



What's happening in the community?

ECD GLOBAL ALLIANCE

2019 Summer Newsletter

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Thank you for your interest and engagement in the work of the ECDGA!

The ECDGA is 10 Years Strong!

Ten years ago, the ECDGA started with three amazing women - Joanna, Kathy, and RuthAnn. They were caregivers on a mission to ensure other patients and families did not feel as alone living with an ECD diagnosis!

Please help us celebrate this milestone by participating in our 10|10|10 Fundraiser. We challenge you to ask 10 of your friends or family to donate \$10 each for a 10 week celebration! See this flyer for more information and helpful tips.



[10|10|10 Fundraiser Guide](#)

View and share our community accomplishments during your fundraising!

[10 Years of Accomplishments Flyer](#)

Want to share your ECDGA story with us? Please email Chesnee at chesnee.green@erdheim-chester.org for more information.

Awareness News

During the recent 5th ECD Awareness Week, over 20,000 people were exposed to information about Erdheim-Chester Disease. Videos about ECD were viewed over 3,000 times and \$1,745 was raised to

benefit the community.



The Undiagnosed

Over the last week, we have talked about the importance of sharing ECD awareness in the medical communities that surround us. Below are pictures and short stories of those that lost their battle with ECD because they were not diagnosed in time to have the chance to fight or have the benefit of effective treatments. They each spent years searching for answers that never came.



Gary Brewer

Gary Brewer fought valiantly for three and a half years, searching for the cause of his worsening medical issues. Gary and Kathy lived in a world of the unknown, feeling very alone in their search for answers. It was not until a month after Gary passed away that the autopsy results revealed the Edith Chester Disease diagnosis. At that point, it became obvious to Kathy that Gary had been suffering from ECD for at least two decades.



Gary Brewer passed away in 2007 undiagnosed.

Thank you to all that participated in educating others about ECD to help the #undiagnosed!

Read these short stories about those that were not given the chance to fight ECD, which is the very reason we will never stop raising awareness of this disease.

[The Undiagnosed](#)

Mark Your Calendar



SEPTEMBER 17- 18, 2020

The 8th Annual ECD Patient & Family Gathering will be held in Rochester, MN at Mayo Clinic.

Will you attend the annual event?

LOCATION

Mayo Clinic in Rochester, MN

DATE AND TIME

09/17/20 6:00pm-09/18/20 7:00pm

The Patient & Family Gathering unites patients and family members, increases their knowledge, and makes a stronger community!



From the Mayo Clinic

Something interesting to share with your doctor:

Mayo Clinic released a consensus statement from their Histiocytosis Working Group. In-depth diagnosis and evaluation information is included

Consensus

Treatment

to assist physicians and patients balance the care for ECD and other histiocytosis. In addition, the Mayo team also produced several videos to help ECD patients with some of their most frequent questions.

Monitoring ECD

ECD & Symptoms

First Mexico Member Tells Her Story

Please take a moment to read about the journey of young woman that faced isolation with bravery and hope. Adriana states, *"I live with the uncertainty that at any moment a part of my body will begin to fail."*

But in the end, she knows she is not alone. *"Now that I am ok, it's time to help me to not think bad things and at the same time help others to be ok and diagnosticate."*

[Read Hope Without Borders](#)



The 7th Annual International Erdheim-Chester Disease Patient & Family Gathering in Milan, Italy was a success! Catch up with the video presentations, which include all slides.

Get to know the speakers in the speaker program, including biographies and photos.

2019 Italy Presentations

Speaker Program

Please join the weekly chat session this Saturday at 3:00 PM US Eastern Time.

A MODERATOR will be online this week to help with any questions! Anyone interested in ECD is welcome to attend. Click [here](#) to enter the chat room area.

THANK YOU to each of our members for making the ECDGA possible!

Together we will achieve great things for all affected by ECD worldwide!

ECD Global Alliance | P.O. Box 775, DeRidder, LA
www.erdheim-chester.org | fundECD.org

