Records

Pediatric Kidney-Pancreas Transplant Recipient Registration Worksheet

The revised worksheet sample is for reference purposes only and is pending OMB approval.

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI[B.] 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[B.] 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: *

Permanent Zip: * -

Provider Information

Recipient Center:

Surgeon Name: *

NPI: *

Donor Information

UNOS Donor ID #:

Donor Type:

Patient Status

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 (verified by IQ score <70 or unambiguous behavioral observation)
- Probable Cognitive delay/impairment (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence)
- Questionable Cognitive delay/impairment (not judged to be more likely than not, but with some indication of cognitive delay/impairment such as expressive/receptive language and/or learning difficulties)
- No Cognitive delay/impairment (no obvious indicators of cognitive delay/impairment)
- Not Assessed

Motor Development: *

- Definite Motor delay/impairment (verified by physical exam or unambiguous behavioral observation)
- Probable Motor delay/impairment (not verified or unambiguous but more likely than not, based on behavioral observation or other evidence)
- Questionable Motor delay/impairment (not judged to be more likely than not, but with some indications of motor delay/impairment)
- No Motor delay/impairment (no obvious indicators of motor delay/impairment)
- Not Assessed

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

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 %ile ST=

Weight: * kg %ile ST=

BMI: kg/m^2 %ile

Growth hormone therapy as a marker for growth delay: * YES NO UNK

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 First Dialyzed: 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

Positive

Negative

CMV IgG: *

- 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

Was preimplantation kidney biopsy performed at the transplant center:

- YES
- NO

Did patient receive any pretransplant blood tranfusions: *

- YES
- NO
- UNK

Any tolerance induction technique used:

- YES
- NO
- UNK

- NO PREVIOUS PREGNANCY
- 1 PREVIOUS PREGNANCY
- 2 PREVIOUS PREGNANCIES

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:

Is growth hormone therapy used between listing and transplant: * YES NO UNK

Bone Disease (check all that apply):

Fracture between listing and transplant: * 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:

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
- Cluster
- Multi-Organ Non-Cluster

Duct Management: *

- 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

Arterial Reconstruction: *

- CELIAC WITH PANCREAS
- Y-GRAFT TO SPA & SMA
- SPA TO SMA DIRECT
- SPA TO SMA WITH INTERPOSITION

- SPA ALONE
- OTHER SPECIFY

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
- 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

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
- ○ Biopsy not done

Was biopsy done to confirm acute rejection:

- Yes, rejection confirmed
- Yes, rejection not confirmed

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=

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 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
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)			
Mycophenolate Mofetil (MMF, Cellcept, RS61443)			
Tacrolimus (Prograf, FK506)			
Modified Release Tacrolimus FK506E (MR4)			
Sirolimus (RAPA, Rapamycin, Rapamune)			
Myfortic (Mycophenolate Sodium)			

Other Immunosuppressive Medications

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

Investigational Immunosuppressive Medications

	Ind.	Days	ST	Maint	AR
Everolimus (RAD, Certican)					

FTY 720		☐			☐	☐
Other, Specify		☐			☐	☐

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Comments: