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**FOR IMMEDIATE RELEASE**

**REGISTRY FOR PATIENTS WITH ERDHEIM-CHESTER DISEASE NOW RECRUITING**

*MSK and ECD Global Alliance collaborate to recruit patients for an ECD-dedicated registry database.*

**DERIDDER, LA, April 6, 2018** – The Erdheim-Chester Disease Global Alliance (ECDGA) announces the launch of the Registry for Patients with Erdheim-Chester Disease led by Memorial Sloan Kettering Cancer Center (MSK), in New York, NY. The next step in building the registry database includes recruiting patients with Erdheim-Chester Disease (ECD) to participate. Primary investigator, Eli L. Diamond, MD, will lead the research team at MSK to collect patient data in order to assist all interested stakeholders in treating patients battling this rare disease.

The registry will be a compilation of data pertaining to the consenting patients' history and the current effects of living with the disease through surveys completed by the patient or a loved one. Additionally, medical reports, scans, and biopsies will be collected directly from the patients' medical providers by the MSK team. The study findings will be used to help scientists advance our knowledge of ECD and its treatment.



*Justin Buthorn, MSK Research Team, Dr. Eli L. Diamond, Lead Investigator, Kathy Brewer, ECDGA President, Jessica Corkran, ECDGA Executive Director*

The objective of this registry is to collect data about as many ECD patients as possible and to understand more about what kinds of health problems are caused by ECD, what happens as a result of different treatments, and how ECD affects people's feelings and attitudes. Scientists will also be tracking how these things change over time for people with ECD. The registry is also designed for investigators to examine what kinds of treatments have been effective for different ECD patients.

"This is a very important moment for Erdheim-Chester Disease," Dr. Diamond said, "rare diseases can benefit in many ways from the existence of patient registry. The knowledge they create improves patient care, and the very existence of a registry makes the disease more visible and gives patients and families a stronger voice."

In 2014, the ECDGA awarded MSK with the funding necessary to develop the Registry for Patients with Erdheim-Chester Disease. The ECDGA is committed to continuing the registry's management and funding so we can continue the accumulation of invaluable information this database will provide to the community. Thanks to the members of the ECDGA, the dedicated medical community, and MSK, this database will be an incredible service to patients living with ECD well into the future.

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.

Learn more on the ECDGA website: [Registry for Patients with Erdheim-Chester Disease](#)

Learn more on the ClinicalTrials.gov website: [Registry for Patients with Erdheim-Chester Disease](#)

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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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