



## **RARE-X Launches Diversity, Equality, and Inclusion Program**

*New RARE-X DEI program assures the diversity of the rare disease community is represented in the first global patient-powered data collection, analysis, and sharing platform*

**Aliso Viejo, CA** — Jan 19, 2020 — [RARE-X](#), a collaborative platform for patient-controlled and structured data collection, global data sharing, and analysis that will accelerate treatments for rare diseases, announces the launch of its Diversity, Equality, and Inclusion Program (DEIP). The program is made possible through grant support from Genentech and Travele Therapeutics.

As U.S. demographics shift, there is a critical need to create more diverse research cohorts. For example, although Blacks and Latinos account for more than 30% of the U.S. population today, they currently account for only 6% of all federally-funded clinical trials. Factors driving lower research participation for communities of color include insufficient training on minority research, cultural and linguistic differences, financial constraints, and inconvenient site locations.

The RARE-X DEIP will ensure the long-term development of an inclusive RARE-X data collection platform. This inclusion will be achieved by supporting underrepresented populations in rare disease research (e.g., clinical trials, data platforms, patient registries, etc.) using grassroots efforts in community-based participatory research (CBPR) methods. Data collection will focus on potential cultural impacts on language, understanding of rare disease, technology limitations, and trust issues within minority communities related to research. This will include additional considerations in literacy, socioeconomic factors, access to technology, adaptive technologies, and most importantly, building trust.

“RARE-X believes that if we remove barriers to access for underrepresented populations to best-in-class technology, with proper awareness, support, and governance, we will enable patients to securely and responsibly share their critical data and become active participants in drug development. And if we get this right, we will help change the landscape for rare disease patients,” said Nicole Boice, co-founder and executive director of RARE-X.

Teneasha Washington, DEIP lead for RARE-X, and CEO of The Washington Group, and assistant professor at the University of Alabama at Birmingham, School of Public Health, will kick-off the DEIP with a scoping project exploring the state of rare disease data collection. The DEIP will provide a series of recommendations for RARE-X as it moves forward, ensuring the platform is demographically representative, including insights into barriers that exist in making datasets inclusive. These recommendations will also be informed by valuable insights from the RARE-X DEI Advisory Council. The Council was strategically developed to include a diverse group of members—rare disease patients, caregivers, community engagement and disability experts, researchers, and biopharmaceutical companies—to serve as the key stakeholders in the

development of each aspect of the project - with the understanding that a diverse council leads to more diverse, robust perspectives.

The Advisory Council includes: Mariah Chrans, IBCLC, Ph.D., Project Director, Cradle Kansas City; Broderick Crawford, President, NBC Community Development Corporation; Eve Dryer, Executive Director of Patient Advocacy, Travers Therapeutics; Veronica Moore, MA, Manager of Patient Advocacy, Horizon Therapeutics; Nancy O'Donnell, Director of Outreach, Usher Syndrome Coalition; J. Stephen Mikita, J.D., Patient Advocate.

“As a result of this project, we hope to expand the traditional definition of diversity. This project will catalyze future efforts on diversity for larger RARE-X initiatives, as well as for others who share an interest in rare disease,” said Teneasha Washington. “In addition, via a literature review, survey, focus groups, and individual interviews, we hope to guide RARE-X’s approach to developing a data portal that inherently incorporates evidence-based strategies informed by a variety of stakeholders on diversity, equity, and inclusion.”

During the 24-month pilot period, RARE-X will ensure its platform is built and structured so ALL rare disease patients can participate easily and work with a trusted partner rooted in patient advocacy that has their best interest at stake.

For partnership inquiries and to support this growing effort, please contact the RARE-X team at [collaborators@rare-x.org](mailto: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](http://www.rare-x.org).

#### **Media Contact:**

Tom Hume, Marketing Communications – RARE-X  
[tomh@rare-x.org](mailto:tomh@rare-x.org)