

eNewsletter

HISTIOCYTOSIS ASSOCIATION

-- March 2025

In this month's newsletter, we cover a variety of topics including histio art, the power of sharing your story, ways to get involved and make a difference, and a deep dive into gene mutations in our latest podcast episode.

Stories from the Community

Aimee is an actress, writer, fashion model, and a passionate advocate for an LCH warrior. Tune in to hear her inspiring story and learn how she's making a difference.

[Watch Aimee's Story Here](#)



Share Your Story

Your story can be a lifeline, offering comfort and connection to others facing the same challenges. Every day, people affected by histiocytic disorders search for stories to help them feel less alone. By sharing your journey, you're helping build a supportive community.

If you're interested in sharing your experience as a patient, loved one, caregiver or advocate, take the first step by completing the [Share Your Story interest form](#). Whether you prefer to submit your story in writing or through a recorded video or interview, a team member will reach out to guide you through the next steps.

Resources

Beyond the Diagnosis Podcast

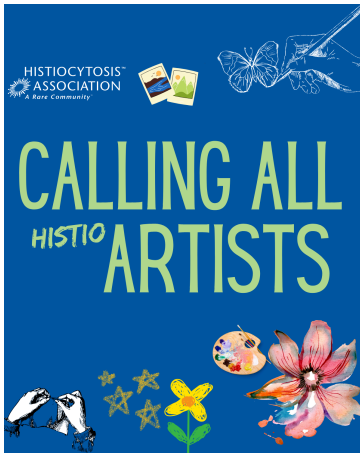


Curious about the latest research on treating Erdheim-Chester disease (ECD)? In this episode, we're chatting with Drs. Goyal, Abeykoon, and Acosta-Medina about their study on MEK inhibitors and what it means for patients. Plus, we'll dive into how genetic mutations can affect patient responses and why ongoing research and collaboration are key to improving outcomes.

Listen below or wherever you find podcasts.

Listen Now

Calling All Artists: Inspire Hope Through Art



Are you a Histo Warrior, family member, or friend with a passion for creating art? We'd love to feature your work!

Last year, 15 talented artists helped us raise over \$17,000 for the Histiocytosis Association through an incredible gallery of artwork. This year, we're expanding our collection and inviting artists of all levels to contribute. Your artwork could be featured and auctioned at a private fundraising event in New York City this May.

If you'd like to learn how you can participate in this special awareness through art project, please review the [Instructions and Entry Form](#). All submissions must be received by Wednesday, May 1, 2025.

For questions, contact the Association office at [\(856\) 589-6606](tel:856-589-6606) or email Melinda Atnip at matnip@histio.org.

We can't wait to showcase your creativity and support the Histo community!

Need a little inspiration? [Check out last year's artist's and their artwork for inspiration!](#)

Share Your Art

Getting Involved

We are incredibly grateful for the support we receive from our community – without you, none of the vital work we do would be possible. It truly takes a village, and in our case, it takes the Histo Community. Your involvement is critical to our programs and the people we serve.

Spring is upon us – a time of growth and renewal. It's the perfect season to get outside, participate in activities, and turn those activities into opportunities to spread awareness and raise funds for histiocytic disorders.

Here's how you can get involved:

- **Host a small event:** Whether it's a bake sale that brings together family, friends, and your local community, or a lemonade stand - every bit counts and helps raise awareness for these rare diseases.
[Create your own D-I-Y fundraising event campaign today!](#)
- **Dream bigger:** Want to organize something on a larger scale? We're here to help guide and support you every step of the way. It takes all of us to make this work. Want to share your idea? Email Allie at events@histio.org to find out how we can help bring your idea to life.
- **Not ready to host an event?** Consider donating to one of the fundraising efforts being organized by other patients and families in the Histo Community. Let them know you appreciate their hard work, as it's for the benefit of the entire community.

Let's continue working together to make a difference!

Check out the upcoming events hosted by our Histo Community!

Histio Hike - April 25-27 2025



Join us for a fun and impactful weekend, April 25-27!

We're so excited to welcome new hikers this year and would love for YOU to join us! It's going to be an amazing weekend full of fun, connections, and plenty of activities.

Enjoy a relaxing hike through beautiful terrain, meet fellow histio warriors and families, and unwind by the bonfire with s'mores. Bring the whole family (and your dog!) for a stress-free weekend in nature with the histio community.

Over 17 histio families are already registered - don't miss out! Be sure to register by April 10th to get your preferred shirt size!

Lace up your hiking boots and join us on the mountain! Can't make it to Shenandoah this year? No worries - you can still be part of the adventure as a virtual hiker or by donating in support of the event.



Hear one hiker's inspiring story and discover why she returns each year - then find out why you should too!

Proceeds from the hike directly benefit the programs of the Histiocytosis Association. We're also thrilled to once again support the Histo Warrior Scholarship, with 10% of the total raised going toward this special scholarship. The more funds we raise, the larger the scholarship award will be for one deserving Warrior applicant being awarded in May 2025.

Help us make a difference!

We hope you will join us for another fun and successful event this year!

Check out the website today to learn more about the Hike and how you can get involved: www.histio.org/histiohikeshen.

Histio Hike



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

The Histio Run in Memory of Jeffrey White is celebrating its 14th year this May. This is a fun 5K run that began after the White family lost their precious little boy, Jeffrey, after a courageous battle with HLH. The run takes place each May in Mannford, OK at a local high school on a Saturday morning.

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 more about this event and/or joining in the run on May 17th, please click [here](#).



Histio Run

Fourth Annual
HLH AWARENESS
CHARITY GOLF OUTING

HLH Awareness Charity Golf Outing - June 26, 2025

The **4th Annual HLH Charity Golf Outing** is held in Plymouth, MI and is so much more than just a day of golf! 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.

Whether you're a golf pro or a first-time putter, this experience will leave a lasting imprint well beyond the last putt of the day! Amidst the golf, contests, camaraderie, spectacular raffle items, and laughter- *one thing is certain* - you're guaranteed to have a fantastic time!

Registration is now open - save your spot on the green before it's too late!



HLH Golf Outing

FOLLOW US

332 North Broadway, Pitman, New Jersey 08071 USA

Tel: +1 856-589-6606

Histiocytosis Association ©2026 All rights reserved.

[Unsubscribe](#) | [View this email in your browser](#)

POWERED BY
blackbaud

