

AMERICAN ASSOCIATION OF
NEUROLOGICAL SURGEONS

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American
Association of
Neurological
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CONGRESS OF
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March 20, 2017

The Honorable Tom Udall
U.S. Senate
531 Hart Senate Office Building
Washington, DC 20510

Dear Senator Udall:

On behalf of the American Association of Neurological Surgeons (AANS) and Congress of Neurological Surgeons (CNS), we are pleased to support your legislation, S. 475, the Cerebral Cavernous Malformations Clinical Awareness, Research, and Education (CCM-CARE) Act. We also thank Senator Heinrich for joining you as an original cosponsor of the bill.

As you are aware, cerebral cavernous malformation (CCM) is a devastating, rare genetic blood vessel disease that impacts the brain and spinal cord in over 600,000 Americans. Most people with the disease do not realize they have it until they experience symptoms, which include neurological deficits, seizures, stroke or sudden death. The only treatment available is brain and spinal surgery, and that can help only certain patients.

Since there is currently no cure for CCM, your legislation would provide crucial insights into this dreaded condition by expanding research at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and the U.S. Food and Drug Administration (FDA), to increase awareness, treatment and prevention of CCM. By conducting basic and clinical research, collaborating on multi-site clinical drug trials and coordinating all federal CCM health efforts to facilitate the exchange of information under the Department of Health and Human Services (HHS), new and innovative treatments can hopefully be discovered.

We thank you for your continued leadership and look forward to working with you on this important legislation.

Sincerely,

Frederick A. Boop, MD, President
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Alan M. Scarrow, MD, President
Congress of Neurological Surgeons

cc: The Honorable Martin Heinrich

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