

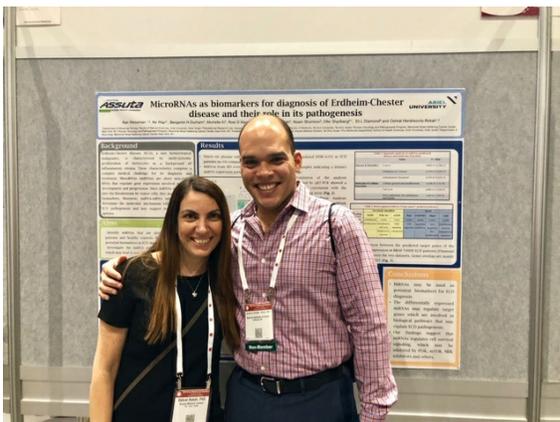


FOR IMMEDIATE RELEASE



## The Erdheim-Chester Disease Global Alliance Raises Awareness of ECD at ASH 2018

*Hematologists eagerly engage with ECDGA exhibitors to learn more about ECD.*



San Diego, CA - December 12, 2018 – Representatives from the Erdheim-Chester Disease Global Alliance (ECDGA) attended the American Society of Hematology (ASH) annual conference in San Diego this past week to raise awareness of Erdheim-Chester Disease (ECD) among attending specialists. The exhibit provided resources developed by ECD Global Alliance medical community members. The trade meeting allowed the Alliance to connect with doctors to offer them information that would help in the diagnosis and treatment of ECD.

ECD is an ultra-rare type of blood cancer that is difficult to diagnosis and can manifest in a variety of complex ways. Hematologists, 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, even possibly reverse damage done by the disorder. The key to a successful or more positive outcome is early diagnosis.

The ECDGA's ASH participation was well-received by the visitors and value was found in reaching out to this group through this large conference. The booth hosted 200 hematologists from around the world, including China, India, Israel and

Brazil. 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 physicians and scientists volunteered with the ECDGA to provide information to booth attendees during the event. Board member, Juvianee Estrada-Veras, MD, National Institutes of Health, and Gaurav Goyal, MD, Mayo Clinic, along with ECDGA President, Kathy Brewer collectively made the event a huge success.

Concurrent with the ECD booth, presentations were provided to share ECD knowledge among hematologist earning continuing medical education credits. Carl Allen, MD (Texas Children's Hospital, Houston) discussed the mutations found in patients diagnosed with histiocytic disorders including ECD. In addition, a number of poster presentations further explaining recent findings in the understanding of ECD were provided by Gaurav Goyal, MD (Mayo Clinic, Rochester), Oshrat Rokah, PhD (Ariel University, Israel), and Julien Haroche, MD, PhD (Hôpital Pitié-Salpêtrière, France).

Learn more about the resources provided at ASH by visiting <http://erdheim-chester.org/resources/>.

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## About ECD Global Alliance

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

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

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