



## **Cavernous Angioma and New Mexico**

Cerebral cavernous angiomas are mulberry-shaped vascular lesions that lay in the capillary bed of the brain and spinal cord. They are prone to hemorrhage and can cause mild to catastrophic neurological deficits and death, seizures, and severe chronic headaches at any age.

In the general population, cavernous angiomas occur in approximately 1 in 200-300 people. The illness may be sporadic - affecting only one family member - or inherited through a mutation on any one of three genes (CCM1, CCM2, or CCM3). In the inherited form, each child of an affected person has a 50% chance of having the illness.

In New Mexico, there is specific mutation on the CCM1 gene among thousands of descendants of the original Hispanic settlers, identified as a genetic founder effect. It is likely that this Common Hispanic Mutation has been passed through at least 17 generations since 1598, resulting in New Mexico having the highest population density of the illness in the world.

Because they are neurovascular lesions, cavernous malformations can present with any of a variety of symptoms; this can make them a diagnostic challenge. A good practice within New Mexico is to consider cavernous malformations in the differential diagnosis for any Hispanic patient presenting with severe headache, seizure, or neurological deficits. Family history and surnames may suggest the diagnosis. Historically, most families were found in northern NM counties, but patients are now found in almost all NM counties. The same gene mutation is also found in more recent immigrants from Chihuahua, Mexico with CCM1.

## **Angioma Alliance in New Mexico**

Angioma Alliance has been active in spreading awareness of the illness in New Mexico. Through our efforts and that of State Representative Jim Trujillo, state legislation was passed in 2007 calling for increased research, health professional education, and awareness of the illness in the state. As a result, in 2008, every member of the New Mexico medical society received a fact sheet with information about diagnosis and treatment of the illness. A study is ongoing through the Department of Health exploring the needs of affected individuals in the state; a report will be submitted to the State legislature in late 2009.

Angioma Alliance has hosted patient conferences in New Mexico. In 2006, the Angioma Alliance national conference was held in Santa Fe. National experts were brought in provide information to patients, and affected individuals were given the opportunity to meet each other for support. In 2008, Angioma Alliance hosted a patient education seminar in Santa Fe in conjunction with Cavernous Angioma Awareness Week which is described in more detail below.

In 2008, as a result of legislation introduced by City Councilor Karen Heldmeyer, the City of Santa Fe called for the creation of Cavernous Angioma Awareness Week. The 2008 event was

held in October and featured a patient seminar, public service announcements with information about cavernous angiomas, and an award ceremony and press conference honoring Councilor Karen Heldmeyer, State Representative Jim Trujillo, and Congressman Tom Udall. Dr. Leslie Morrison from the University of New Mexico and Angioma Alliance members visited family practice offices in the city to provide physician education.

Also in 2008, as a result of advocacy by Angioma Alliance, Congressman Tom Udall introduced legislation into the House of Representatives calling for increased cavernous angioma research, awareness, and education. Angioma Alliance has honored him with the Legislator of the Year Award for 2008.

Angioma Alliance works closely with the University of New Mexico, where more cavernous angioma patients are seen than anywhere in the world. We have submitted joint grant applications related to the genetics of the Common Hispanic mutation and are working together on a grant we received to create and distribute booklets that provide patient instructions on collecting family health history information. Family health history information is vital for identifying who is at risk for developing the illness.

New Mexico Angioma Alliance members have received press coverage in the New York Times, local Albuquerque and Santa Fe newspapers, on local news broadcast, and on the Discovery Health Channel program "Mystery Diagnosis".

## Resources

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