Living Donor Follow-up (LDF) Record Field Descriptions

Living Donor 6-Month and Annual Follow-up (LDF) records are generated at 6 months and 1 and 2 years following the transplant event. The Living Donor Follow-up record is to be completed by the transplant center responsible for follow-up of the living donor at intervals of 6 months, 1 and 2 years from the donation date. The record is to contain only the requested patient information which has been obtained since the last follow-up period; it should not contain information pertaining to the previous or next follow-up period. For example, information provided in the 6-month follow-up should be accurate for the period between discharge and 6 months post-donation.

Note: If the procedure was aborted, and the organ was not recovered, an LDF record will not generate.

- *Note:* LDF records are only applicable to transplant dates after UNet[™] was rolled-out on 10/25/1999.
- *Note:* The 2 year LDF requirement was implemented on March 1, 2008. The first 2 year LDF will not be generated until March 2010.

The LDF must be completed within 30 days from the record generation date. See <u>OPTN/UNOS</u> <u>Policies</u> for additional information. Use the search feature to locate specific policy information on Data Submission Requirements.

Provider Information

Recipient Center: The recipient center information, reported in the Living Donor Registration (LDR) record, will display. Verify that the transplant center name, center code, and the provider number, (the 6-character Medicare identification number of the hospital that performed the living donor transplant), are correct. If the information is incorrect, corrections may be made in the donor's Living Donor Feedback record.

Followup Center: The followup center information, reported in the Living Donor Registration record, displays. If the information is incorrect, corrections may be made in the donor's Living Donor Feedback record.

Donor Information

<u>Name</u>: The donor's name, reported in the LDR record, displays. If the information is incorrect, corrections may be made in the donor's Living Donor Feedback record.

DOB: The donor's date of birth, reported in the LDR record, displays. If the information is incorrect, corrections may be made in the donor's Living Donor Feedback record.

Transplant Date: The transplant date, reported on the Living Donor Feedback, displays.

<u>SSN</u>: The donor's Social Security Number, reported in the LDR record, displays. Verify the donor's social security number is correct. If the information is incorrect, contact the UNet[™] Help Desk at 1-800-978-4334.

<u>Gender</u>: The donor's gender, reported in the LDR record, displays. If the information is incorrect, corrections may be made in the donor's Living Donor Feedback record.

Donor ID: The donor ID number, reported in the LDR record, displays. Each living donor is assigned a unique donor identification number when the donor information is entered into the Living Donor Feedback record. This ID number corresponds to the date the donor information was entered into the OPTN/UNOS computer system.

<u>**Recovery Date:**</u> The recovery date, reported in the LDR record, displays. Verify the date the organ recovery surgery occurred is correct.

<u>Organ</u>: The organ(s) recovered from the donor, reported in the Living Donor Feedback, displays. If the information is incorrect, corrections may be made in the donor's Living Donor Feedback record. (<u>List of Organs Recovered codes</u>)

Previous Status Date: The status date, reported on the donor's previously validated record, displays.

Donor Status

Date of Initial Discharge: The date the donor was initially released to go home, reported in the donor's most recently validated LDR record, displays. The donor's hospital stay includes total time spent in different units of the hospital, including medical and rehabilitation.

Date: Last Contact or Death: Enter the date the donor was last contacted or their date of death using the standard 8-digit format of MM/DD/YYYY. If the donor died, and you have not completed an interim follow-up indicating this event, the 6-month or annual follow-ups should be completed indicating the event. (This is a required field.)

<u>Most Recent Donor Status since [last reported status date]</u>: If the donor is living at the time of the follow-up visit, select the appropriate **Living** entry. If the donor died during this follow-up period or you are completing an interim follow-up, select **Dead**. If donor information is unavailable, select the appropriate **Lost** entry. (This is a required field.) (List of Donor Status codes)

Not seen

Living: Donor seen at transplant center Living: Donor status update by verbal or written communication between transplant center and donor Living: Donor status update by other health care facility Living: Donor status update via other source (e.g. recipient) Living: Donor contacted, declined follow-up with transplant center Lost: No attempt to contact Lost: Unable to contact donor Dead

Cause of Death: If the **Most Recent Donor Status** is **Dead**, select the cause of death from the drop-down list. (This is a required field.) If the cause of death is not listed, select **Other, specify** and enter the cause of death in the **Specify** field. If **Other, Specify** is selected, this field is required. (<u>List of Cause of Death codes</u>)

Infection: Donation/Surgery Related Infection: Not Donation/Surgery Related Pulmonary Embolism Malignancy Domino Liver Donor-Transplant Related Death (Liver donors only) Cardiovascular CVA Hemorrhage: Donation/Surgery Related Hemorrhage: Not Donation/Surgery Related Homicide Suicide Accidental Other, specify

Functional Status: Select the choice that best describes the donor's functional status during the donor's 6-month/annual follow-up period from the drop-down list. If reporting the donor's death, select the choice that best describes the donor's functional status just prior to death. (This is a required field.) (List of Functional Status codes)

Note: The Karnofsky Index will display for adult donors aged 18 and older.

10% - Moribund, fatal processes progressing rapidly

20% - Very sick, hospitalization necessary: active treatment necessary

30% - Severely disabled: hospitalization is indicated, death not imminent

40% - Disabled: requires special care and assistance

50% - Requires considerable assistance and frequent medical care

60% - Requires occasional assistance but is able to care for needs

70% - Cares for self: unable to carry on normal activity or active work

80% - Normal activity with effort: some symptoms of disease

90% - Able to carry on normal activity: minor symptoms of disease

100% - Normal, no complaints, no evidence of disease

Unknown

Note: The Lansky Scale will display for pediatric donors aged 1 to 17.

10% - No play; does not get out of bed
20% - Often sleeping; play entirely limited to very passive activities
30% - In bed; needs assistance even for quiet play
40% - Mostly in bed; participates in quiet activities
50% - Can dress but lies around much of day; no active play; can take part in quiet play/activities
60% - Up and around, but minimal active play; keeps busy with quieter activities
70% - Both greater restriction of and less time spent in play activity
80% - Active, but tires more quickly
90% - Minor restrictions in physically strenuous activity
100% - Fully active, normal
Not Applicable (patient < 1 year old)
Unknown

<u>Physical Capacity</u>: Select the choice that best describes the donor's physical capacity during the donor's follow-up period. If reporting the donor's death, select the choice that best describes the donor's physical capacity just prior to death. (This is a required field.) (<u>List of Physical Capacity codes</u>)

No Limitations Limited Mobility Wheelchair bound or more limited Unknown

<u>Working for income</u>: (Complete for donors 19 years of age or older.) If the donor was working for income during the donor's 6-month/annual follow-up period, select **Yes**. If not, select **No**. If unknown, select **UNK**. If reporting the donor's death, indicate if the donor was working for income just prior to death.

If Yes: Select the donor's working status from the drop-down list. If Yes is selected for Working for income, this field is required. (List of Working codes)

Working Full Time Working Part Time due to Disability Working Part Time due to Insurance Conflict Working Part Time due to Inability to Find Full Time Work Working Part Time due to Donor Choice Working Part Time Reason Unknown Working, Part Time vs. Full Time Unknown

If No, Not Working Due To: If No is selected, select the reason why the donor is not working from the drop-down list. If No is selected for Working for income, this field is required. (List of Not Work Reason codes)

Disability - A physical or mental impairment that interferes with or prevents a donor from working (e.g. arthritis, mental retardation, cerebral palsy, etc.). **Insurance Conflict** - Any differences between a donor and insurance company that prevent

them from working.

Inability to Find Work - The lack of one's ability to find work (e.g. lack of transportation, work experience, over qualification, unavailable work, etc.).

Donor Choice - Homemaker - A donor who chooses to manage their own household instead of performing work for pay.

Donor Choice - Student Full Time/Part Time - A donor who is enrolled in and/or participating in college.

Donor Choice- Retired - A donor who no longer has an active working life such as an occupation, business or office job.

Donor Choice - Other - Any reason not listed above that would prevent a donor from working. **Unknown**

Clinical Information

<u>Current Weight</u>: Enter the donor's current weight in **Ib** (pounds) or **kg** (kilograms). (This is a required field.) If the donor's weight is not available, select the status from the **ST** field (**Missing, Unknown, N/A, Not Done**). (<u>List of Status codes</u>)

Were any of the following procedures performed since [last reported status date]: (List of Procedure Status codes)

CAT Scan: If a scan was performed, select Yes, Normal Results or Yes, Specify Results. If a scan was not performed, select Not Done. If unknown, select Unknown. (This is a required field.) If Yes, Specify Results is selected, enter the results in the Specify field.

MRI: If an MRI was performed, select Yes, Normal Results or Yes, Specify Results. If an MRI was not performed, select Not Done. If unknown, select Unknown.(This is a required field.) If Yes, Specify Results is selected, enter the results in the Specify field.

Ultrasound: If an Ultrasound was performed, select Yes, Normal Results or Yes, Specify Results. If an Ultrasound was not performed, select Not Done. If unknown, select Unknown. (This is a required field.) If Yes, Specify Results is selected, enter the results in the Specify field.

Liver Clinical Information

The following questions display if a liver was recovered from the donor.

<u>Most Recent Values Since [last reported status date]</u>: If not reporting the donor's death, then enter the most recent values during the follow-up period for the tests listed below.

Total Bilirubin: Enter the lab value for total serum bilirubin in mg/dl. (This is a required field.) If the value is unavailable, select the status from the **ST** field (**Missing, Unknown, N/A, Not Done).** (List of Status codes)

SGOT/AST: Enter the lab value for the serum glutamic oxaloacetic transaminase or aspartate transaminase in U/L. (This is a required field.) If the value is unavailable, select the status from the ST field (Missing, Unknown, N/A, Not Done). (List of Status codes)

SGPT/ALT: Enter the lab value for the Serum Glutamic Pyruvic Transaminase/Alanine Aminotransferase in U/L. (This is a required field.) If the value is unavailable, select the status from the ST field **(Missing, Unknown, N/A, Not Done).** (List of Status codes)

Alkaline Phosphatase: Enter the lab value for the serum alkaline phosphatase value in units/L. (This is a required field.) If the value is unavailable, select the status from the ST field (Missing, Unknown, N/A, Not Done). (List of Status codes)

Serum Albumin: Enter the lab value for the serum albumin value in g/dl. (This is a required field.) If the value is unavailable, select the status from the ST field (Missing, Unknown, N/A, Not Done). (List of Status codes)

Serum Creatinine: Enter the lab value for the serum creatinine value in mg/dl. This is a required field.) If the value is unavailable, select the status from the ST field (Missing, Unknown, N/A, Not Done). (List of Status codes)

INR: International Normalized Ratio. Enter the ratio of the prothrombin time (in seconds) to the control prothrombin time (in seconds. (This is a required field.) If the value is unavailable, select the status from the ST field (Missing, Unknown, N/A, Not Done). (List of Status codes)

Kidney Clinical Information

The following question displays if a kidney was recovered from the donor.

<u>Most Recent Values Since last reported status date</u>: If not reporting the donor's death, then enter the most recent values during the follow-up period for the tests listed below.

Serum Creatinine: Enter the lab value for the kidney donor's serum creatinine value in mg/dl taken during the follow-up period. (This is a required field.) If the value is not available, select the appropriate ST field **(Missing, Unknown, N/A, Not Done).** (List of Status codes)

<u>Blood Pressure Systolic</u>: Enter the donor's systolic blood pressure during the follow-up period in the space provided. (This is a required field.) If the value is not available, select the status from the ST field (Missing, Unknown, N/A, Not Done). (List of Status codes)

<u>Blood Pressure Diastolic</u>: Enter the donor's diastolic blood pressure during the follow-up period in the space provided. (This is a required field.) If the value is not available, select the status from the ST field (Missing, Unknown, N/A, Not Done). (List of Status codes)

Donor Developed Hypertension Requiring Medication: If the donor developed hypertension during the follow-up period that required medication, select Yes. If not, select No. If unknown, select UNK. (This is a required field.)

Urinalysis:

Either select the result from the drop-down list for

Urine Protein: (List of Urinalysis Result codes)

Positive Negative Not Done Unknown

or enter the donor's ratio in the **Protein - Creatinine Ratio** field. At least one value is required in one or the other of these fields.

<u>Maintenance Dialysis:</u> If the donor was on maintenance dialysis (22 sessions in a 3-month period) during the follow-up period, select **Yes.** If the donor was not on maintenance dialysis, select **No.** If unknown, select **UNK.** (This is a required field.)

If **Yes, Date First Dialyzed:** If **Yes** was selected for **Maintenance Dialysis**, enter the date the donor first began dialysis using the standard 8-digit format of MM/DD/YYYY.

<u>Diabetes</u>: If the donor developed diabetes during the follow-up period, select **Yes**. If not, select **No**. If unknown, select **UNK**. (This is a required field.)

If **Yes** is selected, select the **Treatment** administered by clicking in the checkbox next to the treatment type. (List of Diabetes Treatment codes)

Insulin Oral Hypoglycemic Agent Diet

Lung Clinical Information

The following question displays if a lung was recovered from the donor.

<u>Activity Level</u>: If not reporting the donor's death, then select the donor's activity level during the followup period from the drop-down list. (This is a required field.) (<u>List of Activity Level codes</u>)

No change in activity level Mild decrease in activity level Moderate decrease in activity level Severe decrease in activity level Increase in activity level Unknown

<u>Chronic Incisional Pain</u>: If not reporting the donor's death, then select the level of chronic pain, from the drop-down list, the donor experienced at the incision site during the follow-up period. If unknown, select **Unknown**. (This is a required field.) (List of Incisional Pain codes)

Mild Moderate Severe Unknown

Complications

The following question displays for all organ types.

<u>Has the donor been readmitted since [last reported status date]</u>: If the donor has been readmitted to the hospital since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**. (This is a required field.)

If **Yes** is selected, you must enter the **Date of the First Readmission** using the standard 8-digit format of MM/DD/YYYY. If the date is not available, select the reason from the status (**ST**) dropdown list (**Missing, Unknown, N/A, Not Done**). (<u>List of Status codes</u>)

Specify Reason for First Readmission: Enter the reason for the first readmission.

The following question displays if a kidney was recovered from the donor.

<u>Kidney Complications since last reported status date</u>: If the donor experienced complications since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**. (This is a required field.)

If **Yes** is selected, indicate the type of complications. If **Other, specify** is selected, enter the type of complication in the **Specify** field. (List of Kidney Complication codes)

Added to UNOS TX candidate waiting list Other, specify

The following question displays if a <u>liver</u> was recovered from the donor.

Liver Complications since last reported status date: If the donor experienced complications since the last report, select Yes. If not, select No. If unknown, select UNK. (This is a required field.)

If **Yes** is selected, you must specify the type of complications by clicking in the checkbox next to the complication. If **Other, specify** is selected, enter the complication in the **Specify** field. (<u>List of Liver</u> <u>Complication codes</u>)

Bile Leak Hepatic Resection Abscess Liver Failure Added to UNOS TX candidate waiting list Other, Specify

The following question displays for all organs except kidney and liver.

<u>Complications since [last reported status date]</u>: If the donor experienced complications since the last report, select **Yes**. If not, select **No**. (This is a required field.)

If Yes is selected, you must enter the type of complications in the Specify field.

Recipient Information

The following information displays when the donor relationship is not a paired exchange or anonymous donation.

Name: The recipient's name, reported on the Living Donor Feedback, displays.

<u>Transplant Date</u>: The transplant date, as reported in **Candidate Removal Information**, displays for any recipient initially listed in WaitlistSM. Otherwise, the transplant date, reported on the **Living Donor Feedback**, displays.

SSN: The recipient's social security number, reported on the Living Donor Feedback, displays.