

111<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# S. 3684

To establish the Cavernous Angioma CARE Center (Clinical Care, Advocacy, Research and Education) at the University of New Mexico, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

AUGUST 2, 2010

Mr. UDALL of New Mexico (for himself and Mr. BINGAMAN) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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## A BILL

To establish the Cavernous Angioma CARE Center (Clinical Care, Advocacy, Research and Education) at the University of New Mexico, and for other purposes.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE.**

4       This Act may be cited as the “Cavernous Angioma  
5       CARE Center Act of 2010”.

6       **SEC. 2. FINDINGS.**

7       Congress finds as follows:

1           (1) Cavernous angioma, also termed “cerebral  
2 cavernous malformations” or “CCM”, affects an es-  
3 timated 1,500,000 people in the United States.

4           (2) Cavernous angioma is a devastating blood  
5 vessel disease that is characterized by the presence  
6 of vascular lesions that develop and grow within the  
7 brain and spinal cord.

8           (3) Detection of cavernous angioma lesions is  
9 achieved though costly and specialized medical imag-  
10 ing techniques.

11           (4) Cavernous angioma is a common type of  
12 vascular anomaly, but individuals may not be aware  
13 that they have the disease until the onset of serious  
14 clinical symptoms.

15           (5) Individuals diagnosed with cavernous  
16 angioma may experience neurological deficits, sei-  
17 zure, stroke, or sudden death.

18           (6) Due to limited research with respect to cav-  
19 ernous angioma, there is no treatment regimen for  
20 the disease other than brain and spinal surgery.

21           (7) Some individuals with cavernous angioma  
22 are not candidates for brain surgery, and no treat-  
23 ment option is available for such individuals.

24           (8) There is a shortage of physicians who are  
25 familiar with cavernous angioma and affected indi-

1 individuals may find it difficult to receive timely diag-  
2 nosis and appropriate care.

3 (9) Due to the presence of a specific disease-  
4 causing mutation, termed the “common Hispanic  
5 mutation” that has passed through as many as 17  
6 generations of Americans descended from the origi-  
7 nal Spanish settlers of the Southwest in the 1590s,  
8 New Mexico has the highest population density of  
9 cavernous angioma in the world. Cavernous angioma  
10 affects tens of thousands of individuals in New Mex-  
11 ico.

12 (10) Other States with high rates of cavernous  
13 angioma include Texas, Arizona, and Colorado.

14 (11) Senate Resolution 148, 111th Congress,  
15 agreed to May 13, 2009, which was adopted unani-  
16 mously, expresses the sense of the Senate that there  
17 is a critical need to increase research, awareness,  
18 and education about cerebral cavernous malforma-  
19 tions.

20 (12) The National Institutes of Health pro-  
21 motes advances in biomedical research by supporting  
22 extramural research at institutes of higher edu-  
23 cation, in part through extramural centers of excel-  
24 lence. These centers promote research through a  
25 multidisciplinary, team-based approach in order to

1 better understand complex biomedical systems and  
2 translate basic scientific discoveries into useful clin-  
3 ical applications.

4 (13) To address the public health threat posed  
5 by cavernous angioma in New Mexico and through-  
6 out the United States, there is a need for a Cav-  
7 ernous Angioma Clinical Care, Advocacy, Research,  
8 and Education Center in order to provide a model  
9 medical system for other such centers, to facilitate  
10 medical research to develop a cure for cavernous  
11 angioma, and to enhance the medical care of individ-  
12 uals with cavernous angioma nationwide.

13 (14) Given the existing programs and expertise  
14 at the University of New Mexico, the first coordi-  
15 nated, centralized Cavernous Angioma Clinical Care,  
16 Advocacy, Research, and Education Center should  
17 be established at the University of New Mexico.

18 **SEC. 3. CAVERNOUS ANGIOMA CARE CENTER.**

19 Part B of title IV of the Public Health Service Act  
20 (42 U.S.C. 284 et seq.) is amended by adding at the end  
21 the following:

22 **“SEC. 409K. CAVERNOUS ANGIOMA CARE CENTERS OF EX-**  
23 **CELLENCE.**

24 “(a) ESTABLISHMENT OF NEW MEXICO CAVERNOUS  
25 ANGIOMA CARE CENTER OF EXCELLENCE.—The Direc-

1 tor of NIH shall establish a coordinated, centralized Cav-  
2 ernous Angioma Clinical Care, Advocacy, Research, and  
3 Education Center of Excellence at the University of New  
4 Mexico (referred to in this section as the ‘CARE Center’)  
5 to provide basic, translational, and clinical research with  
6 respect to new diagnostic, prevention, and novel treatment  
7 methodology for individuals with cavernous angioma, and  
8 to serve as a model for medical schools and research insti-  
9 tutions and to provide support to such schools and institu-  
10 tions.

11 “(b) REQUIREMENTS.—The CARE Center estab-  
12 lished under subsection (a) shall—

13 “(1) consist of full- and part-time cavernous  
14 angioma researchers, clinicians, and medical staff in-  
15 cluding—

16 “(A) a medical director with expertise in  
17 cavernous angioma research and clinical care;

18 “(B) a headache or pain specialist;

19 “(C) an epilepsy specialist;

20 “(D) a psychiatrist;

21 “(E) a neuropsychologist;

22 “(F) a dermatologist;

23 “(G) a nurse practitioner with a specialty  
24 in neurology or neurosurgery;

1           “(H) a nurse coordinator to facilitate pa-  
2           tient advocacy and research;

3           “(I) a research coordinator to facilitate re-  
4           search;

5           “(J) a clinical nurse dedicated to clinical  
6           care and in-patient management;

7           “(K) a radiology specialist;

8           “(L) a clinical vascular fellow;

9           “(M) a basic science postdoctoral fellow;  
10          and

11          “(N) a genetic counselor;

12          “(2) be affiliated with a university medical cen-  
13          ter with an accredited medical school that provides  
14          education and training in neurological disease, in  
15          which medical students and residents receive edu-  
16          cation and training in the diagnosis and treatment  
17          of cavernous angioma;

18          “(3) maintain a program through which  
19          postdoctoral fellows receive research training in  
20          basic, translational, or clinical cavernous angioma  
21          research;

22          “(4) recruit new innovative researchers and cli-  
23          nicians to the field of cavernous angioma care and  
24          research;

1           “(5) establish a continuing medical education  
2 program through which medical clinicians receive  
3 professional training in cavernous angioma care and  
4 patient management;

5           “(6) maintain programs dedicated to patient  
6 advocacy, patient outreach, and education, includ-  
7 ing—

8                 “(A) launching a multimedia public aware-  
9 ness campaign;

10                “(B) creating and distributing patient edu-  
11 cation materials for distribution by national  
12 physician and surgeon offices;

13                “(C) establishing an education program for  
14 elementary and secondary school nurses to fa-  
15 cilitate early detection and diagnosis of cav-  
16 ernous angioma;

17                “(D) coordinating regular patient and fam-  
18 ily-oriented educational conferences; and

19                “(E) developing electronic health teaching  
20 and communication tools and a network of pro-  
21 fessional capacity and patient and family sup-  
22 port;

23           “(7) be capable of establishing and maintaining  
24 communication with other major cavernous angioma

1 research and care institutions for information shar-  
2 ing and coordination of research activities;

3 “(8) facilitate translational projects and col-  
4 laborations for clinical trials; and

5 “(9) establish an advisory board to advise and  
6 assist the Director of the CARE Center composed  
7 of—

8 “(A) at least 1 individual with cavernous  
9 angioma or family member of such an indi-  
10 vidual;

11 “(B) at least 1 representative of a patient  
12 advocacy group;

13 “(C) at least 1 physician and at least 1  
14 scientist with expertise in cavernous angioma  
15 and other relevant biomedical disciplines; and

16 “(D) at least 1 representative of the insti-  
17 tution affiliated with the CARE Center.

18 “(c) DIRECTOR OF CARE CENTER.—

19 “(1) IN GENERAL.—The CARE Center shall be  
20 headed by a Director, who shall have expertise in  
21 cavernous angioma patient care and research.

22 “(2) DUTIES OF THE DIRECTOR.—To promote  
23 increased understanding and treatment of cavernous  
24 angioma and provide the highest quality medical and

1 surgical care for individuals with cavernous angioma,  
2 the Director of the CARE Center shall—

3 “(A) ensure that the CARE Center pro-  
4 vides community-, family-, and patient-centered,  
5 culturally sensitive care;

6 “(B) encourage and coordinate opportuni-  
7 ties for individuals to participate in clinical re-  
8 search studies that will advance medical re-  
9 search and care; and

10 “(C) develop the CARE Center as a model  
11 and training facility for other facilities through-  
12 out the United States that are engaged in re-  
13 search regarding, and care for individuals with,  
14 cavernous angioma.

15 “(d) REPORTING.—

16 “(1) IN GENERAL.—Not later than 2 years  
17 after the date of enactment of the Cavernous  
18 Angioma CARE Center Act of 2010, and biannually  
19 thereafter, the advisory board established under sub-  
20 section (b)(9) shall submit a report on the activities  
21 of the CARE Center to the Secretary.

22 “(2) CONTENT.—The report described in para-  
23 graph (1) shall include—

24 “(A) a description of the progress made in  
25 implementing the requirements of this section;

1           “(B) a description of the amount expended  
2           on the implementation of such requirements;  
3           and

4           “(C) a description of other activities and  
5           outcomes of the CARE Center, as appropriate.

6           “(e) AUTHORIZATION OF APPROPRIATIONS.—To es-  
7           tablish and operate the Care Center, there is authorized  
8           to be appropriated \$2,000,000 for fiscal year 2011.”.

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