



CORPORATE RELATIONS POLICY

The Spina Bifida Association (SBA) considers first and foremost our mission and serving our constituents in all decisions, including whether to enter into a relationship with a for-profit entity. In many cases, activities that fulfill SBA'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 SBA seeks to forge appropriate and productive collaborative relationships with corporations and/or others. SBA realizes, however, that these relationships should be entered into thoughtfully, with careful consideration given to possible unintended effects, especially regarding SBA's relationship with the public. SBA shall avoid conflict of interest, or even its appearance, when accepting donations from, or forming strategic alliances and co-ventures with, corporations with vested interests in how patients or the medical community regard their products.

SECTION I: PURPOSE

This policy is intended to create and manage corporate relationships which expand the reach of SBA's programs, materials and services consistent with our mission, strategic goals and priorities. In addition, it establishes procedures and strategies that shall protect the integrity of SBA and at the same time promote opportunities for growth and increased visibility. This policy is designed to enable the public to better understand the purpose of corporate relationships and appreciate the diligence that is exercised to ensure that the public's trust and faith are not violated by these relationships and to inform corporations of the standards and practices under which SBA shall consider collaborating and forming corporate relationships. Finally, this policy is intended to ensure that any health claims resulting from a corporate relationship must be accurate and beneficial to intended audiences.

SECTION II: CRITERIA FOR EVALUATING CORPORATE RELATIONSHIPS

SBA shall avoid conflict of interest, or even its appearance, when accepting donations from, or forming strategic alliances and co-ventures with, corporations with vested interests in how patients or the medical community regard their products. To assure that conflicts of this kind do not occur, SBA's Board of Directors has determined that acceptance of donations from such commercial enterprises, and the SBA's subsequent relations with these donors, shall be evaluated using the following criteria:

A. Board Approval

The SBA Board of Directors must approve any agreement or action that endorses a specific commercial product, process, service or enterprise.

B. Written Agreement

After an affirmative vote by the SBA Board of Directors, the President and CEO may enter into a corporate relationship only after a written agreement is signed by both the corporate entity and the President and CEO.

C. Required "Must"

1. Corporate relations must ensure that any messages that the general public receive from any relationship that could be viewed as an endorsement of a specific commercial product, service, process, service or enterprise will be in line with SBA priority messages (with the exception of sponsorships for fund raising activities).
2. Written operating procedures for the review and approval of corporate relationships must be developed and used when engaging in relationships with corporations.
3. All corporate relations must be evaluated on an on-going basis using a risk/benefit analysis to identify and manage the risks with reports on the status of all such relationships provided at each SBA Meeting of the Board of Directors. Potential risks to be evaluated include but are not limited to: financial exposure, legal liability exposure, human resources cost, public impact, internal reaction, effect on image or credibility, and confusion between the SBA message and the corporate message.
4. SBA must not accept funding that may adversely affect its nonprofit, tax-exempt status.
5. Strategic alliances, co-ventures, or corporate donation programs must adhere to all applicable national and respective state guidelines, including the BBB Wise Giving Alliance's current Standards for Charitable Accountability and the National Health Council's Standards of Excellence.

D. Privacy of People with Spina Bifida

SBA shall accept support for projects or programs only when the privacy of people with Spina Bifida and their families, or any individual participating in the initiative, is protected by a written agreement specifying the appropriate usage of participant names and addresses.

E. Required Benefit

1. SBA shall at all times exercise independent judgment in all its decision-making on issues affecting the welfare of people with Spina Bifida.
2. SBA shall enter corporate relationships to provide meaningful mission-related benefits to the public or SBA.

3. Benefits to the public include meaningful education or information, or awareness or behavior-influencing information.
4. The potential effect of SBA's position on the commercial interests of a funding source shall not be a relevant factor in the SBA's decision-making process, and SBA shall not enter into relationships that are solely or primarily for the SBA's financial benefit (except for sponsorships of fund raising activities).

F. Use of SBA Name and Marks

1. The use of SBA's name and logo service mark and other service marks on any written correspondence (paper or electronic), video, or other publication or promotional materials not produced by SBA shall be permitted only with prior review and written approval of the President and CEO or his or her designee and is subject to SBA Policies and graphic standards.
2. Moreover, SBA shall not allow its name/logo or identifying marks to be used in any promotion or advertisement that names and compares competing products, unless SBA has determined the superiority of the product with which it is associating and can substantiate its superiority and its permission is sought and received.
3. SBA shall not enter into any agreement that does not provide fair and sufficient value, in funds or in-kind services, for the use of the SBA name and logo as determined by SBA.

G. Consistent with SBA Policies and Positions

1. SBA shall solicit and accept support only for projects and activities that are consistent with SBA's mission and strategic plan, and where there is a reasonable certainty that SBA's credibility and integrity shall be safeguarded.
2. Furthermore, SBA shall have relationships involving only products, services or corporations consistent with the Policies, Standards, Guidelines, positions or principles of SBA.
3. Though most corporate relationships shall involve mission-related products or their manufacturers, relationships with non-mission-related products or companies may be permitted when there is a sufficient mission-related benefit (beyond receipt of funds) to the public or the SBA.
4. SBA shall not enter into a relationship with any corporation that is involved with any products or services that are harmful to people with Spina Bifida.

H. Statement of Relationship (Proclaimer)

1. When, through an SBA approved fundraising effort, a purchase by a consumer causes a donation to be made to the organization, the SBA's name and logo shall be used only if accompanied by a statement describing the donation mechanism or a notice indicating where such a description can be found.
2. Furthermore, whenever SBA is involved in a corporate relationship, an appropriate statement clarifying the relationship between the SBA and the health

message and between the SBA and the corporation and/or product must appear in accompanying materials, unless an exception is specifically granted by the Development Committee or Executive Committee or specified in this Policy.

3. The statement must be conspicuous and legible. Examples of the proclaimer include:
 - a. Sponsorship examples:
 - 1) This program funded as a public service by ABC Company.
 - 2) This program was developed through an educational grant from Company DEF, maker of HIJ product.
 - 3) Product LMN is a proud sponsor of this Spina Bifida Association event.
 - 4) Sponsored by XYZ Company
 - b. Promotion examples (with sample health message):
 - 1) Since half of all pregnancies in the United States are unplanned, women of childbearing age-even if they are not currently planning to get pregnant-should take 400 micrograms (mcg) of folic acid every day to reduce their risk of having a child with Spina Bifida. *The Spina Bifida Association with funding from XYZ product brings this health message.*
 - 2) Studies have shown that if all women who could become pregnant were to take a multivitamin with the 400 micrograms (mcg) of B-vitamin folic acid, the risk of neural tube defects could be reduced by up to 70%.*The Spina Bifida Association brings this message to you with funding from ABC.*

I. Exclusivity and Fees

1. Exclusivity is acceptable in licensed/branded product agreements and sponsorships.
2. Exclusivity is not acceptable in promotions and certifications. Companies may be given the exclusive right to sponsor educational programs and materials only when the associated grant or donation is sufficient to cover the full cost of the program.
3. Exclusivity may be granted to a corporation or product for a particular activity for a specified time period if there is sufficient benefit to the Spina Bifida Association and the public.
4. Administrative fees may be charged a corporation to cover SBA's direct and indirect costs. Sponsorship fees are expected to cover all or a part of the sponsored program or activity.
5. Promotional fees required to otherwise participate in a promotion with the SBA shall not be charged.

J. Prior SBA Approval for Service Marks

All statements, illustrations, advertising, promotional or other materials using or referencing the SBA, its marks or messages for use in conjunction with a

corporate relationship are subject to the advance review and approval by the SBA prior to release or use, unless otherwise provided by Corporate Relations Policy.

K. Editorial and Managerial Control

1. SBA shall maintain complete control of all funds provided by commercial sponsors to support its educational activities.
2. The commercial source shall be permitted to provide funds but not to select conference faculty or other program participants.
3. Furthermore, SBA shall accept support for professional meetings, patient conferences, and symposia only when the program content and selection of speakers are to be determined independently of the funding organization.
4. SBA shall accept funds for projects involving information or education services only when it has complete editorial and managerial control and final approval authority over the materials.
5. Following completion of the materials and prior to publication, the funding source may be permitted to review the materials.

L. Advertising

SBA shall neither permit presentations extolling a commercial product nor allow product promotions to occur at SBA-sponsored meetings or conferences, except in a designated exhibit area.

M. Disclosure

1. SBA shall disclose financial and other benefits it receives from donors or relationships with donors.
2. Moreover, SBA shall disclose the nature of a corporate relationship, including any financial benefit accruing to the SBA resulting from the relationship.
3. The amount of money provided to the SBA by a corporation cannot be subject to non-disclosure.
4. Likewise, disclosure by a corporation is expected regarding a relationship with the SBA, including any financial benefit to the corporation resulting from the relationship.
5. Commercial or competitive information about a specific relationship which is customarily subject to non-disclosure restrictions may be treated as confidential when subject to reasonable non-disclosure agreements.
6. Disclosure information will be posted on the SBA website within six (6) months of the end of the fiscal year.
7. Disclosure information will be easily accessible from the website homepage or the “about us” or “contact us” sections (either on its own page or in an annual report that is posted online.)
8. Disclosure information will include support received by both the national office and affiliates that have more than \$250,000 in annual revenue.
9. Disclosure information will include either:

- a. The name of the individual corporation identified in schedule B of the SBA Form 990 and the aggregate amount of support provided by each corporation OR
- b. The total amount of corporate support from pharmaceutical, biotechnology, and medical device companies as a percentage of total organizational revenue.

SECTION III: CHAPTER AND CORPORATE RELATIONS

Chapter corporate relationships shall be consistent with this Policy and must be conducted within the service area which has been chartered by the SBA National Board of Directors and cannot conflict or compete with national SBA relationships.

SECTION IV: TYPES OF CORPORATE RELATIONS

While each corporate relationship is defined by the terms and conditions of the agreement reached by SBA and the corporation, potential relationships are often characterized by one or more of the following activities which are provided below for reference:

- A. Program Sponsorships: Support provided to conduct 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).
- B. 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.
- C. 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.
- D. 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.
- E. 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 shall donate.

- F. 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.
- G. Licensing: A relationship whereby SBA authorizes a company to develop, produce, market and/or distribute a mission-related product that is marketed under SBA's name, e.g., cookbooks, books, videos and other mission-related educational materials. In return, the organization typically receives royalties.
- H. Certification: A relationship SBA 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.

*Adopted by the Spina Bifida Association Board of Directors April 26, 2009
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