

<b>SPLIT</b>			
\$sitecode	User:	System Date:	Mode: Development
Site Name:			

## Demographics (DEM)

Version: 5.0; 11-30-07

1. Namecode: (NAMECODE ) \_\_\_\_\_
2. Date of birth: (REGDTBIR ) \_\_\_\_\_ (mm/dd/yyyy)
3. Ethnicity: (REGETHNI ) \_\_\_\_\_

Hispanic or Latino - 1  
 Not Hispanic or Latino - 2  
 Not Reported - 0

4. Race:

Not Reported: (REGNOREP ) ☐

*Select the appropriate race(s) according to the descriptions provided in the Forms Instructions.*

- a. Asian: (REGASIAN ) ☐ No - 0 ☐ Yes - 1
- b. Black or African American: (REGBLACK ) ☐ No - 0 ☐ Yes - 1
- c. Native Alaskan or American Indian: (REGNATIV ) ☐ No - 0 ☐ Yes - 1
- d. Native Hawaiian or other Pacific Islander: (REGHAWII ) ☐ No - 0 ☐ Yes - 1
- e. White or Caucasian: (REGWHITE ) ☐ No - 0 ☐ Yes - 1

5. Sex: (REGSEX )

☐ Male - 1 ☐ Female - 2

6. Blood type: (REGBLOOD )

A - 1  
 B - 2  
 O - 3  
 AB - 4

7. Primary liver disease diagnosis following evaluation: (REGPRDIS )

1.01- Biliary atresia  
 1.02- Alagille's syndrome  
 1.04- Byler's disease and Familial cholestasis/ cirrhosis  
 1.05- Idiopathic cholestasis/ cirrhosis  
 1.07- TPN induced  
 \*Additional Options Listed Below

If *Other* selected for any sub group, please specify: (REGAGOTH )

*If 1.01-Biliary Atresia selected for primary diagnosis answer the following:*

Is the participant enrolled in BARC (Biliary Atresia Research Consortium)? (PTINBARC ) ☐ No - 0 ☐ Yes - 1

If yes, what is the 7 digit BARC ID? (BARCID ) \_\_\_\_\_

8. Date consent/assent or data authorization

\_\_\_\_\_ (mm/dd/yyyy) obtained: (CONSDATE)

## Additional Selection Options for DEM

### Primary liver disease diagnosis following evaluation:

- 1.08- Primary sclerosing cholangitis
- 1.09- Biliary strictures
- 1.10- Neonatal hepatitis
- 1.99- Other cholestatic
- 2.01- Acute hepatitis A
- 2.02- Acute hepatitis B
- 2.03- Acute hepatitis C
- 2.04- Subacute hepatitis A
- 2.05- Subacute hepatitis B
- 2.06- Subacute hepatitis C
- 2.07- Fulminant liver failure unknown etiology
- 2.08- Fulminant autoimmune hepatitis
- 2.09- Subacute fulminant liver failure
- 2.99- Other fulminant liver failure
- 3.01- Alpha1- Antitrypsin deficiency
- 3.02- Wilson's disease
- 3.03- Tyrosinemia
- 3.04- Primary hyper oxaluria
- 3.05- Cystic fibrosis
- 3.06- Urea cycle defects
- 3.07- Crigler- Najjar
- 3.08- Glycogen storage disease
- 3.09- Neonatal hemochromatosis
- 3.10- Inborn error in bile acid metabolism
- 3.99- Other metabolic disease
- 4.01- Hepatocellular carcinoma
- 4.02- Hepatoblastoma
- 4.03- Hemangioendothelioma
- 4.99- Other tumor
- 5.01- Accidental overdose
- 5.02- Attempted suicide
- 5.03- Drug induced
- 5.99- Other toxicity
- 6.01- Cirrhosis due to neonatal hepatitis
- 6.03- Cirrhosis due to hepatitis B
- 6.04- Cirrhosis due to hepatitis C
- 6.05- Cirrhosis due to autoimmune hepatitis
- 6.06- Cirrhosis due to unknown cause
- 6.99- Cirrhosis due to other
- 7.01- Budd-Chiari syndrome
- 7.02- Congenital hepatic fibrosis
- 9.99- Other