



2023 SPRING NEWSLETTER

ECD GLOBAL ALLIANCE

Supporting those affected by Erdheim-Chester Disease worldwide

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^ Kathy Brewer and Diane Schriener with Dr. Eli Diamond after he received the first Outstanding Achievement Award.

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 living with ECD and other rare adult histiocytic disorders.

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







IMPACT OF THE ECDGA CONTINUES TO GROW

By Kathy Brewer, ECDGA founder

Thanks to all who attended the ECD Global Alliance annual meeting at Mayo Clinic in Rochester, Minnesota, in April and helped to make it such a wonderful success. It was great to have our community come together again in person to share our ECD experiences and find time for fellowship with each other. It was moving, as always, to see patients, caregivers, and medical professionals come together to share their knowledge, courage, and caring spirit. Hope is provided to all through these interactions. Seeing old friends who are doing well and meeting new friends just beginning their ECD journey was a good reminder of all the ECDGA has accomplished and what is left remaining to accomplish.

In attendance at the event were some who were involved at the beginning of the ECDGA in April 2008. It was then that ECD patients and families first met online and realized that by working together, we could make a difference. Those first chats led to an organizational plan allowing us to work together to improve the lives of all who are affected by ECD around the world. There are old friends who have walked with us on this path and have passed away, and we miss them terribly. They will not be forgotten. Yet, as we meet those who have been more recently affected by ECD, it is uplifting to see how the accomplishments our ECDGA community has provided more hope. We have moved from single individuals searching for information to a community working together to improve the lives of all who are touched by ECD.

Some of the original ECDGA goals, and related accomplishments, that came to my mind as we celebrated the advances in the knowledge and treatment of ECD include:

GOAL	ACCOMPLISHMENT
A place to go to find up-to-date information about ECD	 ECDGA website is available in multiple languages and includes YouTube videos with experts providing information.
A community that works together to learn more about ECD and then shares that knowledge	 The ECDGA is a thriving community that works to educate an ever-growing global community about ECD through webinars, papers, brochures, social media and the website.
Fellowship opportunities for patients and families	 Annual international in-person meetings are held for patients and families, along with additional regional meetings. Patient, caregiver and grief chat sessions are available online.
ECD-focused research	 ECDGA-funded research in excess of \$1.2M has led to additional funding, including larger grants from governmental bodies.
Availability of ECD-knowledgeable doctors to treat patients	 ECD Care Center Referral Network is available with 34 centers identified in 14 countries.
Available treatments	 Two FDA-approved treatments now exist.

Significant gains have been achieved for the ECD community since the beginning of the ECDGA, thanks to passionate members of our community. However, we still have much to do. We believe that ECD is still very much underdiagnosed. For those lucky enough to be diagnosed, it often comes after suffering for too long without the benefit of treatment to prevent organ damage. We know that not all ECD patients can reach Care Centers, and many do not have access to the newer targeted treatments. For patients on treatment, the needs continue in terms of reducing treatment side effects, being able to discontinue treatment, and dealing with financial burdens that often result from high medical costs and inability to work. And we know that many patients and their loved ones continue to be impacted by neurological issues and psychological burdens, while suffering from fatigue and pain.

While the organization works to find solutions to the above, the ECDGA's immediate 2-year focus goals are:

1

Dramatically decrease the time it takes a patient to receive a proper diagnosis

2

Support relevant research to improve the quality of life for people with ECD and their loved ones

3

Build an even stronger global community of informed and connected patients, caregivers and physicians

4

Develop long long-term sustainability for the ECDGA

The ECDGA will continue to work to bring together the community to address these issues and hope that you will continue to be part of these efforts through your generous and kind support, both monetarily and through the use of your unique talents.

HISTIOCYTIC DISORDER FOLLOW-UP STUDY

This study for patients with histiocytic disorders including Erdheim-Chester Disease will help doctors better understand the possible health problems of people with histiocytic disorders. In the future, it aims to help identify people at risk for complications in order to personalize treatments. Findings from the study will help identify people who may need to be followed more closely or would benefit from preventive measures.

FOR MORE INFORMATION [CLICK HERE.](#)



*This study is being led by
Dr. Gaurav Goyal at the University
of Alabama-Birmingham. Contact info:
histio@uabmc.edu; 1-866-438-1640*



Co-hosts Dr. Gaurav Goyal, left, and Dr. Ronald Go, with the ECDGA's Kathy Brewer and Diane Schriener.

THANK YOU FOR A TERRIFIC PATIENT & FAMILY GATHERING

The 2023 Medical Symposium and Patient & Family Gathering was a success by every measure. As a first-time attendee, I was amazed at the collaborative learning and the compassion and joy shared coming together around ECD. So many hugs and smiles.

There are many people to thank, starting with co-hosts **Dr. Ronald Go**, hematologist at Mayo Clinic, and **Dr. Gaurav Goyal**, hematologist at the University of Alabama Birmingham Medical Center. These doctors worked for years (the meeting was originally scheduled for 2020) to plan a program that interested patients, caregivers and doctors alike.

Thanks, too, to all the speakers who generously shared their expertise! If you couldn't attend, you can watch videos and slides from many of the presentations [on the ECDGA website](#).

This year, we were grateful for many generous sponsors. The **Rev. Charles Balnaves** sponsored the Patient & Family Gathering and has been a terrific supporter for many years.

Mayo Clinic Laboratories, Mayo Clinic Division of Hematology, BioMed Valley Discoveries, Qurient Therapeutics and **NeuPharma** also helped make these events possible. These sponsorships reduced the costs for everyone and allowed for travel scholarships for some.

Thank you also to many volunteers — from the board of ECDGA, to our “regulars” running registration, patients and family members alike who pitched in in many ways. And the ECDGA staff who spent hours preparing for the time spent together.

We're already working to nail down plans for the 2024 gathering and we'll let you know as soon as we can so you can save the date!

Jean Pudlo, Interim Executive Director

[Make a
donation
today!](#)

WITH YOUR SUPPORT, OUR WORK IS POSSIBLE

The ECD Global Alliance depends on people like you to support the work that has led to:

- More physicians that can treat ECD
- Supporting research to understand the disease and find effective treatments
- Helping patients find the care and support they need — both medically and personally.

Looking ahead, ECDGA will continue to build awareness so that people are more likely to get diagnosed more quickly and support research for a better understanding of the disease and what patients need to make their lives longer and better.

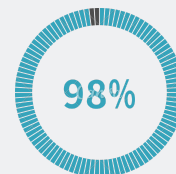
Please consider a gift of any amount.

[DONATE NOW](#)

Together, we can do more!

DOES YOUR COMPANY MATCH CONTRIBUTIONS TO NONPROFITS?

You may be able to double your donation by signing up with your employer for a matching gift. We are grateful to donors who use company matches to double their impact!



98% of our funding comes from private donations

ECGDA HOLDS FIRST AWARDS BANQUET

On a night of firsts, celebrating two doctors making a difference



ECDGA Vice President Diane Schriner and Dr. Eli Diamond, recipient of the first Outstanding Achievement Award from ECDGA, enjoy the banquet on April 27 in Rochester, Minn.



ECDGA founder Kathy Brewer and Dr. Gaurav Goyal pose for a snapshot after the award ceremony and banquet at the Patient & Family Gathering at the Mayo Clinic.

DR. ELI DIAMOND RECEIVES THE FIRST ECDGA OUTSTANDING ACHIEVEMENT AWARD

When Kathy Brewer and others first started the ECDGA, they were told that doing clinical trials on a disease as rare as ECD would probably be impossible. We should not hope for an FDA-approved treatment. But **Dr. Eli Diamond** has made the impossible possible.

Dr. Diamond attended the first International ECDGA meeting held in San Diego in 2013. He was so interested he came and found those of us with the ECDGA in the hotel the day before the meeting! He was full of enthusiasm, he wanted to meet patients and learn from them — and he still does! We obliged and made some introductions.

Now, thanks to Dr. Diamond and his colleagues at Memorial Sloan Kettering Cancer Center, just 10 years later, we have not one, but two FDA-approved treatments. Wow! What an outstanding achievement.

DR. GAURAV GOYAL RECEIVES THE FIRST MARK HEANEY AWARENESS AWARD

Dr. Mark Heaney, a leading hematologist at Columbia University, had a powerful and sustained influence on the ECDGA, from its early days until his passing in 2022. And the first award named in his honor goes to someone following in his footsteps, **Dr. Gaurav Goyal**.

In the words of one of his patients: “Having Dr. Goyal as my doctor has relieved a great deal of the stress of dealing with the disease. I wholeheartedly nominate him because his efforts to better understand this disease offers me a great deal of comfort.”

Dr. Goyal manages the care of many ECD patients as an ECD Care Center lead physician. He is also a leader in educating other physicians. Dr. Goyal hosted a 2022 regional meeting at the University of Alabama-Birmingham, presented at a 2022 patient meeting at the University of Cincinnati, and co-hosted the International Medical Symposium and Patient & Family Gathering at Mayo Clinic in Rochester, Minnesota in April. He is also one of the authors of the NCCN Guidelines for Histiocytic Neoplasms, published in 2021.

We are grateful for his dedication to ECD patients, and for spreading his compassion and enthusiasm to other medical professionals. Thank you, Dr. Goyal. You mean the world to us!



**[SEE THE PRESENTATION
SLIDES + WATCH EVENTS](#)**

[Visit the ECDGA website to view videos
and presentations from the gathering.](#)



Say cheese! Patients, families and doctors gather for a group picture on Friday, April 28 in Phillips Hall at the Mayo Clinic.

GREAT THINGS HAPPEN WHEN WE GET TOGETHER

Photos from the meet & greet, awards banquet, care center sessions and more



Visit the [ECDGA Facebook page](#) or [click here](#) to see more photos.

Josef Lacy: What the patient gathering means to me

Because this was my first time attending the ECDGA Patient & Family gathering, meeting so many people I have strong connections with but whom I've never met in person was extremely meaningful.

There were so many highlights: Connecting with the doctors and researchers I've read and heard so much about. Seeing familiar faces, some of whom I had lost contact with. Meeting new people and having an instant connection with them and getting so much information, especially answers to specific questions. And finally, meeting Kathy Brewer in person along with all the others dedicated to we relatively few. To me, the most important thing was feeling the support and love from those who know exactly what we are dealing with — our struggles, pain, and feelings of loneliness. Even with all that brainpower, we must deal with some trial and error because ECD is such an insidious beast.

What it did for me on a deeply personal level: Recently, I have been hovering in and out of a bad place, treading water, riding infrequent waves of contentment and peace, and after the conference, these past few days had me feeling alive again. I realize now just (how) much my brain and soul were craving more social interaction. Needing to cry or be emotional was perfectly OK. I didn't feel so uncomfortable in my skin. For me, one word comes to mind: catharsis. For me personally, I feel I have a small part to play, and maybe it'll be good for something.

When we split into patient and caregiver breakout sessions:

I did not speak up much at all. Having been in front of groups, I felt comfortable knowing where to go for answers later and letting others bring up things that would be helpful in just being heard. It was my first conference, but I am comfortable in that setting. I didn't want everyone to get tired of me too soon!

How I'm doing with my feelings, problems, and life overall. I'm working on it. We now have this new, weird and wonderful family. A wide assortment of people and personalities are bound together, not by choice. But here we all are, finding strength in each other.

My "AHA!" moment reflecting on the gathering. I think I may have written what I already need. Then again, maybe it really bolstered my need to write like a pretentious freshman English major.



ECDGA SPONSORS MULTIPLE RESEARCH PROJECTS

Thanks to an anonymous donation, and partnering with other groups, ECDGA has been able to sponsor a total of \$470,000 in research grants in the last six months! These projects will help increase the understanding of how ECD works and how to target medications and better understand the impact of the disease over time. All will increase the knowledge of the disease with the aim of improving patients' lives.

We are extremely grateful for a \$500,000 anonymous gift from someone in the community who made this possible. The donor requested specifically that the funded research be focused on making a difference in patients' lives. We expect to offer additional research grants in 2023 as a result of this generous gift as well.

DR. JITHMA ABEYKOON, from Mayo Clinic, was granted the Uplifting Athletes Award in partnership with the ECDGA in late 2022. His project, "Prognostic and Therapeutic Significance of Chromosome Region Maintenance 1 (CRM1) Protein in Erdheim-Chester Disease," aims to find the prognostic significance of CRM1 protein expression and relate this to uncover novel biological pathways and treatments in ECD. ECDGA was an equal partner in funding this \$20,000 award.



DR. EGLE KVEDARAITE, from Karolinska Institutet in Stockholm, Sweden, was awarded \$50,000 to study "Spatial Understanding of Erdheim-Chester Disease Origin and Lesional Microenvironment for Future Precision Medicine." She will use state-of-art techniques to search for clues to ultimately find new targeted treatments that can lead to complete elimination of ECD, rather than suppressing the progression as current therapies do.



In addition, two \$200,000 research grants were awarded in partnership with the **Leukemia and Lymphoma Society** (LLS). Recognizing the overlap between ECD and other blood cancers, LLS has contributed to the funding of these grants because of the leading-edge research that is occurring within the ECD community. We look forward to more collaborations in the future.

The awardees of these grants are **Dr. Gaurav Goyal** and **Dr. Matthew Collin**. Dr. Goyal, the University of Alabama at Birmingham, will study "Survivorship and Symptom Burden in ECD." The aim of this study is to understand the long-term health problems experienced by people with ECD, to be used eventually to counsel patients about long-term effects and devise follow-up guidelines. Dr. Collin, Newcastle University, will focus on "Tracing the Origins of ECD." In this study, he will look to determine how ECD starts in the body with the intent to eventually be able to detect ECD at an early stage and to understand why ECD impacts patients differently.



MENTAL HEALTH GRANT WILL SUPPORT VIRTUAL CHATS

This spring ECDGA received a 2023 RARE Mental Health grant from Global Genes. The \$8,200 grant will support our Virtual Chat programs through improved training and support of volunteer moderators, increasing mental health information presented in the program and webinars on mental health topics for patients and caregivers. **Hannah-Rose Mitchell**, PhD, a clinical psychologist, will be consulting with us on this project.

PATIENT NAVIGATOR: HERE TO HELP YOU!

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 [ECDGA website](#) has an array of information. But, sometimes, you might need information tailored to your circumstance. I cannot offer medical advice, but I am here to share information about how you might find what you need.

You can contact me:

Belinda.Cobb@erdheim-chester.org

or phone: 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!

Question: Are there any guidelines that help explain how to navigate Medicare as a rare disease patient?

Answer: The following toolkit provides a "how-to" guide for people living with rare diseases and advocates to help them make informed decisions and avoid costly mistakes when navigating Medicare.

The Global Genes website provides a toolkit for understanding and navigating Medicare.

[CLICK TO DOWNLOAD](#)



UPCOMING CHAT SESSIONS

ECD PATIENT PEER-TO-PEER VIRTUAL CHAT

We invite all patients to join this chat. Hear from your peers and share your experiences. *Group meets on the last Tuesday of each month at 1:00 p.m. C.T.*

ECD CAREGIVER VIRTUAL CHAT

We invite all caregivers to join this chat. A caregiver is defined as anyone caring for or living with someone living with ECD. This is an opportunity for you to care for yourself. *Group meets on the second Saturday of each even month at 1:00 p.m. C.T.*

ECD GRIEF GROUP VIRTUAL CHAT

We invite all who have lost someone to ECD to join us. YOU remain an important part of our community. Talk with others who understand. *Group meets on the second Sunday of each odd month at 2:00 p.m. C.T.*

INTERNATIONAL VIRTUAL CHATS

- **Spanish chat:** June 13, 2023 @ 1:00 p.m. C.T. For patients, family members, caregivers, friends, and physicians who speak Spanish.
- **Italian chat:** June 14, 2023 @ 12:00 p.m. C.T. For patients, family members, caregivers, friends, and physicians who speak Italian.
- **French chat:** June 16, 2023 @ 8:00 a.m. C.T. For patients, family members, caregivers, friends, and physicians who speak French.

[LEARN MORE ABOUT ECDGA CHATS](#)

ECD PATIENT REGISTRY

FUNDED BY THE ECD GLOBAL ALLIANCE

The Erdheim-Chester Disease Registry, led by Memorial Sloan Kettering Cancer Center, unites leading researchers in building a comprehensive database with ECD patient information. Investigations into the health problems caused by ECD and its treatments can be performed using this database. All ECD patients with medical records written in English are encouraged to participate.

[FOR MORE INFORMATION CLICK HERE.](#)



Dr. Eli Diamond is the principal investigator for the registry. He can be reached at diamone1@mskcc.org or 1-212-610-0243.

ECDGA BOARD OF DIRECTORS

Since its inception in 2008, countless donors, volunteers, medical professionals, and supporters have made the ECDGA what it is today. Thanks to the leadership of our board, patient support, and dedicated physicians, we have created a community filled with hope. The ECDGA is fortunate to have the Board of Directors and Medical Advisory Board volunteer their time and energy to lead the ECDGA into the future.



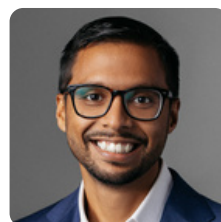
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President



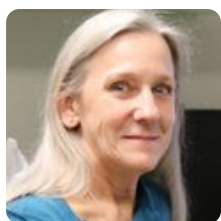
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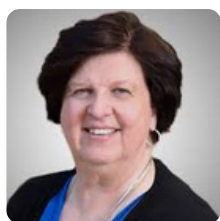
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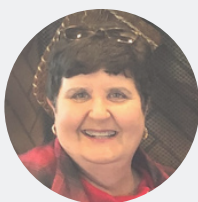


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STAY CONNECTED



BY FOLLOWING US ONLINE