

Urea Cycle Disorders Medical Foods and Supplements Financial Assistance Programs



What is the purpose of this program?

NORD's Urea Cycle Disorders Medical Foods and Supplements Financial Assistance Program offers financial support to patients seeking assistance with high out-of-pocket costs associated with the purchase of medical foods and supplements for the direct care and treatment of Urea Cycle Disorders. The Program provides financial assistance to public and private insured and/or uninsured patients who meet established financial eligibility requirements.

What are the qualification criteria for the Urea Cycle Disorders Medical Foods and Supplements Financial Assistance Program?

This program is designed to help patients who:

- Are a United States citizen or U.S. resident of six (6) months or greater with evidence of residency such as a utility bill showing the patient's name and address
- Have a diagnosis of Urea Cycle Disorder or are under evaluation for the diagnosis
- Are prescribed medical foods and/or supplements to treat UCDs
- Fall within the Program's financial guidelines and adhere to application requirements that are set in advance by NORD
- Meet additional criteria as instituted by NORD to establish need based assistance as such criteria is modified in accordance with regulations or advisory opinions.

How can a patient be referred to NORD for assistance?

Patients may contact NORD directly or be referred to NORD by a case manager or health care professional. Once contact is made with a patient, NORD's RareCareSM Patient Services Representative will guide the patient or caregiver through the application process. Case managers may refer to NORD via our referral portal, RareAccess, at RareAccess.org. Once the referral is received, the patient will be contacted by a Patient Services Representative within 24-48 hours.

What is NORD?

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is an independent charity dedicated to the identification, treatment and cure of rare "orphan" diseases such as Urea Cycle Disorders (UCDs) through education, advocacy, research and patient service programs.

NORD was founded by families struggling to obtain access to treatments and whose advocacy for change led to the passage of the Orphan Drug Act in 1983. NORD assists eligible patients (those with medical and financial needs) afford the treatments and medical services their healthcare professionals have prescribed.

Funding for NORD comes from a variety of sources including corporate donations, foundation grants, public contributions, and membership dues.

What is the basis of NORD's eligibility criteria?

NORD's eligibility criteria are based on reasonable, verifiable and uniform measures of financial need that are applied in a consistent manner on a first come, first-served basis without regard to the source of a patient's referral to NORD, the patient's choice of provider, or the treatments being used by an eligible patient.

FAQ

What is the application process?

A Patient Services Representative will guide the patient or caregiver through the application process during the initial phone call. Permission will be asked to complete a verification of financial status over the phone which may eliminate the need for a patient to submit paperwork to NORD. If the financial verification confirms that the patient falls within the program's financial guidelines and the patient agrees to NORD's Disclosure Agreement during the recorded telephone call, then the application process will be concluded and the patient approved for assistance.

What happens if an applicant does not meet the financial need criteria during the phone call?

If the financial verification process returns a result indicating the patient does not qualify, then the patient can still apply for assistance by completing an application form and providing financial documentation that NORD will review to assess financial need.

Once a patient is accepted into the assistance program, how long are they eligible?

Awards are granted to patients on a calendar year basis for up to 12 months. Patients may reapply if funding continues to be available.

Is there a limit to a patient's financial award?

A decision to place a "cap" on the award or limit the scope of assistance to beneficiaries is at NORD's discretion and is determined based on a variety of factors including the amount of donations received for the Program, as well as the volume of patients applying for support and their anticipated financial need. Applicants are informed that the Program is provided on a voluntary basis and may be discontinued at any time.

How does the payment or reimbursement process work?

NORD offers a debit card allowing authorized purchases for medical foods and supplements. If a debit card is not utilized, NORD will pay the service provider's invoice or reimburse the patient directly for their medical foods and supplements.

All claims submitted for payment or reimbursement must include supporting documentation. Supporting documentation can include, but not be limited to, an Explanation of Benefits statement (EOB), a receipt or evidence of payment statement.

Claims will be processed within 30 days from the date all necessary documentation has been received by NORD.

If a debit card is not used, how long after the date of purchase can the claim/receipt be submitted to NORD?

Service provider invoices or patients' evidence of payment are expected to be submitted within 60 days of the date of service.

NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians. Donations to NORD for this and other programs may be made by contacting NORD at rarediseases.org.

NORD's Urea Cycle Disorders Medical Foods and Supplements Financial Assistance Programs may be contacted by:

Phone: 877-333-1860
Fax: 203-405-0802
e-mail: UCD@rarediseases.org

9am - 7pm (E.S.T.) M - Th and 9am - 6pm Fri

US MAIL to: NORD
Attention: UCD Assistance Program
55 Kenosia Avenue, Danbury, CT 06810