



2023 FALL NEWSLETTER

# ECD GLOBAL ALLIANCE

Supporting those affected by Erdheim-Chester Disease worldwide

Now Accepting LOIs  
Patient Navigator  
ECD Care Centers  
Let's Connect Together

Upcoming Webinars  
Horizon Therapeutics Grant  
2024 Annual Meeting  
Awareness Week

Petition for Treatment in Japan  
Birthday Surprise  
Meet Our New Staff  
Thank you

The ECD Global Alliance is dedicated to the awareness, support, education, and research related to Erdheim-Chester Disease (ECD). The organization works with the global community to accomplish its mission in supporting those suffering with ECD and other rare adult histiocytic disorders.

ECD Global Alliance is a 501c3 patient advocacy group supporting patients living with Erdheim-Chester Disease.

# ECD Global Alliance Is now accepting Letters of Intent for the Early Investigator Research Grant

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*LOIs must be submitted by October 2*

Erdheim-Chester Disease Global Alliance is now accepting Letters of Intent (LOIs) for the 2023 \$50,000 Early Career Investigator grant. The ECD Global Alliance is interested in receiving LOIs for any study that has the potential to lead to an increase in knowledge to eventually help address unmet adult histiocytic patient needs, including those with Erdheim-Chester Disease. LOIs are due by October 2, 2023. Interested individuals can [click here](#) for the LOI packet or contact [Kathleen Brewer](#) for more information.

Since 2010, Erdheim-Chester Disease Global Alliance has awarded over \$1.2 million in research grants. This year the organization will award an Early Career Investigator up to \$50,000 for a two-year funding period. ECD Global Alliance defines Early Career Investigators as individuals who have yet to receive funding for the study of ECD previously and are within seven years of completing either a terminal research degree, medical residency, or equivalent. All qualified and interested Early Career Investigators are encouraged to submit a letter of intent. As appropriate, LOIs should consider including collaboration among investigators from different institutions, translation of findings into the clinical setting, and the use of data available in the ECD Registry housed at Memorial Sloan Kettering under the leadership of [Eli Diamond, MD](#).



# ECD PATIENT NAVIGATOR

FUNDED BY THE ECD GLOBAL ALLIANCE



Hi! As the ECD Patient Navigator, I help patients and their families find the information they need to obtain the best medical care possible. The [erdheim-chester.org](http://erdheim-chester.org) website has a large amount of information. But, sometimes, you might need information tailored to your circumstances. I can't offer medical advice, but I am here to share with you how you might find what you need.

**Please contact me:**

**Email:** [belinda.cobb@erdheim-chester.org](mailto:belinda.cobb@erdheim-chester.org)

**Phone:** 1-337-202-5200 Ext: 100

In this and future newsletters, I will share examples of the kinds of questions I receive, along with the answers provided. I hope this might help you!

[CAREGIVER RESOURCES](#)

**Question:** How does a patient navigator help caregivers?

**Answer:** One way the patient navigator helps caregivers is by providing resources.

Example tips provided to caregivers include:

- Make a list of all the tasks you need help with, and then list all the people who can help you (relatives, neighbors, friends, community resources). Ask for help.
- Look into local caregiver resources that can provide respite care at home or an adult day care facility.
- Look into home-delivered meal programs such as Meals on Wheels.

If you're wondering whether the term "caregiver" applies to you, it probably does. A caregiver is anyone who helps an aging, ill, or disabled family member or friend manage their day-to-day lives.

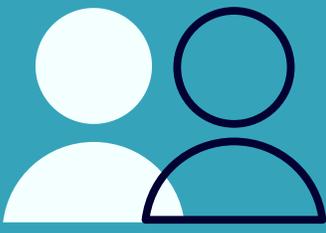
## ECD CARE CENTER NETWORK

[CARE CENTER NETWORK](#)



The ECD Care Center Referral Network is the backbone of quality care for ECD patients. The ECDGA works with leading physicians to build a solid path for institutions willing and able to help these patients find quality care. These centers of care are available to help all ECD patients and the physicians will work with a patient's local medical team.

Patients and local doctors are encouraged to reach out to the contacts at one of these 34 centers for help in diagnosing, treating, and monitoring ECD patients.



## LETS CONNECT TOGETHER

The ECDGA works to identify ways to enhance the exchanges among patients, caregivers, and physicians throughout the year, creating a strong, encouraging network.

### GRIEF CHATS SUNDAY, 2 PM CT

[SEPTEMBER 10, 2023](#)

[NOVEMBER 12, 2023](#)

### CAREGIVER CHATS SUNDAY, 1 PM CT

[OCTOBER 14, 2023](#)

[DECEMBER 9, 2023](#)

### PEER TO PEER CHATS TUESDAY, 1 PM CT

[SEPTEMBER 26, 2023](#)

[OCTOBER 24, 2023](#)

[NOVEMBER 28, 2023](#)



Erdheim-Chester Disease Global Alliance is excited to partner with the Histiocytosis Association, Histiocytosis Association Canada, and Dr. Hannah-Rose Mitchell to offer a two-part self-care webinar series for both caregivers and patients. Part one of the webinar series will focus on caregivers of patients with Histiocytosis, while Part two will focus on patients. **Both webinars by Dr. Mitchell are sponsored by the Global Genes RARE Mental Health Impact Grant, received by ECDGA in 2023.**

### DISEASE, ANXIETY AND DEPRESSION: COPING STRATEGIES FOR CAREGIVERS OF ADULTS- PART 1

[SEPTEMBER 14, THURSDAY, 12 PM CT](#)

[REGISTER HERE](#)

### DISEASE, ANXIETY AND DEPRESSION: COPING STRATEGIES FOR ADULT HISIOCYTOSIS PATIENTS- PART 2

[NOVEMBER 16 THURSDAY, 12 PM CT](#)

[REGISTRATION COMING SOON](#)



# UPCOMING WEBINAR

Erdheim-Chester Disease Global Alliance is excited to partner with the Histiocytosis Association, Histiocytosis Association Canada, and **Kevin O'Brien** (National Institute of Health) to discuss the Side Effects of BRAF and MEK Inhibitor Medications for Histiocytosis patients.

**SIDE EFFECTS OF BRAF AND MEK INHIBITOR MEDICATIONS**  
DECEMBER 7 THURSDAY, 12 PM CT

REGISTRATION COMING  
SOON

## ECDGA AWARDED HORIZON THERAPEUTICS GRANT

The Erdheim-Chester Disease Global Alliance is excited to announce that we've been selected as a 2023 #RAREis™ Global Advocate Grant awardee by Horizon Therapeutics' #RAREis™ program!

As a part of this grant, ECDGA will be able to send two staff members to attend the Advocacy Summit sponsored by Global Genes. This is a great opportunity for our staff to learn how to empower Individuals best while also moving the organization to build capacity and better serve those affected by ECD.

## 2024 ANNUAL MEETING

The Erdheim-Chester Disease Global Alliance has begun planning for our annual conference to connect, share, and learn among peers and professionals. The 2024 Annual meetings will be held in Seattle, WA in April with host Dr. Paul Hendrie. Stay tuned as we finalize our agenda and release more information!



Host Dr. Paul Hedrie

# AWARENESS WEEK IS HERE!

#ENDECD week is here, and we have some big plans! Be sure to follow us on social media, share our newsletter with your friends, and be prepared to get active as we spread the word about ECD and how it impacts people worldwide! Order your gear now by purchasing #ENDECD wear [HERE](#), and be sure to tag us and use the hashtag #ENDECD so we can share the momentum! #ENDECD is a time for you to bring awareness to YOUR story YOUR situation, and pave the way for OTHERS LIKE YOU to navigate this disease easier and with more resources than the ones who came before.

We are asking EVERYONE to participate this year as we work towards a common goal: a day where people from all walks of life are aware of Erdheim-Chester Disease, especially those in the medical community. WE NEED YOU and can't wait to see you share your #ENDECD experience.

## Petition for Approved Treatment in Japan



Although treatment has come a long way for hematological cancers, the newer, targeted therapies are not accessible to patients with histiocytic diseases in many countries, such as Japan. Through collaboration between the ECD Global Alliance, Japan LCH (Langerhans Cell Histiocytosis) Patient Association, Japan LCH Study Group, and the Histiocytosis Association, a petition has been put into motion to approve targeted agents for histiocytosis in Japan, giving ECD and other histiocytic patients hope that these treatments might become accessible to them.

Patient Representatives (two ECD patients and one father of a pediatric LCH patient) and directors of the Japan LCH Patient Association joined in a meeting with the Ministry of Health, Labour, and Welfare (MHLW) to request that BRAF / MEK inhibitors be approved and covered for histiocytosis. Members of the Japanese House of Representatives and a member of the Gunma Prefecture House of Representatives helped coordinate the meeting. Armed with petitions and supporting material, the Japan LCH Patient Association moved to have these targeted therapies approved for the treatment of histiocytic diseases, given the drugs already have an orphan classification and are currently recommended for this use in other countries.

Working together, ECD patients and partners brought significant attention to the need to make these life-changing treatments available to Japanese patients.

# BIRTHDAY SURPRISE

Earlier this month, the ECDGA team got quite the surprise. As Ekta Patel celebrated her birthday, she decided to put together a Facebook Fundraiser with ECDGA as the beneficiary.

Unfortunately, Ekta lost her mother to ECD and she wanted to use this fundraiser to not only honor her memory but to spread awareness to her friends and family on what this disease is truly like. As a rare disease, patients not only struggle (often years) before reaching a diagnosis, but once they have those answers, treatment is limited and sometimes just out of reach, depending on insurance coverage and cost. With a goal of \$1,000, Ekta asked people to contribute what they could, and the support she got was mind-blowing. At the conclusion of Ekta's fundraiser, she DOUBLED her initial goal, with the total reaching just shy of \$2,200.

The ECDGA is humbled and honored to be the recipient of this gift and will use it to further both research and awareness for ECD as we continue to support all those affected by Erdheim-Chester Disease. Want to learn how to have your own birthday fundraiser? Visit <https://www.facebook.com/help/1910205189301966> for a step-by-step guide.



## MEET OUR NEWEST STAFF MEMBER

Hello, Friends of the ECDGA,



I am excited to join the ECDGA Family as the new Marketing and Development Manager. Seeing everything this robust and international organization has accomplished since its founding is genuinely humbling. I look forward to participating in the work as we expand our efforts to improve the lives of those impacted by ECD for patients, families, caregivers, and medical professionals.

Coming from a community development and public health background, I am excited to bring my previous experience to the table as we amp up awareness efforts to attend more medical conferences, open more opportunities for patients, caregivers, and doctors to become connected, and share the story of how ECD can impact not just the individual diagnosed, but the entire family.

**Please tell me your thoughts:** To help me better understand how you have interacted with the ECDGA in the past, please fill out this short survey at <https://forms.gle/2xPPDc28cVsqt2f8> so that I know what we've done well, what we need improvement on, and what you think we can do to best serve those whose lives have been impacted by Erdheim-Chester Disease.

I can't wait to meet each of you, and please feel free to reach out to introduce yourself to me at [Rachel.Smith@erdheim-chester.org](mailto:Rachel.Smith@erdheim-chester.org).

Best wishes,

*Rachel Smith*

[CLICK HERE FOR  
SURVEY](https://forms.gle/2xPPDc28cVsqt2f8)

# ECD STAFF

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## THANK YOU!

We are grateful for your loyalty and dedication to those fighting Erdheim-Chester disease every single day. As we embark on another year together, we hope that you find inspiration, support, and hope in our services and within your community of peers.

THE ECD GLOBAL ALLIANCE IS HERE TO HELP



 [WWW.ERDHEIM-CHESTER.ORG](http://WWW.ERDHEIM-CHESTER.ORG)

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