REQUESTING THE DIRECTOR OF HEALTH TO CREATE A STATEWIDE RARE DISEASE ADVISORY BOARD.

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

WHEREAS, there are 7,000 known rare diseases affecting approximately 30,000,000 men, women, and children in the United States; and

WHEREAS, a person suffering with a rare disease in Hawaii faces a wide range of challenges, including but not limited to delays in obtaining a diagnosis; misdiagnosis; shortage of medical specialists who are familiar with and can provide treatment for rare diseases; prohibitive cost of treatment; and the inability to access therapies and medication that are used by doctors to treat rare diseases, but have not been approved by the federal Food and Drug Administration for that specific purpose; and

WHEREAS, recently, researchers have made considerable progress in developing diagnostic tools and treatment protocols for, and in discovering ways to prevent a variety of, rare diseases; and

WHEREAS, however, much more remains to be done in the areas of rare disease research and the development of new therapeutics; and

WHEREAS, it is essential for the State to establish an advisory body to educate medical professionals, government agencies, and the public about rare diseases as an important public health issue and to encourage the funding of 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 Director of Health is requested to create a statewide rare disease advisory board; and

BE IT FURTHER RESOLVED that the Director of Health is requested to invite the following to serve on the advisory board:

(1) Directors of other state agencies concerned with the provision of care to persons with rare diseases;

(2) Public members, including two physicians licensed to practice medicine in Hawaii who have expertise in treating patients with rare diseases, one of whom shall be a pediatrician who provides care to children with rare diseases; a registered professional nurse licensed in Hawaii who has expertise in providing care to patients with rare diseases; two representatives of hospitals in Hawaii; a representative of the health insurance industry; a representative of the biopharmaceutical industry; a representative of the scientific community who is engaged in rare disease research; two parents of a child with a rare disease; two persons with a rare disease; and two patient organizations that operate within Hawaii; and

(3) Additional at-large members that may be necessary to carry out the duties of the advisory board; provided that the advisory board may advise the Director of Health on appointing at-large members as necessary; and

BE IT FURTHER RESOLVED that the vacancies in the membership of the advisory board be filled in the same manner provided for the original appointments; and

BE IT FURTHER RESOLVED that the advisory board is requested to select a chairperson and vice chairperson from among its members; and
BE IT FURTHER RESOLVED that the advisory board is requested to meet periodically, but at least three times per year; and

BE IT FURTHER RESOLVED that the Department of Health is requested to provide staff services, if necessary, to the advisory board; and

BE IT FURTHER RESOLVED that the advisory board is requested to:

1. Coordinate statewide efforts for the study of the incidence of rare diseases within Hawaii and the status of the rare disease community;

2. Act as the advisory body on rare diseases to the Legislature; state departments, agencies, commissions, and authorities; and private agencies that provide services to, or are charged with the care of, persons with rare diseases;

3. Coordinate with other state rare disease advisory bodies, community-based organizations, and other public and private organizations for the purpose of ensuring greater cooperation between state and federal activities regarding the research, diagnosis, and treatment of rare diseases;

4. Research and determine the most appropriate method to collect rare disease data to conduct thorough and complete surveys of persons diagnosed with rare diseases in Hawaii;

5. Research and identify priorities relating to the quality and cost-effectiveness of, and access to, treatment and services provided to persons with rare diseases in Hawaii, and develop policy recommendations on those issues;

6. Identify best practices for rare disease care from other states and at the national level that will improve rare disease care in Hawaii; and
(7) Develop effective strategies to raise public awareness of rare diseases in Hawaii; and

BE IT FURTHER RESOLVED that the Department of Health is requested to research and report to the Legislature on existing sources of funding that may be used to finance the formation and operation of the advisory board; and

BE IT FURTHER RESOLVED that the advisory board is requested to apply for, and accept, any grant of money from the federal government, private foundations, or other sources, which may be available for programs related to rare diseases; and

BE IT FURTHER RESOLVED that the advisory board is requested to submit a biennial report to the Department of Health and the Legislature on the activities of the advisory board and its findings and recommendations on issues relating to the quality and cost-effectiveness of, and access to, treatment and services to, persons with rare diseases in Hawaii; and

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

OFFERED BY:

[Signatures]

[Names]

[Dates]