## Records ?

## **Pediatric Liver Transplant Recipient Follow-Up 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<sup>B.</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>B.</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.

| Decinions Information   |   |
|---|---|
| Recipient Information   |   |
| Name:   | DOB:  |
| SSN:  | Gender:   |
| HIC:  | Tx Date:  |
| Previous Follow-Up:   | Previous Px Stat Date:  |
|   |   |
| Transplant Discharge Date:  |   |
| State of Permanent Residence: *   |   |
| State of Fermanent Residence.   |   |
| Zip Code: *   |   |
|   |   |
| Provider Information  |   |
| Recipient Center:   |   |
| Followup Center:  |   |
| Tollowap Collection   |   |
| Physician Name: *   |   |
|   |   |
| NPI: *  |   |
|   |   |
|   | Transplant Center   |
|   | Non Transplant Center Specialty Physician   |
| Follow-up Care Provided By: *   | C Britanna Cons Blancisian  |
|   | Primary Care Physician  |
|   | Other Specify   |
|   |   |
| Specify:  |   |
|   |   |
| Donor Information   |   |
|   |   |
| UNOS Donor ID #:  |   |
| Donor Type:   |   |
|   |   |
| Patient Status  |   |
| Date: Last Seen, Retransplanted or Death ★  |   |
|   | LIVING  |
|   | LIVING  |
| Patient Status: *   | • DEAD  |
|   |   |
|   | RETRANSPEANTED  |
|   |   |
| Primary Cause of Death:   |   |
| Specify:  |   |
| opcony.   |   |
|   |   |
| Contributory Cause of Death:  |   |
| Specify:  |   |
|   |   |
|   |   |
| Contributory Cause of Death:  |   |
| Specify:  |   |
|   |   |
| Hospitalizations  |   |
| Hospitalizations:   |   |
| Has the patient been hospitalized since the last patient status date: *   | C YES O NO UNK  |
|   |   |
| Number of Hospitalizations:   | St=   |
|   |   |
|   |   |
| Noncompliance:  |   |
| Was there evidence of noncompliance with immunosuppression medication during this follow-up period that compromised the patient's | C VEO C NO C UNIX   |
| recovery:   | YES NO UNK  |
|   |   |
| Functional Status: *  |   |
|   |   |
|   |   |
|   | <ul> <li>Definite Cognitive delay/impairment (verified by IQ score &lt;70 or unambiguous behavioral observation)</li> </ul> |
| Cognitive Development: ★  | 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   |  |  |  |  |
|  |  |  |  |  |  |
|  | 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)  |  |  |  |  |
| Motor Development: ★   | 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  |  |  |  |  |
|  |  |  |  |  |  |
|  |  |  |  |  |  |
|  | <ul><li>Within One Grade Level of Peers</li><li>Delayed Grade Level</li></ul>  |  |  |  |  |
| Academic Progress: *   | Special Education  |  |  |  |  |
|  | Not Applicable < 5 years old   |  |  |  |  |
|  | Status Unknown   |  |  |  |  |
|  |  |  |  |  |  |
|  | Full academic load   |  |  |  |  |
|  | Reduced academic load  |  |  |  |  |
| Academic Activity Level: *   | Unable to participate in academics due to disease or condition   |  |  |  |  |
|  | <ul><li>Not Applicable &lt; 5 years old/ High School graduate</li><li>Status Unknown</li></ul>   |  |  |  |  |
|  | - Status Girkilowii  |  |  |  |  |
| Primary Insurance at Follow-up: *  |  |  |  |  |  |
| Specify:   |  |  |  |  |  |
| Clinical Information   |  |  |  |  |  |
| Date of Measurement: *   |  |  |  |  |  |
| Height: ★  | ft in. cm %ile St=   |  |  |  |  |
| Weight: <del>*</del>   | lbs. kg %ile St=   |  |  |  |  |
| BMI:   | kg/m <sup>2</sup> %ile   |  |  |  |  |
| Pathology confirmed liver diagnosis at 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 Failure:   |  |  |  |  |  |
| Contributory causes of graft failure:  |  |  |  |  |  |
| Primary Graft Failure  | C YES NO UNK   |  |  |  |  |
| Vascular Thrombosis  | C YES NO UNK   |  |  |  |  |
| Hepatic arterial thrombosis  | © YES © NO © UNK   |  |  |  |  |
| Hepatic outflow obstruction  | © YES © NO © UNK   |  |  |  |  |
| Portal vein thrombosis   | G YES ONO UNK  |  |  |  |  |
| Biliary Tract Complication:  | € YES € NO € UNK   |  |  |  |  |
| Denovo Hepatitis   | G YES O NO UNK   |  |  |  |  |
| Recurrent Hepatitis:   | G YES G NO G UNK   |  |  |  |  |
| Recurrent Disease:   | G YES G NO G UNK   |  |  |  |  |
|  | YES NO UNK   |  |  |  |  |
| Acute Rejection:   | YES ONO UNK  |  |  |  |  |

| Chronic Rejection:  | C YES ONO UNK   |      |  |  |
|---|---|------|--|--|
| Infection:  | C YES C NO C UNK  |      |  |  |
| Patient Noncompliance:  | C YES O NO C UNK  |      |  |  |
| Other, Specify:   |   |      |  |  |
| Discharge Lab Data:   |   |      |  |  |
| Lab Date:   |   |      |  |  |
| Total Bilirubin:  | mg/dl   | St=  |  |  |
| SGPT/ALT:   | U/L   | St=  |  |  |
| Serum Albumin:  | g/dl  | St=  |  |  |
| Serum Creatinine:   | mg/dl   | St=  |  |  |
| INR (ratio):  |   | St=  |  |  |
| Most Recent Lab Data:   |   |      |  |  |
| Lab Date: *   |   |      |  |  |
| Total Bilirubin: *  | mg/dl   | St=  |  |  |
| SGPT/ALT:   | U/L   | St=  |  |  |
| Serum Albumin:  | g/dl  | St=  |  |  |
| Serum Creatinine: *   | mg/dl   | St=  |  |  |
| INR (ratio):  |   | St=  |  |  |
| Diabetes onset during the follow-up period: *   | C YES NO UNK  |      |  |  |
| Insulin dependent:  | C YES NO UNK  |      |  |  |
| Did patient have any acute rejection episodes during the follow-up period: *  Was biopsy done to confirm acute rejection: | Yes, at least one episode treated with anti-rejection agent Yes, none treated with additional anti-rejection agent No Unknown Biopsy not done Yes, rejection confirmed Yes, rejection not confirmed Unknown |      |  |  |
| Postransplant Malignancy: *   | YES NO UNK  |      |  |  |
| Donor Related:  | C YES ONO UNK   |      |  |  |
| Recurrence of Pre-Tx Tumor:   | C YES O NO UNK  |      |  |  |
| De Novo Solid Tumor:  | C YES O NO O UNK  |      |  |  |
| De Novo Lymphoproliferative disease and Lymphoma:   | C YES NO UNK  |      |  |  |
| Treatment   |   |      |  |  |
| Biological or Anti-viral therapy:   | C YES NO Unknown/Cannot disc  | lose |  |  |
|   | Acyclovir (Zovirax)   |      |  |  |
|   | Cytogam (CMV)   |      |  |  |
|   | Gamimune  |      |  |  |

|  | Gammagard  | Gammagard  |   |  |  |  |
|--|--|--|---|--|--|--|
| If Yes, check all that apply:  | Ganciclovir (Cytovene)   | Ganciclovir (Cytovene)   |   |  |  |  |
|  | Valgancyclovir (Valcyte)   | Valgancyclovir (Valcyte)   |   |  |  |  |
|  | HBIG (Hepatitis B Immune Glo   | bulin)   |   |  |  |  |
|  | Flu Vaccine (Influenza Virus)  |  |   |  |  |  |
|  | Lamivudine (Epivir) (for treatm  | nent of Hepatitis B)   |   |  |  |  |
|  | ☐ Valacyclovir (Valtrex)   |  |   |  |  |  |
|  | Other, Specify   |  |   |  |  |  |
| Specify:   |  |  |   |  |  |  |
| Specify:   |  |  |   |  |  |  |
| Other therapies:   | C YES NO   |  |   |  |  |  |
|  | Photopheresis  |  |   |  |  |  |
| If Yes, check all that apply:  | Plasmapheresis   |  |   |  |  |  |
|  | ☐ Total Lymphoid Irradiation (TL   | .l)  |   |  |  |  |
|  | <u>`</u>   |  |   |  |  |  |
| Immunosuppressive Information  |  |  |   |  |  |  |
| Previous Validated Maintenance Follow-Up Medications:  |  |  |   |  |  |  |
|  | Yes, same as previous validate   | ed report  |   |  |  |  |
| Were any medications given during the follow-up period for maintenance:  | Yes, but different than previou  | s validated report   |   |  |  |  |
|  | None given   |  |   |  |  |  |
|  |  |  |   |  |  |  |
| Did the physician discontinue all maintenance immunosuppressive medications:   | C YES NO   |  |   |  |  |  |
| Did the patient participate in any clinical research protocol for immunosuppressive medications:   | C YES C NO   |  |   |  |  |  |
| Specify:   |  |  |   |  |  |  |
| I I I I I I I I I I I I I I I I I I I  |  |  |   |  |  |  |
| Immunosuppressive Medications  |  |  |   |  |  |  |
| View Immunosuppressive Medications   |  |  |   |  |  |  |
|  |  |  |   |  |  |  |
| View Immunosuppressive Medications  Definitions Of Immunosuppressive Follow-Up Medications  For each of the immunosuppressant medications listed, check Previous Maintenprescribed for the recipient during this follow-up period, and for what reason. If a Previous Maintenance (Prev Maint) includes all immunosuppressive medication periods of time which may be either long-term or intermediate term with a tapering  | medication was not given, leave the assume given during the report period, which or go of the dosage until the drug is either ele  | ociated box(es) blank. covers the period from the last liminated or replaced by anothe   | clinic visit to the curren  | nt clinic visit, for varying oce drug (example:  |  |  |
| View Immunosuppressive Medications  Definitions Of Immunosuppressive Follow-Up Medications  For each of the immunosuppressant medications listed, check Previous Mainten prescribed for the recipient during this follow-up period, and for what reason. If a Previous Maintenance (Prev Maint) includes all immunosuppressive medication  | medication was not given, leave the assume given during the report period, which any of the dosage until the drug is either elections. This does not include any in a given at the current clinic visit to begin it for replaced by another long-term mainter  | ociated box(es) blank.  covers the period from the last  liminated or replaced by another  nmunosuppressive medications  in the next report for varying per  enance drug (example: Prednis   | clinic visit to the curren<br>er long-term maintenan<br>given to treat rejection<br>eriods of time which ma   | nt clinic visit, for varying oce drug (example: n episodes.  |  |  |
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| 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              |                   |                   |    |
|  | <b>Prev Maint</b> | <b>Curr Maint</b> | 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    |                   |                   |    |
|  | <b>Prev Maint</b> | <b>Curr Maint</b> | AR |
| Everolimus (RAD, Certican)                       |                   |                   |    |
| FTY 720  |                   |                   |    |
|  |                   |                   |    |