



## NORD Launches New Program Aimed at Providing Caregivers with Relief

May 20, 2019

*Grant program established with gift from Retrophin*

**Washington, DC and San Diego, May 20, 2019**—The National Organization for Rare Disorders (NORD)<sup>®</sup>, the leading independent nonprofit organization representing the 25-30 million Americans living with rare diseases, has launched the Rare Caregiver Respite Program, a first-of-its-kind program aimed at providing caregivers of rare disease patients a much-needed respite. Initial funding for the program was donated by Retrophin (NASDAQ: RTRX), a biopharmaceutical company specializing in identifying, developing and delivering life-changing therapies to people living with rare disease, in honor of its former CEO Steve Aselage's retirement from the company.

Caring for a loved one with a rare disease demands significant time, attention, patience and dedication. NORD's Rare Caregiver Respite Program is designed to give back to caregivers—the parent, spouse, family member, or significant other—of a child or adult living with a rare disorder, and provides financial assistance to enable the caregiver a well-deserved break.

"At NORD, we are proud to have provided a variety of services and assistance to patients over the years," said Jill Pollander, director of patient services for NORD. "The new Rare Caregiver Respite Program allows us to acknowledge the hard work that families and significant others do so tirelessly every day by enabling them some time away while ensuring their loved one is well cared for. It's a thank you we are thrilled to be able to give."

Through the program, NORD will provide financial assistance to eligible caregivers covering up to \$500 annually so that a respite caregiver may be secured to care for a loved one. Potential applicants can reach out to NORD to ascertain if they meet eligibility requirements. The grant may be dispersed throughout a calendar year or be used in a single award. Examples of what the NORD Rare Caregiver Respite Care Program financial assistance may cover include:

- o Registered Nurse (RN) care
- o Licensed Practical Nurse (LPN) care
- o Certified Nursing Assistant (CNA) / Nursing Assistant
- o Home Health Aide (HHA)

"Caregivers in the rare disease community spend a significant amount of time, effort, and resources helping their loved ones—and they rarely get to take a break," said Eric Dube, Ph.D., chief executive officer of Retrophin. "This program is designed to show appreciation for caregivers' generosity. I can't think of a better way to honor Steve Aselage's work in the rare disease community than to support those who dedicate their lives to caring for patients living with rare disease."

The fund continues to accept additional donations to ensure this first-of-its-kind program is sustained for years to come. For more information and instructions on how to apply, visit [rarediseases.org](http://rarediseases.org)

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### **About the National Organization for Rare Disorders (NORD)**

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases. NORD is committed to the identification, treatment and cure of the more than 7,000 rare diseases, of which approximately 90 percent are still without an FDA-approved treatment or therapy. Rare diseases affect 25-30 million Americans. More than half of those affected are children.

NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 35 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research and providing patient and family services for those who need them most. NORD is made strong together with over 280 disease-specific member organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease patient community.

[Rarediseases.org](http://Rarediseases.org)

### **About Retrophin**

Retrophin is a biopharmaceutical company specializing in identifying, developing and delivering life-changing therapies to people living with rare disease. The Company's approach centers on its pipeline featuring late-stage assets targeting rare diseases with significant unmet medical needs, including fosmetpantotenate for pantothenate kinase-associated neurodegeneration (PKAN), a life-threatening neurological disorder that typically begins in early childhood, and sparsentan for focal segmental glomerulosclerosis (FSGS) and IgA nephropathy (IgAN), disorders characterized by

progressive scarring of the kidney often leading to end-stage renal disease. Research in additional rare diseases is also underway, including a joint development arrangement evaluating the potential of CNSA-001 in phenylketonuria (PKU), a rare genetic metabolic condition that can lead to neurological and behavioral impairment. Retrophin's R&D efforts are supported by revenues from the Company's commercial products Chenodal®, Cholbam® and Thiola®.

[Retrophin.com](http://Retrophin.com)

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