Position Description:
Are you passionate about the power of data to transform biomedical disease understanding, research, and medicine development? Are you an organized individual who has a scientific mind who excels at process implementation? Are you detail and process-oriented with the ability to think creatively and be flexible to stakeholder needs? Are you a clear and empathetic communicator? We seek a Clinical Research Assistant to support the Principal Investigator and collaborators in the RARE-X Clinical Research Network efforts.

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 diseases. Enabled by best-in-class technology, patients, researchers, and partners, RARE-X will support patients and advocates to gather structured, high-quality, standardized data to share broadly, benefitting from 21st-century governance, consent, and federated data sharing platform technology. RARE-X intends to build the largest collaborative patient-driven, open-data access platform for rare diseases globally.

The Clinical Research Network Assistant role is to be a trusted and valuable partner to our stakeholders and internal team. The right candidate will support the RARE-X team’s relationships with the RARE-X Clinical Research Data Collection Program and communicate effectively with internal and external clinical research teams, serving as a key part of our program execution process. We are looking for a team member who shares our affinity for organization and is motivated by the RARE-X mission, delivering value to our patient communities and partners.

OVERALL RESPONSIBILITIES
Duties and responsibilities include but are not limited to:

- Supporting the Principal Investigators and Clinical Director(s) in facilitating monthly calls.
- Be the key point person and have a working knowledge of current data collection efforts.
- Assist in the creation of template agreements/contracts/processes towards a flexible and scalable model that can be deployed at additional clinical sites.
- Supporting the Clinical Research Data Collection Program in database entry, training, data quality, and other activities related to the RARE-X database.
- Liaising with clinic coordinators, clinicians, and industry partners when needed.
- Participate in recruitment efforts for data collection.
- Biobank sample inventory coordination with patients for sample collection and tracking.
- Engage with families and understand their concerns regarding clinical research visits.
- Determine study eligibility; consent and enroll patients both in-clinic and via project web-based registration system; data tracking and management.
- Support maintenance of IRB requirements.
- Interact with the study team, clinic staff, and patient support groups.
Facilitate project start-up at other sites.
Coordinate project meetings and conference calls.
Assist in all aspects of the Clinical Research Data Collection Program operations.
Other duties may include managing clinic contact lists.

**Clinical Research Assistant Requirements:**

BA or MA in social sciences, public health, or related field. A minimum of 2-4 years of experience in epidemiology or clinical research is required, including familiarity with IRBs. Willingness to continually self-educate.

Excellent data management skills; experience with databases preferred.
Extremely independent and mature; excellent interpersonal, communications, and organizational skills required.
The ability to learn quickly our database management software is required. Excellent written, verbal, and interpersonal skills & the ability to stay organized, manage multiple tasks, and meet and set deadlines within a complex and semi-remote team environment are required.
Ability to operate as an effective tactical as well as a strategic thinker and make recommendations for the most effective operating of the Clinical Research Data Collection Program

**COMPENSATION AND HOURS REQUIRED**

- Contractor
- Hours: 40 hours per week, The daily schedule can vary based on project priorities and organizational needs.
- Remote: While the RARE-X headquarters team is located across the United States and all meetings are remote. Travel may be required.
- Compensation: Competitive pay for services

*All qualified applicants will receive consideration for employment without regard to race, color, religion, sex, sexual orientation, gender identity, national origin, disability or protected veteran status. All interviews will be conducted remotely.*

RARE-X will be accepting applications for this position through June 1, 2022.

*If interested, please submit your resume to Jobs@RARE-X.org with a cover letter that explains why the position at RARE-X appeals to you, and how your experience & skills qualify you for this job.*

**THANK YOU FOR YOUR INTEREST IN RARE-X.**

May 2022
Organization:

RARE-X is a 501(c)(3) non-profit created by leaders in the fields of patient advocacy, medical research, biopharma, and technology.

RARE-X is piloting a series of demonstration projects, partnering with rare disease communities, to apply technology proven in other large-scale public health and genomic data-sharing initiatives to support the global needs of those developing treatments and caring for rare disease patients.

RARE-X is leveraging existing technology to power patients (in data collection, structuring and responsible sharing), clinicians (in accelerating diagnosis and improving and tracking health outcomes), researchers and biopharma (with the data they need to identify, develop and track the impact of breakthrough treatments and cures).

RARE-X is adapting proven technologies and partnering with leading experts to create a federated data analysis platform, specifically designed by rare community leaders and scaled to support the diverse and expanding needs of rare disease research, development and care, around the world and in all communities.

We believe that rare patient communities, equipped to securely gather and share their data with collaborating researchers and companies around the globe, will significantly expand diversity, equity, and inclusion in research and dramatically accelerate progress across rare diseases.

Our Vision

RARE-X believes that by enabling rare patient communities to more easily gather, structure and securely share critical inclusive data, through a common platform, in collaboration with researchers, drug developers and clinicians anywhere in the world, we will accelerate diagnosis, disease understanding, and development of future treatments and cures across more than 9,500 rare diseases.