

Universal Data Collection

U.S. Department of Health
and Human Services
Public Health Service

Registration



CDC ID

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GENERAL INFORMATION

Date of Visit

month	day	year					

Date Form Completed

month	day	year					

Form Completed by:

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Data entered by:

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CDC Use Only

DEMOGRAPHIC INFORMATION

1. Month and Year of Birth:

Month	Year

2. Sex: Male
 Female

3. Race/Ethnicity:

- White (non-Hispanic)
 White (Hispanic)
 Black (non-Hispanic)
 Black (Hispanic)
 Asian/Pacific Islander
 American Indian/Alaskan Native
 Other _____

4. Place of Birth:

State:

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Or, country: _____
(if other than USA)

5. HTC Status:

- Established Patient
 New Patient
 Transfer Patient

DIAGNOSIS INFORMATION

6. Factor deficiency type: VIII IX
(Check all that apply. If patient has vWD only, skip to #7)
 other _____

- 6a. Baseline factor activity:

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 % check if < 1%

7. von Willebrand Yes

If yes, which type (select one)

- Type 1 Type 3
 Type 2a unknown
 Type 2b other _____

8. Age bleeding disorder first diagnosed:

days	months (Circle one)	age	unknown	years

9. Has patient ever had a bleed? Yes No

9a. If yes, age at first bleed:

days	months (Circle one)	age	unknown

9b. If yes, site of first bleed:

- Head (Intracranial/Extracranial) Oral mucosa
 Circumcision Joint
 Intramuscular injection Unknown
 Other _____

10. Has patient ever received blood products?

- Yes No

10a. If yes, has patient ever received blood products by home infusion? Yes No

10b. If yes, age first received blood products by home infusion:

days	months (Circle one)	age	unknown

11. Age first visited an HTC:

days	months (Circle one)	age	unknown

12. Has patient ever had an intracranial hemorrhage?

- Yes No

12a. If yes, age at most recent occurrence:

days	months (Circle one)	age	unknown

13. Family history of bleeding disorder?

- Yes No

14. Is another person with a bleeding disorder living in the same household as the patient?

- Yes No

15. Has the patient had an analysis of his or her genetic mutation?

- Yes No

If yes, what was the mutation? _____

Date test(s) performed _____

Name and location of lab performing analysis: _____

REGISTRATION FORM

FORM COMPLETION: Complete this form **one time only** for each eligible patient with hemophilia, von Willebrand disease, or other congenital bleeding disorder at the time that the first Annual Form is completed.

Patient CDC ID: The unique 12-digit number generated for each patient by staff at the hemophilia treatment center (HTC) using the CDC ID computer program.

General Information: Enter the date of the visit and the date that this form was completed. Enter the initials of the person completing the form.

1. Month and year of birth: Enter the patient's month and year of birth. Use leading zeros before single-digit months and days.

2. Sex: Check MALE or FEMALE.

3. Race/Ethnicity: Check the racial/ethnic category that the patient considers him(her)self to be. Use the OTHER category to write in racial/ethnic groups not listed.

4. Place of Birth: Enter the place of birth by state (use state abbreviation; e.g., GA, CA) or country, if other than U.S.A. (See Data Forms Manual for state abbreviations)

5. HTC Status:

Check ESTABLISHED PATIENT, if this patient has been seen at this HTC at least once in the past. Check NEW PATIENT, if the patient has never been seen at any HTC before. Check TRANSFER PATIENT, if the patient has been seen at another HTC but now plans to attend this HTC.

6. Factor deficiency type and 6a. Baseline factor activity:

Check factor deficiency type(s). If patient has vWD only, skip to #7. For patients with factor VIII or factor IX deficiency, enter the baseline factor activity.

7. von Willebrand:

Check YES, if the patient has been diagnosed with von Willebrand disease by a physician. If yes, check the multimeric analysis of the vWD.

8. Age bleeding disorder first diagnosed:

Enter the age at which the patient received his/her current diagnosis. If the diagnosis was made at or before birth, enter 0 (zero) days for the age. Designate DAYS, MONTHS, or YEARS as follows: indicate the number of days if age was less than 1 month; the number of months if age was 1 month or more but less than 1 year; or the number of years. If specific age is unknown, give approximate age. If approximate age is unknown, check box labeled AGE UNKNOWN.

9. Has patient ever had a bleed and 9a. Age at first bleed:

Check YES, if the patient has ever had a bleed that was unusual in either duration or amount. If yes, enter the age that the patient experienced the first bleeding episode. Note that this first bleeding episode may not have led to the diagnosis of a bleeding disorder. If the bleed occurred at birth, enter 0 (zero) days for the age. Designate DAYS, MONTHS, or YEARS as follows: indicate the number of days if age was less than 1 month; the number of months if age was 1 month or more but less than 1 year; or the number of years. If specific age is unknown, give approximate age. If approximate age is unknown, check box labeled AGE UNKNOWN.

9b. Site of first bleed: Check the site of the first bleed referred to in item 9a. Use the OTHER category to write in sites not listed.

10. Has patient ever received blood products and 10a. If yes, has patient ever received blood products by home infusion:

Check YES, if the patient has ever received any blood products. Blood products include whole blood, blood fraction or component (platelets, cryoprecipitate, fresh frozen plasma, etc.) or factor concentrates including recombinant and highly purified products (BenefixTM). If yes, check YES, if the patient has ever received blood products outside of the medical setting (e.g., hospital, clinic, emergency room). The infusion may have been performed either by a parent or other relative or by a health care professional such as a nurse or home health care worker. Otherwise, check NO.

10b. If yes, age first received blood product by home infusion:

Enter the age at which the patient first received blood products by home infusion. Designate DAYS, MONTHS, or YEARS as follows: indicate the number of days if age was less than 1 month; the number of months if age was 1 month or more but less than 1 year; or the number of years. If specific age is unknown, give approximate age. If approximate age is unknown, check box labeled AGE UNKNOWN.

11. Age first visited an HTC:

Enter the patient's age when he first visited an HTC. Designate DAYS, MONTHS, or YEARS as follows: indicate the number of days if age was less than 1 month; the number of months if age was 1 month or more but less than 1 year; or the number of years. If specific age is unknown, give approximate age. If approximate age is unknown, check box labeled AGE UNKNOWN.

12. Has patient ever had an intracranial hemorrhage and 12a. Age at most recent occurrence:

Check Yes, if the patient has ever received a diagnosis of an intracranial hemorrhage by a physician. If Yes, enter the age at which the hemorrhage occurred. If the patient had more than one occurrence, enter the age at which the most recent bleed occurred. If the bleed occurred at birth, enter 0 (zero) days for the age. Designate DAYS, MONTHS, or YEARS as follows: indicate the number of days if age was less than 1 month; the number of months if age was 1 month or more but less than 1 year; or the number of years. If specific age is unknown, give approximate age. If approximate age is unknown, check box labeled AGE UNKNOWN.

13. Family history of bleeding disorder:

Check YES, if there is a history of a congenital bleeding disorder in any blood relative of the patient. Otherwise, check NO.

14. Is another person with a bleeding disorder living in the same household as the patient:

Check YES, if another person with a congenital bleeding disorder is currently living in the same household as the patient.

15. Has the patient had an analysis of his or her genetic mutation:

Check YES, if the patient has undergone genetic testing to determine the specific genetic mutation responsible for his/her bleeding disorder. Indicate the results of this testing, if known, and provide the name and address of the laboratory that performed the testing.