



**NORD**<sup>®</sup>  
National Organization  
for Rare Disorders



# RARE DISEASE EDUCATIONAL SUPPORT PROGRAM

## What is the purpose of this program?

The Rare Disease Education Support Program is designed to offer rare disease patients and/or their families/caregivers an opportunity to participate in educational programs and conferences that offer rare disease content. NORD's program provides financial support for registration costs (and once conferences are no longer solely virtual, the program will also provide limited assistance with associated travel and lodging costs for conference participation).

Interested applicants may apply for financial assistance to advance their knowledge, participate in collaborative opportunities, network with peers, medical professionals, researchers, advocacy groups and subject matter leaders.



As the saying goes, knowledge is power. It is vital that people directly impacted by the more than 7,000 rare diseases are armed with the knowledge and information they need to live their best lives while managing their rare condition. One of the pillars of NORD's mission is educating patients and caregivers to advocate for themselves so they can gain access to accurate diagnoses, clinical research, quality care and treatments.



## Who is eligible to apply?

This program is designed for those diagnosed with a rare disease and immediate family/caregivers.

- The applicant or applicant's family member must be diagnosed with, or under consideration for diagnosis of a recognized rare disease.
- The applicant(s) must be a US citizen or permanent resident of the United States for at least 6 months.

Assistance is based on eligibility criteria and funding availability.

## 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.*

**Alone we are rare. Together we are strong.**<sup>®</sup>

## How do I get more information and apply?

Contact NORD's Rare Disease Educational Support Programs

Monday-Thursday 8:30am – 7:00pm ET

Friday 8:30am – 6:00pm ET

 860.556.2208

 203.635.7486

 rdeducate@rarediseases.org

 US MAIL to: NORD  
Attention: RD Educate Program  
55 Kenosia Avenue  
Danbury, CT 06810

## What kinds of assistance are offered in this program?

- Reimbursement for the registration costs of rare disease conferences and educational programs (conferences that provide patient or family scholarships are excluded).
- Classes that are online, virtual or in-person may be eligible.
- Examples of rare disease educational programs include:
  - › General rare disease educational programs or conferences
  - › Disease-state specific programs, or meetings
  - › Workshops that support a specific care aspect for rare disease such as nutrition
  - › Rare disease advocacy meetings
  - › Rare disease support group meetings or workshops
- Limited financial assistance with the cost of travel to a rare disease educational conference or program.
- Limited assistance with the cost of lodging should overnight stay be required in order to attend or participate in a rare disease educational program.

## What is the application process for this program?

The rare disease diagnosed and or his/her family or caregiver may contact NORD by phone, or email to apply.

The RareCare® Patient Services Representative will guide the applicant through the application process, determine eligibility and award assistance.

Awards are granted on a first come, first served basis.

