Records

Pediatric Pancreas Transplant Recipient Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 10/31/2010

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: *

Permanent Zip: * -

Provider Information

Recipient Center:

Surgeon Name: *

NPI#: *

Donor Information

UNOS Donor ID #:

Donor Type:

Patient Status

Primary 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
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 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 Status Unknown
Source of Payment:	
Primary: *	
Specify:	
Secondary:	

Clinical Information : PRETRANSPLANT

Date of Measurement: *	

Height:*	ft. in.	cm	**%ile**	**ST=**
Weight:*	lbs	kg	**%ile**	**ST=**
BMI:	kg/m^2		**%ile**	

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**

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

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:

Clinical Information : TRANSPLANT PROCEDURE

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Procedure Type:

Surgical Information:

If a simultaneous Tx with another organ, was the Pancreas revascularized before or after other organs:

- Before
- Simultaneous
- After
- Not Applicable

Surgical Incision:

- Left
- Midline
- Other

	○ Right
Graft Placement: *	○ INTRA-PERITONEAL ○ RETRO-PERITONEAL ○ PARTIAL INTRA/RETRO-PERITONEAL
Operative Technique: *	○ PANCREAS ALONE ○ CLUSTER ○ MULTI-ORGAN NON-CLUSTER ○ PANCREAS AFTER KIDNEY ○ PANCREAS WITH KIDNEY DIFFERENT DONOR
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

Preservation Information:

Total Pancreas Preservation Time (include Cold, Warm, Anastomotic time): *	______ hrs	**ST=** ______

Clinical Information : POST TRANSPLANT

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.

☐ Insulin

Method of blood sugar control: (check all that apply)
- ☐ Oral medication
- ☐ Diet
- ☐ No Treatment

Date insulin/medication first resumed: ____

Date of Graft Failure: ____

Pancreas Graft Removed: ○ YES ○ NO ○ UNK

Date Pancreas Graft Removed: ____

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:	____

Pancreas Transplant Complications:

(Not leading to graft failure.)

Pancreatitis:*	○ YES ○ NO ○ UNK
Anastomotic Leak:*	○ YES ○ NO ○ UNK
Abcess or Local Infection:*	○ YES ○ NO ○ UNK
Pancreas Transplant Complications: Other	____

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

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	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)					
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)					

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

Investigational Immunosuppressive Medications

	Ind.	Days	ST	Maint	AR
Everolimus (RAD, Certican)					
FTY 720					
Other Immunosuppressive Medication, Specify					

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Comments: