Living Donor 6-Month/Annual Follow-Up

Living Donor 6-Month/Annual Follow-up (LDF) records are generated at 6 months and 1 year 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 six months, and one year. 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: Living Donor Follow-up records are only applicable to transplant dates after UNet's rollout date (10/25/99).

View OPTN/UNOS Policy on Data Submission Requirements for additional information.

To correct information that is already displayed in an electronic record, call 1-800-978-4334.

Provider Information

Recipient Center: The recipient center information, reported in the Living Donor Registration record, will display. Verify the transplant center name and the center code, and the provider number, the 6-character Medicare identification number of the hospital that performed the living donor transplant, is correct.

Followup Center: The follow-up center information, reported in the Living Donor Registration record, will display. Verify the center name, center code and provider number for the center following the living donor is correct.

Donor Information

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

<u>DOB</u>: Verify the displayed date is the donor's date of birth. If the information is incorrect, corrections may be made in the donor's Living Donor Feedback record.

SSN: Verify the donor's social security number is correct. If the information is incorrect, contact the UNetSM Help Desk at 1-800-978-4334.

<u>Gender</u>: The donor's gender, reported in the Living Donor Registration record, will display. 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 Living Donor Registration record, will display. Each living donor is assigned a unique donor identification number at the time OPTN/UNOS is notified a living donor transplant has occurred. 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 Living Donor Registration record, will display. 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, will display. Verify the organ(s) displayed is/are the organ(s) recovered from this donor.

<u>Previous Status Date</u>: The status date, reported on the donor's previously validated record, will display.

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 Living Donor Registration (LDR) record, will display. The donor's hospital stay includes total time spent in different units of the hospital, including medical and rehab.

<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 numeric format of MM/DD/YYYY. The follow-up records (6-month, 1 year) are to be completed within 30 days of the 6-month and year anniversary of the organ recovery date. 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.

<u>Most Recent Donor Status</u>: If the donor is living at the time of the follow-up visit, select the appropriate <u>Living</u> entry. If the donor died during this follow-up period or you are completing an interim follow-up, select **Dead**. Select the appropriate <u>Lost</u> entry in an interim follow-up if the donor has left the country or his/her location is unknown by your institution, and it is unknown if the donor is alive.

Living: Donor seen at transplant center

Living: Donor status update by phone or email correspondence 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

Lost: Unable to contact donor - document attempts to collect

Cause of Death: If the Donor Status is **Died**, select the cause of death. If **Other Specify** is selected, enter the cause of death in the space provided.

Other Cause

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
Donation Related

<u>Functional Status</u>: Select the choice that best describes the donor's functional status during the donor's 6-month/annual follow-up period. 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 adults 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 pediatrics 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 6-month/annual follow-up period. If reporting the donor's death, select the choice that best describes the donor's physical capacity just prior to death.

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: If Yes is selected, indicate the donor's working status.

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, indicate the reason why the donor is not working at the time of listing.

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 prevents 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 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

This section will display for all living donors.

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

Were any of the following procedures performed since [date of the most recently reported patient status]: Indicate whether a CAT Scan, MRI or Ultrasound was performed since the last follow-up record was submitted.

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. If Yes, Specify Results is selected, enter the results in the space provided.

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. If Yes, Specify Results is selected, enter the results in the space provided.

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**. If **Yes, Specify Results** is selected, enter the results in the space provided.

Liver Clinical Information

This section will only display for liver donors.

Most Recent Values: Enter the most recent values during the 6-month/annual follow-up period for the tests listed below.

Total Bilirubin: Enter the lab value for total serum bilirubin in mg/dl. If the value are unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

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

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

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

Serum Albumin: Enter the lab value for the serum albumin value in g/dl. If the value are unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

Serum Creatinine: Enter the lab value for the serum creatinine value in mg/dl. If the value are unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

INR: International Normalized Ratio. Enter the ratio of the prothrombin time (in seconds) to the control prothrombin time (in seconds). If the value are unavailable, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

Kidney Clinical Information

This section will only display kidney donors.

<u>Most Recent Values</u>: Enter the most recent values during the 6-month/annual 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 6-month/annual follow-up period. If the value is not available, select the appropriate **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

<u>Blood Pressure Systolic</u>: Enter the donor's systolic blood pressure during the 6-month/annual follow-up period in the space provided. If the value is not available, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

<u>Blood Pressure Diastolic</u>: Enter the donor's diastolic blood pressure during the 6-month/annual follow-up period in the space provided. If the value is not available, select the status from the **ST** field (**N/A**, **Not Done**, **Missing**, **Unknown**).

<u>Donor Developed Hypertension Requiring Medication</u>: If the donor developed hypertension during the 6-month/annual follow-up period that required medication, select **Yes**. If not, select **No**. If unknown, select **Unk**.

<u>Urinalysis</u>: Enter the donor's **Protein-Creatinine Ratio** or **Urine Protein** within the 6 weeks after the donation. If **Urine Protein** data is available, select **Positive**, **Negative**, **Unknown** or **Not Done**.

<u>Maintenance Dialysis:</u> (22 sessions in a 3-month period) If the donor was on maintenance dialysis during the 6-month/annual follow-up period, select **Yes**. If the donor was not on maintenance dialysis, select **No**. If unknown, select **Unk**.

If Yes, Date First Dialyzed: If the donor was on maintenance dialysis during the 6-month/annual follow-up period, enter the date the donor first began dialysis using the standard 8-digit numeric format of MM/DD/YYYY.

<u>Diabetes</u>: If the donor developed diabetes during the 6-month/annual follow-up period, select **Yes**. If not, select **No**. If unknown, select **Unk**. If **Yes** is selected, indicate whether the Treatment administered was **Insulin**, **Oral Hypoglycemic Agent** or **Diet**.

Lung Clinical Information

This section will only display lung donors.

<u>Activity Level</u>: Select, as appropriate, to indicate the donor's activity level during the 6-month/annual follow-up period.

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>: Indicate whether the donor experienced **Mild**, **Moderate** or **Severe** chronic incisional pain during the 6-month/annual follow-up period. If unknown, select **Unknown**.

Complications

Has the donor been readmitted since last report [date of the most recently reported patient status]: If the donor has been readmitted to the hospital since the last report, select Yes. If not, select No. If Yes, enter the Date of the First Readmission [since last report date] and specify the Reason for first Readmission in the space provided. If unknown, select UNK.

(KIDNEY):

Kidney Complications [date of the most recently reported patient status]: If the donor experienced complications since the last report, select **Yes**. If not, select **No**. If unknown, select **UNK**. If **Yes** is selected, indicate the type of complications. If Other Specify is selected, enter the type of complication in the space provided.

Added to UNOS TX candidate waiting list Other, Specify

(LIVER):

Liver Complications [date of the most recently reported patient status]: If the donor experienced complications since the last report, select Yes. If not, select No. If Yes is selected, indicate the type of complications. If Other, Specify is selected, enter the complication in the space provided.

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

(OTHER ORGANS):

Complications [date of the most recently reported patient status]: If the donor experienced complications since the last report, select **Yes**. If not, select **No**. If **Yes** is selected, enter the type of complications in the space provided.

Recipient Information

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

<u>Name</u>: The recipient's name, reported on the Recipient and Living Donor Feedback, will display. Verify recipient's name is correct.

<u>SSN</u>: The recipient's social security number, reported on the Recipient and Living Donor Feedback, will display. Verify the recipient's social security number is correct.