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[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:**

State of Permanent Residence: *

Permanent Zip: * -

Provider Information

Recipient Center:

Surgeon Name: *

NPI: *

Donor Information

UNOS Donor ID #:

Donor Type:

Patient Status

Primary Diagnosis: *

Specify:

Secondary Diagnosis:

Specify:

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:

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^2 %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

UNK/Cannot Disclose

CMV IgM: *
- 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:

Primary Cause 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

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

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

Specify:

Specify:

Other therapies: ○ YES ○ NO

If Yes, check all that apply:

- ☐ Photopheresis
- ☐ 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)		☐		
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

	Ind.	Days	ST	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

	Ind.	Days	ST	Maint	AR
Everolimus (RAD, Certican)					
FTY 720					
Other, Specify					

UNOS View Only

Comments: