

**FOR IMMEDIATE RELEASE**

November 11, 2015

Erdheim-Chester Disease Global Alliance

337-423-3012

www.erdheim-chester.org



Left to Right: Juvianee Estrada-Veras, MD, Kathy Brewer, ECD Global Alliance President, Amy Teare, Volunteer, Filip Janku, MD, PhD

**GLOBAL EXCELLENCE AWARDS  
GIVEN FOR RARE DISEASE  
ADVOCACY**

*THE ERDHEIM-CHESTER DISEASE  
GLOBAL ALLIANCE HONORS  
ADVOCATES AT PATIENT AND FAMILY  
GATHERING*

**HOUSTON, TX, October 10, 2015 –**

Exceptional contributors recognized at the Third Annual International Erdheim-Chester Disease Patient & Family Gathering (ECD-PFG). The conference, in support of those

affected with the ultra-rare condition, Erdheim-Chester Disease (ECD) honored several community members. Awarded were Juvianee Estrada-Veras, MD from the National Human Genome Research Institute at the National Institutes of Health, Ms. Amy Teare, volunteer from Houston, TX, Filip Janku, MD, Ph.D. from The University of Texas MD Anderson Cancer Center, and Mrs. Gail Hobson, contributor from Lake Tahoe, NV (*not pictured*). Award recipients' each received the Erdheim-Chester Disease Global Alliance (ECDGA) Award of Excellence for their highly engaged contributions to the ECD community. The Marriott Medical Center in Houston, TX held the awards ceremony on Friday, October 8 and Saturday, October 10.

The ECDGA Awards of Excellence are to distinguish exemplary participants in the ECD community. Exemplary behavior heightens advocacy opportunities that make an impact on those affected by ECD.

The first acknowledged was Dr. Janku from MD Anderson Cancer Center. In his honor speech, Ms. Brewer stated, "Last year he volunteered to host the Medical Symposium and Patient & Family Gathering at MD Anderson and he has been engaged to make it happen ever since. Whenever something needed to be done or we had a question, he found time to help us."

In addition to Dr. Janku, Ms. Teare from Houston, TX was honored for being a "powerhouse in helping to make this event extra special." Ms. Brewer noted, "When she heard that we would be having the event in Houston, she went to work. It became her mission to make this the best event possible."

Also recognized, Dr. Estrada-Veras from NHGRI. "[He is] one of the strongest advocates for ECD patients and their families. As a fellow at the NIH, he learned about ECD and since then has worked tirelessly for the community. Dr. Juvianee Estrada-Veras devotes a large portion of his time and energy to helping ECD patients." As quoted from Ms. Brewer.

*"We have globes that signify that we are one global community, all here to support one another as we move together towards tomorrow." - Ms. Kathy Brewer, ECDGA President*

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Also honored were Mrs. Gail Hobson and her late husband, Larry T. Hobson. They were the first family to get involved with the ECDGA in its infancy in 2009 while searching for help for their son, diagnosed with ECD. At a time when few had heard of the ultra-rare condition, let alone knew how to treat and fight it, the Hobsons were motivated to get involved with an organization that wanted to pave a path where one did not exist. In Ms. Brewer's words, "This family's contributions allowed the ECD Global Alliance to gain its footing and immediately become successful in its advocacy work. Since their initial involvement, more people have also become involved, which is exactly what this couple was hoping would happen. Gail and Larry T. Hobson were the first followers of the ECD Global Alliance movement."

The Erdheim-Chester Disease Medical Symposium and ECD-PFG are annual events. The goals of the conferences are to facilitate collaboration and education between medical professional in various specialties about the rare condition, as well as, promote fellowship and education amongst patients and family members. The Fourth Annual International Erdheim-Chester Disease Medical Symposium and Patient & Family Gathering are in Paris, France and hosted by Julien Haroche, MD, Ph.D. from Hôpitalier Pitié- Salépêtrière in Paris, France.

Erdheim-Chester Disease is an ultra-rare condition with no known cause and very often misdiagnosed. It is considered a non-Langerhans histiocytosis, cancer-like (neoplastic) disease. The illness characterized by the accumulation of histiocytes, cells that normally fight infections, in tissue and organs. The tissue and organs become dense and fibrotic due to the infiltration of the histiocytes and can lead to organ failure without finding a successful treatment. Currently, there is no cure for ECD but breakthrough ECD research is at the forefront of science and "precision medicine," illustrating that therapies targeting a specific genetic mutation can be effective, regardless of where cancer originates.

Learn more about Erdheim-Chester Disease and what you can do to help today by visiting [www.erdheim-chester.org](http://www.erdheim-chester.org).

About the Erdheim-Chester Disease Global Alliance:

The ECD Global Alliance, founded in 2009, is a 501(c) 3 non-profit organization dedicated to awareness, support, education, and research related to Erdheim-Chester Disease. To donate, please send a check to ECD Global Alliance | P.O. Box 775 | DeRidder, LA 70634 or go online to <http://www.razoo.com/story/Ecd-Global-Alliance> Thank you for your support!

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