

MAR - 1 2013

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# SENATE CONCURRENT 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

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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

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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

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27           WHEREAS, the clinical course of NF can be quite variable  
28 and unpredictable, and there is no cure; and  
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1 WHEREAS, NF research is a critical part of the military  
2 mission because it directly impacts our understanding of nerve  
3 cells, their degeneration, and nerve pain as well as the  
4 development of treatments for peripheral nerve regeneration  
5 after injury and brain trauma; and  
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7 WHEREAS, under the leadership of Senator Daniel K. Inouye,  
8 the Department of Defense Congressionally Directed Medical  
9 Research Programs were established in 1992 and have administered  
10 more than \$7,123,000,000 in Congressional appropriations and  
11 provided more than 11,315 awards to institutions worldwide; and  
12

13 WHEREAS, the Congressionally Directed Medical Research  
14 Program for Neurofibromatosis has been funded through the  
15 defense appropriations bill for fourteen years and is the  
16 largest single funding source for neurofibromatosis research;  
17 now, therefore,  
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19 BE IT RESOLVED by the Senate of the Twenty-seventh  
20 Legislature of the State of Hawaii, Regular Session of 2013, the  
21 House of Representatives concurring, that Hawaii's Congressional  
22 delegation is urged to:  
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- 24 (1) Support continued funding for the Congressionally  
25 Directed Medical Research Program for  
26 Neurofibromatosis; and  
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- 28 (2) Encourage the renaming of the Congressionally Directed  
29 Medical Research Programs to the "Daniel K. Inouye  
30 Congressionally Directed Medical Research Programs";  
31 and  
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33 BE IT FURTHER RESOLVED that certified copies of this  
34 Concurrent Resolution be transmitted to the members of Hawaii's  
35 Congressional delegation and Director of the Congressionally  
36 Directed Medical Research Programs.  
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