

# Records

## Pediatric Intestine Transplant Recipient Registration 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<sup>B</sup> 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<sup>B</sup> 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:
State of Permanent Residence: *	<input type="text"/>
Permanent Zip: *	<input type="text"/> - <input type="text"/>

Provider Information	
Recipient Center:	
Surgeon Name: *	<input type="text"/>
NPI: *	<input type="text"/>

Donor Information	
UNOS Donor ID #:	
Donor Type:	

Patient Status	
Primary Diagnosis: *	<input type="text"/>
Specify:	<input type="text"/>
Secondary Diagnosis:	<input type="text"/>
Specify:	<input type="text"/>
Date: Last Seen, Retransplanted or Death *	<input type="text"/>
Patient Status: *	<input type="radio"/> LIVING <input type="radio"/> DEAD <input type="radio"/> RETRANSPLANTED
Primary Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
	<input type="text"/>

Contributory Cause of Death:

Specify:

Transplant Hospitalization:

Date of Admission to Tx Center: \*

Date of Discharge from Tx Center:

Was patient hospitalized during the last 90 days prior to the transplant admission:

YES  NO  UNK

Medical Condition at time of transplant: \*

- IN INTENSIVE CARE UNIT  
 HOSPITALIZED NOT IN ICU  
 NOT HOSPITALIZED

Patient on Life Support: \*

YES  NO

- Ventilator  
 Artificial Liver  
 Other Mechanism, Specify

Specify:

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

Source of Payment:

Primary: \*

Specify:

Secondary:

**Clinical Information : PRETRANSPLANT**

Date of Measurement: \*

Height: \*

 ft.  in.  cm %ile ST= 

Weight: \*

 lbs  kg %ile ST= 

BMI:

 kg/m<sup>2</sup> %ile

Previous Transplants:

Previous Transplant Organ	Previous Transplant Date	Previous Transplant Graft Fail Date

The three most recent transplants are listed here. Please contact the UNet Help Desk to confirm more than three previous transplants by calling 800-978-4334 or by emailing unethelpdesk@unos.org.

Viral Detection:

HIV Serostatus: \*

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

CMV IgG: \*

- Positive
- Negative
- Not Done

- CMV IgM: \*
- UNK/Cannot Disclose
  - Positive
  - Negative
  - Not Done
  - UNK/Cannot Disclose
- HBV Core Antibody: \*
- Positive
  - Negative
  - Not Done
  - UNK/Cannot Disclose
- HBV Surface Antigen: \*
- Positive
  - Negative
  - Not Done
  - UNK/Cannot Disclose
- HCV Serostatus: \*
- Positive
  - Negative
  - Not Done
  - UNK/Cannot Disclose
- EBV Serostatus: \*
- Positive
  - Negative
  - Not Done
  - UNK/Cannot Disclose

**Total Bilirubin: \***  mg/dl **ST=**

**Serum Albumin: \***  g/dl **ST=**

**Serum Creatinine: \***  mg/dl **ST=**

**Malignancies between listing and transplant: \***  YES  NO  UNK

This question is NOT applicable for patients receiving living donor transplants who were never on the waiting list.

- Skin Melanoma
- Skin Non-Melanoma
- CNS Tumor
- Genitourinary

If yes, specify type:

- Breast
- Thyroid
- Tongue/Throat/Larynx
- Lung
- Leukemia/Lymphoma
- Hepatoblastoma
- Hepatocellular Carcinoma
- Liver
- Other, specify

Specify:

### Clinical Information : TRANSPLANT PROCEDURE

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Vessel Donor ID:

Procedure Information:

Intestine Only Venous Drainage: \*

Portal  Systemic

Native Viscera Venous Drainage: \*

Portal  Systemic

Procedure Type:

- Whole Intestine
- Intestine Segment
- Whole Intestine with Pancreas (Technical Reasons)
- Intestine Segment with Pancreas (Technical Reasons)

Organ Type: \*

- Stomach
- Small Intestine
- Duodenum
- Large Intestine

Preservation Information:

Total Ischemic Time (include cold, warm and anastomotic time): \*

 hrs

ST=

Risk Factors:

Recent Septicemia: \*

YES  NO  UNK

Exhausted Vascular Access: \*

YES  NO  UNK

Liver Dysfunction:  YES  NO  UNK

Previous Abdominal Surgery: \*  YES  NO  UNK

Number Previous Abdominal Surgeries:

ST=

Dilated/Non-Functional Bowel Segments: \*  YES  NO  UNK

Other:

### Clinical Information : POST TRANSPLANT

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:  YES  NO

IV Dependent:  YES  NO

Oral Feeding:  YES  NO

Tube Feed:  YES  NO

Date of Graft Failure:

- RECURRENT TUMOR
- ACUTE REJECTION
- CHRONIC REJECTION
- TECHNICAL PROBLEMS
- INFECTION
- LYMPHOPROLIFERATIVE DISEASE
- GVHD (Graft Versus Host Disease)
- ISCHEMIA/NEC (Necrotizing Enterocolitis) LIKE SYNDROME
- OTHER SPECIFY

Primary Cause of Graft Failure:

Specify:

Did patient have any acute rejection episodes between transplant and discharge: \*  Yes, at least one episode treated with anti-rejection agent  
 Yes, none treated with additional anti-rejection agent  
 No

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

## Treatment

Biological or Anti-viral Therapy:

YES  NO  Unknown/Cannot disclose

Acyclovir (Zovirax)

Cytogam (CMV)

Gamimune

Gammagard

Ganciclovir (Cytovene)

If Yes, check all that apply:

Valgancyclovir (Valcyte)

HBIG (Hepatitis B Immune Globulin)

Flu Vaccine (Influenza Virus)

Lamivudine (EpiVir) (for treatment of Hepatitis B)

Other, Specify

Valacyclovir (Valtrex)

Specify:

Specify:

Other therapies:

YES  NO

Photopheresis

If Yes, check all that apply:

Plasmapheresis

Total Lymphoid Irradiation (TLI)

## Immunosuppressive Information

Are any medications given currently for maintenance or anti-rejection: \*

YES  NO

Did the patient participate in any clinical research protocol for immunosuppressive medications:

YES  NO

If Yes, Specify:

## Immunosuppressive Medications

### View Immunosuppressive Medications

### Definitions Of Immunosuppressive Medications

For each of the immunosuppressive medications listed, select **Ind** (Induction), **Maint** (Maintenance) or **AR** (Anti-rejection) to indicate all medications that were prescribed for the recipient during the initial transplant hospitalization period, and for what reason. If a medication was not given, leave the associated box(es) blank.

**Induction (Ind)** immunosuppression includes all medications given for a short finite period in the perioperative period for the purpose of preventing acute rejection. Though the drugs may be continued after discharge for the first 30 days after transplant, it will not be used long-term for immunosuppressive maintenance. Induction agents are usually polyclonal, monoclonal, or IL-2 receptor antibodies (example: Methylprednisolone, Atgam, Thymoglobulin, OKT3, Simulect, or Zenapax). Some of these drugs might be used for another finite period for rejection therapy and would be recorded as rejection therapy if used for this reason. For each induction medication indicated, write the total number of days the drug was actually

administered in the space provided. For example, if Simulect or Zenapax was given in 2 doses a week apart, then the total number of days would be 2, even if the second dose was given after the patient was discharged.

**Maintenance (Maint)** includes all immunosuppressive medications given before, during or after transplant *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, or for induction.

**Anti-rejection (AR)** immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode during the initial post-transplant period or during a specific follow-up period, usually up to 30 days after the diagnosis of acute rejection (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.

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

	Ind.	Days	ST
Steroids (Prednisone, Methylprednisolone, Solumedrol, Medrol, Decadron)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Atgam (ATG)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
OKT3 (Orthoclone, Muromonab)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Thymoglobulin	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Simulect - Basiliximab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Zenapax - Daclizumab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Azathioprine (AZA, Imuran)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
EON (Generic Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
Gengraf (Abbott Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
Other generic Cyclosporine, specify brand: <input type="text"/>	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
Neoral (CyA-NOF)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
Sandimmune (Cyclosporine A)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
Mycophenolate Mofetil (MMF, Cellcept, RS61443)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
Tacrolimus (Prograf, FK506)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
Modified Release Tacrolimus FK506E (MR4)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>
Sirolimus (RAPA, Rapamycin, Rapamune)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
			<input type="text"/>



Other Immunosuppressive Medications					
	Ind.	Days	ST	Maint	AR
Campath - Alemtuzumab (anti-CD52)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide (Cytoxan)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL, Arava)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Other Immunosuppressive Medication, Specify <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Immunosuppressive Medication, Specify <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rituximab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Investigational Immunosuppressive Medications					
	Ind.	Days	ST	Maint	AR
Everolimus (RAD, Certican)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
FTY 720	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other, Specify <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>

UNOS View Only	
Comments:	<input type="text"/>