

<< insert Month Date, Year >>

Dear << insert Title, Last Name of government authority >>,

I am writing to ask you to declare that September 11-16, 2017 will be Erdheim-Chester Disease Awareness Week in << insert Local Area >>. On that day, hundreds of people across the U.S. will join the Erdheim-Chester Disease Global Alliance (ECDGA) in observing this special awareness week.

Erdheim-Chester Disease has recently been declared a myeloid neoplasm by the World Health Organization. It is a debilitating and difficult to diagnose disease. Without a proper diagnosis, patients are not able to get proper treatment that can extend their lives and dramatically improve the quality of their lives. For this reason, raising awareness of ECD is critical to bring hope to those who are struggling to find a proper diagnosis and treatment.

As your constituent, I believe raising awareness of ECD is important because here in << insert Local Area >> those affected by the ultra-rare Erdheim-Chester Disease face extreme hardship. They must struggle to arrive at a proper diagnosis, educate members of their medical team about the disease, raise funds for research, and often fight for payment of life saving treatments. Raising awareness is a first step in changing this situation and providing the same support to ECD patients and their families as provided to those with other life threatening diseases.

This ECD Awareness Week, special events and activities are planned in schools, hospitals, universities and medical schools from September 11 - 16. Individuals and families affected by the extremely rare illness will be sharing their stories on social media; in radio, TV, and newspaper interviews; and at community events throughout across the U.S.

The << insert Local Area >> has a strong history of support for its citizens' causes. By declaring September 12 – 16, 2017 ECD Awareness Week in << insert Local Area >> you will help us raise awareness within our community. I hope that you will join me and step forward to show our concern for those who might otherwise feel isolated and let our neighbors living with Erdheim-Chester Disease know that, while their disease is rare, they are not alone.

With best regards,

<< insert Your Name >>

<< insert Your Email >> | << insert Your Phone Number >>

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 11-16, 2017 will be observed as Erdheim-Chester Disease Awareness Week in <<insert Local Area>>.