



ECD GLOBAL ALLIANCE

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# ANNUAL REPORT 2018

A YEAR OF ACCOMPLISHMENTS

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## ABOUT THE ERDHEIM-CHESTER DISEASE GLOBAL ALLIANCE



Kathy Brewer, ECDGA Founder & President

What started with a group representing only six patients, now serves over 500 families worldwide. Kathleen Brewer, President and Co-founder of ECD Global Alliance, is a driven individual who was able to turn heartache into triumph. On July 3, 2007, Kathy's husband Gary succumbed to ECD. Kathy kept her promise to never stop searching for answers.

Kathy's perseverance through the trials and tragedy led her to what ECDGA is today. With an established website and growing ECD community, patients and families encouraged Kathy to finally establish a formal 501(c)3 Nonprofit organization. On August 28, 2009 Erdheim-Chester Disease Global Alliance was officially born.

With the help of countless donors, volunteers, and medical professionals, the ECDGA has been able to support patients and research efforts around the world since its inception nearly ten years ago.

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## GET MORE NEWS!

To sign up for ECDGA newsletters, please complete the [contact form](#) and let us know what you are interested in learning about.

# THE MIRACLE BABY



## MEDICAL MIRACLE - THE RESULT OF A MOTHER'S LOVE

This year's featured article must go to Alice Nilsen's story! She is a bit of hometown hero, our ECD community miracle.

Against the wishes of her medical team, Alice made a life changing decision: stop taking her medication and continue an unexpected pregnancy! Alice managed to beat all the odds! Now, back on her medications, Alice is happy living life and watching her 14-month old daughter, Marie, grow!

Not only was this amazing story used to raise awareness during ECD Awareness Week this year, Alice submitted the story to #MyGivingStory, an annual story challenge. This allowed the chance for ECDGA to get an amazing \$10,000 prize! Thank you, Alice for taking the time to submit your story, and all those that committed to voting every day during the voting period! To continue reading Alice's full story [click this article](#).

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**“DON'T LOSE HOPE  
NO MATTER WHAT  
THE BAD OUTCOMES  
MAY BE, THINGS JUST  
MAY TURN OUT  
GOOD IN THE END  
ANYWAYS!”**

- Alice Nilsen, Patient,  
Advocate, Donor, Fundraiser



# THE VOICES OF ERDHEIM-CHESTER DISEASE

Thank you for telling your stories to the world for more understanding and awareness of ECD!



**"THIS ORGANIZATION GIVES ME AN AMAZING AMOUNT OF INFO AND HOPE"**

- Teresa Keegan, Patient

“

**I NEVER FELT MORE ALONE IN MY LIFE. AM HAPPY TO HAVE ECDGA TO SHARE AND LEARN FROM OTHERS AND TO SOMETIMES READ ABOUT GOOD NEWS AND ABOUT OTHERS WHO CARE. IT HELPS TO KEEP MY SPIRIT UP. THANK U!**

- Anonymous Patient

“

**HAD DEE BEEN DIAGNOSED, IT WOULD'VE NOT ONLY HELPED HIM TO UNDERSTAND WHAT WAS GOING ON INSIDE HIS BODY, BUT GIVEN HIM THE CHANCE TO FIGHT.**

- In Loving Memory from the Royal Family

Gilbert "Dee" Royal, 1961 - 2016



## JOE LOFARO

Patient & Awareness Pro

When ECD awareness is on the rise, it's probably Joe Lofaro!

This year, Joe raised awareness through several different mediums in an effort to educate his community members and gain support for his advocacy group, the ECDGA.

Joe worked within his personal network to schedule awareness talks at his local university.

He also provided interviews for printing and radio explaining his journey with ECD. The most recent article featured his physician, Nishitha Reddy, ECD Care Center Lead at Vanderbilt University, TN.

These efforts also resulted in donations for the ECDGA. Joe still has more in store for 2019, he's a fighter and is committed to all he can to improve the lives of all affected by ECD.



**105** Patients  
Currently  
Enrolled

## ECD PATIENT REGISTRY

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Please support the ECD Registry with your enrollment!

Scientists have made tremendous progress in the fight against ECD in just the past decade, and new studies launch every year. But researchers can't do the work alone; they need information from people like you to conduct their research.

The Erdheim-Chester Disease Registry, led by Memorial Sloan Kettering Cancer Center (MSK), unites leading researchers in building a comprehensive database about ECD. Investigations into what kinds of health problems are caused by ECD, what happens as a result of different treatments for ECD, and how ECD affects people's physical health, psychological well-being, and overall life circumstances. The investigators also want to learn how health, symptoms, and overall quality of life change over time for people with ECD. The ECDGA is committed to continue the registry's management and funding so we can continue the growth of invaluable information this database will provide to the community.

To join the Registry, please email [neuecdregistry@mskcc.org](mailto:neuecdregistry@mskcc.org) or call 212-610-0720.

The Principal Investigator for the ECD Registry is Dr. Eli Diamond, who can be reached at [diamone1@mskcc.org](mailto:diamone1@mskcc.org) or 212-610-0243.

If you are ready to join, follow this consent form online to get started [Registry Consent Survey](#).

Thank you to those that have already registered!

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## Mayo Clinic, Minnesota

Innovative Collaboration for ECD Care



From left to right, Drs. Matthew Koster (Rheumatology), Jay Ryu (Pulmonary), Robert Vassallo (Pulmonary), Aishwarya Ravindran (Pathology), Jason Young (Radiology), Karen Rech (Pathology), Mithun Shah (Hematology), Nora Bennani (Hematology), Ronald Go (Hematology), and Gaurav Goyal (Hematology)”

At the ECD Care Center (CC), Mayo Clinic in Rochester, MN, a multidisciplinary Histiocyte Working Group meets monthly to discuss every case being studied, resulting in an exceptionally collaborative tumor board.

Dr. Ronald Go, the CC team's lead physician, explains the structure of the board. "We discuss every case in our histiocytosis tumor board. Every expert gets to comment on the case even when face-to-face time is not possible."

"This has been very valuable to ECD patients, especially for those travelling from long distances," Dr. Gaurav Goyal explains.

Additionally, this center has been funded by the NIH lymphoma program (SPORE) to collect tissue and blood specimens for all ECD patients in order to pursue cutting edge research.

## CENTERS WELCOMED IN 2018

The ECD Care Center referral network consists of 32 institutions worldwide. These centers are willing and able to prescribe ECD treatments and offer consults.

- Stanford University  
Stanford, CA  
Contact: Beth A. Martin, MD  
Telephone: (866)742-4811 or (650)498-6000  
E-mail: Martinb@stanford.edu
- Duke Cancer Institute  
Durham, NC  
Contact: Richard F. Riedel, MD  
Telephone: +1-919-681-6932  
E-mail: richard.riedel@duke.edu

**FIND MORE INFORMATION AND A LIST OF ECD CARE CENTERS ONLINE:**

<http://erdheim-chester.org/care-centers/>



## 2018 ECDGA MISSION HIGHLIGHTS

### BRINGING AWARENESS TO THE PHYSICIAN

Educating specialists one event at a time

June 12, 2018 - Medical residents and physicians at Houston Methodist Hospital in Houston, TX attended a [Grand Round](#) to learn about ECD from the Columbia University Medical Center ECD Referral Care Center lead physician, Mark Heaney, MD, PhD. [Read More](#)

July 13, 2018 - University of Miami hosted a medical presentation, [Grand Round](#), to further residents' education in histiocytic disorders. Dr. Ronald Go of Mayo Clinic in Rochester, MN, discussed the features and management of Erdheim-Chester disease. [Read More](#)

September 10 - 15, 2018 - During the 4th Annual ECD [Awareness Week](#), an informative ECD flyer was sent to 53 pathologist across the US and to all Care Centers for distribution at their institution; and media engagement reached 30k. [Read More](#)

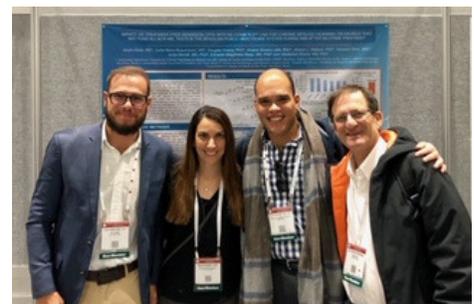
November 15, 2018 - The 6th Annual International Erdheim-Chester Disease [Medical Symposium](#) was held in Orlando, Florida to allow medical professionals to gather and collaborate on the latest ECD research findings and knowledge related to the treatment and care of ECD patients. Thank you to our host Dr. Julio Hajdenberg and Orlando Health! [Read More](#)

December 13, 2018 - Representatives from the ECDGA hosted an exhibit booth at the [American Society of Hematology \(ASH\) annual conference](#) in San Diego to raise awareness of ECD among attending specialists. The exhibit provided resources developed by ECD Global Alliance medical community members. The attendance allowed ECDGA to connect with doctors to offer them information that would help in the diagnosis and treatment of ECD. [Read More](#)



“  
[THE ECDGA HAS HELPED THE ECD COMMUNITY BY] BRINGING EXPERTS TOGETHER TO MAKE COLLABORATIVE PROGRESS.

- Dr. Ronald Go, 2018 Event Attendee



# EVENT HIGHLIGHTS

## The value of supporting our members

The 6th Annual Patient Gathering hosted a total of 109 attendees from eight countries at the Orlando Regional Medical Center in Orlando, FL on Nov. 16. These annual events are vital to continuing education about ECD, as well as maintaining the connections between those battling the rare disease.

“

**JUST DIAGNOSED.  
EVENT EXTREMELY  
VALUABLE**

- 2018 Event Attendee

Rev. Charles Balnaves receives his global award for the Patient Gathering sponsorship.



During the event, patients are brought together to share their experiences, successes, and tribulations among other patients. Physicians and researchers attend to offer their expertise, providing answers to questions that can help clarify confusion regarding how to properly treat ECD.

**TO FIND OUT MORE ABOUT EVENTS,  
VIEW PRESENTATIONS, PHOTOS &  
VIDEOS, SEE OUR WEBSITE.**

<http://erdheim-chester.org/news/eCd-patient-family-gathering/>

Dr. Julio Hajdenberg, ECD Care Center Lead at Orlando Health, graciously hosted this event along with his tremendous staff.

# MATCHING GIFT

THE YEAR-END FUNDRAISER IS BIGGER THAN EVER

"You can say I have a very personal agenda towards this. I see what the organization does for an orphan disease. Because of ECDGA, today I know what future treatment could be available for individuals like myself. I didn't just want to be a patient in the books, but a contributor to the greater good of what ECDGA stands for."

- Mohammad Chowdhury, ECD Patient, Donor, Fundraiser, Advocate

## THANKS FOR YOUR GIVING HEART

With every dollar, comes HOPE

There were 30 fundraisers in 2018. Events included Facebook Birthday fundraisers, city campaigns, calendar and awareness gear sales, and matching gift campaigns. With 99% of the organization's funding coming from private donors, these events are vital to the organization's mission. The ECD community is extremely grateful for these contributions! Please consider the ECDGA for your year-end giving. Thank you!



## THE \$70,000 MATCH ENDS DECEMBER 31

\$48,000 in donations received

*as of December 13, 2018*

"An impromptu invitation by Kathy to be on ECDGA's Board of Directors was all it took for me to say 'yes.' I have been amazed and inspired by the ECDGA community's determination to shed light on this lesser-known disease so that there is clarity in diagnosing it, interest in studying it and a pathway to insuring a better quality of life for themselves, their family and friends. I plan to stick around for the long haul."

- Jean Campbell, Board Member, Advocate, Volunteer, Donor

Checks Payable to:  
ECD Global Alliance  
P.O. Box 775  
DeRidder, LA 70634

Online:  
[www.FundECD.org](http://www.FundECD.org)

Facebook:  
[@ErdheimChesterDisease](https://www.facebook.com/ErdheimChesterDisease)

## HOW TO DONATE

The ECDGA is a 501c3 organization.

THANK YOU TO THE 365 DONORS THAT HAVE GENEROUSLY GIVEN THIS YEAR!

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# THE YEAR AHEAD

The ECDGA remains hopeful about the future for ECD families, but there is still more work to do!

## New Research Grant

The organization is steadfast in exploring the diagnosis, cause, and treatments for Erdheim-Chester Disease. Research grants are awarded based on likelihood of a sustained improvement in the understanding and/or treatment of ECD.

## Care Center Collaboration & Growth

The ECD Care Center Referral Network is the backbone of quality care for ECD patients. This network will continue to improve, grow, and expand as the ECDGA continues to work with physicians to build a solid path for institutions willing and able to help ECD patients find quality care.



"My hope for the future is that we recognize that we are all in this together. Great things can happen when we share our strength, our wisdom and our love."

- Glenn Padnick, Patient, Board Member, Donor, Volunteer, Advocate

## Global Patient & Family Event

The 7th Annual International ECD Patient & Family Gathering will be held in Milan, Italy on July 11-12. This will be an opportunity for the community to expand with its European membership and increase international physician engagement.

## Increase in Physician Awareness

Medical specialists are required to confirm a diagnosis of ECD. To help increase the knowledge in specific fields, the ECDGA has hosted an exhibit booth at specialty medical conferences for two years and will continue to look for these opportunities. Another awareness activity that has been successful are medical Grand Rounds. These meetings are an important teaching tool and ritual of medical education and inpatient care professionals, consisting of information on medical problems and treatment of particular patients or diseases to an audience consisting of doctors, residents and medical students. The ECDGA would like to promote and plan ECD-educational presentations across the US, but funding is needed to propel this project forward. Implementing two to three Grand Rounds is estimated to cost the organization \$6,000. Your help in contacting your physician about participating would also be of great help setting up these initiatives!

## Patient Registry Growth & Recruitment

(See also pg. 4)

The ECDGA is dedicated to the funding the management of this vital resource for the ECD community alongside the Memorial Sloan Kettering Research Team. Patient recruitment for the database is the current focus for 2019, with more involvement from the European teams on the horizon. Participation from all US members is possible and encouraged; while funding is being sought to employ translations in other languages as well.

# GRATITUDE

Without a strong support structure, this organization would not thrive or even exist. Thank you for your part in achieving so much for those affected by ECD!

## Members

Those affected directly by ECD have an important role in the advancement of treatments and scientific discoveries of this disease. Thank you for joining hands with the community to support research and the ECDGA mission!

## Donors

The organization depends on donors to continue its work and plan for the future. Every dollar donated is cherished and a tribute to your confidence in what this organization stands for and accomplishes. Thank you for trusting the Alliance with your hard-earned dollars!

# RESOURCES

Having current and useful sources can be critical to your journey living with ECD.

Receiving an ECD diagnosis can result in an overwhelming amount of questions and concerns for you and your family. Take advantage of the ECDGA website, which can be a useful tool to help you discover and organize your concerns and stay up-to-date on current ECD news and breakthroughs.

## CALENDAR-WORTHY EVENTS

**Feb. 28**

National Rare Disease Day

**July 11-12**

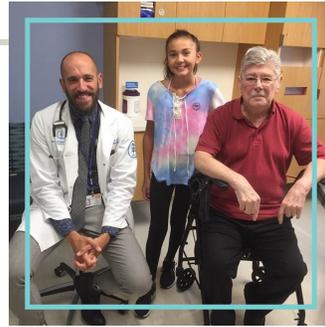
Patient Gathering  
Milan, Italy

**Feb. 28 - June 28**

ECDGA Fundraising Challenge

**Sept. 9 - 14**

5th ECD Awareness Week



Support can come in any form! Raising awareness, donating, and volunteering are only the tip of the iceberg.

## Medical Teams

From awareness to education to one-on-one consults, the ECD medical community has guided and included the ECDGA in their work in very meaningful ways. The organization is honored to be a part of the care and scientific breakthroughs in ECD!

## Volunteers

When time and skill is provided, the Alliance can move forward with less overhead; therefore, maximizing the donation dollars received. Thank you for your helping hands!

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



**2019**  
**SAVE THE DATES**