

Paroxysmal Nocturnal Hemoglobinuria (PNH)



What is the purpose of this program?

NORD's Paroxysmal Nocturnal Hemoglobinuria (PNH) Patient Assistance Programs offer eligible individuals diagnosed with PNH financial support when faced with limited resources to pay for:

- out-of-pocket healthcare costs including premiums, co-pay coinsurance, and/or
- diagnostic, laboratory and radiologic test costs, and/or
- the purchase of physician prescribed medication(s), and/or
- durable medical equipment
- travel related costs associated with direct care and treatment of PNH

Who is eligible to apply for NORD's Paroxysmal Nocturnal Hemoglobinuria Assistance grants?

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 Paroxysmal Nocturnal Hemoglobinuria
- Fall within the Program's financial guidelines and adhere to application requirements established by NORD

What kinds of assistance can I request from NORD?

NORD's program can assist eligible individuals with expenses in a number of categories:

- The PNH Premium Copay Program assists eligible individuals who have health insurance with funding to cover health insurance premiums, deductibles, copayments & coinsurance costs associated with the care of Paroxysmal Nocturnal Hemoglobinuria
 - Some examples of these expenses may be medical expenses paid toward health insurance premiums, as well as deductibles or copayments for a medical office visit or a coinsurance payment for a consult with a specialist, or out-of-pocket expenses for medications prescribed by a physician for the treatment of PNH
- The PNH Medical Assistance Program assists eligible individuals who are uninsured, or who have been denied coverage for medical expenses associated with the care of Paroxysmal Nocturnal Hemoglobinuria
 - Some examples of these expenses may be medical expenses, laboratory & diagnostic testing, durable medical equipment, prescriptions, mileage to and from a PNH associated medical appointment

FAQ

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 PNH 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) in affording 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.

Are there expenses which cannot be covered by NORD's patient assistance program?

Yes, NORD's goal is to be as flexible as possible in regards to patient's assistance needs, but some expenses which are not permissible by law are:

- Federal, state, or local tax payments, including property taxes, child support payments, legal fines and/or fees
- Luxury goods and services or vacation costs are not eligible for consideration.

Paroxysmal Nocturnal Hemoglobinuria (PNH) Patient Assistance Programs



What is the application process?

Awards are granted on a first come, first served basis. Patients may be referred to the program by their health care provider, their case managers, or they may self-refer. The RareCare® Patient Services Representative will guide the applicant through the application process, verify eligibility for inclusion in the Paroxysmal Nocturnal Hemoglobinuria Program(s), determine financial eligibility using our Electronic Income Verification System (EIV) and award assistance.

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

The RareCareSM 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 long before a decision is made on an application for assistance?

The application decision process can take as few as 5 minutes over the telephone. Applications completed and submitted via email, fax or US mail will be processed within three (3) business days of receipt.

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

A decision to place a "cap" on funding or limit the scope of assistance to beneficiaries is at NORD's discretion and is determined based on the amount of donations made to the fund, as well as the anticipated volume of applicants expected to utilize the program, and their anticipated financial need.

How do I apply for assistance from NORD's Paroxysmal Nocturnal Hemoglobinuria Patient Assistance Programs

Phone: 855-567-3814

Fax: 203-517-4297

Email: pnh@rarediseases.org

9am - 7pm (E.S.T.) Mon – Thurs and 9am - 6pm Fri

US MAIL to: NORD

Attention: PNH Assistance Program

55 Kenosia Avenue, Danbury, CT 06810

Is there a fee for applying for assistance?

No, NORD does not charge our applicants when applying for help.

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

Copay and Medical Assist awards are issued for a calendar year.

How does the payment or reimbursement process work?

Premium awards may be prepaid by NORD with appropriate documentation or reimbursed to the patient in accordance with appropriate receipts and documentation.

Copay and Medical Assist awards may be reimbursed to the patient upon receipt of appropriate receipts and documentation.

All claims submitted for reimbursement must be provided within 60 days and include receipts or other evidence of payment, such as a credit card statement.

Reimbursements will be made within ten (10) business days of receipt by NORD.

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.