

R398. Health, Family Health and Preparedness, Children with Special Health Care Needs.

R398-30. Children's Organ Transplants.

R398-30-1. Authority and Purpose.

- (1) This rule is authorized by Section 26-1-5.
- (2) The purpose of this rule is to set forth the process and criteria to determine eligibility for and the awarding of financial assistance to children who need organ transplants.

R398-30-2. Definitions.

- (1) "Department" means Utah Department of Health, Children with Special Health Care Needs Bureau.
- (2) "Fund" means the Kurt Oscarson Children's Organ Transplant Fund in Title 26, Chapter 18a, Kurt Oscarson Children's Organ Transplant Coordinating Committee.
- (3) "Initial Medical Expenses" means medical expenses incurred from evaluation of transplant needs until two years post-transplant or until the age of 18. This includes; assessments and evaluations of prospective listed organ transplant recipients and potential organ donors, surgical costs, treatment, COBRA payments, and spend-downs or other related costs for Medicaid or other public assistance eligibility, but does not include travel and living expenses for recipients or families.
- (4) "Recipient" means a person who:
 - (a) is under the age of 18;
 - (i) is listed for an organ transplant or has received a transplant;
 - (ii) has resided, or whose legal guardian has resided in Utah for at least six months prior to applying for financial assistance; and
 - (b) maintains Utah residency while using the fund.
- (5) "Responsible party" means the adult individual who signed the fund contract for the transplant recipient to receive the financial assistance.

R398-30-3. Allowable Medical Expenses and Organ Transplants.

Recipients may apply for financial assistance for eligible medical expenses for any type and as many organ transplants as needed for the recipient up until age 18. Each recipient shall have a maximum lifetime benefit of \$10,000 based on fund availability and balance. The committee may award a lower lifetime benefit. The fund may pay eligible expenses up to age 20 for services rendered to the recipient while under the age of 18.

R398-30-4. Application Review and Determining Eligibility.

- (1) Eligibility for awarding financial assistance shall be based on:
 - (a) documentation, through physician assessment and evaluation;
 - (b) whether the person is listed or has received an organ transplant;
 - (c) verification and status of prior application efforts to other funding sources such as; Medicaid, CHIP, and SSI;
 - (d) submission by the applicant of a current Patient Financial Responsibility form; and
 - (e) committee review of an approved fund application.
- (2) If the recipient account is closed, the recipient, upon reapplication, will receive a priority review of a new application, so long as the recipient meets eligibility criteria at the time of reapplication.

R398-30-5. Awarding Financial Assistance to Recipients.

- (1) Prior to awarding financial assistance, the committee shall review the recipient's application for assistance to determine:
 - (a) the needs of the recipient both medically and financially; and
 - (b) the existence of other financial assistance, including the availability of insurance or other state aid.
- (2) Each listed or transplant recipient must apply for Medicaid, Children's Health Insurance Program assistance, or other public health coverage provided by the state, before the committee agrees to award any financial assistance.
- (3) As part of the review process, the responsible party of the recipient shall sign a release to allow all medical records of the child to be released to the Department.
- (4) As a part of the review process, the committee shall consider:
 - (a) the success rate of the particular organ transplant procedure needed by the child; and
 - (b) the extent of the threat to the child's life without the organ transplant.
- (5) In addition, the committee shall consider the availability of funds before awarding financial assistance. The committee may create a waiting list and prioritize the list by financial and medical needs. A financial assistance award is not an entitlement. The fund should not incur a deficit.
- (6) The Department shall create a recipient file that shall include information such as: the application, related documentation, correspondence, repayment plans, repayment amounts and the approved contract. This file and documentation will be stored securely for ten years after the recipient reaches the age of 18.
- (7) The committee may review and determine if the recipient is ineligible to receive funds when:
 - (a) the recipient's account has been reviewed and found to be inactive for two years;
 - (b) the Department has made three documented attempts to contact the responsible party or recipient to discuss inactivity without response;

- (c) there is a violation of the terms of the executed contract;
- (d) two years have passed since the transplant; or
- (e) the recipient is no longer a Utah resident.

R398-30-6. Terms for Repayment of Financial Assistance Loans.

- (1) Financial assistance shall be given in the form of an interest free loan. Terms, including amount and time frame for repayment of loans shall be set forth in an initial contract as agreed to by the responsible party and the Department.
- (2) Repayment shall be determined by the Committee prior to the contract being signed.
- (3) Medical expenses shall be submitted within 24 months after an eligible service was rendered.
- (4) Repayments shall begin monthly starting 24 months after the first check has been issued from the fund.
- (5) The Department shall send out annual invoices on the account status and repayment amount to the responsible party.
- (6) The responsible party will be accountable for repayment of the loan.
- (7) The account may go to collections if repayment is not received within the established timeframe as outlined in the contract.

R398-30-7. Waiver or Adjustment of Loan Repayment.

Prior to an account going to collections or if requested by the responsible party, the committee shall review the file and circumstances involved to determine if an adjustment or waiver should be made to the repayment amount or conditions.

KEY: organ transplants

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Authorizing, and Implemented or Interpreted Law: 26-1-5