Living Donor Follow Up

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 90 days of the record generation date.

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.

Follow-up 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^{SM} Help Desk at 1-800-978-4334.

Birth Sex: The donor's Birth Sex, 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.

Recovery Date: 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.

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

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 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 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

Current Weight: 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.

SGOT/AST: 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.

Alkaline Phosphatase: 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.

Platelet count: 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.

Blood Pressure Diastolic: 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 follow-up 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 drop-down 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

Chronic Incisional Pain: 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 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.

Kidney Complications since: 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.

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.

Complications since: 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.

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

Complications Since Uterus Donation: If the donor experienced complications since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**. If Yes, indicate the complications experienced by the donor. If the donor experienced complications that are not listed, select **Other** and enter the complication(s).

Wound Infection
Ureterovaginal Fistula
Nocturia
Meralgia Paresthetica
Bladder Hypotonia
Dyspareunia
Sexual Dysfunction
Pain
- **If Yes: chronic or intermittent/transient**
- **Location:**
- **Abdominal**
- **Pelvic**
- **Vaginal**
- **Other**

Urinary Tract Infection
Other – specify:

Menopausal Symptoms: If the donor has developed menopausal symptoms since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**. If Yes, indicate the symptoms experienced by the donor. If the donor developed other menopausal symptoms that are not listed, select **Other** and specify.

Hot flashes
Mood swings
Other – specify:

The following question displays if at least one other VCA organ was recovered from the donor.

Complications Since Other VCA Donation: If the donor experienced complications since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**. If Yes, indicate the complications experienced by the donor. If the donor experienced complications that are not listed, select **Other** and enter the complication(s).

Pain
If yes: chronic or intermittent/transient
Location – specify:
Loss of function related to donation – specify:
Other – specify:

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

New Onset Psychological Symptoms: If the donor developed new psychological symptoms following uterus donation, select **Yes**. If the donor did not develop new psychological symptoms, select **No**. If unknown, select **UNK**. If Yes, indicate the symptoms experienced by the donor. If the donor developed new psychological symptoms that are not listed, select **Other** and specify.

Anxiety
Depression
Change of mood
Change in body image
Change of eating habits
Suicidal ideation
Other – specify:

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.

Transplant Date: 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.

not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this information collection is 0915-0157 and it is valid until XX/XX/202X. This information collection is required to obtain or retain a benefit per 42 CFR §121.11(b)(2). All data collected will be subject to Privacy Act protection (Privacy Act System of Records #09-15-0055). Data collected by the private non-profit OPTN also are well protected by a number of the Contractor's security features. The Contractor's security system meets or exceeds the requirements as prescribed by OMB Circular A-130, Appendix III, Security of Federal Automated Information Systems, and the Departments Automated Information Systems Security Program Handbook. The public reporting burden for this collection of information is estimated to average 0.27 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Information Collection Clearance Officer, 5600 Fishers Lane, Room 14N39, Rockville, Maryland, 20857 or paperwork@hrsa.gov.