



Follow-up Form

Patient ID ____ - ____ - ____

Date of follow-up (mm/dd/yy): ____ / ____ / ____

Follow-up time-point: 8 Week 6 Month 12 Month

SECTION I: DURING THE FOLLOW-UP INTERVAL...

1. Did the patient have a change in diagnosis? No Yes (*Complete Diagnosis Log*)
2. Was the patient listed or have a change in list status? No Yes (*Complete UNOS/TGLN Log*)
3. Did the patient have or undergo any of the following:

Liver transplantation	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Renal dialysis	<input type="checkbox"/> No	<input type="checkbox"/> Yes
CVVH (patients with native liver only)	<input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> N/A, patient transplanted
Cardiac arrest	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Diagnosed with aplastic anemia	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Post Transplant Lymphoproliferative Disease	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Cancer	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Diagnosed with new onset diabetes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Hospitalized for a reason other than those listed above	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Intubated	<input type="checkbox"/> No	<input type="checkbox"/> Yes

Prior to a transplant? No Yes, number of days _____
 Following a transplant? No Yes, number of days _____
 Died No Yes

3.1 How many combined days has the patient spent in the hospital for any of the above? _____ days
4. Medications: *Review Medication Log and update existing entries as appropriate*
 - 4.1. Is the patient taking any of the following medications?

Seizure medication	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Tacrolimus	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Cyclosporin	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Steroids	<input type="checkbox"/> No	<input type="checkbox"/> Yes
Insulin	<input type="checkbox"/> No	<input type="checkbox"/> Yes
 - 4.2. For patients who have not undergone liver (or bone marrow) transplantation, is the patient currently taking any other medications? N/A, patient transplanted No Yes (*Complete Medication Log*)

SECTION II: ADDITIONAL FOLLOW-UP PROCEDURES

1. Does the patient exhibit any physical evidence of chronic liver disease? No Yes
2. Data and samples collected for **all patients**:

	Follow-up		
	8 week	6 month	12 month
Physical Assessment	PI	PI	PI
BIOCHEM forms	CC	CC	CC
Research Labs/Storage	✓	✓	✓
Neurocognitive Enrollment Criteria		CC	CC
Patient Information Form		PT	PT
PedsQL		PT	PT

CC = clinical coordinator, PI = PI or attending physician,
PT = patient or parent/guardian

NOTES:

- If a patient does not return to the site for the follow-up visit, complete the Off Protocol form to indicate the reason
- If the patient had any liver disease specific diagnostic tests performed during the follow-up interval, complete the appropriate logs to record the results
- Complete the Neurocognitive Enrollment Criteria form for all potentially eligible patients, who were at least 2 year of age at enrollment into PALF

3. Data collected for **Patients enrolled in the Neurocognitive Component**:

6 months, by Coordinator: BRIEF forms

12 months, by Psychologist: BRIEF forms, WPPSI-IV, WISC-IV, VMI-6, K-CPT, CPT-II, ABAS-2, CDI-2, PTSRI, and Validity Rating form