

# Records ?

## Pediatric Kidney-Pancreas Transplant Recipient Follow-Up Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 07/31/2020

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	
<b>Name:</b>	<b>DOB:</b>
<b>SSN:</b>	<b>Gender:</b>
<b>HIC:</b>	<b>Tx Date:</b>
<b>Previous Follow-Up:</b>	<b>Previous Px Stat Date:</b>
<b>Transplant Discharge Date:</b>	<input type="text"/>
<b>State of Permanent Residence:*</b>	<input type="text"/>
<b>Zip Code:*</b>	<input type="text"/> - <input type="text"/>

Provider Information	
<b>Recipient Center:</b>	
<b>Followup Center:</b>	
<b>Physician Name:*</b>	<input type="text"/>
<b>NPI#:*</b>	<input type="text"/>
<b>Follow-up Care Provided By:*</b>	<input type="radio"/> Transplant Center <input type="radio"/> Non Transplant Center Specialty Physician <input type="radio"/> Primary Care Physician <input type="radio"/> Other Specify
<b>Specify:</b>	<input type="text"/>

Donor Information	
<b>UNOS Donor ID #:</b>	
<b>Recovering OPO:</b>	
<b>Donor Type:</b>	

Patient Status	
<b>Date: Last Seen, Retransplanted or Death*</b>	<input type="text"/>
<b>Patient Status:*</b>	<input type="radio"/> LIVING <input type="radio"/> DEAD <input type="radio"/> RETRANSPLANTED <input type="radio"/> NOT SEEN
<b>If Retransplanted, choose organ(s):</b>	<input type="radio"/> Kidney <input type="radio"/> Pancreas <input type="radio"/> Kidney/Pancreas
<b>Primary Cause of Death:</b>	<input type="text"/>
<b>Specify:</b>	<input type="text"/>
<b>Contributory Cause of Death:</b>	<input type="text"/>
<b>Specify:</b>	<input type="text"/>
<b>Contributory Cause of Death:</b>	<input type="text"/>
<b>Specify:</b>	<input type="text"/>
<b>Has the patient been hospitalized since the last patient status date:*</b>	<input type="radio"/> YES <input type="radio"/> NO <input type="radio"/> UNK
<b>Functional Status:*</b>	<input type="text"/>
<b>Cognitive Development:*</b>	<input type="radio"/> Definite Cognitive delay/impairment <input type="radio"/> Probable Cognitive delay/impairment <input type="radio"/> Questionable Cognitive delay/impairment <input type="radio"/> No Cognitive delay/impairment <input type="radio"/> Not Assessed
<b>Motor Development:*</b>	<input type="radio"/> Definite Motor delay/impairment <input type="radio"/> Probable Motor delay/impairment <input type="radio"/> 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
- Not Applicable < 5 years old/ High School graduate or GED
- Status Unknown

Primary Insurance at Follow-up: \*

Specify:

Clinical Information

Date of Measurement:

Height: \*

 ft.  in. cm

ST=

Weight: \*

 lbs. kg

ST=

BMI:

kg/m<sup>2</sup>

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.

Kidney Date of Failure:

Kidney Primary Cause of Graft Failure:

Specify

If Functioning, Most Recent Serum Creatinine:

 mg/dl

ST=

Dialysis Since Last Follow-Up:

- NO
- Yes, returned to chronic maintenance dialysis (ESRD)
- Yes, returned to (or continued on) temporary dialysis

Date Maintenance Dialysis Resumed:

Pancreas Graft Status: \*

- Functioning
- Failed

If death is indicated for the recipient, report graft status up until the instance of death.

Patient using any method of blood sugar control:

YES  NO  UNK

Patient on oral medication to control blood sugar?\*

YES  NO  UNK

Date of medications resumed:\*

ST=

Patient using diet to control blood sugar:\*

YES  NO  UNK

Patient on insulin?

YES  NO  UNK

Date insulin resumed:\*

ST=

Total insulin dosage units:\*

ST=

Insulin duration of use:\*

 days

ST=

C-peptide value:

 ng/mL

ST=

HbA1c:

 %

ST=

Pancreas Date of Failure

Pancreas Primary Causes of Graft Failure

Specify:

Pancreas Graft/Vascular Thrombosis

YES  NO  UNK

Pancreas Infection

YES  NO  UNK

Pancreas Bleeding

YES  NO  UNK

Anastomotic Leak

YES  NO  UNK

Pancreas Rejection: Acute

YES  NO  UNK

Pancreas Chronic Rejection

YES  NO  UNK

Biopsy Proven Isletitis

YES  NO  UNK

Pancreatitis

YES  NO  UNK

Patient Noncompliance

YES  NO  UNK

Other, Specify:

Conv. From Bladder to Enteric Drain Performed:

YES  NO  UNK

Enteric Drain Date:

Pancreas Transplant Complications (Not leading to graft failure):

Pancreatitis

YES  NO  UNK

Anastomotic Leak

YES  NO  UNK

Abscess or Local Infection:

YES  NO  UNK

Other, Specify:

Yes, at least one episode treated with anti-rejection agent

Yes, none treated with additional anti-rejection agent

No

Unknown

Did patient have any kidney acute rejection episodes during the follow-up period:

Did patient have any pancreas acute rejection episodes during the follow-up period:

Yes, at least one episode treated with anti-rejection agent

Yes, none treated with additional anti-rejection agent

No

Unknown

Is growth hormone therapy used during this followup period:\*

YES  NO  UNK

Viral Detection:

Positive

Negative

Not Done

UNK/Cannot Disclose

CMV IgG:\*

CMV IgM: \*

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HIV Serology

- Positive
- Negative
- UKN/Cannot Disclose
- Not Done

HIV NAT

- Positive
- Negative
- UKN/Cannot Disclose
- Not Done

HbsAg

- Positive
- Negative
- UKN/Cannot Disclose
- Not Done

HBV DNA

- Positive
- Negative
- UKN/Cannot Disclose
- Not Done

HBV Core Antibody

- Positive
- Negative
- UKN/Cannot Disclose
- Not Done

HCV Serology

- Positive
- Negative
- UKN/Cannot Disclose
- Not Done

HCV NAT

- Positive
- Negative
- UKN/Cannot Disclose
- Not Done

Post Transplant Malignancy: \*

- YES
- NO
- UNK

Donor Related:

- YES
- NO
- UNK

Recurrence of Pre-Tx Tumor:

- YES
- NO
- UNK

De Novo Solid Tumor:

- YES
- NO
- UNK

De Novo Lymphoproliferative disease and Lymphoma:

- YES
- NO
- UNK

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

Immunosuppressive Information

Previous Validated Maintenance Follow-Up Medications:

Previous Validated Maintenance Follow-Up Medications:

Were any medications given during the follow-up period for maintenance:

- Yes, same as validated TRR form
- None given

Yes, but different than validated TRR form

**Immunosuppressive Medications**

**View Immunosuppressive Medications**

**Definitions Of Immunosuppressive Follow-Up 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.**

**Drug used for induction, acute rejection, or maintenance**

	Prev Maint	Curr Maint	AR
Steroids (prednisone, methylprednisolone, Solumedrol, Medrol, Decadron)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Drugs used for induction or acute rejection**

	Prev Maint	Curr Maint	AR
Atgam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Campath (alemtuzumab, anti-CD52)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cytoxan (cyclophosphamide)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Methotrexate (Folex PFS, Mexate-AQ, Rheumatrex)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
OKT3 (Orthoclone, muromonab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rituxan (rituximab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Simulect (basiliximab)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Drugs primarily used for maintenance**

	Prev Maint	Curr Maint	AR
<b>Cyclosporine, select from the following:</b>			
- EON (generic cyclosporine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Gengraf (Abbott cyclosporine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Neoral (CyA-NOF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Other generic cyclosporine, specify brand: <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Sandimmune (cyclosporine A)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Imuran (azathioprine, AZA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Mycophenolate acid, select from the following:</b>			
- CellCept (MMF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic MMF (generic CellCept)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Myfortic (mycophenolate acid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nulojix (belatacept)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rapamune (sirolimus, Rapamycin)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Tacrolimus, select from the following:</b>			
- Astagraf XL (extended release tacrolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Generic tacrolimus (generic Prograf)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Prograf (FK506)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Zortress (everolimus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Other drugs**

	Prev Maint	Curr Maint	AR
Other immunosuppressive medication, specify: <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other immunosuppressive medication, specify: <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

