



2024 IMPACT REPORT

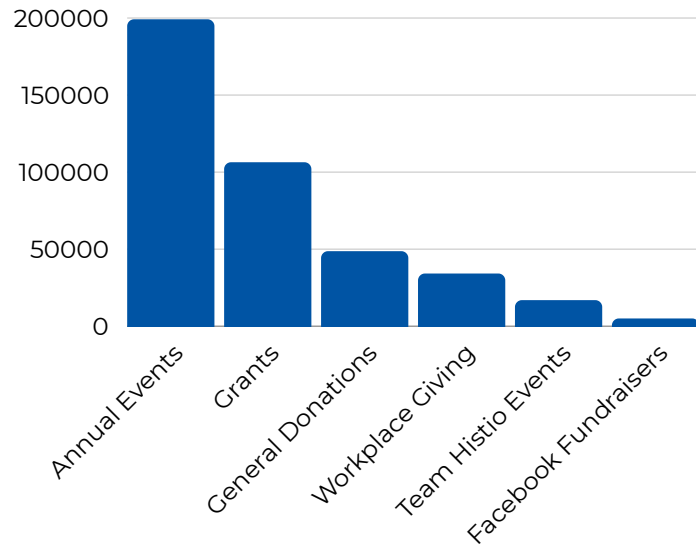
The Histiocytosis Association is powered by the stories of those impacted by histiocytic disorders, by the support and dedication of all who believe in our shared vision of a world free of histiocytosis, and by everyone who generously gives hope, heart, time, ideas, a helping hand, monetary gifts, and 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

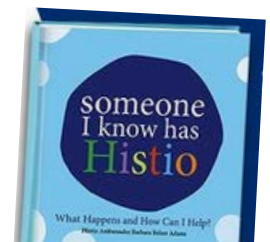


HISTIO TY-FIGHTER 5K



HEROES FOR HISTIO WALK

JEEP SHOWDOWN FOR HISTIO



BOOK FUNDRAISER



MIGHTY MILES' LEMONADE SALE



HISTIO HIKE - SHENANDOAH



ANNA MEMORIAL



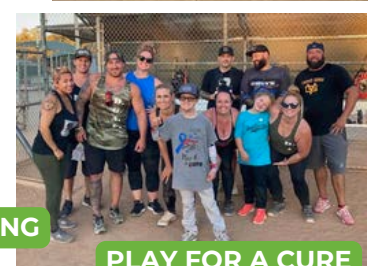
HISTIO AWARENESS ADVENTURE



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

BEYOND THE DIAGNOSIS PODCAST

An educational resource, delivering timely, relevant health and lifestyle information while exploring topics that go "beyond the diagnosis."

3600
all time listens in
44 countries

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 Atmip, Kirsten Neesenstra, Tim Marder, Megan Butler, Robin Ross, Mark Ross, Teresta Macias

Introduction/Purpose

The HistioCytosis Association (HCA) stands alone as a global nonprofit dedicated to the unique needs of patients and families affected by histiocytosis. HCA actively seeks and mobilizes resources to support the needs of patients, families, and providers from around the world, who are impacted by all histiocytosis disorders.

In 2023, the HistioCytosis Association (HCA) 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 HCA staff and Histio Ambassadors were aware of "Care Deserts" areas where few to no providers willing and able to diagnose and treat histiocytosis are located. These gaps caused patients and families to consider traveling or relocating for care, decreasing QoL.

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

Methodology

HCA 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, local, US providers.

1. Audit the International Physician Directory of 415 countries worldwide (as of January 2024).
2. Identify US states without 2 histiocytosis providers.
3. Identify US states with 0-2 pediatric providers.
4. Identify US states with 0-2 adult providers.
5. Identify US states with provider numbers over 2.
6. 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. Identify resources to those providers and specialists.
3. Build relationships with those providers and specialists.
4. Build relationships with local, provincial, and national organizations, and develop CHCs for histiocytosis providers to grow knowledge of histiocytosis, diagnostic criteria, and treatment options for best outcomes.

Results/Findings

International Physician Directory Overall

Number of providers in the International Physician Directory: 4157
Total number within the United States: 2287
Total number outside the US: 1870

RESULTS BY REGION

HISTIO PEDIATRICIAN
US: 10
CANADA: 0
OTHER: 0

HISTIO ADULT PHYSICIAN
US: 10
CANADA: 0
OTHER: 0

STATES WHERE THERE ARE NO HISTIO PROVIDERS

United States Provider Statistics

- 10 US states had 0 providers listed, primarily in the western and eastern areas of the country.
- 10 US states had 1 provider listed for adult patients.
- 10 US states had 1 provider listed for pediatric patients.
- Only 10 US states had 2 providers listed.

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

Collaboration with primary histiocytosis society, NACDS (Recent Patient Advisory Group), and 100+ histio patients locate providers in their area, however major gaps still exist.

Resources/Information

View or Join the HCA Physician Directory

Access the HCA Physician Resource Center

Ambassador Website Landing Page

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

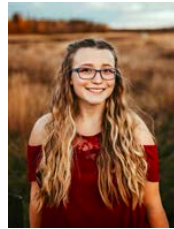
In 2024, we had **28 applicants** and **4 winners** and awarded a **total of \$9400 in scholarship funds**.



HISTIO STUDENT SCHOLARSHIP PROGRAM



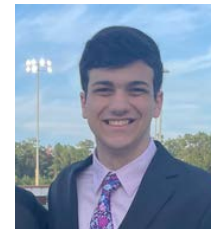
Dominick Strebel



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!**

