



## Global Genes Statement of Objective (SOO) for Next Generation Biomedical Data Collection Program for Rare Disease

### *Did you know?*

Over 10,000 distinct rare diseases impact more than 400 million people globally and approximately 30 million people in the US. This makes rare disease the largest disease community globally, and rare disease affects 1 in 10 Americans.

### *Vision*

Global Genes is dedicated to eliminating the burdens and challenges of rare diseases for patients, their families and disease communities globally.

### *About*

Global Genes is a leading non-profit rare disease organization that advances the healthcare and translational science priorities of all rare disease patients and their families.

We believe that **data is the catalyst for cures**. By empowering patients to contribute, own, and share their data safely and meaningfully, we can accelerate discovery, improve diagnostics, and enable more targeted, life-saving therapies for all rare diseases.

We convene **800+ patient advocacy organizations** and **50+ biopharma partners**, and develop collaborative alliances with the **NIH** and **FDA**. Our programs span **advocacy, education, support, and research enablement**, uniting the rare disease ecosystem around shared priorities. With the rapid rise of genetic testing, newborn screening, **genomic medicine, mRNA technologies, and regenerative therapies**, the opportunity to accelerate cures has never been greater — but it depends on high-quality, accessible, and patient-centered data.

Global Genes fosters meaningful collaborations with scientists, regulators and public health leaders to shape priorities that will accelerate the development of new therapeutics, diagnostics and outcomes measures, supporting the needs of our vastly growing patient community ecosystem. With this Request for Proposal, we seek to foster mission-driven collaboration with industry innovators in data collection, data stewardship, data utilization and insight generation.

## Statement of Objective (SOO)

### *Opportunity*

Global Genes seeks an innovative technology partner to work with us to build the next generation of rare disease data infrastructure — one that is patient-centric, scalable, and globally accessible. This is purpose driven, urgent work.



## ***Why Now***

The convergence of **genomic science, digital health, and patient-powered data** presents an unprecedented opportunity to unlock cures. But without modernized infrastructure and scalable systems, this progress cannot reach those who need it most.

Global Genes seeks to scale the impact of patient data as a strategic asset. With this SOO, we request proposals from any qualified performers to help us expand and modernize our patient-powered biomedical data program.

## ***Rare-X Patient-Powered Biomedical Data***

Our data repository, RARE-X, captures patient-reported data and patient-provided data from over 8500 participants, across 90 diseases (38% ex-US). This data includes patient survey data on symptoms, medical encounters, validated patient reported outcomes, curated lab data, and limited genome and exome sequences.

While the data assets in the current repository are a strong foundation, they are not yet fully optimized for sustainability, aggregation, machine-based reusability or consumption at scale by machine learning algorithms.

Additionally, the processes for providing and storing new data are labor intensive, requiring significant manual labor from data providers (i.e. rare disease patients and caregivers), data stewards (i.e. Global Genes staff) and data consumers (translational science researchers and patient advocates).

All patient-provided data is protected by informed consent, with permission to re-contact rare disease patients and families for future data collection opportunities to characterize rare diseases.

## ***Technical Requirements***

By design, the scope of work in this request for proposals is open-ended and governed by a single statement of objective (SOO):

*We seek a technology partner to lead the digital transformation of this legacy data repository and expand our biomedical data program with a novel patient-centric data collection and management system.*

Prospective Performers will be evaluated on five criteria in a Technical Proposal not to exceed 5 pages.

First, the Prospective Performer shall provide a solution architecture for implementing the objective. The solution architecture may be visualized using any media that effectively communicates the technical approach and the proposed use of technologies to operationalize the objective.



Second, the Prospective Performer shall provide three or more corporate past performance examples that describe projects that demonstrate real world impacts with similar scope.

Third, the Prospective Performer shall provide a concept of operations for scalable data stewardship that incorporates (1) novel data collection methods for new and existing data providers; (2) data management; (3) data provisioning for data consumers; (4) return of value methods to data contributors and disease communities; and (5) efficiencies and expanded ecosystem opportunities for RARE-X. The proposed concept of operations should provide a technical foundation for analytics, but a full analytics stack is beyond the scope of this SOO.

Fourth, the Prospective Performer will provide a description of technical resources and talent for implementing the solution.

Fifth, evidence of procedures and certifications for processing and maintaining data in compliance with global data privacy and security regulations.

***Financial Requirements***

Please submit a letter of support, signed by the Officer in Charge of your organization. Global Genes is a non-profit, and cost sharing is required and must be outlined in the proposal. Beyond cost sharing, we invite proposals for mutually beneficial partnership models that drive financial sustainability through innovative structures and expanded ecosystem opportunities for the RARE-X data assets and advocacy network.

***Additional Information***

Global Genes will hold individual meetings at request from interested proposers November 17 - 25. Q&A Deadline December 12 by 5 pm ET. Meeting requests, questions and proposals should be sent to [rfp@globalgenes.org](mailto:rfp@globalgenes.org).

Technical resources / talent and Figures do not count toward the 5 page proposal page limit.

Global Genes reserves the right to select for negotiation all, some, one, or none of the proposals received in response to this SSO. Global Genes may award only portions of a proposal.

***Exclusion Criteria***

Universities are not eligible.

***Deadline***

Responses are due December 19 by 5 pm ET.