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FOR IMMEDIATE RELEASE

ECDGA Raises Awareness at Endocrinology Conference

Erdheim-Chester Disease Global Alliance participates in ENDO Expo in New Orleans

New Orleans, LA – March 23, 2019 – Representatives from the Erdheim-Chester Disease Global Alliance (ECDGA) attended the Endocrinology Society's annual conference in New Orleans this past weekend to raise awareness of Erdheim-Chester Disease (ECD) among attending endocrinology specialists. The exhibit provided resources developed by ECD Global Alliance medical community members, Dr. Hannah-Shmouni Fady, MD, DABIM, FRCPC, National Institutes of Health, and Carine Courtillot, MD, Hospitals Pitié Salpêtrière. The trade meeting allowed the Alliance to connect with doctors and offer them information that will help in the diagnosis and treatment of ECD.

The ECDGA's ENDO 2019 participation was well-received by the visitors and value was found in reaching out to this group through this large conference. Juvianee Estrada-Veras, MD, ECDGA Board of Director, Kathy Brewer, ECDGA President, and Nancy Feely, RN, John's Hopkins Hospital, managed the ECDGA booth during the event. Booth attendees were excited to learn more about ECD, the recent discoveries being made in this field, and about the ECD Global Alliance's existence to support those affected by the disease. Many of the physicians stopping by the ECDGA booth were surprised to find that rapid advances were being made in the treatment and management of ECD. These specialists expressed their interest in learning about the activities of the ECDGA and becoming more knowledgeable about how to diagnose and care for ECD patients.

The Erdheim-Chester Disease Global Alliance was appreciative to see ECD case studies and research progress showcased through poster and platform presentations from the National Institutes of Health, University of Pittsburgh Department of Medicine, and Mayo Clinic.

ECD is an ultra-rare type of blood cancer that is difficult to diagnosis and can manifest in a variety of complex ways. There are many different endocrine dysfunctions seen in ECD patients. Endocrinologist, together with other clinicians, pathologists and radiologists, play a vital role in identifying ECD. If doctors can accurately and quickly recognize ECD in a patient, there are viable FDA-approved and off-label treatments available to improve quality of life, slow progression of the life-threatening disease, and in some cases, possibly reverse damage done by the disorder. The key to a successful or more positive outcome is early diagnosis. ECD patients typically experience a range of hormonal issues. Endocrinologists are the specialists that help patients manage their hormones to improve their health and quality of life.

[Download](#) this informative guide applicable to endocrinology in ECD!

To learn more about ECD visit <http://erdheim-chester.org/>.

[Erdheim-Chester Disease](#) is an ultra-rare condition that is believed to be under diagnosed. It is considered a histiocytic neoplasm (type of blood cancer). The illness is 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 unless a successful treatment is found.

The [ECD Global Alliance](#) is a 501(c)(3) non-profit organization dedicated to awareness, support, education, and research related to Erdheim-Chester Disease.

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