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

Pretransplant Follow Up (PTF)

Version: 7.0; 11-30-07

Segment *(PROTSEG)*:

Visit Number *(VISNO)*:

Date of last study visit:

_____

The Pretransplant Follow Up form captures data reflecting information from the date of transplant listing to the current follow up visit date.

The Pretransplant Follow Up form captures data reflecting information from the date of the last pretransplant follow up visit to the current follow up visit date.

_____

Status and Listing Information

1. Date of follow-up assessment: *(PTFDTTLE)*   _____ *(mm/dd/yyyy)*

   Date of follow up must be entered to determine ranges for date fields and expectations for age-dependent fields below.

2. Did the participant get listed for an organ transplant other than liver or kidney? *(PTFLISTO)*   ☐ No - 0   ☐ Yes - 1

   If yes, complete this form reflecting events up to time of re-listing and complete a Loss to Follow Up/Exit form.

3. UNOS Status 1a or 1b: *(PTFUNOS)*   ☐ No - 0   ☐ Yes - 1

4. Canadian Status 4 or 4f (equivalent to UNOS Status 1): *(PTFUNOS)*   ☐ No - 0   ☐ Yes - 1

   If yes, complete Status 1 Listing form.

   a. Indicate score type used to list with UNOS: *(PTFSCORE)*   ☐ PELD - 1   ☐ MELD -2

   b. Was the calculated score or exception score used to list the participant? *(PTFALLOC)*   ☐ Calculated - 0   ☐ Exception - 1

      PELD exception score: *(PTFPELDA)*   _____ *(xxx.x)*

      MELD exception score (if ≥12 years): *(PTFMELDA)*   _____ *(xxx.x)*

5. Has transplant candidacy status changed? *(PTFTCC)*   ☐ No - 0   ☐ Yes - 1
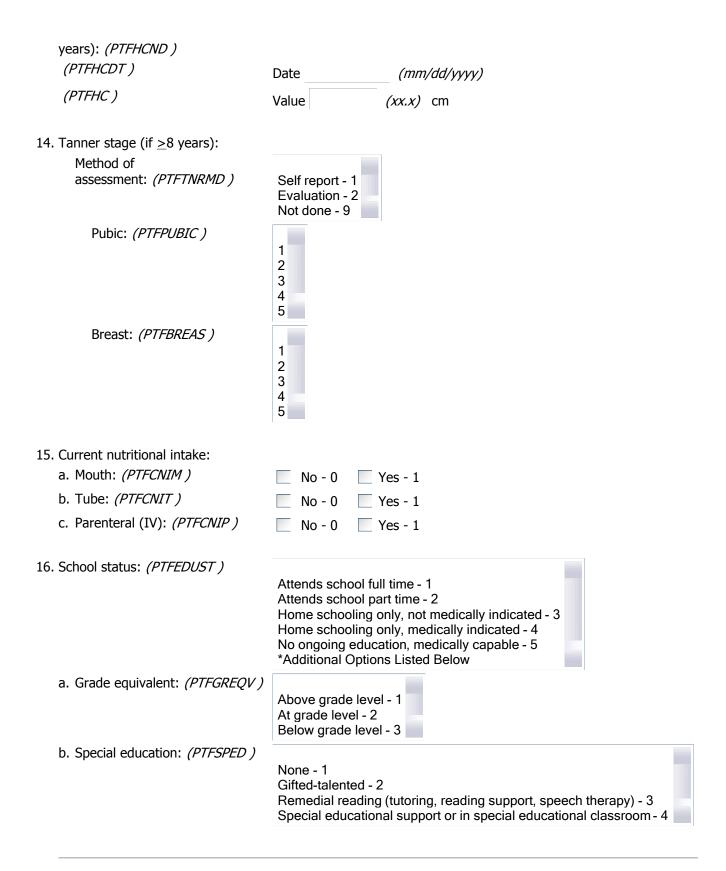
If *Yes*, indicate
status: *(PTFTCS)*

Listed active - 1
Listed, on hold- medical complications - 2
Listed, on hold- adequate liver function - 3
Not listed, patient/parent/guardian refusal - 4
Not listed, medical complications - 5
*Additional Options Listed Below

6. Patient status: *(PTFSTAT)*

ICU - 1
Hospitalized, not in ICU - 2
Not hospitalized - 3

Labs/Procedures

7. Hematology/Chemistries:

Labs from anytime within the acceptable date range shown below can be reported. Labs within the same panel should be reported for the same date.

Date
range: From *(PTFDTLOW)*   To *(PTFDTHIG)*
          (mm/dd/yyyy)   *(mm/dd/yyyy)*

The date of follow up evaluation must be entered before entering the lab date and the chemistry/hematology results. Enter the date when blood was drawn for the majority of the labs.

Date the majority of the labs were drawn: *(PTFCHDT)*   *(mm/dd/yyyy)*

	Common Units (CU)		Standard International (SI)	
Total bilirubin:	*(PTFTOBIL)*	*(xxx.x)* mg/dL	*(PTFTBSI)*	*(xxxxx.x)* µmol/L
Albumin:	*(PTFALB)*	*(xx.x)* g/dL	*(PTFALBSI)*	*(xxx.x)* g/L
Serum creatinine:	*(PTFCRECU)*	*(xx.x)* mg/dL	*(PTFCRESI)*	*(xxxx.x)* µmol/L
Sodium:	*(PTFSODCU)*	*(xxx)* mEq/mL	*(PTFSODSI)*	*(xxx)* mmol/L
Hemoglobin:	*(PTFHEMCU)*	*(xx.x)* g/dL	*(PTFHEMSI)*	*(xxx.x)* g/L
Prothrombin time:	*(PTFPROTM)*	*(xxx.x)* seconds		
INR:	*(PTFINR)*	*(xx.x)*		

8. Is the patient on dialysis/
   hemofiltration? *(PTFDIAL)*   ☐ No - 0   ☐ Yes - 1

9. Did the patient have a renal
   transplant since the last   ☐ No - 0   ☐ Yes - 1
   visit? *(PTFPRITX)*

      If *Yes*, please specify   ☐_____ *(mm/dd/yyyy)*
      date: *(PTFPTDAT)*

Renal Aim

10. Does the participant have any of   ☐ No - 0   ☐ Yes - 1
    the below primary renal diseases
    unrelated to calcineurin inhibitor
    exposure? *(PTFCNI)*

    Primary Renal Diseases: Vesicoureteral reflux, obstructive uropathy, renal hypo/dysplasia, cystic kidney, chronic glomerulonephritis, or other non-CNI disease.

    Renal dysfunction secondary to primary liver disease and renal tubular dysfunction without decrease in GFR do not apply.

       If Yes, indicate
       type: *(PTFCNITY)*

    Vesicoureteral reflux - 1
    Obstructive uropathy - 2
    Renal hypo-/dysplasia - 3
    Cystic kidney condition - 4
    Chronic glomerulonephritis - 5
    *Additional Options Listed Below

       If Other,
       specify: *(PTFCNIOT)*   _____

Assessments

Date of follow up evaluation must be entered in order to display height, weight, and head circumference (participant < 5) and determine if they are reported within the visit window (90 days prior to 30 days post follow up date). If values were not measured within the visit window, indicate 'Not Done'.

11. Height: *(PTFHTND)*   ☐ Not Done

       (PTFHTDT)   Date _____ *(mm/dd/yyyy)*

       (PTFHT)   Value _____ *(xxx.x)* cm *(PTFHTIN)* _____ *(xx.x)* in

12. Weight: *(PTFWTND)*   ☐ Not Done

       (PTFWTDT)   Date _____ *(mm/dd/yyyy)*

       (PTFWT)   Value _____ *(xxx.x)* kg *(PTFWTLBS)* _____ *(xxx.x)*
                                    lbs

13. Head circumference (if < 5   ☐ Not Done

years): *(PTFHCND)*

　(PTFHCDT)

Date _____ *(mm/dd/yyyy)*

　(PTFHC)

Value [ ] *(xx.x)* cm

14. Tanner stage (if ≥8 years):

Method of
assessment: *(PTFTNRMD)*

Self report - 1
Evaluation - 2
Not done - 9

Pubic: *(PTFPUBIC)*

1
2
3
4
5

Breast: *(PTFBREAS)*

1
2
3
4
5

15. Current nutritional intake:
a. Mouth: *(PTFCNIM)*　　[ ] No - 0　　[ ] Yes - 1
b. Tube: *(PTFCNIT)*　　　[ ] No - 0　　[ ] Yes - 1
c. Parenteral (IV): *(PTFCNIP)*　[ ] No - 0　　[ ] Yes - 1

16. School status: *(PTFEDUST)*

Attends school full time - 1
Attends school part time - 2
Home schooling only, not medically indicated - 3
Home schooling only, medically indicated - 4
No ongoing education, medically capable - 5
*Additional Options Listed Below

a. Grade equivalent: *(PTFGREQV)*

Above grade level - 1
At grade level - 2
Below grade level - 3

b. Special education: *(PTFSPED)*

None - 1
Gifted-talented - 2
Remedial reading (tutoring, reading support, speech therapy) - 3
Special educational support or in special educational classroom - 4

Concomitant Medications

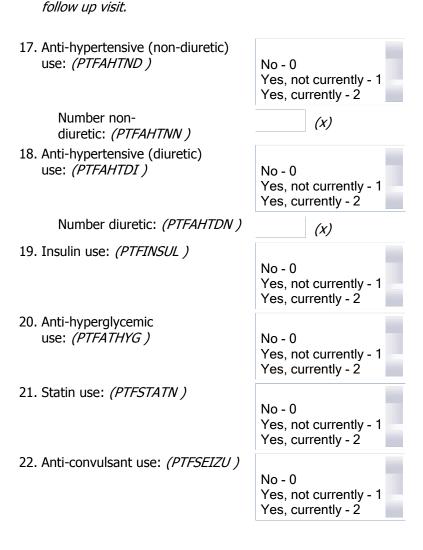*Record medications taken since the time of transplant listing.*
"Yes, currently" indicates that the medication was taken at the time of this follow up visit.
"Yes, not currently" indicates the medication was taken since the time of transplant listing but not at the

time of this follow up visit.

Record medications taken since the last study visit shown above up to the date of this follow up visit.
"Yes, currently" indicates that the medication was taken at the time of this follow up visit.
"Yes, not currently" indicates the medication was taken since the last study visit but not at the time of this follow up visit.

17. Anti-hypertensive (non-diuretic)
    use: *(PTFAHTND)*

    No - 0
    Yes, not currently - 1
    Yes, currently - 2

    Number non-
    diuretic: *(PTFAHTNN)*   *(x)*

18. Anti-hypertensive (diuretic)
    use: *(PTFAHTDI)*

    No - 0
    Yes, not currently - 1
    Yes, currently - 2

    Number diuretic: *(PTFAHTDN)*   *(x)*

19. Insulin use: *(PTFINSUL)*

    No - 0
    Yes, not currently - 1
    Yes, currently - 2

20. Anti-hyperglycemic
    use: *(PTFATHYG)*

    No - 0
    Yes, not currently - 1
    Yes, currently - 2

21. Statin use: *(PTFSTATN)*

    No - 0
    Yes, not currently - 1
    Yes, currently - 2

22. Anti-convulsant use: *(PTFSEIZU)*

    No - 0
    Yes, not currently - 1
    Yes, currently - 2

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: *(PTFCOMME)*

Additional Selection Options for PTF

If *Yes*, indicate status:
Not listed, adequate liver function - 6
Not listed, social reasons - 7
Not listed, insurance coverage - 8
Not listed, live donor - 9

If Yes, indicate type:
Other - 9

School status:
No ongoing education, medically incapable - 6
Not of school age - 7
Attending college/ completed HS/GED - 8