



April 1<sup>st</sup>, 2019

## Health Care Professional and Patient Programs Manager

### About Amyloidosis Research Consortium (ARC)

The Amyloidosis Research Consortium (ARC) is a non-profit global organization founded in 2015. ARC's mission is dedicated to transforming the way research is being done and focuses on what will have the greatest impact on improving the lives of amyloidosis patients. We forge collaborations across industry, academia and regulatory to more rapidly advance the discovery of new treatments.

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 amyloid, and they vary from one another in their biochemical nature and natural history. Some are acquired, and others inherited. In the United States, approximately 4000 people develop Amyloidosis each year. It is currently very underdiagnosed and so that number is expected to rise significantly.

ARC is a patient focused organization empowering and supporting patients while making sure they have access to the best quality of care.

To learn more about the ARC, [visit http://www.arci.org](http://www.arci.org)

### About the Position

ARC is looking for a Health Care Professional and Patient Programs Manager, this role is key for the successful delivery of ARC's ambitious plans. Initially reporting to the CEO, the HCP and Patient Program Manager will contribute to the overall success of the organization by having strategic oversight and day-to-day responsibility for designing, producing and delivering a diverse but targeted portfolio of innovative and engaging hcp and patient programs to improve rate and accuracy of diagnosis and quality of care.

The ideal candidate should understand the educational landscape for medical professionals, as well as the pressing needs of health care provider education to facilitate diagnosis and improve treatment for patients with a significantly under diagnosed rare and life-threatening disease. The ideal candidate should have experience providing support to patients in the rare disease or cancer environment, and will understand the needs and challenges patients face with a life-threatening disease. At the same time, this role will maximise the opportunities to be a strong and convincing advocate for the needs and perspectives of patients, their carers and family members.

This is an opportunity to play a significant role in the shaping and growth of a rapidly expanding organization working at the cutting edge of amyloidosis research, policy, education, information and support. We are looking for an inspirational and experienced professional with a proven ability to design, implement and scale programs, who will drive our strategy for educating health care professionals, supporting patients and ultimately improving quality of care.

## Key responsibilities

### Health Care Professional Programs

- Educational Programs – Work in partnership with the development and leadership team to develop strategy and funding opportunities. Design and implement a strategy encompassing disease awareness and education for the medical community, in close collaboration with the leadership team. Develop educational materials and assets to promote best practice in treatment of amyloidosis. Develop programs for relevant meetings, symposia and congresses
- Disease Awareness - Develop materials and assets to raise disease awareness and promote early diagnosis among relevant HCPs. Liaise with HCPs and industry partners to facilitate collaboration and streamlining of efforts
- Meetings - Represent the ARC at relevant national and international conferences, seminars, and meetings, through booths, presentations, networking and attendance. Position ARC as a leading authoritative voice on not just amyloidosis, but on rare disease generally
- Relationships – Develop strong relationships and partnerships with disease experts by establishing high level of trust and confidence in ARC as an organization. Increase the number of physicians interested in the disease and pursuing careers in the field

### Patient Programs

- Patient Information – Design and implement print, online, in-person information and support programs. Take an innovative approach and maximize the use of digital and related platforms. Ensure a very high-standard of accurate, current and accessible content

- Access to information - Put in place appropriate initiatives to ensure information and support is delivered, in partnership with HCPs involved in the treatment of care of patients and their families, as a structured approach to care
- Patient Support - Be the initial point of liaison for any patient enquiries. Develop and implement appropriate patient and family relationship and engagement strategies, building two-way trust and a high willingness to support and participate in programs and initiatives
- Patient Voice - Represent and champion the needs and perspectives of patients and their families by taking part in relevant internal and external initiatives, advisory boards and committees

### General Responsibilities

- Meetings - Represent ARC at relevant conferences, seminars and meetings through booths, presentations, networks and attendance
- Planning - Work with CEO produce program plans, budget and key performance indicators as part of the annual planning process
- HCP Liason – Act as the initial point of contact for HCPs across various ARC programs, ensuring consistency in communication, dissemination of information, and further relationship development
- General - Work in partnership with other teams to maximize the access to and impact of programs, and ensuring they represent the patients' needs appropriately. Support relevant colleagues to ensure prompt and accurate reporting to funders in accordance with their defined criteria

### Education Requirement:

- Minimum bachelor's degree in a health-related field required
- At least 2 years of professional experience in health services

### Job Qualifications:

- General health and disease biology, treatment and patient information knowledge



- Experience of working with cancer and/or rare disease and/patients, and healthcare professionals
- Experience of working with cancer and/or rare disease healthcare professionals and academic stakeholders
- Exceptional written, oral, interpersonal and presentation skills and the ability to interface well with both internal and external senior positions
- High degree of customer focus towards internal and external stakeholders
- Excellent planning skills and able to manage multiple projects with time demands
- Highly organized with the ability to prioritize and meet deadlines in a fast paced environment
- Self-reliant, good problem solver, results oriented
- Genuine interest and commitment to the ARC mission, with the ability to effectively communicate it
- 20% travel may be required

To apply please send your resume and a cover letter to [arc@arci.org](mailto:arc@arci.org)



Amyloidosis  
Research  
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