

eNewsletter

HISTIOCYTOSIS ASSOCIATION

-- February 2026

The month of February is filled with meaningful momentum as it all leads up to **Rare Disease Day**, which is now less than 48 hours away!!

In this issue, readers will find updates, helpful resources, and opportunities to connect - from support and education to community events and new partnerships. There's a lot happening, and even more ahead, as the community continues to come together to raise awareness, share knowledge, and support one another.

Rare Disease Day

The countdown is on for **Rare Disease Day - February 28th!**

This global day of awareness shines a light on the millions of individuals and families living with rare diseases, including histiocytosis. It's a moment to educate, advocate, and remind the world that rare is everywhere - and worthy of attention, research, and support.

Because when we share our rare, we educate.
When we educate, we build understanding.
And when we stand together, we create change.



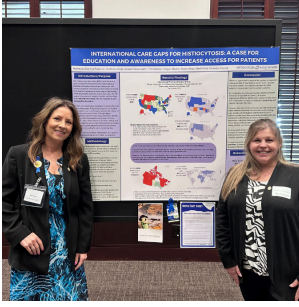
Looking for an easy way to get involved? Start here:

- Share your story - a diagnosis, a milestone, a challenge, or a victory.
- Post a photo of your Histio warrior, your family, or your care team.
- Add a custom Histio Rare Disease Day frame to your profile picture.
- Raise your voice by sharing facts, resources, or why awareness matters to you.

We invite you to answer the question: **From your experience, what do you wish people understood about life with a rare disease?**

[Share your answer](#) with a written story and a photo, or through a video, and we may share it on our social media this Rare Disease Day.

Let's make some noise this Rare Disease Day.



Program and Outreach Coordinator Melinda Atnip and Histo Ambassadors Dena and Ana will be representing histio at a booth at the Rady Children's Health and UC Irvine Rare Disease Symposium & Family Conference on Friday, February 27th, 2026 at the Beckman Center in Irvine, CA.

Learn more about the event [here](#) and come join us in Irvine, CA.

Are you taking part in any Rare Disease Week events? If so, we would love to hear about it - please let us know at outreach@histio.org.

PRV Program Reauthorized

In great news for rare diseases everywhere, the Rare Pediatric Disease Priority Review Voucher (PRV) Program, just got reauthorized for another 5 years as United States law.

The PRV Program is a decade old incentive for sponsors of pediatric rare disease therapies in an effort to expedite the FDA reviews of new drug applications.

This comes as such a comfort to the Rare Disease population, as we continue to strive for more federally funded research for our diseases and improvements for existing treatments, and as a victory for Rare Disease advocates all over the United States.

[Click here](#) to read the press release.

Support

Connection. Understanding. Hope.

Our **Histio Peer Support Groups are back**, and we would love for you to join us. Whether you are a patient, caregiver, or grieving the loss of a loved one, these groups offer a safe, welcoming space to connect with others who truly understand the rare disease journey.

We invite you to explore the different group options and find the one that best meets your needs by visiting our [Peer Support Group page](#):

👉 Learn more and find your group here: <https://histio.org/resource-overview/peer-connection/>

You don't have to walk this journey alone.

We're especially grateful that these programs are led by experienced professionals and patient leadership, including Doris Dahdouh, MSW, LSW, LMSW, INHC; Renee Christensen, Ph.D., CEAP, HHP, PCC; and patient advocate Ana Valdez. Their combined clinical expertise and lived experience help ensure these spaces are thoughtful, supportive, and grounded in understanding.

Not sure which group is right for you? We're here to help.

Please reach out to our Outreach Program Coordinator, Melinda Atnip, at matnip@histio.org. We would be honored to help you find the right space.

Because together, we are stronger. ❤️

Meet Our Support Group Leaders



Doris Dahdouh,
MSW, LSW, LMSW, INHC

Peer-to-Peer
Patient & Caregiver
Support
dorisd@histio.org



Renee Christensen, Ph.D.,
CEAP, HHP, PCC

Grief and Loss
Support
rchristensen@histio.org



Ana Valdez
Histio Ambassador

Peer Connection
anav@histio.org



Questions? Contact Melinda Atnip matnip@histio.org

RareGivers Coalition



The Histiocytosis Association is excited to share that we have joined the Raregivers Coalition, led by Raregivers - an important step forward in how we support caregivers in our histio community.

We know that behind every diagnosis is a caregiver, care partner, or family member carrying an enormous emotional load. Yet emotional health support for rare disease families remains deeply under-addressed. By joining this coalition, we are expanding the resources available to our community and strengthening our commitment to caring for the whole family - not just the diagnosis.

As part of this partnership, we're proud to share the Raregivers Emotional Journey Map and Guidebook - evidence-based, research-informed tools designed to help caregivers recognize emotional strain, prioritize self-care, and access meaningful support. These practical, compassionate resources are created to help caregivers feel seen, supported, and empowered.

We are truly grateful to be part of this growing global network and thrilled to bring these impactful tools to the histio community - because supporting caregivers is essential to strengthening our entire community.

[Journey Map](#)

[Guidebook](#)

Histio Student Scholarship Program

The 8th Annual Histio Student Scholarship Application opens this Friday at 10am!

The Histio Student Scholarship was started in 2019 after more and more pediatric histio warriors were surviving, and thriving, to college age. We created this program to help some of those warriors or close relatives of them, get a kickstart for their college education.

If you or your child is a histio warrior or closely related to one (sibling, parent or grandparent) and enrolling in or currently in an undergraduate education program, then you may be eligible to apply

for a Histo Student Scholarship!

Click below to see full eligibility rules and apply.



HISTIO STUDENT SCHOLARSHIP PROGRAM

Apply here on 2/27

Education

Webinars



Reading Between the Lines: Navigating Healthcare Paperwork and Privacy



PATRICK CAMPBELL MD

St. Jude Children's Research Hospital



We understand that navigating medical forms and protecting your private healthcare information can feel overwhelming and frustrating.

Join us on **March 18th at 1:00 PM EST** for an informative webinar with **Patrick Campbell, MD, from St. Jude Children's Research Hospital**. Dr. Campbell will guide patients and families through common healthcare paperwork and address important privacy concerns.

Topics will include:

- Understanding HIPAA
- Informed consent
- Electronic health records
- And more

Don't miss this opportunity to gain clarity and confidence around your private healthcare information.

Register for the Webinar

Upcoming Events

Histio Hike Shenandoah April 24 – 26, 2026

There's something truly special about this community - and each year at **Histio Hike Shenandoah**, that truth shines.

It's more than a fundraiser. It's a retreat for the heart - a weekend of mountain air, shared stories, laughter on the trail, and the reminder that no one walks this journey alone.

As the 17th annual hike approaches, the community is also nearing an incredible milestone: nearly **\$1 million raised** since the event began. **One million dollars of impact. One million dollars of hope.** And they're so close.



Reaching it will take everyone showing up - to reconnect, to lift one another up, and to take the next steps together.

Discounted registration ends 2/28. Now is the time to secure a spot and be part of something BIG

Register Early Bird til 2/28



Histio Run Saturday, May 16, 2026

You're invited to join us for the 15th Annual Histio Run in Memory of Jeffrey White.

We are dedicated to raising awareness and funding in the fight against histiocytic disorders. Each year, Jeffrey's memory is honored with a 5K run in Mannford, Oklahoma.

This special day brings together histio families, friends, and community members to run not only in honor of Jeffrey, but also in support of local histio warriors Abby and Caleb.

It is a day of remembrance, compassion, and passion — passion to create change for everyone fighting a histiocytic diagnosis.

So lace up your running shoes, grab a friend, and join us as we run for a cause that truly matters. [Click here](#) to register or make a donation.



HLH Awareness Golf Outing Thursday, June 25, 2026

We are beyond **EXCITED** to celebrate the 5th year of this incredible charity event in Plymouth, MI hosted by a dedicated histio family!

HLH GOLF OUTING_ If you want to be part of a truly memorable day, grab your clubs and gather your team. It's going to be a fun-filled scramble filled with friendly competition, big hearts, and an even bigger purpose.

Over the past four years, this event has raised an astonishing **\$222,000**, helping fund multiple research grants dedicated to the fight against histio. Because of this amazing community, real progress is being made.

Join us as we tee off for hope and continue making a difference—together. [Click here](#) to register or make a donation.

Get Involved

40 Years DIY FOR HISTIO



Celebrate a Day



Host an Event



Honor a Loved One

DIY Fundraising

Make It Yours. Make It Matter. DIY for Histo.

[DIY for Histo](#) puts the power to make a difference in your hands. Honor someone you love. Celebrate a milestone. Host a backyard gathering or a community-wide event. Big or small - it all matters.

We have made it simple to create your own fundraiser, share your story, and start raising support in minutes. Have an idea but want a little help bringing it to life? Our fundraising team is here to support you every step of the way.

Because every DIY effort fuels critical research, strengthens our programs, and supports the histio community. And when you take action - big or small - you help drive meaningful change.

D-I-Y For Histo

Become a Youth Ambassador



Do you know someone between the ages of 12 and 17 who is passionate about making a difference for patients and families affected by histiocytosis? Through the [Histo Youth Ambassador Program](#), youth ambassadors partner with a parent/guardian to team up against histiocytosis. Applications are now being accepted for 5 new histio youth ambassadors for 2026.

As a youth ambassador, you will have the opportunity to help raise awareness and funds for histio, while creating great volunteer material for a college resume.

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 Program and Outreach Coordinator, Melinda Atnip, at matnip@histio.org for more information.

Further Reading

Beyond the Diagnosis



Episode 088

**From Patient to Advocate:
A Youth Voice for Rare Disease
Day 2026
w/ Nate Saelinger**

Now Available!

The graphic features a microphone on a tripod in the foreground. In the background, there is a photo of a man and a woman smiling, and the logo for 'BEYOND THE DIAGNOSIS' which consists of a stylized microphone icon with radiating lines.

Episode 088 of the Beyond the Diagnosis Podcast is now available. This week, during Rare Disease Week 2026, we're shining a spotlight on something that moves our community forward in powerful ways: advocacy.

Kathy sat down with Hystio Youth Ambassador to highlight his experience with advocating for hystio at Rare Disease week on Capitol Hill last year.

[Listen to Episode 88](#)

The Hystio Blog



There's a Rare There



Defined by Humanity



Ahead of Rare Disease Day, our Communication and Operations Coordinator, Peter Yanefski, wrote a blog post in a lyrical verse. Expressing the hardships that go along with both a rare disease diagnosis, and living with it in the world.

Then, our Program Outreach Coordinator Melinda Atnip and Fundraising/Patient Advocacy Coordinator Allie McFadden wrote about their experience at the RareGivers leadership retreat they attended in January.

[Read the Blog Here](#)



We are proud to share that **Histiocytosis Association** has **once again earned a Four-Star Rating from Charity Navigator**, the nation's largest and most trusted charity evaluator. This highest-possible rating reflects Charity Navigator's independent, third-party assessment of our effectiveness, accountability, and financial health - and our commitment to these standards year after year.

[Hystio on Charity Navigator](#)

FOLLOW US



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