Brain Vascular Malformation Consortium (BVMC)

At a Glance
- Status: Active Consortium
- Year Launched: 2009
- Initiating Organization: NIH Rare Disease Clinical Research Network
- Initiator Type: Government
- Rare disease
- Location: North America

Research Areas
- Tool Development
- Biomarker Research

Abstract
The Brain Vascular Malformation Consortium (BVMC) is an integrated group of academic medical centers, patient support groups, and clinical research resources dedicated to conducting clinical research in different forms of brain vascular malformations and improving the care of patients with Sturge-Weber syndrome (SWS), Cerebral Cavernous Malformations (CCM), and Hereditary Hemorrhagic Telangiectasia (HHT). Funded by the National Institutes of Health (NIH), BVMC is part of the Rare Diseases Clinical Research Network.

Mission
BVMC’s mission is to conduct clinical research and clinical trials to learn more about these diseases with the goal of developing new and better treatments to improve the care of patients with brain vascular malformations. It also seeks to provide up-to-date information for patients to help them manage their diseases and to assist in connecting patients with support groups, expert doctors, and clinical research opportunities.
BVMC’s goals are as follows:

**Structure & Governance**

This consortium is part of the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research, National Center for Advancing Translational Sciences (NCATS). The RDCRN is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment, and data sharing. Through the RDCRN consortia, physician scientists and their multidisciplinary teams work together with patient advocacy groups to study more than 200 rare diseases at sites across the nation.

Funding and scientific oversight for the RDCRN are provided by NCATS and 10 NIH components: Eunice Kennedy Shriver National Institute of Child Health and Human Development; National Cancer Institute; the National Heart, Lung and Blood Institute; National Institute of Allergy and Infectious Diseases; National Institute of Arthritis and Musculoskeletal and Skin Diseases; National Institute of Dental and Craniofacial Research; National Institute of Diabetes and Digestive and Kidney Diseases; National Institute of Mental Health; National Institute of Neurological Disorders and Stroke; and Office of the Director. In addition, patient advocacy groups provide funds for many of the projects.

**Patent Engagement**

The RDCRN BVMC Contact Registry is a way for patients with Nephrotic Syndrome and their family members to learn about BVMC research studies they may be able to join. Participation is completely voluntary, and participants can withdraw at any time. There is no cost to join the Contact Registry.

**Links/Social Media Feed**

Homepage  http://www.rarediseasesnetwork.org/cms/bvmc/

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Sponsors & Partners

Participant/Sponsor
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Barrow Neurological Institute
Baylor College of Medicine, Texas Children’s Hospital
Cincinnati Children’s Hospital
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Johns Hopkins University
Mayo Clinic, Rochester, NY
Nationwide Children’s Hospital, Columbus
New York University Comprehensive Epilepsy Center
St. Antonius Hospital, Nieuwegein
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Updated: 04/06/2016