

About the EHC

The EHC is a pan-European non-profit umbrella organisation representing 47 national member organisations (NMOs) – and through them more than 120,000 people – and working to positively shape the quality of life of all people with rare bleeding disorders in Europe, through partnership and advocacy.

The value of the EHC

The EHC plays a unique and central role in the European haemophilia and bleeding disorder landscape as an independent, credible and expert patient organisation that is active at both European and national levels to promote better access to diagnosis, treatment, care and patient partnership.

The EHC trains and empowers its members to be expert stakeholders and to contribute to decision-making at multiple levels nationally. Meanwhile, at European level, the EHC engages directly as a reputable and respected patient partner to multiple stakeholders, including the EU institutions, the Council of Europe, the United Nations Development Program, the European Reference Network for rare bleeding disorders – EuroBloodNet – as well as key doctors' and scientific associations, and other patient groups and consortia.

More than 30 years old, the EHC builds, maintains and nourishes an educated and motivated patient advocacy community, contributing to the future of our health system and its sustainability.

Patient-led, volunteer-driven

The EHC is a fully patient-led organisation. This means that it has only patients or family members in its elected leadership body, the Steering Committee. The EHC is also strongly volunteer-driven. This means that all EHC volunteers, including but not limited to Steering Committee members, contribute their time, efforts and expertise for zero financial remuneration by the EHC.

The value of EHC volunteers

The core of any patient community are its volunteers. In addition to its leadership, the EHC benefits from volunteers playing an active role in every aspect of its work and in turn invests in their 'professionalism'. These volunteers include patients themselves as well as family members and a large body of medical, scientific and other high-level experts, including pro-bono service providers. As per above, all volunteers provide their insights and expertise for no financial gain, thereby donating the value of their contributions to the EHC, while also making a broader impact in the healthcare ecosystem. To capture this value¹ and translate it into future patient services, the EHC includes volunteer time in all of its budgets, thereby translating volunteer contributions from a donated service into a tangible financial asset towards the organisation's financial future.

EHC resources

The EHC pursues its mission and objectives in support of patients through financial, staff, contractual and volunteer resources. The EHC's financial base begins with its own members who pay an annual membership fee, determined by the EHC's General Assembly, and EHC volunteers, who contribute a significant amount of non-remunerated work and expertise each year.

Core principles

The EHC's work as well as funding relationships are driven by the following core values and principles:

- Pursuit of public health objectives driven by patient needs
- Full independence
- Mutual respect
- Transparency

¹ Volunteer hours are recorded, accounted for, and reported in the EHC's financial statements based on the EURORDIS-Rare Diseases Europe model, using an average financial equivalent per volunteer hour donated.



- Accountability
- Unrestricted funding for advocacy
- Sustainability of commitment

Financial health and sustainability

The EHC's funding policies are also structured in a manner to help the organisation secure the EHC's future operational and financial health and sustainability. This is a Strategic Objective mandated by the EHC General Assembly and captured in the 2018-2022 Strategic Plan (see Annex 1), Objective 4, to ensure:

- 1) Good governance, succession and leadership planning,
- 2) Transparency in internal financial policies and procedures,
- 3) Neutrality and transparency in external sponsorship policies,
- 4) Ethics, independence, clear codes of conduct and transparency in all stakeholder engagement,
- 5) Adequate staff and financial resources, maintaining a minimum 12-month operational reserve, and diversifying funding when possible.

Funding from the corporate sector

The EHC has a Policy on Corporate Funding, approved by the EHC General Assembly, which sets out the guidelines for working with corporate funding and outlines what companies may and may not expect.

Balanced and diversified funding

As per the above, the EHC prioritises funding relationships with multiple private sector companies (amongst others, to avoid the risks inherent to a relationship with any single funding relationship) and seeks a mix of unrestricted and restricted funding options as well as income-generating activities. Its funding package is structured as follows:

1) *Corporate Giving Program (CGP)*

The EHC's Corporate Giving Program (CGP) was founded in 2013 to serve as the primary source of fully unrestricted funding, thereby creating the critical and central funding pool from which the EHC can run its advocacy work in a fully independent and credible manner.

The CGP therefore acts as a gateway into most other EHC funding streams, whereby CGP support is a requirement to be able to participate in the sponsorship of most other EHC projects and activities.

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 is limited to CGP supporters.

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 the corporate sector, the EHC only accepts grants from companies that support the CGP.

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 supporters 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 supporters receiving first-choice and a 10% discount.

6) ***Public funding***

The EHC consistently seeks public funding opportunities, however it is restricted to a small pool (e.g., EU institutions) as it does not compete against its own members nationally nor against its peers globally. Most EU funding is project-based, time-limited and single-use. Like other patient organisations, the EHC advocates the EU for more and less burdensome core operating grants.

7) ***Charitable donations***

The EHC welcomes charitable donations such as unrestricted financial contributions to its core funding or other specific areas of work. Such donations are historically consistent but small. For this reason, the EHC also invites funding partners to donate any budget contingency left unspent back to the EHC as a value-based contribution towards the EHC's reserves.

8) ***Non-monetary contributions***

The EHC welcomes non-monetary contributions that support its mission, objectives and areas of work. Historically such contributions are small and sporadic.

Financial accountability

The EHC annually conducts an independent, external audit on a voluntary basis. Its final accounts together with this external audit go to the General Assembly held each October. Once these are approved, the EHC publicly, transparently and annually reports its finances and income sources on its website, annual report and to EU institutions including the European Parliament's Transparency Register and the European Medicines Agency (EMA).

Corporate and other sponsors that have provided restricted funding to the EHC may choose to receive a year-end summary report and financial statements, once these have been approved by the General Assembly in October of the following year.

Treatment product neutrality

At no time and under no circumstances does the EHC endorse particular treatment products manufactured by any company, whether or not these companies provide the EHC with funding.

Closing remarks

What is a healthy patient advocacy landscape in Europe worth? What is the value of a well-organised and representative patient community to the health system? Partnering with the EHC and enabling its work is an investment in the future. To ensure both the immediate but also future impact of the EHC, the organisation has numerous and diverse funding streams, and invites all partners to consider not just the cost of a grant, donation or sponsorship, but more importantly: its value.

Overview of specific support

For a more detailed, company-specific overview, see Annex 2.



Annex 1
STRATEGIC OBJECTIVES 2018-2022

Shaping the quality of life of all people with congenital bleeding disorders in Europe, through partnership and advocacy: in substance, in form and into the future.

- 1. Advocate and partner effectively towards improving quality of life for all people with congenital bleeding disorders in Europe.**
 - a. Promote access to optimal treatment and comprehensive care, and support use of safety surveillance systems
 - b. Collect and disseminate relevant data
 - c. Ensure close collaboration and engagement with key stakeholders and institutions on policy and patient access
 - d. Participate in and support relevant European initiatives
 - e. Engage and retain expertise of medical and scientific advisors

- 2. Ensure state-of-the art knowledge and relevant skills for National Member Organisation (NMO) representatives to help them achieve better treatment and comprehensive care nationally.**
 - a. Provide targeted tools, training and education, including through attendance at key conferences
 - b. Translate, analyse and disseminate state-of-the-art knowledge
 - c. Identify, promote and disseminate relevant principles and guidelines
 - d. Co-define pathways for national level support and advocacy
 - e. Promote comprehensive patient co-decision-making in national health care systems from policy to evaluation

- 3. Empower National Member Organisations (NMO) and support their future development**
 - a. Promote NMO independence and accountability
 - b. Promote and facilitate exchange of best practices between NMOs and their members
 - c. Identify, support and empower future generations of leaders
 - d. Provide clear, effective and timely communication
 - e. Support national collection, measurement and dissemination of health-related data

- 4. Ensure EHC's organisational health and secure its future development**
 - a. Ensure good governance, succession and leadership planning
 - b. Ensure transparency in internal financial policies and procedures
 - c. Ensure neutrality and transparency in external sponsorship policies
 - d. Ensure ethics, independence, clear codes of conduct and transparency in all stakeholder engagement
 - e. Ensure adequate staff and financial resources, maintaining a minimum 12-month operational reserve, and diversifying funding when possible



Annex 2

Specific YEAR COMPANY NAME support – brief overview

Overview of COMPANY NAME support

Text

YEAR PROGRAM final budget report*

Overall expenses

Staff costs

Volunteer time and expenses

Total spent

Funding received

Funds allocated to/from the EHC reserve

YEAR PROGRAM final budget report*

Overall expenses

Staff costs

Volunteer time and expenses

Total spent

Funding received

Funds allocated to/from the EHC reserve

*This data is derived from our annual report. The allocation principle has been used only for this purpose. This has not been audited.

