

# Undiagnosed Patient Assistance Program



## What is the purpose of this program?

The NORD Undiagnosed Patient Assistance Program was designed to provide financial assistance to eligible individuals referred by the Undiagnosed Diseases Network (UDN) with out-of-pocket costs associated with:

- Diagnostic testing
- Pre-evaluation testing
- Medical record collection
- Travel for an additional person to accompany a patient to a UDN site

The Undiagnosed Diseases Network (UDN), supported by grants from the National Institutes of Health (NIH), goals are to provide answers to patients and families affected by mysterious conditions and to learn more about rare and common diseases.

## Who is eligible to apply for NORD's Undiagnosed Patient Assistance Program grants?

Patients wishing to apply for assistance through this program must contact the UDN for referral to NORD.

Patients may contact the UDN via email at [UDN@hms.harvard.edu](mailto:UDN@hms.harvard.edu) or by telephone at 1-844-746-4836.

These programs are designed to help patients who:

- Are referred to NORD by the UDN
- Are a United States (US) citizen or US resident of six (6) months or greater who can show evidence of residency
- Are willing to provide HIPAA authorization and sign a waiver of liability

## What kinds of assistance can I request from NORD?

NORD's program can assist eligible individuals with:

- Health insurance deductibles, copayments, and coinsurance costs associated with medical consults and physician ordered laboratory and diagnostic testing from the UDN evaluation.
- Necessary preliminary testing for evaluation in the UDN because they have been denied insurance coverage or do not have insurance coverage.
- Out-of-pocket expenses associated with the initial collection of medical records to facilitate UDN application review.
- Travel costs for an additional person to accompany a patient to the UDN evaluation.

This program does not assist with the cost of any medications

# 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 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.

## 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?

Awards are issued for a calendar year. While an award may be utilized multiple times within the calendar year, at no time can the Program award maximum be exceeded.

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## What is the application process?

Patients must be referred to NORD by the UDN. Upon referral, the NORD Patient Services Representative will guide the applicant through the application process and verify eligibility for inclusion in the program.

## 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 Undiagnosed Patient Assistance Program?

*Contact the UDN for referral. Once approved by the UDN, you may contact the NORD Undiagnosed Patient Assistance Program.*

Phone: 844.858.0451

Fax: 203.798.2289

Email: [undiagnosed@rarediseases.org](mailto:undiagnosed@rarediseases.org)

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

US MAIL to: NORD

Attention: Undiagnosed Program

55 Kenosia Avenue

Danbury, CT 06810