Job Description

Associate Director of Research

May 31, 2022

About Amyloidosis Research Consortium

The Amyloidosis Research Consortium (ARC) is a 501c(3) nonprofit organization founded in 2015, harnessing the power of collaboration and innovation to advance science and both improve and extend the lives of those with Amyloidosis. We are dedicated to transforming the way research is being done and focus on what will have the most significant impact on improving the lives of amyloidosis patients. We forge collaborations across industry, research, clinical care, and regulatory to address unmet need and accelerate the discovery of new treatments. ARC empowers and supports patients by ensuring they have access to the best quality care and information.

Amyloidosis is the term for a group of rare diseases in which an abnormal protein misfolds and deposits as amyloid in organs and tissues, causing damage and eventually organ failure. There are different types of Amyloidosis, and they vary from one another in their biochemical nature and natural history. Some are acquired, and others are inherited. In the United States, approximately 4,000 people develop Amyloidosis each year. It is currently recognized to be wildly underdiagnosed, and therefore that number is expected to rise significantly.

To learn more about ARC, visit **http://www.arci.org.**

About the Position

Are you looking for a meaningful role? Interested in working with a motivated, thoughtful, creative, and friendly team to make a difference? ARC seeks a full-time Associate Director of Research to support ARC's public private partnership, the Amyloidosis Forum (https://amyloidosisforum.org), and oversee ARC's community research initiatives.

The Associate Director of Research, reporting to the Executive Director of Research, will be responsible for partnering with stakeholders across the community to lead ARC's public private partnership (PPP) with the FDA, known as the Amyloidosis Forum, with the goal of accelerating drug development in amyloidosis. This position will also be responsible for overseeing a number of ARC research projects aimed at seeking to better understand amyloidosis patient experiences, perspectives, and outcomes, and will support a small team in the execution of these projects. The

ideal candidate will have an in-depth understanding of the drug development continuum, as well as experience partnering with a variety of different stakeholders, including from academia, regulatory, life science companies, and medical professionals, to design and implement rigorous research programs that inform and guide healthcare bodies, clinical trial design, and patient experience.

Key Responsibilities:

- Manage the ARC/FDA public private partnership (PPP), the Amyloidosis Forum, to accelerate drug development in amyloidosis.
- Engage and partner directly with ARC leadership, the PPP Steering Committee, and the broader amyloidosis community to support setting the overall priorities for the Amyloidosis Forum.
- Work across the amyloidosis community, including patients, expert clinicians and researchers, leading biotech and pharmaceutical companies, regulators, and patients to scope out, design, and execute projects and workstreams through the Amyloidosis Forum.
- Oversee and manage individual Amyloidosis Forum working groups and resulting deliverables, as well as community-wide, public meetings.
- Provide integrative management and oversight to the planning, budgeting, implementation, and execution of ARC' community research initiatives aimed at seeking to better understand amyloidosis patient experiences, perspectives, and outcomes.
- Plan, manage, and implement dissemination activities for the Amyloidosis Forum and ARC's community research initiatives, including publications, presentations, and posters.
- Contribute to the design and implementation of broader ARC research initiatives, including the development and roll-out of disease-specific PROs and a multifaceted data-sharing model.

General responsibilities:

- Manage multiple projects, translating project concepts into timeline- and deliverable-bound project plans in collaboration with ARC staff and subject matter experts.
- Collaborate with ARC's development and leadership team on strategic planning, to identify funding opportunities, and develop a case for support.
- Help strategically position ARC as a leader in the rare disease field through the evaluation and assessment of new project ideas, opportunities, and proposals.

- Collaborate with ARC staff members on communication efforts, including providing website and social media content, and developing quarterly reports for ARC's Board of Directors.
- Stay up-to-date on the amyloidosis treatment landscape, publications, and research, and needs in amyloidosis, as well as cross-stakeholder, collaborative initiatives within rare disease.
- Assume other duties and responsibilities, as needed, that are appropriate to the position.

Skills and Experience

- Master's Degree with 5+ years of progressive responsibility and equivalent experience in clinical research, rare disease, medical technology product development, public health, epidemiology, and/or life science industries. Regulatory experience preferred.
- Knowledge of fundamentals of health outcomes/human subjects research principles and good clinical practices.
- Experience designing and overseeing human research projects; comfortable with quantitative and qualitative data analysis.
- Direct experience managing a team and/or individuals.
- Experience and demonstrated ability to balance and manage multiple priorities, projects and deadlines; ownership of the work and outcomes.
- Highly organized, very detail-oriented, proactive and takes initiative. Ability to perform and prioritize multiple tasks, exercise good judgment, and quickly identify and resolve problems.
- Ability to work independently and collaboratively as part of a team within a dynamic work environment that includes virtual teams.
- Strong interpersonal skills and the ability to build relationships with internal staff, external experts, and other stakeholders. Team management experience preferred.
- Demonstrated experience with communicating science to different audiences and through different media, including websites, emails, presentations, and publications.
- Commitment to professional development and continued learning within an organization.
- Passion for non-profits, health equity, patient engagement, and cross-sector collaboration. Ability to be flexible, compassionate, and creative, while having a sense of humor.
- Experience utilizing MS Office, Salesforce, project management tools such as Wrike, Smartsheet, or Microsoft Project.

This is an exciting opportunity to work at a growing organization, with a team that values a diversity of experience and demonstrates an unwavering commitment to the amyloidosis community.

How To Apply

Applications are reviewed on a rolling basis. To apply, please send a resume, cover letter, and writing sample to Grace Fan at **gfan@arci.org**. Emails without a cover letter and writing sample will NOT be considered.

Please ensure that your resume, cover letter, and writing sample are sent as Word or PDF documents with the titles "your name cover letter", "your name CV", and "your name writing sample." Please put **"Associate Director of Research – Your Name"** in the email subject line and let us know where you saw the post advertised. Thank you!

Additional Information

Office Hours & Requirement

This position is full-time, exempt. 40 hours per week, Monday – Friday 9-5 pm; opportunity to flex workday schedule to meet employee needs.

ARC will require that all employees are vaccinated with exceptions for medical and religious accommodations. ARC may require proof of vaccination. This role may start as a remote position but will transition to a hybrid working arrangement of 40% on-site at our Newton office. Preference given to applicants located in Greater Boston Area.

Interview Process

Please note that we are currently conducting the majority of interviews and onboarding remotely and virtually. We appreciate your understanding.

Benefits Package

We offer a competitive benefits package including generous paid time off, health insurance, dental, vision, Long Term Disability, Life insurance, and more.

- Paid Time Off: Generous paid time off including holidays, sick leave, and vacation time.

- Medical/Dental/Vision: We offer a full range of contributary medical plans, dental & vision plans; all coverage begins as of your start date, no waiting period for new hires.
- Life/Disability: 100% employer-paid Life and AD&D plan, and Long-term Disability plan.
- Flexible Spending Accounts (FSA): Offer both Health FSA & Dependent Care FSA.
- Others such as Employee Assistance Program (EAP), Worker's Compensation, and more.

Equal Employment Opportunity

We are proud to be an equal opportunity employer – and celebrate our employees' differences, regardless of race, color, religion, gender, sexual orientation, gender identity, national origin, age, disability, or Veteran status.