

Subject ID#:

Date: _____

Month / Day / Year

Visit #: 2

MHCS-II Participant Treatment Module

(Form 66)

**Sponsored by:
National Cancer Institute
Viral Epidemiology Branch**

**Conducted by:
Research Triangle Institute
Washington, DC**

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FAMILY AND TREATMENT HISTORY MODULE: Complete this module for subjects who did not return an enrollment survey. Please complete with the subject *during clinic visit*.

SECTION A - Family History

We are interested in how hemophilia occurs in families and our research will look with particular interest at siblings enrolled in our study. Please answer to the best of your knowledge.

Place a "✓" on the line next to the answer.

1. Have any of your relatives had hemophilia or von Willebrand (vW) disease?

- _____ Yes
- _____ No
- _____ Do not know

1a. Have any of your relatives with hemophilia or vW had an inhibitor?

- _____ Yes
- _____ No
- _____ Do not know

2. Do you have any brothers with hemophilia?

- _____ Yes
- _____ No → **Go to Question 3**

2a. How many of your brothers have had hemophilia? #

2b. What hemophilia treatment centers do they attend?

Name of Center 1 (and/or) location: _____

Name of Center 2 (and/or) location: _____

3. Do you have any brothers or sisters with von Willebrand's disease?

- _____ Yes
- _____ No → **Go to Section B**

3a. How many brothers and sisters with vW disease do you have? #

3b. What hemophilia treatment centers do they attend?

Name of Center 1 (and/or) location: _____

Name of Center 2 (and/or) location: _____

SECTION B - History of Treatments for Hemophilia

The next questions are about your use of treatment products during your life.

4. Have you ever received plasma or cryoprecipitate?

- _____ Yes
- _____ No → **Go to Question 5**

4a. How old were you the first time you received plasma or cryoprecipitate? (NOTE: If you were less than 1 year, write # of months)

Age (years) Months (if less than 1 year)

4b. How old were you the last time you received plasma or cryoprecipitate? (NOTE: If you were less than 1 year, write # of months)

Age (years) Months (if less than 1 year)

5. Have you ever received a transfusion of whole blood or red blood cells?

Yes

No → **Go to Question 6**

5a. How old were you the first time you received a transfusion of whole blood or red blood cells? (NOTE: If you were less than 1 year, write # of months)

Age (years) Months (if less than 1 year)

6. Have you ever received a transfusion of platelets?

Yes

No → **Go to Question 7**

6a. How old were you the first time you received a transfusion of platelets? (NOTE: If you were less than 1 year, write # of months)

Age (years) Months (if less than 1 year)

7. Have you ever received non-heat-treated factor concentrate? "*Non-heat-treated*" refers to concentrate products that had no specific viral-inactivation procedure.

Yes

No → **Go to Question 8**

7a. How old were you the first time you received non-heat-treated factor concentrate? (NOTE: If you were less than 1 year, write # of months)

Age (years) Months (if less than 1 year)

8. Have you ever had an unusual health problem, like major surgery or serious injury, for which you needed intensive factor concentrate therapy? Please include only those problems that required at least 50,000 units or 25 bottles of factor concentrate.

Yes

No → **Go to Question 9**

8a. About how old were you the first time you required at least 50,000 units or 25 bottles of factor concentrate? Age

8b. About how old were you the second time you required at least 50,000 units or 25 bottles of factor concentrate? Age

8c. About how old were you the third time you required at least 50,000 units or 25 bottles of factor concentrate? Age

Now we would like to ask about routine treatments you received (not including the times you needed intensive treatment with at least 50,000 units or 25 bottles of concentrate). We are interested in regular usage (either to prevent or to treat a bleed) during specific ages. Please do not include the use during episodes reported above.

9. When you were less than 6 years old, did you use factor concentrate?

Yes

No → **Go to Question 10**

9a. On average, how often did you use factor concentrate when you were less than 6 years old?

6 times per year or less

once per month or less

2-3 times per month

once per week

more than once per week

} → **Go to Question 11**

10. When you were less than 6 years old, did you use plasma or cryoprecipitate?

Yes

No → **Go to Question 11**

10a. On average, how often did you use plasma or cryoprecipitate when you were less than 6 years old?

Never

Occasionally (up to 3 times per year)

Regularly (several or many times per year)

11. When you were 6-12 years old, did you use factor concentrate?

Yes

No → **Go to Question 12**

11a. On average, how often did you use factor concentrate when you were 6-12 years old?

6 times per year or less

once per month or less

2-3 times per month

once per week

more than once per week

} → **Go to Question 13**

12. When you were 6-12 years old, did you use plasma or cryoprecipitate?

Yes

No → **Go to Question 13**

12a. On average, how often did you use plasma or cryoprecipitate when you were 6-12 years old?

Never

Occasionally (up to 3 times per year)

Regularly (several or many times per year)

13. When you were 13-20 years old, did you use factor concentrate?

Yes

No → **Go to Question 14**

13a. On average, how often did you use factor concentrate when you were 13-20 years old?

6 times per year or less

once per month or less

2-3 times per month

once per week

more than once per week

} → **Go to Question 15**

14. When you were 13-20 years old, did you use plasma or cryoprecipitate?

Yes

No → **Go to Question 15**

14a. On average, how often did you use plasma or cryoprecipitate when you were 13-20 years old?

Never

Occasionally (up to 3 times per year)

Regularly (several or many times per year)

15. When you were 21-30 years old, did you use factor concentrate?

I am younger than this age group → **Form complete**

Yes

No → **Go to Question 16**

15a. On average, how often did you use factor concentrate when you were 21-30 years old?

6 times per year or less

once per month or less

2-3 times per month

once per week

more than once per week

} → **Go to Question 17**

16. When you were 21-30 years old, did you use plasma or cryoprecipitate?

Yes

No → **Go to Question 17**

16a. On average, how often did you use plasma or cryoprecipitate when you were 21-30 years old?

Never

Occasionally (up to 3 times per year)

Regularly (several or many times per year)

17. When you were 31-40 years old, did you use factor concentrate?

I am younger than this age group → **Form complete**

Yes

No → **Go to Question 18**

17a. On average, how often did you use factor concentrate when you were 31-40 years old?
_____ 6 times per year or less
_____ once per month or less
_____ 2-3 times per month
_____ once per week
_____ more than once per week

} → Go to Question 19

18. When you were 31-40 years old, did you use plasma or cryoprecipitate?
_____ Yes
_____ No → Go to Question 19

18a. On average, how often did you use plasma or cryoprecipitate when you were 31-40 years old?
_____ Never
_____ Occasionally (up to 3 times per year)
_____ Regularly (several or many times per year)

19. When you were 41-50 years old, did you use factor concentrate?
_____ I am younger than this age group → Form complete
_____ No → Go to Question 20

19a. On average, how often did you use factor concentrate when you were 41-50 years old?
_____ 6 times per year or less
_____ once per month or less
_____ 2-3 times per month
_____ once per week
_____ more than once per week

} → Go to Question 21

20. When you were 41-50 years old, did you use plasma or cryoprecipitate?
_____ Yes
_____ No → Go to Question 21

20a. On average, how often did you use plasma or cryoprecipitate when you were 41-50 years old?
_____ Never
_____ Occasionally (up to 3 times per year)
_____ Regularly (several or many times per year)

21. When you were 51-60 years old, did you use factor concentrate?
_____ I am younger than this age group → Form complete
_____ Yes
_____ No → Go to Question 22

21a. On average, how often did you use factor concentrate when you were 51-60 years old?
_____ 6 times per year or less
_____ once per month or less
_____ 2-3 times per month
_____ once per week
_____ more than once per week

→ Go to Question 23

22. When you were 51-60 years old, did you use plasma or cryoprecipitate?
_____ Yes
_____ No → Go to Question 23

22a. On average, how often did you use plasma or cryoprecipitate when you were 51-60 years old?
_____ Never
_____ Occasionally (up to 3 times per year)
_____ Regularly (several or many times per year)

23. Since you turned 61 years old, did you use factor concentrate?
_____ I am younger than this age group → Form complete
_____ Yes
_____ No → Go to Question 24

23a. On average, how often did you use factor concentrate since you turned 61 years old?
_____ 6 times per year or less
_____ once per month or less
_____ 2-3 times per month
_____ once per week
_____ more than once per week

→ Form complete

24. Since you turned 61 years old, did you use plasma or cryoprecipitate?
_____ Yes
_____ No → Form complete

24a. On average, how often did you use plasma or cryoprecipitate since you turned 61 years old?
_____ Never
_____ Occasionally (up to 3 times per year)
_____ Regularly (several or many times per year)

Thank you for taking the time to answers these questions. Please return the completed module to the Study Nurse.