



eNewsletter

HISTIOCYTOSIS ASSOCIATION

-- March 2024

If you like what you see here and want to ensure that you receive all monthly newsletters, please complete the simple sign-up at the bottom of this newsletter.



Volunteer Spotlight: Ana Valdez

Ana Valdez plays a vital role in our volunteer ambassador team, demonstrating unwavering dedication to raising awareness, providing education, and supporting the mental health of our patients and their families. As a patient herself, Ana understands firsthand the challenges faced by individuals living with rare conditions, and she is committed to offering ongoing assistance to our community.

You may recognize Ana from various platforms where she has shared her expertise and experiences. She has been a featured guest on our podcast, showcased on social media, and highlighted in our executive blog. Additionally, Ana has organized the "Together for the Cure" family community run/walk in Chula Vista, California for the past two years, bringing our community together in support of a common cause.

One of Ana's primary concerns is the mental health of histio patients and their families. For the past year, Ana has served as a peer-to-peer support leader, facilitating group sessions every Thursday. Recognizing the need for culturally sensitive support, Ana initiated Spanish-language support groups at our organization. She also leads a specialized support group for histio ambassadors, fostering a sense of community among those who are dedicated to raising awareness and providing support.

We extend our heartfelt gratitude to Ana Valdez for her tireless dedication to our community and her steadfast support.

Thank you, Ana, for all that you do.

We are thrilled to announce our partnership with OR Asociacion of Spain starting next month, as we come together to complement Ana's efforts to the Spanish-speaking histio patients and families; marking an important step forward in our shared mission of fostering inclusive and accessible support networks.

AVP-D Webinar

HISTIO PATIENTS: WHAT DIABETES INSIPIDUS IS (AVP-D / CDI) AND HOW TO MANAGE IT.

APRIL 4TH 12PM ET

ZOOM WEBINAR - REGISTRATION REQUIRED

On April 4th at 12pm ET we will be holding a webinar with Dr. Chian Atila, in partnership with Got AVP-D and OR Asociacion titled: "Histio patients: What diabetes insipidus is (AVP-D / CDI) and how to manage it."

This webinar will seek to answer questions like:

- How does the body normally regulate fluids?
- What happens with AVP-Deficiency?
- What is desmopressin and how does it work?

And any other questions viewers may have.

This webinar will be available in English and Spanish! Este seminario web estará disponible en inglés y español.

It is free to attend, but registration is required.

Register Today / Regístrese hoy

Speaking of AVP-D, Dr. Lewis Blevens Jr., an endocrinologist who specializes in pituitary management, and co-founder of Pituitary World News, would like to know your opinion on your AVP-D/ DI experience. If you have AVP-D/DI, he knows YOU are the expert, and wants your opinion on treatment.

Click below to take the survey.

AVP-D/DI Survey

**Interested in becoming
a Histio 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 [Histio Youth Ambassador Program](#), youth ambassadors partner with a parent/guardian to team up against histiocytosis. Applications are now being accepted 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: Neurodegeneration in LCH



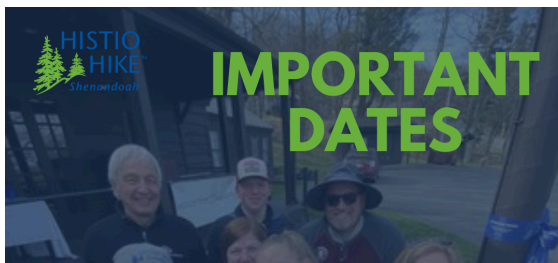
Recently, Deanna Fournier, our Executive Director had the opportunity to sit down with Dr. Kenneth McClain, Dr. Carl Allen and Dr. Jennifer Picarsic, to speak about their paper on Neurodegeneration in LCH patients.

Their paper is building on the Central Nervous System “risks,” discovered 25 years ago, that can stem from LCH.

Click below to see the video and [click here](#) to read the full article.

Check Out the Video

Last Chance for Early-Bird Hike Registration



Don't miss your chance to join us....

You still have time to grab your family and friends...pack up the car and meet us at the Histio Hike in Shenandoah!

Experience an unforgettable weekend for



ROOM BLOCK DEADLINE* - 3/26

EARLYBIRD REGISTRATION ENDS - 3/31

HIKE WEEKEND - 4/26 - 4/28

Luminary link:
<https://histio.donordrive.com/index.cfm?fuseaction=donorDrive.participant&participantID=5885>

yourself at the **15th Annual Histo Hike Shenandoah - April 26-28, 2024**

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!

This is the last week to register before registration goes up by \$15 starting on April 1st!

[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!

You can participate in the hike from wherever you are in other ways.

- Choose the virtual hiker option and join us from your favorite hiking trail.
- Donate to a hiker
- [Purchase a luminary](#) to honor a special person in your life

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

Register Today

Beyond The Diagnosis Episode 063 - Heartbeats of Hope: The Histo Caregiver



Episode 062
From Adversity to Opportunity
Now Available!



Episode 063 of the Beyond the Diagnosis Podcast is now available. In this episode we hear about the caregiver experience from Histo Ambassador and mom to a histio warrior, Barb Adams. She shares an honest and encouraging perspective which will leave you with hope and encouragement for your own histio journey.

Listen Now

Spanish Brochures on Website

¿Puede ser verdad? (Can it be true?)

¡Sí! (Yes!)

¡Los folletos en español ya están disponibles en el sitio web! (Spanish language brochures are now available on the website!)

Compártelos con tus amigos hispanohablantes, úsalos en eventos de concientización o simplemente usa el pdf/imprime para informarte a ti mismo o a tu médico. (Share them with your Spanish speaking friends, use them at events for awareness, or just use the pdf/print out to educate yourself or your doctor.)

Nuevos folletos en español

Our Experience from the 3rd Annual CHOC/UCI Health Rare Disease Symposium Family Conference

Melinda Atnip, our dedicated Outreach Program Coordinator and Southern California resident, recently attended CHOC and UCI's 3rd Annual Rare Disease Symposium and Family Conference. The LIVE event on March 7th, complemented by virtual sessions on the 6th and 8th, served as a dynamic platform for diverse medical, research, and academic professionals to convene.

[Click here to read more on our website.](#)



The Histiocytosis Association is excited to share that we are returning to an in-person, regional meeting format for 2024 because we recognize that connection is a key component in the fight against histiocytosis.

Regional meetings provide a supportive environment where families and patients can learn from others' experiences, share their unique stories, celebrate triumphs, connect with available resources, learn about the latest research, and feel comforted by knowing that they are part of a larger, supportive histiocytosis community.

At a **Histio Patient and Family Regional Education Meeting** you'll learn directly from leaders in histiocytosis care and research on each of the histiocytic disorders (Langerhans cell histiocytosis, hemophagocytic syndromes, Erdheim-Chester Disease, Rosai Dorfman Disease, and xanthogranuloma) and have the opportunity to connect with other patients and families in the region.

Please mark your calendar for these 2024 Dates and Locations:

Please mark your calendar for these 2024 Dates and Locations.

Saturday, June 1 | Orange County, California
Saturday, August 24 | Pitman, New Jersey
Saturday, September 7 | Birmingham, Alabama

More information and registration coming soon! For questions regarding upcoming regional meetings, please email us at outreach@histio.org.

Click here to receive monthly newsletters.

Connect With Us

332 North Broadway, Pitman, New Jersey 08071 USA | Tel: +1 856-589-6606
Histiocytosis Association © 2026 All rights reserved.

[Donate](#) | [Visit our website](#) | [View message in browser](#)

[Unsubscribe](#)