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# HOUSE CONCURRENT RESOLUTION

REQUESTING THE CONVENING OF A STATEWIDE RARE DISEASE TASK FORCE.

- 1           WHEREAS, a rare disease is defined as a disease that  
2 affects fewer than 200,000 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, out of a population of 1,431,000 persons in the  
9 State, more than 143,000 persons in Hawaii are affected by a  
10 rare disease, with more than half of these rare diseases  
11 specific to the Pacific region; and  
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- 13           WHEREAS, while the exact cause for many rare diseases  
14 remains unknown, 80 percent of rare diseases are genetic in  
15 origin and can be linked to mutations in a single gene or in  
16 multiple genes and these genetic diseases may be passed from  
17 generation to generation; and  
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- 19           WHEREAS, a person suffering from a rare disease faces a  
20 wide range of challenges, including:  
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- 22           (1) Delayed diagnosis;
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  - 24           (2) Misdiagnosis;
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  - 26           (3) Shortage of medical specialists familiar with and able  
27 to provide treatment for rare diseases;
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  - 29           (4) Prohibitive cost of treatment; and
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  - 31           (5) Lack of access to therapies and medication that are  
32 used by doctors to treat rare diseases but that may



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1 not be approved by the federal Food and Drug  
2 Administration for a specific treatment; and  
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4 WHEREAS, in recent years, researchers have made  
5 considerable progress in developing diagnostic tools, treatment  
6 protocols, and preventative measures for a variety of rare  
7 diseases; however, much more remains to be done in the areas of  
8 rare disease research and research and development of new  
9 therapeutics; and  
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11 WHEREAS, it is sound public policy that an advisory body of  
12 qualified persons be convened, including persons living with  
13 rare diseases, to:  
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- 15 (1) Encourage and fund research in the development of new  
16 treatments for rare diseases; and  
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- 18 (2) Educate medical professionals, government agencies,  
19 and the public about rare diseases as an important  
20 health issue; now, therefore,  
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22 BE IT RESOLVED by the House of Representatives of the  
23 Twenty-eighth Legislature of the State of Hawaii, Regular  
24 Session of 2016, the Senate concurring, that the Department of  
25 Health is requested to convene a statewide rare disease task  
26 force to be named the Hawaii Rare Disease Task Force (Task  
27 Force) for the purpose of:  
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- 29 (1) Coordinating statewide efforts regarding the study of  
30 the incidence of rare diseases within the State and  
31 the status of rare diseases in the community;  
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- 33 (2) Acting in an advisory capacity on rare diseases to the  
34 Legislature, to state departments, agencies,  
35 commissions, authorities, and to private agencies that  
36 provide services to or are charged with the care of  
37 persons with rare diseases;  
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- 39 (3) Coordinating the performance of its duties with other  
40 state advisory bodies, community-based organizations,  
41 and other public and private organizations related to  
42 rare diseases to ensure greater cooperation between



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- 1 state and federal agencies, including the United  
2 States National Institutes of Health and the United  
3 States Food and Drug Administration, regarding the  
4 research, diagnosis, and treatment of rare diseases,  
5 including by disseminating the research, best  
6 practices, and policy recommendations of the Task  
7 Force using common research collection and  
8 dissemination procedures;  
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- 10 (4) Researching and determining the most appropriate  
11 method to collect rare disease data and information  
12 regarding patients with rare diseases in order to  
13 conduct thorough and complete surveys of rare diseases  
14 diagnosed in the State, subject to all applicable  
15 privacy laws, and ensuring that research and surveys  
16 are conducted in a coordinated manner that is  
17 interoperable with similar research being conducted at  
18 the state and federal levels;  
19
- 20 (5) Researching and identifying priorities relating to  
21 quality, cost-effectiveness, and accessibility of  
22 treatment and services for persons with rare diseases  
23 in the State and developing policy recommendations on  
24 those issues;  
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- 26 (6) Identifying best practices for rare disease care from  
27 other states and at the national level to improve rare  
28 disease care in the State;  
29
- 30 (7) Developing effective strategies to raise public  
31 awareness of rare diseases in Hawaii; and  
32
- 33 (8) Seeking out and applying for or publicizing  
34 information about, as appropriate, grant funding  
35 opportunities from the federal government, private  
36 foundations, or other sources that may be available  
37 for programs related to rare diseases; and



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BE IT FURTHER RESOLVED that the Task Force comprise:

- (1) The Director of Health or the Director's designee;
- (2) The heads of any other state agencies concerned with the provision of care to persons with rare diseases, to be appointed by the Director of Health; and
- (3) The following members of the public, to be appointed by the Director of Health:
  - (A) Two physicians licensed to practice in the State who have expertise in treating patients with rare diseases, one of whom shall be a pediatrician who provides care to children with rare diseases;
  - (B) A registered nurse licensed to practice in the State who has expertise in providing care to patients with rare diseases;
  - (C) Two representatives of hospitals in the State;
  - (D) A representative of the health insurance industry;
  - (E) A representative of the biopharmaceutical industry;
  - (F) A representative of the scientific community who is engaged in rare disease research;
  - (G) Two parents of a child with a rare disease; and
  - (H) Two representatives of patient organizations that operate within the State; and

BE IT FURTHER RESOLVED that the Task Force is requested to:

- (1) Organize as soon as practicable after the appointment of its members;



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- 1           (2)    Select a chairperson and vice chairperson from among  
2                its members;
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- 4           (3)    Appoint a secretary who need not be a Task Force  
5                member;
- 6
- 7           (4)    Meet at least three times annually; and
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- 9           (5)    Report to the Department of Health and the Legislature  
10                biennially on its activities, including findings and  
11                recommendations on issues relating to quality, cost  
12                effectiveness, and accessibility of treatments and  
13                services to persons with rare diseases in the State;  
14                and
- 15

16           BE IT FURTHER RESOLVED that upon or after the initial  
17   convening of the Task Force, the Task Force may advise the  
18   Department of Health on any additional at-large appointments to  
19   the Task Force that are necessary for the Task Force to carry  
20   out its duties within available funding, which may be made on an  
21   ad hoc basis; and

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23           BE IT FURTHER RESOLVED that the Task Force may seek the  
24   assistance and services of employees of any state or county  
25   department, board, bureau, commission, or agency as the Task  
26   Force may require and as may be available to the Task Force; and

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28           BE IT FURTHER RESOLVED that the Department of Health is  
29   requested to:

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- 31           (1)    Research and provide to the Legislature information on  
32                existing sources of funding to finance the  
33                implementation and operations of the Task Force; and
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- 35           (2)    Provide staff services to the Task Force as necessary;  
36                and
- 37

38           BE IT FURTHER RESOLVED that the Task Force is requested to  
39   submit an initial report to the Legislature on its progress no  
40   later than 20 days prior to the convening of the Regular Session  
41   of 2017, and, thereafter, submit subsequent reports biennially



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1 to the Legislature no later than 20 days prior to the convening  
2 of the regular session in each odd-numbered year; and

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

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OFFERED BY: *James S. King*

MAR 11 2016

