

# eNewsletter

## HISTIOCYTOSIS ASSOCIATION

-- May 2025

In this month's newsletter, we're thrilled to announce the upcoming **Histio Patient and Family Summit** this September, recap the inspiring **Histio Hike Shenandoah**, and spotlight a passionate Histio family member who was "ready to rumble" to raise funds for research.

## Just Announced



### Histiocytosis Patient and Family Summit in Seattle:

Join Us in Seattle for the **Histio Patient and Family Summit!**  
📅 September 26–27 📍 Hilton Motif, Seattle, WA

We're excited to invite you to the **Histio Patient and Family Summit** - an empowering and informative event for patients, caregivers, families, advocates, and healthcare partners impacted by histiocytic disorders.

This year is especially unique, as the Summit will take place alongside the **Histiocyte Society's annual meeting**, giving attendees rare access to **some of the world's top histio experts**.

### What to Expect:

- ★ **Expert-Led Sessions** on disease education, research, clinical trials, and treatment advances
- ★ **Interactive Workshops** on pathology, genomic profiling, and navigating care
- ★ **Youth Lounge** for our younger attendees to connect and have fun
- ★ **Community Networking** with others who truly understand your journey
- ★ **Advocacy Tools & Resources** to support you and your loved ones

As part of **Histiocytosis Awareness Month**, don't miss our optional group outing to a Seattle Mariners vs. Dodgers game - where we'll turn the stands into a "**SEA of BLUE**" in celebration of our Histio community!

This is more than a meeting - it's a chance to connect, learn, and be inspired. Space is limited, so we encourage early registration!

👉 Register now at [www.histio.org/2025-patient-and-family-summit/](http://www.histio.org/2025-patient-and-family-summit/)

**Questions?** Email us at [outreach@histio.org](mailto:outreach@histio.org) or call (856) 589-6606

Let's make memories together in Seattle!

## Histio Doctors Under the Microscope:

For the past few months, we have been highlighting histio doctors on our social media during the final week of the month. Now we wanted to bring that to the newsletter audience.

We're honored to begin with **Dr. Oussama Abla**, Director of the Pediatric Histiocytosis Program at Toronto's Hospital for Sick Children (SickKids) and a valued member of our Medical and Scientific Advisory Committee.

Read more about Dr. Abla's history of studying histiocytosis, his hobbies and mentors below.



[Learn more about Dr. Abla Here](#)

## Resources

### Beyond the Diagnosis Podcast



**BEYOND  
THE DIAGNOSIS**

**Episode 078**

**From Misdiagnosis to Mission:  
One Patient's Journey with Rare  
Disease  
w/ Hank Heren**

**Now Available!**

In this episode, Ambassador Hank Heren shares his courageous journey from being misdiagnosed, to finding his purpose in life to help others affected by histiocytosis in the most practical of ways.

Listen below or wherever you find podcasts.

[Listen Now](#)

### New Blog Posts



In this month's blog posts we had two guest writers.

We had a post from our Strategic Communications Associate Peter Yanefski who wrote about his experience at Pitman's Great Chamber of Commerce meeting and how you can get involved in your local community in similar ways. This is the first in his series *From the Desk of Communications*.

Then our second blog post was written by Doris Dahdouh, a social worker who wrote about self-care when you're grappling with a diagnosis of histio.

## Read the Blog

## Getting Involved



As the days grow warmer and brighter, there's no better time to take action and make a difference.

Spring is a season of energy and renewal....it's a perfect time for bringing people together to **raise awareness, inspire hope, and fund progress** in the fight against histiocytic disorders. Whether

it's a walk, a bake sale, a community gathering, or something uniquely yours, your efforts can spark change.

Here's how you can get involved:

- **Where to start?:** Try something simple like a lemonade stand or an ice cream social - every effort makes a difference. In a rare disease community like ours, **even the smallest actions can make a big impact.**

[Create your own D-I-Y fundraising event campaign today!](#)

- **Dreaming Bigger?:** Thinking about a larger event? We are here to support you! If you have an idea but aren't sure where to start, reach out to Allie at [events@histio.org](mailto:events@histio.org) - she'd love to help you bring it to life.
- **Not ready to Host?** No problem - you can still make an impact by donating to fundraisers organized by other Histo patients and families. **Your support lifts their efforts and helps the whole community grow stronger.**

**Let's turn this season of sunshine into a season of impact...together.**

Check out the upcoming events hosted by our Histo Community!

## Histo Run in Memory of Jeffrey White - Saturday, May 17, 2025



The **Annual Histo Run in Memory of Jeffrey White** is celebrating its 14th year! After losing their precious son, Jeffrey after a courageous battle with HLH, the White family decided to organize a 5K to honor his memory. While the Whites are committed to keeping Jeffrey's memory alive, they also use this event to share about other histio survivors in their area, all while raising awareness to help in the fight against histio.

If you are interested in learning how you can support the White family's efforts and/or join the run on May 17th, visit the Histo Run [here](#).

Histo Run

## *Fourth Annual* **HLH AWARENESS** CHARITY GOLF OUTING

### HLH Awareness Charity Golf Outing - June 26, 2025

For its fourth year running, the Annual HLH Charity Golf Outing is swinging for the green to raise green for HLH research. Started by the parents of a pediatric HLH warrior, the focus of this golf outing is to help provide a meaningful impact to those affected by histiocytic disorders. It is so much more than just a day of golf!

There are contests, camaraderie, spectacular raffle items, and laughter- one thing is certain- you're guaranteed to have a fantastic time! Registration is now open so register before it's too late and we'll see you on the green, bright and early on June 26, 2025! Click [here](#) to register or donate.



## HLH Golf Outing

### 16th Annual Histo Hike Recap:



The **16th Annual Histo Hike Shenandoah** is complete and wow, what a weekend!

Hike weekend was nothing short of amazing. We were joined by 21 families of histio angels and warriors, hiking in Shenandoah and virtually for such an important cause. Hikers braved wet trails and made wonderful connections along the way, with several new hike families joining us this year.

Now in its 16th year, we are so excited to announce that the Hike has raised nearly \$42,000 so far this year, bringing the 16-year grand total to \$973,982. WOW! What a community we have, to rally round Histio so fiercely!

A special thank you to the hike's host family, Ryan, Tracy, & Ian Brown, who started this amazing event back in 2010 to not only help fight histio, but to also provide a place of comfort, connection, and hope to other families fighting histio, as Ian did. The hike is a place where families can come together and find solace in knowing they're not alone.

There's still time to support this year's Histo Hike! When you [donate](#), you're helping fund a special opportunity - 10% of all Hike proceeds go directly toward the **Histio Student Scholarship**.

### A Win for Histio!

Meet Adrian, a histio family member who quite literally took some hits for histio! Adrian is the cousin of a histio warrior who wanted to use his new skills as an amateur boxer, to give back

to the Histiocytosis Association. Adrian participated in the "Liberty Bell Brawl" for the Haymakers for Hope - a charity boxing event on April 10th at the Fillmore in Philadelphia.

Adrian was a first-time boxer with no experience and trained for three months to prepare for his first fight in this USA Boxing sanctioned amateur bout.



When asked why he chose to support histiocytosis, he shared that he had watched his cousin bravely battle histiocytosis - and heard firsthand how much the Histiocytosis Association meant to his aunt during that journey. For him, this was a meaningful way to give back.

**Adrian fought hard and, in the end, came out with the 'WIN' - and raised over \$5,000 for the fight against HISTIO!**

Thank you, Adrian! (pictured in blue)

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