Pediatric Thoracic - Lung Transplant Recipient Registration Worksheet

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI® application. Currently in the worksheet, a red asterisk is displayed by fields that are required, independent of what other data may be provided. Based on data provided through the online TIEDI® application, additional fields that are dependent on responses provided in these required fields may become required as well. However, since those fields are not required in every case, they are not marked with a red asterisk.

Recipient Information

Name: **DOB:**

SSN: **Birth sex:**

HIC: **Transplant Date and Time:**

State of Permanent Residence: *

Permanent Zip: * -

Provider Information

Recipient Center:

Physician Name: *

Physician NPI#: *

Surgeon Name: *

Surgeon NPI#: *

Donor Information

UNOS Donor ID #:

Recovering OPO:

Donor Type:

Patient Status

Primary Diagnosis: *

Specify:

Date: Last Seen, Retransplanted or Death *

Patient Status: *

- **LIVING**
- **DEAD**
- **RETRANSPLANTED**

Primary Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Transplant Hospitalization:

Date of Admission to Tx Center: *

Date of Discharge from Tx Center:

Clinical Information : PRETRANSPLANT

Medical Condition at time of transplant: *

- **IN INTENSIVE CARE UNIT**
- **HOSPITALIZED NOT IN ICU**
- **NOT HOSPITALIZED**

Patient on Life Support: * **YES** **NO**

- [ ] Extra Corporeal Membrane Oxygenation
- [ ] Intra Aortic Balloon Pump
- [ ] Prostacyclin Infusion
- [ ] Prostacyclin Inhalation
- [ ] Intravenous Inotropes
- [ ] Inhaled NO
- [ ] Ventilator
- [ ] Other Mechanism

Specify:

Functional Status: *

Cognitive Development: *

- ( ) **Definite Cognitive delay/impairment**
- ( ) **Probable Cognitive delay/impairment**
- ( ) **Questionable Cognitive delay/impairment**
- ( ) **No Cognitive delay/impairment**
- ( ) **Not Assessed**

Motor Development: *

- ( ) **Definite Motor delay/impairment**
- ( ) **Probable Motor delay/impairment**
- ( ) **Questionable Motor delay/impairment**
- ( ) **No Motor delay/impairment**
- ( ) **Not Assessed**

Academic Progress: *

- ( ) **Within One Grade Level of Peers**
- ( ) **Delayed Grade Level**
- ( ) **Special Education**
- ( ) **Not Applicable, too young for school/ High School graduate or GED**
- ( ) **Status Unknown**

Academic Activity Level: *

- ( ) **Full academic load**
- ( ) **Reduced academic load**
- ( ) **Unable to participate in academics due to disease or condition**
- ( ) **Unable to participate regularly due to dialysis**
- ( ) **Not Applicable, too young for school/ High School graduate or GED**
- ( ) **Status Unknown**

Source of Payment:

Primary: *

Specify:

Height Measurement Date:

Height: * ft. in. cm **ST=**

Weight Measurement Date:

Weight: * lbs kg **ST=**

BMI: kg/m^2

Previous Transplants:

Previous Transplant Organ	Previous Transplant Date	Previous Transplant Graft Fail Date

The three most recent transplants are listed here. Please contact the UNet Help Desk to confirm more than three previous transplants by calling 800-978-4334 or by emailing unethelpdesk@unos.org.

Viral Detection:

HIV Serostatus: *

- ( ) **Positive**
- ( ) **Negative**
- ( ) **Not Done**
- ( ) **UNK/Cannot Disclose**

CMV Status*
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HBV Surface Antibody Total*
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HBV Core Antibody: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HBV Surface Antigen: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HCV Serostatus: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

EBV Serostatus: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

Vaccination Status:

Did the recipient receive Hepatitis B vaccines prior to transplant?: *
- YES
- NO
- UNK

Reason not vaccinated:
- Immunity
- Medical precaution
- Time constraints
- Patient objection
- Product out of stock
- Other, specify

Specify:

NAT Results:

HIV NAT: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HBV NAT: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HCV NAT: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

Most Recent Hemodynamics: **Inotropes/Vasodilators:**

PA (sys)mm/Hg: * ST= YES NO

PA(dia) mm/Hg: * ST= YES NO

PA(mean) mm/Hg: * ST= YES NO

PCWP mm/Hg: * ST= YES NO

CO L/min: * ST= YES NO

Most Recent Serum Creatinine: * mg/dl ST=

Most Recent Total Bilirubin: * mg/dl ST=

Chronic Steroid Use: * YES NO UNK

Pulmonary Status (Give most recent value):

FVC: * %predicted: ST=

FeV1: * %predicted: ST=

pCO2: * mm/Hg: ST=

Events occurring between listing and transplant:

Transfusions: * YES NO UNK

Infection Requiring IV Therapy within 2 wks prior to Tx: * YES NO UNK

Dialysis: * YES NO UNK

Episode of Ventilatory Support: * YES NO UNK

If yes, indicate most recent timeframe:

- At time of transplant
- Within 3 months of transplant
- >3 months prior to transplant

Tracheostomy: * YES NO UNK

Prior Thoracic Surgery other than prior transplant: * YES NO UNK

If yes, number of prior sternotomies:

- Unknown if there were prior sternotomies
- 0
- 1
- 2
- 3
- 4
- 5+
- Unknown number of prior sternotomies

If yes, number of prior thoracotomies:

- Unknown if there were prior thoracotomies
- 0
- 1
- 2
- 3
- 4
- 5+
- Unknown number of prior thoracotomies

Prior congenital cardiac surgery: YES NO UNK

If yes, palliative surgery: YES NO UNK

If yes, corrective surgery: YES NO UNK

If yes, single ventricular physiology: YES NO UNK

Pretransplant Titer Information:

Most Recent Anti-A Titer: **Sample Date:**

Most Recent Anti-B Titer: **Sample Date:**

Clinical Information : TRANSPLANT PROCEDURE

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Procedure Type:

- SINGLE LEFT LUNG
- SINGLE RIGHT LUNG
- BILATERAL SEQUENTIAL LUNG
- EN-BLOC DOUBLE LUNG
- LOBE, RIGHT
- LOBE, LEFT

Total Organ Preservation Time From Cross Clamp to In Situ Reperfusion (include warm and cold time):

Left Lung: min **ST=**

Right Lung (OR EN-BLOC): min **ST=**

Lung(s) perfused prior to transplant? YES NO

Perfusion occurred at:

- Recovery Site (donor hospital)
- OPO
- Transplant hospital - transplant site
- Transplant hospital - not transplant site
- External perfusion center

Perfusion performed by:

- OPO
- Transplant Program
- External perfusion center

Total time on perfusion: min **ST=**

Left lung received at transplant center:

- Received at center on ice
- Received at center on pump, stayed on pump
- Received at center on pump, put on ice

Right lung received at transplant center:

- Received at center on ice
- Received at center on pump, stayed on pump
- Received at center on pump, put on ice

Organ Check-in Information:

Left Lung Check-In Date and Time: **Date:** **Time:** Military time **Time Zone:** **ST=**

Right Lung Check-In Date and Time: **Date:** **Time:** Military time **Time Zone:** **ST=**

En Bloc Lungs Check-In Date and Time: **Date:** **Time:** Military time **Time Zone:** **ST=**

Clinical Information : POST TRANSPLANT

Graft Status:* Functioning Failed

If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select Functioning.

Date of Graft Failure:

Primary Cause of Graft Failure:

- Primary Non-Function
- Acute Rejection
- Chronic Rejection/Atherosclerosis
- Other, Specify

Specify:

PostTransplant Titer Information:

Most Recent Anti-A Titer: **Sample Date:**

Most Recent Anti-B Titer: **Sample Date:**

Events Prior to Discharge:

Stroke: * YES NO UNK

Dialysis: * YES NO UNK

Ventilator Support: *

- No
- Ventilator support for <= 48 hours
- Ventilator support for >48 hours but < 5 days
- Ventilator support >= 5 days
- Ventilator support, duration unknown
- Unknown Status

Reintubated: * YES NO UNK

Permanent Pacemaker: * YES NO UNK

Components of ISHLT primary graft dysfunction (PGD) grade

Intubated at 72 hours * YES NO UNK

PaO2 at 72 Hours * mm/Hg **ST=**

FiO2 at 72 Hours * % **ST=**

ECMO at 72 hours * YES NO UNK

Inhaled NO at 72 hours * YES NO UNK

Airway Dehiscence: YES NO UNK

Did patient have any acute rejection episodes between transplant and discharge: *

- Yes, at least one episode treated with anti-rejection agent
- Yes, none treated with additional anti-rejection agent
- No

Immunosuppressive Information

Are any medications given currently for maintenance or anti-rejection: * YES NO

Immunosuppressive Medications

View Immunosuppressive Medications

Definitions Of Immunosuppressive Medications

For each of the immunosuppressive medications listed, select **Ind** (Induction), **Maint** (Maintenance) or **AR** (Anti-rejection) to indicate all medications that were prescribed for the recipient during the initial transplant hospitalization period, and for what reason. If a medication was not given, leave the associated box(es) blank.

Induction (Ind) immunosuppression includes all medications given for a short finite period in the perioperative period for the purpose of preventing acute rejection. Though the drugs may be continued after discharge for the first 30 days after transplant, it will not be used long-term for immunosuppressive maintenance. Induction agents are usually polyclonal, monoclonal, or IL-2 receptor antibodies (example: methylprednisolone, Campath, Thymoglobulin, or Simulect). Some of these drugs might be used for another finite period for rejection therapy and would be recorded as anti-rejection therapy if used for this reason. For each induction medication indicated, write the total number of days the drug was actually administered in the space provided. For example, if Simulect was given in 2 doses a week apart then the total number of days would be 2, even if the second dose was given after the patient was discharged.

Maintenance (Maint) includes all immunosuppressive medications given before, during or after transplant with the intention to maintain them long-term (example: prednisone, cyclosporine, tacrolimus, mycophenolate mofetil, azathioprine, or Rapamune). This does not include any immunosuppressive medications given to treat rejection episodes, or for induction.

Anti-rejection (AR) immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode during the initial post-transplant period or during a specific follow-up period, usually up to 30 days after the diagnosis of acute rejection (example: methylprednisolone, or Thymoglobulin). When switching maintenance drugs (example: from tacrolimus to cyclosporine; or from mycophenolate mofetil to azathioprine) because of rejection, the drugs should not be listed under AR immunosuppression, but should be listed under maintenance immunosuppression.

If an immunosuppressive medication other than those listed is being administered (e.g., new monoclonal antibodies), select Ind, Maint, or AR next to Other Immunosuppressive Medication field, and enter the full name of the medication in the space provided. **Do not list non-immunosuppressive medications.**

Drug used for induction, acute rejection, or maintenance

	Ind.	Days	ST	Maint	AR
Steroids (prednisone, methylprednisolone, Solumedrol, Medrol)	☐		☐	☐	☐

Drugs used for induction or acute rejection

	Ind.	Days	ST	Maint	AR
Atgam	☐		☐		☐
Campath (alemtuzumab)	☐		☐		☐
Cytoxan (cyclophosphamide)			☐		☐
Methotrexate (Folex PFS, Mexate-AQ, Rheumatrex)			☐		☐
Rituxan (rituximab)	☐		☐		☐
Simulect (basiliximab)	☐		☐		☐
Thymoglobulin	☐		☐		☐

Drugs primarily used for maintenance

	Ind.	Days	ST	Maint	AR
Cyclosporine, select from the following:					
- Gengraf			☐	☐	
- Neoral			☐	☐	
- Sandimmune			☐	☐	
- Generic cyclosporine			☐	☐	
Imuran (azathioprine, AZA)			☐	☐	
Leflunomide (LFL)			☐	☐	
Mycophenolic acid, select from the following:					
- CellCept (MMF)			☐	☐	
- Generic MMF (generic CellCept)			☐	☐	
- Myfortic (mycophenolic acid)			☐	☐	
- Generic Myfortic (generic mycophenolic acid)			☐	☐	
mTOR inhibitors, select from the following:					
- Rapamune (sirolimus)	☐		☐	☐	
- Generic sirolimus	☐		☐	☐	
- Zortress (everolimus)	☐		☐	☐	
Nulojix (belatacept)			☐	☐	
Tacrolimus, select from the following:					
- Astagraf XL (extended release tacrolimus)			☐	☐	
- Envarsus XR (tacrolimus XR)			☐	☐	
- Prograf (tacrolimus)			☐	☐	
- Generic tacrolimus (generic Prograf)			☐	☐	

Other drugs

		Ind.	Days	ST	Maint	AR
Other immunosuppressive medication, specify:		☐		☐	☐	☐
Other immunosuppressive medication, specify:		☐		☐	☐	☐