

112TH CONGRESS
2D SESSION

H. R. 4008

To establish the Cavernous Angioma CARE Center (Clinical Care, Awareness, Research and Education) of Excellence, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 9, 2012

Mr. HEINRICH (for himself, Mr. LUJÁN, and Mr. PEARCE) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To establish the Cavernous Angioma CARE Center (Clinical Care, Awareness, Research and Education) of Excellence, 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 2012”.

6 **SEC. 2. FINDINGS.**

7 Congress finds as follows:

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

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

5 (3) Detection of cavernous angioma lesions is
6 achieved through costly and specialized medical im-
7 aging techniques. These techniques are often not
8 readily available where patients live, and require se-
9 dation for children and disabled adults.

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

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

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

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

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

1 viduals 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 thousands of individuals in New Mexico.

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

13 (11) To address the public health threat posed
14 by cavernous angioma in New Mexico and through-
15 out the United States, there is a need for a Cav-
16 ernous Angioma Clinical Care, Awareness, Research,
17 and Education Center of Excellence in order to pro-
18 vide a model medical system for other such centers,
19 to facilitate medical research to develop a cure for
20 cavernous angioma, and to enhance the medical care
21 of individuals with cavernous angioma nationwide.

22 (12) Given the existing programs and expertise
23 in the southwest, the first coordinated, centralized
24 Cavernous Angioma Clinical Care, Awareness, Re-

1 search, and Education Center of Excellence should
2 be established there.

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

4 Part B of title IV of the Public Health Service Act
5 (42 U.S.C. 284 et seq.) is amended by adding at the end
6 the following:

7 **“SEC. 409K. CAVERNOUS ANGIOMA CARE CENTERS OF EX-**
8 **CELLENCE.**

9 “(a) ESTABLISHMENT OF SOUTHWEST CAVERNOUS
10 ANGIOMA CARE CENTER OF EXCELLENCE.—The Sec-
11 retary shall establish a coordinated, centralized Cavernous
12 Angioma Clinical Care, Awareness, Research, and Edu-
13 cation Center of Excellence at a university health sciences
14 research and clinical center in the southwest United States
15 (referred to in this section as the ‘CARE Center’) to pro-
16 vide basic, translational, and clinical research with respect
17 to new diagnostic, prevention, and novel treatment meth-
18 odology for individuals with cavernous angioma, and to
19 serve as a model for medical schools and research institu-
20 tions and to provide support to such schools and institu-
21 tions.

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

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

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

6 “(B) a headache or pain specialist;

7 “(C) an epilepsy specialist;

8 “(D) a psychiatrist;

9 “(E) a neuropsychologist;

10 “(F) a dermatologist;

11 “(G) a nurse practitioner with a specialty
12 in neurology or neurosurgery;

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

15 “(I) a research coordinator to facilitate re-
16 search;

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

19 “(K) a radiology specialist;

20 “(L) a clinical vascular fellow;

21 “(M) a basic science postdoctoral fellow;

22 and

23 “(N) a genetic counselor;

24 “(2) be affiliated with a university medical cen-
25 ter with an accredited medical school that provides

1 education and training in neurological disease, in
2 which medical students and residents receive edu-
3 cation and training in the diagnosis and treatment
4 of cavernous angioma;

5 “(3) maintain a program through which
6 postdoctoral fellows receive research training in
7 basic, translational, or clinical cavernous angioma
8 research;

9 “(4) recruit new innovative researchers and cli-
10 nicians to the field of cavernous angioma care and
11 research;

12 “(5) establish a continuing medical education
13 program through which medical clinicians receive
14 professional training in cavernous angioma care and
15 patient management;

16 “(6) maintain programs dedicated to patient
17 advocacy, patient outreach, and education, includ-
18 ing—

19 “(A) launching a multimedia public aware-
20 ness campaign;

21 “(B) creating and distributing patient edu-
22 cation materials for distribution by national
23 physician and surgeon offices;

24 “(C) establishing an education program for
25 elementary and secondary school nurses to fa-

1 facilitate early detection and diagnosis of cav-
2 ernous angioma;

3 “(D) coordinating regular patient and fam-
4 ily-oriented educational conferences; and

5 “(E) developing electronic health teaching
6 and communication tools and a network of pro-
7 fessional capacity and patient and family sup-
8 port;

9 “(7) be capable of establishing and maintaining
10 communication with other major cavernous angioma
11 research and care institutions for information shar-
12 ing and coordination of research activities;

13 “(8) facilitate translational projects and col-
14 laborations for clinical trials; and

15 “(9) establish an advisory board to advise and
16 assist the Director of the CARE Center composed
17 of—

18 “(A) at least 1 individual with cavernous
19 angioma or family member of such an indi-
20 vidual;

21 “(B) at least 1 representative of a patient
22 advocacy group;

23 “(C) at least 1 physician and at least 1
24 scientist with expertise in cavernous angioma
25 and other relevant biomedical disciplines; and

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

3 “(c) DIRECTOR OF CARE CENTER.—

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

7 “(2) DUTIES OF THE DIRECTOR.—To promote
8 increased understanding and treatment of cavernous
9 angioma and provide the highest quality medical and
10 surgical care for individuals with cavernous angioma,
11 the Director of the CARE Center shall—

12 “(A) ensure that the CARE Center pro-
13 vides community-, family-, and patient-centered,
14 culturally sensitive care;

15 “(B) encourage and coordinate opportuni-
16 ties for individuals to participate in clinical re-
17 search studies that will advance medical re-
18 search and care; and

19 “(C) develop the CARE Center as a model
20 and training facility for other facilities through-
21 out the United States that are engaged in re-
22 search regarding, and care for individuals with,
23 cavernous angioma.

24 “(d) REPORTING.—

1 “(1) IN GENERAL.—Not later than 2 years
2 after the date of enactment of the Cavernous
3 Angioma CARE Center Act of 2012, and biannually
4 thereafter, the advisory board established under sub-
5 section (b)(9) shall submit a report on the activities
6 of the CARE Center to the Secretary.

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

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

11 “(B) a description of the amount expended
12 on the implementation of such requirements;
13 and

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

16 “(e) AUTHORIZATION OF APPROPRIATIONS.—To es-
17 tablish and operate the Care Center, there is authorized
18 to be appropriated \$2,000,000 for fiscal year 2013.”.

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