

SPLIT			
\$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