

## Hereditary Hemorrhagic Telangiectasia (HHT) 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

**Smoking History** Never  Previous  Current  Pack-years, if Applicable \_\_\_\_\_

**Family History of HHT:** Present  Absent  Unknown

If Present, List Affected Family Members: \_\_\_\_\_

**HHT Clinical Diagnosis:** Definite  Possible  Uncertain  Unknown

**HHT Mutation:** endoglin  alk1  smad4  unknown

**HHT Specific Mutation:** \_\_\_\_\_

**Brain AVM Present:** Yes  No  Unknown

**Other AVM Present:** Pulmonary  Liver  Gastrointestinal  Other

If other, please specify: \_\_\_\_\_

Notes: \_\_\_\_\_

Medical History	Present	Absent
Hypertension	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes mellitus	<input type="checkbox"/>	<input type="checkbox"/>
Atrial fibrillation	<input type="checkbox"/>	<input type="checkbox"/>
Myocardial infarction	<input type="checkbox"/>	<input type="checkbox"/>

Other Risk Factors: \_\_\_\_\_