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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Cavernous Angioma CARE Center Act of 2012”.

SECTION 2. FINDINGS.

Congress finds as follows:

(1) Cavernous angioma, also termed “cerebral cavernous malformations” or “CCM”, affects an estimated 1,500,000 people in the United States.
(2) Cavernous angioma is a devastating blood vessel disease that is characterized by the presence of vascular lesions that develop and grow within the brain and spinal cord.

(3) Detection of cavernous angioma lesions is achieved through costly and specialized medical imaging techniques. These techniques are often not readily available where patients live, and require sedation for children and disabled adults.

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

(5) Individuals diagnosed with cavernous angioma may experience neurological deficits, seizure, stroke, or sudden death.

(6) Due to limited research with respect to cavernous angioma, there is no treatment regimen for the disease other than brain and spinal surgery.

(7) Some individuals with cavernous angioma are not candidates for brain surgery, and no treatment option is available for such individuals.

(8) There is a shortage of physicians who are familiar with cavernous angioma and affected indi-
Individually may find it difficult to receive timely diagnosis and appropriate care.

(9) Due to the presence of a specific disease-causing mutation, termed the “common Hispanic mutation” that has passed through as many as 17 generations of Americans descended from the original Spanish settlers of the Southwest in the 1590s, New Mexico has the highest population density of cavernous angioma in the world. Cavernous angioma affects thousands of individuals in New Mexico.

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

(11) To address the public health threat posed by cavernous angioma in New Mexico and throughout the United States, there is a need for a Cavernous Angioma Clinical Care, Awareness, Research, and Education Center of Excellence in order to provide a model medical system for other such centers, to facilitate medical research to develop a cure for cavernous angioma, and to enhance the medical care of individuals with cavernous angioma nationwide.

(12) Given the existing programs and expertise in the southwest, the first coordinated, centralized Cavernous Angioma Clinical Care, Awareness, Re-
search, and Education Center of Excellence should be established there.

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

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

“**SEC. 409K. CAVERNOUS ANGIOMA CARE CENTERS OF EXCELLENCE.**

“(a) Establishment of Southwest Cavernous Angioma Care Center of Excellence.—The Secretary shall establish a coordinated, centralized Cavernous Angioma Clinical Care, Awareness, Research, and Education Center of Excellence at a university health sciences research and clinical center in the southwest United States (referred to in this section as the ‘CARE Center’) to provide basic, translational, and clinical research with respect to new diagnostic, prevention, and novel treatment methodology for individuals with cavernous angioma, and to serve as a model for medical schools and research institutions and to provide support to such schools and institutions.

“(b) Requirements.—The CARE Center established under subsection (a) shall—
“(1) consist of full- and part-time cavernous angioma researchers, clinicians, and medical staff including—

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

“(B) a headache or pain specialist;

“(C) an epilepsy specialist;

“(D) a psychiatrist;

“(E) a neuropsychologist;

“(F) a dermatologist;

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

“(H) a nurse coordinator to facilitate patient advocacy and research;

“(I) a research coordinator to facilitate research;

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

“(K) a radiology specialist;

“(L) a clinical vascular fellow;

“(M) a basic science postdoctoral fellow;

and

“(N) a genetic counselor;

“(2) be affiliated with a university medical center with an accredited medical school that provides
education and training in neurological disease, in which medical students and residents receive education and training in the diagnosis and treatment of cavernous angioma;

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

“(4) recruit new innovative researchers and clinicians to the field of cavernous angioma care and research;

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

“(6) maintain programs dedicated to patient advocacy, patient outreach, and education, including—

“(A) launching a multimedia public awareness campaign;

“(B) creating and distributing patient education materials for distribution by national physician and surgeon offices;

“(C) establishing an education program for elementary and secondary school nurses to fa-
cilitate early detection and diagnosis of cavernous angioma;

“(D) coordinating regular patient and family-oriented educational conferences; and

“(E) developing electronic health teaching and communication tools and a network of professional capacity and patient and family support;

“(7) be capable of establishing and maintaining communication with other major cavernous angioma research and care institutions for information sharing and coordination of research activities;

“(8) facilitate translational projects and collaborations for clinical trials; and

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

“(A) at least 1 individual with cavernous angioma or family member of such an individual;

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

“(C) at least 1 physician and at least 1 scientist with expertise in cavernous angioma and other relevant biomedical disciplines; and
“(D) at least 1 representative of the institution affiliated with the CARE Center.

“(c) DIRECTOR OF CARE CENTER.—

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

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

“(A) ensure that the CARE Center provides community-, family-, and patient-centered, culturally sensitive care;

“(B) encourage and coordinate opportunities for individuals to participate in clinical research studies that will advance medical research and care; and

“(C) develop the CARE Center as a model and training facility for other facilities throughout the United States that are engaged in research regarding, and care for individuals with, cavernous angioma.

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

“(2) CONTENT.—The report described in paragraph (1) shall include—

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

“(B) a description of the amount expended on the implementation of such requirements;

and

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

“(e) AUTHORIZATION OF APPROPRIATIONS.—To establish and operate the Care Center, there is authorized to be appropriated $2,000,000 for fiscal year 2013.”.