

Hemophilia Federation of America

Funding Policies

PREAMBLE

On April 10, 2000, the Board of Directors voted to reverse The Hemophilia Federation of America's long-standing policy refusing to accept donations from pharmaceutical companies involved in the manufacture of products to control hemophilia-induced bleeding. The Federation's decision that now the time is right to accept support from the pharmaceutical industry requires both an explanation and words of caution.

During the late 1970s through the mid 1980s, much of America's blood supply, particularly the stores of antihemophilic clotting factor, was contaminated with two deadly viruses: HIV and Hepatitis C. These viruses are devastating and continue to evoke a terrible calamity in our bleeding disorders community.

At first, both the pharmaceutical industry and certain government offices insisted that the adulteration of clotting factors was an unforeseen and unavoidable accident. Persistent questioning and investigation by our community and its supporters, including the effective efforts of the then newly formed Hemophilia Federation of America, strongly supports the position that appropriate diligence on the part of industry during those times would have substantially reduced, if not prevented, the incursion of these viruses into the medicines that otherwise promised our community a relatively normal, active and productive life.

Organizations professing to advocate on behalf of our community, along with leaders of the medical profession treating bleeding disorders, failed to aggressively and appropriately protect the health and safety of those whose care they had been entrusted. Many felt that this breach of duty resulted, in large part, because those persons and entities did not wish to challenge or provoke the industry that was their major source of funding. Much of our community believes that the failure of the pharmaceutical industry, certain government offices, advocacy groups and members of the medical profession to avert the HIV and Hepatitis C crisis resulted from complacency and disregard for the safety of our community.

As a result of these experiences, the Hemophilia Federation of America was established and takes great pride in its reputation for excellence, reliability and integrity regarding advocacy for our community without regard for any other concerns.

The Hemophilia Federation of America believes that, unlike the actions of the past, industry is now more committed to ensuring product safety. The Hemophilia Federation of America believes furthermore that mandatory government regulations, commissions and other forms of oversight have greatly reduced the chance of history repeating itself, especially since these measures recognize and include meaningful community input.

The Hemophilia Federation of America has chosen to accept industry funding without compromising the federation's integrity, independence or its standing in our community. To those ends, the Hemophilia Federation of America has adopted the following policies, applicable to any and all donors regarding the acceptance of funds

The Hemophilia Federation of America solemnly pledges, now and forever, that it shall be mindful of history and this Preamble. The Hemophilia Federation of America shall enforce these policies strictly, diligently and without exception on behalf of all of our community who live with bleeding disorders and in memory of those of our community who have died.

LEST WE FORGET!

POLICIES

The Hemophilia Federation of America shall accept funds from persons and entities in accordance with the following standards, rules and mandatory policies:

1. The acceptance of funding and contributions by the Hemophilia Federation of America shall be in accordance with the Hemophilia Federation of America's Mission Statement, Funding policies and/or its Bylaws. The Hemophilia Federation of America shall refuse any funds and contributions which violate or appear to violate the letter or spirit of the Hemophilia Federation of America's Mission Statement, Funding Policies and/or its Bylaws.

2. The Hemophilia Federation of America shall not accept any funds which extract a quid pro quo, promises or favors in exchange for funding. There shall not be any mandate, whatsoever, by funding sources regarding the Hemophilia Federation of America programs and projects. The Hemophilia Federation of America shall provide funding sources with information regarding the Hemophilia Federation of America's allocation of funds among the Hemophilia Federation of America's programs and projects upon request.
3. No single funding source shall be allowed to contribute a total of more than 49% of the annual budget of the Hemophilia Federation of America per year.
4. The Hemophilia Federation of America shall not incur any obligation based upon the expectation that funding shall be forthcoming from any source or sources. A contractual and/or legally enforceable pledge agreement for funding is exempt from the prohibitions of this section.
5. There shall be no "name capture" by any funding source for any Hemophilia Federation of America event, program or project.
 1. An "event" is defined as a separate and distinct function of the Hemophilia Federation of America such as Symposium or any other self contained separate function sponsored by the Hemophilia Federation of America such as a sporting or entertainment event and the like.
 2. A "program" or "project" is defined as a part of the general work of the Hemophilia Federation of America or part of one of its events such as "Teen Connection", "Scholarships", "Helping Hands" or the like.
 3. One or more funding sources will be allowed to sponsor a portion of any Hemophilia Federation of America event, program or project, such as a symposium breakout or a golf tournament hole and the like. In all cases where sponsorships are permitted, such sponsorship shall not violate or appear to violate the letter or spirit of the Hemophilia Federation of America's Mission Statement, Funding Policies and/or its Bylaws.
6. The Hemophilia Federation of America shall refuse and/or return any funding or contribution, or the unused portion thereof, whenever the Board of Directors, for any reason whatsoever, has determined that such funding or contribution may result in any

conflict or appearance of a conflict with the Hemophilia Federation of America's Mission Statement, Funding Policies and/or its Bylaws.

SEATS ON THE BOARD OF DIRECTORS AND COMMITTEES

No person who is employed by or receives income from a manufacturer shall serve on the Board of Directors or any Committee of the Hemophilia Federation of America. A person who is "employed by or receives income from a manufacturer" shall mean any person who, individually or through an entity, is an employee or independent contractor of a manufacturer and receives an IRS W-2 form for wages or an IRS 1099 form for compensation. A Manufacturer is defined as a person or entity that is engaged in the manufacture of blood products and/or pharmaceuticals utilized by persons to treat bleeding disorders, to treat conditions related to bleeding disorders and to treat conditions resulting from the use of products to treat bleeding disorders.

The following shall NOT constitute employment by a manufacturer and shall not be subject to the prohibitions of this section:

1. Persons employed by a manufacturer whose employment is not involved with the manufacture of blood products and/or pharmaceuticals utilized by persons to treat bleeding disorders, to treat conditions related to bleeding disorders and to treat conditions resulting from the use of products to treat bleeding disorders.
2. Receipt of IRS form 1099 for reimbursements for travel, meals and other expenses.
3. The direction to a manufacturer to pay income, otherwise receivable by a person, to a charity in lieu of payments such as honoraria or a stipend for services performed.

CLOSE FAMILY MEMBERS

No person whose "close family member" is employed by a manufacturer of blood products and/or pharmaceuticals utilized by persons to treat bleeding disorders, to treat conditions related to bleeding disorders and to treat conditions resulting from the use of products to treat bleeding

disorders shall sit on the Board of Directors or any Committee of the Hemophilia Federation of America.

“Close family members” are defined as:

1. parents, siblings, children and grandparents (related by blood or affinity, including step or half relations);
2. a spouse or significant other;
3. parents, siblings, children and grandparents (related by blood or affinity, including step or half relations) of a spouse or a significant other; and
4. persons who are residents of the same household or homestead regardless of relationship.

The following shall not constitute employment by a manufacturer and shall NOT be subject to the prohibitions of this section:

1. Close family members who receive, as a result of employment in the manufacture, sale or marketing of blood products, less than the aggregate of \$2,500.00 annually in gifts or income, from a manufacturer of blood products and/or pharmaceuticals utilized by persons to treat bleeding disorders, to treat conditions related to bleeding disorders and to treat conditions resulting from the use of products to treat bleeding disorders.
2. Family members who receive educational scholarships or emergency financial assistance from a manufacturer.

POLICIES FOR NON-SPECIFIED SITUATIONS

In the event that the policies herein do not specifically address a funding issue, the following test shall be used in determining whether or not funds will be accepted by the Hemophilia Federation of America.

1. Does the action, activity, relationship, position or function contemplated result in the actual exercise of coercion, intimidation, undue influence or the imposition of either policy or response over the Hemophilia Federation of America?

If the answer is "Yes," the action, activity, relationship, position or function is Prohibited.

2. Would reasonably prudent people believe or perceive that the action, activity, relationship, position or function contemplated would result in the APPEARANCE OR PERCEPTION of the exercise of coercion, intimidation, undue influence or the imposition of either policy or response over the Hemophilia Federation of America?
If the answer is "Yes," the action, activity, relationship, position or function is Prohibited.
If the answer is "No," the action, activity, relationship, position or function is Permitted.

NOTIFICATION OF FUNDING POLICIES

A copy of the Hemophilia Federation of America Funding Policies shall be delivered to all funding sources who contribute more than \$5,000 within a fiscal year. All such funding sources shall acknowledge receipt of these policies which receipt shall contain an agreement to comply with the policies.