

**Cerebral Cavernous Malformation (CCM) Disease Elements**

**Principal Investigator** Responsible for Accuracy of Data (Name): \_\_\_\_\_ **Subject ID Number:** \_\_\_\_\_

**Is this data Longitudinal (Follow-Up) Data?** Yes  No

**Subject Zip Code (1<sup>st</sup> 3 digits):** \_\_\_\_\_ **Country of Residence** \_\_\_\_\_

**Family Member Samples in Repository?** Yes  No  Unknown (subject adopted)  If Yes, list subject ID/s: \_\_\_\_\_

**Year of birth:** \_\_\_\_\_ **Gender:** Male  Female

**Ethnic Category** (as reported by subject)-Check one: Hispanic or Latino  Not Hispanic or Latino

**Racial Categories** (as reported by subject) Check One:

American Indian/Alaska Native  Asian  Native Hawaiian/ Other Pacific Islander

Black/African American  White/Caucasian  More than One Race  Other  Unknown

**Additional Racial and Ethnicity Information:** Ashkenazi  Other: \_\_\_\_\_

**Diagnosed By:** Neurosurgeon  Neurologist  Pediatric Neurologist  Pediatrician  Other   
Primary Care Physician  Psychiatrist  Psychologist  Does Not Apply (Population or Family-Based Control)

**Data Collected By:** Neurosurgeon  Neurologist  Pediatric Neurologist  Primary Care Physician  Pediatrician   
Psychiatrist  Psychologist  Research Coordinator  Registered Nurse  Research Coordinator/ RN

	<b>Present</b>	<b>Absent</b>	<b>Unknown</b>	
<b>Family History of CCM:</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	If present, list family members _____
<b>Known Genetic Syndrome:</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Please specify, if applicable: _____
<b>Known Mutation/s in DNA:</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Please specify, if applicable: _____

Number of CCM lesions on MRI  Single  Multiple

Age at MRI \_\_\_\_\_

Presentation at symptom onset  Seizure  Headache  Clinical stroke  Asymptomatic

Modified Rankin Score 0 1 2 3 4 5 6

**Optional Data:**

Smoking history Never  Previous  Current  Years Smoking, if applicable \_\_\_\_\_

Handedness Left  Right  Ambidextrous