

Position: Patient Engagement Director	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, small committed team of professionals dedicated to supporting the advancement of research leading to treatments that will improve quality of life for people living with Friedreich's ataxia.</i>	

Position Summary:
 Direct FARA's Patient Engagement program and facilitate communications and programs with all stakeholders (industry, academia, patient families, donors and government partners). Develop programs that support the research mission in promoting outreach, education and community building among Friedreich's Ataxia families across the country. Responsible for the upgrade and redesign of the FA Global Patient Registry and building ongoing enrollment to the registry. Work with FARA's volunteer Ambassador Program to support FARA's mission with activities that educate the community and increase awareness of the research process. Serve as a liaison between the patient community and other FARA stakeholders such as the pharmaceutical industry, academic scientists, and governing bodies to promote understanding of the FA condition and incorporation of FA families in research.

The successful candidate will have professional experience working with pharma/ biotech and patient families, understanding of drug development and clinical research, excellent interpersonal/ teamwork skills, and demonstrated interest in the health and human service industry. The candidate will be given the opportunity to show initiative, acquire new skills and grow professionally.

Professional Experience Requirements:	<ul style="list-style-type: none"> • Master's degree required • Prior medical/clinical service experience required • Non-profit experience or experience in related service industry Scientific/research acumen <ul style="list-style-type: none"> • Program Management Experience required • Proficient with a variety of software programs including client relationship management (e.g., Salesforce, Microsoft Office – Word, Excel, PowerPoint, Publisher and Adobe Acrobat)
Skills Requirements:	<ul style="list-style-type: none"> • Focus on customer service and outreach • Strong written and verbal communication skills • Time management and organizational skills • Ability to work in a team setting and lead volunteers • Ability to establish a positive public presence in the community and rally various stakeholders around organization mission

Essential Responsibilities:

Direct FA Global Patient Registry upgrade, redesign and global recruitment/enrollment initiative

- Manage the customized build of a FA Global Patient Registry
 - Research relevant business and functional requirements for the registry
 - Work with academics and pharma on their needs in utilizing the registry to design and implement trials
 - Independently direct project work of contract team including scope of work, deadlines, testing and launch
 - Facilitate the secure transfer of data from the existing platform to the new registry
 - Collaborate with international FA advocacy groups to make the registry user friendly in a global setting
- Design and execute an outreach campaign to identify new FA patients and encourage global enrollment or patient update of existing data for current registrants
- Conduct outreach to families to encourage enrollment and participation
- Problem solve issues as they arise within a team approach

Direct all Patient Engagement activities and facilitate outreach and education of the FA community to engage in the research process

- Assist the Executive Director with outreach to FA patients and families to train and prepare for meetings such as the Patient Focused Drug Development Meeting with FDA
- Design and implement FA patient/ family training on clinical trial process and facilitate/ support their involvement in the drug development process through activities such as informed consent review, serving on a Data Safety Monitoring Board, etc
- Educate the pharmaceutical companies working in FA on the value of patient engagement in research and the ways in which FARA can support these activities
- Assist the Communications Director with written communications to educate the existing FA community and identify new FA patients

Co-lead Ambassador Program of volunteer peer representatives for the FA community with respect to education and interface with stakeholders

- Regularly attend monthly meetings to provide organization and scientific updates as well as engagement opportunities to volunteers
- Facilitate annual training of ambassadors

Ensure accurate, timely and stakeholder friendly communications with all stakeholders. Follow established organizational policies and procedures and compile information and reports as required.

Use a team approach when working with both the Communications team and

Ambassador volunteers.

Demonstrate ability to learn and adapt to changing procedures, methods or processes.

Provide first-rate customer service as front-line client contact.

Ensure that all FARA stakeholders are communicated to in a clear, consistent and timely manner utilizing strong written and verbal skills to address stakeholder needs.

Attention to detail demonstrating accuracy and efficiency in word processing, data entry, and business correspondence.

Coordinate work activity efficiently, and check that work has been carried out to specification.

How to Apply:

Email a cover letter and resume to felicia.derosa@curefa.org . Include "Patient Engagement Director" in the subject. Please include salary requirements. Application deadline 1/6/17.