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: *

Permanent Zip: * -

Provider Information

Recipient Center:

Physician Name: *

Physician NPI#: *

Surgeon Name: *

Surgeon NPI#: *

Donor Information

UNOS Donor ID #:

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:

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:

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
- 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 **ST=**

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 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

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
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:

- ○ 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: *

- 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

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

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)		☐			☐	☐
Atgam (ATG)		☐			☐	☐
OKT3 (Orthoclone, Muromonab)		☐			☐	☐
Thymoglobulin		☐			☐	☐
Simulect - Basiliximab		☐			☐	☐
Zenapax - Daclizumab		☐			☐	☐
Azathioprine (AZA, Imuran)		☐			☐	☐
EON (Generic Cyclosporine)		☐			☐	☐
Gengraf (Abbott Cyclosporine)		☐			☐	☐
Other generic Cyclosporine, specify brand:		☐			☐	☐
Neoral (CyA-NOF)		☐			☐	☐
Sandimmune (Cyclosporine A)		☐			☐	☐
CellCept (Mycophenolate Mofetil; MMF)		☐			☐	☐
Generic MMF (Generic CellCept)		☐			☐	☐
Prograf (Tacrolimus, FK506)		☐			☐	☐
Generic Tacrolimus (Generic Prograf)		☐			☐	☐
Modified Release Tacrolimus FK506E (MR4)		☐			☐	☐
Sirolimus (RAPA, Rapamycin, Rapamune)		☐			☐	☐
Myfortic (Mycophenolate Sodium)		☐			☐	☐

Other Immunosuppressive Medications

	Ind.	Days	ST	Maint	AR

Campath - Alemtuzumab (anti-CD52)	☐			☐	☐
Cyclophosphamide (Cytoxan)	☐			☐	☐
Leflunomide (LFL, Arava)	☐			☐	☐
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)	☐			☐	☐
Other Immunosuppressive Medication, Specify	☐			☐	☐
Rituximab	☐			☐	☐

Investigational Immunosuppressive Medications

	Ind.	Days	ST	Maint	AR
Everolimus (RAD, Certican)	☐			☐	☐
Other Immunosuppressive Medication, Specify	☐			☐	☐

UNOS View Only

Comments: