

# Records

## Pediatric Kidney Transplant Recipient Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 02/29/2012

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI<sup>®</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>®</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"/>
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"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Transplant Hospitalization:	
Date of Admission to Tx Center: *	<input type="text"/>
Date of Discharge from Tx Center:	<input type="text"/>

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

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
- Unable to participate regularly in academics due to dialysis
- Not Applicable < 5 years old/ High School graduate or GED
- Status Unknown

Source of Payment:

Primary:\*

Specify:

Secondary:

Clinical Information : PRETRANSPLANT

**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.*

**Pretransplant Dialysis:** \*

YES  NO  UNK

If Yes, Date of Most Recent Initiation of Chronic Maintenance Dialysis:

ST=

**Serum Creatinine at Time of Tx:** \*

 mg/dl

ST=

**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

Positive

EBV Serostatus:\*

- Negative
- Not Done
- UNK/Cannot Disclose

Was preimplantation kidney biopsy performed at the transplant center:

- YES
- NO

Did patient receive any pretransplant blood transfusions:\*

- YES
- NO
- UNK

Any tolerance induction technique used:

- YES
- NO
- UNK

Previous Pregnancies:

- NO PREVIOUS PREGNANCY
- 1 PREVIOUS PREGNANCY
- 2 PREVIOUS PREGNANCIES
- 3 PREVIOUS PREGNANCIES
- 4 PREVIOUS PREGNANCIES
- 5 PREVIOUS PREGNANCIES
- MORE THAN 5 PREVIOUS PREGNANCIES
- NOT APPLICABLE: < 10 years old
- UNKNOWN

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
- Other, specify

Specify:

Bone Disease:

Fracture in the past year (or since last follow-up):\*

YES  NO  UNK

Specify Location and number of fractures:\*

Spine-compression fracture: # of fractures:

Extremity: # of fractures:

Other: # of fractures:

AVN (avascular necrosis):\*

YES  NO  UNK

### Clinical Information : TRANSPLANT PROCEDURE

#### Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Procedure Type:

#### Kidney Preservation Information:

Total Cold ischemia Time Right KI(OR EN-BLOC): (if pumped, include pump time):  hrs ST=

Total Warm Ischemia Time Right KI (OR EN-BLOC): (Include Anastomotic time):  min ST=

Total Cold ischemia Time Left KI (if pumped, include pump time):  hrs ST=

Total Warm ischemia Time Left KI (include Anastomotic time):  min ST=

Kidney(s) received on:\*

Ice  
 Pump  
 N/A

Received on ice:

Stayed on ice  
 Put on pump

Received on pump:

Stayed on pump  
 Put on ice

If put on pump or stayed on pump:

Final resistance at transplant:  ST=

Final flow rate at transplant:  ST=

Incidental Tumor found at time of Transplant:

YES  NO  UNK

If yes, specify tumor type:

Oncocytoma  
 Renal Cell Carcinoma  
 Carcinoid  
 Adenoma  
 Transitional Cell Carcinoma

Other Primary Kidney Tumor, Specify.

Specify:

### 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.

Resumed Maintenance Dialysis:

YES  NO

Date Maintenance Dialysis Resumed:

Select a Dialysis Provider:

Provider #:

Provider Name:

Date of Graft Failure:

Primary Cause of Graft Failure:

- HYPERACUTE REJECTION
- ACUTE REJECTION
- PRIMARY FAILURE
- GRAFT THROMBOSIS
- INFECTION
- SURGICAL COMPLICATIONS
- UROLOGICAL COMPLICATIONS
- RECURRENT DISEASE
- OTHER SPECIFY CAUSE

Specify:

Contributory causes of graft failure:

Acute Rejection:

YES  NO  UNK

Graft Thrombosis:

YES  NO  UNK

Infection:

YES  NO  UNK

Surgical Complications:

YES  NO  UNK

Urological Complications:

YES  NO  UNK

Recurrent Disease:

YES  NO  UNK

Other, Specify:

Most Recent Serum Creatinine Prior to Discharge:\*

mg/dl

ST=

Kidney Produced > 40ml of Urine in First 24 Hours:

YES  NO

Patient Need Dialysis within First Week:\*

YES  NO

Creatinine decline by 25% or more in first 24 hours on 2

separate samples:

YES  NO

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

Is growth hormone therapy used between listing and transplant:\*

YES  NO  UNK

Date of Measurement:

Height:\*

 ft.  in. cm

ST=

Weight:\*

 lbs kg

ST=

BMI:

kg/m<sup>2</sup>

### 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 immunosuppressive 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)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Atgam (ATG)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
OKT3 (Orthoclone, Muromonab)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Simulect - Basiliximab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Zenapax - Daclizumab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Azathioprine (AZA, Imuran)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
EON (Generic Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Gengraf (Abbott Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Other generic Cyclosporine, specify brand:	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Neoral (CyA-NOF)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sandimmune (Cyclosporine A)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
CellCept (Mycophenolate Mofetil; MMF)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Generic MMF (Generic CellCept)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Prograf (Tacrolimus, FK506)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Generic Tacrolimus (Generic Prograf)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Advagraf (Tacrolimus Extended or Modified Release)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Nulojix (Belatacept)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sirolimus (RAPA, Rapamycin, Rapamune)		<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Myfortic (Mycophenolate Sodium)		<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

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 (Cytoxin)	<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="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
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	
Zortress (Everolimus)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Other Immunosuppressive Medication, Specify	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>