

Rare Caregiver Respite Program

What is the purpose of this program?

NORD's Rare Caregiver Respite Program is designed for caregivers (parent, spouse, family member, or significant other) of a child or adult diagnosed with a rare disorder. Caring for a loved one is a generous gift (though certainly not easy). The program provides financial assistance to enable the caregiver a well-deserved break. Perhaps the caregiver would like to attend a conference, event or have an afternoon or evening away from caregiving...this program can help.

- Examples of what the NORD Rare Caregiver Respite Care Program financial assistance may cover:
 - Registered Nurse (RN) care
 - Licensed Practical Nurse (LPN) care
 - Certified Nursing Assistant (CNA) / Nursing Assistant
 - Home Health Aide (HHA)
- NORD will provide financial assistance to eligible caregivers for up to \$500 annually so that a respite caregiver may be secured to care for your loved one.
- The grant may be dispersed throughout a calendar year or be used in a single award.

Who is eligible to apply for NORD's Rare Caregiver Respite Program grants?

- The rare disease patient caregiver (parent, spouse, family member, or significant other) must submit an application and supporting documentation
- The patient for whom care is being provided must have a confirmed rare disease diagnosis
- The caregiver must be a US citizen or permanent resident of the United States for at least 6 months with evidence of residency such as a utility bill showing the patient's name and address
- The applicant must be willing to undergo a financial evaluation of need and fall within the Program's financial eligibility guidelines that are set in advance by NORD

What is the application process?

Awards are granted on a first come, first served basis to eligible individuals. A NORD Patient Services Representative will guide the applicant through the application process, verify eligibility for inclusion in the Rare Caregiver Respite Program, 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 Patient Services Representative will offer to e-mail, fax, or mail the brief program application and disclosure forms to the applicant. 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.

How do I apply for assistance from NORD's Rare Caregiver Respite Program?

Phone: 203.616.4328

Fax: 203.405.0321

E-mail: CaregiverRespite@rarediseases.org

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 an applicant is accepted into the program how long are they eligible?

Awards are provided on an annual basis (for a calendar year) and as a capped annual award.

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.