



European Haemophilia Consortium Office of the National Member Organisations

EHC POLICY ON FINANCIAL SUPPORT FROM CORPORATE SPONSORS

2012 Revision

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European Haemophilia Consortium (EHC)

EHC HQ
National Member Organisations Office
Rue du Marché aux herbes, 105 B 14
B - 1000 Brussels
Tel. +32-2 521 11 50, Fax +32-2-520 68 66
Email office@ehc.eu

EHC
European Representation Office
Rue de Luxembourg 22-24
B - 1000 Brussels
Tel. +32-2-761 66 27, Fax. +32-2-777 05 10
Email info@ehc.eu

www.ehc.eu



1. INTRODUCTION

1.1. About haemophilia and other rare inherited bleeding disorders

Haemophilia and other rare inherited bleeding disorders are lifelong conditions that prevent blood from clotting properly. People with haemophilia do not have enough clotting factor VIII or IX, proteins in blood that control bleeding. People with von Willebrand Disease have a problem with a protein called von Willebrand factor, and people with other rare inherited bleeding disorders have problems with multiple proteins. People with bleeding disorders do not bleed faster than anyone else, but bleeding may last longer. The main danger is uncontrolled internal bleeding that starts spontaneously or results from injury. Bleeding into joints and muscles can cause stiffness, pain, severe joint damage, disability, and sometimes death. Approximately 60,000 people in Europe have been diagnosed with haemophilia, 35,000 with von Willebrand Disease, and 15,000 with other rare inherited bleeding disorders.

1.2. About the EHC

The European Haemophilia Consortium (EHC) is an umbrella organisation representing 43 patient-led National Member Organisations (NMOs) in Europe.

The EHC's mission is to:

- Improve diagnostic and treatment facilities. Fifty percent of haemophilia patients in Europe receive inadequate care;
- Ensure adequate supply of safe factor concentrates. Many persons with haemophilia were infected with life-threatening viruses such as HIV and Hepatitis C as a result of their treatment in the 1970s and early 1980s;
- Promote patients' rights and raise ethical issues. Minority groups need well-established organisations to help protect their interests;
- Follow and influence developments in European health policy. A number of European health policies affect persons with haemophilia and other rare inherited bleeding disorders both in Europe and worldwide;
- Undertake surveys of haemophilia care, and care for other rare inherited bleeding disorders, in member countries. Statistical material is essential for monitoring national developments and establishing national haemophilia programs;
- Stimulate research in all fields related to haemophilia and other rare inherited bleeding disorders. Developments in biotechnology are of extreme importance to future treatment.

2. EHC FUNDING

2.1. Background and funding of core operations and projects

The EHC needs funds to pursue its mission of promoting care for patients with haemophilia and other rare inherited bleeding disorders. EHC member societies (NMOs) pay an annual membership fee, determined by its General Assembly, which helps to support the EHC's core operations.

The EHC receives external support from the public and private sectors. A large portion of its financial support comes in the form of grants and project funding from corporate sponsors that have an interest in the development of treatments and other services for haemophilia and other rare inherited bleeding disorders.

The EHC appreciates all external support and funding. The EHC accepts financial and non-monetary support with the mutual understanding that it maintains its independence and makes choices based exclusively on the needs and interests of patients.



2.2. About EHC policy on financial support from corporate sponsors

This policy seeks to clarify the EHC's position on funding received from corporate sponsors. It sets out the guidelines for accepting corporate funding and outlines what companies may, or may not, expect from the EHC in return. It does not set out to provide a definition of every possible funding opportunity or relationship, but rather to define a set of principles.

This policy adheres to the sponsorship rules that were approved by the EHC's General Assembly in 2007. This policy was reviewed and revised in 2012.

All staff, volunteers, and the leadership of the EHC must adhere to this policy and perform their duties in accordance with these rules.

3. POLICIES

3.1. Principles relating to corporate sponsors

The EHC welcomes funding from corporate sponsors on the basis of the following principles:

- Efforts will pursue public health objectives driven by patient needs;
- Full independence of EHC;
- Free of corporate bias;
- Mutual respect;
- Mutual benefit, a win-win relationship;
- Accountability;
- Transparency.

The EHC believes it is important to establish and maintain relationships with a variety of corporate sponsors, the scientific community, and other stakeholders in order to enhance communication between the patients, whose interests the EHC represents, and the companies, whose decisions will affect the provision of health services or treatments for patients.

The EHC supports the availability of the widest range of haemophilia and other medicinal products, treatments, and health services. It does not endorse individual medicinal products or treatments. It encourages active partnerships between patients and health professionals, and promotes the discussion of all available options to ensure that patients make informed choices.

Relationships between the EHC and corporate sponsors are based on a mutual partnership in which the EHC preserves its independence and integrity. Any funding received from a corporate sponsor must be committed to the benefit of the NMOs that the EHC represents, must not entail adverse publicity, and can in no way influence the EHC's policy, positions or decisions, whether explicitly or implicitly. EHC-corporate partnerships will focus on broad interests and activities in the areas of haemophilia and other rare inherited bleeding disorders, treatments, public awareness, and patient support, as well as in the areas of social, health, and educational services.

3.2. Balanced funding

The EHC seeks balanced and diversified funding from its NMOs, public and private institutions, and the corporate sector. In order to avoid the risks inherent to a relationship with any single corporate sponsor, or a limited number of sponsors, the EHC seeks to diversify the types and sources of funding it receives from different corporate sponsors. For these reasons, whenever possible the EHC will seek to involve more than one sponsor in its sponsorship opportunities and give priority to those that accept shared sponsorship.



Exclusive sponsorship will be accepted when all potential sponsors have had the possibility to express an interest and no two companies are willing to jointly sponsor. When a company has been an exclusive sponsor, it receives the right of first refusal on extending the sponsorship to the next time period, provided that the pledged sponsorship matches or surpasses the required funding.

3.3. Refusal and exclusion

The EHC does not endorse medicinal products, brands, or health services, and must not appear to do so, nor appear to be in any way partisan.

Decisions about the possibility of inclusion into or exclusion from EHC projects and activities are formally made by the EHC. Decisions about exclusion are based on what the EHC considers a breach of this policy or other Code of Conduct policies, where applicable.

4. TYPES OF FINANCIAL SUPPORT BY CORPORATE COMPANIES

4.1. Unrestricted funding

Unrestricted funding covers direct costs such as personnel, equipment, consultants or suppliers, mission and travel expenses, as well as related indirect costs (e.g. telephone, administrative activities, etc.). It allows the EHC and the funding organisation to develop a mutually beneficial relationship. It provides the EHC with a dependable source of income over a number of years and enables it to develop and implement its core operations and activities. It allows the funding organisation to gain public credit for its support and to receive other benefits that are tailored to its level of commitment.

4.1.1. Corporate Giving Program (CGP)

The CGP functions as a gateway into EHC programming. In order to participate in the funding of most EHC projects and activities, companies must first become members of the CGP by contributing a limited amount of non-restricted funding. Non-CGP members are excluded from most EHC sponsorship opportunities.

CGP membership is divided into three categories (Platinum, Gold or Silver) based on financial contribution levels. In addition to receiving a distinct set of sponsorship benefits per category, CGP members are automatically given the opportunity to participate in the funding of other EHC projects and activities, such as for example of the EHC Round Table of Stakeholders. It is important to note that, where other EHC projects also have funding categories, a company shall not be allowed to provide restricted funding at a higher category than their own CGP category.

The CGP is a critical element of EHC funding as it provides the EHC with a limited amount of unrestricted funding with which to maintain a small but sustainable baseline of operations. This gives the organisation a minimum level of financial security and stability.

4.2. Restricted funding

Restricted funding covers a single EHC project or activity, such as a conference, workshop, or communication tool (i.e. training workshop, newsletter, website, etc.) and covers direct costs, including staff costs. Sponsorship of most EHC projects and activities is limited to CGP members. CGP members also receive advanced copies of the annual sponsorship package and receive first right of refusal.

4.2.1. Projects and activities

The EHC Steering Committee determines on an annual basis which activities the EHC will make eligible for restricted sponsorship. These are outlined in the annual sponsorship package, which is prepared and distributed to potential sponsors each year. The sponsorship package outlines the sponsorship



opportunities, rates, and benefits to the sponsors (i.e. recognition, sponsor participation, etc.). Projects and activities typically include, but are not limited to:

- EHC Round Table of Stakeholders;
- NMO workshops;
- Communications materials (e.g. newsletters, publications, etc.);
- Website;
- Others.

4.3. One-time charitable donations

The EHC welcomes one-time charitable donations from a variety of organisations and companies. While these do not raise an obligation from the EHC to acknowledge support publicly, this information may be announced at the time of the Annual General Assembly.

4.4. Non-monetary contributions

The EHC welcomes non-monetary contributions from a variety of companies and organisations. These may include, but are not limited to:

- Pro bono services such as seconded staff or professional services provided without charge;
- In-kind donations such as computers;
- Other non-monetary contributions such as furniture, printing services, the use of meeting rooms;
- Donations of factor concentrates or other supplies for donation and use, under appropriate medical supervision, at the EHC Annual Conferences.

5. PROCEDURES

5.1. First contact

When approaching a corporate company, the EHC shall provide it with this policy on financial support from corporate sponsors as well as with its annual sponsorship package. The EHC may request information about the company, including its principal business activities and products or services for haemophilia and other rare inherited bleeding disorders. The EHC may also conduct its own research, particularly regarding the company's reputation with patient groups and regulators. Should the EHC have any concerns about a real or perceived conflict of interest, it shall take them to its Steering Committee for discussion and review.

5.2. Written agreements

Prior to entering a sponsorship agreement, both parties must sign and exchange this policy (in the spaces provided below). When financial support is accepted, the EHC and the corporate sponsor shall also sign and exchange a contract, Memorandum of Understanding, letter of agreement, or other written agreement. Only authorised persons from the company and the EHC (its President, CEO, or an authorised member of the Steering Committee) may sign these written agreements.

5.3. Financial and program accountability

Corporate sponsors that have joined the CGP or that provided other forms of unrestricted funding may choose to receive an annual report and financial statements, once they are approved by the General Assembly. Corporate sponsors that have provided restricted funding to a specific project, or activity may choose to receive a year-end summary report and financial statements. Significant one-time donations and non-monetary contributions are presented at the EHC's Annual General Assembly.

5.4. Recognition and visibility



The EHC is pleased to publicly acknowledge corporate sponsors for their financial support. Specific modes of recognition and visibility are outlined in the EHC's annual sponsorship package. These vary per type and level of financial support given.

Prior agreement between the EHC and the corporate sponsor shall be reached on the level of visibility, types of logos and wording used to credit a sponsor, and other types of communication. Prior agreement shall also be reached on the wording and logos that corporate sponsors may use when advertising their EHC support in their own literature or externally. These agreements shall be reflected in the signed contract, Memorandum of Understanding, letters of agreement, or other written agreement. Public communications not captured in the written agreement must be jointly agreed between the EHC President, CEO, or the duly authorised member of the Steering Committee, and the corporate sponsor, and reflected in writing.

The EHC shall give sponsorship recognition to a corporate sponsor and not to products manufactured by these companies. The policy of the EHC is not to accept product advertising. The EHC will not accept advertisements in its publications for factor concentrates or other therapies. When sponsorship recognition is given, the EHC may also state that the acceptance of any sponsorship does not in any way mean the endorsement of any one company or product.

Brussels, September 2012

Signed by: *(Insert name, title, company)*

Signed by: *(Insert name, title, EHC)*

Dated:

Dated: