

111TH CONGRESS
1ST SESSION

S. RES. 148

Expressing the sense of the Senate that there is a critical need to increase research, awareness, and education about cerebral cavernous malformations.

IN THE SENATE OF THE UNITED STATES

MAY 13, 2009

Mr. UDALL of New Mexico submitted the following resolution; which was considered and agreed to

RESOLUTION

Expressing the sense of the Senate that there is a critical need to increase research, awareness, and education about cerebral cavernous malformations.

Whereas cerebral cavernous malformation (in this resolution referred to as “CCM”), or cavernous angioma, is a devastating blood vessel disease that has enormous consequences for people affected and their families;

Whereas cavernous angiomas are malformations in the brain that cannot be detected easily, except through very specific medical imaging scans;

Whereas people with CCM are rarely aware that they have the disease, which makes taking blood thinners or aspirin risky;

Whereas, according to the Angioma Alliance, in the general population, 1 in approximately 200 people has CCM;

Whereas, according to the Angioma Alliance, more than $\frac{1}{2}$ of the people with CCM experience symptoms at some point in their lives;

Whereas, according to the Angioma Alliance, there is a hereditary form of CCM, caused by a mutation or deletion on any 1 of 3 genes, that is characterized by multiple cavernous malformations;

Whereas, according to the Angioma Alliance, each child born to parents with the hereditary form of CCM has a 50 percent chance of having CCM;

Whereas, according to the Angioma Alliance, a specific genetic mutation of CCM called the “common Hispanic mutation”, which has been traced to the original Spanish settlers of the Americas in the 1590’s, has now spread across at least 17 generations of families;

Whereas while CCM is more prevalent in certain States, families throughout the United States are at risk;

Whereas a person with CCM could go undiagnosed until sudden death, seizure, or stroke;

Whereas there is a shortage of physicians who are familiar with CCM, making it difficult for people with CCM to receive timely diagnosis and appropriate care;

Whereas the shortage of such physicians has a disproportionate impact on thousands of Hispanics across the United States;

Whereas CCM has not been studied sufficiently by the National Institutes of Health and others;

Whereas there is a need to expeditiously initiate pilot studies to research the use of medications to treat CCM; and

Whereas medications that treat CCM will enable preventive treatment that reduces the risk of hemorrhage in those who have been diagnosed, thereby saving lives and dramatically reducing healthcare costs: Now, therefore, be it

1 *Resolved*, That it is the sense of the Senate that there
2 is a critical need to increase research, awareness, and edu-
3 cation about cerebral cavernous malformations.

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