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FOR IMMEDIATE RELEASE

ECD Caregiver Study Open

Erdheim-Chester Disease Caregiver Study Open at Memorial Sloan Kettering

DeRidder, LA – February 29, 2020 – Memorial Sloan Kettering Cancer Center (MSK), an Erdheim-Chester Disease Global Alliance (ECDGA) Care Center, is accepting participants for an ECD caregiver study. Such studies are very important to understand the impact of providing care upon on the lives of caregivers. With this knowledge, efforts towards support and advocacy can be more effective and impactful to families living with ECD and other rare diseases.

Preliminary results from this study were published LEUKEMIA & LYMPHOMA on DATE, titled, [*The unique burden of rare cancer caregiving: caregivers of patients with Erdheim–Chester disease.*](#) Study authors performed survey and interview-based research among ECD caregivers to shed light upon the experience of providing care for someone with ECD.

"Our mixed-methods approach allows us to glean rich data from our participants and highlight opportunities to improve informal caregiver's care by, for example, offering supportive interventions to ameliorate anxiety, helping to foster the positive experience of caregiving, and by taking particular notice of informal caregivers of patients with cognitive impairments," explained Eli L. Diamond, MD, a neuro-oncologist at Memorial Sloan Kettering Cancer Center and principle investigator of the trial.

Study Objective: This is an observational study of informal caregivers (ICs) of patients with Erdheim-Chester Disease (ECD) and other histiocytic diseases. This study will collect data cross-sectionally, at a single time point. Caregiver-reported data will be completed in the form of online surveys by the participants themselves using the Research Electronic Data Capture Platform [RedCAP] platform.

Principal Investigator: Eli L. Diamond, MD, Memorial Sloan Kettering Cancer Center

Requested Participant Involvement: Self-identified informal caregiver (anyone who provides unpaid help or support) to an Erdheim-Chester Disease patient, 18 years and older, and proficiency to complete study assessments in English. Participants cannot reside in Europe because of European regulations. Caregivers of patients participating in the Registry for ECD Patients are specifically requested, if possible, and the study team can help facilitate registry enrollment.

ClinicalTrials.gov Identifier: [NCT03990428](#)

For more information on becoming a part of the caregiver study contact Dr. Eli Diamond and his team at 212-610-0720, email: neuhistiores@mskcc.org

For more caregiving resources, visit our website here: <https://erdheim-chester.org/caregiver-resources/>.

To join a caregiver chat group, [contact us](#).

To learn more about ECD visit <http://erdheim-chester.org/>.

[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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