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## Hemophilia Patient Information Form

(PLEASE NOTE: The information requested is in regard to the affected individual with hemophilia. When requesting carrier testing, this form should provide clinical information for the relative with hemophilia)

|   |  |  |
|---|--|--|
| Date                                      | Date of Birth  | Mother's birth place (town & state or country) |
| Name of Patient                           | Mother's race (Asian, Black, Caucasian, Hispanic, Other) |  |
| Patient Identifier or Social Security No. | Country/ethnic origin of mother's family                 |  |

Hemophilia A B      Severity: Mild Moderate Severe

F8 activity level = \_\_\_\_\_

|  |  |
|--|--|
| At what age was hemophilia first diagnosed?  | Did you receive factor replacement within two weeks of giving blood for this study?    Yes    No    When |
| Have you ever been treated with factor replacement on a regular basis (as part of a prophylaxis program)?    Yes    No                         |  |
| When did they begin?   |  |
| How many bleeding episodes into the joints have you had in your life?    1    2    3    4    5    6    7    8    9    10    more               |  |
| How many <u>different</u> joints have you bled into during your lifetimes?    1    2    3    4    5    more                                    |  |
| In the last 12 months (if you are in a prophylaxis program, answer for the 12 months before entering the program):                             |  |
| Estimate how many bleeding episodes into joints you have had with little or no obvious trauma.    0    1-10    11-20    21-30    31-40    more |  |
| How many joints have you bled into?    1    2    3    4    5    more   |  |
| How many episodes of spontaneous bleeding from sites other than joints have you had? _____   |  |
| Estimate how many factor replacements you have received. _____   |  |
| Were these replacements solely for the treatment of bleeding associated with major surgery, dental extractions or major trauma?    Yes    No   |  |
| Over the last 5 years:   |  |
| Estimate how many factor replacements you have received.    0    1-10    11-20    21-30    31-40    more                                       |  |
| How many of these treatments were for spontaneous bleeding?    0    1-10    11-20    21-30    31-40    more                                    |  |
| How many of these treatments were for bleeding associated with surgery or major trauma?    0    1-10    11-20    21-30    31-40    more        |  |
| Estimate how many times you have been hospitalized for bleeding during the last 5 years. _____   |  |
| Have the number of bleeding episodes changed over the course of your lifetime?    Yes    No  |  |
| If yes, describe   |  |
| What other illness do you have?  |  |

**Hemophilia causes excessive bleeding.**

Have you ever had the opposite problem (that is, do you ever get blood clots in your veins or elsewhere)?    Yes    No

If yes, describe

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Please name any other family members (living or deceased) that have hemophilia and their relationship to you.

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| <i>Hemophilia</i>   |  |  |  |
|---|--|--|--|
| <i>Patient Information from Physicians or Nurse Coordinators</i>  |  |  |  |
| <i>Please circle one choice for each question</i>   |  |  |  |
| Has the patient ever been on a prophylaxis program?    Yes    No    Don't know  |  |  |  |
| If yes, during what period of time  |  |  |  |
| Have you treated the patient before onset of the prophylaxis program?    Yes    No  |  |  |  |
| Do you have patient records before onset of the prophylaxis program?    Yes    No   |  |  |  |
| While not on prophylaxis, are the patient's bleeding episodes brought on only by trauma or surgery (i.e., no spontaneous bleeding)? |  |  |  |
| Yes    No    Don't know   |  |  |  |
| If the patient has bleeding episodes with minor or no trauma while not on prophylaxis, about how many episodes per year?            |  |  |  |
| 1-5    6-10    11 or more    Don't know   |  |  |  |
| If the patient is older than 10, approximate number of yearly bleeding episodes in the age range 5-10?                              |  |  |  |
| 1-5    6-10    11 or more    Don't know   |  |  |  |
| Does the patient have a factor inhibitor?    Yes    Previously    Never    Don't know   |  |  |  |
| Does the patient have a history of hemarthrosis with little or no trauma?    Yes    No    Don't know                                |  |  |  |
| If yes, how many different joints have been affected?    1    2    3    4    more    Don't know                                     |  |  |  |
| Additional clinical information on the patient that might be useful.  |  |  |  |