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HDSA AND RARE-X LAUNCH HD DATA COLLECTION INITIATIVE TO ACCELERATE TREATMENTS FOR HUNTINGTON'S DISEASE

New York, NY (May 17, 2023) — The Huntington's Disease Society of America (HDSA) and RARE-X, the Global Genes patient-driven data collection platform, today announced a collaboration to establish a high-quality natural history study to accelerate knowledge development through effective patient-owned data collection, data connection and community pooling of data. The Huntington's Disease Data Collection Initiative (HD-DCI) will enable people with HD to better share their data to accelerate the development of treatments for HD.

With an estimated 41,000 people diagnosed with HD in the United States, it is difficult to gather longitudinal patient data and clinical natural history data for Huntington's disease. This information is critical for patients and their doctors to understand their diseases better, support researcher and biopharma investment in HD, and help determine meaningful clinical endpoints. This collaboration will help break down data silos to make rich natural history data accessible to the research and clinical science communities.

"The days where physicians were the sole keepers of medical insights are coming to an end," said Louise Vetter, President & CEO of HDSA. "For healthcare to achieve its potential, people with HD must be welcomed as true partners, contributing their personal health data and conducting self-assessments using validated online tools to fill in the gaps and create a dataset that truly captures the natural history of HD. The collaboration with RARE-X will help provide vital insights of patients and their caregivers to fill gaps in our understanding of HD and complement clinician-reported datasets."

Together with RARE-X, HDSA will develop and deploy innovative patient-centered models to accelerate research programs and clinical development. This will include a novel structure for engaging "pre-symptomatic" and at-risk individuals with built-in mechanisms to screen for emerging disease symptoms. Importantly, they will establish a novel Care Partner portal that will allow caregivers to provide vital insights to complement the person with HD's lived experiences.

"Patient-reported data is critical to rare disease innovation," said Charlene Son Rigby, CEO of the nonprofit rare disease patient advocacy organization Global Genes, which operates the RARE-X patient data sharing platform. "As rare patient communities like Huntington's disease gather and share their data with collaborating researchers, clinicians, and companies around the globe, they will accelerate diagnosis, disease understanding, and development of future treatments and cures for people with Huntington's disease and may also shed light on other conditions as well."

HDSA and RARE-X recognize the many data gaps that exist in rare disease research and understand the importance of data sharing and data interoperability for researchers. RARE-X offers an automated and structured platform to support standardized data collection while enabling patient communities with proper governance, consent, and technology that can support a data ecosystem built for discovery.

"The creation of a patient-led, virtual data collection initiative addresses some of the persistent inequities in healthcare research. This partnership with RARE-X allows people who can't travel to the sites where most research and clinical trials occur to engage in a large scale natural history study from their own home," said Dr. Arik Johnson, Chief Mission Officer at HDSA. "The HD-DCI will empower people living with HD to become true partners in research, owning their data and sharing their HD experiences as they chose."

Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities during their prime working years and has no cure. Every child of a parent with HD has a 50/50 chance of carrying the faulty gene. Today, there are approximately 41,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

The symptoms of HD are described as having ALS, Parkinson's & Alzheimer's – *simultaneously.*

About the Huntington's Disease Society of America (HDSA)
The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by HD. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today and hope for tomorrow for people with HD and their families. To learn more about Huntington's disease and the work of the Huntington's Disease Society of America, visit www.hdsa.org or call (800)345-HDSA.

About RARE-X & Global Genes
RARE-X is a program of Global Genes focused on supporting the acceleration and development of life-altering treatments and future cures for patients impacted by a rare disease. Enabled by best-in-class technology, patients, researchers, and other technology vendors, RARE-X gathers structured, fit-for-purpose data to share broadly, benefitting from 21st-century governance, consent, and federated data-sharing technology. Through RARE-X, Global Genes is building the largest collaborative patient-driven, open-data access project for rare diseases globally. For more information, visit rare-x.org.

Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of that mission, Global Genes connects, empowers, and inspires the rare disease community to stand up, stand out, and become more effective on their own behalf — helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. Global Genes serves more than 400 million people around the globe, and nearly one in 10 Americans affected by rare diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact Global Genes at 949-248-RARE (949-248-7273) or visit the Resource Hub.

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