Resource Summary Report

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Angioma Alliance DNA/Tissue Bank and Patient Registry

RRID:SCR_004390
Type: Tool

Proper Citation

Angioma Alliance DNA/Tissue Bank and Patient Registry (RRID:SCR_004390)

Resource Information

URL: http://angioma.org/pages.aspx?content=105&id=92

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Description: Angioma Alliance has established a DNA/Tissue Bank and matching clinical database for cerebral cavernous malformations (CCM, cavernous angioma, cavernoma). Our goal is to create the world''s largest collection of CCM genetic samples with matching clinical data to be used as a resource to drive research. We are recruiting individuals with a history of cerebral cavernous malformations to participate in the study. Qualified participants donate a blood sample and complete a comprehensive questionnaire or interview. Blood donation kits will be sent in the mail for participants to take to their doctor, clinic or blood draw center to have their blood drawn. The kit is then mailed to a private lab where the sample is processed. If a surgery is scheduled, the Angioma Alliance DNA/Tissue Bank will work with the participant, the surgeon, and the hospital to coordinate tissue donation. If surgery scheduling allows, dry ice will be shipped to the hospital facility along with a tissue collection kit for use and return to the private lab. The Angioma Alliance DNA/Tissue Bank will attempt to acquire Institutional Review Board approvals at facilities where this is required. The Angioma Alliance BioBank will follow up with participants on a yearly basis to update their clinical information. If the participant has not already had documented genetic testing, we will test their DNA sample for possible CCM1, CCM2, or CCM3 mutation or CCM2 exon 2-10 deletion. If additional causative genes are identified for the illness, we will also test for mutations on these. Participants will not be informed of the results of testing, but if a mutation or deletion is found, they will be informed that results can be released to a diagnostic laboratory in order to obtain follow-up confirmatory clinical diagnostic testing. This could mean a substantial cost savings to the patient whose insurance does not cover genetic testing or who is uninsured. All researchers requesting the use of DNA and/or Tissue samples from Angioma Alliance must complete an application form and material transfer agreement.

Abbreviations: Angioma Alliance DNA/Tissue Bank and Patient Registry

Synonyms: Angioma Alliance BioBank, Cerebral Cavernous Malformations DNA and Tissue Bank, Cerebral Cavernous Malformations (CCM) DNA & Tissue Bank, CCM DNA & Tissue Bank, CCM DNA and Tissue Bank, Cerebral Cavernous Malformations (CCM) DNA and Tissue Bank

Resource Type: biomaterial supply resource, material resource, tissue bank

Keywords: cerebral cavernous malformation, cavernous angioma, cavernoma, clinical, blood, dna, fresh, frozen, ccm lesion tissue, ccm1, ccm2, frozen, paraffin section, slides, ccm3, paraffin-embedded, public

Related Condition: Angioma, Cerebral cavernous malformation, Cavernous angioma, Cavernoma

Funding: Angioma Alliance

Availability: Public

Resource Name: Angioma Alliance DNA/Tissue Bank and Patient Registry

Resource ID: SCR_004390

Alternate IDs: nlx_143719

Record Creation Time: 20220129T080224+0000

Record Last Update: 20260808T190346+0000

Ratings and Alerts

No rating or validation information has been found for Angioma Alliance DNA/Tissue Bank and Patient Registry.

No alerts have been found for Angioma Alliance DNA/Tissue Bank and Patient Registry.

Data and Source Information

Source: SciCrunch Registry

Usage and Citation Metrics

We have not found any literature mentions for this resource.