



NORD[®]
National Organization
for Rare Disorders

NEUROGENE PHASE 1/2: Intracerebroventricular and Intravitreal Administration of NGN-101 for Treatment of Neuronal Ceroid Lipofuscinosis (NCL) Subtype 5 (CLN5) Batten Disease

CLINICAL TRIAL
PARTICIPATION
SUPPORT PROGRAM

What is the purpose of this program?

Deciding to participate in a clinical trial is an important decision for patients and their families. When entering a clinical trial, the expense required for onsite treatment and monitoring may be a barrier to participation. This program lessens that financial burden.



The Batten Disease Clinical Trial Participation Support Program provides individuals enrolled in the Neurogene CLN5 Batten Disease trial with financial assistance for expenses associated with participation in the trial.



Who is eligible for this program?

If you are enrolled in the Neurogene CLN5 Batten Disease trial, and have expenses beyond what is covered by the trial sponsor (Neurogene), the coordinator at the study site will refer you to NORD.

- A NORD Patient Services Representative will assist you in identifying expenses for which you may be eligible for reimbursement.
- These may include expenses incurred as a result of the need for extended relocation for clinical trial/study participation.

Alone we are **rare**. Together we are strong.[®]

About the program

The National Organization for Rare Disorders (NORD®) Clinical Trial Participation Support Program provides financial support for some expenses that are not covered by the Neurogene CLN5 Batten Disease trial.

Expenses for which assistance may be provided include:

- Mortgage assistance while participating in the Neurogene trial, for up to six (6) months or up to the award maximum.
- Rental assistance (permanent residence, not trial location), while participating in the Neurogene trial, for up to six (6) months or up to the award maximum.
- Utility costs (permanent residence, not trial location), while participating in the Neurogene trial, for up to six (6) months or up to the award maximum.
- Other unforeseen eligible expenses related to clinical trial participation, up to the award maximum and excluding any expenses covered by Neurogene, will be reviewed on a case-by-case basis.

Receipts/Reimbursement

- Patient/caregiver must submit receipts for payment of eligible expenses and complete the NORD Expense Reimbursement Form to receive reimbursement.

Who do I contact at NORD for questions regarding the Clinical Trial Support Program?

Contact NORD Batten Disease Assistance Program
Monday – Thursday 8:30 am – 7:00 pm ET
Friday 8:30 am – 6:00 pm ET

☎ Phone 203.405.0585

☎ Fax 203.349.3836

✉ Email BattenDisease@rarediseases.org

✉ US Mail to: NORD
Attention: Batten Disease Clinical Trial Support
55 Kenosia Avenue
Danbury, CT 06810

NORD is Here for You

NORD, 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.