

FOR IMMEDIATE RELEASE:

NIH Researchers Educate Doctors About ECD in New Orleans

Erdheim-Chester Disease and the NIH Undiagnosed Disease Program were the topics of discussion at joint LSU and Tulane University event.



From Left to Right: William Gahl, M.D., Ph.D. Kathleen Brewer, ECD Global Alliance President, and Juvianee Estrada-Veras, M.D.

New Orleans, LA - April 28, 2017 – At the Louisiana Cancer Research Center, Louisiana State University and Tulane medical students and faculty listened to researchers from the National Institutes of Health (NIH) discuss the agency's Undiagnosed Disease Program (UDP) and research being done in Erdheim-Chester Disease (ECD) as part of the UDP. UDP Director, William Gahl, M.D., Ph.D. and ECD researcher, Juvianee Estrada-Veras, M.D. with the NIH were jointly hosted by Lucio Miele, M.D., Ph.D., Louisiana State University Health Sciences Center and Hans Andersson, M.D., Tulane University School of Medicine. The high-profile seminar discussed breakthroughs in precision medicine in treating rare diseases and ECD.

ECD is a life-threatening ultra-rare blood cancer. The only organization dedicated to supporting those affected by ECD, the ECD Global Alliance (ECDGA), is based out of DeRidder, Louisiana and was the catalyst for reaching out to Dr. Miele to organize the event.

The NIH has worked closely with the ECDGA in learning more about ECD. In February, findings from a Natural History Study conducted by Dr. Estrada-Veras were published. The results of the study demonstrated the varied nature of ECD and makes a case that ECD should be adopted by the field of hematology-oncology following the 2016 World Health Organization reclassification of ECD as a blood cancer (histiocytic neoplasm). In addition, Dr. Estrada-Veras was the primary investigator of an NIH clinical trial researching the efficacy of two therapies in the treatment of ECD. Preliminary results shared by early participants are very positive, offering hope to patients who currently have no FDA-approved therapy for their illness.



From Left to Right: Lucio Miele, M.D., Ph.D., event co-host, William Gahl, M.D., Ph.D., and Juvianee Estrada-Veras, M.D.

The talk complemented recent efforts in the building of a Precision Medicine Program at LSUHSC where researchers in New Orleans are very involved in furthering knowledge of human genetics and genomics.

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

For more information about the ECD Natural History Study please see <http://erdheim-chester.org/news/eCD-natural-history-study-case-report/>.

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

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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