



Proclamation *Presented to*

National Organization of Rare Diseases (NORD)

WHEREAS, the National Organization for Rare Disorders is a national, patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them; and

WHEREAS, according to the National Institutes of Health (NIH) there are nearly 7,000 diseases and conditions that are considered rare (each affecting fewer than 200,000 Americans) in the United States; and

WHEREAS, while each of these diseases may affect small numbers of people, rare diseases as a group affects almost 30 million Americans; and

WHEREAS, while more than 450 drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration (FDA), millions of Americans still have rare diseases for which there is no approved treatment; and

WHEREAS, individuals and families affected by rare diseases often experience problems such as diagnosis delay, difficulty finding a medical expert and lack of access to treatments or ancillary services; and

WHEREAS, while the public is more familiar with some rare diseases such as "Lou Gehrig's disease," many patients and families affected by lesser known rare diseases bear a large share of the burden of funding research and raising public awareness to support the search for treatments;

THEREFORE I, DAVID Y. IGE, Governor, and I, SHAN S. TSUTSUI, Lieutenant Governor of the State of Hawai'i, do hereby proclaim February 28, 2016 as

"RARE DISEASES DAY"

in Hawai'i and encourage the citizens of the Aloha State to join with patients, medical professionals, researchers, other government officials and companies developing treatments to raise awareness and to assist those who are affected by these conditions.

DONE at the State Capitol, in the Executive Chambers, Honolulu, State of Hawai'i, on this twenty-sixth day of February 2016.

DAVID Y. IGE
Governor, State of Hawai'i

SHAN S. TSUTSUI
Lt. Governor, State of Hawai'i