

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

Long-term Post Transplant Follow Up (LTF)

Version: 9.0; 12-20-07

Segment (PROTSEG):

Visit Number (VISNO):

Date of last assessment:

Status and Listing Information

1. Date of assessment: (STATDATE) (mm/dd/yyyy)
Date must be entered and be within the visit window to determine expectation for age-dependent fields below. If information obtained on multiple days, enter the date the majority of assessments, procedures, etc. were performed.
2. Did the participant get listed for an organ transplant other than liver or kidney? (LFLISTO) 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.

Assessments

Date of examination must be entered in order to display height, weight, and head circumference and determine if they are within the visit window (90 days prior to 90 days post exam date).

3. Height: (LTFHTND) Not Done
 (LTFHTDT) Date (mm/dd/yyyy)
 (LTFHT) Value (xxx.x) cm (LTFHTIN) (xx.x) in
4. Weight: (LTFWTND) Not Done
 (LTFWTD) Date (mm/dd/yyyy)
 (LTFWT) Value (xxx.x) kg (LTFWTLBS) (xxx.x) lbs
5. Head circumference (if < 5 years): (LTFHCND) Not Done
 (LTFHCDT) Date (mm/dd/yyyy)
 (LTFHC) Value (xx.x) cm
6. Tanner stage (if ≥8 years):
 Method of assessment: (LTFANME) Self report - 1 Evaluation - 2 Not done - 9
 Pubic: (LTFANPU) 1 2 3 4 5
 Breast: (LTFANBR)

1
2
3
4
5

7. Current nutritional intake:

- a. Mouth: (LTFCNIM) No - 0 Yes - 1
- b. Tube: (LTFCNIT) No - 0 Yes - 1
- c. Parenteral (IV): (LTFCNIP) No - 0 Yes - 1

8. School status: (LTFEDUST)

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: (LTFGREQV)

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

b. Special education: (LTFSPED)

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

9. Blood Pressure (LTFBPND)

Not Done

10. Blood Pressure (LTFBPND)

Not Done

Blood pressure - screening measure (if ≥5 years): (LTFBPSYS)

Systolic (xxx)

Blood pressure - screening measure (if ≥5 years): (LTFBPSYS)

(xxx) (LTFBPDIA) Diastolic (xxx) mmHg
(LTFBPDIA) Diastolic (xxx) mmHg

If Systolic or Diastolic above 90th percentile for child's gender, age, and height, as outlined in the reference table in the Forms Instructions, a repeated measure is expected.

If Systolic or Diastolic above 90th percentile for child's gender, age, and height, as outlined in the reference table in the Forms Instructions, a repeated measure is expected.

Was a second measure taken by auscultation? (LTFBPRP2) No - 0 Yes - 1

Was a second measure taken by auscultation? (LTFBPRP2) No - 0 Yes - 1

Blood pressure - second measure: (LTFBP2SY)

Systolic (xxx)

Blood pressure - second measure: (LTFBP2SY)

Systolic (xxx) (LTFBP2DI) Diastolic (xxx) mmHg
(LTFBP2DI) Diastolic (xxx) mmHg

If Systolic or Diastolic above 90th percentile on second measure, a third measure is expected.

If Systolic or Diastolic above 90th percentile on second measure, a third measure is expected.

Was a third measure taken by auscultation? (LTFBPRP3) No - 0 Yes - 1

Was a third measure taken by auscultation? (LTFBPRP3) No - 0 Yes - 1

Blood pressure - third measure: (LTFBP3SY)

Systolic (xxx)

Blood pressure - third measure: (LTFBP3SY)

Systolic (xxx) (LTFBP3DI) Diastolic (xxx) mmHg
(LTFBP3DI) Diastolic (xxx) mmHg

Labs

11. Chemistries and Hematology:

Please enter the date the majority of the labs were run. 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 (LTFDTLOW) _____ (mm/dd/yyyy) To (LTFDTHIG) _____ (mm/dd/yyyy)

Date of assessment must be entered in order to determine if the following are reported within the visit window.

Date the majority of the labs were drawn: (LTFHEMDT) _____ (mm/dd/yyyy)

	Common Units (CU)	Standard International (SI)	Duration Fasting (≥ 5 years old)
Total Bilirubin:	(LTFTOBIL) _____ (xxx.x) mg/dL	(LFTBISI) _____ (xxxxx.x) μmol/L	
Direct Bilirubin:	(LTFDIBIL) _____ (xxx.xx) mg/dL	(LTFDBSI) _____ (xxxxx.xx) μmol/L	
AST/SGOT:	(LTFAST) _____ (xxxxx) U/L	(LTFASTSI) _____ (xxxxx) U/L	
ALT/SGPT:	(LTFALT) _____ (xxxxx) U/L	(LTFALTSI) _____ (xxxxx) U/L	
Albumin:	(LTFALB) _____ (xx.x) g/dL	(LTFALBSI) _____ (xxx.xx) g/L	
Alkaline Phosphatase:	(LTFAP) _____ (xxxxx) U/L	(LTFAPSI) _____ (xxxxx) U/L	
Hemoglobin:	(LTFHGBCU) _____ (xx.x) g/dL	(LTFHGBSI) _____ (xxx.x) g/L	
Sodium:	(LTFSDOCU) _____ (xxx) mEq/mL	(LTFSDOSI) _____ mmol/L	(xxx)
Serum Creatinine:	(LTFSRCRE) _____ (xx.x) mg/dL	(LTFSCSI) _____ (xxxx.x) μmol/L	
Magnesium:	(LTFMAGCU) _____ (x.xx) mg/dL	(LTFMAGSI) _____ (x.xx) mmol/L	
Gamma-Glutamyltransferase:	(LTFGG) _____ U/L	(LTFGGSI) _____ U/L	(xxxx)
Total Cholesterol:	(LFTCHOL) _____ (xxxx) mg/dL	(LFTCHOSI) _____ (xx.xxx) mmol/L	None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LFTCFSD)
LDL cholesterol:	(LFLDLUCU) _____ (xxxx) mg/dL	(LFLDLSI) _____ (xx.xxx) mmol/L	None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LFLDFSD)
LDL cholesterol*:	(LFLDLUCU) _____ (xxxx)	(LFLDLSI) _____ (xx.xxx)	

				None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LTFLD _{FSD})
HDL cholesterol:	(LTFH _{DLCU}) (xxxx) mg/dL	(LTFH _{DLSI}) (xx.xxx) mmol/L		None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LTFH _D FSD)
HDL cholesterol*:	(LTFH _{DLCU}) _____ (xxxx)	(LTFH _{DLSI}) _____ (xx.xxx)		None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LTFH _D FSD)
Triglycerides:	(LTF _{TRIGL}) _____ (xxxx) mg/dL	(LTF _{TRISI}) _____ (xxx.xx) mmol/L		None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LTF _T G _{FSD})
Glucose:	(LTF _{GLUC}) _____ (xxxx) mg/dL	(LTF _{GLUSI}) _____ mmol/L	(xx.x)	None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LTF _G L _{FSD})
HgbA1C:	(LTF _{A1CCU}) _____ (xxx.x) %	(LTF _{A1CSI}) _____ (xxx.x) %		None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LTF _{A1} FSD)
HgbA1C*:	(LTF _{A1CCU}) _____ (xxx.x)	(LTF _{A1CSI}) _____ (xxx.x)		None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LTF _{A1} FSD)
Insulin*:	(LTF _{INSCU}) _____ (xxx.x) µIU/mL	(LTF _{INSSI}) _____ (xxx.x) pmol/L		None (< 4 hrs) - 0 4-8 hours - 1 > 8 hours - 2 Unknown - 9 (LTF _I N _{FSD})
INR:	(LTF _{INR}) _____	(xx.x)		

* Optional

Renal Aim

12. Urine protein/creatinine ratio (LTF_{URIND}) Not Done

Urine protein: (LTF_{UPROT})

Value _____ (xxx.x) (LTF_{URPUT}) Units

mg/dL - 1
mg/L - 2
mmol/L - 3

Urine creatinine: (LTF_{UCREA})

Value _____ (xxx.x) (LTF_{URCUT}) Units

mg/dL - 1
mg/L - 2
mmol/L - 3

13. Date of GFR measurement: (LTFGFRDT) (mm/dd/yyyy)

a. Measured Glomerular Filtration Rate: (LTFGFR) (xxx)

Method: (LTFGFRME) Radioactive tracer - 1 Non radioactive iodine contrast - 2

If radioactive, select type: (LTFGFRRT)

Cr-EDTA - 1
I-iothalamate - 2
Tc-DPTA - 3

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

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: (LTFPRENT)

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

If, Other, specify: (LTFPRENO)

Complications

15. Total number of times admitted to the hospital since last visit: (LTFADMIT) (xx)

a. Total days hospitalized since last visit: (LTFDAYSH) (xxx)

b. Total number of days intubated since last visit: (LTFPCDI) (xxx)

16. Any reoperations related to the liver transplant since last visit: (LTFLEOP) No - 0 Yes - 1

17. Complications since the last visit: (LTFCSLR) No - 0 Yes - 1

a. Treated for rejection: (LTFFREJ) No - 0 Yes, no hospital admission - 1 Yes, admission or prolonged hospitalization - 2

If Yes, complete a Rejection form for each episode

Number of rejection episodes since last visit: (LTFREJEP) (xx)

b. Liver biopsy findings of graft dysfunction (including graft failure): (LTFGRFBX) No - 0 Yes - 1

c. Graft failure- relisted: (LTFGFL) No - 0 Yes, no hospital admission - 1 Yes, admission or prolonged hospitalization - 2

If yes, complete the Retransplant Evaluation form at time of relisting

d. Bone marrow transplant: (LTFBMT) No - 0 Yes - 1

If the participant received a BMT, please complete a Loss to Follow-up / Exit form.

e. Biliary tract complications: (LTFBTC)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

1. Leak: (LTFBTCL)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

2. Intrahepatic stricture: (LTFBTCIS)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

3. Anastomotic stricture: (LTFBTCAS)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

f. Vascular complications: (LTFVC)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

1. Hepatic artery thrombosis: (LTFVCHAT)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

Specify method first used to confirm thrombosis: (LTFHAPAM)

Duplex ultrasound - 1
 CT/MRA - 2
 Visceral angiogram - 3

2. Portal vein thrombosis: (LTFVCPVT)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

3. Other: (LTFOVC)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

If Other, please specify: (LTFVCOTH)

g. CNS: (LTFCNS)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

1. New onset seizures: (LTFNOS)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

2. New onset confusion/ agitation: (LTFVOC)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

3. New onset tremors: (LTFNOT)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

4. Cerebral hemorrhages: (LTFCH)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

5. Cerebral edema: (LTFCERED)

h. Renal complications: *(LTFRC)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

1. Dialysis/ hemofiltration: *(LTFRCDDH)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

If Yes, please specify days: *(LTFRCDDH)*

2. Did the patient have a renal transplant? *(LTFRENTX)*

No - 0 Yes - 1
 _____ *(mm/dd/yyyy)*

If yes, specify date: *(LTFRTXDT)*

i. Pulmonary complications: *(LTFPC)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

1. Diaphragmatic paresis: *(LTFDIAPA)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

2. ARDS: *(LTFPCARD)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

j. Cardiac: *(LTFCA)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

1. Cardiac arrest: *(LTFCA)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

2. Heart failure: *(LTFHF)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

3. Cardiomyopathy: *(LTFM)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

k. Hematologic: *(LTFH)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

1. Leukopenia (ANC<1,000): *(LTFHL)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

2. Thrombocytopenia: *(LTFHTHRO)*

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

3. Aplastic anemia: *(LTFHAA)*

4. Anemia: (LTFHANEM)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

l. Diabetes/ glucose intolerance: (LTFDGI)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

m. GI complications: (LTFGIC)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

1. Bleeding: (LTFBLEED)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

2. Pancreatitis: (LTFPANC)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

3. Bowel perforation: (LTFBPER)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

4. Bowel obstruction: (LTFASBO)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

n. Multi-organ failure: (LTFMLORG)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

o. Other: (LTFCOMOT)

No - 0
 Yes, no hospital admission - 1
 Yes, admission or prolonged hospitalization - 2

If Other, please specify: (LTFOTCOM)

18. Infections since last visit:

HIV:

(LTFIHIV)

Not tested or no - 0
 Yes - 1
 Unknown - 2

Hep B:

(LTFIHEPB)

Not tested or no - 0
 Yes - 1
 Unknown - 2

HCV:

(LTFIHCV)

Not tested or no - 0
 Yes - 1
 Unknown - 2

Pneumocystis:

(LTFIPNEU) Not tested or no - 0
 Yes - 1
 Unknown - 2

CMV antigen (positive serology or PCR):

(LTFICMV) Not tested or no - 0
 Yes - 1
 Unknown - 2

Septicemia:

(LTFSEPTI) Not tested or no - 0
 Yes - 1
 Unknown - 2

19. Symptomatic CMV disease since the last visit: (LTFCMV) No - 0 Yes - 1

a. Confirmed by:

- 1. Blood culture or shellvial positive: (LTFCBCSP) No - 0 Yes - 1
- 2. Histology: (LTFCHIST) No - 0 Yes - 1
- 3. Serology (fever and 4 fold increase in positive IgG or positive IgM): (LTFCSERO) No - 0 Yes - 1

b. Tissue invasion:

- 1. Lung: (LTFCLUNG) No - 0 Yes - 1
- 2. GI tract: (LTFCGIT) No - 0 Yes - 1
- 3. Liver: (LTFCLIVE) No - 0 Yes - 1
- 4. Eye: (LTFCEYE) No - 0 Yes - 1
- 5. CNS: (LTFCCNS) No - 0 Yes - 1
- 6. Other: (LTFCTIO) No - 0 Yes - 1

If Other, please specify: (LTFTISS)

20. Was the participant tested for EBV since the last visit? (LTFEBVTS) No - 0 Yes - 1 Unknown - 9

a. Circulating EBV DNA by PCR: (LTFIEBV)

Negative/Undetectable-0 Positive-1 Not evaluated-2

If Positive, please enter the viral load, units, and source.

Viral load: (LTFVLGT)

< (LTFEBVWL) (xxxxx)
 >

Units: (LTFEBVUT)

copies / 500 ng DNA - 1
 genomes / 10⁵ lymphocytes - 2
 copies DNA / ul - 3
 cells / 10⁶ PBMC - 4
 copies / mcg PBMC DNA - 5
 *Additional Options Listed Below

If Other, specify: (LTFEBVUO)

Source: (LTFEBVSR)

Whole blood - 1
 Plasma - 2
 Serum - 3

21. Did the participant receive preemptive treatment for EBV since the last visit? (LTFEBVPR) No - 0 Yes - 1

22. Symptomatic EBV disease or LPD disease (either EBV related or not): (LTFEBVLP) No - 0 Yes - 1

(If Yes, enroll patient into EBV/LPD protocol)

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: (LTFCOMM)



Additional Selection Options for LTF

School status:

No ongoing education, medically incapable - 6

Not of school age - 7

Attending college/ completed HS/GED - 8

If, Yes, indicate type:

Other - 9

Units:

copies / ml - 6

Other - 9

