



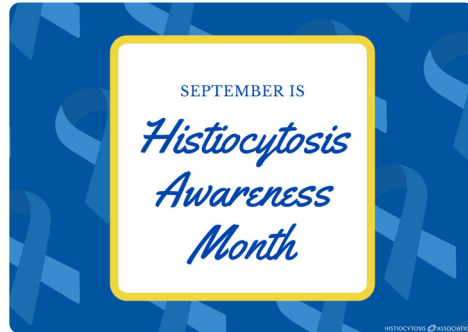
HISTIOCYTOSIS  ASSOCIATION™  
*A Rare Community*

(<https://histio.org/>)

# eNewsletter

## HISTIOCYTOSIS ASSOCIATION

-- August 2023



### Histio Awareness Month Begins Today!

We encourage you to join us and together with other Histio Warriors, families, friends, and supporters in the Histio Community - get involved in Histiocytosis Awareness Month this September.

Our goal is to use this opportunity to spread awareness about histiocytic disorders to a global audience, and to celebrate the lives of Histio Warriors and their families. All throughout the month of September the Histiocytosis Association will continue to help make our voices heard and seek to reach new members of our community and beyond - please join us!

Here are just a few ways you can get involved:

### Educate. Share. Support.

### [Get Your Awareness Gear! \(https://estore.histio.org/\)](https://estore.histio.org/)



### Share

- Use your social network to spread the word about histiocytosis to your family and friends and let's get everyone talking about histio.
- Share our posts, videos and the link to histio.org with your local community, colleagues, family and friends - encouraging them to join the online campaign.
- Share your photos of how you're spreading awareness and send them to outreach@histio.org or tag us on social media so we can share them with the Histio Community.
- Use Hashtags - #IKNOWHISTIO #kNOWHISTIO #HistioAwareness #Histio #Histiocytosis #HistiocytosisAwareness #HistioWarrior #IKnowAWarrior #HistioAwarenessRocks

**See our Socials ([https://www.instagram.com/histiocytosis\\_association/](https://www.instagram.com/histiocytosis_association/))**

## Support

### Share Your Story

Sharing your personal histio experience powerfully illustrates what it's like to live with a histiocytic disorder and encourages and inspires others in their journey.

### Participate

Your fellow Histio community members are working hard to spread awareness and raise funds – please consider participating or donating to support their efforts.

**Share Your Story**  
**(<https://secure.boast.io/site/kudos/MF7UGJ>)**



## Beyond the Diagnosis

The latest episode of the Beyond the Diagnosis Podcast is now available! As we get ready to head into Histiocytosis Awareness Month, join us as we talk with 2 Histio Ambassadors, Drew Freedman and Nate Milam, about the importance of advocacy and awareness in the quest to find a cure.

**Listen Here (<https://histio.org/beyond-the-diagnosis-podcast/>)**



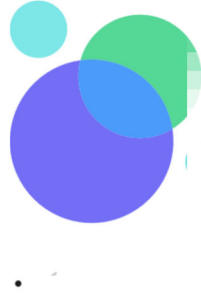
## Resource of the Month: Scientific Alerts

Interested in following the latest research on histiocytic disorders, or specifically for you/your loved one's diagnosis? Our website not only has up to date medical and scientific information, resources, and educational content; we also share a lot about the research that is taking place across all histiocytic disorders. You can stay informed by visiting our website at **Education & Connection | Histiocytosis Association (<https://histio.org/resource-overview/education-connection/>)** - scroll down toward the bottom for our RSS/News Feed AND consider turning on alerts from PubMed to receive alerts when new articles are published related to histiocytosis! **Creating Alerts: PubMed | NIH Library (<https://www.nihlibrary.nih.gov/resources/subject-guides/keeping-current/creating-alerts-pubmed>)**

**Histio News Feed (<https://histio.org/resource-overview/education-connection/>)**

# Connect With Us

## Registry Opportunities



A patient registry collects information about a genetic disorder, or more specifically, a disease from individuals who help connect people with similar experiences. These registries help advance understanding of the disease, and connect patients with other resources.

With a specific disease, Contact Registries collect information that can help researchers advance studies that can help bring about advancement in treatments and research.

- INTO-HLH Registry: (Insight into Hemophagocytic Lymphohistiocytosis) proposed study, a collaboration between Children's Hospital of Orange County (CHOC), Texas Children's Hospital (TCH), National Alliance for Histiocytosis (NACHO), and Sobi Inc. aims to help better define the natural history of HLH. Visit [clinicaltrials.gov](https://clinicaltrials.gov) page, here. Visit <https://hlhregistry.org>
- Adult HLH Registry - Europe: A registry established at the Jena University Hospital for the systematic collection of HLH cases. The registry database was created in collaboration with the Department of Hematology and the Department of Laboratory Medicine. Laboratory chemical data are registered in a secure database.
- Histiocyte Society (HS) and European Society for Immunodeficiencies (ESID) HLH Registry: The HLH Registry is a database implemented as a collaborative project of the HS and ESID in collaboration with the Inborn Errors Working Party (IEWP) of the European Bone Marrow Transplantation Group (<http://www.facebook.com/histio>). Members as participants worldwide are encouraged to contribute to this effort. This international HLH Registry is aimed to collect and analyze clinical, epidemiological, immunological, genetic, treatment and survival data for assessment of feasibility and design of future interventional studies on the treatment of HLH.

\*If you have already enrolled in one of the above studies, you are welcome to enroll in the others, so long as you meet the eligibility criteria. You can also ask your physician or the registry's team if enrolling in one automatically enrolls you in the others. Some registries exist due to the need to focus on a particular set of information, such as geographic location (i.e. Europe v North America). The registry information is shared with other existing registries in a secure, collaborative manner.

[View More](#)

## Upcoming

**Blue Ribbon Run**  
(<https://ni>)  
or leisurely  
however you li

an avid runner  
where, and

The Histo Blue Ribbon Run  
and in recognition of Histo A  
impacted by histiocytic d

run/walk together in spirit  
patients and families

In... 24th in Astoria Park, in Queens, NY  
as a mem... team.

**Together for the Cure - September 16th** (<https://histio.donordrive.com/event/681>)-  
Run or walk your way to the 5K finish line. Then, enjoy food, music, festivities, and fun for the whole family. Come out, HAVE FUN and together, let's raise awareness and funds to help make a difference in the lives of patients and families impacted by histiocytic disorders!  
(<http://www.twitter.com/histiocytosis>)

Click the link below :

We hope we can count on you to participate in spreading awareness in your community in whatever way works for you.

If you have any questions or want to share ideas or what you're planning on doing to raise histiocytosis awareness, please email [outreach@histio.org](mailto:outreach@histio.org)

Or behalf of the Histic Warriors and families Thank you for your awareness efforts.

The Histiocytosis Association Team

**Upcoming Events**  
**(<https://histio.org/get-involved/fundraising-events/>)**

**([http://www.instagram.com/histiocytosis\\_association](http://www.instagram.com/histiocytosis_association))**

**(<http://www.youtube.com/histiocytosisassoc>)**

**[Donate \(https://secure.qgiv.com/for/histiocytosisassociation\)](https://secure.qgiv.com/for/histiocytosisassociation)** | Visit our website

**[\(https://histio.org/\)](https://histio.org/)** | View message in browser

**[http://histio.convio.net/site/MessageViewer?em\\_id=10585.0&pgwrap=n](http://histio.convio.net/site/MessageViewer?em_id=10585.0&pgwrap=n)**

**[Unsubscribe \(http://histio.convio.net/site/CO\)](http://histio.convio.net/site/CO)**

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US & Canada Toll-Free: 1-800-548-2758

Tax ID: 22-2827069

**[Make a Donation today \(Donation2?mfc\\_pref=T&df\\_id=2240&2240.donation=form1\)](#)**

Stay Connected to the Histo Community

**[Sign Up for Our Newsletter \(SSurvey?ACTION\\_REQUIRED=URI\\_ACTION\\_USER\\_REQUESTS&SURVEY\\_ID=1900\)](#)**

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  - **[Ⓜ \(http://www.youtube.com/histiocytosisassoc\)](http://www.youtube.com/histiocytosisassoc)**
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