



# eNewsletter

## HISTIOCYTOSIS ASSOCIATION

-- August 2024

Welcome to the August 2024 Histo eNewsletter. In this issue we'll share social security updates for histio patients, a phase two clinical trial, and announce new events and activities for our upcoming Histiocytosis Awareness Month in September.

### Resources

This August, the Social Security Administration approved an expanded list of histiocytic disorders eligible for compassionate allowances. This means that those applying for Social Security Disability (both with a work history and without a work history, i.e., children) will have a more expedited process. Approval is still not guaranteed, but this is a huge help for anyone going through that process now or in the future.

#### Breaking News!

Helps to get SSDI Medicare/  
Medicaid approvals expedited.



Social Security

This will help people get disability benefits and access to Medicare and/or Medicaid.

We will have more information on compassionate allowances and social security disability in the coming month via two podcast episodes, to help further explain the benefits, process, and things to consider.

The current list of histiocytic disorders or malignancies now includes Follicular Dendritic Cell Sarcoma, Histiocytic Sarcoma, Interdigitating Dendritic Cell Sarcoma (IDCS), Langerhans Cell Sarcoma, Familial HLH, Langerhans cell histiocytosis, Pulmonary Langerhans cell histiocytosis, and Rosai Dorfman Disease.

### September is Awareness Month

**Awareness Toolkit**

**eStore**

**AWAID IN THE**





The 2024 Histiocytosis Awareness Month Digital Toolkit is ready to be downloaded!

Download the toolkit below to learn how to complete a checklist of awareness activities this September, create a custom histio branded profile picture, download brochures, and much more!

[Download Toolkit Here](#)



You can help support histio research and awareness by both purchasing histio branded merchandise *and* wearing to spread the word about histio.

Our Estore is open and ready for the September rush. We even have a new t-shirt: "Proud to Wear Blue"

[Get Your Gear](#)

## New Podcast Episode



Episode 068 of the Beyond the Diagnosis Podcast is now available. In this episode we're excited to kick off our new series, "Meet the Team," where we introduce you to the dedicated individuals working behind the scenes. Our first guest is Peter Yanefski, our Strategic Communications Associate, who plays a vital role in shaping the voice and outreach of our organization. Join us as Peter shares his journey to the Association, the challenges and rewards of his role, and his vision for the future of our communications strategy. Plus, get a glimpse into the person behind the emails, newsletters, and social media posts you see every day!

Check it out at the button below or wherever you listen to podcasts!

[Listen Here](#)

## Volunteer Spotlight

Our volunteer of the month is Karin VanSickle, who has been an important member of our community for over 20 years. Karin, along with the support of her father, Bjorn, has been hosting the Anna Memorial Golf tournament for the past 22 years in memory of Karin's daughter, Anna Rebecca VanSickle, who sadly passed away at six months old after valiantly battling FHLH in March of 2003. When Karin and her husband, Nate, lost their daughter, they were devastated and felt lost.



Karin knew their family had many difficult "firsts" ahead of them - one being Anna's first birthday that coming August. Their family has always been golfers, so Karin's brother suggested a golf tournament in her memory. They didn't know what they were doing but knew they wanted to keep Anna's memory alive and raise money to support the Histiocytosis Association.

That first spring leading up to Anna's birthday, they were busy finding a golf course, deciding how to reach donors and golfers, and coordinating volunteers. What they hadn't anticipated though, was how the tournament would give them a sense of purpose and fill their time. As Anna's birthday neared, they didn't only feel sadness, but also excitement and hope. That first year, they were only focused on one tournament. Little did they know that on August 5, 2024, they would host the 22nd Annual Anna Memorial Golf Tournament.

This event takes place each year on the first Monday of August in Lee's Summit, Missouri. Thanks to Karin and her family's dedication and commitment to helping with the fight against histio, they have raised over \$800,000 for research.

When asked to speak about what this means to them Karin's answer was: "In August, we do not gather to sing Happy Birthday and eat cake, instead we honor Anna by playing golf and trying to do our part in helping find a cure for FHLH. I know she would be proud."

## Research

### Ulixertinib Phase 2 Trial

A new drug, Ulixertinib, designed by BioMed Valley Discoveries is now being studied in compassionate use cases, during the second phase of its clinical trial.

Ulixertinib is being used as a monotherapy, and in conjunction with other cancer therapies to treat 10 types of tumors under the MAPK pathway, specifically ERK, the only node in the MAPK pathway so far without an inhibitor on the market.

Patients, approved under the guidance of principal investigator Dr. Eli Diamond, are starting to receive this inhibitor, only if they have not progressed or tolerated other therapies.

More will be shared on this drug as it continues in Phase 2, and into possible wider use.

For more information, you can read the press release below.

## Read More in the Press Release

## Upcoming Events



The Histiocytosis Association is excited to be hosting one more Histo Patient and Family Regional Meeting this year!

This free meeting offers 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.

Our next meeting is September 7th in Birmingham, Alabama.

## Register for Birmingham Meeting

*Awareness month starts Sunday!*

*Here are the events 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'!



### **Histio Awareness Adventure Hike: September 14<sup>th</sup>**

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 14<sup>th</sup> 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.

## Connect With Us

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