

MAR 03 2017

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## SENATE CONCURRENT RESOLUTION

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

1 WHEREAS, a rare disease is defined as a disease that  
2 affects fewer than two hundred thousand people; and  
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4 WHEREAS, there are 7,000 known rare diseases affecting  
5 approximately 30,000,000 men, women, and children in the United  
6 States; and  
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8 WHEREAS, a person suffering with a rare disease in Hawaii  
9 faces a wide range of challenges, including but not limited to  
10 delays in obtaining a diagnosis; misdiagnosis; shortage of  
11 medical specialists who are familiar with and can provide  
12 treatment for rare diseases; prohibitive cost of treatment; and  
13 the inability to access therapies and medication that are used  
14 by doctors to treat rare diseases, but have not been approved by  
15 the federal Food and Drug Administration for that specific  
16 purpose; and  
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18 WHEREAS, recently, researchers have made considerable  
19 progress in developing diagnostic tools and treatment protocols  
20 for, and in discovering ways to prevent a variety of, rare  
21 diseases; and  
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23 WHEREAS, however, much more remains to be done in the areas  
24 of rare disease research and the development of new  
25 therapeutics; and  
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27 WHEREAS, it is essential for the State to establish an  
28 advisory body to educate medical professionals, government  
29 agencies, and the public about rare diseases as an important  
30 public health issue and to encourage the funding of research in  
31 the development of new treatments for rare diseases; now,  
32 therefore,  
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1 BE IT RESOLVED by the Senate of the Twenty-ninth  
2 Legislature of the State of Hawaii, Regular Session of 2017, the  
3 House of Representatives concurring, that the Director of Health  
4 is requested to create a statewide rare disease advisory board;  
5 and

6  
7 BE IT FURTHER RESOLVED that the Director of Health is  
8 requested to invite the following to serve on the advisory  
9 board:

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11 (1) Directors of other state agencies concerned with the  
12 provision of care to persons with rare diseases;  
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14 (2) Public members, including two physicians licensed to  
15 practice medicine in Hawaii who have expertise in  
16 treating patients with rare diseases, one of whom  
17 shall be a pediatrician who provides care to children  
18 with rare diseases; a registered professional nurse  
19 licensed in Hawaii who has expertise in providing care  
20 to patients with rare diseases; two representatives of  
21 hospitals in Hawaii; a representative of the health  
22 insurance industry; a representative of the  
23 biopharmaceutical industry; a representative of the  
24 scientific community who is engaged in rare disease  
25 research; two parents of a child with a rare disease;  
26 two persons with a rare disease; and two patient  
27 organizations that operate within Hawaii; and  
28  
29 (3) Additional at-large members that may be necessary to  
30 carry out the duties of the advisory board; provided  
31 that the advisory board may advise the Director of  
32 Health on appointing at-large members as necessary;  
33 and  
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35 BE IT FURTHER RESOLVED that the vacancies in the membership  
36 of the advisory board be filled in the same manner provided for  
37 the original appointments; and  
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39 BE IT FURTHER RESOLVED that the advisory board is requested  
40 to select a chairperson and vice chairperson from among its  
41 members; and  
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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:

*[Signature]*

*[Signature]*

*Will Lyne*

*Kal Rhoad*

*Michelle Tidani*

*[Signature]*

*Breene Harris*

*[Signature]*

