Cerebral Cavernous Malformations Clinical Awareness, Research, and Education (CCM-CARE) Act of 2017 (HR 1255 / S 475, 115th Congress)

The Policy

Synopsis

HR 1255 / S 475, the Cerebral Cavernous Malformations Clinical Awareness, Research, and Education Act of 2017 (CCM-CARE Act), aims to expand and coordinate clinical and research activities for cerebral cavernous malformations (CCM) across public and nonprofit private entities. The bill creates opportunities for clinical trials, general research, and investigational new drug (IND) applications to provide more treatment options and cures. The bill would establish coordinating centers and award grants to increase CCM-related research efforts.

The CCM-CARE Act amends the Public Health Service Act to indicate the roles of three government agencies—the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Food and Drug Administration (FDA)—in line with the bill’s goals.

The NIH is designated to fulfill the following tasks:

- Award grants and form cooperative agreements with public and nonprofit private entities;
- Broadly expand research efforts for CCM related to treatments, causes, diagnoses, education, and clinical training; and
- Establish two clinical and research coordinating centers, several participation centers, and a CCM consortium.

The CDC is responsible for carrying out the following actions:

- Award grants and form cooperative agreements with public and nonprofit private entities and provide technical support to collect, analyze, and report data on CCM;
- Establish a national CCM epidemiology program to collect, analyze, and report data on CCM, including data describing the usefulness of particular clinical practices; and
- Create a national surveillance program for CCM that will perform the same activities as the epidemiological program and coordinate with the NIH for sample and data collection.

The FDA is required to perform the following duties:

- Assist in clinical trial preparedness and support programs; and
- Coordinate with clinical centers to facilitate biomarker identification, clinical outcome assessment qualifications, IND applications, as well as adaptive trial design and expedited review pathways.
The Debate

Endorsements & Opposition

Endorsement:

- Angioma Alliance[47], statement[48], March 13, 2017: “We are grateful to Senator Udall for his advocacy on behalf of our New Mexico families and those around the country. His legislation, coupled with our exciting new community engagement effort, will raise awareness and potentially have a dramatic impact on the New Mexico CCM community.”

At present, there has not been any publicly reported opposition to this bill.

Status

HR 1255 was introduced in the House on February 28, 2017. On March 3, 2017, it was referred to the Subcommittee on Health[49] by the Committee on Energy and Commerce[50].

S 475 was introduced in the Senate on February 28, 2017, and referred to the Committee on Health, Education, Labor, and Pensions[51] on the same day.

Recommended Citation

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