# Records

## Pediatric 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® 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.

Name: DOB:

SSN: Gender:

HIC: Tx Date:

State of Permanent Residence: *

Permanent Zip: * -

Recipient Center:

Surgeon Name: *

NPI#: *

UNOS Donor ID #:

Donor Type:

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

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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

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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 or GED
- ( ) Status Unknown

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**Source of Payment:**

Primary: *

Specify:

Secondary:

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Date of Measurement:

Height: * ft. in. cm ST=

Weight: * lbs kg ST=

BMI: $kg/m^2$

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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= _____

**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

HCV Serostatus: *

- Not Done
- UNK/Cannot Disclose
- 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:

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Vessel Donor ID:

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=

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 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: [ ]

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**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

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:

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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

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Definitions Of Immunosuppressive Medications

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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.**

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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) | ☐ | | | ☐ | ☐ |
| Cyclophosphamide (Cytoxan) | ☐ | | | ☐ | ☐ |
| Leflunomide (LFL, Arava) | ☐ | | | ☐ | ☐ |
| Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex) | ☐ | | | ☐ | ☐ |
| Other Immunosuppressive Medication, Specify | ☐ | | | ☐ | ☐ |
| Rituximab | ☐ | | | ☐ | ☐ |

| | Ind. | Days | ST | Maint | AR |
|---|---|---|---|---|---|
| Zortress (Everolimus) | ☐ | | | ☐ | ☐ |
| Other Immunosuppressive Medication, Specify | ☐ | | | ☐ | ☐ |