

POSITION PROFILE

On behalf of our client,
National Ataxia Foundation,
CohenTaylor Executive Search Services
is conducting a retained executive search for its

CHIEF DEVELOPMENT OFFICER





Ensuring no one experiences **Ataxia** alone,
until no one experiences **Ataxia**, period.

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 people with Ataxia and their families. NAF's vision of a world without Ataxia is accomplished through their 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.

They work closely with the world's leading Ataxia researchers and clinicians, promoting exchanges of ideas and innovations in Ataxia discovery.

As a membership organization dedicated to improving lives affected by Ataxia, NAF believes every story can inspire, connect, and empower. Their network of more than 20,000 members plays a vital role in advancing research and accelerating treatments to market.

NAF also offers many educational resources for Ataxia, including a comprehensive library of brochures, fact sheets, books, and its monthly e-newsletter. Other opportunities for the Ataxia community to support include:

- [Annual Ataxia Conference](#)
- [Ataxia Events](#)
- [Facebook Ataxia Support Group](#)
- [NAF Support Groups](#)

NAF's leadership team recently presented its first State of NAF, where each department lead shared an overview of their function and strategic priorities. Watch the video below as they outline their roadmaps for the future.



Presented by NAF Leadership Team



MISSION

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

VISION

A world without Ataxia.

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.

FAST FACTS

- HQ in **Minneapolis, MN**, with fully remote staff located around the country
- **22** staff members
- Revenue of **\$13.2M**

HIGHLIGHTS

- **\$3.3M+** spent on research and drug development initiatives
- **\$1.2M+** spent on education and support programs
- **80%** of NAF's expenses directly supported the programs they offer
- **24** 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

FOR MORE INFORMATION

- Visit their [website](#).
- Visit this [page](#) to learn how Bill Nye the Science Guy is raising awareness about Ataxia.
- Click [here](#) to watch a video to learn more about Ataxia.
- Review their [2024 Annual Report](#).

THE CHIEF DEVELOPMENT OFFICER OPPORTUNITY

After several years of substantial revenue growth, NAF is at a moment ready to support a seasoned senior development leader who can help propel NAF into its next phase of impact within the rare disease patient advocacy field.

Reporting to the CEO and serving as a member of the Leadership Team, the Chief Development Officer (CDO) is the senior executive responsible for setting and executing the philanthropic vision for NAF.

In this role, the CDO will lead the maturation and scaling of NAF's national development function during a period of accelerated growth. As a trusted advisor and thought partner to the CEO, the CDO will bring strategic insight, leadership, and a clear vision for building a best-in-class fundraising operation.

Over the next two to three years, the CDO will design and implement a development structure capable of increasing revenue by at least 50%. This role is intentionally focused on strategy, structure, and leadership – rather than being solely centered on major gifts – and will require a strong point of view on how best to organize fundraising efforts across revenue channels, geographies, or hybrid models to achieve sustainable, diversified growth.

While the CDO will maintain a personal donor portfolio, the primary emphasis of this role is building the systems, team, and strategies that enable long-term philanthropic success across individual giving, major gifts, corporate and foundation support, events, and emerging revenue opportunities.

WORKING RELATIONSHIPS

The CDO reports to the CEO. They will be responsible for leading the current Development Team which includes the roles noted below. As growth continues, they will help shape NAF's future by building and developing the team.

- Development Coordinator
- Regional Development Manager (4)
- VP, Development



KEY RESPONSIBILITIES

Philanthropic Strategy and Vision

- Develop and execute a comprehensive multi-year fundraising strategy aligned with NAF's strategic plan and growth goals.
- Set revenue targets, including the goal of achieving at least 50% revenue growth within three years.
- Determine the optimal structure for the Development department.
- Identify opportunities to diversify and strengthen revenue streams.

Department Structure and Team Leadership

- Lead the expansion of the Development team from four to approximately nine staff over 2 – 3 years.
- Define roles, reporting structures, and success metrics for new and existing positions.
- Recruit, mentor, and retain high-performing development professionals.
- Foster a collaborative, accountable, and mission-driven fundraising culture.
- Work closely with the CEO and other leadership to involve them appropriately in donor engagement.

Revenue Growth and Fundraising Oversight

- Provide strategic oversight across all fundraising functions, including major gifts, individual giving, corporate and foundation support, events, and peer-to-peer fundraising.
- Ensure strong integration between fundraising strategy, communications, and donor experience.
- Maintain a high-impact personal donor portfolio to model best practices and support revenue goals.
- Ensure disciplined forecasting, pipeline management, and performance tracking.

Collaboration and Organizational Leadership

- Serve on the NAF Leadership Team, contributing to organizational strategy and cross-departmental initiatives.
- Partner with the CEO and Development Team to ensure integration across annual giving, corporate giving, events, and marketing.
- Work collaboratively with Finance to develop multi-year revenue projections and stewardship reporting.
- Work closely with both the Community Services and Research departments to understand their funding needs and design communication assets to effectively raise funds to support this programming.

Donor Experience and Stewardship

- Champion a donor-centered culture focused on meaningful engagement, transparency, and impact.
- Elevate NAF's philanthropic brand and storytelling in partnership with Communications.
- Identify opportunities to strengthen donor loyalty, deepen donor understanding of NAF's mission, and elevate NAF's philanthropic culture.
- Represent NAF at key events, conferences, and donor engagements.



THE IDEAL CANDIDATE

The ideal candidate will be an experienced fundraising leader in healthcare or a related field, with a proven track record of leading a comprehensive national fundraising team and raising funds from a broad donor base. They will also have experience leading a team in a hybrid and remote environment.

The successful candidate must have a demonstrated ability to lead in a multifaceted organization, plan strategically, and interact effectively with senior leaders and key volunteers. In addition, an ability to work collaboratively and efficiently with all staff is required.

- **Empathy and Compassion** – Passionate about the mission of enhancing the quality of life for individuals and families impacted by Ataxia. Exhibit keen ability to empathize with others, approaching all interactions with kindness and a deep concern for the well-being of the Ataxia community.
- **Strategic Vision** – Ability to design forward-looking fundraising models that support ambitious growth and long-term sustainability.
- **Leadership and Team Development** – Builds high-performing, collaborative teams; invests in talent development and clear role design.
- **Change Management** – Comfortable leading organizations through growth, ambiguity, and evolution.
- **Relationship Building** – Ability to develop authentic, long-term relationships with donors, board members, volunteers, and internal stakeholders.
- **Cultural** – NAF thrives in an engaged and inclusive culture where staff respect each other and hold themselves accountable for mission delivery. The organization has a small but growing staff that acts in an entrepreneurial fashion without layers of bureaucracy as a barrier to getting things done. Candidates must demonstrate 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.
- **Results-Oriented** – Thrives in a metrics-informed environment with clear goals and accountability.



QUALIFICATIONS

- 10 or more years of progressive fundraising leadership, preferably including experience scaling a national development operation.
- Demonstrated success leading multi-channel fundraising strategies with measurable revenue growth.
- Experience building, restructuring, or significantly expanding development teams.
- Experience leading fundraising planning skills; ability to translate vision into executable plans.
- Proven ability to lead, mentor, and manage senior-level fundraising professionals.
- Ability to travel nationally for donor engagements, events, and conferences.
- High level of professionalism, discretion, and judgement
- Experience in rare disease, biomedical research, healthcare, or patient-impact nonprofits.
- Familiarity with planned giving strategies and bequest stewardship.
- Experience working with executive leaders and board members on donor engagement.
- Track record of leading CRM optimization and data-informed fundraising decisions.

COMPENSATION / BENEFITS / LOCATION

The expected compensation for this role is **\$175,000 – \$190,000**. The actual base salary may be adjusted based on the following considerations: job-related knowledge and skills, location, and experience.

NAF offers a benefit plan – details on the full comprehensive benefits offered will be provided.

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

NAF has exclusively retained CohenTaylor Executive Search Services to conduct this search.

To apply, please send your resume to:
NAF@cohentaylor.com.

All inquiries will remain confidential.

NAF is committed to equal employment opportunity. They 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.

