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| Position: Research Portfolio Manager | Status: Full Time Position |
| Reports to: Executive Director | Supervisory Responsibility: n/a |
| Location: Downingtown, PA Office | Must be willing to travel and work weekends. |
| <i>Join a high energy, committed team of professionals dedicated to supporting the advancement of research leading to treatments to improve quality of life for people living with Friedreich's ataxia.</i> | |

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| <p><u>Position Summary:</u></p> <p>Work with FARA's Executive Director and staff to implement the scientific strategy and operational programs that support the advancement of research and drug development for Friedreich's Ataxia (FA). Work with all stakeholders (industry, academia, patient families, donors and government partners) to achieve this goal through facilitating collaboration, sharing of research tools and ideas, and using the FARA grants program to maximize impact of FARA's research and clinical resources. Direct and manage specific FARA-led efforts to develop tools to accelerate research such as development of new disease models, biomarkers and endpoints. Help FARA organize scientific workshops and meetings, and represent FARA and the FA community at scientific conferences. Participate in the review and oversight of grant applications and awards to external researchers.</p> <p>The successful candidate will have relevant professional experience in research and/or drug development for FA or a related disease (mitochondrial diseases/neurodegenerative diseases/cardiac diseases), have an understanding of the process of basic research, drug development and clinical research, have excellent interpersonal/ teamwork skills, and demonstrated interest in the development of treatments, preferably for rare diseases. The candidate will be provided the opportunity and latitude to show initiative, acquire new skills and grow professionally.</p> |
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| <p>Professional Experience Requirements:</p> | <ul style="list-style-type: none"> • Doctoral degree required • Prior research/clinical experience required • Prior research experience in FA or related diseases although not required, would be an asset • Non-profit (academic or advocacy) experience, specifically grant or program management or experience in related biotech/pharmaceutical industry, although not required, would be an asset • Scientific/research acumen |
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| <p>Skills Requirements:</p> | <ul style="list-style-type: none"> • Strong written and verbal communication skills, including ability to present and explain science to the lay public • Time management and organizational skills • Ability to work in a team setting and independently • Ability to manage projects and teams • Ability to establish a positive public presence in the research community and rally various stakeholders around organizational mission, and build collaboration • Proficient with a variety of software programs including grant management software and client relationship management (e.g., Microsoft Office – Word, Excel, PowerPoint, Publisher, Adobe Acrobat, Wizhive) |
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| <p><u>Essential Responsibilities:</u></p> <p>Support FARA Scientific Research Programs:</p> <p>Working with the Executive Director and Scientific Review Committee (SRC), the Research Portfolio Manager will have responsibility over all aspects of the FARA Grant Program:</p> <ul style="list-style-type: none"> • Initiate requests for proposals, review letters of intent and grant applications with the scientific advisory board (SAB) and scientific review committee (SRC); take part in the internal review process and help to identify external peer reviewers • Assist with the administrative aspects of the grants process; soliciting peer-reviews and obtaining progress reports and negotiating funding agreements with grantee institutions • Manage portfolio for 1/3 of the grants awarded (10-12 grants) – establish relationships with awardees, plan annual visits and/or web meetings for follow up on ongoing research projects; review progress reports and budgets. • Identify new applicants, relevant projects and ideas that merit FARA funding and work with investigators to encourage applications. • Identify new opportunities for FARA’s research mission <p>Manage FARA-led Projects</p> <ul style="list-style-type: none"> • Work with FARA’s SAB & SRC, Executive Director, and outside personnel to assess the needs of the scientific and drug development communities, and initiate and lead new projects to fill those gaps (for example, new disease model development & |
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characterization, drug screens, early discovery/pipeline investigations, biomarker initiative)

- Identify third parties (academic, industry or other) needed to complete projects; engage and encourage collaboration, oversee development of scopes of work
- Manage projects to budget & timelines

Scientific Meetings

- Represent FARA at relevant national and international meetings, reporting back relevant new research ideas, contacts and developments
- Organize smaller FARA-run workshops on specific topics, designing agenda, determining invitees, etc.
- Write summaries of relevant meetings
- Work with other stakeholders to organize biannual International Ataxia Research Conference

Communications

- Facilitate communication among all stakeholders and sectors of the FA research community, cultivating strategic partnerships with other organizations and individuals in pursuit of FARA's research goals
- Contribute to relevant articles in FARA publications and website – including, research funding updates, highlighting scientific publications and advances for the lay community.
- Answer questions from patients and families about research matters
- Educate patients and families about FARA's research activities through webinars, in-person presentation and other means

How to Apply:

Email a cover letter and resume to jen.farmer@curefa.org . Include "Research Portfolio Manager" in the subject. Please include salary requirements. Application deadline: August 15, 2018