

MAR 03 2017

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# SENATE RESOLUTION

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

7  
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,

33  
34           BE IT RESOLVED by the Senate of the Twenty-ninth  
35 Legislature of the State of Hawaii, Regular Session of 2017,



1 that the Director of Health is requested to create a statewide  
2 rare disease advisory board; and

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

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- 8 (1) Directors of other state agencies concerned with the  
9 provision of care to persons with rare diseases;
  - 10  
11 (2) Public members, including two physicians licensed to  
12 practice medicine in Hawaii who have expertise in  
13 treating patients with rare diseases, one of whom  
14 shall be a pediatrician who provides care to children  
15 with rare diseases; a registered professional nurse  
16 licensed in Hawaii who has expertise in providing care  
17 to patients with rare diseases; two representatives of  
18 hospitals in Hawaii; a representative of the health  
19 insurance industry; a representative of the  
20 biopharmaceutical industry; a representative of the  
21 scientific community who is engaged in rare disease  
22 research; two parents of a child with a rare disease;  
23 two persons with a rare disease; and two patient  
24 organizations that operate within Hawaii; and
  - 25  
26 (3) Additional at-large members that may be necessary to  
27 carry out the duties of the advisory board; provided  
28 that the advisory board may advise the Director of  
29 Health on appointing at-large members as necessary;  
30 and

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

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36 BE IT FURTHER RESOLVED that the advisory board is requested  
37 to select a chairperson and vice chairperson from among its  
38 members; and

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40 BE IT FURTHER RESOLVED that the advisory board is requested  
41 to meet periodically, but at least three times per year; and  
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1 BE IT FURTHER RESOLVED that the Department of Health is  
2 requested to provide staff services, if necessary, to the  
3 advisory board; and  
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5 BE IT FURTHER RESOLVED that the advisory board is requested  
6 to:  
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- 8 (1) Coordinate statewide efforts for the study of the  
9 incidence of rare diseases within Hawaii and the  
10 status of the rare disease community;  
11
- 12 (2) Act as the advisory body on rare diseases to the  
13 Legislature; state departments, agencies, commissions,  
14 and authorities; and private agencies that provide  
15 services to, or are charged with the care of, persons  
16 with rare diseases;  
17
- 18 (3) Coordinate with other state rare disease advisory  
19 bodies, community-based organizations, and other  
20 public and private organizations for the purpose of  
21 ensuring greater cooperation between state and federal  
22 activities regarding the research, diagnosis, and  
23 treatment of rare diseases;  
24
- 25 (4) Research and determine the most appropriate method to  
26 collect rare disease data to conduct thorough and  
27 complete surveys of persons diagnosed with rare  
28 diseases in Hawaii;  
29
- 30 (5) Research and identify priorities relating to the  
31 quality and cost-effectiveness of, and access to,  
32 treatment and services provided to persons with rare  
33 diseases in Hawaii, and develop policy recommendations  
34 on those issues;  
35
- 36 (6) Identify best practices for rare disease care from  
37 other states and at the national level that will  
38 improve rare disease care in Hawaii; and  
39
- 40 (7) Develop effective strategies to raise public awareness  
41 of rare diseases in Hawaii; and  
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# S.R. NO. 23

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

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

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


17  
 18 BE IT FURTHER RESOLVED that a certified copy of this  
 19 Resolution be transmitted to the Director of Health.  
 20  
 21  
 22

OFFERED BY: 



Will Zyr  
 Hal Khoury

Michelle Sedani

  
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