

Records

Pediatric Thoracic - Heart/Lung Transplant Recipient Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 10/31/2010

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:	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:*	<input type="text"/>
Date of Discharge from Tx Center:	<input type="text"/>
Was patient hospitalized during the last 90 days prior to the transplant admission:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Medical Condition:*	<input type="radio"/> IN INTENSIVE CARE UNIT <input type="radio"/> HOSPITALIZED NOT IN ICU <input type="radio"/> NOT HOSPITALIZED
Patient on Life Support:*	<input type="radio"/> YES <input type="radio"/> NO <input type="checkbox"/> Extra Corporeal Membrane Oxygenation <input type="checkbox"/> Intra Aortic Balloon Pump <input type="checkbox"/> Prostacyclin Infusion <input type="checkbox"/> Prostacyclin Inhalation <input type="checkbox"/> Intravenous Inotropes <input type="checkbox"/> Inhaled NO <input type="checkbox"/> Ventilator <input type="checkbox"/> Other Mechanism
Specify:	<input type="text"/>

NONE
 LVAD
Patient on Ventricular Assist Device* RVAD
 TAH
 LVAD+RVAD

Life Support: VAD Brand1
 Specify:
 Life Support: VAD Brand2
 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
 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
 Status Unknown

Source of Payment:
Primary:*
 Specify:
Secondary:

Clinical Information : PRETRANSPLANT

Date of Measurement:
Height:* ft. in. cm %ile **ST=**
Weight:* lbs kg %ile **ST=**
BMI: kg/m² %ile

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:*	<input type="radio"/> Positive
	<input type="radio"/> Negative
	<input type="radio"/> Not Done
	<input type="radio"/> UNK/Cannot Disclose
CMV IgM:*	<input type="radio"/> Positive
	<input type="radio"/> Negative
	<input type="radio"/> Not Done
	<input type="radio"/> UNK/Cannot Disclose
HBV Core Antibody:*	<input type="radio"/> Positive
	<input type="radio"/> Negative
	<input type="radio"/> Not Done
	<input type="radio"/> UNK/Cannot Disclose
HBV Surface Antigen:*	<input type="radio"/> Positive
	<input type="radio"/> Negative
	<input type="radio"/> Not Done
	<input type="radio"/> UNK/Cannot Disclose
HCV Serostatus:*	<input type="radio"/> Positive
	<input type="radio"/> Negative
	<input type="radio"/> Not Done
	<input type="radio"/> UNK/Cannot Disclose
EBV Serostatus:*	<input type="radio"/> Positive
	<input type="radio"/> Negative
	<input type="radio"/> Not Done
	<input type="radio"/> UNK/Cannot Disclose

Most Recent Hemodynamics:			Inotropes/Vasodilators:
PA (sys)mm/Hg:*	<input type="text"/>	ST= <input type="checkbox"/>	<input type="radio"/> YES <input type="radio"/> NO
PA(dia) mm/Hg:*	<input type="text"/>	ST= <input type="checkbox"/>	<input type="radio"/> YES <input type="radio"/> NO
PA(mean) mm/Hg:*	<input type="text"/>	ST= <input type="checkbox"/>	<input type="radio"/> YES <input type="radio"/> NO
PCW(mean) mm/Hg:*	<input type="text"/>	ST= <input type="checkbox"/>	<input type="radio"/> YES <input type="radio"/> NO
CO L/min:*	<input type="text"/>	ST= <input type="checkbox"/>	<input type="radio"/> YES <input type="radio"/> NO

Most Recent Serum Creatinine:*	<input type="text"/> mg/dl	ST= <input type="checkbox"/>
Most Recent Total Bilirubin:*	<input type="text"/> mg/dl	ST= <input type="checkbox"/>
Oxygen Requirement at Rest:*	<input type="text"/> L/min	ST= <input type="checkbox"/>
Chronic Steroid Use:*	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK	
Pulmonary Status (Give most recent value):		
FVC:*	<input type="text"/> %predicted:	ST= <input type="checkbox"/>
FeV1:*	<input type="text"/> %predicted:	ST= <input type="checkbox"/>
pCO2:*	<input type="text"/> mm/Hg:	ST= <input type="checkbox"/>

Events occurring between listing and transplant:

Transfusions:*	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Infection Requiring IV Therapy within 2 wks prior to Tx:*	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Cerebrovascular Event:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Dialysis:*	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Implantable Defibrillator:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Prior Cardiac Surgery (non-transplant):	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
	<input type="checkbox"/> CABG

If yes, check all that apply:

- Valve Replacement/Repair
- Congenital
- Left Ventricular Remodeling
- Other, specify

Specify:

Prior Lung Surgery (non-transplant):

YES NO UNK

If yes, check all that apply:

- Pneumoreduction
- Pneumothorax Surgery-Nodule
- Pneumothorax Decortication
- Lobectomy
- Pneumonectomy
- Left Thoracotomy
- Right Thoracotomy
- Other, specify

Specify:

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:

- Heart
- Heart Lung

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

YES NO

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

Heart, Heart-Lung:

 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

Time on inotropes other than Isoproterenol (Isuprel):*

 days

ST=

Ventilator Support:*	<input type="radio"/> No <input type="radio"/> Ventilator support for <= 48 hours <input type="radio"/> Ventilator support for >48 hours but < 5 days <input type="radio"/> Ventilator support >= 5 days <input type="radio"/> Ventilator support, duration unknown <input type="radio"/> Unknown Status
Reintubated:*	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Permanent Pacemaker:*	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Chest drain >2 weeks:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Airway Dehiscence:*	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK

Did patient have any acute rejection episodes between transplant and discharge:*	<input type="radio"/> Yes, at least one episode treated with anti-rejection agent <input type="radio"/> Yes, none treated with additional anti-rejection agent <input type="radio"/> No
Was biopsy done to confirm acute rejection:	<input type="radio"/> Biopsy not done <input type="radio"/> Yes, rejection confirmed <input type="radio"/> Yes, rejection not confirmed

Treatment

Biological or Anti-viral Therapy:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> Unknown/Cannot disclose
If Yes, check all that apply:	<input type="checkbox"/> Acyclovir (Zovirax) <input type="checkbox"/> Cytogam (CMV) <input type="checkbox"/> Gamimune <input type="checkbox"/> Gammagard <input type="checkbox"/> Ganciclovir (Cytovene) <input type="checkbox"/> Valgancyclovir (Valcyte) <input type="checkbox"/> HBIG (Hepatitis B Immune Globulin) <input type="checkbox"/> Flu Vaccine (Influenza Virus) <input type="checkbox"/> Lamivudine (EpiVir) (for treatment of Hepatitis B) <input type="checkbox"/> Other, Specify <input type="checkbox"/> Valacyclovir (Valtrex)
Specify:	<input type="text"/>
Specify:	<input type="text"/>

Other therapies:	<input type="radio"/> YES <input type="radio"/> NO
If Yes, check all that apply:	<input type="checkbox"/> Photopheresis <input type="checkbox"/> Plasmapheresis <input type="checkbox"/> Total Lymphoid Irradiation (TLI)

Immunosuppressive Information

Are any medications given currently for maintenance or anti-rejection:*	<input type="radio"/> YES <input type="radio"/> NO
Did the patient participate in any clinical research protocol for immunosuppressive medications:	<input type="radio"/> YES <input type="radio"/> NO
If Yes, Specify:	<input type="text"/>

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="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Atgam (ATG)	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
OKT3 (Orthoclone, Muromonab)	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Simulect - Basiliximab	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Zenapax - Daclizumab	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Azathioprine (AZA, Imuran)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
EON (Generic Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Gengraf (Abbott Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other generic Cyclosporine, specify brand: <input type="text"/>	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Neoral (CyA-NOF)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sandimmune (Cyclosporine A)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Mycophenolate Mofetil (MMF, Cellcept, RS61443)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Tacrolimus (Prograf, FK506)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Modified Release Tacrolimus FK506E (MR4)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sirolimus (RAPA, Rapamycin, Rapamune)	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Myfortic (Mycophenolate Sodium)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<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="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide (Cytoxan)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL, Arava)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Other Immunosuppressive Medication, Specify <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rituximab	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Investigational Immunosuppressive Medications

	Ind.	Days	ST	Maint	AR
Everolimus (RAD, Certican)	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
FTY 720	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other Immunosuppressive Medication, Specify <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

UNOS View Only

Comments: