A Rare Community

The Histiocytosis Association is a global nonprofit organization dedicated to educating and connecting those who are fighting histiocytic disorders, and ultimately, finding a cure. It is the only organization of its kind, bringing together the patient and medical communities to:

» Grow and share knowledge of histiocytic disorders,
» Provide critical emotional and educational support to patients and families, and
» Identify and fund key scientific research initiatives that will lead to a world free of histiocytic disorders.

Understanding Histiocytic Disorders

Histiocytic disorders are a group of related diseases that are caused by an overproduction of certain cells in the body. Histiocytic disorders include: Langerhans cell histiocytosis (LCH), Hemophagocytic lymphohistiocytosis (HLH), Rosai-Dorfman Disease (RDD), Juvenile xanthogranuloma (JXG), and Erdheim-Chester Disease (ECD).

Every case is different. Patients may experience damage to the skin, bones, lungs, liver, spleen, gums, ears, eyes, or central nervous system. Our website (www.histio.org) goes into detail about each disorder.

Langerhans cell histiocytosis (LCH) is the most common histiocytic disorder and physicians now consider this to be a very rare form of cancer.

A Personal Crusade

The Histiocytosis Association was founded in 1986 by Jeffrey and Sally Toughill, whose daughter Bethany was diagnosed with Langerhans cell histiocytosis at the age of four months. When the Toughills realized there was no existing support community for this rare disease, they created one of their own. What began as a kitchen table operation has become a global organization with thousands of Histio Community members. It is the central hub for information and resources, a bridge between the medical and patient communities, and a world leader in facilitating and financing scientific research into histiocytic disorders.
The Road to a Cure

At the very heart of the Association is a steadfast commitment to driving scientific research. The Histiocytosis Association Research Program was established in 1990 by the Association’s Board of Trustees with the objective of funding the most important and promising research initiatives – those that will lead to more effective treatments, and ultimately, a cure. Each year, the Association embarks on a competitive and rigorous peer-review process, modeled after that of the National Institutes of Health. This process allows the Association to identify the most important grant applications in both laboratory and clinical research. Since the first grants were awarded in 1992, over 198 grants totaling more than $7 million have been awarded to scientists worldwide, leading to extraordinary breakthroughs in the treatment of histiocytic disorders.

True Partners

The Association is particularly proud of its partnership with the Histiocyte Society – a professional medical association comprised of more than 220 physicians and scientists from around the world. Members of the Society are committed to advancing knowledge and improving outcomes for patients with histiocytic disorders through the planning, development, sponsorship, and oversight of clinical research. For more than 30 years, the Histiocytosis Association has served as a partner, administrator, and the primary source of funding for the Histiocyte Society. The Society’s Scientific Committee has been integrally involved in the Association’s Research Program, conducting an intensive review of applications received during the annual funding cycle and sharing its recommendations with the Association’s Board of Trustees.
A Place to Turn

While the search for more effective treatments, and ultimately a cure, continues, the Histiocytosis Association is dedicated to informing and empowering those who live with histiocytic diseases every day. Outreach initiatives for patients and families include:

» Educational materials and resources
» Patient and family networking and educational opportunities
» Histio Patient and Family Educational Webinar series
» Advocacy and awareness activities
» Online virtual histio communities and social media networks such as www.facebook.com/histio
» Online resources and opportunities to get involved on www.histio.org
» A toll-free phone line in the US (1.800.548.2758) and a direct line for all other countries: +1 856.589.6606
» Resources to help raise awareness in your local community during September for our Histiocytosis Awareness Month
» A directory of physicians experienced in treating histiocytic disorders
» A coalition of volunteers with various volunteer opportunities and a Volunteer Ambassador Program
» Histio Student Scholarship program
» eNewsletters to keep you informed
Cultivating Funds

Histiocytic disorders affect fewer than 200,000 individuals in the United States and are considered “orphan diseases.” Subsequently, these disorders do not receive a high priority for government-funded research. The Histiocytosis Association relies on contributions from corporations, foundations, and individual donors to fund critical research, build awareness, and conduct community outreach initiatives. The Association is especially fortunate to receive support from the remarkable volunteer advocates who host fundraising events in their own communities throughout the year. From bake sales to runs and hikes, these special events are a principal source of funding for the Association, and serve as powerful forums to increase public awareness about histiocytic disorders.

An Unwavering Commitment

Until the vision of a world free of histiocytic disorders is realized, the Histiocytosis Association will stand directly beside the patients, families, physicians, scientists, volunteers, and others in this rare community who fight the battle against histiocytic disorders every day. Travelling together on this journey, all roads lead to a cure.
Income and Expenses Overview
Based on the Fiscal Year ending December 31, 2021.

Sources of Income
- Donation, 43%
- Fundraising & Special Events, 30%
- Government Grants, 13%
- Grants/Major Donors, 6%
- In-Kind, 1%
- Investment, 2%
- Workplace Giving Campaigns, 5%

Total Revenue: $1,376,400

Distribution of Expenses
- Fundraising Expenses: 48.1%
- Outreach Initiatives: 38.4%
- Management/General Expenses: 5.7%
- Research/Scientific Initiative: 7.8%

Total Expenses: $1,026,638
While focusing on a cure we continue to work toward our mission of raising awareness about histiocytic disorders, providing educational and emotional support, and funding the very best research. In addition to our many ongoing efforts to support patients, families, caregivers, physicians and researchers, we are especially proud of the following accomplishments:

- Completed website upgrades providing interactive educational opportunities for physicians, patients, and families that provide website visitors with:
  - The most up to date disease information
  - A targeted physician finder by disease
  - A list of local volunteers or warrior families to connect with in any given geographic area
  - Local family groups around the world to connect with Patient Assistance Program information
  - Updated information on treatment and clinical trials globally

- Awarded over $9250 in scholarships to four (4) students in 2021. In its third year, the Histio Student scholarship program supports college or career training education in recognition of the extreme emotional and financial burden placed on patients and their families as a result of being impacted by this disease.

- Hosted four (4) Histio Patient and Family educational meetings; three (3) virtual meetings via Zoom - covering topics including Endocrine Issues, Eyes and Vision, NCCN Treatment Guidelines and one (1) in-person in Memphis, TN.

- Exceeding $7.2 million in total research funded through the Association grant program

- Awarding four (4) new research grants to institutions around the world

- Distributing educational information to more than 500 newly diagnosed patients and families in the past year

- Providing resources and information to more than 24,000 physicians, patients, families and friends since the organization began in 1986

- Maintain a robust Physician Finder Directory with more than 350 doctors worldwide who specialize in the treatment of histiocytic disorders
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