Pediatric Intestine Transplant Recipient Registration 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: **Birth sex:**

HIC: **Transplant Date and Time:**

State of Permanent Residence: *

Permanent Zip: * -

Provider Information

Recipient Center:

Surgeon Name: *

NPI#: *

Donor Information

UNOS Donor ID #:

Recovering OPO:

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:

Clinical Information : PRETRANSPLANT

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
- Probable Cognitive delay/impairment
- Questionable Cognitive delay/impairment
- No Cognitive delay/impairment
- Not Assessed

Motor Development: *

- Definite Motor delay/impairment
- 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, too young for school/ 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
- Unable to participate regularly due to dialysis
- Not Applicable, too young for school/ High School graduate or GED
- Status Unknown

Source of Payment:

Primary: *

Specify:

Height Measurement Date:

Height: * ft. in. cm **ST=**

Weight Measurement Date:

Weight: * lbs kg **ST=**

BMI: kg/m^2

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 Status *

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

HBV Surface Antibody Total *

- 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

Vaccination Status:

Did the recipient receive Hepatitis B vaccines prior to transplant?: *
- YES
- NO
- UNK

Reason not vaccinated:
- Immunity
- Medical precaution
- Time constraints
- Patient objection
- Product out of stock
- Other, specify

Specify:

NAT Results:

HIV NAT: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HBV NAT: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HCV NAT: *
- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

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

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

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

Clinical Information : TRANSPLANT PROCEDURE

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Procedure Information:

Intestine 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

Previous Abdominal Surgery: * ○ YES ○ NO ○ UNK

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

Other: _____

Organ Check-in Information:

Intestine Check-In Date and Time: **Date:** _____ **Time:** _____ Military time **Time Zone:** _____ **ST=** ☐

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
- ○ GRAFT VERSUS HOST DISEASE
- ○ ISCHEMIA/NEC 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

Immunosuppressive Information

Are any medications given currently for maintenance or anti-rejection: * ○YES ○NO

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, Campath, Thymoglobulin, or Simulect). Some of these drugs might be used for another finite period for rejection therapy and would be recorded as anti-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 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 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, 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, 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.**

Drug used for induction, acute rejection, or maintenance

	Ind.	Days	ST	Maint	AR
Steroids (prednisone, methylprednisolone, Solumedrol, Medrol)	☐		☐	☐	☐

Drugs used for induction or acute rejection

	Ind.	Days	ST	Maint	AR
Atgam	☐		☐		☐
Campath (alemtuzumab)	☐		☐		☐
Cytoxan (cyclophosphamide)					☐
Methotrexate (Folex PFS, Mexate-AQ, Rheumatrex)			☐		☐
Rituxan (rituximab)	☐		☐		☐
Simulect (basiliximab)	☐		☐		☐
Thymoglobulin	☐		☐		☐

Drugs primarily used for maintenance

	Ind.	Days	ST	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)	☐		☐	☐	

- 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

		Ind.	Days	ST	Maint	AR
Other immunosuppressive medication, specify:		☐		☐	☐	☐
Other immunosuppressive medication, specify:		☐		☐	☐	☐