ACD Patient Registry Coordinator

The Association for Creatine Deficiencies (ACD), a patient advocacy non-profit, is hiring a part-time Patient Registry Coordinator. The Registry Coordinator will support the CreatineInfo patient registry and natural history study. We want to hear from you if (1) you are interested in a shorter term project to help design the registry surveys or (2) you are interested in a longer engagement to facilitate the long term management of the registry. Number of hours and compensation will depend on experience and mutually decided upon engagement.

The ACD mission is to support the families impacted by Cerebral Creatine Deficiency Syndromes: AGAT Deficiency, GAMT deficiency, and Creatine Transporter Deficiency.

The Registry Coordinator will lead the building and growth of the CreatineInfo international Patient Registry which will be hosted on the NORD platform. The goal of the CreatineInfo registry is to bring together data from creatine deficiencies patients with the ultimate goal of improving care and developing new and better therapies. In the short term, the registry will allow CCDS researchers to conduct longitudinal research in the disease progression for all three creatine deficiencies.

The Registry Coordinator will work with the ACD Board of Directors and academic stakeholders to develop surveys, launch the registry to our family community, and to ensure data is meaningful for research projects. Please note that depending on the experience and interest of candidate responsibilities can be adjusted to emphasize particular areas for the project. For example, a candidate with extensive survey design experience may be considered for that particular aspect of the position with more contributions expected before the registry launches. Similarly, candidates with no survey design experience but willingness to learn may be more interested in ongoing support, project management, and maintenance of the registry.

Responsibilities

- Work directly with the ACD Registry Oversight Board and the ACD Board of Directors to develop goals and timeline for year one
- Design and oversee the implementation of registry surveys
- Ensure regulatory requirements are met: complete R&D and IRB applications, prepare for audits, and report protocol deviations
- Serve as a liaison between the key stakeholders to ensure effective collaboration and to meet research objectives
- Ensure compliance with study protocol, including informed consent, safety and data security requirements
- Track and monitor subject recruitment, study/project progress, and data collection activities
- Perform quality assurance activities for ongoing studies/projects
- Identify issues related to the registry and propose solutions
- Prepare reports, presentations, and data summaries
- Engage with investigators and research subjects requesting information on the repositories
- Work with the Registry Oversight Board and the ACD Board of Directors to ensure the use of the registry data in meaningful and impactful research

Working Conditions

- Competitive pay, commensurate with experience
- Work-from-home
- Flexible schedule with some on-call responsibilities

Qualifications

- BA/BS or higher degree in a scientific- or health-related field 3-4 years of related work experience in clinical, epidemiological, or health services research (an Associate's degree with a combination of relevant work and education equaling four years equivalent will also be considered)
- Excellent communication and interpersonal skills with the ability to collaborate with a diverse group, including university researchers, industry professionals, parents, and patient advocates
- Strong attention to detail and organizational skills
- Solid problem-solving and critical thinking skills
- Ability to adapt to changing priorities and timelines
- Proficiency in Microsoft Office and database management
- Experience working with Patient Registries is preferred
- Rare Disease or pediatric background preferred

Submission Process

- Resume, cover letter, references, and salary requirement
- Interested candidates should send all application requirements noted to auract@creatineinfo.org

Applications received without a cover letter will not be considered.