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Erdheim-Chester Disease Global Alliance www.erdheim-chester.org

NEW YORK PATHOLOGIST AWARDED 2017 GRANT BY ECD GLOBAL ALLIANCE

The ECD Global Alliance awards Erdheim-Chester disease research grant to MSKCC to define the disease-initiating cell population in ECD and compare genetic alterations.

DERIDDER, LA, January 2, 2018 – The Erdheim-Chester Disease Global Alliance (ECDGA) awarded a new research grant to Memorial Sloan Kettering Cancer Center (MSKCC), in New York, NY, to study the rare Erdheim-Chester Disease (ECD). Primary investigator, Benjamin H. Durham, MD will lead the study *Defining the Cell-of-Origin of Erdheim-Chester Disease*.

The aim of this study is to understand the underlying cause of the ultra-rare blood cancer, Erdheim-Chester Disease. The bone marrow cells from ECD patients will be studied to try to determine the cells that cause ECD. With this information, it may be possible to create a successful model of ECD that can be used for future studies by scientists from around the world. A secondary goal for this study will be to compare the gene profile of ECD cells with the cells of other blood cancers that are often seen in ECD patients. It is hoped that this information will have a direct, positive impact on therapeutic options for patients.

Dr. Durham is a hematopathologist and molecular genetic pathologist who has previously identified various genetic mutations associated with ECD. These findings have led to immediate therapeutic options for patients.

The ECDGA is excited to be funding this groundbreaking work and believes it will result in a brighter future for ECD patients and a better understanding of other blood cancers.

Research is a mission-critical goal for the ECDGA. The organization has previously awarded nine (9) medical research grants, devoting over \$650K to ECD medical research. Funding for grants comes from generous, private donations. ECD research efforts, backed in part by the non-profit, have recently led to an FDA approval of a drug called vemurafenib, originally developed to treat other types of cancers, such as melanoma skin cancer, to treat ECD patients with the BRAFV600E mutation.

Erdheim-Chester Disease is an ultra-rare condition with no known cause and is very often misdiagnosed. 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.

Learn more about ECD and other studies by visiting www.erdheim-chester.org.

About the Erdheim-Chester Disease Global Alliance:

The ECD Global Alliance, founded in 2009, is a 501(c) 3 non-profit organization dedicated to awareness, support, education, and research related to Erdheim-Chester disease. To help support the organization, please donate via a check to ECD Global Alliance | P.O. Box 775 | DeRidder, LA 70634 or go online to www.FundECD.org. Thank you for your support!

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