



BARTH SYNDROME FOUNDATION

CORPORATE RELATIONS GUIDELINES

The Barth Syndrome Foundation (BSF) considers first and foremost its mission and serving its constituents in all decisions, including whether to enter into a relationship with a for-profit entity. In many cases, activities that fulfill BSF's mission cannot be accomplished as well alone as they can be through collaboration and alliances among like-minded organizations. It is for this reason that BSF may seek to forge appropriate and productive collaborative relationships with corporations and/or others who fund or sponsor BSF operations, programs, or initiatives, or provide other non-fee-for-service based benefits. For the avoidance of doubt, this policy does not apply to an organization which chooses to make a donation to BSF and seeks nothing in return.

The need arises, therefore, for BSF to establish guidelines that help it take full advantage of opportunities for corporate charitable engagement, but that also serve as safeguards against any possible negative impact that corporate relationships might have on BSF's public image and integrity, whether real or perceived, or which might compromise BSF's ability to effectively fulfill its mission.

Types of Corporate Support

Potential corporate relationships are generally characterized by one or more of the following activities:

- **Program Sponsorships:** For example, support provided to conduct BSF's Conference or SMAB meetings, BSF's BRR or educational programs for patients and health care professionals and public awareness programs. In the case of professional education, the program must be conducted in accordance with the guidelines of the Accreditation Council for Continuing Medical Education (ACCME).
- **Event Sponsorships:** Support provided primarily to underwrite fundraising events, such as walks, bike rides, and black-tie galas. Corporate support typically offsets a portion of the expenses of such events, allowing more of the funds raised to go directly to support the organization's mission.
- **Health Message Promotions:** Activities that direct the consumer to the organization for information on the specific disease or condition in exchange for use of the organization's

name, logo or message in a corporation's product advertising, promotional or educational materials. Not currently in practice or planned for BSF.

- **Strategic Alliance or Partnership:** A significant, long-term and mutually beneficial relationship between an organization and a corporation. Typically, the organization helps supply a health education message or service that is delivered through a company delivery system to better serve people with the particular health interest or condition. It is often a collaborative effort to improve the health information or service provided to the individual. It may not necessarily involve a monetary exchange.
- **Consumer Product Purchase:** A donation to the organization triggered by the purchase of a product by a consumer. Such initiatives are most commonly based on sales during a specific period and/or include a cap on the maximum amount that the corporation will donate. Not currently in practice or planned by BSF.
- **Endorsement:** A recommendation that a product, special feature of a product, attribute of a product and/or the efficacy of a product is superior to other products. Generally, endorsements should be avoided. In particular special scrutiny, including regulatory guidelines, must be applied when prescription and over-the-counter drugs and devices are involved. BSF does not endorse products or services.
- **Licensing:** A relationship where an organization authorizes a company to develop, produce, market and/or distribute a mission-related product that is marketed under the organization's name, e.g., cookbooks, books, videos and other mission-related educational materials. In return, the organization typically receives royalties. Not currently in practice or planned by BSF.
- **Certification:** A relationship where an organization recognizes that a particular product or service of a company complies with or satisfies an applicable or relevant organization standard. Generally, exclusive certifications should be avoided. BSF does not and will not engage in certification.

The definitions above describe the basic types of corporate relationships but are not necessarily separate and distinct. There may be overlap, and hybrid arrangements can exist.

Guiding Principles for Corporate Relationships

- **Independence:** BSF exercises independent judgment in all its decision making related to any corporate relationship.
- **Mission-related benefit:** The relationship provides a meaningful mission-related benefit to the general public or particular constituencies of BSF.

- **Consistency:** The relationship is consistent with BSF principles, public positions, policies, and standards.
- **Adherence:** The relationship adheres to all applicable state and local laws and regulations.
- **Transparent and Non-deceptive communications:** All materials from the corporation or BSF directed to the public will contain accurate and non-deceptive terms or statements such that a reasonable person will understand the nature and extent of the corporate relationship. Specific monetary amounts need not be reported except where a purchase by a consumer causes a donation to be made to BSF, in which case BSF will disclose the amount or percentage of money from the sale which will actually go to the organization, the duration of the campaign (e.g., the month of October), and any maximum or guaranteed minimum contribution amount (e.g., up to a maximum of \$200,000).
- **Endorsements:** BSF does not endorse products or services.
- **Certifications:** BSF does not and will not engage in certification of products or services.
- **Privacy:** BSF has written guidelines that protect the privacy of people participating in corporate-sponsored activities and/or programs.
- **Compliance:** BSF will develop a mechanism to assure compliance with its corporate relations policy.
- **Balance:** BSF evaluates on an annual basis the total amount of charitable corporate support received as a percentage of total revenue.

Written Agreement

BSF will execute a written agreement with the corporation for any activity in which BSF is obligated to meet any terms or conditions. The written agreement must clearly indicate:

- the terms under which the amount of money that will be transferred to BSF is to be determined;
- whether the payment is unrestricted or earmarked to support a particular event or program activity;
- a written description of the mission-driven activity being supported that both parties will agree to use for purposes of disclosure to the general public;

- the manner in which each party will disclose the support to the general public, (e.g., in an easily accessible location on their websites);
- that BSF retains right of approval over all content related to the event or program activity; and
- whether, and if so, how BSF's name, logo and/or any identifying marks will be used by the corporation. BSF shall not allow its name/logo or identifying marks to be used in any promotion or advertisement that names and compares competing products unless BSF has determined the superiority of the product with which it is associating and can substantiate its superiority.

Disclosure

BSF will disclose the most recent annual corporate support received from pharmaceutical, biotechnology, and medical device companies as a total amount and as a percentage of total organizational revenue for the year. This amount and percentage will be disclosed and accessible to the public through posting on the BSF website within six months of the close of the organization's fiscal year.

Operating Guidelines

BSF will develop written operating guidelines for use in the review and approval of corporate relationships based upon charitable giving and/or support, as well as ongoing evaluation of such relationships.

***Adopted by the Barth Syndrome Foundation Board of Directors on January 21, 2010
Amended and Approved December 3, 2019***