

eNewsletter

HISTIOCYTOSIS ASSOCIATION

-- October 2024

Welcome to the October 2024 Histo eNewsletter. In this issue we'll highlight a youth ambassador's volunteer efforts, another deep dive into a staff member, and a fashion fundraiser in its second year.

Resources

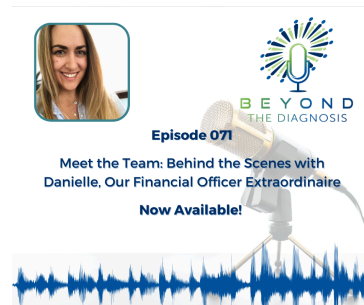
Beyond the Diagnosis Podcast

Episode 071 of the Beyond the Diagnosis Podcast is now available.

In this episode we're bringing you the second in our "Meet the Team," series where we introduce you to the dedicated individuals working behind the scenes of the Histiocytosis Association. On this episode we'll meet Danielle, our Chief Financial Officer.

Join us as Danielle shares her journey to the Association, the challenges and rewards of her role, and her message to the histio community.

Click the link below to listen or find it wherever you listen to podcasts!



Listen Now

Executive Director's Letters Blog

This month, following a busy Awareness Month, Deanna returned to the Executive Letters Blog with a post summarizing the recent podcast where our guests discussed the important updates to the SSA (Social Security Administration) Compassionate Allowance for histiocytic disorders. Our speakers provided guidance on applying for Social Security Disability Insurance and Supplemental Security Income.

Navigating SSI and SSDI Applications for Hystio Disorders



Jane Johnson,
Accredited Disability
Representative



Sandra Lamb,
Disability Representative
and Patient Advocate



[Read the Blog Here](#)



MONKEY GRINS

A monkey & lolli to bring a grin. As you fight hystio to win!



Monkey Grins

You can request a Monkey Grin care package today to bring a smile to your Histo Warrior. Each care package is available once per patient, with special ones for siblings too.

Doug and Kristin Aaron started Monkey Grins in honor of their beloved Warrior, Jenson. While recovering from transplant, Jenson saw a picture of another little boy fighting Histo. He said to his mother, "*I need send him a monkey!*" Big sister Sydney wanted to also help Histo families by including the Warrior's sibling(s) to the care package and lollipops for the family.

If you follow Monkey Grins on social media, you'll see monkeys have been heading to their new homes and into the arms of Warriors and their siblings across the USA.

Request a monkey

Volunteer Spotlight

Our Volunteer of the month is Histo Youth Ambassador Brady! Brady, a high school senior, histio youth ambassador, and proud LCH warrior, recently organized an exciting adventure hike to raise awareness and funds for histiocytosis. And let's just say, it turned into a true adventure!

The adventure hike was set in Alabama, and unfortunately it coincided with the unexpected arrival of Hurricane Francine, which brought heavy rain. Rather than cancel the event, Brady and his mom, Christie, chose to embrace the challenge with courage and determination. Luckily, the weather allowed them to proceed safely!



Undeterred by the rain, they set out for their hike, and it turned out to be a blast! Participants, especially the adults, had forgotten how much fun it was to play outside in the rain; they embraced the elements, made it a day worth remembering, and raised just over \$4600 to help in the fight against histio!

Know someone who is doing great things to spread histio awareness and support the Histo Community? If so, [let us know](#) so we can feature them in an upcoming issue of the Histo eNewsletter.

Interested in becoming a Histo Youth Ambassador?

Are you between 12 and 17 and passionate about making a difference for patients and families affected by histiocytosis? Join the [Histo Youth Ambassador Program](#)! Youth and their parent/guardian team up to support the histio community and raise awareness. Now accepting applications for 2025!

If you are interested in applying, click [HERE](#). If you're unsure about applying but want to learn

more about the program, feel free to email our Outreach Program Coordinator, Melinda Atnip, at matnip@histio.org for more information.

Event Recap



Mary was diagnosed with LCH as a young girl, bravely fought the disease, and emerged victorious. Inspired to help others who have faced histio, she launched Mary's Mission to support families dealing with cancer. On September 14, together with her mom, they held the 2nd Annual Fashion Funds event - a fashion show to benefit the Histiocytosis Association. Since beginning their fundraising journey in 2022, Mary and her mother, Sarah, **have raised an impressive \$2,400.**

We are deeply grateful to the Histo Community for their incredible fundraising efforts. Thank you to everyone who hosts, participates in, or contributes to volunteer-led events throughout the year—your dedication directly supports our mission and the people we serve.

FOLLOW US

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