Brain Vascular Malformation Consortium

The Brain Vascular Malformation Consortium (BVMC) is a multidisciplinary, inter-institutional group of investigators, one of 17 consortia in the Office of Rare Disease Research Rare Disease Clinical Research Network (RDCRN). The diseases under study are: familial Cerebral Cavernous Malformations type 1, common Hispanic mutation (CCM1-CHM); Sturge-Weber Syndrome (SWS); and brain arteriovenous malformation in hereditary hemorrhagic telangiectasia (HHT). Each project is developing biomarkers for disease progression and severity, and has established scalable, relational databases for observational and longitudinal studies that are stored centrally by the RDCRN Data Management and Coordinating Center. Patient Support Organizations (PSOs) are a key RDCRN component in the recruitment and support of participants. The BVMC PSOs include Angioma Alliance, Sturge Weber Foundation, and HHT Foundation International. Our networks of clinical centers of excellence in SWS and HHT, as well as our PSOs, have enhanced BVMC patient recruitment. The BVMC provides unique and valuable resources to the clinical neurovascular community, and recently reported findings are reviewed. Future planned studies will apply successful approaches and insights across the three projects to leverage the combined resources of the BVMC and RDCRN in advancing new biomarkers and treatment strategies for patients with vascular malformations [1].

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Akers AL, Ball KL, Clancy M, Comi AM, Faughnan ME, Gopal-Srivastava R, Jacobs TP, Kim H, Krischer J, Marchuk DA, McCulloch CE, Morrison L, Moses M, Moy CS, Pawlikowska L, Young WL. Brain Vascular Malformation Consortium: Overview, Progress and Future Directions. J Rare Disord. 2013 Apr 1;1(1):5. PubMed PMID: 25221778.