

Records

Pediatric Thoracic - Heart 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:

Specify:

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
 Prostaglandins
 Intravenous Inotropes
 Inhaled NO
 Ventilator
 Other Mechanism

Specify:

Patient on Ventricular Assist Device*

- NONE
 LVAD
 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 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/m²

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

- 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

- Positive

EBV Serostatus:*

- Negative
- Not Done
- UNK/Cannot Disclose

Most Recent Hemodynamics:

PA (sys)mm/Hg:*

ST=

Inotropes/Vasodilators:

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

Cardiac Index

Most Recent Serum Creatinine:*

 mg/dl

ST=

Most Recent Total Bilirubin:*

 mg/dl

ST=

Chronic Steroid Use:*

YES NO UNK

Events occurring between listing and transplant:

Transfusions:*

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

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

NO PREVIOUS PREGNANCY

1 PREVIOUS PREGNANCY

2 PREVIOUS PREGNANCIES

3 PREVIOUS PREGNANCIES

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.

Skin Melanoma

Skin Non-Melanoma

CNS Tumor

Genitourinary

Breast

If yes, specify type:

Thyroid

Tongue/Throat/Larynx

Lung

Leukemia/Lymphoma

Liver

Other, specify

Specify:

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:
- Heart
 - Heart Lung
 - Orthotopic Bicaval
 - Orthotopic Traditional
 - Heart Procedure: * Orthotopic Total (Bicaval, PV)
 - Heterotopic
- 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=

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:

Most Recent Anti-A Titer:

Sample Date:

Most Recent Anti-B Titer:

Sample Date:

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=

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

Was biopsy done to confirm acute rejection: Biopsy not done
 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

Photopheresis

If Yes, check all that apply:

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="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 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"/>
CellCept (Mycophenolate Mofetil; MMF)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Generic MMF (Generic CellCept)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Prograf (Tacrolimus, FK506)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Generic Tacrolimus (Generic Prograf)	<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"/>
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:	<input type="text"/>