

<b>SPLIT</b>			
\$sitecode	User:	System Date:	Mode: Development
Site Name:			

## Lost to Follow Up/ Exit (LFE)

Version: 6.0; 11-30-07

1. Date patient is considered lost to follow up or exited from the registry: *(LOSTDATE)* \_\_\_\_\_ *(mm/dd/yyyy)*

2. Reason for loss or exit: *(LFELOSEX)*

Participant moved to a non-participating center - 1  
 Participant transferred to adult program (post-transplant) - 2  
 Participant reached 18th birthday without a transplant - 3  
 Participant recovered without a transplant - 4  
 Participant removed from list due to other complications - 5  
 \*Additional Options Listed Below

If *Other*, please specify: *(LFESEASL)*

If *Other complications*, please specify: *(LTFREASX)*

*If exited, indicate PELD or MELD score, as applicable.*

Indicate type: *(LFESTYPE)*

☐

PELD - 1

☐

MELD - 2

☐

Not applicable (Status 1) - 9

Last score prior to exit: *(LFESCORE)*

*(xx.x)*

3. Was the patient on artificial or extracorporeal liver support at time of exit or loss? *(LFEARTIF)* ☐ No - 0 ☐ Yes - 1

4. Was the patient on dialysis or hemofiltration at the time of loss to follow-up/exit? *(LFEDIAL)* ☐ No - 0 ☐ Yes - 1

5. Was the patient in the ICU at time of exit or loss? *(LFEINICU)* ☐ No - 0 ☐ Yes - 1

If *Yes*, specify:

a. Intubated: *(LFEINTUB)* ☐ No - 0 ☐ Yes - 1

b. Encephalopathy: *(LFEENCEP)* ☐ No - 0 ☐ Yes - 1

If *Yes*, please specify stage (1-4): *(LFEENSTG)* \_\_\_\_\_ *(x)*

6. School status: *(LFEEDUST)*

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: (LFEGREQV )

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

b. Special education: (LFESPED )

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

*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: (LFECOMNT )

## **Additional Selection Options for LFE**

### **Reason for loss or exit:**

Participant too sick to transplant - 6

Participant listed for non liver or kidney solid organ transplant - 7

Participant received bone marrow transplant (post liver transplant) - 8

Unable to locate participant - 9

Parent refused further follow-up - 10

Participant refused further follow-up - 11

Other - 99

### **School status:**

No ongoing education, medically incapable - 6

Not of school age - 7

Attending college/ completed HS/GED - 8

