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FOR IMMEDIATE RELEASE

Houston Methodist Hospital Grand Round Includes ECD Updates

Mark Heaney, MD, PhD presents Histiocytoses including Erdheim-Chester Disease

Houston, TX, June 12, 2018 – Medical residents and physicians at Houston Methodist Hospital in Houston, TX learned about histiocytic disorders, with an emphasis on Erdheim-Chester disease (ECD) from the Columbia University Medical Center ECD Referral Care Center lead physician, Mark Heaney, MD, PhD. Dr. Heaney discussed the characteristics and management of LCH, Rosai Dorfman and ECD. Grand Round presentations such as these are vital in educating medical professionals of rare diseases and sharing the latest research findings.

In attendance at the presentation was Kathy Brewer, President of the ECD Global Alliance. This presentation was especially poignant for Brewer who stated, “My husband was provided the best medical care possible when he was ill and being treated at Methodist hospital beginning in 2004 until his passing in 2007. At that time, ECD was virtually unknown in the medical community, with extremely limited treatments available. It is comforting to know that today an ECD patient is much more likely to be diagnosed and a successful treatment found.”

ECD is an ultra-rare blood cancer that can affect different organs of the body, in a variety of ways, making diagnosis perplexing to clinicians. Generating physician awareness is a key activity in helping those affected by ECD. Targeting the new generation of doctors through educational discussions will help them become more knowledgeable and offer real-world examples to learn from. With an increase in knowledge of rare disease, a diagnosis can be expedited and those affected will be more likely to receive the best treatment in a timely manner, significantly improving prognosis.

There are a number of possible treatments for ECD that help slow the progression of the disease. Heaney shared with attendees that one treatment is FDA approved, stating, “It is remarkable that a disease as rare as ECD has an FDA approved treatment.”

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 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.



Dr. Mark Heaney (Speaker), Dr. Lawrence Rice (Houston Methodist Hematologist), Kathy Brewer (ECDGA President)

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.

[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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