

eNewsletter

HISTIOCYTOSIS ASSOCIATION

-- February 2024

Histio Student Scholarship Applications Open!



Since 2019, the Histio Student Scholarship Program has been encouraging, celebrating, and supporting the histio warriors, survivors, and their families -- who are now pursuing undergraduate degrees. This year is no exception.

Last year brought in a record 44 applications! This year, we hope even more students are encouraged to apply for the scholarship.

The Histio Student Scholarship Program offers 4 scholarships; 3 dedicated to histio warriors and 1 dedicated to a histio family member. For the full list of eligibility requirements and to apply, please visit [Histio.org/scholarship-program](https://histio.org/scholarship-program)

Applications close March 22nd.

Apply Today

Volunteer Spotlight: Avalon McFadden



This month, we shine our Volunteer Spotlight on Avalon McFadden, a dedicated histio youth ambassador. Avalon's journey as a histio volunteer stems from her younger brother, Hudson, who overcame a rare histiocytic disease called Rosai-Dorfman Disease (RDD). You can read about Avalon's histio journey with her brother [here](#).

For the past two years, Avalon has been an integral part of various initiatives alongside her family. Her contributions include assisting with gift baskets at fundraising events, selling candy nationwide to "take a bite out of histio," helping set up awareness booths at events like a Houston Astros game, and organizing her own successful fundraiser named Histio Hope for the Holidays. Through her efforts, Avalon managed to raise approx. \$1200 to support histio research and patient care.

When Avalon is not volunteering, she enjoys playing select softball, fishing with her family, attending Jeep meets, and indulging in junk food movie nights.

Avalon dreams of being a histio oncology nurse at Texas Children's Hospital, where her brother received treatment.

Interested in becoming a Histio Youth Ambassador?

Are you between the ages of 12 and 17 and passionate about making a difference for patients and families affected by histiocytosis? Through the [Histio Youth Ambassador Program](#), youth partner with a parent/guardian to team up against histiocytosis. Starting on February 29th, we will be accepting applications for 10 new histio youth ambassadors for 2024.

If you are interested in applying, click [HERE](#). If you're unsure about applying but want to learn more about the program, feel free to email our Outreach Program Coordinator, Melinda Atnip, at matnip@histio.org for more information.

Research Corner: New CRISPR Center



Last month, it was announced that University of California Colleges: UCSF, UCLA and UC Berkeley, were teaming up with the DanaHER Corporation and the Innovative Genomics Institute (IGI) to open the DanaHER-IGI Beacon for CRISPR Cures center.

As stated in it's press release last month:

"The new DanaHER-IGI Beacon for CRISPR Cures center will use genome editing to address potentially hundreds of diseases, including rare genetic disorders that have no cure. The goal is to ensure treatments can be developed and brought to patients more quickly and efficiently."

And the first target for these new therapies is Familial HLH.

Maybe something like this?

To learn more about the impact of the CRISPR Cures center on HLH, please see the video of Deanna sitting down with Fyodor Urnov, PhD, IGI's Director of Technology and Translation, who is overseeing the project as well as David Nguyen, M.D., Ph.D., Michelle Hermiston, M.D., Ph.D. who will be focusing on HLH.

We are so grateful that DanaHER and IGI took up the cause of HLH and we are looking forward to the potential gene editing therapies in the upcoming years.

Check Out the Video

Take a Road Trip to the HIKE!





Grab your family and friends...pack up the car and meet us at the Histo Hike in Shenandoah! Experience an unforgettable weekend for yourself at the **15th Annual Histo Hike Shenandoah - April 26-28, 2024!**

The Histo Hike is truly a one-of-a-kind event – it's a fundraiser and a retreat, all wrapped up in one amazing weekend!

Whether you're an avid hiker, a leisurely walker, someone who wants to connect with other histio families, or you simply want to be a part of the FUN - the Hike is calling for YOU!

Don't miss this chance to come together to honor our loved ones, connect with others, and make a big difference in the lives of patients and families impacted by histiocytic disorders!

[Register today](#) as a Day Hiker or come spend the weekend with a great group of people who "get it" in beautiful Shenandoah National Park.

Can't join us in Shenandoah? No worries! Choose the virtual hiker option and join us from your favorite hiking trail.

Visit our [Histo Hike Shenandoah website](#) for more information and to register or donate today.

Register Today

Beyond The Diagnosis Episode 062 - From Adversity to Opportunity



**Episode 062
From Adversity to Opportunity**

Now Available!



Episode 062 of the Beyond the Diagnosis Podcast is now available. In this episode we're joined by Deanna Fournier and Sydney Martin, 2 histio warriors diagnosed as children, to learn about their inspirational stories of turning their adversity into opportunities and the ripple effect that this can have on others facing their own challenging circumstances. Check it out at <https://histio.org/beyond-the-diagnosis-podcast/> or wherever you listen to podcasts!

Listen Now

Tomorrow is Rare Disease Day 2024



RARE DISEASE DAY[®]
IS FEBRUARY 29
THE RAREST DAY OF THE YEAR!

Show Your Stripes[®] for the 1 in 10 Americans with a rare disease.



NORD[®]
National Organization for Rare Disorders



International Rare Disease Day is tomorrow, **February 29th** – *although* every day is *Rare Disease Day* when you are living with or caring for someone who has a histiocytic disorder. The experience is often isolating and lonely but on this special day, we are all urged to come together as one and call attention to the special challenges faced by ‘rare’ patients and those that care for them.

Sponsored in the United States by the [National Organization for Rare Disorders \(NORD\)](#) and internationally by [Eurordis](#) - Rare Disease Day is observed on the last day of February (*the rarest date on the calendar*) to underscore the nature of rare diseases and what patients face. On and around this day, thousands of patients, families, and patient organizations from countries and regions all over the world will participate in awareness-raising activities to elevate public understanding of rare diseases.

Together, let's raise awareness for histiocytic disorders and the rare disease community on Rare Disease Day!

Below are just a few ways you can join us in spreading awareness on Rare Disease Day!

Use your social network to spread the word and let's get everyone talking about histio on Rare Disease Day!

Share Your Histo Story!

Tell the world what it's like to live (*or care for someone*) with a rare histiocytic disorder and why it's important that more people Know Histo.

[Record a short video](#) or send your written story to outreach@histio.org.

Share Your Colors!

Make it a Wear Blue Day! Whether it's a histo t-shirt or your favorite blue sweater, a hat, pajamas, socks, *or even blue hair* – let's all wear blue for histo awareness. Encourage your family and friends to join you, too!

[Download and print](#) a Rare Disease Day poster to hold in your photo.

Show Your Stripes!

Because the zebra has become the official symbol of rare diseases in the United States, we wear stripes to show our support on Rare Disease Day. Ask your friends and family, your neighbors, workmates and/or classmates to wear stripes tomorrow (February 29th) to show support for the rare disease community worldwide.

To learn more about Rare Disease Day, please visit: <https://rarediseases.org/rare-disease-day/>

Connect With Us

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