



John Bel Edwards

GOVERNOR

Proclamation

- WHEREAS,** Erdheim-Chester disease (ECD) is one of the nearly 7,000 diseases and conditions considered rare in the United States, affecting fewer than 200,000 Americans, 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.
- NOW, THEREFORE,** **I, John Bel Edwards,** Governor of the State of Louisiana, do hereby proclaim September 11-16, 2017 as

ERDHEIM-CHESTER DISEASE AWARENESS WEEK
in the State of Louisiana.



*In Witness Whereof, I have hereunto set my hand
officially and caused to be affixed the Great Seal of the
State of Louisiana, at the Capitol, in the City of
Baton Rouge, on this 11th day of September
A. D., 2017.*

John Bel Edwards
Governor of Louisiana