Records

Pediatric Thoracic - Heart/Lung Transplant Recipient Registration Worksheet

The revised worksheet sample is for reference purposes only and is pending OMB approval.

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI[B.] 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[B.] 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
- Intravenous Inotropes
- Prostacyclin Inhalation
- 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 (verified by IQ score <70 or unambiguous behavioral observation)
- Probable Cognitive delay/impairment (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence)
- Questionable Cognitive delay/impairment (not judged to be more likely than not, but with some indication of cognitive delay/impairment such as expressive/receptive language and/or learning difficulties)
- No Cognitive delay/impairment (no obvious indicators of cognitive delay/impairment)
- Not Assessed

Motor Development: *

- Definite Motor delay/impairment (verified by physical exam or unambiguous behavioral observation)
- Probable Motor delay/impairment (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence)
- Questionable Motor delay/impairment (not judged to be more likely than not, but with some indications of motor delay/impairment)
- No Motor delay/impairment (no obvious indicators of motor delay/impairment)
- Not Assessed

Academic Progress: *

- Within One Grade Level of Peers
- Delayed Grade Level
- Special Education
- Not Applicable < 5 years old
- 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/m^2 %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: *
- 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
Cardiac Index: *			

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

Any prior thoracic surgery other than previous transplant: * ○ YES ○ NO ○ UNK

If yes, number of prior sternotomies: [ ]

If yes, 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

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

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.

- ☐ Skin Melanoma
- ☐ Skin Non-Melanoma
- ☐ CNS Tumor

If yes, specify type:

- [ ] Genitourinary
- [ ] Breast
- [ ] Thyroid
- [ ] Tongue/Throat/Larynx
- [ ] Lung
- [ ] Leukemia/Lymphoma
- [ ] Liver
- [ ] Other, specify

Specify:

Titer Information:

Current B Titer		**Sample Date**	
Current A Titer		**Sample Date**	

Clinical Information : TRANSPLANT PROCEDURE

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Procedure Type:

- ( ) Heart
- ( ) Heart Lung

Heart Procedure:

- ( ) Orthotopic Bicaval
- ( ) Orthotopic Traditional
- ( ) Orthotopic Total (Bicaval, PV)
- ( ) Heterotopic

Lung Procedure:

- ( ) 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):

ST=

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 _____

Titer Information:

Current B Titer _____ **Sample Date** _____

Current A 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=** _____

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
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)				
Mycophenolate Mofetil (MMF, Cellcept, RS61443)				
Tacrolimus (Prograf, FK506)				
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						
Other Immunosuppressive Medication, Specify						
Rituximab						

Investigational Immunosuppressive Medications

		Ind.	Days	ST	Maint	AR
Everolimus (RAD, Certican)		☐			☐	☐
FTY 720		☐			☐	☐
Other, Specify		☐			☐	☐

UNOS View Only

Comments: