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GENERAL INFORMATION

Date Form Completed			Form Completed by:	Data entered by:
month	day	year		CDC Use Only

DEMOGRAPHIC INFORMATION

1. Patient Age <input type="text"/> <input type="text"/> Years	4. Race/Ethnicity:	5. Factor Deficiency: (check all that apply)
2. Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female	<input type="checkbox"/> White (non-Hispanic)	VIII <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
3. HTC Utilization (check one):	<input type="checkbox"/> White (Hispanic)	X <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe
<input type="checkbox"/> Frequent (visited HTC at least once per year)	<input type="checkbox"/> Black (non-Hispanic)	vWF <input type="checkbox"/>
<input type="checkbox"/> Infrequent (visited HTC every 2 or 3 years)	<input type="checkbox"/> Black (Hispanic)	Other <input type="checkbox"/> _____
<input type="checkbox"/> Rare (visited HTC every 4 or more years)	<input type="checkbox"/> Asian/Pacific Islander	
	<input type="checkbox"/> American Indian/Alaskan Native	6. Used blood products in the last year?
	<input type="checkbox"/> other _____	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown

MORTALITY INFORMATION

7. Date of death:	10. Cause of death:
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Primary Cause: _____
month day year	Contributing Cause: _____
	Contributing Cause: _____
	Contributing Cause: _____
	Contributing Cause: _____
8. Information source(s):	
(Check all that apply)	
<input type="checkbox"/> Death certificate	11. Please categorize the primary cause of death (Check one)
<input type="checkbox"/> Patient's physician	<input type="checkbox"/> Hemophilia-related
<input type="checkbox"/> Patient's family	<input type="checkbox"/> HIV-related
<input type="checkbox"/> Other _____	<input type="checkbox"/> Liver Disease-related
	<input type="checkbox"/> Suicide
9. Was an autopsy performed?	<input type="checkbox"/> Other
<input type="checkbox"/> Yes	<input type="checkbox"/> Unknown
<input type="checkbox"/> No	
<input type="checkbox"/> Unknown	12. Did the patient have signs or symptoms of neurologic disease in the 6 months prior to death?
	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
9a. If an autopsy was done, check type:	If yes, describe: _____
<input type="checkbox"/> Partial autopsy without brain	_____
<input type="checkbox"/> Complete autopsy with brain	_____
<input type="checkbox"/> Brain autopsy only	_____
<input type="checkbox"/> Unknown	_____

MORTALITY FORM

FORM COMPLETION: Complete this form upon notification of death for any patient age 2 years or older who received any care in the hemophilia treatment center (HTC) and who had a bleeding disorder due to congenital deficiency or acquired inhibitors in which any of the coagulation proteins was missing, reduced, or defective and had a functional level of less than 50% or had a physician's diagnosis of von Willebrand disease.

Patient CDC ID: The unique 12-digit number generated for each patient by staff at the HTC using the CDC ID computer program.

General Information:

Enter the date that this form was completed, using leading zeros before single-digit months and days. Enter the initials of the person completing the form.

Demographic Information:

1. Patient Age: Enter the patient's age in years as of the date of death. Use a leading zero for single-digit ages.

2. Sex: Check MALE or FEMALE.

3. HTC Utilization:

Use the history of patient's visits to the HTC to determine whether the patient utilized the HTC on a FREQUENT, INFREQUENT, or RARE basis. Count only actual visits to the HTC, not phone contacts or written correspondence.

4. Race/Ethnicity:

Check the racial/ethnic category that the patient considered him(her)self to be. Use the OTHER category to write in racial/ethnic groups not listed.

5. Factor Deficiency:

Check all of the factor deficiency diagnoses for which the patient received care at the HTC. If other, please write in the specific diagnosis. For patients with Factor VIII or IX deficiency, check the severity level of the hemophilia according to the following scale: MILD, if the baseline factor activity level was from 6% to 50%; MODERATE, if from 1% to 5%; or SEVERE, if less than 1% of normal.

6. Used blood products in the last year:

Check YES, if the patient used any type of factor products in the last 12 months. Factor products include any kind of factor concentrate (including recombinant products) or any blood product or component (including whole blood, platelets, cryoprecipitate, fresh frozen plasma, etc.). Check NO, if it is known that the patient did not use any blood products in the last 12 months. Check UNKNOWN, if it is unknown whether or not blood products were used.

7. Date of death: Enter the date of death, using leading zeros before single-digit months and days.

8. Information Source(s): Check the source(s) of information that was/were used to complete this form.

9. Was an autopsy performed:

Check YES, if either a partial or complete post-mortem examination was performed on the patient. Check NO, if no autopsy was performed. Check UNKNOWN, if it is unknown whether an autopsy was performed.

9a. If an autopsy was done, check type:

If known, place a check next to the type of post-mortem exam conducted.

10. Cause of death:

PRIMARY CAUSE (also sometimes referred to as the "immediate" cause of death) - Enter the ONE disease, injury, or complication that directly caused the death. If the source of information lists several causes and does not specify the primary cause, enter the first listed cause on this line.

CONTRIBUTING CAUSE - Enter up to four diseases, conditions, injuries, or complications that contributed to the death. Enter one condition only per line.

11. Please categorize the primary cause of death:

Check one of the categories according to the following guidelines:

HEMOPHILIA-RELATED: death was directly a result of hemophilia (implies a bleeding-associated event).

HIV-RELATED: death was a direct result of infection with HIV and may include opportunistic infection, wasting syndrome, or other fatal illnesses related to HIV infection.

LIVER DISEASE-RELATED: death was direct result of liver disease or liver failure.

SUICIDE: death was a direct result of suicide as determined by a coroner.

OTHER: death was a direct result of a known cause not related to the first four groups.

UNKNOWN: cause of death was unknown or undetermined. Does not refer to unknown only by the HTC. Every attempt should be made to find out the cause of death, if it has been determined.

12. Did the patient have signs or symptoms of neurologic disease in the 6 months prior to death:

Check YES, if the patient had any of the following signs or symptoms at any time during the last 6 months of life: dementia, myoclonus, cerebellar ataxia, an abnormal EEG, or any other neurologic disorder. Check NO, if the patient had no evidence of neurologic disease in the last 6 months of life. Check UNKNOWN, if it is unknown whether signs or symptoms of neurologic disease were present before death.