HHT Solutions

399 Bathurst Street, Rm 13MP302
Toronto, Ontario M5T 2S8 Canada

http://www.hhtsolutions.org
info@hhtsolutions.org
Phone: (416) 603-5597
Fax: (416) 603-5622

CHECKLIST FOR ITEMS INCLUDED WITH SAMPLE(S)

Sample(s) prepared according to instructions (***see web site***):

_______ Blood _______ DNA from Blood
_______ Amnio _______ DNA from Amnio _______ Other

_______ HHT Requisition Form (*download from web site*)
_______ Informed Consent (*download from web site*)
_______ Payment or insurance company authorization (*include copy of insurance ID*)
_______ Enclose this page, too, please.

BILLING INSTRUCTIONS

☐ Please bill institution ☐ Please bill patient or third party insurer.

Billing Address:
Institution, Patient or Insurance Provider: ____________________________ Attention: _____________________
Mailing Address: ____ Province/State ___________
Phone: _______________ Fax: _______________ Patient Insurance ID # ______________________________

TEST FEES

Full Screen for Unknown Mutation(s)	CAD	3,650
Less: *Discount for advance payment*		(350)
Test for Known Mutation		
Set-Up Fee, each batch of samples from the same family, all to arrive at same time (2)		150
Test Fee, each sample		400
Less: *Discount for advance payment*		(50)
Test cultured amniotic cells for known mutation (all-inclusive)		850

Terms:
(1) With regret for the delay it causes, we hold reports until payment is received.
(2) Only one set-up fee is charged for multiple blood relatives whose samples arrive at the same time.
(3) A discount is applied to invoices paid in advance. A further discount is available for large-volume orders.

PAYMENT OPTIONS

_____ Payment enclosed.
_____ Payment authorization on letterhead from insurance provider.
_____ MasterCard ☐ VISA ☐ Amount: ____________________________

Account Number: ___________________________________ Expiration Date: ______________________
Cardholder's Name: ____
Signature: ____

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GENETIC TEST REQUISTION

HEREDITARY HEMORRHAGIC TELANGIECTASIA (HHT)

REFERRING PHYSICIAN

Name: ______________________ Address: ______________________

Institution: ______________________ ______________________

Specialty: ______________________ ______________ City: __________

Phone: __________ Fax: __________ Province/State: ______ Postal Code: __________

E-mail: ______________________ Country: ______________________

Contact Person: ______________________ Phone: ______________ email: __________

PATIENT

Name: ______________________ Address: ______________________

Male / Female City: ______________________

Birthdate: Year. ______ Mo. ______ Day ______ Province/State: __________ Postal Code: __________

Parent(s): ______________________ Country: __________ Phone: __________

Referring Institution ID#: ______________

SPECIMEN

Time Obtained: hh : mm (use 24 hr clock) Date Obtained: year—mo.—day

☐10mls ACD or EDTA blood (send at room temp) ☐ DNA (room temperature)

RELATIONSHIP OF PATIENT TO PROBAND

☐ Proband ☐ Parent ☐ Son / Daughter ☐ Brother / Sister ☐ other: ______________
(the *proband* is the person with the initial *molecular* diagnoses of HHT) (specify maternal or paternal)

Patient's clinical diagnosis:

☐ confirmed clinical HHT ☐ Nose Bleeds ☐ Stroke
☐ suspected clinical HHT ☐ Telangiectasia ☐ Liver Shunts
☐ unaffected ☐ PAVM ☐ GI Bleeding
☐ CAVM ☐ Other __________

Family history: ☐ Positive History (attach separate pedigree) ☐ Isolated Case

SPECIALIST AUTHORIZATION

______________________________ ***Referring Specialist***

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Sample Submission Instructions for HHT Genetic Analysis

Turnaround Time: Diagnose unknown mutation, 4-16 weeks; test for known mutation, 2-4 wks; rush for known mutations (prenatal and infants at risk age 3 yrs or less), 7 working days.

Preparing Samples:

All samples must be labeled clearly with at least two patient identifiers (patient name, date of birth, medical record number, for example), plus time and date sample was drawn.

Amniocytes: Send two T25 flasks of cultured amniotic cells or DNA extracted from amniotic cells.

CVS: Send CVS tissue

Blood Samples:

1. Draw 10 mls (for infants 2-5 ml in small or pediatric tubes) of venous blood in yellow-topped ACD tubes or lavender-topped EDTA tubes.
2. Send blood samples for DNA analysis at room temperature; **DO NOT REFRIGERATE.** Samples must be received within 5 days of being drawn.
3. Send blood samples for RNA analysis on 4°C cool packs. **Samples must be received within 48 hours of being drawn.**

Shipping:

US DOT regulations (49 CFR 173.199) require packages containing diagnostic specimens to be triple-packed: 1. Primary receptacles, typically a glass or plastic tube, 2. Secondary packaging, typically absorbent material inside a sealed plastic bag to protect against leakage, 3. Rigid outer packaging, typically a Styrofoam or cardboard box.

Ship all samples in rigid, leak-proof packaging to HHT Solutions at the address above.

1. If possible, please use FedEx, with Next Day delivery and use a FedEx “Diagnostic Specimen Bag”. If you cannot use FedEx, please contact us.

2. For samples from outside Canada,
   a. Mark on the waybill that the specimen is non-hazardous and non-toxic.
   b. Declare value at US$10 so Canada Customs does not need to inspect.
   c. When handled by FedEx, FedEx is the registered customs clearing agent for this parcel.

3. ***Notify Solutions of the courier’s tracking number soon after the parcel is picked up: (416) 603-5597***

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INFORMED CONSENT to PERFORM GENETIC TESTING for Hereditary Hemorrhagic Telangiectasia (HHT)

I, ______________________________, consent to participate, or as applicable, to have my child _______________ participate, in a DNA-based test to identify a genetic abnormality believed to cause hereditary hemorrhagic telangiectasia. I understand this test requires a blood sample from the person to be tested and may require blood samples from blood relatives. I understand that the blood samples will be used to determine if the subject and members of the subject's family carry a genetic abnormality.

By signing below, I acknowledge that:

1. My participation and as applicable, my child's participation, in this DNA testing is voluntary.
2. The removal of up to 10 ml of blood (5 ml for infants) required for the test carries a low risk of discomfort and infection.
3. Although the lab makes every effort to ensure the accuracy of test results, there remains a small possibility of human error and a very small chance that there exists in the subject's DNA a second mutation not identified by the test. Consequently, a remote but real possibility remains that the DNA test results lead to an inaccurate diagnosis.
4. A person whose DNA contains a genetic abnormality associated with HHT does not necessarily develop the disease. A negative test result does not imply that the subject has no chance to develop HHT.
5. All test results are confidential; no information will be printed or released that discloses the patient's identity without my additional written permission. Only the referring physician I designate on the HHT Requisition Form will receive a written report of test results.
6. *HHT Solutions* is not a DNA banking facility and patient DNA samples may not be available for future testing.
7. An error in diagnosis may occur if the true biological relationships of the family members are not as stated in the pedigree submitted with the HHT Requisition Form. It is possible that the test may disclose paternity and I consent that this finding be reported to the physician designated on the HHT Requisition Form.
8. Until the results of this test are reported, the patient and members of the patient's family should still undergo examinations as prescribed by the referring physician.
9. The referring physician reviewed this consent form with me, point by point, and explained the implications of the test results to me. Any questions that I asked have been answered to my satisfaction. I know that I (or members of my family) may ask any questions we have about the collection, use and disclosure of our personal genetic information.
10. If necessary to obtain reimbursement of test fees, *HHT Solutions*, its agents and legal representatives may disclose information that identifies me or my children who are subject to *HHT* genetic testing.
11. I received a copy of this consent form and the referring physician whom I designate on the HHT Requisition Form received a copy of this consent form.

_______________________________________ _____________________

Signature of Subject or Consenting Parent Date

CONSENT SPECIFICALLY FOR FUTURE RESEARCH: After all analysis required to reach a genetic diagnosis is complete, *HHT Solutions* has my consent to use the subject's DNA in an anonymous fashion for research to improve the sensitivity of genetic tests for *HHT*. I have reviewed the HHT Research Fact Sheet.

YES ☐ NO ☐ Signature ___________________________________

Statement of Referring Physician: I reviewed this form with my client, point by point. I offered to answer any questions regarding personal genetic information for the client or the client's children.

_______________________________________ _____________________

Signature of Referring Physician Date

HHT Solutions

Confidential Information about HHT Families

Individual providing information: ______________________________

Date Completed: ______________________________

Proband Name: ______________________ Date of Birth: YYYY/MM /DD HP#______	□ PAVM □ CAVM □ Rare Nosebleeds □ Frequent Nosebleeds	□ GI Bleeding □ Telangiecteses □ Liver Shunts □ Stroke	□ Non-affected □ Other (list below)

***The Proband is the first affected person to participate in a DNA based test with HHT Solutions, to identify a genetic abnormality believed to cause HHT.**

Begin entering family members starting with the proband's parents and following with brothers/sisters and biological children. Use additional sheets as needed to provide information on additional affected family members.

Name of Family Member Relationship to Proband	HHT Symptoms Please check the applicable boxes □ √		
Name:______________ Relationship:__________ Date of Birth: YYYY/MM/DD HP#______	□ PAVM □ CAVM □ Rare Nosebleeds □ Frequent Nosebleeds	□ GI Bleeding □ Telangiecteses □ Liver Shunts □ Stroke	□ Non-affected □ Other (list below)
Name:______________ Relationship:__________ Date of Birth: YYYY/MM/DD HP#______	□ PAVM □ CAVM □ Rare Nosebleeds □ Frequent Nosebleeds	□ GI Bleeding □ Telangiecteses □ Liver Shunts □ Stroke	□ Non-affected □ Other (list below)
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