

1. INTRODUCTION

1.1 – About the EHC

The EHC is an international non-profit umbrella organisation representing 47 national member organisations (NMOs) – and through them more than 120,000 people – dedicated shaping the quality of life of all people with congenital bleeding disorders in Europe, through partnership and advocacy. Created over 30 years ago, the EHC advocates for and monitors improvements in diagnosis, treatment and care.

1.2 – About EHC resources

The EHC needs human and financial resources to pursue its mission and objectives in support of patients. This resource base begins with its own members. EHC NMOs pay an annual membership fee, determined by the EHC's General Assembly, and EHC volunteers contribute a significant amount of non-remunerated work and expertise each year.

2. EHC FUNDING

2.1 – About this policy

This policy seeks to clarify the EHC's position on funding received from the corporate sector. 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. All staff, volunteers and the leadership of the EHC must adhere to this policy and perform their duties in accordance with these rules. This policy adheres to the sponsorship rules that were first approved by the EHC's General Assembly in 2007, then revised in 2012 and again in 2021.

2.2 – Guiding values and principles

The EHC seeks and accepts funding from the private sector on mutual agreement of the following core values and principles:

- Pursuit of public health objectives driven by patient needs
- Full independence
- Mutual respect
- Transparency
- Accountability
- Unrestricted funding for advocacy
- Sustainability of commitment

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

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



2.3 – Balanced & diversified funding

The EHC seeks to balance its funding as much as possible through a mix of unrestricted and restricted funding options as well as sources of earned-income.

Within the private sector, the EHC seeks diversified funding from multiple corporate sources. In order to avoid the risks inherent to a relationship with any single sponsorship, or a limited number of sponsors, the EHC seeks to diversify the types and sources of funding it receives. For these reasons, whenever possible the EHC seeks to involve more than one sponsor in a funding opportunity and gives priority to those that accept shared sponsorship.

2.4 – 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 funding opportunities are formally made by the EHC. Decisions about exclusion are based on what the EHC considers a breach of this or other EHC policies, where applicable.

2.5 – Overview of funding sources

The EHC funding structure, outlined below, includes a mix of private and public, unrestricted and restricted, and income-generating pillars.

Non-industry funding	Industry funding				Other sources of support	
Public sources of restricted & unrestricted funding	TIER 1	Unrestricted funding 'Gateway' Corporate Giving Program (CGP)			Charitable & In-kind donations	
		↓	↓	(↓)		(↓)
	TIER 2	Restricted industry funding (A) Sponsorship opportunities Youth Leadership Workshop Economics Workshop New Technologies WS Leadership Conference World Haemophilia Week European Inhibitor Network VWD Platform Youth Fellowship	(Unrestricted) Grants (B) Think-Tank	(Unrestricted) Earned-income (C) Conferences (Annual, WBD, ...)		(Unrestricted) Fee-for-service (D) Community Advisory Boards (CABs)

Legend:

↓ indicates CGP membership is required

(↓) indicates CGP membership is not required but offers benefits

2.6 – Corporate funding

1) Corporate Giving Program (CGP)

The CGP functions as a gateway into EHC funding streams. In order to participate in the sponsorship of most EHC projects and activities, sponsors from the corporate sector must first become members of the CGP by contributing a limited amount of unrestricted funding at one of three financial contribution levels (Platinum, Gold or Silver). Non-CGP members are excluded from most EHC sponsorship opportunities.

2) Restricted funding

Restricted funding covers specific areas of EHC community services and is associated with a set of sponsorship benefits. Sponsorship is sought from between three to five sets of sponsors,



depending on the required budget, and limited to CGP members. CGP members also receive advanced copies of the annual sponsorship package and receive first right of funding refusal.

3) Think Tank grants

The EHC Think-Tank is an incubator of patient-led advocacy as well as a neutral platform enabling healthcare 'change agents' to co-design long-term systems change in a collaborative, multi-stakeholder environment. The EHC only accepts Think Tank funding in the form of unrestricted grants from public and private sources. From within the private sector, only members of the CGP may contribute grants to the Think Tank.

4) Earned income through conferences

The EHC runs a limited number of public and registration-fee-based conferences per year which target a broad group of stakeholders and for which a separate sponsorship package is circulated. Sponsorship opportunities are open to all prospective sponsors but CGP members benefit from some advantages, which are clearly outlined in the respective sponsorship packages.

5) Earned income through Community Advisory Boards (CABs)

Through a fee-for-service model, the EHC can deliver up to six CABs per year, provided on a first-come, first-served basis, with CGP members receiving first-choice and a 10% discount.

2.7– Other sources of organisational support

As a non-profit organisation, the EHC welcomes public funding, charitable donations and non-monetary contributions towards its mission from sources that meet its core principles and values.

1) Public funding

The EHC welcomes restricted and unrestricted public funding and participates in ad-hoc requests for proposals (e.g., from EU institutions) in line with its core mission, objectives and values.

2) Charitable donations

The EHC welcomes charitable donations such as unrestricted financial contributions to its core funding or other specific areas of work. Credit for charitable donations is given in the annual report and/or publicly acknowledged in the EHC's financial reports.

3) Non-monetary contributions

The EHC welcomes non-monetary contributions that support its mission, objectives and areas of work, such as but not limited to: donations of treatment products and/or medical supplies; pro-bono professional services such as legal or technical support; pro-bono use of meeting equipment, materials or space; or other relevant non-monetary contributions that the EHC considers ethical. Credit for non-monetary contributions is given in the annual report and/or publicly acknowledged in the EHC's financial reports.

3. PROCEDURES

3.1 – First contact

When approaching a prospective corporate sponsor, the EHC provides 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 rare 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.



3.2 – 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.

3.3 – Financial and program accountability

Corporate and other sponsors that have provided restricted funding may choose to receive a year-end summary report and financial statements, once these have been approved by the General Assembly. Unrestricted funding, significant one-time donations and non-monetary contributions are presented at the EHC's Annual General Assembly and/or annual report.

3.4 – 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 and 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 treatment products 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, February 2021

Signed by:

(Insert name, title, company)

Signed by:

(Insert name, title, company)

Dated:

Dated:

