

Universal Data Collection

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

Baby 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				

- 1a. Term Birth (≥ 37 weeks)
 Pre-term: _____ weeks

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:

Or, country: _____
(if other than USA)

5. HTC Status:

- Established Patient
 New Patient
 Transfer Patient

DIAGNOSTIC INFORMATION

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

6a. Baseline factor activity: % check if < 1%

6b. Site of blood draw for factor activity:
 Cord blood Venipuncture Unknown

7. von Willebrand Yes

If yes, which type (select one)

- Type 1 Type 3
 Type 2a Unknown
 Type 2b Other _____

8. Reason for diagnostic testing:

- Mother known carrier Other family history
 Bleeding symptom Unknown
 Other _____

9. Age bleeding disorder first diagnosed:

days	months (Circle one)	years	<input type="checkbox"/> Prenatal	<input type="checkbox"/> Unknown

9a. If prenatal, check diagnostic procedure:

- Chorionic villus sampling
 Amniocentesis Unknown
 Other _____

9b. If there was a prenatal diagnostic procedure, was there a complication?

- Yes No Unknown

10. Birth weight: lbs oz Unknown

11. Birth length: inches Unknown

12. Method of delivery (check all that apply):

- Vaginal Elective C-Section Non-elective C-Section
 Forceps Vacuum Unknown Other

13. Was vitamin K administered at birth?

- Yes No Unknown

14. Was clotting factor concentrate given within 24 hours of birth?

- Yes No Unknown

14a. If yes, reason: Prophylaxis Treatment of bleed

15. HTC contacted before delivery? Yes No Unknown

16. Has patient ever had a bleed? Yes No

16a. If yes, age at first bleed:

days	months (Circle one)	years	<input type="checkbox"/> age	<input type="checkbox"/> unknown

16b. If yes, site of first bleed:

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

17. Is another person with a bleeding disorder living in the same household as the patient? Yes No

BABY REGISTRATION FORM

FORM COMPLETION: Complete this form **one time only** for each eligible patient under 2 years of age with hemophilia, von Willebrand disease, or other congenital bleeding disorder at the time that the first Baby Visit 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.

1a. If the baby was born at ≥ 37 weeks gestation, check TERM BIRTH. If < 37 weeks, check PRE-TERM and enter the total number of weeks gestation.

2. Sex: Check MALE or FEMALE.

3. Race/Ethnicity: Check the racial/ethnic category that the parent/guardian considers the patient 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 and 6b. Site of blood draw for 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 and enter the site from which blood was obtained with which to establish 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. Reason for diagnostic testing: Check all reasons that prompted diagnostic testing for a bleeding disorder.

9. Age bleeding disorder first diagnosed:

Enter the age at which the patient received his/her current diagnosis. If the diagnosis was made at birth, enter 0 (zero) days for the age. If the diagnosis was made before birth, check box labeled PRENATAL. 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 UNKNOWN.

9a. If prenatal, check diagnostic procedure and 9b. If there was a prenatal diagnostic procedure, was there a complication:

If the patient had his/her bleeding disorder diagnosed before birth, please check the diagnostic procedure that was performed. Also indicate whether or not a complication occurred (e.g., bleeding in the mother or the baby) either during or after the prenatal diagnostic procedure. If it is unknown whether a complication occurred, check UNKNOWN.

10. Birth weight and 11. Birth length:

Enter the patient's weight at birth in pounds and ounces and length at birth in inches. If the weight or length at birth is not known, check the appropriate UNKNOWN box.

12. Method of delivery:

Check the appropriate method of delivery for the patient. If the method of delivery is unknown, check UNKNOWN.

13. Was vitamin K administered at birth?

If vitamin K was administered to the patient within 24 hours of the birth, check YES. If there is no record of vitamin K administration at birth, check NO. If it is not known whether vitamin K was administered, check UNKNOWN.

14. Was clotting factor concentrate given within 24 hours of birth? and 14a. If yes, reason:

Check YES, if the patient received any clotting factor concentrate (excluding blood bank and non-plasma products - see page 3 of Baby Visit Form) within 24 hours of the birth. Check NO, if the patient did not receive clotting factor concentrate during the first 24 hours of life. If it is not known whether or not the patient received clotting factor, check UNKNOWN. If yes, check PROPHYLAXIS if the factor infusion was given in the absence of a known bleed. Check TREATMENT OF BLEED if the factor infusion was given to stop a known or suspected bleed.

15. HTC contacted before the delivery?

If either your HTC or another HTC was contacted by medical personnel concerning this baby prior to the birth, check YES. If there was no known contact between an HTC and medical care personnel concerning this baby prior to birth, check NO. If it is not known whether contact between an HTC and medical personnel concerning this baby occurred prior to birth, check UNKNOWN.

16. Has patient ever had a bleed and 16a. 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.

16b. Site of first bleed: Check the site of the first bleed referred to in item 16a. Use the OTHER category to write in sites not listed.

17. 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.