

PhRMA Principles on Interactions with Patient Organizations



Interactions Between Biopharmaceutical Companies and Patient Organizations Advance Biomedical Research, Health Care Innovation, Access to Care, and Patient Services

Biopharmaceutical companies share many common interests with patient organizations including, most importantly, a common commitment to patients and shared mission to discover cures and fight disease. In our joint mission of innovation and service to patients and caregivers, companies frequently work together with patient organizations to sponsor research, provide educational and support services for patients, and award grants to benefit the mission of patient groups. A patient organization is typically a not-for-profit institution that primarily represents the interests and needs of patients, their families, or other caregivers. Biopharmaceutical companies and patient organizations enjoy productive collaborative relationships which benefit the public health. In order to help assure that relationships between biopharmaceutical companies and patient organizations remain true to their goal of advancing biomedical research, health care innovation, access to patient care and services, such relationships should be structured to ensure the independence of the patient organization and appropriate support of the organization's mission. Accordingly, PhRMA establishes these Principles on Interactions with Patients Organizations.

Respecting the Values and Independence of Patient Organizations

All interactions with patient organizations must be consistent with the patient organization's mission and adhere to high ethical standards. The independence of patient organizations must be respected.

When working with patient organizations, companies should ensure that both the involvement of the company and the nature of that involvement are clear from the outset.

No company should require that it be the sole funder of the patient organization or any of its programs.

Documenting Support

Companies that provide financial support or in-kind contributions to patient organizations should have in place written documentation setting out the nature of support, including the purpose of any activity and its funding.

Support for Patient Organizations

Companies may provide financial support for patient organization meetings or other activities provided that the primary purpose of the activity is professional, educational, or scientific in nature, or otherwise supports the mission of the patient organization. When companies hold meetings for patient organizations, companies should ensure that the venue and location are appropriate and conducive to informational communication. In addition, any meals or refreshments provided by a company should be modest as judged by local standards.

Questions & Answers

Q What happens if only one biopharmaceutical company wishes to support a particular patient organization? Is this allowed?

A **Yes.** Many patient organizations are supported by a number of biopharmaceutical companies. There may, however, be situations where only one company wishes to support a particular patient organization or one of its activities. It would be acceptable under these PhRMA principles for that biopharmaceutical company to be the only company providing funding as long as that company does not make its support conditional on the company being the sole funder.

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Q Under these principles, are biopharmaceutical companies allowed to serve as sponsors for patient organization events and fundraisers to support the mission of the patient organization?

A **Yes.** Companies may provide financial support for patient organization activities, including fundraising events and other events where the primary purpose of the meeting is professional, educational, or scientific in nature, or otherwise supports the mission of the patient organization.

