



RESEARCH MANAGER

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
Minneapolis, MN

Size
25 staff members

FY 2025 Revenue
\$13.2 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.

Core Values

NAF's values are grounded in our passion and empathy for the Ataxia community.

- **Caring** – We respect one another and those living with Ataxia.
- **Motivated** – We use our passion to inspire our community to act NOW!
- **Collaborative** – We evolve together and support each other to achieve our mission.
- **Impactful** – We listen to our members to build creative, meaningful programs.
- **Accountable** – We are transparent in our words, actions, and results.





FISCAL YEAR 2025 HIGHLIGHTS

- **\$3.3M+** spent on research and drug development initiatives
- **\$1.2M+** spent on education and support programs
- **80%** of our expenses **directly support** the programs we offer
- **18 Ataxia research grants** awarded
- **674 local support group meetings** hosted
- **99 advocacy meetings** with members of Congress
- **41 clinicians trained** at NAF's Ataxia Clinical Training
- **43 NAF Ataxia Centers of Excellence** around the world

WAYS WE FULFILL OUR MISSION





POSITION DETAILS



Research Manager

Reports to Director of Patient Engagement
Full Time, Exempt

Compensation
\$70,000-\$90,000

Location

All work is performed remotely. Applicants must have reliable internet service from their location.

Position Summary

The Research Manager will oversee several key scientific resource programs within the NAF Research Department, including the creation of a new Ataxia Patient Registry. They will also provide regulatory and logistical support on the NAF Ataxia Cell Line Repository, Ataxia Brain Donation Program, and human subjects research recruitment initiatives. This work will put the Research Manager at the intersection of Ataxia patient, caregiver, and researcher communities. The Research Manager also participates in the implementation of new projects within Patient Engagement and Research Services Branches that support NAF's strategic goals.

This is an ideal position for a collaborative, self-directed researcher who can easily navigate clinical and data analysis environments while also excelling at communicating with patients and family members. The Research Manager works with the guidance and supervision of the Director of Patient Engagement, consistent with NAF's Manager -level expectations.

This position is best suited for candidates with experience in clinical research, human subjects research, regulatory affairs, or research program management. Applicants whose experience is primarily laboratory-based (e.g., molecular, cellular, or animal research) and who have limited exposure to clinical research operations or regulatory oversight may find this role is not aligned with their background.

Qualifications

Required

- Doctoral degree (PhD or equivalent) in biomedical science or related field of study; or Master's Degree (MSc or equivalent) in biomedical science or related field of study combined with clinical research experience.
- Research ethics training in Human Subjects Research, such as OHRP Human Research Protection Foundational Training, TCPS2 CORE Certification, CITI Program Human Subjects Research, or another National-level certification program, is necessary.
- Knowledge of HIPAA, GDPR, and similar data privacy regulations.
- Experience communicating scientific and technical information to a lay audience.
- Strong proficiency in Microsoft Word, Excel, PowerPoint, and Outlook.
- Excellent written and verbal communication skills in English.
- Ability to work independently in a remote environment.
- Experience coordinating patient registries, healthcare databases, or longitudinal clinical research studies.

Preferred

- Experience in rare disease, neurology, or chronic illness communities.
- Experience with quantitative, qualitative, and mixed-methods research methodologies.
- Written and verbal fluency in a language besides English is an asset.

Core Competencies

To be successful in this role, candidates should possess the following skills:

- **Empathy and Compassion** – Passionate about enhancing the quality of life for individuals and families impacted by Ataxia. Exhibits a keen ability to empathize with others, approaching all interactions with kindness and a deep concern for the well-being of the Ataxia community.
- **Communication** – Clear, professional writing and the ability to communicate effectively with staff and stakeholders.
- **Interpersonal** – Has the ability to engage professionally and effectively with both colleagues and members of the Ataxia community, fostering positive interactions.

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- **Cultural** – Demonstrates a deep respect for diversity in all its forms, including race, ethnicity, gender identity, sexual orientation, socio-economic status, age, physical ability or disability, and religious or political beliefs.
 - **Organization** – Ability to track multiple tasks, manage timelines, and maintain accurate documents.
 - **Technical** – Experience with, or the aptitude to quickly learn software such as project management tools, donor databases and other software is essential.



Key Responsibilities

Ataxia Patient Registry (50%)

- In collaboration with the NAF Patient Engagement Director and Chief Scientific Officer, lead the design, development, and launch of a new patient registry for people with Ataxia.
- Key tasks include registry administration, providing feedback on survey design, data analysis, and lead IRB/REB submissions and annual reviews.

Ataxia Cell Line Repository (30%)

- In collaboration with the NAF Chief Scientific Officer, support the design, development, and launch of a new Ataxia cell line repository program.
- Key tasks include developing information consent protocols for tissue donors, coordinating the development and characterization of new cell lines, and assisting researchers in identifying and accessing relevant cell lines.

NAF Ataxia Brain Donation Program (10%)

- Educate Ataxia patients, family members, and clinicians on postmortem brain donation and direct them to relevant donation programs, including the NAF Ataxia Donation Program.
- Assist researchers in identifying and accessing suitable postmortem Ataxia brain tissue samples from various sources.

Research Recruitment Evaluation (5%)

- Review research recruitment applications submitted to the NAF to ensure they meet NAF's internal standards for research across multiple domains (basic, translational, clinical, survey, qualitative, and market research).



Additional Duties (5%)

- This is a remote position, with occasional travel. If the applicant does not live in the Minneapolis/St. Paul area, quarterly travel will be required. All travel expenses are paid. Reasonable accommodation will be made for individuals with disabilities to perform essential job functions.



Benefits Offered

- Medical, Dental and Vision Insurance
- Healthcare flexible spending accounts, FSA or HSA
- Employer-paid basic term life insurance
- Short-term and long-term disability
- Paid parental leave program
- Sick Leave, earn up to one day per month
- Vacation, 15 days per year (20 days after 5 years of service)
- 9 paid holidays plus annual office closure between Christmas and New Year's
- 401(k) plan with employer match



How to Apply

To apply, email your cover letter and CV/resume to Dr. Celeste Suart at research@ataxia.org. Please note "Research Manager" in the subject line.

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.