Purpose: to improve diagnosis and treatment for Cavernous Angioma through clinical research and outreach

BACKGROUND
Cavernous Angioma (Cerebral Cavernous Malformation, CCM) is a disorder of the brain and spinal cord characterized by the development of abnormal blood vessels which are likely to bleed into surrounding brain tissue. This can cause seizure, stroke and death in patients of all ages, including young children.

This illness affects more than 1.5 million Americans, although the disease is rarely diagnosed and sometimes fatal, demonstrating the need for research, improved diagnosis and effective treatment. The U.S. faces a shortage of basic, translational, and clinical research about Cavernous Angioma.

Cavernous Angioma may be found in people with no family history of the illness or caused by mutation in one of three genes (CCM1, CCM2 and CCM3). Cavernous Angioma patients, even those within the same family, often experience a wide range of clinical symptoms, or sometimes no symptoms at all. The late Olympic track star Florence Griffith Joyner passed away from a seizure caused by a Cavernous Angioma hemorrhage, and cyclist Alberto Contador suffered a seizure during a race in 2005 which led to brain surgery due to CCM.

One particular rare form of the illness is genetically tied to those who migrated from Spain in the 16th century across the southwest US (especially in Texas, New Mexico, Arizona and Colorado). Because of this genetic form of Cavernous Angioma, New Mexico is believed to have the highest concentration of affected individuals in the United States.

Medically, very little is known about effective clinical treatment; there is no known prevention or therapeutic treatment, and it is an exceptionally expensive disease to manage. Medication to prevent hemorrhage and lesion development could greatly benefit patients and significantly reduce treatment costs. And since many patients remain undiagnosed but potentially responsive to treatment, screening patients in high risk populations can be very cost:beneficial.

There is a real need for expanded research and coordination among newly created national clinical and research centers and government agencies for effective clinical trials for Cavernous Angioma treatment. These clinical and research centers can support research that benefits from a multidisciplinary, team-based approach aimed at understanding complex biomedical systems, and translating basic scientific discoveries into useful clinical applications. Such a model can be replicated by other diseases. Since some of the genetic forms of the disease are rare, coordination and collaboration among these centers will advance research and translation to patient care.

BILL
This bill would authorize the coordination and expansion of Cavernous Angioma lab research and surveillance activities as well as develop clinical and research centers with the potential to manage a multi-site clinical drug trial. These centers would provide technical assistance and clinical expertise (including diagnosis, genetic and medical counseling and treatment), education and support to develop and use telehealth infrastructure for reaching underserved communities. Clinical and Research centers would also serve as a venue for support groups and provide other resources for patients, providers and caregivers.

GROUPS SUPPORTING/ENDORSEING
Angioma Alliance Scientific Advisory Board  CCM3 Action