

[Click here to view this as a webpage \(http://give.histio.org/site/MessageViewer?current=true&em_id=2081.0\)](http://give.histio.org/site/MessageViewer?current=true&em_id=2081.0)




eNewsletter
HISTIOCYTOSIS ASSOCIATION

SEPTEMBER NEWSLETTER

Thank you for Making this a great Awareness Month!

The histio community has been busy! Check out these photos, and more in the link below. And share yours with us to by tagging us on social media, using the hashtag #histioawareness2022 or emailing them to Outreach@histio.org



See Highlights on our Instagram

(<https://www.instagram.com/stories/highlights/17849886005809391/>)

(https://docs.google.com/forms/d/e/1FAIpQLSfTJcitRUHVk8UxNtXok8sHsMXpyu7HNMLdZkHTM5W3bOhtJQ/viewform?usp=sf_link)

(https://docs.google.com/forms/d/e/1FAIpQLSfTJcitRUHVk8UxNtXok8sHsMXpyu7HNMLdZkHTM5W3bOhtJQ/viewform?usp=sf_link)

Histiocytosis Caregiver Research Article Published!

We are thrilled to share with you a recently published paper about the Caregiver Experience and histiocytosis. The paper is authored by Dr. Eli Diamond, Department of Neurology, Memorial Sloan Kettering Cancer Center, New York, NY with coauthors Deanna Fournier, Executive Director, Histiocytosis Association and Kathleen Brewer, President, ECD Global Alliance. This research study seeks to characterize unmet needs and experiences of caregivers of patients with Erdheim-Chester disease (ECD) and other histiocytic neoplasms (HN). The study also examined ways that caregivers are able to have positive experiences (i.e., finding benefit and meaning) in providing care for patients with histiocytosis.


Dr. Diamond has ongoing caregiver study opportunities as well and is collecting information of those interested. See the links below for the publication as well as more information on the study and additional opportunities.

Please note: these studies currently do not involve hemophagocytic syndromes (HLH), however, should that change in the future, the Histiocytosis Association will update this information!

Caregiver Paper

http://give.histio.org/site/DocServer/One-Sheet_Caregiver.pdf?docID=221

Events

REGISTRATION
OPEN!

OCT 16

BURKE LAKE PARK
FAIRFAX, VA



Register for Ty Fighters

[https://histio.donordrive.com/index.cfm?](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=652&fbclid=IwAR3hdVcy2qTzZgtR9Yg5qb93wmxNTYe12_MjN3MJqdS13s_ZROiuvomP9rE)

[fuseaction=donorDrive.event&eventID=652&fbclid=IwAR3hdVcy2qTzZgtR9Yg5qb93wmxNTYe12_MjN3MJqdS13s_ZROiuvomP9rE](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=652&fbclid=IwAR3hdVcy2qTzZgtR9Yg5qb93wmxNTYe12_MjN3MJqdS13s_ZROiuvomP9rE)

Lindsey's Bridge Run



Stephanie's 'Block Party'



Thank you for helping make the first annual Histo Blue Ribbon Run a great success! Over 40 runners/walkers joined us and helped spread histio awareness across many miles all throughout September!

Not only that, together you raised over \$9,800 through this month long event. Above are just two great examples of Blue Ribbon Runs from histio ambassador's, Lindsey and Stephanie. Share your Blue Ribbon run photos to the email below!

Events

Together for the Cure Recap



Histio Ambassador and LCH Adult patient, Ana Valdez, passionately engaged her hispanic community by putting on a histio awareness event through a 5K Walk/Run and a Family Fun day. The event took place in Chula Vista, CA on 9/10 and had five histio warriors in attendance, four of which shared their histio journeys with the community in both English and Spanish. There were over 200 people in attendance, 46 of which were her amazing volunteers. The family fun day was filled with a car show, bounce house, face painting, food vendors, Zumba dancing, Baile Folklorica Dancers, and a cake walk. Ana stated, "The event was impactful, the community came united to support our histio warriors, and raise awareness for a wonderful cause. The event was cheerful, touching, and hopeful. Our histio warriors felt supported and acknowledged."

Two New Blog Posts!

Our Executive Director, Deanna Fournier, has written two new blog posts this month. Both on different aspects of Advocacy.

The first post is the second in our series on advocacy, focusing on Ambassador Drew's part in Rare Across America, fighting for more advocacy for rare disease in legislation.

The second post focuses on resilience while battling a rare disease. Highlighting one of our ambassador's Andrea and her daughter, histio warrior Victoria



Advocacy Series: Highlighting Rare Across America



Resilience in Rare: The Other Half of the Battle



Executive Letters Blog

[\(https://histio.org/resilience-in-rare-the-other-half-of-the-battle/\)](https://histio.org/resilience-in-rare-the-other-half-of-the-battle/)

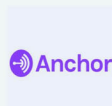
Beyond the Diagnosis

New Episode Available!

The latest episode of the Beyond the Diagnosis Podcast is now available! In this episode Kathy talks with 3 recipients of the 2021 grants to get an update on their progress, and their thoughts of our grant program overall!



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 said you heard it first!



Tune In to Beyond The Diagnosis

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

Clinical Trial Opportunity for Secondary Hemophagocytic Syndromes (sHLH)

There is no standard way to treat sHLH. Some cancer drugs are used to control the disease, but new treatments are needed. ELA026 may represent a new way to target the abnormal white blood cells that cause sHLH. ELA026 is an antibody that attaches to the abnormal inflammatory cells and causes them to break apart. By breaking down these cells, it is believed that the signs and symptoms of sHLH and other inflammatory diseases can be controlled.

View the information sheet linked below for eligibility criteria and locations for this international study.

http://give.histio.org/site/R?i=-JUb25UZ1S8SgIRIZnqEqk4h88ney_ugVwbe6yDVzgH9b1bf1LIUgA

ELA026 sHLH Clinical Trial

http://give.histio.org/site/DocServer/One_Sheet_ELA026.pdf?docID=222

FOLLOW US

<http://www.facebook.com/histio>

<http://www.twitter.com/histiocytosis>

http://www.instagram.com/histiocytosis_association

<http://www.youtube.com/histiocytosisassoc>

332 North Broadway, Pitman, New Jersey 08071 USA

Tel: +1 856-589-6606

Histiocytosis Association ©2026 All rights reserved.

Unsubscribe (<http://give.histio.org/site/CO>) | **View this email in your browser** (http://give.histio.org/site/MessageViewer?em_id=10603.0&pgwrap=n)

POWERED BY
blackbaud (<http://www.convio.com/poweredby>)

Histiocytosis Association, Inc.

332 North Broadway, Pitman, New Jersey 08071 USA

Phone: +1 856-589-6606 | Fax: +1 856-589-6614

Email: info@histio.org

(<mailto:association@histio.org>)

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](http://give.histio.org/site/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](http://give.histio.org/site/SSurvey?ACTION_REQUIRED=URI_ACTION_USER_REQUESTS&SURVEY_ID=1900))

- **f** (<http://www.facebook.com/histio>)
- **X** (<http://www.twitter.com/histiocytosis>)
- **@**
(http://www.instagram.com/histiocytosis_association)
- **▶**
(<http://www.youtube.com/histiocytosisassoc>)