Records

Pediatric Thoracic Transplant Recipient Follow-Up 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:**

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 #:

Donor Type:

Patient Status

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:

Hospitalizations:

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

Number of Hospitalizations: **St=**

Hospitalized for Rejection: YES NO UNK

Hospitalized for Infection: YES NO UNK

Noncompliance:

Was there evidence of noncompliance with immunosuppression medication during this follow-up period that compromised the patient's recovery: YES NO UNK

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

Primary Insurance at Follow-up: *

Specify

Clinical Information

Date of Measurement: *

Height: * ft. in. cm %ile ST=

Weight: * lbs. kg %ile ST=

BMI: kg/m^2 %ile

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:

Current B Titer Sample Date

Current A Titer Sample Date

Graft Function:

Heart:

Ejection Fraction: * % ST=

Shortening Fraction: * % ST=

Pacemaker: * YES NO UNK

Coronary Artery Disease: * YES NO UNK

Clinically Significant Events: YES NO UNK

Lung:

FeV1: * % ST=

O2 Requirement at Rest: * L/min ST=

Bronchiolitis Obliterans Syndrome: *
- NO BOS
- Yes, Grade OP
- Yes, Grade 1
- Yes, Grade 2
- Yes, Grade 3
- Yes, Grade UNK
- Unknown

Bronchial Stricture (Since last follow-up): * YES NO UNK

If yes, Stent: YES NO UNK

Post Transplant Events:

Drug Treated Hypertension: YES NO UNK

Bone Disease (Symptomatic): YES NO UNK

Chronic Liver Disease: YES NO UNK

Cataracts: YES NO UNK

Diabetes onset during the follow-up period: * YES NO UNK

Diabetes: If Yes, Insulin Dependent: YES NO UNK

Renal Dysfunction: * YES NO UNK

If Yes, Creatinine > 2.5 mg/dl: YES NO UNK

Chronic Dialysis: YES NO UNK

Renal Tx since Thoracic Tx: YES NO UNK

Stroke: YES NO UNK

Drug Treated Hyperlipidemia: 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

Was biopsy done to confirm acute rejection:
- Biopsy not done
- Yes, rejection confirmed
- Yes, rejection not confirmed
- Unknown

Postransplant 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

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)
- ☐ Valacyclovir (Valtrex)
- ☐ Other, Specify

Specify:

Specify:

Other therapies: ○ YES ○ NO

If Yes, check all that apply:

- ☐ Photopheresis
- ☐ Plasmapheresis
- ☐ Total Lymphoid Irradiation (TLI)

Immunosuppressive Information

Previous Validated Maintenance Follow-Up Medications:

Were any medications given during the follow-up period for maintenance: *

- ○ Yes, same as previous validated report
- ○ Yes, but different than previous validated report
- ○ None given

Did the physician discontinue all maintenance immunosuppressive medications: ○ YES ○ NO

Did the patient participate in any clinical research protocol for immunosuppressive medications: ○ YES ○ NO

Specify:

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, *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.

Current Maintenance (Curr Maint) includes all immunosuppressive medications given at the current clinic visit to begin in the next report *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.

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, 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.
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.**

	Prev Maint	Curr 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)		☐	☐	☐
Mycophenolate Mofetil (MMF, Cellcept, RS61443)		☐	☐	☐
Tacrolimus (Prograf, FK506)		☐	☐	☐
Modified Release Tacrolimus FK506E (MR4)		☐	☐	☐
Sirolimus (RAPA, Rapamycin, Rapamune)		☐	☐	☐
Myfortic (Mycophenolate Sodium)		☐	☐	☐

Other Immunosuppressive Medications

		Prev Maint	Curr 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

	Prev Maint	Curr Maint	AR
Everolimus (RAD, Certican)	☐	☐	☐
FTY 720	☐	☐	☐