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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

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

<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.			