

## INTRODUCTION

The Histiocytosis Association is a global nonprofit organization dedicated to addressing the unique needs of patients and families dealing with the effects of histiocytic disorders. The Histiocytosis Association connects patient and medical communities around the world with the resources needed along every step of the way, while leading the search for a cure.

**Problem Statement:** The Histiocytosis Association's ongoing survey of the community identified gaps both nationally and globally; these include psychosocial support, equity gaps amongst various cultures, services for patients and caregivers alike, healthcare navigation, expanded access for healthcare services, and newborn screening for rare disease. Bridging the gaps ensures the achievement of a goal to help the patients and families feel less alone and empower each individual to be a catalyst for worldwide change.

## PURPOSE AND GOALS

The Histo Ambassador program was formed to empower and expand our leaders in our community to advance the mission of the Histiocytosis Association.

The Histo Ambassador program aims to:

- Empower and engage individuals to localize education to the medical community; aiding early diagnosis and improving access to therapies for histiocytic disorders.
- Raise histiocytosis awareness both locally and beyond, through outreach projects and fundraising events.
- Create a focus group to identify specific needs of the histiocytosis community.
- Bring **patient voice** into advocacy and research, working alongside the medical community to drive program development and research priorities.
- Actively provide support to other patients and families to increase connections and offer HOPE.

## METHODOLOGY

The Histiocytosis Association identified community leaders to expand and sustain our reach locally, nationally, and globally. Histo Ambassadors are individuals who have first-hand experience navigating a histiocytic disorder diagnosis and passionately want to help.

### STEPS TO BECOME AN AMBASSADOR:

1. Complete an application.(Short and Simple)
2. Complete the interview process.(We want to get to know you better)
3. Sign the Histo Ambassador Agreement.(Your Pledge to the Histo Community)
4. Complete the Histo Ambassador Training.(Educational and Interactive)

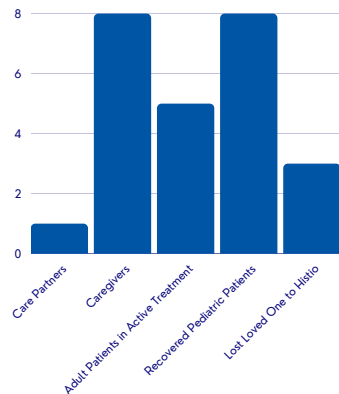
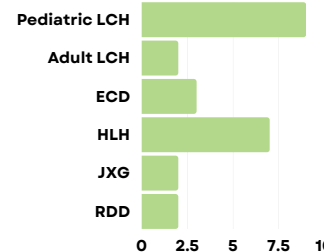
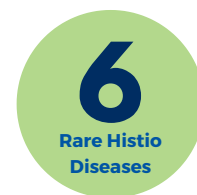
### REQUIREMENTS:

- The role of a Histo Ambassador is a one year commitment.
1. Attend two virtual Histo Ambassador Meet-Ups.(Meetings are once a month)
  2. Attend two educational webinars hosted by the Histiocytosis Association.
  3. Host, or co-host, at least one awareness event/support gathering.

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## RESULTS/FINDINGS

In less than one year, the Histiocytosis Association recruited 25 histio ambassadors representing all five histiocytic disorders (LCH, ECD, HLH, JXG, and RDD) and spanning across 17 states. Collectively the ambassadors represent every aspect of someone affected by a histiocytic disorder (caregivers, care partners, recovered pediatric patients, adult patients, and family members who have lost loved ones to histio). Through their service projects, they have improved and assisted the Association in bridging the gaps for patients and families. They remain steadfast and focused on the pillars of the mission-awareness, education, outreach, research, and advocacy.

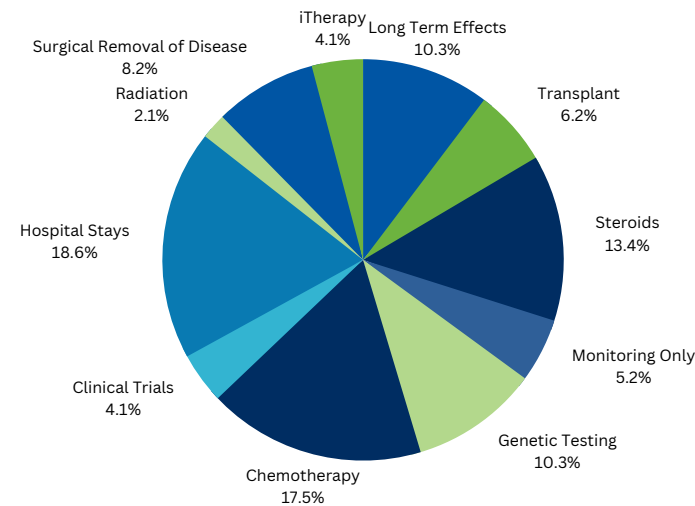


In one (1) year, the Ambassadors' actions and engagement provided evidence of the program's ability to help bridge gaps.



## ANALYSIS

A Histo Ambassadors experience with medications and treatment plans for histiocytic disorders can help us identify and work to solve access and awareness challenges.



Methotrexate, Vinblastine, Cyclophosphamide, Thalidomide, Cobimetinib, Cladribine, Clofarabine, Cytarabine, Hydroxyurea, Trametinib, Vemurafenib, Dabrafenib, Encorafenib, Gamifant, Imatinib, Sorafenib, DDAVP, Rituximab

## CONCLUSION

Creating a Patient Advocacy Leadership Program has proven successful at expanding the Histiocytosis Association's capacity to support its mission and consequently, the histio community. As the program continues to grow and evolve, goals and priorities are driven by increased knowledge of the persistence, scope, and breadth of gaps and challenges that exist for our rare disease community.

As Histo Ambassadors strive to pursue their individual passion projects and collectively work together to bridge gaps for the histio community, they recognize the benefit of collaboration across all key stakeholders (patients, family members, doctors, industry, NIH/FDA, etc.), and are **empowered to make a difference in their communities and to help find a cure for all histiocytic disorders.**

## WEBSITE REFERENCES



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