DEMOGRAPHIC DATA

1.	Date of birth	_ - - Year				
2.	Date this form completed	_ - _ - _ - _ Year				
3.	Date of enrollment visit	_ - _ - _ - _ Year				
4.	Year became patient at your clinic	Year				
5.	Sex	" Male " Female				
6.	Race SELECT UP TO THREE RESPONSES	 White (or European ancestry) Black (or African ancestry) Asian/Pacific Islander American Indian/Alaska Native South/Central American Indian Hispanic/Latino 				
7.	Ethnicity or Ancestry (e.g., German, Cuban)					
8.	Hemophilia type	 Hemophilia A (Factor VIII deficiency) Hemophilia B (Factor IX deficiency) Von Willebrand's disease 				
9.	Severity of Hemophilia	 Mild (>5%) or vW Type 1 Moderate (1-5%) or vW Type 2 Severe (<1%) or vW Type 3 				
10.	What is the subject's hemophilia genetic defect? CHECK ONE RESPONSE.	 Intron 22 Inversion Large Deletion (>200 bp) Small Deletion (#200 bp) Stop Mutation Other, Specify: Unknown 				
11.	Was an inhibitor (antibody to FVIII or FIX) <u>ever</u> detected in the plasma of this subject?	 Yes No ÷ GO TO 12 Unknown÷ GO TO 12 				
	11a. What was the highest inhibitor titer?	Bethesda Units				
recent. If muttiple genotypes detected during the single		Test not doneViral load too low for genotype test				
Year of	f most recent test	Date Not Available				

12.	Does the subject have a sibling with hemophilia?			 Yes No ÷ GO TO BLOOD PRODUCT USAGE Unknown 				
	12a.	Is this sibling a patient at this clinic?	"	Yes ÷ In No	ENROL	L <u>AL</u>	<u>L SIBLINGS</u> IN MHCS-II	
	12b.	If sibling already enrolled, record MHCS-II subject ID#.				_		
BLC	OOD PI	RODUCT USAGE						
13.	Mark	an answer for each product type, and if used	-	•	ar of fir	st use.		
			Ever used?				IF YES:	
	- F-	-4 VIII	<u>No</u>	Yes	Unkno "	<u>own</u>	Year first used	
		ctor VIII ctor IX	"	"	"			
			"	"	"			
		c. Fresh Frozen Plasmad. Cryoprecipitate			"			
	-		"	"	"			
	e. Blood/RBC Transfusionf. Platelets			"	"			
		specified type of blood product	"	"	"			
	g. On	specified type of blood product						
<u>HEI</u>	<u>PATITI</u>	<u>S STATUS</u>						
14.	Accor	ding to the medical record, has the subject	"	Yes ÷				
	ever to	ested positive for hepatitis C virus (HCV)?	"	No		year c	of first positive HCV test	
			"	Unknow	'n			
15.	Has th	ne subject ever had any positive markers	"	Yes				
	indicating hepatitis B virus (HBV) infection?			" No				
		• • • • • • • • • • • • • • • • • • • •	"	Unknow	n			
16.	Has the subject ever been <u>vaccinated</u> against hepatitis B?		"	Yes ÷				
			"	No		year c	of first HBV vaccination	
			"	Unknow	'n			
17.	What	What is the HBV chronic carrier status		Current	carrier			
- / •	of the subject? A chronic carrier is hepatitis B surface antigen positive (HBsAg+) for more than 6 months.			" Former carrier, now HBsAg- " Never a carrier				
				Unknow				
	(1110)	70) 101 more than o months.		C IIIIIO W				

HIV/AIDS STATUS

18.	Has the subject ever <u>tested positive</u> for HIV?	YesNo ÷ GO TO LIVER DISEASE STATUS
19.	What were the results of the subjects most recent CD4 and CD8?	CD4 _ % 10°/L CD8 10°/L
20.	Has the subject ever been diagnosed with AIDS?	YesNo ÷ GO TO LIVER DISEASE STATUS
	Bolded items are cancers to report at Q. 25.	
"	YEAR YEAR	<u>YEAR</u>
"	Diagnosis unknown	Mycobacterium avium (not omy
"	CD4 <200 cells/µL or <14%	lungs, skin, cervical nodes)
"	CMV (not liver, spleen, lymph) _ Candidiasis of esophagus or lungs	Non-mougkin's Lymphoma
"		(not T-cell or CNS Primary)
"		Pneumocystis carinii pneumonia (PCP) _ _ Pneumonia, recurrent bacterial
"	Cryptococcosis, extrapulmonary	(more than once in 12 months)
"	· · · · · · · · · · · · · · · · · · ·	" Progressive multifocal
	for > 1 month	leukoencephalopathy (PML)
"	·	" Pulmonary tuberculosis
"		" Salmonella septicemia, recurrent
"		" Toxoplasmosis of the brain
"		Wasting syndrome
"	Isosporiasis with diarrhea	(emaciation, "slim disease")
	•	" Other multiple or recurrent
"	Kaposi's Sarcoma	bacterial infections at least 2 in
"	Lymphoid interstitial pneumonia (LIP)	a 2-year period
	or pulmonary lymphoid hyperplasia _	·
"	Lymphoma of the brain (CNS Primary) _ _	
тт	VER DISEASE STATUS	
	<u> </u>	ingt have diagnosed? For each one the subject has had
21.		ect been diagnosed? For each one the subject has had, not been diagnosed with any of these, choose 'NONE'.
	record the year of first diagnosis. If the subject has i	Year of first diagnosis
	" NONE	1 cai of thist diagnosis
	" Jaundice, persistent > 1 month	
	" Ascites (hepatic-related)	
	" Hepatic encephalopathy	
	Bleeding esophageal varices	<u> </u>
	" Esophageal varices	<u> </u>
	1 3	11111

22.	Which of the following <u>other conditions</u> has the subject had? For each one the subject has had, record the year of first diagnosis. If the subject has not been diagnosed with any of these, choose 'NONE'.				
	" " " " " " "	He Mi Ap Po Me	PNE epatocellular carcinoma ixed cryoglobulinemia olastic anemia rphyria cutanea tarda embranoproliferative glomerulonephritis her, Specify		Year of first diagnosis
23.	Has the years?	e sul	bject had a <u>liver biopsy</u> in the last 5	"	Yes ÷ SEND COPY OF PATH REPORT(S) No
24.	Is the subject eligible for a liver transplant (or would he be if not HIV positive)?			"	Yes No
CANCER STATUS Be sure to include those cancers you listed in the HIV/AIDS STATUS section.					
25.	Has the		bject ever been diagnosed with any acer?	"	Yes ÷ SEND COPY OF PATH REPORT(S) No ÷ FORM IS COMPLETE. KEY ON-LINE AT https://mhcs-ii.rti.org .
Cance	r #1	a.	Primary site		
		b.	Type	Hi	stologic subtype
		c.	Is this cancer localized to the primary site or metastatic?	"	Localized Metastatic
		d.	Diagnosis date	 	Ionth Year
Cance	r #2	a.	Primary site		
		b.	Type	Hi	stologic subtype
		c.	Is this cancer localized to the primary site or metastatic?	"	Localized Metastatic
		d.	Diagnosis date	_ <u></u>	Ionth Year
REM	 KEY DATA ON-LINE AT https://mhcs-ii.rti.org AND PUT FORM IN SUBJECTS FILE. SEND RTI A COPY OF PATHOLOGY REPORT(S) FOR EACH LIVER BIOPSY AND CANCER DIAGNOSIS REPORTED. IF SUBJECT HAS SIBLING AT CLINIC THAT HAS NOT BEEN ENROLLED, CONTACT AND SCHEDULE APPOINTMENT. 				