

SPLIT			
\$sitecode	User:	System Date:	Mode: Development
Site Name:			

Primary Sclerosing Cholangitis (PSC)

Version: 2.0; 11-30-07

1. Does the patient have co-existing cystic fibrosis, Langerhans No - 0 Yes - 1
 cell histiocytosis, or congenital immunodeficiency? (PSCCONDI)

If Yes, the rest of this form is not required.

If No, complete the form with information from pre transplant through the most recent visit.

Pre-Transplant Information

2. Diagnosed pre-transplant with Inflammatory Bowel Disease No - 0 Yes - 1
 (IBD): (PSCIBD)

If yes, type of IBD: (PSCIBDTYPE)

- 1- Crohn's 2- Ulcerative Colitis 3- Indeterminate Colitis

3. Autoantibodies (pre-transplant most recent results):

**For titers specify > or < only if the lab report specifies it, otherwise leave it blank.*

(PSCANA) ANA Titer: (PSCANAR) Date: (PSCANADT)
 + ANA - Sign (PSCANAGL) < 1: (xxxxx) (mm/dd/yyyy)
 Not Done >

(PSCASM) ASM Titer: (PSCASMR) Date: (PSCASMDT)
 + ASM - Sign (PSCASMGL) < 1: (xxxxx) (mm/dd/yyyy)
 Not Done >

(PSCCLKM) LKM
 + LKM -
 Not Done

(PSCPANCA) Level: (PSCANCR) Date: (PSCANCDT)
 pANCA + (xxxxx) (mm/dd/yyyy)
 pANCA - Not Done

4. PSC diagnosis established by:

(PSCPTMRC) No - 0 Yes - 1 Magnetic resonance cholangiopancreatography (MRCP)

(PSCPTERC) No - 0 Yes - 1 Endoscopic retrograde cholangiopancreatography (ERCP)

(PSCPTLBP) No - 0 Yes - 1 Liver biopsy

(PSCPTPTC) No - 0 Yes - 1 Percutaneous transhepatic cholangiography (PTC)

5. Evidence of injury to:

- a. Extrahepatic ducts (PSCINJEX) No - 0 Yes - 1 Not evaluated - 2
- b. Medium-large intrahepatic ducts (PSCINJML) No - 0 Yes - 1 Not evaluated - 2
- c. Small intrahepatic ducts (usually seen on liver biopsy) (PSCINJSL) No - 0 Yes - 1 Not evaluated - 2
- d. Hepatocytes (piecemeal necrosis or interface hepatitis on liver biopsy) (PSCINJHP) No - 0 Yes - 1 Not evaluated - 2

6. Interventions for PSC pre-transplant:

- Balloon dilation/stent implantation: (PSCPTBAL) No - 0 Yes - 1
- Surgical intervention (including Roux-en-Y reconstruction): (PSCPTSUR) No - 0 Yes - 1

Post-First Transplant Information:

7. Transplanted for PSC: (PSCTRANS)

No - 0 Yes - 1

If Yes, please answer the following:

If No, the rest of this form is not required.

8. Treated with Actigal post-transplant: (PSCACTIG)

No - 0 Yes - 1

9. New diagnosis of IBD post transplant: (PSCIBDPO)

No - 0 Yes - 1

If yes, type of IBD: (PSCIBDTP)

1- Crohn's 2- Ulcerative Colitis 3- Indeterminate Colitis

10. Biliary strictures that developed after 90 days post-transplant: (PSCSTCPO)

No - 0 Yes - 1 NA, not past 90 days - 9

If Yes, please answer the following:

a. Biliary ducts were imaged using:

(PSCPOPTC) No - 0 Yes - 1 Percutaneous transhepatic cholangiography (PTC)

(PSCPOMRC) No - 0 Yes - 1 Magnetic resonance cholangiopancreatography (MRCP)

(PSCPOERC) No - 0 Yes - 1 Endoscopic retrograde cholangiopancreatography (ERCP)

b. Strictures are: (PSCSTRIC)

1- Anastomotic
2- Non-anastomotic extrahepatic
3- Intrahepatic

c. Balloon dilation/stent implantation: (PSCPOBAL)

No - 0 Yes - 1

d. Surgical intervention (including Roux-en-Y reconstruction): (PSCPOSUR)

No - 0 Yes - 1

11. Recurrent Primary Sclerosing Cholangitis after transplant: (PSCRECUR)

No - 0 Yes - 1

If Yes, please answer the following:

a. Date of diagnosis of recurrent PSC: (PSCRCDT)

(mm/dd/yyyy)

b. Diagnosed by:

(PSCRCMRC) No - 0 Yes - 1 Magnetic resonance cholangiopancreatography (MRCP)

(PSCRCERC) No - 0 Yes - 1 Endoscopic retrograde cholangiopancreatography (ERCP)

(PSCRCCLBP) No - 0 Yes - 1 Liver biopsy

(PSCRCPTC) No - 0 Yes - 1 Percutaneous transhepatic cholangiography (PTC)

c. Evidence of injury to:

Extrahepatic ducts (PSCRIJEX) No - 0 Yes - 1 Not evaluated - 2

Medium-large intrahepatic ducts (PSCRIJML) No - 0 Yes - 1 Not evaluated - 2

Small intrahepatic ducts (usually seen on liver biopsy) (PSCRIJSL) No - 0 Yes - 1 Not evaluated - 2

Hepatocytes (piecemeal necrosis or interface hepatitis on liver biopsy) (PSCRIJHP) No - 0 Yes - 1 Not evaluated - 2

12. Listed for re-transplant: (PSCLRTRTR)

No - 0 Yes - 1

a. Date of re-listing: (PSCLRTRTD)

_____ (mm/dd/yyyy)

b. Current status: (PSCSTATU)

1- Waiting
2- Transplanted
3- Removed from the waiting list

1. If transplanted specify date: (PSCSTRAND)

_____ (mm/dd/yyyy)

2. If removed from the waiting list specify reason: (PSCSTREM)

1- Patient recovered
2- Patient too sick to re-transplant
3- Patient died

The Notes field should not be used to communicate information to the SPLIT DCC. This field is intended to be used for notes center staff may find useful when returning to the form.

Notes: (PSCCOMMT)

