NORD®
National Organization for Rare Disorders



CEREBROTENDINOUS XANTHOMATOSIS (CTX) PATIENT ASSISTANCE PROGRAM

PATIENT ASSISTANCE PROGRAM

What is the purpose of this program?

Having a rare disease is difficult. Adding in the complex care required to treat or manage that disease and figuring out how to pay for it makes a rare diagnosis even harder.

NORD's CTX Patient Assistance Program offers eligible individuals financial support to pay for out-of-pocket healthcare costs that are directly related to the care and treatment of this diagnosis.

Who is eligible to apply?

This program is designed to help patients who:

- Have a diagnosis of CTX.
- 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.
- Meet the program's financial eligibility criteria.

What is the application process?

Patients may be referred to the program by their health care provider, their case managers, or they may self-refer.

A NORD Patient Services Representative will guide the applicant through the application process and verify eligibility for inclusion in the CTX Program.

Awards are based on meeting eligibility criteria, funding availability, and are made on a first-come, first serve basis.

What is NORD?

NORD, the National Organization for Rare Disorders, is a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

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) in affording the treatments and medical services their healthcare professionals have prescribed.

Alone we are rare. Together we are strong.®

How do I get more information and apply?

Contact NORD's CTX Program

Monday-Thursday 8:30am – 7:00pm ET
Friday 8:30 am – 6:00pm ET

800-999-6673

203-349-8431

ctx@rarediseases.org

The quickest way to apply is on NORD's website at: bit.ly/patient-assist

Scroll down to CTX and click Apply Online.

US MAIL to: NORD
Attention: CTX Program
7 Kenosia Avenue
Danbury, CT 06810

What kinds of assistance can I request from NORD?

- Individuals who have health insurance may be assisted with financial assistance to cover health insurance premiums, deductibles, copayments & coinsurance costs.
- For individuals who do not have health insurance, NORD may be able to assist with access to health insurance and the associated expenses.

Some examples of these expenses may be:

> *health insurance premiums, deductibles & copayments.*

> *medical office visit or consult.*

> *out-of-pocket cost for medications prescribed by your physician to manage your CTX diagnosis.*

> *out-of-pocket costs for lab services or radiological services.*

> *physician prescribed supportive therapies such as wound care.*

> *physician prescribed specialist consults.*

> *travel related expenses for CTX related medical appointments.*

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

Awards are issued for a calendar year.

Patients are encouraged to reapply annually if continued assistance is needed.

Program assistance is dependent on funding availability.

What happens if an applicant does not meet the criteria of the Electronic Income Verification?

The NORD Patient Services Representative will offer to e-mail, fax, or mail the brief program application and disclosure forms to the patient. The applicant may then complete the application, sign the disclosure form, provide the appropriate financial documentation to verify financial need, and return them via fax, email, or USPS mail.

How does NORD demonstrate compliance with regulations required of charities?

- NORD independently designs its patient assistance programs based on the needs of specific patient communities.
- No pharmaceutical company or donor controls or influences our programs.
- Our patient assistance decisions are based on consistently applied financial eligibility criteria and diagnosis only.
- Patients have their choice of health care provider, treatment and treatment location, and can make changes at any time.
- Patients' privacy and well-being are priorities at NORD. We do not share or provide patient names or data with donors, nor do we disclose or identify donors to patients. Patients are able to make the choices that are best for them because NORD's assistance covers all FDA-approved products available for a diagnosis. Our programs also help with more than medication: patients can use their funds to pay for other physician prescribed services related to their diagnosis such as, laboratory and diagnostic testing, physical and occupational therapy, durable medical and adaptive equipment, and travel to medical appointments.



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