



# 2023 Impact Report

# A Word from our Executive Director

*2023 was quite a year, filled with collaboration and the growth of several of our programs. Realizing that we are nearing the end of the year, I found myself reflecting on not only the accomplishments of this year, but of the last 37 years since the Association was founded.*

*I remember all too well my own journey with Langerhans cell histiocytosis in 1992; the limited information that existed and the limited treatment options. I remember so clearly how much had changed by 2017 when I joined the Board of Trustees; it was evident the impact the discovery of genetic mutations had made on the knowledge, understanding, and treatment options for histiocytosis. Five years later, I am amazed at how the conversation continues to evolve, whereas we are exploring harmonization, and collaboration, pursuing natural history studies, seeing positive outcomes, and having FDA approved therapies for histiocytosis.*

*I cannot wait to see where the next few years will lead us – where you will lead us. You see, all this progress could not have happened without YOUR SUPPORT, your generosity, and your kindness. Your support funds research grants that have brought about drastic changes and saved lives. You have brought us from histiocytic disorders being considered histiocytosis-x, an unclassified group of diseases, to three of the histiocytic disorders receiving classification as rare cancers. There are new treatments, an international effort to improve outcomes, and new graduates of medical schools who are entering the field with knowledge and awareness of histiocytosis. We have come as far as we have, because of YOU.*

*In addition to this progress, we have shared a lot over the last year. We have shared the feeling of togetherness when we met in virtual support groups and regional meetings. We've found bonds with others who share a similar journey and have felt the comfort in being able to share our story with those who understand without much explanation. We have shared tears, laughter, and hope together, and seen firsthand the leaps forward that have been made for treatment options. Your journeys and experiences are etched in my heart and the hearts of the team, forever. We celebrate with you when you are told there is no more histiocytosis found in your body and feel the pain with you when we have to say goodbye and Warriors become angels. We continue this fight so that no one will have to face histiocytosis and everyone has access to a cure.*



# A Word from our Executive Director

*The key to our success is that our community efforts invigorate and inform our research efforts, with YOU as our north star, providing energy, excitement, and funding for research. You have helped realize FDA approved therapies for histiocytic disorders, increased survival rates to nearly 80% for most of the histiocytic disorders, have helped us realize faster and more accurate diagnosis through awareness, and international collaboration that has shown our strength as a rare disease community.*

*We have come so far because of YOU, but we need your help to go further. Over the last several years, we have listened to the community's needs and expanded several programs. These programs have brought new avenues for support and connection. We have worked to provide additional educational opportunities, including webinars and conferences. We have expanded our presence online and through social media to raise awareness with you. We have done much of this work through grants and allocation of time. But we need to grow to fund more research so that we can reach the next stages of treatments – to understand the role of targeted therapy versus conventional therapies, to improve outcomes for those impacted by HLH and malignant histiocytosis, to help bring all the new treatment options to cure.*

*Our ask for this holiday season is that you help us grow our seeds of hope by reaching out to 20 of your friends and family members, asking them to make a commitment to the future of histiocytosis research.*



A handwritten signature in blue ink that reads "Deanna". The signature is fluid and cursive, matching the name of the Executive Director.

Deanna Fournier  
Executive Director

# Big Picture

**57,799**

**Impressions on  
social media**

**\$8,200**

**In 2023 student  
scholarships funded**

**179**

**New Contacts**

**Over 100**

**Attended Support Groups**

**\$200,000**

**in Research Seed Grants Funded**



# Our Resources

## Support Groups

In 2023, we expanded our support groups to include new sessions for the newly diagnosed and family support meetings. We also added a monthly grief group and a monthly Spanish language peer to peer group.



## Physician Finder

At the beginning of this year, we changed the name and URL of our Physician Directory to make it more accessible and easier to type in ([/Find-a-Doctor](#)).

Since then, we have added 12 doctors to our directory all across the world, to make finding a doctor specializing in histio that much easier.





# Our Resources

## Educational Videos

This year we started a series of interviews with physicians in the histio field to discuss recent papers they have authored. Currently, there are 3 videos in the series that have been well received. In addition to learning about the physician's published work, these videos offer a glimpse into why and how they got involved in the world of histiocytosis.



## Resource Directory

### Guidebook Supporting Diverse Caregivers

Guidebook Supporting Diverse Caregivers The National Alliance for Caregiving conducted structured interviews with professionals from patient advocacy groups and diverse family caregivers caring for someone who had been diagnosed with heart disease, blood cancer, lung cancer or lupus, conditions that are known to disproportionately affect diverse communities. With the guidance...

Emotional Support, Home & Family Support

### Post-Traumatic Stress Disorder in Rare Caregivers

POST TRAUMATIC STRESS DISORDER FLYER RARE CAREGIVER -PDF Download

Emotional Support

### Children and Young People with Cancer: A Parent's Guide

This booklet, developed by Children's Cancer & Leukemia Group, is for parents and carers of a child who has been diagnosed with cancer. We hope it answers your questions and helps you deal with some of the feelings you may have. This booklet gives information about children's cancers, the treatments...

Emotional Support

### Helping Parents Heal

Helping Parents Heal (HPH) is a non-profit organization dedicated to assisting bereaved parents. Through support and resources offered, we aspire to help individuals become "Shining Light Parents"—meaning a shift from a state of emotional heaviness to one of hopefulness and greater peace of mind. HPH goes a step beyond other...

Emotional Support

### Stress Relief Products for Caregivers from MyCaringPlan

My Caring Plan is a website focused on caregiving that has been featured on PBS. It takes a very special person to dedicate themselves to the care of another. And yet, caregiving is often one of the most stressful jobs, in large part due to the vital importance of the...

Emotional Support

### Caregiver Resources from MyCaringPlan

My Caring Plan is a website focused on caregiving that has been featured on PBS. As a family caregiver, you may feel it is nearly impossible to take a break. This role often involves an around-the-clock commitment to your loved one, so you may feel you need to be available...

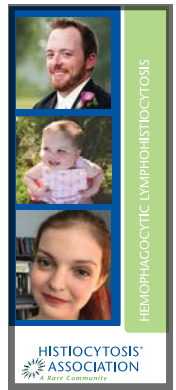
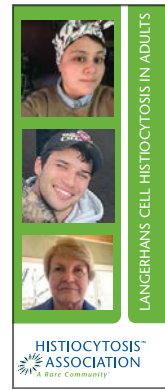
Emotional Support

# 2023 Timeline



**HISTIO STUDENT  
SCHOLARSHIP PROGRAM**

**Had record 42 applicants  
Awarded \$7,200 in scholarships**



**New Brochures Finalized,  
Began Printing**

March

February

April

June

**We care  
about rare  
Raised \$1,558**



**25th Annual Play  
for a Cure**

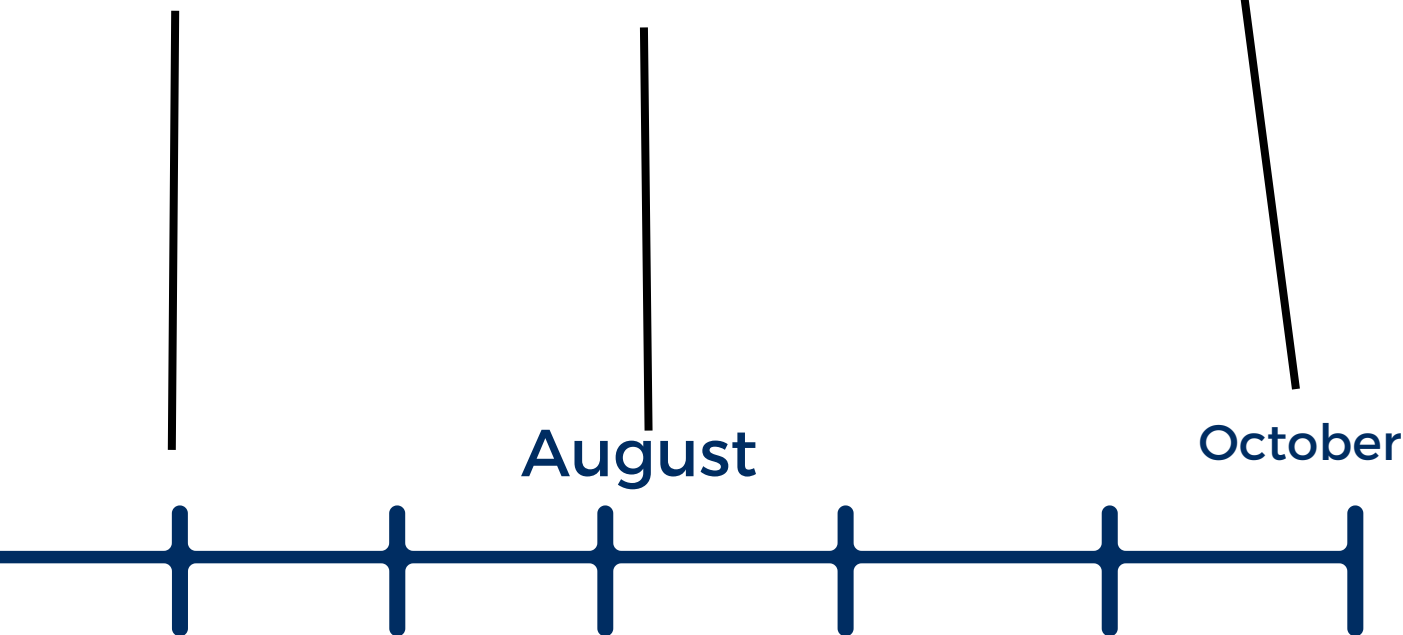


**Raised \$17,843**



Second Annual  
**HLH AWARENESS**  
CHARITY GOLF OUTING  
Raised \$35,176

**Ambassador Poster  
Accepted for 4  
conferences**



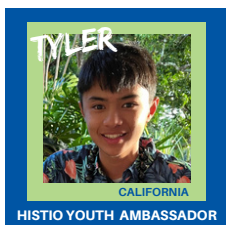
August

October

July

September

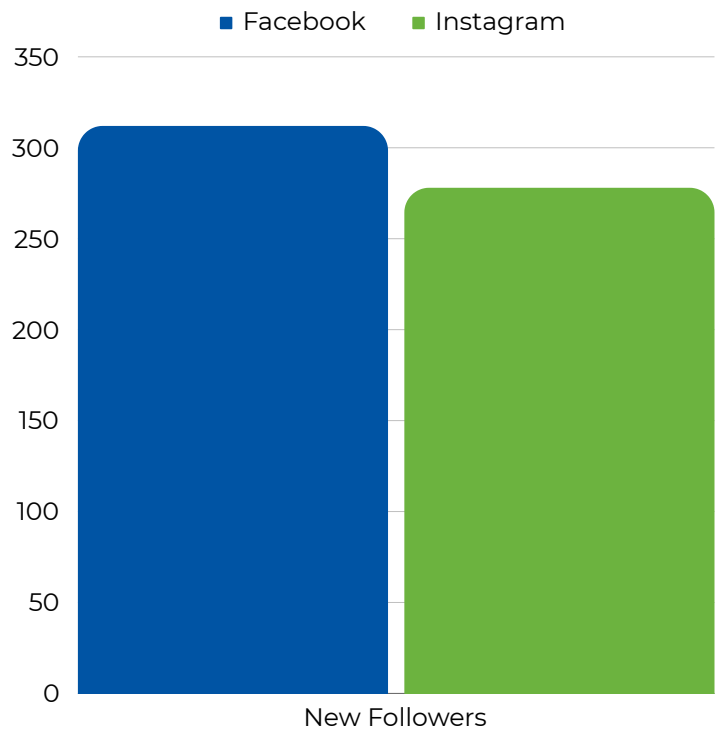
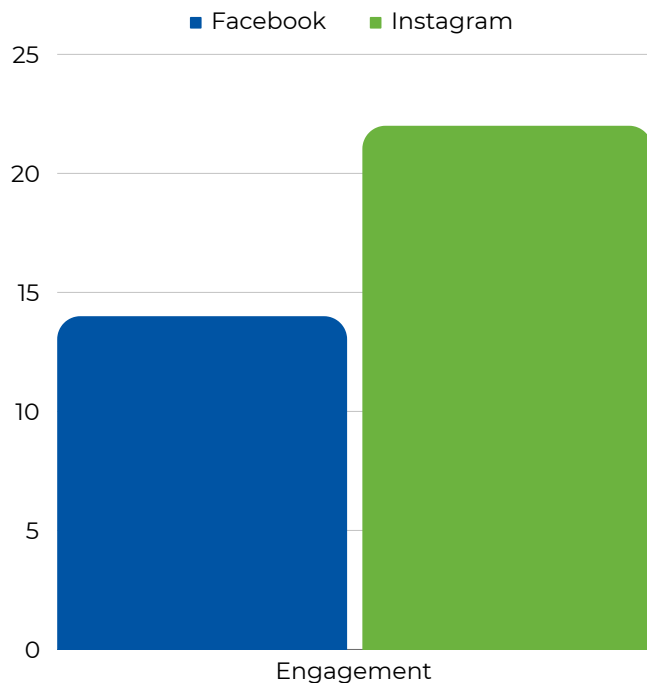
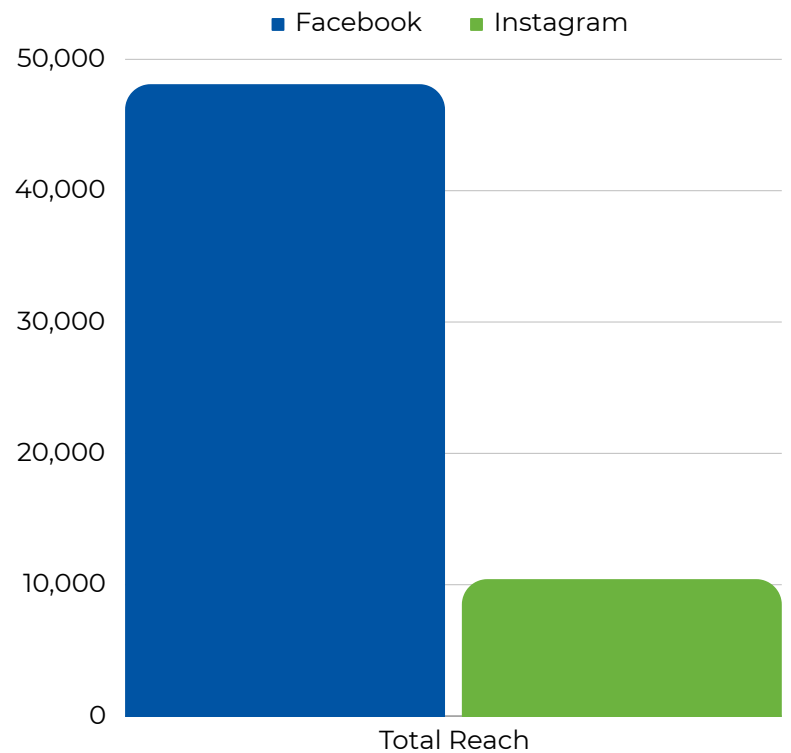
**First Histo  
Youth Ambassador**





# Reach (Social Media)\*

Reach, for social media is defined as eyes (*and sometimes ears*) reached with content. Throughout this year we had a total social media reach of around 59,000 - between our two most popular platforms, Facebook and Instagram. That is 59,000 people gaining first time or further awareness of histio. More details on the reach we had this year, and engagement we gained from it, can be found in the graphs on this page.



**\*From January to October 2023**

# Reach (Television)



**On October 1st, we had a 30-second ad air on TVs in 80+ airports to around 60,000 potential viewers.**

**[Click here to see the ad and its placement in the Chiefs @ Jets game!](#)**

# Top Rated

The Histiocytosis Association's strong financial health and commitment to accountability and transparency have earned us high marks from top charity evaluators, including a 4-star rating from Charity Navigator and a Platinum rating from Candid.

## Charity Navigator



## Candid

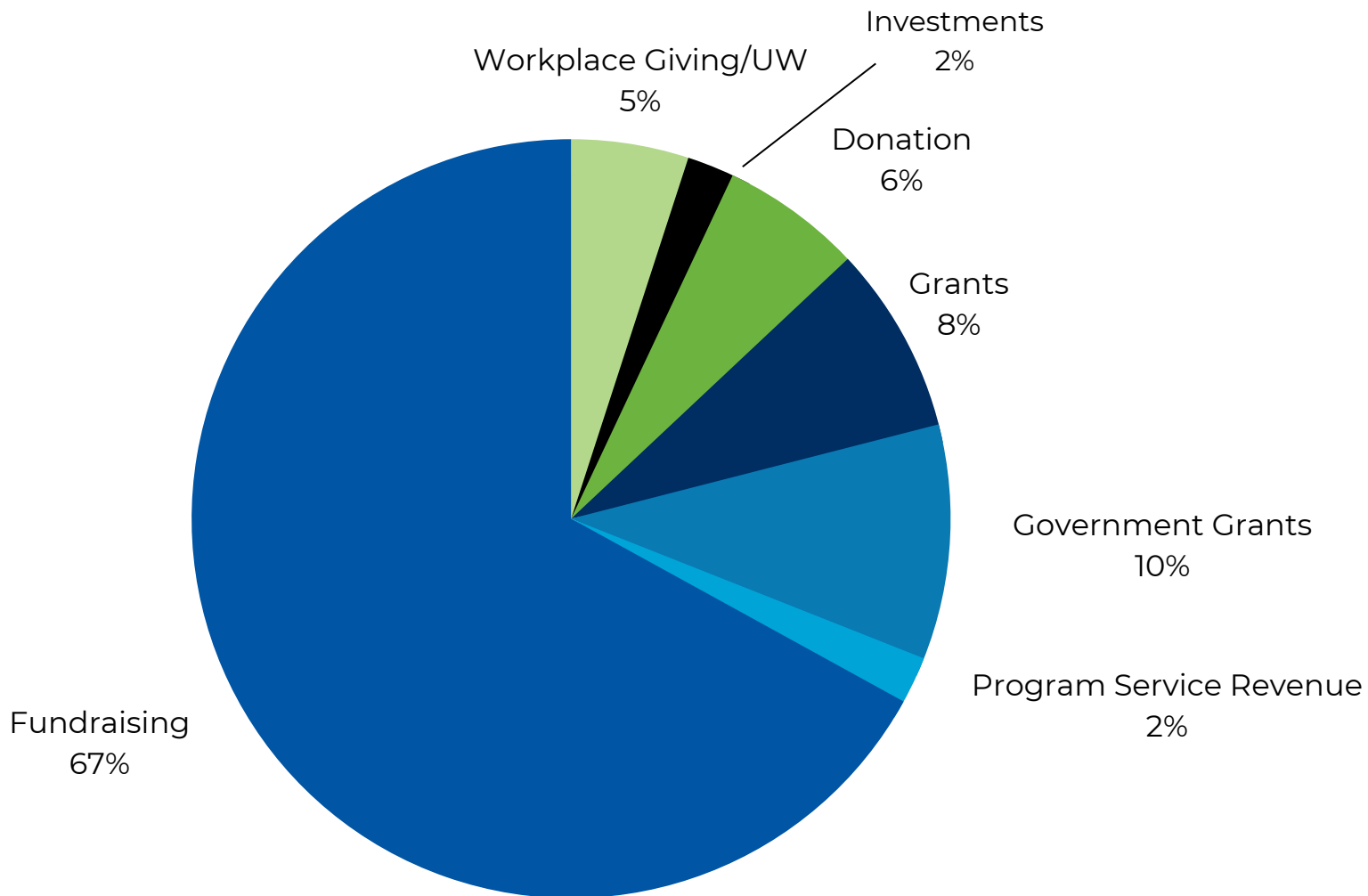


Platinum  
Transparency  
**2023**

**Candid.**



# Revenue



**More than half** of our revenue comes from **fundraising** and the **events** put on by you and your families.

**The impact shown in the pages above is thanks to YOU**