

# Caregiver Paper & Study Opportunity

Recently, Dr. Eli Diamond, published an important paper about the Caregiver Experience and histiocytosis following an analysis of a research project conducted with caregivers of patients with Erdheim-Chester Disease and other histiocytic neoplasms.

"Challenges and positive impact of rare cancer caregiving: A mixed-methods study of caregivers of patients with Erdheim-Chester disease and other histiocytic neoplasms", authored by Dr. Eli Diamond, Department of Neurology, Memorial Sloan Kettering Cancer Center, New York, NY with coauthors Deanna Fournier, Executive Director, Histiocytosis Association and Kathleen Brewer, President, EDC Global Alliance, is a research study that seeks to characterize unmet needs and experiences of caregivers of patients with Erdheim-Chester disease (ECD) and other histiocytic neoplasms (HN). The study also examined ways that caregivers are able to have positive experiences (i.e., finding benefit and meaning) in providing care for patients with histiocytosis.

Dr. Diamond and the study team found that many of the challenges facing histiocytosis caregivers are related to the rareness of histiocytosis and that increased education and social support may help caregivers cope better.

The caregiver study in this article is **ongoing**, and Dr. Diamond will also conduct additional studies focused on histiocytosis caregivers in the future. **If you have interest in participating in research as a caregiver for a histiocytosis patient, please email [neuhistiores@mskcc.org](mailto:neuhistiores@mskcc.org).**

In your email, please provide (1) your name, (2) the age of the patient you are caring for, (3) your relationship to the patient, and (4) their histio diagnosis (i.e. LCH, RDD, etc); you will be contacted as opportunities arise.

*Please note: these studies currently do not involve hemophagocytic syndromes (HLH), however should that change in the future, the Histiocytosis Association will update this information!*



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