



**Contact:**

Jessica Corkran, Executive Director  
ECD Global Alliance  
(337) 502-8034  
jessica.corkran@erdheim-chester.org

**FOR IMMEDIATE RELEASE**

**Miami Physicians Gather to Learn About the Rare Erdheim-Chester Disease**

*Mayo Clinic physician presents Erdheim-Chester Disease and other histiocytic disorders to residents at the University of Miami.*

Miami, FL, July 13, 2018 – University of Miami hosted a medical presentation to further residents’ education in histiocytic disorders. The speaker, Dr. Ronald Go of Mayo Clinic in Rochester, MN, discussed the features and management of Erdheim-Chester disease (ECD) and other histiocytoses. As an ECD Referral Care Center lead physician, Dr. Go is well-versed in care and treatment for these rare patients. The Grand Round presentations hosted by learning institutions provide an essential opportunity to educate upcoming medical professionals and support their experience with the real-world examples and current data.

Representing the ECD Global Alliance (ECDGA) at the presentation was Teresa Mesa, ECD patient and member of the ECDGA. Teresa was responsible for arranging this opportunity to spread awareness of ECD which is considered an extremely rare blood cancer. She refers to Dr. Go’s presentation, *Erdheim-Chester: A Disease in Search of a Diagnosis*, saying “this statement is so true and the reason these talks are so important. Physicians need to know about this disease to make a proper diagnosis. As it is now, patients are sometimes misdiagnosed and go on as such for years.”

Generating physician awareness is important to help those affected by rare diseases. Increasing the knowledge of these conditions within the physician community aims to raise the chances of a timely diagnosis for those affected. Earlier diagnoses and proper treatment directly result in a significantly improved prognosis for patients suffering with ECD.

Dr. Ronald Go states, “In light of the progress we have made with regards to the treatment and understanding of the biology of Erdheim-Chester Disease, early diagnosis now becomes even more important. Raising the awareness of ECD clinical presentation among primary care clinicians, radiologists, and pathologists may help shorten the time to diagnosis.”

The ECDGA, through the support of its generous donors, was able to provide this awareness program. The program requires volunteers and staff to plan the talks through medical school contacts and provide travel



(L to R) Dr. Denise Pereira (UM), Teresa Mesa (ECDGA Member), Dr. Ronald Go (Speaker, Mayo Clinic), Dr. Joseph Rosenblatt (UM)

expenses for the speaking doctors. The program has successfully reached hundreds of young doctors in the US so far and has been well-received by students and faculty alike.

To host or organize a medical professional ECD awareness event at a local university or medical institution contact [support@erdheim-chester.org](mailto:support@erdheim-chester.org) for more information and help.

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[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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