Bloodworks Labs
LABORATORY SERVICES

REQUEST FOR TESTING

HEMOPHILIA ALLIANCE

Bloodworks Bleeding Disorders Lab
921 Terry Ave | Seattle, WA 98104
Phone 206- 568-2184 | **Fax** 866-560-0806 | **Email** bleedingdisorderslab@bloodworksnw.org
Laboratory Staffed Monday-Friday

REASON FOR PARTICIPATION

- ☐ No insurance
- ☐ Insurance claim denied
- ☐ Insurance does not cover testing
- ☐ Out-of-pocket cost is prohibitive
- ☐ Other_____

SAMPLE INSTRUCTIONS

Whole Blood Samples

- DNA mutation testing requires at least 3 ml EDTA whole blood (purple top).

Labeling Samples

- Each submitted sample must be labeled with patient name, DOB, and date of draw.
- All samples must be properly labeled and information must agree with the identification on the RFT.
- A draw date should be on the sample but the sample will still be accepted if the draw information is on the RFT.

SHIPPING INSTRUCTIONS

Send to: Bloodworks
Attn: Bleeding Disorders Laboratory
921 Terry Ave
Seattle, WA 98104

- Do not send samples to arrive on weekends or federal holidays.
- Ship samples with a "cool pack."
- Samples must be sent via overnight express.
- If samples cannot arrive Monday-Frdiay before 1pm, please store the sample at 2 - 8°C until sample can be sent.

Submitting laboratory is responsible for obtaining consent for genetic testing per state law. **New York State Patients only:** Check the box confirming consent was obtained. ☐

PATIENT INFORMATION

ALL * fields are required

***Collection date:** DATE _____ /_____/ _____ TIME_____ ☐am ☐pm

PATIENT NAME:

*LAST	*FIRST	M.I.

Medical Record #	*Sex at birth (M/F)	*Date of Birth (mm/dd/yyyy)

***PROVIDER NAME** (or authorized person ordering test)

*Last_____*First_____

*Email:_____Phone #:_____

***HTC Name:** _____

*HTC #:_____ City, State, Zip:_____

***Main Contact Person:** ☐Same as provider ☐ *Other, fill in below

Name:_____

Email:_____

Phone #:_____Fax #:_____

***SEND REPORT TO:** ☐ Same as main contact person ☐ Other, fill in below

Name:_____

☐ Email:_____

☐ Fax #:_____

For Bloodworks Use Only

Date Received: _____Received by: ____
Comments:

***DNA TESTS:**

- ☐ DNA Hemophilia A
- ☐ DNA Hemophilia B
- ☐ DNA von Willebrand disease

***FAMILY HISTORY:**

☐ Yes ☐ No

FAMILIAL VARIANT c._____, p._____

Relationship to affected patient:_____

***CLINICAL DATA:**

Hemophilia A or B (circle one), please fill out below

Baseline FVIII or IX (circle one) activity:
Assay used: ☐ One stage ____% Date of test:_____
☐ Chromogenic ____% Date of test:_____

von Willebrand disease, please fill out below

VWF activity:
Ristocetin based assay: ☐ VWF:RCo ☐ VWF:GPIbR ___% Date of test:_____
Non-Ristocetin based: ☐ VWF:GPIbM ☐ VWF:Ab ____% Date of test:_____

VWF Antigen:_____% Date of test:_____
aPTT:_____% Date of test:_____
VWF Collagen Binding:_____% Date of test:_____
Multimers: ☐ Normal ☐ Abnormal(choose below) Date of test:_____

- ☐ Loss of HMW
- ☐ Loss of large and intermediate forms
- ☐ All multimers present, reduced intensity

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Clinical Data - Hemophilia A

Please carefully complete the respective clinical data of the patient. This is important for interpretation of genetic findings.

Hemophilia A degree of severity:

☐ Male/Female (>5% - <40%) ☐ Male/Female Moderate (1-5%) ☐ Male/Female Severe (<1%)

☐ Female potential or known symptomatic carrier with FVIII ≥ 40%

☐ Female potential or known asymptomatic with FVIII ≥ 40%

☐ Female potential or known symptomatic with unknown FVIII activity

FVIII Inhibitor History:

History of a FVIII inhibitor? ☐ Yes, please answer questions below. ☐ No

If yes, was it a high titer Inhibitor? ☐ Yes ☐ No

History of immune tolerance induction (ITI)? ☐ Yes ☐ No

Was ITI successful? ☐ Yes ☐ No

Ongoing immune tolerance induction? ☐ Yes ☐ No

FVIII treatments received (exposure days) at time of blood draw:

☐ 0 ☐ 1 - <20 ☐ 20 - 50 ☐ >50 ☐ Has received treatment but number unknown

Bleeding symptoms:

Has patient had a bleeding episode, including heavy menstrual bleeding and/or postpartum hemorrhage:

☐ Yes ☐ No If yes, age at which this first occurred _____ ☐ Unknown

Age at first joint bleed _____ ☐ N/A ☐ Unknown

Has a Bleeding Assessment Tool been performed? ☐ Yes ☐ No ☐ Unknwon

If yes, age at which BAT was taken? _____ BAT score: _____ BAT used: _____

Desmopressin (DDAVP) Testing:

Has the patient been tested for desmopressin (DDAVP) response? ☐ Yes ☐ No ☐ Unknown ☐ N/A

If yes, did they have a positive response defined as at least a double in FVIII level and > 50%?

☐ Yes ☐ No ☐ Unknown

If yes, did they have a positive response defined as maintaining a FVIII >50% for ≥ 4 hours?

☐ Yes ☐ No ☐ Unknown ☐ No ≥ 4 hour timepoint?

Additional information/comments (include clinic notes if available):

Please **complete**, **sign,** and **send** this consent form as well as the RFT and Clinical Data form along with the patient sample(s) to Bloodworks in Seattle, WA.

Permission for Genetic Testing

Informed Consent for DNA Testing for Hemophilia A/Hemophilia B/von Willebrand disease

I agree to participate in testing for genetic variants that cause Hemophilia A (Hem A) [factor VIII deficiency], Hemophilia B (Hem B) [factor IX deficiency], or von Willebrand disease (VWD) [von Willebrand factor deficiency]. I understand that a sample of blood will be drawn from me or my child or legal ward.

The DNA extracted from the blood sample will be used to determine if I or my child or legal ward has a variant in a gene that causes Hem A, Hem B, or VWD. Finding a DNA variant could explain why I or my child is affected with Hem A, Hem B, or VWD or it could determine that I or my child is a carrier of Hem A, Hem B, or VWD.

It has been explained to me and I understand that:

1. In most cases a molecular test directly detects an abnormality (called a DNA variant) in the gene. The chance of finding a variant depends on the sensitivity and specificity of the test. Currently the BW Eastlake Genomics Laboratory is able to find a variant in 95-98% of patients with Hem A and Hem B and varies by type for VWD.
2. The testing is complex and utilizes specialized materials, and there is a possibility that the test will not work properly or that an error will occur. My signature below acknowledges my voluntary participation in the molecular testing, but in no way releases the laboratory and staff from their professional and ethical responsibilities.
3. Results will only be reported to me through my Hemophilia Treatment Center (HTC) provider, physician or genetic counselor who ordered the test. The results are confidential; they will only be released to medical professionals outside my place of medical care with my written consent.
4. Genetic counseling is the process through which patients or relatives at risk for an inherited disorder gain a better understanding of the disorder and what can be learned from genetic testing. This process is recommended for anyone who undergoes genetic testing.
5. The molecular testing performed at Bloodworks in no way guarantees my health or the health of my family member.
6. I understand that any specimen received for testing becomes the priority of the BW Eastlake Genomics Laboratory. All samples will be handled and destroyed according to a BW standard operating procedure for ordering and processing of samples. These samples will not become part of a DNA bank or repository unless I have agreed to participate in research studies and given separate written informed consent for that purpose.
7. **I agree to be contacted for participation in research studies in the future.** ☐ Yes ☐ No

HTC Provider/Physician/Counselor statement: I have explained the molecular testing to this individual. I have addressed the limitations outlined above, and answered this individual's questions.

Name of Provider/Physician/Counselor: _____ Date: _____

Signature Signature of Provider/Physician/Counselor: _____

Patient Name: _____ Date of Birth: _____

Patient Signature: _____ Date: _____

Parent/Guardian Name (if applicable): _____

Parent/Guardian Signature: _____ Date _____

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Bloodworks (BW) Bleeding Disorders Laboratory is accredited to perform blood testing services according to in force government licenses.

Check List

All items below must be completed and checked off before sending sample(s).

- ☐ EDTA tube is filled (>1.5 ml) and labeled correctly
  - ☐ patient name
  - ☐ DOB
  - ☐ date of draw
- ☐ RFT is completed with all required information entered (page 1/3)
- ☐ Correct Clinical Data form is completed (page 2/3)
- ☐ Correct Permission for Genetic Testing form is completed (page 3/3)

  For New York HTCs - use NY specific consent form

Shipping requirements:

- ☐ Overnight shipping
- ☐ Scheduled to arrive on a weekday (excluding holidays)
- ☐ Email Bleedingdisorderslab@bloodworksnw.org with tracking number and number of samples

If a sample cannot arrive during the designated time, please store at 2 - 8°C until sample can arrive between Monday - Friday (no later than 1pm).

No testing will occur until all required information is received.

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