

eNewsletter

HISTIOCYTOSIS ASSOCIATION

June 2023

Camp Out for Histo 2023 - August 12th



Whether you're a lover of the great outdoors and laying under the stars, or want to beat the heat and camp inside, this is the event for you!

The first **10 people** to register will receive an added gift in their camp out kit and those site that raise \$500 by July 20th will be entered into a drawing to win a s'more making kit!

This is a great chance to do something fun together as friends or family - near or far - while raising much-needed funds to continue to fund vital research and a high level of support from the Histiocytosis Association.

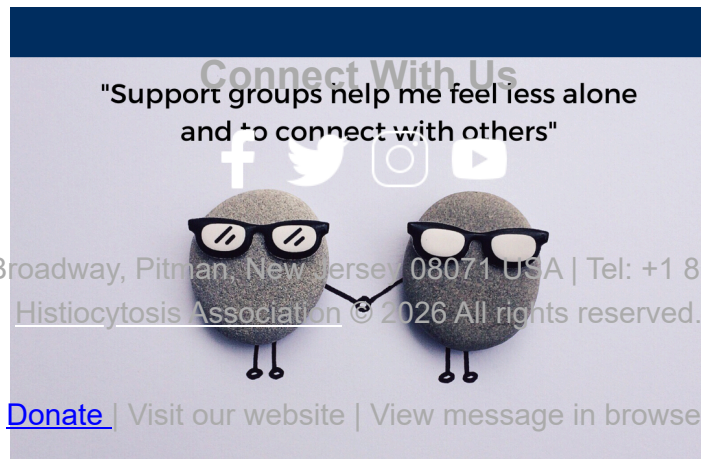
Now in the summer, Camp Out for Histo makes its return on August 12th, wherever you are.

Click the link below for more information and to register.

[Register for the Camp Out](#)

**GET THE SUPPORT
YOU NEED.**

Join a histio support group today.
You are NOT alone.



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Peer and Grief Support [Unsubscribe](#)

The histio journey is challenging -- and you do not have to face it alone. Our Peer to Peer Support Calls are a safe space to share your story, connect with others, and discuss ways to manage stress, frustration, uncertainty, and other aspects of a diagnosis. The calls are an hour long, every other week and we have sessions for patients and caregivers / care partners! No matter where you are in your journey, you will give and receive hope! Visit www.histio.org/peer-chats to see the schedule and sign up today!

In addition to our peer support calls, we are now hosting monthly grief calls as well. For anyone managing the loss of a loved one or change of life due to a diagnosis, we encourage you to join us and Professional Certified Grief Coach Don Eisenhower on Monday July 3rd from 7-8pm EST. Click the link below to save your seat!

[Find Support Here](#)

A graphic for a podcast episode. On the left is the logo for "BEYOND THE DIAGNOSIS", which features a stylized microphone with radiating lines above it. To the right is a portrait of a woman with glasses and a white lab coat, identified as Dr. Caroline Hutter. Below the portrait and logo, the text reads: "Episode 048 - Cultivating the Seeds of Research: Understanding the Grant Scoring Process w/ Dr. Caroline Hutter Now Available!". A large, detailed image of a microphone on a stand is positioned in the foreground, partially overlapping the text.

Beyond the Diagnosis

The latest episode of the Beyond the Diagnosis Podcast is now available! In this episode we're diving into part 2 of 3 about our research grant program. Today we'll talk about how grant applications are scored and how the Histiocyte Society's Scientific Committee makes their recommendations to the Association's Board.

Did you know that you can support this podcast financially so we can continue to bring you relevant and timely information while on your histio journey? Support the Podcast [here](#).

[Listen Here](#)

Kaylen Lindenberg

\$1,000 Recipient



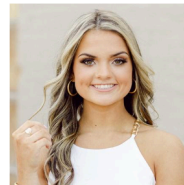
Grace Steffen

\$1,500 Recipient



Kayla Kliminski

\$1,500 Recipient



Maggie Kate Cummings

\$4,200 Recipient

2023 Scholarship Results

We are excited to announce this year's scholarship recipients: Maggie Kate Cummings, Kayla Kliminski, Grace Steffen and Kaylen Lindenberg!

In this, our fifth year of the Histo Student Scholarship, we had an amazing 44 applicants! It's so exciting to see this program grow. This is a testament to the importance of the scholarship program, and the talent of the many deserving applicants. We hope to gain more support in the coming years to further this program.

[Learn More](#)

Two New Blog Posts

Histo Ambassadors Take on the World Orphan Drug Congress



A Guide to Genetic Testing



Two New Blog Posts

In this month's blog posts, Deanna spoke with three Histo Ambassadors who attended the World Orphan Drug Congress, a conference dedicated to discussing ways to advance orphan drug development and improve access to life-saving therapies for rare disease.

Then, Deanna spoke about the importance of genetic testing for histio and rare diseases in general.

[Read the Blog](#)



Rare Across America

Want to join us on the front lines of lobbying for change in policy for histiocytosis and rare diseases?

We are once again participating in Rare Across America and want YOU to sign up to JOIN US! We'd love to be able to participate in all 50-states, but we need your help to do so! Rare Across America 2023 will take place August 7th through the 18th. During this time, rare disease advocates will have the opportunity to meet with their Members of Congress at the Member's in-state, in-district office. To learn more about Rare Across America or to register, [click here](#) or contact RDLA Program Manager, Katelyn Laws, at klaws@everylifefoundation.org. They provide all the training you need, so if you have never done this before but are interested, please sign up!

After you have registered, fill out this [form](#) to let us know you are participating so we can bring you into our pre and post calls as a community!!

[Advocate for Rare](#)





• COMMUNITY OF HOPE •

HLH Genetics Webinar

Our most recent webinar, focused on HLH and Genetics is now up on our [YouTube Channel](#). complete with a Q&A during the last half hour.

In this webinar, Dr. Michael Jordan from Cincinnati Children's Hospital Medical Center joined us for a discussion about a research opportunity for HLH patients and families, the [INTO-HLH Registry](#) and we learned, 'What we do not know about the genetics of hemophagocytic lymphohistiocytosis and how could we all help to fill these gaps?'

To view this webinar and others, go to the [webinars page](#) on our website.

[Learn More About HLH](#)