

FOR IMMEDIATE RELEASE:

Global nonprofit with local roots fights rare disease

The Erdheim-Chester Disease Global Alliance supports those affected by Erdheim-Chester Disease out of DeRidder, Louisiana

DeRidder, LA, - June 28, 2016 – The Erdheim-Chester Disease Global Alliance (ECDGA) is a grassroots 501(c)(3) nonprofit supporting people affected by the ultra-rare cancer, Erdheim-Chester Disease (ECD). DeRidder native, Kathy Brewer founded the ECDGA in 2009 after the passing of her beloved husband, Beauregard Parish school superintendent, Gary Brewer. The small town organization assists ECD sufferers worldwide by raising awareness of ECD, providing patient and caregiver support, advocating for and funding ECD-related research, and promoting education about ECD.

From the rural Louisianan town, people in 43 countries are given resources to help find proper medical care, learn about the rare condition, and connect with each other. Annually, since 2013, the ECDGA has organized and hosted an international patient and family conference joining typically isolated ECD sufferers to learn about current research and medical findings of the disease and provide real-time fellowship.

The ECDGA also hosts annual medical symposia for medical professionals studying and interested in ECD. Close partnerships with medical institutions such as The University of Texas MD Anderson Cancer Center, Memorial Sloan-Kettering Cancer Center, Johns Hopkins Hospital, and the National Institutes of Health and their researchers has placed ECD at the forefront of precision medicine. New genetic findings are providing emerging treatments with promising results. The ECDGA has a leading role in funding this life-saving research.

A host of volunteers and two part-time staffers make the organization's accomplishments possible. The ECDGA highly leverages technology such as video and teleconferencing to stay connected across the globe with its intercontinental talent pool. The dedicated volunteer and staff team has made numerous educational, supportive, and fundraising events possible, generated physician and general public awareness globally, and with the help of their close-knit medical community, facilitated an ECD Referral Care Center hospital network and is developing an ECD Patient Registry.

Learn more about the hometown ECD Global Alliance by visiting their website, www.erdheim-chester.org or support those affected by ECD by donating to the ECDGA at www.fundECD.org.

[Erdheim-Chester Disease](#) is a rare multi-systemic non-Langerhans histiocytic neoplasm with no known cause that is challenging to diagnose and treat. Unless successful treatment is found, organ failure can occur.

Contact:

Elizabeth Silva Anderson

liz.anderson@erdheim-chester.org

(337) 404-6033

(388 words)