

# HISTIOCYTE SOCIETY WEBINAR SERIES

## INTERNATIONAL FAMILY GROUP DIRECTORY



### International Family Group Informational Directory

This guide contains information about various international family groups and is designed to educate about the important work that the family groups are doing and the families that they serve. This resource will be updated as appropriate.



### OVERVIEW:

- Asociacion Argentina de Histiocitosis - Argentina
- Artemis Association for Histiocytosis - Greece
- Divina Foundation - India
- Associazione Italiana Linfoistiocitosi Emofagocitica - A.I.L.E. - Italy
- AIRE Onlus - Italy
- OR Association - Spain
- ECD Global Alliance - USA
- Eric's Journey Foundation - USA
- Liam's Lighthouse Foundation - USA
- Histiocytosis Association - USA



# Asociacion Argentina de Histiocitosis Argentina



## Organization Information:

Contact: Fabio Topa

Website: <http://aah.org.ar/>

Email: [info@aah.org.ar](mailto:info@aah.org.ar)

## Overview of the group:

Our group has its origins 20 years ago and represents patients and relatives of patients from our country as well as from neighboring countries, we formed a group of more than 200 people and we are legally organized as a partnership with a board of directors which I (Fabio Topa) have a responsibility to represent.

## Current activities and focus of the group:

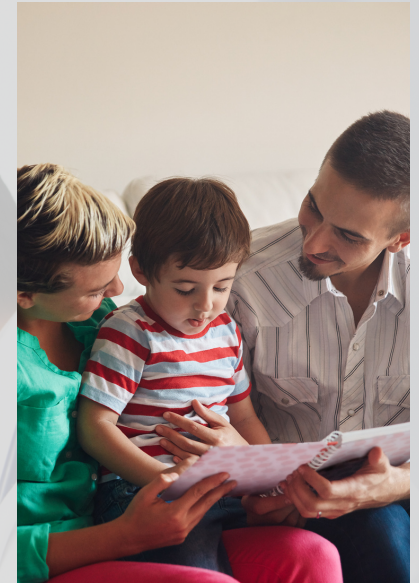
We are currently working with samples of people in communication via networks incorporating more patients and preparing meetings via Zoom on topics of particular interest with professionals who participate in the association and that we see that they are of interest to patients.

## What challenges are your group currently facing?

Our interest is to reach patients as quickly as possible from diagnosis because we know of the problem of being in the face of diagnosis.

## What type of support would help your group to grow?

Communicating with groups around the globe would allow us to gain more experiences and knowledge that can help our community.



## What is your group's vision for the future?

Our desire is to continue incorporating new patients to accompany them in the treatment process and also the life development of young people who are patients of histiocytosis and adults, both cases (young people and adults) who are a little side-by-side.

## Any other comments?

I like all initiatives aimed at supporting collaboration with patients.



# Artemis Association for Histiocytosis Greece



## Organization Information:

Contact: Dora Moustaka

Website: <https://www.histioartemis.org/en/>

Email: [info@histioartemis.gr](mailto:info@histioartemis.gr)

## Overview of the group:

The Artemis Association was established in Greece in 1994. It is a charitable organization, supporting families and fostering research on the causes of Histiocytoses. The Artemis Association is named after a little girl called Artemis who died at the age of eighteen months, suffering from multi-system Langerhans Cell Histiocytosis. The Artemis Association comprises of doctors, parents, patients and their relatives and friends. Its objectives include supporting patients and their families, motivating and funding international research focused on identifying the pathogenesis of the condition and keeping hospitals up to date with the latest treatments. The Nikolas Symposium is a scientific Symposium aiming at identifying rational treatments for Histiocytic Diseases. It was established in 1987 by Apostolos and Elizabeth Kontoyannis, whose son, Nikolas was diagnosed with Langerhans Cell Histiocytosis, as an infant. The meetings bring together clinicians and scientists in an informal setting designed to promote open and intensive discussion. Each symposium focuses on a single scientific topic of relevance to LCH & HLH pathogenesis and up to 35 scientists and clinicians from across the world are invited. The Symposia are held annually in May in Athens. The scientific program is organized by a Steering Committee whose members are elected for a five-year term. Members of the Steering Committee include the Chairman of the Histiocyte Society. We also host the Histiocyte Society Meeting every 5 years in Athens, Greece. The last 17 years we have established an Adult Clinic, operating in one of Athens' public hospitals. We have co-funded approximately €1.000.000 in worldwide research projects over the last 15 years.

## Current activities and focus of the group:

The last 10 months we focused on Covid-19. We have set a target to collect money to support hospitals, doctors and nurses. The distance separating us due to the measures imposed, has not been an obstacle to this target. Quite the contrary, it has brought us closer, thanks to the mobilization of people who offered to help by making videos to promote the action, of companies who donated part of their revenues and thanks to events organized specially for this purpose. A chain of support was set up, a chain of solidarity and love towards our fellow beings. This human chain helped us collect the sum of 365,000 Euros to be used for purchasing hospital equipment, which was offered to "Sotiria" hospital, where the biggest number of patients with COVID-19 are hospitalised.

## What challenges are your group currently facing?

Due to pandemic, we had to cancel all our yearly activities. That makes us feel alone and isolated.



## What type of support would help your group to grow?

More publicity will help anything small or rare to be known, to be heard.

## What is your group's vision for the future?

Through our global research collaboration we hope soon we will be able to find a cure



# Divina Foundation India



## Organization Information:

Contact: Ila Joshi

Website: <https://divinafoundation.org/>

Email: [joshfly73@gmail.com](mailto:joshfly73@gmail.com)

## Overview of the group:

Divina foundation was established on 18th August, 2018 in the remembrance of our Divine Angel DIVINA JOSHI. Divina Foundation is almost 3 years old now and we have been taking baby steps for working towards our mission. So far, we have conducted various awareness programs in the hospitals, scholarship program for a girl child, motivational talk session, regular visit to a shelter home and orphanages, also personally trying to get in touch with those who are going through any traumatic issues due to child loss.

## What is your group's vision for the future?

Divina Foundation aims to:

- To spread awareness about this fatal and rare disease HLH
- To bring together families affected by child loss
- Create ample social media traction globally to have the ball rolling. (In form of Monetary or Expertise donors). (~6-12 Months) (~ \$5k-\$7k)
- Have an on ground Genome sequencing drive in India (Possible other low income group countries in Asia) to create an HLH registry of potential patients and Donors. Providing them Counselling and Consultation with the experts in the fields of clinical psychology, Genetics and Disease management. (~12-48 months) (~ \$50K-\$100K)
- Create state of Art HLH super specialty, facility for less fortunates. (~48-120 Months) (~ \$ 0.5 mn)
- Carry on parallel cutting edge research for development of HLH Immuno-prophylaxis.
- Using strategies like Gene Delivery, Gene-therapy, Immuno-Modulation, Ayurveda-Siddha Traditional Medicine. (~48-120). (\$.5Mn - \$2 Mn)





# Associazione Italiana Linfocitocitosi Emofagocitica - A.I.L.E. Italy



Organization Information:  
Contact: Ugo Ricciardi  
Website: <https://www.aileonlus.org/>  
Email: [info@aileonlus.eu](mailto:info@aileonlus.eu)

## Overview of the group:

AILE was born in 2015, it represents about 30 HLH families - of children and adults.

## What are the current activities and focus of the group:

Support for families, promotion and funding of scientific research



## What challenges are your group currently facing?

In 2020 we recognized the Mario Ricciardi Award to 1st Classified Dr. Canna Scott Assistant Professor, Pediatric Rheumatology, University of Pittsburgh School of Medicine, Pittsburg, United States and 2nd Classified Dr Chinn Ivan Director, Immunogenetics Program, Texas Medical Center - Houston, United States for the best scientific articles published in 2018/2019. For the year 2021, we will fund with 20,000€ a scientific research project on ALLOGENIC STEM CELL TRANSPLANTATION REJECTION to Dr. Pietro Merli of the Bambino Gesù Hospital in Rome. If at the end of 2021 the project reaches its objectives, another 25.000€ will be financed thanks to SOBI.

## What type of support would help your group to grow?

Networking with physicians of HLH reference centers in Italy.

## What is your group's vision for the future?

Being able to increase knowledge of HLH to physicians for timely diagnosis. Promote the study of low-toxicity drugs for treatment protocol and BMHT conditioning.

## What is your vision for collaboration with the Histiocyte Society and with other family groups?

Our vision is to collaborate with HS to exchange and expand scientific knowledge on histiocytosis at an international level; to create a network of family groups and associations that can rely on up-to-date information to help patients and their families; to support HS nationwide to encourage knowledge development.





**Overview of the group:**

AIRI Onlus is the Italian family Association for histiocytosis disease. We have 45 members.

**Current activities and focus of the group:**

Promote the research and the awareness of this rare disease in Italy.

**What challenges are your group currently facing?**

We collaborate mainly with 3 operating medical centers: Firenze dr.ssa Elena Sieni, Milano dr.ssa Emanuela De Juli and dr. Maurizio Aricò.

**What type of support would help your group to grow?**

Have more contacts and knowledge about the most severe cases of histiocytosis.

**What is your group's vision for the future?**

To increase collaboration with young physicians and involve them in research on histiocytosis and also have more treatment centers in Italy.



**What is your vision for collaboration with each other and with the Histiocyte Society?**

We think it is very important that associations support physicians in collaborating with each other on common projects to achieve a better scientific knowledge on histiocytosis. For this reason we consider a duty for all associations to coordinate with each other.



## OR Association Spain



### Organization Information:

**Contact:** Fernando Gotz

**Website:** <http://orasociacion.org/>

**Email:** [presidente@orasociacion.org](mailto:presidente@orasociacion.org)

### Overview of the group:

We represent a group of families and patients affected by LCH and we started our work in 2013. In our organizational structure we are 6 fixed people and we have 30 members that contribute with fixed contributions.

### Current activities and focus of the group:

Our main projects are:

- Siblings' and patients' emotional support plan: we are giving the possibility to parents to participate in many activities and to meet other families in their own situation during the year. We deliver an emotional support plan that is led by two psychologists contracted by our organization.
- We are having workshops every two months around topics like: how to deal with the emotions this long disease is causing to all of us; the relapses; fear and uncertainty; the forgotten brothers and sisters. Also families have the options to have personal sessions, couple sessions, psychomotricity sessions.
- We finance two scientific research projects on Histiocytosis, one around the Neuro-degenerative aspects of LCH, a study done on patients at Sant Joan de Deu Hospital in Barcelona (since 2014 and still ongoing). The second study has started this year and it's on Immunological study of pediatric patients with Histiocytosis at Garrahan Hospital in Buenos Aires, Argetina.
- We organize many activities during the year to raise awareness on Histiocytic aspects, workshops and congresses for physicians and researchers. The last talk we organized in August last year around medicals aspects, a talk led by Carlos Rodriguez-Galindo and Jorge Braier we had 260 doctors and 133 families representatives participating from 19 different countries including: Argentina, Brazil, Chile, Uruguay, Paraguay, Bolivia, Peru, Colombia, Panama, Nicaragua, Venezuela, Santa Domingo, Cuba, Costa Rica, Ecuador, Spain, Italy, Honduras and Israel.

### What challenges are your group currently facing?

Lack of common projects among the different patient's associations and lack of direct communication between the physicians and researchers dealing with Histio projects, among them, and with us the patient's associations.

### What type of support would help your group to grow?

We started meetings to set up a study group on Histiocytosis among the Argentinean, Chile and Uruguay community of doctors, to talk about concrete cases and treatments. We would like to receive support in how to set up a scientific structure to help them in communicating with the rest of groups.





## OR Association (Cont.) Spain



### What is your group's vision for the future?

The vision for next year is: working together

- We must start working with the international community of Histo, we have started to work and we are launching an awareness campaign together with the Histo.org, ECD, the Canadians, Italians (LFH), France (LHF), Brazilians, Argentineans and us in Spain. We believe a better communication about the work we are doing separately is essential.
- Also we need to start seeing what type of global initiatives we may organize together, global grants to research, even doing together fundraising activities as it may attract powerful sponsors/ brands if we start spreading that this disease has a global impact.
- Support and facilitate to local study's physicians groups in South America, support local associations by giving them the possibility to participate in the activities we organize online.
- Impulse a local group in of families and researchers in Israel, we visited Israel in September 2019 and had meeting with many Hospital and interested doctors and researchers.

### What is your vision for collaboration with each other and with the Histiocyte Society?

The vision is to work in a more collaborative way with the other associations around the world and with the HS. We have so many things in common and that's why we believe we should unite forces and resources, the aim is clear: to make a better life of the Histo patients and families. As we are just a few around the world working on the same issues we may share best practices with the rest of associations, we may all benefit from the work already done. Create better communication channels / forums where we can transmit each other (HS and associations) the work we are doing and identify needs we may encounter.





# Erdheim-Chester Disease Global Alliance (ECDGA) USA



## Organization Information:

Contact: Kathleen Brewer

Website: <https://erdheim-chester.org/>

Email: [support@erdheim-chester.org](mailto:support@erdheim-chester.org)

## Overview of the group:

The ECD Global Alliance (ECDGA) is dedicated to awareness, support, education, and research related to Erdheim-Chester Disease. The organization represents patients, caregivers and medical professionals from around the world. Currently the organization represents 683 ECD patients and their families in 63 countries. We also support 33 ECD Care Centers, and the physicians at those centers, that make up the ECD Referral Network across 12 different countries.

## Current activities and focus of the group:

The ECDGA provides the following services:

### Patients/family Support & Education

- Provide information and education to patients and their caregivers via a website, social media, printed material, videos, virtual meetings, annual face-to-face meetings, and one-on-one interactions.
- Provide support via one-on-one communications, social media, peer introductions, virtual chat sessions, and fellowship during face-to-face meetings when possible. This support covers needs of patients/families during each phase of the ECD journey, from pre-diagnosis, to diagnosis, treatment decisions, end of life, and family grieving.

### Medical Professional Support

- Administer an ECD Care Center Referral Network and distribute information among centers
- Host an annual face-to-face Medical Symposium for scientific findings and complex case discussions; in addition to educational talks related to patient care and scientific investigations
- Connect medical professionals unfamiliar with ECD with those who are knowledgeable ECD Research
- Fund ECD/adult histio research studies
- Provide recruitment support for ECD/histio studies

### Awareness Raising Among Medical Professionals

- Promote Grand Round talks
- Provide information at medical conferences
- Provide printed and electronic information to medical professionals

## Current initiatives within the organization include:

- Dramatically decrease the time to diagnosis for people with ECD
- Foster breakthroughs by scientists through collaborative research
- Build a stronger community of informed and connected patients, caregivers and physicians
- Explore increased service to the adult histio community through deepening partnerships with other rare disease organizations
- Establish long-term sustainability for the ECD Global Alliance





## Erdheim-Chester Disease Global Alliance (ECDGA) (Cont.) USA



Major achievements include:

- Establishment of ECD Care Center Referral Network
- Hosting of annual, international Medical and Patient/family meetings
- Funding over \$700,000 in ECD research, to include the establishment of an ECD Patient Registry
- Successfully helping in patient recruitment for the ECD
- Registry, clinical trials and an NIH Natural History Study

Being the catalyst to encourage the medical community to come together to accomplish:

- Publication of consensus guidelines for the diagnosis and management of ECD
- FDA approval of an ECD treatment
- NCCN guidelines for the management of adult LCH, ECD and RDD
- WHO declaration of ECD as a histiocytic neoplasm

### **What challenges are your group currently facing?**

- Sustainable funding to support the organization's programs/initiatives/mission
- Limited awareness within the medical community resulting in an under-diagnosis and delayed diagnosis of ECD
- Adapting to the COVID pandemic

### **What type of support would help your group to grow?**

Increased collaboration between the adult and pediatric medical histio groups - Ease of opening multi-center trials - Sustainable funding - Greater partnerships with pharma, specialty medical organizations, and other patient advocacy organizations

### **What is your group's vision for the future?**

Simple, early diagnosis - Effective and accessible treatments for all regardless of location or mutation status - Eventually, a cure for all

### **What is your vision for collaboration with each other and with the Histiocyte Society?**

Through medical and patient organization collaborations we would hope to accomplish over time the following: (1) help ensure research includes a focus on patient needs, helping to bring about breakthroughs in patient care; (2) increase patient support for all histio disorders worldwide; (3) increase awareness of all histio disorders among all medical professionals to facilitate earlier diagnoses; (4) help with trial recruitments; (4) and possibly help with research funding worldwide.

Through patient advocacy organization collaborations we would hope to accomplish over time the following: (1) improve global patient support; (2) increase organization efficiencies; (3) increase awareness of histio disorders among medical professionals; (4) improve patient care globally; (5) support breakthroughs in patient care/treatments/cures.

Our vision is for the global communities to work together to improve patient outcomes worldwide.

### **Any other comments?**

We appreciate all the HS is doing to help histio patients everywhere. We look forward to continued increasing partnerships with the HS.



## Eric's Journey Foundation USA



### Organization Information:

Contact: Eric Majusiak

Website: <http://www.ericshjourney.org/>

Email: [eric@ericshjourney.org](mailto:eric@ericshjourney.org)

### Overview of the group:

HLH and Stills Disease support and awareness.

### Current activities and focus of the group:

Awareness efforts for Histiocytosis have been a large part of our mission. My website has been used as an education tool and support tool for newly diagnosed adults.

### What challenges are your group currently facing?

Collaboration has been something that has been difficult.

### What type of support would help your group to grow?

The most effect type of support to help with our mission would be marketing.

### What is your group's vision for the future?

The awareness of rare disorders will help speed the diagnoses and treatment of these diseases. We have been able to see change at universities and their understanding which hopefully continues to grow.



### Any other comments?

Eric's Journey started in 2012 after my (Eric Majusiak) diagnosis with HLH. It is great to see more education efforts being taken on.



# Liam's Lighthouse Foundation USA



## Organization Information:

Contact: Michelle Schulze

Website: <https://www.liamslighthousefoundation.org/>

Email: [eric@ericsjourney.org](mailto:eric@ericsjourney.org)

## Overview of the group:

Liam's Lighthouse Foundation (LLF) a non-profit, tax-exempt organization, was established to create and provide educational material and awareness about Hemophagocytic Lymphohistiocytosis (HLH) including Histiocytic Disorders, and to distribute unbiased, factual information to physicians, hospitals, and the community regarding this disease. Our focus is also to bring families affected by HLH/Histiocytosis together and offer support through a variety of resources. We aim at raising much needed funds for continued education of physicians and research to develop safer and more effective treatment methods and ultimately a cure. LLF is also dedicated to bring awareness to the community about the importance of becoming a blood and bone marrow donor.

All work of the organization to date has been performed 100% by valued volunteers or paid for services. There are currently no paid employees of the organization. LLF has 5 board members and a dedicated team of volunteers. All of our board members have been affected by histio in a personal way.

## Current activities and focus of the group:

### CURRENT PROGRAMS:

#### RESEARCH AND GRANT PROGRAM

Proposals are submitted from physicians/scientists who specialize in Histiocytic disorders to fund specific research projects/labs focused on improving the outcome for patients diagnosed with a histiocytic disorder.

#### ALLIANCE SUPPORT PROGRAM

We support other histio-related organizations and/or organizations that allow us to carry out our mission as needed.

#### FAMILY SUPPORT PROGRAM

With this program, we provide financial support to the Social Services program at major institutions that specialize in the treatment of histiocytic disorders, to help support histio families that are struggling with the financial burdens of being away from home while their loved one is receiving treatment. This can include, travel expenses, lodging expenses, and food expenses.

#### AWARENESS AND DEVELOPMENT PROGRAM

This program allows us to participate in opportunities to raise awareness of histiocytic disorders as well as improve community presence and growth of LLF in the general and medical communities.

#### DYNAMITE THE HISTIO WARRIOR DRAGON PROGRAM

Jennifer Mitchell is the mom to LCH warrior Jayden and she is the maker of Dynamite. Jennifer Joined LLF in 2017 and The Dynamite Program was created and has become a staple of her efforts. Dynamite also has Histiocytosis. Jennifer's wish is for every Histiocytosis patient to receive a Dynamite for free! LLF created this program to help Jennifer reach this goal and to support our many families during their fight against Histiocytosis! To date, 760 Dynamites have been crocheted, 714 donated to families in 16 countries.



## Liam's Lighthouse Foundation (Cont.) USA



### FUNDRAISING PROGRAM

This program allows us to raise much needed funds to support the above programs. To do so, we currently carry out the following fundraising events annually.

**5K To Fight Histio** – This event weekend is held in New York City usually in July at Hudson River Park and includes a Meet and Greet event as well as our traditional gathering outside the Today Show to raise awareness. This year, our event was held virtually due to the pandemic. The usual turnout of this event ranges anywhere from 400-550 participants and attendees.

**Memorial Golf Tournament** – This event occurs in the fall season in Northeast Pennsylvania.

**Histio Awareness T-shirt campaign** – This event usually kicks off in August in preparation for September being Histio Awareness Month. These t-shirts are custom made to include the names of histio warriors and angels that are submitted for inclusion.

**Dynamite The Histio Warrior Dragon**- Various fundraising opportunities ongoing throughout the year to help support the cost of materials and shipping.

### **What challenges are your group currently facing?**

Because we do not have any paid employees and are 100% volunteer, there are several challenges we face. Most if not all of our board members and volunteers have full time jobs and volunteer in their spare time which is variable. We also face fundraising challenges because of this.

### **What type of support would help your group to grow?**

Being able to grow our group as an organization would require bringing in enough capital to support a staff of paid employees which would increase amount of time spent on achieving goals, outreach, and networking to name a few. This would allow us to focus solely on the mission of the organization rather than juggling a full time job with volunteer hours.

### **What is your group's vision for the future?**

Our vision for the future is to continue to focus on carrying out our mission and to provide a sense of belonging to our histio families so they do not feel alone in their journeys. I would love to see all of the histio organizations come together as one “coalition” which would allow greater outreach, networking, awareness, and fundraising to support what we all want...a cure for histiocytic disorders.



Liam



## Liam's Lighthouse Foundation (Cont.) USA



### What is your vision for collaboration with each other and with the Histiocyte Society?

I would love to see all of the histio organizations come together as one "coalition" which would allow greater outreach, networking, awareness, and fundraising to support our families better and what we all want...a cure for histiocytic disorders. During the 2019 Histiocyte Society meeting the histio scientists/physicians mentioned they need funding and there is no funding for their research labs. If we don't come together and communicate better, these goals become more difficult to achieve. As an organization leader, I want to connect with our research scientists/physicians and let them know why we exist and find out from them how we can help them achieve their research goals towards safer, more effective treatments for histiocytic disorders. I suggested to a few of them I would like to see our organizations be included in the annual Histiocyte Society meetings in a way that we can connect with our research scientists/physicians in a separate meeting space and learn how we can best help them as well as an opportunity to connect to other histio organizations in another separate meeting space. I feel adding sessions like these to the agenda would greatly benefit us all and our histio community.

### Any other comments?

When I attended the Histiocyte Society meeting in 2019, I realized there was a missed opportunity there. As an organization leader, I want to connect with our research scientists/physicians and let them know why we exist and find out from them how we can help them achieve their research goals towards safer, more effective treatments for histiocytic disorders. I would like to see our organizations be included in the annual Histiocyte Society meetings in a way that we can connect with our research scientists/physicians in a separate meeting space and learn how we can best help them as well as an opportunity to connect to other histio organizations in another separate meeting space. I feel adding sessions like these to the agenda would greatly benefit us all and our histio community.





**Overview of the group:**

The Histiocytosis Association is a global nonprofit, dedicated to raising awareness for all histiocytic disorders, while providing educational and emotional support, and raising funds for research. The Association was founded in 1986 by Jeffrey Toughill, and since then, has supported over 7,000 histio patients, and thousands of family members and caregivers. The Histiocytosis Association is committed to providing information about all histiocytic disorders and related conditions across all age groups, as well as funding research that can lead to better patient outcomes, more understanding of all histiocytoses, and treatments that hopefully can become curative. For over 30 years, the Histiocytosis Association has also supported the work of the Histiocyte Society by acting as Secretariat. The Association collaborates with the Jason Carter Clinical Trials Program, LAM Foundation for lymphangioleiomyomatosis, the National Organization for Rare Disorders (NORD), North American Consortium for Histiocytosis (NACHO), the ECD Global Alliance as well as many other patient advocacy groups around the world, and seeks to be able to connect patients, families, and physicians to the local resources and support they need. The Association has 7 team members and a volunteer Board of Trustees.

**Current activities and focus of the group:**

We focus our work in three main areas: awareness, educational and emotional support, and research. Some of our programs include: educational materials and resources provided both online as well as hard copies for those interested, advocacy and awareness activities across the US and globally, in-person regional meetings and webinars focused on information about histiocytic disorders and beyond, educational videos, physician directory, histio warrior directory, college scholarship program, and a volunteer program. The Association also has a research grant program that entails a competitive evaluation process, reviewed by our Board of Trustees and members of the Scientific community, and the most promising projects are funded as "seed grants".

**What type of support would help your group to grow?**

Continued collaboration across medical community.

**What is your vision for collaboration with each other and with the Histiocyte Society?**

To share research updates on an ongoing basis in various languages across our communities and to share with the HS what we are working on in order to receive support (I also want to catch you up more on the conversations about a Mutual International Collaborative Effort that is underway)

