Company interests and priorities

Rare disease data and approach to academic & industry partnering with Global Genes

Global Genes is a 501(c)(3) nonprofit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. RARE-X is the research platform and data collection program of Global Genes, focused on supporting the acceleration and development of life-altering therapies for patients impacted by a rare disease. Enabled by best-in-class technology and fueled by patient advocacy, RARE-X gathers structured, fit-for-purpose data to share broadly on an open science platform. Through RARE-X, Global Genes is building the largest collaborative patient-driven database for rare diseases globally.

Available rare disease data & research capabilities:

- 80+ rare disease communities are actively collecting data on the RARE-X Data Collection Platform. These data collection efforts are driven by the patient advocacy groups, engendering trust and driving research engagement.
- Currently focused in neurodevelopmental, neurodegenerative and rapidly expanding into other rare disease areas, including genetic disorders of vision and hearing loss.

Available data includes:

- Rich phenotype details, collected in the absence of pre-determined disease-specific symptoms to elucidate novel symptoms
- Molecular data, hand reviewed and curated by a genetic curation team
- Patient-reported clinical outcome measures, collected longitudinally
- With patient permission, all data is shared on an open platform to accelerate research

Specific opportunities and approaches of interest:

Academic Partnering:
- Clinical and laboratory researchers focused on rare pediatric neurologic disorders will find deep phenotyping data to support disease characterization, natural history study and clinical trial design and therapeutic development

Industry Partnering:
- Development of new or expanded data collection programs for specific rare conditions, in collaboration with patient advocacy groups
- Opportunity to identify patients as candidates for clinical research studies
- Creation of consortia to advance collaborative data collection and projects to identify improved outcome measures
- Federation of existing datasets with patient-reported data on RARE-X
- Hybrid natural history studies, in collaboration with academic partners and inclusive of remote participation
- Opportunity to identify patients as candidates for clinical research studies
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Stages of development preferred:
- Translational, Preclinical, Clinical

Types of collaboration preferred:
- Any

Submit Opportunities