

<< insert Month Date, Year >>

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

I am writing to ask you to declare that September 12 - 17, 2016 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 12 – 17th. 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 – 17th, 2016 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 >>