

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

Date of Visit _____ Date Form Completed _____ Form Completed By _____ Data entered by _____

DEMOGRAPHIC/REFERRAL INFORMATION

(1) Month and year of birth:
 ____/____

(2) Race/Ethnicity:
 White (non-Hispanic) White (Hispanic)
 Black (non-Hispanic) Black (Hispanic)
 Asian/Pacific Islander American Indian/Alaskan Native
 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:	Baseline factor activity:	
<input type="checkbox"/> Fibrinogen	____.____%	<input type="checkbox"/> check if < 1%
<input type="checkbox"/> FII (2)	____.____%	<input type="checkbox"/> check if < 1%
<input type="checkbox"/> FV (5)	____.____%	<input type="checkbox"/> check if < 1%
<input type="checkbox"/> FVII (7)	____.____%	<input type="checkbox"/> check if < 1%
<input type="checkbox"/> FVIII (8)	____.____%	<input type="checkbox"/> check if < 1%

- | | | |
|--|--------|--|
| <input type="checkbox"/> FIX (9) | _____% | <input type="checkbox"/> check if < 1% |
| <input type="checkbox"/> FX (10) | _____% | <input type="checkbox"/> check if < 1% |
| <input type="checkbox"/> FXI (11) | _____% | <input type="checkbox"/> check if < 1% |
| <input type="checkbox"/> FXIII (13) | _____% | <input type="checkbox"/> check if < 1% |
| <input type="checkbox"/> PAI-1 | _____% | <input type="checkbox"/> check if < 1% |
| <input type="checkbox"/> α_2 anti-plasmin | _____% | <input type="checkbox"/> check if < 1% |
| <input type="checkbox"/> Other, specify _____ | _____% | <input type="checkbox"/> check if < 1% |
| <input type="checkbox"/> None | | |

(7) von Willebrand Disease:

(7a) Diagnosis (*Select one*)

- | | |
|----------------------------------|---|
| <input type="checkbox"/> Type 1 | <input type="checkbox"/> Type 2N |
| <input type="checkbox"/> Type 2A | <input type="checkbox"/> Type 3 |
| <input type="checkbox"/> Type 2B | <input type="checkbox"/> VWD type unknown |
| <input type="checkbox"/> Type 2M | <input type="checkbox"/> None |

(7b) Baseline activity

- | | |
|-----------|--------|
| FVIII (8) | _____% |
| VWF:RCof | _____% |
| VWF:Ag | _____% |

(8) ABO Blood type

- O A B AB Unknown

(9) Platelet disorder:

- | | |
|---|--|
| <input type="checkbox"/> Glanzmann's thrombasthenia | <input type="checkbox"/> Storage pool defect |
| <input type="checkbox"/> Bernard Soulier | <input type="checkbox"/> Release defect |
| <input type="checkbox"/> Grey platelet syndrome | <input type="checkbox"/> Not specified |
| <input type="checkbox"/> Hermanski-Pudlak syndrome | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Inherited thrombocytopenia | |
| <input type="checkbox"/> 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:

- | | |
|---|--------------------------------------|
| <input type="checkbox"/> Head (Intracranial/Extracranial) | <input type="checkbox"/> Oral mucosa |
| <input type="checkbox"/> Intramuscular Injection | <input type="checkbox"/> Joint |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> 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

(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)*

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

(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.

	Usage for any bleeding problems?	Usage for menorrhagia?	Response to treatment for menorrhagia				
	(Check if Yes)	(Check if Yes)	Excellent	Good	Fair	Poor	Intolerant
Medications/Devices							
Antifibrinolytics (Amicar, Tranexamic Acid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Desmopressin (DDAVP, Stimate)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Oral contraceptives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Levonorgestrel IUD (Mirena)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Other hormonal contraceptives (i.e. patch, ring, implants, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Surgeries							
Dilation and curettage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Endometrial ablation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Uterine artery embolization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hysterectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other gynecological surgery:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Nasal cauterization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Blood/Factor Products							
Clotting factor products	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Blood (packed RBC or whole blood) or plasma products (ex. Blood/plasma transfusion, cryoprecipitate)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Platelet transfusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other							
Other medication, treatment, or surgery Please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

(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.*

	Yes	No	Unknown
Bleeding ovarian cysts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fibroids or fibroid tumors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Endometriosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irregular cycles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breakthrough spotting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Abdominal pain mid-cycle ("Mittlesmerz")	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain during menses (dysmenorrhea)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uterine or cervical polyps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uterine or cervical cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(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*)

(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?

- | <u>First occurrence</u> | <u>Second occurrence</u> | <u>Third occurrence</u> |
|--|--|--|
| <input type="checkbox"/> 1 – 7 days | <input type="checkbox"/> 1 – 7 days | <input type="checkbox"/> 1 – 7 days |
| <input type="checkbox"/> 8 – 14 days | <input type="checkbox"/> 8 – 14 days | <input type="checkbox"/> 8 – 14 days |
| <input type="checkbox"/> 15 days – 6 weeks | <input type="checkbox"/> 15 days – 6 weeks | <input type="checkbox"/> 15 days – 6 weeks |
| <input type="checkbox"/> More than 6 weeks | <input type="checkbox"/> More than 6 weeks | <input type="checkbox"/> More than 6 weeks |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> Unknown | <input type="checkbox"/> Unknown |

(35c) How many days did the post-partum hemorrhage last?

- | <u>First occurrence</u> | <u>Second occurrence</u> | <u>Third occurrence</u> |
|-------------------------|--------------------------|-------------------------|
| ____ days | ____ days | ____ 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.

	Yes	No	Unk	Prophy?		Yes	No	Unk	Prophy?
Red cell transfusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Cryoprecipitate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Desmopressin (DDAVP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Platelet transfusions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FVIII or vWf concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hysterectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fresh frozen plasma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Other- specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.

	Usage for menopause related bleeding? <i>(Check if Yes)</i>	Response to treatment					Intolerant
		Excellent	Good	Fair	Poor		
Medications/Devices							
Antifibrinolytics (Amicar, Tranexamic Acid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Desmopressin (DDAVP, Stimate)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Oral contraceptives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Levonorgestrel IUD (Mirena)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Other hormonal contraceptives (i.e. patch, ring, implants, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Side effect(s)?:
Surgeries							
Dilation and curettage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Endometrial ablation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Uterine artery embolization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hysterectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other gynecological surgery:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Blood/Factor Products							
Clotting factor products	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Blood (packed RBC or whole blood) or plasma products (ex. Blood/plasma transfusion, cryoprecipitate)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Platelet transfusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other							
Other medication, treatment, or surgery Please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	