

MAR - 1 2013

SENATE RESOLUTION

URGING HAWAII'S CONGRESSIONAL DELEGATION TO SUPPORT CONTINUED FUNDING FOR THE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM FOR NEUROFIBROMATOSIS AND ENCOURAGE THE RENAMING OF THE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAMS TO THE DANIEL K. INOUE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAMS.

1 WHEREAS, neurofibromatosis (NF) is the term for three
2 distinct genetic disorders - NF1, NF2, and Schwannomatosis - and
3 is the most prevalent genetic disorder, affecting more than two
4 million people worldwide and making NF more prevalent than
5 cystic fibrosis, Duchenne muscular dystrophy, and Huntington's
6 Disease combined; and

7
8 WHEREAS, NF1 occurs in 1 out of 3,000 births, causes tumors
9 that grow on nerve pathways, and may also lead to blindness,
10 deafness, brain and spinal tumors, severe disfigurements, bone
11 abnormalities, developmental delays, and learning disabilities;
12 and

13
14 WHEREAS, NF2 occurs in 1 out of 25,000 births, causes
15 bilateral acoustic neuromas, brain and spinal tumors, and
16 cataracts, and often leads to hearing loss beginning in the
17 teens or early twenties; and

18
19 WHEREAS, Schwannomatosis affects around 1 out of 40,000
20 individuals, has only recently been recognized, and is less
21 understood than NF1 and NF2; and

22
23 WHEREAS, NF is a life-long disorder that affects both sexes
24 and all ethnic and racial groups equally, and its effects
25 predominantly begin in childhood; and

26
27 WHEREAS, the clinical course of NF can be quite variable
28 and unpredictable, and there is no cure; and

29
30 WHEREAS, NF research is a critical part of the military
31 mission because it directly impacts our understanding of nerve
32 cells, their degeneration, and nerve pain as well as the



1 development of treatments for peripheral nerve regeneration
2 after injury and brain trauma; and
3

4 WHEREAS, under the leadership of Senator Daniel K. Inouye,
5 the Department of Defense Congressionally Directed Medical
6 Research Programs were established in 1992 and have administered
7 more than \$7,123,000,000 in Congressional appropriations and
8 provided more than 11,315 awards to institutions worldwide; and
9

10 WHEREAS, the Congressionally Directed Medical Research
11 Program for Neurofibromatosis has been funded through the
12 defense appropriations bill for fourteen years and is the
13 largest single funding source for neurofibromatosis research;
14 now, therefore,
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16 BE IT RESOLVED by the Senate of the Twenty-seventh
17 Legislature of the State of Hawaii, Regular Session of 2013,
18 that Hawaii's Congressional delegation is urged to:
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- 20 (1) Support continued funding for the Congressionally
21 Directed Medical Research Program for
22 Neurofibromatosis; and
23
- 24 (2) Encourage the renaming of the Congressionally Directed
25 Medical Research Programs to the "Daniel K. Inouye
26 Congressionally Directed Medical Research Programs";
27 and
28

29 BE IT FURTHER RESOLVED that certified copies of this
30 Resolution be transmitted to the members of Hawaii's
31 Congressional delegation and Director of the Congressionally
32 Directed Medical Research Programs.
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OFFERED BY:

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