



# 2024 IMPACT REPORT

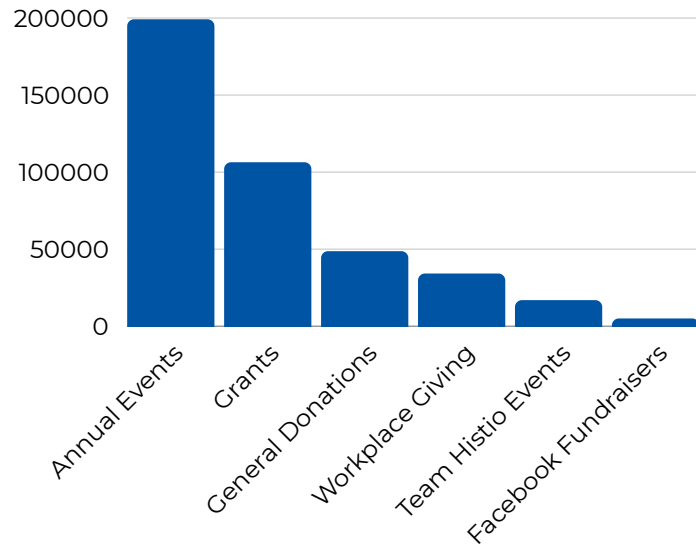
The Histiocytosis Association is powered by the stories of those impacted by histiocytic disorders, by the support and dedication of all who believe in our shared vision of a world free of histiocytosis, and by everyone who generously gives hope, heart, time, ideas, a helping hand, monetary gifts, and other gifts of service and love. **TOGETHER WE DRIVE PROGRESS AND ADVANCE RESEARCH** to one day cure all histiocytic disorders. **THANK YOU** for making this year's progress possible.

# The Power of Community

At the heart of our mission is the steadfast support of our community. Your generosity drives groundbreaking research, sustains vital programs, and ensures patients and families have access to expert education, peer support, and compassionate resources.

## Total Raised by the Community - \$410,318 (as of 11/20/2024)

- Annual Community-Led Events - \$199,182
- Grants - \$106,395
- General Donations - \$48,673
- Workplace Giving/United Way - 34,172
- Team Histio Community Led-Events - \$16,896
- Facebook Fundraisers - \$5,000



HISTIO TY-FIGHTER 5K



HEROES FOR HISTIO WALK

JEEP SHOWDOWN FOR HISTIO



BOOK FUNDRAISER



MIGHTY MILES' LEMONADE SALE



HISTIO HIKE - SHENANDOAH



ANNA MEMORIAL



HISTIO AWARENESS ADVENTURE



TOGETHER FOR THE CURE



HLH AWARENESS GOLF OUTING



PLAY FOR A CURE

# Education & Connection

## Patient & Family Regional Meetings:

These in person meetings are an opportunity for local community members to meet, connect, share, and learn from histiocytosis expert clinicians and researchers.

In 2024, we proudly hosted 3 Regional Meetings  
Orange County, CA; Pitman, NJ; Birmingham, AL

HISTIO  
PATIENT & FAMILY  
EDUCATION MEETING



### WEBINARS

Virtual education sessions on topics related to histiocytic disorders, emotional wellbeing, and support.

**4**  
webinars in 2024

### PEER SUPPORT

Held online, these hour-long sessions create a safe space for patients and family members to share and connect.

**120**  
sessions in 2024

### GRIEF SUPPORT

Moderated by a professional grief counselor; they offer a safe space to connect following the loss of a spouse or child.

**24**  
sessions in 2024

# Awareness Activities

## Histio Ambassador Program

Histio ambassadors are dedicated to spreading awareness and making a difference year-round through a variety of creative and impactful efforts. Whether hosting fundraising events, sharing powerful messages on social media, or speaking directly to their communities, they work tirelessly to inspire action and build support for our cause. Their passion and commitment shine through in everything they do.



In 2024, we welcomed... **7 Ambassadors** **2 Youth Ambassadors**

to our team of dedicated volunteer ambassadors. To date, we have **29 Ambassadors** and **4 youth ambassadors** actively supporting our mission and the Histio Community.

## Ambassador Initiative: Identifying Care Deserts

**INTERNATIONAL CARE GAPS FOR HISTIOCYTOSIS: A CASE FOR EDUCATION AND AWARENESS TO INCREASE ACCESS FOR PATIENTS**

Authors: Deanna Fourmier, Melinda Attrip, Kristen Neesenon, Tim Marder, Megan Butler, Robin Ross, Mark Ross, Teresta Macias

**Introduction/Purpose**

The Histiocytosis Association (HA) stands alone as a global nonprofit dedicated to the unique needs of patients and families affected by histiocytosis. HA currently provides and medical consultation worldwide with essential resources at every step of their journey, including the search for a cure. Each year, the HA supports hundreds of patients, families, and providers from around the world, who are impacted by all histiocytosis disorders.

In 2023, the Histiocytosis Association (HA) launched the Histio Ambassador Program to empower and expand our leaders in our community to advance the mission of the Histiocytosis Association. Through regular engagement with the histiocytosis community, the HA staff and Histio Ambassadors were aware of "Care Deserts" areas where few to no providers willing and able to diagnose and treat histiocytosis and related conditions. These gaps caused patients and families to consider traveling or relocating for care, decreasing QoL.

In 2024, the HA and Histio Ambassadors set a goal to analyze and build a plan to fill these Care Deserts.

**Methodology**

HA staff and Ambassador team conducted a full audit of the Physician Directory, an international database of providers who self-register to provide their expertise to patients, host 453 providers.

1. Audit the International Physician Directory of 453 providers worldwide (as of January 2024).
2. Identify US states without 5 histiocytosis providers.
3. Identify US states with 0-2 providers.
4. Identify US states with provider numbers over 2.
5. Repeat for each country within the database.

Following the audit, begin to act:

1. Identify local providers and specialists willing to join the directory.
2. Provide resources to these providers and specialists.
3. Build sustainable materials, promote good word opportunities, and develop CHCs for healthcare providers to grow knowledge of histiocytosis, diagnostic criteria, and treatment options for best outcomes.

**Results/Findings**

**International Physician Directory Overview**

Number of providers in the International Physician Directory: 453\*  
Total countries within the United States: 228\*  
Total countries: 194\*

**RESULTS**

HISTIO FEELS PHYSICAINS IN THE USA

HISTIO FEELS PHYSICAINS IN THE USA

**STATES WHERE THERE ARE NO HISTIO PROVIDERS**

United States Provider Statistics

- 193 states had 0 providers listed, primarily in the western and eastern areas of the country.
- 91 states had 1-2 providers listed for adult patients.
- Only 8 US states had 3+ providers listed.
- Only 16 US states had 5+ providers listed.

34.2% of the providers listed in the physician directory are located within the United States.

Collaboration with primary histiocytosis society, **HA/CHC** Patient Ambassador Group, HA staff can help patients locate providers in their area, however major gaps still exist.

All of the providers in the directory are in the specialties of histiocytosis and oncology. Specialists specializing but not limited to hematopathology, dermatology, family practice, and pediatrics, would greatly increase the impact of the physician directory.

**Resources/Information**

View or Join the HA Physician Directory

Access the HA Physician Resource Center

Ambassador Website Landing Page

**Conclusion**

There is a urgent need to expand the number of providers willing and able to treat histiocytosis for both pediatric and adult patients. The need for providers for adult patients is more urgent than for pediatric patients.

Increased education of the community provider level and within medical schools has the potential to act as a filling care deserts, with the biggest representation at adult-patient-provider level. Awareness and education activities coordinated by the Histiocytosis Society, Histiocytosis Association, and Histio Ambassador Program can encourage providers to learn about histiocytosis and open seeing patients, can increase listings within the directory.

An annual audit of the HA Physician Directory will ensure accuracy of current listings in the directory and allow for active pursuit of new providers to fill the existing gaps (oncology, specialty, adult/pediatric).

Increased access to a local, knowledgeable provider, ultimately will lower diagnosis and better QoL for patient/family worldwide.

With the invaluable efforts of our ambassadors, we successfully mapped areas lacking histio specialists, highlighting critical "care deserts." Their contributions played a key role in the development of a compelling abstract and poster presentation, showcased at the Histiocyte Society's annual meeting in November 2024.

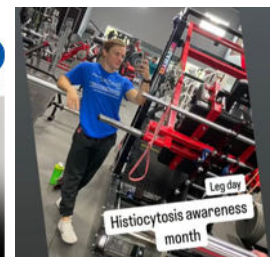
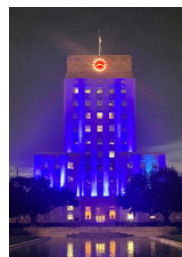


## Awareness Month



### Histio Awareness Month: Aware in the World

September was a month of action and connection as patients and families shared their powerful stories, giving a voice to our rare disease. Kid Correspondent Nate took us on a global journey with stops in London, Paris, and Washington, DC. Communities came together to host awareness tables, share materials, light up landmarks in blue from Pitman to Houston, and amplify our message on social media. Many also participated in fundraising events, fueling hope and progress for the histio community.



# Scholarship Program

## 6th Annual Histo Student Scholarship

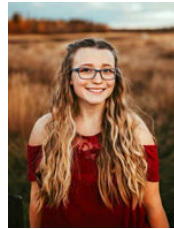
In 2024, we had **28 applicants** and **4 winners** and awarded a **total of \$9400 in scholarship funds**.



## HISTIO STUDENT SCHOLARSHIP PROGRAM



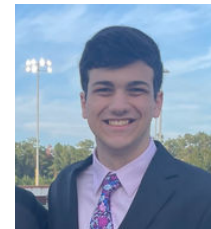
Dominick Strebel



Ava Wilkins



Brinda Shukla



Grant Abel

## Research

Since 1992, the Histiocytosis Association has funded 202 research grants to investigators from around the world, totaling over \$7.5 million.

### Research Grant Program

The number of grants awarded during our annual funding cycle varies each year. It is determined by a variety of factors including, *but not limited to*, the quality of eligible applications received and the availability of funds.



Long time friend, supporter and Histiocytosis Association board member

This travel scholarship fosters collaboration and learning among early-career investigators, ensuring the future of histiocytosis research - an enduring tribute to Joseph Ingrassia's commitment to progress.

**25** grant applications received in 2024

This year we awarded **4** scholarships for a **total of \$2500**.

## Reach on Social Media

By sharing stories and information on social media, and engaging partners around the world, we continue to grow our reach. **This expanded reach helps raise awareness within and beyond the histiocytosis community!**

