**FEMALE UDC REGISTRATION FORM**

*Complete this form for first visit or to re-register females. Shaded items represent questions from regular UDC registration form.*

<table>
<thead>
<tr>
<th>Date of Visit</th>
<th>Date Form Completed</th>
<th>Form Completed By</th>
<th>Data entered by</th>
</tr>
</thead>
<tbody>
<tr>
<td>__ /__ /___ ___</td>
<td>__ /__ /___ ___</td>
<td>________________</td>
<td>________________</td>
</tr>
</tbody>
</table>

**DEMOGRAPHIC/REFERRAL INFORMATION**

1. **Month and year of birth:**
   
   __ /__ /___ ___

2. **Race/Ethnicity:**
   
   - White (non-Hispanic)
   - Black (non-Hispanic)
   - Asian/Pacific Islander
   - Other ___________________

3. **Place of Birth:**
   
   State: __ __
   Or, country (if other than USA): ______________

4. **HTC status:**
   
   - Established Patient
   - New Patient
   - Transfer Patient

5. **Who first referred the patient to an HTC? (check one)**
   
   - Dentist
   - Family practitioner
   - General practitioner
   - Hematologist
   - Internist
   - Obstetrician/Gynecologist
   - Oncologist
   - Pediatrician
   - Surgeon (e.g. ENT)
   - Nurse/Nurse practitioner/Physician assistant
   - Another HTC
   - Family member
   - NHF chapter/Project Red Flag
   - Self-referred
   - Other: ____________________________

**DIAGNOSIS INFORMATION**

6. **Inherited coagulation factor (F) deficiency (Check all that apply):**

   **Factor:**
   - Fibrinogen
   - FII (2)
   - FV (5)
   - FVII (7)
   - FVIII (8)

   **Baseline factor activity:**
   - ___.__% check if < 1%
   - ___.__% check if < 1%
   - ___.__% check if < 1%
   - ___.__% check if < 1%
   - ___.__% check if < 1%
   - ___.__% check if < 1%

*Inactive*
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☐ FIX (9) __.__.__%  ☐ check if < 1%
☐ FX (10) __.__.__%  ☐ check if < 1%
☐ FXI (11) __.__.__%  ☐ check if < 1%
☐ FXIII (13) __.__.__%  ☐ check if < 1%
☐ PAI-1 __.__.__%  ☐ check if < 1%
☐ α2-anti-plasmin __.__.__%  ☐ check if < 1%
☐ Other, specify _______________ __.__.__%  ☐ check if < 1%
☐ None

(7) von Willebrand Disease:
   (7a) Diagnosis (Select one)  (7b) Baseline activity
   ☐ Type 1 ☐ Type 2N FVIII (8) __.__.%
   ☐ Type 2A ☐ Type 3 VWF:RCof __.__.%
   ☐ Type 2B ☐ VWD type unknown VWF:Ag __.__.%
   ☐ Type 2M ☐ None

(8) ABO Blood type
☐ O ☐ A ☐ B ☐ AB ☐ Unknown

(9) Platelet disorder:
☐ Glanzmann’s thrombasthenia ☐ Storage pool defect
☐ Bernard Soulier ☐ Release defect
☐ Grey platelet syndrome ☐ Not specified
☐ Hermanski-Pudlak syndrome ☐ Other
☐ Inherited thrombocytopenia ☐ None

(10) Connective tissue disorder:
☐ Suspected Ehlers-Danlos Syndrome or hyper mobility syndrome
☐ Not specified
☐ Other
☐ None

(11) Diagnosed Hereditary Hemorrhagic Telangiectasia (HHT)/Osler-Weber-Rondu:
☐ Yes ☐ No

(12) Age bleeding disorder first diagnosed: __ __ ☐ days ☐ months ☐ years ☐ Unknown

(13) Has patient ever had a bleed? ☐ Yes ☐ No
   (13a) If yes, age at first bleed: __ __ ☐ days ☐ months ☐ years ☐ Unknown
   (13b) If yes, site of first bleed:
   ☐ Head (Intracranial/Extracranial) ☐ Oral mucosa
   ☐ Intramuscular Injection ☐ Joint
   ☐ Unknown ☐ Other

(14) Has patient ever received blood products?
☐ Yes ☐ No
   (14a) If yes, has patient ever received blood products by home infusion? ☐ Yes ☐ No
   (14b) If yes, age first received blood products by home infusion: __ __ ☐ days ☐ months ☐ years ☐ Unknown

(15) Age first visited an HTC: __ __ ☐ days ☐ months ☐ years ☐ Unknown

(16) Has patient ever had an intracranial hemorrhage? ☐ Yes ☐ No
   (16a) If yes, age at most recent occurrence: __ __ ☐ days ☐ months ☐ years ☐ Unknown

(17) Family history of bleeding disorder? ☐ Yes ☐ No ☐ Unknown
FEMALE UDC REGISTRATION FORM

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(18) Is another person with a bleeding disorder living in the same household as the patient? □ Yes □ No

(19) Has the patient ever had an analysis of his or her genetic mutation? □ Yes □ No □ Unknown

(19a) If yes, what was the mutation? _________________________

Date test(s) performed: __________________

Name and location of lab performing analysis: _________________________________

BLEEDING SYMPTOMS

(20) Has the patient ever experienced any of the following symptoms? If so, was a health care provider intervention (i.e. consultation, procedure, hospitalization) required as a result? (please check all that apply)

<table>
<thead>
<tr>
<th>Bleeding Symptoms</th>
<th>Experienced Symptom?</th>
<th>If yes, Provider Intervention Required?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes □ No □</td>
<td>Yes □ No □</td>
</tr>
<tr>
<td>1. More than one nosebleed per year lasting 10 min or longer</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>2. Oral mucosal bleeding lasting 10 min or longer</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>3. Bleeding during or after dental procedures of concern to health care provider</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>4. Bleeding from minor cuts lasting 5 min or longer</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>5. Bruises larger than a quarter size occurring at least once a month without trauma</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>6. Bleeding after surgery of concern to health care provider</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>7. Menstrual bleeding that required protection change at least every 2 hours on heaviest day</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>8. Bleeding with pregnancy/post-partum of concern to health care provider</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>9. Joint bleeding</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>10. Muscle bleeding</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>11. CNS bleeding</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
<tr>
<td>12. GI bleeding</td>
<td>□ □ □</td>
<td>□ □ □</td>
</tr>
</tbody>
</table>

(21) Has patient ever been diagnosed with anemia by a physician? □ Yes □ No □ Unknown (if no, skip to #22)

(21a) If yes, was anemia the result of a bleeding condition? □ Yes □ No □ Unknown

(21b) If yes, for what bleeding condition? (check all that apply)

- Heavy menses
- Post-childbirth
- Epistaxis
- Surgery or other procedure
- GI bleeding
- Unknown

(21c) Were iron supplements prescribed? □ Yes □ No □ Unknown

(22) Have periods ever been perceived as heavy by the patient? □ Yes □ No

(22a) If yes, at what age did heavy menstrual periods begin? _____ years old □ Unknown
TREATMENT
(23) Please check whether or not the patient has ever used any of the following medications, treatments, or surgeries to treat any bleeding problems. Also, check if the patient used any of the treatments specifically to treat menorrhagia. Please indicate if the response to menorrhagia treatment was excellent, good, fair, or poor.

<table>
<thead>
<tr>
<th>Medications/Devices</th>
<th>Usage for any bleeding problems?</th>
<th>Usage for menorrhagia?</th>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
<th>Intolerant</th>
<th>Side effect(s)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antifibrinolytics (Amicar, Tranexamic Acid)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>Side effect(s)?</td>
</tr>
<tr>
<td>Desmopressin (DDAVP, Stimate)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>Side effect(s)?</td>
</tr>
<tr>
<td>Oral contraceptives</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>Side effect(s)?</td>
</tr>
<tr>
<td>Levonorgestrel IUD (Mirena)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>Side effect(s)?</td>
</tr>
<tr>
<td>Other hormonal contraceptives (i.e. patch, ring, implants, etc)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>Side effect(s)?</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Surgeries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dilation and curettage</td>
</tr>
<tr>
<td>Endometrial ablation</td>
</tr>
<tr>
<td>Uterine artery embolization</td>
</tr>
<tr>
<td>Hysterectomy</td>
</tr>
<tr>
<td>Other gynecological surgery:</td>
</tr>
<tr>
<td>Nasal cauterization</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Blood/Factor Products</th>
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</thead>
<tbody>
<tr>
<td>Clotting factor products</td>
</tr>
<tr>
<td>Blood (packed RBC or whole blood) or plasma products (ex. Blood/plasma transfusion, cryoprecipitate)</td>
</tr>
<tr>
<td>Platelet transfusion</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other medication, treatment, or surgery</td>
</tr>
<tr>
<td>Please specify:</td>
</tr>
</tbody>
</table>

(24) If patient has ever had a hysterectomy, what was her age at the time of the surgery?

_______ ___ years old
☐ Unknown
☐ N/A
REPRODUCTIVE/GYN HISTORY

(25) Has the patient ever been diagnosed with or sought care for any of the following gynecologic abnormalities by a health care provider? Check all that apply.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bleeding ovarian cysts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fibroids or fibroid tumors</td>
<td></td>
<td></td>
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<tr>
<td>Endometriosis</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Irregular cycles</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Breakthrough spotting</td>
<td></td>
<td></td>
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<tr>
<td>Abdominal pain mid-cycle (“Mittlesmerz”)</td>
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<tr>
<td>Pain during menses (dysmenorrhea)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uterine or cervical polyps</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uterine or cervical cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(26) Age at first menstrual period? ___ ___ years old
- □ N/A; premenarche/has not had first period (if N/A, STOP – SURVEY COMPLETE)
- □ Unknown

(27) Has the patient ever tried to get pregnant for a year or more without becoming pregnant?
- □ Yes
- □ No

(28) Has patient ever been pregnant?
- □ Yes
- □ No  (if no, skip to #38)

(29) How many times has patient been pregnant? ___ ___

(30) How many times has patient experienced each of the following pregnancy and/or delivery outcomes? (Please write in appropriate numbers)

- ___ Full term delivery
- ___ Elective termination of pregnancy
- ___ Ectopic, tubal, or molar pregnancy
- ___ 1st trimester miscarriage
- ___ 2nd trimester miscarriage
- ___ Pre-term delivery
- ___ Stillbirth

(31) If patient has ever experienced a miscarriage, did she have a problem with bleeding during miscarriage?
- □ Yes
- □ No
- □ N/A

(31a) During how many miscarriages did patient have a problem with bleeding?
Number: ____

(32) Has patient ever had any problems with bleeding during pregnancy?
- □ Yes
- □ No
- □ Unknown

(32a) During how many pregnancies did patient have a problem with bleeding?
Number: ____

(33) Has patient ever had post-partum hemorrhage of concern to healthcare provider?
- □ Yes
- □ No
- □ Unknown (if no, skip to #38)

(34) Has patient ever had post-partum hemorrhage of concern to healthcare provider within the first 24 hours following delivery of a baby?
- □ Yes
- □ No
- □ N/A (if no, skip to #35)
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34a) If yes, how many deliveries did patient have post-partum hemorrhage within the first 24 hours?
   Number: __

34b) Which mode of delivery was associated with post-partum hemorrhage?
   - Vaginal birth
   - Cesarean section (C-section) birth
   - Both

35) Has patient ever had post-partum hemorrhage of concern to healthcare provider after the first 24 hours following delivery of a baby?
   □ Yes □ No □ N/A (if no, skip to #36)

35a) If yes, after how many deliveries did patient have a problem with bleeding after the first 24 hours?
   Number: __

35b) How many days after delivery did post-partum hemorrhage start?
   - 1 – 7 days
   - 8 – 14 days
   - 15 days – 6 weeks
   - More than 6 weeks
   - Unknown

35c) How many days did the post-partum hemorrhage last?
   □ First occurrence: ___ days
   □ Second occurrence: ___ days
   □ Third occurrence: ___ days

35d) Which mode of delivery was associated with post-partum hemorrhage?
   - Vaginal birth
   - Cesarean section (C-section) birth
   - Both

36) After first post-partum hemorrhage, was patient given treatment prophylactically with subsequent deliveries?
   □ Yes □ No □ N/A

37) Were any of the following treatments given for up to 4 weeks post-partum due to excessive vaginal bleeding of concern to healthcare provider? Also, indicate if treatment was given prophylactically.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Yes</th>
<th>No</th>
<th>Unk</th>
<th>Prophy?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Red cell transfusion</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Desmopressin (DDAVP)</td>
<td></td>
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<tr>
<td>FVIII or vWF concentrate</td>
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<tr>
<td>Fresh frozen plasma</td>
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<tr>
<td>Cryoprecipitate</td>
<td></td>
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<tr>
<td>Platelet transfusions</td>
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<td>Hysterectomy</td>
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<tr>
<td>Other- specify:</td>
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MENOPAUSE

38) Is the patient menopausal (i.e. has not had a menstrual period for 12 consecutive months)?
   □ Yes □ No □ Unknown

39) Has patient ever experienced any signs or symptoms of menopause or perimenopause?
   □ Yes □ No □ Unknown (if no, STOP – SURVEY COMPLETE)

40) What was patient’s age at last menstrual period?
    ___ ___
(41) Please check whether or not the patient has ever used any of the following medications, treatments, or surgeries to treat menopause related bleeding. Also, check if the response to treatment was excellent, good, fair, or poor.

<table>
<thead>
<tr>
<th>Medications/Devices</th>
<th>Usage for menopause related bleeding?</th>
<th>Response to treatment</th>
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<tbody>
<tr>
<td></td>
<td>(Check if Yes)</td>
<td>Excellent</td>
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<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other medication, treatment, or surgery</td>
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<td>☐</td>
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Please specify: