

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 (1st 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
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Hypertension	<input type="checkbox"/>	<input type="checkbox"/>
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Diabetes mellitus	<input type="checkbox"/>	<input type="checkbox"/>
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Atrial fibrillation	<input type="checkbox"/>	<input type="checkbox"/>
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Myocardial infarction	<input type="checkbox"/>	<input type="checkbox"/>
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Other Risk Factors: _____