THE SENATE
TWENTY-NINTH LEGISLATURE, 2017
STATE OF HAWAII

S.C.R. NO. 37

JAN 25 2017

SENATE CONCURRENT
RESOLUTION

URGING THE ESTABLISHMENT OF A RARE DISEASE TASK FORCE.

WHEREAS, a rare disease is defined as a disease that affects fewer than two hundred thousand people in the United States; and

WHEREAS, there are seven thousand different known rare diseases affecting approximately thirty million men, women, and children in the United States; and

WHEREAS, out of a population of 1,431,000 persons in the State of Hawaii, more than 143,000 persons are affected by a rare disease, with more than half of these rare diseases being specific to the Pacific region; and

WHEREAS, the exact cause of many rare diseases remains unknown; eighty percent of rare diseases are genetic in origin and can be linked to a mutation in a single gene or in multiple genes, and these genetic diseases may be passed from generation to generation; and

WHEREAS, it is sound public policy to encourage and fund research in the development of new treatments for rare diseases; now, therefore,

BE IT RESOLVED by the Senate of the Twenty-ninth Legislature of the State of Hawaii, Regular Session of 2017, the House of Representatives concurring, that the Department of Health is urged to establish a Rare Disease Task Force comprised of at least one representative from the Department of Health, persons living with rare diseases, and other interested stakeholders from the community to investigate and make recommendations on issues relating to quality, cost effectiveness, and accessibility of treatments and services to persons with rare diseases in the State; and
BE IT FURTHER RESOLVED that the Task Force is requested to report to the Department of Health and the Legislature biennially on its activities and recommendations; and

BE IT FURTHER RESOLVED that a certified copy of this Concurrent Resolution be transmitted to the Director of Health.

OFFERED BY: 

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