

FOR IMMEDIATE RELEASE

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Erdheim-Chester Disease Global Alliance

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www.erdheim-chester.org

A LEAP FORWARD IN RARE DISEASE TREATMENT

ERDHEIM-CHESTER DISEASE COMMUNITY COLLABORATES TO CHANGE THE COURSE OF A DISEASE

DERIDDER, LA, MAY 15, 2015- A new film provides patients with hope and information. Aimed at increasing awareness of the rare Erdheim-Chester Disease (ECD), the film includes patients and medical professionals sharing how the course of this deadly disease is being changed. By determining the genetic makeup of ECD tumors, researchers are finding that targeted therapies are resulting in dramatic improvements in patient outcomes.

Dr. Juvanee Estrada-Veras and Dr. William Gahl at the National Institutes of Health; Dr. Filip Janku and Tami Barnes, RN with MD Anderson Cancer Center; and Dr. Omar Abdel-Wahab, Dr. Eli Diamond, and Dr. David Hyman at Memorial Sloan-Kettering Cancer Center joined forces to share ECD's medical advancements and expressed their hope for this community. Two ECD patients also make an appearance, sharing their stories and struggles. John DeWitt and his wife Amy from Houston, TX and Vivian Dooley of Ireland have a strong desire to help others who are fighting this disease.

"I want patients to know that there is hope. The research is promising. In a couple of years we were able to move the field around Erdheim-Chester forward significantly."

– Dr. Juvanee Estrada-Veras, National Institutes of Health

Although approximately only 500-550 cases have been described in literature, increased physician awareness has driven a dramatic increase in ECD diagnoses over the last decade. This is a debilitating disease that can affect many organs of the body. The majority of ECD patients are diagnosed between the ages of 40-70, although children have been diagnosed. ECD can affect both men and women, with approximately 60% of reported cases affecting men and 40% women.

The cause of ECD is unknown. However, recent findings suggest a neoplastic or 'cancer-like' disorder, with more than 50% of patients testing positive for the BRAF V600E mutation. This is leading some in the medical community to classify ECD as a cancer rather than an auto-immune disorder.

Watch the inspiring video today by clicking here: <http://youtu.be/Mdk0TcPIDbY>

Get involved! Sharing this video will generate awareness and increase involvement with the organization! To find out more about ECD, symptoms, and treatments please visit 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 donate please send a check to ECD Global Alliance | P.O. Box 775 | DeRidder, LA 70634 or go online to <http://www.razoo.com/story/Ecd-Global-Alliance> Thank you for your support!

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