Records

Pediatric Intestine Transplant Recipient Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 12/31/2011

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.

Name:

DOB:

SSN:

Gender:

HIC:

Tx Date:

State of Permanent Residence: *

Permanent Zip: *

Recipient Center:

Surgeon Name: *

NPI#: *

UNOS Donor ID #:

Donor Type:

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

- 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 < 5 years old/ 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
- Not Applicable < 5 years old/ High School graduate or GED
- Status Unknown

Source of Payment:

Primary: *

Specify:

Secondary:

Date of Measurement:

Height: * ft. in. cm ST=

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 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.

If yes, specify type:

Skin Melanoma

Skin Non-Melanoma

CNS Tumor

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

Specify:

- [ ]
- [ ]
- [ ]

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Vessel Donor ID:

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

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:

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

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)

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:

View Immunosuppressive Medications

Definitions Of Immunosuppressive 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, *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.

Current Maintenance (Curr Maint) includes all immunosuppressive medications given at the current clinic visit to begin in the next report *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.

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, 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.
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.**

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	Maint	AR
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)	☐			☐	☐
CellCept (Mycophenolate Mofetil; MMF)	☐			☐	☐
Generic MMF (Generic CellCept)	☐			☐	☐
Prograf (Tacrolimus, FK506)	☐			☐	☐
Generic Tacrolimus (Generic Prograf)	☐			☐	☐
Advagraf (Tacrolimus Extended or Modified Release)	☐			☐	☐
Nulojix (Belatacept)	☐			☐	☐
Sirolimus (RAPA, Rapamycin, Rapamune)	☐			☐	☐
Myfortic (Mycophenolate Sodium)	☐			☐	☐

	Ind.	Days	ST	Maint	AR
Campath - Alemtuzumab (anti-CD52)	☐			☐	☐
Cyclophosphamide (Cytoxan)	☐			☐	☐
Leflunomide (LFL, Arava)	☐			☐	☐
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)	☐			☐	☐
Other Immunosuppressive Medication, Specify	☐			☐	☐
Rituximab	☐			☐	☐

		Ind.	Days	ST	Maint	AR
Zortress (Everolimus)		☐			☐	☐
Other Immunosuppressive Medication, Specify		☐			☐	☐