Living Donor Follow-up (LDF) 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 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. Data received outside of the collection period, should be entered on the LDF closest to the date that donor was last seen.

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

The LDF must be completed within 60 days of the record generation date. See <u>OPTN 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 follow up 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

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: Verify that the displayed transplant date is correct. The transplant date is determined by the start of the organ anastomosis during transplant or the start of the islet infusion. Organ transplants include solid organ transplants and islet infusions. An organ transplant procedure is complete when *any* of the following occurs:

The chest or abdominal cavity is closed and the final skin stitch or staple is applied

The transplant recipient leaves the operating room, even if the chest or abdominal cavity cannot be closed

The islet infusion is complete

SSN: 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.

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.

Organ: 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)

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 of 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 field is **required**.

Most Recent Donor Status since [last reported status date]: If the donor is living at the time of the follow-up visit, select the **Living**. If the donor died during this follow-up period, select **Dead**. If the donor was not seen during this follow-up period, select **Not Seen**. An annual follow-up form will be generated for this patient next year, if applicable. If donor information is unavailable, you may report the donor as 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 field is **required**.

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 (example; recipient) Living: Donor contacted, declined follow-up with transplant center Dead Lost: No attempt to contact donor Lost: Unable to contact donor

Note: For more information on reporting lost to follow-up patients, see: Reporting Lost to Follow-up

Cause of Death: If the **Most Recent Donor Status** is **Dead**, select the cause of death from the drop-down list. This field is **required**. 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.

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

Physical Capacity: Select the choice that best describes the donor's physical capacity during the donor's followup period. If reporting the donor's death, select the choice that best describes the donor's physical capacity just prior to death. This field is **required**.

No Limitations Limited Mobility Wheelchair bound or more limited Unknown

Working for income: 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. This field is **required**.

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**

Loss of insurance due to donation: 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**. If unknown, select **UNK**. This field is **required**.

Clinical Information

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

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**. This field is **required**.

Liver Clinical Information

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

Most Recent Values Since:

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. If the value is unavailable, select the status from the **ST** field (**Missing, Unknown, N/A, Not Done**). This field is **required**.

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

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

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. If the value is unavailable, select the status from the ST field **(Missing, Unknown, N/A, Not Done).** This field is **required**.

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

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

Date: 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. If the value is unavailable, select the status from the ST field (**Missing, Unknown, N/A, Not Done**). This field is **required**.

Date: 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. If the value is unavailable, select the status from the ST field (**Missing, Unknown, N/A, Not Done**). This field is **required**.

Date: 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). If the value is unavailable, select the status from the ST field **(Missing, Unknown, N/A, Not Done)**. This field is **required**.

Date: 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 (10^3 /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.

Most Recent Values Since:

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. If the value is not available, select the appropriate ST field **(Missing, Unknown, N/A, Not Done).** This field is **required**.

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

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

Date: 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. If the value is not available, select the status from the ST field **(Missing, Unknown, N/A, Not Done).** This field is **required**.

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

Donor Developed Hypertension Requiring Medication: If the donor developed hypertension during the followup period that required medication, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

Urinalysis: Enter the donor's Urine Protein. This field is required.

Positive Negative Not Done Unknown

OR enter the donor's ratio (GM/GM) in the **Protein - Creatinine Ratio*** field. If the lab result does not include a specific value, and instead reports a value that is less than the lowest detectable limit, enter 0. Results for an Albumin-Creatinine Ratio or Microalbumin-Creatinine Ratio may be entered in the Protein-Creatinine Ratio field.

*If the lab result is not measured in GM/GM, use the appropriate conversion method: 1000 mg = 1gm (example: 114mg/gm = 0.114 gm/gm) for accurate data entry.

Maintenance Dialysis: 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 field is **required**.

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.

Diabetes: If the donor developed diabetes during the follow-up period, select **Yes**. If not, select **No**. If unknown, select **UNK**. A patient should *not* be considered as having diabetes based on gestational diabetes only. This field is **required**.

If **Yes** is selected, select the **Treatment** administered by clicking in the checkbox next to the treatment type.

Insulin Oral Hypoglycemic Agent Diet

Note: This information is 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:

If not reporting the donor's death, then select the donor's activity level during the follow-up period from the dropdown list. This field is **required**.

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 dropdown list, the donor experienced at the incision site during the follow-up period. If unknown, select **Unknown**. This field is **required**.

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.

Has the donor been readmitted since:

If the donor has been readmitted to the hospital, due to complications related to donation, since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

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</u>: If the donor experienced complications since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**. This field is **required**.

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 *liver* 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 field is **required**.

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</u>: If the donor experienced complications since the last report, select **Yes**. If not, select **No**. This field is **required**.

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.

<u>Name</u>: 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 Waitlist[™]. 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.