

Proclamation

- WHEREAS, Erdheim-Chester Disease is one of the nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States, according to the National Institutes of Health (NIH); and
- WHEREAS, there is inadequate data on the incidence and prevalence of Erdheim-Chester Disease, but fewer than 600 cases have been documented in the medical literature worldwide since it was first described in 1930; and
- WHEREAS, the cause of Erdheim-Chester Disease is unknown, but genetic mutations have been discovered in the majority of ECD patients leading it to be classified as a myeloid neoplasm; and
- WHEREAS, the symptoms of Erdheim-Chester Disease vary from person to person and can include bone pain, weight loss, night sweats, muscle and joint aches, fatigue, flu-like symptoms, excessive thirst and urination, balance issues, slurred speech, kidney failure, bulging of the eyes, vision issues, rashes, shortness of breath, heart issues, and potentially organ failure; and
- WHEREAS, individuals and families affected by Erdheim-Chester Disease experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to treatments or ancillary services; and
- WHEREAS, Erdheim-Chester Disease, is virtually unknown, leaving patients and their families to bear a large share of the burden regarding critical issues such as raising funds for research, education, and awareness outreach; and
- WHEREAS, generating awareness of the rare disease, Erdheim-Chester Disease, a consistently under-diagnosed disease, will help patients and medical personnel recognize and help find treatment for those affected by the rare disease; and
- WHEREAS, residents of <<insert Local Area>> are among those affected by Erdheim-Chester Disease and
- WHEREAS, every year on the third week of the month of September, patients and caregivers, medical professionals, researchers, and companies developing treatments for rare disease join together to focus attention on Erdheim-Chester Disease.
- NOW, THEREFORE, be it resolved that September 12 – 17, 2016, will be observed as Erdheim-Chester Disease Awareness Week in <<insert Local Area>>.