

HISTIOCYTOSIS  ASSOCIATION™
A Rare Community

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

eNewsletter

HISTIOCYTOSIS ASSOCIATION

July 2023

2023 Patient and Family Conference in NYC



September 23rd
Memorial Sloan Kettering
Cancer Center

Please join us for a Patient & Family Conference on Histiocytic Disorders taking place on Saturday, September 23rd in New York City and online.

This educational opportunity and forum to connect with other patients, families, and physicians will be a valuable experience for anyone who has been diagnosed with a histiocytic disorder or has a loved one who has been impacted. During this all-day event, you will have access to essential medical and research information presented by leading physicians, and the opportunity to connect with others who can relate to your histio journey.

Presentations will include talks that cover all histiocytic disorders, information on clinical trials, emotional support and wellbeing, and a patient and caregiver workshop. There will also be opportunities to connect with other families in person, and an engaging virtual environment for online participants.

TRAVEL ASSISTANCE

A limited number of travel scholarships are available to patients/caregivers to help offset the cost of travel to attend the conference in person - meant for those individuals who would not be able to cover the cost for their participation fully. Assistance is limited and available on a first-come, first-served basis. To learn more and save your seat today [click here](#) (<https://docs.google.com/forms/d/e/1FAIpQLSfJEGhIQJdw1IVKYZTt0rMx9Lffx--xHvpYyZ0HG4b07ZD3dg/viewform>)!

To learn more and save your seat today [click here](#) (<https://docs.google.com/forms/d/e/1FAIpQLSfJEGhIQJdw1IVKYZTt0rMx9Lffx--xHvpYyZ0HG4b07ZD3dg/viewform>)!

Coming to the conference? Stay the weekend and be a part of the **NYC Histo Blue Ribbon Run team!** Join us along with other warriors and caregivers – bond over shared experiences, make memories, be active, and help raise awareness and critical funds to improve lives and cure histiocytic disorders!

Register for the Conference
(<https://www.histio.org/nationalconference>)



Blue Ribbon Run: All September Long

Registration is NOW OPEN.

This September, during Histiocytosis Awareness Month challenge yourself to run (or walk) throughout the month to honor the journeys of those impacted by histiocytic

disorders and help move us closer to a cure.

Whether you're an avid runner or leisurely walker, you can participate in the **Histio Blue Ribbon Run** when, where, and however you like....and at your own pace all September long.

Every step we take will be to honor the Warriors we have lost and those who are still fighting. Our goal is to raise awareness and fund life-saving research to develop more effective treatments and a cure for histiocytic disorders.

Join the movement...create a team, join a team, or register as an individual!

In the NYC area? Register and join us for a family friendly group run on Sunday, September 24th as a member of the **NYC Histio Blue Ribbon Run** team.

Get a headstart - register today! All registered participants receive a t-shirt and run bib...and a chance for some cool fundraising incentives, too!

[Join the Run \(https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=675\)](https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=675)



Spanish Language Support Calls

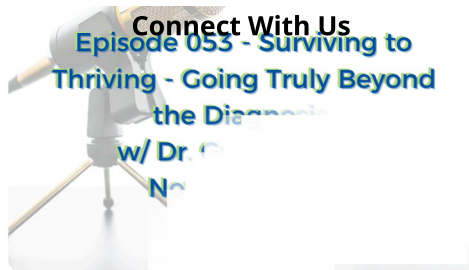
¡Saludos! ¡Estamos muy orgullosos de presentarles que ahora tenemos grupos de apoyo entre pares en Español! Se reunirán el tercer miércoles de cada mes 3-4pm EST/12-1pm PST. ¡Esperamos verte **ahí** (**<https://us06web.zoom.us/j/91012020000>**)!

We are so proud to introduce Spanish Peer Support Groups! They will meet on the third Wednesday of each month from 3-4pm EST/12-1pm PST. We hope to see you **there** (**<https://us06web.zoom.us/j/91012020000>**)!

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

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





New Podcast Available

Episode 53 - Surviving to Thriving New Podcast is now available. In this episode Dr. Gaurav discusses various non-organ challenges which is so crucial to learn

Episode 053 of the Beyond the Diagnosis Podcast provides some practical tips on how to deal with the challenges of this survivorship study to thrive.

[Listen](#)

[podcast/](#)



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

Executive Director's Letter

The Executive Director's Letter is all about his success stories, friends, and local community events and research.

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ELA026



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

Secondary hemophagocytic lymphohistiocytosis (or simply "sHLH") is a severe, but rare, inflammatory syndrome that is triggered by an underlying disease such as cancer, an infection, or autoimmune disease.

autoimmune disease.

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. How it works: 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.

ELA026 is currently in a clinical trial in Europe and the US; see site list below. To be eligible for the trial, patients must have sHLH and be at least 12 years of age; a full list of eligibility criteria can be seen in the study sites linked; you should discuss with your care team if this study is right for you. US study information; EU study information.

For other clinical trials, click [here \(https://histio.org/research/clinical-trials/\)](https://histio.org/research/clinical-trials/).

ELA 026 Locations

<https://www.google.com/maps/d/edit?mid=10LWGimPOL7agh0bmoEJ32pevJD-qg&usp=sharing>

Upcoming Events

Anna Memorial Golf Tournament - August 6th

Camp Out for Histio - August 12th

Blue Ribbon Run: All September

Together for the Cure, September 16th
(http://www.itsgraff.com/histiocytosis_association)

Click the link below for more information on these events

Upcoming Events

(<https://www.youtube.com/watch?v=...>)

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

Donate (<https://secure.qgiv.com/for/histiocytosisassociation>) | Visit our website

(<https://histio.org/>) | View message in browser

(http://histio.convio.net/site/MessageViewer?em_id=10586.0&pgwrap=n)

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

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Tax ID: 22-2827069

[Make a Donation today \(Donation2?mfc_pref=T&df_id=2240&2240.donation=form1\)](#)

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[Sign Up for Our Newsletter \(SSurvey?ACTION_REQUIRED=URI_ACTION_USER_REQUESTS&SURVEY_ID=1900\)](#)

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