

# Records

## Pediatric Thoracic - Lung Transplant Recipient Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 02/29/2012

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI<sup>®</sup> 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<sup>®</sup> 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:	Gender:
HIC:	Tx Date:
State of Permanent Residence: *	<input type="text"/>
Permanent Zip: *	<input type="text"/> - <input type="text"/>

Provider Information	
Recipient Center:	
Physician Name: *	<input type="text"/>
Physician NPI#: *	<input type="text"/>
Surgeon Name: *	<input type="text"/>
Surgeon NPI#: *	<input type="text"/>

Donor Information	
UNOS Donor ID #:	
Donor Type:	

Patient Status	
Primary Diagnosis: *	<input type="text"/>
Specify:	<input type="text"/>
Date: Last Seen, Retransplanted or Death *	<input type="text"/>
Patient Status: *	<input type="radio"/> LIVING <input type="radio"/> DEAD <input type="radio"/> RETRANSPLANTED
Primary Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Transplant Hospitalization:	

Date of Admission to Tx Center: \*

Date of Discharge from Tx Center:

Was patient hospitalized during the last 90 days prior to the transplant admission:  YES  NO  UNK

Medical Condition: \*  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 < 5 years old/ 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

Not Applicable < 5 years old/ High School graduate or GED

Status Unknown

Source of Payment:

Primary: \*

Specify:

Secondary:

**Clinical Information : PRETRANSPLANT**

Date of Measurement:

Height: \*

 ft.  in. cm

ST=

Weight: \*

 lbs kg

ST=

BMI:

kg/m<sup>2</sup>

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 IgG: \*

Positive

Negative

Not Done

UNK/Cannot Disclose

CMV IgM: \*

Positive

Negative

Not Done

UNK/Cannot Disclose

Positive

HBV Core Antibody:\*

- 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

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

PCW(mean) 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=

Oxygen Requirement at Rest:\*

 L/min

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

Pulmonary Embolism: \*  YES  NO  UNK

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

Cerebrovascular Event:  YES  NO  UNK

Dialysis: \*  YES  NO  UNK

Implantable Defibrillator:  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

Previous Pregnancies:

- NO PREVIOUS PREGNANCY
- 1 PREVIOUS PREGNANCY
- 2 PREVIOUS PREGNANCIES
- 3 PREVIOUS PREGNANCIES
- 4 PREVIOUS PREGNANCIES
- 5 PREVIOUS PREGNANCIES
- MORE THAN 5 PREVIOUS PREGNANCIES
- NOT APPLICABLE: < 10 years old
- UNKNOWN

Malignancies between listing and transplant: \*

- YES
- NO
- UNK

This question is NOT applicable for patients receiving living donor transplants who were never on the waiting list.

If yes, specify type:

- Skin Melanoma
- Skin Non-Melanoma
- CNS Tumor
- Genitourinary
- Breast
- Thyroid
- Tongue/Throat/Larynx
- Lung
- Leukemia/Lymphoma
- Liver
- Other, specify

Specify:

#### 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

Was this a retransplant due to failure of a previous thoracic graft:

- YES
- NO

Total Organ Ischemia Time (include cold, warm and anastomotic time):

Left Lung:  min ST=

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

Incidental Tumor found at time of Transplant:  YES  NO  UNK

If yes, specify tumor type:

- Adenoma
- Carcinoma
- Carcinoid
- Lymphoma
- Harmartoma
- Other Primary Lung Tumor, Specify

Specify:

#### 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:

Events Prior to Discharge:

Any Drug Treated Infection:  YES  NO  UNK

Stroke: \*  YES  NO  UNK

Dialysis: \*  YES  NO  UNK

Cardiac Re-Operation:  YES  NO  UNK

Other Surgical Procedures:  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

Chest drain >2 weeks:  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

Biopsy not done

Was biopsy done to confirm acute rejection:

Yes, rejection confirmed

Yes, rejection not confirmed

### Treatment

Biological or Anti-viral Therapy:

YES  NO  Unknown/Cannot disclose

If Yes, check all that apply:

Acyclovir (Zovirax)

Cytogam (CMV)

Gamimune

Gammagard

Ganciclovir (Cytovene)

Valgancyclovir (Valcyte)

HBIG (Hepatitis B Immune Globulin)

Flu Vaccine (Influenza Virus)

Lamivudine (Epivir) (for treatment of Hepatitis B)

Other, Specify

Valacyclovir (Valtrex)

Specify:

Specify:

Other therapies:

YES  NO

If Yes, check all that apply:

Photopheresis

Plasmapheresis

Total Lymphoid Irradiation (TLI)

### Immunosuppressive Information

Are any medications given currently for maintenance or anti-rejection: \*

YES  NO

Did the patient participate in any clinical research protocol for immunosuppressive medications:

YES  NO

If Yes, Specify:

### 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, Atgam, Thymoglobulin, OKT3, Simulect, or Zenapax). Some of these drugs might be used for another finite period for rejection therapy and would be recorded as 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 or Zenapax 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 *for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance drug* (example: Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). 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, Atgam, OKT3, 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.**

	Ind.	Days	ST	Maint	AR
Steroids (Prednisone, Methylprednisolone, Solumedrol, Medrol, Decadron)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Atgam (ATG)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
OKT3 (Orthoclone, Muromonab)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Simulect - Basiliximab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Zenapax - Daclizumab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Azathioprine (AZA, Imuran)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
EON (Generic Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Gengraf (Abbott Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other generic Cyclosporine, specify brand:	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Neoral (CyA-NOF)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Sandimmune (Cyclosporine A)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
CellCept (Mycophenolate Mofetil; MMF)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Generic MMF (Generic CellCept)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Prograf (Tacrolimus, FK506)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Generic Tacrolimus (Generic Prograf)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Advagraf (Tacrolimus Extended or Modified Release)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Nulojix (Belatacept)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sirolimus (RAPA, Rapamycin, Rapamune)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Myfortic (Mycophenolate Sodium)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Other Immunosuppressive Medications					
	Ind.	Days	ST	Maint	AR
Campath - Alemtuzumab (anti-CD52)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide (Cytoxan)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL, Arava)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatex)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Other Immunosuppressive Medication, Specify <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rituximab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Investigational Immunosuppressive Medications					
	Ind.	Days	ST	Maint	AR
Zortress (Everolimus)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other Immunosuppressive Medication, Specify <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>