BREAKING NEWS . . . BREAKING NEWS . . . BREAKING NEWS . . . BREAKING NEWS . . .

HHT Brain AVM Research

In a huge step forward for HHT, the NIH Office of Rare Disease (ORD) and the National Institute of Neurological Disorders and Stroke (NINDS), has awarded a five-year grant to a team of researchers studying HHT and related vascular disorders, as part of a Rare Disease Clinical Research Consortium, to study brain AVMs in HHT. This will be the first large-scale study of brain AVMs in HHT patients, who will be recruited through twelve HHT Centers across North America and through the HHT Foundation. The goal of the study is to determine what genetic and clinical factors signal high risk for hemorrhage from brain AVMs. This study should ultimately help doctors make decisions about brain AVM treatment for individual patients and will drive further research in brain AVM therapies.

The HHT Foundation and NIH researchers will be conducting interviews with brain AVM research participants at the National HHT Patient & Family Conference in St. Louis, MO.

To participate in this study, you must be diagnosed with a Brain AVM, regardless of *whether or not the brain AVM is treated or untreated*. All participants in this research study will be scheduled for a one-half hour consultation with a nurse and a physician either before, during, or after the conference sessions. During this appointment, you will:

- Meet with a nurse to gather consent documents, gather clinical data, review a patient questionnaire, collect records and imaging, and take a saliva sample.
- Meet with a physician to review all of the information gathered by the nurse.

Upon receipt of this enrollment form, the HHT Foundation will contact you with your appointment time. You will need to bring the following items to your appointment:

1. Copy of your physician's letter stating your Brain AVM diagnosis
2. Copy of your brain imaging
3. Dates of symptoms, complications, and/or treatments
4. Genetic test results, if applicable

Please contact the HHT Foundation Office at 800-448-6389 if you have any questions about this study.

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I Want to Participate in HHT Brain AVM Research!

Please schedule my half-hour appointment with a nurse and physician at the National HHT Patient and Family Conference in St. Louis, MO to be held on October 22-24, 2010.

Name____

Address: ____

Phone: ______________________ E-mail: ____________________________________

HHT Center where receive care ____

Preferred appointment time:

❑ ***Early Morning*** (7am–9am) ❑ ***Late Afternoon*** (5pm–7pm) ❑ ***Mid-Day*** (during lectures or workshop sessions)

Return by October 1, 2010 to: HHT Foundation, PO Box 329, Monkton, MD 21111