

A1. Site/Study ID #: \_\_\_\_\_ / G \_\_\_\_\_ A2. Visit Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Month Day Year  
 A3. Staff Initials: \_\_\_\_\_  
 A4. Visit: 1.  Baseline 2.  Year 1 3.  Year 2 4.  Year 3 5.  Year 4 6.  Year 5 7.  LT/ABD 8.  Year 6 9.  Year 7 10.  Year 8  
 11.  Year 9 12.  Year 10 To DCC

A5. Were there any sentinel events during the past year? 1.  Yes, If yes, please complete all that apply. 2.  No – END

A6. If more than one form submitted, this is form \_\_\_ of \_\_\_.

**SECTION B: SENTINEL EVENTS – THIS SECTION MAY BE REPEATED IF MORE THAN ONE EVENT**

Please identify all of the sentinel events that the subject experienced DURING THE PAST YEAR. Please provide EITHER start and stop dates  
 OR Duration of episode.

**B1. Ascites** 1.  Yes 2.  No – Go to B2

Details					
Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Ultrasound Confirmation	Interventions taken (check all that apply)
____ / ____ / ____	____ / ____ / ____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	a. <input type="checkbox"/> None b. <input type="checkbox"/> Paracentesis c. <input type="checkbox"/> Antibiotics d. <input type="checkbox"/> Diuretics e. <input type="checkbox"/> Albumin Infusion f. <input type="checkbox"/> Other: _____
____ / ____ / ____	____ / ____ / ____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	a. <input type="checkbox"/> None b. <input type="checkbox"/> Paracentesis c. <input type="checkbox"/> Antibiotics d. <input type="checkbox"/> Diuretics e. <input type="checkbox"/> Albumin Infusion f. <input type="checkbox"/> Other: _____

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B2. Bacterial peritonitis 1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No – Go to B3				
Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Interventions Taken (check all that apply)
____ / ____ / _____	____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		a. <input type="checkbox"/> None b. <input type="checkbox"/> Therapeutic Paracentesis c. <input type="checkbox"/> Antibiotics d. <input type="checkbox"/> Diuretics e. <input type="checkbox"/> Other: _____
____ / ____ / _____	____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		a. <input type="checkbox"/> None b. <input type="checkbox"/> Therapeutic Paracentesis c. <input type="checkbox"/> Antibiotics d. <input type="checkbox"/> Diuretics e. <input type="checkbox"/> Other: _____

1. Culture		
Date of Culture (mm/dd/yyyy)	Result	Organism Present (check all that apply)
____ / ____ / _____	1. <input type="checkbox"/> Positive 2. <input type="checkbox"/> Negative	a. <input type="checkbox"/> Enterococcus b. <input type="checkbox"/> Escherichia coli c. <input type="checkbox"/> Klebsiella species d. <input type="checkbox"/> Streptococcus species e. <input type="checkbox"/> Staphylococcus species f. <input type="checkbox"/> Other: _____

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_____ / _____ / _____	1. <input type="checkbox"/> Positive 2. <input type="checkbox"/> Negative	a. <input type="checkbox"/> Enterococcus b. <input type="checkbox"/> Escherichia coli c. <input type="checkbox"/> Klebsiella species d. <input type="checkbox"/> Streptococcus species e. <input type="checkbox"/> Staphylococcus species f. <input type="checkbox"/> Other: _____
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**2. Ascites Fluid Analysis**

Date of Analysis (mm/dd/yyyy)	Total white blood Cell count (ml)	Total neutrophil Count (ml)	Gram stain	Specify
_____ / _____ / _____			1. <input type="checkbox"/> Positive 2. <input type="checkbox"/> Negative	
_____ / _____ / _____			1. <input type="checkbox"/> Positive 2. <input type="checkbox"/> Negative	

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**B3. Bones** 1.  Yes 2.  No – Go to B4

**1. Fractures**

Start Date (mm/dd/yyyy)	Ongoing?	Bone (specify)	Side	Interventions
____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Right 2. <input type="checkbox"/> Left	a. <input type="checkbox"/> Casting or splinting
____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Right 2. <input type="checkbox"/> Left	a. <input type="checkbox"/> Casting or splinting

**2. Rickets**

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Bones involved (specify)	Interventions (check all that apply)
____ / ____ / _____	____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No			b. <input type="checkbox"/> Calcium supplementation c. <input type="checkbox"/> Vitamin D supplementation d. <input type="checkbox"/> Bisphosphonate e. <input type="checkbox"/> Other: _____
____ / ____ / _____	____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No			b. <input type="checkbox"/> Calcium supplementation c. <input type="checkbox"/> Vitamin D supplementation d. <input type="checkbox"/> Bisphosphonate e. <input type="checkbox"/> Other: _____

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**B4. Cholangitis** 1.  Yes 2.  No – Go to B5

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Interventions Taken (check all that apply)
____ / ____ / ____	____ / ____ / ____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		a. <input type="checkbox"/> None b. <input type="checkbox"/> Antibiotics c. <input type="checkbox"/> Other: _____
____ / ____ / ____	____ / ____ / ____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		a. <input type="checkbox"/> None b. <input type="checkbox"/> Antibiotics c. <input type="checkbox"/> Other: _____

**B5. Chronic Diarrhea** 1.  Yes 2.  No – Go to B6

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Watery	Bloody	Greasy	Infectious Etiology
____ / ____ / ____	____ / ____ / ____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Specify: _____
____ / ____ / ____	____ / ____ / ____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No 3. <input type="checkbox"/> Specify: _____

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**B6. Coagulopathy** 1.  Yes 2.  No – Go to B7

Start date (month and year) \_\_\_\_\_ / \_\_\_\_\_  
Month Year

Ongoing

Stop Date (month and year) \_\_\_\_\_ / \_\_\_\_\_  
Month Year

- a. Prothrombin time (maximal value): \_\_\_\_\_ sec 88.  ND
- b. INR (maximal value): \_\_\_\_\_ 88.  ND
- c. Partial thromboplastin time (PTT): \_\_\_\_\_ sec 88.  ND
- d. Platelet count: \_\_\_\_\_ 10<sup>3</sup>/mm<sup>3</sup> 88.  ND
- e. Easy bruising: 1.  Yes 2.  No
- f. Epistaxis: 1.  Yes 2.  No
- g. Hematochezia: 1.  Yes 2.  No
- h. Other source of bleeding: 1.  Yes 2.  No
- i. Response to Vitamin K: 1.  Yes 2.  No 88.  ND
- j. Required red cell transfusion? 1.  Yes 2.  No
- k. Required fresh frozen plasma or activated factor VII? 1.  Yes 2.  No

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**B7. Gallstones**

1.  Yes      2.  No – Go to B8

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Symptomatic	Diagnosed By (check all that apply)	Cholecystectomy performed?
____/____/____	____/____/____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	a. <input type="checkbox"/> Ultrasound b. <input type="checkbox"/> CT Scan c. <input type="checkbox"/> MRCP d. <input type="checkbox"/> At surgery e. <input type="checkbox"/> Other (Specify: _____)	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No
____/____/____	____/____/____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	a. <input type="checkbox"/> Ultrasound b. <input type="checkbox"/> CT Scan c. <input type="checkbox"/> MRCP d. <input type="checkbox"/> At surgery e. <input type="checkbox"/> Other (Specify: _____)	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No

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**B8. GI Bleed** 1.  Yes 2.  No – Go to B9

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Site of Bleed: (check all that apply)	Interventions Taken (check all that apply)
____/____/____	____/____/____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		a. <input type="checkbox"/> Esophageal b. <input type="checkbox"/> Gastric c. <input type="checkbox"/> Duodenal d. <input type="checkbox"/> Anorectal e. <input type="checkbox"/> Other (Specify: _____)	a. <input type="checkbox"/> None b. <input type="checkbox"/> Beta-blockade c. <input type="checkbox"/> Vasoconstrictive agent d. <input type="checkbox"/> TIPSS e. <input type="checkbox"/> Endoscopy f. <input type="checkbox"/> Surgical shunt g. <input type="checkbox"/> Ligation h. <input type="checkbox"/> Transfusion i. <input type="checkbox"/> Sclerotherapy j. <input type="checkbox"/> Other (Specify: _____)
____/____/____	____/____/____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		a. <input type="checkbox"/> Esophageal b. <input type="checkbox"/> Gastric c. <input type="checkbox"/> Duodenal d. <input type="checkbox"/> Anorectal e. <input type="checkbox"/> Other (Specify: _____)	a. <input type="checkbox"/> None b. <input type="checkbox"/> Beta-blockade c. <input type="checkbox"/> Vasoconstrictive agent d. <input type="checkbox"/> TIPSS e. <input type="checkbox"/> Endoscopy f. <input type="checkbox"/> Surgical shunt g. <input type="checkbox"/> Ligation h. <input type="checkbox"/> Transfusion i. <input type="checkbox"/> Sclerotherapy j. <input type="checkbox"/> Other (Specify: _____)



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**B9. Hearing Problems**

1.  Yes 2.  No – Go to B10

Start Date (mm/dd/yyyy)	Ongoing?	Specify	Severity	Hearing Aids?
____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Conductive 2. <input type="checkbox"/> Sensorineural	1. <input type="checkbox"/> Mild 2. <input type="checkbox"/> Moderate 3. <input type="checkbox"/> Severe 4. <input type="checkbox"/> Profound	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No
____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Conductive 2. <input type="checkbox"/> Sensorineural	1. <input type="checkbox"/> Mild 2. <input type="checkbox"/> Moderate 3. <input type="checkbox"/> Severe 4. <input type="checkbox"/> Profound	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No

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**B10. Hepatopulmonary Syndrome**

1.  Yes 2.  No – Go to B11

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Diagnostic Test Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Cyanosis	Upright Oxygen saturation	Shunt Fraction	Bubble ECHO cardiogram	Interventions taken
____/____/____ ____-____-____	____/____/____ ____-____-____	____/____/____ ____-____-____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	_____% 88. <input type="checkbox"/> ND	_____% 88. <input type="checkbox"/> ND	1. <input type="checkbox"/> Positive 2. <input type="checkbox"/> Negative 88. <input type="checkbox"/> Not Done	
____/____/____ ____-____-____	____/____/____ ____-____-____	____/____/____ ____-____-____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	_____% 88. <input type="checkbox"/> ND	_____% 88. <input type="checkbox"/> ND	1. <input type="checkbox"/> Positive 2. <input type="checkbox"/> Negative 88. <input type="checkbox"/> Not Done	

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**B11. Hepatorenal Syndrome** 1.  Yes 2.  No – Go to B12

Diagnostic Test Date (mm/dd/yyyy)	Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Duration (days)	Ongoing?	Peak Serum Creatinine	Interventions taken (check all that apply)
____ / ____ / ____	____ / ____ / ____	____ / ____ / ____		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	____ mg/dl 88. <input type="checkbox"/> ND	a. <input type="checkbox"/> None b. <input type="checkbox"/> Dialysis c. <input type="checkbox"/> Vasopressin d. <input type="checkbox"/> Octreotide e. <input type="checkbox"/> Other (Specify: _____)
____ / ____ / ____	____ / ____ / ____	____ / ____ / ____		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	____ mg/dl 88. <input type="checkbox"/> ND	a. <input type="checkbox"/> None b. <input type="checkbox"/> Dialysis c. <input type="checkbox"/> Vasopressin d. <input type="checkbox"/> Octreotide e. <input type="checkbox"/> Other (Specify: _____)

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**B12. Pancreatitis** 1.  Yes 2.  No – Go to B13

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)
____/____/____	____/____/____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	
____/____/____	____/____/____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	

**B13. Portopulmonary Hypertension** 1.  Yes 2.  No – Go to B14

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Diagnostic Test Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Cyanosis	Shortness Of Breath	Oxygen Saturation	Confirmed By Echo-cardiogram	Confirmed By Cardiac Cath	Intervention (Specify)
____/____/____	____/____/____	____/____/____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	____ % 88. <input type="checkbox"/> ND	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	
____/____/____	____/____/____	____/____/____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	____ % 88. <input type="checkbox"/> ND	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No	

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**B14. Pruritis** 1.  Yes 2.  No – Go to B15

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Scratch Score date (mm/dd/yyyy)	Scratch Score	Interventions (check all that apply)
____ / ____ / ____	____ / ____ / ____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		55. <input type="checkbox"/> DK  ____ / ____ / ____	1. <input type="checkbox"/> None 2. <input type="checkbox"/> Mild scratching when undistracted 3. <input type="checkbox"/> Active scratching without abrasion 4. <input type="checkbox"/> Active scratching with abrasion 5. <input type="checkbox"/> Cutaneous mutilation with bleeding and scarring	a. <input type="checkbox"/> None b. <input type="checkbox"/> Partial Biliary Diversion c. <input type="checkbox"/> Ursodiol (e.g. Actigall) d. <input type="checkbox"/> Rifampin e. <input type="checkbox"/> Ileal Exclusion f. <input type="checkbox"/> Antihistamines (e.g. diphenhydramine, Benadryl) g. <input type="checkbox"/> Nasobiliary drainage h. <input type="checkbox"/> Cholestyramine (e.g. Questran) i. <input type="checkbox"/> Other: (Specify) _____
____ / ____ / ____	____ / ____ / ____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		55. <input type="checkbox"/> DK  ____ / ____ / ____	1. <input type="checkbox"/> None 2. <input type="checkbox"/> Mild scratching when undistracted 3. <input type="checkbox"/> Active scratching without abrasion 4. <input type="checkbox"/> Active scratching with abrasion 5. <input type="checkbox"/> Cutaneous mutilation with bleeding and scarring	a. <input type="checkbox"/> None b. <input type="checkbox"/> Partial Biliary Diversion c. <input type="checkbox"/> Ursodiol (e.g. Actigall) d. <input type="checkbox"/> Rifampin e. <input type="checkbox"/> Ileal Exclusion f. <input type="checkbox"/> Antihistamines (e.g. diphenhydramine, Benadryl) g. <input type="checkbox"/> Nasobiliary drainage h. <input type="checkbox"/> Cholestyramine (e.g. Questran) i. <input type="checkbox"/> Other: (Specify) _____

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**B15. Other** 1.  Yes 2.  No – Go to B16

Start Date (mm/dd/yyyy)	Stop Date (mm/dd/yyyy)	Ongoing?	Duration (days)	Specify
____ / ____ / _____	____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		
____ / ____ / _____	____ / ____ / _____	1. <input type="checkbox"/> Yes 2. <input type="checkbox"/> No		

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**B16. Transplant listing** 1.  Yes 2.  No – END

1. Date of listing: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (mm/dd/yyyy) 1.  Ongoing  
 2. Date of removal from list: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (mm/dd/yyyy)  
 3. Reason for removal from list: \_\_\_\_\_

**PELD/MELD score at listing:**

4. Calculated score: \_\_\_\_\_  
 5. Exception score: \_\_\_\_\_  
 6. Status 1 exception requested: 1.  Yes 2.  No  
 7. Weight at listing: \_\_\_\_\_ kg 88.  ND  
 8. Height or length at listing: \_\_\_\_\_ cm 88.  ND  
 9. Head circumference at listing: \_\_\_\_\_ cm 88.  ND  
 10. Growth failure at listing: 1.  Yes 2.  No  
 11. Bilirubin Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (mm/dd/yyyy) 88.  ND  
 12a. Total bilirubin at listing: \_\_\_\_\_ mg/dl 88.  ND  
 12b. Direct bilirubin at listing: \_\_\_\_\_ mg/dl 88.  ND  
 12c. Conjugated bilirubin at listing: \_\_\_\_\_ mg/dl 88.  ND  
 13. Prothrombin time at listing:  
 Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (mm/dd/yyyy) 88.  ND \_\_\_\_\_ sec  
 14. INR at listing: \_\_\_\_\_ 88.  ND  
 15. Creatine at listing:  
 Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (mm/dd/yyyy) 88.  ND \_\_\_\_\_ mg/dl  
 16. Albumin at listing:  
 Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (mm/dd/yyyy) 88.  ND \_\_\_\_\_ g/L

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17. Child's blood type: 1.  A 2.  B 3.  O 4.  AB 66.  Unknown

18. Was the subject SPLIT registered: 1.  Yes 2.  No 66.  Unknown

19. SPLIT center name: \_\_\_\_\_

20. SPLIT center code: \_\_\_\_\_

21. SPLIT Registration Number: \_\_\_\_\_