

Pediatric Intestine Transplant Recipient Follow-Up Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 08/31/2023

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:	<input type="text"/>
State of Permanent Residence: *	<input type="text"/>
Zip Code: *	<input type="text"/> - <input type="text"/>

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

Donor Information	
UNOS Donor ID #:	
Recovering OPO:	
Donor Type:	

Patient Status	
Date: Last Seen, Retransplanted or Death: *	<input type="text"/>
	<input type="radio"/> LIVING
	<input type="radio"/> DEAD
Patient Status: *	<input type="radio"/> RETRANSPLANTED
	<input type="radio"/> NOT SEEN
Primary Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Has the patient been hospitalized since the last patient status date: *	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
Functional Status: *	<input type="text"/>

Cognitive Development: *	<input type="radio"/> Definite Cognitive delay/impairment <input type="radio"/> Probable Cognitive delay/impairment <input type="radio"/> Questionable Cognitive delay/impairment <input type="radio"/> No Cognitive delay/impairment <input type="radio"/> Not Assessed
Motor Development: *	<input type="radio"/> Definite Motor delay/impairment <input type="radio"/> Probable Motor delay/impairment <input type="radio"/> Questionable Motor delay/impairment <input type="radio"/> No Motor delay/impairment <input type="radio"/> Not Assessed
Academic Progress: *	<input type="radio"/> Within One Grade Level of Peers <input type="radio"/> Delayed Grade Level <input type="radio"/> Special Education <input type="radio"/> Not Applicable, too young for school/ High School graduate or GED <input type="radio"/> Status Unknown
Academic Activity Level: *	<input type="radio"/> Full academic load <input type="radio"/> Reduced academic load <input type="radio"/> Unable to participate in academics due to disease or condition <input type="radio"/> Unable to participate regularly due to dialysis <input type="radio"/> Not Applicable, too young for school/ High School graduate or GED <input type="radio"/> Status Unknown
Primary Insurance at Follow-up: *	<input type="text"/>
Specify:	<input type="text"/>

Clinical Information			
Date of Measurement:	<input type="text"/>		
Height: *	<input type="text"/> ft. <input type="text"/> in.	<input type="text"/> cm	ST= <input type="checkbox"/>
Weight: *	<input type="text"/> lbs.	<input type="text"/> kg	ST= <input type="checkbox"/>
BMI:	<input type="text"/> kg/m ²		
Graft Status: *	<input type="radio"/> Functioning <input type="radio"/> Failed		
If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select Functioning.			
TPN Dependent:	<input type="radio"/> YES <input type="radio"/> NO		
IV Dependent:	<input type="radio"/> YES <input type="radio"/> NO		
Oral Feeding:	<input type="radio"/> YES <input type="radio"/> NO		
Tube Feeding:	<input type="radio"/> YES <input type="radio"/> NO		
Date of Failure:	<input type="text"/>		
Primary Cause of Failure:	<input type="text"/>		
Other, Specify:	<input type="text"/>		
New diabetes onset between last follow-up to the current follow-up: *	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK		
Insulin dependent:	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK		
Most Recent Lab date:	<input type="text"/>		
Total Bilirubin: *	<input type="text"/> mg/dl		ST= <input type="checkbox"/>
Serum Creatinine: *	<input type="text"/> mg/dl		ST= <input type="checkbox"/>

Yes, at least one episode treated with anti-rejection agent
 Yes, none treated with additional anti-rejection agent
 Did patient have any acute rejection episodes during the follow-up period: *
 No
 Unknown

Viral Detection:

Positive
 Negative
 UKN/ Cannot Disclose
 Not Done
 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

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 long-term (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 long-term (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 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

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

Drugs used for induction or acute rejection

	Prev Maint	Curr Maint	AR
Atgam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Campath (alemtuzumab)	<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"/>
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

	Prev Maint	Curr Maint	AR
Cyclosporine, select from the following:			
- Gengraf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Neoral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Sandimmune	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic cyclosporine	<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"/>
Mycophenolic acid, select from the following:			
- 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 (mycophenolic acid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic Myfortic (generic mycophenolic acid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
mTOR inhibitors, select from the following:			
- Rapamune (sirolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic sirolimus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Zortress (everolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nulojix (belatacept)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Tacrolimus, select from the following:

- | | | | |
|---|--------------------------|--------------------------|--------------------------|
| - Astagraf XL (extended release tacrolimus) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Envarsus XR (tacrolimus XR) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Prograf (tacrolimus) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| - Generic tacrolimus (generic Prograf) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Other drugs

		Prev Maint	Curr Maint	AR
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"/>