



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

Position Title: Chief Scientific Officer

Location: NAF is based in Minneapolis MN, but this position could be remote

Description of 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. Founded in 1957, NAF is Minneapolis-based non-profit organization established to help persons with Ataxia and their families. The Foundation's vision of a world without Ataxia will be accomplished through its 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. NAF works closely with the world's leading Ataxia researchers, promoting exchanges of ideas and innovation in Ataxia discovery.

Position Overview: NAF is looking to hire a highly motivated and passionate individual to lead our scientific strategy and engage with key stakeholders regarding the discovery and development of treatments and technologies to impact patients. This is a newly created role and, as such, presents a unique opportunity to continue to grow NAF's role in supporting and driving research and clinical activities. The individual hired will engage with Ataxia patients and their families, academic researchers, clinicians, pharma and biotech companies, and other patient groups to ensure each group is aligned regarding research advancements and activities impacting drug discovery and development. The successful candidate will have outstanding relationship-building and communication skills, strong knowledge of drug discovery and drug development, and a passion to make a difference in the lives of patients and their families. To learn more about NAF: www.ataxia.org

Position Responsibilities: This role is multifaceted and will involve engaging in a range of activities to support the mission of NAF. The role has overall responsibility for managing the relationship of NAF with the Ataxia research community, Ataxia clinicians, and the pharmaceutical industry. This position will develop NAF's long-term research strategy and lead the NAF research department providing NAF with guidance on how best to invest its research budget and allocate Research Department staff time. This position supervises the Research Services Director, Manager, and Coordinator positions.

Position Requirements:

- Advanced degree in a life sciences discipline; Ph.D. and/or MD preferred
- Relevant experience in drug discovery and/or drug development, ideally in an industry, academic, or non-profit setting
- Experience supporting Ataxia, movement disorder, or neurodegenerative disease research preferred
- Experience developing strategies and identifying opportunities to support novel areas of research
- Experience helping to develop research tools/models and/or fund research to develop tools/models to help answer important scientific questions to move translational research forward
- Experience working closely with multi-disciplinary teams of scientists and clinicians conducting medical research
- Proven track record of building relationships and establishing and advancing collaborations across and within the non-profit, for-profit, and academic sectors.
- Experience managing research funding and allocating grants preferred
- Knowledge of patient data sharing practices and intellectual property law a plus
- Experience engaging with families and patients to communicate scientific and clinical updates in lay terms
- Strong project management and general organizational skills
- Ability to work independently and effectively in a remote setting
- Excellent attention to detail, strong written and verbal communication skills

Reporting Relationship: Executive Director

Status: Fulltime/Exempt

EEOC Statement: NAF believes in a diverse environment and 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.

Duties and Responsibilities:

1) Create long-term strategy for NAF research funding

- a. Review historical funding to identify trends and gaps in specific research areas
- b. Work with NAF Medical and Research Advisory Board (MRAB) to identify current and future trends
- c. Lead efforts to attract new Ataxia researchers and clinicians by strategically allocating NAF funds to promising initiatives and assisting with mentorship opportunities
- d. Identify potential new reviewers for annual research funding applications
- e. Communicate research funding strategy to NAF Board of Directors
- f. Lead efforts to attract under-represented minority Ataxia researchers and clinicians into the field

2) Lead planning of NAF-sponsored Ataxia Research Meetings

- a. Work with meeting PI's to set focus and theme for meeting
- b. Develop specific meeting agendas in coordination with PI's
- c. Current meetings include:
 - i. International Congress for Ataxia Research (ICAR) in partnership with FARA and Ataxia UK (bi-annual)
 - ii. Face2Face meeting of CRC-SCA (annual)
 - iii. Steering committee meetings of READISCA and the Natural History Study
 - iv. Ataxia Clinical Training for movement disorder fellows (bi-annual?)
 - v. Steering Committee for Ataxia Global Initiative (AGI) meetings
 - vi. Other meetings to be determined

3) Oversee NAF Brain Donation Program

- a. Determine long-term strategy/sustainability of program

4) Provide Internal and External Communication on Ataxia Research

- a. Provide educational content for NAF's various communications channels, with a focus on making Ataxia research and clinical trial opportunities understandable to the lay public
- b. Present NAF research strategy at various meetings of both patient and research communities

5) Build / Expand Relationships with Industry

- a. Establish new and build upon existing relationships with pharmaceutical and biotech companies interested in Ataxia; cultivate relationships through invitations to NAF research meetings, help in recruiting for studies, etc.
- b. Establish relationships with organizations developing technologies that could benefit the patient community (i.e., healthcare IT organizations creating technologies for remote patient monitoring, etc)

6) Miscellaneous

- a. Play key role in NAF Drug Development Collaborative's strategy moving forward

- b.** Assist Community Programs and Services Director with Annual Ataxia Conference – especially regarding medical/research speakers and Birds of a Feather facilitators
- c.** Act as organizational liaison to MRAB; request authors for various communications pieces, periodic reviews of communications materials, facilitate annual meeting, etc.
- d.** Review NAF's current patient registry partner (CoRDS) and make recommendation for long-term registry partner
- e.** Act as organizational interface to NINDS, NIH and FDA in areas involving Ataxia
- f.** Directly supervise Research Services Manager, including assigning job duties and completing annual performance reviews and annual goals
- g.** Interface with NAF Board of Directors to provide strategic research updates