOLLOW US

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