

ECDGA Annual Report 2024



Dear ECDGA Community ,

Thank you for your incredible support throughout 2024. Thanks to your generosity, the Erdheim-Chester Disease Global Alliance (ECDGA) has experienced significant program growth, an expanded global community, and funded essential research to help pave the way for a brighter future for ECD patients.

Support: Empowering the ECD Community

In 2024, the Patient Navigator program, provided personalized support to 84 new patients, bringing the total number of families served to 1,020 across 75 countries. Patients were equipped with essential information about ECD and related treatments. For more information about the ECDGA Patient Navigator program, contact [Belinda Cobb](#).

The Peer-to-Peer Chats were expanded to include more languages (Spanish, French, German, and Italian). Also introduced were location-specific chats tailored for ECD community

members in Australia, New Zealand, and Canada. In addition, regular caregiver chats are now available.

More patients in more locations now have a space to connect with others who understand their journey. If you're interested in joining a peer chat you can click below for more information or to register for a chat .



REGISTER FOR UPCOMING CHAT SESSIONS

ECD Referral Care Center Network

The ECD Referral Care Center Network is available to help patients find knowledgeable doctors to confirm a diagnosis and to provide treatments and ongoing care. The establishment and growth of the Care Center Network helps patients find a medical team with interest and knowledge in treating people living with ECD and other adult histiocytic disorders.

Today there are 41 Care Centers in 17 countries, with three new centers joining the network in 2024. The new 2024 Care Centers are located in Dijon, France; Riyadh, Saudi Arabia; and Dallas, TX USA. All ECD Care Centers provide invaluable access to specialized care and support for people living with ECD and other histiocytic disorders.

LEARN MORE ABOUT ECD CARE CENTERS

Awareness: Raising Visibility of ECD

In 2024, ECD staff and volunteers attended Medical Specialty Conferences for pathology, endocrinology, radiology, and ophthalmology to raise awareness and educate medical professionals on recognizing the signs of ECD and diagnosing it earlier in the progression of the disease.



People from around the world participated in the 2024 ECD Awareness Week. One highlight was the hugely successful Fun Run/Walk/Roll, which set a new worldwide participation record. More than \$22,000 was raised to support the ECDGA's mission while raising ECD awareness in communities across the globe!

Fundraisers like this, combined with donations from our amazing community, allow the ECDGA to expand support and awareness for ECD. If you are interested in hosting a fundraiser, contact the [ECD Global Alliance](#).

Spotlight on the 2024 Seattle ECD Conference

The annual ECD Conference was held in Seattle, Washington, in April 2024. This conference provided a chance for those affected by ECD to learn about resources and the latest information about ECD.



Over 110 medical professionals, scientists, patients, family members, and other interested individuals came together to share their knowledge and experience related to ECD.

The event featured expert presentations and panel discussions that provided information about the current understanding of ECD and status of ECD research. Eleven videos from the Seattle conference are available for those who were unable to attend.

WATCH THE SEATTLE ECD CONFERENCE SESSIONS

Research: Advancing Treatments for ECD

The ECDGA proudly awarded a \$50,000 grant to Dr. Francesco Peyronel at Meyer Children's University Hospital in Firenze, Italy. This research is focused on developing a comprehensive tool to predict ECD patient prognosis and the risk of other disease-related consequences.

Thanks to the generosity of our donors, the ECDGA has funded more than \$1.2 million for ECD research to help better understand the disease and improve patient outcomes.



LEARN MORE ABOUT ECDGA-FUNDED RESEARCH

Survivorship Study

U.S. Patients: Your help is needed! Dr. Gaurav Goyal at the University of Alabama at Birmingham, in partnership with ECDGA, is conducting a Survivorship Study. Your input is invaluable for advancing research to help ECD patients and patients with other histiocytic disorders. To learn how you can participate, contact the [ECD Global Alliance](#).

Education: Empowering the Community

Education remains one of the ECDGA core pillars. In 2024, an ECD overview webinar was presented in German by Dr. Michael Girschikofsky. Another webinar

discussed mental health challenges associated with ECD and was presented by Kevin O'Brien, NP and patient, Josef Lacy. A final conversation webinar was provided for caregivers and was presented by RuthAnn Batchelder. These videos are available for viewing on the [ECDGA YouTube Channel: Webinar Playlist](#).

In 2024, the webinar program was expanded to give both patients and medical professionals access to the latest research and treatment developments. Watch for more monthly expert-led webinars in 2025, providing an opportunity to continue growing ECD knowledge and achieve greater community outreach.

REGISTER FOR UPCOMING WEBINARS

Surpassing Our Year End Goal: A Year of Generosity

In 2024, the ECD Global Alliance was challenged to a bold goal of raising \$90,000 to meet generous match donations. Thanks to your unwavering support, that target was not only met but surpassed!



Every donation is meaningful to help overcome ECD. Whether the donation is large, small, a personal contribution, or comes from a fundraiser such as *The Wine Survivor* or *Friends and Family* letter writing campaign, each donation gets us one step closer to ending ECD. A special thanks to all who participated in the ECDGA fundraisers and programs in 2024! You made it happen!

DONATE HERE

Looking Ahead to 2025

With your help, 2025 is expected to be an even greater year. Here's a sneak peek at some of the programs that are being implemented!

Monthly Webinars are scheduled and will feature information about the latest research, treatments, patient care, and support opportunities. Click [HERE](#) for more information and to register.



Barcelona Conference: The Patient & Family Gathering and Medical Symposium will be held May 26-28. The [Patient & Family Gathering](#) will be held on May 26, and the [Medical Symposium](#) takes place on May 27 & 28. The conference is an opportunity for those living with ECD, their loved ones, medical professionals and scientists to share knowledge and experiences. You can find more information by clicking on the above links.

THANK YOU FOR MAKING 2024 A GREAT YEAR!

Reflecting on all that has been accomplished by working together in 2024 brings hope and gratitude for your support. The dedication and generosity of the ECD community has been the driving force behind these achievements. By working together, the future looks much brighter and more hopeful for all those affected by ECD. Here's to an even more impactful 2025!

With gratitude,

The ECDGA Team

FUND LIFE-CHANGING MEDICAL RESEARCH

With over \$1.2 million USD granted to research and two FDA-approved therapies, the ECD Global Alliance has been a part of the global movement to help people living with Erdheim-Chester Disease

DONATE NOW AT
WWW.FUNDECD.ORG

Our Contact Information

ECD Global Alliance
P.O. Box 775
DeRidder, LA 70634
337-202-5200 ext 100
<https://www.erdheim-chester.org>

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