Retrophin Recognizes Rare Disease Day® 2019 and Honors People Living with Rare Disease and Their Caregivers

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SAN DIEGO, Feb. 28, 2019 (GLOBE NEWSWIRE) -- Retrophin, Inc. (NASDAQ: RTRX) today joins the National Organization for Rare Disorders (NORD), the European Organisation for Rare Diseases (EURORDIS), and others worldwide to recognize Rare Disease Day® 2019. This year's theme, "Bridging health and social care" acknowledges the impact that rare disease has on the day-to-day lives of people living with rare disease and their caregivers. The administration of rare disease care takes significant time, resources and effort for patients and their family and friends.

“On Rare Disease Day, we honor patients and caregivers for their courage to manage the care of rare conditions, and we acknowledge that coordinating care touches all aspects of their lives,” said Eric Dube, Ph.D., chief executive officer of Retrophin “We are committed to integrating the patient and caregiver perspective in all elements of our work so that we can make a meaningful difference in the lives of those we serve.”

As part of its dedication to the rare disease community, Retrophin has sponsored a report by the National Alliance of Caregiving, in partnership with Global Genes, examining the impact that rare disease has on caregivers in the U.S. Rare caregivers are family members or friends who provide unpaid care to one of the 25 to 30 million Americans living with rare disease. 84 percent of rare caregivers perform medical/nursing tasks, and 67 percent say providing care to their care recipient is emotionally stressful with a majority of caregivers feeling highly stressed.[1]

Rare diseases are defined as those that affect fewer than 200,000 people in the United States,[2] and fewer than 1 in 2,000 people in the EU.[3] Roughly 80 percent of rare diseases are genetic, with approximately half affecting children.[2] Rare Disease Day, which is held on the last day of February every year, seeks to build public awareness about rare diseases and their impact on people's lives. It is led in the U.S. by NORD and internationally by EURORDIS. For information on Rare Disease Day participation, visit rarediseaseday.us, or rarediseaseday.org.

About NORD

Established in 1983, the National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. A nonprofit organization, NORD represents the 30 million Americans with rare diseases and is committed to the identification, treatment and cure of rare disorders through patient assistance, education, advocacy, research and patient/family services. For more information about NORD, visit rarediseases.org.

About EURORDIS

EURORDIS is a non-governmental patient-driven alliance of 606 rare disease patient organizations in 56 countries. EURORDIS strives to build a strong pan-European community of patient organizations and people living with rare diseases, to be their voice at the European level, and - directly or indirectly - to fight against the impact of rare diseases on their lives. EURORDIS leads global efforts for Rare Disease Day, which it established in 2008. The observance is celebrated around the world on the last day of February each year with the goal of raising awareness of rare diseases as a public health issue. For more information about EURORDIS, visit eurordis.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

[1]National Alliance for Caregiving. February 2018. Rare Disease Caregiving in America.
[2]Global Genes website. https://globalgenes.org/rare-diseases-facts-statistics/. Last accessed February 5, 2019.
[3]EURODIS website. https://www.eurordis.org. Last accessed February 5, 2019.

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