



## Corporate Relations Policy

### **Mission Statement:**

*The Restless Legs Syndrome Foundation is dedicated to improving the lives of the men, women, and children who live with this often-devastating disease. The organization's goals are to increase awareness of restless legs syndrome (RLS), to improve treatments, and, through research, to find a cure.*

To further its mission, the RLS Foundation (RLSF) may develop appropriate and productive collaborations with corporations and others. These collaborations help expand the reach of RLSF programs, products, and services. These collaborations also help the Foundation manage its operation, as resources are limited.

Such collaborations must accomplish one or more of the following:

- Distribute health information and educational programs to the public.
- Leverage RLSF's resources to provide mission-related programs, materials, and activities.
- Offer the RLSF new means of raising funds and increasing public awareness.
- Increase the overall capacity of RLSF to fulfill our mission.

### **Background:**

First and foremost, RLSF considers our mission and our service to constituents in all of our decisions, including whether to enter into a relationship with a corporation. In many cases, activities that fulfill RLSF's mission cannot be accomplished as well alone as they can be through collaboration among organizations that share our goals. It is for this reason that RLSF has increasingly sought to form appropriate and productive collaborations with corporations and others.

Over the years, corporations have worked with nonprofit organizations in many different ways. Corporations have given outright grants to charities, supported educational programs, and assisted with fundraising efforts. Traditionally, corporations have made donations as part of their commitment to philanthropy. More recently, corporate relationships have closer connections to marketing endeavors. Corporations may be interested in establishing their own corporate image or marketing their products and services. This increasing interest from corporations creates opportunities for RLSF to form collaborations to better accomplish mission-related programs. However, before entering into a collaboration, RLSF must carefully consider whether the relationship may have unintended effects, especially regarding RLSF's relationship with the public we serve.

Because of these concerns, RLSF has established guidelines, which allow us to form productive, appropriate collaborations. The guidelines provide safeguards to help RLSF avoid any negative impact on our public image and integrity. For RLSF to remain viable and to fulfill its mission, public trust is absolutely essential. Relationships between RLSF and corporate partners must enhance, and never detract from, our integrity and credibility.

## **Types of Corporate Relationships:**

1. *Sponsorship or funding:* RLSF voluntarily enters into a relationship involving a corporation or third party that provides financial underwriting or in-kind goods or services to support a Foundation program/product/material, activity or special event. Corporations may be given recognition for their support in the form of a public acknowledgement or credit by the Foundation for its support (e.g., funded or provided as a public service by Acme Corporation). This does not include permitting the use of the RLSF name, logo, or identifying marks, in the corporation's promotion of its products or services.
2. *Health message promotions:* RLSF gives a corporation the right to use its name, logo or message in the corporation's product advertising, promotional or educational materials when accompanied by a statement designating the nature of the relationship (e.g., RLSF and the XYZ Corporation working together to promote healthier sleep quality).
3. *Licensing:* RLSF licenses a company to develop, produce, market and/or distribute a mission-related product that is marketed as a brand product (e.g., RLSF brand books, videos, CD's and other mission-related materials).
4. *Certification:* RLSF certifies or recognizes that a particular product or service of a company complies with or satisfies an applicable or relevant industry-standard criterion; this is distinct from an explicit endorsement or recommendation to buy a particular brand product or service.
5. *Strategic alliance:* A mutually beneficial relationship between RLSF and a corporation in which RLSF helps supply a health education message or service to people with RLS that is delivered through a company delivery system. The collaborative effort may not necessarily involve a monetary exchange.
6. *Cause Marketing:* This generally implies that a donation to RLSF by a corporation is triggered with the purchase of a product that is "marketed" to the public to benefit RLSF. The promotion has an overall health-related public information/education benefit. The promotion is usually of a relatively short duration.

## **General Principles:**

Relations with corporations and foundations are encouraged, provided the credibility and integrity of the RLSF with the public is safeguarded. All collaborations must be consistent with RLSF's strategic goals and objectives and *must be* with strategic partners who share common goals and issues.

In entering into an agreement with a corporation with vested interests in RLS patients, RLSF is determined to avoid conflict of interest, or even its appearance. To assure that conflicts of interest do not occur, the acceptance of funds from such corporations, and RLSF's subsequent relationship to these organizations, shall be governed by the following principles:

1. RLSF will not enter into any agreement that might threaten its not-for-profit status.
2. RLSF's donor and member files shall be protected and remain confidential.
3. RLSF will accept support for projects or programs only with the assurance that the privacy of people with RLS and their families will be protected.

4. RLSF shall at all times maintain an independent position on issues affecting the welfare of people with RLS. The potential effect of such positions on the commercial interests of a funding source shall not be a factor in RLSF's decision-making process.
5. RLSF affiliated support groups will be bound by this Policy.
6. RLSF will not endorse commercial products or services under any circumstances. This precludes RLSF from marketing any RLS commercial product or service under its own name.
7. To minimize or prevent any reasonably implied endorsement of educational materials whenever RLSF is involved in a corporate relationship related to educational materials, a disclaimer stating that RLSF does not endorse any commercial products or services must appear in accompanying materials, unless an exception is granted by the RLSF Executive Committee.
8. Educational programs, materials, and services owned or endorsed by RLSF, whether developed by RLSF, a corporation, or a third party for RLSF, will not include a message which promotes a commercial product or service. RLSF's educational programs, materials and services may, however, carry an acknowledgment based on the following rules:

- a. Normally, this acknowledgment will include only the name of the corporation.

Example: Made possible by an educational grant from the Acme Company.

- b. When approved and deemed to offer RLSF an extraordinary benefit by the Board of Directors, or the Executive Committee acting on behalf of the Board, a particular product or brand name may be included but must always be accompanied by a disclaimer.

Example: Provided as a public service by Acme Company, maker of High Jump Shoes. RLSF does not endorse this or any commercial product or service.

9. Externally-developed education materials/programs and/or the educational components of disease management packages are not considered commercial services, and should be handled on a case-by-case basis.
  - RLSF can endorse educational materials using a standardized review process that includes review by a committee appointed by the Board of Directors. The committee can include scientific and medical advisory board members, outside experts, and support group representatives.
  - RLSF will charge for endorsing educational materials using the following pricing system: a standard flat fee for endorsements (refunded if RLSF decided *not* to endorse the educational materials) **and** an administrative fee for the review process determined by the complexity (i.e., time, materials and overhead) of the particular review process.
10. All educational programs, materials, and services developed by RLSF, or developed on behalf of RLSF by a third party, will be made available to individual RLS patients and providers. RLSF may grant limited market exclusivity for a given time period in exchange for program support.

Example: Exclusivity may be given for a program in the managed care market for one year. However, individual patients or physicians could still purchase the program directly from RLSF.

11. RLSF will accept support from or participate in professional meetings and symposia when the program content is determined by a group of professionals with whom the funding organization does not have a controlling voice.
12. RLSF will not sponsor or participate in presentations that include the intent to promote a commercial product or service unless it is clear that RLSF does not endorse any product.
13. Any funding from a commercial interest received for the purpose of furthering research in the field of RLS will be awarded at the sole discretion of RLSF, based on recommendations of the Scientific and Medical Advisory Board. Research grants will carry an acknowledgement similar to the statement in item #8.
14. Rights previously granted to corporations that are inconsistent with this Policy will be honored and permitted only for the period of time for which they were originally granted. All subsequent relationships and all renewals of existing relationships must comply with this Policy. Any current relationships without an expiration date will be renegotiated and must comply with this policy by December 31, 2003. Future agreements will be for a maximum of three (3) years.

#### **Procedures for Establishing Corporate Relationships:**

Any proposed corporate relationships must be reviewed and approved by the RLSF Executive Staff and the Executive Committee of the Board of Directors to ensure that they support the mission of RLSF, are consistent with RLSF's strategies and priorities, do not conflict with the Foundation's strategic goals, and would not negatively harm the public's perception of the Foundation.

All strategic alliances and co-ventures will require written agreements prior to implementation. Such agreements will require review by the Foundation's legal counsel to confirm that the documents ensure proper use of the RLSF name and logo, protection from liability, and assurance of compensation, as well as that the not-for-profit status of the Foundation is in no way threatened by this partnership.

The relationship must offer one or more of the following benefits:

- public education or communications
- professional education or science programs
- advocacy
- fund raising

#### **Use of RLSF Name and Marks:**

1. RLSF retains final approval of all uses of its name, logo or identifying marks.
2. RLSF must give prior written approval of all copy and artwork in which the Foundation's name, logo or identifying marks appear in company-sponsored materials.
3. RLSF must give prior written approval for all advertising/promotion copy generated by company sponsors that includes references to RLSF.
4. RLSF will consider packaging-based programs that use the RLSF name, logo, and identifying marks only if the corporate partner meets and agrees to the policies set forth in this document.

5. Use by an organization of the RLSF name and mark in the stylized format, its URL(s) and phone number will be permitted only with the express written prior consent of RLSF and subject to RLSF policy and graphic standards.
6. RLSF's name and logo, URL, and phone number may appear on educational materials or products owned or distributed by a for-profit corporation when it is accompanied by a statement that RLSF and the corporation are involved in an educational partnership, and that RLSF is not endorsing a commercial product or service.

Example: RLSF and the Acme Company are proud to be partners in educating the RLS patient. RLSF does not endorse this or any commercial product or service.

7. RLSF's name, logo and phone number can be used, alone or along with references to other patient or professional organizations, with RLSF's prior approval when accompanied by an appropriate disclaimer.

**Exclusivity:**

Exclusive use of the Foundation's name, logo and identifying marks by a product (in a product category) is not implied or automatically given. RLSF will consider exclusivity on an individual program basis. The definition of exclusivity as it relates to product category, type or promotion and time limit will be defined on a case-by-case basis. It is generally recognized that exclusive arrangements will limit RLSF's ability to work with other companies with like products or programs to further the mission of the Foundation, and generally will require a larger contribution to RLSF.

**Disclosure:**

RLSF will disclose the nature of a corporate relationship, including any financial benefit accruing to the Foundation resulting from the relationship when requested. The amount of money provided to the Foundation by a corporation cannot be subject to nondisclosure. Likewise, disclosure by a corporation is expected regarding a relationship with RLSF, including any financial benefit to the corporation resulting from the relationship. Commercial or competitive information about a specific relationship that is customarily subject to non-disclosure restrictions may be treated as confidential when subject to reasonable non-disclosure agreements.

**Limited Financial Support:**

The Foundation mission states: *The Restless Legs Syndrome Foundation is dedicated to improving the lives of the men, women, and children who live with this often-devastating disease. The organization's goals are to increase awareness of restless legs syndrome (RLS), to improve treatments, and, through research, to find a cure.* In furtherance of this mission, the Foundation may not accept financial or other direct or indirect support from entities that have a profit motive arising from products, services, or provision of information concerning the diagnosis, treatment, or cure of the disease if, taken in aggregate from all such sources, the support shall amount to more than twenty-five percent of the annual income of the Foundation. The staff shall report to the Board on a regular basis concerning the amount of such support to provide the Board with data required for keeping this policy in line with best practices.

Approved by RLSF Board of Directors on March 10, 2015.