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 living donor recovery hospital at 6 months, 1 year, and 2 years after the donation date. The information reported should be data collected within 60 days before or after the relevant anniversary of donation. For example, information provided on the 6-month follow-up should be information that was collected from the donor between 4 months and 8 months after donation (up to 60 days before or after the anniversary, to be exact). Events that occur later than submission of the 6-month LDF should be reported on the next LDF.

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 implemented on 10/25/1999.

The LDF must be submitted to UNOS within 60 days of the record generation date. See OPTN Policy 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.

Followup Center: The followup center information, reported in the Living Donor Registration record, displays. **Donor Information**

Name: 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.

Gender: 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.

<u>Donor ID</u>: 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.

Recovery Date: 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. (**List of Organs Recovered codes – See Appendix N**)

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

Donor Status

<u>Date of Initial Discharge</u>: 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.

<u>Date: Last Contact or Death</u>: 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.

Most Recent Donor Status since [last reported status date]: 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, you may report the donor is lost to follow-up on the 6-MO or 1-YR follow up. If the 2-YR LDF has generated, a work order must be submitted to UNOS in order to report the lost to follow up. This is a required field.

Not seen (UNOS use only)

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

Dead

Lost: No attempt to contact donor Lost: Unable to contact donor

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.

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.

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 guieter 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

Physical Capacity: 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.

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.

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.

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**

<u>Loss of insurance due to donation</u>: Indicate whether donor lost health or life insurance due to donation. If not, select **No**. If **Yes**, check all that apply. **Loss of Heath Insurance** or **Loss or Life Insurance**.

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**).

Date: Enter the date the donor was weighed using the standard 8-digit format of MM/DD/YYYY.

ER or urgent care visit related to donation since last follow-up: If the donor required a visit to the ER or urgent care since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**

Liver Clinical Information

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

<u>Most Recent Values</u> <u>Since [last reported status date]</u>: 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**).

Date: Enter the date lab was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

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).

Date: Enter the date lab was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

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).

<u>Date</u>: Enter the date lab was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

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).

<u>Date</u>: Enter the date lab was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

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).

<u>Date</u>: Enter the date lab was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

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).**

<u>Date</u>: Enter the date lab was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

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).**

<u>Date</u>: Enter the date lab was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

<u>Platelet count</u>: Enter the donor's platelet count (10³/mL) during the follow-up period in the space provided.

Note: These tests are not required if you are reporting a living donor's death.

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>: Enter the most recent values during the followup 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).**

<u>Date</u>: Enter the date lab was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

<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).

<u>Date</u>: Enter the date measurement was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

<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).

<u>Date</u>: Enter the date measurement was obtained using the standard 8-digit numeric format of MM/DD/YYYY.

<u>Donor Developed Hypertension Requiring Medication</u>: 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:

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.

Insulin Oral Hypoglycemic Agent Diet

Note: These tests are not required if you are reporting a living donor's death.

Lung Clinical Information

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

Activity Level: Select the donor's activity level during the follow-up period from the drop-down list. This is a required field.

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.

Mild Moderate Severe Unknown

Note: This information is not required if you are reporting a living donor's death.

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**) drop-down list **(Missing, Unknown, N/A, Not Done)**.

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.

Added to UNOS TX candidate waiting list Other, specify

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

<u>Liver 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, 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.

Bile Leak
Hepatic Resection
Abscess
Liver Failure
Added to UNOS TX candidate waiting list
Incisional hernia due to donation surgery
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 <u>Candidate Removal Information</u>, displays for any recipient initially listed in WaitlistSM. Otherwise, the transplant date, reported on the <u>Living Donor Feedback</u>, displays.

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