Pediatric Thoracic Transplant Recipient Follow-Up Worksheet

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:**
Previous Follow-Up:	**Previous Px Stat Date:**

Transplant Discharge Date:

State of Permanent Residence: *

Zip Code: * ☐ - ☐

Provider Information

Recipient Center:

Followup Center:

Physician Name: *

NPI#: *

Follow-up Care Provided By: *
- ○ Transplant Center
- ○ Non Transplant Center Specialty Physician
- ○ Primary Care Physician
- ○ Other Specify

Specify:

Donor Information

UNOS Donor ID #:

Recovering OPO:

Donor Type:

Patient Status

Date: Last Seen, Retransplanted or Death *

Patient Status: *
- ○ LIVING
- ○ DEAD
- ○ RETRANSPLANTED
- ○ NOT SEEN

Primary Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Has the patient been hospitalized since the last patient status date: * ○ YES ○ NO ○ UNK

    Hospitalized for Rejection: ○ YES ○ NO ○ UNK

    Hospitalized for Infection: ○ YES ○ NO ○ UNK

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, too young for school/ 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
- ○ Unable to participate regularly due to dialysis
- ○ Not Applicable, too young for school/ High School graduate or GED
- ○ Status Unknown

Primary Insurance at Follow-up: * [_____]

   Specify [_____]

Clinical Information

Height Measurement Date: [_____]

Height: * [_____] ft. [_____] in.   [_____] cm   ST= [____]

Weight Measurement Date: [_____]

Weight: * [_____] lbs.   [_____] kg   ST= [____]

BMI: kg/m^2

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

   Other, Specify: [_____]

Titer Information:

For those individuals who received a heart and/or lung from a donor with an incompatible blood type, the most recent Anti-A and/or Anti-B titer values must be reported upon graft failure or death.

Titer values entered on the TRR:	
Anti-A Titer at time of transplant:	Sample Date:

Most Recent Anti-A Titer: * [_____]   **Sample Date:** * [_____]

Titer values entered on the TRR:	
Anti-B Titer at time of transplant:	Sample Date:

Most Recent Anti-B Titer: * [_____]   **Sample Date:** * [_____]

Graft Function:

Heart:

Ejection Fraction: *	[_____] %	ST= [___]
Shortening Fraction: *	[_____] %	ST= [___]
Pacemaker: *	○YES ○NO ○UNK	
Coronary Artery Disease Since Last Follow Up: *	○YES ○NO ○UNK	

Lung:

Date Test Performed: * [_____] ST= [___]

FEV1:	[_____] L	ST= [___]
FVC:	[_____] L	ST= [___]
FEF25-75:	[_____] L/sec	ST= [___]

Date Test Performed: * [_____] ST= [___]

FEV1:	[_____] L	ST= [___]
FVC:	[_____] L	ST= [___]
FEF25-75:	[_____] L/sec	ST= [___]

Date Test Performed: * [_____] ST= [___]

FEV1:	[_____] L	ST= [___]
FVC:	[_____] L	ST= [___]
FEF25-75:	[_____] L/sec	ST= [___]

Current supplemental O2 requirements at rest and/or at exercise: *   ○YES ○NO

At rest:

Fio2:	[_____] %	ST= [___]

or

Flow:	[_____] L/min	ST= [___]

With excercise:

Fio2:	[_____] %	ST= [___]

or

Flow:	[_____] L/min	ST= [___]

Post Transplant Events:

New diabetes onset between last follow-up to the current follow-up: *   ○YES ○NO ○UNK

If yes, insulin dependent: ○YES ○NO ○UNK

Most Recent Serum Creatinine: *   [_____] mg/dl   ST= [___]

Chronic Dialysis: *   ○YES ○NO ○UNK

Renal Tx since Thoracic Tx: *   ○YES ○NO ○UNK

Did patient have any acute rejection episodes during the follow-up period: *

○Yes, at least one episode treated with anti-rejection agent

○Yes, none treated with additional anti-rejection agent

○No

○Unknown

Viral Detection:

HIV Serology	○ Positive
	○ Negative
	○ UKN/Cannot Disclose
	○ Not Done

HIV NAT	○ Positive
	○ Negative
	○ UKN/Cannot Disclose
	○ Not Done

HbsAg	○ Positive
	○ Negative
	○ UKN/Cannot Disclose
	○ Not Done

HBV DNA	○ Positive
	○ Negative
	○ UKN/Cannot Disclose
	○ Not Done

HBV Core Antibody	○ Positive
	○ Negative
	○ UKN/Cannot Disclose
	○ Not Done

HCV Serology	○ Positive
	○ Negative
	○ UKN/Cannot Disclose
	○ Not Done

HCV NAT	○ Positive
	○ Negative
	○ UKN/Cannot Disclose
	○ Not Done

Post Transplant Malignancy: *	○ YES ○ NO ○ UNK
Donor Related:	○ YES ○ NO ○ UNK
Recurrence of Pre-Tx Tumor:	○ YES ○ NO ○ UNK
De Novo Solid Tumor:	○ YES ○ NO ○ UNK
De Novo Lymphoproliferative disease and Lymphoma:	○ YES ○ NO ○ UNK

Immunosuppressive Information

Previous Validated Maintenance Follow-Up Medications:

Previous Validated Maintenance Follow-Up Medications:

Were any medications given during the follow-up period for maintenance:	○ Yes, same as validated TRR form
	○ None given
	○ Yes, but different than validated TRR form

Immunosuppressive Medications

View Immunosuppressive Medications

Definitions Of Immunosuppressive Follow-Up Medications

For each of the immunosuppressant medications listed, check **Previous Maintenance (Prev Maint)**, **Current Maintenance (Curr Maint)** or **Anti-rejection (AR)** to indicate all medications that were prescribed for the recipient during this follow-up period, and for what reason. If a medication was not given, leave the associated box(es) blank.

Previous Maintenance (Prev Maint) includes all immunosuppressive medications given during the report period, which covers the period from the last clinic visit to the current clinic visit, with the intention to maintain them <u>long-term</u> (example: prednisone, cyclosporine, tacrolimus, mycophenolate mofetil, azathioprine, or Rapamune). This does not include any immunosuppressive medications given to treat rejection episodes.

Current Maintenance (Curr Maint) includes all immunosuppressive medications given at the time of the current clinic visit to begin in the next report period, with the intention to maintain them <u>long-term</u> (example: prednisone, cyclosporine, tacrolimus, mycophenolate mofetil, azathioprine, or Rapamune). This does not include any immunosuppressive medications given to treat rejection episodes.

Anti-rejection (AR) immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode since the last clinic visit (example: methylprednisolone or Thymoglobulin). When switching maintenance drugs (example: from tacrolimus to cyclosporine; or from mycophenolate mofetil to azathioprine) because of rejection, the drugs <u>should not be</u> listed under AR immunosuppression, but <u>should be</u> listed under maintenance immunosuppression. **>Note: The Anti-rejection field refers to any anti-rejection medications since the last clinic visit, not just at the time of the current clinic visit.**

If an immunosuppressive medication other than those listed is being administered (e.g., new monoclonal antibodies), select Previous Maint, or Current 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.**

Drug used for induction, acute rejection, or maintenance

	Prev Maint	Curr Maint	AR
Steroids (prednisone, methylprednisolone, Solumedrol, Medrol)	☐	☐	☐

Drugs used for induction or acute rejection

	Prev Maint	Curr Maint	AR
Atgam	☐	☐	☐
Campath (alemtuzumab)	☐	☐	☐
Cytoxan (cyclophosphamide)	☐	☐	☐
Methotrexate (Folex PFS, Mexate-AQ, Rheumatrex)	☐	☐	☐
Rituxan (rituximab)	☐	☐	☐
Simulect (basiliximab)	☐	☐	☐
Thymoglobulin	☐	☐	☐

Drugs primarily used for maintenance

	Prev Maint	Curr Maint	AR
Cyclosporine, select from the following:			
- Gengraf	☐	☐	☐
- Neoral	☐	☐	☐
- Sandimmune	☐	☐	☐
- Generic cyclosporine	☐	☐	☐
Imuran (azathioprine, AZA)	☐	☐	☐
Leflunomide (LFL)	☐	☐	☐
Mycophenolic acid, select from the following:			
- CellCept (MMF)	☐	☐	☐
- Generic MMF (generic CellCept)	☐	☐	☐
- Myfortic (mycophenolic acid)	☐	☐	☐
- Generic Myfortic (generic mycophenolic acid)	☐	☐	☐
mTOR inhibitors, select from the following:			
- Rapamune (sirolimus)	☐	☐	☐
- Generic sirolimus	☐	☐	☐
- Zortress (everolimus)	☐	☐	☐
Nulojix (belatacept)	☐	☐	☐
Tacrolimus, select from the following:			
- Astagraf XL (extended release tacrolimus)	☐	☐	☐
- Envarsus XR (tacrolimus XR)	☐	☐	☐

	Prev Maint	Curr Maint	AR
- Prograf (tacrolimus)	☐	☐	☐
- Generic tacrolimus (generic Prograf)	☐	☐	☐

Other drugs			
	Prev Maint	**Curr Maint**	**AR**
Other immunosuppressive medication, specify:	☐	☐	☐
Other immunosuppressive medication, specify:	☐	☐	☐