

Amyloidosis Research Consortium's Corporate Organization Relations Policy

ARC's mission is to improve and extend the lives of those with amyloidosis. ARC is committed to collaborative efforts that accelerate the pace of discovery, expand patient access to the most effective care, and improve short- and long-term outcomes. Working with partners in industry, government, and academia, ARC seeks to spark innovation and to bring promising treatments from labs to clinics. ARC's outreach and education inform and empower patients, families, caregivers, physicians, and researchers.

ARC recognizes that partnership and engagement with various entities can help serve our mission. Patients and their families benefit through these improved endeavors and services that help meet their needs and advance the state of care. As such, ARC will develop a variety of strategic relationships with corporate sponsors and work in partnership with them to achieve our mission through relevant projects, efforts, initiatives, programs, and more. Most relationships will have educational or engagement objectives; others may be intended to create awareness or promote research; and some may be multifaceted in nature. Every single partnership is entered into for the purpose of ultimately recognizing our shared goal: to end amyloidosis and benefit the amyloidosis community.

In order to assure that relationships between biopharmaceutical companies and ARC remain true to their shared goals of advancing research, health care innovation, and improving patient access to care and services, such relationships should be structured to ensure the independence of ARC and appropriate support of our mission. The independence of ARC must be respected in order for ARC to be effective in its mission.

ARC's biopharmaceutical company relations policy is intended to ensure that the corporate relationships entered into by ARC are conducted in a manner consistent with our mission, objectives, and core values. ARC holds itself accountable to the highest standards of good governance, reinforcing the independent and ethical basis of mutual relationships. This ensures that ARC will never compromise its independence or engage in a corporate relationship that will affect ARC's credibility or integrity. This policy outlines best practice consistent with applicable laws, regulations, and industry code of best practice to govern interactions with ARC, to inform collaborations and other activities, to ensure relevance and reasonableness of support, and to minimize the risk of real or perceived undue influence.

Corporate relationships entered into by ARC follow the basic requirements set forth below:

Mission Benefit

The Corporate relationship must provide a meaningful and substantial mission-related benefit to the Amyloidosis community through projects, efforts, initiative, programs, or the execution of ARC's mission.

Independence

While ARC may accept financial support from corporations, ARC always exercises independent judgement in all its decision-making. ARC determines appropriate areas for corporate sponsorships and grant funding. ARC retains sole discretion for the content, quality, and scientific and educational integrity of all grant-funded or sponsored programs, events, and publications. ARC shall avoid any potential conflicts of interest when establishing and maintaining corporate relationships.

Funding

Companies may provide financial support for ARC activities and programs, including but not limited to professional, educational, scientific, specialized projects, core programs, fundraising events or those which otherwise supports the mission of the organization.

Core funding

Funds for core activities will only be received on an unconditional basis. To avoid undue reliance on any particular company, such funds should be balanced and diversified as much as possible to avoid conflicts of interest and guarantee independence.

Project funding

Funds or sponsorships for projects can only be accepted without any conditions imposed on the design and conduct of the project or the dissemination of its results (where applicable), guaranteeing full independence of ARC. Any ensuing publication will be the property of ARC. No information should ever be used to promote the use of any specific product or business of the funder.

Sponsorship of events

ARC may accept funds, or sponsorship for events. Sponsorship should come from more than one source. Sponsors will not exercise any control over the program content or choice of speakers at ARC events.

Communications

ARC is transparent about and publicly communicates its policies regarding relationships with corporate sponsors. ARC materials directed to the public contain accurate terms or statements such that reasonable individuals will understand the nature and extent of the corporate relationship.

Endorsement

Support of programs cannot be conditioned on or offered as a reward for recommendation or promotion of any corporate product, therapy or technology. ARC does not endorse any product for financial gain and/or does not endorse particular products, studies, trials, therapies, or potential therapies.

Privacy

ARC protects the privacy of participants in corporate-sponsored activities and/or programs and does not share mailing or contact lists of any type. Any information that could identify individuals or their family members will not be shared without approval from the individual.

Disclosure

Support for ARC initiatives and programs should be disclosed in a manner that provides reasonable notice of support and/or collaboration. ARC will provide disclosure of funding received from pharmaceutical companies and associations via public documents including the annual report and ARC website. Funding organizations will be acknowledged. The impact of the collaboration should also be communicated back to those who contributed.

Exclusivity

In general, there are no exclusive arrangements in partnerships, projects, efforts, initiatives, programs, or the execution of ARC's mission. ARC resolutely believes it is our role to move the amyloidosis field forward and exclusive partnership could prohibit the success of this. ARC treats all corporate sponsors fairly and honestly. If exclusive partnerships occur due to mitigating circumstances, it may be deemed acceptable as long as that company does not make its support conditional on the company being the sole funder.

Adherence

The corporate partner and relationships will adhere to all applicable state, federal, and local rules and regulations.

Advance Review and Approval

Any use of any kind of the ARC name, logo and/or identifying marks in a corporate relationship must be reviewed and approved by ARC in writing in advance of use, including in statements or any other materials from the corporation.

Written agreement

A written agreement or scope of work will be executed outlining, type of support, and length or duration, between ARC and the corporation prior to implementation of the corporate relationships. The Agreement will clearly indicate (i) the amount of money that will be transferred to ARC; (ii) a written description of the mission-driven activity supported that both parties will agree to use for purposes of disclosure to the general public; (iii) a general timeline of the effort; (iv) whether the consideration is unrestricted or restricted to support a particular event or program activity; (v) the role of a corporate steering committee, if one exists; (vi) that ARC retains complete control of and right of approval over all content related to the event or program activity; and (vii) whether, and if so, how the organization's name, logo, and/or any identifying marks will be used by a corporation.

