
HOUSE 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;
- 23
- 24 (2) Misdiagnosis;
- 25
- 26 (3) Shortage of medical specialists familiar with and able
27 to provide treatment for rare diseases;
- 28
- 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
33 not be approved by the federal Food and Drug
34 Administration for a specific treatment; and



1 WHEREAS, in recent years, researchers have made
2 considerable progress in developing diagnostic tools, treatment
3 protocols, and preventative measures for a variety of rare
4 diseases; however, much more remains to be done in the areas of
5 rare disease research and research and development of new
6 therapeutics; and
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8 WHEREAS, it is sound public policy that an advisory body of
9 qualified persons be convened, including persons living with
10 rare diseases, to:
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12 (1) Encourage and fund research in the development of new
13 treatments for rare diseases; and
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15 (2) Educate medical professionals, government agencies,
16 and the public about rare diseases as an important
17 health issue; now, therefore,
18

19 BE IT RESOLVED by the House of Representatives of the
20 Twenty-eighth Legislature of the State of Hawaii, Regular
21 Session of 2016, that the Department of Health is requested to
22 convene a statewide rare disease task force to be named the
23 Hawaii Rare Disease Task Force (Task Force) for the purpose of:
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25 (1) Coordinating statewide efforts regarding the study of
26 the incidence of rare diseases within the State and
27 the status of rare diseases in the community;
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29 (2) Acting in an advisory capacity on rare diseases to the
30 Legislature, to state departments, agencies,
31 commissions, authorities, and to private agencies that
32 provide services to or are charged with the care of
33 persons with rare diseases;
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35 (3) Coordinating the performance of its duties with other
36 state advisory bodies, community-based organizations,
37 and other public and private organizations related to
38 rare diseases to ensure greater cooperation between
39 state and federal agencies, including the United
40 States National Institutes of Health and the United
41 States Food and Drug Administration, regarding the



1 research, diagnosis, and treatment of rare diseases,
2 including by disseminating the research, best
3 practices, and policy recommendations of the Task
4 Force using common research collection and
5 dissemination procedures;
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- 7 (4) Researching and determining the most appropriate
8 method to collect rare disease data and information
9 regarding patients with rare diseases in order to
10 conduct thorough and complete surveys of rare diseases
11 diagnosed in the State, subject to all applicable
12 privacy laws, and ensuring that research and surveys
13 are conducted in a coordinated manner that is
14 interoperable with similar research being conducted at
15 the state and federal levels;
16

- 17 (5) Researching and identifying priorities relating to
18 quality, cost-effectiveness, and accessibility of
19 treatment and services for persons with rare diseases
20 in the State and developing policy recommendations on
21 those issues;
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- 23 (6) Identifying best practices for rare disease care from
24 other states and at the national level to improve rare
25 disease care in the State;
26

- 27 (7) Developing effective strategies to raise public
28 awareness of rare diseases in Hawaii; and
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- 30 (8) Seeking out and applying for or publicizing
31 information about, as appropriate, grant funding
32 opportunities from the federal government, private
33 foundations, or other sources that may be available
34 for programs related to rare diseases; and
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36 BE IT FURTHER RESOLVED that the Task Force comprise:
37

- 38 (1) The Director of Health or the Director's designee;



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- (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;
- (2) Select a chairperson and vice chairperson from among its members;



1 (3) Appoint a secretary who need not be a Task Force
2 member;

3
4 (4) Meet at least three times annually; and
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6 (5) Report to the Department of Health and the Legislature
7 biennially on its activities, including findings and
8 recommendations on issues relating to quality, cost
9 effectiveness, and accessibility of treatments and
10 services to persons with rare diseases in the State;
11 and
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13 BE IT FURTHER RESOLVED that upon or after the initial
14 convening of the Task Force, the Task Force may advise the
15 Department of Health on any additional at-large appointments to
16 the Task Force that are necessary for the Task Force to carry
17 out its duties within available funding, which may be made on an
18 adhoc basis; and
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20 BE IT FURTHER RESOLVED that the Task Force may seek the
21 assistance and services of employees of any state or county
22 department, board, bureau, commission, or agency as the Task
23 Force may require and as may be available to the Task Force; and
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25 BE IT FURTHER RESOLVED that the Department of Health is
26 requested to:
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28 (1) Research and provide to the Legislature information on
29 existing sources of funding to finance the
30 implementation and operations of the Task Force; and
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32 (2) Provide staff services to the Task Force as necessary;
33 and
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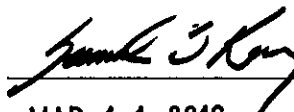
35 BE IT FURTHER RESOLVED that the Task Force is requested to
36 submit an initial report to the Legislature on its progress no
37 later than 20 days prior to the convening of the Regular Session
38 of 2017, and, thereafter, submit subsequent reports biennially
39 to the Legislature no later than 20 days prior to the convening
40 of the regular session in each odd-numbered year; and



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1 BE IT FURTHER RESOLVED that certified copy of this
2 Resolution be transmitted to the Director of Health.
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OFFERED BY:



MAR 11 2016

