

JAN 25 2017

SENATE CONCURRENT RESOLUTION

URGING THE ESTABLISHMENT OF A RARE DISEASE TASK FORCE.

1 WHEREAS, a rare disease is defined as a disease that
2 affects fewer than two hundred thousand people in the United
3 States; and
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5 WHEREAS, there are seven thousand different known rare
6 diseases affecting approximately thirty million men, women, and
7 children in the United States; and
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9 WHEREAS, out of a population of 1,431,000 persons in the
10 State of Hawaii, more than 143,000 persons are affected by a
11 rare disease, with more than half of these rare diseases being
12 specific to the Pacific region; and
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14 WHEREAS, the exact cause of many rare diseases remains
15 unknown; eighty percent of rare diseases are genetic in origin
16 and can be linked to a mutation in a single gene or in multiple
17 genes, and these genetic diseases may be passed from generation
18 to generation; and
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20 WHEREAS, it is sound public policy to encourage and fund
21 research in the development of new treatments for rare diseases;
22 now, therefore,
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24 BE IT RESOLVED by the Senate of the Twenty-ninth
25 Legislature of the State of Hawaii, Regular Session of 2017, the
26 House of Representatives concurring, that the Department of
27 Health is urged to establish a Rare Disease Task Force comprised
28 of at least one representative from the Department of Health,
29 persons living with rare diseases, and other interested
30 stakeholders from the community to investigate and make
31 recommendations on issues relating to quality, cost
32 effectiveness, and accessibility of treatments and services to
33 persons with rare diseases in the State; and
34



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1 BE IT FURTHER RESOLVED that the Task Force is requested to
2 report to the Department of Health and the Legislature
3 biennially on its activities and recommendations; and

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

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OFFERED BY: 





