




Erdheim-Chester Disease Global Alliance

2019 Summary


*Enjoy reading about this year's accomplishments
& highlights within the community.*



The ECD Global Alliance Board and staff want to thank you for another great year! It has been a pleasure serving and working with this great group of patients, families, friends, advocates, physicians, and supporters!

 337.502.8034

 www.erdheim-chester.org

 support@erdheim-chester.org

About the Erdheim-Chester Disease Global Alliance



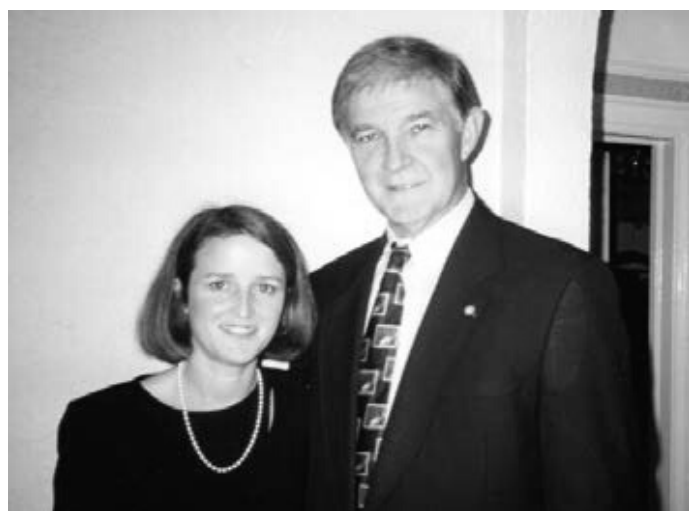
This year, your advocacy group is 10 years strong, supporting those fighting Erdheim-Chester Disease worldwide.

What started with a group representing only 6 patients, now serves 630 families in 58 countries around the globe! The organization has allocated \$650,000 to fund research, held seven patient and family events, eight medical symposia, and educated countless populaces on ECD.

With more physician awareness, 939 medical articles have been published, 30 of which specifically refer to the ECD Global Alliance (ECDGA). Prior to the ECDGA, approximately 326 articles were published between the years 1954 and 2009.

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 ten years ago.

..... *Thank you!*



ECDGA Founder & President, Kathy Brewer, with her husband, Gary Brewer, whom died of ECD undiagnosed.

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Learn more

To find more information about ECD and the community, go to our website here with a click or scan.



Brian Trusty

A man of faith, fun, and fight!

Brian enjoys being the life of the party!
He joys singing and dancing!

For his wife, he threw a huge party that involved him “singing” some of their favorite music! A video of his concert can be viewed here:

<https://www.youtube.com/watch?v=BFWGDBDOyTI>

If you have met Brian at one of the ECD Patient and Family Gatherings, you surely noted a few jokes and enjoyed laughter. He is full of life and tries every day to put a smile on others faces! But, who is the man behind the laughter?

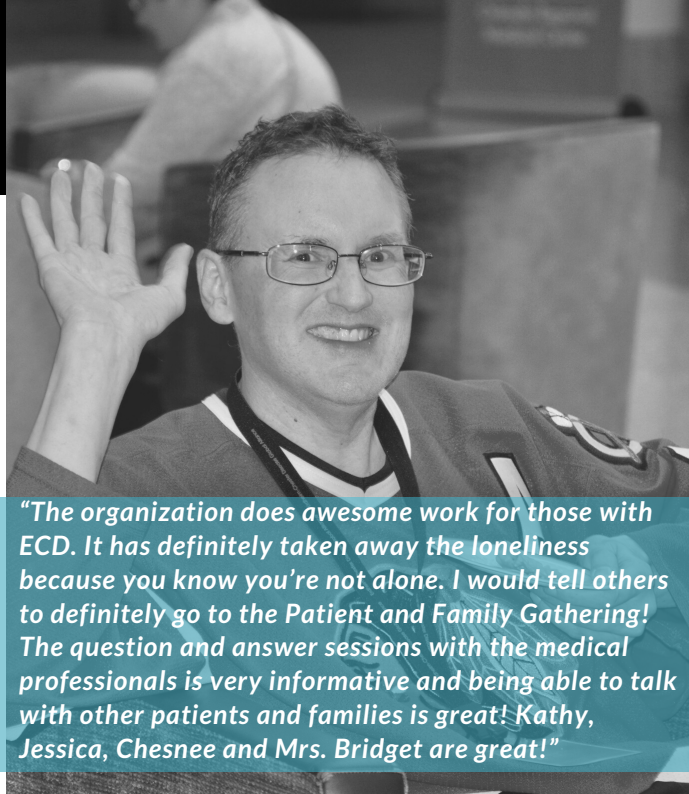
Brian's ECD Journey

Brian first started searching for a diagnosis in 2010, when he noticed balance issues and motion sickness. Seemingly simple symptoms at the beginning, yet with a gradual decline that began effecting his everyday life. Initially, doctors thought it could be as simple as vertigo. As time passed and symptoms worsened doctors even threw around the idea that it could possibly be Lou Gehrig's Disease (ALS).

After noticing a new skin growth, Brian went to see a dermatologist, Dr. Fox, at Silver Cross Hospital in Illinois. After some investigation Dr. Fox diagnosed Brian with Erdheim-Chester Disease.

Brian reached out to the ECD Global Alliance about his diagnosis, treatments, and living with ECD.

To find out more about other ECD treatments visit: <http://erdheim-chester.org/treatments/>.



“The organization does awesome work for those with ECD. It has definitely taken away the loneliness because you know you're not alone. I would tell others to definitely go to the Patient and Family Gathering! The question and answer sessions with the medical professionals is very informative and being able to talk with other patients and families is great! Kathy, Jessica, Chesnee and Mrs. Bridget are great!”

What was your original prognosis in 2010?

“[Dr. Fox] told me I only had three to five years to live.”

At the time of diagnosis, there were no FDA-approved drugs. What were you first treated with?

“I was first treated with Pegasys* and then cladribine,** but I didn't do great with those.”

*Pegasys (Peginterferon- commonly known in the ECD community as interferon or Interferon-alpha) is an immunosuppressive drug that is normally considered the “first-line” of treatment.

**Cladribine (also called 2-CdA) is a chemotherapy drug. Sometimes a doctor will make the decision that chemotherapy is the best way to treat ECD in a particular patient.

Brian's story cont.

Have you ever been a part of a drug trial?

“After the medication wasn’t working it was suggested that I go to New York and visit with Dr. Diamond. Since finances would not allow for multiple visits, I was seen by oncologist at Rush University Medical Center, Dr. Parameswaran Venugopal and Nicklas R. Pfanzelter in Chicago. Dr. Pfanzelter signed off on me being a part of the vemurafenib since the other medicine wasn’t helping. Because it was part of a trial it was free for me! It helped. I take 720 vemurafenib daily and have been on the same dose for four and 1/2 years.”

Who are your biggest supporters?

“Well my wife is definitely my biggest supporter. She takes care of me. Takes me to all of my appointments. She has an extensive background in nursing which helps with my treatment and medication.”

“When I went to the emergency room for my back and neck pain they wanted to give me medication for the pain, but she told them that it would interact with my ECD treatment. They looked into it and she was right, it would have interacted. It’s great that she knows that stuff!”

How do you contribute to your health on a daily basis, outside of your treatments?

“I always eat natural foods. I stay away from artificial foods and food coloring. I also get healthy energy but do have tea and coffee.”

When the weather allows, Brian also enjoys riding his recumbent bike for exercise. Only for a couple of miles and never in direct sunlight.

What's the worst that ECD has brought?

“The worst was all the aloneness, feeling alone with your diagnosis. The psychological impacts were the worst. As my mom says, ‘You can't win the lottery, but you can get this.’ Also, the first drugs used really messed me up. My voice did not match my thoughts and being on prednisone made me gain about 70 pounds.”

What has been the best things it has taught?

“I was finally giving in. I started getting involved with church and the ECDGA. Having a 50th birthday was great and now I can look forward to my 60th and 70th and more thanks to the new drug!”

What would you tell others about the importance of trials and the FDA approval of vemurafenib?

“Never close your door to anything. Always be willing to take a chance. No one knows what the cure-all will be, but never be afraid to try.”

To learn more about current trials and studies, or how you can get involved, visit:
<http://erdheim-chester.org/studies-trials/>

To view an inspiring video made by Brian, visit:

<https://www.youtube.com/watch?v=mNjohoHuh7U>

Or scan/click the code.



Families frequently share words that encourage our team & inspire the work of the Alliance every day...

"I wanted to thank you for your prompt responses full of information and encouragement. ...I printed out the information you sent and have already given a copy to my general physician who took a great interest in the articles and the possibility of there being other proven drug alternatives. (Yay!) ... ***It is comforting to know that I'm not alone on this journey*** and that you and your organisation provide so much support, information and hope."

- ECD Patient

"[ECD] Took my mum 6 years ago - to see the progress made in terms of diagnosis & treatment is fabulous. ***We had to fight (& fail) for treatment*** in the UK 6 years ago and diagnosis then was purely by chance. We definitely knew more than the doctors at the time. Keep the faith and keep fighting."

- Rachel Frondigoun

"When my Dad underwent treatment for Erdheim-Chester Disease the doctors knew less than we did about what it was or how to help and insurance companies refused coverage for treatments as anything was considered "experimental" at the time. Thanks to amazing advocates like Erdheim-Chester Disease Global Alliance so much has changed in the last few years; ***ECD has a name, doctors are more informed, families have more support, and insurance companies finally acknowledge and pay for treatments*** previously denied without the need for appeals!"

- Sarah Binsfield

Our Journey

July 28, 2015 is the day three words changed my family forever. My mom, Joanne, was diagnosed with Erdheim-Chester Disease otherwise referred to as ECD. The doctor's exact words to our family were "well the good news is we know what you have, the bad news is we never heard of it". I remember the exact feeling at that moment. My world was irrevocably shattered. I can't begin to imagine how my mom felt or the insane thoughts that ran through her mind. The one thing I was certain of is that my mom is the toughest woman I know. She made a promise to our family that she would fight this disease at every turn. She has fought ever since the diagnosis.



Every day continues to be a challenge, some days more than others, but my mom is a fighter.

- Shannon Bennich

The fight began immediately after the diagnosis of Erdheim-Chester Disease. Mom and I did our homework. The doctors didn't know much about this disease, so we knew we had to bring as much information to the doctors as possible. We also knew the fight meant arming ourselves with medical information to build our strategy. That's where we came across the ECDGA or Erdheim-Chester Disease Global Alliance. The ECDGA has been a wealth of information and support. Unlike other diseases and cancers, the Global Alliance holds an annual conference bringing both doctors and patients together. My mom and I have had the privilege of attending two conferences to date. In each conference we have learned new and current information, not to mention meeting other patients and building a patient alliance. Many of the ECD patients and caregivers have become family. This family has proven to be a huge support as we go through the many peaks and valleys of this disease. There are many doctors' appointments and it can be frustrating, particularly when doctors don't have answers. In the conference the attendees share their experiences and it is beneficial to 1) obtain information to bring back to our local doctors and 2) hear from other patients and caregivers' frustrations and understand that we are not alone in this battle.

As of this time, I am happy to share that my mom is stronger today than the day she was diagnosed. My mom used to be on oxygen 24/7 and needed a wheelchair to get around. Today she is only required to use oxygen when she sleeps, and she is able to even walk short distances. In the beginning there were frequent hospital visits that often resulted in short term stays. A few hospital stays resulted in a few months in rehabilitation centers. Today, I am thrilled to share that there are a lot less hospital visits and more wellness checks with her different doctors. Every day continues to be a challenge, some days more than others, but my mom is a fighter. I have to say my mom inspires me daily because she doesn't let this awful disease knock her down.

We may not have a cure for this ugly disease YET. However, ECD is not as invisible as it used to be. Just November 12, 2019 our very own township of West Norriton proclaimed the day as Rare Disease day. This is huge in spreading the word to our communities and garnering additional support and fundraising. I am confident of two things 1) mom will win this battle and 2) with the work of the Global Alliance and the efforts of its patients and caregivers, there will be a cure one day. Until that day, I encourage everyone to continue making awareness and educate anyone who will listen concerning ECD!

By Shannon Bennich

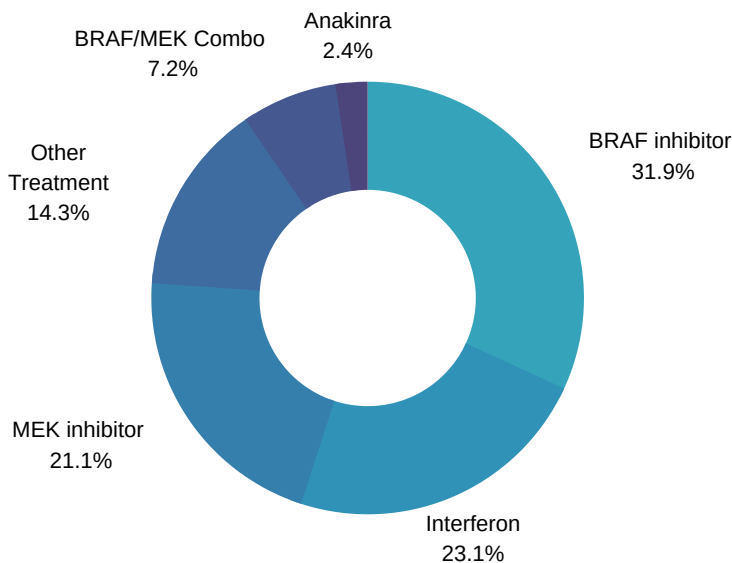


ECD CARE CENTER NETWORK

The following statistics were reported from 12 of the 32 International ECD Care Centers on 292 ECD patients. [Find a center.](#)

Data compiled August 7, 2019

Treatment Stats



Participation Stats

New patients in one year: **107**

Patient deaths reported in one year: **3**

Trials Stats

Number of open trials at these centers: **19**

Number of patients currently in a trial: **4**

New ECD Care Centers are in the recruitment process, these will be announced in 2020. If you know of a physician or center interested in more information about becoming part of the ECD Care Center Network, please have them contact our team.

Professional Involvement & Awareness

Our medical community dedicates hours of expertise to the advancement of care and treatments for ECD patients worldwide every year.

The Histiocytosis Working group at the ECD Care Center Mayo Clinic, in Rochester, MN, has completed the latest comprehensive guidelines outlining Erdheim-Chester Disease. These guidelines provide a Consensus Statement for the Diagnosis and Evaluation of Adult Patients With Histiocytic Neoplasms: Erdheim-Chester Disease, Langerhans Cell Histiocytosis, and Rosai-Dorfman Disease. The article & a short video can be found at [https://www.mayoclinicproceedings.org/article/S0025-6196\(19\)30273-3/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(19)30273-3/fulltext).

Scan or click the code to see the latest ECD Consensus Statement and short video.



An exhibit at the **American Society of Hematology** was hosted, where Kathy Brewer (ECDGA President), Nancy Feely (ECD Care Center Nurse) and Dr. Juvianee Estrada-Veras (ECDGA Board of Directors), engaged with hematologists during this annual event. Educational materials were specifically created for this audience by medical and design volunteers. You can access these resources to give to your doctor on our website.



Care Center physicians at the Mayo Clinic, Drs. Ronald Go and Gaurav Goyal, also created a series of three informative videos about ECD for this year's ECD Awareness Week. These videos are found to be very helpful to new and existing patients. Sharing this information with your treating doctor, who may not be familiar with ECD, may be beneficial as well.

Signs and symptoms

<https://www.youtube.com/watch?v=uXGIGPCv-Bk&feature=youtu.be>



Specialists & long-term monitoring

<https://www.youtube.com/watch?v=gc53FpPXcKM&t=18s>



Treatment options after diagnosis

<https://www.youtube.com/watch?v=5BJSD9eWP8k>



FUNDING

In 2019, \$191k was raised to continue the work of the organization by private donors. See how each of your dollars stack up in each category.

Amazon Smile

By selecting the ECD Global Alliance on Amazon Smile, we receive 0.5% on each purchase.

Corporate Matching

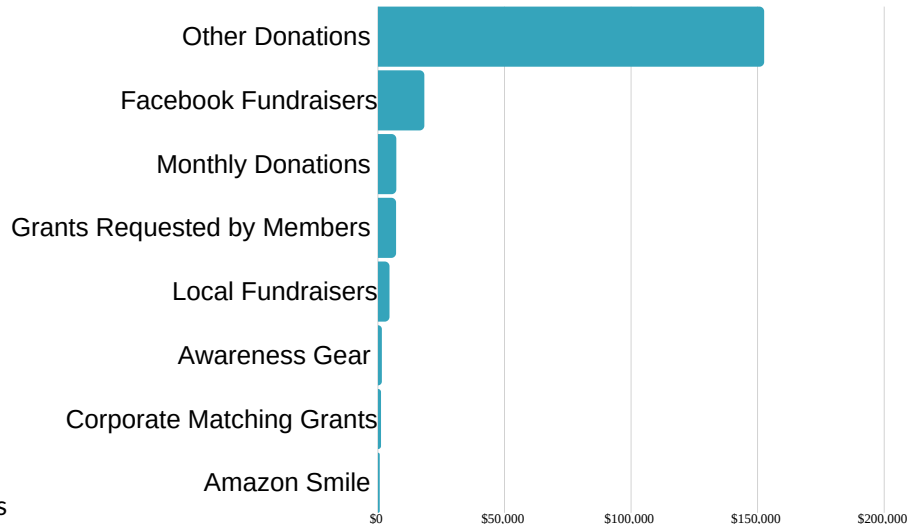
Ask your employer if they will match donations to the ECDGA, this is a simple way to fundraise for your advocacy group.

Grants Requested by Members

Several of our members submitted requests for grants from other foundations, resulting in \$7,000 in funding to our general fund.

Monthly Donations

This can be setup with your bank or through our website donation page, by choosing "recurring" gift. Let us know if you need help!



HOW TO DONATE:

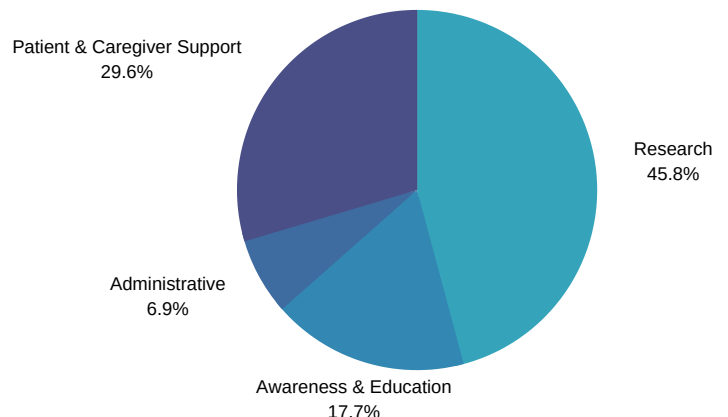
Checks, payable to:
 ECD Global Alliance
 P.O. Box 775
 DeRidder, LA 70634

On our website:
www.erdheim-chester.org
 Facebook:
[@ErdheimChesterDisease](https://www.facebook.com/ErdheimChesterDisease)



EXPENSES

The ECDGA team reduces costs on administrative and overhead fees as much as possible. Research continues to be the highest funded ongoing initiative of the ECDGA.



ANNUAL EVENT REVIEW

Milan, Italy

July 2019

Medical Symposium

A total of 38 medical professionals from around the world gathered at the meeting in Milan, Italy on July 11, 2019. Physicians from *China and Japan joined the meeting this year for the first time!* The symposium united attendees in the discussion of studies, experiences, and knowledge regarding Erdheim-Chester Disease.



Patient & Family Gathering Speakers volunteer their time at these meetings to bring the newest information regarding ECD to the families.

Thank you to our welcoming host, Dr. Lorenzo Dagna, his fantastic assistant Stefania Laus, our dedicated volunteers, medical speakers and staff!

“

[THE ECD GLOBAL ALLIANCE] PROVIDES A DISCUSSION MEDIUM AND RESEARCH FUNDS TO FURTHER OUR UNDERSTANDING OF ECD AT THE BASIC, TRANSLATIONAL, AND CLINICAL LEVELS.

- Benjamin Durham, MD
Memorial Sloan Kettering
Cancer Center



Event video presentations are available on our YouTube channel and website.



Patient & Family Gathering

During the PFG, the medical professionals strongly encouraged the patients to get involved with the work of the ECDGA. One speaker mentions, “The ECDGA has played an important part in improving treatment. I cannot overstate the importance of this organization in helping patients.” *A large percentage of attendees were able to meet and exchange with other families for the first time ever.* Thank you to our financial sponsor, Father Charles Balnaves, for making these connections possible.

“

JUST DIAGNOSED. EVENT EXTREMELY VALUABLE. KNOWLEDGE AND COMMUNITY!

.....

A THOROUGH (PROFOUND) VIEW OF VARIOUS OR ALL ASPECTS OF ECD & DRUGS.

.....

VERY HELPFUL TO MEET OTHERS WITH ECD FOR THE FIRST TIME.

ECDGA IS PUTTING ITSELF IN PATIENTS’ SHOES. HELPING PATIENTS TO SHARE AMONG ONE ANOTHER.

.....

I HAVE DONE A COUPLE OF CLINICAL TRIALS. IT HELPS ME TO BE ABLE TO PROVIDE INFO TO CHECK IF I AM DOING ALL I CAN

”



In Memory of

A special dedication to our members lost in 2019.

Over the past 10 years, the prognosis of ECD has improved tremendously. Patients have lived for more than a decade while managing the disease. A strong support system and the willingness to fight for the care you deserve can carry a family through many hurdles. These are just a few families that have agreed to share something about their loved ones with our community. We are honored to be a part of their journey.

Raina Evans

1991 - January 3, 2019

Raina was an accomplished musician who loved art. She loved life and was always a loving and giving person. She was very independent. A quote: This is the highest wisdom that I own; freedom and life are earned by those alone who conquer them each day anew.

~Johann Wolfgang von Goethe



Rhonda Cockerham

May 22, 1951 - November 3, 2019

Her favorite bible verse: Philippians 4:13
"I can do all things through Christ who gives me strength."

~Submitted by the Family



Tracy C. Cook

February 14, 1958 - April, 4 2019

ECD may have taken your life, but it did not take the precious memories your family will forever cherish. As we strive to "carry on" as you would want us to, we continue to pray for a cure.

~Submitted by the Family





ATTITUDE OF GRATITUDE

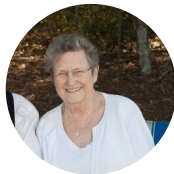
Volunteers & donors, near and far, help the ECDGA continue to grow each year!

What happens behind the scenes?!

Volunteers are the lifeblood of the organization, supporting the community and contributing approximately 1,000 hours of service to numerous essential programs and functions. We want to recognize a few volunteers in this year's newsletter as outstanding examples of dedication and passion for the growing ECDGA membership.

Bridget Gates

For 10 years, since the inception of the ECDGA, Mrs. Bridget has been bookkeeping and managing our accounts to the penny! This is only one of her many tasks since that first year of projects for the Alliance. From event assistance to editing documents, she has been trustworthy support to our team week after week.



Jason Corkran

For several years, Jason has served at annual events, local fundraisers, helped with computer and equipment troubleshooting, acquired sponsorships for fundraisers and raises awareness as much as possible.



Dearbhaile Dooley

The Dooley family as a whole has served the ECDGA with many fundraisers and volunteer hours since their father, Vivian, was diagnosed in 2012. We highlight Dearbhaile for her recent emcee role she filled in Italy, when we were in need of a last minute save! She handled it like a champ and didn't hesitate! She has spent many hours over the years translating our Dutch web pages and managing several other translation volunteers for other languages.



Michael Green

Mike has served at our recent annual event, assisted in local fundraisers, repaired office damage, donated equipment to the staff, and more.



Diane Schriener

As a new Board member this year, Diane has shown her passion for the ECD family with countless hours as Treasurer for the ECDGA, organizing monthly and annual figures while keep our team organized. She has also served on a subcommittee to organize important meetings this year.



Thank you to all of our volunteers and donors for making the future brighter for ECD families!

LOOKING AT 2020

The ECD Global Alliance is ready to continue the fight for our families with more support on the horizon.

New Patient & Caregiver Guide

The ECDGA will coordinate with leading ECD- knowledgeable doctors, nurse practitioners, therapists, a writer, and various patient and caregiver volunteers to obtain accurate and helpful material to create a navigational guide. This comprehensive guide is hoped to assist patients and families throughout their journey with this rare disease. The guide will focus on challenges unique to ECD, with topics including everyday care, navigating the medical system, and family communication help.

New Research Grant

The organization is steadfast in exploring the diagnosis, cause, and treatments for Erdheim-Chester Disease. A young investigator award is currently under review and will be announced early in 2020! The results of other research projects funded by the ECDGA will also be releasing updates in the coming year, so stay tuned.

[Donate toward this fund.](#)

8th Annual International Events

The 2020 events will be hosted on August 31 - 1, 2020 in Rochester, MN at the Mayo Clinic. This will be an opportunity for the community to engage at one of our leading care centers. Hosting this year is Dr. Ronald Go. Registration will be open in January!

[Learn more.](#)

Remember to use our website to stay up to date. Check out the navigation improvements that have been made at www.erdheim-chester.org!

ECD Patient Registry

The ECDGA is dedicated to the funding the management of this vital resource for this rare community alongside the Memorial Sloan Kettering Research Team. Patient recruitment is now at approximately 160 members. Participation from all US members is possible and encouraged; while funding is being sought to employ translations for other languages as well.

[Learn more.](#)



Current Board of Directors

L to R: Dr. Juvianee Estrada-Veras, Glenn Padnick, Jean Campbell, Linda Adams, Kathy Brewer, Diane Schriener

SAVE THE DATE

National Rare Disease Day
February 29, 2020

Patient & Family Gathering
August 31 - September 1, 2020

6th ECD Awareness Week
September 7 - 13, 2020