

# Records

## Pediatric Liver 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<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.

Recipient Information	
Name:	DOB:
SSN:	Gender:
HIC:	Tx Date:
State of Permanent Residence: *	<input type="text"/>
Permanent Zip: *	<input type="text"/> - <input type="text"/>

  

Provider Information	
Recipient Center:	
Surgeon Name: *	<input type="text"/>
NPI#: *	<input type="text"/>

  

Donor Information	
UNOS Donor ID #:	
Donor Type:	

  

Patient Status	
Primary Diagnosis: *	<input type="text"/>
Specify:	<input type="text"/>
Date: Last Seen, Retransplanted or Death *	<input type="text"/>
Patient Status: *	<input checked="" type="radio"/> LIVING <input type="radio"/> DEAD <input type="radio"/> RETRANSPLANTED
Primary Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Contributory Cause of Death:	<input type="text"/>
Specify:	<input type="text"/>
Transplant Hospitalization:	
Date of Admission to Tx Center: *	<input type="text"/>
Date of Discharge from Tx Center:	<input type="text"/>
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

Patient on Life Support:\*

YES  NO

- Ventilator
- Artificial Liver
- Other Mechanism, Specify

Specify:

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<sup>2</sup> %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.

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

Any tolerance induction technique used:

- YES
- NO
- UNK

Pretransplant Lab Date:

SGPT/ALT:

 U/L

ST=

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
- Hepatoblastoma
- Hepatocellular Carcinoma
- Other, specify

Specify:

**Clinical Information : TRANSPLANT PROCEDURE**

Multiple Organ Recipient

Were extra vessels used in the transplant procedure:

Surgical Procedure:

- ORTHOTOPIC
- HETEROTOPIC

Procedure Type:

- Whole Liver
- Partial Liver, remainder not Tx or Living Transplant
- Split Liver
- Whole Liver with Pancreas (Technical Reasons)
- Partial Liver with Pancreas (Technical Reasons)
- Split Liver with Pancreas (Technical Reasons)

Split Type:

Preservation Information:

Warm Ischemia Time (include anastomotic time):

 min

ST=

Total Cold Ischemia Time (if pumped, include pump time):\*

 hrs

ST=

Risk Factors:

Did Patient receive 5 or more units of packed red blood cells within 48 hours prior to transplantation due to spontaneous portal hypertensive bleeding:

- YES  NO  UNK

Spontaneous Bacterial Peritonitis:

- YES  NO  UNK

Previous Abdominal Surgery:\*

- YES  NO  UNK

Portal Vein Thrombosis:\*

- YES  NO  UNK

Transjugular Intrahepatic Portacaval Stint Shunt:\*

- YES  NO  UNK

Incidental Tumor found at time of Transplant:

- YES  NO  UNK

If yes, specify tumor type:

- Hepatocellular Adenoma
- Hemangioma
- Hemangioendothelioma
- Angiomyolipoma
- Bile Duct Cystadenocarcinoma
- Cholangiocarcinoma
- Hepatocellular Carcinoma
- Hepatoblastoma
- Angiosarcoma
- Other Primary Liver Tumor, Specify

Specify:

Clinical Information : POST TRANSPLANT

Pathology Conf. Liver Diag. of Hospital Discharge:\*

Specify:

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.

Date of Graft Failure:

Causes of graft failure:

Primary Graft Failure  YES  NO  UNK

Vascular Thrombosis  YES  NO  UNK

Hepatic arterial thrombosis:  YES  NO  UNK

Hepatic outflow obstruction:  YES  NO  UNK

Portal vein thrombosis:  YES  NO  UNK

Biliary Tract Complication  YES  NO  UNK

Hepatitis: DeNovo  YES  NO  UNK

Hepatitis: Recurrent  YES  NO  UNK

Recurrent Disease (non-Hepatitis)  YES  NO  UNK

Acute Rejection  YES  NO  UNK

Infection  YES  NO  UNK

Other, Specify:

Discharge Lab Date:

Total Bilirubin:  mg/dl ST=

SGPT/ALT:  U/L ST=

Serum Albumin:  g/dl ST=

Serum Creatinine:  mg/dl ST=

INR:  ST=

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)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
Atgam (ATG)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
OKT3 (Orthoclone, Muromonab)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Thymoglobulin	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Simulect - Basiliximab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Zenapax - Daclizumab	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Azathioprine (AZA, Imuran)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
EON (Generic Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Gengraf (Abbott Cyclosporine)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other generic Cyclosporine, specify brand: <input type="text"/>	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Neoral (CyA-NOF)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sandimmune (Cyclosporine A)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Mycophenolate Mofetil (MMF, Cellcept, RS61443)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Tacrolimus (Prograf, FK506)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Modified Release Tacrolimus FK506E (MR4)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sirolimus (RAPA, Rapamycin, Rapamune)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Myfortic (Mycophenolate Sodium)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

**Other Immunosuppressive Medications**

	Ind.	Days	ST	Maint	AR
Campath - Alemtuzumab (anti-CD52)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Cyclophosphamide (Cytoxan)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leflunomide (LFL, Arava)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Other Immunosuppressive Medication, Specify	<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 checked="" type="checkbox"/>	<input type="checkbox"/>

Investigational Immunosuppressive Medications					
	Ind.	Days	ST	Maint	AR
Everolimus (RAD, Certican)	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
FTY 720	<input checked="" type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other Immunosuppressive Medication, Specify	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>

UNOS View Only	
Comments:	<input type="text"/>