

# Records

## Pediatric Kidney-Pancreas 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<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.

Name:  DOB:   
SSN:  Gender:   
HIC:  Tx Date:

State of Permanent Residence: \*

Permanent Zip: \*

Recipient Center:

Surgeon Name: \*

NPI#: \*

UNOS Donor ID #:

Donor Type:

Kidney Primary Diagnosis: \*

Specify:

Pancreas Primary Diagnosis: \*

Specify:

Date: Last Seen, Retransplanted or Death \*

Patient Status: \*  LIVING  
 DEAD  
 RETRANSPLANTED

Retransplanted organ:

Kidney  Pancreas  Kidney/Pancreas

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: \*

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:

Date of Measurement:

Height: \*  ft.  in.  cm ST=

Weight: \*  kg ST=

BMI:  kg/m<sup>2</sup>

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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=

Average Daily Insulin Units: \*  ST=

Serum Creatinine at Time of Tx: \*  mg/dl ST=

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**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

HBV Core Antibody: \*

- UNK/Cannot Disclose
- 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

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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

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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

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Vessel Donor ID:

Procedure Type:

**Surgical Information:**

Was the Pancreas revascularized before or after other organs:

- Before
- Simultaneous
- After
- Not Applicable

Surgical Incision:

- Iliac Fossa PA left/KI right
- Iliac Fossa PA right/KI left
- Left
- Midline
- Right

Graft Placement: \*

- INTRA-PERITONEAL
- RETRO-PERITONEAL
- PARTIAL INTRA/RETRO-PERITONEAL

Operative Technique: \*

- Simultaneous Kidney-Pancreas

Duct Management: \*

- 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

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

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**Kidney and Pancreas Preservation Information:**

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

 hrsST= 

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

 minST= 

Total Cold Ischemia Time Left KI (If pumped, include pump time):

 hrsST=



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
- 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:

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:

HYPERACUTE REJECTION

ACUTE REJECTION

PRIMARY FAILURE

GRAFT THROMBOSIS

Kidney Primary Cause of Graft Failure:  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:

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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

Biopsy not done

Was biopsy done to confirm acute rejection:

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

Was biopsy done to confirm acute rejection:

- Biopsy not done
- 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=

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)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide (Cytoxan)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL, Arava)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input 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 type="checkbox"/>	<input type="checkbox"/>

	Ind.	Days	ST	Maint	AR
Zortress (Everolimus)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input 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"/>