Pediatric Intestine 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:	
Recovering OPO: Donor Type:	
Patient Status	
Date: Last Seen, Retransplanted or Death*	
Patient Status:*	Oliving
	DEAD
	RETRANSPLANTED
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: $*$	
Functional Status: *	
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Cognitive Development:*	Opefinite Cognitive delay/impairment
	OProbable Cognitive delay/impairment
	Questionable Cognitive delay/impairment
	No Cognitive delay/impairment
	Not Assessed
Motor Development: *	Opefinite Motor delay/impairment
	OProbable 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*	OFull academic load
	OReduced academic load
	\bigcirc Unable to participate in academics due to disease or condition
	\odot Unable to participate regularly due to dialysis
	\odot 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.
TPN Dependent:	
IV Dependent:	
Oral Feeding:	
Tube Feeding:	
Tube recard.	TES NU
Date of Failure:	
Date of Failure: Primary Cause of Failure:	
Primary Cause of Failure:	
Primary Cause of Failure: Other, Specify: New diabetes onset between last follow-up to the	
Primary Cause of Failure: Other, Specify: New diabetes onset between last follow-up to the current follow-up: *	
Primary Cause of Failure: Other, Specify: New diabetes onset between last follow-up to the current follow-up: * Insulin dependent:	
Primary Cause of Failure: Other, Specify: New diabetes onset between last follow-up to the current follow-up:* Insulin dependent: Most Recent Lab date:	
Primary Cause of Failure: Other, Specify: New diabetes onset between last follow-up to the current follow-up: * Insulin dependent: Most Recent Lab date: Total Bilirubin: *	YES NO UNK
Primary Cause of Failure: Other, Specify: New diabetes onset between last follow-up to the current follow-up: * Insulin dependent: Most Recent Lab date: Total Bilirubin: *	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
	ONo
	Unknown
Viral Detection:	
HIV Serology	Positive
	ONegative
	UKN/Cannot Disclose
	Not Done
	- Not Done
HIV NAT	Positive
	Negative
	UKN/Cannot Disclose
	ONot Done
HbsAg	Positive
	Negative
	UKN/Cannot Disclose
	ONot Done
HBV DNA	Positive
	Negative
	UKN/Cannot Disclose
	ONot Done
HBV Core Antibody	Positive
	ONegative
	UKN/Cannot Disclose
	ONot Done
HCV Serology	Positive
	Negative
	OUKN/Cannot Disclose
	ONot Done
HCV NAT	Positive
	Wegative UKN/Cannot Disclose
	Not Done
Post Transplant Malignancy: *	
Donor Related:	
Recurrence of Pre-Tx Tumor:	
De Novo Solid Tumor:	
De Novo Lymphoproliferative disease and	
Lymphoma:	

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
	ONone given
	\odot 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 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)				

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)			

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- Generic sirolimus				
- Zortress (everolimus)				
Nulojix (belatacept)				
Tacrolimus, select from the following:				
- Astagraf XL (extended release tacrolimus)				
- Envarsus XR (tacrolimus XR)				
- Prograf (tacrolimus)				
- Generic tacrolimus (generic Prograf)				
Other drugs				
	Prev Maint	Curr Maint	AR	
Other immunosuppressive medication, specify:				
Other immunosuppressive medication, specify:				

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