

HISTIOCYTOSIS  ASSOCIATION™
A Rare Community

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

eNewsletter

HISTIOCYTOSIS ASSOCIATION

-- October 2023



Upcoming Webinars!

Great news! In the next two months there are 3 new webinars that either us or our partners in histio are hosting:

First, on November 14th we will be hosting a webinar on **HLH research and how you can help** (https://us02web.zoom.us/webinar/register/WN_Ae1pGmwvRdum7wnx-3GxMA) with Dr. Michael Jordan from Cincinnati Children's Hospital.

Then, on November 16th our partners at ECDGA will be hosting a webinar on **Mental Health centered around Coping Strategies for histio patients** (https://us02web.zoom.us/webinar/register/WN_RORhxGnpRfadAI-VfGQAQg).

Finally, on December 14th, we will be hosting a webinar with **GotTransition about their family toolkit to young adults in transitional care** (<https://us02web.zoom.us/j/88079944977?pwd=aEFERlg2QmJvMUpWeXE5UGV6cTZ5Zz09>) and how it can help with their histio journey. *More details to come soon.*

All are free, but registration is required.





7th Annual TY-Fighters 5K

TY-Fighters 5K: The 7th annual Ty-Fighters walk was held the first week of October in Virginia. Histo mom & ambassador, Michelle, gathered with almost 30 other participants for a Star Wars themed walk/run to raise funds and awareness for histio.

In addition to the fun costumes worn for the walk, there were also Storm trooper bibs, new this year! With a \$20 donation, a runner/walker would wear a histio warrior to honor their battle with histio. Michelle was able to raise just under \$5k during this year's fundraiser.

On September 24th, Histo warriors, family, friends and Association staff met in Bryant Park for a group run. Misty rain and a chill in the air couldn't stop us from raising histio awareness and bringing it live to you, signs in hand, singing aloud. If you haven't seen the video from our group run in NYC, check it out [here](#), you might even find yourself chanting along with us.

Research Opportunities



Erdheim-Chester Disease

Memorial Sloan Kettering Cancer Center has created a registry for patients with Erdheim-Chester Disease (ECD). The purpose of a patient registry is to create a database of medical information on patients with ECD. The focus of the registry is on understanding the ongoing health challenges, challenges that occur with treatment, and the many ways that ECD affects individuals impacted. With this information, the investigators hope to advance the knowledge that is known on ECD, its treatments, and what is best for patients.

Read the study information here (<https://clinicaltrials.gov/ct2/show/NCT03329274>).
Participate in the registry online, **here (<https://redcap.mskcc.org/surveys/?s=JXWLJMMXFD>).**

Visit the **ECD Global Alliance (<https://erdheim-chester.org/patient-registry/>)** for additional information about the history and data generated so far from the registry.

Connect With Us



International Rare

Disorders Registry

The Division of Haematology is conducting a research study.

is conducting a

This research study is in order to learn more about histiocytic disorders including Langerhans Cell Histiocytosis, Rosai-Dorfman disease, Multifocal Histiocytosis, and Histiocytosis.

histiocytic disorders in being used. The family, Erdheim-Chester disease and the Malignant

This study does not involve any additional treatment.

not impact your/your child's current

If you/your child would like to participate, please email: irhdr.registry@sickkids.ca (mailto:irhdr.registry@sickkids.ca)

ions, please email: sickkids.ca.

Read the Study Introduction Letter: http://www.sickkids.ca/content/uploads/2021/08/IRHDR_I

[stio.org/wp-content/uploads/2021/08/IRHDR_I_06Feb-2019_CLEAN.pdf](http://www.sickkids.ca/content/uploads/2021/08/IRHDR_I)

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

Executive Director's Blog



Through awareness

raise

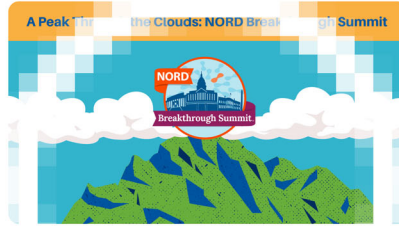
Total Letter

Most Written by one

These letters were written by generalist, and hospitalists across the country. For example, a hospitalist at Bronson Hospital in Michigan wrote a letter from one ambassador and said she is going to snare it with a net of physicians.

To read more about the Letter Writing Campaign, see the blog post about it below, written by our Outreach Coordinator, <http://www.twitter.com/histio>

[Read Here \(https://histio.org/histio-letter-writing-campaign-a-remarkable-success/\)](https://histio.org/histio-letter-writing-campaign-a-remarkable-success/)



Rare Education and Advocacy Conferences

This month our Executive Director Debra Fournier went to separate conferences and panels. The first conference was the NORD Breakthrough Summit. She details her experience in this post, and further posts chronicling her other rare education and advocacy events from this month will be coming out soon.

Read this blog at the button below.

[Read Here \(https://histio.org/histio-letter-writing-campaign-a-remarkable-success/\)](https://histio.org/histio-letter-writing-campaign-a-remarkable-success/)

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=10583.0&pgwrap=n

Unsubscribe (<http://histio.convio.net/site/CO>)

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 \(Donation2?mfc_pref=T&df_id=2240&2240.donation=form1\)](#)

Stay Connected to the Histo Community

Sign Up for Our Newsletter (SSurvey?
ACTION_REQUIRED=URI_ACTION_USER_REQ
UESTS&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>)