POSITION PROFILE

National Ataxia Foundation

CLINICAL RESEARCH COORDINATOR

Full time - Exempt

ABOUT NAF

Ataxia is a rare neurological disease affecting tens of thousands of people in the US and many thousands more around the world. It is progressive, affecting a person's ability to walk, talk, and use fine motor skills.

The National Ataxia Foundation (NAF) was established in 1957 to help persons with Ataxia and their families. Our mission is to accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia. NAF's vision of a world without Ataxia will be accomplished through our primary programs of funding Ataxia research, providing vital programs and services for Ataxia families, and partnering with pharmaceutical companies in the search for treatments and a cure. We work closely with the world's leading Ataxia researchers and clinicians, promoting exchanges of ideas and innovation in Ataxia discovery.

Company Profile

Location	Size	FY 2022 Revenue
Minneapolis, MN	18 staff members	$6 million

VISION

A world without Ataxia.

MISSION

To accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia.

ENSURING THAT NO ONE EXPERIENCES ATAXIA ALONE, UNTIL NO ONE EXPERIENCES ATAXIA, PERIOD.

FISCAL YEAR 2022 HIGHLIGHTS

- **$2.7M+** spent on research and drug development initiatives
- **$500K+** spent on education and support programs
- **81%** of our expenses **directly support** the programs we offer
- **12 Ataxia research grants** awarded
- **415 local support group meetings** hosted
- **79 advocacy meetings** with members of Congress
- Funded **158 genetic counseling sessions** and **80 genetic tests**

WAYS WE FULFILL OUR MISSION

POSITION DETAILS

NAF
National Ataxia Foundation

Clinical Research Coordinator

Full time, Exempt

Reports to Clinical Services Manager

Salary
$58,000 to $63,000

Position Summary

The Clinical Research Coordinator supports the Clinical Operations Branch of the Research Department. This position primarily focuses on coordinating the NAF-sponsored Natural History Study titled Clinical Research Consortium for the Study of Cerebellar Ataxias (CRC-SCA). They will independently manage significant and key aspects of this large multi-site study and oversee one or more associated sub-studies. This individual will independently coordinate the implementation and execution of study operations, including but not limited to maintenance of protocols, contracts, IRB documentation, and best data quality practices. This position will also oversee study timelines, recruitment goals, and invoicing.

Location

Education & Professional Experience

NAF is based in Minneapolis, MN, but this position can be mostly remote. Must be willing to travel quarterly for company-wide meetings and to attend various conferences and perform site visits.

Qualifications

Education & Professional Experience

The successful candidate will have a bachelor's degree in the Sciences or health-related discipline and at least two years of experience in clinical research. Prior experience working face-to-face with patients or research subjects is preferred.

Qualifications (continued)

Preference given to applicants with previous experience in neurology or rare disease. Experience with research protocols and regulatory or governing bodies, IRB requirements and Good Clinical Practice is highly desired. Knowledge of medical terminology is expected. Relevant certification strongly preferred: Certified Clinical Research Professionals (CCRP), Certified Clinical Research Associate (CCRA), Certified Clinical Research Coordinator (CCRC), or Certified IRB Professional (CIP). Prior managerial experience a plus.

Special Skills or Knowledge

- Excellent written and verbal communication skills
- 2+ years clinical research coordinator experience
- Strong interpersonal skills, including the ability to work easily with a wide array of stakeholders including study personnel at various levels of experience and expertise across the world.
- Strong project management skills including ability to meet deadlines and coordinate multiple aspects of ongoing projects.
- Comfortable working virtually and able to travel 5+ times per year.
- Proficient using Microsoft Office 365 suite of applications (especially Excel) and various virtual meeting platforms.

Duties and Responsibilities

CRC-SCA Study Management

- *Study Logistics and Administrative Duties:*
  - Orchestrate invoice submission process for all CRC-SCA reimbursements, quarterly. Implement Quality Control Practices as necessary, for data queries.
  - Maintain funding contracts with each institution's grant management office.
  - Ensure study-related documents (ICFs, Ops Manual, Protocol, CRFs) are up to date and consistent across various sites and databases.
  - Ensure CRC-SCA website and Clinicaltrials.gov are regularly updated.
  - Update coordinator and PI listservs and provide timely communication.

Duties and Responsibilities (continued)

CRC-SCA Study Management

- *Meeting and Communications:*
  - Virtual Meetings: organize invites, prepare agendas, facilitate meetings, and send follow-up content. Encourage action item follow through for various associated parties (All-PI meetings, Lead PI meetings, Data Analysis Group Meetings, Lead Coordinator meetings, All-coordinator meetings, External partner meetings).
  - In-person Meetings: Facilitate annual Face-to-Face meetings of associated study personnel and oversee pre-conference details
  - Respond to any CRC-SCA related questions as appropriate.
- *Study Oversight:*
  - Track Site Engagement by overseeing subject recruitment and study enrollment goals. Determine effective strategies for promoting/recruiting research participants and retaining participants long-term.
  - Work with NAF Patient Engagement Manager and lead coordinators to implement patient engagement strategies that promote patient recruitment and retention.
  - Develop and manage systems to organize, collect, report, and monitor data collection.
  - Report on milestone progress and provide monthly reports to NAF leadership; may require intermittent presentations.
  - Ensure all reporting requirements are met for external funders and other partners in timely fashion.
  - Track status of sub-studies, data analysis projects and use of external partners' billed time.
  - Audit operations to ensure compliance with applicable regulations; provide leadership in identifying and implementing corrective actions/processes.
  - Monitor Institutional Review Board submissions and respond to requests and questions.
  - Oversee serious adverse events reports and assist in resolving study queries.
  - On-site travel may be expected to problem solve or evaluate needs.

Duties and Responsibilities (cont.)

CRC-SCA Study Improvements and New Programs

- Partner with PIs, sponsor, compliance offices, external partners, and clinical coordinators to identify and improve more complex processes as it relates to the conduct of the research study, including but not limited to:
  - Annual funding structure and milestones
  - New site onboarding
  - New coordinator training module
- Implement and integrate GUIDs into current study procedures.
- Provide leadership in determining, recommending, and implementing improvements to policies/processes; define best practices.
- Take direction from leadership regarding new areas of development for CRC-SCA in order to enhance overall robustness of program.

Additional Duties

- Clinical Research Coordinator may be asked to support other clinical research programs, including but not limited to:
  - NAF's no-cost genetic counseling and testing initiative
  - Patient Registry
  - Brain Donation Program
  - Future Clinical Research Programs and Studies

General Expectations

- Follow established organizational policies and procedures.
- Compile information into reports or presentations as required.
- Use a team approach when working with NAF staff, patients, and other stakeholders.
- Demonstrate ability to learn and adapt to changing procedures, methods, or processes.
- Provide first-rate customer service as front-line stakeholder contact.

EEOC Statement

NAF is committed to equal employment opportunity. We do not discriminate in recruitment, hiring, or any other employment practices for reasons of race, color, gender, religion, national origin, gender identity, age, sexual orientation, marital or veteran status, disability, or any other legally protected status.

How to Apply

To apply, email your CV or Resume and a Cover Letter to Kelsey Trace, Clinical Services Manager at kelsey@ataxia.org with subject line, “Clinical Research Coordinator Application.”