

RARE-X Announces Patient Community Data Collection, Sharing, and Platform Enhancements

Further development of data standards and governance, as well as additional case testing, is made possible through support from Traverre Therapeutics

Aliso Viejo, CA —February 23, 2021—RARE-X today announced plans to expand its work helping patient groups collect structured, standardized research-ready data that will better support the development of future treatments. This foundational work is made possible through a funding commitment from Traverre Therapeutics, a biopharmaceutical company dedicated to identifying, developing and delivering life-changing therapies to people living with rare disease.

RARE-X is a non-profit organization dedicated to enabling patient communities to more easily, securely, and openly manage, aggregate, structure, and share their de-identified data on a common platform accessible to researchers and drug developers anywhere in the world. In addition, RARE-X and participating patient communities, including those who may not yet be diagnosed and N-of-1 patients, will have the ability to accelerate diagnosis, drug development, and access to treatments within and across rare diseases.

The lack of common data standards (informing how data is collected and analyzed and how diseases are characterized) can be a significant barrier to innovation. For rare diseases, where patient populations are small, data must be consistently collected and structured, or there won't be enough quality data to be useful for research. RARE-X is taking on the challenge of bringing forward structured validated data, being developed in modules and by domain. The types of data contributed and accessed via RARE-X will be entirely at the discretion of participating patients/patient communities and other data owners. This innovative approach to automating data collection is essential to relieving over-burdened rare disease patients who need to focus on their families and disease management. RARE-X also strives to ensure that patients who collect data are doing so in a well-governed way, where access and participation are easy, where the cost burdens are offset, and where their ownership and ability to share the data is supported.

"We are excited to support RARE-X, who shares our goal of elevating science and service for people living with rare disease," said Bill Rote, Ph.D., senior vice president of research and development at Traverre Therapeutics. "With responsible data ownership and sharing, we believe these efforts can ultimately catalyze patient-inspired development of potential therapeutics for all those affected by rare disease.

"Traverre's support and funding will help move RARE-X's efforts forward with the urgency rare communities demand," said Nicole Boice, co-founder and executive director of RARE-X. "We must work together to establish data standards to ensure patient data is available, inclusive of diverse patient communities, and put to its best use in finding treatments and cures."

For partnership inquiries and to support this growing effort, please contact the RARE-X team at collaborators@rare-x.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 is building the largest collaborative patient-driven, open-data access project for rare diseases globally. For more information, visit www.rare-x.org.

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