About Amyloidosis Research Consortium (ARC)

The Amyloidosis Research Consortium (ARC) was founded in 2015 by Isabelle Lousada, an amyloidosis patient. The ARC addresses critical needs in clinical trials and related research for the underserved group of systemic amyloid diseases.

In the United States, approximately 4000 people develop Amyloidosis each year. This rare disease occurs when an abnormal protein called amyloids builds up in the tissues and organs affecting the shape and how they work. There are many types of amyloidosis each with its own symptoms. AL amyloidosis, the primary amyloidosis, can affect the heart, kidney, liver, and skin. Although receiving an amyloidosis diagnosis is overwhelming, ARC provides patients with helpful resources to navigate the disease and educate themselves on the latest in amyloidosis research and treatments.

Using a collaborative research model, the ARC brings together experts in the field to address the challenges that exist in developing diagnostic tools and carrying out innovative clinical trials. It is committed to building collaborative relationships between patients, academia, industry, foundations, federal funders, and regulators to advance the best research and speed new therapies to market.

The ARC is focused on increasing the amount of research and building a prioritized portfolio of translational research and clinical research to address the urgent, unmet medical needs within in amyloidosis.

Our Solution

Our research model is focused on developing the critical tools, assets and infrastructure needed to accelerate progress.

Regulatory Programs
The ARC has an exceptional relationship with the FDA and other regulatory bodies, developing programs to support the review of new treatments and to ensure patient needs are well understood and fully integrated into the review process.

Scientific Discovery
We use cutting-edge science to identify and test new treatments. For example, our work on biomarkers is helping to improve the specificity and success rate of early stage research. This can help to identify drug candidates that work in specific patient groups, therefore accelerating progress.

Making a significant and material contribution to the curability of systemic amyloidosis diseases.

Physician Programs
The ARC’s awareness and educational programs are extensive and include symposia, round tables and awareness campaigns, as well as ARC publications on disease guidelines and educational tools.

Patient Programs
Patients who are informed and supported are able to make better decisions about their treatment and care. Our programs have been developed to support patients from time of diagnosis to finding an amyloidosis specialist and continues on to help them participate in research studies. ARC also works closely with patients to ensure their preferences and views on the value of products are well understood.
About the Position

The Director of Development position at ARC is an opportunity for an individual who wants to contribute to an organization at an exciting time in its development. Building on an established strategic planning process, the Director of Development will focus on growing ARC’s membership base of patient organizations and pharmaceutical and biotechnology companies, establish strategic alliances with other influential stakeholders in the disease community, broaden ARC’s role as a key thought leader on legislative and regulatory issues that impact the disease community and raise its international profile.

The time is right to implement these efforts. Thanks to international partnerships and the creation of online communities, individuals suffering from systemic amyloid diseases are more able to connect to one another for support, find clinical trials focusing on their medical problems, and bring attention to the issue in general.

The Director of Development, who will partner closely with leadership, must be a proven fundraiser, who thrives on being in a fast-paced, entrepreneurial environment. ARC seeks candidates who have experience working with visionary leaders and the corporate sector, and who bring a well-developed skill set of prioritizing, focusing, and executing. The right candidate will possess demonstrable and strong fundraising progress and outcomes in their career, and be able to show their ability to design a program that is appropriate in scale and pace for an expanding organization. ARC will offer a competitive salary for the right individual and to building out a philanthropic function as return on investment warrants.

Key Responsibilities

- Design and strategy for all areas of fundraising: corporate/foundation support, individual giving, and special events
- Development and presentation of an annual and long-range plan for fundraising, including identification of growth areas and return on investment
- Integrate fundraising plans with overall organizational plans for growth and sustainability
- Contribute to and refine the case for philanthropic support to be effective with a variety of donor audiences
- Identify, cultivate, solicit and steward individual prospects
- Engage senior staff and Board members in individual and organizational giving
- Determine strategies for further engaging membership organizations
- Ensure that systems and practices support a dynamic program
- Serve as a spokesperson for ARC and its mission in the philanthropic community and corporate and government sectors in Washington D.C. and beyond
- Make recommendations for fundraising investments (staff positions, systems, etc.) that are prudent for maximizing opportunity and supporting key strategies
Key Qualifications

- Minimum 7 years fundraising experience w/ proven success in major gifts and corporate, foundation relations
- Experience building fundraising projections, tracking results, and evaluating outcomes to inform future strategy
- Comfortable with industry leaders (preferably pharma), policy leaders and medical professionals
- Success closing gifts ranging from 5- to 7-figures
- Effective interaction with senior leadership, board, donors, and organizations at all levels
- Solid communications skills (writing, interpersonal presentation, and public speaking)
- Familiarity working with member- or chapter-based organizations
- Ability to manage multiple projects concurrently
- Genuine interest and commitment to the mission, with the ability to effectively communicate it
- Ability to travel as necessary
- Desire to lead ARC to the next level of growth

All qualified candidates will receive consideration for employment without regard to race, color, religion, sex, national origin, disability, veteran status, or any other characteristic protected by law.

Please email your cover letter and resume in confidence to:
ARCDOD@developmentguild.com

Katharine Kaplan
SENIOR CONSULTANT
Development Guild DDI

For more information about Amyloidosis Research Consortium please click here

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About Development Guild DDI

Development Guild DDI is a national management consulting firm partnering with leading nonprofits to deliver the strategy, talent, and philanthropic resources that impact organizations and mission delivery. We focus our work across the nonprofit sector, particularly in the fields of education, health & science, the arts, and social justice.

More than 500 clients have shaped the regional, national, and global reach of our extensive relationships, knowledge, and results. Leveraging our work with nonprofit governance and leadership development, we deliver service in two areas: fundraising and executive search.