

eNewsletter

HISTIOCYTOSIS ASSOCIATION

-- July 2024

Welcome to the July 2024 Histo eNewsletter. In this issue we'll explore Grief Resources, highlight histio artists, applaud our volunteers and their important contributions, and preview several events.

Resources

Peer Support



Every Monday this summer, Histio Ambassador Ana will share out a prompt through GroupMe.

We know that the summer-time can get busy and it can be difficult to join the video calls. We are confident this alternative way of connecting will not only introduce you to new people in the histio community but will give you an opportunity to express your thoughts, feelings, and ideas in a whole new way.

Join the Summer Writing

New Podcast Episode



In episode 067 we're diving into the innovative Young Investigator initiatives within the Histiocyte Society, spotlighting the newly formed Young Investigator and Social Media committees. We explore their goals and strategies, highlighting how these efforts are cultivating the next generation of leaders and researchers in the world of histiocytosis. Join us as we discuss the exciting developments and the impact these committees are making on the future of the Society.

Grief Resources

In addition to this past year's additions of new Grief groups, we also want to share several resources with the community on grief, and how people can cope with it. We have a section on our resources page for emotional support, featuring articles on how to help someone who is grieving, and tips for those grieving on how to have a health mindset while grieving.

Grief Support Calls

Grief Resources

Rare Compassion Program



One obstacle to histiocytosis being a rare disease is the lack of knowledge and understanding in the medical community. For aspiring doctors, the Rare Compassion Program provides them with an in-depth and unique opportunity to learn from patients and caregivers impacted by histiocytic disorders - to develop a deeper understanding when they otherwise might not be exposed to this rare condition.

We were thrilled to have the 4 Histo Ambassadors who participated in the Rare Compassion Program last year share their stories with medical students and inform them about histiocytosis.

Click the video below to hear their experiences.

Apply for the Rare Compassion Program

Histo Artists

In April, we put out a Call for Artists interested in participating in a special awareness and fundraising event held each year in NYC to benefit the Histiocytosis Association. The response was amazing – we received contributions from patients, friends, and family members in a variety of mediums, including sculptures, paintings, drawings, and woodwork. Histo artists from as far away as South Africa shared their work with us for our silent auction, which raised over \$17,000.

We are grateful to each of these artists for contributing to the success of our fundraising efforts and helping us bring more awareness to histiocytosis.

We didn't want to keep their creations to ourselves! Click [here](#) to check out the incredible works of art from patients, friends, and family.



Volunteer Spotlight

Our volunteers of the month, Mark and Robin Ross, have once again demonstrated their unwavering dedication and passion by successfully hosting their 3rd annual golf tournament to fund HLH research grants.

Mark and Robin's histio journey began with their son's HLH diagnostic odyssey and recovery, an experience that profoundly impacted their lives. Despite having a strong support system, Mark and Robin initially faced the challenge of navigating HLH without knowing anyone with prior experience of the condition. This motivated them to take action and contribute to raising awareness and funding for HLH research. Their passion and dedication have made a significant impact, and their efforts continue to provide hope and support to others facing similar challenges.



Their total funds raised over the past three years is \$121,755. Each year, the number of participants has grown, reaching 144 golfers this year, along with the support of 20 dedicated volunteers. They have tirelessly devoted countless hours to creating sponsorships, soliciting donations, designing flyers and emails, planning the day-of program, organizing signage, coordinating committee meetings, preparing baskets, prizes, and games, as well as handling setup, takedown, thank you notes, and financials. Their commitment to our cause is truly inspiring.

We are incredibly grateful for Mark and Robin Ross's contributions and are proud to recognize them as our volunteers of the month. Their work exemplifies the spirit of our Histo Ambassadors, transforming personal challenges into a powerful force for good. Thank you, Mark and Robin, for your exceptional dedication and for making a lasting difference in the histio community.

You can read about Ben's Journey and their event [here](#).

Upcoming Events

HISTIO PATIENT & FAMILY EDUCATION MEETING

Saturday, 8/24

Pitman, New Jersey

Saturday, 9/7

Birmingham, Alabama

The Histiocytosis Association is excited to be hosting two more Histo Patient and Family Regional Meetings in 2024. These free meetings offer a wonderful opportunity to meet, connect, and share with other Histo community patients and families and learn about the latest information from experts in the treatment of histiocytic disorders.

For more information, please visit [this link](#).

Awareness month is just around the corner and with that, events are being planned by our community.

Blue Ribbon Run – September 1 - 30

Take steps toward a cure!

Whether you're an avid runner or leisurely walker, you can participate in the Histo Blue Ribbon Run *when, where, and however* you like....and *at your own pace* - all September long.



Be a part of the movement spreading the word about histiocytic disorders *on streets and trails, over bridges and across miles*...in communities everywhere during Histiocytosis Awareness Month.

[Register today](#) to be a part of the 'movement'!



Histo Awareness Adventure Hike: September 14th

If you live in or around Alabama, love nature, breathing in the fresh outdoor air and enjoying a leisurely hike while supporting a great cause - then this might just be the event for you!

Join our newest youth ambassador, Brady, who has organized this hike to help rid the world of histiocytic disorders, one step at a time!

Location: Oak Mountain State Park, Pelham, AL

Date & Time: Saturday, September 14th at 9:00 am

[Registration](#)

So, grab your hiking boots and lace up for a great cause! Register today and join us in making a difference.

Get Ready for Histiocytosis Awareness Month!

Awareness Month is just around the corner, and it's the perfect time to make a difference. Hosting a fundraising and awareness event is a fantastic way to support the mission of the Histiocytosis Association and spread the word about histiocytic disorders. Whether it's a bake sale, a charity run, or a creative DIY event, every effort counts.

Summer FUNdraising Event Ideas:

- **Lemonade Stand:** A classic and fun way for kids and families to get involved.
- **Bake Sale:** Bake some delicious treats for a great cause.
- **Car Wash:** Gather a group of friends and make those cars shine!
- **Hike or Walk:** Organize a group hike or walk in your local park – check out [Brady's event](#).
- **Light it Up Blue Light Night:** Grab some glow sticks, illuminate your home with blue lights and host a small gathering to raise awareness.
- [Grab some awareness swag](#) for your home, office and community.

How to Get Started:

1. **Choose Your Event:** Pick an event that excites you and will engage your community.
2. **Plan & Promote:** Use social media, community boards, and word of mouth to spread the word.
3. **Register Your Event:** Let us know about your event so we can support you with resources and promotion.
4. **Fundraise:** Collect donations and raise awareness about histiocytic disorders.
5. **Share Your Success:** Post photos and updates using hashtags #HistiocytosisAwareness #IkNOwHisto #HistoAware

By coming together, we can make a significant impact and support those affected by histiocytic disorders.

Proceeds from volunteer fundraisers go directly to supporting the Histiocytosis Association programs.

Connect With Us

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