



# eNewsletter

## HISTIOCYTOSIS ASSOCIATION

-- June 2024

With June being at the very center of the year, most of the world is experiencing extremes of weather - the heat of summer forcing many indoors while the cold of winter has others bundling up. We understand that weather can be an additional challenge for individuals with histiocytosis, making navigating these times even more difficult. Wherever you are, we hope you're finding ways to stay comfortable and safe.

## Summer FUN: Ways to give back to the Histo Community

Here in New Jersey, USA, where the Histiocytosis Association is located, summertime is in full swing, and temperatures are rising!

This time of year often means time spent with family and friends, cookouts, celebrations, vacations, and because school's out, sometimes BOREDOM!



Have you already heard the summer break equivalent of 'Are we there yet?', aka 'I'm Bored' one too many times....and its only June?!! Are you all feeling "BLUE"?

Why not get the kids involved and excited about making a difference for the histio community. Organizing a **Summer FUNdraiser** for Histo not only keeps kids engaged and entertained, it also helps them develop life skills and teaches them valuable lessons about empathy, volunteering, and entrepreneurship.

And it's EASY!

From lemonade stands and bake sales, car washes and dog washes, to donating a day of lawn mowing or hosting a neighborhood balloon 'fight' – the sky's the limit!

And the importance of your support of the Histiocytosis Association cannot be underestimated. With your help, we can continue our efforts in the fight against histiocytic disorders.

[Click here](#) to learn helpful tips and find out how you can get started on hosting your

[Click here](#) to learn helpful tips and find out how you can get started on hosting your own **Summer FUNdraiser** and help move us closer to a world free of histio.

## Summer FUNdraising Ideas

# Have you been diagnosed with Arginine VasoPressin-Deficiency/Central Diabetes Insipidus (AVP-D/CDI)?

If so, we want to hear from you.

We are seeking to gather comprehensive data concerning the experiences of individuals diagnosed with AVP-D/CDI ranging from diagnosis to the strategies used for managing the condition.

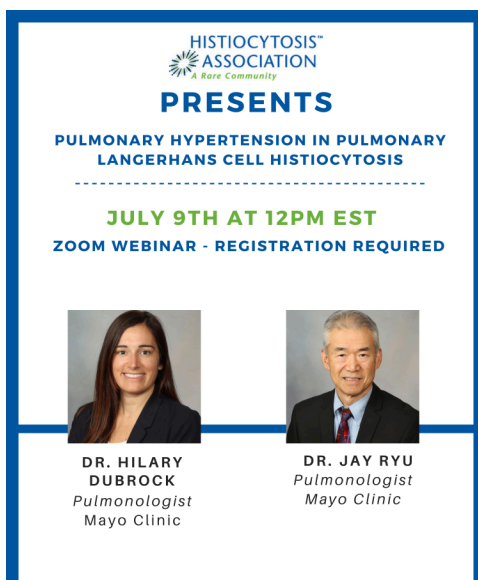
This survey was created by Neuro-endocrinologist Dr. Cihan Atila and Patricia Gildroy, Ph.D., Lead Administrator of Got Arginine VasoPressin--Deficiency Facebook Group, Muriël Marks, Executive Director of the World Alliance of Pituitary Organizations (WAPO) and our very own Deanna Fournier.

Future surveys will be released in the coming year looking for parental and caregiver perspectives on AVP-D/CDI.

Click below to take the survey, currently in English, Spanish and Portuguese. All responses are anonymous.

## Take the Survey

### Upcoming Webinar



HISTIOCYTOSIS™ ASSOCIATION  
A Rare Community


**PRESENTS**

PULMONARY HYPERTENSION IN PULMONARY LANGERHANS CELL HISTIOCYTOSIS


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**JULY 9TH AT 12PM EST**

ZOOM WEBINAR - REGISTRATION REQUIRED



**DR. HILARY DUBROCK**  
Pulmonologist  
Mayo Clinic



**DR. JAY RYU**  
Pulmonologist  
Mayo Clinic

### Beyond the Diagnosis Podcast



**Episode 066**  
**Working Through Grief - Together**  
**w/ Dr. Renee Christensen and David Long**  
**Now Available!**

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On July 9th, we will be hosting a webinar on the connections between Pulmonary Langerhans cell histiocytosis and Pulmonary Hypertension. During this webinar, you'll learn about the ways they overlap, shared causes, and more.

Click below to register for Pulmonary Hypertension in Pulmonary Langerhans cell histiocytosis.

[Register for Webinar](#)

In Episode 66 we're diving into the complex emotions surrounding grief in patients and families dealing with histiocytosis. We'll talk about the different types of grief, the stages of healing, and the importance of dedicated grief support groups. Join us for an enlightening and inspiring conversation about finding strength and community amidst the challenges of histiocytosis.

[Listen Here](#)

## Regional Meeting

### **RECAP: Histo Patient and Family Regional Education Meeting – Orange County, CA**

Our first patient and family gathering of the year was a huge success! Thanks to the several people involved and most especially to our host, Dr. Lilibeth Torno and her team at Children's Hospital of Orange County.

The event featured a CME on the management of HLH/MAS presented by Dr. Grant Schulert, MD of Cincinnati Children's Hospital. A panel discussion followed, with traveling speakers Dr. Beth A. Martin from Stanford and Melissa Hines from St. Jude Children's Research Hospital. Numerous talks were offered, covering a wide range of topics including HLH and critical care, the Ruxo Study, histiocytic disorders in children and adults, HLH and transplant, and survivorship.

Patients from all over Southern California had the opportunity to meet and engage with each other, fostering a sense of community and support. Two support sessions were offered, one for caregivers and one for adult patients, providing a platform for sharing and connection. Ana Valdez shared her inspirational story, moving everyone with her journey.

We had approximately 75 individuals in attendance, including patients, family members, friends, healthcare providers, and volunteers.

Thank you to all who came to support us



during this event. It was incredibly inspiring and heartwarming to see everyone come together locally. This event was yet another example of how, “you are not alone” in this rare disease journey.



*Couldn't attend this meeting?* We're hosting two more meetings this summer. Mark your calendars for:

**Pitman, NJ – August 24th**  
**Birmingham, AL – September 7th**

We hope to see you there!

***Special thanks to our 2024 Regional Education Meeting Presenting Sponsor, Sobi, Inc.***

## Volunteer Spotlight



Angi #341

And finally, our volunteer spotlight shines on Angi White, host of the annual Histo Run in Memory of Jeffrey White.

Meet Angi, a dedicated and inspiring individual within the Histo Community. Angi is the parent of Histo Angel, Jeffrey, who at the age of 8 months was misdiagnosed with Langerhans cell histiocytosis (LCH). Unfortunately, the true diagnosis of hemophagocytic lymphohistiocytosis (HLH) was only made after treatment for LCH exacerbated his symptoms. Tragically, in November 2001, Jeffrey passed away due to complications following a bone marrow transplant.

Despite her immense grief, Angi turned her pain into action. In 2012, she organized the first Histo Run in Memory of Jeffrey in Mannford, Oklahoma. This event not only commemorates Jeffrey's life but also serves as a beacon of hope and support for other local families impacted by HLH and LCH. Through the Histo Run, Angi created a platform for these families to connect, raise awareness, and generate funds to support the Histo Community.

Over the last 12 years, Angi and the Histo Run family have raised over \$40,000 in support of the Histiocytosis Association. We are deeply grateful for Angi's unwavering commitment and her incredible contributions. It is because of volunteers like Angi that we can continue to serve the Histo Community each year.

If you would like to learn more about Angi, Jeffrey and the Histo Run, please [visit here](#).

Know someone who is doing great things to spread histio awareness and support the Histo

Know someone who is doing great things to spread histio awareness and support the Histio Community? If so, [let us know](#) so we can feature them in an upcoming issue of the Histio eNewsletter.

## Connect With Us

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