KORN FERRY®

The Association for Frontotemporal Degeneration

Senior Director of Scientific Initiatives

Position Specification

Date: April 2019

Position Specifications

Role Specifics	
Position	Senior Director of Scientific Initiatives
Company	The Association for Frontotemporal Degeneration
Location	Radnor, PA
Reporting Relationship	CEO
Website	https://www.theaftd.org/

Company Background/Culture

Based in Radnor, PA, AFTD is globally recognized as the leading nonprofit devoted to addressing frontotemporal degeneration (FTD). Bringing changes in behavior, language, personality and movement, FTD is the most common dementia for people under age 60. Established in 2002, AFTD raises awareness of this misunderstood and frequently misdiagnosed disease, while supporting people with FTD, their families and their care partners. We educate healthcare professionals and advance collaborative research to bring earlier diagnosis, treatments, and a cure. With a growing staff of 20 and a national network of volunteers, AFTD has developed an international reach, with research partners and advocacy allies in Canada, Australia and Europe and research funding in support of the best science worldwide. We seek a world with compassionate care, effective support, and a future free of FTD.

Currently there are no biomarkers for this disease, and no approved therapies. Official diagnosis must wait until autopsy. However, in recent years FTD science has made key gains, informing basic understanding across proteinopathy-associated neurodegenerative diseases. This new AFTD staff position reflects both the progress of FTD research into diagnostic and therapeutic development, and AFTD's growth as a dynamic organization, operating as the hub of a community of persons diagnosed, families, healthcare professionals who provide help and support for today, and researchers and volunteers who collaborate to provide hope for tomorrow.

The Opportunity

As a key member of AFTD's senior staff, the Senior Director of Scientific Initiatives (SDSI) will inform organizational strategy and oversee research programs, while personally leading corporate research partnerships and implementation of AFTD's agenda in the clinical science space, with particular focus on:

- Developing and leading a business strategy that enables partnership opportunities with biopharma.
- Leading AFTD's programs that fund and promote FTD clinical studies, including TreatFTD and the Diagnostics Accelerator.

- As AFTD's representative to the FTD Disorders Registry, help develop and lead a strategy that ensures sustainment and growth of the Registry (www.ftdregistry.org) as a robust platform for trial recruitment and patient-centered research. (This Registry is a collaborative LLC, co-owned with our nonprofit partner, The Bluefield Group.)
- Engaging with industry, government and nonprofit stakeholders to establish collaborations that advance FTD clinical science

The SDSI will facilitate communication with all stakeholders and sectors of the FTD clinical research community, cultivating strategic partnerships with other organizations, companies, and individuals in pursuit of AFTD's clinical research goals. The SDSI will help provide strategic leadership for the growing FTD Disorders Registry, contributing to development of its operational business model and ensuring that it is resourced to meet key objectives.

Based in Radnor, PA, the SDSI will be an integral member of AFTD's leadership team, working with the CEO and staff leads for programs, marketing, fundraising and advocacy to ensure that across its broad mission AFTD presents an integrated identity to the external world. Reporting to the SDSI will be the Director of Basic Science & Translational Research, and the Director of the FTD Disorders Registry, who provide significant expertise and depth of knowledge in FTD science, grants management, and Registry science and operations.

Key Responsibilities

Research Business Strategy

- Provide vision and leadership that ensures AFTD's approach to basic, translational and clinical science integrates into a cohesive scientific business plan.
- Develop a deep understanding of the current state of the FTD clinical space to identify gaps and opportunities.
- In partnership with the CEO, and with input from existing scientific staff and expert advisors, set and lead a comprehensive research strategy that leverages the organization's finite financial resources as well as its strategic position at the hub of the FTD community.
- In partnership with the Director, Basic Science and Translational Research, cultivate and evaluate new opportunities and projects that will maximize AFTD's role in advancing FTD translational science and clinical research.
- As a member of AFTD's leadership team, contribute expert knowledge in support of quality decisions regarding internal planning and AFTD's overall strategic direction.

Clinical Research Initiatives

- Lead AFTD's clinical research strategy, defining success metrics and ensuring goals (i.e. those related to development of patient-informed outcomes and advances in tools for early and accurate diagnosis of FTD) are met.
- Serve as AFTD's lead for TreatFTD, a joint program with the Alzheimer's Drug Discovery Foundation (ADDF) that funds and stimulates development of innovative FTD clinical trials.
- Serve as AFTD's business lead with ADDF and Gates Ventures in the Diagnostics Accelerator Initiative for Alzheimer's Disease and Related Dementias, representing AFTD's interests as a partner, developing, enabling and advising on projects with an FTD focus.

- In partnership with clinical experts, industry and other stakeholders, lead the effort to collaborate with the FDA in pursuit of well-defined outcome measures and innovative trial designs to support successful FTD clinical studies. Increase patient- and caregiver-informed perspective on the development of research methodology in FTD.
- Collaborate with AFTD program and communications staff to create, tailor and market educational programs that bring the patient and family perspective to industry and government partners.

FTD Disorders Registry

- Serve as AFTD's representative on the Registry LLC, developing a business strategy, cultivating relationships and leading a plan that successfully positions the Registry as a sustainable, valued and robust resource in FTD research.
- Support the Director of the FTD Disorders Registry in identifying staffing, resources, and technology infrastructure to meet current commitments and take advantage of future opportunities.
- Contribute to development of performance metrics to evaluate and ensure progress toward strategic, business development, and operational goals.
- In partnership with the Director of the FTD Disorders Registry and LLC partners,
    - Analyse, enhance, and ensure effective technology infrastructure to support the Registry.
    - Cultivate and evaluate new opportunities and projects that will maximize the Registry's role in advancing FTD translational science and clinical research.

Stakeholder Relations

- Cultivate and manage relationships throughout the business and regulatory communities in pursuit of AFTD's goals.
- Develop strategies and policies that position and support AFTD as a strong and proactive partner to biopharma in support of clinical research, trials, patient engagement, and development of drugs and treatment.
- Identify and cultivate business opportunities and relationships involving the FTD Disorders Registry, enhancing its visibility and standing in the global clinical scientific community.
- Enhance and leverage AFTD visibility as an international patient advocacy organization and research funder.
- Collaborate and, where possible, lead efforts in pursuit of data sharing across all stakeholders.
- Lead strategic development and management of AFTD's Medical Advisory Council and other science-related advisory panels.
- In addition to the CEO and Director of Basic Science & Translational Research, represent AFTD externally in a growing number of professional meetings, conferences, symposia, and other scientific and research venues.

Administration and Management

- Responsible for budgeting and planning for scientific initiatives.
- Collaborate with the CEO in developing and implementing performance metrics for scientific initiatives to evaluate progress toward strategic and operational goals.
- Foster and promote a culture of high performance, continuous improvement, and learning through ongoing professional development, mentoring, and collaboration.
- Responsible for staffing, hiring, retention, performance review, and professional development of the science team.

- Participate as an active partner to all departments and attend AFTD events/programs, as appropriate.

Professional Experience/Qualifications

- Proven experience as a leader of complex, multi-stakeholder research initiatives with a demonstrated ability to envision, design, and manage such initiatives.
- Minimum 10 years of progressively responsible clinical development experience, preferably in neurodegeneration or rare diseases, with a track record of success in working with and supporting cross-sectoral partners in the clinical trial process from bench science to regulatory review.
- Current working knowledge of the pharmaceutical/biopharma industry, drug development and regulatory process.
- Proven success in cultivating and managing key relationships and consortia, bringing academic and corporate science together with government agencies to achieve diagnostic and therapeutic progress.
- Demonstrated business acumen with proven resourcefulness in setting priorities, creating efficiencies, leveraging opportunities, and developing plans to define and achieve success.
- Track record in fostering a culture of high performance, continuous improvement, and learning through ongoing professional development, mentoring, and collaboration.
- Experience in leading effective HR practices, including the staffing, hiring, retention, and performance review.
- Deep critical thinking and structured problem-solving/analysis skills with ability to develop frameworks for evaluating and recommending cross-functional options and solutions.
- Exceptional written and oral communication skills, along with the ability to connect and communicate effectively with stakeholders at all levels in various fields, including: academia, pharma, biopharma, and government, as well as board members, staff, patients, and families impacted by FTD.
- Ability to operate effectively within AFTD's nonprofit model and structure.
- Ability to inspire research-based hope that drives action such as research participation, event sponsorship, publicity, and increased advocacy.
- Ability to develop a full understanding and ownership of AFTD's mission, values, and potential role in the success of FTD clinical science.
- Willingness to travel, as needed, domestically and occasionally internationally.

Characteristics

- Strong affinity for AFTD's mission.
- Visionary, confident and collaborative as a leader.
- Flexible and self-motivated with ability to think quickly and multi-task effectively.
- Committed to the highest ethical standards with ability to demonstrate empathy, positivity, and sensitivity to the needs of all stakeholders, including persons diagnosed and their families.
- Entrepreneurial drive and innovative, team-based management style.
- Ability to work collaboratively in a small, fast-paced environment.
- Affinity for mentoring and supporting the professional development of others.

Performance Goals (first 6-12 months)

- Develop a strong foundational knowledge of the current status of FTD clinical science and establish productive relationships with key partners in this space.
- Contribute to the development of strategic and business plans for the Registry, to include an assessment of the Registry's current status and a roadmap (operations, technology and funding) for international expansion.
- Lead a multi-stakeholder initiative to pursue a Patient-Focused Drug Discovery meeting with the FDA.
- Develop a corporate relationship policy to guide AFTD's outreach to and collaborations with biopharma.

Education

- M.D., Ph.D. or equivalent advanced degree, preferably related to neuroscience.

Korn Ferry Contacts

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