

# Records ?

## Pediatric Thoracic Transplant Recipient Follow-Up Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 07/31/2020

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	
<b>Name:</b>	<b>DOB:</b>
<b>SSN:</b>	<b>Gender:</b>
<b>HIC:</b>	<b>Tx Date:</b>
<b>Previous Follow-Up:</b>	<b>Previous Px Stat Date:</b>
<b>Transplant Discharge Date:</b>	<input type="text"/>
<b>State of Permanent Residence:*</b>	<input type="text"/>
<b>Zip Code:*</b>	<input type="text"/> - <input type="text"/>

Provider Information	
<b>Recipient Center:</b>	
<b>Followup Center:</b>	
<b>Physician Name:*</b>	<input type="text"/>
<b>NPI#:*</b>	<input type="text"/>
	<input type="radio"/> Transplant Center
	<input type="radio"/> Non Transplant Center Specialty Physician
<b>Follow-up Care Provided By:*</b>	<input type="radio"/> Primary Care Physician
	<input type="radio"/> Other Specify
<b>Specify:</b>	<input type="text"/>

Donor Information	
<b>UNOS Donor ID #:</b>	
<b>Recovering OPO:</b>	
<b>Donor Type:</b>	

Patient Status	
<b>Date: Last Seen, Retransplanted or Death*</b>	<input type="text"/>
	<input type="radio"/> LIVING
	<input type="radio"/> DEAD
<b>Patient Status:*</b>	<input type="radio"/> RETRANSPLANTED
	<input type="radio"/> NOT SEEN
<b>Primary Cause of Death:</b>	<input type="text"/>
<b>Specify:</b>	<input type="text"/>
<b>Contributory Cause of Death:</b>	<input type="text"/>
<b>Specify:</b>	<input type="text"/>
<b>Contributory Cause of Death:</b>	<input type="text"/>
<b>Specify:</b>	<input type="text"/>
<b>Has the patient been hospitalized since the last patient status date:*</b>	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Hospitalized for Rejection:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Hospitalized for Infection:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
<b>Functional Status:*</b>	<input type="text"/>
	<input type="radio"/> Definite Cognitive delay/impairment
	<input type="radio"/> Probable Cognitive delay/impairment
<b>Cognitive Development:*</b>	<input type="radio"/> Questionable Cognitive delay/impairment
	<input type="radio"/> No Cognitive delay/impairment
	<input type="radio"/> Not Assessed
<b>Motor Development:*</b>	<input type="radio"/> Definite Motor delay/impairment
	<input type="radio"/> 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

Primary Insurance at Follow-up: \*

Specify

Clinical Information

Date of Measurement:

Height: \*

 ft.  in.

 cm

ST=

Weight: \*

 lbs.

 kg

ST=

BMI:

 kg/m<sup>2</sup>

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 Non-Function

Primary Cause of Graft Failure:

- 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

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, 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.**

**Drug used for induction, acute rejection, or maintenance**

	<b>Prev Maint</b>	<b>Curr Maint</b>	<b>AR</b>
Steroids (prednisone, methylprednisolone, Solumedrol, Medrol, Decadron)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Drugs used for induction or acute rejection**

	<b>Prev Maint</b>	<b>Curr Maint</b>	<b>AR</b>
Atgam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Campath (alemtuzumab, anti-CD52)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cytoxan (cyclophosphamide)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Methotrexate (Folex PFS, Mexate-AQ, Rheumatrex)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
OKT3 (Orthoclone, muromonab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rituxan (rituximab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Simulect (basiliximab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Drugs primarily used for maintenance**

	<b>Prev Maint</b>	<b>Curr Maint</b>	<b>AR</b>
<b>Cyclosporine, select from the following:</b>			
- EON (generic cyclosporine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Gengraf (Abbott cyclosporine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Neoral (CyA-NOF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Other generic cyclosporine, specify brand: <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Sandimmune (cyclosporine A)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Imuran (azathioprine, AZA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Mycophenolate acid, select from the following:</b>			
- CellCept (MMF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic MMF (generic CellCept)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Myfortic (mycophenolate acid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nulojix (belatacept)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rapamune (sirolimus, Rapamycin)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Tacrolimus, select from the following:</b>			
- Astagraf XL (extended release tacrolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic tacrolimus (generic Prograf)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Prograf (FK506)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Zortress (everolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Other drugs**

	<b>Prev Maint</b>	<b>Curr Maint</b>	<b>AR</b>
Other immunosuppressive medication, specify: <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other immunosuppressive medication, specify: <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

