



## Traverse Therapeutics Recognizes Rare Disease Day 2021 and the Importance of Working Together to Innovate and Address Healthcare Disparities in Rare Disease

February 25, 2021

SAN DIEGO, Feb. 25, 2021 (GLOBE NEWSWIRE) -- Traverse Therapeutics, Inc. (NASDAQ: TVTX) will join the National Organization for Rare Disorders (NORD), the European Organisation for Rare Diseases (EURORDIS), EveryLife Foundation for Rare Diseases, Global Genes, and rare disease advocates and patients worldwide in recognizing February 28 as Rare Disease Day 2021. Rare Disease Day honors the more than 400 million people around the world living with a rare disease, along with their families, caregivers and advocates.<sup>1</sup>

"The drive to develop better treatment options for rare disease patients is personal for us at Traverse because the lives of many of our own team members have been in some way touched by rare disease," said Eric Dube, Ph.D., chief executive officer of Traverse Therapeutics. "Rare Disease Day is an important reminder that we are stronger together in our pursuit to improve access to diagnosis, treatment and care for the rare community."

Consistent with values of being patient-inspired and promoting community, the Company has supported important initiatives occurring this month amongst organizations such as, EveryLife Foundation for Rare Diseases, the Rare Disease Diversity Coalition and RARE-X. These organizations are dedicated to finding solutions to healthcare inequity and to continued innovation in rare disease.

### National Burden of Rare Disease Study

Understanding the true economic cost of living with a rare disease is critical. The National Burden of Rare Disease Study conducted by the EveryLife Foundation for Rare Diseases will be the first-ever to quantify both the direct and indirect costs that families face living with rare disease, and aims to increase awareness of the public health crisis of rare disease and inform policy proposals. Results from this important study are expected on February 25th. [Read more about the National Burden of Rare Disease Study.](#)

### Rare Disease Diversity Coalition

The challenges of living with a rare disease do not always fall equally on people. Traverse Therapeutics has worked closely with the leaders of the Black Women's Health Imperative (BWHI) to spearhead the formation of the Rare Disease Diversity Coalition. In the spring of 2020, BWHI brought together a steering committee of influential, cross-sector leaders who share a passion and a commitment to addressing the racial and socioeconomic disparities among people living with a rare disease. After 10 months of working group meetings, on February 23, the coalition officially launched with more than 200 rare disease diversity health leaders and community members who joined together to endorse an ambitious platform of 11 initiatives to achieve tangible solutions to address issues including delays in diagnosis and treatment for diverse patients. [Read more about the initiatives of the Rare Disease Diversity Coalition.](#)

### RARE-X

The nonprofit organization RARE-X is building a global patient-powered data platform that will enable patient communities to share data in a secure and structured way to assist researchers, drug developers and clinicians in accelerating diagnoses, increasing disease understanding, and developing treatments. The organization is dedicated to removing access barriers to the technology and to reaching racially, socioeconomically and geographically diverse patient communities to ensure that advances in rare disease care can reach all patients. This week RARE-X announced enhancements to data sharing on their platform to better support the development of future treatments. [Read more about the work of RARE-X.](#)

"This important work led by these admirable organizations is collectively helping to increase the body of knowledge available in the rare community and leading the way forward for future innovation," said Dr. Dube

Traverse Therapeutics will celebrate Rare Disease Day on February 26, with a program for its workforce featuring keynote speaker Linda Goler Blount, president of the Black Women's Health Imperative and chair of the Rare Disease Diversity Coalition, and a panel of people sharing their experiences living with rare kidney, liver and metabolic disorders.

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 US by NORD and internationally by EURORDIS. For information on Rare Disease Day participation, visit [rarediseaseday.us](http://rarediseaseday.us) or [rarediseaseday.org](http://rarediseaseday.org).

### About Traverse Therapeutics

At Traverse Therapeutics we are in rare for life. We are a biopharmaceutical company that comes together every day to help patients, families and caregivers of all backgrounds as they navigate life with a rare disease. On this path, we know the need for treatment options is urgent – that is why our global team works with the rare disease community to identify, develop and deliver life-changing therapies. In pursuit of this mission, we continuously seek to understand the diverse perspectives of rare patients and to courageously forge new paths to make a difference in their lives and provide hope – today and tomorrow. For more information, visit [traverse.com](http://traverse.com).

### 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](http://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. 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 people around the world. For more information about EURORDIS, visit [eurordis.org](http://eurordis.org).

## **About Rare Disease Diversity Coalition**

The Black Women's Health Imperative launched the Rare Disease Diversity Coalition to address the extraordinary challenges faced by rare disease patients of color. The Coalition brings together rare disease, patient advocacy, medical and health diversity experts, and industry leaders to identify and advocate for evidenced-based solutions to alleviate the disproportionate burden of rare diseases on communities of color, and help achieve greater equality within the rare disease community.

## **About EveryLife Foundation for Rare Diseases**

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](http://everylifefoundation.org).

## **About RARE-X**

RARE-X is a 501(c)(3) patient advocacy organization focused on supporting the acceleration and development of life-altering treatments and future cures for patients impacted by rare disease. Enabled by best-in-class technology, patients, researchers, and other technology vendors, RARE-X will gather structured, fit-for-purpose data to share broadly, benefitting from 21st-century governance, consent, and federated data sharing technology. RARE-X's goal is to build the largest collaborative patient-driven, open-data access project for rare diseases globally. For more information, visit [www.rare-x.org](http://www.rare-x.org).

<sup>1</sup>Global Genes website. <https://globalgenes.org/world-rare-disease-day/#>. Last accessed February 16, 2021.

Contact:

Chris Cline, CFA

Senior Vice President, Investor Relations & Corporate Communications

888-969-7879

[IR@travere.com](mailto:IR@travere.com)



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