



HISTIOCYTOSIS  ASSOCIATION™  
*A Rare Community*

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

# eNewsletter

## HISTIOCYTOSIS ASSOCIATION

-- September 2023

### Awareness Month Comes to a Close



Every September, we celebrate Histiocytosis Awareness Month - it provides the community with an opportunity to spread awareness about histiocytic disorders to a global audience and to celebrate the lives of Histo Warriors and their families. Having a histiocytic disorder makes us unique and strong, and throughout the month of September, the Histo Community has amplified their voices to new heights, that we hope to capitalize on this year, and eclipse next year.

Thank you to all who participate.

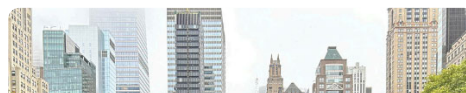


### 2023 Patient and Family Conference on Histiocytic Disorders

This past weekend was the Patient and Family Conference on Histiocytic Disorders in NYC and despite the weather, it was a great experience of education and connection. We had 65 attendees, from 7 countries. 42 online and 23 in person. All there to watch talks by our 6 speakers:

Dr. Yesne Alici, Dr. Eli Diamond, Dr. Ira Dunkel and Dr. Mariko Yabe from Memorial Sloan Kettering Cancer Center (MSKCC), Dr. Michael Jordan from Cincinnati Children's and Dr. Lenat Joffe from Cohen Children's

**We would like to once again thank our sponsor SOBI for helping us host this event.**





### **Blue Ribbon Run**

There is just one day left in this year's Histio Blue Ribbon Run – we're moving closer to our goal!

Fifty-two runners/walkers in our Histio Community, from coast to coast, have been participating in the Histio Blue Ribbon Run all month long. Together, they have raised over \$11,000 and histio awareness in communities across the country.

On September 24th, Histio 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 \(https://www.instagram.com/reel/CxIA3LHOzPH/\)](https://www.instagram.com/reel/CxIA3LHOzPH/), you might even find yourself chanting along with us.

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

### **Events**

During this Awareness Month: People shared their stories. Participated in fundraising events or hosted their own personal campaigns. Liked and shared our posts. Wrote letters to doctors. Wore blue and tied ribbons, and so much more! Here is a recap of some of the big events below.



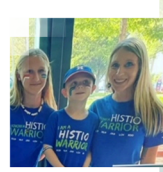
### **Together for the Cure**

On September 16th, Histio Ambassador and LCH Warrior Ana held the second annual Together for the Cure 5K/Fun Run in Chula Vista, CA. With the help of fellow LCH warrior Liz, she hosted a day of fun to raise awareness and funds to help make a difference in the lives of patients and families impacted by histiocytic disorders.

impacted by histiocytic disorders.

## Connect With Us

Seventy-three people participated in the event, where children played, and adults danced and worked out together. In addition to a day of fun and comradery, it was also a day of education where Histo Warriors were able to come together and share their stories and educate the community on histiocytic disorders.



## Astros Game Awareness

Histiocytosis was represented at a Astros stadium! Fundraising event McFadden, set up an awareness Histiocytosis Awareness month.

er awareness event at the Houston histo ambassador, & histo mom Allie s game for childhood cancer &

Allie, along with her daughter, Avalon (a youth histo ambassador) and her histo warrior, Hudson, were able to hand out histo flyers, goodie bags, and pamphlets while educating attendees (<http://www.facebook.com/histio>).



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Histo Am Tennessee. It w a large and univ

Check out t

er game in wareness to y.

<https://www.youtube.com/watch?v=634834468499963>



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



## Youth Ambassador Bake Sale

This summer, we welcomed our first youth ambassadors to the Histiocytosis Ambassador program. Histiocytosis Youth Ambassadors are warriors, friends, and siblings of warriors between 12 and 17 that give their time and energy in support of the mission of the Histiocytosis Association.

With the support of his family and friends, Histiocytosis Youth Ambassador Tyler organized a bake sale in the California community to raise awareness and funds for histiocytosis.

Tyler's bake sale was a great success - raising **\$5000!**

"Organizing the bake sale and everything else as an ambassador has been an amazing opportunity and experience!" -Youth Ambassador Tyler



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

## Heroes for Histiocytosis

On Saturday, Ontario, Drouin raised his effort

ambassador, by the Histiocytosis Association - research

Together, we can be

community and the Fight Line

(CAN)

All of us



## Global Genes Conference

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

In the middle of this month 4 of our Histiocytosis Ambassadors attended Global Genes' 'Week in Rare' Conferences in San Diego, California. First, Nate, Shannon and Ana attended the Rare Health and Equity Forum from the 18th-19th and then joined by Melinda for the Rare Advocacy Summit on the 19th-21st.

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While there, they presented a digital poster highlighting the achievements of the first year of the ambassador program, which you can view here (<https://histio.org/wp-content/uploads/2023/09/Poster-Higher-Quality.png>).  
([http://histio.convio.net/site/MessageViewer?em\\_id=10584.0&pgwrap=n](http://histio.convio.net/site/MessageViewer?em_id=10584.0&pgwrap=n))

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

**<https://histio.org/wp-content/uploads/2023/09/Poster-Higher-Quality.png>**

### **Beyond the Diagnosis**

The latest episode of the Beyond the Diagnosis Podcast is now available! As we get ready to wrap up Histiocytosis Awareness Month listen in as Barry shares his courageous journey living with Erdheim-Chester Disease (ECD) and the hope he found through family, friends, and his medical team.



**[Listen Here](https://histio.org/beyond-the-diagnosis-episode-56-standing-up-to-eed-with-courage-and-hope-w-barry-atnip/)**  
**[\(https://histio.org/beyond-the-diagnosis-episode-56-standing-up-to-eed-with-courage-and-hope-w-barry-atnip/\)](https://histio.org/beyond-the-diagnosis-episode-56-standing-up-to-eed-with-courage-and-hope-w-barry-atnip/)**

**Histiocytosis Awareness Month may be coming to a close, but there are still ways you can help raise awareness and funds to fight histiocytic disorders year-round!**

**We encourage you to continue spreading awareness - sharing your story and experiences in hopes that it will inspire others and continue to raise awareness.**

**The more people who KNOW HISTIO, the more action we inspire.**



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