



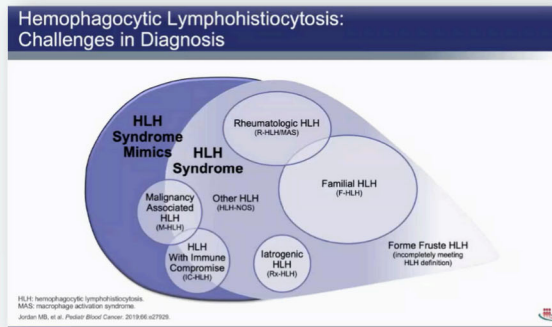
  
**eNewsletter**  
HISTIOCYTOSIS ASSOCIATION

———— JUNE NEWSLETTER

**Education Corner**

**Recent HLH Continued Medical Education Course**

Early in May, we collaborated with Practice Point Communications to host a continued medical education course on Hemophagocytic lymphohistiocytosis (HLH) for medical professionals. Attendance was strong and the presentation very informative. We now have the opportunity to share the recording publicly, and while the recording cannot be viewed for credit, it is still valuable to pass along to your physician!



**HLH Webinar**

(<https://histio.org/resource-overview/webinars/>)



## New study shows pancreatic involvement in diagnoses of Erdheim-Chester disease.

In this case study, a 29-year-old female presented with symptoms of diabetes insipidus for 1 year. Various scans showed accumulation of histiocytes in areas of the brain, increased bone volume, and lesions on an enlarged pancreas which were treated with IFN- $\alpha$  and hormone replacement therapy. Post treatment, scans revealed reduced lesions in the brain and reduction of size of pancreatic lesions. These findings help to reveal rare conditions caused by ECD and discuss the symptoms, implications, and treatment plans.



**Calling All Researchers and Physicians! Have a recent publication you'd like to share for our website and newsletter? Email [Outreach@Histio.org](mailto:Outreach@Histio.org)**

### Histiocytosis Follow Up Study Opportunity

The Histiocytosis Association is collaborating with Dr. Gaurav Goyal at the University of Alabama at Birmingham and a team of volunteers, to conduct a research study to learn about the health of people with histiocytic disorders. The study aims to understand the long-term health effects from the disease and its treatments. The information we collect will be used to make recommendations for the treatment and follow-up of future patients who are diagnosed with histiocytic disorders.

#### Eligibility for this study:

- Diagnosis of a histiocytic disorder in you or your loved one:
  - Langerhans cell histiocytosis
  - Erdheim-Chester disease
  - Rosai-Dorfman disease
- Residing in the United States
- English speaking



## Pancreatic ECD Study

[https://bmcgastroenterol.biomedcentral.com/articles/10.1186/s12876-022-](https://bmcgastroenterol.biomedcentral.com/articles/10.1186/s12876-022-02378-8)

02378-8)

## Follow-up Study Opportunity

[http://give.histio.org/site/DocServer/Histiocytosis\\_Follow\\_Up\\_Study.pdf?docID=181](http://give.histio.org/site/DocServer/Histiocytosis_Follow_Up_Study.pdf?docID=181)

## New Opportunities

### The Histo Ambassador Program

Since we launched the Histo Ambassador Program in March, histio warriors, family members, and caregivers from across the country signed up to participate in a year-long commitment to support, educate, fundraise, and bring awareness about Histiocytosis in their own areas. Now, as of this newsletter, we have 19 Ambassadors from 12 different states and D.C. participating in the program ahead of its first meet up this month.

### 2022 AMBASSADOR CLASS



This past spring, Histo Ambassadors from all over the country painted wooden cars as a way to share their histio story and raise awareness. Off the back the great response to that, we are now launching a new campaign using these cars to help DRIVE OUT HISTIO!

For more information, please reach out to us at [Outreach@Histo.org](mailto:Outreach@Histo.org)

[\\_\(https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=645\)](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=645)

**Email Us for More Info!**

[\\_\(mailto:outreach@histio.org\)](mailto:outreach@histio.org)



### HISTIO STUDENT SCHOLARSHIP PROGRAM 2022 Recipients:



**Jeremiah Hubing**  
\$5,058



**Cade Hoiby**  
\$1,500



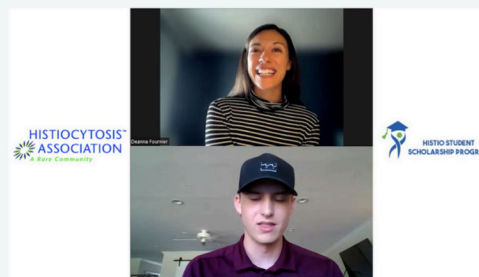
**Illana Close**  
\$1,500



**Ethan Chaung**  
\$1,000

### Histo Scholarship Program

This year we had 29 applicants: 25 warriors and 4 family members. Ethan Chaung is the recipient for the family scholarship and Cade, Illana and Jeremiah are the recipients of the warrior scholarships. Each year the Histo Hike Shenandoah generously donates 10% of funds raised to a histio warrior scholarship; this year Jeremiah was the recipient of that fund. Thank you everyone who helped contribute to the scholarship program!



### Acceptance Video

Acceptance Video

([https://youtu.be/dHY\\_eSh8hDQ](https://youtu.be/dHY_eSh8hDQ))

Scholarship Fund

(<https://histio.org/scholarship-donations/>).

## Upcoming Events



### *Anna Memorial Golf Outing*

August 1st 2022

**Do you love golf? Are you in the Missouri Area?**

Come out to the Anna Memorial Golf Outing, a private golf event hosted in memory of Histo Warrior Anna's August birthday by her family and loved ones each year. This event has made significant contributions to the fight for better treatments and a cure with its long-standing history as a wonderful event.

Email [events@histio.org](mailto:events@histio.org) to learn more!

**1st Annual**

### **HLH Awareness Charity Golf Outing**



**August 26th 2022**

**Midwest! Are you ready to tee off to help cure HLH?**

Come to the HLH Awareness Charity Golf Outing, held at the Beacon Hill Golf & Banquet Center, in Commerce Charter Twp, MI in honor of Benjamin Ross. For general questions please contact: Mark and Robin:

[bensbravehlhjourney@gmail.com](mailto:bensbravehlhjourney@gmail.com).

Anna Memorial Golf Outing

([https://histio.donordrive.com/index.cfm?](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=648)

[fuseaction=donorDrive.event&eventID=648](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=648)).

HLH Awareness Golf Outing

(<https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=647>).

Doctors! Join us in attending  
a free live webinar!  
Saturday July 9th @ 11:00 AM ET

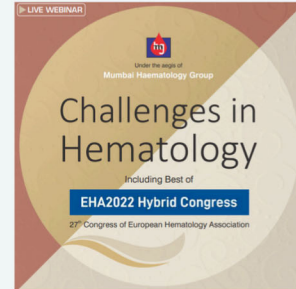


*Dr. Gaurav Goyal*  
University of Alabama  
Birmingham

Hosted by :



**Mumbai Hematology Group**



Part of the 27th Congress of  
European Hematology  
Association

**Email us for the E-Vite**

<mailto:info@histio.org>

## Two New Episodes Available!

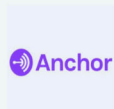
In Episode 17, Kathy speaks with Histiocytosis Association Founder Jeff Toughill about his daughter's battle with LCH, the origins of the association, and much more.



In Episode 18, Kathy speaks with Michelle Phay whose late spouse had HLH. She talks about the promises she made to her husband to keep fighting for a cure after he was gone.



Check it out at <https://histio.org/beyond-the-diagnosis-podcast/> or wherever you listen to podcasts!



Check out the show notes for each episode, where you'll find additional resources, links, and information to expand upon the episode's conversation - and, subscribe to be the first to know when a new episode becomes available. You can say you heard it first!

**Tune In to Beyond The Diagnosis**

[\(https://histio.org/beyond-the-diagnosis-podcast/\)](https://histio.org/beyond-the-diagnosis-podcast/)

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