

Records

Pediatric Kidney-Pancreas 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[®] 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:	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	
Kidney Primary Diagnosis: *	<input type="text"/>
Specify:	<input type="text"/>
Pancreas 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
Retransplanted organ:	<input type="radio"/> Kidney <input type="radio"/> Pancreas <input type="radio"/> Kidney/Pancreas
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: *

Date of Discharge from Tx Center:

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

- YES NO UNK

Medical Condition: *

- 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

Kidney Source of Payment:

Primary: *

Specify:

Secondary:

Pancreas Source of Payment:

Primary: *

Specify:

Secondary:

Clinical Information : PRETRANSPLANT

Date of Measurement:

Height: *

 ft. in.

cm

ST=

Weight: *

kg

ST=

BMI:

kg/m²

Previous Transplants:

Previous Transplant Organ	Previous Transplant Date	Previous Transplant Graft Fail Date
<input type="text"/>	<input type="text"/>	<input type="text"/>

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=

Average Daily Insulin Units: *

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

HBV Surface Antigen:*

- Not Done
- UNK/Cannot Disclose
- 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

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.

- Skin Melanoma
- Skin Non-Melanoma

If yes, specify type:

- 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:

Surgical Information:

Was the Pancreas revascularized before or after other organs:

- Before
- Simultaneous
- After
- Not Applicable
- Iliac Fossa PA left/KI right
- Iliac Fossa PA right/KI left
- Left
- Midline
- Right
- INTRA-PERITONEAL
- RETRO-PERITONEAL

Surgical Incision:

Graft Placement:*

Operative Technique: *

PARTIAL INTRA/RETRO-PERITONEAL

Simultaneous Kidney-Pancreas

Cluster

Multi-Organ Non-Cluster

ENTERIC W/ROUX-EN-Y

ENTERIC W/O ROUX-EN-Y

CYSTOSTOMY

DUCT INJECTION IMMEDIATE

DUCT INJECTION DELAYED

OTHER SPECIFY

Duct Management: *

Specify:

Venous Vascular Management: *

SYSTEMIC SYSTEM (ILIAC:CAVA)

PORTAL SYSTEM (PORTAL OR TRIBUTARIES)

NA/Multi-organ cluster

CELIAC WITH PANCREAS

Y-GRAFT TO SPA & SMA

SPA TO SMA DIRECT

SPA TO SMA WITH INTERPOSITION

SPA ALONE

OTHER SPECIFY

Arterial Reconstruction: *

Specify:

Venous Extension Graft: *

YES NO

Kidney and Pancreas 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=

Total Pancreas Preservation Time (include Cold, Warm, Anastomotic time): *

 hrs

ST=

Kidney(s) received on: *

Ice

Pump

N/A

Received on ice:

Stayed on ice

Received on pump:

- Put 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

Kidney 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:

Kidney Date of Graft Failure:

Kidney 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:

- Kidney Acute Rejection: YES NO UNK
- Kidney Graft Thrombosis: YES NO UNK
- Kidney Infection: YES NO UNK
- Surgical Complications: YES NO UNK
- Urological Complications: YES NO UNK
- Recurrent Disease: YES NO UNK
- Other, Specify:

- Did patient have any acute kidney 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
- 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

- Pancreas Graft Status: * Functioning Partial Function Failed

If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select Functioning.

- Method of blood sugar control: (check all that apply)
- Insulin
- Oral medication
- Diet
- No Treatment
- Date Insulin/Medication Resumed:
- Date of Graft Failure Pancreas:
- Pancreas Graft Removed: YES NO UNK
- If Yes, Date Pancreas Graft Removed:

Pancreas Primary Cause of Graft Failure:

Pancreas Primary Cause of Graft Failure/Specify:

Contributory causes of graft failure:

Pancreas Graft/Vascular Thrombosis:

YES NO UNK

Pancreas Infection:

YES NO UNK

Bleeding:

YES NO UNK

Anastomotic Leak:

YES NO UNK

Hyperacute Rejection:

YES NO UNK

Pancreas Acute Rejection:

YES NO UNK

Biopsy Proven Isletitis:

YES NO UNK

Pancreatitis:

YES NO UNK

Other, Specify:

Did patient have any acute pancreas 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

Biopsy not done

Was biopsy done to confirm acute rejection:

Yes, rejection confirmed

Yes, rejection not confirmed

Pancreas Transplant Complications:

(Not leading to graft failure.)

Pancreatitis: *

YES NO UNK

Anastomotic Leak: *

YES NO UNK

Abcess or Local Infection: *

YES NO UNK

Other:

Weight Post Transplant: *

 lbs. kg

ST=

Treatment

Biological or Anti-viral Therapy:

YES NO Unknown/Cannot disclose

Acyclovir (Zovirax)

Cytogam (CMV)

If Yes, check all that apply:

- 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	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 (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"/>
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="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>