**GENERAL INFORMATION**

<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>month day year</td>
<td>month day year</td>
<td></td>
<td>CDC Use Only</td>
</tr>
</tbody>
</table>

**DEMOGRAPHIC & CLINICAL INFORMATION**

<table>
<thead>
<tr>
<th>1. Zipcode: [___] (first 3 digits)</th>
<th>6. Health Insurance (Check all that apply):</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Weight: [<em><strong>] . [</strong></em>] kg</td>
<td>□ Straight commercial insurance</td>
</tr>
<tr>
<td>3. Length: [___] cm</td>
<td>□ Commercial insurance HMO</td>
</tr>
<tr>
<td>4. Head Circumference: [___] cm</td>
<td>□ Commercial insurance PPO</td>
</tr>
<tr>
<td>5. Is this the FIRST visit to an HTC?</td>
<td>□ Straight Medicare</td>
</tr>
<tr>
<td></td>
<td>□ Medicare HMO</td>
</tr>
<tr>
<td></td>
<td>□ CHAMPUS</td>
</tr>
<tr>
<td></td>
<td>□ State high-risk insurance plan</td>
</tr>
<tr>
<td></td>
<td>□ Uninsured</td>
</tr>
<tr>
<td></td>
<td>□ Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. Has the patient had an analysis of his or her genetic mutation since birth or the last visit?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

**TREATMENT INFORMATION**

<table>
<thead>
<tr>
<th>8. Follow-up diagnostic hemophilia factor activity:</th>
<th>11. Home infusion? □ Yes □ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>[<em><strong>] . [</strong></em>] % □ check if &lt; 1%</td>
<td>If yes, infused by (check all that apply)</td>
</tr>
<tr>
<td>Date Obtained: month year</td>
<td>□ family member</td>
</tr>
<tr>
<td></td>
<td>□ medical care provider</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>9. Treatment type (check one):</th>
<th>12. Highest inhibitor titer since birth or the last UDC visit:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Episodic care</td>
<td>(Bethesda units): [<em><strong>] . [</strong></em>] □ not done</td>
</tr>
<tr>
<td>□ Immune tolerance</td>
<td>Date Obtained: month year</td>
</tr>
<tr>
<td>□ Prophylaxis</td>
<td></td>
</tr>
<tr>
<td>if prophylaxis,</td>
<td>12a. Immune tolerance therapy since birth or the last UDC visit:</td>
</tr>
<tr>
<td>□ Continuous</td>
<td>□ Yes □ No □ Unknown</td>
</tr>
<tr>
<td>□ Intermittent</td>
<td>If yes,</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>10. Central venous access device (CVAD) placed since birth or the last UDC visit:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No □ Unknown</td>
</tr>
</tbody>
</table>

| If yes, type of CVAD (check all that apply)                                  |
| □ Port □ Catheter □ PICC                                                     |

<table>
<thead>
<tr>
<th>10a. CVAD complication since birth or the last UDC visit:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes □ No □ Unknown</td>
</tr>
</tbody>
</table>

| If yes, type of complication (check all that apply)                          |
| □ Infection □ Thrombus □ Mechanical □ Bleeding □ Other                      |

<table>
<thead>
<tr>
<th>Date begun: Mo [<em><strong>] Year [</strong></em>]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Status: □ Successful □ Unsuccessful □ Ongoing □ Unknown</td>
</tr>
</tbody>
</table>
BABY VISIT FORM

FORM COMPLETION: Complete this form at the first visit and at 6 month intervals for all visits made to the treatment center prior to age 2 years. If this is the first visit for which this form is being completed, substitute “during the previous 12 months” for the phrase “since the last visit.”

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.

DEMOGRAPHIC INFORMATION
1. Zipcode of Residence: Enter the first three digits of the zipcode for the patient’s residence (NOT for the HTC that the patient visits).

2. Weight & Height: Enter the patient’s weight in kilograms and height in centimeters without shoes and in light clothing; (2.2 lbs = 1 kg) (1 inch = 2.54cm).

3. Head circumference: Enter the patient’s head circumference in centimeters. Measure the head by placing a flexible measuring tape just above the eyebrows and ears, and around the back of the head where it slopes up prominently from the neck. The goal is to measure the head at the spot where it has the largest circumference. The measurement is read to the nearest 0.3 cm.

4. Is this the FIRST visit to an HTC: If the current visit is the patient’s first visit ever to an HTC, check YES. Count only actual visits to an HTC, not phone contacts or written correspondence. Otherwise, check NO.

5. Health insurance: Check all sources of health insurance coverage for the patient. See Data Forms Manual for more detail about health insurance plans.

6. Medicaid: Federal health insurance program available to persons who are either over 65 years old or disabled.

7. Medicare: State/federal health insurance program for certain needy and low income individuals.

8. Home infusion: Check YES, if patient receives treatment products intravenously outside of the medical setting. If YES, check whether the product is infused by a family member or a care provider. If patient receives treatment products only in a medical setting (e.g., HTC, emergency room), check NO.

9. CVAD complication since birth or the last UDC visit: If the patient had a central venous access device placed for delivery of factor since birth or the last UDC visit, check YES. If yes, check whether a CVAD was placed, check UNKNOWN. If it is unknown whether a CVAD was placed, check UNKNOWN.

10. Follow-up diagnostic hemophilia factor activity: For patients with factor VIII or factor IX deficiency due to hemophilia only, enter the most recently obtained factor activity and date performed. Do not enter factor levels for patients with von Willebrand’s disease.

11. Is this the patient’s first visit since the last UDC visit? Check YES, if the patient received treatment products only in response to bleeding complications since birth or the last visit, check EPISODIC CARE. If the patient is currently undergoing immune tolerance therapy (either initial or maintenance), check IMMUNE TOLERANCE. If the patient received treatment products to prevent bleeding or to prevent rebleeding, check PROPHYLAXIS. If you check PROPHYLAXIS and the patient was recommended to receive treatment products on a regular schedule to prevent any and all bleeding and this therapy was expected to continue indefinitely, check CONTINUOUS. If you check PROPHYLAXIS and the patient received treatment products on a regular schedule for a period of at least 28 days at on least one occasion since the last visit and this therapy was not expected to continue for an indefinite period of time, check INTERMITTENT. You should not check prophylaxis if the patient received treatment products for less than a period of 28 days.

12. Immune tolerance therapy since birth or the last UDC visit: Check NO if the patient did not receive immune tolerance therapy since birth or the last UDC visit. Check UNKNOWN if it is not known whether or not the patient received immune tolerance therapy since birth or the last UDC visit. If the patient received immune tolerance therapy since birth or the last UDC visit, check YES. If yes, also check whether the therapy was SUCCESSFUL or UNSUCCESSFUL. Check SUCCESSFUL only if the patient can be effectively treated for a bleeding episode with a factor dosage appropriate to his/her hemophilia severity and its type. If immune tolerance therapy is no longer being given and the inhibitor is still present, check UNSUCCESSFUL. If immune tolerance therapy is still being given, check ONGOING. Check UNKNOWN, if the status of immune tolerance therapy is not known.

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13. Treatment product(s) used since birth or the last visit: (check all that apply)

- **NONE USED**
- **UNKNOWN**

### Factor VIII, vWF, or Non-plasma Products
- **Recombinant FVIII**
  - Advate
  - Helixate FS
  - Kogenate FS
  - Recombinate
  - ReFacto
  - other, specify __________________

- **Monoclonal FVIII**
  - Hemofil M
  - Monarc-M
  - Monoclate P
  - other, specify __________________

- **Human FVIII containing VWF**
  - Alphanate
  - Humate P
  - Koate DVI
  - other, specify __________________

- **Porcine factor VIII**
  - Hyate-C
  - other, specify __________________

- **Blood bank products**
  - cryoprecipitate
  - fresh-frozen plasma, packed RBCs, or whole blood

- **Non-plasma and topical products**
  - Intravenous desmopressin (DDAVP)
  - Nasal desmopressin (Stimate)
  - Amicar
  - Fibrin glue
  - other, specify __________________

### Factor IX, PCC, and Other Factor Products
- **Recombinant FIX**
  - BeneFIX
  - other, specify __________________

- **Human FIX**
  - AlphaNine S-D
  - Mononine
  - other, specify __________________

- **Prothrombin complex**
  - Bebulin VH
  - Profilnine SD
  - Proplex T
  - other, specify __________________

- **Activated prothrombin complex**
  - Autoplex T
  - FEIBA VH
  - other, specify __________________

- **Concentrates of other factors**
  - NovoSeven (FVIIa)
  - Fibrogammin P (FXIII)
  - other, specify __________________
13. Treatment product(s) used since birth or the last visit: Check or enter all treatment products (including blood products, DDAVP, or Amicar) used by the patient since birth (if this is the first UDC visit) or the last visit. Check NONE USED, if the patient did not use any treatment products since the last visit. Check UNKNOWN, if you do not know whether the patient used treatment products since the last visit or if you are unable to determine which products were used.
INFECTIONOUS DISEASE INFORMATION

14. Status of hepatitis B vaccination (Check one) (see explanation on reverse)

- Completed basic vaccine series
- Currently receiving basic vaccine series
- Never received any doses of vaccine
- Unknown

14a. If vaccinated, check administration route and enter dates, if known.

- IM
- SQ

1st Dose

15a. If >0, number with skull fracture:

15. Number of head injuries since birth or last visit:

16. Number of intracranial hemorrhages (ICH) since birth or last visit?

ICH #1: (check all that apply)

- Site: Intracerebral  Subdural  Subarachnoid  Epidural  Intraparenchymal  Cerebellar
- Confirmed by: Exam  Xray  Ultrasound  MRI  CT  None  Other (specify)
- Associated with: Delivery  Trauma  Thrombocytopenia  Procedural  Spontaneous  Other (specify)

ICH #2: (check all that apply)

- Site: Intracerebral  Subdural  Subarachnoid  Epidural  Intraparenchymal  Cerebellar
- Confirmed by: Exam  Xray  Ultrasound  MRI  CT  None  Other (specify)
- Associated with: Delivery  Trauma  Thrombocytopenia  Procedural  Spontaneous  Other (specify)

ICH #3: (check all that apply)

- Site: Intracerebral  Subdural  Subarachnoid  Epidural  Intraparenchymal  Cerebellar
- Confirmed by: Exam  Xray  Ultrasound  MRI  CT  None  Other (specify)
- Associated with: Delivery  Trauma  Thrombocytopenia  Procedural  Spontaneous  Other (specify)

17. Other bleed since birth or last visit?

17a. If yes, check the site(s) and enter the number of episodes of any other bleeding:

- Circumcision
- Oral / Nasal
- Venipuncture / Heel stick / Surgical site
- Soft tissue hematoma
- Intramuscular hematoma
- Umbilicus
- Joint
- Gastrointestinal (upper or lower)
- Genitourinary, renal
- Pulmonary

LONG-TERM EFFECTS

18. Long-term effects due to bleeding since birth or last visit?

18a. If yes, Check all that apply (see reverse side):

- Focal Neurologic deficit(s)
- Seizure Disorder
- Hydrocephaly
- Neuropathy due to compartment syndrome
- Paralysis
BABY VISIT FORM--

INFECTIONOUS DISEASE INFORMATION

14. Status of hepatitis B vaccination: Please complete this section according to the following guidelines:

- COMPLETED BASIC VACCINE SERIES: the completed basic series for hepatitis B is three doses of vaccine given within a 6-18 month period.
- CURRENTLY RECEIVING BASIC VACCINE SERIES: patient has had at least 1 dose of vaccine within 12 months of the current visit but has not had the complete series.
- NEVER RECEIVED ANY DOSES OF VACCINE: no evidence of vaccination is present in the medical record, and parent denies vaccination.
- UNKNOWN: no record of vaccination in the medical record, and the parent is unsure whether or not the baby has received any doses of vaccine.

14a. If vaccinated, check administration route and enter dates, if known: If the patient has received any vaccinations for hepatitis B, check the box next to the appropriate route of administration, either intramuscular (IM) or subcutaneous (SQ), and enter the dates for each dose, if known.

HEAD INJURY AND BLEEDS INFORMATION

15. Number of head injuries since birth or the last visit: If the patient has experienced one or more head injuries requiring treatment with factor since birth or the last visit, enter the number of head injuries that required treatment with factor. If there has been no head injury that required factor treatment since birth or the last visit, enter 0 (zero).

15a. If >0, number with skull fracture: If the patient has experienced at least one head injury that required treatment with factor since birth or the last visit, enter the number of head injuries with an associated skull fracture that was documented by x-ray or other imaging study. If there has been no skull fracture since birth or the last visit, enter 0 (zero).

16. Number of Intracranial hemorrhages (ICH) since birth or the last visit: If the patient has experienced one or more ICHs since birth or the last visit, enter the number of ICHs. If there have been no ICHs or it is not known whether or not the patient has had an ICH since birth or the last visit, enter 0 (zero).

16a. If >0, fill in the data below: If the patient experienced one or more ICHs since birth or the last visit, check the appropriate boxes that indicate the site(s), the technique(s) used to confirm the ICH, and the factor(s) associated with the ICH for up to three of the events. Check all boxes that apply for each ICH occurrence. If the ICH is confirmed by an unlisted technique or associated with an unlisted factor, please check OTHER and use the space provided to write in the appropriate response.

17. Other bleed since birth or the last visit: If the patient experienced a bleed in one or more of the sites listed in 17a (see below) since birth or the last visit, check YES. If no bleeding at any of the listed sites occurred since birth or the last visit, check NO. Check UNKNOWN if it is not known whether bleeding occurred at any of the listed sites.

17a. Check the site(s) and enter the number of episodes of any other bleeding: If yes, check the box to the left of each site at which bleeding occurred since birth or the last visit. Enter the number of episodes of bleeding in the appropriate box(es) to the right of each site.

LONG-TERM EFFECTS

18. Long-term effects due to bleeding since birth or the last visit: If the patient, as the result of a bleed, developed any of the listed long-term effects since birth or the last visit, check YES. If no long-term effects from a bleed developed since birth or the last visit, check NO. If it is not known whether any long-term effects from a bleed developed since birth or the last visit, check UNKNOWN.

18a. If yes, check all that apply: Check the box next to any long-term effect from a bleed that has developed since birth or the last visit.

DEFINITIONS:

A focal neurologic deficit is an altered or decreased neurologic function, as a result of a bleed in the brain, spinal cord, nerve or muscle, and occurring in a specific location. It may result in an inability to speak, swallow, walk (balance), see or feel.

- Sensation (numbness or abnormal sensation).
- Movement (weakness, increased or decreased muscle tone).
- Speech (difficulty swallowing, hoarseness of voice).
- Vision (vision loss, double vision, decreased visual fields).

Hydrocephaly - a condition characterized by abnormal accumulation of fluid in the cranial vault, accompanied by enlargement of the head, prominence of the forehead, atrophy of the brain, mental deterioration, and convulsions.

Paralysis - loss or impairment of motor function in a part due to lesion of the neural or muscular mechanism.

Seizure Disorder - a condition in which seizures (generalized or focal) recur, or are expected to recur, spontaneously/without new initiating factors and for which the participant has been placed on anti-convulsant medication or therapy.

Neuropathy due to compartment syndrome - A functional disturbance in an extremity due to a bleed into one of the the compartments located in the hand, forearm, upper arm, abdomen, buttock, or entire lower extremity.