



BIO GUIDING PRINCIPLES FOR INTERACTION WITH PATIENT ADVOCACY ORGANIZATIONS

BIO member companies are committed to investing in, discovering, and developing innovative medicines to cure or treat disease and improve the lives of patients. BIO and its members recognize that it is of the utmost importance to understand and consider on an ongoing basis the needs and preferences of the patients we serve. To ensure BIO and its members understand and can thoughtfully address what is most important to patients, their caregivers, and their families, we meaningfully, ethically, and responsibly engage with patient advocacy organizations.

Patient advocacy organizations are typically non-profit entities that advocate for and support the needs of patients and caregivers. These organizations are most closely connected to and can best communicate the perspectives, values, and desires of the constituencies that they represent. Patient advocacy organizations are uniquely positioned to help raise awareness and overcome stigma of medical conditions, provide support and disease education to patients and caregivers, drive the development of new medicines for patients, and advocate for policies that sustain medical innovation and ensure patient access to novel therapies.

The following guiding principles for interaction with patient advocacy organizations are intended to inform BIO member companies as they engage and continue to develop partnerships with the patient advocacy community. These principles are based in large part on certain well-informed existing company practices, as well as patient advocacy organizations' own perspectives on working with industry to achieve goals that are most closely aligned with the interests of the patients they represent. This document is not intended to establish any binding standards or supplant any legal or other requirements that may apply to such interactions; rather, it is intended to reach beyond legal requirements to provide an ethical framework for members of our industry as they collaborate with patient advocacy organizations. Each patient advocacy organization, as well as BIO and its member companies, will abide by its own guidance.



FOSTERING PARTNERSHIP AND VALUING INDEPENDENCE

Partnerships between BIO member companies and the patient community should be based on our shared objectives of developing and ensuring access to treatments that improve patient health outcomes. To that end, BIO and its member companies value and embrace the autonomy of patient advocacy organizations and recognize the importance of their maintained integrity to ensure that they are an independent and trusted voice of patients. We encourage this and recognize that partners in the patient community independently develop public policy and scientific agendas. These may, in some cases, differ from those of BIO and its members but should not impact the relationship between the patient advocacy organization and BIO or its members. BIO member companies should not attempt to compel a stakeholder in the patient advocacy community to adopt a specific policy position.

ADVOCATING FOR POLICIES THAT IMPROVE PATIENT OUTCOMES

Partnerships between industry and patient advocacy organizations may provide opportunities to better understand the complexities of patients' healthcare journeys, their expected outcomes, and the challenges they face enhancing, supporting, and promoting the patient voice. BIO members and patient advocacy organizations work together to communicate these needs and experiences and look for shared solutions for patients and their families.


These collaborations often result in improved public policies around disease education, awareness, patient access to treatments, clinical research, and, ultimately, improved health outcomes.

When collaborating on shared policy objectives, BIO, its members, and the patient advocacy community should work together as equal partners.

SUPPORTING PATIENT ADVOCACY ORGANIZATIONS

BIO and its members, at times, provide financial support* to patient advocacy organizations to support activities which may advance our shared goals of bringing new treatments to patients faster by speeding the pace of innovation, increasing disease awareness, and advancing patient-focused public policies. In some cases, organizations may apply for or choose to utilize industry-provided resources to deliver patient support services administered by patient advocacy organizations, such as peer support programs, awareness events, online forums, and informational brochures. The objective, scope, and deliverables of any collaboration should be transparent and ethical.

*Financial support may include, but is not limited to, sponsorships, grants, donations, and charitable contributions.



BIO and its members should not dictate that a patient advocacy organization receive funding solely from one entity. While there may be circumstances in which a single entity is the sole source of support, patient advocacy organizations are encouraged to identify, when possible, multiple sources of financial support.

Further, financial support provided by BIO member companies should strengthen the mission and should not influence the development of a patient organization's public policy positions, nor should a financial contribution be intended or expected to do so.

BIO recognizes the importance of transparency and its role in developing trust-based relationships with stakeholders, the public, and the patient advocacy community.

VALUING THE PRIVACY OF THE PATIENT COMMUNITY

BIO and its members respect the privacy of data that may be received or collected from patient advocacy organizations. There is no expectation that personal patient or family information will be shared with BIO or its members.

RESPECTING STANDARDS OF ETHICAL CONDUCT

BIO and its members believe that individual patients and their health care providers are best equipped to choose the appropriate course of treatment in order to achieve the best possible outcome. To that end, BIO and its members should not expect promotion or endorsement of a specific product when partnering with or providing financial or other support to a partner in the patient advocacy community.

