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# eNewsletter

## HISTIOCYTOSIS ASSOCIATION

———— JULY NEWSLETTER

### Education Corner

#### 4 Update videos posted

We recently added updated educational videos to the Education & Connection section of our website, with many thanks to the clinicians and researchers who help us continue to bring you the latest advancements to the medical and scientific information related to each histiocytic disorder.

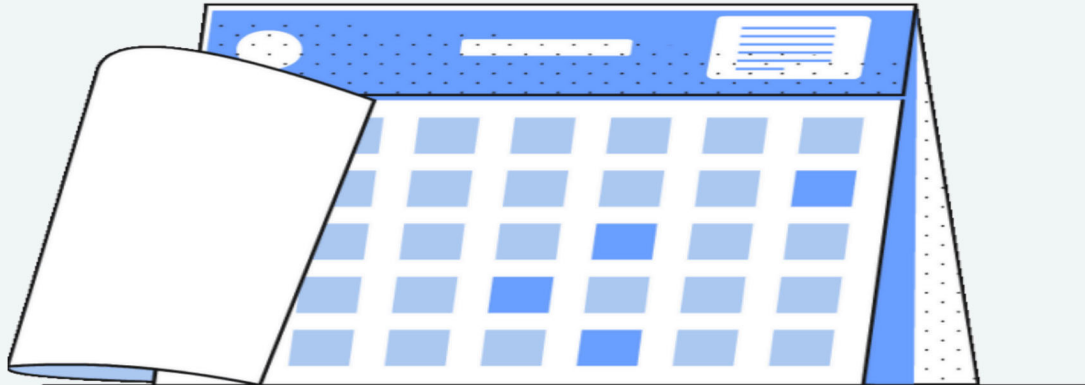


### Educational Videos

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

# The Histiocytosis eNewsletter is now monthly!

You can now expect your Histo updates in your inbox the last Wednesday of every month!



## Surveys

# Physician Survey

**WE NEED  
YOUR HELP TO  
CONNECT OTHERS TO  
YOUR LOCAL HISTIO  
PHYSICIAN!**



Help us increase the number of physicians in our directory who treat adults! As our understanding of histiocytosis increased, it became more apparent that histiocytic disorders impact any age group. Adult patients often have difficulty finding an oncologist or specialists who are familiar with treating histio. Encourage your physician to join our directory (<https://histio.org/resource-overview/histio-physician-directory/>) so that others in your local area can receive the care they need.

Email us at [outreach@histio.org](mailto:outreach@histio.org)

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

**Physician Directory**

[\\_\(<https://histio.org/resource-overview/histio-physician-directory/>\)](https://histio.org/resource-overview/histio-physician-directory/)

## Regional Meeting Interest Survey



We know how important it is to meet, connect, learn, and share with other Histo Community families and physicians. We would like to get back together in person - and we need your help!

We are in the beginning stages of planning a 2-day Histo Patient & Family Meeting in Memphis, Tennessee this November with speakers including histiocytosis medical experts across all histiocytic disorders and patient age groups and resource partners. We are exploring a hybrid option for the event as well.

Please fill out this short survey to help us gather input for planning the event! The survey will take less than 1 minute.



### Interest Survey

([https://docs.google.com/forms/d/e/1FAIpQLSdFo\\_hjUeMFMi3yOmJV7TnD06aPMRAnZjFtQkWmOrMh7jGjAA/viewform?usp=sf\\_link](https://docs.google.com/forms/d/e/1FAIpQLSdFo_hjUeMFMi3yOmJV7TnD06aPMRAnZjFtQkWmOrMh7jGjAA/viewform?usp=sf_link))

### Open Call

## Open call for Videos

Are you comfortable on video?



Do you want to raise awareness for histio?



**Then we are looking for you!**



We are developing a library of Awareness videos to share with our community.

**Open Call  
through  
Aug 7th**

If you're interested in learning more about this opportunity, please contact us at [outreach@histio.org](mailto:outreach@histio.org).

[Open Call Info](mailto:outreach@histio.org)

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



## What you'll need:

- Paint
- Paint brushes
- Your imagination

**For more info on how to receive and return a car, please email [Outreach@Histio.org](mailto:Outreach@Histio.org)**

We hope that you have fun creating your one-of-a-kind car, most importantly, we hope you know that your contribution will be helping raise awareness and funds that will greatly impact patients and families in our Histio Community!

Drive Out Histio

## Paint your own car!

By now you may have seen the painted cars and bios on our social media for Drive Out Histio now is your time to show off your creativity to drive out Histio!



[Paint a Car Today!](mailto:outreach@histio.org)

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

## Upcoming Events

# Together for the Cure

HISTIOCYTOSIS

**5K** & FAMILY  
WALK/RUN **FUN DAY**  
SAT SEPT 10



1121 Bay Blvd, Chula Vista, CA 91911

\*Participate in person or virtually, wherever you are



*First 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: robinross05@gmail.com

[Together for the Cure](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=657)

[. \(https://histio.donordrive.com/index.cfm?](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=657)

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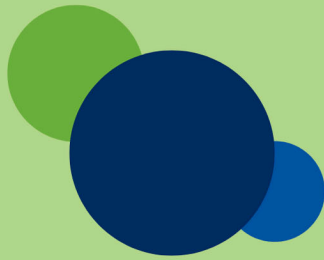
[Register to Golf!](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=647)

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## Peer to Peer Groups

### Hope for Histo A Peer to Peer Forum

Join us to share experiences, to support one another, and to bring hope to the histio community



We are thrilled to be piloting a new program: Hope for Histo - A Peer to Peer Forum for Connection. No one should have to face their histio journey alone. The Histiocytosis Association team is committed to helping foster connection across the histiocytosis community as well as offering our hearts and time to support you as best as we can. We would love to see you join in the discussion.

Advanced registration is required, and seats are limited to 25 participants per group to ensure everyone has an opportunity to share. Registration for one session will sign you up for all future sessions.

Thank you for your patience as we begin to launch this new program. If you have any ideas or questions, we want to hear from you! [Info@histio.org](mailto:Info@histio.org)

Peer to Peer

[\(https://histio.org/resource-overview/peer-chats/\)](https://histio.org/resource-overview/peer-chats/)

## Beyond the Diagnosis

### Two New Episodes Available!

In Episode 19 Kathy receives a mid-year update from the Histiocytosis Association Executive Director Deanna Fournier.



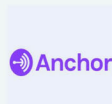
**Episode 019**  
A 2022 Mid-Year Update from the Histiocytosis Association w/ Deanna Fournier  
Now Available!



In Episode 20 Kathy and Cancer and Careers' Deputy Director Rachel Becker explore work and career while living with Histiocytosis.



**Episode 020**  
Work, Beyond the Diagnosis: A Conversation with Cancer and Careers w/ Rachel Becker, LMSW  
Now Available!



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 said you heard it first!



Tune In to Beyond The Diagnosis

[. \(https://anchor.fm/histio\)](https://anchor.fm/histio)

## New Donation Acknowledgement eCard Function

Enter A Gift Amount:

\$35.00  \$50.00  \$100.00  \$250.00  \$500.00  Other

I want to make this a monthly gift.










Yes, this is an honor or memorial gift.

*\*If you would like to send an eCard to acknowledge your loved ones, click [here](#). It will open in a new page; so you will want to revisit that page after you finish processing your donation. Thank you for your generosity!*

Now when you make a special gift to the Histiocytosis Association online, you can create and send an eCard to acknowledge your gift to friends and family.

Enter multiple email addresses on separate lines or separate them with commas.  
(Note: We respect your privacy and do not send unsolicited email to the addresses you enter. For further information, see our Privacy Policy)

Select a Card:

 Birthday <input type="radio"/>	 Congratulations <input type="radio"/>	 Give Hope <input type="radio"/>	 Happy Birthday (2) <input type="radio"/>
 In Honor of <input type="radio"/>	 In Memory <input type="radio"/>	 In Memory (2) <input type="radio"/>	 In your Honor <input type="radio"/>
 Thank you <input type="radio"/>			

There are numerous eCards to choose from including tribute (honor/memorial), birthdays and anniversary celebrations and special holidays, too.

### New Donation eCard

[http://give.histio.org/site/Donation2?](http://give.histio.org/site/Donation2?1400.donation=form1&df_id=1400&mfc_pref=T)

[1400.donation=form1&df\\_id=1400&mfc\\_pref=T](http://give.histio.org/site/Donation2?1400.donation=form1&df_id=1400&mfc_pref=T)

 July Blog Post Newsletter

### Executive Director's Letters

<https://histio.org/industry-update-from-the-world-orphan-drug-congress/>

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