Retrophin Recognizes Rare Disease Day 2020 and the Importance of Working Together Toward More Equitable Access to Care

February 28, 2020

SAN DIEGO, Feb. 28, 2020 (GLOBE NEWSWIRE) -- Retrophin, Inc. (NASDAQ: RTRX) will join the National Organization for Rare Disorders (NORD), the European Organisation for Rare Diseases (EURORDIS), and rare disease advocates and patients worldwide to recognize February 29 as Rare Disease Day 2020. This year, the theme, “Rare is many, rare is strong and rare is proud!,” reframes perceptions of what it means to be rare with the goal of highlighting the need for more equitable access to diagnosis, treatment and care for the millions of people worldwide living with a rare disease.

“Part of equitable access to care is ensuring that each person living with rare disease is heard,” said Eric Dube, PhD, chief executive officer of Retrophin. “People with mobility disabilities, communities of color, those living in geographically remote areas – we must work harder to reach all people and to understand their needs. This Rare Disease Day, we celebrate that rare is many, rare is strong, rare is proud – and rare is incredibly diverse.”

As part of the company’s continued commitment to people living with rare disease, Retrophin supported *Rare Disease Week on Capitol Hill,* February 24-28, a program of the EveryLife Foundation for Rare Diseases. Rare Disease Week brings rare disease community members from across the country together to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators. During Rare Disease Week, Dr. Dube spoke about the company’s dedication to collaboration with the goal of ensuring patients have a voice in policymaking, product development, and regulatory decision making, at the Congressional Rare Disease Caucus briefing in the Senate.

In addition to participating in Rare Disease Week on Capitol Hill, Retrophin is celebrating Rare Disease Day by hosting a panel of patients and advocates to highlight the gaps in access for those living with rare diseases and the innovative new solutions to bridge them.

Rare diseases are defined as those that affect fewer than 200,000 people in the United States, and fewer than 1 in 2,000 people in the EU.[1] 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-Rare Diseases Europe is a unique, non-profit alliance of over 800 rare disease patient organisations from 70+ countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. Rare Disease Day was launched by EURORDIS and its Council of National Alliances in 2008 and brings together millions of people in solidarity. EURORDIS coordinates the global community in organising Rare Disease Day, which takes place on the last day of February each year to raise awareness of the impact that rare diseases have on over 300 million people around the world.For more information about EURORDIS, visit eurordis.org.

About EveryLife

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science-driven public policy. The Foundation does not speak for patients, but instead provides the training, education, resources and opportunities to make patient voices heard. By activating the patient advocate, the Foundation believes it can change public policy and save lives. For more information about EveryLife Foundation for Rare Disease, visit everylifefoundation.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 sparsentan, a product candidate in late-stage development for focal segmental glomerulosclerosis (FSGS) and IgA nephropathy (IgAN), rare disorders characterized by progressive scarring of the kidney often leading to end-stage renal disease. Research in additional rare diseases is also underway, including partnerships with leaders in patient advocacy and government research to identify potential therapeutics for NGLY1 deficiency and Alagille syndrome, conditions with no approved treatment options. Retrophin’s R&D efforts are supported by revenues from the Company’s commercial products Chenodal ®, Cholbam®, Thiola® and Thiola EC®.

Retrophin.com

1. National Institutes of Health, Genetic and Rare Diseases Information Center (GARD) website. https://rarediseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases. Last accessed February 16, 2020
2. Global Genes website. https://globalgenes.org/rare-diseases-facts-statistics/. Last accessed February 16, 2020.

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Source: Retrophin, Inc.